The University of Texas at TYLER
The Graduate School

University of Texas at Tyler
Scholar Works at UT Tyler

Nursing Theses and Dissertations

School of Nursing

Spring 5-5-2015

Illness Beliefs and Adherence among Louisiana Adults with Type 2 Diabetes

Denise L. Stagg

Follow this and additional works at: https://scholarworks.uttyler.edu/nursing_grad

Part of the Nursing Commons

The University of Texas at TYLER
The Graduate School

ILLNESS BELIEFS AND ADHERENCE AMONG LOUISIANA ADULTS WITH

TYPE 2 DIABETES

by

DENISE L. STAGG

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
School of Nursing

Sally Northam, RN, PhD, Committee Chair

College of Nursing and Health Sciences

The University of Texas at Tyler
May 2015

The University of Texas at Tyler
Tyler, Texas

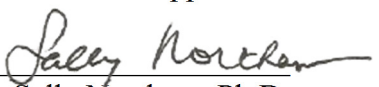This is to certify that the Doctoral Dissertation of

DENISE L. STAGG

has been approved for the dissertation requirement on
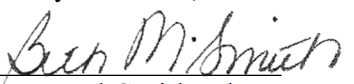
April 14, 2015

for the degree of Doctor of Philosophy in Nursing

Approvals:
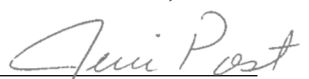
_____ *Sally Northam*
Dissertation Chair: Sally Northam, Ph.D.
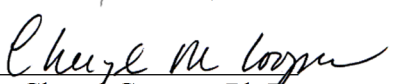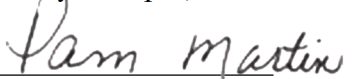
_____ *Beth M. Smith*
Member: Beth Mastel-Smith, Ph.D.
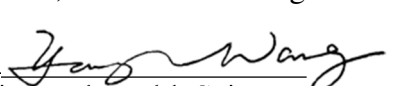
_____ *Jeri Post*
Member: Jeri Post, Ph.D.

_____ *Cheryl M. Cooper*
Member: Cheryl Cooper, Ph.D.

_____ *Pam Martin*
Chair, School of Nursing

_____ *Yong Wang*
Dean, College of Nursing and Health Sciences

Acknowledgements

To my husband, Jimmie Stagg, this would not have been possible without your calm, rational, supportive nature. I thank you and I love you. To my son, Jude Stagg, who did without Mommy on too many occasions; I love you and hope to spend so much time with soon. Furthermore, I would like to thank Dr. Sally Northam, my Dissertation Chair. Your infinite wisdom, expertise and supportive guidance kept me moving forward with hope, during this academic journey. I would also like to thank Dr. Lynn Wieck for your expert guidance in writing and formatting. I have learned so much from the both of you and I am forever grateful. You have both expanded my knowledge and perspective on so many levels.

Table of Contents

List of Tables

List of Figures

Abstract

ILLNESS BELIEFS AND ADHERENCE AMONG LOUISIANA ADULTS WITH
TYPE 2 DIABETES

Denise Stagg

Dissertation Chair: Sally Northam Ph.D.

The University of Texas at Tyler

May 2015

Type 2 diabetes mellitus (T2DM) is having an enormous impact on the health of

the nation. New cases of diabetes are diagnosed yearly across all states. Currently, 9.3%

of the population has diabetes (Centers for Disease Control and Prevention {CDC},

2014). While the prevalence of this disease is nationwide, it is not evenly distributed.

Louisiana currently has a rate of 11.5%, with some parishes having rates of 14.5% (CDC,

2014). This rate places increased demands on healthcare and financial systems in

Louisiana. Cultural elements and population distribution may be parts of this

phenomenon. While many studies explored new medications and treatments, few studies

were devoted to the perception of those who have been diagnosed with T2DM.

Furthermore, there were limited studies conducted using samples of participants from

Southern Louisiana. This exploratory research study focused on the perception of illness

held by a sample of persons with T2DM from Southern Louisiana and is reported in two

articles for publication. One manuscript (chapter two) focuses on the cultural elements and the history of Southern Louisiana. This manuscript highlights the need for further research using a sample of participants from Southern Louisiana to explore the variables which may impact the current status of T2DM. A second manuscript (chapter three) is a report of the findings regarding perception of illness as a means to determine impact on self-care activities of those diagnosed with T2DM. This study examined the variables of illness representation using the Self-Regulatory Model of Illness as the theoretical framework. Conclusions and recommendations regarding management of persons with diabetes in Louisiana are offered.

Keywords: *T2DM, adherence, self-care activities, Cajuns, Southern Louisiana, perception of illness, Self-Regulatory Model*

Chapter One

Illness Beliefs and Adherence among Louisiana Adults with Type 2 Diabetes

Overall Purpose of the Study

Type 2 diabetes mellitus (T2DM) is a growing concern for the United States. This silent but deadly disease leads to multiple body system problems when not properly managed. The Centers for Disease Control and Prevention (CDC) contends that 29.1 million people in the United States currently have diabetes (CDC, 2014). This figure includes those who have been diagnosed with diabetes and those who have diabetes, but have not yet been diagnosed. These numbers are expected to increase as the obesity rates of the nation increase.

T2DM can result in multi-system health problems. According to the American Diabetes Association (2015), uncontrolled diabetes can result in kidney disease, high blood pressure, stroke, neuropathy leading to pain and possible extremity amputation, skin conditions, eye conditions leading to blindness, gastroparesis, and hyperosmolar hyperglycemic nonketotic syndrome. Although there are several others factors associated with an increased risk of developing these multi-system side-effects, these complications are primarily the result of uncontrolled blood sugar. According to Kantharidis, Wang, Carew, and Lan (2011), "Current treatments have resulted in only a partial reduction in this risk" (p.1832). Healthcare providers monitor blood sugar levels via the lab test hemoglobin A1c (HbA1c).

These blood tests are recommended two to four times a year depending on the type of diabetes and the use of medication to control blood sugar (Mayo Clinic, 2013). Patients monitor blood sugar levels by performing daily or weekly capillary blood glucose (CBG) tests or by checking the glucose level using a urine test strip. Maintaining blood glucose levels can be achieved through the use of prescription medications, diet, and exercise. Currently, the most highly recommended method of controlling blood sugar levels is the responsibility of the patient in the form of self-care activities. These activities include taking prescribed medication, following a diet consisting of foods with a low glycemic index, monitoring blood glucose levels, exercising, and doing foot assessments.

Cultural beliefs and values can have an impact on health care practices and life styles. According to the National Institutes of Health (n.d.), culture plays a significant role in health care by influencing "beliefs and belief systems surrounding health, healing, wellness, illness, disease, and delivery of health services" (para 1). For this reason, health care providers should be well versed in the cultural practices of the patients they serve. Understanding the perceptions of patients in terms of cultural values, beliefs systems, and health practices can impact health promotion and disease prevention. Increasing awareness of cultural implications and diabetes best-practices is paramount for healthcare providers of all disciplines.

The sample for this study was drawn from persons living in the southern part of the state of Louisiana. Although this area is known as "Cajun Country," the sample was not limited exclusively to native Cajun persons. Southern Louisiana is known for having very distinct cultural elements which are encompassed in the term

"Cajun" as both a descriptor and a way of life. This *Cajun* lifestyle is most notably represented in the music, food, festivals, religious practices, and family dynamics of the region. Cajuns' heritage and food practices make them particularly susceptible to dietary health problems, such as obesity and diabetes (Oriol, 1995). Whether one is a Louisiana native or not, living amidst the influence of the Cajun culture makes persons with T2DM at risk for the same types of excesses that have set Louisiana apart as having a disproportionate number of persons with diabetes. Louisiana currently has rates of diabetes which are far greater than those of the nation. According to the Center for Disease Control and Prevention (2012), 10.3 % of the adult population was diagnosed with diabetes, with an additional 6.1% being told they had pre-diabetes. Concurrently, as the rate of diabetes rises, so do the costs associated with the disease. The Pennington Biomedical Research Center at Louisiana State University (2014) reports the direct and indirect cost of diabetes in Louisiana has risen to $5.4 billion per year. This increase in prevalence and the financial impact support a need for further research on understanding diabetes in Louisiana.

A review of literature was performed to determine the current state of the science as it pertains to cultural perceptions and diabetes. Only a few studies were found which used a sample from Louisiana. This review focused on studies regarding diabetes and self-care activities. Priority was given to studies which attempted to understand patients' perceptions of health and illness. While studies were noted to assess cultural elements in terms of diabetes, no study was found that used a

Louisiana sample. Understanding how cultural perceptions may impact adherence to health care activities in Louisiana was a noted gap in current literature.

Perception of illness and treatments associated with managing and preventing illness is an important aspect of cultural competence. Practicing culturally competent care leads to more patient-centered care. Understanding what elements may lead to a higher incidence in disease presence in a specific region is important in community focused care and interventions. The need for further understanding of the implications of diabetes in Southern Louisiana and the perceptions held by Southern Louisiana residents reflects the overall purpose of this study.

Introduction of the Articles

Two articles provide the scope of the problem and research findings that include an assessment of the target population. Manuscript one, "Health Promotion Adherence Issues in the Southern Louisiana Population," has been submitted to the *Online Journal of Cultural Competence in Nursing and Healthcare*. The purpose of this manuscript was to discuss the unique history and cultural attributes of the Cajun population of Southern Louisiana. These attributes were then discussed in relation to the presence of T2DM. A review of literature highlighted the few studies that used a sample of participants from Louisiana and more closely focused on the management and treatment of diabetes in rural and vulnerable populations. Few studies could be located which were less than 10 years old. While these studies did use a sample of participants from Louisiana, very few examined the perception of the participants or the self-care activities recommended to manage T2DM. Recommendations call for more research into best practices for helping rural and vulnerable populations to

understand and manage their own diabetic journey.   Furthermore, it is recommended that researchers not ignore the small regional groups throughout the country, such as Louisiana Cajun communities, whose heritage, genetics, cultural traditions, or geography might predispose them to increased susceptibility to chronic diseases like diabetes. Learning how to manage the most vulnerable groups can have implications that are translatable into actions and treatments that may help persons with diabetes from many locations and living conditions

Manuscript two, "Illness Beliefs and Adherence among Louisiana Adults with Type 2 Diabetes" is a report of original research regarding the perception of illness and its relationship to adherence to self-care activities. The research was an exploratory study using the Self-Regulatory Model of Illness (Leventhal, Brisette, & Levanthal, 2003) as the theoretical framework. The study analyzed the findings from a group of 97 residents of Southern Louisiana with a diagnosis of T2DM. Findings indicated a significant relationship between some independent variables of illness perception and some dependent variables of self-care activity adherence. The theoretical model developed for this study did not predict adherence to self-care activities based on perceptions of illness. The study did identify valuable information regarding perceptions of illness within the sample. Of the sample of diabetics who had been prescribed medications, 85.1% reported taking the medication everyday as instructed. But while they take medications, many do not perform other self-care activities to protect themselves from the ravages of uncontrolled diabetes, including glucose checks and foot checks. The findings show a need for further research

regarding self-care activities and elements which can enhance or increase adherence to self-regulatory actions in persons with diabetes.

Chapter Two

Health Promotion Adherence Issues in the Southern Louisiana Population

Abstract

Louisiana is a state rich in culture and heritage. Currently, Southern Louisiana has an increasing prevalence rate of type 2 diabetes mellitus (T2DM) which is disproportionate in the nation. Further investigation and research focusing on Southern Louisiana with its predominant Cajun culture could prove instrumental in improving health outcomes related to T2DM in this susceptible region. The use of the Self-Regulation Model of Illness as a theoretical framework for future research may be beneficial in understanding cultural components of illness perception in Southern Louisiana residents with T2DM. A current review of literature focused on illness perception and self-care activities related to management of T2DM. Focus was placed on studies which used Louisiana residents as a sample population; however, there was a paucity of literature including Louisiana residents. In addition, few studies focused on all self-care activities recommended for diabetes management. Further research is needed.

Keywords: d*iabetes, T2DM, Louisiana, Southern Louisiana, perception of illness, adherence*

Manuscript 1

Health Promotion Adherence Issues in the Southern Louisiana Population

Louisiana is a state rich in culture. The most notable of these cultures is Cajun, predominately found in Southern Louisiana. The culture boasts of good food and good times spent with family and friends. This is evident in many festivals of Southern Louisiana which center around food, music, and heritage. An unfortunate parallel of these cultural activities is evidence that Southern Louisiana residents are experiencing incredibly high percentages of type 2 diabetes mellitus (T2DM). While technology and medical interventions increase to treat and manage T2DM, more individuals in Southern Louisiana are diagnosed with this disease every year. A culturally sensitive approach to analyzing this occurrence may lead to new interventions and methods of managing T2DM in Southern Louisiana residents.

Diabetes in Southern Louisiana

Louisiana covers 43,562 square miles and, as of 2013, has an estimated population of 4,625,470 people with 768,088 people living in rural Louisiana (Rural Assistance Center, 2014). The presence of diabetes is not new in Louisiana, but the increase in both incidence and prevalence of diabetes places Louisiana in a vulnerable situation. According to the Centers for Disease Control and Prevention (CDC, 2011), 8.3% of the population in the nation has diabetes. Ninety to ninety-five percent of these cases consist of T2DM, also known as adult onset diabetes. While these numbers are high, they are not evenly distributed throughout the nation. The majority of these cases are found in the Southern states including Louisiana. According to the Department of Health and Hospitals (DHH) of Louisiana (2012), in 2010 approximately 10.3% of adult

8

population of Louisiana was diagnosed with diabetes. This rate is much higher than the national rate of 8.3% and only accounts for those with a known diagnosis of diabetes. Rates vary across the state with some areas having a rate as high as 14%. In addition to the high rate of diagnosis, Louisiana has the second highest diabetes mortality rates in the nation (DHH of Louisiana, 2012) which in turn dramatically impacts the state's health, well-being, and financial climate. DHH of Louisiana (2010) reports the total costs of diabetes to Louisiana were approximately $2,431,000,000 in 2006. Furthermore, 6.1% of this population has been told they have *pre-diabetes* (CDC, 2012). These increases in financial burden caused by diagnoses of T2DMare difficult to maintain for the state and the people. Further analysis of the lifestyle of Southern Louisianans could provide valuable information to assist in decreasing these numbers and improving the overall health of the state.

