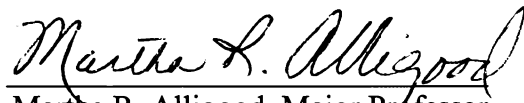


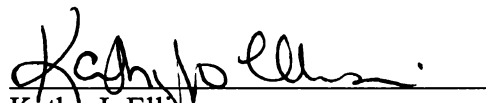
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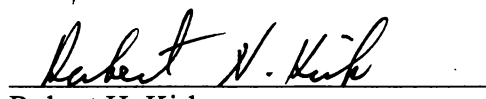
I am submitting herewith a dissertation written by Gregory Allen Casalenuovo entitled "Fatigue in Diabetes Mellitus: Testing a Middle Range Theory of Well-Being derived from Neuman's Theory of Optimal Client System Stability and the Neuman Systems Model." I have examined the final paper copy of this 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.


Martha R. Alligood, Major Professor

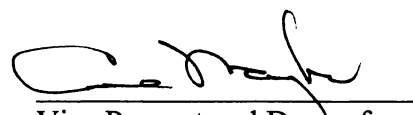
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FATIGUE IN DIABETES MELLITUS: TESTING A MIDDLE RANGE
THEORY OF WELL-BEING DERIVED FROM NEUMAN'S THEORY OF
OPTIMAL CLIENT SYSTEM STABILITY AND THE NEUMAN SYSTEMS
MODEL

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

Gregory Allen Casalenuovo
May 2002

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DEDICATION

This dissertation is dedicated to my wife, Judy, and to my children Tiffani, Spencer, and Allison, who have given me unending love and support during the last several years as I pursued my doctoral education. I also dedicate this work to my mother, Mary Tanner, who has given me invaluable educational opportunities through her support and love.

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Finally, I want to thank Dr. Bob Martin and Mrs. Debbie Martin for their ongoing friendship throughout this process. They provided prayer and support during my defense and much needed editorial review and assistance.

ABSTRACT

The purpose of this study was to test a middle range theory of well-being in adults with diabetes mellitus derived from Neuman's Theory of Optimal Client System Stability and the Neuman Systems Model. The relationships among stress, well-being, and fatigue in adults living with diabetes mellitus were examined to test the theory that disruption in well-being in adults living with the stress of diabetes mellitus leads to greater fatigue.

Data were collected from a convenience sample of 87 adults with Type 1 and Type 2 diabetes mellitus. Subjects completed a questionnaire packet that was designed to elicit demographic information, a measure of their stress related to living with diabetes mellitus, a measure of the physiological, psychological, sociocultural, developmental, and spiritual well-being, and a measure of their level of fatigue. Data were analyzed using bivariate correlation and hierarchical multiple regression.

The findings of this study revealed initial support for the relationships proposed by the middle range theory of well-being. Stress scores ranged from 2 – 70 (possible 0 – 80) with a mean of 26.14, standard deviation of 18.21, and a median of 20 and supported that living with diabetes mellitus is a stressor. Stress was significantly correlated with all variables and in the anticipated direction and supported that stress of living with diabetes mellitus is disrupting to client well-being. Fatigue scores ranged from 9 – 63 (possible 9 – 63) with a mean of 38.83, standard deviation of 14.66, a median of 39.00, and a mode of 63 and supported that disrupting client well-being leads to energy depletion. Finally, stress and

well-being accounted for 32% of the variance in fatigue scores and provided support for the proposed theory. Additionally, the psychological interacting variable of well-being best explained the functioning of the overall well-being in this sample.

This study provides the initial testing of the Theory of Well-Being and establishes the groundwork for a program of research. Implications for nursing practice include nursing interventions directed at strengthening client well-being to reduce fatigue. Recommendations for research included further testing of the theory and instrument development.

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CHAPTER I

INTRODUCTION

Chronic illness is an altered health state that is not corrected by surgical technique or a course of medical therapy. Chronic illness lasts more than 6 months and the demands of the illness never completely abate. Chronic illness accounts for the majority of illness in the United States. In 1998, of the top ten illnesses responsible for the deaths of Americans, six of them were chronic illnesses including coronary artery disease, malignant neoplasms, cerebrovascular disease, chronic obstructive pulmonary disease, diabetes mellitus, and chronic liver disease (Murphy, 2000). It is well established that living with a chronic illness is stressful and diabetes mellitus is no exception (Sidell, 1997).

Diabetes mellitus is a chronic illness affecting approximately 16 million people in the United States. It is estimated that over 150,000 people will die from diabetes mellitus annually and the financial cost of diabetes mellitus will exceed 100 billion dollars each year (American Diabetes Association, 2000). In Tennessee, approximately 194,000 adults are diagnosed with diabetes mellitus, accounting for 4.9% of the adult population. The financial burden in Tennessee is about \$8.8 billion annually (American Diabetes Association, 2000).

Diabetes mellitus is a disorder of glucose metabolism. The individual with diabetes mellitus either does not have enough insulin for proper glucose metabolism or the insulin produced does not work properly. The role of insulin is to allow for the movement of glucose from the blood stream into the cell with the glucose then utilized as a source of energy. If insulin production is too little or

the insulin is unable to perform properly, the result is an abnormally elevated blood glucose level.

There are two predominant types of diabetes mellitus. Type 1 diabetes mellitus is an autoimmune destructive disease of the islet of Langerhans cells of the pancreas. When the islet cells are destroyed, eventually there is no insulin produced for adequate glucose metabolism. Usually beginning in childhood or adolescence, about 10% of the people with diabetes mellitus have Type 1.

Type 2 diabetes mellitus is the form of the disease that usually begins in adulthood. The insulin production in Type 2 diabetes mellitus may be normal, elevated, or decreased; however, the body is unable to utilize the insulin produced. The end result is the same as with Type 1, inadequate glucose metabolism. About 90% of the people with diabetes mellitus have Type 2.

The treatment for both types of diabetes mellitus is essentially the same, with the significant difference being the need for medication. With Type 1 diabetes mellitus, the individual requires insulin injections to replace the missing insulin. With Type 2 diabetes mellitus, the individual may or may not require medication. If medication is required, oral hypoglycemic agents (pills), insulin by injection, or a combination of both may be used to improve glucose metabolism. With both types of diabetes mellitus, diet, exercise, and self-monitoring of blood glucose levels are all used to maintain adequate control of the blood glucose levels.

Diabetes mellitus is a stressful chronic illness, requiring significant life-style changes in order to manage it effectively. Individuals with diabetes mellitus

strive to balance the demands of self-care and the need for 'normalcy' in their daily lives. This balance is achieved when the individual with diabetes mellitus decides to assume control and actually does assume control. Assuming control involves significant learning and requires supportive and collaborative relationships (Paterson, Throne, & Dewis, 1998).

Diabetes mellitus affects every aspect of an individual's life. It places constant and daily demands on the individual and family while often having an unpredictable course. Living with diabetes mellitus requires frequent adjustments to management and often, despite the best management efforts one can muster, complications from diabetes mellitus still occur. Still, individuals can lead satisfying and productive lives (Gregg, Robertus, & Stone, 1989; Landis, 1996; Pollock, 1989).

Emotional responses to living with diabetes mellitus are varied and play into the stressful nature of the illness. During the initial period of learning that diabetes mellitus is present, the individual may experience anxiety, depression, and frustration. As the disease progresses, there is depression and fear about the short-term complications. As the disease reaches the end of its progression, helplessness and hopelessness may develop as long-term complications occur, adding new stress on the individual and family (Gregg, Robertus, & Stone, 1989).

In addition to the emotional responses identified, there are common fears related to living with diabetes mellitus, and apprehension regarding the management routine required for control. They are "(1) fear of uncertain future and physical deterioration, (2) concerns about insulin reaction, (3) fear of medical

complications, (4) worries regarding sexual performance, (5) concerns related to professional and other life goals, and (6) fear of early death” (Livneh & Antonak, 1997, p. 208). Thus, the stress of living with diabetes mellitus can be overwhelming to the individual.

Nursing has long recognized the importance that stress and the reaction to stress play in the role of health. Stress, as a term, appeared in scientific literature in the 1930's and in the nursing literature in the 1950's. For nursing, it has become a construct used in practice and research. Nursing theory development has evolved around the stress concept (Leidy, 1989; Lyon, 2000).

In the 1950's, Hans Selye described the reaction to stress, known as the General Adaptation Syndrome, as the response to stressors. Stressors were the noxious stimuli that initiated the response. He described three successive stages of reaction to stress: alarm reaction, stage of resistance, and stage of exhaustion. The alarm reaction is the stage in which the individual's body activates an all out defense toward the stress. This is a non-specific response (Selye, 1976).

The continuance of stress leads to the stage of resistance. This stage has become known as the 'fight or flight' reaction. Adaptive energy is directed toward reversal. Resistance is focused on the facilitation of adaptation to the stress exposure and is characterized by the utilization of a genetically determined quantity of adaptive energy (Leidy, 1989; Lyon, 2000; Selye, 1976).

With unrelenting or severe stress, the body is no longer able to contend with the stressors and the stage of exhaustion follows and can lead to the development of diseases of adaptation. This final stage is characterized by the

depletion of the individual's adaptive energies, resulting in generalized fatigue and sense of exhaustion. However, these adaptive energies can be replenished from reservoirs throughout the body (Leidy, 1989; Lyon, 2000; Selye, 1976).

With prolonged exposure to the recognized stressors of living with diabetes mellitus, a reaction or instability may develop. Fatigue, as a protective mechanism, is an index of the effect of stress on the adaptive mechanisms.

Fatigue is a self-recognized state in which the individual perceives a sense of tiredness, weariness, exhaustion, and a decreased ability to complete necessary physical and/or mental tasks (Aistars, 1987; Norris, 1982).

Most people describe a fatigue state at some point in their lives. Fatigue was originally used as a lay term for self-realized inadequacy associated with feelings of weakness (Hart & Freel, 1982). It has also been described as a multidimensional, complex phenomenon that influences the activities in which an individual chooses to engage (Gardner, 1991; Nail & King, 1987). More recently, it has been defined as "the awareness of a decreased capacity for physical and/or mental activity due to an imbalance in the availability, utilization, and/or restoration of resources needed to perform activity" (Aaronson, et al., 1999, p. 46).

Fatigue is a part of daily life in both wellness and illness states. Individuals experience fatigue after a hard day's work or after an exercise session. After being up late at night, an individual may encounter fatigue the next day.

Nursing's interest in fatigue stems from the fact that individuals with acute and chronic illnesses come to nurses with their complaints of fatigue. The fatigue

may be directly associated with their illness or an effect of their therapies and thus occurs in a variety of situations. Therefore, nurses are often the health care providers who intervene in response to clients' need for relief from this condition.

Fatigue has been researched in both wellness and illness states. Early researchers conducted studies in aviation and industrial settings, as well as with daily activities such as driving automobiles. This early research provided the foundation for fatigue research to move into the health care arena, specifically with illness states.

During the early period of fatigue research, the focus of study was on healthy individuals and the population of research subjects was in industry. Fatigue Research Board of England carried out extensive research based in industry. The studies dealt with the ideas of work hours, shift change, lighting, ventilation, and work place design. It was during this time that Muscio (1921) suggested the abandonment of the term fatigue because what was called fatigue was not a single entity, but a variety of unrelated phenomena. Not everyone shared Muscio's view, believing that the difficulty in defining fatigue was in a failure to appreciate its complexity (Piper, 1989). Poffenberger (1928), during the same period, developed the first tool to measure tiredness.

While the focus of fatigue research continued within industry, it was during the 40's and 50's that the focus of the research broadened to aviation. While not considering the subjective aspects of fatigue, Bartley and Chute (1947), in their seminal work on fatigue, provided a much more thorough monograph on the subject than had been previously done. They emphasized the complex nature

of the phenomenon and for the first time introduced the notion that normal processes of rest did not relieve chronic fatigue.

Tool development for fatigue continued during this period as well. Pearson and Byars developed their tiredness scale for airmen (Pearson, 1957). The Pearson Byars Fatigue Feeling Checklist was developed to measure the subject's fatigue at the time of checklist completion. It was also during this time that Dorpat and Holmes (1955) first linked the occurrences of fatigue with a health alteration, pain.

The focus of fatigue research has continued to broaden. Brown (1967) and Crawford (1961) studied driving and accident involvement and their relationship to fatigue. It was in the 1960's that the first international fatigue conference was held (Piper, 1989). This early fatigue research has provided a solid foundation from which research in illness has been developed.

Several disciplines have examined fatigue in chronic illness. Various chronic illnesses have been the focus of investigations in medicine, health psychology, and nursing. Studies have been conducted with chronic illness populations such as cancer (Blesch, et al., 1991; Irvine, Vincent, Graydon, Bubela, & Thompson, 1994; Jamar, 1989; Rhodes, Watson, & Hanson, 1988), rheumatoid arthritis (Belza, Henke, Yelin, Epstein, & Gilles, 1993; Crosby, 1991), congestive heart failure (Schaefer, 1990; Schaefer & Potylycki, 1993), end-stage renal disease (Srivastava, 1989), human immune virus infection (Darko, McCutchan, Kripke, Gillin, & Golshan, 1992), Parkinson's disease (Friedman & Friedman, 1993), brain injury (LaChappelle & Finlayson, 1998), unilateral

neglect (Robertson & North, 1993), and multiple sclerosis (Ford, Trigwell, & Johnson, 1998; Hart, 1978). However, despite the amount of published research on fatigue in chronic illness, reports of research on fatigue in diabetes mellitus have not been published in the nursing or health care literature.

Statement of Problem

In clinical practice as a diabetes nurse specialist, many clients with diabetes mellitus have reported fatigue. They described varying degrees of fatigue, and the causes they suggested for its presence also varied from client to client. At times, fatigue prevented clients from being able to complete the daily tasks needed to manage their diabetes mellitus because of an actual lack of energy or the feeling that they did not want to do anything. At times, this lack of energy added to the loss of metabolic control of their diabetes, which further aggravated their fatigue states.

Because of the tediousness of living with diabetes mellitus every day and not being able to take a break from the routine of management, this fatigue also creates stress in their lives. This multidimensional aspect and stressful nature of living with diabetes mellitus is characteristic of living with any chronic illness (Moos, 1977; Taylor & Aspinall, 1993; Woods, Yates, & Primono, 1989). In addition to the reports of fatigue from clients, they also asked questions about what could be done to alleviate the fatigue or prevent its recurrence. Thus, the lack of understanding about the nature of fatigue in this client population points to the need to formally study this clinical problem to generate knowledge to support the nursing care of the growing population of individuals with diabetes mellitus.

Since the mechanisms of fatigue in diabetes mellitus are not completely understood, there is a need to study the various factors that may influence the nature of fatigue and its development. It is proposed that fatigue in diabetes mellitus develops from a disruption of client well-being. The Neuman Systems Model, specifically Neuman's Theory of Optimal Client System Stability, provides a wholistic framework to study these factors in persons with diabetes mellitus who identify themselves as experiencing fatigue. The five interacting variables of well-being: physiological, psychological, sociocultural, developmental, and spiritual, may act singly or in combination and may lead to the development of fatigue that hinders the individual's ability to perform to his or her usual capacity. No study has been reported in the literature that explored fatigue in persons with diabetes mellitus. Thus, the experience of fatigue in diabetes mellitus warrants investigation.

Purpose of the Study

The purpose of this study was to test a middle range theory of well-being in adults with diabetes mellitus derived from Neuman's Theory of Optimal Client System Stability and the Neuman Systems Model. The relationships among stress, well-being, and fatigue in adults living with diabetes mellitus were examined to test the theory that disruption in well-being in adults living with the stress of diabetes mellitus leads to greater fatigue.

