

ABSTRACT

TYPE 2 DIABETES MELLITUS BELIEFS AND EXPERIENCES

By Mary Cappelle

The aim of this study was to determine if there are specific factors that positively influence the beliefs, behaviors, experiences, and self-management of Type 2 diabetes mellitus in adult patients. A qualitative study was completed involving five participants from northeast Wisconsin who have had Type 2 diabetes mellitus for at least 1 year duration and were between the ages of 40 and 65 years. Participants were selected using the snowball method. Interviews were conducted, transcribed and assessed using the Colaizzi method.

Four specific themes were identified from the transcripts including: *In the beginning, transitioning and the future, discussing a regimen, and searching for deeper meaning*. *In the beginning* described how the participants found out they had diabetes, trying to understand the cause of the illness, and how life with diabetes is a burden that needs to be faced every day. In *transitioning and the future*, the participants showed how overwhelming diabetes is when diagnosed and their feelings of anger, guilt, frustration, and regret that they did not do more to prevent getting this illness. *Discussing a regimen* was the third theme and incorporated the diet, exercise, testing of blood sugars, medication, and following treatment recommendations from their primary care providers. Finally, beliefs and *searching for deeper meaning* described how some participants were influenced by their cultural or family beliefs and family support and how this affected the self-management of diabetes. Further recommendations for nursing research and practice were made related to the beliefs and experiences of adults with Type 2 diabetes mellitus.

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by

Mary Cappelle

A Clinical Paper Submitted
In Partial Fulfillment of the Requirements
For the Degree of

Master of Science in Nursing

Family Nurse Practitioner

at

University of Wisconsin Oshkosh
Oshkosh, Wisconsin 54901-8621

January 2010

APPROVAL

Rozanne Heubrich, PhD Advisor

January 21, 2010 Date Approved

PROVOST AND
VICE CHANCELLOR

L R Am

1/22/2010
Date Approved

FORMAT APPROVAL

Julie Kumbel

1/21/2010 Date Approved

ACKNOWLEDGMENTS

I would like to acknowledge and thank the men and women who have unselfishly shared their stories and experiences with me. I would like to extend a special thank you to Dr. Roxana Huebscher for her knowledge of diabetes, her support and encouragement.

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CHAPTER I

INTRODUCTION

“Diabetes is a chronic illness that requires continuing medical care and patient self-management education to prevent acute complications and to reduce the risk of long-term complications” (American Diabetes Association, 2008a, p. s5). The incidence and prevalence of diabetes mellitus (diabetes) is growing worldwide. The World Health Organization (WHO) (2006) estimates that 180 million people worldwide have diabetes and this number will likely double by the year 2030. In the United States, approximately 23.6 million Americans (7.8%) have diabetes with increased prevalence in many of the Midwestern States (Centers for Disease Control and Prevention [CDC], 2007). In Wisconsin, an estimated 329,000 adults have diabetes (Wisconsin Diabetes Prevention and Control Program, 2004).

Type 2 diabetes mellitus accounts for 90% to 95% of all diabetes cases, with onset usually after the age of 30 years. Prevalence of Type 2 diabetes mellitus increases with age (CDC, 2007). Individuals between the ages of 45 and 65 years have the largest increase in diabetes diagnosis (CDC, 2007).

In 2007, total medical costs for diabetes care in the United States were \$174 billion. Direct medical costs related to diabetes were \$116 billion. Indirect costs, such as those resulting from disability, work absences, and premature mortality was \$58 billion (CDC, 2007). The risk of death for individuals with diabetes is twice as great than for individuals without diabetes, with an approximate decrease in life expectancy of 20 years if blood glucose levels are not controlled (CDC, 2007; Edelman & Henry, 2005).

The prevalence of diabetes varies depending on race, ethnicity, and gender within the U.S. population. Diabetes is more prevalent among American Indians, Alaskan Natives, Latinos, and non-Hispanic blacks. Today, individuals are becoming overweight and obese due to eating more high-fat foods and increased amounts of those foods, and participating in less physical activity (Edelman & Henry, 2005). The increased incidence of new cases and prevalence of diabetes, especially among the 40 to 65 year old age group, is associated with obesity, family history of diabetes, history of gestational diabetes, and impaired glucose metabolism (CDC, 2007).

Diabetes is defined as “a group of metabolic diseases characterized by hyperglycemia resulting from defects in insulin secretion, insulin action, or both” (American Diabetes Association, 2008b, p. s55). The two main pathophysiological process of diabetes involve autoimmune destruction of the β -cells of the pancreas progressing to insulin deficiency and abnormalities causing resistance to the action of insulin (American Diabetes Association, 2008a). There are three main categories of diabetes and glucose intolerance: Diabetes mellitus (DM) Type 1 or 2, impaired glucose tolerance (IGT), and gestational diabetes mellitus (GDM). Determining which category to assign to an individual depends on the “circumstances present at the time of diagnosis” (American Diabetes Association, 2008b, page s55). However, an individual may be assigned to one category but later fall into a different category due to the specific circumstances. According to the American Diabetes Association (2008a), diabetes mellitus can be further divided into several clinical subclasses to help differentiate the specific cases.

- Type 1 diabetes mellitus under the age of 30 years (β -cell destruction leading to absolute insulin deficiency)

- Type 2 diabetes mellitus (T2DM) with insulin resistance or predominantly insulin secretory defect relative to insulin deficiency
- Gestational diabetes mellitus
- Malnutrition-related diabetes mellitus
- Genetic defect of β -cell function, genetic defects in insulin action, or genetic syndromes associated with diabetes
- Diseases of the exocrine pancreas
- Endocrinopathies
- Drug or chemical induced diabetes
- Infection induced diabetes
- Immune-mediated diabetes

Type 2 diabetes mellitus occurs mainly in adults over the age of 30 years.

Patients aged 40 to 65 years are the fastest growing and most prevalent group of patients with Type 2 diabetes mellitus and will be the target population for this study (Uphold & Graham, 2003; WHO, 2006). Type 2 diabetes mellitus (T2DM), also known as adult-onset diabetes, accounts for over 90% of all cases and reflects individuals with insulin resistance or decreased insulin production (American Diabetes Association, 2008b). Many of these individuals do not require insulin until much later in the progression of the disease. There may also be a genetic component for developing T2DM (Edelman & Henry, 2005). However, several risk factors may increase the chance of developing T2DM including, age, sedentary lifestyle, and abdominal-visceral obesity (Ligaray, 2007).

The Centers for Disease Control and Prevention (2007) utilized survey and study data to compile national estimates for the impact of diabetes. Their results showed

adults with diabetes and heart disease have death rates of 2 to 4 times higher than adults without diabetes. The risk of stroke is 2 to 4 times higher if the person has diabetes (CDC, 2007; Ligaray, 2007). Diabetes is the leading cause of new cases of blindness in adults aged 20 to 74 years and the leading cause of end-stage renal disease, accounting for 44% of new cases in 2005 alone (Ligaray, 2007).

About 60% to 70% of adults with diabetes have mild to severe forms of nervous system damage including: Impaired sensation in their feet or hands, slowed digestion of food in the stomach, carpal tunnel syndrome and other nerve problems...30 percent of people with diabetes aged 40 years or older have impaired sensation in the feet (lacking at least one area). Severe forms of diabetic nerve diseases are a major contributing cause of lower extremity amputation (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], National Diabetes Statistics, 2007, p. 8).

Periodontal disease is more common in adults with diabetes, especially in “persons with poorly controlled diabetes (Hemoglobin A1c>9 percent) (who) were nearly three times more likely to have severe periodontitis than those without diabetes (NIDDK, 2007, p. 8).

Co-morbid conditions often are found in patients with diabetes, further complicating their ability to understand and manage the disease. Depression often is found in patients with diabetes and is associated with greater functional disability; decreased adherence to diet, exercise, medication, and self-monitoring of blood glucose recommendations; hyperglycemia; worsened complications from diabetes; and overall increased higher health care costs and mortality (De Groot, Pinkerman, Wagner & Hockman, 2006). In addition, Krein, Heisler, Piette, Makki, and Kerr (2005) found “the

presence of chronic pain was significantly associated with poorer overall diabetes self-management, even after adjusting for the presence of depressive symptoms, general health status, number of other co-morbid conditions, and priority given to diabetes care” (p. 68).

Acute complications related to diabetes, including biochemical imbalances, can lead to both non-threatening and threatening life events, such as hypothyroidism, anemia, gastric paresis, and diabetic ketoacidosis and hyperosmolar (nonketotic) coma (CDC 2007). Individuals with diabetes are also more prone to infections and often face longer recovery times from illness or surgery, often with a worse prognosis (CDC, 2001). Previous research has clearly documented that intensive diabetes medical treatment, proper self-management of diabetes, and effective coping mechanisms may prevent or delay the onset of unwanted complications (Diabetes Control and Complications Trial Research Group, 1993; Funnell & Kruger, 2004; Ligaray, 2007).

Practicing nurses and primary care providers continue to assist patients with diabetes education in order to improve their ability to manage their disease and prevent or delay disease complications while attempting to maintain a good quality of life. Diabetes is a disease that can be managed through the collective efforts of the patient, primary care provider, diabetes educators, and nursing staff (CDC, 2001; The Diabetes Control and Complications Trial Research Group, 1993; Gillibrand and Flynn, 2001).

Medical models often focus on achieving a stable blood glucose level as the main factor to achieve homeostasis with diabetes (The Diabetes Control and Complications Trial Research Group, 1993). However, this limited viewpoint may hinder alternative management options in the treatment of diabetes. The conventional models of healthcare delivery have failed to meet the needs of persons with diabetes (CDC,

2001). In response, new models have emerged to address societal changes (changing demographics, new technology, limited healthcare resources) that focus on patient care quality of life (CDC, 2001). Management of any chronic disease also needs to include the psychological, social, and emotional aspects. Therefore, holistic approaches to the care of diabetes are needed to help identify what patients with diabetes understand and perceive as achieving a 'balanced' lifestyle (Gillibrand & Flynn, 2001). Identifying specific physical, psychological, social factors, and beliefs related to living with diabetes and patient self-management of diabetes can help medical providers and patients uncover ways to cope with this chronic and life-altering disease (CDC, 2001; Daniel & Messer, 2002; Krein et al., 2005; Vermeire et al, 2007).

