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among diabetic women**

Primomo, Janet, Ph.D.

University of Washington, 1989

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Patterns of Chronic Illness Management, Psychosocial
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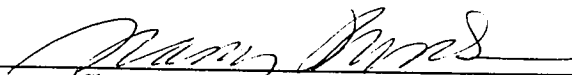
Janet Primomo

A dissertation submitted in partial fulfillment
of the requirements for the degree of

Doctor of Philosophy

University of Washington

1989

Approved by 
(Chairperson of Supervisory Committee)

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to Offer Degree School of Nursing

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Abstract

Patterns of Chronic Illness Management, Psychosocial
Development, Family and Social Environment and
Adaptation Among Diabetic Women

by Janet Primomo

Chairperson of the Supervisory Committee:
Professor Nancy F. Woods
Department of Parent and Child Nursing

On a daily basis, individuals with chronic illness must cope with complex treatment regimens and symptoms of illness as they try to integrate these demands into their personal, family, social, and work lives. Furthermore, personal, illness, and environmental factors may influence how people cope with and adapt to chronic illness. The overall purpose of this study was to generate knowledge about the processes by which women manage and adapt to a chronic illness that mandates daily intervention. Factors that influenced adjustment to illness were also examined.

Semistructured interviews and standardized instruments were used to generate data on diabetes management, psychosocial development, family and social factors, and psychosocial adaptation in 40 women with diabetes mellitus. The average age of women was 38 years. Most women were married with a school-aged child, moderately well educated, middle to upper-middle class, and employed outside the home. Thirty-five of the women had insulin-dependent diabetes. The mean duration of illness was 13 years.

Responses to an open-ended interview guide on diabetes management were used to generate key elements of the diabetes regimen from the

perspective of the participants. A core variable, Clinical Safety Work, evolved that integrated the key elements of the regimen. A typology of illness management patterns was derived also from the interview data. The six patterns of diabetes management ranged from rigid to flexible approaches. The illness management patterns were linked to stages of psychosocial development, family and social factors, and psychosocial adaptation.

Women whose management style was most chaotic had few anchors in their lives such as other family members, and/or were not employed, and had the lowest incomes of the sample. These women were the most anxious and depressed. Furthermore, they had the lowest stage of psychosocial development. Women with higher stages of psychosocial development were more likely to take control of their diabetes regimens and some were able to adjust their regimens to accommodate the demands of family and work.

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ACKNOWLEDGEMENTS

I wish to express sincere appreciation to Professor Nancy F. Woods for her expert guidance throughout my doctoral education and especially with the preparation of this manuscript. Thanks is extended to Professor T. Albrecht, my Graduate Faculty Representative, for her continued encouragement. The expert clinical advice provided by Professor C. Blainey has been invaluable and I gratefully acknowledge her contributions. I am indebted to Professor J. Quint Benoliel for her mentorship over the years. She has helped me to think critically about my work. Professor N. Chrisman is recognized for pushing me to clarify my theoretical framework of adaptation to chronic illness. Special recognition and thanks is given to Edythe Ellison Hough and Sandra K. Johnson (Mitchell) for their contributions to the early phases of this work. In addition, I am deeply grateful to Professor Fran Lewis for her willingness to provide access to the Family Impact Study sample and for her continued encouragement and support throughout my doctoral education. I am truly fortunate to have had the opportunity to work with such outstanding scholars and supportive human beings.

I am indebted to Monica Jarrett, Ph.D. for her assistance with the statistical analysis of the data. Also, the contributions of Nancy J. Packard, Ph.D. and Melissa Gallison, R.N., M.N. to the data analysis on diabetes management patterns are gratefully acknowledged. Thanks also to Sandra Ryan, R.N., M.N. for her critical review of the diabetes-related instruments.

My husband and friend, Gary Zarker, deserves special recognition for allowing our lives to be Driven by the Dissertation for a period of time. His contributions included "managing the hard disk," writing an R-Base program for a portion of the data set, functioning as a critical but helpful listener, putting the baby to bed every night, and much more. Thanks also to my friends, especially Kitty Grupp, Lisa Harris, Kathy Lee, Deb Tombari, and Bernice Yates for their unfailing support. Last but not least, the women who participated in the study are gratefully acknowledged.

This research was supported in part by a National Research Service Award (#NU 05765) from the Department of Health and Human Services, and a grant from the Hester McLaws Scholarship Fund offered by the University of Washington School of Nursing.

Dedicated

to my parents, Gene and Bena Primomo,
for nurturing my love of learning and
encouraging me to be all I want to be.

CHAPTER 1
INTRODUCTION

Individual, illness, and environmental factors may influence how a person copes with and adapts to chronic illness (Bieliauskas, 1983; Mechanic, 1977; Moos & Tsu, 1977; Strauss et al., 1984). Variability in illness management may depend on a number of factors such as severity of illness, the length of time the person has had the illness, family composition, social environmental factors, or the age or psychosocial development of the person. There is increasing evidence that psychosocial development, in particular, may be an important factor in how people manage their illness and that health and well-being depend on both of those factors (Ahlfield, Soler, & Marcus, 1985; Hamburg & Inoff, 1983; Hauser & Pollets, 1979; Jenny, 1984). However, there are few studies that provide knowledge about development, the management of illness regimens, and environmental factors in populations of chronically ill individuals. The overall purpose of this study, then, is to explore what life is like when a woman lives with chronic illness. Furthermore, factors that might influence how women manage and adapt to diabetes mellitus are explored.

Statement of the Problem

The experience of chronic illness challenges the individual's physical, social, psychological, and cultural integrity. On daily basis, individuals with chronic illness must cope with treatment regimens and symptoms of illness as they try to integrate the illness

demands into their personal, family, social, and work routines. Nurses are in a position to provide comprehensive care to people with chronic illness and to assist them and their families in the management of a complex treatment regimen. Unfortunately, there is little theoretical or empirical knowledge about the different ways people approach the management of their illness or the factors that might influence people's ability to manage their illness successfully. What is needed is information that goes beyond the diagnosis, treatment, and adherence to medical treatment aspects of chronic illness. Information on how individuals live their lives when they have a chronic illness is necessary.

Theoretical Framework

The concept of adaptation provides a theoretical orientation from which aspects of coping with chronic illness, factors that influence the management of chronic illness, and outcomes of the adjustment process can be explored. Adaptation is defined as a transactive process between the individual and her environment. The process of adaptation has cognitive, behavioral, physiological, psychological, and social components and involves the skills, capabilities, and intrapsychic processes of the individual in dealing with the challenges at hand (Mechanic, 1977). Mechanic used the term "illness behaviors" to refer to the "varying perceptions, thoughts, feelings, and acts affecting the personal and social meaning of symptoms, illness, disabilities, and their consequences" (Mechanic, 1977, p.79). The adaptive process is manifested in various illness behaviors, regulatory actions, or management patterns. The goals of adaptation

include the maintenance of the individual's integrity and functioning as well as keeping distress within manageable limits (Silver & Wortman, 1980). Moos and Tsu (1977) developed a conceptual model for understanding the crisis of physical illness that was altered slightly for this study (Figure 1). The major concepts in the model include personal characteristics, illness-related factors, social-environmental factors, illness management patterns, and adaptive states.

One important individual characteristic that may influence how women manage and adapt to chronic illness is psychosocial development (Jacobson, Rand, & Hauser, 1985). Psychosocial development is viewed as an evolutionary process that has both cognitive and emotional components and influences behavior (Erikson, 1963; Kegan, 1982; Levinson, 1986; Loevinger, 1966). Theories of psychosocial development are predicated on the assumption that differences between human beings exist and that these differences are at the very core of each individual's constitution. In other words, development is a "master trait" that influences every experience the individual has. Psychosocial development is thought to proceed in stages or levels with higher levels represented by increasing complexity of thoughts and personal maturity (Hauser, 1976). Psychosocial development, then, has the potential to help explain variations in ways women manage and adapt to the complicated treatment regimens necessary in chronic illness.

Although a number of developmental theorists consider variations dependent upon gender, the point in the life span, and situational

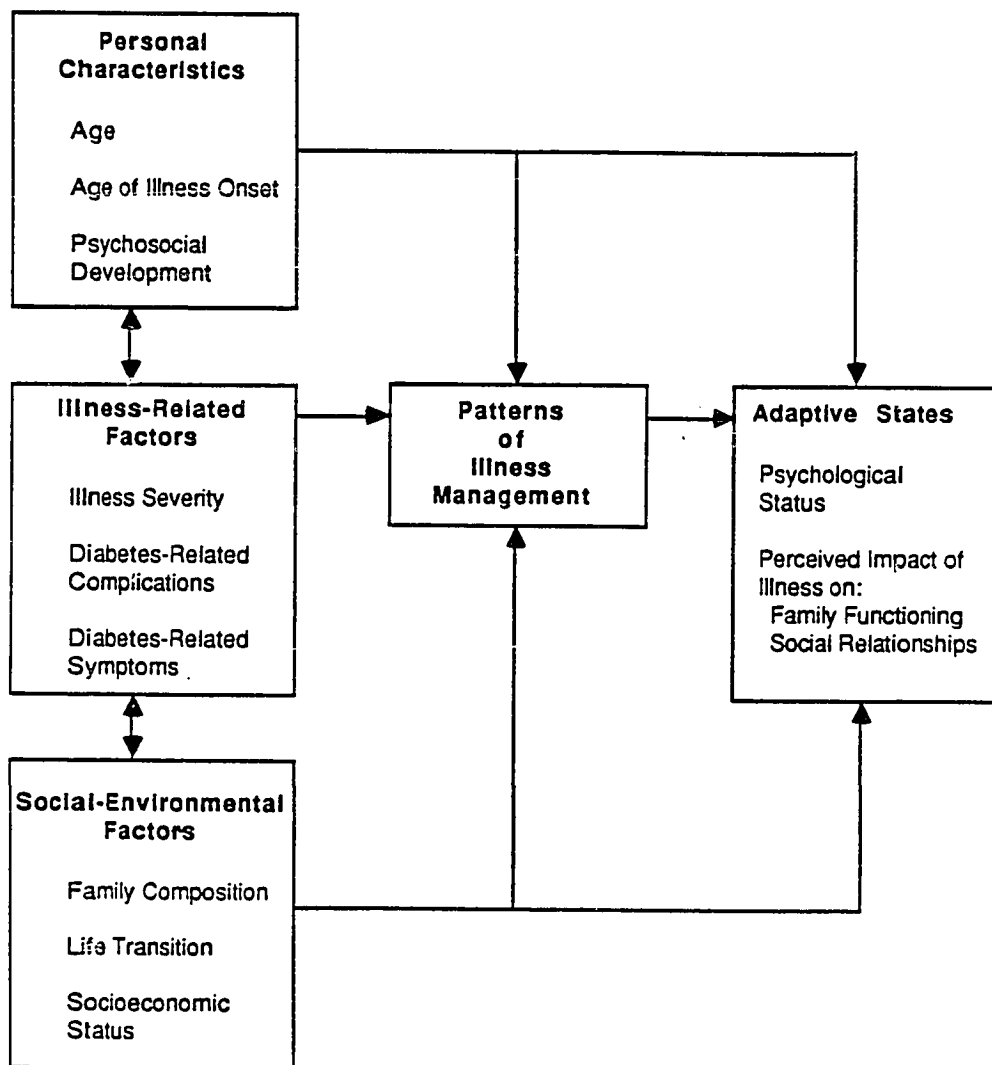


Figure 1
Factors Influencing Adaptation to Diabetes

factors, most empirical knowledge about adult development has been reported from "normal" population groups composed primarily of male, middle aged, middle class subjects (Gould, 1980; Levinson, 1980, 1986). The few scholars who have studied women suggest that women place greater emphasis on the inclusion of others rather than independence or autonomy from others (Gilligan, 1982). The notion of independence is considered to be characteristic of development in men (Gilligan, 1982). Furthermore, very little is known about psychosocial development in individuals who have chronic illnesses despite the notion that chronic illness may have a pervasive impact on individuals and those around them. There is a great need to build a knowledge base about human development in adult women, and particularly, the experiences of women with chronic illness (Dunbar, Patterson, Burton, & Stuckert, 1981; Jenny, 1984; Stevenson, 1985; Sullivan, 1978).

Diabetes is one chronic illness that may have pervasive effects on psychosocial development (Holmes, 1986). This occurs in part because diabetes requires that the person manage the illness independently, yet at the same time, rely on others for assistance. Health care providers and family members are involved in monitoring the diabetic person's mental state and occasionally have to treat the person for an emergency episode. Thus, the person who is striving to achieve independence may receive contradictory messages about his or her ability to function independently. Similarly, if a person who is relatively independent is diagnosed with diabetes, the dependence on others can be a threat to the self-concept. The experience of having

others continually monitor a woman's physical condition can be a frustrating experience for her. For example, one woman with diabetes commented that "Everyone is aware of my medical problems and they're watchful and concerned when we're out doing things. I know they're watching out for me. Sometimes I feel like I'm under glass (Family Impact Study Subject #27. Lewis, Woods & Ellison, 1986)." Thus, having diabetes can be considered a direct threat to the individual's development and maintenance of autonomy.

The notion that personality characteristics may influence adaptation to chronic illness has been explored in a number of studies (Lowery & DuCette, 1976; Pollock, 1986; Schlenk & Hart, 1984). Although these studies do not identify psychosocial development in their framework specifically, the constructs examined, such as internality or externality in relation to others, clearly are related to psychosocial development. For example, results from a study of Black women who had diabetes suggested that those with the personality characteristic of internal locus of control initially had better disease control than those who had an external locus of control. Over time, however, women with an external focus incurred fewer problems than those with an internal locus of control (Lowery & DuCette, 1976). In a similar study, Schlenck and Hart (1984) suggested that for individuals with diabetes, both an internal locus of control and one aspect of external control, the belief in powerful others, were not only compatible, but advisable. This combination could encourage those with diabetes to be responsible for their own health yet, at the same time, recognize and seek help when needed (Schlenck & Hart,

1984). In a related study, Pollock (1986) suggested that people with diabetes who had a personality variable called "hardiness" tended to have better physiological and psychological adaptation than those who did not have the characteristic. Individuals who were "hardy" demonstrated a commitment and involvement in life, a view that change was challenging, and the belief that they had influence over events and others around them (Pollock, 1986). Pollock (1986) suggested that those who made meaning of their experiences in an independent way had better disease outcomes than those who were influenced by others. Taken in combination, these studies provide strong evidence that the way people perceive the world around them may be an important determinant in how well they manage and adapt to chronic illness. Furthermore, the individual's perception of her relationship with the environment is an integral part of psychosocial development.

To date, there is very little empirical work on psychosocial development, diabetes management, and adaptational status in adults. In one exploratory study of adults with diabetes, chronological age was associated with variations in adaptation to diabetes (Jenny, 1984). Chronological age is often considered an important developmental marker. Different profiles of self-care were found among four different age groups based on a questionnaire that examined diabetes compliance and the health belief model. The young group (ages 16-24) reported a great deal of frustration related to the impact that diabetes had on their life styles. For those in the middle group (ages 25-45) family problems and special concerns contributed to the barriers in adhering to the diabetes regimens. Diabetes was viewed as

a burden due to the difficulties associated with the regimen. The older group (ages 46-65) had the highest level of health motivation, but diet and exercise presented the greatest problems. The aged group (ages 66 and older) had more health problems and functional deficits, and less social support. Jenny's (1984) work represents an attempt to explore age related differences in adaptation to chronic illness.

In another study, personality characteristics of people with diabetes and subsequent illness control were examined and the data underscore the appropriateness of using developmental theory when trying to understand illness management. In examining personality patterns of people with long term diabetes mellitus, the authors concluded that "certain personality characteristics (such as hypochondriasis) interfere with acceptance of and adaptation to the disease and the requirements for its management" (Murawski, Chazan, Balodimos, & Ryan, 1970, p. 263.). Specifically, the person who can not sort out physical body symptoms from anxiety and depression may be more apt to develop complications of diabetes (Murawski et al., 1970). Interestingly, women who demonstrated personality traits of constraint, self-centeredness, and less emotional involvement with others (traits that are less typical of women) tended to have better health than women who did not have this trait. The degree of assertiveness in regimen management by women seemed to be a key factor in adaptation to diabetes. Therefore, "being a slightly non-normal female might help in managing diabetic illness" (Murawski et al., 1970, p. 263).

These studies raise important questions about individual characteristics, such as psychosocial development and age, the management of diabetes, and adaptation to diabetes. Does the way a woman with diabetes manages her illness depend upon her level of psychosocial development, and how does her management style subsequently influence her adaptation? Developmental theory may offer a new and different perspective on the many ways in which people manage their diabetes and their subsequent health status.

Much less literature is available on the influence of environmental characteristics on women's management of and adaptation to chronic illness. The environment is defined as the social, economic, cultural, and physical world surrounding the individual. The social environment includes family composition, such as the presence of a partner and the number of children, roles, interpersonal relationships, social support, and social norms and values. There is some evidence that family factors play an important role in chronic illness management. In one study, Jenny (1984) reported that adults between the ages of 25 to 45 perceived family problems and special concerns about family members to be barriers to their diabetes control. Economic factors include income, work opportunities, and the availability and access to health care. Because diabetes is an expensive illness to treat, adequate financial resources are vital in successful management of the illness (Davidson, 1986). Social stigma about individuals with chronic illness is an important environmental influence in how people manage and adapt to chronic illness (Strauss et al., 1984). For example, job discrimination against people with

chronic illness poses a major barrier to the attainment of economic security. The belief systems of individuals make up cultural component of the environment and may play a significant role in the person adapts to chronic illness (Given, Given, Gallin, & Condon, 1983). Physical aspects of the environment include proximity to transportation. The role of environmental factors in women's abilities to manage diabetes treatment routines has been understudied. Furthermore, the influence of family, social, economic, factors on adaptation merits further exploration.

Significance for Nursing Science

The importance of integrating theories of life span development in nursing science is increasingly being recognized. For example, Stevenson (1983) suggested that adaptation to chronic illness may vary depending on psychosocial development and the point in the life span, and Kriteck (1985) has suggested that one way in which nursing diagnoses could be classified might be based on the developmental stage of the client. Theories of psychosocial development have the potential not only to expand knowledge about chronic illness, but also to provide theoretical and empirical information on the effectiveness of therapeutic interventions. Thus far, there has been little knowledge to guide nurses in designing appropriate therapeutic interventions for adults with chronic illnesses such as diabetes. One important study that points out the importance of integrating developmental constructs with therapeutic strategies suggested that differences in the personality variable of field dependence and independence could be traced to preferences in the type of health care

provider used (Karp, Winters, & Pollack, 1969). Adults with diabetes who were field dependent, or socially dependent on others, used clinics rather than private physicians for their health care. Those who had a field independent orientation used private physicians. In the clinic situations, contact with a number of people was made, whereas, in the physician offices, the range of interpersonal interactions was smaller (Karp et al., 1969). Incidentally, women tended to be more field dependent than men, a finding that is supported in the developmental literature. Thus, by knowing about a person's orientation to others, a fundamental notion in psychosocial development, it may be possible to guide people toward treatment alternatives that best meet the individual's needs.

In addition to providing empirical and theoretical knowledge on psychosocial development and diabetes that could later be used to suggest therapeutic alternatives, results may be useful to health care professionals as they try to understand how individuals with diabetes manage their illness. Nurses have been involved in developing teaching protocols for persons with diabetes for decades and have recognized an important role in providing long term, individualized support. For example, in 1965, Krysan outlined the different types of services nurses could provide diabetic patients such as assessment and counseling to "bring to light many social, economic, physical, and emotional factors which affect the learning process (Krysan, 1965, p. 105). Teaching self-care included not only information about diet, exercise, and medication, but also "how to adapt the diet to the individual culture, schedule, budget, and eating habits of the

particular family" (Krysan, 1965, p. 105). Thus, each person's diabetes regimen is an individualized routine that requires not only education, but education within the context of understanding the person's unique life experiences. There is very little empirical information to guide nurses in individualizing their therapeutic interventions for clients.

Furthermore, although health care professionals should recognize the importance of understanding the diabetic person's regimen from the perspective of the patient, in practice, they seem to lack insight into the effects that managing a diabetes regimen has on the patient's life style (Bille, 1986; Warren-Boulton, Auslander, & Gettinger, 1982; Welborn & Duncan, 1980). Investigators in two recent studies reported findings on simulations involving health care professionals who followed diabetes routines (Warren-Boulton et al., 1982; Welborn & Duncan, 1980). Health care professionals found the regimen involved numerous problems related to diet, urine testing, time constraints, loss of spontaneity, injections, and geographic problems such as placement of supplies in the household. Health care workers who participated in these simulations of diabetes routines reported increased sensitivity to and patience with diabetic clients, increased involvement in planning the patient's regimen with the client, and increased counseling with family members about the difficulties in maintaining the regimen. In other words, through the experience of simulating the diabetic experience, health care workers gained insight about what it is really like to live with the illness and practitioners subsequently utilized that knowledge in their own

practice. These results underscore the importance of utilizing a phenomenological perspective (Benner, 1985) to study the experience of illness from the diabetic person's perspective. More research is needed to assist health care providers better understand how people with diabetes manage their illness.

Results from this study contribute to the body of knowledge about individual and environmental characteristics that influence how people live with and adapt to chronic illness. The study is a first step in understanding how people manage their illness regimen within a developmental framework. This knowledge may assist nurses and other health care professionals who work with people who have diabetes in understanding individual differences in management strategies and health outcomes, and in developing therapeutic strategies appropriate to developmental status and factors in the social environment that influence illness management and adaptation.

Purpose of Study

The overall purpose of this study was to explore ways women live with, manage, and adapt to diabetes mellitus. Individual characteristics such as developmental stage, age, and age of illness onset were identified. The relationships among individual characteristics, patterns of illness management, and adjustment to illness were examined. Furthermore, the relationship of illness factors and environmental factors such as socioeconomic status and family composition were explored in relation to developmental stage, illness management patterns, and adaptation. Specific research questions focused on:

1. Describing aspects of the diabetes regimen from the women's perspective.
2. Identifying patterns of diabetes management.
3. Describing the developmental stage of women.
3. Developing demographic and adaptive profiles of women with diabetes mellitus according to the patterns of diabetes management.
4. Examining the relationships between diabetes management patterns and stages of psychosocial development.
5. Exploring the relationships between development, diabetes management patterns, illness characteristics, environmental factors, and psychosocial adaptation.
6. Exploring the degree to which the individual's psychological structure (as measured by developmental stage) incorporated an illness identity.

CHAPTER 2

REVIEW OF THE LITERATURE

Living with diabetes mellitus has important ramifications for many aspects of the person's every day life. An individual's daily routine must be tightly scheduled around insulin injections, meals, and self-monitoring of glucose levels. The focus of most diabetes research has been on the biomedical aspects of the disease or adherence to treatment regimens. Researchers have rarely asked how people manage their diabetes regimen along with the other aspects of their life although it is clear that psychosocial factors are extremely important in the management and control of the illness (Hamburg & Inoff, 1983; Surwit, Scovern, & Feinglos, 1982). In this chapter, pertinent literatures on diabetes mellitus, psychosocial development, social-environmental factors, and adaptation to diabetes are reviewed and the potential relationships among the constructs are explored.

Background Information on Diabetes Mellitus

Diabetes mellitus, a progressive chronic illness that requires ongoing treatment, is characterized by impaired metabolism of glucose. The etiology of diabetes mellitus is not clear. Scientists suggest a genetic, environmental, or infectious origin (Carter Center, 1985). Some scientists believe diabetes onset may be precipitated by severe environmental or emotional stress including loss (National Diabetes Data Group, 1985). However, the relationship between psychological factors and onset of diabetes is far from conclusive (Grant, Kyle,

Teichman, & Mendels, 1974; Hauser & Pollets, 1979; Holmes, 1986).

In diabetes, carbohydrate and lipid metabolism are greatly altered and are manifested in chronic high blood sugars that seem to cause vascular complications. The metabolic alteration of food products is caused by a deficiency in the quantity or efficiency of insulin, a hormone needed by the body to regulate glucose levels. A detailed description of diabetes is beyond the scope of this discussion. The reader is referred to other sources for further information (Davidson, 1986; National Diabetes Data Group, 1985).

According to the U.S. Department of Health Education and Welfare, there are approximately 5.8 million diagnosed diabetics in the United States and an additional four to five million undiagnosed diabetics (National Diabetes Group, 1985). Each year, approximately 500,000 people are newly diagnosed with diabetes (National Diabetes Group, 1985). Diabetes occurs in diverse groups of people of all ages and both genders.

The National Diabetes Data Group (1985) identified the major types of diabetes mellitus. The three most common types of diabetes are gestational diabetes, insulin-dependent diabetes, and non-insulin-dependent diabetes. Gestational diabetes, occurring during pregnancy, is the result of high demands on the body and accounts for about 2 to 5% of diabetes (National Diabetes Group, 1985). Type I or insulin-dependent diabetes (IDDM) accounts for 5 to 10% of diabetes. People with IDDM do not produce their own endogenous insulin or produce only minimal amounts. Treatment requires the injection of insulin at least once daily. About half of all persons with IDDM are over 20 years of

age. The third major and most common type of diabetes is Type II or non-insulin-dependent diabetes (NIDDM). NIDDM accounts for the remaining 85 to 93% of people with diabetes. People with NIDDM produce insulin. However, the insulin is not effective in lowering blood glucose. Treatment in NIDDM focuses on lowering insulin resistance by diet, weight loss, and sometimes oral hypoglycemic medications or insulin. Symptoms common to both IDDM and NIDDM are extreme thirst, frequent urination, constant hunger, weight loss, fatigue, itching, blurred vision, slow healing of infections, and pain or numbness in the extremities.

Diabetes decreases life expectancy (Holmes, 1986); moreover, it is the leading cause of disability in people over 45 years of age, the leading cause of new legal blindness for individuals under 65 years of age (Carter Center, 1985), a major cause of neurological and vascular disorders which may necessitate the loss of limbs, and a leading cause of kidney degeneration which may require dialysis (Turk & Speers, 1983). Kidney failure is 23 times more common and amputations are 16 times more common in individuals with diabetes than in the general population. Furthermore, the incidence of stroke and coronary heart disease in diabetics is higher than the general population (Carter Center, 1985).

Experts in both the clinical and research aspects of diabetes suggest that diabetes produces pervasive alterations in every aspect of the individual's life (Hamburg & Inoff, 1983; Holmes, 1986). Family relationships may be altered because of the routinization of every aspect of daily life. For example, family members are

frequently required to eat specific foods at structured times because of the diabetic person's need for food "on schedule." Also, family members and others in the social environment must live with the mood changes caused by fluctuations in glucose levels (Anderson & Auslander, 1980; Kornblum & Anderson, 1985; O'Brien, 1979; Piening, 1984). Finally, the family often must act as part of the person's management team and provide assistance with medications and diet (Benoliel, 1970). Persons with diabetes may be concerned about their ability to maintain role expectations at home or at work. Access to employment, economic opportunities, and health insurance are valid concerns for people with diabetes (Entmacher, 1983). Diabetes also creates cognitive and psychological challenges for the individual. Because diabetes may be hereditary, there may be guilt feelings about passing the disease on to offspring (Ahlfield et al., 1985; Kornblum & Anderson, 1985). In addition, there are many reports showing that having diabetes is associated with psychological symptoms (Murawski et al., 1979; Sanders, Mills, Martin, & Horne, 1975).

Diabetes is a chronic illness that profoundly alters physiological functioning as well as the quality of the person's life. The goal of health care providers is to maintain a stable clinical course and avoid complications. Health care providers recognize that the course of the illness is influenced by the interaction between physiological and psychological factors and that effective control of diabetes depends primarily on the individual's day-to-day management of the illness (Bruhn, 1977; Given, Given, Gallin, & Conlin, 1983). However, very little is known about the management of diabetes

regimens and symptoms. Research in this area is greatly needed to develop effective therapeutic modalities for people who have diabetes.

The Management of Diabetes Mellitus

People with diabetes must learn to regulate their lives on a daily basis according to the physical symptoms of the illness and the treatments required. A great deal of responsibility is placed upon the individual and those around her in order to maintain the complex regimen that diabetes mandates. Diabetes may, in fact, be more complex than other illnesses. For example, recent data from the Family Impact Study suggests that women with diabetes had more demands related to treatment regimens and the evaluations of their treatment than two other chronic illness groups (breast cancer and fibrocystic breast disease (Lewis et al., 1986)).

The self-care regimen for persons with diabetes includes diet planning, timing and spacing of meals, self-monitoring of blood and urine glucose, insulin injections, skin care, and exercise (Turk & Speers, 1983). A brief description of a daily routine for a person with diabetes may help to illustrate the complexity of living with this particular chronic illness. Immediately upon awakening, a fasting blood test is completed by pricking a finger tip with a sharp lancet, placing a small drop of blood on a chemically treated plastic strip, and then "reading" the color on the strip according to a chart. Today, many people use electronic monitors that automatically "read" and record the glucose level. Prior to home self-monitoring of blood, a "double void" urine specimen was obtained by emptying the bladder, waiting thirty minutes and then voiding again in order to obtain an

accurate test specimen for urine glucose and ketones. About a half-hour before eating, an insulin injection, with the dose adjusted according to the test results, must be given. The insulin is drawn into the syringe accurately and then injected into the body in a different place every day. Materials used must be disposed of safely. Many health care providers advise patients to test their blood glucose before each meal, at bedtime, and even at 3 a.m. in the morning in order to avoid night reactions! Some people with diabetes require more than one injection daily to maintain adequate glucose control and a sliding scale of insulin to cover their glucose levels during the day. People with diabetes are encouraged to keep records of blood and urine tests and insulin doses to show their health care providers. Also, a record of injection sites is often kept so that rotation of the sites does not depend on memory alone (Surwit et al., 1982).

Regular meal patterns are necessary with diabetes in order to avoid hypoglycemia or hyperglycemia. Usually, the person must eat three meals a day and snacks at regular intervals, avoid foods with sugars, and use a complex system of dietary exchanges if deviating at all from the recommended fat, protein, and carbohydrate allotments. People with diabetes should carry identification stating they have diabetes. It is important to carry supplies such as food, testing equipment, insulin, and equipment for an injection in case a reaction should occur. If the person is planning on strenuous exercise, a reduction of the daily insulin dose or extra food intake is necessary to avoid hypoglycemia. In addition to these regimens, people with diabetes must inspect their feet daily for pressure areas or early

signs of infection, purchase and store supplies, and manage the necessary equipment. Persons with diabetes must carry out this complex regimen of monitoring glucose levels, insulin injections, and regulated food intake in concert with the other aspects of their lives.

Not only is the regimen for diabetes complex but changes in the regimen are quite common. For example, in the Family Impact Study, over half the women with diabetes reported changes in medication regimens in the 4 months prior to data collection (Lewis et al., 1986). Changes in diet and treatments were reported by 29% of the sample during the same previous four months. Visits to the physician or health care provider were made by 73% of the women, and 43% stated they had experienced new medical problems. Hospitalizations occurred in 18% of the women (Lewis et al., 1986). Thus, the individual who lives with diabetes not only must maintain a strict schedule and complex regimen but also must learn to live with frequent alterations in that regimen.

Research scientists have reported an appalling low level of adherence to the diabetes regimens prescribed by health care providers (Glasgow, Wilson, & McCaul, 1985; Raymond, 1984; Schlenk & Hart, 1984; Surwit et al., 1982). Because of the complexity of the regimen, this is not surprising. Adherence to regimens is assumed to be necessary for successful diabetes control, the avoidance of hypoglycemia or hyperglycemia, and the prevention of long-term degenerative changes and complications. However, conclusive evidence has yet to be reported between glycemetic control and the development of

complications. The literature on adherence or compliance to prescribed regimens is plagued with problems (Glasgow et al., 1985). First, it is very difficult to compare a person's behavior with medical advice when the prescriptions given are often vaguely stated. The prescription to "exercise" is an excellent example of a prescribed treatment that is rarely defined specifically for the person. The person with diabetes may be told that exercise is one aspect of good diabetes management. However, the person may not be told how to adjust the insulin dose to accommodate the increased activity. Secondly, diabetes requires that the individual "self-manage" on a continual basis without the direct assistance of a health care provider. For example, though a specific calorie diet may be suggested, the person must make daily choices about specific foods to be eaten. Finally, compliance is difficult to evaluate and compare among individuals with diabetes because of tremendous variation in individual routines. Thus, adherence, as currently used, is not particularly useful for understanding how the people manage diabetes.

As stated, diabetes is a chronic illness that requires constant vigilance on the part of the person. Individuals with diabetes are encouraged to become "professional diabetics" by their health care providers as well as by the American Diabetes Association (Davidson, 1985). They must learn to monitor their glucose levels numerous times a day, evaluate their mental state for hypoglycemic symptoms, eat a special diet at regular times, inject themselves with insulin at least once a day, exercise regularly, and examine and care for their skin and feet. This intensive self-monitoring regimen must occur within

the context of the person's every day life. Thus, the individual with diabetes must organize and independently monitor every aspect of her physical self together with her every day responsibilities of family and work life in order to survive.

In conclusion, very little is known about the different ways people with diabetes go about managing their diabetes on a day-to-day basis. Furthermore, factors that may influence illness management and coping in adults with diabetes are not well understood. There is evidence in the literature that individual characteristics may be important in illness management and subsequent diabetes control. Nerenz and Leventhal (1983) have suggested that individual characteristics may influence a person's self-management of illness. They suggested that an individual with a well-differentiated self-system who is able to deal with everyday life experiences may be more capable in limiting the impact of the illness to specific areas in their lives than the person with a less differentiated self-system (Nerenz & Leventhal, 1983). The notion that adults have different characteristics through out the life span is a common assumption among developmental theorists. Thus, developmental theories may be one potentially useful way to explore individual differences in the management of diabetes.

