Factors that Facilitate Patient Activation in Self-Management of Diabetes: A Qualitative Comparison across White and American Indian Cultures

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by

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ABSTRACT

Factors that Facilitate Patient Activation in Self-Management of Diabetes: A Qualitative Comparison across White and American Indian Cultures

A dissertation presented to the Faculty of the Heller School for Social Policy and Management

By: Nicole Schneider, MSSW, MA

The United States (US) is plagued by a high-cost health care system producing lower than desired patient quality outcomes. In 2012, the Patient Protection and Affordable Care Act was enacted to financially incentivize cost-effective models of care that improve the health of US citizens. One emerging solution is engaging patients with chronic conditions in self-management practices.

Guided by Krieger's Eco-Social Theory, this study used semi-structured interviews, scales and a questionnaire to detect factors that facilitate patient activation of self-management in patients with type 2 diabetes. Managed and unmanaged participants were equally represented in the study sample. White participants and participants from two American Indian[1] tribes located in Northeast Wisconsin were included in this study. Findings indicated the establishment of routine behavior and the ability to identify healthy alternatives when routines were disrupted support patient activation of self-management. Experiencing success such as weight loss was also identified as a factor in facilitating patient activation. Social roles and responsibilities challenged unmanaged patients.

[1] The term "American Indian" is used in this dissertation to describe populations of people indigenous to the United States of America.

The study concluded that community, culture and environment have both a negative and positive influence on patient activation of self-management of type 2 diabetes. The current epidemics of obesity and diabetes create an apathetic response to the type 2-diabetes diagnosis that affects subsequent treatment and self-management in the communities studied. Aspects of local cultures such as unhealthy regional and tribal foods, lack of options for menu items low in carbohydrates and sugar in restaurants, high consumption of soda and alcohol and holidays/tribal events provide significant challenges for unmanaged patients. Workplace policies surrounding health insurance premiums had an impact on attendance at educational events but not on sustaining self-management behaviors. Positive aspects of the workplace include the imposition of structure and routine and the emotional support of colleagues. Warm seasons were also found to activate self-management by providing an opportunity for outdoor exercise and healthier modes of food preparation.

Consistent with a previous study, high rates of childhood trauma were found among the study groups. However, findings did not support the hypothesis that levels of childhood trauma were linked to self-management. While some evidence of historical grief and loss along with associated symptoms was found among the American Indian populations, there was no correlation between managed condition and level of grief and loss. Further examination of the connection between childhood and historical trauma to the current obesity and diabetic epidemics in these communities is recommended. Recommendations for changes to public health and health care policy are included.

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Chapter 1: Type 2 Diabetes and Self-Management Strategies

US Health Care and Type 2 Diabetes

Attempting to address concerns with consistent growth in US health care expenditures, the US government enacted the Patient Protection and Affordable Care Act in 2012. Under this legislation, health care providers and health care systems are financially incented to improve the health of the population they serve. Due to the high cost of treating chronic conditions, one strategy projected to be cost-effective is engaging patients in the self-management of chronic conditions. Self-management strategies assist the patient in slowing or even stopping the natural trajectory of disease. Following these suggested strategies can simultaneously lower health care utilization/costs and improve the health and quality of life for many patients. This qualitative study was designed to determine factors that facilitate patient activation in patients with one chronic condition, type 2 diabetes. The study examined the differences in managed versus unmanaged patients. Semi-structured interviews were conducted with study groups and responses to the interview questions as well as responses to several scales and a questionnaire were examined. Building on the knowledge of previous research and guided by Nancy Krieger's eco-social theory, the study examined the impact of community-level resources, culture, childhood trauma and historical trauma on the self-management of type 2 diabetes. In order to

achieve the study aims, participants were recruited from two different American Indian[2] tribes in Northern Wisconsin and responses were compared to a group of Whites.

This chapter describes the health policy issues of cost and quality in the US health care system as they relate to chronic disease. Background information on one high cost chronic condition – type 2 diabetes – is provided. Concepts in self-management of diabetes are described and previous studies in self-management are presented. This is followed by a discussion regarding complicating variables affecting self-management such as the social complexity of patients and connections between culture and health.

The Costs and Quality Associated with the US Health Care Delivery System

The growing overall cost associated with health care delivery remains at the center of the health policy debate, as the United States (US) now spends over 17% of its Gross Domestic Product (GDP) on health care and related expenses. Up from just 3.9% of GDP in 1965, rising costs are due to increases in both the price per unit of service and volume (Aaron & Ginsburg, 2009; Wallack, 1999; Oberlander & White, 2009; Andersen et al. 2003). High costs associated with system inputs such as advanced medical technology, new pharmaceuticals and physician and specialized health care professionals' salaries all contribute to the price per unit while increases in the incidence and prevalence of disease also add cost (Andersen et. al, 2003). (Refer to the next section titled *Incidence and Prevalence of Chronic Conditions and Diabetes* for specific information on this topic.)

The Dartmouth Institute for Health Policy and Clinical Practice confirmed in a comparison of US and other nations that higher spending does not translate into higher quality

[2] There are many terms used to describe people indigenous to the United States. The term "American Indian" was chosen over "Native American" and "First Nation People" because researchers in the studied communities agreed it seemed to be the most commonly used term in recent research.

(Fischer et. al, 2009). Operating one of the most expensive systems in the world, the US struggles to achieve desired quality. Quality in health care is measured by individual health outcomes, population-level health outcomes and the effectiveness of the process by which care is delivered (Donabedian, 2005; McGlynn et al., 2003). Quality is critical to the debate about health care costs because an improvement in quality has been shown to reduce costs (Porter, 2010; Schoen et al., 2007; Starfield, Shi, & Macinko, 2005; Baicker & Chandra, 2004; Leatherman et al., 2003).

Costs, Quality and Chronic Care Populations

Diseases persisting over time are called chronic conditions. Common chronic conditions are heart disease, diabetes (and related conditions of obesity and hypertension), many cancers, mental health and pulmonary disorders (such as asthma and chronic obstructive pulmonary disease). Health care expenditures for chronic conditions account for 75% of our total health care dollars and 90% of Medicare & Medicaid spending ("Partnership to Fight Chronic Disease," n.d.; Stanton & Rutherford, 2005). The majority of these expenditures can be attributed to a small fraction of the population. In fact, a close examination of US health care expenditures reveals that 5% of the US population accounts for over 50% of total health care costs (Stanton & Rutherford, 2005). This category is largely composed of older adults, defined as age 65 or older. According to the National Council on Aging (n.d.), 90% of older adults have at least one chronic condition and 75% have more than one.

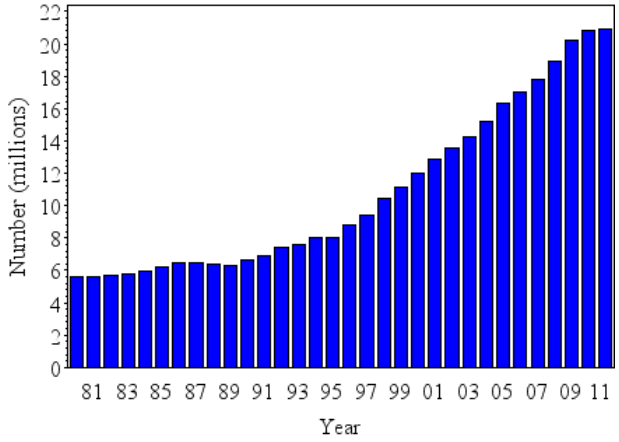
The cost for treating chronic conditions has reached $277 billion annually (Bodenheimer, Chen & Bennett, 2009). Yet treatment represents only a fraction of the total cost to society. Lost productivity is estimated at more than $1.1 trillion, bringing the overall cost for chronic conditions in the US to $1.3 trillion (DeVol, Ross, Armen & Bedroussian, 2007). Moreover,

chronic disease carries additional societal costs not easily quantified. Individuals, families and communities collectively experience the burdens of chronic disease. These burdens include stress, constraints on time, daily disruptions, hassles and other strains not easily quantified (Hunt, 2003). Combined, these stressors negatively impact the emotional and physical health of the caregiver and strain relationships in and among family members who often function as the caregivers (Chou, 2000). Because these factors are difficult to value, they are not included in the total cost of treating chronic conditions in the US, making the true cost to society of chronic conditions well above current estimates.

Incidence and Prevalence of Chronic Conditions and Diabetes

The US has experienced an alarming increase in the incidence (new cases within a specific time period, usually a year) and prevalence (total existing cases at a given moment in time) of chronic conditions. The Milken Institute, a nonpartisan think tank dedicated to solving global challenges, predicts an average of 42% increase in chronic disease cases by the year 2030 (DeVol et al. 2007). Prevalence of chronic disease is typically reported by disease category. For the chronic condition of diabetes, prevalence has tripled since 1980, as shown in Table 1 by the Centers for Disease Control and Prevention.

Table 1: Number (in Millions) of Civilian, Non-institutionalized Adults with Diagnosed Diabetes, US, 1980-2011



Source: US Centers for Disease Control and Prevention, last reviewed on Nov 19, 2013.

As the incidence and prevalence of diabetes rises, health care expenses attributed to diabetes also rise. A breakdown of these costs in 2012 is listed in Table 2.

Table 2: Health Care Expenditures in the US by Diabetes Status and Type of Service, 2012 (in Millions of Dollars)

	Population with diabetes					
	Attributed to diabetes		Total incurred by people with diabetes		Population without diabetes	Total*
Cost component	Dollars	% of U.S. total	Dollars	% of U.S. total		
Institutional care						
Hospital inpatient	75,872	16%	123,726	26%	351,618	475,344
Nursing/residential facility	14,748	17%	28,622	32%	59,744	88,366
Hospice	32	0.3%	1,600	13%	10,889	12,489
Outpatient care						
Physician office	15,221	8%	31,443	17%	155,226	186,669
Emergency department	6,654	6%	14,119	12%	105,111	119,230
Ambulance services	218	11%	453	23%	1,534	1,987
Hospital outpatient	5,027	6%	11,354	13%	76,144	87,497
Home health	4,466	9%	11,269	23%	37,264	48,533
Podiatry	212	12%	458	25%	1,349	1,807
Outpatient medications and supplies						
Insulin	6,157	100%	6,157	100%	0	6,157
Diabetic supplies	2,296	100%	2,296	100%	0	2,296
Other antidiabetic agents†	12,137	100%	12,137	100%	0	12,137
Prescription medications	31,716	12%	59,067	22%	208,662	267,729
Other equipment and supplies‡	1,063	4%	3,593	15%	20,076	23,669
Total	175,819	13%	306,293	23%	1,027,617	1,333,910

Data sources: NIS (2010), NNHS (2004), NAMCS (2008–2010), NHAMCS (2007–2009), MEPS (2006–2010), NHHCS (2007), and NHIS (2009–2011). †Includes oral medications and noninsulin injectable antidiabetic agents such as exenatide and pramlintide. ‡Includes, but not limited to eyewear, orthopedic items, hearing devices, prosthesis, bathroom aids, medical equipment, and disposable supplies. *Numbers do not necessarily sum to totals because of rounding.

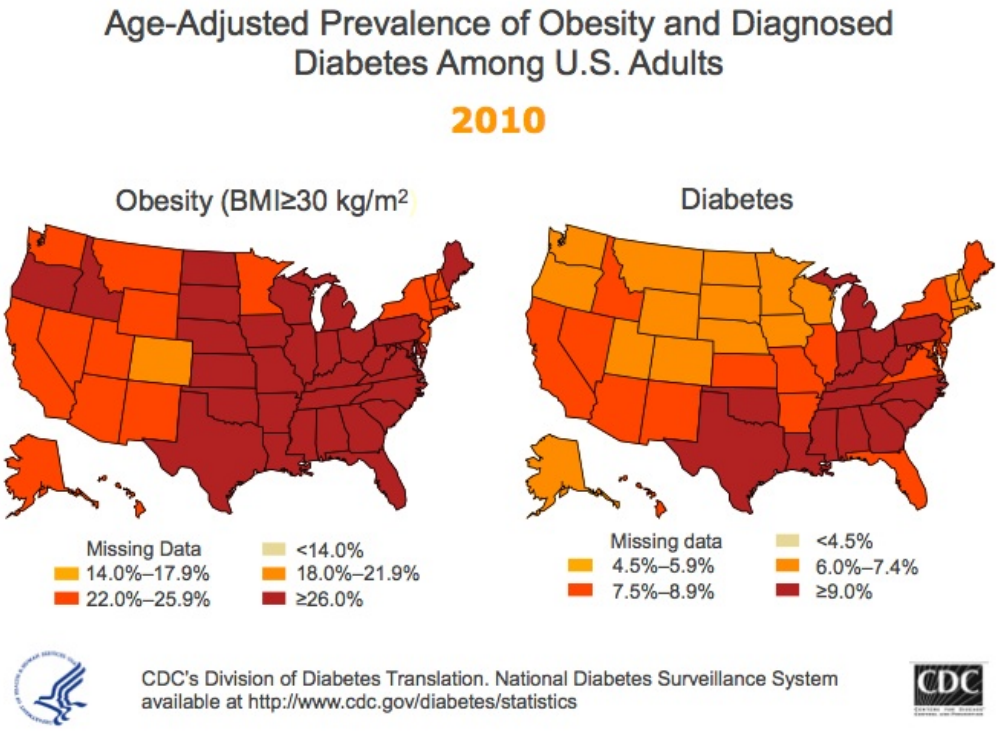
Source: American Diabetes Association. (2013). Economic Costs of Diabetes in the US in 2012. *Diabetic Care*. 36(4): 1033-1046.

Among the 22.3 million Americans treated for diabetes in 2012, over half (12.4 million) relied on public insurance provided by the US government (American Diabetes Association, 2013).

The disturbing trend in the increase in chronic disease and diabetes are due in part to an aging population. Every day in the US, 10,000 people celebrate their 65th birthday (Cohn &

Taylor, 2010). However, transnational comparisons show US rates of chronic disease climbing faster than similar countries in Europe. Given that aging populations are a global phenomenon, climbing US prevalence is currently blamed on increasing rates of poverty as well as a rise in behavioral risk factors associated with obesity, the primary cause of type 2 diabetes. As illustrated in Figure 1, the US Centers for Disease Control visually demonstrated the correlation of diabetes to obesity using state-level data in the map below (Centers for Disease Control, 2011).

Figure 1: Centers for Disease Control, Division of Diabetes Translation, Age Adjusted Prevalence of Obesity and Diagnosed Diabetes Among US Adults



Data suggest that people in lower socio-economic groups, specifically those with an income that falls below the Federal Poverty Level, carry a greater burden of chronic conditions (Bodemheimer et al., 2009). In the US, poverty rates and minority status are linked. According to the Office of Minority Health and Centers for Disease Control (2012), minority groups such as African Americans and American Indians experience chronic conditions, like diabetes, at nearly twice the rate of White Americans, an issue that will be discussed in greater detail below in the

section titled *Culture and Health*. Due to the high incidence and prevalence of chronic disease, both public and private health care analysts have suggested increased efforts to engage patients in disease management strategies in an attempt to improve quality of health while also controlling health care costs (MA Health Care Quality and Costs Council, 2009). This study explores activation of self-management in patients with type 2 diabetes.

Diabetes, the Disease and Treatment

Diabetes, often called diabetes mellitus, is a metabolic disease. The human body employs a chemical process to break down food to either convert the calories to energy or store it as fat. Insulin is a hormone produced by the body's pancreas and utilized in this process. When the pancreas cannot produce insulin or cannot produce a sufficient amount of insulin, a person is considered to have diabetes. As a medical diagnosis, diabetes is considered be one of two types. Type 1 diabetes, in which the pancreas creates little or no insulin, typically occurs in adolescents and accounts for 10% of all diabetes cases. The leading cause of type 1 diabetes is genetic composition and therefore type 1 is not preventable. Treatment for type 1 diabetes is daily insulin injections, as well maintaining a healthy lifestyle with a low-sugar and low-carbohydrate diet in conjunction with daily exercise. Type 2 diabetes is a metabolic disorder that is characterized by hyperglycemia (high blood sugar) in the context of insulin resistance and relative lack of insulin. Unlike type 1, type 2 diabetes generally can be prevented. Type 2 accounts for 90% of the diabetes cases in the US. It develops over time and occurs when the body will no longer produce a sufficient amount of insulin to convert calories (specifically sugar) into energy. In the US, 80% to 90% of obese or overweight people have been diagnosed with type 2 diabetes (Diabetic Care Services, 2014). According to the Centers for Disease Control (CDC, 2012), obesity is caused by an imbalance in calorie intake and energy output. As a person

gains body weight (through consumption of a high amount of calories, usually including high-fat, high-carbohydrate foods without sufficiently using these calories in daily movement or exercise) the pancreas cannot produce or regulate insulin to maintain normal functioning and in some cases stops working altogether. Interestingly, the CDC (2012) recognizes that obesity is linked to biology (genes and metabolism) as well as behavior, culture, environment and socio-economic status.

Treatment and management of type 2 diabetes can be a difficult task. In addition to medical interventions such as oral medications and injectable insulin, the American Diabetes Association (ADA, 2013) recommends patients engage in daily self-management activities. This includes monitoring blood glucose multiple times a day with a finger puncture and blood glucose monitor. Results of the blood test may indicate a need for a food item (if blood sugar is low) or medication such as an insulin injection (if blood sugar is high). Nutrition and menu planning targeting a limited amount of carbohydrates and daily physical activity are important aspects of self-management in type 2 diabetics. In addition to the actions described above, regularly scheduled care visits should include a primary care visit for the purpose of monitoring a patient's overall health and glucose level management at least every six months and perhaps quarterly if the condition is uncontrolled. Blood tests monitor a patient's hemoglobin A1c, a measure of the average blood glucose over the past 3 months. A person is considered to have unmanaged diabetes when their A1c is greater than or equal to 7 (Mayo Clinic Staff, n.d.). In addition to primary care visits, regular foot and eye exams must be conducted. Foot care is especially important to diabetics. Diabetes can cause nerve damage and decreased blood flow to the extremities, preventing foot wounds from healing and promoting infection. If foot conditions persist without treatment, amputations of toes, feet and even legs become necessary for survival.

Loss of blood flow can also damage a person's retina and threaten the loss of sight. Regular eye exams are needed to check for this condition called diabetic retinopathy. In addition, blood pressure is closely monitored as diabetics are at a greater risk for cardiovascular disease.

The health system has generally responded to the growing number of type 2 diabetics by offering one-on-one sessions between a newly diagnosed patient and a certified Diabetes Educator. Some communities, mainly through Aging and Disability Resource Centers, have responded to the diabetes epidemic by providing Diabetes Self-Management Programs with standardized curriculum. Both approaches attempt to engage patients in self-management behaviors because, as Funnell and Anderson (2000) note, 95% of diabetic care is performed by the patient outside of the health care system.

Diabetes and Health Policy

The US government supports the principles of self-management as an avenue to achieve the aims of controlling costs, improving the health of the population and improving the experience of patients. The American Recovery and Reinvestment Act of 2009, a precursor to the Patient Protection and Affordable Care Act of 2012, provided $650 million for wellness programs, a portion of which supports state's efforts to provide chronic disease management programs (Catalog of Federal Domestic Assistance, 2010). Additional government initiatives, such as Healthy People 2020, provide support aimed at improving the health of the nation and reducing health disparities (healthypeople.gov, 2013). As an inter-governmental agency project, Healthy People 2020 identifies and tracks national health priorities, two of which are related to increasing the portion of the population which reports self-management of diabetic conditions (healthypeople.gov, 2013). In 2010, the US Department of Health and Human Services (2010) produced a report entitled "Multiple Chronic Conditions: A Strategic Framework" detailing the

government's financial and other interests in improving the lives of people with chronic conditions. Included in this framework is a recommendation to provide financial support for self-management (US Dept. of Health and Human Services, 2010). Clearly, these policy efforts demonstrate the US government's strategy of using self-management as one solution to reduce health care costs and improve the health of the population. To address disparities present in the burden of diabetes, the Balanced Budget Act of 1997 led to the development of the "Special Diabetes Program for Indians" and provided funds for diabetes education and awareness to American Indian Tribes through 2013 (Indian Health Services, 2013). More information on the issue of disparities in type 2 diabetes is presented in the *Culture and Health* section below.

Self-Management Research

Nursing Outcome Classifications describe diabetes self-management as actions used to treat diabetes and prevent the progression of the disease (Mosby's Medical Dictionary, 2009). Self-management is intensive and requires daily, monthly and yearly activities described above. Despite resources available at the individual and community levels, patients report difficulty in self-managing (Booth et al., 2013; Jones et al., 2013; Vest et al., 2013; Majeed-Ariss, Jackson, Knapp & Cheater, 2013; Rahimian Booger, et al., 2013; Rendle, et al., 2013; Nam, et al, 2011; Lopez-Class & Jurkowski, 2010; Audulv, Asplund, Norberg, 2009; Bayliss, Ellis and Steiner, 2007; Jerant, von Friederichs-Fitwater & Moore, 2005; Peyrot et al, 2005).

Community-Level Self-Management Programs

Stanford researcher Kate Lorig developed a Chronic Disease Self-Management Program (CDSMP) in the early 1990's. The standardized curriculum for a 6-session, weekly class was built on the premise of self-efficacy, a concept defined by Bandura (1977) to designate an

individual's confidence in his/her ability to manage her/his disease symptoms (see also Lorig & Holman, 2003).

Evaluation of the effectiveness of this program has yielded mixed results. While some studies have found the program to improve health outcomes associated with chronic disease, such as increasing quality of life and decreasing health care costs, others have found no connection and question the long-term results (most studies conclude six months after graduation) (Foster et al., 2009). In addition, CDSMPs, and therefore the evaluation of these programs, suffer from participation-related selection bias, with those who enroll likely to be more motivated to manage their disease than those who do not enroll. Because of this selection bias, studies considering factors associated with program participation and program completion are also included in this section.

In 2009, the Cochrane Library published a study that reviewed all random control trials involving Chronic Disease Management Programs. In the aggregate, the study encompassed 17 individual studies (including both done by Lorig) and over 7,000 subjects. The 80-page rigorous report, "Self-Management Education Programmes by Lay Leaders for People with Chronic Conditions" (Foster et al., 2009), chronicles no significant effects on health status, health-related quality of life, or psychological health and no effect on health care utilization. There are moderate effects on self-efficacy, but Lorig herself admits she is unsure of the connection between self-efficacy and self-management behaviors (Lorig, 2001). Specifically the report finds,

> In the short term, lay-led self-management education programmes have a small, clinically unimportant impact on health status, improve two health behaviours (cognitive symptom management and self-reported frequency of aerobic exercise), and increase self-efficacy to manage symptoms. There is currently no evidence of an effect on healthcare use, and the evidence on clinical measures is very sparse. (Foster et. al, 2009, p. 14).

Also indicated was the participation-related selection bias and the completion bias that may accompany the evaluation of this type of intervention (Foster et al., 2009). Simply stated, there may be something systematically different about the people who enter the program and the people who are able to complete the program from those who do not join or complete the program. The bias in both program entry and completion may occur because of the skills, health or support needed to simply attend the class. Therefore, the results of completers may not be due to the actual content of the class itself.

The Cochrane Review was important in shaping future evaluations of Chronic Disease Management Programs by calling for more research into longer-term effects of the programs; investigation of the underrepresentation of men, children and adolescents; and the use of biomarkers to determine disease deterioration and control, as well as research investigating how the intervention is experienced by participants with particular focus on drop-out and low completion rates (Foster et al., 2009). In addition to these suggestions for further research, Foster et al. (2009) indicated a greater understanding of program participants might identify factors leading to successful self-management.

In recent years, the CDSMP model has evolved to be disease specific. The programs related to diabetes vary widely in content and structure, with only some utilizing a set curriculum. The absence of a structured curriculum is thought to be more reflective of and responsive to the real-world dynamics, affecting patients' ability to self-manage (Lewis et al., 2014). This, however, makes evaluations of the programs even more challenging. A recent evaluation of diabetes self-management program noted statistically significant positive changes in patient-reported outcomes such as health-related quality of life and diabetic-related clinical measures such as A1c numbers, blood pressure and triglyceride levels (Lewis et al., 2014). While

generally positive (it was noted the program did increase health care-associated costs), this report also noted selection and secular trend bias could not be ruled out (Lewis et al., 2014).

Since the Cochrane Review was published in 2009, only one study has been published specifically addressing the characteristics of participants and non-participants in the US. Published in 2012 with the financial support of the Agency for Healthcare Research and Quality, this study detailed the specific factors associated with attendance at a CDSMP (Dattalo et al., 2012). Consistent with the previous studies on CDSMP, a low number (22.8%) of people invited to the intervention attended five or more classes (Dattalo et al., 2012). The study used a fixed effects regression model to test factors independently associated with participation in CDSMP. Dattalo et al. (2012, p.2) considered "demographic factors, health status, patient activation, health activities and patient perceptions of the quality of their health care." Adjusting for site differences, the study found higher self-rated health status and poor ratings of physicians were positively associated with program attendance (Dattalo et al., 2012). These findings suggest that an individual's health status and judgment of her/his physician's competence play a significant role in self-management.

The dominant view of self-management emphasizes an individual's control of his or her behavior. It is not common for structural factors to be considered in the delivery of diabetes self-management education. The Robert Wood Johnson Foundation's Diabetes Initiative (Fischer, et al., 2005) has asked researchers and evaluators of diabetic self-management programs to consider an ecological approach to self-management explaining:

> An ecological approach to self-management integrates the skills and choices of individuals with the services and support they receive from (1) the social environment of family, friends, worksites, organizations, and cultures; and (2) the physical and policy environments of neighborhoods, communities, and governments. Self-management from an ecological perspective requires access to a variety of resources, including services provided by professionals and support for the initiation and maintenance of healthy behaviors. A range of influences cause behavior, including interventions and influences applied directly to the individual, as well as social, organizational,

community, governmental policy, and economic factors.

