THE PROCESS BY WHICH PERSONS WITH TYPE 2 DIABETES
MANAGE THEIR DISEASE

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by

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THE PROCESS BY WHICH PERSONS WITH TYPE 2 DIABETES MANAGE THEIR DISEASE

Co-Directors of Dissertation: Margaret O. Doheny; Carol A. Sedlak

The purpose of this study was to describe the process by which persons with type 2 diabetes mellitus self-manage their disease. Diabetes, a chronic disease, requires complex, individual, long-term self-management. Grounded theory methods were used to develop a theoretical framework. Participation criteria included adults over 18 who had a diagnosis of type 2 diabetes mellitus of one to two years and had participated in a Diabetes Self-Management Skills and Training (DSMT) program. A selective sample of 21 participants was recruited from health care facilities in Northeast Ohio.

_Dealing with Type 2 Diabetes_ was identified as the psychosocial problem shared by participants. The psychosocial process for this problem was called _Evolving Diabetes Self_. The psychosocial process of _Evolving Diabetes Self_ encompasses four phases with interrelated categories within each phase that impact the psychosocial problem of _Dealing with Type 2 Diabetes_. The four phases are as follows: (a) _Getting the Diagnosis_, (b) _Realizing Options_, (c) _Making Decisions_, and (d) _Living the Consequences_.

This study provided a theoretical framework for describing the processes by which individuals with type 2 diabetes manage their disease. Type 2 diabetes is a chronic disease requiring complex and lifelong changes. Health care providers are in an integral position to facilitate change from an acute care emphasis to a chronic care framework within organizations (insurance, hospitals, and out-patient departments) as well as to change policies and reimbursement protocols for care of diabetics.
CHAPTER I

INTRODUCTION

The purpose of this study was to discover the process by which persons with type 2 diabetes mellitus self-manage diabetes. Diabetes, a chronic illness, involves self-management. Nurses function in many settings and may encounter persons with diabetes at any point along this process of disease management. Knowing that diabetes is complex, challenging, and may change over time increases understanding of chronic disease management when planning individualized interventions.

Diabetes mellitus, a grouping of diseases with the symptom of high blood glucose, results from defects in insulin action, insulin production, or both (Center for Disease Control [CDC], 2005; American Diabetes Association [ADA], 2009). A variety of metabolic conditions produce this effect, thus the different types of diabetes, yet all share the common symptom of elevated blood glucose. Type 2 diabetes, which comprises 90 to 95% of all cases of diabetes, is the most common form of the disease. Once referred to as adult-onset diabetes, type 2 is strongly associated with obesity and a sedentary lifestyle and is typically associated with increasing age (ADA, 2009; Flegal, Carroll, Ogden, & Johnson, 2002).

Type 2 diabetes is due to insulin resistance that occurs at the cell receptor level and prevents the passage of insulin into the cell. To compensate for rising blood glucose levels, the pancreas secretes additional insulin. Over time, overproduction of insulin by
the pancreas leads to a decrease of the ability of beta cells to produce insulin in the pancreas. Type 2 diabetes may be controlled by diet; by diet and oral medication; by diet, oral medication and insulin; or by diet and insulin. The treatment regime is dependent on the degree of beta cell failure.

**Background and Significance**

Currently, there are 23.6 million persons with diabetes in the United States (U.S.), a number expected to double by 2050 (Boyle et al., 2001; National Institute of Diabetes and Digestive and Kidney Diseases [NIDKD], 2007). Diabetes mellitus is the sixth leading cause of death by disease in the U.S and contributes to higher rates of morbidity such as heart disease, blindness, kidney failure, lower extremity amputations, and other chronic conditions. Nationally, both direct and indirect medical expenditures attributed to diabetes in 2007 were estimated at $174 billion (ADA, 2009; Brandle et al., 2003).

The literature provides evidence that the devastating complications of diabetes can be prevented or reduced through glycemic control (Diabetes Complications and Control Trial [DCCT] Research Group, 1993; DCCT Research Group, 1995; DCCT/Epidemiology of Diabetes Interventions and Complication [EDIC] Study Research Group, 2005; United Kingdom Prospective Diabetes Study [UKPDS] Group, 1998). Both the DCCT and the UKPDS are landmark studies which showed evidence that for every one percentage point reduction in the A1c (a laboratory test that is a weighted measure of the average blood glucose value for the last 3 months), the risk for eye disease, kidney disease, and nerve disease decreased by 35%, and the risk of diabetes-related death decreased by 25% (DCCT, 1993; UKPDS, 1998).
Diabetes, a chronic disease, requires complex individual long-term self-management. These complex self-care tasks involve diet, medications, blood glucose testing, exercise, and symptom management. Self-management requires an awareness of the symptoms for both hypoglycemia and hyperglycemia and knowledge of how to treat each of these conditions. Hypoglycemia is defined as blood glucose below 70 mg/dl and hyperglycemia is defined as blood glucose 180 mg/dl. These complex required skills are not innately known but must be learned in partnership with health professionals through education and counseling (Lawton, Peel, Parry, Araoz, & Douglas, 2005; Nagelkerk, Reick, & Meengs, 2006).

Persons with diabetes are responsible for self-managing their disease. This responsibility involves making decisions for controlling blood glucose that, if left unchecked, may result in the consequence of long-term complications. Long-term complications may include heart disease and stroke, blindness, nephropathy, neuropathy, and peripheral vascular disease with subsequent lower limb amputation. The responsibility of making decisions can be overwhelming, as these decisions impact the health and well-being of persons with diabetes. This is because decisions about self-management are within the control of the persons who have diabetes, not by the health care professionals who prescribe treatment for them. These daily decisions may involve what to eat, levels of physical activity, how stress will or will not be managed, and if or when to perform self-monitoring of blood glucose. The consequences of developing long-range complications and a reduced quality of life are based upon the person’s diabetes self-management decisions (Anderson & Funnell, 2005).
Persons with diabetes manage this complex disease process with many daily decisions that lead to actions. This is done along the person’s life span and can be impacted by many influencing factors. These factors may be identified within the context of the immediate problem, within the process of the life continuum, and represent a critical juncture. Influencing factors may include cognitive abilities, emotional state, cultural background, spiritual beliefs, economic situation, ability to access care, social support, caretaker responsibilities, attitude about the disease, physiological status, and relationships with health care providers (Weiner, 2004). Little is known about how points in time such as a crisis situation may influence self-management decisions. These points in time are called critical junctures. For the purposes of this study, those who have had diabetes type 2 between one and two years were of interest. It had been noted within this researcher’s clinical practice that the diabetes self-management skill set starts to wane at this time frame. The literature is unclear why this skill set wanes during the one to two year period.

Critical junctures are points in time or a crisis situation during which decisions must be made. Critical junctures may be described as the landmarks, transitions, and alterations of how someone with diabetes responds to self-management (Paterson & Thorne, 2000). Strauss and Corbin (1998) described points in time as contingencies, as events that are not planned or anticipated and require some sort of problem solving response for self-care management. Examples of contingencies or critical junctures that may be experienced by persons with diabetes include loss of health insurance, stressful life events that affect both self-management and blood glucose levels, and experiencing a
hypoglycemic episode. These are a few known examples of critical junctures for persons with diabetes; others may be uncovered during data analysis.

Historically diabetes self-management training (DSMT), a framework of care delivery and quality administered by the ADA, has been considered an important component of diabetes management because 95% of all care is done by the patients themselves (Brown, 1988, 1990; Norris, Engelgau, & Venkat-Narayan, 2001; Siminerio et al., 2006). DSMT programs based on the ADA guidelines encompass the following content areas: signs, symptoms, and treatment of both hyperglycemia and hypoglycemia; nutrition; medications and activity; monitoring blood glucose; the action, side effects, precautions of oral and injectable diabetes medication; wearing a diabetes identification band; food pyramid model; carbohydrates portion/serving sizes; low fat food choices; low salt food choices; self-care when sick; problem solving high or low blood glucose levels; activity effects on blood glucose from stress; depression; prevention of long-range complications; foot care; and prevention of cardiovascular risks/complications (Funnell et al., 2009).

The traditional approach regarding diabetes management has been didactic. A healthcare professional instructs the patient about the disease, demonstrates the operation of blood glucose monitors, instructs how to take diabetes medications, and gives instruction on warnings of adverse events such as hypoglycemia. The emphasis has been on knowledge acquisition. The knowledge acquired, however, does not always lead to behavior change and desired outcomes (Krichbaum, Aarestad, & Buethe, 2003; Whittemore, 2003).
Management of Diabetes

Diabetes self-management is a complex process that involves more than 150 skills and a wide range of topics with which persons with diabetes must become competent (Siguroardottir, 2005). Self-management, an important outcome of diabetes management, impacts health status, health care costs, and development of long-range complications. Self-management, one of six elements of the Chronic Care Model (CCM), has been the least studied and is discussed later in this chapter.

Complexity of diabetes self-management. Diabetes is described as a process that involves a complex interplay between social, contextual, and personal factors that evolve over time (Paterson & Thorne, 2000). Currently, expertise in diabetes self-management has been presented along a trajectory starting at the time of diagnosis and is characterized by sequential phases. However, the sequential phases serve to enhance only the understanding of the expressive components of diabetes, while still little is known about how people change as related to their perceptions of self-management and how they make decisions over time.

The sequential phases of DSMT are listed as survival level, intermediate level, and advanced level. The survival phase involves information needed to perform DSMT until further outpatient follow-up appointments are attended. The intermediate phase involves additional information to enhance the diabetes skill set and diabetes care. The advanced level of diabetes care information involves a more involved skill set for diabetes care, such as caring of self while on an insulin pump. The expressive components of diabetes are those that are readily seen and used to evaluate what is
considered good glycemic control. A few examples of expressive components are the A1c laboratory test and blood glucose values from self-monitoring of blood glucose. The question remains as to why some persons with long standing diabetes become unable to sustain the effective self-management skill set and experience worsened glycemic control with the passage of years (Paterson & Thorne, 2000; Weiner, 2004). The complexity involved to acquire expertise in diabetes self-management leaves gaps as to what is known about these processes and how they may be influenced (Paterson & Thorne).

To address the complex nature of diabetes disease management, national standards for diabetes self-management skills and training programs were developed and tested under the auspices of the National Diabetes Advisory Board (NDAB). The standards are designed to promote quality diabetes self-management skills and training programs nationwide. The NDAB, a steering committee made up of many diabetes organizations, developed, tested, and distributed the standards. A Task Force was convened in 2006 to review and revise the standards based on available evidence and expert consensus which were approved in 2007 (Funnell et al., 2009). The interventions are based on the expressive components evident for measuring success with diabetes management. Examples of expressive components are A1c results and blood glucose values that are within range. However, these expressive components of diabetes management do not reflect the perception of self-management experienced by the patient.

*Standards of care for diabetes self-management.* The ADA (2009) devised prevention interventions through a multidisciplinary taskforce and has outlined standards of care and education. Activities for effective diabetes self-management consist of and
require knowledge of the following: (a) when and how to take medication, (b) blood glucose monitoring, (c) diet and diet adjustment, (d) physical activity, (e) foot care, (f) problem solving if the blood glucose is too high or too low, (g) sick day guidelines, and (h) the effects of stress on the diabetes regime, especially the diet. Healthier outcomes, such as symptom control, improved blood glucose values, improved adherence, and fewer complications are achieved through implementation of these diabetes self-management skills (Lenz & Shortridge-Baggett, 2002; Funnell et al., 2009).

The Diabetes Self-Management Skills and Training Guidelines developed by the ADA (2009) are a skill set of interventions taught by expert diabetes professionals within a multidisciplinary setting. Diabetes self-management focuses on educating the patient about the disease, medications, diet, and self-monitoring of blood glucose with a meter. Persons with diabetes may receive these instructions individually or within groups. Current diabetes self-management programs place strong emphasis on knowledge acquisition. The knowledge acquired, however, does not always lead to behavior change (Krichbaum et al., 2003; Funnell et al., 2009). Koro, Bowlin, Bourgeois, and Fedder (2004) found no improvement in glycemic control for persons with type 2 diabetes in their comparison of results for the National Health and Nutrition Examination Survey (NHANES) for the years 1988 to 1994 versus the years 1999 to 2002.

Surveillance System (1995 to 2002) was also analyzed (CDC, 1998, 2003). In the past
decade, the proportion of patients with diabetes who had poor glycemic control, defined
as an A1c greater than 9.0%, showed a non-statistically significant decrease of 3.9%.
Only 42.3% of adults in the NHANES 1999 to 2002 survey had A1c levels at the
American Diabetes Association goal of less than 7%, and of this group 14% had A1c
levels above 10%. Saadine et al. concluded that although there have been national
improvements in diabetes care over the last decade, one in five patients with diabetes still
has poor glycemic control.

The Diabetes Attitudes, Wishes, and Needs (DAWN) Program, an international
collaborative partnership, was initiated in 2001 by Novo Nordisk, the International
Diabetes Federation, and an international expert advisory panel. The expert advisory
panel was comprised of representative spokespersons from medicine, nursing, dietary,
education, and psychology, and addressed advocacy issues related to improving a person-
centered approach to diabetes care (Skovlund & Peyrot, 2005). The DAWN study gave
evidence that reported adherence to recommendations for diet, exercise, medication
taking, glucose testing, and appointment keeping was low. Only one in five persons with
diabetes reported that there was complete adherence with all aspects of their treatment
regime. Several gaps were identified from the DAWN study as related to diabetes self-
management. There was a failure to fully address individual barriers to achieve full health
and quality of life among persons with diabetes. This study suggests that providers of
diabetes health care require an improved understanding of the social and psychological
problems faced by persons with diabetes.
Nursing and chronic care. Nurses are uniquely positioned during this time of transition of health care from that of acute care to chronic care. Nurses who have a specialty in chronic illnesses such as diabetes may be recognized as key providers. Diabetes, as a chronic disease, is associated with many co-morbid conditions that not only affect quality of life for the individual, but are also an economic concern at a national level. Due to the increased rise of diabetes in the U.S. population, payers, providers, and legislators are becoming more aware of the disease of diabetes and its management as a problem (American Nurses Association [ANA], 2003).

Nurses have historically made efforts to improve care and decrease complications through nursing’s scientific knowledge, which has evolved into a holistic patient view. Nurses are positioned, therefore, to practice with emphasis on self-management education for patients and families in many settings and locations. Interdisciplinary collaboration, now considered fundamental to diabetes care delivery, requires nurses at both a basic and advanced practice level to contribute fully on behalf of the person with diabetes (ANA, 2003).

Nursing as part of the integrated team approach. Diabetes self-management is provided within the context of an integrated team approach; nurses are a part of the team. An integrated team is defined as a multidisciplinary group of professionals with a collective combination of expertise in nursing, medical treatment, medical nutrition therapy, teaching skills, and behavioral psychology (Funnell et al., 2009). Nursing is in a unique position to assist patients with lifestyle changes due to a practice based on a holistic view of the person with diabetes as opposed to an adherence approach which
assumes that one size fits all for diabetes interventions. An integrated rather than adherence approach is predicted to improve the success of patients in diabetes self-management programs. The integrated approach incorporates the ability to analyze behavior, attitudes, and physiological data on patients (Whittemore, 2000). Nursing has involvement with individual patients and patient groups to promote health and prevent the progression of an illness. In the event of acute or chronic illness, nursing often is involved with providing instruction about procedures, problem solving behaviors, or total behavior change.

**Barriers to accessing diabetes care.** An identified barrier for individuals not receiving DSMT has been access, especially in communities in which the nearest program may be too distant (Siminerio, Piatt, & Zgibor, 2005). Another barrier may be the traditional manner in which DSMT is prescribed and delivered. Currently, physicians refer patients to hospital-based DSMT programs, which is consistent with the present health delivery system. In the near future, there are growing prospects for online and community-based DSMT programs.

Most ADA-recognized programs, which are hospital-based, are based on the acute care model and most insurers reimburse based on this model. Both diabetes education and medical nutrition therapy are reimbursed by most third-party payers who have governing policies that determine reimbursement; these policies force a “front loading” for the interventions. The current national (United States) format for Diabetes Self-Management Skills and Training (DSMT) involves 10 hours, comprised of a 1-hour individual session and 9 hours of group classes. After the first year, an additional 3 hours of medical
nutrition therapy (MNT) are available but only if a registered dietitian delivers the intervention. Front loading occurs when all of the interventions are given at once at the beginning of care, such as when a patient is first diagnosed. This practice does not take into consideration the chronic nature of the diabetes or changes in condition that may occur over time. The front loading follows the acute care model, which is not congruent for a chronic disease process (Garfield et al., 2003; Powell, Glover, Probst, & Laditka, 2005).

*Grounded Theory*

The grounded theory method is used for this study to discover how persons with diabetes (a chronic disease) of 1 to 2 years make decisions over time about their diabetes self-management. Interventions for diabetes self-management that are given at one time, usually at the time of diagnosis, are often not retained due to the stress of the illness, or if retained, lose effectiveness over time as certain aspects of self-management may be forgotten or ignored.

Grounded theory, a method of inquiry developed by Glaser and Strauss (1967), is both a way to do qualitative research and a way to create inductive theory (Cutcliffe, 2000; Eaves, 2001; Jeon, 2004; Schreiber & Noerager-Stern, 2001). Grounded theory, which stems from sociology, is an approach that makes possible the study of meanings of events for people. This assumes that meanings are shared through a common language and socialization. Through grounded theory research, social processes composed of meanings are clarified and made public (Jeon, 2004; Schreiber & Noerager-Stern, 2001; Strauss, 1987; Strauss & Corbin, 1998). This method was employed to discover the
meaning of events for persons with diabetes as related to their disease management. This method was also used to explore how management of their disease impacts life events or how life events impact the management of the disease over time. Life impacting events may be found within the contextual factors and critical junctures.

This nurse researcher used grounded theory to discover the process by which persons with type 2 diabetes mellitus self-manage diabetes. Grounded theory implies causality with an antecedent and a consequence tied to a process and is a method that will uncover complex and hidden processes (Jeon, 2004; Schreiber & Noerager-Stern, 2001). The research approach, called the paradigm of inquiry, is not a specific method or technique, but a style of doing qualitative analysis. This style of analysis includes distinct features of theoretical sampling, methodological guidelines, constant comparisons, and use of a coding paradigm to ensure conceptual development and density (Strauss & Corbin, 1987). To answer the research question, the grounded theory approach was chosen to uncover not only what is visible, such as diabetes self-management expectations to ensure metabolic control, but also what might not be apparent for persons with diabetes. Persons with diabetes live with the disease in relationship with others (spouse, family, community), in interaction with their environment, within their culture, and in interaction with the health care system. The person with diabetes deals with his or her disease within complex systems. Within grounded theory, symbolic interactionism is used to understand the complex world from the view of those who live it.

In summary, several factors are cited in the literature as the cause for the lack of performance of diabetes self-management and the lack of improved glycemic control
since the inception of diabetes education, now referred to as DSMT. The first factor is the heavy emphasis on knowledge acquisition, which did not translate into behavior change; second is the existence of an acute care system, which is not congruent with a chronic disease process such as diabetes; the third is that existing DSMT programs within the acute care model are not accessible to all persons with diabetes; fourth are contextual factors (examples of these factors for the individual with diabetes may include ethnicity, gender, age, educational level, social class, poverty status, diabetes type and severity, emotional state, and psychological state), which may change over a lifetime; and fifth is the complexity of the diabetes self-management regime. Little is known about how people change as related to their perceptions of self-management and how they make decisions over time. Of interest to this nurse researcher is how persons with the chronic disease of diabetes with a duration of between 1 and 2 years self-manage this complex disease, and which factors influence this process over time,

In clinical encounters, both patients and health professionals bring their own worldview shaped by a variety of psychosocial and cultural factors, some of which are formed in childhood. This worldview bias influences the interpretation, perspective, and understanding of methods of treatment, goals, and expectations for diabetes management. When the worldview of health professionals is not embraced by a patient, he or she is often blamed or labeled as “non-adherent” or “non-compliant.” This brings into question the current worldview of diabetes management held by health professionals (Anderson & Robins, 1998). Kinmonth, Woodstock, Griffin, Spiegel, and Campbell (1998) advised health professionals to take care not to focus on the disease while paying little attention to
the unique experience of each patient. Gillibrand and Flynn (2001) advised the use of more qualitative methods in diabetes research with the goal of producing a more meaningful picture of the issues that are important to the person who suffers from the condition. The grounded theory method, which uncovers social processes over time, is a method that can best uncover the process by which persons with diabetes manage their disease over time.

Research Questions

The following research question guides this study: What is the process by which persons with type 2 diabetes manage their disease? Supporting sub-questions of interest include the following: (a) What are the contextual factors influencing diabetes self-management skills and training (DSMT)? (b) What are the critical junctures of diabetes self-management? (c) What decisions occur at the critical junctures?

Definition of Terms

For the purpose of this study, the following conceptual and operational definitions are provided.

*Diabetes Self-Management Skills and Training (DSMT)*

*Conceptual definition.* The DSMT program consists of a 1-hour individual session with the diabetes nurse or the diabetes dietitian. In addition, a nurse and dietitian team conducts 9 hours of group sessions on diabetes self-management skills. Per Medicare insurance guidelines, these hours are for the lifetime of the participant. Additional hours may be covered for the person with diabetes if there is a change in condition such as the evolution to the use of insulin therapy in which further instruction is needed. Other
insurers usually follow the guidelines set forth by Medicare; however, there are exceptions in which coverage may differ (ADA, 2009; Powell et al., 2005).

All patients have the right to be informed of the clinical standards for care to which they are entitled for optimal management of their diabetes. These clinical standards involve access to a blood glucose monitor, being informed of ADA guidelines for target blood glucose levels, having an A1c laboratory test every 3 to 6 months, having a dilated pupil exam every year, a lipid profile every year, a urine test for micro-albumin every year, a dental exam every 6 months, blood pressure management within the range of 130/80 or below, access to a flu vaccine every year, and a pneumonia vaccine once in a lifetime with a booster every 5 to 7 years (Funnell et al., 2009).

*Operational definition.* All participants for this study completed a DSMT program. Diabetes self-management behaviors were defined as the self-reported performance of behaviors such as self-blood glucose testing, food plan choices, taking medications, exercising, and examining the feet. The physiological clinical indicators tracked in this study are the A1c and blood glucose values.

*A1c Laboratory Test*

*Conceptual definition.* The hemoglobin A1c (A1c) lab value is a weighted average measure of the blood glucose over the past 6 to 8 weeks and is used to measure metabolic control (Bio-Rad Laboratories Diagnostics Group, 2002). The ADA considers the A1c to be the gold standard criterion by which to indicate either improved or worsened metabolic control for persons with diabetes (American College of Endocrinologists/American Association of College of Endocrinologists ([ACE/AACE],
Both the American College of Endocrinologists (ACE) and the American Association of Clinical Endocrinologists (AACE) Diabetes Roadmap and the American Diabetes Association identify A1c as a key target for glycemic control. The key glycemic goal, as identified in the 2009 ADA position statement Standards of Medical Care in Diabetes, is an A1c less than 7%. The ADA further recommends preprandial (before meal) plasma glucose levels of 90 to 130 mg per dl. The goal of therapy in controlling diabetes is to achieve an A1c as close to normal as possible in the absence of hypoglycemia. Glycemic control is best evaluated by a combination of results from A1c levels and self-monitoring of blood glucose. If A1c goals are not met despite reaching before meal goals, the ADA recommends targeting postprandial (after meal) blood glucose levels to be less than 160 mg per dl (ADA, 2009).

Operational definition. To maintain consistency, all A1c lab values were analyzed within the same hospital laboratory at each designated site and should be within a specific range of 3.9 to 6.1% for quality control (Bio-Rad Laboratories Diagnostics Group, 2002). The A1c goal for patients in general is an A1c goal of equal to or less than 7% and without significant hypoglycemia (ADA, 2009). This value was obtained from the patient’s medical record. The A1c is performed every 3 to 6 months based on ADA clinical standards of care (ADA, 2009).

Self-Monitoring of Blood Glucose (SMBG)

Conceptual definition. Blood glucose monitoring is a measurement of glucose (sugar) in the blood. The process of self-monitoring of blood glucose is a measurement performed by the patient using a portable home glucose reflectance meter. A finger stick
to obtain blood is performed by the patient, that is then applied to a blood glucose monitoring strip and a blood glucose value can then be obtained (United States National Library of Medicine & National Institutes of Health, 2006).

*Operational definition.* The range for blood glucose for this study followed the American Diabetes Association (ADA) guidelines, which are 90 to 130 mg/dl prior to meals, equal to or less than 160 mg/dl 2 hours after meals, and 110 to 150 mg/dl at bedtime (2009). These values were obtained from logbooks, through meter memory features in the blood glucose meter, or the patient’s medical record. Patients may perform blood glucose checking several times a day based on their treatment regime.

*Contextual Factors*

*Conceptual definition.* The wider social context is the study of the behavior of human beings within their social environments and is considered a potential strength of grounded theory. Social processes are processes in which the “actor” may be a group, an organization, or society at large (Schreiber & Noerager-Stern, 2001). Contextual and personal factors may exert influence on health knowledge, psychological, material, and structural factors that shape self-care behaviors. Examples of these factors for the individual with diabetes may include ethnicity, gender, age, educational level, social class, poverty status, diabetes type and severity, emotional state, and psychological state. From a systems perspective, it has been suggested that the relationship with one’s health care provider and access to care may be other influencing contextual factors (Schoenberg & Drungle, 2001; Siguroardottir, 2005). Context involves the identification of factors that are relevant to the immediate problem across the life span of persons with diabetes,
which may include cognitive abilities, emotional state, cultural background, spiritual beliefs, economic situation, access to care, social support, caretaker responsibilities, attitude about their disease, and their relationship with health care providers (Weiner, 2004).

Operational definition. Contextual and personal factors may be self-reported during the interview process and from the demographic profile. Examples of these factors for the individual with diabetes may include ethnicity, gender, age, educational level, social class, poverty status, diabetes type and severity, emotional state, and psychological state. By using grounded theory, human behavior may be studied within its social context by uncovering structural processes. Social processes are processes in which the “actor” may be a group, an organization, or society at large (Schreiber & Noerager-Stern, 2001).

Nies and McEwen (2007) described a microscopic versus a macroscopic approach to the care of persons with disease and the resulting interventions planned. In a microscopic approach the individual and perhaps family is examined as related to responses to health and illness. The emphasis is on behavioral responses to individual illness or lifestyle patterns with interventions aimed at modifying behavior through changing of perceptions or belief systems. The macroscopic approach examines interfamily and intercommunity themes in health and illness. There are attempts to delineate the factors that perpetuate the development of illness or an exploration of interventions that promote health. The emphasis in a macroscopic approach is that of social, economic, and environment factors that are precursors to illness or exacerbate existing illness. Interventions may involve addressing social and environmental factors, or social and political action.
The complexity of the health problems of today are better addressed through the emphasis of a collaborative process within the communities in which persons live through community-based participatory research (CBPR). The definition of CBPR is a collaborative process that equitably involves all partners in the research process and recognizes the unique strengths that each brings. The aim of CBPR is to combine knowledge and action to improve the health of the community and eliminate health disparities (Minkler, Glover-Blackwell, Thompson, & Tamir, 2003). The current health system emphasizes episodic and individualized care that has done little to stem the tide of chronic illness to which 70% of American deaths can be attributed (CDC, 2007).

**Critical Junctures**

*Conceptual definition.* Critical junctures are points in time or a crisis situation in which decisions must be made. Critical junctures may be described as the landmarks, transitions, and alterations of how someone with diabetes responds to self-management (Paterson & Thorne, 2000). Strauss and Corbin (1998) described points in time as contingencies (critical junctures). Contingencies are defined as events that are not planned or anticipated and which require some sort of problem solving response to manage them. Examples of contingencies or critical junctures that may be experienced by persons with diabetes may be the following: (a) loss of health insurance that usually covered diabetes medication and blood glucose testing supplies which results in self-pay for these items, (b) stressful life events, and (c) experiencing a hypoglycemic episode and realizing that they have forgotten their blood glucose monitor and concentrated sweets for treatment. If persons with diabetes lose health insurance they may opt to reduce or
eliminate medications and blood glucose testing if they are unable to bear the cost of out-of-pocket expenses. Experiencing stressful life events may affect both self-management and blood glucose levels. Persons with diabetes may eliminate or decrease self-management care temporarily to contend with the stress evoking event and the stress may cause higher than normal blood glucose levels. These are a few known examples of critical junctures for persons with diabetes; others may be uncovered.

*Operational definition.* Critical junctures are points in time or a crisis situation in which decisions must be made by persons with diabetes. These events are not planned or anticipated, but require some sort of problem solving response to manage critical junctures. Currently, expressive components are used to evaluate good glycemic control for diabetes. Expressive components are those measures that are readily available, such as the A1c laboratory test and blood glucose values from self-monitoring of blood glucose. This nurse researcher is interested in identifying events leading to decisions for self-management by persons with type 2 diabetes and decisions, if any, that occurred. A comparison was made between expressive components, such as A1c and blood glucose values, points in time, and the context under which self-management decisions occurred.

*Decisions*

*Conceptual definition.* Decisions involve patterns of responses to situations and treatment changes based on the ability of the person with diabetes to pick up on relevant cues about actual or potential diabetes-related problems. Decisions involve problem detection, appraisal or analysis, and evaluation (Hill-Briggs, 2003; Paterson, 2000).
**Operational definition.** Decisions based on diabetic participants’ responses and actions/choices taken to an unanticipated/anticipated diabetes management event such as hypoglycemia or dietary management.