Psychosocial Development

One particularly useful conceptualization of individual differences that may help to explain how people manage illness situations uniquely is that of psychosocial development. Psychosocial development is viewed as an inherent biological, psychological, and

social process that is influenced by the person's interaction with the environment (Kegan, 1982). The process of development occurs over time and proceeds according to an orderly pattern. A number of factors such as chronological age, birth cohort, and the occurrence of life events are believed to influence the individual's developmental process. In this study, the psychosocial processes of human development are of particular interest in examining individual variations in the management of illness.

Although many theories of psychosocial development have been explicated, some are more useful than others in examining how adults cope with chronic illness. For example, scientists and scholars have only recently begun to explore development throughout the adult life span (Bee & Mitchell, 1984; Erikson, 1963; Levinson, 1980; Loevinger, 1966). Most of the theoretical formulations on adult development in the literature include sequential stages and developmental tasks, but they vary on the number of stages and types of processes involved. For example, Erikson (1963) emphasized the social tasks that the individual is involved in throughout the life span. Levinson (1980, 1986) emphasized the life structures or tasks and the transitions that occur for men during the adult years. The development of the "ego," or the master trait, is the focus of Loevinger's (1966) theory and covers the entire life span also. The constructive-developmental model of human development (Kegan, 1982) integrates cognitive-developmental theory with the changes that people experience in the interpersonal or environmental context as they evolve through life. In the next section, selected theories are reviewed and the potential

relationships between the theories and chronic illness management are explored.

Erikson's Eight Stages of Man

Erikson (1963), one of the early theorists to propose a life-span developmental model, recognized adulthood as a period of continual change rather than a static period. Erickson's writings were influenced by his training with Anna Freud and his extensive clinical work as a psychotherapist with men, women, and children. Each of Erikson's eight psychosocial stages is characterized by a unique set of social tasks related to the individual's self development. In his theory, Erikson viewed the stages as sequential and hierarchical. Failure to successfully resolve the tasks at one stage would preclude development in the successive stage. Furthermore, he identified an alternative to each stage that would occur if the person does not successfully complete the tasks relevant to that stage.

The stages most relevant to middle adulthood include Stages V (Identity vs. Role Confusion), VI (Intimacy vs. Isolation) and VII (Generativity vs. Stagnation). Identity formation occurs primarily during late adolescence and involves both sex-role identity and career or occupational identity. If the person is not successful in developing a sense of role identity, a state of role confusion occurs.

In early adulthood, the task of establishing intimacy is undertaken. Intimacy includes "the capacity to commit... to concrete affiliations and partnerships and to develop the ethical strength to abide by such commitments" (Erikson, 1963, p. 263). This stage involves the "ability to regulate cycles of work, procreation, and

recreation and the creation of a family environment conducive to the development of offspring" (Erikson, 1963, p. 266). The person who is not successful in achieving intimacy experiences isolation primarily in the social arena.

Erikson's seventh stage of generativity involves the creation and guidance of children, products or ideas. This is a stage of social productivity in which the person focuses on bringing up a family and contributing to society. Those who fail to use their creative efforts in making society a better place face stagnation or the inability to influence future generations through their efforts.

Erikson's theory has been used by numerous theorists to explore the impact that chronic illness may have at different points in the life span (Eisenberg, Sutkin, & Jansen, 1984; Hauser & Pollets, 1979; Sullivan, 1978). For example, during the identity formation stage, chronic illness may severely limit a person's ability to choose a career. Developing a self-concept as a functioning adult may be hampered. Chronic illness may be an important factor in limiting the individual's ability to form intimate relationships and a sense of isolation may result. In the generativity stage of adulthood, physical limitations of chronic illness may limit the person's ability to contribute to family and community life. Furthermore, if chronic illness has been a factor in limiting the life experiences of a person, it is possible that the person's self-conception will be limited to that of a "sick person" (Eisenberg et al., 1984).

Erikson's theory of man's stages (1963) is especially useful as a way to examine the individual's point in the life cycle. The theory

helps to explicate the specific tasks that the person is involved with, such as building a career or raising a family. Erickson's theory, then, provides one way to study individual differences in adaptation to chronic illness.

Loevinger's Theory of Ego Development

Loevinger (1966, 1979), another scientist interested in individual differences and life span development, developed a theory of ego development that has been empirically tested. Loevinger described ego development as a master trait that is conceptually distinct from physical, psychosexual, and intellectual development. The ego provides an overall frame of reference and takes into account the integrative processes of the person. She equates ego with the self, unity of personality, individuality, opinion about self, and the whole attitude toward life. She strongly stated that ego IS the search for meaning, and not just something that the ego does. Thus, "at the most general level we can describe Loevinger's concept of ego development as referring to the framework of meaning which one subjectively imposes on experience" (Hauser, 1976, p. 930).

The course of ego development is marked by potent sources of conflict such as fear of retaliation, fear of punishment, and shame or guilt. Therefore, at every stage, different conflicts appear, and at the highest stage, the conflict is embraced. Loevinger described "milestones" of ego development including stages and transitional phases. Each higher stage is more complex than the last and none of the stages can be skipped. Table 1 shows the stages, interpersonal style, conscious preoccupations, and cognitive style associated with

Table 1

Loevinger's Milestones of Ego Development^a

Stage	Impulse Control "Moral" Style	Interpersonal Style	Conscious Preoccupations	Cognitive Style
Preconformist Presocial (I-1)	...	Autistic	Self vs. nonself	...
Symbiotic (I-1)	...	Symbiotic	Self vs. nonself	...
Impulsive (I-2)	Impulsive, fear	Receiving dependent, exploitive	Bodily feelings, especially sexual and aggressive	Stereotypy, conceptual confusion
Self-protective Delta	Fear of being caught, externalizing blame, opportunistic	Wary, manipulative, exploitive	Self-protection, wishes, things, advantages, control	...
Transition from self-protective to conformist (Delta /3)	Obedience and conformity to social norms are simple and absolute rules	Manipulative, obedient	Concrete aspects of traditional sex roles, physical causation as opposed to psycho- logical causation	Conceptual simplicity, stereotypes
Conformist (I-3)	Conformity to external rules, shame, guilt for breaking rules	Belonging, helping, superficial niceness	Appearance, social acceptability, banal feelings, behavior	Conceptual simplicity, stereotypes, cliches
Transition from conformist to conscientious; self- consciousness (I-3/4)	Dawning realization of standards, contingencies, self-criticism	Being helpful, deepened interest in interpersonal relations	Consciousness of the self as separate from the group, recognition of psychological causation	Awareness of indi- vidual differences in attitudes, in- terests and abili- ties; mentioned in global and broad terms

(table continues)

Table 1 continued

Stage	Impulse Control "Moral" Style	Interpersonal Style	Conscious Preoccupations	Cognitive Style
Postconformist Conscientious (I-4)	Self-evaluated standards, self-criticism	Intensive, responsible, mutual concern for communication	Differentiated feelings, motives for behavior, self-respect, achievements, traits, expression	Conceptual complexity, idea of patterning
Transition from conscientious to autonomous (I-4/5)	Individuality, coping with inner conflict	Cherishing of interpersonal relations	Communicating, expressing ideas and feelings, process and change	Tolerance for paradox and contradiction
Autonomous (I-5)	Add ^b : Coping with conflicting inner needs	Add: Respect for autonomy	Vividly conveyed feelings, integration of physiological and psychological causation of behavior, definition, role conception, self-fulfillment, self in social context	Increased conceptual complexity; complex patterns, toleration for ambiguity, broad scope, objectivity
Integrated (I-6)	Add: Reconciling inner conflicts, renunciation of unattainable	Add: Cherishing of individuality	Add: Identity	

^aFrom Hauser, S. (1976)

^b"Add" means in addition to the description applying to the previous level

each stage (Hauser, 1976). Hauser integrated empirical findings into the table showing Loevinger's theory.

The first stage (I-1) is made up of two phases. In the Presocial stage, the infant is unaware of all but immediate needs of gratification. Aspects of the environment are not distinguished. In the Symbiotic stage, the mother is distinguished from the rest of the environment as a strong attachment figure.

In the second stage (I-2), the Impulsive stage, the gratification of physical needs and impulses is the driving force of the individual. The third stage, Self-protective (Delta), is one in which the person becomes increasingly self-sufficient. The individual recognizes that there are rules. However, those rules are only followed to the extent that they are in the person's self-interest. Hauser (1976), based on his examination of empirical work on Loevinger's theory, identified a transitional stage between the Self-protective stage and the next stage, the Conformist stage. In this transitional stage the person is both obedient and responsive to social norms, yet manipulative.

The Conformist stage (I-3) is the fourth stage. The need for approval from others drives the person to obey rules simply because they are rules. The next phase is actually a transitional phase (I-3/4) in which the emergence of introspective capacities and self-awareness is present. The person begins to recognize that the context of a given situation may provide important clues on the "right way" to handle a situation (Hauser, 1976). This phase was developed from empirical evidence.

The fifth stage, the Conscientious stage (I-4), is characterized by the person generating his or her own set of rules rather than accepting those of peers or authority. The capacity for self-criticism is present at this level. A third transitional phase (I-4/5) has been identified between the Conscientious stage and the Autonomous stage. During this transition, the person is able to tolerate paradoxical relationships and interpersonal transactions are viewed in greater complexity.

In the sixth stage, the Autonomous stage (I-5), the person is better able to face directly and cope with inner conflict. The ability to tolerate the solutions of others is present this stage. Mutual interdependence is characteristic of interpersonal relationships. The final stage, the Integrated stage (I-6), is characterized by the cherishing of individual differences rather than just tolerance of them and the reconciliation of conflicting demands rather than just coping with them. This stage is primarily a theoretical one since only about 1% of all people would fall into this stage (Loevinger & Wessler, 1970).

Loevinger's model of ego development provides theoretical explanations for the notion of cognitive consistency or resistance to change as well as developmental transitions. The individual tries to maintain a stable and consistent view of the self by ignoring discordant observations of the self. However, if new and challenging information is not filtered out and the person fails to maintain a meaningful and coherent integration of the self, the self-conception is questioned and anxiety may be generated. Because the search for

coherent meaning in experiences is the essence of the ego, the anxiety produced by discordant observations may provide the impetus for change and growth in an attempt to resolve the anxiety. It is precisely this experience of anxiety that is the hallmark of developmental transitions.

Loevinger's theory has been empirically tested and revised over the past 2 decades (Hauser, 1976). Although the original empirical measure was designed for girls and young women, men and women of all ages have been studied. Evidence for the sequential nature of the stages has been reported through both cross-sectional and longitudinal studies. For example, stage progression with increasing age during childhood and adolescence in a cross-sectional sample of 191 boys and girls ages 9-18 years was reported (Loevinger & Wessler, 1979). A similar progression of ego development stage in a sample of 107 boys grades 8-11 was reported (Loevinger & Wessler, 1979). In six of eight longitudinal studies, a statistically significant mean rise in ego level was reported according to Loevinger (1979). Also, studies which used theory relevant interventions have provided support for the stages. Loevinger reviewed a number of studies that involved the use of experimental interventions. A significant rise in ego development occurred in groups receiving the experimental intervention as compared with control groups (Loevinger, 1979).

Additional evidence for the presence and sequentiality of stages has been demonstrated in the greater use of adjacent stages as compared with non-adjacent stages (Loevinger & Wessler, 1970). Furthermore, the notion of asymmetry of comprehension or the ability

to understand the thinking of lower ego levels but not of higher ego levels provides support for Loevinger's theory. Redmore and Waldman (1975) provided evidence for this phenomenon in a study of 146 college and graduate students.

Finally, external validity of Loevinger's theory has been demonstrated through correlational studies with other developmental conceptions (Loevinger, 1979). Specifically, significant relationships between Loevinger's Sentence Completion Test and ego identity status using Erikson's theory of development were reported (Loevinger, 1979). Kohlberg's theory of moral development has also been compared to Loevinger's ego development theory with moderate correlations. Loevinger (1979) summarized that moral and ego development are related but are not the same constructs.

Loevinger's theory has been used with two samples of diabetic adolescents (Hauser, Jacobson, Noam, & Powers, 1983; Hauser, Pollets, Turner, Jacobson, Powers, & Noam, 1979). The researchers reported a lower level of ego development for adolescents with diabetes as compared with normal groups and a higher level of ego development for girls with diabetes when compared with diabetic boys. What is not known, however, is whether ego development was temporarily interrupted by diabetes or if there is an arrest in ego development. The authors are currently involved in longitudinal research to examine this important question. Jacobson, Rand, and Hauser (1985) studied adults with diabetes. In a sample of adults with diabetes, the most common stage of ego development was the transition between the Conformist and Conscientious stages (I-3/4). Ego development was not related to

diabetes control, life events, or symptoms (Jacobson et al., 1985).

In summary, Loevinger's theory of ego development is based on the notion that ego development occurs throughout the life span and involves increasingly complex thought processes. The theory has been widely tested and is supported through the empirical validation. Although many studies have used Loevinger's theory, the studies have focused primarily on children and young adults. There is much to gain through studying ego development in adults with chronic illness.

Kegan's Constructive-Developmental Model of Human Development

One of the most recent theoretical conceptions of life span development was developed by Kegan (1982). Kegan's model builds partly on the work of Piaget, a cognitive-developmental, and Loevinger (1966). The basic premises of the model are:

1. Personality development occurs in the context of interactions between the person and the environment;
2. People construct their own reality (constructivism), and the activity of being a person is an activity of meaning making; and
3. People evolve through stages or eras according to principles of stability and change (development).

In the constructive-developmental model, Kegan views development as an increasingly complex and continual process of integration and differentiation from the social environment. Each stage of development is characterized by a qualitatively different way of making meaning about the person's world. This model is particularly useful in determining the meaning ascribed to life situations and may illuminate the meaning ascribed to the illness experience.

The individual develops according to a process in which the relationship to objects or persons in the environment is continually evaluated. The process involves a shift in how a person defines himself or herself in relation to the environment. The self develops, then, as the individual engages in embedding or integrating himself or herself in the environment and subsequently separating or differentiating from it. In the constructive-developmental theory, Kegan (1982) uses the term "culture of embeddedness" as a way to describe the context in which interactions between the person and the outside world or environment occur. The "culture of embeddedness" is not absolute and varies according to the stage because it is based on the person's own internal construction of the environment. Regardless of the stage, however, the culture of embeddedness has three basic functions. First, the culture of embeddedness provides a sense of confirmation or support for the person's present stage of development. Confirmation serves to hold the individual in the present balance. Another function is that of contradiction or questioning of the current meaning-making systems which help promote the individual's emergence from the current stage to the next stage. Contradiction facilitates the person to "let go" of thought patterns and actions of the "old stage." Third, the culture of embeddedness functions to provide continuity through the period of transformation so that parts of the "old" self can be successfully reintegrated as an object in the new self. Thus, the person experiences continued support while changes are integrated in the evolution to the next stage (Kegan, 1982).

According to Kegan, the individual follows a path of development which include stages or balances. Within each balance, the individual's self-definition and the way of relating to the environment differs depending on the way the self is viewed in relation to people or objects (Kegan, 1982).

Similar to Loevinger's theory (1966), the constructive-developmental model is based on an assumption that as individuals go through developmental transitions, they may experience anxiety and depression which are associated with the loss of the "old" self. Frequently, anxiety occurs because of the separation from the old cognitive organization. During the transitional periods, there is great deal of contradiction. These transitional periods are considered to be somewhat disorganized compared to the more organized stages in which the person is primarily confirmed.

The six stages or balances described by Kegan (1982) are listed in Figure 2. A brief description of the stages is provided.

Stage 0, the Incorporative Balance (ages 0-2), is characterized by the lack of a sense of self and no separation of self from the environment. The infant is thought to be undifferentiated from the environment at this stage. The infant acts only on a reflexive level and is only reflexes and movements. The progression to the next stage is marked by the presence of object permanency and frequently is manifested in viewing the mother as an object in the environment.

In Stage 1, the Impulsive Balance (ages 2-5), the self is separate from the reflexes, movements, and sensations that characterized Stage 0. Now, the person is embedded or subject to his

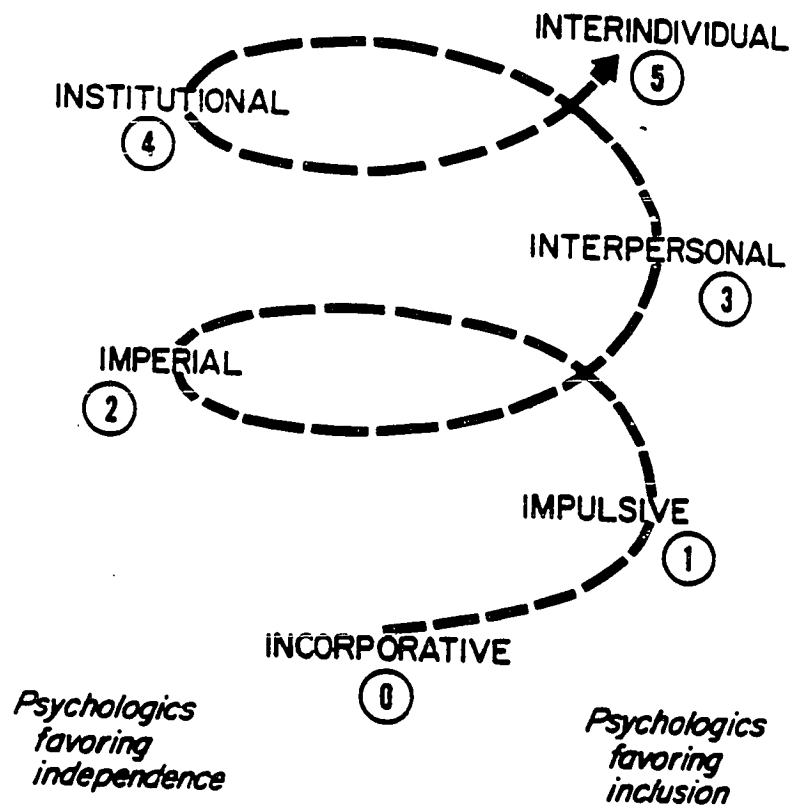


Figure 2

The Constitutions of the Self
from The Evolving Self, Kegan, R.

or her own impulses and perceptions that coordinate reflexes and movements. The infant can not separate the self from perceptions, but, rather is his or her impulses and perceptions. The progression to the next stage occurs when the child begins to realize that others are not regulated by his or her own desires. The capacity to take impulses and perceptions as object rather than be those impulses is characteristic of the next stage.

In Stage 2, the Imperial Balance (ages 7-12), needs, interests, and wishes form the structure in which the self is embedded. The child now realizes that he or she has the capacity and the power to take command of his or her own impulses and make things happen. Other people are considered to be "that by which I either do, or do not, meet my needs, fulfill my wishes, pursue my interest" (Kegan, 1982, p. 91). The needs, wants, or desires of others are not understood by the Stage 2 individual.

Stage 3, the Interpersonal Balance, occurs usually in adolescence. However, no discreet ages are offered by Kegan (1982). In this stage, interpersonal and reciprocal one-to-one relationships become the culture of embeddedness. The person can take as object his or her own needs, interests, and desires and is able to coordinate those needs with other's needs. The person is organized around the expectations of others, nurturance of others, and affiliation with others. The person becomes his or her reciprocal relationships; self-definition is based on relationships with others. Kegan differentiates the interpersonal balance from intimacy: Rather than sharing the self with another, the other is required in order to bring

the self into being. In this stage, the person is limited by his or her inability to recognize the influences of interpersonal relationships and is therefore controlled by them.

Stage 4, the Institutional Balance, occurs in the adult years and is characterized by the individual being an institution that coordinates its own need fulfillment. The self is constructed as a system that coordinates work, relationships, and activities and is therefore, in authority over the self. The main goal becomes the maintenance of integrity. Rather than "being my relationships" as in Stage 3, the person "has relationships" in Stage 4.

Stage 5, The Interindividual Balance, occurs in the adult years also. In this balance, the self is capable of coordinating its own self-system as well as the institutional lives of others. The person is aware of the way choices affect others and is respectful of the choices of others. The person is able to embrace and experience his or her own conflict as well as accept the conflict others experience. The person at the interindividual stage recognizes the fragile interdependence with others. According to Kegan, this stage brings together the worlds of work and love. "If one no longer is one's institutions, neither is one any longer the duties, performances, work roles, or career which institutionality gives rise to. One has a career, one no longer is a career" (Kegan, 1982, p. 105).

Kegan's constructive-developmental theory of human development has been tested empirically and validation for the stages has been demonstrated in a number of doctoral dissertations (Lahey, Souvaine, Kegan, Goodman, & Felix, 1988). Goodman (1983) studied psychosocial

development and communication in family triads (father, mother, and pre adolescent son) in a clinic and nonclinic sample. His research demonstrated the viability of using the constructive-developmental model as a model of individual variability. However, he did not find developmental differences between the clinic and nonclinic groups.

The stages of Kegan's constructive-developmental model have similarities with Loevinger's levels of ego development. Table 2 shows the common stages between both models. The major difference between the theories are Kegan's elaboration of the cultures of embeddedness and the number of potential stages in Kegan's model. Although early theoretical work formed the basis for the six stages in Kegan's model, the empirical testing of the model has led to the identification of transitional periods between the stages. Kegan (1986) now suggests that there are 21 empirical "stages" in the theory including the transitional phases. It is possible that Kegan's theory will be revised based on empirical evidence.

Women's Development

As stated, there is very little empirical work on women's psychosocial development. One notable exception is Gilligan's (1982) work on moral development in women. This is similar in some ways to Kegan's theory of psychosocial development. Interestingly, both of these theories were developed at Harvard's Graduate School of Education. The work by Gilligan (1982) on moral development in women challenged Kohlberg's theory on moral development by explicating the differences between men and women. According to Gilligan (1982), men and women are socialized differently and this difference in

Table 2

Comparison between Stages in Kegan's Theory of Psychosocial
Development and Loevinger's Theory of Ego Development

Kegan	Loevinger
Stage 0 Incorporative Stage	I-1 Pre-social Stage
Lack of a sense of self No separation of self from the environment	Environment is not distinguished Unaware of all but immediate needs
Stage 1 Impulsive Stage	I-2 Impulsive Stage
Self is separate from reflexes but embedded in own impulses	Gratification of physical needs and impulses drives person
Stage 2 Imperial Stage	Delta Self-protective stage Opportunistic
Self is embedded in needs, interests, wishes	Initiation of self-control
Stage 3 Interpersonal Stage	I-3 Conformist Stage
The person is embedded in mutual relationship	Identification with a group
Stage 4 Institutional Stage	I-4 Conscientious Stage
The self coordinates its own self-fulfillment	Increased sense of personal responsibility
Stage 5 Interindividual Stage	I-5 Autonomous Stage
Recognizes the fragile interdependence with other	Mutual interdependence and ability to cope with inner conflict
	I-6/Integrated Stage Cherishing individual differences and reconciling conflicting demands

socialization accounts for men focusing more on separation and individuation from others and rights. Women focus more on connection to others, empathy, and responsibility. To men, dependence means the lack of autonomy, but to women independence means the lack of connection to others. Interdependence to men means reciprocity, while to women it means connection. This work is especially important in relation to the constructive-developmental model of human development (Kegan, 1982) in that Kegan has integrated both "voices" into the theory. The different "voices" of women and men, according to Kegan, may be the different evolutionary stages represented by the interpersonal and institutional balance. Thus, although Gilligan's important differences between the sexes, it fails to present a universal perspective from which one can view development.

There are other developmental theorists who have focused on differences in the sexes. For example, Giele (1983) suggests that as women get older, they may become more independent and autonomous. This observation suggests a developmental transition from a more interpersonal stage to an institutional stage in Kegan's terms.

What is known about adult development has been reported primarily from "normal" population groups (Gould, 1980; Levinson, 1980, 1986; Loevinger, 1979). Currently, there are no developmental theories about individuals with chronic illness. Theories of development may provide clues in understanding the individual variations in the management of chronic illness. For example, the person's current life stage (Erikson, 1963) may help to illustrate differences between young mothers with child care responsibilities and women who no longer have

children in the home. Furthermore, theories of psychosocial development based on cognitive evolution, such as the constructive-developmental model, may help explain differences in how individuals manage chronic illness.

Social and Environmental Factors in Chronic Illness

The influence of environmental factors on illness management and adaptive responses is an understudied area. Environments are defined as complex systems surrounding the individual and include physical, social, economic, and cultural elements. Environments may support or not support health depending on the balance and interaction of the elements. There is some evidence that family factors play an important role in the day-to-day management of diabetes (Benoliel, 1970; Glasgow & Toobert, 1988; Jenny, 1984; Strauss et al., 1984). Family responsibilities may be perceived as a barrier in the adherence to diabetes treatment (Jenny, 1984). Alternately, if a person with diabetes lives alone and has no one to assist with the day-to-day management of the illness or in an emergency situation, it is possible that adaptive states might be compromised. Benoliel (1970) described different styles of parenting in families with diabetic children. Furthermore, these styles were linked to the child's health. Supportive and nonsupportive interactions with family members around diabetes regimens were examined by Glasgow and Toobert (1988) in a sample of 127 adults with NIDDM. Support from family members for diabetes routines predicted adherence to the regimen in Glasgow and Toobert's work.

Sociocultural factors in the environment seem to play an important role in how individuals manage and adapt to chronic illness (Dimond, 1983; Ragucci, 1979; Strauss et al., 1984). Cultural beliefs and values are determinants of health seeking behaviors. Social stigma about chronic illness and diabetes in particular may influence how an individual interacts with others in social settings. Social roles may be altered because of chronic illness.

Ragucci (1979) addressed concerns employers may have when members of their work force have diabetes. Employers who fear insulin reactions on the job, excess absenteeism, poor job performance, and adverse effects on group medical insurance rates may discriminate against people with diabetes and limit job opportunities. Without adequate income and access to medical care, the management of chronic illness is greatly compromised.

Adaptation

Adaptation on the part of the person to chronic illness may be thought of as either a process or a response (Scott, Oberst, & Dropkin, 1980; Mechanic, 1977). The process of adaptation is a transactive one between the individual and the environment. It is multidimensional and includes cognitive, psychological, social, and physical components. Adaptation may be considered a response to the internal and external environment also. Again, the individual is thought to respond to situations or events physiologically, psychologically, and socially. Physiological responses include biological functioning. Psychological responses include mood alterations. Social responses involve perceptions of interactions

with others. Adaptation as described in this study reflects a holistic nursing perspective. The concepts of adaptation and environments are delicately interrelated and the discussion of one of the concepts includes elements of the other. The construct of adaptation and its relation to chronic illness, environments, and psychosocial development are explored in the next section.

Although adaptation is a multidimensional construct, physical, psychological, and social dimensions are at least somewhat related (Breslow, 1972; Ware, 1986). For persons with chronic illness, and diabetes in particular, the relationship between physical and psychological aspects of health is slightly stronger than for either the general population (Ware, 1986) or other chronic illness groups (Pollock, 1986). For example, Mazze, Lucido, and Shamoon (1984) found a significant association between good metabolic control in diabetes and the absence of psychological symptomatology. They also found the converse to be true: Poor metabolic control was associated with depression, anxiety, and a lower quality of life. It is not surprising, then, that individuals with severe diabetes and complications of diabetes reported more depression than those with less severe disease (Murawski et al., 1970). One explanation for poorer disease control might be that psychological disorders such as anxiety and depression may negatively affect compliance with the treatment regimen (Hauser & Pollets, 1979; Holmes, 1986). The interrelationships among the various dimensions of health underscore the importance of examining adaptive responses from a multidimensional framework.

Psychological Adaptation

Chronic illnesses, and diabetes in particular, are considered to affect psychological well-being. Psychological adaptation is defined broadly as the absence of anxiety and depression. Depression, a common problem associated with many chronic illnesses as well as many other life problems, is well defined in the literature. Depression is considered to be a mood or affective state primarily but it may also have behavioral and somatic manifestations. In this study, depression is defined as: (a) an alteration in mood characterized by sadness, loneliness, apathy, feelings of worthlessness, self-blame and recurrent thoughts of death; and (b) physical alterations such as poor appetite, insomnia or hypersomnia, loss of libido, and fatigue (Beck, 1967; Radloff, 1977; Zung, 1974).

The importance of examining depression as a marker of adaptation to chronic illness cannot be underestimated. Research literature on diabetes suggests that the illness may be associated with high amounts of depressive symptomatology (Murawski et al., 1970; Sanders, et al., 1975; Sullivan, 1978). The literature on depression also contains evidence that women are differentially vulnerable to depressive symptoms (Weissman & Klerman, 1977). Although emotional difficulties frequently accompany all chronic illnesses, there is some evidence that those with diabetes experience even more symptomatology than other groups. For example, in the Family Impact Study, women with diabetes reported significantly higher emotional disturbances and depression than the other illness groups (Lewis et al., 1986). Also, in a comparison study of "normal" adolescent girls and those who had

diabetes, the physiological manifestations of depression such as fatigue, appetite and bodily preoccupation were significantly higher for the girls with diabetes (Sullivan, 1978). Sullivan suggested that depression associated with diabetes could be marked by a heightened awareness of bodily sensations and physical status. However, in a study of adults with Type I diabetes, the source of depression was most often related to the fears related to the future, complications, disability, and hypoglycemia (Sanders et al., 1975).

The notion of loss is common to most theories of depression. Loss associated with a person's health (as in chronic illness) as well as loss related to developmental change are considered to be important in this study. Developmental expressions of despair, specifically depression and anxiety, are associated with developmental transitions (Kegan, Noam, & Rogers, 1982). When the organization of the individual's meaning making system is challenged, such as in developmental transition, an uneasy feeling often results. The prospect of change, furthermore, generates thoughts of loss of the present self and the integrity of the person's sense of coherence. By examining the different stages of development, it is possible to suggest what may cause the tension for the individual, and what the individual is threatened with losing. For example, Kegan and others suggested that anxiety in Stage 3-4 may result from feeling the loss of self as a person when fusing with another while at the same time feeling selfish because of putting the self first. Similarly, feelings of being unbearably lonely may characterize depression at these stages. Thus, using the constructive-developmental model to

examine anxiety and depression allows the investigator to examine what it is the person may be depressed about.

Anxiety, a concept that has also been used widely in the literature on psychological adaptation, is a common response to illness as well as a result of the conflicts and frustration inherent in the human experience (Lambert & Lambert, 1985). Although scientists vary slightly in their description of anxiety, there is general agreement that anxiety is an uncomfortable emotional state triggered by the perception of environmental danger. Anxiety is further defined as an internal state of tension, worry, nervousness, restlessness, dissatisfaction, and inadequacy (Spielberger, 1972). Anxiety may function as a signal to mobilize resources and take action aimed at the reduction or elimination of the source of anxiety. Spielberger distinguished between two types of anxiety. Trait anxiety refers to a predisposition to perceive the world as threatening. It is a general and situationally independent type of anxiety as compared to state anxiety, which is the actual experience of being in an anxious state (Spielberger, 1972).

Social Adaptation

As stated, adaptation is multidimensional and has physical, psychological, and social aspects. This definition supports the holistic approach of nursing, and suggests that every thread of the person's being ought to be considered in assessing the person's health status (Popkess-Vawter, 1983). Social adaptation is defined as the ability to function in the social arenas desired and incorporates role functioning, interpersonal relationships, vocational, and community

involvement (Breslow, 1972; Haberman, Woods, & Packard, 1985; Morrow, Chiarello, & Derogatis, 1978; Popkess-Vawter, 1983). What seems most important in relation to social health is the change imposed on the individual due to the illness and the individual's satisfaction with current social roles.

Very little research is available concerning the social functioning of individuals with chronic illness. Morrow and others (1978) conceptualized both the psychological and social aspects of adjustment to illness. Based on experiences with patients in clinical practice, a scale was developed along the dimensions of health care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, and psychological distress (Morrow et al., 1978). Haberman and colleagues (1985) developed the multidimensional construct of demands of illness to describe the illness-related events experienced by individuals and families in response to health problems. The demands of illness construct includes the perceived effect of the illness on family functioning and social relationships (Haberman et al., 1985). Early work supports the different domains of psychosocial adjustment (Haberman et al., 1985; Morrow et al., 1978; Pollock, 1986) and validates the importance of examining social and psychological aspects of health.

Physical Health

Physical health is one dimension of the construct of adaptation. The physiological functioning of an individual with chronic illness is considered a way of gauging how well the illness is managed. In other

words, the physiological manifestations of illness can be thought of as an outcome state of illness management. Physical health is defined as the individual's perception of physiological well-being, the absence of complications associated with the disease, and the control of specific symptoms. This definition aligns most closely with the biomedical model of health which often is defined as the absence of disease. The goal that health care providers strive for with their clients who have diabetes is the maintenance of normal levels of blood sugar. By keeping the levels of blood glucose in the normal range, the incidence of diabetes complications may be reduced. Complications of diabetes mellitus such as neuropathy, visual changes, vascular disorders, and kidney degeneration are thought to occur as a result of poor glucose control over time (Turk & Speers, 1983). Thus, complications of diabetes mellitus provide one way of examining physical health status.

