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The Only Way Out Is To Die: Perceptions and Experiences of Rural, Homebound, Older Diabetics

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To the Graduate Council:

I am submitting herewith a dissertation written by Sharon Robbins George entitled "The Only Way Out Is To Die: Perceptions and Experiences of Rural, Homebound, Older Diabetics." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

Sandra P. Thomas, Major Professor

We have read this dissertation and recommend its acceptance:

Joanne Hall, Janet Witucki-Brown, Mary Ziegler

Accepted for the Council:
Carolyn R. Hodges

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

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Accepted for Council:

Anne Mayhew
Vice Chancellor and Dean of
Graduate Studies

(Original signatures are on file with official student records.)

THE ONLY WAY OUT IS TO DIE: PERCEPTIONS AND EXPERIENCES OF RURAL, HOMEBOUND, OLDER DIABETICS

A Dissertation
Presented for the
Doctor of Philosophy Degree
University of Tennessee, Knoxville

Sharon Robbins George
December, 2005

DEDICATION

This dissertation is dedicated to Dr. Sandra P. Thomas to whom I am grateful beyond measure. She is an exemplar of the ideals representative of nursing and sets a standard to which all nurses should follow. Dr. Thomas represents preeminence in research and teaching. She encourages and provides the freedom for her students to explore and discover perceptions, experiences, and meanings of the world in which nursing is grounded. She is a model of excellence who challenged my thinking and promoted nursing scholarship.

This study would not have been possible without her continuous guidance, caring, wisdom, and humor. When I faced personal, difficult, circumstances, Dr. Thomas generously and selflessly gave her time and support. It was she who taught me to "keep on, keeping on." Dr. Thomas embodies the characteristics of the quintessential nurse.

ACKNOWLEDGMENTS

It is with great appreciation and humility I thank the ten participants in this study. They graciously opened their homes and hearts to share their perceptions and experiences of a disease that causes them enormous sacrifice every day of their lives.

I was privileged to have been surrounded with an extraordinary dissertation committee. Dr. Sandra Thomas, Chair, Dr. Joanne Hall, Dr. Janet Witucki-Brown, and Dr. Mary Ziegler made contributions individually and collectively to my doctoral education and this dissertation. They believed in and encouraged this research throughout its progression. Their support and confidence in me were sustaining throughout this study.

I want to specially acknowledge my husband for his unfaltering devotion, during adverse circumstances, in helping me continue at the College of Nursing. He became a wonderful “nurse” and added new dimensions to the vow “in sickness and in health.”

ABSTRACT

The purpose of this phenomenological study was to investigate the meaning of diabetes, as perceived and experienced by rural, homebound, 65-year and older, diabetics requiring insulin. The sixty-five year and older persons are disproportionately affected by diabetes. They are more likely than younger diabetics to have co-morbidities, disabilities and difficulty preventing diabetic complications. Guidelines for diabetes management and treatment developed by the American Diabetes Association are not specifically targeted for the 65-year and older population. Phenomenological research was used to examine and describe the understanding of diabetes from perspectives of older diabetics.

A purposive sample of participants was recruited from Senior Agencies referrals in a Southern State, following University of Tennessee Institutional Review Board approval. Participants were 65 years of age or older, female, required insulin, homebound, lived alone, lucid, English speaking, and willing to participate. Unstructured, audiotaped, face-to-face interviews were conducted individually in each person's home.

Thomas and Polio's (2002) phenomenological method, which begins with bracketing, was used for collecting and analyzing the qualitative data in this study. Data was reviewed by the researcher and selected transcripts were read aloud to members of an interpretive, interdisciplinary, phenomenology research group at The University of Tennessee, Knoxville, to determine emerging themes described by the participants. The group assisted the researcher in identifying thematic structures from the data.

This phenomenological study revealed that diabetes had forever changed lives. Four figural themes emerged; the predominant theme was "you just go on." Remaining themes were: “your body will let you know: if you miss it you’ll wind up in a coma;” I thought I was fine, but I wasn’t;” and “only way out is to die.”

Participants seemed pleased to have the opportunity to describe their experiences to a professional health care provider. Their perceptions and experiences of living with diabetes led to introspection and existential questioning. The participant’s experiences were unique in quality and meaning.

Based on the outcome of this study, this population requires a different approach to diabetes self-management. Understanding an older person’s perceptions and experiences with diabetes may provide a foundation for considering new diabetic protocols. Nursing interventions could include diabetes regimens planned with consideration of the context of the person’s life, which could be more efficacious than conventional regimens.

TABLE OF CONTENTS

Chapter I

Introduction

Diabetes is one of the nation's most prevalent, debilitating, and deadly diseases. Its complications are a leading cause of death and health care costs in the United States. The American Diabetes Association (ADA) estimates that direct and indirect costs of the disease reach approximately $100 billion dollars yearly (ADA, 2002). The Center for Disease Control reports there are nearly 18 million people in the United States with diabetes mellitus with approximately 800,000 new cases being diagnosed each year (ADA, 2005). The number of adults with diabetes in the world will rise from 135 million to 300 million in the year 2025 (King, Auber, &, Herman, 1998).

The prevalence of diagnosed diabetes in the older population is expected to increase 44% in the next 20 years (Harris, 2001). Elderly diabetic patients utilize the health care system more than elderly non-diabetics. About 30% of diabetics aged 65-74 years are hospitalized each year (Harris, 2001).

Demographics of the United States are changing with the percentage of people aged 65 and older increasing from 4% of the total population in 1900 to a projected 20% in 2030. Total direct medical expenditures for diabetics aged 65 and older exceeded $27 billion in 1997 (ADA, 2002). Indirect costs attributable to diabetes, such as disability or time lost from employment, accounted for an additional loss of $1,375 million among diabetic individuals aged 65 or older (ADA, 2002).

The elderly are disproportionately affected by diabetes. Approximately 3 million people over 65 years of age have diabetes in this country, which is 20% of the elderly population (Wallace, 2003). Aging brings a progressively increasing vulnerability to chronic illness (Hickey & Stilwell, 1992). Diabetic elderly are more likely to have co-morbidities, diabetic complications, and disabilities than younger diabetics. Complications of diabetes lead to frequent hospitalizations, end stage renal disease, cardiovascular disease, infections, lower extremity amputations, hypertension, stroke, and retinopathy. These statistics plead for attention to the national need for ongoing diabetes education and aggressive treatment at all levels of health care.

Stance of the Researcher

I believe all individuals are unique and have the right to choose how they will self-manage their disease. I view each person with their body, mind, and spirit actively participating in the world around them; it is their reality. It is an interactive process with their world, known only to them, as they perceive it. The meaning of diabetes to the 65-year and older person is an integral part of who they are. Learning more about this meaning will help nurses understand the clients' perspective. "Nursing's central concern is with man in his entirety. The process of life and its concomitant, death, are dynamic events of great complexity… knowledge of life's distinctive characteristics is basic to understanding the multiple manifestations of human behavior" (Rogers, 1970, p.41).

Each person is a whole made up of interdependent parts, which are physical, mental, emotion, and spiritual. When one part is not working at its best, it impacts all of the other parts of that person. Moreover, the whole person, including all of the parts, is constantly interacting with everything in the surrounding environment.

Holistic nursing is an approach to life, rather than a focus on illness. It considers the whole person and how he or she interacts with their environment. Holistic health emphasizes the connection of mind, body, and spirit. The goal is to achieve well-being with the entire body functioning the very best that is possible. Nurses should view every diabetic person as a holistic being to facilitate optimal attainment of health.

Based on my beliefs in holistic health and conviction that each person’s reality is what they say it is, I chose existential phenomenology to examine the research question.

Problem

A few researchers have studied rural and homebound populations but not with diabetic participants. Quantitative and qualitative diabetes studies have been conducted on the 65-year and older group, but have not addressed perceptions and experiences of this population. There were no qualitative studies found that investigated the perceptions and experiences of rural, homebound, 65-year and older, diabetics, who require insulin.

Purpose

The purpose of this phenomenological research is to understand and describe the perceptions and experiences of diabetes among rural, homebound, 65-year and older, diabetics, requiring insulin. The study may enhance nursing knowledge and prescribe distinct interventions for an important phenomenon, about which little is known.

Theoretical Perspective

In Margaret Newman's Theory of Health as Expanding Consciousness (1986), person is viewed as a conscious being with a specific pattern. This view has strong connections to Rogers's science of unitary human beings. The nurse is a facilitator who helps the individual, family, or community to focus on its specific pattern. The central tenet of the Theory of Health as Expanding Consciousness is that health, itself, is the expansion of consciousness, a union of disease and non-disease into the total pattern. The meaning of a person's existence and health, according to Newman (1986) is found in developing the process of expanding consciousness, which is the person's ability to interact with their environment. Health is the visible manifestation of the unseen pattern of person-environment.

There is no basis for rejection of any experience as irrelevant. Fundamental components in Newman's theory are pattern recognition and sensing into self (Newman, 1990). Pattern recognition includes the nurse's observation of a client's current interaction and flow of the interaction. The nurse's task is not to change the person's pattern, but to recognize it as information, which represents the whole, and relate to it as it is revealed (Newman, 1994). Sensing into self is paying attention to one's inner experience and trusting it as a valid understanding of the information. The process of nurse client interaction involves meeting, forming shared consciousness, and moving apart. When this is accomplished, the pattern becomes evident and the client discovers truth and understanding (Newman, 1989).

Pattern recognition, which is the basis of nursing interventions, is “moving from looking at parts to looking at patterns. The pattern is information that depicts the whole, understanding of the meaning of all the relationships at once” Newman, 1986, p.13).

Research Question

This study is guided by the following research question: What are perceptions and experiences of diabetes among rural, homebound, 65-year and older, diabetics, requiring insulin?

Limitations and Delimitations

This study was delimited to rural, homebound, diabetic, individuals, aged 65 or older living in Southeastern, United States communities. The ten participants ranged in age from 65 to 85. They lived alone in rural areas. Inability to leave their homes without assistance of another individual qualified them as homebound. Requiring insulin refers to dependence on the medication regardless of the type of diabetes. Dependence on insulin means the body does not have the ability to metabolize carbohydrates. This requires daily, subcutaneous, self-administration of insulin.

The sample in this study was a purposive sample whose names were obtained, after receiving their consent, from community agencies for the elderly. The participants in this study were not ethnically diverse. There were 3 Caucasian females and 7 African-American females. The study did not have male participants because two of the men available became cognitively impaired prior to the interview. The other participants did not have or exhibit any known cognitive impairment and progressed through the interviews without any problems.

Participants in this age group, with years of diabetes, may exhibit levels of physical disabilities and decreased auditory acuity. All participants exhibited physical disabilities and two had minimal problems hearing. However, this did not impede the interview; everyone was able to proceed without difficulty.

The results of this study are only reflective of the group of participants investigated and cannot be generalized to the total population, although researchers (Morse, Penrod, & Hupcey, 2000), have described ways to implement qualitative research findings into practice. The findings of this study could be subject to other interpretations by different researchers, even though meaningful similarities to other studies may emerge.

Significance of the Study

Studying rural, homebound, 65-year and older, diabetic persons is significant because of a need for holistic and developmental understanding of diabetes among this unique group. There are no specified, diabetes treatment differences for the 65-year and older population. They are yet to be identified as a unique group in need of a different protocol from the usual guidelines established for all adult diabetics.

The lifespan of people in the United States is increasing; therefore, people over the age of 65 are likely to live long enough to develop long-term complications of poor glucose control. Identification of lived experiences, as told by this population, may contribute to improved diabetes care and subsequent prevention or minimizing of complications for this specific population.

Guidelines for diabetes management developed by the American Diabetes Association are not specific for the elderly population, only the adult population, which includes elderly. There are no diabetes treatment differences targeted for the 65-year and older population. Developmentally, the 65-year and older have been identified as having physiological changes during the aging process, which places them at greater risk for diabetes and diabetes related complications. The older individual has established years of patterns and behaviors, making adherence to, or change in, a diabetic protocol very difficult and challenging.

Existential advocacy is the essence of nursing and it is the nurse's participation, the give and take and dialogue with the patient, which helps determine the unique meaning for the patient (Gadow, 1980). Existential phenomenology means to take the human being as he exists: living, acting, and feeling, in the moment. Existentialism seeks not only to understand humankind in concrete situations and the lived moments, but the person's responses to these moments. This is the reason existential phenomenology was chosen as the method to investigate the research question. The significance of this study lies in its potential to increase understanding of how this exclusive population perceives and experiences their diabetes.

Rural, homebound, 65-year and older individuals were selected because one of the more important social trends over the last 30 years has been the demographic change that reflects the “graying of America.” With the explosive growth of this gerontological population relative to other age groups, their issues and concerns warrant greater attention. It is estimated that one-quarter of those aged 65 and older live in areas defined as rural, and that 20 percent of Americans over age 65 are homebound (Smiciklas-Wright, Lago, Bernardo, and Beard, 1989). Several rural communities have seen an increase in the proportion of seniors that is largely due to outmigration of youth and aging-in-place of adults. Despite their growing numbers, very little is known about the rural elderly. Much of the gerontological literature focuses on urban/rural comparisons. Some researchers have used the term rural disadvantagement when highlighting rural versus urban differences on health dimensions (Nelson, 1980).