**Implications of the Study**

The findings of this study will provide nurses and other health care professionals with an increased understanding of the process by which those with diabetes manage their disease. With this knowledge, nurses will be able to assist persons with diabetes to make better individualized self-management decisions. Diabetes self-management is provided within the context of an integrated team approach; nurses are a part of the team. Nurses are in a unique position to assist patients with lifestyle changes due to a practice based on a holistic view. The success of patients in diabetes self-management is predicted to improve with an integrated rather than an adherence approach. The integrated model incorporates the ability to analyze behavior, attitudes, and physiological data on patients (Whittemore, 2000). Nurses have involvement with individual patients and patient groups to promote health and prevent the progression of an illness. In the event of acute or chronic illness, nurses often are involved with providing instruction about procedures, problem solving behaviors, or total behavior change (Paterson & Thorne, 2000).

**Summary**

The literature informs with studies that focus on persons newly diagnosed with diabetes, diabetes studies related by age of persons with diabetes, and by type of diabetes. Most studies mentioned duration of diabetes as demographic information of samples; some studies, however, did not mention diabetes duration.
The focus of this study was on persons with diabetes with the duration between 1 and 2 years to discover how individuals self-manage their disease as indicated by A1c and blood glucose control. The latter were chosen over newly diagnosed persons with diabetes because a decline in the diabetes self-management skill set is noted for some and not for others. This researcher is interested in why this occurs. Expertise in diabetes self-management has been presented along a trajectory starting at the time of diagnosis and is characterized by sequential phases. However, the sequential phases serve to enhance only the understanding of the expressive components of diabetes, while still little is known about how people change as related to their perceptions of self-management and how they make decisions over time. For the purposes of this study, persons who have the diagnosis of type 2 diabetes between one to two years were recruited.

This dissertation represents a first step toward this program of research on diabetes self-management as a chronic illness within the current health care system. The knowledge gained from this study may provide a foundation for future research on this topic. Diabetes, a known complex and challenging disease, requires self-management done by people who have the disease. Currently, little is known about how people change based on their perceptions of diabetes self-management and how they make decisions over time. This study may assist health care professionals, which include nurses, to understand chronic disease management when planning individualized intervention.
CHAPTER II
REVIEW OF RELATED LITERATURE

In this review of literature chapter, the major health care problem of diabetes mellitus is discussed. The current status of diabetes, diabetes self-management and education, and theoretical models used for diabetes self-management are presented.

Diabetes and Current Status

Diabetes is a chronic disease that can be threatening to life and can lead to complications not only of cardiovascular disease, but also blindness, kidney failure, and lower extremity amputation. The following section includes a discussion of the toll of diabetes, a discussion of type 2 diabetes, financial costs of diabetes, and customary educational interventions for diabetes.

The Toll of Diabetes

Diabetes is a major health care problem in the United States (U.S.), affecting approximately 23.6 million people (8% of the U.S. population). Of this total, 17.9 million persons have been diagnosed with diabetes, but the remaining 5.7 million are unaware that they have the disease and therefore are left untreated. In addition, there are approximately 57 million persons with a pre-diabetes state, defined as fasting blood glucose levels between 100-125 mg/dl (ADA, 2008; CDC, 2005; NIDDKS, 2007).
Diabetes is the sixth leading cause of death in the U.S. Even with more sophisticated medications, technologies, and strategies to control the disease, the chronic nature of diabetes requires daily self-care to prevent both short- and long-term complications (NIDDKS, 2007). Those with diabetes have twice the incidence of heart attack or stroke versus those without the disease. People with type 2 diabetes, the most common form of diabetes, are treated as a heart attack equivalent due to the strong link between cardiovascular disease and diabetes (ADA, 2008; Hope Outcomes Prevention Evaluation [HOPE] Investigators Study, 2000; US Preventive Services Task Force, 2004).

In the U.S. the leading cause of adult blindness is attributed to diabetes, accounting for approximately 8% of all new cases. On an annual basis 12,000 to 24,000 persons in the U.S. lose their sight due to diabetes (NIDDKS, 2005). Kidney disease associated with diabetes may progress to end-stage renal disease (ESRD), which may lead to dialysis or kidney transplantation. In 2000, 43% of all new cases of ESRD, approximately 41,000 cases, were the result of diabetes. In the same year, 2000, 183 persons with diabetes underwent daily dialysis or kidney transplantation (NIDDKS). Approximately 60 to 70% of persons with diabetes have mild to severe nerve damage, which may lead to loss of sensation in feet and legs, amputation, silent myocardial infarction, and sudden death (Gordois, Scuffham, Shearer, Oglesby, & Tobian, 2003; Vinik, Maser, Mitchell, & Freeman, 2003). From the years 2000 to 2001, over 82,000 amputations were performed among persons with diabetes, accounting for 60% of the non-traumatic, lower-extremity amputation in the U.S. (Gordois et al.).
Complications of diabetes are preventable. Findings from the Diabetes Complications and Control Trial (DCCT) and the United Kingdom Prospective Diabetes Study (UKPDS) have demonstrated that blood glucose control greatly reduces the risk of developing complications. The DCCT, a 10-year seminal study for type 1 persons with diabetes, was ended early due to the correlation between the reduction in A1c and the development of long-range complications. Those with type 1 diabetes will always be dependent on insulin for survival (CDC, 2005). The DCCT, conducted on individuals with type 1 diabetes, showed evidence that lowering the blood glucose level for an average A1c of 7% or lower reduced the risk of eye disease by 63%, nerve disease by 60%, kidney disease by 54%, and cardiovascular events by 78% (ADA, 2008; DDCT Research Group, 1993, 1995). The UKPDS (1998) demonstrated that aggressive blood glucose management for individuals with type 2 diabetes could reduce the risk of diabetes complications for this group as well. The study results showed evidence of a reduction of complications by 37% for micro-vascular and a reduction of 14% for macro-vascular (Stratton et al., 2000). The evidence indicates that for every percentage point reduction in the A1c, the risk for eye disease, kidney disease, and nerve disease was decreased by 35%, and the risk of diabetes-related death decreased by 25% (DCCT, 1993; UKPDS).

The Epidemiology of Diabetes Interventions and Complications (EDIC) Study Research Group followed 93% of the original DCCT cohort (mean follow up of 17 years) to compare the effects of intensive versus conventional therapy on the long-term incidence of cardiovascular disease (CVD). In this study a CVD causing event is defined
as a nonfatal myocardial-infarction (MI), confirmed angina, need for coronary artery revascularization, stroke, or death. A life-table analysis of the cumulative incidence of a first CVD event demonstrated that intensive management was associated with a 42% reduction in the risk of any CVD event. The results provided evidence that intensive management reduced the incidence of CVD (DCCT/EDIC Study Research Group, 2005).

Type 2 Diabetes Defined

Diabetes mellitus, a grouping of diseases with the symptom of high blood glucose, results from defects in insulin action and/or insulin production (ADA, 2009; CDC, 2005). A variety of metabolic conditions produce this effect, thus the different types of diabetes, yet all share the common symptom of elevated blood glucose. The most common form of diabetes is type 2, which makes up 90 to 95% of all cases of diabetes. Once referred to as adult-onset diabetes, type 2 is strongly associated with obesity and a sedentary lifestyle and is typically associated with increasing age (ADA, 2009; Flegal, Carroll, Ogden, & Johnson, 2002).

Type 2 diabetes is due to insulin resistance that occurs at the cell receptor level and prevents the passage of insulin into the cell. This causes the pancreas to secrete additional insulin to compensate for rising blood glucose levels to maintain blood glucose. Over time, overproduction of insulin by the pancreas leads to a decrease of the ability of beta cells to produce insulin in the pancreas. Type 2 diabetes may be controlled by diet; by diet and oral medication; by diet, oral medication, and insulin; or by diet and insulin. The treatment regime is dependent on the degree of beta cell failure.
In the review of the literature, seminal studies related to type 1 diabetes have been included. To differentiate type 1 versus type 2 diabetes a definition is provided. Type 1 diabetes is caused by an autoimmune response that destroys the insulin producing beta cells of the pancreas. Although type 1 diabetes usually occurs in children, the disease onset can occur at any age. Approximately 5 to 10% of the diabetes population has type 1 diabetes. Those with type 1 diabetes will always be dependent on insulin for survival. The risk factors may be genetic, environmental, or autoimmune (CDC, 2005).

Risk Factors

Individuals over the age of 45 with the following risk factors should be screened for type 2 diabetes: All persons age 45 years old and above, especially with a body mass index (BMI) greater than 25. If the screening blood glucose value for this group is normal but the other criteria remain, a repeat screening is recommended in another 3 years. At least 20% of patients over the age of 65 years have diabetes and the number is expected to grow in the coming decades. Older persons with diabetes have higher rates of premature death, functional disability, and co-morbid conditions than those who do not have diabetes (ADA, 2008).

For persons under 45 years of age, the following risk factors warrant screening for type 2 diabetes: (a) overweight (defined as a BMI over 25), (b) habitual physical inactivity, (c) a first degree relative with diabetes, (d) hypertensive (defined as a blood pressure 140/90 mm/HG or higher), (e) low high density lipoprotein (HDL) cholesterol level (defined as 35 mg/dl or less), (f) a high triglyceride level (defined as more than 250
mg/d), (g) history of vascular disease, (h) other clinical conditions associated with insulin resistance (an example is acanthosis nigicans), and (i) pre-diabetes (ADA, 2008).

Pre-diabetes is a classification that is considered a diabetes risk factor regardless of age. Persons have pre-diabetes if their fasting blood glucose is 100 mg/dl to 125 mg/dl. Normal blood glucose is 99 or lower, while the diagnosis of diabetes is a value of 126 mg/dl or higher (ADA, 2008). Those with pre-diabetes are at risk for development of type 2 diabetes, but disease manifestation may not occur. There is also risk for the development of heart disease and stroke. An estimated 41 million persons are categorized as having pre-diabetes. Of those 20 years of age and over, approximately 1.5 million people are newly diagnosed with diabetes each year (Stern, Williams, & Haffner, 2002; CDC, 2005).

Women may exhibit additional risk factors of polycystic ovarian syndrome (PCOS), babies weighing greater than 9 pounds, or if the diagnosis of gestational diabetes mellitus (GDM) is experienced during the pregnancy. Individuals at risk are those who belong to certain ethnic/racial populations, have a strong family history, and/or are obese. During pregnancy, these women receive treatment to normalize maternal blood glucose and to prevent congenital complications for the fetus. Of the women who experience gestational diabetes, an estimated 5 to 7% will be found to have type 2 diabetes. Of all women who have had gestational diabetes, 20 to 50% have a chance of developing type 2 diabetes within the following 5 to 10 years especially if they are members of a high-risk ethnic group (ADA, 2008). Ethnic and racial groups at greater risk are African Americans, Hispanic/Latino Americans, American Native Indians, some Asian
Americans, and Native Hawaiians and other Pacific Islanders (ADA, 2008; McNeely & Boyko, 2004). Other types of diabetes are caused by infections of the pancreas, surgery of the pancreas, use of steroid drugs, and other illnesses. These account for 1 to 5% of all diagnosed cases of diabetes (CDC, 2005).

Cost of Diabetes

Diabetes is an expensive disease, in both economic cost and cost to human life. The total annual economic cost of diabetes in 2007 for both direct and indirect expenditures was estimated to be $174 billion (ADA, 2008). This includes $116 billion in direct medical expenditures, which include complications and co-morbidities and treatment costs, and $58 billion for indirect costs attributed to disability and mortality. The figure of $174 billion underestimates the burden of diabetes because it does not account for intangibles such as unpaid care-giving or a higher use of health services by persons with diabetes. One out of every 10 health care dollars is spent on diabetes and its complications. One in 5 health care dollars is spent on caring for someone with diagnosed diabetes (ADA, 2008).

In 2007 diabetes-related hospitalizations totaled 24.3 million days. The average cost for hospital inpatient stay due to diabetes is $1,853 and $2,281 due to diabetes-related chronic complications, including neurological, peripheral vascular, cardiovascular, renal, metabolic, and ophthalmic complications. In 2007, $58.3 billion was spent on inpatient care, while $9.9 billion was spent on physician’s office visits for diabetes (ADA, 2008). In 2007, diabetes accounted for 15 million work days absent, 120 million work days with reduced performance, 6 million reduced productivity days, and
107 million work days lost due to unemployment disability attributed to diabetes (ADA, 2008).

In summary, diabetes, which is now in epidemic proportions, is a complex disease process that involves financial and quality of life costs for persons who are affected. Ninety percent of the populations of persons who have diabetes are type 2. Most care of diabetes is done by the person who has the disease, so that attention to the process by which this self-care is done is of value to study. The historical evolution of diabetes education is described in the next section.

Diabetes Self-Management Education

For persons who have diabetes, current treatment interventions should involve diabetes self-management skills and training (DSMT; Kulkarni, 2006); however, this does not always equate with behavior change and improved metabolic control (Krichbaum et al., 2003). Diabetes self-management skills and training involve a complex skill set that affects every aspect of life for a person with diabetes. The grounded theory method is employed to discover the complex processes and daily decisions of diabetes self-management made by those living with the disease. This section addresses the progress of diabetes self-management education in recent decades in the U.S. A review of the literature includes studies on the topic of diabetes self-management.

Historically, DSMT (Norris, Lau, Smith, Schmid, & Engelgau, 2002), a framework of care delivery and quality administered by the American Diabetes Association (ADA), has been considered an important component of diabetes management as 95% of all care is done by patients themselves (Brown, 1988, 1990;
Norris, Engelgau, & Venkat-Narayan, 2001; Siminerio et al., 2006). The traditional approach regarding diabetes management has been didactic. A healthcare professional instructs the patient about the disease, demonstrates the operation of blood glucose monitors, instructs how to take diabetes medications; and gives instruction on warnings of an adverse event such as hypoglycemia. The emphasis has been on knowledge acquisition. The knowledge acquired, however, does not always lead to behavior change and desired outcomes (Krichbaum et al., 2003; Whittemore, 2000).

To evaluate the progress of diabetes care in recent decades in the U.S., Saadine et al. (2006) analyzed data from the third National Health and Nutrition Examination Survey (NHANES III) from 1988 to 1994 and the more recent NHANES data from 1999 to 2002. Data from the Behavioral Risk Surveillance System (1995 to 2002) were also analyzed (CDC, 1998, 2003). In the past decade, the proportion of patients with diabetes who had poor glycemic control, defined as an A1c greater than 9%, showed a non-statistically significant decrease of 3.9%. Only 42.3% of adults in the NHANES 1999 to 2002 survey had A1c levels at the American Diabetes Association goal of less than 7% and of this group 14% had A1c levels above 10%. The conclusion reached was that although national improvements in diabetes care have occurred over the last decade, one in five patients with diabetes still has poor glycemic control (Saadine et al.).

The Diabetes Attitudes, Wishes, and Needs (DAWN) Program, an international collaborative partnership, was initiated in 2001 by Novo Nordisk, the International Diabetes Federation, and an international expert advisory panel. The expert advisory panel for this study was comprised of representative spokespersons from medicine,
nursing, dietary, education, and psychology who pooled strategies that would improve a person-centered approach to diabetes care (Skovlund & Peyrot, 2005). This study provided evidence that reported adherence to recommendations for diet, exercise, medication taking, glucose testing, and appointment keeping was low. Only one in five persons with diabetes reported that there was complete adherence with all aspects of their treatment regime. The DAWN study identified several gaps as related to diabetes self-management. There is a failure to fully address individual barriers to achieve full health and quality of life among persons with diabetes. The study suggested that providers of diabetes health care require an improved understanding of social and psychological problems that are faced by persons with diabetes.

**Self-Management**

A range of competencies are needed for participants who have type 2 diabetes in order to have control of their disease. These competencies are in the form of diabetes self-management skills and training. Providing both diabetes education and self-management skills and training is not new for health professionals; however, optimal delivery of these interventions has been a struggle (Cooper, Booth, & Gill, 2003). The next section provides an historical evolution of the literature on diabetes education and self-management skills and training. The historical evolution is divided by years of occurrence.

**Before 1990.** Beginning in 1988, several meta-analyses emerged on the topic of diabetes education and diabetes self-management skills and training (Brown, 1988, 1990, 1992, 1999; Fain, Nettles, Funnell, & Charron, 1999; Jack et al., 2006; Norris et al.,
Prior to 1990, studies focused on educational strategies to increase knowledge; however, there was no minority involvement or any comparison ethnic groups (Brown, 1999; Glasgow, 1999; Glasgow, Ruggiero, Eakin, Dryfoos, & Chobanian, 1997; Glasgow, Strycher, Hampson, & Ruggiero, 1997; Peyrot, 1999). Studies were conducted only in outpatient hospital program sites with little or no description of the intervention, which could have ranged in length from 5 minutes to 36 hours. There was no comprehensive curriculum, a dietary focus was missing, and follow-up appointments for booster education were rare (Brown, 1999; Glasgow, 1999; Glasgow & Osteen, 1992; Glasgow, Ruggiero, et al., 1997; McCaul, Glasgow, & Schafer, 1987; Rose, Fliege, Hilderbrandt, Schirop, & Klapp, 2002; Rosenstock, 1985).

Most of the early studies done in the 1980s regarding diabetes self-management lacked a theoretical framework (DCCT, 1993; Fain et al., 1999). Only half of the research designs listed as experimental had a control group and the remaining studies were quasi-experimental. Other studies were one group pre/post test. All of the studies involved manipulation of an independent variable, the treatment variable. Random assignment and controls, however, were absent (Brown, 1990, 1992, 1999; Day, 2000; Day, Bodmer, & Dunn, 1996; DCCT, 1993, 1995; Fain et al., 1999; Glasgow, 1999; Glasgow, Ruggiero, et al., 1997, Peyrot, 1999; Rose et al., 2002). The duration of diabetes, if mentioned, is included as a range for demographic information for targeted samples.

1990 to 1999. The studies after 1990 focused on knowledge and behavior strategies involved culturally diverse ethnic groups. Studies provided better descriptions of interventions, although the studies were still not sufficient for replication. Program
length with a comprehensive curriculum was from 3 hours to 90 hours with occasional
follow up from 2 to 36 months after initial interventions. A few had separate programs on
diet, foot care, and self-monitoring of blood glucose (Brown, 1999; Day, 2000; Day et al.,
1996; DCCT, 1993; Dunn, Beeney, Hoskins, & Tuttle, 1990; Fain et al., 1999; Glasgow,
1999; Glasgow, Ruggiero, et al., 1997; Peyrot, 1999; Rose et al., 2002). The duration of
diabetes, if mentioned, is included as a range for demographic information for targeted
samples.

Overall findings of meta-ethnographic studies regarding the lived experience of
diabetes were that “learning to balance” is integral to the adaptation and management of
diabetes (Paterson, Thorn, & Dewis, 1998). The “learning to balance” was described as
two phases: (a) deciding to assume control and (b) assuming control. The second phase of
assuming control is considered critical, but this decision remains dynamic and may
change as related to life events and duration of diabetes. The studies, obtained from
computerized searches of six databases, included phenomenology, ethnography,
exploratory, grounded theory, focus groups, and case studies. The majority of the studies
had samples comprised of insulin dependent Caucasian females who were type 1.

In Canada, Ellison and Rayman (1998) studied self-management among 17
women with type 2 diabetes who were considered to be exemplar. Focus groups were
used with the participants who ranged between 46 to 69 years of age. The sample was
diverse from a cultural, occupational, and educational perspective. Diabetes duration
ranged from 1 to 35 years. Four structured focus groups generated data. The interviews
were taped, constant comparison used, and diabetes specialists conducted a review. The
authors described a developmental process of self-management with three distinct phases: (a) management as rules, (b) management as work, and (c) management as living. The progression from rules to work occurred only after there was conceptualization of diabetes as work. The progression to living with diabetes did not occur until there was recognition of themselves as successful managers.

“Transformation” was described by participants as a “new awareness of what you could be,” “a light dawning that things could be different,” or a “coming to terms with me as a diabetic and me as the person I wish to be.” The transformations would often result in significant changes in values, beliefs, assumptions, and/or the practices in living with diabetes. The construct of “transformation” was uncovered by Paterson, Thorne, Crawford, and Tarko (1999) in their grounded theory study related to self-care decisions and type 1 diabetes of 15 to 41 years duration. The authors described transformation as an evolving process, not as a stage or element, so that persons with diabetes should not be classified as either transformed or not transformed (Paterson et al., 1999; Paterson & Thorne, 2000). The study involved only those persons with type 1 diabetes, which is a different experience from those with type 2 diabetes.

Several meta-analyses of randomized trials for diabetes self-management education (DSME) and type 2 diabetes were completed. A total of 72 studies were derived from 84 articles with the conclusion that in the “short term” DSME supports the positive achievement of positive clinical outcomes. Duration of diabetes was not addressed in this meta-review (Norris et al., 2001). In 2002, Norris and colleagues published an analysis of 31 studies related to the effects of DSME on A1c. Results
indicated a short-term improvement of the A1c, but this was not sustainable, with an increased A1c experienced within 1 to 3 months (Norris et al., 2002).

Norris and colleagues (2001) published a meta-analysis for the literature on DSMT from 1980 through 1999. In this meta-analysis the literature that was reviewed showed that most studies had internal validity threatened. Examples of threatened internal validity were a lack of a blinded assessor, high attrition, contamination of the control group, unintended co-interventions, response-set bias, deficient reliability and validity of self-care and dietary instruments. Additionally, inadequate description of the study interventions and participants, lack of detail on allocation concealment, and lack of documentation of behavioral theories for basing interventions were noted. A few studies demonstrated the effectiveness of self-management training on cardiovascular disease related events and mortality. Duration of diabetes is not mentioned in this meta-analysis (Norris et al.).

In the 1990s, research studies evolved to include more theoretical frameworks as diabetes education moved from pure didactic to a study of empowerment models that had emerged. It was apparent that factors other than knowledge were needed to achieve long-term behavior change, which accounts for the lack of a relationship between knowledge and glycemic control (Norris et al., 2001).

four components: (a) problem solving skill, (b) problem solving orientation, (c) disease specific knowledge, and (d) transfer of past experience. A search was conducted from databases from the years 1980 to 2001 using the words *problem solving* and *decision making*. Of the 21 studies that met inclusion criteria, only 11 studies reported assessment of problem solving and the relationship with disease self-management. The meta-review concluded that clear relations between problem solving ability and diabetes management have not been established. A critical limitation identified for affecting the relationship between problem solving and diabetes self-management is a lack of a chronic disease framework within the context of disease self-management. The duration of diabetes in this meta-review was 8 to 18 years.

Health care professionals should ensure patients’ full understanding regarding the diagnosis of diabetes and that the diagnosis encompasses self-care as part of the treatment intervention. A study done in Scotland by Parry, Peel, Douglas, and Lawton (2004) examined how a new diagnosis of diabetes was perceived by a sample of 40 persons with type 2 diabetes. Results included a perception that physicians were unwilling to both deliver and confirm the diagnosis. A second appointment needed for confirmatory lab work of fasting blood glucose levels was difficult to obtain, thus delaying the start of lifestyle interventions. Patients perceived the long wait for appointments as meaning they were not at risk for the disease or that the diabetes was mild. This study involved only newly diagnosed patients with diabetes and not the perceptions of those with diabetes of longer duration.
Conflicts in problem solving with diabetes from exemplar groups and those with poor glycemic control were described in a study in Denmark by Zoffmann and Kirkevold (2005). In addition, the perspective of health care providers was sought regarding patient interactions. The main conflict uncovered was that of separating life and the diabetes disease process. Problem solving approaches that were uncovered involved the following: (a) A compliance-expecting approach left the pattern unchanged, (b) a failure-expecting approach dead-locked the pattern, and (c) a mutuality-expecting approach appeared to neutralize the conflict. This grounded theory study involved 11 patients with duration of diabetes under one year and health professionals, solely nurses. The nurses were not diabetes care specialists but were included if they had one year of experience in a specialized diabetes unit. The conventional individual and group interventions for the hospital for diabetes self-management were not made known.

Preventative care among minority patients with diabetes was the focus of the review performed by Kirk et al. (2005). Of the 36 studies that met the search criteria, the majority of the data indicated that the rates of diabetes monitoring for these preventative measures were low regardless of the population being studied. This meta-review involved studies from 1993 to 2003 with the inclusion criteria that reported data on specific ethnic minorities as related to accepted diabetes-related care prevention measures, such as dilated pupil examination, foot examinations, taking of lipid profiles, nephropathy assessment, and influenza vaccination. Among the ethnicity studies, the major differences reported were lower rates for eye examination, influenza vaccination, and lipid profile testing among Hispanics and African Americans as compared to non-
Hispanic whites. It is concluded that despite the availability of evidence-based guidelines, rates of diabetes preventative care are low, particularly among some measures in ethnic minority groups. The duration of diabetes was not mentioned in this review of diabetes-related studies.

In order to achieve an A1c of 7% or less, health professionals often burdened patients with complex treatment regimes which resulted in hypoglycemia, weight gain, and costs with uncertain benefits. This was found in randomized studies of persons with type 2 diabetes which suggested that healthy lifestyles, preventative care, and cardiovascular risk reduction be prioritized in terms of patient context as well as clinical context. The authors defined patient context as the ability by patients to cope clinically, psychologically, and financially (Montori & Fernandez-Balsells, 2009).

Through the review of the literature on diabetes self-management, it can be concluded that behavior change strategies were more effective than didactic when combined with medication adjustment and the reinforcement of educational messages. Researchers questioned the effectiveness of traditional interventions for diabetes self-management. In a meta-analysis of 73 published studies, Brown (1992) indicated that glycemic control improved only temporarily between 1 and 6 months after patient education. A study by Yong, Power, and Gill (2002) involving re-education, dietary advice, and insulin dose adjustment for persons with type 1 diabetes indicated an improvement in glycemic control for 60% of patient participants, while 40% indicated deterioration of the A1C. Researchers concluded that the paternalistic approaches that expect compliance and adherence should be avoided as this tends to deprive patients of
initiative (Anderson et al., 1995; Glasgow & Anderson, 1999). Other studies focused only on persons with type 1 diabetes, who may have experiences different from those with type 2 diabetes, and some focused only on the experiences of an exemplar group of persons with diabetes as opposed to those with poor glycemic control (Paterson & Thorne, 2000).

Several studies for diabetes self-management have been done in countries other than the United States, which operates under a different health care system. The United States has systemized interventions for diabetes self-management (DSMT) through the American Diabetes Association (ADA) Standards of Care; whereas in the studies mentioned from other countries, the DSMT interventions are not made known. Studies related to diabetes education and diabetes self-management have informed on persons newly diagnosed with diabetes, diabetes studies related by age, and by type of diabetes. Most studies mentioned duration of diabetes as part of demographic information of samples, and some studies do not mention duration.

Quality of life (QOL) outcomes following diabetes self-management was the subject of a meta-analysis done by Cochran and Conn (2008) which involved twenty studies of at least five participants with either type 1 or 2 diabetes. One study was published in 1991, but the rest were published after the year 2000. Interventions for diabetes self-management varied greatly; two studies offered 15-minute sessions, while four studies offered sessions that lasted 3 hours. Most studies offered interventions in increments of 4 months or less, while some spanned 4 years. Interventions based on a theoretical framework were reported in only three studies; seven studies used individual
appointments for interventions, and thirteen used group format. Over half of the studies delivered interventions using didactic and discussion methods, while only two studies provided tailored individual interventions. Few of the studies represented minorities, who have the greatest prevalence of diabetes within their populations. The authors concluded that a statistically significant effect size for treatment groups supported the hypothesis that interventions to improve DSMT increased QOL. There was no improved QOL for control groups.

Metabolic control outcomes (measured by the A1c) as affected by health behavior change interventions were the subject of a meta-analysis involving type 1 diabetics (Conn, Hafdahl, LeMaster, Rupper, Cochran, et al., 2008). Twenty-four studies that were included between 1970 and 2005 had at least five participants, provided a health behavior intervention, and measured the A1c after the intervention was completed. Studies involved single group or two group comparison with enough data to calculate metabolic control effect size. These studies were included in the meta-analysis to contribute to synthesis of findings; however, due to small study size, there was a lack of statistical power to detect treatment effects. The authors concluded that there was a statistically significant improvement of metabolic control (based on the A1c) with diverse interventions. However, even after accounting for effect size, the studies indicated that there was wide variation among prescribed interventions for clinical significance. The authors advised further research to develop interventions which might result in improved health behaviors among persons with type 1 diabetes that would lead to improved metabolic control.
Future research. Future research that focuses on a more holistic view to identify predictors and other correlates of glycemic control was recommended because knowledge acquisition by itself is not sufficient. Similar results were noted in the review of chronic diseases. To obtain this holistic view, qualitative studies are suggested (Norris et al., 2001). In addition, the Chronic Care Model (CCM), a new model of care as opposed to the traditional acute care model, offers a new paradigm for care delivery for chronic diseases. Diabetes, as a chronic disease, involves self-management. Self-management, one of six elements of the CCM, is the least studied. It has been observed by this nurse researcher that the diabetes skill sets wanes between the 1 and 2 year time frame. The least studied element of the CCM, self-management, was studied for persons with type 2 diabetes within this time frame.