The presence or absence of physical symptoms associated with blood glucose fluctuations provides additional evidence about the individual's physical health status. Specific blood glucose symptoms such as peripheral neuropathy, appetite changes, or mental changes, are highly idiosyncratic, and there are no absolute standards for which symptoms indicate high or low blood sugar levels (Gonder-Frederick, Cox, Bobbitt, & Pennebaker, 1986). For example, women reported more symptoms that were "false alarms" or not associated with fluctuations in glucose levels than males (Gonder-Frederick et al., 1986). There does seem to be agreement, however, that the presence or absence of blood glucose symptoms among insulin-dependent diabetics

tends to be accurate in reflecting blood glucose levels (Pennebaker, Cox, Gonder-Frederick, Wunsch, Evans, & Pohl, 1981). Thus, the identification of blood glucose symptoms from the person's own perspective may provide a way to examine glucose control.

Diabetes Management, Psychosocial Development, and Adaptation

Researchers and practitioners recognize the importance of identifying psychosocial and behavioral factors that influence diabetes management and adaptation in order to build a knowledge base for the development of treatment programs. However, there is little theoretical knowledge that guides current interventions. Surwit and others (1982) concluded that "successful treatment of the diabetic depends entirely on how well the patient can change and maintain a new pattern of behavior" (p. 341). Recently, a number of alternative treatment programs based on different paradigms have been tested with inconclusive results. These include the use of group therapy (Tattersall, McCulloch, & Aveline, 1985), social learning approaches (Kaplan, Chadwick, & Schimmel, 1985), and social coping skills assertiveness training (Gross & Johnson, 1981). For the most part, health care providers have assumed that psychological interventions should be aimed at changing personality variables that influence poor management of the illness (Surwit et al., 1982). However, the underlying assumption of these paradigms, that a consistent personality pattern differentiates people who have better disease outcomes, has not been demonstrated (Kubany, Danowski, & Moses, 1956; Surwit et al., 1982). Furthermore, these treatment programs are not based on the notion that different individuals may have different ways

of making meaning of their experiences and may manage their illness differently. Moreover, the complexities of the treatment regimen that effect every aspect of the person's life have not been considered. Specific social and environmental characteristics such as family composition, employment status, and income might influence the person's ability to manage chronic illness. Social-environmental factors may effect how well the person adapts as well. The use of a developmental perspective in studying diabetes management and adaptation may help to demonstrate a range of individual characteristics and management styles that influence the person's overall health.

The relationships among psychosocial development, diabetes management, social environmental factors, and adaptation are beginning to be explored empirically. The authors of preliminary studies suggest that the developmental perspective is a promising one which may shed light on individual and environmental differences, illness management, and adaptation in people who have diabetes. More information is needed about the role of family factors in illness management and adaptation to illness. Furthermore, the influence of adequate income and employment on the adaptive processes of people with chronic illness mandates study.

A number of important questions about personality characteristics, management of diabetes, environmental factors, and adaptation to illness have been raised. Does the way the individual with diabetes manages her illness depend upon her level of psychosocial development, and how does that management style influence her illness control? How

do environmental factors influence women's management styles and adaptation? Developmental theory may offer a new and different view on the many ways in which people manage their diabetes. This knowledge is critical in developing nursing theory that guides nurses in caring for patients with diabetes.

CHAPTER 3

METHODOLOGY

Research Design

The design of this exploratory, descriptive study was cross-sectional. Multiple measures and methods were used to investigate individual characteristics including psychosocial development, patterns of illness management, social-environmental factors, and psychological and social adaptation to the illness in women who had diabetes mellitus. Eligible participants completed an in-person interview and a questionnaire booklet. Qualitative analysis was used to identify patterns of diabetes management. Procedures recommended by the authors of the developmental measures were used to evaluate the developmental data. Both the qualitative and quantitative data were used in statistical analyses to explore relationships among the major study variables.

Sample

In order to generate knowledge about adaptive processes in an understudied group, a homogeneous sample of adult women with diabetes mellitus was used. Although generalizability of the research findings would be limited by using one gender in a specified age range, a fuller description of the variations in women's lives was possible. The use of a homogeneous sample was based on an assumption that a more consistent interpretation of instruments would occur using one gender than if a sample of both genders were used (Blalock, 1982). Although studying one gender may limit the generalizability of the findings,

the opportunity to recognize patterns and subsequent similarities and differences in women with diabetes was enhanced.

Criteria for Selection

In order to generate a homogeneous sample, sample selection criteria were established in this study. Participants included women:

- 1) diagnosed with diabetes mellitus;
- 2) between the ages of 25 and 50 years of age;
- 3) able to read and write English;
- 4) willing to complete the questionnaires; and
- 5) willing to complete the in-person interview.

Sample Recruitment

Participants for this study were recruited from a variety of sources (Table 3). The majority of participants were recruited from a completed study on the impact of a mother's chronic illness on family life, the Family Impact Study (FIS) (Lewis, Woods, & Ellison, 1986). At the completion of the FIS, participants were asked if they were willing to be contacted if further study were planned. The women with diabetes mellitus who responded affirmatively were sent an introductory letter (Appendix A). The investigator then called potential participants to discuss the study and arrange an interview if they were interested. The second source of participants was the American Diabetes Association. The Executive Director of the American Diabetes Association, Washington Affiliate provided names of support group leaders in the Seattle area. The leaders were contacted directly by the investigator. The study was explained to the group leaders and if they were willing to announce the study in their group

Table 3

Source of Participants (N = 40)

Source	Number of Participants	Percent
Family Impact Study	22	55.0
Diabetes Support Groups	12	30.0
Family Functioning Study	3	7.5
Advertisments	3	7.5
<u>Total</u>	<u>40</u>	<u>100 %</u>

they were sent information about the study. Group leaders had potential participants sign on a list which was returned to the investigator. The investigator then directly contacted each potential participant to discuss the study further, determine whether the woman met the selection criteria, and schedule an interview if the woman was interested. Almost one-third of the participants (n = 12) were obtained from diabetes support groups.

Participants were recruited also from advertisements (n = 3) (Appendix B) that were posted around the University of Washington campus. These women called the investigator directly for additional information about the study. If the woman met the selection criteria and was willing to participate, an interview was scheduled. The final source of participants (n = 3) was an ongoing longitudinal project, the Family Functioning in Chronic Illness Study (FFCI) (Lewis & Woods, 1986). Names of potential participants who responded to advertisements for that study but were ineligible according to sample selection criteria initially were screened by a research assistant from the FFCI to ascertain their willingness to be contacted about the current study. The names then were given to this investigator who called the subjects to discuss the study further and schedule an interview if desired.

Protection of Human Subjects

Procedures established by the University of Washington Human Subjects Review Board were followed for the protection of the participant's rights. During telephone contact, the investigator elaborated on the voluntary and confidential nature of the study, the

need to complete a written consent form, and the procedures involved. Participants were told they could withdraw from the study at any time and decline to answer any of the questions. Prior to beginning the interview, an in-depth explanation of the study was given and a signed consent form was obtained. Permission to tape record portions of the research interview was obtained. Each woman was given a copy of the consent form signed by the investigator for her personal records (Appendix C).

Procedures for Data Collection

Most interviews were conducted in the woman's home (n = 37) with the remaining three taking place at the University of Washington as requested by the participant. Each interview required about 2 to 2-1/2 hours in the home. Two participants required a second visit to complete the in-person interview. Self-report instruments and a consent form were mailed ahead to each woman for her to complete at her leisure. The completed instruments were collected at the time of the interview. The in-person interview involved both structured as well as open-ended questions. Upon completion of the study, each participant received \$10.00.

Methods for Data Collection

A combined qualitative and quantitative methodology was used to examine the relationships among individual characteristics (developmental stage, age, and onset age of illness), illness management patterns, illness context (the number of complications, and diabetes symptoms), social-environmental factors, and psychological and social adaptation to illness. A summary of the constructs,

dimensions, and measures appears in Table 4. In the following section, each measure is described in terms of what is measured, how the responses were constructed, the meaning of a high score, and any data transformation performed. Reliability and validity data for the measures as available in the literature or from the authors of the instruments also are reported. Data reliability is reviewed using internal consistency reliability for the structured measures and interrater agreement for the qualitative methods used in the study (Table 5).

Developmental Status

Psychosocial development was conceptualized as a process that has distinctive stages or milestones based upon the individual's core functioning. Ego development is a master trait that provides a framework for how a person makes meaning of her experiences (Hauser, 1976). In this study, psychosocial development was operationalized in two ways: Kegan's (1982) Subject-Object Interview; and Loevinger's (1970) Sentence Completion Test. The Subject-Object Interview was used primarily as a measure of construct validity with the Loevinger Sentence Completion Test. Killien's (1982) Transition status questions were used to assess whether or not the woman perceived herself to be in a period of stability or change. Each of these three measures is reviewed in the next section.

The Subject-Object Interview. Kegan and his associates developed an open-ended interview schedule which was used in this study to assess psychosocial development. The Subject-Object (S-0) Interview Guide is designed to tap the individual's unselfconscious

Table 4

Constructs, Dimensions, and Measures

Constructs/Dimensions	Measures
<u>Psychosocial development</u>	
Level of psychosocial development	Subject-Object Interview (SOI) (Kegan, 1986)
Ego development stage	Sentence Completion Test (SCT) (Loevinger & Wessler, 1970)
Transition status	Self-description scale (Killien, 1983) Open-ended interview item (Primomo, 1987)
<u>Diabetes Management Patterns</u>	
	Semistructured interview (Primomo, 1987)
<u>Physical Health</u>	
Diabetes symptoms	Diabetes Symptoms Checklist (Primomo, 1987)
Perceived diabetes control	Structured interview item
Blood glucose rating	Structured interview item
Perceived illness severity	Structured interview item
Number of diabetes complications	Structured interview item
Perceived overall health	Structured interview item
Number of other health problems	Structured interview item
Number of recent illness	Structured interview item
Weight status	Body Mass Index

(table continues)

Table 4 continued

Constructs/Dimensions	Measures
<u>Psychological well-being</u>	
Absence of depressed mood	Center for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977)
Absence of anxiety	State Anxiety Inventory (STAI) (Spielberger, Gorsuch, & Lushene, 1970)
Mental health counseling	Structured interview item
<u>Social health</u>	
Family functioning	Demands of Illness Inventory Family Functioning Subscale (DOII) (Haberma, Woods, & Packard, 1987)
Social relationships	Demands of Illness Inventory Social Relationships Subscale (DOII) (Haberma, Woods, & Packard, 1987)
<u>Background Data</u>	
<u>Illness context</u>	
Age of illness onset	Structured interview item
Duration of illness	Structured interview item
<u>Environmental context</u>	
Marital status	Structured interview item
Family life cycle stage	Based on marital status, ages of children
Income	Structured interview item
Employment status	Structured interview item
Educational level	Structured interview item

Table 5

Internal Consistency Reliability Estimates (N = 40)

Measure	Number of Items	Cronbach's Alpha
Transition Status	5	.84
Diabetes Symptoms	36	.90
Depression (CES-D)	20	.91
Anxiety (STAI)	20	.95
Demands of Illness (DOI)	125	.97
<u>DOI Dimensions</u>		
Physical Symptoms	12	.82
Personal Meaning	16	.91
Family Functioning	35	.92
Social Relationships	10	.84
Self-Image	9	.87
Monitoring Symptoms	11	.88
Treatment Issues	32	.84
Sentence Completion Test of Ego Development (SCT)	36	.86

"epistemology" or "principle of meaning-coherence."

The interview procedure is based on the Piagetian semi-clinical interview in which the interviewer tries to determine the person's subject-object structure or underlying epistemology. In order to understand how interpersonal and intrapersonal experiences are organized by the individual, the person is given 10 cards with one of the following words written on each of them: 1) Angry; 2) Anxious, nervous; 3) Success; 4) Strong stand, conviction; 5) Sad; 6) Torn 7) Moved, touched; 8) Lost something; 9) Change; and 10) Important to me (Kegan, 1986; Lahey, Souvaine, Kegan, Goodman, & Felix, 1988). Then she is asked to think about situations in the recent past in which she experienced or felt any or all of the feelings on the cards and to write down on the cards anything that comes to mind.

Next, the interviewee is asked to choose the cards she wants to talk about and the order in which the cards are to be discussed. Subjects are told that the approximate length of time for the interview is one hour and that the goal is to learn "how you think about things," "how you make sense of your own experience," and that they do not have to talk about anything they do not want to talk about. The interviewer probes for the underlying structure by exploring "why" the content area chosen by the interviewee is important. Interviewer training assists the interviewer in developing probing techniques that help to elicit not only what the subject has to say, but more importantly, in what sense it is a concern to the subject.

The interviews are audiotaped and transcribed. Next, the transcripts are analyzed to locate statements in which structure is clarified, and these are taken as the unit of analysis. Typically, eight to fifteen such units of analysis or "bits" are present in an interview. Each bit is scored independently. Formulation process sheets are used to record the scoring of the "bits," and the rater's hypotheses about the interviewee's stage of development (See Appendix D). An overall score is arrived at using the complex algorithm suggested by Kegan (1986) and Lahey and others (1988) which involves examining the range and frequency of stages of the scored bits. The process of scoring the interview begins with the rater reviewing the scores assigned to the "bits" and assigning an overall hypothesis or hypotheses about the stage. A general rule is that at least three "bits" must reflect a hypothesis. The rater then conducts a critical analysis from the notes on the formulation process sheets and portions of the interview and attempts to reject alternative hypotheses until a final stage is reached. On many interviews, rather than assigning a discrete score to each interview, a range of scores is given (Kegan, 1986; Lahey et al., 1988).

Kegan's theory distinguishes five increasingly complicated epistemologies believed to evolve in sequence with each successive epistemology containing the last. The assessment procedure distinguishes four gradations between any two epistemologies, so that a total of 21 distinctions is operationally possible. An example is provided in Appendix E that describes the same content in a "bit" of data as it may sound in five different stages.

Well over 150 S-0 interviews have been conducted with children as young as 10 years and adults as old as 70, both men and women, psychologically healthy and troubled persons, and people of all social classes. Interrater reliability for overall scoring on the S-0 Interview is between .75 and .95 (Kegan, 1986). Lahey and others (1988) reported additional preliminary evidence for reliability and validity of the S-0 interview. Test-retest reliability was examined by Lahey through the administration of an adapted version of the S-0 interview on two separate occasions no more than 2 weeks apart. On the first occasion, the interview focused on the domain of "work" and the second focused on "love." Correlations between the scores were .82 (Spearman's coefficient) and .83 (Pearson's r). Percent agreement between the two scores within 2/5 of a stage was .95, with 1/5 of a stage was .81, and exact agreement was .50. Lahey argues that the percent agreement scores obtained are very close to those reported on the Moral Judgment Interview based on the work of Kohlberg, a well established measure (Lahey et al., 1988).

Inter-item consistency within the S-0 interview was assessed by Villegas using a "modified S-0 interview." Her design allowed for the comparison between one "item" (strong stand) and the other "items" taken as a whole. A correlation of .96 was obtained between the two versions of the interview (Lahey et al., 1988).

Preliminary evidence for construct validity of the S-0 interview has been reported (Lahey et al., 1988). For example, moderate positive correlations between the S-0 interview and a measure of Piagetian stage, Kohlberg's moral Judgment Interview, and Loevinger's

Sentence Completion Test have been reported by Lahey and others. Longitudinal investigations are currently under way to evaluate further the reliability and validity of the S-O interview.

In January, 1986, the investigator completed interviewer training with Kegan and the Subject-Object Associates at Harvard University. Dr. Kegan formally agreed to the use of the S-O Interview and served as a consultant.

Loevinger's Sentence Completion Test. Psychosocial development also was measured using The Washington University Sentence Completion Test of Ego Development (SCT) (Loevinger & Wessler, 1970). The SCT was developed as a measure of ego development or development of the self and is based on Loevinger's theory of ego development (Loevinger & Wessler, 1970). The rationale behind the SCT is that the person supplies the frame of reference through which she relates to herself and the world around her. An assumption underlying the method is that "every person, although exhibiting variability in her responses and other behaviors, belongs in principle to one and only one point on the I-level scale" (Loevinger & Wessler, 1970, V.1, p.22). The original SCT was developed for women and consisted of 36 sentence stems which the respondent completes. The respondent is asked to complete sentences such as, "When I am criticized... " or "For a woman, a career is...". A number of forms have since been developed for women, girls, men, and boys. To illustrate the technique used in the SCT, Hauser (1976) provided responses to the same sentence stem for different stages of ego development. For example, sentence completions for the stem, "When people are helpless..." appropriate

to the different stages are:

Self-Protective Stage ... "I don't like to be bothered with them."

Conformist Stage... "I try to help them."

Conscientious Level... "I sympathize, unless they are unwilling to help themselves."

Autonomous Stage... "it is best to aid them to help themselves than to prolong their helplessness and dependency on others" (Hauser, 1976, p.931,932).

Loevinger states that the items (sentence stems) can be used interchangeably as long as 36 items and the appropriate scoring manual for the item is used. In this study, seven alternative items developed by Loevinger were substituted for seven of the items on Form 81 (Appendix F). A supplementary scoring manual for these seven items was obtained from Loevinger.

The training and scoring manual on the SCT was used according to the recommended procedures to rate the responses to the sentence stems and to score the overall instrument (Loevinger & Wessler, 1970). The scoring manual allows researchers to train themselves in the scoring method (Loevinger & Wessler, 1970). The two volume manual covers the theory of ego development, a thorough description of the reliability and validity of the measure, the specific rules for coding responses, chapters covering the scoring of each of the 36 sentence stems, and two set of practice exercises. According to the authors, the manual is a "rationalized manual" in that all empirical differences among categories are rationalized in terms of the theory.

The woman's response to each of the 36 sentence stems is coded individually for ego development level by matching it with response categories in the coding manual. When interpretation of the response is difficult, the rules outlined by Loevinger and Wessler (1970) are followed. For example, if a similar category is not present in the manual, the authors recommend looking for similar ideas or content in other sentence stems, rereading the introductory materials or the chapter on how ego development manifests itself in the sentence completions for clues, and finally, relying on the general theory to code the response.

Based on the scores for the 36 sentence completions, an overall ego development score is calculated using one of the algorithms described by Loevinger and Wessler (1970). The most common algorithm and the primary method used in this study is the "automatic total protocol rating." Loevinger and Wessler argue that this method preserves the notion of each individual having a core level of functioning. With this algorithm, the woman's overall ego development score is based on the cumulative frequency distribution of the woman's scores on the individual 36 sentences. The woman's frequency configuration of scores is matched with a table of values (the "automatic ogive rule") and assigned a level of ego development. Table 6 depicts the automatic rules for assigning a stage of ego development and provides an example to illustrate. Alternative scoring algorithms include a "borderline" classification system that also uses the cumulative frequency distribution of scores but allows for the rater to make a judgment based on the overall themes and

Table 6

Automatic Rules for Assigning Total Protocol Ratings
to the Cumulative Distribution Frequency of Item
Ratings on the Sentence Completion Test^a

Total Protocol Rating is: (Ego Development Stage)	If there are:
I-6	No more than 3 ⁴ ratings at I-5
I-5	No more than 31 ratings at I-4/5
I-4/5	No more than 30 ratings at I-4
I-4	No more than 2 ⁴ ratings at I-3/4
I-3/4	No more than 21 ratings at I-3
I-3	More than 21 ratings at I-3 but fewer than six ratings at Delta/3
I-2	At least 5 ratings at I-2
Delta	At least 6 ratings at Delta
Delta/3	At least 6 ratings at Delta/3

Note: Apply these rules in the order given, from I-6 to Delta/3.

Example: Assume the 36 item ratings from a protocol formed the following distribution.

Item Rating	I-2	Delta	Delta/3	I-3	I-3/4	I-4	I-4/5	I-5	I-6
Freq- uency	1	1	0	11	10	12	1	0	0

We obtain the following cumulative distribution.

Item Rating	I-2	Delta	Delta/3	I-3	I-3/4	I-4	I-4/5	I-5	I-6
Freq- uency	1	2	2	13	23	35	36	36	36

Applying the absolute rules, the distribution would be classified I-4.

^aLoevinger and Wessler, 1970, pp. 129-130.

patterns in the test as well as the rater's knowledge of ego development theory. Loevinger and Wessler recommend that only experienced raters use the "borderline" scoring system. Another method for obtaining a "total protocol rating" is the item sum rating of the responses to the 36 sentences. This method is useful in research designs that consider ego development as a continuous variable, however, the item sum score may be associated with verbal fluency according to Hauser (1976).

The SCT has been used in research studies for over 15 years (Loevinger, 1986). Reliability of the SCT has been demonstrated both at the level of the scoring techniques and the test itself. Loevinger reports interrater agreement scores of 85% following completion of the scoring manual (Loevinger & Wessler, 1970). Hauser, therefore, concluded that, "the manual, with its self-training exercises, is sufficiently clear so that high agreement can be maintained across different scorers who have been trained only by the manual itself (Hauser, 1976, p. 934,935).

In this study, interrater agreement was assessed in a number of ways. First, the investigator completed one set of 20 practice exercises for each of the sentence stems and then compared her ratings with the ratings in the manual. Exact agreement between the investigator's rating and those in the manual was 89%. Percent agreement within one stage discrimination was 96%. A second set of 20 practice SCT's in the manual was completed next. Exact agreement between the investigator's ratings and the manual's ratings was 86% and the percent agreement within one discrimination was 97%. Finally,

10 additional SCT were obtained from the Henry A. Murray Research Center at Radcliffe College (P. Barasch, personal communication, August 12, 1987) so that interrater agreement could be assessed on a sample of women in the same age range as the women in this study. Exact agreement between the investigator's ratings and those scored by researchers trained by Loevinger was 75% and 95% within one stage discrimination. Since Loevinger and Wessler (1970) reported exact agreement ranges between two coders from 50-80% with a median of 61%, and 88-100% agreement within one discrimination, the agreement scores obtained by this investigator are more than adequate to provide evidence for data quality.

Reliability and validity of the SCT have been discussed extensively in a number of publications (Hauser, 1976; Loevinger & Wessler, 1970), and therefore, are mentioned only briefly here. Reliability testing was conducted by Redmore and Waldman (1975) in two studies in which the high values of the coefficients were in agreement with those found by Loevinger and Wessler. For example, Redmore and Waldman reported split-half reliability correlations of .90 and .85 and internal consistency coefficients between .80 and .89. In this study, Cronbach's alpha for the SCT was .86 and the split-half reliability correlation between the two halves was .77.

Validity, the degree to which the SCT measures ego development, has been demonstrated in a number of studies (Hauser, 1976). Construct validity has been demonstrated in longitudinal studies by noting the rise in ego development over time (Loevinger, 1979). The sequentiality of stages also provides evidence for construct validity.

For example, results from cross-sectional studies of different age groups were that older children tended to have higher ego development than younger children (Loevinger & Wessler, 1970).

Validity of the SCT also has been demonstrated by examining the relationship between the SCT and other measures of ego development. Loevinger (1979) reported evidence of significant relationships between the SCT and other measures of ego level such as ego identity status based on Erikson's theory of development (Loevinger, 1979).

In summary, the SCT has been widely used in research. Numerous studies have supported the reliability of the scoring procedures and the test itself. In addition, empirical testing using the SCT has supported the validity of the instrument. Permission for use of the SCT was requested; however, according to Dr. Loevinger permission is not necessary because the instrument is in the public domain.

Relationship between Subject-Object Interview and Sentence Completion Test. The relationship between the scores on the two developmental measures, the Subject-Object Interview and the Sentence Completion Test, was examined on a subsample of women to assess the degree to which the two measures examine a similar construct. In addition, the two measures of psychosocial development were compared to assess the reliability of the investigator's scoring technique on the Loevinger Sentence Completion Test. If similar scores were found on the Subject-Object Interviews rated by Kegan's group with the Sentence Completion Tests rated by the investigator, this would lend additional support for the investigator's reliability as a rater.

Table 7

Comparison of Developmental Stages (Loevinger and Kegan) on Random Sample of Women (n = 10)

Subject Number	Loevinger's Stage of Ego Development	Range of Stages (Kegan)										
		2	2(3) (Imperial)	2/3	3/2	3(2)	3	3(4)	3/4 (Inter-personal)	4/3	4(3) (Institutional)	4
1	I-3/4						3	—————	3/4			
10	I-3/4							3(4)	—————	3/4		
13	I-4		2(3)	—————			3					
14	I-4			2/3	—————		3					
18	I-4	2	2(3)	—————								
20	I-3/4					3(2)	—————	3(4)				
21	I-4							3(4)	—————			4
26	I-3/4						3	—————	3(4)			
35	I-3/4					3(2)	—————	3				
40	I-3				3/2	—————	3					

Because of the complexity of the interviewing and scoring processes, a random subsample of 10 interview transcripts was selected for scoring by Kegan and his associates. For each woman, a tentative range of scores rather than a discrete score was given because of the limited amount of scorable data on the interviews (S. Beukema, personal communication, October 18, 1987). Tentative ranges of scores for the 10 interviews rated by Kegan's group were between the imperial (I-2) and the institutional (I-4) stages (Table 7). One woman's interview (Participant #18) was rated in the Imperial stage suggesting that her primary motivator was her own needs, wishes, and wants. In the Imperial stage, institutions such as the family are recognized as institutions of authority and role differentiation. Four women (Participant #13, 14, 35, and 40) had interviews that were rated predominantly in the imperial to interpersonal transition. In other words, these women were moving away from being embedded in their needs, wishes, and wants toward mutuality and interpersonal concerns. The Interpersonal stage was the predominant stage assigned to interviews from Participants #1, 10, 20, and 26. For these women, interpersonal and reciprocal one-to-one relationships become a critical factor in their meaning making structure. The scoring on one transcript (Participant #21) ranged between the interpersonal and institutional stages. This woman began to show glimpses of her capacity for independence, self-identity and being embedded in personal autonomy rather than interpersonal relationships. For 6 of the 10 interviews, the range of scores on the Subject-Object Interviews corresponded well with the scores on the Sentence

Completion Tests (Table 7). In three of the four interviews (Participants #13, 14, and 35) where the correspondence between stages was weaker, the emotional tone of the Subject-Object Interview was quite depressed. This could have influenced the rating of the interview. Furthermore, the depression scores for those women tended to be higher than the mean sample score and in two cases the scores were above the cutoff marking depression (Radloff, 1977).

These findings lend support to the construct validation of the Subject-Object Interview. Goodman (1986) also found a moderate correlation between the Subject-Object Interview and the Loevinger Sentence Completion Test (Lahey et al., 1988). The investigator's ratings on the Loevinger Sentence Completion Test corresponded moderately with the independent ratings by Kegan's group on the Subject-Object Interview, an instrument with similar theoretical underpinnings. In a crude way, this validates the investigator's reliability as a rater of the Sentence Completion Test.

Transition status questions. The purpose of the third and final set of developmental status measures was to determine whether or not the woman was in a stable or transition period and to assess the relationship between the woman's report of transition in her life and the developmental transitions described in theories of psychosocial development. The degree to which women were experiencing a period of transition or stability was examined in two ways. First, a five-item self-description scale developed by Killien (1982) was used. This semantic differential scale contained items that measured stability versus change, certainty versus uncertainty, satisfaction versus

dissatisfaction, security versus insecurity, and happiness versus unhappiness (Appendix G). The items, stable and satisfaction, were recoded so that a low score reflected stability and a high score reflected change or transition. A reliability coefficient using Cronbach's alpha for the scale was .77 (Killien, 1982). In this study, the reliability coefficient obtained was .84.

The second measurement of transition status used was an open-ended question in which the woman was asked whether she was in a period of stability or change at the present time (Appendix H). Responses were categorized according to the woman's self-report.

Frequency of illness-related responses on Sentence Completion Test. Content analysis was conducted by the investigator to analyze the frequency of responses from the SCT that referred to the woman's experience with health and illness. A similar approach was used in a study of adolescents with diabetes using Loevinger's Sentence Completion Test to measure ego development (Hauser et al., 1979). The three content categories developed by Hauser and others were: (a) mention of death or fears of object loss; (b) mention or referral to diabetes; and (c) a general response which revealed concerns about health. Each response on the SCT was examined and responses that fit into the categories were recorded. A total score for each category was computed next. Chi square analysis gave evidence that those with lower levels of ego development had more concerns about separation and object loss than those with higher levels of ego development (Hauser et al., 1979). In this study, a similar approach was used to examine how the illness experience related to psychosocial development. The

specific categories developed for this study are reported in the Chapter 5. Illness-related responses were coded and then used in the statistical analysis to explore the relationship with the major study variables.

Management of Diabetes

Each woman who has diabetes mellitus must manage a complex treatment regimen as well as physical symptoms. Although each woman's medication, diet, exercise, and testing routine is unique, it is likely that some common patterns exist in how women go about managing their routines on a day-to-day basis. A qualitative approach to data collection and analysis was used in this portion of the study to explore how women managed their diabetes. Qualitative research methods are designed to seek the individual's view and to reflect more accurately the complexities of the world as experienced by the person (Strauss, 1987). Thus, interviewing provided a means of constructing the reality of each woman. The semi-structured interview guide used to generate data is described below.

Management of Diabetes Interview Guide. A semi-structured interview guide focusing on the management of the diabetes routine and diabetes symptoms was developed to gather data on how women managed the illness regimen on a daily basis (Appendix I). Women were asked how they managed their diet, medication regimen, exercise, blood sugar and urine monitoring, and hyperglycemic and hypoglycemic episodes in the context of their lives (work, child care responsibilities, and family life). Emphasis was placed on probing for behaviors and actions that the woman took in response to symptoms, persons who

helped the woman with her illness routines, and the situations that made it difficult for her to maintain good control of her diabetes.

From the qualitative analysis of the diabetes management data, categories describing key elements of diabetes management and a typology of different management patterns were developed. The categories and patterns of diabetes management are described in Chapter 5. The identification of styles or patterns in qualitative research is frequently the most useful way to interpret findings (Glaser, 1978; Strauss, 1987). For example, a study about the influence of family on the developing identity of diabetic adolescents identified styles of family influence (Benoliel, 1970). The four styles, protective, adaptive, manipulative, and abdicative, seemed to be related to the tensions in family relationships. Kornblum and Anderson (1985) also suggested that patterns of managing diabetes symptoms can be delineated. For example, when faced with a meal delay, one person may respond flexibly and eat a snack, while another may become irritable and demand supper immediately.

Adaptation to Illness

Adaptation to illness was conceptualized as having both psychosocial and physical components. In this study, individual adaptation was assessed using measures of psychological well-being. Family and social adaptation were assessed by exploring the extent to which women perceived their illness to effect family functioning and social relationships. The illness context and physical health status of the woman also were explored. A description of each of the measures used follows.

Psychosocial Adaptation

Depression. Psychological health is compromised frequently when a person experiences chronic illness. One of the most common ways to study psychological health is through the study of depression.

Depression, a psychological disorder that manifests in a complex pattern of symptoms, was defined in this study as the report of dysphoric mood. Measurement of depression provided a psychological measure of health or well-being as well as an indication of construct validity for the development variables.

Depression was measured using the Center for Epidemiological Studies - Depression Scale (CES-D) (Radloff, 1977). The CES-D is a self-report measure of the frequency in which symptoms of depressed mood are experienced (Appendix J). The CES-D, which was developed for use with community populations, consists of 20 items selected to represent the major symptoms in the clinical syndrome of depression. Approximate completion time of the instrument was five to ten minutes. Content areas of the CES-D include depressed affect, positive affect, somatic complaints, and interpersonal transactions. For each item, the individual was asked to rate how much of the time during the past week she experienced the feeling. Responses ranged from rarely or none of the time (less than one day=0) to most or all of the time (5 to 7 days=3). A summed score was calculated and used in the analysis. The CES-D is scored such that high scores indicate higher depressive symptoms. Results on the CES-D correlate well with clinician ratings on the Hamilton Depression Rating Scale and with the results on the SCL-90 depression scale. The CES-D was found to correlate highly with

scores on the Zung Depression Scale (.90) and the Beck Depression Scale (.81) (Myers & Weissman, 1980). According to national norms, a score below 16 indicates the absence of depression (Radloff, 1977). Selected sample means for working women were 3.6 and 4.5 for homemakers (Newberry, Weissman, & Myers, 1979).

Internal consistency reliabilities for the general population and patient samples were reported by Radloff (1977). Alpha coefficients ranged between .84 and .85 for 3 samples in the general population and .90 for a patient sample (Radloff, 1977). Test-retest correlations at 3 months (N = 378) were moderate ($r = .48$) as expected in that the CES-D was designed to measure the current level of depression (Radloff, 1977). In the Family Impact Study, internal consistency reliability coefficients for the first three occasions of data collection ranged between .86 and .90. Stability coefficients ranged from .51 to .62 over 9 months of data collection (Lewis et al., 1986). In the current study, internal consistency as measured by Cronbach's Alpha was .90.

Anxiety. Another common psychological effect of chronic illness is anxiety. When an individual has a chronic illness, fear and worry often are generated because of the uncertainty of the illness trajectory and concern about complications and symptoms. Furthermore, developmental transitions are accompanied by nervousness and fear. The State-Trait Anxiety Inventory (STAI) (Spielberger, Gorsuch, & Lushene, 1970), a 40-item self-report measure which provides information about a person's level of both state and trait anxiety was used to measure anxiety. The state form of anxiety is the transient

feeling of fear or worry which most people experience from time to time. The trait form is the relatively stable tendency of an individual to respond anxiously to a stressful situation. In this study, trait anxiety was the form of anxiety measured because both development and chronic illness were thought to have long term rather than transient consequences (Appendix K).

