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THE LIVED EXPERIENCE OF BECOMING A DIABETIC:

A PHENOMENOLOGICAL STUDY

A Dissertation in

Nursing

by

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ABSTRACT

Type 2 diabetes mellitus is a chronic disease that affects an estimated 25.8 million persons or 8.3% of the U.S. population, who are at high risk for major health complications (CDC, 2011; NDIC, 2012). Control of the disease depends largely on the diabetic’s adoption of self-care and health management strategies designed to control serum glucose levels. Diabetes Self-Management Education (DSME) is one process recommended to facilitate health behavior change and usually an expectation for the person recently diagnosed. However, outcomes of the formalized DSME programs are inconsistent and the overall process of self-care learning in the context of a recent diagnosis of diabetes is poorly understood.

The purpose of this phenomenological study was to enhance the understanding of the initial lived experience of becoming a diabetic. The focus was on the individual’s engagement with learning new self-care activities and initiating changes in self-care commonly recommended in order to control serum glucose and generally manage the disease progression. The focus of the study was not on how learning occurs or is accomplished as a process but rather on uncovering the key elements and the context of the actual experience itself to gain information not previously explored.

Using an interpretive phenomenological method of inquiry (van Manen, 1990), this study investigated the lived experience of becoming a diabetic in 10 adults recently diagnosed with type 2 (often referred to as ‘adult onset’) diabetes. The participants (8 females and 2 males) ranged in age from 39 to 77. Most (9) had been diagnosed within 1 to 1.5 years of this study. Analysis of the data obtained from open-ended interviews
revealed three themes of the lived experience of becoming a diabetic: (a) hearing the news (diagnosis), (b) sorting it out, and (c) moving on. Although these themes framed the experience for all of the participants, they were not in a fixed order. Improved understanding of the experience of becoming a diabetic and responses to the disease, as revealed in this study, provides new insight into how to best support patients in similar situations. Implications for nursing practice, education, and research are also identified.
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CHAPTER 1

Introduction

Type 2 diabetes mellitus is a chronic disease that affects an estimated 25.8 million persons or 8.3% of the population in the United States (Centers for Disease Control [CDC], 2011; National Diabetes Information Clearinghouse [NDIC], 2012). The precursor to type 2 diabetes, prediabetes, also known as impaired glucose tolerance (IGT) and/or impaired fasting glucose (IFG), affects 35% of adults aged 20 years and older, and 50% of adults aged 65 years and older (CDC, 2011; NDIC, 2012). Once diagnosed, the risk of death among persons with diabetes is two times greater than the general population (CDC, 2011; NDIC, 2012).

Type 2 diabetes characterized by insulin resistance and impaired insulin secretion (Smeltzer, Bare, Hinkle, & Cheever, 2010) has historically appeared only in adults over the age of 30 and the obese, but recent statistics document an increase in the diagnosis of type 2 diabetes in youths aged 10 to 19, with higher rates in U.S. minority populations (NDIC, 2011). In adults, type 2 diabetes accounts for 90 to 95% of all diagnosed cases of the disease (NDIC). Type 1 diabetes characterized by destruction in pancreatic beta cells (Smeltzer, et al.) is usually diagnosed in children and young adults, and gestational diabetes is characterized by any degree of glucose intolerance that occurs during pregnancy (American Diabetes Association [ADA], 2011; NDIC, 2012; Smeltzer, et al., 2010). Each type of diabetes has unique trajectories and treatment plans. This study focused on the experience of persons diagnosed with adult onset type 2 diabetes mellitus because they represent the majority of diabetes cases. Type 2 diabetes mellitus is signified by the term “diabetes” or the acronym T2DM in this dissertation.
The progression from prediabetes to type 2 diabetes is not inevitable. Lifestyle changes have demonstrated a decrease in the progression of the disease and an overall reduced incidence of the onset of diabetes in high-risk persons (CDC, 2007). It is estimated that successful self-management and glycemic control could prevent 231,000 deaths, save more than $174 billion, and avoid 15 million sick days (ADA, 2009; CDC, 2011; NDIC, 2012). Given the prevalence of diabetes and the personal and monetary costs of the disease, healthcare providers are charged with exploring strategies to help their patients better manage diabetes and prevent complications.

Control of blood glucose is considered key to the prevention of the progression of T2DM; unfortunately less than 47% of persons with diabetes are meeting the recommended goals for control of blood glucose (Healthy People, 2010). Despite evidence-based standards of care (ADA, 2011) and standardized treatment programs, it has been found that consistent results for interventions with recently diagnosed diabetics vary widely in actual control of blood glucose and the associated complications of diabetes (National Institute of Diabetes and Digestive and Kidney Diseases, 2004, 2012). Strategies to teach patients the facts about their diagnosis and to support health behavior changes in order to control the disease are a basic part of the treatment guidelines (ADA, 2011; NDIC, 2012). Formal and standardized self-management strategies, e.g., Diabetes Self-Management Education (DSME), have been in place for some time (initial publication 2000; most recent major revision March 2007). However, treatment outcomes (Funnell, et al., 2012; Mensing, et al., 2006) show that DSME initiatives for the treatment of type 2 diabetes are not consistently yielding the expected results (Jack, 2003).
The American Association of Diabetes Educators (ADE) recommends outcome measurements of DSME at four levels: (a) immediate measures of diabetes knowledge or learning; (b) intermediate psychological and behavioral measures of initiating and adopting self-care; (c) post-intermediate measures of physiological indicators of disease (e.g., serum glucose, weight), process (eye and foot examinations), and program (smoking cessation, pre-conception counseling) participation; and (d) long-term measures of overall health, quality of life, costs incurred, and complications related to diabetes (Peeples, Tomky, Mulcahy, Peyrot, & Siminerio, 2007, p. 797). The reason for the difficulty of achieving consistently positive outcomes of DSME at the evaluation points is poorly understood. More information is needed to explore what happens when persons are diagnosed with diabetes, their response to DSME, and their overall response to the expectation to change their health behavior. Specifically, research is needed that can improve understanding of the actual experience of the recently diagnosed diabetic who is attempting to learn new self-management strategies. Therefore, the focus of this study was on the early stages of immediate and intermediate diabetes isolated by Peeples, et al.

Background

The complications and co-morbidities of diabetes that can be limited by the control of blood glucose include retinopathy, peripheral neuropathy, and renal disease (CDC, 2011; NDIC, 2012). Glycemic control can be accurately monitored through periodic glycosylated hemoglobin (HbA1c) levels, a serum test which reflects the average blood glucose control over the prior 2 to 3 months (ADA, 2009). Every percentage point reduction in HbA1c reduces the risk of microvascular complications (eye, kidney, and nerve diseases) by 40% (CDC, 2011; NDIC, 2012).
Diabetes Self-Management Education addresses multiple topics on prevention, detection, and the treatment of the disease: nutritional and medication management; recommendations for physical activity; biological parameters, e.g., blood glucose for monitoring progress, and acute/chronic complications (Funnell, et al., 2012). Strategies to help the diabetic address psychosocial issues and general health promotion needs are also emphasized.

The National Standards for DSME are revised and reviewed approximately every five years by key organizations and federal agencies in the diabetes education community (Funnell, et al., 2012). Current standards are based on the findings of a task force organized by the American Association of Diabetes Educators and the American Diabetes Association (ADA) who met in the summer of 2006. The standards were approved in March 2007. The following organizations were represented on the task force: the American Dietetic Association, Centers for Disease Control and Prevention (CDC), and the American Pharmaceutical Association. The task force was comprised of a person with diabetes, several health services researchers/behaviorists, registered nurses, registered dieticians, and a pharmacist (Funnell, et al.). The DSME standards are designed to be applicable to any healthcare setting. Although institutions can adapt these standards, they are recognized as the guiding principles for diabetes education and form the basis for certification of diabetes education programs (ADA, 2010; The Joint Commission, 2010). Additionally, the ADA is one of three organizations which certify educational programs that adhere to the nationally recognized DSME standards. The ADA program, known as the ADA Education Recognition Program, is endorsed by the
Centers for Medicare and Medicaid Services and may be tied to reimbursement (ADA, 2010).

DSME has been developed to provide the knowledge, skills, and tools necessary to effectively improve self-care behavior (National Diabetes Education Program, 2009). Some studies have demonstrated that DSME is associated with the achievement of positive health-related outcomes and a reduction in the complications associated with diabetes (Mensing, et al., 2006). However, research has not yielded consistent findings related to the effectiveness of DSME (Adolfsson, et al., 2008; Clark, Hampson, Avery, & Simpson, 2004; Jack, 2003; Leeman, 2006; Siminerio, Ruppert, Emerson, Solano, & Piatt, 2008; Walker, Stevens, & Persaud, 2010). Although DSME programs have moved from didactic presentations to more empowerment-based models (Funnell, et al., 2010), the programs continue to be instructor-driven or formal programs in contrast to learner-driven strategies. Programs incorporating behavioral and psychological strategies, age and culturally appropriate content, and group education sessions have demonstrated some improved but inconsistent outcomes (Funnell, et al., 2012).

Self-management (self-care) behaviors are the focus of outcome evaluations for DSME (Funnell, et al., 2012). It is a clinical standard (ADA, 2011) that patients diagnosed with diabetes will receive DSME, and the majority of the healthcare insurance industry reimburses for the education programs. In some care settings, patient attendance at these programs is viewed as a quality indicator (Department of Health and Human Services, 2009).

Learning to understand and accomplish self-care behavior change is recognized as a very complex process. Multiple studies have focused on factors that may impact health
behavior change in response to educational approaches (Chlebowy & Garvin, 2006; Jack, 2003), but a best approach for accomplishing change has not been identified. However, recent studies reinforce the belief that accomplishing health care behavior change is highly individualized (Schoenberg, Traywick, Jacobs-Lawson, & Kart, 2008; Jack, 2003).

While substantial information about diabetes and the application of DSME in multiple populations is readily available, there is a lack of clarity surrounding the individual experience of learning diabetes self-management. Golding, Brown, and Foley (2009) discussed the undervaluing of learning outside formal programs which may account for the limited research studies outside of the adult learning and human resources fields. Furthermore, there is a lack of research on the interplay between various learning approaches and the impact of learning approaches adopted by the person for daily self-care. Therefore, a fresh research perspective was needed to uncover additional information about this unique experience. The purpose then of this study was to enhance the understanding of the lived experience of becoming a diabetic as reported by persons learning new self-care activities and initiating changes in self-care designed to control their serum glucose and generally manage their diabetes. This research included gathering information about the actual experiences of recently diagnosed diabetics and those related to learning self-management. Preferred information sources, how information was prioritized and incorporated into daily life, and the meaning given to this experience by the recently diagnosed diabetic were the focus of this investigation. Since very little is actually known about the experience of recently diagnosed diabetics when
they are learning to make the health and lifestyle changes recommended in DSME programs, a phenomenological research process was applied to the research questions.

**Statement of the Problem**

Diabetes is a disease with major complications. Control of the disease depends largely on the diabetic person’s adoption of self-management strategies to control their serum glucose. DSME is one process recommended to support the accomplishment of health behavior change, and diabetes education is an expectation for the individual who is diagnosed with diabetes. DSME programs are reimbursed by a majority of insurance companies, and patient participation in these education programs is generally viewed as mandatory by providers and often considered a quality indicator for healthcare settings (ADA, 2010; The Joint Commission, 2010). Unfortunately, the outcomes of the formalized DSME programs are inconsistent, and the overall process of actual self-care learning in the context of a recent diagnosis is poorly understood.

**Research Questions**

The research questions for the study were: (a) What is the actual experience of persons learning self-care to manage their diabetes? (b) How do persons diagnosed with diabetes make sense of or perceive the meaning of a diagnosis of diabetes related to their personal future? (c) What is the meaning of self-care to persons diagnosed with diabetes? (d) How do persons diagnosed with diabetes make sense of the information they receive to manage their condition? and (e) How do persons diagnosed with diabetes perceive the directions they receive from healthcare providers to change their self-care behavior?
Purpose of the Study

The purpose of this interpretive (hermeneutic) phenomenological study was to enhance the understanding of the lived experience of becoming a diabetic as reported by persons recently diagnosed. The focus of the study was on individuals learning new self-care activities and initiating changes in self-care designed to control their serum glucose and generally manage their diabetes in order to gain new insights into possible ways to improve the care of these individuals. The focus was not on how learning occurs or is accomplished; instead, it was on uncovering the key elements and the context of the experience to inform planning, teaching, and learning for persons with this diagnosis.

Theoretical Perspective

The inductive method of phenomenological research provided a way to explore the diabetic experience in its context (Morse & Field, 1995), and the hermeneutic (interpretative) phenomenological method facilitated the construction of a full description of some aspects of the diabetics’ lifeworld (van Manen, 1990). Phenomenology enhances the understanding of the lived experiences of the individual and their intentions within their daily life experiences (Heidegger, 1962). Exploring the experience of becoming a diabetic as reported by persons learning new self-care activities and initiating changes in self-care designed to control their serum glucose and generally manage their diabetes was the focus for this study. The lived experience of persons learning self-care to manage their diabetes and their incorporation of new information into their daily lives represented the phenomenon of interest.

Information gained from this research has the potential to provide fresh insight into understanding self-care learning, specifically in the context of a recent diagnosis of a
serious chronic disease such as diabetes. Acquisition of knowledge and improved understanding of the experience can uncover ways to improve the self-care measures that are key components of successful self-management in type 2 diabetes (ADA, 2005).

**Significance of the Study**

Diabetes is a chronic disease that affects millions of people. Once diagnosed, the risk of death among persons with diabetes is two times greater than the general population (CDC, 2011; NDIC, 2012). Additionally, there are significant personal and financial costs associated with diabetes. Successful self-management and glycemic control is essential to prevent or limit complications of the disease. Adopting self-care behaviors is paramount to the successful management of diabetes. Evidence-based standards outline the recommended treatment protocols and formalized patient education strategies (DSME) (ADA, 2011). Approximately half the population diagnosed with diabetes (56.8%) report receiving a course or class in diabetes (Health Indicators Warehouse, n.d.). While 53% of persons with diabetes are meeting recommended goals for control of blood glucose, data were not found to indicate the level of glucose and symptom control in persons who attend diabetes education programs compared to persons who do not attend such programs. In contrast, 16.2% of persons with T2DM reported carrying out all of the self-care recommendations (Funnell, 2006), but less than 12% of people with diabetes are meeting the recommended goals for control of blood glucose, blood pressure, and cholesterol (NIDDK, 2004).

Therefore, the clinician needs to understand the diabetic patient’s experiences in the context of their problem-solving strategies, interpersonal relationships and family experiences, and how personal experiences are integrated within the DSME education
process. The findings from this study have the potential to enhance understanding of the total experience of persons learning about and initiating new self-care activities to control their serum glucose and generally their manage diabetes.

**Assumptions**

This study was based on the following assumptions related to persons diagnosed with diabetes:

- Persons with diabetes are exposed to information about recommended self-care strategies when diagnosed with the disease.
- Persons with diabetes make some attempt to adopt recommended changes.
- The actual experience of learning self-care and its application to daily life can be stated by the participants.
- Knowledge gained from understanding this experience has the potential to provide fresh insight into the meaning of self-care learning in the context of diabetes.

**Limitations of the Study**

It is understood that the findings are limited to the study population and cannot be generalized based on the methodology (phenomenology) used. The goal of using phenomenology is to accurately describe the experience of the phenomenon under study for specific participants in one context (Morse & Field, 1995). Phenomenology does not generate theories, develop general explanations, or state empirical facts; instead, it offers accounts of experience, space, time, body, and human relations as we live them (Morse & Field, 1995; van Manen, 1990).
Conceptual Terms

The following terms were used for this study:

*Type 2 Diabetes Mellitus (T2DM)*: characterized by insulin resistance and impaired insulin secretion, occurs more commonly in people over the age of 30 and in the obese (Smeltzer, et al., 2010).

*Type 1 Diabetes Mellitus (T1DM)*: characterized by a destruction of pancreatic beta cells, occurs more commonly in children and young adults (ADA, 2011; Smeltzer, et al., 2010).

*Gestational Diabetes*: any degree of glucose intolerance, with onset during pregnancy (Smeltzer, et al.).

*Prediabetes*: a condition in which individuals have a higher than normal blood glucose, but not high enough to be classified as diabetes. Persons with prediabetes have an increased risk of developing type 2 diabetes, heart disease, and stroke (NDIC, 2012).

*Diabetes Self-Management Education (DSME)*: formal diabetes education programs that are based on standardized criteria.

*Self-care*: defined by Orem as “the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health and well-being” (Polit & Hungler, 1999, p. 113).

*Bracketing*: the act of suspending one’s beliefs in the reality of the natural world in order to study the essential structures of the world (van Manen, 1990). In interpretive phenomenology, it is understood that absolute bracketing is not possible (Smith, Flowers, & Larkin, 2009).
**Hermeneutics**: the interpretation of the structure of everydayness (Dreyfus, 1991, p. 34); the theory and practice of interpretation (van Manen, 1990, p. 179).

**Hermeneutic (interpretative) phenomenology**: a qualitative research tradition, drawing on interpretative phenomenology, which focuses on the lived experience of humans and how they interpret those experiences (Polit & Beck, 2006, p. 501).

**Meaning**: the significant quality, implication of a hidden or special significance (*Merriam-Webster*, 2011).

**Lived meaning**: describes those aspects of a situation as experienced by the person in it (van Manen, 1990, p. 183).

**Learning**: the act or experience of one who learns (*Merriam-Webster*, 2011).

**Formal learning**: teacher driven, institutionally-sponsored, classroom-based, and highly structured learning (Marsick, Watkins, Callahan, & Volpe, 2006).

**Informal learning**: learning accomplished outside of formalized educational programs such as: talking with others, collaborating with others, observing others, searching the internet, reviewing magazines and journals, sharing materials and resources with others, observing others, reflecting on actions, and trial and error (Lohman, 2005). For the purpose of this study, incidental learning was not differentiated from informal learning.

**Health Behavior Change**: adopting a lifestyle change in response to a perceived need.

**Chapter Summary**

In summary, diabetes is a serious chronic disease affecting millions of persons. The ADA (2011) and the American Association of Clinical Endocrinologists (AACE, 2011) publish well-defined guidelines for patient education designed to support the management of the disease. Despite evidenced-based standards of care and treatment
programs based on these standards, the majority of persons with diabetes are not meeting the recommended goals for control of their blood glucose (Healthy People, 2010) and the progression of the disease. It is known that persons diagnosed with diabetes learn to manage their condition from multiple sources. The utilization and outcomes of formal DSME learning have been well documented in the diabetes literature; however, no clearly successful model of DSME has been isolated. In addition, there is a paucity of research addressing what actually happens when the diabetic attempts to change health behaviors based on DSME guidelines. Given the complex nature of learning to acquire knowledge and change health behavior, it is important to better understand and clarify how persons take up learning in the context of the individual’s actual experience. Hermeneutic phenomenological research provides a method to study experiences in their context. Clarifying the experience of the recently diagnosed diabetic, therefore, has the potential to add new information that can improve the understanding of the person’s response to diagnosis and to the teaching/learning of self-care strategies used; and can open new options that may improve health outcomes for this high-risk population.
CHAPTER 2

Review of the Literature

This chapter addresses the literature that informed this study and provides a background on the preconceptions and perspectives of the investigator. The literature included in this section was consciously challenged during her analysis of the data for the study to facilitate gaining new insights on the experience of becoming a diabetic when learning about it and initiating self-care management.

Phenomenology

Given the scope of the phenomenological movement beginning in the nineteenth and early twentieth century, the focus of this overview of phenomenology was limited to the areas most relevant to this study. The early philosophers of phenomenology were faced with several questions, including what is true (epistemology) and what it means to be alive or not alive (ontology) (Munhall, 2007). The prevalent view of existence then did not address the question of being; instead the focus was on living. Phenomenology grew out of the concern that the natural sciences did not capture the human experience, and that positivism was inappropriately applied to human concerns (Cohen, 1987). This approach represented the shift from an epistemological account of the subject contemplating objects to an ontological account of explaining occurrences in terms of an intelligible being (Dreyfus, 1991). Thus phenomenology provided for the study of relationships that could be understood independently of empirical or experimental cases, or science (Spiegelberg, 1960).

Phenomenology is a philosophical perspective that provides a framework and method for studying a person’s lived experience; it is the study of essences, and provides
an in-depth description of the person’s experience (Smith, et al., 2009; van Manen, 1990, p. 39). The purpose of phenomenology is to describe a particular phenomenon, or the appearance of things as a lived experience; it is both a way of thinking or perspective, that is, a philosophy, and a research method (Streubert Speziale & Carpenter, 2007). Phenomenology is a careful examination of the human experience, and understanding the essential qualities of the experience in turn can illuminate the experience for others. To accomplish this, one must focus on the particular object in its own right, and then move the focus to the perception of the object and away from the object itself (Smith, et al., 2009). Phenomenology has been influenced by multiple philosophical perspectives and theorists, which inform hermeneutic phenomenological research. The phenomenology movement is commonly divided into three phases: the Preparatory Phase, the German Phase, and the French Phase (Spiegelberg, 1982).

**The Preparatory Phase**

Two persons considered to be key scholars in the preparatory phase of the phenomenological movement were Frantz Brentano (1838-1917) and his student Carl Stumpf (1848-1936) (Cohen, Kahn, & Steeves, 2000). Brentano was considered by many to have set the stage for the phenomenological movement, and although he did not claim to be a phenomenologist, the term phenomenology occurred in his unpublished writings (Spiegelberg, 1982). Husserl credited Brentano’s philosophical perspective and his influence with preparing the ground work for phenomenology (Spiegelberg).

Brentano called for a reformation of philosophy, and pushed to establish it as a rigorous science that could address questions unanswered by organized religion (Cohen, 1987). Brentano sought to base psychology on descriptive psychology, rendering it
scientific. Descriptive means that it is based on “a careful intuitive consideration of the structural properties of the phenomena” (Spiegelberg, 1982, p. 35). Additionally, Brentano is credited with discussing the value of inner perception or an awareness of our own psychic phenomena and reintroducing the concept of *intentionality*, described as directed towards something (Cohen, 1987, p. 32; Cohen, et al., 2000; Munhall, 2007, p.114; Spiegelberg, 1960).

Carl Stumpf (1848-1936), Brentano’s student, is credited with the spread of phenomenology and for founding experimental phenomenology. Stumpf used the term phenomenology and designated it as a field of study with an important place in scientific research. Stumpf founded experimental phenomenology, a method where knowledge is the consequence of the analysis of empirical material (Cohen, 1987). Phenomenology according to Stumpf was the “the first layer in the study of every established science” followed by causal research investigating the relationship between phenomena (Spiegelberg, 1982, p. 57). Stumpf also introduced phenomenological methods into the field of psychology, and the method was transmitted to other active researchers in the field (Cohen, et al., 2000; Spiegelberg, 1960). Husserl and Stumpf’s developments in phenomenology were parallel, although Stumpf’s version was considered “limited in scope” compared to Husserl’s (Spiegelberg, p. 61).

**The German Phase**

The German phase of the movement was led by Edmund Husserl (1859-1938) and his student Martin Heidegger (1889-1976). Their work greatly influenced the philosophical perspectives that served as a basis for the development of the phenomenological research methodology (Cohen, et al., 2000; Spiegelberg, 1960).
Husserl.

Husserl was a central figure in the phenomenological movement (Spiegelberg, 1960). He proposed a phenomenological reorganization which would help an objective scientist in the clarification and critique of unclear fundamental concepts and assumptions (Spiegelberg, p. 80). In Husserl’s view, modern science was unable to cope with problems of ultimate truth, validity, value, and meaning. Thus, he advocated a separation of modern science and scientific philosophy. According to Husserl, philosophy, specifically phenomenology, would restore contact with the deeper concerns of man, which would in turn strengthen science. Husserl did not intend to abolish science, but contended that phenomenology allowed for the study of relationships that could be understood independently of empirical or experimental cases, or science (Spiegelberg). Phenomenology evolved over time for Husserl, with the final stage of his work focusing on transcendental phenomenology which entailed suspending all transcendent claims or assertions about reality other than that of consciousness itself (Cohen, 1987). Husserl also proposed a philosophical perspective and a research process or method to study a phenomenon.

Husserl studied the way we know or comprehend the existence of objects, things themselves or the Sachen (Maggs-Rapport, 2001, p. 376; Spiegelberg, 1960). According to Husserl, the term intentionality describes the relationship between the process occurring in consciousness and the object itself, and the process of consciousness (Smith, et al., 2009, p. 13; Spiegelberg, 1960). Intentionality is also described as presenting the unity of things by examining consciousness as in the world and consciousness of something (Cohen, et al., 2000, p. 6). Therefore, the experience, knowing, or
consciousness of something, in turn leads to a relationship between the object and the awareness of the object.

Moving to a philosophical attitude involves questioning one’s unexamined presuppositions about the world (Spiegelberg, 1960; Stewart & Mickunas, 1990). Husserl described several methods for achieving this: the first, which is *phenomenological reduction* or reducing a problem to its basic elements, is a way of listening and opening ourselves to the phenomenon itself (Keen, 1975). The *phenomenological epoche* entails suspension of previously held beliefs in order to examine the dimensions of the experience. Finally, the natural attitude towards the world is expected to be placed in *brackets* or set aside during the analysis process in order to achieve objectivity. The terms phenomenological reduction, epoche, and bracketing are used interchangeably to refer to this process of separating the past knowledge of the researcher from present consciousness in order to consider all that is analyzed with a fresh perspective or objective viewpoint (Husserl, 1964; Stewart & Mickunas, 1990).

According to Husserl (1964), the intent of the phenomenological epoche is to identify the core structures and features of the experience. To achieve this, one needs to put aside the everyday world and focus on the perceptions of the actual lived experience. This process is assisted through *reductions*, a process of changing perspective that leads away from distractions towards the phenomenon under consideration (Smith, et al., 2009, pp. 13-14). This process is also known as *eidetic reduction*, which refers to reduction from particular facts to general essences (Cohen, et al., 2000, p. 7; Husserl, p. xvii).

According to Husserl, transcendental *subjectivity* requires a further reduction, a *transcendental reduction*, the process of looking at the nature of consciousness or the
process of creating awareness or consciousness (Husserl, 1964, p. xviii; Smith, et al., 2009, p. 15). Transcendental reduction involves *bracketing* the content of consciousness in order explore consciousness itself (Husserl; Smith, et al.).

In this view, after the series of reductions, the researcher is left with the phenomenon itself, as it actually appears, and in this state, can describe the phenomenon. According to Husserl, the series of reductions and reflections enables the researcher to capture the essence of the experience (Smith, et al., 2009). The phenomenon can then be presented without construction, interpretation, or explanation (Maggs-Rapport, 2001). From Husserl’s perspective, the series of reductions and reflections enables the researcher to capture the essence of the experience (Smith, et al.). Husserl’s work provides a basis for understanding phenomenology both as a philosophy and a research method.

**Heidegger.**

Heidegger studied under Husserl, but his interests moved beyond the description of experience to the interpretation of human experiences. In *Being and Time* he emphasized the importance of human experience as it is actually lived in the context of time and the meaning given to those experiences, because being is temporal (Cohen, et al., 2000; Heidegger, 1962). Heidegger sought to move closer to operational phenomenology and away from Husserl’s theoretical perspective. Husserl was primarily concerned with the description of individual processes, whereas Heidegger was primarily concerned about existence, practical activities, relationships, and making meaning in this world (Heidegger, 1962; Smith, et al., 2009).

The concept of *worldliness* was centered on the individual with a range of possibilities and meaningful options, and the world of daily experience (Smith, et al.,
2009, p. 17; Spiegelberg, 1982, p. 388). Defining the Dasein was central to Heidegger’s perspective. Dasein or being there refers to the human capacity to comprehend existence (Cohen, et al., 2000, p. 5; Heidegger, 1956, p. 29; Heidegger, 1962, p. 150). Dasein also relies on the existence of others, which encompasses Heidegger’s notion of intersubjectivity or Being-with, or the overlapping relational nature of one’s engagement with the world (Heidegger, 1962, p. 160; Smith, et al., 2009, p. 17).

Heidegger also addressed the transcendental reduction process of a leading phenomenological vision to understand the being of the Being (Dreyfus & Wrathall, 2005). Heidegger focused on more than just describing a phenomenon, rather on understanding or interpreting it as it was actually experienced (Maggs-Rapport, 2001). Hermeneutic phenomenology is designed to “construct a full interpretative description of some aspect of the lifeworld “ (van Manen, 1990, p. 18). Heidegger’s shift to the meaning of the experience initiated the onset of interpretative phenomenology.

The works of Husserl and Heidegger are compared and contrasted, with the former concentrating on an in-depth description of the phenomenon, and the latter focusing on an interpretation of the meaning of the experience (Maggs-Rapport, 2001). The object of concern for Husserl was subjective consciousness, with Heidegger’s focus being on the objective being or making meaning in the world (Spiegelberg, 1960). This difference in philosophical perspectives represented a branching of the phenomenological movement, as some of Husserl’s followers continued to emphasize descriptive methods and moved towards existentialism, while Heidegger’s followers continued with interpretative methods and moved towards hermeneutics.
The French Phase

The French phase began when Husserl’s papers were moved to Louvain shortly before his death (Cohen, et al., 2000). The French movement is characterized by a close association with existentialism (Spiegelberg, 1982). The key figures in this phase were Gabriel Marcel (1889-1973), Jean-Paul Sartre (1905-1980), and Marcel Merleau-Ponty (1908-1961). However, Merleau-Ponty did not consider himself a phenomenologist; rather he focused on the exigency of being, or something experienced in the face of the possibility that everything is merely appearance and illusion (Spiegelberg, 1982, p. 451). Marcel emphasized the mysteriousness of being and saw participation as fundamental to the conception of human existence (Spiegelberg). Phenomenology was an introduction to the analysis of being (Cohen, 1987).

Neither did Sartre consider himself a phenomenologist, and only reluctantly accepted the term existentialist given him by others. He is credited with being a novelist, playwright, critic, and editor as well as a philosopher, phenomenologist, and political figure (Cohen, 1987; Spiegelberg, 1982). While Sartre defined his position within phenomenology in relation to Husserl and Heidegger, he saw it as a basic tool for ontological existentialism. Sartre’s objective was “to reconcile the object and the subject” (Cohen, p. 33; Spiegelberg). Sartre emphasized the developmental process of being human. For Sartre we are always becoming ourselves; this is an ongoing project. Sartre discussed nothingness. In this view the things absent are as important as those present (Smith, et al., 2009, p. 20). Sartre’s philosophy evolved through four phases: an involvement in destructive philosophy in the pre-phenomenology period; the second phase was more concrete; the third phase was phenomenological ontology which was
influenced by Heidegger, and the final phase, phenomenological existentialism coincided with his political involvement (Cohen).

Merleau-Ponty wanted to show that a science of human beings is possible; he stressed the importance of considering the individual’s experience (Cohen 1987). Similar to Heidegger, Merleau-Ponty emphasized the situated and interpretative quality of our knowledge about the world. However, he moved away from Heidegger and described the embodied nature of our relationship to the world (Smith, et al., 2009). Merleau-Ponty envisioned Husserl’s eidetic reduction as a means rather than an end. In his view phenomenology was a way to “catch the facts in their uniqueness prior to all linguistic formulations” (Spiegelberg, 1982, p. 352).

Parallel Development

During the development of philosophical phenomenology, a parallel development was occurring among therapists (Cohen, 1987; Cohen, et al., 2000). This development was later described by Binswanger, Ellenberger, and May as the Daseinanalyse or the existential-analyst movement. The movement arose from the need to understand why therapeutic techniques were or were not successful, and to understand what is happening in the patient’s existence. This movement was influenced by the work of Husserl and Heidegger (Cohen, 1987).

Phenomenological Research and Nursing

Current nursing research is influenced by the works of Husserl, Heidegger, and the Dutch phenomenologists. The Duquesne School of Phenomenology is influenced by Husserl’s eidetic or descriptive phenomenology (Cohen, et al., 2000). Giorgi, Colaizzi, Fischer, and van Kaam (Cohen, et al., 2000) are researchers from this school and are
commonly referenced in nursing research. Heidegger’s phenomenology has guided the school and is referred to as Heideggerian hermeneutics and interpretative phenomenology (Cohen, et al., 2000). The Dutch phenomenology of the Utrecht School has also been referenced in nursing research. Van Manen has written helpful texts describing Dutch and Heideggerian phenomenology, particularly hermeneutic phenomenology (Cohen, et al., 2000; van Manen, 1990). In summary, Duquesne researchers focus on eidetic description, Heideggerian hermeneutics followers focus on interpretation and the hermeneutic phenomenology approach, which combines features of descriptive and interpretative phenomenology (Cohen, et al.). In many instances the delineation between methods is blurred and there is some overlap.

**Hermeneutic Phenomenology**

Hermeneutic (interpretative) phenomenology is a research approach that is built on the descriptive phenomenology of Husserl (Cohen, et al., 2000). Husserl was interested in describing in detail the lived experience. Heidegger expanded this to include understanding the phenomena of the world, how we go about understanding the world presented to us, and understanding the being itself (Cohen, et al., 1990, p. 5).

Hermeneutic phenomenology for Gadamer involved researching how persons go about understanding the world they live in (Cohen, et al., 1990; Gadamer, 1989).