Southern Louisiana and Cajun History

Understanding Louisiana history is a first step to understanding the cultural practices of today. Louisiana is known as one of the largest territorial gains in the history of the United States, purchased by Thomas Jefferson in 1803 from France. The ancestors of today's *Cajuns* were located in an area known as *Acadia*, now Nova Scotia, Canada, during the 16th century. They called themselves *Acadians.* At this time, the colonists made their living from what the land provided and were a thriving community until the British won this Nova Scotia territory during battle (Cajun Country, 2006). The Acadians refusal to pledge their unconditional allegiance to the British crown resulted in property confiscation and families being loaded onto ships for exile in the British colonies, known as *The Grand Derangement* (Conrad, 1983). King Louis XV of France

was able to rescue many of the deported Acadians, many of whom chose to settle in Louisiana. According to Conrad (1983), the Acadians longed for a place where they could "devote their lives to God, family, and the land without interference from outsiders" (p.12). The Acadians, now known as *Cajuns,* then settled along the bayous and swamps of Louisiana where they prospered and are still present today. Their ties to God and Catholicism are still strong, as "the Catholic religion exerted considerable influence on the quality of life within the Acadian family" (Ancelet, Edwards, & Pitre, 1991, p.73). Throughout their history, Cajuns have learned self-reliance, the importance of family ties, and appreciation for good food and celebration. These traits are still present in many of the residents of Louisiana who embrace their Cajun heritage.

The geography of the area where the early Cajuns settled did not lend itself to easy living. Gaudet and Mcdonald (2003) describe the Cajuns of Southern Louisiana as the *Prairie Cajuns*, the *Wetland Cajuns* and the *River Cajuns,* based on where they were settled. The hot, humid temperatures and the large areas of swamps provided both refuge and sustenance in spite of a sometimes difficult existence. But the Cajuns prospered in this land by adapting and working with what they had available and developing close ties to others within the area. The early Cajuns made their living primarily by farming, trapping, and fishing. With low level flat plains and plenty of rainfall, rice and sugar cane farming were common. Today rice fields and sugar cane fields are a common site, and occupations in agriculture are passed from one generation to the next. Once rice fields have been harvested, they are frequently used as crawfish ponds by local farmers. The trappers of Louisiana learned to live off what the land provided in the form of alligator, deer, duck, bear, raccoon and crawfish. Hunting and fishing are still large parts

of the lifestyle of Louisiana and have been made into several reality TV shows, such as *Swamp People, Son of Guns,* and *Duck Dynasty.* The rich and hardy foods which provided staples for the Southern Louisiana people are still prepared and enjoyed today. Many people of Southern Louisiana still consume boudin sausage, gumbo, jambalaya, crawfish etouffee, and other traditional food options rich in flavor, spices, and fat content on a daily basis. These foods are frequently sought out and enjoyed by many tourists year round which further encourages the perpetuation of questionable dietary choices by the native Cajun population and many residents transplanted from other areas.

Celebration of family and life was always part of the Cajun culture. The oldest festival is known as *Courir du Mardi Gras*, which is closely tied to Roman Catholicism as the celebration between Christmas and Lent (Ancelt, Edwards, & Pitre, 1991). Its premise is to indulge in food, drink, and fun until the time of Lent arrives, which is marked by fasting and obedience. The celebrated Mardi Gras holiday has become a popular event for tourist destinations. While observed differently in several locations of Southern Louisiana, the overall effect remains one of celebration, sharing, and preparation for spiritual devotions. Celebrations are frequent in all 22 parishes which make up the region known as *Acadiana.* From the Boudin festival of Scott, Louisiana to the Zydeco festival now in New Orleans, one thing remains constant: celebration of food, life, and fun. Each town in the Acadiana area is known for a special festival which celebrates food, music, or art, all unique to Louisiana culture and heritage. For example; the town of Scott hosts the *Boudin Festival,* the town of Breaux Bridge hosts the *Crawfish Festival,* and the town of Rayne hosts the *Frog Festival.* With so much celebration and love for life, it is no wonder that the most popular Cajun phrase is

"Laissez les bons temps rouler" which translated means "let the good times roll." The focus on good times and good food may provide some insight into why Louisiana has one of the most disproportionate rate of T2DM, a chronic disease shown to be related to obesity.

Organizational Framework

Understanding the significance and importance of culture on the residents of Southern Louisiana is facilitated by a review health and illness from the perception of the people of Southern Louisiana. The organizational framework used for this analysis is based on Leventhal's Self-Regulatory Model of Illness (SRM), also known as The Common Sense Model of Illness (Leventhal, Brisette, & Levanthal, 2003). SRM is a theory which focuses on the ideas and beliefs which individuals have regarding their diagnosis of disease or dysfunction. The SRM suggests that individuals respond to avoid danger and fear (Harvey & Lawson, 2009). This avoidance occurs on two levels which are independent of one another: the cognitive and emotional processes. SRM considers the patient an active problem-solver whose behavior reflects individual attempts to "close the gap between his/her current status and goal or ideal state" of being (Harvey & Lawson, 2009, p.7). According to the SRM, both processes (cognitive and emotional) involve three stages: illness representation, coping, and evaluation. The illness representation involves the individual's beliefs about the illness: what caused it, how severe is it, how does one treat it, etc. The action plan, or coping stage, includes self-care activities to manage the disease process and based on individual beliefs. The evaluation stage occurs when the individual assesses self-care activities and determines if measures were effective. This evaluation then leads to modification of the representation of the

illness and/or the coping strategies of self-care activities. According to Harvey and Lawson (2009), "Leventhal's Self- Regulatory Model….currently seems to offer the best system for identifying the determinants of patient self-care behavior" (p. 5).

The SRM concept of illness representation is further divided into five main components: identity, cause, time line, consequences, and curability/controllability. Each of these elements considers the physical and emotional representation. *Identity* encompasses the individual's beliefs concerning the illness and the associated symptoms. *Cause* centers on the individual's beliefs regarding possible causes such as heredity, lifestyle, and environment. *Time line* involves the individual's belief about the duration, acuteness, or cyclic nature of the illness. *Consequences* concern the individual's perceived physical, psychological, or financial consequences of the illness. Further research by Lau and Hartman (1983) into chronic diseases led to the inclusion the fifth component of *curability* or *controllability*. *Curability/controllability* involves individual beliefs regarding the ability to cure or control the disease, how effective current treatment suggestions are, and perceptions of personal control. The SRM components form the basis of a plan to foster the involvement of persons with chronic illness to take control of the management of their self-care.

The American Diabetes Association suggests that patients with T2DM take part in self-care activities to manage their diabetes. There are five patient self-care activities recommended for people with diabetes: diet, exercise, medication, blood sugar checks, and foot care. These five behaviors are considered the self-care activities associated with the evaluation phase of the SRM, as applied to those with T2DM. Figure 1 demonstrates the relationship of the variables and is used the review of literature
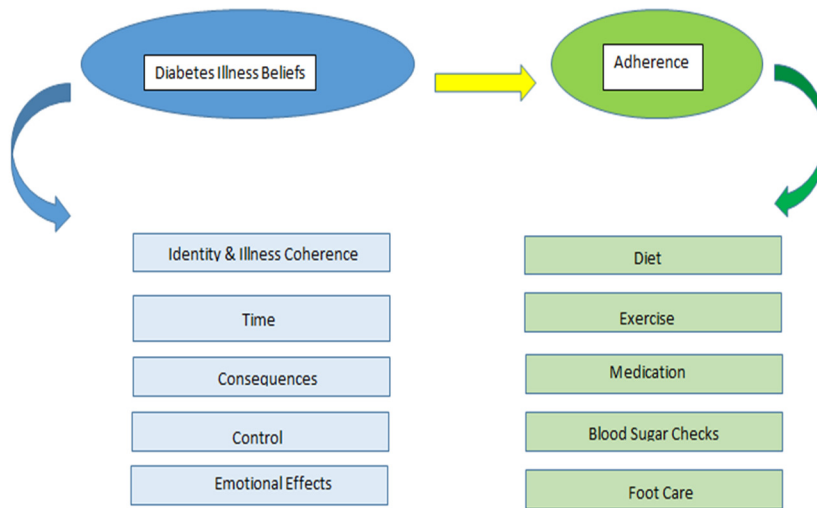
Figure 1. Illness Representation and Its Effect on Variables of Self-care Activities
(Adapted from Leventhal's Self-regulatory Model)

Review of Literature

A review of literature was performed to determine the extent to which people with T2DM were recruited for research in Louisiana and to examine illness perception and self-care activities. Few studies in the last 10 years were found which used Louisiana residents as the target sample; also, limited studies were found devoted to perceptions of illness, self-care adherence, or health seeking behaviors of persons with diabetes. For the purposes of this review, studies published as late as 1995 were used.

Cajun Health

Although the population of Louisiana has benefited from an influx of new residents representing many different geographic areas, the Cajun culture still exerts a strong influence on religious practices, social relationships, and eating patterns. The impact of the Cajun culture on health outcomes of the Louisiana population cannot be discounted and is discussed as the context in which all Louisiana residents reside whether

they choose to engage in the cultural practices or not. Multiple opinions exist regarding

Cajun health beliefs, but little research has been conducted on the topic. The literature

was reviewed to determine health beliefs regarding the five dependent variables of

adherence portrayed in the theoretical model. While no one article focused on all five

variables of self-care activities related to diabetes, some articles discussed health care

beliefs in general. Garg, Filozof, Etheredge, and Maney (1998) gauged Louisiana

residents' health beliefs, with an emphasis on Cajun heritage. The study focused on

adults in central Louisiana and used the Behavioral Risk Factor Survey (BRFS) to

determine health behaviors. The study added a survey question asking participants if

they perceived themselves as Cajun. Of the 2,029 respondents, 537 self- identified as

Cajun and were more likely to be married, white, male, with a high school education, and

employed for wages. Upon comparing the Cajun results of the BRFS to the 1995

national results of the BRFS, Cajun responses were significantly different than the

national responses on all of the survey items (Garg et al., 1998). The researchers reported

"Cajuns were three or more times more likely to be current smokers, binge drinkers, or

chronic drinkers" (Garg et al., 1998, p.90). In addition, Cajuns perceived their overall

health to be worse than others and were less likely to take preventative health measures.

The researchers suggest that "strong cultural ties to rural isolated populations and

resistance to change contribute to …fatalism" (p.90). While this study offers some

possible insight into the health behaviors of self-identified Cajun persons, it has not been

replicated recently. While not all Louisiana residents self-identify as Cajun via genetic

heritage, many may still practice the lifestyle and newer residents may adopt many of the

common cultural practices. This lifestyle likely impacts individual perceptions of T2DM, self-care activities of diabetes, and lifestyle changes to self-manage diabetes.

Oriol (1995) discussed Cajun traditions and their impact on health. Oriol focused on food and the use of faith healers, known as traiteurs. Oriol noted the frequent use of roux in Cajun cooking which involves a deep browning of flour in oil as the base for many Cajun dishes. The frequent use of pork, in the form of sausage and boudin, are also staples of the Cajun cuisine. Oriol (1995) noted "Cajuns are reluctant to give up the foods they love despite the high incidence of diseases associated with excessive fat intake" (p. 28). This statement is reminiscent of cultural pride which can be seen throughout Louisiana permeating eating patterns beyond the immediate Cajun cultural group. The impact of faith on the Cajun culture is also described by Oriol (1995) in this statement: "although prayer is the primary ingredient in any treatment, some traiteurs uses remedies such as poultices, oils, and salves" (p. 28). While religion was noted to be a very large part of the Cajun culture, little recent research was located to support a high use of traiteurs only, in lieu of physicians or healthcare professionals and their relationship to adherence to professional advice about the management of chronic illnesses.

Adherence Issues

This review of literature also focused on self-care activities of people with diabetes living in Louisiana. O'Hea et al. (2005) described dimensions of locus of control and the relationship with adherence to medical regimen for diabetes. The sample of participants was from the rural parts of Baton Rouge, Louisiana, which is considered Southern Louisiana. A sample of 119 participants, predominantly female and African

American, was asked to complete the expanded Multidimensional Health Locus of Control Scale (HLOC) which measured patients' beliefs that external forces control their diabetes. Adherence to medical regimen was measured by the participants' HbA1c levels. While O'Hea et al. (2005) reported finding weak relationships between the five health locus of control factors and adherence to medical advice. O'Hea (2005) discussed the importance of the locus of control noting some relationship to better HbA1c levels. While this study investigated participants' perception of internal or external control, the perception of control of self-care activities performed was not examined. The marker for adherence to medical regimen was determined based on HbA1c levels. This study did lay the founding for using HbA1c levels as a means to discuss and measure diabetes adherence in Southern Louisiana residents.