The remainder of this chapter presents the current literature on factors associated with self-management of diabetes. The majority of the focus addresses individual-level factors. Subsequent chapters on theory and methods of this study explain how this study was designed to bridge the gap between individual and structural factors associated with self-management.

Factors Associated with Self-Management

Existing qualitative studies on factors associated with self-management focus on the barriers rather than factors that facilitate self-management. These studies provide an understanding of the difficulty patients experience in controlling this disease through self-management, which consists mainly of lifestyle and behavioral changes. Topics examined typically include individual-level factors of health status, psychosocial factors such as knowledge and information, attitudes and beliefs about diabetes and behavior change, and interactions with physicians and health systems. In regard to an individual's motivation to change, authors have studied responsibility attribution and how social comparisons affect self-management. Variables at the societal- and community-level have been studied, although less frequently. These variables include social support and social circumstances. A literature review of these topics is presented here.

Health Status and Self-Management

Because regular exercise is essential to self-management of diabetes, a patient's health status can make a significant difference in his/her ability to self-manage. Jerant and colleagues (2005) found weight-related factors, including difficulty exercising and chronic fatigue, were barriers to self-management. Bayliss and colleagues (2007) conducted a telephone survey

(n=352) with patients 65 and older with a diagnosis of coexisting diabetes, depression and osteoarthritis. This study also concluded lower levels of physical functioning were associated with difficulties in self-management (Bayliss et al., 2007). Similarly, Booth et al. (2013) found common co-morbidities such as arthritis and past surgeries limited a patient's ability to exercise.

Based on this prior research, this study included interview questions asking participants to describe their health. This allowed for comparisons between and among well-managed and unmanaged diabetic patients in terms of health status and provided insight into patients' perceived health.

Psychosocial Factors, Knowledge, Information, Attitudes and Beliefs about Change

Psychosocial factors, including mental status and attitudes and beliefs about change, are often considered in studies regarding self-management. Depression has been identified as a main barrier to self-management and was the subject of a 1992 literature review in *Diabetes Care* by authors Rubin and Peyrot. More recent studies confirmed this finding (Bayliss et al. 2007; Jerant et al., 2004).

In a systematic review of literature on black and ethnic minority patients' views on self-management of type 2 diabetes that included 54 qualitative studies, Majeed-Ariss et al. (2013, p. 9) found "more studies reported negative attitudes and behaviours and a lack of knowledge than did those identifying good knowledge, and positive attitudes and behaviors about diabetics."

In an article not included in the systematic review, Booth et al. (2013) confirmed these findings. Based on focus groups with newly diagnosed diabetic patients, Booth et al. (2013) concluded that a lack of knowledge and a negative perception of the desired behaviors inhibited self-management.

In an additional systematic review of literature regarding barriers to diabetes self-management, Nam et al. (2011) reported inconsistent findings in outcome research regarding how and if knowledge (including beliefs and attitudes) affects health behaviors. Although some patients possessed the necessary knowledge, this alone did not lead to desired health outcomes (Nam et al. 2011).

These studies show psychosocial factors are barriers to diabetes self-management. However, adult psychosocial functioning is strongly linked to childhood socioeconomic status (Harper et al., 2002). This indicates a life course perspective should be considered in future studies of type 2 diabetes. The life course perspective strongly influenced the design of this study and led to the inclusion of several scales such as the Adverse Childhood Events (ACE) scale. Regarding the main research question - "What factors facilitate patient activation of self-management in type 2 diabetics?" – this study hypothesizes that societal variables such as historical and childhood trauma, tribal poverty and inclusion in a minority population influence adult psychosocial functioning and therefore self-management.

Physician and Health System Interactions and Self-Management

All types of barriers to self-management are of interest to providers and health systems as they face monetary penalties for low-quality or unmanaged diabetic patients. Community-level variables such as access to health care systems such as primary care providers, Indian Health Services and CDSMP, were a focus of the study. Guided by eco-social theory (described in detail in the next chapter), this study included open-ended questions to capture information on participants' perceptions of the availability, accessibility and effectiveness of community-level resources. The questions were designed based on evidence of previous research. For example, Jerant and colleagues (2005) found poor interactions with physicians to be a barrier to self-

management and Jones and colleagues (2014) found lack of access to health professionals to be a barrier to self-management. In a study in rural Australia by Jones Smith and colleagues (2013), participants also reported regular access to health care providers was essential to self-management. Studying black and ethnic minorities with type 2 diabetes, Majeed-Ariss et al. (2013, p.8) found:

> Patients' perceptions of their health professionals were shaped by the cultural and linguistic appropriateness of the health-care exchange; in circumstances when the consultation was perceived to be inappropriate patients referred to health professionals' inability to relate the them. For example, patients were critical of health professionals' dietary recommendations that were perceived as expecting the patient to reject culturally traditional foods.

This information established a baseline for interview questions regarding American Indians and White participants' perceptions of access to and quality of health care systems. Differences among American Indian tribes in resources as they affect diabetes and self-management have not previously been studied. Refer to *Appendices* for copies of the Interview Guide and scales included in this study.

Family and Social Support and Self-Management

In analyses of factors that facilitate self-management, social factors often surface as significant. Limited family support has been shown to act as a barrier to self-management of chronic conditions (Jerant et al., 2005). This study examined the role of others (individual people) and communities in assisting the patient in managing his/her condition. Cross-cultural comparisons were made in regards to the study groups' perceptions of assistance in managing diabetes.

Because eco-social theory focuses on the environment and the workplace, this study asked questions about support in the workplace. One previous study by Weijman and colleagues (2005) used nine items in a survey to assess social support in the workplace. These questions

included “Do you have a good relationship with your colleagues?” and “Can you rely on your supervisor when you experience problems at work?” (Weijman et al., 2005, p.89) Ultimately the authors concluded that the level of social support at work positively correlated with active self-management (Weijman et al., 2005). In a study about ethnic minorities, Majeed-Ariss et al. (2013) found the patients had a need for their condition to be understood by others. Booth et al. (2013) came to a similar conclusion after patients stated they did not want to eat or appear different from others when in a group setting such as the workplace or at holidays and celebrations.

Societal Variables and Social Circumstances

Societal variables and social circumstance such as poverty, rural geography and access to food, exercise and transportation are included in this study, based on previous research findings. A study from Booth and colleagues (2013) reveals that social circumstances can indeed inhibit self-management, such as a person’s built environment or climate making outdoor exercise difficult. In rural Australia, Jones, Crabb, Turnall and Oxlad (2014) identified a lack of access to food, transportation and opportunities to exercise as barriers to self-management.

Studies show that living in poverty makes menu planning challenging for patients with type 2 diabetes. In semi-structured interviews with low-income diabetics, Rendle et al. (2013) found that the high cost of lean proteins, cycles of food availability that accompany public assistance and available work and the emotional stress of financial problems, negatively affect self-management. Booth et al. (2013) came to a similar conclusion, citing “limited incomes” as a barrier to self-management. Nam et al. (2011) found that cost of treatment presented a barrier to diabetics seeking treatment, as was inadequate health insurance. In addition, Nam et al. (2011)

demonstrated that lack of either transportation or money to use public transportation contributed to the failure to control a diabetic condition.

Majeed-Ariss et al. (2013) cited several studies that found social stigma associated with type 2 diabetics contributed to non-disclosure of diagnosis and therefore inhibited self-management. This same study concluded that in communities where the condition was common, there was an apathy that affected self-management (Majeed-Ariss, et al., 2013).

The populations of interest to this study are located in both rural and suburban areas. Questions regarding built environment, food acquisition and access to tribal resources, such as exercise facilities, were included in the interview after careful consideration of the studies presented here. Authors Brown et al. (2004, p. 63) suggest "Because type 2 diabetes is common in all populations in industrialized nations but disproportionally affects socially and materially disadvantaged adults, it may serve as a model condition for evaluating the associations between SEP [socioeconomic position] and health among persons with chronic conditions." The study presented here concentrated on community-level tribal resources through a comparison between American Indian tribes with substantially different tribal resources.

Motivation to Change

Even when a person has the knowledge, he/she may not be motivated to change deeply ingrained behavior. One goal of this study was to examine the difference between unmanaged and managed patients, including the patients' social and environmental circumstances. Reviewing the literature in this area, Booth et al. (2013) concluded that a lack of understanding contributed to the motivation to change and the practicalities of making lifestyle changes inhibited self-management.

Audulv et al. (2009) studied responsibility attribution associated with self-management in Sweden. The authors concluded people who do not self-manage assign responsibility for controlling illness to others (Adulv et al., 2009). A German study by Schafer et al. (2013, p. 499) found similar results, reporting "the degree of feeling informed and responsible for diabetes management" correlated with participation in diabetes community programming.

In an attempt to improve provider communication with patients, Gorawara-Bhat, Huang, and Chin (2008) recruited participants who were actively seeking health care for their diabetic condition. The study concluded that successful patients make both upward and downward social comparisons to motivate themselves to engage in self-management practices (Gorawara-Bhat et al., 2008). These comparisons were either upward, such as, "I look at him and I could see what could happen" or downward, such as "some people's minds is worse than mine" (Gorawara-Bhat et al., 2008, p. 413).

Responsibility attribution and social comparisons are worth considering on both the individual level and structural level. An individual's perception on health and illness as well as the influence of familial and community perspectives on health and illness may provide insight into patient activation. These topics were reflected in both the semi-structured interview and questionnaire portions of this study with all study groups. An interview question "What does [the most important people in your life] say about your health?" was included along with written survey questions such as "Which answer below reflects *your opinion* for who has the most responsibility for your health: Doctor/Nurse, Me, Family, Community, Higher Power/God". In addition, an entire measure devoted to patient activation was included. Researcher Judith Hubbard developed this tool, known as the Patient Activation Measure (PAM). (See *Chapter 3* for more specific information on the PAM.)

Pilot Project Results

Curious about the natural trajectory of patient activation, this author conducted a qualitative research pilot project in late 2011 with a small sample of people who enrolled in a chronic disease self-management disease program at the Brown County Aging and Disability Resource Center (BCADRC) in Green Bay, Wisconsin.[3] The BCADRC reported difficulty in filling CDSMP classes, even though most Center members were eligible to attend and the financial cost was minimal. All course participants (N=140) in 2011 were contacted for a phone interview, excluding 2 participants who had died. Those who did not complete the course were contacted twice. Twenty-five participated in the study, of which 10 had not completed the course.

Results indicated those who failed to complete the course were searching for the motivation to manage their own condition and were looking for a connection to others (Schneider, 2011). Those who completed the course did not report this, but instead reported searching for skills to assist them in self-management (Schneider, 2011). Non-completers also identified social issues and social roles that demanded action or mental energy that interfered with class attendance. People who enrolled but were unable to complete the course made the following statements (Schneider, 2011, p. 10):

> My mind wasn't focused at that time in my life. I had so many other things going on in my life. I thought I could just teach myself, but I never have the time to concentrate on myself.
>
> Something else came up in my life right at that time. I had to deal with those things immediately.
>
> I have so many other commitments. It was nothing to do with the actual course. Several family commitments came up all at once.

[3] This study was deemed exempt by the Brandeis Internal Review Board and was assigned protocol number 12072. Brandeis Professor Nina Kammerer was the Primary Investigator.

This is consistent with information regarding social determinants of health or the established fact that non-biological factors influence a person's health and led to the use in this study of the eco-social theory described in next chapter.

These results were consistent with previous research reporting similar factors interfered with daily self-management of diabetes. In Sweden, Audulv and colleagues (2010) found life circumstances made self-management less important at times in the participants' lives. Working in the United Kingdom, Booth and colleagues (2013) identified social circumstances as a barrier to self-management. In a small qualitative study in rural Australia (n=18), Jones and colleagues (2014) noted patients identified the lack of time in their daily schedule and the absence of supportive relationships as additional barriers to self-management.

Social Complexity: Socioeconomic Status, Culture and Health

Previous research, including participants' responses in the pilot project, allude to the complex interaction of health maintenance behaviors and the social environment, specifically, social structures which include family roles and responsibilities. As payment models change to include quality bonuses based on medical outcomes and the Centers for Medicaid and Medicare penalize systems for readmissions, there is a resurgence of interest in the concept of social complexity as it relates to delivering health care. For example, the National Quality Forum recently initiated a study regarding socio-demographic variables (income, education, race and primary language) and associations with 30-day readmissions (Rice, 2014).

Previously, complex patients were thought to be patients with multiple conditions, but now social factors are also being considered. Authors Safford et al. (2007, p.382) defined the complex patient as one who has "socioeconomic, cultural, behavioral, and environmental circumstances" negatively contributing to his/her ability to care for him or herself. While these

socio-demographic variables have been studied in relation to the burden of disease, studies that go beyond identification of socio-demographic variables related to self-management are limited. Extensive literature searches revealed few studies regarding diabetes and social instability or social complexity and only a subset of these studies was conducted on populations within the US. The most recent study was published in the *Iranian Journal of Public Health*. Using survey analysis, the authors found that among Iranians perceived social support indirectly affected self-management (Rahimian Booger et. al, 2013). This was due to a patient's perceptions of the efficacy of self-management behaviors and the reactions of others to his/her success (Rahimian Booger et. al, 2013). A 2011 US publication reviewed all literature published between 1990 and 2009 related to diabetes and self-management (Nam et al, 2011). This review identified patient- and structural-level factors such as limited income inhibited diabetic patients from seeking care and adhering to a medication regime (Nam et al, 2011). It showed mixed results in studies that addressed social support and self-care and cautioned that social support needs to be understood in the context of both racial and gender differences (Nam et al, 2011).

Culture and Health

Another important factor impacting patient self-management success is culture. Culture influences a patient's beliefs and attitudes about a variety of factors that affect self-management, including attitudes towards food, definitions of quality of life and efficacy of the health care system (Nam et al., 2011). Nam et al. (2011) conclude their study by calling for a greater understanding of culture and the function of culture within a socio-structural context as it relates to diabetes self-management. Indeed, many variables of interest in the self-management literature are affected by culture and poverty, as Audulv and colleagues (2010) note in their research on responsibility attribution. Vest et al. (2013, p. 2) came to understand that the patient

burden in self-management is more difficult for racial and ethnic minorities due to "limited access to health care resources, competing survival demands and other social, economic and cultural barriers related to poverty status." These factors can be attributed to the dominant culture and make them structural in nature. In fact, when using an eco-social perspective to consider diabetes self-management, Fisher and colleagues (2005) agree that consideration of the perspective of both the individual and the culture in which a person was raised is essential when delivering diabetes self-management education to a patient. The study described here is challenged to consider the dominant and the minority culture as well as the individual perceptions of health and illness.

A scan of the literature addressing diabetes self-management in the African American and Latino communities revealed more than two-dozen studies focusing on these populations. However, the studies regarding Native Americans/Alaskan Natives and diabetes self-management were limited. Kim et al. (2012, p. 2324) reported a "paucity of research in the current literature on how elderly Asian and AI/NA [American Indian/Native Alaskan] adults manage their diabetes." A search in pubmed and google scholar found four peer- reviewed articles regarding a specific Indian tribe and type 2 diabetes. Two of the articles focused on discovering a genetic link to obesity and type 2 diabetes; these were conducted with the Lakota/Dakota (Daniels, 1999) and Pima (Baier & Hanson, 2004) tribes. One article discussed the beliefs about diabetes and medication adherence among the Lumbee Indians in North Carolina (Jacobs, Kemppainen, Smith Taylor & Hadsell, 2014). The fourth article by Tiedt and Sloan (2014) focused on the perception of unsatisfactory care as a barrier to diabetic self-management for the Coeur d'Alene Tribe in Idaho (N=10). Teidt and Sloan (2014, p. 3) concluded significant barriers to diabetic self-management were "Communication barriers

includ[ing] miscommunication, distrust, and teaching/learning methods [and] [o]rganizational issues related to quality and access." It is difficult to compare tribal cultures within the United States because while all tribes were subject to federal laws, such as the 1905 enrollment mandate, each state interacts with tribes differently. Tribes have and continue to experience imperialism and colonialism in different ways. For example, in Montana, after receiving land for reservation establishment, the Flathead reservation was opened again to White settlers (DeLeane O'Neal, 1996). Over the course of the late 1980's and early 1990's in Wisconsin, eleven federally recognized tribes received exclusive rights to establish gambling or gaming as a source of revenue for tribes. Also note that the literature on people indigenous to other countries is not represented here for similar reasons.

The six studies described below reflect a broader, more inclusive definition of American Indian and therefore, may be reflective of the population of interest to this study. Using logistic regressions, Kim at colleagues (2012, p. 2324), the study concluded the American Indian and Alaskan Native population is less likely than the white population to "see a doctor, visit an ED, and take medication to reduce heart attack risk, but were more likely to take insulin, oral diabetic medication or both," indicating significant disparities in diabetic self-management behaviors (Kim et al., 2012, p. 2319). Issues like the ones identified in this study affect diabetic outcomes and compound the disparities in the incidence and prevalence of diabetes diagnosis. American Indians with diabetes are 2.8 times as likely to die from it than American Whites (Indian Health Services, 2011), while African Americans are 2.2 times as likely to die from diabetes than Whites (CDC, 2013). Kim and colleagues (2012) recommend further studies examining racially sensitive interventions to activate the American Indian population in managing diabetic

conditions. The study presented here acknowledges that both structural and cultural interventions need to occur.

Of the six studies considering diabetes and American Indians, three were quantitative and compared questionnaire responses between Whites, African Americans and American Indians. Two of the studies (Quandt et al., 2009; Grzywacz et al, 2012) were similar, in that they examined patients' beliefs about disease and health care. Both of the studies concluded that African American and American Indians/Alaskan Native had similar beliefs about the cause, symptoms, medical management and consequences of diabetes (Quandt et al., 2009; Grzywacz et al, 2012). For example, Grzywacz and colleagues (2012) also noted that differences between groups (pertaining to self-management and causes of the disease) were attributable to socio-economic status rather than race or ethnicity. In addition, Quandt and colleagues (2009) found statistically significant ethnic and racial differences in willingness to adopt healthy behaviors associated with self-management. Grzywacz and colleagues (2012) used education level as a proxy for socio-economic status and concluded their findings were related to the high rates of poverty among the populations surveyed. Quandt and colleagues (2009, p.6) came to a similar conclusion, however, it was inferred that the differences between Whites and the responses of the ethnic minorities was due to "[in] general, ethnic minorities in these communities have[ing] higher rates of poverty and less formal education."

Five studies explored alternative models of care and the impact of patients' beliefs about diabetes and health systems on self-care (Shaw, 2013; Kim et al, 2012; Grzywacz, 2012; Hendersen, 2010; Quandt, 2009,). In a qualitative study uncovering the "resources, roadblocks and turning points" in managing diabetes among Alaskan Natives, Shaw et al. (2012) reported participants' emotional responses to experiences (e.g., a difficult encounter with a health care

provider and a death of a relative or friend) as the motivation to actively managing their diabetic conditions. Shaw et al. (2012, p.89) classified these emotional experiences with the theme "spirituality," which was defined as "a diverse resource that can serve to guide personal behavior, provide emotional reassurance or give comfort to others." This information contributed to the development of the interview guide for this study.

Study Justification Based on Previous Research

An understanding of the previous qualitative research regarding self-management provides the foundation for this study. Examined as a whole, the existing literature shows the gap in knowledge of the differences between managed and unmanaged patients, as well as effective strategies to treat American Indians. These and other studies, such as Glasgow, Tolbert and Gillette, 2001, identify the need to understand the similarities and differences of barriers for diabetic patients across ethnic and racial groups. In addition, knowledge that social circumstances complicate the diagnosis and treatment of this disease calls for alternative theories when attempting to understand self-management of type 2 diabetes. This author could only locate one article (Whittemore, Milkus and Grey, 2004) mentioning eco-social theory in the context of type 2 diabetes. This was an article regarding prevention and medical management of the disease and did not represent original research on self-management. When using an eco-social perspective to examine type 2 diabetes in American Indians and the White population in Northeastern Wisconsin, all identified factors in previous research were included either in an interview question or on a questionnaire or other validated measure administered in this study. (Please refer to the *Appendices* for the Interview Guide, the questionnaire and additional scales.)

In summary, the available literature and the pilot project highlight the need for identifying factors that would facilitate self-management behaviors. Most literature on factors

associated with self-management focus on barriers to and not facilitators of self-management. This study was designed to compare and contrast responses from unmanaged and managed diabetics in order to discover how managed participants overcame known barriers to self-management. Health status, psychosocial factors such as depression, social circumstances, interactions with health care providers, family and social support, responsibility attribution and social comparisons are all significant when studying type 2 diabetes. However, previous studies collectively call for a deeper understanding of connections between cultural and environmental-level variables that facilitate self-management and patient activation, not simply identifying patient beliefs about barriers to self-management. Absent from the diabetes literature is any mention of childhood or historical trauma, even though there is a known link between childhood circumstances and adult psychosocial functioning (Harper et al., 2002). This is coupled with the fact that few studies were conducted in the US and even fewer included the American Indian population. Despite the diabetic crisis in Indian health, no studies compare the social circumstances and available resources as they relate to diabetes between two different American Indian tribes. In fact, literature on facilitation of self-management of diabetes among American Indians is generally limited. Author Mitchell (2012, p.78) states:

> By acknowledging the unique historical and social circumstances that had led to increased rates of diabetes and other health disparities among Indian people,
> social work practitioners can gain a better understanding of how the trauma
> experienced by generations past still affect Indian health today.

This study was designed to fill these gaps.

Chapter 2: Eco-Social Theoretical Framework

This study is designed to explore patient activation of self-management of type 2 diabetics. The main research question is "What factors facilitate patient activation of self-management in type 2 diabetics?" Additional research questions regarding the relationships between trauma (including childhood and historical trauma) and self-management are considered, as is the relationship among the community, culture, environment and self-management. Three unique groups were chosen for the study. A White group was included as well as two American Indian groups with substantial differences in tribal resources. There are two cohorts within each group, one of individuals who were successfully managing and the other of individuals who were unsuccessful. (See *Chapter 3: Research Methods and Study Design* for inclusion criteria.)

Type 2 diabetes is considered an obesity-related disorder and is the cumulative result of poor diet and sedentary lifestyles. As noted in Chapter 1, the American Diabetes Association (ADA) recommends engaging in self-management with daily, monthly and yearly tasks ("Treatment & Care", 2014). Currently, the US health care system delivers these services from a rational choice perspective. Providers assume once a person is diagnosed and is given information about the disease and self-management, he or she will engage in self-management behaviors to slow or reverse the illness trajectory. While diabetes care is physician directed and monitored, 95% of diabetes care is the responsibility of the patient outside the health system (Funnell & Anderson, 2000). However, the ADA's recommendations demonstrate the enormity of the task of self-management and the complex behavior changes required to sustain self-

management efforts. Even though the consequences of unmanaged diabetes are severe and include amputation, blindness and death, many people are unable to change behavior and successfully self-manage the illness. Nancy Krieger, a leading theorist in social epidemiology, has developed an eco-social theory to understand the interplay between biology/genetics and society – complex social factors including culture, socio-economic status and environmental influences expressed through biological signs of disease or physical/mental illness.

Central to Krieger's theory is the concept of embodiment. Embodiment as defined by Krieger, is one's life experiences, culture and environment expressed through individual health (Krieger, 2005). This study uses Krieger's definition of embodiment. The challenge of eco-social theory is to consider an individual's health as an expression of family, community, population, society, environment and ecosystem experiences over time (Krieger, 2005). In Krieger's (2005, p.351) words:

> Embodiment, a concept referring to how we literally incorporate, biologically, the material and social world in which we live, from conception to death; a corollary is that no aspect of our biology can be understood absent knowledge of history and individual and societal ways of living.

Eco-social theory can explain difficult and complex concepts in health such as disparities in the burden of chronic disease. In the mid-1990's, Kaiser Permanente, a large health system in the western United States, and the Centers for Disease Control and Prevention collaborated to conduct a wide-scaled (n =>17,000) research project comparing childhood exposure to trauma and unhealthy behaviors in adulthood. This study became known as "Adverse Childhood Experiences" or ACE. An ACE score is determined by the amount of exposure to traumatic events in one's childhood. Adult patients in Kaiser's health delivery system were asked to recall adverse events occurring in their childhood. These events include physical, sexual and psychological abuse. In addition to these, household dysfunction including substance abuse, mental illness of family members and having one's mother treated violently were also categories

in the survey. Other categories included experiencing a divorce of parents and criminal behaviors of family members (Felitti et al., 1998). Results were compared to the health status of the adult participants. Heart failure, diabetes, obesity, lung disease, fractures, and liver disease were among health-related questions. The study reported that the more exposure to childhood trauma (or the higher a person's ACE score) the more unhealthy events and behavior were reported in adulthood (Felitti et al., 1998). Following Krieger's eco-social theory, ACEs could be identified as a pathway to embodiment. Administration of the ACE scale in this project offered a tool to study these issues. Examining self-management of type 2 diabetics with an eco-social perspective offers a framework to understand embodiment of diabetes, including adverse events experienced by the community and in childhood. (An explanation of how adverse events can be measured is included in the next paragraph.) This level of understanding could contribute to the development of a successful intervention or guide health and social policy in the US.