Hermeneutics is also described as “an attempt to show the pre-philosophical understanding of man in the world that is basic to various disciplines so that this understanding can become the basis of philosophical reflection” (Stewart & Mickunas, 1990, p. 145). Hermeneutics is seen as a means to interpret underlying assumptions and to bridge disciplines. Hermeneutics is not external to phenomenology but is instead a way
of seeing a preunderstanding of a body of knowledge. Stewart and Mickunas interpreted
Heidegger’s hermeneutics as being concerned with the interpretation of being and
Gadamer as concerned with the interpretation of language (Gadamer, 1989).

Hermeneutic phenomenology is a significant contribution of the Dutch
phenomenologists, a body of work interpreted by van Manen (Cohen, et al., 2000, p. 9).
Hermeneutic phenomenology combines features of the Husslerian phenomenologists and
researchers grounded in Heideggerian philosophy. Hermeneutic phenomenology is
described as a method of “bringing out the normally hidden purposes of such goal-
determined beings as man” (Spiegelberg, 1982, p. 385). Hermeneutics, the theory of
interpretation, includes elements of both descriptive (Husslerian) and interpretative
(Heideggerian) phenomenological perspectives. Hermeneutics in research primarily
refers to interpretation that accompanies the description in a phenomenological study

Hermeneutic phenomenology is focused on the attempt to construct a full
interpretative description of some aspect of the lifeworld (van Manen, 1990, p. 10). Van
Manen describes phenomenology as “a systematic attempt to uncover and describe the
structures, the internal meaning structures of the lived experience” (p. 10). In turn,
hermeneutics includes both description and interpretation of these structures. The goal of
phenomenology is to gain an enhanced understanding of the meaning of a lived
experience. Phenomenology is not designed to solve problems but to clarify the
significance and meaning of certain phenomenon. On the basis of the understanding of a
phenomenon gained by this method, it is possible to “act more thoughtfully and tactfully
in certain situations” (van Manen, p. 23).
Van Manen’s (1990) phenomenological approach focuses on four procedural activities: turning to a phenomenon of interest, investigating experiences as we live them, reflecting on the essential themes of the phenomenon, and describing the experiences through writing and rewriting. Van Manen emphasizes maintaining an orientation to the research question and considering the relationship between the parts and the whole. He emphasized four existential themes as guides for reflection: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relations (relationality or communality) (p. 101). According to van Manen, the four existential themes can be differentiated but not separated because together they form the lifeworld or the lived world of the individual. He also provided descriptions of both this perspective and a methodology for hermeneutic phenomenological research.

**Adult Learning**

Although the process of learning per se is not the focus of this study, the investigator’s background in nursing, patient education, and her particular interest in DSME has included an exploration of learning principles and learning theories. This background is reviewed here to explicate some of the prior knowledge that needs to be set aside (or bracketed) to enable the investigator to reveal the essence of the experience of being diagnosed with and managing type 2 diabetes as it was actually lived by the study participants.

It is commonly recognized that learning in children is different from learning in adults. Pedagogy is described as the art and science of teaching children. In contrast, andragogy is a perspective and an attempt to focus on the needs of adult learners (Knowles, Holton, III, & Swanson, 2005). Knowles has established common perspectives
about adult learners: adults need to understand why they need to learn something; adults are responsible for their own decisions; they bring experience to learning situations; their readiness to learn is influenced by their real-life situations; adults are life-centered in orientation to learning, and internal pressures are motivations for learning (Knowles, 1990, pp. 57-63; Knowles, et al., 2005, pp. 64-69). Because the population receiving DMSE is composed of adult learners, it has been recommended that these programs incorporate behavioral and psychosocial strategies, and develop programs that are culturally and age appropriate (ADA, 2011) in an effort to improve outcomes. Therefore, incorporating adult learning perspectives has been considered an essential component when developing DSME programs.

Learning is viewed as a transformational experience that occurs by elaborating on existing frames of reference, learning new frames of reference, transforming points of view, or by transforming habits of mind (Mezirow & Associates, 2000). Transformative learning is the process of examining, questioning, validating, and revising perceptions of experiences (Cranton, 1994). The preferences of adult learners, supported by the work of Knowles, Mezirow, Cranton, and other theorists, provide valuable insight into planning formal programs for these learners. This work also suggests that formal learning models, such as DSME, might be readily augmented by informal learning sources of information. Based on these premises, it is reasonable to expect that a new diagnosis of diabetes could prompt the adult to search for information beyond or in addition to DMSE programs as well as information from their healthcare provider. Promoting health and incorporating self-care strategies into daily living could motivate the search for information to
supplement formal programs (Hernandez, Bradish, Rodger, & Rybansky, 1999; Paterson, 2001).

**Learner-Driven Versus Teacher-Driven Activities**

DSME is traditionally provided in formal educational sessions. However, the premises of adult learning theories also inform healthcare providers that learning occurs outside of formalized programs. The presence of learner-driven activities supports the notion that the adult learner may seek information to augment the DSME programs. The concept of learner-driven activities or activities that are initiated outside formal education—termed informal learning—arises from the human resources and adult education literature. This literature contributes to understanding the experience of adult learning. In this study, the term ‘informal learning’ is generally defined as learner-driven learning activities accomplished outside of formalized educational programs.

Informal learning has been defined and discussed in several articles and studies. For example, Tough (1999) discussed the presence of informal learning in his work from the late 1960s to the early 1970s. Tough contrasted learning planned by the professional and learning planned by an *amateur*. The amateur planner included the learner, a friend, and a democratic group of peers (Tough, 1978, p. 9). Applications of knowledge or anticipated use are common motivators for this type of learning. It is seen as a social phenomenon with a great deal of human interaction. Tough also discusses informal learning and differentiates intentional versus unintentional learning; the examples provided are consistent with later works that contrast informal and incidental learning.

According to Watkins and Marsick (1992), informal learning is learning from experience that takes place outside of formally structured, institutionally-sponsored,
classroom-based activities. Informal learning can be planned or unplanned, but there is an awareness that learning is taking place. Strategies for informal learning include self-directed learning, networking, mentoring, and coaching. Incidental learning is a subset of informal learning and is largely unintentional, unexamined, and embedded in the person’s belief system. Strategies for incidental learning include learning from mistakes, the internalization of meaning about the actions of others, and learning through covert interpersonal experiences. Both types of learning take place in the course of daily events. In incidental learning, the learning is buried in the interaction or event itself. The learner needs to attend to the by-product messages and see them before learning can occur (Cseh, Watkins, & Marsick, 1999; Marsick & Watkins, 2001; Watkins & Marsick, 1992). These definitions of informal learning are similar to the earlier work of Tough (1999).

Schugurensky (2000) differentiated informal learning by three types: self-directed, incidental, and tacit learning (also referred to as socialization). Self-directed learning is described as learner-driven, intentional, and conscious. Incidental learning is described as learning without intent but awareness that learning occurred, and is therefore unintentional and conscious. Finally, tacit learning is described as the internalization of values, attitudes, behaviors, or skills in everyday life, and is therefore unintentional and unconscious. The learning is later recognized through a retrospective process. These terms and the differentiation of learning types by Schugurensky are similar to the previous definitions provided by Tough, Watkins, and Marsick. Commonalities exist between informal and self-directed learning, and between incidental (Watkins & Marsick, 1992) and tacit learning (Schugurensky, 2000).
Livingstone (2001) differentiated between formal education, non-formal education, and informal learning or training. Formal education was described as a setting where the teacher as the authority delivers a curriculum from a pre-established body of knowledge, whereas non-formal or further education was described as the learner opting to acquire further knowledge or a skill. Informal learning was defined as any activity involving the pursuit of understanding, knowledge, or skill which occurs without the presence of externally imposed curricular activity (Livingstone, 2001, 2002). Informal learning occurs outside of formal learning settings, and the terms of the learning are determined by the learners. Livingstone further distinguishes between informal intentional learning and informal intentional training with the addition of a mentor in the training component. Self-directed, informal learning is described as undertaken by the learner’s terms, without prescribed curricular requirements or a designated teacher. At this point, Livingstone does not provide a definition of incidental learning.

Eraut (2004) differentiated three types of informal learning as implicit, reactive, and deliberative. Implicit learning is described as unconscious and the absence of knowledge about the material learned. Reactive learning is intentional and occurs when there is little time to think about learning; it is “near-spontaneous” learning (Eraut, p. 250). In contrast, deliberative learning occurs in the presence of goal setting and planning for learning. Eraut also described a continuum of learning with informal learning and formal learning on opposing ends and mentoring in the center. Eraut’s definitions of learning are consistent with prior definitions. Commonalties are noted between informal (Watkins & Marsick, 1992) and reactive and deliberative learning (Eraut) and incidental (Watkins & Marsick) and deliberative (Eraut).
After reviewing the definitions of informal learning, similarities were found among them; the most common is the discussion of intentional versus unintentional and conscious versus unconscious learning. These terms can be used to differentiate between informal and incidental learning. In the simplest sense, with informal learning the learner has consciously sought learning, or the learning has occurred unconsciously as in incidental learning, and was later recognized as having occurred. Additionally, the notions that the activity is learner-driven and that the learning occurs outside of a formal learning setting are also commonalities across the definitions.

Golding, Brown, and Foley (2009) reviewed definitions of formal and informal learning with a focus on conceptual terrain and power relations (p. 35). They compared formal education, non-formal education, and informal learning in addressing the valuing of formal, structured learning over informal learning. This undervaluing translates into a lack of economic value and power, which in turn places this type of learning outside of policy and research priorities. The unstructured nature of informal learning contributes to power and value perceptions. The authors recommended ongoing research in adult and community education and learning.

Although the work on informal learning and formal learning and the theoretical premises of Marsick and Watkins (1992, 2001, 2006) are interesting to consider, the literature on informal learning and formal learning principles was consciously challenged in the analysis of data in this phenomenological study in order to facilitate the gain of new insights on the actual experience of learning and initiation of new self-care strategies in the recently diagnosed diabetic patient. Research that explores the actual interaction of
various approaches to learning provides a fresh view of the learning experiences of the diabetic in the actual context of their daily life, including individual differences.

**Informal Learning**

Watkins and Marsick (1992) discussed a theoretical framework for understanding informal learning in the workplace. Informal learning occurs outside of the classroom and is described as the following: an independent learner-driven activity that may occur in the classroom. It is not typically classroom-based or highly structured; the learning is integrated with work or daily routines, and it is an inductive process of reflection and action (Marsick, Watkins, Callahan, & Volpe, 2006). Examples of informal learning include talking with others, collaborating with others, observing others, searching the internet, reviewing magazines and journals, sharing materials and resources with others, reflecting on actions and trial and error (Lohman, 2005). The work of Marsick and Watkins (1992, 2001, 2006) helped provide a theoretical perspective to enhance the exploration of types of learning found in this population. However, research that explores the interaction of various approaches to learning is warranted to explore real world experiences with diabetes self-care learning in the context of daily life.

Marsick and Watkins’ theory (2001) is rooted in the work of Dewey, Argyis, Schon, and Mezirow. Marsick, et al. (2009) discussed Dewey’s premise of problem solving through reflective thought as a theory informing informal and incidental learning. Reflective thought occurs at the “disjuncture” between what is expected and what occurs. This in turn leads to re-evaluation which prompts problem solving through trial and error (Marsick, et al., 2006, p. 572). Dewey’s work focused on reflective thinking and reflection as rational problem solving (Cranton, 1994). This is evident when considering
the development of informal learning theory and independent learning which includes reflection and action.

Argyis and Schon developed the idea of theory in action, which built on Dewey’s work of identifying the “disjuncture” as a trigger for learning the course of action (single loop learning) to achieve goals (Marsick, et al., 2009, p. 572). If this is unsuccessful there is a change to double loop learning, where one examines values, assumptions, and values that frame the situation. This reframing leads to more effective solutions which the individual then learns to implement.

Mezirow and Associates (1990) addressed transformative learning which includes the stages of “disorienting dilemma”, self-examination of assumptions, exploring options, developing an action plan, and reintegration into life (Cranton, 1994; Merriam & Caffarella, 1999, p. 321; Mezirow & Associates, 1990). The disorienting dilemma or critical points could be the stimuli for informal learning; additionally, there are commonalities between the stages of self-examination, reflection and action, and informal learning.

These elements are seen as critical to a conceptual understanding of informal and incidental learning: learning from experience, the organizational context, a focus on action, non-routine vs. routine conditions, the tacit dimension of knowledge, delimiters to learning, and enhancers to learning (Watkins & Marsick, 1992). The key concepts of triggers, interpreting the experience, examining alternate solutions, learning strategies, producing proposed solutions, assessing intended/unintended consequences, lessons learned, framing the context, and the context (work environment) are clearly defined by Watkins and Marsick. The critical elements and concepts are relational in nature.
According to Marsick, et al. (2009), their model depicts reflection that occurs when encountering a problematic experience, and the learning of ways to understand and address the challenges. These authors further describe the model components of problem solving steps and learning steps. The model appears linear, yet Watkins and Marsick (2001) describe the progression as an “ebb and flow”, the model being neither linear nor sequential (p. 28). They further state that with each new insight the learners go back and question earlier understandings.

In 2001, Watkins and Marsick revised their earlier theory, changing their model to reflect their revisions and contrasting informal learning with formal learning as part of their framework. Formal learning is typically institution based and highly structured. In contrast, informal learning is neither, and the control of learning is the responsibility of the learner. Informal learning is seen as including task accomplishment, resulting from interpersonal interaction, sensing organizational culture, or resulting from trial and error experimentation. The healthcare provider can apply these findings by recognizing, encouraging, and supporting informal learning.

Marsick, et al. (2009) identified the following as weaknesses of the original model: appears linear and cognitive, focuses on individual learning within the workplace context, and does not explain the role of context in learning. The authors recommend thinking about informal and incidental learning as “an amoeba-like process, multidimensional in nature, consisting of iterative cycling back and forth among phases of the process” (Marsick et al., p. 591). This kind of learning is often enmeshed with action, although, in informal learning, reflection can occur at any stage and because of its relationship to action the learning is unarticulated and preverbal.
The work of Marsick and Watkins (1992, 2001, 2006), while interesting to consider, was consciously challenged in the analysis of the data in this study in order to facilitate the gaining of new insights on the lived experience of becoming a diabetic for persons recently diagnosed. The focus of the present study was to develop a better understanding of the actual experience of individuals learning new self-care activities and initiating changes in self-care to control their serum glucose and generally manage their diabetes.

The Health Belief Model

The Health Belief Model (HBM) (Rosenstock, 1974) is a framework that is often used to study health behavior change in individuals. This model is designed to explore the transition from knowledge acquisition to behavior change. It is necessary to consider behavior change when exploring the experience of learning self-care in the recently diagnosed diabetic.

The HBM postulates that health-seeking behavior is influenced by the person’s perception of the posed threat and the value associated with actions aimed at reducing the threat (Polit & Hungler, 1999). The major components of the HBM are perceived susceptibility, perceived severity, perceived benefits and costs, motivation, and enabling or modifying factors (Polit & Hungler). The HBM is potentially useful to predict whether or not individuals would use preventative measures and to suggest interventions to promote health protecting behaviors for them (Pender, Murdaugh, & Parsons, 2002). Perceived barriers are considered to be the most powerful dimension for explaining or predicting behavior with perceived susceptibility also identified as an important predictor (Pender, et al.).
According to Rosenstock (1974), the implicit concepts of the model are based on the premise that an individual exists in a life space composed of regions that are positively valued, negatively valued, or neutral. Disease, if presented, would be negatively valued and would be expected to exert a force moving the person away from that region. Daily activities consist of being pulled by positive forces and repelled by negative forces. The theory proposes that in order for an individual to take action to avoid a disease they need to believe they are personally susceptible to it and that its occurrence would have at least a moderately severe effect on some aspect of their life. The individual believes that taking an action would be beneficial by reducing their susceptibility or severity and that the action would not entail overcoming important barriers such as cost, convenience, pain, or embarrassment (Rosenstock). A cue to action is needed to set this process in motion (Rosenstock).

Models such as the HBM have been used in health care as a framework to study factors influencing behavior change or taking on self-care strategies. This model provides one way to view the person seeking information about illness and/or adopting lifestyle changes to influence their health status, and identifies what are considered key junctures in learning. This commonly cited model was also part of the background knowledge considered in the analysis of the data for this study.

Learning in the Context of Illness

This section reviews in detail additional literature and research studies that influenced the development of this study. This overview is provided to add to the background knowledge that the researcher had prior to the initiation of the study. This literature review enhanced her reflection on the phenomena being studied and proved
useful in the interpretation of the results. However, the literature was consciously questioned and held only as a potential source of explanation throughout the research process to ensure that what the study participants revealed was reported as it actually occurred for them in the context of their daily lives.

**Learning and Chronic Illness**

Keeping, English, and Fleming-Courts (2001) conducted a focus group in a qualitative study to examine how patients with end stage renal disease (ESRD) on continuous ambulatory peritoneal dialysis (CAPD) learned to care for themselves. The sample consisted of 8 participants (6 women and 2 men). The authors defined formal learning as learning that is sanctioned by an institution that bestows academic credibility on the learner while defining informal learning as that which occurs outside of educational institutions and may consist of short courses, conferences, and seminars. Additionally, they defined informal learning as everyday learning, which occurs outside the classroom and is intentional, and indicated that mentoring, tutoring, or self-directed learning can facilitate informal learning. According to Keeping, et al., nurse educators in the dialysis setting use informal learning methods to teach self-care practices to patients. The researchers identified the following three themes that emerged from the focus group sessions: understanding medical and professional language, trusting their own experience, and living on the border of life and death. The following factors were identified as contributing to learning: the experience of change, the influence of context, action, and the presence of non-routine conditions. Their study provided insight into the unique learning experience of this group of patients and techniques for facilitating learning and behavior change.
Thorne, Paterson, and Russell (2003) also conducted a focus group in a qualitative study to understand how everyday self-care decision making is learned and experienced. Their sample consisted of individuals with self-care expertise, nominated by their clinicians, and with a longstanding diagnosis of one of the four following chronic diseases: type 1 diabetes, type 2 diabetes, HIV/AIDS, or multiple sclerosis. “Learning: the Decision to Assume Control” (p. 1,341) was a common theme among all the participants who expressed a commitment to controlling the disease rather than being controlled by the disease. The participants recalled this as a conscious decision at an early point in their illness trajectory. Some participants were motivated to assume control by encountering preventable complications and understanding the relationship between the disease outcomes, self-care decisions, and secondary prevention. Intensified learning was a characteristic of the decision to assume control. Two additional themes were identified: “Fine Tuning: The Disease-Specific Context of Self-Care” (p. 1,342) and “Evaluating: Quality Measures for Self-Care Decision Making” (p. 1,347). Discussion related to the fine tuning theme focused on body listening and the impact of the disease trajectory. In the initial phase of the disease, participants said they had adjusted to the “enormity of the challenge” of self-care decision making, which was followed by periods of stability when routines and practices were effective, and, finally, during times of crisis and change, self-care would predominate. The final theme related to evaluating self-care decision making. The participants identified their use of experts and biologic measures and creating individual standards as a means to evaluate self-care practices, and discussed the complexity of self-care and balancing their expectations of the healthcare provider. The findings of this study point to critical times in the chronic illness trajectory when the
individual with chronic illness seeks information in an effort to assume control. This also suggests the importance of perceived control in the process of taking action. Thorne, et al.’s study provides a collective versus individual perspective on self-care decision making, and was not time limited, e.g., recently diagnosed.

Rogers, et al. (2004) reported the results of a qualitative study the purpose of which was to explore physical activity, knowledge, attitudes, and behaviors among breast cancer patients during adjuvant therapy. The sample of 12 female breast cancer patients attended focus groups. Social cognitive theory as described by Bandura was the framework for the study. The responses of the participants and the research questions were categorized according to the eight constructs of social cognitive theory: self-efficacy, environment, behavioral capability, expectations, expectancies, self-control and performance, and observational learning and reinforcement (internal and external). Learning was evident in the participants’ statements regarding the importance of exercising with friends, gathering information through group exercise, and the advice they would give to a woman with breast cancer. Several participants stated that their medical provider did not give recommendations about exercise; consequently, they sought information independently. Their study provides valuable information regarding the breast cancer patient’s experience of learning, including the importance of exercise guidelines and the benefit of peer support and group exercise programs.

Norr, Norr, McElmurry, Tlou, and Moeti (2004) reported their findings from a quantitative study examining if peer group intervention for HIV prevention improves HIV prevention attitudes, knowledge, and behavior in urban women. The intervention addressed general barriers to change and gender-inequality barriers to behavioral change.
Their sample consisted of 400 women in Botswana, with the study design identified as a quasi-experimental pre- and post-test design with an intervention and a delayed control group. The intervention occurred over six 90-minute weekly or biweekly peer education sessions. The sessions in peer education were conducted in workplaces. However, the sessions were not employer sponsored or sustained by the workplaces and thus did not occur during work time. The data analyses were comprised of the findings of the pre- and post-tests, with 130 matched tests available (98 intervention and 32 delayed control). The authors reported significant post-test differences in the women’s knowledge about HIV transmission, sexually transmitted infections, and prevention behaviors after the intervention. The intervention was associated with a significantly higher positive attitude towards condoms, condom self-efficacy, and an increase in safer sexual behaviors. These research findings demonstrate the success of peer group education in this setting, as the peer group strategy continued for five years after completion of the research study. The authors acknowledged that a national mass media campaign addressing HIV and AIDS may have impacted the findings. However, the knowledge of the intervention group was significantly greater than that of the control group in lieu of the media. The results of Norr, et al.’s study demonstrate that peer education and peer groups may be valuable as strategies to promote learning and behavior change.

Cox and Oakes Westbrook (2005) completed a qualitative study using grounded theory to describe the process for learning home infusion therapy and the nursing actions that assisted the learning. The sample consisted of 7 caregivers (4 women and 3 men). In their study the patient was the spouse or the child of the caregiver. Five themes were identified as: “Can I do this?”, “What is in it for me?”, “Learning how to do it”, “What
was helpful and not helpful to my learning?” and “Doing it myself at home” (p. 102).
The themes occurred across these 4 domains: the caregiver domain, the instructional
process domain, the nurse-teacher domain, and the context domain. The participant
statements provided examples of learning or gathering information which occurred
through explanation, demonstration, written materials, and follow-up with knowledgeable
resources such as the nursing unit and equipment supplier. Additionally, it was reported
that learning occurred through return demonstration, trial-and-error, and home
organization. The outcome of this study provides information about the domains of
learning and learning strategies for nursing educators to consider when planning patient
education sessions, and strategies for supporting the caregiver and patient after discharge.

Andersson, Johansson, Nilsson, and Sahlberg-Blom (2008) reported the findings
of their phenomenological study describing the experience of living with urinary
incontinence among persons who did not desire further assessment and treatment. The
sample consisted of 11 female participants. The authors reported the emergence of three
themes: “learning to live with it despite difficulties”, “other illnesses are more
important”, and “reluctance to seek care” (pp. 118-119). Learning was evident when the
participants reported understanding their bodies as a method of problem-solving, meeting
with others, and sharing their experiences of living with urinary incontinence, which they
saw as a source of insight into dealing with the problem. Andersson, et al.’s study
documents the experience of living and learning self-care in persons with urinary
incontinence, which may or may not relate to recently diagnosed diabetics.

Costantini, et al. (2008) reported their findings from an exploratory qualitative
study that examined the self-management experiences of persons with mild to moderate
chronic kidney disease. The sample consisted of 14 participants (6 males and 8 females). The findings discuss their process of “renegotiating life with chronic kidney disease.” The two themes identified were: “discovering kidney disease” and “learning to live with kidney disease” (p. 149). Learning occurred when the participants discussed searching for clues or evidence and self-monitoring as reasons for treatment modification. The results of their study provide a unique perspective on the role of the acceptance of the disease in this patient population. The diabetic’s individual perceptions related to their diagnosis were explored in the present study.

These six studies were selected to illustrate the learning experiences of individuals with health concerns (Andersson, et al., 2008; Costantini, et al., 2008; Cox & Westbrook, 2005; Keeping, et al., 2001; Rogers, et al., 2004; Thorne, et al., 2003) and, the seventh, as an education strategy for HIV prevention (Norr, et al., 2004). The findings from these studies provided additional support for the need for the present study as a means to improve understanding of the learning experiences of recently diagnosed diabetics. Phenomenological research can enhance the understanding of the experience of persons’ understanding of self-care to manage a health concern, specifically diabetes.

Learning in the Context of Diabetes

Traditionally, diabetes education is provided through teacher-driven or formal sessions, with formal learning or teacher-driven sessions being the focus of the research and planning. Most studies of diabetes education have examined patient learning that occurs in formal learning programs (Clark, et al., 2004; Jack, 2003; Leeman, 2006). Additionally, research has been conducted related to a specific setting, patient population, or format of the DSME program (Adolfsson, Starrin, Smide, & Wikblad, 2008; New,
Siminerio, Ruppert, Emerson, Solano, & Piatt, 2008; Walker, Stevens, & Persaud, 2010). Learning and adopting self-care techniques or successful diabetes self-management are often evaluated as a function of adherence, which is measured by self-report questionnaires, pill counts, or physiologic measures (Bartels, 2004; Chlebowy & Garvin, 2006; Egede, 2003; Glasgow, Peeples, & Skovlund, 2008; Johnson, 1992; Tu & Morrison, 1996; Weiner & Long, 2004). Learning experiences outside of the formal setting, or informal learning, were noted in several studies (Burke, Earley, Dixon, Wilke, & Puczynski, 2006; Getz Jeanfreau, 2005; Gillard, et al., 2004; Hernandez, Bradish, Rodger, & Rybansky, 1999; Paterson, 2001; Scollan-Koliopoulos, O’Connell, & Walker, 2007; Tu & Morrison, 1996).

Diabetes is viewed as a serious chronic disease with a high risk for complications. In Healthy People 2020 (2010) there were 16 objectives plus corresponding sub-objectives earmarked for diabetes (including type 1, type 2, and gestational diabetes). Currently, 56.8% of adults diagnosed with diabetes report ever receiving a course or class related to diabetes self-management. The established target is 62.5%. Additional objectives are directed toward biological measures, e.g., blood glucose control and blood pressure control. An objective for lipid control is in development (Healthy People, 2010).

Evidence of learning has been captured in studies of persons with diabetes. Tu and Morrison (1996) conducted a quantitative study that addressed the self-care practices of the indigent. The sample consisted of 61 persons with type 2 diabetes. Data sources included interviews, self-report instruments, and glycosylated hemoglobin results. The authors reported that non-adherence to diabetes self-care activities was a function of knowledge deficits. These authors further identified that 26.2% of the subjects reported
learning about self-care, blood glucose monitoring specifically, through friends, family, and neighbors diagnosed with diabetes. The findings of their study support the presence of multiple types of information sources utilized in this population and the influence of knowledge deficits on self-care. However, the study did not explore the individual’s actual experiences of interpreting and understanding their self-care needs.

Gillard, et al. (2004) conducted a longitudinal quantitative study to determine if participation in eye disease screening clinics contributed to patient understanding and impacted self-care behavior and glucose control. The methods of evaluation were self-reported medication use, self-management behavior, and glycosylated hemoglobin. The study targeted African Americans. The sample consisted of 98 individuals with diabetes, with most of the participants being African American women. Examples of learning strategies in this study included learner-driven discussions with the nurse educator, information station selection, and selection of clinic-sponsored publicity materials. Gillard, et al. reported an increase in insulin use (p=.02), increase in self-glucose monitoring (p<.01), and a decline in mean glycosylated hemoglobin results (p=.03). The measures were compared at the first, second, and third exam visits. The results of Gillard, et al.’s study show the presence of a variety of strategies to gather information and the impact on self-care behaviors and health outcomes. However, it did not explore the actual experiences of the participants.

Scollan-Koliopoulos, et al. (2007) studied the effects of multigenerational legacies of diabetes on health beliefs and behaviors in a quantitative study. The convenience sample consisted of 123 participants with family histories of diabetes. The data were collected through surveys addressing self-care behavior, illness representation,
recollection of family member’s illness representation and complications, and perceived social consequences of diabetes. The following theories were discussed as influencing the study: family systems illness and disability (Rolland), social learning theory (Bandura), and illness representation (Leventhal) (p. 509). The authors reported significance in the following areas: perception of disease control in family members was associated with perception of control in the participants (p=.03), and the presence of social consequences for family members was associated with increased perception of social consequences for the participants (p=.01). This study discussed the influence and interpretation of a prior generation’s experiences with diabetes on the generation studied.

Shaini, Venkatesan, and Ben (2007) reported the findings of a pre-experimental design study utilizing an education intervention and a pre/post-test. The purposes of the study were to assess the knowledge level of home care management and effectiveness of a structured teaching program, and to determine the association between pre- and post-test knowledge. Purposive sampling was used to obtain the sample of 50. Post-test results revealed an increase in home care knowledge, a pre-test score mean of 19.50 and a post-test score mean of 30.06. Learning sources and strategies were captured when the participants identified television shows, radio programs, newspapers, and pamphlets as information sources. The value of formal patient education as an intervention was also documented in this study.

Ellison and Rayman (1998) studied the experience of learning self-management in a focus group in a qualitative study. The 17 participants were women with type 2 diabetes nominated by experts from the diabetes treatment and research center as exemplars of self-management. The criteria for nomination were the following: no diabetes-related
hospitalization in the prior 12 months, mean glycosylated hemoglobin 7% or less (agency acceptable mean) for the prior 12 months, active participation in self-care management, possessing personal confidence, and management flexibility (evaluation method unknown). The investigators identified three phases of learning as part of the process, which were management-as-rules, management-as-work, and management-as-living (p. 325). Movement through these phases was “heralded by identifiable transitional events” (p. 325). The transitional points were described as moving from phase one to two when managing diabetes is viewed as “work.” The participant became engaged in the work of self-management and made conscious decisions about personal responsibility; this was noted as a fluctuating process. The participants moved from phase two to three after the perception of being a “successful” self-manager, which included a wide range of management strategies and a high level of confidence. The findings of this study further support the notion of critical points in the diabetes trajectory and learning of self-care. Ellison and Rayman’s study provided a collective versus individual perspective, as the individual’s perceptions related to understanding and adopting of self-care were explored.

The experience of learning about diabetes was presented in a study conducted by Hernandez, et al. (1999) regarding self-awareness in diabetes and the understanding of cues, sensations, and circumstances that persons with diabetes and their families experienced. The sample of persons with type 1 diabetes consisted of four females and their family members who attended a series of four focus group sessions. The study was the initial phase of a program designed to develop and pilot test an educational program. The participants described usual and unique body cues for hypoglycemia, hyperglycemia, and euglycemia or self-awareness strategies which enabled them to tune into their body
cues and sensations. As the participants reported symptoms, they were embedded in a life event or incident in contrast to listing the symptoms alone. The focus group study provided a collective perspective, including examples of learning through trial and error and reading body cues. Hernandez, et al. explored individuals’ experiences of learning or understanding self-care.

Hill-Briggs, Cooper, Loman, Brancati, and Cooper (2003) conducted a focus group in a qualitative study to explore and compare diabetes-related problem solving in urban African Americans with type 2 diabetes. The sample consisted of two focus groups. Group one contained persons in good control (N=8, HbA1c <8.0) and group two contained persons with poor control (N=7, HbA1c >9.0). A component of this study was to question the participants to determine their transfer of past experiences and prior learning to new situations. The study results identified examples of both positive and negative transfer of past experiences. The participants in good control discussed learning from their own experiences, and from family members, friends, and acquaintances. The participants discussed preventing complications, asking older family members their secrets of living with diabetes, and getting recipes from friends or acquaintances. The participants with poor control identified family or personal experiences of observing poor self-management and outcomes, and learning that having these problems and outcomes appear to be inevitable. The participants were able to verbalize learning about self-care through education classes, yet they tended to repeat ineffective behaviors or model unhealthy patterns observed in others. The results of Hill-Briggs, et al.’s study show the presence of a variety of learning strategies, the high rate of utilization of informal
sources, and further support the need to research the individual experience of learning about self-care in the adoption of health-promoting behaviors.

Burke, et al. (2006) conducted a focus group in a qualitative study addressing the patients’ perspectives of their diabetes appointments. The data were collected through two focus groups with four participants in each. The prominent themes in this study were time, control, information, family influences, and the physician-patient encounter. In this study, in addition to the office visit and physician-obtained information, the participants self-selected print materials, the internet, and family for obtaining disease-related information. The authors recommended that physicians help patients evaluate information sources. The results of their study show the variety of information gathering strategies utilized and further support the need to improve understanding of this phenomenon of learning and initiating self-care. Phenomenological research provides a mechanism to enhance the understanding of this phenomenon.

According to many studies in the literature, living with diabetes is akin to a balancing act. Research has been conducted to look at coping with complications. Nyhlin (1990) conducted a grounded theory, qualitative study with the aim of gaining understanding into the coping strategies of persons with diabetes who were experiencing long-term complications. Three categories were identified based on participant responses: “coming to terms”, “keeping going” and “making sense” (p. 1,023). These categories formed a continuum in the order presented. The patient’s movement through the phases varied as new challenges were presented. According to Nylin, in the “coming to terms” stage, seeking advice, information gathering, and learning the rules of being a diabetic patient were common coping strategies. In the “keeping going” stage, making
adjustments and organizing daily life were common strategies. In the “making sense” stage, creating positive meaning and reappraising life were common strategies.

Uncertainty was a common issue for the participants in the study. Nyhlin’s study supports the intense nature of periods of learning for the person with diabetes and the active process of seeking information which needs to be better understood.