On the 20-item trait anxiety form, respondents rate feeling statements such as "I feel satisfied with myself," and "I lack self-confidence," according to how they generally feel on a 4-point intensity scale labeled "not at all, somewhat, moderately so, and very much so." A total anxiety score is obtained by summing the responses.

The STAI takes about 10 minutes to complete. The STAI has been used extensively in research and is well documented (Spielberger et al., 1970). Internal consistency of the trait scale, measured by Alpha coefficients, ranges from .89 to .91 across male and female samples of working adults and high school and college students and from .86 to .95 for the state scale. The stability of the STAI was evaluated on high school and college students with test-retest intervals ranging from 1 hour to 10⁴ days. As might be expected, the magnitude of reliability coefficients decreased as a function of interval length. For the trait scale, the coefficients ranged from .65 to .86, and for the state scale, the range was from .16 to .62 (Spielberger et al., 1970). In this study, the internal consistency reliability estimate using Cronbach's Alpha was .95.

Family and social relationships. A chronic illness often is accompanied by a set of unusual family and social demands which have

to be managed by the person. The extent to which women perceived their illness to influence their family and social relationships was of interest. The perceived impact of chronic illness on family and social relationships can be considered an indicator of how the individual is coping with the demands imposed by an illness as well as the extent to which the illness affects the individual's life.

The construct of illness demands was developed by Woods, Haberman, and Packard (1985) based on the individual and family stress and coping literature as well as clinical impressions. It is a multidimensional construct and is defined as the hardships, stressors, or experiences associated with the illness that arise over the course of an illness (Haberman, Woods, & Packard, 1985). Dimensions of illness demands include physical symptoms, personal meaning, family functioning, social relationships, self-image, monitoring symptoms, and treatment issues.

The Demands of Illness Inventory (DOII) (see Appendix L) was developed in 1984 and adapted in 1987. The 1987 version of the DOII was used to examine the woman's perception of demands imposed by the illness. The DOII is a 125-item self-report measure in which the woman is asked to rate on a 5-point Likert-type scale ranging from "not at all" to "extremely" the extent to which she has experienced each of the items in the past 2 weeks. The entire instrument was administered in this study; however, the family functioning and social relationships subscales were of primary interest in the analysis. The family functioning dimension includes adaptation on the part of the family to the illness, partner caretaking, decision making, and work

patterns. For example, changing meal patterns, family members taking responsibility for household tasks, emotional support needs, and financial changes are addressed in the family functioning subscale. The social relationship dimension included transactions with the environment, reactions of others, and social activities. For example, going out less with friends, overprotectiveness of people, and keeping up with usual routines are items on the social relationships subscale.

The DOII has been used in studies of families experiencing chronic illness in an adult family member (Lewis et al., 1986). Internal consistency on the 1984 version of the total scale estimated by Cronbach's Alpha was .94 for chronically ill mothers and .93 for the partners of the women (Haberman et al., 1985). Subscale internal consistency as estimated by Cronbach's Alpha ranged from .63 to .93. Stability coefficients over two occasions were .47 for the women and .73 for the partners (Haberman et al., 1985). In this study, the internal consistency for the 1987 total scale (1987 version) using Cronbach's Alpha was .97 and for the subscales .82 to .92 (Table 5).

Physical Health

Health Status Questionnaire. Physical health status was measured using both a semistructured interview format (Appendix M) and a Diabetes Symptom Checklist. Questions on the semistructured interview included the : (a) woman's diabetes history (age at onset; duration of illness); (b) current medication regimen; (c) frequency of home blood glucose monitoring; (d) most recent blood glucose rating; (e) number of diabetes related complications (eye, renal, and vascular changes); (f) perceived severity of illness; (g) perception of glucose control;

(h) perceived overall health; (i) other health problems and treatments; (j) height and weight; and (k) health problems of family members.

Diabetes Symptoms Checklist. The Diabetes Symptom Checklist (DSC) is a 36-item list of symptoms which occur commonly in diabetes. It was developed for this study and is based on the work of Bulbitt, Shaw, Hodes, and Bloom (1976) and Pennebaker, Cox, Godner-Frederick, Wunsch, Evans, and Pohl (1981) (Appendix N). Diabetes symptoms left untreated are life threatening and may possibly lead to serious complications of the disease. The symptom categories on the DSC include general and peripheral nervous system symptoms (altered sensation, poor coordination, tingling, and burning in extremities), thirst, extreme hunger, visual disturbances, gastrointestinal symptoms (appetite changes or nausea), genitourinary symptoms (urinary changes, and vaginal itching), changes in mental status, attacks of sweating, apprehension, nervousness, palpitations, and malaise. Women were asked to rate the extent to which they experienced each of the symptoms in the past 2 weeks according to a 5-point Likert-type scale ranging from 0 (not at all) to 4 (a great deal). Higher scores denoted higher frequency and intensity of symptoms. In this study, internal consistency reliability estimated by using Cronbach's Alpha was found to be .90.

Background Variables

Age, sex, education, occupation, employment status, family composition, and income were obtained using an interview format (Appendix O). From the data on family composition (marital status,

and the number and ages of children), a family life cycle variable based on the work of Duvall (1977) was developed for each woman.

Procedures for Data Analysis

Overview

A number of qualitative and quantitative techniques were used to examine the relationships among individual characteristics such as age at illness onset and developmental stage, illness management patterns, social-environmental factors, and adaptation to illness. In addition, specific group characteristics were examined to determine the extent of variation in developmental stage, illness management, the social environment, and adaptation. The procedures for data analysis are discussed below.

Analysis of Data

Developmental measures. Analysis of the Subject-Object Interview began with the transcription of the interview tapes. Each interview lasted about an hour and the average length of a transcript was about 12 pages. The transcripts then were checked for accuracy. Because of the complicated scoring methods for the S-O interview, a subsample of 10 randomly generated interviews was sent to Kegan and his associates for scoring. These 10 interviews were coded for developmental stage and used in exploratory analyses.

The Sentence Completion Test coding required a number of steps and began with the transcription of the responses into an R-BASE data management program. Loevinger and Wessler (1970) recommend scoring all responses to a sentence stem rather than the woman's total SCT. Thus, the R-base program was useful in that it allowed for sorting of the

responses in two different ways: (a) according to a particular subject; and (b) according to a particular sentence stem. All of the women's responses to individual sentence stems were coded according to instructions in the training manual from the authors. Once all 36 sentences were coded, the individual ratings were transcribed onto a copy of each woman's SCT so that the cumulative frequency distribution could be determined. A level of ego development or a total protocol rating was assigned to each woman's SCT according to the "automatic rules" discussed previously. The 36 individual sentence ratings and the stage of ego development then were entered into an SPSS program for use in the statistical analyses.

Process of qualitative analysis for Diabetes Management Interview data. The semistructured interview on diabetes management was transcribed and checked for accuracy. The diabetes management portion of the interview ranged from 20 minutes to over an hour with transcripts resulting in a length of between 8 and 19 pages. Following transcription, a random number table was used to generate 10 transcripts for category development and initial coding. Line-by-line coding was completed on each of the ten interviews as recommended by Spradley (1979). On each transcript, key emic phrases were underlined and then the emic phrases were written in the margin (Chenitz & Swanson, 1986). The emic phrases were then written on cards according to general content area.

Data were organized around key areas of the diabetes regimen present in the literature. Spradley referred to this process as domain analysis (Spradley, 1979). These general content areas were

management of symptoms, self-monitoring of the blood sugar, diet and food management, the administration of insulin or oral medications, exercise routines, and how others facilitated or hindered the diabetes routines. A separate card was used for each subject and category to facilitate category development. This was followed by the first attempt to generate codes for the emic statements. A process of constant comparative analysis (Glaser & Strauss, 1967) was used to generate the substantive codes.

Following identification of the first set of conceptual codes, two additional transcripts were generated randomly in order to obtain a more accurate representation of the data and to help saturate the coding scheme. In the first set of 10 interviews, the investigator realized that four out of the five women who were noninsulin dependent were "randomly" generated. Categories, definitions, and coding rules were established based on the 12 transcripts. Ten additional transcripts were generated randomly for "reliability" coding. From these transcripts, 41 segments of data representative of the coding categories were used. Two nurse researchers independently coded the data segments. Percent agreement was used to compare the investigator's assignment of codes to the data segments with the independent coders' ratings. Two-way agreement between the investigator and each of the independent coders reached 80%.

Following the bias reduction process, the coding categories were refined slightly to decrease redundancy as advised in the critical review by the two nurse researchers. In the process of category development, a core variable called clinical safety work evolved from

the data. This core variable served as an organizer for the categories and was used to integrate and describe the coding categories. Patterns of diabetes management also were delineated through the process of the qualitative analysis. Three nurse experts reviewed the patterns of management as a means of validating the investigator's work. The nurse experts believed that the patterns of management did represent their experiences with how people manage chronic illness. These patterns were based on the primacy of specific behavioral patterns represented in the coding categories and also are described in Chapter 5.

Once the category scheme was finalized, all interviews were coded. A coding sheet was developed to facilitate this part of the analysis (Appendix P), to help in the delineation of the pattern or patterns of management, and to facilitate computer entry of the codes. When an interview could not be assigned to one pattern of management, a primary and a secondary pattern were assigned to each woman's interview. Consensual validation was used in cases where the investigator was unsure of the pattern of management.

Description of findings. All data from the structured questionnaires were coded and entered into an SPSS program for computer analysis. Following the reduction and computer entry of data, descriptive statistics and measures of central tendency were obtained on the structured questionnaires. Measures of internal consistency reliability also were obtained on the standardized instruments. Demographic information, stages of ego development, management patterns of diabetes, and the various measures of health

were examined for frequencies and measures of central tendency.

Analyses of relationships among variables. Crosstabulations and correlational procedures were used to examine the relationships among variables in the study. Descriptive statistics on the standardized instruments, demographic variables, and illness context variables were used to describe the characteristics of women according to the patterns of diabetes management. Analysis of variance was used to examine group characteristics for the various patterns of management. Social and environmental factors such as family composition, educational status, and income were used in ANOVA procedures in order to develop a richer description of women's lives. In addition, chronological age and the age at illness onset were used in ANOVA procedures. This grouping flows logically from developmental theories that use age as markers. The assumption is that being diagnosed with diabetes at certain times during the life span may influence development. Differences in illness severity (often associated with the length of time the individual has lived with the illness) were of interest also. The number of years since diagnosis, an important factor in how the individual experiences her illness (Kornblum & Anderson, 1985), was examined. Furthermore, the number of years an individual has lived with a chronic illness may have importance in how pervasive the illness experience has been on the individual's psychosocial development. The length of time since diagnosis may have a critical effect on how much the individual has integrated the "illness self-concept" into her own self-concept.

The final research question addressed was the degree to which the woman's illness identity is part of her overall identity or developmental structure. To examine this question, a content analysis of the Loevinger's Sentence Completion Test was conducted to determine if and to what extent diabetes was discussed as part of the woman's underlying identity. The frequency of illness-related responses on the SCT was used in correlational analysis with other variables.

CHAPTER 4

DESCRIPTION OF THE SAMPLE AND RESEARCH MEASURES

In this chapter, the sample is described according to demographic, family, and illness characteristics. The stages of psychosocial development and transitional status are described and the relationship between transition and development is reviewed. Results on the measures of psychosocial adaptation (depression, anxiety, demands of illness on family functioning and social relationships) are reported.

Description of the Sample

Demographic Characteristics

The sample was relatively homogeneous and consisted of 40 moderately well educated, middle to upper-middle class women with diabetes. Most women were employed, living with a partner, and had a school-aged child. Demographic characteristics are shown in Tables 8, 9, and 10.

The mean age of the women was 38.3 years (SD = 6.3) with an age range of 27 to 50 years. The average age of the partners was 40.9 years (SD = 6.5) with a range of 30 to 54 years. Women, as were their partners, were fairly well educated with the average educational level falling between some college and college graduate. About 65% of women worked full or part time, 22.5% were currently not working outside the home, 10% were unable to find work, and one woman (2.5%) was unable to work because of her illness. All 30 partners were employed full time. The most common occupational category for the women based on

Table 8

Demographic Characteristics of the Sample (N = 40)

Characteristic	Mean	Median	SD	Range
Subject's Age (years)	38.3	38	6.3	27-50
Partner's Age (years)	40.9	39	6.5	30-54
Number of Years Married	14.6	15	8.1	1-30
Age of Oldest Child Living at Home (years)	13.3	13.5	4.5	1-20
Number of Children Living at Home (total=50)	1.3	1.0	1.0	0-4
Total Number of Children (total=73)	1.8	2.0	1.5	0-6
Number of Others at Home	.175	.0	.501	0-2

Table 9

Marital Status and Income of Sample (N = 40)

Characteristic	n	%
<u>Marital Status</u>		
Married First Husband	24	60.0
Married Second Husband	6	15.0
Divorced	5	12.5
Never Married	3	7.5
Widowed	2	5.0
<u>Income</u>		
\$5,000-9,999	2	5.3
10,000-19,999	6	15.8
20,000-29,999	10	26.3
30,000-39,999	6	15.8
40,000-49,999	7	18.4
50,000-59,999	1	2.6
60,000-69,999	2	5.3
70,000 or more	4	10.5

Table 10

Characteristics of the Sample: Education, Classes,
Employment Status, Occupation, Ethnicity (N = 40)

Characteristic	Subject		Partner	
	n	%	n	%
<u>Education</u>				
High school	4	10.0	4	13.3
Some college	21	52.5	9	30.0
College graduate	10	25.0	12	40.0
Master's degree	4	10.0	3	10.0
Doctorate	1	2.5	2	5.0
<u>Taking Classes</u>				
No	33	82.5	29	96.7
Part time	4	10.0	1	3.3
Full time	3	7.5	--	--
<u>Employment Status</u>				
Unwillingly unemployed	4	10.0	--	--
Not employed	9	22.5	--	--
Part time	9	22.5	--	--
Full time	17	42.5	30	100.0
Unable to work	1	2.5	--	--
<u>Occupation</u>				
Semi-skilled	--	--	2	6.7
Skilled/manual	2	5.0	5	16.7
Clerical/sales	7	17.5	1	3.3
Semi-professional	9	22.5	3	10.0
Minor professional	2	5.0	8	26.7
Administrative	7	17.5	5	16.7
Major professional	1	2.5	6	20.0
Doesn't apply	12	30.0	--	--
<u>Ethnicity</u>				
Caucasian	37	92.5	27	90.0
Black	2	5.0	2	6.7
Native American	1	2.5	1	3.3

Hollingshead's (1975) titles was semiprofessional (computer operators, secretaries, therapists) followed by administrative and clerical or sales. For the partners, the most common occupational category was minor professional (26.7%) followed by skilled/manual (16.7%) and administrative (16.7%). Most women in the sample were Caucasian (92.5%) with Black and Native American being the predominant ethnic background for the other women. This ethnic pattern held for the partners of the women. The median household family income was in the range of \$30,000 to \$35,000.

Family Factors

Family and environmental factors such as marital status, the point in the family life cycle, and the number of children were considered to be critical areas that could affect both psychosocial development, psychosocial adaptation, and diabetes management. Most women in the sample were married (75%), 12.5% were divorced, 7.5% were never married, and 5% widowed. The divorced or widowed category and the never married category were combined to form a not married category. The average length of marriage was approximately 15 years. Six women (15%) in the study had never had any children. One woman had recently experienced the death of her only son. For those with children, the mean number was 1.8 children (SD = 1.5) and of those children, 1.3 (SD = 1.0) children were living at home. The children ranged in age from 1 to 20 years and the oldest child living at home had a mean age of 13.3. Only 12.5% of the women (five women) in the sample shared their living space with people other than nuclear family members.

For each woman, family life cycle stage was categorized according to stages suggested by Duvall (1977). Duvall identified predictable tasks that individual family members and families as a whole experienced. The stages were: (a) early marriage; (b) childbearing family; (c) preschool family; (d) school age family; (e) family with teens; (f) family as a launching center; and (g) aging families. In the current study, Duvall's stages were adapted to account for single women, and the post-parenting family rather than the aging family. The family life cycle stage was determined in two different ways for each woman in the sample based on the age of the oldest child and then the age of the youngest child (Table 11). The mode for family life cycle based on both the oldest and youngest child's age was the school aged category. Four women were single without children, three women were coupled without children, and one family was post-parenting. The number of women who were categorized in the pre-school, school aged, adolescent, and launching families varied depending on the age of the oldest or youngest child. The number of family life cycles for each subject was also calculated. Most of the women were categorized as having children in only one family life cycle (67.5%), however, 32.5% of the women had children whose ages spanned two or three family life cycles.

In addition to family life cycle stage, women were questioned about the presence of illness, injury, or special needs among family members. Well over half of the women (65%) reported having at least one family member with an illness, injury, or special needs such as a child with a developmental disability. The mean number of family

Table 11

Characteristics of the Sample: Family Life Cycle Stage (N = 40)

Characteristic	n	%
<u>Family Life Cycle Stage</u> (Based on <u>Oldest Child</u>)		
Single/No children	4	10.0
Coupled/No children	3	7.5
Pre-school	2	5.0
School-aged	12	30.0
Adolescent	10	25.0
Launching	8	20.0
Post-parenting	1	2.5
<u>Family Life Cycle Stage</u> (Based on <u>Youngest Child</u>)		
Single/No children	4	10.0
Coupled/No children	3	7.5
Pre-school	5	12.5
School-aged	16	40.0
Adolescent	8	20.0
Launching	3	7.5
Post-parenting	1	2.5
<u>Number of Family Life Cycles</u>		
1	27	67.5
2	10	25.0
3	3	7.5

members with such a problem was 1.2 (SD = 1.04).

Characteristics of Illness

Descriptive information of the nature of the women's diabetes is presented next. Table 12 shows the type, history, and treatment of diabetes, frequency of blood sugar monitoring, and perceived blood sugar control. Table 13 shows the perceived severity of diabetes, perceived health, complications of diabetes, and other health problems. Information on medications and weight status is reported on Table 14. Measures of central tendency for continuous variables such as the duration of diabetes, age of onset, number of daily insulin injections, number of recent illnesses, and actual blood glucose rating are reported on Table 15.

Type of Diabetes

Diabetes is an illness that has many variations and treatments. According to the National Diabetes Data Group (1985), there are numerous types of diabetes ranging from insulin-dependence to prediabetic states. The most common types of diabetes are insulin-dependent diabetes mellitus (IDDM) and non-insulin-dependent diabetes mellitus (NIDDM). In this study, 87.5% of the women (n = 35) reported having IDDM. Four women currently were controlled on oral hypoglycemic agents and one woman was being treated by diet alone.

Diabetes History

Women discovered they had diabetes in a number of ways. Forty percent had specific diabetes symptoms such as weight loss, excessive urination, or thirst and sought treatment for those symptoms. For a quarter of the women, diabetes was diagnosed while they sought medical

Table 12

Characteristics of Illness (N = 40)

Characteristic	Number	Percent
Type of Diabetes		
Insulin-dependent	35	87.5
Noninsulin-dependent	5	12.5
How Diabetes Was Discovered		
Had diabetes symptoms	16	40.0
Had other physical problems	10	25.5
During pregnancy/lactation	9	22.5
Acute illness episode	4	10.0
Other	1	2.5
Family History of Diabetes		
No	27	67.5
Yes	13	32.5
Stress at Time of Diagnosis		
No	23	57.5
Yes	17	42.5
First treatment		
Insulin	21	52.5
Oral medications	12	30.0
Diet only	7	17.5
Current treatment		
Insulin	35	87.5
Oral medication	4	10.0
Diet only	1	2.5
Frequency of Blood Glucose Monitoring		
At least once a day	22	55.0
Every one to three days	6	15.0
Greater than every three days	10	25.0
Does not test blood	2	5.0
Perceived Glucose Control		
Very well	6	15.0
Moderately	15	37.5
Fairly well	15	37.5
Not very well	4	10.0

Table 13

Characteristics of Illness (N = 40)

Characteristic	Number	Percent
Perceived Illness Severity		
Not very serious	7	17.5
A little serious	8	20.0
Moderately serious	12	30.0
Very serious	13	32.5
Perceived Overall Health		
Excellent	6	15.0
Good	29	72.5
Fair	5	12.5
Poor	0	0.0
Diabetes-Related Complications		
Retinopathy	14	35.0
Peripheral neuropathy	10	25.0
Gastrointestinal disturbances	8	20.0
Slow healing/infections	5	12.5
Hyperglycemia	3	7.5
Gynecological	2	5.0
Hypoglycemia	2	5.0
Renal	2	5.0
Coronary artery disease	1	2.5
Hypertension	1	2.5
Peripheral vascular disease	1	2.5
Types of Other Health Problems		
Musculoskeletal	13	32.5
Thyroid	11	27.5
Gynecological	8	20.0
Hypertension	7	17.5
Cardiovascular	5	12.5
Psychological	5	12.5
Ear/nose/throat	4	10.0
Infections	4	10.0
Eye	3	7.5
Fibrocystic breast disease	3	7.5
Allergy	2	5.0
Gastrointestinal	2	5.0
Neurological	2	5.0
Respiratory	2	5.0
Other	4	10.0

Table 14

Characteristics of Illness (N = 40)

Characteristic	Number	Percent
Types of Medications		
Hypertensives	9	22.5
Thyroid	9	22.5
Antidepressants	6	15.0
Antihistamines	6	15.0
Muscle relaxants	6	15.0
Analgesics	3	7.5
Antibiotics	3	7.5
Electrolytes	3	7.5
Gastrointestinal	3	7.5
Sex hormones	3	7.5
Vitamins	3	7.5
Seizure	2	5.0
Other	6	15.0
Weight Status According to BMI		
At desired weight	28	70.0
Underweight	1	2.5
Overweight	11	27.5
Perceived Weight Status		
At desired weight	12	30.0
Underweight	2	5.0
Overweight	26	65.0

Table 15

Characteristics of Illness: Continuous Variables (N = 40)

Characteristic	Mean	Median	SD	Range
Duration of diabetes (in years)	12.8	11.0	8.4	2 -34
Age at diabetes onset (in years)	25.6	27.0	10.6	8 -46
Years on insulin therapy	12.3	8.9	11.0	0 -34
Number of daily injections	1.9	2.0	1.2	0 - 5
Number of diabetes complications	1.2	1.0	1.7	0 - 9
Number of other health problems	2.0	2.0	1.4	0 - 5
Number of medications	1.5	2.0	1.4	0 - 6
Number illnesses in past 2 months	.5	0.0	.7	0 - 3
Actual glucose rating	167.9	160.0	69.4	50-400
Height in inches	65.4	65.0	2.5	61- 71
Weight in pounds	154.4	140.5	40.6	106-275
Body Mass Index (BMI)	25.5	23.0	6.0	17-41

help for other physical health problems. The next most common time of discovery was during pregnancy or lactation during which 22.5% of the women first learned they had diabetes. A small percentage of women, 10%, had an acute diabetes-related illness episode that led to the diagnosis of diabetes. A family history of diabetes was reported in about one third of the sample. Over 40% of the women in the sample stated that they were experiencing a time of stress (pregnancy, family illness, or unemployment) at the time of diagnosis. All of the women who reported experiencing stress at the time of diagnosis were older than 18 years of age when diagnosed. The duration of diabetes ranged from 2 to 34 years with an average duration of 12.8 years (SD = 8.4). The mean age of diabetes onset was 25.6 years (SD = 10.6) with a range of 8 to 46 years. Nine women were diagnosed with diabetes prior to age 18.

Diabetes Treatment

When first diagnosed, about half of the women were started immediately on insulin, 30% were treated with oral hypoglycemic agents, and about 17% were given special diets alone as treatment. Current treatment modalities were insulin (87.5%), oral medications (10%), and diet only (2.5%). For the women on insulin, the average length of time on insulin was 12.3 years (SD = 8.9). For the 35 women on insulin, the average number of daily injections was 2.0 (SD = 1.3) and the number of injections ranged from 1 to 5. One woman was on continuous insulin pump therapy.

Monitoring of Blood Glucose

The frequency of home monitoring of blood glucose varied considerably in this sample. More than half of the women ($n = 22$) in the sample tested their blood glucose at least daily. Twenty-five percent of the women reported that their most recent self-monitoring of blood glucose was at least 3 days prior to the interview. Two women stated they did not test their blood. Women were asked what the result of their most recent self-monitored blood glucose test was. The women's actual blood glucose ranged from 50 to 400 mg with an average rating of 167.9 ($SD = 69.4$). Ninety-two percent of women reported recent blood glucose ratings between 80 and 240 mg.

Perceived Glucose Control

Women were asked to rate how well they thought their blood glucose had been controlled over the past week on a 4-point scale ranging from very well controlled (1) to not very well controlled (4). The mean perceived control score was 2.4 ($SD = .87$) or between moderately and fairly well controlled. The median and mode category for perceived glucose control was 2 or moderately well controlled.

Perceived Illness Severity and Health

When women were asked to rate how serious they perceived their own illness on a 4-point scale, with 1 indicating not very serious to 4 indicating very serious, the mean was 2.8 ($SD = 1.1$) or moderately serious. The mode was 4, suggesting that most women considered their illness very serious. When asked to rate overall health on a 4-point scale, with 1 indicating excellent and 4 indicating poor, the mean was 1.98 ($SD = .53$) or closest to the "good" category. The mode was also

"good" for perceived overall health.

Complications of Diabetes

The frequency and type of diabetes-related complications were requested from the women. The average number of complications experienced by the women in this sample was 1.2 (SD = 1.7). Almost half the sample (19 women) did not report any diabetes-related complications and one woman reported nine. The most common complications of diabetes experienced by the women in this sample were retinopathy or eye problems (35%), peripheral neuropathy (25%), gastrointestinal disturbances (diabetic diarrhea or gastric distress, 20%), and slow healing and infections (12%). A few women reported gynecological problems including difficulties with pregnancy, vascular disease, and renal problems. The most common types of surgeries reported were laser surgery for retinopathy (15%), and gynecological surgery (15%).

Diabetes Symptoms

A symptom checklist was used in order to assess the type and frequency of diabetes symptoms. The presence of symptoms is considered a short-term indicator of women's diabetes control. The range of scores on the Diabetes Symptom Checklist (DSC) was between 2 and 80 and the mean score was 24.8 (SD = 16). The most commonly experienced symptoms reported included sleepiness (1.6), attacks of hunger (1.3), increased thirst (1.2), blurred vision (1.1), vaginal itching (1.1), poor concentration (1.1), urinating at night (1.1), attacks of sweating (1.1), headache (1.1), and numbness or tingling in limbs (1.1). The symptoms that were reported least included painful

urination (.08), cloudy urine (.25), nausea (.33), shortness of breath (.33), constipation (.33), foul smelling urine (.36), and stomach pain (.38).

Other Health Problems

Eighty-five percent of the women reported one of more health problems in addition to diabetes with an average number of 2.0 (SD = 1.4). Thirteen women (almost 33%) reported musculoskeletal conditions such as arthritis or carpal tunnel syndrome. Thyroid disorders were reported by about 28% of women; gynecological problems were present in 20% of women; hypertension and fluid retention were reported by 17.5% of women, and cardiovascular problems were present for 12.5% of the sample. Psychological difficulties, primarily depression, were reported by 12.5% of women.

Seventy percent of women took medications for illnesses other than diabetes. The average number of medications used was 1.5 (S.D.=1.39) with a range of 0 to 6. Hypertensive and thyroid medications were the most common types of medication used (22.5% each) followed by antidepressants (15%), muscle relaxants (12.5%), and antihistamines (12.5%).

Illnesses in Past 2 Months

The mean number of illnesses in the past 2 months was .5 with a standard deviation of .7. Most of the women in the sample (62.5%) reported not having any illnesses in the previous 2 months. An additional 30% of women had been ill only once in the past 2 months, and only three women reported more than two illness episodes. About 22% of the women in the sample reported having been hospitalized in

the past year; However, only three of the women reported that the hospitalization was related to their diabetes.

Body Mass Index

Women were asked to report their height and weight in order to calculate body mass index (BMI), a measure frequently used in clinical health assessments. The mean weight of the women was 154.4 pounds (SD = 40.6) with a range from 106 to 275 pounds. The reported height ranged from 61 to 71 inches and the mean height was 65.4 inches (SD = 2.5). Body mass index was determined by calculating the ratio of body weight in kilograms/(height in meters)² (Thomas, McKay, & Cutlip, 1976). Overweight and underweight status are given values which fall above and below 20% of the "desirable weights" established by life insurance companies. In this study, 70% of the women were in the desired weight range, 27.5% were overweight, and one woman was underweight. Interestingly, when women were asked whether they thought they were at their desired weight, overweight, or underweight, only 30% of women reported they were at their desired weight; 65% thought they were overweight, and 5% considered themselves underweight. Crosstabulations were used to explore further the relationship between actual weight status and perceived weight status. Fifteen women (37.5%) considered themselves to be overweight when they were in the normal range according to the BMI standards. Mitchell (1986) found that 75% of healthy women tended to overestimate their body size. It is possible that women with a chronic illness such as diabetes are more aware of dietary needs and more realistic about body size than healthy women.

Mental Health

When asked about mental health counselling in the past year, almost 33% of women (n = 13) stated they had seen a mental health counselor during that time period.

Description of the Research Measures

Standardized measures were used to generate data on development, transition status, and psychosocial adaptation (depression, anxiety, and family and social illness demands). Each of the research instruments is described in the next section. Measures of central tendency for all the variables were computed and are shown in Table 16. The descriptive statistics reported are means, standard deviations, medians, and ranges of scores. All calculations were performed on the total sample. If missing data were present, those participants' data were not included in the calculations. In addition to the results on the standardized measures, the results from the analysis of the open-ended interview on the management are reported.

Developmental Status

Loevinger's Sentence Completion Test. The primary method used to evaluate psychosocial development on all women was the Washington University Sentence Completion Test (SCT) developed by Loevinger and Wessler (1970). The ego development stages of women in this study ranged from the Conformist stage (I-3) to the Autonomous stage (I-5) with the most frequent stages being the Conformist/Conscientious transition (I-3/4) and the Conscientious stages (I-4) (See Table 17). The stages of development of women were similar to those reported for another sample of adults with diabetes. Jacobson, Rand, and Hauser

Table 16

Descriptive Statistics for Measures (N = 40)

	Mean	SD	Median	Range	Possible Range	High Score
Completion Test Sum	184.7	18.5	184.0	149-226	36-324	↑ Ego de- velopment
Transition Status	16.6	6.1	16.0	5-32	5-35	↑Change
Depression (CESD)	12.7	9.9	9.0	0-40	0-60	↑Depression
Anxiety (STAI)	38.2	12.3	35.0	21-65	20-80	↑Anxiety
Diabetes Symptoms	24.8	16.0	22.0	2-80	0-144	↑Symptoms
<u>Demands of Illness (DOI)</u>						
<u>Dimensions</u>						
Physical Symptoms	9.4	7.4	8.0	0-34	0-48	↑Demands
Personal Meaning	21.9	12.2	21.0	0-64	0-64	
Family Functioning	25.0	19.3	20.0	0-80	0-140	
Social Relationships	9.2	6.9	7.5	1-26	0-40	
Self-Image	8.0	6.9	6.0	0-27	0-36	
Monitoring Symptoms	15.5	8.1	16.5	0-34	0-44	
Treatment Issues	25.0	12.6	24.0	4-51	0-128	
Total Scale	115.0	55.8	104.0	11-230	0-500	

Table 17

Frequency Table of Ego Development Stage (Loevinger) (N = 40)

Stage	Frequency	Percent
Conformist	3	7.5
Self-awareness (Transition stage)	14	35.0
Conscientious	13	32.5
Individualistic (Transition stage)	4	10.0
Autonomous	6	15.0

(1985) reported a median stage of I-3/4 for diabetic adults whose average age was 40 years. Only three women had ego development ratings at the Conformist stage (I-3) in which the primary mode of operation is identification with a group. The responses to the sentence stems by the women in the I-3 stage tended to be concrete statements, generalizations, passive acceptance and reactions, and statements rather than evaluations. The sentence stem, "Being with other people," evoked responses such as "is fun," "is nice," "is enjoyable," or "makes me very happy."

The Conformist/Conscientious transition (I-3/4), the stage of heightened self-awareness, was the most frequent stage (n = 14). These women tended to respond to the SCT in a slightly more differentiated way. They were conscious of feelings, internal states, and inward virtues. A beginning ability to evaluate the self and situations was present at times. They recognized the importance of social expectations. In response to the stem, "Raising a family," women in the I-3/4 stage responded "is a full time job," is very important to me," "is fun and a big responsibility," and "is out of the question for me because of my diabetes and my eyes."

Thirteen women were rated in the Conscientious stage (I-4) which is characterized by an increased sense of personal responsibility. Women in this stage responded to stems with a sense of individuality and the ability to contrast feelings and actions. They demonstrated a sensitivity and respect for others and the capacity to self-evaluate with some psychological insight. They could balance and weigh contradictions and compare two points of view. The I-4 woman responded

to the stem, "When people are helpless," with "they need family and friends to give them support," "they need to be listened to," "they usually need some help with their self-esteem," and "they are vulnerable."

In the transition stage between the Conscientious stage and the Autonomous stage (I-4/5), the person has a heightened sense of individuality. Four women were found to be in the I-4/5 transition stage. Responses to the stems were characterized by a sense of increasing conceptual complexity, internalization, valuing the freedom of expression and individuality, and the ability to stand aside and evaluate oneself. For example, responses to the stem, "A woman feels good when," were "she talks with other intelligent, thoughtful women," or "she has a loving, compassionate friend in her partner." The stem, "Rules are," evoked responses such as "best when they are as flexible as possible and only as many as required," or "necessary but can be confining."