Research Question

The following research question was explored in this study. What are the relationships among stress, well-being, and fatigue in adults with diabetes mellitus?

Ancillary Question

The following ancillary question was explored in this study. Which interacting variable of well-being (physiological, psychological, sociocultural, developmental, or spiritual) best explains the functioning of the normal line of defense in adults living with the stress of diabetes mellitus?

Theoretical Perspective

Neuman Nursing Science

Betty Neuman first developed the Neuman Systems Model in 1970 as a teaching model for graduate nursing education at the University of California, Los Angeles. Neuman published her first article about the model in 1972 and her first book chapter in 1974. Her book explicating the model is now in its fourth edition (Neuman, 2002). The first use of the model with baccalaureate nursing education was in 1975 at Neumann College in Aston, Pennsylvania. In addition to the United States, it is currently used in Canada, Europe, Australia, China, Japan, and Korea. As a nursing model, it provides a full representation of the discipline of nursing, serving as a curriculum guide, guiding clinical practice in a variety of settings, and providing guidelines for nursing research (Lowry, Hinton-Walker, & Mirenda, 1995; Neuman, 1997).

Betty Neuman and the Neuman Systems Model have contributed significantly to the body of nursing science. In developing the Neuman Systems Model, she drew principles from Gestalt, stress, and dynamically organized system theories. Her purpose in developing the model was to organize nursing within a broad systems perspective to provide a logical approach for students who were dealing with the growing complexity of the nursing field (Neuman, 2002).

The Neuman Systems Model has been used extensively in practice, education, and research. Research utilizing the model has focused on various areas of nursing in clinical practice, administration, and education. Clinical practice research has been conducted in acute and chronic illness populations. The chronic illness populations that have been utilized include cancer (Ali & Khalil, 1989; Blank, Clark, Longman, & Atwood, 1989; Hinds, 1990; Loescher, Clark, Atwood, Leigh, & Lamb, 1990; Molassiotis, 1997; Sabo & Michael, 1996), multiple sclerosis (Crigger, 1996; Knight, 1990), pain (Koku, 1992; Radwanski, 1992), ventilator dependency (Lowry & Anderson, 1993), acquired immunodeficiency syndrome (Peri, 1995), and laxative dependency (Rodrigues-Fisher, Bourguignon, & Good, 1993). Despite the wide array of research utilizing the Neuman Systems Model, no studies have been reported that drew their sample from the diabetes mellitus population. Thus, there is a need to further Neuman science in this clinical area of nursing practice.

Neuman Systems Model

The Neuman Systems Model is a wellness model that uses a system theory approach with the person or client as a wholistic, multidimensional system open

to interaction with environmental stressors. Stress and reaction to stress are the two major components of the model. The first priority of nursing is to determine the nature of the stressors and their threat to the client system (Neuman, 2002).

While the Neuman Systems Model incorporates all phases of the nursing process, there is an emphasis on assessment and intervention. The client is assessed for the effects of environmental stressors and then assisted with personal adjustments necessary for an optimal wellness level. "Optimal means the best possible health state achievable at a given point in time" (Neuman, 2002, p. 25).

According to the Neuman Systems Model, the client's central core, basic structure and energy resources, are surrounded by a series of concentric circles. These concentric circles represent the protective mechanisms of the client's central core or system integrity. Each concentric circle contains similar but distinctive protective elements and functions in five interacting client variables: physiological, psychological, sociocultural, developmental, and spiritual (Neuman, 2002).

The normal line of defense represents the usual wellness level of the client. It is the normal adaptational level of health for a client and is the standard for determining deviancy from the usual wellness state. It is developed over time and is the result of previous behavior, defining stability of the system. System stability is the state of balance requiring energy exchange as adequate coping takes place to retain, attain, or maintain system integrity (Neuman, 2002).

Stressors are stimuli that produce tension from within the internal and external environments of an individual and there may be more than one stressor at

any one time interacting with an individual. Stressors are classified as intrapersonal, interpersonal, or extrapersonal and have the potential to produce a reaction within an individual. Intrapersonal stressors are “internal environmental forces occurring within the boundary of the client/client system, for example, conditioned response or autoimmune response” (Neuman, 2002, p. 22).

Interpersonal stressors are “external environmental interaction forces occurring outside the boundaries of the client/client system at proximal range, for example, between one or more role expectations or communication patterns” (Neuman, 2002, p. 22). Extrapersonal stressors are “external environmental interaction forces occurring outside the boundaries of the client/client system at distal range, for example, between one or more social policies or financial concerns” (Neuman, 2002, p. 22). The time of stressor occurrence, nature of stressor, intensity of stressor, condition of individual at time of stressor occurrence, and the amount of energy required to adjust are important factors (Neuman, 2002).

Surrounding the normal line of defense is the flexible line of defense. It represents a protective cushioning system for the client’s normal line of defense and protects the client from stressor invasion. It is illustrated as accordion-like, contracting and expanding in response to stressors. It expands to provide greater protection when needed. In the expanded state, it serves to keep the client free from reactions to stressors, while in the contracted state it provides little protection. Thus, the flexible line of defense represents the client system cushioning in relation to stressors (Neuman, 2002).

Since the variables in the flexible line of defense are subject to rapid change, they are best conceptualized as acquired situational variables, not ones that have become an inherent and stable part of the client. Examples include perceived social support and current nutritional status (Gigliotti, 1997).

The lines of resistance are those protective factors surrounding the central core of the client, which are activated when the normal line of defense has been penetrated. When the lines of resistance have been penetrated, the client demonstrates reaction symptomatology. If the lines of resistance are effective in reversing the reaction to stressors, reconstitution toward wellness is facilitated. Ineffective reconstitution leads to energy depletion and death. Thus, the lines of resistance represent client system resistance in relation to stressors (Neuman, 2002).

Because the variables of the lines of resistance are activated after a stress reaction and are learned over time, they have become stable and inherent variables in the client. They may be either natural or acquired. Examples include personality type or coping responses (Gigliotti, 1997).

Neuman views health of the client as a continuum with wellness and illness on opposing ends. Embedded in this continuum is the flow of energy between the client and the environment. Wellness or “optimal client stability” represents adequate energy levels for harmonious functioning of the five interrelated variables, that is, physiological, psychological, sociocultural, developmental, and spiritual, of the total system needs being met. Optimal system stability is “the best possible wellness state at any given time” (Neuman,

2002, p. 23). Illness, or a reduced state of wellness, represents a state of depleted energy, which if not corrected, will ultimately lead to death of the client (Neuman, 2002).

Neuman's Theory of Optimal Client System Stability

Derived from the Neuman Systems Model, Neuman's Theory of Optimal Client System Stability utilizes the metaparadigm definitions and concepts of the Neuman Systems Model as the basis for the more concrete definitions needed for a middle range theory. Neuman's Theory of Optimal Client System Stability proposes that stressors are capable of disrupting the stability of the client system and consequently disturbing energy balance.

A client system is exposed to stressors in the environment. These stressors are tension-producing forces that have the potential to disrupt system stability, the state of balance requiring energy exchange to retain, attain, or maintain system integrity and wellness. The usual level of wellness for the client system represents adequate energy levels for harmonious functioning of the five interacting client variables. Ideally, the composite of the five interacting client variables provides stable functioning in relation to stressors (Neuman, 2002).

A reaction to stress occurs when the normal line of defense has been penetrated and the lines of resistance have been activated. In a stable client system, if the lines of resistance are effective in reversing the reaction to stressors, reconstitution leads to energy balance. Ineffective reconstitution leads to energy depletion and reaction symptomatology is not reversed (Neuman, 2002).

Neuman's Theory of Optimal Client System Stability is based on the following assumptions from the Neuman Systems Model (Neuman, 2002):

1. Each individual client or group as a client system is unique; each system is a composite of common known factors or innate characteristics within a normal, given range of response contained within a basic structure (p. 14).
2. The client as a system is in dynamic, constant energy exchange with the environment (p. 14).
3. Many known, unknown, and universal environmental stressors exist. Each differs in its potential for disturbing a client's usual stability level, or normal line of defense. The particular interrelationships of client variables – physiological, psychological, sociocultural, developmental, and spiritual – at any point in time can affect the degree to which a client is protected by the flexible line of defense against possible reaction to a single stressor or a combination of stressors (p. 14).
4. Each individual client/client system, over time, has evolved a normal range of response to the environment that is referred to as a normal line of defense, or usual wellness/stability state. It represents change over time through coping with diverse stress encounters. The normal line of defense can be used as a standard from which to measure health deviation (p. 14).
5. When the cushioning, accordion-like effect of the flexible line of defense is no longer capable of protecting the client/client system against an environmental stressor, the stressor breaks through the normal line of defense. The interrelationships of variables – physiological,

psychological, sociocultural, developmental, and spiritual – determine the nature and degree of the system reaction or possible reaction to the stressor (p. 14).

6. The client, whether in a state of wellness or illness, is a dynamic composite of the interrelationships of variables – physiological, psychological, sociocultural, developmental, and spiritual. Wellness is on a continuum of available energy to support the system in an optimal state of system stability (p. 14).
7. Implicit within the client system are internal resistance factors known as lines of resistance, which function to stabilize and return the client to the usual wellness state (normal line of defense) or possibly to a higher level of stability following an environmental stressor reaction (p. 14).

Neuman's Theory of Optimal Client System Stability proposes that stressors are capable of disrupting the stability of the client system and consequently disturbing energy balance.

A Middle Range Theory of Well-Being

Derived from Neuman's Theory of Optimal Client System Stability, this middle range theory of well-being developed for this research proposes that disruption in well-being in adults living with the stress of diabetes mellitus leads to greater fatigue. Therefore, this theory provides an explanation of the development of fatigue in diabetes mellitus.

The relationship statements for this theory are:

- (1) If living with diabetes mellitus is a stressor, and
- (2) if the stress of living with diabetes mellitus is disrupting to client well-being, and
- (3) if disrupting well-being in clients living with the stress of diabetes mellitus leads to depletion of energy,
- (4) then disruption in well-being in adults living with the stress of diabetes mellitus leads to greater fatigue.

A conceptual-theoretical-empirical structure of this middle range theory of well-being is shown in Figure 1 (Fawcett, 2000).

Definitions of Terms

For the purposes of this study, the following definitions were used:

- (1) Living with diabetes mellitus was the stressor as measured by the total score on the Problem Areas in Diabetes Survey instrument.
- (2) Well-being was the client's level of stability and was measured in each of the five interacting variables:
 - (a) physiological well-being was the hemoglobin A1C result within the last 3 months,
 - (b) psychological well-being was the total score on the Well-Being Questionnaire 12,
 - (c) sociocultural well-being was the total score on the Social Well-Being Index,

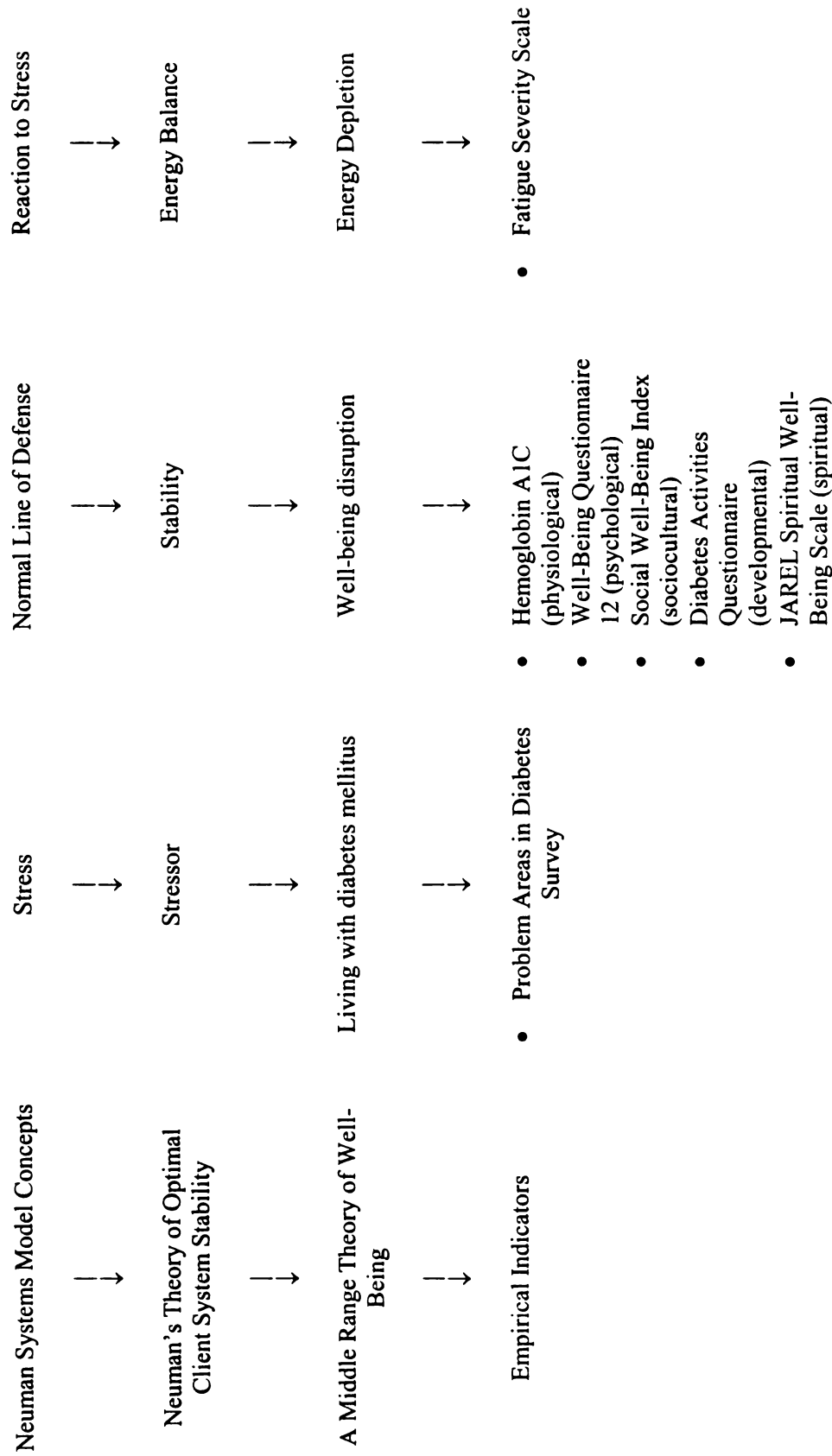


Figure 1: Conceptual-Theoretical-Empirical Structure for Testing a Middle Range Theory of Well-Being

- (d) developmental well-being was the total score on the Diabetes Activities Questionnaire, and
 - (e) spiritual well-being was the total score on the JAREL Spiritual Well-Being Scale.
- (3) Fatigue was a manifestation of client system instability as measured by a total score on the Fatigue Severity Scale.

Limitations and Delimitations of the Study

1. This beginning study was delimited to a convenience sample of adults, aged 25 – 84.
2. This study was conducted in one geographic area.
3. This study was conducted with one endocrinologist's office practice.

Significance of the Study

The findings of this study support a growing body of knowledge related to fatigue in chronic illness. Fatigue in the chronic illness of diabetes mellitus had not been studied; therefore, this study contributes knowledge of diabetes mellitus to the list of representative chronic illnesses. Expanding the list of chronic illnesses will further expand our understanding of fatigue in chronic illness as it provides yet another source of comparison for the body of knowledge related to fatigue in chronic illness.