Paterson (2001) investigated self-care decision-making and the relationship to empowerment in a grounded theory, qualitative study. The sample consisted of 22 persons with type 1 diabetes. The participants were self-nominated and nominated by physicians as self-care experts. They provided the definition of expert self-management as being the ability to make trustworthy decisions about self-care and maintaining good glycemic control (values not provided). Data were collected through the participants’ audiotapes of self-care decision making, interviews, and focus groups. Paterson contrasted experiential insights, authoritative knowledge, and power. A theme in this qualitative study was the “discounting” (p. 577) or devaluing of patient knowledge and experiences by healthcare providers. Paterson also reported that providers did not recommend the necessary resources to help these patients make informed decisions. The types of learning or information gathering in regard to diabetes were revealed in this study through participant comments. These results show the presence of experiential knowledge and the use of resources in type 1 diabetics for decision making which further support the need to research this phenomenon in persons with T2DM.

Getz Jeanfreau (2005) studied transitions toward self-management in persons with type 2 diabetes in a grounded theory study. “Development of the Diabetic Self” was the proposed theory (p. 76). The data were collected through semi-structured interviews with
11 participants. These themes were identified: the diagnostic event, followed by a continuum entitled “Beyond Diagnosis” which contained the following themes: multiple transitions, transition resolution, and self-management. Getz Jeanfreau also discussed “Learning and doing” (p. 109) as a prominent theme. The participants identified three sources of learning: learning from health professionals, through independent or self-directed activities, and from diabetes mentors or models (p. 109). The findings of Getz Jeanfreau’s study were consistent with the principles of adult learning, and support the need to enhance understanding of the experiences in persons with recently diagnosed T2DM.

Marshall, Carter, Rose, and Brotherton (2009) researched the experiences of children and their parents living with type 1 diabetes mellitus (T1DM) in a phenomenological study. The researchers interviewed the children (diagnosed with T1DM) and their parents. The central theme identified was “normal”, with four subthemes: transition, attachment, loss, and meaning (p. 1,703). The children described transition as “moving on” and becoming independent, while the parents described this as changes in the parent-child relationship. Both groups discussed attachment in terms of the parent-child relationship and changes as the child became more independent; also the parent’s need to check on the child and the “physical work” of managing the child’s illness (p. 1,707). Loss for the parents was discussed in terms of their loss of a healthy child, freedom, and confidence. Age at diagnosis appeared to affect the children’s sense of loss; for example, one child described the “loss of health” (p. 1,707). Meaning was described as the consequences of diabetes and the impact on life, for example, bodily changes, disruption, and intrusion into family life. The central theme of “normal” was
described as achieving normality, the sense that living with diabetes became normal and “being normal” was seen as something to aspire to (p. 1,708). Marshall, et al.’s study reported living with diabetes unique to children with T1DM and their parents.

In a phenomenological study, George and Thomas (2010) researched the experiences and perceptions of self-management in insulin-dependent, home-bound older (65 to 85) people living in a rural area. Four themes were identified. The first, “Your body will let you know: If you miss it you’ll wind up in a coma” (p. 1,096), described the experience of diabetes as a bodily phenomenon, including experiences of frustration and mistrust with healthcare providers. The second theme, “I thought I was fine, but I wasn’t” (p. 1,096), described the struggle between the healthcare provider’s advice and personal knowledge and experience, and the participants developing their own diabetes regimen which included high-risk behaviors. The third theme, “Only way out is to die” (p. 1,096), described the belief that diabetes took over and dictated their lives, and the participants’ awareness and acceptance of the prognosis. The final theme, “You just go in” (p. 1,097), included management and reconciliation with a disease that would eventually claim the participant’s life and the influence on their daily choices since the “only way out is to die.” George and Thomas’ study reported living with diabetes as unique to insulin-dependent, home-bound, rural living, older adults. In contrast, the present study considered the experiences of gathering information to manage diabetes for adults recently diagnosed with T2DM.

The literature cited on diabetes research provides an overview of the studies of persons learning to live with diabetes. Learning in these studies was described in terms of the source of information, namely, friends, family members, and role models (Burke, et
al., 2006; Getz Jeanfreau, 2005; Tu & Morrison, 1996) as well as experience, self-awareness, and understanding body cues (Hernandez, et al., 1999; Hill-Briggs, et al., 2003; Paterson, 2001; Scollan-Koliopoulos, et al., 2007). However, the intent of the study reported here was to enhance the understanding of the lived experience of becoming a diabetic for persons recently diagnosed, not to determine how learning occurs or is accomplished, as addressed in other studies. The literature addressing learning was consciously challenged in the analysis of the data in this phenomenological study in order to facilitate gaining new insights on the lived experience of the recently diagnosed diabetic patient. Research is warranted that explores the experience of gathering information in the recently diagnosed diabetic in the actual context of their daily life. Therefore, exploring the experiences of persons in this population was a means to achieve this.

**Rationale for Using Hermeneutic (Interpretative) Phenomenology**

Phenomenology is useful when studying a new topic or when a fresh perspective is needed on a previously studied topic (Cohen, et al., 2000). When considering diabetes, the disease process, complications of the disease, and the lifestyle changes and interventions recommended for disease management are clearly understood. Standardized patient education (DSME), recommended strategies for teaching adult populations, and evidence of critical junctures when learning increases in individuals with chronic conditions are available. Professional experience and the literature provide examples of patient-driven or informal learning strategies used by individuals. But the unknown or unclear aspects of the disease include the actual experience of becoming a diabetic and learning about and initiating self-care. Given the limited success of DSME to yield
positive outcomes, a fresh perspective is warranted. Therefore, the intent of this study was to enhance understanding of the experience of becoming a diabetic, including how information is prioritized and incorporated into daily life.

According to van Manen (1990), hermeneutic phenomenology is the attempt to construct a full interpretative description of some aspect of the lifeworld. Therefore, hermeneutic phenomenology includes both description and interpretation. Persons with diabetes engage in the experience of learning self-care. Hence, the experience of becoming a diabetic and learning about new self-care activities to manage diabetes and their application to daily life for improved outcomes represent the phenomena of interest. Van Manen’s focus on educational research (1990) and the prior use of hermeneutic phenomenology as a research method within the discipline of nursing (Diekelmann, 2001; Ironside, 2003; Lorenz, 2010; Marshall, et al., 2009; McCloughen, O’Brien, & Jackson, 2011) further support the selection of this method. The purpose of this study was to enhance understanding of the lived experience of becoming a diabetic, reveal and interpret the underlying structures and meaning of this experience, and create an understanding that supports the ability to “act more thoughtfully and more tactfully” (van Manen, 1990, p. 23) in providing care for the diabetic.

**Chapter Summary**

This chapter has provided an overview of the areas in the literature that were the basis for this study, including phenomenology, hermeneutic phenomenology, formal and informal adult learning, the Health Belief Model, learning in the context of chronic illness, and learning in the context of diabetes. This literature was consciously challenged in the analysis of data in this phenomenological study to facilitate gaining new insights.
on the actual experiences of the recently diagnosed diabetic patient. A cyclical approach to bracketing of all preconceptions of the experience under investigation was accomplished through intense engagement with each participant, adherence to the interview script, and the use of reflection (Smith, et al., 2009).

Because formalized DSME programs, developed from evidence-based standards of care, do not demonstrate consistently positive outcomes in all individuals with diabetes, it is clear that something is not working. The individual’s experience with DSME needs to be explored to improve understanding of their move to adopt new self-care strategies that are considered critical for successful treatment and the care and maintenance of diabetes.

Since it is a treatment standard that persons diagnosed with diabetes receive education in management strategies through formalized DSME programs in the health care setting (ADA, 2011) more needs to be known about the experience in the context of daily life. Healthcare providers are aware that information gathering occurs inside and outside the formal DSME programs. Time and time again healthcare providers hear patients express what they learned from family members, friends, and other sources, e.g., “a friend told me about . . . ” or “on the internet I read . . . ” or “my father, mother, or friend has diabetes and I remember . . . ” But it is not known what interactions or activities are integral parts or what most impacts the outcomes of therapy. The clinician needs to understand the patient’s experiences in the context of their problem-solving strategies, interpersonal relationships and family experiences, and how they integrate within the DSME education process. Examples of the impact of experience on learning self-care have been explored in studies conducted in healthcare and diabetes research.
(Hernandez, et al., 1999; Paterson, 2001). However, the findings are limited and more needs to be known about the actual experience of learning about and initiating self-care in order to gain deeper insight into the care and treatment strategies that may best support persons learning to manage this disease. Specifically, the aspects of DSME and other self-care experiences that have the most meaning to the patient and those that are not meaningful need to be more clearly understood. The intent of this research was to enhance understanding of the actual meaning of the lived experience for the study participants.
CHAPTER 3
Research Design and Method

Extensive research and literature addressing learning to accomplish self-care in chronic illness, e.g., diabetes has been published. Despite this body of information, there is a lack of understanding about what actually happens when persons diagnosed with diabetes are expected to learn new behaviors or learn about and initiate self-care. In regard to Diabetes Self-Management Education, multiple studies have been conducted to measure the outcomes of learning. However, more information is needed to better understand the process of engaging in learning to adapt self-care in response to a diagnosis of diabetes.

The use of qualitative methods to study the actual learning experiences of the participants has the potential to provide information to fill in some of the gaps in the current research. Qualitative design methods have been utilized to improve understanding of some patient behaviors in diabetes self-management, e.g., transitions towards self-management, self-awareness in diabetes, and coping strategies in diabetes (Getz Jeanfreau, 2005; Hernandez, et al., 1999; Nylin, 1990). The inductive method of qualitative research enhances understanding and is useful for exploring this experience (Diekelmann, 2001; Morse & Field, 1995; van Manen, 1991).

In particular, phenomenology facilitates the understanding of the lived experiences of the individual and their interactions within their “lifeworld” (Morse & Field, 1995, p. 22). In this study, the phenomenon under consideration was the experience of becoming a diabetic and the elements and dynamics of learning about and initiating self-care designed to manage the disease. Phenomenology provides a means for
understanding the process from the participant’s perspective (Patton, 2002), and an opportunity to understand the essence or core meaning of the experience.

Hermeneutic phenomenology, a research method based on phenomenological philosophy, is focused on the attempt to construct a full interpretative description of some aspect of the lifeworld (van Manen, 1990). Van Manen describes phenomenology as “a systematic attempt to uncover and describe the structures, the internal meaning structures of the lived experience” (p. 10). In turn, hermeneutics includes both a description and an interpretation of these structures. Hermeneutic phenomenologists study how persons interpret their lives and make meaning of what they experience (Cohen, et al., 2000). Persons with diabetes engage in the experience of learning about and initiating self-care. Therefore, the description and interpretation of the experience of becoming a diabetic engaging in learning about self-care to manage diabetes and the application of that experience to daily life for improved outcomes represents the phenomena of interest. The intent of this study was to provide a rich description of the experience of becoming a diabetic and learning self-care, and the meaning embedded in that experience.

Diabetes research has been conducted using phenomenology. Examples include studies addressing the lived experience of diabetes in older rural persons (George & Thomas, 2010) and the perceptions of diabetes in children and their parents (Marshall, et al., 2009). However, the lived experience of becoming a diabetic in recently diagnosed adults had not been explored.

**Participant Sampling**

Persons recently diagnosed with diabetes were recruited from a diabetes center where the researcher had an established relationship and where the center administrators
were open to allowing access to recruit patients for the study. The center serves a community of several counties in both urban and rural areas.

The goal was to procure a sample of 6 to 10 participants (Morse & Field, 1995; Smith, et al., 2009), which is considered adequate for a phenomenological study. Based on the methods literature, this sample size would be adequate to gather sufficient data regarding the experience, to demonstrate meaningful similarities and differences between the participants, and to produce a rich account of the phenomena being studied (Cohen, et al., 2000; Munhall, 2007; Polit & Beck, 2006; Smith, et al., 2009). The purposive sample ensures that the participants have experience with the phenomena and are homogenous in general characteristics according to the criteria of the method. This sampling approach was designed to ensure data appropriateness and data adequacy (Morse & Field). Ten adults (8 females and 2 males) ages 39 to 77 were recruited and took part in the study.

The presence of critical points or junctures in the diabetes illness trajectory are described in the literature, and the increased need for patients’ learning is noted at these critical points (Ellison & Rayman, 1998; Nhylin, 1990; Thorne, et al., 2003). The point of first diagnosis has been identified as one of the most critical points. Treatment of type 2 diabetes is commonly initiated at the point of diagnosis with changes implemented every 2 to 3 months, depending on the person’s response to interventions (ADA, 2011; Robertson, 2008). Treatment plans are individualized. However, current standards recommend initiating medication management (e.g., Metformin administration) in combination with lifestyle changes (nutrition and exercise) at the diagnosis point (ADA, 2011). The present study explored the self-care experiences of persons recently diagnosed with diabetes within the context of the actual treatment plan they were prescribed.
Type 1 diabetes is usually diagnosed in children and young adults and has a
different trajectory, while type 2 (adult onset) occurs more commonly in people over the
age of 30 and in the obese (Smeltzer, et al., 2010) with a diagnosis peak in the fifth
decade (Ignatavicius & Workman, 2002), whereas the diagnosis of gestational diabetes is
unique to pregnant women (Smeltzer, et al.). The treatment approaches and the
experiences of these different types of diabetes vary markedly. Only the type 2 patient
was the focus of this study. Therefore, only participants who had experience with the
phenomena of the T2DM diagnosis, and men and women over 30 years of age recently
diagnosed with T2DM, were recruited for the study. The sample was limited to men and
women over 30 to ensure recruitment of patients with T2DM.

The diagnosis of T2DM was specified because the trajectory and the treatment
plans vary significantly among the types of diabetes. Initially recruitment was limited to
persons diagnosed within the previous 6 months. However, in December 2011,
recruitment was extended to include persons diagnosed within 5 years. This enabled the
investigator to find type 2 diabetics who were relatively recently diagnosed and still
engaged in learning about self-care. The rationale was that some of these diabetics would
have had more opportunity to engage in treatment and learning about self-care after an
extended amount of time had lapsed after their initial diagnosis. Women diagnosed with
gestational diabetes were excluded since the features and treatment of this type of the
disease are unique. The ability to understand and speak English was also an inclusion
criterion, as the investigator was not proficient in other languages and could not assure
participants access to culturally appropriate translation services.
Recruitment

The participants were recruited through physician and staff referrals, and recruitment materials made available in the diabetes center (See Appendix A: Recruitment Materials). The participants either elected to contact the researcher, or the researcher contacted them to enroll them in the study. If contacted by the researcher, the participant gave permission to the staff at the recruitment facilities for the researcher to make contact. During the initial contact by phone, the researcher explained the study to the prospective participant. To determine their eligibility for enrollment in the study at that time, she verified the prospective participant’s diagnosis of T2DM, time elapsed since their diagnosis, age, and pregnancy status for female participants. The purpose and details of the study and a written consent form were reviewed, and signed consent was obtained at the initial meeting between the participant and the researcher.

During recruitment, the researcher met with the staff of the center to review and discuss the research project, and she was available to the staff via phone and email to answer questions related to the study as necessary. The researcher reviewed the center intake forms and attended the four diabetes education classes which patients referred to the center attended, in order to better understand the context of the common experiences of the study participants.

Data Collection

Data were collected during individual one-on-one interviews. Each interview was audio recorded and ranged from 45 to 90 minutes. The interviews occurred in the participant’s home or in an environment outside the center setting that was suitable for recording an interview and protecting their privacy, based on their preference. These
included the participant’s place of employment or the unoccupied office space at the primary investigator’s workplace.

Each interview began with the collection of the participant’s demographic data, including age, race, level of education, family history of diabetes, co-morbid conditions, and time elapsed since diagnosis. The remaining questions focused on a discussion of their experiences with the diagnosis of the disease, the prescribed components of diabetes management, various levels of self-care, and their description of types of formal diabetes education they have completed along with other learning experiences. The interview was semi-structured and proceeded with open-ended questions. (A list of the interview questions is in Appendix B.)

The interview questions underwent several revisions based on feedback from faculty experts in the area under study. Additionally, a professional colleague who has experience with the phenomenological research method and personal experience with diabetes reviewed the interview questions and confirmed their appropriateness. Discussion of the interview questions prompted this colleague to share her experiences of the phenomenon under study with the investigator.

Prior to the interview, the study participants were informed that all identifying data would be removed from their final transcripts to assure their anonymity. At the completion of the interview, the participant received a $20.00 gift card to a business of their choice to help offset personal expenses involved in their participation.

The researcher also audio recorded field notes and maintained a diary/record to augment and supplement the data obtained from the participant interviews. Her field notes included the interview location, observations of the environment, interview content,
and her impressions related to the interview (Morse & Field, 1995, p. 115). The researcher also documented her analysis process in a diary/record (Smith, et al., 2009). The field notes and diary/record were included in the data set to enhance understanding of the phenomenon being studied.

**Data Management**

All digitally recorded interviews were coded, and only the researcher knew the identity of the participants. All study-related information was stored in a locked file cabinet in the researcher’s locked office and saved to a secure network site. A hired transcriptionist completed verbatim transcriptions of the interviews. Prior to analysis of the transcripts the researcher reviewed the typed transcripts against the audio taped interviews, and edited the transcripts to assure accuracy. Additionally, the researcher continuously monitored the overall research process to assure participant and data security.

**Data Analysis**

The data analysis process for this study was based on van Manen’s (1990) methodological approach, although additional resources were used to clarify the procedures (Cohen, et al., 2000; Smith, et al., 2009). Essential to the data analysis is the concept of identifying the fore-conception, or the prior experiences, assumptions, and preconceptions the researcher, reader, or listener brings to the experience (Smith, et al.). Heidegger (1962) asserted the need to “make the scientific theme secure by working out these fore-structures in terms of the things themselves” (p. 195). It is understood that the researcher should give priority to the new object (what is being said in the interviews) rather than the fore-structure (what is known about adult learning and diabetes.
education), yet recognize that the understanding of the fore-structure may evolve or change after understanding the new object (Smith, et al.). This process is described as cyclical and dynamic, and is similar to bracketing. Bracketing, which is defined by van Manen as setting aside our beliefs and preconceptions totally, is recognized to be very difficult, if not impossible. Therefore, in hermeneutics it is considered important “to make explicit our understandings, beliefs, presuppositions, and theories . . . to hold them deliberately at bay” in order to reveal the true essence of the experience (van Manen, p. 47).

The goal of the data analysis in a qualitative study is to make a thick description that captures and communicates the meaning of the lived experience of the participants (Cohen, et al., 2000; Polit & Hungler, 1999). The hermeneutic circle guides the data collection and analysis. In this process “parts of the text are understood in relationship to the whole and vice versa” (Cohen, et al., p. 72). The individual texts are then understood in comparison to all texts, and the process reverses. The hermeneutic circle applies to the units of data, participant statements, the context, the processes of interpretation, and writing of the findings. Each aspect is considered from the smallest unit to the largest and then in reverse. These methods were applied during analysis of the data in this study.

Double hermeneutics, as discussed by Smith, et al. (2009), includes the researcher in this process. Accordingly, the researcher is making sense of the participant who is making sense of the experience. The researcher while not a participant has access to the participant’s experience; through the interview or report, the researcher sees this through their “experientially informed lens” (p. 36). Here the participant’s meaning making is “first order” while the researcher’s sense making is “second order” (p. 36). The
researcher strives to both understand the “insider’s perspective” and stand alongside the
participant to see the experience from a different perspective and inquire about it (Smith,
et al.). This process was applied during the data analysis for this study.

Van Manen (1990) described these four procedural activities for conducting a
phenomenological study: (a) turning to a phenomenon of interest, (b) investigating
experiences as we live them, (c) reflecting on the essential themes of the phenomenon,
and (d) describing the experiences through writing and rewriting. Van Manen emphasizes
maintaining an orientation to the research question and considering the relationship
between the parts and the whole. Analysis begins during the interviews when the
researcher is actively listening and thinking about the meaning of what is being said
(Cohen, et al., 2000). The more detailed analysis process continues with converting the
interview data and field notes into digital form. Line-numbered transcripts are used to
facilitate transcript review and data reproduction. This process encourages “reflective
engagement with the participant’s account”, making the analysis a “joint product of the
participant and the analyst” (Smith, et al., 2009, p. 80).

The data analysis process for this study continued with the researcher reading and
rereading the interview transcripts. The researcher first listened to the interview during
the reading of the transcripts to fully capture the participant’s words; then she added
contextual information to her field notes to facilitate her engagement with the
participant’s responses. The researcher then immersed herself in the data by reading
through the transcripts and notes several more times. The aim of such immersion is to
establish an “orienting gestalt” or some initial interpretation of the data that will drive
coding in subsequent phases (Cohen, et al., 1990, p. 76).
The next step in the analysis was data transformation or data reduction, whereby the researcher made decisions about what was relevant and what was not (Cohen, et al., 2000). This process is similar to editing, where the researcher can reorganize the interviews related to topics, eliminate digression and simplify language without changing the nature of the interview (Cohen, et al.).

Thematic analysis followed with line-by-line coding in which the researcher underlined phrases and isolated tentative themes. Then she labeled the themes, extracted passages with similar themes, and compared them side by side. Passages with similar themes were then grouped and sub-divided as necessary into categories or elements within the selected themes. Passages were identified as “exemplars” or textual data in the participant’s language that captured the essential meanings of the themes (Cohen, et al. 2000). Thematic analysis is not a rule-bound process but an act of “seeing” meaning, or the means to get at the notion of the experience and to structure the experience (Cohen, et al., 2000; van Manen, 1990, p. 79).

Van Manen (1990) clarified the “features of themes” as a form of capturing the phenomenon of interest, the experience of focus, and emphasized that a theme is not a thing. Themes represent the desire to make sense, or the sense we make of something; it is the openness to something and the process of invention, discovery, or disclosure. Themes “relate to the phenomenon” as a means to get at the notion, a way to give shape to the notion, a description of the content of the notion, and a reduction of the notion (van Manen, pp. 87-88).

According to van Manen (1990), phenomenological research centers on the human lifeworld or the lived world as experienced in everyday situations or relations (p.
101), and existential theme analysis is a means to capture this phenomenon. Therefore, to deepen the analysis of the structures of the experience of becoming a diabetic, the text was also subjected to further analysis using the existential themes van Manen identified as guides for reflection. These four themes include lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality) (p. 101). According to van Manen, these four themes can be differentiated but not separated, because together they form the lifeworld or the lived world of the individual who is the subject of the phenomenological study.

The final step of writing and rewriting, crucial to interpretative phenomenology, is the creation of the text or the object of the research process (van Manen, 1990). Writing and rewriting documents based on the research analysis involves the hermeneutic circle or the movement from the parts to the whole at all levels of the process. Essential is memo writing or maintaining a diary/record to support the interpretative process and the transformation of the field text to the narrative text (Cohen, et al., 2000). Language is the central concern in phenomenological research, and writing is the very activity of doing phenomenology (van Manen). These methods were applied during analysis of the data for this study.

The goal of hermeneutic phenomenological research is to “report things as they appear to be encountered in the field and the field text, rather than as the researcher would have them” (Cohen, et al., 2000, p. 86). Strategies to reduce bias assist with accomplishing this goal. Thus, the researcher used a two-pronged approach for reducing bias. The first was accomplished by the identification of her personal preconceptions that included considering details of the literature reviewed before conducting the study. Her
second strategy for reducing bias was to subject the study to outside scrutiny and validation by a dissertation committee member who had experience with the phenomenological research method. Additionally, the transcript analysis and theme development were conducted with an expert researcher (dissertation committee chairperson) who has experience with the phenomenological method. Two participant transcripts with corresponding themes and excerpts that were viewed by the researcher as exemplars were also shared with two researchers familiar with the method, but not engaged in the study. During this session the researcher, the dissertation committee chairperson, and the two researchers discussed the evolution of the themes, excerpts from the participant transcripts, and the evolving themes that were confirmed to be present in the data. The primary themes and elements of the themes were also shared with the professional colleague who had previously reviewed the interview questions; she confirmed the themes and elements that had emerged from the interview transcripts as representative of her personal experiences as a diabetic.

Although it is recognized that absolute bracketing in a study such as this is not possible, the researcher paid close attention to and reflected on her fore-structure or fore-conceptions throughout the analysis process (Smith, et al., 2009). She also employed critical reflection, another bias reducing strategy. This strategy is described as the internal work of the researcher designed to make the inquiry rigorous, and is reflected in the writing and rewriting in the final stage of the analysis process. External scrutiny was accomplished through maintaining an audit trail, member checking, and faculty consultations. The end product was a thick, written description which included quotations
from the original interviewee transcripts, explains the interpretation process to the reader, and facilitates reader interpretation and validation of the findings (Cohen, et al., 2000).

Credibility, dependability, confirmability, and transferability are criteria that were also applied to assure the “trustworthiness” of the findings (Polit & Beck, 2006, p. 332). Although the researcher in this study bracketed her experience, her background in nursing and interest in DSME have added to the credibility of this study. The researcher maintained an audit trail to support the dependability and confirmability of the study results. The following records were maintained as components of the audit trail: interview transcripts, data analysis notes, methodological notes, personal notes, interview question guides, tables of themes, and drafts of the research report (Cohen, et al., 2000; Polit & Beck, 2006, p. 336; Smith, et al., 2009, p. 183). Transferability or the extent to which the findings can be transferred to other groups or settings was enhanced by providing thick or rich descriptions of all aspects of the research study. Strategies previously mentioned, such as field notes, memos, and the audit trail, in addition to detailed information about the setting and the participants, contributed to the detailed description of the study. As previously stated, the dissertation chairperson, who has experience with the method, served as a consultant and supervised the study, including the data collection and analysis processes.

**Human Subjects Protection**

This proposal was presented to and approved by the Institutional Review Board (IRB) at the Office for Research Protection (ORP) at The Pennsylvania State University and the health network which had oversight of the diabetes center where the participants were recruited. (See Appendix C: IRB Approval). The researcher returned to both
organizations for permission to amend the recruitment criteria in December 2011. The location for recruitment of the participants was a diabetes center within a health network. The recommendations and approval were reviewed with the representatives of the center. Preliminary verbal permission to access patients at this location was obtained from the center as part of completing the dissertation proposal. In compliance with human subject protection ethical mandates, informed consent was reviewed with and obtained from all participants. (See Appendix D: Informed Consent.) Measures were established to assure the comfort of the participants. They were informed that they could withdraw at any time and could choose not to answer any question(s). Nothing in this study was deemed as hazardous to the participants; however, it is recognized that the sharing of illness history has the potential to cause the participants to become upset during the interview. However, none of the participants became upset during their interview. If this had occurred, the interview would have been stopped for a period of time, and the participant would have been reminded that they could withdraw from the study if desired. The participants would be referred back to their health care provider for additional education information or support services.

**Conclusion**

The purpose of this phenomenological study was to enhance the understanding of the lived experience of becoming a diabetic for persons recently diagnosed. The focus of the study was on individuals learning about new self-care activities and initiating changes in self-care designed to control their serum glucose and generally manage their diabetes. Although clear standards for patient education (DSME) are utilized in this population, and professional experience and the literature provided examples of multiple factors that
may influence learning in this population, very little is known about the actual experience of recently diagnosed diabetics learning to make the health and lifestyle changes recommended in DSME programs. The intent of this phenomenological study was therefore to enhance the understanding of the experience of becoming a diabetic as reported by persons recently diagnosed.
CHAPTER 4  
Study Results and Analysis

Reflection about an experience is a means to render it special. Reflection also brings obscure or hidden experiences to the forefront (van Manen, 1990). Interviewing is a method which allows the gathering of information and the development of an understanding of a phenomenon (van Manen). The participants in this study were questioned about their experiences related to their diagnosis of diabetes within the past five years. The purpose of this study was to enhance the understanding of the lived experience of becoming a diabetic for persons recently diagnosed. The focus of the study was on individuals learning about new self-care activities and initiating changes in self-care designed to control their serum glucose and generally manage their diabetes. Analysis of the participants’ interview transcripts revealed the essence of their experience of becoming a diabetic. It clustered around three key points, which ultimately were identified as the experiential themes: encompassing the diagnosis point or hearing the news, sorting out the diagnosis, and moving on or forward. Their experience of learning self-care was captured when the participants discussed their own experiences. However, it became apparent that any one experience cannot be isolated without the benefit of hearing the whole story. This chapter is organized in the following manner: participant information, theme identification and theme analysis, summary and conclusions.

The Study Participants

The sample for this study included 10 adults diagnosed with type 2 diabetes (T2DM) within the past five years. The participants were recruited from a diabetes center, with the help of the staff, and through word-of-mouth referral. The adults ranged
in age from 39 to 77; there were 8 females and 2 males. Seven participants had been
diagnosed within the previous year, two within one and a half years, and one within the
past five years, including time with pre-diabetes. The participants’ information was
gathered using demographic questions at the time of their individual interviews. Their
T2DM status was not obtained unless volunteered or revealed during the interview. Only
a brief background on each participant is shown in Table 4.1, to maintain their
anonymity, and a pseudonym for each is used to report the findings from their interviews.
The participants are presented in the chronological order of their enrollment in the study.

Table 4.1

*Summary of the Study Participants’ Demographics*

<table>
<thead>
<tr>
<th>Order of Interview</th>
<th>Assigned Pseudonym</th>
<th>Age</th>
<th>Time Since Diagnosis</th>
<th>Medications: Oral, injection</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Pam</td>
<td>54</td>
<td>3 months</td>
<td>Oral, injection</td>
</tr>
<tr>
<td>2</td>
<td>Sally</td>
<td>60</td>
<td>1 month</td>
<td>Injection</td>
</tr>
<tr>
<td>3</td>
<td>Lenny</td>
<td>62</td>
<td>4 months</td>
<td>Oral</td>
</tr>
<tr>
<td>4</td>
<td>Debbie</td>
<td>39</td>
<td>17 months</td>
<td>Oral</td>
</tr>
<tr>
<td>5</td>
<td>Martin</td>
<td>77</td>
<td>3 months</td>
<td>Oral</td>
</tr>
<tr>
<td>6</td>
<td>Karen</td>
<td>44</td>
<td>7 months</td>
<td>None</td>
</tr>
<tr>
<td>7</td>
<td>Diane</td>
<td>59</td>
<td>3.5 weeks</td>
<td>Oral</td>
</tr>
<tr>
<td>8</td>
<td>Jane</td>
<td>62</td>
<td>2 months</td>
<td>Oral</td>
</tr>
<tr>
<td>9</td>
<td>Cathy</td>
<td>42</td>
<td>18 months</td>
<td>Oral</td>
</tr>
<tr>
<td>10</td>
<td>Carol</td>
<td>64</td>
<td>5 years</td>
<td>Oral, injection</td>
</tr>
</tbody>
</table>
**Participant #1: Pam**

Pam is a 54-year-old, Black female, alert, oriented, and articulate. She was diagnosed three months prior to the interview. Her current treatment consisted of diet, oral (Janumet) and sub-cutaneous injection medications (Byetta), and self-monitoring of blood glucose with glucometry testing (glucometry). Pam is also diagnosed with and being treated for hypertension. There is a positive family history of diabetes mellitus (DM) in her mother and maternal grandfather. She completed technical school and one year of college. Pam works in health care in a home care setting (position unknown). She readily answered questions, reflected on the questions asked, did not appear to withhold responses, but did not expand beyond the scope of the interview questions.

**Participant #2: Sally**

Sally is a 60-year-old Caucasian female, alert, oriented and articulate. She was diagnosed one month prior to the interview during an emergency hospital admission. Her current treatment consists of diet, sub-cutaneous injection medications (Levemir & Novolog), and glucometry. Sally is also diagnosed with bipolar disorder, hypertension, obstructive sleep apnea, migraines, gastro-esophageal reflux disease, allergic rhinitis, visual disturbances (but continues to drive), lung nodules, and hepatosplenomegaly. Sally has a remote history of an eating disorder. There is a positive family history of DM in her maternal grandmother. She is a registered nurse who completed an associate’s degree and earned credits towards a bachelor’s degree but is not currently working related to a hip condition. She uses a walker for ambulation, and during the interview discussed a desire to change to a cane to assist with ambulation. Sally readily answered
questions, reflected on the interview questions, and volunteered information to augment her answers.

**Participant #3: Lenny**

Lenny is a 62-year-old Caucasian male, alert, oriented, and articulate. Lenny was diagnosed four months prior to the interview, and reported he had been “pre-diabetic” for several years. His current treatment consists of oral medications (names unknown) and glucometry. Lenny is also diagnosed and in treatment for elevated cholesterol. He has a history of myocardial infarction with cardiac stents placed. There is a remote (grandmother’s sister) family history of DM. Lenny completed high school and is currently employed working in sales. He readily answered the interview questions and volunteered information to expand on his answers.

**Participant #4: Debbie**

Debbie is a 39-year-old Caucasian female, alert, oriented, and articulate. She was diagnosed 17 months prior to the interview. Her current treatment consists of diet, oral medication (Glumetza), and glucometry. She has a past medical history of insulin resistance, and is currently receiving treatment for polycystic ovary disease, hypothyroid disease, and hypertension. Debbie also sees a fertility specialist. There is a positive family history for DM in her mother (diet treated T2DM, deceased from respiratory disease) and her siblings (brother and sister both in their early 50s). Debbie completed high school and earned some college credits, she is currently employed in the entertainment industry. She was animated during the interview, readily answered the interview questions, and volunteered information to augment her answers.
**Participant #5: Martin**

Martin is a 77-year-old Caucasian male, alert, oriented, and articulate. Martin was diagnosed three months prior to the interview. His current treatment consists of diet, oral medication (Metformin), and glucometry. He denies other medical concerns at this time. He self-treats with vitamins and herbal supplements for elevated blood sugar, hypertension, and prostate health. There is a positive family history for DM in his mother (diagnosed late in life, death related to a fall), and adult son (50 years old, T2DM treated with insulin). Martin’s first wife passed away in 1998 with a history of T2DM. Additionally, his two sons-in-law have a positive history of DM. Martin completed the 10th grade, and currently works part-time as a delivery driver. He spoke in flat tones, readily answered questions, reflected on responses, did not appear to withhold information, but did not volunteer information beyond the scope of the interview questions.

