2001

Perceived Problem Areas for Adults Living with Diabetes

Valda Tolliver
Grand Valley State University

ScholarWorks Citation

Tolliver, Valda, "Perceived Problem Areas for Adults Living with Diabetes" (2001). *Masters Theses*. 584.
https://scholarworks.gvsu.edu/theses/584

Perceived Problem Areas for Adults Living with Diabetes

by

Valda Tolliver. BSN. RN

A THESIS

Submitted To
Grand Valley State University
in partial fulfillment of the requirements for the
degree of

MASTER OF SCIENCE IN NURSING

Kirkhof School of Nursing

2001

Thesis Committee Members:

Linda D. Scott. PhD. RN

Kay Setter Kline. PhD. RN

Cheryl Valachovics. MSN. RN

ABSTRACT

PERCEIVED PROBLEM AREAS FOR ADULTS LIVING WITH DIABETES

By

Valda Tolliver, BSN, RN

The purpose of the study was to examine the perceived problem areas for adults living with diabetes. A descriptive design using the Problem Areas in Diabetes Scale (PAID) among a convenience sample of 24 African Americans provided the data in this study. King's (1971) conceptual framework for nursing provided the theoretical foundation.

Data indicated that 83% of the sample did not perceive living with diabetes as a serious problem. However, the majority of them identified food deprivation and coping with diabetes, in addition to worrying about the future and possible serious complications from the disease as problematic. These results suggest that individuals' beliefs and perceptions of living with diabetes may be unique and varied.

DEDICATION

This work is dedicated to three of the most important women in my life, Annie Summers, Amani Perkins-Tolliver, and Tishara Tolliver. These women have inspired me to become a better person. To my mother Annie whom I love dearly, not only for her wisdom and knowledge, but also for her unconditional love and support over the years. I want to thank her for teaching me the importance of obtaining a good education. To my beloved daughter Tishara Tolliver, who was the source of my inspiration and motivation for starting and completing this scholarly project. Last but not least, to Amani Perkins-Tolliver, my beautiful granddaughter; the one who has restored joy, hope, and happiness to my life once again.

Acknowledgments

I wish to acknowledge gratitude to the following:

*Annie Summers for her endless support and encouragement for this work.

*Linda Scott, PhD, RN for her endless hours of guidance, support, expertise, and humor through the completion of this work.

*Barbara Harris, MSN, RN for her support of this project, my career as a nurse, and for being a mentor and role model.

*My two sisters, Vivian Ellis and Cynthia Gillion who have always provided me with love, support, and sound advice no matter what time of the day or night I called them.

*My two sons, Tyson Tolliver and Tyler Crump who supported me through this project by being patient and understanding when I juggled schoolwork and motherhood.

*My two best friends, Mary Dotson and Michele Williams for their endless hours of support and encouragement, and for being good listeners.

I want to thank all my other friends, relatives, and teachers that offered words of wisdom and provided me with encouragement and support throughout this project.

TABLE OF CONTENTS

TABLE OF CONTENTS

CHAPTER

LIST OF TABLES

TABLE

LIST OF APPENDICES

APPENDIX

CHAPTER 1

INTRODUCTION

Diabetes mellitus (DM) affects some 16 million people in the United States (U.S.) and is the fourth leading cause of death by disease (Bramlett, Kim, Poon, & Wright, 1998). It is a complex group of disorders that include a disturbance in metabolism and use of glucose that is secondary to a malfunction of the beta cells in the pancreas. There are at least four sets of factors that influence the development of DM: genetic, metabolic, microbiologic, and immunologic.

There are two dominant forms or syndromes of diabetes, Type 1 or insulin dependent diabetes mellitus (IDDM) and Type 2 or non-insulin dependent diabetes mellitus (NIDDM). In both cases, the abnormally elevated blood glucose is called hyperglycemia. Type 1 DM can occur at any age during childhood, but peaks around puberty. It is characterized by beta cell destruction, usually leading to absolute insulin deficiency. The management of Type 1 DM is complex and demanding, involving two or more injections of insulin per day, regular blood glucose monitoring, regular exercise, and a healthy sugar restricted diet. In addition, this form is usually quite difficult to regulate.

Type 2 is a form of DM that occurs predominantly in adults over the age of 40. People with Type 2 DM are generally obese, have insulin resistance, and are usually relative (rather than absolute) insulin deficient. Because there is usually some insulin present in the blood, diet alone or the use of prescribed hypoglycemic agents controls one's hyperglycemia.

Diabetes mellitus can result in serious long-term complications such as renal disease, retinopathy, peripheral vascular disease, heart disease, and neuropathy. Historically, 20-30 years ago treatment was aimed simply at preventing symptoms such as increased thirst, hunger, urination, irritability, weakness, and fatigue. However, as physicians began to suspect that hyperglycemia was directly related to or responsible for some of the complications of DM, the goal of therapy moved towards normalizing blood glucose levels to the greatest extent possible.

Moreover, diabetes can be associated with premature death. It is believed to be underreported on death certificates, both as a primary and secondary cause of death. According to the American Diabetes Association, diabetes contributed to 193,140 deaths in 1998. As such, the emphasis in care of the diabetic patient is to control the disease, prevent or minimize complications, and reduce mortality. There is strong evidence that clearly shows a strong correlation between the effects of intensive treatment of diabetes and the development and progression of long-term complications (The Diabetes Control and Complications Trial Research Group, 1993; United Kingdom Prospective Diabetes Study, 1993). These studies showed that lowering blood glucose delayed the onset and slowed the progression of microvascular complications.

Nurses encounter patients with DM in a number of different health care settings such as an outpatient clinic, physician's office, or inpatient hospitalization. Each setting requires different nursing approaches to the patient with diabetes. In addition, patients need different nursing care strategies according to their state of health, culture, learning ability, lifestyle, developmental stage, and social support. Although in clinical settings nurses use physiological data to determine the capacity of disease management strategies, patients acknowledge their own expertise in self-management in the context of how they feel and what they believe is necessary to achieve well-being (Burrus, Liburd, & Burroughs, 1998). In order to be effective, the nurse must assess the patient's state of health and learning ability as well as psychosocial and direct care needs, prior to any intervention.

There is little known about how people cope with the demands of diabetes in relation to how they perceive and make self-management decisions over time. The complexity and skill involved in recognizing, responding, and interpreting body cues associated with hypo- or-hyperglycemia requires a certain level of expertise. Yet, living with diabetes has many dimensions. For example, each person with DM responds uniquely to situations and interventions. One person might feel discouraged when thinking about living with DM or struggle with hyperglycemia, where the other may not (Pollock, 1993). No one person responds to the many demands of diabetic management, as does the next and therefore should not be treated as the same.

Since there is no cure for DM, it requires the individual to modify or maintain a complex set of behaviors to manage the disease on a daily basis. Patients with DM must incorporate decisions about insulin, diet, exercise, and foot care into their daily lives. For instance, the course of treatment involves medication compliance and diet adherence, as well as observation for signs and symptoms of complications.

Effective management is achieved when the person maintains the behaviors of medication compliance and diet adherence in order to keep blood glucose levels within a targeted range, thus preventing long-term complications of DM. However, maintaining daily lifestyle changes is a difficult and demanding process for the individual with DM, not a simple event. Maintaining this lifestyle requires adaptation and change. Incorporating the changes necessary for successful diabetes self-care into individuals' lifestyles may lead to additional stress and can interfere with or obstruct personal harmony and balance. In addition, lifestyle changes and psychosocial adaptation may threaten the individual's ability to perform activities of daily living (ADLs) and the ability to maintain independence.

Respecting and valuing what patients have learned from living with DM is critical to provide effective care. Nurses often focus on control, particularly stressing compliance with prescribed regimens rather than focusing on the impact of living with this chronic disease. Until nurses know a great deal more about how patients with DM struggle to attain and maintain glycemic control, they cannot develop supportive partnerships or achieve positive health care outcomes. The importance of knowing and understanding patients with DM as individuals, as people with unique goals and ways of perceiving and living with their illness, is an essential element in the nurse-patient relationship. Yet, few nurses understand the range of attitudes, coping mechanisms, and management styles used by patients with diabetes.

It is not surprising that patients with DM often experience feelings of emotional distress and lack motivation in self-managing their disease (McDonald, Tilley, & Havstad, 1999). Unfortunately, the dynamics of living with a chronic disease such as DM is difficult to summarize concisely in terms of its emotional impact. Yet it is imperative that nurses understand the areas with which individuals struggle in order to facilitate effective adaptation and self-care management techniques. For this reason, the purpose of this study was to examine the perceived problem areas for adults living with diabetes.

CHAPTER 2

CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

Conceptual Framework

Imogene King's interacting model (1971) is the conceptual framework selected for this study. According to King, health concerns related to nursing can be grouped into three dynamic interacting systems: personal, interpersonal, and social systems (King, 1971). The nurse must understand given aspects of all three systems in order to treat the individual holistically and effectively. King also identified specific assumptions and 16 concepts upon which her framework was based, however only the concepts of perception, goals, self, interaction, communication, role, and decision-making will be used for this discussion. Moreover, these selected concepts will be discussed separately within each specific interacting system.