Second, the findings of this study contribute to a body of knowledge regarding living with diabetes mellitus. Currently, the literature reflects that the daily routines needed for management of diabetes mellitus are stressful and tedious. Clinical practice supports this notion that fatigue is a frequent complaint

in this client population. This study extended knowledge by measuring stress levels in persons with diabetes mellitus in relation to well-being. Therefore, this study contributes to the development of an understanding of fatigue in this population. Further, this study provides an additional perspective and new knowledge about persons living with diabetes mellitus.

Third, the use of a wholistic model provides a comprehensive framework that addresses aspects of the human experience not previously reported in research on fatigue. This study is significant in that it examines the relationship between spirituality and fatigue in this diabetes mellitus sample.

Finally, the findings contribute to nursing science utilizing the Neuman Systems Model. This study supports the use of the Neuman Systems Model and Neuman's Theory of Optimal Client System Stability as a framework from which middle range theories can be derived (Alligood, 2002). Studies that address nursing practice questions with a wholistic nursing perspective generate nursing outcomes and contribute to the discipline of nursing. Additionally, the stress of living with diabetes mellitus, the functioning of client well-being, and fatigue as a reaction in adults with diabetes mellitus has not been the focus of studies utilizing the Neuman Systems Model. Therefore, this study demonstrates the utility of the Neuman Systems Model for both nursing research and nursing practice.

CHAPTER II

REVIEW OF THE LITERATURE

The purpose of this study was to test a middle range theory of well-being in adults with diabetes mellitus derived from Neuman's Theory of Optimal Client System Stability and the Neuman Systems Model. The relationships among stress, well-being, and fatigue in adults living with diabetes mellitus were examined to test the theory that disruption in well-being in adults living with the stress of diabetes mellitus leads to greater fatigue. This chapter will review the literature on the concept of fatigue, research on fatigue in chronic illness, and the impact of living with diabetes mellitus as a stressor.

Fatigue

Definitions and Descriptions of Fatigue

Definitions and descriptions of fatigue are found throughout the literature of industry, medicine, and physiology. Fatigue is a complex multidimensional phenomenon. It has been associated with discomfort, decreased mental and motor skills, and increased aversion to tasks. Fatigue also has been described as the failure to sustain some form of physical activity, a consequence of muscular activity. Fatigue is a protective mechanism, an index of the effect of early stress on adaptive mechanisms. Fatigue is described as universal, occurring with almost every illness and is often the first indication of a disease process (Aistars, 1987; Grandjean, 1970; Hargreaves, 1977; Holder-Powell & Jones, 1990; Kroenke, Wood, Mangelsdorff, Neier, & Powell, 1988; Manu, Lane, & Matthews, 1988; Norris, 1982).

Numerous definitions and descriptions of fatigue have been given in the nursing literature. Fatigue is described as a subjective, self-recognized state of tiredness, weariness, weakness, and exhaustion, a lack of energy, decreased capacity for mental and physical work, and an inability to continue usual activities. Fatigue has been described as a multidimensional, complex phenomenon that influences the activities, which an individual chooses to engage, possibly resulting in activity aversion. Fatigue is a whole body response, integrating physiologic, psychological, and situational factors and influenced by circadian rhythm. If inappropriate and extreme, fatigue results in impaired functional status and diminishes the satisfaction with life and impacts the quality of life. It is a pervasive personal problem directly and indirectly attributable to most illnesses and results from prolonged stress. It is recognized as an imbalance of accessibility, use, and renewal of needed resources (Aaronson et al., 1999; Aistars, 1987; Carpenito, 2000; Hart & Freel, 1982; Kellum, 1985; Morris, 1982; Nail & King, 1987; Piper, 1993; Piper, Lindsey, & Dodd, 1987; Ream & Richardson, 1996).

There have been a variety of fatigue typology systems developed. Physiologists and physiotherapists categorize fatigue as central and peripheral (Gibson & Edwards, 1985; Holder-Powell & Jones, 1990). Grandjean (1970), from his work in industrial hygiene, put forth the following categories: mental, physical, psychological, nervous, pathological, and emotional. Nurses have categorized fatigue as normal, pathophysiological, psychological, situational, and maturational (Carpenito, 2000; Gift & Pugh, 1993; Hart & Freel, 1982; Kellum,

1985). Hubsby & Sears (1992) reported a type of fatigue that they described as unique to multiple sclerosis which they named MS fatigue. Classification of fatigue as acute and chronic is also evident in the nursing, industry, and aviation literature (Cameron, 1973; Gift & Pugh, 1993; McFarland, 1971; Piper, 1989). The documented prevalence of fatigue in chronic illnesses supports the need to study it in individuals with diabetes mellitus.

The Development of Fatigue

The actual mechanisms of fatigue development, even at the muscular level, are not fully known and various theories have been proposed to explain the mechanisms. While little is known about fatigue development in healthy populations, even less is known about fatigue development in illness situations (Piper, 1993).

Fatigue development has been conceptualized as a multifactoral process or series of events. Kellum (1985) stated that fatigue is an interactional process involving the physical environment, physiologic, psychological, and situational factors. Bartley's (1965) description of fatigue as a series of events encompassed the physiologic and psychological factors and their interactions and effects. The series of events were impairment, disorganization, discomfort, decrease in activity, and fatigue. Each event occurs at a different level of functioning: cellular, systemic, subjective, objective, or evaluative and the initial disturbance could occur at any level as well. While fatigue is the final response, all levels of functioning are eventually involved.

Fatigue development has been also conceptualized as basic to human protective mechanisms. Norris (1982) proposed that fatigue might be the common denominator among protective mechanisms. She stated that the following protective mechanisms precede, accompany, or follow fatigue: nausea, vomiting, anorexia, constipation, diarrhea, chilling, perspiration, weakness, immobilization, thirst, hunger, itching, disorientation, and pressure sores.

Finally, fatigue development has been conceptualized to be a result of the stress response. Aistars (1987) proposed that prolonged stress was the cause of fatigue in cancer patients. She stated that many energy-depleting factors inflict constant physical and mental stress on the patients. Living with chronic illnesses and diabetes mellitus and all that is required regarding treatment and management has been recognized as a stressor (Moos, 1977; Taylor & Aspinwall, 1993).

Grandjean (1968; 1970) suggested that the most likely site for fatigue development is in the reticular formation of the midbrain and medulla. The reticular formation is the area of the brain related to consciousness, arousal, depression, sleep, and wakefulness and during the stress response the reticular formation is stimulated. With chronic stimulation of the reticular formation, cortical activity is reduced and fatigue is the outward manifestation.

Manifestations of Fatigue

The classification systems for manifestations of fatigue are as varied as the typology classifications. Most of the work related to manifestations has been completed on healthy people. Komoike and Horiguchi (1971) classified fatigue manifestations as weakened activation, weakened motivation, and physical

disintegration. Yoshitake (1971) described the manifestations as the dull, sleepy factors, a decline of work motivation, and somatization of feelings of mental and sensory incongruity. The most frequently reported nursing classification of manifestations presented is subjective versus objective (Carpenito, 2000; Hart, Freel, & Milde, 1990; Kellum, 1985; Piper, Lindsey, & Dodd, 1987; Rhoten, 1982).

The subjective dimension of fatigue is the perception of the person. Examples of what individuals reported in my clinical practice regarding fatigue are “having no pep”, “tired and worn out”, “exhausted”, “having no energy”, “feeling weary”, “need to rest”, “can not do the things I used to do”, “feeling weak”, and “feeling pooped.” Somatic complaints may also be given as subjective manifestations.

The objective dimension of fatigue has a variety of physiologic, biochemical, and behavioral variables. Indicators of the physiologic variables include melatonin, electromyogram, heart rate, oxygen content, blood glucose level, hormone levels, serum electrolytes, and temperature changes. The biochemical indicators include pH changes, muscle biopsies, and lactate and pyruvate levels (Piper, 1989). The behavioral factors include general appearance, attitude, speech, concentration, and activity levels (Aistars, 1987). The multifaceted nature of the manifestations of fatigue supports a multidimensional study.

Research on Fatigue in Chronic Illness

Research on fatigue in chronic illness has grown over the past two decades. The reasons for this expansion within nursing include the vast amount of research literature on fatigue that is easily accessible, the acceptance of a nursing diagnosis for clinical practice and research, and the consumer's attention to chronic fatigue syndrome. The earliest nursing research on fatigue in chronic illness was the work of Hart (1978) with patients with multiple sclerosis. In her retrospective study of 335 multiple sclerosis subjects and 30 healthy control subjects, Hart analyzed the differences in daily fatigue feelings, types of fatigue symptoms, and activities related to fatigue. Fatigue was measured with the Pearson Byars Fatigue Feeling checklist. Multiple sclerosis subjects reported more severe feelings of fatigue than the control subjects and the less mobile multiple sclerosis subjects reported more fatigue. There was no significant difference in the types of fatigue symptoms and types of activities related to fatigue reported by both groups. A limitation of this study was the fact that the fatigue measurement was done retrospectively. The Pearson Byars Fatigue Feeling Checklist was designed to measure how subjects think they felt as they look back. Also, we do not know what impact fatigue had on the memory and recall of the subjects with multiple sclerosis.

Since Hart's work, nursing research of fatigue has focused on the following chronic illnesses: cancer (Blesch, et al., 1991; Irvine, Vincent, Graydon, Bubela, & Thompson, 1994; Jamar, 1989; Rhodes, Watson, & Hanson, 1988), rheumatoid arthritis (Belza, Henke, Yelin, Epstein, & Gilless, 1993; Crosby,

1991), congestive heart failure (Schaefer, 1990; Schaefer & Potylycki, 1993), end-stage renal disease (Srivastava, 1989), human immune virus infection (Darko, et al, 1992), Parkinson's disease (Friedman & Friedman, 1993), brain injury (LaChappelle & Finlayson, 1998), and unilateral neglect (Robertson & North, 1993). There is a need to study fatigue with a wholistic nursing framework such as the Neuman Systems Model. Given the multidimensional nature of fatigue, the literature review of this body of research on fatigue in chronic illness will be presented through the client variables of physiological, psychological, sociocultural, developmental, and spiritual.

Physiological Variables

Many physiological variables have been shown to have a significant relationship with fatigue in the chronic illness. Studies have included measures of physiological parameters (e.g., hemoglobin, hematocrit, white blood cell counts, and pH), measures of physiological functioning (e.g., ejection fraction, pulse, and mobility), and measures of symptoms (e.g., pain, nausea, vomiting, and difficulty sleeping). Jamar (1989), in a sample of 16 women receiving chemotherapy for ovarian cancer, examined symptom distress, mood state, sleep pattern changes, and activity levels as potential indicators of fatigue. Fatigue was measured using the Pearson Byars Fatigue Feeling Checklist. Fatigue was significantly correlated with total symptom distress and nausea as measured by the Symptom Distress Scale. Additionally, subjects with a higher fatigue level had a lower hemoglobin level.

Blesch et al. (1991) studied the physiological, biochemical, and behavioral correlates of fatigue in 33 lung cancer subjects and 44 breast cancer subjects who were receiving chemotherapy and/or radiotherapy. Fatigue was measured using the Rhoten Fatigue Scale. The following physiological variables were studied: disease status at interview, stage of disease at diagnosis, duration of illness, medical treatment for cancer, height, weight, percent change in weight, pain, and performance status (measured by the Zubrod Scale). Physiologically, both groups had more fatigue that was positively correlated with their pain severity. In the breast cancer group, the longer the subjects had their illness, the higher their reported level of fatigue. The following biochemical variables were studied: serum albumin, hemoglobin, hematocrit, white blood cell count, serum sodium, serum potassium, serum calcium, serum alkaline phosphatase, serum bilirubin, SGOT, SGPT, narcotic use, antiemetic use, currently receiving antineoplastics, and currently receiving radiation therapy. There were no significant relationships between the biochemical variables and fatigue. A limitation of this study was that the biochemical variables were not measured concurrently with the other variables. As the authors stated, "The time lapse between the measurement of these variables and fatigue may have allowed time for the person to achieve physiologic homeostasis" (p. 86). Another limitation of this study was the use of the Rhoten Fatigue Scale that was developed for use in an acute post-surgical population. While the authors stated that their purpose in using this scale was to validate its use in a cancer population, there was no mention of this in the findings or discussion sections.

In a prospective study of 104 cancer patients undergoing chemotherapy or radiotherapy, with a healthy control group ($n = 53$), Irvine, Vincent, Graydon, Bubela, and Thompson (1994), investigated the prevalence and correlates of fatigue. Fatigue was measured with the Pearson Byars Fatigue Feeling Checklist. The physiological variables studied were weight, weight change, hemoglobin, hematocrit, white blood cell count, duration of disease, stage of disease, cycle of chemotherapy, radiation dose, and time since surgery. The subjects with lower white blood cell count, symptoms distress, and functional abilities reported significantly higher fatigue. The limitation of this study was the fact that data was collected on the control group only once and on the cancer subjects twice. This creates the difficulty of knowing whether the differences are due to treatment effects versus measurement effects.

Berger (1998) studied the patterns of fatigue, activity, and rest and their relationships during adjuvant breast cancer chemotherapy in 60 women who had been previously treated with surgery. Fatigue was measured using the Piper Fatigue Scale. Activity and rest were measured using wrist actigraphs, “a useful, noninvasive method of objectively quantifying actual movements of an individual” (p. 53). Fatigue scores were higher at the time of treatment and lower at the midpoint between treatments. Statistically, the differences at treatment time and midpoint were significant; however, the change over time was not. Thus the perception that fatigue worsens over time was not supported. Fatigue and activity levels were negatively correlated at most treatment and midpoint times. A limitation of this study was the self-reporting of fatigue was subject to what the

authors called a resetting phenomenon, which would limit the responses of the subjects.

Crosby (1991), in a two-phase study, sought to identify the factors believed to contribute to fatigue in rheumatoid arthritis and to examine the relationships among these factors. In phase one, sixty-four of 100 nonrandomized subjects with rheumatoid arthritis identified rheumatoid arthritis disease activity as the primary cause of their fatigue. Additionally, they identified disturbed sleep and increased physical effort as factors contributing to their fatigue. In phase two, the relationships between these three factors were examined in 15 of the original 100 subjects. The study subjects were divided into a group with rheumatoid flare and a group without. A control group of 12 age and gender matched subjects was utilized in the second phase. Fatigue was measured “by using a 10 centimeter vertical visual analogue scale with the anchors of ‘no fatigue’ (0%) versus ‘extremely fatigued (100%)’” (p. 977. Disease activity was operationalized as joint pain measured by the Modified McGill Pain Inventory, disturbed sleep as sleep fragmentation measured by night EEG sleep studies, and increased physical effort as reduced functional ability measured by walking time and grip strength. While analysis revealed that the flare group has higher pain scores and more awakenings, there was not significant difference in fatigue scores among the groups.

Belza, Henke, Yelin, Epstein, and Gilliss (1993) described the prevalence of fatigue, examined the relationship between fatigue and use of health care services, and identified the correlates of fatigue in 41 adults with rheumatoid

arthritis. Fatigue was measured utilizing the Multidimensional Assessment of Fatigue Scale, a tool that is a combination of visual analogue scales and multiple choices items. Physiological variables included functional status, sleep, and selected demographics. The subjects that reported a higher level of fatigue had greater overall pain, poorer sleep quality, less physical activity, increased number of comorbidities, and more functional limitations. Limitations of this study include minimal attempts to control fatigue associated with questionnaire completion. Thus, fatigue could have been a confounding factor toward the end of questionnaire completion.