**Participant #6: Karen**

Karen is a 44-year-old Caucasian female, alert, oriented, and articulate. She was diagnosed seven months prior to the interview. Her current treatment consists of diet, exercise, and glucometry. She has a past medical history of gynecological surgeries (two procedures), increased heart rate, and obstructive sleep apnea (uses continuous positive airway pressure device at night). Karen has a history of gestational diabetes. In the first pregnancy she received insulin treatment at the end of it, and in the second pregnancy, insulin treatment was started early (children ages 8 and 10). Karen’s mother is diagnosed with T2DM. Karen is a bachelor’s prepared registered nurse. She spoke at a fast pace,
readily answered questions, reflected on responses, and volunteered information beyond the scope of the interview questions.

**Participant #7: Diane**

Diane is a 59-year-old Caucasian female, alert, oriented, and articulate. She was diagnosed just three and a half weeks prior to the interview during an emergency hospital admission. Her current treatment consists of diet, oral medication (Glucophage twice daily, Glimepiride daily), and glucometry. Diane has a past medical history of stenosis of multiple arteries and was treated with four cardiac stents, a carotid endarctectomy (2000), and balloon treatment for right renal artery stenosis. She also has stenosis in her cranial arteries, and has had four transient ischemic attacks in the past. Diane is diagnosed with and receiving treatment for hypertension, elevated cholesterol, arthritis and vascular problems. There is a family history of DM in her father of type 1 diabetes mellitus (T1DM) and maternal aunts and uncles (T1DM). She completed high school and certified nursing assistant training. Diane readily answered questions, reflected on her responses, did not appear to withhold information, and volunteered information beyond the scope of the interview questions.

**Participant #8: Jane**

Jane is a 62-year-old Caucasian female, alert, oriented, and articulate. She was diagnosed two months prior to the interview. Her current treatment consists of exercise, diet, oral medication (Metformin), and glucometry. Jane is diagnosed with and receiving treatment for hypertension, elevated cholesterol, and gastro-esophageal reflux disease. There is a family history of DM in her sister (recently deceased) and paternal grandmother. She also has a grandson diagnosed with DM (14-year-old T1DM). Jane
attended and completed high school, and she is currently employed in a supermarket (chain). Jane readily answered questions, reflected on responses, and volunteered information beyond the scope of the interview questions.

**Participant #9: Cathy**

Cathy is a 42-year-old Caucasian female, alert, and oriented. Her speech pattern was difficult to understand at times, but she maintained eye contact throughout the interview and appeared engaged in the conversation. Cathy was diagnosed with DM 18 months prior to the interview. Her current treatment consists of exercise, diet, oral medication (Metformin), and glucometry. Cathy is also diagnosed with and receiving treatment for depression, possibly bi-polar disorder (medication use intermittent due to finances), hypertension, and elevated cholesterol. There is a family history of DM in her mother (T2DM), maternal grandmother, and paternal grandfather. Cathy has a boyfriend who was recently diagnosed with DM after amputation of multiple toes (and possibly forefoot) and is a source of information for her about DM. She stated that she “completed” 12th grade, but did not directly state that she graduated from high school, and is currently employed in a fast food restaurant. Cathy readily answered questions during her interview, did not appear to withhold information, but did not volunteer information beyond the scope of the interview questions.

**Participant #10: Carol**

Carol is a 64-year-old Caucasian female, alert, oriented, and articulate. She was diagnosed with DM within five years (around 2007) prior to the interview, including time with pre-diabetes. Carol is uncertain about her diagnosis date, but she provided an estimate. Her current treatment consists of exercise, diet, oral (Glucophage, twice daily),
sub-cutaneous injection medications (Levemir twice daily, Humolog before meals), and glucometry. Carol has a past medical history of neuropathy, elevated cholesterol, asthma and arthritis (knees). She is currently receiving treatment for hypothyroidism, hypertension, and gastro-esophageal reflux disease. There is a family history of DM in her mother and maternal grandmother (both deceased). She completed a master’s degree, and is currently employed in a social service agency. Carol readily answered questions and volunteered information to augment her answers beyond the scope of the interview questions.

Identification of Themes

In phenomenological research, interviewing is a means to gather information and develop a rich and deep understanding of the personal phenomenon (van Manen, 1990). During the interviews, the sharing of personal experiences, stories and incidents, and the interaction with the interviewee permits the interviewer to get close to the actual lived experience of the participant. Through interpretative analysis, the text that results from the interview provides a way for the researcher to capture the essences of the participant’s experiences. The themes are understood as structures of the experience so that as one analyzes the phenomenon and determines the themes, the experiential structures are uncovered or revealed (van Manen).

Cohen, et al. (2000) offered terms for delineating themes, with a broader category of themes to include sub-themes, categories, or elements. Adopting their language, the data analysis for this study will be reported as themes and elements contained in these themes. In this study, three themes emerged as the primary structures of the lived experience of becoming a diabetic: (a) hearing the news, (b) sorting it out, and (c)
moving on. Although the themes are reported as framing the experience for all the participants, they did not appear in the same sequence or in a fixed order. Each theme contained three elements that clustered around key points. The participants described their responses on hearing the news: blocking the message, reflecting on the past (choices that may or may not have impacted their diagnosis), and the fear of “knowing” that was associated with the diagnosis. At other points, when sorting it out and taking in information about the diagnosis, the key thematic elements included: knowing about the disease through comparison with others, engaging in activities in an effort to understand the disease and keep focused on the diagnosis, and developing plans for seeking information from individuals and other support system options. When descriptions of moving on were discussed, they included movement toward recognizing a “new reality” as it related to the diagnosis, making choices to engage in or not to engage in activities to promote health, and in most, but not all, achievement of a new level of awareness, which appeared as a culmination of the process of “becoming” a diabetic, although returns to other phases were common. The three primary themes and thematic elements are summarized in Table 4.2.
Table 4.2

Summary of the Primary Themes and Thematic Elements

<table>
<thead>
<tr>
<th>Primary Theme</th>
<th>Thematic Element</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing the news</td>
<td>Blocking the message</td>
</tr>
<tr>
<td>Hearing the news</td>
<td>Reflecting on the past</td>
</tr>
<tr>
<td>Hearing the news</td>
<td>Fear of “knowing”</td>
</tr>
<tr>
<td>Sorting it out</td>
<td>Knowing by comparison to others</td>
</tr>
<tr>
<td>Sorting it out</td>
<td>Working to understand and stay aware</td>
</tr>
<tr>
<td>Sorting it out</td>
<td>Recognizing support options</td>
</tr>
<tr>
<td>Moving on</td>
<td>Movement toward a new reality</td>
</tr>
<tr>
<td>Moving on</td>
<td>Choosing action versus inaction</td>
</tr>
<tr>
<td>Moving on</td>
<td>Achieving a new level of awareness</td>
</tr>
</tbody>
</table>

Presented in this fashion, the process appears linear. However, each component of the participant’s experience of diabetes may be at a different point. For example, the participant may take medications as prescribed but not modify their diet or check their blood glucose. The person may move within the process over minutes, days, or weeks. Most of the participants appeared to progress through the process, regroup, then emerge at a different place, or return to an earlier place in a dynamic ebb and flow of coming to understand the meaning of the experience.

Analysis of the Themes

According to van Manen (1990), phenomenological research centers on the human lifeworld or the lived world as experienced in everyday situations or relations (p. 101), and existential theme analysis is a means to capture this phenomenon. Therefore, to deepen the analysis of the structures of the experience of becoming a diabetic, the text
was also subjected to further analysis using the existential themes van Manen identified as guides for reflection. His four existential themes are lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality) (p. 101). The four existential themes can be differentiated but not separated because together they form the lifeworld or the lived world of the individual.

All themes have similar depth; each theme is significant in explaining the meaning of the experience or the experiential structures for the participants. The themes from the results of the data analysis are presented in the order noted in the prior section. The theme and elements of the theme are listed, then followed by transcript excerpts to illustrate the data (Cohen, et al., 2000).

The thematic analysis section is organized first by providing examples of the themes from the participants. This is followed by a discussion of the themes in relation to the existential themes emphasized by van Manen. Transcript excerpts have been selected as exemplars of each theme and related key thematic elements.

**Hearing the News**

The participants were initially asked about the time of diagnosis, and they (with the exception of Cathy) responded, describing their experience in some detail. Their descriptions included an awareness of the diagnosis but a lack of response or follow through, or blocking the message, reflecting on past choices that may have impacted their diagnosis, or their fears or concerns associated with the diagnosis.

**Hearing the News: Blocking the Message**

The theme and key thematic element *Hearing the news: Blocking the message* was evident in statements by some participants. Their descriptions included being present
during the office visit with the provider but not actually hearing the news, an awareness of the diagnosis but a lack of response or follow through, or blocking the message. Sally described some resistance to her diagnosis or an avoidance of it:

See, that’s (hemoglobin A1C) the kind of stuff I should look up …. I didn’t really read it (medication information sheet). I guess I should. It’s funny. I don’t know. Sometimes my way of not thinking about it is just not looking too deeply into, you know, something.

Lenny shared discussions with his family doctor at the time of his diagnosis:

The doctor – the original family doctor diagnosing, OK, now you’re diabetic. He did talk to me about a bunch of stuff. It didn’t sink in. It just, you know, his mouth was moving and I was hearing him, but I wasn’t remembering any of it. And the family doctor did spend a bunch of time that first day with me, explaining this and talking about that and so on and so forth. It all went in one ear and out the other. It just did.

He also described not trusting the accuracy of the blood work:

And part of it’s mental block, part of it’s self-denial, and part of it’s I didn’t think the test wasn’t right. It just couldn’t change that quick, in my opinion, because I have so much vast medical background (laughter).

During the course of the interview Lenny revealed that he did not take any medication or initiate dietary changes until a later visit to his family doctor.

Debbie, also diagnosed with polycystic ovary syndrome, and experience with insulin resistance, reported and described denial or blocking of her diabetes diagnosis in the following statement:
And the doctor basically said that it was more polycystic ovary syndrome than it was diabetes, so, of course, in my mind I wasn’t diabetic.

*Martin* discussed a significant weight loss in the prior year and on reflection wondered if it were due to diabetes or a thyroid condition. He further described prolonging seeking health care despite the urgings of his wife and other family members:

And I just probably just ignored it or whatever. I just said OK and we’ll deal with it sometime down the road (voice faded off). And maybe, like my wife says now, she said I should have gone like she wanted to me to go a long time before I ever went. And she said maybe I wouldn’t be in the position I’m in now. So that’s more or less it.

*Karen* described what she considered was a miscommunication between herself and her provider, which ultimately prolonged beginning diabetes education classes and treatment interventions to manage her condition:

She (family doctor) referred me to (an endocrinologist). And actually – excuse me – in June there was a miscommunication on our part. She wanted me to have the classes that June, but I thought she was going to look into it and she thought I was going to look into it until I came back in. That’s how I got into the classes.

After a scheduled follow-up office visit, *Karen* began diabetes education classes, approximately six months after her initial diagnosis.

In contrast, *Jane* acknowledged the diagnosis of T2DM from the first office visit and participates actively in her self-care. On the surface she appeared adjusted to the diagnosis, yet she showed features of blocking the message when she discussed her blood glucose readings in the following statement:
But I’m not – maybe I’m not right in not being overly worried, because it’s not that high. You know, if it would go over – well, except for that 200 when I wasn’t feeling good. You know, it was only up to 143. Now, what I know about diabetes, which is nothing, really – am I wrong?

Because I was told by somebody that has it that, you know, two and 300, then maybe you worry, but 143 isn’t something to worry about. I don’t know if I’m wrong or not. Because, like I said, I don’t know. You know, what do I know?

In further discussion, Jane said she was acting to follow treatment based on her diagnosis but does not buy into the seriousness or severity of her condition.

Carol discussed her struggle between the inevitability of her diagnosis and her acceptance of the diagnosis:

I just kept saying, no it’s not going to happen, it’s not going to happen. But it was inevitable, given my weight and my diet, poor diet. So it took me a long time.

I’m just (too) hard-headed once in a while to admit to it.

When Hearing the news: Blocking the message, the participants described being physically present during the time of diagnosis, but not accepting, receiving or processing the diagnosis. Lenny visually described the provider’s mouth moving, the information going in one ear and out the other as a clear example of blocking the message that he was diabetic. The participants also described their disbelief about the information or their way of avoiding or not attending to the diagnosis.

Hearing the News: Reflecting on the Past

Upon hearing the news that they had diabetes, some participants reflected on their past choices, others described self-care choices that possibly had contributed to their
diabetes diagnosis or ignoring the symptoms of diabetes. This is captured in the theme and key thematic element *Hearing the news: Reflecting on the past.*

*Pam* described symptoms of thirst which she interpreted as a side effect of hypertension medication despite understanding the symptoms of diabetes:

And I knew the symptoms (of DM) because my mom had them. And I believe it had to be in June I experienced this real increased thirst …. Then I said, well, you’re hypertensive and the blood pressure medication you’re taking is a diuretic and maybe that’s what’s doing it, but I knew better. So I finally surrendered and I went to the doctor’s after having the symptoms for at least a month ... I still put off going to the doctor’s. When I finally went, he said I believe you are (a diabetic) …You know, that’s when he started treating me right away.

*Sally* was diagnosed during an emergency admission to the hospital. She discussed issues related to weight and impact on diagnosis and she also discussed prescribed lab work that she did not attend to:

I think my biggest train of thought is that I feel annoyed with myself, because if I had listened to people telling me to lose weight, even over the past five years, I feel I wouldn’t be in this position. So I’m pretty annoyed at myself. But I also had several prescriptions from my family doctor to get blood work done and I never got it done. You know, I feel fine. So I just let it go (voice gets louder and laughs). That’s really – I’m just annoyed.

*Lenny* reflected on the time from when he was pre-diabetic to when he was diagnosed with diabetes and his choice not to start medication or make the recommended lifestyle changes:
What happened in August, the family doctor prescribed Metformin and gave me a monitor to check my blood sugar. And one of the things that I thought, because my sugar levels from whenever back in March were still borderline, how from March to August do my levels go crazy? Because apparently they went crazy. I’m thinking, didn’t I fast long enough before the blood work was done? What went on? And I did not take that medication. I just didn’t. And he had blood work scheduled for three months later. And I went for the blood work, this time urine test also and it was still obviously diabetic. Actually, the levels went higher….So the original medication I did not take.

Looking back Martin discussed his weight loss and his choice to defer seeking healthcare in spite of an obvious change in his health:

And I don’t know where it was going. I got on the scale and it would just – dropping. Dropping somewhere, probably bad. It was just unbelievable how it was dropping. And even now I look at myself in the mirror and I’m skin and bones.

Throughout the course of the interview Carol discussed her weight and her past lifestyle choices, which are illustrated in the following statements:

I kept saying, I’m an intelligent person, I should be able to control what I eat and control this with diet and exercise and maybe years ago I could have if I had actually done it, but I didn’t do it. So here I am.

So that (pre-filled insulin pens) wasn’t too bad. To me, it was more – um- (pause) it was like admitting failure. You know, that I should have been able to watch what I eat, you know. I was disgusted with myself, kind of. Not at being sick. I
mean, if you get sick, you get sick. But I felt that most of this I brought on myself because of my weight and not eating right and that kind of thing. So it was, you know, a bummer.

Hearing the news: Reflecting on the past occurred at the time of diagnosis for some participants when they discussed lifestyle choices prior to diagnosis, missing clues to diagnosis, or delay in initiating self-care as recommended by their provider. This response appeared to be a way to process the diagnosis and a necessary step before sorting out the diagnosis or starting the work of self-care after becoming a diabetic.

Hearing the News: Fear of “Knowing”

At their diagnosis, it was common for the participants to describe their concerns or fears related to diabetes and its diagnosis. The discussions centered on the meaning of the diagnosis based on prior experiences, the potential consequences of the disease, the impact on subsequent generations or the need for ongoing treatment. In essence, the participants discussed the lifelong nature of the diagnosis. The theme and key thematic element Hearing the news: Fear of “knowing” reflects this pattern.

Pam’s deceased mother was a diabetic and she shared her mother’s story during the interview, illustrating the fears she associated with her own diagnosis:

I was actually – I was overwhelmed at first. Then I think I started to get depressed because the reality of being a diabetic was overwhelming. I suspected it, but to be a diabetic – I don’t want to be a diabetic the rest of my life (voice trails off). I have officially become my mother, and my mother died (voice gets louder) as an indirect result of complications from diabetes….And I just didn’t – the reality (the diagnosis) was just too much....
…injections made me really sick at first, but I’m able to tolerate them now. My mind is willing. I know what the complications are and I don’t really want to be in renal failure (lowers voice). And I’ve always had a fear of losing a limb. I’ve always had a fear (voice gets louder).

*Sally* related concerns regarding potential complications of diabetes in the following statement:

I don’t want to lose my eyesight. I don’t want to lose my limbs because I enjoy walking around comfortably. I don’t think I want to go through that. I can’t say, but it seems a pretty rough course, you know. No options, I guess (voice trails off). It’s pretty (sigh) – just like there’s no argument. You just have to do it….There’s no options. You just have to do it. If you like living.

*Lenny* expressed similar concerns related to potential complications that surfaced at the time of his diagnosis:

Actually, I was devastated, to be quite honest with you, because of the repercussions from diabetes. Blindness, loss of limbs, it goes on and on and on. So I was not happy at all. (long pause) Boy, I’ll tell you what, there were a bunch, I guess. Confusion. What now? Again, the fact that there are a multitude of side effects. Mortality. A lot. A lot of things went through my mind and all at one time. And at the same time, not knowing what to do. Because I know with the diabetes, at least I’ve been told, the lights can go out just like that.

*Debbie* (39 years old at the time of the interview) reflected on her perceived future health at the age of 70 years in the following statement:
So do I want to be one of those people that, God forbid is going to cost a billion dollars to take care of their diabetes 30 years from now, or will it be where I don’t have it (diabetes) and I won’t have to worry about it, or will it be that I’m just borderline again because of it. So that’s kind of a long-term situation to think about. But that’s really important in my mind, because I don’t want to have to struggle at 70. That’s kind of not what I was thinking I was going to do at 70. I was thinking, like parachuting out of a plane at 70 or something.

Martin focused on his fear of needles including phlebotomy, glucometry, and injections after being diagnosed:

Right away, he (internist) talked about, you know, insulin and needles. And because he said – he’d never seen somebody as high as mine was that wouldn’t go on insulin. This is more or less what he told me. And I looked the doctor in the eyes and I said, you know, I will do everything in my power to not (louder) do that, because I don’t want to do it. I hate doing these blood – I mean, when I prick my fingers with these, and take my blood sugar, and really, when I – I think I only ever had two blood tests in my life up until three months ago.

He then expressed concern about the potential of insulin treatment in the following statement:

I mean, (the internist) wasn’t going to put me on insulin right away, but he more or less, I guess sort of said that down the road somewheres that this could very well happen. And I worried – I mean, he didn’t say anything more.
Diane has an extensive cardiac and vascular disease (stenosis) history. In the following statement she compared diabetes to the cardiac events she had experienced in the past, with diabetes being more troublesome:

I was more concerned about the diabetes then the heart attack. Because I’ve worked in a nursing home. I was a CNA. I see what diabetes can actually do. I mean, I’ve seen what a heart attack and a stroke can do, as well, but diabetes scares me more. You know, I’ve seen people who don’t watch their blood sugars, who have lost their toes, their legs, gone blind. I’ve had a resident that – his blood sugar was so high, he was in a coma for a long time and when he came out of it he didn’t know anything. So I saw what diabetes firsthand can do. So like I said, diabetes scares me more than the heart disease. You know, I figure if I’m going to have a heart attack, I just pray that the next time that it’s a big one and it just takes me fast, you know? Where, with diabetes, I don’t want to go blind and it definitely is affecting my vision. And that’s one of my biggest fears.

Diane continued:

But that was scary (cardiac catherization). You know, but like I said, this (diabetes) scares me more. I don’t know why (laughter). I don’t know why.

Jane discussed her perception of the diagnosis with some denial of associated fear. However, her tone of voice and increased volume at this point in the interview suggested that it disturbed her more than she consciously wanted to openly admit:

I didn’t get upset. I guess I’m just used to dealing with negative things in a positive way. And so he said I would take a pill, you know, instead of insulin, so I knew that was a good thing (voice gets louder). Because, oh, my grandson – I
forgot. My grandson has childhood diabetes. He got diagnosed a year ago. He’s in (a southern state).

Carol described her fear based on her perspective of her future:

I think it’s frightening. I think I’m – I think about dying a lot. I don’t mean suicidal, I mean the fact that I don’t think I have a long lifespan ahead of me. Um – I – you know, I think, wow, it would be nice to outlive my mom by 14 years. At the rate I’m going, I’ll be lucky to live as long as she (her mother) did, because I am carrying the weight. And I’m heavier than she ever was. A lot heavier.

So, I know (voice gets louder) all the damage it (diabetes) can do to my body. I know that it’s a powerful disease, I guess. And I feel blessed that the medicines are available that we have today, that I don’t have cancer, knock on wood. You know, that it’s just diabetes.

When Hearing the news: Fear of “knowing”, the participants revealed their fears related to their diagnosis of diabetes, and how it was necessary to process or come to terms with those fears in order to attend to the diagnosis. Upon learning of their diagnosis or Hearing the news, the participants (with the exception of Cathy) described a variety of responses to their diabetes. It appeared that they needed to process this response in an effort to come to terms with the diagnosis and to begin the work of sorting it out and attending to it. Cathy reported the situation at her diagnosis point but did not dwell on her response to Hearing the news.

Existential Themes When Hearing the News

Lived space (spatiality) is described as a felt space. It is a pre-verbal notion, yet the space where a person finds themselves can affect how they feel (van Manen, 1990).
When *Hearing the news*, the participants in this study described the space where they first learned of their diagnosis, for example in their provider’s office. The participants also described the act of getting themselves to that place, for example deciding or “surrendering” and scheduling an appointment, or the situation that led to an emergency admission (*Sally* and *Diane*) to the hospital and their diabetes diagnosis. Additionally, the diagnosis of diabetes necessitated finding space or room in their lives for it and the necessary care.

Lived body (corporeality) refers to the physical or bodily presence in the world, and in this state one can both reveal and conceal something about themselves (van Manen, 1990). The participants in this study focused on their bodily symptoms prior to and at the time of diagnosis when *Hearing the news*. They also described not listening to their body and missing clues to the change in their health.

Lived time (temporality) is a subjective time which includes the temporal dimensions of past, present, and future (van Manen, 1990). When *Hearing the news*, the participants discussed time in multiple situations, including the point in time of their diagnosis, the time span between the onset of symptoms and diagnosis, and the time until they enacted lifestyle changes in an effort to manage their health. At the point of diagnosis, the participants reflected on the impact of their past choices, and their view of diabetes today and in the future. They described the disease as a lifelong process that encompasses the past, present, and future.

Lived human relation (relationality or communality) refers to meeting others in shared interpersonal space. This human relation permits a transcendence of self and insight into the purpose and meaning of life (van Manen, 1990). The participants in this
study discussed family relationships as they framed their experience at diagnosis, for example a family history of diabetes or the impact of their diagnosis on other members of the family when *Hearing the news*. Several participants discussed the impact of diabetes on work and work relationships. They also related to others with the diagnosis as persons they were now connected with in some way.

**Sorting It Out**

The participants were asked what they have done to learn to care for themselves since their diagnosis. All responded and described an experience. These descriptions included reflecting on their perceptions of persons they know with diabetes, including family and friends. Those who were healthcare workers also described experiences with patients who had the disease. The participants described activities undertaken to understand their own diagnosis and a need to be aware of or attend to the variables such as diet, medications, or schedules. They responded to these questions and discussed resources that have been helpful or not. In some cases, specific individuals were identified or the statements were generalized, such as needing to find a class or a book.

**Sorting It Out: Knowing by Comparison to Others**

The theme and key thematic element *Sorting it out: Knowing by comparison to others* was evident in statements made by some participants. For some, these experiences (both positive and negative) were seen as previews for what they could expect with a diagnosis of diabetes.

*Pam* described her experiences with patients in the following statement:

Yes, not just in her (her mother), it’s in all the patients I’ve taken care of with diabetes. I’ve taken care of a lot of diabetics and given them their pills and given
them their injections and monitored their diets and, you know, covering the lows, covering the highs and stuff like that. And it didn’t seem like they were enjoying their life (voice gets louder and rate of speech increases).

Pam’s mother was a diabetic, and Pam herself had experiences as a healthcare provider with patients with diabetes. These experiences appeared to influence expectations for Pam and were present during our conversation, both in the forefront and the background.

In the following statement Sally described a conversation she had with a friend about being diagnosed:

Yeah, I told them I was diabetic, but I didn’t ask them a lot of questions. One person told me a lot. It was her husband who is diabetic and he did not get a handle on anything. He wouldn’t eat stuff, he wouldn’t – he did nothing, really, to control his diabetes. It’s a friend of mine, and he ended up with the leg amputation, you know.

Sally’s experiences of persons diagnosed with diabetes included her mother, grandmother, and friends.

Lenny has a remote family history of diabetes and a neighbor with it. He described his neighbor, who has diabetes, in the following statement:

And then obviously this thing pops up (diabetes diagnosis), which can create a lot of other things. So it’s not been fun. And it won’t be, obviously. Although the one salvation to it is – the next-door neighbor is 80-something years old. So I am, from time to time, when I get depressed – and I do, I’ll think about the next-door neighbor, 80 years old. Every morning he gets up and he meets his buddies at
Burger King that he used to work with and he’s constantly on the go here and there and doing this and doing that. So if he can do it, why can’t I?

During the course of the interview Lenny described meals he shared with his neighbor. He views him as a person with diabetes, but not as an information source or a support.

Debbie discussed her concerns about family members with diabetes starting with her brother:

My brother right now has diabetes and he is probably the one that is struggling the most – he just is so stubborn that he wants to eat mashed potatoes and wants to do his normal routine with all the white things that he’s not supposed to eat, and refuses to basically stop any of that, and so even though I’ve learned from myself, and I try to give him information on it, he just totally ignores me, and I’m going to eat what I’m going to eat, and whatever, so I just – I’ll give information as I know it’s the appropriate thing. So he’s struggling the most. And I don’t want to say that that’s because he’s a male, but I think it is partially, and he’s been set in his ways on how he’s going to eat and that’s just the way he’s going to be. Plus, he’s single, so he’s on his own. There’s nobody there that’s going to holler at him for doing something that he shouldn’t be doing.

Debbie described her attempts to inform her brother about self-care. She continued, discussing her sister and aunt. She had both positive and negative examples that influenced her perceptions of outcomes for persons with diabetes and herself.

My sister, she maintains it and takes her medicines and my aunt just recently passed away about a month ago, not from diabetes but from Alzheimer’s. But she did have lots of complications from the diabetes. She had lost part of her foot and
a lot of that has to do with being part of the Alzheimer’s situation as well. Even though she was in a care center, the diabetes just took control over her body. Martin had experiences with diabetes through his first wife (deceased), son, and two sons-in-law. These experiences appeared to influence the way Martin viewed his diagnosis. The following statement pertains to his deceased first wife:

Yes, she (deceased first wife) had it probably pretty severe, really. She was on insulin. And back then, I mean, she had – she gave herself (insulin) with these needles.

Bear in mind that Martin’s fear of needles was previously revealed. He then discussed his sons-in-law who have the disease:

But I look at it, a couple other people, just like – I got two son-in-laws. I mean, I could go to my two son-in-laws and the one, he takes two different pills. And he don’t monitor his sugar. He don’t even have a meter. The doctor tells him. And he’s on this Metformin and something else. He takes two pills, I guess, for his blood sugar. And I’m only on this one lousy pill and I think, why do I have to do this? And that sort of made me frustrated. But then again, maybe this doctor is more – wants me to watch it because we, you know, went to him, really, first doctor I actually had. I never had a family doctor.

Karen discussed her experiences as a healthcare provider as a reference point for caring for her own diabetes:

Online. I’ll look. But it’s a lot different taking care of somebody that has diabetes in, like, the recovery room or as a nurse from that aspect than it is taking care of
yourself. You know? We take their blood sugar, we give them insulin, we look for signs and symptoms of, you know, the hypoglycemia in the recovery room.

In Karen’s view, caring for one’s self is different than caring for a patient with diabetes, and in some ways this knowledge does not transfer into self-care.

Diane revealed experiences from her family and from her role as a healthcare provider. Her uncle is a person managing his self-care who seemed to support Diane’s understanding of how to care for herself:

 But yeah, he (uncle) said once in a while he cheats, but he’s insulin-dependent, so then he’ll give himself a little bit more, he said. He was diagnosed when he was 43 and he’s now 75. And he said he really watches (stressed). And I know he does, because I know the family used to always say, well, he can’t eat that or he won’t eat this. But you know what? He’s still alive. You know, he’s very diligent with what he eats, you know. And at the class they were saying – because I get up at 4:00 in the morning, you know, that, like, every four hours or so I should eat a little something. And I looked at him and said, oh, my God, if I eat every four hours, I said, I’m going to look like a heifer. You know, so I had him all laughing. But I realize what they mean, that you’ve got to be sensible about what you eat.

Diane also discussed her father as an example of a person having difficulty managing his self-care. She considered him a negative role model for her self-care:

 Now when I look at the way – when we go out to eat and what he (father) ate – and I used to always call it because he kept a journal, too, of his numbers and I’d say why are they so high? And he’d say, oh, they’re alright. They weren’t alright.
*Jane* discussed her sister (recently deceased) as an example of a person with diabetes who had an impact on her need to take care of herself, because she believed her sister did not care for herself:

But my sister, she had – I think – I don’t know if she was on the pill. I know she wasn’t taking insulin. I know she was doing the test, but then she went and dropped her insurance, and then of course she didn’t get that. And then as far as I know it went haywire. And I think back, because she had called me on a Saturday night before everything went down, and she was – sounded like she was drunk. And she doesn’t drink. Well, maybe she did this time, you know? I didn’t know. Because she was talking in circles….And then when I read this paper and it said that, you know, you can get lethargic and, I’m saying, that might have been it, you know, she just – it was up over 300, her glucose count. So – that’s what I’m thinking, you know.

*Jane* came to understand her sister’s symptoms based on information she had recently read about diabetes, but also discussed her observations of her sister’s unsuccessful self-care:

(So I wonder) could the type 2 get worse if you wouldn’t watch your diet and everything? And I don’t want to give in to the insulin thing. Pricking my finger, I’m – ouch – all the time, you know. It doesn’t hurt, really, but I don’t really want to be an insulin person, you know. So if I wouldn’t watch my diet, it (diabetes) could get worse? Obviously my sister’s did.
Cathy discussed her mother and boyfriend (recently diagnosed) as examples of people with diabetes that she used to determine what might be true for her own care. She first compared herself to her mother:

Well, she has – she goes – she’s on insulin and stuff, so that’s a little different than me, so, you know. (laughter)

Later she discussed her boyfriend’s response to the disease:

You know, and her – and my boyfriend has diabetes, and he is type 2, too, and he got his toes taken – some toes taken off from the diabetes. And he just recently found out that he has diabetes too, not too long ago and stuff. But-because he was at the doctor and they got them taken off, some of them. Well, something was wrong with his one foot, so he went in to get it checked and they had to admit him into the hospital because they said that it was gangrene, I guess, and then when they did the one toe they had to take off three toes and then they ended up having to take the whole thing off eventually, because it was – He’s doing better, but he’s still not listening to a lot of the stuff he should be doing, which don’t help him, either. Because he’s drinking regular soda and stuff like that, which isn’t good for you. (laughter) Which, I know that, but he don’t listen. And some of his eating habits, I think he should be doing a little bit better than he does, too.

Carol discussed the history of diabetes in several family members starting with her mother:

She had a better insulin regimen. My mother actually, over time, lost weight. She’s the only person I’ve ever heard of who came off of insulin when they, you know – and I’m sure maybe there are more people out there, but as her dementia
got worse her appetite – and with the neuropathy and her stomach, she lost a lot of weight. Well, over time then, they took her off the insulin and then they had her on – I think they just had her on Glucophage, and even that, one night her sugar levels dropped down to, like, 40 or below and they took her off even the pills at that point.

Then I guess it makes sense that when she (her mother) lost weight she could still, yeah. I had just – because, I mean, there’s so much diabetes in my mom’s family. Now, she was an only child. But my grandmother’s siblings and all of their kids – I mean, men and women, they all – almost was a given that they all had diabetes.

Carol also shared a story from her brother-in-law about a diabetes education class he attended:

Probably the idea that you do need to take care of yourself, and that very simple things do make a difference. And my brother-in-law went to a diabetic class and their instructor did something really interesting. She had them all – it was an after supper class; it was an evening class, so they’d all pretty much had supper. So they came in, the first thing they did when they came to class was they stuck, you know, did a finger stick and got their numbers, and then they all went outside for a 15-minute walk. And they came back in and everybody’s numbers had dropped by 30 to 50 points. From just walking for 15 minutes.

