SELF-REGULATION: NEGOTIATING TREATMENT REGIMENS IN INSULIN-DEPENDENT DIABETES

by

Rae L. Jayne

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA

San Francisco

SELF-REGULATION: NEGOTIATING TREATMENT REGIMENS

IN INSULIN-DEPENDENT DIABETES

in trying to get hold of things
m y s t e r i o u s
we try to invent something definite
and mystery can never be defined
or must always be redefined
or better yet
come at newly and indirectly
through stories and things around us

Sister Corita,
Footnotes and Headlines

ACKNOWLEDGEMENTS

It is a difficult task to thank all the people involved in helping me complete this dissertation. I would not be writing this acknowledgement now, if it had not been for the many friends and colleagues whose continuous support and belief in my abilities helped me arrive at this point.

I owe particular thanks to my wonderful dissertation committee for moving me through the dissertation process. As chairperson, Sally Rankin has been a incredibly valuable guide and friend throughout the experience, and I thank her heartily. It is hard to imagine how the last few years would have been if Sally's good advice, council, and superb editing had not been there when I really needed it. As my academic advisor, she has provided me with opportunities to interact with the nursing research community to further foster my research skills and interests. Catherine Gilliss pulled my qualifying examination together for me and orchestrated both the challenge of that examination and the impetus to move onto the proposal phase. Gaylene Becker will always hold a special place as my emotional mentor. She has done more for my confidence building than she may know; her positive attitude and belief in the value of my work has buoyed me up many times. Last, but definitely not the least, Leonard Schatzman has given the gift of himself, his insight, and his intellectual curiosity. How lucky I feel to have known Lenny at the end of his academic career

when he had more time to spend prodding his last group of students through the anchoring of qualitative analysis in scientific thought. I am grateful for his challenging intellect and his personal warmth, despite his gruff exterior.

Every member of the faculty who taught a doctoral level course has in some way contributed to this dissertation, but I would like to acknowledge Dr. Jeanne Hallburg and Dr. Ida Martinson for their special care along the way. Jeanne really is responsible for starting my doctoral career and Ida, with her warm heart and Kleenex box, kept me going when I was ready to quit. The support staff in the Department of Family Health Care Nursing have been terrific, answering all my questions about computers and xerox machines. I am particularly grateful to Georgiana Bratz, Peggy Huang, Dr. Martha Nolte, and Dr. John Karam for shifting the load in the Diabetes Center and for being so empathetic. I am also indebted to Hazel Georgetti for all the hours of transcription and for her positive approach to life. I would also like to thank the Babes on Pumps for their good humor and validation of the concepts discovered in this study. Special thanks and appreciation go to Jeff Kilmer for formatting this dissertation and being a truly stabilizing force in the midst of chaos.

I would also like to acknowledge the people who shared their stories with me. I hope the dissertation does justice to them in their heroic efforts at living life with

diabetes. A tremendous thank-you goes to my fellow doctoral students, Susan Kools, Roberta Durham, Mariann McCarthy, and Linda Norton for their constructive criticism in the process of analysis. A very special thanks to Sally Higgins for literally pulling me along behind her in the doctoral process.

I greatly acknowledge the love and support of my family, especially my son Ken Bradshaw, my parents Marguerite and Ambler Klein, and my cats Albert and Wanda. Most importantly, I dedicate this dissertation to the person who helped me the most in finishing this project, my husband and best friend, Donald R. Jayne. Without his support, his incredible patience, and his Macintosh computer, this project would never have been completed.

Finally, I want to acknowledge the sources of funding that supported this dissertation: The National Center for Nursing Research (NIH, NRSA), Diabetes Research and Education Foundation, UCSF Graduate Research Award, and Sigma Theta Tau (Alpha Eta Chapter).

ABSTRACT

SELF-REGULATION: NEGOTIATING TREATMENT REGIMENS IN INSULIN-DEPENDENT DIABETES

Rae Louise Jayne

The purposes of this investigation were to examine the variant processes of self-regulation, defined as a process of negotiating and accommodating the demands of everyday life commitments with the complexity of diabetes treatment, and to generate theoretical concepts related to self-regulation from data provided by people living with diabetes. The model of self-regulation developed in this study contrasts personal decisions about diabetes care with the compliance model.

A substantive, grounded theory was constructed using a convenience sample of 30 subjects with Type 1 diabetes. Sixteen men and 14 women were interviewed on two occasions, two to three months apart using a semi-structured interview guide. Demographic data, visual analogue scales (VAS) estimating the subjects' perceptions of current diabetes control and effort expended to manage treatment, and blood samples testing glycosylated hemoglobin (GHb) were also collected. The methodology of grounded theory and dimensional analysis were used to analyze the qualitative data; Pearson correlations were used to evaluate relationships between the demographic data, VAS scores, and the GHb levels.

Findings indicated that subjects evolved into self-regulating behaviors for managing diabetes treatment through a series of temporal phases designated as Becoming Diabetic, Confronting the Illusion of Promised Normality, and Pragmatic Sufficiency. Movement through these phases varied according to the individual's assessment of various factors experienced in managing diabetes treatment. A form of natural analysis used by the subjects described a process of decision making related to self-management practices. Data revealed that participating in everyday life experiences was the predominant consideration in self-management decisions.

Health care provider implications are that the phases of development and the process of natural analysis appear to have a greater impact on treatment adherence than prescriptions imposed by health care providers. Thus, attempts to assist patients with normalization within the constraints of diabetes may be key to developing treatment plans that are consistent with metabolic control and the social realities of the patient.

Nancy H. Rankin, PhD, RN
Adviser

Rae L. Jayne
Candidate

TABLE OF CONTENTS

CHAPTER 3 (Continued)

CHAPTER 5 (Continued)

CHAPTER 7 (Continued)

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

THE STUDY PROBLEM

Purpose of the Study

The purpose of this research is to investigate general and variant processes of self-regulation in insulin dependent adults with diabetes mellitus. This study is designed to examine the process of self-regulation from a patient perspective and seeks to generate theoretical concepts related to self-regulation from data provided by people living with the illness.

Self-regulation is defined here as a process of negotiating and accommodating the demands of everyday life commitments with the complexity of diabetes treatment. It develops over time and is contingent on the interaction of personal perceptions of the diabetic condition with the environmental context in which a diabetic person lives. Self-regulation attempts to integrate the definition(s) given to diabetes by the individual living with the illness, the social contexts in which the person lives and in which self-management takes place, and the importance the diabetic individual places on health outcomes in attempting to balance illness demands with everyday life activities. A proposed model of self-regulation contrasts personal decisions about diabetes care with the compliance model designed to convince individuals with diabetes to adhere to professionally prescribed treatment regimens.

The specific aims of this research are to describe and explain:

a) how the process of self-regulation develops in adults with insulin dependent diabetes;

b) the relationship between self-regulation and compliance with prescribed diabetes treatment regimens; and

c) the extent to which an understanding of self-regulation influences diabetes control.

The long-term goal of this research is to develop a nursing framework to guide interventions with people with diabetes that is consistent with metabolic control and the social realities of the client.

Introduction to the Problem

Diabetes mellitus is a multifaceted syndrome characterized by alterations in the metabolism of carbohydrates, fats, and proteins. The pathophysiology of diabetes results in abnormal blood glucose levels. Over a period of time, elevated blood glucose levels lead to a number of micro-and macrovascular anomalies. These changes in the vascular system produce complications such as visual impairment or blindness, end-stage renal disease, peripheral vascular disease, and coronary artery disease. The complexity of the illness is matched by the complexity of the treatment needed to maintain the blood glucose levels within a range that will prevent these complications. Since fluctuations in blood glucose levels occur rapidly and

continuously throughout the day, the self-regulatory activities that must be managed by the person with diabetes, in the context of a clinically derived regimen for diabetes control, are on-going and require constant attention. Because complications of diabetes occur in the presence of uncontrolled blood glucose levels and because practitioners think they know how to control blood glucose levels, these practitioners find it difficult to understand why patients do not comply with the treatment regimens prescribed to accomplish this control. Research regarding compliance has attempted to identify factors which contribute to non-compliant behaviors.

Statement of the Problem

Non-compliance to diabetes treatment regimens is defined as the patient's failure to fulfill clinical prescriptions recommended by the health professional (Sackett & Haynes, 1976). Non-compliance with regimens is most often characterized in the compliance literature as a problem arising from the psychological makeup of individuals with diabetes (Dunn & Turtle, 1981), the degree to which the family of the diabetic is considered functional and supportive (Anderson & Auslander, 1980; Schafer, Glasgow, McCaul, & Dreher, 1983), health belief motivation or health locus of control (Alogna, 1980; Cerkoney & Hart, 1980), or the relationship between patients and their health care providers (DiMatteo & DiNicola, 1982). Compliance is

generally measured by indices such as the timing of daily insulin injections, number of blood tests performed versus the number ordered, and adherence to prescribed calorie and exercise routines.

Limitations of the Compliance Perspective

Relatively little research literature is available on how the person with diabetes views the treatment regimen, analyzes the need to adhere, and decides what actions to take in controlling the illness. Equally limited is literature analyzing how the social and environmental contexts in which a diabetic person lives affect the perceptions and actions she/he takes in managing diabetes regimens.

The traditional compliance literature does not provide a description of the decisions patients make in relation to the outcome variables measured. Existing studies fail to take into account the variability in individual responses to insulin, food intake and exercise. The compliance model reflects the assumptions of health care professionals that prescriptions will necessarily result in metabolic control if they are followed. Further, professional perspectives suggest that the solutions for non-compliance are to educate the patient, reinforce desired behaviors, and improve patient-provider relationships. The compliance model also assumes the centrality of professional health expectations

in personal health decisions (Cox, 1989; Glasgow, McCaul, & Schafer, 1987; Hayes-Bautista, 1976; Trostle, 1988).

Studies that have attempted to identify and describe the behaviors diabetic patients actually engage in (Anderson, S., 1988; Hamera et al., 1988; Jayne, 1988; Kelleher, 1988; O'Connell et al., 1984; Peyrot, McMurry, & Hedges, 1987) have demonstrated that many variables are negotiated in combining a human, social existence with the self-care procedures necessary to control the symptoms of this chronic illness. These studies reveal that self-regulation of diabetes is not necessarily related to controlling the long-term metabolic effects of the disease as much as it is controlling symptoms and maintaining a sense of well-being. In the context of multiple social identities, the importance a person gives to her/his diabetes identity in various social situations, and how visible the illness is in these situations, influences compliance to regimens. Metabolic control is further influenced by factors related to personal perceptions and meanings the individual attaches to diabetes.

This study provides a systematic analysis of the process in which people with diabetes engage as they attempt to integrate the complexities of diabetes self-management into the context of their social lives. Analysis of this process is necessary in order to generate a nursing framework that reflects more accurately human responses to this illness than the prescriptive model of compliance.

Significance

Historically, nursing has played a central role in educating and training people with diabetes to adopt the self-care practices necessary to control blood glucose levels (Allison, 1973; Backscheider, 1974; Etzwiler, 1967). Even in the innovative nurse managed clinics developed by Allison and Backscheider, in which Orem's nursing theory of self-care was used to organize the clinic practice, the prescriptive or compliance model served as the philosophical basis. The goal of nursing care was to assist the client in following the prescribed treatment plan; the individual's definition of self-care was rarely taken into consideration.

Leventhal and Johnson (1983) state that the difference between medicine and nursing lies in the fact that physicians are trained to diagnose and prescribe in order to cure or retard the progress of disease. This approach leads to behavioral research that focuses on the development of procedures to increase patients' compliance with prescribed regimens.

In contrast, nursing has defined its roles as diagnosing and treating the human responses to illness (ANA, 1980). Leventhal and Johnson (1983) further describe the nurse as the professional who acknowledges the patients' perceptions of their illnesses, the impact of the illness on their lives, and the strategies they use to respond to their

illness experiences. A nursing orientation, according to Leventhal and Johnson, "recognizes the patient as an active problem solver and attempts to enter his problem solving domain...so the patient can achieve more accurate understanding and more effective regulation of his illness and treatment" (p. 194).

This study proposes to examine the extent to which an understanding of self-regulation provides nursing with a means of intervention that reflects the client's own health expectations.

Clinical Significance

The clinical significance of this study is to provide a nursing framework for negotiating treatment options with clients that will reasonably control blood glucose levels, be relevant to the life situations of the person, and decrease the practice of blaming patients for noncompliance. In the past, client noncompliance was seen as a pathological unwillingness to cooperate with medically prescribed treatment regimens; poor metabolic outcomes were assumed to be related to poor patient compliance (Anderson & Auslander, 1980; Dunn & Turtle, 1981; Hoover, 1980; Sims & Sims, 1989; Trostle, 1988). It is now clearer that complete metabolic control is not possible even when clients do everything they can to attain control (Cox, Gonder-Frederick, & Pohl, 1984; Glasgow, McCaul, Schafer, 1987; Lowery & DuCette, 1976). Endocrine events that are still not well understood are

recognized as factors that disrupt metabolic balance and these are events over which patients have little control. It would seem reasonable, therefore, to re-evaluate treatment regimens that require patients to "walk...a tightrope between quantity of life and quality of life" (Sims & Sims, 1989, p. 18).

Theoretical Significance

An underlying hypothesis of this study is that people with diabetes, like other human beings, naturally and qualitatively analyze their own experiences in order to make sense of them. Actions taken on the basis of this analysis are directed at maintaining health and well-being as defined by persons with chronic disorders. The majority of compliance research has attempted to predict what behaviors or personal characteristics correlate with good or poor metabolic control. This study, in contrast, investigates the personal, social, and health explanations individuals use to understand and interpret their illness in order to clarify the perceptions that clients consider important to diabetes control. Analysis of the conditions under which decisions about self-regulation and compliance take place, of the actions taken to attain metabolic control, and of the consequences of these actions, will generate a theoretical conceptualization for describing and explaining self-regulation from data reported by clients with diabetes.

Summary

This study, in short, presents a patient perspective on compliance to diabetes treatment regimens. In this chapter, the purposes and aims of the research are presented and the long-term goal of enhancing nursing practice through a theoretical model of self-regulation is introduced.

The dissertation is organized into six chapters. The chapter that follows, Chapter 2, reviews and discusses literature relevant to compliance with diabetes treatment regimens and the development of the process of self-regulation. Chapter 3 discusses the details of the research methodology and the processes used in the initial approach to data analysis. Chapter 4 presents a description of the sample, reports on the quantitative data analysis, and the conceptual structure of self-regulation based on qualitative data. Chapters 5 and 6 illustrate the phases of development in a model of self-regulation. The final chapter, Chapter 7, summarizes the findings and presents implications for nursing practice, education and research.

CHAPTER 2

OVERVIEW OF THE LITERATURE

Background

Diabetes mellitus is a chronic illness that is characterized by abnormal levels of glucose in the blood. Elevation of blood glucose, i.e., hyperglycemia, results from either insufficient or total lack of insulin. If hyperglycemia is not controlled, glucose levels build up in the blood and, over time, contribute to very serious complications that affect sensory and autonomic nerves as well as large and small blood vessels. Hypoglycemia, i.e., low blood sugar, may also result from the treatment of diabetes, especially when insulin is used. If blood glucose levels drop too low, unconsciousness and seizures may occur. Diabetes treatment endeavors to keep blood glucose at a normal level through diet, exercise, self-glucose monitoring and medication regimens. Care is directed at prevention of complications as opposed to reversal of the illness (American Diabetes Association, 1991; Danowski, Ohlsen, & Fisher, 1980).

Maintaining blood glucose levels within an acceptable range using the above mentioned modalities requires an extraordinary effort on the part of the diabetic person. Current methods are complex and intrusive. As noted in Appendix A, controlled blood glucose levels means a fasting blood glucose of 140 mg/dl or less, 175 mg/dl

postprandially, and a glycosylated hemoglobin of 8%. In order to achieve such levels of glucose control, the patient must constantly assess physiological symptoms, consult blood glucose monitoring devices, and review medical management guidelines in an effort to manipulate a continually changing situation. Besides acquiring the skills and information necessary to carry out the procedures, clients must be educated to comprehend, analyze, and integrate the information they gather about themselves.

Faced with this complex and inconvenient therapeutic regimen that requires a lifetime of constant monitoring, many diabetics find it difficult to comply. How and why people with diabetes do or do not comply with treatment regimens is the subject of a plethora of literature that attempts to analyze the issue of compliance. The review of literature that follows describes the literature relevant to this study from three perspectives: the medical and behavioral models, the illness experience model, and the self-regulation model.

Definitions and Explanations of Compliance in Medical and Behavioral Models

As noted in Chapter 1, compliance literature regards the problems with regimen adherence as a problem of patient behavior or patient-physician interaction. The solutions advanced are generally to educate the patient, reinforce desired behaviors, and improve patient-provider

relationships (Trostle, 1988). The great majority of compliance research reflects the perspectives of health care professionals as opposed to those of patients.

Assumptions underlying research on compliance include the idea that self care practices are uniformly optimal for all people with diabetes. Compliance is measured by indices such as the timing of insulin, number of blood tests done vs. number ordered, and adherence to prescribed calorie and exercise routines. The problem with these assumptions is that they do not take into account the decisions patients make on the basis of these outcomes, believing that all people respond to insulin, food intake and exercise in the same manner (Cox, 1989).

Phenomena such as the extent of noncompliance (Cerkoney & Hart, 1980; Watkins, Williams, Martin, Hogan, & Anderson, 1967; Williams, Martin, Hogan, Watkins, & Ellis, 1967), the psychological makeup of individuals with diabetes, the functioning of families with diabetes (Anderson & Auslander, 1980; Orr, Golden, Myers, & Marrero, 1983; Schafer, Glasgow, McCaul, & Dreher, 1983), barriers to adherence (Alogna, 1980; Cerkoney & Hart, 1980), and the relationship between patients and their health care providers (Di Matteo & Di Nicola, 1982; Pendleton, House, & Parker, 1987) have become the focus of intense study in an effort to explain and correct noncompliant behavior. Full compliance or noncompliance with the entire regimen serves as the outcome variable in these studies.

In the following section, literature is reviewed that defines compliance and noncompliance, describes the extent of noncompliance in patients with diabetes, the psychological and behavioral factors related to noncompliance, and patient-physician relationships.

Definition of Compliance

In the seminal work by Sackett and Haynes (1976), compliance was defined as "the extent to which the patient's behavior (in terms of taking medications, following diets or executing other life-style changes) coincides with the clinical prescriptions" (p. 1). The authors further state that "the presentation of compliance data has clinical relevance only when it is related to the simultaneous achievement of the treatment goals" (p. 3). This definition influenced compliance literature in two major ways:

1) It indelibly associated the control of diabetes with compliance to physician directed regimens, i.e., control resulted from complying with the prescribed treatment. The physician, in other words, determined the dose of medication to be given and the time it was to be taken, the specific diet to be followed without variation, and the kind of monitoring to be completed accurately and precisely at the times ordered. Completing these actions as ordered was assumed to lead directly to control of blood glucose levels. Compliance was measured by the extent to which the patient accomplished these activities.

2) The patient's performance of the prescribed regimen became the focus of the indices of compliance or noncompliance. Noncompliance is defined as "the failure of the patient to fulfill the clinical prescription as it was intended by the practitioner" (Hays & Di Matteo, 1981, p. 37). Patient noncompliance with the medical prescription suggested a lack of knowledge, rebellion, or emotional instability (Leventhal, Zimmerman, & Gutmann, 1984; Trostle, 1988).

Problematic in this definition is the assumption that following or complying with the regimen will, in fact, lead to an acceptable range of blood glucose levels (see Appendix A). In reality, control of blood glucose does not automatically result from compliance with the behaviors prescribed. Furthermore, patients may have different sets of standards by which to judge diabetes control. For some, having control of diabetes may mean not having more than one blood glucose greater than 250 mg/dl a day while, for others, it may mean not having a hypoglycemic episode during a 24 hour period.

The Extent of Noncompliance

The rate of noncompliance with diabetes treatment regimens is notoriously high. Sackett (1976) reports that compliance with short-term regimens decreases rapidly as the days of treatment increase, and the level of compliance in long-term therapy is approximately 50%. J. Anderson (1989)

reports that reviews of compliance with diabetes diet regimens show that while 80% of patients received a written diet plan, only 53% actually use it. Cerkoney and Hart (1980) report that two of their 30 subjects (7%) complied with all the components considered necessary for diabetes control. Fifteen (50%) complied with 70% of the behaviors measured.

Watkins et al. (1967) were the first to observe diabetic patients in their homes. They were interested in the relationships between what people knew about diabetes, what they actually did to manage their illness, and how this manifested itself in their level of diabetes control. The results showed that 80% (n=48) of the 60 patients in the study administered their insulin in an unacceptable manner, over 50% (n=31) made errors in insulin dosing, 45% (n=27) incorrectly or inadequately used urine test results, 73% (n=44) did not match food amounts and timing to fit insulin use, and over 50% (n=31) performed foot care poorly.

In a larger study of 213 diabetes patients completed at the same time, Williams et al. (1967), reported a high frequency (n=151, 71%) of poor or very poor diabetes control. The authors noted that the incidence of insulin errors such as taking the wrong dose, filling the syringe incorrectly, mixing more than one kind of insulin incorrectly, using the wrong kind of insulin and incorrectly using the markings on the syringe, increased with the duration of the illness.

There are two points of particular importance in these classic studies. One is that people who scored higher on the knowledge test complied with recommended therapy better than those with lower scores. However, an inverse correlation was shown between level of knowledge and metabolic control. Patients with greater knowledge scores had poorer blood glucose control. The authors conclude that

> because of our still inadequate understanding of the biological nature of the disease, we are not able to make the appropriate medical recommendations which would allow many patients to achieve good control. This is often true even when all of the other factors cited in this paper are favorable (Williams et al., 1967, p. 458).

Even though the techniques used in these early studies are no longer in use (i.e., sterilization of syringes and urine testing), the levels of noncompliance noted in these studies continue to be referred to in articles appearing nearly twenty years later (Cerkoney & Hart, 1980; Rainwater & Giordano, 1984) as indicators of the extent of noncompliance among diabetic patients. However, the suggestion that medical science was unable to provide adequate recommendations for control is rarely noted.

In the 1980s, self-monitoring of blood glucose (SMBG) became the newest hope for aiding in diabetes management and control. Studies on the extent of patient compliance with SMBG continue to follow the pattern of viewing diabetes control solely in terms of patient behaviors. The context or conditions under which the patient performs these tasks

are not identified. The research asks only if it is done as prescribed.

The validity of SMBG records compiled by patients has been challenged in several studies in which glucose meters with memory chips have been used without the subjects' knowledge (Mazze et al., 1984; Wysocki, Green, & Huxtable, 1989; Ziegler et al., 1989). In these studies, inconsistencies between patients' logbook records and the results found in the memory chips have shown patients to be grossly unreliable. Mazze et al. (1984) find that 74% of 19 adult subjects added fabricated values to their logbooks. Ziegler et al. (1989) report that 8 of their 14 subjects fabricated an average of one out of three blood test measurements. Further, the number of blood tests noted in the logbook and those recorded in meter memory were identical in 3 subjects and discordant in eleven. Reliability of results were enhanced after patients were informed of the memory chips in the meters (Mazze, Pasmantier, Murphy, & Shamoon, 1985). Mazze et al. (1984) suggest that the logbook errors represented attempts on the patients' part to present a more positive clinical picture of their diabetes control to the professional. The question of why a person would feel it necessary to present a positive image was not addressed.

Psychological and Behavioral Factors in Compliance

The literature comparing psychological and behavioral components of diabetes control is second only, in volume, to the literature available on the physiology and biochemistry of diabetes. Two prominent psychological frameworks, health locus of control and the health belief model, have attempted to relate personality traits and beliefs to compliance with diabetes treatment regimens. This research to identify factors that will categorically describe the kinds of people who will and will not comply with prescribed treatment plans persists (Alogna, 1980; Becker, 1974, 1979; Becker & Janz, 1985; Cerkoney & Hart, 1984; Glasgow, McCaul, & Schafer, 1986; Lowery & Ducette, 1976; Schlenk & Hart, 1984).

Health Locus of Control

In this construct, an internally controlled person differs from an externally controlled person in the extent to which each will engage in information seeking and in the extent to which she/he will allow her or himself to be influenced by others. The assumption is that internals are superior to externals in information gathering and utilization of information gained.

