THE ROLE OF COURAGE IN THE EXPERIENCE OF PATIENTS WITH DIABETES COMPLICATIONS

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Abstract

The Role of Courage in the Experience of
Patients with Diabetes Complications

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Over ten million Americans have diabetes mellitus, a chronic metabolic disease with multiple complications. The person with diabetes complications may experience progressive debilitation from such serious conditions as blindness, kidney failure, nerve damage and cardiovascular disease. These complications are progressive and life-threatening, requiring treatments which may be painful, exhausting and often unsuccessful. The patients have multiple tasks to perform in order to cope with this devastating physical illness. They are thrust into a unique emotional experience which has not been investigated by nurses. The experience necessitates drawing upon patients' inner resources. Nursing research into their experience is essential.

In an effort to illuminate the experience of the patient with disabling complications of diabetes so that nurses may be better able to assist individuals through the experience, a phenomenological exploration and philosophical analysis of the role of courage was conducted.

Courage has been viewed as a virtue, a gift, a potential to be developed. The role of courage in facing

certain complications of chronic illness bears exploration. The study of courage and its development, with related nursing implications, may better help the patient to face life and death.

The related literature for this study included courage, psychosocial adjustment to diabetes and chronic illness, phenomenology, coping and diabetes pathophysiology and complications.

The phenomenological method, an inductive, descriptive research method concerned with the investigation and description of all phenomena, was used. The research design consisted of a qualitative approach, using a small sample of middlescent diabetic patients with disabling complications. These patients were interviewed in home settings. The transcripts of these patient interviews were subjected to thematic analysis in order to generate descriptive profiles of the meaning of courage for these patients.

Five theme categories were derived which described the various dimensions of courage in the experience of the patients: philosophical, health care, physical, psychological, and interpersonal. The study of courage was found to have an impact on the practice of nursing and implications were drawn for improved nursing intervention for this group of patients.

DEDICATION

This dissertation is dedicated to my mother, Geraldine McDonald Donohue, who has provided an environment of intellectual stimulation and striving, love and support, throughout my life.

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CHAPTER I

INTRODUCTION

Background of the Problem

Over 10 million Americans, or 5% of the total population have diabetes mellitus, a chronic metabolic disease. This disease has multiple complications. The person with diabetes complications may experience progressive debilitation from such serious conditions as blindness, kidney failure, nerve damage and cardiovascular disease. These complications are progressive and life-threatening, requiring treatments which may be painful, exhausting and not always successful. These patients suffer many losses. They have many nursing problems. These include fears of death, incapacitation, pain and abandonment (Parets, 1967). They have multiple tasks to perform in an effort to cope with this devastating physical illness. These tasks encompass such processes as obtaining knowledge and skill necessary for self care, maintaining a positive concept of self, adjusting to altered relationships, grieving over losses, handling physical discomfort and maintaining a feeling of being in control (Miller, 1983). These patients are thrust into a unique life experience, which has not been investigated by nurses. The experience necessitates drawing upon patient resources and those of others, usually nurses. Yet, patients with such overwhelming problems, may be isolated from adequate,

informed and comforting care from nurses. Some have been referred to diabetes nurse specialists for intervention but the majority are cared for by general staff nurses. Not enough is known about the experience of these individuals to provide a strong framework for nursing intervention. Thus, nursing research into their experience becomes essential. "If the concerns and perceptions of the recipients of nursing services are considered unimportant factors in nursing research, then nurses may indeed be providing nursing care that is more meaningful to themselves than patients" (Tinkle and Beaton, 1983, p. 31). According to these authors, an important goal of nursing research is to provide findings that will have an impact on the delivery of health care services, a necessity for the diabetic population.

In an effort to illuminate the experience of the patient with disabling complications of diabetes so that nurses may be better able to assist individuals through the experience, a phenomenological exploration and a philosophical analysis of the role of courage in dealing with the many nursing problems of patients with diabetes complications were conducted.

Statement of the Problem

What is the role of courage and how is it experienced and manifested in the person with diabetes complications? To what extent can these findings be used to provide

improved nursing care services to these persons?

Subproblems

1. Is courage a universal phenomenon?
2. Is courage an untapped resource in persons with chronic illness?
3. How do patients with diabetes complications view courage?
4. Are these patients fearful of the complications? If not, what keeps them from being afraid?
5. What do these patients associate with courage and/or its development?
6. How do tasks of middlescence relate to the development of courage?
7. What philosophic concepts of courage can be applied to these patients?
8. Do patients with diabetes complications develop courage? If so, why? If not, why not?
9. What sustains the person through the development of courage?
10. Is courage already present in this group and, if so, can it be drawn upon?
11. If patients are able to develop courage, do they function at a higher level of feeling and response to the world?
12. Do patients view nurses as able to inspire the development of courage?

Working Definitions of Terms

Courage has been defined as the moral strength which allows a person to face any danger, trouble or pain steadily (The World Book Dictionary, 1963). This definition was chosen, for the purposes of this study, as a starting point. The definition of courage evolved with the study through the patients' identification and description of personal situations of courage. This is referred to as the lived-experience of courage. The definition of courage is also augmented in the related literature section.

Diabetes Mellitus is a chronic syndrome involving both metabolic and vascular abnormalities. Alterations in carbohydrate, protein and lipid metabolism are caused by a relative or absolute lack of effective insulin action (Davidson, 1981).

Insulin dependent diabetes is termed Type I diabetes, representing an absolute lack of insulin available within the body. Type II diabetes refers to non-insulin dependent diabetes, representing a relative lack of insulin available within the body.

Diabetes complications are microvascular (retinopathy, neuropathy, nephropathy) and macrovascular (heart and blood vessels) metabolic changes due to hyperglycemia that can lead to pathologic changes in multiple organ systems (Pirart, 1978).

Delimitations

Review of literature was restricted to works written in English. Literature was drawn from areas of nursing, philosophy, psychology, theology, anthropology and physiology.

Patients chosen for this study were English-speaking for interview purposes. They had at least one of the triopathy of diabetes complications. Patients with cardiovascular complications were included as these complications, too, are associated with the triopathy of retinopathy, neuropathy and nephropathy. Both male and female patients were included in the study, within an age of 30 to 55. Both Type I and Type II diabetic patients were accepted for study.

Assumptions

1. Courage is a desirable quality in facing life with diabetes complications. (Shelp, 1983)
2. All patients with diabetes complications, experience loss, fear, and grief due to these complications. (Parets, 1976)
3. One of the important roles of nurses is to meet the physical and emotional needs of diabetic patients. (Smith, 1981)

Working Hypothesis

Courage is a meaningful part of the experience of the patient with diabetes complications. Its presence or

absence will significantly affect how the patient faces life and death. Nursing, because of its central role in existential issues of life and death, has an impact on the patient's development of courage.

Significance of the Study

It is this researcher's belief that the essence of excellence in nursing is to provide caring for the patient. In an effort to provide such caring, a nurse must explore the human experience of the patient. Phenomenology, as a research method, can "serve nursing's goal to understand experience" (Oiler, p. 178).

Certain nurses have developed or alluded to the concept of phenomenology in their writings. Taddy (1975) in attempting to set forth a phenomenological basis for nursing practice points to phenomenology as being the appropriate research method when investigating the human experience.

> Existential phenomenology holds that, in dealing with man as the subject of the human sciences, there are areas of human existence which can be investigated adequately with the methods of traditional science. But there are other aspects of human existence, namely, the specifically personal and human experience, for which the methods of science are inappropriate. (p. 11)

Parse (1981) has developed a theory of nursing partly based on the works of the existential phenomenologists. "Paramount in this theory is man's participation in and perspective of health as it is co-created through interrelationships with others" (p. 82). The humanness of

man's experience can be analysed through such a theory.

Aside from an analysis of the humanness of man's experience, phenomenology can assist the nurse in perceiving the patient's reality. Loretta Zderad, in discussing the concept of empathy, proposes that the nurse needs to grasp the patient's unique view of reality. She writes of the "human movement toward oneness" (1969, p. 662) by sharing the other's being in a situation. Carper (1978) writes of a similar phenomenological awareness in a discussion of nurses' patterns of knowing. She emphasizes the importance of nurses' development of skills of perception and empathy for the lives of others, in order to better understand patients.

These are patient care issues that are relevant to nursing yet are often seriously neglected. Smith (1981) points this out and uses the examples of recovery from and survival of illness issues. She emphasizes the need for creatively assisting the patient to cope with these personal issues and further emphasizes that this assistance is the domain of the nurse.

> Many patients are confronting fundamental issues of life and death and of the quality and purpose of life-issues that are frequently obscured by daily preoccupations. The nurse who develops the skills and sensitivity to tune in to patients' existential concerns has an opportunity for personal growth that continues as long as he or she works with patients. This is a humanizing influence on nursing practice, that provides nurses with a depth and richness of experience

> that may be denied to those nurses who limit themselves to the performance of routine tasks. The nurse frequently comes away from contact with a patient feeling more sure of values and priorities. The patient's care was not just a job to be done; it was an experience of growth, insight, a surer sense of reality, and a deepened appreciation of the gift of life. In such moments the nurse often realizes that he or she gave and received a great deal during that experience with the patient. Thus, nurses are touched as survivors are touched, by the fundamental facts of existence. (p. 94)

Despite the philosophic framework and direction proposed by these theorists, the reality of the experience of developing diabetes complications has not been investigated by nurses. Nurses care for these patients in a variety of ways and in a variety of settings. Yet, little is known of the feelings a patient may experience as he or she loses vision, kidney function, nerve feeling and effective heart and blood vessel function. Diabetes attacks, with great ferocity, major organs of the body, threatening life and bringing the awareness of death close to the individual with diabetes. In facing life with diabetes complications and death due to them, courage can be viewed as integral to this human experience.

Courage has been viewed as a virtue, a gift, a potential to be developed, by certain authors. The role of courage in facing certain complications of chronic illness bears exploration. Few nursing studies have focused on the role of courage in illness and yet examples of it are

observed daily. There has been great emphasis in today's society on curative aspects of medicine and less emphasis on the nursing processes that are vital to recovery or maintenance of emotional health during chronic illness (Leininger, 1978). The maintaining of a person's emotional health during illness is a responsibility of nursing, distinct from medicine. The quality of this person's life and the reintegration of the physical, mental, emotional, and spiritual aspects of such a life is also a responsibility of nursing, distinct from medicine.

The diabetic patient with complications is a unique person with many and varied problems. The study of courage and its development, with related nursing implications, may better help this patient to face life and death.

CHAPTER II

RELATED LITERATURE

The literature for this study includes a description of the pathophysiology of diabetes and its complications. Psychosocial adjustment to diabetes and chronic illness is reviewed as well as general coping models. Finally, an analysis of literature related to courage is presented.

Diabetes Mellitus

Diabetes Mellitus is a chronic metabolic disease characterized by a high level of blood glucose, known as hyperglycemia. Hyperglycemia results from a relative or absolute lack of insulin, the hormone which allows glucose to enter body cells to be used for energy production. Without this hormone, glucose remains in the blood stream, creating damage. Type I diabetes (insulin-dependent) is characterized by an absence of insulin within the individual's body. This form of the disease usually occurs in youth and can be caused by viruses or immune system abnormalities that damage the pancreas. Type II diabetes (non-insulin dependent) is characterized by an inability of the body to use insulin, meaning that an individual may have normal insulin levels but the insulin can not be used effectively. Obesity and heredity, working hand in hand, are the major factors that may cause the development of this form of the disease. That is, obesity causes a state of insulin resistence in a genetically susceptible individual.

It is important to note that both forms of the disease, although with varying effects, are capable of producing the devastating complications which are described in the next section (Soeldner, 1982).

> Rates of atherosclerotic cardiovascular disease and amputation appear to be higher in Type II diabetes than in Type I diabetes. People with Type I diabetes are 3.7 times more likely to develop prcliferative diabetic retinopathy than those with Type II diabetes and people with Type I diabetes are 15 times more likely to develop end-stage renal disease than those with Type II diabetes. Rates of diabetic retinopathy and diabetic nephropathy increase dramatically with duration of diabetes. (The Carter Center, 1985, p. 395).

Complications of Diabetes

Complications of diabetes involve abnormalities of large blood vessels (macroangiopathy), small blood vessels (microangiopathy), and the peripheral and autonomic nervous system. Three body systems have classically been damaged by diabetes leading to the use of term, diabetic triopathy. This triopathy involves the eyes (retinopathy), kidneys (nephropathy) and nerves (neuropathy). Pirat (1978) describes in his study how this close association of diabetes complications deserves the term, triopathy.

> If this study is stretched out to include the preceding year and the following year, the coincidence is even greater: out of 100 patients suffering from neuropathy, 26 had nephropathy and 65 had retinopathy; out of 100 with nephropathy, 89 had neuropathy and 86 retinopathy; finally, out of 100 effected with retinopathy, 61 had neuropathy and 24 had nephropathy. (p. 180)

Each of these three complications of diabetes is described in the following sections.

Retinopathy

The diabetic individual is 25 times more prone to legal blindness and visual handicap then the non-diabetic person. Diabetic retinopathy is the leading cause of permanent visual loss in diabetic persons. The retina is light-sensitive tissue at the back of the eye which transmits visual impulses from the optic nerve to the brain. As a result of microangiopathy, the blood vessels that nourish the retina leak. These blood vessels may become weak, narrowed or blocked. These changes are characteristic of background retinopathy and include bulges of the vessel wall (microaneurysms), fluid leaks (exudates) and blood leaks (hemorrhages). At this stage, vision may not be effected. In the more advanced form of retinopathy, termed proliferative retinopathy, new and abnormal blood vessels are formed within the retina. The formation of new vessels (neovascularization) is in response to a lack of oxygen supply within the retina. These new vessels are fragile and prone to hemorrhage. Vitreous hemorrhage and retinal detachment may result from this serious form of retinopathy (Bradbury and Aiello, 1982).

After a 10-year duration of diabetes, half of all patients have retinopathy. After 15 years, more than 80% of all patients have some retinopathy, although it may not

affect the vision (The National Diabetes Advisory Board, 1980).

Diabetic retinopathy frequently produces no symptoms so patients are advised to see an opthalmologist regularly in order to detect its presence (Aloia, Donohue-Porter and Schlussel, 1984). It is essential that early signs of visual impairment are identified and appropriate referrals made for treatment and rehabilitation (Cleary, 1985).

Although treatments are available for diabetic retinopathy, these treatments are uncomfortable and hold certain risks. Laser therapy (photocoagulation) is used to seal off leaking blood vessels within the retina. Photocoagulation, the use of thermal energy to coagulate areas of the retinal capillary bed, has many functions. These include destroying abnormal vessel growth, sealing leakage and treating the retina after a vitrectomy. A vitrectomy is the removal and replacement of the vitreous humor that has been infiltrated by hemorrhage (Blevins, 1979). Although photocoagulation is an essential treatment, the laser beams, at times, destroy sensitive healthy eye tissue as they strike at the hemorrhaging blood vessels. Sometimes, too, laser therapy cannot be performed until a hemorrhage has completed. Patients are then asked to wait as long as a year prior to the start of laser therapy. During that time, the clarity of their vision may fluctuate dramatically, and their final vision outcome is uncertain.

Nephropathy

Diabetes is presently the second leading cause of end-stage renal disease (ESRD) in the U.S. and accounts for approximately 25% of new cases. At the present time, approximately 7,600 Americans are receiving treatment for ESRD due to diabetes (The Carter Center, 1985).

The kidney is responsible for filtering the wastes from the blood. This filtration process occurs in thousands of clusters of capillaries called glomeruli. In diabetic patients with kidney disease, the basement membrane of the capillaries of the glomeruli become thickened, leading to plugging and leaking (Blevins, 1979). Small blood vessel changes within the kidney as well as basement membrane thickening and accelerated atherosclerosis in the renal artery are also responsible for diabetic kidney disease (D'Elia, Kaldany and Miller, 1982).

The incidence of diabetic kidney disease in patients who developed diabetes before age 20 is much greater than in those patients who developed diabetes as adults. Patients who were diagnosed as having diabetes prior to the age of 20 have approximately a 50% chance of developing diabetic kidney disease after 20 years duration. This can be contrasted with those patients who were diagnosed after age 40 who have only a 2-4% incidence of diabetic kidney disease after 20 years duration (The National Diabetes Advisory Board, 1980).

Because the kidney has a great deal of reserve function, symptoms of kidney disease are usually not noticed until about 90% of kidney function is lost. When the filtering ability of the kidney decreases to about 25% of normal, renal insufficiency occurs. Laboratory tests such as creatinine and blood urea nitrogen are used to estimate kidney function. When the filtering capacity falls to less than 5-10 percent of normal, end-stage renal disease has occurred and treatment becomes necessary (Aloia, Donohue-Porter & Schlussel, 1984).

Treatment for diabetic nephropathy ranges from special restrictive diets to kidney transplants. Three standard treatments are peritoneal dialysis, hemodialysis and renal transplants. Peritoneal dialysis involves the insertion of a cleansing fluid into the membrane covering the abdominal internal organs. Waste products can be released from this membrane and insulin can be added to the cleansing fluid to facilitate glucose control. This procedure must be done several times a day. Hemodialysis refers to the cleansing of the blood's waste products through hook-up to an artificial kidney machine. This is the most widely used treatment and involves several cleansings per week. Surgical transplantation of a kidney provides the best rehabilitation for the patient but has certain disadvantages such as the difficulty in finding donor organs and rejection and infection (Friedman, 1982).

Patients experiencing renal failure need an integrated plan of care including essential learnings in order to view all options. Their world is filled with exhausting treatments, baffling choices and difficult decisions.

Neuropathy

Diabetic neuropathy is believed to result from excess sorbitol and/or reduced myoinositol in nerves. Both of these abnormalities result from hyperglycemia. In poorly controlled diabetes, an excess amount of glucose enters nerve cells. Some excess glucose is metabolized to sorbitol. Accumulation of sorbitol leads to damage of the nerve cell. Myoinositol is necessary for the proper functioning of nerves. It has been found to be excreted in the urine in large amounts in uncontrolled diabetes. Reduced levels in nervous tissue may contribute to diabetic neuropathy (Kozak, 1982).

Diabetes may cause nerve damage in both the peripheral and autonomic nervous systems. The various neuropathies are the most common among the major diabetes complications. "Diabetic neuropathies comprise a polymorphous group of disorders ranging from those characterized by acute onset of reversibility to those characterized by insidious onset, continuous progression, and complete irreversibility" (Kozak, 1982, p. 288).

These neuropathies may include mononeuropathy, diabetic opthamoplegia, polyneuropathy, amyotrophy, gastroparesis

diabeticorum, diabetic enteropathy, neuropathic bladder, and impotence. Although the mortality and morbidity from nervous system disorders may not be as great as from retinal or renal lesions, disability from the neuropathies can be severe enough to dominate the entire clinical picture (Spritz, 1978). For example, patients with peripheral neuropathy may have constant, unrelieved tingling, burning or numbness in their hands and feet.

Neuropathy can interfere with the patient's mobility and balance, digestive and elimination patterns, and sexuality (Blevins, 1979). New pharmacologic treatments are being offered to patients but at the present time, neuropathy still has a tremendous negative impact on the person with diabetes complications.

Cardiovascular Complications

The heart and blood vessels are also affected by diabetes. In the United States, diabetic persons are twice as prone to coronary heart disease, twice as susceptible to stroke and five times as likely to develop arterial disease of the limbs. Approximately 75 percent of the deaths among diabetic persons is due to cardiovascular disease. In fact, diabetes is characterized by accelerated vascular disease (Kozak, 1982).

"Vessels of all sizes are affected, from the aorta down to the smallest arterioles and capillaries. The aorta and large and medium-sized arteries are affected by accelerated,

severe atherosclerosis" (Blevins, 1979, p. 270). Development of vascular disease can be accounted for by a variety of factors such as obesity, hyperlipidemia, hypercholesterolemia and hypertension, all characteristics of diabetes (Blevins, 1979).

Vascular disease includes both stroke and peripheral vascular disease. If the brain is deprived of oxygenated blood because of a blockage (cerebral thrombosis, cerebral embolus or cerebral hemorrhage), a stroke results. Peripheral vascular disease occurs in the small arteries of the legs and feet, causing less oxygenated blood to be available to tissues. This can result in pain, infection, gangrene and ultimately to disabling amputation. Finally, if blood supply to the heart is blocked due to atherosclerosis, the diabetic individual experiences a myocardial infarction. All three of these examples of vascular disease are life-threatening and potentially disabling (Blevins, 1979).

Complications and Glucose Control

Pirat (1979) investigated diabetes and its degenerative complications in a prospective study involving 4,400 patients. This study conclusively showed that diabetic triopathy is a function of the duration and intensity of diabetes and more precisely of hyperglycemia.

This study had major conclusions which are integral to the exploration of diabetes complications. The incidence

and prevalence of neuropathy, microangiopathy (retina, glomerulus) and to a much lesser extent macroangiopathy (heart, lower limbs) are functions of the known duration of diabetes. Age, sex, obesity and a family history of diabetes were seen to have no effect on the development of triopathy. Probably the major conclusion drawn from this study was that poor control is definitely related to a higher prevalence and incidence of neuropathy and microangiopathy. Pirat's final recommendation was to "encourage physicians to strive toward normoglycemia" (1978, p. 261).

This recommendation has been at the heart of a major conflict in the care of the diabetic patient. In the past, certain studies have shown that vascular disease and neuropathy were absent in 20 to 40% of insulin-dependent diabetics who had survived forty years (Oakley, Pyke and Tattersall, 1974) leading to controversy over whether hyperglycemia should be avoided. Because the control of hyperglycemia involves a great deal of restrictions and self-management on the part of the diabetic individual, it is helpful to have strong supportive evidence that hyperglycemia is harmful and may lead to the development of complications. This is a controversial area as noted in a recent study by Feldt-Rasmussen and colleagues suggesting that the pathologic processes causing early renal disease are not reversed during twelve months of strict metabolic

control (Feldt-Rasmussen, Mathiesen, Hegedus & Deckert, 1986). Still, the present day philosophy, based in a large part on the Pirat (1978) study, is that control of diabetes is essential. Rifkin (1978) defended this position in the article, "Why Control Diabetes"? According to him "Proponents of good control believe that the goals of appropriate therapy for diabetes should include an all-out effort to obtain levels of fasting and postprandial blood, serum or plasma glucose values as close to those of the non-diabetic as possible" (p. 747). The demands placed on the diabetic person in order to achieve this control are great and have tremendous psychosocial implications. Therefore it follows that a review of the psychosocial literature regarding diabetes complications is necessary, and will be prefaced by a discussion of the timing of diabetes complications in the life cycle.

Time Framework of Middlescence

Because many of the complications of diabetes do not develop until 15 to 20 years after the diagnosis of the disease, the individual is often in the middlescent stage of life. Middlescence, or middle adulthood, carries with it certain developmental tasks. According to Erikson, (1963) the core conflict of the middle years is "Generativity vs Stagnation." The middle-aged adult who is generative has a sense of enterprise and perseverance. This person has certain responsibilities: family, work, home and community,

for which he or she is directly or indirectly responsible. If the developemental task of generativity is not achieved, a sense of stagnation develops. According to Erikson, the person becomes self-absorbed and is unable to move beyond his or her self-absorption.

The middle-age adult, therefore, faces certain maturational crises and tasks to cope with at the same time that a multiplicity of diabetes complications are developing. These tasks may include achievement of adult social responsibilities, maintenance of satisfactory career performance, assistance in the raising of children and care of aging parents, development of friendships, enjoyment of leisure time, economic stability and adjustment to the physiologic changes of middle life (Havighurst, 1948). The impact of diabetes complications on the performance and completion of these tasks needs exploration. The disease and its aftermath hit hardest at a time of change, stress, and perhaps changing life direction.

Psychosocial Aspects of Diabetes

The literature available regarding the psychosocial aspects of diabetes is not as large as one would expect of a disease affecting over 10 million Americans. In 1939, Daniels published the classic early literature review entitled "Present trends in the evaluation of psychic factors in diabetes mellitus." In this review only 23 articles dealing with emotional factors were found of over

3,000 on diabetes mellitus in the Quarterly Cumulative Index Medicus. A similar disproportion exists today. Twenty-seven more articles were reviewed by Stuart Hauser and Daniel Pollets in 1979.

In general, psychosocial aspects of diabetes were viewed in various frameworks throughout past years. In the early studies of Menninger (1935) diabetes was viewed as the direct result of psychological disturbances. In the late forties and 1950's, the diabetic individual's adaptation to his environment was examined. Mirsky (1948) reported findings of poor adaptation characterized by hurt pride, intensified fears and feelings of inadequacy. Hinkle and Wolf (1952) described stressful life events as the precipitating factors in changes in diabetes control. A quest for a "diabetic" personality resulted in studies which reported higher levels of depression in diabetic groups. Murawski and associates (1970) administered the Minnesota Multiphasic Personality Inventory to 112 adults who had diabetes for 25 to 48 years. Analysis of the test data revealed a high depression score for the entire sample. Participants expressed pervasive feelings of pessimism, hopelessness and depression in their test responses. In sharp contrast to this, a review by Dunn and Turtle (1981) has shown that there is not one consistent personality pattern common to diabetic individuals. In their landmark study, "The Myth of the Diabetic Personality" they

criticized many previous psychological studies for poor methodology, biased sampling and lack of control groups. Swift and his associates' study (1967) in which the diabetic child was found to have a poor self-image, increased anxiety and more pathologic hostility came under such an attack.

Studies performed by Minuchin and associates (1975) have revealed poor family interactions as noted by direct family observations of diabetic patients who were prone to the development of multiple, suddenly recurring bouts of ketoacidosis. This has reawakened an interest in the stress response and its effects on diabetes. Surwit and Feinglos (1983) found glucose tolerance to improve following initiation of relaxation therapy in selected patients.

The late seventies and early 1980's have witnessed more studies which are directed to the bio-psycho-social model, examining the interaction of diabetic control and psychosocial factors.

Hauser and Pollets (1979) described how diabetic individuals are often preoccupied with an awareness of their diabetes and an accompanying sadness. In studying 164 adolescents between the ages of 11 and 19, they found that the longer the duration of the diabetes, the more likely it was for the patient to have a low self-esteem. Dupois (1980) investigated the relationship between metabolic control and psychosocial issues. He studied 10 insulin-

dependent diabetic patients who were classified as depressed according to psychological studies and considered in poor metabolic control. After giving them 8 months of intensive classes on home monitoring and blood glucose, exercise and small group discussions, these patients demonstrated a large decrease in their depression and an increase in their blood glucose control.

Although the concept of metabolic control is an important one, Bruhn (1977), in writing "Self-Concept and the Control of Diabetes" warns that psychosocial influences are always present and should be investigated. "Psychosocial influences in the clinical course of diabetes are working at all stages of the disease and cannot be ignored, even when good control is achieved" (p. 96). Surwit, Scovern and Feinglos (1982) recommend a behavioral approach to the study of psychosocial aspects of diabetes. Because other means of study have failed to give insight into new management or help for the patient, these researchers advocate the study of disease-behavior interactions.

Jay Skyler (1981), in an editorial on psychosocial issues in Diabetes Care, emphasizes that present research into the psychological aspects of diabetes is inadequate.

> Too often the design of psychological studies has been the use of standardized instruments on a cross-section of diabetic subjects, perhaps in comparison with a control group. Yet the instruments themselves have inherent problems. For

> the most part, the instruments have been designed to quantify some psychological parameters that generally characterizes human beings. Although some of these parameters may be of interest in regard to diabetes, these instruments have not been designed to assess parameters of specific interest in diabetes. The conventional standardized instruments may be irrelevant to diabetes per se. (p. 656)

Psychosocial Aspects of Diabetes Complications

Very few articles dealing with psychosocial aspects of diabetes focus on the chronic complications. The majority of articles examine the etiology of diabetes and its psychological precipitants, difficulties in daily self-management and personality factors. One of the few articles that addresses the psychological implications of diabetes complications was written by Isenberg and Barnett (1965). These researchers focus on the multiplicity of diabetes complications and their effect on psychologically significant body parts. They describe the complex response to diabetes complications as being affected by the patient's previous emotional reaction to the disease.

