

PROBLEMS AMERICAN INDIAN/ALASKA NATIVE ADULT PATIENTS
FACE WHEN ATTEMPTING THE LONG TERM SELF MANAGEMENT
OF THEIR TYPE II DIABETES DISEASE PROCESS

by

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A thesis submitted in partial fulfillment
of the requirements for the degree

of

Master of Nursing

in

Family Nurse Practitioner

MONTANA STATE UNIVERSITY
Bozeman, Montana

April 2010

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April 2010

ACKNOWLEDGEMENTS

I would like to acknowledge my daughter Brianna, my parents, and family for their tremendous support in making this thesis and my graduate studies possible. Without their support it would not have been possible. I would also like to acknowledge my late grandparents Irvin and Sarah Stewart for their love, support of my educational endeavors and instilling in me the importance of my Native American culture and practices. Lastly, I would like to acknowledge Patricia Holkup, my thesis chair, without whom this thesis would surely have gone unwritten. My thanks for her support and guidance during this process cannot be expressed enough.

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ABSTRACT

The American Indian/Alaska Natives people are plagued by Type II Diabetes. The poor management of this disease process has dire effects on the morbidity and mortality of this population. It is imperative to identify the challenges that this group of people face with the self-management of Type II Diabetes. The conceptual framework for this study was based on Dorothea Orem's health deviation of self-care requisites. These health deviations result from the disease state and are used for diagnosis and treatment (Orem, 1985). The literature review and the discussion of results with the relevant literature were organized according to Orem's six themes of health deviations in the self-management. A qualitative research method, involving open-ended interviews with five Native American participants, was used. The participants were asked questions regarding their diagnosis, challenges in self-management, knowledge of long term effects, and additional needed resources. The data were analyzed using Luborsky's (1994), method of thematic analysis to identify the challenges Native American adults encounter in the self-management of Type II Diabetes, resulting in 8 topics. These included: a) feelings about Type II Diabetes diagnosis and the implications for lifestyle changes, b) prior experiences with family who have Type II Diabetes, c) challenges and lifestyle changes in managing Type II Diabetes, d) personal contributing factors to poor management, e) support systems for managing Type II Diabetes, f) identification of good management of Type II Diabetes, g) knowledge of long term effects of Type II Diabetes, h) additional support and resources needed to manage Type II Diabetes. Diabetes is a complex disease process that requires ongoing education and consistent medical care. It is essential that health care providers evaluate and tailor their care to the challenges of their patient population to improve the health status of those with Type II Diabetes.

CHAPTER 1

INTRODUCTION

Type II Diabetes is an epidemic condition affecting the American Indian/Alaska Native AI/AN population (Indian Health Service, 2008). The Association of American Indian Physicians (AAIP) states that “American Indian/Alaska Natives (AI/AN) suffer from some of the highest rates of diabetes in the world, and have the highest Type II Diabetes prevalence rate in the United States” (Association of American Indian Physicians, 2004, p. 31). With this diagnosis there are a multitude of self-care responsibilities that must be implemented to maintain a healthy state. Failure of self-care will result in detrimental comorbid conditions associated with Type II Diabetes.

Background and Significance of the Study

Research on the problem of diabetes management is vital to the health of the AI/AN population. According to the AAIP, “AI/ANs have long experienced lower health status, ranging from lower life expectancy to disproportionate disease burden, as compared with the general U.S. population” (American Academy of Indian Physicians, 2004, p. 24). The Indian Health Service reported that AI/ANs have the highest rate of Type II diabetes in the United States, being afflicted with diabetes at a rate 2.9 times greater than the general population. Overall AI/ANs have a 190% greater mortality rate related to diabetes than the general population (IHS, 2008).

In a study by AAIP, costs for treatment of an individual with controlled diabetes were estimated to range of \$4,000 to \$9,000 per year (American Academy of Indian Physicians, 2004, p.28). The cost increases exponentially for the treatment of a diabetic with complicating comorbid conditions. The effect of uncontrolled diabetes has multisystemic physiologic consequences. According to research by Dokken (2008), individuals with diabetes have an increased risk of coronary artery disease, stroke, high blood pressure, retinopathy, nephropathy, neuropathy, amputations, dental disease, and complications with pregnancy. Dokken states that the “pathophysiology is complex and multifactorial” (Dokken, 2008, p. 160). All of these potential complications could be alleviated with better management of the disease process. The resources needed to care for these individuals include increased health care professionals in the areas of internal medicine, nursing, nephrology, cardiology, internal medicine, dietetics, pharmacology, and ophthalmology. Additional needed resources include inpatient health care and medications to treat and stabilize the complications. It is imperative that resources be directed toward improving the long term management of Type II Diabetes.

Problem Statement

On initial diagnosis, a patient in the IHS system is given education from his or her physician, nurse, diabetic educator, nutritionist, and pharmacist. All the tools for a positive outcome are in place for an individual to succeed in managing a diagnosis of diabetes. Yet, evidence from research shows AI/ANs with Type II Diabetes are still greatly impacted with the comorbidities that result from a lack of control as evidenced by

greater incidences of: coronary artery disease (CAD), peripheral vascular disease (PVD), retinopathy, nephropathy, neuropathy, stroke, and infections (AAIP, 2004, p. 35). It is imperative that we find the break in the system that prevents AI/ANs from maintaining control of their Type II Diabetes.

Purpose

Diabetes is a disease that affects every bodily system (Huether and McCance, 2003). According to Huether and McCance (2003), complications of diabetes include: retinopathy, coronary artery disease, peripheral vascular disease, stroke, nephropathy, neuropathy, and infection. Failure to manage the disease process results in life threatening complications.

American Indian/Alaska Native adults are genetically predisposed to diabetes and often suffer the damaging effects of diabetic complications (IHS, 2008). Therefore, it is imperative to identify the problems AI/AN patients face when attempting to manage their disease process so that measures can be taken to help the patient decrease the destructive effects related to poor control of Type II Diabetes.

The purpose of this research is to identify the problems AI/AN adult patients face when attempting the long-term management of their Type II Diabetes disease process.

Research Questions

The research will be guided by the following question: What problems do AI/AN adult patients face when attempting the long term management of their Type II Diabetes disease process?

Conceptual Framework

The conceptual framework for this research is Dorothea Orem's Self-Care Deficit Theory of Nursing. According to Marriner-Tomey and Alligood (2006), Orem's theory of self-care posits that individuals have the ability to care for themselves to maintain healthful functioning (2006, p. 269). Orem's theory states that there are developmental self-care requisites that include: "provision of conditions that promote development, engagement in self-development, and the prevention or overcoming of effects of human conditions and life situations that can adversely affect human development" (Marriner-Tomey & Alligood, 2006, p. 270). The developmental self-care requisites can be divided into two categories:

"1) The bringing about and maintenance of living conditions that support life processes and promote the processes of development, that is, human progress toward higher levels of the organization of human structures and toward maturation, and 2) Provisions of care either to prevent the occurrence of deleterious effects of conditions that can affect human development or to mitigate or overcome these effects from conditions" (Orem, 1985, p. 95).

The specific lack of meeting these requisites by the diabetic patient can be evaluated by Orem's theory of therapeutic self-care demand. Orem's theory specifies that there are care measures and factors that are needed to fulfill the requisite for health

maintenance (Marriner-Tomey & Alligood, 2006, p. 271). These requisites include the elements of maintenance, promotion, prevention and provision. Identifying which specific requisite is not being met will serve as a guide to interpret the findings from this research (Marriner-Tomey & Alligood, 2006, p. 271).

Definitions

The following terms with their definitions will be used in this research study.

American Indian/Alaska Native: “A person having origins in any of the original peoples of North and South America (including Central America) and who maintain tribal affiliation or community attachment” (U.S. Census Bureau, 2000). For the purposes of this research, the definition will be adult members of an American Indian tribe in a rural state in the northwest United States.

Blood Glucose (BG): “The amount of glucose in a given amount of blood. It is noted in milligrams per deciliter (mg/dl)” (National Institute of Health, n.d.).

Hemoglobin A1C: A test that gives an average percentage range level of an individual’s blood glucose over a period of three months. (American Diabetes Association, 2008).

Long term management of Type II Diabetes: A five year period following the diagnosis of Type II diabetes in which an individual has been responsible for managing his or her disease.

Perceptions: “The process of using the senses to acquire information about the surrounding environment or situation” (Encarta, 2009). The operational definition is: the

patient's ability to identify the positive impact on daily blood glucose and HgA1c levels by following a diabetic diet and exercise regimen for 30 minutes a day for maintenance of long term management of diabetes.

Type II Diabetes: A condition characterized by hyperglycemia resulting from the body's inability to use blood glucose for energy. Either the pancreas is not able to make enough insulin or the body is unable to use the insulin correctly." (National Institute of Health, n.d.).

Assumptions

The following assumptions may serve as a guide in identifying those tenets in Orem's self-care deficit theory that are disregarded in AI/AN's control of their Type 2 Diabetes. These assumptions may serve as a framework from which to understand the findings of this study.

Orem: "Human beings require continuous, deliberate inputs to themselves and their environments to remain alive and function in accordance with natural human endowments" (Taylor, 2006, p. 272). When diagnosed with a disease process patients must filter through an enormous amount of information.

Orem: "Human agency, the power to act deliberately, is exercised in the form of care for self and others in identifying needs and making needed inputs" (Taylor, 2006, p. 272). Patients need to be taught the many aspects of diabetes management to maintain a healthy status in their disease process. They must then act on this information with purposeful actions related to diet and exercise to achieve long term management.

Orem: “Mature human beings experience privations in the form of limitations for action in care for self and others involving and making of life sustaining and function-regulating inputs” (Taylor, 2006, p. 272). Education is the first step to empowerment and self care. A deficit in self care education will result in limitations of long term management.

Orem: “Human agency is exercised in discovering, developing, and transmitting ways and means to identify needs and make inputs to self and others” (Taylor, 2006, p. 272). It is crucial that diabetic patients maintain an ongoing support system after diagnosis of diabetes. There are new questions and uncertainties that patients identify after the initial diagnosis.