Lowery and Ducette (1976) cited studies supporting the two aspects of cognitive differentiation between internally and externally controlled people, but noted that work prior to theirs was conducted under laboratory conditions. They attempted to study the construct when the information subjects received was part of their ongoing, real life

activities. The purpose of their study was to test whether differences in control of diabetes existed between internal and external persons. The assumption was that the internals would "be more adaptive in the situation where diabetes must be understood in order to be controlled" (p. 359).

The results supported the assumption that internals were more active seekers of information. However, results indicated that, over time, externals were identical on the information test and showed a decrease in the number of problems associated with uncontrolled diabetes. The authors surmise that information to gain control is based on the assumptions that the information is specific enough to be of value, and that such information can lead to control. The problem occurs when the internal realizes that "his disease cannot be completely controlled even with the information available" (p. 361). The internal rebels at not being able to control the disease and gives up the control originally possessed.

The authors suggest that externals are not interested in control and do not believe that having information is of any value. Therefore, the externally controlled person does not actively gather information at the disease onset, but learns about the disease through experience with it.

Alogna (1980) separated obese non-insulin-dependent diabetic subjects into compliant (n=25) and noncompliant (n=25) groups to see if a difference existed between internal and external traits. Using t-tests, no significant

differences were noted between the groups on the demographic variables of sex, race, marital status, education, duration of disease or complications. Each patient was also administered the health locus of control scale and the perception of severity of disease index based on the health belief model. The results indicated that there was a significant difference between the groups in the perception of severity of disease index ($p<0.04$) but no significant difference between the groups on the health locus of control. Alogna states there was a trend toward internal control in the compliant subjects.

Schlenk and Hart (1984) report statistically significant relationships between compliance and social support ($p<0.001$), powerful others' health locus of control ($p<0.01$), and internal health locus of control ($p<0.05$) in a group of 30 insulin-dependent diabetic outpatients. A multiple regression analysis found that social support and the powerful others health locus of control accounted for at least 50% of the variance in compliance when all the variables were entered as a set and reached significance levels of $p <0.005$ and <0.001 respectively. Other variables entered, including internal health locus of control, did not add significantly to the compliance prediction accuracy.

These studies demonstrate a possible influence of locus of control that, under certain circumstances, may affect compliance and control of diabetes. The conclusion drawn from these three studies is that compliance and control are

complex concepts and no one factor consistently identifies those who comply with the regimen over time and those who do not. Further, as Lowery & DuCette (1976), Watkins et al. (1967), and Williams et al. (1967) suggested, it may not be compliance-related characteristics of the patient that ultimately influence control as much as the probability that the information given to the patients by health professionals actually leads to diabetes control.

Health Belief Model (HBM)

Research using dimensions of the HBM to identify relationships with diabetes compliance has focused on specific factors such as perception of severity (Alogna, 1980) or barriers to adherence (Glasgow, McCaul, & Schafer, 1986). Nurse researchers Cerkoney and Hart (1980) attempted to correlate compliance items considered necessary for good control with all of the dimensions of the health belief model (i.e., perceived severity, susceptibility, benefits, barriers, costs, and cues for action).

Thirty insulin-requiring diabetic subjects were interviewed in their homes six to twelve months after attending a diabetes education course. Level of compliance was determined through self-report and direct observation for insulin administration, urine testing, dietary adherence, hypoglycemia management and foot care.

Health belief motivation was tested using an adaptation of the Standardized Compliance Questionnaire (Sackett, Becker, MacPherson, Luterback, & Haynes, 1974). Responses

to each aspect of the health belief model were made on a 5-point Likert scale. A positive correlation of $r=.50$, $p<.01$ occurred between the subjects' total compliance scores and a composite score of their level of health belief motivation. Those who perceived their diabetes as serious ($r=.42$, $p<0.05$) and responded to cues for action ($r=.40$, $p<0.01$) were more compliant with their treatment regimen. However, the authors state that the correlation obtained ($r=.50$) would only account for 25% ($r^2=.25$) of the variance in compliance levels of this sample and could not be used as reliable clinical predictors of compliance.

Despite the fact that the HBM acknowledges the importance of patients' beliefs in compliance, there is an assumption that health related beliefs are the most significant factors in decision making about compliance with treatment regimens. Ignored are other aspects of personal experience that may affect how illness treatment is managed (Conrad, 1985).

The interview data collected from subjects in Cerkoney and Hart's (1980) study reveals some important information about patient compliance. Twenty-eight of the 30 subjects are reported to believe that treatment could control their diabetes. However, in the interview it was ascertained that most patients defined "treatment" as taking insulin. Few of the subjects included diet in their understanding of treatment. Six of the 30 subjects who denied having difficulty adhering to their diet turned out to have

essentially modified their perceptions of the prescription. Instead of following the exchange lists and calorie counts, the subjects who rated themselves as compliant with diet just "avoided sweets" (Cerkoney & Hart, 1980, p. 596). When compliance to areas considered important to control is studied, it must be made clear whose perspective of compliance is really under investigation.

In the interview process, Cerkoney and Hart (1980) identified two subjects who had daily insulin reactions but did not recognize them as such. Despite the fact that both were able to accurately list the signs and symptoms of hypoglycemia, they denied experiencing reactions. This example is reminiscent of earlier findings suggesting that knowledge scores were not positively related to long-term metabolic control (Lowery & DuCette, 1976; Watkins et al., 1967; Williams et al., 1967).

Impact of Patient-Physician Relationships on Compliance

The quality of patient-physician relationships has been widely accepted as a variable related to compliance with medical treatment (Becker, 1976; Garrity, 1981; Stimson, 1974; Trostle, 1988). Di Matteo and Di Nicola (1982) note in the introduction to their book on achieving patient compliance that the patient-practitioner relationship is the most important variable in understanding compliance behavior. The literature generally contains a wide array of methods for improving compliance such as having the provider

give explicit information, sharing expectations about appropriate behaviors, discussing ways to increase patient responsibility for compliance, giving strategies for aiding the patient in compliance behavior, and improving communication and interactional skills (Garrity, 1981; Rost, 1989; Sanson-Fisher, Campbell, Redman, & Hennrikus, 1989).

The patient-physician interaction literature approaches the problem of compliance from the perspective that noncompliance has resulted from flaws in the interaction (Conrad, 1985). This medical model perspective has traditionally viewed the patient as a recipient of medical expertise that will treat the illness and thereby improve the patient's quality of life. Physicians have been taught to direct treatment toward the disease and view the patient as an intervening factor (R. Anderson, 1985). Patient behavior, according to this model, remains the basic problem and finding ways to manipulate the behavior is seen as the solution to the problem.

Some authors challenge the assumptions underlying the importance of the patient-physician relationship in shaping compliance behavior and suggest approaching compliance from the patient's perspective (R. Anderson, 1985; Conrad, 1985; Hayes-Bautista, 1976; Stimson, 1974; Trostle, 1988). The issue of compliance and noncompliance arises from a decision making framework of probability outcomes and fails to account for how the patient views the problem and actions necessary to solve it (Conrad, 1985; Leventhal, Zimmerman, &

Gutmann, 1984). R. Anderson (1985) suggests viewing manipulations in the diabetes treatment regimens as a problem to be solved through negotiations between patient and professional in order to close the gap between medical recommendations and actual self-management practices. He adds that it is equally legitimate for the patient to try to influence the behavior and attitudes of the practitioner as it is for the practitioner to do so with the patient.

Summary

The traditional perspective of medical and behavioral research on compliance views the patient as the passive recipient of care and advice from the omniscient medical expert. Research on compliance has focused on describing the personal characteristics, situational barriers, or inadequate resources of the subjects and has paid little attention to the relationships between the variables tested. In most cases, the variables are chosen by the researcher and have not included variables of importance to patients living with the illness under study.

Indications for Reframing Compliance

Some authors suggest a need to reframe compliance to better reflect the centrality of personal, rather than professional health expectations. In fact, Trostle (1988) declares that compliance is an ideology invented by medicine to maintain power and control over health decisions and is

not about the efficacy of treatment at all. Hayes-Bautista (1976) suggests that patient noncompliance or treatment modification is not the result of stupidity or ignorance, but rather a means of exerting some personal control over their health care.

Hayes-Bautista (1976) adds that patients' have their own explanations for compliance or noncompliance. They usually do not explain their behavior "in terms of age, sex, education, marital status, social class, norms, values or other variables often used by social scientists..." (p. 233). In research on the personal meaning of diabetes, Anderson, Nowacek, and Richards (1987) explain that attitudes toward the illness have an impact on control, and that diabetes education should include explorations of personal meaning along with knowledge and skills acquisition.

Adhering to a diabetes regimen may not be the first priority for all patients at all times. Therefore, attaining metabolic control may only be one of many outcomes that need to be assessed (Kelleher, 1988; Gerber & Nehemkis, 1986; The DCCT Research Group, 1988). Without consideration of the roles and obligations imposed by the environmental context of a patient, prescribed regimens may not be achievable or realistic.

The Experience of Living with Diabetes

Recent studies have begun to examine multiple interactions among personal and social environments as influences on patient compliance (Anderson, Nowacek, & Richards, 1987; Glasgow & Toobert, 1988; Robbins, 1988; Schafer, McCaul, & Glasgow, 1986; Sims & Sims, 1989). Additionally, literature exploring adherence to different aspects of the treatment plan and the relationship of each component of the regimen to compliance and control have begun to appear (Glasgow, McCaul, & Schafer, 1987). This research is in contrast to the more limited view of compliance as adherence to the entire regimen. Other studies attempt to gain the patient's perspective on compliance and describe how people manage their lives with diabetes accordingly (Ary, Toobert, Wilson, Glasgow, 1986; Daschner, 1986). These studies are primarily cross sectional, representing a short period in a person's life, and do not show how people may change over the course of the disease.

Research on compliance behaviors that takes the environmental context of the person with diabetes into account is reported by Kelleher (1988) and Peyrot, McMurry, and Hedges (1987). Both of these studies use a qualitative approach to describe the social interactions that shape an individual's diabetes identity and how these relationships contribute to diabetes regulation. These studies provide information that is different from the traditional research

in that the perspective of persons with diabetes is explored within natural contexts such as marriage and work obligations.

With few exceptions, however, literature about compliance does not include research with descriptions or analysis of the actual experiences of clients living with diabetes. Neither does it take into consideration the multitude of variables that are negotiated in combining a human, social existence with the self care procedures necessary to control the symptoms of chronic illness.

Two concepts of importance in understanding patients' decisions about adherence to treatment plans are considered here. One relates to the internal cues people with diabetes use to control the symptoms they experience. The other concept deals with how the identity a person develops as "diabetic" affects her/his conformity to the treatment regimen.

Internal Cues for Symptom Control

Strauss et al. (1984) suggested that people with chronic illness come to manage disease symptoms based on their ingenuity, judgement, and individual assessments. In an example of research examining this form of self regulating activity, O'Connell et al. (1984) and Hamera et al. (1988) used a model of self-regulation and control theory described by Leventhal (1980) and Carver and Scheier (1982) to evaluate symptom-associating and action-taking

behaviors in Type II diabetic patients. In the model developed by O'Connell et al. (1984) and Hamera et al. (1988), a person appraises whether an existing state matches a predetermined standard of well-being. If a difference between the current state and the predetermined standard exists, the person will make changes to reduce the discrepancy. When the discrepancy is resolved by some action, the person ends the appraisal. This process is continuously repeated when a person detects a change in well-being.

In the first study (n=38), employing structured interviews, the authors reported that patients use an internal feeling of well-being as a standard for evaluating blood glucose levels. Seventy-nine percent associated specific symptoms with high blood glucose and 45% associated specific symptoms with low blood glucose levels. Seventy-three percent modified their behavior when the symptoms were recognized. Actions taken corrected the symptoms some of the time and had no effect or made symptoms worse at other times. A significant positive relationship ($p < .02$) was established between long-term glucose control as measured by glycosylated hemoglobin (HbA_1) and action-taking behaviors.

In the second study (n=173), analysis of covariance was used to more carefully analyze the relationships between the independent variables of symptom association and action taking and the dependent variable of metabolic control measured with HbA_1. Results again showed that patients

confidently associated symptoms of either high or low blood glucose levels and took action when symptoms were present. Most of the subjects did not confirm the symptoms with objective self blood glucose monitoring. In this study, no significant relationship was found between metabolic control and self-regulating behaviors.

Important here is that the nurse researchers recognized the significance of the continuous self-monitoring activities that become automatic in chronic conditions. They examined the patients' beliefs in the validity of their symptoms and then analyzed the effectiveness of actions taken based on those beliefs. Examining the meaning of these self-regulating activities in relation to regimen adherence adds a dimension to the self-regulation framework that the medical and psychological models failed to appreciate: individuals with diabetes have personal, internal standards for diabetes control that clearly influence adherence behavior.

Despite the duration of diabetes, having the methods available for self monitoring of blood glucose, or the level of formal education, subjects used internal, self-regulatory processes to evaluate and act on their symptoms. The fact that no relationship existed between HbA_1 and self-regulation may be explained by the following rationale: a) what patients considered high, normal, or low glucose levels do not coincide with professional goals, b) symptom recognition may not be accurate, and c) actions taken may

not appropriately improve the blood glucose levels. The authors conclude that actions are taken to relieve symptoms when patients detect a change in their usual state and these actions are designed to relieve symptoms in general and not necessarily to normalize glucose levels.

Identity as a Diabetic Person

The problems of incorporating diabetes into daily living are similar to those a person experiences in developing other identities such as student, wife, or parent. As a person's self-perception undergoes profound changes in assuming these kinds of new identities, "some...find it difficult to attribute a meaning to their diabetes, and find it difficult to incorporate the treatment regimen into their everyday lives" (Kelleher, 1988, p. 140).

In a study describing the actual experience of living with diabetes, Kelleher (1988) collected data on 30 diabetic adults through semi-structured interviews. Twenty of these people were randomly selected from a registry of 217 patients set up by three general practitioners. Five were newly diagnosed and were recruited during their first appointment at a hospital outpatient clinic. The other five had been recently hospitalized and were designated by a medical consultant "as being diabetics with problems." Both insulin dependent and non-insulin dependent people were included. The patients were interviewed once by an interviewer using a checklist of questions. The broad

sampling reflects a qualitative approach attempting to maximize comparisons among subjects.

Three themes emerged that provide a background for understanding patient strategies for complying with diabetes regimens: a) feeling healthy or normal, b) being in control, and c) experiencing a loss of spontaneity. "Control" was the most commonly recurring theme. This control did not mean keeping blood glucose levels within medically acceptable limits, but referred to how much the subjects felt *they* were in control of the diabetes.

The strategies developed to manage diabetes were designated as *coping*, *adapting*, and *worrying/agonizing*. The *coping* group controlled the diabetes but made it fit in with daily life. This group made changes in their regimen to accommodate life circumstances even if the changes made were not in accordance with medical advice. "The role of diabetes was for them a less salient role in their identity than being a husband, a wife, a worker, or a mother." (p. 153).

The *adapting* group accepted the symptoms of diabetes as normal. This group would limit their eating and drinking activities with their friends rather than adjust their medications to fit the circumstances. These people withdrew from a number of previous social activities that focused on eating and drinking rather than expose themselves as abnormal or deviant.

The *worriers* and *agonizers* were unable to accept diabetes as a normal part of life and saw themselves as unhealthy. The agonizers were different from the worriers in the degree of concern they felt about having the condition. Many agonizers expressed feelings of being depressed about their diagnosis. Diabetes was dominant in their identity because it interfered with all of their other social roles.

Most of the participants (60%) regarded themselves as healthy, even those experiencing symptoms of high blood glucose levels. With or without symptoms, they did not feel their diabetes treatments dominated their lives. This "sense of well-being...may be derived from a wider range of meaning given their diabetes than those provided by the medical diagnosis and assessment of their physical statement of health by doctors" (p. 143).

The results of the study are based on a single interview and do not reflect how changes occur over time with diabetes. Future research would do well to look at how people with a new diagnosis adjust over time to the demands of the regimen and to observe whether people remain permanently in one category or move back and forth between the various categories.

In a cross-sectional study using participant observation, interviews, and analysis of medical records, Quint (1969), Quint-Benoliel (1970) conducted exploratory research designed to facilitate the development of a

conceptual framework for understanding and investigating chronic illness as a social process in diabetic children and their families. Nine families, complete or partial, were interviewed. Thirteen individuals with diabetes, 8 girls and 5 boys, lived in these families. The ages of the children with diabetes ranged in years from 5 to 19. Parents and siblings of the children with diabetes were interviewed.

The intent of the study was to determine the impact of diabetes and its treatment on social behaviors and emerging identities. In particular, the meaning of diabetes as a social crisis in families and the emergence of a diabetes identity when the diagnosis occurs in childhood or adolescence was studied. The investigator wanted to ask specifically: a) how does the child or adolescent with diabetes learn what is involved in being a diabetic, and b) how does she/he behave in response to this knowledge?

The analysis showed that families are the most important factor in the social environment as the child begins to understand both the personal and social meanings of having diabetes. Parenting styles designated as protective, adaptive, manipulative, and abdicative were shown to "create learning fields that either enhance or inhibit the young diabetic's choice of role-performance in the direction of conformity with medically recommended practices of care" (Quint-Benoliel, 1970, p. 25).

Additionally, Quint's (1969) interviews with the children revealed that diabetes camp had a significant impact on providing the children with information on what their status as chronically ill people meant and on how they should approach the diabetic role. The children's main concern with treatment procedures focused on the public visibility of these procedures. Successful control for the children meant the ability to obscure the signs that they were different from others and to send the signal that nothing was wrong or abnormal.

The introduction of the Quint (1969) study stated that it was designed to facilitate the development of a conceptual framework for understanding and investigating chronic illness as a social process. A problem with the study was that the concepts discussed, i.e, social visibility, status passage, socialization by reference group, and role identity, were not used to categorize the analyzed results, nor were the concepts organized into a paradigm that could be used for further research.

Summary of Illness Experience Literature

Several concepts emerge from research on the experience of living with diabetes: a) from the patient's perspective, regulating diabetes is not necessarily related to controlling the metabolic effects of the disease as much as it is to controlling symptoms and maintaining a sense of well-being, b) in the context of multiple social identities, the relative importance a person gives to her/his diabetes

identity will influence compliance with the prescribed treatment regimen, and c) controlling the social visibility of the illness influences compliance with the treatment regimen.

Quint-Benoliel's work illustrates the centrality of the family in providing diabetic children with background attitudes that influence conformity to diabetes regimens. Hamera et al. (1988), Kelleher (1988), and O'Connor et al. (1984) illustrate the existence of self-regulating activities in adults that are combined with medical prescriptions to achieve a sense of personal control over the illness. An important area not examined in the diabetes literature concerns processes central to the formation of attitudes that influence adults' decisions about conformity to diabetes treatment regimens. If the family is central to the formation of diabetic children's attitudes related to compliance, what factors and what relationships influence the personal and social meanings given diabetes in adults? Corbin and Strauss (1987) and Kaufman (1988) suggest that the meaning given to an illness shapes the effort people make to manage and control that illness. The research described herein studies influences on adult self-regulation activities and seeks to clarify these processes and meanings among adults with diabetes.

Before turning to the theoretical perspective of this study, it is important to review literature related to a

self-regulation model which is relevant to the current inquiry.

Leventhal's Common-Sense or Self-Regulation Model

Background

The Common Sense or Self-Regulation Model developed from studies looking at the effect of fear-arousing communications on preventive health care actions. It is, essentially, a cognitive processing model. These studies were conducted using the psychological framework of drive theory that suggested a drive, such as fear, would precede performance of an activity. Therefore, fear-arousing information could be used to make people comply with health related activities (Keller, Ward, & Baumann, 1989; Leventhal & Johnson, 1983; Leventhal, Singer, & Jones, 1965).

Leventhal, Singer, & Jones (1965) realized that fear communications instigate problem solving activities related to the subject's perception of the presence of danger. If an individual developed a plan of action to deal with the danger, the subject was more likely to take action to reduce the danger. Continuing studies led Leventhal and his colleagues to believe that people generate their own construction or representation of health threats and plan health related action based on these representations.

These representations are constructed from accumulative experience over time and are an integration of knowledge gathered from the media, personal and health professional

input, symptoms and body sensations, and past experience with illness. The model views four factors as the key features of a person's construction of health threats: 1) identity or concrete symptom identification, 2) cause such as improper food habits or stressful life events, 3) time line or the perception of how long the illness will last, and 4) what the perception of the consequences are (Keller, Ward, Baumann, 1989; Leventhal, 1982; Leventhal, Zimmerman & Gutmann, 1985; Meyer, Leventhal, & Gutmann, 1985). Interpretation and synthesis of these factors will influence how a person will cope with illness.

Leventhal, Zimmerman, & Gutmann (1985) suggest that action taken will depend on: 1) the individual's belief that she/he can manage the health threat and the emotional response to the challenge, 2) the individual's strategies for dealing with problem situations, and 3) the individual's evaluation of whether the action has been effective or not.

In summary, the Self-Regulation Model views patients as being actively involved in choosing their own goals for health care. These goals will develop from their perception of the labeled illness, their selection of responses needed to reach their goals, and their evaluation of the goal attainment (Leventhal, Zimmerman & Gutmann, 1985).

Research Using Model Concepts

Mechanisms of Self-Regulation

Leventhal and Johnson (1983) were interested in developing a model of self-regulation under stress. Their experiments were designed to increase the understanding of the processes of self-regulation during health threats and to suggest interventions to aid self-regulating behavior in patients undergoing stressful treatments. Their goal was to help distinguish between emotional (fear reduction) and coping behaviors during stressful procedures.

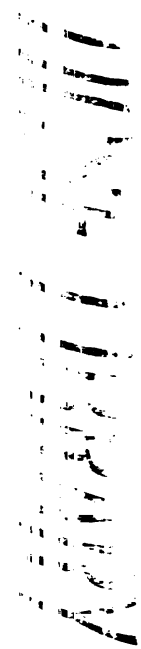
Through a number of experiments conducted in hospital settings and under laboratory conditions, Leventhal and Johnson (1983) concluded that fear reduction and coping strategies needed to be approached through separate activities. Further studies indicated that giving procedural and sensory information to subjects affected different components of the experience.

Their experiments increased in complexity as control groups with no instruction were compared to groups given procedural instructions only, those given sensory information only, and groups given combined procedural and sensory instructions. Results indicated that self-regulation of emotional responses and coping behavior were enhanced by combining information about sensations to expect and action instructions together.

Leventhal concluded that sensory information had a direct effect on emotional response while Johnson felt

sensory information had a direct effect on coping behaviors. They both conclude that sensory information does not provide patients with new information but increases the effectiveness of existing responses. Both agree that procedural instructions are important in constructing new coping responses to stressful situations and that further research is needed to detail "the process by which cognitive intervention affects emotional or coping behaviors" (p. 248).

Finally, they conclude that people experience illness and medical treatment in personal, symptomatic terms, and that the absence of symptoms is associated with health. In the absence of illness symptoms, activities needed to sustain health will not be maintained. Health interventions need to include cues for helping patients know when their illness is in control as well as out of control.



Problems with Cognitive Model

Leventhal and Johnson (1983) state that their objective is to look at the processes by which situational and personal factors exert control over behaviors. They recognize the importance of the patient's experience in building the schema from which the person will take health action, but they fail in the experiments to pay attention to responses to illness in the context of everyday life. All of the experiments involved experiences of short time duration, and the interventions were organized according to two types of cognitive responses: emotional or coping

behavior. Cast removal instructions with children, instructions for pelvic exams, cholecystectomy and herniorrhaphy procedures, emersion of arms in cold water or squeezing with blood pressure cuffs are used to build evidence for the effectiveness of preparatory information in decreasing stress and increasing coping behaviors. The model merits further consideration with the caveat that health action does not take place in a social vacuum and may be influenced by more than cognitive considerations.

The Example of Hypertension

Meyer, Leventhal, and Gutmann (1985) interviewed 230 people about hypertension in order to uncover variables that affect noncompliance with blood pressure treatment regimens and to determine how "common-sense" representations of high blood pressure affect compliance behaviors. The hypotheses of this study were: 1) subjects will develop representations of hypertension based on both concrete symptoms and abstract labels, 2) the representation of the illness will reflect an acute illness model and be considered a short-lived problem, and 3) the representation will guide patients' behavior.