Murimi and Harpel (2010) conducted a qualitative study with Louisiana residents. Barriers and motivators for participants and non-participants in a community outreach program aimed at screening for chronic diseases and promoting preventative health measures were examined. The study consisted of six focus groups: three groups of community outreach program non-participants and three groups of participants. The study found that one of the main motivators for participation was the fact that food was served. A second motivator found was "fun". The participants had suggested that the outreach should be more fun, with more time to socialize. One participant stated that if her siblings could not go, "I just didn't go. Didn't want to come alone" (p. 279). When identifying barriers to participation, the researchers found that health being a "low priority" was an issue. Other participants did not see a reason to attend because of their age stating a belief that health screening was for older persons. Another attendance

barrier identified in all non-participants was a responsibility to work and family. Murimi

and Harpel (2010) further indicated "adherence to daily routine, laziness, and lack of

health problems were each identified by one focus group" (p. 277) as potential barriers to

attendance. This study included several of the variables of the Self-Regulatory Model of

Illness (Leventhal, Brissette, & Leventhal, 2003). Perception of illness was not explored

in the study, but several subjects noted age as a reason for illness and the presence of

notable symptoms as a way to identify the presence of the chronic condition. These

findings may be possible indicators for low adherence to self-regulatory practices. The

motivation of the outreach being fun and social was also linked to the emotional aspect of

the SRM. This study added new insight into the cultural beliefs and lifestyle of the

people of Louisiana This study also offered some insight to new interventions which

could be performed to enhance community involvement.

Dutton, Johnson, Whitehead, Bodenlos, and Brantley (2005) explored barriers to

exercise with a sample of participants diagnosed with T2DM from Louisiana. Their

study found that the most common barriers included "lack of time, social support, and

equipment, as well as medical and physical barriers to activity" (p.1209). Analysis of

data revealed participants' perceived importance of exercise in controlling their diabetes

was negatively associated with the number of barriers endorsed ($r = -0.29$, $p < 0.01$).

These findings lend support to the use of the SRM to determine if the perception of the

activity warrants continuance or participation in the activity of exercise as self-care.

According to Dutton et al. (2005), 75% of participants reported that exercise was

extremely important in controlling their diabetes and 18% reported it as *important*. What

was missing from this study was the number of participants who actually participated in exercise.

It is clear that the few studies on Southern Louisiana residents and their health self-care practices do provide an underlying context of cultural influence. The high level of diabetes in this region provides an impetus to seek causal evidence along with possible strategies to promote healthier lifestyles with the goal of better health outcomes. This review of the literature offers a roadmap for researchers seeking to have an impact on the health of vulnerable populations.

Recommendations

The importance of including culture as an element of healthcare outcomes cannot be understated. Louisiana is a state with unique historical roots which continue to influence the residents' health behaviors. More research should be undertaken to better understand current perceptions of diabetes and diabetic management of Louisianans. Changing behavior to incorporate health promotion behaviors has always been a challenge for nurses and other providers. Resistance to change may have cultural ties (Garg et al., 1998), but a need for further research was evident. The idea of *fatalism* in the Cajun culture could be further investigated to determine if it is a mitigating or modifying factor in health self-management of persons from Southern Louisiana. In the past decade, Louisiana has implemented several new health interventions to assist in combatting obesity and diabetes, yet diabetes rates still increase. More research is needed to determine if the practice of using traiteurs, or native faith healers, is still prevalent in Louisiana (Oriol, 1995) and its impact on health outcomes. While not all Louisiana residents self-identify as Cajun via genetic heritage, many may still practice

the lifestyle. This lifestyle likely impacts individual perceptions of T2DM, self-care activities of diabetes, and lifestyle changes to self-manage diabetes. Further research devoted to several aspects of perception of illness using the SRM and independent self-care activities may lead to more understanding of how to decrease the prevalence of T2DM in Louisiana and increase adherence to medical regimen. Self-care activities are promoted to help clients control the outcomes of their diabetes which includes control of secondary conditions such as foot ulcers, vision problems, kidney impairment, and sexual difficulties. Additional research should use the secondary conditions as measurement markers of successful interventions. Understanding how Louisiana clients perceive self-care activities could lead to a better understanding of lifestyle management, disease prevention, and health promotion.

The studies reviewed did offer insight into delivering patient-centered care by implementing aspects of cultural beliefs and lifestyle of the people of Louisiana. Three variables are noted: fun, food, and family. Increasing the fun factor associated with diabetes management could increase patient participation. Healthcare institutions could develop community outreach aimed at diabetes management and understanding. Such outreach efforts could be organized to be social gatherings, open to both diabetics and non-diabetics. These meetings could be aimed at involving those in rural communities to create a support network. With the frequency of festivals and celebrations which mark Louisiana's public image, healthcare industries have an opportunity to be involved and spread knowledge and encourage active self-management. Booths could be set up with a focus at increasing diabetes awareness among the residents by offering education, management, and screening. Information regarding local healthcare practitioners and

services could be provided to all who visit the booth. The festive and open environment of such locations aids in the social aspect of gaining support from the local community.

Food is an important social and cultural element for Louisiana residents and should not be overlooked. Local dieticians could partner with health industries, as well as with university students majoring in healthcare, to create outreach programs which focus on ethnic recipes and food preparation methods which are diabetic-friendly while maintaining the Cajun tradition. Cooking booths or stations could be set up to serve Louisiana favorites which have been modified to decrease blood sugar spikes and increase nutritional content. These booths could be set up at the multiple festivals which occur in Louisiana as well as in local healthcare settings. Healthy samples with recipes could be provided to all who visit the booth. Access to easy "how to" videos on preparation could also be included as an online component with a focus on eating healthy across the lifespan.

Family is a very important element in Louisiana. The idea of supporting and caring for one's family is a long-held Cajun belief which is valued in the Southern Louisiana area. Healthcare workers should consider having family members present at patients' appointments. Incorporating the assistance of the family in the management of the family member with diabetes could lead to increased knowledge and better outcomes. Emphasis should be placed of the health of the individual with diabetes and the relationship and importance of support and care of the entire family. Educating multiple family members on the self-care activities promotes the knowledge and cohesion of the family unit. This can lend support to the family member who is diagnosed with diabetes.

Conclusion

Louisiana enjoys a deep-seated sense of pride in its culture and heritage which is well known for its delicious, unique cuisine and love of family and fun. While the music, festivals, and open nature of the Louisiana people have made it a popular tourist destination, Louisiana residents are experiencing serious health concerns, particularly T2DM, which is having a dramatic impact. Although research is being done nationally, very little has been devoted to Louisiana and its unique cultural lifestyle. Further research into the illness perception of people with diabetes in Southern Louisiana could prove beneficial in managing the current diabetic population and assisting in increasing health outcomes. Understanding the importance of culture as a variable in health care outcomes is paramount. Delivering healthcare services in conjunction with an appreciation of cultural practices and values could have a positive impact on the citizens of Louisiana and the search for better outcomes for all persons who are faced with the challenge of living with a chronic illness like diabetes.

References

Ancelt, J., Edwards, J., & Pitre, G. (1991). *Cajun country*. Jackson, Mississippi: University Press of Mississippi.

Cajun Country. (October, 2006). Introduction Cajun Country. Retrieved June 23, 2014 from http://pages.cs.wisc.edu/~jmeaux/cajun.html

Conrad, G. (1983). *The Cajuns: Essays on their history and culture (3rd ed)*. Lafayette Louisiana: Center for Louisiana Studies University of Southern Louisiana.

Centers for Disease Control and Prevention, (2011). Diabetes: Successes and opportunities for population-based prevention and control at a glance 2011. *Chronic Disease Prevention and Health Promotion.* Retrieved from http://www.cdc.gov/chronicdisease/resources/publications/aag/ddt.htm

Centers for Disease Control and Prevention. (2012). *Diabetic report card*. Retrieved from http://www.cdc.gov/diabetes/pubs/pdf/diabetesreportcard.pdf

Department of Health and Hospitals in Louisiana. (2010, January) *Diabetes prevention and control program: 2007 diabetes report*. Retrieved from http://new.dhh.louisiana.gov/assets/oph/pcrh/diabetes/7056.pdf

Department of Health and Hospitals in Louisiana. (2012). *2012 Louisiana diabetes fact sheet*. Retrieved from .http://new.dhh.louisiana.gov/assets/oph/pcrh/diabetes/2012_Louisiana_Diabetes_Factsheet.pdf

Dutton, G., Johnson, J., Whitehead, D., Bodenlos, J., & Brantley, P. (2005). Barriers to physical activity among predominantly low income African American patients with type 2 diabetes. *Diabetes Care, 28*(5), 1209-1210. doi:10.2337/diacare.28.5.1209

Garg, R., Filozof, E., Etheridge, G., & Maney, E. (1998). Health behavior in a Cajun

population. *Journal of Cultural Diversity 5*(3), 89-93.

Gaudet, M., & McDonald, J. (2003). *Mardi gras, gumbo, and zydeco; Readings in*

Louisiana culture. Jackson Mississippi: University Press of Mississippi.

Harvey, N. & Lawson, V. (2009). The importance of health belief models in

determining self-care behavior in diabetes. *Diabetic Medicine, 26*, 5-13.

doi:10.1111/j.1464-5491.2008.02628.x

Leventhal, H., Brissette, I., & Leventhal, E.A. (2003). The common-sense model of self-

regulation of health and illness. In Cameron, L.D. and Leventhal, H. eds. *The*

Self-regulation of Health and Illness Behaviour. New York: Routledge.

O'Hea, E., Grothe, K., Boden, J., Boudreaux, E., White, M., & Brantley, P. (2005)

Predicating medical regimen adherence: The interactions of health locus of

control beliefs. *Journal of Health Psychology 10*(5), 705-717. doi:

10.1177/1359105305055330

Oriol, M. (1995). Cajun traditions and their impact on health care. *Journal of Cultural*

Diversity 2(1), 27-29.

Lau, R.R., & Hartman K.S. (1983) Common sense representations of common illness.

Health Psychology, (2), 167-185.

Murimi, M., & Harpel, T. (2010). Practicing preventive health: The underlying culture

among low income rural populations. *The Journal of Rural Health, 26.*

doi:10.1111/j.1748-0361.2010.00289.x

Rural Assistance Center. (2014). *Louisiana.* Retrieved from

http://www.raconline.org/states/louisiana

Chapter Three

Illness Beliefs and Adherence among Louisiana Adults with Type 2 Diabetes

Abstract

Significance: Type 2 diabetes mellitus (T2DM) is increasing in Southern Louisiana. Although T2DM is managed through self-care activities, cultural elements and values can impact how Louisiana diabetics manage their disease process. Understanding which elements increase adherence to self-care activities can assist healthcare providers to promote better outcomes for diabetic clients.

Purpose: The purpose of this research is to explore the relationship between perception of illness and adherence to self-care activities to manage T2DM.

Method: An exploratory study framed within Leventhal's Self-Regulatory Model of Illness was used to explore input from adult diabetics. Independent variables of identity, illness coherence, time, consequence, and control were analyzed for their impact on the dependent variables of diet, exercise, foot care, blood sugar monitoring and medication adherence. Data analysis methods included multiple regression and Pearson's correlation.

Results: Residents of Southern Louisiana ($N = 97$) with T2DM included 49.4% over 65 years old, 54.6% female, and 81.4% Caucasian. Identity was significantly correlated with exercise, $r=.23$, $p <.05$. Consequences measure was significantly correlated with exercise, $r = .21$, $p <.05$. Timeline cyclical was related to foot care, $r = .25$, $p <.05$.

25

Conclusion: While this study did not support the model as a predictive measure of self-care activity, elements of illness perception were found to have a relationship with elements of self-care adherence in people of Southern Louisiana with T2DM. Further research is needed to clarify what elements lead to increased self-care activities to manage T2DM.

Keywords: *Louisiana diabetics, T2DM, diabetes mellitus, perception of illness, self-care activities, adherence*

Manuscript 2

Illness Beliefs and Adherence among Louisiana Adults with Type 2 Diabetes

Type 2 Diabetes Mellitus (T2DM) is a growing concern for the United States. The Centers for Disease Control and Prevention (CDC, 2014a) reports that approximately 29.1 million people currently have diabetes. This number accounts for 9.3% of the US population. The CDC explains the estimate includes both diagnosed and not yet diagnosed individuals with diabetes which equates to 21 million diagnosed and 8.1 million undiagnosed. T2DM is a chronic disease, usually with adult onset, affecting the body on both a macrovascular and microvascular level. Management of T2DM requires frequent healthcare interventions. While health care professionals assist in diagnosing and managing a patient's diabetes, the majority of management interventions are carried out by the patient in the form of self-care activities. The American Diabetes Association (2013) estimates the total cost of diabetes as $245 billion in 2012 compared to $174 billion of 2007. These figures stress the urgent need for interventions that promote self-management of this disease.

The Louisiana Diabetes Dilemma

While the high number of people nationwide with diabetes is alarming, this disease is having an even greater impact on the state of Louisiana. More than 10% of the adult population of Louisiana currently has diabetes with 6% having pre-diabetes (Department of Health and Hospitals of Louisiana, 2012). The CDC (2015) reports that in 2012, 11.5 out of every 100 adult persons in Louisiana were diagnosed with diabetes. Louisiana also has a high rate of mortality and limb amputation secondary to diabetes. The CDC (2013) calculates the mortality rate of diabetes in Louisiana as 26.4 per

100,000 as compared to 20.8 for the U.S. Increasing knowledge to assist people with T2DMin managing their diagnosis through self-care activities is needed in Louisiana. Understanding which elements can impact adherence to self-care activities can further impact efforts taken by healthcare professionals.

The unique cultural heritage of Louisiana, which is based on rich foods, gala celebrations, and an active night life, has made it a desirable site for tourist trade. This same environment may also contribute to the problem of high rates of obesity and diabetes among the population. Unfortunately, the higher rate of T2DM in Louisiana also explains its higher percentage of both heart and renal disease, ranking fifth in the nation for heart disease and first in the nation for renal disease (CDC, 2014b). Due to the increase in the presence of T2DM in Louisiana, this exploratory study examined perceptions of the illness and its impact on adherence to self-care activities in a sample of Louisiana adults.