Orem: “Groups of human beings with structured relationships cluster tasks and allocate responsibilities for providing care to group members who experience privations for making required, deliberate input to self and others” (Taylor, 2006, p. 272). It is essential that the diabetic patient identify that the health care team is available to answer questions related to each disciplinary specialty. There are many facets of education, diet, exercise, and medication that each team member is an expert in.

Summary

The health status of the American Indian/Alaska Natives is in dire jeopardy because of the effects of uncontrolled Type II Diabetes. The American Association of Indian Physicians states that “because AI/ANs have higher rates of diabetes, they also suffer from higher rates of long-term diabetes complications, disability, and premature

death” (Association of American Indian Physicians, 2004, p.34). It is imperative to identify the barriers and the factors that contribute to the low health status.

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

Literature search results related to the barriers of long term self management of Type II Diabetes will be discussed and analyzed in this chapter. Although there were numerous studies that evaluated the obstacles of maintaining control of Type II diabetes, there was not any research specifically related to Native Americans and control of Type II Diabetes. Dorothea Orem's Self-Care Deficit Nursing Theory (SCDNT) will provide the organizing framework for this review. Three central concepts, as outlined by Dorothea Orem, constitute the SCDNT: 1) self-care, 2) self-care deficit, and 3) nursing system. They are discussed below.

Self-care

Self-care is defined as “the production of actions directed to self or to the environment in order to regulate one's functioning in the interest of one's life, integrated functioning, and well-being ” (Orem, 1985, p. 31). Specific actions are required to maintain this optimal level of health. These actions are health requisites. Insufficiency of these actions results in health deviations. Self-care has external and internal orientations. The external orientations of self-care actions include: “1) knowledge-seeking action sequences, 2) assistance- and resource-seeking action sequences, 3) expressive interpersonal actions, and 4) action sequences to control external factors” (Nursing

Concepts of Practice, 1985, p. 111). The internal orientation self-care actions include: “1) resource-using action sequences to control internal factors and 2) action sequences to control oneself (thoughts, feelings, orientation)” (Orem, 1985, p. 111).

There are specific self-care requisites that are required by an individual in a disease state. These are identified as health-deviation self-care requisites. These requisites “arise from both the disease state and the measures used in its diagnosis or treatment” (Orem, 1985, p. 99). There are six categories in health-deviation self-care requisites. These six categories of health- deviation self care requisites will serve as guides in identifying the problems of Native American adults and the management of Type II Diabetes.

“1) . . . seeking and securing appropriate medical assistance . . . with pathological states,

2) being aware of and attending to the effects and results of pathological conditions and states,

3) effectively carrying out medically prescribed measures to regulate the pathological condition,

4) being aware of and attending to or regulating the discomforting or deleterious effects of medical care measures performed or prescribed,

5) modifying the self-concept (and self- image) in accepting oneself as being in a particular state of health and in need of specific forms of health care,

6) learning to live with the effects of pathological conditions and states and the effects of medical diagnostic and treatment measures in a life-style that promotes continued personal development” (Orem, 1985, p. 99).

Self-care relates to the individual who is identified in Orem’s theory as the self-care agent (Orem, 1985). This individual has specific responsibilities in achieving and maintaining health and well-being which is recognized as self-care requisites. Self-care in

this research project is related to the capability of an adult with Type II diabetes to manage his or her disease process. To achieve this management there are specific self-care requisites that must be performed. Orem states “the ways and means for meeting particular self-care requisites can be described in terms of 1) general method and 2) required operations or actions” (Orem, 1985, p. 87). These specific requisites and the means of operations for achievement are identified as a therapeutic self-care demand.

Self-care Deficit

Self-care deficit is defined as “a relationship between self-care agency and therapeutic self-care demand in which self-care agency is not adequate to meet the known therapeutic self-care demand” (Orem, 1985, p. 31). As a result of the self-care deficit, it is surmised that the self-care agent is in need of assistance by nursing. The specific reason and circumstances that give rise to the self-care deficit “provides guides for the selection of methods for helping and understanding patient roles in self-care” (Taylor, 2006, p. 273).

Nursing System

Nursing System is defined as

“a continuing series of actions produced when nurses link one way or a number of ways of helping to their own actions or the actions of persons under care that are directed to meet these person’s therapeutic self-care demands or to regulate their self-care agency” (Orem, 1985, p. 31)

A self-care deficit can either be partial or complete. It is crucial for a provider to identify what level of the knowledge spectrum the patient with Type II Diabetes is experiencing in the management of their disease process. Once established, this information “provides

guides for the selection of method for helping and understanding patient roles in self-care” (Taylor, 2006, p. 273).

For the purposes of this research, the tenets of health-deviation self-care requisites and nursing system in Dorothea Orem’s SCDNT in relation to Type II Diabetes care are coupled together. Once a self-care deficit is identified, as partial or complete, there are specific nursing system actions that are employed by both the patient and the nurse. Orem (2001) posits that the partially compensatory system has required actions by both the nurse and the patient. She identified the following

“patient actions: a) performing some self-care measures, regulating self-care agency, and b) accepting care and assistance from the nurse. Nurse actions include: a) performs some self-care measures for the patient, b) compensates for self-care limitations of patient, and c) assists the patient as required” (Taylor, 2001, 273).

Orem’s theory defines the wholly compensatory system with nursing actions as including “accomplishing the patient’s therapeutic self care, compensating for the patient’s inability to engage in self-care, and supporting and protecting the patient” (Taylor, 2001, 273)).

The supportive-educative system includes patient actions of “accomplishing self-care and regulating the exercise and development of self-care agency” (Taylor, 2001, 273).

Organization of the Literature Review

The literature search results are presented according to their correlation with Orem’s categories of health- deviation self-care requisites.

Self-care Requisite #1

The following articles relate to Orem's self-care deficit and nursing systems premise. A study by Dettori et al. (2005) reported a relationship between a supportive nurse-patient relationship and the reduction of self-care deficits. Education and preventive care are critical components in the self-management of diabetes. Dettori et al. (2005) explored the barriers of diabetes self-management in rural Montana. They found that the provision of one-to-one diabetic education by a diabetic nurse in rural areas resulted in improvement in patients' management of their diabetes and prevention of complications. Education was provided on the self-management behaviors of: a) diabetes education, b) self-monitoring blood glucose (SMBG), c) HgbA1c, d) blood pressure, e) foot examination, f) immunizations (influenza and pneumococcal), and g) life style changes. Results indicated that self-care behaviors improved with the intervention of a diabetic nurse.

It is also crucial to identify participant characteristics of diabetic patients needing intervention with self-management behavior. Thoolen et al. (2007) found that individuals with diabetes responded to interventions at different times of their illness. Three categories were identified. The first category were non-participants who did not view their disease process as life threatening and who did not participate in interventions of self-management. It was found that these individuals were less educated but reported a higher level of self management activities. The second category included individuals who were intensely treated at the onset of their diagnosis of Type II Diabetes; these people were more likely to participate in interventions if they were approached in the first year

of their diagnosis. The third category included individuals who had basic care after diagnosis. This category of individuals more readily participated in diabetes self-management two to three years after diagnosis. Educational level was the most significant factor in patients' participation in interventions of self-care management. The increased level of overall diabetes education resulted in the participation of an individual in self-management activities. An individual with a lower education level had increased difficulty in understanding diabetic self management in relation to: a) written materials, b) goals, and c) expectations. The researchers concluded, "given that type 2 diabetes is more prevalent in those with a lower socioeconomic background, one must conclude self-management interventions are missing a significant proportion of diabetes patients, an undesirable situation that needs to be addressed" (Thoolen et al., 2007 p. 472).

Engagement of individuals with a lower education level should include interventions that are face-to-face with information being presented in a clear and simple manner.

Ultimately, the success of self-management interventions hinges on the diabetic patient accepting the intervention as being beneficial to their health. Aspects related to time of diagnosis, educational level, and socioeconomic classes are co-factors.

Oster et al. (2006) investigated the relationship between preventive service utilization and self-management behaviors of individuals belonging to a Managed Care Organization (MCO) and race/ethnicity. Health care in the United States is managed by a variety of systems for the delivery of services. Most MCOs provide free preventative health care services as part of their membership. Ideally, if one has access, it seems that one would take advantage of those services that are universally covered. Research by

Oster et al. found that Blacks and Hispanics had lower use of preventative services compared to whites in areas of: a) vaccination, b) cholesterol checks, c) dental exams, d) HgbA1c tests, e) dilated eye exam, and f) foot exams. Self-management practices were lower for blacks than whites in relation to: a) diet, b) exercise, and c) smoking; whereas, the only difference between self-management between whites and Hispanics was in relation to diet. With this information, the researchers concluded the importance of determining “what types of patient/provider interventions can help narrow the preventive service gap in the diabetes population (Oster et al., 2006, p.174).

Self-care Requisite #2

Sprague et al. (2006) identified effective diabetes education as a key component in maintaining health with diabetes. Goal setting was a central component in this study. This process involved “identifying behaviors that the patient associates with valued outcomes (experiences), greater confidence to perform behaviors (self-efficacy), positive reinforcement, and other constructs presumed to maximize goal (behavior) attainment” (Sprague et al., 2006, p. 245). This study reported that 86% of the participants said that goal setting was useful in the management of their diabetes. The goals set by the participant related to: a) self monitoring of blood glucose, b) exercise, and c) diet. There are many personal factors that can hinder this capability. Upon diagnosis, it is essential that education from a physician, dietitian, and diabetes educator be involved. As diabetes management is an ongoing process it is important that goals be set. Goal education related to self care contributes to the positive outcomes of self-care activities. Goals set during education include: diabetes specific education, adherence to the diabetes regime,

and evaluation of diabetes control. Education of these topics fosters positive outcomes of self-care.

Sprage et al. (2006) reported that those individuals who received diabetes education, parameters, and guidelines by a health-care professional were more likely to have goals of management of their Type II Diabetes, which they attempted to maintain after diagnosis. Individuals whose goals had changed from the initial diabetes education had increased difficulty in maintaining a diet plan and SMBG regimen.