The results of interview analysis and follow-up chart audits showed that subjects knew hypertension was an asymptomatic illness. However, in the four groups investigated, 46% of the normotensive control group, 71% of the new treatment group, 92% of the continuing treatment group, and 94% of the re-entry to treatment group said they

could identify symptoms of elevated blood pressure. More people could identify symptoms as the time since diagnosis increased.

More people in the newly diagnosed group considered the problem a short term one and more of those in continuing treatment recognized hypertension as a chronic problem. Seventy-five to eighty percent of the subjects had ideas about what caused hypertension ranging from heredity, to diet, to environmental situations at home and at work that produce stress.

The authors conclude that people do construct representations or models of hypertension that reflect prior experience with illness and that evolve and change over time. A high percent of subjects felt they could identify symptoms of hypertension and these symptoms could be used to monitor blood pressure even though results showed no significant correlation between symptoms and actual blood pressure levels taken. Subjects generally felt that hypertension was of limited duration and was caused by environmental conditions.

The authors noted that a small number of people recognized linkages between the cause, symptoms, and the physiological mechanisms of hypertension. People who did make these connections were no more likely to take medications as prescribed than those who did not link them.

Two conclusions from the study were: 1) compliance was predicted if there was a perception that treatment had a

positive effect on decreasing symptoms, and 2) the patient's view of the duration of the illness and duration of treatment predicted whether people stayed in or dropped out of treatment.

The authors conclude that information gathered regarding illness representations yields knowledge of the mechanisms that underlie the actions taken by patients. The authors describe illness representations as definitions of problems or statements of conditions for goals. These definitions and conditions will guide action and are important factors in understanding illness behaviors.

Summary

This study represents an expansion of the medical model's conception of compliance as a dichotomous outcome resulting from stable patient characteristics, situational barriers, and/or inadequate motivation or education. The concepts developed in the Self-Regulation Model suggest that a person's understanding of an illness may be the critical factor in decisions about continuing treatment or illness control.

This research team collected six month follow-up data from charts on two of the four groups studied (newly treated (n=65) and re-entry to treatment (n=65)), and did a follow-up interview with the newly treated group (n=65). It is unclear whether the original interview guide was used at the second interview. Further, the information gathered on coping and adherence was reported only for the continuing

treatment group. This is unfortunate, particularly given their three level index of adherence that classified patients as taking medication as prescribed, missing randomly and infrequently, and systematically departing from the regimen. Information on the other groups would have contributed knowledge about longitudinal changes in self-regulating behavior. Some clients reported that they complied with the prescribed regimen "for their health" and "for their doctors." Theoretical sampling among these groups would have provided information beyond the model concept of symptom driven compliance.

Processes of Self-Care

Keller, Ward, and Baumann (1989) report results from three research series using the Common-Sense Model to study processes relevant to self-care behaviors. They review their research investigating how illness representations are formed from sensory experience, how representations of illness influence symptom reporting, and how illness representation is linked to coping.

Attempting to investigate the relationship between illness representations and sensory experiences, the authors studied 67 cancer patients receiving chemotherapy to see if the tendency to repress negative emotions influenced their responses to the side effects of treatment. The results showed that those who repressed negative emotions reported significantly fewer and less severe treatment side effects. Further laboratory experiments with 60 healthy subjects

showed that repression influences a person's ability to detect high levels of sensation stimuli. The conclusion drawn was that repression influences the extent to which a person can detect sensations and thereby influences the formation of a health threat representation. After looking at how blood pressure readings and moods and symptom reporting were related, the authors concluded that personal representations of illness influence symptom reporting even if the symptoms are inaccurate in estimating actual physiological levels.

The authors further tested to see if symptom reporting could be modified by the Common-Sense Model dimensions of label, cause, and time line. Subjects (n=80) were given false feedback on blood pressure levels and evaluations of daily stress levels. Subjects given high blood pressure feedback showed a significant interaction between low stress and cardiovascular symptoms. The authors conclude that subjects who were told they were in a low stress environment and who believed blood pressure to be uninfluenced by environmental factors, looked for symptoms other than stress to represent their problem with elevated blood pressure. Subjects told they were in the high stress feedback group and who believed blood pressure to be labile, figured the elevation was a temporary, nonpathological problem related to environmental stress. The authors feel that the study supports the hypothesis that symptom reports, once an illness label is known, are modified by beliefs regarding

the presence of alternative causes and beliefs about the duration of the labeled illness.

Using the label "aging," the authors studied what effect a label has on coping behavior. In older adults, the results indicated that a large number of symptoms and physical changes were related to aging. The subjects tended not to report these problems to health care providers, suggesting that they accepted these problems as part of aging. Because this study implied that associating physical symptoms with the label "aging" influenced the selection of coping responses to these symptoms, the authors conducted a laboratory experiment with 332 subjects ranging in age from 18 to 78 years. The subjects were randomly given one of four illness scenarios describing symptoms varying in duration, ambiguity, and severity.

The authors reported that regardless of the respondents age or scenario given, attaching a set of symptoms to the aging label resulted in a lower likelihood of seeking treatment and in decreased emotional distress about the symptoms. Confusion in the representation of a symptom as aging or as illness may lead to confusion in selecting an appropriate coping response.

Extrapolation to Diabetes Self-Management

The studies reviewed by Keller, Ward, and Baumann (1989) using the concepts of the Common-Sense Model provide a template for assessing problems in diabetes compliance and self-management research. These studies indicate that

illness representations are influenced by individual difference in beliefs about cause, time line, and symptom sensations. An illness representation may be based on beliefs and symptom interpretations that do not stimulate self-management activities. If a person with diabetes is not attuned to the symptoms of high or low blood sugar, inadequate or improper actions may be taken to correct these deficits.

The authors suggest a person's representation of an illness can influence the symptoms people will monitor. Beliefs about illness will determine what symptoms people choose to monitor in evaluating health status. How symptoms are interpreted as illness threats will have an impact on actions taken to correct the problem. If a diabetic patient interprets lethargy as a normal part of the label "diabetic," she/he may ignore, for instance, the symptoms of hyperglycemia and fail to adjust the diet or medication regimen to correct the problem. The consequences of continuous high blood sugars can lead to devastating and permanent disabilities over time. Assessing people's representation of illness and connecting the constructions of the illness with self-management choices provides a means of identifying at what point health information may be most helpful to the patient.

Research articles using the concepts developed in the Common Sense or Self-Regulation Model related to diabetes have already been reviewed. In these studies, Hamera et al.

(1988) and O'Connell et al. (1984) support the model by demonstrating that subjects associated symptoms with blood glucose alterations, and took action when symptoms were present. The authors found no relationship between these self-regulating actions and actual metabolic control.

Hamera et al. (1988) conclude that they incorrectly assumed that the standard of well-being their subjects used to compare their symptom state included an internalized blood glucose level that fell within the prescribed therapeutic limits. Their studies indicate that quite the opposite occurred, and subjects' perceptions of blood glucose levels ranged well beyond the limits of prescribed metabolic control. Further, subjects' perceptions of symptoms were inaccurate and actions taken did not necessarily control blood glucose within appropriate ranges to gain metabolic control.

Hamera et al. (1988) and O'Connell et al. (1984) limited their studies to the cognitive processes of interpreting and reinterpreting symptoms related to blood glucose fluctuations. Questions left unresolved in their studies included: Is self-regulation only symptom recognition and management? What other factors influence self-care actions? Are there great differences between their Type II and Type I diabetic subjects? Investigation on how representations about diabetes were formed in these subjects and how their representations influence the symptom

reporting would further the concept development of the model.

Summary of Common Sense or Self-Regulation Model

This model provides a structure for assessing a person's representation of illness threats. It provides a means for better understanding the decisions patients make about self care behaviors that either promote or ignore illness threats. The studies presented support the model's concepts regarding illness representation formation, the relationship between these illness constructions and symptom reporting, and how personal beliefs influence action taken to cope with the illness.

The major problem with the model is that it remains very cognitive and, despite a limited discussion about environmental influences on illness representations, no research has investigated the interaction between actions taken to control illness threats and everyday social interactions and activities.

Summary

The literature review disclosed that despite the recognition that diabetes is a complex disease with multiple invasive procedures needed to control blood glucose levels and prevent complications, compliance literature has traditionally focused blame for noncompliance on personal characteristics of the patient. Further, medical and

behavioral models have cast the patient as a passive receiver of expert medical opinion disregarding the patients' perceptions of the illness experience.

The review ascertains that research describing the experience of living with diabetes is limited and has succeeded in describing and categorizing the experience but has not produced theoretical hypotheses based on a naturalistic analysis. The research on the Common Sense or Self-Regulation Model moves the early compliance literature beyond the confines of the medical model and focuses on the patient's interpretation of illness meaning as a vehicle for explaining compliance to medical treatment. However, the model maintains a purely cognitive approach to illness management. Environmental factors such as home and work stress are only acknowledged in the research as important in the construction of beliefs about cause of illness. What is left unrecognized in the model is the impact of the social environment on illness management actions.

Treatment regimens and self-care standards designed to modify the pathophysiology of a chronic disease must consider the context in which the person performing these activities is situated. Context is defined by Webster's dictionary as "the whole situation, background, or environment relevant to a particular event, personality, [or] creation." This context evolves from continuous interactions between a person and his/her environment over an entire lifetime.

Compliance with treatment regimens from the diabetic person's perspective may be related to the degree to which her/his identity with diabetes is incorporated into the activities and roles of everyday life. An individual's compliance behaviors may be influenced by the interaction of multiple personal characteristics and multiple settings requiring role variations. From this perspective, compliance is not a set of rigid or constant behaviors. Instead, compliance becomes a complex interaction between a particular setting, its role requirements, and a choice of self care behaviors based on the priority given diabetes in that setting.

Levine (1969) reminds us that perceiving the environment merely as a setting for the individual organism denies the dynamic exchange that is constantly affecting both organism and environment. In order to capture the complexity of the interactions involved in compliance with diabetes treatment regimens, a theoretical perspective and research methodology is chosen that permits the examination of multiple perspectives in the person and environment interchange.

Theoretical Perspective

The theoretical framework of symbolic interaction is used to guide the research. Symbolic interaction developed in the early 1900s from a synthesis of sociological perspectives that were generated by the American social

theorists Charles Cooley and William I. Thomas, by psychologist and philosopher William James, and by philosopher and educator John Dewey. Further, the intellectual traditions of Pragmatism, Behaviorism, and Darwinism helped George Herbert Mead (1934) to form the theoretical perspective of symbolic interaction.

Turner (1986) describes how Mead reorganized the concepts of mind and self developed by earlier social scientists to explain how mind, social self, and society arise and survive through symbolic interaction. Mead emphasized human interaction as the basis of social organization. He described how meaning to human beings is a result of the mind's capacity to interact with objects in the environment. Through this interaction, humans construct and shape lines of action by continuously interpreting these social interactions and selecting those actions that facilitate survival and adjustment to the environment.

Development and assessment of self also occur through interaction and interpretation of social experiences with others. Repeated encounters progressively teach individuals how to appropriately respond in their particular environment. The continuous interaction allows the individual to take on the abstract values of the larger society over time.

The major premises of symbolic interaction, as summarized by Blumer (1969), are:

1) Human beings act toward things and events on the basis of the meanings and interpretations things have for them.

2) The meanings and interpretations of things and events are derived from social interactions with other human beings, and

3) Meanings within a situation are modified through an interpretive process used in successive social encounters.

Symbolic interaction is useful in studying self-regulating behavior in people with diabetes because it emphasizes the importance of the interactive processes between the individual, the context, and how these interactions shape meaning and define action. Through the interactionist perspective, self-regulation is conceptualized as an ongoing process by which individuals with diabetes negotiate and coordinate the significance of diabetes in their lives with the treatment regimens prescribed to help them maintain control over the consequences of uncontrolled blood glucose levels. Self-regulation is characterized as a process that develops over time and is contingent on the interaction of personal characteristics and environmental factors.

Assumptions

Using the premises of symbolic interaction as a framework, this investigation assumes the person with diabetes is an active participant in decisions related to

diabetes self-management. Self-regulating health behaviors result from an interactive process in which situational events are interpreted and given meaning by the individuals analyzing the situation. Definitions of a situation are learned from past experience and are altered by interpretations taking place at the present time. Further, the meanings give rise to actions in response to these interpretations. Self-management behavior or action is explained by discovering the meaning and value a person attaches to specific experiences (Schroeder, 1981). The perception and interpretation of these experiences is paramount in deciding what meaning to attach to the interaction and the direction of action to be taken (Blumer, 1969, Turner, 1986).

Based on these premises of symbolic interaction, an individual's standards of metabolic control and compliance with prescribed regimens to gain metabolic control will vary according to current interpretations of the situation. Further, the value a person attaches to the importance of control and compliance will also vary according to changing definitions of the illness situation.

Research Questions

Considering the premises and assumptions of the symbolic interaction perspective, the following research questions are used to guide the investigation:

1) How does a person's understanding of the nature of diabetes affect the development and modification of self-regulation?

2) Under what conditions/contexts does self-regulation develop? How do these conditions affect the ability to comply with treatment regimens prescribed by health professionals?

3) What strategies do persons with diabetes use to self-regulate their diabetes? How do these differ from professional suggestions? How effective are these strategies in maintaining metabolic control?

4) What implications does self-regulation have for nursing efforts to facilitate client self-management outcomes?

The method used to investigate these processes must be able to uncover the meanings diabetic patients have regarding their diagnosis, discover the variety of situations they see as modifiers of their illness representation, and determine how these situations become conditions for self-regulating treatment actions. The methodology of grounded theory and analytic framework of dimensional analysis are deemed consistent with the epistemology of symbolic interaction and are the methods chosen to study self-regulation in Type I diabetic persons. These methods are presented in the following chapter.

CHAPTER 3

RESEARCH METHODOLOGY

Introduction to the Method

As described in Chapters 1 and 2, the problems of diabetes management from the patient's perspective are not well represented in compliance research. For the purposes of this study, a grounded theory approach is selected as the best means of arriving at theoretical concepts generated from the data provided by people actually living with diabetes.

Stern (1980) suggests that grounded theory is most appropriately used: 1) in areas where little or no research has been done previously and is able to provide a means of identifying variables that describe what problems exist in the area, and 2) in investigations of familiar situations where a fresh look at the processes involved may add new insight to understanding the situation. It is this latter application that makes it appropriate for a research study on compliance in diabetes treatment regimens.

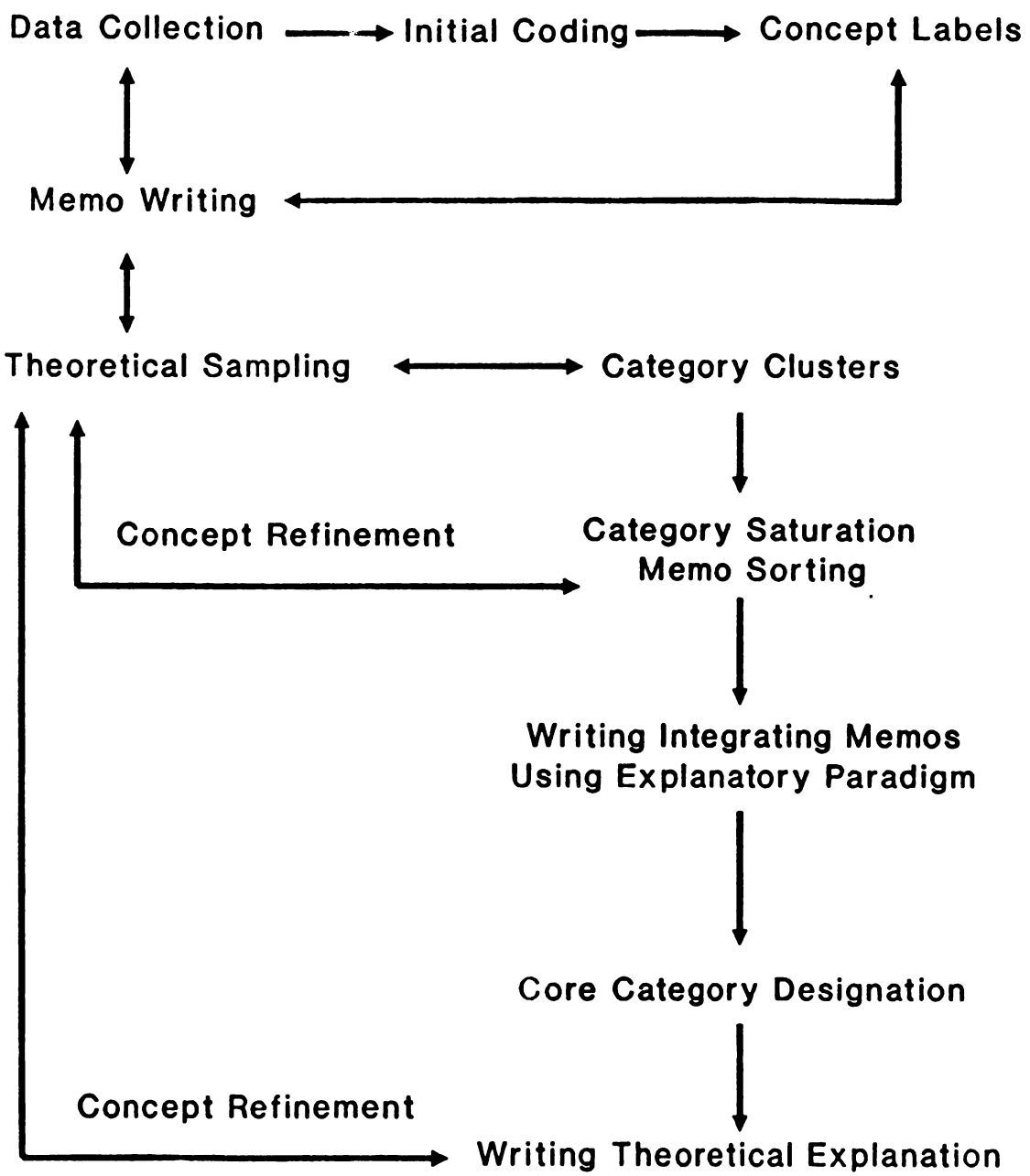
In grounded theory, as developed by Glaser and Strauss (1967), theoretical concepts are inductively generated as they emerge from the data collected, and are linked into patterns and relationships to explain human conduct in the social settings under investigation. A core variable or process is identified that describes the characteristics of a particular group of people and answers questions related

to how the subjects under investigation respond to conditions within the social context. The primary aim of the grounded theory method is the construction of theory based on the lived experience of the group being investigated rather than on verification of existing theories, concepts, or categories (Charmaz, 1990; Chenitz & Swanson, 1986; Corbin & Strauss, 1990; Glaser, 1978; Glaser & Strauss, 1967).

In grounded theory methodology, data collection and analysis proceed simultaneously (see Figure 3-1). Even an interview with one subject provides materials that may lead the researcher to re-direct future data collection. This new material may hold an important concept not recognized earlier and may alter the original interview questions or change the sample selection. This methodology seeks to achieve theoretical insights through constant comparative analysis of the researched phenomenon with similar phenomena or with similar subjects. For instance, comparisons are made between people diagnosed with diabetes as children and as adults to discover similarities and differences. The similarities and differences between diabetes and asthma or arthritis might be compared to help identify dimensions related to chronic illness. Concepts that emerge from this comparative analysis, such as the importance of energy rationing or dietary restrictions, focus the direction of the continuing research. Initially, grounded theory starts with a general focal interest and seeks to locate persons

Figure 3-1

Levels of Research and Analysis in Grounded Theory Method



involved in the experience of interest to the researcher. The researcher then proceeds to gather data based on observations and interviews (Schatzman & Strauss, 1973). The researcher may also use other sources of data such as public and private documents related to the area of interest to further explain and validate the emerging theory (Glaser & Strauss, 1967; Schatzman & Strauss, 1973; Strauss, 1987).

The analytic framework used to analyze and integrate the findings of this study is known as dimensional analysis (Schatzman, 1986). Dimensional analysis provides a structure paralleling the natural analytic processes people engage in as they attempt to understand problematic experiences that are not readily understood by recognition and recall methods used to solve past dilemmas (Schatzman, 1991).

The details of the method and how it was implemented in this study will be developed later in the chapter after the study design and data collection methods are described. The remainder of the chapter will describe the design of the study, the data collection methods used, and the data analysis procedures described above.

The Design

In order to describe and explain the process of self-regulation in people with diabetes, a purposive sample of 30 people with insulin dependent diabetes (IDDM) were interviewed on two occasions, two to three months apart,

using a semi-structured interview guide. The first meeting with participants consisted of the interview itself, collection of demographic information, the use of a visual analogue scale estimating the subject's perception of current diabetes control, and a blood sample drawn for glycosylated hemoglobin (GHb) level. The second meeting included additional interview questions, collection of the visual analogue scale material and another blood sample for a repeat Ghb level. The purpose of two meetings scheduled two to three month apart was to investigate possible changes in Ghb levels over that time and how, if at all, these changes were related to self-regulating activities discussed by the subjects during the interviews.

Setting

The sample population was drawn from patients who attended the diabetes training and management course at the Diabetes Center at the University of California, San Francisco. This center represents a cross-section of the multi-cultural, multi-ethnic populations of the San Francisco Bay Area. People attending the course come from diverse socioeconomic backgrounds, receive follow-up care in both private and public settings, and represent both genders and all age groups.

Subjects

A purposive sample of 30 subjects representative of insulin dependent diabetic clients who attended the Diabetes Center at the University of California, San Francisco was initially chosen. The subjects for the study, both men and women, and were required to meet the following criteria:

1) Age: between 20 and 55 years

2) Duration of illness: between 5 and 20 years

3) No severe diabetes complications requiring specialized medical treatment such as renal dialysis, total blindness, or immobility due to cardiovascular or peripheral vascular disease.

4) English speaking and able and willing to give consent to participate in the study.

Type I or insulin dependent diabetes (IDDM) was defined, for the purposes of this study, as the type of diabetes requiring insulin use from the onset of diagnosis without the prior use of oral hypoglycemic agents. In fact, the sample included subjects who were placed on oral hypoglycemic agents at diagnosis because they were thought, due to their age, to be persons with Type II diabetes, or because the subject initially refused to use insulin for treatment. The subjects, who originally hoped to attain control with oral agents, went on insulin within a short time of their diagnosis because of the severe deterioration of their health and probable Type I status. One subject had attended the Diabetes Center a number of years after her

diagnosis and was on large doses of replacement insulin. At the time of the study, the subject was on a combination of insulin and oral hypoglycemic agent treatments.

U.S. Bureau of Census (1990), National Center for Health Statistics (1990), and National Diabetes Data Group (1985) statistics indicate that, in the United States, the incidence of IDDM is similar in males and females (27.8 and 27.9 per 1,000 cases, respectively) and is 1.5 times higher in whites than blacks. As with African-Americans, Asian and Hispanic populations in the U. S. have a predominance of Type II, or non-insulin dependent diabetes and comprise only 1.5% of adults with diabetes. The subjects in this study reflected a representative sample of the IDDM population and included 16 males and 14 females. Twenty-nine subjects were Caucasian, one was African-American.

In grounded theory and dimensional analysis, subject sampling is both selective and theoretical. Prior to the onset of the study, the researcher develops a selective sample relatively representative of a population determined to be capable of providing information about the area of research interest. Inclusion and exclusion criteria are formulated in order to limit the research task. A sample size is also decided on initially to provide a core for each of the inclusion categories. In this method, opportunities for developing theory emerge rather quickly in the data gathering process. This ongoing analysis may suggest that alterations in sampling are needed, and the exact number of

subjects and inclusion criteria may change as the study progresses. The researcher must be willing to adjust the selected sample to pursue emerging hypotheses that offer theoretical possibilities. This is referred to as theoretical sampling and occurs when, through preliminary analysis, some factors become theoretically more important than others and it becomes necessary to pursue fresh samples to follow up on the emerging theoretical concepts. Theoretical sampling is used in grounded theory methodology to achieve a full range of variation in the sample rather than limit the variability of the investigation with a prestructured design. In this study, four additional one-time interviews were included to validate theoretical leads that emerged from the data. In the final sample reported in this study, one of the subjects was not a patient in the Diabetes Center but a registered nurse as well as a certified diabetes educator and clinical trials research nurse. He was chosen because he represented patients who teach themselves intensive insulin therapy without the benefit of support from a structured diabetes education program. Four subjects had no private health insurance or a regular job to support self-care activities considered important to good diabetes control. The insights these subjects provided into surviving diabetes without financial backup added useful variation to the emerging theoretical analysis.