Repeatedly overlooked in the gerontological literature are those rural elderly who are homebound. Homebound, rural, 65-year and older represent a small but significant subgroup of older adults. They are a marginalized society, difficult to identify. They live in geographically dispersed communities that face many challenges with delivery and access to health care services. Homebound elderly have been described with expressions such as “unknown,” “unsought,” and “unreached” (Brickner, 1993). It is not surprising that homebound elders with diabetes have not been included in research studies.

This subpopulation relies increasingly on family and non-family networks for support systems. Often, these support services have diverse funding sources, different levels of coordination or contribution, and even differing definitions of who is considered homebound and qualified to receive services.

Whether as clients, consumers, or care receivers, the rural, homebound, 65-year and older are perceived as individuals who are largely unable to improve their lives without assistance. As their disabilities increase, there may be a corresponding change in social, financial, and cognitive forces that may lead to despair, depression, and hopelessness. The degree of success that various systems have in addressing the multifaceted needs of rural, homebound, older diabetics becomes a salient problem in health care. In light of these issues, it is imperative to develop an understanding of rural, homebound 65-year and older diabetics, fill critical gaps in nursing research literature, and document their needs, perspectives, and perceptions so informed decision-making that leads to self-management can occur.

Chapter II

Literature Review

In this chapter, literature pertinent to older diabetics is reviewed, with delineation of gaps in the extant literature. An in-depth review of broad-based multidisciplinary literature was conducted to establish what is known and not known about the phenomena. Databases specific to several disciplines were searched. Absent from the literature were qualitative studies describing perceptions and experiences of living with diabetes among rural, homebound, 65 and older, diabetics, requiring insulin.

Organization of the Chapter

This first section of this chapter contains a review of extant literature concerning the impact of education, acceptance, and self-management on diabetic persons. Each topic is addressed separately. The last section in the literature review specifically addresses diabetes among the elderly and developmental issues they face. The chapter concludes with what is known and unknown about rural, homebound, elderly persons.

Diabetes Education

Individuals with diabetes provide about 95% of their own care (Anderson, Funnel, Butler, Arnold, Fitzgerald, & Feste, 1995) and diabetes education is used as a tool towards the development of self-management practices. People with diabetes make many choices every day that affect their disease. The focus of diabetic education has been to provide effective information that promoted behavioral change, which improved choices, better health, and reduction of complications. This was accomplished with a pedagogical approach which included lecture content, knowledge tested for accuracy, and demonstration-return demonstration of the necessary skills to self-manage (Bradley, 1995; Brown, 1992). This strategy may not necessarily lead to long-term adherence to diabetes regimens. Consideration of extemporaneous factors with clients, who have had diabetes for many years, may show a different result.

Jack, Liburd, Vinicor, Brody, and McBride-Murry (1999), determined that diabetic education has not considered the impact of patients' social circumstances and physical environment. They assert that diabetes education research needs to include both traditional psychological measures such as depression, coping, or stress and the environmental context that influences diabetic patients. These authors noted that in many diabetes education studies, interventions are inadequately defined, with no rationale given that supports a particular education methodology. The researchers are correct in this assumption. Nursing must consider defining interventions that not only support a specific educational method, but one that includes exploration and accommodation of the individual's experiences. The researchers contend the difficulties diabetics experience when trying to learn and maintain self-management skills may be related to external conditions which impair self-management responses. Directly applicable to rural, homebound diabetics are obstacles in their physical environment that inhibit self-management. For example, the ability to move about in a wheelchair could be confined to circumscribed areas because a ramp was not available. Nurses must consider environmental factors because these factors influence the course and outcome of a person's disease.

A new research paradigm in diabetes education was suggested by Jack, Liburd, Vinicor, Brody, and McBride-Murry (1999). The new paradigm would focus on a public health approach aimed towards comprehensively viewing diabetes clients and their challenges with diabetes self-management. The new paradigm could be a positive influence on rural, homebound diabetics because it may increase their visibility in the medical community.

In a study of diabetic Indians, Blais, Lucarz-Simpson, and Warwick (1991), reported adult members of Indian Reserve questioned the effectiveness of their diabetes care because increasing numbers of their population were being diagnosed with complications. They experienced ambivalence, hopelessness, inadequacy, and isolation with their diabetes, because self-management still resulted in increased hospital admissions, increased mortality due to renal failure, and increased amputations. This created anger, fear, and frustration among the group, which further contributed to their discouragement in adhering to medical treatment and confusion in understanding their disease.

Barriers identified by the researchers for the Indian Reserve diabetic population included insufficient diet information, misinformation about diabetes, and cultural issues such as traditional feasts and food preparation that had been previously excluded from their diabetic education. This study did not investigate their perceptions of diabetes or assess their concerns about the increasing complications, which created enormous alarm. It may have been more beneficial if health care providers had listened to their experiences to arrive at a mutually acceptable diabetic regimen.

Similar to the Blais, Lucarz-Simpson, and Warwick (1991) study, a randomized, clinical investigation by Brown, Upchurch, Garcia, Barton, and Hanis (1998), was conducted to improve the health for adult, diabetic Mexican Americans through the use of educational interventions. The researchers stated that self-care practices of diabetic minorities have received little attention in the literature and none of their participants reported receiving any diabetes education beyond short explanations provided during doctor's office visits.

The researchers explained that patient's knowledge of diabetes self-management was essential, but it did not always translate into positive behavioral change or improve adherence to desired techniques. The interventions, designed to lower blood glucose and delay onset of complications, included culturally appropriate instructions in nutrition, self-monitoring of blood glucose, exercise, and support groups. Their interventions also took into account the participants' cultural values, socioeconomic status, educational background, access to care and health beliefs.

In a paper describing evidenced-based recommendations to improve outcomes of adult education in diabetes and symptom management, Rutledge, Donaldson, and Pravikoff (1999) asserted that the content of disease management education programs must be tailored to self-care management needs and capacities of the client. They believe client education is the core to disease management, and the effectiveness of educational strategies depends upon a therapeutic, collaborative level of provider and client interaction. The authors contend that the basic structure of successful diabetes management programs is built on mobilizing the patients as active participants and collaborators in their health care. This is a worthwhile diabetes intervention model that appears to be based in the holistic care model.

The patient and healthcare provider need to agree upon a common goal, and elements of the plan must be adapted to the patient's lifestyle, preferences, and environment to promote patient adherence. Undoubtedly, patient commitment is a vital component of adherence. Eliciting the clients preferences is best served by listening to the client describe their experiences and offering choices based on what is available and realistic for the client.

Fundamental for consideration in the development of diabetes education programs are content, teaching method, and person doing the teaching. A commonality with health education content is that the health professional often provides too much detail regarding pathophysiology and too little information in the daily management of diabetes (Tripp-Reimer, Choi, Kelley, and Enslein, (2001). It is important for the nurse to access the patient's beliefs and current practices with their diabetes, and use that information as a foundation on which to build their diabetes regimen.

As focus in diabetes research changed from evaluating achievement of multiple outcomes such as weight loss, glucose control, and regular exercise. It became evident from the alarming increase in complication rates that simply improving a person’s knowledge did not necessarily lead to behavioral changes essential towards effectively managing the disease (Bradley, 1995; Brown, 1992). In a meta-analysis of the diabetes patient education literature by Brown (1992), it was determined that utilizing diverse educational strategies in teaching self-management produced the greatest effect on knowledge level, but not on self-management outcomes such as injection skills, glucose control, and weight loss. Glycemic control was shown to be more influenced by the person’s behavioral patterns.

In a randomized control study of patient empowerment, Anderson, et al. (1995) reported that health care providers need to identify and isolate specific behaviors which are thought to contribute to glycemic control and move from the focus on cognitive outcomes to behavior outcomes. They stated there is a need to construct and test models that represent holistic approaches to diabetes, which may generate improved outcomes for the disease.

Diabetes Acceptance

Acceptance is conceptualized as the desire to take possession of one’s chronic illness. It does not imply resignation, but integration of the disease into one’s lifestyle (Dion, 1990). Implicit attributes of acceptance are taking control, connectedness, openness, and vigilance. Richardson, Adner, and Nordstrom (2001) noted that individuals with a higher acceptance of their diabetes demonstrated higher coping ability.

Implicit in the notion of acceptance is that one must realistically accept their disease to move on with life. The rural, homebound, older diabetic faces continual issues of acceptance as their disease progresses. It is a concept linked to their behavior, which accordingly, must follow prescribed adherence in order to demonstrate acceptance of their disease. It is unrealistic to expect a diabetic of 20 or more years to feel the same way as they did at the time of diagnosis. Acceptance is an ongoing process. Acceptance is an antecedent to self-management for individuals with chronic and disabling illnesses (Stuifbergen & Rogers, 1997). Acceptance directs self-efficacy, which eventually leads to self-management.

Acceptance of diabetes can facilitate personal growth by increasing the person’s self-worth, sense of personal freedom, and self-awareness. Acceptance can eliminate tension surrounding previously unresolved issues, freeing energy used for fear, worry, and frustration (Haase, Britt, Coward, Liedy, & Penn, 1992). The research suggests that acceptance of diabetes includes psychological, physical, and spiritual benefits which lead to a sense of inner peace and control. Acceptance results in a sense of being connected with oneself and the essence of one’s being.

Many diabetics need to go through a period of emotional adjustment before they can accept their diabetes (Cox, 1994). When people realize their disease is forever, emotional reactions similar to grief, such as shock, denial, anger, and depression have been reported by several researchers (Cox, 1994; Dion, 1990; Kintner, 1997; Price, 1996). In a phenomenological study of adolescents with asthma, Kintner (1997) reported that adolescents who felt resigned acceptance expressed reluctance to take ownership of their chronic illness. The adolescents perceived they were socially isolated, therefore were resistant to learning about and sharing the disease. Whether intentionally or not, participants in the Kintner (1997) study were remiss about their disease and need for treatment. This study reflects the dilemma of rural, homebound, diabetics, who also face social isolation. They are not accessible by urban transportation, such as bus or train route. They are confined to their homes until someone provides transportation, assistance, and even social interaction. It is easy to understand why older diabetics who face these daily obstacles may become resistant to learning about the disease and unmotivated in self-management

Because feelings and patterns of behavior change with time, it is essential to continually appraise the ongoing needs of the diabetic. This is especially pertinent to older diabetics who have been living with their disease for many decades. They started out with one set of assumptions about their disease and through years of experiences, other assumptions evolved. Older diabetics may have a sense of understanding and perception of diabetes upon initial diagnosis, which makes them more likely to follow diabetic protocols and regimens at the beginning. Years of managing diabetes may later bring remorse and sense of despair, thereby decreasing initial feelings of acceptance. At this point, the older diabetic may be willing to follow the protocol as rigidly.

A large number of nurses surveyed by McDonald, Tilley, and Havstad (1999) reported that acceptance of long-term diabetes management was the initial problem they encountered with diabetic patients. There is a plethora of literature on this subject. Dion (1990) noted that people who accepted diabetes, which included the consequences of having the disease in their lives, experienced greater satisfaction. Not surprisingly, people who reported devastating, life-threatening complications of diabetes had significantly lower acceptance of their condition than people who reported no complications.

Diabetes Self-Management

Self-management is both a structure and a process. Personal change in chronic illness is an unrelenting burden that incorporates being vigilant of body responses, carefully planning of activities of daily living, and constantly learning new strategies to deal with the illness on a day-to-day basis. Self-management is a complex construct and the term “self-management” makes reference to activities and events people undertake to create order, discipline and control in their lives. Providing education for diabetes clients is an accepted standard of nursing practice and intervention for promotion of self-care management.

Self-management programs make the assumption that if clients know the rationale of why, and how to manage diabetes, they will be more motivated to apply the information, which leads to making effective self-management decisions (Anderson, Blue, & Lau, 199l; Patterson, Thorne, & Dewis, 1998). Much of the diabetes self-management literature is from the perspective of health professionals relying on prescriptive, education-focused, professionally delivered programs. This presumes that if people are provided with adequate education, they will self-manage their disease

(Donaldson, Rutledge, & Pravikoff, 1999; Hill, 1995). This also presumes that self-management information means the same thing to all people.

It is crucial to be aware of the factors which impact the diabetic person's ability to successfully execute self-management. The factors may be as complex as human behavior responses to health threats or simply not receiving appropriate education to perform the necessary skills. It is widely accepted that individualization of diabetes self-management regimens strengthens adherence, which ultimately improves outcomes. Research supports this view by asserting that specific content of diabetes education should be based on what is needed by the client. Self-management education should be adapted to include social, environmental, and contextual factors, because these impact management regimes (Rutledge, Donaldson, & Pravikoff, 1999).

Emphasizing personal barriers to diabetes care, Simmons (2001) asserted that if nurses are to achieve high quality diabetes care to enable self-management; they must realize the problems of providing care to diabetics that arise from the biomedical model through which diabetes care is delivered. Knowledge itself does not necessarily create the ability to enhance self-care if other priorities and barriers exist. Listening to clients describe their priorities and barriers should be a central concern and priority for nurses. The author stated that clients need to learn how to carry out self-care and cope with complex health systems.