There is interest in the study of persons with diabetes of both exemplar glycemic control as well as those with poor glycemic control, as still little is known about how people change as related to their perceptions of self-management and how they make decisions over time. Exemplar is defined as a participant who had A1c and blood glucose values in range. Exemplars provided insight regarding the ability to integrate the “normal self” with the “diabetes self.” Type 2 persons with diabetes were included to uncover similarities and differences of their perceptions of DSMT. Those with a diagnosis between 1 to 2 years duration opposed to the newly diagnosed were studied to uncover the contextual factors, the critical junctures, and decisions made over time related to for DSMT.
Contextual Factors

The wider social context is the study of the behavior of human beings within their social environments and is considered a potential strength of grounded theory. Social processes are processes in which the “actor” may be a group, an organization, or society at large (Schreiber & Noerager-Stern, 2001). Contextual and personal factors may exert influence on health knowledge, psychological, material, and structural factors that shape self-care behaviors. Examples of these factors are ethnicity, gender, age, educational level, social class, poverty status, diabetes type and severity, emotional state; and psychological state. From a systems perspective, it has been suggested that the relationship with one’s health care provider and access to care may be other influencing contextual factors (Schoenberg & Drungle, 2001; Siguroardottir, 2005). Contextual factors may influence the performance of diabetes self-management.

Patients’ perspective in their attempts to adapt to their disease of diabetes was the focus of a grounded theory study conducted by Nyhlin (1990). The author obtained data from 48 interviews of individuals with type 1 insulin-dependent diabetes. This sample was grouped into three clusters: (a) 21 insulin–dependent participants considered well adapted and without vascular complications, (b) 17 participants with complications, and (c) 10 newly diagnosed participants. Except for the cluster descriptions, duration of diabetes is not mentioned. Specific findings were not reported for the comparative analyses that were conducted both within and between groups, but conclusions were made. The first is that within the literature there are major weaknesses of treating diabetes as a medical disturbance versus patients’ perspective of medically caring for
themselves while considering social and psychological issues. The second finding is that there was emphasis within the interviews on the difficulties, fears, and anxieties related to the health care system. The third is the need for the consideration of context of the lives of persons with diabetes by the health care system (Nyhlin, 1990).

A significant oversight in the study of chronic illness is the failure to consider the influence of personal and social context (Paterson, 2000). This may emanate from a positivist view as a result of a researcher’s perspective of chronic illness as something that may be studied apart from contextual factors. Whittemore and Roy (2002) described self-management as integral to living with chronic illness, with a recognition that there are behaviors to be learned to accomplish daily management. They pointed out, however, that the adaptation to chronic illness does not identify self-management behaviors as an important influence. Instead, self-management behaviors are considered to be contextual stimuli that influence the patient’s perception of the impact of the illness. An example was given in a Denmark study by Zoffmann and Kirkevold (2005) in which the core category of keeping life and disease apart was identified. Although both patients and professionals had the goal of improved glycemic control, each gave opposing priorities as to how to achieve this. Patients and professionals listed different priorities regarding the problem solving process and decisions for diabetes self-management as relates to life context.

In clinical encounters both patients and health professionals bring their own worldview. Worldview is defined as the family, community, organizations, and society that surround individuals, which is an influence that assists individuals to interpret the
meaning and understanding of their world (Schrieber & Noerager-Stern, 2001).

Worldview is a way of knowing that involves preconceived assumptions, ideas, and judgments about diabetes management and treatment. Contextual factors, however, reside only with patients who make decisions about diabetes self-management based on their own life situations. The context may include the health care system and the relationships that patients have with health care providers.

Worldview is shaped by a variety of psychosocial and cultural factors, some of which are shaped in childhood. This interpretation and perspective influences the understanding, methods of treatment, goals, and expectations of diabetes management. When the worldview of health professionals is not embraced by a patient, he or she is often blamed or labeled as “non-adherent” or “non-compliant.” This brings into question the current worldview of diabetes management held by health professionals (Anderson & Robins, 1998). Kinmonth and colleagues advised health professionals not to focus solely on the disease and to pay attention to the unique experience of each patient (Kinmonth et al., 1998). Gillibrand and Flynn (2001) advised the use of more qualitative methods in diabetes research with the goal of producing a more meaningful picture of the issues that are important to the person who suffers from the condition.

In the past, the trend has been to describe living with a chronic illness (such as diabetes) as a burden. Findings derived from qualitative research regarding diabetes as a chronic illness experience provide a basis on which clinical wisdom can be constructed. The knowledge obtained may assist health professionals to understand their patients and
to appreciate the embedded complexities of the chronic illness experience (Thorne & Paterson, 1998).

In this study there is an interest as to why some persons with diabetes of duration of 1 to 2 years remain unable to sustain the effective self-management skill set and experience worsened glycemic control with the passage of years (Paterson & Thorne, 2000; Weiner, 2004). The complexity involved to acquire expertise in diabetes self-management leaves gaps as to what is known about these processes and how best to influence these processes (Paterson & Thorne). Still little is known about how people change as related to their perceptions of self-management and how they make decisions over time. Contextual factors may influence the performance of diabetes self-management.

Critical Junctures

Critical junctures are points in time or a crisis situation in which decisions must be made. Currently, expertise in diabetes self-management has been presented along a trajectory starting at the time of diagnosis and is characterized by sequential phases (Paterson & Thorne, 2000). However, the sequential phases serve to enhance only the understanding of the expressive components of diabetes, while still little is known about how people change as related to their perceptions of self-management and how they make decisions over time. The expressive components of diabetes are those that are readily seen and used to evaluate what is considered good glycemic control (Paterson & Thorne, 2000). A few examples of expressive components are the A1c laboratory test and blood glucose values from self-monitoring of blood glucose. The literature informs with
Another term often used to describe critical junctures is contingencies (Strauss & Corbin, 1998). Contingencies are defined as points in time and are events that are not planned or anticipated but which require some sort of problem solving response to manage them. The following are examples of contingencies or critical junctures that may be experienced by persons with diabetes: (a) loss of health insurance that usually covered diabetes medication and blood glucose testing supplies which results in self-pay for these items, (b) stressful life events, and (c) experiencing a hypoglycemic episode and realizing that they have forgotten their blood glucose monitor and concentrated sweets for treatment. If persons with diabetes lose health insurance they may opt to reduce or eliminate medications and blood glucose testing if they are unable to pay the cost of out-of-pocket expenses. Experiencing stressful life events may affect both self-management and blood glucose levels. Persons with diabetes may eliminate or decrease self-management care temporarily to contend with the stress evoking event and the stress may cause higher than normal blood glucose levels. These are a few known examples of critical junctures for persons with diabetes.

Paterson et al. (1998) alluded to critical junctures; a meta-study involving 158 research reports related to chronic illness. Findings were incorporated from meta-theory, meta-methods, and meta-data analysis. The inclusion criteria for the studies were (a) qualitative research in which investigators focused on the insider perspective of living with a chronic disease, (b) the sample participants for each study had a chronic illness
diagnosis, (c) the research studies were published in English between 1980 and 1996, (d) there was enough of a data trail to demonstrate data analysis, and (e) demographics of the participants were included.

The conceptual and organizing themes varied between the studies from the 1980s as compared to the 1990s. By studying chronic illness from the “insider perspective,” the authors concluded that health care professionals should target interventions based on needs of participants, rather than the health care professionals’ expectations of participants. The authors discovered other findings: (a) Chronically ill persons are idealized and presented as strong, powerful and competent; (b) the relationship between participants and health care providers is that of a partnership with a recognition of participants as having expertise for their illness; (c) there is recognition that managing a chronic illness can be overwhelming; and (d) individuals who have a chronic illness may differ in ability to manage their illness at various times or points in their lives (Paterson et al., 1998).

For the purposes of this study, persons who have a diagnosis of type 2 diabetes between one and two years were recruited. The literature for diabetes education and diabetes self-management has centered on persons newly diagnosed with diabetes, diabetes studies related by age, and by type of diabetes. Most studies mentioned duration of diabetes as demographic information of samples, and some studies did not mention duration. It was of interest to focus on persons with diabetes with the duration of between 1 and 2 years to discover how they self-manage their disease. The latter category was chosen over newly diagnosed persons with diabetes because of the decline in the diabetes
self-management skill set noted for some and not for others. This study focused on those who were in poor metabolic control as well as those who were considered exemplar, which was identified based on the A1c value.

**Decision Making**

Diabetes, as a chronic disease, does not have a cure and persons with this disease require a regime over their lifetime for both disease and symptom management. Diabetes self-management is complex and the medical regimes can be intrusive to the lives of persons with diabetes. Problem solving, which involves decision making, is a process in which there is a translation of self-management techniques into actual self-managing (Hills-Briggs, 2003). Learning how persons with diabetes make decisions over time can help in understanding the complex nature of the chronic disease self-management of diabetes. Maintaining glycemic control through intensive diabetes self-management is a challenge and involves four behaviors: (a) self-monitoring of blood glucose (SMBG), (b) a food plan, (c) physical activity plan, and (d) medication. There is a relationship among these four behaviors that functions like a self-regulation process with the SMBG as the error detector that guides the controlling response. The mastery of these four behaviors is crucial to self-management decision making and enacting corrective responses. An example is not only being able to perform the SMBG but then to use the data to make a decision regarding treatment. This may involve adjusting the time or amount of medication, the amount or types of food chosen, or the adjustment of the time or amount of physical activity (Hills-Briggs, 2003).
Bonnet, Gagnayre, and Ivernois (1998) did a survey study of diabetes educators regarding patient learning and mastery. The authors concluded that the key challenges of chronic disease self-management are moving beyond the transmission of information and the instillation of lasting and reliable behaviors. The highest rate of persisting errors and the lowest levels of mastery were for self-management skills that required decisions to solve problems that had multiple variables. Teaching of practical hands-on skills seemed easier and produced fewer errors. Diabetes educators confirmed that mastering a reasoning or decision making process required more effort than merely learning factual information or technical procedures (Bonnet et al.).

Diabetes, a complex and challenging chronic disease, requires understanding and mastery of self-management information to make effective decisions to solve problems related to diabetes care and glycemic control. Still, little is known about how people change as related to their perceptions of self-management and how they make decisions over time.

The literature on diabetes self-management have shown several areas where gaps are present and give recommendations for future research (Norris et al., 2001). The first is to identify personal behavior change measures more accurately to include context of living with diabetes, quality of life, satisfaction, and expanded physiological parameters. The second area is to acquire knowledge of which program strategies produce change in the psychosocial factors that result in behavior change. Examples are contracting, coaching, goal setting, and participation in groups versus attendance at individual appointments. The third is to study health-based educational and community based
model. The last identified gap is the need to borrow appropriate outcomes from other chronic disease management models believed to be effective (Norris et al., 2001, 2002; Polonsky, 2000; Rapley, 1991).

Other important variables to consider include reporting on the characteristics of the target population, recruitment methods and representativeness of the participants, and collecting measures of self-efficacy and patient-provider interaction (Glasgow & Osteen, 1992; Hampson, Glasgow, & Foster, 1995; Skelly, Marshall, Haughey, Davis, & Dunford, 1995). The intent of this study is to uncover personal behavior change within the context of living with the disease of diabetes and decisions made for self-management. The physiological measures of A1c and blood glucose levels are tracked to make comparisons between chosen behavior and glycemic control. The element of self-management taken from the Chronic Illness Model (CCM) is addressed as it is considered new and the least studied element. This leads to a discussion of some of the theoretical approaches on which diabetes self-management has been researched.

The “process of transitions” created by individuals when faced with changes in their health or illness status was described by Meleis, Sawyer, Im, Hilfinger-Messias, and Schumacher (2000). The authors explained that participants tend to be more vulnerable to risks which affect their health during these transitions. Their premise was that to understand and uncover risks, the process of transitions need to be understood. This process consists of types and patterns of transitions, properties of the transition experiences, facilitating and inhibiting conditions, process indicators, and nursing
therapeutics. Transition experiences are described as diverse, complex, and multi-dimensional.

Possible transition experience examples which could make participants vulnerable and at risk are described: (a) illness experiences (diagnosis, surgery, rehabilitation or recovery), (b) developmental and life span transitions (pregnancy, childbirth, parenthood, menopause, aging, death), and (c) social and cultural transitions (migration, retirement or family care giving). Of interest in this study was the definition of a healthy transition characterized as both process and outcome indicators. Also of interest are the process indicators patterns of moving toward health or toward vulnerability feeling connected, interacting, being situated, and developing confidence (Meleis & Trangenstein, 1994). Other transitions of interest are two outcome indicators: mastery of new skills needed to manage the transition and the development of a fluid yet integrative identity (Meleis et al., 2000).

Transitions occurred over time, therefore, identified process indicators either moved participants toward vulnerability and risk, or in the direction of health. Thus, with a specific disease process, if the process indicators could be identified, early assessment and intervention could facilitate healthy outcomes. Observed patterns of this process that comprised healthy transitions were (a) feeling connected, (b) interacting, (c) being situated, and (d) developing confidence. Two outcome indicators emerged from the authors’ analysis as that of mastery of new skills needed to manage the transition and the development of a fluid yet integrative identity (Meleis et al., 2000; Meleis & Trangenstein, 1994).
Meleis et al. (1994, 2000) described a “process of transitions” which was created by individuals when faced with changes in their health or illness status. The authors stated that participants tend to be more vulnerable to risks which affect their health during these transitions. Their premise was that in order to understand and uncover the risks, the process of transitions would need to be understood. This process consists of types and patterns of transitions, properties of the transition experiences, facilitating and inhibiting conditions, process indicators, and nursing therapeutics. Transition experiences were described as diverse, complex, and multiple dimensional (1994, 2000).

Theoretical Models Used with Diabetes Self-Management

Theoretical approaches tested with diabetes are the Health Belief Model (Rosenstock, 1974, 1985), Social Cognitive Theory (Bandura, 1977), Locus of Control Theory (LOC; Rotter, 1966), Transtheoretical Model (Prochaska & DiClemente, 1982; Prochaska & Velicer, 1997), and personal or self-regulation models (Leventhal, Brisette, & Leventhal, 2003). A new model, the Chronic Care Model (CCM), is starting to emerge as a possible framework in which to manage the chronic illness of diabetes. These various theoretical models and their relationship to diabetes management will be described in this section.

Health Belief Model

The Health Belief Model states that health related action is dependent upon an occurrence that is simultaneous. The health-related action depends upon three classes of factors. The first is the existence of health concern or motivation to make health issues relevant, the second is the belief that there is susceptibility to a serious condition
(perceived threat), and the third is the belief that there are benefits to following a certain health recommendation to reduce the perceived threat. The latter decision is weighed as to the costs of overcoming the perceived threats (Rosenstock, Strecher, & Becker, 1988). Rosenstock (1974) stated that several requirements are needed for behavior change and their need for a reason to make the change. Psychological models such as the Health Belief Model emphasize that attitudes and beliefs are a major component of health behavior, and constructs from this model have been associated with diabetes management. Personal models are predictors of self-care behavior because beliefs about treatment effectiveness followed by perceived seriousness are strongly associated with self-management. For example, avoidance of serious consequences and the benefits of making the change outweigh costs of maintaining the status quo (Hampson & Glasgow, 1996).

The utility of the health belief model for predicting behavioral adherence with the diabetes regimen and glycemic control among adolescents with insulin-dependent diabetes mellitus was tested by Bond, Aiken, and Somerville (1992). The benefit, cost and cue constructs were related to compliance in the theoretically expected positive direction. The construct of threat interacted with benefit and cost in the prediction of compliance, and with the addition of cues predicated metabolic control. The greatest compliance achieved was with low perceived threat and high perceived benefit versus cost. Poor metabolic control was associated with high threat and cues. As age increased, adherence to exercise, injection, and frequency components of the regimen decreased.
Day (2000) attempted to identify factors operative in any one clinical practice for effective diabetes self-management. Several models were used, one of which was the Health Belief Model. The results indicated that a range of factors contributed to effective self-management: knowledge, self-management skills, perception of standards achieved, perceived benefits versus barriers, and locus of control. Traditional didactic approaches with the provision of information did not improve outcomes; instead, it was suggested to provide a chronic disease framework for diabetes education and care.

Social Cognitive Theory

Banduras’s Social Cognitive Theory (SCT) is defined as the belief and confidence one has about his or her capability to learn and perform behaviors at certain levels within certain settings. The SCT states that human achievement is dependent on the interaction one has with behavior, personal factors, and environmental conditions (Bandura, 1977, 2000). Self-efficacy is found to be highly context or situation dependent; therefore, measurement tools must be specific to the task or the activity. The self-efficacy expectations for behavioral activities are operationally defined by having patients rate their perceived judgment or confidence in ability to perform the specific activity at a given point in time (Bandura, 1977, 2000; Stretcher, DeVillis, Beecher, & Rosenstock, 1986).

Since the 1980s, research has presented evidence about the importance of self-efficacy in metabolic control, health-related quality of life, coping and problem solving, self-care adherence, diet adherence, insulin therapy, and blood glucose testing (Anderson et al., 1995; Glasgow, 1999, Grossman, Brink, & Hauser, 1987; Rose et al., 1993;
Variables identified as influential with diabetes self-management skills and training are beliefs, attitudes, problem solving ability, and self-efficacy (Shortridge-Baggett & van der Bijl, 1996; Whittemore, 2000).

**Locus of Control Theory**

Derived from the social learning theory, the locus of control (LOC) theory (Rotter, 1966) involves explanation of outcomes such as metabolic control by two factors: internal LOC or personal effort and external LOC or environmental factors (Tillotson & Smith, 1996). Most individuals are stronger in one versus the other.

Surgenor, Horn, Hudson, Lunt and Tennent (2000) developed scales for their study about diabetes self-management to measure concept dimensions related to various levels of sense of control, mechanisms to maintain control, motivations for control, and the agent for control (self or others). Metabolic control was found to be associated significantly with an overall sense of control as opposed to poor metabolic control, which was associated with feelings of inadequacy and loss of psychological control (Surgenor et al.).

**Transtheoretical Model of Change**

The Transtheoretical Model of Change (Prochaska & DiClemente, 1982) states that persons are in different stages of motivational readiness for change to engage in health promoting strategies. Stages of change are precontemplation, contemplation, preparation, action, and maintenance (Prochaska & Velicer, 1997). The focus for this model is to enhance the motivation for those who are not motivated to self-manage, change, or maintain behaviors (Ruggiero et al., 1997).
Of interest to this study and the use of the Transtheoretical Model of Change (TTM) with diabetes, treatment was conducted by Jones et al. (2003). Diabetes usual treatment (TAU) was compared with pathway to change (PTC) interventions, with the latter based on the Transtheoretical Model of Change (TTM), to determine whether the PTC intervention would result in a greater readiness to change, greater increases in self-care, and improved diabetes control. The PTC consisted of stage-matched personalized assessment reports, self-help manuals, newsletters, and individual phone counseling designed to improved readiness for self-monitoring of blood glucose (SMBG), healthy eating, and/or smoking cessation. The sample was comprised of 1,029 individuals with either type 1 or type 2 diabetes in one of three pre-action stages for SMBG, healthy eating, or smoking. There was improvement by 6.5% for those in the PTC versus the control for healthy eating; for smoking there was a greater than 10% improvement in the PTC group versus the control but there was not a statistical significance improvement shown in the A1c from the PTC group versus the control group.

Personal or Self-Regulation Model

The personal or self-regulation model involves individuals’ personal perception of their illness, which will determine their emotional and behavioral response to a health threat. Personal perception is the individual’s belief of factors that are central to the experience of illness and management. Skinner and Hampson (2000) tested this model and found that perceived impact of diabetes and supportive family/friends were predictive of the well-being of adolescents with diabetes. Other researchers found this to be true of adults when similar results were obtained (Glasgow et al., 1997; Hampson et
al., 1995; Rubin, Peyrot, & Saudek, 1989, 1993). Personal models were found to mediate the relationship between social support and behavioral outcomes (Glasgow et al., 1997). Scales developed by Surgenor et al. (2000) measured concept dimensions related to various levels of sense of control, mechanisms to maintain control, motivations for control, and the agent for control (self or others). It was found that metabolic control was associated significantly with overall sense of control as opposed to poor metabolic control, which was associated with feelings of inadequacy and loss of psychological control.

The Chronic Care Model

In the United States providing optimal health care for persons with chronic conditions is a major concern. According to the Institute of Medicine (IOM, 2006), care that is delivered is often not the type of care that should be received by patients with chronic conditions. In the early 1990s IOM called upon health care organizations to design and implement organizational support processes that would lead to more effective care delivery for persons with chronic illness (Wagner, Austin, & Von Korff, 1996). The Chronic Care Model (CCM) is congruent with these recommendations, which conceptualizes care as productive interactions between informed activated patients and prepared multidisciplinary practice teams (Hroscikoski et al., 2006; Wagner, Bennett, et al., 2005).

The CCM, derived at Group Health Cooperative, was based on a survey of best practices, expert opinion, interventions from the literature that showed promise, and quality improvement work in diabetes, depression, and cardiovascular disease. Group
Health Cooperative is the sixth largest health maintenance organization in the United States (Wagner, Davis, Schafer, VonKorff, & Austin, 1999).

The CCM, a framework that is in contrast to the traditional acute care model, provides a systematic approach that has shown to improve processes and outcomes (Bodenheimer et al., 2002; Wagner, Austin, et al., 1996). The CCM is based on the premise that effective chronic disease programs are delivered through partnerships with health systems and communities. The CCM is comprised of six key elements: (a) The first is the health care system, which serves as a foundation by providing structure and goals; (b) the second is community to provide links to resources within the community; (c) the third element is decision support, which ensures providers have access to evidence based guidelines; (d) the fourth element is clinical information systems that provide timely access to data about patients and patient populations using clinical information systems; (e) the fifth element is self-management support with a shift from didactic patient education to encouragement and support for more effective self-management, an area considered new and incomplete; and (f) the sixth element of the CCM is a delivery system design that will restructure medical practices to facilitate a team approach to care (Bodenheimer et al.; Wagner, Austin, et al.).

Most (ADA) recognized programs are based on the acute care model and most insurers reimburse based on this model. The fifth element, self-management, is considered new and the least studied. The focus of this qualitative research study is diabetes self-management within the context of some elements of the CCM. The grounded theory method is used to discover how persons with the chronic disease of
type 2 diabetes make decisions over time about their self-management. This nurse
researcher has observed, in clinical practice, a decline in diabetes skill set between 1 and
2 years after diagnosis.

Interventions to improve chronic care were undertaken in a meta-analysis by Tsai,
Morton, Mangione, and Keeler (2005) for the purpose of identifying elements of the
chronic care model in the empirical data. Out of 1,345 abstracts, 31 studies were
identified as related to diabetes; other disease processes studied were asthma, congestive
heart failure, and depression. The authors found that interventions with at least one
element of the CCM were consistent with beneficial effects on clinical outcomes and
processes of care across all conditions studied. Limitations, however, included the
inability to assess the intensity of the implementation, small sample size, and lack of
study of the impact of all elements of the CCM as a package.

Historically, health professionals have attempted to understand the behavior of
persons with diabetes, first by emphasizing acquired knowledge, then by attempting to
understand the beliefs and attitudes toward diabetes and diabetes treatment. Relating
diabetes self-management to various theoretical models occurred. Even though extensive
research has been attempted to address this issue, achieving adequate control of glucose
levels in persons with diabetes has remained elusive (Glasgow, Toobert, & Gillette,
2001). Although progress has been made related to behavioral aspects of diabetes care at
the individual, patient-provider level, and the health care system level, gaps have been
identified. Research is needed to investigate the applicability and impact of the CCM,
especially as it relates to minority populations (Glasgow et al., 2001).
The Impact of Nursing on Diabetes Self-Management

Nurses are uniquely positioned during this time of transition of health care from that of acute care to chronic care. Nurses who have a specialty in chronic illnesses such as diabetes will be recognized as key health-care providers. Diabetes, as a chronic disease, is associated with many co-morbid conditions that not only affect quality of life for the individual, but are an economic concern at a national level. Due to the increased rise of diabetes in the U.S. population, payers, providers, and legislators are taking note of diabetes. Nurses have historically made efforts to improve care and decrease complications through nursing’s knowledge, which has evolved into a holistic patient view. Nurses are positioned, therefore, to practice with emphasis on self-management education for patients and families in many settings and locations. Interdisciplinary collaboration, now considered fundamental to diabetes care delivery, positions nurses at both a basic and advanced practice level to contribute fully on behalf of the person with diabetes (ANA, 2003).

A study by Davidson (2003) reflected favorably on the involvement of nurses in diabetes care. In a small, randomized trial, outcomes of 99 low-income minority patients who received nurse-directed care were compared to 80 patients who received physician-directed care. Patients who experienced nursing intervention experienced better short-term glycemic control than those who experienced solely physician intervention. Diabetes self-management is given within the context of an integrated team approach, which may include nurses.
An integrated team is defined as a multidisciplinary group of professionals with a collective combination of expertise in medical treatment, medical nutrition therapy, teaching skills, and behavioral psychology (Funnell et al., 2009). The integrated team approach incorporates the ability to analyze behavior, attitudes, and physiological data on patients. Still little is known about how people change as related to their perceptions of self-management and how they make decisions over time. This nurse researcher is interested in the study of persons who have had type 2 diabetes diagnosed between one and two years. A qualitative study using grounded theory was the method chosen to best answer the research question and sub-questions posed by the researcher. The following research question guides this study: What is the process by which persons with type 2 diabetes manage their disease? Supporting sub-questions of interest include the following: (a) What are the contextual factors influencing diabetes self-management skills and training (DSMT)? (b) What are the critical junctures of diabetes self-management? (c) What decisions occur at the critical junctures?

Implications for Future Research

The literature related to diabetes self-management skills indicates the need for future research in several areas of unmet needs. The first is an alternate understanding of the conceptualization of the everyday self-care decisions made by persons with diabetes as based on the personal and social context of their lives. Examples of these personal and contextual factors are ethnicity, gender, age, educational level, social class, poverty status, diabetes type and severity, emotional state, and psychological state (Schoenberg & Drungle, 2001). The current conceptualization of self-care under an acute care model
often holds the person with diabetes responsible for disease-related problems and symptoms that may be due to the disease progression (Paterson et al., 2001). The second is to identify personal behavior change measures more accurately to include quality of life, satisfaction, and expanded physiological parameters. The third area is to acquire knowledge of which strategies produce change in the psychosocial factors that result in behavior change. The fourth area is to identify critical junctures in diabetes self-management that may impact its performance. Examples of critical junctures are the loss of health insurance or stressful life events. A fifth area is that of decision making. Identifying how persons with diabetes make decisions over time can help in understanding the complex nature of the chronic disease self-management of diabetes. A sixth area is to study health-based educational and community based models, and the last identified gap is to borrow appropriate outcomes from other chronic disease management models believed to be effective. The Chronic Illness Model (CCM) is one model that holds promise for the disease of diabetes, especially the least studied aspect, that of self-management (Paterson et al., 2001; Polonsky, 2000).
CHAPTER III

METHOD

The grounded theory method was used in this qualitative study to develop a theoretical framework to analyze the process by which persons with diabetes type 2 manage their disease. Supporting sub-questions that were explored involved contextual factors, critical junctures, and the decisions made regarding diabetes self-management at critical junctures. Little is known about how people with diabetes between 1 and 2 years post diagnosis change as related to their perceptions of diabetes self-management and how they make decisions over time. This chapter contains information regarding the method, sample, setting, instruments, procedure, interview questions, data analysis, and evaluative criteria.

The focus of this study was to explore the experiences of adults with diabetes mellitus between 1 and 2 years duration and the processes they may or may not use to manage their disease. The following research question guided this study: What is the process by which persons with type 2 diabetes manage their disease? Supporting sub-questions of interest include the following: (a) What are the contextual factors influencing diabetes self-management skills and training (DSMT)? (b) What are the critical junctures of diabetes self-management? (c) What decisions occur at these critical junctures?
The grounded theory method was used in this qualitative study to discover the processes that occur during the self-management of type 2 diabetes. This section includes a description of grounded theory, the sample, setting, instruments, procedure, interview questions, data analysis, and evaluative criteria.

Grounded Theory

Grounded theory, a method of inquiry developed by Glaser and Strauss (1967), is both a way to do qualitative research and a way to create inductive theory (Cutcliffe, 2000; Eaves, 2001; Jeon, 2004; Schreiber & Noerager-Stern, 2001). Grounded theory, which stems from sociology, is an approach that makes possible the study of meanings of events for people. This assumes that meanings are shared through a common language and socialization. Through grounded theory research, social processes composed of meanings are clarified and made public (Jeon, 2004; Schreiber & Noerager-Stern, 2001; Strauss, 1987; Strauss & Corbin, 1998). This method is employed to discover the meaning of events for persons with diabetes as related to their disease management. This method further explores how the management of their disease influences life events or how life events influence the management of the disease over time. Persons with diabetes live with the disease in relationship with others (spouse, family, community), in interaction with their environment, within their culture, and in interaction with the health care system.

In this study grounded theory was used to reveal the experiences of persons with diabetes in response to life processes and circumstances while managing their diabetes. Grounded theory is a process and a method to uncover complex and hidden processes
(Jeon, 2004; Schreiber & Noerager-Stern, 2001). The research approach, called the paradigm of inquiry, is not a specific method or technique, but a method of doing qualitative analysis. This style of analysis includes distinct features of theoretical sampling: methodological guidelines, constant comparisons, and use of a coding paradigm to ensure conceptual development and density (Strauss & Corbin, 1998).

To answer the research question *What is the process by which persons with type 2 diabetes manage their disease?* the grounded theory approach was chosen to uncover not only what is visible, such as diabetes self-management expectations to ensure metabolic control, but also what may not be apparent to persons with diabetes. Persons with diabetes live with the disease in context of relationship with others (spouse, family, community), in interaction with their environment, within their culture, and in interaction with the health care system; as such, persons with diabetes deal with their disease within complex systems. In grounded theory, symbolic interactionism is used to understand the complex world from the view of those who live it.