Procedures for Recruitment

All participants of the UCSF Diabetes Center are routinely asked, at the end of the course, if they are willing to serve as research subjects. People who met the inclusion criteria were sent a letter (Appendix B) explaining the study together with a postcard which they were to return if they were not interested in participating. If the card was not returned within two weeks, potential subjects were telephoned to set up an initial interview time. Data collection took place either in the subject's home, a different place of choice, or over the phone. All subjects were interviewed in person at the first meeting. Four subjects completed the second interview by phone. They completed the blood tests and visual analogue scales by mail.

Every attempt was made to explain the study and the procedures for data collection before participation began. Written consent (Appendix C) was obtained from all subjects. Because the study included two finger punctures for Ghb levels and could, theoretically, lead to skin infection, precautions were used to prevent infection in the subjects including handwashing prior to the puncture and the use of a single-use disposable lancet for each subject at each collection. Confidentiality was maintained through use of code numbers on files and audio tapes. Furthermore, subjects were guaranteed that no names would be used in publications arising from the study, and all tapes were

destroyed at the end of the study. The study received approval (#H1832-06832-01) from the Human Research Committee at the University of California, San Francisco.

Data Collection Methods

Interviews

Working from an interview guide (Appendix D), semistructured interviews are used in grounded theory methodology to obtain descriptions and explanations of the subject's own experience in his/her own words. These interviews, more like directed conversation, allow the subjects to freely describe their view of the situation and allow events or themes to arise that can be compared with other those of other subjects (Sandelowski, Davis, & Harris, 1989).

In this study, the first interview focused on a discussion of the subject's initial response to the diagnosis of diabetes. The second interview focused on how the person currently manages her/his diabetes, how care practices have evolved over time, and what and who enhances or constrains diabetes management. The themes did not remain totally segregated in one interview or the other. Topics related to regimen practices, such as number of injections or the regularity of blood testing, were described in both interview sessions. The interviews were tape recorded in most cases and transcribed verbatim. On three occasions, the tape recorder was not used because of

mechanical problems. Extensive field notes were taken in those instances.

The interviews were originally scheduled to last approximately one hour. In reality, only one interview took an hour; the remaining 59 interviews took between one and a half and two hours. This additional time with the subjects allowed the researcher to validate many comments by returning to questions and approaching issues from different perspectives. The subjects expressed surprise at being given ample time to explain their story to a nurse. For most, their experience with health professionals was quite the opposite. Many commented that health care professionals rarely listened to what they had to say but rather focused on the client's inability to comply with one aspect of the regimen or another.

Since the subjects knew the investigator was an experienced diabetes clinical specialist, many had questions regarding regimen management. As time went by and the investigator became more experienced, it became easier to tell subjects that their questions would be addressed once the interview was completed.

In addition to the formal interviews transcribed in this study, the investigator gathered experiential data from extensive discussions with a large number of diabetes clients outside of the study, from knowledge gathered through reading and discussion of diabetes literature, from hundreds of hours of client observation in the work setting,

and from nearly three decades of personally living with Type I diabetes.

Demographic Information

Demographic information was gathered in the first interview. Specifically, this information included current age, age at diagnosis, occupation, source or sources of health insurance, complications of diabetes, nature of the current diabetes regimen (i.e., number of injections), and ethnic identity. In addition, subjects were asked whether they had experienced complications such as retinopathy, nephropathy, neuropathy, or cardiovascular problems (See Table 4-1).

Visual Analogue Scale

In an effort to better understand the relationship between the subjects personal evaluation of their control and the actual level of control as determined by a glycohemoglobin blood test, visual analogue scales (Appendix E) were utilized. Visual analogue scales (VAS) have been used as a means of measuring feelings or sensations regarding subjective phenomenon such as severity of fatigue, intensity of pain, and sensations of dyspnea (Krup, LaRocca, Muir-Nash, & Steinberg, 1989; Stensman, 1989; Wilson & Jones, 1989). Because a VAS measures a changing variable, reliability and validity testing are problematic. However, Aitken (1969) demonstrated that ratings in two experiments

with the same subjects assessing the degree of asphyxia were consistent over both trials. The VAS is used in this study as means of measuring the subjective estimate of the subject's perception of metabolic control. The scores were used to evaluate how well a person felt the self-regulating decisions affected blood sugar control. The Estimate of Diabetes Control Visual Analogue Scale, developed for this study, is a 100 millimeter solid horizontal line anchored by the words "Poor Diabetes Control" at the 0 point and "Diabetes Control As Good As It Can Be" at the 100 point.

An example of how the emerging data alters data collection is reflected in an experience that occurred in the second interview. When the subject was asked to estimate her degree of control on the VAS, she asked: "What about my effort? Doesn't that count? Sometimes I can't control the numbers, but I've really tried! That's what I want the doctor to look at. I want him to ask about this too" (004)[1]. From that point on, a second VAS was used to estimate the effort expended to attain diabetes control. A 100 millimeter line was used with the words "Little Effort Expended at the 0 point and "As Much Effort As I Can Expend" at the 100 point. This new VAS was mailed to the first subject interviewed with an explanation of what it was about and how to mark the line.

---

[1] Numbers in parentheses represent identification code numbers for study subjects.

All subjects stated that they saw the concepts of control and effort as distinct issues in diabetes management. Most subjects commented that they felt the concepts were linearly related, i.e., as the effort increased, so to did the level of control. Several subjects volunteered that they felt the effort was inversely related to control. In other words, doing what they needed to do to control the blood sugars would be so routine that the effort would be automatic. Other subjects, such as the person (004) referred to above, suggested that illness work and illness control may not be related at all. The variability in this relationship began to emerge as an important condition for self-care choices.

Subjects marked an "X" or "/" on the spot along the line that best represented their estimation of their current metabolic control and effort expended to gain control. The marks were measured in millimeters using the same ruler and a score was assigned each scale ranging from 0 to 100 (see VAS, Appendix C). The scores are discussed in Chapter 4.

Glycosylated Hemoglobin

Glycosylated hemoglobin blood tests have been used over the past decade to estimate the long-term control of diabetic patients. This test replaced the older system of 24 hour urine collections used to determine over-all glucose control. The glycosylated hemoglobin (Ghb) is a blood test that measures the number of molecules of glucose that are

attached to the red blood cells (RBC). Glucose attaches to proteins in an nonenzymatic, irreversible reaction. Elevation of glycosylated proteins is related to the height of the glucose concentration and the length of time the blood glucose is elevated. As the life of the RBCs is approximately two to three months, the Ghb indicates the average blood glucose level during the 60-90 days prior to the test. For this study, Ghb was analyzed using Self Assure/GHb test kits from Evalulab, Palm City, Florida. This test kit uses blood collected from a finger puncture that is applied to filter paper dipped in glucose oxidase. Little, McKenzie, Wiedmeyer, England, and Goldstein (1986) report a correlation of $r = .96$ ($p < 0.0001$; $n = 78$) between GHb measured from samples collected on glucose oxidase treated filter paper that had been stored for 14 days and those measured by affinity chromatography from frozen whole blood or hemolysates. In this study, the GHb levels were used to compare the subjects estimated level of control (VAS) with the quantified blood sample level.

Data Analysis

Background

In this section, some of the analytic processes used in the data analysis for this study are described. This is followed by a discussion of how the analysis was implemented The integration of the findings is presented in Chapter 4.

Definitions and Descriptions of Analytic Methods

The Dimensional Analysis Framework

Dimensional analysis (Schatzman, 1986) is an analytic perspective related to the grounded theory approach in that it embraces the idea that theory is generated directly from empirical data and not from received concepts. Dimensional analysis differs from grounded theory in the staging of the analytic operations and is an analytic variation of grounded theory (Schatzman, 1991).

Dimensional analysis postulates that any phenomenon under study is complex and has multiple parts, attributes and contexts. In the process of analysis these attributes are designated, differentiated, and integrated to produce a new understanding of the phenomenon. The dimensional analysis framework provides a means of logically relating components discovered in the data.

The dimensional analysis framework, as conceptualized by Schatzman (1986, 1988, 1991), has structural components that guide the analysis in a logical process and assists the research by sorting and linking attributes in a causal, conditionally situated matrix. This matrix is presented in Table 3-1.

Aspects of problematic situations or events are viewed from a designated perspective. A study can have a number of possible perspectives, but one is ultimately more fruitful and is chosen to frame the integration of the developing theory. For example, in this study, possible perspectives

include: living a normal life, accepting a diabetic identity, or negotiating diabetes treatment regimens. The particular perspective chosen is that dimension of the data that gives the greatest explanatory power to the phenomenon under study. It further guides the placement of the other dimensions into positions within the explanatory matrix.

The attributes or considerations found in the data are designated as abstract dimensions with descriptive properties. For instance, "duration of diabetes diagnosis" is a dimension, while "ten years" is a property describing that dimension. The dimensions describing the situation under study are located in a particular context such as a work setting or the patient-physician relationship. Conditions are events seen as enhancing or constraining actions taken. For instance, the availability of insurance to pay for diabetes supplies is a condition that influences the number of blood tests taken. The lack of insurance leads to consequences related to blood glucose control.

Dimensionality is a concept that is central to the dimensional analysis approach. This refers to the intuitive sense that any phenomenon considered problematic and needing analysis has multiple and distinguishable attributes. The concept of dimensionality serves to assist the analyst in understanding "what all" considerations are involved in a phenomenon. Schatzman (1991) describes dimensionality as a kind of human thinking that directs language towards analytic processes in problematic situations when

Table 3-1

Components of Dimensional Analysis Framework

Perspective	The line of thought that guides inquiry; organizes the dimensional categories and provides a lens for viewing the other dimensions and placing them in the matrix; the dimension with the greatest explanatory power.
Dimensions/ Properties	The attributes of the phenomenon under study; dimensions are abstract characteristics of the phenomenon and provide a context for qualitatively or quantitatively measuring the concept; properties are more concrete attributes of the phenomenon and describe or measure dimensions.
Context	The boundaries, parameters, or background in which the object of analysis occurs.
Conditions	The qualifiers or prerequisites that shape views, events and interactions.
Action/ Interactions	The responses or activities carried out that are shaped by the perceived conditions in accordance with the chosen perspective.
Consequences	The outcomes or results of the actions taken.

recognition and recall of past forms of analysis fail to provide sufficient understanding of the current problem to make sense of it and to prepare for action.

In this study, the problem of managing the complexity of the diabetes treatment regimen is not adequately addressed by the traditional explanations offered by the compliance paradigm. An explanation of "what all is going on" when people make decisions about self-care practices can

be explored using the dimensional analysis framework to bring a new understanding to the problem.

In the first step of dimensional analysis, interviews and other documents used to gather data are carefully read to begin identifying recurring themes and concepts. In order for these concepts to be available to the analyst, they must be labeled or given a name. This is an key part of the analysis in that, without a vocabulary that identifies the concepts, the research will remain descriptive. Designation of the dimensions of the problem provides the tools needed for analysis to proceed and is accomplished by abstracting multiple aspects of the problem under study. This first step is referred to as dimensionalizing the data (Schatzman, 1986; 1991) and defines the complexity of the problem.

This process appears very similar to open coding of grounded theory but is operationally different in that the dimensions of the experience are identified or designated with a provisional label without regard to how important they are or what meaning they hold in the experience described. In this step, "the analyst will attend first to the identification and assembly of considerations before patterning them" (Schatzman, 1991, p. 310). Later, when a sufficient number of components or dimensions are named and labeled and when no new concepts appear in the data, the dimensions will be assigned to the different matrix components. This placement of data into the matrix

components allows the analyst to develop explanations about the relationships between the coded dimensions.

Dimensionalizing begins when data is collected from a number of interviews and the analyst begins to search for concepts embedded in the data. In this study, the investigator noted general themes related to: 1) the evolving meaning of diabetes and the dawning realization of the illness' impact on everyday life activities, 2) the complexity of the treatment regimen prescribed, 3) the self-care practices needed to carry out the regimen, and 4) the view subjects had of the care they were receiving.

Once the analyst believes the important dimensions found in data are designated and their properties are described, a perspective is chosen. In this step, the perspective is chosen from among the dimensions as the one that explains and subsumes the other dimensions and helps organize the continuing theoretical process. As a more encompassing concept, the perspective serves as a lens that frames the discovered dimensions and allows the rest of the dimensions to be placed within the explanatory matrix. At the beginning of this study, this investigator thought that self-regulation on the part of diabetic subjects was the focus of self-care decisions. Analysis of the data using the dimensional analysis framework suggested that self-regulation functioned more as a condition for self-care action or as a consequence of decision making about diabetes treatment practices.

The last step in dimensional analysis is to place the designated dimensions into the analytic framework from the perspective chosen to give the greatest explanatory power to the data. This is the integration phase and is depicted in Figure 3-2. In this phase, dimensions derived from the data are defined as context, conditions, actions, or consequences. Placement in the framework gives structure to the analysis of study data and provides a means for demonstrating relationships between the identified dimensions.

Figure 3-2

Integrated Dimensional Analysis Framework

Perspective (Lens)

Dimensions/Properties (Attributes)

Context (Boundaries)	**Conditions** (Qualifiers)	**Action** (Responses)	**Consequences** (Outcomes)

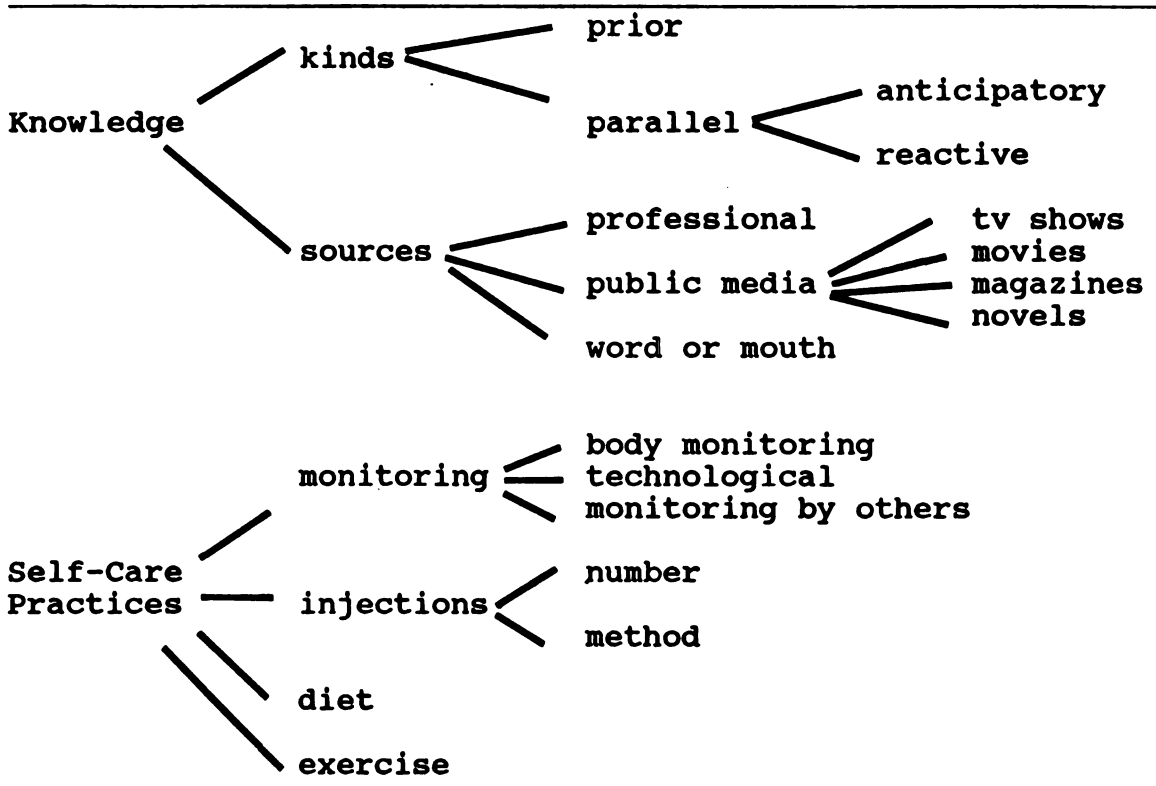
Initial Approach to Data

Interview data in this study were analyzed using coding, memoing, and the application of the explanatory matrix of dimensional analysis. After the first five interviews and after combining notes from a pilot study with five other diabetic subjects, the investigator began to code

dimensions. This coding attempted to discover themes that appeared in these interviews and to identify concepts describing the complexity of the diabetes experience. For example, gaining knowledge about diabetes was a major theme. This dimension was subdimensionalized into kinds of knowledge and sources of knowledge. Kinds of knowledge could be further classified as prior or parallel, meaning that knowledge about diabetes resulted from prior experience or from experience since the diagnosis (see Figure 3-3).

Figure 3-3

Examples of Initial Dimensionalizing-Dimensions, Sub-dimensions, and Properties



Prior knowledge was described by a subject when she said: "[T]he first thing that happened was that I knew I was diabetic before I was diagnosed ... because there is diabetes in my family and I was experiencing all the classic symptoms" (002). Parallel knowledge relates to knowledge gained as the experience with the illness continues and is further described by reactive and anticipatory properties. This kind of knowledge is demonstrated by a subject saying, "[O]ne night I wake up and there are three paramedics around me, upstairs in the bedroom. It was the first time I ever went into insulin shock. I had reactions and stuff but never went into insulin shock, and this time really taught me a lesson" (029)! After this experience, the subject began using anticipatory knowledge by waking up every night at 3:00 a.m. to check his blood sugar level and eating or taking more insulin depending upon the results.

Another example of an important dimension was the theme of self-care practices. This concept was subdimensionalized into monitoring, injections, diet, and exercise. Monitoring was further classified into body monitoring, technological monitoring, and monitoring by others (see Figure 3-2). Subjects tended to describe body monitoring in the following way: "I'll buy an apple...if I feel like I need something" or "It's not what I call real low blood sugar, but I can definitely tell my energy is dropping" (028). Technological monitoring entails using the glucose meters or visual strips to quantify glucose levels. Monitoring by others is

described by statements such as: "My wife...was the big reason behind the push [to change doctors]. She said 'I think you need to go see a specialist...there's got to be a better way to manage this'" (028).

As soon as these designations appeared, questions were raised about how knowledge developed, how knowledge was integrated as experience with the illness grew, and how knowledge affected self-care practices. These questions were integrated into further interviews to see how the subjects varied across this dimension. In what ways were they similar? In what ways were they different? How did these similarities and differences affect decision making about the prescribed regimen?

In trying to identify the complexity of concepts described by the subjects attempting to follow their prescribed diabetes regimens, a list of dimensions common to all subjects was produced (See Figure 4-1). As the dimensions, subdimensions, and properties were designated, a number of relationship questions were posed. For example, did the intensity of the regimen influence the degree to which a person scrutinized their control? Did intensity of regimen increase self-care practices and ultimately have an impact on control as reflected in the GHb? These kinds of questions directed the investigator back to the data to compare and contrast the subjects.

As the analysis continued, it became clearer that certain designations occurred in the subjects' references to

both their personal goals and their social roles. For example, subjects described "Normalcy" in various ways but generally understood this to mean that they saw themselves as people able to carry out roles in work, relationships, and recreational activities in the same way as friends or acquaintances without diabetes. "Performance" or "performing" was also important to subjects as it was to everyone else in their cultural or subcultural group.

These concepts helped to describe the diverse milieus in which decisions about diabetes self-care were made. The challenge of balancing diabetes care with social demands began to emerge as a significant factor that influenced self-regulating decisions about diabetes treatment.

Theoretical memos were generated as a way of organizing codes that appear frequently and begin to suggest hypotheses. These theoretical memos direct the researcher's attention to codes that persist from one interview to another and appear to have universality and suggest significant relationships with other codes. It is through the sorting of memos that linkages between emerging categories and concepts are made and the developing theory is generated. In this study, memos were generated that related to chronicity, performing, the differences between self-care and self-regulation, knowledge as structure, the meaning of transparency, and balancing directed attention to the evolving theme of living a normal life in the context of constantly changing illness work.

An explanatory matrix, or coding paradigm, facilitates the analysis of relationships by providing a systematic analytic ordering of the categories or dimensions abstracted through the coding and memoing processes (Glaser, 1978; Schatzman, 1991; Strauss & Corbin, 1990). In this process, a code is converted to form the core category or perspective of the theory. This category is usually a process (Glaser, 1978) and account for most of the variation in the data, i.e., it explains the phenomenon under study and systematically links the codes and categories designated earlier in the study. The explanatory operations suggested by Schatzman (see Figure 3-1) are used to analyze the data in this research.

Strauss and Corbin (1990) suggest that diagramming parts of the emerging theory may help clarify relationships between dimensions. This process forces the investigator to visually delineate dimensions and relationships. Diagrams attempt to structure relationships between the dimensions in order to evaluate positions in the explanatory matrix, and are used to push the integration of concepts forward (Strauss, 1987). Examples of diagramming are found in Chapters 4 and 6 (see Figures 4-2 and 6-1).

The procedures listed above have been designed to progressively move the meanings embedded in the data to more abstract levels in order to integrate the categories and concepts into a well organized theoretical explanation of a phenomenon rather than merely describe the data.

Reliability and Validity of Qualitative Data

Lincoln and Guba (1985) argue that the criteria drawn from the quantitative research perspective may not be appropriate for judging the results of qualitative research. The different philosophies behind these methods lead to different claims about knowledge and require separate criteria for analysis of truth or trustworthiness. The rigor of this study is evaluated on redefined criteria pertinent to qualitative research.

Validity is achieved by ensuring that the subjects who participate in the study are accurately described and identified. This is accomplished in the proposed study by triangulation of data collection methods using interviews, documentation of client perceptions of control, blood test, and review of medical records. Prolonged personal contact between subjects and investigator during two interviews allows verification and elaboration of ideas presented in the first interview. Reliability is achieved through the use of questions that are repeated in both interviews, by restating or by using "alternative form questions" (Brink, 1989) within the same interview in order to check the dependability of the subject and his/her information, and by comparing the responses of other informants to establish "equivalence" (Brink, 1989) between data. The trustworthiness of the research analysis is enhanced by the application of the explanatory paradigm (see Figure 3-1) to all data. Consultation and auditing of emerging categories

and concepts by a qualitative analysis group led by Dr. Leonard Schatzman at the University of California, San Francisco assisted in verifying the theoretical constructions that were developed. Informing subjects of findings and verifying with them the relevance of concepts generated also established the validity of the analysis (Lincoln & Guba, 1985; Sandelowski, Davis, & Harris, 1989).

Quantitative Analysis

Descriptive statistics are used to characterize the sample population. Pearson correlations evaluating the relationship between the subjects' perceptions of metabolic control and efforts expended in self-management practices (VAS scores) and the GHb test are used to further enhance the qualitative findings related to self-regulating behavior. In addition, the relationships between selected demographic variables (age, intensity of therapy, duration of illness, gender, etc.) and the VAS and GHb values will be evaluated with correlation coefficients to further identify factors that influence self-regulation. These findings are presented in Chapter 4.

Summary

This chapter has explained the methodology and process of analysis used in this investigation. The design, procedures and tools for data collection were described. Dimensions denoting the complexity of living with a diabetes

treatment regimen were identified and described using initial dimensional analysis techniques.

The process of defining compliance with diabetes regimens, from the perspective of living a normal life, was developed through the procedures described in this chapter. The chapters that follow will elaborate on the analysis and integrate the findings within the analytic matrix of dimensional analysis.

CHAPTER 4

FINDINGS AND THEIR CONCEPTUAL STRUCTURE

The next three chapters present the findings discovered in the present research and the conceptual schemas which organize these findings. Subjects in this study stated they hoped the analysis would "tell it like it is," and give their perspective on how people with diabetes make decisions about how they manage their diabetes. An earlier pilot study and hundreds of hours of clinically related discussion with diabetic patients led the investigator to the conclusion that self-regulation of treatment regimens was an inevitable and inherent part of diabetes management. The question remained as to the process(es) that informed the individual's analysis and eventual decisions about diabetes self-care. Analysis of the data in this study revealed: 1) a process of self-regulation develops over the progression of a complex illness such as diabetes and 2) self-management actions that result from self-regulating decisions seem contrary to professional advice in some cases. These data also identified a system of analysis used by the subjects in making these self-management decisions.