Type 2 Diabetes Management

According the American Diabetes Association (2015), T2DM is a chronic condition that requires multiple life style changes for effective management. People diagnosed with diabetes must monitor their diet to maintain an adequate caloric intake without unduly increasing blood glucose levels. People with diabetes are advised to eat foods with low glycemic indexes to prevent elevations in circulating blood sugar. Blood sugar levels must be checked, and regular physical activity is encouraged to help maintain proper blood glucose levels. People with diabetes are often prescribed medications to help control diabetes that may involve taking multiple pills or injections sometimes several times a day. Finally, diabetics need to avoid tissue injury to

extremities, especially the feet. This may require a change in footwear, limiting the amount of time the feet are exposed to the environment, and daily inspections of feet and toenails for possible injury. These varied tasks to self-manage the disease require discipline and diligence.

Diabetes is not just a disease affecting the blood sugar. It can also impact body systems causing CHF, sleep apnea, chronic inflammatory conditions, and decreased wound healing, which may lead to limb amputation (Creagor & Luscher, 2003). Macrovascular diseases associated with diabetes include atherosclerosis and medial calcification, as well as microvascular consequences such as retinopathy and nephropathy.

T2DM is a manageable, sometimes preventable or reversible, disease given specific life-style changes and accommodations. Poor management of T2DM leads to co-morbidities which can result in an increase in hospitalization (Lau & Nau, 2004) thus having an impact on the costs associated with T2DM. This study explored why some diabetics exhibit increased adherence to recommended self-care activities while others do not. The purpose of this study was to improve understanding of the effect of perception of illness and its impact on adherence to self-care activities. The independent variables included the illness representation of diabetes (identity, illness coherence, time, consequences, control, cause, and emotional effects). These variables were tested to determine their relationship to the dependent variables of self-care activities (diet, exercise, blood sugar monitoring, medication usage, and foot care) among Southern Louisiana adults to foster a better understanding of this population with disproportionate disease prevalence and complications resulting from T2DM.

Review of Literature

A review of literature was performed using search engines of CINAHL and PubMed. Multiple search terms were used (Louisiana AND health, Louisiana AND diabetes, illness perception, diabetes self-care activities, adherence to self-care, perception) to locate articles within the last 10 years. Because of the paucity of articles relating to Louisiana and diabetes self-management in a vulnerable southern population with cultural norms that include rich, fatty foods, the time span for article review was extended to 10 years. Perception of illness in diabetes with a focus on adherence to self-care activities was the goal of the literature review. If individuals do not perceive T2DM as a threat, or believe they can make a difference in their own outcomes through self-care activities, then interventions are likely to be unsuccessful. This literature review demonstrates a gap in understanding an individual's perception of illness and its effect on adherence to self-care activities.

Illness Representation

Illness representation means the actual signs and symptoms that the patient recognizes and seeks to manage as a way to be healthy (Leventhal, Brisette, & Leventhal, 2003). Several studies on patient illness representation of diabetes were located. The first noticeable gap in these studies was that no study involved a sample from Louisiana. Two studies focused on culture using a sample from the Appalachian region (Carpenter, 2012; Della, 2011) and explored illness representation, or perception of illness, from a standpoint of perceived threat. These studies compared findings to self-care measures which may have some applicability to a Southern Louisiana population which shares low socioeconomic status and potential vulnerability for health access and on-going care with

an area like Appalachia. Carpenter (2012) studied appraisal of diabetes and self-management variables using the Cognitive Appraisal of Health Scale to measure the perceived threat of diabetes and the Summary of Diabetes Self-Care Activities (SDSCA) tool to measure adherence to self-management. Correlations were measured between self- management and cognitive appraisal variables. Significant findings with a preset alpha of .05, showed a negative association between threat and general diet ($r = -.31$), and a positive association between challenge and general diet ($r = .35$), supporting the theoretical tenet that "interventions targeting the perception of diabetes as a challenge rather than a threat would contribute to the understanding of adherence" (p.726). Appalachians, like Louisiana residents, have a high percentage of T2DM.

Della (2011) also studied persons in the Appalachia region focusing on perceptions of susceptibility and severity of diabetes. This study used an adapted Dutch scale, created for use with at-risk populations, which measured the perceived susceptibility and the perceived severity of a diabetes diagnosis. Upon analysis of the findings, Della (2011) found that perceptions of susceptibility among the sample were only slightly above midpoint of the scale. The patient's perceptions of risk were lower than actual risk, leading the patient to view diabetes more as a challenge than a risk.

Adriaanse et al. (2008) reported 85% of low risk and 81% of high risk subjects perceived diabetes as a moderate to very serious disease; however, they did not perceive their own risk as high or even borderline. The lack of risk perception may explain why some persons with diabetes do not place a high priority on management activities, such as medication compliance and foot care.

Medication adherence is often considered the backbone of diabetes management and control. However, this activity also appears to be susceptible to patient perceptions. Mann, Ponieman, Leventhal, and Halm (2009) used the Brief-Illness Perception Questionnaire to gather data about patient perceptions using the Self-Regulation Model of Illness (SRM) as a framework. The findings indicated that the sample of inner-city patients with diabetes "frequently hold disease and medication beliefs that are inconsistent with a chronic disease model of diabetes" (p.281). Furthermore, the study indicated that these beliefs were robust predictors of poor medication adherence in this vulnerable population. This finding seems to emphasize the importance of perception when tailoring interventions to promote self-care. Yang et al. (2009) also examined the prevalence of non-adherence with oral hypoglycemic and antihypertensive medications. The sample consisted of secondary data sources of Medicare Part D enrollees with diabetes. Medication adherence was calculated as the proportion of days covered (PDC), or the number of days with medication on hand, and the time to fill the claim for new medication. The data were then categorized according to comorbidity scores. Using multivariate models where age was a continuous variable, they found that non-adherence with medications was especially high for patients <65, regardless of other demographic characteristics. This study was a cross-sectional analysis of secondary data covering six states; Alabama, California, Florida, Mississippi, New York and Ohio and three of the six states are in the Delta region of the South with a higher prevalence of diabetes. Jacobs, Kemppainen, Taylor, and Hadsell (2014) also studied medication adherence in a vulnerable population, the Lumbee Indians, using the SRM as the theoretical framework. The study showed a positive relationship between consequences and medication

adherence ($r = .38$, $p < .05$) providing further support for the importance of linking illness perception and risks to the need for adherence to provider recommendations.

The subjectivity of illness perception highlights the challenge of gaining patient buy-in to the need to adhere to provider recommendations. Studies of adherence have demonstrated the capricious nature of both intent and actual compliance with proven diabetic management standards. Broadbent, Donkin, and Stroh (2011) performed a cross-sectional study consisting of 49 persons with type 1 diabetes and 108 persons with type 2 diabetes. Participants answered questions on the Brief Illness Perception Questionnaire-Revised (Brief IPQ-R) and a descriptive survey to measure adherence. The results of the study demonstrated that 86% of prescribed insulin users who reported being adherent with medication "all the time" had lower ratings of the consequences of diabetes and higher perceptions of personal control than less adherent patients ($p < 0.05$). Additionally, 22% of the sample reported complete adherence with diet recommendations; this finding was associated with perceptions of fewer consequences ($r = -0.22$, $p < 0.01$), higher personal control ($r = 0.34$, $p < 0.001$), higher treatment control ($r = 0.20$, $p < 0.05$), fewer symptoms, and the belief that diet management could help diabetes control. Of the sample, 17% who reported adherence with exercise were also associated with higher perceptions of personal control ($r = 0.20$, $p < 0.05$), illness coherence ($r = 0.18$, $p < 0.05$), and perceptions that exercise could help diabetics ($r = 0.30$, $p < 0.001$) and prevent heart problems ($r = 0.21$, $p < 0.005$). The study suggested that altering a patient's perception may improve adherence.

Nevertheless, altering patient perceptions remains a challenge. French, Wade, and Farmer (2013) analyzed prediction of self-care behaviors of people with T2DM using

the Illness Perception Questionnaire Revised (IPQ-R), the Diabetes Self Care Activities (DSCA), and Beliefs about Medication Questionnaire (BMQ). They also explored the beliefs about the importance of diet and exercise. Findings suggested that beliefs about behavior were as important as beliefs about illness in predicting health-related behaviors. Petricek et al. (2009) investigated illness perception in patients with T2DM mellitus and its association with the degree of control over relevant cardiovascular risks. A sample of 250 was given the Brief Illness Perception Questionnaire - Revised and assessed for cardiovascular risk factors. Illness perception was related to cardiovascular risk Using multivariate logistic regression, the data supported that patient's concern about illness was a significant predictor ($p < 0.001$) of body mass index (BMI); patient's perception of personal control over illness ($p < 0.001$) and concern about illness ($p = 0.048$) were significant predictors of fasting blood glucose level; patient's perception that treatment can control illness ($p = 0.009$) was a significant predictor of total cholesterol; patient's understanding of illness ($p = 0.01$) was a significant predictor of blood pressure. Concern about and perception of illness seems to have an impact on notable indicators of successful diabetic management.

The literature describing *illness representation* seems to indicate that the threat or presence of actual symptoms is not enough to ensure adherence to positive health behaviors. Lack of risk awareness or acknowledgement of risk, in spite of recognized signs of illness, may provide some insight into why medication compliance and healthy eating patterns are not priorities for the diabetic populations in these studies and why they may not form an adequate basis for active engagement in self-care activities.

Self-Care Activities

Influencing the diabetic person to engage in active self-care is the basic goal of almost all health providers. However, self-care activities are usually internally generated from a belief that self-care activities contribute to outcomes to an extent that will actually prompt behavior modification. Blue (2007) used the Theory of Planned Behavior as it relates to intention to be physically active and eat a healthy diet. While this study did not address all elements of self-care for diabetics, it demonstrated perceived diabetes risk was not associated with intentions to be physically active or to eat a healthy diet. DePalma et al. (2011) explored whether the perception of responsibility for disease onset would influence the self-management activities of diabetics. The study used the SDSCA to measure activities and a two-question survey which asked how responsible the patient felt for the diabetes diagnosis (scale of 1 -10). They measured self- blame using the question "How do you generally react when you experience diabetes-related stressful events: I blame myself" (scale of 1-4). Anger was evaluated via the State-Trait Anger Expression Inventory, and social support was evaluated using the Diabetes Family Behavior Checklist. The authors noted that perceptions of responsibility and subsequent anger, self-blame and negative social support may interfere with effective diabetes management.

King et al. (2010) used multiple regression to analyze how psychosocial variables explained variance in self-management variables. The study found that community and environmental support were more important for patient self-care adherence than healthcare team support. The study also found that self-efficacy and problem solving factors were independently associated with self-management outcomes. Using multiple regression analysis, the study found that healthy eating patterns and physical activity

35

were related to behavior specific self-efficacy and environmental support variables accounting for by 23% and 19% of the variance respectively. Grant et al. (2013) studied the effect of education using diabetic genetic counseling on the self-reported motivation and prevention program adherence over 12 weeks ($N = 108$). This study found of the 42 high genetic risk, 32 low genetic risk, and 34 untested control subjects, there were few statistically significant differences in motivation, attendance, and weight loss after genetic counseling intervention. The study found that while higher-risk participants said the counseling made them more motivated; there were no significant differences in program attendance or weight loss (Grant, 2013). The ability to link emotional responses, such as motivation or desire to engage in self-care management, to actual clinical outcomes remains elusive creating an on-going challenge for diabetes service providers and the diabetic population themselves.

The usual solution to improving compliance with self-care management is an education intervention. Clark (2009) studied the effects of education on newly diagnosed diabetics ($N = 168$). The study offered educational sessions on basic diabetes knowledge and skills by a diabetes nurse. Perceived self-efficacy for nutrition was found to explain 11- 13% of the variance in diabetes self-management dietary behaviors. Interestingly, there were no significant changes in perceived exercise self-efficacy or perceived social support over the six months of education sessions. The study suggested that healthcare professionals might improve dietary compliance of people newly diagnosed with diabetes by tailoring the education program to increasing self-efficacy and self-confidence.

Based on the findings from the reported studies, it is necessary to conduct further research into illness identification and comprehension and self-care management of

diabetic symptoms. Increased education and knowledge does not necessarily increase

adherence to self-care activities (Grant, 2013), although some success has been seen in

focused education interventions (Clark, 2009). Perception of illness may have an impact

on adherence to self-care activities (Carpenter, 2012; Della, 2011); however, perception

of risk, individual responsibility, and severity of symptoms may also impact self-

management of T2DM (Adriaanse et al., 2008; Blue, 2007; DePalma, Rollison, &

Camporese, 2011). The use of the Self-Regulatory Model may be beneficial in assessing

a deeper understanding of a patient's perception of illness and how this perception may

impact self-care activities to manage the illness (Broadbent et al., 2011; Petricek et al.

2009). Few studies were found that directly addressed the illness identification and self-

management practices of a group of vulnerable diabetics within specific regions of the

US. An exploratory study of Louisiana residents is indicated to add information specific

to Louisiana in light of the disproportionate impact of T2DM on the residents of this area.