This study posits that the concept of embodiment has the potential to explain the absence or presence of self-management behaviors in type 2 diabetics. Obesity and lack of exercise are considered the cause for 95% of type 2 diabetic cases, but what is the cause of these behaviors that result in obesity? Why do some diabetics engage in self-management while others do not? Eco-social theory considers behaviors that impact health as an expression of experiences developed over time (including trauma and adverse childhood events) and influenced by culture (social roles and norms), socio-economic status (workplace environment, resources, health literacy) and geography. Extending the concept underlying ACEs, this study examined historical trauma as a potential pathway to embodiment. Maria Yellow Horse Brave Heart (2003, p.7) defines historical trauma as "the cumulative emotional and psychological wounding over the lifespan and across generations, emanating from massive group trauma experiences." Auerhahn

and Laub (1998) describe the process of trauma being passed on from one generation to the next either directly or indirectly. The authors explain direct transmission of trauma as second and third generations experience vicarious trauma through story telling (Auerhahn & Laub, 1998). Indirectly, the transmitted trauma can stress adults and inhibit psychosocial functioning and parenting skills of adults (Auerhahn & Laub, 1998; Evans-Campbell, 2008). On a community-level, the effects of historical trauma for the American Indian population include loss of land and culture (Evans-Campbell, 2008), traditional diets and professions, and the political/decision making structure of tribal life. Walters et al. (2011) have begun the process of studying how historical processes are embodied. To measure historical trauma this study included the Historical Trauma Exposure and Symptoms scales.

Acknowledging social complexity, Krieger's (2005, p.353) eco-social theory outlines:

> Cumulative interplay between exposure, susceptibility and resistance, expressed as pathways of embodiment, with each factor and its distribution conceptualized at multiple levels (individuals, neighbourhoods, regional or political jurisdiction, national, inter- or supra-national) and in multiple domains (e.g. home, work, school, other public settings), in relation to relevant ecological niches, and manifested in processes at multiple scales of time and space.

Krieger's theory has the capacity to explain the impact of social structure at differing levels and across time on health. Krieger and Smith (2004) describe this in terms of a biological organism evolving while at the same time engaging in limited social production and social consumption. Consider Krieger and Smith's (2004, p.94) definition of social consumption:

> Social Consumption: engage in socially delimited processes, relationships, and institutions contingent on one's social position, involving acquisition and consumption of goods and services, as well as ideas and information, required to meet basic needs (for physical survival) and social needs (for a socially meaningful life).

Then consider a type 2 diabetic living in this context. Consider how one acquires information, goods and services needed to self-manage one's condition. While recent research on type 2 diabetes has not typically used Krieger's theory, results could be understood using the eco-social

lens. For example, the studies presented in the first chapter on psychosocial factors such as depression (Jerant et al., 2005; Bayliss et al., 2007), beliefs about health system effectiveness (Jerant et al., 2005; Jones et al., 2014) and negative attitudes towards desired behavior change (Booth et al., 2013) concluded that these factors interfered with the successful self-management of diabetes. Using eco-social theory to interpret these results, these factors are then understood in the context of a lifetime of experiences that become part of the corporeal, an individual's body. For Krieger, a factor such as a person's belief system is likely something that biologically develops and changes over the course of a lifetime. In addition, the eco-social theory encourages consideration of the hundreds of possible community and cultural influences on someone's beliefs and attitudes about health and health care. For example, one's own health system access and quality; past experiences with providers, health status and the health status and experiences of family, friends and community members, both historical and present, could potentially shape a belief system. Beliefs lead to behaviors, which consciously or unconsciously lead to a literal embodiment of our past. Krieger and Smith (2004, p.92) encourage corporeal aspects of embodiment, but agree: "by emphasizing the literal nature of embodiment and refocusing on key aspects of what bodies do, we can potentially generate new insight into the ways societal conditions shape expression of biologic traits, population distribution of disease, and social inequalities in health." For type 2 diabetics, the embodiment takes the shape of excess fat and results in obesity. Embodiment can also occur through experiences associated with membership in a cultural minority group. Colonization, historical and continuing trauma (in the form of loss of sovereignty, language and culture and of discrimination) could also affect one's belief system and lead to embodiment. Adelson (2005) provided an example of the friction that exists between the biomedical model and Canadian Aboriginals when she described patients treated in a

paternalistic way by the health care provider prescribing a treatment plan in which the patient has little or no input. This is an example of connecting past experiences which modern-day expression of disease. Similarly, adult psychosocial functioning could be affected by unresolved grief that surfaces during specific times of the year with ceremonies remembering past trauma.

Attempting to understand the concept of embodiment as it relates to type 2 diabetes, associations with ethnic or regional groups, whether majority or minority, has the potential to impact physical health. Cultural attitudes of expected social norms and roles (e.g., expected menus, care-giving responsibilities to children and grandchildren), socioeconomic variables (access to healthy food and fitness centers and time away from work/responsibilities to shop and prepare healthy meals), environmental realities (neighborhood safety allowing exercise outdoors, access to walking trails) are often different than those of the majority culture. These variables can both facilitate and impede self-management. Using Krieger's terminology, these become pathways to embodiment. Viewing the study by Gorawara and colleagues (2008) through the lens of Krieger's theory according to which experiences across the lifespan are expressed through biological signs of disease, the finding that a patient's willingness to self-manage may be influenced by making both upward and downward social comparisons seems to confirm Krieger's theory. A diabetic may witness the death of a loved one or a community member who experiences a diabetic-related amputation. These events may positively or negatively influence a patient's willingness to self-manage, thereby becoming a pathway to embodiment.

This study posits that social complexity is a powerful concept in self-management. Safford et al. (2007, p.382) defined the socially complex patient as one who has "socioeconomic, cultural, behavioral, and environmental circumstances" negatively contributing to his/her ability to care for his or herself. The results of the pilot study conducted by this researcher point to the

need to learn more about the lives and life histories of type 2 diabetics. An emergent theme when coding responses was "life is complicated." Those participants expressing an interest in the community Self-Management Programs but not able to attend or complete the program were able to identify life challenges that became barriers to self-management (Schneider, 2011). Barriers expressed as expectations of culture and obligations to fulfill social roles were reported by the majority of respondents (Schneider, 2011).

Addressing known societal barriers to self-management is where other theory types and the health care delivery system that relies on these theories fail. The medical model relies on rational choice theory. Health care systems determine best practice protocols and target outcomes. Providers use these protocols to proscribe treatment for patients who have had limited input into either the protocols, targeted outcomes or what is considered by the provider to be necessary treatments. Nurses and social workers associated with the health system provide people with transportation vouchers to attend programs. Health plans have attempted to eliminate barriers to treatment by removing the cost to the patient for necessary labs. Still, patients do not come in for services or follow treatment plans. From the perspective of rational choice theory, day in and day out people chose to make unhealthy nutritional choices, they do not want to exercise, and they chose not to attend medical appointments. Rational choice theory must conclude that a non-compliant patient values something greater than they value their health. This theory does not consider the important sociological concepts outlined here. Lindenburg (1992) identifies the limits of rational theory in explaining complicated sociological concepts and wonders what is involved in a transformative assumption, or what does a patient consider when determining change is needed? Natural consequences of untreated diabetes are amputations, loss of vision and early death. Subscribers to the rational choice theory conclude that these are

consequences from the accumulation of poor choices. Following rational choice theory, people simply need to choose to self-manage, choose to purchase and prepare healthy meals, engage in regular physical activity and monitor their glucose on a daily basis. They need to value their health above all other factors when making daily decisions. For diabetics, the health care system assumes these self-care behaviors begin in earnest the day a patient is diagnosed. A patient is given the information and on that information she should act. Certainly, some do. But others cannot or choose not to, and there is more to be understood in the space between understanding the disease, acceptance and action. As Krieger's theory would suggest, the presence or absence of action (self-management) must be understood in the context of a patient's life history, culture and environment. For this reason, the study presented here considered patients who are well managed as well as those who are unmanaged.

Following Bandura's theory of self-efficacy (described in Chapter 1: Community Level Programs), perhaps people cannot manage their diabetes because they simply do not have confidence in their ability to self-manage. For-profit companies such as Insignia have developed products such as "Coaching for Activation," based on this theory. This approach does not address the factors known to complicate self-management, the social complexity that patients reported in this researcher's pilot study. Even if a diabetic educator facilitates self-efficacy, people face cultural and environmental barriers that interfere with self-management. Even if a person believes in self-management and has the information and confidence that he or she can self-manage a chronic condition, life is still complicated. For example, insurance coverage and access to quality health care may be sporadic and interfere with obtaining the necessary blood glucose testing supplies, medication acquisition and lab work. Mental health interferes with daily living. Retail stores within reasonable driving distance selling affordable healthy food are

limited. Changing family dynamics and support systems such as when grandparents raise grandchildren, create time constraints and strain relationships. Krieger (2005, p.353) calls on researchers to find the cues and clues in the "dynamic social, material, and ecological contexts into which we are born, develop, interact, and endeavor to live meaningful lives."

There exists a connection between culture, environment and health. Eckersley (2007, p.193) describes culture as "the language and accumulated knowledge, beliefs, practices and assumptions and values that are passed between individuals, groups, [and] generations" operating on many levels within society. Samuels et al. (2012) remind readers that culture is influenced by local factors, as well as political and economic landscapes.

Researchers acknowledge the connection between culture and health, however, little is known about the differences, if any, in fostering sustainable behavior change among racial and ethnic minorities versus Whites. As stated in Chapter 1, Kim and colleagues (2012, p.2324) reported the "paucity of research in the current literature on how elderly Asian and AI/NA (American Indians and Native Alaskans) adults manage their diabetes." The article goes on to conclude significant racial and ethnic disparities exist in the quality of care for American Indian diabetic patients (Kim et al. 2012). Among these disparities, the authors noted that AI/NA were less likely to have been seen by a physician in the past 12 months than Whites and less likely to take medication to reduce the risk of heart attack (Kim et al., 2012). This study explores how three different ethnic groups, two of which are within one ethnic minority - American Indians - experience the diagnosis and management of type 2 diabetes. Within and between group comparisons allows the study to go beyond the traditional research looking at individuals and examine societal similarities or differences such as culture and community level income and resources. The study is mindful of the intersectionality of ethnicity and socio-economic status

and considers past research from Grzywacz, et al. (2012) suggesting the racial and ethnic disparity in health care is more likely the effect of socio-economic status than culture.

Complementing Krieger's theory is the concept of syndemics from medical anthropology. Singer and Clare (2003, p. 425) describe a syndemic as "two or more epidemics … interacting synergistically and contributing, as a result of their interaction, to excess burden of disease in a population." In this study the two epidemics of obesity and diabetes are related and act together to create a disparity in minority populations. Syndemics present a challenge to intervene not only in each epidemic, but also in the space where the two meet. A systematic literature review conducted by Papas et al. (2007) linked obesity with environmental factors such as the disparities of opportunities to engage in physical activity and access to healthy food in the form of proximal distance to and price. This illustrates the narrow focus of previous research and the challenge in designing interventions in the space where the two epidemics interact, rather than simply addressing one causal factor in one of the epidemics.

Guiding the design and analysis of this study are both Krieger's eco-social theory and the concept of syndemics. This framework allows the analysis to focus on structural forces that shape the epidemics of obesity and diabetes. The study examines historical trauma, childhood trauma, community and environment as possible pathways to embodiment of disease and considers their effects on self-management behaviors in a White population and two American Indian tribes with substantially different tribal resources. The research aim is to determine if a relationship exists between cultural, familial and environmental pathways and active self-management of type 2 diabetes. Research questions reflects this aim:

R1: What factors facilitate activation of self-management in patients with type 2 diabetes?

R2: How do community, culture and environment affect American Indians' and Whites' ability to self-manage type 2 diabetes?

R3: Does trauma (including childhood and historical trauma) influence activation of diabetic self-management?

Chapter 3: Research Methods & Study Design

Introduction

This study was designed to gain a deeper understanding of activation of self-management in type 2 diabetic patients. Qualitative research methods were chosen to understand the research questions supporting this aim. The main research question is: "Which factors facilitate activation of self-management in patients with type 2 diabetes?" The study sample includes equal numbers of type 2 diabetic patients considered by their health care provider to be well managed and unmanaged. The secondary aim of the study is to explore the impact of trauma, culture and environment on one's ability to engage in self-management behaviors. Two additional research questions directly address the secondary aim. The second research question: "How do community, culture and environment affect American Indians' and Whites ability to self-manage diabetes?" led to the inclusion of three distinct ethnic groups, a White and members of two American Indian tribes located in Northeast Wisconsin, the Oneida Tribe of Indians and the Stockbridge Munsee Band of Mohican Indians. Responses of American Indian participants were compared with the responses of White participants. A group comparison of the two tribes was also conducted.

The third research question, "Does trauma (including childhood and historical trauma) influence activation of diabetic self-management?" led to the inclusion in the study design of self-administered scales addressing childhood trauma as well as an assessment of trauma related

symptoms. American Indian participants were also asked to complete an instrument measuring historical grief and loss and associated symptoms. (Refer to the *Sample Selection* and *Subsample* sections below.)

The design of this study was built not only on the previous literature described in *Chapter 1*, but also on a past Heller dissertation. Almas Dossa's dissertation, "Organizational, Provider, and Client Influences on Elder Participation and Outcomes in Disability Prevention Programs" investigated the connection between provider and organizational level variables in Chronic Disease Self Management Programs (CDSMP) programs to health status. In the study, Dossa (2007) found minority status to be negatively correlated with program completion. In the study's conclusion, Dossa (2007) suggested in-depth interviews to understand why elders remain or how elders are retained in community-based programs. This study considers Dossa's findings and broadens the interview questions to address all self-management behaviors in minority and White populations.

Hypotheses

The study aim was to detect how successful patients overcome barriers to self-management and the differences between the White and American Indian populations, as well as the similarities and differences across two American Indian tribes. Foundational knowledge for this study originated not only from previous literature and Dossa's dissertation, but also from the pilot project conducted by this researcher (described in *Chapter 1: Pilot Project Results* section). The content of the study was also guided by Krieger's epidemiological eco-social theory (described in *Chapter 2: Eco-Social Theoretical Framework*). Building on this foundation of knowledge, the study posited that social complexity interacts with self-management. "Social complexity" has been defined by health care researchers Safford and colleagues (2007, p. 382) as

a patient experiencing "socioeconomic, cultural, behavioral, and environmental circumstances." Krieger's eco-social theory, the Adverse Childhood Events Study, and other studies discussed in *Chapter 2* explore pathways to embody disease. This study considers how these known pathways affect current health behaviors. Therefore, this research study hypothesizes the following with respect to each of the research questions:

R1: What factors facilitate activation of self-management in patients with type 2 diabetes?

H1: Factors facilitating activation in well-managed patients are absent or less present in unmanaged patients.

R2: How do community, culture and environment affect American Indians' and Whites' ability to self-manage diabetes?

H2a: People who successfully manage diabetes have relied on aspects of their culture to support self-management efforts.

H2b: Those who are unsuccessful have not or cannot overcome social roles, behaviors and other circumstances that become barriers in the intensive self-management that diabetes requires.

R3: Does trauma (including childhood and historical trauma) influence activation of diabetic self-management?

H3: Childhood trauma and historical trauma will be found to inhibit self-management.

Analysis plans allow these hypotheses to be tested by comparing responses within categories of the sample. Sample classifications are described in detail in the next section *Sample Selection*. Briefly, the sample contained responses from White patients who are both

successful and unsuccessful in self-management. Additional diabetic participants from two American Indian tribes were recruited. Those participants were also classified as successful or unsuccessful in self-management. The basis for classification is described below.

Two American Indian tribes were chosen for their common geography, but vastly different resources in the built environment. This reflects the pathways of embodiment Krieger identifies in her eco-social theory.

Sample Selection

This study utilized a purposive sampling strategy, which has two dimensions, one based on the two pairs of categories, managed/unmanaged disease and White/American Indian, as well the other inclusion criteria of being 18 or older, and the other, which is known as theoretical sampling in the grounded theory tradition based on the emergent findings. In the beginning of the qualitative study, adult participants with identified characteristics were recruited. Desired characteristics included people age 18 years or older with a diagnosis of type 2 diabetes who identify as White or American Indian. Eligible American Indians were members in either the Oneida Indians of Wisconsin or the Stockbridge Munsee Mohican Band of Indians.

As the study progressed, sample recruitment was driven by an iterative process, which allowed sampling for range. For example, if an entire subsample was male, a female that met the criteria of that subsample was sought (Miles & Huberman, 1994). This model was considered by the Robert Wood Johnson Foundation's Qualitative Research Guidelines Project to be evidence of a rigorous design (Robert Wood Johnson Foundation, 2012). The qualitative sampling strategy described here was selected for its usefulness in triangulating information specific to chronic disease, social complexities and self-management.

This strategy ensured quality data collection. This research included 5 people in each subsample, for a total of 30 participants. This was the sample size suggested by several research methodologists (e.g. Flick, 2009, Creswell, 1998) and the researcher found it was sufficient and allowed for information saturation. When the planned sample was obtained, recruitment ceased.

The sample was chosen first on age and diagnosis of type 2 diabetes. Participants were required to be a minimum of 18 years of age and have been diagnosed by a health care provider as having type 2 diabetes. Sample selection was then based on cultural affiliation (White, Oneida or Stockbridge Munsee) and on a classification of successful/managed or unsuccessful/unmanaged type 2 diabetes condition. Determining classification of successful or unsuccessful self-management was made using the hemoglobin A1C score on each potential participant's last visit to a health care provider. At the time of the design of this study, the American Diabetic Association (ADA) considered patients with a Hemoglobin A1c below 8.0 to be managed. It should be noted that guidelines were updated in 2012 and now suggest that an A1c below 7 represents successfully managed diabetic condition. A secondary classification was made based on enrollment in one of the two studied American Indian tribes. Enrollment was required as an indicator of their ability to access tribal resources. Table 2 reflects the population sample of this study.

Table 3: Factors Facilitating Activation: Study Groups

	Successfully Managing Diabetes HA1C = < 8	Unsuccessfully Managing Diabetes HA1C > 8
White Patients, ages 18+	5 participants	5 participants
American Indians, ages 18+ Oneida Indians of Wisconsin	5 participants	5 participants
American Indians, ages 18+ Stockbridge Munsee Band of Mohican Indians	5 participants	5 participants

Subsamples

Two tribes were chosen for their common culture and geography and substantially different community resources. Including subgroup sampling was appropriate for this study due to the desire to compare subgroups (Onwuegbuzie & Leech, 2007). Subgroup analysis also included between tribe comparisons of Oneida or Stockbridge Munsee participants. This method, encouraged by Onwuegbuzie and Leech (2007), noted subgroup comparison can occur using multiple attributes. In addition, these authors suggest the threshold for subgroup comparison is a minimum of 3 cases per subgroup, which this study, with 5 cases per subgroup, exceeded (Onwuegbuzie & Leech, 2007).

The Oneida Indians of Wisconsin are considered to be a significantly wealthier tribe than the Stockbridge Munsee. According to a report filed by the Wisconsin Legislative Fiscal Bureau, Oneida has a 6 times greater net revenue from gaming than the Stockbridge Munsee (Johnson, 2013). This allows for a multi-million dollar operating budget, supporting a membership of over 3500 people. To support health and wellness, the tribe operates a fully functioning, all-encompassing health and wellness program. This includes a clinic with primary providers and specialists on staff, as well as behavioral health, dental, audiology, optical, asthma and allergy clinics. On the Oneida reservation, physical therapy, diabetic educators and laboratories are available for members. This tribe also operates a state-of-the-art fitness center, and the "Oneida Community Integrated Food Systems" where tribal members grow organic foods made available to their tribal membership at low cost. In addition to this, the tribe operates a buffalo farm and apple orchard. It provides members with culturally sensitive childcare and a nursing home on the reservation. By comparison, the Stockbridge Munsee band of Mohican Indians has a much smaller operating budget with fewer community resources, supporting a smaller tribe of

approximately 1,200 members. It operates a health and wellness center with primary care providers and one diabetic educator on site. The Stockbridge Munsee Tribe also has a food assistance program for eligible members and operates elderly center that provides daily meals to members. Neither tribe currently offers a Diabetes Self-Management Program.

The White sample in this study was drawn from a three county (Brown, Kewaunee and Calumet) region located in Northeastern Wisconsin. The largest city is Green Bay, with a population of 105,000 and the total population for the three counties is 325,000. In this three county region, the per capita income ranges from $25,282 in Kewaunee County to $28,907 in Calumet County (US Census Bureau, State and County QuickFacts). However, absent a membership system like the one that is federally required of the tribal governments, the study cannot assume equal access to community resources such as health care.

Recruitment

The sample was recruited through various means. The first source of referrals was from the researcher's professional contacts within community organizations and health systems serving diabetic patients. Professional contacts included members of both named American Indian Tribes.

Professional contacts were asked to identify health care providers who have shown an interest in serving diabetic patients and promoting self-management. Providers were then asked to invite interested participants using a poster advertising the research. Prior to the commencement of the study, the poster advertisement and study design were approved by Brandeis University Institutional Review Board (IRB). (See *Appendix B* and *Appendix C* for examples of advertisements used to recruit participants.)

In addition to these contacts, the research project was promoted through advertisement at Indian Health Centers on both reservations. The IRB-approved poster regarding the research was placed in the gathering spaces of health systems and community-based sites with verbal permission of the site managers.

As interviews were conducted, the range-based sampling methodology used here allowed the investigator to recruit additional participants based on gender. Advertisements describing the project were periodically e-mailed as professional contacts were developed. Advertisements targeting desired subsample populations were used and varied slightly in content. However, the Brandeis IRB prior to the start of the project approved all advertising material.

Interviews

All participants signed a written consent form prior to the interview. (See *Appendix A* for a copy of the Consent Form used in this study.) All participants consented to voice recording the interview as part of the informed consent process.

Semi-structured interviews were conducted with all participants. (See *Appendix I* for a copy of the Interview Guide.) Participants were informed during recruitment and during the process of informed consent that participation would last approximately 1.5 hours. All interviews occurred in a location mutually agreed upon by the investigator and the study participant. The location was determined with the understanding of the potential of sensitive information to be collected, but also depended on available public space in rural areas. Upon conclusion of the oral interview, study participants were asked to complete several scales described below. (Please refer to the *Appendices* for copies of all scales used in this study.) After interview completion, participants were each given $50 in cash as compensation for their time and effort.

Interviews were organized in part, using a life course perspective. This perspective includes the effect of culture and contextual influences and lends itself to providing information that can be used in designing interventions (Wethington, 2005). This perspective has seven organizing principles as presented by Wethington (2005, p.116) and shown in Table 4.

Table 4: Key Concepts of the Life Course Perspective

Table. Key Concepts of the Life Course Perspective

Concept	Definition	Example(s)
Trajectories	Stable patterns of behavior or health across time	Tobacco use, chronic disease
Transitions	Changes in social roles or responsibilities	Divorce, birth of first child, change in job responsibilities
Turning points	Transitions that are major changes in ongoing social role trajectories; life takes a different direction	Educational decision that affects career path
Cultural and contextual influences	Events and externalities that shape and constrain the process of change and adaptation	The Great Depression, race, gender, neighborhood factors that affect childhood
Timing in lives	The interaction between age or stage of the life course and timing of event or transition	Age at the time of a major event, such as the Great Depression; age at birth of first child
Linked lives	Dependence of the development of one person on the presence, influence, or development of another	Influence of spouse on the other's health behaviors
Adaptive strategies	Conscious decisions that people make to improve their health or well-being or social norms that frame the way in which decisions are made to adapt to external changes	Changes in health behavior; individual coping strategies, such as taking action, denial, avoidance, or reappraisal of the threat

Of these, transitions, turning points, cultural/contextual influences and adaptive strategies are of most importance to this research and are aligned with the eco-social theory chosen for this study.

Scales

Several measures were used in conjunction with the interviews. Scales were considered when comparing participants with managed conditions to those with unmanaged conditions. The scales were also used when making comparisons between White and American Indian participants. Scales were used primarily to support the qualitative information collected in the interview and to gather additional information about participants. At Weiss's (1994) suggestion, scales were conducted after the oral interview concluded in order not to discourage discursive

responses to open-ended questions. Information gathered from these scales was used in several ways. The majority of information from the scales was used independently of the information gathered in the interview. In a few areas, the information was used to triangulate information gathered from the interview, such as support a participant receives from others in self-managing or factors patients identified that facilitate self-management. Subsample comparisons of responses from the scales were made. The following sections describe in detail each of the five scales used: a check of findings from previous literature (developed by this researcher), the Historical Trauma Exposure and Symptoms, the Adverse Childhood Events Scale, Trauma Symptom Checklist 40, and, finally, the Patient Activation Measure. All instruments used in this study are attached in the *Appendices*.

Check of Findings from the Previous Literature

In order to understand if findings of previous literature hold true for the populations included in this study, this researcher designed an 11-item questionnaire. Each question represented a finding from previous studies on type 2 diabetics. The participants were asked to circle the response option that best represented their response. Answer choices were as follows: Strongly Agree, Agree, Neither Agree nor Disagree, Disagree and Strongly Disagree. (Refer to *Appendix D* for a copy of this instrument.)

Historical Trauma Exposure and Symptoms

While the Adverse Childhood Events scale is useful for the general population, an additional tool is needed to capture trauma that occurred in past generations but manifests itself in the daily life of families and communities. Historical trauma, a concept developed by Maria Yellow Horse Brave Heart (2003, p.7), is defined as "cumulative emotional and psychological wounding, over the lifespan and across generation, emanating from massive group trauma

experiences." This trauma includes generations of assault by the US government and others. Trauma and grief experienced in this community result from loss of land, loss of language and culture through the forceful removal of younger generations forcibly placed in boarding schools and the loss of traditional spiritual practices.