King's (1971) general systems framework reflects the patient as a personal system within the environment that coexists with other personal systems. Individuals are constituents in a group that involve interpersonal systems, and interpersonal systems contribute to social systems.

The person or individual is what constitutes the personal system. King conceptualized individuals as social, rational beings that interact with the environment and others (King, 1971, p.83). Each person is viewed as unique, with individual responses to actual or potential health problems. Since the patient with diabetes is not hospitalized for the majority of one's illness, the patient must learn to maintain a complex set of behaviors in order to achieve optimal glycemic control. The patient has the power to make decisions about self-managing this chronic disease. Understanding the patient's perceptions of living with DM will allow the nurse to intervene sensitively and effectively.

The concept of perception has been of great interest to nurses. "Nurses have been aware of this important factor in their care of patients and it has been documented from the time of Nightingale" (as cited in Bunting, 1993, p.168). Perceptions are important because both the nurse and patient perceive each other in the nurse-patient dyad, and then make individual judgments based on their perceptions. The nurse and patient must interact and share perceptions to ensure that mutually identified goals have been met. Quite often this process involves some type of learning activity in which the two have a goal in mind. This goal is usually centered specifically on the concept of health. Nursing is generally represented as a helping process with the primary focus on interpersonal interactions between the nurse and the patient.

The meaning of DM is understood to be totally linked to the experience and management of the disease process (Alcozer, 2000). Patients interpret and comprehend the diagnosis of DM from the perspective point of their self and their reality. The meaning that is made from the diagnosis of DM and subsequent responses (i.e. dietary and physical behaviors) are regulated through self and personal reality.

Self is the other main concept from the personal system used in this discussion. It is the composite of a person's thoughts and feelings about who one is and why one exists. It is a representation of an individual's presence, reality, and being. The patient's perception of himself or herself is highly individualized and the nurse must recognize this uniqueness as such.

Both the nurse and patient are unique individuals, each with their own personal system. Each of them enters into the relationship with their own set of perceptions, desires, thoughts, needs, and feelings. The uniqueness and responses of the patient and the nurse to themselves, the environment, events, and expectations based on judgments and reactions to each other's perceptions often are not congruent with one another. This is particularly true for the concepts of power, authority, and decision-making in diabetes self-management.

The interpersonal system is the second interacting system within King's framework. Within the boundaries of this system, two or more individuals interact with each other or a situation. A major feature of King's conceptual framework is the social act of human interaction (Sieloff-Evans, 1991). Since the nurse and patient are viewed as mutual participants in the decision making process, the interaction that occurs between them is affected by the quality of their relationship. Specifically, the nurse must have knowledge of role, communication, and transaction to understand interactions central to interpersonal functioning. Since interactions occurs within social systems, including family, educational, and work systems, nurses require knowledge or understanding of key concepts such as control, authority, and decision making in order to function properly.

Mutuality and the sharing of information are crucial factors in the nursing process. Without mutuality and collaboration, the selection of goals and the process of identifying a means to reach them cannot be attained. Interactions between the nurse and patient occur throughout the nursing process. The nursing process directs the nurse in looking for problems and anticipating care needs of the patient. The goals, needs, and values of the nurse and patient influence the interaction process. Thus the process of interaction discussed in relation to the interpersonal system is applicable to the nurse-patient relationship. The center of helpful interactions with nurses is that they know and value the patient as an individual. It is argued that nurses' perspectives and the diabetes care that emerges from them, fail to address aspects that are meaningful to people living with DM (Trief, Grant, Elbert, & Weinstock, 1998). Moreover, the health of the person living with diabetes is a dynamic process that changes with time and varies according to life circumstances. For the person with DM, the emphasis or the focus of achieving and maintaining glycemic control is knowing, understanding, and interpreting what diabetes means to them and how to live with this chronic illness.

Transaction and communication are two major concepts of interpersonal systems. Transactions are basic to goal attainment and include bargaining and negotiating, and sharing a frame of reference by communicating how patients with DM incorporate the illness into their lives on a daily basis. Transactions lead to goal attainment, effective care, and growth and development. They require perceptual accuracy in the nurse-patient relationship and ultimately congruency between role performance and role expectation for the nurse and patient.

Communication is involved in transactions. Communication is the vehicle by which the nurse and patient share information and ideas. Communication and transaction are integral parts of the nurse-patient relationship. Within this process, the patient and nurse establish and maintain a relationship where they try to achieve valued goals. These goals include health promotion, health maintenance, and recovery from illness.

The social system is the remaining system with King's (1971) framework. It is within this system that the roles of the nurse and the patient are identified and sets of expected behaviors occur. Patients with DM often experience increased levels of stress while managing this chronic disease. Major lifestyle demands, worrying about achieving and maintaining glycemic control and the possibility of complications are a few of the issues with which some struggle (Guttmann-Bauman, Flaherty, Strugger, & McEvoy, 1998).

The expected role of the patient with DM is to take charge of the disease and perform or adhere to the treatment goals given by health care providers (HCPs). The role of the patient with DM is managing the disease on a daily basis. Effective management is measured by the patient's ability to adhere to the five areas of diabetic management. They are: a) adherence to a prescribed diet and medication regimen; b) glucose monitoring; c) hypoglycemic control; d) exercise; and e) foot care. For example, the patient is expected to maintain the blood glucose level within a targeted range. This involves eating a nutritious, lowfat, and calorie-restricted diet. The patient is also expected to check a blood glucose level prior to meals and take some form of medication that lowers the blood sugar, either insulin or an oral hypoglycemic agent. For the insulin-requiring patient, a decision to increase or decrease the prescribed amount of insulin may depend on the blood glucose level or other precipitating factors. Time, stress and diet management are factors that influence perceptions, beliefs, and attitudes about self-care.

On the other hand, the nurse often assumes this role for the hospitalized patient, checking the blood glucose level and administering medications. Since the nurse and the patient are viewed as an interacting dyad within the health care system, the interaction that occurs between them is affected by perceptual congruency. In other words, the successful outcome of diabetes self-management is affected by the attitudes of both the nurse and the patient (Ruggiero, et. al 1997). In addition, it affects the actions, information, and energy exchanged in the nurse-patient relationship, which ultimately influences the perceptions of the other and vice-versa (Hunt, Arar, & Larme, 1998).

However, depending on the context of the situation and the management goals desired, an offer for assistance might be perceived as either helpful or intrusive. Furthermore, the nurse might not agree with the role or decision-making ability of the patient, in treating this chronic illness. According to Willoughby, Kee, Demi, and Parker (2000), an important component of patient education is to exchange and share information with patients that empower them to make informed decisions about their diabetes management. Often the nurse promotes conflicting advice, such as "take charge, but comply or adhere" to the prescribed regimen (Hernandez, 1995, p.33).

The impact generated by diabetes, such as worrying about anticipated effects and patient satisfaction with him or herself in self-managing this disease, are all factors that influence the decision-making process. These decisions are based on the patients' perception and attitude about their disease. If the nurse fails to recognize the unique responses or the coping strategies of the person living with DM, the patient may be perceived as non-compliant. For example, the nurse often focuses on the patient's physiological symptoms, lifestyle, and behaviors. Blood glucose and other chemistry values, like the glycosulated hemoglobin (HbA$_{1c}$) generally define successful self-care management. The patient is perceived as non-compliant or unaccepting of the illness when these values are unusually elevated. Elevated blood glucose and HbA$_{1c}$ levels are indicators of poor glycemic control.

Yet, the patient may struggle with larger issues versus maintaining a specific blood glucose level. Decisions about diet management, difficulty taking time off work or difficulty in getting an appointment are issues patients with DM face on a daily basis. Awareness of their own bodies and what works best for them are factors that influence self-management decisions all the time. Therefore, it is crucial that nurses understand what the perceived problem areas of living with DM are in order to establish mutual goals and effective interventions.

Review of the Literature

In an effort to provide a basis for examining the perceived problem areas for adults living with DM, existing research was reviewed that investigated personal representations of this phenomenon. Although there is a massive and diverse amount of writings in the areas of diabetes that spans across medical, nursing, and the social sciences literature, there is limited qualitative and quantitative data specific to the perceived problem areas for adults living with diabetes.

Patient perceptions of diabetes.

Hatrick (1998) conducted a qualitative research study in an effort to understand the personal meaning and significance of diabetes for people living with this condition. Study participants were recruited using purposive convenience sampling of people with Type 1 DM. Subjects varied with regard to employment status, lifestyle, marital status, and family situation. Specific data regarding socioeconomic status (SES) and educational level were not collected. Letters and flyers were sent out to agencies and persons who had potential contact with people with Type 1 DM. Attempts were made to include a diverse sample in order to ensure the entire scope was understood. However, only Caucasian subjects participated. The sample consisted of 10 patients, eight women and two men.