Self-care Requisite #3

Behavioral adherence to Type II Diabetes health maintenance care practices is the cornerstone of successful management. Wilhide et al. (2008) studied individuals who were at risk for diabetes complications. They provided patients with an educational intervention consisting of eight modules that addressed: a) diabetes (disease, diagnosis, and treatment), b) medication management, c) diet and nutrition, d) exercise, e) periodicity, f) self-management, g) smoking cessation, and h) when to contact a physician. There was an initial evaluation of each participant's knowledge and current lab values of HgbA1c and cholesterol to assess which of the modules was appropriate for any give individual. Wilhide et al. (2008) also did a cost analysis, over a six month period, of interventions for 1,289 participants, evaluating both direct and indirect costs. Evaluation of direct costs included hospital, physician, and medication cost. After interventional behaviors were implemented the patients who achieved a target level of their HbA1C or improved their levels by 1% point had a cost avoidance of \$5,292,322. Those individuals in the group who met the target blood pressure or improved their blood pressure had an

additional cost avoidance of \$1,760,936. Within the group those who had met a normal level goal for HbA1C, blood pressure, and cholesterol combined, had a cost avoidance of \$349,320. “The total cost avoidance estimated for the 1289 members was \$7,402,578” (Wilhide et al., 2008, p. 173-174). This study strongly supports the cost effectiveness of educational interventions for diabetes management educational interventions. The authors also concluded that interventions needed to be specifically tailored to each patient’s individual educational needs for self-management to be successful.

Siminerio et al. (2005) studied the concept of the implementation of a chronic care model in the care of the diabetic patient. There were three phases of the research process. Phase one was a collection of data from patient charts. Phase two addressed interventions at different levels. Decision support was targeted towards physician education and interventions specific to American Diabetes Associations (ADA) Standards of Care (2008). Self-management education topics included comprehensive diabetes education, goal setting, and strategies for behavior changes. Phase three involved re-evaluation of the adherence of ADA Standards of Care and the clinical outcomes.

Siminerio et al. (2005) concluded that a major barrier was lack of educational services for the provider and patient for the successful treatment of diabetes. There were five groups of barriers identified: a) psychological (health beliefs, motivation, and self-efficacy), b) educational (poor diabetes knowledge or awareness of educational services), c) internal physical (preexisting comorbid conditions, physical effects, physical effects/discomfort with treatments), d) external physical (finance, physical access, limited range of services related to MD or support staff, and e) psychosocial (discrimination due

to having diabetes, lack of support from friends or family, inappropriate cultural messages.

Research by Cavanaugh et al. (2008) identified a direct correlation between individuals with a low level of literacy and a low level of numeracy to a decreased level of diabetes self-management skills. Cavanaugh et al. (2008) defined specific operations related to the management of Type II Diabetes. He utilized the Diabetes Numeracy Test to evaluate participant levels of knowledge. Some of the components were to: exercise (calculate total grams of carbohydrates in one container of snack chips, exercise (calculate the carbohydrate intake needs for planned exercise duration), glucose monitoring (identify values with in target range of 60-120 mg/dl, calculate date needed to refill strips for a glucose monitor) (Cavanaugh et al., 2008).

His research concluded that a patient's level of quantitative skill (numeracy) is related to effective management of Diabetes. Successful diabetes management revolves around the literacy of numbers. Diabetes is a disease that requires literacy of numbers. There are many areas of diabetes disease management that require numeracy: blood glucose meter readings, reading nutrition labels, calculating carbohydrate intake, and medication dosages (Cavanaugh et al., 2008). Critical to reading these values is the interpretation of the values. Actions based on these values and interpretations must be performed by the diabetic patient to control their diabetes. It was found that a level of adequate literacy is ninth grade. Low literacy is a factor in poor glycemic control. Poor glycemic control has dire effects for a diabetic patient.

Self-care Requisite #4

Research by Sprague et al. (2006) can be categorized into Dorothea Orem's fourth category of health-deviation self-care requisites. Being aware of and attending to or regulating the discomforting or deleterious effects of medical care measures performed or prescribed is critical to therapeutic self-care demands. Self-efficacy is the conviction of an individual that he/she can maintain a healthy state. Patient beliefs and behaviors are critical in the management of diabetes.

To achieve self efficacy in the management of Type II Diabetes an individual must have a goal. The core features of setting a goal should include:

“1) defining the problem or recognizing the need for change, 2) identifying a long-term outcome, 3) identifying behavioral goals toward that outcome, 4) identifying barriers to change as well as resources and strategies to facilitate change, 5) monitoring progress toward the goal, and 6) obtaining feedback” (Sprague et al., 2006, p. 245).

Findings of this research by Sprague et al. (2006) found a positive correlation for patients who received advice from their health care provider regarding diabetes self-management related to diet, exercise, and self monitoring of blood glucose (SMBG) and goal setting.

It was identified that some individuals in this study based their feelings of diabetes self-management control on subjective factors and not on core activities of SMBG, diet regimen, and exercise plan. These individuals concluded that if they were feeling well, the management of their diabetes was good. It is crucial that the health care provider educate patients on utilizing quantitative measurements (blood glucose level, weight, and a diabetic meal plan) for the identification of good diabetes self-management. It is important that there be an ongoing evaluation of how the patient has incorporated the

diagnosis of diabetes into his/her self-concept, activities for management of diabetes, goals for self management, and outcomes (Sprage et al., 2006).

Self-care Requisite #5

Fisher's et al. (2008) research explored the feelings of being overwhelmed or of being a failure with diabetes management. They concluded that diabetes-specific distress leads to a negative effect with self-management. A state of distress, specifically depression, is an unhealthy state. Its negative effects lead to poor bio-behavioral management. (Fisher et al., 2008). They found that individuals with diabetes and diabetes specific distress had poorer self-management and increased comorbidities. This distress was directly related to the diagnosis of diabetes and its management. For this study, the Diabetes Distress Scale was created to evaluate the levels of distress. This tool is significant because it differentiates between diabetes distress and depression. The two effects are not synonymous with each other and create separate and distinct effects on the management of diabetes. The specific areas of distress that were appraised were: a) emotional burden (feeling overwhelmed with diabetes, b) physician-related distress (access, trust, and care), c) regimen related distress (concerns related to diet, physical activity, and medications), and d) interpersonal distress related to not receiving support from others (Fisher et al., 2008). In evaluating the results they concluded that individuals with high levels of distress had higher: a) HbA1c levels, b) cholesterol levels, c) caloric intake, d) saturated fat intake and e) decreased intake of fruits/vegetables, and physical activity.

The modification of self-concept and image was supported in a study by Duangdao and Roesch (2008) in which the coping strategies of patients with diabetes were evaluated. They identified the fact that individuals with approach focused coping and problem focused coping skills had positive psychological and physiological outcomes. Duangdao & Roesch (2008) explored self-efficacy in a study evaluating the relationship of coping dimensions and adjustment to diabetes. The specific coping dimensions evaluated were: a) avoidance focused, b) approach focused, c) emotion-focused, and d) problem focused. The dependent variables examined were overall adjustment, depression and anxiety. Duangdao & Roesch (2008) suggested that increased responsibilities in chronic illness can lead to stress and the “management of this stress via coping strategies is crucial for psychological and physical health” (p. 292). Results from this study indicated that individuals with diabetes who managed stress with approach coping and problem-focused coping had better psychological and physiological effects. With these specific approaches individuals experienced fewer symptoms of depression and anxiety compared to those individuals who utilized an avoidance focused and emotion focused coping mechanisms. The researchers concluded that “successful adjustment to a chronic illness yields a variety of positive health outcomes including lower psychological distress, better adjustment to disease, low negative effect and positive self-appraisal of well being” (p. 296).

Self-concept is also affected by the previous experiences of a diabetic, such as relationships with members of their family who have diabetes. Scollan-Koliopoulos et al. (2007) evaluated the impact of the multigenerational legacy of diabetes. Individuals

whose family members had high control of diabetes also perceived themselves as having high control of their own disease process. Conversely a negative perception could have a negative influence. Those individuals whose family members felt that diabetes was associated with a stigma had a similar perception. These positive and negative influences all have a cumulative effect on behavior. The behaviors of compliance to noncompliance all stem from these initial exposures to diabetes self-care in regard to medication, diet, and exercise adherence. The authors concluded that education must be focused on individuals' representations of the illness and explore their perception of control and consequences of non-adherence.

Self-care Requisite #6

An on-going supportive-educative system was studied by Bray et al. (2008). Diabetes is a life-long disease that requires management of many facets of daily living. In today's health care system interaction with a physician is time constrained. In Bray's et al. (2008) study there were two groups, one with participants who received diabetic care provided by a physician alone, and one with participants who received diabetic care provided by a physician in addition to the services of a diabetic life coach. Bray et al. (2008) identified that when working with the life coach, the participant

“developed treatment plans, established goals in accordance with national guidelines, and arranged for regular contact times to monitor progress. Between meeting times, participants were encouraged to contact their life coaches as needed for questions or support” (p. 120).

There was an increased focus on diet and exercise.

Implementation of a life coach significantly improved: a) self-management of HgbA1c levels, b) blood pressure, c) cholesterol, d) medication adherence, e) meal plan, and f) activity level. These improvements were sustained over the period of the study. This research supports the ongoing needs of a diabetic patient that should be addressed not only after diagnosis but also throughout the continuum of care. Success of self-management is greater if a multidisciplinary life coach model is employed. This person assists with: a) education, b) behavior change, and c) support to implement changes that are sustainable. It is important to assess barriers of self management related to: a) lack of knowledge, b) treatment plans that are not working, c) difficulty in making lifestyle changes, d) lack of support, and e) cost of glucose strips, care, medications, education. Self-management interventions need to be implemented at different times during medical treatment and self-management education needs to be tailored to patients with a lower education level.

Gaps in the Literature

The literature review yielded much information regarding Type II Diabetes management problems. However, there were gaps in the literature regarding information specifically related to the Native American population. The only study that could be compared to the AI/AN population was the study by Oster et al. (2006), because the AI/AN population is eligible to receive health care and preventative health care services at no cost from the Indian Health Service. Similar to Oster's et al. study, what is needed is the identification of those interventions that will narrow the preventative service gap

for the AI/AN population, which Oster et al. (2006) concluded was critical in the diabetes population.