For the American Indian community, Les Whitbeck (2004) has developed a tool to capture historical loss and grief. This tool captures both exposure and symptoms manifesting themselves in current conditions of the individual. The scale takes 10-15 minutes to complete, consists of 29-questions and is free for researchers to use. A copy of this scale is provided in *Appendix E*.

Adverse Childhood Events

In the late 1990's Kaiser Permanente, a large health system in the western United States, conducted a massive research project comparing childhood exposure to trauma and diseases in adulthood. This study became known as "Adverse Childhood Experiences" or ACE. The Robert Wood Johnson Foundation recently republished the study, which was originally housed in the CDC. An ACE score is determined by the amount of exposure to traumatic events in one's childhood. Events include physical, sexual and psychological abuse. Other categories of trauma are related to household dysfunction and include substance abuse, mental illness, mother treated violently and criminal behavior committed by a family member (Felitti, 1998). Results were compared to the health status of adults. Adults were asked about heart failure, diabetes, obesity, lung disease, fractures, liver disease and more. Over time the scale was validated and associations were made for thousands of respondents. The more exposure to childhood trauma (or the higher a person's ACE score) the more diseases were reported in adulthood (Felitti et al., 1998). This study follows Krieger's eco-social theory and

considers ACEs a pathway to embodiment. The ACE scale was administered to the entire study population. *Appendix F* provides a copy of the ACE calculator.

Trauma Symptom Checklist 40

John Briere's Trauma Symptom Checklist 40 (TSC-40) was included in this study to assess symptoms of past trauma (Briere, 1996). This 40-question scale is a research tool, not a clinical tool. As such, it allows researchers to assess symptomatology in adults related to traumatic events occurring at any point prior to administration. The tool has an overall score of 1-40. Six subscales are included and represent dissociation, anxiety, depression, and sexual abuse trauma index, sleep disturbance and sexual problems.

This scale was chosen over other scales for several reasons. First, the tool can be self-administered in a short amount of time (10-15 minutes). Second, the TSC-40 includes useful subscales for this project. Lastly, the tool does not require one event be identified and can measure symptoms from multiple traumatic events. The Adverse Childhood Events Study revealed that multiple traumatic events have a greater impact on unhealthy behaviors in adulthood (Felitti et al. 1998). A copy of the TSC-40 is provided in *Appendix G.*

Patient Activation Measure

Patient activation is a concept similar to self-efficacy. Chubak et al. (2012, p.1316) state that patient activation occurs when "knowledge, skills, beliefs, and behaviors necessary to manage their illness over time, 'activates' patients," who "become engaged, effective members of their health care team." However, no research exists regarding which factors contribute to a patient being activated (Hibbard et al., 2007; Rask et. al 2009).

The Patient Activation Measure (PAM) was created to measure a person's ability and willingness to manage his/her health and health care. The tool is also said to have predictive

capabilities, including the ability to predict whether a person will engage in self-management behaviors that are disease specific (Hibbard et. al, 2008). This measure is proprietary. However, the researcher sought and was granted permission to use this measure for this research project. (Permission to use this tool was sent as a part of the IRB application.)

The PAM is an individual-level measure. This researcher was interested to test correlations between this measure and other measures. She was also interested in between-group comparisons of responses to this measure, such as correlation of managed condition or level of trauma symptoms experienced to PAM scores.

Analysis

Interviews were recorded by this researcher on a Mac Book Pro laptop computer and transcribed verbatim by a professional transcriptionist. Transcriptions used in quotations from interviews are naturalistic. Spoken responses and other reactions from the interviewer are captured using square brackets [ ] and presented in italics. A reaction, such as laughter, made by the participant is in parentheses, for example, (laugh). Three ellipsis dots indicate a pause from the speaker, whereas four indicates the statement is not continuous, that is, a segment of what the interviewee said is not presented. The researcher corrected grammatical errors that would distract the reader from its content. A word or phrase emphasized by the participant is italicized.

Data generated from these interviews were coded using NVivo software for themes or nodes. Some of the initial codes were a priori codes generated by the researcher, although the analysis did allow for posteriori codes grounded in the data (Charmaz, 2006; Glaser & Strauss, 1967). NVivo software nodes were assigned to samples of text. It was possible for text blocks to be assigned to more than one node.

Prior to subgroup analysis, cases were considered independently. Subsequently, comparisons of responses to interview questions between subgroups were made. Subgroup analysis considered similarities and differences in groups of respondents based on inclusion in a cultural minority group or self-management classification.

Data gathered from the scales were summarized using descriptive and simple statistics. The primary purpose of this data was to enhance the information collected in the interview phase. That is, it was collected and used primarily to enrich the qualitative study rather than to investigate statistically significant relationships. Stata 11 was used to conduct pair wise correlations, t tests, an exact logistic regression, chi-square tests, Fischer's exact test, Chronbach's Alpa and a power analysis. Subgroup analysis of scale data was completed to reveal any patterns in the data. Results are presented in the next chapter.

Chapter 4: Results

Introduction

This qualitative research study aimed at identifying factors that facilitate activation in patients with type 2 diabetics. Using a semi-structured guide, interviews with 30 type 2 diabetics were conducted. Members of three different race groups were eligible for participation in this study; a White population was included as well as members from two American Indian tribes in Northeastern Wisconsin, the Oneida Tribe of Indians and the Stockbridge Munsee Band of Mohican Indians. The two tribes were chosen for the similar culture and geography but substantial differences in available community/tribal resources. Each group had a total of 10 participants, with an equal number of managed (A1c <= 8) and unmanaged (A1c > 8) participants in each group. The sample was younger than anticipated. Tables 5 and 6 show the breakdown of participants' age by racial group and managed condition. The sample is younger than was anticipated with 25 of the 30 participants under the age of 60. The managed sample had more people over 60 years of age (4 versus 1). Results of the interviews are presented here, organized into themes relevant to each research question.

Table 5: Participants Age by Racial Group

Age	Stockbridge Munsee	White	Oneida
20-30	2		1
31-40		2	2
41-50	4	2	2
51-60	2	5	3
61+	2	1	2

Table 6: Participants Age by Managed Condition

Age	Managed	Unmanaged
20-30	1	2
31-40	2	2
41-50	3	5
51-60	5	5
61+	4	1
Total	15	15

After the interviews concluded, participants were asked to complete several scales developed by outside researchers and administered with expressed permission from the developers. These included the Adverse Childhood Events Scale, Trauma Symptom Checklist and Patient Activation Measure. American Indian participants were also asked to complete the Historical Grief and Loss scale, including measures of grief and loss as well as a measure of current symptoms related to historical trauma. In addition, all participants completed a questionnaire developed by this researcher for the explicit purpose of this study. This tool included questions that represented results of past studies of barriers in diabetic self-management. The scales and questionnaire were administered for the purpose of comparing the responses from American Indian and White groups as well as comparing the responses between managed and unmanaged diabetic patients.

Results of the interviews and each tool are presented here. To simplify the presentation of results, this section is organized by research question and related hypothesis. The first section compares and contrasts interview responses from managed and unmanaged participants as they relate to facilitating activation. The interaction of the identified factors and self-management are described in detail below.

The answers to the questionnaire regarding findings of previous diabetes studies and the PAM tool are included in this section. Next, the interview questions related to culture,

community and environment are presented as well as differences in responses across ethnic groups. The third section outlines the childhood and historical trauma related scale results from the ACE, TSC-40 and Historical Grief and Loss scales.

Factors that Facilitate Activation of Self-Management of Type 2 Diabetes

Much of recent published literature focuses on the barriers to self-management. This study was designed to examine the factors facilitating activation of self-management in type 2 diabetics and hypothesized that factors facilitating activation in well-managed patients are absent or less present in unmanaged patients. In order to better understand the concept of activation, the study included both patients who were well managed and those who were unmanaged.

Information relating to the first research question, "What factors facilitate activation of self-management in type 2 diabetics?" is presented here. Descriptions of the participants' perceptions of his or her health are provided first. The life course perspective promoted collection of this information and it is relevant in the discussion of patient-centered approaches to care. Themes related to patient activation include the establishment of daily routines, social support, emotions/mental health, experiencing success, financial incentives, social roles, attitudes about food and aspects of the workplace as playing a role in facilitating their self-management efforts. However, social support and financial incentives did not always translate into sustained self-management actions.

Perceptions of Diabetes and Perceived Health

The life course perspective, which guided the study design, encouraged the examination of the participants' perceptions of their diagnosis, living with diabetes and their health in general.

In the life course perspective, these issues may represent turning points or trajectory changes for patients and offer some insight into the knowledge and motivation necessary for successful self-management. Many participants, representing all study cohorts, were not surprised by their diabetes diagnosis. As a managed Stockbridge Munsee male said, "My mother had, well everyone had it." Like this participant, others attributed their lack of surprise to the fact that many family members had diabetes and felt the disease is genetic. As one managed White female explained, "Well, I have 2 sisters that have diabetes so I was expecting it. In fact, I was expecting to be the first, not the last of the 3 sisters. … My father has it too." An unmanaged Oneida female explained, "There was a history on my father's side of the family." Another unmanaged Oneida female described her diagnosis:

> I still struggle with it. I some days feel, why me? [I have] two brothers who don't have anything. I told the doc I got stuck with everything. My parents both have it.
> …
> We hear Native Americans and Mexicans would get it, so I'm screwed either way, because I am both. We hear that most natives will catch diabetes.

Type 2 diabetes is preventable, even though most participants described the diagnosis as inevitable. In a study among low-income urban American Indians in the Midwest, the perception of the cause of diabetes was diet and lack of exercise, although the authors did note several participants felt the incidence was high "among Indians" and at least one other participant thought the disease was hereditary (Lautenschlager & Smith, 2006, p.308). In rural North Carolina, Grzywacz and colleagues (2012) found the majority of high- and low-income Whites (N= 205) and high- and low-income American Indians (N=168) agreed with the statement, "Diabetes runs in families." The fear is that a lack of surprise makes it unlikely the participants saw the diagnosis as a turning point and could lead to an apathetic response in management and treatment of the disease. In addition, a lack of knowledge about diabetes (Booth et al. 2013) and misconceptions about the seriousness of the disease (Nam et al., 2011) have also been seen as

barriers to self-management. However, in this study both managed and unmanaged participants expressed similar views and knowledge was not related to activation (these findings are reported later in this section).

When participants from all cohorts discussed their health, many talked about other health conditions from which they were suffering. However, unmanaged participants seem to avoid thinking about their diabetes, saying things like "I try to block it all out I guess" (Stockbridge Munsee male), "I don't put diabetes way up there, it's not, its like I have more issues" (Stockbridge Munsee male) and "It's like everything. You have to regulate, it's too much" (White female). Some unmanaged patients prioritized other health conditions over diabetes. For example, after relating in detail his progression and interventions related to heart problems, an unmanaged White male responded "Ah…no" when asked if he ever looked for information on how to live well with diabetes. An Oneida male illustrated the challenges unmanaged patients had with managing diabetes amid other health problems. He said,

> Um, right now I am unemployed because of a surgery that I had. [*Ok*] I was in a car accident about 7 years ago, but then with the diabetes and everything else, you know, it's hard to hang in there. [*Ok*] I have nerve damage from the car accident, but I was thinking maybe part of that had to do with the diabetes.

The comments above and the one below by an unmanaged Oneida female demonstrate the confusion and overwhelming nature of multiple health problems.

> I'm not sure [what my response was to the diagnosis]. It kind of threw me for a loop [*yeah*] I think. But I was also going through, I believe at the same time because it was a while ago, I was diagnosed with breast cancer and endometrial cancer, so I had the whole thing so. And I believe it was right around the same time.

Denial was found to be a barrier to self-management in a previous study by Jones and colleagues (2013) and co-morbidities, a barrier by Nam et al. (2011) and Bayliss, Ellis and Steiner (2007). In a study about chronic illness, Audulv, Asplund and Norbergh (2010) noted the overwhelming burden patients feel when constantly thinking about their illness and related behavior.

Managed participants discussed their health in a more holistic manner, and achieving optimal health seemed to mean addressing all of their health concerns. They were confident in the plans established to manage type 2 diabetes. As one Stockbridge Munsee female stated, "And actually I suffer from depression [*yeah*] and so working out kind of really helps with that too so I kind of just know that I have to do it (laughs)." Like this Oneida female, many managed patients reported, "always working on something" in regards to their health.

Unmanaged participants often avoided medications because of undesirable side effects, yet few of them communicated with the provider regarding the situation. For example, an unmanaged Stockbridge Munsee male stated,

> I started a new medication and I have skipped a couple of times because sometimes it makes my blood pressure…my blood sugar goes too low and then I don't feel good [*right*] so once. So, if I have a lot of stuff to do, active, I will occasionally skip that, actually skipped a few times because it leaves me constipated.

All participants were asked to describe their health in general. Despite having at least one chronic condition, many reported their health as "excellent" or "fine." Responses such as "I would say that I am in good health" (unmanaged White female) and "I'm in fairly good shape you might say. [*ok*] I got…with my diabetes, I've got heart disease [*ok*] and I had a bypass when I was 62 and then I had a stent out in probably 5 years ago" (managed Stockbridge Munsee male). A managed White male responded he was "Healthy, energetic, younger than my years" just before handing over a list of 10 medications he was taking, and a managed White female said "my health is really good" before describing high blood pressure and cholesterol medications, a heart medicine and a water pill. The fact that people with one (or more) chronic condition described themselves as healthy is line with research on healthy aging. Hung, Kempen and DeVries (2004, p.1373) completed a literature review on healthy aging in which they concluded,

> In general, lay definitions (as described in 11 studies) included more domains (independency, family, adaptation, financial security, personal growth, and spirituality) and more diversity in the

> healthy ageing concept than academic views (which tend
> to focus more on physical and mental health and social functioning in later life). Certain domains were valued differently across cultures.

More recent research by Bacsu and colleagues (2014) also showed definitions of healthy aging among policy makers and researchers differ from those among older adults living in rural Canada. Bacsu and colleagues (2014) concluded that instead the morbidity/morality dynamic that seems to be the foundation of healthy aging initiatives, older adults consider social interactions, optimal mental health, physical activity, independence and cognitive health when discussing healthy aging.

In summary, participants in all categories talked about diabetes as part of their communities, family histories and even genetic make-up. Unmanaged patients tended to prioritize other health conditions above their diabetes and avoided not only thinking about their condition, but also medications because of unpleasant side effects. In contrast, managed patients were more likely to discuss their health in a more holistic manner, with many believing achieving optimal health meant addressing all of their health concerns. Interestingly, when participants described their health in general, they often reported it was "good." This leads the researcher to think, just as in the healthy aging research, that there is more involved in health for diabetic patients than illness and symptoms.

Routines

Patients who were well managed reported that being in a routine made it easier to comply with recommendations from the health system in regards to both medication compliance and lifestyle modifications (diet and exercise). After receiving a diagnosis of type 2 diabetes, the majority of managed patients began building a routine to include necessary modifications, working towards self-management. As one Oneida female said, "Medications are nothing, it's a

routine. You know, seriously? It's just a habit, you get in that routine as long as you are taking them." When a routine changes for reasons out of their control, such as unforeseen travel for work, this group had the motivation, confidence and awareness to adjust along with the will power to resist repeating destructive behaviors such making poor food choices when dining out. One white male explained "If I go to work in the morning and they tell me I have to run to Indiana, if I have an unplanned day. Check [blood sugar] and adjust. Once you learn it, it's easy."

Managed patients had a difficult time answering the interview question, "Describe a day when you just can't manage well." Typical of answers to this question, a Stockbridge Munsee female answered, "It's not really difficult to manage."

Unmanaged patients also reported that being in a routine aided their self-management efforts. However, this group was much more likely to cite disruptions in daily life that altered their plans. As one Stockbridge Munsee male said, "I've got um, some issues with um, maintaining my routines that are in place because my kiddies are, keep me hopping from one thing to another." This group failed to adjust when an outside force such as the workplace did not impose structure and routine. Two members of the unmanaged group were typical, "When I keep to my, um, routine, everything is good and numbers are good" (Stockbridge Munsee male) and "I am definitely better Monday through Friday. The work schedule really straightens me out. Weekends, I am just sloppy" (White female).

This finding that the establishment of routines aids in self-management is consistent with other literature and was the general conclusion of a systematic review of barriers to diabetes self-management by Nam, et al. (2011).

Social Support in Self-Management Activities

Regardless of the state of their diabetic condition and race classification, most participants reported that the fear of their condition worsening facilitated activation of self-management. Fear of hospitalization, becoming dependent on others, having to take more medications or inject insulin, and the fear of amputations or vision loss were all reported as factors that facilitated motivation of self-management. Common responses included, "I don't want to lose the eyesight and feet" (managed Stockbridge Munsee female), "amputations are a biggy" (unmanaged Stockbridge Munsee female), "I don't want to fall over dead!" (unmanaged Stockbridge Munsee male) and "I don't want to lose …feelings in my fingers" (managed White male). This is consistent with the research conducted by Vest and colleagues (2013) who found low-income participants were concerned with becoming a burden to family members.

In addition to the fear of the condition worsening, answers to the question, "What motivates you to manage your condition?" also elicited responses of a person or people with important relationships to the participant, such as spouses, children or grandchildren. When participants elaborated on this answer, they often described their desire to be alive to see grandchildren grow and help take care of them, or enjoy retirement with a spouse. A managed White male answered, "My wife. … We've been married 44 years. It's been a great trip."

Despite these commonalities in what motivated participants to manage, there was a major cultural difference in *who* helped participants manage. Only 6 of the 20 American Indian participants responded that they managed the disease by themselves with no help from others, while 6 of the 8 White participants reported managing alone. Both Stockbridge Munsee and Oneidas discussed the roles their intimate partners, spouses, children and extended families played in self-management. In a systemic review of diabetes self-management literature, Nam

and colleague (2011) found mixed results on the impact of social support. This is discussed more in the section *Culture, Community and Environment* below.

Emotions and Mental Health

All participants were asked, "How do you feel now about your diagnosis?" When comparing managed and unmanaged participants' responses, unmanaged participants were more likely to have an apathetic emotional response, as one White female said, "Um, I don't know. Indifferent, I guess." Many reported being "in denial" that they had diabetes. Managed participants often reported neutral or positive emotional responses and had the ability to make the diagnosis a part of their life. For them, diabetes was something they adjust to and move forward. "You know what – this is nothing" was the response from one Oneida female, and a Stockbridge Munsee female said, "Well at least its not cancer." When managed patients expressed negative emotions, it was often used to motivate them to self-manage. For example, a managed person reported frustration with the current state and wanted his/her condition to be even better. They often wanted to discontinue current medications such as insulin injections. One Oneida man woke up in the hospital from a diabetic coma and was told by his doctor for the first time that he was diabetic. He describes the situation,

> He came in and um, asked me why I wasn't taking my medication. I said 'What are you talking about?' He said, 'You are diabetic'. I said, 'Great.' Then he said that you have got to take shots for the rest of your life and I said 'Kiss my ass!' (Laughs) Apparently, you don't know me!

This man started insulin immediately, but was able to devise a self-management plan leading to significant weight loss. He is no longer on any medication for diabetes. Conversely, when asked to describe how they felt about their diagnosis and living with diabetes, unmanaged participants gave answers like "inconvenient" (Stockbridge Munsee male) and managing is "too much" (White female).

In the interviews, there was a subtle difference in how managed and unmanaged people dealt with a misstep in self-management. There were examples in both groups of a time when a participant behavior deviated from desired behavior. Well-managed people discussed the ability to forgive themselves on days they "slipped" on their diet or skipped their exercise. As an Oneida male explained "You can't, um, you have to be very flexible when you are doing stuff or managing stuff and you have to be forgiving of yourself once in a while." Unmanaged participants described a similar concept, although in this group it appeared more a rationalization to skip medications for a longer period of time or to not follow any diet plan. This cohort discussed the rationalization that occurred *prior to* a behavior such as a White female saying "I mean somebody brings cake at work (right), it's like, ok, I'll just have one little piece, and then later on I'll be better" or a Stockbridge male saying, "When I skip my pills and basically tell myself well one day doesn't hurt." The difference then seemed to be that the managed participants had a slip that was not typical and discussed forgiving themselves *after* the event occurred, indicating they may not even have been aware they were deviating. While the concept described here does not appear explicitly in prior research studies, the positive effects of forgiveness and the negative effects of resentment on blood sugar levels was discussed in *Pacific Standard: The Science of Society*, an online magazine (Jacobs, 2010).

Participants also talked about the emotional highs and lows associated with changes in blood sugar levels; however, unmanaged participants discussed this more frequently. A White male said, "I get ugly [when my sugars go high]" and Stockbridge Munsee female said, "I mean, you don't really mean to be angry [*right*] but little stuff sets you off, you know, when your sugar is really high." Many described being irritated and/or depressed due to the diabetic diagnosis and status of their condition. An Oneida female said, "it can take days" to get her sugars back under

control. When this participant was asked if there was anything more she wanted to say to help the researcher understand what it was like living with diabetes, she responded, "I don't think people understand the depression that comes along with it." Likewise, when the researcher asked an unmanaged Stockbridge Munsee male to describe the emotions associated with type 2 diabetes, he responded with one word: "depression" and an unmanaged White female said, "I got very depressed from it [the diagnosis]." In addition to the taped and transcribed excerpts above, after the interview was over, an unmanaged Oneida female discussed her foul mood, which she attributed to diabetes. She said many times she just wants people, her boyfriend in particular, to leave her alone. During the interview, she described how negative emotions stop her from reaching her goals; "I get crabby at myself. Depends on the mood. If I am crabby, I am just going to eat, I am going to get something. Then I feel bad about it later." One managed Oneida female also noted, "Mood makes a difference [in self-management]."

In a large study conducted in 13 countries with diabetic patients and health care providers, Peyrot and colleagues (2005) found diabetic-related psychosocial problems were common (41% of patients). Findings here suggest this number may be even higher.

Experiencing Success

A factor that clearly facilitated activation in both the managed and unmanaged participants was experiencing success, including witnessing weight loss on a scale at home, an A1c number taken at the doctor's office falling into managed range or simply feeling physically better when they ate well or exercised. One unmanaged Stockbridge Munsee man said,

> I think the one positive about all of this was that by being able to keep that diet, I was able to drop about 50 to 60 pounds off of what I used to be. So that has really been a good thing. [*Yeah.*] That tells us about a secondary motivator about trying to keep going because I am wearing clothes I haven't worn in years and um, my life goal, if I can down to what I weighed when I was in my late 20's, early 30's, then I am going to spoil myself and go shopping.

Success allows people to tolerate prescribed lifestyle changes.

Financial Incentives

In addition to this, having a financial or material incentive was a motivator for some participants. Whether the incentive was to attend a diabetic-related tribal event for a free pair of gym shoes or a chance to win a raffle, these incentives motivated people to attend a health-related event. As a managed Stockbridge Munsee male stated:

> Ahhh…well I get a lot of letters from the tribe [*ok*] but I never go to that stuff [*ok*]. I usually manage it myself. [*Ok*] It's never got out of hand where I couldn't manage it so I just never went to the meetings. [*Ok*] I did go there once I think to get a pair of tennis [shoes] they were giving away but I had to go to the meeting first and meet with her [diabetes educator] first, so I could get them free tennis [shoes]. I did do that.

Similarly, an unmanaged Oneida female said, "I went [to Just Move It! Oneida] just so I could get in the raffle! (Laughs). I mean, whatever it takes and it worked for me [to attend the event] and I did win."

Another reported factor that facilitated activation was when local employers tied insurance premiums with a health assessment. One unmanaged Oneida female explained:

> [I]n our tribe, in our insurance, through our health insurance, they have the new preventative offer through, I don't know if it is Obama Care but the Federal Government requires that our insurance offers reasonable alternative solutions, RAS [reasonable alternative standards for insurance purposes], [*yep*] that motivates me.

However, while the incentives motivated people to attend a program or class, unmanaged participants often reported that it did not lead to sustained self-management efforts. For these unmanaged participants, having information did not translate into self-management activities. During an interview with a White male, his mother walked by the interview and said, "Yeah he knows exactly what he is *supposed* to do, but ask him if he does it." Another respondent reported: "And that is kind of why I don't go to the community diabetes [events], they have

luncheons, they have little seminars. I know what I should do. I just don't do it. I should eat a salad, you know? Cheeseburger is better" (Stockbridge Munsee male).

Social Roles and Attitudes about Food

Several managed female participants cited currently or previously living alone as a facilitator of self-management. This was mentioned in relation to the difficulties faced when fulfilling the expectations of a social role, including cooking for a family or group of people. Responses such as this one from a managed Stockbridge Munsee Female were common:

> When I was single and probably down at my lowest [weight], I lived by myself. Um, I didn't have to worry that there was stuff to eat for the grandson and I didn't have to worry that I was cooking supper for a family and I didn't have to do all of that, you know. So a lot of times what was in my refrigerator, there was nothing in my refrigerator, which helped me because I am a snacker. If it isn't there, then I didn't need to worry about it and although I ate out, I would order a salad, you know, so…

Complaints about not having enough carbohydrates to get through a day of physical work in farming or construction were common in both groups. There was a perception by the female participants that some male family members felt that healthy meals such as salad and meat presented without a starch or carbohydrate were not appropriate for men, they were not "real food". An unmanaged White female responded "It is hard to have a family who loves all this pasta and this and that and 'Chicken, we are having chicken again?' " Male participants also reported feeling this way.

