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STRATEGIES FOR SURVIVAL WITH DIABETES: AN INVESTIGATION OF THE
STRUCTURAL FACTORS IMPACTING HEALTH DISPARITIES AND CHRONIC
DISEASE MANAGEMENT

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STEVEN DAVID GOMEZ
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STRATEGIES FOR SURVIVAL WITH DIABETES: AN INVESTIGATION OF THE
STRUCTURAL FACTORS IMPACTING HEALTH DISPARITIES AND CHRONIC
DISEASE MANAGEMENT

A DISSERTATION APPROVED FOR THE
DEPARTMENT OF ANTHROPOLOGY

BY

Dr. Katherine Hirschfeld, Chair

Dr. Diane M. Warren

Dr. Lesley Rankin-Hill

Dr. Lori L. Jervis

Dr. B. Mitchell Peck

I dedicate this work to my mother, Maria C. Gomez, who died in 2010. She provided my first glimpse into what life is like with diabetes. I will never forget our trips to the library as a young child and her ability to ignite my passion for learning and education.

I love you and miss you every day.

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ABSTRACT

This study was designed to 1) discover the strategies diabetes patients employ as they negotiate the economic and other structural factors influencing their everyday lives and 2) find out about participants' ability to maintain good health in light of the interaction between participants' personal health care strategies and the effects of each person's strategy implementation on their overall effectiveness in chronic disease management. I collected quantitative descriptive data and qualitative interview data from 32 participants, visiting with participants for extended periods of time at Health for Friends clinic and in the homes of 15 of these participants. My study results yielded nine thematic areas of data about the complex structural and macro level impacts on individual diabetes management. The results of this study can be used to modify and formulate new local, state, and national public health programs that serve marginalized patient populations. The findings from this study will also contribute to theoretical understandings of the relationship between socioeconomic inequality and individual health behaviors and decision-making. Additionally, study results can be applied to research on other health disparities in other regions in the United States and across the world where certain groups of people are unequally suffering from a disease.

PREFACE

My anthropological research interests continue despite my work as a clinical social worker for the Department of Veterans Affairs, and it has been an interesting personal challenge to maintain my identity as an anthropologist while working as a professional social worker. After sharing some details of my education and professional work experience, I will speak about how my curiosity and personal experiences round out my practitioner-scholar identity and form the foundation of my present and future interest in clinical practice and social science research.

While it makes perfect sense to me, my professional education, training, and clinical practice experience trajectory is often regarded as unusual to my colleagues. I get lots of questions about why I chose my particular education and training track, and what I imagine doing with my education and experience in the future. After graduating with a Bachelor of Science degree in psychology from Texas A&M University in College Station, Texas in 2003, I entered a doctoral program in clinical psychology at the University of North Texas. After a few years in the program, completing coursework, research, teaching, and practice experience requirements, I came to understand my interests as being a better fit within the discipline of anthropology, and in particular, medical, or applied medical, anthropology. So, I applied for admission to the master's program in applied anthropology at the University of North Texas while enrolled as a Ph.D. student in clinical psychology, and was accepted. I alerted my clinical psychology doctoral program of my desire to make a change in my career training track, and they wished me well. I completed Master of Science degrees in

psychology and applied anthropology at the University of North Texas in the spring of 2007.

That following fall, I started the doctoral program in anthropology at the University of Oklahoma in Norman. It was then that I began working with my program advisor, Katherine (Tassie) Hirschfeld, Ph.D., an anthropology faculty member who shares my interests in medical anthropology, applied medical anthropology, and the political economy of health. Armed with formal training in both psychology and anthropology, I decided that I wanted to pursue a mixed methods research study utilizing both quantitative and qualitative data collection techniques. My goal was to conduct a holistic examination of the experience of living with diabetes in the context of societal factors that are mostly out of each of my study informants' individual control, such as the lack of resources that come with living in poverty, and the challenges faced as people attempt to manage their health without health insurance.

While satisfied with the choice I had made to switch career trajectories from clinical psychology to medical anthropology, I began to miss one essential aspect of my previous work: direct clinical practice. It takes one set of skills to sit with someone experiencing difficulty in life and collect research data on them, and another skill set to attempt to partner with a person and help them improve their quality of life by facilitating positive change and growth. I knew that I needed to continue fostering this second, practice-oriented skill set, but I was not sure how I would do so, given the curriculum of the doctoral program in anthropology.

After consultations with Dr. Hirschfeld, other faculty, my wife, and friends, and some creative utilization of previously completed psychology coursework, I applied for

admission to the Master of Social Work program in the, now named, Anne and Henry Zarrow School of Social Work at the University of Oklahoma. I was admitted to the program in 2009, and began in earnest to pursue a MSW degree while simultaneously completing my Ph.D. in anthropology, with emphases in medical and sociocultural anthropology. I owe a great deal of gratitude to those important individuals in my life that believed in me and my interests, and who gave me their blessing as I pursue my career and professional goals.

I marched along in both graduate programs, completing requirements for both. I successfully passed my written and oral comprehensive exams defense for anthropology in the spring of 2010, and then finished my first social work practicum field placement that following summer. I completed this social work field placement at the University of Oklahoma Health Sciences Center, OU Physicians Family Medicine Center in Oklahoma City, under the supervision, instruction, and guidance of an exceptional Licensed Clinical Social Worker. At this clinic, I was able to do direct practice work with patients mostly coming from surrounding areas, and who were often poor and used Medicaid and/or Medicare for their health and mental health care services. I learned a great deal about how social work practitioners can impact the lives of those living with chronic diseases, and several of the patients I worked with carried diabetes diagnoses.

In January of 2011, I began my second social work practicum field experience at the Oklahoma City Veterans Affairs Medical Center. By this point in my MSW program, I had declared “direct practice” as my chosen area of concentration, instead of “administration and community practice,” because of my interest in clinical work. I had the good fortune to find supervision and mentorship by an excellent team of clinical

social workers while at the Oklahoma City VA Medical Center. They quickly took interest in my interests and afforded me opportunities to enhance my professional training, including conducting individual and group psychotherapy, participating in home visits in the community, in addition to teaching a skills-based course on diabetes management and mental health.

Soon after graduating with my MSW degree in August 2011, I started what was to be a short stint as a mental health counselor in a private practice counseling agency in Oklahoma City that mostly served children and families. I soon decided that my goal was to work with adults living with both chronic disease and psychiatric diagnoses, and so I began applying to VA medical centers and clinics in a variety of areas across the country, based on my positive experience at the Oklahoma City VA as a practicum student. After sending out lots of applications via the USA Jobs portal online, I finally got a hit for a social worker position in the Health Care for Homeless Veterans (HCHV) program at the Michael E. DeBakey Veterans Affairs Medical Center in Houston, Texas. I had a challenging telephone interview conducted by an interview panel on a chilly afternoon in December while sitting in my parked car, and found out shortly after that I had been selected for the position. My wife and I were thrilled at the opportunity to move back to Texas, where we are originally from, and I enthusiastically accepted the job offer.

I worked about eight months in the HCHV program at the VA Medical Center in Houston. The job was challenging and interesting, and I spent a significant part of my time in the community, doing home visits and helping link veterans to affordable housing opportunities in the context of addressing their physical and mental health

problems. The home visit component of my work in the homeless program reminded me very much of my ethnographic fieldwork, and I drew parallels between my role as a social worker and my training as an anthropologist.

In late summer 2012, an internal job announcement was made for our Social Work Service, and jobs were posted for social workers in the newly redesigned General Mental Health Clinic (GMHC). I seized this next opportunity to enhance my clinical practice skills, expressed my interest in one of the positions, interviewed, and was offered a job. I was again excited to be making a good career move that would afford me new and different professional opportunities.

In my professional capacity as a social worker in the GMHC, I provided individual and group psychotherapy to veterans with a variety of physical and mental health diagnoses, including diabetes and its mental health problem correlates. I also engaged veterans in case management and assessment, and enjoyed the intellectual and professional freedom and support to pursue my interests based on my training in psychology, anthropology, and social work. The administration within the GMHC welcomed me openly and viewed my unique education, training, and career path as an asset to the services provided in the clinic.

Change is an inevitable part of life, and my professional work experience is no exception. Once my wife found out she was pregnant, the extended late hours I was working in the GMHC would soon no longer be good for my family. When I was told I would not be able to work a standard schedule when my baby was born, I quickly began looking for another job at the Houston VA that would give me the opportunity for new, beneficial experiences, while at the same time allow for the work-life balance necessary

when having a new baby, and our first. I applied for a position as a program coordinator back in the HCHV program, working as liaison between the VA and a community agency that facilitates the implementation of an intensive, nine month residential case management treatment program for homeless veterans with chronic and severe mental illness diagnoses. This program is called the Critical Time Intervention program and its purpose is to provide a safe, facilitative transition environment for veterans to stabilize and set clear goals for living in the community in the least restrictive environment possible. I interviewed and was offered the position, to start in February 2014. In this position, I gained useful program administration experience, while at the same time sharpened my clinical knowledge base and skill set.

I completed the clinical supervision necessary to qualify for Texas state clinical social work licensure in May 2014, the same month my son was born. I sat for the clinical social work licensing exam in August 2014 and passed, and I am now a Licensed Clinical Social Worker (LCSW) in Texas. This is the highest level of licensing available to practice independent, advance practice clinical social work. Earning this independent clinical practitioner license means I have much more freedom to explore different career options. I was originally interested in working within the VA health care system because of my experiences as a social work graduate student, when I witnessed veterans' struggles managing both chronic physical diseases, like diabetes, and mental health problems. As the fall season of 2014 approached, I again explored my options for practicing social work in a setting that would afford opportunities to increase my work with a patient population similar to my informants at Health for Friends clinic. I found this opportunity in San Antonio, Texas.

After the birth of my son, my wife and I began talking about the possibility of us moving back “home” to where we grew up, in the San Antonio area. A job posting became available with the South Texas Veterans Health Care System (STVHCS) for a primary care social worker in one of the VA outpatient clinics a few miles from the main VA hospital in San Antonio. I applied for the position, completed another challenging telephone interview, and was offered the position. My wife and I thoroughly discussed the pros and cons of moving to San Antonio, and I eventually accepted the position to transfer. I was excited to be working in a primary care environment, where I planned to incorporate my direct clinical practice skills with my professional interests in chronic disease management, continuing the exploration of the strategies used by patients I met with for my dissertation research.

I started working at the Balcones Heights VA Outpatient Clinic in San Antonio in early January 2015. I was immediately met with a patient population at the clinic that was aging, with multiple and chronic medical, and often times, mental health diagnoses. I experienced a steep learning curve with regard to case management, as I was the only primary care social worker for a clinic with 8 patient aligned care teams, or PACTs, each with about 1,200 to 1,500 patients. Many patients I worked with had type 2 diabetes diagnoses, with varying levels of successful management of the disease. As a social worker in primary care, I was able to spend a longer amount of time with the patients during appointments than was often possible with medical providers, who had many patients scheduled in one day, one after another. I continued to rely on my ethnographic and clinical interviewing skills to assess each patient’s needs and formulate a plan for addressing their multiple, intersecting concerns. I learned a lot

about how primary care patients negotiate their environments in order to try and have their needs met. I was reminded often of my work with my study participants at Health for Friends, and know that if not for VA health care, many of the patients I encountered would struggle in the same ways of my study participants.

After working for the VA for three years and obtaining my independent advance practice clinical license, I felt it was time to seek out a promotion; however, I knew this could be an important opportunity for me to find a senior social worker position that could serve as a culmination of my previous social work and anthropological training and experience. Several new job postings with the South Texas Veterans Health Care System became available as the months passed. One in particular caught my attention; this was a position vacancy announcement for a mental health social work case manager with the Homeless Patient Aligned Care Team (HPACT), which is the primary care team dedicated to serving the homeless veteran population. Now quite familiar with the process, I applied for the promotion, interviewed, and accepted the position. My first day as HPACT primary care senior social worker was September 1, 2015.

During my interview preparation, my interview, and soon after starting in my new role, I knew this job would be a good fit for me. My team consists of myself as the senior social worker and team coordinator, along with a psychiatrist, psychologist, RN, LVN, and physician. I am the only full time HPACT staff member on the team, and I provide clinical services to HPACT patients, along with coordinating HPACT efforts via administrative duties. I work with patients daily who are homeless, at risk of being homeless, or who are now housed but have a history of homelessness. These patients are living with the social determinants of health that I have read and researched about

for years. I assist these veterans with systematically addressing the intersecting medical, mental health, and psychosocial problems that have brought them to seek help from the VA and our primary care team. The effectiveness of this model of integrating services targeting homelessness and the social determinants of health into VA primary care has recently been demonstrated (O'Toole, Johnson, Aiello, Kane, and Pape 2016).

Most HPACT patients have exceedingly complex needs, and many have been diagnosed with type 2 diabetes, along with other chronic diseases. Their struggles to manage diabetes, along with the many other diagnoses they've been given, often mirror the lived experience of the participants in my research study. The structural factors that impact health disparities and chronic disease management are often most pronounced among those who are homeless, as they lack basic human necessities like shelter and food. I feel that my work and research has led me to be well suited for my current professional position, and it serves as a nice culmination of my interests, training, and work experience at this point in my professional life.

Talking about diabetes strictly as a medical or clinical disease denies the very real, contextual, lived experience of the disease. Indeed, it is important for biomedical practitioners to understand that people live their diseases, and their diseases do not just exist within them as separate entities. Importantly, a comprehensive, systematic, and contextual analysis of diabetes is what I found to be necessary to move forward with my research and my hope is that, in the future, significant improvements can be made in how we treat those with diabetes, and in how we prevent the disease's incidence among future generations. In this perspective, speaking about diabetes patients who struggle with diabetes management as being "non-compliant" denies and erases the social and

structural factors that impact their ability to manage their disease, regardless of their education and knowledge about how best to maintain good health.

My mother and father were both diagnosed with type 2 diabetes within a few years of each other. I never gave the disease much thought before my parents were diagnosed, even though I knew that other members of my biological family had the disease, including my maternal grandmother and a few paternal aunts and uncles. Over the years, I witnessed how my mom and dad managed the disease in similar and different ways, and my interest intensified as I listened to more and more stories from my parents about the challenges they faced, the struggles they overcame, the battles they lost, and what everyday life was like living with a pervasive chronic disease. I remember how my mom used to tell me about how diabetes affected everything in her life: all of her physical body, her participation in daily activities, and her mood.

In June of 2010, my mom died unexpectedly of a heart attack that was no doubt related to her type 2 diabetes. Unfortunately, my mom was right about diabetes affecting her entire being. She was always quite in tune with her body and body processes, and I wonder if she knew how the disease was taking its toll on her body's internal workings and systems, despite her best efforts to live healthy with the disease. Losing my mom unexpectedly was the most devastating experience of my life. I know I will never fully "move on" from the loss, and those among us who have experienced death, loss, and grief know that asking someone to "move on" is unrealistic, foolish, and just plain stupid. The experience has marked my life for good, and I am still learning how to incorporate my grief and strong sense of loss into my everyday life, my hopes

and dreams for the future, and my professional identity as a social science researcher of diabetes and chronic disease.

Thus, for me, my professional life and personal life are intertwined in ways that cannot be broken or denied. My family's experience with diabetes blends in with my professional research on diabetes, the books and articles I read about the disease, and the classes in which I have learned to develop my professional positioning. For me, all these experiences ebb and flow into each other like a series of streams and rivers with no apparent beginning or end. From this point onward, I seek to make sense of diabetes in context of the intersecting challenges that impact everyday life and that make diabetes a disease of the total human experience: biological, ecological, social, economic, political, historical, and cultural. To understand diabetes in any other way would not only be a disservice to those with the disease, but a violent act in erasing the human experience inextricably linked to a diagnosis of diabetes.

CHAPTER ONE: INTRODUCTION

While a master's student in applied anthropology at the University of North Texas, I decided I wanted to work with an American Indian group and focus on a health issue for my required applied thesis project. After doing some preliminary research, I found that American Indians were disproportionately suffering from diabetes, and type 2 diabetes in particular, when compared to other standard identified ethnic minority groups, and to the majority White/European American population. This significant health disparity fascinated me in a way that left me significantly concerned. I thought to myself: why was it that this particular group had higher morbidity and mortality rates due to diabetes, and in particular, type 2 diabetes? What is it about this group that translates into a greater likelihood for getting sick? What could be going on to cause or contribute to this well-documented health disparity? I had learned enough at that point in my professional anthropology training to know the answer must be complex.

One of the most important lessons that an anthropological education teaches is a holistic perspective. What others from other disciplines sometimes regard as existing in a vacuum, we as anthropologists inextricably link to the situational and contextual factors that impact all of our lives. Thus, our work as anthropologists is necessarily muddy and often times more complicated than we initially anticipate. We think about and imagine the world in layers, and we seek to provide depth to our descriptions and analyses, so as to make better sense of the intersecting phenomena that give rich meaning and depth to our experience as *Homo sapiens*.

Armed with this anthropological perspective and a desire to understand the diabetes health disparity among American Indians, I decided to contact the Chickasaw Nation of Oklahoma and their Diabetes Care Center in Ada. I had reservations about

making this cold call. I was sensitive to the fact that, for centuries, American Indian groups have often been used as data mines. A review of the social science and humanities literature reveals that many of my anthropological predecessors gathered all sorts of data from often vulnerable American Indian communities, with varying levels of informed consent.

It was from my initial telephone call that I had the good fortune to meet Bobby Saunkeah, RN, CDE, diabetes program manager at the Center. He and his team of diabetes care experts at the Chickasaw Nation's Diabetes Care Center gave me the go ahead to design and implement a research project I titled *Implementing Best Practices: Program Evaluation and Program Development for an American Indian Gestational Diabetes Program*. This project was based on the needs of the Diabetes Care Center, as identified by Mr. Saunkeah and his colleagues, making it relevant to the issues confronted by their staff and patient population. This is standard best practice in applied anthropology research: it is client-driven, seeking to address a problem provided by the client and/or agency, and results in deliverables, or a set of recommendations, for taking action to address and potentially solve the problem studied.

My discussions with Mr. Saunkeah revealed that he and his team wanted a better understanding of and in-depth information about the needs of the women enrolled in their array of services targeting those with gestational diabetes, which is diabetes diagnosed during pregnancy. This is something that Diabetes Care Center staff wanted to do on their own, but simply did not have the time, given their busy patient care schedule. My goal was to collect systematic information on the lived experience of both health care practitioners in the clinic and current and former patients. My plan was to

use this data in order to glean a sense of what the Center did well and what could be done differently so as to improve patient care. I collected thirty interviews total (10 from key personnel and professional staff, 10 from current patients, and 10 from former patients), which led to a variety of important themes elicited from the transcribed data.

The results from this research study hit me like a hundred insulin filled syringes. As I read through and analyzed interview after interview, my anthropological good sense took over and profoundly impacted how I saw and experiencing the data. It was at this time in my research career that my inner sense of being a medical anthropologist began to flourish. I knew that how I wanted to make sense of the data I collected would best fit an anthropological perspective, and that this perspective would ultimately benefit the Chickasaw Nation Diabetes Care Center and its patients with its comprehensive and holistic approach.

As a budding medical anthropologist, and an increasingly critical one, I was captivated by the fact that the results of my research project with the Chickasaw American Indian community alerted me to many of the structural and macro-level factors informants recognized as being directly related to the individual experience of diabetes. There was no denying my informants' stories of how environmental circumstances, that were often beyond their control, often negatively impacted their ability to manage their disease. My research participants were quite savvy about their own circumstances, and they identified many factors in their lives they believed were positively and negatively impacting their health.

Beyond tales of blood sugar checks, soda pop, insulin injections, and fried foods, participants talked about how things like how being poor, being geographically

isolated in a rural area, or lacking access to fresh foods impacted their disease.

Furthermore, participants in my study shared about how stress, depression, and other mental health problems negatively impacted their management of diabetes, making it harder to cope with the daily requirements of diabetes management. Upon analysis of my data, it became abundantly clear that diabetes cannot be fully understood in solely biological and medical terms.

For years, health researchers from a variety of disciplines have sought to explain why some groups of people have poorer health outcomes than others. As such, health researchers and clinical practitioners alike have proposed a multitude of hypotheses about why health disparities exist, each of them informed by the theory and research used in the proponents' respective academic and professional discipline.

Anthropologists, unfortunately, have been relatively underrepresented in the discussion on diabetes health disparities.

This thesis attempts to address this issue by combining qualitative and quantitative methods to explore the lived experience of diabetes among a population of low income patients utilizing a free community clinic in central Oklahoma. I designed my social science diabetes research study utilizing quantitative and qualitative data collection techniques in order to 1) discover the strategies diabetes patients employ as they negotiate the economic and other structural factors influencing their everyday lives and 2) find out about participants' ability to maintain good health in light of the interaction between participants' personal health care strategies and the effects of each person's strategy implementation on their overall effectiveness in chronic disease management.

Study participants consisted of a sampling of low-income, uninsured patients with diabetes being served by a non-profit health clinic in central Oklahoma. Quantitative inventory scales were administered to assess patient experience of their own physical and mental health. Semi-structured interviews were conducted with patients in order to elicit important themes relevant for my study's focus and to ground the analysis of diabetes treatment best practice models in the experience of low-income and uninsured diabetes patients. I also visited the homes of consenting diabetes patients, where I conducted a household survey and interview, in addition to a one-time photographic food inventory assessment. I utilized participant observation, the hallmark of an anthropological approach to research, throughout the study, in which I kept field notes of the relevant experiences, interactions, and observations I had with patients, clinic staff, and the community.

While in the early stages of formulating my ideas for a dissertation research project, I thought it might be prudent to volunteer at Health for Friends before I decided to pursue a formal research partnership with the agency. Thus, field research began in late October 2009 and continued through the end of 2010, when I completed my final home visit. A total of 32 people were recruited to participate in my research regarding their experiences as type 2 diabetes patients, each providing an extensive amount of both quantitative and qualitative data for analysis. Of these 32, 15 were able to volunteer for further in-depth sampling and permitted me to visit them in their homes for additional interviewing and photographing of their food.

My research reveals important considerations. First, my research illuminates the importance of qualitative research methods in understanding health disparities. Rich

textual data provides an in-depth perspective into people's lives and their lived experience of disease. Second, my research shows how the structural, macro-level barriers those in poverty face (e.g., lack of health insurance, low income, unemployment, underemployment, social isolation, inadequate housing, food insecurity) limit options for diabetes patients when they are faced with managing their own health. Health for Friends provides some options, but analysis of my informant data demonstrates the paucity of local, state, and federal resources for those managing chronic disease and living in poverty. Interestingly, my research provides an opportunity to find out how Health for Friends diabetes patients coped with their health care before the Patient Protection and Affordable Care Act of 2010 impacted the clinic's health care practices. The most important finding from my study was with regard to the constraints placed on patients' ability to maintain their health and diabetes management given their living in various states of poverty. These limitations had the potential to manifest as sources of stress, anxiety, and depression, as they often had adequate diabetes management knowledge but lacked the social and economic ability to implement their knowledge.

Knowledge of a patient's lived experience of diabetes is critical to fully understanding a person's overall conceptualization of health, their ability to maintain good health, and how the medical profession may or may not be meeting the needs of vulnerable patient populations. Furthermore, given the current tenuous economic situation in the United States, the present study's research focus on the analysis of the intersection of socioeconomic and health disparities is immediately relevant to some of the nation's most pressing public health and health policy concerns. Ultimately, the

results of this study can be used to modify and formulate new local, state, and national public health programs that serve marginalized patient populations. The findings from this study will also contribute to theoretical understandings of the relationship between socioeconomic inequality and individual health behaviors and decision-making.

Additionally, study results can be applied to research on other health disparities in other regions in the United States and across the world where certain groups of people are unequally suffering from a disease.

CHAPTER TWO: ANTHROPOLOGY OF DIABETES

Introduction to Diabetes

As the leading diabetes organization in the United States, the American Diabetes Association and their associated website offers a wealth of basic and more detailed information about the different types of diabetes, common symptoms, diagnosis, and treatment planning. There are three main types of diabetes: type 1, type 2, and gestational diabetes. Type 1 diabetes is diagnosed due to the body's inability to produce insulin on its own. Without insulin, the body cannot process and absorb glucose effectively, which is essential to sustain life. People diagnosed with type 1 diabetes must take insulin in order to survive. About 5% of those with diabetes are diagnosed with type 1 diabetes (American Diabetes Association 2016). Type 2 diabetes is much more common than type 1 diabetes and is the most common form of diabetes; it is characterized by the body not using insulin appropriately. Over time, the body is unable to produce enough insulin on its own to keep up with the demand, and extra glucose accumulates and exceeds normal levels (American Diabetes Association 2016). Gestational diabetes, the third type, is diabetes that develops during pregnancy. Gestational diabetes is diagnosed by a woman's physician based on glucose tolerance testing. These women have not previously been diagnosed with diabetes before becoming pregnant. While the root cause of gestational diabetes remains unknown, hormone changes during pregnancy are thought to be a contributing factor. The result is insulin resistance, and a lack of the necessary amount of insulin needed to process glucose in the body (American Diabetes Association 2016). Proper diagnosis of diabetes is made by a medical professional and consists of performing blood glucose and other relevant tests to determine the level of insulin resistance.

Diabetes incidence in the United States has steadily increased over the previous decades. Data from the Centers for Disease Control and Prevention (CDC) spanning the years 1980 – 2014 demonstrate that diabetes rates have nearly quadrupled for adults age 18 and older during that time frame. According to the 2014 National Diabetes Statistics Report published by the United States Centers for Disease Control and Prevention, there are approximately 29.1 million people with diabetes in the United States, which is about 9.3% of the total population. Interestingly, this estimate includes those diagnosed with the disease (21.0 million people), and those suspected of having the disease but are undiagnosed (8.1 million people). According to 2014 CDC diabetes surveillance data for Oklahoma (Centers for Disease Control and Prevention 2016), the age-adjusted percentage of individuals with diabetes in the state is 10.9%. Analysis of CDC data about the duration of diabetes demonstrates the high number of new cases diagnosed in recent history. Data from 2011 are used to show that 61.2% of adults age 18 – 79 have been diagnosed with diabetes for 10 years or less (Centers for Disease Control and Prevention 2011).

With early detection and intervention, proper treatment, and necessary lifestyle modifications, those diagnosed with diabetes can live long and productive lives and mostly avoid the detrimental side effects of poorly controlled diabetes. Diagnosis and treatment is particularly important for type 2 diabetes, as this is the most common form of the disease and the type that develops over time. Diabetes is a disease that impacts the entire body system, so complications can arise in multiple areas of the body. Complications of poorly controlled diabetes include a variety of skin and eye problems, including infections and vision loss, neuropathy (nerve damage), foot problems, kidney

disease, stroke, gastroparesis, heart disease, and mental health problems like depression (American Diabetes Association 2016). Complications are exacerbated by other chronic health conditions, like hypertension (high blood pressure) and hyperlipidemia (high blood cholesterol). Diabetes is currently the seventh leading cause of death in the United States, with 20.9 deaths per 100,000 standard population in 2014 (Murphy et al. 2014).

Common perceptions of diabetes conjure up ideas about avoiding eating sweets, constantly measuring blood sugar, painfully injecting insulin, taking many medications, maintaining a strict diet, and needing to get lots of exercise. The public perception of this chronic disease can be frightening, particularly for those who live with the diagnosis on a daily basis. It is also troubling that diabetes is indicated as a leading cause for a variety of other serious health concerns, as is stated above, such as stroke, heart disease, kidney failure, lower limb amputations, and blindness. Furthermore, a diagnosis of diabetes becomes even more worrisome when paired with other chronic conditions. Therefore, when thought of in biomedical terms, diabetes often intersects with other health conditions to put the diagnosed person at risk for a variety of complications and frighteningly poor health outcomes.

In addition to the human body's impact on the individual course of diabetes, our broader environment influences the disease, sometimes in a manner not immediately apparent. Unfortunately, present economic conditions in the United States negatively impact the health of the country's citizens, often in predictable, multiple, and intersecting ways. This is especially true for those diagnosed with diabetes and other chronic diseases. Financial strain is challenging many individuals and families as they

strategize and budget resources for the necessities of everyday living, including food, shelter, electricity, and clothing. The changing job market and, in some areas, high unemployment rate means that an increasing number of people are competing for fewer jobs, making economic stability elusive for those most vulnerable to the social and economic pressures of our society. Additionally, since health insurance coverage is often linked to one's employment, many Americans must go without health insurance or have coverage that comes and goes with their job. While recent health care legislation and the Patient Protection and Affordable Care Act (2010) were created and implemented to counteract this problem, the fact remains that millions continue to go without health insurance or have limited coverage. This means that crucial access to preventive care, proper disease management, and life-saving medications are out of reach for a significant portion of our country's population.

The implications of this economic reality are staggering. For many people in the United States, critical decisions must be made about the amount of money spent on health care, medications, food, and the quality of food purchased. These decisions have a direct impact on the health of people with diabetes because good management of the disease often requires daily medications, in addition to a nutritious and well-balanced diet within a context of minimal stress and good quality of life. While anthropologists and other social scientists have studied diabetes in the past, more work needs to be done combining the social and biological sciences in ways that examine the structural, or macro-level, forces that impact the unequal distribution of the disease, particularly in vulnerable populations. This grounded approach to studying what many think is simply a biological phenomenon is particularly important in the United States at this moment in

time, given such an approach's relevance to the vulnerabilities and structural constraints discussed above.

Social Determinants of Diabetes

Public health practitioners and scholars agree that diabetes is a widespread health crisis in our society that manifests from a variety of interconnected origins. I designed my study in order to find out the strategies individuals use as they negotiate the multiple components of their lives that impact their health. This includes systemic, institutional problems like poverty and lack of universal health insurance, as well as manifestation of these problems within individual lives, such as lack of reliable transportation to get to a grocery store that offers a variety of fresh and healthy foods at an affordable price. My goal is to seek consilience among theories focusing on structures and institutions with those focusing on individual behaviors and risk factors in order to provide a more comprehensive understanding of how diabetes is lived on a daily basis among people facing multiple barriers to being healthy. My idea was not to collect a series of stories of failure and learned helplessness, however; I also hoped to find narratives of hope, courage, and resilience, in order to showcase the creative ways people living with diabetes live their lives and promote their own health as best they can. Thankfully, my informants' stories reflect a diversity of experiences that characterize daily life living with a chronic disease.

A disease like diabetes particularly lends itself to a social analysis of its determinants, especially because the factors that lead to the development of diabetes, such as obesity, high blood pressure, and a poor diet, are intimately connected to the environment, both natural and human made. Chaufan's (2004) deconstruction of the

critical social components of diabetes etiology and prevalence provides a comprehensive discussion of the social determinants of diabetes that is well suited to the goals and results of my present study.

According to Chaufan, while diabetes rates are drastically changing and diabetes has been labeled as an “epidemic” in the United States, attitudes toward the cause and treatment of diabetes, in addition to the appropriate research on diabetes, have changed relatively little over the years. Clearly, even though diabetes has reached epidemic status in the United States, it does not affect everyone the same. Research consistently demonstrates that diabetes disproportionately affects those from an ethnic minority background who also live in communities with poor economic conditions.

Interestingly, however, theories explaining the etiology of diabetes that have gained popularity and traction in the United States too often attempt to explain the development of diabetes in terms of genetics or lifestyle of the individual. Within these perspectives, diabetes researchers and practitioners speak of risk factors and individual choices that lead one to become more or less likely to develop diabetes. Furthermore, lifestyle is a repeated important theme for health care providers when trying to monitor the course of diabetes in people already diagnosed. Since genetic and lifestyle approaches to understanding diabetes are popular and, thus, influential, it naturally follows that these frameworks for thinking about diabetes tend to support biomedical and behavioral research and public health efforts, often with the goal of finding a “cure” for and raising awareness of the disease, particularly among high-risk populations (Chaufan 2004).

As Chaufan (2004, 259) simply puts, however, “the causal role of lifestyle is an important truth only to the extent that people have actual control over their lives.” This fact reflects the main idea of Chaufan’s chapter: the sociocultural and political realities in which those with diabetes are situated in are often overlooked and not given the same scientific investigation that genetic and lifestyle causal models are given. Carolyn Smith-Morris (2004) asserted the same truth in the same year and called for increased attention to the political and economic factors that impact diabetes development among American Indians, with particular focus on promoting political-economic transformations alongside diabetes interventions among the Pima (Akimel O’odham) Indians in Arizona. Paul Farmer (1997) adds that, regarding compliance with health care, “throughout the world, those least likely to comply are those least able to comply” (353). In the process of trying to make sense of the patient, or afflicted person’s perspective, according to Farmer, a paradox occurs, where this increased focus on the sick exaggerates their agency in the healing process.

Arguing from a social epidemiological and critical medical anthropological framework, Chaufan urges us to consider the structural factors, and indeed the structural violence, in the United States that continues to make certain people more vulnerable to developing diabetes than others. The fact that structural inequality and poverty exist demand that those of us interested in health disparities consider patterns of disease development that go beyond traditional biological explanations. Poverty, oppression, and discrimination have an exceedingly significant impact on the lives of millions of people in our country and beyond. Only when we take these powerful human-made forces seriously in terms of their impact on human health will we understand how

disease develops and spreads within a population. This is a major point that I hope becomes clear through the words and experiences of my research informants.

While not discrediting the important personal behaviors that are involved with diabetes management, Chaufan goes on to note that genetic and lifestyle models of diabetes often ultimately result in blaming the individual with diabetes for being responsible for developing the disease, as if something *about* them has caused them to develop diabetes. While this may be true to some unknown extent (as biological research is still developing and expanding in this area), the critical structural and societal forces at work in the development and maintenance of diabetes in the United States have been erroneously ignored or downplayed for too long. If our ultimate goal is to completely prevent diabetes, then we, as proponents of health research, promotion, and practice, create a real problem if our models that inform our work even covertly suggest that our patients are to blame for their disease. I feel confident that I can reasonably suggest that it will be difficult to motivate someone by first informing them, even subtly through meta-communicating blame, that it is their *inherent* fault they are sick. Chaufan (2004, 263) reminds us that “information about the benefits of healthy nutrition does not make healthy foods accessible.” Facts such as this, that speak to the real world mechanisms of health oppression, bring into question the true range of personal choice behaviors those with diabetes have, particularly if they are poor and do not have health insurance or regular access to health care providers.

It is important for those of us in the United States to understand that the answers policymakers formulate about how best to attack health disparities, including diabetes, are imbedded in how these influential people formulate their understandings of the

health disparities problem. Policymakers' causal models will, in turn, be reflected in which lines of research (socioeconomic or biomedical and behavioral, for example) are valued as important and, therefore, funded. According to Chaufan (2004), policy and research that values and understands the structural variables in the diabetes epidemic will lead to the overall improvement of the fight against reducing, and eventually eliminating, the diabetes epidemic. I agree with Chaufan's assertion, and it is a reason why I formulated my research topic in a way that would give me data to inform important others about factors that make people prone to being sick that cannot be easily located with their flesh and blood bodies.

Critical medical anthropology is an approach to doing medical anthropology that examines both the micro-level and macro-level forces that interact in order to impact human health and illness. Essentially, critical medical anthropology takes an all-encompassing stance on issues related to human health, including both the natural and human-made environment. Examples of the macro-level and structural aspects of human health examined within critical medical anthropology include areas like the analysis of government systems, distributions of poverty, discrimination, public policy, and international relations, and how these affect human health. With regard to micro-level and contextual phenomena, analyses are directly related to the individual's experience of structural factors, such as the individual experience of discrimination, a patient's response to medical treatment, patient access to quality health care, patient beliefs about appropriate health care treatment, and the management and prevention of a disease as experienced by individuals. Therefore, while critical medical anthropologists emphasize the social, political, and economic impact on human health, they are also

interested in individuals' daily lives with regard to how they are impacted by the structures and institutions we create.

Often times within studies aimed at a cultural analysis of type 2 diabetes, social and economic factors become apparent that are directly related to the experience of those with the disease. Reviewing my discussion of Chaufan's 2004 work in the previous pages of this document provides an excellent example of this fact. These social and economic factors are sometimes intertwined with the concept of ethnicity, resulting in significant associations illuminated between a person's self-ascribed ethnic identity, their socially recognized ethnic identity, and their social and economic circumstance and positioning within society. Life situations, structural factors, and particular circumstances that people negotiate in their daily lives are shown to be strongly patterned with society's organization and allocation of resources to those of different ethnic minority groups. Therefore, ethnic and cultural factors sometimes have the potential to become intertwined, synergistically, with other potentially oppressive socioeconomic characteristics, leading to differential access to valuable health resources needed for the best opportunity to live a life of good health.