The Autonomous stage, characterized by the recognition of the value for both the individual and the group, was the stage for six women. These women were able to express and cope with conflicting feelings, choices, rules and demands, express concern for the meaningfulness of their goals, and demonstrate creativity and a high level of conceptual complexity. Examples of responses to the stem, "Women are lucky because," were "they have more emotions than men and thusly get more out of life, although depending on how those emotions are handled, they can also cause more problems," and "most women have a great capacity for love and caring of humanity."

Although none of the women were rated at the I-6 or Integrated stage, this may be because of the difficulty in scoring higher level protocols. It is possible that some of the women whose SCT were rated I-5 might have been at the Integrated stage. An example of an I-6 response to the stem, "For a woman a career is," was "an individual choice - important to some but not for others. A woman's choice in this matter should be respected." This response characterizes the Integrated stage in that it weighs and evaluates different roles expectations, allows for the preservation of individual choice and identity.

Although the discrete stages identified by Loevinger (1976) were of primary interest in this study, one alternative method of deriving total protocol rating was used. In order to place ego development scores on a continuum, a sum of the 36 items was computed (King, 1986; Loevinger & Wessler, 1970). The scores ranged from 149 to 226 with a mean value of 184.7 (SD = 18.5). The correlation between the sum scores and the discreet stages was $r = .94$, $p = .000$.

Transition status. The purpose of the final developmental measure, whether or not the woman perceived she was in a transitional period in her life, was twofold. The first reason was to determine whether each woman was in a stable or a transitional time in her life. Secondly, the relationship between perceived transition status and developmental stages that are considered transition stages was of interest. Transition status was measured in two ways: (a) women completed a 5-item self-descriptive semantic differential scale (Killien, 1983); and (b) women responded to an open-ended question

about current life state.

According to the results on the semantic differential subscale, women reported being in a neutral zone rather than viewing their lives as being stable or changing. Scores ranged from 5 to 32 and the mean for the sample was 16.6 (SD = 6.1) with the higher end of the scale suggesting more change than the lower numbers.

Responses to the open-ended question were coded first into four distinct categories: (a)stable; (b)transition; (c) circumstances are changing, I'm not; and (d) I'm changing and so are my circumstances (Table 18). For reasons of parsimony, the three categories identifying any change were collapsed into one so that two categories, stable and change, remained. In response to the open ended questions, women in the study more commonly reported being in a period of change or transition than in a stable period in their lives. One-third of the sample ($n = 14$) reported being in a period of stability whereas the remaining 65% reported some change or transition in their lives. Of the 26 women who reported being in transition, 18 women reported being in a period of transition, six felt they were stable but their situations or circumstances were changing, and two women stated they were stable and changing at the same time.

The relationship between the two measures of transition status was explored using correlational analysis between the semantic differential questions and the response on the open-ended question (stable or changing). The two measures of transition status were moderately correlated ($r = .43$, $p < .01$).

Table 18

Self Report of Transition Status on Open-Ended Question (N = 40)

Category	Number	Percent
Stable period	14	35.0
Transition or change	18	45.0
Circumstances are changing, I'm not	6	15.0
Circumstances are changing and so am I	2	5.0

Relationship between developmental status and transition status.

In order to examine the relationship between developmental stage and transition status, a number of separate analyses were carried out. First, the stages in Loevinger's model of ego development were collapsed into two categories according to whether the women were in transition or non-transition stages. Twenty-two women were in the non-transition stages I-3, I-4, and I-5. Eighteen women were in Stages I 3/4 and I 4/5, the stages considered to be transition stages. Nonparametric analysis of variance was used to explore the relationship between the scores on the semantic differential transition scale and developmental stage. Chi-square was used to examine the relationship between the open-ended transition question and the developmental variable. No significant relationships were found between stages of development that are considered to be transitional stages and the transition variables (the semantic differential transition scale or the open ended question on transition status). Women's perception of whether or not their lives were changing was unrelated to the notion of transition between stages of psychosocial development in this sample.

Psychosocial Adaptation

Depression. Women in this study reported more symptoms of depression on the Center for Epidemiological Studies - Depression Scale (CES-D) than have been documented in community samples. However, for the sample as a whole, the mean score did not exceed the cutoff to be considered depressed (Radloff, 1977). According to Radloff (1977), the average score for a national sample was 8.7 (SD

= 8.4) and the cutoff score to identify depression was 16. The mean score on the CES-D in this sample was 12.7 (SD = 9.7), and the range of scores was between 0 and 40. Items on the CES-D that had the highest mean scores were: I could not get going (1.1), I felt hopeful about the future (.95), my sleep was restless (.95), I felt depressed (.85), and I felt sad (.83). Items with the lowest means were I felt that people disliked me (.28), I thought my life had been a failure (.40), and I did not feel like eating (.40).

Anxiety. Another measure of psychological state used in this study was the Spielberger State Trait Anxiety Inventory (STAI). For the women in this study, the scores on the STAI were slightly higher than those reported by Spielberger and others (1970). The women's mean score was 38.2 (SD.= 12.3) and the scores ranged from 21 to 65 with the higher numbers suggesting more anxiety than the lower numbers. In Spielberger's sample (1970), a mean score of 36.2 (SD = 9.3) for women between the ages of 19 and 39 was reported. A mean score of 35.0 (SD = 9.31) was reported for women ages 40 to 49 (Spielberger, 1970). Items with the highest mean scores in the present study included: felt rested (2.7), I lack self-confidence (2.2), I am calm, cool, and collected (2.2), I am content (2.1), and I make decisions easily (2.1). Items with the lowest mean scores included: some unimportant thought runs through my mind and bothers me (1.6), and I feel like a failure (1.6).

Feelings of depressed mood and anxiety were common among women in this sample. This relationship between psychological affect and diabetes has been documented in the literature (Lustman, Griffith,

Clouse, & Cryer, 1986; Murawaski et al., 1970; Rodin, 1983; Sanders et al., 1975). Furthermore, the differential impact of depression on women has been reported (Weissman & Klerman, 1977).

Illness demands. Women experienced a variety of family, social, treatment, symptom, personal meaning, and self-image demands associated with their illness. The mean number of reported demands of illness according on the total Demands of Illness Inventory (DOII) was 115.2 (SD = 55.1) with a range from 11 to 230. The mean values, standard deviations, medians, and ranges for each of the seven DOII subscales are listed on Table 16. The specific kinds of demands of illness reported by the women are reviewed in order to illuminate the experiences of women living with diabetes.

Interestingly, items on the total DOII with the highest means were in the treatment accommodation, symptom monitoring, and personal meaning subscales. For example, the items with the highest mean value included having to be more regimented in eating times (2.5), making her entire life more regimented (2.0), worrying about illness complications (2.2), worrying about health getting progressively worse (2.1), thinking about the illness being unending (2.1), considering the value of life for her (2.0), and considering how long she might live (2.0). On the overall DOII, the items with the lowest reported means included wondering why treatments was being given even though symptoms had subsided (.00), feeling worse rather than better after the treatment (.10), having difficulty finding suitable clothing (.10), partner having to change work patterns (.11), having to change child care arrangements (.13), and questioning if the adverse effects

of treatment outweigh the benefits (.15).

The family and social relationships subscales of the DOI were of particular interest. Score on the family functioning subscale scores ranged from 0 to 80 with a mean of 24.3 (SD = 19.3). Items on the family functioning subscales with the highest mean values included having to change meal patterns (1.5), deciding what is really important (1.4), needing more emotional support from family (1.3), worrying about how children were reacting to the illness (1.2), and needing the partner to be more sensitive to moods (1.2). Items with the lowest mean values included the partner having to change work patterns (.11), having to change child care arrangements (.13), not having enough money to support the usual lifestyle (.23), not being able to work at her job (.26), and revising rules for the children (.28). On the social relationships subscale, the scores ranged from 1 to 26 with a mean score of 9.2 (SD = 6.9). The items with the highest reported means included others not really understanding what she is going through (1.8) and having to help others understand the illness (1.6). The item with the lowest mean was others acting differently toward her (.51).

Summary of Descriptive Findings

The study sample consisted of 40 women who had diabetes mellitus. The average age was 38 years. Most women were married with a school-aged child, moderately well educated, middle to upper middle-class, and employed outside the home. The median household family income was between \$30,000 and \$35,000.

Most women (87.5%) had insulin-dependent diabetes mellitus. For the women on insulin, the number of daily injections ranged from 1 to 5 with an average of 2 per day. The mean duration of illness was 13 years and the average age at diagnosis was 26 years. Over 90% of women self-monitored their blood glucose, but only half of those women tested their blood sugar at least once a day. The recommendations for blood glucose monitoring are for multiple daily tests (Diabetes Data Group, 1985). Therefore, women did not test their blood sugar as frequently as recommended. Women reported an average self-monitored blood glucose rating of 170 mg for their most recent test. This is slightly higher than the ideal blood sugar range of 80 to 140 mg recommended by the Diabetes Data Group (1985).

Diabetes severity was assessed in a number of ways. Long-term diabetes control was assessed by asking the women to report the number of diabetes-related complications. Half of the women did not report any diabetes-related complications. Of those who experienced complications, the most common complications were retinopathy, neuropathy, or gastrointestinal disturbances. Diabetes-related symptoms as measured by frequency and intensity of symptoms was used as an indicator of short-term diabetes control. The wide range of diabetes-related symptoms reported by women indicated that the day-to-day manifestations of the illness varied a great deal. Women's perceptions of their diabetes severity, diabetes control, and overall health were assessed also. Women rated their illness as being moderately serious. They considered their diabetes to be fairly well to moderately well controlled. They rated their perceived overall

health good.

The developmental stage of women was assessed using the Washington University Sentence Completion Test. The most frequent stage of ego development was the transition stage between Conformist and Conscientious stages. According to the results on a semantic differential scale that measured transitional status, women were in a neutral phase rather than either a transitional or stable state. However, on an open-ended question assessing perceived transitional status, 65% of women responded that they were experiencing some element of change in their lives.

Women's adaptation to diabetes was examined. Depressed mood, anxiety, and perceived illness demands on family and social relationships were assessed. Women in the sample reported more depression and anxiety than normal populations and a variety of illness-related family and social demands.

CHAPTER 5
PATTERNS OF DIABETES MANAGEMENT

One of the major goals of this research was to explore the different ways in which women coped with their diabetes routines on a day-to-day basis. Diabetes mellitus is an illness that requires intensive patient involvement and complex skills in order to maintain stable metabolic control. An underlying assumption was that common patterns existed in how women managed their illness. A semistructured interview format was used to elicit data on how women dealt with the major aspects of their diabetes regimen such as medication management, food, monitoring of blood glucose, management of symptoms, and exercise (Johnson et al., 1986). Domain analysis was used to identify categories and develop a typology of patterns of management. In addition to the search for patterns of diabetes management, a core variable emerged from the qualitative analysis that integrated the major categories. The core variable, clinical safety work, is described and is followed by the description of the patterns of management. The specific categories and their properties and definitions are described in Appendix Q.

Description of Clinical Safety Work

The core variable, clinical safety work, helped explain the interrelationships among the categories and the major action occurring in the data (Strauss, 1987). The investigator assigned the term clinical safety work to define the daily work involved when a woman lives with diabetes. The term was originally used by Strauss and

others (1984) to describe the work patients with diabetes do when they are hospitalized. In this study, clinical safety work encompassed all the complex tasks the woman engaged in such as administration of medications, dealing with food as an integral part of the treatment, controlling symptoms, monitoring the blood sugar, modifying the regimen to prevent a reaction, organizing and planning for activity and exercise, and dealing with the people around her. Complicating the illness management process was the reality that even slight alterations in any part of the regimen affected other parts.

The process of clinical safety work was engaged in each and every day. Clinical safety work involved "being a clinical practitioner 24 hours a day" (Benoliel, 1975). One woman described some of the dimensions of clinical safety work as she reviewed her daily routine.

As soon as I get up in the morning, I check my blood sugar and take my shot and I take the same amount of ultra lente all the time and the regular (insulin) is about the same unless my sugar is real high in the morning. I'll take a little bit of extra regular (insulin) or if it is real low, I also regulate the regular to what I'm going to do. If I'm going to go play a game of tennis in the morning then I would take a little bit less, maybe a couple units less and eat a little more for breakfast. (Participant #24).

The continuous, never ending repetitious nature of the diabetes routine also stood out. Another woman described how diabetes never goes away.

That's the thing. You've got to anticipate, you've always got to be a step ahead of it, you know, keep ahead of the surprises, you're still going to get surprises in there but you've got to keep on it...I think that's one of the stresses, too is that you're not going to wake up one morning and well it's all gone. It stays with you for the duration you know. It's not something you can take a vacation from, it's there every day of the year, constantly and it never goes away so...you just get tired of it all,

just like anything else you need a break from the routine, but you can't. (Participant #3).

Clinical safety work was defined as a process with numerous interacting dimensions and tasks that women with diabetes engaged in on a daily basis. The major dimensions of clinical safety work were blood sugar monitoring, managing the blood sugar and modifying the regimen to prevent reactions, medication management, management of food as part of treatment, managing exercise as treatment, and the use of allies. Each of the dimensions and their interrelationships with other dimensions is described next.

Blood Sugar Monitoring

Blood sugar monitoring was a multiphasic self-appraisal process that involved both routine information gathering about blood glucose levels as well as increased information seeking when the woman felt that things were not quite right. In their monograph on living with chronic illness, Strauss and others (1984) referred to a similar process called "reading the signs."

Blood sugar monitoring involved paying close attention to symptoms (the cues or warning signs that the blood sugar might be high or low), deciphering what the warning signals meant, recognizing patterns that might influence her blood glucose, and actively testing the blood sugar to validate symptoms. Women varied in the degree of vigilance practiced on the blood sugar monitoring dimension of clinical safety work. One woman described her routine blood sugar monitoring and a special case that prompted her become more vigilant in her blood sugar testing.

Usually in the morning I try to do one [blood sugar test] before I take my insulin when I first get up and then...sometimes I only do one a day, depends upon how I'm feeling. You know, if I'm feeling kind of shaky and I can't determine for sure whether it's.. which way we're going, then I maybe will take it a couple, three times a day. (Participant #13)

The experience of symptoms, the subjective appraisal or evidence of physical disturbance, provided a trigger for the coping response. Women reported the subjective experience of both low (hypoglycemia) and high (hyperglycemia) blood sugar. One participant described how she felt when she was "out of control," an emic phrase referring to symptoms of high blood sugar.

I don't like it to go up to 270. ...I feel my body...your body gives you signs so I feel like.. when I get up ..the signs are usually the flutteriness, the stickiness in the joints and um just a ..I guess a funny feeling then I begin to get alarmed. (Participant #17).

Women tried to related their symptoms of high or low blood sugar to intensifying factors or triggers such as stress or skipping a meal. For example, some women reported that they thought stress had a tendency to raise their blood sugar. This impression has been documented in the diabetes research literature. Hansson, Henggeler, and Burghen (1987) reported a direct relationship between stress and metabolic control. The ability to recognize their patterns helped women explain why their blood sugar was high or low. One woman described the kind of pattern recognition and detective work she did in figuring out what was happening with her blood sugar. She described a process of "checking in" with her blood sugar when she experienced "feeling low."

Well, if I start having insulin reactions for no reason that I can relate it to, for example, if I've skipped a meal, obviously I'm going to have one and I know I've got it coming. But if it's eleven o'clock and I go into one for no reason that I can think of, I might test to find out what the problem is or if I just feel like the blood sugar's going to ... you start feeling really sluggish or dragged out or just aren't feeling well... and there's nothing...no other reason that I can relate it to, I think well I better check in and see what's happening. (Participant #21)

The ambiguity in deciphering symptoms of low blood sugar from other physical sensations was described by a woman who was breast feeding her infant.

It's been a lot harder for me to control (my blood sugar) since I'm nursing her because I can't tell the difference between just being real hungry because I'm a nursing mother and feeling really hungry because my blood sugar is going low... (Participant #22)

Some of the women did not experience symptoms of low blood sugar and therefore did not have the physical warning factors to trigger them to action. The inability to detect symptoms or warning factors seems to be associated with increased duration of diabetes. This phenomenon is thought to result from nerve damage (National Diabetes Data Group, 1985). The duration of diabetes and the ability to detect symptoms were not related in this sample. One woman described her inability to detect symptoms.

I very seldom have any symptoms. I can get down to like in the 20's, and I'm fine. I mean, I'm not like shaking or anything. Usually, I mean in the past way back when I first had diabetes I used to get the typical sweating and shaking and that type of thing. But in the last 8 years it's like I've gone past that phase and something's happening in my body where I've gone past the phase of noticing if I am shaking or sweating. I don't know, and it goes past that and it just goes to the point where it's just kind of gradually crept up, and then before I know it I'm so low that I don't realize it, and there's nothing I can do about it, you know. In the cases that's happened, which is not

often, luckily, my husband's been here. Cause otherwise I don't know what would happen. (Participant #40).

The process of blood sugar monitoring involved paying close attention to symptoms, testing the blood sugar, and figuring out what the experience of symptoms and results of the blood sugar monitoring meant. This self-appraisal phase is critical in blood sugar management. A description of the next phase of clinical safety work, managing the blood sugar to prevent a reaction, follows.

Managing the Blood Sugar to Prevent a Reaction

While appraising the blood sugar situation and gathering the necessary information, women engaged in the process of regimen modification. An integral part of treating either high or low blood sugar was being prepared with emergency food and supplies. Women carried a wide variety of sugar substances such as sugar packets, life savers, candy bars, juice, fruit, and glucose tables in their purses or pockets. Most women kept some kind of food stash in their desks at work or in their cars. One woman talked about traveling with her "portable deli" so she always had food if needed (Participant #36). Another woman said "I'm always the one with the bag of food" (Participant #2). Being prepared with her insulin and blood monitoring equipment was essential to another woman. She showed me her "medium wilderness organizer first aid kit" in which she carried all her supplies in (Participant #3). In contrast, some women relied on having to purchase something if they felt their blood sugar was low. Strauss and others (1984) similarly discussed organizing for crisis as a dimension of living with chronic illness.

The experience of low blood sugar required immediate treatment to prevent passing out from hypoglycemia. Women varied in the degree of precision in which they modified their regimens. One woman described her use of glucose tablets to treat hypoglycemia because each one "brings me up about 15 milligrams...and within 10 minutes you can feel that you're really alert again...if you eat fruit or anything, it takes too long" (Participant #3). This woman's approach to dealing with an insulin reaction is contrasted with another woman's treatment of low blood sugar during a night reaction.

Usually my heart's pounding and I'm sweating and that wakes me up and then it's like so startling that usually I just am so out of it...I just get down here and I start munching down food, I eat too much...by the time I'm awake, oh my god, I just ate a whole box of graham crackers or something like that then my sugar's too high in the morning.
(Participant #33)

Rather than reacting right away, some women waited to see what their blood sugar would do over time. "If it's high that day, I usually watch it for a couple of days just to see if it's due to something that happened that day, or maybe something I'd eaten or whatever" (Participant #40). Other women would adjust their insulin dose immediately based on a high blood sugar result. "If my vision is poor then I have to test my sugar because my blood sugar would be up and then of course I'd adjust my insulin anywhere from two to six units" (Participant #18). Other women managed their blood sugar by reducing their food intake, watching what they ate, or exercising. All these strategies have been reported by O'Connell and others (1984).

Even though the women treated their high or low blood sugar episodes, some talked about paying the consequences of having a reaction with a lingering headache or utter exhaustion. "I felt yukky the whole rest of the day just like my head was someplace else" (Participant #20).

To summarize, modifying the regimen occurred after women experienced symptoms of high or low blood sugar. For the most part, women practiced self-management in dealing with the day-to-day fluctuations in blood sugar rather than consulting with health care providers. Modifications to the diabetes regimen often involved altering insulin doses. The next section elaborates the dimension of medication management.

Medication Management

Because diabetes is a disease that mandates a fine metabolic balance between insulin and glucose levels, management in one dimension affects other dimensions. The administration of medications was a complex process that women approached with varying degrees of rigidity or flexibility. Some women tried very hard to maintain a very stable routine and did not adjust their insulin but maintained a consistent dose and time and ate very regularly. Other women highly desired flexibility in their day-to-day management. Determining the amount of insulin and the time to inject it involved complex decision making based upon symptoms, blood sugar levels, planned activities, and food intake. One woman talked about how she decided the amount of insulin to take.

It depends..I go on what my blood sugar reads for that morning and judge what I should take from that and especially if I'm going to exercise one morning you take less than what you would [if you weren't going to exercise]. (Participant #5)

Another talked about juggling the timing of her evening insulin dose.

If we're going out to eat or something, I'll take regular insulin before I leave work so that when I get home I can eat but then that means I have to take my long acting (insulin) in another shot. In other words, I already do three so I don't like to split it up but I kind of play that by ear. Usually, I try to, when I get in the door, take both together and then wait half an hour before I eat something but some nights my scheduling or we're going out to eat or something just doesn't jibe with that. (Participant #19)

The fear of experiencing a low blood sugar reaction drove some women to maintain a blood sugar that was higher than they might have been advised by a health care provider. Although the women might have desired flexibility in their insulin doses and timing, not having an insulin reaction was of prime importance. "I guess one of my biggest worries is I'm real afraid about getting sick and passing out and leaving the kids" (Participant #33). "I tend to float along pretty high...I've had a couple of reactions when I just felt awful enough that I wanted to make sure it didn't happen again" (Participant #7).

My biggest fear regarding all this...my most proximal fear is having a reaction so I tend to overcompensate for that and so um...usually I will have just eaten more than I should have. (Participant #1).

I guess because I'm uncomfortable talking to other people about diabetes I try and down play a routine so that when we're hiking I don't have insulin reactions...and that's why I usually take it on the high side rather than the low side because I don't want to disrupt routines. (Participant #6)

In review, medication management was interrelated with other key aspects of the diabetes regimen for women. Food and exercise management, symptoms, and the social environment played an important role in how women went about managing their medications.

Managing Food as Treatment

Food took on special meaning for women because it was an integral part of their treatment. The types of food eaten and the timing of meals and snacks must be calculated carefully in order to maintain an ideal blood sugar level. Too much or too little food eaten earlier or later than needed can threaten the fine balance needed to maintain adequate functioning. As with the other dimensions of clinical safety work, women exhibited variability in how they approached the management of food as treatment.

Although most clinicians prescribe specific diabetic diets for people with diabetes, women exhibited variability in how they followed the prescriptions. Some women followed a prescribed diet. "I'm on an ADA diet and I try to stay at about 1200 calories" (Participant #34). "I follow the basic exchange diet with cheats here and there, usually I do a pretty good job" (Participant #22). Other women took the prescriptions loosely. "I try and follow what I think is a common sense. I don't eat a lot of fats...I eat lot of complex carbohydrates and green vegetables and stay away from meat. We eat a lot of fish." (Participant #25) Still other women were not strict about their diet. "I wouldn't say there's anything I deprive myself of, and I never really think, oh my God, I shouldn't have that because it's got sugar in it" (Participant #39).

The regularity and timing of meals was another dimension of food management. Some women tried to eat their meals at very regular times and followed rigid time schedules even on weekends. For others, the timing of a meal might be juggled to accommodate a special event. In other words, there was room for flexibility and special planning was done to allow for a "treat." Regularly scheduled meals were simply not a part of the treatment regimen for other women.

Meal time is variable. I mean sometimes I feel like eating at five and sometimes I don't eat until 8:30 and then the time of my shot varies of course. Um..sometimes I eat out with a friend and so um...I don't stick to a real...I'm not very strict about my diet like two breads and one meat or whatever, I don't use that ...exchange stuff. (Participant #1)

Different approaches to the management of food were found in the data. The categories varied on the degree of caution exercised in relation to food management and took into account the woman's desire for regularity on a daily basis as well as how the woman dealt with eating in social settings. One woman talked about eating sensibly by ordering plain cooked food and asking for her food without sauces. Another woman asked about the ingredients of restaurant foods and avoided eating foods if she did not know what was in them. Women used a variety of strategies to adjust their food intake for the day or for a particular meal in order to achieve flexibility. They might save calories by eating less throughout the day so a larger meal could be eaten later. These women wanted to find a way around the situation in order to do what they wanted to do.

Occasionally if we go out to dinner then I have something at the normal time that we would have dinner to just kind of hold me over...if we're going to go out to dinner like at

7:30 or 8 o'clock, I would have something at the normal time that we would eat and then I don't run into problems with a late dinner. (Participant #34)

Another strategy used was to eat what was desired or served and then "cover" their blood sugar with insulin. "If we go out to dinner I may know that I'm going to run a little high and I try to cover it by taking a little extra regular in the evening" (Participant #25).

Managing food as treatment involved temporal juggling, making special plans for eating out, adjusting the insulin dose, and trying to remain disciplined about food in a society that encourages self-indulgence (Benoliel, 1975). Benoliel's (1975) description of diabetes as an illness in which "the commonplace in living becomes uncommon" is supported in the dimension of food as treatment.

Management of Exercise

Although exercise is recognized as an important part of diabetes treatment for most people with diabetes (Horton, 1988), most women did not exercise regularly as part of their diabetes routines. Some were sporadic exercisers. For example, this woman was limited by her physical condition.

My plans are eventually to try to work out an exercise routine. This infection in my foot kind of threw that out of whack because I was just about into my third day of swimming every day when this occurred and the doctor said I need to keep it out of water until it's completely healed, My neuropathy kind of limits what I can do physically because of the fact that I don't have any feeling in my feet and part of my legs. I was going to try and incorporate a good daily walk along with the swimming but without being able to tell if there's a rock or anything in my shoe it's going to kind of knock that idea... (Participant #16)

As with the other dimensions of clinical safety work, medications, food intake and their timing had to be carefully

considered. Women tried to be conscious of what and when they ate when they prepared for exercise. Because exercise is thought to increase the sensitivity of body cells to insulin, blood glucose levels during or after exercise may be lowered (Hanson, 1988). A common strategy to prevent a blood sugar reaction was to eat more. An alternative strategy was to decrease the insulin dose. Women's level of comfort in adjusting their insulin dose varied. Some women admitted they did not know exactly how to make adjustments so they guessed about dosages and eating. Emergency food often was carried in case of low blood sugar. A few women stated they monitored their blood sugar closely during exercise. One woman discussed her frustration with trying to find the magic formula for exercise.

I wish I knew what the combination was where if I wanted to go play ball all day or um..go bowling all day or go running or whatever...I'm kind of limited, I don't know how much I can do before I have to eat again and I don't like that...I like to be controlled over my body instead of my body being controlled over me and that's something you have to bear and live with..everybody's so different, why can't they come down with a formula that you need so much insulin and this is what you would eat if you wanted to go ride bikes all day or whatever. (Participant #23)

Exercise, therefore, posed special problems for women with diabetes. The timing and amount of food as well as the dosage and timing of insulin had to be calculated carefully. Although frequent blood sugar monitoring is recommended during and after exercise (Diabetes Data Group, 1985), few women talked about doing this on a routine basis.

The Use of Allies

The final dimension of clinical safety work involved the woman's perception of the people around her. Women talked about the people around them in qualitatively different ways. Most women had people who were generally supportive. Support groups functioned to help some women feel supported and some women talked about their partners as supportive of their moods. Another way allies functioned was to act as rescuers from the imminent dangers of an insulin reaction. One woman's strategy was to have her children call 911 if she ever passed out. Family members or work associates would bring the woman juice or emergency food if they sensed she was having an episode of low blood sugar.

I have those glucose tablets at work, the girls are aware of the...Here at home I always have juice or something so I'm not as prone to having them here at the house as I am every place else...My son is very aware of orange juice and sugar. His main problem is getting me to drink it..but he mixes it, he's got it right there and he tries to force it, but of course it's hard to force your mother. (Participant #18)

Another subtle distinction in the supportive roles played by allies was that of protecting them from external stress. Protecting others intervened on behalf of the woman, eased the tension in the situation, or gave people information on the woman's need to eat at a specific time. One woman described how her daughter "scurries around and tries to make things easier for me if she knows things are tense. She tries to organize things so we can eat on time..she tries to keep the tension level down..she's a good kid" (Participant #13). One woman talked about how her husband "runs interference" for her and "passes on information about diabetes to other people. He tends to be

real good about letting other people know what diabetes is like and how it affects me and our family" (Participant #7).

Some of the women's allies were more involved in the diabetes routines than others. Giving insulin injections on a regular basis or taking over the insulin and blood testing routines when the woman was sick are examples of what involved others did.

I have a friend who is diabetic and we talked about how diabetics need somebody to take over when they are sick. That's how you feel when you're real sick with the flu, you just can't handle trying to figure out what to do. So I do all I can not to get sick and my husband's real good if I can tell him how much. He knows he's gotta get in there and see that I get my insulin. (Participant #24).

Not everyone in the social environment was supportive. Hindering others were people who openly placed obstacles in the way of the woman's ability to manage her diet or were unsupportive. Strauss and others (1984) referred to these people as conflicting others. One woman talked about the attitude of her family.

I would say I get such little support from anybody on this, it's sort of like hey this is my fault. This is the attitude of my mother, my sister, my husband, that I guess sometimes I start a real self-pity trip. That it's my fault I didn't take care of myself, and this and this is...so handle it yourself. This is really an attitude that they have. (Participant #37).

One woman discussed how she had to cook on one burner because her husband had been remodeling the kitchen for 14 months. She stated they were apt to eat out more or bring food in. "It's all either deep fried, put between buns or anything we're not supposed to be eating" (Participant #14).

Some women felt that there was absolutely no one to help them with their diabetes routines. Although almost all the women felt that

the illness routines were their responsibilities, most women believed they were not totally alone in every aspect of management. One woman who felt there was no one to help her stated:

My husband wouldn't know how to do a blood test, he wouldn't know how to inject insulin, he knows nothing about it and he's not too interested really. (Participant #6)

Women described the involvement of others in their diabetes routines in a variety of ways ranging from hindering to supportive. Most women believed there was someone to help them in emergency situations such as when experiencing an insulin reaction but not with the day-to-day tasks such as injections and blood sugar monitoring.

Summary

Clinical safety work is an abstraction that identifies and integrates the complex aspects of diabetes management. The responsibility for metabolic control of diabetes lies with the woman herself. The complicated set of skills includes the administration of medications by injection several times a day. Furthermore, many women must make decisions about the amount of insulin they inject, when to inject it, and what body site to use for the injection. In order to check on their blood sugar levels and to determine the amount of insulin to use, most people prick their own blood by poking a finger, putting a drop of blood on a test strip, and reading the amount of blood glucose. Although experts recommend multiple daily tests of blood glucose, women in this sample tested their blood sugar less frequently and talked about making dosage decisions based on their symptoms rather than test results.

Individuals with diabetes also must follow a specific diet based on the amount of calories as well as types of foods and eat at regular times in order to maintain an even blood sugar level. If normal blood sugar levels are not maintained, there is a price to pay. Many women went to extremes to avoid an insulin reaction in which they could pass out. Even if the reaction did not progress to the point of passing out, the physical manifestations of low blood sugar were extremely unpleasant and lingering. Eating too much has its consequences, too. When more food is injected than can be metabolized, women experienced symptoms such as feeling sluggish.

There are no magic formulas for maintaining diabetes control. The delicate balance of diet, insulin, and exercise was unique for each woman and some women were more aware of their own bodily responses than others. Complicating the balance among blood sugar, food, and insulin were environmental factors such as the women's family, work, or social life. The needs of others and a woman's own responsibilities had to be attended to also. Family members sometimes were barriers to the woman's ability to maintain diabetes control. Work environments that discouraged women from carrying snacks were potentially deleterious to their abilities to treat an impending insulin reaction. Social situations, such as potluck dinners, often created extreme challenges for women who had to eat specific foods within a narrow time range.

One woman's comments summarize the daily routine necessary when living with diabetes.

I used to think, oh, taking the shots, that's the worst of it. Then they tell you, no, it's not taking shots, it's also eating X amount of food at a specific time. And you think, how much worse can this get? Then you find out what a juggling act this is. It's all the little variables that go with it. (Participant #36)

Patterns of Diabetes Management

In addition to the core variable, clinical safety work, patterns of diabetes management were identified from the interview data. An assumption was made that some overall communalities existed in how women managed their diabetes. These communalities or patterns described the behaviors and strategies women used to live with diabetes on a day-to-day basis.

The patterns of diabetes management were based upon the variability in how women managed their insulin, blood sugar monitoring, food, and exercise as well as women's descriptions of why they went about their treatment regimens as they did. Women's description of their diabetes routines in relation to their family, work, and social lives were important in delineating the patterns of diabetes management. Throughout the description of clinical safety work, the variability in the ways women approached the management of their illness routines was discussed. For example, some women were very rigid in their meal scheduling and others ate rather irregularly.

The patterns were based on the investigator's interpretation of the overall configuration of categories and dimensions of clinical safety work. However, after each interview was coded for the categories and the patterns of management, the frequencies of the salient categories that defined each pattern were examined. This

served as a means of checking on the investigator's interpretation of the patterns.

Although women might exhibit more than one pattern of management or alternative patterns at different points in their lives, an assumption was made that emphasis was given to one over another at the time of the study. Therefore, when a woman described more than one pattern of management, the primary or predominant style was used in the analysis. However, the secondary patterns were noted, also. The six patterns or styles of diabetes management that were identified are described next. Table 19 shows the frequency distributions of the primary and secondary patterns of diabetes management.