The interview tapes were transcribed verbatim, noting significant communication components such as voice tonations. Rich and powerful descriptions illuminating the meaningful experiences or impact of living with DM emerged throughout the study. The participants described the impact of living with diabetes using terms such as "the envelope of diabetes," "the walls of diabetes," "unknown terrain," "a cloud looming," "a ball and chain that you drag around," and "a noose around your neck" (Hatrick, 1998). Furthermore, thematic analysis of interview data illuminated six major themes: 1) the meaningful experience of living with DM; 2) diabetes as a loss and gain; 3) diabetes as culturally influenced; 4) the power of health care professionals; 5) the authority of the diabetes regimen; and 6) diabetes control.

Most participants described diabetes as meaningful and in relationship to everything else in their lives. In addition, tension generated from the personal meaning of diabetes and the diabetic regimen ensued. For example, the fluctuations and uncertainty of DM was a source of anxiety, pressure, and strain for most of the participants. Many stated that no matter how well they adhered to the diabetic regimen, fluctuations often occurred. They also described how diabetes meant loss. Some of the losses identified were "loss of a child, loss of the inability to have children, loss of relationships, loss of sexual function, and at times loss of dignity" (Hatrick, 1998, p. 79). In relation to the personal meaning of diabetes, some depict the double meaning of the person with DM and the disease versus the person with DM and the diabetic regimen. The battle for control and the integration of DM into "one's self and one's life" is a source of pressure and stress that living with diabetes may cause.

The qualitative research design was one of the strengths of this study. Through this approach, HCPs can learn firsthand the turmoil faced by patients with diabetes. This is important because too often HCPs view DM as a physiological disease, rather than an illness (Conrad, 1987; Kleinman, 1978). The article by Hatrick also showed insight into aspects that living with DM causes, such as limitations to one's daily life, feeling unwell, tired, and worried. These findings may suggest a tendency to over-simplify diabetic management or an incongruency in perceptions or goals of DM self-management by HCPs.

McCord and Brandenburg (1995) conducted a qualitative research study where 14 subjects with Type 2 DM participated. The participants were placed in two groups, compliant and noncompliant. The compliant group was defined as those that maintained a blood glucose level <126 and had regular physician care visits, whereas the non-compliant group rarely checked their blood glucose and did not take the disease seriously. The compliant group (n= 7) consisted of five females and two males, whose age averaged 64.1 years. The non-compliant group (n= 7) was comprised of three females and four males, whose age averaged 56.3 years. The purpose of the study was to examine the beliefs, attitudes, and reported experiences of the subjects. The data collection was obtained by interviewing the participants over a four-week study period. The interviews lasted between 20 to 45 minutes in length, were audiotaped and transcribed verbatim. An open coding system was used to categorize and analyze the statements of the participants.

Seven major themes were identified after analyzing and coding the interviews: (1) the meaning of DM and its impact on the patients' lives; (2) their understanding of the disease; (3) compliance with health care and treatment; (4) the positive effects of DM on their lives; (5) feelings of frustration; (6) the seriousness of DM; and (7) the imminent outcome of their disease. For most participants, the meaning of DM meant problems and complications. There were only a few participants that reported little effect of DM on their life. In fact, all but two subjects reported that DM was inconvenient or that it interrupted their daily schedules.

There were only three notable differences between the two groups. The non-compliant groups admitted to not following their doctors' instructions, wanted nothing more from their physician, and were more likely to believe that DM was not a serious disease. Conversely, the compliant group routinely collaborated with their physician, followed instructions given to them, and believed uncontrolled DM would lead to serious long-term complications.

Alcozer (2000) conducted a secondary study analysis of interviews that described the perceptions and meanings of Type 2 DM. The original sample included 20 Mexican American women with varying lengths of time since diagnosis. The women participated in two to three open-ended interviews that lasted one to two hours, as well as in 112 hours of observations of family and diabetes-related activities. The secondary analysis was conducted in concurrence with or duplicated the original study, incorporating interpretive interactionism methods to explore the lived experiences of the women. The demographic variables of age, marital status, education, and income were also examined.

Data analysis was an interactive process. Several themes emerged throughout this study with respect to perceptions and meanings of DM such as: (1) having diabetes; (2) describing diabetes; (3) taking care of diabetes; and (4) the meaning of diabetes. Results of the study concluded that the participants viewed DM as a complex and confusing illness. The participants described confusion concerning care and the information received from both their HCPs and family members. From the HCPs, the information such as believing one has borderline DM meant that their diabetes was not as serious as having the disease itself. For example, using insulin to regulate their diabetes was perceived as being more serious. Relatives lead them to believe it was important to get up during the night in order to "pee out the sugar." Some participants reported eating too many sweets as a way of getting DM. Another significant finding among this group of Mexican American females was that they attributed meaning to their symptoms. In other words, having diabetes meant problems. They defined these problems as low blood sugar reactions and constantly watching what they ate, as well as being consumed by the time and energy involved with treatment of the disease.

A strength of Alcozer's (2000) study was its use of an existing database with concurrent data collection process. This is advantageous because it involves minimal expense and provides the ability to analyze existing data for other purposes. One limitation of the study was incongruent or inconsistent meanings of the concepts being studied. Clarifying concepts that provide simple explanations for specific treatment plans in the language participants understand was recommended.

Kyngas and Barlow (1995) conducted a study that investigated the personal meaning and perceived impact of living with DM. The sample size consisted of 51 Finnish adolescents, 28 males and 23 females. Interview data were examined using constant comparative analysis. This process involved asking questions about the data and making comparisons for similarities and differences between the concepts. The interviews dealt with two topics; (1) the meaning of diabetes and (2) the impact of diabetes on their lives. Whereas descriptions of DM as a 'habit' were considered positive between the two main themes that emerged, the issue of DM as a threat also surfaced. The core concept of control emerged from descriptions of the personal meaning of DM. Negative personal feelings associated with the meaning of DM such as “death,” “prison,” “hell,” and “nightmare” indicated the limited freedom these subjects experienced. Others had difficulty describing their disease, so the researchers solicited their responses through drawings.

Two main categories emerged when the subjects described the impact of living with DM: (1) a threat to physical well-being and (2) a threat to psychosocial well-being. Physical threats to well-being and a threat to life’s equilibrium were represented in several categories such as pain, complications, and hypoglycemia. The impact of diabetes on the psychosocial well-being of the subjects was associated with fear, depression, worry, lies, and guilt. Many subjects reported fear was “in their minds” everyday. For most of them fear, particularly in relation to complications, such as amputations, going blind, and having kidney disease was reported most often.

Thoughts, feelings, and behaviors affect our health and well-being. Recognizing the importance of these powerful influences on health and disease is consistent with our evolving efforts in understanding how psychosocial and behavioral factors affect health and disease processes.

Patient perceptions of managing diabetes. Glasgow, Hampson, Strycker, and Ruggiero (1997) conducted a study that examined personal beliefs and social-environmental barriers related to diabetes self-management. A total of 2,800 individuals were sent a survey that included questions on sociodemographic and health status characteristics, as well as psychosocial factors and diabetes self-management. A raffle for monetary prizes was used as an incentive for participation. The final recruitment rate was 74.4% (n = 2,056) where 988 individuals with Type 2 DM were representative of the U.S. population with this type of DM. The remaining 1,068 individuals with Type 1 DM were enough to permit examination of subgroup differences.

This quantitative study focused on several issues related to perceived problem areas of diabetes self-management. Two instruments from previous research were used. A 31-item scale assessed challenges to glucose testing, regular physical activity, healthy low-fat eating, and diabetes medication. Given the difficulty of dietary adherence compared with other self-management areas, Glasgow et al. (1997) used an additional 27-item questionnaire that assessed more detailed barriers to dietary self-management. The internal consistency coefficients for both instruments exceeded .70.

Respondents felt that DM was a serious disease and that self-management activities would control or reduce the likelihood of long-term complications. However, beliefs about the seriousness of one's DM were not predicative of any specific aspect of self-management. Yet, when respondents perceived barriers to exercise ($R^2 = .20$), diet ($R^2 = .24$), and glucose testing ($R^2 = .26$), self-care management was significantly affected. Greater barrier scores were significantly associated with being female, younger, more highly educated, Caucasian, having Type 1 DM, and having managed care or no insurance. In all cases, the psychosocial and behavioral factors were much stronger predictors of emotional distress that was any combination of demographic and other pertinent characteristics.

One of the greatest strengths of this study was the size and heterogeneity of the sample from around the U.S., including the modest African American sample size ($n = \geq 100$). Confidence in the conclusions about the psychosocial measures was enhanced through the use of hierarchical regressions, which controlled for demographic and medical factors. The use of two potentially important psychosocial factors perceived personal barriers and representations of illness (used in combination) rather than in isolation helped strengthen the study.