> These complications are multiple, often coming one after the other to the same patient, and they affect many psychologically significant body parts. The possibility of any one of these complications causing a serious emotional reaction in the patient is heightened by the presence of previous, unresolved, emotional problems concerning his illness. (Isenberg and Barnett, 1965, p. 1133)

They also emphasize that most patients fearfully anticipate the development of complications and when they occur.

experience a crisis similar to when they first received the diagnosis of diabetes. Hamburg and Inoff's article "Coping with Predictable Crises of Diabetes" clearly delineates these specific predictable crises of diabetes and associated strategies for coping with them. Special attention is given to the development of chronic complications as a crisis state.

> When severe complications have occurred, there is the major task of coping with the grief associated with the actual loss of of body function or intactness. This loss is more than the loss of bodily integrity. It usually includes loss of cherished life goals and actual or perceived loss of love and regard from valued persons. The type and location of the complications and the alternatives available for re-establishing a basis of self-worth also define the exact nature of the coping tasks for the patient and family. (Hamburg and Inoff, 1983, p. 412)

Guthrie (1982) describes the diabetic patient's inability to feel whole or to start, again, to undergo treatment when faced with continuing complications of the disease. "The thought of becoming totally blind, of being more dependent on others, of decreased body function associated with or without pain, are significant factors that may lead to psychological crippling" (p. 25).

Findings of a study, originating in Japan, of severely ill diabetic patients and their coping behaviors demonstrate a lack of emotional response and potential to cope with complications of the disease. Sixty-two diabetic patients were selected for interview and were found to have

neglected the medical treatment and diet therapy for significantly longer periods of time than their age-sex-duration matched controls who did not have complications. The incidence of childhood parental separation was significantly higher in the severe group than the mild group, and the severe group of diabetic persons was found to have lost mastery over its life-threatening disease (Sinzato, Tamai, Nakagawa, and Ikemi, 1985).

Nurses may often avoid the subject of complications because it is a very difficult subject to broach. (Crigler-Meringola, 1982) Blevins (1979) encourages nurses to assist patients to talk about the development of diabetes complications in order to help them face reality. Although these general admonitions are helpful, there are few specific literature references directed to the emotional reactions of the diabetic patient experiencing complications. "Just as there is a paucity of knowledge on the coping strategies utilized by those with diabetes, there is even less knowledge on the reaction to complications" (Oehler-Giarratana, 1979, p. 194).

The complications of blindness can be used as an example of the lack of communication that often is present between the health professional and patient.

> The physician, not wanting to upset the patient or family, may decide not to communicate poor prognostic information; the patient may sense a prognosis of blindness or visual loss but may hesitate to share this fear with his or her family

> or physician; the family may suspect the probability of visual loss but not communicate these fears to the patient or physician. As a result, the patient is not given assistance in identifying fears or in coping with them. In denying the individual knowledge of the prognosis, the assumption is made that he cannot cope with the crisis, and thus he is denied the opportunity to do so. (Oehler-Giarratana, 1979, p. 193)

Diabetic individuals are aware of potential complications. Diabetic retinopathy is the leading cause of blindness between the ages of 21 and 65. Blindness has also been noted to be the most feared disability in America (Skyler, 1980). "It is not surprising, therefore, that diabetic patients dread the potential complications in general, and diabetic retinopathy in particular" (p. 172).

In a study examining psychosocial crises during diabetic renal failure, 29 patients who refused or threatened to refuse to continue dialysis were interviewed. Profound visual impairment was the major handicap leading to loss of independence as well as self-esteem for the group who refused further therapy (D'Elia, et al., 1981). Other findings of this study illuminate the tremendous level of disappointment experienced following failure of a kidney transplant, the loss of independence due to time commitments of dialysis and the pain of increasing dependence on family members.

For some patients with visual problems from diabetes, denial has been viewed as a defense mechanism preventing

them from seeking help. Because there is often a fluctuating loss of vision, this variation creates a false hope and holds patients from entering rehabilitation programs early (The National Diabetes Advisory Board, 1980).

For patients with diabetic kidney disease, much pessimism may be verbally and non-verbally transmitted from professionals. "For many years widespread pessimism has influenced the approach of clinicians towards diabetic patients with renal insufficiency" (D'Elia, Kaldany & Miller, 1982, p. 269).

Patients with neuropathies may experience frustation due to lack of knowledge regarding the etiology and treatment of these nerve disorders. "Despite their frequent occurrence, they are perhaps the most inadequately studied of the complications of diabetes, and little is known about them" (Kozak, 1982, p. 288).

Psychosocial Aspects of Chronic Illness

Because there is little written about the direct psychosocial effect of any and all of the diabetes complications, some knowledge may be gained by examining general emotional reactions to chronic illness. Parets (1967) identifies seven patterns of emotional reactions to chronic illness. These include depression as the person becomes gradually aware of the implications of the chronic disease. When realization comes that dreams and wishes from the pre-illness state will not be met, hostility and

aggression may then be experienced. Anxiety reactions may be seen and are usually related to how acutely close and serious the patient regards the threat to his life. Dependency, another emotional reaction, may occur if the patient feels incapable of defending himself and shifts the emotional burden to one who is stronger. Parets cautions that if this is allowed to continue the patient may become anxious, thinking that he can never be helped or is not worthy of help. Guilt reactions may be seen. A patient may feel guilty for failing to remain well or from harboring undisclosed hostile feelings. The final emotional reaction described by Parets is hypochondriasis. Patients experiencing this may feel that their illness renders them weak and so may severely limit their life-style.

Parets (1967) also identifies five important determinants of a patient's reaction to a chronic disability. These include the patient's premorbid personality, body image, previous experiences with illness, concept of the current illness and the attitude of physicians and nurses. Each of these determinants needs full assessment. According to Parets, emotional problems flourish among the chronically ill because of fears. Through patient interviews and clinical assessment, Parets identifies seven fears common to individuals with chronic illnesses. These are fears of death, incapacitation, pain, abandonment, spreading disease to others, loss of self-

esteem and disturbance of interpersonal relationships.

In summary, little information has been systematically gathered concerning the psychosocial impact of the chronic complications of diabetes. What has been presented paints a picture of frustration, hopelessness and lack of communication and information for the diabetic individual. How, then, can these individuals cope with diabetes complications? Models of effective coping will be now discussed. One of these models includes courage in its discussion of coping. This, too, will be addressed.

Coping

Coping is defined by Lazarus and Folkman (1984) as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Here, coping implies effort and is process-oriented. The authors emphasize that coping should not be equated with mastery over the environment; that is usually impossible. Instead, effective coping is viewed as that which allows the person to tolerate, minimize, accept or ignore what cannot be mastered.

Coping is also defined as "problem-solving behavior, designed to bring about relief, reward, quiescence, and equilibrium" (Weisman, 1978, p. 264). Weisman further describes coping as negotiating a series of obstacles and delineates several common coping strategies. These include

seeking information, seeking consolation, redefining the problem, blaming others, denying, resigning oneself, and finding emotional release (Weisman, 1984).

Miller defines and describes coping tasks in Coping with Chronic Illness: Overcoming Powerlessness.

> Coping tasks are those particular challenges that must be faced and overcome so that the individual preserves integrity, restores or maintains a positive concept of self, and functions effectively in relationships and life roles. Individuals with chronic health problems may be challenged to cope with multiple complex tasks. (1983, p. 18)

Some of the coping tasks described by Miller include maintaining a positive concept of self, grieving over losses, adjusting to altered relationships and maintaining control.

Little and Carnevali (1976) have identified courage as an integral part of the coping experience. These nurse researchers list courage as an area of functional coping deficit, stating that clients experience difficulty in attaining or maintaining effective living if they lack courage as a resource.

Little & Carnevali stress the need for assessment of a potential deficit of courage, but emphasize that there are not at present, very effective therapeutic interventions available to assist clients in dealing with this deficit.

Nursing Studies of Courage

Nursing literature on courage is limited. Haase (1985)

provides a phenomenological study of courage in chronically ill adolescents. Using unstructured interviews, nine chronically ill adolescents were asked to identify and discuss a situation of courage. An essential structure of courage was developed including such characteristics as patients' evaluation process, coping strategies, alterations in relationships, and acknowledgement and acceptance of the lived-experience of courage as contributing to the patient's definition of self. Haase emphasizes that the situation of courage occurs in "a spiral regressive-progressive manner" (p. 158).

Haase's exploration of courage focuses, in part, on the daily lived-experiences of courage related to the myriad of procedures and treatments performed. She characterizes these as "mini lived-experiences of courage" which gradually prepare the patient to face the broadly defined situation of courage (p. 145). Her implications, then, are for further study into the terrible strain of the ill patient and resources available from health care professionals. Haase views courage as a bridge between fear and action. She characterizes it as a gradual development of coping skills and attitudes, necessitating creativity and social supports.

Lanara (1974) examines the concept of heroism found in classical Greek literature and the Bible in order to relate heroism to nursing philosophy. Lanara identifies love as the most noble form of heroism. The study suggests that

nursing offers many opportunities for nurses to be heroic and to show a spirit of caring. Courage is an area of nursing knowledge and skill that requires more research. It will now be explored.

Courage: A Philosophic Discussion

An exploration of courage provides the conceptual framework within which to understand the experience of the diabetic person with complications. The word courage brings to mind many meanings, feelings and descriptions. A dictionary definition presents a short, unemotional definition: "the quality of mind or spirit that enables one to face difficulty, danger, pain, etc. with firmness and without fears (The Random House Dictionary of English Language, 1967, p. 334). Others, such as Nietzsche, describe courage in emotion-laden terms, as a power of life to affirm itself (Cited in Tillich, 1952). Still others elucidate what courage is by stating what it is not. "True courage is not brutal force of vulgar heroes, but the firm resolve of virtue and reason" (Alfred North Whitehead, The International Dictionary of Thoughts, 1975, p. 173).

In this review of selected literature related to courage, courage will be described and investigated through the writings of philosophers, psychologists and others. It will be viewed in relation to such themes as suffering, hope, vulnerability, self-esteem, love, fearlessness, control, culture and commitment.

In attempting to describe courage, an examination of its linguistic derivation may be helpful. The Greek word for courage is andreias, which means manliness, indicating a military connotation of courage. The German language has two words that mean courageous, tapfer and mutig. Tapfer refers to firmness and importance. Mutig is derived from mut, suggesting a matter of the "heart", the personal center. The French-English word, courage, is derived from the French "couer," heart (Tillich, 1952). The derivation of the word, courage, displays its historical importance.

Paul Tillich, in his classic work The Courage to Be, describes courage as essential, an ontological concept.

> Courage as a human act, as a matter of valuation, is an ethical concept. Courage as the universal and essential self-affirmation of one's being is an ontological concept. The courage to be is the ethical act in which man affirms his own being in spite of those elements of his existence which conflict with his essential self-affirmation. (p. 3)

The phrase "in spite of" here should not go unnoticed because it shows a theme that is often repeated. Tillich supports and expands the works of such philosophers as Spinoza and Nietzsche who describe this self-affirmation as courage. Nietzsche describes the many aspects of life, its ambiguity. Yet, it is the power of life to affirm itself in spite of such ambiguity that Nietzsche calls courage (Cited in Tillich, 1952).

Tillich's analysis of courage ultimately becomes

theological in nature. The ultimate source of courage, for Tillich, is absolute faith or what he terms the "God above God" (p. 186). Courage is found in all of human existence and is a key component of being itself, an ethical reality. Tillich addresses many concepts of courage but one of particular importance to this study is the relationship of vitality and courage. Vitality, for Tillich, is life power and is necessary for courage. Life includes both fear and courage as elements of a life process in a changing but essentially established balance.

> A life process which shows this balance and with its power of being has, in biological terms, vitality, i.e., life power. The right courage therefore must, like the right fear, be understood as the expression of perfect vitality. The courage to be is a function of vitality. Diminishing vitality consequently entails diminishing courage. To strengthen vitality means to strengthen the courage to be. Neurotic individuals and neurotic periods are lacking vitality. Their biological substance has disintegrated. They have lost the power of full self-affirmation, of the courage to be. Whether this happens or not is the result of biological processes, it is biological fate. The periods of a diminished courage to be are periods of biological weakness in the individual and in history. (Tillich, 1952, p. 79)

Tillich asserts that the more vital strength a being has the more it is able to affirm itself. This aspect of Tillich's analysis of courage has great significance when investigating severely debilitated persons.

St. Thomas Aquinas explored courage and, in his doctrine of courage, discusses the duality of the meaning of

courage. Here, courage is viewed as strength of mind which is capable of conquering whatever threatens the attainment of the highest good. It is united with wisdom (and temperance and justice) as the four cardinal virtues. St. Thomas Aquinas subordinates courage to wisdom because of his belief in the priority of intellect over will. Two important aspects here should be noted. First, that Aquinas mentions courage in relation to the attainment of a higher good and secondly, that there is a dispute as to the comprehensiveness of courage as a virtue (Tillich, 1952). This latter problem will be addressed first.

Is courage a comprehensive virtue? A virtue has been defined as a disposition or trait that involves a tendency to act in certain kinds of ways in certain situations (Shelp, 1984). According to Rollo May, courage cannot be grouped as one of several virtues. "Courage is not a virtue or value among other personal values like love or fidelity. It is the foundation that underlies and gives reality to all other virtues and personal values" (1975, p. 4). For May as well as Tillich, courage is an ontological concept. May further segregates courage into physical, moral and social modes but insists that in each sphere, courage implies commitment, either to action, to sensitivity or to relating to other human beings in spite of doubt.

The first of May's categories is physical courage which is the most primitive form. Traditionally, this dealt with

man's ability to protect himself but recently this form of courage can be viewed as degenerating into brutality. May proposes this form of courage to be reworked into a use of the body to cultivate sensitivity. Listening with the body is a view of this form of courage presently emerging through the influence of yoga and meditation.

The second category is moral courage, involving a sensitivity to human suffering. It is dependent on one's capacity to perceive the experience of others. It is rooted within actions based on empathy.

Social courage, the third category, is the courage to relate to other human beings. It is the capacity to risk one's self in the hope of achieving meaningful intimacy. This intimacy is authentic, requiring an investment, over time, in a relationship that will demand an increasing openness.

The final category, creative courage, refers to man's discovery of new forms and symbols, patterns on which a new society can be built. May uses the examples of artists and writers who stretch beyond limits and find new meaning in existence as models of creative courage. The ultimate issue involved in courage, for May, is commitment.

MacIntyre (1984) has identified courage as a virtue central to moral life. Here, though, virtue is not viewed as innate but as an acquired human quality. "We hold courage to be a virtue because the care and concern for

individuals, communities and causes which is so crucial to so much in practices requires the existence of such a virtue" (p. 192). According to MacIntyre, the virtue of courage has its role in human life because of its connection with care and concern.

World leaders have recognized courage as a comprehensive virtue. "Courage is rightly esteemed the first of human qualities because it is the quality which guarantees all others" (Sir Winston Churchill, The International Dictionary of Thoughts, 1975, p. 173). John F. Kennedy, too, recognizes the importance of courage and its necessity "in spite of".

> The courage of life is often a less dramatic spectacle than the courage of a final moment; but it is no less than a magnificant mixture of triumph and tragedy. A man does what he must in spite of personal consequence, in spite of obstacles and dangers and pressure and that is the basis of all human morality. (Kennedy, The International Dictionary of Thoughts, 1975, p. 174)

It has already been mentioned that courage is often described in relation to the attainment of a higher good. In the next paragraphs, courage in relation to nobility will be explored.

Courage has been related to the element of the soul called thymos. This is considered the spirited, central position in the soul, bridging the gap between reason and desire. "It is the unreflective striving toward what is noble" (Tillich, 1952, p. 3). According to Tillich,

philosophers such as Plato and Aristotle praised the goodness and beauty of courage, considering it noble.

Modern day philosophers still relate nobility and courage, emphasizing that an external goal must be morally worthy in order for a courageous act to be considered noble and the agent virtuous. "Courage, in the sense of virtuous, deals with how to live the noble life and to die that noble death" (Shelp, 1984, p. 356).

Death figures predominantly in readings concerning courage. Becker, in The Denial of Death describes the universality of the fear of death. He describes how much those who do not fear death are admired.

> We admire most the courage to face death, we give such valor our highest and most constant adoration; it moves us deeply in our hearts because we have doubts about how brave we ourselves would be. (1973, p. 11)

Fox and Swazey in The Courage to Fail describe the high probability of failure found in transplantation and dialysis. They discuss how these methods are used to fend off death and describe how this dramatic defense against death is typical of modern Western, particularly American culture. They consider that patients' participation in transplantation and dialysis takes a supreme form of courage and asks of them "the courage to fail". Death is viewed, here, as the pinnacle of failure.

Shelp, too, sees periods of illness or incapacitation as times when courage is necessary to face death. "One

lesson is that courage may be required to surrender the good of life for the good of death" (1984, p. 357).

Part of such a surrender may involve suffering. This concept, too, is related to courage. Viktor Frankl in Man's Search for Meaning describes how some people can retreat from terrible suffering to a life of inner riches and spiritual freedom. He describes how suffering, whether great or small, can fill the human soul; yet he describes the courage to suffer as the greatest courage.

Battenfield (1984), drawing from the work of Frankl, attempts a conceptual description of suffering, describing "finding meaning" as the apex of the suffering experience. Throughout readings in courage, the concept of "finding meaning" is noted. Frankl identifies that concentration camp prisoners were able to remain courageous in such a setting when they were able to derive meaning from their suffering. "Courage, however, is to be derived not only from found meaning, but from a search for meaning, and from a concomitant hope that the search will be fruitful" (Dagi, 1983, p. 432).

Smith (1981) after interviewing 86 patients recovering from major physical illnesses, delineates certain themes critical to the issue of survival. These include the strengthening of personal growth, use of group support and the development of an appreciation of nature's beauty. During a time of intense illness and suffering, certain

patients were able to seek and find meaning in their existence.

Hansell (1976) describes the importance of a comprehensive system of meaning in an individual's life. Each person carries a residue of notions, expressible in words and images, which guide his decisions in the conduct of affairs. "Any person in a state of attachment to his comprehensive system of meaning has a regular flow of experience which suggests to him what is important, proper, conventional, or conversely, what is wrong, outside of duty, or outside of his style-of-life" (p. 45). Linkage to a comprehensive system of meaning is considered vital to an individual's life.

Kubler-Ross, in 1969, wrote the classic description of suffering through dying and death. She develops a structure with five stages: denial, anger, bargaining, depression and acceptance. It is of interest to note that courage does not play as important role in her writings as does hope to which she devotes an entire chapter.

Hope and courage are closely related. According to Wilkes, author of The Gift of Courage,

> Hope is, after all, the twin, the other side of the coin, the warp to the woof of courage. Courage and hope are inseparable. Where we find one, we will find the other; where one is absent, so is the other. The gift of courage becomes the gift of hope. When we have courage, we can hope; in the absence of courage there is hopelessness. When we despair of finding a solution, it

> is to magic and to wishful thinking that we appeal, not to hope. Hope is based on courage, and courage is found in facing what is there, not in turning from it. (Wilkes, 1979, p. 102)

Kubler-Ross (1969) describes how patients' fields of future possibilities shrink as their disease progresses and yet they continue to battle with cancer. She credits this to the phenomenon of ever-present hope (p. 142). Hope, like courage, is difficult to define. It has been described as an emotion, expectation, illusion, and disposition (Miller, 1985). Hope can be viewed as a desire to achieve a certain goal. According to Miller, it is a powerful resource which may nurture a person's transition from weakness and vulnerability to full human functioning.

Vulnerability, too, relates to courage. According to Shelp (1984) the expression of courage is often most evident in circumstances where a human being is most vulnerable, such as during illness. This reinforces the importance of investigating such a construct in relation to ill patients.

> Without vulnerability, without risk, courage has no place. But the nature of human existence is such that life is vulnerable at every point. This means that courage is relevant not only to those circumstances in which danger is clearly defined. Courage understood descriptively and potentially evaluatively also is relevant to all of life which is subject to those unpredictable events that are threatening, the most extreme of which can bring death. (Shelp, 1984, p. 355)

Aside from the themes of illness and death,

vulnerability can be viewed in relation to courage. Kennedy in Profiles in Courage emphasizes that the nation's leaders who demonstrated great courage were vulnerable. They wished re-election and continued public approval and yet had to take risks in order to demonstrate their courageous attributes.

Wilkes (1979) argues that risk is an integral part of courage and emphasizes that moments of risk are moments of potential growth and enrichment for an individual. In fact, application of courage at the point of risk is essential to human growth.

The development of courage demonstrates two common themes: self-respect and support and love of others. These will now be discussed.

Self-respect has been viewed by Mackenzie (1962) as a "spring" for moral courage. Here, interestingly, courage is viewed as something that needs to be constantly rejuvenated and the author asserts that self-respect will revive or refresh courage. Schwartz (1981), too, writes of the reservoir of courage and how nurses must learn to refill it. Showing respect for the dignity of the patient as a human being, for Schwartz, is most important. She maintains that this is done by recognizing the patient's need for self-esteem, particularly as one ages. Self-respect or self-esteem can be a base for courage for some individuals.

Kennedy, in describing how the men he wrote of in

Profiles in Courage were motivated by national interest, also is quick to point out that they also had self-interest in mind.

> On the contrary, it was precisely because they did love themselves - because each one's need to maintain his own respect for himself was more important to him than his popularity with others - because his desire to win or maintain a reputation for integrity and courage was stronger than his desire to maintain his office - because his conscience, his personal standard of ethics, his integrity or morality, call it what you will - was stronger than the pressures of public disapproval - because his faith that his course was the best one, and would ultimately be vindicated, outweighed his fear of public reprisal. (Kennedy, 1955, p. 259)

Another important base for courage appears to be the love and support of others. Frankl describes the importance of love to carry one through suffering. He describes how love can help one to endure in the following passage.

> In a position of utter desolation, when man cannot express himself in positive action, when his only achievement may consist in enduring his sufferings in the right way - an honorable way - in such a position man can, through loving contemplation of the image he carries of his beloved, achieve fulfillment. (1939, p. 59)

Love is a potent emotion and has particular meaning as one is facing death.

> The more we incarnate ourselves in love, the more vulnerable we are by death, the death of those we love and by our own death. Conversely, the more interest in life fades, the less we feel grief and pain because we have already psychologically anticipated death. (Moltman, 1972, p. 104)

The continued theme of love, support and friendship can be found in the writing of Helen Keller. Blind, deaf and mute from birth, Helen Keller can be considered a woman of courage and accomplishment. In an effort to analyze her philosophy of courage, the support of her friends and loved ones seems apparent.

> It has been said that life has treated me harshly, and sometimes I have complained in my heart because many pleasures of human experiences have been withheld from me, but when I recollect the treasure of friendship that has been bestowed upon me I withdraw all charged against life. If much has been denied me, much, very much has been given me. So long as the memory of certain beloved friends lives in my heart I shall say that life is good. (Keller, 1902, p. 42)

Wilkes (1979), too, agrees that a central ingredient in the development of courage is the personal experience of relationships based on trust, truth and clear expectations. According to Wilkes, "where there are such nourishing relationships, courage will develop, and where there are not, courage will be lacking" (p. 36).

Erich Fromm, in The Act of Loving, describes the important and intense nature of love among all human beings and its necessity in allowing one to realize full human potential. "Genuine love is an expression of productiveness and implies care, respect, responsibility and knowledge." (p. 50) These ingredients, too, may set the stage for the development of courage.

Courage can be viewed as active or passive. Passive

forms of courage relate to endurance where active forms relate to bravery or fearlessness. Rachman (1982) investigates certain military aspects of courage, looking at what features distinguished decorated bomb disposal operators from non-decorated operators. Adequate training, good reliable equipment and group cohesion were all factors that contributed to courage in this group. One personal feature distinguished the group, as well: a significantly superior all round psychological health and body fitness. "The opposite characteristic to that reported by the decorated soldiers is described as `hypochondriasis,' and on this scale most of the decorated operators returned a zero score. "In other words, they had no bodily or mental complaints whatsoever" (p. 102). This lack of physical and mental complaints as a feature that facilitates courage has great importance when investigating a non-healthy group.

Other investigators, in studying military aspects of courage, attempt to differentiate it from fearlessness. In one study, bomb disposal operators were asked to make difficult discriminations under the threat of shock. Lower cardiac rates were noticed in the decorated group than the non-decorated during this experiment. The lack of physical symptoms characterizes their actions as fearless.

> A person might be quite willing to approach a frightening object or situation, even though he experiences a high degree of subjective fear and unpleasant bodily reactions. Such persistence in the face of subjective and bodily sensations of

> fear is one definition of courage - to continue despite one's subjective fear. This type of courageous behavior is an example of uncoupling, in which the person's observable behavior advances beyond his subjective discomfort. On the other had, if a person enters a seemingly dangerous situation but experiences little or no subjective fear or accompanying physiological response, his conduct is correctly described as fearless rather than courageous. (Cox, Hallam, O'Connor & Rachman, 1983, p. 107)

Control is an issue that bears further exploration in relation to courage. In military research it is noted that rear gunners develop more psychological problems than fighter pilots who incur more injuries. This has been explained by the lack of control that the rear gunners have over their environment (Rachman, 1978).

Lack of control has consistently been mentioned as a problem in coping with chronic illness and is thought to lead to such problems as hopelessness and powerlessness (Miller, 1983). Control, too, may be essential in the development of courage. The need for some control over the experience of being chronically ill is explored by Forsyth, Delaney and Gresham (1984). These researchers point out a particular management style in certain chronically ill patients which they term "vying for a winning position" (p. 181). Central to this concept of vying for a winning position is cognitive work which patients perform in order to mentally battle their disease. They take stock of their abilities, consider their limitations, and redesign an

agreeable life-style to work around complications or symptoms. "The strategic redefinitions seemed to help patients derive satisfaction from a sphere of activity that might seem ungratifying if not aggravating to others" (p. 185). Such creative efforts lead to control of the situation, enabling patients to experience their situation in, perhaps, a courageous way.

In related literature regarding health professionals and courage, Earl Shelp (1983), eloquently portrays the physician as the sustaining presence in the patient's development of courage. He portrays both the patient and the physician as having courage and, in fact, states that courage is needed by all who enter the clinical profession. He vehemently asserts that courageous clinicians can help patients to sustain the development of courage. In fact, he cautions that patients should not be over protected and "denied an opportunity to be courageous" (p. 424). "Over the course of time, patients in relationships with clinicians may not only recover physical strength, when this is possible, but also develop a moral character with which to live and die with honor" (p. 425).

Dagi (1983) disputes Shelp's claims in an article published in the same issue of The Journal of Medicine and Philosophy, stating that if one does not have meaning in one's life, it may be very difficult to have courage.

> Courage in the face of death can adopt the mein of serenity, but it need not. Unless

> one is sufficiently fortunate to have lived well with a philosphy that finds meaning even in adversity, one might be bitterly reluctant to consider the prospect of leaving this world, and equally bitter at the thought of continuing a crippled existence. (Dagi, 1983, p. 43)

In both contrasting views courage can be seen as important. Its cultural expression, too, may differ.

An individual's expression of courage may vary greatly, often depending on his cultural background. Moses and Cross (1980) relate the differences seen in the personal expression of courage in the face of illness.