*Symbolic interactionism.* Grounded theory originated from the social sciences and is specifically the symbolic interaction tradition of social psychology and sociology (Glaser & Strauss, 1967). Symbolic interactionism, founded in the early 1900s by George Mead from the Chicago sociological tradition, was influenced by American pragmatism from the views of John Dewey (Eaves, 2001; Jeon, 2004). Pragmatism is described as a continual process of adaptation by human beings who are within a constantly changing world. This process is made possible by existence of a mindset that contemplates any given situation at a point in time. Herbert Blumer, a sociologist, further advanced
symbolic interactionism as a research theory and approach. According to Blumer this is done by identifying three basic premises. The first is how human beings act toward anything that has meaning for them, the second is the meaning that is derived from the objects based on social interaction, and the third premise is that meaning is arrived at through an interpretive process (Schrieber & Stern, 2001). Symbolic interactionism, a process by which meaning is developed, explores the nature of meanings represented in interactions both between and among human beings. These meanings are then understood only through interpretation. A major element of symbolic interactionism is that of meaning, which assists in the understanding of human behavior, interactions, and social processes. The researcher must grasp the meanings of the experiences of subjects within a particular context to obtain full understanding of the social process (Cutcliffe, 2000; Jeon, 2004).

As a theory about human behavior, symbolic interactionism is an approach to the study of both individual human conduct and human group life. Symbolic interactionism is concerned with the meanings of events for people and the symbols used to convey those meanings. The focus of symbolic interactionism is how these events or reality is defined by the persons who experience them and how these persons act according to their beliefs, or the experiential aspects of human behavior. Symbolic interactionism is when people are in a continuous process of interpreting and defining as they move from one situation to another (Eaves, 2001).

As an inductive method, grounded theory is the study of the phenomena it represents, which may be either substantive or formal. A substantive theory is relevant to
the people concerned and can be modified. A formal theory is developed further than a substantive theory and meets the criteria of fit and relevance and can be easily modified. In the grounded theory approach, relevance means that core problems and processes start to emerge. The inductive method of grounded theory was used with persons with diabetes to uncover the representative phenomena regarding how they manage their disease.

Sample

Individuals over age 18 with a diagnosis of type 2 diabetes mellitus between one and two years and who had participated in a DSMT program were recruited for the study. The sampling frame was comprised of participants for a selective sample recruited from those referred to three hospitals with DSMT programs and a physician’s office. Participants who use these hospital facilities are from diverse ethnic (African American, Hispanic, Asian, Sudanese, and Caucasian) and socioeconomic (urban to upper middle class) backgrounds. In this sample the ratio of women to men was approximately equal (see Table 1).

A selective sample was comprised of 22 individuals. The actual number could not be determined a priori (Morse, 1991, 2002; Sandelowski, 1993), but rather was determined as data were collected and analysis began. The final number of 21 participants who were interviewed to reach theoretical saturation was dependent on the quantity and the richness of data that were obtained (Schreiber & Noerager-Stern, 2001). Participants who experienced treatment failure as well as those who experienced successful diabetes management were included in the study. Participants previously
Table 1. Characteristics of Participants (n=21)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7 (33)</td>
</tr>
<tr>
<td>Female</td>
<td>14 (67)</td>
</tr>
<tr>
<td>Age in Years</td>
<td></td>
</tr>
<tr>
<td>&lt;30</td>
<td>0 (n/a)</td>
</tr>
<tr>
<td>31-50</td>
<td>5 (24)</td>
</tr>
<tr>
<td>51-70</td>
<td>10 (48)</td>
</tr>
<tr>
<td>71-90</td>
<td>6 (28)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>White (Non-Hispanic)</td>
<td>19 (90)</td>
</tr>
<tr>
<td>Black (Non-Hispanic)</td>
<td>2 (10)</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>7 (33)</td>
</tr>
<tr>
<td>Never Married, Divorced/Separated,</td>
<td>14 (67)</td>
</tr>
<tr>
<td>Widowed</td>
<td></td>
</tr>
<tr>
<td>Employment Status</td>
<td></td>
</tr>
<tr>
<td>Employed for Wages/Self-employed</td>
<td>5 (24)</td>
</tr>
<tr>
<td>Homemaker/Retired/Unable to Work</td>
<td>16 (76)</td>
</tr>
</tbody>
</table>

attended the DSMT Program and met the following criteria: (a) previous experience of DSMT interventions and (b) over the age of 18 years, and (c) a diagnosis of type 2 diabetes mellitus between one and two years.

Setting

Persons with type 2 diabetes were recruited from the diabetes self-management skills and training programs (DSMT) from three hospitals that hold American Diabetes Association (ADA) accreditation and a physician’s office. The accreditation ensures that
the programs meet the ADA national standards for diabetes care; as such, comprehensive
diabetes care and education were available at the three hospitals. The hospitals and the
physician’s office were in different locations in Northeast Ohio. All of the hospital
diabetes programs served both inpatients and outpatients with type 1, type 2, and
gestational diabetes. One hospital has a 476 bed capacity and offers six outpatient
centers. The second has approximately a 300 bed capacity and reports serving 130,000
patients per year. The third has a 499 licensed bed capacity and reports 338,495
outpatient visits per year. The physician’s office reported a robust practice where two
thousand persons with type 2 diabetes are seen per year (Peggy Smith, RN, personal
communication, June 1, 2009). Among the three hospitals and the physician office, the
ethnicities served are African American, Hispanic, Asian, Sudanese, and Caucasian; on
rare occasions, Pacific Islanders are serviced by the program. Outside interpreters are
provided as needed if a language barrier exists. The diabetes program staff in the three
hospitals is comprised of registered nurses who are certified diabetes educators (CDE),
dietitians, an exercise physiologist (at one site), and a community outreach coordinator at
another site. Two of the three hospital diabetes programs are staffed by endocrinologists.
All interviews (n=21) were conducted in person in a private room provided at each of the
three hospital sites. Interviews ranged from 42 minutes and 42 seconds, to 104 minutes
and 57 seconds, with an average of 47 minutes and 7 seconds. All participants were
diagnosed with type 2 diabetes with duration between one and two years. All participants
had attended a diabetes self-management skills and training program (DSMT).
Data collected for this study involved demographics, the A1c, and blood glucose levels. The following section addresses the instruments that were used.

**Demographics.** Participants completed a demographic and health history form that was devised for the purpose of this study (see Appendix A, Health Information and Demographic Form). This instrument was used to obtain information about age, gender, race, marital status, history of employment, educational level, insurance status, income range, type and duration of diabetes, use of insulin, history of depression, awareness of the last A1c result, and the presence of long-term complications. Information that was not completed by the participant was obtained from the medical record (see Appendix A). The information compiled from this instrument to aid in sample description is depicted in Table 2.

**A1c.** The A1c was obtained from the participant’s medical record after the interview was completed to avoid researcher bias. This ensured the accuracy of the lab value and/or provided the lab value in case participants did not know their most recent A1c. The Hemoglobin A1c (A1c), a weighted measure for the average blood glucose for the past 3 months, is measured per venipuncture sample. The Variant II Hemoglobin A1c Analysis System was used by the hospital laboratories to determine results. The Variant II is an automated instrument based on chromatographic separation of the A1c on a cation exchange cartridge that quantitatively determines Hemoglobin A1c. The software generates a sample report and a chromatogram for each sample. Normal range is
Table 2. Health Characteristics (n=21)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration of Diabetes</td>
<td></td>
</tr>
<tr>
<td>1 year</td>
<td>5 (24)</td>
</tr>
<tr>
<td>2 years</td>
<td>16 (76)</td>
</tr>
<tr>
<td>Insulin Use</td>
<td>4 (19)</td>
</tr>
<tr>
<td>Oral Medication Use</td>
<td>17 (81)</td>
</tr>
<tr>
<td>Adjunct Use of Diet</td>
<td>19 (90)</td>
</tr>
<tr>
<td>Treatment for Depression</td>
<td>2 (10)</td>
</tr>
<tr>
<td>Blood Pressure Issue</td>
<td>15 (71)</td>
</tr>
<tr>
<td>Blood Pressure Medication Taken</td>
<td>14 (67)</td>
</tr>
<tr>
<td>Dietary Intervention</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Cholesterol Issues</td>
<td>16 (76)</td>
</tr>
<tr>
<td>Cholesterol Medication Taken</td>
<td>14 (67)</td>
</tr>
<tr>
<td>Dietary intervention</td>
<td>2 (10)</td>
</tr>
<tr>
<td>Diabetes Complications</td>
<td>14 (67)</td>
</tr>
<tr>
<td>Heart Problems</td>
<td>7 (33)</td>
</tr>
<tr>
<td>Circulation Problems</td>
<td>4 (19)</td>
</tr>
<tr>
<td>Skin Problems</td>
<td>7 (33)</td>
</tr>
<tr>
<td>Digestion Problems</td>
<td>9 (43)</td>
</tr>
<tr>
<td>Eye Problems (e.g. retinopathy)</td>
<td>8 (38)</td>
</tr>
<tr>
<td>Kidney Problems (e.g. nephropathy)</td>
<td>3 (14)</td>
</tr>
<tr>
<td>Problems with Nerves (e.g. numbness, pain, feelings of hot and cold)</td>
<td>10 (48)</td>
</tr>
</tbody>
</table>
3.9 to 6.1% for quality control. Based on the manufacturer’s recommendation, quality control tests are run each day that A1c tests are done (Bio-Rad Laboratories Diagnostics Group, 2000). The A1c goal for patients is suggested to be equal to or less than 7% (ADA, 2009).

**Blood glucose.** Participants were asked to provide their blood glucose log encompassing the last two weeks from the date of the interview of blood glucose values obtained from self-monitoring of blood glucose at home (done per finger stick). Copies of the log were made and the documents were identified by a number system. If the blood glucose log was available in the participant’s chart, it was accessed there as well. In the event that the participant was not performing self-monitoring of blood glucose, the most recent blood glucose levels recorded in the medical record were used. This information was collected along with the lipid profile to aid in the identification of those participants who were exemplar.

The process of self-monitoring of blood glucose is a measurement performed by the participant using a portable home glucose reflectance meter. A finger stick to obtain blood is performed by the participant; the blood sample is then applied to a blood glucose monitoring strip and a blood glucose value can then be obtained (United States National Library of Medicine & National Institutes of Health, 2006). To determine if sample blood glucose values were within range, they were compared to the American Diabetes Association guidelines for self-monitored blood glucose, which are 90 to 130 mg/dl prior to meals, equal to or less than 160 mg/dl two hours after a meal, and 110 to 150 mg/dl at bedtime (ADA, 2009). These values were obtained from logbooks, through meter
memory features in the blood glucose meter, or the participant’s medical record.

Participants may perform blood glucose checking several times a day based on their
treatment regime.

Procedure

The study sites were selected to reflect diversity of the target population served at
each facility. Approval was obtained from the institutional review board (IRB) at Kent
State University (see Appendix B, Kent State University Permission Letters) from the
three hospitals (see Appendix C, Mercy Medical Center Permission Letters; Appendix D,
Lakewood Hospital Permission Letters; and Appendix E, Fairview Hospital Permission
Letters) and the medical director gave his approval to do the study at the physician’s
office (see Appendix F, Physician’s Office, Medical Director Letter of Permission). Two
of the three hospitals gave permission for media advertisement. Flyers (see Appendix G,
Recruitment Flyer) that included the study description, contact numbers, and the
inclusion criteria were made available at each site. Flyers were posted at each hospital in
the diabetes program location, physician offices that refer to the DSMT program, and at
each hospital’s diabetes support group location.

Introductory meetings were held with the registered nurses and dietitians and
other health care provider staff of the diabetes self-management skills and training
programs (DSMT) at the hospitals and the physician’s office to describe the study and
address inclusion criteria. They were given recruitment flyers to distribute to potential
eligible patients. The registered nurses, dietitians, and other health care professionals who
worked at each site were asked to identify DMST program patients who might meet the study criteria.

A flyer was given at the time of the clinic appointment, and if there was interest in participating in the study, direction was given to call the phone number listed on the flyer. For former DSMT program participants who were not coming to the clinic or DSMT program on a regular basis, the program coordinator identified participants who might meet the study criteria and mailed a letter (see Appendix H, Patient Letter) with information about the study description, a flyer with inclusion criteria, and contact information if interested in participating in the study.

Flyers for patient distribution, which included the study description, were made available at introduction meetings. The flyer content included the following: (a) inclusion criteria, (b) permission to tape the interviews, (c) location of the interview, (d) request to copy blood glucose log books for the past two weeks, (d) interview length of approximately 1 to 1½ hours, (e) completion of a 21-question health information and demographic questionnaire, (f) permission to access the medical record for A1c results and incomplete demographic information, (g) possible re-contact via phone for clarification of the interview information, and (h) notice of compensation of a $25 gift merchandise card at the end of the interview. Two hospitals and the physician’s office gave IRB permission to use advertisement for the purpose of recruitment in a variety of local media such as community newspapers, mailings, and bulletins (see Appendix I, Sample Advertisement).
Those interested in participating were asked to call a toll free phone number to learn about the study. A separate line with a designated 1-866 phone number was installed on the researcher’s home phone. This phone was used to call potential participants, thus avoiding identification of the nurse researcher through caller identification mechanisms on the telephone. When the potential participant called the 1-866 phone number, a pre-recorded message (see Appendix J, Pre-recorded Message) repeated the inclusion criteria and requested the potential participants to leave a number where the nurse researcher might reach them. The pre-recorded message addressed the issue for those potential participants who were homeless and/or without a phone by asking for the number of a relative/contact person.

When the potential participant was contacted via phone, introductions were made, the study was explained, and the inclusion criteria reviewed (see Appendix K, Phone Script). If the potential participant met the criteria and agreed to participate in the study, a convenient date and time was selected by the potential participant to meet for the interview. A designated private space in the diabetes center at the hospital was used for the interview. Potential participants were asked to provide their name, address, and phone numbers to send directions, maps, parking information or a cab voucher (if needed). A reminder phone call was made to each potential participant with date, time and location of the interview; a prompt to bring their blood glucose logs, and information of whom to call in case of cancellation. Potential participants were directed to leave a message on the 1-866 phone line if they decided either to cancel or to withdraw
participation from the study. Those potential participants who wished to reschedule their appointments were contacted.

On the day of the 1 to 1½-hour interview, a quiet, private environment free of interruptions was provided at each designated hospital. The study purpose was explained and the potential participant was asked to read and sign the informed consents for participating in the study (see Appendix L, M or N [Hospital Informed Consent Forms]), audio-taping of the interview (see Appendix O, Consent to Audio-Tape), to be re-contacted for clarification of the interview data (see Appendix P, Consent to Re-Contact), and to have the medical record data reviewed after the interview for the A1c, blood glucose values, and other incomplete health information and demographic information (see Appendix A, Health Information and Demographic Form). After the interview, participants’ self-reported blood glucose logs of the past 2 weeks were photocopied and coded, and identifying information was removed.

Copies of the consent forms were given to the participant at the time of the interview. Participants were instructed that the information they provided was confidential within the limits of the law. Participants were free to stop their participation in the study at any time or refuse to answer questions. They completed a brief demographic data sheet prior to the interview (see Appendix A, Health Information and Demographic Form). Participants were asked interview questions (Appendix Q, Interview Question Guide) consisting of how they manage their diabetes (e.g. what is the most challenging aspect of diabetes self-management?), taking approximately 1 to 1½ hours. An interview guide was constructed but the actual interview questions were
determined by the participant’s responses. According to Schreiber and Stern (2001), the interview guide is for the researcher and does not dictate the course of the interview. If the participant, for example, was having difficulty understanding the questions, the wording was simplified or more structure was provided. The interview helped the participant to share his or her story without undue restriction or interference from the perspective of the researcher.

If any participant had become distressed during the interview, the nurse researcher would have determined if the interview should cease and whether or not the participant needed emotional support. If immediate assistance were required, the individual would have been taken to the emergency room. Otherwise, available contact numbers for mental health professionals at each respective hospital were provided for the purpose of follow-up referral if needed.

Following the completed interview, the medical record data of each participant for A1c and blood glucose values for the past 12 months were reviewed. Demographic information that was incomplete on the demographic questionnaire was gathered from the participant’s medical record which may have included: age, gender, race, marital status, employment status, year diagnosed with diabetes, latest blood pressure reading, latest cholesterol reading, if prescribed insulin, blood pressure medication or cholesterol lowering medication and any complication (heart, circulation, skin, digestion, eye, kidney or physical nerve issues), and history of depression.
Interview Questions

To facilitate the participant to form any answer rather than select from a set of possible answers, data collection consisted of audio-taped, semi-structured interviews with open-ended questions (see Appendix Q, Interview Question Guide). The open-ended questions were modified based on emerging themes and patterns. Other instruments included demographic and health information, post-interview summary, memos, medical records, participant-contributed sources and field notes.

Data Analysis

This section addresses data analysis, which includes coding, memoing, and theoretical sampling. Data were analyzed using the grounded theory method and principles based on Glaser and Strauss (1967) and Schreiber and Noerager-Stern (2001).

In the data collection phase, Glaser and Strauss recommended use of multiple data sources on the same phenomenon; these “slices of the data” are differing views or vantage points from which the researcher can understand a category to develop the properties of the category. According to Glaser and Strauss (1967), this technique provides for a multifaceted investigation to fully saturate the category. Data are collected and analyzed simultaneously and with flexibility to facilitate adjustment during the data collection process as the findings emerge. During the data collection phase, the data are collected, ordered, and analyzed simultaneously. The data are broken down, conceptualized, and reconstructed in new ways. During this phase, coding occurs, types of analysis that occur as an integrated whole. Coding is not linear and it does not follow a
strict sequence (Eaves, 2001; Jeon, 2004; Strauss & Corbin, 1998). Each interview was transcribed by a professional transcriptionist.

First level coding. In first level coding the transcript was carefully read; words or parts of the story that hold a particular meaning were selected. The researcher attempted to use the words of the participant, which preserves the participant perspective, to develop codes. In this study, first level coding was approached in three ways: (a) line-by-line analysis, (b) evaluating sentences or paragraphs, and (c) examining the transcript as a whole. Codes typically emerge quickly during first level coding and new codes are added as new data are analyzed (Montgomery & Bailey, 2007; Schreiber & Noerager-Stern, 2001).

Second level coding. Second level coding involved taking the first level codes and combining into categories. The goal of second level coding, according to Glaser (1978), is the development of “an emergent set of categories and their properties which fit the data, and are relevant for integrating into a theory” (p. 56). Critical to second level coding is the constant comparison of existing codes with new data for the purpose of identifying similarities and differences. In this study, this was accomplished by reading through transcripts and other documents to carefully examine the data for select words, phrases, or stories for single units of meanings (Montgomery & Bailey, 2007; Schreiber & Noerager-Stern, 2001).

Questions were asked initially to break down the data as to what, where, how, when, and how much. Data were then compared and grouped into similar incidents that were given the same conceptual label. When concepts are grouped at a higher abstract
level, the process is called categorizing (Eaves, 2001; Pandit, 1996). This was accomplished by second level coding in which similarities among concepts were noted and categories were identified. A process was used to compare the first level codes against incoming data, existing data, and the identified categories. The identified categories were then compared to the data and codes. Following Schreiber and Noerager-Stern (2001), there was comparison of specific incidents to abstractions so that the incident was compared to incidents, and then the incidents were compared to the concept to determine both similarities and differences.

_Third level coding_. During third level coding the relationship between categories was examined. There is movement between inductive and deductive thinking, evaluating the relationships among the concepts (Montgomery & Bailey, 2007; Schreiber & Stern, 2001). Data analysis involved comparison as categories emerged. From each category, sub-categories or properties were explored as each emerged. Code and property labels were assigned with word descriptors. Codes were compared for differences and similarities and then organized into categories. Looking for any relationships among categories reduced the categories further. Once identified, core concepts that linked data and the categories were labeled. There was ongoing comparison among the data, common emerging themes, and the literature as themes emerged (Dick, 2002). Through third level coding, the focus was to examine for possible relationships among categories. At this stage, both inductive and deductive thinking were used as hunches and possible formulated hypotheses were tested through further data collection and analysis (Schreiber & Noerager-Stern, 2001).
Memoing. As part of the grounded theory method, memoing was done during the coding stage to assist in tracking categories and properties that are a part of the evolving system of the research process. Memoing is an ongoing process of data collection and analysis comprised of note making questions and ideas from the perspective of the researcher. The purposes of memoing are to make explicit for open examination the researcher’s pre-existing assumptions, to serve as a record for decisions about methods during the course of the study, and to assist in data analysis and speculation about the data (Schreiber & Noerager-Stern, 2001). Three types of memos were used: code memos, theoretical memos, and operational memos. Code memos focus on conceptual and category labeling. Operational memos contain directions related to the evolving research design. A third method to assist with coding, diagramming, was used to depict relationships among concepts (Eaves, 2001; Schreiber & Noerager-Stern; Strauss & Corbin, 1998).

Theoretical sampling. The selection of the first subject was important as this was a basis for the theoretical framework. The next step was to test and develop the framework by the selection of additional subjects where constant comparison occurred. The principle aim of theoretical sampling is to strengthen the emerging theory by filling in categories that may require further refinement or development (Eaves, 2001; Pandit, 1996). Closure or saturation was reached when the new data were minimal and the data were repeated. The final step was to examine differences and similarities of the emerging theory with the extant literature. Memos and diagramming were written constantly for the course of the study and could take whatever form was the most comfortable for the
researcher. An example is in the form of a journal (Eaves, 2001; Pandit, 1996; Schreiber & Noerager-Stern, 2001).

**Evaluative Criteria**

Philosophically, researchers make claims about what is knowledge (ontology), how we know it (epistemology), what values go into it (axiology), how it is written about (rhetoric), and the processes for studying knowledge (methodology) (Creswell, 1994, in Creswell, 2003). Stating a knowledge claim means that a research project is started with certain assumptions about how and what will be learned during the inquiry. These claims are called paradigms, philosophical assumptions, epistemologies, ontologies, or broadly conceived research methodologies.

Credibility, auditability, applicability and dependability, and confirmability are identified as recognizable inquiry criteria for qualitative studies. In quantitative studies parallel inquiry criteria would be internal validity, external validity, reliability, and neutrality (Lincoln & Guba, 2000).

**Credibility.** Truth value or credibility is reflected in the results as a true representation of participants of this sample of persons with diabetes by looking for repeated themes and verifying reported answers as to intended meaning. Credibility relates to the trustworthiness of the findings. Suggested methods for enhancing credibility in research practice are to: (a) facilitate participants to guide the inquiry process, (b) compare theoretical construction generated against participants’ meanings of the phenomenon, (c) use the participants’ actual words in the theory, and (d) articulate the researcher’s personal views and insights about the phenomenon explored. The latter is
accomplished through use of a personal journal developed by the researcher; use of post comment interview sheets, referred to as memo writing (Appendix R, Post Interview Memo Form) as a tool; and monitoring how the literature was used (Chiovitti & Piran, 2003). The nurse researcher may contact participants again to clarify or review findings.

Auditability. Auditability occurs when another researcher can follow the audit or decision trail of the original researcher at every stage of data analysis. Two methods to accomplish auditability are to specify the criteria built into the researcher’s thinking and to specify how and why study participants were selected. Strauss and Corbin (1998) derived standard questions as criteria to approach transcribed interview data. The researcher is to focus on what is occurring in the data, the action the data represents, conceptual codes or labels that are part of the participant’s vocabulary, the context of the code and if encompassed by a broader code, and if codes reflect similar patterns (Chiovitti & Piran, 2003). Peer group de-briefing was accomplished by having dissertation chairs read the data analysis and findings to see if the same conclusions are reached.

Applicability and dependability. When the study was completed, applicability or generalizability was addressed by determining how the relevant findings in the sample are as compared to the entire population of persons with diabetes. Findings may be applicable only to this sample. Adhering closely to the grounded theory method and giving a clear explanation of methods, so that if the study were to be repeated the same findings would occur with the same subjects or the same group at a later time, addressed dependability or consistency.
**Confirmability.** Neutrality or confirmability was accomplished for this study by bracketing to ensure that the findings are those of the participants and not the researcher’s own bias (Denzin & Lincoln, 2000). Fittingness, described as transferability, pertains to the possibility that the research findings have meaning for others in similar situations. The two methods to address fittingness are to delineate the scope of the research in terms of sample, setting, and level of theory, and to relate the literature to each category that emerged from the theory (Chiovitti & Piran, 2003).

**Summary**

The grounded theory method was used to discover processes and to identify critical junctures and influencing contextual factors during diabetes self-management. The complexity involved to acquire expertise in diabetes self-management leaves gaps as to what is known about these processes and how they may be influenced (Paterson & Thorne, 2000). Little has been known about how people change as related to their perceptions of diabetes self-management and how they make decisions over time. Adults over the age of 18 years old, with type 2 diabetes mellitus with duration of one to two years were the focus of this study. It had been noted during this researcher’s clinical practice that a decline in diabetes skill set occurs within this time frame.
CHAPTER IV
FINDINGS

To answer the research questions, a theoretical framework was developed that revealed how persons with type 2 diabetes self-manage their disease. The grounded theory method was used with persons having type 2 diabetes of the duration of one to two years. The following is the major research question that guides this study: What is the process by which persons with type 2 diabetes manage their disease? Followed by the supporting sub-questions of interest: (a) What are the contextual factors influencing diabetes self-management skills and training (DSMT)? (b) What are the critical junctures of diabetes self-management? (c) What decisions occur at the critical junctures?

*Dealing with Type 2 Diabetes* was identified as the psychosocial problem shared by participants. The psychosocial process for this problem was termed *Evolving Diabetes Self*. The psychosocial process of *Evolving Diabetes Self* encompasses four phases with interrelated categories within each phase that impact the psychosocial problem of *Dealing with Type 2 Diabetes*. The *Evolving Diabetes Self* is comprised of four phases: (a) *Getting the Diagnosis*, (b) *Realizing Options*, (c) *Making Decisions*, and (d) *Living the Consequences*. As participants moved along their trajectory of dealing with their diagnosis of diabetes, the process was found to be multidimensional, complex, dynamic, and fluid. The process does not have a completion point (see Appendix S, Data for Theory Development).
The Sample

Twenty-one participants diagnosed with type 2 diabetes between one and two years participated in the study. Participants were recruited from three hospital diabetes programs and a physician’s office in Northeast Ohio. Twenty-two participants agreed to participate in the study; however, during the interview one individual revealed a diabetes diagnosis of more than two years. The information from that interview was therefore not included in the data analysis.

The sample included 7 men and 14 women. Participants ranged in age from 34 to 87 years. Five participants reported having had diabetes type 2 for the duration of one year, while 16 participants reported having the disease for two years. Four participants reported using insulin, 17 participants reported use of diabetes oral medications to control their diabetes, and 19 reported using diet as an adjunct control for diabetes. Table 1 on page 70 depicts the demographic characteristics of the sample.

The Interviews

Participants with type 2 diabetes of between one and two years duration who had completed a Diabetes Self-Management Skills and Training (DSMT) program and had an interest in the study were recruited to participate in the interviews. The sampling frame was comprised of participants (see Table 1) for a selective sample recruited from individuals referred to three hospitals with DSMT programs and a physician’s office. The interviews took place in a private room provided by each of the participating hospital sites. Audio-taped semi-structured interviews comprised the primary source of data for the research study. General open-ended questions were used to guide the interview
process, which was the primary instrument for data collection. The general open-ended
questions were modified based on emerging themes and patterns. Using an interview
guide, participants were asked interview questions (see Appendix Q, Interview Question
Guide) consisting of how they managed their diabetes (e.g. what is the most challenging
aspect of diabetes self-management?), which took approximately 1 to 1½ hours to
complete. According to Schreiber and Stern (2001), the interview guide does not dictate
the course of the interview; it is a tool for the researcher. For participants who had
difficulty understanding the questions, simplified wording or more structure was
provided. Although some participants were tearful while telling their stories, no one
experienced extreme distress during the interview process.

Instruments

Instruments included demographic and health information, the post-interview
summary, memos, the medical record, participant contributed sources, such as self-
monitoring blood glucose logs, and field notes. After the interview, the medical record
data for A1c and blood glucose values done within the previous 12 months were
reviewed (refer to Table 2, page 73). Demographic information that was incomplete on
the demographic questionnaire was gathered from the participant’s medical record and
included the following: age, gender, race, marital status, employment status, year
diagnosed with diabetes, latest blood pressure reading, latest cholesterol reading, if
prescribed insulin, blood pressure medication or cholesterol lowering medication, and
any complication of the disease (heart, circulation, skin, digestion, eye, kidney or
physical nerve issues). A history of possible depression was obtained because of the
strong link between diabetes, depression, and the performance of diabetes self-management.

Data Analysis

Data analysis was conducted by both the investigator and her dissertation chairs through in-person group meetings and phone conferencing. The theoretical model in Figure 1 was developed based on the grounded theory method which involved coding at a first level, second level, and finally a third level of coding (Schrieber & Stern, 2001).

First Level Coding

To accomplish first level coding, each interview was read line by line two to three times, to choose words and phrases that had been stated by the participants and therefore had meaning for them. Interviews were read a third and perhaps a fourth time to choose paragraphs in which the words and phrases occurred to further capture the meaning behind the identified words and phrases of the participants. Written memos were completed after each interview.