<div align="center">Theoretical Model: Self-Regulatory Model of Illness</div>

The Self-Regulatory Model of Illness (SRM) is a theory about the ideas and

beliefs individuals have regarding a diagnosis of disease and how these ideas impact

coping strategies (Leventhal, Brisette, & Leventhal, 2003). SRM, also known as the

Common Sense Model of Illness or Personal Model of Illness, was developed by

Leventhal in the 1960's. According to the SRM, individuals respond to stimulus on a

cognitive and emotional level in effort to avoid danger and negative emotions (Harvey &

Lawson, 2009). The SRM implies that the patient is an active problem-solver. The

patient attempts to solve the problem or control the problem through actions. The SRM

consists of three stages: illness representation, coping, and evaluation. The illness

representation is how the patient views the illness. Illness representation is derived from both the cognitive and the emotional representations of the variables of *identity, time, cause, consequence*, *control,* and *curability*. The coping stage includes self-care activities aimed at managing the disease. In the evaluation stage, the individual assesses the effectiveness of self-care activities. Based on the individuals evaluation of the outcome of the self-care activities, modifications to coping strategies may ensue. This evaluation may also lead to a reevaluation of how the patient perceives the illness. According to Harvey and Lawson (2009), "Leventhal's Self- Regulatory Model currently seems to offer the best system for identifying the determinants of patient self-care behavior" (p. 5). The following model in expanded variable form was created by the researcher and used to guide the study.
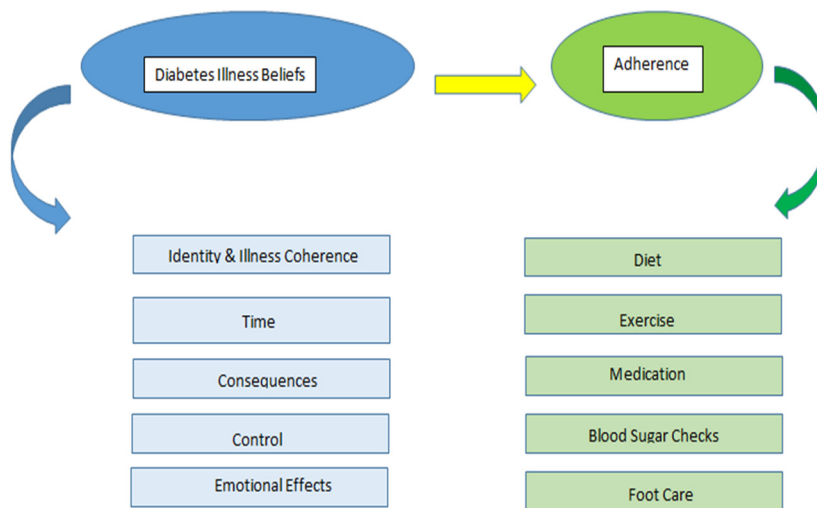
Figure 1. Illness Representation and Its Effect on Variables of Self-care Activities (Adapted from Leventhal's Self-regulatory Model)

Conceptual and Operational Definitions

The independent variables to be used as predictors of adherence in Louisiana diabetic adults are *illness belief, time, consequences, control,* and *emotional effects.* The dependent variable will be operationalized by the five diabetes management parameters: diet, exercise, medication, blood sugar checks, and foot care. Conceptual and operational definitions are offered to clarify how variables were defined and measured.

Diabetes Illness Beliefs

The conceptual definition of *diabetes illness beliefs* is based upon the *illness representation* in the *SRM* which is defined as the patient's beliefs and expectations about an illness or somatic symptoms (Leventhal, Brisette, & Leventhal, 2003). This variable was operationalized by the measurement of the five independent variables subsumed within it and was measured using the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002). This questionnaire consists of three categories. The first category list 14 dichotomous (yes/no) items about symptoms of illness: "I have experienced this symptom since my illness" and "This symptom is related to my illness". The second section measures views about the illness and has 38 statements the subject rates with a scale of "strongly disagree, disagree, neither agree or disagree, agree, or strongly agree". The last section measures causes of illness and consists of 18 items to which the individual responds with "strongly disagree, disagree, neither agree or disagree, agree, or strongly agree". Finally, the questionnaire concludes with the individual listing in rank order the three most important factors now believed to have caused the illness.

The sub-set of variables to determine *diabetes illness beliefs (see Figure 1)* are specified as subscales within the IPQ-R (Moss-Morris et al., 2002); conceptual definitions arise from this source. These variables are *identity, illness coherence, timeline (acute/chronic), timeline cyclical, consequences, personal control, treatment control, emotional representations, and causes.*

Identity is conceptually defined as "the symptoms the patient associates with the illness" (Weinman, Petrie, Moss-Morris, & Horne, 1996, p.431). Identity was operationalized first by identifying symptoms present within the individual, and second, by recognizing these symptoms as a result of the disease process. This subscale derives a sum score range of 0 – 14, as there are 14 symptoms listed which can be recognized as a result of the disease process.

A second variable, illness *coherence,* refers to "the way in which the patient evaluates the …usefulness of his or her illness representation" (Moss-Morris et al., 2002, p.2). Illness coherence is operationalized with statements such as "My illness is a mystery to me" and "The symptoms of my disease are puzzling to me." This variable was operationalized using the IPQ-R subscale of IP24 – IP28, which produced a score range of 0-25.

Time refers to "the perceived duration of the illness" (Weinman et al., 1996, p.431). This variable was operationalized using the IPQ-R timeline subscale of items IP1 –IP5 + IP18 which has a range of 0-30. *Timeline cyclical* refers to whether or not the individual perceives the disease process as cyclic, associated with a pattern which repeatedly occurs within the individual. This variable was operationalized using the IPQ-R subscale items IP29 – IP32, which produces a range of 0-20.

Consequences are defined as "expected effects and outcomes" (Weinman et al., 1996, p.431). These can be physical, financial, emotional, or social in nature. This variable was operationalized using the IPQ-R subscale items IP6 – IP11 producing a range of 0-30.

Control refers to "how one …recovers from the illness" (Weinman, et al., 1996, p.431). The IPQ-R has two subscales to reflect control. The first is *personal control. Personal control* reflects the individual's perception of their ability to control disease symptoms. This variable was operationalized using the IPQ-R. Statements include "There is a lot which I can do to control my symptoms" and "What I do can determine whether my diabetes gets better or worse." This subscale consisted of items IP12 – IP17 and produced a range of 0-30. The second subscale for *control* is *treatment control items. Treatment control items* refer to the perception of the individual regarding the current medical treatment plan. This variable was operationalized using the IPQ-R. It contained statements such as "My treatment will be effective in curing my diabetes." This subscale consisted of items IP19 – IP23 and produced a range of 0-25.

Emotional representations refer to "the emotional responses generated by the illness" (Moss-Morris et al., 2002, p.2). This variable was operationalized using the IPQ-R subscale. Statements include "I get depressed when I think about my diabetes" and "My diabetes makes me feel angry." The subscale consists of items IP33 – IP38 and produced a range of 0-30.

Causes refer to the "personal ideas about an etiology" (Weinman et al., 1996, p.431). The IPQ-R was used to operationalize this variable. This particular variable is

reflected in items C1 – C8 but did not produce a sum score. Instead it was used as a

grouping variable (those who do/those who do not believe in a specific causal factor).

Adherence

Adherence (see Figure 1) reflects the SRM construct of *self- regulation* which is

conceptually defined as the function of the representation of illness and the ongoing

coping methods and appraisal of the coping methods (Leventhal, Diefenbach, &

Leventhal, 1992). *Adherence* was operationally defined using a 15 item instrument called

the Summary of Diabetes Self- Care Activities (SDSCA) questionnaire of Toolbert,

Hampson, and Glasgow (2000) to measure the different activities performed and

frequency these activities were performed on a daily and weekly basis. The activities of

self-care included medication, diet, exercise, blood sugar testing, and foot care. The

questionnaire concluded with a listing of recommendations and asked the individual to

check all those recommended by a personal healthcare provider.

Diet refers to the consumption of foods low in glycemic index (ADA, 2014a). This

variable was operationalized using the SDSCA subscales of *general diet* and *specific diet.*

This produced a score range of 0-35. The items included questions such as "How many

of the last seven days have you followed a healthy eating plan." The client will then

choose a number of 0-7.

Exercise refers to "aerobic exercise, strength training, flexibility

exercises/stretching, balance exercises…recommended for people with diabetes" (ADA,

2015b). This variable was operationalized using the SDSCA subscale of *exercise* and

produced a range of 0-14. It included statements such as "On how many of the last seven

days did you participate in at least 30 minutes of physical activity?"

Medication refers to the prescribed oral medications and/or insulin to assist people with diabetes maintain healthy blood glucose levels (ADA, 2015a). This item was operationalized using the SDSCA subscale of medication and produced a range of 0 – 7. This subscale consisted of one item. The question is "On how many of the last 7 days did you take your recommended diabetes medication?" The client then chose a number of 0 – 7.

Blood sugar testing refers to the use of a blood glucose meter to determine blood glucose level at that point in time (ADA, 2009). It was operationalized using the SDSCA subscale of *blood sugar testing* and produced a range of 0-14. It included questions such as "On how many of the last seven days did you test your blood sugar?"

Foot care refers to the recommendation for persons with diabetes to perform daily foot inspections for red spots, cuts, blisters, and swelling (ADA, 2014b). It was operationalized using the SDSCA subscales of *general foot care* and *specific foot care,* which produced a range of 0-35. It includes statements such as "On how many of the last seven days did you check your own feet?"

Research Hypotheses

Based on the adapted Self-Regulatory Model of Illness and current state of the science, the following hypotheses were studied:

Among Southern Louisiana Adults with T2DM:

H1: Those who believe heredity caused their diabetes have lower adherence to self-care activities than individuals without that belief.

H2: Those who believe aging caused their diabetes have lower adherence to self-care activities than individuals without that belief.

H3: Those who believe that diet and eating habits caused diabetes have higher adherence to self-care activities than individuals without that belief.

H4: The diabetic illness variables of identity/illness coherence, time, consequence, control, and emotional effects explains variance in diet.

H5: The diabetic illness variables of identity/illness coherence, time, consequence, control, and emotional effects explains variance in exercise.

H6: The diabetic illness variables of identity/illness coherence, time, consequence, control, and emotional effects explains variance in medication.

H7: The diabetic illness variables of identity/illness coherence, time, consequence, control, and emotional effects explains variance in blood sugar checks.

H8: The diabetic illness variables of identity/illness coherence, time, consequence, control, and emotional effects explains variance in foot care.

Methods

Design and Sample

A cross-sectional, exploratory design was used to test the eight hypotheses. A sample of 97 participants with a known diagnosis of T2DM was recruited to take part in the study. Power analysis was performed using G*Power 3.1for Windows XP and indicated a sample size of 92 to achieve a medium effect size with a power of 8.0 and significance level of 0.05). The Institutional Review Boards of the University of Texas at Tyler and the University of Louisiana at Lafayette approved the study. Participants were recruited from multiple church gatherings and physician offices throughout the Acadiana region of Southern Louisiana. Speeches were made at church services to discuss the research and ask for volunteers (Appendix C). Two rural physicians assisted in

recruitment efforts of participants through their office visits. Inclusion criteria were (a) resident of Louisiana and (b) formal diagnosis of T2DM. Exclusion criteria included non-Louisiana resident and any medical diagnosis which would impair cognitive functioning, such as Alzheimer's disease or dementia.

Instrumentation

Instruments included three surveys. A demographic survey (Appendix D) gathered data related to age, gender, race, marital status, residency, home situation, time since diabetes diagnosis, family health history, and provider information. The IPQ-R (Appendix F) was used to gather data related to the independent variables of illness perception. The SDSCA (Appendix E) was used to gather data related to the dependent variables of adherence.

Data Collection

The research was explained to each participant. Time was allotted for questions and answers. A consent to participate in the research study was signed by each participant, and they were given a copy (Appendix A). The setting consisted of meeting rooms on the church grounds or examination rooms in physicians' offices. Assistance was provided to participants who required the forms to be read aloud due to vision changes. Data collection took place over four months from May 2014 to September 2014

Data Analysis

The International Business Machines (IBM) Statistical Package for the Social Sciences (SPSS) version 20.0 was used to analyze data. A preset alpha of .05 was used to determine significance. Exploratory data analysis was performed using guidelines from *Discovering Statistics Using SPSS* (A. Fields, 2013). Reliability analysis was performed on items of the subscales of both the IPQ-R and the SDSCA using Cronbach's

alpha. The subscales of timeline (α = .72), consequences (α = .73) personal control (α = .83), illness coherence (α = .84), and emotional representation (α = .78) of the IPQ-R all had acceptable reliability. However, the subscales of treatment control (α = .63) and timeline cyclical (α = .68) had less reliability. This is similar to the findings of French (2013) in treatment control (α = .40), but in contrast to timeline cyclical (α = .87). The subscales of exercise (α = .84), general diet (α = .93), and blood sugar checks (α = .92), of the SDSCA all had adequate reliability. The subscale of general foot care had less reliability (α = .636). However, the subscales of specific foot care and specific diet showed poor reliability and had not been reported previously. Pearson's correlation coefficients were used to determine relationships between IPQ-R subscales and the SDSCA subscales. T-tests were used to test differences between groups for H1, H2, and H3. Multiple regression was used to test H4, H5, H6, H7, and H8.

<center>Results</center>

Sample Description

A sample of 97 participants was recruited. Demographic data is shown in Table 1 (Appendix H); however, the sample can be characterized as slightly more females (55%), and mostly Caucasian (81%). About half of the sample were over age 65 (49%) and slightly over half (53%) were married. Participants reported they lived in Louisiana from 2 to 90 years with 97% residing in Louisiana for 10 or more years. The time diagnosed with diabetes ranged from 1 to 40 years with 44.3% diagnosed for 10 or more years. Seventy-nine percent had a family history of diabetes, and 17% were not on any prescription diabetic medications to manage diabetes. Fifty-two percent were prescribed pills only, and 7%were prescribed injections only. Twenty-five percent were prescribed

pills and injections to manage diabetes. Almost everyone (95%) had some form of medical coverage. BMI ranges from 16.6 to 56.14 with 69% having a BMI of 30 or greater indicating obesity.

Hypotheses Testing

Hypothesis 1: Participants who believed heredity caused their DM had lower adherence than those without that belief. Hypothesis #1 was rejected ($t(76) = -1.85$, $p =.07$). Unequal groups sizes with most adults ($N = 67$) recognizing heredity does cause DM (and only 7 who did not) explained the non-significant results (for those who didn't attribute DM to heredity ($M = 56.3$, $SE = 6.1$) versus those who recognized heredity as a cause ($M = 60.9$, $SE = 1.7$). Using Pearson's correlation, heredity was found to have a relationship with diet. Belief in heredity as a cause of diabetes was significantly related to general diet, $r = .26$, $p = .01$, and specific diet, $r = .25$, $p = .016$, indicating this belief is related to diet adherence.