There is increasing recognition of the need for further in-depth exploration of health beliefs and views of patients' with diabetes that influence their ability to make lifestyle changes in order to manage their disease (Frank, 2002; Gillibrand & Flynn, 2001). Studies have attempted to identify specific factors that help individuals with diabetes better self-manage their disease, prevent or delay complications, and maintain a quality of life (Krein et al., 2005; Smith et al, 2003; Vermeire et al, 2007). Lack of communication with caregivers, poor adherence to treatment regimens, lack of patient's knowledge and understanding about diabetes, and poor relationships with healthcare providers are potential obstacles that may interfere with a patient's ability to effectively live with diabetes (Edelman, Olsen, Dudley, Harris, & Oddone, 2002; Vermeire et al., 2006). Patients' "positive health beliefs about their illness (illness representation)" may help improve their diabetes self-management behaviors (Searle et al, 2007, p. 621). Other studies have found that a patient who receives positive feedback, as well as constructive negative feedback, may be better able to manage their diabetes (Holt,

2002). Furthermore, self-efficacy, or the overall patient belief that he or she has the tools, knowledge and skills to manage diabetes, can be empowering and produce better self-management (Frank, 2002).

Much of the research in diabetes life experience and self-management utilized quantitative measures to analytically identify the frequency of specific factors, such as coping, self-efficacy, optimal treatment measures, quality of life, and diabetic and co-morbid complications (Daniel & Messer, 2002; Edelman et al., 2002; Vermeire et al., 2007; Vileikyte et al., 2006). Unfortunately, the understanding of specific behaviors experienced in everyday life is often vague or overlooked altogether (Frank, 2002; Smith et al., 2002).

Significance to Nursing Education

Optimal management of diabetes requires significant effort from both medical and nursing health professionals and the patient. The rapidly growing number of individuals with diabetes and the increased potential for poor outcomes demonstrates the importance for providing optimal diabetes care, understandable diabetes education, and the tools necessary for patient self-management (Krein et al., 2005). Identification of the patient beliefs about diabetes or “illness representations,” understanding of risk for complications (health threats), and coping mechanisms and behaviors will allow medical providers to provide effective diabetic treatment (Daniel & Messer, 2002; Kelly et al., 2004; Smith et al., 2003; Vermeire et al., 2007).

Assessment of specific psychosocial factors and health beliefs may help determine some of the reasons why a patient may not be managing his or her diabetes (American Diabetes Association, 2008a). “A psychosocial screening should include but

is not limited to attitudes about the illness, expectations for medical management and outcomes, affect/mood, general and diabetes-related quality of life, resources (financial, social, and emotional) and psychiatric history” (American Diabetes Association, 2008a, p. s6-s7). Advanced practice nurses have the opportunity to assess patients with diabetes while learning about their health beliefs, self-management skills, and identifying specific factors that may affect their ability to successfully cope with the illness and continue with everyday activities (Holt, 2001; Frank, 2002). One of the roles of the advanced practice nurse is to help the patient determine diabetes management goals and provide ongoing educational interventions, tools, motivational factors, and holistic support in order to achieve those goals (Diabetes Care, 2008). Evidence suggests that connecting the relationship between illness representation and the importance of understanding coping cognitions and coping behaviors will help the patient and provider in the management of Type 2 diabetes mellitus (Kelly et al., 2004; Gillibrand & Flynn, 2001; Tan, 2004; Searle, Normal, Thompson & Vedhara, 2007; Smith et al., 2003). Therefore, if healthcare providers are aware of the connection between health beliefs, coping mechanisms, and self-management behaviors, they can facilitate and potentially influence adherence and perseverance with self-management of Type 2 diabetes mellitus.

Problem Statement

Diabetes is a life-long chronic condition that affects 7.8% of Americans (CDC, 2007). Studies have shown that specific factors related to co-morbid conditions, knowledge of the disease and its severity, awareness of complications, healthcare delivery, and health beliefs can affect adherence to the self-management of diabetes

and lead to unwanted complications (Gillibrand & Flynn, 2001; Funnell & Krueger, 2004; Searle et al., 2007). If a patient with diabetes fails to maintain adequate self-management practices the consequences may be irreversible and life-threatening.

Research Question

Are there specific factors that positively influence the beliefs, behaviors, experiences, and self-management of Type 2 diabetes mellitus in adult patients?

Definitions of Terms

Conceptual Definitions

Type 2 Diabetes Mellitus: “A group of metabolic diseases characterized by disordered glucose metabolism and inappropriate hyperglycemia due to defects in insulin secretion, insulin action, or both” (Diabetes Care, 2008b, p. s55). Criteria for adult patient diagnosis of Type 2 diabetes mellitus, according to the American Diabetes Association (2008a, p. s5) requires one of the following conditions:

- Symptoms of diabetes (polyuria, polydipsia, and unexplained weight loss) and a plasma glucose of 200mg/dl or higher at any time of the day without regard to time since last meal
- Fasting (no caloric intake for eight hours) with plasma glucose of 126 mg/dl or higher
- Two-hour plasma glucose of 200 mg/dl or higher during an oral glucose tolerance test using a glucose load containing the equivalent of 75 grams of anhydrous glucose dissolved in water

Self-management: “Activities that people undertake to create order, discipline and control in their lives” (Kralik, Koch, Price, & Howard, 2004, p. 260). Self-management is a “multi-dimensional construct involving complex processes where the purpose was to create order from the disorder imposed by illness” (Kralik et al., 2004, p. 262). According to Kralik et al. (2004), this construct is based on the four themes:

1. Recognizing and monitoring the boundaries affecting life with Type 2 diabetes.
2. “Mobilizing the resources (by) identifying, understanding and making the most of what was available to help one live well” (p. 262).
3. Patient learns to live with their chronic illness (diabetes) “through a process of shifting self-identity as the individual grasped the sense of self that was before illness intruded on their life” (p. 263).
4. Balancing, pacing, planning and prioritizing daily activities with planning being the key to self-management of life with a chronic illness.

Adult: Individual who is fully developed and matured.

Operational Definitions

Type 2 Diabetes Mellitus: A participant who reports a diagnosis by a medical provider of Type 2 diabetes mellitus of over 1-year duration.

Self-Management: “Process initiated to bring about order” in the interviewed participant’s life (Kralik et al., 2004, p. 259).

Adult: Male or female subject of any race or ethnic origin who is between the age of 40 and 65 years and has Type 2 diabetes mellitus, as reported by the participant.

Assumptions

1. Adults will be accurate and honest in responding to questions regarding their self-care management of diabetes.
2. Management of Type 2 diabetes mellitus is a complex process and can be affected by both internal and external factors.

Chapter Summary

Diabetes is a growing public health challenge and identified as one of the major issues to be addressed by Healthy People 2010. The long-term complications from diabetes are affected by physical, social, and psychological factors and associated with increased health care usage and costs. These costs are further increased if factors negatively affecting an individual's ability to adapt to life with Type 2 diabetes mellitus are not identified and dealt with accordingly.

CHAPTER II

THEORETICAL FRAMEWORK AND REVIEW OF LITERATURE

Introduction

The purpose of this study is to determine if there are specific factors that influence the beliefs, behaviors, experiences, and self-management of Type 2 diabetes mellitus in adult individuals. This chapter describes the conceptual framework of Leventhal's Commonsense Model (Leventhal, Leventhal & Schaefer, 1992) and review of literature pertaining to the individual's lived experience with diabetes including self-management behaviors.

Theoretical Framework

Leventhal's Commonsense Model (Leventhal, et al., 1992) has been used to help understand the "strategies individuals use to protect themselves against health threats" (p. 109). The Commonsense Model (CSM) has also been referred to as the "Illness Perceptions Model, the Illness Representations Model, the Self-Regulatory Model, and the Parallel Process Model" (Hale, Treharne, & Kitas, 2007, p. 904). Leventhal's research began in the late 1960's studying the impact of fear messages in acute situations and their effect on people taking health-promoting actions (wearing seatbelts, smoking cessation) (Reynolds & Alonzo, 2007). The goal of Leventhal's research was to find out "the cognitive aspects of how people represent or understand illness, their emotional reactions to illness, and their procedures to cope with and appraise its outcome" (Leventhal et al., 1992, p. 110). Leventhal's model began with "three main constructs of (i) 'representation' of the illness experience that might guide (ii) action

planning or 'coping' responses and performance of these, followed by (iii) 'appraisal,' or monitoring of the success or failure of coping efforts" (Hale et al., 2007, p. 904). The researcher studied the CSM identifying the "active parallel cognitive processing of how people regulate their responses both to 'illness danger' ('What is the health threat, what can I objectively do about it?'), and to the person's regulation of 'emotional control' ('How do I feel about it, what can I do to make myself feel better about it?') (p.904). There are five specific components around the key construct of illness representation.

1. Identity: The cognitive component of internal or external stimuli that identifies a label or name given to a specific condition that leads to a health threat and/or emotional reaction (Leventhal et al., 1992).
2. Cause: The individual's ideas about the perceived cause of the condition including environmental, behavioral, and genetic factors, internal personal weaknesses, and improper health behaviors (Leventhal et al., 1992; Watkins et al., 2000).
3. Time-line: The predictive belief about how long the health threat will last (acute, chronic, or cyclical) and the expected duration (Leventhal et al., 1992). The beliefs about the length of the health threat will be re-evaluated over time (Kelly et al., 2005).
4. Consequences: "The perceived physical, psychological, social, and economic impact of the disease" (Watkins et al., 2000, p. 1511).
5. Curability/controllability: Beliefs and procedures used for coping with a health threat and specific plans used to control the health threat. "Each (procedure) has a specific response for controlling the threat and individual beliefs about his or her ability to perform the response" (Leventhal et al., 1992, p. 111).

The components of the CSM in relation to illness representation is cumulative and an ongoing process where the “individual is constantly constructing, updating, or reconstructing representations of setting and feelings, generating and executing procedures for coping, evaluating or appraising outcome” (Leventhal et al., 1992, p. 115). The ill person experiences a variety of symptoms which “are interpreted and become the focus for coping procedures used in planning and acting to deal with health threats (Leventhal et al., 1992, p. 115).

The goal of the CSM is to “describe the types of social and psychological factors involved in commonsense thinking and...to describe the mechanisms and processes that underlie and/or generate the observations” (Leventhal et al., 1992, p. 110). At the very core of Leventhal’s CSM are the concepts of self-management, lived experience, and diabetes, which will be used to for the purpose of this research.