Glasgow, Toobert, and Gilette, (2001) recommend assessing barriers to self-management, including the individual's motivation, potential for self-management, and social support system. These are factors they identified as effective in improving self-management. If nurses are aware of impediments to diabetes management, then interventions can be modified to improve outcomes.

The level of self-management that people maintain daily depends on their perception of their ability to perform the activities with an expected outcome. Glasgow, Toobert, and Gilette (2001) determined that the strongest and most consistent barriers to effective self-management of diabetes were low self-efficacy and low levels of family social support. Rural diabetics are at risk for not receiving social support because they may live too far from family. The risk for lack of social support is increased if the rural person is also homebound.

In summary, diabetes research has identified predictors of adherence to self-management skills and studies on diabetes education have concentrated on patients' level of knowledge about their diabetes and blood glucose levels as study outcomes (Brown, 1992). However, specific, self-management priorities have not been defined in the literature for the older diabetic. Assessing priorities from the patient's perspective could lead to more comprehensive treatment plans.

Diabetes in 65-Year and Older Individuals

Adherence by the elderly to dietary therapy, physical activity, and medication regimes may be compromised by comorbid conditions and psychosocial limitations. Rosenstock (2001) reported that the principles of managing diabetes in the elderly are not different from those in younger patients, but the priorities and therapeutic strategies need to be individualized. The objectives of treatment are to improve glycemic control in an approach that involves diet and exercise combined with insulin. Treatment decisions are influenced by age, life expectancy, comorbid conditions, and severity of vascular complications, but Rosenstock states that glucose control in the elderly can be managed with practical intervention. This article did not address the limitations faced by homebound, elderly diabetics, and a straightforward treatment plan to enhance adherence. Rosenstock (2001) acknowledges that even if treatment is individualized, strict glycemic control may not be achieved in all patients and indeed, may not even be desirable in some elderly diabetics.

Longitudinal data from the Berlin Aging Study was used to examine adapting to aging losses by Lang, Rieckmann, and Baltes (2002). These authors stated that resource-rich older persons have a higher survival rate, spend more time socializing, sleep more often and longer, as compared to resource-poor older adults. The findings suggest that older people who are rich in sensorimotor-cognitive and social-personality resources are better functioning in everyday life and exhibit fewer negative age differences than resource–poor adults. Their report did not specify existence of disease among the participants, thus making it is difficult to determine applicability of the findings to rural, homebound, elderly who require insulin. However, it is known that rural, homebound are not able to socialize due to situational circumstances. Accordingly, this could contribute to a decreased survival rate for this population.

There are several unique problems in the management of 65-year and older diabetic patients. Visual disturbances occur as a result of the normal aging process, which in this group, are further exacerbated by poor glucose control. Decreased activities of daily living results in decreased food intake and may contribute to a hypoglycemic state.

If the elders are physically inactive, they are more predisposed to obesity. Adding to this conundrum, it is expected many of our elderly will become cognitively impaired, which may further decrease adherence with diabetes self-management. Although effective medications, methods of delivery, and methods for self-monitoring have improved the clients' ability to control glycemia, normal metabolic control remains difficult to achieve.

With diabetes becoming more prevalent, risk for serious complications forces the medical community to become more proactive with issues of self-management. The older population is of enormous concern because they are not as mobile, are often confined at home, and may have less financial resources for proper food and health care. They often have less access to health care to learn more about self-management, or ascertain if their self-management is indeed effective.

Effective and long-lasting metabolic control of diabetes requires major changes in lifestyle that may be difficult to initiate and maintain for older adults. It is imperative to elicit their perceptions regarding factors that promote or inhibit their ability to make changes in their dietary and exercise regimens. Nursing should not base diabetes care solely on physical symptoms. It is essential to incorporate holistic approaches instead of management by a strictly medical model.

Rural Homebound Population

“Homebound” was selected as the delimitation for the sample in the present study because the homebound population shares a disproportionate morbidity and disability rate compared to the nonhomebound (Ganguli, Fox, Gilby, Belle, 1996). There is a need for home-based health services for the 65-year and older in medically underserved rural areas. Isolated rural communities lack the full range of health professionals necessary to run accredited diabetes teaching centers compared resources for urban diabetic counterparts. Rural diabetics must travel greater distances, spend more money, and make greater time commitments, if they wish to see a diabetes specialist or attend a diabetes treatment clinic. Many 65-year and older diabetics simply cannot accommodate those constraints.

Studies confirm that newly diagnosed diabetics who live in urban areas see their physician more frequently and are more likely to be admitted to the hospital. They are referred to diabetic specialists more frequently than rural diabetics (Gobrial, Mekael, Anderson, et al., 2002; Overland, Yue, & Michael, 2001; Reid, Starfield, Forrest, et al, 1999). This often reduces the debilitating consequences of the disease or eases the impact of its consequences.

Summary

Past emphasis in diabetes self-management has been focused on involving individuals with their own care, teaching about their disease and the necessary skills to self-manage and improve outcomes. Yet, this approach has not been overwhelmingly successful in prevention of complications or adherence to protocols. Knowledge of diabetes and its sequelae is essential, but insufficient, for improving glycemic control or preparing people to manage the overwhelming array of potential health problems that result from poor glycemic control.

Many studies have investigated how to improve health outcomes for diabetics. What was discovered is that diabetics need more than knowledge to manage their disease. Nurses need to explore the person's reaction to their disease and perceptions of how the disease impacts their lives, as well as the client's ability to effectively self-manage.

Identifying factors that help or hinder self-management is relevant for nursing practice. Identifying methods that effectively impact those factors is equally as relevant. It is incumbent upon nurse researchers to identify practical assessment methods, and strong intervention models, which may improve the life of rural, homebound, older diabetics, who require insulin. A qualitative, phenomenological research approach is a beginning towards finding innovative, nursing interventions for the older diabetic.

Chapter III

Methodology

Phenomenology is considered subjective and unique to the individual (Burns & Grove, 1997). The purpose of this study was to describe the perceptions and experience of diabetes among rural, homebound, 65-year and older, diabetic, who requires insulin. It is this researcher's goal to provide rigorous insights about this phenomenon about which little is known or publicized. This chapter will describe the methodological approach used to answer the research question and will discuss in depth the study design, sampling strategy, data collection procedures, and data analysis procedures. Beginning the chapter will be the connection between the philosophical framework used for this study and choice of research methodology.

Historical Perspective

Qualitative research has its origins in the types of field research conducted by anthropologists as they observed day-to-day behavior of their participants. This type of approach was standard for sociologists in the 1920's and 1930's. The strength of qualitative methods is in reliance on the written or spoken word or observable behavior of a group or individual being studied as the primary source of data for analysis. The purpose of such research leads to a greater understanding of the world as seen from the unique vantage point of the people being researched.

Qualitative research emphasizes process, meaning, the social construction of reality, and the researcher-participant relationship. It is based on an interpretive-constructivist approach in which multiple realities exist, and it is the researcher-participant interaction that creates the findings.

One assumption of qualitative research is that qualitative methods lend themselves to discovering meanings and patterns. Qualitative researchers seek understanding through inductive analysis, moving from specific observation to the general. Thomas and Pollio (2002) note, "…experimental studies of nursing phenomena cannot shed light on the meaning of what is happening to those who are experiencing it. When our concern is the meaning of human experience, we need to use a qualitative approach" (p.6).

Inquiry that requires collaboration between the researcher and individual who has direct experience of the phenomenon needs an epistemology to underpin the inquiry process and its outcomes. It is the constructivist epistemology that fits this requirement. Lincoln and Guba (1985) suggest that constructivism is a paradigm for the study of human interaction. They state that qualitative approaches by which researchers explore how people perceive specific issues are based on a naturalistic philosophy, which recognizes that reality is constructed and shaped by the human mind.

A type of qualitative research is phenomenological research. The research methods that were developed from phenomenological philosophy are congruent with nurses' larger worldview (Munhall, 2001). The phenomenological method of inquiry offers researchers an approach to a person's experience that gives the participant a voice.

Phenomenology arose from a 20th century philosophical movement designed to describe experiences as they present themselves to consciousness. It is an approach without theory, deduction or assumptions. The German philosopher and mathematician Edmund Husserl founded phenomenology in the early 1900's. In attempts to discover the real essence of a phenomenon, Husserl (1964) explained that this occurs after bracketing personal biases and living with the descriptions of the phenomena until meanings emerge. Husserl believed that bracketing allows the person to be more objective in identifying the essences of the experience. Bracketing presumes researchers are capable of separating their knowledge from personal experience and observation.

An alternative view from Husserl's belief regarding bracketing was described by Heidegger (1927/1972). He adapted Husserl's views on phenomenology and combined them with insights derived from existential philosopher Soren Kierkegard (1980). Heidegger was primarily concerned with the meaning of Being and the nature of human existence, as explained in his work *Being and Time* (1927/1972). Heidegger did not believe it was possible to bracket one's assumptions. Our meanings are co-developed through our experience as being human, which includes the world in which we live. Heidegger is recognized for creating the philosophical science of existential phenomenology.

French philosopher Maurice Merleau-Ponty, heavily influenced by the work of Husserl and Heidegger, based his work upon accounts of perception and defined phenomenology as the effort to describe an experience as it is without considering causal explanations (1945/ 1962). For Merleau-Ponty, the “lived experience” of phenomenology was central for human involvement in a world. In order to describe a lived experience, it must first be disclosed. This is accomplished through bracketing and phenomenological reduction (1945/ 1962). It was his contention that phenomenological reduction exposes the connection that binds oneself to the world. Therefore, complete reduction is not possible. It would distort reality.

Intentionality is another important phenomenological concept. Thomas and Pollio (2002) explained Merleau-Ponty’s intentionality as the directedness of consciousness. Perception is always oriented toward phenomena in the world. Person and world co-construct each other. The phenomenology of Merleau-Ponty “tries to give direct description of our experience as it is, without taking account of its psychological origin and the causal explanations which the scientist, the historian, or the sociologist may be able to provide” (1962, p.vii). “The aim of Merleau-Ponty’s phenomenology is to describe the human experience on its own terms” (Thomas & Pollio, 2002, p.13.).

Research Design

Qualitative, existential, phenomenological research was selected as the method of research for the question: What are the perceptions and experiences of diabetes among rural, homebound, 65-year and older, diabetics, who require insulin? This method best allows the researcher to understand the meaning of the experiences as perceived by the participants. Understanding the lived experience is the essence of phenomenology.

Face-to-face interviews were selected because this method of researching a small number of participants allows the researcher to discover patterns and relationships of meaning (Thomas & Pollio, 2002). The phenomenological method is consistent with a holistic framework and allows the participant the opportunity to describe what is important to them, as it is perceived.

The procedure used for this research is from Thomas and Pollio (2002), who rely primarily on the philosophical foundation of Merleau-Ponty (1945/1962). The participant interviews occurred in a private area in their homes, which allowed them control and comfort in their environment. No specific directions were supplied to participants, thus they were free to discuss any life experience they perceived as representing their diabetes.

Sample Selection

A purposive sample consisted of previously identified individuals that met study criteria, agreed to participate in the study, and were able and willing to talk at length about their diabetes. There are no firm criteria for sample size in qualitative research. A sample size of between two and ten is considered adequate. Polit and Hungler (1999) state that a guiding principle in sampling is data saturation, and with a fairly homogeneous sample, fewer than 10 may be quite sufficient. Thomas and Pollio (2002) state that an appropriate sample size ranges from 6 to 12.

An in-depth phenomenological interview conducted with a small sample of participants experiencing similar situations provides enormous power to their stories. In an emerging research design, the number of participants is not predetermined. Since purposive sampling is designed to provide maximum variation, the researcher must know when sufficient participants have been interviewed (Lincoln & Guba, 1985; Seidman, 1998; Thomas & Pollio, 2002). Many researchers discuss a point in the interview in which the researcher has heard the same information being reported. When nothing new is being heard, it is time to conclude that new information will likely not be obtained. This is referred to as saturation (Douglas, 1976, Glaser & Strauss, 1967, Lincoln & Guba, 1985, Seidman, 1998).

A list of rural, homebound, 65-year and older, diabetics who required insulin was obtained from a local senior referral organization by speaking face to face with the nurse who follows their clients. Inclusion criteria were: rural, homebound, 65 years or older, requiring insulin, living alone, English speaking, willing to participate, and lucid (clearness of mind). Two men on the list were not interviewed because they were experiencing cognitive impairment. All remaining participants were able to give consent in an informed manner and all voluntarily agreed to participate including the tape recording of their dialogue. Once participants had been recruited and agreed to participate, demographic data of age, length of years with diabetes, gender, marital status, and income was collected. Questions relating to diabetes self-management and teaching were also asked. The demographic characteristics and responses to the diabetes questionnaire are presented in Table 1 (Appendix H).