A great example of an attempt to make sense of the social and economic factors associated with one's ethnicity comes from the work of Walsh et al. in 2002, when they published an article on "unpacking" the cultural factors associated with patient adaptation to type 2 diabetes. In their research, these authors identified what they call "ecocultural domains" that demonstrated better performance than ethnicity at teasing apart important variation in health service outcomes among Hispanic and non-Hispanic White type 2 diabetes patients at a Veteran's Affairs clinic in Tucson, Arizona. Walsh et

al. (2002) believe that future analysis of ecocultural factors, such as economic marginality, amount of domestic help, and social support, will prove better at producing responsible and effective service delivery than simple analysis of ethnicity. This is because ethnicity does not operate in our society in a vacuum. Ethnicity gets wrapped up with other socioeconomic markers that make some more vulnerable than others at developing preventable diseases that are significantly impacted by the environment. Thus, these authors make the case for a critical medical anthropological approach to understanding the incidence and prevalence of type 2 diabetes because they indicate both individual and societal factors as synergistically impacting individual bodies.

Similarly, in a qualitative study of lifestyle and self-management of diabetes, de Alba Garcia et al. (2007) interviewed 31 diabetic patients with good glycemic control and 31 diabetic patients with poor glycemic control in Guadalajara, Jalisco, Mexico. These researchers' goal was to highlight the strategies used by patients with good control of their blood sugar, so that these methods could be used in the future when working with patients with poor blood glucose control. Importantly, these researchers note the macro-level environmental factors in the type 2 diabetes epidemic, and hope their results can inform future structural policies. In this way, de Alba Garcia and his colleagues are contributing to a balanced approach to making sense of the diabetes epidemic, that takes into account personal and societal factors in the development of the disease. The results of this research clearly demonstrated qualitative differences between those type 2 diabetes patients with good and bad glycemic control. These differences included social and economic aspects of the patients' environments, such as

economic concerns of the study participants, employment issues, family support levels, and appropriate exercise and quality food intake.

Being from a low socioeconomic status frequently has direct implications for the management of disease, and type 2 diabetes is no exception, especially since the disease is intricately connected to self-management and available resources in the person's environment. This is a major factor of living with diabetes that I continuously highlight in my current study, since all of my research informants were identified as living in poverty, based on United States Federal standards, and lacked health insurance. Those living in rural and poor locations, such as those that chose to participate in my research study, often have a toughest time managing their diabetes because of their geographic isolation and lack of transportation that creates significant barriers to accessing health promoting resources. In fact, as I will discuss in more detail in a later section of this project, some of my study participants lived in rural areas characterized by isolation, which presented continuous problems for optimally managing their own health care.

For another international example of the interconnected nature of personal and societal influences on diabetes, Valenzuela and his colleagues (2003) conducted a study in a small rural community in the southern Mexican state of Morelos. As is true for many rural towns in Mexico, limited demographic data was available. These researchers' goal was to investigate the beliefs and knowledge afflicted individuals had regarding type 2 diabetes. Not surprisingly, Valenzuela et al. (2003) found that, while patients in their study had a strong desire to control their type 2 diabetes, important social and economic barriers perpetuated health problems and prevented study participants from living their most healthy life. Issues related to these barriers included

lack of guidance and information, lack of money for medication and blood glucose testing equipment, and the central role that social support played, received from family, friends, and neighbors, in successfully living with the disease. Some respondents expressed fear that having type 2 diabetes could cause significant and unwanted emotional and economic burden on their families.

These same themes were prevalent in my present sample of low-income diabetes patients who lack health insurance in Norman, Oklahoma. Participants repeatedly mentioned the important role that others played in the management of their diabetes, from providing emotional and psychological support to material support in the form of money, diabetes testing supplies, or food. Notions of social support being helpful in living successfully with diabetes are vital to consider when completing a comprehensive psychosocial and economic assessment of a person diagnosed with diabetes. Rural geographic location, without reliable transportation, has the potential to isolate individuals and prevent them being staying connected to others who can be instrumental in helping those diagnosed live a better life. Anthropologists agree that our species is a social species, and the social instincts of our ancestors should be recognized in the present day as being an important part of what keeps us healthy, informed, and connected.

In an intriguing testament to the link between structural oppression and individual physiological response, Scheder (2006, 288) conducted a “biochemical analysis of a stress-related catecholamine system enzyme in matched diabetic and nondiabetic Mexican-American farm workers.” Her results demonstrated that a migrant lifestyle, fraught with significant life changes, ongoing uncertainty, increased incidence

of stressful life events, greater potential for broad psychosocial stress, and overarching social inequality, “act via a series of physiological responses to culminate in hyperglycemia” (2006, 304). This example presents a vivid, and biological demonstrable, depiction of the intimate connection between macro and micro level forces in the individual expression and experience of type 2 diabetes, which is at the heart of a critical medical anthropological analysis of this health disparity. In this way, as I discuss in earlier paragraphs, the social and economic realities in which we all live become embodied within ourselves, manifest within our physical bodies, sometimes leading to the development of acute and chronic diseases.

Recently, researchers Myra L. Clark and Sharon W. Utz (2014) performed a critique of the literature on the social determinants of diabetes, examining research published between 2000 and 2013. Their review highlights the critical need of more studies that examine the role of the social and economic factors that influence the individual experience of disease. It is concerning that only 20 research studies were available that met the researchers’ criteria for inclusion in their literature review. Obviously, more work needs to be done that examines the social determinants of diabetes, particularly with larger sample sizes and with the inclusion of anthropological methods, such as ethnographic interviewing, in order to provide the necessary depth and lived experience that situates other data in context. This call to action was emphasized by a former United States Surgeon General, who wrote about the need to include the social determinants of health in our nation’s collective fight for eliminating health disparities (Satcher 2010).

Examining the intersection of race, poverty, and geographic location, Gaskin, Thorpe Jr., McGinty, Bower, Rohde, Young, LaVeist, and Dubay (2014) utilized survey and U.S. Census data to conclude that place and geography matters when examining risk for developing type 2 diabetes, such that African Americans and poor Caucasians are at greater risk for developing diabetes when they live in a poor neighborhood. These authors provide a critique of concentrated poverty as it contributes to the development of diabetes, including limited access to fresh fruits and vegetables and limited walkability of the neighborhood. These authors argue that policies should address concentrated poverty and will have the added benefit of reducing the diabetes risk for the community.

Also addressing poverty's influence on diabetes, Hsu et al. (2012) provide an interesting examination of the role of universal health care coverage in type 2 diabetes incidence and inequality. Using data from a national health insurance program in Taiwan, these authors came to the unfortunate conclusion that poverty is significantly associated with a rise in type 2 diabetes rates, insufficient diabetes management and care, and a delay in initial diagnosis. Clearly, the social determinants of diabetes that are inextricably linked with the lived experience of poverty continue to have a negative impact on individuals diagnosed with diabetes, despite the availability of universal health care coverage.

Biological and Genetic Conceptualizations of Diabetes

My goal in designing my current research project is to highlight the social and environmental factors that impact the incidence, prevalence, and maintenance of chronic disease, and in particular, diabetes. In this way, people's individual bodies are

inextricably intertwined with their environments, broadly and inclusively defined. Despite this fact, it is important for medical anthropologists, like me, who tend toward a critical medical anthropological theoretical and practice orientation, to know the arguments proposed by those who favor biological and genetic explanations for the higher incidence and prevalence of diabetes in some population groups instead of others. This biological and genetic information can prove useful in a comprehensive analysis of the biomedical consequences of how our species organizes its communities and society at large.

Scientists have made numerous attempts over the past several decades at explaining type 2 diabetes utilizing theory and methods from the biological and genetic sciences. These researchers believe, as well as their funders, that focusing their efforts on the biological bases of diabetes will serve to best treat and prevent the disease from growing incidence in the population. Sampling the literature reveals the extensive efforts laboratory scientists make to find increasingly specific and molecular causal factors for the disease. While no specific genes have been conclusively agreed upon as the “cause” of type 2 diabetes, researchers in this area feel confident that continued efforts will reveal the true biological and genetic basis of the disease.

Often times, particular racial/ethnic groups are the focus of study for scientists interested in searching for genetic differences that, they believe, can make certain groups of people more susceptible to disease than others. Inherent in this argument is an assumption that those from different racial/ethnic groups differ in biological and genetic ways that are significant enough for scientific scrutiny. Therefore, while not often explicitly stated, these biomedical scientists send a message that transforms the race and

ethnicity concepts from a socially constructed phenomenon to one that is biological in nature.

Neel's (1962) "thrifty gene" hypothesis is an instance of a geneticist's approach to making sense of the diabetes health disparities observed in some Native American groups in the United States. Simply put, this hypothesis purports that pre-historic Native American hunter-gatherer populations had to adapt to changing periods of feast and famine, and only those who were best able to store fat and nutrients during times of famine lived to reproduce and pass genetic inheritance of this ability to offspring. In today's modernized environment where food is relatively plentiful, those who have inherited this thrifty gene, the hypothesis postulates, are no longer adapted to the environment and therefore have higher rates of being overweight, being obese, and type 2 diabetes.

Individuals of Mexican descent provide an interesting perspective for researchers studying the genetics of type 2 diabetes. Anthropologists and other scientists have demonstrated that the majority of the population in Mexico has some level of American Indian ancestry in their genetic material, resulting from the extensive Native population in the country at the time of Spanish contact. Of all racial/ethnic minority groups in the United States, American Indians and Alaska Natives have the highest prevalence rate diabetes, with an estimated 15.9% of the population aged 20 years and older with diagnosed diabetes. Their non-Hispanic white counterparts have a prevalence of 7.6% (Centers for Disease Control and Prevention 2014).

Scientists have speculated that having American Indian genetic material makes a person more prone to developing diabetes, due to a hypothesized genetic susceptibility

found among those with American Indian ancestry. For those of Mexican descent, whose ancestral background includes both American Indian and European roots, the amount of suspected American Indian ancestry has been correlated with prevalence and risk of developing type 2 diabetes. Therefore, the biological and genetic lens used by these researchers to view type 2 diabetes results in a tertiary or minimal mentioning of ethnicity. When mentioned, ethnicity is clearly associated with genetic ancestry and genotypic and phenotypic expression.

The 1996 work of Hanis et al. provides an example of efforts to locate specific type 2 diabetes susceptibility markers on the human genome among those of Mexican descent. These authors studied 330 affected sibling pairs from 170 sibships in a Mexican American sample from Starr County, Texas, a rural country located on the border with Mexico. This specific county was noted as being ideal for a genetic study of type 2 diabetes due to its high Mexican American population, high prevalence of the disease, and suspected American Indian population admixture. High rates of type 2 diabetes are assumed here to be directly linked to the fact that American Indian ancestry accounts for a significant amount of the genetic material in the Mexican American community along the Texas-Mexico border. Using non- and quasi-parametric linkage analysis, Hanis and his colleagues (1996) were able to find one marker, *D2S125*, which demonstrated considerable linkage to type 2 diabetes. According to the researchers, the presence of this marker is interpreted as evidence of an important genetic component in the development of type 2 diabetes that is specific to Mexican Americans. Therefore, these researchers demonstrate an inherent aspect of these research participants' genetics makes them susceptible to developing a chronic disease.

Further north, Chakraborty et al. (1986) conducted a study of Mexican Americans in San Antonio, Texas with the same idea, that having American Indian genetic admixture in a population means that population will be at increased risk for developing type 2 diabetes. These researchers used neighborhood status (barrio, transitional, and suburb) as a measure of socioeconomic and cultural status in their genetic survey of 1,237 Mexican Americans (including a diabetic, control, and intermediate group). These authors also cited a lack of research that seeks to corroborate ethnicity with a genetic assessment of a group. Chakraborty et al. (1986, 448) demonstrated a significant relationship between type 2 diabetes prevalence and the genetic structure of their study population. They report a “clear and statistically significant relationship between the degree of Amerindian admixture in each population stratum and prevalence of NIDDM in both males and females.” The researchers go on to note the importance of genetics over the environment when they claim that “the genetic difference between the diseased and normal individuals rather than that between the neighborhood groups is responsible for the pattern observed.” Thus, having less American Indian ancestry was found to be associated with a decreased risk for developing type 2 diabetes, according to how these researchers organized their study and interpreted their data.

Finally, in a more recent study of type 2 diabetes patients and controls in Mexico City, Mexico, Martinez-Marignac and her colleagues (2007) continued the tradition of hypothesizing about the relationship between American Indian ancestry and the incidence and prevalence of type 2 diabetes. They offered admixture mapping as a tool to assess for genetic risk factors in the development of type 2 diabetes. These

authors cited the unique genetic contributions from the original peoples of Mexico (e.g. the Aztecs/Mexica), Europeans (Spanish), and West Africans in the composition of the peoples of modern day Mexico. With regard to ancestry estimates, Martinez-Marignac and her fellow researchers (2007) estimated American Indian contribution to the sample at 65%, European at 30%, and West African at 5%. With American Indians having a higher prevalence of type 2 diabetes, these authors note the future implications for studying type 2 diabetes genetic risk factors with admixture mapping methodology. Clearly, they believe that genetic analysis is the best way to make sense of the complex processes that contribute to the development of the disease.

Barker (1990) was influential in developing research on the fetal origins of the adult development of chronic diseases like diabetes. The fetal origin, or thrifty phenotype, hypothesis, as it has come to be known, proposes a relationship between fetal environmental health and the subsequent development of disease and health disparities. Hales and Barker (1992) examined the thrifty phenotype hypothesis in the context of the development of type 2 diabetes. The hypothesis was also investigated by de Boo and her colleagues (2006), as well as Fernandez-Twinn et al. (2006). These scholars found convincing evidence of how a poor and inadequate fetal environment, largely stemming from poor maternal health, can actually program the fetus, based on a poor fetal environment, to anticipate a compromised environment later on in life outside of the womb. This biological pre-programming leads to the development of diabetes in the child, as he or she grows and develops to adulthood. This unfortunate cycle then has a chance of continuing, as the now grown female child's body is compromised during the pregnancy of her own child.

In a 2010 editorial, Yajnik reviewed studies of the fetal programming process in diabetes and notes there is still much to learn about how specifically this process works so that more precise interventions can be created, including more knowledge about critical periods of growth and development in fetal development and fetal programming that contribute to the eventual expression of diabetes. The author asserts that more emphasis should be placed on the health of girls and young women in order to prevent fetal programming of diabetes in a future fetus. Similarly, Berry, Boggess, and Johnson (2016) offer a state of the science paper that links the obesity epidemic to the development of type 2 diabetes in women of childbearing age. The authors call for health care providers to be more proactive in their discussions with girls and young women when obesity is a concern and educate them about the risks of fetal programming in the development of type 2 diabetes as part of a comprehensive health and weight management program. Main risk factors for fetal programming and future development of type 2 diabetes are low birth weight and pregnancies in which the mother is diagnosed with gestational diabetes, which point to important nongenetic risk factors for the development of the disease (Vaag et al. 2014).

Cultural Approaches to Making Sense of Diabetes

In addition to a biological and genetic emphasis, some researchers take a strikingly different approach and favor a mostly cultural analysis of chronic diseases like diabetes. As expected, researchers exploring cultural models of type 2 diabetes give the most attention to measures of ethnicity as a proxy for studying cultural beliefs and practices when making sense of the individual experience of disease. In this regard, ethnicity is important because of the cultural elements integral to one's affiliation with a

particular ethnic group. These cultural elements in turn form the foundation in a person's explanatory model of diabetes, expressed in a person's epistemology, or way of knowing about the disease in the context of their experience. While culture is a tenet of anthropological research, its relationship to the anthropological study of diabetes is up for debate, has long held beliefs about racial and ethnic differences in diabetes prevalence and incidence have given way to more critical approaches to the study of the disease that examine multiple causal factors (Ferzacca 2012).

For the critical medical anthropologist, culture is important because one's socially constructed and ascribed cultural identity has the potential to make a variety of community resources more or less available to a person diagnosed with a chronic disease, such as adequate health care, reliable transportation, and affordable fresh and healthy foods. Thus, culture and ethnicity matter in how they impact the arrangement of the natural and human-made environment, and how one's affiliation with a particular ethnic group impacts the existence of barriers and facilitators to maintaining optimal health in an individual's environment. Using Mexican ethnic identity affiliation as an illustrative example of culture's role in type 2 diabetes research and practice, the following examples illuminate how the individual cultural experience of disease, and diabetes specifically, is used as a lens for analysis.

Daniulaityte (2004) presents research on how type 2 diabetes patients attending Social Security clinics in Guadalajara, Jalisco, Mexico make sense of their diabetes experience within the context of culture. This provides a stark contrast to the work of biomedically oriented researchers studying those of varying levels of Mexican descent diagnosed with diabetes. The purpose of this analysis is to reveal how a particular

ethnic group, in this case individuals in Mexico, make sense of their unique cultural and environmental experience. This author used a cultural consensus model of type 2 diabetes to analyze diabetes scenarios in an interview and test for each patient's level of cultural knowledge, level of cultural sharing, and to validate cultural themes of type 2 diabetes etiologies. Overall, what was most important in explaining the cause of type 2 diabetes for the patients in this study, according to the authors, were emotional (emotional distress) and environmental (stress, anxiety, urbanization, economic problems) causal explanations of the disease. Interestingly, those with better control of their diabetes exhibited higher levels of cultural knowledge about diabetes etiology. Furthermore, this cultural knowledge exhibited by patients is directly influenced by changes in society, including modernization, rapid growth, and the resulting changes in food quality and availability. This attests to the social and economic influences on people's cultural knowledge and beliefs of health and disease, and is the type of data that critical medical anthropologists look for among cultural analyses of disease.

Additionally, traditional Mexican culture is known to exhibit ideas about gender roles and each gender's relationship to health and health care. These roles demonstrated an important relationship to cultural knowledge in Daniulaityte's work (2004), with women having more cultural knowledge than men with regard to health and type 2 diabetes. Importantly, there was no consensus among participants as to the hereditary or genetic aspects of type 2 diabetes risk inheritance. The results of this study demonstrate the community's role in creating cultural knowledge about the cause of disease, and how this knowledge can be in direct opposition to traditional biomedical frameworks employed by health professionals in treatment and prevention efforts.

Particular aspects of culture can also be influential in providing facilitators to effective management of type 2 diabetes. Several studies have examined the Mexican American experience in order to find out what is unique about Mexican and/or Mexican American culture that shapes their explanatory models of disease and ways of knowing about where type 2 diabetes comes from and how best to provide treatment. Coronado et al. (2004) conducted this type of study with six focus groups with a total of 42 Mexican Americans in rural Washington State. These researchers found that participants held two separate and parallel belief systems about the etiology of type 2 diabetes, including a model of environmental and behavioral risk factors (e.g. heredity, eating excess sugar, eating excess grease, and obesity) and another of emotional and folk risk factors (e.g. fright/susto, anger, joy, and sadness). When asked about how to treat type 2 diabetes, participants also endorsed two separate models, but these were found to be integrated with each other, as opposed to distinctly separate models of etiology. Treatment models included biomedical treatments (e.g. diet and exercise, oral medication, and insulin injections) and natural/folk therapies (e.g. cactus, aloe vera, silk cottonwood tree, and tree spinach).

In this analysis of type 2 diabetes utilizing a cultural lens, investigators have the opportunity to discover, as Coronado et al. (2004) did, how those with type 2 diabetes make sense of their disease, and how their cultural beliefs produce rational ways of understanding cause and ultimately engaging in treatment. This is important information for a critical medical anthropologist to have when providing an analysis and description of the everyday life of those with a diagnosis of type 2 diabetes. Cultural knowledge, beliefs, and attitudes are embedded within the broader societal structures in

which people live, and culture influences, and is impacted by, the social and economic systems in place, as well as the political and historical environments in which cultural practices manifest and thrive.

As another forty-nine Mexican American patients in South Texas were given open-ended interviews by Hunt and her colleagues (1998) in order to elucidate causal models of type 2 diabetes and their relationship to treatment behaviors that is particular to this group. Results indicate that participants personalize their illness experience in ways unique to their own life course and life events. While most participants indicated diet and/or heredity as part of the etiology of type 2 diabetes, few remarked that these biomedical risk factors were the only cause of the disease. These authors introduce “Provoking Factors” as important to understanding type 2 diabetes in this Mexican American population, and define these as “specific events and behaviors from their past” (1998:966). In this way, type 2 diabetes patients personalize the impersonal concepts of biology and genetics often cited as the root cause of diabetes.

Lastly, based on longitudinal work conducted by Leslie Korn in a small indigenous community in rural western Mexico, Korn and Ryser (2006) wrote about the diabetes experience and its relationship to nutritional trauma and traditional medicine. Taking a holistic and cultural view, these authors describe how traditional knowledge of an indigenous community can be valued and validated, along with the group’s culture, in order to combat chronic diseases like type 2 diabetes. Traditional knowledge includes the use of traditional remedies and traditional medicine in treating disease, the cultivation, harvesting, and preparing of traditional foods that are endangered due to rapid development and globalization, and an overall validation of local and contextual

ways of making sense of the world. The end result is validation of the group's culture and an increase in group cohesiveness.

Qualitative Diabetes Research

There are many examples from within the previous decade of the effectiveness of qualitative research methods when used to study the patient experience of type 2 diabetes, including factors that influence the ability of patients to successfully manage their diabetes. Researchers have found qualitative methods, and in particular, ethnographic interviewing, to be a vital component of diabetes research and a best practice method of obtaining in-depth and contextual information about the lived experience of diabetes within a particular environment, broadly defined.

Salamon et al. (2012) studied adolescents using semi-structured interviews in order to find out about their lived experience of type 2 diabetes in order to inform future studies of youth with type 2 diabetes, as well as to inform future interventions by making them more specific to the youth experience of the disease, including self-management behaviors and motivators for improving their health. In a study of general practitioners, nurses, and patients diagnosed with diabetes, Goetz et al. (2012) studied the role of social support in type 2 diabetes management using focus group and semi-structured interview data. These authors found that social support plays a vital role in the management of diabetes and identified barriers and facilitators to providing enhanced social care to patients both during the clinical encounter and in the community. Also attesting to the important role of social support is focus group and semi-structured interview research by Goldman, Ghorob, Eyre, and Bodenheimer (2013) examining the perspectives and roles of peer coaches, who are diabetes patients

trained to provide diabetes management support to peers, when working with low-income diabetes patients. Benefits were found for both the peer coaches and their patient peers, with peer coaches playing 3 important roles in the treatment of their peers: role model, supporter, and advisor.

Recent qualitative studies examining diabetes education have been completed in order to improve best practices in diabetes patient care. Eborall et al. (2016) analyzed in-depth semi-structured interview data from nineteen adults from ethnically diverse backgrounds in order to determine the impact of a standardized diabetes education curriculum for newly diagnosed patients. These researchers' results highlighted the importance of balancing positive and negative messages about the disease in ways that optimize patient self-management behavior. Schwennesen, Henriksen, and Willaing (2016) utilized semi-structured interviews to examine patient explanations for not attending type 2 diabetes management education classes and found both organizational and individual factors that contribute to non-attendance, with the recommendation that future type 2 diabetes education programs be tailored to the specific needs of and barriers within the target population. Lastly, researchers in Norway followed up with patients who participated in diabetes management education groups and used semi-structured interviews to discover the factors that facilitated lifestyle changes being implemented and maintained long term (Rise, Pellerud, Rygg and Steinsbekk 2013).

As in my study, qualitative diabetes researchers have also examined the barriers and facilitators to effective diabetes management. Jeragh-Alhaddad, Waheedi, Barber, and Brock (2015) performed a qualitative study, utilizing semi-structured interviewing, of Kuwaiti patients with type 2 diabetes in order to find out the barriers to taking

medication. The researchers found that a variety of factors contribute to medication non-adherence, including issues related to the health care system, medical providers, and religious, sociocultural, and personal belief systems. In a study of rural type 2 diabetes patients and health care providers, focus group and interview data was used to examine barriers and facilitators to effective diabetes management in rural South Australia. Data revealed the intrapersonal, interpersonal, structural/macro level factors that impact one's ability to effectively manage diabetes in a rural environment (Jones, Crabb, Turnbull, and Oxlad 2014). In a qualitative study of food security issues among low income people living with diabetes, Cuesta-Briand, Sagers, and McManus (2011) found that, despite the fact that participants had a good understanding of the nutritional requirements needed to manage diabetes successfully, key barriers to securing quality food, such as access to healthy food, relying on others for meals, and the higher cost of healthy food, prevented them from utilizing their knowledge. Studies such as this contribute to the growing body of data about what health promotion factors need to be considered when working with type 2 diabetes patients.

The role of mental health in the management of diabetes has received increasing attention in recent years. In an interesting study, Peel, Parry, Douglas, and Lawton (2004) studied 40 newly diagnosed individuals with type 2 diabetes with in-depth interviews to find out about their emotional reactions to their diagnosis and their views about diabetes education at the time of diagnosis, which is often a highly emotional time. These researchers found that study participants felt that not enough health education was given at the time of diagnosis, and that participants' emotional reaction to their diagnosis depended on the route to their diagnosis, whether it be by the patient

already suspecting they had diabetes, getting sick and being tested, or getting diagnosed as part of a routine health care visit. The important role of emotional support in diabetes management was also highlighted by the results of a semi-structured interview study of an international sample of low income Latinos in Chicago, low income African American women in North Carolina, and middle income Caucasians in the United Kingdom (Kowitt et al. 2015). Beverly et al. (2012) studied self-blame and perceived responsibility for non-adherence to healthy diabetes management by interviewing both physicians and type 2 diabetes patients. They found that patients often blame themselves for their diabetes management failures, and physicians often feel responsibility for their patients' failures. These perceptions are barriers to improved diabetes management that need to be addressed during the clinical encounter between patient and health care provider.

Mendenhall et al. (2012) examined stress, depression, and the lived experience of diabetes across income groups in urban India. Results from their work indicate that stressors are experienced differently depending on income group, with the lowest income group in the study endorsing the most depression and less access to diabetes related health care, which can result in increased diabetes related health complications. Hansen and Cabassa (2012) discovered pathways to depression care and barriers to help-seeking for low-income Latinos diagnosed with diabetes and depression, with implications for prioritizing mental health care among those with diabetes and facilitating help seeking behaviors. Finally, in an intriguing mixed methods study, Mendenhall et al. (2015) documented the synergistic relationship among physical, psychological, and social suffering among low-income residents of Nairobi, Kenya.

Their research highlights the need for contextual analysis of the patient experience of diabetes, as it is heavily influenced by social, economic, and psychological factors.

Health Disparities

Hypotheses for the root cause of diabetes have the potential to inform a range of public health initiatives, including public policy prevention and intervention programs. The discipline of anthropology, along with other fields in the biomedical and physical sciences, has a history of being interested in observed difference in human health, growth, and development. This has especially been true in the United States. The coming together of European and Native American populations, along with others from all regions of the world, has meant that the United States has been the site of a unique experiment in human diversity for centuries.

Far too often in our discipline's developmental history, anthropologists' fascination with difference among our species has led some to falsely argue that this diversity should be attributed to the existence of a fundamental difference between species. This archaic argument posits that human variation was the result of humans not all being the same biologically and genetically. As we know, this line of reasoning has provided fuel for discriminatory and racist fires for centuries. An unfortunate example comes from Francis Galton's eugenics work, in which the goal was to engineer a particular genotype, and therefore, phenotype, that was valued over others (Galton and Galton 1998). Clearly, this was a movement to eliminate undesirable traits, and therefore people, in our communities.

Researchers today have a tendency to conceptualize health disparities based on biological, sociocultural, economic, political, and ecological factors as they attempt to

make sense of the significant differences in health indicators as measured within and across human populations. Importantly, the way in which group membership is defined also impacts how health disparities manifest, as well as the particular theoretical lens used to examine these differences.

Health disparities are measurable differences in the status of health between different groups of people, typically measured at a broader, population level. In the United States and other industrialized nations, researchers examine health disparities from the perspective of the differences between the majority population and minority groups, defined as a minority by their smaller population numbers, reduced power and influence in society, reduced societal representation, and secondary economic and political impact in comparison to the majority population. Researchers in the United States are most interested in measuring health differences with regard to race and ethnicity, and a review of the literature in social science, biological science, and public health confirms this assertion.

In the United States, emphasis on racial/ethnic factors in health disparities typically results in distinguishing between the majority white, European American population and the rest of the country's citizens. Minority groups that are held in comparison to the majority include those representing the most widely studied racial/ethnic groups, such as African Americans, Hispanics/Latinos, Native Americans/Alaska Natives, and Asian Americans. Therefore, minority populations often find themselves being measured with regard to their overall adequacy and ability to achieve health in comparison to their supposedly better functioning, healthier, European American counterparts. In this way, the lifestyle, culture, and health of

European Americans is privileged and used as a benchmark of success in achieving health.

Importantly, health disparities do not only have to be measured with regard to race and ethnicity. For example, differences in socioeconomic status or geographic location, regardless of race and ethnicity, can lead to notable health disparities. This socioeconomic perspective on health disparities is particularly relevant to this research study, because it is believed that a diabetes patient's social and economic status has a significant and measurable impact on the way he or she manages his or her own health. In fact, the way in which a researcher chooses to measure a health disparity will no doubt directly influence the potential outcomes of a scientific investigation of health disparities. Various theoretical explanations and scientific posturing also inform the decision about which methods for eliminating health disparities should be used, which then frames a discussion on which factors most contribute to the existence of health disparities in the United States.

Anthropological Approach to Health Disparities

Anthropologists have long been interested in observing and measuring the physical and health-related differences among different groups of people over the course of many years. Observations of racial/ethnic disparities in health and other facets of human growth and development have led some to call for radical action in producing a healthier population, such as Francis Galton's coining of the term "eugenics" mentioned above (Galton and Galton 1998). Franz Boas (1916), in response to the eugenics movement and other similar perspectives that prioritized biology and genetics over social and cultural influences, demonstrated how human biology cannot be

understood in a vacuum, void of sociocultural and economic factors, in his physical anthropology studies on generations of United States immigrants. Importantly, Boas' work had clear policy implications for the United States' stance on the influx of eastern European immigrants. By using a powerful anthropological perspective, Boas showed biology could not be used to explain a perceived inadequacy of brain and intellectual development argued by others to be attributable to those who were racially and ethnically different from the Western European Caucasian population.

In 1981, Stephen Jay Gould, in the spirit of Boas, published "The Mismeasure of Man" in loud protest to the privileging of genetics in cognitive functioning and intellectual ability. In 1994, Herrnstein and Murray published their notorious book, "The Bell Curve," that sought to demonstrate that African Americans are inherently inferior to their white counterparts, have genetically-based below average intelligence, and therefore should not be the recipients of, according to this argument, wasteful social welfare programs. This frightening argument is a reminder of the power of how one's theoretical orientation and methodological selection can inform an argument that has drastic implications for our diverse society, in ways that rank its citizens in terms of their inherent value, based on supposed science. Clearly, purported differences in human health and mental functioning have been met with plenty of debate and contention in our anthropological legacy.

Thus, when thinking about health disparities in diabetes and the factors that influence people's ability to manage the disease, it is crucial to remember that one's conceptualization of the diabetes health disparity and the best ways to combat the unequal distribution of the disease depends on the theoretical orientation, and associated

toolkit of methods, that one brings to the table. Therefore, the contributing factors to health disparities can be understood with regard to the theoretical orientation that privileges some factors, illuminating them for potential intervention, while masking others, pushing them to the shadows, and rendering them invisible.

Importantly, definitions of group membership, necessary to make sense of health disparities and suggest possible interventions, are also guided by the theoretical orientation and way of making sense of differences in health that is espoused by the professional in charge of the health disparity analysis. In my research with diabetes patients receiving medical care in a non-profit community health clinic for individuals with low income and without health insurance, my interests lead me to prioritize the macro-level structural factors impacting the individual experience of disease, such as one's income, housing status, transportation accessibility, and geographic area of residence.

How we as professionals define group membership matters to those we seek to define, categorize, and ultimately help. The foundation of my work in this research study is a concern with how poor people are able to live their lives in a healthy, fulfilling way when they are faced with all the challenges that go along with not only being poor, but also with managing a potentially debilitating chronic disease. Therefore, my targeting of those who are poor and lack health insurance means that I am categorizing this group and treating them as "other," or as a minority group in comparison to those who are not defined as living in poverty and who have health insurance. By categorizing individuals as not poor versus poor and having health insurance versus not having health insurance, I am attempting a contextualized

explanation of the lived experience of diabetes among those whom the disease tends to have its most significant impact. Ultimately, I hope to inspire macro-level and structural changes to eliminate a health disparity based on social and economic status.

Studying uninsured poor people with diabetes is especially relevant when one considers the group membership of those in power – the scientists, health experts, politicians, and the like, who frame the national and international agenda on health disparities research, funding, and intervention. If this group of people in charge of health disparities research is limited in scope, meaning it does not represent a diversity of ideas and perspectives that spans the range of the social and biological sciences, the consensus on agreed upon best practices to combat health disparities will be severely limited. Whether this group of influential people is made up mostly of biologists, geneticists, ecologists, political scientists, economists, anthropologists, or psychologists will directly impact the measurement of health policy because certain ideologies will be privileged over others. Some voices will be heard loudly, while others will fall silent. In the following sections, I will present a sampling of the voices of those from the most influential anthropological theoretical perspectives in health disparities research.

Critical and Political-Economic Factors

Anthropological approaches to understanding and combating health disparities that prioritize political and economic factors are of special relevance to my current study, as they played a significant part in how my research participants experienced their day to day lives with diabetes. The term critical medical anthropology (CMA) is used in order to describe an endeavor that integrates the vast literature on political economy with the growing literature on the political economy of health and critical

approaches to medical anthropology (Baer 1982, Singer 1987). Since then, the medical anthropology literature has been awash in discussion, dialogue, and debate on the role of critical, macro-level perspectives in the research and practice of medical anthropology.

CMA approaches emphasize the structured political, economic, social, and historical influences on the unequal distribution of disease. In this view, the systems and environments created by humans can make us sick, resulting in the potential for marginalized groups to be prone to greater incidence and prevalence of disease. Therefore, not surprisingly, concern about health disparities is at the heart of a CMA perspective, and researchers who investigate the political, economic, social, and historical factors in the development and proliferation of health disparities define their study groups by these structures and people's inclusion or exclusion within each.

A nice example of the macro-level political, economic, historic, and social influences on health disparities comes from the work of Singer et al. (1998) when they deconstructed, and subsequently reconstructed, the alcohol problem of "Juan Garcia," a Puerto Rican immigrant living in New York. These scholars successfully situated Juan's alcohol problem, and the alcohol problems facing many other Puerto Rican men during the time of their study, in historical, political, economic, and social context. This type of contextual analysis is a key aspect of an anthropological approach to studying health, and what sets the discipline apart from others that maintain varying degrees of interest and involvement in human health research and practice. The authors of this study traced history back to the introduction of alcohol to Puerto Rico by the Spanish, and linked the consumption of alcohol with the cultural construction of reward after a hard day's work

that came to define machismo identity for Puerto Rican men. Out of a job, and thus left without a way to express his male identity, these CMA investigators argued that Juan used drinking as a way to socialize and demonstrate machismo behavior, which were important attributes for men like him to have in Juan's society and culture.

Other examples of the structural influences on health abound from the work of Paul Farmer (1996) as he has revealed the nature of structural violence and its impact on the unequal distribution of human suffering. Farmer's publication of *Partner to the Poor: A Paul Farmer Reader* (2010) provides his audience with an exceptional representation of Farmer's and his colleagues' work illustrating the critical and political-economic perspective in medical research and practice. Farmer argues, throughout his collection of writings, that social and political forces are often left out of analyses and explanations of health disparities. Not until these essential structural factors are considered and understood, Farmer urges, will we be able to eliminate the world's health disparity problems.

Eliminating Health Disparities: Best Practices and Future Challenges

In 1979, the United States Department of Health and Human Services created a set of goals and objectives aimed at improving the health of the American people on a variety of measures and factors. They called this proposal *Healthy People 2000*, and subsequent versions and goals for 2010 and 2020 have been adopted. Provisions to eliminate health disparities are a significant component of this program proposal. While objectives with accompanying goals have been offered, there are still no clear solutions as to what to do about the health disparities that only appear to grow in scope and magnitude in the United States and beyond.

As I emphasized earlier, the perspective, or theoretical and methodological lens, espoused by those in charge with regard to the cause and elimination of health disparities is the one that will naturally be prioritized and influence research funding and outcomes. We, as a citizenry, need to be mindful of the fact that the *Healthy People* documents are ultimately an artifact of an institution of the United States government. How those scientific investigators define group membership, whether by race, ethnicity, socioeconomic status, geographic location, gender, age, sexual orientation, disability, or some other characteristic, will frame the national dialogue on our health disparity problems. As a consequence, the dominant perspective one takes will naturally illuminate some aspects of the health disparities problem while rendering other factors out of view. As anthropologists, we need to understand the culture of the institutions, organizations, and agencies that frame our national, and international, perspective on health disparities. This understanding will assist us in making sense of what can realistically be done to eliminate health disparities based on a comprehensive understanding of the problem, instead of knowledge that is biased by the perspective of those in charge of the discussion and debate.