Hypothesis 2: Those who believed aging caused their DM had lower adherence than those without that belief. Hypothesis #1 was rejected ($t(67)= -.9$, $p=.37$). Unequal group sizes again undermined the ability to discern differences and also demonstrated that more adults recognized aging impacts DM.

Hypothesis 3: Those who believed that their behavior caused diabetes have higher adherence to self-care activities than individuals without that belief. Hypothesis #3 was accepted ($t(70) = -2.387$, $p =.02$). Only two individuals felt diet did not cause DM ($M = 35$, $SE =10.0$) versus those who recognized diet matters and had significantly higher adherence behaviors ($M = 60.64$, $SE = 1.7$). While statistically significant, the small

group size of two for those who believed diet caused DM undermined statistical conclusion validity.

Hypotheses 4-8: The diabetic illness variables of identity, time, consequence, controllability, and emotional representation explained variance in diet, exercise, medication, blood sugar checks, and foot care. While the individual surveys performed well in terms of internal consistency reliability, most failed to meet the assumptions for multiple regression with normality issues and multicollinearity issues. Thus, it was not surprising that each of the regression hypotheses failed to yield statistically significant models in prediction of any of the outcomes of diet, exercise, medication, blood sugar checks, and foot care.

Correlations

Three variables were found to be related to at least one of the outcome indicators of adherence. Identity was significantly related to exercise, $r=.23$, $p <.05$. Consequences were significantly related to exercise, $r = .21$, $p < .05$. Timeline cyclical was significantly related to foot care, $r = .25$, $p < .05$. While these correlations cannot predict adherence levels, they are significant in that they can account for some of the variance of the adherence scores of exercise and foot care as shown in Table 2 (Appendix H). Multiple regression was used to test H4, H5, H6, H7, and H8. Using MR, Identity was found to be a significant predictor for exercise adherence, $R2 =.05$, $F(1, 95) = 5.26$, $p <.05$, 95% CI [.053, .729], but as this is only one variable of a regression model, it is deemed a correlational finding.

Clinical Findings

While testing did not reveal many statistically significant findings, several findings were clinically useful. Limited variance in reporting of results accounted for less statistical significance, but it led to interesting clinical findings in terms of percentages of the sample which held certain perceptions of their diabetes and their ability to influence their diabetes. Descriptive frequency was used to determine findings of individual items of each instrument. Frequencies of the IPQ-R were assessed in terms of those who answered "strongly agree or agree" as shown in Table 3 (Appendix H).

In terms of individual items of the SDSCA, adherence scores were low with the exception of medication. Of 97 participants, 81 required daily medication, while 16 were not prescribed any medication. Of those 81 participants, 85.1% reported taking their prescribed medications every day as directed by their healthcare provider. In regards to the blood glucose testing sum (0 – 14), only 34 of 97 participants received a score of 14 indicating perfect compliance with recommended glucose monitoring. Twenty-five participants received a score of 0 indicating that blood glucose was not tested. In regards to foot care (0 -14), only 19 of 97 participants received a 14, indicating that they performed daily inspections of their feet. Twenty-one of 97 received a score of 0, indicating they did not inspect their feet or the inside of their shoe for the week.

<div align="center">Discussion</div>

T2DM is a serious condition for Southern Louisiana residents. While the findings in this study do not support the model for prediction of self-care activities, it does lead to some interesting findings. Individual variables of illness perception were found to be significant in relationship to individual variables of adherence.

<div align="center">49</div>

Identity and Consequences

Identity was significantly related to exercise, indicating that if one can identify symptoms of the disease process and have an understanding of the process, that person may be inclined to adhere to or participate in exercise programs. In this sample the most frequent symptom noted and associated with diabetes was fatigue. No participant had an amputation or diabetic wound at the time of this study. All other symptoms had very low percentages when asked if it was related to diabetes within the sample. This is interesting in that diabetes has been called a *silent disease*. It is a disease with few outward symptoms until further damage is done on a macrovascular and microvascular level. The insidious nature of the disease supports the CDC's (2014a) estimates that approximately 8.1 million Americans have diabetes but currently do not know.

Control

The study found that 85.1% of the sample who had been prescribed medication by their health provider were adherent in taking that medication daily. This is in contrast to reported low medication adherence among other population groups, such as Yang (2009), who reported that non-adherence with medication therapy was especially high. Concurrently, 87.65% of this sample agreed that adhering to their treatment can control their diabetes indicating rationale for medication adherence. Unfortunately, adherence to all other self-care activities was low. Ninety-one percent of participants noted that "the course of my diabetes depends on me", with 86.6% reporting "I have the power to influence my diabetes"; yet overall individual sum scores of the SDSCA were medium to low in supporting adherence to self-care activities of diet, exercise, blood sugar checks, and foot care. This sample had a sense of control, but they did not do important self-care

activities like blood sugar and foot checks. This finding lends support to the findings of French, Wade, and Farmer (2013) who found that "beliefs about behavior are at least as important as beliefs about illness in predicting health-related behaviors" (p.327).

Illness Coherence

As with the study of Jacob, Kemppainen, Taylor, and Hadsell (2014) of the Lumbee Indians, this sample of participants from Southern Louisiana also viewed heredity as a cause of T2DM and noted the importance of taking medication. While adherence to medication prescriptive instructions was present, a willingness to modify behavior or lifestyle was not demonstrated. Southern Louisiana residents place great emphasis on food, festivities, and family life. Adopting new diets and exercise regimens may prove difficult for some who have been steeped in the tradition of eating rich foods, particularly when very few negative symptoms can be felt by a particular disease process.

Limitations

This study explored the perceptions and adherence to protocols of people with diabetes living in Southern Louisiana. Some limitations to external validity must be considered. The population for this sample was predominantly over 65 years old (49%). A sample with more variance in age may lead to a deeper understanding of perception and its effect on adherence. Power analysis indicated a sample of 92 was sufficient; however, higher sample numbers may have led to more variance. While no participants demonstrated mobility issues, 69% of the sample had a BMI greater than 30. This may have had some impact on their ability to perform exercise and may have been a contributor to low adherence scores for this variable. This study did not provide support for the model or hypotheses, but it did add to the understanding of diabetes management

in Southern Louisiana adults who have been shown to be at disproportionate risk for diabetes in the US (DHHS Louisiana, 2012).

<div align="center">Recommendations</div>

This study emphasizes the need for more research in relation to self-care activities and adherence initiatives for diabetics in Southern Louisiana. In terms of self-care activities, further research is indicated to determine if patients perceive all self-care activities as equally important elements of treatment. While the ease of taking medications is demonstrated in this study, life style changes needed for adherence to self-care activities deserve attention. The low adherence to foot care is particularly troubling in this vulnerable group and warrants closer study to determine if health beliefs apply to this finding. Diabetic foot conditions are responsible for more hospital admissions than any other aspect of this chronic condition, and persons with diabetic foot infections are at a greater risk for expensive hospitalizations (Kosinski & Lipsky, 2010). New strategies for engaging vulnerable persons in self-care activities should be a priority. Diabetic education could focus on the importance of self-care activities as a way to decrease negative outcomes of T2DM. Studies of persons with noted symptoms or side effects of diabetes are indicated as it pertains to behavior changes. These findings could then be compared to those with little or no noticeable symptoms to determine if the presence of symptoms is related to adherence to self-care activities. Further studies are recommended to determine if the variable of time living with diabetes is related to self-management using a sample of those who are newly diagnosed and those who have had T2DM for some time longer than a year. Culturally centered research in terms of socioeconomic

status, quality of life, and motivation for life style changes might also be potentially instructive.

Health care providers are in a unique position to discuss perceptions and goals with their patients in a patient-centered format. Taking time to explore each patient's unique perspective regarding the disease process may prove beneficial for short term and long term outcomes. Assisting patients in determining small changes to lifestyle or behavior may also increase willingness and motivation to engage in positive health behaviors. Increasing awareness of symptoms in a disease such as diabetes may be indicated as an avenue to earlier diagnosis. Finally, it is clear that this sample of diabetic persons from Southern Louisiana is not practicing optimal self-care diabetic health behaviors. Further study based on a cultural approach using dietary modifications of traditional Cajun foods should be given a chance to determine its acceptance. At least it would call attention to the importance of dietary management as an important aspect of diabetic self-regulation; at best it could change a culture and push diabetic adherence toward becoming a cultural norm.

<div align="center">Conclusion</div>

Type 2 diabetes mellitus is having an enormous impact on Southern Louisiana. As obesity rates rise, so do cases of diabetes. This study highlights the need for further investigation into the disproportionate rates of T2DM in Louisiana. While levels of adherence to behavior changes may not be high, medication adherence among Southern Louisiana adult diabetics was positive. Further research into self-care activities identifying the best elements to promote and influence those activities is needed. Health care providers are in a prime position to assist those in their communities by increasing

<div align="center">53</div>

their understanding issues related to optimal adherence and developing patient-centered

approaches to improve outcomes.

References

American Diabetes Association. (2014a, May 14). *Glycemic index and diabetes.*

Retrieved from http://www.diabetes.org/food-and-fitness/food/what-can-i-
eat/understanding-carbohydrates/glycemic-index-and-diabetes.html

American Diabetes Association. (2014b, October 10). *Foot care.* Retrieved from

http://www.diabetes.org/living-with-diabetes/complications/foot-
complications/foot-care.html

American Diabetes Association. (2015a) *Medication.* Retrieved from

http://www.diabetes.org/living-with-diabetes/treatment-and-care/medication/

American Diabetes Association, (2015b). *Types of activity.* Retrieved from

http://www.diabetes.org/food-and-fitness/fitness/types-of-activity/

American Diabetes Association. (2009). All about blood glucose. *Toolkit No. 15.*

Retrieved from

http://professional.diabetes.org/PatientEducationLibraryDetail.aspx?pmlPath=All
_About_Blood_Glucose_fc347408-a063-4457-841b-
101c91780f67&pmlName=All_About_Blood_Glucose.pdf&pmlId=43&pmlTitle
=All%20About%20Blood%20Glucose%20-
%20English&utm_source=dorg&utm_medium=Online&utm_content=bgtesting&
utm_campaign=pem&s_src=vanity&s_subsrc=dorg

American Diabetes Association. (2013). Economic costs of diabetes in the U.S.

Diabetes Care, 1 – 14. doi: 10.2337/dc12-2625

American Diabetes Association. (2015). *Complications.* Retrieved from

http://www.diabetes.org/living-with-diabetes/complications/

Adriaanse, M., Twisk, J., Dekker, J., Spikerman, A., Nijpels, G., Heine, R., & Snoek, F.

(2008). Perceptions of risk in adults with a low or high risk profile of developing

T2DM: A cross-sectional population based study. *Patient Education and*

Counseling 73, 307-312. doi: 10.1016/j.pec.2008.06.009

Blue, C. (2007). Does the Theory of Planned Behavior identify diabetes-related

cognitions for intention to be physically active and eat a healthy diet? *Public*

Health Nursing 24(2), 141-151.

Broadbent, E., Donkin, L., & Stroh, J. (2011). Illness and treatment perceptions are

associated with adherence to medications, diet, and exercise in diabetic patients.

Diabetes Care, 34, 338-340. doi: 10.2337/dc10-1779

Carpenter, R. (2012). Appraisal of perceived threat of diabetes and the relation to

adherence for adults in Appalachia. *Journal of Health Care for the Poor and*

Underserved, 23(2), 726-728. doi: 10.1353/hpu.2010.0049

Centers for Disease Control and Prevention. (2013). Death: Final data for 2010.

National Vital Statistics Reports 61(4). Retrieved from

http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_04.pdf

Centers for Disease Control and Prevention. (2014a). *2014 National Diabetes Statistics*

Report. Retrieved from

http://www.cdc.gov/diabetes/data/statistics/2014StatisticsReport.html

Centers for Disease Control and Prevention. (2014b) *Stats of the state of Louisiana.*

Retrieved from http://www.cdc.gov/nchs/pressroom/states/LA_2014.pdf

Centers for Disease Control and Prevention. (2015). *National Diabetes Surveillance System.* Retrieved from http://gis.cdc.gov/grasp/diabetes/DiabetesAtlas.html

Clark, A. (2009). Effects of routine education on people newly diagnosed with type 2 diabetes. *European Diabetes Nursing*, 6(3), 88-94. doi: 10.1002/edn.142

Creager, M., & Luscher, T. (2003). Diabetes and vascular disease pathophysiology, clinical consequences, and medical therapy: Part I. *Circulation: American Heart Association*, *108*, 1527-1532. doi: 10.1161/01.CIR.0000091257.27563.32

Della, L. (2011). Exploring diabetes beliefs in at-risk Appalachia. *The Journal of Rural Health 27*, 3-12. doi: 10.1111/J.1748-0361.2010.00311.x

DePalma, M., Rollison, J., & Camporese, M. (2011). Psychosocial predictors of diabetes management. *American Journal of Health Behavior, 35*(2), 209-218. doi: http//dx.doi/10.5993/AJHB.35.2.8

Department of Health and Hospitals of Louisiana. (2012). *2012 Louisiana Diabetes Factsheet.* Retrieved from http://new.dhh.louisiana.gov/assets/oph/pcrh/diabetes/2012_Louisiana_Diabetes_Factsheet.pdf

Fields, A. (2013). *Discovering statistics using SPSS* (3rd ed). London. Sage Publications Ltd.