> Personal courage in the face of illness takes many forms, not necessarily all dependent upon the seriousness of the malady or the extent of the pain. Some cultures demand stoicism, silence and withdrawal; others encourage a vociferous and hyperactive attack on the unseen foe. Some races are taught that the victim should continue the fight until collapse; others that subjugation and the acceptance of the outcome are the proper expressions of human dignity, especially if death seems to be imminent. Asian peoples are likely to retreat into the family fold and let the disease enfold them with a hush. Middle Easterners face medical traumas with moaning, waiting, and the wringing of hands. It is mainly the Western Christian culture that seems to expect the sick or dying to carry on in the face of recognized odds, putting up a good front and not letting one's friends and relatives down while there is still strength in the lip muscles to manage a smile. (p. 231).

Commitment, too, figures prominently in courage. A recent study by Asarian (1981) provides a phenomenological approach to the study of courage. It has as its outcome the identification of commitment to values, and strength of

interpersonal relationships as components of the essential structure of courage. Asarian uses a multi-level data collection process, including informal interview, written protocol and formal interview of 3 pairs of observers and actors in three unrelated situations of courage. He asks observers to identify a courageous person and describe the situation which led to such an identification. He asks the actors to describe the situation of courage as well as to describe a situation where they lacked courage. Of the three situations, one is characterized by Asarian as dignified acceptance, involving an acceptance of personal limitations due to dealing with terminal cancer. The other two situations are characterized as assertive determined, because they involved a direct assault.

Asarian uses a qualitative approach, including reflective analysis, to identify an essential structure of courage. "The structural understanding revealed in the present study suggests that courage is a behavioral commitment to values despite fear, conflict and risk because of the intersubjective and perceived worth of these values" (p. 159).

Asarian asserts that courage is a social phenomenon, grounded in the perception of the other. Courage is sustained by others and it reciprocally inspires and encourages both the person and others.

For Asarian, the dignified acceptance form of courage

is related to chronic illness and existential issues of life and death. The human being is continually reasserting his or her existence through the lived experience of courage.

> The act of courage itself draws a kind of border around the actor's world. It lays bare where the actor stands, what he/she is, what possibilities are, and what apparent limitations are. In being courageous the subject struggles to stretch these limits through confronting them. Hence, in courage the actor is being-toward personal limits and being-toward-the limits of the world. Both moments of this dialectic signify a certain taking up and expressing responsibility where the subject becomes a whole in an ontic sense. This mediation of the actor's commitments and the world is a bringing together of existence-in-the world. It is a small moment of being-towards-one's death. Philosophically one might view each individual moment of chosen and lived courage as a kind of rehearsal for the ultimate challenge of the phenomenon-being-toward-death. Each time a subject factually lives out courage he is moving toward his own wholeness. Hence, each time a person is able to be courageous one is defining oneself, one's commitments, and one's world. (p. 189)

Courage has been seen as being essential in facing life, suffering and death. It has been viewed as related to hope, vulnerability, self-esteem, love and control. There are cultural differences seen in the expression of courage. Commitment is an essential part of the experience of courage. This concludes an overview of the review of literature on courage.

CHAPTER III

METHODOLOGY

This chapter includes a description of the phenomenological approach as well as the role of phenomenological exploration and philosophical analysis. The research design is described, including preliminary field work observations.

A Phenomenological Approach

Phenomenology is a science of experience, a study of consciousness (Thevenaz, 1962). The phenomenological method is an inductive, descriptive research method which has as its task the investigation and description of all phenomena, including the human experience (Omery, 1983). Phenomenology concerns itself with the meaning of an experience as well as the experience itself, a concept attractive to nursing.

> The nursing profession is proud of its identification as a humanistic discipline. The profession's values and beliefs include a view that the human phenomenon is holistic and meaningful. The phenomenological methods share such values and beliefs. They consider all that is available in the experience under study, both subjective and objective, and strive to understand the total meaning that the experience has had for the participants. (Omery, 1983, p. 62)

The founder of Phenomenology was the philosopher, Edmund Husserl. He broke with the traditional thought of natural sciences being the only appropriate model of inquiry and experimentation. He believed that philosophy was capable of explaining human existence but only if philosophy

became rigorously scientific.

> Philosophy is a rigorous science for Husserl in the sense that is an investigation of the most radical, fundamental, primitive, original evidences of conscious experience; it goes beneath the constructions of sciences and common sense towards their foundations in experience. (Thevanaz, 1962, p. 18)

Husserl, in describing how phenomenology deals with a different kind of observation than natural science states the following:

> A phenomenon, then, is no `substantial' unity; it has no `real properties', it knows no real parts, no real changes, and no causality; all these words are here understood in the sense proper to natural science. To attribute a nature to phenomena, to investigate their real parts, their causal connections - this is pure absurdity, no better than if one wanted to ask about the causal properties, connections, etc., of numbers. It is the absurdity of naturalizing something whose essence excludes the kind of being that nature has. (1965, p. 107)

Husserl wrote of the need to go beyond direct observation in order to truly understand a phenomenon.

> And now how different the seeing of things shows itself to be on closer analysis. Even if we retain under the heading of attention the notion of an undifferentiated and in itself no further describable `seeing', it is, nevertheless, apparent that it really makes no sense at all to talk about things which are `simply there' and just need to be `seen'. On the contrary, this `simply being there' consists of certain mental processes of specific and changing structure, such as perception, imagination, memory, predication, etc., and in them the things are not contained as in a hull of a vessel. (Husserl, 1964, p. 9)

It is seen that phenomenology is involved in the observing and describing of layer after layer of each level of the experience with which it is involved. "Phenomenology aims primarily at a reflective study, as faithful as possible, of the phenomena in their directly presented articulation, with their constituent parts, their connections and their whole-making characteristics" (Spiegelberg, 1975, p. 193).

Ricoeur's study of phenomenology (Cited in Reagan & Stewart, 1978) notes that phenomenology never describes merely for the pleasure of describing. Instead, the description is effective only in the service of a great plan such as rediscovering the place of man in the world or recovering his metaphysical dimensions.

In describing the human uses of the phenomenological approach, Spiegelberg offers the following enticing summary of its benefits.

> I suggest that phenomenology in its descriptive stage can stimulate our perceptiveness for the richness of our experience in breadth and in depth; that in its search for essences it can develop imaginativeness and the sense for both what is essential and what is accidental; that in its attention to ways of appearance, it can heighten the sense for the inexhaustibility of the perspectives through which our world is given; that, in its study of their constitution in consciousness it can develop the sense for the dynamic adventure in our relationship with the world; that by suspending of existential judgment it can make us more aware of the precariousness of all our transsubjective claims to knowledge, a ground for epistemological humility; and that in its hermeneutic phase it can keep us open for concealed meanings in

> the phenomena.
> (1975, p. 70)

Although there is conflict between those that follow the path of natural science and those that embrace phenomenology, most of the writers in phenomenology emphasize that it provides a complementary method of scientific research; it is not a replacement for the natural process of scientific inquiry and experimentation.

> So long as the phenomenologist recognizes that his procedure is one type of method which is to be subsumed under methods in general, so that he does not disparge the `naive' theorizing of those who use naturalistic methods and the various explanatory devices that are so valuable practically, he may take his place, cooperatively, among thinkers concerned with problems that are of real and lasting significance. (Farber, 1943, p. 572)

Phenomenological Exploration and Philosophical Analysis

The research approach in use in this study was that of phenomenological exploration and philosophical analysis. Phenomenological exploration involved the use of many of the steps identified by Spiegelberg (1975) as common to all areas of research in phenomenological philosophy. These include direct exploration, analysis and description of particular phenomena, as free as possible from unexamined presuppositions and is termed descriptive phenomenology. The probing of these phenomena for typical structures or essences, and for the essential relations within and among them is another step, phenomenology of the essences. Phenomenology of appearances means giving attention to the

ways in which such phenomena appear, in different perspectives or modes of clarity. These three steps were used during the phenomenological exploration of the role of courage in the experience of diabetic patients with disabling complications.

Another step, termed hermeneutic phenomenology, refers to interpretation designed to unveil otherwise concealed meanings in the phenomena. This interpreting of the meaning of the phenomena is central to philosophical analysis. Philosophical analysis and understanding implies reflection and critique, essential to hermeneutic phenomenology.

> If a radical critique of life is called for, this can only mean that one must resolve to stop at nothing - which expresses the fundamental sense of phenomenology. In this sense, phenomenology is in no way merely one more metaphysical stance alongside others; it is rather understandable solely as the central discipline of philosophy itself: that of fundamental criticism.... (Zaner, 1975, p. 139)

Hermeneutic phenomenology has been defined as a method of bringing out the normally hidden purposes of such goal-determined beings as man (Spiegelberg, 1982). Hermeneutics uses methods that go beyond mere description of what is manifest and tries to uncover hidden meanings. Extrapolation beyond what is directly present within the phenomena under study is part of hermeneutical interpretation. An important structural characteristic of hermeneutical phenomenology is being-in-the world. A human being exists within the framework of an encompassing world

with which it belongs together. This intimate relationship is examined in light of consciousness, knowledge, moods, temporality and history by most hermeneutic philosophers such as Heidegger (Spiegelberg, 1982). It was Martin Heidegger who developed hermeneutic phenomenology in order to interpret the ontological meaning of such human conditions.

The questions chosen to ask the present study participants in regard to their experience were planned in order to gather the richness of their experience through phenomenological exploration. The hermeneutical approach of viewing the patient as existing within the framework of an encompassing world provided structure for the later philosopical analysis.

Within hermeneutics, there is a relationship between an interpreter and what he or she seeks to understand. Is it not nursing's role and responsibility to understand the experience of the patient? The phenomenological approach is a powerful method of sharing and interpreting the reality of the patient's experience. Nursing, through the phenomenological method, can share in such a reality, as it opens itself up to understanding.

> It is true, of course, that understanding requires effort and care, imagination and perceptiveness, but this is directed to the pathos of opening ourselves to what we seek to understand - of allowing it to speak to us. (Bernstein, 1983, p. 137)

The role of phenomenological exploration and

philosophical analysis in this study has been discussed. The following section deals with varied aspects of research design.

In an effort to clarify the goals of this study, preliminary fieldwork was undertaken and will now be described.

Preliminary Fieldwork: Process & Outcomes

As a diabetes nurse specialist for over five years, this researcher had often been asked to see patients with disabling complications of diabetes. Staff nurses request such consultation from a nurse specialist in this position because of the multiplicity of complex problems these patients experience. The role of the nurse specialist includes assessing the patient, providing education and emotional support to the patient and family, and guiding the nursing staff in planning care for the patient. This consultation is bound by the intense time constraints found in the acute care setting. Many questions regarding patients' experience of their illness, the disabling complications, or reorientation of their lives, often go unasked and unanswered. It became this researcher's desire to learn more about the experience of the diabetic patient with complications.

In preparation for the field work this researcher sought advice from the anthropology faculty, used guided readings to develop knowledge of the field study method, and

drew upon clinical experience in the preparation of a series of questions to be asked during preliminary fieldwork.

The writings of two nurse researchers were particularly helpful in understanding the process of qualitative research. Jeanne Quint Benoliel (1983) describes the collection of qualitative data to determine the socializing influences of life-threatening disease on identity development in a group of diabetic adolescents. She emphasizes important ethical considerations involved in participant observation studies such as negotiation, responsibility, and confidentiality. Dorothy Smith, in Survival of Illness: Implications for Nursing, too, emphasizes the importance of patient interviews to investigate sensitive issues and describes how she formulated the questions she asked based on literature review.

Preparation for field study included learning to negotiate the interview, preparing to observe in the field, and discovering the importance of field notes (Bogdan and Biklen, 1982). It also included focusing the questions in a way that would facilitate communication. Both structural and descriptive questions were necessary to complement one another (Spradley, 1979).

At the time of the preliminary fieldwork interview, this researcher's tentative focus was an inquiry into the general experience of having diabetes complications.

Questions were formulated from clinical experience and readings on the impact of chronic illness (Parets, 1967).

The diabetic patient interviewed as part of preliminary fieldwork was a 31 year old female patient who has had insulin dependent diabetes for 21 years. She is now partially blind and experiencing early kidney failure.

The interview setting was the patient's home and she consented to the use of a tape recorder. The interview was semistructured in that certain questions were prepared yet many were open-ended and allowed for her participation and discussion. They included:

1. When was the first time you found out that you had diabetes complications? (structural)
2. How did this occur? (structural)
3. Did you realize these complications were related to diabetes? (structural)
4. How did you feel when these complications began to develop? (descriptive)
5. Who helped you deal with these complications? (descriptive)
6. Did the nursing staff, during your last hospitalization, ever ask you how you felt about diabetes complications? (structural)
7. If not, were you upset that you had not been asked more questions about your feelings? (descriptive)
8. Do you think about the diabetes complications often?

(descriptive)

9. Have they changed your life? If so, how? (descriptive)

10. What are your family members' reactions to the diabetes complications? (descriptive)

11. Do their reactions have an impact on you? (descriptive)

12. What was the most difficult aspect of dealing with the complications? (descriptive)

13. Do you practice diabetes self-management? (structural)

A number of themes were identified from this meeting. These themes included dealing with incompetence, taking risks, recognizing the inevitability of complications and their vague time table, as well as lack of support from nurses. These will now be more fully described.

This patient had experienced early diabetic retinopathy that had gone undetected by two physicians although she had complained of blurred vision, and seeing haloes and floaters. When she developed hypertension and kidney problems, no physician ever explained to her how these multiple conditions were linked to diabetes. Instead, she went from one physician to another with no coordination of care. This experience has been well-documented as being common for the person with diabetes complications (Friedman, 1982).

When treatments were finally offered to this patient, they held much risk. For example, she was told that laser therapy for her eyes was necessary but that it could damage healthy eye tissue as well. She was left to make a decision without adequate support or information and admitted that, at that time, she was not assertive enough to seek out appropriate education.

She spoke of feeling that complications were inevitable. She remembered a family member telling her that she could probably lose a leg when she grew up, because of diabetes. She stated that when she did eat sweets she would think: "It doesn't matter, diabetes will hurt me anyway."

She stated that she was often accused of "cheating" on her diet by doctors and nurses. She said she would admit it when she did go off the diet and, so, would feel terrible when she was accused unfairly.

She did not remember a nurse ever asking her how she was dealing with complications. She felt this was not unusual since she thought nurses would have expected her to have emotionally adjusted to diabetes of such long-standing.

The patient stated that her single greatest problem was the vague time table presented for the development of complications. At her last hospitalization for evaluation of her kidney status, she was not given any time period when her kidneys might fail totally. Yet, she stated that each time she attended Renal Clinic, she was told to be careful

of her left arm and not to allow it to be used for blood drawing. She said she knew that meant the physicians were thinking about dialysis access but were afraid to mention it to her. She ended by saying that perhaps she, too, was afraid of hearing too much definite information.

This patient was considered a key informant, one participant who was interviewed in-depth initially and whose discussion of her experience gave rise to even more questions concerning the experience of living with complications. This researcher next developed a broad set of questions regarding the entire experience of the development of complications. After much reflection, the question of courage and its development was selected as the primary research focus. The other questions derived from the preliminary fieldwork were also discussed as the research continued and many of them have been listed in Chapter 1.

The observations that were made during the preliminary fieldwork re-emphasized the relevance of studying this group of patients. It also provided an opportunity for this researcher to develop and validate crucial interviewing skills. The audiotape recording and thematic observations were shared with an anthropologist for validation that a) the interview technique was clear and unbiased and b) the data reflected in the thematic observations was appropriately descriptive of the interview. After this

verification, the research design was implemented and this will be described next. The following sections detail various methodologic steps including a description of the sample, data sources, production and analysis.

Combined Qualitative Methodologic Approach

The specific phenomenological method used in this study was protocol analysis of transcribed tape-recorded interview descriptions of the experience of diabetes complications and the role of courage obtained from nine participants. Using two session interviews within home settings, spontaneous descriptions of the experience of courage within the specific situations of living with disabling complications were obtained. These descriptions were analyzed in order to identify the structure of courage in patients with disabling complications. This structure was then philosophically analyzed in order to reveal the experience of the patient.

A combined methodology was used for interpretation of patient data. The phenomenological approach as described by Husserl, Spiegelberg, Omery and others provided the philosophical framework for the study. The ethnographic methods of Spradley and the qualitative design of Bogdan and Biklen allowed for the accurate production of the data through patient interviews. The analysis methods of Colaizzi were used in order to provide a description of courage for these patients. This description of courage was then philosophically analyzed.

A "combined" methodology has been successfully defended by Swanson-Kauffman (1986). "The combined qualitative strategy described is offered as a nursing-appropriate methodology that fits our unique phenomenon of discernment, namely, persons, environments, health, and nursing" (p. 59).

Research Design

The design consisted of the qualitative approach, using a cross-section of diabetic patients with disabling complications. These patients were seen on a short-term basis over a period of three months, for two in-depth interviews. Patients were interviewed in home settings whenever possible.

The Sample

Patients were chosen according to purposeful sampling (Bogdan and Biklin, 1982) whereby particular subjects were included in order to facilitate the expansion of the developing theory. These patients had at least one of the triopathy of complications already mentioned. Cardiovascular complications were not excluded. Ten patients were approached to join the study and one refused. The sample consisted of nine individuals, both male and female. Complications are equally distributed between sexes so that aspect did not need to be limited, although differences in responses between sexes were analyzed. The age range was of middlescence since that is the usual area

of the development of complications. The sample was limited to individuals living within a reasonable distance.

Data Sources

The bulk of the data came from semi-structured interviews with diabetic individuals. The majority of the patients were former clients of a Diabetes Education Center or clinic associated with a teaching hospital. All patients had been previously known to this researcher during her work as a diabetes nurse specialist. No patient was selected without previous consultation with the attending physician. Initial contacts with the patient were made either face-to-face or by telephone. Home interviews provided data from additional sources, such as the family. Other data sources included the patients' medical records in order to supplement the description of their physical condition. This included type of diabetes, duration, treatment, physical findings, and laboratory values. A demographic data form was also used at the time of the interview and may be found in the Appendix.

Participant Welfare

Each participant was given a verbal explanation of the purpose of the study. The fact that participation was voluntary and could be stopped at any time was discussed. The verbal description of the data collection procedure included the following: a) participants would be asked to be interviewed in their home settings. b) the participant

would be asked to describe aspects of living with diabetes as well as his or her feelings and thoughts concerning courage. c) the patient would be free to stop at any time, due to fatigue or emotional upset. d) the information would be obtained by audio-tape recorded interview. e) the participant would be asked to review certain data collected to validate it.

In compliance with the rules and regulations of Adelphi University School of Nursing's Human Subjects Review Committee, an application was made and approved for the passage of this study. See Appendix A.

Interview Format

The process of data production took place over a period of approximately three months. First interviews were completed approximately five weeks after data collection began. Second interviews were completed approximately 12 weeks after data collection began. The interview schedule included questions that were basic to each interview but the interviewer remained free to word questions so they were meaningful to each respondent. All interviews were conducted by this researcher. Each interview was approximately one hour in length, and carried out in a face-to-face manner. All but one of the patients were interviewed in their home setting. This allowed for the inclusion of data which was observational in nature.

Colaizzi (1978) has emphasized the importance of the

phenomenological method, imaginative listening, in obtaining patient data. Descriptions gained through interviews are often richer than written data and require the researcher to attend to the subjects' nuances of speech and gestures.

> Not only must the interviews be taped and transcribed, but the researcher must be present to his subject(s) in a special way. While his subject does provide him with data, the researcher must realize that his subject is more than merely a source of data: he is exquisitely a person, and the full richness of a person and his verbalized experiences can be contacted only when the researcher listens to him with more than just his ears; he must listen with the totality of his being and with the entirety of his personality. (Colaizzi, 1978, p. 64)

Giorgi (1970) has described this as an engaged relationship, wherein the interviewer becomes the true instrument of the study. This also means that the interviewer brings certain assumptions to the study. In this study, the researcher felt that courage was a desirable quality in facing life with diabetes complications. The researcher also felt that a potential existed for nursing to improve care for these patients if more of their experience was revealed. The interviewer dwells with the data during both the actual interview and the analysis. "Contemplative dwelling is the undistracted reading and re-reading of the descriptions with the intent to uncover the meaning of thelived experience for the subject" (Parse, Coyne & Smith, 1985, p. 19).

Interview Schedule

Three semi-structured interview questionnaires were

devised. See Appendices B, C & D. The Emotional Reactions Response Form and the Courage Response Form I were used in the first interview and were designed to gradually introduce the concept of courage. The Courage Response Form II was used only at the second meeting, when it was assumed that both the investigator and participant felt more at ease in discussing stressful, emotional issues. As Benoliel (1983) suggests, the "tell me about" question was a frequent opener as well as the use of changing question structure and order, if necessary, to match the respondent's own phraseology, readiness and mood. Each patient agreed to have the interview taped for the purposes of transcript analysis. Each, also signed a consent form at the start of the interview. See Appendix E. A demographic data form was filled out by this investigator prior to any taping, in order to assure completeness of data and to gradually lead into the interview format. See Appendix F.

Data Analysis

This phase of the research was initiated with the taking of detailed field notes and taping of all interviews. Analysis of data took place by using the notes and transcripts to create descriptive profiles of the meaning of courage for these patients. The method of phenomenological data analysis as described by Colaizzi (1978) was used.

Colaizzi's method of data analysis begins with the reading of each description of the phenomenon. Significant

statements, those directly pertaining to the phenomenon, are then extracted. The meaning of these statements is then formulated as the researcher attempts to spell out its significance through the use of "creative insight" (Colaizzi, 1978, p. 59). This refers to the interpretation of the significance of the meaning of the statement, by the researcher, within the context of the protocols, field setting and participant observation. It involves intuiting meanings, based on intense reflection. This process is repeated for each patient's description (protocol). Formulated meanings are then organized as aggregates into clusters of themes. Themes emerge which are common to all subjects' protocols. The clusters of themes are referred back to the original protocols in order to validate them. The results are integrated into an exhaustive description of the investigated topic. An effort is made to formulate this description into a statement of identification of the essential structure of the phenomenon.

Validity and Reliability

It has been maintained that phenomenological data is valid to the extent that the subject's experience of the phenomenon has been exhaustively tapped (Colaizzi, 1978). For this study, validity and reliability issues were attended to in the following ways:

1) Preliminary fieldwork was undertaken in order to develop knowledge of the field study method.

2) During preliminary fieldwork, an expert ethnographer reviewed audiotape and thematic observations to determine this researcher's reliability in assisting patients to share their experience.

3) Two doctorally prepared nurse researchers, one master's prepared diabetes educator and one master's prepared psychiatric nurse specialist, reviewed the tentative interview questions for clarity and meaningfulness which aided in obtaining the fullest description of the patient experience as possible.

4) Content validity of the interview schedules was sought by asking each patient at the conclusion of each interview if there was anything that was not asked about that he or she felt should have been addressed. Content validity was also sought by relating the clinical data to literature accounts of courage.

5) Avoidance of bias or idealization of the concept under study was attempted by inquiry into the lived absence of the phenomenon. It has been suggested that asking participants about their least courageous times helps to examine the life-world reality rather than an idealization. This acted as a safeguard against idealization on the part of the researcher of the courage of certain participants. (Asarian, 1981).

6) Reliability depended on this researcher's reliance on multiple data sources such as observation of the home

setting, field notes, observation of speech patterns, gestures and body language as well as the transcribed protocols of the patients.

7) A sample of the transcripts was reviewed with two doctorally prepared nurse researchers in order to validate the coding system. This included the derivation of the significant statements, their meanings, the emerging theme clusters and categories.

8) Construct validity was sought by sharing the fundamental structure of the phenomenon with the participants, following data analysis, to determine if it accurately described their experience.

This concludes a description of the methodology used in this study. The next chapter will focus on analysis of the data.

CHAPTER IV

ANALYSIS OF DATA

Description of Sample

The six women and three men in the study ranged from age 29-55 with a total group mean age of 39 (SD-9.64). The mean duration of illness for the group was 24.5 years (SD-6.15). All patients were insulin treated, although two patients were not insulin-dependent.

Access to each patient's medical records completed the total picture of the impact of diabetes complications. The social and medical conditions of these nine patients are fully profiled in Appendix G. A short table of the patients' pertinent information now follows. See Table 1. As noted, the nine patients had disabling complications of the disease. Table 2 depicts their complications history.

Patient Profiles

Each of the nine patients was profiled and these descriptions can be found in Appendix G. The profiles describe not only the patients' pertinent diabetes-related information but also their appearance, attitude and aspects of their home environment.

TABLE 1

DESCRIPTION OF SAMPLE BY DEMOGRAPHIC VARIABLES

AND TRIOPATHY OF COMPLICATIONS

		SEX	AGE	TYPE OF DIABETES MELLITUS*	DURATION (YRS)	COMPLICATIONS		
						RETINOPATHY	NEPHROPATHY	NEUROPATHY
PT	1	F	42	I	29	XXXX	XXXX	XXXX
PT	2	F	29	I	12	XXXX	XXXX	XXXX
PT	3	F	37	I	32	XXXX	XXXX	XXXX
PT	4	F	54	II	25	XXXX		XXXX
PT	5	F	33	I	22	XXXX	XXXX	
PT	6	M	38	I	25	XXXX	XXXX	XXXX
PT	7	F	32	I	25	XXXX	XXXX	
PT	8	M	31	I	20	XXXX	XXXX	XXXX
PT	9	M	55	II	31	XXXX	XXXX	XXXX

* I = Insulin-Dependent Diabetes
*II = Non-Insulin Dependent Diabetes

TABLE 2

DESCRIPTION OF PATIENTS' COMPLICATIONS

COMPLICATIONS	OCCURENCE IN 9 PATIENTS
RETINOPATHY	
Severe retinopathy	9
Detached retina	2
Vitrectomy	3
Laser Treatments	> 100 (as a group total)
NEPHROPATHY	
Post-Kidney Transplant for ESRD*	1
Hemodialysis	2
Continuous Ambulatory Peritoneal Dialysis	1
Attending Renal Clinic (pre-shunt)	2
Proteinuria	3
NEUROPATHY	
Painful Tingling and Numbness	7
Impotence	3
Severe Hypoglycemia	1
VASCULAR	
BTK** amputation	1
Foot amputations	1
Post M.I.***	1
Ischemic Heart Disease	1
Hypertension	6

*ESRD = End Stage Renal Disease
**BTK = Below the Knee
***MI = Myocardial Infarction

Protocols

Nine taped interviews were generated from the first series of interviews and are referred to as protocols. Seven more taped transcripts were generated at the time of the second interview schedule. Two patients were not taped during the second interviews due to the seriousness of their condition. One patient, instead, was interviewed by phone and the other during a short hospital visit and two follow-up phone calls.

Extraction of Codes

The sixteen protocols and other field notes were subjected to intense analysis. Because of the enormous amount of data to be analyzed, a combination of coding methods of significant statements was used.

Within the 16 protocols, a total of 48 codes was derived. According to Bogdan and Biklen (1982), the codes should encompass topics for which there is the most substantiation as well as topics that need exploration. For the purposes of clarity and data reduction, it is recommended that codes be limited to under 50.

The data was coded by hand; the codes acted as markers in breaking down protocols into meaningful units. Thus, the coding system facilitated data analysis. When a new code was instituted, previously examined protocols were re-examined for the newly recognized code. Repetitions of codes were retained for each individual protocol. Code

files were maintained for each individual patient as well as for each of the 48 codes.

A sample of the transcripts was reviewed with a doctorally prepared nurse researcher in order to validate the coding system. Significant statements were studied systematically in order to arrive at a sense of their meaning. The formulated meanings of the statements were developed within the context of the protocol. The formulated meanings were coded as closely to the stated expressions as possible to ensure that while moving beyond the expressed statement, they did not lose ties with it. For example, the statement "I was not prepared for the development of complications" was coded as LoP - lack of preparation. A listing of the coded formulated meanings are found in Appendix H.