Thankfully, investigations of the varying perspectives on health disparities are being done. Lee (2009) conducted an analysis of 204 published biomedical and public health studies that included race and ethnicity as a variable of interest. Surprisingly, she found that the vast majority of researchers did not appropriately operationalize what was meant by the terms race and ethnicity or state explicitly what results suggested that demonstrated racial and ethnic health disparities. Both Lee (2009) and Halfman et al (2005) note the clear policy implications from these devastating omissions. There is real

potential for public health policy, that naturally flows from biomedical and public health research, to willingly prioritize biomedical reasons for health disparities over all others, especially if racial and ethnic factors are not fully explained. The logical result is that private and public research funders will concurrently prioritize research that looks at eliminating health disparities from a primarily biomedical perspective. Since research funding is ultimately finite, this will also result in the neglect of other important approaches to the elimination of health disparities that examine such factors that are often of interest to medical anthropologists, such as the social, economic, and political influences that are inextricably bound with the sociocultural construct of race and ethnicity. Money, and therefore political power and economic systems of funding, have the potential to lead the way in setting the national, and international, dialogue on speculations about what causes health disparities and how best to create environments of health equity. Privileging biomedicine, for example, could lead to the prioritization of pharmacogenomics and could continue to contribute to a racialized view of human biology that lacks a contextualized and perspective of health, illness, and disease for which anthropologists continuously fight. As anthropologists, it is our responsibility to combat narrowed views of health disparities, and work to provide holism and context to the national and international public health and health care conversation. These essential efforts will not only provide a better opportunity for adequately addressing the elimination of health disparities, but will also offer a view of racial and ethnic disparities that is contextualized in a way that discourages, and outright denies, strictly biological interpretations of racial inequality in health.

Gravlee (2009) offers one of the most promising approaches to health disparities research, and subsequent health disparities elimination, in the context of what appears to be an unclear vision within the academic community regarding the best way to tackle differences in health that persist along racial and ethnic fault lines. The central idea and focus of Gravlee's proposal is a call for a new synthesis of perspectives from both sociocultural and biological anthropology that seeks answers to the problem of how race actually becomes biology, or how the social construct of race leaves permanent, biological markers and indicators on the human body. Gravlee argues that race becomes biology in two ways: 1) by systemic racism becoming embodied on individuals and groups through human biology, as the effects of racism prove to have harmful biological consequences, and 2) by noted racial and ethnic health disparities in these bodies fueling a racialized view of human biology. The result is an unfortunate and harmful vicious cycle that plays off popularized views of race and biology as being conceptually equal.

Gravlee (2009) utilizes a model of nested causes of embodiment (Krieger 2005) to demonstrate the way the existence of race as a sociocultural phenomenon, and the lived experience of race, ethnicity, and racism among people, is literally embodied on human biology, on the bodies and biological makeup of individuals and populations. This is a biological phenomenon that ultimately has the potential to manifest through genetics and be passed along across generations of our species. Gravlee also adopted a useful model of health disparity transmission across the life span that incorporates research from life span epidemiology and developmental biology (Kuzawa and Pike 2005). In this model, as we saw with the thrifty phenotype hypothesis mentioned earlier

regarding the fetal origins of later development of disease, socioeconomic inequality can be transmitted across generations through the perpetuation of compromised and afflicted bodies that have succumb to the embodiment of discrimination and racism. Importantly, this biological imprinting of social and economic inequality can happen on a micro, mezzo, and macro level. For example, Gravlee noted research suggesting that individual health problems like elevated blood pressure, heart disease, and persistently high levels of stress can be directly related to both experienced and perceived discrimination. At the mezzo level, neighborhoods with poor environmental health conditions, such as those with poor air quality or lack of access to a variety of healthy and fresh foods, have been shown to depress the health of groups of people living in such a neighborhood, despite their individual biological and genetic differences. Another example from current events comes from the Flint, Michigan lead water contamination tragedy, in which the citizens of Flint have been poisoned by their drinking water because of the decisions of the city's leadership. Additionally, global crises and widespread mistreatment of entire populations of people on a macro level scale can negatively affect the health of current and future populations by creating public health problems that are transmitted biologically and genetically.

Gravlee also offers a critique of the race concept that is especially pertinent in the United States, where health disparities are frequently measured, as I discussed earlier, by differences in race and ethnicity and are demonstrated to exist disproportionately among minority racial and ethnic groups. While a goal of my current research study was not to demonstrate racial and ethnic differences in the experience and management of diabetes, the strong relationship between being a member of a

particular racial and ethnic group and being of low socioeconomic status suggests both phenomena combine to create individual experiences of marginalization and health oppression among those living with chronic disease.

Gravlee's critique of race addresses three issues: 1) that race is not equal to human variation – the race concept is not complex enough to deal with the reality of human genetic variation and human biological diversity, 2) that race is not equal to biology – claiming that race is not biology inadvertently still prioritizes a reductionist view of genetics and biomedicine that must be eliminated, and 3) race is not a myth – ever since Montagu (1997) declared race as a “myth,” we have had to deal with a “no-race” anthropology (Harrison 1995) that has, unfortunately, resulted in race sometimes being taken out of the discourse of anthropology.

According to Gravlee, while outright denial that race is not biology was good in spirit, the fact remains that the “race is not biology” mantra has not made it to the general public, who still understand race to mean fundamental biological differences exist because, in fact, genetic diversity does exist. This belief is perpetuated by the vicious cycle introduced above, where social and economic inequality impacts individual biological and health differences, which in turn creates a false appearance of racial differences in human biology and human health indicators. This is a fascinating interpretation of the race and biology dialogue that begs for a nuanced understanding of how the social construct of race and biology and genetics interact in our modern world in ways that are more complex than commonly identified. Wiedman's 2012 ethnohistorical review of Native American foodways, experience of modernity, and the political-economic forces that led to disproportionate development of diabetes among

Native Americans similarly speaks to the ways unfair policies and programs manifest biologically. Recently, Non and Gravlee (2015) wrote a brief article for a Vital Topics Forum in *American Anthropologist* that continues the argument for anthropologists to critically examine the ways that socioeconomic inequalities becoming embedded in biological and genetic pathways via epigenetic processes. This approach to studying health disparities remains in line with a critical medical anthropological approach but adds the sophistication of demonstrating how societal policies and procedures that continue discrimination and disparities manifest in the individual bodies of its citizens.

Ultimately, says Gravlee, we need to come to understand a more diverse sense of human biology through a radical critique of race as a sociocultural phenomenon that directly impacts human biology, in a way that demonstrates how race has the potential to actually become biology, manifesting itself in biological ways. Non and Gravlee (2015) continue this call to action presently when they write that “a priority for future research is to clarify the biological pathways through which sociocultural experiences can affect health” (738). I would add economic and political experiences this statement, as they have been proven to impact the individual experience of diabetes and other chronic diseases.

Since social class and race are intimately tied in the experience of health (Adler et al. 1995), a radical contextualization (Chapman and Berggren 2005) of race is crucial to future work on health disparities. Luckily, anthropologists are just the scholars to tackle this contextualization challenge, and Gravlee notes that we can do this through either an “anthropology of medicine” approach (e.g., studying racism in health care and health care delivery) or an “anthropology in medicine” approach (e.g., ethnographic

work within medicine that grounds and contextualizes health disparities and the lived experience of racism and discrimination, noting directly biological and genetic consequences of human-made disparities on the health of the human body).

Chapman and Berggren (2005) call for a “radical contextualization” of racial and ethnic health disparities, emphasizing three important anthropological contributions to health disparities research and action: 1) using ethnography to contextualize discrimination and contribute to a literature on the actual lived experience of disparities, 2) studying up (Nader 1972) the powerful institutions and stakeholders who are in charge of providing health care, and up the biomedical institution with a critique of medicalization and biomedicine, and 3) by creating, through synthetic sociocultural and biological research, new models of biocultural pathogenesis of poor health, illness, and disease.

Fortunately, this type of work is being done, and it is my attempt, with my current research study, to help contribute to this central role of anthropology as an applied and activist discipline in public health and health disparities research. Another example of these efforts comes from Gravlee and his colleagues, who, in 2009, published an interesting study of race, discrimination, and blood pressure in Puerto Rico. These researchers found that culturally defined categories of color specific to those in Puerto Rico, and not conventional categories of race, were a significant factor in measured high and low blood pressure. Ethnographic and epidemiological methods were used to contextualize the study of discrimination, racism, and blood pressure to the specific cultural components of the community studied.

Further attesting to the need to contextualize health disparities with regard to race and place, Gaskin and his colleagues reviewed data from the 1999-2004 National Health and Nutrition Examination Survey and the 2000 U.S. Census to examine the role of race and poverty in a community sample of those with diabetes. Results indicated that economic factors (i.e., living in poverty) made it more likely that both White and Black citizens would be diagnosed with diabetes. These researchers concluded that public health policymakers must consider poverty when addressing diabetes health disparities, and not just race (Gaskin et al. 2014).

Merrill Singer's use of the term "syndemic" presents a best practice method of making sense of health disparities, in a way that also promotes the applied and activist responsibility of medical anthropology. In his work with colleagues in 1991 and again in 2006, Singer et al. speak about the AIDS epidemic in the inner city urban areas of the United States as an example of a syndemic, using the term to denote the interconnected health and social problems that need to be understood in the context of the spread of HIV/AIDS among inner city residents. Syndemic analysis lends itself to ethnographic methods of health disparity analysis, due to its emphasis on the dynamic interplay of social and biological forces on human health that are often fleshed out with in-depth, holistic investigation of a particular geographic and environmental area. Speaking of syndemics when examining complex disease experiences like that of diabetes allows for the examination of critical relationships among the factors that influence the production of disease, in addition to the environmental context in which it manifests (Singer and Clair, 2003).

With all the good work that has been done in the constant fight for equality in health, it is clear that improvements are being made and that research is moving forward and increasingly demonstrating that a holistic approach to understanding health disparities is not only necessary, but possible. I hope to be a part of this movement toward creating an expanding fund of knowledge that prioritizes the lived experience of health, illness, and disease when making sense of how socially and culturally constructed phenomena come to rest on the bodies of our species. As I have repeatedly emphasized above, defining group membership is a simple, yet powerful, act that sets the course for the theoretical orientation and research methods that will be used to make sense of why observed differences in health indicators exist. So, this review of health disparities research reveals that the act of measuring health disparities, and how investigators make sense of the difference they observe and record, will influence whether or not the potential for eliminating said health disparities can be realized, and if so, how one should approach such an enormous task.

I believe one of the best opportunities to eliminate health disparities calls for an emphasis on equity in health and healthy environments, which includes the equal opportunity for all people to be healthy in any defined area. Individual differences will never give way to group homogeneity, and as long as there is social, political, and economic stratification and inequality, there will be the potential for health disparities. As anthropologists, Gravlee (2009) and Chapman and Berggren (2005) serve as a reminder that much work needs to be done and vast opportunities exist to act as a corrective force in the national health disparities dialogue. We need to better understand the relationship between social and economic inequality, oppression, and social

injustice with regard to its direct impact on individual bodies, biology, genetic potentials, and the creation of environments where health oppression unfortunately thrives. Anthropologists have long been keenly aware of the delicate interplay of natural and human-made systems, and the consequences these systems have for our species and the environments we call home. Exciting opportunities await us, if we as anthropologists venture out with our research findings and take them to audiences outside our close-knit social science professional circles.

Taking an increasingly active stance should be an important component of the professional role of any anthropologist researching health disparities. No longer can anthropologists reserve our data for safe audiences of like-minded individuals in academic settings. We need to take risks and translate our scientific findings to the public in creative ways that engage and encourage further work at eliminating health oppression and encouraging communities of health equity. Following Carolyn Sargent's (2009) call for an increasingly engaged anthropology amidst the ongoing health care debate in the United States, we should reach out to our colleagues from other subfields within anthropology, and most importantly, to those concerned others in other areas of public health research, teaching, and health care delivery, as we fight for health equity in our country and beyond.

A Place for Anthropology in Public Health

It is clear that anthropology has an important role in public health theory, research, and practice. Anthropologists offer a critical ethnographic analysis of the span of health experiences, from individuals to institutions and systems. Therefore, we are well-informed professionals that contribute to the betterment of our society and improve

the quality of life of its citizens. Anthropology brings to public health three broad contributions that serve to bridge the gap between the local and structural experience and interpretation of health, illness, and disease.

First, anthropology provides the discipline of public health with deep, contextual knowledge about local realities and the lived experience of those suffering from disease. For example, through the use of participant observation and ethnographic research methodology, anthropologists document the experience of public health programs on the ground, or how public health programs enacted from government bureaucracy are being experienced daily by both patients and providers. Second, anthropologists provide a holistic understanding of the macro-level forces that influence the spread and prevention of disease. By speaking directly with patients, conducting community-level ethnography, and ultimately relating this information to the systemic and macro-level factors influencing public health, anthropologists can make sense of the distribution of illness across broad populations, the effects of poverty and discrimination on poor health, and the broad impact of public health policy on people's health experiences. Anthropology's third important contribution to public health is the ability to inform and create public health policy with the knowledge gathered from local engagement with those directly affected by public health programs. Anthropology's localized and structural knowledge is highly valuable and relevant and should be put to use in order to inform responsible public health policy.

Several anthropologists and a few epidemiologists have noted, over the last few decades, the positive productivity that would result from increased collaborations between medical anthropologists and public health professionals. Inhorn (1995) argues

that myths about the nature of epidemiological and medical anthropological work have kept these two disciplines unnecessarily separated when, in reality, the two fields have more in common than not. Hahn (1999) published an influential volume in this regard titled *Anthropology in Public Health* in which he compiled a collection of essays, almost exclusively completed by anthropologists, for a public health audience.

According to Hahn (1999, 21), there are three ways in which anthropology could and should make itself more viable and useful in public health: 1) by the effective translation of anthropological theories, practices, and concepts into public health language and for public health audiences, 2) education, focusing on the integration of medical anthropology in professional education in schools of public health, and 3) organization, with medical anthropology and public health professional organizations, institutions, and agencies creating helpful and productive links for future work and collaboration. Instead of the traditional approach of public health that provides public health for the people (emphasis on top-down approach), anthropology in public health, according to Hahn, gives the opportunity for public health *by* the people (emphasis on bottom-up approach). Hahn feels that the biggest struggle for an effective anthropology in public health will be the recognition of the unique cultural and social aspects of the discipline of anthropology and the successful translation of anthropology into public health language, understanding, and concepts.

Directly related to these broad contributions is Hahn's (1999, xvii) discussion of three important contexts involved with anthropological research and practice in public health. First, the political context of public health programs and health disparities should always be examined, as political change and political decision-making can have

a lasting impact on the distribution of poor health and the allocation of health care services. Next, Hahn notes the crucial understanding needed of the bureaucracy involved with a country's public health system. As Hahn notes, "public health projects are often conceived and born in public health agencies and/or academic settings," and familiarity with and understanding of the bureaucratic decision-making system is essential for the creation of responsible and relevant public health programs. Finally, Hahn notes anthropology in public health's greatest challenge, which involves a lack of critical self-evaluation among anthropologists. Anthropologists working in public health are challenged with the task of engaging in effective translation of their own ideas, knowledge, and terminology to those working in all aspects of the public health sector. Effective translation will only be achieved once anthropology, as a discipline, critically evaluates its own biases and the social and cultural differences between itself and other disciplines involved with the provision of health care (Hahn 1999, xvii).

This process of self-reflection and self-appraisal is essential if anthropologists are going to effectively engage policy makers and the general public with their ideas for progressive improvements of the health care system. Our discipline cannot afford to be mistaken for an obscurely academic and out of touch endeavor that has no relevance to the improvement of our society. At the same time, we must also maintain our dignity and depth of knowledge that makes us uniquely qualified to tackle society's most pressing public health problems.

CHAPTER THREE: THE FIELD SITE

The State of Oklahoma is centrally located within the United States of America, north of Texas and south of Kansas. According to statistics collected by the United States Census Bureau, the population estimate of the state as of July 1, 2015 is 3,911,338. This reflects a 4.3% population increase since base estimates on April 1, 2010. As of July 1, 2014, 75.1% of Oklahoma's population is White alone, 7.7% are Black of African American alone, 9.0% are American Indian and Alaska Native alone, 2.1% are Asian alone, 0.2% are Native Hawaiian and Other Pacific Islander alone, and 5.9% reported themselves as being members of two or more race groups. 9.8% of Oklahoma residents are Hispanic or Latino of any race, with 67.0% of the population being White alone, not Hispanic or Latino. Regarding housing, there were 1,699,438 housing units in Oklahoma as of July 1, 2014, with the owner occupied housing unit rate between 2010 – 2014 being 66.5%. The median value of a home in the state during this same time frame was \$115,000. Among the 1,450,117 households in the state counted during this time, there were 2.56 persons per household. 86.7% of Oklahoma's population was a high school graduate or higher between 2010 – 2014, and 23.8% of the state's population reported having a bachelor's degree or higher. The number of Oklahoma residents living in poverty in 2014 was 16.6% (United States Census Bureau 2016).

The City of Norman is located within Cleveland County, situated centrally within the State of Oklahoma. Norman is just 10 miles south of Oklahoma City, which is the state's capital and largest city, making it a hub for cultural, health care, business, and political activity in the state. According to the 2010 U.S. Census, Norman had a population of 110,925. Local data from the city in 2014 have the population at the

beginning of that year at 117,528 (City of Norman 2016). Norman is a growing city that is heavily influenced by the cultural and economic impact of the University of Oklahoma campus.

The age of Norman's residents is mostly evenly spread across generations, with the majority of its residents being 15 to 64 years old. Most recent available data indicate that 50.3% of Norman's population is female and 49.7% is male. The overwhelming majority of Norman residents are classified as White (81.1%), with 3.8% American Indian and Alaska Native, 4.1% Black or African American, 3.4% Asian, 5.4% Hispanic or Latino, 6.5% identifying as belonging to two or more racial groups, 1.1% identifying as "other," and 0.2% Native Hawaiian and Other Pacific Islander. At last count with statistics available, there were 49,137 households in Norman with 2.53 persons per household. 58% of these households were owned by their residents, while 42% were rented. The average new home value in Norman in 2013 was \$224,000. Per capita income for the city is \$28,267 and median household income is \$48,248. Unemployment rate is 3.7%. Regarding education, most recent available data have the number of high school graduates in the city at 93.1% and college graduates at 43.4% (City of Norman 2016). Norman's poverty rate was most recently noted as 18.1% (United States Census Bureau 2016).

Health for Friends community health clinic is centrally located within Norman, Oklahoma, providing relatively close and convenient health care access to most people living within Norman's city limits. Since 1985, Health for Friends has been providing free and reduced cost health care to the medically underserved. What started as a small clinic in a former motorcycle garage has grown into a modern clinic offering medical,

pharmacy, dental, and social work services. Services for women are offered at another clinic nearby. Health for Friend's mission is "to provide patient-centered health care to the medically needy for better lives and better communities" (Health for Friends 2016). When I was working in the clinic, patients had to show proof of being Norman residents and had to meet certain income guidelines. Since then, Health for Friends has been able to open up their services to those regardless of Norman residency, and the clinic now serves those from Norman and surrounding, more rural, communities. Furthermore, Health for Friends now also accepts Medicaid and Medicare coverage and accepts self-pay patients regardless of their income. Still, Health for Friends remains committed to being the sole option for health care the medically underserved in the community, including the homeless, and is committed to maintaining that focus as their services continue to expand (Health for Friends 2016).

Of note, the Patient Protection and Affordable Care Act, was signed into law by President Barack Obama in 2010, which was during the time of my research. I recently spoke with Health for Friends Chief Executive Officer, Brian Karnes, JD, MPH, about how the Patient Protection and Affordable Care Act has impacted patient care at Health for Friends. Unfortunately, according to Mr. Karnes, this health care legislation has not had much of a positive impact on the patient population of Health for Friends. Since Oklahoma legislators did not approve to expand Medicaid services, most of their patients who did not have health care coverage (e.g., Medicaid) continue to remain uninsured. Additionally, since many Health for Friends patients live in poverty, they are unable to afford the premiums for private health insurance coverage (B. Karnes, personal communication, March 23, 2016). In more recent news, the Oklahoma Health

Department has eliminated state funding for community health centers, which includes Health for Friends. In follow up communication with Mr. Karnes about this development, he stated the clinic would have to stop accepting new patients that do not have health insurance in order to focus on providing the highest quality health care possible to their existing patients. Currently, Health for Friends serves 1,204 uninsured adults and 65 uninsured children (B. Karnes, personal communication, April 19, 2016). Thus, the health care situation for the medically underserved in Oklahoma does not appear to have significantly improved in the ways I and the staff and patients of Health for Friends had been hoping. Those living in poverty and without health insurance in Norman, and in all of Oklahoma, continue to face macro-level barriers to optimizing their health that leave them with limited options for improving their quality of life.

CHAPTER FOUR: RESEARCH AND RESEARCH METHODS

Anthropological field work is based on the anthropologist spending an extended period of time with the people he or she is studying, getting the hang of daily life in the community. Our field work as anthropologists sets us apart from other disciplines interested in human behavior and social and cultural life because we seek to become a part of the group we study, or at least get to know them on a deeper, more personal level than other human scientists. This often seemingly informal method requires the researcher to achieve a level of community proficiency in which he or she no longer feels like an outsider. Of course, this process is necessarily subjective, and the moment an anthropologist no longer feels like an outsider may appear to come gradually or all at once. It is also based on the researcher's perceptions of their own experiences and interactions with others in the community.

Another essential part of anthropological field work is the researcher's ability to achieve the comfort of an insider while maintaining the objectivity of an outsider. This is particularly true when anthropologists have reached a level of community aptitude in which they feel like a full participant in community life, and native community members recognize the anthropologist in the same regard. Not surprisingly, accomplishing this balance of both an emic and etic perspective in anthropological field work has been written about for decades. The tension created by these two approaches is one of the fundamental challenges to quality scholarship for the anthropologist, and this tension is often unique to our discipline. Both sources of potential data collection, emic and etic, have advantages and disadvantages, and the test posed to the anthropologist is to decide which aspects of an emic and etic approach are most useful

in formulating logical hypotheses about observed behavior and community life in the population studied.

I had the good fortune of living within the community I studied for the duration of my graduate studies at the University of Oklahoma. My wife and I moved to Norman, Oklahoma in June 2007, and I had ongoing opportunities to experience everyday life in the community for years before embarking on my formal research study in Norman. In addition to living in Norman, I went to school and worked there, which afforded me the chance to boost my sense of community citizenship. This also helped me to be socially and culturally familiar with Norman and surrounding rural towns when interviewing my study informants and visiting them in their homes. I spoke to my research participants at length about their health and health care experiences as a fellow Norman resident who also cared about health care and my own access to community services. I was able to converse with and interview my informants in a way that felt like two Oklahomans having a casual chat about everyday life in Oklahoma, despite the fact that I am originally from Texas and lived in Texas for most of my life.

As the months and years passed, I lived through the cycles of the community, attending local festivals, eating at local restaurants, and shopping at local grocery stores. Of particular relevance to my study were my experiences of and strategies for acquiring food in the Norman area. This includes both prepared food, such as that found at a restaurant, and grocery store shopping for meal preparation at home. Importantly, food acquisition and community food ways were common topics in my interviews about living with diabetes and managing the disease. I often could relate to my informants' experiences of shopping for food at some of the same grocery stores I shopped at in the

same community. I remember one instance in particular when I saw one of my research participants shopping at a local “big box” grocery store/super store as I was there too, shopping for groceries. I resisted the urge to observe this person’s behavior and reminded myself that, on that day, I was at the store as a Norman resident, not as an anthropologist. Instances like this were not unusual, as it is difficult to separate field work from personal time when living in the same town as study informants. While I never engaged with study informants while on personal time, I maintained an anthropological lens once I started my research, as I lived each day in Norman. I often reflected on my experiences as a citizen of the community and used those reflections to inform my ideas about how the social and economic context of my informants impacted their individual experience of diabetes.

Research Location

The epicenter of my research and data collection was Health for Friends community health clinic in Norman, Oklahoma. I met my participants for the first time in the clinic and collected data there, in addition to in the homes of patients granting consent. At the time of my research, Health for Friends was only able to serve residents of Norman who met certain poverty guidelines and had no health insurance. This also often included patients who were technically homeless, but who were staying in the Norman area. At the time of my research study, the clinic provided medical, dental, and prescription drug assistance to those in most medical need in Norman.

Since my time at the clinic, Health for Friends has expanded its services, and now offers social work services and a new second clinic location, the Health for Friends Women and Children’s Center, which as the name suggests, offers a special collection

of services aimed at meeting the health care needs of women and children who often have no other option to obtain quality health care. The main clinic has expanded its services, and now also provides health care to those with Medicare and Medicaid, and accepts self-pay patients, regardless of their household income. In addition, the clinic's previous requirement of Norman residency for all patients has been lifted, and health care at the clinic is now available to those regardless of their physical address and residency.

Health for Friends continues to be an asset to the Norman area because it provides the best option for quality health care to a population that often has no other alternative to receive essential preventive, general medical, dental, and integrated social service care. At the time of my research, the agency relied heavily on donations, fundraising, and grants in order to continue to provide high quality health care to those who may not receive it anywhere else. Health for Friend's mission and advocacy on behalf of the medically underserved is an expression of their belief that quality health care is a human right, and that all people deserve the chance to be optimally healthy, regardless of their circumstances. Norman is a healthier community because of Health for Friends' presence.

Research Preparation

My taking up of residence in Norman before, during, and after collecting data for my study no doubt helped me be a better anthropologist, researcher, and observer. From our residence in Norman, my wife and I sampled Oklahoma social and cultural life for years and grew to become familiar with Oklahoma and its people. While I did feel like I had the hang of community life as a local, my status as a graduate student and

anthropologist in training afforded me the etic perspective necessary to stay objective in my observations when necessary to formulate informed conclusions about my hypotheses about human health behavior.

In addition to the point of view I gained as an eventual Oklahoma resident, my professional training aided me greatly in developing a research project with the perspective and tools to collect the data necessary to make informed statements about my research participants and their lived experience of diabetes. With my undergraduate and graduate training in psychology, I learned invaluable tools to objectively observe human behavior, including quantitative research methods like survey research and clinical questionnaires. My training in psychology also gave me the initial opportunity to hone my professional interpersonal skills, including listening, reflecting, summarizing, and expressing empathy and unconditional positive regard.

My graduate training in social work guided my anthropological research much like my psychology experience did, and in addition to improving my clinical and interpersonal listening and communication skills, my social work studies and practice have kept me keenly aware of social injustices and the role of advocacy and action in my work. Finally, my graduate studies in anthropology, including applied, sociocultural, biological, and medical anthropology, provided the foundation of my research and gave me the theoretical underpinnings of my hypotheses and conclusions. The result of synthesizing my education and practice experience is a mixed methods research project informed by anthropological theory and guided by a movement toward action and advocacy on behalf of those most vulnerable among us living with chronic disease.

The purpose of my volunteer work was to 1) become familiar with the agency's culture, organizational functioning, and patient population, particularly those diagnosed with diabetes, 2) gain experience that would help me think of a relevant research topic to propose to the agency director and my dissertation committee, 3) become a familiar face among the clinic staff, in order to transition myself to becoming an eventual researcher alongside the health care providers, and 4) give my time, energy, and skill set to those in the community who utilized Health for Friends for their health care needs. I decided to volunteer there once a week on Fridays after looking over my schedule and figuring out where I had some free time.

I made no demands to the Health for Friends staff about the specific nature of my volunteer work. I was happy to assist wherever needed. My duties included simple activities like filing patient charts, labeling folders, and restocking supplies. I also had the opportunity to engage in more challenging aspects of patient care, including using my Spanish language skills to answer phone calls from Spanish speaking patients and community members and interpret, when possible and appropriate, for Spanish speaking patients at the clinic. I spent a total of 117 hours as a volunteer at Health for Friends.

I first proposed my dissertation research idea to Health for Friends' Executive Director, Brian Karnes, JD, MPH, who immediately granted me permission to conduct my study at the clinic. I then submitted my dissertation research proposal to The University of Oklahoma Institutional Review Board (IRB) as I began to wrap up my volunteer experience at Health for Friends. Once my project was approved, I had my first day of data collection at the clinic I kept field notes of each of my visits with research participants in order to provide more depth and context to the data I was

collecting. Additionally, while at the clinic as a researcher, I still participated in volunteer activities as needed, in between study participants and if I had additional free time. Thus, in addition to the 117 hours I collected as a clinic volunteers, I added about another 50 hours of clinic time conducting individual interviews and volunteering as needed, in addition to the approximately 20 hours I spent conducting home visits and interviews.

Participants

All of my study participants were 1) adult (at least 18 years old) men and women, 2) had a history/diagnosis of diabetes of any type, and 3) were a current (or very recent) patient of Health for Friends clinic. I also opened study participation to relatives of diabetes patients in order to allow them to give input about my informants' lived experience of diabetes. All research informants were deemed appropriate and qualified to participate by the stipulations created by me and approved by The University of Oklahoma IRB. All study enrollees maintained the cognitive ability necessary to complete my research study on a fully voluntary basis and expressed total ability to understand the study materials and procedure.

Participants were recruited directly by me, as principal investigator, at Health for Friends clinic. In addition to contacting potential study participants directly, I also educated clinic staff members about my study and encouraged them to refer potential participants to me for follow up and screening for study enrollment. I posted recruitment flyers on brightly colored paper around the clinic to draw attention to my study, its purpose, and its criteria for participation. Study informants remained

anonymous throughout their participation in my study. No personally identifiable information was kept for the purpose of data analysis or data presentation.

Procedure

All participants first received an informed consent form that was reviewed and approved by The University of Oklahoma IRB. This form outlines the purpose and nature of my research study, including potential risks of participation and confidentiality of data. The form highlights the fact that participation in my research was completely voluntary, and could be withdrawn at any time without penalty. Informants were also given the opportunity to consent to audio recording of their interview responses, consent to a home visit for data collection, and consent to having the food in their home photographed. The informed consent form also contains contact information for me and my faculty research adviser at The University of Oklahoma. Study participants were given a blank copy of this form to keep for future reference.

Participants were then given a Health Insurance Portability and Accountability Act (HIPAA) authorization form, in which they consented to disclose their protected health information for research purposes. Lastly, each participant completed a demographic questionnaire developed by me, as outlined above.

Regardless of their future, more in-depth participation in a research-based home visit, all study participants completed the packet of questionnaires and the semi-structured patient interview on site at Health for Friends clinic. For those willing and able, I made a home visit and completed the semi-structured household survey and interview, in addition to the photographic food inventory. Each participant's data was

assigned a number in the order of their participation. Numbers were in no way tied to names, as each informant's research responses were kept anonymously.

Participants were compensated for their participation in my study, and this compensation was approved and approved by the OU IRB. Informants were compensated with a \$10 Walmart gift card for completing my quantitative surveys, a \$20 Walmart gift card for completing a patient interview, and a \$30 Walmart gift card for allowing me to visit them at their home and complete a household survey and interview, as well as a photographic food inventory.

Demographic questionnaire. Thirty two adults participated in my research study, each providing an extensive amount of both quantitative and qualitative data for analysis. Of these 32, 15 volunteered for further in-depth sampling and permitted me to visit them in their homes for additional interviewing and photographing of their food. Each study participant completed a demographic questionnaire I designed in order to obtain basic information about each participant.

Ages of my participants range from 21 to 64, with a mean age of 47.5 years old (one participant did not indicate an age, so I used 50 for her age in order to obtain the average of all participants). Regarding gender, 17 (53%) participants are male and 15 (47%) are female. For marital status, 15 people endorsed being single, 6 are married, 9 are divorced, 1 person endorsed being separated, and 1 person said they were widowed. Education level varied across the sample, with 5 people saying they have a less than high school education, 8 with a high school education, 12 with some college, 6 college graduates, and 1 with a graduate/professional school education.

Of the available racial/ethnic groups provided for participants to mark on the demographic questionnaire, study volunteers responded in the following ways: 2 Asian or Asian American, 3 African American or Black, 3 Hispanic or Latino, 2 Native American, American Indian, or Alaskan Native, 20 White, European American, Caucasian, or Anglo, and 2 of mixed racial/ethnic backgrounds. For diabetes status, 2 participants have type 1 diabetes and the rest (30) have type 2 diabetes. Six of my study volunteers were employed, and 25 marked themselves as being unemployed, with one respondent omitting this item. The average number of people in the home for my study sample is 2.63, with an average of 2.03 adults and 0.60 children. Lastly, each respondent was asked to designate the income category that best reflects their current household income. Twelve respondents said their income was \$0-\$10,000/year, 12 said theirs was \$10,000-\$20,000/year, 7 said \$20,000-\$30,000/year, and 1 endorsed \$30,000-\$40,000/year.

Project aims & hypotheses. My project aims and hypotheses are what guided my initial research planning and what I sought to discover after collecting and analyzing my data. My aims and hypotheses are as follows:

Aim 1

To explore and identify the ways in which low-income and uninsured patients of a non-profit health clinic in Oklahoma negotiate the structural/macro-level factors that influence the development and burden of diabetes.

Aim 1 Hypotheses

1. It is possible to identify the strategies members of the community develop to negotiate the structural limitations on diabetes care.

2. The strategies individuals use to negotiate the structural limitations on diabetes care are based not only on the biological aspects of the disease, but also on structural/macro-level factors, including economic constraints, food availability, social support, physical environment, geographic location, community resources, cultural practices, and previously reinforced social behaviors.
3. The strategies individuals use to negotiate the structural limitations on diabetes care have an influence on patient health, including physical and mental health.

Aim 2

To examine the different diabetes management and prevention approaches commonly used by people managing diabetes, given the strategies people employ to deal with the structural factors of the disease.

Aim 2 Hypotheses

1. The strategies people employ to manage diabetes do not completely align with what is suggested in commonly used diabetes management and prevention practices.
2. The diabetes management strategies people develop for a variety of life circumstances sometimes do not optimize health, which includes a holistic perspective on physical and mental health.

CHAPTER FIVE: QUANTITATIVE DATA

Quantitative inventory scales were administered to assess each informant's experience of their own physical and mental health. Participants were asked about their overall health locus of control, in addition to their attitudes and beliefs about their health locus of control as it relates to managing diabetes. I used two additional mental health questionnaires in order to assess participants' current amount of perceived life stress, as well as their tendency toward experiencing depression and anxiety. I did not use these mental health measures as diagnostic tools, but rather as an evaluation of depression and anxiety traits of participants at the time of my study in order to add to further contextualize study data. Data from these questionnaires will be used to give a richer description of the mental health of my study sample at the time of data collection and are only used to compare scores within the members of my study and not to a normative population. This is similar to the mixed methods approach utilized by Mendenhall et al. (2012) in their study of stress and diabetes in socioeconomic context, in which depression data was gathered to explore concordance among depression and social stress. The data from the mental health questionnaires I used will further be used to examine for potential relationships between mental health and diabetes management outcomes.

Multidimensional Health Locus of Control Scales, Form B (MHLC-B; Wallston, Wallston, and DeVellis 1978)

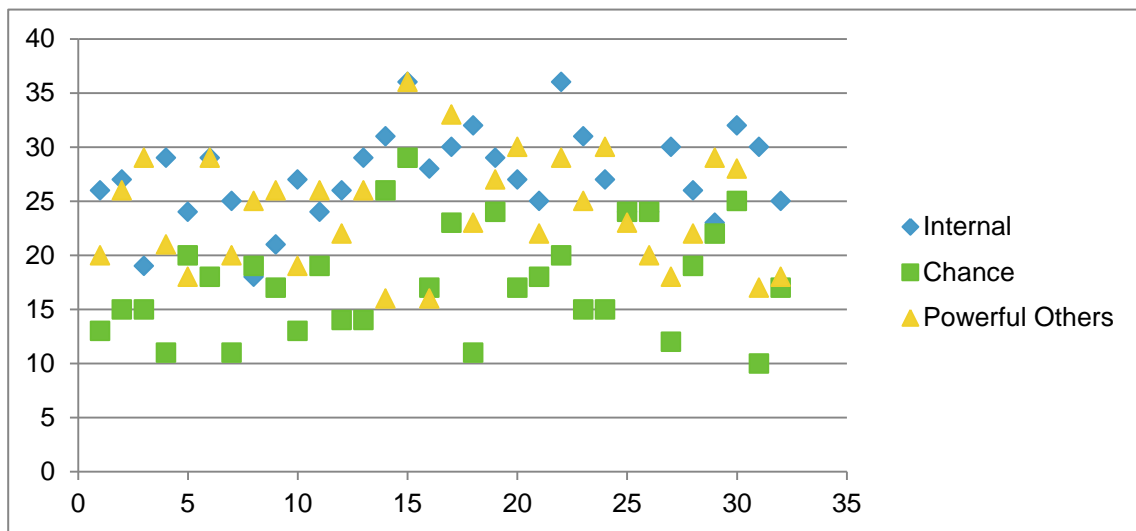
The MHLC was developed as a measure of health locus of control that is divided into three subscales that represent three dimensions of health locus of control. These subscales were confirmed after the original authors performed descriptive statistical analysis as well as intercorrelational analysis of the measure's items. The

subscales are: Internal Health Locus of Control (IHLC, e.g., “If I become sick, I have the power to make myself well again.”), Powerful Others Health Locus of Control (PHLC, “If I see an excellent doctor regularly, I am less likely to have health problems.”), and Chance Health Locus of Control (CHLC, “Often I feel that no matter what I do, if I am going to get sick, I will get sick.”). The authors developed a Form A and a Form B version of the MHLC, and each can be used as an equivalent form to measure the subscales described above. I chose to use Form B for my study, which consists of 18 items. Scoring is completed by summing the number assigned to each response, with 1 = “Strongly Disagree” and 6 = “Strongly Agree.” No items require reverse scoring before summing and providing final scores for each subscale. The authors did not intend for a total MHLC score. The higher the score, the more the respondent endorses a particular locus of control.