Carol went on to say that she tried this activity when walking her dog and noticed a similar decrease in blood glucose.

When Sorting it out: Knowing by comparison to others, the participants in this study provided clear examples of knowledge gained through others. They recalled some
examples from past observations, some were observed more recently, and some were examples of conversations shared with others.

**Sorting It Out: Working to Understand and Stay Aware**

When discussing which strategies to take on for self-care, the participants reflected on what they had learned about it, and they shared both new and past learning experiences. The participants also shared how they make sense of the diagnosis. This is captured in the theme and key thematic element *Sorting it out: Working to understand and stay aware*.

*Pam* described her challenges with diet and medications and keeping aware of what was important:

And sometimes it still comes back that I’ve got to do this the rest of my life. I’ve got to be mindful of everything I eat…and we have to always be conscious of what we’re eating. It’s very difficult to grasp all the time. I have to take medication every day… I’m watching everything I eat. Since I’ve been diagnosed I have diligently downsized my portions….I’m just really mindful of what I eat now and how I eat, and I have to remember to take my medicine. I’m good with taking it in the morning and I’m not good with taking it at night (voice trailed off).…– I’m always good with the first dose, but I’m not always good with the second dose. I think by the time I get ready to take the second dose, I’m more depressed or in refusal because I’ve got to do – the pill is so big.

Later she discussed information sources and the challenges involved in incorporating a work schedule with making food choices:
Once I learned that I was diabetic, I decided to go online and pull up some information about diabetes and how to live with it. Pulling up the information online is OK, but it’s not as good as talking to somebody who lives with it and what their stumbles and trials and tribulations are. Talking to somebody that’s going through the same thing I’m going through. The internet tended to be too technical. Talking to some of the people in the classroom and then talking to the dietician, because my diet is my main concern simply because of my work schedule….so that’s the hardest part is what am I going to be able to eat, and how will I be able to comply (voice gets louder) and eat healthy at night. If I eat three square meals a day, what happens when I’m up all night?

*Pam* also discussed the challenge of incorporating daily changes into her life; she used words such as “mindful, willing and conscious” during the interview.

Also during her interview *Sally* discussed sorting out medications, glucometry, and diet. The first example illustrates her experiences with glucometry and medications:

It was just – it took a while. It probably was a few days before I felt comfortable just doing the monitoring. I’m usually not very good about doing my medications. I’ll realize, like at night, that I don’t have a pill that I need to take at night or in the morning and in a day or two I’ll get it filled.

*Sally* then discussed gathering information to learn about self-care:

It’s kind of radical but I can kind of jump to that. You know, I know the food’s important. I read – I read a lot of the stuff, so now you’re a diabetic kind of stuff and I feel like I don’t need to read that, but I did just in case there was something that I didn’t know.
She continued to talk about being overwhelmed by the amount of information available:

It just – I think what happens to me is sometimes I get so tired of being my own case manager I can’t stand it anymore and I just think, well, you know what, they just need to tell me, watch out for this, this, and this. Because I don’t want to read the PDR (Physician’s Desk Reference), you know? Because I worry a lot. The more knowledge I have, the worse that gets. So I think that’s my own way of setting limits, kind of denying. I operate in denial big time.

*Lenny* discussed other information sources and his neighbor while trying to sort out information on his own blood glucose levels:

There’s information that I’ve seen on the Internet of various things that are somewhat useful, but also somewhat confusing. I read in some cases eating fruit is a good thing, and in other cases it elevates your blood sugar because it’s whatever food group. So there’s some confusing signals sent. Again blood sugar somewhere around 100, 110 is supposed to be good. That’s the point. And I question, just because, again, in all of my vast medical knowledge….Again, a little bit early on here and I’m questioning, is the proper blood sugar level for (Lenny) 110 or should it be 70 or should it be 130? You know? Does one size fit all, I guess is what I’m saying. My next-door neighbor is diabetic, he’s 80-some years old and he and I had a little conversation last night….And he just said to me, I’m checking my blood sugar levels like you’re checking your blood sugar levels. He said, (Lenny), I feel good at 200. So, I don’t know.

*Lenny* then described his blood glucose levels and overall well-being in the following:
I check my finger and as long as it looks like I’m not going to blow up in a 
minute, we’re having a good day. It’s 70, it’s 80, it’s 90, it’s 100, we’re having a 
good day. If it’s, you know, then forget it. We’re having a good day, (Lenny), 
move on.

During the course of the interview Lenny appeared to question blood glucose levels and 
diagnosis and also used current blood glucose levels as a reason to limit his degree of 
participation in self-care.

Debbie described understanding diabetes when monitoring blood glucose levels 
and making dietary changes based on results:

I do check my blood sugar. I don’t have to do it every day, according to my 
endocrinologist, but I do – what she wanted me to do was do it every three days or 
when I remember to do it in the morning, but more so after a meal just to see what 
I was eating and how it was making my blood sugar spike or what it was so that 
way I could learn to have a better diet and not be able to eat the same type of 
things, like that I would probably be doing now.

Throughout her interview Debbie showed that she was willing and able to make the 
necessary changes (on most days).

Martin also discussed coming to understand the impact of diet and blood glucose 
levels:

So until the next morning, why, this stuff is laying in your body (evening meal). 
So that’s probably why it (blood glucose) might be a little higher. And that’s, 
that’s, that’s it. (silence) (blew out air) Well, my reaction probably was, you 
know, and then, you know, what should I eat? And this is more or less a lot – they
tell you it’s lifestyle, you know, and how you eat. And really, you know, you need to exercise.

*Martin* discussed hearing information from a radio show that addressed health topics and compared this information to his blood glucose levels:

You know, they (radio show) talk about diabetes quite a bit. And they more or less said that when you get up in the morning it needs to be – it should be 100 or less. It needs to be under 100. And really (voice gets louder) that’s where I have the biggest problem, where my blood sugar should be in the morning. The morning one is higher than what I think it should be. And this is what I said. I thought that the doctor would say something, that we need to get it down lower in the mornings, because it usually was running around 120. That’s where it’s been sort of running. And the evenings, why, if I would take it before I eat, say around 5:00, why it usually is around 100 – it’s usually around probably about 110, 115. A couple of times I came home and actually – it was only two times. One time it was.

He was trying to understand his symptoms and the prescribed medication treatment plan.

*Karen* described trying to understand the relationship between blood glucose levels and exercise:

I seem to be checking it a lot more frequently than I really should. They want me to do fastings periodically, like one or two times a day, just fastings two hours after meals. Two hours after dinner, before bedtime. But I seem to be checking it a lot more to see where I am during the day with my activity.
During the course of the interview Karen discussed her efforts to lose weight through diet and exercise changes. She also discussed blood glucose levels and symptoms:

That’s when I start increasing my sugar thing. I notice I start to feel a little shaky when I’m under 100 (chuckle), which kind of concerns me, because I would like to be under 100, but now the other day at work I felt a little bit funny in my head, and when I checked it I was 97, which is not extremely low, but is probably low for my body to get used to if it was used to being at 170. I know I’m going to feel changes in my stability, I guess, if you want to call it that, as my sugars start to come down and maintain lower.

Karen is trying to coordinate her diet, exercise, symptoms, and blood glucose levels.

Diane discussed blood levels established by the American Diabetes Association (ADA) and the American College of Endocrinology (ACE) in relation to her self-care and personal goals:

I just checked it right before you got here and it was 179, which is the ADA, it’s 140 to 180, so it’s right there. Now, the ACE, they want it below 140, you know? So I questioned that at class yesterday. I said, why are there two standards? Why isn’t there one universal standard? You know? So for me, I’m trying to go for the ACE standard, you know, to get it as low as I can, but I just barely got into that guideline, you know, with the ADA, which is, like, all right, but I wish it was lower. Some days I get up in the morning and it’s 110, some days I get up and it’s 165 and I think sometimes it’s because it just depends how active I am after dinner, you know?.... If I’m active right after dinner, I take notice the next morning it is lower. I have a hard time walking because of my hips.
Diane also discussed blood glucose levels and dietary choices:

And so then I anticipate what my numbers are for the next morning, you know. So I’m trying to watch, like you said, what foods and how it affects me. You know, it’s like if I have a baked potato it does seem to be higher in the morning. If I have poultry and a salad it’s definitely lower (voice trailed off). So I do take notice. It all depends on what you eat and how much you eat. You know, so I’m curious as far as portion control with meats. That’s one of the biggest things, you know.

And then so my blood sugar was – excuse me – I think it was 160 this morning. So that had me upset. And it’s like, OK. It’s probably because you were awake all these hours and didn’t eat, you know?

She also discussed her symptoms and that of a class participant and the relationship to her own blood glucose levels:

– so you hear different people’s accounts of what they went through. He was itching all over. I get this – when my numbers are up I get this burning sensation in my mouth like if I would put peroxide in my mouth. My tongue, my gums, and I know that my numbers are up. And if I do my blood, they’re up. They’re up in the 180s to 200.

Diane spent a considerable amount of time trying to understand her diagnosis and the recommended self-care changes. Jane discussed her blood glucose levels and information received from others:

Well, it was 143 when they – when the doctor first told me, and then I think like a week or two weeks later it was down – might have been three weeks – it was
down to 133. And then somebody told me, well, that’s low, you don’t really have to worry about it.

Jane continued, relating her attempts to incorporate recommended dietary changes into her daily life:

Well, they said something, too, about a dietician, but, you know, the only thing with a dietician, even though she can give me pointers or he can give me pointers – then they give you this big – I’m afraid they’ll give me this big menu you’ve got to eat. Then it’s always more than I eat now. It probably would be good things, and it probably would be diet-friendly, but it’s more than I eat (voice trails off).

You know what I’m saying?

Cathy described information she received when attending a seminar with her boyfriend. He was the intended audience, but she went along for support:

Well, to test your blood often. You know, to make sure you’re doing that properly and stuff. Because I was at a seminar over at (medical center) one time with her – with my boyfriend – and they said you should make sure you take your blood sugar and stuff, you know, to check it regularly and stuff, because having it too high and stuff, which I’d been, ‘till everything gets regulated and everything, you know (laughter). It was – I don’t know – they – he had to sign up for it. I’m not sure if it was really a class. They just talked about different things in the seminar. It was like a seminar and then they tried to portion foods and stuff out there and stuff, and you got to sample some of them at the end. But I don’t know if it was really a class or not.
Cathy received limited education on diabetes self-care, which seemed to be due to a provider change and insurance and finance-related issues.

Carol discussed her challenge to lose weight and the influence of medications on her weight fluctuation. She identified issues she planned to discuss with her healthcare provider:

And that’s a question, actually, that I haven’t discussed with my doctor is that I know I need the insulin. I know I’d be in real trouble if I wasn’t taking it, especially the way I eat and don’t pay attention to my diet, but I wonder if that doesn’t make it more difficult for me to lose weight, to a certain extent, too. And I haven’t had a chance to do more reading on that, but I was thinking that I had read an article at some point that insulin makes your retain or has a tendency to have you retain – I know Actos, the reason I came off of the Actos was because I had been on it for a while. Maybe as long as two years, being prediabetic, and all of a sudden within – now my thyroid will do that, too. My thyroid will trigger and I will – I once time gained 20 pounds in a month.

Carol continued, discussing books and resources she used in an effort to understand her diagnosis:

I’ve looked through them (books), you know, I read pieces about the, you know, how to plan the menus and I’ve read about the, I guess the term would be the physiology of why things happen the way they do and why you become diabetic. I don’t say that – I can’t spout it back out to you, the medical terms, but I understand, and I understand the difference between type 1 and type 2 diabetes. And the class that I took years ago. So – and of course the things the doctor said.
And just healthy eating in general, like the food pyramid and carbs. I understand counting carbs. And that, basically, the counting of carbs and understanding that came from the diabetes course years ago. So I knew that before I started reading, really the books that I have at home now, like Diabetes for Dummies, and I don’t remember the other names, but I do remember that particular one.

While Carol described information-gathering experiences and getting access to information, she struggled with consistently enacting health-promoting lifestyle changes.

When Sorting it out: Working to understand and stay aware, the participants in this study described information gathering and learning that occurred as they tried to make sense of their diagnosis.

**Sorting It Out: Recognizing Support Options**

When trying to make sense of the diagnosis and trying to understand necessary changes, the participants discussed searching for and identifying sources of support. In a majority of cases, support was viewed as a positive factor. Sources of support were described as a specific person or resources in general, such as a class, a healthcare provider, or a print or internet resource. This is captured in the theme Sorting it out: Recognizing support options.

Pam discussed the information from diabetes classes and identified her individual needs in the following statement:

….major thing we really want to know is, OK, we have to live with this possibly for the rest of our lives, so how do we go about a regular, routine diet, a routine meal, a routine way of living? That’s what we want to know….The Tuesday class was a little over our head. It wasn’t over mine (voice gets louder) so much, but at
that point I’m not looking at it – I’m not doing it from a nurse’s point of view. I’m a patient now, and that’s too much information for me. I just want to know what do I need to do to keep the numbers right and bring them down, and how do I eat? Meal planning….because we all come from different races, so because this is my culture [Black woman] and this is how I eat, how can I plan a meal and stay within my culture?...But I think that’s pretty much, a lot of us why we came, because how do we eat healthier and stick to foods that we like? And I still don’t know that yet.

Pam revealed that she wants information from the patient perspective and not the healthcare provider perspective. She also introduced the need for having dietary information incorporate race and cultural needs. Notice in the previous excerpt that Pam transitioned from the use of “we” to “I” during the conversation. Sally described interactions with her daughter in the following statement:

I was then starting to get mad at my daughter and because I feel like she sort of discounts (voice gets louder) the adjustment that it is. Not intentionally. I love my daughter and she’ll do anything for me, but I guess I felt like, oh, because here’s medicine, she kind of perceived that, oh, well, that’s not a problem, just take the stuff and go on with it.

While Sally’s daughter is a source of support, their relationship has changed since diagnosis. She continued, describing her daughter’s resourcefulness when they were dining out:

There’s nothing you could do to modify that (food selection) except just eating the baked potato at (a restaurant) (laughter). So, you know, that’s an idea. Like
my daughter is giving me ideas. I don’t normally think to look at the Web site, but we’re right in the restaurant and I have my phone so I can look it up. Not anything written.

Sally and her daughter used the internet to review menu options prior to ordering dinner.

Lenny discussed the lack of access to people with diabetes in his life and the need to find someone to discuss diabetes with:

Other than the next-door neighbor, I can’t think of anybody I know with diabetes. So, you know, especially with guys. How guys operate. You know, yeah, Bill has this, hey, Bill, let’s go for a beer, I want to talk to you. And you sit down and you talk to somebody that you’ve know for a while that you know you can trust and you get some insight. I don’t have that situation. Whatever I’m going to learn with this, I’m going to learn from this class and whatever else. Trial and error, I guess. So that’s the one thing. I hate to say this, but it would have been good if my family had a history, because, you know, somebody would have said somewhere along the line at a family gathering or something, would have talked about Aunt whoever’s diabetic issue. There isn’t any.

Lenny spoke about his neighbor and his plans to find information sources. Ideally, Lenny prefers to have a man his age with a history of diabetes as a support person during this time:

So again, the support network from a family standpoint isn’t there. That there’s somebody that you can go talk to. Or a friend. I don’t know. And like I said, the next-door neighbor – excuse me (cough) – he’s a good guy. I mean, he really is, but he does a lot of yes and nos. You’re not going to get a lot of info from him.
That’s just the way it is. Other than when he’s mad. No. Something made him mad about something and then he’ll spout off. So that’s how that part of it is….Well, that’s what I’m fully expecting, and if not, I’ll have to go seek out info someplace, you know. Through my network [works in sales] with customers and this and that, you know, who knows. I’ll just conveniently bring it up from time to time. Hey, guess what, you know. I saw the doctor and. And maybe somebody that I’ve been acquainted with has a customer….Will spring on, oh yeah, I’m diabetic, too. And maybe you can have a conversation and find out. We’ll find out how that goes moving forward. Again, the National Diabetes Association and that kind of thing, they probably know what they’re doing, so reaching out to them for whatever you can gain. It’s all a part of it.

*Debbie* described several sources of support, including her husband, sister-in-law, mother-in-law, and workplace-based healthcare providers:

My mother-in-law actually gave me a couple of books and one of them actually scared me to death (chuckle) just from reading it. Articles that I come across that may be, you know, interesting to read. Sometimes my mother-in-law will send them to me. I have looked up and tried to – it partially was part of self-diagnosing myself and understanding the PCOS at the very beginning, and then of course when my mother was sick I always looked up things that she was diagnosed with, so I did read about it and understand, and understand the things that can – of course, the worst-case scenarios of what can happen probably stand out more than anything else, but yes. Who – what would we do without the Web today?

She continued, describing her primary healthcare provider and her workplace:
Well, my primary healthcare provider, Dr. (family MD), she has been wonderful over this because she knows that – how stressed out I’ve been over making sure that I try (louder) to get healthy, is what my husband and I put it. Where I currently work, we have an unbelievable health program where they offer a free wellness care center and we also get free pharmaceuticals, so – free gym, there’s a free gym, a free dietician.

*Debbie* reflected on taking an active role in her self-care by partnering with her healthcare provider:

> So that way I can partner with them to understand how I should. And I laugh with them. I say, even with the diabetes, could you just go food shopping with me? Because that’s probably part of the problem, because when you go food shopping, you just want everything that looks good and that’s not necessarily what you should be picking up. And they crack up. I’m grateful to have those resources available.

Similar to Lenny, *Debbie* spoke about finding others diagnosed with diabetes for support:

> I think that you have to find as many people to talk to about it and understand what – you may not have what I have, but you have something, so we can talk about it and be able to find a resource that may be able to help me figure out more, and then I would take another avenue and go into the doctor or find somebody in my – talk to my well-nurse or talk to the dietician. And of course the Web. Always, though sometimes you don’t want to read some of that stuff on the Web, because it freaks you out. Because you don’t want to read what you think is
you and then have it be horrible. But resources – using any resource that you possibly can is what I’ve tried to do to learn more about what I have and what I can do and what doctors are the right doctors. I think we’ve changed. Our world is not just, you’re going to see your primary doctor anymore. You have to understand what all these specialists are and who can do what. What’s – you know, who’s the right specialist for you to see? And that’s the route.

During the course if the interview Debbie described interactions with healthcare providers that were both positive and negative. She also described the types of written materials she prefers. Martin described his wife as a source of support:

I say, really, I’m a big boy; I should be able to do this. But my wife always went along when I went for my blood tests. She always went along. Yeah. She held my hand. She says, don’t look, OK? No, really, it didn’t hurt, I’ll tell you that much. It didn’t hurt, but it’s just the notion, I guess, of getting blood taken. I don’t like it.

He continued to discuss his wife’s support:

My wife went out and bought a few books, I know that. She told me I was supposed to read them, but I didn’t. (laughter) OK, she got one that said this is Diabetes for Dummies. Well, I’m not a reader. I’m really not. Now, my wife’s a reader. She’ll read books to no end, but me, I’m not – I’m not a person to sit down and read books. I never was.

Martin’s wife accompanied him to doctor’s office visits and diabetes education classes. She also gathered materials that she read and then shared the relevant information with him.
Karen described her family members as sources of support in the following excerpts. The first statement relates to her mother:

Also, there was something else in the class that both my mom and I didn’t know.

She’s going with me as my support person. I figured the information would do her good, too. And she’s been a really good support, too.

Karen then talked about her sons, mother, and husband:

My boys are very conscientious. They see me checking my blood sugar, they want theirs checked, too, to be sure. And, mine’s good, mine’s good. Mommy’s is too high (chuckle). They know. And they watch what I put in my mouth and what I eat. So I mean, it’s good. I think it will benefit all of us.

I don’t find it – like I said, I’m trying to be positive about it. I have a lot of support. Even just my three boys – my husband and my two little boys. They’re very supportive. My mom is very supportive. She used to watch me when I was diabetic and I said, you know what? You’re going to tell me this but you’re eating it and you’re diabetic.

Additionally Karen described meal planning and preparing groceries lists with her husband, and her sons joining her during exercise.

Diane described her estranged relationship with her father. The relationship is a source of stress for her and viewed by her as not supportive:

Yes, but he (father) has dementia, also, and him and I, we haven’t spoken in over a year because I can’t – the stress. The stress with him, I couldn’t handle anymore. It was really bad. He was very demanding and he did not understand my health issues, which he should have, because I have the exact same thing except
for the diabetes, which my mom had, and she died. So he knows what she went through. And he would make fun of me and it would hurt my feelings, because it was like, I’m going through the same thing my mom went through, only I have it 20 years younger than she did, you know? And I used to say to him, I hope I live to see 60, you know? What are you talking about? So, he’s a Pennsylvania Dutchman, very stubborn, and his way is the right way. And his way is not the right way.

She continued to depict their relationship:

But it got to the point it wasn’t worth getting upset about anymore. You know? And then we just had a big blowout, and so right now we’re not talking. And right now I really don’t want to be talking to him. It’s like, I just don’t need that extra stress in my life (voice trailed off). It’s terrible, I love him dearly, but I don’t like him as a person.

*Diane* described her husband and uncle as positive examples of support in her life.

In the following, *Jane* discussed people at the workplace as examples of support:

No (friends with DM). Well, there’s one with – I really haven’t talked with her. There’s this one girl at work. She said she went to the eye doctor and the doctor said by looking at her eyes that she has diabetes. Now, the doctor said something about getting my eyes checked again. I haven’t for a couple of years. They don’t feel like they’ve changed, but I still have to call and make an appointment, but I was so tired of making appointments I haven’t done it. Yeah, so I’ve got to get my eyes checked. But that’s it. We haven’t talked about it otherwise. I told her, man, (co-worker), I said, I’ve got the shakes. She said, your blood sugar’s low. So I
don’t know how she knew. But I had told her that I got diagnosed with it, you
know. I don’t tell everybody at work. But they say, too, on one of my pill bottles,
it said to wear a bracelet or something…. I did say something to my new manager
that I just got diagnosed, you know, and the assistant store manager, I had told
him, but, you know, whether they’ll remember if anything happens, I don’t know.
But that’s it. I don’t talk too much about it. Just informed my kids (do not live
locally). And then they asked – well, it says about having a caregiver.

*Jane* considers a co-worker as a source of support, and she also views her children who
do not live locally as sources of support.

*Cathy* described two encounters with healthcare providers; one offered support,
the other appeared less supportive:

So I want to get like, a regular doctor that I can see all the time. You know, that
will help me a little bit more than he’s done now with the diabetes. Because my
insurance asked me if he helps me or tells me certain things for my diabetes, and
he really doesn’t. The other one that I used to have used to say different things,
like to help me, like exercise and stuff, when she was there, but she left and she
moved down the line because she got her license to be a regular doctor and she
moved down the line to do that. That I used to see there.

*Cathy* also pointed out her limited access to healthcare providers due to her limited
resources. At the time, she did not have any minutes left on her cell phone, which was a
barrier to accessing resources to manage her health care:

Well, I want to – I – when I get my phone card again, I want to try to call different
places up to get, like, information on things, like for the hospital and stuff. You
know, if there’s any classes on anything that I can get through my insurance. You
know, tell them what insurance I have and stuff. You know, to see if I can help
myself a little bit better.

During the course of the interview Cathy discussed her lack of access to the internet, print
materials about diabetes, and inconsistent use of mental health medications. She has
uninterrupted access to her diabetes medications.

Carol did not share any example of recognizing support options. When sorting
out their diagnosis, all the other participants provided examples of the elements of this
theme. When the participants attempted to Sort out their diagnosis, information gathering
and learning were evident. They provided examples of coming to understand diabetes
through the experiences of others. They identified sources of information which included
previous knowledge, diabetes classes, and members of these classes, print media,
internet, radio, family and friends. They revealed learning through monitoring their body
responses to medications, diet, and exercise. The participants spoke about sources of
support which included current sources and plans for follow-up or to seek new supports.

Existential Themes When Sorting It Out

Lived space (spatiality) is a space where a person finds themselves which can
affect how someone feels (van Manen, 1990). The participants in this study described
finding space to provide self-care. This space encompassed work, family, and social
situations. Their Knowing by comparison to others reflections described persons and
places and their observations of persons with diabetes. The key thematic elements
Working to understand and stay aware and Recognizing support options also included
descriptions of places where the participants sorted out their diagnosis and found support.
The lived body (corporeality) refers to a person’s physical or bodily presence in the world (van Manen, 1990). The participants described the physical or body symptoms they experienced when *Working to understand and stay aware*. Their narratives included noting physical sensations, then checking blood glucose for greater understanding. They also discussed the impact of food, activity, and stress on their blood glucose and body functions.

Lived time (temporality) includes dimensions of past, present, and future (van Manen, 1990). When *Sorting it out*, the participants discussed needing or lacking time to set aside for self-care and reflection on the meaning of the diagnosis and their self-care needs. Time was discussed regarding the coordination of medications, meals, and blood glucose monitoring. The participants also discussed the lifelong nature of diabetes.

Lived human relation (relationality or communality) when *Sorting it out* included meeting others in a shared space (van Manen, 1990) to accomplish their care needs. The participants often described their perceptions of diabetes through their relationships with others and comparison with their experiences with the disease. ‘Others’ encompassed family, friends, co-workers, and patients of participants who were healthcare providers. The participants also discussed the impact of their diagnosis on their relationships with family members and in the workplace and other situations where they did not necessarily reveal their diagnosis of diabetes. Some of the participants described social or work situations that affected their ability to carry out self-care needs.

**Moving On**

The participants were asked about changes to their daily life and what they were doing differently since their diagnosis; all responded and described their experiences in
detail. They talked about taking on new behaviors and realizations about self-care or life changes. Some participants revealed an emotional response to their diagnosis. Their responses centered on their plans to incorporate activities, make role changes since diagnosis, make clear choices or decisions to participate (or not participate) in treatment recommendations, and look at the future in light of their diagnosis. There was a shift in the participants’ verb tense from past to present and future. In some, the shift occurred later in the interview, while in others there was a give and take or back and forth throughout the course of the interview. Some never voiced a clear transition.

**Moving On: Movement Toward a New Reality**

The theme and key thematic element *Moving on: Movement toward a new reality* involved a discussion of the participants’ changes in activities in response to their diagnosis, and planning an activity change or a role shift (from caregiver to patient).

*Sally* shared how she feels about diabetes and its impact on her daily life:

> I was so frustrated, I said, if we can’t figure this (glucometer) out in five minutes, I’m just going back to the emergency room for my insulin because I can’t deal with this. That was – that was the worst part of it (trailed off)…..But I still hate it (upward inflection in her voice). I sit down to meals and forget to check my blood sugar. Sometimes I remember after the meal. Twice I took the wrong insulin.

She went on to describe her struggle with trying to incorporate the use of insulin into her daily life, her sense of loss of control, and her response to this loss.

> I’m not really - I haven’t bonded with the insulin yet, because like I said, it’s kind of – I kind of feel like I slide by the seat of my pants. I probably could figure
something out to make myself remember to check my blood sugar before I eat. So I guess I suddenly don’t want to because (laughter), you know, it would be easy to, I don’t know, put something on the table like a note. Because I always sit at the same place. But I haven’t done that, so I guess it’s my own control. You give up a lot of control, and that’s hard for me. I don’t like it (voice trails off). I don’t know, there might come a day when I don’t mind it, but I can still tell you I don’t like it. But I’m stuck and I don’t have anyone else to blame. That’s kind of the bottom line (trails off). I just – I don’t like it at all (voice trails off). It’s just – it’s a nightmare, I hate it. I’m fixed on that. I’m just – I’m annoyed and angry that now I have this now to deal with. I’ve just like had enough, you know?

*Lenny* described the challenge of incorporating recommended dietary changes:

Now that’s in the course of research that I’ve done. Eating small meals throughout the day as opposed to one big one or not eating all is the way to go. Unfortunately, with what I do [works in sales] – and this isn’t an excuse, with what I do, pulling that (dietary changes) off isn’t the easiest thing for me. And that’s been me and that has to change. I’ve got to stop and take the time to have those, you know, little, I don’t know, meals you want to call them, snacks, whatever.

He continued by discussing the impact of medications on his daily life:

So I’m taking that now (medications). There’s a gang of pills. A gang of pills. And I’m not a gang of pill taker.

*Lenny* reflected on his diagnosis of diabetes, sharing gender and generational perspectives and their meaning for him:
And, you know, part of this is, you know, you’re a male, you’re a baby boomer, we’re indestructible, you know. Not too long ago, as you are well aware, males didn’t go to doctors. It just didn’t work that way….So with that going on, we still have this, you know, wait a minute, it can’t happen to me. You know, there’s no diabetes in my family. That test has got to be wrong. So, you know. And again, the other part of this is, you go with the baby boomer attitude here. We’re – although I wasn’t there. We’re still Woodstock time here, you know. And we’re not 62 years old, having these difficulties popping up.

Debbie described her reality shift after an appointment with an endocrinologist:

I think what I was disappointed was, with her, was that she put me on Glucophage – on Glumetza, and I think that I’ve been doing this for so long now that I was hoping there was going to be a miracle of some sort. I don’t know what miracle I’m thinking of, but I think because I struggle with my weight and that’s all because of everything, and stress – stress plays a big thing on all that – I was hoping that she was going to be just the one that was going to say, here is this and you’re going to take this and everything is all going to be back to normal. And that didn’t happen. She just put me on another medicine. Now, granted, I’m happy about that medicine because it’s definitely better, but I was still waiting for something that was going to be better and I don’t really know what that would have been. Just my mind, I guess, had me set on something. It was kind of disappointing (voice lower), to say the least.

Later Debbie continued to express a hope to return to “normal” or her pre-diabetes diagnosis state and her disappointment with the outcome of the appointment:
I’m not – I’m not at that point where I can tell you that I hate diabetes, because it’s not affected me where I am disabled from it or – I’m still at a lower stage as opposed – because it’s just been diagnosed. Am I annoyed that I have it? Yes. Extremely. If I could lose the weight and figure out how to try to get rid of it, I would do it in a heartbeat, because I don’t want to have it. Genetics – genetics are a fabulous thing and can be the worst thing ever, depending on how you’re dealt those cards. I have a lot of different things on both family sides that it’s a crap shoot. God knows what I will have in another 20 years because that’s just the way it is. So should I sit here and cry about it? No. I have to be that type of person that’s going to try and move forward and I’m always the one that sees the cup as half-full as opposed to half-empty, so I need to – my mind and my body don’t always work with me the way I want it to, but in my mind I want to be proactive and try to make it work and take it so I can get rid of it. My body, on the other hand, dictates it otherwise. So that’s where the frustration comes and why I can be annoyed (her voice gets louder) with having diabetes, not so much angry with it. Just annoyed.

Martin reflected on his overall state of health, and described being low on energy, tired, experiencing a decreased activity tolerance, and the reality of his current state:

Well, you know, to get myself back to where I should be. Anywhere close to it. Probably I’ll never get back to where I really, really was. Maybe a couple years ago or a year ago. I would just like to get close. And that’s my biggest thing (sigh). And, like everybody tells me that I should be thankful that I didn’t have
anything else. Like, I was going through life that I never had to go to the doctor for, is what everybody tells me. And this, they tell me, is nothing compared to what it could be, or whatever it is, just now that I sort of got to watch myself. That’s, I would say, the biggest thing (voice trailed off).

*Martin’s* comments suggested his coming around to accept this change but at the same time hoping for improvement. Later he discussed diabetes education classes and his desire to learn how to “fix” this (diabetes):

> You want to know how to fix it, not how it started. You want to know how to fix it. Not how it started or what happened in your body that – because, you know, even like today. They more or less say it’s because I’ve gotten older. My body changes. That’s more or less why I have this. It’s – I don’t think I did anything wrong that I got this. I, or, you know, abused my body. It’s just that as you get older, things wear out and this is probably what happened. Things wore out or it didn’t work as properly. And so consequently this is what happened, and so now all I want to do is fix it (laughter) – to a degree. I really don’t care how it started.

*Karen* reflected on the reality that her current exercise routine was less effective than she thought, and on her current state of limbo and the need to gather more information and to move forward:

> Online I’ve also looked at, like, exercising, cycling, see how much – with a class it was a very eye-opening experience to see that what I was walking was only considered moderate, on the lower end of moderate, then to burn a lot more calories than that. So that was surprising….But that’s really about it. I feel like
Karen also discussed the potential complications of her diagnosis, the impact on her children, and the realities embedded in the diagnosis of diabetes for her:

I’m not looking at it as a death sentence. I know there’s a lot of things that can happen with having a disease and having, you know, I’ve seen people who lose their limbs because of diabetes and the neuropathies, and you know, the heart disease and blood pressure. I’m 44 years old. Like I said, I have an almost 8-year-old and a 10-year-old. I need to be around a long time.

Diane reflected on her overall well-being, the impact of diabetes on her daily life, and, for her, the reality of her level of energy:

And, so, you know, I don’t hardly ever plan anything ahead anymore. If someone invites me to something, I’ll say I’ll try to come but I can’t promise. I don’t know how I’m going to feel that day. Some days I’m very tired. Some days it’s like, get up and move around. You’ve got to move around, you can’t just lay around, your blood sugars will go up just laying around. I’m sure the medicine will help so much, but you’ve got to help yourself, as well.