Research studies have shown empirical evidence for the use of the CSM in predicting “the cognitive aspects of how people represent or understand illness, their emotional reactions to illness, and their procedures to cope with and appraise its outcome” (Leventhal et al., 1992, p. 110). Kelly et al. (2005) used the CSM to understand the individual’s perceived cancer risk associated with the testing for the BRCA1/2 mutation. Watkins et al. (2000) investigated “the relationships among cognitive representations of diabetes, diabetes-specific health behaviors, and quality of life” using the CSM (p. 1511). The CSM was used to develop and provide validity of the Patient Interpretation of Neuropathy (PIN) Questionnaire related to foot care in individuals with diabetes (Vileikyte et al, 2006). Brissette, Levanthal and Leventhal (2003) used their own CSM to assess “observer ratings of health and sickness” and

found the observers' results showed a high correlation with the severity of the participant's self-reported health conditions (p. 471).

Searle et al. (2007) used the CSM to "examine the relationships between illness representations and the relative importance of coping cognitions and coping behaviors in the context of the management of type 2 diabetes" (p. 621). The CSM is also known as the Self-Regulatory or Self-Management Model that emphasizes the inter-related components of interpretation (label and cause), coping (cure and control), and appraisal (time-line and consequences) in order to maintain an individuals "status quo" in life (Searle et al., 2007, p. 622). This study "demonstrated that illness representations are direct predictors of both coping cognitions and coping behaviors in patients with type 2 diabetes" (p. 621).

The CSM has been used in many studies of perceived health threats and chronic conditions in relation to coping cognitions and behaviors. Past research shows a high correlation between physical, cognitive, psychosocial, and behavioral factors associated with diabetes (Daniel & Messer, 2002; Smith et al., 2003; Vermeire et al, 2007; Vileikyte et al., 2006). However, few studies have "been directed at understanding how individuals with the disease (diabetes) conceptualize and experience life with this chronic condition" (Gillibrand & Flynn, 2001, p. 502). This study qualitatively investigated the factors of illness representation and health beliefs that influence the daily experiences of living with diabetes and the ability to self-manage the disease.

Literature Review

This literature review provides an overview about the beliefs and values of adults with Type 2 diabetes mellitus. This includes: Illness beliefs and complications,

experiences, coping, obstacles to adherence, co-morbid conditions, and self-management of diabetes.

Health Beliefs and Complications in Type 2 Diabetes Mellitus

Daniel and Messer (2002) conducted a study evaluating the perceptions of disease severity and barriers to self-care of aboriginal persons with Type 2 diabetes mellitus. The study used a sample of 16 male and 18 female volunteer participants from a community-based diabetes diagnostic and risk factor screening initiative (Daniel & Messer, 2002). The participants were all “registered” Indians of British Columbia’s rural Okanagan region. The participants were evaluated based on their glycemic markers, health beliefs about diabetes (susceptibility, severity, benefits, and barriers), knowledge about diabetes, and self-care of the disease at the start of the study and again 18 months later (Daniel & Messer, 2002).

Statistical analysis was completed using linear regression models and adjusting for age and gender. The results showed that “high perceived severity of diabetes and low perceived barriers to therapeutic behaviors were related to healthful HbA1c concentration as well as reductions in HbA1c” (Daniel & Messer, 2002, p 2). They found that issues related to control of diabetes and the risk of complications were not perceived as important as the autonomy of the individual and the belief or perceptions about the disease upheld by that person.

Tan (2004) completed a correlation study to determine if there was a “relationship of health beliefs and complication prevention behaviors among Chinese individuals with Type 2 Diabetes Mellitus” (p. 71). This study used a sample of 128 Chinese individuals with Type 2 diabetes mellitus of greater than 1-year duration who

were mentally alert and not pregnant. The sample was obtained from Chinese patients attending outpatient clinics in both urban and rural settings around Malaysia.

The examiner created a 60-item diabetes health belief questionnaire for the purpose of this study. The questionnaire consisted of items including: Patient demographics, knowledge assessment on diabetes complication and risk factors, and the “five sub-scores of the Health Belief Model (perceived susceptibility, perceived severity, perceived health benefits, perceived barriers, and perceived ability to follow recommendations”) (Tan, 2004, p. 72). Using a pilot study, this questionnaire was reviewed for content validity.

Data analysis was performed using descriptive statistics, Spearman correlation, and the Mann Whitney U-test (Tan, 2004). This analysis found that 72% of the subjects were aware of diabetes complications and its risk factors. However, “few practiced complication preventive measures because of lack of perceived seriousness of diabetes and lack of perceived susceptibility to diabetes complications...and there was no significant correlation between health beliefs and settings, genders, disease duration and treatment mode (Tan, 2004, p. 71).

According to Tan (2004), many of the study’s participants had knowledge about diabetes complications and risk factors but did not fully understand the significance of diabetes complications to their life.

Vermeire et al. (2007) completed an international meta-ethnography qualitative study to determine which variables can be identified to explain adherence and non-adherence behaviors of treatment recommendations for Type 2 diabetes mellitus. The study attempted to answer three questions: What are the differences and similarities of the obstacles to adherence for people living with Type 2 diabetes in each country? Are

these obstacles the same in countries with different health care systems? Can the data from parallel, international, multilingual qualitative studies be synthesized to answer the first two questions (Vermeire et al., 2007, p. 26).

Data was obtained from 39 focus groups of 246 individuals with Type 2 diabetes representing seven different European countries. Noblit and Hare's meta-ethnography was applied to the data, making a qualitative meta-analysis in order to find specific themes or categories in the translated data (Vermeire et al., 2007). Results of the study demonstrated "obstacles to adherence are common across countries, and seem to be related less to issues of the healthcare system and more to patient's knowledge about diabetes, beliefs and attitudes and the relationship with healthcare professionals" (Vermeire et al., 2007, p. 25).

Tan (2004) identified in individuals with Type 2 diabetes mellitus "poor complication preventive behavior...associated with lack of perceived seriousness of diabetes and lack of perceived susceptibility to diabetes complications" (p. 71).

Gillibrand and Flynn (2001) studied the lived experience of patients with a chronic illness (Diabetic Disease State) and identified that patients felt the control of their condition had been "externalized to the health care professionals responsible for their care" rather than patient self-management (p. 501). They have also shown that many patients do not realize the severity of the risk of complications that could occur during the course of the disease (Daniel & Messer, 2002; Tan, 2004).

Illness Experience of Adults with Type 2 Diabetes Mellitus

A qualitative research study was conducted by Smith et al. (2003) to discover the health beliefs, perceptions of the disease, and subsequent lifestyle modifications of adults with Type 2 diabetes mellitus participating in structured diabetes shared-care

service. This research study included 25 randomly selected participants over the age of 30 who had Type 2 diabetes mellitus for greater than 1-year duration. The participants were “stratified geographically” to ensure random representation from urban, affluent suburbs, and semi-rural locations in a Northern European setting.

This study utilized focus groups, and the data was analyzed using the “Framework” method allowing the analyst to “create meaning and connections between different themes identified in the data collection” (Smith et al., 2003, p. 854). Specific themes relating to diabetes were identified in the data including: frustration with the disease and lack of understanding of complications, difficulties and stress of life with diabetes, victimization and powerlessness related to living with diabetes, coping mechanism (humor and deviance), positive effect of nursing care, communication issues and “too busy” care providers, positive hope for the future, and economic barriers to care (Smith et al., 2003). The results of this study emphasized the importance of identifying the patient’s beliefs and perceptions about diabetes and the need for effective care delivery. Furthermore, patients continue to lack knowledge about the diabetes, risks associated, and susceptibility to complications (Smith et al., 2003).

Edelman and Henry (2005) studied the effect that the label of “diabetes” can have on individuals with this chronic illness and their overall perception of well-being 1 year after diagnoses. The study was conducted with 1255 participants aged 45 to 64 years at an outpatient Veteran Affairs Medical Center in the United States between October 1996 and March 1999. Initially, the participants were screened using a glycosated hemoglobin measure. One year after diagnosis, these participants were again assessed using the glycosated hemoglobin measure and also given the Kaplan-Feinstein co-morbidity index for patients with diabetes, the Framingham Physical Activity

Index, the HRQoL with the Medical Outcomes Study Short Form 36, the Physical Component Scale, and Mental Component Scale (Edelman & Henry, 2005).

Data was analyzed with descriptive statistics and multivariate analysis using linear regression. The results showed no relation between a participant knowing if he did or did not have the diagnosis of diabetes, receiving the label of “diabetes”, and his overall quality of life 1 year after the receiving the diagnosis. Co-morbid conditions, including anxiety and depression, did have a significant impact on the participant’s view of quality of life (Edelman et al., 2005). Physical activity is the “only element of diabetes treatment known to have a positive effect” on the participant’s quality of life (Edelman et al., 2005, p. 1025). This study showed that the “labeling effect” of having diabetes was not significant in respect to the individual’s overall quality of life (Edelman et al., 2005).

Illness Beliefs and Coping

Searle et al., (2007) studied coping cognitions and coping behaviors in relation to illness representations in patients with Type 2 diabetes. They found that “illness representations are direct predictors of both coping cognitions and coping behaviors in patients with Type 2 diabetes” (p. 621). The researchers recognized that a focus on the patient’s belief about diabetes may be more beneficial than trying to “manipulate patients’ coping cognitions” to improve “patients’ health behaviors” (Searle et al, 2007, p. 621). This study utilized the CSM, which proposes, “illness representations are directly related to coping and, via coping, to adaptive or maladaptive outcomes” (Searle et al., 2007, p. 622).

Utilizing a prospective design, Searle et al. (2007) assessed 134 patients ages 32 to 86 years using the Revised Illness Perceptions Questionnaire (IPQ-R), Personal Models of Diabetes Interview (PMDI), Food Frequency Questionnaire, Baecke Habitual

Physical Activity Questionnaire, Medical Models of coping Questionnaire, and the Medication Adherence Report Scale at the start of the study and again 12 months later. The data collected was analyzed using independent t tests and chi-square tests to identify differences between demographics and clinical status of the participants.

The IPQ-R and PMDI examined the core dimensions of illness representations framework including: Cyclical timeline (illness variability and unpredictability), timeline (perceived course or duration of having diabetes), consequences (perceived impact diabetes has on patient's life), treatment control (patient's belief in treatment for diabetes), personal control (patient's perceived belief in their ability to control their diabetes), identity (patient with diabetes), cause (perceived cause of diabetes), emotional representation (emotional states of fear, anxiety, depression, and anger, associated with and as a response to illness), and illness coherence (extent illness 'makes sense to the patient') (Searle et al., 2007).