Characteristics of the Sample

Participants in this study consisted of a sample of 10 women recruited by invitation, ranging in from age 65 to 85. Among this group, eight were African American and two Caucasian. Everyone received Social Security as their only source of income. One graduated from high school, the rest had not. All but one was a widow, and length of time with diabetes ranged from 7 to 39 years. Five participants had been diagnosed over 25 years and five diagnosed less than 12 years.

Participants were asked how often they self-tested for blood glucose. Responses indicated haphazard testing. One participant did not check because the glucometer was broken. Another participant admitted she did not check at all. Four participants reported checking from 3 to 5 times a week and four reported checking from 1 to 2 times a day.

Participants were asked how often their blood glucose was tested by their health care provider. Only one responded she did not know (DK) and the rest reported from 2 to 3 times yearly. When they were asked if they knew if they had ever had an HgbA1C (glycosylated hemoglobin), everyone responded they "didn't know."

When questioned about eating habits, such as eating differently since their diagnosis of diabetes, nine responded that they had made changes; one said no. All participants reported eating at least once per day, but no one ate according to their health care provider's recommendations or recommendations of the American Diabetes Association. Eating was sporadic and unscheduled. Five participants reported eating 3 to

4 times a day, everyone else ate less. Four participants stated they avoided sweets/sugar. One participant said she did not avoid any foods and another stated she eats too much. Two participants avoided canned foods, one avoided meat.

Participants were asked if they had received any special teaching for their diabetes. The responses varied and were described in a combination of settings. For example, one participant learned from her doctor and television. Two stated they had received teaching from their doctor exclusively, and one said from her doctor and self-teaching. Other responses included family and friends. Two participants were self-taught, obtaining their diabetes knowledge through experience and observation with other diabetic family members.

Procedure

Role of the Researcher

The researcher created the opportunity for participants to share their experiences (Streubert & Carpenter, 1999). The researcher then became a participant and the data collection instrument (Munhall, 2001). The researcher helped participants describe their lived experiences without leading the discussion. Through in-depth conversations the researcher strives to gain entrance into the participant’s world. Data collection is facilitated by the researcher when participants are made to feel comfortable as they describe their perceptions and experiences. The researcher recognized personal characteristics such as manner of speaking, accent, and age could interfere with data collection.

Determining themes is the researcher's major role. The method to decide what was thematic was based on the researcher's reflection of recurring patterns in the interviews (Thomas & Pollio, 2002). Immediately after each interview, notes of interest were written into the researcher's reflexive journal. A number of patterns were identified and the meaning of words was considered in the context in which they were spoken. The patterns were subsequently related to the data as a whole. Themes were summarized and the interpretive, phenomenology research group and the researcher decided if they were representative of the experience of the phenomenon described by the participant.

Bracketing

Although Merleau-Ponty did not believe that complete bracketing of assumptions and experiences is possible, the researcher must attempt to bracket her own experiences in order to understand the experiences of participants in a study (Thomas & Pollio, 2002). This is a way of looking at one's own preconceived ideas and expectations and is fundamental to phenomenological research. Being aware of one's preconceived thoughts minimizes the potential for distortion in data collection and analysis. I bracketed my experiences prior to beginning the study by asking another nurse knowledgeable regarding phenomenological methodology to interview me. The bracketing interview followed the same process that was followed with the participants. It was audio taped, transcribed, and reviewed by the interpretive, interdisciplinary, phenomenology research group at the University of Tennessee.

The process of bracketing reminded me that I must not insert my own perceptions and experiences into the participant's descriptions. Through the bracketing interview, I recognized my own biases that resulted from several years of teaching diabetes to clients, nurses, and students, as well as providing direct nursing care to diabetic individuals. I held preconceived ideas of how a person should self-manage. For example, I viewed that absence of self-management was due to lack of intrinsic motivation and insufficient diabetes education. Further, if the diabetic person accepted their diagnosis, received proper and appropriate education, and was comfortable with the necessary skills, they would be able to self-manage without any problems. I also believed the diabetic person needed to follow a prescribed regimen set forth by the health care provider; if they did not, severe complications would result. I viewed hyperglycemia as one of the most serious outcomes of poor self-management, therefore, if someone developed complications, it must be due to improper management.

Sadly, during the last few months of this study, my husband was unexpectedly diagnosed with diabetes. Without any warning or family history, his life was turned around. This major event created new meaning for diabetes. The perception I developed though observing and helping my spouse with self-management brought feelings I had not previously considered. I found myself more empathic and my views of improper management were completely revisited and changed.

This experience intensified my interest in diabetes perceptions and experiences; I was now a stakeholder in the chronic disease. This made bracketing even more important. As the researcher, one must stay objective, nonjudgmental, and not assume the role of nurse. It was difficult to separate from that role. Through my spouse, I had the opportunity to see, first-hand, the difficulty a diabetic person goes through every day of their life. For example, decisions must be made, often quickly, if there is a change in blood glucose. Appropriate diet consumes the day if the person follows the diabetic diet.

The continual bracketing I practiced throughout the data collection and analysis helped me experience the interview process from the participant's perspective, and I was able to set aside preconceived ideologies of how diabetics should self-mange their disease. This resulted in an unexpected revelation that abiding by the tenet of Thomas and Pollio's method, I was able to truly listen, remaining nonjudgmental, to what my participants were describing. Their stories became more alive; I found myself drawn-in and captivated by what they were saying. I did not expect to feel so moved. After reflecting on the bracketing interview, I was able to understand the emotional turmoil and physical limitations diabetes can place on a person's life. I was better prepared to conduct the interviews with participants.

Pilot Study

A pilot interview was conducted after the bracketing interview. The purpose of a pilot interview is to refine the interview question and approach. The participant for this interview was an 85 year old, rural, homebound, diabetic. She read the consent form and explanation of the study. The interview was audio taped, transcribed, and presented to the interdisciplinary, phenomenology research group at the University of Tennessee, Knoxville, for analysis. Based on the outcome of the pilot study, no major revisions were required. After the pilot interview, the researcher had an increased awareness of potential distractions, learned the average length of time most interviews would require, and felt more confident during subsequent interviews.

Data Collection

Initial contact with the participants took place after receiving permission from the agency (see Appendix C). The agency's home health nurse initially visited the participants and provided potential participants with the following information: consent to release name and telephone number (see Appendix D), introduction and purpose of the study, nature of the data to be collected, approximate time required, benefits and risks related to participation in the study (see Appendix E).

Informed consent was obtained from each participant at the time of the interview (see appendix F). The consent form was written at a reading level appropriate for the participants and all participants received a copy of the consent form to keep. The consent form included an accurate explanation of possible benefits and risks to participation in the study. Such benefits to the participants can include "catharsis, self-awareness, healing, and empowerment" (Thomas & Pollio, 2002, p. 25). I believe it is important for the participant to feel understood and this research method offers this advantage. One in-depth interview per participant was conducted and two participants were re-interviewed after the themes were identified, to ensure I had correctly depicted their initial description of their diabetes experience.

The procedure involved in-depth, tape-recorded interviews, and dialogue with the participants. A small, unobtrusive tape recorder with a flat microphone was used. The microphone was placed in a location where the participant would not be distracted by its presence. The tape recorder was used to capture the participant’s exact words and prevent distraction from the researcher by note taking while they were talking.

Before beginning the in-depth interview, the issue of lucidity was measured by a verbal mini mental exam. I discreetly asked the participant the current date and a question about current events. I spent time getting to know the participant, which also provided an opportunity for the participant to become familiar with me. When I was certain the participant was comfortable with the recorder and me, I asked if they were ready for me to turn on the tape recorder.

The interviews lasted from one to two hours and began with the question: “Please tell me what it is like for you living with diabetes.” From this point, the participants could discuss the topic in any fashion they chose, and all started with an account of how terrible diabetes is to them. This way of starting the dialogue proved to be significant.

Thomas and Pollio (2002) suggest the interview should be not terminated prematurely. Often people lose their concentration or the mind drifts to another subject but then returns to the topic and the researcher risks losing valuable information if the interview is terminated too quickly. In keeping with Thomas and Pollio methodology, I did not leave the interview until I was certain the participants had said all they had wanted to say about their diabetes. I paraphrased and summarized during the interview to ensure I understood what the participant wanted to describe. This afforded both of us the opportunity for immediate clarification and a smooth termination of the interview.

Field notes were written before each interview and immediately after leaving each participant’s home. The setting for each interview was described, the environment surrounding the inside and outside of the home, the drive to the interview, who greeted the researcher, and presence of others at the home was noted. Nonverbal communication, the researcher’s personal reactions, and any interruptions were documented in the field notes.

Since all participants were considered to be living in rural areas, the drive to their homes became a challenge. Clear, concise directions were necessary to find their location. On four occasions, the researcher stopped and called the participant to clarify directions. If a physical address was available, a map-quest search on the Internet served to obtain clear directions prior to leaving for the interview.

The interviews occurred in a quiet environment selected by the participant within their home in an area where they felt most comfortable talking. One interview was conducted on the participant’s front porch; the other interviews were in the participants’ kitchen or living room. Prior to the interviews, the participants had various issues they wanted to discuss. For example, one participant needed assistance with understanding a new form for obtaining diabetic supplies; another participant requested an explanation of a new medication. I was asked to look at a foot because of a sore that would not heal, a glucometer that was not functioning properly, legs for swelling and discoloration, prescription labels, diabetic shoes, bruises from insulin injections, tumor nodules on the back, and insulin syringes. Everyone seemed quite relieved and very thankful to have their questions addressed.

After the interviews, and during two of the interviews, the participants shared photos and stories of their family and asked questions about mine. Everyone had a few additional questions about their diabetes, but for the most part, their questions and concerns were addressed at the beginning.

In the field notes, nonverbal communication was noted, as was the demeanor of the participants during the interview process. All the participants spoke slowly and quietly; on occasion it was difficult to hear what they were saying when their voice trailed off describing an experience that bothered them. They sat very quietly and recounted experiences in a somber tone of voice.

At the end of each interview, the participant was asked "is there anything else you would like to say about your diabetes?" The participants were always appreciative of the opportunity to describe their illness and a few moments were spent summarizing what they had said. They expressed pleasure that I came and thanked me. Upon my departure, each person's parting words were "now you be careful out there."

Data Analysis

Responses were immediately transcribed and analyzed using the existential, phenomenological method described by Thomas and Pollio (2002). Starting with the first interview, all audiotaped interviews were transcribed verbatim and then read while listening to the audiotape. This was done to ensure accuracy with the transcription. Once accuracy was verified, the transcripts were read and reread to gain insight and a sense of the lived experience as described by the participants. This method provided an analysis of the data that was systematic, disciplined, and reflective. It afforded the opportunity for meaningful comparison across all the data.

To determine emerging themes described by the participants, the data from selected transcripts was reviewed and read aloud by volunteer members of an interpretive, interdisciplinary, phenomenology research group at The University of Tennessee, Knoxville, moderated by experts Dr. Sandra P. Thomas and Dr. Howard R. Pollio. The group members were familiar with and have extensive experience utilizing the Thomas and Pollio (2002) method of analyzing phenomenological research data. During data analysis, the group facilitated bracketing whenever the researcher's personal assumptions were noted. One purpose of the group is to maintain rigor of the phenomenological method (Thomas & Pollio, 2002). This is very helpful to the researcher since the existential-phenomenological interpretation is a process of relating parts to the whole. The initial reading of the transcript in its entirety is to identify the parts that stand out. For example, the group notes and discusses words or phrases that seem to be important in the participant’s description of his or her experience. These are known as “meaning units” and are the basis for the themes. After the transcripts are read, the researcher collaborates with the research group on the themes that have emerged.

Examining other transcripts without assistance of the group, the researcher decided which themes were figural, based on reflection and analysis of recurring patterns among the transcripts. The researcher looked for themes supported across interviews, and then considered the meaning and use of specific words and the relational use of the words to the participants’ description as a whole. After reading each interview, emerging themes were summarized and noted.

After transcripts were completely analyzed, the interpretive group assisted the researcher in selecting the best descriptive phrase for each theme, a phrase that was consistent with the description of the participants’ experience in their own words. Interpretations from the research group were considered along with rereading of all transcripts for deciding the thematic structure. The researcher independently completed the thematic structure of the data and validated it by specific textual comments from the participants. The thematic structure was then presented to the interpretive research group for their concurrence.

In addition to presenting the formalized thematic structure to the research group, Thomas and Pollio’s method specifies that the structure be presented to participants for their response to its validity. I revisited two participants. I wanted to preserve the confidentiality of participants, so I elected to bring only the written themes on a small piece of paper. I showed it to the participants and asked if it confirmed the thematic structure as accurate. I verbalized some of the descriptors; both were able to recognize their own experiences in the findings. One participant added, “This is really good.” The second participant, through quiet affirmation, expressed being amazed at the themes and seemed relieved to hear there were other diabetics sharing the same experiences. It appeared comforting to both participants to have had the opportunity to describe their experiences to a health care provider willing to listen. They expressed gratitude for the additional visit.