Revolving Around the Social Milieu

The most common pattern of management was revolving around the family or the social milieu (n = 11). These women often knew what to do to manage their diabetes well but got hung up somewhere along the way. They were able to recognize the factors that influenced their blood sugar control such as stress or inattention to the regimen. The social milieu played an important role for these women in that they simply could not get to their diabetes routines. Women talked about their busy schedules, hectic or inconsistent eating patterns, and variable medication and monitoring patterns. Women's diabetes routines depended on their work or their family's schedules or interactions with the social milieu. Emphasis was placed on social interaction directing their eating, insulin, and testing routines. Although these women might exercise care in diabetes management, they acknowledged that their management routines could be better. Their

Table 19

Frequency Distribution: Patterns of Diabetes Management (N = 40)

<u>Predominant Pattern</u>	<u>Number of Women</u>	<u>Percent</u>
Revolving Around the Social Milieu	11	27.5
Calculating Adjuster	11	27.5
Driven by the Clock	8	20.0
Chancer	6	15.0
Straight Arrow	3	7.5
Minimizing the Routine	1	2.5

<u>Secondary Pattern</u>	<u>Number of Women</u>	<u>Percent</u>
No secondary pattern	15	39.5
Calculating Adjuster	9	22.5
Revolving Around the Social Milieu	5	12.5
Minimizing the Routine	5	12.5
Driven by the Clock	4	10.0
Chancer	2	5.0
Straight Arrow	0	

overall management seemed to reflect their priorities in life. The diabetes routines became increasingly problematic when women felt they were split too many ways.

Women who exhibited this pattern tried to prevent the diabetes-related demands from affecting their family and social situations. Women preferred not to let their diabetes interfere with their family, their children's activities, and their social relationships. Disruptions in the diabetes routines were commonplace as women tried to minimize the impact of diabetes on others and to maintain as normal an existence as possible. Diabetes was viewed as the woman's responsibility. One woman stated, "why should everyone around me pay the price?" Although women took responsibility for diabetes themselves, they did tend to use allies when needed. One woman's description of her difficulty in getting her dinner insulin injection is characteristic of someone who Revolved Around the Social Milieu.

I test before dinner and then take my shot..that's the one where I really have problems because I've got hungry kids and I'm trying to get dinner done and the baby wants to eat and for a while there I wasn't always getting that evening shot because I hate to take a shot without testing, it's just something I never do. So I skip the shot and end up with blood sugars of 180 or higher at bed time. (Participant #22)

Calculating Adjusters: Juggling the Routine to Fit My Life

Calculating adjusters (n = 11) seemed to take a good deal of control over their diabetes routines rather than let diabetes dominate their life. These women were proactive and willing to take the responsibility for diabetes management into their own hands. They were able to figure out a way to do what they wanted to do and seemed

to achieve freedom and flexibility. Calculating adjusters were able to recognize the triggers that affected their blood sugar, routinely or aggressively monitored their blood sugar, exhibited flexibility but were careful in their insulin administration and food intake, and planned for emergencies.

Obstacles were present for these women, but careful planning helped them to work around the challenges posed. Adjusters talked about varying their insulin doses based on their planned exercise or activities, symptoms, actual or anticipated food intake, and blood glucose levels. Although women maintained fairly regular meal patterns, there was room for exception. In other words, they decided their insulin dose(s) based on the day they were going to have. They depended upon their known patterns to adjust, were comfortable in that they knew their margin of safety, were information seekers, and were secure in their modifications they made in their routines. The calculating adjuster is characterized by one woman's statement.

You have to decide whether you really want to do something. If it's something you really want to do, you can always find a way around it. That's how I came onto the packing it around in the little red Torino because we'd leave the hotel in the morning, wander around and never come back until after dinner. Well, I didn't want to have to come all the way back to our hotel no matter where we were just to take a shot and then go back to eat so it all worked out. You can always figure out some way to do it. (Participant #2)

Being Driven by the Clock

Diabetes seemed to dominate life in subtle ways for the eight women who were driven by the clock. Life revolved around the diabetes regimen. The day-to-day existence was characterized by a very regimented and scheduled life. It was as if life were lived in a

time capsule with eating, in particular, being the most important organizing factor for the day. These women might have felt they were a slave to food. One woman described how she had to eat at a certain time because her insulin was peaking. They were very rigid and regimented in their diets and medication administration. Diligent planning ahead and being prepared for emergencies were characteristic of the women who were driven by the clock.

One woman talked about how her family was influenced by her management pattern of being driven by the clock.

My family watched a TV program on Channel 4 about a month ago where they were talking about the mother who had diabetes and how the whole family traveling revolved around when you're going to have to eat next and then my 16 year old just looked at me and said, sound familiar? (Participant #31)

Chancers

Women who were chancers (n = 6) juggled their diabetes regimens but did so in a haphazard and somewhat careless way. Some women admitted to guessing or playing around with their routines and not really knowing what would happen. They did not know quite what to expect when they juggled their insulin doses or eating patterns and they did not monitor their blood sugar aggressively. They tended to be inconsistent in their eating patterns and did not follow prescribed diets. Chancers displayed a great deal of inconsistency in the times they administered their insulin and may have used insulin to cover an overindulgence of food. These women seemed less able to recognize their triggers that influenced blood sugar control. They tended to want to avoid low blood sugar reactions and preferred to run their

blood sugars high to avoid a reaction. The chancer pattern is described by this woman.

I don't know the routines yet or the formulas to use to make all that precise. I know that there's a way you're supposed to measure, eat so much for so many...or shoot up with so many units of this in order to eat so much of that. Or shoot up so many of this if your blood sugar happens to be this much higher. I don't have those down yet. Up to this point, it's all been sort of juggling and pick and choose and a lot of guess work, that's the word, a lot of guess work. (Participant #26)

Straight Arrows

Women who were straight arrows were able to juggle their medications, eating, and exercise routines, but they did so with hypervigilance. Straight arrows tried to maintain very tight control of their blood sugars and were not afraid to experience hypoglycemia that could result from tight control. These women were strict followers of their special diabetic diets and were quite regimented in their eating patterns. They knew their own patterns and the factors that influenced their blood sugar control. Planning ahead, preparing for exercise, and knowing precisely what to do and expect was characteristic of these women.

I don't know what it's like to eat anything without calculating the grams of carbohydrate, protein and fat in it, I don't know what it's like to do any activity without estimating how much ..how many calories that activity is going to burn and knowing how to compensate for it. I don't know what it's like just to be a free spirit and do whatever you want to do on a whim, cause I always have to plan. (Participant #31)

One woman's hypervigilance is characteristic of the straight arrow.

What I'm kind of giving you is my minimum testing times and then you know as far as 7, 10, 12, 3 and then at 5 again

before dinner...and lets see at bedtime I usually do it at 10:30 between 10:30 and 11:00. And then like I told you before I drive..it just makes me feel more comfortable too, it's more like a habit you know. I don't think about it too much I just do it. (Participant #3)

Minimizing the Routine

Minimizing the diabetes routine is a pattern characterized by doing as little as possible in relation to diabetes. There was only one woman in the sample who demonstrated the minimizer pattern as her predominant pattern of management. However, five women seemed to be minimizers as a secondary pattern. Theoretically and clinically, this pattern was observed to exist; if the sample size were larger it is possible that more minimizers might have been identified.

The minimizer pattern was characterized by women who tried to conceal their diabetes, compartmentalize the diabetes routines, and/or do what was easiest. Keeping the status quo and symptoms at a minimum was important so that diabetes did not interfere family, work or the social routines. Minimizers talked about feeling like the "odd one out" and managed their diabetes in such a way as to limit intrusion on social interactions. There was a sense of denial or avoidance on the part of the women to deal with diabetes. Minimizers wanted to avoid hypoglycemia at all costs and might run their blood sugars high to alleviate the possibility of a reaction. The following quote describes the minimizer.

There's this part of me that always wants to pretend that it's not there or just push it away or turn away from it and so I have this one part of me that's kind of perfectionist and would like to do well and the other part doesn't even admit that it's part of me....I don't like to feel different from everybody else and that comes up at work and just different places where you're with people who don't know

you.. because you're different when you have diabetes and I hate that and so that's another part of what makes it hard.
(Participant #1)

Summary

The six patterns of diabetes management were developed from the different ways that women went about their daily clinical safety work. The patterns were based on the degree of variability women talked about in their diabetes regimen as well as the family, social, and work factors that might have influenced her behaviors and management strategies. In Chapter 6, a profile of each pattern is described according to the demographic, illness, and psychosocial characteristics of women in the different groups. The relationships among the patterns of diabetes management and other study variables are reported and discussed also.

CHAPTER 6
RELATIONSHIPS AMONG DIABETES MANAGEMENT, DEVELOPMENT,
ENVIRONMENTAL FACTORS AND PSYCHOSOCIAL ADAPTATION

In order to develop a better understanding of women's experiences when they live with diabetes mellitus, the relationships among individual and environmental characteristics, illness-related factors, patterns of diabetes management, and psychosocial adaptation were explored. Research questions that involved relationships between constructs are addressed in this chapter. Demographic and adaptive profiles for each pattern of diabetes management are reviewed in the final section of the chapter.

Relationship Between Illness Management Patterns and Ego Development

The relationship between the patterns of diabetes management and developmental stage was one of the major questions in this study. Table 20 shows the crosstabulation between patterns of management and ego stage. Tests of statistical significance were not appropriate to use because of the small number of subjects in each cell. However, it seemed that women who were Chancers fell into the lower levels of ego development and women who Revolved Around the Social Milieu had higher stages of development.

Another approach was used to describe the relationship between developmental stage and patterns of illness management. Mean values of the developmental stage variable were compared for each pattern of management (Table 21). Women whose predominant pattern of management was Chancer had the lowest level of ego development. These women

Crosstabulation Developmental Stage with
Illness Management Pattern (N = 40)

Developmental Stage		Patterns of Management				
		Driven by the Clock	Revolving Around Social Milieu	Calcu- lating Adjusters	Straight Arrows	Chancers
I-3	Conformist	1		1		1
I-3/4	Transition	3	3	2	2	4
I-4	Conscientious	2	4	6		1
I-4/5	Transition	1	3			
I-5	Autonomous	1	1	2	1	1

Table 21

Mean Level of Development Stage (Loevinger) by
Patterns of Management (N = 40)

	Mean	Loevinger's Stage
Chancer	5.4	Conformist/Conscientious Transition
Driven	5.8	Conscientious
Straight Arrow	6.0	Conscientious
Calculating Adjuster	6.0	Conscientious
Revolving Around the Social Milieu	6.2	Slightly Higher than Conscientious

tended to be mainly in the Conformist or the transitional stage between Conformist and Conscientious. The women who were Driven by the Clock tended to be slightly higher on the developmental continuum and were closest to the Conscientious stage. Women who followed either a Straight Arrow or Calculating Adjuster pattern were found to have a developmental stage at the Conscientious level. The women who Revolved Around the Social Milieu had the highest developmental stage and were found to be slightly above the Conscientious stage.

Although the differences observed for the patterns of diabetes management according to developmental stage were not statistically significant, the distinctions are important ones to explore theoretically. Women who were Chancers had the lowest stage of development. At the Conformist stage of development, conformity to external rules and belonging to social groups is a vital component in how women make meaning of experiences. At the transition between the Conformist and Conscientious stage, a beginning realization occurs that internal standards can be developed. The Chancers, therefore, seemed less able to cope with the demands of the diabetes treatment regimen, a regimen that mandates internal and independent regulation as opposed to external regulation. The women who were Straight Arrows, Calculating Adjusters, and Driven by the Clock had roughly the same ego developmental stage, the Conscientious stage. According to developmental theory, at this stage, women are able to set their own standards, evaluate their own standards, and be responsible for themselves. It is likely that these women did possess the internal skills necessary to maintain a complicated regimen, one that requires

a person to make significant alterations in daily routines based on the immediate symptoms of diabetes. The women who Revolved around the Social Milieu had the highest stage of development. The mean ego development level was slightly higher than the Conscientious stage. Beyond the Conscientious stage, women are able to recognize and value the needs of others. They are able to cope with conflict, tolerate contradictions and paradox, and cherish interpersonal relationships. Women who Revolved Around the Social Milieu knew what to do to manage their diabetes well but talked about not being able to get to their diabetes routines because of the needs of others around them. They were able to recognize their own needs and manage their illness regimen as well as they could while taking the need of others into account. The sense of responsibility for others and interdependence with others is a common theme in the literature on women's development (Gilligan, 1982).

Individual Characteristics

Individual characteristics such as developmental stage, age, age of illness onset, and perceived transition status seem to play an important role in how individuals adapt to chronic illness (Hauser & Pollets, 1979). The relationships among individual characteristics and the measures of adaptation were examined using correlational analyses and the results are reported in this section. Table 22 shows the correlational results for selected study variables.

Developmental stage. The only significant association between ego development and the major demographic variables, illness context, and psychosocial adaptation measures was with depression. Women at

Table 22

Correlation Matrix of Major Variables (N = 40)

	Depression	Anxiety	Transition	Family Functioning Demands	Social Relationships Demands	Complications	Diabetes Symptoms	Age
Ego Development	-.27*	-.02	-.02	-.04	.10	.04	.09	.07
Depression		.71***	.55***	.52***	.39**	.13	.27*	-.04
Anxiety			.77***	.27*	.23	.02	.27*	-.04
Transition				.23	.32*	.12	.28*	-.11
Family Functioning Demands					.78***	.40**	.54***	.15
Social Relationships Demands						.46**	.52***	.09
Complications							.56***	.10

*p < .05.

**p < .01.

***p < .001.

the higher stages of ego development reported significantly less depression than women at the lower stages of the developmental spectrum ($r = -.27, p < .05$). It is possible that women with fewer capabilities to make sense of their world and their experiences when faced with the complexities imposed by a chronic illness tended to respond with feelings of depressed mood.

One of the common markers of human development, chronological age, was unrelated to ego development ($r = .07, p = .33$). Loevinger, Cohn, Bonneville, Redmore, Streich, and Sargent (1985) as well as other developmental theorists suggested that although ego development can continue throughout life, for the majority of people it tends to stabilize after adolescence and the early adult years and is not necessarily related to age. The finding that higher levels of ego development were found among both older and younger women in this study supports the notion that ego development may be unrelated to chronological age.

It is interesting to note that ego development was not associated with age of diabetes onset ($r = .18, p < .13$). Women who were diagnosed at a younger age with diabetes did not have a lower stage of development. Hauser and others (1979) reported a lower stage of ego development in adolescents with diabetes as compared with nondiabetic adolescents. It may be that development is delayed for adolescents with diabetes, but not arrested, and that adolescents diagnosed with diabetes catch up with nondiabetics by the time they reach their adult years.

The illness context (number of complications, perceived severity of illness, and diabetes related symptoms) was unrelated to ego development. Although it is impossible to address the issue of developmental regression caused by chronic illness, it is interesting to note that none of the measures of illness was related to developmental stage.

It is also important to comment on the lack of a relationship between ego development and educational status ($r = .21$, $p < .10$). Critics of the SCT frequently suggest that ego development may be related to educational level. In this sample and as reported by Loevinger (1985), this was not the case.

Age. Chronological age was related negatively to the woman's perception of her blood glucose control ($r = -.46$, $p < .01$). In other words, younger women considered their blood sugar to be less well controlled than older women. Because diabetes is an illness that may become more serious as the amount of time living with the illness increases, it is possible that younger women (who had lived with diabetes for a longer time) had more severe disease than the older women. Another explanation is that the younger women were simply less careful in their illness management and maintaining a "normal" blood sugar was not one of their priorities. Furthermore, it is possible that the younger women were simply more open and honest about being less careful with their diabetes. Alternatively, the younger women, especially those in the child bearing years, may have had a different philosophy about what "perceived blood sugar control" meant than the older women. The younger women tended to have been diagnosed at an

earlier age and had lived with the diabetes regimen for longer. If they had borne children while diabetic, they had to maintain their blood sugar strictly in as normal a range as possible in order to prevent birth defects. Thus, it is possible that the younger women had a more stringent definition of diabetes control than older women in the sample.

Transition status. Life transitions, though unavoidable, seemed to carry with them negative aspects. Women's perceived transition status based on the semantic differential scale was significantly related to psychological health, diabetes symptoms, education, income, and social relationship demands. The anxiety measure correlated highly with the women's report of transition ($r = .77, p < .000$). In other words, women who felt their lives were changing had more anxiety than women who considered their lives to be relatively stable. The relationship between life transition and feelings of anxiety has been reported in the literature (Grant et al., 1974). The question of potential operational confounding between the measures as well as the similarity between the concepts as measured deserves mention. When examining the two measures, there is some item overlap with the words happy, satisfied, and secure appearing on each form.

Depression was related positively to transition status ($r = .55, p < .001$) also. The more change women reported in their lives, the greater the depressed mood. For these women, the life transition may have taken the form of the loss of a partner, job, or their own health. The relationship between loss and depressed mood has been documented (Bowlby, 1980). Once again, there is some item overlap

with the word happy being present on both forms; however, the instruments are more different than alike and the relationship between life transition and depression has been reported.

The frequency and intensity of diabetes symptoms were associated positively with transition status ($r = .28, p < .05$). Women who reported feeling in transition tended to report more day-to-day symptoms of diabetes such as feeling hungry or increased thirst. The experience of diabetes symptoms has been associated with blood glucose fluctuations (Pennebaker et al., 1981). Furthermore, diabetes symptoms are considered to be a reliable indicator of physiological state. The social relationships subscale on the DOII was related to transition status ($r = .32, p < .05$) in the correlational analysis as was income ($r = -.37, p < .01$). The greater the woman's economic resources the less likely she was to report being in a transitional state. Transition for women, then, might have included altered employment status and a loss of income. Education played an important role in women's lives; women who were more highly educated tended to be protected from life transition. Alternately, education might have permitted women to earn a better living.

In conclusion, the more transition women reported in their lives, the greater were the physical symptoms related to diabetes and psychological disturbances. Furthermore, change in women's lives seemed to have financial as well as illness repercussions. Adequate income may play a vital role for women with diabetes in that it buffers environmental transactions that might otherwise make illness control very difficult. The reality that, for some women, diabetes is

an illness that manifests in transitional mood states cannot be overlooked.

Social and Environmental Factors

Factors in the social environment were related to the woman's report of her recent blood glucose rating, perceived control of diabetes, perceived severity, and social adaptation. The relationships among environmental factors and psychosocial variables are shown in Table 23. Table 24 shows the relationships among environmental factors and illness characteristics.

Income, education, and employment status. As expected, women who were employed reported greater income ($r = .31, p < .05$) and higher educational levels ($r = .41, p < .01$) than those who were not employed. Education is frequently considered to be a key factor in women's economic well-being. Interestingly, education, and income were unrelated for women ($r = .09$). In other words, even though women might have had access to advanced education this did not translate directly into jobs and greater earning power. A number of explanations are possible. Some women might have been in the process of completing their educations and were not fully employed. Alternately, women might have had unstable diabetes that precluded full-time employment. Job discrimination because of diabetes must not be overlooked.

Income was related negatively to the rating of the blood glucose and to transition status. Women with higher incomes and higher educational levels, factors that are confounded to a degree, reported lower blood glucose levels than women with fewer socioeconomic

Table 23

Correlation Matrix: Environmental Factors with Psychosocial Adaptation (N = 40)

	Income	Education	Employment Status ^a	Marital Status ^b	Number of Children	Number of Family Life Cycles
Depression	-.17	.12	-.19	.16	-.11	.01
Anxiety	-.25	.18	-.12	.17	-.10	-.03
Demands of Illness (Total Scale)	-.09	.11	-.09	.15	.19	.05
Family Functioning Demands	-.09	.09	-.14	.13	.33*	.14
Social Relationship Demands	-.30*	.03	-.27*	.23	.13	-.03

*p < .05

^aHigher value = Employed^bHigher value = Not married

Table 24

Correlation Matrix: Environmental Factors with Illness Characteristics (N = 40)

	Income	Education	Employment Status ^a	Marital Status ^b	Number of Children	Number of Family Life Cycles
Perceived severity	.22	.10	.09	-.04	.28*	.17
Perceived control	.05	.12	-.18	.18	-.42**	-.36*
Perceived health	-.06	.08	-.04	.03	-.10	-.20
Complications	-.09	.01	-.16	.03	.00	-.10
Actual Blood Glucose	-.33*	-.33*	-.35*	.17	-.26	-.22
Diabetes Symptoms	-.08	.03	-.21	.11	.11	-.06

*p<.05

^aHigher value = Employed^bHigher value = Not married

resources ($r = -.33$; $p < .05$). Women who worked outside the home reported lower blood glucose ratings ($r = -.35$, $p < .05$) and fewer illness-related demands in the area of social relationships ($r = -.27$, $p < .05$) than women who did not work outside the home. For women, work seems to be a source of social integration and may consequently function to protect women's health (Nathanson, 1980).

The important role of the environmental context in illness management is underscored by these findings. It seems that women who had greater social advantage had more stable illness than women with fewer family supports and economic resources. For some women, it seemed that work was an organizing factor in their lives and provided structure that helped them adapt to their illness successfully. One woman talked about how her current job helped her maintain regular eating patterns because of the scheduled meal breaks. This is in contrast to women who did not work outside the home and instead had highly flexible daily routines that varied day-to-day according their children's activity schedules. An alternative explanation is that women who have stable diabetes were able to work outside the home. Alternately, women who have very unstable diabetes and a number of debilitating diabetes-related complications may be physically unable to maintain employment.

Because the treatments for diabetes (insulin, syringes, blood monitoring equipment) are extremely expensive, adequate income to cover the cost of diabetes may be a vital factor in women's ability to manage their illness. Financial resources also might alleviate anxiety about how the costs of daily treatment will be covered.

Number of children. There was a relationship between family size and perceived control of diabetes. Women who had more children reported better diabetes control ($r = -.42, p < .01$) (note: Perceived diabetes control was scaled so that high numbers represented poor control). The women with more children also tended to be older ($r = .51, p < .000$) than women with fewer children and had a later age of diabetes onset ($r = .26, p = .053$). There was also a trend for women who had more children to report lower blood sugar ratings than those with fewer children ($r = -.26, p = .055$). Women who were diagnosed with diabetes at a later age tend to have types of diabetes that are less brittle than women with diabetes onset at an early age. However, women with more children also reported increased perceived severity of illness ($r = .28, p < .05$) and greater family functioning demands ($r = .33, p < .05$). One possible explanation for these findings is that women with more children were more aware of illness-related factors and tended to keep their illness in better control. If women perceived their illness as severe, yet had a large family depending on them, they might have been more likely to try to keep their illness well controlled. It is possible that women's illness management patterns are a function of their role demands. Interestingly, women who had the greatest number of children followed either the Straight Arrow or Driven by the Clock pattern of management. In both of these patterns, women paid a great deal of attention to their diabetes routines. It appears that better diabetes control was associated with these patterns of management.

Illness Characteristics

The relationships among the illness-related variables are reviewed in this section. The intercorrelation matrix on Table 25 shows the relationships among the illness-related variables.

Diabetes symptoms. The frequency and intensity of diabetes-related symptoms on the DSC were related to the number of recent illnesses reported ($r = .33, p < .05$), perceived severity of diabetes ($r = .33, p < .05$), and perceived overall health ($r = .32, p < .05$). Symptom patterns and recent illnesses, factors that might be considered a short-term view of what is happening with the illness on a day-to-day basis, seemed to play a role in the perception of the woman's overall health as well as the severity of her diabetes. In other words, the more diabetes-related symptoms a woman reported, the more severe she viewed her diabetes and the poorer she perceived her overall health. Furthermore, the more diabetes-related symptoms women reported, the more depression, anxiety, transition, and family functioning and social relationship demands they experienced.

Number of diabetes-related complications. Although there is not yet conclusive evidence, many researchers believe that uncontrolled blood glucose levels may lead to the development of retinopathy, neuropathy, nephropathy, and other serious complications of diabetes (National Diabetes Data Group, 1985). The presence of complications was used as an indicator of long-term diabetes control. The number of diabetes-related complications was related to increased diabetes symptoms ($r = .56, p < .001$), the number of daily injections ($r = .35, p < .05$), perceived overall health ($r = .48, p < .001$), and the number

Table 25

Correlation Matrix of Illness Characteristics (N = 40)

	Dura- tion	Compli- cations	Symp- toms	# In- jection	Blood Glucose	Per- ceived Control	Per- ceived Severity	Per- ceived Health	Recent Illnesses
Age at Onset	-.80**	-.39*	.03	-.49***	-.06	-.25	.20	.03	-.06
Duration of Illness		.43**	.02	.46**	-.11	-.04	-.14	-.17	.06
Number of Complications			.56***	.26*	.19	.11	.21	.48***	.44**
Diabetes Symptoms				.04	.20	.12	.33*	.36*	.33*
Number of Daily Injections					.38**	.11	.08	-.04	.07
Blood Glucose Rating						.32*	.03	.20	.40**
Perceived Diabetes Control							-.08	.19	.24
Perceived Severity								.25	.43**
Perceived Overall Health									.37**

*p < .05. **p < .01. ***p < .001.

of recent illnesses reported by women ($\underline{r} = .44, p < .01$). Women who reported more complications had a younger onset age ($\underline{r} = -.39, p < .01$) and greater duration of illness ($\underline{r} = .43, p < .01$). It is well documented in the diabetes literature that the greater the duration of illness, the more likely the individual is to experience complications of the illness. Diabetes-related complications, long term effects of the disease, were related not only to the duration of the illness but also to symptoms, the short-term experience of the illness that may contribute to further complications. Furthermore, the women with more diabetes-related complications perceived themselves to have poorer health than women with fewer complications and more recent illnesses. Interestingly, the greater the number of complications the woman reported, the more likely she was to manage her diabetes symptoms aggressively with multiple daily injections of insulin. It appears that women with greater experience with diabetes (longer duration) managed their illness with multiple injections so that their diabetes would be optimally controlled.

The relationship between blood glucose rating and the number of daily injections merits comment because the number of daily injections is conceptually similar to the medication management category in Clinical Safety Work. The blood glucose rating reported by the women was related negatively to the number of daily insulin injections the women gave ($\underline{r} = -.33, p < .05$). It appeared that the women who had better diabetes control possibly were more active in their diabetes management.

These relationships help to illuminate the factors that women take into account when rating perceived health and illness severity. Diabetes-related symptoms, the number of complications, and recent illnesses, factors that could limit their ability to function, rather than the actual rating of their blood sugar or their perceived glucose control seemed to play an important role in how serious the woman perceived her illness and the quality of her overall health. It is equally possible that women interpreted the words severity and control differently. For example, the women in the Straight Arrow pattern might have rated their glucose control to be poor if they had recent blood sugars of 160. However, a woman who chose to run her blood sugar on the high side may have perceived her blood sugar to be very well controlled if she had the same rating.

Relationships between illness characteristics and psychosocial adaptation. The number of diabetes-related complications was related to the perception of family ($r = .40, p < .01$) and social demands ($r = .46, p < .001$). For example, one woman who experienced severe diabetic diarrhea talked about how sometimes the diabetic diarrhea left her so debilitated that she was not able to take her children to their after school activities. She also talked about how she was uncomfortable staying at other people's homes. The number of complications, therefore, seemed to impose some limits on the woman's perception of her ability to function in social and family settings.

Diabetes symptoms were related positively to depression ($r = .27, p < .05$), anxiety ($r = .27, p < .05$), family functioning demands ($r = .56, p < .000$), and social demands ($r = .52, p < .01$). The day-to-day

interference of diabetes symptoms affected not only the woman's mood state but also her perception of how the family and social routines were influenced by her illness. Alternatively, the demands of the social environment on top of a complicated illness regimen might have been so great that some women could simply not attend to everything. Feelings of depressed mood and diabetes symptoms might result from the inability to cope with such great demands.

The perceived severity of illness was related to the perception of illness demands on family functioning ($r = .36, p < .05$) and social demands ($r = .26, p < .05$) as were perceived health and family demands ($r = .37, p < .05$) and social relationship demands ($r = .27, p < .05$). The number of recent illnesses was related to depression ($r = .31, p < .05$), family functioning demands ($r = .33, p < .05$), and social demands ($r = .39, p < .01$). Perceived glucose control was related to anxiety ($r = .33, p < .05$). Taken as a whole, it is apparent that complications of diabetes as well as the day-to-day symptoms of the illness influenced the woman's perception of her family and social context. Although perceived illness severity was related to symptoms and recent illnesses, the number of complications, a means of evaluating illness severity objectively, was not.

Frequency of Diabetes and Health Related Content on the Sentence Completion Test

A content analysis of the responses to the Sentence Completion test was undertaken to determine the frequency of concerns mentioned related to health and illness. Four original categories were developed based on the work of Hauser and others (1979). The first

category was the mention of death (the woman's or others') or fears of object loss. For example, the stem "At times she worried about" evoked responses such as "dying" and "dropping dead." Coded in the second category was the mention of the word diabetes or its treatment. For example, responses to the stem "Sometimes she wished that," were "she wasn't a diabetic," and "diabetes had a cure." The mention of eating, whether in context of diabetes treatment or in general, was coded in the third category. Characteristic responses to a number of stems were "staying on my diet," "overeating," and "feeling guilty when I cheat on my diet." The fourth category was the general mention or concern about the woman's health or the health of others. For example, in response to the stem, "When they avoid me," one woman responded, "I tend to consider it to be because of my health problems." The fifth and final category, the mention of self-degrading remarks, was also coded. For example, one woman responded "I am a female who has little going for her. I am overweight, lazy, balding and ill - a mess."

Each woman's Sentence Completion Test was examined and responses that fit into the categories were recorded. A total score for each category was computed. Eight women (20%) mentioned death in relation to others or themselves. Diabetes or its treatment was mentioned by only five women (12.5%); one woman mentioned diabetes. A reference was made to eating or meals by seventeen women (42.5%). A general mention or concern about health was referenced by over half of the women (n = 21). Self-depreciating comments were made by 10 women in the sample.

Relationship Between Illness Content and Ego Development

In order to examine how the illness experience related to psychosocial development, Pearson's correlation coefficients were computed between ego development stage, the Sentence Completion Test sum score and the frequency of the five categories identified above (Table 26). The lower the woman's ego development as measured by the sum score, the more likely she was to mention themes of diet, food, or eating ($r = -.26$, $p = .052$). When ego development stage was used, the correlation coefficient between development and eating content was $r = -.22$, $p = .09$. There were no other significant correlations between the categories and ego development sum score, nor were there any significant relationships between the categories and ego development stage. Although ego development was not significantly related to any of the categories, the trend that eating was mentioned more frequently by women at lower developmental levels is interesting. Women at lower levels of ego development tend to think in concrete terms and be more concerned about basic needs such as eating. At higher ego levels, women's thought processes are more complex and focus on self-actualization and the interdependence with others. It is possible also that women at lower stages of ego development had more difficulty with managing the complex food-related aspects of treatment than women at higher stages of development.

Next, a combined variable called frequency of health-related responses was created by summing the number of times death, diabetes, eating, or health was mentioned. The frequency of health-related responses ranged from 0 to 7 with a mean of 1.75 (SD = 1.9). The

Table 26

Correlation Matrix Illness Experience Variables
With Developmental Stage (N = 40)

	Mention of Death	Mention of Diabetes	Mention of Eating	Mention of Health	Self- degrading Comments
Ego Development Stage	-.12	-.07	-.22	.07	-.06
Total Mention of Illness Experience	.10	.60***	.77***	.83***	.31*
Mention of Death		.12	.11	.02	.15
Mention of Diabetes			.34*	.22	.19
Mention of Eating				.44**	.35*
Mention of Health					.17

*p < .05.

**p < .01.

***p < .001.

median and mode were one. Pearson's correlation coefficients were computed. No significant relationships were found between the frequency of health-related responses and either the sum score or the stage of ego development. Women at all stages of development responded to sentence stems on the Sentence Completion Test with health-related or diabetes-related concerns in equal proportions.

The frequency of health-related responses was used in correlational analyses with other major study variables (Table 27). The frequency of health-related responses was positively related to diabetes symptoms ($r = .39, p < .01$), perceived health ($r = .29, p < .05$), number of recent illnesses ($r = .36, p < .05$), perceived social relationship demands ($r = .35, p < .05$), and total demands of illness ($r = .41, p < .01$). The relationship between frequency of health-related responses and the number of complications was $r = .25, p = .06$. From these results, it seems that the more frequently women mentioned health-related or diabetes-related concerns, the more diabetes symptoms they reported, the worse their perceived health, the more recent illnesses they experienced, and the greater their perceived illness-related demands in the area of social relationships.

Demographic and Adaptive Profiles of Women According to the Patterns of Illness Management

Characteristics of the social environment, the illness, and psychosocial adaptation are useful to broaden the description of each of the subpopulations of women who managed their diabetes in different ways. To develop these profiles, the mean values on the standardized

Table 27

Correlation Matrix: Illness Experience Variable
With Major Study Variables (N = 40)

	Frequency of Health or Illness Content on Sentence Completion Test
Diabetes Symptoms	.39**
Diabetes Complications	.25
Perceived Diabetes Control	.22
Perceived Health	.29*
Perceived Severity	.23
Recent Illnesses	.36*
Social Relationship Illness Demands	.35*
Family functioning Illness Demands	.24
Educational level	-.23

* $p < .05$.

** $p < .01$.

instruments and the other variables were compared across the groups (Table 28). Analysis of variance was used to test for significance of differences between the mean values for the groups.