Using Ruggiero and Prochaska's (1993) transtheoretical model of change as a framework for their study, Sullivan and Joseph (1998) conducted a qualitative research study on diabetes self-management. The sample consisted of 10 subjects, five females and five males with Type 2 DM. Among the participants, nine were Caucasians and one was African American / Native American from a local university. The purpose of the study was to examine the level of difficulty patients encountered when making changes in diabetes self-management. Data collection using a combination of audiotaped telephone interviews and videotaped focus groups was completed. Focus groups and interviews provided in-depth information about the attitudes, values, beliefs, and interests of the clients being studied. These methods are valuable for learning participants' perceptions and have been found to be beneficial in previous studies.

Most of the participants responded with some degree of difficulty as they described behavior change expectations. They perceived the diagnosis of DM as serious and were fearful. The terms "easy," "difficult," and "impossible" emerged throughout the interview process. The difficulty was expressed in terms of the amount of time and energy spent managing the disease.

Diet, exercise, and blood glucose monitoring (BGM) were the three areas of behavioral change with which the participants struggled. For most of them, diet was seen as the most difficult area to manage. Some described effective changes they learned over the course of managing their disease and shared these tips in the feedback sessions. Several members of the group discussed exercise, its value in diabetic management, and reasons why they had not yet changed their behavior and attitudes about it. Incorporating BGM behavioral changes were reflected in ways similar to exercise management. The participants expressed the pros of BGM such as, fewer mood swings and hypoglycemic episodes, as well as a sense of controlling the disease rather than having the disease control them. Yet, reasons why they failed to incorporate testing on a regular basis were also cited.

Using focus groups provided useful insight into a broad range of beliefs and attitudes associated with behavioral change. Data obtained regarding patients' perceptions and opinions provided a basis for encouraging, promoting, and maintaining effective health care management strategies. Understanding the range of attitudes and ways of perceiving and living with this illness is an essential element in the nurse-patient relationship. This study supports a need for additional research in this area because of the limited amount of studies on this phenomenon.

Using an exploratory approach, a qualitative study relevant to variables that influence diabetes self-management was conducted by Samuel-Hodge et al. (2000). The purpose of the study was to identify how culturally relevant psychosocial issues and behaviors affect diabetes self-management. Specifically, the researchers sought to gain insight into the daily struggles in the areas of diet and physical activity. A convenience sample of 70 southern African American women with Type 2 DM was used. Subjects were recruited from two sites, a university-based outpatient internal medicine practice and from community centers in urban and rural communities. Of the ten focus groups interviewed, seven were from the university site and the remaining three were from the community centers. At the university setting, the average group size was five participants, while ten individuals usually participated at community centers. The focus group discussions were held during a five-month period. The discussions were scheduled over 90 minutes and each participant received a twenty-dollar cash incentive at the end of the discussion. A co-moderator took notes and audiotaped the discussions of each focus group.

A list of recurring themes was derived after further exploratory and interpretive analysis. The women described their perceptions of illness, diabetes management, and the multi-caregiver role as a considerable amount of stress in their lives. The dominant and most consistent themes were: (1) spirituality as an important factor in general health, disease adjustment and coping; (2) general life stress and multi caregiving responsibilities interfering with daily disease management; and (3) the impact of diabetes manifested in feelings of dietary deprivation, physical and emotional "tiredness," "worry," and fear of diabetes complications.

The impact of diabetes was expressed in both physical and psychological circumstances. Feeling physically tired and physically sick was often associated with other co-existing medical conditions like hypertension, heart disease, and arthritis. The emotional impact of diabetes was more powerful and expressed as fear of suffering, "worrying" about diabetes, and feeling nervous and tired. Religion and family members were sources of support and aided in the coping ability of the participants. Similar themes consistent with other qualitative research methodology emerged throughout Samuel-Hodge et al.'s (2000) study related to issues of life satisfaction, practices in coping, and sources of social support.

Welch, Jacobson, and Polonsky (1997) conducted a correlational research design study where participants from an outpatient clinic were used. Diabetic patients volunteered to participate in this longitudinal study (n = 256) that consisted of Type 1 (n = 135) and Type 2 (n = 121) individuals with DM. The sample was comprised of 48% males and 52% females. In addition, the Type 2 patients were subsequently divided according to the type of treatment received. For example, they were separated into insulin-treated (n = 85), tablet-treated (n = 28), and diet-treated (n = 8) groups. Mean HbA_{1c} levels were 10.4% among treatment groups, compared to 9.9% (of the total study sample).

The purpose of the study was to evaluate psychometric properties of the Problem Areas in Diabetes Scale (PAID). It is a 20-item measure of diabetes specific emotional distress that assesses a wide range of feelings related to living with DM and its treatment, including anger, guilt, fear, worry, and depressed mood. It is a 5-point Likert scale with a range from 0 (not a problem) to 4 (serious problem) with higher scores indicating greater emotional distress. Welch et al. (1997) reported a Cronbach alpha coefficient of .95 for the PAID.

The percentage of patients in study treatment groups reporting serious problems for individual PAID items varied. Areas that scored the highest were; (1) worrying about the future and the possibility of serious complications; (2) feeling guilty or anxious when you get off track with your diabetes management; (3) feeling scared when you think about living with diabetes; (4) feeling discouraged with your diabetes regimen; and (5) worrying about low blood sugar reactions. Worry about the future and the possibility of serious complications was identified as a serious problem between the IDDM group (Type 1) and both the NIDDM (Type II) insulin-and-tablet treated groups (45%, 34%, and 32% of patient respectively). However, the NIDDM tablet-treated group scored higher on the PAID item that addresses feeling scared when you think about living with diabetes (35.7% of patients) compared to 26.7% for the IDDM group, and 21.1% for the insulin-treated NIDDM group.

Conversely, the percentage of patients indicated the following as the least problematic; (1) not having clear and concrete goals for your diabetes care; (2)

uncomfortable interactions around diabetes with family and friends; (3) not accepting diabetes; (4) feeling that friends and family are not supportive of diabetes management efforts; and (5) feeling unsatisfied with your diabetes physician. Although perceived as not problematic overall, being unable to accept diabetes was scored the highest (10.7% of patients) among the tablet-treated NIDDM group. Feeling that friends and family are not supportive of diabetes management efforts scored least between IDDM and tablet-treated NIDDM groups (5.9%, and 7.1% of patients respectively), while higher scores were reported among insulin-treated NIDDM group (8.2% of patients).

Furthermore, comparisons were made on mean PAID scores between Type 1 and Type 2 insulin-treated patients first, then among the Type 1 and Type 2 insulin and tablet-treated groups. Type 1 patients scored significantly higher than the Type 2 on the PAID total score ($p < 0.002$). Comparisons of Type 1 with Type 2 insulin-treated patients showed that they differed significantly ($p < 0.02$) and Type 1 with Type 2 tablet-treated patients showed significant difference ($p < 0.05$). Type 1 patients scored significantly higher than the Type 2 patients on the PAID total score.

In all three comparisons, simple regression analyses showed neither duration of diabetes nor sex to be significant of PAID scores. No differences were found between Type 2 insulin and tablet-treated subgroups. This scale confirmed specific sources of diabetes distress with which the patient is struggling. In addition, given the association between emotional functioning and health related perceptions, this information of emotional adjustment to life with DM is particularly useful to nurses.

The results of Welch et al.'s (1997) study reflected the enormous emotional impact (i.e. worry, fear, guilt) of living with diabetes. Feeling burned out by the constant effort to manage diabetes, the physical and emotional energy expended, and apprehension associated with complications was all highly endorsed as a serious problem. One of the greatest strengths in this study was that it provided empirical data, adding to the limited amount of quantitative research relevant to this problem. Other strengths of the study were the sample size, and the multi-comparison analysis among the various treatment groups.

Limitations of the Research

This literature review was conducted in an effort to fully understand the personal meaning and significance of diabetes. The review disclosed a partial summary of recent studies that investigated problem areas for those living with DM. Numerous studies have been previously conducted that examine how persons with DM perceive, cope, and adjust to their illness. However, many were not research based and few were nurse-led studies. Another limitation of the literature search was that there were very few studies that included Hispanic and African Americans with Type 2 diabetes.

An assumption of qualitative research is that when HCPs understand the lived experience of DM, they can appreciate the health needs of those with similar experiences. While the article written by Hatrick (1998) provided useful information relative to understanding the meaningful experience of diabetes, the homogeneous ethnic background of Caucasian patients was one of the limitations of the study. Because the study was limited to Caucasian subjects, it failed to give insight to ethnic differences or to assess the variations in culture and race. A second limitation was that the subject pool typically consisted of Type 1 patients. However, throughout this literature review the feelings described by these patients is fairly consistent with Type 2 diabetics also.

Kyngas and Barlow (1995) led a qualitative study where the personal meaning and perceived impact of living with DM was investigated. A major strength of this study was to obtain the stories from the participants who actually lived the experience. However, one limitation was the cultural context of the study. The meaning and impact of DM among this group of Finnish adolescents may be unique to their culture and may not be a true representation in other countries and cultures. Furthermore, the adolescent patients were between the ages of 13 to 17, had Type 1 DM, and a number of them (n = 18) were unable to describe their disease verbally. Instead, they were invited to illustrate the meaning of DM in a drawing.