Protection of Human Subjects

One of the most fundamental obligations of a researcher is to protect participants of a research study by taking actions to ensure ethical safeguards exist. This study was responsive to ethical requirements set forth by the University of Tennessee, Knoxville and protection requirements as identified by federal and state policies. The policies were reviewed and adhered to throughout the development of this research. Institutional review processes were undertaken with institutional approval from the University of Tennessee Institutional Review Board before initiating this study. Prior to any engagement with participants and collection of data, a fully informed consent process occurred and was followed.

Participants were given, verbally and in writing, information regarding purpose, benefits, and risk of the research study. Participants were asked to completely read the informed consent. Signatures were obtained prior to participants being involved in the study. Each participant was given a copy. Participation was voluntary and the individual could withdraw at any time they desired. As required by Institutional Review Board policy all participants were furnished with the telephone numbers of the principal investigators and the Institutional Review Board should they have further questions. Participants were assured confidentiality would be maintained and their names and addresses would not be used anywhere in the study.

In-depth interviews require participants to reconstruct their experience as it relates to the topic of inquiry. During this process, a level of intimacy may develop between the researcher and participant, which could lead to the participant sharing an aspect of their life that could leave them exceptionally vulnerable. Participants have the right to be protected against vulnerability. Consequently, researchers can protect themselves against any misunderstanding of the process by seeking informed consent. This requires the researcher to be explicit about the purpose of the study and clarify what he/she intends to do. It is a method of providing to the participants ahead of time as much information as possible about the interview without contaminating the results. None of the participants withdrew from the study. All interviews were audiotaped and transcribed.

The transcriptionist, (see Appendix G), all members of the dissertation committee, and all members of the University of Tennessee, Knoxville, interdisciplinary, phenomenology research group signed a confidentiality statement (see Appendix H). All statements are stored and locked with the transcripts. All audiotapes and transcriptions had no names or identifying information; and they are kept locked in a cabinet in the researcher’s office.

Streubert and Carpenter (1999) state that all research may have an effect on the participants in some way. During this study, there was concern for the participants experiencing an emotional response from describing their experiences. Protection of their emotional response was foremost over the research. It is important for the researcher to not depart from the role of instrument in the investigation to that of a counselor. Albeit the demeanor of the interviews was somber, none of the participants requested the interview be stopped or demonstrated needing additional assistance. Should they require any assistance later on, each participant was provided with a contact number for the researcher.

Reliability

Reliability is construed differently in phenomenology because no two interviews are identical (Thomas & Pollio, 2002). Reliability is supported by closely studying the themes found in one interview with themes that match in the other interviews. A measure of the relevance of a phenomenological study is in its value in bringing new insights about the phenomenon (Thomas & Pollio, 2002). There are judgments made by the researcher about the data and its relation to a truthful representation of the participants’ experience. It is compared with known information and is verified across participants. This constant comparison helps establish that reliability has been met.

The themes in this study are similar across transcripts. Their significance may be enhanced if replication occurred to broaden and extend the original themes. However, the aim of replication is to not repeat the themes from the original study. A different population would be used to broaden the themes that emerged from this study, but not change the thematic structure established in the original analysis.

Validity

Burns and Grove (1997), state validity is a measure of truth or accuracy of a claim. Validity is determined by whether or not the researcher investigated what they intended to investigate. It is concerned with presenting plausible interpretation and understandings related to the phenomena. It “is not determined by the degree of correspondence between a description and some external reality criterion” (Thomas & Pollio, 2002, p. 41). Qualitative validity focuses on identifying and knowing the underlying attributes of the phenomenon and the ability to show congruency, meanings and relationships of findings. According to Leininger (1985), qualitative validity should be based on knowing and understanding the phenomena to the fullest possible extent. A measure of validity for this study occurred with two of the participants verifying the accuracy of the data interpretation. Pragmatic validity will be established if clinicians find that the study provides new insights about diabetic clients.

Generalizability

External validity is concerned with the extent to which the study can be generalized. Often qualitative research is cited as not generalizable, although Thomas and Pollio (2002) point out that each reader who derives insight from the findings of a phenomenological study may be thought to extend its generalizability. Clinicians can apply these study findings in practice, using them to open dialogue with older diabetic patients about concerns and issues that may be similar to those of the study participants.

Summary

Phenomenology is the study of lived experience from the unique perspective of the person engaged in the experience. Phenomenologists believe there is not just one reality and that each person has their own reality. Phenomenological researchers try to gain an understanding of the person's perceptions of their reality. The purpose of this study was to explore the perceptions and experiences of rural, homebound, 65-year and older, diabetics, who require insulin. This was an existential, phenomenological research design using Thomas and Pollio's phenomenological research procedure. Findings will be presented in the next chapter.

Chapter IV

Findings

"The only way you can get out of it, I think, is dying out of it." (Participant)

Participants were asked to describe their experiences of what it is like for them having diabetes. For this group, this was an unfamiliar method of interacting with a health care professional. However, after an initial adjustment period, participants willingly and sincerely described their experiences with diabetes. Everyone serenely depicted what their life is like with diabetes and how they managed diabetes in their own way. Each spoke in a quiet tone, sitting on a chair or sofa. Experiences were discussed with a somber affect. There was very little laughter during the interviews and descriptions of specific events seemed to bring back to immediate consciousness the reality that they have a serious and intrusive disease, for which there is no known cure.

Each person seemed pleased to have the opportunity to talk about diabetes without any restrictions on scope or time. They were ready to talk and often their voices would trail off at the end of describing an experience. It was as though it had left them with lingering thoughts or questions and they were forced to think about their long experience with diabetes. Past experiences were recounted as though still fresh in their memory. Expressions would change as painful experiences such as first using a needle were described. Pain was reflected in facial grimaces, and from time to time, a melancholy appearance and sadness permeated the discussion. The burden of carrying all the physical and lifestyle changes with diabetes appeared to be reflected in their faces.

Using the participant's own words, specific themes emerging from this research will be discussed. Four, figural themes were interrelated across all the interviews and were contextualized by the existential grounds of world and body. The world of an older, homebound diabetic in rural Alabama is greatly restricted. Few people populate this small world. Most participants have few visitors and get out of their homes infrequently, perhaps to church or a family gathering when someone provides transportation. Most cannot walk very far. Nine are severely limited in mobility; three use a cane, seven use a wheelchair, walker or cane. Alone, residing in modest homes, they are surrounded by personal items and family photos which bring them pleasurable memories. Their source of income is from Social Security and all receive Medicare insurance benefits. In the world of these older diabetics, a limited income, with no supplemental medical insurance, increases dependency on public health care services.

A glimpse of the participants' world is provided in the following description of one participant, who was quite difficult to locate. She lived beyond an unmarked, rural, dirt road. Her mobile home, with a well-worn wheelchair ramp attached to the front, was bordered by an abundance of high, green grass. Buried in the front were two tomato plants that the participant proudly called her garden. She was tethered to oxygen tubing from her nasal cannula to the large, rolling, continuous positive airway pressure machine, containing the oxygen tank. Requiring this machine for sleep, and continuous oxygen to assist with breathing, the participant had approximately ten feet of oxygen tubing to move around her environment. I could not help but notice the strain on the tubing as she was leaning out the door, smiling and beckoning me into her home.

Diabetes is experienced as a bodily phenomenon, most notably when the body signals that they must take action. Participant's narratives were dominated by frightening episodes of hypoglycemia, as captured in the phrase, "Your body will let you know: If you miss it you'll wind up in a coma" (Theme One).

Participants believed that conventional diabetes management techniques did not work for them, nor did health care providers listen to their perceptions and views. The disconnect between participants and providers is captured in Theme Two, "I thought I was fine, but I wasn't." Trapped in their bodies and doomed to the constraints that diabetes places on their lives, participants perceived that the "Only way out is to die" (Theme Three). Stoic endurance exemplified all of the participants as shown in the phrase, "You just go on" (Theme Four).

The thematic structure is illustrated in Figure 1. The structure represents the interrelationship across all four themes as never ending. It depicts "You just go on" at the top of the structure because that is where the participants can either begin or end their diabetes experiences. Going on represents the resignation resulting from living for years with disruptive hypoglycemia episodes ("Your body will let you know, if you miss it, you'll wind up in a coma"). Across from this theme in the diagram is the participants' perception that "I thought I was fine, but I wasn't." Flowing from a logical sequence of

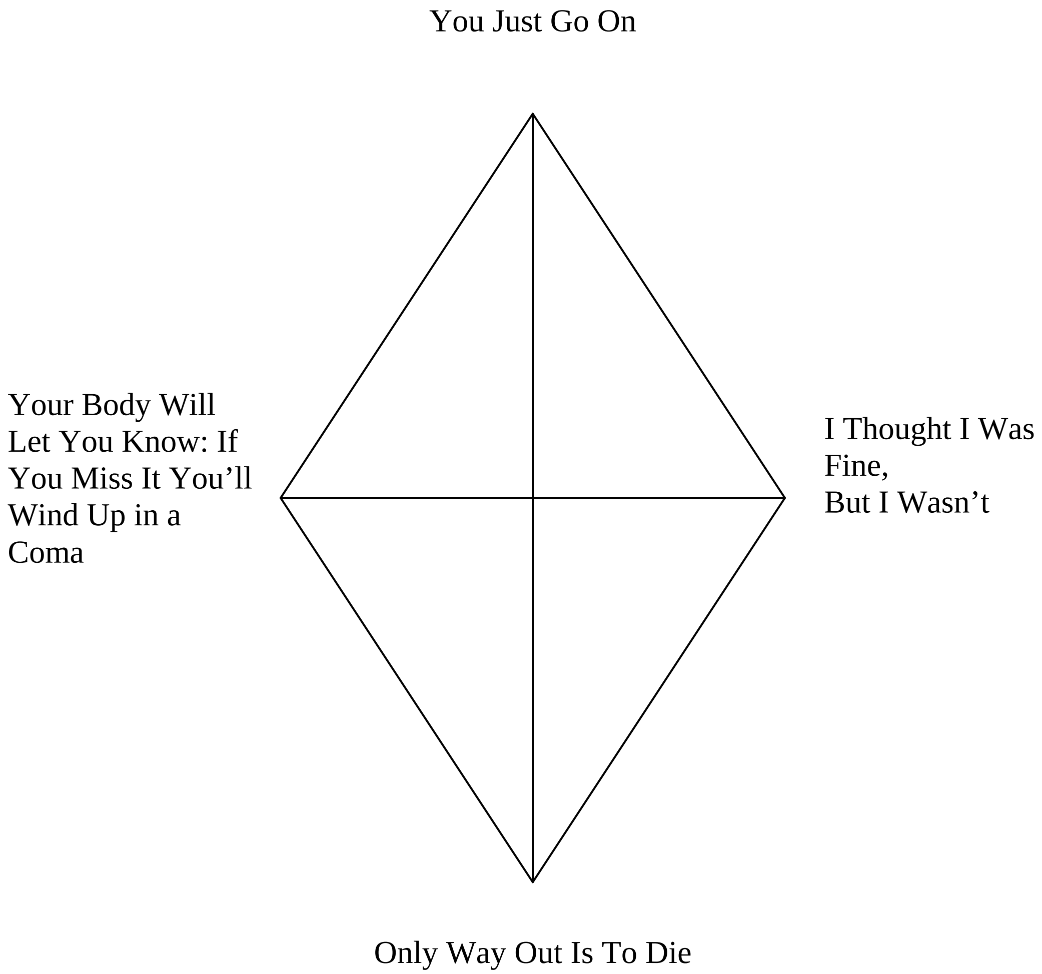

Figure 1. Thematic Structure

adverse disease-related events, participants arrived at the conclusion, the “Only way out is to die.” For the participants, if their only way out is to die, then “You just go on,” which is inextricably connected to the other three themes. Each theme will be discussed in greater detail. Pseudonyms are used to protect the confidentiality of participants in the following sections.

Your Body Will Let You Know: If You Miss It You’ll Wind Up In A Coma

Theme One: “Your body will let you know: If you miss it you’ll wind up in a coma.” This theme embodies the choice participants made to manage their diabetes only when changes in their body mandated action, lest adverse consequences ensue. It involved participant’s emotional descriptions of feelings in their body antecedent to hypoglycemia. One participant said, “you feel like you’re gonna die.”

Most participants stated this was their biggest fear, and what they paid the most attention to. It was a feeling and a clue to what was about to happen. It was their common trigger to actively respond to the disease. The bodily cues of hypoglycemia that dominated their descriptions included “started floating” “awful,” “nervous,” “black out,” “swimmy headed,” “knees like jelly,” “scary” and “slipping away.”

Over time the participants evolved their own self-management techniques. They chose to manage their disease only when they absolutely had to do so. They believed they can control diabetes with, just in time intervention, as their physical symptoms peak and they rapidly descend towards hypoglycemic coma. They appear to prefer this approach to traditional, regular regimes intruding on their daily lives.

Sarah, 77 years old, using a walker, believed in her world it was important to be physically closer to the refrigerator so she did not have far to go when she became hypoglycemic. Her descriptions of experiences with hypoglycemia indicated how she copes; she shook and pointed her fingers, gesturing when she declared, “there is my bed and there is the refrigerator. I know when it has got low, I have to make it to the freezer, and back in the bed before I black out.”