Another gap in the literature was related to information pertaining to Dorothea Orem's Self-Care Deficit Theory and Type II Diabetes care. No articles were found that related Orem's theory to the management of Type II Diabetes. The current research will help to identify problems of self care management in the disease process of Type II Diabetes related to the Native American population. Orem's Self-Care Deficit Nursing Theory (SCDNT) will provide clear direction for actions by the patient and nurse for successful management of Type II Diabetes.

A third gap in the literature relates to the second category of health-deviation self care requisite addressing the topic of the patient being aware of and attending to or regulating the discomforting or deleterious effects of medical care measures performed or prescribed. The researcher seeks to identify the relationship of self-care deficits and poor diabetes management, morbidity, and mortality in the effective management of Type II Diabetes by the Native American patient.

CHAPTER 3

RESEARCH DESIGN AND METHODS

Introduction

The purpose of this research is to identify the problems AI/AN adult patients face when attempting the long term management of their Type II Diabetes disease process. This research project used an exploratory, descriptive design to study the challenges of Type II Diabetes management among Native American adults. Type II Diabetes is a lifelong diagnosis that can be managed but not cured. An exploratory design was used because there is very little information regarding this topic in the literature.

Sample Recruitment

The sample will be selected from a Native American reservation in a northwestern state. The sample consisted of five Native American Adults with Type II Diabetes

Procedures for Data Collection

Discussion of Rights of Human Subject and Consent Process: Consent was received from the Native American Tribe to interview participants on the reservation, but because of privacy issues, it won't be placed in an appendix. The IRB application was submitted to the Montana State University Bozeman Institutional Review Board. Approval to perform the research was granted (Appendix A). The participants were approached by an intermediary who is a retired LPN who worked in a small town on a

reservation community for 20 years. The intermediary explained to the patient: a) who the interviewer is, b) the purpose of the interview, c) time involved, d) privacy rights, and e) what their contribution of an interview will be towards the research regarding Native Americans with Type II Diabetes (Appendix B). They were then invited to participate or decline. If they chose to participate they gave their contact information to the intermediary so the researcher could contact them. The researcher then called the participant to set up an interview time that was convenient for them. After the data was analyzed, two participants from the research read Chapters 4 and 5 to assure that privacy of the participants had been maintained.

Interview Process: Prior to beginning the interview the researcher discussed with the participant the Informed Consent Form for Participation in Human Research (Appendix C). Once all questions were answered, the participants signed the informed consent form and were given a copy to retain for his/her records. The participants were told that the title of the study is “What problems do American Indian adult patients face when attempting the long-term management of their Type II Diabetes disease process?” They were told the purpose of this research was to identify the problems AI/adult patients face with the long term management of their Type II Diabetes disease process. The participants were told that the interview would be audio tape recorded and that they would be free to stop the interview process at any time, if they felt the need to do so.

Open-ended, In-depth Interviews: Prior to beginning the interview, the participants were asked demographic questions, (Please see Appendix D for the entire

interview schedule). Once rapport had been established, the interview was begun with the following two open-ended questions. “What was it like for you when you were first diagnosed with Type II Diabetes?” After their response to the first question, a second was asked: “How has it been for you living with Type II Diabetes over the years since your diagnosis?” In addition to expanding and clarifying questions asked during the course of the interview, and depending on the initial responses by the participant, the researcher asked the following sub-questions: a) “What changes have you had to make in your life to manage your Type II Diabetes?” b) “What are the easiest aspects of managing your Type II Diabetes?” and c) “What are the most difficult aspects of managing your Type II Diabetes?”.

Once the interview ended, if the content hadn’t emerged in the interview, one directed, follow-up question was asked. This question was: “How can you tell if you are managing your Type II Diabetes well?” Again, based on the participants’ responses, three additional questions were asked for clarification and expansion purposes. The sub-questions were: “What do you think happens if a person is not able to manage his or her Type II Diabetes? “What kind of health care support services are available to you in the management of your Type II Diabetes? and “What services do you think are needed to improve the management of your Type II Diabetes?”

Personal Notes: Personal notes were kept during the data collection process. The personal notes were placed in two categories. The first category was directed towards recording thick, contextual description and included the following: place of interview, participant’s body language during the interview, participants understanding of interview

question. The second category contained information regarding the researcher's record of the analytical thinking regarding topics and themes and patterns of the interview.

Method of Data Analysis

Luborsky's (1994), method of qualitative data analysis was used for this research study. This thematic data analysis method consists of three inductive steps involving searching for themes, patterns, and topics. They are defined below and are listed in an order depicting analysis from the verbatim interview (themes), to collecting the themes into patterns, and finally putting the patterns into summarizing statements (topics).

Themes: Themes are defined as "the manifest generalized statements by informants about beliefs, attitudes, values or sentiments" (Luborsky, 1994, p. 195). The identification of themes allow for providing: "clear orientation to work that seeks to understand and reflect the informant's own views and words" and "uses manifest and explicit statements rather than inference and background knowledge about the person or situation" (Luborsky, 1994, p. 195). Qualitative research, with the utilization of open ended questions, allows for recognition of the themes that "serve as a metaphor that individuals use to unify separate elements and experiences into an overarching meaning" (Luborsky, p. 195, 1994).

Once the interview is complete and the information is analyzed, the interview process and transcription of the information provides a dual development of themes recognition. The body language and tone of voice of the participant provide many hints of the lived experience. Conversely, the identification of these thematic elements

provides a view point of this lived experience that may not had been recognized as the participant provides his/her story orally. Therefore, it is important to consider all these elements to identify themes. The process of theme identification is to distinguish statements that are repeated by the participant or marked as having great meaning Luborsky (1994). The repetition of words or phrases marks events of a larger idea.

Patterns: Patterns are characterized as described “findings from the researcher’s frame of reference” (Luborsky, 1994, p. 195). According to Luborsky (1994) based on the results of the cumulative data from the interviews the researcher builds categories of observations and analyses. The process of categorizing the data is subject to the researcher’s identification of patterns. The analysis of the transcribed interviews allows the researcher to identify main themes and statements of support.

Topics: Topics are described as “summarizing the content of replies by many people to a question (Luborsky, 1994, p. 195). This idea is a separate from the identification of themes. It is a list of the responses by the participants of a topic.

Data Management: Data management was performed by transcribing the interviews. An inductive approach to identifying the relevant themes, then patterns, and finally topics was utilized. The themes were then collapsed into a consistent area. A three column approach to data management was used. The left column contained the verbatim transcribed interview, the middle column contained the themes (“ . . . statements by the informants about beliefs, attitudes, values, or sentiments” (Luborsky, 1994, p. 195). The

right column held the identified patterns that emerged among the themes. Once all the patterns were identified, they were then grouped into summative categories, or topics.

Procedures for Assessing Trustworthiness of Research

Just as with quantitative research there are criteria: validity, reliability, generalizability, and objectivity, for assessing the rigor of a study, there is a similar need for assessing the trustworthiness of qualitative research. The researcher utilized criteria standards outlined by Guba & Lincoln (1989). The criterion for evaluating research utilizes the concepts of: credibility, transferability, dependability, and confirmability.

Credibility: Assessing the trustworthiness of research in relation to credibility of research requires that the focus be on “establishing the match between the constructed realities of respondents (or stakeholders) and those realities as represented by the evaluator and attributed to various stake holders” (Guba & Lincoln, p. 237, 1989). This is accomplished through: prolonged engagement, persistent observation, peer debriefing, member checks, negative case analysis, and progressive subjectivity.

The researcher utilized the procedures for assessing trustworthiness of prolonged engagement through the transcription of data, and reading and re-reading each transcript. Member checks were built into the project by asking participants prior to the interview if the researcher could call them following the interview if she had needed clarification of interview content. The peer debriefing criterion was met through consultation with the researcher’s thesis committee during the data analysis process.

Transferability: The procedure for assessing trustworthiness of research in relation to the concept of transferability is performed by evaluating external validity. This concept is defined as an “empirical process for checking the degree of similarity between sending and receiving context” (Guba & Lincoln, 1989, p. 241). In this process

“the burden of proof for claimed generalizability . . . [from a quantitative perspective] . . . is on the inquirer, while the burden of proof for claimed transferability . . . [from a qualitative perspective] . . . is on the receiver” (Guba & Lincoln, 1989, p. 241).

As outlined by Guba & Lincoln (1989) transferability judgments are based on the provision of extensive and thick descriptions of: time, place, context, and culture.

The principles of transferability were accomplished by providing enough description in which the reader can see the researcher’s context of observation of the participant’s life. This was done by providing examples of verbatim text from the interviews and demographic information of the participants’ lives related to: living situation, economic status, number’s of diabetics in local area.

Dependability: The procedure for assessing trustworthiness of qualitative research in relation to dependability is ensuring there is “stability of the data over time” (Guba & Lincoln, 1989, p. 242). Procedures for ensuring dependability include: trackable changes and shifts and documentation of the logic of process and method decisions.

The procedure for assessing trustworthiness of research in relation to dependability was met by keeping personal notes of analytical process and data management. These will be kept for seven years. For each of the interviews data were

extracted to identify themes, patterns, and topics. A three column approach to link patterns to themes and topics was used.

Confirmability: Assessment of confirmability in procedures for trustworthiness of research is completed by “assuring that data, interpretations, and outcomes of inquiries are rooted in contexts and persons apart from the evaluator and are not simply figments of the evaluator’s imagination” (Guba & Lincoln, 1989, p. 241). This concept is based on a confirmability audit. In confirmability audit “both the raw products and processes used to compress them are available to be inspected and confirmed by outside reviewers of the study” (Guba & Lincoln, 1989, p. 241).

The process to attain confirmability was achieved by presenting examples and quotes from the interviews relating to themes, patterns, and topics. Data analysis papers will be kept for five years.