As described in Chapter 2, the compliance literature from the medical and behavioral model perspective made no attempt to evaluate the impact of everyday life experiences on disease control. This is probably due to the lack of a biopsychosocial framework in the medical literature.

Compliance, according to the medical model, means accepting the prescription of medicine and the concomitant behaviors inherent in the prescription without consideration of the real life interest, needs, and experiences of people who live with the disease.

Leventhal and colleagues (Leventhal & Johnson, 1983; Leventhal, Zimmerman, & Gutmann, 1984; Meyer, Leventhal, & Gutmann, 1985) attempted to explain patient self-regulation based on the assessment of physical symptoms and the psychological response to those symptoms. In that model, self-regulation is conceptualized as a dynamic process constructed from an individual's illness representation, actions taken to control the illness, and appraisal of those actions which then lead to alteration of the illness representation. While this model acknowledges the dynamic reconstruction of illness representations through cognitive analysis, it fails to address how the modifications in health definitions affect emotions and social activities. It further fails to address how valued social activities affect emotion, health definitions, and health practices.

The findings of this study are organized into three chapters. The first of these, Chapter 4, presents a description of the sample subjects, contains descriptive statistics of the sample, and reports on the analysis of information gathered through the use of the visual analogue scales for control and effort and on the glycosylated hemoglobin values collected at each interview. Chapter 4

also presents the conceptual structure of the qualitative data gathered in the interview portion of the study. The conceptual structure and three developmental phases of self-regulation are presented along with an explanation of the natural analysis demonstrated by the subjects in reaching self-regulating decisions.

Description of the Sample

The following segment presents the demographics and descriptive statistics of the sample, and reports the correlations between the subjects' perception of the degree of their diabetes control and effort expended to control blood glucose levels and the glycosylated hemoglobin test results. The study consisted of a purposive sample of 30 subjects. All 30 subjects were interviewed on two occasions with approximately three months between the first and second interview. One subject refused to complete the glycosylated hemoglobin test and the visual analogue scales at the time of the second interview. The correlations and analysis of variance procedures conducted on the visual analogue scales and the glycosylated hemoglobin levels, therefore, were performed with twenty-nine complete data sets.

Sample Characteristics

The sample consisted of 16 males (53%) and 14 females (47%). Sixteen of these subjects were diagnosed before the age of 20 and 14 were diagnosed between the ages of 20 and

45. Fifty-three percent of the sample had been diagnosed with insulin-dependent diabetes for more than ten years (see Table 4-1).

Twenty-nine of the subjects were Caucasian and one was African-American. The high ratio of Caucasian subjects fits the ethnic pattern for Type 1 diabetes (National Diabetes Data Group, 1985). Twenty-eight of the subjects were employed and two were not at the time of the first interview. Only twenty-four of the subjects had insurance. Part-time employment and self-employment were indicated as reasons for lack of private insurance coverage. One unemployed person received Medical insurance coverage.

The intensity of the insulin regimen was calculated based on the number of injections given per day. Twenty-two subjects (73%) took four injections a day or used an insulin pump. At the beginning of the study, three were using an external insulin pump. By the end of the study, five were on pumps and a sixth person went on the pump one month after the last interview. Three subjects (7%) took three injections per day and five (17%) changed the number of injections they took each day, either increasing or decreasing the number as they themselves determined the need.

Twenty-three (77%) of the subjects reported no diagnosis or treatment for chronic complications related to diabetes. Two subjects (7%) reported problems with retinopathy requiring treatment. Two subjects (7%) have

Table 4-1

Demographic Characteristics of the Sample

	N	%
Gender		
Male	16	53
Female	14	47
Age at Diagnosis		
<10	7	23
10-19	9	30
20-30	11	37
30-50	3	10
Duration		
5-10 years	14	47
10-20 years	16	53
Intensity of Regimen		
1 shot	1	3
3 shots	2	7
4+ shots or pump	22	73
variable	5	17
Employment		
Yes	28	93
No	2	7
Insurance		
Yes	24	80
No	6	20
Ethnicity		
White	29	97
Afro-American	1	3
Presence of Complications Needing Treatment		
Retinopathy	3	10
Neuropathy	3	10
Nephropathy	3	10
Cardiovascular	1	3

problems with gastroparesis, and one subject has tested positive for urine protein (microalbuminuria), signalling the beginning of decreased renal functioning. One subject has both retinopathy and microalbuminuria. Another reported positive indicators for neuropathy (gastroporesis), cardiovascular complications (hypertension), and the onset of nephropathy.

The mean current age of this sample at the first interview was 30.6 years (S.D. $\pm$ 7.3). Fourteen of the subjects were between 20-30 years of age, fifteen were between 30-40 years of age. One subject was 55 years of age at the time of the first interview. The mean duration of disease was 12 years (S.D. $\pm$ 4.27) and ranged from six years to twenty years.

Demographic Correlations

Pearson correlations using subject demographics (see Table 4-2) indicate that a significant correlation exists between neuropathy and cardiovascular complications ($r=0.69$, $p=<0.001$) and between the presence of nephropathy and cardiovascular disease ($r=0.56$, $p<0.001$). The presence of retinopathy was negatively correlated to age at diagnosis and duration of illness, but with this sample did not quite reach a statistically significant value. Not surprising, a significant, positive correlation existed between employment and insurance ($r=0.53$, $p<0.001$). In this sample, the variables of gender, ethnicity, and the presence of

retinopathy did not significantly correlate with other demographic variables collected and do not appear in Table 4-2.

Table 4-2

Correlation Matrix of Significant (p<.05) Sample Demographics, Visual Analogue Scale (VAS Scores, and Glycosylated Hemoglobin (GHb) Levels

	Age DX	AgeCurr	Duration	Intensity	Employed	Insurance
Age DX	1.00	0.92	-0.75	—	0.38	—
AgeCurr	0.92	1.00	-0.43	—	0.50	—
Duration	-0.75	-0.43	1.00	—	—	—
Intensity	—	—	—	1.00	—	—
Employed	0.38	0.50	—	—	1.00	0.53
Insurance	—	—	—	—	0.53	1.00
Neuro	—	—	—	—	—	—
Nephro	—	—	—	—	—	—
Cardio	—	—	—	—	—	—
VASCON1	—	—	—	0.39	—	—
VASEFF1	—	—	—	—	-0.52	-0.51
GHb1	—	—	—	—	—	—
VASCON2	—	—	—	—	—	—
VASEFF2	—	—	—	—	—	—
GHb2	—	—	—	—	—	—

Table 4-2 (Cont.)

Correlation Matrix of Significant (p<.05) Sample Demographics, Visual Analogue Scale (VAS Scores, and Glycosylated Hemoglobin (GHb) Levels

	Neuro	Nephro	Cardio	VASCON1	VASEFF1	GHb1	VASCON2	VASEFF2	GHb2
Age DX	—	—	—	—	—	—	—	—	—
AgeCurr	—	—	—	—	—	—	—	—	—
Duration	—	—	—	—	—	—	—	—	—
Intensity	—	—	—	0.39	—	—	—	—	—
Employed	—	—	—	—	-0.52	—	—	—	—
Insurance	—	—	—	—	-0.51	—	—	—	—
Neuro	1.00	—	0.69	—	—	—	—	—	—
Nephro	—	1.00	0.56	—	—	—	—	—	—
Cardio	0.69	0.56	1.00	—	—	—	—	—	—
VASCON1	—	—	—	1.00	0.41	—	0.45	—	—
VASEFF1	—	—	—	0.41	1.00	-0.42	0.45	0.56	0.49
GHb1	—	—	—	—	-0.42	1.00	-0.48	-0.52	0.73
VASCON2	—	—	—	0.45	0.45	-0.48	1.00	0.69	-0.72
VASEFF2	—	—	—	—	0.56	-0.52	0.69	1.00	-0.63
GHb2	—	—	—	—	-0.49	0.72	-0.72	-0.63	1.00

Relationships between VAS, GHb, and Demographics

Perception of Metabolic Control

The correlations between the visual analogue scale scores measuring the subject's perception of her/his level of glucose control and the demographic variables listed in Table 4-2, revealed a significant positive correlation between the variable of regimen intensity ($r=0.39$, $p<0.05$). This indicates that a person's sense of control increases as the intensity (number of injections per day or self-adjustment) increases. When the perception of control was retested at Time 2, the relationship was positive, but was quite weak ($r=0.02$) and not significant.

Estimate of Effort Expended

The correlations between the visual analogue scale scores measuring the subject's estimate of effort expended to manage diabetes care and the demographic variables listed in Table 4-2 indicated a significant correlation between employment ($r=-0.52$, $p<0.01$) and having insurance ($r=-0.51$, $p<0.01$). As noted earlier, insurance and employment were highly related to each other. As unemployment increased, estimates of effort to manage diabetes care decreased; as employment increased, estimates of effort to manage diabetes care increased. These results may be related to a lack of resources needed to intensify glucose monitoring and to buy appropriate foods for those who are unemployed and without insurance. The employed subjects may have also felt that they were working very hard at fitting any efforts to

control diabetes into their busy work lives, and therefore, gave themselves higher scores on effort.

At both Time 1 and Time 2, subjects' perceptions of glucose control and estimates of effort expended to manage care were related to one another in a positive direction. Control and effort at Time 1 were correlated at $r=0.41$, $p<0.01$. At Time 2 the correlation was $r=0.69$, $p<0.001$.

Glycosylated Hemoglobin Levels

The normal range for the laboratory values of glycosylated hemoglobin used in this study was 5.9 - 7.5%. This range represents levels of glycosylated hemoglobin in the non-diabetic population. Diabetic people are considered to have achieved acceptable control if the value is approximately equal to 8% (ADA, 1988; see Appendix A). At Time 1 (n=30), there were six subjects (20%) with levels less than 7.5%. At Time 2 (n=29), there were four subjects (14%) with levels less than 7.5% (see Table 4-3).

The American Diabetes Association guidelines consider a glycosylated hemoglobin of 10% or below fair control (ADA, 1988, see Appendix A). In this sample at Time 1, twenty-one subjects (70%) were between 7.5% and less than or equal to 10.0%, three (10%) were greater than 10.0%. One subject (3%) was greater than 11.0%. At Time 2, 19 subjects (66%) were between 7.5 and less than or equal to 10.0%, six subjects (21%) were greater than 10.0%, and two subjects (7%) were greater than 11.0%. The subject who was greater

Table 4-3

Levels of Glycosylated Hemoglobin

	GHb ≤7.5%	GHb 7.5≤10%	GHb >10%
Time 1	n=6 (20%)	n=21 (70%)	n=3 (10%)
Time 2	n=4 (14%)	n=19 (66%)	n=6 (21%)
Guidelines	7.5% normal	8% acceptable	10% fair / >10% poor

than 11.0% at Time 1, decreased at Time 2 into the high 10% range. The two subjects who were greater than 11.0% at Time 2 rose from a 9.3% and 10.0% respectively at Time 1.

At Time 1, the estimate of effort expended was negatively related to the glycosylated hemoglobin at a significant level ($r=-0.42$, $p<0.05$). As efforts to manage glucose went down, the glycosylated hemoglobin rose. Perception of diabetes control was weakly correlated with the glycosylated hemoglobin level at Time 1 ($r=-0.29$, NS).

At Time 2, in contrast to Time 1, perceptions of control were negatively and significantly correlated with glycosylated hemoglobin results ($r=-0.72$, $p<0.001$). Perception of efforts to manage diabetes were significantly

correlated with glycosylated hemoglobin at Time 2 and were more strongly correlated ($r=-0.63$, $p<0.001$) than at Time 1 ($r=-0.42$, $p<0.05$). These results suggest that between Time 1 and Time 2, the subjects perceptions of their control and effort went down. These perceptions were accurately reflected in a rise in glycosylated hemoglobin levels (see Table 4-4). Scatterplots of these correlations did not indicate any obvious outliers responsible for the dramatic increase in correlations (see Appendix F).

Table 4-4

Means and Standard Deviations of Visual Analogue Scale (VAS) Scores and Glycosylated Hemoglobin Measurements

N=29	TIME 1		TIME 2	
	M	SD	M	SD
VASCONTROL	68.345	20.356	65.345	20.640
VASEFFORT	69.828	20.036	64.724	25.251
GHB	8.645	1.237	9.007	1.231

Possible explanations for this change may be that the glycosylated hemoglobin results from the first meeting, sent to the subjects between the first and second interviews, made the subjects more conscious of their glucose status and allowed for a more accurate assessment of control and effort at Time 2.

The fact that this information did not result in better metabolic control might be explained by the fact that the Christmas and Jewish holidays occurred between many of the interviews. The abundance of party foods and the unpredictable eating schedules during these holidays pose challenges for most insulin dependent people. However, participating in these holiday activities may have been more important than achieving metabolic control.

The information about the glycosylated hemoglobin levels does not necessarily lead to better choices related to metabolic control, but could be used to help clients choose new self-management options. The use of natural analytic processes as an assessment and intervention tool in understanding client thinking about self-management actions will be discussed in the more detail.

Analysis of variance (Table 4-5), comparing glycosylated hemoglobin levels, indicated a significant

Table 4-5

Analysis of Variance Glycosylated Hemoglobin: Time 1-Time 2

Source	DF	SS(U)	MSS	F	P
Between Subjects	28	73.66621			
Within Subjects	29	13.50500			
Time	1	1.90086	1.90086	4.587	0.0411
Error 1	28	11.60414	0.41443		

difference between Time 1 and Time 2 ($F=4.587$, $p<0.05$). No significant differences in estimates of control and effort were found between Time 1 and Time 2.

Summary

The results of the measures used by the subjects to estimate individual levels of diabetes control and the amount of effort expended in managing the diabetes regimen were compared with laboratory values for glycosylated hemoglobin levels. These values reflect average blood glucose control over the past several months. As a group, the subjects accurately related estimates of effort and control (VAS scores) to glycosylated hemoglobin levels. At Time 2, there was a stronger correlation between the subjects estimates of decreasing effort and control and a rising glycosylated hemoglobin levels.

Conceptual Structure of Self-Regulation

Developmental Phases of Self-Regulation

The following discussion is intended to give the reader a general description of three temporal phases discovered in this study to explain the development of self-regulation in people with Type I diabetes. An explanation of the general contexts in which self-regulation develops is also given. An organizing perspective, natural analysis (Schatzman, 1986), will also be proposed as a structure for analyzing the

continuous assessments made by the subjects as they moved through the developmental phases of self-regulation.

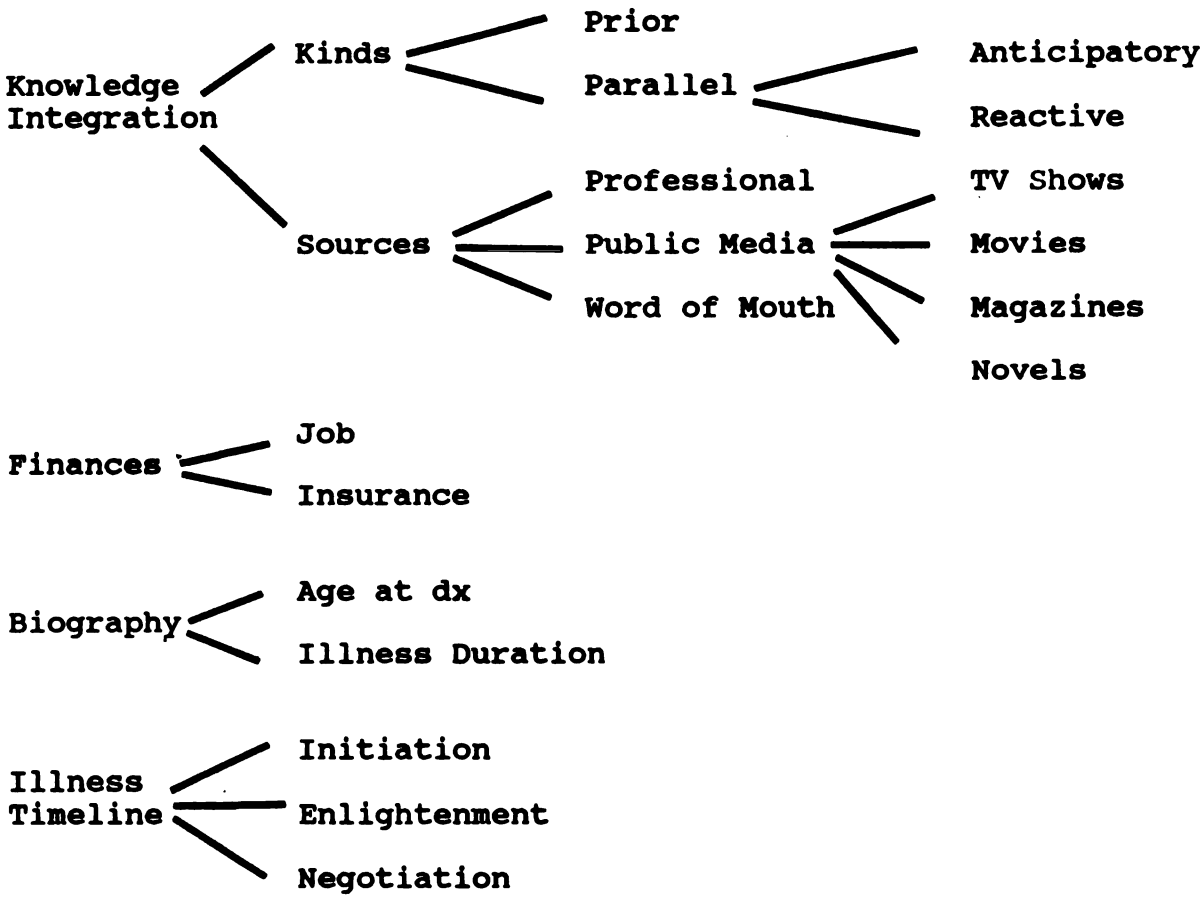
The initial data analysis led to the compilation of dimensions describing the complexity of the attributes influencing self-regulating practices (see Figure 4-1). As each respondent's account unfolded, these dimensions were expressed and the range of attributes involved in her/his efforts at controlling diabetes described. The most significant finding was that from the perspective of people with Type I diabetes, *living a "normal" life was at least as important as following the prescribed treatment regimen.* Living a normal life was the central consideration in the actions of the subjects in this sample.

As the dimensions were categorized through continuous coding, three other major components relevant to the development of self-regulation evolved along with "living a normal life." These abstracted dimensions were designated as: Becoming Diabetic, Confronting the Illusion of Promised Normality, and Pragmatic Sufficiency. These three components represent temporal phases that subjects passed through as they developed self-regulating behaviors related to their treatment regimens (see Figure 4-2 for a diagram of the relevant components of self-regulation).

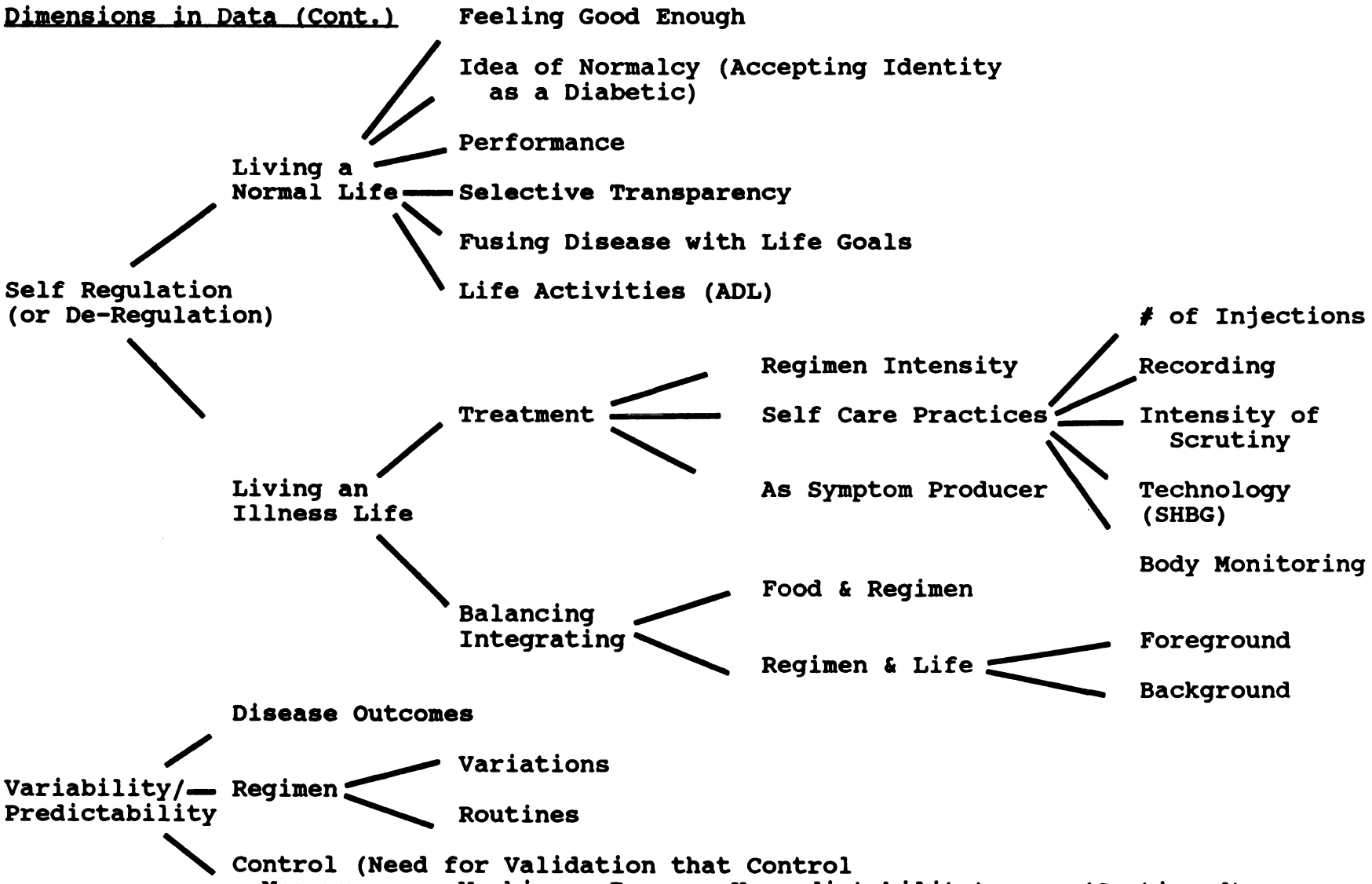
Each subject progressed over time through these phases as they came to understand what having diabetes meant to them and to deciding what actions to take to control the disease symptoms. Each of these temporal phases are

Figure 4-1

Dimensions in Data



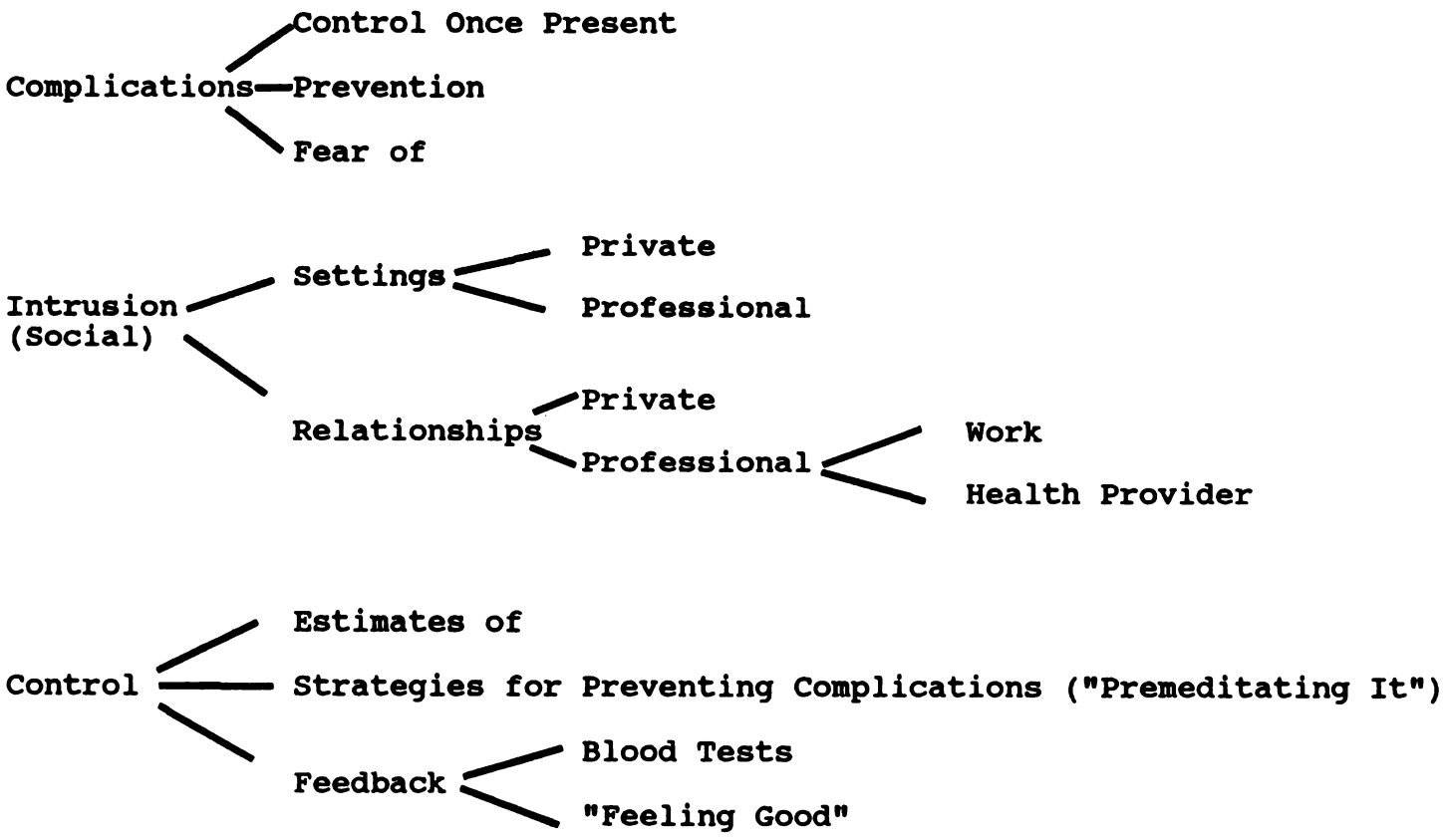
(Continued)


Dimensions in Data (Cont.)
Feeling Good Enough
Idea of Normalcy (Accepting Identity as a Diabetic)
Performance
Living a Normal Life
Selective Transparency
Fusing Disease with Life Goals
Life Activities (ADL)
Self Regulation (or De-Regulation)
# of Injections
Regimen Intensity
Recording
Treatment
Self Care Practices
Intensity of Scrutiny
As Symptom Producer
Technology (SHBG)
Living an Illness Life
Body Monitoring
Food & Regimen
Balancing Integrating
Foreground
Regimen & Life
Background
Disease Outcomes
Variations
Variability/ Predictability
Regimen
Routines
Control (Need for Validation that Control Measures are Working - Reverse Unpredictability)

(Continued)

Figure 4-1 (Continued)

Dimensions in Data



furthered described and explained by specific properties and conditions related to their development. The details of those descriptions and qualifiers will be discussed in Chapters 5 and 6.