Hypoglycemic feelings were recalled with incredible detail, as though the participants had just experienced an episode. Emily’s description was poignant, “I take my insulin, and it (blood sugar) goes down at night; I am completely wet and I start shaking. It feels like my heart’s coming out of my chest, when it gets to 90, I hit the floor.” At this point, she would frantically try to find something to eat before she “passed out.”

Experiences of hypoglycemia also generated fear of sleep. Not responding to their bodily cue for hypoglycemia could cause a coma. One participant stated, “I’m afraid I would have just slept, slept, slept, if they hadn’t found me.” What stood out most for people was dread of falling asleep. They worried they would not be able to wake up and being alone, intensified this apprehension. “I’m afraid I won’t wake up” said Mary. Others expressed “it’s scary,” “afraid to be alone,” “not easy waking up,” It appears if one slept, the possibility of not waking could occur. Fear of sleeping and not waking in time, or being unable to respond, was profound for them. Emily stated, “what would I do, I’m here by myself, of course I’d call 911, but what if I’m passed out.”

For some participants, fear of sleep determined how they spent their days. Driven by fear of falling asleep at night, creative ways were adopted to stay awake as much as possible during the night. Dorothy said she consumed a lot of “coffee all day and evening to stay awake.”

In the participant’s world, they did not use traditional methods to control their diabetes. Rather than systematic blood glucose testing and rigorous diet, they allowed physical symptoms to trigger their response. Accordingly, they did not respond with medication or food until their symptoms reached crisis proportions. Sarah describes, “I don’t have to check (blood glucose) everyday, no way. I just don’t do it.” She further expresses that she is not like the “rest of the diabetics.” She eats “all the chocolate I want” and perceives, “it don’t do nothing to my sugar.” However when her sugar gets low, she describes, “I would get dizzy, feel like I’m gonna pass out any minute, I’m trying to feel my way to the refrigerator.”

The participants listened to their body’s signal for hunger and if they did not have these signals, they would not eat. Most had their own system worked out for eating. “I only eat one meal a day” said one participant. Others stated, “I don’t eat (to control sugar) too much,” “I try to manage it by what I ate.” Helen described she would eat “an egg in the morning, that’ll lay until dinner time and at dinner time I get a cup of coffee and whatever I have in there I eat.”

The diabetic diet specifies eating small, frequent, meals and a snack throughout the day. The diet is designed to prevent hypoglycemia episodes and severe fluctuations in blood sugar. The participants did not eat on a schedule or follow American Diabetes Association guidelines. Irregular eating patterns contribute to glucose imbalance and interfere with insulin metabolism. Linked to this precarious practice of self-management is theme two.

I Thought I Was Fine, But I Wasn't

Theme Two: "I thought I was fine, but I wasn't." Participants chose, what turned out to be, high-risk behaviors that had worked for many years. However, as the disease progressed, they developed irreversible, disabling, diabetic complications.

Participants perceived they would be fine with diabetes if they took their insulin and ate "right." They believed "doing the right thing" would keep their diabetes under control. For most, their sense of "fine" was demonstrated by self-management behaviors and strategies that provided them the greatest degree of freedom without causing adverse consequences. Julie explained, "Sometimes I cut my shot in half." She made this decision because taking the entire amount would require eating more food, which she said is "too much eating, I'd gain weight."

They struggled between what the doctor advised and their personal knowledge and experience. Most felt compelled to devise their own diabetes regimen without the advice of a health care provider. Julie believed her self-management left her "feeling better" than doing what was medically recommended. In her world, she was "doing fine." However, years of adjusting her insulin and eating behaviors created unpredictable blood glucose levels and severe hypoglycemia episodes. Clearly, this participant was not fine.

Margaret said, "I followed my diet plan, I got this surgery, I thought I was doing good, I thought if you take the insulin you'd be just fine, and that's what I was doing, but I wasn't fine." It was her expectation eyesight would be normal after surgery, and it wasn't, "they didn't explain to me that that was not a reality."

Participants expressed that conventional diabetes management techniques did not work for them. They perceived health care providers as being unwilling to listen, and directing them to follow a regimen they could not follow. This created frustration and mistrust. Descriptors of provider responses included "didn't believe me," "wouldn't listen," "tried to tell them," "doesn't help." One participant described if her sugar was too high, "I take a little more insulin than I've been taking." Another stated, "I go by how much I eat or how much I don't." Their self-prescribing diabetes management ultimately led to accelerating progression of the disease, leaving the participant to wonder what went wrong: "I did everything I was supposed to."

Libby adamantly describes "I told them they couldn't put me on a diabetic diet; I know what I can and can't have." The frustration she experienced led to implementing a diet plan whereby she ate what she wanted. This included consuming large amounts of chocolate, which Libby stated with absolute certainty, "it don't do anything to my blood sugar." Vividly describing experiences with severe hypoglycemia, and suffering from chronic, debilitating diabetic complications requiring a walker and cane, Libby was visibly not fine.

Participants appeared to be disconnected with doctors and other health care providers, often referring to healthcare providers as an undifferentiated "they" rather than using their names. Participants expressed not being provided information which directly related to self-management. Margaret says "they didn't explain to me." Recalling an experience occurring ten years ago, Evelyn succinctly describes, "he (doctor) made me come everyday and he'd take a blood sugar count. He kept taking my sugar. He didn't tell me how to give myself a shot." She states, "I had to get another doctor."

Only Way Out Is To Die

Theme Three: Participants know diabetes is a lifelong process and a disease for which there is no known cure. Through their own experience with diabetes and their observations of the impacts of the disease on family and their own bodies, participants feel trapped in their bodies and doomed to the constraints the disease places on their lives. "I know I'm not going to get better," stated one of the participants.

Diabetes had taken over and dictated how they were to live each day for the remainder of their lives. Neither traditional medicine nor their own experiences give them any hope for significant improvement in their condition; in fact, quite the contrary, most are faced with escalating degradation in the quality of their lives and the condition of their diabetes. They believe "the only way out is to die."

Participants are cognizant and realistic about the prognosis and are somber in their acceptance of their condition. Depictions of this theme include “there’s nothing you can do about it,” “they say they don’t have no cure for it,” “nothing you can do,” “you never will get well.”

The participants believed they do what they can to accommodate their disease and try not to let it consume their lives, “I just take my diabetes and don’t worry about it.” They have an air of acceptance and resignation. “I know I’m not going to get better.” This permeated across all the transcripts explicitly. They had lived and experienced diabetes for many decades and their bodies had been ravaged with the disease. Annie remarked, “It (diabetes) has messed it (body) up.”

One participant whose diabetes spanned over 30 years, who was confined to a wheelchair, and required someone else to prepare her insulin doses for the week, stated remorsefully, “there’s nothing you can do about it, you can’t be cured, I know that.”

Despair and discouragement was imbedded in descriptions. Everyone affirmed they were doing “the best they could” with their disease. Exemplars include, “I try,” “I got use to it,” “I do everything I should,” “I just make out best I can.” Participants recognize they can’t recover; diabetes is for life, therefore the only way out is to die. This belief brought thoughts of resignation and links to the predominant theme of the study: “you just go on.” Although participants described there was no way out of diabetes, their perceptions reflected both resignation and acceptance. They accepted the vulnerability diabetes imposes as an inevitable consequence.

You Just Go On

Theme Four: This theme, “you just go on” reflected stoic endurance exhibited by these participants as well as resignation to management of a disease which placed them into situations where they can look forward only to further degradation of their physical condition. Helen, a diabetic of 35 years, facing another amputation, surviving all of her siblings (none of whom had diabetes), stated, “you just go and do what you got to do.”

They have spent a lifetime managing diabetes to the best of their ability. In essence, they were doing everything they knew to keep their lives going in spite of their diabetes. Forced to recognize the limitations this disease brought, they became resigned to continue living a highly restrictive lifestyle. Mary stated “it’s hard for me, but I try it. But it bothers me. Something I’ve got to do. So you just go on.”

Going on for some participants meant not allowing diabetes management to interfere with what they ate. Eating appeared to be their sole remaining pleasure. Mary, who uses a wheelchair, states her diabetes is “pretty bad, but I just eat whatever I want because it don’t bother me none.” She said, “I just do what I got to do.” Others acknowledged they were frequently guilty of “eating something I know I have no business eating.”

Part of “just going on” is sometimes to defy what people tell them, because, after all, they already know the “only way out is to die.” So why shouldn’t they indulge their sugar craving sometimes? As they perceive it, nothing has ever really helped them anyway. Sarah defiantly states, “I do fine until that sugar craving comes, I love chocolate and they don’t know where chocolate goes in my sugar. It doesn’t run my sugar up. I can eat all I want.”

Another participant confesses “I love the sweets; I’d make a cake every weekend and eat it up all through the week. My sugar’d be over 600.”

The participants did not expect to get better. Living day to day with their disease, they reconciled themselves to the decision that you just go on. This is reflected in, “I’ve been a diabetic for so long, you gets used to it. The longer you do it, you get use to it.” … “In other words, you have to do it so long, and you just do I says, doing what come naturally.”

The strategies used by participants to enhance their quality of life involved adopting the mind-set of getting used to diabetes and being able to go on. The enjoyment they experienced was found in what they ate. Maintaining their disease so they could go on proved to be challenging to independence and daily choices.

Summary

The goal of this study was to describe perceptions and experiences of rural, homebound, 65-year and older, diabetics who require insulin. The analysis of participant interviews revealed a constant struggle with diabetes. Not only is it a lifelong disease, it engulfs almost every aspect of their daily lives. They are never free of the burden of diabetes. Participants were continually trying to live and adopt ways of self-management that minimized the constant intrusion of the effects of diabetes on their remaining years of life.

This phenomenological study revealed that diabetes brings about despair and resignation after years of trying to self-manage. Lives are forever changed when the diagnosis is made and being diabetic sets up a lifestyle requiring constant, daily, responsibility, and vigilance to keep the disease under control. Otherwise, the diabetic person is beset with complications. The participants were continually trying to integrate diabetes into their lives, and balance the disease within their unique perspectives and experiences.

The diabetic persons in this study found their daily lives revolved around the continuous themes of “your body will let you know: if you miss it you will wind up in a coma,” “I thought I was fine, but I wasn’t,” “only way out is to die,” and “you just go on.” These themes powerfully captured their perceptions, experiences, and perceived meaning of diabetes. The themes are poignant and reflective of people who have endured diabetes for many years and echoed throughout the transcripts. The themes exemplify a sense of continuity to the transcripts.

Participants spoke of the meaning of diabetes with voices low and intonation reflecting sadness and despair during descriptions of what they do to manage. Everyone described their experiences in much the same way; even though no one participant knew any other, it became evident early in the interviews they were experiencing diabetes similarly. No one mentioned being angry; they had resigned themselves to diabetes because “you just go on.”

Participants perceived that adopting their own self-management regimen was something that worked better than traditional regimens recommended by health care providers. Consequently, self-management was on their terms. Sadly, this unconventional approach contributed to diabetic complications, disabilities, and hypoglycemic episodes.

Persistent across the interviews was the resignation of being burdened with a lifelong disease. It was a profound interruption in their lives. “It’s a bad load,” stated one participant. All were suffering with complications and disabilities, which added to their burden. They were alone, not able to leave their homes without assistance. It was one more problem to bear. For these participants, “you just go on,” is the only life and future that remains.

Chapter V

Discussion

This is the first qualitative study of rural, homebound, 65-year and older diabetics, requiring insulin. This study is the first to describe the resignation and weariness of the older diabetic and the first wherein hypoglycemia is so prominent in the lives of the participants. Hypoglycemia dictated activities of daily living, eating, and insulin administration schedule for this population. It ruled their bodies and behavior and was a major imposition in their life.

In the world of the aging, rural, homebound diabetic, the patient has dealt continuously with self-management of the disease for protracted periods of time. Through that experience they have come to rely on the signals their bodies provide to initiate treatment interventions and to manage such fundamental life functions as eating. They rely on the physiological symptoms their bodies provide which indicate the more extreme changes in blood sugar levels rather than adhering to patterned diet and regular blood sugar testing to maintain their condition within narrower, more controlled bounds.

Perhaps this is a function of age, perhaps it is part of the learning to live with, and acceptance of, the disease as a constant companion through a significant portion of their lives, but the norm is an apparent decision, conscious or otherwise, to intervene with the treatment of their diabetes only when, in their view, it is absolutely required. In this way, they are able to minimize the amount of their remaining time, spent conscious of, and actively dealing with, the realities of the disease.

The renowned world expert on aging, Baltes along with Mayer (2001) dispels the notion that quality of life inevitably declines after middle age. The SOC Model of Aging (Selection-Optimization-Compensation Model) developed by Baltes describes three factors that make the person a "successful ager." Selection refers to choices people make from the changing options available to them. Optimization is the process of making the most of opportunities to fulfill personal goals, and compensation refers to strategies used that allow people to continue to do what it important to them. The Baltes model can be applied to participants in this study although their disease limited their quality of life. They did make a selection of how they would self-manage, optimized this choice by trying to enjoy favorite foods without all the restrictions; and the compensation was evident in the strategies that allowed them to continue to live each day on their terms.