Later she discussed the need for additional educational information to assist with incorporating dietary changes into her life:

I understand that there will be times that if I’m going to a party or if I’m going out to dinner, but I’ve got to learn how to eyeball size portions, be smart about what I eat, you know? And that’s what I want to know. You know, so that’s why I’m really looking forward to tomorrow (next diabetes education class).
Jane reflected on her blood glucose levels, sharing that a friend told her not to worry about her levels (blood glucose initially 143 then 133), then stated:

Yeah, but it’s not that I’m worried or anything, but I’m not that I’m going to fool around with it either, you know?

Later Jane discussed her sister’s recent passing, which she believes was due to complications of diabetes:

So, like I said, I don’t know really if it was diabetes, but I’m not going to fool around with it either.

Jane appeared to move between not accepting her diagnosis and the reality that her sister may have passed away due to diabetes, which she felt could foretell her own future. The memory of her sister’s death also seemed to motivate her to work on her own self-care.

Thus, Cathy discussed her challenge to move forward with caring for her diabetes despite her depression:

Well, I want to change, like, my eating habits and stuff and that, but sometimes it hard with the depression and everything, you know. Until I get my medicine and stuff on the right track, you know, for that, I don’t think that helps, either.

Carol described her challenges with managing her diabetes because of her work responsibilities:

I think it’s very – um — because I’m still working full time and I’m the director of administration here – so that’s a very big stress – for me, it’s a very stressful job. It’s very time consuming, and with my other medical stuff that’s going on, it just takes a lot of time and energy that I don’t have (emphasized). I feel like it’s really frustrating, because it’s like a catch-22. If I felt better, I could do a better job of
taking care of myself, but I feel like crap. Sorry. Most of the time. And the fatigue is phenomenal. So to spend the weekend – I spend the weekends recuperating.

Later she discussed her lack of energy and the impact it had on her dietary planning. She also revealed the deterioration in her health:

So I just – I need – I want the time and the energy to sit down and plan a reasonable diet and a reasonable menu plan that makes sense and I can’t – I just don’t have the emotional energy or the physical energy to do that right now. So I feel like it’s catch-22. If I have more time and energy, I would use that time and energy to do things to feel better, but I don’t feel well enough to get there to do that, and maybe that’s – and sometimes I feel like that’s a cop-out, but sometimes that’s just the reality. I do recognize that it’s a reality. And in the last year, I really can tell I feel much worse. My health has deteriorated in the last year.

It is interesting to note that Carol’s time since diagnosis (5 years) was the longest of the 10 participants. During the interview she revealed that she continues to struggle with fitting self-care into her life and taking action to manage her diabetes in a consistent way.

When Moving on: Movement toward a new reality, the participants in this study described self-care activities they incorporated into their daily lives or plans for such activities, a shift in their roles or a recognizable change in their health status since diagnosis.

Moving On: Choosing Action Versus Inaction

The participants discussed the choices they made to incorporate self-care components or not to follow self-care recommendations, as well as plans to make changes. During their interviews, they stated whether or not they took medications,
monitored their glucose, or followed the recommended dietary changes. The following statements illustrate the theme and element *Moving on: Choosing action versus inaction*.

*Pam* talked about her internal struggle with insulin injections, medication, and dietary management:

I just don’t want to do it. If I have company or I’m out in public and there’s no place to discretely do an injection, then I won’t do it. That’s pretty much what my day is about. Actually they gave us a list of places (for dietary information) that we could go, so yes, I intend to, because I know that if I don’t address it now (voice gets louder) that I’m going to be back into risk and put myself back in risk.

What I do have to do is start adamantly incorporating carbohydrates, and I think that’s the biggest struggle for me, carbohydrates. ….So I don’t know.

Willingness is the key.

During her interview *Pam* described her “struggles” with trying to follow dietary and medication recommendations.

*Sally* reflected on the challenge of being a healthcare provider and a patient coupled with the assumptions by healthcare providers regarding her understanding of diabetes and her need for more diabetes information from her providers. She then discussed diabetes education classes:

I know that they have classes or something. I could go to that. I haven’t made too much of an effort.
So I think I’m keeping track of my blood sugars. That’s good, because I normally wouldn’t be one to do something like that. Probably making the food available is the best thing.

She also discussed family and needing to follow recommendations to manage her diabetes for the sake of her grandchildren:

He’s (grandson) very good with everything, you know. And I love them and I really want to be with them forever. So I have to do this.

*Lenny* described going on the internet to get information about medication side effects and blood glucose levels, but at the same not reading materials sent to his home:

I did my research on the internet for side effects of the metformin….Other than going on the internet and seeing the blood sugar level should be about 110. I don’t – I can’t sit here and tell you that I have had – now, I will also tell you that the health coach sent information and that I haven’t opened up the envelope yet. There’s a very good possibility that there’s information in there that would be useful and I haven’t read it yet.

Later he discussed his glucometer use and his choice to leave it at home on work days.

And I guess I should probably carry that thing (glucometer) around with me. She (diabetes educator) had mentioned it when we were talking about whatever, and that would probably be a good move. I guess, you know, something else could be going on, your blood sugar’s fine, if you’re able to check it and you’re all the sudden dizzy, lightheaded and something’s going on, and you check your blood sugar and it’s fine. Well, there’s something else going on, (Lenny), you know? But again, should probably carry it, but again –
Lenny works in sales and drives many miles each day. During the interview he described an episode that he believed was a hypoglycemic reaction, although he said that he does carry a bottle of apple juice in the car on most days for such occasions.

Debbie described books and pamphlets she has read about diabetes and the influence on her approach to self-care. Later she spoke about diabetes as a “journey” and her choices to take action or not:

Yes, because like I had said earlier, some things have scared the heck out of me from reading it and that’s what’s motivated me to pay attention better. Now that doesn’t say that I’m not going to go and have a candy bar in my pocketbook. But (voice gets louder) I know that I can’t have that every week or every day. And it’s probably going to continue to be a crazy journey until it’s all done or until I have a set thing that I think I’ll be able to handle. And, you know, there’s always curve balls thrown into it, so I’m anticipating that. But being able to – being able to have people to talk to and things be said and understand them and being able to ask questions and being able to – that’s what motivates me to keep trying to figure it all out.

Sometimes we’re our own worst enemies. I say that for myself. I’m my own worst enemy. I know I shouldn’t have that hot chocolate or that fabulous Starbucks coffee with all regular sugar, but I do and then I’m mad at myself that I do it.

Although she views herself as her “worst enemy” Debbie also sees herself as a cheerleader. She revealed that she has coordinated her providers and care to limit fragmentation and improve her health outcomes:
And my primary is my fertility doctor’s neighbor, so I mean, it’s a whole – but, you know, that’s how you – I orchestrated that because I wanted them to all be able to help me get better.

She takes an active role in self-care and care coordination.

*Martin* shared his choices to take action related to food and his difficulty with his frustration and impatience with his diet and glucose monitoring needs:

But they keep on you and I have to just watch myself. I guess candy – candy’s sort of – I gotta watch as far as candy goes. Baked stuff. Cakes and cookies. Whatever have you. This is a bad time of the year (the holiday season). Yeah. It’s a difficult time right – and yeah. You know, it’s – I think it’s frustration, or I don’t have patience. I just don’t have the patience. I often told my wife that she needs patience. Well, right now I think I need patience and that’s the biggest thing. That I need patience (voice trailed off).

She (*Martin’s* wife) more or less says I should take my sugars at more even now – especially now since the doctor told me that I only needed to take them five times a week. Why she gets on me that I need to take them more often. I sort of renege on them, maybe a little bit...So if I have to take them every now and then or every couple of days and they’re within range now. If they were out of whack (voice gets louder)– if they were out of whack, which I could – I mean, really out of whack, there’s no question I would, right away I would start taking them more often and see. Couldn’t get them down. Because I know (emphasized) that I need to keep these things down. I really do. I know (emphasized) that I need to keep my sugar levels down. And if I can – and, you know, if every time I take it and I...
feel, if within a respectable range. And once they would get up to past 170, I would say that’s a non – that would be no good and I would absolutely do something differently. I would try (emphasized) to get these things down, because I know now that I need (emphasized) to do this.

*Martin* revealed that using his blood glucose results was a means of making self-care decisions.

*Karen* also discussed her efforts to take action to control her food choices and exercise in order to lose weight:

I’ve cut down a lot (emphasized) on what I’m eating. With the two boys, I notice – you know, you sit back and see what you’ve been eating….I’m active, but I’m more active behind the wheel than I am physically and we run through, you know, McDonalds or Burger King or that, and I find myself eating too much on the go and we need to change that, even for them, to give them better eating habits.

She (primary care physician) wants me to try diet. She is very realistic. She only wants me to lose, like, 10 to 15 pounds till I see her next, and I’m trying very hard. It just seems like it doesn’t come off as quickly as it goes on (chuckle). So I’m walking. I try to walk at least five mornings in a week on the treadmill. And I’m watching what I eat. I’m very conscious of what I’m eating and that. But sometimes you get a craving and I’m putting more stuff in my mouth than what I should be.

*Diane* reorganized her kitchen to foster her portion control and is planning to begin an exercise program:
And I have my measuring cups hanging right there on that hook, so they’re not even in the drawer. You know, so I just — No, I just put them there. I put them there. I had them in the drawer. It’s like, no. They’re right there, all the time now. And I use them.

You know, so that’s why the measuring cups are hanging, you know? Because otherwise, if they’re not there and they’re not handy, I know me. I won’t use them. You know? And I like Cheerios. I would fill up a whole dish instead of being smart about it, and then wonder why everything’s sky-high.

You know, so I’m definitely eating healthier. That I am doing. And I feel better. I really do feel better. It’s just, I’ve got to get this weight off. You know, so I have to be more active. So, like I said, tomorrow I call and get that interview set up to start going up to the (nursing home) to start working out up there. So I’m looking forward to that, because then I’ll be meeting people up there, and in the summer time they walk outside up there.

*Jane* shared taking action through dietary changes she had incorporated since her diagnosis and plans for exercise:

Well, I watch my carbohydrates more. I didn’t really start exercising that much because of the cold weather. I don’t like going out in the cold. (laughter) But, you know, the only thing is, I watch my carbohydrates at work, because there isn’t much I can do there.

The insurance – I think it (insurance) covers a little bit (exercise class), but I’m not sure, you know, how much. You know, I think there is a program. I didn’t
check into that. I think I’ll do more after I go to the class and learn more, you know?

_Cathy_ discussed her food choices:

But still a lot of the stuff doesn’t help too much because I overeat and stuff like that, which I shouldn’t be doing. Instead of eating smaller meals and stuff, you know, which don’t help it.

Well, I know sometimes they say eat smaller meals, but the nutrition stuff I’m a little –like, you know, preparing it and stuff, I’m not good at stuff like that. I mean, I know how to cook and everything, but, you know, to do stuff like, for my diabetes, that’s what’s the hard part for me.

During her interview _Cathy_ revealed that an insurance company representative called her, but she was unable to follow up because there were no minutes left on her cell phone:

So it might have been her, because she was supposed to call me every so often to see how I’m doing with my diabetes and stuff like that. She’s going to also work with my doctors to see if the medicines are doing the right job for me, you know, with the diabetes and stuff like that, to help me get it under control better and stuff.

_Cathy_ also indicated her plans to contact the insurance representative and work on setting up diabetes care and services.

_Carol_ shared her difficulty with maintaining her medication schedule and her challenges with meal planning:

Well, I have to remember the injections and I am very good at remembering the morning and evening injections, the Levemir. I’m not as compliant with the
Humalog that I have to take just before meals. Some of that is, I do forget periodically. Even at dinnertime, at home. It’s right on the table, right next to me, and I’ll get halfway through my meal and remember I didn’t take it just before I ate, so I take it then. I figure it’s better late than never. But I am not (emphasized) compliant with time. Like, I’m not a regimented person, so sometimes – and with my other health conditions, going up and down stairs is difficult, and so I live in a two-story house.

I keep saying that when I retire what I want to do is literally write a cookbook that gives you, like, eight weeks worth of menus, daily menus that are all measured out, and have with them shopping lists. Because every time you see – if you ever look at a diet plan, very often – if they give you the menus, it will say, well today for breakfast have an English muffin and an egg and some fruit, and then tomorrow you have this, and then the next day you have this and that. And you probably don’t have an English muffin anymore for the rest of the week. Well, who the heck shops like that? You know? You’ve got to have something – if I buy a thing of English muffins, they’ve got to be gone pretty much by the end of the week. So, or freeze half of them and use the half of them the next time or something. But you can’t put together, you know, half a cup of blueberries this morning and you don’t have any for the rest of the week. What? You’re supposed to throw them away?

During her interview Carol revealed that her provider discussed bariatric (weight-loss) surgery as an option. She is resistant to this option:
So it’s – you know, it’s the Nike commercial. Just do it. Either I’m going to do it (lose weight) on my own or it’s not going to happen is what it comes down to. So. *Carol* investigated the bariatric surgery with her insurance company and discovered that the procedure is not covered by her policy. This knowledge reinforced her philosophy of self-care for weight and diabetes management. She has continued her dietary regimen and acknowledged the potential positive or negative impact of even one dietary change:

And that’s the part that I think is so frustrating, is like, and that’s what I say to my doctor. I’m not a stupid person. And I’m not an uneducated person. I have educated myself about what I need to be doing. But making myself (emphasized) do what I’m supposed to be doing is a whole different ballgame. Frustrating. It’s just really frustrating.

*Carol* discussed her strategy for making a successful dietary change to lose weight:

And basically, pick one thing. And that’s kind of what I do. When I’m trying to do it, when I’m trying to take care of myself, I will pick one thing to get rid of out of my diet, and it’s usually soda. Because that’s the – that’s where I consume the most sugar calories the fastest, you know, so I will – and I realized last summer I was drinking the sweet tea from McDonalds. I like sweet tea, OK. Well, my assistant [at work] and I were talking one day and I said something about, you know what, I have gained two or three pounds in the last two weeks. And she said something about it. And then we started talking and she had gained a couple of pounds. And we were both drinking sweet tea. So we both stopped and almost immediately most of the weight came back off, you know? So pick one thing and cut that out of your diet. And if you can cut it out – because I can go without for a
while, and then if I have it, it’s almost like a trigger and then I want it more. You know, like the soda, especially. I can cut it out for weeks at a time and then I’ll have one and then it’s like, oh, I had one, I can have another one, kind of thing.

Among the participants, conscious decisions or choices about taking part in recommended self-care were the focus of this theme and key thematic element of Moving on: Choosing action versus inaction.

**Moving On: Achieving a New Level of Awareness**

The theme and key thematic element *Moving on: Achieving a new level of awareness* encompasses future plans the participants have made for dealing with their diabetes, and “I” statements in this regard. In some cases their statements revealed a self-actualization of sorts. Some participants processed information and made sense of their diagnosis during the course of the interview; others moved back and forth about it throughout the interview. This theme and element was evident to some degree in all the participants, because some their statements revealed ownership of the diagnosis, whereas for others it involved an awareness of their future with a diabetes diagnosis. Pam’s statement illustrates this theme and element:

> The useful information is, I can live with diabetes and function very well (voice gets louder). It’s how I perceive it and what am I willing to do to stay or follow the directions so I don’t get the complications that come with diabetes.

Her mother had suffered from complications of the disease, which eventually contributed to her death. In Pam’s view, her mother had not done well managing the disease. But Pam appeared to realize that she does not have to have her mother’s
outcome, as there are other options or potential outcomes for herself. *Pam* acknowledged a back-and-forth or give-and-take type of experience:

The most important thing is to keep an open mind. Don’t see it as a hopeless situation. It’s treatable and you can live with it and I haven’t gotten there, but you can live a happy life with it if you follow directions. If you’re willing – and, see, following directions and eating portion sizes, that’s something you have to surrender that you have to do for the rest of your life. It’s doable; you just have to be willing to be able to do it. That’s the most important thing, your willingness. Because if you’re not willing, you’re not going to take your medicine, you’re not going to follow a diet, you’re going to wind up with all the complications and make yourself miserable. In the beginning it tends to be a lot and it tends to be overwhelming and you have to take each day individually. My willingness is there and I fluctuate back and forth with it. Right now I fluctuate back and forth with it. I know it’s doable.

*Pam* spoke about her “willingness” to “surrender” to lifelong self-care.

*Sally* revealed her lack of choices over her lifetime with a diabetes diagnosis as another example:

…..because I always wished I had (gone to nursing school), but I didn’t want to because I had no other choice. And that’s always kind of been the main theme of stuff. And now here I am again. You know, I’m doing this because I have no choice. I’m just tired of that – you know theme (voice trails off). And I wonder – I mean, I know enough that if I would do some things I wouldn’t run into some of
these situations. Like, I couldn’t have avoided my husband being killed, but I
could have not had diabetes.

She continued, sharing her emotional response to her diagnosis:

But I just – you know, I’m just sick of – I’m sick of having to worry about all this
stuff. So this has been really – exhausting doesn’t even cover it. I just can’t stand
the thought of having this diabetes (voice trailed off). But then there are children
who have it.

*Lenny* made a comparison to his cardiac history and a cardiac stenting procedure
and the lifelong nature of diabetes:

At least in my mind, with being diagnosed and now realizing that this isn’t
something I can just fix tomorrow. This is going to go on forever. And that part of
it is not a good thing.

He is 62 years old, working in a second career after displacement from his prior job. He
is concerned about health insurance and self-care expenses:

And, you know, in all honesty, I’m hoping this company lets me work until I’m
70 because God only knows that I need it. But one of the other things that I need
to get educated on is what goes on with Medicare and Medicaid moving forward.
OK, now I’ve got this affliction, and later on, when I need things, what’s going to
go on? You know? I also would like to be able to put food on the table and, you
know, just a lot of stuff…if the company gets rid of me, then I’ve got to pay
health coverage and do this and do that, you know. Just, you know. It will all pass
though. So.
Lenny expresses uncertainty about his future with diabetes, especially in regard to health insurance coverage. Debbie spoke about being unable to “fix” her diabetes and her future:

I mean, I have it (diabetes), so there’s nothing I can do. I can’t control the fact that I got it. I have to learn how to fix it to the point, if I can or cannot. And that’s another thing that I think I’m going to struggle with, because if I can’t fix it, then what? I haven’t really thought that far out, to be honest, on what will be in the next five or 10 years, but, you know, I do know that I’m getting close to 40, so things in my body are already going to have started to change. That will play another role on how it all goes. But, you know, ultimately, when I’m 70 years old, I need to figure out what’s happening now, so that way when I’m 70 I’m not struggling either. So, you know, health goals are probably a good way to put it. Trying to have better health goals and see how it is – not so much of – it’s not like personal, but it’s also – well, I guess it is personal, but it’s also, what’s going to happen in 30 years with our economy and money and health insurance?

Similar to Lenny, Debbie expressed concern about having health insurance in the future. Debbie continued:

And granted, I have cried. I’ve been emotional about it, but crying’s not going to get you to get it done. It’s not going to – it’s going to make me feel better for a minute and it’s definitely a good thing to do, but if I don’t sit back and realize what I need to fix, so I’ll have a conversation with her (co-worker). You really need to try to focus on being your own cheerleader….And I’m like, talk to me whenever you want to, you know? And so she’ll come over and talk to me about it, but she still cries. Because she looks at it as half empty and she wants to have a
baby. And granted, I get it. Trust me, I totally get it. But on the flip side, you know, there’s reasons for everything, and you’ve got to go with the flow and try to get yourself healthy and try to – you know, if you don’t get yourself healthy, then what?

Debbie also spoke about taking care of one’s self and trying to get healthy and helping a co-worker to accomplish the same outcomes. Martin spoke about provider follow-up and monitoring in the future:

I mean, he’s going to keep an eye on me. He told me. He as much as told me. He says, I’m going to keep an eye on you, OK (voice gets louder)? So I know it’s going to be at least every six months. But this time we’ll go with four months and then we’ll go from there. And I know he’s going to keep an eye on me. He more or less said it right off the bat. Yeah.

Karen reflected on the health of her family, especially the health of her sons when looking to the future:

And I just want to make sure that my boys stay in a healthy lifestyle and look out for my husband as well as my mom.

Karen’s mother has T2DM and her husband was diagnosed with “pre-diabetes.”

Karen looked at her future this way:

I just wish it was four weeks from now, that I have all (emphasized) the pieces together. Then maybe I can see some progress in my weight loss or, you know, when you walk four miles a day and you don’t see the scale coming down, there’s something I’m doing wrong. Because I know I’m definitely eating less than what
I was before. I’m probably just not eating the right things in the right times. I’ll call you (the researcher) in four weeks.

And I know all that I need to do, it’s just having to get from point A to point B, and it’s a hard road (emphasized).

Karen’s current treatment consists of diet, exercise, and glucometry. She reflected about the possible transition to medication:

Just be positive. There’s always a way. Like I said, my goal is not to go on medication. If I do go on medication I’m not going to look at it as a failure. It’s to help me. And just because I go on doesn’t mean I can’t come off. And that’s one way. The way my sugars are running, I’m becoming realistic that I’m probably going to end up on medication. I don’t know why my fastings aren’t running higher. That’s why I’d like to sit down with the dietician. I’m positive. Any step that it comes. If I end up on the medication, I know I can get off of it, and if I can, it’s for a reason. I just have to start thinking I need to be healthy, I need to be healthy. And (son 1) and (son 2) are my reasons. And my husband, too (chuckles).

According to Karen, the transition to medication is a possibility. Diane shared her perspective on managing her diabetes:

(You need to…) become as knowledgeable about it as you can. You know, even though I am afraid of it because I know what it can do, but I’d tell someone don’t be afraid of it, learn everything you can about it and how to control it. You know?

And if your numbers are high, look at it as falling off the wagon. If you go out to eat or something and you’re at a place where they really don’t have things that you really should eat – you go to a rib house or something like that with all these
sauces that are sweet and that, just be smart about what you eat. Realize that your sugars are going to be up and you’ve got to work on bringing them back down.

Later Diane spoke about the lifelong nature of diabetes, and similar to other participants, the inability to fix this condition:

But work at it. It’s a never-ending project now. It’s a constant. It’s not something that you can take a pill for and it’s going to be fixed. It’s something that you have to be aware of day in and day out, and I am. And I’m not depressed about it. And I’m not even angry about it, because I’ve seen it. You know, so I know what it is. I think if I wouldn’t know what it is and all that, I think I would be really angry and depressed and, oh, I’m gonna die. I’m just not that type. It’s like, everyone says with all my ailments and everything I’ve gone through in the past – well, since I’m 40, they’ve said how – you’re such a strong-willed person. I said, ‘Well, what else can you do?’

Diane shared waiting to see what the results of future blood work would show:

So we’ll see. See how it goes. But I’m kind of anxious when they do my next A1C to see what it is. I’m really excited about that because I really am trying hard, you know. And it really isn’t a pain or hard to do (emphasized). I thought it would be a lot harder than what it is. And it really isn’t.

Jane also spoke about her future with diabetes:

I mean, I’m concerned but I’m not worried. I don’t know, you know what I mean? I’m not going to let it take a hold of me. Is that what I’m saying? Yeah. But I respect it (voice gets louder, then laughs).

Similar to Karen, Cathy spoke about her child when considering her future with diabetes:
Well, I’m trying to handle it better because of my daughter. You know, because of supporting her and to be there longer for her and stuff, too, you know.

*Carol* reflected on her health conditions of fibromyalgia, elevated cholesterol, and diabetes:

….I can’t – because I can’t retire. I’m not in a position where I can retire. I have to work. And I can’t work when I feel like that, in that much pain. You know, I just – so, you know. (hesitation). It’s, you know, again, a catch-22, where you’re between a rock and a hard place or whatever cliché you want to use. This is the reality of it. So at some point, if I do get to the point where I can spend more time taking care of me, maybe I will extend my life. But do I see me living 14 years longer than my mom, to 90? No. You know, the – I just – the reality – even though we have better medicines now. Like, I think my mom lived as long as she did because there were – she had the blood pressure meds that my grandmother didn’t have.

During the course of her interview, *Carol* (64 years old) shared that if she could stop working or retire, she would have time to care for herself. But at this time, because of finances and insurance, she cannot stop working. She also discussed her familial history of diabetes and concerns for her daughter:

And I worry about her because of, you know, the genetic predisposition – her getting diabetes. I don’t think my son will. He doesn’t have the tendency to gain weight. He’s usually pretty thin. Well, he’s a little heavy now because he’s not been working out like he should, but I worry about my daughter because it does seem to be following the female line. I mean, this is three generations, you know.
Carol then discussed health insurance and co-pays:

Yeah, no, I recognize that I’m very fortunate, you know, that I do have the insurance. It’s going to enable me to live longer. I mean, if we didn’t have the insurance, the cost of the medications – I mean, if I’m paying $2,000 a year just in co-pays – like I said, I don’t even think about what it would cost without it.

Similar to Lenny, Carol shared concerns about affording self-care and health care in general in the future as both participants are in their 60s.

When Moving on: Achieving a new level of awareness, the participants in this study appeared to make sense of their diagnosis and an aspect of self-care related it. In their statements, some of them revealed ownership of the diagnosis while others were able to see their future as having a diabetes diagnosis.

**Existential Themes When Moving On**

Lived space (spatiality) is a space where a person finds themselves and which can affect how they feel (van Manen, 1990). When Moving on, the participants in this study discussed planning time or space in their lives for getting diabetes information and performing self-care. Excerpts from their interviews revealed both success and struggles with fitting self-care into their daily lives. Further, they described their emotional responses to their diabetes and the resulting lifestyle changes. Moving on involved adapting to diabetes in their lives, which encompassed the reality of accepting the diagnosis, making self-care choices, and being aware of their condition and circumstances now and in the future.

Lived body (corporeality) refers to the physical or one’s bodily presence in the world (van Manen, 1990). As reported in the previous sections, the participants discussed
coming to understand or know their body since their diagnosis. When *Moving on*, they discussed plans for their self-care and self-care activities, which included the use of medications, diet, glucometry, and exercise. They also described responding to and caring for their body in light of their diagnosis, revealing the essence of their lived body experience.

Lived time (temporality) includes dimensions of past, present, and future (van Manen, 1990). This existential theme was evident when the participants changed their verb tense from past to present and future during their interviews. They spoke about care choices today and in the future. Additionally, they spoke about planning to get and learning the information necessary for their self-care. When *Moving on*, the participants also discussed the lifelong nature of diabetes, and what they would do to manage it and face the eventualities that may come with it.

Lived human relation (relationality or communality) includes meeting others in a shared space (van Manen, 1990). When *Moving on*, the participants continued to talk about relationships with family, friends, and co-workers, and their sense of a new community by sharing with other persons diagnosed with diabetes. Several participants spoke about the familial occurrence or tendency towards having diabetes, and concern for the health of their children or grandchildren. There was discussion about improving their personal health and the health of their family and about role changes. Finally, there was conversation about improving their personal health in order to be around or present for future generations. The interviews revolved around the relationships in the lives of the participants.
**Summary of the Findings**

The aim of this study was to enhance the understanding of the experience of becoming a diabetic as reported by several persons learning about new self-care activities and initiating changes in their self-care to control their serum glucose and generally manage their diabetes. The interview questions started with the participants’ diagnosis point, followed by provider self-care recommendations, coming to understand self-care, and changes to their daily life. The analysis of the interview transcripts revealed the essence of the experience of becoming a diabetic for 10 individuals. However, it became apparent that one cannot isolate or understand any individual element without the benefit of hearing the whole story of this experience. The resultant three main themes were: *hearing the news, sorting it out, and moving on*. Key points clustered around the themes and elements that expanded the understanding of this experience.

Movement toward becoming a diabetic is not linear in nature; there are back-and-forth movements to the experience, as suggested by the participants. Additionally, certain aspects of self-care may occur or change at different points. This summary will address the presence of four key aspects of self-care: medications, diet, glucometry, and exercise, which were of concern to the study participants when reflecting on their diabetes and possible complications.

**Self-Care When Becoming a Diabetic**

The following issues of self-care were described by the participants: medication management, dietary management, glucometry, exercise, and complications from diabetes.
**Medication Management**

Nine of the 10 participants were taking medications to manage their diabetes. When *Hearing the news*, one revealed blocking the diagnosis information and choosing not to take medication. This participant started the prescribed medication at a later point after repeated laboratory results. When *Sorting it out*, the participants spoke about having difficulty adhering to the medication schedules, and some talked about the challenges experienced with insulin injections. The participants discussed medication side effects, coordinating blood glucose testing with medications, and observing the medication management of other diabetics. Their plans for the future and medication choices were discussed in *Moving on*. Additionally, the participants spoke about potential medication changes in the future, for example, starting oral medications or injections, or the hope for medication reduction or stoppage.

**Dietary Management**

All of the participants discussed their dietary changes during the interview. Their perceptions of food, weight, and the influence of the diagnosis of diabetes were revealed in *Hearing the news*. However, discussion of food was most prominent in *Sorting it out* and *Moving on*. The participants spoke about previous eating habits, specific dietary changes, and provided examples of carbohydrate counting and reading labels. They commented on the eating habits of other diabetics, offering examples of both good and bad food choices. They also discussed plans for incorporating dietary recommendations and moving forward with doing so. *Carol* shared her dietary challenge comparing it to alcohol addiction:
You know, she said maybe work with a nutritionist, but you know, I’ve been around it and, I mean, I’ve been around people with diabetes my whole life. I know what I should and shouldn’t be eating. I don’t know. And maybe it’s a cop-out, but I also think about, like, people who are – and I’ve said this to a friend before who was working with alcoholism (pause). I said, one, you cannot do alcohol and all you have to remember is just don’t do alcohol for an addiction. You drive down the road between your house and work, you’re not passing 30 or 40 restaurants, drive-throughs, grocery stores, Quick Marts where you can buy alcohol. If you want alcohol, you’ve got to go to a beer distributor or you’ve got to go to the liquor store. They’re not even open on Sundays. Now, bars are. Yes. You can go to the bar on Sunday. But there aren’t as many of those. It’s – I don’t know.

This excerpt reveals the pervasiveness of food and diet planning for the diabetic. The participants spoke about the social nature of food, for example, its presence at family, work, and social events. Pam shared one such example:

But I go out to eat – I go out to eat once a week or every two weeks and that’s how – that’s my reward to myself. I vaguely go out to eat at least once a week. I usually don’t cook on a Friday.

The participants essentially revealed that food and dietary challenges are present everywhere, and that they make many decisions about food during the course of the day. In essence, food and dietary challenges are a constant. Given the lifelong nature of diabetes for many participants, dietary management was generally viewed as overwhelming.
**Glucometry**

Glucometry was discussed in *Sorting it out* and *Moving on*. For several participants this was a difficult skill to master, but once mastered, the next challenge was coordination of blood sugar readings with meals and medication. Some continued to struggle with developing this skill. Glucometry was also viewed as an important information source; for example, this was a source of feedback regarding food choices, and for monitoring response to exercise, illness, or stress. The participants shared making choices to increase or decrease glucometry frequency based on judgments about their progress and overall state of health.

**Exercise**

Exercise was discussed in *Sorting it out* and *Moving on*. One participant (*Karen*) was actively engaged in regular exercise while the remaining participants discussed provider recommendations for it. The participants discussed road blocks to exercise such as weather (interviews were conducted in late November through mid-February), or lack of equipment or access to an exercise facility or classes. Work schedule and health status (obesity, arthritis, low energy level, mobility challenges) were also discussed as obstacles to exercise. Two participants discussed formal plans for accessing classes and planned to incorporate regular exercise into their self-care in the future.

**Participants’ View of the Risk of Complications**

Potential complications of diabetes were discussed during the interviews, and the participants were well aware of them. Fear of potential complications was revealed in all the themes. Some participants appeared to have visual images or graphic pictures of persons suffering from complications of uncontrolled diabetes, often those of relatives.
Images and fears arose when *Hearing the news* of their own diagnosis. In some participants, seeking treatment or confirming their diagnosis was delayed despite the presence of these images. Preventing complications was verbalized in *Sorting it out* and *Moving on*. They recognized that self-care choices directly influence the prevention or risk of complications. They also shared their hopes to prevent their own complications in continued efforts to work, enjoy interactions with family and friends, and to read in order to be informed about managing the disease. The risk of complications was in both the forefront and the background for most of the participants.

**Existential Themes When Becoming a Diabetic**

The existential themes emphasized by van Manen (1990) were evident throughout the participant interviews about their experience of becoming a diabetic. Lived space (spatiality) was revealed when the participants discussed finding space in their lives for diabetes or making room for it. They also described the spaces or places of their diagnosis and where they were provided self-care. Diabetes is a medical condition intertwined with a lived body (corporality) experience, and the participants in this study provided clear examples of this reality. From their descriptions, it was found that persons with diabetes experience symptoms both when well and when ill, and that they also experience unique physical sensations related to the use of medications, food, diet, and exercise. To effectively manage diabetes self-care, the person must become attuned to their body which serves as a guide for this experience.

Lived time (temporality) is considered to be an integral part of diabetes and self-care, and the participants’ statements supported this notion. Similar to space, it was found that the diabetic needs to find time in their life for dealing with the disease and self-care.
Managing time is a significant component of diabetes self-care, since there are important schedules for medications and glucometry testing, and food intake is “timed” to coincide with taking medications to maximize intended actions and prevent side effects. In some cases, diabetes was viewed as a lifelong experience encompassing the past, present, and future. Lived human relations (relationality or communality) also had an influence on the experience of becoming a diabetic, as was evident when the participants spoke about the other persons in their lives. The others sometimes served as examples of diabetes management. Sometimes these others were family members, including preceding generations who had been diagnosed with diabetes, or future generations whom they hoped would not get the disease. Still others were the numerous healthcare providers the participant encountered and other persons with diabetes who became a support network that shared their experience and advice with them once they were diagnosed. The participants also revealed roles that evolved during the experience of becoming a diabetic and role changes. Therefore, the existential themes described by van Manen (1990) emerged from the analysis of the participants’ experiences of becoming a diabetic during the interview process.