Second Level Coding

To accomplish second level coding, the words and phrases identified in first level coding were combined into categories. The words and phrases used by participants were checked for similarities and differences. Similar words and phrases were grouped under the best category phrase that depicted the meaning of what participants were expressing. To further raise the level of abstraction and to expose the properties and the dimensions of the categories, a comparison of existing categories with new data was made. To raise the level of abstraction, the best categories were identified, reviewed, and then collapsed
further. Comparison with written memo notes was also done. The data, which were analyzed over time, evolved into the table entitled *Data for Theory Development* (see Appendix S, Data for Theory Development).

Grounded theory method experts agree that mentorship is crucial in learning the method; therefore, group analysis was used (Schrieber & Stern, 2001). The investigator along with the dissertation chairs contributed to framework development and raising the level of abstraction. The investigator reflected on the meaning and experiences of the participants in managing their type 2 diabetes and the study’s research question and sub-questions. To uncover further categories from the data interview analysis, memo notes and group meeting notes were compiled and reviewed.

*Third Level Coding*

To accomplish third level coding of the categories and to view interrelatedness of the categories, the categories were moved to abstraction. The identified categories were further analyzed based on their relatedness. As data analysis evolved, some categories were eliminated, renamed or subsumed into other categories based on participant interviews, the literature, memos, and other field notes. Diagramming was constructed to assist the researcher to stand back from the data and examine how the categories were related.

The information related to transitions was reviewed and definitions from both a dictionary and a thesaurus were noted. Exemplar interviews were reviewed. An exemplar was defined as a participant whose A1c and blood glucose values were in range. The exemplars had a readily available resource, themselves, a friend or relative who was
knowledgeable and able to provide timely feedback. The exemplar participants gave insight into how decisions were made toward healthy transitions and how they “knew how far to go” with choices made with diabetes self-management. Paterson and Thorne (2000) addressed the term of strategic non adherence, which involves the ability by exemplar participants to make self-management decisions within a safe range that would not compromise metabolic control. In order to answer the research question a theoretical model was developed.

Theoretical Framework

Grounded theory was used to uncover a shared psychosocial problem experienced by participants who had type 2 diabetes between one and two years duration. The psychosocial problem described by participants in this sample was that of *Dealing with Type 2 Diabetes*. The psychosocial process, how participants resolve the problem, was *Evolving Diabetes Self*.

The process of *Evolving Diabetes Self* is comprised of four phases: (a) *Getting the Diagnosis*, (b) *Realizing Options*, (c) *Making Decisions*, and (d) *Living with the Consequences*. Each phase has components related to how participants view, make decisions, and experience self-management of their diabetes. A theoretical framework was developed to explain how participants self-manage their type 2 diabetes between one and two years duration.

Explanation of the Model

The following is a discussion addressing the major research question: What is the process by which persons with type 2 diabetes manage their disease? (see Figure 1,
Evolving Diabetes Self). The figure is a pictorial representation of the process that begins with *Getting the Diagnosis* indicated by the box at the top of the framework; from this box there are bidirectional arrows between the other phases: *Realizing Options, Making Decisions*, and *Living the Consequences*. Within each phase are categories of how participants responded to that particular phase of the process of self-managing their type 2 diabetes. The categories are labeled within each phase with bidirectional arrows to depict how the categories are fluid within each phase. Supporting sub-questions related to contextual factors influencing diabetes self-management, and critical junctures of diabetes self-management and decisions made at the critical junctures throughout the *Evolving Diabetic Self* are discussed later in this chapter.

The model may be read from top to bottom. However, the model is depicted with bidirectional arrows between the phases and categories to indicate the variation among participants and the fluidity of the process. Diabetes type 2 is a disease process that is a lifelong evolving process and there is no end point.
Figure 1: Evolving Diabetes Self
Psychosocial Problem: Dealing with Type 2 Diabetes

For all participants *Dealing with Type 2 Diabetes* is a shared life problem. Schreiber and Stern (2001) described a psychosocial problem as a phenomenon that is viewed from the participant’s perspective and is a shared problem. The psychosocial problem shared by participants in this study is *Dealing with Type 2 Diabetes*. This psychosocial problem was commonly described by participants after being diagnosed with diabetes as a life challenge. Many participants described the diagnosis of diabetes as a “life change” they had to “deal with” and “come to terms with at their own rate.” The term *Dealing with Type 2 Diabetes* was chosen because participants themselves used this descriptor to depict their active involvement in their own care. *Dealing with Type 2 Diabetes* indicates that instead of a treatment being “done for them” or “to them,” as persons with diabetes they must “perform” the self-management treatments for themselves. It is not a passive process but one in which the person with diabetes actively participates. In response to the shared problem of *Dealing with Type 2 Diabetes*, participants responded with the psychosocial process of *Evolving Diabetes Self*. The response by participants within each phase to the overall experience of dealing with diabetes indicates a process that is complex, multidimensional, concurrent, and fluid.

Psychosocial Process: Evolving Diabetes Self

*Evolving Diabetes Self* is the psychosocial process by which participants responded to the psychosocial problem of *Dealing with Type 2 Diabetes*. *Evolving Diabetes Self* was identified as the underlying psychosocial process for the phases and categories within each phase. Some participants had insight into the process, while others
did not. A psychosocial process is defined as having more than one state of being and is labeled with a gerund (Schrieiber & Stern, 2001). A gerund, a verb form with an “ing” suffix, captures change over time. This change may not be recognized by participants during an event or even after an event has occurred. Some participants may have an awareness of events as they occur, while others may not have an overall sense of the process. In grounded theory, this is a perspective called symbolic interactionism that illuminates relationships between individuals and society. Understanding human conduct requires study of both overt and covert behaviors (Schrieiber & Stern, 2001). *Evolving Diabetes Self* is complex, multidimensional, concurrent, and fluid. The process does not have a completion point, has more than one state of being, and changes over time.

As some participants who have insight into this process expressed, “I mean I can’t have my doctor with me 24 hours and holding my hand the whole time. I mean really it’s like retooling; you have to change your whole way of thinking and that’s hard.” *Evolving Diabetes Self* involves more than one state of being and is a process that changes over time. Participants moved along their trajectory with the psychosocial process of *Evolving Diabetes Self* to address their psychosocial problem, which was *Dealing with Type 2 Diabetes*. The process was multidimensional, complex, dynamic, and fluid. The process did not have a completion point. For several participants the trajectory began even before *Getting the Diagnosis* of diabetes type 2. Some participants described expecting the diagnosis of diabetes as they witnessed or cared for family members who had the disease.
Getting the Diagnosis

Participants described being diagnosed with type 2 diabetes as inconvenient and a restrictive disease. Although some were aware that diabetes is a serious disease, some embraced the situation. Others experienced grief, loss of life as they knew it, fear of dying, and lifestyle change. Participants felt on edge and expressed fear of change and the fear of their unknown consequences of having the disease, which were captured within the category called being on edge. The findings indicated that some participants took ownership by helping themselves. Most were aware that diabetes was a serious situation of which they could take control, but that it had to be done daily in terms of self-monitoring medications and glucose levels.

Diabetes treatments (medications, blood glucose self-monitoring supplies, healthful food choices) were described as extra expenses. These activities were further described as structuring other daily activities in a different way. Examples indicated were self-monitoring of blood glucose, taking medication, and eating prior to leaving for work in the morning. The diabetes self-management activities occurred while fulfilling the role of a parent getting children ready for school or as a caregiver for a family member. Participants spoke about identifying issues connected to priorities related to weighing options for food choices and the time needed to care for their diabetes.

Paying out-of-pocket if insurance did not cover or only partially covered the prescribed item was described as a challenge. Healthful food choices suggested at the DSMT programs were described as more expensive to buy and prepare. Participants described giving up foods that they used to enjoy in terms of type, portion size, and
timing of eating. Participants also spoke about their diabetes care as “a lot of stuff which is confusing and scary if not done correctly.” Some stated they were not as serious as they thought they should be in caring for themselves. Some expressed concern about future generations and the diabetes disease process being passed along. “I hope my kids don’t get it” was stated by several participants.

Those identified as exemplar described a different response. Although they knew diabetes is a serious disease that requires attention, they embraced the situation. As one participant stated, “I learned these little tactics like eating the things I really wanted for breakfast and not tons of them, not gigantic servings; then I could spread it out.” There was a sense of helping themselves as opposed to a fear of the change that the diagnosis of diabetes brings. The two categories in this phase of Getting the Diagnosis are being on edge and helping yourself. The being on edge category will be addressed first.

**Being on edge.** Participants expressed a variety of emotions when diagnosed with diabetes. They described fear, loss, grief, anger, and denial. Participants described the loss of life as they had known it. This category is described as knowing that a big change has occurred that has some serious consequences in their lives. The next several comments made by participants express some of the changes and feelings that the diagnosis of type 2 diabetes brought to their lives. Some participants described expecting type 2 diabetes because family members either living or deceased had type 2 diabetes. As one participant stated, “… you are on edge about diabetes.” One participant described this time of her life as: “I was not very happy … a pretty serious change … I had to cram
all of this into my schedule … it’s important to know what can happen if you don’t take care of it.”

Another participant voiced concerns related to her thoughts about diabetes and mortality, “Am I going to die of this stuff? I mean am I going to die of a stroke? Am I going to die of a heart attack?” Another participant spoke about the difficulty of incorporating diabetes management into her lifestyle at first, “… I just figured [that] this is one more thing that I just got to put up with … I just don’t want to do it … I kind of ignored it. I thought [that] maybe if I ignored it, it would go away.”

Anger was expressed by another participant upon finding out that she had type 2 diabetes. Because her mother and grandmother had type 2 diabetes, the participant knew that there was a possibility of getting the disease.

No, I was mad, because I thought I was [pause] through a long period of my life where I didn’t eat any sweets or any goodies and I thought that I was, you know, I thought well everybody that I worked with always said to me how healthy I always ate. But then it seems like after I found out I just went nuts and started eating everything I could get my hands on. I know it sounds crazy but I just kind of did that and I was mad, I think. Although I don’t know why I would be because my grandmother and my mother were both type 2 diabetics and I should have figured I was in line for it. And when I think back, in retrospect it may have happened a lot earlier to me if I would have been eating sweets and anything I wanted. But I was very careful for quite a few years and then when I found out though that I was a diabetic, it’s been kind of down hill since then.
For most, this category of *being on edge* marked the beginning of their trajectory; however, for several participants such as the one who expressed anger in the previous paragraph, the trajectory began even before the diagnosis with diabetes. Several participants described expecting the diagnosis of diabetes as they witnessed or cared for family members either living or deceased who had type 2 diabetes. One participant stated:

> So I had a maternal grandmother that [sic] was diabetic and as a little kid you know I’d see her and I thought this is going to catch up with me some day because my father’s brothers and my dad was [sic] diabetic, so I’ve got it on both sides of my family. I’ve got a double whammy I’m going to be diabetic. I’d been expecting it for years. I know [that] it was hitting me from all over, so I just expected it.

*Helping yourself.* The next category in this phase is that of *helping yourself,* defined as the point participants realized that they have diabetes, the disease was not going away, and they had to take ownership by helping themselves. Participants described that they knew that diabetes was a serious condition over which they had to take control. Participants advised, “That’s life, that’s living, get off it and do something.” Participants indicated that diabetes is something that is dealt with every day in terms of self-monitoring of blood glucose, taking medications, and perhaps involving insulin injections. These activities are described as structuring other daily activities in a different way. Identifying issues related to priorities and weighing options for food choices and the time needed to care for their diabetes was described. As one participant stated:
One should not go through life feeling sorry for themselves, period. And although, I mean, you have grief periods and you think, well, why was I involved in having diabetes? ...Well, because that’s what happens to you. That’s life. That’s living. Get off it and go do something.

This same participant elaborated further how she takes control of her disease process:

Well, you have to say to yourself, you are in control. Nobody else is going to do this and you have to do it. And however you can get there, it’s a means to the end, in my book. And this is the way I do it and it works and I’ve been very happy doing it. And you’re not going to be able to do things you really want to do unless you learn how to control it, so get it through your head right now that’s you’re the patient or the person who has the diabetes has to be in control of the situation.

When asked how diabetes affected thoughts about future plans, this same participant stated the following about unconventional thinking:

Well, I’ve never entered into anything about my future. Simply because, like I said, I figured I have the darn stuff, you have to manage it. It’s not going to go away. So once I got it and got the plan, I’ve just continued to do it and it sort of fits into the rest of my unconventional thinking.

The challenges of eating out were described by another participant regarding choices made from the menu:

You know, I come and go and if I want to go out to lunch I go out to lunch. I look at the menu and I know I don’t want all this pasta and I don’t want all these
sauces and so you know I eat salads and I eat chicken and you know but every once in a while I will splurge and have a steak but there are certain restaurants I don’t go to because of their emphasis on the carbohydrate things so you know I’ve made adjustments.

Another participant described self-monitoring of blood glucose on a daily basis as informing her about blood glucose levels but as something that requires time:

Well just the fact that I have to take the time to poke my … I poke my arm; my fingers were too sensitive and to poke them again, I thought, no way. So this meter I can do my arm and you know I got a big area on both sides to do and but it’s just the fact that I have to do it and it’s something else that takes time. I don’t mind doing it you know, it’s interesting, I’m always waiting to see what the numbers are going to pop up.

The impact of diabetes medication being prescribed made another participant change her eating habits:

Well I think I did it gradually but I think once I had to go on medicine I think it really hit home. I started to do it and my eating habits just started to change within the last year or so and I started to change my eating. Last fall I started to use the smaller plate. I just did a little bit, a little bit as I went. And then all at once I was there.

Participants described realizing that diabetes was not going to go away; they knew that the diagnosis was serious and would require change on a daily basis.
Realizing Options

The phase of *Realizing Options* includes the acquisition of information. All participants had participated in a Diabetes Self-Management Skills and Training (DSMT) program prior to participation in this research project. Others had supplemented their DSMT programs with other resources such as Web sites, books, or libraries. Participants advised being sure that the information sources were reliable. At the time of their diabetes diagnosis, participants sought information to care for this complex disease in which 95% is self-care by the participants themselves. Several participants advised, “Get the facts” or “assume that you know zero and then go from there.” There are two categories in this phase: *being overwhelmed* and *taking it on*.

*Being overwhelmed.* This category was defined by participants as feeling overwhelmed with the complexity and consequences of diabetes and diabetes self-management. Participants indicated that diabetes was something that could not be ignored yet they had difficulty making diabetes a priority at times. One participant described this scenario at the office of her physician after being diagnosed:

I started to cry because I was confused with this stuff, you know, two thousand instructions, you know, [it is] overwhelming, [with] everything going on. I did have a lot of things that were overwhelming. So I would just get, just try to treat [it]. I think that the diabetes is the major part of my being overweight, okay? Is this creating the other serious issues, you know? I might be talking in circles here. The right hand does not know what the left hand’s doing, okay. Try to be on the
same page, okay. It’s already confusing as it is now, and we look to them to clarify it for us, just to, you know.

Many participants described being concerned about the consequences if they, “don’t do it right” or “if they mess up it is permanent.” Several participants described the importance of “getting the facts” and questioned the reliability of the information, “…don’t listen to what other people tell you, find reliable sources.” Participants indicated that diabetes was something that could not be ignored but that there was difficulty in making diabetes a priority at times. As one participant stated,

... it’s hard when you know that the doctor’s telling you to do things and they are good for you but then when you are faced with the reality of your day-to-day life. Sometimes choices that you want to make, you necessarily can’t.

The other category in this phase is that of taking it on.

Taking it on. This category is defined as embracing diabetes self-management information and the act of taking on the disease itself. As another participant stated, “Watch everything, it’s a lifetime thing, you control it, you can do it.” If there were a delay in entering a diabetes class or seeing the diabetes nurse or dietitian, then participants suggested supplementing with the Internet and library as a way to get information about diabetes. Several participants who were identified as exemplars spoke about an ability to use both self-monitored blood glucose values and laboratory values to benchmark their diabetes status. One participant stated:

Well, you have to say to yourself, you are in control. Nobody else is going to do this and you have to do it. And however you can get there, it’s a means to the end,
in my book. And this is the way I do it and it works and I’ve been very happy doing it. And number two, I can see it in the lab work. And I make him give me copies of it, so I take it home and look at it very closely.

Only thing I can say is once I test myself, I take my medicine and I know according to the level of my sugar that I’m all right. I test and it comes back … if it comes back high, first thing I do is look to be sure I got the right code numbers and the testing stuff is done right, you know, and then when I’ve settled that in my mind, then I realize that if it came back high, just get out there and move.

Participants involved with taking it on obtained as much information as possible. They stressed that the information must be from reliable sources. They are proactive in obtaining information about their diabetes, including blood glucose and laboratory results. The next phase, Making Decisions, is where the participants used the information to make choices about their diabetes care.

Making Decisions

As the evolving model and the interview data were reviewed further, the phase Making Decisions emerged. Participants described making decisions by weighing options as to where they were situated in life, their developmental stage in life, their affecting surrounding systems (family, environment, health care system, insurance or lack of insurance), and their changing or dynamic disease state. Making Decisions will be discussed here, although it is realized that decisions may be interspersed throughout this dynamic model. Making Decisions involves transitions that are influenced by four categories: being situated, living developmental state, being affected by surrounding
systems, and changing and dynamic disease state. Being situated is defined as placing of self in time, space, and relationships (Meleis, 2000). Living developmental state is defined as one’s age and lifespan stage; being affected by surrounding systems is defined as the wider social context of not only health care systems but other social systems, such as family, church and community; and changing and dynamic disease state is defined as degree of metabolic control and presence of co-morbid conditions.

Major decisions that were identified throughout the four categories included finances to pay for prescribed medical regimes and dietary regimes, access to purchase healthful food choices, time to perform the medical and dietary regimes, competing priorities, and presence of co-morbid conditions. Diabetes treatments (medications, blood glucose self-monitoring supplies, healthy food choices) were described as expensive. Although some participants indicated that they had information about diabetes self-management skills and training, they described being challenged in applying this information in their lives on a daily basis.

The DSMT activities are explained as structuring other daily activities in a different way. An example may be self-monitoring of blood glucose, taking medication, and eating prior to leaving for work in the morning. The diabetes self-management activities occurred while fulfilling the role of a parent getting children ready for school or as a caregiver for a family member. Participants spoke about identifying issues related to priorities connected to weighing options for food choices and the time needed to care for their diabetes. They experienced an ambivalence regarding identity of being a person with diabetes.
Being situated. Within the category of being situated an ambivalence of their diabetes identity was evident, which is described as a conflicted state between the normal self versus the diabetes self. The conflicted view was described by participants as viewing their lives through a “bifocal lens” and depended on the degree of integration the participants had regarding what they described as their “normal self” versus their “diabetes self.” This determined the process of how decisions were made regarding diabetes self-management. One participant stated:

[D]iabetes is so strange because it’s just one of those, like I said before, is that since you can live with it and it’s manageable, even if you are not doing the right things you know like I said it’s not like it’s a death sentence, even though it actually could be a death sentence you know but it’s just not looked at that way, so I think it makes it easier for those of us who have it to not take it as seriously, even though I’m sitting here and intellectually I know I should do this.

There was a comparison of their lives before diabetes based on their attitudes, practices, and experiences. How participants viewed themselves regarding the diabetes diagnosis made a difference regarding how they made decisions in this category, for example, choosing foods or portion sizes that are known to make blood glucose rise or that may cause weight gain. As one participant stated regarding being situated:

Oh before I just used to eat anything, but now, you know, I’ll look at I already had that piece of fruit, already had that piece of cake and you think to yourself, the cake’s just going to make me sick, you know, it makes you sick. What I ate. I used to love macaroni and cheese and all those noodles and spaghetti and they
make you sick. And how I feel, if I, you know, if I don’t feel sick. Like I told you, if you eat something and you eat three, four pieces of cake ‘cause it tastes good, then you’re sitting there thinking, why did I do that?

And you can preach ... and I think to myself; everybody told me ... it didn’t matter. I wanted that and that was it. I wanted that piece of food; it didn’t matter if it was going to blow me up like a balloon. I wanted it anyway, but it takes years of understanding what you did before and what this does, what happens when you do this [now].

A participant described an aura surrounding type 2 diabetes, especially for those who are obese to whom blame was assigned by others for having the disease, particularly if metabolic control as defined by medical standards was not achieved. One participant stated, “If you have type 2, because I think a lot of people think, especially with the weight factor, that you’ve brought it upon yourself.” Another participant said, “… you’re not constantly sitting there thinking, ‘I have diabetes, I have to do this,’ but it’s like right there under the surface, you know that you have it.”

An ambivalence regarding identity of being a person with diabetes was experienced some participants. Decisions regarding diabetes self-management were filtered through the bifocal view of normal self versus diabetes self, which was often conflicted. Eating differently, especially in social situations, while at work, or on vacation were the decisions described in this category. Other decisions involved related to being situated are the timing and performance of self-monitoring of blood glucose, timing and taking of medications, and the timing and performance of activity. One participant spoke
about her self-monitoring of blood glucose, how it was delayed, and what she did about it:

It’s hard to remember. You know, you’re busy doing things and ... I’m supposed to do it at 12 noon and at midnight, because that’s the time we figured, 12 hours apart, and I told her that probably would be the best because it’s in the middle. But then you get busy doing something, you look at that clock and it’s 2:00 and oh-oh. Well, I’ll just do it now. It’s the best I can do. I can’t turn the time back.

Being situated with diabetes is similar to Meleis’ (2000) work with migrant workers as placing of self in terms of time, space, and relationships. They understood their new life in the United States by comparing it with their old life as a migrant worker. Likewise persons with diabetes often make comparisons between their normal self versus diabetes self by using this bifocal view to make daily decisions regarding their care. This comparison helped them to make meaning of their experiences, of how diabetes is incorporated into their lives, by situating themselves in terms of time, space, and relationships. There is a comparison of their lives before diabetes based on their attitudes, practices, and experiences. Just as with the immigrants who experienced this as multidirectional in that sometimes their pre- versus post immigration experience was favored, persons with diabetes may favor their pre- versus post-diabetes diagnosis at different times. As one participant expressed,

[T]hat I can lose my sight, I can lose limbs, I can die. I could die from it. Before I was diagnosed I lived different. I mean, I pretty much ate what I wanted to and I
can’t do that no more. I got to watch out what I do. I mean, from cuts, anything. I gotta [sic] just be cautious on everything I do and it’s scary.

Another participant stated:

[C]hanges in the diet from what any normal person can just pick up whatever and they don’t have to take into consideration you know what’s in this you know how much is in this you know. You said the most challenging thing? And then also too I mean the having to, you know like ... nobody understands what it’s like to have to prick yourself with a needle every single day you know for the rest of your life, if they’ve never had to do that before, so of course that’s something that would definitely be.

Participants described application of diabetes self-management skills and training within this category as a comparison or conflict between their normal self versus their diabetes self. Participants viewed their lives through a bifocal lens which determined the process of how decisions were made regarding diabetes self-management. Eating differently, especially in social situations, while at work, or on vacation were the decisions described in this category. Other decisions involved the timing and performance of self-monitoring of blood glucose, timing and taking of medications, and the timing and performance of activity. Another category in this phase is that of living developmental state.

Living developmental state. This category is defined as the developmental state of the participant’s life and age. This made a difference in terms of being single, married, or
divorced, and years of education. The experience of being a caregiver and therefore being on the back burner was described by the following participant.

Well, there’s been so many surgeries in the last two years and all, the husband and the chemo, and his surgeries, and traveling to Columbus and coming back and taking care of him. And a daughter that’s a high risk for pregnancy, so trying to get through all those. You know you do worry about all your kids and the grandkids and then if they’re going to be okay.

Well, every morning you know you get up, you take your blood, and then you go and you have your breakfast and then you, I’m really bad about not having snacks in between, or there’s so much that’s going on in my life that I take the back seat. So you know I might not have lunch for hours, which I’m only hurting myself, I know that. I’ve got to be better about controlling what I do. Sometime you just have to say, wait a minute I need to do this. It’s hard to do though, hard to do. I think that’s the hardest thing, taking the time just to take care of it. I think it would probably be an easier transition if I did that. I did it in the beginning and there was still just as much stuff going on. Then you let other things creep in. I mean, I think it has a lot to do with your stress factor, what’s going on with your life, what’s happening too. I don’t know if it affects sugar but I’m assuming it must.

Being a single mother affected diabetes self-management choices for this participant because she had conflicting priorities.
You know so of course you have my job, my schooling and my son you know and all that you know tends to come first over my own health. So yeah, I would have to say it is lower on the priority list. Again, I’m not a … I’m a functional person, okay. I have a job, I’m a mom; I’m a single mom, okay. And I do, you know … I’m not a nutcase here.

Choices to perform diabetes self-management often involved being in conflict with her roles as an employee, a student, and a mother. She found those roles in competition with diabetes self-management. Choices made in this category involved the price of healthy foods versus buying food for the entire family, timing of the self-monitored blood glucose levels, and timing of a second dose of diabetes medication. She described what it was like for her to make food choices while in the grocery store:

It guess it’s just too, and since I have a 6-year-old, it’s hard to eliminate sugar out of everything you know and that’s just the way the stores are set. Everything you know there is good food out there that’s good for you but a lot of it’s also much more expensive too. You know there’s some great grocery stores you can go to and get organic stuff and that but everything is just so much more expensive than all the things that are packed with all the bad stuff for you. So it’s hard when you know what the doctor’s telling you to do things and they are good for you but then when you are faced with the reality of your day-to-day life sometimes choices that you want to make, you necessarily can’t, you know so.

Well yeah, just with the increase, let alone you know for all the, and that’s how you can rack up just astronomical amount of money just in the produce
section before you even get to the rest of the store. I mean it’s just you know if you are trying to buy all fruits and vegetables but everything is just you know it’s all like macaroni and cheese, that’s horrible for you. That’s like 30 cents for a box of it you know I mean there’s just a big difference so....

Because of her role as a mother, an employee and as a student, another participant would forget or delay self-monitoring of blood glucose or a second dose of medication. This participant described the difficulties that she had with managing diabetes while at her job:

And here like I said in my job, how am I going to get through the rest of the day. It’s only four o’clock and I’m going to be here till nine o’clock. Oh-mi-god, and I feel like … and then I figure to test my … and then I figure out, go get something to eat that I can take the Metformin with, or something like that, you know. No, I don’t. Two days a week are my late nights. I work till nine o’clock, but three days I work from 8 to 4:30, so. I’m working a goofy schedule, you know. I got two kids, two teenagers, and two, oh. Just all this stuff. I don’t have time to address a lot of this stuff. I don’t have time to where other pressing issues have to be dealt with right now. That’s part of why it’s not an easy solution to deal with this one because I know I’ve got other things that I still have to take care of.

How friends reacted in social situations to the blood glucose meter and insulin administration was described by the following participant:

And I think that’s the hardest part is, because people think it’s like a wallet or a camera and then when they find out that it’s your insulin and your monitor and
your glucose tablets, they just start to freak on you. So, and then my friends have a hard time, ‘cause we go out to watch, like, sports events at the bar and there’ll be drinking and I can’t really drink and they go, “You used to drink with us!” Participants described application of diabetes self-management within this category within the context of age and state of developmental life.

**Being affected by surrounding systems.** Systems that may affect participants and their diabetes self-management include the health care system, health care providers, and either having insurance or not. System could be the community-wide social context, which involves socioeconomic status, family, social network and support, culture, church, location of health facilities, type of grocery stores and availability of fresh food markets, schools, transportation, safety, environmental hazards and community resources (parks, nature walks, community center with a pool or exercise equipment). One participant spoke about the community center that was a great distance for her to drive so she did not use it. Due to the distance and time involved to do the activity, the participant decided not to go:

> [M]y insurance paid for a membership at the rec center but it’s not that close to me. And I figure by the time I get there and I change my clothes and I get in and I come out and I have to shower and wash my hair to get the chlorine out and get dressed and drive back home, the time I’ve spent swimming, I might have lost 3 hours out of my day. I don’t want to do that every day. So, and you know I’ve got other activities and I thought “when do I fit this in?”
Frustration with lack of insurance coverage in order to be followed by an endocrinologist was expressed by this participant:

One thing, I would like to go to an endocrinologist because I think I could cut out a lot of different specialists’ visits and possibly manage it better, but none of the local ones will take the Medicaid HMO. I don’t even think they take Medicaid period. Some of the physicians will take fee-for-service card but not the Medicaid HMO cards, but they won’t take either. In some ways I’d feel more comfortable going to an endocrinologist, you know, for management.

Advice was offered by the same participant regarding her repeated experience at office appointments:

I would say, secondly, and this happens repeatedly. I’ve taken my time to fill out your paperwork because this is my history; take the time to read it. If you don’t have the time, then don’t quadruple book patients. I understand people want to see you; I understand there’s a money issue, but there’s also misdiagnosis issues, missed issues.

Experience with her health care provider regarding prescribed medications and insurance coverage was expressed by another participant:

You know, just because you have insurance, it doesn’t mean it’s going to cover the pills that the doctor wants to prescribe to you, so they really need to look at the patient and figure out if they can afford it and take that extra time. Not just script it out, hand it to them and say, “See ya in a couple weeks.” ‘Cause I’ve been there. I’ve had the doctors that do that, make out the script and don’t bother
to see if you have, you know, what kind of insurance that you have. “Is this going to be affordable?” Or anything else.

You can’t treat by just what the book says or what the medical logs say, and that. You’ve got to go by what the patient’s work schedule is, what’s going on in their life. It’s not all about … you’ve got to look at the person to understand if they can afford the meds that you want to put them on. My one doctor wanted to put me on Actos. It’s a diabetes pill. Took it to the pharmacy and it was $127 that I had to pay. So sometimes they need to make sure that the patient can afford it and if they can’t, then find something that’s going to help them, you know, get the pills that they need to get healthy.