Schaefer (1990), utilizing Levine's Conservation Model, investigated fatigue in 23 patients with congestive heart failure related to myocardial injury. A visual analogue scale was used to measure the severity of fatigue. Variables under investigation included heart rate, temperature, hemoglobin, blood gases, blood glucose, ejection fraction, self-worth, and ability to socialize. Lower ejection fraction, pH, and oxygen saturation were correlated with a higher severity of fatigue. Limitations include a lack of understanding about how to use the visual analogue scale by subjects and the measurement of fatigue based on recall. Because a majority of subjects reported that their fatigue occurred only once in a while, any fatigue at the time of the study could have distorted their recall.

Schaefer and Potylycki (1993), in a study designed to extend the previous study, examined fatigue in 38 subjects with congestive heart failure related to myocardial injury and valvular disorders. Like the previous study, this study was also based on Levine's Conservation Model. To address the concerns with the

visual analogue scale in the previous study, the researchers utilized three measures of the severity of subject fatigue: the visual analogue scale, a graphic rating scale, and a numerical rating scale from 1 to 10. Unlike the early work, there were no significant relationships between physiological variables and fatigue. There was no significant difference in the fatigue between the myocardial injury group and the valvular disorders group. The subjects reported the fatigue to be the result of stress, physical activity, and disease. One limitation of the study was the use of simplistic descriptions of acute versus chronic fatigue, which may have missed the true nature of fatigue. Also, the visual analogue scale was always presented first to the subjects and some older subjects had difficulty understanding it. This could have introduced bias into the subsequent measures of fatigue.

Srivastava (1989), in a sample of 27 hemodialysis patients, examined the relationships among fatigue and activity level, subjective quality of life, mood states, and fatigue symptoms. Fatigue was measured utilizing a graded linear scale, a clinical aggregate score, and the Pearson Byars Fatigue Feeling Checklist. The graded linear scale was a line ranging from 0 to 100, with 0 equated with total exhaustion. The clinical aggregate score was calculated by summing the following variables: patient's perception of fatigue being a problem (scale of 0 to 4), frequency, duration, sleep, daily living/thought, and activity. There was a significant positive correlation between level of fatigue and the number of symptoms, that is, the higher the feeling of fatigue, the more numerous the symptoms. The limitations of this study include (a) lack of psychometric data on

two of the three fatigue tools, and (b) conduct of the interviews in the dialysis units, which was less than ideal. The environment may have been a confounding variable.

In summary, there have been a large number of physiological variables studied in relationship to fatigue in various chronic illnesses. Only three variables have demonstrated a statistically significant relationship throughout the literature. Fatigue and physical mobility were reported to have a negative correlation in multiple sclerosis, cancer, and rheumatoid arthritis (Belza et al., 1993; Crosby, 1991, Hart, 1978; Irvine et al., 1994). Pain and fatigue were reported to have a positive correlation in cancer and rheumatoid arthritis (Belza et al., 1993; Blesch et al., 1991; Crosby, 1991). Finally, duration of illness was found to have a positive correlation with fatigue in cancer and rheumatoid arthritis (Belza et al., 1993; Blesch et al., 1991). All other physiological variables had a single event of statistically significant correlation or no significant relationship to fatigue.

The key limitations with the literature regarding physiological variables include small sample sized and unidimensional measures of fatigue. This study utilized a larger sample size and a multidimensional measure of fatigue.

Psychological Variables

A few psychological variables have been reported to have a significant relationship with fatigue in chronic illnesses. Two studies utilized the Profile of Moods Scale (POMS) to investigate the relationship between fatigue and the psychological variables. Jamar (1989) and Blesch et al. (1991), in studies of cancer subjects, found that fatigue was correlated with mood disturbance. They

found fatigue to be positively correlated with the depression-rejection, anger-hostility, and fatigue-inertia subscales of the POMS and negatively correlated with the vigor-activity subscale. Additionally, Blesch et al. (1991) reported that the tension-anxiety and confusion-bewilderment subscales were positively correlated. Utilizing the Linear Analogue Self-Assessment Scale to measure mood disturbance, Irvine et al. (1994), in their study of subjects receiving chemotherapy and radiotherapy, also reported a significant correlation between mood disturbance and fatigue. The analysis was done with a total score. The subscales mentioned in the article were anxiety, confusion, depression, and anger. No individual subscale data was presented.

Unlike Jamar (1989) and Blesch et al. (1991) in their cancer samples, Srivastava (1989) found that there was no correlation between depression and fatigue in subjects with end-stage renal disease. Srivastava (1989) did report that there was a significant negative correlation between fatigue and perceived quality of life.

Sociocultural Variables

Only one sociocultural variable has been reported to have a significant relationship with fatigue in chronic illness. Belza et al., (1993) reported that being a female was a significant factor in their study of 41 adults with rheumatoid arthritis. This was thought to be because women typically do more housework and there is no distinct endpoint to these functions. Social support and helplessness were not found to be significant in relationship to fatigue in rheumatoid arthritis (Belza et al., 1993).

Developmental Variables

The developmental variable, subject age, has not shown any consistency in relationship to fatigue. While Schaefer and Potylycki (1993) reported a positive correlation between fatigue and age in a congestive heart failure sample, Belza et al. (1993) and Schaefer (1990) did not support this finding. Additionally, Belza et al. (1993) found no significant relationship between educational level and fatigue.

Spiritual Variables

There were no studies found that examined the relationship between fatigue and any spiritual variables. This is a definite lack in the knowledge base of fatigue in chronic illness. This study fills that need.

Use of Nursing Theory in Research of Fatigue in Chronic Illness

Of the 15 studies reviewed, five identified the use of a model or theoretical framework. Two studies, Blesch, et al. (1991) and Crosby (1991) utilized Piper's framework for examining fatigue in cancer subjects. Irvine, Vincent, Graydon, Bubela, and Thompson (1994) used an energy analysis model developed by the authors in the examination of fatigue in cancer. Schaefer (1990) and Schaefer and Potylycki (1993) utilized Levine's conservation model in their investigations of fatigue with cardiac disease.

In summary, there are four significant deficits in the knowledge development of fatigue in chronic illness. First, there is no published nursing research of fatigue in diabetes mellitus. Second, there has been limited utilization of nursing theory in the study of fatigue in chronic illness. Third, there is no

published study looking at the spiritual dimension of the phenomenon of fatigue. Finally, the sample sizes of the studies reviewed have been small.

This study was a formal investigation of fatigue in diabetes mellitus, a type of chronic illness, testing the middle range theory of well-being derived from Neuman's Theory of Optimal Client System Stability. The five interacting variables of physiological, psychological, sociocultural, developmental, and spiritual well-being, included the unexplored spiritual dimension. The sample size of this study exceeded most of the previous published studies of fatigue in chronic illness.

The Stress of Living with Diabetes Mellitus

In clinical practice as a diabetes nurse specialist, many clients with diabetes mellitus report fatigue. At times, the fatigue has prevented clients from being able to complete the daily tasks needed to manage their diabetes mellitus because of an actual lack of energy or the feeling that they did not want to do anything. Additionally, the tediousness of living with their diabetes mellitus every day and not being able to take a break from the routine of management has also created stress in their lives. This multidimensional aspect and stressful nature of living with diabetes mellitus is characteristic of living with any chronic illness (Moos, 1977; Taylor & Aspinwall, 1993; Woods, Yates, & Primono, 1989). Given the multidimensional nature of these stressors and their impact on well-being, the literature review will be presented through the interacting variables of well-being: physiological, psychological, sociocultural, developmental, and spiritual.

Impact on Physiological Well-Being

There is support for the physiological impact of diabetes mellitus in the literature. Callaghan and Williams (1994), in a qualitative study with 11 subjects with type 1 diabetes mellitus, explored the issue of living with diabetes mellitus. The subjects identified that the greatest challenge of living with diabetes mellitus as keeping the blood glucose within an acceptable range. They reported having to exert conscious effort over a normally automatic and unseen physiologic process, which is blood glucose regulation.

LeMone (1996) examined the impact of diabetes mellitus on sexuality in 20 women with type 1 and type 2 diabetes mellitus. She identified four categories of physical effects of diabetes mellitus on sexuality. They were fatigue, effects on menstrual cycle, effects on vaginal lubrication, and effects on sexual response. While this study did not focus on fatigue as a concept, it was a common theme discussed as a problem in general, as well as associated with sexuality.

Wu et al., (1998) studied the impact of type 1 diabetes mellitus in 143 adult subjects. The subjects reported that their diabetes mellitus impacted their physical functioning, bodily pain, and vitality. The authors stated that this study finding supported previous research.

Impact on Psychological Well-Being

The psychological impact of diabetes mellitus has also been the focus of research. Lundman and Norberg (1993) examined coping strategies in 20 adults with type 1 diabetes mellitus. They identified five patterns of coping strategies and looked at their relationship to the subjects' hemoglobin A1C. The subjects

with the lowest hemoglobin A1C were those subjects who utilized the coping strategy labeled 'expertise.' This "strategy involved a feeling of competence and an ability to manage the disease without too much emotional impact" (p. 202). Those subjects with the highest hemoglobin A1C used emotion-based coping strategy. "The common core was lack of objective blood glucose measurement and reasoning based on emotions" (p. 202).

Van der Does et al., (1996) studied the relationships among emotional well-being, general well-being, and glycemic control in 188 adults with type 2 diabetes mellitus. They found that better well-being and perception of health were associated with a lower hemoglobin A1C level. Additionally, they reported that higher depression and tension scores on the Profile of Moods Scale was related to a higher hemoglobin A1C level. Petterson et al., (1998) studied the relationship between well-being and treatment satisfaction in 734 adults with type 1 and type 2 diabetes mellitus. Women reported more depression and anxiety than men and reported less well-being.

Callaghan and Williams (1994) identified that fear of short-term complications, hypoglycemia and hyperglycemia, was a motivation for ongoing attention to management plan. When hypoglycemia or hyperglycemia did occur, the subjects blamed the disease for their occurrence. Subjects reported that they have to be constantly aware of their bodies as they depend on the symptoms to detect a problem. Uncertainty in regards to illness trajectory and long-term complications developing was a prominent theme.

Impact on Sociocultural Well-Being

Studies have examined the sociocultural impact of diabetes mellitus also. Wu et al., (1998) found that diabetes mellitus impacted subjects' social function and role performance. Callaghan and Williams (1994) reported that diabetes mellitus impacted work and employment. Subjects had to give priority to the disease while at work in regards to management as well as the possibility of hypoglycemic reactions on the job.

In LeMone's (1996) study on sexuality, the physical effects identified also impacted interpersonal relationships. Two women stated there were times because of the diabetes mellitus that they did not even want their partners to touch them. Wikblad and Montin (1992) studied coping in 55 subjects with type 1 diabetes mellitus. They reported that eight subjects socially isolated themselves as a coping mechanism. One subject stated, "You have to avoid social life, it is too tough otherwise" (p. 319). They also found that diabetes mellitus impacted the family structure. Another subject stated, "My husband always has to stay home from work if I have gastroenteritis" (p. 319).

White, Richter, and Fry (1992) studied 193 adult women with both type 1 and type 2 diabetes mellitus. They found that social support and use of palliative coping strategies were significant predictors in the adjustment process to diabetes mellitus. They reported that the greater the perceived social support, the better the adjustment. They also reported that the use of wishful thinking or behavioral efforts to escape or avoid the problem was associated with poorer adjustment to diabetes mellitus.

Impact on Developmental Well-Being

Two studies were identified that looked at the developmental impact of diabetes mellitus. The variables reflecting developmental issues in living with diabetes mellitus were age of subject and duration of illness. Lundman, Asplund, and Norberg (1990) explored living with diabetes mellitus in 182 adults with type 1 diabetes mellitus. They found a positive relationship with younger age and feelings of anxiety, lack of freedom, insecurity, and low self-esteem. They also reported a positive relationship between shorter duration of illness and feelings of insecurity, increased worries about eye and kidney damage, the impression that planning affects people around the subjects, greater problems in connection with food, and greater difficulty in connection with the need for regularity.

Petterson et al., (1998) studies the relationship between well-being and treatment satisfaction in 734 adults with type 1 and type 2 diabetes mellitus. They reported that subjects with longer duration of illness were more depressed and lacking in energy, positive well-being, and general well-being. There was no significant relationship with age of subject.

Impact on Spiritual Well-Being

One study was identified that examined the spiritual impact of having diabetes mellitus. Landis (1996) explored the relationships among uncertainty, spiritual well-being, and psychosocial adjustment in 94 adults with type 1 and type 2 diabetes mellitus. She reported that there was significant negative relationship between uncertainty and spiritual well-being and a significant negative relationship between spiritual well-being and psychosocial adjustment.

She also found that spiritual well-being had a mediating effect on psychosocial adjustment problems in adults with diabetes mellitus.

In summary, it is well documented that living with diabetes mellitus is a source of stress. The impact of diabetes mellitus is pervasive in that it affects the physiological, psychological, sociocultural, developmental, and spiritual aspects of an individual's well-being. There is a need to understand the wholistic impact of diabetes mellitus on well-being. This study is designed to address that need.

Summary

Fatigue has had a place of interest in nursing since nursing began. Nursing has developed many definitions and typologies of fatigue for clinical use. Nursing has identified the subjective and objective dimensions of fatigue. While the development of fatigue is not completely understood, we continue to explore that dimension of fatigue.

Fatigue has been the focus of research in several disciplines and has been studied since the early 1900's. In nursing, fatigue has been studied since the early work of Hart in 1978. Since that time, fatigue has been examined in several acute and chronic illness states. A deficit in the body of research on fatigue in chronic illness is the examination of fatigue in diabetes mellitus.

Studies have examined the physiological, psychological, sociocultural, and developmental variables related to fatigue. There have been no studies reported that examined the relationship between spirituality and fatigue.

There have been many physiological variables studied in relation to fatigue. However, only three variables have demonstrated a significant

relationship: physical mobility, pain, and duration of illness. Unlike the physiological variables, less attention has been given to the psychological, sociocultural, and developmental variables. A correlation between depression and fatigue has been demonstrated in cancer subjects while in the renal disease that correlation was not supported. The correlation between being female, a sociocultural variable, and fatigue has been demonstrated in rheumatoid arthritis. Developmentally, the relationship between subject age and fatigue has been tested with mixed support. The relationship between educational level and fatigue has not been supported.

The use of nursing theory has been limited in nursing studies of fatigue. Piper's framework was utilized in two studies while Levine's conservation model was also used in two. An energy analysis model was used in one study. Thus, a clear lack of nursing theory in research on fatigue exists.

Living with diabetes mellitus has been shown to be a stressor for the individual and significant others. Diabetes mellitus affects physiological, psychological, sociocultural, developmental, and spiritual well-being. Physiologically, living with diabetes mellitus affects the physical functioning of individuals, specifically sexuality. The psychological impact of living with diabetes mellitus has been demonstrated in fear and depression. The fear of complications looms over the individual and at times becomes a motivation for management. Depression has been related to a higher hemoglobin A1C level and in women more than men. Living with diabetes mellitus impacts work, role performance, social function, and interpersonal relationships. Age of subject and

duration of illness has been correlated with problems anxiety, lack of freedom, self-esteem, and treatment satisfaction. There is an uncertainty associated with diabetes mellitus that impacts the spiritual well-being of subjects also.

There is adequate support that living with diabetes mellitus is stressful and this stress may lead to the development of fatigue. However, there have been no reported studies examining the experience of fatigue in clients living with the stress of diabetes mellitus. Additionally, there is a lack of nursing theory utilized in fatigue research. Thus, this study was designed to test a middle range nursing theory of well-being in diabetes mellitus.

CHAPTER III

METHODS

The purpose of this study was to test a middle range theory of well-being in adults with diabetes mellitus derived from Neuman's Theory of Optimal Client System Stability and the Neuman Systems Model. The relationships among stress, well-being, and fatigue in adults living with diabetes mellitus were examined to test the theory that disruption in well-being in adults living with the stress of diabetes mellitus leads to greater fatigue.