French, D. Wade, A., & Farmer, A. (2013) Predicting self-care behaviours of patients with type 2 diabetes: The importance of beliefs about behavior, not just beliefs about illness. *Journal of Psychosomatic Research, 74,* 327-333. doi:10.1016/j.psychores.2012.12.008

Grant, R. W., Obrien, K., Waxler, J., Vassy, J., Delahanty, L., & Bissett, L. (2013). Personalized genetic risk counseling to motivate diabetes prevention. *Diabetes Care, 36,* 13-19. doi: 10.2337/dc12-0884.

Harvey, N., & Lawson, V. (2009). The importance of health belief models in determining self-care behavior in diabetes. *Diabetic Medicine, 26*, 5-13. doi: 10.1111/j.1464-5491.2008.02628.x

Jacobs, A., Kemppainen, J., Taylor, J., & Hadsell, C. (2014). Beliefs about diabetes and medication adherence among Lumbee Indians living in rural Southeaster North Carolina. *Journal of Transcultural Nursing, 25*(2), 167-175. doi: 10.1177/1043659613515718

Kosinski, M.A., & Lipsky, B.A. (2010). Current medical management of diabetic foot infections. *Expert Review of Anti-infective Therapy, 8*(11), 1293-1305.

King, D., Glasgow, R., Toobert, D., Strycker, L., Estabrooks, P., Osuna, D., & Faber, A. (2010). Self-efficacy, problem solving, and social environmental support are associated with diabetes self-management behaviors. *Diabetes Care, 33*(4), 751-761. doi: 10.2337/dc09-1746

Lau, R.R., & Hartman, K.S. (1983). Common sense representations of common illness. *Health Psychology,* (2), 167-185.

Lau, D., & Nau, D. (2004). Oral antihyperglycemic medication nonadherence and subsequent hospitalization among individuals with type 2 diabetes. *Diabetes Care 27*(9), 2149-2153. doi: 10.2337/diacare.27.9.2149

Leventhal, H., Brissette, I., & Leventhal, E.A. (2003). The common-sense model of self-regulation of health and illness. In Cameron, L.D. and Leventhal, H. eds. *The Self-regulation of Health and Illness Behaviour*. New York: Routledge.

Leventhal, H., Diefenbach, M., & Leventhal, E. (1992, April). Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research, 16*(2), 143-163. doi: 10.1007/BF01173486.

Mann, D., Ponieman, D., Leventhal, H., & Halm, E. (2009). Predictors of adherence to diabetes medications: The role of disease and medication beliefs. *Journal of Behavioral Medicine 32,* 278-284. doi: 10.1007/s10865-009-9202-y

Moss-Morris, R., Weinman, J., Petrie, K. J., Horne. R., Cameron, L.D., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology and Health 17,* 1-16. doi: 10.1080/08870440290001494

Petricek, G., Vrcic-Keglevic, M., Vuletic, G., Cerovecki, V., Ozvacic, Z., & Murgic, L. (2009). Illness perception and cardiovascular risk factors in patients with type 2 diabetes mellitus: Cross sectional questionnaire study. *Croatian Medical Journal, 50,* 583-593

Toolbert, D. Hampson, S., & Glasgow, R. (2000, July). The summary of diabetes self-care activities measure. *Diabetes Care, 23*(7), 943-950. doi: 10.2337/diacare.23.7.943

Weinman, J., Petrie, K., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health 11*(3), 431-445. doi: 10.1080/08870449608400270

Yang, Y., Thumula, V., Pace, P., Banahan, B., Wilkin, N., & Lobb, W. (2009).

    Predictors of medication nonadherence among patients with diabetes in Medicare

    part D programs: A retrospective cohort study. *Clinical Therapeutics, 31*(10),

    2178-2188. doi: 10.1016/j.clinthera.2009.10.002

Chapter Four

Conclusions and Recommendations for Future Research

Type 2 Diabetes Mellitus (T2DM) is a growing health hazard in the United States. This condition has reached near epidemic proportions in the state of Louisiana as the CDC reports that 11.5 per 100 adult persons are diagnosed with diabetes (CDC, 2015). As the rate of obesity increases in Louisiana, the rate of T2DM is expected to increase. Diabetes is responsible for multiple negative outcomes on a multi-system level when not properly managed. Money allocated to healthcare costs associated with diabetes will continue to rise. Just as Louisiana is unique in the impact felt from diabetes, it is also unique in culture and life style. Cultural elements which impact life style and behavior can be important to the management of health conditions and chronic diseases. While much research can be found related to new diabetic medications and diabetic testing for blood glucose levels, very little is aimed at understanding behavior choices and life styles. This lack of insight into how and why diabetic persons make the health choices they do signifies a huge gap in treatment, especially, in Louisiana and other areas with large numbers of vulnerable, susceptible persons.

To answer the questions about how to curb the disastrous sequela of uncontrolled or poorly treated diabetes, it is essential to continue to study susceptible groups. Further research in the form of qualitative, quantitative, and mixed methods studies could provide valuable information for healthcare providers and diabetic patients along with their caregivers. Research aimed at studying the perception of symptoms of T2DM in relation

to the adherence of self-care activities could assist in furthering knowledge of the disease. This study showed the limitations of current self-care efforts, but new ways to approach diabetic education and support are needed. Incorporating new technology, such as texting and social media websites, is just beginning to be tested for impact in helping diabetic persons self-manage their disease within a burgeoning social networks. Studies like this one can help point out a pathway to improved outcomes by point to areas where self-care behaviors are less than adequate, such as foot care and dietary compliance with recommended guidelines. Research aimed at developing a deeper understanding of whether or not patients perceive the physical symptoms of T2DM and associate these symptoms with the disease of T2DM would be informative for healthcare providers. Furthermore, the association of symptoms with lesser or greater adherence to self-care activities is a question worthy of study. An exploratory study of two groups: those with notable symptoms and negative outcomes of diabetes, and those with minimal reportable symptoms of diabetes, to determine differences in adherence to self-care could prove beneficial in advancing the current knowledge.

Further research regarding the patient's perception of treatment could prove beneficial as well. Understanding what the patient categorizes as treatment, prescribed medication only, or even self-care activities could assist healthcare providers in delivering focused and individualized patient-centered care. In the study reported in Chapter Three, the sample showed an agreement rate of 87.6% when responding to the statement "my treatment can control my diabetes", yet the sample only showed high rates of adherence for a single one of the five self-care measures, i.e. taking medication. Further research aimed at determining what the patient considers important in terms of

controlling diabetes could prove beneficial in increasing understanding of diabetics and asking patients what they need to increase their diabetic control might help to inform health care regulator as they seek to improve outcomes.

Further research from a multidisciplinary approach is recommended. All levels of health care providers come into contact with diabetic patients. Each discipline offers a unique perspective in terms of assessment and intervention. A multi-layered approach to understanding elements impacting self-care activities provides an opportunity to increase knowledge and thus increase adherence interventions for future interaction.

Increasing awareness of diabetes and its negative impacts falls within the realm of all healthcare providers. Research involving longitudinal studies can increase understanding of behaviors and relationship to interventions. Knowing what elements can impact adherence and what elements lead to self-care activity choices could lead to new methods of managing diabetes. Samples should include those with a diagnosis of diabetes and those at risk of developing diabetes. T2DM continues to be a health issue for many in the Unites States. The Southern states hold a higher percentage of those with T2DM. Cultural beliefs, behaviors, and values impact self-care activities. Further research is needed to curb the outpouring of financial resources and human suffering caused by chronic diseases like T2DM. Studies of special populations with unique susceptibility to adverse consequences, such as the vulnerable populations of Louisiana, can help to identify the outer margins of health delivery needs in order to improve outcomes for persons suffering from a disease like T2DM.

This study was an attempt to visualize the situation of diabetes health in a vulnerable population in Southern Louisiana. Two aspects under patient control,

adherence and self-care activities, were measured in order to grasp the perceived status and needs from the patient perspective at this pivotal point in history. Healthcare is being reformed, and changes to health delivery are happening at a frenetic pace. Technology is increasing both the visibility and the urgency of this change. Studies like this one focus on the least empowered and the most likely to be forgotten in the fast-paced health changes of the 21st century. This study of a small group of vulnerable persons in a small state with big health challenges represents the best of what healthcare does when we make sure that no one gets left behind in our quest for optimal healthcare for all.

References

American Diabetes Association. (2015). Complications. *Living with diabetes.* Retrieved

from http://www.diabetes.org/living-with-diabetes/

Centers for Disease Control and Prevention, (2012). *Diabetic report card*. Retrieved

from http://www.cdc.gov/diabetes/pubs/pdf/diabetesreportcard.pdf

Centers for Disease Control and Prevention. (2014). *2014 National Diabetes Statistics*

Report. Retrieved from http://www.cdc.gov/diabetes/data /statistics

/2014StatisticsReport.html

Centers for Disease Control and Prevention. (2015). *National Diabetes Surveillance*

System. Retrieved from http://gis.cdc.gov/grasp/diabetes/DiabetesAtlas.html

Kantharidis, P., Wang, B., Carew, R., & Lan, H. (2011. Diabetes complications: The

microRNA perspective. *Diabetes, 60*(7). 1832-1837. doi: 10.2337/db11-0082

Leventhal, H., Brissette, I., & Leventhal, E.A. (2003). The common-sense model of self-

regulation of health and illness. In Cameron, L.D. and Leventhal, H. eds. *The*

Self-regulation of Health and Illness Behaviour. New York: Routledge.

National Institutes of Health. (n.d.). Cultural competency. *Clear communications.*

Retrieved from http://www.nih.gov/clearcommunication/ culturalcompetency.htm

Oriol, M. (1995). Cajun traditions and their impact on health care. *Journal of Cultural*

Diversity, 2(1), 27-29.

Pennington Biomedical Research Louisiana State University. (2014, November).

Economic burden of diabetes demonstrates need for early intervention. Retrieved

from http://www.pbrc.edu/news/?ArticleID=253

THE UNIVERSITY OF TEXAS AT TYLER
Informed Consent to Participate in Research

Institutional Review Board #
Approval Date:

1. **Project Title**:   Diabetes Mellitus: The Impact of the Variables of Illness Representation on Diabetes Self-Care Activities

2. **Principal Investigator:** Denise Stagg

3. **Participant's Name:**

To the Participant:

You are being asked to take part in this study at The University of Texas at Tyler (UT Tyler). This permission form explains:
- Why this research study is being done.
- What you will be doing if you take part in the study.
- Any risks and benefits you can expect if you take part in this study.

After talking with the person who asks you to take part in the study, you should be able to:
- Understand what the study is about.
- Choose to take part in this study because you understand what will happen

4. **Description of Project**

The purpose of this study is to ask persons with diabetes to explain their feelings of diabetes and to determine if these feelings can impact the self-care activities the person chooses to perform. Nurses and doctors can use your story to help develop treatments for diabetes and better serve the patient who is diagnosed with diabetes.

5. **Research Procedures**

If you agree to be in this study, we will ask you to do the following things:
- You will be asked to give information about your current state of health

- Your height, weight, race, gender and income level will be included in your state of health

- You will be asked to fill out 2 questionnaires which will record your feelings about your diabetes and your self-care activities you perform to manage your diabetes.

6. Side Effects/Risks

You may experience some emotional distress when answering the questions about your diabetes, thought we do not expect this to be a common problem. Should you feel distressed, you may speak to the researcher and she can help you if needed.

7. Potential Benefits

Nurses and doctors can help other diabetics and newly diagnosed diabetics better care for themselves by learning of the feelings of those living with diabetes.

.
Understanding of Participants

8.   I have been given a chance to ask any questions about this research study. The researcher has answered my questions.

9.   If I sign this consent form I know it means that:

- I am taking part in this study because I want to. I chose to take part in this study after having been told about the study and how it will affect me.

- I know that I am free to not be in this study.   If I choose to not take part in the study, then nothing will happen to me as a result of my choice.

- I know that I have been told that if I choose to be in the study, then I can stop at any time. I know that if I do stop being a part of the study, then nothing will happen to me.

- I will be told about any new information that may affect my wanting to continue to be part of this study.

- The study may be changed or stopped at any time by the researcher or by The University of Texas at Tyler.

- The researcher will get my written permission for any changes that may affect me.

10.   I have been promised that that my name will not be in any reports about this study unless I give my permission.

11. I also understand that any information collected during this study may be shared <u>as long as no identifying information such as my name, address, or other contact information is provided</u>). This information can include health information. Information may be shared with:

- Organization giving money to be able to conduct this study
- Other researchers interested in putting together your information with information from other studies
- Information shared through presentations or publications

12. I understand The UT Tyler Institutional Review Board (the group that makes sure that research is done correctly and that procedures are in place to protect the safety of research participants) may look at the research documents. These documents may have information that identifies me on them. This is a part of their monitoring procedure. I also understand that my personal information will not be shared with anyone.

13. I have been told about any possible risks that can happen with my taking part in this research project.

14. I also understand that I will not be given money for any patents or discoveries that may result from my taking part in this research.

15. If I have any questions concerning my participation in this project, I will contact the principal researcher: Denise Stagg at 337-482-6878 or email at dns1874@louisiana.edu.

16. If I have any questions concerning my rights as a research subject, I will contact Dr. Gloria Duke, Chair of the IRB, at (903) 566-7023, gduke@uttyler.edu, or the University's Office of Sponsored Research:

The University of Texas at Tyler
c/o Office of Sponsored Research
3900 University Blvd
Tyler, TX 75799

I understand that I may contact Dr. Duke with questions about research-related injuries.

17. **CONSENT/PERMISSION FOR PARTICIPATION IN THIS RESEARCH STUDY**

I have read and understood what has been explained to me. I give my permission to take part in this study as it is explained to me. I give the study researcher permission to register me in this study. I have received a signed copy of this consent form.

_____   _____
Signature of Participant   Date

_____   _____
_____
Signature of Person Responsible (e.g., legal guardian)   Relationship to Participant

_____
Witness to Signature

18. I have discussed this project with the participant, using language that is understandable and appropriate. I believe that I have fully informed this participant of the nature of this study and its possible benefits and risks. I believe the participant understood this explanation.