The Food Frequency Questionnaire was used as a self-report dietary assessment tool; whereas, the self-report Baecke Habitual Physical Activity Questionnaire was used to assess the level of daily and weekly level of exercise. Oral medication compliance was assessed using the Medication Adherence Report Scale (Searle et al., 2007). Finally, the Medical Models of Coping Questionnaire measured the coping cognitions of confrontation, acceptance, avoidance, and coping styles of patients with diabetes (Searle et al., 2007).

This study "demonstrated that illness representations are direct predictors of both coping cognitions and coping behaviors in patients with type 2 diabetes," where coping cognitions are "the beliefs about an illness" and lead to specific coping behaviors (diet, physical activity, and medication) (Searle et al., 2007, p. 621). The results also showed

that coping cognitions and behaviors operate together; therefore, focusing more on the “beliefs about diabetes” may be more beneficial than “manipulating patients coping cognitions to improve health behaviors” (Searle et al., 2007, p. 621).

Self-Management in the Treatment of Type 2 Diabetes Mellitus

Kralik et al. (2004) conducted a study attempting to identify how people living with a chronic illness understood the meaning of self-management. The study utilized patients with arthritis; however, the researchers’ goals were to apply their findings to individuals with chronic illness.

Data was obtained from nine participants who were asked to “write (or record) an autobiography about their life and experiences of living with illness” (Kralik et al., 2004, p. 259). The data was then reviewed to identify common themes, issues, or concerns from the transcripts. The data revealed that self-management is a multi-dimensional construct where the individual is trying to create order from the disorder often experienced when living with a chronic illness (Kralik et al., 2004). Four themes were identified: “Recognizing and monitoring the boundaries; mobilizing the resources; managing the shift in self-identity; and, balancing, pacing, planning and prioritizing” (Kralik et al., 2004, p. 262).

The researchers found that individuals were able to learn about their perceptions, beliefs, and experiences about living with a chronic illness through positive and negative daily experiences. Furthermore, the individual’s daily life was restructured to adapt to the personal limitations, boundaries, structure, and self-identity of having a chronic illness. Therefore, self-management allows the individual to find and maintain order in their lives based on their perceptions, beliefs, experiences, and activities (Kralik et al., 2004).

An ethnographic study completed by Gillibrand and Flynn (2001), “explored and described the patient’s perceptions of the diabetic disease state, complications and lifestyle” (p. 504). The study attempted to explore the “culture” of diabetes through qualitative interviews with 18 participants from the inner city area of central Liverpool, England.

The interviews were obtained, transcribed, and categorized using a visual matrix and data analysis-coding. Three major categories emerged from the data, including information-knowledge of illness; psychological burden of diabetes (feelings of shock, despair and anxiety); and, rationalizing, a “process by which someone attributes their understanding and reasoning for their chronic illness to credible motives, without an analysis of deeper unconscious motives, in order to provide plausible reasons for their reaction and behavior” (Gillibrand & Flynn, 2001, p. 506). A subcategory of reality avoidance (not wanting to know about the effects of having the disease of diabetes) was also identified (Gillibrand & Flynn, 2001). This study found that individuals “with diabetes experience and describe complex psychological effects and coping mechanisms in having a chronic illness,” which can be either self-managed or given up to the externalized control of “health professionals responsible for their care” (Gillibrand & Flynn, 2001, p. 501).

In another study, Watkins et al. (2000) investigated “the underlying cognitive predictors of diabetes-specific health behaviors and quality of life” using Leventhal’s (1992) self-regulation model of illness/CSM (p. 1511).

“Cognitive representation of illness” allows the individual to organize information of the illness and to guide monitoring of symptoms, actions and related consequences via the psychological parameters of: “Identity (understanding of the disease in terms of

symptoms and labels)”; consequences (perceived physical, psychological, social, and economic impact of the disease); timeline (time of onset, expected duration and possibility of recurrence); cause (environmental, behavioral, and genetic factors); and controllability” (possibility of cure or slowing of progression)” (Watkins, et al., 2000, p. 1511).

Data was obtained through a mailed survey completed by 296 adults ages 20 to 90 years. Secondary analysis and structural equation modeling was used to identify relationships among cognitive representations, specific health behaviors in diabetes, and the individuals overall quality of life. The findings indicated that the cognitive representation constructs of level of understanding of diabetes and perceptions over control of diabetes were “the most significant predictors of outcome” (Watkins et al., 2000, p. 1511).

Co-morbid Conditions and Their Effect on Type 2 Diabetes Mellitus Self-Management (De Groot et al., 2006) conducted a study to assess the rates of depressive symptoms, treatment, and satisfaction from a multi-cultural sample of adults with Type 1 and Type 2 diabetes mellitus. “This study was conducted with a cross-sectional community-based survey design...with a convenience sample” (De Groot et al., 2006, p. 549). There were 221 predominantly female, middle-class participants with Type 2 diabetes. Co-morbid depression is “two times greater in patients with diabetes than in the general population...and associated with greater functional disability; decreased adherence to diet, exercise, medication, and self-monitoring of blood glucose recommendations; hyperglycemia; worsened diabetes complications...and mortality” (De Groot et al., 2006, p. 549).

Data was obtained using The Center for Epidemiologic Studies Depression Scale (CESD) and statistical analysis was completed using χ^2 and student's *t* tests. Results demonstrated high rates of depressive symptoms across all ethnic groups assessed. This study demonstrated that depression and diabetes often co-exist, and treatment of the depression symptoms can help an individual with diabetes to achieve an acceptable quality of life.

The landmark study, The Diabetes Control and Complications Trial Research Group (1993), demonstrated that optimal glycemic control delayed the onset of microvascular complications (retinopathy, nephropathy, and neuropathy). Glycemic control also helped slow the progression of macrovascular diseases (cardiovascular, ophthalmic, and neurological).

Chronic pain is common in the general population and the leading reason people seek medical care. Krein et al. (2005) conducted a study to determine the effect and consequences of chronic pain on adults who also have diabetes. A cross-sectional method was used to study 993 Department of Veterans Affairs outpatient individuals with chronic pain and diabetes self-management. Chronic pain is defined as, "pain present most of the time for 6 months or more during the past year" (Krein et al., 2005, p. 65). Krein et al. (2005) found "the presence of chronic pain was significantly associated with poorer overall diabetes self-management, even after adjusting for the presence of depressive symptoms, general health status, number of other co-morbid conditions, and priority given to diabetes care" (p. 68). Therefore, competing demands in the self-management of diabetes needs to be addressed, including co-morbid conditions and chronic pain when planning diabetes treatment (Krein et al., 2005).

Chapter Summary

This chapter described the conceptual framework of Leventhal's Commonsense Model (1992) pertaining to illness representation and self-management of Type 2 diabetes mellitus. Research discussing the health beliefs, illness presentation, illness experiences, effect of co-morbid conditions, and self-management of Type 2 diabetes mellitus was presented.

CHAPTER III

METHODOLOGY

Introduction

The purpose of this study was to determine if there were specific factors that influenced the beliefs, behaviors, experiences, and self-management of adults with Type 2 diabetes mellitus. In this chapter, the study design, population, sample, sample setting, and procedures for data collection is discussed. Data analysis procedures and limitations of the methodology are also discussed in this chapter.

Study Design

A qualitative descriptive study was conducted in order to explore and discover specific factors related to the beliefs, behaviors, experiences, and self-management of adults who have Type 2 diabetes mellitus from Northeast Wisconsin. Through open-ended questions and recorded interviews, this researcher attempted to identify specific factors in order to better understand the experience of adapting to life with diabetes. The study included five adults, age 40 to 65 years, who have Type 2 diabetes mellitus.

Population, Sample and Setting

The target population for this study was adults with Type 2 diabetes mellitus. The accessible population was male and female adults, aged 40 to 65 years, who live in Northeast Wisconsin. A sample of three male and two female adults was obtained using the snowball technique. A pilot study involved one individual to test the research question relating to the beliefs, behaviors, experiences and self-management of Type 2

diabetes mellitus. This individual referred another potential participant for the study (snowball technique). The researcher contacted the potential participant and a time and public location was scheduled to complete the interview. At this time, the researcher asked if the interviewee was aware of other adults who may be interested in participating. Five to ten participants is often an adequate number to achieve saturation in qualitative research; however, saturation was not the purpose of this study (Specialize & Carpenter, 2007).

Inclusion criteria consisted of (a) desire to participate in the study, (b) able to answer interview questions, (c) able to speak English, and (d) have Type 2 diabetes mellitus for at least one year. Exclusion criteria included (a) individuals under the age of 40 years or over the age of 65 years, (b) individuals with other forms of diabetes mellitus (Type 1, gestational) by self-report, or (c) individuals who have Type 2 diabetes mellitus for less than 1-year duration.

Data Collection Instruments

After IRB approval, data was collected by the researcher through tape-recorded interviews at an agreed upon public location (restaurant corner booth during non-busy times or private office), field notes were taken during the interview, and a demographic questionnaire was completed. Written permission to participate in the study and for the recording of the interview was obtained. Participants were informed that they may stop at any point and that their care will not be affected.

Participants were asked to complete a basic demographic questionnaire sheet prior to the interview (Appendix B). The questions for the demographic questionnaire included, age, gender, ethnic background, occupation, marital status, whether they had

been diagnosed with Type 2 diabetes mellitus by a medical professional, and what month and year they were diagnosed with Type 2 diabetes mellitus. A fictitious name was assigned to each participant to protect confidentiality. The probe question, "Tell me what life has been like since you were diagnosed with Type 2 diabetes mellitus and how you have managed this illness?" was used as a guide for the researcher. This question helped address the individual's experiences and ability to self-manage Type 2 diabetes mellitus. When necessary, the researcher asked other questions to clarify what the participant said. The length of time for the interviews lasted approximately 20 to 60 minutes. This method of investigation was appropriate for this study because it did not lead the participants in answering the question.

Procedures for Data Collection

Prior to the start of the study, permission was obtained from the Institutional Review Board and the Protection of Human Participants at the University of Wisconsin Oshkosh (IRB). After IRB approval was obtained, a pilot study was completed with one individual with Type 2 diabetes mellitus and who had expressed interest in participating in the study. Confidentiality was maintained throughout the entire research process. There is no identifying name listed on the tape or transcript, as each participant was given a fictitious name in order to protect confidentiality and anonymity. Each participant voluntarily participated and gave permission to audiotape the interview through written consent (Appendix C). All tapes, transcripts, demographics, and consent forms are stored in a separate locked file box in the researchers home and will be kept for a period of 3 years. No one other than the researcher and chairperson has or will have access to the data.