Summary

A qualitative analysis of the challenges of Type II Diabetes management among Native American adults provided a “direct representation of an individual’s own point of view and descriptions of experiences, beliefs, and perceptions” (Luborsky, 1994, p, 190). There is little to no research in this area. To provide quality health care, providers must uncover the challenges faced by this population. Qualitative research provided the insight into the participants’ perceptions of these challenges. This research through, the process of identifying themes, patterns, and topics, identified the perceived barriers that Native American’s with Type II Diabetes face in everyday life.

CHAPTER 4

RESULTS

Introduction

The purpose of this research was to identify the problems American Indian adult patients face when attempting the long-term management of their Type II Diabetes. Open-ended interviews were conducted to arrive at an understanding of the challenges faced and the resources utilized in long-term management of Type II Diabetes. The data were analyzed using Luborsky's (1994), method of thematic analysis.

Sample

Five participants with Type II Diabetes from a Native American Tribe on a Reservation in the Northwest were recruited by an intermediary for this research. All participants were Native American adults who have had a diagnosis of Type II Diabetes for at least five years or greater. The participants ranged in age from 48 years old to 69 years old. There were three males and two females. Three of the participants are employed, one unemployed, and one retired. The educational level of the participants ranged from high school graduate to a Masters graduate. Three of the participants were bilingual with their Native language and English. The other two participants spoke only English. Religious practices ranged from Christianity to Native American beliefs. Three participants practiced a combination of both religions. Two of the participants received health care services from providers both at the Indian Health Service as well as health

care providers outside of the Indian Health Service. The remaining three participants received their health care services exclusively through the Indian Health Service. All of the participants have other comorbid conditions ranging from: neuropathy, retinopathy, renal failure, hyperlipidemia, and anemia.

To protect the identity and privacy of the participants they will all be referred to in the masculine pronoun in the results. Additionally, the results have been reported in a manner to respect cultural customs.

Results

Data analysis included the identification of themes composed of direct quotes relevant to the long-term management of Type II Diabetes, in each interview. Next, patterns and similarities of responses from among the themes identified in each interview were noted across all interviews. These patterns were then collapsed into categories or topics. The topics identified were:

- Feelings about Type II Diabetes diagnosis,
- Prior experiences with family who have Type II Diabetes,
- Challenges and lifestyle changes in managing Type II Diabetes,
- Personal contributing factors to poor management,
- Support systems for managing Type II Diabetes,
- Identification of good management of Type II Diabetes,
- Knowledge of long term effects of Type II Diabetes,
- Additional support and resources needed to manage Type II Diabetes.

Feelings about Type II Diabetes Diagnosis: There was a wide spectrum of emotions associated with the diagnosis of Type II Diabetes from the participants. All of the participants found it hard to accept the diagnosis of Type II Diabetes. A common emotion was denial. Participants expressed feelings of shock and devastation when they were “faced with the fact” that their symptoms were indicative of an illness. Some participants did not feel like they were “sick”; other participants had no outward symptoms and were diagnosed on routine lab work. Both of these situations fed into the feelings of denial. Additionally, there were those who were ill but who did not associate the symptoms they were feeling, increased thirst, increased urination, and blurry vision, to a diagnosis of Type II Diabetes.

There were varying degrees of reactions by the participants after their diagnosis. One participant described his mindset about his diagnosis as starting out well. He “wanted to command it” and make the necessary changes related to diet and exercise. Another stated that for him it was only a diagnosis and not something he put his attention towards. He followed by saying that he “didn’t take any special efforts to take care of myself. I was me and I wasn’t sick because there was no onward signs of me being a diabetic.” A third participant indicated that the implications for a lifestyle changes were “hard for me to do... knowing that I have to.”

Prior Experiences with Family Members who have Type II Diabetes: Past experiences of diabetes in their families shaped the participants’ responses and reactions to their new diagnosis. Four of the participants had family members with Type II diabetes. Their experiences with these family members helped motivate them in making

the necessary changes following their diagnosis in order to manage their diabetes.

Because of their family members' experiences, these participants were familiar with the key aspects of diabetic management related to diet and exercise. One participant explained, "My mother was a diabetic. She had a clinical diet that she followed so I just kind of, with her urging, I started following her diet." One participant learned about the negative consequences of poor management from his family member. He stated that he "didn't want that for himself." It was painful for him to see what could happen if he did not manage his diabetes.

Challenges and Lifestyle Changes in Managing Type II Diabetes: All of the participants acknowledged the need for changes in their lifestyles related to medication, diet, exercise, and weight loss. However, the challenge was staying consistent with the necessary changes and making them a life-long change and not only a temporary change. One participant stated, "It's been a real wake-up as far as lifestyle because everything that I put into my body when I eat I think about how this is going to raise my blood sugars."

The level of commitment maintaining the changes varied over time. Even those participants who had the diagnosis of diabetes for a long period of time stated that there are still times when they were challenged to maintain the status quo for management of Type II Diabetes related to a consistent regimen for: diet, exercise, proper medication use. One participant stated, "I started out really well...And then I gotten ... lazy with it. Very lazy." Another participant stated, "I don't know, (diabetes) it's kind of a tricky

disease trying to find the right foods or find the things that's supposed to keep it under control.”

Upon diagnosis, four of the participants visited with a diabetes educator regarding the elements of a diabetic diet. However, they reported that it was still challenging to maintain a diabetic diet and knowing what was acceptable in the diet. Several of the participants reported that they would benefit from ongoing visits. Similarly, the participants described challenges to safety when exercising in their community. The community that the participants live in is a rural area at the base of a mountain range. The threat of animals and adverse elements of the weather often were barriers in daily exercise.

Another theme regarding challenges in managing Type II Diabetes that emerged from the research was access to a consistent primary care provider. Although the local health care clinic has a provider everyday at the facility, the providers are there on a rotating basis from the main IHS hospital two hours away. Often you do not see the same provider at each visit. One participant attributed the lack of support and continuity at his health care facility as the biggest reason why I don't do all the things that I need to be doing.” He reported that it is difficult to have to keep explaining his health problems every time he goes. He feels that the system is overwhelmed by all of the people who seek health care at this facility with fewer providers. He stated, “I'm aching for consistency and putting people in place that need to be healthy. We won't be healthy until that happens. We won't.”

Personal Contributing Factors to Poor Management: One participant implied that physical care of one's self requires a positive and healthy mental status. Some participants spoke of feelings of depression, which impinged on management of their Type II Diabetes. One stated that his resolve with the diagnosis of diabetes "wavered due to depression." Another stated that his depression was a major contributor to lack of motivation, physical movement, eating, and overeating. The symptoms of depression worked against their control of diabetes. A majority of the participants felt their symptoms of lack of motivation and depression were related to personal losses they had experienced recently in their lives.

Support Systems for Managing Type II Diabetes: Many of the participants have had contact with various health care providers necessary for good management of diabetes. These included primary care providers, diabetic educators, dietitians, optometrists, podiatrists, and dentists. Some participants, however, felt that as time passed they lost the ongoing support and guidance of these individuals in the management of their Type II Diabetes. One participant stated,

"The doctor that I had she was good with all of us but then she's gone and it seemed like it collapsed. It just collapsed and we don't ... some of the doctors are over there (Indian Health Service) they have too many people. They can't take all the people that need them. I'm not blaming doctors, I'm blaming the system. They need to get all the people that we need in place in order for us to (be healthy)."

One of the participants expressed coming full circle in his illness. He has experienced the gamete of comorbid conditions of Type II Diabetes in his 45 years with the illness related to neuropathy, retinopathy, and renal failure. He shared his thoughts about what an effective approach from health care providers to patients with Type II

Diabetes should include. First there should be “early warning... Tell them straight out what’s going to happen to them if they don’t take care of that Type II Diabetes: kidney failure, blindness, have them talk to people that are experiencing these.” Secondly, he felt it was important for diabetic patients to take an active part in their disease process by communicating with their physicians. He saw this as helping to maximize these support systems that are available.

Outside of the health care system the participants found strength and support from religion, family, friends, and coworkers. Faith and religion were strong influences in helping these participants maintain periods of a healthy status or to assist them in times of illness. Many of the participants reported encouragement from family members to follow the regimen for management of their Type II Diabetes. The support of family members helped the participants to rally through the ups and downs.

Continued education was another source of support that some participants identified. This type of education was seen as coming from published literature, television, and information from the American Diabetes Association. One participant stated that it was vital for individuals to actively seek out information related to their diagnosis. This participant believed “if we keep our eyes open and our ears open” then the information was there.

Identification of Good Management of Type II Diabetes: Regardless of how well the participants were managing their diabetes, all of the participants kept an eye on how their diabetes was affecting their physical functioning. They identified several ways they had to monitor how well they were managing their Type II Diabetes. These ranged from

physical feelings to the quantitative results of their blood glucose. The participants said that when their blood glucose levels were low or high they could feel or observe the physical effects. One participant said, “I really feel good that my body is in sync with everything. I don’t feel sick. I just feel great and that’s when I know I am doing everything I am supposed to be doing.” Other participants stated they gauged their management by how well they healed from illness or infection. One of the participants identified numbness and tingling in his extremities, which he attributed to his high blood sugar. Some of the participants correlated a cause and effect relationship between their experiences with fluctuations in glucose levels with symptoms of fatigue, stress, illness, unbalanced diet. The identification of these factors led some participants to make healthier lifestyle choices of diet and exercise to improve their well being. Regardless of differing ways to monitor how well they were managing their Type II Diabetes, all of these participants filtered the perceptions of their physical functioning through the fact that they have diabetes

Knowledge of the Long Term Effects of Type II Diabetes: All of the participants had some knowledge of the adverse bodily effects of Type II Diabetes related to blindness, kidney failure, and amputations. They had seen friends and family who have had to deal with these effects.

One of the participants could be considered a modern day warrior in the fight against diabetes. He has gone full circle from diagnosis, mismanagement, kidney failure, and dialysis. He has lived with Type II Diabetes for 45 years and stated that in the beginning it was not explained to him the “dangers” and ramifications of poor control. He

is a staunch advocate for sharing his journey with Type II Diabetes. He felt it was important that we discuss this information openly to be properly informed.