_____   _____
Researcher/Principal Investigator   Date

Consent to Use Facility to Conduct Research

Consent to use the facilities of _____

to recruit research participants and to conduct research study has been sought by Denise

Stagg PhDc, dissertation student of University of Texas at Tyler. The participants for this

study will be sought on a voluntary basis. They will be free to participate in the research

as they choose, and also to stop their participation in the research as they choose. The

research study proposed consists of three written surveys and a measurement of height

and weight for data collection. Time frame for research participation is estimated to take

1 to 2 hours of the participant's time in only one session. I,

_____, grant permission, for the above named

facility, to be used during this research study.

_____Print name

_____Title

_____Signature

VOLUNTEERS NEEDED!

DO YOU HAVE DIABETES TYPE TWO?

If you or someone you know has been diagnosed with diabetes type two, also known as adult onset diabetes, please consider being part of this community focused research. Diabetes is a growing concern for many residents of Southern Louisiana. Your assistance in this research could help bring new information forward on the nature of diabetes and its effect on those affected by diabetes. This research is anonymous. Your identifying information will not be recorded. All that is needed is a completion of three documents and a measure of your height and weight. This process is not expected to take more than 30 minutes to 1 hour of your time. Privacy will be provided for weight and height obtainment. The research will take place on the church grounds in a suitable room after weekend services are completed. Please consider being part of this much needed research and help in the development of new knowledge which could benefit so many people of this area and the state of Louisiana. Please call Denise Stagg at 337-781-4062 or 337-482-6878 for more information.

Appendix D: Demographic Survey

Demographic Survey

Please circle the response that best represents your current status

1. Please indicate your gender
    a. Male
    b. Female
2. How would you describe your race?
    a. Black or African American
    b. Asian
    c. White
    d. American Indian
    e. Two or more races
3. Are you Hispanic?
    a. Yes
    b. No
4. Please write your current age in the space provided?
    a. _____
5. What is your current marital status?
    a. Single
    b. Married
    c. Separated
    d. Divorced
    e. Widowed
6. How long have you lived in Louisiana? (enter the number of years please) _____
7. Please enter the number of adults currently living in your home_____
8. Please enter the number of children <18 currently living in your home _____
9. How long have you been diagnosed with diabetes? (enter a number please) _____
10. Do you have a family history of diabetes?
    a. No
    b. Yes
11. What is your current use of medication to control your diabetes?
    a. No medication at this time
    b. Pills only
    c. Injections only
    d. Pills and injections
12. How often do you see your doctor?
    a. Only when you are ill
    b. Once a year
    c. Twice a year
    d. More than twice a year
13. Do you currently have any form of healthcare coverage? (Medicare, Medicaid, private insurance)
    a. Yes
    b. No

Appendix D. (Continued)

This section is to be completed by the researcher

_____

___

     14. Height _____
     15. Weight _____
     16. BMI   _____

Appendix E: Summary of Diabetes Self-Care Activities

The Summary of Diabetes Self- Care Activities * Revised

The questions below ask you about your diabetes self-care activities during the past 7 days. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick.

Please circle the number which best represents the number of days for each

question

Diet
How many of the last SEVEN DAYS have you followed a healthful eating plan?

0 1 2 3 4 5 6 7

On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products?

0 1 2 3 4 5 6 7

5A. How many of the last SEVEN DAYS did you space carbohydrates evenly through the day?

0 1 2 3 4 5 6 7

Exercise
On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?

0 1 2 3 4 5 6 7

Blood Sugar Testing
On how many of the last SEVEN DAYS did you test
your blood sugar?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you test your sugar the number of times
recommended by your healthcare provider?
0 1 2 3 4 5 6 7
Medications
6A. On how many of the last SEVEN DAYS, did you take your recommended
diabetes medication? If you not on medication please choose "NA" option

0 1 2 3 4 5 6 7 NA

Foot Care

On how many of the last SEVEN DAYS did you check your feet

 0   1 2 3 7 4 6 7

Oh how many of the last SEVEN DAYS did you inspect the inside of your shoes?

0 1 2 3 4 5 6 7

9A. On how many of the last SEVEN DAYS did you wash your feet?

0 1 2 3 4 5 6 7

10A. On how many of the last SEVEN DAYS did you soak your feet?

0 1 2 3 4 5 6 7

11A. On how many of the last SEVEN DAYS did you dry between your toes after
washing?

0 1 2 3 4 5 6 7

Smoking
Have you smoked a cigarette—even one puff—during the past SEVEN DAYS?
0. No
1. Yes. *If yes*, how many cigarettes did you smoke on an average day?
Number of cigarettes:_____

Self-Care Recommendations
1A. Which of the following has your health care team (doctor, nurse, dietitian, or diabetes educator) advised you to do? Please check all that apply:

____ a. Follow a low-fat eating plan

____ b. Follow a complex carbohydrate diet

____ c. Reduce the number of calories you eat to lose weight

____ d. Eat lots of food high in dietary fiber

____ e. Eat lots (at least 5 servings per day) of fruits and vegetables

____ f. Eat very few sweets (for example: desserts, non-diet sodas,

    candy bars)

____ g. Other (specify):_____

____ h. I have not been given any advice about my diet by my health care team.

2A. Which of the following has your health care team (doctor, nurse, dietitian or diabetes educator) advised you to do? Please check all that apply:

____ a. Get low level exercise (such as walking) on a daily basis.

____ b. Exercise continuously for a least 20 minutes at least 3 times a

    week.

____ c. Fit exercise into your daily routine (for example, take stairs instead of elevators,

    park a   block away and walk, etc.)

____ d. Engage in a specific amount, type, duration and level of

    exercise.

____ e. Other (specify):

____ f. I have not been given any advice about exercise by my health care team.

3A. Which of the following has your health care team (doctor, nurse, dietitian, or diabetes educator) advised you to do? Please check all that apply:

____ a. Test your blood sugar using a drop of blood from your finger and a color chart.

____ b. Test your blood sugar using a machine to read the results.

____ c. Test your urine for sugar.

____ d. Other (specify):

____ e. I have not been given any advice either about testing my blood or urine sugar

level by my health care team.

4A. Which of the following medications for your diabetes has your doctor prescribed? Please check all that apply.

____ a. An insulin shot 1 or 2 times a day.

____ b. An insulin shot 3 or more times a day.

____ c. Diabetes pills to control my blood sugar level.

____ d. Other (specify):

____ e. I have not been prescribed either insulin or pills for my diabetes.

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

YOUR VIEWS ABOUT YOUR ILLNESS
Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

I have experienced this symptom *since my illness*. This symptom is *related to my illness*

Pain	Yes	No	_____	Yes	No
Sore Throat	Yes	No	_____	Yes	No
Nausea	Yes	No	_____	Yes	No
Breathlessness	Yes	No	_____	Yes	No
Weight Loss	Yes	No	_____	Yes	No
Fatigue	Yes	No	_____	Yes	No
Stiff Joints	Yes	No	_____	Yes	No
Sore Eyes	Yes	No	_____	Yes	No
Wheeziness	Yes	No	_____	Yes	No
Headaches	Yes	No	_____	Yes	No
Upset Stomach	Yes	No	_____	Yes	No
Sleep Difficulties	Yes	No	_____	Yes	No
Dizziness	Yes	No	_____	Yes	No
Loss of Strength	Yes	No	_____	Yes	No

We are interested in your own personal views of how you now see your current illness. Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	My illness will last a short time					
IP2	My illness is likely to be permanent rather than temporary					
IP3	My illness will last for a long time					
IP4	This illness will pass quickly					
IP5	I expect to have this illness for the rest of my life					
IP6	My illness is a serious condition					

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP7	My illness has major consequences on my life					
IP8	My illness does not have much effect on my life					
IP9	My illness strongly affects the way others see me					
IP10	My illness has serious financial consequences					
IP11	My illness causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my illness gets better or worse					
IP14	The course of my illness depends on me					
IP15	Nothing I do will affect my illness					
IP16	I have the power to influence my illness					
IP17	My actions will have no affect on the outcome of my illness					
IP18	My illness will improve in time					
IP19	There is very little that can be done to improve my illness					
IP20	My treatment will be effective in curing my illness					
IP21	The negative effects of my illness can be prevented (avoided) by my treatment					
IP22	My treatment can control my illness					
IP23	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My illness is a mystery to me					
IP26	I don't understand my illness					
IP27	My illness doesn't make any sense to me					
IP28	I have a clear picture or understanding of my condition					
IP29	The symptoms of my illness change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My illness is very unpredictable					
IP32	I go through cycles in which my illness gets better and worse.					

IP33	**I get depressed when I think about my illness**					
IP34	**When I think about my illness I get upset**					
IP35	**My illness makes me feel angry**					
IP36	**My illness does not worry me**					
IP37	**Having this illness makes me feel anxious**					
IP38	**My illness makes me feel afraid**					

CAUSES OF MY ILLNESS

We are interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	**STRONGLY DISAGREE**	**DISAGREE**	**NEITHER AGREE NOR DISAGREE**	**AGREE**	**STRONGLY AGREE**
C1	**Stress or worry**					
C2	**Hereditary - it runs in my family**					
C3	**A Germ or virus**					
C4	**Diet or eating habits**					
C5	**Chance or bad luck**					
C6	**Poor medical care in my past**					
C7	**Pollution in the environment**					
C8	**My own behaviour**					
C9	**My mental attitude e.g. thinking about life negatively**					
C10	**Family problems or worries caused my illness**					
C11	**Overwork**					
C12	**My emotional state e.g. feeling down, lonely, anxious, empty**					
C13	**Ageing**					
C14	**Alcohol**					

In the table below, please list in rank-order the three most important factors that you now believe caused <u>YOUR illness.</u>   You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-
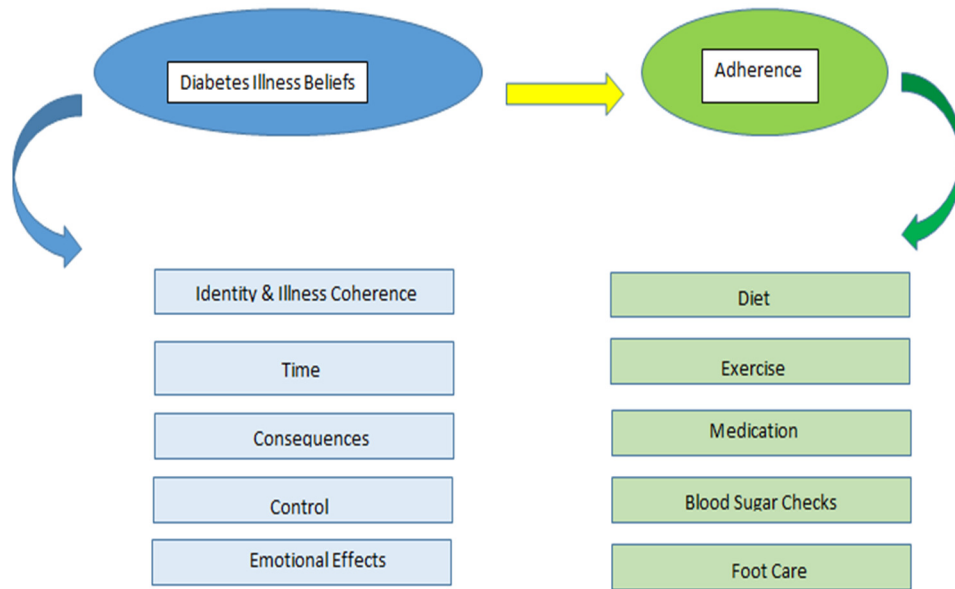
1. _____

2. _____

3. _____

Figure 1. *Illness Representation and its Effect on Variables of Self-care Activities*

Appendix H: Tables

Table 1.

Summary of Sample Demographics

Demographic	Percentage
Gender	
Female	54.6
Race	
African American	17.5
Caucasian	81.4
Hispanic	1
Marital Status	
Single	11.3
Married	53.6
Divorced	18.6
Widowed	16.5
Time lived in Louisiana	
Greater than 10 years	97
Time diagnosed with diabetes	
Greater than 10 years	44.3
Medication usage	
No meds	16.5
Pills only	51.5
Injections only	7.2
Pills and injections	24.7

Table 2.

Significant Correlations between Independent and Dependent Variables

	Identity	timeline	consequences	Personal control	Treatment control	Illness coherence	Time cyclic	Emotion
General diet	-0.95	-.009	-.047	.002	-.022	.131	-.028	-.193
Specific diet	-.040	.178	-.072	-.074	-.079	.093	.149	.098
Exercise	.229*	.169	.209*	-.092	-.167	-.129	.051	.100
Bld glucose testing	-.005	.066	.018	-.162	-.098	-.035	.140	-.073
General foot care	.092	.045	.134	-.029	.053	.198	.125	-.015
Specific foot care	-.052	-.046	-.121	-.027	-.020	-.015	.252*	.064
Medication	-.197	.072	-.091	.064	-.064	.045	.034	.026

*Note: Pearson Correlation significant 2 tailed * p,.05*

Appendix H. (Continued)

Table 3.

Independent Question Analysis

IPQR Item	Statement	Percentage of "strongly agree or agree"
IP3	*My diabetes will last a long time*	77.3
IP6	*My diabetes is a serious condition*	82.5
IP7	*My diabetes has major consequences*	71.1
IP12	*There is a lot I can do to control symptoms*	88.7
IP13	*What I do can determine whether my diabetes gets better or worse*	90.8
IP14	*The course of my diabetes depends on me*	91.7
IP16	*I have the power to influence my diabetes*	86.6
IP21	*The negative effects of my diabetes can be prevented by my treatment*	74.2
IP22	*My treatment can control my diabetes*	87.6
C4	*Diet or eating habits is a cause of my diabetes*	87.0