Prior to participation in the study, the researcher contacted each participant by phone or in person. Information was given to the participant about the study content and procedures for confidentiality and anonymity.

Data Analysis

Interviews were analyzed using the Colaizzi method where significant factor statements that influenced the participants beliefs, behaviors, and experiences of living with Type 2 diabetes mellitus were extracted (Speziale & Carpenter, 2007). Initially, the researcher analyzed what the subjects said in their interviews and then described the phenomenon of interest. The researcher then analyzed the probe question used for the study. Raw data was transcribed verbatim for each participant. Next, the researcher reviewed the participant's verbal discussion and transcription of his or her experiences of living with Type 2 diabetes mellitus. The researcher then read and reread the verbatim transcriptions and field notes. This allowed the researcher immersion in the data and identification of significant statements. Common topics were identified from the statements in order to understand the participant's meaning from the original context. These meanings were then separated into categories or themes common to all the participants. Transcripts were again reviewed and a participant was contacted if clarity was required. This completed a final validation. These statements were recorded on a computer printout and separated into categories. The final phase identified common themes found in the experiences of adults with Type 2 diabetes mellitus (Speziale & Carpenter, 2007).

Study Limitations

The anticipated limitations of this study include: 1) small sample size, 2) single geographical location, 3) information obtained at only one point in time, 4) specific age parameter, and 5) specific diagnosis of Type 2 diabetes mellitus. Therefore, generalizations of the findings may be limited to this population and may not hold true for other diagnoses, ethnic groups, age groups, or other parts of the United States.

Chapter Summary

This researcher used a qualitative descriptive approach to identify specific themes present in the experiences of adults with Type 2 diabetes mellitus. The sample consisted of three adult males (including the pilot study) and two adult females aged 40 to 65 years with Type 2 diabetes mellitus in Northeast Wisconsin. Contact of potential participants was obtained through the snowball technique, where one participant referred the researcher to other potential participants. Each tape was analyzed to extract data and identify specific themes or categories. Data analysis was conducted using the Colazzi method.

CHAPTER IV

RESULTS AND DISCUSSION

Introduction

The purpose of this study was to determine if there are specific factors that influence the beliefs, behaviors, experiences, and self-management of Type 2 diabetes mellitus in adults. This author presents demographic information and identifies themes and participant examples in this chapter. Additionally, a discussion of the results as they relate to previous research is also included.

Sample Description

A convenience sample of 140 potential participants were contacted by the researcher attending two classes containing senior level one and senior level two nursing students at a Midwestern university. A brief presentation was given to the students, and then willing participants were asked to sign up for an open interview time slot. The sample for this study was 21 volunteer, senior level nursing students who met the criteria for sample selection and agreed to participate.

Participants were recruited from Northeastern Wisconsin who met the criteria for the study which included: (a) a desire to participate in the study, (b) the ability to answer interview questions, (c) the ability to speak English, (d) a diagnosis of Type 2 diabetes mellitus for at least one year, and (e) an age between 40 and 65 years.

Initially, a pilot study was conducted with one individual to test the probe question: "Tell me what life has been like since you were diagnosed with Type 2 diabetes mellitus and how have you managed this illness?" This individual was an

acquaintance of the researcher and met the above-mentioned criteria. The answers provided by this initial interview did relate to the study's research question: "Are there specific factors that positively influence the beliefs, behaviors, experiences, and self-management of Type 2 diabetes mellitus in adult patients."

Other potential participants were contacted using the snowball technique. The initial participant referred the researcher to another potential participant who was interested in participating. The researcher then contacted this individual and asked if they were willing to participate. If this person agreed, then an interview time was scheduled in a public place. This process was repeated for each participant interviewed. Fictitious names were given to each participant to protect confidentiality.

Each interview was completed face-to-face and took place in a public location selected by the participants. All participants were willing to discuss their behaviors, beliefs, and experiences with diabetes and how they self-managed the disease. The interviews lasted approximately 20 to 60 minutes. Written informed consents for the interview and to be audio-taped were signed by each participant prior to data collection. Four interviews were conducted at local area restaurants in a secluded corner during non-busy times of the day. One interview was conducted at the participant's place of employment in his office to ensure privacy.

The researcher did a follow-up phone call to all participants after all interviews were complete in order to determine if there were additional specific factors that positively influenced their experiences with diabetes mellitus. The results of these interviews were recorded and reviewed by the researcher. New data obtained was incorporated into the descriptions listed in the results of the study.

Demographic Data

Five participants were interviewed for this study including the pilot person. On a demographic questionnaire participants were asked to report their age, gender, ethnicity, occupation, marital status, if they were diagnosed with Type 2 diabetes mellitus, and the month and year of diagnosis.

Three of the participant's in the study were male and two were female. Their ages ranged from 43 to 63 years, with a mean age of 52.8 years. Four of the participants were Caucasian and one was Native American. Two of the participants were married, two divorced, and one individual was single (never married, divorced, or widowed). The occupations of the five participants varied. Four of the participants were employed and one was retired. The duration of time from when the participants were diagnosed with Type 2 diabetes mellitus to the time of interview ranged from 8.4 years to 21.11 years. Table 1 describes the demographic information.

Table 1

Demographics

Participant	Age	Gender	Ethnicity	Marital Status	Occupation	Duration of Illness (years)
Mike (pilot)	58	Male	Native American	Divorced	Highway Maintenance	8.4
Jon	48	Male	Caucasian	Married	Customer Service Tech	3.4
Kathy	63	Female	Caucasian	Divorced	Retired	21.11
Paul	52	Male	Caucasian	Married	Chaplain	13.5
Jen	43	Female	Caucasian	Single	Restaurant Manager	12.1

The following is a brief introduction of the subjects.

Mike is a 58-year-old Native American male who completed the pilot portion of the study. Mike is known by the researcher and voluntarily agreed to participate. Mike is divorced and currently lives on his own. He works full-time for the highway department in maintenance. He has had diabetes for 8.4 years and received care through his primary care provider and dietician through the local Native American health center.

Jon is a 48-year-old Caucasian male who works in the healthcare field as a customer service technician. He is currently married and is the only one in his immediate family who has diabetes. The changes he has made regarding diet, exercise, and stress levels have benefited his entire family. He has had diabetes for the past 3.4 years. He continues to learn about diabetes and ways to self-manage the illness.

Kathy is a retired 63-year-old Caucasian female who is currently divorced and lives alone. She has had diabetes for over 21 years, the longest of the participants in the study. She has other health issues including “artery problems” (peripheral artery disease) that she also deals with on a regular basis but has a good support system from family and friends.

Paul is a 52-year-old Caucasian male who has had diabetes for over 13 years. He recently was switched to sliding scale insulin and struggles with balancing his carbohydrates and proteins with the insulin. He currently works as a chaplain at a major healthcare facility and feels he receives emotional support from his wife, friends, and his faith.

Jen is a 43-year-old Caucasian female who is currently single and was recently engaged to be married for the first time. She is a manager for a local restaurant shop

and continues to struggle with eating too many carbohydrates from bread. She also struggles with not exercising or making good food choices outside of work. Her fiancée is understanding of her diabetes and tries to motivate her to be more active.

Research Question

Are there specific factors that positively influence the beliefs, behaviors, experiences, and self-management of Type 2 diabetes mellitus in adult patients?

Results

Data was collected through the use of a non-structured interview process. Each participant was asked the same open-ended question: Tell me what life has been like since you were diagnosed with Type 2 diabetes mellitus and how have you managed this disease? Participants reported their beliefs, behaviors, experiences, and self-management of Type 2 diabetes mellitus. The interviews were audio taped, transcribed verbatim, and analyzed using the Colazzi method. As described in Speziale & Carpenter (2007), the steps used in the Colazzi method of data analysis were: (a) The researcher described the phenomenon studied, (b) participants' descriptions of the phenomenon were collected and read by the researcher, (c) specific statements from the interviews were extracted and organized into clusters of themes' (d) description of the extracted statements arranged by themes were explained in the study' (e) participants were re-interviewed by phone to identify specific factors that positively influence their experiences' and, (f) any new information revealed was incorporated into the description of the results of the study.

Four major themes emerged relating to the patients' beliefs, behaviors, and self-management of diabetes. These themes were illustrated by specific factors and personal experiences that influenced the participants' self-management of diabetes. These themes were: (a) *In the beginning*, (b) *transitioning and the future*, (c) *discussing a regimen*, and (d) *searching for deeper meaning*. Under the theme of *in the beginning*, there were four subcategories: (a) *How it started, cause and reasoning*, (b) *experiences of others*, (c) *trying*, and (d) *adapting to a chronic disease*.

The theme of *transitioning and the future* has four subcategories: (a) *feelings of being overwhelmed, denial, anger, frustration, and guilt*, (b) *regrets and wishes*, (c) *friend and family support*, (d) *complications and fears for tomorrow*.

In the theme of *discussing a regimen*, there were two subcategories, (a) *exercise and diet*, and (b) *testing blood glucose levels and following recommendations*.

Finally, the theme of *searching for deeper meanings* has four subcategories: (a) *cultural beliefs, genetics, and consequences*, (b) *faith and spirituality*, (c) *hope and beliefs*, (d) *meaning for life*.

In the Beginning

In the beginning, participants described how they felt when they were first diagnosed and trying to understand what caused the diabetes. They shared their experiences with family members and others who have had diabetes. Many of the participants felt they were "trying" to understand about their illness and following treatment recommendations. They also shared how they have adapted to life with a chronic disease.

How it Started, Cause And Reasoning

Initially, their primary care provider saw two of the participants for causes other than diabetes. Mike states, "When I was first diagnosed, it started with my kidney. I developed stones. After the tests were done, the doc let me know I had diabetes." Jon, also shared a similar experience, "...I originally started with some acid reflux issues and found out my sugars were quite high...I thought it was a heart attack from the pain and tightness inside...and they did some tests on me and that is when they found out it was diabetes and my sugars were high..." Two of the participants knew that their health habits would put them at risk for developing diabetes. Jon explains, "I was at a weight of about 290 pounds. I am 5 foot 8, which I know is heavy, and I was in my own business, which is somewhat stressful itself." Paul also reports, "I knew at the time I was diagnosed, I was overweight some." Kathy claims her onset of diabetes was "gradual" and "really didn't believe" that she had diabetes, initially. Mike furthered questioned why he now had diabetes, "Being Indian and all other people, the question is where did this come from and why? I know it's passed on in many ways, but, how did it start?"