The experience of living with diabetes was grounded in world and body. Existential phenomenology views the world existing in and through the body. Thomas and Pollio (2002) write that the body is the focal point of living meanings and the place the person occupies within their world. "The lived body is worthy of serious philosophical and empirical investigation" (Thomas & Pollio, 2002, p. 52). The participants' lived experiences were manifested by their bodily responses within their world, which consisted of a restrictive environment, interrupted only with an occasional visit to the doctor or church. They “listened to their bodies” for cues to self-manage their diabetes. The participants could not “go on” unless they responded to their body; philosophically, it is where they began.

Many of our experiences are subtly affected by the quiet meanings the world holds for us (Thomas & Pollio, 2002). The participant’s world was a place they perceived they had control and made decisions (how much will I eat, what will I eat, how much insulin will I take or not take). Their world revolved around diabetes and from it emerged behaviors not supported by health care providers. But it was their world, as they perceived and experienced it, so the participants redefined and adapted to feel in control of their lives.

Participants perceived that their self-management was working. Descriptions of developing and implementing their own protocol for management seemed successful until they experienced hypoglycemia. Even with the dire consequences of this symptom, participants returned to the same management techniques once the crisis had resolved.

Zauszniewski (1996b, 1997c) determined that elders who used self-help and help-seeking strategies had better psychological well-being and physical functioning than those who did not use these strategies. However, these studies were conducted with healthy elders. Next, Zauszniewski, Chung, and Krafcik (2001) conducted a quantitative research study with 137 elders who had chronic illness. They tested the five-stage social cognitive model for predicting health of elders. These researchers reported that elders who had a greater number of chronic conditions were less resourceful than those with fewer. They attributed this to fact that physical limitations may prevent interaction with other people, which in turn, either prevents elders from developing resourcefulness or utilizing their resourcefulness.

In still another study, Zauszniewki and colleagues found that positive cognitions and acceptance of diabetes were significantly correlated (Zauszniewski, McDonald, Krafcik, and Chung, 2002). Although this was a quantitative study with type 2 diabetic women, their findings are relevant to the figural themes in this study. The researchers concluded that women who experienced greater discomfort from diabetic symptoms seemed to have stronger motivation to participate in self-management plans. The researchers recommended that nurses should develop programs which strengthen cognitive factors that help diabetics cope with their devastating symptoms of diabetes. This strategy would be applicable to the elderly participants in this study.

Implications for Nursing

Practice

Each nurse brings to clinical encounters their worldview and personal behavior that has been shaped by cultural and psychosocial factors during their growth and development. This world view influences the way nurses interpret diabetes. It involves understanding symptoms, implementing treatment, and explaining the disease to the client. When clients do not meet the goals and expectations set forth by their health care providers, they are labeled “noncompliant.” This is a judgmental term that implies a failure to act or behave appropriately. Nurses often blame the clients for not taking care of their diabetes and believe it is the client's fault if they develop complications. Especially when the nurse is making recommendations, there is an implied expectation that the instructions will be carried out by the client.

The "noncompliance" view conflicts with Margaret Newman's Theory of Health as Expanding Consciousness (1986). In this theory Newman states the person is a conscious being with a specific pattern. The person interacts with his or her environment and their health is a visible manifestation of person-environment (Newman, 1986, 1994).

In support of Newman's theory, Hernandez (1995) and Hartrick (1998) state that nurses' perspectives, and the diabetes care they deliver, often fail to address aspects of the disease that are meaningful to people living with diabetes. They believe, as does Newman, it is essential to consider personal experiences and meanings of diabetes to the person in order to provide holistic nursing care.

Newman's theory views the nurse as a facilitator to help clients focus on specific patterns. Health is expansion of consciousness. Meaning of one's existence and health is found in the process of expanding consciousness. It is not enough to treat the symptoms and the disease; nurses must treat the individual experiencing the disease. This prescribes listening to their stories as they recount what is meaningful to them. Expecting a significant change in a client's behavior simply because they are "told" what to do to improve the outcomes of their diabetes is not realistic and did not occur with the participants in this study.

Experiences related by the participants in this study do not reflect noncompliance in their view. Each described how they managed diabetes, knowing it was not considered appropriate under the instructions of their health care provider. It was, nonetheless, self-management within their world view. What is learned from this is that nurses can better understand the behavior of clients, if time is taken to ask them about their perceptions and the context in which they care for their diabetes. Nurses may come to realize the choices clients make are appropriate for them if they understand the client's perceptions and environment. Self-management practice that intrudes on important phenomena such as food preference, activity level, and health beliefs must be considered by the nurse when providing diabetic education. It is ultimately a conscious risk undertaken by the client whom the health care profession needs to understand, accept, and accommodate.

Newman (1986, 1990, 1994) recognizes dialogue as a meaningful aspect of life experiences. This theoretical perspective helps nurses prepare for interaction with clients and facilitates recognition of the client's patterns. An exemplar of lack of dialogue is found in this study's theme, "I thought I was fine, but I wasn't." As noted in the previous discussion of this theme, the participants perceived that health care providers would not listen to them; consequently, in their world, a meaningful dialogue did not occur.

The use of directives, guidelines, and continuing education courses is not likely to be successful in changing health care practices towards diabetics until nurses examine their own beliefs about diabetes and their attitudes toward its treatment. Newman's theory states the nurse must respect the client's choices. It is through self-awareness and acceptance of others that nurses can better plan and implement nursing care for the 65-year and older, rural, homebound, diabetic.

It is the nurse's responsibility, as a health care professional, to set aside preconceived notions and expectations (bracketing). Newman's theory asserts that nurses need to observe the client's pattern. The nurse needs to be aware of the environment in which the client will be taking care of their diabetes and develop teaching strategies that are realistic, appropriate, and applicable for the homebound person who will not have easy access to the health care delivery system.

Newman (1986, 1990, 1994) defined nursing as the act of assisting people to use the power within them to evolve towards higher levels of consciousness. Nursing interventions that may support the Theory of Health as Expanding Consciousness and provide pragmatic and sensible diabetes regimens within the context of a person's life include:

- Promote and assist the client to discuss their perceptions and experiences
- Present opportunities for listening
- Accept participants' perspective on self-regulation of their own regimen
- Explore options for diets realistic to the person's choice

Education

The older diabetic, living alone in remote areas, exemplifies why health care professionals need to consider the most effective methods of diabetic education.

Participants in this study were fixated on hypoglycemia. Surprisingly, no one mentioned anything about hyperglycemia; it was as though hyperglycemia did not exist, or they did not make the connection between hyperglycemia and diabetic complications. A moving exemplar of this assumption is the question from Helen, who is facing an amputation: "Do you think this has anything to do with my sugar?" Clearly, the participants had inadequate knowledge about hyperglycemia.

It is not enough to use traditional teaching methods with diabetics whose environment and world limit their ability for basic self-management skills. Newman's theory describes experiences within a cultural context and explores health as persons continuously interacting with their environment and patterning their behavior. Health care providers need to consider the pattern in which the person self-manages and moves around their physical surroundings. Physical limitations existed among all the older homebound participants in this study.

Success or failure of diabetes education may be determined by whether patients believe they are able to influence their own lives or whether they believe that external factors are in control. Implicit in this is understanding external factors in rural, homebound, older diabetics, because they may have external barriers in place now that were not there originally.

Education plans should be individualized and negotiated in partnership between nurse and client. If client's views and beliefs are not taken into account at the outset of an educational program, the end result may be perceived inadequate and lead only to short-lived changes in behavior. The development of programs and interventions to augment diabetes care will have to be collaborative, including clients, dietitians, nurses, doctors, and other experts on diabetes care so that all can agree on what is realistic. Continuing to force diabetes care into an intellectual, financial, and psychological system designed for acute care, will continue to frustrate clients and providers and may not improve blood glucose levels, complications, or the escalating costs associated with diabetes.

Nursing educators can teach future nurses ways to manage diabetes that view the person from a holistic perspective. Educators need to teach students to consider the uniqueness of each person and how they perceive their diabetes as a chronic disease. If nurses acquire a greater understanding of what it is like to live with diabetes, they may be able to expand the knowledge on present perceptions of diabetes, and contribute to the development of holistic models of diabetes care that are age appropriate.

Diabetes education is currently designed from the acute care medical perspective. Newman (1994) suggests changing the traditional view to a new view that includes the “meaningful aspect of health.” Diabetes education should teach the holistic perspective and incorporate the client’s insight and experiences.

Nurse educators need to teach students the proper attitudes, knowledge and skill to care for the 65-year and older, rural, homebound diabetic. Students need to know that this population is unique and special skills are required to care for the older population.

Beyond their diabetes needs, the older population has physical, emotional, psychosocial, and financial needs worthy of consideration. Nursing students need to be aware of their own feelings about care for the older population and learn to accommodate, without being judgmental, clients who are not amenable to their diabetes regimen. This can be accomplished by teaching students how to bracket their preconceived ideas.

Nurse educators may want to consider teaching strategies that provide nursing students with essential skills to teach diabetes to their clients. Traditionally, nurses provide diabetes knowledge to clients, then expect compliance after dispensing the necessary information for diabetes self-management. This teaching model is useful for conveying information but is not sufficient to influence personal habits (Anderson, 1986; Blais, Lucarz-Simpson, & Warwick, 1991; Clement, 1995; Donaldson, Rutledge, & Pravikoff, 1999). As the data in this study showed, personal behavior change such as physical exercise and eating habits did not occur, even though the participants knew that is what they should be doing for diabetes self-management. As a matter of fact, most were physically unable to exercise.

Diabetes self-management education needs to consider each person, not their disease. Newman's (1994) theory states that each person is a conscious being with a specific pattern and the nurse is the facilitator to help focus on the specific pattern. Nurses must not exclude behavior patterns in the course of teaching diabetes self-management. According to Newman, the nurse's responsibility is not to change the behavior, but to observe it. Nurses will not be able to function as facilitators without understanding the client's pattern and accepting it as a behavior that must be accommodated. In Newman's theory, this means the nurse must let go of control.

Gerontology should be required as part of a nursing curriculum to provide current information and research to nursing students as they learn to care for the older population. Gerontological research could be promoted by nurse educators who, in addition, could make research findings accessible to clinically based nurses to augment their knowledge and care of this population. Rural, homebound, older, diabetics need to be heard. The diabetes complication rate for this population continues to rise. Therefore it is imperative nurses listen to patients as they describe diabetes experiences. The information nurses will glean may determine how and what they will teach.

Research

Gerontological nursing care should be based on scientific knowledge generated from research. Qualitative, phenomenological research may bring to light what is essential for nurses to know in order to deliver diabetes care to the rural, homebound, patients who are a growing and vulnerable population. Additional phenomenological research could provide a unique perspective on the role of nurses in health care delivery to the 65-year and older diabetic.

Diabetes is a life long illness that is uncertain, requiring complex medical regimens and significant lifestyle adjustment (Conrad, 1987). Phenomenological health research may assist nurses to modify health care interventions for rural, 65-year and older, homebound diabetics. It is important to enable this population to achieve a balance in their lives and a sense of well-being. The present study reveals new insights into patients’ suffering that goes beyond enduring physical limitations, revealing the extent of frightening hypoglycemic episodes and despair. Through systematic phenomenological investigation of the diabetes experience, research may illuminate further insights with the disease and suffering that occurs. This may lead to a better understanding of, and care for rural, homebound, 65 year and older diabetics, who require insulin.

Conclusion

The essence of the older diabetic’s lived experience is found in the figural themes described in this study. Existential phenomenology was effective as a research methodology to understand and interpret the participants’ experiences. This method provided an advantage of having data come directly from the participants instead of being filtered through and forced into predetermined categories.

The existential phenomenological method allowed for immediate clarification of the data at the time of the interviews. This helped the researcher avoid inaccurate inferences and assumptions, and allowed participants to see that the researcher was actively listening to them. Utilizing this method affirms that the knowledge and understanding gained is complete and accurate.

Newman’s (1994) Theory of Health as Expanding Consciousness is a philosophy congruent with existential phenomenology. It is about who we are and how we perceive our lived experiences. Each person has their own reality. Their behavior and experiences are not independent of each other. Newman (1994) explains that when a person is paying attention to their inner experience, it is sensing into self. “Sensing into self” is supported and reflected in the figural theme, “Your body will let you know: If you miss it you’ll wind up in a coma.” Sensing into self kept the participants from severe hypoglycemic coma when they reacted to their scary feelings of “floating” or “passing out.”

When managing diabetes is viewed from a participant’s perspective, the issues appear more of self-regulation of one’s own regimen rather than complying with or not complying with doctor’s orders. This is a view that sees participants active in their treatment. They evaluated the orders set forth by their medical provider in comparison to what they knew about their disease. They evaluated the therapeutic efficacy of diet and medication against the possible outcomes. The decision to modify their diet and insulin was rational, from their perspective.

The results of this study challenge the traditional compliance paradigm in which current diabetes education is grounded. Newman (1986) recognizes dialogue as a meaningful aspect of life experiences. Therefore a new paradigm would promote listening to the client’s experiences and replace adherence relationships with collaborative ones between clients and nurses. Noncompliance is viewed by nurses as deviant and a problem to be remedied. This research on the lived experiences of diabetes questions this unsatisfactory compliance model.