**Individual Meanings When Becoming a Diabetic**

Reflecting on the participants and the stories they shared allowed the researcher to consider their placement or location in light of the themes and key thematic elements that emerged from their interviews. Even though most of the themes and key thematic elements just discussed were present during the individual interviews, there was a transition or prominent theme for each participant as follows.
Pam (3 months since diagnosis) appeared to process the diagnosis of diabetes during the course of the interview, and essentially stated that she can manage her diabetes and not be like her mother and suffer from complications of the disease that led to death. Pam recognized the need for continued work on self-care, hoping to avoid the same outcome as her mother’s. Pam was moving between Sorting out and Moving on.

Sally (1 month since diagnosis, emergency admission) shared her experiences at diagnosis and her efforts at self-care. She spent considerable time reflecting on the past and the impact on the diagnosis of diabetes. Sally was in the process of moving from Hearing the news to Sorting it out.

Lenny (4 months since diagnosis) related his initial response of blocking the diagnosis of diabetes and his delay in initiating self-care. At the time of the interview he was participating in some aspects of self-care and discussing plans to do so in the future. Lenny was bridging between Sorting it out and Moving on.

Debbie (17 months since diagnosis) was actively engaged in self-care behaviors, and in her view, “partnering” with her healthcare providers to maximize her care. While realistic and accepting of the diabetes diagnosis, she was hoping for a return to “normal” and her pre-diabetes state. During the course of the interview she acknowledged the possibility that she may need to continue with medication for the treatment of her diabetes and discussed her plans to optimize self-care. Debbie seemed to transition to Moving on.

Martin (3 months since diagnosis) revealed that he delayed seeking diagnosis despite significant weight loss and continued to question the accuracy of the diagnosis.
With the support of his wife, he was participating in self-care recommendations. *Martin* was transitioning between *Sorting it out* and *Moving on*.

*Karen* (7 months since diagnosis) was actively taking action to improve her health. Despite these efforts she was not achieving the results she envisioned. *Karen’s* current treatment does not include medications, though during the course of the interview she shared her hope to continue her current treatment plan and not require medications. Towards the end of the interview she acknowledged that if medication is added she will actively continue self-care. *Karen* was transitioning from *Sorting it out* to *Moving on*.

*Diane* (3.5 weeks since diagnosis, emergency admission) was actively taking action to improve her health. She was immersed in *Sorting it out* and attending to self-care. It is important to bear in mind that she has experience with chronic illness and has been diagnosed with vascular disease which has affected multiple body systems. *Diane* already appeared to have transitioned to *Moving on*. Given her recent diagnosis one wonders if this transition was due to her experience with chronic conditions or her perception of the nature of diabetes when compared to vascular disease.

*Jane* (2 months since diagnosis) was actively involved in self-care and gathering information and resources about diabetes. Despite this high level of engagement she seemed to doubt the diagnosis of her diabetes. *Jane* appeared to consider the implications for herself of the recent passing of her sister, which she perceived was related to complications of diabetes as she processed her own diagnosis. In some ways her sister’s death seemed motivation for self-care. *Jane* was transitioning between *Hearing the news* and *Sorting it out*. 

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Cathy (18 months since diagnosis) was focusing on the barriers she perceived to self-care. She was having difficulty establishing and maintaining a relationship with a consistent healthcare provider and accessing information about diabetes. Cathy was moving between Sorting it out and Moving on.

Carol (5 years since diagnosis) was focusing on the barriers she perceived to self-care. She has access to information about diabetes and the necessary resources but appeared to view her life situation as limiting. Carol described being in a “catch 22” situation where her energy level and her work impeded her self-care ability. She was not consistently committed to action or taking the necessary steps to manage her diabetes. Carol was moving between Sorting it out and Moving on.

The participants’ revelations of their lived experience of diabetes were summarized in this manner to facilitate understanding their unique experience of becoming a diabetic. The participant summary provides a framework for considering recommendations for developing interventions and education for diabetes in Chapter 5.

Shared Meaning of the Lived Experience of Becoming a Diabetic

The themes uncovered through the analysis of the transcript data for this study revealed the shared meaning of the experience of being diagnosed diabetic. The three themes that emerged as the primary structures of this lived experience were: (a) hearing the news, (b) sorting it out, and (c) moving on. All the participants in this study (with the exception of Cathy on hearing her news) shared similar experiences surrounding these themes. The disruptive nature of diabetes on daily life was common for the participants. Each component of self-care was challenging to some degree for the participants. These revolved around mastering a skill, e.g., glucometry or insulin injections, then
coordinating the timing of the intervention with another kind of treatment. The participants’ statements revealed that food and dietary challenges are present everywhere, requiring many decisions during the course of the day about food. In essence, food and dietary challenges are a constant. Given the expectation that their diabetes would be lifelong for most of the participants, dietary management was viewed as overwhelming. Certain emotional responses to their diagnosis of diabetes was shared by most, including fear, depression, anger, and hatred. The common perception among the participants was that diabetes is a lifelong condition which for the most part cannot be “fixed” or cured. Rather it’s a matter of learning to live with it. The future with a diagnosis of diabetes for the most part was viewed as manageable and positive but at the same time challenging.

Conclusion

In this study, the interplay of the experience of becoming a diabetic, and understanding and initiating self-care management was apparent. The diagnosis point or Hearing the news was influenced by efforts both conscious and unconscious on the part of the participants to block the message. They reflected on their past choices and the impact on their diagnosis, or their fear of knowing the diagnosis. For some participants, the fear of the disease and its effects on them prolonged their seeking care or initiating treatment recommendations. In some participants these responses to their diagnosis prevented them from accepting it, which in turn affected their understanding of the disease and initiation of self-care.

When the participants attempted to Sort out their diagnosis, they were also focused on understanding information related to diabetes. They provided examples of understanding the disease by comparing theirs to others. Family members, friends, and
co-workers were identified as sources of information; these examples were presented as both positive and negative sources. The participants identified such sources of information as previous knowledge of the disease, diabetes classes, and cohorts in these classes, print media, internet, radio, family, and friends. They revealed having gained knowledge through monitoring their body; for example, checking blood glucose when noticing symptoms or checking blood glucose after meals and exercise. The participants also spoke about sources of support, which included current options and plans to follow up and seek new opportunities to learn about the disease. Sources of professional support included healthcare providers, dieticians, and diabetes educators. The participants also spoke about revealing their diagnosis and reaching out to family and friends for support.

In most participants, their support was viewed as a positive experience. However, two participants shared their choices related to support that they viewed as a negative influence. One participant spoke about a stress-producing family relationship and the decision to sever ties with this family member. Another shared the choice to change healthcare providers after an appointment she viewed as unsupportive.

*Moving on* encompassed a discussion surrounding incorporating diabetes and the recommended changes into daily life. The participants spoke of their plans for changes and the actual choices they made. Their statements were characterized by increased ownership of their role in treatment and “I” comments, for example:

The useful information is, I can live with diabetes and function very well (voice gets louder). It’s how I perceive it and what am I willing to do to stay or follow the directions so I don’t get the complications that come with diabetes. *(Pam)*
At this point the participants also spoke about the future, which for the most part was described as challenging yet positive. In some, a new level of awareness about the reality of their diagnosis seemed to evolve during the course of the interview. It was as if things came into perspective during the conversation, or the conversation was a means to share and process this experience in a new way.

The participants openly shared components of diabetes self-care throughout their interviews. Medications and self-glucose monitoring were described as challenging for the participants, with some adapting to them faster than others. Food and dietary challenges were discussed by all the participants; yet, while some were able to master the skills of medications and self-glucose monitoring, dietary management was still quite difficult for most. It became apparent that food and dietary challenges were viewed as a constant and overwhelming issue for most participants. Exercise was discussed, with a majority of the participants not actively engaged in it. Some discussed barriers to exercise while others discussed plans for exercising.

The context of this experience is clearly dynamic, individualized, and far more complex than commonly appreciated by healthcare providers. Understanding the complexity of the diabetic’s experience provides a new basis for planning educational interventions with this population.
CHAPTER 5
Discussion

The purpose of this phenomenological study was to enhance the understanding of the lived experience of becoming a diabetic reported by a number of persons recently diagnosed. The interviews focused on the study participants’ sharing of what it meant when they first learned that they had diabetes, the work they did to learn about self-care since their diagnosis, and their overall response to this experience. The discussion of the findings is organized around the three themes that emerged as the primary structure of the experience and the key thematic elements within those themes that were previously reported in Chapter 4. These included: (a) *Hearing the news* (blocking the message, reflecting on the past, and fear of knowing); (b) *Sorting it out* (knowing by comparison with others, working to understand and stay aware, and recognizing support options); and (c) *Moving on* (movement towards a new reality, choosing action versus inaction and achieving a new level of awareness).

The findings of this study were considered in relation to the literature presented in Chapter 2, which is significant because it provides the background knowledge, theories, and research commonly applied to self-care learning and patient education of persons with diabetes and other chronic health problems. This literature review was also significant because it provided evidence of the prior knowledge of the researcher that needed to be set aside to ensure that her understanding truly represented what was actually revealed by the data (interview transcripts) without bias. The focus of the study was not on how learning about diabetes occurs or is accomplished, as reported in previous research, but rather on uncovering the key elements and the context of the
experience through the application of a phenomenological methodology (van Manen, 1990). An improved understanding of the key elements and context of an experience as provided by interpretative phenomenology does not isolate measurable factors, rather it provides a new viewpoint that can make it possible for nurses and other healthcare providers to “act more thoughtfully and tactfully in certain situations” (van Manen, p. 23). The findings of this study therefore provide a fresh view of the patient’s experience when diagnosed with type 2 diabetes that suggests changes in the healthcare provider’s approach that would have the potential to improve the quality of care for these persons.

The findings clarify areas of overlap between previous research and this study along with revealing new information. The implications for nursing practice and education are also reported as well as recommendations for future research. The limitations and strengths of this study are also discussed.

**Hearing the News**

All but one participant readily recalled in detail the point in time of the diagnostic event, *Hearing the news*, and talked about it as a very significant memory. The focus of the participants’ memories on *Hearing the news* (diagnosis) varied but included the thematic elements *Blocking the message; Reflecting on the past* (choices that may or may not have had an impact on the development of their diabetes); and a somewhat pervasive *Fear of knowing* that the diagnosis really applied to them.

The participants’ descriptions of multiple episodes of ignoring or blocking clues that they had diabetes and an overall sense of disbelief that the diagnosis was true suggested they were *Blocking the message*. Costantini, et al. (2008) reported similar findings in a study of the experiences of persons with mild to moderate chronic disease.
who consistently looked for clues to support their medical diagnosis, and maintained denial of the diagnosis when they perceived there was a lack of evidence to support it. Similarly, the participants in this study discussed doubting the laboratory study results reported by their healthcare provider or ignoring physical signs and symptoms of diabetes, although they acknowledged retrospectively that they actually had the necessary knowledge to connect their symptoms with a diagnosis of diabetes.

The study participants also spent considerable time reflecting on factors they felt had contributed to their diagnosis, why clues to their diagnosis were overlooked, and generally spent time Reflecting on the past. Some participants identified their weight as a controllable antecedent to their diagnosis, for example, “if I had listened to people telling me to lose weight, even over the last five years, I feel I wouldn’t be in this position” (Sally). And, “I should be able to control what I eat and control this with diet and exercise and maybe years ago I could have if I actually I had done it, but I didn’t do it. So here I am.” (Carol). Several other participants expressed evident frustration over their past reflections on missing clues or early warning signs that postponed their seeking diagnosis and treatment, or in some cases, not initiating treatment once it was recommended after their diagnosis. These were similar to reflections on past “high-risk” behaviors by diabetic patients in a study of home-bound individuals with advanced type 1 diabetes mellitus (George & Thomas, 2010, p. 1,096). However, no other studies were found in the literature that reported individuals’ frustrations or disappointment with their healthcare history related to diabetes, or the preoccupation with the concerns common among the recently diagnosed individuals in this study.
At the time of diagnosis, the study participants also shared that they were often preoccupied with general fears or concerns about having diabetes, which were associated with their strong *Fear of knowing* that was related to prior experiences and memories of others they knew who had been diagnosed with diabetes, the course of their disease, and the treatments involved in their care. Andersson, et al. (2008) related similar findings in a study describing the experience of living with urinary incontinence among persons who did not desire further assessment and treatment. The authors identified the theme “reluctance to seek care” (p. 118) in which the participants avoided contact with healthcare providers. The reasons for avoidance included negative treatment experiences that others had shared with them, lack of comfort with the provider, and the belief that they may not be taken seriously. Some overlap also exists in the findings between those reported by Andersson, et al. and those of this study as related to the *Fear of knowing* associated with treatment and the associated avoidance of diagnosis and treatment due to different types of *Blocking the message*, which resulted in delayed action to get the diagnosis confirmed or to initiate provider recommendations for changes in self-care.

Getz Jeanfreau (2005), who studied transitions toward self-management in persons with type 2 diabetes in a grounded theory study, reported on a “diagnostic event” category (p. 79) where the participants recognized the relationship between symptoms and their family history of diabetes. However, they did not report concerns similar to those of *Blocking the message, Reflecting on the past, or Fear of knowing* as found in this study. The concerns or fears related to a diagnosis of diabetes or the *Fear of knowing* that the study participants had the disease also centered on the perceived meaning of the diagnosis based on past experiences, the potential consequences of the disease, the need
for ongoing treatment, and the lifelong nature of the problem. The participants appeared to have an image or representation of a person or persons with diabetes in mind, and vividly recalled them at the time of their own diagnosis (Hearing the news). Although the literature review did not report evidence of Fear of knowing at the diagnosis point, the general influence of recall or transfer of experiences for the person with diabetes was reported by Scollan-Koliopoulos, et al. (2007). They studied the effects of multigenerational legacies of diabetes on health beliefs and behaviors, and found evidence to support the perceptions of their study subjects which included a transfer of disease control and social consequences from prior generations to themselves. In addition, Hill-Briggs, et al. (2003) explored and compared diabetes-related problem solving in urban African Americans with type 2 diabetes, reporting that observations of persons in poor control led to perceptions that poor control was the inevitable outcome of the disease. However, their study focused on the impact the perception had related to ongoing care, and did not report any findings related to the time of first diagnosis.

When reflecting on their Hearing the news, the participants in the current study discussed the time surrounding the diagnosis point, which included their symptoms prior to the actual appointment, the office visit itself, and/or the time period after their diagnosis. The findings of this study shed light on the participants’ experiences surrounding their diagnosis as being much more complex than previously reported in other studies. In this study, the impact of the participants’ diagnosis was even found to influence their ability to learn about and initiate self-care, a finding that is important because the time of diagnosis often serves as a starting point for planning care for persons with this disease. Therefore, teaching the diabetic about their disease during the visit
when they first receive their diagnosis may have limited value. Instead, helping the patient clarify the meaning of their diagnosis to them personally may be more useful at that time.

**Sorting it Out**

The study participants reported spending considerable time reflecting on what they did to understand how to care for themselves since the time they were diagnosed, as a process of *Sorting it out*. During this time, they often focused on persons they knew with diabetes and spent time trying to understand what was happening to themselves by learning what it involved for others or *Knowing by comparison to others*. They also related that they spent time engaged in learning how to care for themselves as an active process of *Working to understand and stay aware* in order to know what they really needed to do in response to being a diabetic. And integrated with their efforts to actively ‘sort out’ what was happening to them were their ongoing struggles with *Recognizing support options* that were or were not useful.

When the participants in this study discussed their understanding or knowledge of diabetes, it had often been gained through experiences they had shared with other persons who had a history of diabetes, or from understanding the disease through observations or interactions with others, that is, through a *Knowing by comparison to others* process. The participants in this study also revealed their responses to their perceptions of disease control in others and transferred or applied this information to their current situations, which included choices they made to disclose or withhold their diagnosis of their diabetes from others, for example: “I did say something to my new manager that I just got diagnosed, you know, and the assistant store manager, I had told him, but, you know,
whether they’ll remember if anything happens, I don’t know. But that’s it. I don’t talk too much about it.” (Jane). A study conducted by Scollan-Koliopoulos, et al. (2007) reported similar findings regarding the effects of multigenerational legacies of diabetes on health beliefs and behaviors, discovering that the perceptions of disease control and the presence of social consequences were often understood through observing others or comparing self to others. They also reported that some of their participants limited their diabetes disclosure if they perceived diabetes to be a stigma. Hill-Briggs, et al. (2003), who studied diabetes problem solving in urban African-Americans with type 2 diabetes, also identified the transfer of past experiences and learning to new situations as common. The participants in their study provided both positive and negative examples of family members and friends managing their diabetes. The study group that had poor control of the disease had difficulty coming to terms with their diagnosis, and voiced experiencing depression and negative expectations, suggesting that the transfer of expectations also affected the outcomes of their treatment.

Knowing by comparison to others often led to connections with persons the participants viewed as supportive and was integrated with Recognizing support options. Said Debbie,

I actually have, in my own peer system at work. My – I’ve been there for 19 years and it’s like a family. So, you know, if you don’t look good on one day they’re going to ask you why you don’t look good and what’s wrong, because you know the people so well. You know them. So it has led me to learn that there’s a lot of people that I work with that have been diabetic for a long period of time, so I have (louder) been able to speak with people that deal with it on a daily basis…. You
tend to talk more with people that you are – have something in common with – work-related or whichever.

The participants shared both positive and negative experiences during this time. Tu and Morrison (1996) reported findings in a study researching self-care practices of diabetics where the subjects reported learning about diabetes, specifically blood glucose monitoring from friends, relatives, and neighbors, which illustrates that their understanding of the disease process seemed to involve *Knowing by comparison to others* and *Recognizing support options*.

Dietary management and food in general were revealed as an area of concern for the participants in the current study when they were *Working to understand and stay aware*. Pam shared her concerns related to dietary management:

No, because they were just as confused as I (laughter). Yeah. A lot of them in the classroom were prediabetic, so they weren’t diagnosed as being diabetic. There was one guy that was definitely diabetic, but he wasn’t there for all the classes, and he was taking the insulin as well. He was having problems with food management as well. I think we were all having problems with calibrating – it’s overwhelming. Then you’re like, I don’t want to do it. Every time I read a label I don’t want to do it anymore (voice trailed off).

Jane shared concerns related to meal planning: “…the only thing with a dietician, even though she can give me pointers or he can give me pointers – then they give you this big – I’m afraid they’ll give me this big menu you’ve got to eat. Then it’s always more than I eat now. It probably would be good things, and it probably would be diet-friendly, but it’s more than I eat (voice trailed off).” Tu and Morrison (1996) also reported
deterrents to dietary management including emotional status and depression, and unfamiliarity with food choices which were similar to the findings related to diabetic dietary management in this study. Cathy shared her perception of the relationship of her depression and food management (when Moving on): “Well, I want to change, like, my eating habits and stuff and that, but sometimes it’s hard with the depression and everything, you know. Until I get my medicine (antidepressants) and stuff on the right track, you know, for that, I don’t think that helps, either.” Shopping and having food choices available is a challenge as shared by Carol:

I keep saying that when I retire what I want to do is literally write a cook book that gives you, like, eight weeks worth of menus, daily menus that are all measured out, and have with them shopping lists. Because every time you see – if you ever look at a diet plan, very often – if they give you the menus, it will say, well today for breakfast have an English muffin and an egg and some fruit, and then tomorrow you have this, and then the next day you have this and that. And you probably don’t have an English muffin anymore for the rest of the week. Well, who the heck shops like that? You know? You’ve got to have something – if I buy a thing of English muffins, they’ve got to be gone pretty much by the end of the week. So, or freeze half of them and use the half of them the next time or something. But you can’t put together, you know, half a cup of blueberries this morning and you don’t have any for the rest of the week. What? You’re supposed to throw them away?

Dietary challenges for the study participants included their coordination of food with medications, portioning, and balancing meals. In addition, they discussed the social
nature of food: “But I go out to eat – I go out to eat once a week or every two weeks and that’s how – that’s my reward to myself” (Pam). Therefore, the social impact of diet change may also need to be explored with these patients.

The presence of self-awareness and understanding of body cues as a means to understand their response to medications, diet, and exercise was also revealed in this study, for example, according to Debbie:

I do check my blood sugar. I don’t have to do it every day, according to my endocrinologist, but I do – what she wanted me to do was do it every three days or when I remember to do it in the morning, but more so after a meal just to see what I was eating and how it was making my blood sugar spike or what it was so that way I could learn to have a better diet and not be able to eat the same type of things, like that I would probably be doing now.

Understanding body cues was reported in other studies (Andersson, et al., 2008; Costantini, et al., 2008; Hernandez, et al., 1999; Thorne, et al., 2003). Understanding physical and body symptoms and using this information to understand and guide self-care was discussed by several participants in the current study when they talked about Working to understand and stay aware, for example:

That’s when I start increasing my sugar thing. I noticed I start to feel a little shaky when I’m under 100 (chuckle), which kind of concerns me, because I would like to be under 100, but now the other day at work I felt a little bit funny in my head, and when I checked it I was 97, which is not extremely low, but is probably low for my body to get used to if it was used to being at 170. (Karen)
Therefore, helping patients tune into body clues is an important part of the self-care process.

Most of the participants in this study talked about the issue of coordinating medications, food, and self-monitoring of blood glucose using glucometry testing (glucometry) when working to understand and stay aware:

I think the harder part is that when you’re not in the medical field and you don’t understand how your body all is connected other than taking classes when you’re younger, then you just go with what your flow is, with your normal daily routine. Sometimes I don’t eat breakfast, sometimes I do or I’ll eat it late, and then I’ll have lunch, or sometimes I won’t have dinner, so I definitely don’t do a great routine, and that’s probably something that I noticed more so now because I’m paying attention. (Debbie)

As Pam indicated, “– I’m always good with the first dose, but I’m not always good with the second dose. I think by the time I get ready to take the second dose, I’m more in depression or refusal because I’ve got to do – the pill is so big. I just don’t want to do it.” Costantini, et al. (2008) identified self-monitoring as a strategy for treatment modification and discussed their study participants organizing their days around medications and doctor’s appointments. Therefore, helping patients work on the intricacies of time management for their individual lives may be an important part of diabetic care.

Other participants in the study also revealed using body cues to understand and guide their self-care when working to understand and stay aware, for example, Diane:
And so then I anticipate what my numbers are for the next morning, you know. So I’m trying to watch, like you said, what foods and how it affects me. You know, it’s like if I have a baked potato it does seem to be higher in the morning. If I have poultry and a salad it’s definitely lower (voice trailed off). So I do take notice. It all depends on what you eat and how much you eat. You know, so I’m curious as far as portion control with meats. That’s one of the biggest things, you know.

Some days I get up in the morning and it’s 110, some days I get up and it’s 165 and I think sometimes it’s because it just depends how active I am after dinner, you know?.... If I’m active right after dinner, I take notice the next morning it is lower.

Hernandez, et al. (1999) studied self-awareness in diabetes, and the understanding of cues, sensations, and circumstances that persons with diabetes and their families experienced. The authors reported their participants describing usual and unique body cues for hypoglycemia, hyperglycemia, and euglycemia, or self-awareness strategies which enabled them to tune into their body cues and sensations. This is an example of informal learning or learning by trial and error as defined by Watkins and Marsick (1992). This finding reinforces the need to engage in conversations with patients to determine how they are using body cues to make decisions to help them ensure that their approach to self-care is the best they can adopt.

Combinations of thematic elements were revealed in this study’s participants when monitoring their responses to medications, diet, and exercise, and the information and the persons they chose to use as sources of support when Sorting it out:
But yeah, he (uncle) said once in a while he cheats, but he’s insulin-dependent, so then he’ll give himself a little bit more, he said. He was diagnosed when he was 43 and he’s now 75. And he said he really watches (stressed). And I know he does, because I know the family used to always say, well, he can’t eat that or he won’t eat this. But you know what? He’s still alive. You know, he’s very diligent with what he eats, you know. (Diane)

Thorne, et al. (2003) researched self-care decision making in persons with the following chronic diseases; type 1 diabetes, type 2 diabetes, HIV/AIDS, and multiple sclerosis. The participants reported using the advice of experts (specialist healthcare providers and other persons with the disease) and biologic measures as a means to evaluate self-care practices. Andersson, et al. (2008) reported similar findings in a phenomenological study describing the experience of living with urinary incontinence where participants reported learning about their own bodies and basing self-care choices on this information along with advice from peers. Combinations of the thematic elements Working to understand and stay aware and Recognizing support options were also identified in the current study.

The gathering of information about diabetes and self-care through interactions with members of the healthcare team, interactions with diabetes class members, and through printed materials, internet sources, and radio programs was commonly shared in this phenomenological study. Additionally, the participants learned about the disease through interactions with family members, friends, and co-workers, for example: “So, you know, that’s an idea. Like my daughter is giving me ideas. I don’t normally think to look at the Web site, but we’re right in the restaurant and I have my phone so I can look it
up. Not anything written” (Sally). Using information sources and strategies to acquire information similar to those uncovered in Working to understand and stay aware and Recognizing support options were discussed in multiple studies (Burke, et al., 2006; Cox & Oakes Westbrook, 2005; Getz Jeanfreau, 2005; Gillard, et al., 2004). Their participants’ information sources included members of the healthcare team, print materials, internet sources, and trial and error experiences, with several of these activities described as independent or self-selected opportunities (Burke, et al.; Cox & Oakes Westbrook; Getz Jeanfreau; Gillard, et al.). Family, friends, and role models or diabetes mentors were also identified as information sources (Burke, et al.; Cox & Oakes Westbrook; Getz Jeanfreau; Gillard, et al.).

When Recognizing support options, it was common for the study participants to discuss searching for and identifying sources of support. In a majority of cases, their discussions of support involved positive experiences. Their sources of support were described as a specific person or resources in general, such as a class, a healthcare provider, or a print or internet resource. They commonly indicated a preference for peers as an information source to assist with understanding their diagnosis and necessary self-care. Numerous other studies identified finding support, resources, or systems of support as important. The influence and the recognition of peers as a preferred source of support was mentioned in several studies (Andersson, et al., 2008; Burke, et al., 2006; Hill-Briggs, et al., 2003; Norr, et al., 2004; Paterson, 2001; Rogers, et al., 2004), as was reinforced by the participants in this study. They also shared the importance of peers as an information source when Recognizing support options. The success of peer education programming as an intervention in HIV education was reported by Norr, et al. Peer
interactions as a source of information were mentioned by Rogers, et al. in a study exploring physical activity, knowledge, attitudes, and behaviors among breast cancer patients during adjuvant therapy. Andersson, et al. reported the findings of a study describing the experience of living with urinary incontinence, and meeting with others, and sharing experiences of living with this condition as a source of insight into dealing with this health concern. Hill-Briggs, et al. (2003), who researched urban African Americans with type 2 diabetes, reported that participants asked family members about their secrets for living with diabetes (p. 1,023). In a study of persons with this disease, Burke, et al. reported that participants consulted family members for disease-related advice.

When *Recognizing support options*, the study participants also emphasized a preference for the exchange of information that occurred with other members (peers) of their diabetes education classes as opposed to the professional leading the class. For instance, *Pam* said,

Talking to somebody that’s going through the same thing I’m going through. The internet tended to be too technical. Talking to some of the people in the classroom and then talking to the dietician, because my diet is my main concern simply because of my work schedule… so that’s the hardest part is what am I going to be able to eat, and how will I be able to comply (voice gets louder) and eat healthy at night.

According to *Diane*, “– (in the diabetes classes) you hear different people’s accounts of what they went through. He was itching all over. I get this – when my
numbers are up I get this burning sensation in my mouth like if I would put peroxide in my mouth.”

The participants also described asking family, friends, and co-workers for information about diabetes. Lenny described his plan to seek out a male co-worker or colleague as a source of information to increase his understanding of diabetes and self-care:

Well, that’s what I’m fully expecting, and if not, I’ll have to go seek out info someplace, you know. Through my network with customers (works in sales) and this and that, you know, who knows. I’ll just conveniently bring it up from time to time. Hey, guess what, you know. I saw the doctor and. And maybe somebody that I’ve been acquainted with has a customer —… Will spring on, oh yeah, I’m diabetic, too. And maybe you can have a conversation and find out.

Therefore, an important part of these participants’ care may be to determine which sources of information they most value or trust.

In most cases, the study participants described supportive or positive interactions with physicians, diabetes educators, dieticians, and health coaches from their workplace or their health insurance provider: “Well, my primary healthcare provider, Dr. (family MD), she has been wonderful over this because she knows that – how stressed out I’ve been over making sure that I try (voice gets louder) to get healthy, is what my husband and I put it” (Debbie). However, negative or unsupportive experiences were also revealed in the study, as illustrated by Sally:

I was then starting to get mad at my daughter and because I feel like she sort of discounts (voice gets louder) the adjustment that it is. Not intentionally. I love my
daughter and she’ll do anything for me, but I guess I felt like, oh, because here’s medicine, she kind of perceived that, oh, well, that’s not a problem, just take the stuff and go on with it.

Paterson (2001) reported examples of an unsupportive or negative experience in a study investigating self-care decision making and the relationship to empowerment in persons with type 1 diabetes. A theme in his qualitative study was the “discounting” (p. 577) or devaluing of patient knowledge and experiences by healthcare providers. Paterson also reported the perception that providers did not offer necessary resources to help patients make informed decisions. Getz Jeanfreau (2005) also reported negative experiences with healthcare providers in a study of transitions toward self-management in persons with type 2 diabetes, which resulted in a change of healthcare provider. Andersson, et al. (2008) studied the experience of living with urinary incontinence among persons who did not desire further assessment and treatment. In their study some participants were “reluctant to seek care” (p. 118) because the provider did not pursue reported symptoms or because they perceived the need to be in pain or test positive for a urinary tract infection in order to receive treatment. These are examples of perceived unsupportive interactions with healthcare providers. George and Thomas (2010) researched the experiences and perceptions of self-management in insulin-dependent, home-bound older (65 to 85) people living in a rural area. According to one theme, “Your body will let you know: If you miss it you’ll wind up in a coma” (p. 1,096), experiences of frustration and mistrust with healthcare providers were reported. Therefore, it is important that providers not assume that the diabetic patient will automatically honor their advice simply based on their expert status.
One participant in this study shared a negative experience she had with a healthcare provider, which prompted her change of provider: “You’re (physician) not interested in what I’m concerned about, so how, if you’re not interested – but then, you have to separate that and say, well, that’s just that doctor, I need to find somebody else that cares, but then you’re discouraged over how to fix that” (Debbie). Another participant revealed a break in a family relationship “…we haven’t spoken in over a year because I can’t – the stress. The stress with him (her father), I couldn’t handle any more. It was really bad. He was very demanding and he did not understand my health issues, which he should have…. And right now I really don’t want to be talking to him. It’s like, I just don’t need that extra stress in my life (voice trailed off)” (Diane). Because she viewed her father as unsupportive, she said she decided to limit her involvement with him as a means to decrease her stress and the potential negative impact on her overall health. Therefore, it may be important to help patients sort out positive and negative support options in order to create the best environment to support the quality of their care. Fortunately, in most cases, the participants in this study emphasized the importance of having support options and viewed theirs as positive.

The findings of this study and other research reinforce the influence of the information or knowledge on diagnosed diabetics gained through observing other persons diagnosed with the disease. The observations shared by the study participants were of others managing their condition well and of persons suffering from complications of diabetes. Based on these findings, the recently diagnosed diabetic may need more help than previously known to sort out their observations and clarify their strategies to prevent the onset of complications.
The participants in this study also relied heavily on the interpretation of their body
cues and physical sensations to adopt new self-care measures, as reflected in other
research. However, the findings in this study suggest that patients want more time with
healthcare providers to share and confirm their insights on self-care, and to use their
insights to make changes that fit their lifestyle. This finding suggests that providers need
to give their diabetic patients an opportunity to share their insights and confirm the
appropriate actions based on individual needs. Finally, the findings indicate that persons
newly diagnosed are actively looking for support but may need help finding the resources
that are most useful for them individually.

**Moving On**

Some participants made changes in their daily lives and described having a
different viewpoint about the disease at some point in time after their diagnosis. This
change in viewpoint experienced as *Moving on* included: *Choosing action vs. inaction;*
*Movement towards a new reality*, and, in limited cases, *Achieving a new level of
awareness* as thematic elements. At this point after their diagnosis, the participants
described taking on varied types of new behaviors and their realizations about self-care or
life changes that were part of becoming a diabetic. Some participants revealed an
emotional response to their diagnosis, such as, “But I just – you know, I’m just sick of –
I’m sick of having to worry about all this stuff. So this has been really – exhausting
doesn’t even cover it. I just can’t stand the thought of having this diabetes (voice trailed
off). But then there are children who have it” (*Sally*). Yet another participant related,
“I’m not – I’m not at that point where I can tell you that I hate diabetes, because it’s not
affected me where I am disabled from it or – I’m still at a lower stage as opposed –
Participant responses centered on plans to incorporate activities, role changes since diagnosis, clear choices or decisions to participate (or not participate) in treatment recommendations, and to look at the future in light of their diagnosis. The literature that addresses similar transitions in persons with diabetes were categorized as assuming control (Thorne, et al., 2003), coping (Nyhlin, 1990), and accomplishment of role transitions (Marshall, et al., 2009).