First Phase - Becoming Diabetic

When subjects first received the diagnosis, they were often naive about what was involved in the self-management of the illness. This was true even for those who had known someone with diabetes before their own diagnosis. Their naivete was expressed in comments such as: "I really somehow, in my mind, thought, 'oh, this is not going to be bad, I'm going to be skinny.'" (015) Others naively resolved that the diagnosis would not change their lives: "The first day I was hysterical, after that I got a hold of myself; I decided I was not letting it change my life...I just was not going to allow it to change anything." (002)

During the Becoming Diabetic phase, the subjects were told what the diagnosis was and what they had to do to survive with the illness. At this time, the subjects were highly dependent on health care professionals to help them manage their newly diagnosed problem. Survival skills were taught at this point. Information was shared on such topics as defining diabetes, testing, diet, insulin administration, site rotation, timing of injection, and signs and symptoms of hypoglycemia and hyperglycemia--in short, a simplified course in the physiology and technology of diabetes. Survival skills training included attempts to inform the

subject about the on-going nature of self-management. In his primer on patient education, Kilo (1982) stated:

> With regard to the restrictions and adherence demanded of patients by their regimens, the nurse educator will tell them, "This is what we expect of you in order to maintain your good health." This positive, supportive, informative role on the part of the nurse educator can be very effective in giving a diabetic patient the will to learn how to take care of himself and to keep going over the long course of years (p. 29).

Subjects were reassured at his point that if they carried out the tasks prescribed for them, blood glucose levels would be controlled, and a person with diabetes could look forward to living a "normal life." The popular diabetes literature contains testimonials by people with diabetes claiming diabetes has not stopped them from doing what they choose to do in life. For example, in a publication that claims to want to help the person with diabetes lead a healthier, happier life, a diabetic woman writing about her experience with running stated:

> After I was diagnosed with diabetes, I was told by a health professional, "Don't feel you're different from any other person. You have the capacity and determination to succeed in whatever you set your mind to do. You could even run marathons." (Correa, 1992)

Such instructional materials emphasize the theme of being able to live a normal life--as long as certain procedures and actions are undertaken. With the exception of a few vocations such as flying airplanes or serving in the armed service or law enforcement, people with diabetes

are generally assured that diabetes will not interfere with their work or social relations.

Nevertheless, from the moment of diagnosis, the fear of complications of long-term diabetes affects the person with diabetes. While they are taught they, too, can lead normal lives, they are simultaneously receiving messages about blindness, kidney failure and heart disease. Complications from diabetes are included in the survival skills training to underscore the importance of following the regimen. Sensitivity to these messages varies over time and depends on the individuals experience, first or second hand, with complications. A subject who, at the time of the study, was facing a number of complications remembers:

> I think it's kind of proportional to how close you perceive those complications as reality for you. I know for me, back in the beginning when I didn't really think that was going to happen to me, [my attitude was], who cares? Now, when I feel a lot closer to those and they really seem like they are right around the corner, that's [fear of complications] a lot of what keeps me going [working on glucose control]. (015)

Generally, Becoming Diabetic is a phase in which the newly diagnosed individual begins to learn new information on self-management practices related to diabetes care. In this phase, the treatment is seen as a solution to the illness. Subjects are instructed to take the insulin and follow the prescribed diet and "it" will be out of the way allowing normal living to continue.

Second Phase-Confronting the Illusion of Promised Normality

In the next phase of experience with diabetes, the subjects experience a period of enlightenment in which it becomes clear that treatment itself causes symptoms and that the prescribed treatment can never lead to true normality. In Confronting the Illusions of Promised Normality, the individual becomes increasingly knowledgeable about the complex interactions that exist among insulin, food, and activity levels. As experience with the illness grows, the subtleties of timing and balancing the components of the regimen begin to supplement the original survival skills.

A number of subjects in the study mentioned that, after the initial diagnosis and treatment, they did not receive educational follow-up, nor were relationships between important care variables related to them by health care providers. Subjects typically acquired new information to help them with treatment only after changing providers or aggressively searching for answers to questions that were never adequately addressed. In speaking of this lack of information, one subject in the study related:

> I understood at the time [of diagnosis] that the pancreas was not producing any insulin at all, or it's so little that I needed shots of insulin to make up for that...But a lot of things I didn't understand...that I've learned at the [university medical center] course. [A]fter leaving [local hospital at time of diagnosis], I understood I needed to watch what I ate, but the emphasis was more on "don't eat sugar" and so forth, as opposed to watch[ing] the carbohydrates. It's [a] much simpler approach, you know, "don't' eat a sugar donut," but not "watch out how much spaghetti you're eating!" (028)

Once the subjects experience either high or low blood glucoses as a result of treatment, they initially question their competence in handling the contingencies of the illness. It becomes clear that the prescribed treatment does not make the illness go away as might be the case with more acute illnesses. At this point, subjects instinctively begin to experiment with adaptations to the prescription and to self-regulate the regimen given to them at diagnosis. This revelation was expressed by one individual as follows: "We'll stick with the regimen they tell us because we have faith it's going to take our diabetes away. When it doesn't, we say '<u>forget this</u>!' (004) Self-regulation begins when the imbalance between the illness life and normal life is perceived and acknowledged.

<u>Third Phase - Pragmatic Sufficiency</u>

In Pragmatic Sufficiency, an equilibrium is struck between what people have been told to do and what they decide they need to do in order to balance the illness demands with their efforts to live normally. This equilibrium is tenuous and remains dynamic at best. Expressions such as, "the frustrating thing is that you can do it [a regimen] and for three months it works, and [then] the next three months it doesn't work" (015) characterize this phase and set the stage for decisions by the individual to adjust her/his treatment plan.

As the analysis proceeded, it became clear that while "normality" was an impossible goal, subjects were

overwhelmingly motivated by their desire to live as normal a life as possible. The disease and its treatment are fraught with unknowns and unpredictability. Complications never occur in a predictable fashion and may result from any of a number of factors such as blood glucose level, dietary intake, activity patterns, and stressful life events. The long-term sequelae are similarly unpredictable and appear to be related not only to blood glucose levels, but also hereditary factors and life style preferences.

Reshaping both the prescribed regimen and the tasks of everyday living such as eating, working, and interacting with significant others is a never ending challenge. Timing of food intake, injections, activity, and rest become extremely important in preventing both acute and chronic complications, and yet must be negotiated with other demands of life and with life partners.

For example, blood glucose monitoring may be difficult to perform when one is expected to accompany one's spouse to a business related cocktail party. Ordinarily, the social obligation would be dominant in this situation. However, a low blood glucose reaction at this party can force a reordering of priorities. Eating half a tray of hors d'oeuvres at once might help to avert a crisis and yet one must factor in how this will appear to others. Ultimately, the sense of obligation to one's spouse may outweigh the need for tight metabolic control, and the blood glucose will

be allowed to rise in order not to provoke a hypoglycemic episode.

This shifting or juggling of physiological, social, and psychological needs becomes necessary in the struggle to approximate normality. While the needs of the body are often dominant, social or psychological needs may well assert themselves, making the diabetes regimen less important. Since the monitoring of a normal life is conditioned by the diabetes, and the monitoring of the diabetes is conditioned by the demands of a normal life, modifications are made in both.

Consequently, the changing dynamics of diabetes provide conditions for an altered interaction between person and body which, in turn, forces the reconstruction of a defined biological reality. Actions related to body maintenance require radical modification on the part of the person with diabetes. These modifications, in turn, significantly affect major non-body relationships and activities.

As people progress through the phases described above, they continuously evaluate the changing situation using a natural analytic structure to assess the situation and make choices about self-management actions. This natural, analytic schema is presented in the following section.

Natural Analysis

Schatzman (1986) theorized that "human beings analyze their own data or experiences quite naturally, without

instruction in it." Analysis of these data is an attempt to bring to the awareness of the readers how people with diabetes engage in analytic work about their illness "as a way of making sense of their world" (Schatzman, 1986, p. 1).

Analysis of these data disclose an organizing perspective used by the subjects to help them decide what the constantly changing diabetes situation means to them personally. This "schema for personal meaning" is used by the subjects to help define the options they see available for self-management actions. It provides a structure for assessing and reassessing decisions about carrying out the originally prescribed diabetes treatment plan and decisions to modify it over time.

The Schema for Personal Meaning

The schema for personal meaning, developed by Leonard Schatzman at the University of California, San Francisco and refined in graduate seminars over a number of years, is depicted in Figure 4-2. The six dimensions represent components of a natural analytic process. It attempts to describe the central features of how a person processes what is personally important or problematic. The understanding a person has of her/his current situation is molded by past experience, and changes as time passes and new knowledge is gained. Based on these understandings, sensitivities and tolerances to diabetes symptoms and a "normal life" develop. If a person is not sensitive to a symptom or a problem, her/his tolerance for continuing in the same manner will be

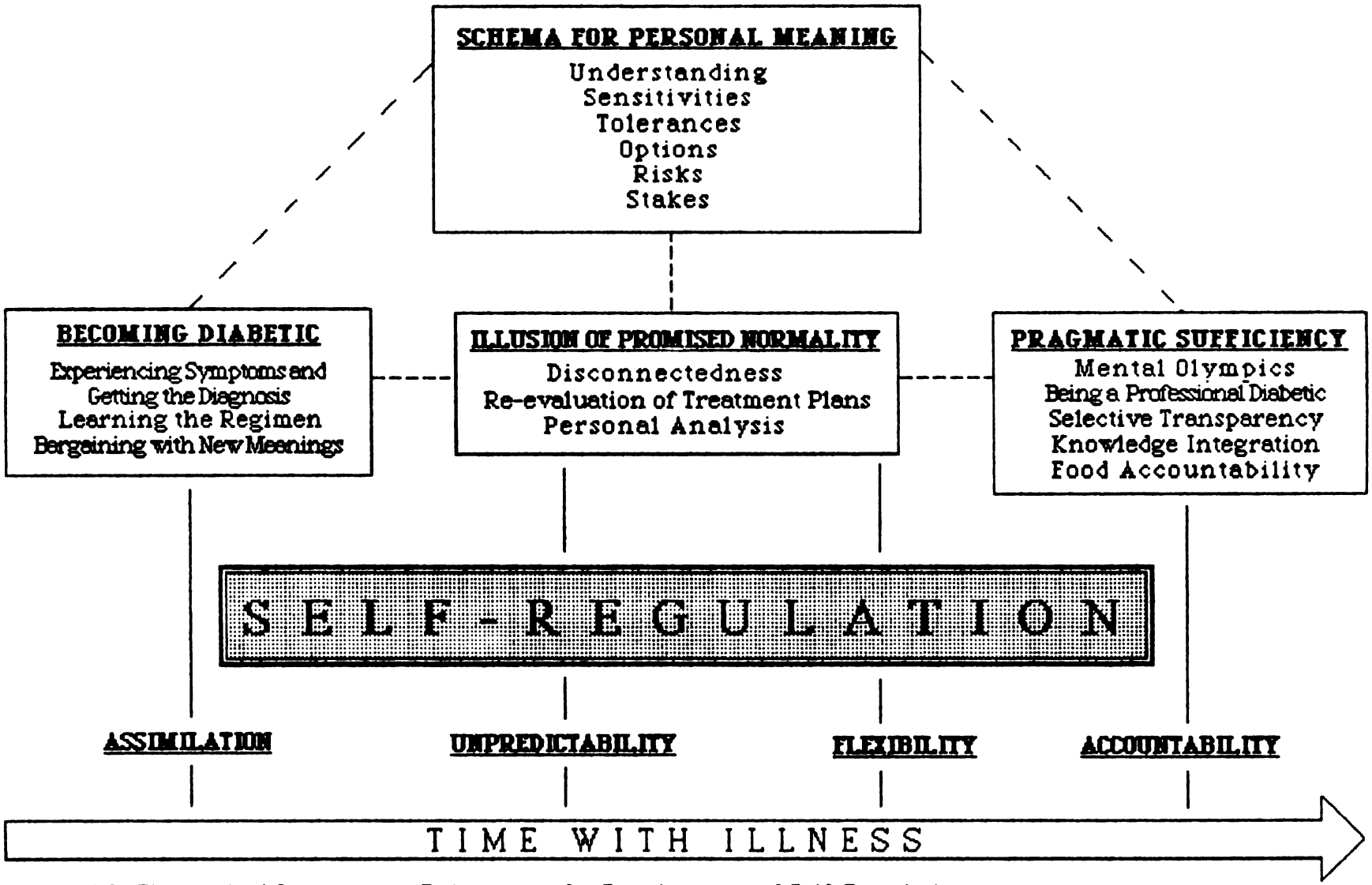
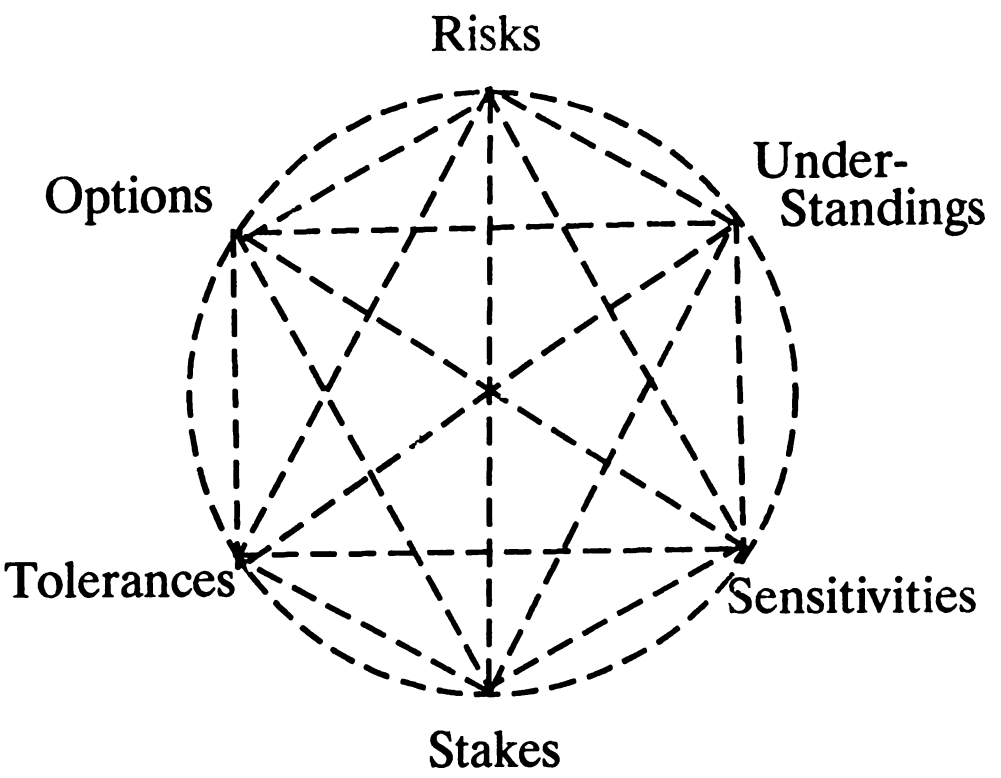


Figure 4.2. Theoretical Components Relevant to the Development of Self-Regulation

Figure 4-3

Schema for Personal Meaning



quite high. If, on the other hand, that same person exhibits great sensitivity to a problem, tolerance for maintaining present actions becomes quite low. The tolerance level will determine the degree of shifting a person is willing to engage in as she/he considers the options available. The degrees of sensitivity and tolerance will further determine the acceptability of alternative options. The *options* are described in terms of chances; *risk* means the amount and kind of danger one considers the various options to have while *stake* is the value placed on the options and actions, the value at risk in this situation.

An Example of Using the Schema in a Diabetes Related Issue. In this example, a person with diabetes ceases to accept co-workers' invitations to go out for pizza and beer after work as he did in the past. The individual realizes is that it is not worth it to go out with "the gang" because the food and drinks affect his glucose levels. In order to participate in these activities, he has to take extra insulin and check his glucose levels frequently to see if the insulin covers the carbohydrate intake. This involves carrying with him testing equipment, syringes, insulin and repeatedly getting up from the party to perform the self-care actions in private. In the past, when he has attempted to cover the special foods, he has spent the rest of the night and sometimes the next day, battling the elevations in blood glucose that these evenings produce. Not going out

with his friends makes him feel isolated and unsociable, but he is not willing to accept the inconvenience of increased diabetes management and lack of control.

At some point, he becomes aware of information in the lay literature describing subcutaneous insulin infusion pumps and wonders if wearing a pump would allow him more flexible insulin dosing and the ability to take insulin without having to carry a syringe. A new understanding about self-management develops in the context of a new option. This person, however, is not very sensitive to this information because he decides the pump would be too complex to use. Balancing the options of no social life with having to learn a whole new treatment regimen, he decides he can tolerate not going out with friends more easily than acquiring the skills necessary to use the pump.

Another person may receive the same information about pumps, but be highly sensitive to the message as a result of a great desire for more flexibility in eating and a frustration with the inability to engage in normal social interactions with his co-workers. He may also know someone who wears a pump and realize the advantages of intensifying his regimen. In this case, intolerance of the present situation is high enough to initiate more information gathering regarding pump options. Not wanting to be further restricted because of dietary inflexibility, he may decide the stakes of pump use are worth the technical training needed to operate it.

This example demonstrates the process of analysis used by a person attempting to resolve a problem. The components of the schema--understandings, sensitivities, tolerances, options, risks and stakes--provide a means of accounting for individual difference in actions taken in problem solving circumstances.

Summary

This chapter presented data describing the sample subjects, descriptive statistics, and correlations gathered in the research process. The conceptual structure of a model for self-regulation and the personal meaning schema was explained and an example was given. Further development of a self-regulation model will be discussed in Chapters 5 and 6.

CHAPTER 5

PROCESSES IN DEVELOPING SELF-REGULATION: BECOMING DIABETIC AND CONFRONTING THE ILLUSION OF PROMISED NORMALITY

The purpose of this chapter is to describe the analytic concepts discovered in the first two developmental phases of self-regulation outlined in Chapter 4, Becoming Diabetic and Confronting the Illusion of Promised Normality. The schema for personal meaning, also described in Chapter 4, will be utilized to explain how new understandings of the illness occur over time and how these understandings determine the kind and degree of activity an individual will engage in while attempting to control the illness.

Becoming Diabetic

In the process of developing self-regulating behavior, persons with diabetes invariably find themselves confronting the diagnosis and having to assume an identity as "diabetic." This is an experience universal to all people with diabetes although individuals differ in their response to the diagnosis and to this newly accquired identity as a person with diabetes. In this study, each individual's understanding of the symptoms, and of what these symptoms meant, was tempered by the person's past experience and knowledge level related to diabetes. There are three processes that emerged from the data to describe and explain

the properties, contexts, and conditions under which the first developmental phase of self-regulation develops: Experiencing Symptoms and Getting the Diagnosis, Learning the Regimen, and Bargaining with New Meanings.

Experiencing Symptoms and Getting the Diagnosis

Initially, subjects who were over the age of five at the time of diagnosis (n=25, 83%) described experiencing physiological changes that alerted them to some kind of health problem. Some, because of a family history, had experience with the symptoms. One subject stated, "I knew it was [diabetes] because my grandmother and my uncle both have it. . . . I knew what the symptoms were. . . . There's no really mistaking it with anything else (030).

Other people, who had no experience with the illness, recounted incidents such as,

> I had no clue. I did not know what diabetes was up to that point. I went on probably a week or two with a really acute thirst and urination. I started losing weight. Within about a week I lost about 10 pounds, so I knew something was wrong... I mean, [when they told me], I literally said, "What's that?" I knew it didn't sound good, and I knew it meant something that wasn't just going to go away. I was stunned (009).

In addition to weight loss, extreme thirst and copious urination, many subjects remember the lethargy and lack of energy they experienced before the diagnosis.

> It's a four hour drive from Seattle to Portland, and I remember I had to get out at every rest stop and sleep by the side of the road because I could barely stay awake. I was drinking cokes, you

> know, to use the caffeine to stay awake. Then I got to my friends' house in Portland, they showed me my room and I said, "I got to go to see a doctor tomorrow, I'm feeling terrible" (008).

Some subjects gained information from others who seemed to "know." One, traveling in Europe with her mother, had been increasingly thirsty. "It was such an urgent kind of thirst. It was like, if I don't get something to drink right now, I'm going to shrivel up! I told my mother and she said, 'Oh, you probably have diabetes'" (010).

This person eventually bought test tape to check her urine for sugar. When asked how she knew about this test, she stated: "Well, it's something that everybody always knows about...I had known there was something that you could dip or do something to, and you would know you had diabetes." The test indicated a high level of sugar in the urine. "I said, 'OK, that's what you got.' So, I took myself to the doctor, and I told her, 'I have diabetes'."

Two other subjects knew to check their suspicions with semi-quantitative testing and knew they had diabetes before receiving an official diagnosis. One subject, whose father and sister had diabetes, discovered that his sugar was four times the normal level:

> Well, my sister and my father had it, so they were very keen on symptoms when they first arose. I'm quite fortunate to have that, because I first lost about 10 pounds over a period of maybe a month, urinating quite a bit at night. My sister suggested I test my blood sugar [on her meter] and I was close to 400 (018).