Integrating Newman’s theory into nursing interventions, the nurse must consider the client’s pattern if any adaptations or modifications are required. It is unlikely nurses will be successful in implementing change if they do not understand the client’s pattern. The client has developed this pattern over several years, as evidenced by Libby who eats all the chocolate she wants. In order for Libby to modify her diet, the nurse, according to Newman and existential phenomenology, needs to gain insights and understanding of the client’s experiences and patterns. Nurses need to develop a conceptual perspective on managing diabetes for the older adult that is grounded in world and body. Reframing the problem may provide a new view for developing appropriate and pragmatic nursing interventions.

The distinguishing contribution of this study has been the rich description of diabetes and its interminable affect on the participants. They realized “the only way out is to die,” so they stoically “went on” without resentment or anger about their disease. The challenge for nursing is to adopt interventions that reflect and incorporate the perceptions and perspectives of the clients. This may ultimately make the difference in supporting this vulnerable population’s quality of life, for as long as possible, until “you die out of it.”

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APPENDICIES

APPENDIX A:

DEMOGRAPHICS AND QUESTIONNAIRE RESPONSE

Table 1.

Demographics and Questionnaire Response

Name	Age/Diab Length	Gen. Race	Inc	M.S.	H.S. Ed.	Self B.S.	MD B.S.	HA 1 6 mo	Eat Diff?	How Often?	Fd Avoid	Diab Ed.
1. Carol	85/ 10	F/C	SS	W	no	Broke	3/yr	DK	yes	2-3/d	Rice	TV/MD
2. Mary	84/ 39	F/AA	SS	W	no	2-3/wk	DK	DK	yes	3/d	Starch	TV/ Oth.
3. Sarah	77/ 25	F/AA	SS	W	no	0	2/yr	DK	yes	1/d	Meat	TV/Oth/ Hosp.
4. Annie	79/ 30	F/AA	SS	W	no	2/d	2/yr	DK	yes	3-4/d	Sweets	Family
5. Grace	80/ 7	F/AA	SS	M	yes	2/d	3/yr	DK	yes	3-4/d	Sweets	Clinic
6. Helen	65/ 8	F/AA	SS	W	no	1/d	2/yr	DK	yes	3-4/d	Sweets	Self/MD
7. Emily	77/ 12	F/C	SS	W	no	5/wk	2/yr	DK	yes	1-3/d	Bacon/ Lg cans	Self/ Fam.
8. Evelyn	68/ 10	F/AA	SS	W	no	3/wk	2-3/yr	DK	yes	3-4/d	Can Fd/ Sugars	Self/ Clinic
9. Kate	80/ 26	F/AA	SS	W	no	3-4/wk	2-3/yr	DK	yes	1-4/d	Eat too much	MD
10. Libby	81/ 35	F/AA	SS	W	no	2/d	2-3/yr	DK	no	3-4/d	Nothing	MD

Age/Diab. Length = current age and length of time with diabetes
Gen/Race = Gender; FC = female Caucasian; FAA = female African American
Inc. = Income, SS = Social Security, M.S. = Marital Status, H.S. Ed = graduated from high school
Self B.S. = how often self-tests for blood glucose; MD B.S. = how often doctor tests for blood glucose
HA 1 6mo = hemoglobin A1c test every 6 months: DK = doesn't know
Lg = large, fd = food

APPENDIX B:

QUESTIONNAIRE

QUESTIONNAIRE

1. How long have you known you have diabetes?
2. Have you had any special teaching about diabetes?
3. Have often do you have your blood sugar checked by a doctor or nurse?
4. How often do you check your blood sugar?
5. Have you had a hemoglobin A1C level done in the past 6 months?
6. Do you eat differently since you have known about your diabetes?
7. Do you avoid any foods?
8. How often do you eat?
9. Educational level?
10. Income adequacy?
11. Marital Status?

APPENDIX C:

AGENCY AGREEMENT

TARCOG

Top of Alabama Regional Council of Governments
115 Washington Street, S.E. Suite A • Huntsville, AL 35801-4883
Telephone (256) 533-3330 • Fax (256) 533-3442

Area Agency on Aging Economic Development Planning

Board Officers

Philip Anderson	Kenneth Baldwin	Stanley Menefee	Paula Phillips	Richard Showers, Sr.
President	*Vice President*	*Secretary*	*Treasurer*	*Ex-Officio*

Robert B. Culver - Executive Director

March 18, 2005

Ms. Sharon R. George
1426 Chandler Road
Huntsville, AL 35801

Dear Ms. George:

I am delighted that you plan to conduct a study on senior adults with diabetes, and related treatment compliance issues.

My office would be glad to work with you to make this study more successful. We could do this by identifying several senior clients who have been diagnosed with diabetes, and are currently participating in our Medicaid Waiver program. We could ask their permission to take part in the study, obtain formal consent, and after receiving that, then pass their names, addresses, phone numbers, etc. on to you so that you could contact them directly to conduct the study. I know that we share the priority of protecting the confidentiality of client information.

We agree that this is a group with identified needs, and we would welcome any information gained from your research as to how to increase the likelihood of the seniors better managing their own care with doctors' advice and medication.

Please let us know your time frame for this project, and if there is anything further we could do to help you.

Sincerely yours,

Nancy

Nancy Robertson
Director of Aging Programs

NDR:nh

APPENDIX D:

CONSENT TO RELEASE NAME/TELEPHONE NUMBER

CONSENT TO RELEASE NAME/TELEPHONE NUMBER

I give permission to be contacted by Sharon R. George regarding the research study on the experience of living with diabetes which is described in the Letter of Introduction which was given to me today.

I understand that giving my permission to be contacted does not place me under any obligation to participate in the study explained in the letter.

I agree to have my name and telephone number released to Sharon R. George.

Name: ________________________________

Telephone Number: ______________________

Agency: _______________________________

Agency Representative: ___________________

APPENDIX E:

INTRODUCTION TO THE STUDY

Introduction to the Study

You are invited to participate in a study which will explore your experiences, thoughts, and feelings about your diabetes. A goal of this study is to obtain formation that will help health professionals to better provide assistance for people with diabetes.

You will be asked to participate in a 60-90 minute audiotaped interview in your home and at a time of your choice. You will be asked to share your experiences, thoughts, and feelings about your diabetes. You may be contacted by me after the interview to make sure I have understood your comments and thoughts. At least 15 diabetics will be included in this study.

There is little risk to participating in this study. Some people may find it upsetting to discuss their problems and experiences. You may find it beneficial to discuss your experiences with diabetes. You are under no obligation to participate in this study, you can withdraw any time you want, and your decision will have no effect on any services that you are receiving or will receive in the future.

If you are interested in participating in this study, please sign the form giving this agency permission to release your name and telephone number to me. I will be telephoning you in two to four weeks to further explain the study and answer any questions that you may have. If you are still interested in participating after our telephone conversation, we will arrange an interview time that is convenient for you. If you should wish to speak to me before I telephone you, I can be reached at (256) 824-2440. If you choose to participate in this study, any information given will be treated in a confidential manner and your privacy will be protected in any presentations, publications, or reports of findings from the study.

I want to thank you for taking the time to consider being in this study. If you decide to participate, I will be happy to answer any questions you may have and provide you with a diabetes pamphlet afterwards.

Investigator:
Sharon R. George, RN, MN (256) 824-2440
Doctoral Candidate, College of Nursing, University of Tennessee, Knoxville

APPENDIX F:

INFORMED CONSENT

Informed Consent

I have been told about a study that Sharon George is doing on living with diabetes. This research is part of the requirements for her doctorate. The purpose of this study is to discover my experiences, thoughts, and feelings about diabetes.

She wants to speak with me because I am a person aged 65 or older, have diabetes, and live in a rural community. Mrs. George says that what she learns from me and the others in her study may help other diabetic people. Health care providers will have a better idea about what people with diabetes want and need to live a better life.

This study is not about my state of health, or about how well I keep up with my diet or insulin. I will not be asked questions about how I take my insulin or other medications. Mrs. George will not make any judgment or offer her opinions about my care. Any questions about my condition will be referred back to my regular health care provider or the agency that helped Mrs. George contact me.

I understand she will interview me about my experiences being diabetic. The interviews will be audiotaped, and will last about an hour. However, on the day she comes to talk with me, I can talk as long as I need to about my diabetes.

All interviews will be kept confidential. After the interview is completed, Mrs. George will have a professional secretary type up the conversations that have been recorded on tape, and the secretary will erase any names or identifying data, such as the names of doctors or towns, from the tapes. My name and my family's name will not be used and no one will be able to tell we were part of this study. At no time will my words be identifiable with my name. All interview tapes will be kept locked in a file cabinet in Mrs. George's office for a period of 3 years. After that, the tapes will be destroyed.

Participant's Initials_________

While many people have found it helpful to talk about their diabetes, for others, talking about diabetes or other health concerns may bring out some unpleasant feelings such as worry. Mrs. George is not a counselor and can’t help me that way, but she will give me the names and phone numbers of agencies that I can call.

I know that I am under no obligation to participate in this study. I have been told that I am free to answer or not answer any questions. I can withdraw any time I want, and my decision will have no effect on any services that I am receiving or will receive in the future. My audiotape will be destroyed if I withdraw from this study.

If I have questions at any time about the study or the procedures, I may contact Mrs. George. The contact information appears below. If I have questions about my rights as a participant, I can contact the University of Tennessee, Knoxville, Compliance Section of the Office of Research at (423) 974-3466, or write them at 1534 White Avenue, University of Tennessee, Knoxville, Tennessee 37996-1529.

Principal Investigator:

Sharon R. George, MN, RN
Doctoral Candidate
University of Tennessee, Knoxville
College of Nursing
Phone: (256) 824-2440

Program Director:

Dr. Sandra Thomas
University of Tennessee
College of Nursing
1200 Volunteer Boulevard
Knoxville, Tennessee 37996
Phone: (865) 671-2213

I have read the above information and agree to participate in this study. I have had the study explained to me and I have been given an opportunity to ask questions. I understand that I may ask further questions at any time in the future by contacting the investigator. I have received a copy of this consent form.

Participant’s Name (Print) ____________________________________

Participant’s Signature ______________________________________

Date______________

APPENDIX G:

TRANSCRIPTIONIST CONFIDENTIALITY AGREEMENT

Transcriptionist Confidentiality Agreement

As the transcribing typist for this research project, “The Lived Experience of Rural, 65-Year and Older, Homebound, Insulin Dependent Diabetics,” I understand that I will be listening to tapes of confidential interviews. The information on these tapes has been revealed by participants who have volunteered in good faith, assured that their interviews would remain strictly confidential. I understand that I have a responsibility to honor this confidentiality agreement. I hereby agree not to share any information in these tapes with anyone other than the investigator, Sharon George, M.N., R.N. Any violation of this agreement would constitute a serious breach of ethical standards, and I pledge not to do so.

____

Transcribing Typist Name (Print)

____

Signature Date

APPENDIX H:

PHENOMENOLOGY GROUP CONFIDENTIALITY AGREEMENT

Phenomenology Group Confidentiality Agreement

As a member of this phenomenology group, I understand that I will be reading transcripts of confidential interviews for the research study, “The Lived Experience of Rural, 65-Year and Older Homebound, Insulin Dependent Diabetics.”

The information in these transcripts has been revealed by research participants who have volunteered in good faith, assured that their interviews would remain strictly confidential. I understand that I have a responsibility to honor this confidentiality agreement. I hereby agree not to share any information in these transcripts with anyone other than the investigator, Sharon George, M.N., R.N. or other members of this phenomenology group. Any violation of this agreement would constitute a serious breach of ethical standards, and I pledge not to do so.

Signatures	Date

VITA

Sharon Amanda Robbins George was born in Rumford, Maine on March 21, 1948. After graduation from Dixfield Regional High School in 1966, she attended New England Baptist Hospital School of Nursing in Boston, Massachusetts where she earned a Diploma in Nursing in 1969. She graduated from the Medical College of Georgia, Augusta, Georgia in May 1976, receiving a Bachelor of Science in Nursing. She was awarded a Masters of Nursing degree in Adult Medical-Surgical Nursing from the University of Washington, Seattle, Washington in May 1984.

She practiced nursing in Frankfurt, Germany as a civilian nurse at the 97th General Army Hospital for two years, where she was awarded the Army Commendation Award for meritorious service. She has held numerous nursing positions in inpatient, outpatient, community, and education. She has practiced nursing for 33 years and has taught nursing 27 years. She is a volunteer for the American Cancer Society and The American Red Cross. She is a wife and mother of three children. She is a member of Sigma Theta Tau, Omicron Delta Kappa, Who’s Who Among Americas Teachers, Southern Nursing Research Society, and the American Nurses Association. In 2001, she was admitted to the doctoral program in the College of Nursing at the University of Tennessee in Knoxville. She received her Doctorate of Philosophy in Nursing from the University of Tennessee in Knoxville, December, 2005.