Research Design

A descriptive, correlational design was used to examine the relationships among stress, the interacting variables of well-being (physiological, psychological, sociocultural, developmental, and spiritual) and fatigue in adults with diabetes mellitus. Correlation designs provide a method of examining relationships among multiple variables as they naturally occur, without researcher intervention (Polit & Hungler, 1999). Thus, the descriptive correlational design is best suited for exploring the relationships among stress, well-being, and fatigue.

The independent variables were stress and well-being. The empirical indicator reflecting the stress of living with diabetes mellitus was the Problem Areas in Diabetes Survey (PAID). The sum score was used as the indicator of overall stress level. The empirical indicators reflecting the interacting variables of well-being were the following: physiological, hemoglobin A1C (A1C); psychological, Well-Being Questionnaire 12 (W-BQ 12); sociocultural, Social Well-Being Index (SWBI); developmental, Diabetes Activities Questionnaire

(DAQ); and spiritual, JAREL Spiritual Well-Being Scale (JAREL). The dependent variable was fatigue and the empirical indicator was the Fatigue Severity Scale (FSS).

Sample and Setting

The target population was adults with diabetes mellitus. The eligibility criteria for inclusion in this study were: (1) between the ages of 25 and 84 years, (2) diagnosed with diabetes mellitus more than one year prior to enrollment in the study, (3) English speaking, (4) able to read English, (5) had a recent A1C, within three months, and (6) be cognitively intact. Sample size for this study was determined by utilizing power analysis. An effect size of 0.30, a significance criterion alpha of 0.05, and a power of 0.80 was used to establish the sample size for this study at 83 (Burns & Grove, 2001).

The questionnaire packet was sent to a convenience sample of 110 to ensure an adequate sample size. The adjusted sample size was 87 and was collected in two phases.

Phase 1

During Phase 1 of data collection, 28 questionnaire packets were distributed to those attending a diabetes mellitus health fair who requested one. Two packets were not returned, four subjects had not had diabetes mellitus for more than one year, and one subject did not have a recent A1C. The final sample size for Phase 1 was 21.

Phase 2

During Phase 2, 395 office patients from an endocrinologist's office were invited to participate in this study in three mailings. Eighty-two patients requested questionnaire packets for a response rate of 21%. Six subjects did not have a recent A1C, two subjects had not had diabetes mellitus for more than one year, and eight packets were not returned. The final sample size for Phase 2 was 66.

Protection of Human Subjects

An endocrinologist in East Tennessee was contacted for utilization of a local diabetes mellitus health fair (Phase 1) and her office clients (Phase 2) as the target population. The endocrinologist was given a copy of the study proposal and provided with a verbal explanation of the study. Permission was obtained to utilize both the local diabetes mellitus health fair and the endocrinologist's office population.

Once permission to utilize the endocrinologist's office was obtained, application was made to the University of Tennessee, Knoxville to conduct the research. Institutional review board approval was obtained through the College of Nursing, University of Tennessee, Knoxville and Research Compliance Services of the Office of Research, University of Tennessee, Knoxville with a Form B. A locked file cabinet was obtained for the purpose of data storage and only the investigator and the major professor had access to the data.

Human subjects were protected during Phase 1 and Phase 2 of data collection with the same protection as described below. Subjects were told that

this study was a part of the investigator's educational program and what the purpose of the study was. They were told that their participation was voluntary and that there was no penalty for declining participation. They were told that there was a questionnaire packet (see Appendix A) to fill out that would take approximately 30 – 45 minutes to complete and that it included questions about them as individuals and their experience of living with diabetes mellitus. They were given a copy of the informed consent to participate to read (see Appendix B). The informed consent to participate included the following information: (1) how their name was obtained, (2) that this study was a part of an educational program, (3) the purpose of the study, (4) the nature of data to be collected, (5) how the data will be collected, (6) expected duration of data collection and the study, (7) that anonymity would be maintained by (a) destroying their name, mailing address, and phone number after receiving their packet, (b) that the packets would be identified by number only, and (c) reports would be of aggregate data with no mention of individual data, (8) the absence of costs to them, (9) potential risks and benefits of the study, (10) confidentiality, (11) voluntary nature of participation and withdrawal, and (12) investigator contact information. The investigator then answered any questions that were raised. In Phase 2, to maintain anonymity, the endocrinologist's office manager assisted with the invitation to participate in the study.

Data Collection Procedure

Phase 1

Arrangements were made to attend the local diabetes mellitus health fair. An area was set up to provide the investigator a place to explain the study and to obtain informed consent.

Once informed consent was obtained, subjects were given their copy of the investigator-signed informed consent to participate and a questionnaire. They were given the opportunity to complete questionnaire on-site or take it home and return it by mail in a self-addressed, stamped envelope that was provided to them. If they chose to fill it out on-site, they were provided a place to complete the questionnaire. When the questionnaire was returned to the investigator, the subjects' A1C was obtained from the A1C testing site at the health fair and written on the demographic information sheet.

Subjects were thanked for their participation and reminded that they could call the investigator if questions arose at any time. Subjects, who requested a summary of the study, were mailed an abstract of the study.

Phase 2

The office manager generated mailing labels of potential subjects from the computer database of office appointments. The first mailing included patients seen in the office during the previous 10 weeks. The second and third mailings included patients seen in the previous month. Potential subjects were mailed a letter of introduction (see Appendix C) and an informed consent to participate for

the study from the endocrinologist's office. The signed informed consent to participate was returned to the investigator at a personal mailbox address.

Once the investigator received the signed informed consent to participate, a questionnaire packet was mailed to the subjects. They were asked to return the questionnaire packet to the investigator within a week in the postage paid envelope provided.

The questionnaire packet contained a demographic form, the questionnaire, the subject's copy of an investigator-signed copy of the informed consent to participate, and a self-addressed, stamped envelope for return of the questionnaire packet to the investigator. The subjects were asked to complete the questionnaire and return it to the investigator in the envelope provided. If the investigator had not received the packet within two weeks, the subject was called to see if there were any questions. Once the investigator received the questionnaire packet, the endocrinologist's office manager was contacted to provide the most recent A1C.

Data Collection Instruments

The subjects completed the following instruments for the study. A demographic form was used to collect data to develop the sample description. The A1C was obtained from the subjects' office medical records or at the diabetes mellitus health fair.

Demographic Form

The following information was collected on the demographic form: zip code, age, gender, ethnicity, marital status, highest grade completed in school,

religious affiliation, level of activity, occupation, recent hospitalization, recent illness, type of diabetes mellitus, year diabetes mellitus was diagnosed, medication(s) used to control diabetes mellitus, other medications taken regularly, attendance at a diabetes education program, year diabetes education program was completed, financial burden of diabetes mellitus, use of tobacco, and use of alcohol.

Problem Areas in Diabetes Survey

The Problem Areas in Diabetes Survey (PAID) was the measure of stress of living with diabetes mellitus. The original purpose of the PAID was to measure psychosocial adjustment specific to diabetes mellitus. It was tested in a sample of 451 adult female subjects with both type I diabetes mellitus and type II diabetes mellitus, all of whom required insulin. The instrument is comprised of 20 Likert-type items. The response set is from 'no problem' (0) to 'serious problem' (4). Scoring of the instrument is computed by summing the total item responses. A high value indicates a high level of diabetes-related distress. Reliability analysis revealed a high internal consistency for the tool. The Cronbach alpha was 0.95 for the tool with an item-to-total correlation range of 0.32 to 0.84 with a mean correlation of 0.68 (Polonsky et al., 1995). This instrument has not been used with any other adult chronic illness samples.

Hemoglobin A1C

Hemoglobin A1C (A1C) within the expected laboratory reference range was the measure of physiological well-being. A1C is a measure of the person's amount of red blood cell glycosylation; that is, the amount of glucose bound to

the red blood cells. The A1C represents an average blood glucose level over the past two to three months in an individual because the red blood cell life span is 120 days. Thus, an elevated A1C reflects an elevation in the blood glucose over the last two to three months. In an adult with diabetes mellitus, the presence of elevated blood glucose indicates a situation in which the blood glucose is available for utilization as an energy source; however, with an inadequate level of circulating insulin or insulin that works improperly, the glucose is not utilized by the body. Thus, the adult with diabetes mellitus potentially has a lack of energy source and is at risk for the development of fatigue. For clients with diabetes mellitus, an A1C level of < 6.5 is the target.

Well-Being Questionnaire 12

The Well-Being Questionnaire 12 (W-BQ 12) was the measure of psychological well-being. The original purpose of the W-BQ 12 was to facilitate the identification of serious psychological problems. It was tested in a sample of 739 adult subjects with both type I diabetes mellitus and type II diabetes mellitus. The instrument is comprised of 12 Likert-type items. There are three subscales, negative well-being (NWB), energy (ENE), and positive well-being (PWB), and a total scale general well-being (GWB). The response set is from 'not at all' (0) to 'all the time' (3). Scoring of the instrument is done as follows: $GWB = 12 - (\text{item 1} + \text{item 2} + \text{item 3} + \text{item 4}) + (6 + \text{item 5} + \text{item 6} + \text{item 7} + \text{item 8}) + (\text{item 9} + \text{item 10} + \text{item 11} + \text{item 12})$. A high value indicates a high level of psychological well-being. Reliability analysis revealed a high internal consistency for the tool. The Cronbach alphas were: 0.73 - 0.84 for the NWB

subscale, 0.77 - 0.84 for the ENE subscale, 0.80 - 0.83 for the PWB subscale, and 0.88 - 0.91 for the GWB total scale. Convergent and discriminate validity were established by correlation with the Hospital Anxiety and Depression Scale (HADS) and the trait scale of the State-Trait Anxiety Inventory (STAI). The Pearson product moment correlation coefficients with the HADS were: 0.54 - 0.72 for the NWB subscale, 0.54 - 0.61 for the ENE subscale, 0.56 - 0.69 for the PWB subscale, and 0.69 - 0.76 for the GWB total scale. The Pearson product moment correlation coefficients with the STAI were: 0.61 - 0.72 for the NWB subscale, 0.52 - 0.69 for the ENE subscale, 0.55 - 0.71 for the PWB subscale, and 0.70 - 0.82 for the GWB total scale (Pouwer, van der Ploeg, Ader, Heine, & Snoek, 1999). This instrument has not been used with any other adult chronic illness samples.

Social Well-Being Index

The Social Well-Being Index (SWBI) was the measure of sociocultural well-being. The original purpose of the SWBI was to facilitate the identification of the social circumstances of individuals with regard to social contact or activity and social ties or resources. It was tested in a sample of 4603 subjects aged 14 and older. The instrument is comprised of 10 items, three open-ended items and seven Likert-type items. There are two subscales: social contacts and social resources. The response set of the seven Likert-type items varies. One question is from 'better than usual' (1) to 'not as well as usual' (3). One question is from 'very active, attend most meetings' (1) to 'do not belong to any groups or clubs' (4). One question is from 'every day' (1) to 'less than 5 times a year' (7). The

remaining four questions are from 'every day' (1) to 'not at all in past month' (6). Scoring of the instrument is done according to rules in Appendix D. A high value indicates a high level of social well-being. Reliability analysis revealed a good internal consistency for the tool. The internal consistency coefficients were: 0.84 for the social resources subscale, 0.72 for the social contacts subscale, and 0.68 for the social well-being index total scale. The stability coefficients were: 0.68 for the social resources subscale, 0.55 for the social contacts subscale, and 0.68 for the social well-being index total scale. Face and content validity were established (Donald & Ware, 1982). This instrument has been used in a sample of adults with Alzheimer's disease.

Diabetes Activities Questionnaire

The Diabetes Activities Questionnaire (DAQ) was the measure of developmental well-being. The original purpose of the DAQ was to measure client/subject adherence to the diabetes regimen. It was tested in a sample of 72 adult subjects on insulin and 81 adult subjects on oral hypoglycemia agents. The instrument is comprised of 13 visual analogue items of 100 millimeters length. There are two subscales, lifestyle/monitoring and treatment, and a total scale. The response set is 'never' (0) to 'always' (100). Scoring of the instrument is done by measuring the length of the marks from the 'never' anchor and summing the values. Items 1, 2, 3, 4, 5, 9, and 10 comprise the lifestyle/monitoring subscale and items 6, 7, 8, and 12 comprise the treatment subscale. All 13 items comprise the total scale. A high value indicates a high level of self-reported adherence to the diabetes regimen. Reliability analysis revealed a high internal consistency for

the tool. The Cronbach alphas were: 0.81 for the lifestyle/monitoring subscale, 0.72 for the treatment subscale, and 0.82 for the total scale. Test-retest reliability revealed a Pearson product moment correlation coefficient of 0.78, indicating a good stability. Content validity was established by a review of the literature, personal diabetes education experience, and review by a panel of diabetes education experts. Construct validity was established by factor analysis. Principal component analysis with varimax rotation extracted two factors, which were lifestyle/monitoring and treatment (Hernandez, 1997). This instrument has not been used with any other adult chronic illness samples.

JAREL Spiritual Well-Being Scale

The JAREL Spiritual Well-Being Scale (JAREL) was the measure of spiritual well-being. The original purpose of the JAREL was to establish a nursing diagnosis for spirituality. It was tested in a sample of 294 adult subjects ranging in age from 55 to 97 years across the health-illness continuum. This instrument is comprised of 21 Likert-type items. There are three subscales, faith/belief dimension, life/self-responsibility, and life satisfaction/self-actualization, and a total score. The response set is from 'strongly disagree' (1) to 'strongly agree' (6). Scoring of the instrument is done by summing the values. For negatively worded statements, the values are reversed. A high value indicates a high level of spiritual well-being. Reliability analysis revealed a high internal consistency for the tool. The Cronbach alpha was 0.85 for the entire sample. Test-retest reliability revealed a Pearson product moment correlation coefficient of 0.88, indicating good stability. Content validity was established by a review of

the literature, grounded theory, and review by a panel of spiritual well-being and gerontology experts (Hungelmann, Kenkel-Rossi, Klassen, & Stollenwerk, 1989). This instrument has been used in samples of older women, professional nurses, nursing faculties, and nursing students.

Fatigue Severity Scale

The Fatigue Severity Scale (FSS) was the measure of fatigue. The original purpose of the FSS was to facilitate the identification of fatigue in chronic illness populations. It was tested in a sample of 25 adult subjects with chronic progressive multiple sclerosis (MS), 29 adult subjects with systemic lupus erythematosus (SLE), and 20 healthy adult subjects (NHA). The instrument consists of nine Likert-type items. The response set is from 'strongly disagree' (1) to 'strongly agree' (7). Scoring of the instrument is done by summing the ratings of the nine items. A high value indicates a high level of fatigue. Reliability analysis revealed a high internal consistency for the tool. The Cronbach alphas were: 0.81 for the MS group, 0.89 for the SLE group, 0.88 for the NHA group, and 0.88 for the entire sample. Test-retest reliability revealed a Pearson product moment correlation coefficient of 0.81, indicating good stability. Convergent validity was established by correlation with the visual analogue scale. The Pearson product moment correlation coefficient was 0.68 with a $p < 0.001$ (Krupp, LaRocca, Nuir-Nash, & Steinberg, 1989). This instrument has been used in several other adult chronic illness samples: cancer, eosinophilia-myalgia syndrome, rheumatoid arthritis, post-lyme syndrome, chronic fatigue syndrome, poliomyelitis, amyotropic lateral sclerosis, and depression.

Data Analysis

A codebook of the variables was developed and maintained. Data were entered into SPSS (the Statistical Package for the Social Sciences) for Windows, Release 10.0.5, Standard Version and checked for accuracy. Data were stored on two diskettes and kept with the raw data. Access to diskettes and raw data was limited to the investigator and the major professor.