In addition to not being able to indulge in carbohydrates, portion control was difficult for many participants, particularly the unmanaged participants. Comments such as "You just have to watch your portion control which that isn't easy either" (Oneida female) and "They always say a deck of cards, palm size of mashed potatoes, yeah I eat 3 of them" (Stockbridge Munsee male).

Positive and negative reactions from family members were discussed across study groups. The difference appeared to be how participants reacted to the displeasure. More often unmanaged participants bowed to wishes of family members and continued to cook foods high in fat, carbohydrates and sugar and then attempted to not eat this food when they served it to family members. But, as many as four participants reported that a family member assumed responsibility for grocery shopping and preparing meals after diabetes was diagnosed. Like the women who thought it was easier to manage when they lived alone, the sense of not having to think about preparing meals reportedly made managing easier for these participants. This was typically due to a spouse or family members preparing meals. For one unmanaged White female, not having to think about preparing meals came from a liquid meal replacement program supervised by her physician. She remarked that this was the easiest time she had managing her disease (and it was considered managed at that point in time):

> There was only one time that I managed it the best and that was um, I did the HMR [Healthy Meal Replacement] diet through work and I did 500 calories a day of five shakes, 100 calories a piece and that was all I ate all day long for 9 months. Well, I shouldn't say 9 months. So I did that for 6 months because they would only let you do it for so long and it's, it's medically watched and I was off all my meds, I could control my blood sugars very well because I wasn't eating anything. … I didn't feel like I had to think about it every minute of the day of what I was eating, when I was eating it, how I, how much I was eating, you know because it, there was no thought to it. I ate the 500, I ate 5 shakes a day and you know, so I just think it cleared a lot out of, but I mean you can't sustain that, you can't keep doing that so…

Unmanaged participants described eating as a way to self-sooth or improve their mood (as also the *Emotions* section above). In regards to the weight loss involved in self-management of type 2 diabetes, participants' often mentioned the image of him or herself (or loved ones also struggling with this disease) as a larger person. Comments such as "I am a little heavier guy" (Oneida male) and "Short, fat and ugly" (White female) were common among this group. When describing her unmanaged mother with the same condition, a Stockbridge Munsee female said "'Oh well, I'm the big girl', like she just kind of gave herself that label and um, I don't know if

she [doesn't] think she can change or what it is." These findings are not reported in previous literature on diabetes self-management.

Workplace

According to participants in this study, the workplace can have a positive effect on self-management when it provides structure and routine. A few reported that support from colleagues and co-workers can be another benefit of the workplace. As one managed Oneida female described:

> At work, a co-worker is also diabetic, fit guy and he has encouraged me. He was the one who told me to eat a boiled egg and toast in the morning. He says the protein will help me throughout the day. He is encouraging me at work. Everyone thinks of everyone's condition at a potluck. It's really kind of neat; we are all very supportive of each other.

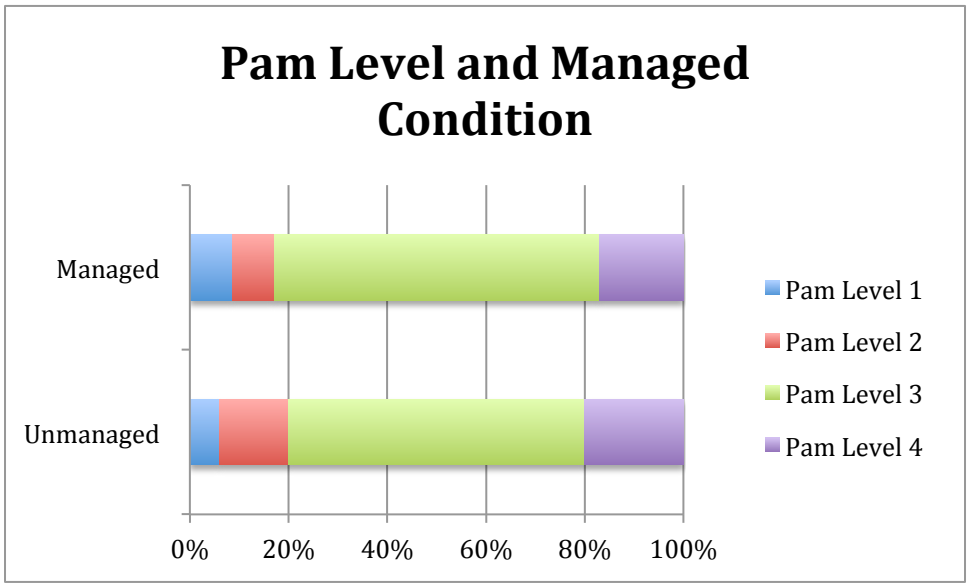
Work-sponsored, health-related events were thought to be positive; however, few participants attended the events in the absence of a financial incentive offered (as was described earlier in this section). Reasons for not attending included feeling as if one already possessed the information that would be given at the event or wanting time to relax and socialize with co-workers. In 2013, Iranian researchers Rahimian Booger and colleagues called for more mixed methods research on the socio-structural variables of community and workplace. This section presented information related to individual impacts of the workplace, while workplace policies on the structural level are discussed in the section titled *Culture, Community and Environment* below.

Patient Activation Measure (PAM)

This study was designed to detect factors that facilitate activation of self-management in type 2 diabetics by examining similarities and differences in managed and unmanaged patients. Patient activation is a concept similar to self-efficacy described in Chapter 2. Chubak et al. (2012, p. 1316) note that patient activation occurs when "knowledge, skills, beliefs, and

behaviors necessary to manage their illness over time, 'activates' patients," who "become engaged, effective members of their health care team." One scale related to this concept was included in this study. The PAM was administered to all study participants and results in a raw score ranging from 0-100 and a corresponding level determined by Insignia researchers to be 1-4, with 4 representing the highest level of activation. Using Stata version 11.0 software, pair wise correlations were conducted and revealed that neither the raw PAM score (-0.1638) nor the corresponding PAM level (-0.2208) significantly correlated to the management of the disease. Results of a Fisher's Exact Test (p=0.763) also indicated no significant relationship between PAM level and having a managed diabetic condition. Attempting to adjust for the small sample size, an exact logistic regression also did not reveal a significant relationship between PAM level and managed condition (Pr >= .5169). Figure 2 below illustrates the results that management does not correlate with PAM level.

Figure 2: Pam Levels sorted by Managed Condition

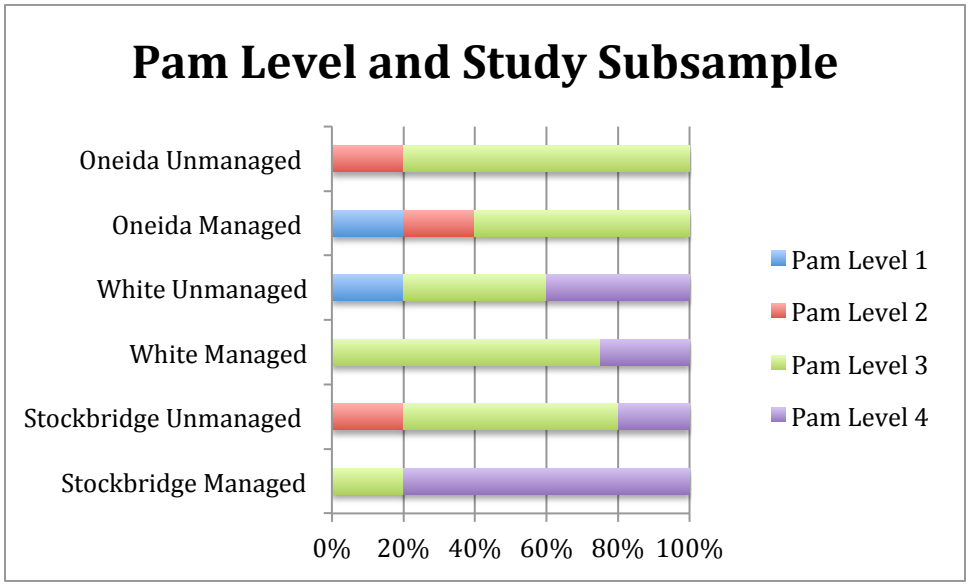


Similarly, Figure 3 illustrates that analysis by study group shows a fairly equal distribution into the highest PAM levels, 3 and 4 regardless of ethnic category or managed condition. T tests to

determine statistically significant differences in managed and unmanaged conditions within each racial group did reveal significance for Stockbridge Munsee (pr = .4845) and Whites (pr = .3631) but not Oneidas (pr = .7893).

The PAM was used in this study to enhance the qualitative information collected in the interview. Although statistically significant results were not detected, the fact that the populations were highly activated may reveal information about the tool or about the natural progression of activation.

Figure 3: Distribution of PAM Level by Subsample



Potential explanatory factors for these results are discussed in detail in the next chapter of this study. However, this researcher believes these issues are related the generally unreliability of this tool and the to small sample size. Insignia, the owner of the tool, changed the definition of Level 3 and 4 during this study. These results reflect the last categorization made by Insignia. In addition, when a power analysis was conducted with this data the estimated power of this model was low (.1842) and the estimated sample size needed to determine the effects at the means and standard deviations found in this study was N=92. Tests were conducted to investigate possible

correlations between the PAM and other scales. Interestingly, there were significant negative correlations detected between PAM level and ACE total ($p=0.0027$) and PAM level and Trauma Symptoms ($p=0.0045$) as measured by the TSC-40, which are discussed in further detail below.

Previous Literature Questionnaire

Participants were asked to complete a questionnaire that included questions designed by this researcher to confirm findings from previous research studies. The purpose of this questionnaire was to determine if there were differences in managed and unmanaged patients. The questionnaire included 11 questions and is presented in the appendices of this dissertation. The first 10 questions were to be answered with a 5-item Likert scale including with the response options: strongly agree, agree, neither agree nor disagree, disagree and strongly disagree. The 11th question and corresponding answers are described below.

Analysis of the first question, "I need support/encouragement from my family and friends to manage my condition" revealed differences among participants based on management of their diabetic condition, as well as differences among racial/ethnic categories. Managed patients were more likely to disagree or strongly disagree with the statement than unmanaged participants. Figure 4 shows a comparison of the answers by diabetes classification, while Figure 5 shows answers by ethnicity.

Figure 4: Previous Literature Questionnaire, Question 1 Sorted by Managed Condition

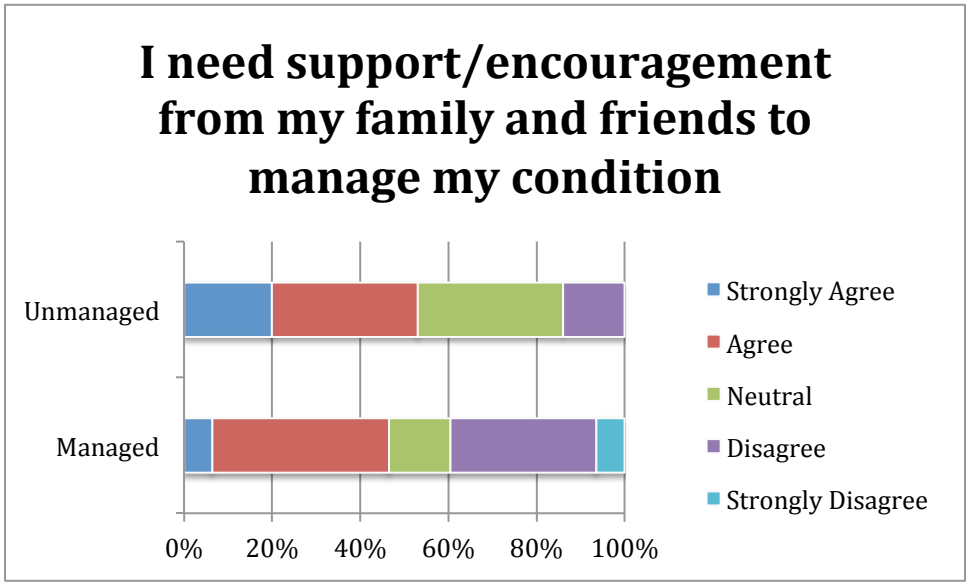
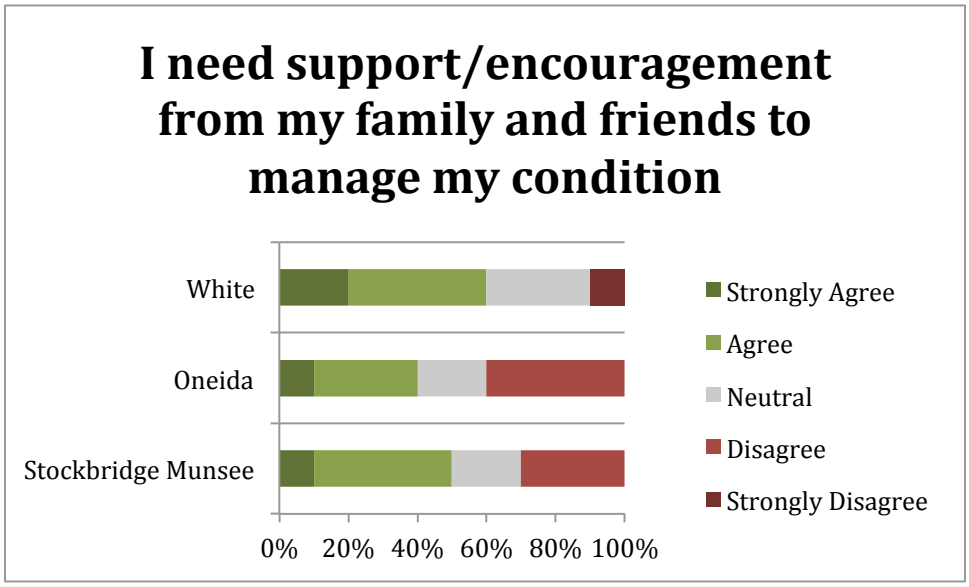


Figure 5: Previous Literature Questionnaire, Question 1 sorted by Ethnic Group

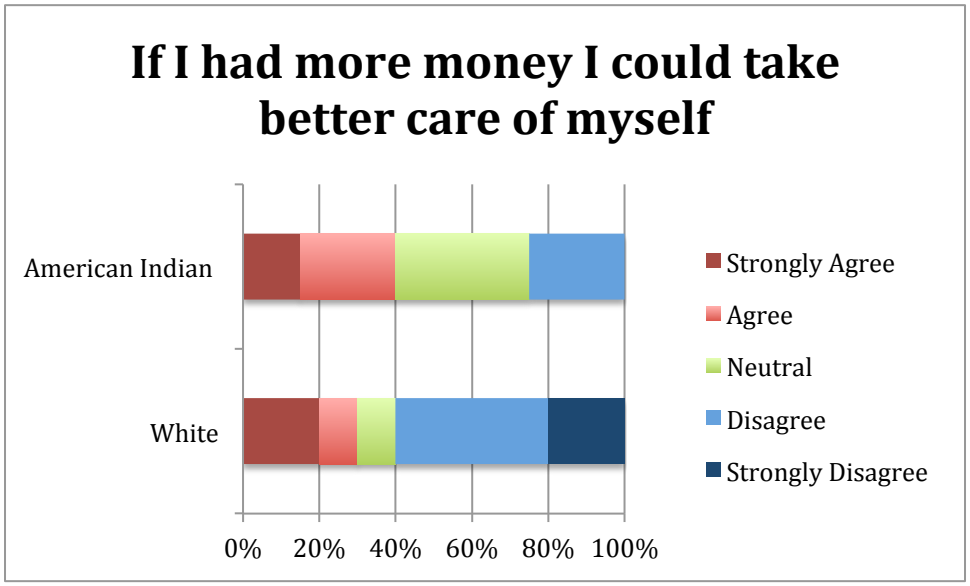


The second question stated, "I worry about what people would say or think if I only ate healthy foods." No response differences were detected among ethnic groups or among the differing classifications of self-management of participants. Similarly, analysis of the responses to third

question, “I wouldn’t be able to spend time with my family or friends if I had to make healthy choices all of the time,” did not detect any differences among participant groups.

Reflecting socio-economic concerns, the fourth question, “If I had more money, I could take better care of myself,” revealed a difference in the participant groups. American Indians, regardless of tribal affiliation, were more likely to agree or remain neutral when answering this question. The researcher did not collect economic status of the study participants, reasoning for this decision is discussed in the *Limitations and Challenges* section in *Chapter 5*. However, this finding could be understood in the context of American Indians having the highest poverty rates among all ethnic minorities in the US (Macartney, Bishaw & Fontenot, 2013).

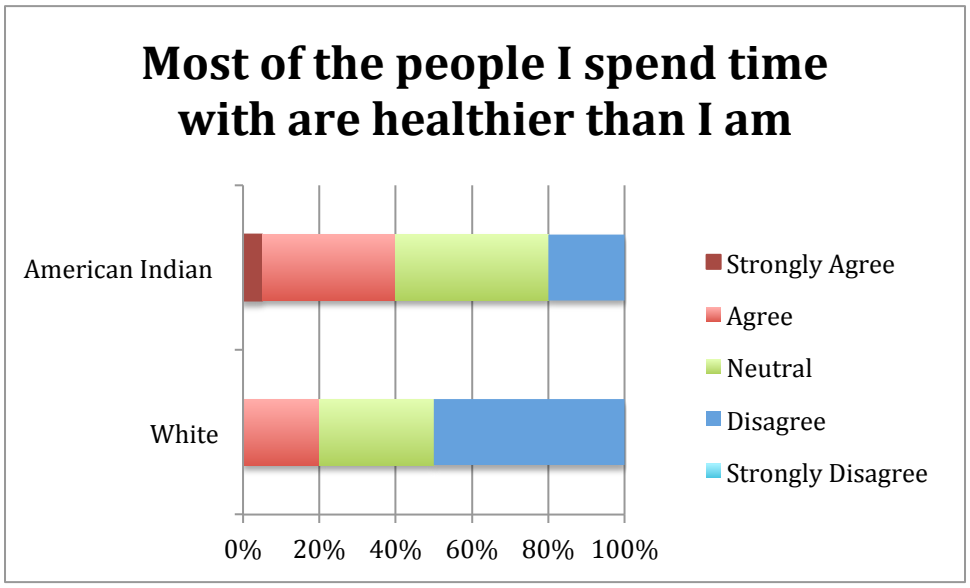
Figure 6: Previous Literature Questionnaire, Question 4 sorted by Ethnic Group



Participants in all group overwhelming responded that the choices they make affect their health and wellness and that they trust their health care provider. Like questions 6 and 7, there was no differences detected in the answers to questions 8 and 9, “I am able to buy fresh food when I need it,” and “I can go to an exercise facility when I need to or what to.”

American Indians as a group were more likely than Whites to be neutral or give an affirmative response to the 10th statement, "Most of the people I spend time with are healthier than I am." These results are discussed in the next chapter.

Figure 7: Previous Literature Questionnaire, Question 4 sorted by Ethnic Group



The last question asked, "Which answer below reflects *your opinion* for who has the most responsibility for your health? Doctor or nurse, Me, Family, Community, Higher Power/God." Of the 30 study participants, 29 choose "Me" as the answer, and one managed American Indian chose "Family."

In summary, the Previous Literature Questionnaire did reveal differences in responses between study groups. American Indians were more likely than Whites to respond neutrally or agree that most of the people they spent time with were healthier than they were. American Indians were also more likely to agree that if that had more money they could take better care of themselves. Managed people were more likely than unmanaged people to disagree that they needed support and encouragement from others to manage their condition.

Community, Culture and Environment

A secondary aim of the study was to develop a deeper understanding of the role community, culture and environment have on the ability to self-manage type 2 diabetes. The second research question, "How do community, culture and environment affect American Indians' and Whites ability to self-manage type 2 diabetes?" led to several specific interview questions regarding these topics. The researcher had two distinct hypotheses; first, that people who successfully manage diabetes have relied on aspects of their culture to support self-management efforts and second, that those who are unsuccessful have not or cannot overcome social roles, behaviors and other circumstances that become barriers in the intensive self-management that diabetes requires.

The results of this research did not clearly fall in-line with the hypothesis, although they were indicative of structural aspects associated with self-management of type 2 diabetes. Discussions regarding community tended to focus on community-sponsored events and access to community resources such as affordable health care and supplies including Indian Health Services and other community health care providers. For tribal members, the use of community resources in the form of commodity foods emerged as a topic in the interview. The topic of "culture" revealed a robust discussion about tribal and community identity among the American Indian participants. This often led to reflection on contemporary versus traditional lifestyles and the effect lifestyles have on diabetes. Contemporary lifestyle factors such as time constraints to prepare healthy meals and eating away from home were discussed among participants in all study groups. The high amount of soda and alcohol consumption was discussed in relation to contemporary lifestyles, as was the unhealthy nature of tribal and regional foods. Holidays and tribal events also presented challenges in sustaining self-management efforts. When asked about

the interaction of the environment with type 2 diabetes, both American Indians and Whites discussed the negative impact of the workplace and the effect of climate on self-management.

Community

The term "community" can have numerous definitions. This study allowed for participants to define the concept of community. When participants pressed for a definition of either, "culture" and "community", the researcher would respond; "It can mean a number of different things. You can answer the question using what community means to you." Most often, community was discussed in regards to the resources it provided to residents, such as community-sponsored events or programs and other community resources, such as commodity foods or food assistance programs. Commodity foods are surplus products (i.e., cheese and peanut butter) purchased by the federal government to support farm prices. The food items are then distributed to local and tribal governments. Access to affordable health care and diabetic supplies was also discussed and is included in this section because it is a structural issue. The tribes included in this study both offer health care clinics funded through Indian Health Services. For Whites, access to affordable health care is also a community-level issue in Wisconsin due to the lack of providers who accept Medicaid and Medicare and the prohibitive cost of diabetic supplies.

Common community-related responses to the question above could be divided into two categories: events and resources. Community-sponsored events or programs, such as diabetes education seminars, were most often mentioned in a positive light, even if they were not well attended by community members or study participants. More specific information is below in the *Events* section. Responses regarding available community resources included the "food

desert" for the Stockbridge Munsee tribe and the unhealthy nature of commodity food from the tribal food assistance programs.

Events

Tribal events often surfaced in the section of the interview that discussed community and diabetes. Most often mentioned were events such as "Just Move It Oneida," which is a community walk and diabetes education seminars during lunch break. These events are discussed in relation to motivation to self-manage diabetes in the first section of this chapter.

Resources

Frequently talked about in the interviews in relation to tribal resources were government subsidies. These subsidies or commodities are food provided to tribal members (this is different than the Supplemental Nutrition Program, which offers vouchers). Participants thought this was hypocritical of the tribe because it offers educational seminars about healthy eating but then distributes unhealthy food such as processed cheese, bread and high-sugar peanut butter. Said one managed Oneida male, "When I was younger, we used to get government food which was probably the worst food you can get. It was canned food, cheese, shredded beef, flour, um, I mean at the time you thought it was the greatest thing, but it would have like 2 inches of grease on top of it." Participants thought the food was reflective of contemporary culture. Many participants, both White and American Indian remarked that having more money would allow them to take better care of themselves. Examples of these responses include a managed Oneida male who said "You would be healthier if you had more money to purchase healthier food." A managed Oneida female tied the two issues of commodities and money together, responding, "they have commodities, some people who earn commodities. They…it is more carb-based foods. You know, and I know that is what the government gives them and you are blessed and

you are thankful for what you get, but it costs money to eat well, you know, more vegetarian type." One managed Oneida male even joked, "I told my tribe, I said, instead of giving us … a ham, they should just hand out that blood testing picker thing."

Both Whites and American Indians discussed the difficulty they experienced in accessing and paying for health care, whether it was local services or Indian Health Services. For one White participant on Medicaid, the difficulty resulted in partial amputation of his foot. Noticing a pain and sore toe, he attempted to get an appointment with a provider who would accept Medicaid (this is a common problem which has received media attention in recent years). The only available appointment was over 3 weeks away. As it drew closer, the condition worsened and he felt forced into an emergency room visit. Previously, he avoided the emergency room because of the anticipated financial charges. By the time he was seen in the emergency room, his toes had turned black, indicating that they were not receiving any blood flow, and were promptly amputated along with a section of his foot. For two other American Indians, one Oneida and one Stockbridge Munsee, missing one appointment (due to employment and childcare schedule changes) meant a 3-month wait for another appointment. Another Oneida participant familiar with tribal administration discussed at length the financial problems the tribe experienced with Indian Health Services (IHS) when the government experienced a "shut down" last summer. The IHS relies on the US Federal government payments to pay salaries of health care workers, but also to pay facility fees, such as utilities for refrigerating medications.

Monetary resources affect self-management as both American Indian and White participants reported hardships in affording medications, diabetes-related supplies and insurance premiums. However, this topic was discussed as a barrier to self-management more often by unmanaged participants than by managed participants. When asked to describe what is was like

to live with diabetes, a Stockbridge Munsee male said, "Big bunch of bills." A White female said, "My A1c right now is not good because I am not taking all of my insulin because my insurance was switched and it is $600.00 a month right now." Both were unmanaged. When asked how her community could wipe out diabetes, a White female responded, "If the drugs didn't cost so much. I think the cost of the drugs that you have to be on are just ridiculous."