Development of Theme Clusters

The coded formulated meanings were organized into clusters of themes and theme categories. These themes were continually referred back to the original protocols for validation and the ensure the commonality of themes. For example, the coded formulated meanings of loss, depression, fear, grief, dependency and rage were organized as a theme cluster of Unpleasant Emotions under the Theme Category of Psychological Dimension.

The theme clusters which emerged fell into five categories including a) Philosophical Dimension b) Health

Care Dimension c) Physical Dimension d) Psychological Dimension and e) Interpersonal Dimension. Nineteen theme clusters were identified. See Table 3. Each of the theme categories will be described. Pertinent references will be given from the patients' protocols in order to clarify how themes emerged.

Development of Theme Categories

One of the categories, the Physical Dimension, will now be used as an example of the process of developing theme clusters and categories from the coded formulated meanings extracted from the protocols. A listing of the coded formulated meanings is found in Appendix H. The coded formulated meanings of BI (body image) and SI (self-image) formed Theme Cluster 3A - Body and Self-Image. The coded formulated meanings of RIS (risk), OH (overwhelming hospitalizations), FR (fear) and FOP (fear of pain) formed Theme Cluster 3B - Risk-taking and High Technology. The coded formulated meanings of VUL (vulnerability), LOS (loss), DEP (dependence), PC (poor control) and FW (feeling well) formed Theme Cluster 3C - Physical Vulnerability. The coded formulated meanings of DSM (diabetes self-management tasks), LOD (lack of distractions), RES (restrictions of diabetes), NRL (no release from disease) and IND (independence) formed the final Theme Cluster 3D - Diabetes Self-Management. Together, these Theme Clusters comprised the category of Physical Dimension.

TABLE 3

CATEGORIES OF THEMES AND THEME CLUSTERS

OF PATIENTS' EXPERIENCE OF COURAGE

THEME CATEGORY 1 - Philosophical Dimension

Theme Cluster 1A - Fluctuating Nature
Theme Cluster 1B - Turning Points
Theme Cluster 1C - New View of World and Relationships
Theme Cluster 1D - Spiritual Outlook

THEME CATEGORY 2 - Health Care Dimension

Theme Cluster 2A - Lack of preparedness
Theme Cluster 2B - Medical/Nursing Incompetence
Theme Cluster 2C - Role of Nurses
Theme Cluster 2D - Ways of Helping
Theme Cluster 2E - Faith in primary physician

THEME CATEGORY 3 - Physical Dimension

Theme Cluster 3A - Body and self-image
Theme Cluster 3B - Risk-Taking and High Technology
Theme Cluster 3C - Physical Vulnerability
Theme Cluster 3D - Diabetes Self-Management Tasks

THEME CATEGORY 4 - Psychological Dimension

Theme Cluster 4A - Unpleasant Feelings
Theme Cluster 4B - Pleasant Feelings

THEME CATEGORY 5 - Interpersonal Dimension

Theme Cluster 5A - Self View and Others' Perceptions
Theme Cluster 5B - Love and Support of Others
Theme Cluster 5C - Disruption of Personal Relationships
Theme Cluster 5D - Tasks of Middlescence

Description of Theme Categories

The following is the description of the researcher's engagement with the patient's reality of experiencing diabetes complications. Meaning and structure have been extracted from the experience through a focus on the role of courage. Nursing, because of its intimate relationship with human beings during life, suffering and death, needs to uncover and understand more of the experiential meaning of courage and illness for the patient.

Theme Category 1 - Philosophical Dimension

Philosophical theme clusters which emerged included the fluctuating nature of courage, its turning points, its resulting new view of the world and relationships, and the role of spiritual outlook in its development.

Fluctuating Nature (Theme Cluster 1). The first theme cluster was derived from the patients' consensus that courage is a fluctuating state and can be nurtured. In saying this, they displayed the belief that courage is not developed once and for all, or present in all situations. Instead, the general feeling was that courage was related to the patient's present situation and the supports available. Some patients found certain situations intolerable and found courage difficult to initiate and/or maintain. PT#1 described how courage, for her, is a transient state.

> Courage is, to me, a person who is strong and determined to go through fire and brimstone and all that kind of stuff. I don't know if I have that. I guess I do

> because I keep making an attempt, but I lose my courage. I think it's because of depression.

All patients agreed that it was possible to regain courage. Patients were asked if they felt that nurses were capable of giving them a feeling of courage. Many used the word inspiration in their answers. The concept of human to human interaction, in the form of inspiration, became very important in describing how patients were able to face complications courageously. This will be explored further in the next chapter.

Turning Points (Theme Cluster 1B). The second theme cluster was derived from the turning points that all patients could recall and explain in their development of courage. Each patient described both a low and a high point in facing diabetes-related complications. PT#3 described her worst point as coming during the time she was on dialysis.

> I wasn't functioning. I was very different from most people on dialysis. Most people right after dialysis would be revived, you know. I was wiped out. I wouldn't recover until the next day at dinner time and, of course, the next day after that, I would be back on. There were only a few hours every few days when I felt I was functioning.

This patient viewed that period as one time that she felt totally devoid of courage. She sought psychological counseling after contemplation of suicide, and used that to assist her through that time. She spoke of being able to

face her amputation several years later, with courage, and a change in her philosophical outlook.

> My personal philosophy has changed to `you just make the best of it'. It's not going to help me any to sit and pout about it.

Pt. #7, too, saw a change in the development of courage as she adjusted to the situation.

> I guess when it first hits that's when I'm the least courageous. It's better when I can sit down and think about it and talk to other people and they tell me it's going to be o.k. I guess the first initial shock of each complication, that is when I am the least courageous.

Pt. #5 also reflected a change in the development of courage as her complications developed. The first diagnosis of eye complications was very frightening and she stated she felt the least courageous during this time. During a recent hospitalization, she was tested for a possible cancerous growth and described her feelings in the following way:

> I think I had the most courage the last time I was in the hospital and they found out I had the sarcoid. They went in with an indefinite diagnosis, you know. I knew all the possibilities and what could be wrong and what they were trying to find out. I thought then no matter what happens you just have to conquer that.

Table 4 lists the least and most courageous times in the lives of the nine patients. Within this theme cluster, patients could pinpoint a period in their lives when courage was either absent or present. Least courageous times, in regard to diabetes complications, revolved around the

TABLE 4

PATIENTS' REFLECTIONS ON THE ABSENCE AND PRESENCE OF COURAGE

	LEAST	MOST
PT#1	during winter months/ shut in	birth of daughter
PT#2	when unable to receive accurate medical information	attempting to get well in order to conceive a child
PT#3	during dialysis	adopting a son
PT#4	first diagnosis of eye complications	receiving husband's sustained support
PT#5	first diagnosis of eye complications	facing recent cancer scare
PT#6	during dialysis	adopting a daughter
PT#7	first diagnosis of eye complications	during recent engagement
PT#8	being restricted from sports in youth	facing vitrectomy
PT#9	being overwhelmed by crippling effect	when turning to religion

experience of dialysis for two patients and the initial shock of eye complications and possible blindness for three patients. Patients described more general times where it was difficult to summon courage as during the closed-in winter months, adjusting to the crippling effects of complications and when unable to receive answers from their doctors. Frustration and anger around these times, were expressed. The most courageous time periods described were during the birth and adoptions of children, and during recent hospitalizations when patients felt they had overcome another health obstacle and battled on.

Assessment of such critical time periods for the absence and presence of courage will aid in improved nursing intervention and will be discussed in the Chapter six.

New View of World and Relationships (Theme Cluster 1C). The third theme cluster in the philosophical dimension of courage, centered on the idea that an individual's life, experiences and perceptions may change after developing courage to cope with complications. Meaning seems to be derived from adversity. Two patients' words illustrated this. Pt.#4 described her changed perception of and strengthening relationship with her husband.

> I always babied him. He was my life so he never had to do. He didn't have to pick up his dish. Then, when this (blindness) happened to me, he was like a different person. He really amazed me that he could do what he does.
>
> That's the hardest part - that I can't do

> it anymore. Even to get dressed or pick out socks or clothes. I can't see to do it, you know. It changes your whole life. It really does. Parts of it is for the better. Like this new finding in my husband, the way he is. Now I would never have known this if I was still doing what I was doing.

While Pt. #4 described a change in relationship with one significant other, Pt. #8 described a change in his relationship and outlook to many others:

> I'm more conscious of other people's problems, you know. I think that's from being in the hospital, too. A friend of mine that I met at dialysis, the guy, we got really close, and he's all messed up. He has been on dialysis for a long time. He has one arm, he is in a wheelchair and you know it didn't make a difference because I didn't see it. (Pt. #8 was blind and regained his eyesight after vitrectomy). And now it doesn't make a difference even when I can see it but you know at that time maybe I would have shunned away from him because of his problems and it didn't make a difference, you know, because I didn't know he had those problems. Not that it's worth losing your sight over, but I know that it made me a lot better person inside. Just seeing other people, their problems and how they cope with their problems.

This changed world view following an experience which necessitated courage has been addressed by such authors as Frankl and Battenfield and will be further explored in the next chapter.

Spiritual Outlook (Theme Cluster 1D). The final theme cluster explored how patients' spiritual outlooks had an effect on the development of courage. All patients were able to discuss the nature of the role of religion in the

development of courage. Several did state that they were not religious and did not find any spiritual means helpful in developing courage. PT #1 derived strength from a spiritual focus when facing the disease.

> My religion has helped me get through the terrible things I was told in the beginning about my eyes, and facing blindness. I never knew anyone who was blind. And I thought, oh God, they said I could only have one child and you sent me this one. You would not have sent her if you did not mean for me to take care of her.

When faced with the need to be courageous, several patients derived comfort from the idea that a spiritual force was present to care for them.

> I wouldn't think I'm overly religious but I do believe there is someone watching over me. (Pt. #8)

> I have a strong belief in God, and that he is really taking care of everything and he is watching over me. (Pt. #3)

The majority of the patients did find religion helpful in the development of courage but stressed that they had to take an active part in developing such an attitude. Those who did not find religion helpful did not say they were without courage but that they derived it from other sources. Much of the anger associated with the development of complications can be seen in Pt. #7's attitude towards religion and courage.

> I think I've always not been a religious person. I grew up and went to Temple once in a while but I don't really have a religious outlook. I don't understand when so many things are happening and

> everybody says they are happening for a reason. I don't really believe it. No, I really don't have faith. I guess, if anything, I just have faith in myself that I will get through it. But I don't think somebody else up there is taking care of me.

This completes exploration of Theme Category 1 - Philosophical Dimension. The first two theme clusters reflect the changing nature of courage as it fluctuates and is nurtured. Low and high points in its development are noted. The third theme cluster addresses giving meaning to the situation as patients developed a new view of their world and relationships. The final theme cluster explores the role of religion in the development of courage.

Theme Category 2 - Health Care Dimension

Health care theme clusters which emerged included lack of preparation for the development of complications, exposure to health care incompetence, the role of nurses and their interventions in the development of courage. Faith in the primary physician was the final theme cluster noted.

Lack of Preparedness (Theme Cluster 2A). This theme cluster was derived from the overwhelming response from each patient that the devastation from the complications came without warning. All felt that they would have faced complications in a courageous manner more easily if they were better prepared for them.

When patients stated that they were unprepared for the development of diabetes complications, they usually meant

that all of the varying complications were not, in their mind, linked together as diabetes related. The following situations illustrate this:

> When we first moved here, I was still driving. So if we had known at that point that I wasn't going to drive anymore, we would have maybe looked for something nearer to town. (Pt. #1)

This patient found out about the extent of her eye problems during her first and only pregnancy.

> When I first had my first hemorrhage, I didn't know what was happening and when I went to the eye doctor when I was pregnant, the eye doctor said - don't you know what is going to happen? You could be blind tomorrow. That's how he told me; you could lose your vision. I said, do you mean black blind and he said maybe shadows. I thought, this can`t be happening to me. This just can`t be happening, without warning. I hadn't read about diabetes complications. I didn't read the way I read now.

Many patients felt angry that they were not given enough information about the threat of complications. A repeated theme was that courage might have been developed more fully if the patient had adequate warning. Although all patients admitted that they might have been given information about complications, all agreed that initial information about the serious sequelae of diabetes was too general and scanty. Pt. #2 described her feelings in the following way.

> When they talked about complications, they just said it in such a general way that it seemed so foreign. You know, oh well, you can go blind. Well, you know you're not

> going to go blind. You know, they would talk about the very far end of what could happen. And it was so far removed, that it just didn't seem real. And the amount of emphasis that they put on the complications was nothing compared to what they said about, well, just keep tight control, whatever that meant. I had no idea. When I went out to the Clinic, I saw some of these people. I began to see what it is, nerve damage. They say diabetic neuropathy. You know you can get diabetic neuropathy. So what's that? Big deal. What does that mean to me, nothing. When I saw these young people, 22, with diabetic neuropathy not being able to eat for almost the rest of their life bcause their stomach can no longer tolerate or digest food. Now that's something real. If someone sat down with me and said you could lose all the nerves that digest your food and have to live on some type of tube up your nose, that is something I can relate to. You tell me you're going to get diabetic neuropathy is like, yeah, fine, thank you. It doesn't mean anything to me.

It is important to note that the average duration of these patients' diabetes was over 24 years. Patient education was not a priority in the health care system at their time of diagnosis. Today's emphasis on patient education allows the person with diabetes to hear the appropriate information necessary for self-care and, perhaps, to take a courageous stance built on accurate information.

Many of the patients felt that they were not informed of the possibility of diabetes complications from the beginning but others said that no health care professional ever linked their various symptoms to diabetes for them.

Patients said that they saw many different sub-specialists and were never informed that all of the varying complications were due to diabetes. This leads to the next theme reflecting patients' anger and hostility towards the health care system.

Medical/Nursing Incompetence (Theme Cluster 2B). This theme cluster concerned the frequent episodes of incompetence on the part of the health care team to which these patients were exposed. Many patients stated that they experienced frightening episodes of mismanagement, particularly in the hospital setting. These episodes frightened and angered them but also gave them the stimulus to develop courage to handle their diabetes complications in a knowledgeable manner. Some examples of mismanagement and poor interactions between health care providers and recipients follow:

Pt. #3 described the first time she experienced both her first injection and insulin reaction. She clearly was still filled with rage and resentment as she spoke.

> The first time I had insulin I was in the hospital and the nurse came with Regular Insulin. She said, here, do it. Give yourself the shot. I freaked out. Because I never held a needle before and I couldn't do it. I couldn't give it to my legs. And she finally just pushed it in. In about 20 minutes, it was visiting hours and my dad came to see me and I was having an insulin reaction. Never knowing what an insulin reaction was, I didn't know what was going on. I just stood up looking at my father and I just sort of slid down and sat on the floor and he didn't know what

> was going on. He got the nurse and she got me up and said now come on, stop acting for your father. Stop this acting for your father. You were fine a minute ago. Come on, now, don't put on an act. She put me back in bed. And then another nurse came in and felt my hands and said they were cold and clammy and to get me some juice.

Many patients, aside from describing intensely difficult situations when hospitalized, also described their anger against the health care system in general, particularly as it related to coping with a handicap.

> They would put my food tray near me but not lift the cover or help me to eat. None of them offered to help and I couldn't see. (Pt. #4)

> They were supposed to get me special syringes to help me see the second dose. That was supposed to take 48 hours; it took me three months. (Pt. #8)

> Handicapped bathrooms are just such a laugh. I don't know if you know this but most handicapped bathrooms, if you go in with the wheelchair, you can't close the door behind you. (Pt. #3)

As patients described their feelings of anger and betrayal by health care workers and the health care system, they emphasized that instances like those described stimulated them to protect themselves from future harm. Patients had to learn to fend for themselves. Their intense feelings of anger were used as a mobilizing and energy generating force.

> I know exactly what to do if I have to go into the hospital now. Doctors ask me what to do. Last week when I was in the eye hospital, they asked me how to adjust my

> insulin. They might know what they are doing but I make sure I know what's going on. (Pt. #8)

The next two theme clusters are related and focus on the role of nurses in the development of courage and their ways of helping.

Role of Nurses (Theme Cluster 2C). This theme cluster focused on what patients viewed as the role of the nurse as she cared for patients with devastating complications of diabetes. All nine patients emphatically stated that they believed that nurses were capable of "inspiring courage." Although some of the patients said that they had never had an interaction with a nurse that did inspire courage, all felt that there was a potential for this in a nurse-patient relationship. The most frequently stated reason for thinking this, was that nurses were underpaid and unsung, and must therefore be altruistic.

> I think nurses certainly don't get paid enough. They certainly don't get glorified enough. So they are in it for the people. (Pt. #2)

> No one ever says, well, let's sit down and talk about how you feel today. But if I ever had a bad problem or decision, I would go to a nurse because at least they would try. And when I feel that people are trying I have hope and courage to face things. (Pt. #2)

Ways of Helping (Theme Cluster 2D). This theme cluster represented the exploration, with patients, of how nurses could inspire the development of courage. All patients could describe what they felt would be a good nursing

approach. Central to this nursing approach would be a caring attitude, knowledgeable manner and an interest in the patient's emotional outlook. When asked how a nurse could inspire courage, the following descriptions were given by patients.

> A nurse could inspire courage by her knowledge, definitely knowledge. If I just wanted sympathy and compassion, I would go to my mother. I need someone to give me the facts, so I can face things. (Pt. #2)
>
> All I knew was that I had to decide to go on to a life support system and this nurse came in and sat down and said, hey, you know, if you have any questions, let's talk about them. And that was a big release off of me because she could help me. It wasn't only her knowledge. Her knowledge helped but it was her kindness. (Pt. #8).
>
> I think if they just told me the truth and sat with me for a while. The problem is that they are so overworked. (Pt. #3)
>
> If someone just came in and asked me how I felt emotionally about the complications, I would open up. (Pt. #5)

Although only one patient could describe a nurse-patient interaction that led to the development of courage to face dialysis, each of the other patients emphasized that through gestures of caring, nurses could have an impact on the development of courage. The quality of the human to human interaction was generally seen as more important in its development than any technical expertise on the part of the nurse.

Faith in Primary Physician (Theme Cluster 2E). This theme cluster noted the significant role of the physician in

the development of courage. These patients saw many different physicians frequently. Eight, though, mentioned one doctor (usually the diabetologist) who coordinated care and gave them the strength, support and hope to face the multiplicity of complications courageously.

> He is always there when I have a problem and when I call he always gets back to me. This gives me confidence. (Pt. #6)
>
> He always asks me how I am doing emotionally. (Pt. #4)
>
> My doctor doesn't talk down. He talks to me like I'm on his level. We also have a laugh. He goofs on me; I goof on him. You know, a little bit of humor makes me more at ease. (Pt. #8)

On the other side of the spectrum, the lack of a sustaining presence of a physician was detrimental to the development of courage.

> Every time I go to one doctor he tells me the other doctor totally mishandled me. Everyone of them. So you begin to think that, well, if I went to another doctor after these, they are going to turn around and say he's a jerk. You know, so I have no faith in the medical profession at all. None. (Pt. #2)
>
> Once during a hospital stay, my blood sugar elevated and the doctor came in and he said to me I'm the Resident or whatever it was, he was not my regular doctor. I'm going to give you a shot to cover. I said, don't do that because I've just had a reaction and I've eaten so much, that's why it's high. Let it go down on its own. And I begged him because of the terrible reaction I had. I begged him not to give me that cover shot. He gave it to me anyway and I had another reaction. It was so unnecessary and you know, an apology was made to me but I had begged him not to do that. There are few

> doctors that I trust, and I'm always afraid when I go to the hospital. (Pt. #1)

For these patients, courage was difficult to sustain without the support of a physician.

This completes a description of Theme Category 2 - Health Care System Dimension. The first two theme clusters reflect the isolation and despair that is often seen in this group of patients. The second two theme clusters, though, reflect the hope and anticipation these patients have regarding nursing's intervention in their care. The final theme cluster reflects the need for one sustaining relationship in the health care system.

Theme Category 3 - Physical Dimension

Physical theme clusters which emerged included the role of body image and self-image as well as physical vulnerability in the development of courage. The relationship of risk taking and high technology to courage was another theme cluster. The final theme cluster, entitled diabetes self-management tasks, concerns the patients' self-management of the disease.

Body and Self-Image (Theme Cluster 3A). This theme cluster was derived from the exploration of patients' body and self-image changes stemming from debilitation due to diabetes. All patients were able to express their feelings about such changes. Certain patients could relate their feelings about the changes to the role of courage in their

lives.

> It's difficult to be courageous sometimes because I feel I'm such a waste. Certain life choices were taken out of my hands but I feel I could have handled it better. I don't have a good self-image of myself. You see a person as a horse or a cart. I feel like I'm the cart and diabetes is the horse, pulling me along rather than me pulling it along. (Pt. #1)

Another patient viewed the changes in body and self-image that diabetes brought as a constant battle to be fought.

> It used to bother me very much, how I looked. But there are things that I just can't control. I put on thirty pounds since February and I'm a big bloat but I can't let just the physical side represent me. I look in the mirror and I say that girl is going to be getting better and that girl is not me. (Pt. #2)

Pt. #3 had a tremendous amount of changes in her body which were reflected in her self-image, and even pursued her in dreams.

> It bothered me that the weight gain changed the shape of my face. I had nightmares about that and everything else. I would dream that I would go to a dance and no one would dance with me and I'd have to come home alone. It's really weird. You know, I've been married 15 years and I'm having nightmares that I'm a teenager and nobody wants to go out with me.

There was no doubt that each of the patients had damages inflicted upon his or her self-image. Yet, each was able to move beyond those feelings and continue with life tasks.

Risk-Taking & High Technology (Theme Cluster 3B). This theme was a result of exploring the underpinnings of the body image changes. These patients had undergone drastic

treatments for diabetes which resulted in altered body images. When these treatments were explored, the concept of risk-taking within high technology treatment options such as dialysis, transplantation or photocoagulation was uncovered. The concept of risk is intimately bound to the development of courage and patient examples of such will now be given.

> The doctor said I should decide soon whether to go for the eye treatments but that he wasn't sure if they would work. If they didn't work, they could even destroy my vision. I was pretty upset. (Pt. #5)

> I've been scared to death about dialysis, the strain on the heart, the long hours, needles, since the first day I knew I had a kidney problem. (Pt. #6)

Although fear of high technology treatment options was present, each of the patients took risks and accepted the challenge of treatment. At certain times, the highly technical environment seemed a catalyst for the development of courage.

> I think when I had to really face the eye problem, I was extremely courageous. I remember when I had my eyes anesthesized for the first time, there was nothing worse than lying there watching someone put needles in your eyes. I always said if I could get through that, I'll get through anything. (Pt. #1)

> If they keep coming up with something else new to help me, no matter how different or painful, I will try my best to take it on. (Pt. #9)

Physical Vulnerability (Theme Cluster 3C). This evolved following discussions of all the physical changes

brought about by the disease. Physical vulnerability was a commonly identified feeling. Patients felt it was difficult to maintain a courageous stance when feeling so vulnerable. Some of the feelings of physical vulnerability dated back to early experiences with diabetes.

> I was raised feeling overprotected. Don't get a job, my father said. Rest, rest all you can. It was always rest, take it easy. My mother would pick me up from school, from my activities and it was always because I was not well. (Pt. #1)

Another patient saw the complications of diabetes as causing a sudden physical vulnerability and an abrupt change in self-image.

> The complications definitely make me physically vulnerable and that annoys me. I used to participate in 41 mile bike races, do back, hand stands and work the balance beam. So I saw myself as someone who worked very hard to achieve outstanding skills and now I can't do any of these. That doesn't make me any less of a person but I am vulnerable. I'm not used to feeling just mediocre. (Pt. #2)

Other patients felt that they had to be protective of their bodies to prevent further damage.

> I'm very afraid of falling, naturally, because of my kidneys. I know my bones will probably break but more importantly, I could lose my kidney. You know that could happen. (Pt. #3)

> After a vitrectomy, there is very little depth perception. I have to be very careful. Plus, the neuropathy, makes me lose balance. I fall easily. (Pt. #6)

Certain specific aspects of diabetes create physical vulnerability.

> Especially if you are having an insulin reaction....You are extremely vulnerable. Talk about vulnerability. In an insulin reaction. I am totally gone. (Pt. #1)

The multiple nature of the diabetes complications accounts for the descriptions of feelings of physical vulnerability. The patients were able to describe their feelings of physical fragility and their impact upon the experience of living with diabetes complications. Physical changes such as vision loss, imbalance, confusion from an insulin reaction occured abruptly, leaving patients feeling frightened and vulnerable.

Diabetes Self-Management Tasks (Theme Cluster 3D). The final theme cluster for the Physical Dimension, was drawn from discussions of diabetes self-management. Self-management involves the patient taking responsibility for monitoring blood glucose, diet, exercise and medication adjustment. Two aspects of this theme cluster were patients' frustrations regarding the never ending demands of self-management and their pride and creativity in controlling certain aspects of their physical care.

All patients emphasized that there was no release from diabetes and from proper self-management.

> Because of my restrictions, I have no distractions. I need to get away from it. (Pt. #1)

> This thing (continuous ambulatory peritoneal dialysis) bugs me - having to do it everyday. There is no vacation from it. (Pt. #6)

Yet, as difficult as self-management might be, patients embraced the sense of power and control it offered. Patient #6 described how he handles home dialysis to suit his life-style.

> A lot of people combine activities, they drain their dialysis while they eat lunch. Not me, I like to keep everything separate. I want to enjoy my lunch and then I do my exchange.

Diabetes self-management, for another patient, released her from fear.

> My major fear is of having a reaction at night during sleep. I always test my blood before bed. I have not had a reaction since I bought the blood testing machine. (Pt. #3)

For another, the pain of blood-letting was tolerable because it freed her from dependence.

> The blood glucose self-testing machine is simple, quick and less frustrating because I can see the results myself. I used to have to wait until someone came home. It's made me feel more independent. (Pt. #1)

Each patient felt that some control of his or her environment was possible through diabetes self-management. Another result of diabetes self-management is improved metabolic control. Patients reported feeling better when in better control and more able to cope with the demands of diabetes complications.

> I feel much better when my sugars are right and then everything comes easy. (Pt. #2)

> Being in control of the diabetes does relate to courage because you physically

> feel better and so your whole mind is brighter. You're not bogged down like the terrible time you get when you have a high sugar. (Pt. #1)

Metabolic control led to an emotional control over the disease for certain patients.

This completes exploration of Theme Category 3 - Physical Dimension. The first theme cluster reflects the abrupt and devastating body and self-image changes experienced by these patients. The second theme cluster explores patients' risk-taking abilities in their interactions with highly technical health care. Physical vulnerability is explored in the third theme cluster. The final theme cluster examines how the rigors of diabetes self-management aid in giving patients some mastery over their situation.

Theme Category 4 - Psychological Dimension

In order to more fully understand the patients' experience of living with diabetes complications, questions regarding their general emotional reactions were asked. These feeling states, then, were offered in response to the diabetes complications, not only in response to the development of courage.

Psychological theme clusters which emerged were grouped into two opposing sections. Unpleasant Feelings (Theme Cluster 4A) was composed of the following: Loss, Depression, Fear, Grief, Dependency, Rage, Guilt, Isolation, and Frustration. Pleasant Feelings (Theme Cluster 4B) was

composed of the following: Positive Thinking, Humor, Problem-Solving, Hope and Patience.

Patients moved freely between the two states of pleasant and unpleasant feelings. Each feeling was interconnected to another. Due to the large number of feelings noted, only brief excerpts from the protocols will be presented. Theme Cluster 4A revealed Unpleasant Feelings.