Descriptive statistics (frequency distribution, measures of central tendency, and measures of variability) were utilized to describe the characteristics of the sample, to provide descriptive information about the variables under investigation, and to examine the data set for homogeneity, skewness, and linearity, findings that could affect the correlational procedures. All study variables were measured at the interval level.

Computing Cronbach alpha, a measure of internal consistency, assessed reliability of the instruments. Internal consistency indicates that all the subparts of the tool measure the same characteristic. In early predictive research, using instruments with a modest reliability of .70 is acceptable (Nunnally & Bernstein, 1994).

A multiple regression model was utilized to examine the relationships among stress (Problems Areas in Diabetes Survey), well-being (A1C, Well-Being Questionnaire 12, Social Well-Being Index, Diabetes Activities Questionnaire, and JAREL Spiritual Well-Being Scale), and fatigue (Fatigue Severity Scale) in adults with diabetes mellitus (see Figure 2). The five interacting variables of well-being were examined as a set or whole to have conceptual and theoretical

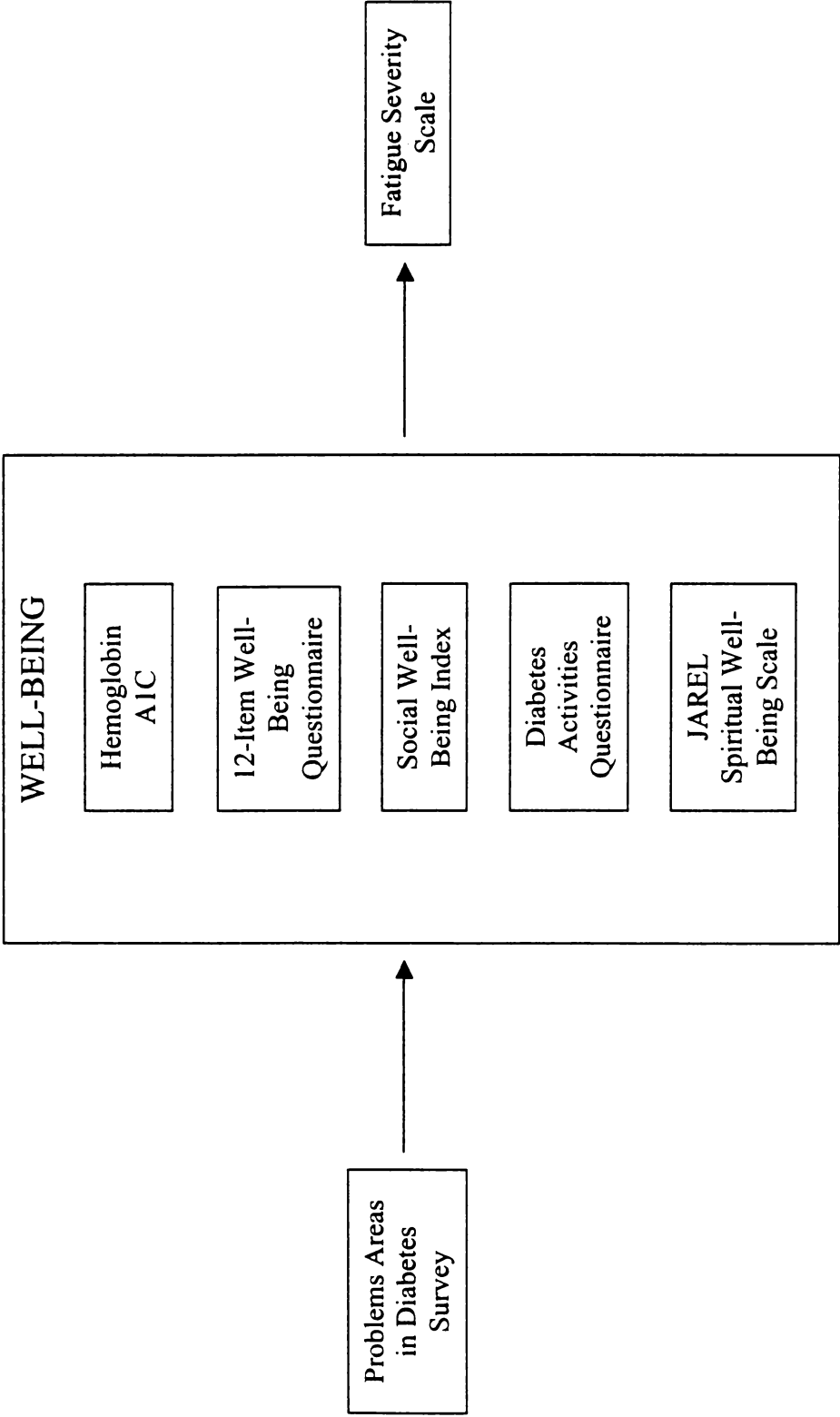


Figure 2: A Model for Testing a Middle Range Theory of Well-Being

congruence. Multiple regression allowed for the determination of whether there is a significant relationship between the independent variables when taken as a group and fatigue. Additionally, multiple regression allowed for the determination of whether the coefficient for a single independent variable was significant while holding the other independent variables constant and whether a single independent variable accounted for a significant amount of variance in fatigue beyond what is accounted for by the other independent variables.

The following assumptions underlie multiple regression: (1) For multiple regression, both the independent and dependent variables should be assessed at the interval or ratio level. However, nominal level data may be utilized if it is dummy-coded or effect-coded appropriately. (2) Each subject in the sample will contribute one score on each of the independent variables and one score on the dependent variables. These sets of scores should represent a random sample from the population of interest. (3) For any combination of independent variable scores, the dependent variable should be normally distributed. (4) For any combination of independent variable scores, the dependent variable should demonstrate a constant variance. (5) A given observation should not be affected by or related to any other observation in the sample. (6) The relationship between the dependent variable and each independent variable should be linear. (7) The errors of prediction should be normally distributed and the distribution of errors should be centered at zero. (8) The independent variables should be measured with error (Hatcher & Stepanski, 1994; Norusis, 2000).

A problem encountered with multivariate analysis is multicollinearity. Multicollinearity exists when two or more independent variables demonstrate a high degree of correlation with each other. Multicollinearity creates a problem with confidence in the validity of the regression model. Multicollinearity can cause the regression coefficient estimates to fail to demonstrate statistical significance, be biased, or even demonstrate the wrong sign (Hatcher & Stepanski, 1994). Multicollinearity was assessed utilizing tolerance levels. "Since tolerance is a proportion, its values range from 0 to 1. A value close to 1 indicates that an independent variable has little of its variability explained by the other independent variables. A value close to 0 indicates that a variable is almost a linear combination of the other independent variables." (Norusis, 2000, pp. 467 – 468). It was determined that multicollinearity was not a problem within the data and the independent variables were orthogonal.

CHAPTER IV

RESULTS

The purpose of this study was to test a middle range theory of well-being in adults with diabetes mellitus derived from Neuman's Theory of Optimal Client System Stability and the Neuman Systems Model. The relationships among stress, well-being, and fatigue in adults living with diabetes mellitus were examined to test the theory that disruption in well-being in adults living with the stress of diabetes mellitus leads to greater fatigue.

Sample Characteristics

Information was collected on several demographic characteristics to describe this sample. The majority of the sample was female ($n = 60$, 69.0%) and Caucasian ($n = 82$, 94.3%). The ages ranged from 25 to 81 years with a mean of 59.07 ($SD = 13.05$).

Seventy-two subjects (82.8%) reported having type 2 diabetes mellitus. The duration of illness ranged from 1 – 53 years with a mean of 15.66 years ($SD = 12.22$). Diabetes mellitus medications included insulin only ($n = 25$, 28.7%), oral agents only ($n = 26$, 29.9%), both insulin and oral agents ($n = 29$, 33.3%), and no medications ($n = 7$, 8.0%). Sixty subjects (69.0%) had attended a diabetes mellitus educational program. Fifty-four subjects (62.1%) reported that diabetes mellitus was not a financial burden.

Additionally, the majority of the subjects were currently married ($n = 69$, 79.3%) and retired ($n = 32$, 36.8%) or homemaker/housewife ($n = 14$, 15.0%). Fifty-six subjects (63.2%) reported an activity level of very active or active.

Twenty-nine subjects (33.3%) completed high school and an additional 21 (24.1%) completed a Bachelor's degree.

Hemoglobin A1C

The A1C values ranged from 5.2 – 11.4 with a mean value of 7.1 and standard deviation of 1.3. These values are all within the target range or above.

Reliability of Instruments

Problem Areas in Diabetes Survey

The total reliability alpha calculated for the PAID was .96 with an item-to-total correlation range of .39 to .89 and a mean correlation of .71. These values compare favorably to those obtained for the original scale (Polonsky et al., 1995). Range, mean, and standard deviation were calculated and are presented in Table 1. The reliability of the PAID was adequate for this study.

Well-Being Questionnaire 12

The initial measure of reliability of the W-BQ 12 was inadequate for this study and is a limitation. The total reliability alpha calculated for the W-BQ 12 was .51. Therefore, the index of reliability was calculated and determined to be .71, which is satisfactory. The index of reliability "... measures the dependability of test scores by showing how well obtained scores agree with their theoretically true values. The index of reliability gives the maximum correlation, which the given test is capable of yielding in its present form" (Garrett, 1958, p. 349). The item-to-total correlations ranged from .04 to .44 and a mean correlation of .20. The reliability and correlation values were lower than the values for the original study (Power, van der Ploeg, Ader, Heine, & Snock, 1999). The range, mean, and

Table 1. Ranges, Means, and Standard Deviations for A1C, Problem Areas in Diabetes Survey, Well-Being Questionnaire 12, Social Well-Being Index, Diabetes Activities Questionnaire, JAREL Spiritual Well-Being Scale, and Fatigue Severity Scale

Variable	Instrument/Measure	Possible Range	Actual Range	Mean	SD
Stress	Problem Areas in Diabetes Survey	0 – 80	2 – 70	26.14	18.21
Physiological Well-Being	Hemoglobin A1C	< 6.5 *	5.2 – 11.4	7.1	1.3
Psychological Well-Being	Well-Being Questionnaire 12	0 – 36	14 – 36	27.03	5.35
Sociocultural Well-Being	Social Well-Being Index	7 – 47	12 – 42	28.72	7.36
Developmental Well-Being	Diabetes Activities Questionnaire	0 – 1300	347 – 1300	872.92	189.07
Spiritual Well-Being	JAREL Spiritual Well-Being Scale	21 – 126	63 – 124	102.55	14.99
Fatigue	Fatigue Severity Scale	9 – 63	9 – 63	38.83	14.66

*. Target value

standard deviation were calculated and are presented in Table 1. Thus, the reliability of the W-BQ 12 was adequate for this study.

Social Well-Being Index

The total reliability alpha calculated for the SWBI was .78. The item-to-total correlations ranged from .08 to .68 with a mean correlation of .46. The reliability value for this study was higher than in the original work (Donald & Ware, 1982). Range, mean, and standard deviation were calculated and are presented in Table 1. The reliability of the SWBI was adequate for this study.

Diabetes Activities Questionnaire

The total reliability alpha calculated for the DAQ was .77. The item-to-total correlations ranged from .13 to .56 with a mean correlation of .39. The total reliability alpha for this study compared well to the original work (Hernandez, 1977). Range, mean, and standard deviation were calculated and are presented in Table 1. The reliability of the DAQ was adequate for this study.

JAREL Spiritual Well-Being Scale

The total reliability alpha calculated for the JAREL was .88. The item-to-total correlations ranged from .11 to .74 with a mean correlation of .49. The total reliability for this study compared well with the original study (Hungelmann, Kenkel-Rossi, Klassen, & Stollenwerk, 1989). Range, mean, and standard deviation were calculated and are presented in Table 1. The reliability of the JAREL was adequate for this study.

Fatigue Severity Scale

The total reliability alpha calculated for the FSS was .94. The item-to-total correlations ranged from .50 to .87 with a mean correlation of .76. The total reliability for this study was slightly higher than in the original work (Krupp, LaRocca, Nuir-Nash, & Steinberg, 1989). Range, mean, and standard deviation were calculated and are presented in Table 1. The reliability of the FSS was adequate for this study.

Research Question

- What are the relationships among stress, well-being, and fatigue in adults with diabetes mellitus?

This middle range theory of well-being proposes that disruption in well-being in adults living with the stress of diabetes mellitus leads to greater fatigue. The results are presented through the lens of the theoretical relationship statements.

Relationship statement 1: Living with diabetes mellitus is a stressor.

Results were obtained with descriptive statistics. Stress scores ranged from 2 – 70 (possible 0 – 80) with a mean of 26.14, standard deviation of 18.21. The median was 20. This median value reveals that 50% of the sample scored 21 – 70 on the PAID. These findings support the relationship that living with diabetes mellitus is a stressor.

Relationship statement 2: The stress of living with diabetes mellitus is disrupting to client well-being. Results were obtained using bivariate correlation (Pearson's r). Pearson's correlations (Table 2) revealed that stress was

Table 2. Correlations Among Stress, Physiological Well-Being, Psychological Well-Being, Sociocultural Well-Being, Developmental Well-Being, Spiritual Well-Being, and Fatigue (n = 87)

Variable	1	2	3	4	5	6	7
1. Stress	--	.33***	-.64***	-.28**	-.27**	-.33***	.48***
2. Physiological Well-Being		--	-.05	-.13	-.07	-.18	.26**
3. Psychological Well-Being			--	.38***	.28**	.43***	-.49***
4. Sociocultural Well-Being				--	.35***	.51***	-.24*
5. Developmental Well-Being					--	.29**	-.17
6. Spiritual Well-Being						--	-.28**
7. Fatigue							--

***. Correlation is significant at the 0.00 level (2-tailed)

**. Correlation is significant at the 0.01 level (2-tailed)

*. Correlation is significant at the 0.02 level (2-tailed)

significantly correlated with all variables and in the anticipated direction, that is, as stress rose, the interacting variables of well-being declined. These findings support the relationship that the stress of living with diabetes mellitus is disrupting to client well-being.

Relationship statement 3: Disrupting well-being in clients living with the stress of diabetes mellitus leads to depletion of energy. Results were obtained utilizing descriptive statistics. Fatigue scores ranged from 9 – 63 (possible 9 – 63) with a mean of 38.83, standard deviation of 14.66. The median was 39 and the mode was 63. This reveals that 50% of the sample scored 40 – 63 on the FSS. These findings support the relationship that disrupting well-being in clients living with the stress of diabetes mellitus leads to depletion of energy.

Theory statement: Disruption in well-being in adults living with the stress of diabetes mellitus leads to greater fatigue. Results were obtained using hierarchical multiple regression. Fatigue scores were regressed on the linear combination of stress and the five interacting variables of well-being. The first step was entering stress into the model. Stress alone accounted for 23% of the variance in fatigue, $F(1,85) = 25.60$, $p = .000$, adjusted $R^2 = .22$.

The second step was to enter the interacting variables of well-being into the model. They accounted for an additional 9% contribution to variance in fatigue score, $F(5,80) = 2.04$, $p < .09$. This final model explained a total of 32% of the variance of the fatigue score, $F(6,80) = 6.22$, $p < .000$, adjusted $R^2 = .27$. These findings provide partial support for the theory that disruption in well-being in adults living with the stress of diabetes mellitus leads to greater fatigue.

Ancillary Question

- Which interacting variable of well-being (physiological, psychological, sociocultural, developmental, or spiritual) best explains the functioning of the normal line of defense in adults living with the stress of diabetes mellitus?