Experiences of Others

All five of the participants had experiences with other family members who had diabetes. Mike states.

The learnings I've been through in the last 10 years, the teachings were harsh for me, seeing diabetes in my family and friends and what they went through. I still see in my mind, the fear and frustration that they have gone through.

Jon had an "...aunt that was diabetic growing up and she was very heavy...probably 400 pounds...and I remember she would have injections for probably 30 years...and she died at 60..." Kathy reports, "Diabetes runs in my family. I had an

aunt that passed away and had several amputees of her legs.” Paul directly lived with a parent that was diabetic:

I had some experience of living with somebody who had diabetes in the family. I remember how some things changed around the house, and some of the things we went through...now I am the person and not someone else.

Jen had two family members with diabetes:

My mom had diabetes at my age, and my brother has it now...my brother has had diabetes since he was 24, but he is overweight and drinks a lot. He hasn't taken it seriously at all...he is headed to self-destruction.

Trying

Part of the process of having a chronic illness is going through the process of trying to understand the disease of diabetes, and trying to comply with recommendations. Four of the participants tried to live their lives with the disease and avoid complications. Mike claims that living with diabetes is “...a very hard habit to keep my body and mind in check.” Kathy feels that her experience in living with diabetes is “as well as can be, it's a pain in the butt...” Accepting the burden of self-care is often one of the greatest challenges in living with diabetes (Sigurdardottir, 2004). Paul reports,

I am not there yet, but I'm trying to change my habits...I'm not there yet and haven't been so far with exercise. It's not my favorite part of the management system, but I would think the other things I have a little better handle of.

Jen claims, “I try to make healthy choices, but it is hard. I am trying and my average sugar is better than ever. My doctor says I just need to keep working at it...”

Adapting To a Chronic Disease

Understanding and complying is a challenge with chronic illness. Dealing with diabetes is part of a learning process, as reported by three of the participants. Jon reports that he is "...taking the time to be more aware of what you are eating...of your surroundings...(I)t really makes you aware of what you are eating and what your health situation is." Paul feels that he continues to "learn to cope" and he is "moving forward." Jen reports, "I continue to learn what I need to do, and continue to work at it. I may never be perfect, but at least I am trying..."

Three of the participants felt that having diabetes was a burden as they learn to adjust and accept having the disease. Kathy claims,

I never let it get me down. I don't think, "poor me, poor me" because there are a lot of people that do that...that's not me. I have never been that way and because, ok, this is a stinking part of my life and bear with it...you go down fast if you dwell on it.

Jen feels that "eventually, you get used to diabetes over time, the longer you have it...I think I am accepting it more now." Living with diabetes can change a person's life, as Mike describes, "Diabetes has changed my life and how I feel where life is going with it, and how I'm going to do healthwise from now on." Kathy realized that a change from pills to insulin is not a temporary fix after she asked her doctor, "How long will I have to take that?" Her doctor stated, "Once you start, it's for the rest of your life."

Having a chronic illness like diabetes requires significant changes in and individual's life. In a study on individuals with diabetes, Lin, Anderson, Hagerty, and Lee (2007) showed that diabetes has a significant impact on life from the time of diagnosis throughout the course of the disease. Individuals also need to process what is the disease of diabetes and what caused the diabetes (Gillibrand & Flynn, (2001). They also

need to “try” and follow medical and nursing recommendations while continuing to learn how this disease will affect and change their lives.

Transitioning and the Future

Another step in this process is transitioning from the overwhelmed, shocked feeling of receiving the diagnosis; to the denial, anger, and frustration of having this illness, along with the guilt of not doing more to prevent it. Some individuals looked to friends and family for support. Some individuals were not thinking about tomorrow and did not see life’s changes for the better in their future.

Feelings of Being Overwhelmed, Denial, Anger, Frustration, And Guilt

Four of the participants’ felt overwhelmed when they were first diagnosed with diabetes. Mike reports,

A lot of things went through my mind from that day on, shots, sugar tests, change of eating habits. I think the change of food is what bothered me the most, bland food with no taste. I couldn’t have my sweets...the do’s and don’ts were overwhelming for me...

Jon had an eye-opening experience when he learned about his diabetes:

When I was diagnosed, you start to realize you are not as healthy as you used to be and some of the daily habits that you run around with on a daily basis is a lot of stress related things that cause you to not eat properly sometimes. So the food intake and exercise, maybe wasn’t getting the right things done for my health, and it really hits you when something major happens...that’s an eye-opener for me and I am like, “wow.” I don’t want to get into that situation, the stuff you are battling, and your health is working against you if you are not working with it, so there is no doubt that it’s an eye opener for me.

Paul reports, "There always is the initial shock that you actually have something..." Jen states, "I was really shocked when I found out I had diabetes." Kathy struggled with hypoglycemia earlier in life and was shocked when she found out she had diabetes: "How could I have diabetes after having the opposite [hypoglycemia]...I thought they were off of their rockers..."

Once the shock and overwhelming feelings started to decrease, two of the participants reported they wanted to deny that they had diabetes. Jen reports, "At first, I denied that I had diabetes and went on about my life...I really didn't know what diabetes meant..." Jon reports, "It took a long time to believe that I was diabetic, and there is some denial there and it's true because it's all working against you if you don't believe it."

Paul shared that, initially, there was anger, frustration, and guilt.

When first diagnosed, there was a lot of anger. A lot of anger, a lot of frustration and I think that's because I knew diabetes ran in my family. There was some anger, some frustration, and some guilt for not doing everything you could to avoid getting diabetes. I think every time things have changed drastically, those have been some of the feelings...

In a study by Smith et al. (2003), emotions of anger and frustration were reported from subjects when they were unable to understand and control their fluctuating blood glucose levels.

Regrets and Wishes

Feelings of regret for not doing more to avoid or delay the onset of diabetes were reported by two of the participants. Jen states, "I knew I should be eating better and exercising...my mom died from the disease, you would think I would know better." Paul

also wishes he would have listened more to his diabetic educator when he was first diagnosed.

If only I listened a little bit more to a few things, because one of the first things I was told was, "It is not what happens today. Today's results you will find out 10 years down the road." I don't know...as a diabetic person that I really believed that in the beginning; now I do more.

Friend and Family Support

Three of the participants used friend and family support to help them transition and live with their diabetes, now and in the future. Jen reports, "My fiancée is really supportive. He likes to work out and be active. He is trying to get me out more with walking and hiking." Kathy states, "My family all knows I have it, and they check in once awhile to see how I am doing. See if I want to go to eat..." A study by Nagelkerk, Reick, and Meengs (2006) found a recurring theme that "social support, especially spousal support" positively influenced individuals self-management of diabetes (p. 157). This was demonstrated by Paul, who clearly relies on his wife and friends to keep him focused on eating right and living with diabetes.

I really do have a great wife that has been very understanding and we talked through quite a bit. I would say that's really the key...[Gloria] and the help she gives me, and has been there for me along the way. She has helped me deal with it...The other thing is having that, really having some good people around me that were good encouragers...people that understand...when I am getting awfully moody...any day, "You better check your blood sugar, you better check your attitude about things so you don't let things get out of hand"...to really realize that you don't do anything alone, by yourself...

Complications and Fears for Tomorrow

Sometimes, individuals with diabetes do not foresee how the choices and changes they make today impact their future. Mike states, "Forgive me...but sometimes my heart doesn't see a life's change for the better is coming." He further explains, "I look, listen and laugh, cry and try to feel life around me everyday. Sometimes, that's why I am quiet. I think of the day that's happening and try not to think of tomorrow coming." Jen knows what she needs to do but claims, "I just don't have the energy, I know I should be exercising. I know I should be eating better, but it is still hard..." Kathy also struggles with changes she knows she needs to make. "There are a lot of things I should change, but I really haven't..." She shared the example, "You are supposed to have a snack before bed, I just don't do that..." Despite not making the changes she needs to, Kathy still reports, "I just hope I am here long enough to see my grandchildren grown and things like that; and, help out, and know what I can do and what I can't."

In the theme, *transitioning and the future*, participants shared their feelings of shock, denial, anger, frustration and guilt related to living with diabetes. Many felt denial that they had the illness and this was often following by anger, frustration, or guilt. Some felt regrets that they did not take their family history seriously, watching what they ate or how much they exercised. Paul wished he had listened more to his diabetic educator from the beginning. Jon had an outside influence to keep him on track and motivated to manage his diabetes. Mike felt that his future was bleak and getting through today was his focus and not looking forward to more tomorrows. Each participant had varied experiences, but each person struggled with understanding, accepting, and trying to find ways to manage their diabetes.

Discussing a Regimen

Exercise and Diet

The next major theme that was expressed by all five participants was *discussing a regimen*. A study conducted by Tan (2004) found that if symptoms of diabetes are present, individuals are more likely to adhere to treatment regimens. Two of the participants found that exercise should be part of their daily regimen but was not regularly scheduled. A study by Edelman, et al. (2002) found that physical activity was the only factor in the treatment of diabetes to have a positive influence on an individual's quality of life. Jon found that having a physical aspect to his job was helpful, "I think it has become better and (I) actually lost 35 pounds, mostly because I have a more physical job, which sometimes might be better for me healthwise to be more active..." This is consistent with a study by Koch (2002) that found individuals who exercised regularly reported perceived greater benefits than those who did not exercise regularly. Jen struggled to find the energy to exercise regularly, "I walk occasionally on my days off, but I am too tired after work...I just don't have the energy. I know I should be exercising."

Two of the participants found that their goals were to manage both diet and exercise as part of their regimen. Mike reports, "I'm trying to eat better and exercise, trying to do my body right." Paul claims he has been "...studying on carbs and putting my meals together and watching what I eat at meal times and trying to get to the goal of exercising." Vermeire et al. (2007) also demonstrated this behavior by Paul in a study where "...people learn how their body reacts to different foods, activities, and medications, they can also develop ways to manage their diabetes" (p. 30).