Besides the sample limitations, Alcozer (2000) excluded men from this study. In addition, the sample was limited to Mexican Americans with Type 2 DM. Because the study involved a secondary analysis, the database was limited to the variables of interest from the primary study.

The studies by McCord and Brandenberg (1995) and Welch et al. (1997) were physician oriented and not nurse-led studies. In the study led by McCord and Brandenberg, the subject pool is not a true representation of most Type 2 patients with DM. All of the patients were Caucasian, highly educated, and living healthy lifestyles. With the exception of the small sample size, the study led by Glasgow and associates (1997) held similar limitations. The primary limitations in this study were the coexisting reliance on self-reported measures of self-management and its cross-sectional design. The researchers used the process of mailing large volumes of surveys nationally in an attempt to reduce expenses and obtain a high response rate.

Limitations of the study conducted by Welch et al. (1997) included case-mix bias of the clinic used including the dramatically different profile of patients with DM. The patients were primarily Caucasian, medically insured, and well-educated. In addition, they were highly motivated to attend their clinics regularly and to volunteer to participate in the study. Finally, the PAID's clinical utility requires further examination including temporal reliability.

Summary and Implications for the Study

This literature review presented inconsistencies in how living with DM is perceived (Hunt, Arar, & Larme, 1998; McCord & Brandenburg, 1995) or a limited amount of studies that have researched the problem areas of living with DM (Welch et al., 1997). A gap in the literature also exists that concerns the examination of this phenomenon among African Americans. In addition, studies have focused on specific concepts rather than the totality of the experience (Glasgow et al., 1997; Samuel-Hodge et al., 2000). Inasmuch as DM is not a curable disease, there may be little social pressure to study this phenomenon. This study will help decrease the gap in nursing knowledge about this phenomenon, specifically with African Americans and serve as a basis to improve and increase health care outcomes.

Research Questions and Hypothesis

This study attempted to answer two research questions. The first question for this study was: What are the perceived problems of living with diabetes mellitus? The second question was: What are the differences in perceived problem areas by type of treatment used? It was hypothesized that those subjects treated with insulin would perceive DM as a serious problem and would score significantly higher on the PAID scale than the diet or tablet-treated subjects.

CHAPTER 3

METHODOLOGY

Research Design

A descriptive design was used to examine the magnitude of diabetes mellitus (DM). More specifically, the study examined patient perceptions of problem areas associated with having DM. Data were collected using a self-report questionnaire.

Sample and Setting

The sample was selected from a general population of individuals that attended a predominantly African American church located in a large urban city in the Midwest. Three hundred questionnaire packets were distributed to church members as they attended services on selected days. With a congregational size of approximately 2,300 members, it was hoped that a sufficient sample could be recruited. Only individuals who met the following inclusion criteria were eligible to participate in the study:

1. Participants must be at least 18 years of age.
2. Participants must be able to read and comprehend the questionnaire.
3. A diagnosis of diabetes mellitus has been made by a health care provider.
4. Treatment for diabetes mellitus can be with insulin, oral agents, diet, or any combination thereof.

Of the 300 questionnaire packets distributed, only 24 were returned for a response rate of 8%. As a result, the convenience sample for this study (n = 24) consisted of 14

(58.3%) females and 10 (41.7%) males. Their ages ranged from 32 to 78 years (M = 54,63; SD = 13.10). The sample was predominantly African American (95.8%), with one Caucasian female and one Native American male participating in the study.

The majority of the participants (n = 18) were either currently married (n = 7), separated, (n = 1), or divorced (n = 10). Five individuals reported that they were single or never married and one individual did not provide this information. Most of the participants (95.8%) stated that they had children of their own. While 20.8% of the participants (n = 5) graduated from high school, six (25%) reported having a college education. However, of the remaining 12 participants, the level of education completed ranged from fourth to twelfth grade.

Disease duration or the length of time since the participants had been diagnosed with DM was also examined. Of the 22 participants who provided this information, the years of living with DM ranged from 2 to 21 years (M = 10.14; SD = 5.91). When asked about the treatment regime used to manage their DM, more than half (56.5%) reported using oral tablets. Table 1 summarized the type of treatment used by the participants to manage their disease.

Instruments

Two instruments were used to collect data for this study: (1) a demographic data tool (Appendix A) and (2) the PAID scale (Appendix B). The demographic tool was used to collect information concerning the participants' age, gender, race, educational level, as well as the duration of DM, including the treatment type.

Table 1

Type of Diabetic Treatment

Treatment Type	n	%
Diet	2	8.3
Insulin	5	20.8
Tablet	13	54.2
*Combination	3	12.5
Unknown	1	4.2

* Note. * = Both Insulin and Tablet

The PAID is a 20-item measure of diabetes specific problem areas related to living with DM that was developed by the Joslin Diabetes Center in Boston, MA. It measures a wide range of feelings related to living with DM and its treatment. Affective responses include anger, fear, guilt, mood, worry, and depression. Permission to use the PAID scale has been granted by the author (Appendix C).

The PAID has been rescaled since its first introduction for greater ease of interpretation. Its possible standardized scores range from 0 – 100, with higher scores indicating greater emotional distress. This scoring approach is similar to that used by other well-established measures such as Medical Outcomes Study Short Form 36 (Anderson et al., 1997). It is common for measures to be converted from raw scores to a standardized scale to make them easier to administer, understand, and interpret.

There are three steps involved in scoring the PAID:

1. There are five response options available for each PAID question ranging from 0 (not a problem) to 4 (serious problem).
2. Sum the total obtained for all of the 20 PAID items.
3. Multiply this total by 1.25 to produce a total score that ranges from 0 - 100.

Earlier research showed that the PAID had high internal reliability (coefficient alpha = .95) and support for construct validity from factor analyses (Welch et al., 1997). For this study, the PAID questionnaire was used in its entirety, without modifications. The reliability analysis of this instrument showed a Cronbach alpha coefficient of .92. These reliability coefficients provide evidence that the scale is internally consistent and that the scores may be a true representation of the results. According to Polit and Hunger (1995) reliability coefficients range between 0.0 and +1.0, where high numbers express a higher level of internal consistency. Reliability coefficients of .70 or greater is considered acceptable to use.

Human Subjects Considerations

The Grand Valley State University Human Research Review Committee (HRRC) reviewed the research proposal for its human subjects considerations (Appendix D). The proposal was accepted and approved by the HRRC and the Senior Pastor at the data collection site.

Data Collection Procedure

1. Data collection occurred on Sunday when the participants had already assembled at the church in one of the classrooms. All three adult Sunday school groups were approached consecutively on the same day.
2. An introduction by the researcher was given to the potential participants at the beginning of the Sunday School class.

3. The researcher explained the research process in laymen terms. Participants were informed about the duration of the study and were provided with an estimated length of time required for their participation in the study. They were informed that the study is part of a degree requirement by the researcher.
4. The potential participants were informed that their participation is voluntary and their identity and responses would be kept confidential. In addition, the participants were informed that the completed surveys would be kept in a secure location.
5. The participants were informed that they may withdraw from the study at any time.
6. Participants were informed that there are minimal risks to their participation. While participants will not experience any direct benefits from their participation, they were informed that their involvement will facilitate a better understanding of the experience of living with diabetes.
7. Participants were given the opportunity to ask questions about the study or their participation.
8. Once all questions had been answered, questionnaire packets were distributed to all Sunday school adult participants.
9. To maintain confidentiality, the participants were instructed to place all questionnaires (completed or not) in a sealed blue box clearly labeled "Problem Areas in Diabetes questionnaire," located near the main door of the church. This box had a large slot in it on top so that each participant could easily drop the questionnaire packet into it.
10. Participants were informed that return of a questionnaire packet implied consent to participate in the study.
11. Each participant received a copy of both the researcher's name and phone number and

the HRRC chairperson's information as a resource to contact for comments, questions, or complaints related to the research. This information was on a 3 x 5 inch index card attached to each questionnaire packet (Appendix E).

12. Each participant received an index card to provide their address if they desire to receive a summary of the research findings. Participants were instructed to place this card in the sealed box separate from their questionnaire.

The procedure was implemented according to the stated plan. However, only five individuals completed the questionnaire packet. Therefore, the data collection procedure was repeated following the same steps, one month from the initial distribution.

Threats to Validity

There were two major threats to validity that were evaluated for this study, selection and history. Selection of the participants posed a major threat to validity for several reasons. Sociocultural attitudes, beliefs and ideas about research participation exist. The social stigmatism of being identified as a diabetic exists among the African American population (Burrus, Liburd, & Burroughs, 1998). Perhaps the threat of being labeled as such may be a risk for some individuals to participate.

Based on these attitudes, respondent bias was another possible threat on the validity of this study. Because the participants were not randomly selected, having been derived from a convenience sample, created another possible threat on the study's validity.