Beta weights, standardized multiple regression coefficients, were reviewed to examine the relative explanatory power of each of the interacting variables of well-being to the functioning of the normal line of defense. Of the five interacting variables, only psychological well-being demonstrated significance at the $p < .01$ level (Table 3).

Multicollinearity was tested with this set of independent variables. The tolerance levels were computed with a range from 0.49 to 0.84. Therefore, the potential problem of multicollinearity was not present.

Table 3. Summary of Hierarchical Regression Analysis for Variables Predicting Fatigue in Adults with Diabetes Mellitus (n = 87)

Variable	β	t	p
Step 1			
Stress	.48	5.06	.00
Step 2			
Stress	.19	1.44	.15
Physiological Well-Being	.18	1.73	.09
Psychological Well-Being	-.34	-2.57	.01*
Sociocultural Well-Being	-.02	-.20	.85
Developmental Well-Being	.00	-.02	.98
Spiritual Well-Being	-.03	-.28	.78

Note: $R^2 = .23$ for Step 1; $\Delta R^2 = .09$ for Step 2 ($p < .08$)

*. Significant

CHAPTER V

DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

The purpose of this study was to test a middle range theory of well-being in adults with diabetes mellitus derived from Neuman's Theory of Optimal Client System Stability and the Neuman Systems Model. The relationships among stress, well-being, and fatigue in adults living with diabetes mellitus were examined to test the theory that disruption in well-being in adults living with the stress of diabetes mellitus leads to greater fatigue.

Discussion

Nursing science, specifically Neuman nursing science, is advanced through the development and testing of nursing theory based on the Neuman Systems Model. Stress and reaction to stress are the two major components of the Neuman Systems Model, and from these concepts, Neuman's Theory of Optimal Client System Stability was derived. The Theory of Well-Being was derived from Neuman's Theory of Optimal Client System Stability and tested in adults living with diabetes mellitus (stress) as an explanation of the development of fatigue (reaction to stress) as a function of their level of well-being (normal line of defense).

The impact of living with diabetes mellitus as a stressor has been well supported in the literature. The all-encompassing effects include an impact on physiological well-being (Callaghan & Williams, 1994; LeMone, 1996; Wu et al., 1998), an impact on psychological well-being (Van der Does et al., 1996; Lundman & Norberg, 1993), an impact on sociocultural well-being (Callaghan &

Williams, 1994; LeMone, 1996; White, Richter, and Fry, 1992; Wu et al., 1998), an impact on developmental well-being (Lundman, Asplund, & Norberg, 1990; Petterson et al., 1998), and an impact of spiritual well-being (Landis, 1996). The findings from this study support the pervasive nature of the impact of living with diabetes mellitus as a stressor on the physiological, psychological, sociocultural, developmental, and spiritual well-being of individuals and extend the knowledge by utilizing a wholistic framework for studying all of these variables in one sample.

Stress as a factor in the development of fatigue has also been supported in the literature. Severe and unrelenting stress, with or without chronic illness, impacts the energy resources of an individual and leads to fatigue (Aistars, 1987; Grandjean, 1968; 1970; Leidy, 1989; Lyon, 2000; Selye, 1976). The findings of this study support the relationship between stress and fatigue and extend the knowledge to include living with diabetes mellitus as a stressor.

System stability is the state of balance requiring energy exchange as adequate coping takes place. This stability is developed over time and represents the normal adaptational level of health and the usual wellness level of an individual. The normal line of defense represents client system stability (Neuman, 2002). The findings from this study support the proposition that disrupted well-being is a factor between the stress of living with diabetes mellitus and the fatigue experienced by adults living with diabetes mellitus.

The well-being of the individual represents adequate energy levels for harmonious functioning of the five interacting client variables, physiological,

psychological, sociocultural, developmental, and spiritual, and the total energy needs of the body. It is the combination of the five interacting variables in unison that provide protection for the individual against a reaction to stress. These five interacting variables comprise the normal line of defense in the individual (Neuman, 2002). While all five of the interacting variables can be functioning at a high level, it is possible for different levels of functioning to be present at one time. The findings of this study answer the question that the psychological interacting variable best explains the functioning of the normal line of defense in this sample.

Conclusions

Research Question

- What are the relationships among stress, well-being, and fatigue in adults with diabetes mellitus?

This middle range theory of well-being proposed that disruption in well-being in adults living with the stress of diabetes mellitus leads to greater fatigue. The findings from this study that examined the relationships among stress, well-being, and fatigue in adults with diabetes mellitus supported the proposed theory.

Ancillary Question

- Which interacting variable of well-being (physiological, psychological, sociocultural, developmental, or spiritual) best explains the functioning of the normal line of defense in adults living with the stress of diabetes mellitus?

While the five interacting variables played a role in the functioning of the normal line of defense, only psychological well-being demonstrated significance. It represented an area of weakness in the normal line of defense in this sample of adults living with diabetes mellitus.

Recommendations

Application to Practice

The severe and unrelenting nature of the stress of living with diabetes mellitus as a mechanism for the development of fatigue has application for clinical nursing practice. The Neuman Systems Model suggests that primary prevention be implemented to reduce the impact of a stressor on an individual before a reaction occurs. Based on the model, early recognition and identification of the stressors that are impacting an individual with diabetes mellitus is a primary responsibility of nurses. Identification of stressors and interventions to reduce the impact of stressors that are present is of utmost importance. In this way, nurses can use the Neuman Systems Model to guide their practice and help clients recognize the stressors of living with diabetes mellitus, suggest ways to reduce their stress, and possibly prevent the development of fatigue.

The well-being of adults living with diabetes mellitus is a mediating factor on the experience of fatigue. This is a key area for nursing intervention, the area of strengthening the normal line of defense. Identification of the normal line of defense interacting variables in this study provides the basis for nursing assessment and intervention. Assessment, focusing on all five interacting variables of well-being, is the essential first step. Intervention should then be

directed at each of the five interacting variables. Nursing intervention that would support the psychological interacting variable of well-being of individuals should be identified and implemented to provide continued strength in this area.

However, nurses should place attention on the other four interacting variables as areas of possible disruption as well. Interventions that would improve the physiological, spiritual, developmental, and sociocultural interacting variables of well-being, as well as psychological, would strengthen the normal line of defense by supporting these areas of strength and weakness and lessen the possibility of disruption that could lead to fatigue.

The following recommendations are suggested:

1. A comprehensive, wholistic assessment of clients with diabetes mellitus should be completed to identify the stressors of living with diabetes mellitus. It is recommended that a multidimensional, wholistic approach be utilized to identify the physiological, psychological, sociocultural, developmental, and spiritual nature of interpersonal, intrapersonal, and extrapersonal stressors. Early recognition provides an opportunity for nurses to intervene and thus reduce the impact of these stressors on the client and the development of fatigue.
2. Diabetes education programs need to include a thorough discussion of the physiological, psychological, sociocultural, developmental, and spiritual impacts of diabetes mellitus on the individual, family and significant others. Early recognition of the effects of the impact will facilitate early intervention. Diabetes education programs could include discussions of

interventions directed at strengthening the psychological well-being of clients and could strengthen the focus on stress management for this client group. It is also suggested that the national guidelines for national certification of diabetes education programs strengthen the psychological component of programs.

Future Research

Fatigue is not a new problem for adults living with diabetes mellitus. However, it is a chronic illness that has not received as much study attention as others illnesses, such as cancer, rheumatoid arthritis, and congestive heart failure. The review of the literature and the findings of this study support the continued investigation of this phenomenon as an area of interest for the discipline of nursing.

The following recommendations are suggested:

1. Replicate this study to test this middle range theory of well-being using other samples. This would provide further support for the relevance of this theory to nursing practice. The sample of this study was predominantly Caucasian. Diabetes mellitus is a major health problem in the African-American and Native American populations, thus examination with these groups would be greatly beneficial. This sample was primarily from one geographic area and one endocrinologist's office. A study within a more diverse geography would extend the testing of this theory. Finally, a study with the inclusion of clients receiving primary care for their diabetes mellitus from a family practice or internal medicine provider

in contrast to those receiving care from a specialist would be beneficial.

2. Develop an instrument to measure fatigue as conceptualized by the Neuman Systems Model and linked with Neuman's Theory of Optimal Client System Stability and this middle range Theory of Well-Being through the experience of individuals living with diabetes mellitus. There is a lack of instruments based on Neuman Systems Model and this would further expand Neuman nursing science. There is also a lack of instruments in nursing that focus on the issue of living with diabetes mellitus and this would expand the availability of tools for nurses involved in diabetes care.
3. Design and conduct studies that include other factors, such as physical mobility, pain, duration of illness, mood disturbance, and gender, which may have relevance to the development of fatigue in individuals living with diabetes mellitus. The review of literature on fatigue in chronic illness revealed that these variables had a statistically significant relationship with fatigue in multiple sclerosis, cancer, and rheumatoid arthritis. Other variables studied, but no significance found, included age, sleep quality, and comorbidities. These studies would provide a broader view of the experience of fatigue in diabetes mellitus.
4. Continue to examine the concept of fatigue through a multidimensional approach. An examination of the physiological, psychological, sociocultural, developmental, and spiritual aspects of fatigue would provide a broader view and understanding of the fatigue experience in

living with diabetes mellitus. An area of opportunity for study is the issue of fatigue as a part of the stress of living with diabetes mellitus.

5. Conduct intervention studies designed to test nursing approaches aimed at strengthening the normal line of defense in adults with diabetes mellitus.

This would further the practice of diabetes nursing care and further expand Neuman nursing science. Additionally, this would provide an opportunity for further theory development based on the Neuman Systems Model.

Summary

The purpose of this study was to examine the relationships among stress, well-being, and fatigue in adults living with diabetes mellitus to test a middle range theory of well-being derived from Neuman's Theory of Optimal Client System Stability and the Neuman Systems Model. The findings support this theory's proposition that disruption in well-being in adults living with the stress of diabetes mellitus leads to greater fatigue. This study also revealed that there was a weakness in the client psychological interacting variable of the normal line of defense. This beginning study provides the initial testing of the theory and establishes the groundwork for a program of research on fatigue in chronic illness for further theory development and testing in Neuman nursing science.

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APPENDICES

APPENDIX A
QUESTIONNAIRE PACKET

**NURSING STUDY OF DIABETES MELLITUS
QUESTIONNAIRE PACKET**

Thank you for agreeing to participate in the diabetes study. I am a nurse and doctoral candidate at the University of Tennessee, College of Nursing. My goal is to learn new information that will improve the nursing care of persons with diabetes, like you. Your participation is greatly appreciated.

GENERAL INSTRUCTIONS: This packet contains a general information form (demographic sheet) and 6 sets of questions. The complete packet will take 30 - 45 minutes to complete. Each set of questions has its own instructions so please read the instructions carefully. You can take your time completing the packet and feel free to take a break if you get tired. If you have any questions you may call the study investigator, Mr. Greg Casalenuovo, at (865) 659-2556. Leave a message if he does not answer and he will return your call as soon as possible.

PLEASE CONTINUE TO THE NEXT PAGE

DEMOGRAPHIC INFORMATION

DIRECTIONS: Where there is more than 1 choice, circle the answer that BEST describes you. Fill in the blanks where appropriate.

- Zip Code: _____
- Age: _____
- Gender: Male Female
- Ethnicity: Caucasian African-American Native American Hispanic
Asian Other: _____
- Marital Status: Never married Currently married Not currently married
- Highest grade completed in school: _____
- Religious Affiliation:

- Level of Activity: Very active Active Not very active Not active
- Occupation: _____
- Have you been admitted to a hospital within the last six (6) months? No
Yes If yes, please explain _____

- Have you had an illness that did not require admission to a hospital within the last six (6) months? No Yes If yes, please explain

- Type of diabetes mellitus: Type 1 Type 2
- Year that your diabetes mellitus was diagnosed: _____
- Names of medication(s) used to control diabetes mellitus:

PLEASE CONTINUE TO THE NEXT PAGE

DEMOGRAPHIC INFORMATION continued

- Names of other medication(s) taken on a regular basis (include both prescription and over the counter:

- Have you ever attended a diabetes education program: Yes No
- Year that you completed diabetes education program: _____
- Do you feel that diabetes is currently creating a financial burden for you?
Yes No
- Do you use tobacco? No Yes – If yes, what type, how much, and how often? _____
- Do you use alcohol? No Yes – If yes, what type, how much, and how often? _____

PLEASE CONTINUE TO THE NEXT PAGE

QUESTION SET #1

DIRECTIONS: Please circle the number that **BEST** indicates your degree of agreement with each statement. Circle only **ONE** answer for each statement. There is no right or wrong answer.

	Strongly Disagree						Strongly Agree
My motivation is lower when I am fatigued.	1	2	3	4	5	6	7
Exercise brings on my fatigue.	1	2	3	4	5	6	7
I am easily fatigued.	1	2	3	4	5	6	7
Fatigue interferes with my physical functioning.	1	2	3	4	5	6	7
Fatigue causes frequent problems for me.	1	2	3	4	5	6	7
My fatigue prevents sustained physical functioning.	1	2	3	4	5	6	7
Fatigue interferes with carrying out certain duties and responsibilities.	1	2	3	4	5	6	7
Fatigue is among my three most disabling symptoms.	1	2	3	4	5	6	7
Fatigue interferes with my work, family, or social life.	1	2	3	4	5	6	7

PLEASE CONTINUE TO THE NEXT PAGE

QUESTION SET #2

DIRECTIONS: Please circle the number that BEST indicates the degree to which each item is currently a problem for you. Circle only ONE answer for each item. There is no right or wrong answer.

	Not a Problem	Minor Problem	Moderate Problem	Somewhat Serious Problem	Serious Problem
Not having clear and concrete goals for your diabetes care	0	1	2	3	4
Feeling discouraged with your diabetes treatment plan	0	1	2	3	4
Feeling scared when you think about living with diabetes	0	1	2	3	4
Uncomfortable social situations related to your diabetes care (e.g. people telling you what to eat)	0	1	2	3	4
Feelings of deprivation regarding food and meals	0	1	2	3	4
Feeling depressed when you think about living with diabetes	0	1	2	3	4
Not knowing if your mood or feelings are related to your diabetes	0	1	2	3	4
Feeling overwhelmed by your diabetes	0	1	2	3	4
Worrying about low blood sugar reactions	0	1	2	3	4
Feeling angry when you think about living with diabetes	0	1	2	3	4

PLEASE CONTINUE TO NEXT PAGE

QUESTION SET #2 (continued)

DIRECTIONS: Please circle the number that BEST indicates the degree to which each item is currently a problem for you. Circle only ONE answer for each item. There is no right or wrong answer.

Feeling constantly concerned about food and eating	0	1	2	3	4
Worrying about the future and the possibility of serious complications	0	1	2	3	4
Feelings of guilt or anxiety when you get off track with your diabetes management	0	1	2	3	4
Not “accepting” your diabetes	0	1	2	3	4
Feeling unsatisfied with your diabetes physician	0	1	2	3	4
Feeling that diabetes is taking up too much mental and physical energy every day	0	1	2	3	4
Feeling alone with your diabetes	0	1	2	3	4
Feeling that friends and family are not supportive of your diabetes management efforts	0	1	2	3	4
Coping with complications of diabetes	0	1	2	3	4
Feeling “burned out” by the constant effort to manage diabetes	0	1	2	3	4

PLEASE CONTINUE TO THE NEXT PAGE

QUESTION SET #3

DIRECTIONS: Please circle the number on each of the following scales to indicate how often you feel each phrase has applied to you in the past few weeks. Circle only ONE answer for each scale. There is no right or wrong answer.