Additional Resources Needed to Manage Type II Diabetes: There were a wide range of additional needed resources voiced by the participants. The most urgent need was increased access to health care providers. One participant felt the health care system was overwhelmed by all of the people who seek health care at this facility where there are few providers. He felt there needed to be consistency. It is difficult and frustrating to not have a consistent primary care provider. Each time he goes to his health care clinic he must re-explain his medical history and current health care needs.

The rural town where the participants live is two hours from the main IHS hospital. Although there is a small clinic in their community that provides basic services for their health care needs, in order to access additional health care resources, they must travel this long distance. Also, adding to the stress are the factors of absence from work, available monetary resources, and transportation to travel this distance. In the winter time this can be very challenging to travel this distance. Many of the participants feel that there must be increased access to additional resources in their local facility. Although the equipment to provide services for dental, optometry, podiatry, and diabetic education is available at their local health care facility, often there are no medical personnel to provide the services. The needed medical personal are available at their local health care facility only once a month. They felt it is imperative that there be consistent access to the following spectrum of health care personnel to manage their Type II Diabetes: health care providers, diabetic educators, dietitians, optometrists, and dentists.

Summary

This study explored the experience of managing long-term Type II Diabetes from a sample of 5 Native American participants. Emerging from this study were themes that indicated both barriers and strengths related to long-term management of Type II Diabetes. The barriers were related to inconsistent access to health care personal, limited health care services (optometry, podiatry, dental, diabetic education), and a lack of a safe environment to exercise. The strengths were emotional and educational support from family and friends in dealing with their Type II Diabetes.

CHAPTER 5

CONCLUSION

Introduction

This qualitative study explored the problems American Indians/Alaska Native adults face when attempting the long term management of their Type II Diabetes disease process. Using Luborsky's (1984) approach, analysis of the data resulted in the identification of eight topics. The discussion of the results related to the relevant literature, the limitations of the study, and implications for nursing will presented in this chapter.

Results Relevant to the Literature

Orem identified six categories of health-deviation self care requisites. These self-care requisites were used to organize the review of the literature in Chapter 2. They will also be used to organize the discussion of the results of this study that were relevant to the literature reviewed. The self care requisites are:

- “1) . . . seeking and securing appropriate medical assistance . . . with pathological states,
- 2) being aware of and attending to the effects and results of pathological conditions and states,
- 3) effectively carrying out medically prescribed measures to regulate the pathological condition,
- 4) being aware of and attending to or regulating the discomforting or deleterious effects of medical care measures performed or prescribed,

5) modifying the self-concept (and self- image) in accepting oneself as being in a particular state of health and in need of specific forms of health care,

6) learning to live with the effects of pathological conditions and states and the effects of medical diagnostic and treatment measures in a life-style that promotes continued personal development” (Orem, 1985, p. 99).

Self-care Requisites #1: Two articles related closely to the first self care requisite of seeking and securing appropriate medical assistance ... with pathological states (Orem, 1985), Thoolen et al. (2007) found that individuals respond to education and medical intervention at different stages in their disease process. They contended there are various intervals when interventions should be introduced to motivate and support patients in achieving optimal self-care. Results from this research also indicated that an individual’s perception of an action as being beneficial to their health was also a factor related to their participation in self management interventions. They also suggested that self-management participation occurs at intervals in a participant’s disease process that could be based on “emotional and cognitive states in which they are looking for additional support to deal with their diabetes” (Thoolen et al., 2007, p. 471).

Findings from the current study supported the results of Thoolen et al’s. (2007) study. The participants varied in degrees of seeking, and securing, appropriate medical assistance with their diabetic condition. The acceptance by the participants of their diagnoses laid the ground work for how they would manage their disease processes and seek appropriate resources. Responses among participants ranged from wanting to “command” the disease process to not wanting to take any special efforts in care of their Type II Diabetes. According to Thoolen the acceptance of a diagnosis of Type II

Diabetes and the current level of perception of self-management will motivate the participant to seek additional self-management guidance. This was evident with one of the participants when he stated, “I was me and I wasn’t sick because there was no onward signs of me being diabetic... (I) didn’t take any special efforts to take care of myself.” There was a period of five years until this participant really acknowledged that he had Type II Diabetes and then adopted the appropriate self-management behaviors related to diet, exercise, and medication.

Thoolen et al. (2007) identified that educational level was also a factor in self-management behavior, “the more educated the patient, the more likely he or she was to participate in and complete the intervention” (p. 472). Thoolen et al. (2007) discussed education from a formal standpoint; this idea could be applied to a participant’s level of understanding of Type II Diabetes. This could include diagnosis, diet, exercise, and medication, and consequences of mismanagement. All of the participants in the study had either some college experience or had graduated from college with a master’s degree and all still had some difficulty. One of the interviewees indicated that initially he was not educated in terms of the long term consequences of poor management. He since has become very passionate about the needed early warning, “Tell them straight out what’s going to happen to them if they don’t take care of that Type II Diabetes: kidney failures, blindness, have them talk to people that are experiencing these.” All of the participants in this study felt that there was deficiency in their knowledge of Type II Diabetes.

Oster et al. (2006) discussed the relationship between preventive service utilization and self-management behaviors of individuals belonging to a Managed Care

Organization (MCO). There are similarities that can be drawn from their research and the participants in this study. The majority of participants in this research receive their health care services from the Indian Health Service (IHS) which is comparable to a MCO. Oster et al. (2006) found that different racial/ethnic groups utilized preventive services from their MCO at different levels. Their findings indicated that it was important for an MCO to identify “what types of patient/provider interventions could help narrow the preventive service gap in the diabetes population” (Oster et al., 2006, p. 174). The participants in the current study clearly identified the need within their health care system, the IHS, for consistent primary care providers and increased access to services.

Self-care Requisites #2: According to Sprague et al. (2006) “diabetes management is the key to maintaining the health, quality of life, and longevity of patients with type 2 diabetes mellitus. Patients handle 95% of their own care associated with the management of this chronic disease process” (p. 245).

Diabetes education must contain the components of self-care behaviors of diet, exercise, medication, and self-monitoring blood glucose. Once the patient is equipped with this knowledge a key component to successful self-management is goal setting. Goal setting provides the frame work for the

“process of identifying behaviors, (self-control) that the patient associates with valued outcomes (expectancies), greater confidence to perform behaviors (self-efficacy), positive reinforcement, and other constructs presumed to maximize goal (behavior attainment) (Sprague et al., 2006, p. 245).

The participants in the current study all had an initial consults with a physician and diabetic educator but each participant felt after the first consult, the support ceased in

varying degrees. Three of the participants stated that they needed ongoing consistent support to manage their Type II Diabetes. One participant reported he felt “frustrated with it (diabetes) because you don’t know exactly where you’re sitting and if you’re doing the right thing.” He would like ongoing guidance and support from a health care provider to validate he is doing the right activities to manage his diabetes.

The participants in this research were aware of their pathological condition but needed additional support to attend to the effects and results of pathological conditions of their Type II Diabetes. The recommendations by Sprague et al. (2006) for education and goal setting for these participants could improve their self-management of their Type II Diabetes.

Self-care Requisites #3: A research report by Wilhide et al. (2008) exemplified the process of carrying out medically prescribed measures to regulate the pathological condition. They described eight factors that need to be addressed in educating people about the management of their Type II Diabetes. These included: a) diabetes: diagnosis, disease, and treatment, b) medication management, c) diet and nutrition, d) exercise, e) periodicity, f) self-management, g) smoking cessation, and h) when to contact a physician. Wilhide et al. (2008) asserted that it was important to tailor care for each individual to successfully meet all of these factors of self-management. When all of these elements were addressed, there was a significant decrease in comorbid conditions associated with poor control of Type II Diabetes.

When understood from the perspective of the eight factors identified by Wilhide, deficiencies in personal knowledge of Type II Diabetes were described by four of the

participants. While all of them had been given information that would fit within the eight factors during their initial consultation, a majority of the participants felt they needed ongoing education and support to successfully manage their diabetes. The one participant who has had Type II Diabetes for 45 years felt he was proficient in all needed areas described by Wilhide, but only after he experienced the devastating results of the long term consequences of unmanaged care, including neuropathy, retinopathy, and renal failure. He changed his self-management behaviors to include a proper diet and exercise, and he maintains contact with his physician. He has confidence in his self-management activities to improve and maintain a productive life. He states that “if you take care of yourself then you can live to be an old man like me.”

Siminerio et al. (2005) explored barriers related to the long-term management of Type II Diabetes. These five barriers were: a) psychological (health beliefs, motivation, and self-efficacy), b) educational (poor diabetes knowledge or awareness of educational services), c) internal physical (preexisting comorbid conditions, physical effects, physical effects/discomfort with treatments), d) external physical (finance, physical access, limited range of services related to MD or support staff), and e) psychosocial (discrimination due to having diabetes, lack of support from friends or family, inappropriate cultural messages). Siminerio et al. (2005) described a chronic care model for the diabetic patient. The components of this model included: a) decision support, b) self-management education, and c) delivery of health care in a rural setting.

The participants in this current study all talked about some aspects of psychological, educational, internal physical support, external physical support, and

psychosocial barriers for self-management. For example, from a psychological perspective interviewees mentioned a lack of motivation and self-efficacy. Lack of motivation was attributed to feelings of depression. Some of the participants questioned their self-efficacy related to their current self-management practices. They did not know if what they were doing to maintain their diabetes was enough.

Although a majority of the participants in this study acknowledged they received some education about Type II Diabetes, they felt the education needed to be ongoing. They wanted the foundation of their knowledge to be reinforced and built upon as new advances in treatment of the disease are found. One participant actively sought out his own information. He stated, "It is there we just need to look for it."

The internal physical barriers of preexisting comorbid conditions, physical effects, psychosocial effects and discomfort with treatments were also identified by the participants. Three of the participants in this research were experiencing problems with hypertension, retinopathy, neuropathy, and renal failure. It is difficult to manage these comorbid conditions in addition to their Type II Diabetes. With hypertension and renal failure there are additional medications and restrictions in their diet. Retinopathy hinders vision and can make it difficult to independently take their medications or draw up insulin. Neuropathy causes numbness and tingling in the peripheral extremities and may make it difficult to exercise. In relation to the discomfort with treatments one participant identified that it was difficult for him to give himself insulin shots. It was easier to take oral medication to control his diabetes. Unfortunately, at the time of the interviews, an oral medication regimen would not keep his blood sugar levels normal.