Researchers originally created a larger pool of potential scale items written on a 5th to 6th grade reading level. The MHLC was initially standardized on a sample of people 16 years of age and older as they waited at gates at a metropolitan airport. Responses from 115 participants were used for the final analysis and scale development. This included 49% males and 51% females, 74% with at least a college education, and a mean age of 42 years old. 55% of scale development respondents listed their state of residence as Tennessee, with 22% stating they lived in the Nashville metropolitan area (Wallston, Wallston, and DeVellis 1978).

According to the scale developers, scoring the MHLC-B consists of summing the values for each subscale, without the need for reverse scoring. Each subscale is independent of each other, meaning it is not possible to report a total MHLC-B score.

The higher the score, the more the respondent endorses a particular locus of control. I created a spreadsheet and entered data for all respondents in order to plot for analysis. Numbers on the x axis represent the participant number assigned to each volunteer in my study. Numbers on the y axis represent subscale scores. The resulting scatter graph, demonstrating data for each question answered for all participants as well as my sample's locus of control profile, is below:



Graph 1: MHLC-B Results

Graph 1 demonstrates that, overall, my study participants endorse a locus of control consistent with the important role of internal factors influencing their own health, as well as the role of important and powerful others in maintaining their health. Study participants were less likely to attribute chance as the primary locus of control of their health.

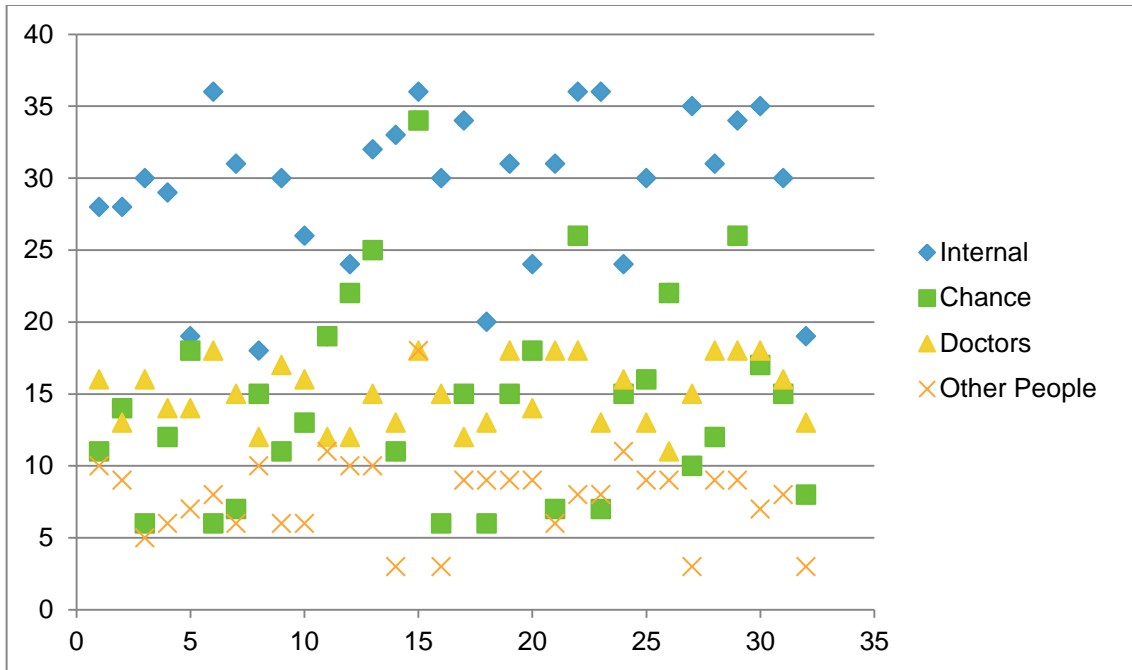
Multidimensional Health Locus of Control Scales, Form C (MHLC-C; Wallston, Stein, and Smith 1994)

Unlike Forms A and B, Form C was created to be specific to a medical condition existing in a target sampling population. For my study, I used Form C in order to assess

my informants' beliefs about their health locus of control about diabetes. Informants were instructed to insert the term "diabetes" each time they read "my condition" in the measure in order to have the measure be tailored to assess for diabetes health locus of control. Participants in the initial development of the MHLC-C came from five different groups: those suffering from chronic pain ($N = 111$), those with rheumatoid arthritis ($N = 273$), two groups of cancer patients ($N = 42$ and $N = 51$), and patients diagnosed with type I or type 2 diabetes ($N = 111$).

Statistical reliability and validity analyses established four subscales: Internality (e.g., "If my condition worsens, it is my own behavior which determines how soon I will feel better again."), Chance (e.g., As to my condition, what will be will be."), Doctors (e.g., If I see my doctor regularly, I am less likely to have problems with my condition."), and Other (Powerful) People (e.g., Other people play a big role in whether my condition improves, stays the same, or gets worse."). Scoring and interpretation is the same as Forms A and B described above. The higher the score, the more the respondent endorses a particular locus of control.

Scoring and interpretation is the same as Form B described above. The higher the score, the more the respondent endorses a particular locus of control. I created a spreadsheet and entered data for all respondents in order to plot for analysis. Numbers on the x axis represent the participant number assigned to each volunteer in my study. Numbers on the y axis represent subscale scores. The resulting scatter graph, demonstrating data for each question answered for all participants as well as my sample's locus of control profile, is below:



Graph 2: MHLC-C Results

Data from Graph 2 reveals that, when specifically questioned about their perceived health locus of control for diabetes, the majority of respondents believe they have the most control over their own diabetes management, which characterizes them as having a predominantly internal diabetes locus of control. Diabetes management locus of control outcomes related to chance, doctors, and other people are overall less prevalent in my study sample.

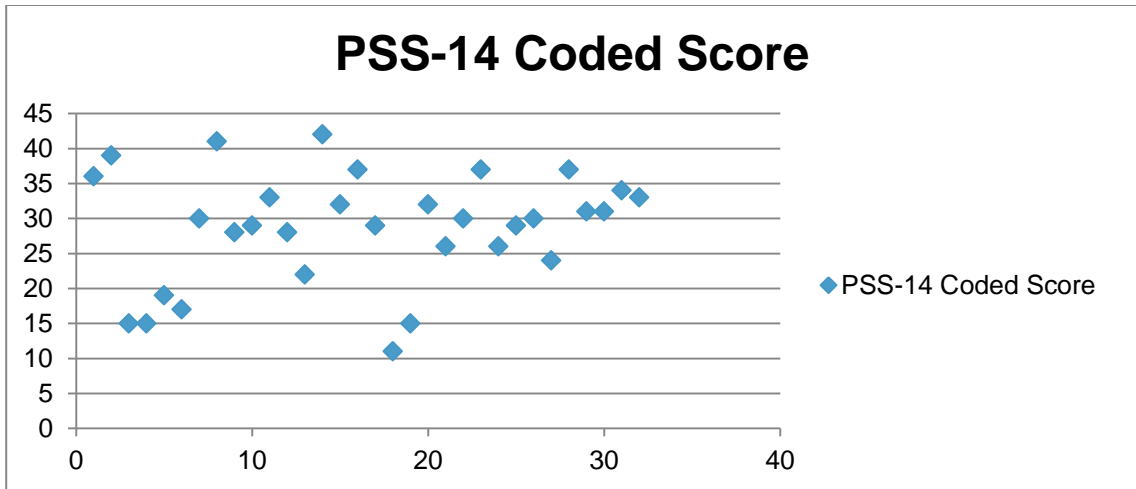
Perceived Stress Scale (PSS-14; Cohen, Kamarck, and Mermelstein 1983)

The PSS-14 is a 14 item measure that was created in order “to measure the degree to which situations in one’s life are appraised as stressful” (p. 385). The authors intended the measure to be used in the community among those with at least a middle school education. Original reliability and validity data were gathered by sampling two groups of college students and one smoking-cessation group both before and after treatment. The first group of college students consisted of 121 male, 209 female, and 2

sex not specified college freshman living on campus at the University of Oregon. Mean age of respondents was 19.01, with $SD = 2.75$. The second college student sample was composed of 53 females, 60 males, and 1 sex not specified introductory personality psychology students. Mean age for these respondents was 20.75 with a $SD = 4.41$. In the smoking-cessation group, 27 males and 37 females in a smoking-cessation program at the University of Oregon completed the study, with a mean age of 38.4 years.

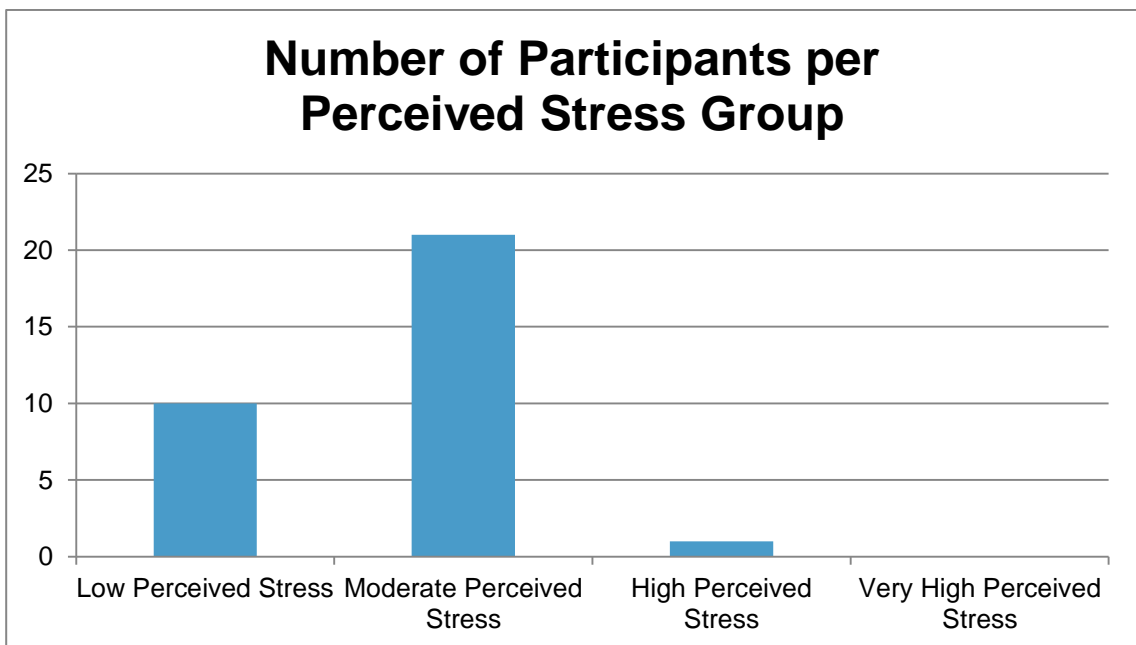
When completing the questionnaire, respondents are asked to evaluate their feelings and thoughts during the previous month. Scoring is completed by first reverse scoring 7 positive items, then summing the scores on all 14 items. Individual item scores range from 1 = "Never" to 5 = "Very Often." Item examples include "In the last month, how often have you felt confident about your ability to handle your personal problems?" and "In the last month, how often have you felt nervous and 'stressed'?". Higher scores equate to a higher rate of self-perceived stress.

As with the above measures, I created a spreadsheet and entered data for all respondents in order to plot for graph analysis comparing individuals in my sample. Numbers on the x axis represent the number assigned to each study volunteer. Numbers on the y axis represent each participant's score on the measure. The resulting scatter graph, which offers a perceived stress profile for my sample at the time of their participation, is found below.



Graph 3: PSS-14 Results

To further describe my study sample regarding their PSS-14, I divided my sample into four quartiles of perceived stress endorsement, creating 4 perceived stress groups based on their overall score on the measure: low perceived stress (1st quartile), moderate perceived stress (2nd quartile), high perceived stress (3rd quartile), and very high perceived stress (4th quartile). Results for the number of participants in each perceived stress group are represented below in the following bar graph:



Graph 3A: PSS-14 Perceived Stress Groups

Data analysis reveals that most study participants endorsed only a moderate amount of perceived stress.

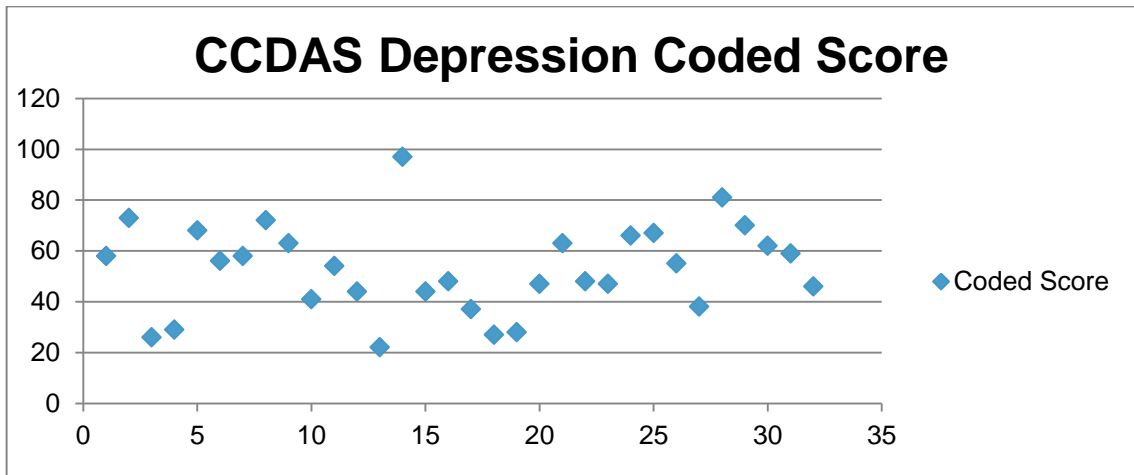
Costello-Comrey Depression and Anxiety Scales (CCDAS; Costello and Comrey 1967)

The CCDAS is a combined 14 item depression scale and 9 item anxiety scale. The authors performed statistical analyses in order to narrow each measure down to the best items that represent each construct measured, depression or anxiety. According to the authors, the CCDAS was developed after being administered to normative samples of hundreds of males and females from a variety of occupations and from a range of ages. Samples included both clinical and nonclinical populations. Both the depression and anxiety measures have reported acceptable reliability and validity.

Respondents are asked to circle the number that best represents their response to each item, with a range of 9 = “Absolutely” or “Always” to 1 = “Absolutely not” or “Never.” Examples of items from the depression scale include “I feel that life is worthwhile” and “My future looks hopeful and promising.” Anxiety items include those such as “I am a very nervous person” and “I am calm and not easily upset.” After reverse scoring items on each scale, all items are summed for each scale, giving a total depression and total anxiety score. Higher scores mean higher endorsement of depressed mood and anxiety. According to the authors, these scales do not substitute for more clinically-oriented or diagnostic scales of depression and anxiety, but rather provide a measure of an individual’s tendency to experience depressed mood or anxiety.

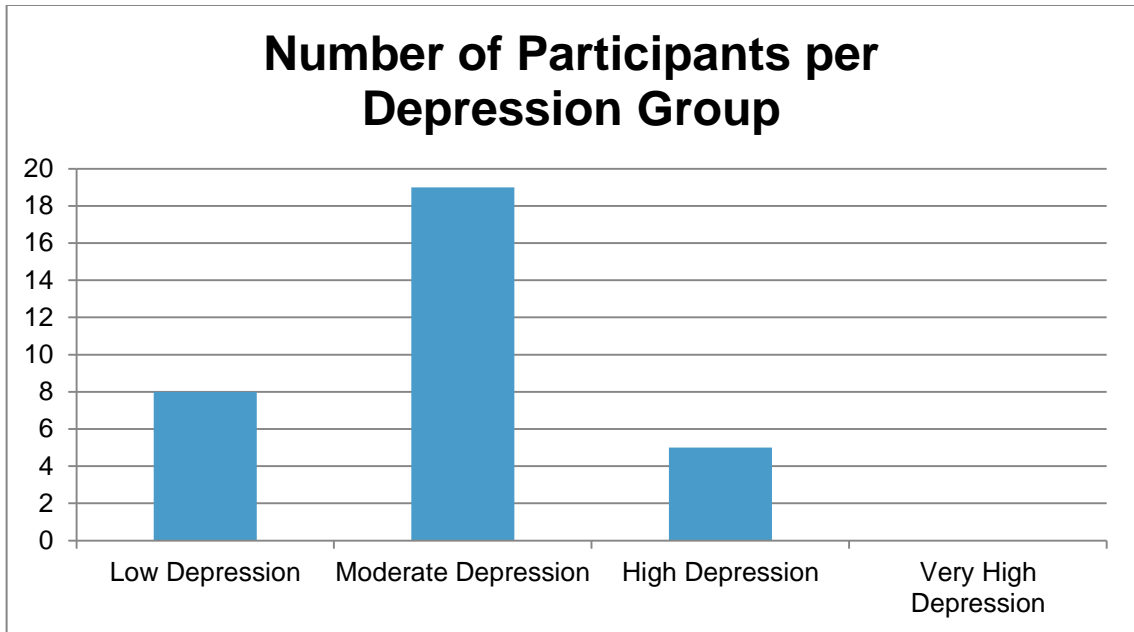
Again, I created a spreadsheet and entered data for all respondents in order to plot for graph analysis comparing individuals in my sample on their self-report of

depression and anxiety experiences. Numbers on the x axis represent the number assigned to each study volunteer. Numbers on the y axis represent each participant's score on the measure. The resulting scatter graphs, which offer a depression and anxiety profile for my sample at the time of their participation, are found below.



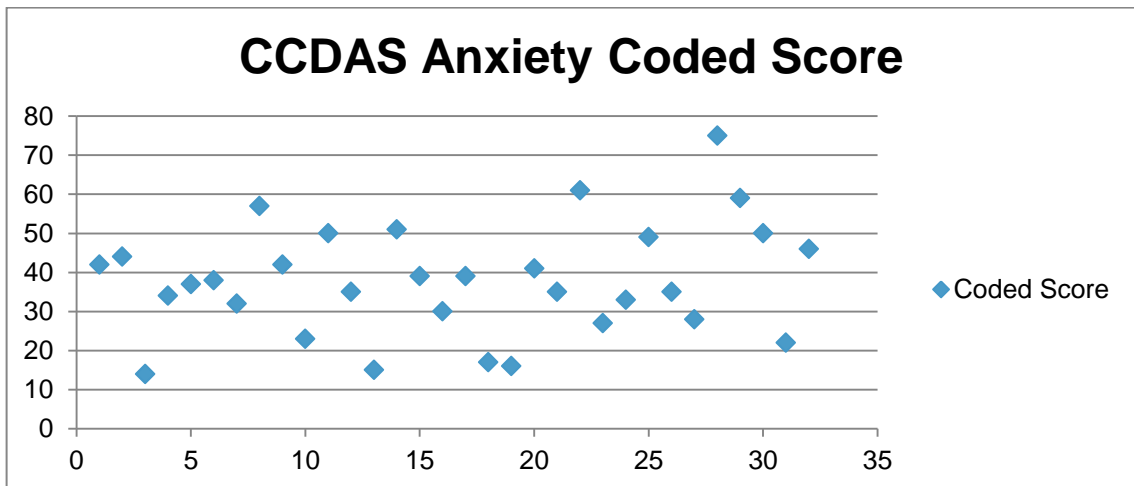
Graph 4: CCDAS Depression Individual Score Results

To further describe my study sample regarding their CCDAS depression scores, I divided my sample into four quartiles of depressed mood endorsement, creating 4 depression groups based on their overall score on the measure: low depression (1st quartile), moderate depression (2nd quartile), high depression (3rd quartile), and very high depression (4th quartile). Results for the number of participants in each depression group are represented below in the following bar graph:



Graph 4A: CCDAS Depression Groups

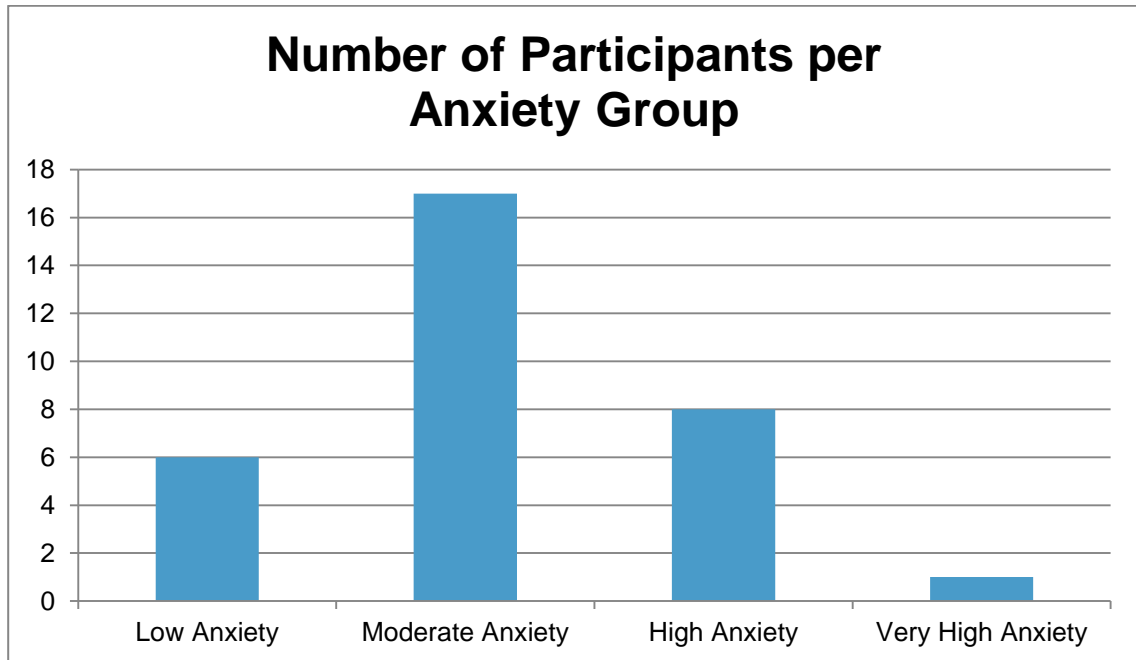
Data analysis reveals that most participants endorsed only a moderate amount of depressed mood.



Graph 5: CCDAS Anxiety Individual Score Results

To further describe my study sample regarding their CCDAS anxiety scores, I divided my sample into four quartiles of anxiety endorsement, creating 4 anxiety groups based on their overall score on the measure: low anxiety (1st quartile), moderate anxiety

(2nd quartile), high anxiety (3rd quartile), and very high anxiety (4th quartile). Results for the number of participants in each anxiety group are represented below in the following bar graph:



Graph 5A: CCDAS Anxiety Groups

Data analysis reveals that most participants only endorsed a moderate amount of anxiety.

CHAPTER SIX: QUALITATIVE DATA

Measures

I conducted extensive semi-structured patient interviews I created with participants in order to elicit important themes relevant for my study's focus and to ground the analysis of diabetes treatment in the experience of the low-income and uninsured diabetes patients and relatives who participated in my research. All informants completed the above data collection measures, regardless of their further, and more in-depth, participation in my study. I completed quantitative surveys and patient interviews with informants on site at Health for Friends clinic. For those informants that volunteered for additional research participation, I completed a home visit and an additional household survey and interview and took photographs of the food they had in their home at the time of my visit. Throughout my study, I kept participant observation field notes that contain my thoughts and reflections on my work in the field. The details of the data collection tools I used in my research are discussed below.

Patient Interview (Gomez, 2009)

I developed my own patient interview for my dissertation research based on my previous research with the Chickasaw Nation Diabetes Care Center in Ada, Oklahoma that I completed for my master's thesis in applied anthropology. My patient interview is a semi-structured qualitative interview that is divided into questions about specific themes I am interested in for my study hypotheses. My patient interview themes are: 1) Barriers to Care and Disease Management, 2) Facilitators to Care and Disease Management, 3) Structural Factor: Economic & Financial Constraints, 4) Structural Factor: Food Availability, 5) Structural Factor: Social Support, 6) Structural Factor:

Physical Environment & Geographic Location, 7) Mental Health & Physical Health, and 8) General Structural Impact Discussion.

Interviews were completed in a wide range of time frames, depending on the talkativeness of my informants. Within each question, I included prompts for myself as interviewer to help an informant provide more information if they appeared to have trouble understanding the question or providing more in-depth reflections on their experiences. While I did create a printed interview protocol for me to use with each interview, I tailored the question wording when asking my study participants, when appropriate, in order to facilitate their understanding of my questions. A copy of my patient interview can be found in Appendix A.

Household Survey and Interview (Gomez, 2009)

I created and conducted a household survey and semi-structured interview. My household survey was also inspired by my previous work with the Chickasaw Nation. Like my patient interview, my household interview was divided into separate themes that are relevant to my study hypotheses. These include the following: 1) Economic Status, 2) Employment Status, 3) Geography, and 4) Food. I also gathered basic information about the people living in the home, including the number of adults and children, and the number of people diagnosed with diabetes and their type (I or II). A copy of my household survey and interview can be found in Appendix B.

Photographic Food Inventory

I completed a food inventory while on each home visit. After discussion with a dissertation committee member, I decided to use photography as a way to quickly and easily capture the food content of my informants' homes while I visited them for the

home study portion of my research. Photographs were taken of all the food in the home informants were willing to disclose at the time of my home visit. My food inventory consisted of many photographs I took of the food and food storage facilities within each study participants' home. I used a pocket digital camera to take all photos for later analysis. These photographs were meant to enhance and add additional context to my qualitative interviews both at the clinic and in participants' homes.

Field Notes

As I mentioned earlier, I kept field notes about each of my experiences collecting data as a participant observer in the clinic, in people's homes, and in the community with my research participants. My field notes were particularly useful when I jotted down what participants narrated to me about their food as I was taking photographs. Furthermore, keeping field notes gave me the opportunity to situate my study participants in deeper environmental context, in addition to allowing me a space for personal reflection on my field work. I reviewed my field notes while analyzing my research data and used insights from my field notes to inform my conclusions about my data and implications for future research and practice.

Qualitative Research Results

I conducted extensive semi-structured patient interviews with all participants in my research study, as described in previous sections of this manuscript. I conducted patient interviews with informants on site at Health for Friends clinic. For those informants that volunteered for additional research participation, I visited them in their home and completed an additional household survey to and interview to gather supplemental information to the in-depth patient interviews I completed with each

participant at an earlier time. Additionally, I took photographs of the food study participants had in their home at the time of my visit.

I designed each interview to be divided into content and topic area themes, while at the same time, allowing for discussion between me and the informant to flow across thematic areas. My patient interview served as the main format for gathering qualitative data is a semi-structured interview that is divided into the following thematic content areas: 1) Barriers to Care and Disease Management, 2) Facilitators to Care and Disease Management, 3) Structural Factor: Economic & Financial Constraints, 4) Structural Factor: Food Availability, 5) Structural Factor: Social Support, 6) Structural Factor: Physical Environment & Geographic Location, 7) Mental Health & Physical Health, and 8) General Structural Impact Discussion.

Like my patient interview, my supplemental household interview was divided into separate themes, which are: 1) Economic Status, 2) Employment Status, 3) Geography, and 4) Food. These themes mirrored themes developed in my individual semi-structured interview I completed with participants in the clinic. I also gathered basic information about the people living in the home, including the number of adults and children, and the number of people diagnosed with diabetes and their type (I or II). Each patient interview and household survey and interview was transcribed from my digital voice recorder to a Microsoft Word document. I then uploaded each transcribed interview document to the ATLAS.ti qualitative data analysis software program for coding and analysis.

I read and reviewed each transcribed interview for the purpose of discovering important themes and topics that are relevant for the goals of the current project. While

I designed each interview to naturally separate into thematic areas for coding, I added additional codes to capture important recurring content across all content areas that manifested while reading and coding interview data. I then performed query analyses using the ATLAS.ti software on each code in order to illuminate these themes from the interviews I completed with study participants. After, I spent a considerable amount of time reviewing and analyzing each thematic query report in order to uncover further evidence of thematic discussions with each broader categorical theme. These themes reveal in-depth contextual information about my participants, including details of their worldview, social and economic struggles, experience living with diabetes, and strategies used to cope with barriers one faces when diagnosed with a chronic disease.

What follows is a discussion of the major themes and topics created from analysis of qualitative interviews, both at the clinic and in the home. Each theme is presented separately for the purpose of understanding important issues and concerns within each theme. After presenting my interview themes, I will begin my discussion of my interpretation of the photographs I took of the food in my informants' homes. After this discussion, I will revisit my project's aims and hypotheses, outlining an interpretation of my data based on my original research questions. Lastly, in the discussion section, I will integrate my quantitative and qualitative data findings, personal and professional experience, and ideas for potential interventions within the context of my hope for future research directions on the social determinants of chronic disease and health. This will also include recommendations for improving patient care when working with those with low income and other negative social determinants of health.

Throughout the following discussion, I use the terms “participant” and “informant” interchangeably to describe the patients who participated in my study and shared their personal stories about their daily life with diabetes. In the blocks of interview text I have shared, a “P” is used to signify the words of the participants, and “SG” is used as my initials for my part in the interviews.

Interview theme: Barriers to care and disease management. This theme describes informants’ struggles with managing diabetes and their perceived barriers to engaging in effective diabetes management. Not surprisingly, participants in my study identified a large variety of barriers to managing their diabetes in ways they know they should; importantly, it was often the case that participants were unable to implement the knowledge they already had about healthy diabetes management due to these barriers and lack of options and choices about how best to manage their own health. Therefore, it was often not a matter of more education needed, but the availability of more options, both real and perceived, for those with low income and without health insurance.

Lack of health insurance, and associated lack of access to consistent health care, was mentioned as important barriers. Before coming to Health for Friends, participants noted the high cost of health care being a barrier to seeking treatment. One participant in particular noted their reluctance to seek health care because of the cost and stated the following:

Yes. I’ve started getting the bills in the mail, and I am going, I looked at my husband and said, this is why I wasn’t going because it is already close to \$5,000. I said, you can forget our credit report because it is going to take me forever to pay this off. That’s why people don’t go. They have enough bills and they are afraid of putting more bills, more burdens on their family. My job is to take care of my family, not to put more burdens on them.

- Participant

Since health insurance is often tied to one's employment, job loss also directly impacts individuals' willingness to seek health care, even when they know they have a disease that requires consistent follow up. For example, one participant noted how his job loss meant that he stopped receiving treatment for his diabetes:

Correct. I was getting it in Texas, but I was, it was 2008 and I was working, so I was making the money, I could afford to pay for it. And down there, kinda place they got, they called it (inaudible) and your doctor visits cost you \$5 or \$10, and your medicines are anywhere from \$5 to \$20. I was doing alright while I was working. But when it got to where I couldn't work and I lost my job, I couldn't pay for it no more. There was nobody else that would help me.
- Participant

Health for Friends serves as a vital resource to help those who lack health care coverage seek health care without fear of excruciating medical bills. Awareness of the clinic's presence in the community, and the low cost services they offer, can certainly be a source of motivation for people to seek the help they need.

Because of the significant need for the health care services Health for Friends provides, the clinic can often be busy with patients. One participant in particular noted how the business of the clinic impacted her care and also came to be perceived as a barrier:

I guess the biggest thing is the only place I can afford medical care is here. This is a great place but it is very busy. I was supposed to come in for a checkup in early October and it has been continuously rescheduled, and I am going to, I think I am scheduled for the 22nd of this month, and I haven't made it since October for the big check-up.
- Participant

When I mentioned how busy the clinic was getting, staff changes, hiring new providers, and dropping Fridays as clinic days (at the time of my research study), this participant went on to say:

I know they have, the last scheduled appointment I was here and I sat here for 4 hours and I had to go pick my brother up at work, and they were very apologetic that I had been sitting so long but it had been a bad day here, things had gone very wrong, and I understand that. I guess the economics of it is I just can't go down to a regular doctor. I am not sure how much, I mean as long as I can get in here, that is great. This place has gotten busier. I am sure they are, yeah I am quite sure they have a lot more patients.

- Participant

Funding and support for Health for Friends, and other community clinics that serve the medically underserved, is vital for these important organizations to be able to serve all those in need and to retain quality staff.

Further in-depth conversation with participants about the intersection of employment and health reveals additional barriers those with diabetes face when they are dealing with instability in the work place or no job at all. Not surprisingly, those participants who were unemployed talked about their struggles with managing diabetes while having no income and no health insurance. Interestingly, beyond financial and health insurance concerns, one participant also made a connection between being unemployed and how not having a job directly impacts his health and diabetes management. He said:

P: Maybe because I don't have enough activity. There is no job. No activity. Most of the time, I am at the home. Or asleep. Make my condition worse, by sleeping too much.

SG: It is making it worse because you are not as active?

P: Exactly. I am not working. Every day.

SG: What did you used to work before?

P: I was working in the Texas panhandle drilling.

This participant realizes that, when he is working, he is beneficially active, which helps him better manage his diabetes. His lack of activity, due to unemployment, results in a situation that will, as he says, “make my condition worse.”

Furthermore, having diabetes can also create challenges and barriers to sustaining employment, which in turn have a cyclical effect on an individual's health, making it harder to effectively manage diabetes. This was especially true for participants in my study who were truck drivers with commercial driver's licenses. For example,

SG: Did you have any issues with your vision or anything like that?

P: Not back then but I do now. Now I have cataracts. I can't see out of my right eye at all and the left eye I can see very little.

SG: Can you still drive?

P: No. I can't drive anymore. Because you have to pass the vision test and I can't pass that. Now I am very limited on what I can do. Driving as far as driving a truck, I'll never do that again because I am on insulin. Once you start taking the shots, the DOT says you can't drive anymore because it is a hazard. And it really started to complicate my life because now, on all the shots and everything, it is hard to work because I have to keep worrying about taking the shot.

In this example, the participant notes how the consequences of his diabetes management, which include taking daily shots of insulin, in addition to the physical consequences of the disease itself, such as vision loss, have resulted in his inability to work and earn income. This, in turn, creates a barrier for the participant to have the financial resources needed to manage his disease. This same participant went on to say the following about this experience:

P: It is hard to find a job doing it, and when you can't work it is like the stress. And they say stress and something else can make it go up.

SG: It does.

P: That's, I am constantly stressed out because I can't work. And when I do get something that I can do on the side, it makes it hard to do it because I am constantly carrying around needle and insulin with me. It's not always easy to find food that you.

Another participant felt she was discriminated against by an employer because of her diabetes status. She described those with diabetes as being a “liability” to potential employers:

P: That was the other reason why, the diabetes, cuz I knew I had it. I went ahead and told employers that I had it, because I knew I had it, but I knew there was not much I could do about it. I know it is illegal, they didn't come out and tell me I wasn't getting the job because of the diabetes but the conversation would go over within one or two sentences well we have others to consider as well, we will get back with you and I wouldn't hear from them again.

SG: I wonder, what do you think is the reason?

P: Because diabetics can pass out very quickly if something goes wrong with their glucose, they have to stop and check the levels, for short stint there I was working for Wal-Mart. I would work 6 -7 hours with no breaks. I ended up passing out at work. I didn't return because they were refusing and I kept telling them I have to check things. I have to get something to eat. Sorry we have no one to take over for you. I wouldn't get my break, not even a 15 minute break to get an apple or something in there. And just, we are a liability.

SG: Huh. Okay.

P: We are a liability.