The Brown County Aging and Disability Resource Center offers CDSMP (Chronic Disease Self-Management Programs) for the cost of the workbook. For approximately $25-$35 the patient can enroll in six classes held once per week. Despite this low-cost resource, none of the study participants reported attending this class and one even remarked, "No, I am not comfortable with [sharing in] social situations" (unmanaged White female). Nine participants (6 managed and 3 unmanaged) had attended a seminar describing diabetes sponsored by their employer, insurance company or tribe. According to the participants, the seminar was not helpful in facilitating activation. All but 2 participants had meet one-on-one with a diabetic educator or nutritionist. This offered practical information to the participants such as reading food package labels for sugar and fat content, understanding portion control and counting carbohydrates. Of the 28 people who had such meetings, only 3 reported this intervention to be of little use. Some of the participants using Indian Health Services reported using the diabetic educator as part of a plan to sustain or restart self-management behaviors. As one managed Oneida female said, "She keeps me on track." An unmanaged Stockbridge Munsee male also reported meeting regularly with the diabetic educator and said, "Well we discuss what things are going on in my life, what is working, what is not working, and they give me suggestions to make things work."

Culture

Participants were asked in the interview to describe the role culture played in his/her life, living as diabetic. A common definition of "culture" was not offered to the participants, allowing them to interpret the meaning of the term. Regardless of ethnicity, participants commonly responded that culture was associated with a wide range of lifestyle issues that made controlling type 2 diabetes difficult. However, this question did elicit a discussion about tribal identity that this researcher felt important to include in the results. American Indian participants reflected on the difference between traditional versus contemporary lifestyles and the effect on diabetes. Issues with contemporary lifestyles such as time constraints for food preparation in a fast-paced world and the high levels of soda and alcohol consumption make self-management difficult. Participants also felt pressure to reject regional and tribal foods and experienced holidays/cultural celebrations as challenges to maintain healthy eating habits.

Cultural Identity

The issue of cultural identity surfaced in the interview portion of this research. Comparative analysis of responses of American Indians revealed the reluctance of the Stockbridge Munsee participants to admit an association with the tribe. This is a tribe located in a rural area with few resources, when compared to the wealthier and more suburban Oneida Nation. A managed Stockbridge Munsee male pointed in the interview to how his behavior was different from "the Indians". When the researcher pressed if he was tied to the Stockbridge culture, he said "Not really. A lot of tribal members are but, um, I'm not really." This man pointed to a few pictures and objects in his home that were representative of tribal life, but said he would not have displayed them, but was persuaded by his wife. An unmanaged Stockbridge male noted he was raised in the city of Milwaukee, "so I don't really have a lot of native culture,

I guess, although I lived with native people all my life. …. I don't really have any traditions, I don't do any ceremonies or anything like that." Another Stockbridge unmanaged male said, "I don't, uh, associate with the tribe stuff. [*you don't?*] I'm not into it. …. I'm not the 'native boy'." When asked to describe the role culture played in her life, an unmanaged Stockbridge female asked to skip the question by saying "It is a tough question. I'll skip that one." One unmanaged Stockbridge man stated that culture does not play a role in his life, and he expanded on his answer by saying, "Our tribe has…there is debate on what our tribal traditions and cultures are."

Responses were more positive from the Oneida participants. A managed female said,

> I think um, as I get older, I take more pride in being Native American because it is such a small group, so when I hear people talk about Native Americans and my sons are very, um, they are half black and um, so, they say 'we are out [of the conversation]' because all you do is talk about Native American this, Native American that, or did you hear this or (laughing), you know, I keep educating them about it so I want them to take pride in being Native American also.

Another female described her interaction as "moderate," saying she keeps up with the business and politics of the organization. An unmanaged male described the sober drumming circles that he participates in and the physical nature of drumming and dancing providing him the "exercise that we all need." He also attends ceremonies at the long house. An unmanaged male said he is "actually more native than what I am, well I am half Irish, half native and I believe in the native way more than what I do in, I still like my Irish heritage."

The researcher chose to include this discussion on tribal/cultural identity because it relates back to the larger discussion on embodiment, which is presented in more detail in *Chapter 5*.

Contemporary versus Traditional Lifestyles

The discussion on tribal identity often led to a reflective wondering about the effect of contemporary versus traditional lifestyles on type 2 diabetes. When lamenting problems the

current fast-paced lifestyle brings, many American Indian participants provided historical references to hunting and gathering lifestyles of the past, as they wondered aloud if the health of the community would improve by returning to a lifestyle that provided physical work and healthier meals. An Oneida male explained,

> If I could do the things that I see as part of my culture and [*yeah*], it would help a lot positively with the, you know, the gathering or just constantly yeah, being out there and being active, you know, then with the hunting and fishing, you know you are eating better and providing the food, you know, maybe not so much fried [*yeah*], but we eat like a lot of berries, a lot of wild rice and that kind of stuff where if we were to continue to eat like that, just you know my family, I think our sugars would be managed better and we would get under better control of the diabetes.

A Stockbridge Munsee man expressed similar views. When asked how the community could stop or slow the incidence of diabetes, he responded,

> Go back to eating natural foods [*yeah*], like from your home garden, you know? Because like a lot of like McDonald's and stuff is all bad for you, you know, I mean, and you know you've got kids so they like to go there to eat, you know, [*yeah*], but yeah. I mean get back to that healthy way of eating, you know? That would actually help.

When talking about changing lifestyles, an unmanaged Stockbridge Munsee female discussed the mindset of the past,

> Well, the things that we have, the different stories that talk about food and um, you know, I will be talking about wild rice, I will be talking about you would bow hunt and get your food and um, there were times where you didn't have food and all we had, we had to make it last throughout your group, you know, and it was a lot harder before the community itself, Piggly Wiggly [a grocery chain] and everything else around here, you know? [*Right.*] So, I think it is just through sharing all the stories and talking about things [*yeah*] so. And like you said, for instance, the Oneidas have stories, they talk about the three sisters [*right, like the corn*] bean and squash.…In being Menominee we just, we are, you know, we are all about our well-being and our [wild] game. In fact, they had a celebration of sturgeon, a sturgeon feast and I was at that just last Saturday. But the food is more of a medicine, more than it is something that you consume, you know? It helps you overall and that is the mindset they have always had.

This perspective also surfaced among the Oneida participants. As one male stated,

> Culture plays a role where they would like to go back to their old ways of healthy eating [*yeah*] um…will they ever get back to, we call it restorative eating, re-colonization, you know, corn, beets, squash, meat, venison, whatever, low fat meats and stuff like that. Actually I call it the

> cave man diet, meat, nuts and vegetables and some of that. Um, and berries and um, that is what they had back then.

Contemporary circumstances of the obesity and diabetes epidemics in the American Indian communities were discussed frequently as well. As one managed Stockbridge Munsee male said,

> Well, unfortunately, I think in this culture, diabetes is becoming a norm. [*Yeah*.] And so, it used to be when I grew up the only person I knew that had diabetes was my grandma. And now I would have to say that I know too many people with diabetes so to me, it is almost, I think it hurts because it is not this, "oh my God, you have diabetes?" [*Ok*.] You know, where when my grandma was diagnosed, she was very upset when she got diagnosed with diabetes, and I mean, it was just, it was hard for her.

Trying to describe why the Stockbridge Munsee have a difficult time controlling diabetes, another managed Stockbridge Munsee man said, "Lose some weight and you can hold it down pretty good (*ok*) but as far as…but most Indians are huge anyways, you know?" Later in the interview he tried to explain, "An Indian lives their whole life to eat, you know? Me? I don't do that. I eat just enough to survive."

As American Indian participants talked about the past, there was an attitude of apathy and fatalism. One managed Oneida male described the situation when he said, "I think it has become the norm [diabetes diagnosis] and people are desensitized to it and I think that is unfortunate because in some cases they maybe accept it as part of the sentence of being Native American." This issue is related to the discussion earlier that many people in the study, whether or not they were a member of an American Indian tribe, felt type 2 diabetes was genetic.

While a few Whites made references to the busy lifestyles of today, having multiple adults in the workforce, the influence of fast food, alcohol and soda, there was no wishing of a return to the past. The only White participant who mentioned healthier eating in the past was an employee at the Stockbridge Munsee tribal offices. Even with this knowledge, her words did not indicate a longing for a different lifestyle.

These findings are interesting in a rural/suburban culture and could be understood in the context of the current socio-political environment for American Indians.

Time Constraints

The current faster-paced lifestyle and having more family members engaged in the workforce placed constraints on time available to menu plan, grocery shop and prepare healthy meals. An unmanaged White female explains, "Back when I was a kid, I don't think it is was as bad as it was now because you didn't have two working parents. You didn't have the lifestyle that you have." When asked how the community could live better with diabetes, or how the community could get rid of the disease, one managed Oneida female said "Parenting. Do you see all the Oneida kids who are overweight? Parents control the food. Parents are not home to make meals or are too tired so they don't make the best meals. … People are tired at the end of the day." An unmanaged White female also said,

> I think our culture of, that I come from a full-time working people and you know, our life is just so fast paced that you know I don't always have time to plan so the planning part is not good so we tend to probably go out to eat more than we should or grab things along the way that we probably shouldn't. Um, so I think that is a big negative in the whole community thing.

As exemplified in this example, time constraints often led to eating at restaurants, or picking up food from restaurants.

A White male described the last time he was hospitalized for a cardiac event. After work his wife and children rushed to the hospital but, missing dinner, stopped at a McDonald's and brought the food to the hospital. The participant reported knowing he was disobeying the nurses by eating anything at all, but continued to eat cheeseburgers and French fries with his family sitting on his hospital bed. As Stockbridge Munsee man already cited said, "I should order a salad. Cheeseburger is better."

Managed participants seemed to carefully choose restaurants, whereas unmanaged participants described having difficulty in making healthy food choices when eating away from home. There is one known study on the impact of restaurant food on type 2 diabetes. The study was conducted by Krishnan and colleagues (2010) with African American women and found eating burgers, fried chicken and fried fish in restaurants (as opposed to these same meals prepared at home) indicated a risk for type 2 diabetes. Eating pizza or Mexican food in a restaurant did not indicate the same risk (Krishnan et al., 2010). This would be consistent with this study's finding that unmanaged participants have a harder time making healthier choices when eating away from home. The impact of regional and tribal foods is discussed in the greater detail in the section on *Culture* below.

Alcohol and Soda Consumption

Alcohol consumption is an accepted aspect of the Northeast Wisconsin culture. Martin Lewis (2010) tracked alcohol consumption trends by state using aggregate data from a variety of sources, including the National Institute of Health. He cited Wisconsin residents as among the highest consumers of alcohol in the nation (Lewis, 2010). Participants in every subgroup discussed alcohol use and its effect on the diabetic self-management. Some reported reducing their alcohol intake and others stopped drinking entirely. A managed White male described how he lowered his alcohol intake because "it's easier to do without it than deal with the grief that you have with it." A managed Oneida male joked, "I never was a big drinker anyway. I don't like beer, now I know why." Proudly an unmanaged Oneida man said,

> When I went to the specialist, they put me on the diabetic [*ok*] plan and at that point I was still drinking and I know there is a high amount of sugar in alcohol and sometimes I would go to my appointment after having, you know, a night of drinking and my diabetes numbers would be way out of control and through my life, I had made different changes and then decided, this was back in about 1997 [*ok*], I quit drinking.

An unmanaged White female talked about the community in which she lives. She said,

> The other thing about community is that we live in Wisconsin. The people in Wisconsin like to go to sporting events and they like to drink. This kind of puts a whole damper on that subject. And I was never really a huge drinker anyway but it just, you know, even socially you just can't do it. It just…it plays big havoc with your numbers.

Likewise, soda was mentioned in 9 of the 30 interviews. It was most often a topic among managed participants as was representative of each managed subgroup. Six managed participants discussed their change from regular to diet soda or abstaining from soda altogether. The 3 unmanaged participants discussed their addiction to regular soda and reported reducing amounts consumed, but not abstaining. After one unmanaged White female described herself as a "pepsi-aholic" the researcher asked if she felt the need to cut back or abstain from the sugary soda. The woman responded, "You know I can't stay on a diet so I never do that [quit drinking Pepsi altogether]. I drink more water." While the topic of alcohol use does not appear often in diabetes-related research, "pop" (soda-pop) was discussed as one cause for the high incidence of type 2 diabetes among low-income, urban American Indians in the Midwest (Lautenschlager & Smith, 2006).

Regional and Tribal Foods

In addition to this, many discussed the regional and tribal foods that health care providers consider to be among the forbidden foods. Trying to avoid fried cheese curds, bratwurst (a fatty German pork sausage) and traditional Indian foods like fry bread and Indian tacos were among the responses to the interview question, "Can you describe the role culture plays in your life, living now as a diabetic? Is that the same or different than the role culture played in your life before you were diagnosed?" As a Stockbridge Munsee male stated "Well, people cook fry bread around here a lot and that has a lot of sugar (laughs) so yeah, it does, you know, I mean, it

is a lot of our bread. You know what we eat? We eat a lot of fried food [*yeah*], you know so that is a major part of, you know."

Responses similar to the one above were common across study cohorts. Soda, fried meats and cheeses are a large part of the diets of many people in Wisconsin, contributing to the state's obesity epidemic. Nearly one-third of all adults in Wisconsin are obese (State of Obesity, n.d.). As an example, a regional delicacy is fried cheese curds. Cheese curds are formed during the cheese making process when a solid pulls away from the liquid used to make cheddar cheese. These curds are then pulled away and further processed and pasteurized. They can be eaten fresh, but are often fried to serve in restaurants and at festivals, such as the state fair. Cheese making is a large part of the dairy industry that fuels the Wisconsin economy. Bratwursts are a German sausage, a surviving custom from an area of Northeast Wisconsin settled by German farmers. Talking about her participation in a diabetic education class, a managed White female said, "I learned I can't eat brats. (laughs) Very sad. They actually carried around like a bag of fat to show you how much was in a brat and it was like … nope, not eating that anymore!" The ability to eat traditional foods was considered a quality of life issue among the Chinese population (Nam et al. 2011) and among Blacks (Majeed-Ariss et al., 2013).

As is custom in this area of Wisconsin, Friday nights are reserved for a "Fish Fry," which typically means eating outside the home. (This tradition stems from the large number of Catholics settling in the area. During a period of the religious calendar, called "Lent," Catholics are prohibited from consuming meat on Fridays. This has extended to a Friday night Fish Fry tradition at local restaurants that is now popular throughout the year.) Managed participants discussed carefully choosing their restaurants or food when dining out. As the participant explained, "As long as I eat at home [I'm in control]. We go out just about every Friday night.

We pick certain restaurants because we know the restaurants and we know they use low fat and the food isn't greasy so it has less of an effect." According to one White female, "I'm going to say there is not a lot of support for low-sugar options in culture. [*ok*] Low carb…it is hard to find when you are out and about. [*ok*] Unless you just carry it with you. …. Eating out is hard." A White male described how he avoided restaurants as much as possible. Unmanaged participants had a difficult time making these choices when dining out. One Stockbridge Munsee female lamented,

> I love that they [have] the menus now where it is always the calorie count and that. I wish they would do more carb count though. This is 2 carbs, you know, if you ordered a McDonald's salad, chicken wrap, it is 4 carbs [*right*]. It would make it so much easier for us on the fly because fast food unfortunately is part of our lives.

There was more information on eating away from home in the section *Time Constraints* above.

Tribal Events and Holidays

Difficulty in self-managing was reported by all groups when discussing traditions such as holidays, tribal celebrations and other cultural events such as pow-wows. An unmanaged Oneida male said, "There is not too much healthy food at the pow-wow." Other responses indicated that these types of events typically center on food and alcohol. A managed White female stated, "When we got together, it was all food or alcohol, you know?" and a managed Stockbridge Munsee male said, "Oh yeah. Thanksgiving. Christmas meals, you know? Those are tough ones. We have a real big family so we always have a real big meal." A managed White female explained the situation well when she said,

> Everything is food based. Every celebration has got food that is not good for you and desserts especially. You know, that is one thing. We used to eat dessert at every supper. I can't do that. You just have to stay away from the sugar. I mean, it goes straight into your blood stream so yeah, it is the food, you know, I can't think of anything that we did as a family as a child that didn't relate to food. You know, we didn't have tennis matches or [*right*], you know? (Laughs.)

An unmanaged White female said, "It's huge around here. I mean, what do you do? You go to parties, you know you get invited to parties around the holidays and in the summer, BBQ's, all it is, is food and drink, you know? It's crazy how it is a huge thing, you know, in our society. People put a big emphasis on it." For the unmanaged participants, these holidays and workplace food days often represented the start of a downward spiral of not eating healthy, which was then followed by several days of blood sugar spikes and blood sugar lows.

Social Support

As noted in the first section of this chapter in Factors Facilitating Activation, there were significant differences in the responses of White participants when asked, "Who helps you manage your condition?" While 6 of the 8 White participants[4] responded they managed by themselves, only 3 of 10 Stockbridge and 3 of 10 Oneidas said the same. American Indians relied much more heavily on friends and family to help them manage. The following response was typical of the responses from White participants, "No one [helps me manage]. Myself. I make all the meals." More typical of the American Indian participants were the following two responses. In the words of a managed Stockbridge female:

> My mom [helps me manage the most], you know, she, which I have helped her too. …. We go grocery shopping together and get the foods, the better foods and if she does cook us dinner, we go by her, you know, she will make the healthier stuff, even if I am the only one who eats it.

And according to a managed Oneida male, "Well, my partner obviously helps me manage. He does most of the food shopping," were more typical of the American Indian participants.

Similarly, all of the respondents could identify people in their lives, mainly relatives or spouses who also have also been diagnosed with type 2 diabetes. Many had relatives that had

[4] Two of the White participants were not specifically asked this question due to direction of the interview.

experienced a diabetes-related amputation, and one White male had an amputation himself. Very few White participants offered to help family members or friends or received help from these people. An unmanaged White female admitted she "very rarely" offers to help her diabetic sisters manage the disease. She said, "I try not to…if they ask me questions or something like that, I answer them but I try not to preach because I'm not any better than they are about compliance." Another unmanaged White female was told by family members to "get off your soap box" when she tries to help. She says of diabetes in her family, "it's a touchy subject."

Although American Indians accepted help from others in managing their own condition, like Whites, very few of them offered to help others. "We don't really talk about" diabetes as a family and "we just don't discuss it" were responses from a managed Stockbridge Munsee female. An unmanaged Oneida male admits, "A lot of it has to do with the alcohol and drugs [*yeah*], and I kind of just back away from that stuff and I just see what is going on. I really don't try to fix anybody [*yep*]. I just know what I should be doing."

Summary

In summary, interview questions asked explicitly about the connection between diabetes and culture. Participants talked about tribal identity, and difficulties faced by Stockbridge Munsee population may have led to a negative perception of tribal affiliation. Oneida participants seemed to present their tribal affiliations in a positive light and even members who described themselves as "moderately" affiliated with the Oneida tribe followed tribal politics and business. Contemporary lifestyles presented challenges to diabetic patients with faster-paced lifestyles not allowing time to prepare healthy meals at home. High amount of alcohol and soda consumption in the region were noted and all participants felt pressure to reject the unhealthy regional and tribal foods. Cultural holidays and tribal events also presented a challenge for the

participants because of the amount and nature of foods, as well as the alcohol consumption that often accompanies these celebrations.

Environment

With reference to their physical environment in relation to their condition, participants were asked, "When thinking about where you live and work, in what ways does your physical environment impact your condition? Your neighborhood? Your home?" Those reporting on the perceived safety of their neighborhood for exercise typically did not exercise outdoors due to the climate. The most common response was related to the workplace. Participants frequently discussed issues such as the structure of the workday, the type of job, workplace policies regarding food, exercise and employer-sponsored health insurance. The second most common response was in regards to climate and neighborhood safety.

Workplace

Although the workplace could provide support, routine and structure to assist in self-management, it was more frequently noted by participants that food days, often referred to as "pig-out days" often derailed their self-management plans. Many of the American Indian participants find employment in tribal casinos. This environment is often a smoky one, where employees receive food at no charge. This is typically unhealthier fare, such as fried chicken, that the casino restaurants are trying to discard. The type of job a participant held reportedly affected health. A managed Oneida female described her work history and related health,

> These sedentary jobs kind of destroyed my health. But I went from…I used to be a manager at Wal-Mart and I developed metabolic syndrome [diabetes] because I would only eat once a day [*yeah*] and realized the damage that it did over time so now I am struggling with that um, plus this position [administrator for the tribe] where I sit all day long so, diminishing, but I am a work in progress.

An unmanaged Oneida male described the effect factory work had on his diabetic condition,

> I was a factory worker and I was constantly moving all night and it was kind of hard to watch the sugars throughout that. [*yeah*] So I would be, like the energy drinks because it was 3rd shift so that would shoot my sugars up. [*yeah*] And other nights it would be really low and it would just change so much, it was…it was everything that they said diabetes would be. (Laughs)**….** Yeah, I would get home and check my sugars and they would be past the 200's mark but then the next day, I would kind of look at that. And then the next day when I was at work, I would try to not have so much sugar and then I would be getting a low half way through the night [*yeah*] so yeah, that did have a big impact on it.

Both Oneida and Stockbridge Munsee participants made inter-tribal comparisons of workplace policies with each other and with a neighboring tribe – the Menominee Nation. One Menominee policy of particular interest to the participants was allowing employees to receive a half an hour for a lunch break; however if employees were using their lunch break to exercise, they would be granted a full hour, without having to make up the lost work time in their day. This was explained as a positive policy, but when asked if the study participant would use the time, both interviewees who mentioned the policy said they would not use the time because the activities they would engage in would require they showered before returning to work. They felt this was either unpleasant or an hour would not offer them enough time to do the exercise they wanted. One Oneida woman employed by the tribe had to obtain a written note from her provider stating she should be allowed to store food at or near her desk. Snacking helps diabetics maintain steady blood sugar. Studies that do include workplace issues tend to focus on support from colleagues (Vest et al., 2013), rather than on the structural issues created by the workplace policies and the physical requirements of jobs.

Climate

Another reported factor that facilitated activation of self-management was the climate. Northeast Wisconsin has four distinct seasons, winter, spring, summer and fall. Winters account for the longest season lasting almost 6 months of the year, from November into late March or early April. In a typical year, planting crops and home vegetable gardens begins in late May,

when average temperatures climb to 66 degrees and the chance of frost substantially declines (Current Results, n.d.). Farmers' markets, where fresh, locally grown produce can be purchased, begin in July (average temperature 80 degrees) and run through the fall season into October when average temperatures drop back down to 57 degrees (Current Results, n.d.). In addition to having access to relatively inexpensive (as compared to purchasing food in a grocery store) and healthy food, participants reported that the climate makes it more enjoyable and less of a hassle to exercise (outdoors) and grill meat as opposed to frying food indoors in butter or oil, adding fat and calories. (Diabetics are at higher risk for cardiovascular disease and diabetic educators therefore teach lowering overall fat content.) As a managed Stockbridge Munsee female reported, "it is easier to be healthier in the summer," and she went on to explain,

> Well, especially for the exercising, I like to go for jogs and walks. I walk our dog and you know, I can go home from work and go for a walk, where if it is snowing out, I am kind of limited to what I can do for working out. And in the summer, it's…you know you eat, you can eat cooler stuff like a salad and, or a sandwich or something where in the winter you are cold so you really don't want anything cold.

According to an unmanaged White female, "Midsummer, yeah, I'm really on top of it." She said she is "very active and then the fresh vegetables and I love grilling. I am a gardener, so I just have to find a niche for the winter time because it just, ugh, I don't want to leave the house when it is cold, I don't want to go anywhere." A managed Oneida man made similar statements, "I do a lot of grilling when I can, when it is not 40 below with the wind chill factor or winter vortex does not allow me to grill. I am fat because I live in Green Bay, Wisconsin." An unmanaged White male said he is "less active" in the winter. "Living in Wisconsin, there is just, you know, you are not going to go out and walk, you are not going to go jump in your pool, you are not going to do that kind of stuff" he said. A Stockbridge Munsee female who monitors her weight said, "The last time I did a weight check, I put on 5 pounds, but I am waiting for it to get nicer again so I can get back outside and walk again."

An interesting and related aspect of climate and the workplace was the impact of farming on the lifestyle of local diabetics. Farmers who participated in the research, regardless of the state of their condition or ethnic group, reported they needed more calories to make it through a physical 16-hour workday. As one unmanaged White male who farmed stated, "[I need to eat] like more in the summer time when we are working 16 hours a day versus in the winter time, you can get by on less." Several managed farmers reported the positive health effects of altering the diet of their own livestock to produce leaner meats and baking their own bread to lower the sugar content. Unmanaged participants who farmed for a living reported grabbing readily available, pre-packaged or processed food in order to maintain a quick pace to keep up with their workload. These participants were less likely to walk as part of their day and reported relying on small vehicles to move from one place to another, whereas diabetic farmers who successfully managed their condition used the physical nature of farm work to count for exercise.

Childhood and Historical Trauma

The third research question addressed in this study was, "Does trauma (including childhood and historical trauma) influence activation of diabetic self-management?" The researcher hypothesized that unmanaged patients have higher incidence of adverse childhood events or experience greater symptoms of historical trauma than managed patients. Issues of trauma did surface in the interview stage, but information was mainly gathered in scales and tools collected at the interview's conclusion.

Childhood Trauma & Trauma Symptoms

While trauma and other adverse childhood events were not specifically a part of the interview stage of this study, two American Indian participants offered specific information

about adverse events occurring in childhood. Three briefly mentioned the lack of food and childhood poverty in the course of the interview.