Three of the participants found that diet was a main focus of their regimen. A study by Nagelkerk et al., (2006) found that diet was “the most challenging aspect of diabetes care” (p. 156). Paul reports that “(I)t’s been a lot of regimen stuff at different times as far as watching what I eat, watching how much sweets I eat.” Jon continues to learn how much he should eat and to learn how to make his own meals: “I just have to eat what I have to eat, and I realize that for myself and my family...I seem to be very much aware that sometimes, I just need to make my own meals.” Jen still views her relationship with dietary behaviors as a burden, which is consistent with a study from Watkins et al. (2000). Jen claims, “I know I should be eating better but it is still hard...you change your food choices.” In the study by Nagelkerk et al., (2006), it was found that “...many struggled with reframing their eating habits to promote a healthy body and lifestyle” (p. 156).

Testing Blood Glucose Levels and Following Recommendations

Part of the regimen of living with diabetes is regularly testing your blood glucose levels and taking the medications prescribed by the primary care provider. Kathy is on insulin and is aware that she “has to eat, and I know to take my insulin, and when you go someplace, you gotta make sure you have it with you.” Taking medication for diabetes was not a favorite part of the regimen for Mike, “...the pills I have to take is another issue I deal with, not my favorite.” Kathy also struggled with weight control, “...trying to control your weight is hard. I’ve gained more weight now than I ever have, and I know it’s because I am so inactive...”

Four of the participants felt that part of their regimen was to try and follow what their primary care provider or diabetic educator recommended. In a study by Watkins et al. (2000), the researchers found that adherence to a treatment regimen actually

improved the overall quality of life in individuals with diabetes. For Jon, the main factor in his regimen,

...is keeping track of your intake...I do what the doctor tells me...that in combination with medications, and listening to what my doctor tells me, in my diet and all of those will hopefully get another 20 years, I hope.

Paul found help from his diabetic educator and taking diabetic classes, “ I had a great diabetic educator...and went to some classes right away and tried to understand things...she was really, very, very good...” Kathy claims “If you don’t follow your regimen a little bit, you’re in trouble...Listen to your doctor.” Kathy also admitted that she doesn’t follow everything her doctor says’ “I’m supposed to wear a medical alert bracelet or charm or whatever; I do very rarely. When I go and see the endocrinologist, I make sure I have it on.” Jen’s primary care provider needed to confront her about having continued high blood sugars. She reports, “I am still not good about checking my blood sugars... My sugars are still high and I had a big talk with my doctor who told me more about the complications of diabetes. Again, I was in shock.”

Discussing a regimen was a consistent theme for all the participants in the study. Some focused more on diet or exercise or a combination of both. Other participants focused more on testing their sugars, managing their insulin, and weight control, besides their diabetes. All of the participants tried to follow at least some of the recommendations of their primary care provider to some degree in their attempts to manage their illness and achieve an acceptable quality of life.

Searching for Deeper Meaning

Cultural Beliefs, Genetics, and Consequences

Throughout life, individuals form beliefs regarding or related to their culture, genetic history, childhood, and understanding of life's challenges. Mike is Native American and struggles between the traditional Native American ways versus "The White man's ways." He reports,

I question the White man's way of life, for the better? All the way up to this day, when I ask what's wrong with this picture? For me, putting White people on the pedestal. This is from my eyes, my learnings.

Jen learned to accept the messages and beliefs of her mom from her childhood. "My mom always told me that if you can walk and talk, then you really weren't sick. I always believed that. I guess I am still learning to change that." Paul was aware that his genetic history put him at risk for diabetes. "I am actually the fourth generation to have diabetes from my father's side of the family. So I knew that was always a possibility." Despite this, Paul has formed his own understanding about having diabetes.

Ultimately, I am responsible for how I manage my body...what happens today is not so much what's going to happen now, but the results are really down the road in long-term non-management or long-term uncontrolled diabetes.

Being responsible for managing your body was demonstrated in a study by Nagelkerk et al., (2006), which found "(T)hose who were more proactive in their diabetes care, expressed a greater sense of empowerment and control, and were more likely to integrate self-management into everyday living" (p. 157). Kathy reports that having diabetes is a serious illness, "Don't think it's a joke, because it really isn't. And, you don't go and pig out for a day or so and say, 'It's not going to make any differences.'"

Jon knows that if he does not work to manage his diabetes, he will not be able to be certified through the Department of Transportation.

My new job is with the DOT certification (Department of Transportation) for driving vehicles and I am required to be healthy enough to do this, so I do what the doctor's tell me, and then you get certified. If you wouldn't do what the doctor's tell you, then you wouldn't be certified. So, it's really cut and dried there, and maybe it was a good thing I was forced to do that.

Faith and Spirituality

Two of the participants found deeper meaning in understanding diabetes through their faith and spirituality. This is also demonstrated in a study by Garrow & Egede (2006), who found that people with diabetes were more likely to use prayer than people without diabetes. Paul shared that at the time of his diagnosis he was a pastor of an area church. He has always relied on his faith to get him through the tough times in his life. "I guess because faith is part of our life that anything that happens really begins to get filtered through... I think I was able to filter things through..." He also explained,

(His) faith, and at times wrestling with providential and sovereignty of God at times as things happen and why, why they happen. I think a lot of it was really my faith that really helped me to deal with some of the different feelings that I was having.

Kathy relies on her faith for strength and understanding of her diabetes.

I got a very strong faith...I got this (diabetes) for a reason, and whatever the reason may be, and I think that is why I am still here. I guess I still have things that haven't been done yet. I don't know what they are yet. I am the only one in my family of 10 kids that has all these health issues ever since I was a little girl.

And, I thought, well, maybe God made me the strong one because I can handle it.

Hope and Beliefs

Three of the participants believe that their hope for a long future life helps them cope with diabetes. Jon believes that the positive changes he has made to manage his diabetes have provided hope for his future with the disease.

I've made some changes for the good, I hope. You kind of realize that in your 40's you don't want to die, and you want to make it past your 50's, and past your 60's, and into your 70's, I hope.

Jon believes he has "hope for the future and will live a productive long life" if he manages his diabetes. Paul feels that diabetes has "increased his ability to cope with the diabetes and still live my life...some days are harder than others...as long as I am still living and breathing, I can still learn ways to be more healthy with diabetes." This is consistent with a study by Sigurdardottir (2004) that found an individual's higher level of self-efficacy including, "managing diabetes outside the home...coping skills, achieving diabetes goals...readiness to change and managing the psychosocial aspects of diabetes" is a strong predictor of better self-care and metabolic control (p. 306).

Meaning for Life

Three of the participants have attempted to find a deeper insight and understanding about why they were chosen to get this disease. Jen continues to struggle with understanding why she was diagnosed with diabetes, "I just thought I would be lucky enough not to get it." She continues wondering, "What was this going to mean for my life?" Paul needed to decide if he was going to accept, deny, or rebel against having diabetes.

The simple fact of the matter is that you have to come back to what you want to rebel against and learn to accept and say “ok.” How am I going to rebel, to deny. I can have all the denial I want, but it doesn’t change the facts when the tests are the tests, and the results are the results. You know how you feel; you know how you are feeling. You have diabetes that is uncontrolled...and the wiser thing is to as quick as possible to start getting some of those things in control.

Mike struggles with understanding the true meaning for his life with diabetes:

“Diabetes is another factor in my life, I’ll deal with for now...to me it’s what Diabetes tells me I have to do...this disease, the magic challenge.”

In this final subcategory, participants reported that their experiences with diabetes were influenced by factors including cultural beliefs and messages and beliefs learned in childhood. Furthermore, a few sought answers through prayer and their faith, while others tried to maintain a positive attitude and look towards having a long healthy future.

Chapter Summary

This study used a qualitative approach to identify specific factors that positively influence the beliefs, behaviors, experiences, and self-management of Type 2 diabetes mellitus in adults. Four themes emerged from the interviews conducted: (1) *In the beginning*, (2) *transitioning and the future*, (3) *discussing a regimen*, and (4) *searching for deeper meaning*. *In the beginning* described how the participants found out they had diabetes and understand the cause of the illness. Furthermore, the participants described how life with diabetes is a burden that they need to bear while adapting to changes they try to follow and learn from. In *transitioning and the future*, the participants

shared how overwhelming diabetes was at the beginning, their feelings of anger, guilt, frustration, and regret that they did not do more to prevent getting diabetes. A few of the individuals did not see a positive outlook for their future and just hoped they would be around to see their grandchildren grow up. *Discussing a regimen* was the third theme and incorporated diet, exercise, testing of blood sugars, medications and following treatment recommendations of their primary care providers. This became a daily ritual for some of the participants, but others struggled, not understanding the importance of finding the balance in managing their diabetes. Finally, *searching for deeper meaning* described how some participants were influenced by their cultural or family beliefs and how this affected their management of diabetes. Furthermore, some participants relied on their family and friends for support and looked to their faith to give them strength and courage in understanding and living with diabetes.

All of the participants in the study had some feeling of being overwhelmed or shocked by their diagnosis and during initial education about diabetes. They all had experiences with family members or other individuals in the community who also had diabetes. Diet, exercise, and following a regimen were consistent factors for all of the participants to some degree. Some focused on finding a balance, where others tried to balance one specific area before battling another area. This is consistent with other research studies relating to the beliefs, behaviors, experiences and self-management of living with diabetes.

CHAPTER V

SUMMARY, CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

The purpose of this study was to ask what life was like since diabetes and to determine specific factors that influence the beliefs, behaviors, experiences, and self-management of Type 2 diabetes mellitus in adult individuals. The study summary, conclusions, implications, and recommendations for further research are presented in this chapter.

Summary

Sample Demographics

There were five participants interviewed for this study -- three male and two female. The participants were between the ages of 43 and 63 years. Four of the participants were Caucasian and one was Native American. All participants were from Northeast Wisconsin communities. Four of the participants were employed full-time in various occupations and one participant was retired. Two of the participants were married, two were divorced, and one was single (never married or widowed). Disease duration ranged from 3.4 years to 21.1 years, with an average duration of 10.5 years.

Four themes that influenced participants with Type 2 diabetes were identified. The themes of *in the beginning, transitioning and the future, discussing a regimen, and searching for deeper meaning* were identified as the specific factors that influenced the participants' self-management of diabetes. This is consistent with research studies conducted in the area of beliefs, experiences, and self-management of Type 2 diabetes mellitus.

Conclusions

Participants shared their shock, fear, anger, and denial when they were initially diagnosed with diabetes mellitus. Participants shared feelings of frustration over high blood glucose levels. Five of the participants knew of their risk of getting the disease. These individuals felt guilty for not doing more to control their weight or for not being physically active to avoid or delay the diagnosis. Gradually, the participants' denial changed to finding ways to understand and live with their lives with diabetes.