In response to the question regarding what health care providers could do differently when treating diabetes, this participant voiced her wish for the following:

I think I need, we probably need someone to follow through with us every week. Bring in your food diaries, because when I went to Weight Watchers I lost 6 ounces in a month and that was watching. There wasn’t anyone there to say, well let me look at your food diary and see where maybe you’re going wrong. In my case that’s it and there could be a lot of people out there like that.

Some of the challenges experienced while performing DSMT were described by participants as within the surrounding systems of community, financial issues for both medical and dietary regimes, insurance issues, and challenges they experienced with health care providers. Choices within this category involved: whether to exercise, because of the distance and time involved to attend a recreation center; whether to make
an appointment with an endocrinologist due to lack of insurance coverage; and whether prescriptions are obtained due to the high cost. Participants advised that their health care professionals take into consideration cost of medication, other diabetes supplies and food while prescribing medical and dietary regimes, to be sure that the plan is realistic. Another request from participants was that of an easy plan and an accountability system with their health care provider, especially as relates to the food plan. The next category describes the challenges that participants experienced with the disease process of diabetes.

*Changing and dynamic disease state.* Participants made choices in this category based on metabolic control, disease progression, symptoms of acute and chronic complications, and the presence of co-morbid conditions. This category is defined as degree of metabolic control, disease progression, symptoms of acute and chronic complications, and the presence of co-morbid conditions. For example, participants described that they felt that their disease had progressed if they became insulin using. This was significant for both participants and their families in terms of viewing diabetes as more serious. Participants viewed diet controlled and the use of oral agents as meaning that their diabetes was not as serious versus the use of insulin in which they perceived that their diabetes as worsened. As one participant stated about her progression from oral diabetes medications to the use of insulin:

Well like I said, it was on my mom’s side and on my dad’s side so I knew what my aunt and my grandmother was going through with the shots, so I go, “Oh God, what’s going to happen now?” And everyone goes “Oh, you’re just on a pill; it’s
okay, it’s okay.” Well now I’m on the insulin. So now you really got to watch, you know, really watch what you’re doing and everything, so.

Participants described acute complications that they experienced, in particular hypoglycemic reactions. One participant described this as the “Steel Magnolia” feeling (in reference to a scene from a movie of the same name in which the lead character has diabetes and experiences a severe hypoglycemic reaction). Others described hospitalizations due to acute disease states (e.g. infections) which exacerbated their diabetes by significantly raising blood glucose. Participants were fearful of long-range complications described as foot and leg amputations, blindness, and kidney failure. Participants described the impact of co-morbid conditions such as heart disease, lipid issues, obesity, stroke, and myocardial infarction. Grief and loss were a common theme among some participants. One participant, after experiencing a hypoglycemic episode while on a trip, expressed that she did not want to be away from her family, doctors, and medical facilities:

Well, I feel I have had to give up traveling because I’m concerned about being away from home and away from my daughter or something. Only because I went on a bus trip one time and I thought, not feeling really good. I was dizzy, very lightheaded and I didn’t have my medicines with me so I couldn’t take … that was before I thought about taking the stuff with me … you know and I don’t want to push it and advertise, tell everybody that I have it and so I just don’t go.

Within this category, the application of diabetes self-management skills and training involved awareness of the consequences of uncontrolled diabetes both acute and
long-term. Participants described their experiences in detail as this category often made an impact in making the diagnosis of diabetes a reality in their lives. For some this provided incentive to take their diabetes more seriously in applying diabetes self-management. As one participant stated, “… it made it more real and I knew that I had to take it serious.” This participant decided not to take vacations, even short day trips, after she experienced hypoglycemia; she was afraid to be away from her physician.

Several participants were unaware of how to treat a hypoglycemic reaction as they could not remember the information from Diabetes Self-Management Skills and Training (DSMT) programs. Other participants treated hypoglycemia with foods not recommended to achieve a quick rise in blood glucose. Participants described over-treating hypoglycemia episodes with 16 ounces of regular soda instead of 4 ounces of regular soda. Several participants did not know what comprised normal blood glucose levels, what was considered too low and what was considered too high. Several participants did not make the connection of using of the blood glucose meter as a tool to assist with this issue. Although several participants knew how to operate the meter, collect the blood glucose levels and record blood glucose values, they did not know the meaning of the numbers.

A few participants had co-morbid conditions which impacted decisions as to which disease process was a priority for follow-up appointments, purchasing medications, and food choices. Several participants with diabetes and heart disease, for example, were prescribed both a diabetes and low sodium meal plan. From the
participants’ perspective, this is challenging when choosing food options. As one participant stated:

  Diabetes is just a hard thing to deal with. It’s getting a lot easier, they’re finding a lot of ways to help people with diabetes, but diabetes is a hard thing to deal with, a lot of people with a lot of problems. A lot of problems, when you have multiple problems, it’s hard to deal with. You’ve emotional problems and physical problems; it’s hard to deal with all of it: cholesterol, diabetes, physical problems, mental problems. It’s hard to deal with all this at once.

Another participant described her concern about figuring out portion sizes and her concern about being able to calculate grams of carbohydrate:

  So going back, that was something else I was afraid of. My math skills are not horrible, but they’re not great. On the SAT I think I have a 600 out of a 700 group. I mean, it’s just … to try and look at every piece of food and calculate that, I was worried I wouldn’t be able to figure that out. So when I took the classes and learned about counting carbs and subtracting fiber, it’s like, oh I am so glad. Grams vary, but for some reason, I have very good recall, I have very good eyeball perception and I’ve actually tried … okay, half cup of cereal has so many carbs and I’ll just pour it in a bowl and then measure it. I have not had to measure food. If I want steak I get a real thin cut, like a third of a pound or .3 pound, you know. I have very good visual observation.

The price of food and how she supplements with a food bank was described by another participant:
Actually what we do is we’ll go to the grocery store and we try to hit places that have the sales, like out where my mom lives there’s a grocery store that has five packages of different meats for five for 20 bucks, so we’ll go out there and get $40 worth of the meat, so there’s chicken, steaks, hamburgers, kielbasa. So that helps. Sometimes we’ll go to Stouffer’s and get the macaroni-and-cheese and that’s a big pan, and then we’ll make that and then take it to work the next day. So we really try to make sure that I have food. If, there’s a couple of times that we didn’t have food in the house and we ended up going to the food bank just to get something in the house so that I had something to eat. So you gotta do what you gotta do. You know, I make too much money to get food stamps but I could have tried to get on Medicaid because I am a diabetic and I’m on insulin but I can still work.

The meaning of blood glucose values that are self-monitored was mentioned by this participant as important. She advised that health care professionals stress this more and indicate what the blood glucose values mean:

Or what you should have at certain times of the day. And if you checked at a certain time is it better to have this or that. I personally need that, I think there should be, they should stress that a little. Instead of, I mean you can take your blood but if you don’t understand it, what, you’re just writing it down?

Major decisions that were identified throughout the four categories included finances to pay for prescribed medical regimes and dietary regimes, access to purchase
healthful food choices, time to perform the medical and dietary regimes, competing priorities, and presence of co-morbid conditions.

Living the Consequences

Living the Consequences is the phase in which participants live with the results of their decisions whether positive or negative or with an unawareness of the impact of their decisions. The two categories in this phase include waiting for the other shoe to drop and knowing how far to go. Several participants described expending a great deal of effort on managing their diabetes with very little to show for it. Several participants expressed their greatest feared consequences of diabetes as being amputation of feet and legs, blindness, kidney failure, and death. Advice given by participants was that of “living with it” as routine or automatic. Participants, however, expressed living with the condition whether they were within metabolic control as defined by medical standards or not. Metabolic control of participants was made known to the researcher by the A1c and laboratory values obtained from medical records. The outcome of the trajectories may be a transition toward either vulnerability or toward health; therefore, the consequences that participants described while living with diabetes may be positive or negative.

Waiting for the other shoe to drop. In this category most participants described fearing the unknown consequences of diabetes and mentioned blindness as their greatest fear. Participants expressed concern regarding the trajectory of the diabetes disease process and a worsening state. Choices were made that involved some participants opting not to do anything and to just wait for the other shoe to drop. This was done as
participants found treatment regimes to be complex, time consuming, feared the negative effects of hypoglycemia, or found that the financial costs were too high. Instead they hoped for the best by following what they felt they could do. Statements such as “when it hits it hurts” or “waiting for the other shoe to drop” were expressed by participants. One participant questioned her treatment:

Am I getting myself better or am I digging myself a bigger hole? Am I creating more problems by doing all that or is all this stuff necessary? Am I on the road of feeling better or? I feel like I’m on the road of total confusion here, ‘cause I don’t know … I’m trying to think. I don’t. I really. I don’t know how to answer it. I’m trying to think of how … do I have to wait for the brick to drop on my, to hit me on the head, or whatever, to get me to take it serious enough? I don’t know how to answer that. Yeah. But again, I don’t want to wait till I’m blind till I take it serious. I don’t want to wait until I’m missing a foot till I take it serious. Okay. I guess I’m waiting for it to get better before it gets worse. I keep trying to find ways to make it better before it gets worse. Do you understand what I’m saying? It’s just pretty much figuring out how I’m going to deal with it. Like I said, waiting for the brick to fall, okay, as to how severe or where, where do I stand as far as my own particular therapy? Where do I stand in that picture? Am I asking for the impossible because there’s no way of knowing where I stand, how … I don’t know. I guess I’m more afraid of it now than I was. Is diabetes ranked up there with cold and flu?
Okay, you know, am I going to have to suffer these consequences with the eyes and the feet and, you know, strokes and stuff like that? I don’t know. I just don’t know, and that’s the scary part of it. Not knowing the future, okay? Is what I’m doing now going to affect the future? Yeah, it does, but to what extent? So that’s how it’s affecting … the fear.

Other participants spoke about “being stuck” and “being back to square one.” Participants expressed interest in knowing how their diabetes was faring in terms of future consequences, “how severe is severe?” or “knock on wood that you are in betterness [sic] cause when it hits you, it hurts.” Several expressed not knowing what to expect with diabetes and that diabetes was a serious illness that could not be ignored. One participant asked, “… how many warnings am I going to get before it just kills me? I don’t know.” Another category in this phase is that of knowing how far to go in which participants described how they used the DSMT information and other resources to assist them in managing their diabetes.

Knowing how far to go. This category is defined as ability by participants to use objective measures such as blood glucose values, lab values, and physical symptoms in balance with food intake and activity. This was done in a strategic or pre-planned way, as they were able to stay within metabolic control while manipulating medications, food intake, or activity. Choices included in this category involved performing self-monitored blood glucose readings, proactively requesting laboratory values from their clinics, careful selection and timing of food choices, and performing and timing of activity. In addition, within this category participants had a knowledgeable resource person who
could provide timely feedback. Several exemplars among the sample participants were identified through the A1C and laboratory values obtained from the medical records. Exemplar is defined as a participant who had A1c and blood glucose values in range. Exemplars provided insight regarding the ability to integrate the “normal self” with the “diabetes self.” This was done through the ability to “own and apply” the information received about diabetes care activities. They described “playing with it” and “knowing how far I can go.” They used their self-monitored blood glucose values and laboratory values to assist themselves in this application process. The exemplars had a readily available resource, themselves, a friend, or relative who was knowledgeable and able to provide timely feedback. As one participant stated in the knowing how far to go category:

    I keep everything organized. Keep all my phone numbers in this little business card thing, and I try to keep everything together. I try to keep all my lab work until … after a couple months, I throw it away. I have a list of my medications in there. I keep them all written down. So I’m on like 18 different kinds, but I don’t take them all … some of them are PRN.

    Playing with or figuring out DSMT was described by the following participant as needed, as each situation is different:

    Play with it all and figure it out yourself. If you have questions, call your advisor or your technician or whoever tells you about diabetes, but you have to figure out your own lifestyle. And I think it’s true of little kids as well as with older people. I think kids need to be told, “This is the way it’s done.” But if they can’t do it that way all the time, then they need to figure out how they can do it.
I can see it in the lab work. And I make him give me copies of it, so I take it home and look at it very closely, and when I test and it comes back … if it comes back high, first thing I do is look to be sure I got the right code numbers and the testing stuff is done right, you know, and then when I’ve settled that in my mind, then I realize that if it came back high, just get out there and move.

The importance of support received from a significant partner regarding her diabetes was described by the following participant:

She keeps a list of all my meds with her, so if I’m at work and I have to go to the hospital, she gets off work and comes, she has the meds, she has a copy of my medical log. We keep one monitor with me and then one monitor with her, then, in like, her car so if we’re out and it drops … so she’s very good at keeping the diabetes monitors and keeping all that stuff together.

It’s like, she does my pills, she makes sure that I have the insulin, she makes sure I have the needles and the wipes and … it’s like, “Stop!” She’s like, “Well I’ve got to make sure you have this.” “I have it. If I get low, I’ll fill it.” “Well, no, ‘cause you forget. You get sidetracked.”

This same participant advised the following regarding health professionals and the importance of seeing a diabetes doctor:

Don’t be afraid to ask questions. If your doctor don’t want to answer your questions, then get another doctor, and that. Especially go see a diabetic doctor, especially. Don’t wait till you’re out of control and in the hospital and, you know, don’t … catch it now and then get on the path so that you know what’s going on.
So that you know what you can eat and what you can’t eat and how much that you can have, ‘cause it really will help.

The benefits of having a person knowledgeable about diabetes readily available to answer questions and to provide advisement was described by the following participant:

I talked to my wife and my sister-in-law, who’s a nurse, and they explained to me what it was and it wasn’t going away. ... Well, she is a nurse practitioner and she helped explain actually what the diabetes is because before I had... another doctor and he didn’t explain things well. Well they explained to me what it was and what I had to do to control it. Then I went and saw a dietitian and then the doctor started testing my blood sugars three times a day and I realized I was overweight and I was eating a lot junk that I didn’t really need.

My wife helps me a lot. I mean she will see me eating something I shouldn’t be or you know she will mention it to me and sometimes I’ll get mad at her and I’ll tell her, from the TV shows, “what, are you the diabetes police now on my food” and then we’ll go at it and usually she is right but you like to think you have control and that you know what’s good for yourself.... Yes, it’s immediate feedback and in the A1Cs, which right now I get about every 6 months, is a long-term look at its past and how I’ve done.

_Dealing with Type 2 Diabetes_ was identified as the psychosocial problem shared by participants. The psychosocial process for this problem was called _Evolving Diabetes Self_. The psychosocial process of _Evolving Diabetes Self_ encompasses four phases with interrelated categories within each phase that impact the psychosocial problem of
Dealing with Type 2 Diabetes. The four phases are (a) Getting the Diagnosis, (b) Realizing Options, (c) Making Decisions, and (d) Living the Consequences. The process is multidimensional, complex, dynamic, and fluid. The process does not have a completion point. For several participants the trajectory began even before Getting the Diagnosis of type 2 diabetes. Some participants described expecting the diagnosis of diabetes as they had witnessed or cared for family members who had the disease. Evolving Diabetes Self involves more than one state of being and is a process that changes over time.

Contextual Factors and Critical Junctures

This next section addresses the three supporting sub-research questions. The first is, What are the contextual factors influencing diabetes self-management skills and training?

Contextual Factors

Contextual factors were self-reported during the interview process and in the demographic profile. The wider social context is the study of the behavior of human beings within their social environments. In this sample, contextual factors reported by participants that influenced diabetes self-management involved whether they were expecting the diagnosis of diabetes, feared consequences of the diagnosis, availability of finances to pay for prescribed medical and dietary regimes, access to healthful food choices within environments where participants lived, time involved to perform the medical and dietary regimes, competing priorities (such as a role as a caregiver, parent or
employee), and co-morbid conditions (such as celiac sprue, hypertension, hyperlipidemia, heart disease, obesity).

A participant spoke about expecting the diagnosis of type 2 diabetes as she has current or deceased family members with the disease:

My life … eating, watching what I eat, trying to get sleep, taking care of the body – my grandmother had diabetes, my uncle had diabetes, my other aunt had diabetes and all three of them died. And then I have friends that were diabetic, so to me when I was told I had diabetes, and then having loved ones die, it was like lessons and that ‘cause all the ones I knew had it have died since I have been diagnosed. So I really watch my pills and what I’m doing and exercising and watch my food intake and everything else, so.

Diabetes treatments (medications, blood glucose self-monitoring supplies, and healthful food choices) were described as extra expenses. Participants described paying out-of-pocket if insurance did not cover or only partially covered the prescribed item.

… and some of the prescriptions that I have, Metformin, yes, you can go to Wal-Mart, and get it for four dollars a bottle, okay? But sometimes when I go to take, get some stuff, you know, these things can run anywhere from 15 up to 40 dollars, you know, just for a one-month’s supply. Yeah, and I have insurance; I have good insurance, but my prescriptions cost me … you know, when you have six of this stuff here, seven of this stuff there every month, you know, what are you going to do? What do you do?
Healthful food choices suggested at the DSMT programs were described as more expensive to buy and prepare. A participant stated the following about financing prescribed food plans:

Well it ain’t so much that … well, I can’t afford to eat breakfast, lunch and dinner. You know, so that kind of … I don’t know how that’s going to affect me being a diabetic and they saying I’ve got to maintain a diet, a certain diet for, when I don’t have the finances to do so, you know.

Participants described giving up foods that they used to enjoy in terms of type, portion size, and timing of eating. A participant described her struggle with her food plan:

I mean at first when I was told I went out and I bought like the whole wheat flour instead of the regular you know and tried to make changes in my diet and everything and then things would just slowly slip back.

Giving up or limiting certain foods was considered a loss by the following participant who stated:

I had to give up a lot of stuff. Sweets and different pastas and I had to add vegetables and stuff. I ain’t a big vegetable person. I had to … and fruit, you know. I had to focus on stuff like that and keep fat out of my diet and just a lot of different things that was different to me. Because, like, if I wanted it, I ate it. You know what I mean? I can’t do that. I shouldn’t do it. And every time I did, I’d mess up, you know what I mean.

The fear about the possible complications that could be experienced with diabetes was expressed by the following participant:
Your sugar goes up … you don’t know what your sugar’s going to be like. You got to worry about, what are you going to have, high blood sugar or low blood sugar? Your fingers are numb. You’re sore all the time and you’ve got to worry about your feet, whether you’re going to lose your foot. Lose your leg and have to go on dialysis, and so you got to worry about all that, and you can lose your eyesight. It’s hard, you know.

The challenges of working swing shifts and trying to manage her diabetes with insulin were described by the following participant:

Well, that’s it, that’s the hardest, ‘cause like, I haven’t given myself my shot now because I’m off. So I’m off for two so I have to give my shot this afternoon and then again before we go to bed. Then when I go on my night shift, then I sleep, get up at two, give myself the shot … so I got to …

The difficulty experienced with prioritizing the problems of diabetes within her life, especially the co-morbid conditions was shared by the following participant:

Diabetes is just a hard thing to deal with. It’s getting a lot easier, they’re finding a lot of ways to help people with diabetes, but diabetes is a hard thing to deal with, a lot of people with a lot of problems. A lot of problems, when you have multiple problems it’s hard to deal with. You’ve emotional problems and physical problems; it’s hard to deal with all of it: cholesterol, diabetes, physical problems, mental problems. It’s hard to deal with all this at once. But I’m doing it. I can do it and I know I can.
Examples of contextual factors reported by participants that influenced diabetes self-management involved expecting the diagnosis of diabetes, feared consequences of the diagnosis, availability of finances to pay for prescribed medical and dietary regimes, and for prescribed dietary regimes. Other contextual factors were access to healthful food choices within the environments where participants lived, time involved to perform the medical and dietary regimes, competing priorities (an employee who may work swing shifts), and co-morbid conditions (hyperlipidemia, heart disease, obesity).

**Critical Junctures**

This next section addresses the second and third research sub-questions which are interrelated: What are the critical junctures of diabetes self-management? and What choices are made at critical junctures? Critical junctures occurred when participants experienced the acute complications of hypoglycemic and hyperglycemic episodes. In this sample, critical junctures occurred when participants began to use insulin. In the literature, critical junctures are usually described as major life events such as relocation, marriage, birth of a child, or death of a close relative (Schrieber & Stern, 2000). Critical junctures are points in time or a crisis situation in which decisions must be made by persons with diabetes. These events are not planned or anticipated, but require some sort of weighing of options for management.

When describing their experiences, participants focused on the complex changes that the diagnosis of diabetes brought to their lives. Participants described hypoglycemic episodes that were severe enough to require treatment. Others described hospitalizations
due to acute disease states (e.g. infections) which exacerbated their diabetes by significantly raising their blood glucose. As one participant stated:

It’s scary/irritation. I have had, for some reason, two possibly three hypoglycemic episodes in the past month or two and I am unaware that I am hypoglycemic. And I would like to be keeping better track of that right now and I’m unable to do so because there’s not enough strips to test that frequently. Like if I have a hypoglycemic episode, you’re supposed to check 15 minutes later. Well, I’ve got three strips that day; there’s not enough to accommodate that.

When describing hyperglycemia issues a participant stated:

I know it’s going to be high. I know I can’t check it two or three times and sometimes, and this is wrong, but sometimes I don’t check it at all because it’s frustrating to me that I can’t monitor it better. Or if I know I’m getting sick and I’ve checked it two or three times a day and I know there’s not enough strips, then I might skip the next day. That bothers me.

The following participant described her experience when blood glucose levels were found to be too high:

When I had the high blood sugars my face was always really beet red. It looked like I was about to explode. I don’t sweat that much when it’s under control. When it’s not under control and my sugars are high, you have like a sugary smell to you and like with me, my face gets real red, like I’m about to explode, and I have the high sugary smell, so that’s how that I know if it’s low or high, and that.
Another example of a critical juncture for participants is when they became insulin using (defined as progressing from diet controlled to oral agent controlled to now insulin using) as participants described feeling that their disease had progressed. This was significant for both participants and their families as viewing diabetes as more serious. A participant stated:

… at that time I was thinking I ain’t the type of person that’s going to deal with taking pills and if I had to shoot myself in the stomach or whatever with insulin, I feared that. I was scared of it all.

Taking insulin in front of friends and family was an issue for the following participant. She described how she was asked not to give herself insulin in their presence:

“I’m on insulin now, I’m a diabetic, you know.” “Well, I didn’t know you was a diabetic.” “Well, I don’t like to tell people that I’m a diabetic, ‘cause” … then I’ll go in the back room and give myself a shot and that’s it. So, but you get different reactions from people when you tell them you’ve got to go and take your insulin or you got to go do something. They’re like, “What you gotta do?” “I’m just going to do something; I’ll be right back.” “Well, what are you gonna do?” “You really don’t want to know.” My mom and dad have a real hard time with me now being on the insulin ‘cause I’m giving myself the shots and everything and my mom’s like, “Just don’t do it in the house. Don’t.”

Critical junctures are usually described as major life events such as relocation, marriage, birth of a child, or death of a close relative (Schrieber & Stern, 2000). However, in this sample of participants critical junctures involved experiencing acute
complications of hypoglycemic and hyperglycemic episodes, and progressing to the use of insulin. Choices made at critical junctures involved not self-monitoring blood glucose level more frequently during hyperglycemia or hypoglycemia due to the high cost of the strips, and not administering insulin in front of friends and family. Additional data collected during this study are presented in (Appendix T).

Summary

The purpose of this study was to describe the process by which persons with type 2 diabetes mellitus self-manage their disease. The psychosocial process of Evolving Diabetes Self encompasses four phases with interrelated categories within each phase that impact the psychosocial problem of Dealing with Type 2 Diabetes. The four phases are (a) Getting the Diagnosis, (b) Realizing Options, (c) Making Decisions, and (d) Living the Consequences. The psychosocial process called Evolving Diabetes Self is the process used by participants in response to the psychosocial problem shared by participants in this study, which is Dealing with Type 2 Diabetes. Through this sample of persons over the age of 18 who had type 2 diabetes of between one and two years, grounded theory methodology was used to develop a theoretical framework. The diagnosis of type 2 diabetes and subsequent self-management skills and training (DSMT) is an evolving process that is chronic, complex, and does not have an end point.

This psychosocial problem was described by participants after being diagnosed with diabetes and is a shared life challenge. Many participants described the diagnosis of diabetes as a “life change” they had to “deal with” and “come to terms with at their own rate.” The term Dealing with Type 2 Diabetes was chosen because participants
themselves used this descriptor to depict their active involvement in their own care. The response by participants within each phase to the overall experience of dealing with diabetes indicates a process that is complex, multidimensional, concurrent, and fluid.

In *Getting the Diagnosis* participants described being diagnosed with type 2 diabetes as an inconvenient and restrictive disease. The findings pointed out that some participants took ownership by *helping themselves*. Most were aware that diabetes was a serious situation of which they could take control, but that it had to be done daily in terms of self-monitoring medications and glucose levels.

The phase of *Realizing Options* included the acquisition of information. Participants described *being overwhelmed* with the complexity and consequences of diabetes and diabetes self-management, while other participants were involved with *taking it on* where they obtained as much information as possible.

Participants described *Making Decisions* by weighing options within the categories of *being situated*, *living developmental state*, *changing and dynamic disease state*, and *being affected by surrounding systems*. Major decisions that were identified throughout the four categories included finances to pay for prescribed medical regimes and dietary regimes, access to purchase healthful food choices, time to perform the medical and dietary regimes, competing priorities, and presence of co-morbid conditions.

*Living the Consequences* is the phase in which participants live with the results of their decisions whether positive or negative or with an unawareness of the impact of their decisions. In the *waiting for the other shoe* to drop category, participants expressed interest in knowing how their diabetes was faring in terms of future consequences. In
contrast, in the *knowing how far* to go category, choices included performing self-monitored blood glucose readings, proactively requesting laboratory values from their clinics, careful selection and timing of food choices, and performing and timing of activity.

Contextual factors reported by participants that influenced diabetes self-management involved whether they were expecting the diagnosis of diabetes, feared consequences of the diagnosis, availability of finances to pay for prescribed medical and dietary regimes, and for prescribed dietary regimes, access to healthful food choices within environments where participants lived, time involved to perform the medical and dietary regimes, competing priorities, and co-morbid conditions.

Critical junctures occurred when participants experienced the acute complications of hypoglycemic and hyperglycemic episodes especially when participants began to use insulin. Choices made at critical junctures involve not self-monitoring blood glucose level.
CHAPTER V

DISCUSSION

Diabetes, a chronic illness, involves self-management. The purpose of this study was to uncover the process by which persons with type 2 diabetes mellitus manage diabetes. Grounded theory method was used to discover how persons with diabetes (a chronic disease) of 1 to 2 years duration make decisions over time about their disease self-management. A qualitative study design using grounded theory was chosen to best answer the research questions posed by the researcher. The following primary research question guided this study: What is the process by which persons with type 2 diabetes manage their disease? Supporting sub-questions were: (a) What are the contextual factors influencing diabetes self-management skills and training (DSMT)? (b) What are the critical junctures of diabetes self-management? (c) What decisions occur at the critical junctures?

Sample participants were drawn from areas surrounding three hospital diabetes’ programs and a physician’s office in Northeast Ohio; all had participated in diabetes self-management skills and training programs (DSMT) and had type 2 diabetes of duration between one to two years. Participants shared rich in-depth experiences regarding how they made decisions on a daily basis regarding diabetes self-management. They described not only physical aspects of diabetes management but other aspects of their lives
impacted by the diagnosis of diabetes. Some participants expressed having an expectation of getting a diagnosis of diabetes at some point in their life since they had witnessed family, living and deceased, with the disease. They described knowing that they had to deal with the diagnosis of diabetes and that this is a disease not to be ignored. Participants expressed fear and trepidation about possible short or long-term consequences.

*Dealing with the Diagnosis of Type 2* diabetes is described as the common psychosocial problem of the participants. *Evolving Diabetes Self* is the psychosocial process that persons with type 2 diabetes use to manage their disease and is comprised of four major phases that occur over time: *Getting the Diagnosis, Realizing Options, Making Decisions*, and *Living with the Consequences*.

The following section is organized around the phases of the *Evolving Diabetes Self*. In this current study, experiences of participants when diagnosed and how knowledge was acquired were uncovered in the *Getting the Diagnosis* and the *Realizing Options* phases. Experiences by participants indicated a far more complex process when making decisions about diabetes self-management on a daily basis that went beyond information acquisition alone. These complex processes were uncovered in the *Making Decisions* phase within the categories of *being situated, being affected by surrounding systems, living developmental stage, and changing and dynamic disease state*.

Most programs recognized by the American Diabetes Association (ADA) are based on the acute care model and most insurers reimburse based on this model. The front loading of DSMT follows the acute care model, which is not congruent for a chronic disease process (Garfield et al., 2003; Powell, Glover, Probst, & Laditka, 2005).
Both diabetes education and medical nutrition therapy are reimbursed by most third-party payers, which have governing policies that determine reimbursement; these policies force a “front loading” for the interventions. The current practice for diabetes self-management is based on information acquired that may not always lead to behavior change and desired outcomes. This practice does not take into consideration the chronic nature of the diabetes or changes in condition that may occur over time.

The findings of this study describe a beginning understanding of some of the processes that might impact decisions made regarding diabetes self-management from the patient’s perspective. Current practice emphasizes information acquisition, especially at the time of diagnosis. The information acquired, however, did not always lead to behavior change and desired outcomes, consistent with Krichbaum et al. (2003) and Whittemore (2000). As one participant expressed:

 Probably if I had somebody follow up maybe more often than every three months and just saying checking your blood every three months, and looking over the stats and you know maybe if you touched base every week, even if it’s not with a doctor or someone. I think it’d be more helpful because once you let a month go by, two months go by then you backslide.