All participants were characterized as having low income, and they often talked about how carefully budgeting the money they had was necessary in order to survive. As was expected, being on a fixed, low income had consequences for successful diabetes management. Because of limited funds available to purchase food, participants noted that they found themselves not eating healthy and nutritious foods, instead eating what would last and make them feel full. For example, the following narrative describes the dilemma poor people with diabetes face when making decisions about the food they purchase, given their limited income:

I don't know I just try to, I am pretty good at saving money, not spending a whole lot, but I had trouble buying food having, by the time I pay all my bills, having enough money to buy food, particularly healthful food. Because I paid all my bills first, and then that is it. I'm on OEC which is very high electricity. And one of my checks goes to trying to buy food and pay other bills and my second check goes to paying my utilities my car note, my car insurance. So there is very little money, and I make too much money to get food stamps. I make too much

money to get help paying my utilities. If they get real high like this one this month I thought was going to be lower and it is higher than it has ever been. It is real difficult. And I try to pay my bills first, but a lot of times, there is not much money left over for food.

- Participant

This next participant talked about the decisions she has to make about buying healthier foods for herself, but being unable to purchase enough of these foods to feed her entire family. The result was a stressful meal preparation situation where the participant found herself akin to running a restaurant:

P: Something I was discussing with my husband last night was we can't really afford to buy brown rice for everyone or the whole wheat pastas for everyone.

SG: They cost more?

P: They cost a lot more. Because we shop at Sam's, we can buy the bulk rice there that will last us a month. And but not so much the brown rice. So I was saying maybe I can fix them still what they've been having, fix a different pot of just the brown rice. Basically running my house like a restaurant like I'm the special needs person that has to have the separate dish. That's mainly the only solution we have been able to come up with for my diet.

Indeed, food was an often discussed topic when it came to participants talking about what makes it difficult for them to manage their diabetes effectively. Participants with families and significant others talked about the struggles they face when attempting to feed themselves and others, as others are not always fond of diabetes friendly foods. This next selection is a dialogue among me, the participant, and the participant's wife that highlights this struggle:

P: Uh, yeah, because we have teenage kids who eat, uh, honey buns and they eat...

P wife: It's like, ohh, diet food again? I mean, they just, they don't want it.

P: And so if she cooks, for example, sloppy joes is one of my favorite, I'll just throw that out, you know she cooks sloppy joes for the kids, I can't walk by that stove and not eat 'em, you know, so yeah it does affect

SG: So do you find that sometimes you cook two meals, or how does that work?

P wife: Oh, I do that a lot.

P: A lot.

SG: Ok, wow.

P wife: And everybody's like, I wouldn't cook it, but I said, well, if I had made chicken and rice, he's not going to eat it, so, and I just feel like I can't please them all (laughs).

A single father in my study shared his frustration with having to feed himself and give his son food that would make his son happy:

G: What are some things that you struggle with in managing your diabetes?

P: My diet

SG: Tell me about that.

P: Since I am a single dad of one child, it is hard to make meals for him and also for me. Children don't like eating skinless chicken. It makes it a little bit harder. It is very hard when you go out to eat to get a good meal.

SG: Why?

P: McDonald's don't really have anything. I can eat half of a cheeseburger. And there's less quantity of food when I go out to eat, meaning I will still be hungry when I get done eating my meal.

Another informant, who lives with her boyfriend without diabetes, talked about the challenges and compromises she has to make when purchasing for herself and her boyfriend:

P: My boyfriend that lives with me, we have to compromise on a lot of things, like I have eggs, bread, meat.

SG: So you say compromise, what do you?

P: Compromise is like, he likes to get, how do I explain this? He likes white bread. Well, instead of just getting regular old white bread, we have to read the ingredients, see which ones have more nutrients in them.

SG: He doesn't have diabetes?

P: Exactly.

SG: You mean compromise on your food.

P: I gotta compromise on my food, yeah.

SG: Do you usually, is that successful when you do that, or do you?

P: Yeah, we usually get what we usually get, but there are some things like bread, pasta, rice, and stuff like that, that we have to really compromise on. He love his macaroni and cheese, and he made me a pot of that, and I ate a bowl, and I had bad results on that.

SG: What was bad?

P: I had really bad cramping to the point I was curled up on the couch, and it was not good because, being a diabetic, you can have, wheat pastas, vegetable pastas, but not really, you know, starch, white, and yeah. And he just, he got a box of Kraft macaroni and it is the only thing he can make. I didn't want to

make dinner. I didn't think anything about it until after I ate the bowl. It took about 20 minutes before it kicked in. I was like, oh no!

I will elaborate further on how food impacts diabetes management when reviewing the data from my code theme on food availability.

Study participants expressed a wide variety of struggles, barriers, and problems with eating healthy. Challenges included difficulty controlling food portions and overeating, cooking for one person and cooking healthy meals, managing cravings for unhealthy foods, limited food options available when at work, personal food preferences that may not be diabetes friendly, and eating outside the home at restaurants, fast food establishments, community centers, etc.

Eating out at fast food or more traditional restaurants was often mentioned as a source of frustration when attempting to effectively manage diabetes. For example:

When you go out to eat, and you can order some of the things, but like at fast food restaurants, everything they have is either fried or some are grilled or flame broiled, but you can't always get what you have to have. And it is like, I don't know, it is a constant struggle and you are thinking about it but, it is like what can you do? Food is very hard for me, anyways, to eat like they want me to.

- Participant

Another participant also mentions this problem:

P: Um, one of the trying things is trying to find something, a menu at a restaurant.

SG: Okay, that's a really good point and you're not the only one's who's said that, so tell me more about that.

P: You have to try and limit yourself to what you, what you can eat, and uh, a lot of the restaurants have desserts with a lot of sugar and don't have any desserts or anything that would be diabetic.

Interestingly, an issue that is of particular relevance to those with low income is the food available to them served by community organizations for free, such as churches or homeless shelters. Those participants who sought nutritional assistance from these

organizations often commented on how their food, while appreciated, was not always appropriate for a diabetic diet:

SG: Oh okay. Okay, anything else that makes it hard for you?

P: Well, a lot of times the food that I, uh, that the church fixes for when we have meals at church, you know, they don't, uh, fix it just for diabetic people, so I have to really watch what I eat.

SG: What kind of food do they have that you say is not for diabetics?

P: Well like pastas, apple pie, cherry pie, coconut pie, and everything else

SG: Okay, and how often do you eat at the church?

P: Not very often

SG: (Laughs) Okay. Anything else that makes it hard?

P: Oh, when the church goes out to eat pizza or tacos and stuff.

SG: Uh huh

P: And they do that about every Wednesday night or Sunday nights.

The situation was similar at the local homeless shelter:

P22: Right before February 15, 2009, I was homeless for a month and a half. Let me tell you what, Salvation Army, if you are diabetic, that is not the best place to go to eat.

SG: Why?

P22: All you do is have cramps; they eat a lot of pasta stuff.

SG: This is good information because other people have said the place they are grateful for the food that is served but if you are diabetic it is not always.

P22: It is not good for diabetes. They give you salad, they give you fruits, but it is mostly pastas and stuff. It is because whatever places could donate to the Salvation Army is what you have to deal with.

For those participants who were able to work, the demands of their jobs often presented challenges to eating healthy and, therefore, managing their diabetes. One fast food employee was well aware of her problem with working and eating:

P25: I don't eat right. I work at Sonic and I eat out almost every night. I don't, I never cook.

SG: Okay.

P25: Because I am always working. And we always go out.

She went on to say the following about how her inconvenient work schedule impacted her ability to engage in healthy eating habits:

P: Sometimes we will have cereal. Like today, we will go grocery shopping and get a few things like cereal, bread, and eggs. But usually, I go to bed like at 3am, and I wake up about 11, and then it is time for lunch.

SG: Do you have a weird shift?

P: Usually I work from 3pm – 11pm. It takes me a long time to wind down.

SG: Right, to go to sleep, and then by the time you wake up, at 11am, you have already missed breakfast.

P: Yeah.

SG: So then you eat lunch like a noon time meal, and then when do you eat again after that?

P: Probably either at work, I will get like a corn dog or something. And then, but usually it is like after work, probably, we will go and get like McDonalds or something.

SG: So it is late?

P: Oh yeah, it is like midnight.

For those with jobs that require a lot of driving and to be out on the road away from home, the barriers are especially significant:

P: Other than that? That is my main barrier. It is me disciplining myself and not eating the chocolate and the candy and snacking.

SG: Why do you think that is hard for you?

P: I drive all day. I am a courier. When I am hungry, instead of stopping and eating, I grab a hamburger, or battling a salad, I grab a bag of potato chips.

SG: What does that mean a courier? What do you do?

P: I drive around and drive papers to somewhere for Bob Moore. I drive their papers from one office to the other.

SG: So you do that all day? So you are on the road all the time.

P: I am on the road all the time.

SG: That would be hard, I would think.

P: You eat something besides a potato chips, it is a lot easier for me to stop at 7-11 and grab a bag of potato chips instead of, okay an apple is better for you, and it is the same level of sugar, but an apple is better instead of a bag of potato chips.

SG: Right.

P: And even though I get, also they have the really bad variety of, instead of having wheat bread, everything is on white bread. I'm like "I'm starving."

Another participant, a truck driver, and his wife had this to say about how the participant's job impacted his ability to eat healthy:

P: When I am driving the truck, and I'm out on the road, it's very hard to eat right.

SG: Okay, tell me about that.

P: You know, I eat a lot of Subway, you know, um, low calorie stuff, but you still gotta have the bread, you know what I mean. I eat wheat bread. I try to, but it's very hard on the road to eat right, I mean you're in a truck stop, you're in a fast food place, you're, you know, a lot of times I'll have chicken wings or something like that, that um, chicken wings and a glass of tea, you know, and that'll be my dinner, you know but

P wife: Well, and a lot of times, like he thinks that he's doing good, like he thought that this Wendy's chili would be good, but I looked it up and I'm like, no it's got tons of carbs in it. I mean, he thinks that they're good, but they're not.

P: You know, like chili, you know, chili's supposed to be good, I mean, it's just meat...

P wife: Meat and tomatoes, but it's not...

P: Meat and tomatoes, what could be wrong with that?

Also related to low income was informants' lack of funds to purchase diabetes management essentials, like blood glucose monitor test strips; this in turn impacted how often they tested their blood sugar levels versus the recommended testing frequency.

For example,

SG: Then you only test, you don't test as much as you would like to because you run out faster.

P: No. I would like to do like you are supposed to, and I think that is 4 times a day. Supposed to test. Like you are saying, they are very expensive, like \$1 apiece.

The below dialogue provides another example:

SG: This is type 2 diabetes. You take 5 meds now, including the stuff for neuropathy. How often do you check your blood sugar each day?

P: I check about twice a week.

SG: Okay.

P: Because of the expense.

SG: Of?

P: The strips. They charge me for strips here. I know they would probably give them to me, but

SG: The expense of the strips.

This participant stopped testing her blood sugar altogether because of the cost of test strips:

P: So I don't seem to have, from what I understand, it is worse to go up and down than to be consistently high. Mine seems to go up and down. I can't test anymore so I don't know what my blood sugar is.

SG: You have the meter but not the strips.

P: Not the strips anymore I can't afford them. They are over \$1 a strip. That is outrageous. Something particularly for a type 1 it is life threatening that you can't get it. I don't know if Medicare covers it. I just don't know. And I just haven't been able to afford them and cuz they are expensive. It is all just kind of overwhelming.

Along with food, healthy eating, and nutrition, exercise and physical activity are often brought up in the context of a discussion about effective diabetes management. While participants in my study knew about the importance of being physically active when successfully managing their diabetes, they often noted numerous barriers to being able to implement some kind of regular exercise. Barriers mentioned in my study include: psychosocial stressors and family responsibilities, like caregiving, that make it difficult to find time to exercise, working/employment, thinking a gym membership is needed to exercise, lacking motivation and/or energy to exercise, living in an environment that is not conducive to being physically active, and physical complications of diabetes, such as neuropathy, that make it painful, difficult, and/or impossible to be regularly physically active.

Discussing the relationship among the physical environment, the physical consequences of diabetes, and exercise, this participant shared the following:

Well, yeah, I think. That is another thing I was doing that I stopped doing. I was walking, when I first started to walk I could walk about a ¼ a block when I first found out I had diabetes. ¼ block around. After about a month and a half, I could walk a mile. And I was that bad. I was that bad. It was hard for me to walk from my front door to my car. Painful, had a lot of neuropathy. I was fat, too. But anyway. Of course I don't mind walking through the trailer park which is a pretty dismal place, but I suppose other people might like nicer places to go. I guess I could see that. Having, I know some people go to the mall. I have a neighbor that keeps trying to get me to go to the mall and walk there. She doesn't want to walk around the trailer park. I don't want to go to the mall.
- Participant

Another participant had this to say about her physical environment and its negative impact on her ability to be physically active, which in turn serves as a barrier for effective diabetes management:

I know all those factors, the high cholesterol, the high blood pressure, all of this stuff is a factor for my mother died of heart disease in the family, and I just don't seem to be able to make enough, start walking, doing other things. I feel overwhelmed that I can't do anything. I know part of that is a factor of isolation. People go well you can walk, well if you want to walk where pickup trucks with confederate flags on the back and their rifle rack on the back driving 80 miles an hour yeah you can walk. They don't see you. They don't pay attention. I gotta get out of there but I don't know where I would go because I can't get any money to go anywhere so I am overwhelmed. I feel if I could get back into Norman.

- Participant

I discuss this phenomenon further in my analysis of my separate code theme for the physical environment's impact on diabetes management.

As I mentioned earlier, the painful physical disorders of the body often present as barriers to effective diabetes management, because they prevent the person from engaging in a level of physical activity known to be effective. These can include chronic pain issues and other injuries unrelated to a diabetes diagnosis, in addition to physical symptoms and consequences of diabetes. For diabetes, the physical consequence most often talked about in the context of a discussion about exercise is neuropathy. Unfortunately, even when an individual's diabetes is eventually well-controlled, the lasting effects of the irreversible damage caused by neuropathy can remain painful and only made somewhat better with pharmaceutical intervention. For example, this excerpt from dialogue between me, a participant, and his wife illustrates this issue:

P: Um, exercise would be great, but, I'm setting in, you know, whenever I'm working I'm driving a truck all the time, so you don't get a whole lot of exercise other than eating

P wife: And his feet hurt too bad to really exercise

P: Yeah, my feet hurt too bad to get out and walk a bunch, you know, I mean I'll pay for it if I do, just like yesterday I walked down and planted a tree, and you know, and last night I had hell with my feet, it's probably a hundred yards down to the fence, you know

SG: How long has that been going on, with the neuropathy?

P: Just the last year or so, hadn't it?

P wife: It's been the worst.

P: Yeah, this last year

SG: It's getting worse

P: It's getting worse, yeah, as I go up, you know, I mean, there's some days that I'm like let's just go over and tell 'em to cut my feet off, you know, I mean, let's get that out of the way

SG: And I don't know that there's that many treatments they have now for neuropathy. There's only so much they can do.

P: Right, she said once the damage is there, there's no replacing it. It's just, you try to keep from getting any worse.

Another participant shared her perspective:

I am not typically physically active in my own. I worked as, in fast food, and so at work, I would be on my feet and moving quite a bit. But as far as then my personal life, not as much, but I have begun walking. I am just not doing as good a job as that, as I wish that I could make myself do. And it is a combination, you want to do it, and then your feet kind of hurt too, so there is a yin and yang of oh can I overcome this pain? To be physically active. It is, there is an amount of struggle.

- Participant

This woman noted both the problems with her physical environment and neuropathy pain that prevent her from being as physically active as she would like to be:

P: Yeah, it is dangerous to walk in the street.

SG: That is important because that prevents you from getting exercise.

P: Right, and I prevent myself, too. I can't completely blame all that stuff. I need diabetic shoes because my feet kill me, it is really hard for me to walk now, but diabetic shoes are over \$100 a pair, and that is another thing I called to try to find help getting diabetic shoes and no one can help me. If I could afford Medicare, maybe I could get them but I can't afford \$110 a month not right now.

Patients talked about numerous physical complications and consequences of diabetes and diabetes management, in addition to auxiliary health problems, that were also barriers to effective diabetes management. This also included informants' ignoring, misunderstanding, or misinterpreting their physical symptoms as not being actual symptoms of poorly controlled diabetes. While the focus of my study was on the social and structural, or macro, determinants of diabetes health disparities, physiological barriers to successful diabetes management and care cannot be ignored.

Regarding physical complications, participants cited vision problems, neuropathy, frequent thirst, frequent urination, lack of energy, problematic wounds, and even diabetic coma as complicating barriers to maintaining optimal health and diabetes management. Indeed, these symptoms and consequences of poor diabetes management serve as red flags that diabetes is not properly controlled. Neuropathy specifically was often mentioned as a particularly painful and permanent experience that limited mobility even after the participant was able to get better control over their diabetes. For example, one participant relayed the following:

It is like a constant pain in your legs. And if you stand up for thirty or forty minutes, they start feeling weak and saying no, you gotta sit down. When you sit down, it helps it for a little bit but then they start hurting from sitting down. It is a constant up and down thing. And trying to walk, I can walk maybe a block and a half, and I have to stop, and sit down on something to get my legs back. And that, they say it is, if you got diabetes, you are going to have neuropathy. It is like nerve damage. That also puts a limit on what you can do. And if I had to, if I didn't have a way to go, trying to walk somewhere to get something is a constant battle.

- Participant

As is often the case with those diagnosed with diabetes, informants in my study were also managing other chronic health problems, like high blood pressure and high cholesterol. Managing these other chronic conditions contributed to the complexity of

managing overall health, and can lead to feeling overwhelmed. One participant in particular noted this when they said:

I know all those factors, the high cholesterol, the high blood pressure, all of this stuff is a factor for my mother died of heart disease in the family, and I just don't seem to be able to make enough, start walking, doing other things. I feel overwhelmed that I can't do anything.

- Participant

Furthermore, problems with memory were a contributing factor to ineffective diabetes management. Participants talked about their struggles with remembering to take medication and to get the necessary supplies. The following excerpts from patient interviews provide examples of a participant's inability to remember to take prescribed medications:

Example 1:

SG: (Chuckles), um, so, okay, one of them is food, what is another area that you find difficult?

P: Um, trying to uh, just remember to take the medication

SG: Okay, tell me more about that

P: Sometimes I forget to take it, and I have to, I catch myself and my wife's a nurse, so

SG: Oh, well good, she can help out. So how often would you say you forget usually, like in a week?

P: Oh, probably twice a week.

Example 2:

P: The medicine's a good thing, yeah

SG: And you take those regularly, right, is that, or what, how often do you?

P: Well, I try to take them regularly, I try. I miss sometimes, you know, but the morning ones I'm real good about. The apple I was telling you I ate in the morning, I'm real good about those.

SG: Uh huh.

P: It's the noon and evening ones that I, I slack on pretty good, you know, and that's the ones for neuropathy, I mean, it's ones I need to be taking all the time.

SG: Is it just that you forget?

P: I forget, yeah, I forget, and I leave 'em, you know, and I just, yeah. I just forget, you know.

Regarding ordering necessary supplies:

SG: Okay, well good. So, what other struggles do you have, trying to make, trying to manage your diabetes the best you can? What other things make it hard to do that?

P: Well, when I don't have the supplies.

SG: Okay. How often does that happen, where you find you don't have the supplies? I'm assuming you get your medicine here, the insulin and stuff.

P: It's when I forget to call it in.

Lastly, despite most participants having adequate knowledge of diabetes and the recommended diabetes management strategies, some identified lack of education and lack of understanding as diabetes management barriers. The most often cited problem was not knowing what specifically to focus on eating in order to prevent blood sugar from rising. The following provide examples from the words of my participants:

Well, I really just really don't understand it. I mean, a lot, I mean, really, I really don't know exactly what am I supposed to eat. I know I am not supposed to eat sugars and stuff like that, but sometimes I just have to.

- Participant

I would like to learn more about diet. That is my main thing that I still need to focus on. I still don't know what has high sugar content. Obvious sugar, yeah, I can eliminate white sugar a lot more than a fruit. What breaks down to sugar?

- Participant

The one struggle I face is not knowing what foods have the least amount of sugar in it. Yeah that is the one thing that I am learning to do is how to deal with that because there is so much processed food out there. And I thought stuff that grew out of the ground was not going to turn to sugar but I am finding out I can't eat beans no more. I love beans. And I got to give them up.

- Participant

Another participant talked about her needs for continuing education after the initial information she received after being newly diagnosed. She shared that she was not a mental state to be able to retain all the new information she was being offered at the time, and would have benefitted from review of key concepts:

It is just so confusing. I just feel like I am so overwhelmed and my brain is shut down. I can't seem to absorb anything. I feel like if I were able to go, I know they have once monthly meetings at Norman Regional. I feel like if I were close

enough that I could get a support group that I might be able, between a couple of people, maybe we could figure out what all this means. I find the information that is given is very unclear, particularly the information I got from my doctor. Was real old and didn't make any sense. I think probably, maybe if I took that diabetes education class again and knew what kind of questions to ask it might be more helpful. But when you are first diagnosed with something your brain goes like this and they may have told us when the best time to check your blood sugar and stuff but I don't remember. It is just all so overwhelming and I feel like at the time I was first diagnosed I didn't know the kind of questions to ask because I didn't know what was coming up. But when I started keeping track of my blood sugar when I was able to afford the strips and do all the stuff, there were a lot of things I didn't understand and I didn't understand why after you eat your blood sugar is supposed to rise and why does mine drop but I didn't know all that when I went to the class at first because I had only been recently diagnosed. When I went there I thought I didn't really have it but I really didn't think I really had diabetes. When that first blood thing was 150 and all the people that had diabetes for a number of years they said oh honey that is not that bad but it brought home to me that they must be able to tell from my face, honey it isn't that bad, the other people, I really didn't think I really, really had it and that was pretty concrete proof that you know you do. Have it. I feel like maybe if I hadn't been in such a stressful job that was just killing me, and not just me but everyone that works there, maybe I would have been able to keep it from going over. I know it can be helped because my neighbor before he sold his house was diagnosed with type 2 and I have never seen anyone his doctors couldn't believe it either. He got on the program and he reduced his need for medication. He followed everything religiously. I know that you can, I don't guess you are ever not a diabetic anymore but he kept it under control.

- Participant

It is important to note that while these participants provide examples of a lack of knowledge, their discussion of not knowing what they should eat in order to improve their diabetes indicators reveals their knowledge of a critical relationship between food consumption and diabetes, which is a basic foundation of diabetes management philosophy.

Interview theme: Facilitators to care and disease management. This theme focuses on what informants feel helps them manage diabetes successfully. Among this theme are participant excerpts highlighting resilience and resourcefulness despite structural barriers to best practice in diabetes management. Furthermore, analysis of this

theme reveals the creative ways participants were able to implement healthy diabetes management based on accurate knowledge gained in formal and informal ways.

First, I was pleased to discover that Health for Friends itself was noted as a major facilitator for improvement and success in diabetes management. Study informants shared their positive feelings and beliefs about Health for Friends as assisting with diabetes supplies, low cost medicine, regular medical checkups, and the opportunity to participate in beneficial research studies. Participants also talked about Health for Friends staff members providing motivation to improve their diabetes management. For example,

P: Anyway, I got a lot of positive feelings, I'd be here about every week, saying I hate to bother you again but I am peeing blood again. And just watching the weight drop, the blood pressure come down, boy it sure come down was a really positive motivating experience. It may sound corny but it was really true. And then at home it was exciting, when you are thinking, I ought to poke my finger and maybe I'll be down in the 70s.

SG: So that instant feedback or response that you would get from your decreased blood pressure and blood sugar that you got at home and from here was kind of motivating you to keep going.

P: Yeah. I mean, these people here are really, really, really deserve their, they are big motivators. They are big motivators. The staff here. I don't know if you were around when Julie Morris, she quit recently. I, a great loss to the community. She has gone onto something else but she was great.

Another participant spoke similarly of the staff as motivators:

Well, I am so blessed and happy and thankful that I have a place like Health for Friends to come to. I came here expecting to be herded in and herded out like a piece of meat, we don't care about, but I found these people here to be very caring. My doctor is extraordinary to me and she is actively tries to help. She really is just a wonderful doctor. Dr. Connery. It is like, the relationship becomes that I want to please this person because she gives me positive motivation whenever I do make the right choices. So it is a very positive thing to come here to get, so that is one of my major things that is helping me manage this thing.

- Participant

The fact that study informants noted the staff members as powerful tools of positive change is a testament to the vital importance of rapport and relationship building in the clinical medical encounter. This has long been established as an essential factor of treatment in psychotherapeutic treatment, and has been studied by medical anthropologists for decades in their efforts to improve communication and treatment between provider and patient in the clinical encounter.

Related to the positive influence of important others, many study participants noted the positive role of social support in the management of their diabetes, including support from family and friends. This facilitator for successful diabetes management was mentioned in a variety of ways, including others providing support with proper diet and eating, encouragement with exercise, medication management, being around others with diabetes and seeing their success, and assisting with facilitating a positive outlook. For example, this participant describes the ways in which others have been instrumental in her management of diabetes:

Getting enough rest. And, actually, I get a lot of support from my immediate group of friends. Like you met Mary Jane and she and I have been working together on this. She was diagnosed as pre-diabetic a year ago, and so we have been kind of working together on this. My stepmother is very helpful. And I have a couple of other friends that they will get onto me, it is like my friend, he has gotten onto me several times, it is like, and he is ruthless. Do you really think I want you to die? If you eat that, you are going to die. It is like, well, hell. So, that helps a lot too.

- Participant

Education, via diabetes seminars and informational groups, was described as a facilitator for healthy diabetes management that also often depends on interactions with others and social groups. This included diabetes camp for children, individualized

attention within programming at a local hospital, as well as information obtained from the internet.

Established best practice tools and strategies were, not surprisingly, noted as facilitators' effective diabetes management. These include taking proper medications as prescribed, having necessary diabetes supplies (e.g., test strips for a glucometer), and checking blood sugar regularly, getting adequate exercise and physical activity, and eating a healthy diet. The frequent mentioning of these factors not only indicates their importance of them in my participants' lives, but also demonstrates participants' knowledge of how they can make an positive impact on their experience of diabetes by engaging in specific beneficial behaviors. Thus, they demonstrate an understanding of the relationship between health behaviors and diabetes.

Several participants talked about how they gained this knowledge by reflecting on their own negative experience of the disease, in addition to that of family members and important others in their lives with diabetes. Diabetes symptoms, once ignored or not well understood, can now serve as indicators of poorly managed disease. For example,

*SG: You, before you passed out at work, were you having any symptoms of diabetes that you now realize? Like blurred vision, people have frequent thirst.
P: Yeah, I was real thirsty and I did have the blurred vision. And that is what I am saying now, is whenever I get the blurred vision and I get the headache and the dizziness, I know now. But I never even thought about having diabetes. I was shocked.*

Another participant notes how pain from diabetic neuropathy motivates her to do a better job of managing the disease:

Honestly, the funny part or ironic part might be that the diabetes caused neuropathy in my feet which is a pain. So now, the pain actually motivates me to

do better in my diet because I don't want it to get worse. So it is kind of like catch 22 or some other phrase you might want to use there.

- Participant

This participant went on to provide this insightful narrative:

I feel, at this stage in my life, the choices I have made to change my life in a more positive way, I kind of feel like the diabetes is, to be diagnosed with diabetes just focused my attention on my health, so that I can no longer ignore it and act like I don't have anything to deal with. So with, it ties in with the neuropathy. Knowing that I have this condition, I am much more aware and have a desire, because I have worked in the health care profession and I can see where it can lead to, and I don't want to go there so it is helping me, whereas opposed some people might ignore their condition and say I want to eat what I want to eat and do what I want to do which will lead them to a negative place with their body.

- Participant

Getting feedback about how one is managing diabetes by reviewing diabetes indicators was mentioned as a facilitator for healthy diabetes management. This includes vital signs, A1C, and blood glucose reading. Knowing others who have suffered from complications from diabetes also provides knowledge and motivation for personal improvement in diabetes management. The following participant mentions this in his narrative about what helps him manage his diabetes:

A lot of it I learned in the 12 step program that I participated in for 10 years. Also, I am counseling that I received the first four or five years after I quit drinking, and on the internet. There were some plethora of information about diabetes and how to manage it on the internet, and I read a lot of it. And that is where I got the thing, I thought there were things I should never do again, and that was where I got the information about if you want to have a coke, have a coke, just don't have 2 liters. If you want to have a cookie, have a couple of cookies, just don't eat the whole package. Like I said, sometimes I am more successful at that than others. But I make the effort because I have known people that had type 1 diabetes and people that had type 2 diabetes and had problems with it. It is not a fun disease.

- Participant

Another participant shared the following:

P: Well I've seen what happens when you don't eat properly. My grandfather, I've watched them cut one leg off, and I've watched them cut the other leg off, and then I watched him die.

SG: Okay. Anything else that you've seen, that has gone on with you that's helped you?

P: I've watched my dad

SG: Okay

P: Um, put his insulin on the dash of his pickup and it get hot

SG: Okay

P: And he still gives himself a shot, he goes in diabetic coma

Yet another participant shared the struggles she witnessed with her husband before he died:

Just past experience. My husband was, we were married for 25 years. And about the last 15 of them, he had to, every complication other than amputation. He suffered through every complication of diabetes that there is on record and some that I think he set the record for. Past experience tells me how I need to manage it. Not that I always do, but I know what to expect and what can happen if my daughter, with her diabetes, is, hers is, she was diagnosed when she was 18. She has had it for, she is, will be 32.

- Participant

An interesting fact that arose when asking informants about their experience with diabetes was that many talked about finding out they had diabetes when being seen by a professional for a seemingly unrelated problem; thus, they were diagnosed with diabetes in the context of seeking help something else. This included seeing a health professional in the context of a dentist visit, eye doctor visit, routine non-diabetes related check-up, physical health exam for employment, routine blood work, blood sugar screening at health seminar, and help seeking for other ailments, such as urinary tract infection, bladder infection, and yeast infection.

Furthermore, some participants' familiarity with diabetes symptoms led them to seek medical attention, which resulted in a diagnosis of diabetes. For example, when asked about how he got to have diabetes, this participant said:

I don't know. I just start just like overnight, becoming thirsty, going to the bathroom. Just feeling tired. And I got concerned because my mom was diagnosed as a diabetic and I went through that with her and the symptoms seemed so, almost the same as hers. So I decided to go to the emergency room. I went to the emergency room. My blood sugar was 600 something.
- Participant

Another participant said:

It was in my family, my father had it, had, got diagnosed about almost when he was 15. And they had the classic symptoms, rashes, and dizziness, blurriness, and I remember that. And that is what I had, the classic symptoms.
- Participant

Interview theme: Structural factor: Economic & financial constraints. The content of this theme explores how informants' personal financial situation impacts their diabetes management, including residual effects from the state of the current United States economy. It comes as no surprise that my participants experienced their low and inadequate incomes as significant barriers to effective diabetes management. Participants talked about income and money in ways that indicated the severe negative impact being poor has on one's ability to effectively manage their diabetes.

First, participants discussed the most obvious burden of having limited income and how that created challenges and barriers in nearly every aspect of their lives. They consistently talked about their budget and how their limited income puts restrictions on their lives that they are fully aware of. For example, when asked if there was anything she wished could be different that would make it easier for her to manage diabetes, this participant said:

Our budget. Plain and simple. It's the one challenge that I wish I could be able to wipe out. If I didn't have as much of a budget it would be a snap to manage it. Because there is a lot of foods out there that I can have but I just can't afford.
- Participant

When talking about his inability to earn a sufficient income, this participant said:

P: The abilities that I have to make the money, it's never enough to really impact any, my health or do anything towards improving my health. If I could go out and get a regular job and make \$500, \$600 a week, then yeah, that would definitely go towards my health. In two or three different ways. I would be working, and I wouldn't be sitting around watching TV or something. But making \$20 a week or \$25 every two weeks is not even enough sometimes to cover my tobacco. So the cash that I get now, I don't even, does not go towards my health or anything like that.

- Participant

More specifically, participants' personal financial situation directly impacted their purchasing and subsequent consumption of food. Many participants consistently shared how their limited incomes also limited their food choices. This is a critical barrier to understand for low income individuals with diabetes because food and nutrition are an integral part of successfully managing the disease. In-depth examination of this barrier provides a vivid demonstration of the structural and macro level impact of income inequality and poverty on the individual experience of diabetes.

Numerous participants stated that having little to no income meant they were unable to afford desired healthier food options, or sometimes to even purchase much food at all. This created a perpetually frustrating situation for participants; participants often knew what they should be eating in order to better manage their diabetes, but perceived themselves to be unable to afford a healthier diet. For example, when asked what felt like was out of his control, this participant said:

P: The food situation.

SG: How so?

P: I can't always eat what I need to. And once again, it falls under the category of finances. If I had the money to be able to do that, it would be better.

This participant had this to say about grocery shopping:

P: ...So I don't do shopping and I don't know a lot about the prices at grocery stores and things, but I know from looking at the ticket when he gets home, that yeah. There is not enough money. We are raising teenagers, and it is, they are

both in the 8th grade and graduate this year, so there is things that come up that are outside the monthly budget and everything. Finances do make it hard. If you try, it is harder to diet and eat healthy than it is to.

SG: Why do you feel that is true? I don't want to guess, I probably can, but.

P: Because, for example, if you want to buy anything sugar free, it is twice the price of anything with a cup of sugar in it. So, that aspect of it is. Zach is always, you should at least drink a Glucerna or something, you know. And it is, I am not in any different boat than anybody else is. It is just high these days.

When talking about the quality of the food purchased, this participant had the following interesting perspective to offer with regard to her ability to purchase quality food, given her low income:

P: When you get really, really broke, you have a choice between calories and food, and calories are cheap.

SG: What do you mean between calories and food?

P: 25 lb. bag of Asian rice will cost you \$12. I have a rather insane survivalist neighbor that back in the early 90's canned up an unbelievable amount of beans, dried beans, pinto beans, red beans, and she still has cases stacked to the ceiling. They are very, actually canned in a can, like a coffee can, and have done very, very well. And I work on her computer and her car, and she is so poor she pays me back in cans of beans, so I eat a lot of beans because we are broke. If I weren't broke, I wouldn't eat beans. I would go out and buy turkey and salad materials and stuff like that.

Another participant provides another clear example:

P: I get less quality care. Less quality nutrition.

SG: Tell me more about that. You were talking about that earlier.

P: I can get oranges and apples and fresh fruit, fresh green beans, but I can't afford them unless they are on sale because the money that I have is not near what I need to get these quality products. Better quality meat. I can't afford steak where I can cut it into cubes. I have to get hamburger meat when means I eat less quality. Good examples.

This barrier was also mentioned when informants talked about going out to eat. For example,

I look at the grains on them, at McDonalds and stuff. I can't eat at McDonalds, and you know where a child loves to go: McDonald's and Burger King. It is too expensive to go to the nicer restaurants where I could pick out better foods for me. So it has a lot of price cost of food. It has a lot to do with what I eat at home too.

- Participant

These participant narratives also demonstrate a common theme revealed within interviews with many of my informants: informants had at least a working knowledge of healthy eating recommendations for those living with diabetes, but expressed frustration at their perceived inability to implement those recommendations, given their financial constraints. One of my informants was very clear about this discrepancy between knowledge and ability to make healthier choices when she shared the following regarding an experiment on living on food stamps that law makers in Tulsa, Oklahoma reportedly completed:

Oh the law makers, yes. And they said that poor people, for lack of a better term, aren't necessarily unhealthy because they are not educated, they are unhealthy because all they can eat is macaroni and cheese and white bread, so you still can't make it to the end of the month. So it doesn't matter how much you know about good eating, you cannot feed yourself on food stamps in a healthy fashion. As a diabetic, if I am eating low grade, massive quantities of carbs, I am dead. My sugar levels will just go through the roof and it won't matter, even if you put me on insulin, it won't matter. I won't be able to exercise enough.

- Participant

Regarding health care, participants recounted about the numerous ways their low income negatively impacted their access to adequate health care. First and foremost was their inability to obtain affordable health insurance, which is what qualified them to receive their care at Health for Friends. This includes participants' inability to afford necessary diabetes medications, as well as the cost of medications (for both diabetes and other conditions) having a significant financial impact on a budget that is already stretched thin. These financial realities have a significant negative impact on

participants' ability to manage their diabetes successfully, as the disease requires ample resources including nutritious and healthy food, medication, and blood sugar monitoring supplies. Several participants specifically mentioned blood sugar monitor test strips as being a costly financial burden.

Not surprisingly, participants also expressed their gratitude for the health care Health for Friends is able to offer, as they would likely have no other option to receive consistent primary care services were it not for Health for Friends. Indeed, a few participants mentioned their unwillingness to seek emergency or other emergent medical care because of the cost. One of the consequences of the affordable health care available to the medically underserved at Health for Friends is that it makes the clinic very busy with patient care. The following participant noted this as a challenge she has observed while a patient at Health for Friends:

P: Yeah, well as far as it impacts me, I think back to it, this place is busier than it was and the resources are stretching further than they have been. I bet, I just know more and more people are losing their insurance and thank God for places like this. But this place has gotten very much busier since I came here in April.