Loss

> The eye doctor said I definitely can't lift too much. My neighbors have joined exercise and aerobic classes and bowling. I would have loved to join and be part of it, but I can't. (Pt. #1)

Depression

> Two weeks can't go by and I will feel depressed and then I have to fight it and it will be gone. It comes and goes because I get sad. (Pt. #2)
>
> I get very depressed. I go through all too frequent crying spells. (Pt. #6)

Fear

> I don't think you are ever without fear. You are never really secure. (Pt. #6)
>
> I was definitely afraid to go to the hospital because I've had things done to me in the hospitals that put a big fear into me. (Pt. #1)

Grief

> The person I was before the diabetes complications is gone. I feel bad, you know. Sometimes I see myself as not being able to do things anymore. (Pt. #2)

Dependency

I don't know if I ever want to live independently or not but I feel I couldn't because there is no way I could afford it. My entire salary just pays the medicine. (Pt. #5)

In good weather I ask someone to push the wheelchair to my daughter's school, a couple of blocks away. I couldn't see asking anybody to pick up the wheelchair and put in the car. (Pt. #3)

Rage

If doctors and nurses would only mean it when they say if you need something, let me know. They stand there for a minute and then run out of the room. (Pt. #7)

Guilt

Maybe if I took care of myself when I was younger. My mother used to tell me to be careful of what I ate because diabetes was in the family. I would have a jelly donut and dunk it in the pepsi-cola. If only I had listened. (Pt. #9)

I was always heavy. Now, I think if I would have done this or listened to that. It catches up with you in the end anyway. If you don't pay attention, it catches up. I believe that surely now. (Pt. #4)

Isolation

I just eat too much when I'm with my family and to stay on the diet I have to stay separate from them. Not to eat the food with my family isn't so major. Some people say, so what's the big deal? But it's me, I'm upstairs locking myself in a room, saying, it's a big deal to me. (Pt. #5)

Frustration

I bring a list of questions (to the doctor) and I don't get much of an answer. And the doctors annoy me. I had a terrible swelling

problem and one doctor told me I was just a chunky girl. Then an allergist told me to avoid certain foods and get allergy shots. The next doctor told me I had a malnutrition problem. I find them all incompetent. How am I supposed to do the right thing if they are all incompetent and I'm supposed to trust them. (Pt. #2)

Theme Cluster 4B revealed Pleasant Feelings.

Positive Thinking

When I think things are going to change, I always think they're going to change for the better. If you think in a positive way, positive things come back to you. It's really like you have control of your destiny by putting out positive forces. (Pt. #2)

Problem-Solving

I'm trying to change my priorities and look at my time now as being used to fight diabetes complications, not just as time I can't be doing regular work. (Pt. #2)

I'm going to go to the Human Resources Center and have them adjust the car. Either I have to have the pedal adjusted for the left foot or I can have the hand control put on. I want to start driving again. (Pt. #3)

Humor

This whole past year I really didn't get down. People may say I have a good attitude considering what's happening. I have the kind of personality that I kind of goof on things. If something bad happens, I laugh about it. Humor may be my escape or defense but it helps things not to get to me. (Pt. #8)

Hope

Medical science makes me feel hopeful. They are trying to find ways to help people like me. (Pt. #3)

I always have to hope. I hope I don't go totally blind because then I don't know what I would do. I hope I just stay like this.

(Pt. #4)

Patience

> I try to be patient while all this is going on. Patience helps the time to pass. I know I didn't get sick over night. I know it's going to take a long time for the body to redo damage that has been going on for years. But there is no question in my mind that I'm not going to be like this permanently. I just need to be patient. (Pt. #2)

This completes the description of the various feelings experienced by patients within Theme Category 4 - Psychological Dimension. The first theme cluster reflects the unpleasant feelings and experiences of patients as they live through the experience of diabetes complications. The second theme cluster describes certain pleasant feelings that enable patients to face life with these complications.

Theme Category 5 - Interpersonal Dimension

As questions regarding the role of courage in facing life with diabetes complications continued to be explored, a fifth and final category emerged with a focus on the interpersonal nature of courage. Interpersonal theme clusters which emerged included Self-view and Others' Perceptions of Courage, Love and Support of Others, Strains in Personal Relationships and Tasks of Middlescence.

Self-View and Others' Perceptions (Theme Cluster 5A). This evolved following discussions of how patients viewed themselves and if they felt courageous. Other people's perceptions of the patients' courage were usually different from their perception. The majority of patients did not see

themselves as courageous. Yet, they said that courage was a word their friends and relatives often used in describing them. For most patients, courage was too dramatic a word to use in describing how they faced their every day situation.

Because this theme cluster held particular meaning in the exploration of courage, each patient's response will be briefly described. The three responses were given as patients discussed the meaning of courage, their view of themselves as courageous and how other people perceived them.

PT. #1

MEANING	Courage means, to me, a person who is strong and determined to go through fire and brimstone and all that.
SELF-VIEW	But I don't know if I have that. I guess I do because I'm always making an attempt." I strive to face hard times and not give up, that's courage.
OTHERS' PERCEPTION	My mother and my aunt, who I have a special bond with, think I have all the courage in the world.

PT. #2

MEANING	Courage means to face up to your fears and deal with them objectively.
SELF-VIEW	I don't feel I need courage because my situation is going to change. I need patience to continue to actively help myself even though the results aren't coming quickly. To rise above fear, that's courage. But I don't live my life in fear because I'm going to get better. I don't have to rise above anything and smile in the face of despair.
OTHERS' PERCEPTION	People think I'm tough. They probably

would say I'm courageous. I always think that I haven't reached the mark yet when others think I'm over it.

PT. #3

MEANING	Courage means overcoming handicaps.
SELF-VIEW	I never thought of myself as courageous. I am so afraid of pain but all the terrible things that have happened haven't really been that painful and that's made them easier to cope with.
OTHERS' PERCEPTION	People are always telling me how brave I am and that they think I have courage.

PT. #4

MEANING	Courage means bravery, like people who are in the service (military).
SELF-VIEW	I could never be courageous, like Helen Keller. I'm a coward. But I try to do the best I can each day. That's not courage, it's living. Either that or cry all day.
OTHERS' PERCEPTION	My husband thinks I'm brave and so does my family.

PT. #5

MEANING	Courage is facing things straight.
SELF-VIEW	I don't see myself as courageous. I think I have to live with this and get to the point where it doesn't always upset me. It is just something you have and you exist with.
OTHERS' PERCEPTION	I never thought about courage so I don't think other people did either.

PT. #6

MEANING	Courage is being able to deal with all these things or with any kind of conflict without letting it bother me.

SELF-VIEW	I feel like I don't have enough courage. In some respects, it (diabetes) is destroying me, driving me crazy. I go through a lot of self-inflicted pain by not being able to deal with it.
OTHERS' PERCEPTION	I'm not sure if other people think I'm courageous. I don't have other people around anymore. People use to think I was bright and witty.

PT. #7

MEANING	Courage means strength and faith.
SELF-VIEW	I guess, in a way, I have courage. There are always going to be mountains that I'm going to have to climb over.
OTHERS' PERCEPTION	I would think that other people think I'm very courageous and very brave. I guess I put on a good show. I don't know if everybody sees that sometimes it's real scary.

PT. #8

MEANING	Courage means the ability to cope with situations.
SELF-VIEW	I think I cope with this o.k. I'm not particularly courageous. Pain doesn't bother me. I like to be independent and I like to take a chance rather than sit back and just let it be.
OTHERS' PERCEPTION	The only time I think about courage is when other people tell me how good my attitude is. The nurses in the hospital used to say things like that all the time in the hospital.

PT. #9

MEANING	Courage, to me, is if there is a burning building and someone runs in and saves someone. That's courage.
SLEF-VIEW	There's no courage in what I do. If I want to stay alive, I do what I'm supposed to do.

OTHERS' PERCEPTION At work, different people come up to me and say - you have some outlook on life. They say I've had setbacks and they notice I just will not give up.

Theme Cluster 5A demonstrated that patients were able to state their own definitions of courage. Strength, bravery, faith and coping were some synonyms used. Although many patients said they felt courage was a dramatic word, only two used dramatic definitions of its meaning. Only two patients thought they were courageous but almost all, with two exceptions said that others usually perceived them as having courage. This made them feel positive about themselves and their experiences. They derived much contentment from other people's perceptions of their courage. Each patient felt that the development of courage would be helpful and each was open to discussion about how it might develop.

Love and Support of Others (Theme Cluster 5B). This theme cluster also related to other people's impact on the lives of these patients. Theme Cluster 5B was derived from all the statements of patients regarding the necessity of love and support of others in the development of courage. Without exception, each of the nine patients agreed that the love and support of other persons were an integral part of the development of courage. The following accounts from the protocols demonstrate this belief.

> Love and support of others helps 100% in giving you courage. I feel if someone is behind you and they are going to help you,

> you will have the courage to get through it. If you had to do it on your own, I think it would be harder to have the courage. It's almost like you have to have someone to be courageous for. (Pt. #7)

This support can help keep a healthy self-image alive.

> I've known my girlfiends since I was 14 and they remember me before I was diabetic and I was athletic and won awards and did everything. That's how they remember me. And no matter how sick I get they always remember me as that person and that helps me. (Pt. #2)

If love and support are not available, it becomes difficult to face the experience of diabetes courageously.

> I don't think my family considers that I need support for what I'm going through. I've had diabetes since I'm nine. They have learned to live with it. It's hard because I'll say something that seems important to me and it will just be like, ignored. (Pt. #5)

Most patients were aware, though, that their emotional needs were complex and might not be easily met.

> Sometimes I desperately need someone outside. I need someone to talk to and lean on. You get to the point when doing it in the family, you start to feel like you're imposing on them 24 hours a day. Not just imposing, I mean, I don't want to wind up hurting anyone. (Pt. #6)

Theme Cluster 5B reflected the importance of love and support from others in the development of courage. Patients felt courage was almost impossible to attain without some kind of emotional support. They did realize that such needs extracted a high emotional toll from family and friends.

Disruption of Personal Relationships (Theme Cluster

5C). This evolved out of discussion about the intensity of interpersonal relationships and how these have an effect on courage. Patients described situations where they felt they were becoming courageous in handling certain aspects of the disease and then had a disruption in personal relationships which they found devastating. Three patients used the words, "being let down" by others to describe this sense of interpersonal abandonment.

> I had one close friend since the first grade that I was so disappointed in. She didn't come over when I was shut-in for months. I needed a favor and she refused me. I found the transportation, after the kidney transplant, hard and I had to get to one treatment and I asked her to take me and she refused. That really bothered me. (Pt. #3)

> If I need to call someone now, after I used to do it myself and they say no - it kills me. It might just be that I need milk when they go to the store and they give you an excuse. I used to drop everything for anyone. (Pt. #4)

> Sometimes I get very hurt because I have nice neighbors but nobody ever thinks if I'd like a trip to the Mall. I mean, we could split up; I want to be on my own, and then meet again at a certain time. My sister-in-law told me not to feel let down because people are very busy with their own lives. I know it but I've lived here 14 years and I don't like to have to ask. (Pt. #1)

Aside from feelings of being abandoned by neighbors or friends, there were some patients who felt diabetes complications may have caused disruption in their marriages.

> I was badly hurt. I didn't want the divorce. I woke up one morning and she

> said that she wanted out. Whether she pushed the panic button because of my illness, starting to go blind and all, I really can't pinpoint it. It happened and that was it. (Pt. #9)

The four married woman patients responded in similar manners when asked about their marital relationships. Each emphasized that her husband was supportive, loving and loyal but each, too, wistfully admitted that her husband did not easily talk about his feelings about diabetes complications.

> My husband doesn't talk a lot. I often try to ask him if these things bother him. I don't know; he never complains. It drives me crazy because I don't know what bothers him. But he's my greatest support. (Pt. #3)

> My husband is there for me. He cares and I know he suffers with it but I don't get a give and take exchange in talking with him about it. He doesn't talk about his feelings. (Pt. #1)

It is interesting to note that the men studied felt they were able to talk about their feelings, in depth, to significant others if the need arose. Yet, two of the three men interviewed seem less concerned about talking out their problems. In fact, a common thread in their discussions was characterized by the following quotation. "I don't like to give anybody else my problems." (Pt. #8)

Tasks of Middlescence (Theme Cluster 5D. For many patients, the strongest stimulus in the development of courage was connected to interpersonal tasks of middlescence, particularly childrearing and employment. Patients derived much inspiration, strength, and meaning

from the following situations.

> I volunteered to be a Troop Leader, even though it was difficult. I wanted to make my son proud of me. I haven't yet figured out why I got sick. But I do think there's a reason I got my eye sight back and the kidney. I want to stay strong because I I want to be around to watch my son grow up. (Pt. #3)

> I decided to have a baby and once I made that decision I had to find out about the diabetes complications, face them, and put them in order. I wanted something so badly and considered it so important that the diabetes had to be put into control. (Pt. #2)

> What mostly keeps me going is my daughter, and I am, God dammit, going to see the kid graduate High School. (Pt. #6)

For Pt. #1, having a child was important to her as far back as the initial diagnosis.

> I said, am I a diabetic? And he said, yes, you are a diabetic and the first thing I said to him was, can I have children? When he said yes, I thought, everything is going to be O.K.

Childbearing and childrearing provided important stimuli for the development of courage for these patients. Work, too, was an important task of this middlescent group.

> The only time I miss work is when I am in the hospital. I don't like to miss work. I go in, even if I don't feel good, because if I sit alone in an apartment, I'm worse off. (Pt. #9)

Even for those patients who were too disabled to work, some contribution to their Community or church appeared necessary for their continued social development. Several patients volunteered at a Diabetes Education Center while others were

involved in specific hobbies, such as arts and crafts. All but one patient, who was extremely isolated, could be considered generative, according to Erikson's theory of middlescence. Patients said that these important interests contributed to their development of courage.

This completes exploration of Theme Category 5 - Interpersonal Dimension. The first theme cluster reinforces the social nature of courage and how patients respond positively to others' perception of them as courageous. The second theme cluster emphasizes that the love and support of others is integral in the development of courage. The third theme cluster flows from the second, exploring how disruption of interpersonal relationships due to diabetes complications may hinder the development of courage. The final theme cluster examines how the tasks of middlescence may have a tremendous positive impact upon the development of courage.

Description of Courage in Diabetic Patients with Disabling Complications

A description of courage in these diabetic patients was derived from the theme clusters and categories. That description is presented in the following sections.

Philosophical Dimension

The lived-experience of having disabling complications of diabetes includes the facing of life and death by the patient. Courage is part of this process and is seen as a

dynamic state. Courage is viewed as being able to be nurtured, by one's own resources or through the inspiration of others. There is a fluctuating nature to courage. There can be movement towards and away from courage, depending upon situations and supports. Turning points in the development of courage can be elicited and examined. Critical time periods for the absence or presence of courage, too, can be examined.

In order to develop courage, one must search for meaning in the situation. Even if meaning is not found or understood, the search itself is an essential part of the experience. Each individual makes a personal decision about how he or she will face a situation of courage. The person evaluates this decision as an on-going process. There is a feeling that the courageous situation changes the self in an irrevocable manner. An individual's life, experiences and perceptions may change dramatically after developing courage to deal with complications. The person changes and realizes the change. The individual becomes the person he is because of how he has lived the experience. Spiritual outlook is particularly important in the formation of courage. Faith in God is a theme which emerges for patients as they encounter situations necessitating courage. At times, there is a conflict to maintain faith but they are sustained through their own prayers and often the prayers and beliefs of others.

Health Care Dimension

As persons with diabetes complications live their experience, they are in frequent contact with the health care system. Their relationships with health care personnel assume great importance to them. They are acutely responsive to not only the information they receive from professionals but the way in which such information is given. Initial information about the serious sequelae of diabetes was considered too general and scanty. This leaves patients unprepared, delaying their realization of their ill state and making courage difficult to develop. The lack of patient education is interpreted, by some, as a lack of caring on the part of the health professional.

In general, health care professionals are viewed as genuinely caring. Yet, there are multiple instances of patient mismanagement which leave individuals feeling betrayed by the system, powerless and fearful of future encounters. This fear forces patients to assume great responsibility for their own care when hospitalized. Hospitalizations and procedures, then, are viewed by patients as small examples of the experience of courage.

Nurses play an important role in the patient's perception of the experience of courage. Patients feel that nurses are genuine, open and understanding and that they are capable of entering into their experience and of assisting them in the development of courage. Patients recognize that

due to time pressures, interpersonal differences and different educational skills, it is not always possible to receive adequate nursing intervention. Yet, patients give examples of how nurses could inspire courage. These include listening, being there, providing comfort through problem solving discussions, use of touch and humor, and aiding family members by providing their knowledgeable perspective and reinforcing the patient's strength.

The relationship which is experienced with the patient's physician is of primary importance to the situation of courage. These patients perceive the doctor to be powerful and authoritative, but in a caring and concerned way. They feel that very few others can understand the multitude of problems that they have and will have to overcome. The primary physician becomes a consistent, supportive force in the lived experience of courage. Absence of such a support creates great difficulty within the experience.

Physical Dimension

Body image changes, due to physical debilitation, are characteristic of these patients' experience. These include diminished vision, which for all patients remains the greatest threat. Physical changes such as loss of balance, coupled with poor vision, leads to decreased self-image as the individual becomes more dependent on others, even to leave the house. Such changes affect the patient's daily

life-style, interpersonal relations, and ultimately, the quality of life. Courage becomes difficult to summon when faced with overwhelming physical problems. The multiplicity of the complications gives rise to a feeling of physical vulnerability, creating even more of a loss in self-image.

The physical complications of the disease create problems which must be treated. Treatment involves much risk and often takes place in highly technical environments. The concept of risk is intimately bound to the development of courage. Patients often use examples of the risks involved in treatment options as small examples of the lived experience of courage. Fear is present during procedures and treatments, particularly fear of pain and failure. Fear is reduced by trust in health care professionals, by increased education and religious beliefs. The fear is recognized as part of the experience of courage, as is acceptance of the risk. The highly technical environment is a source of anxiety for the patient. Its distressing elements can be reduced by adequate explanations prior to a procedure and support during it. Laser therapy is a major source of anxiety for patients.

The major method of coping with complications while attempting to live through the experience courageously is self-management. This refers to the patient assuming responsibility for monitoring blood glucose, diet, exercise and medication adjustment. Although this requires

stringent, physical demands on a daily basis, patients acknowledge it as a creative and controlling process which allows them pride and power. This, in turn, allows them to experience their situation as courageously as possible.

Psychological Dimension

Patients hold on, in varying intensity, to an array of feelings which occur in the lived-experience of courage. Unpleasant feelings usually appear at the beginning of the development of complications but they may never disappear entirely and may be easily reawakened. Terrible anger and mistrust easily resurfaced as certain patients described past experiences. Certain responses, particularly related to body image changes, are related to the grieving process. These include feelings of shock, disbelief, anger and depression. Other feelings occur as the multiplicity of complications becomes apparent. These include loss, fear, grief, dependency, rage, guilt, isolation and frustration.

Pleasant feelings also occur throughout the experience. These feelings help to balance the negative ones. Certain pleasant feelings aid in giving the patient the ability to clearly and concretely handle the situation. These include positive thinking and problem-solving. Another pleasant feeling, humor, allows the patient to temporarily distance himself from the problem. Two others, hope and patience, are feelings which help the patient transcend the experience. Hope, particularly, is an important part of the

experience of courage. It has a sustaining effect on the individuals, even as they face their most difficult moments. When patients talk about the lived absence of the phenomenon of courage, the time when courage was at its lowest ebb, they say that they had lost hope during that period of time. Sources of hope include religious beliefs, medical science explorations, and family support.

Interpersonal Dimension

Courage, for these patients, depends on interactions with others. It is a social phenomenon. In speaking of their own self-view of courage, few patients feel that they are courageous. Yet, many feel that others view them as possessing courage. Others' perceptions are very important because they allow patients to feel and enjoy feeling courageous. The patient, alone, does not see his courageous act, but is capable of viewing it through the eyes of others. Love and support of others are a vital part of the lived experience of courage. Others, here, include family members, close friends, clergy, health care professionals and other patients. Family members, in particular, are perceived as loving and helpful. Patients are aware that the role of the family member is not easy and that their sacrifices are often made and overlooked. Patients who are not close to family members see that as a distinct disadvantage to the development of courage.

Patients are so emphatic about the interpersonal nature

of courage that they seem very dejected when their personal relationships unravel. Personal relationships are disrupted, at times permanently, due to the demands of the disease. There is a sense of fear of becoming isolated from others, as patients describe how they are often disappointed by others and terribly grateful when they receive kindness.

The interpersonal tasks of middlescence such as child rearing and employment, offer patients great stimuli to develop and sustain courage. Individuals are eager to see their children grow or to bring to fruition employment-related tasks. These goals help them to redirect their efforts to experience life courageously.

The Structure of Courage in Diabetic Patients with Disabling Complications

The following structure of courage has been derived from the previous description.

Courage, for diabetic patients with complications, is a dynamic state which can be nurtured by one's own resources or through the inspiration of others. Part of the process of developing courage includes a search for meaning of the situation and part of its outcome is a changed self and world view on the part of the diabetic individual. The process is aided by religious beliefs. A turning point in the development of courage can be noted.

Patients' encounters with nurses and physicians hold great promise for assistance in development of courage.

Patients are open to health care professionals helping them to realize their own potential of courage.

Courage becomes difficult to maintain when faced with extreme physical vulnerability. Physical changes occur and create profound alterations in the quality of life. Courage becomes essential at the precise time when the individual has the most difficulty in summoning it. Diabetes self-management provides a way to actively deal with the situation. As patients experience the courageous situation, a variety of both pleasant and unpleasant feelings arise. Each response is deeply felt and necessary to the patient's living of the experience.

Patients realize that their situations require courage within the context of the interpersonal relationships. As they grow more aware of their own capacity for courage, they also become aware of the support they derive from other human beings. Efforts to experience life courageously continue.

Courage is characterized by commitment. This commitment is to many aspects of the experience-interpersonal relationships, religion, health care professionals, diabetes self-management. Patients live the experience of courage as they continue to be committed to a search for meaning in the experience.

Validation of the Structure of Courage

A synopsis of the fundamental structure of courage was

sent to seven of the participants and they were asked to validate that this was representative of their experience. There were no disagreements noted in the way the structure of courage was portrayed.

Summary of Findings

The protocols of nine diabetic patients with disabling complications of diabetes were analyzed. Formulated meanings were derived from significant statements and coded for analysis. These meanings were organized into clusters of themes. Five theme categories and nineteen theme clusters were identified. From the theme clusters, a description of courage was derived and the structure of courage was identified.

CHAPTER V

INTERPRETATION OF FINDINGS

The concepts associated with courage identified in Chapter 2 are now examined in light of the description and structure of courage identified in the previous chapter. New realizations uncovered through reflection and interpretation are also examined.

Coping and Courage

Coping was reviewed in the related literature according to three models. Lazarus and Folkman's (1984) view of effective coping was that of a process which allows a person to tolerate, minimize, accept or ignore what cannot be mastered. Weisman (1978) described coping as problem-solving using a set of distinct strategies. Miller (1983) defined coping as overcoming challenges in order to preserve individual integrity, maintain a positive self-concept and function within relationships.

The patients in this study coped with complications in the manner most like that described by Miller. The theme clusters showing the necessity of relationships oflove and support as well as their importance to patients' self-image attest to this. Some of the creative strategies which patients devised in order to overcome disabilities were like Weisman's description, of the problem-solving steps of redefining the problem and seeking emotional release. For example, Pt. #3 used a variety of problem-solving steps to

creatively assert her independence. Pt. #2 re-examined her life-style in a creative way and viewed it as a time now devoted to fighting diabetes complications.

In general, patients felt that coping was a less powerful word than courage and the majority of patients were unwilling to describe themselves in a dramatic way. Yet, the meeting of their experience as a challenge, the strong tie-in to faith, and the overwhelming power invested into interpersonal relationships seemed to be more like the lived-experience of courage, as described by Asarian, Tillich, May and other authors, different from coping.

Hope and Courage

Hope alone, has been viewed, by Kubler-Ross (1969) as a phenomenon which allows patients to continue to battle with cancer. Miller (1985) has identified hope as a tremendously powerful resource which allows full human functioning. The capacity for human growth and potential allows for the development of hope. "An existential philosophy, which views human beings as having an unlimited possibility of becoming and growing through crisis, also can be a source of hope" (Miller, 1985, p. 23).

Hope and courage are closely related. In one analysis, they were described as "inseparable" (Wilkes, 1979, p. 102). Without courage, for Wilkes, there is only hopelessness. Patients in the present study confirmed the findings of Wilkes regarding the special interrelationship

of hope and courage. Hope was identified as one of the pleasant feelings that enabled patients to face life with diabetes complications. When patients described feelings of hope they emphasized their importance in the development of courage. For example, Pt. #3 described hope in medical science and future cures as allowing her to feel courageous enough to bear the complications.

Suffering and Courage

The role of suffering in the development of courage was examined in Chapter Two in relation to the meaning derived from suffering. Kubler-Ross's classic five stage structure of suffering involved descriptions very similar to those of patients in the present study. These can be seen clearly in the cases of patients 1, 2, and 7 who displayed a variety of emotions including depression and rage. Each of her five stages: denial, anger, bargaining, depression and acceptance could be seen at some point in the lives of these patients. Two of the stages, anger and depression, were strongly identified within the psychological dimension of courage. Through the wide variety of psychological reactions the patients experienced, a search for meaning within the suffering was attempted.

Frankl identified the courage to suffer as the greatest courage possible. Yet, for Frankl as well as others such as Battenfield (1984) finding meaning in one's suffering is an essential part of the experience of courage. Dagi (1983)

expanded the concept of meaning even more when he emphasized that it is the search for meaning, not only the finding of meaning in life that is necessary for the experience of courage. For Dagi, to demand that a person must find meaning in life in order to find courage is too restrictive.

> People may choose to live in ignorance of their fate and condition so long as others are not adversely affected, and perhaps it is best that we not be compelled to live up to an ideal of personal autonomy. The freedom of choosing one's own style of living and dying should be, prima facie, respected. (Dagi, 1983, p. 434)

Many of the patients in this study described periods in their lives filled with bitterness and rage as they struggled to understand the meaning of their experience. One who stands out as a prime example is Pt. #7 who had a long history of bitterness and rage toward her situation. The struggle was not easy and not always constant. Yet, she and the other patients never gave up the struggle completely for any long period of time. In an effort to find meaning in their life experience, they often re-examined their philosophy of life and often evolved a new view of the world and others, as can be seen in the descriptions of Pt. #4 and Pt. #8 pages 85-86. This new view perspective is in keeping with the findings of Smith (1981) who described patients who survived major physical illnesses, in part, by seeking and finding meaning in their existence. Those patients developed a deeper appreciation of nature's beauty and used group support as two ways of re-evaluating meaning in their

existence. Patients in the present study, particularly Pts. #1 and #4 commented on how such simple things as the beauty of sitting in the sun or being surrounded by loving family members give purpose to their existence and made them feel courageous.

Patients identified the development of a new view of the world and others as part of the experience of courage. An individual's life, experiences and perceptions may change during the development of courage to cope with complications. Meaning, for some, can be derived from the adversity. If meaning cannot be derived, the exploration of meaning may be enough to sustain the individual.