The external physical barriers of finance, physical access, and limited range of services related to physician or support staff were barriers for a majority of the participants in this study. They did not have private insurance. They depended on the Indian Health Service for their care, and they were confined to the availability of providers in their rural area who are sent to their facility. Often the health care providers come in on a rotating basis so there is no consistency in primary care providers. One participant stated he felt that the system was overwhelmed and that there needed to be a provider specifically for diabetic patients to ensure quality care. Some of the specialty services related to dental, optometry and podiatry were only provided on a monthly basis at their rural facility. If they needed access to these services outside of this scheduled time they had to travel two hours to the main facility to obtain them.

The psychosocial factors of discrimination due to having diabetes, such as lack of support from friends or family, and inappropriate cultural messages was not a large factor for these interviewees, but they did have some concerns and recommendations. One participant shared that he found it difficult to eat an appropriate diabetic diet when attending family or cultural activities. Because the incidence of Type II Diabetes is so large, a second participant felt that as an ethnic group Native Americans should be educating children about the importance of eating healthy as a preventive measure. A third participant felt that there should be open educational forums to discuss the trials of Type II Diabetes and to educate others who have been newly diagnosed. These forums could possibly avert complications. A fourth participant felt that people should come together as a community, have support groups, and exercise together.

Research by Cavanaugh et al. (2008) explored the relationship of literacy, numeracy, and diabetes self-management related to diet, exercise, and medication. Findings in this study indicated that “low diabetes-related numeracy skills are common in patients with diabetes and are associated with lower diabetes knowledge and perceived self-efficacy” (Cavanaugh et al., 2008, p.743). Having less than a ninth grade level of education was related to a low diabetes numeracy level.

None of the participants in the current study had difficulty with numeracy skill and all had education above the ninth grade level. All have graduated from high school, have attended some college or have graduated with a master’s degree. However, even with this advanced education participants still continued to have difficulty in the management of their Type II Diabetes, although the difficulties were not related to numeracy skills.

Self-care Requisites #4: Research by Sprague et al. (2006) exemplifies Orem’s (1985) fourth requisite of being aware of and attending to or regulating the discomforting or deleterious effects of medical care measures performed or prescribed by the physician. Sprague et al, (2006) suggested that individuals must go through the following process when coming to terms with a new diagnosis: “1) defining the problem or recognizing the need for change, 2) identifying a long-term outcome, 3) identifying behavioral goals toward an outcome, 4) identifying barriers to change as well as resources and strategies to facilitate change, 5) monitoring progress toward the goal, and 6) obtaining feedback” (p. 245).

There must be tangible outcomes that can be measured in relation to self-management activities (diet, exercise, medication, blood glucose monitoring). Results from Sprague et al. (2006) indicated that some participants based the evaluation of their self-management of their diabetes on how they felt physically. They perceived that if they were feeling well physically they were managing their diabetes appropriately. Sprague et al., stressed that this behavior should not be a substitute for quantitative monitoring of the diabetic disease process.

The five participants in this study were at differing stages in the process outlined by Sprague et al. (2006). Some of them had difficulty with identifying behavioral goals toward an outcome. There were specific challenges in maintaining consistency with self-management behaviors of diet and exercise. One participant responded that he just did not know if he was doing what he was supposed to be doing to manage his diabetes. This participant needed feedback about how he was doing with managing his diabetes.

Participants also identified barriers to change as well as resources and strategies to facilitate change. Some of the participants found difficulty in sustaining a diet regimen. Another barrier was a safe place to exercise. The participants knew that exercise was crucial to the self-management of their diabetes but they lived in a rural area that does not have access to facilities with the necessary space or equipment. Fear of animals or inclement weather also kept people indoors.

Another barrier that the participants identified was consistent access to a primary health care provider. Often they saw a series of different providers at their local health care clinic for diabetes services. These participants felt that they could not receive

consistent feedback when there was not a regular provider for diabetes care available. In an effort to maintain consistency in health care providers, one of the participants left the Indian Health Service to obtain health care by a diabetes specialist an hour away from his home.

Regarding tangible outcomes of diabetes self-management, all of the participants equated good management with how they felt physically. When they felt ill they would then quantify their glucose level with their blood glucose monitor. But there was little consistency in checking their glucose level on a daily basis.

Self-care Requisites #5: A study by Fisher et al. (2008) discussed the concept of diabetes distress. Findings suggested there was a distinction between diabetes distress and depression. Diabetes distress is related to the diagnosis of diabetes and self-management. Fisher et al. (2008) concluded that the cumulative effects of diabetes distress are a result of one or combined factors of: a) emotional burden (feeling overwhelmed with diabetes, b) physician-related distress (access, trust, and care), c) regimen related distress (concerns related to diet, physical activity, and medications), and d) interpersonal distress (not receiving support from others). Diabetes distress results in “high levels of negative affect...linked to poor biobehavioral disease management” (Fisher et al., 2008, p. 250).

All of the Native American adults with Type II Diabetes in this research identified one or more areas of diabetes distress to varying degrees. The greatest area of distress was physician-related. The participants were concerned about access to a consistent primary care provider for their diabetes. A majority of the participants felt overwhelmed with emotional and regimen related distress related to changes of diet, exercise, and

medication. They did find support from family members in adapting to these changes and adhering to a diabetic regimen.

Duangdo & Roesch (2008) studied coping methods of individuals with diabetes in their adjustment to self-management activities. They identified four coping patterns: a) avoidance focused, b) approach focused, c) emotion-focused, and d) problem focused. The results of their research demonstrated that individuals who utilized approach focused and problem focused strategies for coping had improved psychological and physiological outcomes. The utilization of avoidance and emotion-focused coping methods had a negative effect on psychological and physiological outcomes.

The participants in this study used varying degrees of all of these coping patterns depending on their personal situation. One of the participants used strong approach and problem focused coping mechanisms. For him these positive coping mechanisms had evolved over time. When he was first diagnosed with Type II Diabetes, 45 years ago, he avoided his diagnosis. However, after five years, he accepted and was able to face his diagnosis and started to incorporate self-management activities into his daily life. He stated the management of diabetes is caring about himself. He felt that patients must take an active role in the management of diabetes and be assertive in communicating with their health care providers. When he goes to the doctor, he is very open, "I tell them everything, you know, what's wrong with me... what happened and including whatever I'm in there for." He has learned how to interface with the health care system and is not intimidated by it. With his long term diabetes, continuity for him has been more with the system rather than any given doctor.

Another participant used approach and problem focused coping mechanisms in the management of his diabetes. He stated that diabetes has a” lot to do with my everyday life.” He is aware of things he needs to improve for his health status and what can harm his health status. He actively searches for the latest information regarding diabetes care and feels that “if we keep our eyes open and our ears open” the information is there.

A study by Scollan-Koliopoulos et al. (2007) explored the concept of a multigenerational legacy of diabetes and self-care behavior. They stated that coping is affected by learned behaviors from family members who also have a diagnosis of diabetes. This influence can provide either positive or negative reinforcement for self-management activities and psychological responses.

As stated in the introduction of this research, Type II Diabetes is an epidemic condition affecting the American Indian/Alaska Native AI/AN population. All of the participants in this research had family members with this disease process. All of the participants discussed the support they received from friends and family members in managing their Type II Diabetes. The participants’ family members provided a wealth of information and encouragement to the participants regarding adherence to diet, exercise, medication, and medical regimens. One participant stated that living with diabetes “was an easy transition for me because I seen my mother do that, and I was able to follow along with that.” He indicated he was eager to share the story of his personal experiences as a Native American facing the diabetic disease process.

In addition to learning about ways to manage their diabetes, the participants in this study also learned from other family members, friends, and community members

about the consequences of poor diabetes self-management. They have seen the complications of diabetes related to blindness, dialysis, and amputations. Seeing what could potentially happen to them if they didn't care for their Type II Diabetes created fear but at the same time reinforcement for adherence to a medical regimen.

Self-care Requisites #6: Bray et al. (2008) explored a life coach model of care versus a traditional model of care by a physician for diabetic patients. The role and relationship of the life coach and the participant is to work together one to one, establish a treatment plan, establish goals, meet regularly to monitor progress, and be available between appointments for questions and support. With this model, the participant has increased access to someone for questions and support. The results of the research found improvements and sustained results in areas of: a) self-management of HgbA1c levels, b) blood pressure, c) cholesterol, d) medication adherence, e) meal planning, and f) activity level.

Diabetes is a life-long disease process that requires management of many facets of daily life. The participants in the current study acknowledged that they struggled daily with self-management activities of diet, exercise, and medication adherence. They identified numerous times that consistent access to health care personnel was one of the greatest needs for effectively managing their Type II Diabetes.

Limitations

One limitation in this research relates to the demographics of the sample. The five participants represented a minority of the population on this Reservation because they

had higher educational and employment status. These participants expressed the need for additional education and resources. The need may be greater for those who are disadvantaged in the areas of education and employment to maintain a self-management of Type II Diabetes.

Another limitation of this research may be the desire on the part of the participant to give only socially acceptable information during the interview. A third limitation may be that the research findings may not be generalized to all Native American/Alaska Natives outside of this studied region in the Northwest.

Implications

Nursing Practice: The implications for nursing practice include a variety of possibilities. Nurses in all levels of education could implement programs to teach and mentor individuals with Type II Diabetes and those at risk for Type II Diabetes.

Early proactive intervention is very important. Education for school age children could be one approach. In the Native American culture the elders of the Tribe represent wisdom. It would be beneficial to have elders of the Tribe who have Type II Diabetes speak to the children about the importance of maintaining a healthy and active lifestyle.

Local community support groups could be formed. These groups could serve as a link for individuals who have Type II Diabetes with those who are recently diagnosed. A second community support group could also be formed for the prevention of complications from uncontrolled Type II Diabetes. Learning and physical activities could be geared towards diet, exercise, and foot care.