SG: Which like you said, you have to wait longer, and the appointments get rescheduled and stuff.

P: Well, and they don't have as many test strips to hand out and things like that. It is funny, I've lived here for 40 years, and last April is the first time I have ever come here. I had heard of it before. Up until then I had always had a job that had whatever rudimentary insurance, we had. Or I was able to pay, since I have been self-employed a lot of my life, I have always been able to pay the doctor, but I finally had to come here and really, I get better care here than I have gotten at paid doctors in a long time. I have noticed since then, that is probably the biggest impact the economy has had on the way I see diabetes management. This place is just getting busier.

Interview theme: Structural factor: Food availability. This theme explores the food available to informants in the areas they live, and the ways this food impacts personal diabetes management. Also explored are the usage of food stamps and other

public assistance food programs and how utilizing these programs for securing food impacts diabetes management. Many participants talked about the food they have access to, and eat, in negative terms, noting how they feel that their food consumption negatively impacts their management of diabetes. As was demonstrated in the previous section, participants' food availability is intimately tied to their income, and food and income are often discussed together. Despite the challenges, there were also several instances of participants talking about how the food they eat is a positive influence on their health. Whether good or bad, participants made a strong connection between the food they eat and their health, particularly as it relates to how they are able to effectively, or ineffectively, control their diabetes.

First, there were many instances where participants talked about the perceived lack of quality food in their community, both from grocery and smaller convenience stores and when going out to eat at a restaurant. Furthermore, perception of a lack of sufficient quality and healthy food at grocery and convenience stores meant not having quality and healthy foods in the home. The following participant was rather outspoken about this issue:

I think when you walk in Walmart 99% of the stuff should be dumpsterized. It isn't fit for human consumption. It is sugar, it is fat. Try to find something in there that doesn't have those things, there isn't much. I think the American diet is unbelievably unbelievable. It is amazing that we eat that crap.
- Participant

Another participant talked about his experience with food available in grocery stores in the United States versus his native country:

You go to the supermarket, you don't have any choice. Everything is high sugar. It is really hard to find some kind of food without sugar. Natural food. Natural food you almost don't have natural food over here. Everything is chemical treated, genetic manipulation. Nothing is natural here. Here they don't have

yucca. The yucca is a root like this, but here it is like this. It has been manipulated. I know the natural one. I know what it is.

- Participant

Further complicating dissatisfaction with available food is the apparent lack of education about what foods someone with diabetes should be purchasing. The following participant had this to say about making choices in the grocery store:

It is no real education about diabetes. As far as going to a restaurant, everything is so fatty. And fried food, you know, French fries, and in the grocery store, unless you get educated what to buy, they really have, it is not quite available to you. In grocery store. So it is more or less, you have to educate yourself to know what labels to read and there is no support, I feel.

- Participant

When speaking about food available to them in restaurants, many participants did not have a favorable evaluation. For example:

When you go out to eat, and you can order some of the things, but like at fast food restaurants, everything they have is either fried or some are grilled or flame broiled, but you can't always get what you have to have. And it is like, I don't know, it is a constant struggle and you are thinking about it but, it is like what can you do? Food is very hard for me, anyways, to eat like they want me to.

- Participant

Another participant expressed his strong opinion when talking to him about the food he has available to him in the community:

People have to take control of their healthy, of the people, the nation. They have to control Kentucky Fried Chicken, and Pizza, Cici Pizza, all of this stuff; you cannot find healthy food in a restaurant here. It is just junk food. You spend a lot of money, you get good food. No, no, where to go? A lot of sugar in it, a lot of salt. Look at the stuff that is killing you. A lot of fat. Salt and sugar. It is too, let me tell you, over there, you cannot drink, it is too much sugar, in the food, when it is a French fry, it is like eating a piece of salt. Pure salt. Man, that and fat. Because everything is fried. As I told you, Kentucky Fried Chicken, you will have a heart attack really fast. This is impossible food. All, you go over here, in the whole town, you cannot find a single restaurant that is healthy. Not a single one.

- Participant

Analysis of my data also revealed many instances of participants noting that, in their opinion, healthier food is expensive and often times unaffordable. This single father talked about this when sharing the knowledge he learned about how to best shop at the grocery store for healthy foods versus the reality of his fixed and limited budget:

P: I learned that from when I was on Medicaid they did a group study, group program and they gave me a pamphlet, and in that pamphlet, they told us to go on the outside of the store. Don't go on the inside of the store. Do that if you have to, but canned vegetables have sodium in them and they have a lot of stuff that is not good for you at all.

SG: So they told you to do the outside

P: for healthier diet.

SG: Okay. And have you been able to do that?

P: I do it some. I can't do it as much as I want.

SG: Why?

P: Green beans cost a whole lot more on the outside and I have to feed me and my child. A lot of things I have to get for my son are not from the outside.

Macaroni and cheese. He loves that. It is not on the outside, they are on the inside. The noodles and pasta, that stuff they want you to try to stay away from.

This next excerpt from a participant dialogue also demonstrates the same battle between having a fixed budget and wanting to purchase healthier foods from the grocery store:

P: The food that I'm buying right now? No, I don't like a lot of the stuff I'm buying now, you know, but you gotta take what you gotta take, you do gotta put something in your body or you're gonna die.

SG: What are you buying now that you don't like?

P: Well, we don't like pork, but we buy it because it's cheaper than, you know, cause we gotta have some kind of meat in our body, gotta have some kinda protein besides beans, cause I can't just eat beans, they kill me. And uh, (pause) that's about the only difference. I don't buy as much, uh, fresh vegetables and stuff because they're too expensive.

Having a fixed low income and a perceived inability to purchase healthy foods sometimes meant participants would buy lower quality food, or generic food items, in order to cut costs. In this way, some participants perceived healthy foods to overall not be as accessible and not as readily available as unhealthy foods. Recognizing many foods as unhealthy, participants also made the link between the consumption of

unhealthy foods and detrimental effects on their blood glucose levels and overall diabetes management.

Interestingly, several participants talked about the food available to them for free from family members, shelters, community organizations, and churches. These participants talked about the barriers they faced when trying to eat a diet that lends itself to healthy diabetes management in the context of being completely dependent on others for their nutrition. This resulted in complex and conflicting feelings, including gratitude for the assistance yet disappointment in the lack of diabetes friendly food available. For example, at church:

P: Well, a lot of times the food that I, uh, that the church fixes for when we have meals at church, you know, they don't, uh, fix it just for diabetic people, so I have to really watch what I eat.

SG: What kind of food do they have that you say is not for diabetics?

P: Well like pastas, apple pie, cherry pie, coconut pie, and everything else

The following dialogue is from a participant's recounting of what it was like to be homeless and diabetic, relying on local organizations for food:

P: At one point I was homeless.

SG: When was that?

P: Right before February 15, 2009, I was homeless for a month and a half. Let me tell you what, Salvation Army, if you are diabetic, that is not the best place to go to eat.

SG: Why?

P: All you do is have cramps; they eat a lot of pasta stuff.

SG: This is good information because other people have said the place they are grateful for the food that is served but if you are diabetic it is not always.

P: It is not good for diabetes. They give you salad, they give you fruits, but it is mostly pastas and stuff. It is because whatever places could donate to the Salvation Army is what you have to deal with. Food and Shelter for Friends, it has an equalness there. A lot of times, whenever they are low on certain foods that are good for diabetics, like salads, wheat products and stuff, you just have to deal with it, but mostly they make a balance of everything. You have your meat, you have your dairy. They make a great balance.

SG: They do a better job than Salvation Army does?

P: Yes, because Salvation Army, they get donations from like, Olive Garden, and some other places, and it is all frozen. All they do is stick it up in their freezer. If you are, if there is enough people there that have food stamps, sometimes some of the people will switch off and go buy stuff, but you have to have a list of people who are diabetic so they know exactly what kind of balance they need to go and buy. They are usually pretty good about it. I know whenever me and my boyfriend stayed there, there was me and four other people, three of them being diagnosed with diabetes, and two of us being borderline, so whenever people had their food stamps, they would be, they would know exactly, they need to get some salad, some kind of meat product.

SG: So they would spend your food stamps for you?

P: No. There was at least four people that were staying at Salvation Army that had food stamps, and what they did was go personally to the store, Wrights IGA, buy the food, prepare it, and serve it. We try not to, with us being, at the time we had a pretty good group going on. So we always cleaned the dishes. We tried not to eat the Salvation Army food because a lot of people were having bad reactions, I guess you could say. Like some of us would have diarrhea, especially the diabetics would have diarrhea and stomach cramps.

SG: Oh my gosh. It is like you were getting some kind of bacteria/

P: It was the pastas because it is a lot of pastas, and not a really good balance of food, and you can only do what you can't the Salvation Army, you either eat what they got or you don't eat at all.

Despite these negative appraisals of food availability in the Norman community, some participants had no major complaints about their food and did not feel the food available to them negatively impacted their ability to successfully manage their diabetes. Some talked about purchasing quality, fresh foods from a local farmer's market. Others mentioned visiting a local dairy or catching fresh fish to eat. Still other participants mentioned healthy and culturally familiar/native foods that can still be purchased in the Norman/Oklahoma City area. Finally, those that utilized food stamps spoke favorably of the benefit program. They talked about how having food stamps helped them by being able to stretch out their food budget, allowing them to buy the food they need and to be able to buy healthy foods.

Interview theme: Structural factor: Social support. Data in this content theme reveal the role of important others in informants' own diabetes management.

Participants also discussed their perception of having enough social support, and how having little social support impacts personal diabetes management. Interestingly, many participants noted the strong influence others in their lives have in the management of their diabetes.

Other people were useful in a variety of ways that often had a positive influence on their ability to manage their diabetes and associated behaviors; this included providing general support, emotional, psychological, and spiritual support, assisting with eating healthier, being positively influential with regard to exercise and being active, assisting with diabetes treatment and management, and providing financial assistance. For example, the following participant had this to say about others in her life:

My mother especially because she raised me on it so she is number 1 support on that. She jumps me a lot about it but it is because she cares. Like my girlfriend. What I mean by jumps is "have you taken your insulin for the meals you have eaten today?" and I tell her yes. If she says that I am lying, I will say I have friends that she knows that they will tell on me because they care for me, so I have no back up support.
- Participant

Another participant talked about the encouragement and support he gets from his friends:

Well, just, you know, my buddies are like, you know, you can't eat that, just encouragement, yeah, they're really good about that, or man you really look good since you've lost that weight, or, you know, I get a lot of encouragement from my buddies.
- Participant

Others are often helpful when trying to stick with a healthy eating plan, particularly when managing diabetes. This informant talked about the role of family in keeping everyone eating healthy:

I don't lean towards my coworkers. It is mostly family, my boyfriend, and his family. We all have a diabetic diet. We stick to it. His family does that because his dad is diabetic. His mom eats like a diabetic to make sure that his younger brother and her don't get it. And basically, we are all, we try to stay with it.

- Participant

Another participant shared how those close to her provide her with vital information that help her trouble shoot problems and come up with solutions when managing her diabetes:

P: Yeah. Family. And I have my friend. She helps me a lot because she is diabetic from forever and she helps me to, you know, I feel sick, I call her, I feel like this, what do I do now, she says do this and do that. You know what I mean? That helps a lot.

SG: So your family and friends give you support and they offer you advice when you feel sick. Any other kind of support they can offer you?

P: Yeah, when I really sick and I cannot do nothing myself, I try myself first. If I still like nothing work, nothing works, I call my family, but I be the first one to take care myself. On my own. I don't call my family when I am in the fire. I try to put the water on the flame, and then.

SG: And then if you can't put it out,

P: That's what I do.

While the majority of participants talked about the positive influence other people have in their lives and in the management of their diabetes, a few others noted the negative impact others have. For example, others' lack of understanding of diabetes can lead to comments that are not supportive:

I mean, you know, I would like, you know, okay, forget lunch if you want to eat that piece of chocolate cake over there for that birthday today, you know, you know my grandkids have a birthday party. I know I'm going to have to go to it, and they get upset if grandma don't take a piece of cake. We try to tell them grandma's a diabetic, you know, they seen me scraping all the icing off, and "why in the hell ain't that so good for her?" you know, it's stuff like that...

- Participant

As another example, the following dialogue demonstrates how family perceptions of what it means to be healthy can result in an unsupportive social network for someone attempting to manage diabetes:

P: My people don't know how to stay on no diet. That is why they are overweight now. Shoot. If I got around my sister, do you know my sister loaded up and came down for Thanksgiving? This man have a heart condition. She loaded that man plate, he had a plate and I look at him and I said, whooo eeee he going to eat all that, but he was a skinny little old thing. Shoot. When she got good with that plate, I didn't see never did at the bottom of the plate, she covered the whole plate with food. It was one of those big old square kind. And she filled it; she loaded up like, I said, I see why she can't lose no weight. It wasn't a space on that plate for nothing.

SG: So it sounds like your family and friends don't support you

P: Because they don't go on no diet they don't care about you going on one. I got kin folks that act like big and fat is healthy. When my grandmother was littler, she thought being fat was healthy. She thought being overweight was healthy.

SG: Your grandmother did?

P: My grandmother. I was raised by my grandmother and she thought being overweight was healthy. You walk around her skinny; she thought you needed some meat on your bones. She would come with vitamins trying to fatten you up. Nuh huh. They think being fat is healthy.

SG: People that you know?

P: Uh huh. So I learned don't talk about no losing no weight around them. Shoot. Nuh huh.

Some informants noted that they feel they did not have enough social support at the time of the interview. When asked about how lacking social support can negative impact personal diabetes management, informants mentioned how their success in managing the disease would be impacted, lacking things like transportation assistance, help with navigating bureaucratic systems, making it easier to make the wrong food choices, and social isolation.

Interview theme: Structural factor: Physical environment & geographic location. The content of this theme pertains to the relationship between the informants' physical/geographic environment around where they live and their personal diabetes management. Participants made strong connections between their physical environment and the opportunities available to manage their own health. This included both positive

and negative characteristics of their geographic spaces that either helped or hindered their efforts at maintaining a healthy lifestyle.

My study informants were often easily engaged in a discussion of what they perceived as barriers and negative aspects of their physical environment that made it difficult for them to effectively manage their diabetes. Not surprisingly, participants often talked about opportunities for exercise in the context of their conversations about their physical environment. Informants noted not having access to places to walk, be active, or exercise outdoors as a major barrier to improving their health and diabetes management. They noted the presence of stray dogs as being problematic. For example,

P: I don't because there are too many stray dogs in the neighborhood. We strictly go to the campus. We park at Megan's apartment and walk there. On the days that are really, really bad, we go to Sooner Mall. And we will walk the mall inside. Just walk around the mall.

SG: And you said that your neighborhood has too many stray dogs to walk around.

P: Yeah, I don't feel comfortable.

Snakes and tics were noted as a barrier to physical activity outdoors in rural areas. Also contributing to a lack of neighborhood and environmental safety noted by some informants was the presence of uneven walking surfaces, traffic, and unsafe drivers:

SG: So, the neighborhood, the part of Norman where you live, does it impact?

P: Well, it kind of does. It's hilly, and uh, I don't feel safe. The roads aren't safe. Traffic is too (pause), uh, traffic is, people are too fast on those country roads. They'd kill you, they come up flying over those hills. They'll kill you.

SG: Someone else told me that too, they didn't feel safe walking.

P: Nu uh.

SG: Walks along the road, they said the big trucks drive by too fast.

P: It ain't just big trucks. It's teenagers. It's these middle aged guys that think they gotta speed up and down the hills and see if they can think it's a roller coaster.

Additional notable barriers to effective diabetes management and the maintenance of a healthy lifestyle shared by my participants included not living near

medical or health facilities, not living near a grocery store, living near to places that sell unhealthy food (e.g., convenience store, fast food restaurant), and social isolation. One participant in particular spoke at length about how her social isolation negatively impacts many aspects of her health:

It is just I can't get help with anything. Anywhere. I can't get help with my utilities if they are real high. Like this month, I don't know how I am going to pay that. It is really stressful and that aggravates everything. I this whole condition has been really overwhelming and I can't seem to absorb everything I have to do. It seems so confusing. I am hoping that eventually it will get back to normal, but until then I have a 40 mile round trip just to come in. I can only afford to come into town about twice a month because of the gas. So I am pretty isolated and I don't have any support group. I can't go in weekly, I can't afford the gas to go in so I am stuck in the middle of nowhere by myself. Literally in the middle of nowhere.

- Participant

This same participant went on to elaborate further about her experience of social isolation:

I don't know that I have any others except I guess I am always hoping that if I do this all of a sudden everything will fall into place. That moving into Norman, that will help. I know that I need to be around more people, being sitting isolated is not good because you tend to just think about all the stuff that is going on and it is not helpful. And I just feel like that I feel like in a way I have a plan to get out even though it is going to ruin everything my credit and everything, I feel like if I move into town, and I lived in Norman, that will help a lot. I'll be able to walk better. I could maybe join the Y, something. To get around people or be in a structured class or situation like that. And if I could go to those support groups, other diabetics will probably have good strategies that they can explain that make sense. I feel like that is sort of a plan but it is not really much of a plan.

- Participant

Other participants talked about the positive aspects of their physical environments that allowed for conditions conducive to better diabetes management.

These were often in contrast to the barriers identified by the participants noted above.

Most noted was the presence of place to walk, be active, and exercise outdoors. This participant shared her appreciation for her physical environment when she said:

I am blessed. I have a wonderful apartment. Some people, I tell them where I live, they say, eew, Emerald Greens, but in actuality, it is a nice place because I can safely walk during the daytime and it is a nice environment to walk in because it is not congested with a lot of people. It is almost like a little pocket of a rural area that I get to live in. So my little area, I think positively impacts my ability to get out and walk. If I choose to do so. And I love everything about my little apartment, so that means a positive environment – mentally it is positive, so I don't feel like I am in a congested area so there is less stress. Natural stress that can be, involve feeling closed in and stuff like that.

- Participant

Other positive and facilitative characteristics of the physical environment mentioned by participants included living near health and medical facilities, feeling safe and secure in nearby environments that are clean and peaceful, seeing other people being physically active in the neighborhood, and quality public transportation.

Interview theme: Mental health & physical health. Informant responses within this theme relate to their discussion of the relationship between their physical health, with a focus on diabetes, and mental health. More specifically, informants were asked to discuss how having diabetes impacts their mood and mental health, including how they think and feel on a daily basis. Data from this theme provided highly interesting results, as participants narrated about their personal mental health struggles as they live their lives managing diabetes. While some participants noted positive thoughts, feelings, and emotions resulting from effective diabetes management, many mentioned the negative consequences of living with the disease. This includes both how pre-existing mental health disorders can make diabetes management more difficult and how ineffective diabetes management and resulting physical consequences like high

blood sugar can exacerbate mental health symptoms and contribute to unwanted stress, anxiety, and depression.

The two most common mentioned mental health symptoms that were complicated by diabetes, and vice versa, were depression and anxiety. Here is an example of this relationship, shared by the following two separate participant exchanges:

Example 1:

SG: You mentioned the neuropathy, anything else besides what we said that are struggles you face when managing your diabetes?

P: Other than the mental.

SG: Tell me about the mental. You already kinda told me.

P: It is depressing. I found out I have always had depression, but it hasn't been as strong as it is now that I have diabetes. And with the diabetes, I am having health problems, and it is causing me not to work, and I just stay stressed, and then I get in a depressed mood. And I guess you'd call it chronic or severe depression, but that makes me hurt even more.

Example 2:

P: Yeah. Having diabetes has really messed with my mental health.

SG: Tell me how. We have already talked about it some.

P: It has caused more stress on me, which has caused depression. And just hopelessness. Because it is like the more I have tried to control it, the more I try to do, it is like it is not working. I can't see any improvement. And that kind of just sucks the life out of you. So I get feeling like, it is going to kill me, I wish it would kill me. That really happens quite often. So the diabetes is really playing a big part of my mental health.

Another participant talks about her depression in the context of medication management:

Yes. That is, I am really depressed about it because I am having to take so much medicine. I am depressed that no matter what I have done in the past or recently, it isn't helping out. It's overall, it gives me a lot of stress. I get irritable a lot, which the doctor said was from my high blood pressure.

- Participant

Another talks about depression in the context of diabetes management in general:

P: Sometimes I get really depressed over it.

SG: And you mentioned that before. Tell me about that.

P: I just, I'm tired of being, having to stick myself. I'm tired of, uh, having to count all my foods, you know, I don't know how to explain it.

SG: You're doing great

P: Other than, uh, it's just stressful. It's stressful in itself, just having to do all that stuff, keep up with your blood sugars, I know you've gotta do it to stay alive, but it still...it's a real pain in the butt.

Regarding anxiety specifically, the following participant shared his difficult struggle with his constant worry and fear about the negative consequences of his diabetes:

The only thing that I haven't mentioned is the fear. You constantly live in fear that you are going to wake up one day and your kidneys ain't gonna work. Or you are going to have to go lose a leg or lose an arm. I mean, I have already lost my eyes. And it is a constant fear of, knowing or thinking that I ain't got it under control and it is going to shut down some of my organs. That is the only thing that we missed. That really bothers me.

- Participant

This next participant talked about how overwhelming the management of diabetes can be, leading to increased stress:

I feel like my mental status and the stress I am feeling is keeping me from seeing clearly the things I need to do and just the feeling of being overwhelmed makes me tend to do nothing. I try, I don't drink soft drinks anymore, I am trying to do stuff better, but I just think being isolated, it is just so hard because it is so easy, I don't feel like eating, I don't eat regularly. I know you are supposed to do all that stuff, and I know what you are supposed to do, it just seems overwhelming sometimes.

- Participant

The following participant shared about how she ineffectively manages her stress in a way that directly impacts her diabetes in a negative way:

The stress thing. When I get stressed, eating something with some kind of fast carbohydrate load will make me feel temporarily better but then I feel worse and the only cure for that is to eat something else. It is almost like while you are eating it you will feel better, 5 minutes after you stop, I honestly think I feel worse. I really do. I think that just about makes me lie down and go to sleep.

- Participant

Informants also used a variety of negative adjectives to describe their mental health while living life with diabetes. Participants described themselves as being embarrassed, hopeless, mad and angry, cranky, moody, irritable, irrational, frustrated, aggravated, disappointed, fearful, worried, and overwhelmed. The widespread use of these negative terms participants used to describe their mental status while living with diabetes is a testament to the multidimensional burden the disease can have on an individual's overall well-being.

Interestingly, several of my study participants identified a critical synergistic relationship between stress and blood sugar, in addition to a broader relationship between diabetes and stress and depression. Many participants strongly felt that experiencing negative mental stress raised their blood sugar level and, overall, worsened their experience of diabetes. For example:

P: I don't know if I would call it a struggle. I have noticed a lot of highs in my blood sugars just in the last several weeks, but I have been, I think it is stress and pain management that is.

SG: Tell me about that. This area of stress and diabetes is becoming more of a thing that people are paying attention as the link.

P: I think it is a link. We are raising grand kids. It is becoming more and more common. They are 14 and 15 years old. A 14 year old girl and a 15 year old boy. There is your stressor. We have had a lot of problems with the boy.

This next participant provides another example of this synergistic relationship:

P: It sucks. I have two jobs to pay off loans. And to help pay my car payment.

SG: How does that impact your health and diabetes management?

P: All it does is stress me out. It doesn't really help.

SG: So the not having enough money is what you are telling me stresses you out?

P: Yeah.

SG: What can you tell me about the stress?

P: It gives me anxiety. A lot of times I have heartburn from it. And it kicks my depression in because I don't know how I am going to do everything but I still end up doing it, no matter what.

SG: And, does it affect your diabetes specifically in any way? This situation?

P: It probably raises my blood sugar.

When talking about the management of diabetes and mental health, this next participant made the connection between poor diabetes management and its effect on stress, which in turn makes it less likely that she will effectively manage diabetes. She started this discussion by saying the following about how her diabetes affects her mental health:

I really do think my diabetes affects me in a lot of ways. Because if I don't manage, I have noticed that if I don't manage, keep my diabetes under control, then it tends to make me feel jittery inside and I feel stressed. I don't know. I have all these crazy mood different feelings when it is high.

- Participant

When asked to consider further about how stress could potentially impact her blood sugar, she went on to say:

That could be true. I never thought about that. Just recently, I have been really stressed. I am going to say just in this week, or whatever, and yes my blood sugars have changed just from the stress.

- Participant

This next participant talked extensively about the negative impact a tornado had on her family and their livelihood during the course of my data collection phase of my research project. This tornado struck the Norman area and caused significant damage. When talking about how she managed her diabetes and blood sugar levels during this natural disaster, this participant noted how stress raised her blood sugar levels repeatedly:

SG: Now, you mentioned at the beginning, and you said that makes your blood sugar go up.

P: Yeah, well if I get real stressed, or...

SG: Tell me about that.

P: if I'm in real bad pain.

SG: So the stress makes your, makes your blood sugar increase? And you've checked it when you've been stressed?

P: Oh yeah.

SG: How high does it go?

P: Sometimes in the two hundreds, and I haven't done anything other than be just really stressed out, and you know, like, when we were having all this stuff

with the tornado, and we were so stressed out then, I would stay in the two hundred all, it was like all the time. I mean, all the time.

SG: So, those times that you checked it and it's high, and it stayed high, you're saying that the only thing that you've had is stress, you haven't had like a lot of sugar or anything to...so that's how you're making that connection. And that's a very real connection that people are just now learning more about the, the connection between uh...

P: Stress.

SG: Stress and...

P: Stress will kill you.

SG: Diabetes.

P: And stress will kill you.

SG: And it's interesting, because you're saying that, you know, your life circumstances lead you to be stressed, and then, which makes your blood sugar go up, which means you have to do more diabetes management, which makes you stressed, so it's kinda like a circle.

P: A big fat circle.

Speaking more broadly about the relationship among diabetes, stress, and depression, the following participant said:

SG: So the stress, diabetes links to you to stress and the depression, and the stress and depression in turn influences your blood sugar from diabetes, from what you are telling me.

P: It is a real roundabout circle there. If I didn't have stress, I probably wouldn't have the depression. And I probably would have a better hold on my diabetes, but, no one can snap their fingers and say, here is money to pay off everything that you need so you can have a better life.

In an interesting statement, the next participant starts off by talking about the importance of individual responsibility and decision-making when managing diabetes, then soon talks about disparities between rich and poor people, and how these disparities impact mental and physical health.

That is up to the individual person. It is not about having money or not. I am not this way because I am poor. I am fluffy because I was born this way. I was born chubby and I had my skinny moment whenever I was before 4 and 6 and since then I have been fluffy all my life. It depends on your heritage, your blood type. It is not, because if you are poor or you are rich. Rich people indulge themselves but they have more money to fork out to tell people, hey, fix me now. While you have, they have the money to go have their surgeries, go fix their bodies in unnatural ways, while poor people have to do it the all-natural way, which

causes more stress, causes more people to have more problems, like depression. Bipolar. All your diseases are coming from stress. If there was less stress on the world, I bet you there wouldn't be as many diseases out there as there is now. Diabetes can swing from having too much stress, a person relieves stress by eating, eating causes obesity, and obesity in general is connected to diabetes. My mom is 180 pounds and actually, last time I saw, she was 170 and she has diabetes. It is all the stress. My mom has been stressed out since I was born. She was only 18. She has me and my two brothers. She is stressed 24/7.

- Participant

This next participant talked about depression specifically when talking about the relationship between the management of both mental and physical health:

I have had depression all throughout my life. It would get worse in fall and spring. It was very manageable, with God and my spiritual beliefs, but now that it has become more of a physical challenge, also, with my ability, it has caused more depression to be overwhelming. And I know it, but there is nothing more, it is out of my control, and I know it is out of my control. It is controlled, but it is out of my control. Like chronic illnesses people have, you have less control over it. And I consider diabetes a chronic illness.

- Participant

The following dialogue speaks to the relationship among having little to no income, stress, and diabetes management:

SG: How does your personal financial situation impact your ability to manage your diabetes? The income or money that you have, how does that impact your ability to manage your diabetes?

P: Can't buy nothing.

SG: Tell me more about what you mean about that.

P: You gotta have money for food, clothing,

SG: How does that impact your diabetes?

P: Because it stresses me out, not being able to have any.

SG: What does that stress do to your diabetes?

P: Makes me eat more.

SG: Okay. How often would you say that happens?

P: About three times a day.

SG: Everyday?

P: Yeah.

Speaking again about how the stress of financial burden impacts diabetes management and mental health, this participant recognized the problematic coping behaviors she engaged in:

SG: Is there any other way that your situation, financial situation impacts your health or your diabetes?

P: Sometimes sleepless nights. I am worried about that.

SG: So sleepless nights because you are worried,

P: Worried about money, worry about how long am I going to pay for the bills. It is part time and I am going to have to ask my oldest son to help a little bit and stuff. I want him to go to school instead of helping. I don't want to hold him back.

SG: How often do you have sleepless nights of worry?

P: At least 5 times a week.

SG: That is very frequently. How does that affect your diabetes, do you think?

P: Ridiculous. A lot. Instead of a snack, oh the popcorn sounds good, or peanut butter and jelly sandwich sounds good, on white bread. Or I have soup with pasta.

SG: You are associating the snacking with stress?

P: Yeah. Snacking with stress. Or just sit there. Instead of eating all day, I eat everything at one time. That is also my problem. I eat everything at one time. And of course you get diabetes sugar, it plunges down and way back up.

This next participant talked about the connection between the stress hormone cortisol and diabetes management in the following dialogue. Interestingly, as with many other instances of participants talking about the relationship between mental and physical health, this discussion arose organically when talking about other stressors, such as a participant's personal financial situation.

P: Well, the stress of where I am is, it probably is taking a toll. I believe, I frankly believe that it is also making it harder for me to lose weight.

SG: Tell me about that.

P: I believed in the cortisol effect. And I really think that I should be having more rewards for the effort that I am putting in. Again, it may be aging, I don't know. But I really think that it is the ongoing stress because my body has never been this uncooperative. I have accomplished a lot, but it is just so slowed down. I have had the past few years, especially the past 6 months, inescapable, ongoing, high levels of stress. So.

SG: Okay. How is that affecting your diabetes do you think? Or do you think it is affecting your diabetes?

P: I think it is affecting it in that I would be, I would doubtless have better energy and I might even be getting closer to my 80 numbers that I am striving for. If I wasn't under all this stress. My body was cooperating with losing more weight. So I do think I probably have a wash of cortisol in my system. I try not to think about that because I do think that is somewhat of a mind/body connection, so I try not to say that, but I am going logically, I should be having more of a payoff. What is stopping it? I think it is probably, you know.

Despite these negative words used to describe life with diabetes, others in my study were quick to note the positive thoughts, feelings, and emotions they have experienced while living with and managing the disease. Some participants talked about being motivated to do better once they were diagnosed with diabetes, including experiencing a “wake up call” to improve their health once they were diagnosed. Another mentioned the positive feelings they gain when they manage their diabetes well. So, for example, instead of feeling a whole host of negative feelings when managing diabetes, this participant simply described her perspective on the diagnoses when she said:

Cause like, the way I figure, it's not like a death sentence or anything, it's just a condition you have to deal with.
- Participant

Drawing on her relationship with others, the following participant found motivation from witnessing her husband's battle with diabetes:

SG: Okay, these questions are about the connection between mental and physical health. Does having diabetes and managing diabetes impact your mood or overall mental health in any way?

P: Yeah, I think it does.

SG: How so?

P: I think it does. Just, especially with seeing what my husband went through. Now I don't think it is necessarily affected my mental health negatively, I think it has probably given me a more mental picture of, if you don't do this, this is where you could be.

Related to this positive experience is this next participant drawing on her experience working in health care and using the knowledge of the negative consequences of poor diabetes management to motivate her to improve her own health:

I feel, at this stage in my life, the choices I have made to change my life in a more positive way, I kind of feel like the diabetes is, to be diagnosed with diabetes just focused my attention on my health, so that I can no longer ignore it and act like I don't have anything to deal with. So with, it ties in with the neuropathy. Knowing that I have this condition, I am much more aware and have a desire, because I have worked in the health care profession and I can see where it can lead to, and I don't want to go there so it is helping me, whereas opposed some people might ignore their condition and say I want to eat what I want to eat and do what I want to do which will lead them to a negative place with their body.

- Participant

This next participant found motivation from checking her blood sugar levels with her glucometer and was able to maintain a mental framework that challenged her to improve her diabetes management:

If you don't know where you are at it is hard to tell what you need to do. It also is just a big motivator. You see it, you wrote it down in your little log. Actually for one of the meters that I ran out of strips for I have the cord you can plug into the computer and downloaded the software and it made lovely charts. It was a lot of fun.

- Participant

Interview theme: General structural impact discussion. This broad theme further explored informants' perception of macro level influences on their micro experiences of having diabetes. Topics include informants' wishes for what could be different to make diabetes management easier, anything about diabetes management informants feel is out of their control, and informants' suggestions for societal change to address the growing diabetes epidemic in the United States. Within this thematic code, I also challenged informants to consider a relationship between societal inequality and the development of chronic disease within individuals of any given community.

While some participants struggled with making a connection between macro and micro factors that impact their health and the well-being of society, others spoke at length about this relationship. They noted key characteristics of social and economic inequality in the United States that create environments where poor people have less opportunity to be successful in managing their health and chronic diseases like diabetes.

Many participants made more general comments about wanting to have better control over their diabetes, or to find an easier way to manage the disease than with cumbersome medications, painful insulin injections, dietary constraints, etc. Looking back on the past, this participant said:

Oh I just, like I said, wish it was different than what it is now, I mean, you know, if I had tight control of it back in, you know, if I could have gotten control of it 30 years ago I wouldn't be in the shape I'm in now maybe. I think I would have better control over it.

- Participant

One of the most common macro influencers on diabetes management was participants' personal economic situation. This was almost always characterized by financial hardship, limited funds for health care, inability to afford health insurance, and reliance on others for survival, including family, friends, and local and federal government programs like homeless shelters, churches, and the food stamp/Supplemental Nutrition Assistance Program (SNAP).

Participants overwhelmingly talked about economic and financial constraints and the struggles of living in poverty when talking about the general structural factors that negatively impact their ability to manage their diabetes successfully. These constraints include those that are the result of living on a fixed and low income, unemployment, underemployment, having medical expenses other than those related to

diabetes, taking care of loved ones, and trying to manage diabetes effectively. For example, this participant talked about multiple loans she is trying to pay off and the associated problems with having a limited income:

I have signature loans. One was to get Christmas. And my electricity at the time, it ended up getting shut off the day I was going to pay the electricity, and it got shut off because apparently, OG&E doesn't know how to take care of their accounts. And how to send out their bills, so I end up having to turn around and pay two hundred something. I got a \$250 loan for that. I went and paid it all, got my electricity turned on. It took 3 days for them to turn it on. My boyfriend has asthma. He almost got sent to the hospital for having an asthma attack. OG&E doesn't care. They want documentation. He doesn't have health insurance but he has documentation from when he was younger and they wouldn't accept it.
- Participant

Financial hardship for this single mother of two meant complications for managing diabetes effectively:

Time, you know, I am a single mother of two. And plus working and trying to find another job. That is part of my stress and sometimes I will forget my pills and go back and get my pills. That is why I forget my pills because I am running and running. Before I know it is like, you know.
- Participant

This next informant found herself comparing her financial status to that of her friend, and she found herself limited in her options for better self-care:

Trying to find work and then when I am working, doing that and getting everything else taken care of in my life takes everything I've got. Whereas this friend of mine is wealthy and she is retired, and she goes to the gym for 2 – 3 hours a day. When is that going to happen for me? I do what I can, but I would like to do more. I would like to think I could do more.
- Participant

This same informant went on to talk about the limits that limited finances put on those with diabetes, despite having the information and education about how best to manage the disease:

Well, I think with, we kind of covered it, but it's this disconnect between, uh, those of us that, even if we have the information, when you don't have the funds

to pursue treatment or proper nutrition, so, you know, education isn't the entire answer. Now, some people don't avail themselves of it. Some people don't connect the facts with their future health, you know, I understand all that. But, even if you're someone like me and you want to, when you minus finances out, I think maybe that's the most important thing I want to say. When you minus adequate finances out, nothing else matters.

- Participant

Speaking specifically about food stamps, this informant noted the essential nature of food stamps to supplementing an adequate diet:

They need to raise the income limit for food stamps so more people get it. When I first retired because I had to wait 2 months to get my first check, I did qualify for food stamps, and once those went away, that makes a big difference. Food stamps are a God send. That is about all single people can get in this state.