Vulnerability and Courage

Each of the patients in the present study described himself as physically vulnerable. This physical vulnerability could be reinterpreted as physical fragility. Patients often felt over-protective of their bodies and wished to protect them from future harm. A loss of a transplanted kidney, a fall due to neuropathy, confusion due to hypoglycemia were described by Pts. #3, 6 and 1 (p.99) as evidence of their intense physical vulnerability. Each patient felt it was difficult to maintain a courageous stance when feeling so vulnerable. Shelp (1984) has argued that there can be no courage without vulnerability and that courage is most often seen in times of great human vulnerability such as illness. "The surrender of the myth

of omnipotence and immortality is perhaps the most difficult and requires the greatest courage" (Shelp, 1984, p. 357). Shelp has viewed periods of sickness as vulnerable times which can still be used to provide a setting within which one learns about and develops the courage necessary to life. Patients did not describe the difficulty of vulnerability in any way adding to their development of courage; instead it was a major block for many of them. As one patient put it: "I am so afraid of something else going wrong with my body that it's hard to be courageous". Patients were able to equate risk-taking with an active stance such as accepting a challenge. In contrast, they described their intense vulnerability as holding them back from becoming fully courageous. It is important to note that these patients were affected by multiple damages to their body, leading to a level of physical vulnerability of unknown intensity. This led to their strong desire to prevent future harm to their bodies. This need to avoid harm is similar to what has been seen in previous research in regard to patients' physical vulnerability. In a study of personality traits in 46 diabetic patients, harm avoidance was found to be the strongest single need of these patients when tested with the Jackson Personality Research Form E. This personality trait is associated with fear and anxiety (Rottkamp and Donohue-Porter, 1983). Patients often feel victimized by a disease that leaves them physically frail,

debilitated and vulnerable. An atmosphere where courage could more easily develop and be nurtured is denied to this group of patients. The concept of vulnerability is linked to one's sense of self-esteem, which will now be addressed.

Self-Esteem and Courage

Certain authors analyze whether an action can be judged as courageous by examining whether the results of the action are of benefit. Rorty (1986) addressed this point. "Only those who act from their judgments of what is best, all things considered, qualify as courageous" (p. 155). In order to make such judgments, an individual must have confidence in his own ability to make choices. He must have self-esteem which becomes an integral part of the experience of courage.

Kennedy, in Profiles in Courage, emphasized that the statesmen who made courageous decisions were being true to themselves, despite personal consequences. They had a need to maintain their own self-respect. MacKenzie (1962), too, has viewed self-respect as the basis for the development of courage, along with truth, justice, compassion and common sense. Schwartz (1981) in instructing nurses on how they might encourage patients to be courageous, maintained that showing respect for human dignity was a key issue. Lanara (1974), too, emphasized that self-respect is necessary for heroic actions and that a person's dignity may be threatened by illness. Asarian (1981) maintained that courageous

actions are taken because, if they are not, self-respect and self-worth would be destroyed.

Patients in the present study did not always have high self-esteem but they did know and could express what goals were important to them. They were then able to meet the goals or strive to meet them, through the experience of courage. For example, one man's self-esteem had faltered because he could no longer work and had to remain at home on dialysis. Yet, for him, courageous action was still necessary and possible, to allow him to achieve the higher good of effective parenthood. For him, being able to sustain his suffering braverly during and after his daughter's arrival home from school was very important. There were other similar examples in the present study and a common bond seen was each patient's ability to value his own self worth and recognize what it was that he wished to achieve.

Patients achieved their goals within a setting of commitment and this will be discussed in the section describing new realizations of the study.

Risk-Taking and Courage

The patients in this study recognized risks inherent in their medical situations and chose to take them. The risk taking behaviors were associated with high technology treatment options such as laser surgery or transplantation. Such risk taking behaviors involved the experience of

courage as identified by Fox and Swazey (1974).

> The probability of failure in transplantation and dialysis is high. These therapeutic innovations are in a stage of development characterized by fundamental scientific and medical uncertainties, and they are applied only to patients who are terminally ill with diseases not amenable to more conventional forms of treatment. In this context, the death of the patient is the archetype and pinnacle of failure for all concerned. Confronting this situation with courage is an ultimate value shared by physicians and patients. As they themselves recognize, the supreme form of courage that participation in dialysis and transplantation asks of them is the courage to fail. (Fox and Swazey, 1974, p. XV)

In the present study, patients chose to take great risks in order to receive medical benefits which would improve their life-style. Each risk-taking situation had a two-fold impact upon the experience of courage. It prompted the development or expression of courage at the present time and it allowed for its expression to return at a future time. For example, Pt. #1 described that when she was faced with the risk of eye surgery and accepted it, she felt truly courageous, a feeling that returned to her throughout other experiences later in the course of her complications. Courageous behavior, during a risk-taking situation, allowed for the deepening of the experience of courage for these patients.

This finding is in keeping with Haase's description of mini-situations of courage. Haase (1985) identified mini-situations of courage, usually involving technical or

painful procedures. It was through almost daily encounters with such situations that chronically ill adolescents gained knowledge and a sense of competency about the experience of courage. In the present study, hospitalizations and procedures, too, were viewed by patients as small examples of the experience of courage. For these patients, acceptance of the risk is recognized as part of the experience of courage.

This finding also supports the analysis of courage by Wilkes (1979) who asserts that moments of risk are moments of potential growth and enrichment for an individual.

Risk-taking within a demonstration of courage has been cited by Walton (1986) as a noble act.

> Perhaps the courage of persons with catastrophic illnesses is a little different in nature from the more usual examples of courage cited where the imminent danger could be avoided by foregoing the noble end. Yet it often seems to me even nobler and more impressive, in its way, than the danger confronting acts of combat or life-saving of others that are more usually cited. Where the threat is directly to one's own existence and well-being, as in catastrophic illness or disability, the danger is more than just a risk or possible consequence. It is an actuality of the most proximate sort. (Walton, 1986, p. 93)

Fearlessness and Courage

Military studies that have addressed courage and fear often portray them as being complete opposites. (Rachman, 1982) Traditionally, too, courage has been associated with bravery of a militant nature. Yet, Cox (1983)

differentiated fearlessness and courage by explaining how fear is present in certain military battle situations but the fear is overcome and appropriate action taken because of courage.

Tillich (1952) in his comprehensive analysis of courage, also examined military aspects of courage and acknowledged a soldier as a prime example of courage, facing the greatest sacrifice-death. Yet, in analyzing the role of fear within the experience of courage, Tillich viewed courage as a bridge between fear and action. The relationship of fear and courage in the present study is similar to the findings of Cox and Tillich. All patients had experienced fear; it was noted as one of the unpleasant feelings present within the psychological dimension of courage. In fact, fear never totally left the patient's experience even if the patient felt he was courageous at a particular time. Fear was controllable through courage but never totally eliminated. It was one aspect of the many facets of the experience of courage.

When patients in the present study discussed the role of courage in the experience of their illness, they did draw upon the military connotations of courage. They discussed "battling and overcoming complications" and "fighting not to let this get me down". This opposition to the enemy, seen as illness and suffering, has been described as central to the experience of courage.

> A person of traditional courage, for whom courage is centrally active in eliciting other dispositions, tends to interpret situations as occasions for confrontation and combat. Even when soldierly andreia has become moral fortitude, and courage requires ostracism or exile, the courageous person tends to see herself in an oppositional stance: habits of endurance, persistence, risk-taking become strongly developed, sometimes dominant. The enemy may have moved inward: courage may be required to withstand disease, flaws of character, or the temptations of certain trains of thought. Yet courage still treats its domain, its objects, as External Others, to be endured, overcome or combated. (Rorty, 1986, p. 155)

The majority of the patients expressed fear of being physically overwhelmed by the complications causing continued suffering, not of death itself. This finding supported research by Gregg (1980) which found fear of incapacitation prevalent, more so than death, in the long-term diabetic population. "Indeed, it may be the process of dying rather than actual death that is the primary source of anxiety" (Gregg, 1980, p. 249). The development of diabetes complications has been identified as one of the most intense fears of diabetic persons (Lockwood, Frey, Gladish, & Hess, 1986).

Love and Courage

The love and support of others had a profound effect on the development of courage for each of the patients in the present study. This finding confirmed the assertion of Frankl (1939) that in the loving contemplation of beloved others, one can draw strength to endure in the midst of

desolation. Wilkes, too, in his analysis of courage (1979) spoke of the nourishing interpersonal relationships that are a central ingredient in the development of courage. He maintained that there is a connecting link between covenant relationships with others and courage. "Courage continues to live in the covenant that gives us trust in life, allows us to speak the truth, and binds us into relationships of clear and mutual expectation" (Wilkes, 1979, p. 54).

Fromm (1956) has emphasized the importance of love in human experiences. "The affirmation of one's own life, happiness, growth, freedom is rooted in one's capacity to love" (p. 50). The love and support theme cluster (5B) dominated the interpersonal dimension of the present study. Without exception, each of the nine patients agreed that love and support of others was essential to the development of courage. This is best demonstrated by the description of Pt. #7, p. 110) This finding, too, supports the investigation into courage in chronically ill adolescents by Haase (1985), who found loving relationships to be integral to the development of courage.

Culture and Courage

Moses and Cross (1980) related the cultural differences seen in the personal expression of courage in the face of illness. The patients in the present study did not exhibit noticeably different forms of courageous expression. Although the nine patients were from varying ethnic

backgrounds, they were all native born Americans living in close geographic proximity. Male/female differences in expressions and descriptions of courage were seen, as had been previously noted (p. 114). Females were more verbal and descriptive of their situations and could more easily share their multiple problems. The males in the study were more reticent about describing the problems involved in facing diabetes complications.

Control and Courage

The concept of control as an important part of the experience of courage evolved from the studies of Miller (1983). Lack of control has been viewed as a most serious problem in coping with chronic illness. Patients in the present study identified lack of control as a barrier to the development of courage. This lack of control extended over various areas of patients' lives: decision-making, relationships, choices and diabetes self-management.

When patients were able to gain control, they felt more capable and powerful. The area where control's benefits was most frequently seen was in diabetes self-management. Patients freely embraced the demands of self-monitoring of blood, multiple injections and dietary adherence in order to gain the benefits of power and mastery over their condition. Such mastery then allowed for the expression of courage within the situation.

Certain findings in this study relating to control

mirrored the positive findings of Forsyth, Delaney and Gresham (1984). These researchers found certain patients with chronic illness worked hard to assert themselves in areas where they could exert some control. They reshaped their reality to fit their needs and did so creatively. In the present study, certain patients, too, combined creativity and control in order to derive courage to face their experience. One young mother took control of her son's Scout troop and although wheelchair bound, created new and stimulating programs which allowed her child to feel proud of her. Her actions were planned with great forethought in order to fulfill her mothering role.

The Ontological Nature of Courage

This study did not have as its sole aim to investigate whether courage was an ontological concept for these patients. Yet, the writings of Tillich and May were explored as part of developing a framework for the analysis of courage in these patients' experiences. Both Tillich and May viewed courage as ontological in nature, an essential part of being for the human individual. For Tillich, courage is the self-affirmation of one's being. Patients in this study were able to reaffirm their own selves in spite of tremendous hardship. They were able to maintain interrelationships with other humans and to sustain commitments to things of value to them. This was not, though, an easy task and patients described great difficulty

and suffering within their experience. Tillich has stressed the role of vitality in developing courage. The patients in the present study were not filled with the "life force" described by Tillich (1952, p. 79). They were extremely ill and weak and perhaps this made the lived experience of courage more difficult to sustain.

May viewed courage as a comprehensive virtue, involved in creativity and commitments. The patients in this study were able to describe multiple areas of creativity in relooking at their life situation and searching for meaning in it. As a group, all nine patients were committed to at least one value and this commitment strengthened their courage.

It is difficult to determine if these patients displayed courage as more a situationally developed concept or an ontological one. Certain situations called for courageous behavior and its expression seemed to encourage future examples. Patients often spoke of feeling the need to develop courage in a particular situation. Is courage then an innate quality or one which is developed? Courage, in these patients, may be viewed as an ontological concept but its expression may be situationally developed. This will be discussed further in the next section, entitled New Realizations regarding the role of courage.

This concludes an examination of the concepts associated with courage identified in Chapter 2 as they

relate to the description and structure of courage identified in the present study.

The next section examines new realizations regarding the role of courage uncovered through hermeneutics.

New Realizations

This study has uncovered six areas of realization concerning the nature of courage for these patients. These will now be examined. Two of the major areas of realization about the nature of courage involve commitment and creativity, supporting the work of May and Asarian. A third area of realization concerns the social nature of courage and expands the concept Asarian has termed sociality. The fourth realization concerns the role of inspiration in the nature of courage. This realization will be addressed in detail in Chapter VI and is viewed as a unique contribution of the study to nursing. The final two realizations explore the roles of middlescent tasks and the use of humor in the nature of courage.

The realizations and discussion which follow are viewed as beginning descriptions of connecting links within the experience of courage, not as finalized descriptions. Each aspect of the experience bears further exploration and analysis.

Commitment

Courage is characterized by commitment. In the structure of courage derived in this study, patients

were found to live the experience of courage as they continued to be committed to a search for meaning in the experience. Commitment occurred in many aspects of the experience including interpersonal relationships, religion, health care professional relationships, diabetes self-management tasks. Patients were committed to their established values such as loyalty to family members or honesty to themselves despite fear or risk.

Asarian's study derived an essential structure of courage which had as its major component commitment to values and interpersonal relationships. For Asarian, courage is a behavioral commitment to such values, despite hardship, due to the perceived worth of the values. In Haase's phenomenological study, commitment to values was not an integral part of the experience of courage. She explains this by describing how her adolescent population may not have fully formed their value system. In the present study, the patients were able to describe things of value and meaning to them. This was asked directly and also described freely within the interviews. Again and again, courage was characterized by commitment. Courage was particularly linked to commitment when patients were asked to describe the lived absence of the phenomenon, the time of experience when they were the least courageous. When patients described that experience, they often described it as a loss of their core commitments, a separation from things of

meaning and value to them, like health status, loving relationships, honesty from the medical community. (See Table 4) This would lead to feelings of shame or failure. Commitment to values or to interpersonal relationships was described in strong, forceful terms. Patients had to confront the possiblity of betraying what had meaning for them and losing courage. When they were able to sustain such commitments, courage was sustained. The major commitment was a search for the meaning of the situation.

Creativity

Part of the process of developing courage included a search for meaning of the situation, as previously described. Part of its outcome is a changed self and world view on the part of the diabetic individual. This is the connecting link to creativity as identified in the structure of courage in this study.

Patients become creative in an effort to remain courageous. Specific examples within their everyday life described how they become expert problem solvers in order to overcome their handicaps. In the more general view, they displayed creativity in building a new view of themselves and the work around them.

The relationship between courage and creativity is a reciprocal one. This means that courage allows for a creative struggle for expression, and the resulting creativity allows for the sustenance of courage. For

example, Pt. #3 created, through a daily, emotional struggle, an affirmation of her life and responsibilities as a daughter, wife and mother. She recognized increasing limits to these roles and creatively designed ways to maximize her potential for fruitfully living through her responsibilities. Many of the other patients visibly created ways to courageously live through the experience of disabling complications of diabetes.

But visible creations are not the only ways that courage and creativity interconnect. Asarian (1981) discusses the creation of the expanded perception of one who is present to others' courageous actions. The experience of courage may open up one's perception of the world and the person may discover himself opening and changing the ways he relates to others. This happened in the case of Pt. #8 who found that he developed a new feeling of friendship with others, who before, he considered unlike himself due to differences in age, background or personality. This allowed him to feel more content with the experience of living with complications. As his ability to view himself with more introspection and creativity grew, he and others like him were able to view obstacles as possible facilitators and to begin to accept support from others. This changed view of the self and the world around them sprung from creativity. The unique relationship of courage and creativity has been described by Asarian who views creativity as the heart of

courage. May, too, views courage as creative. As patients in this study struggled to take risks and remain committed, they displayed the activity May has described as creative courage.

So, commitment and creativity can be viewed at the very center of the phenomenon of courage. Patients had a deep realization of the importance of their commitments to certain beliefs that forced them to act or decide to act in a certain manner. The action chosen, then, is continually reshaped and creatively interpreted to allow for the sustenance of courage.

Social Nature of Courage

Each of the dimensions of courage which evolved from the present study formed the structure of courage. Each has great meaning in viewing the entire picture of courage. Yet, the interpersonal dimension of courage was the area of most intense emotional outpouring by each of the patients interviewed in this study. The theme clusters of self-view and others' perceptions, love and support of others, disruption of personal relationships and tasks of middlescence were clearly highly emotionally charged areas of discussion for these patients. Their attachment to other human beings and its effect on the lived experience of courage was one of paramount importance.

The interpersonal dimension was identified as a major theme category in this study and, so, supports the

findings of Asarian's phenomenological study of courage. Asarian has viewed sociality as the theoretical foundation of courage, describing it as "the intensely interpersonal character of a deeply personal phenomenon" (1981, p. 197). This aspect of the phenomenon is crucial to his study. Because the findings of the present study are strikingly similar, Asarian's concept of courage as a social judgment and revelation will be reviewed.

Asarian viewed courage as a social judgment, meaning that it emerges in the eyes of another, the observer. Courage, then, is not a direct experience but instead is socially constituted. Participants in Asarian's study had great difficulty in describing themselves as courageous. In the present study, the same difficulty emerged and has been described. Yet, patients were able to describe other people's perceptions of them as courageous and these perceptions held great meaning. In order to have become aware of their own courage, it was necessary that they reflect and meditate upon their actions and decisions. Usually, this was done by evaluating their own and others perceptions of life situations. Other people were able to facilitate the patients' awareness of courage. This finding supports the previous work of Asarian and Haase in this area of the social nature of courage.

The patients' identification of areas of courage in their lives evolved in a social way. The sustaining nature

of courage, for these patients, was due to the social nature of human relationships. Without exception, the nine patients stated that the expressions of love and support from others played a key role in the maintenance of courage. These relationships nurtured patients as well as challenged them. They provided connecting links to the world. Patients expressed terrible fear of losing relationships with others and becoming isolated. Strength and support was derived from such loving relationships which allowed patients to continue to be committed and creative within the experience of courage. Patients were encouraged by such relationships and felt inspired by them.

The role of inspired encouragement is an important part of the description of courage. Courage has been described as the embodiment of human character and expression in its most integrated form. Yet, the behavior of courage, the act, can be considered only a moment of ordinary expression, "the final objectification of the phenomenon" (Asarian, 1981, p. 202). That act, according to Asarian, presupposes relationships to other persons which have occurred before and are primarily those of encouragement or inspiration. This is the key issue for nursing to be aware of and which will be fully addressed in the next chapter. The role of inspiration in the development of courage will be examined next.

Inspiration

Inspiration was often described by patients as the force needed to stimulate courage. Patients used the words "inspire courage" particularly in describing their perception of a nurse's role. Jourard (1971) described the role of inspiration in the life of man. Jourard has described "inspiriting" events as those relationships which give an individual a sense of identity, worth, hope and purpose. These events take place within human relationships, necessitating man developing an ability to make himself known to others, self-disclosure.

Patients in the present study derived courage from the loving relationships of others but also agreed that there was potential in the relationship with nursing staff for inspiration or encouragement of the development of courage. This impetus for the development of courage, given from a nurse to a patient, was viewed by patients in the present study as a possible inspiriting event.

The next area of realization regarding the role of courage in diabetic patients with complications deals with the time frame of middlescence.

Middlescence

The patients in the study were all of the middlescent age range. The question posed in Chapter One regarding this age span asked if the tasks of middlescence relate to the development of courage. Findings in this study do point to

the developmental tasks of child-rearing and occupational activity being important stimuli for the expression of courage in certain situations.

Tasks of middlescence was a theme cluster noted within the Interpersonal Dimension of courage. Patients derived much meaning from situations such as making a conscious decision to stabilize diabetes in order to conceive a child, raising children, attempting to continue to work as long as possible. Even for patients unable to work, some contribution to the church or community seemed a necessary part of life. Eight of the nine patients could be considered generative, according to Erikson, and these patients described their contributions and commitments as essential to the experience of courage. This is an important aspect of the experience of courage which places an emphasis on patients' seeking of meaning in their lives. It is certainly helpful to know what aspect of their age and life situation holds perhaps the most meaning and may stimulate an expression of courage. This is new and unique information which is also pertinent to this population since many of the devastating complications of the disease unfold during middlescent years.

Humor

Certain patients in the present study did report that positive feelings such as the use of humor helped in sustaining courage. Patients described tremendous enjoyment

from sharing a smile or laugh with a health professional. Certain patients admitted to trying not to take themselves seriously all the time and to see some levity, even if it be absurd or sarcastic, in certain situations. Haase (1985) reported similar findings in her study of chronically ill adolescents. They, too, appreciated humor used by health care personnel, and used humor as a means of distraction. Frankl (1939) reported the use of humor which offered a brief respite from tremendous suffering in concentration camps. He called humor a weapon of the soul in the fight for self-preservation. "It is well known that humor, more than anything else in the human makeup, can afford an aloofness and an ability to rise above any situation, even if only for a few seconds" (p. 68). This mechanism bears further exploration within the experience of the diabetic patient facing life with complications.

This concludes an analysis of areas of realizations concerning the nature of courage, according to the patients perspectives. In the next chapter, the role of nursing within the experience of courage, will be examined.

CHAPTER VI

COURAGE AND THE PRACTICE OF NURSING

What does understanding the experience of courage offer to the practice of nursing? This question, and others, will be explored in this chapter.

Why should Nursing Investigate the Patient Experience?

The patient's lived experience of illness, suffering, courage and other emotions is part of his or her reality as a person. Nursing has accelerated in its development as a profession filled with much technical wonderment. Its role in assessing and intervening in the emotional experience of the patient undergoing illness, though, has lagged behind. A void has been left in patient care. "Yet the patient, for all the superb physical and technical improvements in his environment, feels lonely and even abandoned, because nobody cares for him as a person" (Lanara, 1974, p. 6).

Nursing seeks to develop improved theories of practice. These theories of practice arise from an understanding of patient experience (Vaillot, 1966). It is the role of nursing to investigate the experience of the patient in order to better understand it, and, ultimately, to provide care. Caring is essential to nursing and in an effort to provide excellence in care, detailed investigation into patients' feelings and experiences becomes essential. Such investigation is not removed from the practice of nursing but instead is an integral part of excellence in

practice. Lanara (1974) encourages nurses to investigate emotionally charged aspects of life such as suffering and fear of death, not to avoid such subjects.

> Therefore, these aspects - suffering and its transcendence - for the nurse do not remain in a sphere of remote philosophical investigation; they constitute aspects of every day life which demand confrontation. (p. 120)

Nurses have the responsibility to remove such aspects from the remote areas of practice into an area of central concern.

Reflective philosophical investigation is necessary for the continued growth of the nursing profession. Individual conscious reflection on the patient's problems and experiences provides a background for improving and refining nursing interventions. "In a reflective state the nurse analyzes, considers relationships between components, synthesizes themes or patterns, and then conceptualizes or symbolically interprets a sequential view of this past lived reality" (Paterson and Zderad, 1976, p. 79). Here, Paterson and Zderad show that a nurse can use conscious reflection to discover what has transpired during a nurse-patient relationship.

The conscious reflective act, the mulling over and analyzing, the capacity for a contemplative experience, all are part of a scientific approach. Intense reflection on the patient experience and its meaning, not a passive acceptance of its occurence, becomes the key point in

distinguishing a scientific method in nursing (Polanyi, 1958).

The person is the subject of nursing's science and, so, nursing must immerse itself in all of the experiences of a human being. This immersion will reveal the many meanings that experiences hold for individuals. These meanings can be expressed to and understood by nurses if they remain open to opportunities of disclosure and dialogue between the patient and the nurse.

Dialogue refers to the spontaneous, alive, reciprocal sharing that occurs between individuals. "The process is not exclusively in you or the other person, but rather between people as a reciprocal, spontaneous, and mutually flowing process" (Lynch, 1977, p. 219). The process of dialogue between patient and nurse demands genuineness and openness as well as confrontation of one's inner values on the parts of both involved individuals. Humanistic nursing is considered "lived dialogue" (Paterson and Zderad, 1976, p. 25).

By entering into dialogue, a nurse learns more of the patient experience and its meaning. The nurse also grows more as a person. Jourard (1971) calls the entering into dialogue, a rehumanizing event. Nurses assess patients in a variety of ways which are usually related to health and illness parameters. This clinical assessment is not to be undervalued but it must be recognized that for nursing to

use all of its power as a profession to help patients, an in-depth view is needed. Dialogue and reflection of the patient as a living human person with many and different experiences is essential to the helping, caring relationship between nurse and patient. This, then, is why nursing should investigate the patient experience.

How does a Focus on the Patient Experience of Courage Illuminate the Nurse-Patient Relationship?

The investigation of courage provides a framework for nurses to understand the experience of the patient. Because courage has been described as a strongly interpersonal phenomenon, its investigation can yield knowledge of the human character of the nurse-patient relationship. Asarian (1981) describes courage as being symbolic of human character and expression in its most integrated form.

> There is a kind of incarnated appreciation for the supreme, elegant conduct of courage. It is a special event, an incarnated beauty before the eye of the observer or, as we have referred to it in our structural description, a behavioral art form. Courage is then, the embodiment of human character and expression in its most integrated form. However, this behavioral art form is only the moment of ordinary expression, the final objectification of the phenomenon. It presupposes relationships to others which are primarily those of encouragement. (p. 201)

From this belief comes a clear picture of the interrelationship of courage and the nurse-patient relationship. Nurses remain at the bedside of the hospitalized patient or within the personal setting of the

home bound individual during periods of intense human emotion.

> In observing the responses of clients and families in extremis, in being privileged to learn some of their innermost thoughts, wishes, hopes and fears, and in listening to their life stories, the thoughtful nurse develops a deeper understanding of their lives and of her life as well. (Bejamin and Curtis, 1985, p. 271)

Nurses are privy to expressions of courage by patients, the "special events" described by Asarian. These expressions of courage presuppose a prior relationship of encouragement, found within the nurse-patient relationship.

The nurse and patient stand together as two separate human beings. Yet their separateness can be bridged by courage. Nurses can encourage and "in-courage" patients. Nurses can encourage patients, in the traditional sense, of assisting and helping them to develop their own expression of courage. A nurse, as a human being, is capable of reflecting upon a situation and expressing encouragement to a patient who is in need of such intervention in order to more fully express the act of courage. Nurses can also "in-courage" patients by providing an environment where the courage of the nurse is made totally known to and offered to the patient. This environment occurs within the context of an existential nurse-patient relationship. During an intense nurse-patient relationship, the nurse helps the patient's body and mind to heal by conserving the patient's energy and taking on the tasks that the healthy individual

would ordinarily do. The nurse then offers physical strength, mental stability and when necessary, a courageous spirit, for use until the patients's own inner strengths are mobilized (Lanara, 1974). This happens every day throughout the world as nurses and their patients interact. Yet, the intensity of the nurse-patient relationship and its potential for human growth for both members often goes unrecognized. The figures of both nurse and patient, within the relationship, become illuminated and intertwined through the investigation of courage.

Do Patients Recognize Nurses as a Source of Inspiration For Courage?

In the present study, each patient views nurses as capable of encouraging the expression of courage. The patients express feelings that nurses could assist them to be courageous in a variety of ways. These include acts such as listening to them, asking questions about their experiences, touching them, staying by their side during difficult procedures. Most importantly, patients seem eager for some offerings from the nurse as a person rather than a professional, a sharing of humanness.

Lanara (1974) recognizes nurses as a source of inspiration to patients. She views a time of suffering for a patient as also a time of reawakening and potential for future growth.

> Crisis removes the shell that separates the person from his experience. The

> patient is the person, and nursing may enhance this possibility. Inherent in the nursing process is the potential to help the patient integrate his illness into the stream of his life experiences and derive positive psychological gains from this apparently negative and painful event. (p. 42)

It is of interest to note that Lanara's rich exploration of heroism as a nursing value does not contain any patient perspectives of the role of nursing. In order to fully meet the needs of the group to which we are accountable, patients, it is necessary to inquire how they view the nurse's role in the development of courage. Patients in the present study use the word inspiration when discussing how a nurse might assist in the development of courage.