Chancers. Women who were Chancers seemed to be the most vulnerable group for physical and psychosocial problems. They reported more depression than any other group; in fact, the mean depression score was above the score considered to mark depression in community samples (Radloff & Locke, 1986). In addition, there was a trend in the depression scores across the groups to be different ($p = .088$). The Chancers reported a high level of anxiety also. The mean anxiety score was higher than national norms reported (Spielberger, 1970). A significant difference in mean anxiety scores for the different patterns of management groups was present ($p = .02$). The Chancers perceived themselves to be experiencing more change and transition than the other groups. The mean differences across groups approached significance ($p = .077$). This group also reported the highest number of family functioning and social demands as a result of their illness.

All six women who were categorized as Chancers had insulin-dependent diabetes. The Chancers reported the least well controlled blood sugar. There was a significant difference in how women perceived their glucose control to be controlled ($p = .02$) across the women in various patterns. Furthermore, Chancers reported the highest number of diabetes-related symptoms; however, they perceived their illness to be the least severe.

Table 28

ANOVA Table: Major Study Variables by Patterns of Diabetes Management

	Patterns of Diabetes Management (Mean ± SD)						F
	<u>Driven by the Clock</u>	<u>Revolving Around</u>	<u>Calculating Adjuster</u>	<u>Straight Arrow</u>	<u>Chancer</u>		
Ego Development	5.8 ± 1.3	6.2 ± 1.0	6.0 ± 1.2	6.0 ± 1.7	5.4 ± 1.3		.47
Depression	14.4 ± 10.1	14.2 ± 9.6	8.7 ± 6.5	3.0 ± 2.6	19.0 ± 13.0		2.21
Anxiety	35.8 ± 13.5	44.9 ± 12.8	33.2 ± 7.2	24.7 ± 2.5	44.3 ± 11.3		3.37*
Transition	15.8 ± 7.2	18.5 ± 4.7	14.3 ± 5.4	11.0 ± 2.0	20.4 ± 6.8		2.31
Age	39.6 ± 8.8	37.7 ± 4.1	41.0 ± 6.2	36.7 ± 6.7	34.3 ± 4.9		1.43
Income level	10.7 ± 2.4	9.9 ± 3.9	9.3 ± 3.2	10.0 ± 2.6	5.7 ± 2.2		2.49
Educational level	4.1 ± .6	4.5 ± 1.2	4.2 ± .4	4.7 ± .6	5.0 ± 1.2		1.21
Number of children	2.4 ± 1.9	1.8 ± 1.3	1.9 ± 1.4	2.7 ± 1.2	.7 ± 1.0		1.65

Table 28 continued

	<u>Driven by the Clock</u>	<u>Revolving Around</u>	<u>Calculating Adjuster</u>	<u>Straight Arrow</u>	<u>Chancer</u>	<u>F</u>
Onset Age	29.8 ± 12.5	27.9 ± 9.9	27.1 ± 10.1	12.0 ± 5.3	20.7 ± 6.4	2.43
Duration in years	9.9 ± 5.9	9.8 ± 7.8	13.9 ± 8.5	24.7 ± 10.7	14.0 ± 7.3	2.52
Diabetes Symptoms	24.0 ± 15.7	24.6 ± 13.9	25.6 ± 21.5	16.0 ± 16.4	28.6 ± 11.5	.31
Number of Complications	.4 ± .7	.6 ± .9	2.0 ± 2.6	1.7 ± 1.5	1.6 ± 1.7	1.53
Number of injections	1.1 ± 1.0	1.5 ± 1.2	2.4 ± 1.0	3.0 ± 1.0	2.9 ± 1.3	3.49*
Actual blood glucose	149.7 ± 51.4	195.1 ± 88.8	174.7 ± 69.5	130.3 ± 25.1	146.0 ± 55.4	.94
Perceived diabetes control	1.9 ± .8	2.9 ± .8	2.3 ± .6	1.7 ± 1.2	2.9 ± .7	3.38*
Perceived severity of illness	2.8 ± 1.3	2.5 ± 1.2	3.2 ± 1.0	3.0 ± 1.0	2.4 ± 1.0	.68
Perceived health	1.9 ± .6	2.0 ± .4	2.0 ± .6	2.0 ± .0	2.0 ± .6	.08
Mention of Health or Diabetes on SCT	1.0 ± 1.3	2.4 ± 2.0	1.6 ± 2.0	.7 ± .6	2.3 ± 2.6	.94

Table 28 continued

	<u>Driven by the Clock</u>	<u>Revolving Around</u>	<u>Calculating Adjuster</u>	<u>Straight Arrow</u>	<u>Chancer</u>	<u>F</u>
Demands of Illness (total scale)	116.0 ± 51.6	110.1 ± 45.8	106.5 ± 51.7	87.7 ± 123.4	152.0 ± 44.2	.92
Family Functioning Demands	30.6 ± 16.1	20.7 ± 13.3	19.9 ± 12.8	24.3 ± 38.7	36.4 ± 31.7	.91
Social Relationship Demands	9.0 ± 8.3	7.7 ± 5.9	8.7 ± 6.5	7.0 ± 9.5	13.6 ± 6.5	.91
Image Demands	6.3 ± 5.0	6.3 ± 4.2	7.2 ± 6.8	6.3 ± 10.1	15.8 ± 8.6	2.72*
Monitoring Demands	15.9 ± 7.4	16.0 ± 8.4	14.1 ± 6.6	10.0 ± 14.8	19.0 ± 8.1	.75
Personal Meaning	23.0 ± 8.5	23.9 ± 9.8	23.5 ± 16.3	11.3 ± 15.5	19.9 ± 11.3	.73
Treatment Demands	24.5 ± 12.2	25.8 ± 12.4	20.5 ± 10.4	21.0 ± 26.1	34.2 ± 7.7	1.25

* p < .05
df: Between Groups = 4 Within Groups = 35

The Chancers tended to be single (5 of the 6 women were single), younger, and had the fewest number of children. They were the most highly educated yet had the lowest income (under \$15,000 a year) of any of the groups, with the difference in income among the groups approaching significance ($p = .06$). What emerges from this description of Chancers is the picture of a vulnerable individual; a young, single, highly educated woman with limited economic resources, who has a high level of anxiety, mood disturbances, family and social demands, and symptoms of diabetes. Women who were Chancers seemed to have a somewhat chaotic and unstructured lifestyle.

Driven by the Clock. The women who managed their diabetes as if they were Driven by the Clock were in striking contrast to the Chancers; they did not exhibit the risks and vulnerability observed for the Chancers. Women who were Driven were older when their diabetes was diagnosed. Using ANOVA to test for differences in means, the differences in average onset age among the groups approached significance ($p = .06$). Six of these women were on insulin, one was diet controlled, and one was on oral medications. The fewest number of daily injections was reported by these women. The groups based on the management patterns were significantly different from each other on the number of daily injections ($p = .02$). Women who were Driven by the Clock reported the fewest number of diabetes-related complications also. This result would be expected because diabetes-related complications tend to be associated with greater duration of illness.

The women who exhibited the Driven by the Clock pattern were found to have the lowest educational level of the groups. In

contrast, they had the highest income of all the groups. Among all the groups, the difference in income approached statistical significance ($p = .06$). All eight women were married. It is interesting to note that this subgroup of women had average depression scores that were in the high end of the normal or not depressed range. In summary, women who were Driven by the Clock were older at the time of diagnosis, had lived with the illness for a shorter period of time, had fewer complications, and were married and economically more secure. Although they reported symptoms of depressed mood, they had fewer psychosocial problems than the Chancers. For the women who were Driven by the Clock, their lives and possibly their families' lives were organized around diabetes.

Straight Arrows. Although there were only three women who seemed to manage their illness very rigidly (Straight Arrows), the group characteristics were different than for the other groups. Straight Arrows reported the least amount of psychological distress. The Straight Arrow group reported lower anxiety levels and the difference among the groups was significant ($p = .02$). There was a trend for the mean depression scores to differ across the various patterns of management ($p = .08$). The Straight Arrows had the lowest mean score for depressed mood. These women reported a lower level of transition in their lives and this group difference approached significance ($p = .08$). Furthermore, they had the fewest demands of illness in the area of social relationships and fewest overall demands of illness.

The Straight Arrows were the women who had the youngest age of diabetes onset and had the greatest duration of diabetes. There was a

trend for the mean age of onset and duration of diabetes to be different ($p = .06$) among the groups of women who had various patterns of illness management. Interestingly, the Straight Arrows perceived their blood glucose to be better controlled than the other groups. This difference among the groups was significant ($p = .02$). All of these women were on insulin and they gave themselves more daily injections of insulin than the other groups ($p = .02$). Though the differences were not significant, they reported the fewest diabetes symptoms and the lowest blood glucose rating among the groups. The Straight Arrows all were married and had the greatest number of children at home.

The picture that emerges from this description of women who managed their illness rigidly as Straight Arrows is that of women who had lived with diabetes for many years and probably since childhood. They experienced few symptoms of diabetes, were active in their diabetes management and perceived their illness to be well controlled. Furthermore, these women seemed least plagued by depressed mood, anxiety, and change in their lives. In short, the picture is one of a woman who adapted quite well to living with diabetes. This woman might be considered to be the ideal patient by the health care provider because of her ability to maintain stable blood glucose levels and her positive psychosocial well-being.

Calculating Adjusters. Women who managed their illness as Calculating Adjusters are not described easily according to any of the psychosocial measures, illness characteristics, or social environmental variables. In other words, women who were Calculating

Adjusters seemed to have a wide range of psychosocial adaptation, a variety of social and environmental characteristics, and variability in the context of their illness. Most of these women were married, however (8 out of 11). The only illness-related variable that was common to all the calculating adjusters was the mode of treatment. All 11 women who were Calculating Adjusters had insulin-dependent diabetes. Although the Calculating Adjusters were found to have slightly higher mean values for the number of complications of diabetes, recent illnesses, perceived illness severity than the other groups, none of the differences was significant. In fact, the higher mean values for the illness context variables could have resulted from one woman (an outlier) with nine complications and very brittle diabetes who was characterized as a Calculating Adjuster. In general, this pattern also could be considered an "adaptive" pattern. These women seemed able to manage their diabetes well without interference in their family and social lives. Again, these women might be considered "ideal" patients by health care providers.

Revolving Around the Social Milieu. The final pattern of management to be discussed is Revolving Around the Social Milieu. Most of the women who Revolved Around the Social Milieu were married. Also they were more likely to have insulin-dependent diabetes. The women who managed their diabetes around the social environment had a high level of anxiety, as did the Chancers. The mean difference in anxiety among the groups was significant ($p = .02$). They also reported the poorest perceived blood sugar control as did the Chancers; the difference in perceived control was significantly

different among the groups ($p = .02$). The women who Revolved Around the Social Milieu reported a higher actual blood sugar rating than the other groups. They had the fewest recent illnesses and had lived with diabetes for the shortest amount of time. They seemed to be women who had lived most of their lives without diabetes. The short-term control of their illness was less optimal than some of the other groups. However, they did not view their illness as influencing their family and social relationships. Thus, the women who Revolved around the Social Milieu seemed to pay a price; they experienced anxiety possibly because they knew their patterns were influencing their illness control. However, they did not perceive their family and social lives to be affected by their illness.

Validation of Qualitative Findings

One final exploration of the data on patterns of management was undertaken. Because some of the women ($n = 25$) in the sample demonstrated both a primary and secondary pattern of management, new categories were developed that took into account both of the patterns of diabetes management. Women who were Driven and did not have a secondary pattern of management were combined with the women who were Straight Arrows. These women ($n = 9$) were categorized as extremely regimented and assigned the code "1". The next category was made up of women ($n = 5$) who were very regimented. They were women who had a primary and secondary patterns of Calculating Adjuster and Driven regardless of the order. They were assigned a code "2". The moderately flexible category ($n = 8$) was assigned a code "3". These women were primary Calculating Adjusters who did not have a secondary

patterns, or calculating adjusters whose secondary pattern was Chancer. The fourth category represented the women who were somewhat regimented or quite flexible in their diabetes management ($n = 7$). These women were those with both a primary or secondary pattern of Revolving Around the Clock and Calculating Adjuster. The fifth and final category was those women who were very loosely regimented, highly flexible, and almost chaotic in their management. These women ($n = 11$) were Chancers, Chancers with a secondary pattern of Minimizers, or Revolved with a secondary category of Minimizers.

The rank ordered categories then were used in nonparametric correlational analyses with the other major variables of interest in the study in order to explore the relationships. Significant relationships were found between flexibility in management and psychological adaptation, family context, and illness characteristics (Table 29). The women who were highly flexible and almost chaotic in their illness management (the Chancers) reported more depressed mood ($r = .30, p < .05$), more anxiety ($r = .50, p < .001$), and more transition in their lives ($r = .39, p < .05$) than other women. Based on the frequency of health and illness-related responses to the Sentence Completion Test, higher frequencies of illness responses were associated with more a chaotic management style ($r = .26, p < .05$). The women at the high end of the flexibility continuum perceived their illness to be least well controlled ($r = .48, p < .001$). The "chaotic managers" tended to have fewer children ($r = -.36, p < .05$), and were single or divorced ($r = .49, p < .001$).

Table 29

Spearman's Correlation Coefficients Between Degree of
Flexibility in Management and Major Variables (N = 40)

	Flexibility in Management ^a
Depression	.30*
Anxiety	.50***
Transition	.40**
Number of Children	-.36*
Marital Status ^b	.49**
Age	-.22
Perceived Diabetes Control	.48*
Frequency of Illness Related Responses on Sentence Completion Test	.26*

^aBased on 1 = very rigid to 5 = extremely flexible.

^bMarried = 0; unmarried = 1.

* $p < .05$.

** $p < .01$.

*** $p < .001$.

The results from the correlational analysis lend support to the qualitative description of the women's profiles according to the patterns of management. The overall findings were that women with a more regimented and rigid style of management reported better psychological adaptation than women whose patterns were higher on the flexibility continuum. The better adapted women were married, had more children, and perceived their diabetes to be under better control. It is possible that the structure these women had in their lives helped them to maintain routines such as regular eating patterns that are essential to successful diabetes control. The most vulnerable group of women in the sample was the group was women who were not partnered. The lack of anchors in the lives of chancers seemed to make diabetes control difficult. These women reported the greatest amount of psychological distress and they perceived their illness to be in poor control.

Summary

Qualitative and quantitative methods were used to explore the relationships among psychosocial development, environmental characteristics, illness management patterns, and adaptation among women with diabetes. Ego development was significantly related to psychological adaptation as measured by depressed mood. Six patterns of illness management were derived from interview data using qualitative analyses. Although it is not possible to draw conclusions from the results about either short term or long term health status, there were differences in adaptive states for the women based on the patterns of illness management. Women who were best able to manage

the illness seemed to be those who were able to put their diabetes routines first or to manage flexibly their regimens. Furthermore, some of these women demonstrated the ability to integrate their diabetes routines with their family and social demands. The women who were most vulnerable were those who had the least structure in their lives and did not have access to a supportive partner. These women seemed to manifest the greatest amount of psychological distress and they reported the greatest transition in their lives. It may be that women with a serious chronic illness such as diabetes, when facing the day-to-day routine alone, respond with greater mood disturbances. These mood disturbances might influence the women's abilities to manage the diabetes routines successfully.

CHAPTER 7

DISCUSSION AND CONCLUSIONS

Living with a chronic illness such as diabetes mellitus requires that the person follow a complex treatment regimen on a daily basis. Furthermore, individual as well as environmental factors influence how the illness is managed and how the person adapts to the illness. This cross-sectional investigation was designed to describe the daily tasks and work mandated when women live with diabetes mellitus from women's perspective. The core variable that emerged from domain analysis and constant comparative analysis, Clinical Safety Work, was used to describe and integrate the many aspects of the treatment regimen. Six patterns of diabetes management were delineated to describe the different approaches that women used to manage their illness regimens on a day-to-day basis. The patterns of illness management provided an organizing framework for discussing variations in how women adapted to diabetes. Variations in women's social and family lives according to the patterns of diabetes management were addressed also.

An equally important purpose was to explore the relationships among psychosocial development, illness management patterns, and adaptation in women with diabetes mellitus. Psychosocial development was measured and compared to patterns of illness management to see whether developmental stage accounted for variations in the different ways women managed their illness. Relationships between individual characteristics, family and environmental factors, illness characteristics, and psychosocial adaptation were examined. Results

from this exploratory work provide the basis for hypothesis generation and model development.

Overview

In this chapter, the major findings of the study are discussed. Implications for nursing practice and theory generation are identified. Limitations of the research design and recommendations for future research are offered.

Patterns of Diabetes Management

Revolving Around the Social Milieu

The most frequent pattern of diabetes management was Revolving Around the Social Milieu. Women dealt with their diabetes but not to the exclusion of their family and work lives. This pattern is consistent with the growing body of literature on women's roles, development, and cognitive processes (Belenky, Clinchy, Goldberger, & Tarule, 1986; Gilligan, 1982). Women value their connections to others, their interdependence, and live their lives around the themes of caring for others, responsibility, and empathy.

Although the relationship was not a statistically significant one, the women who managed their illness in the Revolving Pattern had the highest stage of ego development. According to developmental theorists, at the higher stages of ego development women are able to cope with ambiguity, conflict, and integrate the needs of others (Loevinger & Wessler, 1970). This finding, though very tentative, is an exciting one that may help explain variability in illness management patterns and adaptation to illness.

Women who Revolved Around the Social Milieu reported more anxiety than some of the other group. Furthermore, these women considered their diabetes to be poorly controlled and reported a higher blood sugar rating than the other groups. They did not experience more symptoms or complications of diabetes, however. It is possible that there is a price to pay for allowing family and social milieu to take precedence over diabetes routines sometimes. Women who managed their diabetes in this way were aware of what they should be doing ideally to keep their diabetes in good control, but they did not always make diabetes their main priority. Instead, they attended to the needs of their family or their social responsibilities. The conflict they experienced between the needs of others and their own needs could be manifested in the report of anxiety. Jenny (1984) reported that barriers to diabetes regimen adherence were special concerns and family problems. The attitudes of health care providers who may not recognize the barriers to women's management could have contributed to women's experiences of anxiety.

Alternative explanations about the experience of anxiety can be raised. Scientists often consider anxiety to be a negative characteristic when, in fact, a certain degree of anxiety may be desirable. When anxiety is defined as an active tension the nature of anxiety may be motivating. The fact that anxiety may be a symptom of diabetes is another possible explanation.

Calculating Adjuster: The "Flexible Diabetic"

Another frequent pattern for women was the Calculating Adjuster Pattern. These women were very conscious of their diabetes routines

but carefully altered them in order to achieve the freedom and flexibility they desired to maintain control of their lives. This pattern is one that is frequently encouraged by clinicians and is prevalent in the lay diabetes literature. Hanssen (1988) described how people with diabetes can "live the flexible life" by giving themselves frequent injections of regular insulin to mimic normal pancreatic activity and monitoring their blood glucose carefully.

Calculating Adjusters exhibited few psychosocial or physical difficulties. The developmental stage of women who were Calculating Adjusters was closest to the Conscientious stage of ego development. In this stage, the woman is able to function as an independent person and attend to her own needs. It appears that diabetes is an illness that forces the individual to operate in this mode. Health care providers emphasize that the management of the illness is primarily the woman's responsibility. They encourage people to be "professional" in their management of diabetes. Women who are at a Conscientious stage of development may deal quite well with the regimentation required by an illness like diabetes. Furthermore, because there is little inherent conflict in how women make meaning of their life experiences and how they are encouraged to manage their illness, manifestations of anxiety and depression are less common.

Diabetes as the Organizer: Straight Arrows and Driven by the Clock

Some women seemed to organize their lives as well as their family's around their diabetes regimens. These women attended to their diabetes routines and might be considered "ideal" patients by health care providers. Women who managed their illness in this way

were either Straight Arrows or Driven by the Clock. The distinction between the two patterns was based on the degree to which the woman took control of her diabetes routines. Women who were Driven by the Clock tended to be somewhat passive about their diabetes management. They did what they had to do and lived a fairly regimented existence, but they did not exhibit a willingness or desire to adjust their medication routines or eating patterns. For example, women who were Driven by the Clock might have used a rigid insulin schedule that required them to eat very regularly as opposed to a flexible insulin schedule. The fear of a hypoglycemic reaction might have been a decisive factor in the woman's desire to maintain her scheduled meals. Women who were Straight Arrows, on the other hand, tended not to fear a low blood sugar episode, but rather tried to maintain what is considered to be tight blood sugar control. Straight arrows were willing to make adjustments in their medications based on the information they obtained from self-monitoring their blood sugar.

Women who were Driven by the Clock tended to follow their prescriptions for diabetes treatments rigidly. These women had the fewest complications, the shortest duration of diabetes, and were diagnosed at an older age than the women within other patterns. The association between shorter duration of diabetes and fewer complications has been documented (Diabetes Data Group, 1985). In other words, the longer a person has had diabetes, the greater are the chances of experiencing complications of the disease. Although women who were Driven by the Clock had depression scores that fell within the not depressed range, the score was close to the cutoff that marked

depressed mood. Other than a tendency for women to report some degree of depressed mood, they seemed to have adapted quite well. Women who were Driven by the Clock attended to their illness routines carefully. What is not known, however, is the effect that the management pattern may have had on the woman's family from the family's perspective. Because a subsample of the women who participated in this investigation were part of The Family Impact Study it is possible to explore how family members were affected by women's management patterns through secondary analysis of the FIS data set.

Although the Straight Arrow pattern was not a common one in this sample, the adaptive states of these women were strikingly different from those of the women with other patterns. These women reported the fewest symptoms of depressed mood, anxiety, and life change. They perceived their illness to be under good control, and they reported the lowest blood sugar ratings. Furthermore, they aggressively managed their diabetes with frequent injections. The Straight Arrows had the longest duration of diabetes and were diagnosed with diabetes at a younger age than women exhibiting other patterns.

The developmental status of the Straight Arrows, the women Driven by the Clock, and the Calculating Adjusters was generally in the Conscientious stage. There are some similarities between being in the Conscientious stage and the concept of hardiness. Hardiness is characterized by a commitment and involvement in life, the view that life is a challenge, and independent versus conformist modes of thinking (Pollock, 1986). The individual's perception of control over her situation is characteristic of a hardy individual. Pollock (1986)

reported that hardiness was associated with better psychological and physiological adaptation. The adaptive patterns of women in the Straight Arrow and the Calculating Adjuster patterns were similar to those found with hardy individuals.

Chancers: Managing Diabetes in a Life that Lacks Structure

Chancers were the most vulnerable group of women. These women tended to be inconsistent and somewhat careless in their diabetes management. The age and developmental stage of these women, though not significantly different, was lower than for the other groups. At the lower stages of psychosocial development, the individual is less able to cope with complexities and ambiguities than at higher stages of development. The Chancers reported the greatest amount of psychological difficulty, the highest amount of transition, the highest frequency and intensity of diabetes symptoms, and the highest perceived demands of illness on family and social relationships. Furthermore, Chancers tended to have the lowest income, the fewest children, and they tended to be single. Single women with a life-threatening illness such as diabetes may have the most difficult time in managing their illness compared to women who live in a more structured environment. This may be in part because of the fewer number of financial resources available to single women. Alternately, single women might have had fewer people to assist in illness management. Furthermore, the social life of an active single woman might complicate her ability to complete her diabetes routines.

Psychosocial adaptation of women who demonstrated the Chancer pattern of management was marked by anxiety and negative mood state.

Women who were Chancers talked about not accepting their diabetes and attending to their diabetes routines in a haphazard way. The notion of wishful thinking and avoidance is related conceptually to the Chancer pattern of diabetes management. Patterns of coping responses have been linked to the adjustment process in diabetes (Felton & Revenson, 1984). Coping responses included wishful thinking fantasies such as the avoidance of reality. Wishful thinking seemed to divert attention from dealing with the immediate diabetes regimen at hand and was associated with poor adjustment (Felton & Revenson, 1984). The vicious cycle of self-pity and nonacceptance in wishful thinkers seemed to erode the potential for a positive outlook (Felton & Revenson, 1984).

On the other hand, information seeking strategies, including the pursuit of emotional support, were related to better adjustment outcomes (Felton & Revenson, 1984). Information seekers had an optimistic mind set, were more accurate in their perceptions of reality, and were better informed about the meaning of symptoms and how to deal with symptoms. The women who managed their illness as Straight Arrows and Calculating Adjusters seemed to demonstrate some of the characteristics of information seekers. In particular, they were more likely to use blood sugar monitoring to gather information about their blood sugar levels, more willing to adjust their insulin doses based on the results of blood sugar monitoring and symptoms, and were more knowledgeable about the management of symptoms than the other groups.

Individual and Environmental Factors

The role of the individual and social-environmental factors in the management of and adaptation to chronic illness was of interest. One individual characteristic, developmental stage, was related to depression. Women with lower levels of ego development reported more depression than women at higher stages of development. Hauser and others (1979) reported that diabetic adolescents with lower stages of ego development manifested more self-esteem impairment, negative self-conceptions, and depressive symptoms than those with higher levels. It may be that at the lower levels of ego development, when the person tends to think in concrete, stereotypical terms, some of the complicated medical interventions necessary to manage diabetes are not well comprehended. This might result in less than optimal illness control.

King (1986), in a study comparing generic nursing students and returning registered nurses (RN) found that the returning RN had a higher level of ego development and varied educational needs and goals. The difference in ego development between RN and nursing students influenced their perceptions of the educational process. Alternative treatment approaches that take into account the need for specific details and concrete advice may be indicated in the treatment modalities of women with lower stages of ego development. Furthermore, the support offered should be more concrete and less abstract (Hauser et al., 1979).

Women in this study who were in the stage of ego development characterized by autonomy and independence managed their illness as

Calculating Adjusters or Straight Arrows and exhibited few psychosocial symptoms. Nerenz and Leventhal (1983) suggested that individuals with a differentiated self-system would be better able to cope with the complexities of chronic disease management.

There is a paucity of literature that attends to the significant influence that the social and environmental context has on women's ability to manage chronic illness. Family and social environmental factors were associated with women's patterns of illness management and with adaptation to diabetes in this study. Women with diabetes who have a complex treatment regimen to follow seemed to do better if they lived within a structured environment such as a family. These women were better able to maintain regimented meal schedules and might have been highly organized because they had to be available to meet the needs of their families. The role of marriage and an accessible partner to assist with the diabetes regimen also was a stabilizing factor that was associated with better adaptive states. Although women who have the demands of a family may perceive at times the family to be a barrier to the ideal management of diabetes, women who are alone and have little structure in their lives may have the most difficult time managing their diabetes and may demonstrate the poorest adaptive states.

Socio-economic factors seemed to play a role in women's adaptive outcomes. Women with lower incomes or who were unemployed reported higher blood sugar levels, more social relationship demands, and more transition in their lives. Interestingly, income and education were unrelated. Work provides women with a source of social integration,

economic power, and has been shown to have a protective effect on health status (Nathanson, 1980). Alternately, if a woman's disease state precludes employment, she may be compromised psychologically, socially, and economically. Women who experienced life transitions such as the loss of a job or partner had greater mood disturbances and higher blood glucose levels. It is possible that transition exacerbates unstructured routines. The deleterious consequences of life transitions on women with chronic illnesses that require day-to-day vigilance merit further exploration.

Having a chronic illness may intensify economic deprivation through increased costs, work disruptions, and disability (Davidson, 1985; Ragucci, 1979). Diabetes is an expensive disease. Adequate financial resources to purchase insulin, syringes, blood testing equipment, and special foods is necessary to maintain good control. A supportive environment for women with chronic illness must include access to adequate economic resources and health care, especially for women with fewer family supports.

Psychosocial Adaptation

Women with diabetes mellitus reported more depression and anxiety than normal populations. Depressed mood and anxiety were associated with greater life transition, family and social relationship demands of illness, and diabetes symptoms. Depressed mood and anxiety have been reported commonly among adults with diabetes (Lustman et al., 1986; Murawski et al., 1970). Lustman and others reported that symptoms of depression and unstable diabetes often overlap. The course of depression in diabetes is often more chronic and serious

than in nondiabetic groups (Lustman et al., 1986). Furthermore, there is some evidence that life changes and events negatively influence the metabolic control of diabetes (Jacobson et al., 1985). Taken together, these findings lend support to the exploratory results reported here. Women who are experiencing transitions in their lives may have a more difficult time with the management of their illness. Transitions, such as being unemployed, may exacerbate the woman's ability to structure her daily routine and manage her illness effectively. The cycle of depression, anxiety, and poor illness control during difficult periods in women's lives mandates alternative treatment for depression. More intensive and long term therapy may be indicated. Economic support including health insurance for women who are in transition seems indicated, also.

Implications for Nursing Practice and Theory Generation

The overall goal of this research was to generate knowledge about how women lived with chronic illness and the factors that influenced their ability to manage and adapt to chronic illness. Although the results must be interpreted cautiously, the knowledge generated on the various patterns of diabetes management is useful to nurses in helping them to understand the different ways women go about the daily work of managing diabetes. A structured environment seemed to help women manage the complex, time-directed treatment program for diabetes. Nurses can assist women in understanding the demands that diabetes places on their lives and how the environmental demands can influence their ability to manage their illness.

With the emphasis in nursing today on family research and services, it is vital not to overlook women who fall outside the traditional definition of family. When developing services for women with chronic illness, the needs of single women who may be facing life transitions alone must be addressed. The more malevolent illness trajectory and somewhat chaotic pattern of illness management for single women deserves greater attention.

Furthermore, nurses must be aware of the variety of environmental factors that influence women's patterns of management and adaptive states. At times, families seem to create barriers to successful diabetes management. However, families also provide anchors for women and a structured environment that may facilitate the management of chronic illnesses that require regimentation. The balance between the barriers created by a family and the benefits of a family structure is not well understood.

Economic resources were related to the women's management style and psychosocial adaptation. The provision of adequate financial resources for women with chronic illness is a critical factor that mandates public policy changes. Policy in the work setting also might be addressed. Work environments could be restructured to insure that women have scheduled breaks so they can monitor their blood sugar, administer insulin, and eat regularly. In addition, women must be empowered to act as their own advocates in the work environment.

It is far too early for clinicians to recommend one style or pattern of management over another, however. Questions remain such as what is the most efficacious pattern of management and what are the

most appropriate outcome measures to use. The best indicators of quality of life are yet to be determined. However, it may be that the best measure of diabetes control is the report of diabetes-related symptoms given that symptoms directly influence the woman's quality of life. Furthermore, although normal blood glucose levels are believed to play a role in preventing diabetes-related complications, a Straight Arrow pattern in which tight control is achieved may result in serious episodes of hypoglycemia. What are the consequences for family members who constantly must live their lives around the woman's diabetes routines and with the fear of her potential medical crises?

Recommendations for Future Research

Future research should be directed toward refinement of the patterns of diabetes management. Replication of the patterns of diabetes management in another sample of women is recommended. Extending the research by studying the management patterns in men would be an important contribution. Longitudinal research to examine the patterns of diabetes management over time is another important direction for future research. Whether management patterns are sustained over time and different life situations or are altered depending on the woman's current life circumstances or psychosocial development remains to be answered. If life transition influences diabetes management, does the pattern of management change once stability is attained? Once depression is treated and mood state is improved, might the attention given to illness management be greater?

Situational factors also might influence women's diabetes management patterns. Women who are planning to bear children may

manage their diabetes as Straight Arrows prior to conception and during pregnancy to insure that the fetus has the best possible chance of a healthy life. However, once the baby is born, the rigid and demanding routines to maintain tight diabetes control may be changed to accommodate the needs of the new baby.

The developmental stage of women is another area that merits future exploration. The relationship between developmental status and depressed mood was weak. However, the theoretical relevance to illness adaptation is important and should be pursued in a larger study. If, indeed, developmental status, management patterns, and adaptive outcomes are related, the development of models of care to fit the needs of women at various stages of development could be addressed. Alternative measures of psychosocial development, such as Kegan's Subject-Object Interview yielded a rich source of qualitative data on developmental stage. The analysis of the remaining Subject-Object Interviews obtained in this study is planned.

The development of a theoretical model on the management of chronic illness in women and hypothesis generation about the factors that influence the management and adaptation to chronic illness is a logical step in the process of knowledge generation. Based on the results from this investigation, specific hypotheses about illness characteristics, diabetes management patterns, individual and environmental factors, and adaptation include:

1. The Chancer Pattern of diabetes management is more likely in women with lower developmental stage, greater life transition, fewer socio-economic resources, and greater mood disturbances.

2. The Revolving Around the Social Milieu Pattern is associated with greater role demands and higher stage of development.

3. The Calculating Adjuster, Straight Arrow, or Driven by the Clock Patterns of diabetes management, when controlling for developmental stage, psychological mood state, and socio-economic status, are more common than the other patterns when women have severe illness as measured by the number of diabetes-related complications and diabetes symptoms.

Limitations of the Research

Results from this study provide a framework for understanding the various ways that women with diabetes mellitus manage their day-to-day lives and illness routines. Ego development, a construct that has theoretical relevance in how women manage and adapt to chronic illness, was used to explore variations in illness management patterns and psychosocial adaptation. The family and environmental context seemed to play a major role in how women managed their routines and their adaptive state.

Results, however, must be interpreted with caution because of the small number of women studied. Although there may be similarities in how women manage and adapt across various types of chronic illnesses, the generalizability of the findings is limited to women who live with diabetes mellitus. Furthermore, generalizability is limited because the sample was a voluntary and purposive one and the demographic and illness characteristics were not representative of the population of women with diabetes. Interpretation of the standardized instruments may have varied from woman to woman introducing additional sources of

error.

Qualitative methods were used to generate patterns of illness management. The development of these patterns was subject to the investigator's biases. Efforts were made to reduce the bias imposed by the investigator. Coding categories and the patterns of diabetes management were critiqued by several nurse researchers. However, interpretation of the interview data by another investigator might yield different categories and patterns.