Participants described making decisions based on how diabetes “fit” into their lives. An ambivalent or a conflicted bifocal view was described regarding how diabetes might fit into their lives. This conflicted view was influenced by where participants were situated in life and their view of themselves in terms of their “diabetes self” versus thinking of themselves as their “normal self.” This view influenced decisions about
diabetes self-management. This is consistent with work done by Zoffmann and Kirkevold (2005) who studied known conflicts in problem solving with diabetes from both exemplar groups and those with poor glycemic control. The authors uncovered the main conflict experienced by participants as that of separating usual life and what needed to be done for the diabetes disease process.

Participants described making decisions by weighing options based on where they were situated in life, their developmental stage in life, their affecting surrounding systems (family, environment, health care system, and insurance or lack of insurance), and their changing or dynamic disease state. For example, 11 participants described experiencing an episode of hypoglycemia, which made the diagnosis very real to them. One participant called this the “Steel Magnolia” effect, derived from the title of a movie in which the lead character has diabetes and experiences an episode of hypoglycemia. For some, this provided incentive to take their diabetes more seriously in applying diabetes self-management. When describing their experiences, participants focused on the complex changes that the diagnosis of diabetes brought to their lives. Participants experienced an ambivalence regarding identity of being a person with diabetes. Decisions regarding diabetes self-management were filtered through the bifocal view of normal self versus diabetes self, which was often conflicted. Eating differently, especially in social situations, while at work, or on vacation were the decisions described in this category. Other decisions involved the timing and performance of self-monitoring of blood glucose, timing and taking of medications, and the timing and performance of activity.
This is consistent with Paterson, Thorne, et al. (1999) and Paterson and Thorne (2000) where persons with diabetes experienced a transformational process, which is described as an evolving process rather than a stage or an element. Persons with diabetes should not be classified as either transformed or not transformed. This current study revealed a psychosocial process called Evolving Diabetes Self in a sample of persons with type 2 diabetes as being different from that experienced by persons with type 1 as described by Paterson and Thorne. A critical limitation regarding the relationship between making decisions and diabetes self-management was lack of a chronic disease framework within the context of disease self-management, which is consistent with the work of Hill-Briggs (2003). This current study reinforces the work of Paterson, Thorne, et al. (1999); Paterson and Thorne (2000); and Hill-Briggs (2003) that diabetes is chronic, complex, and with no end points. Information acquisition alone does not reflect the entire experience of those with type 2 diabetes in managing their disease on a daily basis. Instead, how persons with type 2 diabetes make decisions is embedded within their personal context and critical junctures.

**Getting the Diagnosis**

Participants expressed a variety of emotions when diagnosed with diabetes. They described fear, loss, grief, anger, and denial. Participants spoke about the loss of life as they had known it. Participants expressed that the diagnosis of type 2 diabetes was inconvenient and a restrictive disease process. Diabetes treatments (medications, blood glucose self-monitoring supplies, healthy food choices) were described as expensive. These activities were further described as structuring other daily activities in a different
way. Examples were self-monitoring of blood glucose, taking medication, and eating prior to leaving for work in the morning. The diabetes self-management activities occurred while fulfilling the role of a parent getting children ready for school or as a caregiver for a family member. Participants spoke about identifying issues connected to priorities related to weighing options for food choices and the time needed to care for their diabetes. This is consistent with work done by Skovlund and Peyrot (2005), who reported results of the Diabetes, Attitudes, Wishes and Needs (DAWN) study in which adherence to recommendations for diet, exercise, medication taking, glucose testing, and appointment keeping was low. Only one in five persons with diabetes reported that there was complete adherence with all aspects of their treatment regime. For most, this phase marked the beginning of their trajectory; however, for several participants, the trajectory began even before the diagnosis with diabetes. Some participants described expecting the diagnosis of diabetes as they witnessed or cared for family members either living or deceased who had type 2 diabetes.

**Realizing Options**

*Realizing Options* is the phase in which the acquisition of information occurred. All participants had participated in a Diabetes Self-Management Skills and Training (DSMT) program. Others had supplemented their DSMT programs with additional resources such as Web sites, books or libraries. Several participants described being overwhelmed with the complexity of diabetes self-management, while others took the information in stride. Participants described feeling overwhelmed by the complexity and consequences of diabetes. They indicated that diabetes was something that could not be
ignored yet they had difficulty in making diabetes a priority at times. Some individuals spoke about determining information sources that were reliable and supplementing with information from the Internet and the library. However, acquiring the information did not always lead to application in terms of changed behavior.

This is consistent with studies where current treatment interventions involve those of DSMT which are often didactic; however, this does not always equate with behavior change and improved metabolic control (Krichbaum et al., 2003; Kulkarni, 2006). This is consistent with work by Bonnet et al. (1998), who surveyed diabetes educators regarding patient learning and mastery. Diabetes educators confirmed that mastering a reasoning or decision making process required more effort than merely learning factual information or technical procedures.

Making Decisions

Once the diabetes self-management information was acquired, how participants moved through the Making Decisions phase was based on the categories within this phase: being situated, living developmental state, being affected by surrounding systems, and changing and dynamic disease state. These categories influenced how and if the information learned about diabetes was applied to daily life situations. This current study is consistent with the premise that a significant oversight in the study of chronic illness is the failure to consider the influence of personal and social context (Paterson, 2000; Whittmore & Roy, 2002; Zoffman & Kirkevold, 2005). This is consistent with the work of Nyhlin (1990) and Montori and Fernandez-Balsells (2009) regarding prioritizing healthy lifestyles, preventative care, and cardiovascular risk reduction within patient
context. They defined patient context as a patient’s ability to cope with the medical, psychological, and financial aspects of diabetes. These findings are similar to the work on transitions by Meleis et al. (2000) in which transitions were defined as process indicators that move participants in the direction of health or toward vulnerability and risk. The authors found that pattern of responses that characterized healthy transitions included feeling connected, interacting, being situated, developing coping, and developing confidence.

*Living the Consequences*

*Living the Consequences* is the phase in which participants lived with the results of their decisions, whether positive or negative, or with a lack of awareness of the impact of their decisions. Several participants described a great deal of effort expended on their diabetes with very little to show for it. This is consistent with a meta-analysis findings by Brown (1992) that indicated glycemic control improved only temporarily between 1 and 6 months after patient education. This is consistent with work by Yong et al. (2002) that involved re-education, dietary advice, and insulin dose adjustment for persons with type 1 diabetes. These interventions showed an improvement in glycemic control for 60% of patient participants, while 40% indicated deterioration of the A1C. Other studies concluded that current practice of diabetes care, which includes DSMT, has paternalistic approaches that expect compliance and adherence and should be avoided as these approaches tend to deprive patients of initiative (Anderson et al., 1995; Glasgow & Anderson, 1999).
Contextual Factors and Critical Junctures

Contextual and personal factors were self-reported during the interview process and from the demographic profile. The wider social context is the study of the behavior of human beings within their social environments. Examples of these factors for the individual with diabetes included ethnicity, gender, age, educational level, social class, poverty status, diabetes type and severity, emotional state, and psychological state.

Contextual factors were self-reported during the interview process and in the demographic profile. Some contextual factors reported by this sample of participants which influenced diabetes self-management were the following: expecting the diagnosis of diabetes, fearing consequences of the diagnosis, and lacking financing for prescribed medical and dietary regimes. Other contextual factors reported were accessing healthful food choices within environments where participants lived, time involved to perform the medical and dietary regimes, and competing priorities (such as a role as a caregiver, parent or employee). Additional contextual factors involved the effects of co-morbid conditions (such as celiac sprue, hypertension, hyperlipidemia, heart disease, obesity).

This is consistent with studies which addressed the wider social context, context within a systems perspective, relationship with health care providers and access to care (Minkler et al., 2003; Schoenberg & Drungle, 2001; Schrieber & Stern, 2000; Siguroardottir, 2005).

Critical junctures are points in time or a crisis situation in which decisions must be made by persons with diabetes. These events are not planned or anticipated, but require some sort of weighing of options to manage them. When describing their
experiences, participants focused on the complex changes that the diagnosis of diabetes brought to their lives. Critical junctures occurred when participants experienced the acute complications of hypoglycemic and hyperglycemic episodes. In this sample critical junctures occurred when participants began to use insulin. This is consistent with studies by Strauss and Corbin (1998) that described contingencies as points in time, and are events that are not planned or anticipated and which require some sort of problem solving response to manage them. This is consistent with studies by Paterson et al. (1998), which found that individuals who have a chronic illness may differ in ability to manage their illness at various times or points in their lives (Paterson et al., 1998). The emphasis has been on the sequential phases and the expressive components of diabetes, instead of how people change and make decisions over time (Paterson & Thorne 2000).

**Decisions Made at Critical Junctures**

Choices made at critical junctures involve not self-monitoring blood glucose level more frequently during hyperglycemia or hypoglycemia due to the high cost of the strips, and not administering insulin in front of friends and family.

**Further Model Development**

Various components of the model could be augmented using a larger sample that is varied in terms of characteristics (age, ethnicity, gender, employment) and using follow-up interviews with each participant in further studies. Findings indicated that getting the diagnosis of diabetes is an integral phase of the psychosocial process of the evolving diabetes self. Participants described the phase of *Getting the Diagnosis* as being inconvenient and restrictive. Although some were aware that diabetes is a serious disease,
some embraced the situation; yet others experienced grief, loss of life as they knew it, fear of dying, and lifestyle change. Participants felt on edge and expressed fear of change and the fear of unknown consequences of having the disease, which were captured within the category called being on edge.

The findings indicated that some participants took ownership by helping themselves. Most were aware that diabetes was a serious situation of which they could take control, but it had to be done daily in terms of self-monitoring medications and glucose levels. With more in-depth questioning regarding the specific circumstances at the time of being diagnosed, especially identifying individuals who helped and who did not help (family members, health care staff) with acceptance of the diagnosis, researchers could provide a better understanding of the influences on how one views getting the diagnosis. Further study and using a phenomenological approach and deeper questioning would help researchers explore how the emotional impact of getting the diagnosis of diabetes was initially perceived and the emotions experienced over time as the severity of the diabetes increased.

During the phase of Realizing Options, some participants described the feeling of being overwhelmed by the complexity of diabetes; while others were able “take on” the information. Participants described taking it on in terms of the information about diabetes and a “taking on” of their disease. They described feeling overwhelmed by the complexity and consequences of diabetes. They indicated that diabetes was something that could not be ignored yet they had difficulty in making diabetes a priority at times. Some individuals spoke about determining information sources that were reliable and
supplementing with information from the Internet and the library. Further model development would involve more in-depth interviewing and focus on particular areas that participants find overwhelming in dealing with the reality of taking on the day-to-day choices of self-management (diet, exercise, medication use). Participants identified as exemplars could be role models for determining ways to develop interventions for helping diabetics self-monitor blood glucose values and laboratory values to gauge their diabetes status and diminish the sense of being overwhelmed.

Changes and transitions occur in the Making Decisions phase of the process of the evolving diabetes self. Participants described their ambivalence regarding their diabetes identity, a conflicted state between the normal self versus the diabetes self. Further model development could involve in-depth interviewing regarding the ambivalence that individuals experienced and life stage issues such as family and work support, focus regarding the wider social context, and the effect on making decisions about diabetes self-management.

In the being affected by surrounding systems category, further model development would involve use of more in-depth interviewing. Participants mentioned the impact of short-term complications, long-term complications, and co-morbid conditions as having an effect on decisions about diabetes self-management. For some, the significance of the disease of diabetes was not realized until one of these physical issues manifested. Further study using a phenomenological approach and deeper questioning would help researchers explore how physical issues (heart disease, hypertension, obesity, blindness, amputation) impact decision making about diabetes self-management.
In the model entitled *Evolving Diabetes Self*, the phase of *Living the Consequences* is described as participants living with the results of their decisions whether positive or negative. It is a portion of the theoretical model that could be further explored by using a longitudinal design to investigate how the initial phases of the process *Evolving Diabetes Self* affect progression through the various subsequent phases of the process. Individuals who described *waiting for the shoe to drop* (those who wait in anticipation of dreaded consequences), while others described *knowing how far to go* (ability to integrate the normal self with the diabetes self and ability to “own and apply” the information received about diabetes self-management activities) could be further explored using exemplars as the role models.

The sub-research questions were the following: What are the contextual factors, what are the critical junctures, and what decisions are made at critical junctures as related to diabetes self-management? Contextual factors were self-reported during the interview process and in the demographic profile. In this sample, contextual factors reported by participants and that influenced diabetes self-management involved whether they were expecting the diagnosis of diabetes, feared consequences of the diagnosis, availability of finances to pay for prescribed medical and dietary regimes, access to healthful food choices within environments where participants lived, time involved to perform the medical and dietary regimes, competing priorities, and co-morbid conditions.

Critical junctures are usually described as major life events such as relocation, marriage, birth of a child or death of a close relative (Schrieber & Stern, 2000). However, in this sample of participants, critical junctures involved experiencing acute
complications of hypoglycemic and hyperglycemic episodes, and progressing to the use of insulin. Choices made at critical junctures involve not self-monitoring blood glucose level more frequently during hyperglycemia or hypoglycemia due to the high cost of the strips, and not administering insulin in front of friends and family. Contextual factors and critical junctures are areas to consider for further model development. These are areas that cannot be ignored when providing diabetes interventions and future phenomenological study is recommended.

Clinical Recommendations

Several clinical practice recommendations have emerged from this study. The *Evolving Diabetes Self* theory developed in this grounded theory study attests to the importance of uncovering the process by which persons with type 2 diabetes mellitus manage their diabetes. Gaining this information will help to develop individual plans of care for those with diabetes. Clinical recommendations incorporate the following: prevention of diabetes, the individual with type 2 diabetes, and systems.

The following are examples of preventative recommendations. Screen those in high risk groups (ethnicity, first degree relative with diabetes, and a history of gestational diabetes) to implement life style changes to prevent progression to full blown type 2 diabetes. Next, address the obesity issue at the individual and community levels. Weight loss goals should be realistic and with a gradual weight loss. Other measures to address with diabetes prevention include keeping medical appointments, avoiding tobacco use, and implementing a physical activity plan.
Diabetes is a complex disease process that is lifelong and changes over time. For the individual with type 2 diabetes, recommendations involve medical care in the form of resources and support as a part of diabetes self-management. However, for participants with diabetes type 2, the focus is self-managing their disease on a daily basis, not actual medical care. The traditional acute care model, which favors front loading of interventions, does not support the lifelong nature of the diabetes disease process. Participants with type 2 diabetes do not cross a magic line of demarcation going from good to poor metabolic control. Instead, the more that one can stay within normal blood glucose range throughout life, the less chance of the development of feared complications.

At a systems level the following recommendations are suggested. First, assisting individuals with type 2 diabetes to achieve this goal of self-management requires furthering diabetes self-management skills beyond the front loading of information. Providing support, such as resources, is required on an ongoing basis and will help individuals with type 2 diabetes apply the information within the context of their daily lives when making decisions about diabetes self-management. This will necessitate changes in how diabetes self-management interventions are delivered and reimbursed. Changes will need to be made within organizations (insurance, hospitals, and out-patient departments), policies, and reimbursement of care of diabetes to switch focus from an acute model to that of a chronic model. Diabetes is a chronic, complex, lifelong disease with no end point. The current model is based on the acute care model which front loads the DSMT interventions and does not take into account the chronic nature of diabetes.
Participants described some of the challenges they experienced performing DSMT within the surrounding systems of community, financial issues for both medical and dietary regimes, insurance issues, and challenges they experienced with health care providers. Choices within this category involve: whether to exercise due to the distance and time involved to attend a recreation center, whether to make an appointment with an endocrinologist due to lack of insurance coverage, and whether prescriptions can be obtained due to the high cost. Participants advised that their health care professionals take into consideration cost of medication, other diabetes supplies, and food when prescribing medical and dietary regimes to ensure that the plan is realistic. Another request made by participants was that of an easy plan and an accountability system with their health care provider, especially as related to food planning. An example is to mirror the intensity and type of aftercare and community support implemented by twelve step programs.

A second recommendation is involvement of a multidisciplinary team approach emphasizing lifestyle intervention with medical management. Health professionals are often the primary caregivers for patients and families who are dealing with a diagnosis of diabetes type 2. They attend to the changes and demands that affect the daily lives of patients and families. Providers need to support realistic treatment regimes that account for context and critical junctures, taking into account that diabetes is lifelong and changes over time. In this sample, critical junctures occurred when participants experienced the acute complications of hypoglycemic and hyperglycemic episodes, and when participants began to use insulin. Choices made at critical junctures involve not self-monitoring blood
glucose level more frequently during hyperglycemia or hypoglycemia due to the high cost of the strips, and not administering insulin in front of friends and family. By attending to experiences described by exemplars within this study, health professionals can assist participants and families weigh options by providing follow-up support for individually set treatment goals.

A third recommendation is to help persons with type 2 diabetes become aware of the wider social context, especially the influence of community. A surrounding system can include the health care system, health care providers, and the insurance industry. Participants spoke about the location of community recreation centers, the length of time to reach the centers, and the timing of exercise programs as being inconvenient. Diabetes was described as an expensive disease due to the financial cost of all aspects of treatment. Food was identified as the biggest challenge in terms of type, portion, timing, and cost.

A fourth recommendation is to move diabetes self-management skills and training (DSMT) away from the acute care hospital setting to the community setting, locations such as local community pharmacies and super stores where there may also be the presence of an advanced practice nurse who could do simultaneous medical management. Changing the physical setting may ensure the success of this type of program, moving from an acute model to a chronic disease model, in terms of the reimbursement of diabetes care.

Limitations

Sample participants were drawn from three hospital diabetes programs and a physician’s office in Northeast Ohio and all participants had participated in a diabetes
self-management skills and training program (DSMT). Although participants gave
detailed descriptions about their daily self-management decisions, a limitation is that the
small sample of 21 participants made comparisons based on differences of gender, age,
marital status, or co-morbidities a challenge. Although study criteria included those
starting at the age of 18 years, only two participants under 34 years of age who met the
study criteria set up interview appointments, but then did not show up for the interview.
Another limitation was that the youngest person in the sample was age 34.

Future Research

Suggested future research may involve a study using the phases from this research
study, especially as related to the Making Decisions phase and the transitions within the
categories of being situated, living developmental life stage, being affected by
surrounding systems, and changing and dynamic disease state. Future research may
entail a longitudinal study of this sample in 5 years to see if the self-reported
interpretation by participants about their diabetes self-management has changed. A
similar study may be done which involves those with type 1 diabetes to compare with
current sample findings. Multiple interviews over time might provide additional
information of the process of the Evolving Diabetes Self, especially in the phase of
Making Decisions. Further research is suggested regarding the influences of
multidisciplinary teams on diabetes self-management in terms of ongoing follow-up
support.
Conclusion

The purpose of this study was to describe the process by which persons with type 2 diabetes self-manage their disease. In response to the psychosocial problem of Dealing with Type 2 Diabetes, participants in this study identified the psychosocial process of Evolving Diabetes Self as the process by which they managed their diabetes on a daily basis. Evolving Diabetes Self involved four phases: Getting the Diagnosis, Realizing Options, Making Decisions, and Living with the Consequences. Several participants spoke about expecting the diagnosis of diabetes in their lives because both current and deceased family members had type 2 diabetes. Once the diagnosis was received under the Getting the Diagnosis phase, participants described fearing the change and the unknown consequences of having the disease.

Contextual factors reported by participants in this sample that influenced diabetes self-management involved whether they were expecting the diagnosis of diabetes, feared consequences of the diagnosis, and if finances were available to pay for prescribed medical and dietary regimes. In addition, access to healthful food choices within environments where participants lived was considered another contextual factor. The time involved to perform the medical and dietary regimes, competing priorities (such as a role as a caregiver, parent or employee), and co-morbid conditions (such as celiac sprue, hypertension, hyperlipidemia, heart disease, obesity) all influenced diabetes self-management.

In this sample, critical junctures occurred when participants experienced the acute complications of hypoglycemic and hyperglycemic episodes. Participants described
hypoglycemic episodes that were severe enough to require another person to assist them in treatment. Others described hospitalizations due to acute disease states (e.g. infections) that exacerbated their diabetes by significantly raising blood glucose. Another example of a critical juncture for participants was when they became insulin using (defined as progressing from diet controlled to oral agent controlled to now insulin using), as participants described feeling that their disease had progressed. This was significant both for participants and their families as viewing diabetes as more serious. As participants moved along their trajectory of dealing with their diagnosis of diabetes, the process was found to be multidimensional, complex, dynamic, and fluid. The process did not have a completion point and is an evolving process.

As diabetes type 2 is complex, lifelong, and alters over time, changes are suggested within policies of organizations (insurance, hospitals, and out-patient departments) and reimbursement for care of diabetes that will switch focus from an acute model to that of a chronic model. There needs to be involvement of a multidisciplinary team approach which emphasizes lifestyle intervention along with medical management. Another suggestion is to study the wider social context and the effect on diabetes self-management, especially the influence of community. These changes can lead to fewer hospitalizations, complications, lower health care costs, and improved health of persons with type 2 diabetes.

Summary

The purpose of this study was to describe the process by which persons with type 2 diabetes mellitus self-manage their disease. The diagnosis of type 2 diabetes and
subsequent self-management skills and training (DSMT) is an evolving process that is chronic, complex, and does not have an end point. The psychosocial process of Evolving Diabetes Self encompasses four phases with interrelated categories within each phase that impact the psychosocial problem of Dealing with Type 2 Diabetes. The four phases are (a) Getting the Diagnosis, (b) Realizing Options, (c) Making Decisions, and (d) Living the Consequences. The psychosocial process called Evolving Diabetes Self is the process used by participants in response to the psychosocial problem shared by participants in this study, which is Dealing with Type 2 Diabetes.

Type 2 diabetes is a chronic disease requiring complex and lifelong changes. The current practice of front loading DSMT does not take into account the chronic, complex and lifelong nature of diabetes. Health professionals need to provide a delivery system that provides on-going supports to address the chronic nature of the diabetes disease process. These may be in the form of telephone support as well as multidisciplinary team approaches that emphasize life style intervention as well as the medical regime. When providing DSMT, health professionals need to take into account the contextual and critical junctures to avoid hardship for persons with diabetes who attempt to follow the prescribed regimes. Health care providers are in an integral position to facilitate change from an acute care emphasis to a chronic care framework within organizations (insurance, hospitals, and out-patient departments) as well as to change policies and reimbursement protocols.
REFERENCES
REFERENCES


# Appendix A

## Health Information and Demographics Form

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Date</th>
</tr>
</thead>
</table>

### DEMOGRAPHIC AND HEALTH HISTORY FORM

Write in the blanks or circle your answer.

<table>
<thead>
<tr>
<th>Age: _____ years</th>
<th>Race: ___ White (Non-Hispanic)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>___ Black (Non-Hispanic)</td>
</tr>
<tr>
<td></td>
<td>___ American Indian</td>
</tr>
<tr>
<td></td>
<td>___ Hispanic</td>
</tr>
<tr>
<td></td>
<td>___ Other Non-Hispanic</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender: ___ male</th>
<th>Martial Status: ___ Married</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>___ Divorced or Separated</td>
</tr>
<tr>
<td></td>
<td>___ Widowed</td>
</tr>
<tr>
<td></td>
<td>___ Never married</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment status: ___ Employed for wages</th>
<th>Do you have any of the following?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Diabetes complications</td>
</tr>
<tr>
<td></td>
<td>Heart problems</td>
</tr>
<tr>
<td></td>
<td>Circulation problems</td>
</tr>
<tr>
<td></td>
<td>Skin problems</td>
</tr>
<tr>
<td></td>
<td>Digestion problems</td>
</tr>
<tr>
<td></td>
<td>Eye problems (Rhopathy)</td>
</tr>
<tr>
<td></td>
<td>Kidney problems (Nephropathy)</td>
</tr>
<tr>
<td></td>
<td>Problems with nerves (for example, numbness, pain, feelings of hot or cold)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Do you take insulin? Yes No</th>
<th>Do you take diabetes pills? Yes No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet controlled? Yes No</td>
<td></td>
</tr>
</tbody>
</table>

Have you been treated for depression since being diagnosed with diabetes? Yes No

Do you take medicine for high blood pressure? Yes No

What was your last blood pressure? _____

Do you have high cholesterol? Yes No

Do you take medicine for high cholesterol? Yes No

Health history and demographics... thoman... may 1.07
Appendix B

Kent State University IRB Permission Letters

KENT STATE UNIVERSITY INSTITUTIONAL REVIEW BOARD
APPLICATION FOR APPROVAL TO USE HUMAN RESEARCH PARTICIPANTS

Send completed forms to one of the reviewers designated for your Department or Katherine Light, Research and Graduate Studies, 113 University Auditorium LOG NUMBER: CB

Forms can be downloaded from http://www.kent.edu/academic/irb/docs/

Please type all information. HANDWRITTEN FORMS WILL NOT BE ACCEPTED. Move through the document using TAB or Move. Do not use the enter Key. To mark a box, click with the mouse.

Name: Joan Ellen Thomas

Telephone: 440-331-4662  Address: 21778 Greenhouse Line, Rocky River, Ohio  Email: jthoman@com.net

44614

Department: College of Nursing  Faculty Rank/Student Status: Doctoral student

Project Title: The Process by Which Patients with Diabetes Manage Their Disease.

Type of Project:  □ FACULTY RESEARCH  □ External Funded (Agency: ) Include copy of Proposal

STUDENT DIRECTED RESEARCH (Advisor: Peggy Dobrey, RN, PhD and Carol Sadak, RN, PhD)

Thesis  □ Dissertation  □ Course Requirement (Course #: )

□ Other (Specify: )

Duration of Project: Starting Date: July 25, 2007 (but not before approval is obtained)

Ending Date: August 31, 2008

I certify that the research procedures for this project and the method of obtaining consent (if any), as approved by the Kent State University Institutional Review Board, will be followed during the period covered by this research project. Any future changes will be submitted for Board review and approval prior to implementation.

If this project involves approval/permission from other institutions, the principal investigator (and the faculty advisor if the PI is a student) must sign below to certify the following statement: "I/we will not begin research at other institutions before having obtained their permission to do so."

Principal Investigator  Date  Faculty Advisor (IF PI is a student)  Date

Action Taken:

By REVIEWER:

☐ Level I, Category:

☐ Level II, Category:

☐ Level III, To Full Board

Project Involves:

☐ Descriptive

☐ Waiver of Consent

Primary Reviewer  Date

By KSU INSTITUTIONAL REVIEW BOARD:

☐ Approved, Level I

☐ Approved, Level II

☑ IRB Comments:

☐ Ineligible

☐ Irresponsible

.date

RECEIVED

JUL 3 0 2007

KSU IRB

175
January 9, 2009

Joan Thomas, RN, MSN  
Nursing  

Re: 08-17: “The Process by Which Persons with Type 2 Diabetes Manage Their Disease”

Dear Ms. Thomas:

The Kent State University Institutional Review Board reviewed your Annual Review and Progress Report for continuing review purposes. Protocol approval has been extended and is effective through August 8, 2009.

Federal regulations require that “An IRB shall conduct continuing review of research...to determine or extend the degree of risk, but not less than once per year...” The IRB has determined that this protocol requires an annual review and progress report. Due to the delayed 2008 annual review of this protocol, we will require it to be reviewed again on its regular schedule in accordance with the original approval date. Therefore, this protocol will need to be reviewed by the IRB prior to the study expiration date of August 9, 2009.

The IRB will forward an annual review reminder notice to you by email as a courtesy. Please note that it is the responsibility of the principal investigator to be aware of the study expiration date and submit the required materials. Please submit review materials (annual review form and copy of current consent forms) one month prior to the expiration date.

HRSA regulations and Kent State University Institutional Review Board guidelines require that any changes in research methodology, protocol design, or principal investigator have the prior approval of the IRB before implementation and continuation of the protocol. The IRB must also be informed of any adverse events associated with the study. The IRB further requests a final report at the conclusion of the study.

Kent State University has a Federal Wide Assurance on file with the Office for Human Research Protection (OHRP); FWA Number 0000183.

If you have any questions or concerns, please contact me at 330-672-2704 or tfschaefer@kent.edu.

Sincerely,

Tonya Frederick, R.N., B.S.N.  
Research Compliance Administrator

Cc: Peggy Doherty, Ph.D.
Appendix C
Mercy Medical Center (MMC) IRB Permission Letters

June 12, 2007

Joan Thoman
21778 Gatehouse Lane
Rocky River OH 44116

In Re: The Process by Which Persons with Type 2 Diabetes Manage Their Disease
Our Study #2007009

Meeting Date: 6/5/2007

Dear Ms. Thoman:

This letter will serve as formal notification that the Mercy Medical Center’s Institutional Review Board approved the above-referenced research proposal and consent form for a period of one year.

Research investigators are responsible for obtaining informed consent and for ensuring that no human subject will be involved in the research prior to the obtaining of the consent. Please ensure that each person signing the written consent form is given a copy of the form. The form must be the one reviewed and approved by the IRB. Keep the consent documents signed by subjects for a period of three (3) years after the final IRB approval period.

As principal investigator for a study involving human participants, you assume certain responsibilities to Mercy Medical Center and the Mercy Medical Center’s Institutional Review Board, specifically noted in the enclosed Investigators’ Agreement for FDA-IRB Compliance. You must be sure that this form is processed quickly so that you may proceed with the study. The letter constitutes formal notification of IRB approval and may be provided to the sponsor company to verify the approval by the IRB of the above-referenced study. The Mercy Medical Center IRB is compliant with 21CFR56.