What is the Role of the Nurse in Inspiring Courage?

A nurse must be prepared emotionally to deal effectively with human to human interactions within the framework of courage. Nurses view suffering every day but to consciously reflect on it and its impact requires much.

> To deal effectively with the suffering patient is not easy, nor something that comes to the nurse naturally, automatically, or simply out of good intentions. It requires hard work, practice, continuing learning, evaluation, continuous searching for meaning for her own life. It requires courage, persistence, patience, strength to withstand failure and frustration that usually accompanies service to other people. (Lanara, 1974, p. 142)

The nurse who gives of his or her own humanness, according to Lanara, is heroic. Within this heroism, there is

transcendence whereby the nurse enhances the patient's environment and ability to develop courage. The role of the nurse can be examined according to three concepts, derived from this study's description and structure of courage: inspiration, caring and high technology environments.

Inspiration: An essential part of inspiration is the sustaining presence that a nurse can be for a patient. Patients, in the present study, describe tremendous feelings of vulnerability and fear. It is during these times that another presence of strength can assist the patient in developing courage. A nurse can recognize the patient's insecurities and fears and help to bring them out in the open. He or she can be fully present to the patient and open to accepting any of these feelings. The reality of pain, suffering and death can be helpfully explored by both parties. The discussion of such a reality is a difficult task.

> For those who invest their lives in showing care and concern for others, an admission of their limited powers and uncertainty may not come easily. Sharing this knowledge with patients who have placed themselves in their care can itself be a form of encouragement in which the parties discover the finitude of the human condition, define what in life is important, recognize the present dangers, and decide what certain goods are worth. Patients must not be denied an opportunity to be courageous. They should not be over-protected or under-protected. In this sense, encouragement becomes a duty of care-providers. Patients can be better equipped to be courageous and the goods associated with courage realized if they have adequate information regarding their condition,

> therapeutic options, and prognosis. The sustaining presence of clinicians symbolizes the patients' value to the community. This affirmation by others may enable the patient to affirm himself or herself as a prerequisite to courageous conduct. (Shelp, 1983, p. 424)

Aside from remaining a sustaining or encouraging presence to the patient, the nurse can also inspire courage by motivating the patient to observe and analyze who he thinks is courageous or inspiring as a human being. In the present study, the majority of patients at the time of the first interview could not name a person who they thought of as courageous. Yet, at the second interview, after a time of reflection, patients not only could name a courageous person, but also seemed to derive pleasure and meaning in the discussion of the courage of others.

Walton (1986) emphasizes that the very fact that courageous actions are inspiring is the ultimate basis of justification for their moral merit as acts of excellence. Courageous actions can inspire courage in others. An ill patient in the depths of despair may be too weak to even contemplate examining past heroes and their actions in order to be inspired. In many cases, the nurse can stimulate the patient to do so and help him to widen and deepen his relationship with his environment.

Sidney Jourard, in The Transparent Self, writes of how nurses can create "inspiring events" for their patients. He describes the potential that nurses have for meaningful

interaction with patients and the power that is present in the nurse-patient relationship. Yet, he, too, says that it is not easy to sustain such an intense relationship. In order to do so, the nurse must become open and comfortable with her own feelings and open to the variety of differences in others. "She never assumes that she knows a patient before she has taken steps to become acquainted and reacquainted with the reality of his self, his inner experience" (Jourard, 1971, p. 204). Such attempts to know a patient aid in sustaining his identity and integrity, allowing him to be less vulnerable. For Jourard, patients can receive inspiration from others, particularly nurses, if they believe that somebody genuinely cares about them. This belief reinforces the importance of the quality of the nurse-patient relationship. It also supports the role of the nurse as outlined in the present study, as one of a caring person.

Caring: The essence of excellence in nursing is caring. Assisting patients to find courage within themselves and to express it is a manifestation of the caring behaviors of nursing.

The term nursing is derived from nurturance, which conveys the concept of caring. Leininger (1978) states that the caring construct is one of the richest intellectual and theoretical domains of systematic inquiry. She views caring as the most unifying, dominant and central, intellectual and

practice focus of nursing. "There is no discipline that is so directly and intimately involved with caring, needs and behaviors, than the discipline of nursing" (Leininger, 1978, p. 13).

Leininger emphasizes that if the nursing profession is challenged to justify its existence, that caring behaviors will be the critical variables to be presented and defended. Leininger has studied the caring variable as a scientific and humanistic base for transcultural nursing theory. Nurses must blend both humanism and science in an approach to man's health. Often, the humanistic aspect is overlooked. Leininger speaks of the paradox that "qualities that make man human and sustain man's human striving are least studied or documented" (1978, p. 176).

Nurses are particularly involved in human striving. Investigating the human experience of developing diabetes complications and seeking how and if courage evolves in such a situation, is within the domain of nursing. The structure of courage, in this study, reveals that patients' encounters with nurses and physicians hold great promise for assistance in the development of courage. It also reveals that patients are open to health care professionals helping them to realize their own potential for courage. Aiding the patient to develop or express courage is a powerful caring act.

High Technology Environments: The role of the nurse in

regard to courage can perhaps be most easily seen in the highly technical environments which patients encounter. Later in this chapter some of the more elusive ways that nurses assist patients to develop courage, such as searching for meaning, will be addressed. The role of the nurse in the highly technical, immediate and life-threatening world is more visible as she physically and emotionally protects and supports the patient.

There are two aspects of the high technology environment to be considered here. One involves interpreting the technology for the patient so he may begin to know what is expected of him, in terms of courage. The other is aiding the patient during fearful confrontations with pain and procedures.

The first issue involves the dehumanization that has occurred within the health care environment due to increasing technology. The technology has become essential to the saving of lives and the health care system will never again be without it. Instead, recognition must be made of the stress placed upon patients, particularly chronically ill individuals, who are continually battling for survival within the system. It is the role of the nurse to interpret for and assist the patient to effectively deal with the reality of such an environment.

Society expects nursing to stand against the stream of dehumanization in health services (Lanara, 1974). The

nurse can be viewed as a bridge, closing the gap between the patient and the highly technical environment. It is always the nurse who has the vision of what a scientific discovery will really mean to the patient, in regard to his physical, psychological and sociological dimensions. Because of this, the nurse becomes the appropriate person to assist the patient in developing courage.

A patient in the present study describes a striking example of this. He explained that when he first learned that his kidneys had failed, he was told by a group of doctors who surrounded his bed. They offered him three options, transplantation, hemodialysis and peritoneal dialysis. They asked him to consider these and they all left the room. For the next seven hours he felt that his life had fallen apart and he was overwhelmed with confusion and fear. The evening nurse in charge of his care came to his room after her shift was completed and sat with him, explaining again what the doctors had said, talking with him, calming and reassuring him. The patient realized that the nurse was giving him extra time that had not been available earlier in the evening and that the nurse had recognized his intense need for assistance. The patient stated that he would never forget this nurse. He attributed his gathering courage directly from this nursing intervention.

This incident is not an isolated occurrence for

patients with diabetes complications who are frequently given news of poor outcomes, baffling choices and confusing treatment options. Nurses need to be attuned to the chaos that is present within this group of patients. Dr. Eli Friedman, noted nephrologist, has described how patients with end stage renal disease have been `protected' from the `truth' about diabetes complications and are unable to mobilize personal resources to cope with the illness and find courage to face transplants or dialysis. He describes the need for a "life plan" for these patients, made early on in the progression of the disease, which would include increased education about diabetes and rehabilitation counseling (E. Friedman, Personal Communication, January 8, 1983). Nurses are in close contact with these patients during moments of intense crisis and could facilitate the initiation of such a life plan.

The second issue when examining the nurse's role in helping the patient to be courageous during highly technical encounters deals with the confrontation of pain and procedures. By investigating the experience of courage, many aspects of patients' fears are clarified. These fears are important for nurses' knowledge in order to provide better preventive care. For example, patients in this study agreed that blindness is the worst fear they experience. This finding is also reflected in the literature on handicaps and disabilities. A single finding such as this

yields much in terms of nursing implications. Laser therapy, vitrectomies and other eye surgeries have become commonplace in the health care system. The nurse must not lose the realization of what these procedures mean to the diabetic patients who receive them. A tremendous amount of watchful care, and emotional support is necessary during the nursing of such patients.

Certain patients in the present study said that they were quite fearful of pain. Haase (1987) identified many mini-situations of courage where patients face intrusive procedures and attempt to deal with them. Each situation then allows the patient to develop skill and strength to face the next one. The handling of pain or the adjusting to new equipment are smaller areas where courage is needed and which ultimately create the broader picture of courage. Patients in the present study too find these small encounters where courage was needed to be ultimately helpful in developing a stronger, courageous outlook. It is during these instances that the role of the nurse is also seen to be of extreme importance. Patients recognize that they need nurses who are highly competent to assist them in technical environments, but they also desire nurses to be caring, interested and trustworthy in their relationship with them. They need to share the experience of pain or intrusion with someone else, usually a nurse. Blumberg and Drummund (1963) emphasize how sharing the experience of the patient is an

important nursing intervention.

> Human beings need someone to share with. The long term patient has this need too. Through sharing, the misery is diluted. To be brave in an emergency is one thing; to be brave for years is different and more difficult. Some patients are required to be heroes every day. (Blumberg & Drummond, 1963, p. 30)

The role of the nurse has been examined in light of three concepts - inspiration, caring and high technology environments. A key focus of the structure of courage for patients in this study was a search for meaning in their experience.

How Can a Nurse Assist the Patient in a Search for Meaning in the Experience of Diabetes Complications?

An important part of the experience of courage is a search for meaning within the patient situation. The patients in the present study agree that although meaning can not be found all the time, the search for it is necessary. Nurses can be viewed as partners during the journey of the patient to reflect and understand the experience of diabetes complications. Nurses can help to lessen the suffering of the patient as they assist the patient to find meaning. Again, because nursing is a profession that interacts with human beings during critical life periods, nurses are able to develop an awareness of intimate, individual human problems. Meaning is unique to each human's perception and nursing has historically valued the uniqueness of the individual and his or her perception.

"Personal meaning is a fundamental dimension of personhood and there can be no understanding of human illness or suffering without taking it into account" (Cassell, 1982, p. 641). Nurses can help patients to find meaning in their suffering by inquiring and accepting what is meaningful to them in life in general. Within the patients' beliefs and values, some meaning will be assigned to the present injuries. This may reduce the amount of suffering for the patient who then feels he has obtained some control over his own attitude toward his situation.

A nurse's presence and genuine interest in a patient as a human being gives that patient dignity and respect. In an existential way, the nurse may even be thought of as providing meaning and existence to a patient in helping him interpret his environment (McMorrow, 1982). Educational efforts, emotional support and nursing interventions such as touch can provide this.

Patients are frequently asked by nurses, "How do you feel?" but less frequently are asked "How do you feel about this, your illness and its impact?" This question and others like it must now be asked by nurses if they are going to succeed in successfully caring for patients, particularly in assisting the development of courage.

An individual's search for meaning, particularly in illness and suffering is closely related to transcendence. Patients in the present study spoke of experiencing the

world in another improved way, following acceptance of meaning in a situation. The development of courage allows them to transcend their present situation of suffering. Transcendence is related to wholeness, a concept identified by nursing as important for patient care.

> Transcendence is probably the most powerful way in which one is restored to wholeness after an injury to personhood. When experienced, transcendence locates the person in a far larger landscape. The sufferer is not isolated by pain, but is brought closer to a transpersonal source of meaning and to the human community that shares those meanings. (Cassell, 1983, p. 642)

Cassell continues on to say that the experience of transcendence is deeply spiritual. Religion does not have to be involved in a structured sense, but spirituality is key. The dimensions of courage found in this study involve both philosophy and theology. Patients agree that some spiritual outlook has to be decided upon in order to face life with diabetes complications. The spiritual outlook then contributes to finding meaning in the situation, allowing for transcendence.

Nurses are sometimes fearful of discussing spiritual issues with patients, thinking such concepts are too personal for general discussion. In terms of limited time for nurse-patient interactions, spirituality ranks low on a list of priorities for assessment and discussion. Yet, nurses lose some of the most powerful information that they can gain about their patients when they overlook this

dimension of their patients' lives. Persons need a basis to derive strength and courage in order to transcend their present situation. This can, at times and for certain individuals, flow forth from spirituality. Persons also need others to discuss and grapple with existential issues of life and death, in order to find transcendence. Nurses can be the other half of the interpersonal dimension of transcendence, assisting the patient to find and sustain courage to do so.

The concept of transcendence is viewed as the final goal of excellent patient care. The patient who is able to transcend his situation of suffering is not denying or being isolated, but instead becomes integrated more fully within the world around him.

The description of courage presented in this study illuminates many aspects of transcendence. Hope, patience, positive thinking and humor are some examples of how individuals, within the framework of courage, transcend the experience of suffering diabetes complications. It is essential that nurses learn more about issues of transcendence, particularly patients' attempts, in order to facilitate the changes in conduct, world view, relationships and self-image which accompany the act of transcending the given situation. Patients with courage to face the continued complications of diabetes feel that they are able to transcend the immediacy of their present situation, and

experience the world in a different manner. Beauty in nature, leisure activities, simple joys of family life become more important and cherished by such patients. Rather than feeling debilitated from the complications, they instead feel more open and alive to the world around them. A profound change occurs in their perception of themselves and others. The development of courage allows them to grow as human beings, to reshape their view of the world. Stephen Crane in The Red Badge of Courage eloquently describes an individual's experience of transcendence.

> So it came to pass that as he trudged from the place of blood and wrath his soul changed. He came from hot plowshare to prospects of clover tranquility, and it was as if hot plowshares were not. Scars faded as flowers.
>
> It rained. The procession of weary soldiers became a bedraggled train, despondent and muttering, marching with churning effort in a trough of liquid brown mud under a low, wretched sky. Yet the youth smiled, for he saw that the world was a world for him, though many discovered it to be made of oaths and walking sticks. He had rid himself of the red sickness of battle. The sultry nightmare was in the past. He had been an animal blistered and sweating in the heat and pain of war. He turned now with a lover's thirst to images of tranquil skies, fresh meadows, cool brooks - an existence of soft and eternal peace. Over the river a golden ray of sun came through the hosts of leaden rain clouds. (Crane, 1951, p. 266)

The previous section has examined what the understanding of the experience of courage can offer to nursing. In the following section specific implications for

the clinical practice of nursing will be given. Three other areas of nursing: administration, education and research will be addressed.

Implications for the Clinical Practice of Nursing

There are four major implications to be drawn from this study for the clinical practice of nursing. The first involves patient strengths. The findings of this study reveal that although patients often feel fearful and vulnerable while experiencing diabetes complications, they are also capable of drawing upon great inner strengths. They are capable of creativity and assertiveness in dealing with the complications.

The essentials of excellent nursing care that can draw upon patients' own inner resources to help them become more positive and assertive have been historically identified. Nurses traditionally have been encouraged to respect the patient's power of thinking. Florence Nightingale, as early as 1860, addresses the role of the nurse in providing caring measures to patients, such as giving them positive things to think about and providing a fresh and vital presence in their life. She emphasizes that the ill patient still retains an undiminished power of thinking and ability to reflect upon his surroundings.

> Do observe these things with the sick. Do remember how their life is to them disappointed and incomplete. You see them lying there with miserable disappointments, from which they can have no escape but death, and you can't remember to tell them of what would give them so much

> pleasure, or at least an hour's variety.
>
> They don't want you to be lachrymose and whining with them, they like you to be fresh and active and interested, but they cannot bear absence of mind, and they are so tired of the advice and preaching they receive from everybody. no matter whom it is, they see. (Nightingale, 1969, p. 103)

Nightingale implores nurses to address the needs of patients in regard to their mental state and to provide them with areas of reflection for positive thinking.

Patients spoke at great length about their need to assert themselves, particularly during hospitalizations, due to poor experiences in their past medical treatment. This leads to the nursing implication that nurses must realize that patients' strengths may be related to the past life history they bring to their present situation. For example, the patient who is unfortunately labeled as difficult to deal with, may be acting in an aggressive manner in order to defend himself from what has happened in the past. Patients who cried for help during hypoglycemic reactions and were ignored or patients who were labeled as non-compliers when they were not given sufficient education, enter the hospital with feelings of distrust and hostility. Often, patients describe their feelings of courage as ones that were forced to develop in response to past harms. These feelings of courage were also linked to creativity as patients were able to develop unique individual styles of coping with their situations. Recent studies such as "Vying for a winning position: management styles of the chronically ill"

portray patients as active self-managers, not as hopeless individuals.

The concept of the chronically ill patient as an assertive, creative person attempting to take charge of his life may be new to nursing (Forsyth, Delaney, Gresham, 1984). Nursing must realize that this is a real possibility and guide patients to such an outcome. Patient education, the domain of nursing, must be directed at creating an informed individual ready to make decisions.

The second major implication from this study for clinical practice is the meaning of interpersonal relationships for the patient's development of courage. The importance of the love and support of others is crucial for the patient's continued courageous stance. Courage involves commitment and this commitment is strengthened and upheld by the patient's interpersonal relationships. Nurses must attempt to include the family members and loved ones into any of the crucial teaching, decision-making and reflection that occurs in the hospital setting or at home. A loved individual derives the strength necessary for courage from others.

Is it possible that a spirit of love could permeate today's nursing care? According to Lanara (1974), it is not only possible, but it is the major contribution that the nursing profession can make to society. Loving care means a devotion to the welfare of others. This devotion can be

recognized by the patient and prevent even the most ill patient, from feeling alone in his suffering. Lanara uses the example of loving listening that can be used as a nursing intervention to display to the patient the caring presence of the nurse. Courage can then be awakened as the patient realizes that the love and support of the nurse is available.

The nurse must place love for fellow man tempered with justice, into clinical practice. Love can be considered not as self-sacrifice but as self-affirmation, involving integrity and respect for others and one's self (Tillich, 1952).

> She ought to bring the best thought she can and fullest knowledge she may acquire to the task of determining what specific actions and policies promise best to be the embodiment of brotherly love to men served in the area of her responsibility. Such love involves the patient exploration of the best ways for the provision of the best possible care men need. It involves tireless efforts toward humanizing and personalizing nursing care, toward reversing today's tendency for inhuman and depersonalized, uncaring care. (Lanara, 1974, p. 169)

Nursing can make an effort to humanize and personalize care by increasing its competence in communication. Communication is the means by which the nurse-patient relationship is initiated and maintained. Although nursing is often dominated by task activity, the emphasis should be moved to an effective use of language and listening. A movement away from routine communication toward interaction

more adapted to the feelings, perceptions and motives of the patient is necessary (Kasch, 1984).

The third implication for the clinical practice of nursing involves the timing of expressions of courage in an individual's life. All patients in the study could describe critical periods in their life when they were with, and without courage. This becomes important knowledge for nurses because assessment of the patient's ebb and flow of courageous expression in the past can influence his present care. For example, one patient feels that the winter months find her totally without courage because she feels closed up in her home due to failing eyesight. Knowledge of this might allow the nurse to plan extra nursing intervention from community sources during the winter months for this patient. The same patient states she felt filled with courage following the birth of her daughter, although diabetes complications were severe then, too. Important life events have a great impact on the development of expression of courage. Assessment of the most valued experience in an individual's life provides the nurse with a great deal of information to improve caring. Maslow (1964) discusses the impact of peak experiences in an individual's life. Many of the most courageous times that patients describe were during peak experiences of their lives.

> In the peak experiences, there tends to be a loss, even though transient, of fear,

> anxiety, exhibition, or defense and control, of perplexity, confusion, conflict, of delay and restraint. The profound fear of disintegration, of insanity, of death all tend to disappear for the moment. Perhaps this amounts to saying that fear disappears. (Maslow, 1964,p. 59)

Nurses are with patients during peak experiences in their lives. Their role of encouragement or inspiration of courage comes into play at such times. Assessment of this aspect of the diabetic patient's life history can improve the clinical practice of nursing.

The fourth and final implication for the clinical practice of nursing based on this study of courage involves collaboration. For nursing care for this group of patients to improve, collaboration with other health professionals, particularly physicians must be attended to.

In the present study, patients identify the role of the primary physician to be of great importance in sustaining courage. These patients are very ill and have to see many different physicians. For certain patients, one physician who could be relied upon for emotional support, allows them the trust and security necessary to maintain courage. In an effort to display the tremendous contribution nursing can make to society, the role of the physician and the intensity of the physician-patient relationship is often underplayed, by nurses. The relationship between a doctor and patient, particularly one of long-standing such as these diabetic patients develop, is an intense valued one. Nurses must

recognize this and begin to share the responsibility for patient care in an arena of open trust and communication.

Earl Shelp has written at length about the patient-physician relationship as a context for courage. Both nursing and medicine can benefit from his following realizations.

> Courage is required of those who choose a profession that embodies care and concern. And encouragement is properly one of their duties. Admissions of finitude and uncertainty may not come easy to those who desperately want to help others in distress. The honest disclosure of diagnosis, therapeutic options, and prognosis can itself be a process of encouragement in which the parties discover the nature of the human condition, define what is important within life, recognize what dangers exist and decide what certain goods are worth. This process of disclosure can be a form of encouragement that can enable patients to choose to retain or surrender autonomy. (Shelp, 1984, p. 358)

Nurses and physicians can work together to encourage patients and sustain their efforts at courage. Physicians are important to patients with disabling complications of diabetes and can often provide nurses with insightful life histories of the patient. Nurses must become attuned to opportunities for collaboration within the context of courage.

Implications for Administration of Nursing

The findings of this study point to the role of the nurse as one that is important in the patient's development of courage. In order to facilitate such development the

nurse must be sensitive to the emotional, as well as the physical needs of the diabetic patient with complications. This sensitivity of the nurse can only be initiated and maintained by a supportive nursing administration. If the nurse is asked to respect the dignity and worth of each individual patient, his or her own worth should be shown respect by those who supervise and facilitate the nursing practice. The administration of any organization, hospital, university, community service, needs to examine its philosophy and expand it, if necessary, so that it reflects a nurse-patient relationship capable of inspiring courage.

It is easy for policy statements to reflect a commitment to a philosophical approach to nursing, but a supportive nursing administration must move beyond the written word into demonstratable areas of supporting nurses' dedication to patients. Regular teaching sessions for nursing staff should include philosophical issues such as dealing with suffering, establishing trust, offering hope and inspiring courage. The nursing administration has to support such existential issues as well as technical topics.

Problems unique to nursing administration can be viewed in a philosophical way in order to remind nurses of their tremendous impact on patients' lives. For example, coping with the rigors of night nursing is seen as a complex

problem for nursing administration. Yet, a philosophical approach to such a problem, set within the framework of courage, would prove enriching to the nursing staff. Lanara (1974) addresses the problem of night nursing, including the element of sacrifice a nurse needs to remain at the bedside of the suffering throughout the night. The patients' greatest needs become evident during the night when nurses often have the sole responsibility. If the nursing administration is aware that patients' vulnerabilities and fears intensify during the night, they can direct and support staff nurses' goals of inspiring courage during these times. Although night nursing remains grueling in its intensity, the nursing staff will feel they are being enriched as professionals if they are providing excellence in nursing care, recognized by a philosophically supportive nursing administration.

Excellence in care leads to a discussion of a major implication that this study has for nursing administration, examination of the role of virtues, such as courage, within the practice of nursing. This is an implication for administration because it is this group which controls and sets standards for the practice of nursing. In today's nursing world, much emphasis has been placed on obtaining the external goods such as salary increments, career promotions, and professional recognition. This emphasis has been needed in a growing profession, but the internal

goods of the practice such as satisfaction in using one's skill and talent to care for others have often been overlooked (Benjamin and Curtis, 1985). An examination of the role of virtues, such as courage, in patient care is needed by nursing administrators to assist nurses to better understand the varied aspects of their profession. Alasdair MacIntyre, in After Virtue includes courage as an essential component to any practice with internal goods and standards of excellence. He clearly delineates the differences between practices and institutions. Medicine and nursing constitute practices; hospitals are institutions. Institutions are concerned with external goods. Because practices and institutions have an intimate relationship, care must be taken to guard against the ideals of the practice becoming threatened by the institution's competitive need to acquire money, power and status. The vigilance needed to prevent this, according to MacIntyre, appears in the form of the virtues. "Without them, without justice, courage and truthfulness, practices could not resist the corrupting power of institutions" (p. 194).

A growing awareness of the importance of courage in institutions helps nurses to re-examine their own moral traditions and philosophies. Ideals of practice will not shatter if the role of such virtues of courage is maintained by nurses, singly and in groups. The ideals, however, will not flourish if nursing administration does not support

nurses' acts of courage which are displayed in various ways. "A nurse must also be courageous, not only in caring for persons with infectious diseases or in handling potentially dangerous drugs and materials, but in speaking out to safeguard clients from incompetent, unethical, or illegal practices of other health care workers" (Benjamin and Curtis, 11985, p. 270). If nursing administrators begin to value courage within the practice, more patients will benefit from the kind of nursing care which includes a philosophical approach. When the virtues such as courage or justice and honesty are valued and remain so within the profession, nursing will not emphasize technical over human skills within the practice. ".... a practice, in the sense intended, is never just a set of technical skills, even when directed towards some unified purpose and even if the exercise of those skills can on occasion be valued or enjoyed for their own sake" (MacIntyre, 1984, p. 193). Nursing administrations can foster an environment of professionalism and integrity by supporting their nurses who display courage.

The implications for nursing administration are to increase the awareness and support of the role of courage within the nurse-patient relationship. To do so will fulfill standards of excellence in practice. To fail to do so will rob both the patient and the nurse from an enriching experience.

Implications for Education in Nursing

The implications for education of nurses drawn from this study will focus on both basic educational preparation and professional education opportunities.

The implication for basic educational preparation of nurses that can be drawn from the study of courage is that a fully integrated curriculum, highlighting the humanities, is necessary for successful nursing practitioners. The humanities help to prepare nursing students to face the existential issues of life, death and suffering. It is a difficult task to ask a young nursing student with little personal life experience to grasp the meaning of critical life experience. The study of the humanities can help to reveal much of the world to the nursing student.

> The humanities offer the nursing student a rich source of others' experiences to broaden her own view of things. In studying the works of the great creators, the student is in constant dialogue with the author, agreeing here, disagreeing there, and in so doing, building for herself a common intersubjectively grounded fund of knowledge. Great artists deal with existential situations. Nursing students also experience these very situations with patients in a very real way, sometimes on an almost daily basis. The student comes in frequent contact with pain, suffering and death, not from a theoretical point of view only, but as actually experienced by fellow human beings. (Taddy, 1975, p. 253)

Courage is a central existential issue of particular importance to nursing. Patients in this study identify nurses as capable of inspiring courage. A broad educational

background facilitates the understanding of courage and its role in the life of the patient. A sensitive faculty, too, is necessary to teach nursing students about humanistic values and to instill in them respect for the meaning of life for the patient.

After a basic educational preparation, the nurse enters an organizational system which, may, or may not support these ideals. Support of such existential issues as part of the domain of nursing must be given by administration and can be given through staff education efforts. A key person to become involved in such educational efforts is the clinical nurse specialist. For example, the diabetes nurse specialist may have gained much information on the life history of certain patients with complex problems. Part of that information may deal with such philosophical issues as the patient's development of courage. The clinical specialist should be encouraged and expected to share such information with the staff. In this way more information is transmitted that will ultimately improve patient care. Part of strengthening our existing practice of nursing is to ensure this flow of information from the specialist to the generalist. Not all clinical specialists work within a staff development model and instead, concentrate solely on patient care. Here, specialized knowledge is not transmitted to the nursing staff generalists who may feel inadequate in certain areas of nursing care. Certain

results of this study, particularly the ways in which patients feel courage can be developed by the nurse, are needed to be known by staff nurses. These include human ways of caring such as touch and listening. The staff nurse, through education from the clinical nurse specialist, could improve her own nursing practice and give excellent patient care.