Historical events may have affected the participants' willingness to participate in this study. The Tuskegee Syphilis Experiment (1932-1972) was a non-therapeutic experimental study where the federal government infected 623 African American males with syphilis and left them untreated. "The shame, anger, and medical racism exhibited by the government using African Americans as human guinea pigs has left a natural tendency of mistrust, apprehension, and willingness to participate in future research studies" (Jones, 1993, p.127).

CHAPTER 4

RESULTS

The purpose of this study was to examine the perceived problem areas of diabetes for adults living with this chronic illness. The research questions posed were: What are the perceived problem areas of diabetes mellitus, and what are the differences of perceived problem areas by type of treatment used? The research hypothesis was those treated with insulin would perceive DM as more problematic and would score significantly higher on the PAID scale than diet or tablet-treated subjects. Data analysis was conducted using the Statistical Package for Social Science (SPSS). The level of significance was $p < .05$ for all statistical procedures.

Perceived Problem Areas

To answer the first research question, descriptive statistics was used to give a picture of the areas that the participants living with DM perceive as problems. According to the PAID scale, items could be scored from 0 (not a problem) to 4 (serious problem).

When examining the 20 specific problem areas, the areas that were perceived as more serious involved food, coping, and managing their disease. The mean item ranks ranged from .88 (discouraged with treatment plan) to 2.00 (food deprivation). Based on these results, living with DM was not perceived as a serious problem.

With the exception of food deprivation, the areas that were most problematic were psychosocial in nature; that is, they evolved around coping-type issues. The PAID item that ranked the lowest concerned discouragement with their DM treatment plan. Table 2 contains a summary of these results.

Table 2

Rating of Problem Areas

Problem Area	No %	Minor %	Serious %	Mean Rank
Food deprivation	16.7	12.5	70.8	2.00
Worrying about complications	8.3	20.8	70.9	1.83
Feeling burned out by DM	20.8	16.7	62.5	1.71
Guilt or anxiety	16.7	20.8	62.5	1.71
Uncomfortable with social situations	16.7	16.7	66.6	1.67
Concerned about food and eating*	16.7	16.7	62.4	1.67
Moods or feelings	4.2	33.3	62.5	1.67
Not accepting DM*	20.8	20.8	54.2	1.67
Unsatisfied with physician	33.3	8.3	58.4	1.46
Angry about DM	33.3	12.5	54.2	1.33
No clear goals for DM care	33.3	12.5	54.2	1.33
Coping with complications	33.3	29.2	37.5	1.33
DM taking up too much time	29.2	33.3	37.5	1.29
Worrying about low blood sugars	20.8	41.7	37.5	1.25
Feeling alone	37.5	20.8	41.7	1.17
Overwhelmed by DM	29.2	33.3	37.5	1.17
Feeling depressed	25.0	37.5	37.5	1.17
Feeling scared	41.7	20.8	37.5	1.08
Lack of family support	37.5	25.0	37.5	1.08
Discouraged with treatment plan	50.0	25.0	25.0	0.88

Note. DM = diabetes mellitus ; * = Missing data.

The top five areas perceived as problematic differed between the various treatment groups. Concern about complications associated with living with DM, food issues, and coping abilities appeared to be consistent factors in diabetes management. Among the diet-controlled treatment participants, the most problematic areas were: 1) concern about food and eating; 2) food deprivation; 3) feeling burned out by DM; 4) guilt or anxiety; and 5) worrying about complications.

The insulin-only using participants perceived somewhat different areas as problematic. They perceived the following areas as most problematic: (1) DM taking up too much time; (2) concerned about food and eating; (3) moods or feelings; (4) coping with complications; and (5) worrying about complications.

The participants using tablets to manage their DM perceived a different set of areas as problematic. For them, these areas were perceived as problematic: 1) worrying about complications; 2) guilt or anxiety; 3) food deprivation; 4) feeling burned out by DM management; and 5) not accepting DM.

Finally, the combination treatment group perceived the following areas as problematic: 1) no clear concrete goals for DM care; 2) feeling burned out by DM management; 3) moods or feelings; 4) food deprivation; and 5) uncomfortable within social situations.

PAID Scoring

The possible standardized scores for the PAID instrument could range from 0 to 100. The actual scores for the participants ranged from 3.75 to 66.25, with a mean PAID score of 35.57 (SD = 17.38). Approximately 83% of the PAID scores were less than 50 suggesting that living with DM may not be perceived as a serious problem among the participants.

Treatment Type Problem Areas

The second research question of this study was: What were the differences in perceived problem areas by treatment type? According to the results, the PAID scores varied by treatment type. In particular, participants who were on an insulin treatment regime had higher mean PAID scores than those who were managed by diet, oral medications, or a combination of diet and medication (Table 3).

Table 3

Paid Scores by Type of Treatment

Treatment Type	n	Mean	SD
Insulin only	5	44.25	18.78
Diet	2	38.12	20.32
Tablet	13	33.84	16.70
Combination	3	32.50	22.81

Note. Missing data for one participant.

Research Hypothesis

It was hypothesized that the insulin treated group would score higher on the PAID scale than the other groups. The unequal group size, in addition to the small number of participants in each group prohibited statistical analysis. Of the 23 participants in the study, there were only five insulin-using participants. Therefore the hypothesis was not tested.

Additional Findings

The data were analyzed further by performing correlation procedures. More specifically, Pearson r correlations were conducted that examined relationships between the PAID scores with the age of the participants and the length of time since diagnosed with DM. The results indicated that no relationship was present between the age of the participants and their PAID scores. A weak, non-significant relationship was noted between the length of diagnosis and their PAID scores ($r = .25$; $p = .27$).

CHAPTER 5

DUSCUSSION

Examination of the perceived problem areas adults with diabetes face was the purpose of this study. There were two research questions posed for this study and one hypothesis. The research questions in the study concerned the perceived problem areas of DM and the differences in perceived problem areas by treatment type used. It was hypothesized that subjects treated with insulin would perceive DM as a more serious problem and would score significantly higher on the PAID scale than diet or tablet-treated individuals. Although the hypothesis was not tested due to insufficient sample sizes, there were some descriptive differences worth discussing.

According to the scoring of the individual PAID items, areas that were given a score of three was considered to be somewhat of a serious problem and a score of four indicated this area to be a serious problem. From the data collected, none of the participants identified any one item with a score of three or four. There were four items where the mean was 2.40 and 2.50. Given these scores, the data suggest that the participants did not perceive DM as a serious problem. In addition, 83% of the participants' scores totaled less than 50 points out of a possible 100, indicating that living with diabetes was not a serious problem for them. However, coping with the chronicity of DM and the effects on their lifestyle may be still an issue for them.

Research that investigates the experience of chronic illness must consider a person's perceptions of what constitutes a meaningful life and what is helpful in attaining that quality. This includes what areas they perceive as problematic too. For the diet-only controlled group, the areas they perceived as most problematic were centered primarily on food. They indicated feeling constantly concerned about food and eating and expressed feelings of deprivation regarding food and meals. This tends to make sense because dietary intake has a direct effect on blood glucose levels. This group also described emotional concerns that living with diabetes causes. Worrying about the future and the possibility of serious complications, as well as feeling burned out by the constant effort needed to manage diabetes, were scored the highest among this group.

The tablet-only treated group tended to struggle with some of the same issues as the diet-only controlled group. While food deprivation and feeling burned out by the constant effort to manage diabetes were two of the same themes that emerged in both the diet-controlled and tablet-only groups, worrying about the future and the possibility of serious complications was identified as the most problematic among participants who managed their own DM with only oral medications.

To a lesser degree, the combination treatment group scored food deprivation as one of the top five areas they struggled with. For them, the area that they perceived and scored as most problematic was not having clear and concrete goals about their diabetes care. This may be explained by a number of reasons, ranging from unclear goals between themselves and their HCPs to a lack of knowledge about this complicated disease.

Clinically, the primary focus of DM is self-care management. Treatment is aimed at keeping blood glucose levels within a targeted range to prevent long-term complications. As a rule, HCPs tend to focus more on clinical data rather than what patients perceive as problematic for them. Perhaps the participants could be trying to please HCPs rather than internally dealing with their own personal issues associated with the chronicity of this disease.

Finally, the insulin-only group struggled with some of the same issues as the other treatment groups. They indicated worrying about and coping with the possibility of serious complications from DM and food deprivation more than the other groups. In addition, they expressed feeling that DM was taking up too much of their mental and physical energy everyday as a serious problem for them. While the insulin-only group scored higher than the other treatment groups, it cannot be said with certainty that those five truly did perceive DM as a serious problem. There could be several possible explanations for these findings. Perhaps the insulin-only group does not perceive diabetes as a serious problem because they have gained expertise in living with such a chronic disease. They may have developed coping skills, which have enabled them to adapt and change. Another possible explanation is that they assume a more active role in self-care as they manage this disease, are motivated to regulate their blood glucose levels, and receive more autonomy and support from their HCPs.

Overall, the majority of studies has been qualitative, and examines how people adapt to and manage DM (Glasgow et al., 1997; Sullivan & Joseph, 1998). While the use of qualitative research into living with DM may give a broader perspective of this phenomenon, it does not provide an ability to compare specific concepts.