	All the time			Not at all
I have crying spells or feel like it.	3	2	1	0
I feel downhearted and blue.	3	2	1	0
I feel afraid for no reason at all.	3	2	1	0
I get upset easily or feel panicky.	3	2	1	0
I feel energetic, active, or vigorous.	3	2	1	0
I feel dull or sluggish.	3	2	1	0
I feel tired, worn out, used up, or exhausted.	3	2	1	0
I have been waking up feeling fresh and rested.	3	2	1	0
I have been happy, satisfied, or pleased with my personal life.	3	2	1	0
I have lived the kind of life I wanted to.	3	2	1	0
I have felt eager to tackle my daily tasks or make new decisions.	3	2	1	0
I have felt I could easily handle or cope with any serious problem or major change in my life.	3	2	1	0

PLEASE CONTINUE TO THE NEXT PAGE

QUESTION SET #4

DIRECTIONS: Please circle the choice that BEST describes how much you agree with each statement. Circle only ONE answer for each statement. There is no right or wrong answer.

	Strongly Agree	Moderately Agree	Agree	Disagree	Moderately Disagree	Strongly Disagree
Prayer is an important part of my life.	SA	MA	A	D	MD	SD
I believe I have spiritual well-being.	SA	MA	A	D	MD	SD
As I grow older, I find myself more tolerant of others' beliefs.	SA	MA	A	D	MD	SD
I find meaning and purpose in my life.	SA	MA	A	D	MD	SD
I feel there is a close relationship between my spiritual beliefs and what I do.	SA	MA	A	D	MD	SD
I believe in an afterlife.	SA	MA	A	D	MD	SD
When I am sick, I have less spiritual well-being.	SA	MA	A	D	MD	SD
I believe in a supreme power.	SA	MA	A	D	MD	SD
I am able to receive and give love to others.	SA	MA	A	D	MD	SD
I am satisfied with my life.	SA	MA	A	D	MD	SD

PLEASE CONTINUE TO THE NEXT PAGE

QUESTION SET #4

DIRECTIONS: Please circle the choice that BEST describes how much you agree with each statement. Circle only ONE answer for each statement. There is no right or wrong answer.

	Strongly Agree	Moderately Agree	Agree	Disagree	Moderately Disagree	Strongly Disagree
I set goals for myself.	SA	MA	A	D	MD	SD
God has little meaning in my life.	SA	MA	A	D	MD	SD
I am satisfied with the way I am using my abilities.	SA	MA	A	D	MD	SD
Prayer does not help me in making decisions.	SA	MA	A	D	MD	SD
I am able to appreciate difference in others.	SA	MA	A	D	MD	SD
I am pretty well put together.	SA	MA	A	D	MD	SD
I prefer that others make decisions for me.	SA	MA	A	D	MD	SD
I find it hard to forgive others.	SA	MA	A	D	MD	SD
I accept my life situations.	SA	MA	A	D	MD	SD
Belief in a supreme being has no part in my life.	SA	MA	A	D	MD	SD
I cannot accept change in my life.	SA	MA	A	D	MD	SD

PLEASE CONTINUE TO THE NEXT PAGE

QUESTION SET #5

DIRECTIONS: For this set of questions, instructions are given with each individual question. Provide the answer that BEST represents your situation. There is no right or wrong answer.

About how many families in your neighborhood are you well enough acquainted with, that you visit each other in your homes? **(Enter the number on the line.)**

_____ families

About how many close friends do you have – people you feel at ease with and can talk with about what is on your mind? (You may include relatives.) **(Enter the number on the line.)**

_____ close friends

Over a year's time, about how often do you get together with friends or relatives, like going out together or visiting in each other's homes?

(Circle one)

- Every day.....1
- Several days a week2
- About once a week3
- 2 or 3 times a month.....4
- About once a month5
- 5 to 10 times a year.....6
- Less than 5 times a year7

During the past month, about how often have you had friends over to your home? (Do NOT count relatives.)

(Circle one)

- Every day.....1
- Several days a week2
- About one a week.....3
- 2 or 3 times in past month4
- Once in past month.....5
- Not at all in past month6

PLEASE CONTINUE TO THE NEXT PAGE

QUESTION SET #5

DIRECTIONS: For this set of questions, instructions are given with each individual question. Provide the answer that BEST represents your situation. There is no right or wrong answer.

About how often have you visited with friend at their homes during the past month? (Do NOT count relatives.)

(Circle one)

- Every day.....1
- Several days a week2
- About once a week3
- 2 or 3 times in past month4
- Once in past month.....5
- Not at all in past month6

About how often were you on the telephone with close friends or relatives during the past month?

(Circle one)

- Every day.....1
- Several times a week2
- About once a week3
- 2 or 3 times4
- Once5
- Not at all in past month6

In general, how well are you getting along with other people these days – would you say better than usual, about the same, or not as well as usual?

(Circle one)

- Better than usual.....1
- About the same.....2
- Not as well as usual.....3

PLEASE CONTINUE ON THE NEXT PAGE

QUESTION SET #5

DIRECTIONS: For this set of questions, instructions are given with each individual question. Provide the answer that BEST represents your situation. There is no right or wrong answer.

How often have you attended a religious service during the past month?

(Circle one)

- Every day.....1
- More than once a week.....2
- Once a week.....3
- 2 or 3 times in past month.....4
- Once in past month.....5
- Not at all in past month.....6

About how many voluntary groups or organizations do you belong to – like church groups, clubs or lodges, parent groups, etc. (“Voluntary” means because you want to.)
(Write in number. If none, enter “0”)

_____ Groups or organizations

How active are you in the affairs of these groups or clubs you belong to? (If you belong to a great many, just count those you feel closest to. If you don’t belong to any, circle 4.)

(Circle one)

- Very active, attend most meetings.....1
- Fairly active, attend fairly often.....2
- Not active, belong but hardly ever go.....3
- Do not belong to any groups or clubs.....4

PLEASE CONTINUE TO THE NEXT PAGE

QUESTION SET #6

DIRECTIONS: The questions below will ask you about personal experience with diabetes. Each question is designed to find out about your experience with the activities related to your diabetes. Remember that the word educator can refer to any member of the health care team (doctor, nurse, exercise therapist, etc.). For each of the questions below, put a mark (|) through the place on the line that shows your answer. Make sure the mark goes right through the line (see example below). Make only ONE mark on each line.

EXAMPLE: _____

Never

Always

I follow my meal plan exactly as suggested by my dietitian.

I try to keep my weight within the range suggested by my educator.

I exercise as often as my educator advised me to.

I only do exercises/activities recommended by my educator.

I exercise at the times suggested by my educator.

Each day I take exactly the number of injections/pills prescribed by my doctor.

I take insulin/pills at the times prescribed by my educator.

I only adjust the dose of my insulin/pills if my educator tells me to.

PLEASE CONTINUE TO THE NEXT PAGE

QUESTION SET #6

DIRECTIONS: The questions below will ask you about personal experience with diabetes. Each question is designed to find out about your experience with the activities related to your diabetes. Remember that the word educator can refer to any member of the health care team (doctor, nurse, exercise therapist, etc.). For each of the questions below, put a mark (|) through the place on the line that shows your answer. Make sure the mark goes right through the line (see example below). Make only ONE mark on each line.

EXAMPLE: _____

Never

Always

I test my blood sugar as often as suggested by my educator.

I test my blood sugar at the times suggested by my educator.

I treat low blood sugar reactions with the type of food/drink/ candy advised by my educator.

When I have a reaction I only eat/drink the amount suggested by my educator.

I examine my feet daily.

THIS IS THE END OF THE PACKET.

Thank you again for taking your valuable time and completing this packet. This study will be better because of your participation. Remember to call Mr. Casalenuovo if you have any questions at (865) 659-2556.

NOTE: The font, Times Roman, size 14, was used in the questionnaire packet.

APPENDIX B
INFORMED CONSENT TO PARTICIPATE

**The University of Tennessee
Office of Research
Research Compliance Services**

INFORMED CONSENT FORM

Fatigue in Chronic Illness: Testing a Middle Range Theory of Fatigue in Diabetes Mellitus Derived from Neuman's Theory of Optimal Client System Stability

You are invited to participate in a nursing research study. The purpose of this study is to examine the relationships among stress, well-being, and fatigue in adults living with diabetes mellitus. There will be about 150 participants in this study.

INFORMATION

Once you have carefully read this informed consent form, if you want to participate in this study, sign one copy to return to the investigator in the envelope provided. The other copy is for you to keep.

Once the investigator receives your signed informed consent form, he will mail you a study packet. The study packet will include a demographic information sheet and six sets of questions for you to answer.

The purpose of the demographic information sheet is to provide the investigator with a description of all the participants who complete the study. This information will be used for the whole group of participants and not for any one individual.

The six sets of questions will take about 30 – 45 minutes for you to answer. Please be careful and answer all the questions. When you have finished answering the questions, please put the study packet into the self-addressed, stamped envelope and mail it to the investigator. Please return the study packet to the investigator in one week. If the investigator has not received the packet in that time, he will call you to follow-up.

Once the investigator has received your study packet, he will contact your doctor's office and obtain your most recent hemoglobin A1C.

PLEASE TURN PAGE OVER

RISKS

There are minimal risks involved in participating in this study. You may experience some emotional upset while answering the questions. If anything arises while you are completing this packet, please contact your primary health care provider or doctor. Remember that you are still under the care of your primary health care provider or doctor and this study in no way changes that.

BENEFITS

There are three (3) benefits you can receive participating in this study. First, I will provide you with a brief report of the study when it is completed. You and your doctor may use the information to identify any areas of diabetes health promotion. Second, while you are filling out the form and answering the questions, you can consider your own life situation. You may identify things that you can do to improve your personal level of functioning. Finally, the information gained from this study may help all people with diabetes learn to live with the disease better. As well, health care providers may use the information to better provide care to people with diabetes.

CONFIDENTIALITY

The information in the study will be confidential. The information will be stored in a securely locked file and will be made available only to the investigator and his faculty advisor. No reference will be made in oral or written reports which could link any individual to the study.

The study packets are numbered so that the investigator can keep up with their return. These numbers are assigned to your name. Once the investigator has received your study packet, he will destroy the sheet that has your name and the study packet numbers on it. Your informed consent form and questionnaire will be kept in different files.

Also, your primary health care provider or doctor will not be aware of your participation in this study.

PLEASE CONTINUE TO NEXT PAGE

CONTACT

If you have questions at any time about the study, you may contact the investigator or his faculty advisor.

Greg Casalenuovo, MSN, APRN, BC, CDE
Doctoral Candidate, Nursing
University of Tennessee
Knoxville, TN
(865) 659-2556 (cell phone)

Martha Alligood, PhD, RN
Faculty Advisor
University of Tennessee
Knoxville, TN
(865) 974-6804 (office)

If you have questions about your rights as a participant, contact the University of Tennessee, Knoxville, Office of Research, Research Compliance Services section at (865) 974-3466.

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at anytime without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed, your data will be destroyed. To maintain your confidentiality, your participation in this study will not be known to your primary health care provider or doctor.

PLEASE TURN PAGE OVER

CONSENT

I have read the above information and agree to participate in this study. I have received a copy of this form.

Your Name (print) _____

Your Signature _____

Date _____

Your Mailing Address _____

Your Phone Number _____

Would you like to receive a summary of the study findings?

(Circle one) YES NO

Investigator's Name (print) Greg Casalenuovo

Investigator's Signature _____

Date _____

NOTE: The font, Verdana, size 14, was used in the study document.

APPENDIX C

SAMPLE LETTER OF INTRODUCTION

**NURSING STUDY OF DIABETES MELLITUS
LETTER OF INTRODUCTION**

December 8, 2001

PMB #363
1345 Oak Ridge Turnpike
Oak Ridge, TN 37830

Dear Sir or Madam,

I am a nurse and a doctoral candidate in nursing at the University of Tennessee, Knoxville. I am completing my dissertation on living with diabetes mellitus.

I worked with Dr. Elaine Bunick from 1989 through 1995 when I was the Diabetes Nurse Educator at Methodist Medical Center in Oak Ridge. Dr. Bunick and I worked on several projects during that time and continue to be professional colleagues.

She has agreed to work with me on this project. Her office is sending you this letter inviting you to participate in this nursing study of diabetes mellitus.

Enclosed is an informed consent form that will give you the information about this study. If after reading the information, you want to participate, please fill out the informed consent form on the back page and sign it. Then mail it back using the enclosed, self-addressed, stamped envelope.

It will come to me and not Dr. Bunick's office. This way your participation remains confidential. Once I have received your informed consent form, I will then mail you the questionnaire to fill out and return to me.

Thanks for your time and consideration. I look forward to hearing from you. If you have any questions, please feel free to call me at 865-659-2556. Please leave me a message and I will call you back as soon as possible.

Sincerely,

Greg Casalenuovo, MSN, APRN, BC, CDE
Doctoral Candidate, Nursing
University of Tennessee, Knoxville

APPENDIX D

TABLE D.1: SCORING RULES FOR THE SOCIAL WELL-BEING INDEX

Table D.1. Scoring Rules for the Social Well-Being Index

Abbreviated Item Content	Precoded Value	Revised Value
Neighborhood family acquaintances	0	0
	1	1
	2	2
	3	3
	4	4
	5	5
	6	5
	7	5
	8	5
	9	5
	10	5
	11 or higher	6
Close friends and relatives	0	0
	1	1
	2	2
	3	3
	4	4
	5	5
	6 through 9	5
	10 through 20	6
	21 through 25	7
	26 through 35	8
	36 or higher	9
Visits with friends/relatives	1	4
	2	4
	3	4
	4	3
	5	2
	6	2
	7	1
Home visits by friends	1	3
	2	3
	3	3
	4	3
	5	2
	6	1

Table D.1. Continued.

Abbreviated Item Content	Precoded Value	Revised Value
Visits to homes of friends	1	3
	2	3
	3	3
	4	2
	5	2
	6	1
Telephone contacts	1	5
	2	4
	3	3
	4	3
	5	2
	6	1
Getting along	1	3
	2	2
	3	1
Attendance at religious services	1	5
	2	5
	3	4
	4	3
	5	2
	6	1
Voluntary group membership	0	0
	1	1
	2	2
	3	3
	4	4
	5 or higher	5
Level of group activity	1	4
	2	3
	3	2
	4	1

Source: Donald, C. A., & Ware, Jr., J. E. (1982). *The Quantification of Social Contacts and Resources*. Santa Monica, CA: Rand. pp. 75 – 76.

Vita

Gregory A. Casalenuovo was born in Lynchburg, Virginia on December 2, 1953. He attended public school in Rustburg, Virginia, where he graduated from Rustburg High School in 1972. Following graduation, he attended Central Virginia Community College and Lynchburg General-Marshall Lodge Hospital, School of Nursing, where in June, 1976, he received a Diploma in Nursing. After working as a staff nurse and Assistant Head Nurse for five years in the areas of surgical nursing, critical care, and emergency, he entered the University of North Carolina, Chapel Hill and received a Bachelor of Science in Nursing degree in May, 1984 and a Master of Science in Nursing degree in May, 1989. He continued to work in the roles of nurse educator and clinical specialist in the areas of critical care, cardiology, and diabetes management. In 1993, he entered the University of Tennessee, Knoxville to pursue the Doctor of Philosophy degree in nursing. The doctoral degree was conferred in May, 2002.

Greg is currently teaching at Carson-Newman College, Division of Nursing in Jefferson City, Tennessee and serves in the college Honors Program. He maintains memberships in several professional organizations, including President-Elect for Sigma Theta Tau International, Rho Mu Chapter. He is married to Judy Casalenuovo and they reside in Oak Ridge, Tennessee with their three children, Tiffani, Spencer, and Allison.