The view the participants had of their present and future lives in light of the diagnosis of their diabetes was revealed as being caught in *Choosing action versus inaction:*

I’m not really - I haven’t bonded with the insulin yet, because like I said, it’s kind of – I kind of feel like I slide by the seat of my pants. I probably could figure something out to make myself remember to check my blood sugar before I eat. So I guess I suddenly don’t want to because (laughter), you know, it would be easy to, I don’t know, put something on the table like a note. (*Sally*).

Others looked to the future and some *Movement toward a new reality,* as viewed by *Lenny:* “At least in my mind, with being diagnosed and now realizing that this isn’t something I can just fix tomorrow. This is going to go on forever. And that part of it is not a good thing.” Nyhlin (1990) conducted a grounded theory study with the aim of gaining understanding of the coping strategies of persons with diabetes on experiencing long-term complications. Nyhlin reported that uncertainty was a common issue for the participants in the study. Three categories were identified based in this study: “Coming to terms”, “Keeping going”, and “Making sense” (p. 1,023), which form a continuum in the
order presented. Features of the categories “Keeping going “ and “Making sense” are similar to the thematic elements revealed in Moving on as identified in this study, because Nyhlin’s participants discussed coming to terms with daily care in the presence of health deterioration and reflected on the potential complications with diabetes and their perspectives on the future. As in the current study, the present and future life changes due to diabetes were areas of concern reported by Nyhlin as they related to coping with the disease. The findings in the current study reveal the contextual issues that may explain why coping is difficult.

Moving on was identified when the participants discussed plans to engage in self-care, choices to participate in or not participate in recommended self-care, and personal realizations of their future life changes due to their diagnosis of diabetes. Thorne, et al. (2003) researched self-care decision making in persons with the following chronic diseases: type 1 diabetes, type 2 diabetes, HIV/AIDS, and multiple sclerosis. They reported that self-care decision-making was the outcome of a decision to gain control over management of their disease. After the decision point the participants were engaged in on-going “fine tuning” of self-care (p. 1,342). In contrast, the participants in this study, with the exception of one, had only been diagnosed in the preceding 18 months, with several having been diagnosed fewer than 6 months before.

Choosing action versus inaction was a thematic element uncovered in this study that indicated that the participants were first considering some action to take to support needed changes regarding some component of their self-care. They shared their choices to engage in activities related to self-care. Sally’s comment was typical: “So I think I’m keeping track of my blood sugars. That’s good, because I normally wouldn’t be one to do
something like that. Probably making the food available is the best thing.” Diane said, “And I have my measuring cups hanging right there on that hook, so they’re not even in the drawer. You know, so I just—No, I just put them there. I put them there. I had them in the drawer. It’s like, no. They’re right there, all the time now. And I use them.” At the same time, the participants were surprisingly candid about their choices not to participate in components of self-care, for example: “I just don’t want to do it (insulin injections). If I have company or I’m out in public and there’s no place to discretely do an injection, then I won’t do it. That’s pretty much what my day is about” (Pam). This ongoing struggle to take or not to take action was clearly visible in others too: “I will also tell you that the health coach sent information and that I haven’t opened up the envelope yet. There’s a very possibility that there’s information in there that would be useful and I haven’t read it yet” (Lenny). Diabetes self-management strategies or self-care choices have been reported in quantitative studies as a function of adherence, which was measured by self-report questionnaires, pill counts, or physiologic measures in several studies (Bartels, 2004; Chlebowy & Garvin, 2006; Egede, 2003; Glasgow, et al., 2008; Johnson, 1992; Tu & Morrison, 1996; Weiner & Long, 2004). The underlying contextual features of adherence to self-care recommendations were clarified by the reports of the participants in this study.

Role changes, with a focus on the change from caregiver to patient, the impact of diabetes on the male role and the shift to becoming a diabetic, and the changes in health associated with their diagnosis were part of the thematic element Movement towards a new reality. One participant related, “And, you know, part of this is, you know, you’re a male, you’re a baby boomer, we’re indestructible, you know. Not too long ago, as you are
well aware, males didn’t go to doctors. It just didn’t work that way….So with that going on, we still have this, you know, wait a minute, it can’t happen to me. You know, there’s no diabetes in my family” (Lenny). Another participant related, “And, so, you know, I don’t hardly ever plan anything ahead anymore. If someone invites me to something, I’ll say I’ll try to come but I can’t promise. I don’t know how I’m going to feel that day.” (Diane). The transition from healthcare provider to patient was also shared:

The Tuesday class was a little over our head. It wasn’t over mine (voice gets louder) so much, but at that point I’m not looking at it – I’m not doing it from a nurse’s point of view. I’m a patient now, and that’s too much information for me. I just want to know what do I need to do to keep the numbers right and bring them down, and how do I eat? (Pam)

In a phenomenological study Marshall, et al. (2009) researched the experiences of children and their parents living with type 1 diabetes mellitus (T1DM). The central theme identified was “normal”, with four subthemes: transition, attachment, loss, and meaning (p. 1,703). The authors reported changes in the parent-child roles and the relationship of children and their parents, a sense that living with diabetes became normal and was something to aspire to (p. 1,708).

Some participants in the current study made a clear shift to one of owning the disease and looked to the future when Achieving a new level of awareness. “The useful information is, I can live with diabetes and function very well (voice gets louder). It’s how I perceive it and what am I willing to do to stay or follow the directions so I don’t get the complications that come with diabetes” (Pam). The participants also discussed plans for incorporating self-care and some decisions surrounding self-care when
Achieving a new level of awareness. Thus, Debbie commented, “I mean, I have it (diabetes), so there’s nothing I can do. I can’t control the fact that I got it. I have to learn how to fix it to the point, if I can or cannot. And that’s another thing that I think I’m going to struggle with, because if I can’t fix it, then what?” Getz Jeanfreau (2005) studied transitions toward self-management in persons with type 2 diabetes in a grounded theory study. “Development of the Diabetic Self” was the proposed theory (p. 76) which described a process that culminated with integration of self-management into daily life. The thematic element Achieving a new level of awareness included integrating self-care. The participants in the current study also discussed the potential impact of diabetes on family members and long-term concerns related to work and insurance.

When Achieving a new level of awareness, the participants discussed their perceived future with diabetes, for example, “Just be positive. There’s always a way. Like I said, my goal is not to go on medication. If I do go on medication, I’m not going to look at it as a failure. It’s to help me. And just because I go on it doesn’t mean I can’t come off. And that’s one way” (Karen). Diane framed the future realistically:

But I work at it. It’s a never-ending project now. It’s a constant. It’s not something that you can take a pill for and it’s going to be fixed. It’s something that you have to be aware of day in and day out, and I am. And I’m not depressed about it. And I’m not even angry about it, because I’ve seen it. You know, so I know what it is.

Most of the participants in this study did not speak about death, but they discussed the lifelong nature and the potential complications of diabetes, with the exception of Carol who focused on an early death being a potential consequence of the disease. They
discussed the lifelong nature of diabetes, both in the thematic elements of *Movement towards a new reality* and *Achieving a new level of awareness*. George and Thomas (2010) researched the experiences and perceptions of self-management in insulin-dependent, homebound older (65 to 85) people living in a rural area. Four themes were reported, two of which are relevant to this discussion. The theme the “Only way out is to die” (p. 1,096) described the belief that diabetes took over and dictated their lives, and the participants’ awareness and acceptance of the prognosis. The theme “You just go in” (p. 1,097) referred to management and reconciliation with a disease that would eventually claim the participant’s life and the influence on their daily choices since the “only way out is to die” (p. 1,096). The participants in the current study discussed the nature of diabetes and the amount of space and time required by the necessary self-care. For the most part they accepted the diagnosis, although a hope for an improvement in the disease or a decrease in their medications was present in most of the thematic elements.

The findings of this study, as reflected in other research studies, represent the transitions and choices experienced by persons with type 2 diabetes. In the current study, the participants spoke about plans to incorporate components of self-care into their daily lives, implement choices related to self-care, and gave their view of the future. They seemed to enjoy the opportunity to share their experiences, and, in some cases, appeared to even process their diabetes diagnosis during the course of the interview. Healthcare providers may have opportunities to share these kinds of interaction if they can engage in conversation with patients for extended periods of time, especially at the time of diagnosis.
Becoming a Diabetic and Learning Principles

The results of this study represent a basis for understanding the context of the experience of becoming a diabetic and reveal insights that can help plan educational experiences that fit the needs of the individual as they learn the principles of this disease.

The theoretical perspectives and assumptions of Knowles (1990) regarding the adult learner include the following: adults need to understand why they need to learn something; adults are responsible for their own decisions; they bring experience to learning situations; readiness to learn is influenced by real-life situations; adults are life-centered in orientation to learning, and internal pressures are motivation for learning (Knowles, 1990, pp. 57-63; Knowles, et al., 2005, pp. 64-69). Consideration of these perspectives in light of the findings of this study suggests the need to find ways to listen to patients as individuals before they start educational sessions. The findings also suggest the newly diagnosed diabetic’s need for time to assimilate the imperative to change health behavior and how engaging in these changes affects all aspects of their lives.

When diagnosed or Hearing the news about their diagnosis, the participants revealed they were often caught up in Blocking the message, Reflecting on the past (choices that may or may not have impacted their diagnosis), and the Fear of knowing that may or may not have been personally realistic. Their identified responses to their diagnosis may have influenced their readiness to learn about self-care. Most of the participants presented these responses as initially being road blocks to their engaging in learning activities and the adoption of self-care behaviors (Knowles, 1990, pp. 57-63; Knowles, et al., 2005, pp. 64-69). Reflecting on the past and Fear of knowing the diagnosis revealed that the person’s experience with or knowledge of diabetes at the point
of their diagnosis may not be useful and may actually serve as a barrier to their learning about and initiating proposed self-care changes.

The participants were often preoccupied with Knowing by comparison to others, Working to understand and stay aware, and struggling to Recognize support options as they tried to Sort out the meaning of the disease for them personally. At the time the participants were trying to understand the physiological body changes associated with diabetes and recommended self-care activities, they often turned to observations of others and previous learning experiences that may not have been useful. Initially, the impact of diabetes on their daily life was a major preoccupation, with changes in their food choices being a much more overwhelming part of real-life situations than revealed by other studies. While the study participants demonstrated a readiness to learn, they also expressed the need to Sort out the meaning of the diagnosis for themselves personally, which was a primary motivational force for learning (Knowles, 1990, pp. 57-63; Knowles, et al., 2005, pp. 64-69). The meaning of the diagnosis to the patient personally may need to be addressed before initiating any teaching on the actual interplay between diet, medications, exercise, and glucometry testing in order to increase their motivation toward changes in self-care.

When Moving on, the participants discussed Movement towards a new reality, Choosing action versus inaction, and Achieving a new level of awareness. The participants discussed their plans for adapting their lives to diabetes, revealed their choices of self-care, and discussed their future in light of their diagnosis. During this time they applied earlier learning experiences as they continued to learn and fine tune their
self-care strategies. Learning about and understanding diabetes also occurred as the participants experienced role changes during this process.

The participants in this study received information about diabetes and self-care in formal education sessions delivered by a healthcare provider (formal learning). However, they reported a preference for learning by observation and interactions with persons already diagnosed (informal learning). According to Watkins and Marsick (1992), informal learning occurs outside of the classroom and is described as independent learner-driven activity that may occur in the classroom. Examples of informal learning include talking with others, collaborating with others, observing others, searching the internet, reviewing magazines and journals, sharing materials and resources with others, reflecting on actions, and trial and error (Lohman, 2005). The participants in the current study described learning about diabetes through observing family members, friends, and the patients they cared for. In an effort to better understand diabetes and recommended self-care activities, the participants used sources such as print media, the internet, and radio programs. They also gathered information through interactions with others and through trial and error as they monitored their responses to self-care. Many of these activities could easily be incorporated into formal diabetes education classes.

The interplay between the perspectives of adult learning (Knowles, 1990, pp. 57-63; Knowles, et al., 2005, pp. 64-69) and the experiences reported by the study participants are useful to consider. The high degree of engagement in informal learning activities (Lohman, 2005; Marsick & Watkins, 1992) as a means to process and understand self-care by the participants provides insight into the actual measures they may undertake to understand their healthcare needs. The information from this study
could prove valuable for healthcare providers who are planning diabetes education sessions and help improve the healthcare providers’ ability to interpret their interactions with diabetic patients during office visits.

**Implications for Nursing Practice and Education**

The challenge of becoming a diabetic became evident from the study participants’ descriptions of their personal experiences. Nurses need to know how to approach the diabetic patient to be most effective when delivering care. Information gained from this study can enable nurses to understand the diabetic experience from the participant’s perspective and provides insight into what we can do as nurses. Patient education is a key intervention that nurses can provide to support these patients throughout this experience.

Opportunities exist to improve care at several junctures in the experience. The diagnosis point appears to be an important moment in time for the participants. In this study there were several responses to *Hearing the news* or the diagnosis point; *Blocking the message, Reflecting on the past* and *Fear of knowing* were the key thematic elements. Typically the patient is seen 3 to 6 months after the initial appointment, but based on study findings it may be best to schedule a follow-up appointment or contact the patient within the first few weeks. In some cases, the participants in this study delayed initiating self-care behaviors as they processed their diagnosis. Contact from a member of the healthcare team could prove helpful with clarifying the diagnosis and treatment plan at that time, before the patient goes to informal sources that may or may not be accurate. Providing education and offering the support necessary to help the person process the diagnosis and initiate self-care may be most essential at the time of their diagnosis.
Since participants spent considerable time *Sorting out* the meaning of their diagnosis and reported primarily understanding diabetes through observation and interactions with others, it may be very useful to ask patients what they know about diabetes and how they have gotten the information so as to clarify their current knowledge before they attend formal classes. It could be useful to consider how patients in this study were stuck or slow to initiate self-care because of their past experiences or informal information they had received that really immobilized them.

The participants discussed monitoring their responses to self-care interventions as a means to understand diabetes and plan self-care. They also discussed information sources and situations where they gathered information. Most of the participants in this study preferred to get information about diabetes from a person similar to themselves or a peer. Referral to a support group or organizing formal education sessions to promote peer interactions has the potential to improve the facilitation of patient learning about diabetes. The participants in the study discussed support options that they had used, or plans for using certain others. The difficulties many had in making choices and getting information suggest that nurses could intervene and educate patients about the various healthcare providers, information resources, and support options available to promote their self-care.

The participants in this study discussed their experiences, which were captured in the theme *Moving on* and the key thematic elements of *Movement toward a new reality, Choosing action versus inaction,* and *Achieving a new level of awareness.* The ongoing nature of the learning needs in these patients also suggests that nurses may need to continue with patient education and support the patient through exploring and helping them overcome perceived barriers to self-care. Nurses could also support the patient with
role transitions and clarify patient questions concerning incorporating actual self-care into their daily life.

The information gathered in this study could change the patient provider interaction in treating cases of diabetes. On the basis of the understanding gained through this study, it is possible for nurses and other healthcare providers to “act more thoughtfully and tactfully in certain situations” (van Manen, 1990, p. 23). Information exists to support modifying provider history and intake questions to better determine the status of the person diagnosed with diabetes. Specifically inquiring about the changes and barriers to self-care, then problem-solving with the person concerning the appropriate resources or educational information may be needed.

The information gathered in this study has the potential to influence the education of nursing students regarding patient education and nursing interventions to promote positive outcomes in persons diagnosed with diabetes and other chronic conditions. The complex and highly individualized nature of the experience of becoming a diabetic revealed in the study findings needs to be part of the information nursing students learn. Individualization of patient care is stressed in nursing practice and education. The findings of this study can reinforce this concept and increase understanding of the importance of this approach. Incorporating the strategies previously mentioned into nursing education has the potential to improve the outcomes in the patients these future nurses care for.
Recommendations for Further Research

The findings from this study have provided new insight into the experience of becoming a diabetic and the context of the initiation of changes in self-care in this population. Several implications for research became evident that could be considered. A starting point for further research could be in repeating a similar project and collecting biologic measures such as hemoglobin A1C and blood glucose levels. This research strategy has the potential to provide insight into how the degree of blood glucose control may alter the participant responses and experiences. Extending this project to other groups of persons with diabetes is another consideration.

Extending this project by using the same phenomenological research method, and interviewing both the person with diabetes and the healthcare providers engaged in caring for them, could provide additional insight into the key features of the patient-provider interaction that impact the diagnosis experience. Also, development of a grounded theory study to identify key factors at the time of diagnosis could lead to a framework to support intervention testing.

An intervention study to test the most effective way to support a person diagnosed with diabetes could include an established schedule of patient provider interactions or patient contacts to gauge the effect of scheduled or time-sensitive support on patient outcomes (amount of time with patient). However, translating any time-related intervention to practice could prove challenging due to the time limits placed on healthcare visits and insurance reimbursement for services provided. Development and testing of educational brochures or programs to augment the materials provided through formal diabetes education also have the potential to improve outcomes.
Since the participants in this study preferred peer interactions as a means to gather information, additional research to better understand the impact of peer interactions could lead to identification of ways to better utilize informal learning sources to enhance the quality of patient outcomes. Understanding these interactions and then developing and testing a method to reinforce them are other avenues for future research. Currently some peer interactions occur in formal diabetes education classes, organized support groups, and through patient developed mechanisms. Formally building onto and facilitating these interactions may be useful to consider.

**Limitations of the Study**

The participants from this study represented a small sample (N=10) of persons recently diagnosed with type 2 diabetes (T2DM). The participants were recruited from a diabetes center and by word of mouth; the sample was comprised of 2 males and 8 females ranging in age from 39 to 77. A majority of the participants had the means to secure health care and the resources necessary to manage their health. They discussed concerns regarding eligibility for services, insurance co-pays, and healthcare coverage in future years. One participant had difficulty securing and maintaining access to the resources necessary to manage mental health issues and to maintain contact with providers. Therefore, with the exception of one participant, the range of socio-economic status of the study participants was somewhat limited in nature. While the homogeneity or similarity of the participants could be viewed as a limitation, in phenomenological research this condition and experience with the phenomenon of interest are criteria for the method. Each of the interview transcripts tells a comprehensive story surrounding the experience of becoming and responding to being a diabetic. The transcript analysis
revealed a rich account of the phenomenon with meaningful points of similarities and differences between the participants, satisfying the conditions of phenomenological research (Cohen, et al., 2000; Munhall, 2007; Polit & Beck, 2006; Smith, et al., 2009).

A sample of 10 participants is reasonable in a phenomenological study, although it too may be viewed as a limitation (Smith, et al., 2009). The data revealed a rich account of the experience under investigation. Thus, it is possible that extending this research to a larger group of participants or to various healthcare settings may yield additional or different results.

The data collected in this study were limited to information obtained during the individual interviews. While demographic information was obtained from each participant, the current status of their treatment and response to treatment (biologic measures) was not obtained unless volunteered or revealed during the course of the interview. Access to the current status of diabetes care for future studies has the potential to provide greater insight into the participant’s experiences and provide additional elements to consider, e.g., the participant’s progress since diagnosis. Gathering this type of information in a future research project could be meaningful.

**Strengths of the Study**

The purposive sampling procedure used for this study assured that the enrolled participants had experience with the phenomenon of interest. All of the participants described their experiences in their own words, and, for the most part, were eager to tell their story. They freely expressed themselves and provided additional information to augment the research questions. A gift card was offered each participant during the
scheduling of the interview, with most reluctant to accept it, further indicating a sincere interest in being involved in the study for its own purposes.

The researcher met with the staff of the center to review and discuss the research project, and was available to them via phone and email to answer questions related to the study as necessary. The researcher reviewed the center intake forms and attended the four diabetes education classes which patients referred to the center attended. This was done in an effort to better understand the context of the common experiences of many of the study participants.

The interview questions underwent several revisions based on feedback from faculty experts in the areas under study. Then a professional colleague who has had experience with the research method and personal experience with diabetes reviewed the interview questions and confirmed their appropriateness. Discussion of the interview questions prompted this colleague to share her experiences with the phenomenon under study.

Interview transcript analysis and theme development were conducted with the assistance of an expert researcher (dissertation committee chairperson) who has had experience with the research method. Two anonymous participant transcripts with corresponding themes and excerpts were shared as exemplars with two researchers familiar with the method. During this session the researcher, the dissertation committee chairperson, and the two researchers discussed the evolution of the themes, excerpts from participant transcripts, and the evolving themes identified by the investigator were confirmed to be present in the data. The primary themes and elements of the themes were reviewed with the professional colleague who had previously reviewed the interview
questions and who confirmed the themes and elements, and shared correlated personal experiences as examples of the themes and elements as representative of her personal experience as a diabetic.

**Conclusion**

The findings of this study revealed the complexity of the diagnosis of diabetes coupled with the challenges of adoption and engagement in self-care for the study participants. On the basis of the understanding gained through this study, it is possible for nurses and other healthcare providers to “act more thoughtfully and tactfully in certain situations” (van Manen, 1990, p. 23). The findings shed new light on the healthcare provider’s understanding of the diabetic’s experience. For example, the patient response to diagnosis or their impending diagnosis is far more complex than previously understood. The provider may have sensed the complexity or felt that truly understanding the experience was just out of reach. Now, through this study, there is a much better understanding of the diabetic’s personal experience. Healthcare providers recognize the significance of a cancer or other terminal illness diagnosis and manage patient encounters accordingly. Therefore, based on this study’s findings, the response to a diagnosis of diabetes has similar features and warrants adjustments in the care provided. The participant perspective that a diagnosis of diabetes was more serious or threatening than a heart attack or cardiac emergency was enlightening information.

The findings of this study also revealed the previously uncovered randomness or haphazard engagement in patient self-care activities and the structures that influence their consistent adoption and engagement. The disruptive nature of diabetes self-care was revealed along with the sense of the overwhelming impact that it has on the participants’
daily lives. Most were able to master the skills of medication administration and glucometry, whereas their consistency in managing self-care varied. The time constraints imposed by the need for workable management strategies were viewed by most as very disruptive and more difficult to get used to and maintain than expected.

Dietary management was the most challenging component of self-care for the participants, the impact of changes in food and eating habits taking on levels of importance not previously understood by this author. Their statements essentially revealed that food and dietary challenges are present everywhere, requiring many decisions about food in the course of a day. Food and dietary challenges are a constant. Given the lifelong nature of diabetes, and dietary management being overwhelming, suggests the need for a long-term focus on how to deal with the dietary expectations.

The significant influence of observing others engaged in diabetes self-care was validated in this study, although the influence of these observations at the point of diagnosis had not been found in prior research. Also, the degree to which persons understand self-care and responses to it through monitoring of their body cues was validated, indicating a need for long-term reinforcement of the patient’s knowledge related to glucometry, physical signs and symptoms of blood sugar changes, and risks of developing complications.

The context of this experience of diabetes is clearly dynamic, individualized, and far more complex than commonly appreciated by healthcare providers. Understanding this complexity provides an improved basis for planning educational interventions and reinforces the value of individualized teaching and learning strategies in the care of this patient population, particularly for nursing.
REFERENCES


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APPENDIX A
Recruitment Materials

(Poster Six Months)

A Nursing Research Study:
The Experience of Learning Diabetes Self-Care

Have you been told that you have diabetes?

Were you diagnosed within the last 6 months?

Are you at least 30 years old?

Are you willing to share your story about learning to manage diabetes?

If you can answer “yes” to these questions, you may be eligible to join the study. Please talk to the staff or call Marianne Adam, RN, CRNP at 610-625-7765.
### A Nursing Research Study, Pennsylvania State University School of Nursing

<table>
<thead>
<tr>
<th>School of Nursing</th>
<th>If you have questions concerning the research and research-related risks or injuries, or for information regarding patients' rights in research studies contact:</th>
</tr>
</thead>
<tbody>
<tr>
<td>201 Health &amp; Human Development East University Park, PA 16802</td>
<td></td>
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<tr>
<td>Marianne Adam, RN, CRNP</td>
<td>Chairperson</td>
</tr>
<tr>
<td>Telephone 610-625-7765</td>
<td>Institutional Review Board</td>
</tr>
<tr>
<td>Email <a href="mailto:adamm@moravian.edu">adamm@moravian.edu</a></td>
<td></td>
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</tbody>
</table>

[210]
A Nursing Research Study:
The Experience of Learning Diabetes Self-Care

Have you been told that you have diabetes?

Were you diagnosed within the last 5 years?

Are you at least 30 years old?

Are you willing to share your story about learning to manage diabetes?

If you can answer “yes” to these questions, you may be eligible to join the study. Please talk to the staff or call Marianne Adam, RN, CRNP at 610-625-7765.
### A Nursing Research Study, Pennsylvania State University School of Nursing

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</table>
APPENDIX B
Interview Guide

Screening Questions:

- Have you been diagnosed with type 2 diabetes, non-insulin dependent diabetes?
- When were you diagnosed?
- How old are you?
- Female participants: Are you or could you be pregnant?

Demographic Questions:

- How old are you?
- What is your race?
- What is the highest level of education you completed?
- When were you diagnosed with type 2 diabetes, non-insulin diabetes?
  - How long ago?
  - In which month?
- Do you have any other health conditions?
  - Please name the conditions.
- Do you have a family history of diabetes?
  - Which family member(s)?
- Describe the treatment plan recommended by your provider.
  - Medications, diet, checking blood glucose
- Did you participate in diabetes classes/education sessions?
  - How many classes/sessions did you attend?

Interview Questions:

- Tell me about the time and place and how you learned you have diabetes.
- What were your initial thoughts/feelings when you were told that you have diabetes?
• Now that you have been diagnosed with diabetes, describe what your daily life is like? What is different from your life prior to knowing you had diabetes?

• Since you were told you have diabetes, describe what you are doing differently, if anything? How did you decide what to do about the diabetes?

• Tell me about a time that is a good example of what it is like for you learning to manage diabetes.

• Tell me about a time that stands out for you—one you will never forget—that is a good example of how it has been for you to make recommended changes.

• Can you tell me about any conversations you had with your healthcare provider about the need to manage your weight or change your diet to prevent diabetes? What was your reaction when you were given this information? How did it make you feel?

• Tell me about a time, one you will never forget, that is an example of what you have done to get information about your health after you first learned you were diagnosed with diabetes?

• Thinking about what you have been told, what stands out as a time that you remember as being the most useful? Not useful? Can you tell me about that time and what made that a useful/not useful experience?

• Probes: What does this mean to you? What is it like to have this [experience]?
APPENDIX C:
IRB Approval

Institutional Review Board/Office of Research Protection Approval Documents

Institutional Review Board Approval Recruitment Facility

September 1, 2011

Nannette Adam, RN
100 Cokes Creek Avenue
Blindon, PA 19512

RE: (SLNI 2011-82) - the Experience of Living Diabetes Self Care - A Hermeneutical Phenomenological Study

To: Mr. Adam

The above-mentioned IRB study was reviewed on August 30, 2011 and found to be a minimal risk study: 

I, therefore, approved this expedited review for an 12 month period.

This IRB expedited review is based on the understanding that you will:

- Provide the following information:

  The institutional review board is registered with the FDA and complies with all OHRP, 21 CFR 81 and 21 CFR 86. To the extent these Federal regulations are in agreement with the ICH Guidelines, we are also in OHRP compliance.

Please feel free to contact me, at [redacted], should you have any questions regarding this or other issues.

Sincerely yours,

[Redacted]

To indicate your acknowledgment of this approval and conditions, please sign below and return a copy of this letter to [redacted], Asst. Vice President, IRB Office.

[Signature]

Nannette Adam, RN.
Office for Research Protections Approval Pennsylvania State University

Date: September 26, 2021
From: Office for Research Protections
To: Mairah K. Adam
Re: Determination of Exemption

IRB Protocol ID: 37950
Follow-up Date: September 16, 2021
Title of Protocol: The Experience of Learning Diabetes Self-Care: A Permanente Pharmacoepidemiology Study

The Office for Research Protections (ORP) has received and reviewed the above referenced submission application. It has been determined that your research is exempt from IRB initial and ongoing review as currently described in the application. You may begin your research. The category within the federal regulations under which your research is exempt is:

45 CFR 46.02(b)(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior, unless: Information obtained is recorded in such a manner that subjects can be identified, directly or through identifiers linked to the subjects, and the information is not recorded in such a manner that subjects can be reidentified after the completion of the research; or 

Given that the IRB is not involved in the initial and ongoing review of this research, it is the investigator’s responsibility to review ORP Policy #43, “Research Review Process and Exemption” which outlines:

- What items need to be exempt and how determinations are made
- What changes to the research protocol are and are not required to be reported to the ORP
- Ongoing adverse event determination including serious adverse events and complaints, reporting closed cases to the ORP and research departments
- What occurs at the time of follow-up

Please do not hesitate to contact the Office for Research Protections (ORP) if you have any questions or concerns. Thank you for your continued efforts in protecting human participants in research.

This correspondence should be maintained with your research records.
APPENDIX D:
Informed Consent

CONSENT FOR CLINICAL RESEARCH STUDY

TITLE: The Experience of Learning Diabetes Self-Care: A Hermeneutic Phenomenological Study

PRINCIPAL INVESTIGATOR: Marianne Adam, RN, CRNP Graduate Student

PHONE NUMBER: 610-625-7765

You are being asked to take part in this study because you are newly diagnosed with type 2 diabetes mellitus.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to enhance understanding of the actual experience of newly diagnosed diabetics learning self-care strategies designed to help them manage diabetes. The findings of this study may help health care providers identify ways to improve the care of persons diagnosed with diabetes.

HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?

A minimum of 5 and up to 20 patients will participate.

WHAT IS INVOLVED IN THE STUDY?

You will be interviewed and the interview will be recorded. It will take about 60-90 minutes to complete the interview. You could, with your permission be contacted one additional time for additional questions or to clarify information from the interview.

HOW LONG WILL I BE IN THE STUDY?

The study will involve one or possibly two interviews.

You may stop participating at any time.
**WHAT ARE THE RISKS OF THE STUDY?**

Nothing in this study is deemed as hazardous, however it is recognized that the sharing of illness history has the potential to cause the participants to become upset during the interview. You can choose not to answer any question(s) and withdraw at any time.

**ARE THERE BENEFITS TO TAKING PART IN THE STUDY?**

If you agree to take part in this study, there may or may not be direct medical benefit to you. You will be providing information that will help health care providers have a better understanding of the learning process for persons newly diagnosed with diabetes and the strategies that work best. This knowledge can help health care providers to provide better care for people with diabetes.

**WHAT ABOUT CONFIDENTIALITY?**

Your participation in this research is confidential. The data will be stored and secured in a locked office in a password protected file. In the event of a publication or presentation resulting from the research, no personally identifiable information will be shared.

**WHAT ARE MY RIGHTS AS A PARTICIPANT?**

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. You do not have to answer any questions you do not want to answer. Leaving the study, or choosing not to take part, will not result in any penalty or loss of benefits to which you are entitled.

**WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?**

For more information concerning the research and research-related risks or injuries, you may contact Marianne Adam, the investigator in charge, at (610) 625-7765. In addition, you may contact the Chairperson of Institutional Review Board at for information regarding patients’ rights in research studies.

**WHERE CAN I GET MORE INFORMATION?**

Please contact Marianne Adam, investigator in charge at (610) 625-7765 with questions about this study.
You will get a copy of this form.

**SIGNATURE**

I agree to take part in this study.

_____________________________  _______________
Participant                  Date

_____________________________  _______________
Person Obtaining Consent      Date
VITA

Marianne T. Adam, MSN, RN, CRNP
100 Cedrick Ave. Blandon, PA 19510
(610) 625-7765
adammt@moravian.edu

Education:
The Pennsylvania State University  August 2012
PhD, Nursing; Dissertation:  
_The Lived Experience of Becoming a Diabetic: A Phenomenological Study_

Allentown College  August 2000
Post Master’s Certificate Family Nurse Practitioner

Adelphi University  October 1984
Masters of Science, Nursing Service Administration

SUNY College of Technology  May 1982
Bachelor of Science, Nursing (cum laude)

SUNY at Farmingdale  May 1980
Associate of Applied Science, Nursing (Dean’s list)

Academic Appointments:
Assistant Professor  July 1999 to Present
St. Luke’s School of Nursing, Moravian College, Bethlehem, PA

Nursing Instructor  December 1991 to August 2001
St. Luke’s School of Nursing (Diploma Program), Bethlehem, PA

Clinical Practice:
Family Nurse Practitioner, per diem and PRN  November 2008 to Present
Blandon Medical Group (LVPG August 2010) Blandon, PA

Professional Presentations/ Research:
Poster presentation, American Academy of Nurse Practitioners National Conference, June 2007
Indianapolis, IN. Poster title: “Adult Learning: Applying Theory to Practice.”

Research Assistant for Heart Failure Study (to Dr. J. Hupcey), 2006/2007 academic year.

Poster presentation, American Academy of Nurse Practitioners National Conference, June 2006,
Grapevine, TX. Poster title: “Impacting Adherence and Compliance in Clients with Diabetes: Your Mission
Should You Choose to Accept It.”

Research Assistant, project of Dr. Gabbay, et al. (5-year NIH grant) Nurse Case Management. Developed
and presented Adult Education and Learning Styles, and Health Literacy portions of curriculum to
registered nurses during the education portion of the study May 2006.

Grants/Awards:
Nursing Excellence Award, St. Luke’s Hospital and Health Network, Moravian College, May 2008.

Recipient of Pauline Thompson Clinical Nursing Research Award, Nursing Foundation of Pennsylvania,