Another man, who had experienced profound fatigue that he related to stress in his life, was working as an orderly in a hospital:

> So one day I decided to test my urine and it was the most fluorescent orange that it could ever have been, and I almost dropped dead! A nurse's aide who was a student nurse on the floor and knew me really well came up and said, "God, who's urine is that?" I said, "Karen, it's mine." She just goes, "Oh, would you stop kidding" (001).

One 33 year old subject (007) said that he was diagnosed while trying to sell plasma. His blood glucose tested at 800mg/dl [almost eight times normal] and he was referred immediately to a hospital.

Children under the age of five at the time of the diagnosis were less clear in their memories. One young women said she remembered her mother sitting at the admissions' desk at Children's Hospital and crying while she played on the climbing sculpture in the waiting room "and wonder[ed] why mom was crying" (012). Another man recalls:

> I was four, it was a couple of days before Thanksgiving and we were making stuffing in our kitchen. I don't know if I had been to the doctor. I don't remember how the doctors found out but I had all the classic symptoms, was really hungry, eating a ton, peeing like crazy, peeing my bed all night. So I guess we got a call and they said "bring him in." So I missed Thanksgiving. Packed up my pajamas and my teddy bear, and off I went (003).

Once the diagnosis is given, the person and his or her family is faced with the awesome task of learning to do the self-care activities necessary to control the physiological changes in the body. The diagnosis, however, also means

coming to terms emotionally with a "failed body" (Strauss et al., 1986). How a person defines her/himself as healthy or ill must now be reshaped in response to the diagnosis. What has been taken for granted before diagnosis, now must be reevaluated.

From an interactionist perspective, the work of reshaping one's personal definition of a chronic illness involves integrating personal history with the new illness. This leads to a reconstructed picture of the self. How a person comes to terms with these changes will determine the meaning given the illness and, in turn, will shape the efforts people make to manage and control their illness (Corbin & Strauss, 1987; Kaufman, 1988).

This reconstruction of self evolves as the illness continues and the person confronts the limitations and complications resulting from the disease. This reshaping process is tested, and re-evaluated as experience with the illness is gained. As Schatzman's (work in progress) schema for personal meaning suggests, these new understandings change a person's sensitivities to, and tolerances of, the illness as it affects not only the body but also valued aspects of a normal, social existence. Events related to illness understandings and problems present the individual with new options and evaluation of new risks and stakes. In this process, dimensions of importance to the subjects move into place in their personal explanatory matrix as new contexts and conditions, setting the stage for further

illness consequences. Actions taken will change over time as the consequences of past actions are reanalyzed and reshaped in light of new understandings.

Figuring out how to deal with the failed body means meeting the physiological challenges of controlling blood glucose levels with the treatment methods available. This work requires a tremendous amount of learning and skills development to manage multiple daily contingencies. The knowledge that a person receives affects her/his ability to make choices about self-management options, but as many of the subjects in the study demonstrated, knowledge does not always lead to compliance with the prescribed treatment regimen.

Learning the Regimen

Another important component in Becoming Diabetic is learning the details of the diabetic regimen. Learning the regimen is a multi-level experience and consists of learning not only a new vocabulary or illness language, but also how to inject insulin under the skin, how to begin self-monitoring body changes related to diabetes, and how to be on a life-long dietary regimen.

From the very beginning of the diagnosis, the subjects understood that the medical regimen must be undertaken with careful monitoring of the body in addition to the monitoring of relationships and activities. One subject recalls thinking initially, "This isn't going to go away...but you

would be able to live a very normal life. What causes problems is mismanagement and lack of control of the blood sugar" (004).

Despite the need to inject insulin everyday, several subjects remembered how much better they felt once they were diagnosed and began taking insulin:

> It was pretty shocking to me to suddenly find myself in this position of being basically dead and revived by the miracles of modern medicine. Basically, all the life I've got now is given to me by the fact that I happened to be born now, and not 100 years ago (008).

> When I started taking insulin I felt like I could run a marathon. I mean it was such a dramatic change because I had been so weak and tired (015).

Learning a New Vocabulary

People described the early experience as a time when the directions seemed clear. They learned quickly that there were things that needed to be done on a regular basis. One subject, who went to diabetes camp at age eight, recalled knowing by that age that he was "... taking two shots a day and that was something that was important and not to miss and definitely part of my routine" (003). He had to tell his counselor, as he was going to bed his first night at camp, that he needed an additional injection.

In the beginning, most people were not exposed to complex issues such as the pathophysiology of diabetes, detailed kinetics of insulin, or the explanation of glycosylated hemoglobins; knowledge of these topics evolved over time. However, the mechanics of injections, the

technology of monitoring, and the regimentation of diet were concepts that were an essential part of the regimen.

Mechanics of Injections

As mentioned above, certain skills must be acquired immediately after diagnosis in order to get the blood glucose under control. Injecting insulin is not an option but rather is necessary for life and must be done on a daily basis. Skills center around the mechanics of drawing up the insulin and learning to inject it under the skin. People without diabetes imagine the injections to be the most difficult part of having diabetes. The subjects in this study stated that the mechanics of injections did not pose a major problem. Even for the children, self-injection was performed by some as early as age six or seven in some cases. Questions regarding the taking of injections revealed such comments as:

> The shots have never bothered me. From the very beginning I had no problems with taking six shots a day. I mean, that doesn't bother me at all (004).
>
> The needles, the shots, are so easy now. It's nothing; any of that is really easy (011).
>
> The shots didn't bother me much; that was no big deal (015).

Technological and Informal Monitoring

Monitoring of blood and urine for glucose and ketones must also be taught soon after diagnosis. Monitoring has always been part of the regimen. In the past, urine monitoring was most common; more recently self monitoring of

blood glucose has replaced urine sugars. Nevertheless, urine ketones remain part of the regimen.

In addition to technological monitoring, informal body monitoring of the symptoms related to dropping or elevated blood sugars is extremely important. This type of body monitoring must be done continuously, and is performed almost unconsciously. Subjects mentioned this in statements such as:

> I can feel it when it gets into the 200s; I can feel it (020).
>
> I knew when I left here this morning I was probably around 70 [mg/dl]. I ate a piece of candy and went running over to the [meeting] (001).
>
> The technology started me off, so I would know what my body was telling me, then I guess I sort of dropped the technology and [was] just going with the body...occasionally I'll go to the technology for a specific reason. [When] I'm getting a few signals from my body...I'll check with technology (010).

Informal body monitoring occurs on a continuum. At one end are people who have little confidence in their own informal monitoring; at the other are those who have great confidence in their own ability to monitor. For those who trust this ability, the regimen monitoring stays in the background for varying lengths of time. They may begin technical monitoring when illness occurs. Others rely upon their informal monitoring because they cannot afford the cost of glucose strips: "I won't buy visuals [glucose strips that do not need a meter to be read], I'll wait until

I get the bucks together to get the special strips that the machine needs" (010).

The subjects who are most fearful of complications, who do not have confidence in their personal monitoring, or who are anxious that they will miss some aberrant fluctuation in blood glucose, tend to be heavy technological monitors. They may have confidence for brief periods of time when an unpredictable change throws them into a panic and they begin to doubt their informal monitoring skills. In such cases, the person becomes subservient to the technology. "You have to test, it's as simple as that...you can't be guessing, no way!" (029). In the middle of the continuum are subjects who have learned the technology and have incorporated it into their informal monitoring.

Regimentation of Diet

The diabetic diet is mentioned most often as the worst part of living with diabetes. The prescribed diet is without sweets and has carbohydrate, fat, and protein intake precisely calculated and distributed throughout the day to counter the peak activity of the insulin given. The word diet is not associated so much with the restriction of foods but with structure, regimentation, and lack of freedom. The diet remains a major confounding factor in trying to maintain a normal life. This is true not only because food plays such an important role in socialization but also because a heavily structured diet allows for little, if any, spontaneity in eating.

> I definitely focus around when I am eating, when I have to eat. I tend to eat dinner at a certain time and I eat lunch at a certain time. Everything I do is very much, you know, I am always conscious of that (018).

> I remember one of the first questions I asked was, because I loved milk, I drank these big milk cartons, "Does that mean I am not going to be able to drink milk?" They said, "Well, you can drink a little bit; you have to drink everything in limited amounts" (009).

> The hard part was the fact that I would have to decide that I was going to eat this for breakfast, this for lunch, and this for dinner and stick to that! (004).

The challenge to subjects is fitting the dietary routines into everyday activities. Subjects described the tension that exists between knowing what needs to be done, being willing to do it, and actually being able to carry out the treatment plan:

> I went up to Mt. Shasta for Christmas and we went snow skiing one day...My blood sugar was low the entire afternoon...I had to make sure I had enough snacks...enough raisins...[E]very time we would ride up on the chair lift I was trying to eat raisins, and I still couldn't get my blood sugar up...I felt terrible that whole afternoon. When I went up there I had to make sure I had...my snacks even though I was going to be with the family (009).

Integrating the treatment program into everyday life activities takes creativity and energy. Noncompliance with regimens usually occurs when, for example, it becomes too risky to perform an injection in public, to do finger punctures and blood testing, or when the timing of food intake does not coincide with work schedules or social and recreational activities.

Bargaining with New Meanings

A third factor associated with Becoming Diabetic relates to accepting the diagnosis of a chronic illness requiring permanent life-style-changes. While cognitive and psychomotor skill development is taking place, an emotional level of experience is also occurring. Subjects responded to the failed body phenomenon by testing to see if it was actually true. Had the diagnosis really changed what they considered normal life behaviors? Could they, despite the diagnosis, live life as they had before?

Again, recognition of new meanings comes with the need to change dietary patterns. Subject 001 stated that the hardest part of the diagnosis was "giving up the donuts. Oh, yeah, giving up the donuts!..My favorite was chocolate covered vanilla cream filled donuts." Subject 007 said that the first thing he did after diagnosis was to go to a donut shop: "I wasn't ready to accept it." This subject stated the most difficult problem for him was "taking it seriously...I was mystified by it" (007).

These actions appear wild and rebellious. In such cases, the personal meaning schema helps to clarify the subjects thought processes. Study participants such as these understood they had been diagnosed with an illness that was chronic, could not be cured, required daily injections of insulin, and needed dietary restrictions to be controlled. How tolerant or sensitive they were to this information depended on their cumulative knowledge about

diabetes. Subjects 001 and 007 doubted what they had been told and headed for the donut shop to test the diagnosis. Subjects 005 and 011, similarly, explained how as children they stopped to buy candy everyday after their paper routes. For these individuals, donuts and candy were still options, the associated risks seemed minimal, and the benefits gained from eating donuts and candy outweighed the fear that the body could no longer deal with what they had once taken for granted. In short, the need to feel normal outweighed the risk of complications. The action of eating "forbidden" foods made subjects feel normal because they were doing exactly what everyone else did.

The Honeymoon

Defining new meanings is complicated by the capricious nature of diabetes. One of the "dirty tricks" of diabetes is a phenomenon called *the honeymoon* that often occurs soon after diagnosis. With the initiation of diabetes treatment, the diminishing pancreatic output of insulin is temporarily reversed or stalled. The pancreas recovers enough to begin producing insulin again. At this point, blood sugars respond dramatically and injected insulin doses need to be decreased in response.

> It was not hard to control. I mean, the first couple of years. I know for a fact...I was on the thing of not having to take too many shots. So, I took my dinner shot mixed with Regular [short acting insulin] and the Lente [intermediate acting insulin], I would get by till one o'clock the next day, no problem at all (029).

If a person is not warned about this phenomenon, s/he may believe the diabetes is cured, insulin is no longer needed, and the diagnosis was a mistake. Unfortunately, this honeymoon phase is usually over within a year (Davidson, 1986).

Summary of Becoming Diabetic

In the phase of Becoming Diabetic, a person begins to "know" what the illness is. The regimen is taught and the person begins to monitor his/her status through technological and intuitive means. It becomes apparent that individuals must also learn to balance life activities with the regimen. As time passes, an awareness grows that the diabetes regimen is problematic and this leads to a sense of unpredictability. One questions how much ambiguity and unpredictability one can tolerate. The kind of monitoring and the degree of adjusting an individual engages in is determined by the level of tolerance s/he develops for these activities. The process of defining what diabetes means is constantly changing and evolving as time passes, and the regimen is analyzed and changed in terms of the new knowledge gained.

Confronting the Illusion of Promised Normality

The following processes emerged from the study data to describe and explain the properties, contexts and conditions under which the second developmental phase of self-

regulation, Confronting the Illusion of Promised Normality: Disconnectedness, Re-evaluating Treatment Plans, and Personal Analyzing.

The second component in the process of developing self-regulating behavior results from subject's experience with blood glucose levels that fluctuate between hyperglycemia and hypoglycemia. These frequent fluctuations occur despite strict adherence to the prescribed regimen and lead to the realization that treatment of diabetes will not result in a cure. In some cases, treatment may cause problems of its own. With time, subjects understand that theirs is not a normal situation and that they must develop ways to deal with the capriciousness of diabetes treatment. "The hardest part for me was that even if I did everything I was supposed to, I didn't get perfect control; so, what was the point?" (014).

The frustration caused by this unpredictability is expressed in statements such as: "I mean nobody is stable. Do you know any stable diabetics? I grew up thinking that this was just a labile time and I'll be stable one day. We should get rid of that romantic notion" (022) or "I hate it when the doctor says you can live a normal life. PLEASE, what does that mean, anyway? I think that's total bullshit" (025).

R. Anderson (1985) refers to this shift in perspective when he states that, "While many health-care practitioners see the treatment regimen as a solution, patients may see it

as another part of the problem of having diabetes...Many patients view the treatment of diabetes as more of a problem than having the disease" (p.32).

Disconnectedness

The dimension of disconnectedness is both a property helping to describe the developmental phase of Confronting the Illusion of Promised Normality and a condition under which self-regulating behavior develops. The confrontation between what is prescribed and what is actually experienced becomes a pivotal or transitional phase in a person's decision making processes regarding self-regulation. According to Chick and Meleis (1986), one of the defining characteristics of transitions is disconnectedness. Disconnectedness is associated with the disruption of ties from the past on which a person's security depends. Further, it is associated with loss of familiar reference points, incongruity between past expectations and present perceptions, and the discrepancy between needs and the means to satisfy these needs.

> When you loose the faith in the insulin to do exactly what you wanted it to do, is key. I used to believe that it was like this perfect balance; it was like if I did it perfectly, the insulin would never fail me; it will always absorb exactly as much as I wanted. Or, it would happen on this perfect curve the way that my first doctor used to describe it (025).
>
> It's enough to have to take insulin, and it's enough to have to worry about going blind, I WANT COOKIES" (024).

In this transitional phase of understanding diabetes, subjects began to contemplate or experiment with new regimen plans. The prescribed regimen left many unanswered questions about incorporating blood sugar control into the activities of daily living.

> It's impossible to manage your diabetes perfectly...you just can't live life like that. I did for about a year when I was first diagnosed diabetic...[Y]ou can't manage your diabetes perfectly because <u>life</u> isn't perfect. (027)

> 026: It always struck me that it would be great if all diabetics were sort of, very pragmatic, highly organized, lived very disciplined lives, and loved schedules. Unfortunately, I think God has a sense of humor, at least in my case. And he certainly married me to the wrong disease, I'm afraid.

> RLJ: Because your life is so varied, you mean?

> 026: It's not so much my life as it is my <u>soul</u>! The hardest thing in the world for me is to try to be very systematic and orderly in my existence... routines don't come easy.

<u>Problems with the Treatment</u>

Sadly, the perfect tool to control blood glucose levels has yet to be developed. As a result, subjects learn that, despite their best efforts, they must live with unpredictability. The following excerpts are intended to convey the trauma caused by blood glucose variability and the ways in which everyday experience is changed by these events.

<u>Hypoglycemia</u>. The most common problem affecting those with diabetes is hypoglycemia. This results from an imbalance between available glucose and insulin levels in the blood. Because the bodies of people with diabetes lack

the mechanism to turn off the insulin supply when blood glucose falls, insulin dependent people must carefully monitor everyday events:

> Now I have to be real careful because of the highs and lows of diabetes. The blood sugar goes higher a lot easier and when I exercise I have to be super careful that it doesn't go too low...It's an unbelievable balance act. (029)

One of the subjects who had exercised regularly before the diagnosis of diabetes and who vowed not to let diabetes change her life, describes the point she began to accept the implications of life with diabetes:

> I was coming down the slopes and I kept falling, I couldn't stand up; I kept falling and standing up, falling and standing up. The instructor came over and said, "Are you OK, should I get you a stretcher?" "I'm fine;" I never told her a thing. I didn't know I was in such bad shape, I never knew what was happening. She took my skies, I walked and fell almost every other step. By the time we got down to the bottom of the hill I was sprawled on the ground because I couldn't stand. My husband was standing [there] watching. He reacted with anger; he said,"you better have a damn good reason why you are now an hour and a half late." I just fell down, he got me into the lodge, bought me orange juice and a bagel. It took most of the afternoon to come around enough to get back to the hotel. When I came home I said [to myself], "Yes, you can live a life like everybody else, but you do have to make changes to your life; you really have to admit that you are different" (002).

Other subjects described feeling perfectly healthy when, out of the blue, they found themselves experiencing unusual blood glucose levels. It is this sudden loss of control that underscores the unpredictability of the illness and treatment regimen.

> I woke up and everything was normal, normal routine, normal schedule, normal everything. I tested myself, knew approximately where I was at and everything was fine. Evidently the insulin started reacting sooner or something was off. I was trying to get ready, I was trying to tie my tie, and I couldn't function. I could not get the tie tied, and that's like shifting a gear, you don't think about it, it's just automatic. I didn't even realize at that moment that I was so low. I did panic, and that impressed upon me that you cannot be in control, and it is unpredictable and as much as you do there are going to be those moments. (009)

Still another subject, who developed diabetes as a young person, observed the following:

> There were a couple [hypoglycemic reactions] in my parent's home that I had in high school and early college years where I was alone. I remember waking up on the floor of my bedroom and my night shirt is just soaked with sweat and I can't get up and walk. I can't [even] get [out] a cry for help. I remember being in my parent's hallway--they've got a bannister--and just pulling myself down the hallway by the rungs of the bannister, not being able to go down the stairs, so I slid down the stairs...I think that scared me enough (024).

Hyperglycemia. The imbalance between blood glucose and insulin levels can also result in hyperglycemia. In this case, there is a lack of insulin in the blood. As a result, glucose builds up in the blood stream and is unable to enter the cells of the body where it is needed to produce energy. In severe instances, when insulin, fluids, and nutritional intake are not carefully monitored, ketoacidosis may occur. If insulin levels are not increased, the body responds to its energy starved cells by releasing stored glucose from fat cells. In turn, excess sugar and by-products of fat breakdown accumulate in the blood stream. These products

include ketone bodies. Without adequate insulin, the ketones build up and can cause death if left untreated. Increased amounts of insulin are often needed to overcome the elevated glucose levels and ketones. The experience of hyperglycemia, like hypoglycemia, leads to a feeling of vulnerability, and disconnectedness to a healthy, normal past. Poor medical advice only aggravates the situation:

> I knew I had the flu and was throwing up; it was really bad. I called the health center doctor and he said to take half of my NPH and skip the Regular. Well, by that time I am sure I was probably actually already in ketoacidosis. I realized things were getting really bad, and he said to come into the center. One of my roommates was going to walk with me to the health center which was probably half a mile away. It was the middle of winter too, and when I got outside I was hyperventilating [Kussmaul's breathing, a symptom of ketoacidosis] by that time, and it was like "I just can't do this. You might as well let me die here or else you have to find a car because I cannot walk that far." She finally did find me a car and I was in ICU after that one (015).

Each episode, whether grave or relatively minor, has a cumulative effect on the psyche of the person with diabetes, "Because with diabetes and with the ups and downs, I'm constantly mentally monitoring...Where is [the blood glucose] now? Am I high, am I low? Most of the time I know, but there are times, still, that I don't (009).

Re-evaluating Treatment Plans

As the subjects confronted their illness, they found themselves exploring new treatment options by necessity. The data in this study confirmed that the lack of

predictability in diabetes control and the difficulty of organizing life around standard regimens leads people to re-evaluate the treatment plans.

> Once I went back to work, it took two weeks to find the right doses of insulin for me. The first three days I was passing out. I didn't tell my endocrinologist, even though my head nurse on the floor was coming close to freaking out because I was breaking out in sweats, I had to get scrubs because my white clothes got soaked (001).

These events led the subject to try a drastic adjustment in his treatment plan. He described the changing situation as follows:

> During this two weeks phase, where I was dropping my insulin in small amounts, one day, it was Saturday, I was off work, and I said: "I am not diabetic, my sugar is dropping, forget it, I am not diabetic." So I didn't take my insulin that Saturday, and everything was OK. Didn't take it Sunday, everything went along, but I felt a little cranky ...and then Monday morning, I had to be in DKA. Everything ached, my stomach was horrible, everything was the pits, so I took my insulin. About three hours after I took my insulin I felt better, I felt normal. That convinced me that I was diabetic, but I just needed to fix the amount [of insulin] to be better (001).

Another subject stated that her regimen of four shots a day was not part of a prescribed treatment plan but rather one she had developed in response to her own physical needs:

> A friend of mine at camp (diabetic camp for children where this subject was a counselor) was on it. So I changed basically because she started talking about it. [I] was having some problems--my morning sugars were high, or having unwanted reactions, having to eat at the wrong time like in the middle of the afternoon because my NPH was peaking, things like that. I was talking to her, and she really liked it...I switched over...up there at camp (022).

Personal Analysis

In the process of Confronting the Illusion of Promised Normality, the subjects analyzed their treatment options using an organizing perspective such as the Schema for Personal Meaning (see Figure 4-2). This personal analysis sets the stage for self-regulation to become the central consequence of self-management practices rather than professionally derived standards of metabolic control.

The constant, never ending need to be vigilant, the continuing intrusion of the treatment into daily activities, and input from sources other than health care providers all influence an individual's willingness to comply with prescribed regimens. New understandings often lead to new options that may contribute to a greater semblance of normalcy. As new options are investigated, the risks and stakes are analyzed and new actions undertaken based upon the analysis.

Invariably, the subjects described a point at which they no longer attempted to deny the illness but rather struggled to balance living an illness life and living a normal life. This is what happened in the camp experience noted by subject 022. Unhappy with the problems the current regimen was causing, she analyzed the situation based on new information, concluded the status quo was intolerable, and set out to affect a major change in her treatment regimen. The subject who described sliding down the stairs at her parents' house to get help for a low blood glucose,

similarly, found her situation intolerable and set out "to keep my blood sugar high;...have high sugar and then I wouldn't be hypoglycemic" (024).

Summary of Confronting the Illusion of Normality

In this developmental phase of self-regulating behavior, the subjects recounted diabetes treatment stories that described their growing disillusionment with the probability of living a normal existence. Quality of life issues were also discussed. One subject (005) acknowledged that adhering closely to the treatment regimen might give him a few additional years of life, but wondered at what cost at this point in his life. He was aware of the risks of long-term complications, but he was willing to accept the consequences in order to have fun while he is able. He concluded that he would adhere to a three injections per day regimen but would test his blood glucose only once every two to three days when he wants "to know what's going on" (005).

Another subject, when asked what she believed constituted a good quality of life, replied: "It means living as normally as I can with this disease. It means having a whole f------ apple for my lunch" (024)! She had been told by a dietitian that she could only have half an apple with her lunch, something no normal, non-diabetic person would ever do.

It is this conflict surrounding treatment issues that actually propels the subjects into the third phase of self-

regulation revealed in this study. Subjects in this phase actively self-regulate the prescribed treatment plan in order to balance the illness demands with their individual expectations for normalcy and performance in life activities.

Summary

This chapter has presented the first two phases in the development of self-regulation: receiving the diagnosis of diabetes and confronting the illusion of promised normality. As persons with diabetes progress through these stages, they must learn new ways of dealing consciously with activities that, in the past, were accomplished unconsciously. As they learn the regimen for treating diabetes, they are also reconstructing an image of who they are as a person--a person with an illness that forever alters one's social relationships and requires continuous self-management. The chapter also presented the idea that diabetes does not truly allow a person to live a normal life and that treatment itself can contribute to feelings of abnormality. In the chapter that follows, the last phase in the self-regulation model, i.e., pragmatic sufficiency, is examined and the concepts discovered in this investigation are summarized.