For the second research question, comparisons were made to determine the differences in PAID items by the type of treatment used. Descriptive statistics varied by treatment type. Although there was no specific item that was consistently identified by all four-treatment groups, worrying about complications was ranked in the top five responses by three of the four groups.

The hypothesis of this study was not tested. Once the data were collected, the groups were too uneven to calculate differences. The insulin-only group was too small ($n = 5$), thus inhibiting testing of the research hypothesis.

Relationship to Conceptual Framework

King's general systems framework reflects the patient as a personal system within the environment that coexists with other personal systems (Sieloff-Evans, 1991). The findings of this study did not vary from the selected concepts within King's general systems framework. From the data collected, the participants perceived themselves within a social system. Some of them expressed feeling uncomfortable in social situations related to their diabetes care. Others expressed feeling that friends and family members were not supportive of their diabetes management efforts. The data collected supported the framework in that what participants' interpret and comprehend from the perspective point of their self and their reality. The participants' perception of what areas were problematic for them is highly individualized. Their decision-making and treatment behaviors are based on perceptions and attitudes about their disease.

Relationship of Findings to Previous Research

In contrast to previous studies, Welch, Jacobson, and Polonsky (1997) examined the psychometric properties of the PAID scale. The results of that study were similar to the current research findings of this study. The participants of this study were placed in similar groupings according to treatment type used. Food deprivation, worrying about the future and possible serious complications, and coping were similar themes that emerged as most problematic. However, group sizes were larger in that study than the current study, which allowed multiple comparative analyses between the various treatment groups. The results of Welch's study were congruent in that they confirmed specific sources of diabetes distress with which the participants struggled.

Another study conducted by Samuel-Hodge et al. (2000) conveyed similar results. The impact of diabetes expressed in terms of dietary deprivation, worrying, coping, and fear were some of the same issues uncovered as a result of the current study. A study conducted by Hatrick (1998) identified similar problem areas, but not as an overwhelming, encompassing event as Samuel-Hodge et al. (2000). Most of the participants were diet-controlled or used oral medication to control their disease. Perhaps they did not perceive DM as a serious problem because they perceived their disease as less severe.

Strengths and Limitations of the Study

There were two major factors that strengthened this study. The first and by far the most important contributing factor was the predominantly African American sample. This was a major contribution to our overall knowledge of diabetes. While the knowledge gained was not representative of all African Americans, it may raise our awareness from their perspective point. The study also provided useful information that can be used to provide recommendations for nursing practice, education, and future research.

The greatest weakness of this study was the limited number of participants. Participating in the study was voluntary and those who chose not to participate may have yielded higher PAID scores than those that did participate. In addition, a larger sample size may have allowed the researcher to test the hypothesis. It may have also yielded higher PAID scores and detected differences among treatment groups. Another weakness is that the subjects were not randomly selected or randomly assigned to different treatment groups.

Convenience was the easiest sampling method for the investigator. However, other methods are better and may have yielded an unbiased sample. In addition, the results of this study are not generalizable and not typical of a true representation of the African American diabetic population. Perhaps recruiting subjects outside of the church service may have yielded a greater sample size. The participants were more involved in worship services and showed little interest in completing the survey packet as requested.

Implications and Recommendations

In clinical areas that range from inpatient hospitalization to the outpatient setting, mutuality and the sharing of information is an integral part of the nurse-patient relationship and the nursing process. Since the hospital length of stay is limited for individuals with DM, the continuation of care extends to the outpatient setting. Nurses need to concentrate on what areas are problematic for individuals with DM, rather than focus on physiologic measures that determine success. In addition, nurses should be aware of and recognize the difficulty living with DM causes. Worrying about food and the possibility of serious complications are real fears people with DM struggle with everyday. Nurses need to know their clients as individuals and value the expertise they have gained in living with diabetes.

As nurses set mutual goals with clients and develop therapeutic interventions aimed at improving self-care, they can support the management decisions clients make knowing what areas are problematic for them. Nurses can encourage patients' willingness to assume an active role in self-care. Health care providers should explore ambivalence and uncertainty (if they are an issue) and help patients resolve them if patient preferences are to be respected in the overall treatment plan.

Implications for Nurse Administrators

Administrators can use these data to provide and promote continuing education opportunities for staff in both acute care and outpatient settings. Encouraging staff to attend conferences and seminars, read literature, and access information on the World Wide Web increases their knowledge of living with DM. This knowledge will help them recognize and articulate their roles in the care of persons experiencing diabetes in any setting where they access care.

Implications for Nurse Educators

Since there is no cure for DM, education becomes a major focus in DM management. Education is one way to improve glycemic control, quality of life, and save money through patient teaching and proper medical care. The new, lowered diabetes diagnostic criterion established by the American Diabetes Association in 1997 may have significant public health benefits for a person experiencing DM. These new guidelines were established in an effort to increase early detection of DM and reduce long-term complications. Early identification brings a greater likelihood of appropriate treatment early in the disease process.

Nurse educators can focus on early detection and prevention of the disease. This in turn can decrease the economic and emotional burden of DM. Stressing empathy for the patient with DM is another crucial area of nursing education. Valuing what patients have learned as they balance DM is important in the nurse-patient relationship. It cannot be stressed enough that through their experience and experimentation with strategies from managing their illness, patients are often the experts on diabetes self-management. Nurse educators should also include in curricula how to apply behavioral principles in order to modify individual health-impairing behaviors and lifestyles.

Recommendations for Future Research

Living with DM is well documented in the literature. However, the totality of this experience is only partially documented in the literature. Recommendations and implications for future research are great for several reasons. First of all, there have been few nurse-led studies in this area and the cause of Type 2 DM is not well understood. Decreasing morbidity and mortality are good reasons why developing therapeutic relationships early is important. A critical need exists in research into how to most effectively implement knowledge of DM. Additional research is needed to gain knowledge about the disease and discover new interventions.

It is possible the PAID scale probably did not adequately capture the problem areas of DM. It only partially disclosed some of the issues with which diabetics struggle. However, combined with other instruments or qualitative methods, the PAID may be useful to fully understand the scope of problems living with DM causes. Other studies, such as the Behavioral Risk Factor Surveillance System, and Nurses' Health Study II can be expanded to quantify the association between risk factors and the development of a disease such as DM and to link patients with nursing research.

Furthermore, there have been few studies documenting the perceived problem areas of DM among non-white ethnic populations. Obtaining adequate non-white sample populations is crucial to any type of research. While this study supports Welch et al.'s (1997) findings of perceived problem areas for individuals living with DM, it showed the additional need for research in this area among non-white ethnic populations.

It is also recommended that nurse researchers, who are interested in exploring phenomena among African Americans, obtain adequate knowledge beforehand about the population of interest. The environment in which the study is being conducted is crucial to the outcome and so is the timing of data collection. In retrospect, perhaps if the survey would have been distributed at the end of the class session rather than in the beginning, the results may have yielded a greater response rate.

A final recommendation for future investigations that explore chronic conditions would be to use qualitative methods and a nurse theorist in that area of expertise. While King's framework provided the theoretical basis for both qualitative and quantitative studies, perhaps using another theorist that supports the lived experiences of individuals may give us more insight.

APPENDICES

Appendix A

Demographic Data Tool

APPENDIX A

Demographic Tool

Instructions: Please provide an answer for each question. All answers are confidential and will be used for research purposes only. Complete and return both forms and place in the blue box located near the main door of the church. Thanks for your participation in this study.

1. What is your marital status ? Married Single Divorced Widowed Separated

2. What is your gender ? Male Female

3. Do you have any children ? Yes No

4. What is your age ? ________________

5. What is the highest grade completed ? ________________

6. What is your race or ethnic background ? ________________

7. How many years have you had diabetes ? ________________

8. Please circle the letter that describes how your blood sugar levels are treated.

   a. Diet controlled only (not taking pills or insulin)

   b. Insulin only

   c. Tablet-treated only

   d. Insulin and tablet-treated

Thank you for participating in this study.

Appendix B

Problem Areas in Diabetes (PAID) Questionnaire

Appendix B

Problem Areas In Diabetes (PAID) Questionnaire

INSTRUCTIONS: Which of the following diabetes issues are currently a problem for you? Circle the number that gives the best answer for you. Please provide an answer for each question.

	Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem
	▼	▼	▼	▼	▼
1. Not having clear and concrete goals for your diabetes care?	0	1	2	3	4
2. Feeling discouraged with your diabetes treatment plan?	0	1	2	3	4
3. Feeling scared when you think about living with diabetes?	0	1	2	3	4
4. Uncomfortable social situations related to your diabetes care (e.g., people telling you what to eat)?	0	1	2	3	4
5. Feelings of deprivation regarding food and meals?	0	1	2	3	4
6. Feeling depressed when you think about living with diabetes?	0	1	2	3	4
7. Not knowing if your mood or feelings are related to your diabetes?	0	1	2	3	4
8. Feeling overwhelmed by your diabetes?	0	1	2	3	4
9. Worrying about low blood sugar reactions?	0	1	2	3	4
10. Feeling angry when you think about living with diabetes?	0	1	2	3	4
11. Feeling constantly concerned about food and eating?	0	1	2	3	4
12. Worrying about the future and the possibility of serious complications?	0	1	2	3	4
13. Feelings of guilt or anxiety when you get off track with your diabetes management?	0	1	2	3	4
14. Not "accepting" your diabetes?	0	1	2	3	4
15. Feeling unsatisfied with your diabetes physician?	0	1	2	3	4
16. Feeling that diabetes is taking up too much of your mental and physical energy every day?	0	1	2	3	4
17. Feeling alone with your diabetes?	0	1	2	3	4
18. Feeling that your friends and family are not supportive of your diabetes management efforts?	0	1	2	3	4
19. Coping with complications of diabetes?	0	1	2	3	4
20. Feeling "burned out" by the constant effort needed to manage diabetes?	0	1	2	3	4

Appendix C

PAID Scale Authorization

APPENDIX C

Date: Tue, 24 Oct 2000 16:13:48 -0400
From: "Welch, Garry" <Garry.Welch@joslin.harvard.edu>
To: 'vcr' <crumpv@river.it.gvsu.edu>
Subject: RE: PAID scale

Valda,

Thank you for your interest in the PAID. You have permission to use the PAID in your research. I would not recommend that you alter it as you will disconnect yourself from the existing body of research (see ref list) and make your results harder to interpret. You essentially will have a measure based on face validity rather than the range of validity evidence we now have (concurrent, construct, responsiveness, etc). There are no subscales. The total score is generated. A number of factor analytic studies have not supported subscales but strongly support the presence of a general factor and hence use of a total test score. The PAID is freely distributed for clinical and research uses. I would appreciate if you keep me informed of any results that emerge from your work as that helps us track the performance of the measure in different settings. We do now have a clinical software tool (Accu-Chek Interview) that includes the PAID and does the assessment and report generation automatically. Let me know if that would help you.

Good luck

Sincerely

Garry Welch, PhD
Investigator and Assistant Professor
Behavioral and Mental Health Research
Joslin Diabetes Center

Appendix D

Human Subjects Review Committee Approval

APPENDIX D

GRAND VALLEY
STATE UNIVERSITY
1 CAMPUS DRIVE • ALLENDALE, MICHIGAN 49401-9403 • 616/895-6611

May 9, 2001

Valda Tolliver
1425 Plymouth Ave SE
Grand Rapids, MI 49506

RE: Proposal #01-192-H

Dear Valda:

Your proposed project entitled **Perceived Problem Areas for Adults Living with Diabetes** has been reviewed. It has been approved as a study, which is exempt from the regulations by section 46.101 of the Federal Register 46(16):8336, January 26, 1981.

Sincerely,

[redacted]

Paul A. Huizenga, Chair
Human Research Review Committee

Appendix E

Study Contact Information

APPENDIX E

Participant Contact Information

Valda Tolliver, BSN, RN
Grand Valley State University
Kirkhof School of Nursing Graduate Student
242-4819

If you have questions regarding your participation in this study, please contact:

Professor Paul A. Huizenga
Chair, GVSU Human Research Review Committee
(616) 895-2472
or
Dr. Linda D. Scott
Thesis Chairperson, Kirkhof School of Nursing
(616) 336-7171

LIST OF REFERENCES

REFERENCES

Alcozer, F. (2000). Secondary analysis of perceptions and meanings of Type 2 diabetes among Mexican American women. The Diabetes Educator, 26, 785-795.

American Diabetes Association. (1998). Standards of medical care for patients with diabetes mellitus. Diabetes Care [On-line serial], 20. Retrieved on April 9, 1999 from http://www.diabetes.org/Diabetes Care/Supplement 197/s5.htm.

Anderson, R.M., Fitzgerald, J.T., Wisdom, K., Davis, W.K., & Hiss, R.G. (1997). A comparison of global versus disease-specific quality-of-life measures in patients with NIDDM. Diabetes Care, 20, 299-305.

Bramlett, M.H., Kim, J.S., Poon, L.W., & Wright, L.K. (1998). Racial differences in health status and health behaviors of adults. Diabetes Care, 21, 243-250.

Bunting, S.M. (1993). The concept of perception in selected nursing theories. Nursing Science Quartly, 4, 168-174.

Burrus, B.B., Liburd, L.C., & Burroughs, A. (1998). Maximizing participation by Black Americans in population-based diabetes research. Journal of Community Health,23, 15-27.

Conrad, P. (1987). The experience of illness: Recent and new directions. Research in Sociology of Health Care, 6 (Special Issue), 1-31.

Glasgow, R.E., Hampson, S., Strycker, L.A., & Ruggiero, L. (1997). Personal model beliefs and social-environmental barriers related to diabetes self-management. Diabetes Care, 20, 556-561.

Guttmann-Bauman, I., Flaherty, B.P., Strugger, M., & McEvoy, R.C. (1998). Metabolic control and quality of life self-assessment in adolescents with IDDM. Diabetes Care, 21 915-918.

Hartick, G.A. (1998). The meaning of diabetes: Significance for holistic nursing practice. Journal of Holistic Nursing, 16, 76-87.

Hernandez, C.A. (1995). The experience of living with insulin-dependent diabetes: Lessons for the diabetes educator. The Diabetes Educator, 21,(1) 33-37.

Hunt, L.M., Arar, N.H., & Larme, A.C. (1998). Contrasting patient and practitioner perspectives in Type 2 diabetes management. Western Journal of Nursing Research, 20, 656-677.

Jones, J.H. (1993). Bad blood Tuskegee syphilis experiment. Crown Publishers, Location: Publisher New York: Crown Publishers, Inc..

King, I. (1971). A theory for nursing systems, concepts and process. Austin, TX: John Wiley & Sons, Inc.

Kleinman, A. (1978). Concepts and a model for the comparison of medical systems as cultural systems. Social Science and Medicine, 12, (3), 85-93.

Kyngas, H., & Barlow, J. (1995). Diabetes: An adolescent's perspective. Journal of Advanced Nursing, 22, 941-947.

McCord, E.C., & Brandenburg, C. (1995). Beliefs and attitudes of persons with diabetes. Clinical Research and Methods, 27, 267-271.

McDonald, P.E., Tilley, B.C., & Havstad, S.L. (1999). Nurses' perceptions: Issues that arise in caring for patients with diabetes. Journal of Advanced Nursing, 30, 425-430.

Polit, D.F., & Hungler, B.P.(1995). Nursing research principles and methods. (5th. Ed.). Philadelphia: J.B. Lippincott Company.

Pollock, S.E. (1993). Human responses to chronic illness: Physiologic and psychosocial adaptation. Nursing Research, 35, 90-95.

Ruggiero, L., Glasgow, R.E., Dryfoos, J.M., Rossi, J.S., Prochaska, J.O., Orleans, C.T., Prokhorov, A.V., Rossi, S.R., Greene, G.W., Reed, G.R., Kelly, K., Chobanian, L., & Johnson, S. (1997). Diabetes self-management: Self-reported recommendations and patterns in a large population. Diabetes

Care, 20, 568-576.

Ruggiero, L., & Prochaska, J.O. (1993). Readiness for change: Application of the transtheoretical model to diabetes. Diabetes Spectrum, 6,(1), 21-60.

Samuel-Hodge, C.D., Headen, S.W., Skelly, A.H., Ingram, A.F. Keyserling, T.C., Jackson, E.J., Ammerman, A.S., Elasy, T.A. (2000). Influences on day-to day self management of Type 2 diabetics among African American women. Diabetes Care,23 928-933.

Sieloff-Evans, C.L. (1991). Imogene King: A conceptual framework for nursing. Newbury Park, CA: Sage.

Sullivan, E.D., & Joseph, D.H. (1998). Struggling with behavior changes: A special case for clients with diabetes. The Diabetes Educator, 24,(1), 72-77.

The Diabetes Control and Complications Trial Research Group (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. New England Journal of Medicine,14, 977-986.

Trief, P.M., Grant, W., Elbert, K., & Weinstock. (1998). Family environment, glycemic control, and the psychosocial adaptation of adults with diabetes. Diabetes Care, 21, 241-255.

United Kingdom Prospective Diabetes Study Group (1993). Effect of intensive blood-glucose control with Metformin on complications in overweight patients with Type 2 diabetes. (UKPDS 34). Lancet, 352, 854-865.

Welch, G.W., Jacobson, A.M., & Polonsky, W.H. (1997). The problem areas in diabetes scale: An evaluation of its clinical utility. Diabetes Care, 20 760-766.

Williams, G.C., Freedman, Z.R., & Deci, E.L. (1998). Supporting autonomy to motivate patients with diabetes for glucose control. Diabetes Care, 21 1644-1651.

Willoughby, D.F., Kee, C.C., Demi, A., & Parker, V. (2000). Coping and psychosocial adjustment of women with diabetes. Diabetes Educator, 26 105-112.