Two of the participants' ability to manage their diabetes was influenced by effective diabetic education provided by diabetic educators and their primary healthcare providers. This education was often overwhelming and the participants expressed feelings of wishing they listened and learned more initially. This education led to further understanding of diabetes for some of the participants. However, four of the participants shared that diabetes was a continual learning process and that they were trying to comply with recommendations from nursing and medical staff.

The themes identified in this study can be incorporated into Leventhal's Commonsense Model (1992). The five specific components of identity, cause, time-line, consequences, and controllability were demonstrated in the participants' interviews as they tried to find ways to live with and manage their diabetes (Leventhal et al., 1992). The participants were "identified" as having a specific disease and the disease's perceived health threat or consequences if not controlled (Leventhal et al., 1992). The participants who had a genetic predisposition to diabetes were more able to identify the reason or cause of the disease. Individuals who were inactive, overweight, or had other related health issues took a longer time to accept the diagnosis and understand the cause of their diabetes. All of the participants were aware that diabetes is a chronic

illness. When Paul needed to start insulin, his anger and frustration again surfaced, similar to when he was first diagnosed. Knowledge of the risks and consequences from uncontrolled diabetes were more acute in those participants who had more interactions and experiences with other diabetic patients. Most of the participants understood the risk of complications if they did not control their blood sugars. This is consistent with the study conducted by Kelly et al. (2005), which found individual's perceived risk was related to the time since diagnosis of diabetes, duration of time since diagnosis, and personal or family medical history. Finally, all the participants were aware that there is no cure for diabetes and the best way to manage the disease was to follow their treatment regimen and to rely on family, friends, and their faith to cope with the disease.

This study illustrated the main components of Leventhal's Commonsense Model (1992). This study identified a few factors that influence the beliefs, behaviors, experiences, and self-management of diabetes through the four themes identified (*in the beginning, transitioning and the future, following a regimen, and searching for deeper meaning*). Not all of the experiences and beliefs by the participants positively influence their self-management of diabetes; however, diabetes is a continual learning process, and all participants were trying to find ways to manage their illness.

Implications

This research identified some factors that influenced the experiences of adults with Type 2 diabetes mellitus. Four themes were identified, along with subcategories further defining each theme. Identifying the individuals' level of understanding about the cause and treatment of diabetes is essential. This helps address individual motivation to follow treatment regimens, including self-management of the illness outside of the

clinical setting. This also assists in identifying the individual patient's understanding of the perceived risk of consequences and negative outcomes relating to their diabetes. Furthermore, recognizing and addressing individual emotional responses to diabetes, in addition to providing medical and nursing care, may improve the patient's self-efficacy and ability to manage their diabetes. This is important for clinical practice, where optimal management of diabetes requires effort from healthcare providers working collaboratively with the patient. Furthermore, identifying an individual's cultural, family and personal beliefs, and support system may assist in providing effective education, in developing an acceptable treatment regimen, and in improving the individual's willingness to manage their diabetes.

Limitations

This researcher identified several limitations in this study. This was a small qualitative study and has not attempted to generate theory but to ask what life was like since diagnosis with diabetes to determine a view of the beliefs, behaviors, experiences, and self-management of Type 2 diabetes in adults. The sample size was limited and the participants were all from Northeast Wisconsin communities, so, therefore, not representative of other urban or rural communities. Four of the sample participants were Caucasian, so this study may not be representative of the beliefs, behaviors, experiences, and self-management of individuals with diabetes from other ethnic groups or other Caucasians. Two of the participants were married in this study, two were divorced, and one was single (not divorced or widowed). This study may not be representative of all married, divorced, or single individuals with diabetes in northeastern Wisconsin. Only one retired individual was interviewed in this study. As a person grows

older, more co-morbidities arise which can make self-management of diabetes more challenging. The age group selected for this study was meant to be representative of the middle-age adult versus the over 65-year-old adult. Education level of the participants was not assessed, although all could read and write English. Differences in education level may directly affect the understanding of the disease state of diabetes and influence a person's ability to manage the disease.

Implications for Further Research

This study used a qualitative approach to identify what life was like since diagnosed with diabetes in order to ascertain a few factors that positively influence the beliefs, behaviors, experiences, and self-management of diabetes in adults. Based on this study, further research using specific questions identifying the beliefs related to diabetes mellitus and the threat of long-term consequences from diabetes may be helpful in the clinical setting. More research is needed on the level of understanding of diabetes and an individual's ability and willingness to manage their diabetes outside the clinical setting. Improved understanding of the self-management process and regimens for diabetes may assist primary care providers and educators to develop more individualized treatment plans throughout the course of the illness. More discussion about the factors leading to the onset of diabetes, the treatment regimen, and common emotional responses of others diagnosed with diabetes may help alleviate some of the overwhelming and fearful feelings experienced by many patients with diabetes. A focused research study with Native American adults may be helpful to incorporate traditional cultural beliefs and practices into diabetic teaching plans. Furthermore, studies which focus just on male or just on female beliefs, behaviors, and experiences

with Type 2 diabetes mellitus may help primary care providers further understand ways to promote self-management of diabetes and to encourage their patients to follow treatment recommendations.

Recommendations

1. Identify specific questions that address the beliefs of individuals with diabetes after initial diagnosis and through the course of the disease.
2. Conduct research that focuses on the individual's level of understanding of diabetes and how this influences their ability to self-manage their diabetes.
3. Perform research on a larger sample size containing more diverse cultures and ethnicities.
4. Conduct a multi-site research study to evaluate if the results are the same or different among the sites.
5. Perform research on alternative age group categories to ascertain differences in the beliefs, behaviors, and self-management of diabetes.
6. Conduct research on male and female participants separately to evaluate if the beliefs behaviors, and experiences differ.

Chapter Summary

This study presented a few factors that influence the beliefs, behaviors, and experiences of adults with Type 2 diabetes mellitus. This study utilized five volunteer participants, ages 43 to 63 years, from Northeast Wisconsin who had diabetes mellitus for at least 1-year duration. Participants were selected using the snowball technique and their interviews were assessed using the Colaizzi method. The four themes -- *In the*

beginning, transitioning and the future, discussing a regimen, and searching for deeper meaning were identified and presented with examples from the participant transcripts.

Further research is needed to identify specific factors that influence the beliefs, behaviors, and experiences of adults with diabetes. Further research is also needed to help further identify factors that will promote improved self-management of adults with diabetes, so that clinicians can be more proactive in their treatment plans for patients with diabetes. Also, further research on specific ethnic or gender groups may provide further insight into the experiences and beliefs of these individuals. Diabetes continues to be a complex disease that requires continual learning, transitioning, and management by the individual with this diagnosis.

APPENDIX A

UW Oshkosh IRB Approval Letter



June 25, 2009

Ms. Mary Cappell
2552 Finger Road
Green Bay, WI 54302

Dear Ms. Cappelle:

On behalf of the UW Oshkosh Institutional Review Board for Protection of Human Participants (IRB), I am pleased to inform you that your application has been approved for the following research: Type 2 Diabetes Mellitus Beliefs and Experiences.

Your research has been categorized as NON-EXEMPT, which means it is subject to compliance with federal regulations and University policy regarding the use of human participants as described in the IRB application material. Your protocol is approved for a period of 12 months from the date of this letter. A new application must be submitted to continue this research beyond the period of approval. In addition, you must retain all records relating to this research for at least three years after the project's completion.

Please note that it is the principal investigator's responsibility to promptly report to the IRB Committee any changes in the research project, whether these changes occur prior to undertaking, or during the research. In addition, if harm or discomfort to anyone becomes apparent during the research, the principal investigator must contact the IRB Committee Chairperson. Harm or discomfort includes, but is not limited to, adverse reactions to psychology experiments, biologics, radioisotopes, labeled drugs, or to medical or other devices used. Please contact me if you have any questions (PH# 920/424-7172 or e-mail: rauscher@uwosh.edu).

Sincerely,

A handwritten signature in black ink, appearing to read "Rauscher" with a flourish at the end.

Dr. Frances Rauscher
IRB Chair

cc: Dr. Roxana Huebscher
1610

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APPENDIX B
Demographic Questionnaire

Demographic Questionnaire

Participant code name: _____

Current age: _____

Have you been diagnosed with Type 2 diabetes mellitus by a medical provider
(physician, nurse practitioner)? Yes _____ No _____

What month/year were you diagnosed with Type 2 diabetes mellitus?

Appendix C
Participant Consent Form

University of Wisconsin Oshkosh Consent Document

Type 2 Diabetes Mellitus Beliefs and Experiences

I, Mary Capelle, a Family Nurse Practitioner student at the University of Wisconsin Oshkosh, am conducting a study on the beliefs and experiences of adults aged 40 to 65 years with Type 2 diabetes mellitus. Your participation in this study will assist me in identifying and understanding factors related to the specific beliefs and experiences in individuals with Type 2 diabetes mellitus. Furthermore, society may benefit from the identification of these factors for the development of new individual, group, and community treatment programs for adults with diabetes.

I would like to interview you by audiotape and obtain demographic information. I will be collecting data at one point in time and your participation is voluntary. I may call you afterward to clarify information if needed. Participation in this study may not benefit you directly, but will assist me with my research.

The information gathered through the interview and questionnaires will be recorded in anonymous form. I will not release information about you to your health care provider, or anyone else in a way that could identify you. If at any time you wish to withdraw from the study, you may do so without penalty. If it is your wish to withdraw, any personal information will be destroyed at your request.

Once the study is completed, I would be happy to share the results with you. In the meantime, if you have any questions, please ask or contact me at: Mary Capelle, University of Wisconsin Oshkosh, Graduate Program, College of Nursing, 800 Algoma Boulevard, Oshkosh, WI 54901-8660 (920) 424-2106.

If you have any complaints about your treatment as a participant in this study, please call or write:

Chair, Institutional Review Board for Protection of Human Participants
UW Oshkosh c/o Grants Office
Oshkosh, WI 54901
(920) 424-1415

Although the chairperson may ask for your name, all complaints are kept in confidence.

I have received an explanation of this study and agree to participate. I understand that my participation in this study is strictly voluntary.

Signature: _____

Date: _____

I agree to be tape recorded for purposes of this research interview.

Signature: _____

Date: _____

This research project was approved by the University of Wisconsin Oshkosh, IRB for Protection of Human Participants for a 1-year period, valid until December 2009.

Thank you for your time and effort.

Sincerely,

Mary Capelle, RN, FNP student

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