Conclusions

This study was designed to explore individual, family, and environmental factors that influenced women's patterns of diabetes management and their adaptive processes. The relationship of lower developmental stage to depressed mood and haphazard patterns of management was weak but merits further study because of the theoretical potential to explain variations in adaptation as well as potential treatment implications for nursing. The role of the social environment, in particular the structure imposed by having a family, a stable job, and adequate income, was associated with better psychosocial adaptation. Although individual and psychological factors may influence women's abilities to adapt to chronic illness, these fail to account for the social and environmental context that played a significant role in women's lives.

The growing knowledge base in nursing science includes more than the diagnosis and treatment of human responses to health and illness (ANA Social Policy Statement). Before nursing science enters the prescriptive realm of theory generation and practice, it is vital to

develop first a better understanding of how people live their lives when they are faced with health and illness situations that place them at risk for suboptimal adaptation. This exploratory study contributes to an understanding of the various ways that women approach the work of living with and managing a chronic illness. Pursuing this direction in nursing research will facilitate the development of theoretically guided practice to assist women in living and managing their lives with chronic illness in optimal ways.

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APPENDIX A

Introductory Letter

UNIVERSITY OF WASHINGTON
SEATTLE, WASHINGTON 98195

School of Nursing

Dear Family Impact Study participant,

Although some time has passed since your final interview with the Family Impact Study, you may recall that we asked if you would be willing to participate in further study. I am pleased to inform you that a small follow-up study is planned.

I am one of the original members of the Family Impact Study team and am planning a study for my dissertation research. In this project, I am interested in how women with diabetes manage their illness and also, what is important to them and how they make sense of what is happening to them.

The study involves only one interview in your home (or at the University of Washington if you prefer) at a time and date that is convenient to you. Only the mother in the family will be interviewed. You will have the opportunity to ask questions about the study and will be asked to sign a consent form. The interview will last about 1 1/2 to 2 hours. A questionnaire will be mailed to you for you to complete at your leisure and will be picked up by me during the interview. In this study, I will request your permission to tape record parts of our conversation.

You will receive \$10.00 for your participation in the study. The information you provide on the questionnaire will be seen only by myself and my supervisory committee. Your participation is completely voluntary. The services provided by your physician will in no way be jeopardized if you refuse to participate.

I will call you in the next few weeks to discuss the study, answer any questions you may have, and set up the first interview if you choose to participate. (If you have moved since the end of the Family Impact Study or if you prefer, please feel to call me anytime.) Thank you for your continued interest in this important research endeavor. I look forward to meeting some of you again!

Sincerely,

Janet Primomo, R.N., M.N.
Doctoral Candidate
545-0855 or 789-7024

An Equal Employment Opportunity/Affirmative Action Employer

APPENDIX B

Advertisement for Subjects

RESEARCH STUDY ON MANAGING DIABETES

Janet Primomo, R.N., M.N. of the University of Washington School of Nursing is conducting a study on how women who have diabetes mellitus manage their diabetes routines. The study consists of one interview in the home with \$10.00 paid after the interview. If you are interested in learning more about the study, please call Janet Primomo at 545-0855 or 789-7024.

RESEARCH STUDY ON MANAGING DIABETES

Janet Primomo, R.N., M.N. of the University of Washington School of Nursing is conducting a study on how women who have diabetes mellitus manage their diabetes routines. The study consists of one interview in the home with \$10.00 paid after the interview. If you are interested in learning more about the study, please call Janet Primomo at 545-0855 or 789-7024.

APPENDIX C

UNIVERSITY OF WASHINGTON
School of Nursing

Consent Form

Purpose and Benefits

The purpose of this study is to gather information on the many ways women who have diabetes manage their diabetes routines. I am also interested in how individuals think about things and how they make sense of their experiences.

This information is needed to increase our understanding about how individuals manage diabetes so that we can develop appropriate kinds of nursing and health services to assist individuals who have diabetes.

Procedures

The study involves one interview session. The interview will be conducted in your home (or at the University of Washington if you prefer) at a time and date convenient to you. The interview is planned so that it lasts no longer than 1 1/2 to 2 hours. You will also be asked to fill out some questionnaires. Most people take about one hour to complete these questionnaires.

My contact with you will include:

Completing a short questionnaire about your health.

Completing questionnaires in which you describe your own feelings and attitudes. Some of the questions included are of a personal and sensitive nature, such as rating how much you agree with statements like "I felt that I was just as good as other people," or completing sentences such as "Raising a family...". Other questions ask how your illness has effected your sexuality, your feelings about your own mortality, and your feelings about your family's future.

Participating in a one-hour interview about how you manage your diabetes, how you think about things in your life, and how you make sense of your experiences. This interview will be audiotaped and the interviewer will make notes about your answers.

Risks

There are no physical risks involved in this study. No names of the interviewed individuals will appear on any of the final reports. Sometimes people may experience a temporary discomfort when discussing their feelings or their situation. If you are uncomfortable and want further assistance in dealing with these feelings, I would be happy to assist you in obtaining a referral to an appropriate resource.

The information you provide on the questionnaires will remain confidential and will be seen only by my dissertation research supervisory committee. No one at your physician's office will see the results of your interviews. When reports are written, summary information will be reported and it will not be possible to identify any individual. The questionnaire information will be retained for 10 years.

The audiotapes of your interview will be used only for research purposes. At all times, the audiotapes will be under the control of the investigator. They will be stored at the University of Washington in a locked place. They will not be used for any other purpose without your written consent.

Your participation in the study is voluntary and you are free to withdraw at any time in the study. Your care at the University of Washington Hospital and Clinics will in no way be affected by your decision to participate or not participate in this study.

Other Information

You are free to ask questions before consenting. You may refuse to answer any questions during the interview or on the questionnaires. If you complete the study, you will be paid \$10.00 for your participation.

Date

Signature of Investigator

Janet Primomo, R.N., M.N.
Doctoral Candidate
School of Nursing SC-72
University of Washington
Seattle, WA 98195
(206) 545-0855 or 789-7024

Subject's Statement

The study described herein has been explained to me and I voluntarily consent to participate in the interview. I have had an opportunity to ask questions. I also understand that future questions I may have about the research or about subject's rights will be answered by Janet Primomo.

Date

Signature of Subject

copies to: Subject
Project file

SUBJECT-OBJECT ANALYSIS
Overall Formulation Sheet

Name or Code of Interviewee: _____

Analysis Page #: _____

A. Tentative Overall Hypotheses (minimum of 3 bits reflective of each hypothesis):

B. Rejected Tentative Hypothesis/Hypotheses and Reason(s) for Rejection:
(use back of sheet if necessary)

1. Hypoth: _____ Why rejected:

2. Hypoth: _____ Why rejected:

C. SINGLE OVERALL SCORE (minimum of 3 bits reflective solely of this score):

D. Testing S.O.S. If you have not already justified your rejection of scores on either "side" of the S.O.S., do so here:

E. Interview "Power" (# of bits reflective of S.O.S.):

APPENDIX E

EXAMPLES OF SUBJECT-OBJECT INTERVIEW CONTENT ACCORDING TO ASCENDING STAGES OF PSYCHOSOCIAL DEVELOPMENT

Stage 3 Interpersonal Stage

I've been just doing some of the things I like to do by myself rather than either not go or try to get Randy to go with me. He really prefers to sit at home and watch TV, and I used to just sit there with him or not go out. But now I realize that he really doesn't mind just doing that by himself and that he really feels better if I go off to an art museum by myself, because then he doesn't feel as if he's depriving me of going or as if he really should go. Before, it really was a strain between us because we didn't get to go as much as I'd want or we'd go and he really wouldn't like it and I'd feel guilty for making him come. Going by myself occasionally makes both of us happier and even makes things between us a lot smoother.

Stage 3(4) Interpersonal Stage with a Glimpse of Institutional Stage

But now I just go out more on my own if that's what I want to do. [How does that work?] It's not good for me to be so dependent on Randy. Randy helps me to see that. He keeps saying I have to do more what I want to do and I really do feel that it's important for me to decide myself. [Why is that important to you--deciding for yourself?] I'm an adult, and I think it is time that I started making my own decisions, don't you think?

Stage 3/4
Primarily Interpersonal Stage but also
Institutional Stage

Now I just go out more by myself and don't wait around for him. When I want to go to a new art exhibit I'll tell him about it and say, "Honey, I'd like you to come if you want to; I'm going to go." Of course he doesn't come and I'd enjoy it more if he did, but at least I get to go. To tell you the truth, though, sometimes I wonder if doing it this way is much better than not going, because even though he doesn't say that much I can see that it hurts his feelings that I just go out without him and I feel like I'm being a bad wife. "Why don't I just stay here with him and watch T.V.? It's not so bad and he works so hard?" But then I get mad and think, "Don't I have the right to do some things I like to do? It isn't fair of him to make me feel guilty." And so I go, but I end up feeling guilty about it.

Stage 4/3
Primarily Institutional Stage but also
Interpersonal Stage

I just go by myself now. I feel guilty about it sometimes because I know he'd rather I didn't go and that I'd just stay home with him. I can see him there feeling sad or mad about my decision and I feel myself changing my mind, right on the spot, that it's not right for me to go and I can just get stopped in my tracks. [So what happens?] Sometimes I don't go and sometimes I go. [How are you able to go?] I remind myself that it doesn't make sense to stay because then I only end up punishing him for my decision to not go. We both end up unhappy then.

Stage 4(3)
Predominantly Institutional Stage with some
Remnants of the Interpersonal Stage

I just go by myself now. He doesn't like it a lot of the time but I think it's not only better for me but better for us. I've just had to accept the fact that there are some things I'm not going to get from him and he has to do the same thing. He's married to a woman who likes to go on nature hikes and see art exhibits and though he doesn't like to do either of those and doesn't have to do them, he has to understand that I do and that sometimes I'm going to do these things rather than be with him. I know he doesn't like it but I try not to dwell on that. And I'm aware that there's this part of me that doesn't want him to either--I find it much easier when he doesn't dwell on his not liking my going out. [What makes it hard if he does dwell on that?] Well, I just have to work hard to remember that although I can be sad about his not liking it, I do think it's very important for me to honor my own interests. [It's very important.] Yes, because I'm not me if I don't.

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These consist of pages: 223-224
229-230
232-240
244

U·M·I

APPENDIX G

Killien's Semantic Differential Scale

How would you describe yourself, in general, right now? Below are pairs of words that indicate a range of feelings. Please place an "X" between each pair of words to indicate how you would describe yourself right now.

1. STABLE: _____:_____ : _____:_____ : _____:_____ : _____:_____ :CHANGING
 extremely quite slightly neutral slightly quite extremely
2. UNCERTAIN: _____:_____ : _____:_____ : _____:_____ : _____:_____ :CERTAIN
 extremely quite slightly neutral slightly quite extremely
3. SATISFIED: _____:_____ : _____:_____ : _____:_____ : _____:_____ :DISSATISFIED
 extremely quite slightly neutral slightly quite extremely
4. INSECURE: _____:_____ : _____:_____ : _____:_____ : _____:_____ :SECURE
 extremely quite slightly neutral slightly quite extremely
5. UNHAPPY: _____:_____ : _____:_____ : _____:_____ : _____:_____ :HAPPY
 extremely quite slightly neutral slightly quite extremely

APPENDIX H

Transition Status Question

Throughout life, there seem to be periods in which things in your life do not change a great deal and other times when things seem to be changing a lot. Think about your life in general at the present time. Would you describe yourself as being in a period of change or stability right now?

APPENDIX I

DIABETES MANAGEMENT INTERVIEW GUIDE

The purpose of the following questions is to ascertain how people manage their lives when they have diabetes. I am interested not so much in how diabetes affects ones life, or the problems that it causes, but rather, **HOW THE PRESCRIBED DIABETIC REGIMEN IS MANAGED BY THE PERSON.**

1. Tell me about your daily routine in regard to what you do for your diabetes. Probe for:
 - Monitoring urine and blood through testing
 - Insulin administration
 - Diet - Meals and snacks
 - Exercise
 - Sleep patterns
 - Family and social activities
 - Symptom management - how do you know when you're off?
 - how does it bother you?

2. How consistent is your routine from day to day?
Probe for flexibility.

3. Tell me about how you manage your diabetes when you are sick.

4. What kind of changes in your diabetes control do you notice during menstruation? How do you handle them?

5. If you expect to engage in strenuous exercise, how do you manage your insulin and eating?

6. How do you manage your regimen when you are at work or out of your home? How do you manage eating out?

7. How do you manage your routine when you go on trips?
8. What circumstances make it difficult for you to maintain your regimen?
(Probe) What interferes with your diabetes management?
9. Who assists you with your diabetes? husband, children, friends, professionals?
10. In what ways, if any, does having diabetes interfere with or keep you from doing things you want to do?
11. When you have questions about your diabetes routines, how do you go about getting information?
12. Are you a member of a diabetes association or other support group?
 yes
 no
- If yes, how often do you attend meetings?
 Weekly
 Every other week
 Monthly
 A few times a year
 Never
- How helpful have the meetings been?
 Very helpful
 Helpful
 Somewhat helpful
 Not at all helpful

APPENDIX M

HEALTH STATUS QUESTIONNAIRE

INTERVIEWER STATEMENT: The next questions have to do with your health status and how you manage your diabetes.

1. When did you first discover you had diabetes?

_____ month _____ year

Note: Calculate age of onset (Year of diabetes onset - Year of birth) _____

Calculate number of years with illness (Current year - year of diabetes onset) _____

2. What was the first treatment you received for your diabetes?

3. What kind of insulin are you now taking?
How often?

4. Thinking back over your urine and blood testing this past week, how would you rate your glucose control?

- ___ Very well controlled (1)
- ___ Moderately controlled (2)
- ___ Fairly well controlled (3)
- ___ Not very well at all controlled (4)

What were the results on your most recent blood/urine test? When was that?

5. Have you had any complications related to your diabetes? ___yes___no
If yes, please describe and give dates.

6. Have you had any surgery related to your diabetes? ___yes___no
If yes, please describe and give dates.

7. In general, which word best describes how you view your illness?

- Not very serious _____ (1)
- A little serious _____ (2)
- Moderately serious _____ (3)
- Very serious _____ (4)

8. Do you have any other major health problems? ___yes___no
If yes, please describe.
9. Are you taking any medications for other health problems?
___yes___no
If yes, what are the medications?
10. In general, which word best describes your health?
- Excellent _____(1)
Good _____(2)
Fair _____(3)
Poor _____(4)
11. Have you had any illness episodes in the past 2 months that caused an absence from school or work, or a major change in your routine?
___yes
___no

If yes, how many? ___
Please describe.
12. How many illness episodes required a call or visit to your health care practitioner?_____
13. Have you been hospitalized in the past year? ___yes___no
If yes, how many times? _____
Please describe.
14. Have you had any accidents in the past year that required medical attention? ___yes___no
If yes, when was the accident?
Please describe.
15. Has anyone in your family experienced illness, accidents or injury in the past year? ___yes___no
Please describe.

16. Have you seen a mental health counselor in the past year?
___yes ___no
17. How tall are you?_____ "
18. What is your present weight?_____
Do you feel that you are now: ___at desired weight (1)
___underweight (2)
___overweight (3)

APPENDIX O

BACKGROUND INFORMATION

1. Who lives at home with you?

<u>Name</u>	<u>sex</u>	<u>age</u>	<u>relationship</u>
woman	—	—	_____
partner	—	—	_____
children	—	—	_____
	—	—	_____
	—	—	_____
others	—	—	_____

How many children in the family? _____

How many children currently live at home? _____

2. What is your marital status? _____

Currently married and living with husband	1
Currently married and living with 2nd or 3rd husband	2
Never married, but living with a partner	3
Divorced and living with a partner	4
Separated and living with a partner	5
Never married	6
Divorced	7
Separated	8
Widowed	9

If married or living with a partner, "How many years have you married (or with your partner?" _____

3. What was the last grade of school that you completed? _____

or use:	Elementary school	1	_____ partner
	Junior high school	2	
	High school graduate	3	
	Some college or technical school	4	
	College graduate	5	
	Master's degree	6	
	Doctorate	7	
	don't know	8	

4. What is your employment status? _____
- | | | |
|-------------------|---|---------|
| Not working | 1 | partner |
| Retired | 2 | |
| Working part-time | 3 | |
| Working full-time | 4 | |
5. Are you taking any classes? _____
- | | | |
|-------------------|---|---------|
| No | 1 | partner |
| Part-time student | 2 | |
| Full-time student | 3 | |
6. What kind of work do you do? _____
- partner?
7. Name of job or position. _____
- partner
8. Please look at this card and tell me the number next to the amount that comes closest to your family's total income last year. Be sure to include all sources such as wages and salaries from all family members, social security or retirement benefits, and interest income.
1. Under \$3,500
 2. \$3,500 - 4,999
 3. \$5,000 - 6,999
 4. \$7,000 - 9,999
 5. \$10,000 - 14,999
 6. \$15,000 - 19,999
 7. \$20,000 - 24,999
 8. \$25,000 - 29,999
 9. \$30,000 - 34,999
 10. \$35,000 - 39,999
 11. \$40,000 - 44,999
 12. \$45,000 - 49,999
 13. \$50,000 - 59,999
 14. \$60,000 - 69,999
 15. \$70,000 or more
 16. no answer
9. To what ethnic group do you belong? _____
- | | | |
|-----------------|---|---------|
| White | 1 | partner |
| Black | 2 | |
| Native American | 3 | |
| Asian | 4 | |
| Hispanic | 5 | |
| Other | 6 | |
| don't know | 8 | |

APPENDIX P

DIABETES MANAGEMENT CODING SHEET

SUBJECT ID ___ (columns 4-49: 1=yes 0=no)

4	Feeling low - symptoms of low blood sugar	SYMPTOMS
5	Feeling out of control - high blood sugar	
6	Figuring it out - Deciphering ambiguous cues	FIGURING
7	No detectable warning factors symptoms	
8	Recognizing patterns	
9	Heightened vigilance	BS MONIT
10	Routine vigilance	
11	Occasional vigilance	
12	Watching	MANAGING BS
13	Regimen modification	
14	Low blood sugar management	
15	High blood sugar management	
16	Planning for the unexpected	
17	Seeking consultation	
18	Paying the consequences	
19	Adjusters	MED MANAGEMENT
20	Flexible adjusters	
21	Running it on the high side	
22	Adjusting in a tight range	
23	Rigid Adherers	
24	Occasional adjusters	
25	Special diabetic diets	DIETS
26	Common sense diets	
27	No special diets	
28	Rigid - Very regular	MEAL REGULARITY
29	Flexible - Room for exception	
30	Variable - Inconsistent	
31	Sensible Eaters : being on guard	APPROACHES
32	Food Adjusters :making allowances	
33	Indulgents - "Covering" food with insulin	
34	Chancers	
35	Regular	EXERCISE
36	Sporadic	
37	No exercise	
38	Awareness of food intake	PLANNING FOR EXER
39	Monitoring blood sugar closely	
40	Adjusting insulin	
41	Increasing food intake	
42	Guesswork	
43	Helping others	OTHERS
44	Supportive others	
45	Rescuers from danger	
46	Protecting others	
47	Involved others	
48	Hindering others	
49	No others	
50	Predominant Pattern of Diabetes Management	
51	Secondary Pattern	
	(1) Being driven by the clock	
	(2) Minimizing the routine	
	(3) Revolving around social milieu	
	(4) Calculating adjusters - Juggler	
	(5) Straight arrows - Juggler	
	(6) Chancers - Juggler	

APPENDIX Q

DIABETES MANAGEMENT CODES

Symptoms or "Feelings" - Warning Factors:

Symptoms were defined as the subjective appraisal or evidence of physical disturbance. Symptoms are the threatening event that trigger the coping response. Women described the "feeling" they experienced when their blood sugar was high or low. For example, "I get the feeling that things aren't right" (#6, p 1). The types of symptoms reported by women in this study fell into two general categories, "feeling low" and "feeling out of control."

1) **Feeling low - symptoms of low blood sugar (hypoglycemia):** Women talked about the experience of low blood sugar as "feeling low." They reported feeling dizzy, nervous, faint, weird, spacy, fuzzy, light headed, worn out, slowed down, hungry, and grouchy. Having trouble concentrating and getting work done, and not being able to think straight or reason were symptoms commonly reported. They also had shakes, sweating, quivers, headaches, and palpitations. They felt that their body didn't cooperate, and they could feel things going down.

2) **Feeling out of control- symptoms of high blood sugar (hyperglycemia):** Some women described how they felt when they thought their blood sugar was high and out of control. They experienced dry mouth, thirst, feeling hot, a feeling that things aren't right, blurred vision, leg aches, tired, heartburn, and not feeling hungry.

3) **Figuring it out: Deciphering ambiguous cues:** Women talked about trying to get a sense of what was going on with their blood sugar. Using the information gained from paying attention to warning factors or symptoms, they tried to appraise the situation and diagnose what was happening. They tried to figure out whether they were really having symptoms or were just experiencing stress, or whether they were experiencing real hunger or an insulin reaction (#22). They would attempt to decipher whether the blood sugar was high or low, or which way they were going (high or low blood sugar). A constant awareness about the feeling associated with low or high blood sugar was described.

4) **No detectable warning factors or symptoms:** Some women did not experience the sensations or feelings of low or high blood sugar (#35, p.4; #40, p. 2-3). The inability to detect symptoms or warning signs seems to be associated with increased duration of diabetes; in other words, with increased duration of illness, perhaps the ability to detect symptoms or the sensitivity to symptoms decreases. This means a woman may go into a reaction very quickly without having any warning during which she could actively monitor her blood sugar.

5) **Recognizing patterns, triggers or intensifying factors:** The ability to recognize patterns and know what to expect from their bodies was evident in some women. They described trying to explain what was happening based on the type of day experienced. They considered any intensifying factors that might have influenced diabetes control (tension, rushed day, poor eating). They tried to relate the feelings, symptoms, or blood sugar level to something they had eaten or not eaten, or the stress they were experiencing. This involved watching for cues when things have happened the might influence the blood sugar (#29) (stress, skipping a meal).

Active blood sugar monitoring (testing or symptom validation: Some women reported testing their blood sugar to check out where they were (the blood sugar) prior to taking action on how they were feeling (the symptoms they experienced). Some women were very aggressive monitors, others were not.

6) **Heightened vigilance during specific situations:** Some women talked about testing more frequently during times of illness, pregnancy, menstruation, potlucks, vacations, or when symptoms appeared. This type of aggressive monitoring would be considered a preventive measure to maintain normal blood glucose levels.

7) **Routine vigilance - Steady pattern of testing and monitoring:** Some women reported testing their blood sugar very regularly (on at least a daily basis or regularly when symptoms appeared).

8) **Occasional vigilance - Variable testing:** Testing for these women was sporadic, inconsistent, or infrequent on a day to day basis. They might have talked about their testing routines as varying day to day due to hectic circumstances.

Managing the Blood Sugar to Prevent a Reaction

Women talked about what they actually did when they were "running into trouble" or when they found themselves "in trouble" (blood sugar). This might be the considered the coping process following self appraisal of the blood sugar. When women experienced symptoms or feelings, action may or may not have been taken. The strategies women used to prevent and manage a reaction episode include:

9) **Watching - Riding it out for a while:** Some women did not immediately act but rather waited to see what their blood sugar would do over time. They were interested in looking for patterns and wanted to get more information before they began to modify their routines.

Regimen modification: Treating it: .

10) **Low blood sugar management:** Most women coped with low blood sugar by eating or drinking something when their blood sugar was low.

11) **High blood sugar management:** Women reported increasing their

regular insulin and watching what they ate (eating carefully and less). Some might have reported "taking a little regular to bring it down." The literature suggests some people exercise, and reduce food intake (O'Connell et al, 1984). Women did not talk about high blood sugar as being as much of a problem as low blood sugar was.

12) **Planning for the unexpected - preparing and playing it safe:** Strauss and others (1984) similarly discussed organizing for crisis as a dimension of chronic illness. In the current study, the category "preparing" included carrying food and supplies in case of a reaction. Bringing food or emergency sugar was a strategy used to prepare for physical exercise. Preparedness may be a key differentiating factor in the women's styles since not all women were prepared to deal with a change in blood sugar.

13) **Seeking consultation or supplementing information:** For the most part, women talked about dealing with the day to day fluctuations in blood sugar on their own rather than consulting with anyone. Although the predominant method of management was self-management, some women did seek consultation for special conditions such as sickness.

14) **Paying the consequences of having a reaction:** After experiencing a reaction, women talked about feeling utterly exhausted, having a lingering headache, and not feeling well for the remainder of the day.

Medication Management

Most of the women (35 out of 40) in this sample were on insulin therapy. The remaining five women were on oral medications or were diet controlled. There are different modes or styles of medication administration which are described as follows:

Adjusters: Women talked about adjusting their insulin dose(s) based on their planned activities for the day, their current blood sugar, the food they had eaten or were planning to eat, and how they felt. Within the general category of adjusters, there were different sub-categories.

15) **Flexible Adjusters:** Some women highly desired flexibility and the self-determination to make decisions about how their time management for the day would proceed. Many of these women were on multiple daily injections in order to achieve this flexibility. They talked about playing around with their insulin, food, exercise, and testing.

16) **Running it on the high side:** The fear of experiencing low blood sugar drove these women to maintain a blood sugar that was higher than they might have been advised by their physicians or believed was ideal. They may have exhibited a desire for flexibility

but talked about how important not having an insulin reaction was. They discussed not wanting their diabetes to interfere with their lives. In order to prevent this from happening, they tried to avoid having a hated low blood sugar episode by running their blood sugar on the high side.

17) **Adjusting in a tight range:** These women tried to maintain their blood sugar in a narrow, clinically acceptable range (between 80-120). They strived for excellence in blood sugar management and talked about how strict they were in every phase of management. They were "straight arrows" when it came to the management of their medication.

18) **Rigid Adherers:** These women tried very hard to maintain a very stable routine and did not exhibit the same amount of desire to achieve flexibility in their lives as did adjusters. For the most part, they did not adjust their insulin but maintained the same dose and adjusted with food instead. It is possible that these women were on oral medications or diet controlled or were newly diagnosed insulin dependent diabetics.

19) **Occasional Adjusters - Variable Management:** These women talked about the time of their medication varying depending on schedules (work, family, or social). They fell somewhere in between the rigid schedulers and the adjusters with no one pattern standing out clearly.

Food as Treatment

Food takes on a special meaning for people with diabetes because it is an integral part of their treatment regime. The types of food eaten and the timing of meals and snacks must be carefully calculated in order to maintain an ideal blood sugar level. Too much or too little food eaten earlier or later than needed can threaten the fine balance needed to maintain adequate functioning. Although most practitioners prescribe specific diets for people with diabetes, women followed the prescriptions loosely. Three different types of diets as well as variations in the timing of their meals emerged from the data. In addition, there seemed to be some overall patterns in how women managed food in social settings.

Types of diets: Women talked about different types of diets they followed.

20) **Special diabetic diet:** Some women followed an exchange, calculated diet or weighed their food. They tended to be strict in how they ate.

21) **Common sense diet:** Many women talked about eating sensibly and having a well balanced diet. They "avoided" the obvious (sugars) but did not follow strictly a diabetic diet. They talked about

flexibility in their diet for social occasions.

22) **No special diet - not strict about diet:** These women talked about eating what they wanted to without concern for special diets.

The regularity and timing of meals seemed to have dimensions:

23) **Rigid - Very regular:** These women desired to eat their meals at very regular times and followed rigid schedules. For some, even the weekends were quite consistent.

24) **Flexible - Room for Exception:** The timing of a meal might be juggled to accommodate an occasional social event. The basic meal pattern is regular, but there is room for some flexibility. Women talked about planning for special meals and adjusting their daily food intake and insulin to allow for their "treat."

25) **Variable - Inconsistent meal times due to hectic schedules:** Family, work or social activities seem to impinge on the regularity of meals. Women talked about some regular meals, but emphasized the inconsistencies mandated by their own or their family's schedules. **Approaches to food management:** The categories for approaches to food management emerged in relation to how women dealt with eating in the social environment (when eating out or when at social functions) as well as how women coped with the need for regularity on a daily basis. The categories varied on the degree of caution exercised in relation to food management.

26) **Sensible Eaters:** These women watched what they ate carefully and reported being on guard as well as trying to behave through periods of cravings. Some of the specific strategies they used included being on guard. Women asked about the contents of foods as well as how they were prepared. They talked about carefully choosing fairly plain and basic food whenever possible. Picking and choosing foods from the menu as well as from the plate once the food arrived was another strategy. Women talked about not eating or avoiding foods that were not on their diet.

27) **Food Adjusters:** The food intake for the day or meal as adjusted according to the blood sugar level or planned activities. They were able to be flexible and find a way around the situation in order to do what they wanted to do.

One strategy some women used to adjust food intake was saving calories and making allowances. Eating less throughout the day so a larger meal could be eaten later was reported by some of the women.

28) **Indulgers - "Covering" food eaten with insulin:** Women talked about eating the foods served and then "covering" their blood sugar with the insulin they thought they needed. This might have been done when eating in others homes, potlucks, or restaurants.

29) **Chancers:** Some women showed little or no caution in what they ate and when they ate. They might have inconsistent eating patterns and be fairly free in their diet. These women might also take chances with food by not preparing for emergencies. For example, they may not carry emergency food or supplies on a daily basis. The emergency food might be viewed as a temptation and women stated they would eat it if they had it with them.

Managing Exercise as Treatment

Some of the women exercised routinely while others were less regimented. There were identifiable strategies that women used to manage their treatment regimes when they exercised.

Frequency is one dimension of exercise:

29) **Regular:** Regular exercise was reported by some women. Some had a regular exercise routine but were limited by their physical condition in the types of activities they could engage in.

30) **Sporadic:** Some women did not have regular exercise routines but did exercise on weekends or vacations, or led fairly active lives. They might have talked about their attempts or desire to get into a regular exercise routine.

31) **No exercise:** These women did not exercise. They might talked about not exercising for fear of a low blood sugar reaction.

Planning for exercise: Women who reported exercising talked about their strategies for integrating exercise into their treatment regimens. They had to consider their food intake and insulin needs as they organized and prepared for exercise. The various strategies women used to organize for exercise included:

32) **Awareness of food intake:** Women were conscious of what and when they ate. They wanted to be sure that their blood sugar would be adequate for the exertion planned. Some women timed their exercise for before or after a meal or made an effort to eat something before or after their activity so that their blood sugar would be adequate. Also, emergency food was carried in case of low blood sugar during exercise.

33) **Monitoring blood sugar more closely:** Some women tested their blood sugar more during exercise or paid closer attention to how they were feeling.

34) **Adjusting (decreasing) insulin dose:** One pattern of preparing for exercise was to decrease or adjust the insulin dose. Some women were very comfortable with this while others preferred not to alter their insulin dose and to eat more instead.

35) **Increasing food intake:** For some women, exercise preparation

was managed by eating more to cover the increased energy consumption rather than decrease the insulin dose. These women felt more comfortable with this approach to covering the increased energy expenditure during exercise. They might fear having a low blood sugar reaction and this strategy helped them avoid it. Although similar to the category "awareness of food intake," this strategy goes beyond awareness of food intake and eating before exercise and involves the woman's knowledge about the balance among insulin, blood sugar, and exercise.

36) **Guesswork:** These women did not know exactly how to make adjustments so they guessed about dosages and eating.

The Use of Allies

Women talked about the people around them in qualitatively different ways. Some people functioned as helpers, others as hindlers, and some women did not believe they could depend on anyone else for assistance. The use of allies (agents is the word used by Strauss) may be a key factor in differentiating styles or patterns of management and may be critical in linking development with management styles. All people with diabetes may need allies, but the extent to which they develop and use allies in their management strategies may differ. Three categories of allies seem to emerge.

Helping others: (Cooperating or assisting - Strauss). Helping others were people who supported the woman in a general sense or intervened on her behalf. The interveners might monitor or check in with the woman to make sure she was not having a reaction. They might give her food and make her eat if necessary, give shots, test the blood sugar, function as consultants, try to limit stress or conflict, or try to protect her from having to explain diabetes to others. Although all these behaviors may fall under "helping allies," there are different levels of involvement present.

37) **Supportive others:** Women talked about other people being supportive of their illness in a general sense. They might have used the word "supportive" and described how someone was understanding of their moods.

38) **Rescuers from danger:** These allies might intervene and help the woman with extreme circumstances such as when she was experiencing low blood sugar. The ally might encourage the woman to have food, or provide sugar, or simply call 911.

39) **Protecting others:** Protecting allies tried to limit the external stress for the woman. This might have been by giving other people information about the woman's need to eat at a specific time, trying to ease the tension in a situation, or helping with the preparation of dinner. Protecting others might intervene on behalf of the woman.

40) **Involved others:** The administration of insulin or glucagon requires a different kind of and possibly greater involvement on the part of the ally than reminders about eating. Involved others might administer insulin on a regular basis, help test occasionally, and serve as a consultant in a professional role. A greater degree of intervention is present with involved others.

41) **Hindering others:** Hindering others are defined as those people who do any of the following: challenge the diet - ie. kids baking cookies; eating in social settings (late dinners, potlucks), disagree about places to eat, what to eat, misunderstand the nature of diabetes or contribute to the woman feeling like she is the "odd one out." Strauss and others (1984) referred to these people as conflicting others.

42) **No others:** Some women do not feel there is anyone to help them with their diabetes. They specifically talk about the illness being their responsibility and they must look after it totally on their own.

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