- Participant

When asked what they wished could be different in the management of their diabetes, many participants said they wished they had more money and were in a better financial situation. This is an interesting finding in my study because participants often responded with a socioeconomic solution for their physical health problem when asked about what they wished could be different from their life with diabetes. For example, this participant stated succinctly, when asked what she wished could be different:

Our budget. Plain and simple. It's the one challenge that I wish I could be able to wipe out. If I didn't have as much of a budget it would be a snap to manage it. Because there is a lot of foods out there that I can have but I just can't afford.

- Participant

Another participant made similar statements:

P: Yeah, I wish I had more money, so I could buy the right stuff.

SG: And when you say buy the right stuff, can you tell me what you mean by that?

P: The diabetic stuff.

SG: You mean the food?

P: Yeah. Food.

SG: Okay, anything else that you wish that you could get with having more money? Is there any other way having more money would change things for you besides being able to buy?

P: Everything. Yeah.

This next participant made a connection between personal financial situation and opportunities for exercise and social interactions:

Yeah, and somehow I think it would be better...that I had enough funds that I could work part-time because I do like working, but I would like time to exercise like my friend, and really be dedicated to it, and, um, I'd like to have a bigger circle of friends so that I was more engaged in life, because I really do think that's a big de-stressor in life.

- Participant

Regarding nutrition and exercise, this participant said more money would help him live a better quality of life:

P: Well, I think more money. Because if I had more money, I could< I think I could get more exercise into my lifestyle.

SG: How so?

P: Well, as I mentioned before, might choose to get a gym membership, where you have a place where you can go and it helps motivate you in different ways. Or buy home equipment and have the room to be able to do that kind of thing. That would be the biggest thing that I wish. Sometimes I wish that I could, if I had a wish list, I would have someone that would probably try to look for one of those food service companies that can provide dietary appropriate dietary meals that would give you different culinary experiences so you are not eating the same thing so you can really enjoy life a little bit more like that. Those are the things.

Informant responses to what they felt was out of their control were also revealing with regard to what they felt had a major negative impact on their daily life with diabetes. Economic struggles were again mentioned as an important aspect of the diabetes experience, and felt to be out of the participants' control. Furthermore, the

consequences of diabetes and diabetes management, including emotional distress, were also mentioned as being experienced as being out of control. For example, the following participant said:

P: The diabetes is out of control. To me.

SG: How?

P: Cause I don't know what I am doing. That is what it is. I would like the knowledge of what I am supposed to eat and what I am not supposed to eat. That is where I am lost at. Then she comes in here and tells me that I can eat some of that stuff, that I ain't supposed to be eating but just a little bit of it. Do you know what this is like? That is like telling me that I can eat these 2 little squares of chocolate, and no more than that. Y'all don't understand.

Another participant talked about feeling like her diabetes management is out of control, which can feel very discouraging:

Yeah, sometimes when I take, particularly on days when I have been really good, and it has happened a few times, not a lot, but a few times, I will check my blood sugar and it will be high and it is like, what the fuck. I had salad for lunch. And didn't have any bread today and I didn't drink any milk, I didn't eat any fruit, I had vegetables and fish for dinner. It is like what do you mean it is 315? And that discourages me a lot.

- Participant

When challenged to think about how inequality in society might influence chronic diseases like diabetes, informants gave a variety of responses. They noted employment discrimination, the challenges associated with not having health insurance and adequate health care, personal experiences with living in poverty, racial inequality and racism, food inequalities (e.g. differential access to healthy versus non-healthy foods) and their impact on health and diabetes management, lack of social assistance programs and resources, and modern society and its associated conveniences (e.g., ease of access to fast food) and their associated negative impact on diabetes. Clearly, some participants in my study felt the societal infrastructure and bureaucracy are not arranged

in their favor as members of a low socioeconomic class. For example, this participant had this to say about her perspective:

SG: Would you say that poor people are more stressed in general than people that have more resources?

P: Yes I do because there are not enough resources out there for people that don't have enough money to afford insurance and stuff. They don't have the resources and go, hey, I'm sick. Instead they have to wait until they are so sick that they have to go to the hospital. And the hospital is what diagnosed them and you don't know if the hospital really cares about them. If I were to get a stomach ache that was so bad and I walked into Norman Regional, Norman Regional wouldn't give me any pain medicine. Wouldn't tell me anything except take some Tylenol and go to bed. I am being serious. I went in there because I was having cramps really bad. Because I take Naproxen. I got to Health for Friends. They told me take Tylenol. I told them I can't because of my diabetic medicine I can't take Tylenol. They said then find something you can and threw my papers at me and told me to walk out.

Interview theme: Strategies. I used this code often in conjunction with the other thematic codes described above. Informants' responses received this code when they discussed any personal strategy used to cope with diabetes management. Analysis of this code provided extensive information about the multitude of ways informants in my study managed their diabetes; this was important for my study, since I am interested in how peoples' experience of diabetes, given their structural/macro environment, influences their decision making when managing their disease. Strategies ranged from those that were potentially harmful to effective diabetes management, to others that promoted optimal health despite social and economic barriers and hardships. Reviewing the data from this code provided insight into what works and what does not work when participants managed their diabetes and how the availability or absence of choices makes diabetes management an easier or more difficult task.

Analysis of interview data revealed the strategies informants used to mitigate the physical consequences of their diabetes. For vision problems, this included getting eye

glasses, specialized eye treatments, and taking vitamins for improving vision. Other interventions included dental treatment, wound care, pain medications, and assistive devices and auxiliary treatments for the debilitating effects of diabetic neuropathy. Indeed, neuropathy was often mentioned as a complicating and limiting factor by my study informants; this was true even for informants who had relative good management and control of their diabetes. For example, this informant talked about the strategies he uses to remain as ambulatory as possible, despite his neuropathy:

P: Yes, with diet, I brought my lunch a couple of times where we go out to eat. And with the neuropathy in my feet, I have a cane and a walker that I will use when it gets really, really, really bad. The walker comes first, then the cane. The cane is in my car.

SG: You use the cane first and then the walker?

P: Yes.

SG: How often do you find yourself using those?

P: The cane, I use any time that I go like to, see at Walmart, I use the carts, but anytime I know I am going to go more than 20 – 30 feet, I will take the cane out of the car with me. The walker, when they start swelling really bad, I will load the walker up and I will use it.

SG: You switch to the walker.

P: Yes, using both arms to try to relieve the pain. These are the things when I know I have to do things. If I can get by when my feet start hurting that bad, if I put them up above my head, and lay down, then I do that.

Numerous participants talked about the health care strategies they implemented as they attempted to manage their diabetes in the context of living in poverty and without health insurance or consistent health care. One obvious strategy, that was highly effective for participants to begin managing their diabetes effectively, was to seek help from Health for Friends clinic and enroll as a patient. Some participants noted they sought health care from other low income or free health clinics in other communities, before coming to Norman. Health for Friends was absolutely vital for the participants in

my study, as they provided free and reduced cost health care checkups, diabetes management, and diabetes supplies, such as test strips and glucometers.

Reviewing informants' discussions about accessing diabetes blood glucose test strips provided interesting examples of the ways those in poverty navigate the management of their diabetes. Overall, my study participants recognized that regularly taking their blood glucose readings helped them better manage their diabetes. Some went further and stated that keeping a blood glucose reading log helped them even more to manage their diabetes. Given the socioeconomic characteristics of my sample, however, regularly checking blood sugar was not always easy. Participants mentioned getting test strips and other supplies from friends, and one even mentioned stealing test strips from the store; however, the most frequent strategy mentioned was informants talking about stretching out their test strip supply by testing their blood sugar levels less frequently than what was recommended. For example, this informant mentioned rationing test strips and the effect on her motivation:

P: Probably the biggest thing is lack of test strips. To be honest, I ration really, I like to take my blood sugar and I get a positive feeling if I can make it go down but if you don't have any strips, you can't check it so you don't have that positive feeling of looking at it going wow, look at that.

SG: Have you gotten strips from here?

P: Yeah sometimes they have them sometimes they don't.

SG: It is based on donations.

P: Yeah and sometimes they'll have the strips but they won't have the coding chip that you put in the meter so they don't work. When they have them they are good about giving them out but I feel bad about taking them sometimes because I know they aren't rich.

This same participant later talked about only testing her blood sugar when she feels something might be wrong, instead of testing regularly, like she prefers:

SG: These last few questions are kind of general thinking about your everyday life. Is there anything you wish could be different that would make it easier to manage your diabetes?

P: Test strips.

SG: Test strips?

P: Test strips.

SG: Having more, having a good stock of them?

P: I'd like to do it 3 times a day.

SG: Right now you do none?

P: I've got about 4 or 5 left. And I haven't done them in a long time. I only do it when I feel really weird. And sometimes it will be really weird low. I'll be down in the 60s which for me is pretty low. Very low. Or sometimes I'll, I get this thing and again it is stress related and it used to only happen when I went to Wal-Mart and was going to pay with a check. If I was going to pay with cash it was okay. My blood pressure was high, in my ears, I can't hear anything but boom, boom. Only when I was paying with a check. Checks panicked me. I don't pay, I always go with cash. Sometimes that happens, and when I take my blood sugar then, it usually is high enough to make me feel unhappy. It might be 140s. Something like that. And so I don't test very often because I am hoarding my few strips I have left for the times I would really like to know what is going on.

When talking at home with the following informant, he shared that he takes physical cues from his own body to deal with plummeting blood sugar levels:

P: No. I don't eat a whole lot. I'm wrong on that, I know, especially being a diabetic. I find myself in shock and then having to eat, and I shouldn't do that.

SG: So do you check your sugar during the day?

P: (Nods yes)

SG: And what is it usually? Is it usually normal range, or?

P: Usually it's a little high.

SG: Okay, what's high for you?

P: 170, 180

SG: So you don't eat usually until dinner time, and, so, does your blood sugar go low?

P: It plummets sometimes, yeah, that's what I was saying. It plummets. I can feel it when it does.

SG: What does it feel like when it does?

P: Real, real, real good. High.

SG: Oh, that's how you feel?

P: Yes.

SG: Oh really? Okay.

P: Yes, yes. It's hard to eat then.

SG: You don't feel nauseous or sick or anything?

P: No.

SG: That's interesting, cause some people say they feel like sick when they get low.

P: No, no, I get high, real high, just; I mean, feel like I smoked a big fat one. I'm serious.

SG: You're the first person that's told me that.

P: Oh really?

SG: So then you eat something and that feeling goes away?

P: Yup.

SG: Okay, hum.

P: Sugar's the best for it, but yeah.

Another positive consequence of being a patient at Health for Friends meant the opportunity to participate in diabetes research studies, including mine. While participation in my research study afforded a monetary award in the form of a Walmart gift card, other research opportunities offered participants diabetes supplies and/or medicine. Regarding prescription medicine, informants in my study talked frequently about the importance of taking their prescribed medication as a positive strategy for controlling diabetes, noting its essential role in good diabetes management. This included participants giving themselves extra insulin and adjusting their insulin intake based on their own assessment of their needs. It was unclear if this practice was recommended by their health care provider. For example:

P: Well adjusting the medications maybe. Because if, cause what I'm doing is I'm basically looking at what I'm eating, I'm adjusting my insulin myself.

SG: Okay.

P: Um because when I take the ins, when I take the measurements to see where I'm at, I'm looking at increasing my next dosage.

SG: Okay.

P: Because I'm taking 3 shots of the Humalog: in the morning, at lunch, and at dinner; well, when I check it 2 hours after I eat, I see where my blood sugar is then. So when I eat my lunch, I'm taking another measurement to see where my blood sugar is before I eat lunch. If it's up above what I feel is normal, then I take an extra, I'm taking 5 units so I increase it to 7 or 8.

SG: Okay, you're doing that on your own and testing throughout the day.

P: Right.

SG: Okay.

P: And what happens is my uh insulin runs out quicker than what is on my prescription.

More concerning was an instance of an informant admitting that she stretched out her insulin in order to make it last longer due to inability to afford the medication. This was also soon after the participant and her family lived through the tornado mentioned earlier as having an impact on some of my study participants. She first said:

SG: Um, so have you used any strategies to deal with not having enough money to buy...

P: Go without

SG: Okay, yeah you mentioned that

P: And I have been known to go without taking insulin

SG: How, how long?

P: I went 2 months with not a drop of insulin in my body

SG: Recently?

P: Yeah

SG: Wow. What happened to you?

P: I was pretty sick. I just take like a shot once every 3 days or once a week.

SG: To make it go...

P: To make it last, but see my pen's only good for 28 days. Then you got to throw them away, whether you used them or you don't.

She went on to say the following:

SG: And when you were not taking your insulin for, and you said that was recently where you went for about 2 months without taking it, were you checking your blood sugar during that time?

P: No, I didn't care.

SG: Okay. Why do you think you didn't care?

P: Well, I mean, this was right, well I guess it...this happened right after the tornado, so I guess it hasn't been 2 months, I guess it's been about a month.

SG: Uh huh.

P: But I didn't have it. Everything that was in the ice box I was scared was no good because that's where the insulin was...

SG: Uh huh.

P: Couldn't replace it. So, I went without.

SG: And you didn't check your blood sugar either. Did you have any symptoms?

P: Oh yeah.

SG: What did you have?

P: Dizziness, real, uh, sweats, all kinds of stuff.

SG: Uh huh. And, uh, you are taking the insulin now though again?

P: Uh huh.

Participants also talked about the medication they take for other chronic health conditions, such as high blood pressure and high cholesterol, as being an essential strategy for maintaining good health.

Access to health education served as an important resource for participants to gather reliable information in order to inform their personal diabetes management strategies. Informants sought this information from a variety of sources, including contacting a diabetes association, using the internet to search for diabetes information from credible diabetes association websites, contacting a local health department, getting diabetes reading materials, talking with a health care provider, or joining a group, structured program, or class.

Study informants had a lot to say about their strategies with managing their nutrition, including strategies for acquiring food, preparing food, and eating. First, there were many instances of participants sharing their experience with eating less or not eating at all; this strategy was implemented for a variety of reasons, including financial constraints, attempts to save money, in addition to reasons more directly related to management of diabetes. For example, as an instance of eating less:

P: Yeah, I do eat a lot less.

SG: Eating less than you know you should, correct?

P: Yes, considering I was already skipping meals before I was confirmed with diabetes, being diabetic it is even worse now, because if I make a meal that I know I can't have, or I will only eat the meat and the vegetable portion, no carbs, I end up getting hungry within 2 hours, I'm hungry. And I haven't gotten used to that one yet.

SG: Yes, It is expensive to eat the things they say like snack on almonds, and stuff, and to have that constantly.

P: Oh the nuts are very expensive.

This next informant shared her daily eating habits, which include eating less and skipping meals:

Not really, like I said, it is kind of hard for me to, I try to, I really am trying to eat right, but the times I go out to eat and stuff like that, I just don't, I don't think those are good times. But mainly if I am at home, I don't really eat that much. I maybe wake up in the morning and cook a few things like a couple of eggs and bacon or sausage, maybe have me a waffle or something. And throughout the day, sometimes I just don't eat. I don't eat lunch. I may just eat a small snack or something like that, and just wait until it is dinner time and eat something then.

- Participant

Speaking about portion control, this next had admitted earlier that she does not know what to eat nor does she know how much she should eat when following a diabetic diet.

In order to compensate for this lack of understanding, she decided to eat smaller amounts of her desired foods.

Yeah. I eat pretty much what I want to eat but I try to eat less amounts of it. I try to cut down on my bread. Bread products. Like at church, they serve us lunch every week, we start our service at 1, but they serve us lunch at noon every Sunday. They have beans and rice quite a bit. I try to tell them to cut down on the rice just give me a piece of corn bread. That way I am not double breading.

- Participant

Speaking about her experience in the aftermath of the tornado, the following participant was left with little financial resources, and therefore had to make some difficult decisions about her nutritional intake:

P: Yeah, I mean, trying to buy groceries, I mean, I, you know.

SG: Tell me about you having to buy groceries.

P: Trying to buy the things that I need to buy, you know, fresh fruits, fresh vegetables and stuff that I need, or replacing food that was lost during all this stupid storms and stuff.

SG: So, how are you, are you able to do things like buy the food you're supposed to buy?

P: No

SG: Okay.

P: I just make do with what I come up with and count the carbs off of anything that, you know, I'm not eating like a lot of vegetables like I was and stuff like that, and...

SG: And so, I can guess what the reason is, but what is the reason why you're not buying the foods that...

P: There's no money to

SG: Okay, yeah, that's what I had figured, but I wanted you to say it

P: There's no money.

SG: So what do you, what do you find yourself buying instead?

P: Canned...vegetables.

SG: What else?

P: Nasty old pork that's, you know, like buying pork instead of beef, or chicken because it's cheaper than to buy, yeah.

SG: Um.

P: Or going without, and not having no meal.

SG: Okay, tell me about going without.

P: Not having like meat for your dinners or nothing. Make a pot of beans and, or, uh, and I can't hardly eat them because they tear up my stomach, or make potato soup, which that's not good for you.

SG: Uh huh. How often do you do that?

P: Oh, couple times a week. And we might live off of that for 2 or 3 days.

This next woman, speaking to me in her home, shared the challenges she faces trying to strategically manage her blood sugar level, based on her food consumption, given the limitations of her medication management with type 2 diabetes:

Especially while I'm talking steroids right now, so...we probably, typical of most diabetics, and probably cheat a little, you know. I think I told you before, both my daughter and my husband, my first husband passed away from conflicts of diabetes, and uh, my youngest daughter just turned 32, um, but uh, she's diabetic also, so I've had a long history...I've had a pretty good education on it, but still, and I'm fairly well disciplined, I think, even with my eating habits...I don't take, I can't just take another pill like if you were type 1 and give yourself a little more insulin. I can't just take another pill, so I try to, I try not to snack or cheat or anything if my sugar is high, and there have been a few times when it's

ran a little high, you know, either stress or infection or something going on, you know, and it comes up, but I really try to watch it, because I know what the effects can be, and, you know, what's ahead if I don't, and I'm really not anxious to start on insulin, so, I manage it fairly well, I think.

- Participant

Despite financial constraints, there were many times participants shared their efforts to eat a healthy diet and to purchase and prepare healthy food to have at home. This is a positive finding, since most participants in my study appeared to have at least a working knowledge of how food impacts diabetes. As was noted earlier, some participants were able to seek out the diabetes related health information they needed to better inform them about food and nutrition. They demonstrated resourcefulness and a desire to learn more about how best to manage their disease. The following participant noted how she was able to buy cheaper cost food but did not feel like she was compromising her ability to buy healthy, nutritious food:

SG: So buying the food, so how does it impact buying the food? What does it mean for you when you go buy food that you don't have enough money? As much as you would want? Does it influence what kind of foods you buy?

P: Yes, it has to. You buy the generic, the cheaper stuff. Not necessarily it is bad for you because it is not all bad for you. A lot of it you get the same identical food, just a cheaper price. It may not taste quite as good but you still get the same type food.

This next participant shared her success story with making significant changes to his diet after being diagnosed with diabetes:

SG: So, so far, since you've had the diagnosis since January, what are your challenges or struggles been in managing your diabetes?

P: Uh, well, really eating regularly, and uh, just watching to make sure I don't get low blood sugar really, nowadays, and uh, just trying to stay away from, huh, soda really.

SG: So how much soda were you drinking before, would you say?

P: Oh, before I was drinking a ton of soda, all the time, like that, I'd drink a two liter a day.

SG: Okay, and now?

P: Now, I don't drink any soda, at all.

SG: Wow, so you were able to just stop.

P: Yeah.

SG: I know some people can't, they have a hard time.

P: I know, but I was like, I never wanted to be that bad again cause, it was horrible.

SG: So you had 2 liters a day of regular soda?

P: Yeah.

The following participant found that focusing on purchasing healthy food, and eliminating junk food, actually resulted in her grocery costs reducing:

SG: So tell me about your grocery store strategy.

P: Usually try to buy, uh, less processed stuff now

SG: Okay.

P: And more, uh, you know, just uh, I don't know what you'd call it, not processed but, more prepared I guess.

SG: Okay, so like less processed food and more, like natural food?

P: Yeah, like uh, that hasn't been processed as much, just uh...

SG: Right, so have you noticed a difference like at the, like in the grocery bill, by doing that?

P: Uh, it's uh, slightly less nowadays, but uh, but I don't know if we're buying as much junk as we used to.

SG: Okay. So, you had said that, eating healthier costs more, and it does, but your grocery bill now is less, what is...

P: Well, it's probably because we've stopped buying so much soda and...

SG: Okay.

P: Just junk food all the time. I used to buy like 3 or 4 bags of chips; don't do that anymore.

SG: So your, so you would buy like one soda for each day, or?

P: Yeah.

This participant pays attention to his physical diabetes symptoms and adjusts his diet accordingly:

P: Yeah, I, (pause) I try to eat right whenever I know, I, like when I had a night like last night, then the next day I pretty much concentrate on eating right, I know, and just like right now I know my blood sugar's high right now.

SG: What happened last night that?

P: My feet were hurting real bad and my hands were hurting real bad, and so today I'll lay off the doughnuts and stuff, you know.

The following is an example of an informant sharing the dramatic changes he needed to make to his diet in order to be successful at managing his diabetes:

P: Not really. This is something else that you have to take care of. You know? Something additional. Because before you didn't care about your health, you eat whatever you find. Right now you have to be careful. You have to think. I have to live a lot like reading to be familiar with the kind of food, how many carbohydrate, sugars, proteins, fat. And right now, I know how to handle my food.

SG: And before you didn't have to think about that?

P: Sure. Before I didn't think about that. Right now I have the discipline to say, okay, 2 hamburgers is too much. In one day. 2 sodas is too much for my body. I don't need it. It is better for water. Something change soda for water because let me tell you, I like Coca-Cola. I like it. I was drinking 2 liters Coca-Cola every day. Sure. That's why I got in trouble. That was it. Look at that. Over there we don't have peaches. We don't have apples. But peaches is my favorite fruit. But here, you look and you won't find a fresh peach. You have to buy in the...

SG: In the syrup, sugar syrup.

P: exactly. Too much sugar in there. I was eating like 1 can of peaches. 1 pound of peaches every night. Before I go to sleep. Also like a 1 pound of sugar, too. But, hey. Artificial sugar. It is not natural sugar. That was my problem.

This next participant had a lot going on in her personal life at the time of my home visit, but was still able to manage her diet effectively and keep it a priority:

P: Yeah, so, but what I've had to do in trying to lose weight and working with my numbers, uh, and I was thrilled with the 5.6, but my goals are different than the ADA's. The ADA's I think are too high, but anyway, um, what I had to come to, just like getting the computer and paying for it and stuff, I've had to decide right now what works for me, and I'm thinking about re-vamping what I do, but right now, this is working and I don't have time, you know, if you re-do your diet and you really are, I don't mean dieting, but looking at how you put nutrition into your body, um, it takes some concentration, it really does, and some planning, and then scheduling and all that kinda stuff, so, since all I've been able to concentrate on has been trying to get ready for work and look for work and all that, um...

SG: It's a tradeoff...

P: Yeah, I've been doing what I felt was going to work for bringing my numbers down and be very controlled so that I wasn't doing nervous eating, because I don't really have much of an appetite, but I can nervous eat you under the table, and that's a problem, so I keep all temptation out of here, and so, anyway, that's why I have these around.

SG: Yeah, makes sense, and it's probably not a good time right now to be trying to re-vamp your entire diet when you're trying to...

P: No, I've got a pile of books in my car from the library because I was going to do it, and then a friend of mine's brother died and so I wound up...and I'm not bragging on this, I was thankful that they let me do it, um, they had someone that could feed the dogs in the pin, but the rest of the time they would have been

in the hot garage, and I just couldn't bear to hear about something happening to one of their dogs, so, anyway I lost about, when all was said and done, from start to finish, quite a few days of this preparation time, so that's where my new diet planning went. And no, I'll get settled in to this job, and I'll look at it again.
SG: Right, you'll develop your routine for the job, and how things go throughout the...

P: Yeah, and it'll mean more cooking and all that kind of stuff, but that can't happen right now, so I have to have what I, at the moment, considering most convenient, controlled effective way to eat, and that's what you see here.

SG: Yeah, that looks great, because I know a lot of people would let that go when they get something, like a new life stressor...

P: Yeah, well.

SG: Convenient, controlled, and effective. I like that.

Visiting food pantries often presented at least some limits as to what food the individual can get, as food pantries run largely on food donations. This next informant spoke to me in his home about the strategies he employs in his efforts to improve his diet with the foods available to him at a local food pantry:

SG: So when you go to the, do they like, I'm assuming they don't just let you take whatever you want.

P: No, there's usually, uh, like, a singular household usually doesn't get a whole lot. You might get a few cans of this and that, whatever, but, um, sometimes, you know, you need that, but they tend to give a lot, they tend to give a lot of fattening stuff, cause their food too and...you know the canned stuff has a lot of sodium in it, so what I usually do is, I drain it, and then rinse it off so there's not as much salt, cause my blood pressure's a little higher than I'd like, too, so I'm trying to, trying to work on that, too.

SG: So you're saying that the food pantries often give out foods that are fattening or high sodium?

P: Yeah, cause they're canned goods, you know, most of them don't have storage, you know, facilities to store stuff like, you know, freezing meat and things like that, and um, and a lot of them, it's donations and, you know, it's easier to donate cans of stuff, you know, but, I think you can kind of use it, if you, you know, like I said, I try to wash a lot of the salt and stuff off, so, cause I like salt, too, so...

Other meal and food strategies mentioned by participants included the following: preparing diabetes friendly food for self and other food for the rest of the family, having family members encourage and help the participant to eat healthy,

avoiding going out to eat (e.g. at restaurants) because of difficulty finding food good for diabetes management, taking a diabetes meal “cheat sheet” or reference guide to a restaurant if going out to eat, monitoring personal carbohydrate intake, meal planning and making menus for home cooked meals, utilizing food stamps to supplement nutrition, and utilizing food pantries, local shelters, and churches for food.

Strategies involving social support were often mentioned in the context of discussion of how important others can be beneficial to diabetes management. This participant talked about how her boyfriend was instrumental in helping her manage her diabetes:

Not really, my boyfriend helps me out with making sure I do stuff for my menu, whenever I need to do, calling to have refills, he makes sure I am pretty much up, on top of my game, especially with me working over nights, and I have a second job on the side.

- Participant

One participant talked about how the time she spends with her friends can help her cope better with diabetes and its associated challenges:

SG: Is there anything you do in your daily life in order to help yourself successfully manage your diabetes we haven't already talked about?

P: Laughter.

SG: Tell me about laughter.

P: We tell jokes, you should see my friends, I always get jokes from my friends, it makes me laugh.

SG: How does that affect your diabetes?

P: Just letting the stress out when I am laughing. I am not worried about that. Don't worry about that. So that is one thing with my friends, you feel like you need to laugh once in a while.

Not surprisingly, some participants noted that being around others with diabetes, and experience with managing diabetes, is helpful in their own struggles with diabetes.

For example:

P: Yeah. Family. And I have my friend. She helps me a lot because she is diabetic from forever and she helps me to, you know, I feel sick, I call her, I feel like this, what do I do now, she says do this and do that. You know what I mean? That helps a lot.

SG: So your family and friends give you support and they offer you advice when you feel sick. Any other kind of support they can offer you?

P: Yeah, when I really sick and I cannot do nothing myself, I try myself first. If I still like nothing work, nothing works, I call my family, but I be the first one to take care myself. On my own. I don't call my family when I am in the fire. I try to put the water on the flame, and then.

SG: And then if you can't put it out.

P: That's what I do.

Next, informants talked a lot about exercise and being active as an effective strategy to use to manage their diabetes. Despite varying levels of physical activity, participants acknowledged wanting to be physically active and to exercise. Physical activity was not necessarily regimented or structured and included relatively simple activities like walking, riding a bike a short distance, dancing, or taking the stairs. One participant talked about his belief about how exercise helps his body process insulin better:

P: Exercise. I love that.

SG: Tell me about that.

P: When you exercise it helps the insulin stay flowing through your body, if you sit around all the time and take insulin shot you start building calluses in your skin and when that happens you start pocketing insulin.

SG: What does that mean? That doesn't sound good.

P: When you pocket insulin, it is tough tissue around the areas you have to inject yourself. What happens is that tough meat won't let the insulin get through, when you go to exercise that tough tissue will work itself out and let that insulin come out at once. That is when you will have a really low blood sugar or you can go into a seizure.

The following participant's comment about walking demonstrates his understanding that physical activity does not have to be complicated to be effective. This is especially important for people with diabetes who do not have substantial financial resources for

things like gym memberships, or who have physical impairments that make certain types of exercise unreasonable:

When I can, I get out and try to just walk around as much as I can, because they say if you get exercise or something, it kind of helps lower it. Like I said, I am limited on that but I do what I can. Hopefully someday, I will be able to get my eyes fixed. And I will be able to go back to work because right now I can't see a thing out of the right eye and it has been that way for almost 3 years now. And the left eye is just starting to get worse. This last year. And I came here and they got me an appointment at Dean McGee.

- Participant

Another participant talked about physical impairments creating a barrier to physical activity and exercise, but his tenacity and incremental exercise techniques served as strategies for maintaining activity:

I stop and take a break. Even, now I got a bicycle. And before, I tried to ride one, and it was like my legs would cramp up. And just within a block, my legs would cramp up. And now it is, I can go a little bit more and a little bit more, but I just ride it around in circles. I just ride around the parking lot or next to us in the church parking lot to see how far I can go or try to get my legs where I can.

- Participant

Another participant shared her story of strategizing to exercise more by adding a little at a time in order to work up to greater and greater exercise:

Well, yeah, I think. That is another thing I was doing that I stopped doing. I was walking, when I first started to walk I could walk about a ¼ a block when I first found out I had diabetes. ¼ block around. After about a month and a half, I could walk a mile. And I was that bad. I was that bad. It was hard for me to walk from my front door to my car. Painful, had a lot of neuropathy. I was fat, too.

- Participant

Working around the home was noted by this next participant as a way to stay active, and as a result, better manage diabetes. Of note is the fact that this type of physical activity and exercise does not require expenditure of additional financial resources:

P: Oh also, we, that's another thing that keeps us busy, we have 4 horses now, so I take care of the horses and brush them and saddle them up, so you know, so that right there gives me something that I'm doing instead of sitting around twisting my fingers.

SG: Sure.

P: And I help clean house, I help my sister with the kids, so you know, I live a very active life.

In its simplest form, exercise can just be walking and moving around the house, which this next participant recognizes as significantly helping with blood sugar management:

P: I, when I say high, I know that is high, but high, I have never seen my sugar over, for example, day before yesterday, it was 303. And it is generally because I have been hurting so bad and I couldn't get up and move around. Usually, if I, when I see that it is high, if I can get up and do anything at all, not exercise like lifting weights, but moving, just general moving around the house, doing things, it brings it down pretty quick.

SG: Okay.

P: and I have never, I have been fortunate as long as I have had diabetes, I have never had a low. So, just exercise when I need to. Movement.

Informants in my study engaged in a variety of strategies in order to mitigate against the negative impact of having limited, and sometimes no, income in the context of managing a disease that often demands a lot of one's resources. For example, some informants said they borrowed money from other people, had other people contributing to their personal finances, or bartered for what they needed. Other strategies mentioned included working temporary jobs, creating a family budget, and applying for financial medication assistance from a medicine manufacturer or prescription medication assistance program.

Informants had lots to say about their financial strategies related to food acquisition. First, some used grocery shopping lists to try and maintain a grocery budget. The following excerpt is from a husband and wife who went to Walmart each day for their food:

P: We make a list and decide how much money we have for that day. We are day to day so how much money we have for the day so we plan what we are going to eat lunch and dinner. And we make a list.

SG: So you go to the grocery store every day and make the food for that day?

P: Yeah. It is right next door to Super Walmart. It works out well. We walk over there.

A few more savvy informants paid attention to the sale ads from local grocery stores in order to get the best deals. The following informant combined sale ads with list making in order to maximize her limited financial resources:

P: I go, I check out the ads that I get in my mailbox and I make a list, and I shop from that list only.

SG: Very good, I think that is one of the best things that you can do. A lot of people don't do that. They just go and buy.

P: Whenever we do that, go to the store and just go and buy, we watch the prices, see if there is something cheaper, off brand. We usually get store brand items.

An excerpt from dialogue from a home visit provides another example:

P: Well, I try to, I always read the, um, you know the flyers that come out and everything, and if there's something, you know, sometimes Homeland will have something good, you know, and I'll go there if it's...

SG: On sale or something

P: Yeah, like, you know, 10 for a dollar or stuff like that. Um, so, like I said, I try to find stuff that's on sale and um, like I said I try to, you know, eat a lot of fresh foods or, um, I buy the, those vegetables you can steam in the...I finally after years broke down and got a microwave about a year ago, and I don't cook much in it, I just mostly, you know, do steam, you know those vegetables.

SG: The ones in the bag

P: Yeah

SG: Those are good

P: And I try to eat, make most of my meal vegetables and then maybe just a little bit, and, like I said I'm kinda getting used to doing without pasta and potatoes but it's been a little hard sometimes.

The two most common strategies related to food acquisition and financial strain were buying cheap, less expensive food and stretching out meals and food reserves. The following informant's husband was very honest about the food they bought, which

included food which was not recommended for a diabetes diet, but was relatively inexpensive:

P: Lists. We buy cheap stuff to eat. TV dinners. Meatloaf and stuff.

SG: Tell me about the cheap stuff. You use the microwave, correct?

P: McDonald's. Dollar menu type of meals. Which isn't good.

SG: How often would you say you go to McDonald's dollar menu?

P: Once or twice a week.

SG: Okay. What else? Anything else?

P: Baked potatoes.

SG: What other kind of foods like that that aren't the TV dinners.

P: Bread.

SG: No rice, right?

P: No, we buy the Uncle Bens microwave rice you stick the pack in the microwave. It isn't as sticky and doesn't make her blood sugar go up like the homemade rice she makes. I eat a salad or turkey sandwich.

Interestingly, this next informant did not compromise the healthy quality of the food she was buying. Instead, she shifted to a less expensive but healthy alternative:

SG: Right, so when the cost goes up, what do you do?

P: I have to move to something at a lesser amount, either I'm not getting, um, I have to buy something cheaper, uh, per pound

SG: Okay.

P: So like, uh, say for instance uh Jonathan apples, they're 49 cents a pound; I can get the Pink Ladies for like 29 cents a pound, so I have to look at the cheaper...

SG: So you just like shift to a different kind of apples

P: Yeah

Another informant mentioned a specific shopping strategy he uses in an effort to maintain a healthier diet, though financial constraints limit his ability to implement this strategy on a regular basis:

P: I learned that from when I was on Medicaid they did a group study, group program and they gave me a pamphlet, and in that pamphlet, they told us to go on the outside of the store. Don't go on the inside of the store. Do that if you have to, but canned vegetables have sodium in them and they have a lot of stuff that is not good for you at all.

SG: So they told you to do the outside

P: for healthier diet.

SG: Okay. And have you been able to do that?

P: I do it some. I can't do it as much as I want.

SG: Why?

P: Green beans cost a whole lot more on the outside and I have to feed me and my child. A lot of things I have to get for my son are not from the outside. Macaroni and cheese. He loves that. It is not on the outside, they are on the inside. The noodles and pasta, that stuff they want you to try to stay away from.

Recognizing the financial limits of her ability to purchase fresh fruits and vegetables, this next informant makes compromises in order to eat the best diet she can:

SG: So you talked about wishing you had a farmers market year round. What strategies do you use to deal with these issues about the food in your area? You are on a limited budget. There are only so many foods available. What kind of things do you do on a daily/ weekly basis to try to handle that?

P: Try to get maybe one good fruit or vegetable in there, at least a couple of times a week to supplement canned, which aren't as healthy.

SG: Sure, because sometimes they pack those fruits in heavy syrup.

P: I try not to get any even in light syrup unless it is on sale and then I have a tendency to wash them, I always drain it off, but sometimes I rinse it off.

Participants shared their strategies for stretching out their food and meals because of their limited income. For example, this informant talked about freezing food and modifying her diet:

SG: Right. So, the strategies you use to kind of fight against these barriers that deal with money, are you said freezing food.

P: Yeah.

SG: You said making your money go further when you buy food because you said you...

P: I cut down my protein, uh, and try to eat more fruits and vegetables. I try to eat 5 meals, small meals a day to keep the blood su..., glucose level.

SG: And you're able to do that even with a limited income?

P: Uh huh.

In fact, freezing food to store it for longer was an often mentioned strategy for maintaining perishable foods for a longer period of time:

So we buy, you know, we freeze stuff, we got two ice boxes, we got one in the utility room that we keep frozen food in, and then we keep the fresh milk and veggies in there, and then the other ice box in the next house is the left overs and the food that we take out of, at that time for eating.