One of the five who discussed this subject, a managed Stockbridge Munsee male detailed the poverty that he experienced growing up on the reservation. His mother was a cook at a logging camp and his father a logger. His father was killed in a logging accident at the young age of 41. He and his siblings often only had to eat what they themselves hunted and killed. This included deer, rabbit and even squirrels in times when deer and rabbit could not be caught. Shortly after sharing this, the participant remarked, "Sometimes I just want a sweet roll with my coffee, you know? Now I have food, really good food, and I can't even eat it."

When completing the Adverse Childhood Events scale (see description and aggregate results below), an unmanaged Oneida female talked about her experience being taken away from her mother at the age of six. She was brought to a boarding school operated by a religious order. She repeatedly asked why she was being taken away and did not receive an answer from the adult who transported her from her home to the boarding school. Upon arrival, her head was shaved and alcohol was poured over her head and it ran over her entire body. Cold, crying and asking for her mother, she was told by a nun (the participant presumed the woman to be a nun and described the habit or clothing the woman was wearing in detail) that her mother was a stupid Indian who never really wanted her and could not properly care for her. Crying and visibly shaken, when she was done telling the researcher this story, the participant said,

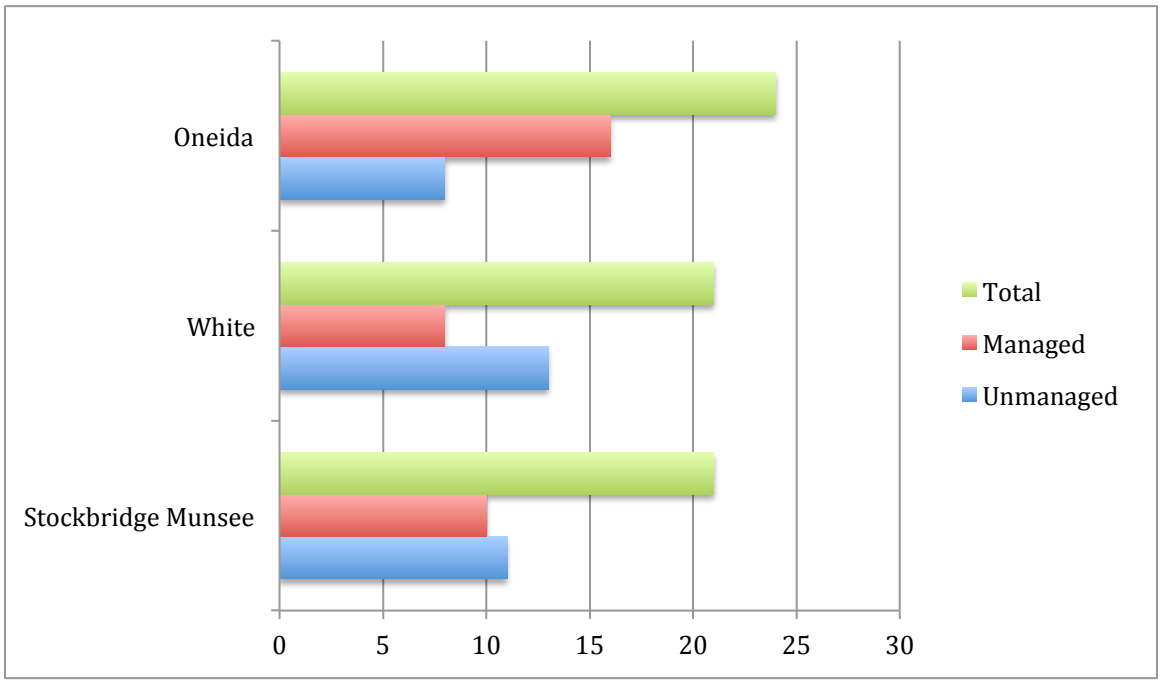
> Still to this day, my body, look at me. I can't even drive by this place. It's in [name of place], up there you know? I want you to know this. I will write the truth on here. These things happened to me [pointing to the Adverse Childhood Events survey] but *it was* ***not my family*** that did them. My family would never do that.

Upon completion of the interview, participants were asked to complete a questionnaire and several scales. For the purpose of this study, the researcher was interested in the scale's

association with either managed or unmanaged conditions. However, a chi-squared test examining the relationship between ACEs and having a managed condition was not significant ($p=0.097$).

Results of the ACE scale in this study indicated a high level of ACEs among study participants, with 26 of 30 participants reporting at least 1 adverse event occurring in childhood. Only 4 participants (1 Stockbridge, 1 Oneida and 2 Whites) reported no ACEs, or 0 events. Of these, 3 were considered to have their diabetic condition managed. Of the 26 participants reporting an ACE, 20 reported more than 1 and 8 participants (3 Stockbridge, 3 Oneida, 2 Whites) reported 4 or more adverse childhood events. Only 2 of the 8 reporting 4 or more events were unmanaged; the other 6 were managed. In the end, 66 adverse events were recorded for 26 people with 32 belonging to unmanaged participants and 34 to managed participants. The events were divided almost equally among race groups, with 21 for Whites, 21 for Stockbridge Munsee and 24 for Oneidas. When compared to general populations, the number of people in this study experiencing 1 ACE was high (87%, as compared to 61.7%) (Stevens, 2014). The number experiencing four or more in this study (26.6%) was also higher than the general population (16.7%) (Stevens, 2014). A possible explanation for these differences is that the study population included exclusively people who are exhibiting unhealthy behavior in adulthood.

Figure 8: Total ACEs Reported by Ethnic Group



The most common ACE reported was "Did you live with anyone who was a problem drinker or alcoholic or who used street drugs?" with 12 out of 30 answering "yes." However, a further breakdown of this ACE reveals an equal number of managed and unmanaged participants in this category. Analysis by racial minority revealed twice as many Oneidas (6) answering "yes" as Whites (3) or Stockbridge Munsee (3).

The second most common ACE reported was parents separated or divorced, which was endorsed by one third of respondents. Once again, the affirmative respondents equally represented managed and unmanaged patients, although 8 out of the 10 were American Indian, when 6 or 7 out of 10 (that is, two-thirds) would have been more reflective of the population included in this study. American Indians were disproportionately represented among affirmative responses.

The question, "Did a parent or other adult in the household **often** or **very often** … push, grab, slap, or throw something at you? **Or Ever** hit you so hard that you had marks or were injured?" elicited the third greatest amount of affirmative responses and did reflect the

hypothesis that a greater amount of affirmative responses came from unmanaged participants. However, the opposite was true for the question, "Did you **often or very often** feel that … No one in your family loved you or thought you were important or special? **Or** Your family didn't look out for each other, feel close to each other, or support each other?" where double the amount of affirmative responses came from managed participants, although this question only elicited 6 affirmative responses.

One ACE question asked about sexual trauma and abuse. Four respondents answered affirmatively they had experienced sexual trauma in childhood. Of these participants, 3 were managed and 1 was unmanaged. Of the 3 managed participants, 2 indicated on the TSC-40 (described below) that they continued to experience symptoms related to sexual abuse. The only unmanaged participate indicating the occurrence childhood sexual abuse did not currently experience symptoms from this trauma according to the TSC-40.

People have different ways to manage trauma. John Briere's Trauma Symptom Checklist 40 (TSC-40) was implemented as a part of this study in order to assess symptoms of past traumatic events (Briere, 1996). As noted, this is a 40-question scale designed to capture symptoms related to traumatic events. This is a research tool, not a clinical tool. As such, it allows researchers to assess symptomatology in adults related to traumatic events occurring at any point prior to administration. The tool has an overall score of 1-40. Six subscales are included and represent dissociation, anxiety, depression, and sexual abuse trauma index, sleep disturbance and sexual problems. Cronbach's alpha calculated for the TSC-40 showed that results for the total, as well as each sub-scale are in statistically acceptable range. See Table 7 below for exact results.

Table 7: Cronbach's Alpha for TSC-40, Total and Subscales

```
. alpha tsctotal tscdis tscanx tscsati tscsleep tscsex tscdepress, item label detail

Test scale = mean(unstandardized items)

                          item-test  item-rest  interitem
Item          |  Obs  Sign   corr.      corr.       cov.      alpha   Label
--------------+-------------------------------------------------------------------------
tsctotal      |   30    +   0.9916     0.9712    1.111341   0.8492   TSC TOTAL
tscdis        |   30    +   0.8142     0.7636    2.785211   0.7765   Dissociation
tscanx        |   30    +   0.7545     0.6989    2.944751   0.7884   Anxiety
tscsati       |   30    +   0.7762     0.7308    2.990268   0.7901   Sexual Abuse Trauma Index
tscsleep      |   30    +   0.8175     0.7695    2.805134   0.7775   Sleep Distrubance
tscsex        |   30    +   0.5153     0.4216    3.222146   0.8131   Sexual Problems
tscdepress    |   30    +   0.8256     0.7748    2.730038   0.7727   Depression
--------------+-------------------------------------------------------------------------
Test scale    |                                 2.655556   0.8148   mean(unstandardized items)
```

Testing for a pair wise correlation between the total of Adverse Childhood Events and the total on the TSC-40 revealed a significant correlation at p=0.0288. However, a chi squared test examining the total score for the TSC-40 and having a managed condition was not significant. This test result and the results of the sub-scales tests with managed condition are presented in Table 8 below.

Table 8: Chi-Squared Tests for Managed Condition and TSC-40 Total and Subscales

Chi-2 Managed Condition and TSC-40 Subscales	Chi-2(5)	P value
TSC – Total Score	11.333	0.729
TSC – Depression	3.833	0.699
TSC – Sexual Abuse Trauma Index	2.182	0.823
TSC – Dissociation	.311	0.989
TSC – Anxiety	4.743	0.448
TSC – Sleep Disturbances	4.076	0.538
TSC – Sexual Problems	6.386	0.270

As discussed earlier in this first section of this chapter, a pair wise correlation between the TSC-40 total score and PAM level was negative and significant (p=.0455).

Although high levels of adverse childhood events were experienced by participants in this study population, the ACE score did not significantly correlate with managed condition or patient activation as measured by the PAM. ACE scores did significantly correlate with trauma symptoms as measured by TSC-40, and the TSC-40 was also significantly negatively correlated to the PAM. Further explanations of these results are in discussed in the next chapter. The scales were intended to augment the information collected in the interview stage and small sample and subsample sizes can potentially interfere with detection of statistically significance results.

Historical Trauma

While the Adverse Childhood Events scale was useful for the study population as a whole, an additional tool was needed to capture trauma that occurred in past generations but manifests itself in the daily life of families and communities. Historical trauma a concept made known by Maria Yellow Horse Brave Heart, is defined as is a "collective complex trauma inflicted on a group of people who share a specific group identity or affiliation – ethnicity, nationality, and religious affiliation" (Evans-Campbell, 2008, p. 320). This trauma includes generations of state-sponsored oppression led by the US government. Trauma and grief experienced in this community result from loss of land, loss of language and culture through the forceful removal of younger generations who were placed in boarding schools, and the loss of traditional spiritual practices.

The American Indian participants were asked to complete The Historical Grief and Loss tool developed Les Whitbeck (2004). This tool is described in Chapter 2. The scale quantifies the amount of grief and loss experienced by a person. The averages of the measures of grief and loss and of symptoms associated with grief and loss for both American Indian groups

participating in this study are listed in Table 9 below. Lower numbers represent less grief and lower amounts of symptoms. These numbers represent answers such as "seldom" and "yearly, or only on special occasions" when attempting to measure the frequency of memories or symptoms.

Table 9: Mean Historical Grief-Loss and Historical Grief-Associated Symptoms

	Historical Grief &Losses – Group Average	Associated Symptoms – Group Average
Stockbridge Munsee	1.895	1.824
Oneida Nation	2.150	1.429

A t-test to determine if the responses from the two American Indian groups were significantly different from one another was not significant for the historical grief and losses scale (p=0.2976) but was significant for associated symptoms (p=0.0445). The Stockbridge Munsee group experienced more symptoms even though the Oneidas had more grief and loss. However, using all American Indian responses in one category and testing with managed condition was not significant for either Grief and Loss (p=0.9996) or Symptoms (p=0.9970). This result could be due to the small, non-random sample. These results are important for this study and are discussed in detail in the next chapter.

Chapter 5: Discussion, Practice and Policy Solutions

Much of recent published literature focuses on the barriers to self-management. This study was designed to examine the factors facilitating activation of self-management in type 2 diabetics and hypothesized that factors facilitating activation in well-managed patients are absent or less present in unmanaged patients. In order to better understand the concept of activation, the study included both patients who were well managed and those who were unmanaged.

This chapter includes a summary and analysis of the results presented in Chapter 4. Presented first is the summary of findings in regards to the first research question, "What factors facilitate activation of self-management in type 2 diabetics?" These results are followed by the summary of findings from the other two research questions regarding the effects of culture, community and environment on self-management and the association of childhood and historical trauma on self-management. Implications for health policy as well as health care practice and policy are discussed before the limitations and study challenges are presented. The chapter concludes with suggestions for future research.

Factors Facilitating Self-Management

Responses relevant to the first research question, "What factors facilitate activation of self-management in type 2 diabetics?" provided support for the hypothesis: factors in managed patients were absent or less present in unmanaged patients. This was most notable when participants discussed the daily routines needed to achieve optimal health. In regards to this

factor, responses of managed patients differed from unmanaged patients when discussing the ability to routinely adhere to medication schedules and the discipline to live a healthy lifestyle. Both groups discussed the importance of a routine in successful self-management. However, when daily routines changed, the managed participants were able to make the necessary adjustments.

The nature of the motivation to self-manage type 2 diabetes was the same for both managed and unmanaged participants. The majority of participants were motivated to self-manage by the fear of their condition worsening. These participants were concerned with their condition deteriorating to the point of having to depend on others for daily needs and care. Although all cohorts discussed having to manage other health conditions such as cardiovascular disease, depression and cancer, unmanaged participants seem to prioritize these health conditions above the diabetes. This finding that health status of the patients is a factor in self-management is consistent with other studies (Dattalo et al, 2005; Booth et al, 2005; Jerant, et al., 2005; Bayliss et al., 2007). However, managed participants were also dealing with other health issues. These participants discussed their health in a more holistic manner, meaning they seemed to view achieving optimal health as addressing all of their conditions concurrently, rather than prioritizing one of them.

The question of what motivated people to manage diabetes led to an interesting finding. In addition to the fear of their condition worsening, respondents indicated that relationships and important people in their lives also motivated them to self-manage. This was true across all study cohorts. However, when asked "Who helps you manage your diabetes?" the majority of White participants answered that they managed by themselves, whereas the majority of

American Indians in both groups studied listed family members who played a significant role in their management of type 2 diabetes.

Participants in this study reported family members often complained about changing to a healthier diet with lower amounts of carbohydrates and sugars. It was typical for an unmanaged participant to continue offering carbohydrates and foods higher in fat content to others when preparing meals for his or her family. The unmanaged participants then needed to stop themselves from eating these foods during the meal. Managed participants were able to establish a new routine and insisted upon making healthier changes in their lives and the lives of others around them. This finding was also supported in the data gathered from the questionnaire testing information from previous literature. Managed participants were more likely to disagree or disagree strongly with the statement, "I need support/encouragement from my family and friends to manage my condition." This concept could be furthered explored in the context of self-esteem, self-efficacy and social roles.

When looking at the necessary lifestyle modifications for successful self-management, which often include weight loss and weight management, there were three unmanaged participants who referred to their self-image as being a "bigger person." This is also an interesting concept to consider for future studies and is discussed below in the section on *Culture, Community and Environment*.

Managed participants had a difficult time answering the question, "Describe a day when you can't manage, or don't manage well", although this group did discuss forgiving him or herself on occasion for a sweet treat or not engaging in exercise. The unmanaged participants did not mention forgiveness, but did discuss their rationalization when deviating from desired behavior. Statements from unmanaged participants were similar to "it's only a couple days of

missed medication or exercise" but then admitted they experienced difficulty in returning to healthy behaviors. Many participants also discussed difficulty in managing their emotions such as anger and depression was associated with fluctuating blood glucose levels.

In addition to rationalization of unhealthy behaviors and the difficulty in managing emotions that accompany low and high blood sugar levels, unmanaged patients often cited the undesirable side effects of medications and/or referenced changes in medications by providers as a reason why they did not adhere to a medication regimen. Thus, medication side effects and difficulty in accessing providers both in Indian Health Services and in other community resources should be addressed as a follow-up to this study.

Setting small, achievable goals with patients should be a priority for health care providers and employers, as witnessing personal success seems to motivate people in all cohorts studied. Companies that tie health insurance premiums to behavior or results should consider setting small "events" throughout the year to earn points towards insurance deductions. Consistent with a previous study on type 2 diabetes, this study found that information is not always translated into action (Nam et al. 2011).

This study found that the Patient Activation Measure (PAM) levels did not correlate with health status (or having a managed condition). This was unexpected and may be the result of complications inherent in the PAM tool. This result is discussed in further detail in the *Limitations* section below. More discussion on PAM as it relates to Adverse Events and Trauma Symptoms is found below in the *Childhood and Historical Trauma* section.

Culture, Community and Environment

The second research question, "How do community, culture and environment affect American Indians' and Whites' ability to self-manage type 2 diabetes?" was designed to explore

the impact of culture, community and environment (mainly the workplace) has on type 2 diabetes. The study hypothesized, first, that people who successfully manage diabetes have relied on aspects of their culture to support self-management efforts. There was no support for this hypothesis, and, in fact, there was discussion by both Whites and American Indians about fast-paced lifestyles, soda and alcohol consumption and the unhealthy nature of regional or tribal foods. There was speculation by members of the American Indian community that returning to pre-contact ways of living would positively impact their health.

Only two of the American Indian participants reported using aspects of their culture positively in support of their self-management efforts. One unmanaged Oneida discussed finding a sober drum group allowed him to positively connect to his culture and one unmanaged Stockbridge Munsee discussed trying to support members of his drumming circle when they traveled to perform. Although this represented a positive connection to culture, it did not correlate with having successfully self-managed diabetes. In addition to this finding, the Stockbridge Munsee culture itself was presented in an overwhelmingly negative light throughout the course of interviews with both managed and unmanaged participants. The connection between culture and diabetes is most often studied as it relates to beliefs about the cause and the effectiveness of treatment. This study attempted to ask about the explicit connection between self-management and the hypothesis was to uncover the ways that culture can activate self-management, as was found in a 2010 study by Long and colleagues. Long et al. (2010) discovered living in neighborhoods where people generally worked together was associated with better diabetic control for Black US veterans. In the larger space that holds the relationship between social capital and diabetes, social capital itself has been determined by Holtgrave and

Crosby (2006) to be protective against diabetes and obesity. The process of activating social capital in self-management, however, remains unclear.

Further examination of culture in this study revealed that contemporary, fast- paced American culture was more of a barrier to self-management than a facilitator. In the case of the American Indian participants, there was discussion about resuming lifestyle and practices of the past might positively impact their health. Both White and American Indians talked about the fast-paced lifestyles they currently lead. For both ethnic groups, alcohol and soda consumption were identified as obstacles to achieving optimal health. Both groups also discussed ethnic and regional foods that health care providers have classified as forbidden foods. Cheese curds, bratwursts, Indian tacos and fry bread were all seen as having a negative impact on health. This would be an interesting addition to a future study on body image and its impact on self-management. Fast-paced lifestyles impacted participants' ability to grocery shop and prepare healthy meals at home. Low-sugar, low-carbohydrate options in local restaurants seemed limited to participants, although the managed participants referenced an ability to order items in a way that would reduce carbohydrates and sugars. These findings were consistent with previous literature on the ability to consume cultural/traditional foods as a quality of life issue among the Chinese by Nam et al. (2011), the high consumption of soda among low-income American Indians (Lautenschlauger and Smith, 2006) and unhealthy foods purchased away from by African American women (Krishnan et al., 2010)

The study provided support for the second hypothesis, that those who are unsuccessful have not, or cannot overcome social roles, behaviors and other circumstances and these become barriers in the intensive self-management that diabetes requires. This was discussed in detail in the above section on factors that facilitate activation. When participants resumed social roles or

the role of caregiver after a diabetes diagnosis, unmanaged participants tended to prepare foods requested by family members. These tended to be foods higher in carbohydrates and fats. Managed participants in these same social roles were generally able to change the food they prepared for everyone in their household. Previous literature in this area considers social support and not specifically social roles, although gender roles are commonly discussed in studies of diabetes in African American and Latina women (Majeed-Ariss, et al. 2013).

The ability to overcome societal norms in the communities in which participants lived was discussed by both American Indians and Whites. Participants often described the fact that obesity and diabetes are common in the Northeastern Wisconsin and tribal communities. All participants could list names of other type 2 diabetic patients they personally knew, and half of the participants knew of someone who either had an amputation, or had themselves experienced an amputation due to this condition. Participants described a sense that with so many diabetics in the community, having type 2 diabetes seemed unavoidable and that type 2 diabetes was not only a regular part of their community, but also a part of their genetic make-up. Many felt they were destined to have type 2 diabetes. Misconceptions and lack of knowledge about the disease are generally considered to be barriers to self-management (Booth et al., 2013; Nam et al., 2011), however, this study found similar views expressed by all study groups, managed as well as unmanaged. In addition, many unmanaged participants expressed knowledge but were not activated in self-management.

Community resources and personal financial resources were reported to impact self-management in both White and American Indian groups; however, American Indian participants were more likely to agree or remain neutral to the question, "If I had more money, I could take better care of myself." Interview responses suggested American Indians are concerned about

having to travel long distances to obtain and purchase healthy food items, whereas Whites are concerned about affording insurance premiums and the cost to join a fitness center. Tribal members are able to utilize tribal fitness centers and Indian Health Services at no cost to them personally. Many American Indians referenced this benefit as a positive aspect of tribal membership. This study was designed to include tribal members with equal access to resources, thus eliminating the concern that access issues are the reason for activation. Findings indicate that "access" to Indian Health Services was not consumer/user friendly and participants waited for appointments that needed to be rescheduled due to complications with employment and childcare. In addition, the acceptance of government insurance and changes in employer-sponsored insurance were barriers for Whites. There is still more to be understood in the activation of self-management when resources such as the fitness centers are available and remain underutilized.

When discussing the environmental impact on type 2 diabetes, responses most often included the topics of climate and workplace. According to participants of all ethnic groups, the winter climate in Northeast Wisconsin made it more challenging to self-manage type 2 diabetes. The climate was discussed in many activities related to self-management, including preparing foods and outdoor exercise or physical activity. Previous studies such as Auchincloss et al. (2009) indicate the more neighborhood resources are associated with lower incidence of type 2 diabetes in New York City and Baltimore. Climate must, however, be considered with this strategy of improving neighborhood resources. In addition to parks and walking trails, cold weather communities should also consider low-cost rentals of winter equipment such as cross country skis and snow shoes.

The workplace had both positive and negative effects on self-management. Participants regarded the positive aspects of the workplace as the emotional support provided by colleagues. The workplace can also provide structure and routine to support people in medication adherence and in eating limited portions of food, when they brought a lunch to work. Portions were then limited due to forethought of packaging an appropriate amount prior to traveling to the workplace. However, the workplace can negatively affect self-management in many other ways. Changes in daily schedules or routines, such as unexpected travel or special food celebration days, are difficult for unmanaged patients. Work environments sometimes limit the ability to store fresh food or the ability to snack throughout the day (snacking can be crucial to control blood sugars). In addition, the workplace environment that includes rotating shift work or sedentary jobs can negatively affect the lifestyle of diabetics. Farming was discussed as both a positive (in being able to exercise and control the quality of meat eaten) and a negative (needing more calories to work longer days and being pressed for time and unable to prepare healthy meals) in relation to self-management. Recent Swedish research found lower incidence of coronary heart disease (a diabetes-related condition) among farmers as a results of quality of meals and physical nature of the required work (Thelin & Holmberg, 2014). Thelin and Holmberg (2014) called for a greater understanding of the positive impact of the farming lifestyle on diabetes. This study offers some support for this finding, as some farmers discussed making bread with lower sugar contents and altering the feed of their cattle to produce leaner meats. However, unmanaged farmers in this study pointed to the need for a higher caloric intake and reliance on equipment such as a tractor such as John Deere's Gator to move from place to place.

Health insurance provided through the workplace could present a positive or motivating influence on self-management when it offered incentives to lower premiums through achieving greater health or attending educational events. However, this did not lead to sustained changes in behavior for most. Health insurance companies and employers should offer regularly scheduled events as a better way to sustain healthy behavior throughout the year.

Cultural events such as holidays or pow-wows were difficult for unmanaged patients. Establishing plans to effectively manage during these events should be a part of the overall strategy with patients and is related to the discussion on establishing routines and small manageable goals in the above section *Factors Facilitating Self-Management.*

Childhood and Historical Trauma

The third research question addressed in this study was, "Does trauma (including childhood and historical trauma) influence activation of diabetic self-management?" The researcher hypothesized that unmanaged patients have higher incidence of adverse childhood events or experience greater symptoms of historical trauma than managed patients.

The findings of this study did not support this hypothesis. There was no determined relationship between the total number of Adverse Childhood Events (ACEs) and whether or not the individual was successful in self-management. In addition, of the 8 participants reporting more than 4 ACES, 6 were considered managed. The study did however support the original ACE study with 26 of 30 participants reporting at least one ACE and 20 reported more than 1, demonstrating the relationship between disease in adulthood (a diabetes diagnosis) and adverse events occurring in childhood.

As described in the *Results* section, the PAM measure negatively correlated with Adverse Childhood Events (ACE) totals and trauma symptoms from the TSC-40. Practically, individuals

with a lower amount of adverse events and current trauma-related symptoms were more willing to take part in their health and health care. However, the relationship between successful self-management and the PAM proved not be statistically significant. This could be due to power issues in the data or issues in the PAM tool itself, described in the *Limitations and Challenges* section of this chapter.