Should you have any questions or if I can be of any further assistance, please feel free to contact me.

Sincerely yours,

A. Leslie Abel
Chairman, IRB

ALA tons
May 13, 2008

Joan Thoman, RN, MSN, CNS
21778 Gatehouse Lane
Rocky River, OH 44116

In Re: The Process by Which Persons with Type 2 Diabetes Manage Their Disease

Our Study #2007066 Meeting Date: 5/7/2008

Dear Ms. Thomen:

This letter will serve as formal notification that the Mercy Medical Center’s Institutional Review Board granted continuing review approval for the above-referenced protocol and consent form (Version dated May 31, 2007) for a period of one year.

Enclosed please find an Investigators’ Agreement for FWA-IRB Compliance form that must be signed and returned to me. Please be sure that this form is processed quickly so that you may proceed with the study. This letter constitutes formal notification of IRB approval and may be provided to the sponsor company to verify the approval by the IRB of the above-referenced study. The Mercy Medical Center IRB is compliant with GPO018421CFR56.

Should you have any questions or if I can be of any further assistance, please feel free to contact me.

Sincerely yours,

A. Leslie Abel
Chairman, IRB

ALA:toc
April 15, 2009

Joan Thoman, RN, MSN, CNS
21778 Gatehouse Lane
Rocky River, OH 44118

Protocol Title: The Process by Which Persons with Type 2 Diabetes Manage Their Disease
Our Study #2007009

Meeting Date: 4/1/2009

Dear Ms. Thoman:

This letter will serve as formal notification that the Mercy Medical Center's Institutional Review
Board reviewed the progress report for the above-referenced protocol.

The Board would like to request that you send us a copy of your final dissertation; we would
very much like to hear the results of your study.

This letter constitutes formal notification of IRB review and may be provided to the sponsor
compny to verify the approval by the IRB of the above-referenced study. The Mercy Medical Center is
compliant with 45CFR46210CFR5.

Should you have any questions or if I can be of any further assistance, please feel free to
contact me.

Sincerely yours,

Leslie Abel
Chairman, IRB

1320 Merity Plaza NW, Cincinnati, Ohio 45208-2200 513-459-3500 www.cincinnati.mercy.com
Appendix D
Lakewood Hospital (Lkwd) IRB Permission Letters

December 28, 2007

Joan Thomas, RN, MSN, CNS, CDE
21776 Gatehouse Lane
Rocky River, OH 44116

RE: The Process By Which Persons With Type 2 Diabetes Manage Their Disease

Dear Ms. Thomas,

At its meeting Tuesday, December 18, 2007, 12 Noon, the Lakewood Hospital Institutional Review Board, which is in compliance with the regulations of the Food and Drug Administration as described in 21 CFR parts 50 and 56, as well as the International Conference on Harmonization (ICH) Good Clinical Practice (GCP) Guidelines for IRBs, approved the above referenced protocol and informed consent form for a period not to exceed one year. It is important that the signed consent form is on the medical record of each participant.

"One change was requested: Protocol Application, Section VII, Page 6, second paragraph, second sentence -- "If a participant requires immediate assistance, they will be taken to the hospital emergency room," will be changed to "If a participant becomes distressed during the interview, the nurse researcher will determine if the interview should cease and whether or not the participant needs assistance. The nurse researcher will attempt to contact your doctor. If your doctor cannot be reached, or you require immediate assistance, then you will be taken to the hospital emergency room."

Please see that this change is made and a copy showing the change be sent to: Joyce Harris, Lakewood Hospital, Medical Staff Office, 14519 Detroit Avenue, Lakewood, OH 44107.

Please inform the Board of any changes to the protocol, as well as any change of Principal Investigator during the period of your study.

Report to the Board immediately if any unanticipated problems, serious injuries or deaths occur during the study.

The Board requires that you submit a status report for continuing review, no later than one year from the time of approval of the study. (A status report form will be sent to you for completion.)

Finally, please notify the Board should you complete or suspend the study, and submit a final report within three months of its completion or termination.

Sincerely,

A. Walborn
Chairman
Lakewood Hospital Institutional Review Board

/ls

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Cleveland Clinic
Andrew Tree, JD
Chairman, CCR IRB
J. M. Callahan, MS, MBA
Director, CCR IRB
13501 Terrace Rd
East Cleveland, OH 44112

December 3, 2008
Joan Thoman, RN, MSN, CNS, CDE
Kent State University College of Nursing
PO Box 5190
Kent, OH 44242

Re: IRB# 08.12.100 Protocol Title: The process by which persons with type-2 diabetes manage their disease

Dear Ms. Thoman:

This letter will confirm that your application for continuing review of the above-captioned study was reviewed and granted expedited approval by the Chairman of the CCR IRB, effective immediately. This action will be reported to the full Board. It is noted that you are conducting this study at both Fairview and Lakewood Hospitals and it is closed to enrollment.

You are granted permission to conduct your study as described above effective immediately. The study is subject to continuing review on or before 12/2/2009, unless closed before that date.

The IRB approval period for this study will expire on 12/2/2009. You are reminded to submit a continuing review application up to 30 days prior to the expiration date, ensuring that no research activity takes place beyond the expiration date. If you are not renewing, a protocol closure form must be submitted.

Please note that any changes to the study as approved must be promptly reported to and approved by the CCR IRB. Any unanticipated problems or adverse events that are serious, unexpected, and associated with the research must be promptly reported to the CCR IRB.

Should you have any questions or concerns, please do not hesitate to contact me at 216-761-7079.

Sincerely,

J. M. Callahan, MS, MBA
Director, CCR IRB
CIM
Appendix F
Physician’s Office, Medical Director Letter of Permission

ABRAMS EYE CENTER, INC.
Marc A. Abrams, M.D., Ph.D.

MEMORANDUM

TO: IRB Chairperson
FROM: Marc A. Abrams, M.D., Ph.D.
CC: Joan Thoman
DATE: January 7, 2008
RE: Permission

Joan Thoman has my permission to access patients from my ophthalmology practice for her dissertation research entitled, The Process by Which Persons with Type 2 Diabetes Manage Their Disease.

This research may assist patients with diabetes and the health professionals who care for them in planning diabetes care. We look forward to working with Joan on her dissertation.

Signature
Date:

MAAJ
Appendix G
Recruitment Flyer

Participants Needed for Diabetes Study

The Process by Which Persons with Diabetes Manage Their Disease
A research study on what it is like for persons with diabetes to manage their disease

Researcher needs men and women:
• Over the age of 18 years
• Having type 2 diabetes between 1 and 2 years
• Who attended a Diabetes Self-Management Skills and Training Program
• Who speak and understand English

Participation includes:
• A confidential 1-1½ hour interview
• Bringing your self-reported blood glucose logs of the past 2 weeks
• Completion of an information questionnaire of 21 questions after the interview
• Permission to access your medical record for A1c (an average of the blood glucose for the last 3 months) results and blood glucose values over the past 12 months
• Possible re contact via phone for clarification of the data.
• Being paid with a $25.00 merchandise gift card for participation,

If you are interested in the project call:
Joan Thoman, RN, MSN, CDE, research nurse and doctoral student at 1-866-446-7965

I would appreciate your involvement in this important project. The information you provide could help nurses and other health professionals to provide care and support that will help individuals who have diabetes.

Joint PhD Program between The University of Akron and Kent State University Colleges of Nursing
Appendix H
Patient Letter

KENT STATE UNIVERSITY

Consent to Participate in a Research Study

Study Title: The Process by Which Persons with Type 2 Diabetes Manage Their Disease

Principal Investigator: Joan Thoman, RN, MSN, CNS, CDE
Doctoral Candidate/Student Kent State University
1-866-446-7665 designated phone number

Sponsor: None at present but may possibly obtain in the future

Please carefully review this consent document. The purpose of a consent document is to provide you with information to help you decide whether you wish to participate in this research study. Your decision is completely voluntary and will not affect your medical care if you choose not to participate. It is important for you to ask questions and understand the research risks, benefits and alternatives.

- You are being asked to participate in a research study
- Your participation is voluntary
- Carefully consider the risks, benefits and alternatives of the research

You may refuse to participate, or may withdraw your consent to participate in any study at any time, and for any reason, without jeopardizing your future care at this institution, or your relationship with your diabetes educator or doctor. You do not have to participate in research in order to receive treatment.

1. INFORMATION ON THE RESEARCH

Why Are You Being Asked To Take Part In This Research?
You are being asked to take part in this study because you have had type 2 diabetes of 1 to 2 years duration. I want to do research to learn more about how you self-manage your diabetes and how you make decisions about your diabetes care on a daily basis.

College of Nursing
P.O. Box 6199 • Kent, Ohio 44242-0001
Administration: 330-672-7090 • Faculty: 330-672-5886 • Fax: 330-672-2433
Email: nursing@kent.edu • http://www.kent.edu/nursing

IRB APPROVED
MAR 1 2 2008

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Appendix L
Hospital Informed Consent (MMC)

KENT STATE UNIVERSITY

MERCY MEDICAL CENTER CONSENT FORM

Protocol Title: The Process by Which Persons with Type 2 Diabetes Manage Their Disease

Investigator: Joan Thomas, RN, MSN, CNS, CDE
Doctoral Candidate/Student Kent State University
1-888-446-7985 designated phone number

Sponsors: None at present but may possibly obtain in the future

Introduction

My name is Joan Thomas; I am a registered nurse who is a certified diabetes educator (CDE). I am doctoral candidate working on my Doctorate Degree in Nursing at Kent State University College of Nursing. I want to do research to learn more about how you self-manage your diabetes and how you make decisions about your diabetes care on a daily basis.

What are some general things you know about research studies? Research studies are designed to gain scientific knowledge that may help other people in the future. You may or may not receive any direct benefit from participating. There may also be risks associated with participating in research studies.

Your participation is voluntary. You may refuse to participate, or may withdraw your consent to participate in any study at any time, and for any reason, without jeopardizing your future care at this institution, or your relationship with your diabetes educator or doctor. You do not have to participate in research in order to receive treatment.

STUDY PURPOSE

What is the purpose of the study and how long will it last? I want to do research on the process of daily diabetes management. I want to do this because diabetes is a chronic disease that involves a variety of self-management actions (e.g., blood sugar testing, deciding what and when to eat, taking medications etc.). I want to learn more about how you make decisions about managing your diabetes on a day-to-day basis. I am especially interested in studying persons who have had diabetes for 1 to 2 years because that is when problems caring for diabetes seem to happen. Persons who have had diabetes for 1 to 2 years have not been studied much so I would like to find out why these problems may be happening.
STUDY SUMMARY

If you decide to take part in this study, you will be asked to do the following:

- Participate in a 1 to 1½ hour in-person, audio-taped interview with the researcher at the hospital diabetes education department at Mercy Medical Center, 1320 Mercy Drive N.W., Canton, Ohio 44708.
- Bring your self-reported blood glucose logs of the past 2 weeks which will be photocopied and coded by the nurse researcher to remove any identifying information.
- Complete a one-page information form of 21 questions asking about yourself and your diabetes.
- Give permission for the researcher to look at your medical record after the interview to obtain the following information: A1c (an average of the blood glucose for the last 3 months) results, blood glucose values over the past 12 months, information regarding your age, gender, race, marital status, employment status, year diagnosed with diabetes, latest blood pressure reading, latest cholesterol reading, if prescribed insulin, blood pressure medication or cholesterol lowering medication and any complication (heart, circulation, skin, digestion, eye, kidney or physical nerve issues). In addition, any history of possible depression due to the high link between diabetes, depression and the performance of diabetes self-management.

Your taped interview and medical information will remain private, but the nurse researcher will analyze the interviews of those that participated to find out what most people with diabetes experience, and how this affects caring for your diabetes.

You will be compensated with a $25 merchandise gift card after the interview.

POTENTIAL RISKS

In the rare event you become distressed during the interview, the interview will be stopped and I will stay with you until you feel better. If you indicate that you are depressed, I will encourage you to seek follow up medical care. If needed there is an emergency room available.

POTENTIAL BENEFITS

What are the possible benefits?

You will help those (health professionals) who care for person with diabetes to better understand what it is like to manage diabetes so that they can use this information to provide better care in the future. Your participation will allow me to learn about the process of managing diabetes on a daily basis and any resulting decisions. This information may improve the health care for persons with diabetes in the future.

FINANCIAL INFORMATION

There are no costs to you for participation. You will receive a $25 merchandise gift card for your participation after the completion of the interview.
Appendix M
Hospital Informed Consent (LKwd)

KENT STATE UNIVERSITY

CONSENT FORM
Lakewood Hospital

Protocol Title: The Process by Which Persons with Type 2 Diabetes Manage Their Disease.

Investigator: Joan Thomas, RN, MSN, CNS, CDE
Doctoral Candidate/Student Kent State University
1-800-446-7355 designated phone number

Sponsors: None at present but may possibly obtain in the future

INTRODUCTION

My name is Joan Thomas, I am a registered nurse who is a certified diabetes educator (CDE). I am doctoral candidate working on my Doctorate Degree in Nursing at Kent State University, College of Nursing. I want to do research to learn more about how you self-manage your diabetes and how you make decisions about your diabetes care on a daily basis.

What are some general things you know about research studies? Research studies are designed to gain scientific knowledge that may help other people in the future. You may or may not receive any direct benefit from participating. There may also be risks associated with participating in research studies.

Your participation is voluntary. You may refuse to participate, or may withdraw your consent to participate in any study at any time, and for any reason, without jeopardizing your future care at this institution, or your relationship with your diabetes educator or doctor. You do not have to participate in research in order to receive treatment.

STUDY PURPOSE

What is the purpose of the study and how long will it last? I want to do research on the process of daily diabetes management. I want to do this because diabetes is a chronic disease that involves a variety of self-management actions (e.g. blood sugar testing, deciding what and when to eat, taking medications etc.). I want to learn more about how you make decisions about managing your diabetes on a day to day basis. I am especially interested in studying persons who have had diabetes for 1 to 2 years because that is when problems arise for diabetes seem to happen. Persons who have had diabetes for 1 to 2 years have not been studied much, so I would like to find out why these problems may be happening.

College of Nursing
P.O. Box 5190 • Kent, Ohio 44242-0590
Administration: 330-672-7990 • Faculty: 330-672-3688 • Fax: 330-672-2433
E-mail: nursing@kent.edu • http://www.kent.edu/nursing
FINANCIAL INFORMATION
There are no costs to you for participation. You will receive a $25 merchandise gift card for your participation after the completion of the interview.

ALTERNATIVE TREATMENTS
You do not have to participate in this study to receive diabetes education and treatment. If you decide not to participate in this study, you will continue to receive diabetes education from your usual diabetes educator(s) and treatment from your regular doctor if needed. You may decide not participate at any time, for any reason and would just leave a message on the 1-866-446-7985 line indicating this choice.

PRIVACY
How will your privacy be protected? Any information obtained about you during this study will be treated as strictly confidential to the full extent permitted by applicable law. To ensure confidentiality, a code number will be assigned to you. Your name and any other potentially identifying information will not be used on any data you provide. You will not be identified in any report or publication about this study. Your code number will be used to identify the data collected on you. Information for all those who participate as a group will be reported as a summary.

At the end of the study, all forms with your name or other identifying information will be kept in a locked file in the advisor’s office at Kent State University, College of Nursing. Only the principal investigator and the study advisors will have access to these forms. After completion of the study, the forms will be kept for three years.

Any results from your blood sugar logs, lab work, and typed information from audio-tapes which have no personal identifying information, will be kept for three years. Audio-taped information will be typed on paper and identified with a code. The audiotapes will be erased after study completion.
Appendix N

Hospital Informed Consent (FGH)

KENT STATE UNIVERSITY

Consent to Participate in a Research Study

Study Title: The Process by Which Persons with Type 2 Diabetes Manage Their Disease

Principal Investigator: Joan Thoman, RN, MSN, CNS, CDE
Doctoral Candidate/Student Kent State University
1-800-446-7985 designated phone number

Sponsor: None at present but may possibly obtain in the future

Please carefully review this consent document. The purpose of a consent document is to provide you with information to help you decide whether you wish to participate in this research study. Your decision is completely voluntary and will not affect your medical care if you choose not to participate. It is important for you to ask questions and understand the research risks, benefits and alternatives.

- You are being asked to participate in a research study
- Your participation is voluntary
- Carefully consider the risks, benefits and alternatives of the research

You may refuse to participate, or may withdraw your consent to participate in any study at any time, and for any reason, without jeopardizing your future care at this institution, or your relationship with your diabetes educator or doctor. You do not have to participate in research in order to receive treatment.

1. INFORMATION ON THE RESEARCH

Why Are You Being Asked To Take Part In This Research?
You are being asked to take part in this study because you have had type 2 diabetes of 1 to 5 years duration. I want to do research to learn more about how you self-manage your diabetes and how you make decisions about your diabetes care on a daily basis.

College of Nursing
P.O. Box 5190 • Kent, Oh 44242-5190
Administration: 330-672-7320 • Faculty: 330-672-3086 • Fax: 330-672-3433
E-mail: nursing@kent.edu • http://www.kent.edu/nursing

IRB APPROVED
MAR 1 2008

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Why Is This Study Being Done?

The purpose of this study is to do research on the process of daily diabetes management. I want to do this because diabetes is a chronic disease that involves a variety of self-management actions (e.g., blood sugar testing, deciding what and when to eat, taking medications, etc.). I want to learn more about how you make decisions about managing your diabetes on a day-to-day basis. I am especially interested in studying persons who have had diabetes for 1 to 2 years because that is when problems caring for diabetes seem to happen. Persons who have had diabetes for 1 to 2 years have not been studied much so I would like to find out why these problems may be happening.

How Many People Will Take Part In The Study?

From 3 different hospitals approximately 50 people will take part in this study.

What Is Involved in the Study?

If you decide to take part in this study, you will be asked to do the following:

- Participate in a 1 to 1-1\text{½} hour in-person audio taped interview with the researcher at the hospital diabetes education department at Fairview Hospital, 3035 Woodside Road, Rocky River, Ohio 44116 or Fairview Hospital, 18101 Lorain Ave., Cleveland, Ohio 44111
- Bring your self-reported blood glucose logs of the past 2 weeks which will be photocopied and coded by the nurse researcher to remove any identifying information
- Complete a one-page information form of 21 questions asking about yourself and your diabetes.
- Give permission for the researcher to look at your medical record after the interview to obtain the following information: A1c (an average of the blood glucose for the last 3 months), results, blood glucose values over the past 12 months, information regarding your age, gender, race, marital status, employment status, year diagnosed with diabetes, latest blood pressure reading, latest cholesterol reading. If prescribed insulin, blood pressure medication or cholesterol lowering medication and any complication (heart, circulation, skin, digestion, eye, kidney or physical nerve issues). In addition, any history of possible depression due to the high link between diabetes, depression and the performance of diabetes self-management.

College of Nursing
P.O. Box 5190 • Kent, Ohio 44242-0001
Administration: 330-672-7000 • Faculty: 330-672-3856 • Fax: 330-672-2433
E-mail: nursing@kent.edu • http://www.kent.edu/nursing

IRB APPROVED
MAR 1 • 2008
Your taped interview and medical information will remain private, but the nurse researcher will analyze the interviews of those that participated to find out what most people with diabetes experience, and how this affects caring for your diabetes.

You will be compensated with a $25 merchandise gift card after the interview.

How Long Will You Be In The Study?

You will be contacted to participate in one interview that will last from 1 to 1 1/2 hours. There may be a rare case when the nurse researcher may re-contact you a second time by phone to be sure that she understood your diabetes story correctly.

2. RISKS AND DISCOMFORTS

What Are The Risks Of The Study?

There are no physical risks associated with this study. There is, however, the potential risk of loss of confidentiality. Every effort will be made to keep your information confidential, however, this can not be guaranteed. Some of the questions we will ask you as part of this study may make you feel uncomfortable. You may refuse to answer any of the questions and you may take a break at any time during the study. You may stop your participation in this study at any time.

In the rare event you become distressed during the interview, the interview will be stopped and I will stay with you until you feel better. If you indicate that you are depressed, I will encourage you to seek follow up medical care. If needed there is an emergency room available.

3. BENEFITS

Are There Benefits To Taking Part In The Study?

You will help those (health professionals) who care for person with diabetes to better understand what it is like to manage diabetes so that they can use this information to provide better care in the future. Your participation will allow me to learn about the process of managing diabetes on a daily basis and any resulting decisions. This information may improve the health care for persons with diabetes in the future.

College of Nursing
P.O. Box 5190 • Kent, Ohio 44242-0001
Administration: 330-672-7930 • Faculty: 330-672-6886 • Fax: 330-672-2433
E-mail: nursing@kent.edu • http://www.kent.edu/nursing

IRB APPROVED
MAR 1 2008
4. ALTERNATIVES

You do not have to participate in this study to receive diabetes education and treatment. If you decide not to participate in this study, you will continue to receive diabetes education from your usual diabetes educator(s) and treatment from your regular doctor if needed. You may decide not participate at any time, for any reason, and would just leave a message on the 1-888-446-7965 line indicating this choice.

5. PRIVACY AND CONFIDENTIALITY

Will Your Information Be Kept Private?

The medical and research information recorded about you will be used within this doctoral dissertation study and/or disclosed outside of this study as part of this research, or for your treatment, payment for health care services, or health care operations. Tests and procedures done solely for this research study may be placed in your medical record to indicate your participation in this study. Upon completion of the study, you may have access to the research information if contained in the medical record.

Your access to research information about you will be limited while the study is in progress. Preventing this access during the study keeps the knowledge of study results from affecting the reliability of the study. This information will be available should an emergency arise that would require your treating physician to know this information to treat you best.

Your research information may be disclosed to the principal investigator, the research study Sponsor and its agents, the IRB research review staff, the U.S. Food and Drug Administration (FDA) may inspect records, and study dissertation advisors. The researcher must comply with legal requirements that mandate disclosure in unusual situations so no guarantees can be made. Otherwise, the information recorded about you as part of this research will be maintained in a confidential manner. It is possible that information disclosed about you outside of this study could be re-disclosed and no longer protected by federal privacy laws.

Your research information may be used and disclosed indefinitely, but you may stop these uses and disclosures at any time by writing to Joan Thoman, Doctoral Student at Kent State University College of Nursing, P.O. Box 5180, Kent, Ohio 44242. If you do so, any information previously disclosed cannot be withdrawn. The researcher will not use or disclose the information collected in this study for another research.
purpose without your written permission, unless the Institutional Review Board gives
permission after ensuring that appropriate privacy safeguards are in place. The
Institutional Review Board is a committee whose job is to protect the safety and
privacy of research subjects.

If you choose not to sign this consent form, you will not be permitted to participate in
this research study.

6. RESEARCH RELATED INJURIES

What Happens If An Injury Occurs?

Your participation in this research study is voluntary. Refusing to participate will not
alter your usual health care or involve any penalty or loss of benefits to which you are
otherwise entitled. If information generated from this study is published or presented,
your identity will not be revealed.

In the rare event that you experience psychological distress, physical injury or illness
as a result of participating in this research study, medical care is available. There are
no plans to provide compensation for lost wages, direct or indirect losses. The
researcher will not voluntarily provide compensation for medical expenses or any
other compensation for research-related injuries. Further information about research-
related injuries is available by contacting the Institutional Review Board at the
following number (216) 473-7126.

7. COSTS

What Are The Costs?

There are no costs to you for participation. You will receive a $25 merchandise gift card
for you participation after the completion of the interview.

8. VOLUNTARY PARTICIPATION

What Are Your Rights As A Participant?

Your participation in this research study is voluntary. Refusing to participate will not
alter your usual health care or involve any penalty or loss of benefits to which you are
otherwise entitled. If information generated from this study is published or presented,
your identity will not be revealed.
10. SIGNATURE

Statement of Participant

I have read and have had verbally explained to me the above information and have had all my questions answered to my satisfaction. I understand that my participation is voluntary and that I may stop my participation in the study at any time. Signing this form does not waive any of my legal rights. I understand that a copy of this consent will be provided to me. By signing below, I agree to take part in this research study.

Printed name of Participant

Participant Signature

Date

Statement of Person Conducting Informed Consent Discussion

I have discussed the information contained in this document with the participant and it is my opinion that the participant understands the risks, benefits, alternatives and procedures involved with this research study.

Printed name of person obtaining consent

Signature of person obtaining consent

Date

College of Nursing
P.O. Box 2590 • Kent, Ohio 44242-0201
Administration: 330-672-7950 • Faculty: 330-672-3686 • Fax: 330-672-3433
E-mail: nursing@kent.edu • http://www.kent.edu/nursing

IRB APPROVED
MAR 1 & 2008
Appendix O
Audio-Tape Consent Form

Title: *The Process by Which Persons with Type 2 Diabetes Manage Their Disease*

I agree to audio-taping

at ________________________________

on ________________________________.

Signature __________________________ Date __________
Appendix P
Consent to Re-contact Participant

KENT STATE UNIVERSITY

Study: The Process by Which Persons with Type 1 Diabetes Manage Their Disease

Are you interested in receiving a copy of the research findings from this project?

_____ yes  _____ no

Are you interested in receiving correspondence regarding the project?

_____ yes  _____ no

If yes to either question, how or where should I send this information?

Name/Initials (Mailing address):

Street/Box #: __________________________ State: ______ Zip Code ______

Would you be willing to return for a second interview?

_____ yes  _____ no

Would you be willing to read and comment on the findings?

_____ yes  _____ no

If yes, please provide a telephone number where you can be reached.

__________________________________________________________

May I leave a message? _____ yes  _____ no

Signature ___________________________  Date ____________
Appendix Q
Interview Questions Guide

1. What does having DM mean to you?
   a. What changes have you had to make?

2. Tell me about how you managed your diabetes when you were first diagnosed?
   a. What thoughts or feelings went through your mind when you were first diagnosed?
   b. What decisions did you make regarding your management of diabetes then?
   c. Is there an incident that stands out that would help me to understand what it was like for you when first diagnosed with diabetes?

3. Tell me about how you manage your diabetes now after having it for 1 to 2 years.
   a. What thoughts or feelings do you have now about your diabetes?
   b. What decisions do you make now regarding management of your diabetes?
   c. Is there an incident that stands out that would help me to understand what it is like for you to have diabetes?

4. Tell me a story about the most difficult or challenging aspects of having diabetes?

5. Tell me a story about the easy or smoother aspects of having diabetes?

6. Tell me a story that would help me to understand how having diabetes affects your day-to-day life.

7. Tell me a story that would help me understand the things that have helped you manage your diabetes since
   a. First diagnosed
   b. Currently

8. Tell me a story that would help me to understand the things that have helped you manage your diabetes after 1 year.

9. How do you know that your diabetes is well controlled or well managed?
10. Tell me a story that would help me understand how having diabetes affects your thoughts about your future.

11. How have the important relationships in your life changed since your diagnosis of diabetes?

12. What advice would you have for healthcare professionals who work with individuals who have diabetes?

13. What advice would you have for someone who has experienced a diagnosis of diabetes?

14. Considering all that has been said today, is there anything else you would like to add?
### Appendix R

**Post Interview Memo Form**

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1. From perspective of the researcher what are the main issues or themes in this interview?
2. Synopsis of the interview information based on the following (taken from the interview questions)?
3. Feelings about having diabetes
   a. Feelings when diagnosed.
   b. Feelings now
4. What is it like to manage diabetes on a daily basis? In terms of components of DSMT?
   a. Testing the blood sugar
   b. Taking medications
   c. Planning meals
   d. Exercise and physical activities
   e. Prevention of complications
   f. Foot care
   g. Eye care
   h. Kidney care
   i. Cardiovascular care
   j. Low blood sugar issues and concerns
   k. High blood sugar issues and concerns
   l. Sick day management issues and concerns
5. What helps in diabetes self-management?
   a. Testing the blood sugar
   b. Taking medications
   c. Planning meals
   d. Exercise and physical activities
   e. Prevention of complications
   f. Foot care
   g. Eye care
   h. Kidney care
   i. Cardiovascular care
   j. Low blood sugar issues and concerns
   k. High blood sugar issues and concerns
   l. Sick day management issues and concerns
6. What hinders diabetes self-management?
   a. Testing the blood sugar
   b. Taking medications

199
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<td>7.</td>
<td>What are the &quot;most easy&quot; components of diabetes self-management?</td>
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<td>How the health care system either hampered or facilitated diabetes care and self-management?</td>
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<td>Anything else that may have occurred to the nurse researcher as germaine or enlightening during this contact?</td>
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Clinical Indicators for the Sample (n=21)

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<td>8 (38)</td>
<td>64-167 mg/dl</td>
</tr>
<tr>
<td>Overlap Post Prandial Laboratory Blood Glucose</td>
<td>1 (5)</td>
<td>149 mg/dl</td>
</tr>
<tr>
<td>Triglycerides</td>
<td>19 (90)</td>
<td>33-509 mg/dl</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>19 (90)</td>
<td>114-292 mg/dl</td>
</tr>
<tr>
<td>High Density Lipo Protein</td>
<td>19 (90)</td>
<td>26-101 mg/dl</td>
</tr>
<tr>
<td>Low Density Lipo Protein</td>
<td>19 (90)</td>
<td>60-197 mg/dl</td>
</tr>
<tr>
<td>Very Low Density Lipo Protein</td>
<td>4 (19)</td>
<td>12-38 mg/dl</td>
</tr>
<tr>
<td>A1c</td>
<td>20 (95)</td>
<td>5.2% and 11.3%</td>
</tr>
</tbody>
</table>