Nurses are human beings who are in a continuous process of growing and learning about themselves and others. Education reflecting existential concepts such as courage remains necessary to such growth.

Implications for Research in Nursing

A major implication in the area of nursing research, drawn from this study, is that an investigation into the philosophical issues of importance to patients, such as courage, is meaningful for nursing. Today, nursing research strives for an examination of the patient's physical, emotional and spiritual needs and yet this framework is often undervalued by certain groups of nurses and physicians who remain concerned only with the physical status of the patient. It is necessary for nursing to re-examine the philosophical traditions that link the mind and body, and to place them into the perspective of nursing. A reflection upon the existential issues involved in patient care, including an examination of nursing's past, will lead nursing into future excellence in practice.

Specific implications for nursing research can be derived from the present study.

1. Patients in the present study did not find other diabetic patients, in individual or group settings, helpful in nurturing the development of courage. This is in contrast to Haase's study of chronically ill adolescents who derived much meaning from interactions with other patients. The patients in the present study were older and more debilitated. They expressed no interest in inspiring other patients, perhaps because they had great unmet needs themselves. This is an important area for future research because traditionally diabetes education and counseling occur in group settings. These settings may not be as conducive to the emotional experience of the patient.

2. Diabetes self-management tasks were very helpful, according to patients, in developing courage. Self-management has been investigated in regard to improving metabolic blood glucose control and certain psychological frameworks, but never as an impetus for a positive philosophical outlook for patients. This bears further research by nurses.

3. The behaviors described by patients that helped nurses to inspire courage included touch, being there, listening and other caring behaviors that need further investigation, particularly within the diabetic population.

4. Patients described many feelings regarding courage

and the experience of diabetes complications that generate much needed nursing research studies. These include the feelings of hope, patience, positive thinking and faith. Differences between male and female expressions of courage need further research.

5. Courage was found to be characterized by strong and loving interpersonal relationships. A study of courage within the framework of the family unit would be necessary.

6. This study did not address nurses' attitudes about courage, their patients' or their own. This type of study is necessary to complete the total picture of the nurse-patient relationship.

CHAPTER VII

SUMMARY AND CONCLUSION

Courage isn't a brilliant dash,
A daring deed in a moment's flash;
It isn't an instantaneous thing
Born of despair with a sudden spring
It isn't a creature of flickered hope
Or the final tug at a slippery rope;
But it's something deep in the soul of man
That is working always to serve some plan.
Edgar A. Guest

Courage is indeed deep within the soul of man, with many layers to its experience. Intense and powerful emotions are elicited when courage is described. Commitment, love, vulnerability, nurturance, change, all are dynamic images found in the multiple dimensions of the experience of courage.

This study represented an inquiry into the role of courage in the experience of the diabetic patient with complications, for the purpose of advancing professional nursing practice for this group of patients. It was suggested that these patients, due to their multiple problems, are underserved and that more appropriate and directed nursing care could be derived from the study of their experience. The patients' experiences were studied using the framework of courage as the basis of analysis.

Courage was viewed as a meaningful part of the experience of the patient with diabetes complications. Its presence or absence was thought to significantly affect how the patient faces life and death. Nursing, because of its

central role in existential issues of life and death, was viewed as having an impact on the patient's development of courage.

As nurses strive to provide caring, the essence of nursing, they must explore the human experience of the patient. In order to illuminate the experience of the patient with disabling complications of diabetes so that nurses may be better able to assist individuals through the experience, an exploration of the role of courage was conducted.

Related literature including diabetes pathophysiology and complications was examined. Psychosocial adjustment to diabetes in general and to chronic illness was also reviewed. There was little available literature related to psychosocial adjustment to complications. Courage was analyzed according to many related sources including literature, philosophy, psychology, and religion.

A phenomenological approach to the experience of courage was used. The phenomenological method, an inductive, descriptive research method which has as its task the investigation and description of the meaning of the human experience, was considered appropriate and attractive to a nursing investigation. Preliminary fieldwork guided the research design which combined aspects of ethnography with phenomenology.

Nine diabetic patients with severe complications were

interviewed in home settings. The transcripts from these interviews were analyzed according to the phenomenological method proposed by Colaizzi. Five theme categories were derived which described the various dimensions of courage in the experience of the patients: philosophical, health care, physical, psychological and interpersonal. Intense reflection upon these categories provided a description of courage, and finally, the structure of courage for the individuals studied.

The structure of courage for patients in this study revealed it to be a dynamic state which can be nurtured by the individual's own resources, or through the inspiration of others. The development of courage was intimately tied to a search for meaning in the situation. The outcome of courage was seen as a changed self and world view on the part of the diabetic individual. The experience of courage was rooted in interpersonal relationships with others. Patients' encounters with nurses and physicians were found to hold great promise for assistance in the development of courage.

Guest's poem depicts courage as always working to serve some plan. That plan is to give continued support, life, meaning and enthusiasm to the patient's present situation. Not one of the nine patients lost all enthusiasm for life or chose other options of isolation. They did indeed grapple with these thoughts but were able to continue to choose a

vital life through courage.

The clinical findings of the study were compared and contrasted to the related literature. Courage was interpreted in light of coping, hope, suffering, vulnerability, self-esteem, risk-taking, fearlessness, love, culture, and control as well as its ontological nature. There were also new realizations regarding courage, stemming from reflection upon the clinical findings. These included a description of courage and commitment, creativity, social nature, inspiration, middlescence, and humor.

Courage was found to be profoundly related to a variety of meaningful aspects of individuals' lives, aspects where nursing is deeply involved. Therefore, the study of courage has an impact on the practice of nursing and holds great promise for improved nursing intervention. The practice of nursing was explored with emphasis on the importance of studying the patient experience, and the components of the nurse-patient relationship. Nursing's role in the development of courage was viewed in relation to inspiration and caring, particularly in highly technical environments. The search for meaning and the role of transcendence was explored with emphasis on nursing's participation. Implications for nursing in the areas of clinical practice, administration, education and research were given.

Many nurses mistakenly believe that a group of patients with complex health problems such as the one presently

studied needs only highly specialized technical care. Instead, patients tell us, in a variety of ways and if we listen, that they are more in need of human to human interaction than the technical solutions so often offered. Nurses can help patients to develop and draw on their own reserves of courage through caring, humanistic practices. This is a complex nursing intervention, to interweave the pattern of meaning and commitment in the patient's life to the present situation and assist the patient in the recognition of his or her own strengths and potential. It is not an easy task. It requires that the nurse draw upon inner reserves of patience, understanding and persistence in order to fully offer help to the patient. The nurse and patient can both be enriched by their connection within the experience of courage. Nurses can make patients feel less vulnerable, more self-assured, less fearful, more in control, less at risk, more hopeful and loved. All of these feelings have a tremendous impact on the patient's ability to develop and sustain courage. When nurses realize and use the power they hold to relate to the humanity of each nursing situation, particularly that of courage, the experience of patients will be greatly enriched.

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APPENDIX A

ADELPHI UNIVERSITY
MARION A. BUCKLEY SCHOOL OF NURSING

FORM A
HUMAN SUBJECTS REVIEW COMMITTEE
SCREENING FORM

Title of Project The Role of Courage in Patients with Diabetes

Hypothesis Complications:A Phenomenological Exploration & Philosophical Analysis

Chairperson or Project Advisor Dr. Barbara Kos-Munson

Committee Members Dr. Stephen Greenfield Dr. Barbara Rottkamp

Research Tools and Methodology: Check all that apply.
Questionnaire [___] (Append)
Face-to-face interview [X]
Experimental intervention/manipulation [___] (Explain)

Other (explain)

Subjects (check all that apply):

Healthy Volunteers	[___]	Pregnant Women	[___]
In-patients	[___]	Children	[___]
Out-patients	[X]	Psychiatric Patients	[___]
Seen in home settings		Minorities	[___]

Other [___] (Describe)
Ages of subjects 29-55
What provision is made for protecting subjects' anonymity?
Describe Code numbers used for patient transcripts
Is control group used? No [X] Yes [___] Describe

Brief description of sample Nine patients with disabling complications of diabetes were interviewed in their home settings

Append: 1) Brief abstract of study.
2) Consent Form (not needed for paper and pencil tests or questionnaires.)

[redacted]
Advisor's Signature

Patricia Donohue-Porter

ACTION - To be completed by Human Subjects Review Committee

Deferred ____ Referred for full review ____ Full review not required X

Reasons minimal risk

Signature [redacted]
Chair HSRC

APPENDIX B

Appendix B

GENERAL EMOTIONAL REACTIONS RESPONSE FORM

Interview I*

1. How are you feeling now?

2. Describe a routine day for you (as you experienced it in the past week) - the entire 24 hours. Let's start with when you get up in the morning until you get up the following morning.

3. What are the things that are important that you must do?

4. What are the things you don't get to do that you'd like to do?

5. What are the things you truly dislike doing and you avoid?

6. What makes you very happy, contented and what makes you sad, angry?

7. What complaints do you have of yourself, your family, the doctors(s), nurses(s), caregivers, your community, society, your representatives, any organizations?

8. What would you say keeps you going?

9. If you would wish for one thing in your life right now, what would it be?

Semi-structured questions asked at the initial interview.

APPENDIX C

Appendix C

COURAGE RESPONSE FORM I*

1. What does courage mean to you?

2. Can you tell me about someone you know who is courageous? What is he or she like?

3. How do you feel about your diabetes complications? What impact do they have on your life?

4. Do you feel that you need courage to deal with them? If yes, why? If no, why not?

5. If yes, who helps you to develop and sustain courage through these complications?

6. When have you felt the least courageous? What was the most difficult aspect of dealing with diabetes complications?

7. When have you felt the most courageous? Did you feel hopeful at that time?

8. If you have been able to find courage, how has this changed your life?

9. Has a nurse ever asked you about how you feel regarding diabetes complications? Do you think nurses could give you a feeling of courage?

10. Final comments:

* Semi-structured questions asked at the initial interview.

APPENDIX D

Appendix D

COURAGE RESPONSE FORM II*

1. How can courage help you through suffering?

2. What makes you feel hopeful?

3. How would you describe yourself as a person?

4. How do others describe you?

5. How does the support and love of others give you courage?

6. Do the complications of diabetes make you feel vulnerable? How?

7. What obstacles have you had to contend with as you've coped with the disease? Have you taken risks while coping with diabetes complications?

8. How much, in what ways, are you able to participate in your management of diabetes (in decisions about your life)?

9. How does being in control relate to courage?

10. How do you think a nurse could give you a feeling of courage?

11. Final Comments:

* Semi-structured questions asked at the second interview.

APPENDIX E

Appendix E

CONSENT FORM

I, _____. give my permission to be interviewed by Patricia Donohue-Porter for purposes of nursing research. I understand that the results of this research, in regard to individual patient identification, will be kept completely confidential. I realize that the purpose of the research is to explore the experience of having diabetes complications.

Signed _____

Date _____

APPENDIX F

Appendix F

DEMOGRAPHIC DATA SHEET*

1. Patient Name:
2. I.D. #:
3. Address:
4. Telephone #:
5. Type of Diabetes:
6. Duration of Diabetes:
7. Age:
8. Height:
9. Weight:
10. Treatment: (Diet, Meds, Exercise)

11. Complications History:

12. Family Members:

13. Physician's Name:

14. Dates: Initial Interview
Follow-up Interview

*Completed by the researcher at the initial interview

APPENDIX G

PATIENT PROFILES

PATIENT PROFILE

PT #1

This 42-year old female has had Type I diabetes for 29 years and takes a split/mixed dose of insulin. She is overweight at 134 pounds on her 5'2" frame. She attempts to follow a Weight Watcher's diet, self-monitors her blood glucose and administers her own insulin using a magnifier. She has severe retinopathy, hypertension, peripheral neuropathy and evidence of proteinuria.

The patient is a homemaker and lives with her husband and daughter. She had been a school teacher prior to marriage and is a college graduate. She is Roman Catholic. She finds strength in her religion to face her disease. She also relies on patient education as a coping mechanism.

This patient's physical appearance is attractive. She looks younger than her stated age and wears make-up, a stylish hair-do and is concerned about the extra pounds she is constantly battling to lose.

I was welcomed graciously by this patient who lived in a colorful, well-furnished home. I was struck immediately by the color of the patient's home surroundings - a sunny yellow. Interestingly, she was making every effort to keep her surroundings stimulating as her vision was diminishing.

The interviews were conducted in a large, airy kitchen around a round dining table. She was neatly dressed in a bright yellow warm-up suit and seemed to view the interview

as a social event that she had been anticipating. She introduced her daughter and her husband who both joined us briefly during parts of the interview. She was not nervous during the interviews and freely shared her thoughts.

PATIENT PROFILE

PT #2

This 29-year old female has had Type I diabetes for 12 years and takes multiple injections of insulin. She is overweight, weighing 168 pounds at 5'2". She attempts to follow a 1500 calorie diet, monitors her blood and examines her feet. She must be given her insulin injections by her husband or sister due to her failing vision. She has severe retinopathy, neuropathy in both legs, hypertension and early kidney failure.

The patient was employed in a supervisory position in the computer field until six months prior to the interview. She had to stop working due to her deteriorating physical condition. She is a college graduate. Her religion is Roman Catholic. She lives with her husband of two years and her primary desire is to start a family. This patient feels she has been mistreated by many health professionals and freely admits her anger and distrust.

Since my last meeting with this patient, six months prior to our first interview, she had changed considerably in physical appearance. She weighed at least 40 pounds more, although much of this was due to fluid retention. Her lower legs were swollen to twice their size and she had noticeable facial and periorbital edema. Her vision had recently worsened and she had developed a squint. She looked and acted more fatigued than I had ever seen her

before.

I was received into a large, airy, beautifully decorated home. All shades of the color blue were attractively displayed. This young woman and her husband collect antiques as a hobby and display lovely pieces. Her failing eyesight concerns this talented and precise homemaker. This patient displayed a variety of emotions during the interview, ranging from anger to acceptance. She emphasized the need for patience and humor in dealing with diabetes complications. The patient has a supportive husband who I had met prior to these interviews.

PATIENT PROFILE

PT #3

This 37-year old female has had Type I diabetes for 37 years and takes a single A.M. dose of insulin. She has a prescribed diet of 1000 calories which has recently been increased to 1800 calories to provide for wound healing of her amputated leg. She is 5'5" and weights 150 lbs. She performs daily foot inspection, tests her blood glucose and gives her own insulin. She has severe retinopathy including laser treatment and vitrectomy, kidney failure necessitating a kidney transplant, severe painful neuropathy of the left leg and a BTK amputation of the right leg due to diabetes-induced circulatory problems.

This patient is a homemaker. She is a college graduate and has been a school teacher prior to becoming ill. She is Jewish. She has a supportive family and one son. This patient seeks out current patient education information in order to cope with the illness.

This patient's physical appearance has been greatly altered due to diabetes. She is on steroidal medications which cause overweight as well as a swollen face. This is distressing her. She has failing vision, an unstable gait, easy fatigue and is wheelchair bound for part of each day.

This patient was the most physically ill of any interviewed. She recently underwent an amputation and was receiving physical therapy during the month I interviewed

her. She postponed our second interview for several days due to fatigue and pain from neuropathy.

Although her physical condition is threatened, this patient's mental state is usually quite good. She is humorous, alert and vivacious. She was an eager participant during both interviews.

This patient had a neat and clean home which was mainly taken care of by her husband. He is a school teacher and was off during the summer months of the interviews. I met him each time I visited their home. The couple are parents to a son who was away at day camp during the interviews. Pictures of him were everywhere. He is, according to his mother, the reason she maintains a continuing spirit of hope and positive outlook.

PATIENT PROFILE

PT #4

This 54-year old patient has had Type II diabetes for 25 years and takes a single morning dose of insulin. She is very overweight at 204 lbs on a 5'2" frame. She does not follow a diet and participates little in diabetes self-management. She has severe retinopathy with a history of multiple laser treatments and a detached retina. She has had a MI and has peripheral neuropathy and proteinuria.

The patient is a homemaker and lives with her husband. She is house bound usually, due to her poor eyesight. She had not completed a high school education and uses the television as her only company during the day. Her religion is Catholic. She has two adult children who live in a distant state. Pictures of them and her grandchildren line the wall. The patient has little support in coping with the illness.

The patient's physical appearance is poor. She wore a shabby robe during the interview and her hair was unkept. Interestingly, she had several bottles of nail polish on the coffee table and attempts to continue to manicure her long fingernails. This aspect of body image remains important to her.

The patient lives in a house which appears abandoned at first glance. Old tires, automobile parts and refuse line the front lawn. Inside, the home is poorly lit, with dust

covering all areas of the living room and the patient's belongings scattered all over. The patient's vision is so poor that she does not realize the mess she is living in most of the time. She left on her stove burners recently because she could not see them and almost caused a fire. Immediately, following our interview, a home nursing care referral was made.

The patient is less depressed than her surroundings would suggest. She states that her husband works six days a week until late in the evening and so cannot help around the house. He does check her blood glucose and administers her insulin each morning. On Sundays, he takes her riding in a side-car on his motorcycle and they spend a joyful day with members of the cycle club. She becomes most enthusiastic when speaking of this day and their bond with the motorcycle club. Her outlook towards the disease is one of acceptance of complications as her "lot in life". She has feelings of abandonment by friends and family.

PATIENT PROFILE

PT #5

This 33-year old female has had Type I diabetes for 22 years. She takes a split/mixed dose of insulin daily and performs all aspects of diabetes self-management. She has severe retinopathy, including laser treatments as well as hypertension and early kidney failure. She has recently been diagnosed as having sarcoidosis.

The patient is the oldest of many children and lives at home with her parents and siblings. She completed nurse's aid training after high school and is employed part-time as a home health aid. She is Catholic and finds religion a source of support in coping with diabetes.

The patient is shy and reserved. She is neatly dressed but quite overweight at 5'2" and 200 pounds. She has a rather flat affect and an extremely nasal voice which is, at times, difficult to understand. If one did not make an attempt to draw her out and listen carefully, she could be easily overlooked in a crowd.

This patient had been visited during my preliminary field work so I was already comfortable in her home. Since she is one of many children, the home setting was active and we were often interrupted. The taping took place in her living-room and I met a number of her family members including her mother and father. Everyone seemed interested in the "celebrity status" that the interviewing seemed to

give the patient.

She was enthusiastic during all three interviews in regard to sharing feelings. One issue she felt strongly about was her dislike of group activities or sessions for diabetes. She felt she had to cope alone and did not like being categorized as only a diabetic by health professionals.

PATIENT PROFILE

PT #6

This 38-year old male has had diabetes for 25 years. He takes a total of 175 units divided up and placed into his peritoneal dialysis runs. He is 6' and weighs 140 lbs and was unsure of his dietary requirements. He performs self-monitoring of blood glucose as well as performs his own continuous ambulatory peritoneal dialysis. He has retinopathy including a vitrectomy in the left eye and laser treatments to both eyes. He is on CAPD due to end stage renal failure and has constant pain in the lower extremities due to neuropathy. He is impotent and has ischemic heart disease.

This patient had been employed as a business man until becoming disabled due to diabetes. He would like to work and is frustrated by being unable to do so. He lives with his wife and young son. His religion is Catholic and he is a college graduate. At the time of the interviews, he was finding the complexity of his medical problems overwhelming.

This patient is tall, thin and very ill-looking. It seemed an effort for him to open the door to me. He had his mother present in the house during the first visit and his young daughter during the second. He did not look well enough to remain alone. I did not meet his wife who works full-time.

The house was messy and cluttered; a broken front door

was in need of repair during both meetings. This patient performs CAPD and the equipment was carefully set aside but in a corner of a cramped, dusty dining room. Pictures of his daughter and paintings done by her filled the walls and refrigerator, bringing the only sign of brightness into the home. There was no adequate ventilation, leaving the home stifling.

During the interview, this patient broke down and wept as he discussed his depressed feelings and lack of independence. He is receiving professional psychological counseling at the present time.

PATIENT PROFILE

PT #7

This 32-year old female has had Type I diabetes for 25 years. She takes a single dose of insulin each morning, and strictly follows a 1500 calorie ADA diet. She exercises, tests her blood but prefers not to give her own insulin. Her boyfriend does this and helps in the preparation of her meals. She has a small amount of proteinuria, hypertension and pyorrhea. Her outstanding complication is retinopathy including laser treatments, a detached retina and a cataract in the left eye.

The patient had been living with her boyfriend for several years. She works full-time as a secretary. She is Jewish and is adamant in expressing how useless she feels religion can be in coping with diabetes. She has often expressed anger and frustration with the demands of diabetes.

This patient is slender, weighing 110 lbs at 5'1" and is neatly dressed. She has severe strabismus which creates awkward eye contact.

I did not interview this patient in her home due to an unstable home situation. Instead, both interviews took place at a Diabetes Education Center. This patient had been known to me for at least three years and during that time she always complained about the burden of diabetes and her coping efforts. I had not seen her for six months prior to

the interview. The day of the first interview she was radiant having had recently become engaged. She was delighted to display her ring, appearing outgoing, verbal and happy. Her mood persisted during the second interview. She still was able to freely discuss her anger and despair over the diabetes but had a far more positive attitude than ever previously noted.

PATIENT PROFILE

PT #8

This 31-year old male patient has had Type I diabetes for 20 years. He takes a single dose of insulin each morning. He weighs 155 lbs and is 5'9" tall and follows a 2,400 calorie ADA diet. He tests his blood once a day and gives his own insulin. He has had two vitrectomies for retinopathy. He also has neuropathy, severe infections and is presently on hemodialysis for end stage renal disease.

The patient has been a bartender until his most recent bout with complications and is not employed. He is a high school graduate and of the Catholic Religion. He lives alone in a rented apartment. His sister lives close by and helps him when necessary, with diabetes self-management. He emphasized his need for independence and his desire not to burden others with his problems. He has a positive outlook and copes by trying to understand more about each complication.

This patient is attractive, healthy looking, outgoing and friendly. He is neatly dressed and concerned about his appearance.

This young male patient lives alone on the top floor of a two story home. Because of his failing eyesight and also because he was frequently hospitalized between our meetings, his apartment often looked like a disaster area, including cigarette ashes on chairs, dirty dishes in the sink. During

my second visit, though, he had just attempted to paint a spare room and was quite interested in his surroundings.

This patient had the unique experience of regaining his eyesight after a vitrectomy. He was still overwhelmed by this and eager to talk about it. He was quite introspective and well able to communicate his feelings. He said he has always loved talking to people. He acted like a good host during both interviews, being very sociable.

PATIENT PROFILE

PT #9

This 55-year old male patient has had Type II diabetes for 31 years. He weighs 171 lbs and is 5'6" and has little knowledge of his diet. He does not monitor his blood glucose but does take his own insulin injections. He has had multiple laser treatments for diabetic retinopathy. He has hypertension, impotence, renal failure necessitating hemodialysis and toe amputations due to circulatory problems.

The patient works part-time and lives alone. He is divorced but is close to his two sons. He has great faith in his doctor and relies on this to sustain courage. He is a high school graduate and of the Greek Orthodox religion.

This patient's physical appearance is of a debilitated, ill man who is unsteady on his feet. The patient looked physically ill and weak during this interview but had not yet been placed on dialysis. At the scheduled time of the second interview, he was hospitalized and dialysis begun.

This patient was interviewed in his apartment that was immaculately kept and well-decorated. He was dressed in clean but disorganized manner. He is an open, friendly man who uses humor to cope with his serious illness. He did break down and cry twice during the interview but wanted to continue to freely share his thoughts.

APPENDIX H

Appendix H

CODED FORMULATED MEANINGS

1. LOP = Lack of preparation for complications made courage difficult to develop.

2. DSM = Diabetes self-management tasks were difficult and time consuming but also gave a sense of control over the disease.

3. AAS = There was great anger evidenced against the health care system for its disinterest.

4. LSO = Love and support of others, family members and friends, was essential to the development of courage.

5. TOM = Tasks of middlescence, such as child rearing or employment, gave needed impetus to courage's development.

6. MM = Medical mismanagement was present during the diagnosis and treatment of diabetes complications.

7. OPP = Other people's perceptions of courage had an effect on the patient's perception of his or her own courage.

8. NR = The nurse's role has an impact on the development of courage in a variety of non-technical ways.

9. ROP = The role of the physician is a sustaining presence in the development of courage.

10. PA = Patients were aware of attempts they made at developing courage.

11. LOC = Loss of control made courage more difficult to maintain.

12. REL = Religion has a special place in the development of courage, either facilitating or blocking it.

13. EED = Early experiences with diabetes had an effect on patient's perceptions of their own courage.

14. BLD = Being let down by others was a devastating experience and one that made courage more

difficult to maintain.

15. TP = Patients could describe turning points in the development of courage.

16. HOP = The role of hope was to transcend the patient's experience and influenced courage.

17. LOD = Lack of distractions from diabetes self-management made the disease grueling in intensity.

18. ROD = Relationships with other diabetic patients did not seem to provide any insight into the development of courage.

19. SI = Patients could talk about their own self-image and how it related to courage. The more positive the image, the more courage the patient was able to elicit.

20. PTC = Problems to cope with, related to the diabetes, were described by patients as both barriers and incentives to the development of courage.

21. RIS = Patients felt they needed to have courage in order to take risks but also that the risks primed them to be courageous.

22. AS = Assertiveness is a meaningful part of the experience of courage.

23. FW = Feeling well, particularly being free from pain, made it easier to be courageous.

24. BI = Body image changes had to be met and adjusted to, necessitating courage.

25. GR = Grief was a strong emotion which often blocked the development of courage.

26. LOS = Loss was experienced on both physical and emotional levels.

27. FR = Strong feelings of fear were noted in a variety of situations dealing with complication progression and treatment.

28. DEP = The progressive nature of the complications led to strong feelings of dependence.

29. IND = Patients' struggle to maintain independence made

them feel more courageous.

30. FOP = Fear of pain was intense for certain patients and required the deepest search for courage to conquer it.

31. RES = Continued restrictions of diabetes made patients feel they had no outlet from the disease.

32. NRL = The stringency of diabetes self-management tasks made patients feel they had no relief from the disease.

33. OH = The amount of times that patients were hospitalized for complication-related problems was overwhelming to them.

34. DEF = Patients defined courage in a variety of ways, usually involving nurturance and fluctuation.

35. PAT = Patience was used to transcend the experience and influenced courage.

36. FRU = Frustration was a commonly seen reaction to the experience of complications.

37. ROPR = A reordering of priorities aided patients in developing control and courage within the experience.

38. PT = An intentioned effort was made to sustain positive thinking throughout the experience.

39. VUL = Both physical and emotional vulnerability were present within the experience of complications and courage.

40. DEPR = Depression was an intense unpleasant feeling that made courage more difficult to express.

41. PC = Poor metabolic control made courage difficult to express or sustain.

42. HUM = Humor was helpful in transcending the experience of complications and aided in the development of courage.

43. HOB = Hobbies were useful in temporarily transcending the experience of complications.

44. GU = Guilt was an unpleasant emotional response felt

during the experience of complications.

45. ETW = Experiencing the world in a different manner, after the development of courage, was usually a positive experience realized after much introspection.

46. THER = Professional therapy to aid in psychological adjustment to the complications had to occasionally be sought.

47. ISO = A sense of isolation or potential isolation remained within the experience of complications.