The Trauma Symptom scale TSC-40 also yielded unexpected results. Neither the total score of trauma-related symptomatology nor any of the six subscales (depression, sexual abuse indications, dissociation, anxiety, sleep disturbances or sexual problems) correlated with the management of type 2 diabetes. Possible explanations for this finding are discussed in the *Limitations and Challenges* section below.

Historical Trauma

The "Historical Grief and Loss Scale" measured historical trauma. This tool revealed relatively low levels of currently experienced grief and loss symptoms related to historical trauma. However, in the interview portion of the study there was speculation about returning to traditional ways of living and the positive impact this could have on the health of the tribal population. One unmanaged participant described a traumatic situation when she was taken to a boarding school, thereby offering support to the connection between ability to self-management diabetes and historical trauma, as this person's experiences undoubtedly impact her inability to self-manage today.

Implications for Practice and Policy

The results of this study can be used to develop recommendations for health care providers and policymakers at the local and national levels. Health care providers should assist type 2 diabetics in establishing routines so that predicable, healthy patterns of behavior are

attained and sustainable. When attempting to foster sustainable behavior change, patients and providers should consider alternate plans for weekends and other common occurrences such as expected and unexpected travel, holidays or special events. If climate varies, this should also be considered, especially if appointments are required on a quarterly basis. Medication side effects should be discussed, along with assurance that calls in-between appointments to discuss problems like side effects are welcomed, and, in fact, are the responsibility of the patient to initiate. Small, achievable goals should be set with unmanaged patients so success builds upon itself. Family members and other people involved in significant relationships should be engaged for the purpose of assisting in self-management of unmanaged and newly diagnosed patients.

Consistent with eco-social theory and the embodiment of disease, the high prevalence of adverse childhood events and trauma-related symptoms in the diabetic population suggest several strategies. First, the communities need to prevent and treat early childhood trauma. Second, diabetic services should be trauma-informed and shaped. Providers should have knowledge about the impact of trauma and the connection with disease in adulthood. Health care providers have their own culture which begins in medical school and largely centers around a medical model that considers an individual's physical functioning. The model has slowly expanded to include economic factors, but typically the economic factors considered are in relation to compliance of the prescription for treatment (i.e. transportation to appointments and at-home care following an acute injury). This study suggests the culture of providers needs to be influenced to include trauma-informed practices. This solution has the potential to impact the root of the behavior that has been embodied in the individual and is being expressed as physical illness. More information is needed about the connection of childhood and historical trauma to managed diabetic conditions.

Public health campaigns should deliver a basic level of information such as the cause and prevention of type 2 diabetes. Although several government agencies such as the Centers for Disease Control and Prevention and the US Department of Health and Human Services advertise materials geared toward American Indians on their websites, the materials are not readily available for purchasing. Funding should be made available to push information to the general public at little or no cost. In addition to structural interventions, interventions with messaging specific to the dominant culture are also needed, as was indicated from the White population included in this study.

Events sponsored by health insurance companies or employers should be held frequently throughout the year and small successes in self-management, such as incremental weight loss or weight maintenance and falling A1c numbers, should be incentivized and rewarded. These smaller, more frequently held events would support consistent progress towards self-management goals and should go beyond providing basic information and discuss strategies to translate information into action plans and sustaining healthy behavior.

There was an expressed interest from the American Indian communities included in this study to return to traditional ways of living in attempt to positively impact their health. Overtly making connections between the positive impact of pre-contact foods and the traditional way of life on health should be considered. One way to do this would be to emphasize the change to pre-contact foods from the contemporary American Indian foods of fry bread and Indian tacos. By doing this, a weight loss plan harnesses culture in a positive way (return to traditional foods) rather than negatively (rejection of recently adopted foreign foodstuffs). There is currently a *Traditional Foods Project* developed by the CDC that includes public service announcement touting culture as a source for health (Diabetes Control and Prevention, n.d.) and elementary

school curriculum designed for American Indians (tribalconnections.org, n.d.). This study would support the need for this effort to be brought into the American Indian communities.

In relation to the health care policy environment, this study provides support for an expanded version of the current patient-centered approach to care. Currently this approach means tailoring medications and modifications to patient needs; however, this study suggests taking the patient-centered approach one step further. Providers should inquire what optimal health means to a patient. This information would assist providers when establishing manageable goals with patients and connect them to outcomes established by the patient. For example, if achieving optimal health means traveling in retirement, then the goal of improving or maintaining physical functioning would be a means to that end. If optimal health means maintaining independence, then goals should reflect this aim. Newer versions of the diabetic self-management programs support should contribute to this effort as they currently do not incorporate standardized curriculum.

This study indicated asking unmanaged or newly diagnosed patients to identify key people in their lives that might assist them in self-management activities would be beneficial. A new tactic might be to have associated family members and others periodically complete an evaluation of self-management activities. This could have several desired effects. First, supportive family members could combat complaints about healthier meals. Second, they could encourage exercise and assist in making healthy choices when dining at a restaurant or planning for holidays or pow-wows. This may also serve as a form of education and prevention for family members themselves. Health systems can further tailor care to the patient by integrating behavioral health when needed or building trauma-informed support services. All providers should be educated on the prevalence and effect of trauma in the general population.

Building in flexibility into provider schedules would open up access to both tribal and community health systems and could facilitate activation for many patients. Appointments booked months in advance are in conflict with the current fast-paced lifestyle that most Americans lead today, and in one severe case presented here, led to a costly and preventable amputation.

Tribal and workplace policies can also be changed to provide more support to people with chronic conditions. For example, allowing multiple breaks in a shift for moderate exercise and snacking would help many self-manage. In addition, health insurance companies, like tribes, could remove the cost for maintenance of a chronic condition, such as lab fees, co-payments and diabetic testing equipment. Health insurance companies or employers might change their policies to include membership to fitness centers. For example, one local company will reimburse membership fees if an employee checks in at the center a minimum of 12 times per month or 3 times per week.

In regards to health policy, funding for neighborhoods and communities to provide safe, well-lighted walking trails and to address food deserts should be provided. Communities need to continue to address policies related to alcohol and soda consumption. It is also critical to note the connection between alcohol consumption and childhood abuse (Schwandt, Heilig, Hommer, George, & Ramchandani, 2013). For example, every year for the past ten years, the dental society in a three county area in Wisconsin has proposed a state tax on soda that would fund free dental care. This has been seriously debated in State government, but has never passed. Policy should also consider supporting innovative efforts by the health systems. For example, in a neighboring community of Appleton, Wisconsin, one health system has worked with local restaurants to highlight low-sugar and low-carbohydrate options on their menus. Furthermore,

money for public health campaigns regarding the cause and prevention of type 2 diabetes should be provided.

Limitations and Challenges

This study had several challenges and limitations. First, because of the in-depth nature of the interview, the study was based on a relatively small sample (N=30) and sub- samples (N=5). While statistical techniques were employed to correct for this, the sub-samples were too small to note correlations. In addition, the recruitment process capitalized on professional contacts and was not random. However, the advantage of qualitative work is that is can develop rich data in an unexplored area, allowing us to identify a range of previously unknown opinions and an understanding of reasoning behind such opinions. Thus, future studies can build on these results to develop a larger study. Also, qualitative work such as the study presented here allows for basis of generalization about social processes, patterns, forces and structures.

In addition to this, because the study was conducted in rural areas and in two relatively small tribal communities, the researcher made a conscious choice to omit demographic characteristics of participants. The original decision arose out of concern for the ability for participants to be identified. Additional rationale was based on the analysis of resources at the community- rather than the individual-level. The combination of tribal affiliation, health and other demographic information would have allowed for participants to be identified. This choice limited the study in the area of socio-economic status, a factor that did periodically surface in the interviews and again on the questionnaire.

In the analysis of the data, not having documented the severity of participants' diabetic condition and co-morbid conditions proved to be a limitation. Related to this problem is the absence of information on study participants' health status. Moreover, there is no measure that

captures how much effort a person used to self-manage or how much support they actually received from family members. For example, a few of the participants could manage their condition without having to modify their lifestyle and simply take one oral medication per day. This could be due to the severity of their illness as well as the nature of their previous lifestyle. Unmanaged participants reported using a lot of energy and effort to attempt to manage, including inject insulin, menu plan, prepare healthy foods and exercise, but still have an unmanaged condition. This could be due to the natural trajectory of the illness and was not captured in this study. The nature of this illness presents a challenge, as some people can feel the effects of this illness and some cannot, thereby complicating the perceived effort needed to manage the condition. For some diabetic patients, high and low blood sugar triggers a physical or emotional symptom. This prompts the patient to check their sugar and treat it with food, exercise or medication.

In addition to this study, the researcher has significant professional experience with the use of the PAM tool. The learning experience using the PAM tool in a professional health clinic across disease states and clinical areas has demonstrated that PAM is an extremely sensitive tool. One possible conclusion drawn from the current study experience and combined with the past professional experience is perhaps that this tool is measuring a reflection of beliefs and values but not actions. This is a subtle twist to the concept of self-efficacy, discussed in the *Theory* chapter in this document and represents the fundamental question for self-management: "I believe my actions can positively affect my health, but I do not take those actions." Complicated concepts related to self-management, such as the complexity of behavior related to social roles and the lasting impact of past adverse childhood and historical trauma were advanced by this

study. However, the process that allows managed patients to move through these challenges in still not well understood.

The study also experienced challenges in defining important concepts and classifying participants. For example, when asked to describe their health status, most people responded they were in good health, although to be eligible for the study they must have had at least one chronic condition, type 2 diabetes. One managed participant said he was in "near excellent" health but subsequently produced a list of 12 medications he was currently taking. A true understanding of what health means for each individual might assist in the development of strategies for self-management. Definitions of culture also varied for individuals and made analysis of responses to questions relating to culture challenging for this researcher.

Related to the challenge of defining culture, the classification of study participants based on race/ethnicity was complicated. Prior to the study, the researcher considered the issue solved by asking for tribal affiliation. While this was generally a straightforward way to classify participants as people enrolled in a tribe based on blood quantum, many participants considered their culture to be representative of more than one ethnic group, whether that was another American Indian tribe or another racial/ethnic group altogether. For example, participants in the study mentioned White, Black, Mexican and other American Indian Tribes when asked in the interview about the relationship of culture to type 2 diabetes.

Future Studies

Future studies on type 2 diabetes should carefully consider the concerns described above and capture the health status of the individual such as severity of diabetic condition and intensity of self-management efforts, triangulate information on culture, and devise a measure to quantify the effort spent on self-management activities. Capturing health status can assist the researcher

in knowing the severity of the disease and the symptoms experienced by the patient. This would offer an indication of how much effort is perceived by the patient to achieve successful self-management. Triangulating information on culture by capturing the identity of an individual and the tribal events and traditions in which one participates has the potential to demonstrate a clear pathway to embodiment. For example, the Stockbridge culture was presented by its' members in a negative light. The role of this culture in identity development likely affects food choices, lifestyle and other health-related behaviors. Conversely, understanding this same connection between the identity of the Oneidas (which was much more positively described) and current behaviors could offer clues on how to reach an unmanaged population by positively connecting with culture. This would have to consider the embodiment of inequality and a life course perspective in light of studies that have found a correlation between optimism and other chronic illnesses such as cardiovascular health (Scheier, et al., 1989; Kubzansky, 2001; Giltay, et al. 2004; Tindle, et al., 2009; Kim, Park & Peterson, 2011).

In addition, future studies could consider body image, as it relates to many factors identified here. For example, these studies could consider a connection between membership in a poverty-stricken tribe and the perception of being a larger person.

Researchers Sendhil Mullainathan and Eldar Shafir have recently developed a concept called the Theory of Scarcity. The theory describes how having too little of something changes human behavior and can consume a person (Mullainathan & Shafir, 2013). This theory holds true for a multitude of problems, from too little time to too little money. One becomes focused on not having enough and the authors describe this a "bandwidth tax" (Mullainathan & Shafir, 2013). This distraction leads to poor decisions and a lack of acknowledgment of the long-term consequences of these poor decisions (Mullainathan & Shafir, 2013). That concept should be

explored with type 2 diabetics, as the unmanaged diabetics reported thinking about diabetes all the time, every meal, every day, yet they continued to make poor choices related to eating. When considering the concept of syndemics (obesity and diabetes), and the contemporary circumstances of the tribal members (childhood and historical trauma, lifestyle and workplace issues), this theory could offer straightforward explanations of a pathway to embody inequality.

Appendices

Appendix A – Institutional Review Board Approved Informed Consent Form

Factors that Facilitate Activation of Self-Management
in Patients with Type 2 Diabetes

Research Purpose:
By signing below, you are giving consent to participate in a research project. This research is designed to provide a better understanding of living with and managing type 2 diabetes.

Your Participation:
Your participation is *completely voluntary*. You can stop your participation *at any time* during the process. You will be interviewed in person by Nicole Schneider. Nicole is currently a doctoral student at the Heller School for Social Policy and Management at Brandeis University in Waltham, MA.

In the interview, you will be asked about living with diabetes, your family, culture, childhood and the environment in which you live and work. After the interview, you will be asked to complete several questionnaires or surveys. These surveys will ask you about your motivation to manage your condition and events in your history and childhood, including events that may have been traumatic. This may be uncomfortable or provoke unhappy memories.

Your participation in this project is expected to last 1.5 hours and you will receive $50 in cash upon completion of the interview.

Risks and Benefits:
The anticipated risks to you as a participant are minimal. At times you may be uncomfortable speaking about your health. Remember, at any time, you can stop the interview or refuse to answer any of the questions. A benefit to you may be to allow your story to be told and recorded. The information from this project will be used to help other diabetics.

An audio recording of the interview will be stored on a password-protected computer. The written information from the scales will be scanned into and attached to your electronic record and will then be destroyed.

Records/Documentation:
Your name, gender and age will be collected and stored along with your interview transcript. Your interview will digitally recorded and later transcribed by a professional transcriptionist. Your digital records will be kept on a password-protected computer. Your written records will be kept in a confidential and locked file at the home of the researcher, until which time they can be safely destroyed.

Contact Information:
Questions about the research can be directed to: Nicole Schneider (920) 737-6335 or nicoles@brandeis.edu. Nicole will also share with you the results of the research if you chose. Approximately 30 people are participating in this project.

If you have questions about your rights as a research subject please contact the Brandeis Institutional Review Board at irb@brandeis.edu or (781) 736-8133.

You may voluntarily stop your participation at any time!

I agree to have the interview audio-recorded. o yes o no _____
initial

By signing below, you are stating you have read the information listed above, have been information of the risks and benefits of the study, and agree to participate.

_____ _____
Signature Date

Research Opportunity for Type 2 Diabetics

Type 2 Diabetes is the most common type of diabetes and is a growing problem for many Americans.

This research project is aimed at understanding how people live with and manage Type 2 diabetes. Participants wil be interviewed in person. Questions will be asked about your medical condition, your family, culture, childhood and environment. At the end of the interview, you will be asked to complete several questionnaires/surveys.

The interview and surveys will take approximately an hour and a half (1.5 hours) to complete. For your time you wi receive **$50 in cash**. You must be 18 years of age or older to participant. Call or text Nicole at the number below. This research has been reviewed by the a Institutional Review Board at: Brandeis University, Waltham, MA irb@brandeis.edu

Research Opportunity Nicole (920) 737-6335

Appendix C: Institutional Review Board Approved Research Advertisement – American Indians

Research Opportunity for Type 2 Diabetics

Type 2 Diabetes is the most common type of diabetes and is a growing problem for many American Indians.

This research project is aimed at understanding how people live with and manage Type 2 diabetes. Participants will be interviewed in person. Questions will be asked about your medical condition, your family, culture, childhood and environment. At the end of the interview, you will be asked to complete several questionnaires/surveys.

The interview and surveys will take approximately an hour and a half (1.5 hours) to complete. For your time you will receive **$50 in cash**. You must be 18 years of age or older to participant. Call or text Nicole at the number below.
This research has been reviewed by the a Institutional Review Board at: Brandeis University, Waltham, MA irb@brandeis.edu

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Appendix D: Previous Literature Questionnaire

I identify my ethnicity or culture as:	White	Oneida	Stockbridge-Munsee
My last lab results showed my hemoglobin A1c as:	8.0 or under	greater than 8.0	

Answer the following questions. Circle your answer.

1) **I need support/encouragement from my family and friends to manage my condition.**

Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree

2) **I worry about what people would say or think if I only ate healthy foods.**

Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree

3) **I wouldn't be able to spend time with my family or friends if I had to make healthy choices all of the time.**

Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree

4) **If I had more money, I could take better care of myself.**

Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree

5) **I know how to feel better when I start to feel down or depressed.**

Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree

6) **I trust my health care provider.**

Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree

7) **The choices I make affect my health and wellness.**

Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree

8) **I am able to buy fresh food when I need it.**

Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree

9) **I can go to an exercise facility when I need to or want to.**

Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree

10) **Most of the people I spend time with are healthier than I am.**

Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree

11) Which answer below reflects *your opinion* for who has the most responsibility for your health.

Doctor or nurse Me Family Community Higher Power/God

Appendix E: Historical Grief and Loss Scale

Historical Grief-Losses – Adult Form

Our people have experienced many losses since we came into contact with Europeans (Whites). I will read you types of losses that people have mentioned to us, and I would like you to tell how often you think of these.

1	2	3	4	5	6	9
Several times a day	Daily	Weekly	Monthly	Yearly or only at special times	Never	Don't know/ Refused

1. The loss of our land
2. The loss of our language
3. Losing our traditional spiritual ways
4. The loss of our family ties because of boarding/residential schools
5. The loss of families from the reservation/reserve to government relocation
6. The loss of self-respect from poor treatment by government officials
7. The loss of trust in whites from broken treaties
8. Losing our culture
9. The losses from the effects of alcoholism on our people
10. Loss of respect by our children and grandchildren for elders
11. Loss of our people through early death
12. Loss of respect by our children for traditional ways

Historical Grief-Associated Symptoms – Adult Form

Now, I would like to ask you about how you feel when you think about these losses.

1	2	3	4	5	9
Never	Seldom	Sometimes	Often	Always	Don't know/ Refused

How often do you feel…

13. Sadness or depression
14. Anger
15. Like you are remembering these losses when you don't want to
16. Anxiety or nervousness
17. Uncomfortable around white people when you think of these losses
18. Shame when you think of these losses
19. A sense of weakness or helplessness
20. A loss of concentration
21. Bad dreams or nightmares
22. Feel isolated or distant from other people when you think of these losses
23. A loss of sleep
24. Feel the need to drink or take drugs when you think of these losses
25. Rage
26. Fearful or distrust of the intentions of white people
27. There is no point in thinking about the future
28. Like it is happening again
29. Like avoiding places or people that remind you of these losses

Appendix F: Adverse Childhood Events

Finding Your ACE Score

While you were growing up, during your first 18 years of life:

1. Did a parent or other adult in the household often or very often…
Swear at you, insult you, put you down, or humiliate you?
or
Act in a way that made you afraid that you might be physically hurt?
Yes No
If yes enter 1 _____

2. Did a parent or other adult in the household often or very often…
Push, grab, slap, or throw something at you?
or
Ever hit you so hard that you had marks or were injured?
Yes No
If yes enter 1 _____

3. Did an adult or person at least 5 years older than you ever…
Touch or fondle you or have you touch their body in a sexual way?
or
Attempt or actually have oral, anal, or vaginal intercourse with you?
Yes No
If yes enter 1 _____

4. Did you often or very often feel that …
No one in your family loved you or thought you were important or special?
or
Your family didn't look out for each other, feel close to each other, or support each other?
Yes No
If yes enter 1 _____

5. Did you often or very often feel that …
You didn't have enough to eat, had to wear dirty clothes, and had no one to protect you?
or
Your parents were too drunk or high to take care of you or take you to the doctor if you needed it?
Yes No
If yes enter 1 _____

6. Were your parents ever separated or divorced?
Yes No
If yes enter 1 _____

7. Was your mother or stepmother:

Often or very often pushed, grabbed, slapped, or had something thrown at her?

or

Sometimes, often, or very often kicked, bitten, hit with a fist, or hit with something hard?

or

Ever repeatedly hit at least a few minutes or threatened with a gun or knife?

Yes No

If yes enter 1 _____

8. Did you live with anyone who was a problem drinker or alcoholic or who used street drugs?

Yes No

If yes enter 1 _____

9. Was a household member depressed or mentally ill, or did a household member attempt suicide?

Yes No

If yes enter 1 _____

10. Did a household member go to prison?

Yes No

If yes enter 1 _____

Now add up your "Yes" answers: _____ This is your ACE Score

Appendix G: Trauma Symptom Checklist – 40

TSC-40 How often have you experienced each of the following in the last two months? 0 = Never 3 = Often

1. Headaches	0 1 2 3
2. Insomnia (trouble getting to sleep)	0 1 2 3
3. Weight loss (without dieting)	0 1 2 3
4. Stomach problems	0 1 2 3
5. Sexual problems	0 1 2 3
6. Feeling isolated from others	0 1 2 3
7. "Flashbacks" (sudden, vivid, distracting memories)	0 1 2 3
8. Restless sleep	0 1 2 3
9. Low sex drive	0 1 2 3
10. Anxiety attacks	0 1 2 3
11. Sexual over activity	0 1 2 3
12. Loneliness	0 1 2 3
13. Nightmares	0 1 2 3
14. "Spacing out" (going away in your mind)	0 1 2 3
15. Sadness	0 1 2 3
16. Dizziness	0 1 2 3
17. Not feeling satisfied with your sex life	0 1 2 3
18. Trouble controlling your temper	0 1 2 3
19. Waking up early in the morning and can't get back to sleep	0 1 2 3
20. Uncontrollable crying	0 1 2 3
21. Fear of men	0 1 2 3
22. Not feeling rested in the morning	0 1 2 3
23. Having sex that you didn't enjoy	0 1 2 3
24. Trouble getting along with others	0 1 2 3
25. Memory problems	0 1 2 3
26. Desire to physically hurt yourself	0 1 2 3
27. Fear of women	0 1 2 3
28. Waking up in the middle of the night	0 1 2 3
29. Bad thoughts or feelings during sex	0 1 2 3
30. Passing out	0 1 2 3
31. Feeling that things are "unreal"	0 1 2 3
32. Unnecessary or over-frequent washing	0 1 2 3
33. Feelings of inferiority	0 1 2 3
34. Feeling tense all the time	0 1 2 3
35. Being confused about your sexual feelings	0 1 2 3
36. Desire to physically hurt others	0 1 2 3
37. Feelings of guilt	0 1 2 3
38. Feelings that you are not always in your body	0 1 2 3
39. Having trouble breathing	0 1 2 3
40. Sexual feelings when you shouldn't have them	0 1 2 3

Appendix H: Patient Activation Level (PAM)

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and not just what you think others want you to say.

If the statement does not apply to you, circle N/A.

1.	When all is said and done, I am the person who is responsible for taking care of my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2.	Taking an active role in my own health care is the most important thing that affects my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3.	I am confident I can help prevent or reduce problems associated with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4.	I know what each of my prescribed medications do	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5.	I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6.	I am confident that I can tell a doctor concerns I have even when he or she does not ask	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7.	I am confident that I can follow through on medical treatments I may need to do at home	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8.	I understand my health problems and what causes them	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9.	I know what treatments are available for my health problems	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10.	I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
11.	I know how to prevent problems with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
12.	I am confident I can figure out solutions when new problems arise with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
13.	I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

Appendix I: Interview Guide

Interview Guide

Interviewer/Student: Nicole Schneider

I want to talk with you about living with Type 2 Diabetes. The interview has 3 main parts: your Diagnosis and daily living, how self-management of diabetes relates to your culture and community and how your environment helps or hurts your condition. After that, I have some scales that I'd like you to complete. Is that ok? You can stop at any point that you are uncomfortable.

Part 1: First I am going to ask about your diabetes diagnosis and your daily living with this illness.

How did you learn that you had diabetes?

What was your response to the diagnosis?

How do you feel now about your diagnosis?

Describe what it is like living with diabetes. Probe about self-management if they don't offer. Medication management, etc. When is it difficult to manage your condition? [Can you describe your role in managing your physical health.]

How was your life different before the diagnosis than after it? Do you see yourself differently now than before the diagnosis?

Can you describe a time when you were managing your disease best?

Can you describe a time when you felt you couldn't manage your condition at all, or where not managing well?

What motivates you to manage your condition? Who helps you manage?

Do you know others who have this same condition? If so, how do they get by? Do they help you? Do you help them?

Part 2: Now I am going to ask about your culture and community as it relates to your condition.

Can you describe the role culture plays in your life, living now as a diabetic? Is that the same or different than the role culture played in your life before you were diagnosed? [Encourage answers to both the Same and Different here].

Who is the most important person in your life? Describe the nature of the relationship. What would he/she say about your physical condition? [what about concrete actions and emotional support – per NINA]

Where do you seek information about how to live with your condition? Have you ever heard about or attended a community program to learn about self-management? If so, did that change the way you self-manage?

Have you ever met with a diabetic educator? If so, how did the session change what you do to live with your illness?

Part 3: Diabetes and Environment

Thinking about where you live and work, in what ways does your physical environment impact your condition? your neighborhood? Your home?

What would help you or others in your community live better with diabetes?

Conclusion:

Is there anything I have not asked or is there anything else you think I should know that would help me understand your experiences with living with diabetes? What would help you or others in your community live better with diabetes?

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