- Participant

In addition to freezing, this single father is a self-proclaimed “hoarder” of food:

SG: So you don't have to go to the grocery store often, because you have enough food.

P: I have food, I stock it. I am a hoarder because when I was a child, we didn't have food. Because of when I was a kid. I am a hoarder, so I really make sure I have a lot. I more or less go to the store for perishable items on a regular basis and the sale items. Like milk, you have to have milk.

SG: It won't last a month.

P: Right. I freeze some of it but it just doesn't taste the same. I can deal with it but he can't deal with it.

The following informant spoke to me about how financial support from her mother kept her in better health, because her limited financial resources were inadequate for maintaining optimal diabetes management:

So, you know, I think we kind of went over this in the first part of the interview. If you don't have the support that I've had, like help from my mother. Again, I would be in serious trouble because I'd have to be eating rice and potatoes and macaroni and cheese and hot dogs and, you know. And even then, you can't, I mean that's just crap and you can't really even live on crap for \$200 a month.
- Participant

Lastly, mental health strategies were mentioned as vital ways to manage the psychological effects of living with and managing diabetes. Most strategies produced positive results, like engaging in meditation, yoga, or biofeedback, going for a walk, reading, listening to music, working, laughter, relying on faith, religion, spiritual beliefs, and prayer, working to maintain a positive attitude, and taking prescribed psychiatric medications. Finding support from other people was mentioned more than once as being a useful strategy, as in the following example:

SG: Okay. Um, so what affect can little social support have on your ability to successfully manage your diabetes? And this is also including like family and friends.

P: (Pause) Well, I mean, my family and friends hear what's going on with my life, and my um, my abilities not to buy certain things, uh, so they you know, they, some people are like, they're there to listen, you know, giving their ear.

SG: How does that, does that...

P: It helps relieve some of the stress, you know, you're getting it off your chest. If I didn't have family or friends to, you know, be there to hear my (pause) (sighs) frustrations, you would be bottling it up and just become more overwhelmed.

Instead of engaging with others and finding support from a social network, one informant specifically mentioned isolating from others as being helpful:

SG: So when you get stressed out, what do you do to help the situation? Or to make it better, if anything?

P: Just get everybody to leave me alone, and go for a walk (chuckles). If I can't go for a walk, I'll go set in the backyard.

One informant who battled neuropathy pain talked about his good fortune to find someone willing to donate a scooter to him so he could get around. He directly linked his ability to be mobile and get out of the house to his maintenance of good mental health in the following dialogue:

P: You know, I have major depression. I had a little bit of depression before I had the diabetes, but as it's progressively gotten worse, so has my depression.

SG: So your diabetes and depression have both gotten worse together?

P: Even more so, yeah.

SG: Why do you think that is?

P: Because I'm not able to do what I used to be doing. I'm a very active person. I'm a very active person (H12's son comes home).

SG: So, you're a very active person, but now you're not as active, so that's contributing to your depression?

P: And the more inactive I get, the more depression I get, because I don't like that at all.

SG: Sure, that's understandable, completely

P: I mean, the complications seems to be getting worse and worse, you know, and that doesn't work good for me.

SG: So, what, have you ever felt that you needed to seek treatment for the depression?

P: I take Wellbutrin twice a day, once in the morning and once in the evening time.

SG: And you get that from the community mental health from Alameda?

P: Uh huh.

SG: Okay, cause I know that Health for Friends doesn't usually do psyc meds.

P: Right, they do me over there. I go there twice, I go for counseling there and then I go for depression group.

SG: Great, that was my next question, if you were in any also kind of counseling too. That's wonderful.

P: I'm a very active person, trying to take care of my needs. At first, diabetes, I was denying it. Then once I stepped into accepting it, you know, then I was more active in getting it taken care of.

SG: Well good.

P: Denial is a big thing that people get, you know, when they have any major illness.

SG: So then you're taking the medicine and going to the individual and group?

P: Uh huh.

SG: And how's that been for you? Do you think it's effective?

P: Well, it gets me out of the house for starters. That's the first thing that it does. It keeps me active, you know, getting me out of the house. I think it helps me out some. I don't know what I'd do without it, you know. They moved me to counseling because my depression's getting worse. I was just in group, and now they've moved me to do counseling. I think it regulates it more so when there's other people that has the red flags that can see if something else is majorly wrong with me, because, you know, when...depression is very dangerous whenever you're just staying in your home, because, you know...

SG: Because you can ruminate, and you're just kinda stuck with your own thoughts, and, exactly.

P: Yeah, I don't want to go there, and I try to keep the best I can.

Other mental health strategies that participants admitted to engaging in were counterproductive to overall health and quality of life, but did provide temporary relief from mental health stress. This included smoking cigarettes to relieve stress, eating carbohydrates to provide temporary relief from stress, and self-proclaimed emotional eating. For example, this participant shared in detail about her strategy for combating stress with carbohydrates:

P: The stress thing. When I get stressed, eating something with some kind of fast carbohydrate load will make me feel temporarily better but then I feel worse and the only cure for that is to eat something else. It is almost like while you are eating it you will feel better, 5 minutes after you stop, I honestly think I feel worse. I really do. I think that just about makes me lie down and go to sleep.

SG: That is what happens after you eat carbs, right?

P: Yes. The only cure for that is to eat some more carbs. Right then. When you are highly stressed you for sure lose track of what you're intending to do. Your goals or something like that. Also you just say, hey fuck it. I'm going to eat this. I did that with half a box of cookies last night, just.

Finally, this next participant talked with me and his wife about his tendency to eat to relieve emotional stress:

P: Just this month, I've had a lot of stress. I've had, my mother, my step-mom of 40 years, they tell us she's got 3 weeks to 3 months tops. My granddaughter was born with bladder extraphy (said this way), um...

P wife: But do you think you're a, like an emotional eater or anything like that, I mean do you think you eat when you're stressed out?

P: I do, I think I eat sweets when I'm stressed out, yeah. Um, just, I've just had one thing, you know I was in the tornado the other day, our house got tore up, our truck got tore up big time, um, I mean I've just had a bad 3 weeks.

Photographic Food Inventory Analysis

Regarding my photographic food inventory, I took a total of 635 photographs of my informants' food while conducting 15 home visits. For ease of categorization, I performed an impressionistic analysis of the photos to arrive at three categories of food I found in participants' homes: healthy, moderately healthy, and unhealthy. This was based on conventional wisdom regarding nutrition and a healthy diet for those with diabetes. Examples of food from each category are represented in the following photographs:

Healthy. The following are examples of photographs that portray the healthy food choices of some participants that I found while conducting my photographic food inventory analysis.



Healthy Photograph 1



Healthy Photograph 2



Healthy Photograph 3



Healthy Photograph 4

Moderately healthy. The following photographs offer an example of food I found in the homes of participants that was neither healthy, like fresh fruits and vegetables, fish, and lean meats, nor unhealthy, like foods high in carbohydrates, sugars, processed foods, and desserts high in fat and calories.



Moderately Healthy Photograph 1



Moderately Healthy Photograph 2



Moderately Healthy Photograph 3



Moderately Healthy Photograph 4

Unhealthy. The following are photographs that represent the unhealthy foods that participants had in their homes. These foods often do not help with diabetes management, and their consumption has the high potential to hinder efforts to better control blood glucose levels.



Unhealthy Photograph 1



Unhealthy Photograph 2



Unhealthy Photograph 3



Unhealthy Photograph 4

Overall, most participants had some food in their home that could be considered at least moderately healthy, even if it was just a simple can of vegetables. Participants varied on the amount of food they kept in their homes, which was often a direct reflection of their economic status and their ability to acquire food on a consistent basis. It was also sometimes a reflection of their ability to store and keep food in their home. For example, one participant lived with her husband in a small motel room, and they frequented the grocery store daily because they lacked a kitchen and the associated storage space for food. They kept just a few food items on hand in their motel room and used a mini refrigerator to keep a few things cold. As was discussed within my qualitative data analysis, some participants also found themselves at the mercy of food

assistance programs in the community and the donations they received. As canned goods are typical for these types of food banks, they are often passed on directly to those utilizing their services.

CHAPTER SEVEN: INTERPRETING DIABETES: STRUCTURAL CONSTRAINTS ON INDIVIDUAL EXPERIENCE

Now that I have shared the quantitative and qualitative results of my research, it is important to revisit my original research aims and hypotheses in order to find out if the data I collected is supportive. My first aim was to explore and identify the ways in which low-income and uninsured patients of a non-profit health clinic in Oklahoma negotiate the structural/macro-level factors that influence the development and burden of diabetes. This first aim included three hypotheses. My first hypothesis proposed that it is possible to identify the strategies members of the community develop to negotiate the structural limitations on diabetes care. The data I collected for this research study supports this hypothesis. Informants in my study were readily able to discuss the variety of behavioral strategies they implement in their daily lives to combat the structural and macro level impact that poverty, inequality, and health oppression has on their experience of living with diabetes. The strategies informants shared were amenable to being categorized into different aspects of living with diabetes and were used to negotiate their lived experience of the disease. These categories, or thematic areas, were discussed in detail previously, with examples given from the text of qualitative interviews I conducted with study participants.

The second hypothesis states that the strategies individuals use to negotiate the structural limitations on diabetes care are based not only on the biological aspects of the disease, but also on structural/macro-level factors, including economic constraints, food availability, social support, physical environment, geographic location, community resources, cultural practices, and previously reinforced social behaviors. The data from my research study affirms this hypothesis as well. Numerous instances were given of

informants describing how the strategies they have implemented in their lives, both adaptive and maladaptive, are not only based on biological aspects of diabetes, but on the biopsychosocial and economic factors that impact their lived experience of the disease. This is particularly true for my study sample, since they live in poverty and receive their health care from a health clinic that serves a medically underserved and uninsured population. The examples of informant testimony presented in this research study show how most participants had at least a working knowledge of how best to manage their diabetes, but were forced to negotiate their management of the disease based on poverty, broadly defined, that limited the choices available to study participants.

The third hypothesis for the first aim of my study states that the strategies individuals use to negotiate the structural limitations on diabetes care have an influence on patient health, including physical and mental health. My data supports this hypothesis; participants in my study continued to engage their diabetes management strategies because they served a purpose in their lives and helped them cope with the consequences of having the disease. The strategies they shared with me were directly influenced and shaped by the limitations they experienced given they mostly lived in poverty and lacked health insurance. The strategies they enacted impacted their physical health and management of diabetes; sometimes, this was more obvious than others, as when participants used strategies regarding food and nutrition, medication management, and exercise. Additionally, strategies for mental health management specifically were implemented in order to relieve anxiety, stress, and depressed mood that were often exacerbated by daily diabetes management.

My second research study aim was to examine the different diabetes management and prevention approaches commonly used by people managing diabetes, given the strategies people employ to deal with the structural factors of the disease. This second aim included two hypotheses. My first hypothesis states that the strategies people employ to manage diabetes do not completely align with what is suggested in commonly used diabetes management and prevention practices. While there were many instances of study participants engaging in strategies that are regarded as beneficial for healthy diabetes management, there were also other instances of participants engaging in survival strategies that could potentially put them at risk of negatively impacting their diabetes management, including less frequent blood sugar testing and eating cheaper foods high in calories and carbohydrates but low in overall nutritional value. It is also important to note that, even when participants talked about attempting to utilize the diabetes health education and information they already had, participants talked extensively about the barriers they faced when trying to do things like eat healthy and exercise; these barriers were largely out of the participants' control, such as being at the mercy of a food pantry or church when attempting to acquire food, or being limited by painful neuropathy when trying to exercise. Therefore, despite education and best efforts, some participants experienced limited choices and options when it came to implementing their diabetes management strategies. These barriers and limitations often originated on a macro level and were experienced as largely out of the control of the individuals who participated in my study.

My second hypothesis of my second research study aim states that the diabetes management strategies people develop for a variety of life circumstances sometimes do

not optimize health, which includes a holistic perspective on physical and mental health. Related to the discussion above about my first hypothesis of my second aim, optimization of health was sometimes not achieved by the strategies my study participants employed in order to manage their diabetes as best they could, given their structural/macro constraints in which they live their lives. Driven by the diabetes health education knowledge they already had, many study participants found they were unable to live their lives in ways they wished they could due to social and economic barriers, including poverty, lack of health insurance, social isolation, and structural inequality. Optimal diabetes health, as constructed by the governing bodies of our national, and international, public health experts, is defined in biological terms, with goals that are to be obtained by all those afflicted with diabetes, despite their social and economic circumstance. My study participants' efforts to live their best lives were sometimes met with frustration, causing or exacerbating existing mental health problems, resulting in uncertainty and unpredictability about the future course of their disease.

Examined holistically, the results of my quantitative and qualitative data analysis give a picture of what life is like with diabetes when living and poverty and without health insurance. Most significantly, choices for personal diabetes management are limited when macro and structural resources are limited as well and experienced as constraining. Wiedman (2012, 606) provides a nice summative statement regarding this critical problem when he asserts that “structural chronicities restrict the decisions, alternatives, and agency that individuals can take to improve their physical and mental well-being.” Furthermore, diabetes management limitations are experienced regardless of the individual's education about and familiarity with healthy diabetes management.

When an individual has a good level of education about how best to manage their diabetes, the resulting disparity between knowledge and ability to implement that knowledge can result in frustration, anxiety, stress, and depressed mood.

Overall, participants in my study maintained an internal locus of control about their overall health and their ability to manage their diabetes. While a positive finding, this also means that these participants are likely to experience frustration as their internal locus of control is challenged by their social and economic circumstances. Thankfully, my study results indicate that most study informants were experiencing only a moderate level of perceived stress, anxiety, and depression; however, it is important to consider the vulnerability of my study participants and others with the same socioeconomic profile as they negotiate their lived experience of diabetes within the context of the broader constraints placed on their individual choices.

Implications abound for health care practitioners treating low income patients with diabetes. As I will discuss further in my next chapter, initial and follow up assessment of diabetes patient functioning should include an analysis of and consideration for the patient's social and economic context. This will give health care practitioners valuable data about how their patients experience the disease on a daily basis, including their perceived ability and inability to implement the healthy diabetes management strategies discussed within the clinical encounter. Furthermore, the patient's mental health should be at least briefly assessed, as diabetes management can be experienced as a complicated burden among those with limited choices for self-care.

Medical anthropologists, through their training, are well-equipped to work with and study those with diabetes living in poverty. Anthropology is a holistic discipline,

and diabetes is a complex and multi-fascinated disease. Medical anthropologists working with those struggling to manage their diabetes must be comfortable talking about a wide range of topics that are not always readily associated with the diabetes experience, such as economic hardships, unemployment and underemployment, social support, mental health, and geography and the physical environment. My study results speak to how my participants experienced the macro level constraints on their ability to implement what knowledge they have of how best to manage diabetes. Medical anthropologists studying similar populations should also find that their participants experience their biological health in social and economic context, and these experiences cannot be separated. The ability, or inability, of any given individual managing this potentially devastating chronic disease is determined not only by personal decision making and motivation, but also by the limits and choices their broader environment has set forth due to the societal structures we create and enable to continue. It is additionally important to consider whether the constraints revealed by diabetes patients are real or perceived, as this distinction has direct implications for intervention; it is only through repeated meetings with patients, to include ethnographic interviewing and participant observation when able, that a clearer understanding of these constraints and limitations will be possible.

CHAPTER EIGHT: CONCLUSIONS, LIMITATIONS, AND RECOMMENDATIONS

At the beginning of this document, I stated that I designed my social science diabetes research study in order to 1) discover the strategies diabetes patients employ as they negotiate the economic and other structural factors influencing their everyday lives and 2) find out about participants' ability to maintain good health in light of the interaction between participants' personal health care strategies and the effects of each person's strategy implementation on their overall effectiveness in chronic disease management. I collected quantitative descriptive data and qualitative interview data, visiting with participants for extended periods of time at Health for Friends clinic and in their homes. I volunteered at Health for Friends for a year prior to starting my research study in order to get to know the staff, patient population, and become part of clinic life. Overall, my study yielded much more additional information beyond the strategies my informants use to manage their diabetes diagnoses in their daily lives. By spending time at Health for Friends as a participant observer, in addition to spending time with informants both in the clinic and in their homes, I learned about the details of their lives and what they perceive to help and hinder their ability to manage their health in their biopsychosocial and economic context. They shared their successes and failures and the importance of others in their lives, as they seek information and guidance on how to live better.

Results from my study indicate that the patient experience of diabetes is complex and absolutely impacted not only by biological correlates and the physical consequences of having the disease, but also psychological, social, and economic factors that shape the individual experience of diabetes and place limitations on any given person's ability to manage their disease to the best of their ability. Study

participants readily shared the wide array of strategies they use in their attempts to live their best lives in the context of structural and macro level forces that give and take away possibilities for maintaining optimal health. They shared numerous barriers to and facilitators for recommended diabetes management best practices; importantly, these participants mostly had at least a good working knowledge of how best to manage their disease.

Frustration, anxiety, stress, depression, and other mental health symptoms were more likely to manifest as a result of any given participant being unable to implement healthy diabetes care management strategies due to their limited financial resources, social isolation, lack of access to diabetes supplies, limited nutritional resources, general poverty, or some other limiting factor. As these participants opened up their homes to me, I witnessed the sociological indicators of their economic constraints, with varying levels of modern comforts that ranged from some artifacts of comfort, like a television or a computer, to the stark contrast of having little to no personal effects at all, except for basic necessities. In each home, informants' food provided a visual representation of the details of their nutritional acquisition and food consumption stories shared, and most talked about the limits they face when trying to maintain a healthy diet in accordance with suggested diabetes management guidelines. Given these realities, health care practitioners use of the term "non-compliant" to talk about diabetes patients' struggles with successfully managing their diabetes is problematic and damaging because it erases the critical context of their lived experience of diabetes. Managing diabetes is not simply a matter of personal choice.

An important connection that was further developed in my research study is the critical relationship between physical and mental health in diabetes. As I stated previously, the two most common mentioned mental health symptoms that were complicated by diabetes, and vice versa, were depression and anxiety, with particular emphasis on symptoms of depression. The relationship between depression and diabetes is one that I have witnessed and worked with directly in my professional work as a licensed clinical social worker with the Department of Veterans Affairs. I had the fortunate opportunity when working at the Michael E. DeBakey VA Medical Center in Houston, Texas to be trained in and to have practiced with a structured intervention for veterans, living in rural and isolated areas, diagnosed with diabetes and a depressive disorder and who also experience difficulty managing their diabetes. This structured approach blends elements of motivational interviewing and cognitive behavioral therapy techniques in order to simultaneously address symptoms of depression that also impact the healthy management of diabetes, such as automatic negative thoughts and lack of behavioral engagement in preferred and enjoyed activities that often keep people physically active, like walking or biking. This intervention was created by VA researchers in response to the growing concern for patient mental health in the management of chronic disease.

Data from my research study indicates that almost all participants endorsed a tendency to experience some depression and anxiety symptoms, some more so than others. In 2012, researchers published an analysis of the very large California Health Interview Survey 2007 and found that survey participants diagnosed with type 2 diabetes were significantly more likely to experience serious psychological distress,

including anxiety and depression, versus those not diagnosed with type 2 diabetes (Shin et al. 2012). The clinical symptoms of depression can and do negatively impact diabetes management, such as lack of appetite or eating too much, sleeping too little or too much, and lack of motivation to exercise or be physically active. The relationship between mental and physical health in diabetes is synergistic, with participants in my study reflecting on how their stress and anxiety can increase their blood sugar levels, and repeated high blood sugar levels can leave them feeling depressed about their ability to successfully manage their disease, which can potentially lead to decreased motivation and future poor outcomes. Study informants developed a variety of ways to counteract the negative impact of their mental health symptoms. While most were positive, some were not, like emotional eating and smoking cigarettes. It is essential that clinical diabetes care management include a prominent mental health assessment, so that medical practitioners have a more holistic picture of the patient's quality of life with diabetes, including barriers and facilitators to successful diabetes management. This is necessary and should be considered best practice in diabetes care, as my study clearly indicates that individuals experience diabetes in ways that impact, and are impacted by, previously occurring or newly developed mental health conditions. This is especially true for the medically underserved, who often experience limited choices and macro level constraints on their ability to successfully manage diabetes. This makes this population particularly vulnerable to future mental health problems, which will impact their ability to manage their diabetes successfully. Results from a longitudinal study of depression and anxiety in a type 2 diabetes patient sample support my assertions and

call for repeated mental health assessment as part of routine diabetes care (Fisher et al. 2008).

Related to concerns about mental health impact on the lived experience of diabetes and diabetes management is the fact that my study affirms that the social nature of humans reflects the importance of nurturing the social aspects of diabetes management. Participants talked about the influence of important others in their lives, as they provide social and emotional support, basic and practical support, economic support, and a sense of social connectedness to others with the disease than can also help reduce feelings of social isolation. This potential for a sense of togetherness when becoming part of a supportive social network cultivates and facilitates the innate social nature of our species. Researchers in Sweden recently conducted a study with diabetes patients experiencing psychosocial distress and found that those experiencing psychosocial stressors in their lives perceived the influence of having diabetes to be more negative than those that did not (Gåfvvels, Rane, Wajngot, and Wändell 2014).

I encourage diabetes care providers to think critically about their patients' social environments and their social networks and, if possible, foster the potential for increased connectedness among others that reduces feelings of isolation, which can leave patients feeling anxious, stress, depressed, and vulnerable to diabetes related complications. This can be accomplished by utilizing group psychotherapy and group psychoeducation techniques and formats, group diabetes appointments, or other new and creative formats that facilitate the sharing of experiences as recommendations for creating and enhancing a clinical therapeutic environment of health, balance, and well-being. Recent research in nursing demonstrates the effectiveness of shared or group

medical appointments for those diagnosed with type 2 diabetes. In a study of low-income diabetes patients' exercise and goal-setting activities at a free health clinic, Dickman, Pintz, Gold, and Kivlahan (2012) found that patients who participated in shared medical appointments were significantly more successful in achieving self-created health goals and spent significantly more time exercising. Similarly, Jessee and Rutledge (2012) found that type 2 diabetes patients who participated in coordinated group visits in an underserved area of Appalachia had better diabetes clinical outcomes, in addition to improved diabetes-related knowledge and self-efficacy.

From this assertion comes my recommendation for providers and those who care for patients with diabetes to ensure patients receive an assessment of their social network and social support system. This type of assessment is often best achieved by a professional in the social sciences, such as an applied anthropologist or a social worker, as both are trained to examine individuals in their greater environmental context, broadly defined. After analyzing my data, it was clear that support from others was important, as there were participants who mentioned having not enough or ineffective social support and participants who talked about how helpful having social support was in their diabetes management efforts. A social network or social support assessment would be useful to find out if social support is low or inadequate, which would prompt the provider to recommend the patient participate in more socially oriented diabetes interventions like those mentioned above, including attending groups and classes with other people diagnosed with diabetes. Of course, the availability of such group level interventions in a given community will determine if they are an appropriate recommendation in the first place.

Given the above information, one of the most significant lessons learned from my research is the essential emphasis on tailoring diabetes management and interventions for the patient, perhaps starting a health assessment with a brief qualitative and ethnographic interview about the patient's lived experience of diabetes. A psychosocial assessment, which is a classic tool of social work practice, of each diabetes patient is needed to assess the multi-dimensional nature of their lives and how diabetes weaves through the person's life experience, creating both barriers for and facilitators to effective diabetes management. Even though diabetes management recommendations have shifted from teaching strict strategies of what someone can and cannot eat to eating a varied diet with moderation in mind, it is important to ask a diabetes patient what works best for their personality style. Some patients may want to be told strictly what they can and cannot eat because that rigidity will make it more likely they will stick to a successful diabetes management plan. A participant of mine that I introduced earlier in this study talked about this very issue when she talked about her inability to limit herself to just a small portion of chocolate. She would rather "leave it in the store" than bring it home and be tempted by eating more than she should for the day. So, for this informant, being told what to eat and what to avoid fits her personality style better than giving her the liberty of eating chocolate in moderation.

Regarding the economic factors in one's ability to successfully manage diabetes, a diabetes-focused psychosocial assessment should also include an economic assessment of the patient. This type of assessment could utilize the budgeting and grocery shopping strategies already utilized by the individual, in addition to introducing new strategies for maximizing nutritional gain for minimal cost. Some of my study

informants shared their savvy strategies for food acquisition, including creating grocery lists, shopping only sale ads, creating a budget, applying for and using food stamps, and eating free meals from community agencies. Ideally, the social science professional who works with the diabetes patient and performs the diabetes-centered psychosocial assessment would work with medical providers and evaluate the patient's assessment data and assist with creating a personal economic nutrition acquisition plan that creates clear goals for strategies to maximize a healthy diet on limited income. Furthermore, this social science professional could assist the patient with getting linked up with community resources, including applying for food stamps if necessary.

Not only is it important to situate the lived experience of diabetes among individuals within broader biopsychosocial, economic, and political contexts, but it is also crucial that we understand diabetes patient care within the broader context of the policies and legislation that guide the provision of patient care. As was noted earlier, health care for the medically underserved in Oklahoma has not significantly improved for the staff and patients of Health for Friends. Those who live in poverty and who lack health insurance continue to face macro-level barriers to optimizing their health that leave them with limited options for improving their quality of life. The Patient Protection and Affordable Care Act (2010) has not impacted citizens of each state equally, as states had the option of opting out of Medicaid expansion. Those who are poor often do not have the financial resources to purchase private health insurance plans, so they continue to struggle to manage their diseases without all necessary resources. Medical anthropologists can join other professionals as they lobby their state governments for resources and funding for expansion of health insurance so that more

citizens can receive the full benefit of the health care they need to maintain a better quality of life.

Developing good rapport is crucial to any professional relationship between patient and provider. This is especially true when working with individuals with diabetes, as sensitive and personal information will likely come up during the course of an initial interview, and it is important for the patient to feel safe, validated, and heard. When working with a new diabetes patient, rapport can be improved if the provider assesses the individual regarding the healthy living knowledge they already possess; this will foster a sense of partnership with the patient and validate the knowledge they bring with them to the clinical encounter, no matter how much it aligns with currently recommended diabetes management best practices. After the assessment is complete, the provider and patient can work together to build on the patient's existing knowledge, modifying maladaptive existing strategies and promoting adaptive ones, while at the same time introducing new and useful diabetes health education material. This can be achieved in a variety of novel ways that meet the needs of the patient population in their sociocultural, economic, and environmental context. An approach similar to the one I mentioned earlier at the VA, combining motivational interviewing and cognitive behavioral therapy techniques, can be effective because it allows the diabetes patient to set their own concrete goals and address their own potential barriers to implementing their goals. In this way, the development of diabetes management goals is unique and tailored to the needs of the individual, based on how they want to improve their lives.

Importantly, my study results indicate that not everyone lacked the health education necessary to successfully manage their diabetes. Instead, many lacked choices

for healthy living due to their structural constraints, like low income, lack of health insurance, limited access to a variety of fresh and healthy foods, and resulting stress and mental health problems. It also important to consider that at least some of these lived constraints participants experienced might be perceived versus actual and impacted by the individual's perceived stress level and ability, or inability, to manage confounding mental health symptoms of anxiety and depression.

Furthermore, I recommend continuous and follow up diabetes psychosocial assessment and education. One of my informants in particular, introduced earlier as someone who was initially overwhelmed by the new diabetes information she received at diagnosis, demonstrated the importance of following up and revisiting diabetes education information with the patient, cycling back to review information previously introduced. This informant talked about getting lots of information initially, but her ability to retain this information was interrupted and compromised by the realization of being diagnosed with diabetes and the initial emotional consequences of the diagnosis.

The above recommendations reflect an applied medical anthropological perspective used to improve practice care guidelines when working with those with diabetes in low-income and impoverished areas. Applied medical anthropologists often seek integration among their own professional interests and the needs of the people with which they work. They orient their research and practice based on the anthropological theoretical domain that makes the most sense for solving the problem. These domains include biological, ecological, ethnomedical, and critical approaches to applied medical anthropology. How the applied medical anthropologist orients himself or herself to the applied task at hand influences how they approach their research design and practice.

For me, I continue to seek consilience among my professional training backgrounds in anthropology, social work, and psychology. Importantly, there is no one correct way to do applied medical anthropology work. In fact, part of the beauty of applied medical anthropology is the flexibility of approach a holistically trained anthropologist has in applying medical anthropology theory.

Raymond Firth, in his 1981 acceptance speech of the SfAA Malinowski Award, called anthropology an uncomfortable science (Firth 1981). This statement has continued relevance for the work that applied medical anthropologists undertake in their professional roles across the globe. By making this statement, Firth pointed out that what we do as holistically trained social scientists, unique among our other social science colleagues, does not always make us popular or well-liked. Our science is uncomfortable because, as applied anthropologists, we are often called to work on projects that are certain to reveal highly undesirable aspects of the human condition. We are often put in uncomfortable positions where we must ethically reveal uncomfortable information that speaks to the nuanced and contextualized nature of a community's problems, often with no easy solution. Human health is a topic that affects and unites us all because, no matter our global position or social and cultural context, health, sickness, disease, and illness unite in their expression of humanity.

Applied medical anthropologists tackle problems of human health that have not been successfully captured and addressed by the individualistic and biomedical approach that has achieved dominance over the last century in the provision of health care. Applied medical anthropologists utilize their comprehensive toolkit of methods and resources in order to document the lived experience of contextualized health

problems that link up both the micro and macro perspectives. They take a praxis approach, letting theory guide their work on the ground and, in return, make changes and tweaks to theories based on the data collected from the field. Their work should inform public health policy in order to create change informed from the bottom up. Applied medical anthropology has at its core a concern for the unequal distribution of disease and the whole host of factors that influence the manifestation and possibilities for poor or good health. I hope to someday extend the results of my current research study into an applied anthropology project, in which I can implement my recommendations in professional practice. I am hopeful that my current position as clinical social worker for the homeless patient aligned primary care team will afford me opportunities to marry my interests and practice in a way that gives reverence to the macro-level factors impacting the homeless veterans with whom I work.

Limitations of my current study should be considered and addressed by future researchers who investigate the complex ways that macro-level factors impact the individual experience of diabetes. First, my study's smaller sample offers limitations on my ability to fully generalize my results to other populations. Furthermore, my sample included only residents of a small town, and surrounding even smaller communities, in central Oklahoma. Future research on the complex factors that impact diabetes management is needed in larger, more urban areas, to find out what unique factors impact urban residents when compared to their more rural counterparts. Additionally, it would be interesting to find out what those living in poverty and with diabetes do for health care if they do not have access to a low-income health clinic for the uninsured, like Health for Friends, in their community. The citizens of Norman, Oklahoma are

extremely fortunate to have Health for Friends in their community, and certainly their diabetes management strategies would be different if they did not have access to this affordable care.

Lastly, I want to make note of the resilience of my study participants and their drive to survive despite multiple challenges to maintaining optimal health, as defined by themselves and their own perspective and belief system, in addition to that of the primary care and public health establishment. The extensive details informants shared with me about their lives should not only be read in the context of strategies for survival with diabetes, but also as enduring stories of perseverance in the face of adversity. The stories my informants were so gracious to share are a testament to human strength. I am forever grateful for their generosity and remain inspired by their lives.

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APPENDIX

Appendix A: Patient Interview

Strategies for Survival with Diabetes: An Investigation of the Structural Factors Impacting Health Disparities and Chronic Disease Management *Patient Interview*

Interview/Participant #: _____

Interview Date: _____

Interview Time: _____

Interview Location: _____

I'll be asking you some questions about your experience with managing your diabetes. I'm interested in finding out about the specific challenges you face as you live with diabetes. I'm also very interested in finding out what strategies you use in your daily life to try and be successful in managing your diabetes.

Barriers to Care and Disease Management

1. First, I'd like for you to think of some specific experiences you've had in your life that can help me to understand any struggles you face as you live with and manage your diabetes.

2. What exactly do your struggles involve?

3. Overall, what do you feel are the barriers, if any, that can make it difficult for you to effectively manage your diabetes?

4. What exactly are the strategies you use, if any, to fight against the barriers you talked about above?

Facilitators to Care and Disease Management

1. On the other hand, what are some experiences you've had that demonstrate what in life can help you manage your diabetes successfully?

2. What do you feel helps you manage your diabetes?

Structural Factor: Economic & Financial Constraints

1. How does your personal financial situation impact your ability to manage your diabetes?

2. How does the current economic crisis in the United States impact your ability to manage your diabetes?

3. What specific strategies do you use, if any, to fight against these influences in an attempt to manage your diabetes successfully?

Structural Factor: Food Availability

1. What do you think about the different types of food available to you in your area?
 - a. Grocery stores, farmer's markets, convenience stores, restaurants, fast food, etc.

2. How does the food available in your area impact your management of diabetes?

3. Do you use food stamps or any other government assistance program for food and nutrition? If so, how does using these programs affect the management of your diabetes?

4. What specific strategies do you use, if any, to deal with any issues involved with food choices and food availability?

Structural Factor: Social Support

1. What role does the support of family, friends, co-workers, etc. have in the management of your diabetes?

2. Do you feel you have enough social support?

3. What affect can little social support have on your ability to successfully manage your diabetes?

4. What specific strategies can someone use to deal with not having enough social support?

Structural Factor: Physical Environment & Geographic Location

1. Does the physical environment around where you live impact your ability to manage your diabetes successfully?
 - a. Neighborhood, block, part of Norman, etc.

2. How could your geographic location in the city impact your personal health and diabetes management?

3. If your geographic and physical environment can have a negative impact, what can realistically be done to fix this problem? (probe for strategies here)

Mental Health & Physical Health

1. Does having diabetes and managing your diabetes impact your mood or your overall mental health?

2. What kind of impact does your daily experience of living with diabetes have on your mood, what you think, and how you feel? (probe for impact on mental health)

General Structural Impact Discussion

1. Thinking about your everyday life, is there anything you wish could be different that would make it easier for you to manage your diabetes?

2. What do you do in your daily life in an attempt to help yourself successfully manage your diabetes? (probe for strategies)
 - a. Saving money, decreasing medicine dosage, changing eating behavior, etc.

3. Is there anything you experience while living with diabetes that you feel is out of your control?

4. How do you think inequality in society influence chronic diseases like diabetes?

5. Is there anything we missed in our discussion that impacts your ability to successfully manage your diabetes?
 - a. Macro environment, government (city, state, national), health care system, etc.

6. What are your suggestions for change?
 - a. Change in health care system, social environment, economic situation, etc.

Interview Notes

Appendix B: Household Survey & Interview

Strategies for Survival with Diabetes: An Investigation of the Structural Factors Impacting Health Disparities and Chronic Disease Management

Household Survey & Interview

Interview/Participant # (match with individual interview where appropriate): _____

Interview Date: _____

Interview Time: _____

Interview Location: _____

I'll be asking you some questions about your family and home that specifically relate to your experience of living with and managing diabetes. With your permission, I'll also be taking photographs of the food in your home to get an idea of what you have to eat on an ordinary day like today.

Number of Adults in the Home: _____

Number of Children in the Home: _____

Number of People Diagnosed with Diabetes in the Home: _____

of Adults with Diabetes: _____ # of Children with Diabetes: _____

Adult Type: _____ Child Type: _____

Economic Status

1. What is the combined monthly income for your household?

2. Do you use or have a budget for your monthly household expenses?
 - a. If YES, would you mind sharing your budget with me in order to find out what your money is spent on each month?
 - b. If NO, how would you say your money gets spent each month?
 - i. Probes: housing, electricity, clothing, food, water/trash/sewage, car, etc.

Employment Status

1. How many people have paying jobs that live in your household?

2. On average, how many hours per week does each employed person in your household work?

Geography

1. Where is the nearest grocery store or market from here, and what store is it?

2. On average, how many times do you visit the grocery store for food each week?
Each month?

Food

1. How much money would you say you spend on food each week (both eating out and groceries to make meals at home)?

2. Do you use food stamps or any other government assistance program for food and nutrition?
 - a. If YES, what is the amount of benefits you receive each month?

Tell me about your experience when you go to the grocery store or wherever you purchase food for your home.

3. Do you make and use a grocery list when you go grocery shopping?
 - a. Do you have a grocery list I can look at?

4. How do you know what you will be cooking or fixing to eat for meals throughout the week?
 - a. Probes: meal list, menu, etc.

5. Do you go out to eat, like getting fast food, going to a restaurant, or some other place? If so, where do you like to go?

6. What are some of your most favorite foods to eat?
 - a. How often do you eat your favorite foods?

7. What are some of your least favorite foods to eat?
 - a. How often do you eat your least favorite foods?

8. What foods do you eat most often?
 - a. Breakfast

 - b. Lunch

 - c. Dinner

 - d. Snacks

9. (If CHILDREN live in the home): Do you have different foods that you feed your children? If so, what are they?

10. Where does most of the food you eat come from? Where do you grocery shop?

Interview Notes