In the clinical setting nursing practice measures could incorporate diabetes as a discussion component of care at every clinic visit. This could be as simple as asking each patient how the care of their Type II Diabetes is or asking if they have any questions regarding their Type II Diabetes. Questions could be answered or referrals made to the appropriate health care provider. At a general level, diabetes prevention and care could include increasing the availability of current diabetic literature at clinics and in the schools. Literature could also be made available at local community gathering areas such as senior centers, the post office, and tribal offices. A quarterly newsletter about diabetes could be created and sent to interested individuals. The content of this newsletter could contain information about ideas for diet, exercise, and new developments in diabetes care.

Nurses could also advance their education to become certified as diabetes educators and serve as life coaches. The evidenced-based practice model of a life coach outlined by Bray et al. (2008) is a model that could decrease the disparities of the diabetic AI/AN. A life coach would provide education, classes, coaching, reminders, and feedback on an individual basis. This would provide an on-going supportive-educative system. Diabetes is a life-long disease that requires management of many facets of daily living.

Nursing Education: A suggestion for nursing education is immersion into the group of people you are serving. The economics and resources of individuals living on Tribal Reservations are often vastly different from that of individuals in urban communities. There may not be resources or facilities to obtain the components needed to

maintain a diabetic lifestyle. It is important to work with the available resources and needs of the patient.

Knowledge of the culture of a group is an important factor in providing care. Because the researcher is Native American, cross-cultural issues did not arise in the interviews conducted for this study. It is important that all levels of providers have cross-cultural competency and sensitivity for their patients. This awareness will assist providers in tailoring diabetic interventions that are culturally appropriate. Current interventions are based on research of the predominant cultures.

Another component of nursing education is the recruitment of more Native nurses in all levels of nursing education and nursing practice. Currently there are two programs that support this component. The Indian Health Service provides scholarship opportunities for the education of Native people in the area of health care. After completion of their education they are given employment opportunities on Reservations. Another local recruitment source is the Caring For Our Own program at Montana State University College of Nursing. This program actively recruits Native Americans into its nursing program. Native students are provided support and mentoring as they progress through the nursing program.

Nursing Research: There are many implications for nursing research in the area of Type II Diabetes and Native Americans. This research had Native American participants who all completed high school, had some formal college education, or had graduated from a Master's program. One area of research would be to specifically target those who have not completed high school nor have formal education (from the predominant

culture's understanding of education) beyond a high school degree. Interviews with a sample representative of people with less formal education may reveal different challenges or resources based on type of educational and other available resources.

As stated in the literature the implementation of a life coach program improves quality of life and outcome of individuals with Type II Diabetes. Nursing research could be done to identify what culturally specific components would be needed to successfully use the life coach concept with Native Americans who have Type II Diabetes.

Nursing Policy/Programs: Nursing policy and programs in the area of Type II Diabetes can encompass a wide range of areas. To empower the role of nursing in the management of Type II Diabetes it is important to build a foundation of knowledge. One way to do this is through monthly educational in-services, offer classes for certification as diabetes educators, and education to be a life coach. This could improve the care and health status of Native American's with Type II Diabetes as well as those at risk.

Nurses can also lead programs to improve the health of patients with Type II Diabetes. They can accomplish this by leading exercise groups and educational classes regarding nutrition. Another program that can be implemented by nursing is to evaluate the nutritional content of breakfast and lunches served at local schools and senior centers. They could reinforce positive nutritional foods that are being served or make recommendations for improvement.

Summary

Type II Diabetes is a complex disease process. Proper management and control will decrease the mortality and morbidity associated with this disease process. Coupled with the results from this study, the available literature reviewed for this project and Orem's nursing theory provided a framework for understanding an approach to and the provision of care of patients with Type II Diabetes.

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APPENDICES

APPENDIX A

PROPOSAL ACCEPTANCE MEMORANDUM



INSTITUTIONAL REVIEW BOARD

For the Protection of Human Subjects

FWA 0000165

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MEMORANDUM

TO: Niccle Merchant and Patricia Holkup

FROM: Mark Quinn *Mark Quinn*
 Chair, Institutional Review Board for the Protection of Human Subjects

DATE: January 18, 2010

SUBJECT: *What Problems Do American Indian/Alaskan Natives (AI/AN) Adult Patients Face When Attempting the Long-Term Management of Their Type II Diabetes Disease Process?* [NM011810]

The above proposal was reviewed by expedited review by the Institutional Review Board. This proposal is now approved for a period of one-year.

Please keep track of the number of subjects who participate in the study and of any unexpected or adverse consequences of the research. If there are any adverse consequences, please report them to the committee as soon as possible. If there are serious adverse consequences, please suspend the research until the situation has been reviewed by the Institutional Review Board.

Any changes in the human subjects aspects of the research should be approved by the committee before they are implemented.

It is the investigator's responsibility to inform subjects about the risks and benefits of the research. Although the subject's signing of the consent form documents this process, you, as the investigator should be sure that the subject understands it. Please remember that subjects should receive a copy of the consent form and that you should keep a signed copy for your records.

In one year, you will be sent a questionnaire asking for information about the progress of the research. The information that you provide will be used to determine whether the committee will give continuing approval for another year. If the research is still in progress in 5 years, a complete new application will be required.

APPENDIX B

DRAFT SCRIPT FOR THE RECRUITER

Draft Script for the Recruiter

Nicole Merchant, RN is a Montana State University College of Nursing Master's student who is performing research to identify the challenges of Native American adults with long-term management of Type II Diabetes. She is seeking participants to share their personal stories in managing their Type II Diabetes.

The research will consist of an interview that will take approximately 60 minutes to 120 minutes of your time. Every effort will be made to maintain the privacy of your personal information. Your name will not be identified in any reports and/or publications resulting from this study.

If you are interested in assisting Nicole in her research I'd like to ask for your contact information, so that Nicole can call you to arrange a meeting time and place.

APPENDIX C

SUBJECT CONSENT FORM

SUBJECT CONSENT FORM
FOR
PARTICIPATION IN HUMAN RESEARCH
AT MONTANA STATE UNIVERSITY

Study Title: What problems do American Indian/Alaska Native adult patients face when attempting the long term management of their Type II Diabetes disease process?

You are being asked to participate in a study that is attempting to describe the challenges of Native American adults with Type II Diabetes. You have been asked to be in this study because you are a Native American who has had Type II Diabetes for the last five years

What is the purpose of this study?

The purpose of this study is to gain insight to identify the problems AI/AN adult patients face when attempting long term management of their Type II Diabetes disease process

Who will participate in this study?

Native American adults with Type II Diabetes who've had the diagnosis for a minimum of five years.

What will happen during this study?

If you agree to participate in this study you will be asked to take part in an interview in which you will be asked to share your experiences and challenges with control of your Type II Diabetes. The interviews will be tape-recorded so they can be transcribed and entered into a computer.

How long will the study last?

Your interview may take anywhere from 60 to 120 minutes. Following the interview, if additional questions about the content of the interview arise, the interviewer may call you to clarify any points of confusion.

What are the risks of the study?

Your participation in the study involves low risk.

What are the benefits of the study?

This study may be of no direct benefit to you. However, the study may assist health care providers to improve the health status of the Native American patients by providing tailored care based on the results from this study.

Will it cost me anything to be in this study?

You should not have any financial costs for participating in this study. Interviews will be done at a time and place that is convenient for you.

Will I be paid for participating in this study?

Each participant will receive the four culturally appropriate gifts in appreciation.

What about confidentiality?

Every effort will be made to maintain the privacy of your personal information. The tape-recorded interviews will be identified with a code. The key to the codes and the signed consents will be kept in two separate locked files, and destroyed after 5 years. Audio tapes will be destroyed after transcription. Transcripts will be entered into a computer with a protected password. All identifying information will be removed from transcripts. Portions of these de-identified transcripts may be shared with my thesis committee for analytical purposes. The members of my thesis committee are: Patricia Holkup, PhD, RN; Carolyn Collis, MN, RN; Hillary Corson MN, RN; Jane Scharff, MN, RN Your name will not be identified in any reports and/or publications resulting from this study.

Is being in the study voluntary?

Participation in this study is completely voluntary. You may withdraw from this study at any time. Any data gathered to that point will be destroyed.

Who is funding the study?

As a master’s thesis, this is an unfunded study.

What if I have questions?

All questions are encouraged. If you have questions about the study, please contact Nicole Merchant RN, at (406) 861-6613 or nmerchant.2001@yahoo.com or my advisor, Patricia Holkup, PhD, RN at (406) 243-2543 or pholkup@montana.edu . This study has been approved by the Human Subjects Committee at Montana State University-Bozeman. If you have questions about your rights as a study participant, please contact the Chairman of this committee, Mark Quinn, at (406) 994-5721.

Authorization from adult participants

AUTHORIZATION: I have read the above and understand the discomforts, inconveniences, and risks of this study. I _____ (print name) agree to participate in this research. I understand that by signing this form, I have not given up any of my legal rights. I understand that I may later refuse to participate, and that I may withdraw from the study at any time. I have received a copy of this form for my own records.

Signed _____ Date _____

Witness _____ Date _____

Researcher _____ Date _____

APPENDIX D

INTERVIEW QUESTIONS

Interview Questions

Demographic questions

1. Occupation
2. Education level
3. Age
4. Language
5. Religion (traditional vs. other)
6. Health Care Site (IHS or non IHS facility)
7. Other family members who have diabetes
8. Resources and support
9. How many people live with you in your home
10. Co-morbid conditions (any diabetic complications currently experiencing)

Open-ended interview questions

1. What was it like for you when you were first diagnosed with Type II Diabetes?
2. How has it been for you living with Type II Diabetes over the years since your diagnosis?
3. Sub-questions
 - a. What changes have you had to make in your life to manage your Type II Diabetes?
 - b. What are the easiest aspects of managing your Type II Diabetes?
 - c. What are the most difficult aspects of managing your Type II Diabetes?

Follow-up directed interview questions

1. How can you tell if you are managing your Type II Diabetes well?
 - a. What do you think happens if a person is not able to manage your Type II Diabetes?
 - b. What kind of health care support services are available to you in the management of your Type II Diabetes?
2. What services do you think are needed to improve the management of your Type II Diabetes?