CHAPTER 6

PROCESSES IN DEVELOPING SELF-REGULATION: PRAGMATIC SUFFICIENCY - ATTAINING A DYNAMIC EQUILIBRIUM

The purpose of this chapter is to describe the analytic concepts derived from the study data to explain the last developmental phase related to self-regulation in diabetes treatment regimens. This phase is designated as Pragmatic Sufficiency and reflects the subject's efforts to integrate diabetes self-management into everyday life activities. The last section of this chapter will summarize the findings within the context of the explanatory matrix of dimensional analysis presented in Chapter 3.

Pragmatic Sufficiency

Having learned how to take care of the diabetes and having confronted the abnormalities that result from treatment, subjects in this study entered a third phase in the development of self-regulation. In this third phase, the major theme of living a normal life becomes dominant. The subjects accept the responsibility of changing their treatment regimens to fit the activities of daily living rather than fitting life into the treatment regimen.

> I just want to live...a normal life. You know, really do whatever everybody else does. And yet, when you do that it's such a frantic pace for everybody, there isn't enough time to spend on the diabetes. Where are your options? Does that mean that you wouldn't do what you want to do if you slowed down and take all that care (006)?

Definition of Pragmatic Sufficiency

Pragmatic, in this context, refers to a concern with everyday affairs and practices. The concern, in other words, is not with theory or speculation. Sufficient is defined as ample, enough, or as much as is needed. In the context of diabetes self-management, pragmatic sufficiency means doing enough to control symptoms, but in such a way that it fits into a person's everyday activities and does not interfere with the flow of work and relationship activities.

Pragmatic Sufficiency represents the point in time when the available options, risks, and stakes are evaluated and a plan of action is constructed. Pragmatic Sufficiency describes the process of choosing between glucose control, compliance with the prescribed plan, and what one needs or wants to do on a daily basis. Self-regulation of the regimen is seen as a means of having control over life options; Pragmatic Sufficiency provides the mechanism for gaining this control. In the developmental phase of Pragmatic Sufficiency, the subjects openly confronted the reality of living with diabetes and spoke honestly about their decisions on how to care for their diabetes: "I'm being real honest here, I assume that's what you want--honesty rather than to try to tell you what [I'm] supposed to do" (006).

This conceptualization is in contrast to what patients understand professional standards of self-care to be. These data indicate that subjects felt that the medical model of compliance ignores many of the day-to-day dilemmas confronting the diabetic person. Analysis reveals that compliance is conceptualized by the subjects in terms of a continuum. People choose a degree of compliance--from very little to absolute with no variance from the plan. Most people will choose what pragmatically fits into the rest of their activities. Subjects expressed frustration with what they considered unrealistic expectations of care providers for completing assigned self-care activities. Pragmatic Sufficiency is defined by a subject as a "place where you can live; [it recognizes] there <u>are</u> other parts of your personality...When you can, you do [what you are supposed to do]," and "when you can't, you don't. I just can't be a full-time diabetic." (014) This frustration with what subjects define as unrealistic expectations is also expressed by the following subject:

> Doctors think their patients do what they tell them, but they don't. They do for some period of time and then they realize what doctors tell patients is not realistic. I spent a year before I figured out that I couldn't do what the doctors and the dietitians were telling me to do. That didn't make sense; that didn't help me any, it helped them. I mean, it used to frustrate me tremendously, they would feel great and I was miserable (027).

The concept of Pragmatic Sufficiency and the dimensions listed earlier in Figure 4-1 such as normalcy, performance,

feeling good enough, and balancing/integrating emanate from *in vivo* concepts expressed by the subjects as they describe their lives with diabetes. These *in vivo* concepts illustrate what Pragmatic Sufficiency means and describe the conditions that result in the self-regulated adjustments that inevitably occur and modify prescribed regimens.

Mental Olympics

The term mental olympics was used by a subject who recently chose to start using an insulin pump. This term helps explain how pragmatic sufficiency relates to self-regulation in diabetes treatment regimens. The subject who coined the term observed that his decision to use an insulin pump rather than needle and syringe makes air travel, an important part of his work, much more manageable. The pump resembles a beeper and releases a minuscule amount of insulin into the body every hour throughout the day, allowing a person to put off eating at prescribed times while keeping the blood glucose levels from rising precipitously. With the pump, "I don't have to play the mental olympics with the food cart in a plane." (027) His frustration with air travel, prior to the decision to utilize the pump, is evident in the following passage:

> [I would] try to decide where I am with respect to the bathroom and the food cart; whether it makes more sense to give yourself insulin before they pull out the food cart because you are going to get your meal early, or give yourself insulin after you eat your food because it's going to take them so long to serve you...You're sort of thinking, there they are with the food cart, they are behind me. Now, are they going to start at

> the back of the plane or start at the front of the plane. OK, they are going to probably start at the front of the plane. Now, are there a lot of people on the plane, or are there a few people on the plane? Then it depends on what kind of plane you are on; if the bathrooms are behind you, then you're OK, because you can go back. But if the bathrooms are at the front of the plane, then you have to give yourself insulin after they've served you because you can't get around the food cart and you can't give yourself insulin there because if it is a full plane, it takes them almost an hour or so to get to you. By the time they get you your food, you're desperate. So what you end up having to do, is to give yourself insulin as you get your food. [This] is extremely annoying because,... they are so fast picking up the plates they might think that you were done while you're trying to go give yourself a shot (027).

According to the traditional definition of compliance, a person who does not take an insulin injection a half an hour before eating a meal is noncompliant. When flying, this is often difficult to achieve. Frequently, the individual finds himself in a situation of taking an insulin injection too early, leading to hypoglycemia, or waiting until after the meal is served, leading to post-prandial hyperglycemia. In either case, he is noncompliant with the medication regimen and is forced to make a judgement that depends on the situation, not the prescription.

This type of situation occurs much more frequently than is acknowledged by health care professionals. Diabetics regularly attend meetings that run too long and interfere with a meal, accept invitations from a boss who wants to go to lunch early to beat the crowd, are pressured to appear at cocktail parties, or find themselves sharing birthday cake

with colleagues. These situations require survival skills that are usually not covered in educational classes. As one person stated, "Pragmatism is really the point here. You have to kind of keep your wits about you to keep feeling good...you have to keep all these different factors together." (025)

Being a Professional Diabetic

Pragmatic Sufficiency forms an integral part of how a person identifies her/himself as other than chronically ill. It further influences the actions one takes to maintain these non-disease related identities. If one needs to work full-time, self-regulation choices help to make this feasible. One subject (014) described the difficulty of being, what she termed, "a professional diabetic" in the face of "all this other stuff going on that I'm having to deal with." She explained how changing conditions in real life influence treatment compliance.

> Very few people are in a position to be professional diabetics...I was a professional diabetic when I was pregnant. I was very aware of the disease all the time. When you have it on your mind all the time, it just doesn't allow you to get a lot of other stuff done. It was number one all the time. Now, [I] can put it third, fourth, or fifth on the list. You can do it, but it's not the thing that is shaping everything else you do (014).

These concepts illustrate how life activities can place limits on a person's ability to comply completely with a treatment regimen and demonstrate the context in which self-regulating decisions become necessary to approximate

normalcy. Subjects complained of inadequate preparation and support from health care professionals in managing these real life situations that preclude compliance. "Nobody talks about what you do when you can't do all these things you're supposed to do." (014)

It appears that, in real life, compliance is influenced strongly by a host of other demands being made on an individual's time and energy. Diabetes care, as important as it may be, cannot remain the focus of attention. While events such as pregnancy or the onset of a complication may focus attention on the diabetes, other life events usurp this focus of attention and, for that period of time, become of primary importance.

Other Dimensions of Importance Emerging from the Data

Several other dimensions must be mentioned in the discussion of Pragmatic Sufficiency. Data analysis in this study suggests that concepts of selective transparency, knowledge integration, and integrating forbidden foods into life play a significant role in self-regulation of treatment regimens.

Selective Transparency

One finds that, with diabetes, some individuals are more comfortable engaging in self-care activities in front of strangers and some less so. This tolerance of public exposure will affect the level of care a person is willing to provide for themselves in normal social interactions.

"Selective Transparency" describes the range of tolerance subjects have to be seen publicly monitoring glucose levels, injecting insulin, or displaying symptoms of the illness as, for example, in hypoglycemia. Fear of stigmatization plays a major role in selective transparency.

In describing "Selective Transparency," one subject (028) stated, "The key thing to me, is to make the diabetes transparent to people. Ninety-nine percent of the people that I deal with have no idea that I have diabetes, [it] just doesn't come up, and if they were to find out they would be in shock. That's the way I want to manage it." Transparency is selective in that not everyone feels the need to hide her/his diabetes or not to the same extent. When asked how diabetes self-care fit into his social relationships, one subject stated:

> It's never been an issue, really. Ninety percent of our social group would have an idea of what to do "if I went down", and that is comforting. Every time I whip out my [blood glucose] meter, people's ears perk up and ask "what's that?" That's the first thing to talk about: "this is what I do eight times a day, and this is why I do it." If they want to know more, I go into it. (003)

Subject (028) stated that he had not mentioned his diabetes to his co-workers:

> In the back of my mind, I do sometimes think I could tell them, but I think there are times where you do worry about them looking at you in a little different way. [They] might think, 'be careful about the types of responsibilities you give him.' (028)

As a result of this decision, he performs his testing and injections discretely. "I've got a nice office area. There's a lot of privacy so it's really easy to do testing, and [I can] give myself a shot uninterrupted." (028)

Selective Transparency is a very personal determination and is deeply rooted in the individual's temperament and character. In general, the greater need for transparency, the greater the inclination to delay diabetes self-care until the appropriate degree of privacy is attained.

Knowledge Integration

Knowledge Integration is an important component of Pragmatic Sufficiency because the integration of past experience and cumulative knowledge does not occur until a person has lived a sufficient time with the illness and has confronted the difficulties in treating the illness. Knowledge Integration also relates to the feeling expressed by many of the subjects that, in the final analysis, they alone are responsible for their diabetes care and must make many of the decisions by themselves, without professional help. It further relates to the feeling, expressed by some, that they have become more knowledgeable than some of the practitioners caring for them.

An example of Knowledge Integration is provided by a subject who was hospitalized for renal surgery that left her with decreased kidney function in one kidney. She recalls finding a book in the education classroom at the hospital that, she says, "kind of opened my eyes to the fact that

there was more than just one way to treat diabetes and that what I needed was a little something different." (023) After researching further, she came to the conclusion "that [I] had to take in all this information and then weigh it and decide what applies to me. What can I use, what doesn't apply to me at all...and then take some and leave some of it" (023). Eventually, she had the courage to approach her physician to discuss her regimen:

> First of all I asked him: "I would like to change my insulin regimen from Lente to NPH, and secondly, I would like to use Regular as well." What I had read in the Bernstein book made good sense to me and it just seemed more manageable taking it that way then the one injection. Well, he said yes to everything..."Ok, fine, whatever, sure," and so [he] wrote prescriptions and whatever. I kind of thought: "Gee, I don't think he knows anything." I wasn't really sure what to think of his attitude. But [I thought]: "it's OK,... I'll be careful and I'll handle it." So, that was how I got on what eventually came to be multiple injections. (023)

Yet another example involves this subject's decision to go on an external insulin pump. She had attended several training sessions and was to go on the pump with insulin a week after the last meeting with the diabetes nurse educator. One evening at her home in the countryside, she realized she had left her intermediate acting insulin miles away in the nearest town and would be unable to take her bedtime injection. After a brief hesitation, she hooked herself up to the pump, which only uses Regular insulin, the kind she had in the house. Most remarkable about this story is the fact that physicians often hospitalize patients for

this procedure feeling that they need medical guidance to accomplish this task. This subject's level of knowledge integration and her need for Pragmatic Sufficiency guided her self-regulation decision making.

Her decisions about self-regulation also reflect the natural, analytic processes of the personal meaning schema. In both incidents, events in the disease history prompted the individual to learn about a new treatment regimen. The integration of this new information is enhanced as the person becomes increasingly intolerant of the vagaries of the current treatment and begins to consider new options. These attempts at making sense of the situation are at the center of the choices finally made. There are two steps in this process: 1) new understandings occur on a cognitive, intellectual level, and 2) the new understandings are subjected to a cost-benefit analysis. A person considers the risks in using this new information and the analysis is eventually integrated into some self-regulating action.

The subjects in this study explain that health care providers typically assist with the first of these steps but are less skillful in helping people accomplish the second. Rather than discuss the issues of concern to the client, standard answers are provided. In reality, the self-regulation actions engaged in by people with diabetes may be different than those prescribed by the professional. In one case, an objective standard is prescribed, in the other is an effort to identify a fit between the cognitive

understanding and "all the other stuff going on that I'm having to deal with." (014) It is this "other stuff" that goes into the equation and leads to the balance achieved.

Food Accountability

The perpetual diet of people with diabetes constitutes still another factor that greatly influences self-regulation decisions and actions. Every one of the interviews conducted contained references to the struggle with the diabetic diet.

For a person with diabetes, the relationship to food is a complex one. Food is both a therapy used to control blood glucose levels and a danger that leads to hypoglycemia and/or hyperglycemia. One subject expressed it this way:

> "Normal people, if they want to think about their food, fine. If you want to be responsible as a diabetic, that's not part of the choice. . . . It's more like you've got to, or at least you've got to pay the piper at some point." (025)

The nutritional needs of the person with diabetes require near constant surveillance. This includes the decisions that must made at bedtime regarding the need to eat or not to eat in order to avoid problems during sleep. Overnight blood glucose control is problematic due to the inadequacy of the insulins available. Subjects complained about severe low blood sugars or elevated fasting sugars during the night resulting from adjustments in diet and medication. People with diabetes are required daily to spend a great deal of energy and thought monitoring their situations and taking action by eating or not eating in

order that glucose levels respond to insulin dosing. One subject stated: "I mean, only people who have eating disorders...think as much about food as we do." (025)

In addition to needing to balance food intake and medication, people with diabetes must always consider the types and amounts of food ingested. As the subject above stated, a non-diabetic person can indulge in "pleasure" foods if they choose without considering such issues as glucose toxicity. The Exchange Lists for Meal Planning contains a list of foods "for occasional use." According to this guide,

> Moderate amounts of some foods can be used in your meal plan, in spite of their sugar and fat content as long as you can maintain blood-glucose control...Because they are concentrated sources of carbohydrate, you will note that the portion sizes are very small. (ADA, 1986, p. 24)

According to this dietary guide, a piece of cake with no icing equals two starch (30 grams of carbohydrate) and two fat exchanges (90 calories). Cookies, "two small (one and three-quarters inches across)" are counted as one starch and one fat exchange. Snack chips are listed as one starch and two fat exchanges for each one ounce portion. One-half cup of ice cream equals one starch and two fat exchanges. These foods, according to the recommendations, may be substituted for the assigned exchanges in the prescribed meal plan, not added to the daily allotment.

In an effort to feel like a "normal" person, self-regulating actions integrating these types of foods into the diet are undertaken after careful analysis. "I have to take in all these factors and find the way to balance them...all I can do is the best I can do, and that includes allowing myself to have the forbidden foods." (025) This subject goes on to describe her internal struggle of desiring "normal" foods and yet fearing the consequences:

> I want to be able to have indulgences with food in the same way that other people do, not everyday, of course. But, you know, I don't want to feel like I am going to be creating the dangling retina because I've had this [cookie or some ice cream]. (025)

Other life problems may also influence one's ability to adhere to a strict diet. Three of the women in the study reported cases of emotional and sexual abuse as children that led to eating disorders and weight problems. As one recalled,

> I just couldn't stop eating...It's more on issues, not about food. [For example,] alcoholism is not about food, but what's underneath it. It's a need that's got to do with your life and [you need to] start taking a look at what's going on with you. (024)

Another, who had been sexually abused as a child, stated:

> I was always a fat kid...I wonder had I not gotten diabetes, would I have as many problems with food as I did. I think it brought it out even more with all the emphasis on food, but I think there were some basic problems already. (015)

Still another women said that, even as a child, she knew what foods were right and wrong, but "always had a low

self image, so it didn't matter to me that I was hurting myself by eating wrong foods." (006)

These women shared a general pessimism about their diabetes. They understood for many years that they were predestined to have the complications of diabetes and saw no need to try to control their eating disorders. "What I knew was that I couldn't do what I was supposed to do...I wasn't capable of doing it." (024)

Events in each women's life began to change their understanding about the disease's consequences and eventually led them to seek psychological counseling and/or support/self-help groups. Unable to tolerate their feelings about themselves and their illness, they sought information to change their regimens as well as their outlook. After undergoing therapy, one women said: "I could say, I care enough about myself not to kill myself...I finally got the diet, or started working towards getting my diet, under control." (015)

In light of these stories, the conceptualization of compliance as either following or not following prescribed treatment regimens seems over simplified and insulting to those attempting to care for their disease under difficult life circumstances. During this investigation, people were asked what they did to control their diabetes. A variety of self-regulating activities were identified in these conversations and, as can be seen in the following section,

exemplify the types of actions designated in this study as self-regulation.

Integrating Self-Regulation

The following are examples of self-regulating actions taken by the subjects as they evolved into the Pragmatic Sufficiency phase. The responses reveal an integration of the components discussed in the material above and illuminate the subject's personal conceptualization of the meaning of diabetes control.

A young woman with a 13 year history of diabetes responded in the following way when asked whether the issue of control, i.e., keeping her diabetes in control, changed over the years:

> It's changed in terms of what's available to control it. What blood testing has done is given me attainable control...I don't think I'll ever be in perfect control. I don't think that's possible. (Pause). Control, if I'm considering myself in control, it means my sugars are running fairly stable...The way I look at it, 90% of them should be under 200 mg/dl. And if those over 250 or 300 are only 10% of the time, I don't worry about it. . . . This is all on my own (see Appendix A for ADA guidelines for diabetes control). I've come up with my own sense. I realize I cannot compare myself to anyone else--that I have to sort of set up standards for myself. (022)

Another subject described how she adjusts her insulin to accommodate both diabetes control and her weight problems:

> What I'll do is, if I want to feel OK, then I'll increase insulin if I know that my blood sugar is high. If I can just handle not feeling that great, then I'll just do it at a lower level, because I know that the more insulin I give myself, the more weight I gain. So, it's like a Catch 22 situation. (006)

In responding to how many injections he was taking a day, one subject described his efforts at self-regulating his insulin dosage. He explained that the dosages he was prescribed gave him too much freedom and that he found himself constantly eating and "shooting up," but not achieving good glucose control. He was taking a mixture of fast-acting (Regular) and intermediate acting (NPH) insulin in the morning, and "then [I] check my blood sugar in the afternoon before dinner and so, maybe, a shot then. And then a shot of a small amount of NPH before I go to bed." (007) He goes on to say:

> I had trouble with the recommended dosages that came out of the teaching center, you know. It was like in the morning taking even amounts of Regular and NPH. I seem to have better luck taking like one fourth of Regular and the rest NPH. (007)
>
> RLJ: How do you decide, if you are not glucose monitoring, what you are going to take?
>
> 007: Just feeling; like just guessing; and taking five units of insulin to cover a meal, you know, the carbohydrates and stuff like that.
>
> RLJ: You mean you might take a little less or a little more?
>
> 007: Uh huh. It's like committing a major sin. It's like the priest giving out three Hail Mary's; it depends on what the sin is.

Another young man, who said he had not seen a physician for at least nine months, described his insulin regimen in the following way:

> I'm still taking four shots a day, which includes a shot at lunch but that varies now when I'm working; sometimes I would not take a shot at lunch. In the morning, I take anywhere from five to seven Regular, this is when I'm working, usually, and ten units NPH. At lunch anywhere from 2-6 units Regular; dinner, I'll take 12 units Regular and bedtime, I'll take 12 units NPH...This is definitely something that I have sort of developed on my own." (018)

A subject who chose to switch to an insulin pump in order to improve his blood glucose control and increase flexibility in eating stated:

> If it's three o'clock in the afternoon and I want a bowl of yogurt, I can go have some, could be frozen yogurt. I can have a frozen yogurt as long as I give myself some insulin for it." (027)

The following subject described her dilemma with wanting to eat junk food "like, for instance, my housemate brings home some ice-cream." (025) When this happens, she increases the number of injections per day to cover the extra food:

> If I find that I have really screwed up, [or] like I've got like a binge kind of feeling coming on, then I try to bring it back into reality by saying, "OK, I think I am going to give myself another shot now"...Food always equals shot...I would say that's probably the credo that I just keep in mind. (025)

The following excerpts demonstrate the full range self-regulating actions can take:

> So what I do, and this is a habit now, even though I don't get the best night's sleep, it's for my peace of mind...About three o'clock in the morning, I get up and test my blood. Sometimes it might be real low, other times it might be high. If it's high, I give myself a little supplemental [insulin]; if it's low, I make sure I eat something. (029)

> You see, I was also, the last month or so, I've been substituting. Like instead of eating a sandwich and an apple for lunch, I'll have a candy bar. That's two carbohydrates and three fats, or something like that. (011)

> Maybe it [the dose of Regular insulin] would go up from five to six...Fish and pasta is a five, but a potato and chicken is a six. (010)

All of these examples demonstrate the dynamic nature of the decisions that these people make about their regimens. Situations are analyzed based on experience with past events that have resulted in high or low blood glucose levels, and personal decisions about the regimen are made. Each situation is set in a real life context where the balance between living a good diabetes life and a normal life are considered. Variation in the self-regulating choices from one subject to the next is explained by the fact that each person individually asks what the situation is, what conditions currently prevail, what actions are possible, and what the consequences will be. The result of this analysis is the pragmatic sufficiency described by the subjects.

Summary of Pragmatic Sufficiency

Pragmatic Sufficiency, in short, describes the situation in which the person with diabetes achieves a

balance between the need to control the blood glucose levels and the need to participate in certain life activities. Decisions about the relative importance of the diabetes treatment regimen vs. participation in everyday social interactions are made and self-regulating actions are taken in response to these decisions.

Theoretical Conceptualization of Components Relevant to Self-Regulation

The grounded theory, as revealed in this study, serves to explains the development of self-regulation in diabetes treatment regimens among insulin dependent subjects. This conceptualization contrasts previous models of compliance with a perspective on diabetes self-management arising from the viewpoint of people experiencing the illness. The following discussion links the descriptions provided above to a theoretical conceptualization based on the analyzed data.

A basic assumption of this research is that human beings continuously conduct analysis of problems in order to alleviate those problems. This research led the subjects through an analysis of their own self-management decisions and resulted in a systematically constructed theoretical conceptualization explaining the process of self-regulation.

The analysis of the data indicates that *understanding* what diabetes means to a person and *developing* self-regulating behavior towards the treatment are not part of a

linear relationship between personality characteristics and isolated events. Instead, the process of choosing or not choosing to follow medical advice and manipulating that advice to meet individual needs is the end result of a complex analytic process leading to a privately negotiated set of actions. Self-regulation represents an interaction between dynamic constructions of a person's understanding of diabetes, how these understandings affect a person's perception of her/his place in the social world, and how valued social activities affect health practices.

Concepts Abstracted from Theoretical Analysis

Three temporal phases in the development of self-regulation emerged in the analysis: Becoming Diabetic, Confronting the Illusion of Normality, and Pragmatic Sufficiency. In addition, the initial dimensions of importance in the development of self-regulation, clustered and labeled in a more abstract manner, were: 1) assimilation, 2) unpredictability, 3) flexibility, and 4) accountability.

Passage through the phases of development of self-regulation is interwoven with the dimensions of assimilation, unpredictability, flexibility, and accountability to form a complex pattern leading to self-regulation. This pattern is further influenced by the natural analysis that takes place as problematic situations arise and solutions are sought (refer to Figure 4-2).

As the evolution of self-regulation is occurring over time, the subjects are continuously analyzing the present context and making decisions based on their evaluation. The subject's tolerance of the situation is analyzed and new options are considered. This analysis then leads to a sorting and prioritizing of the considerations under analysis, organizing decisions about actions and conceptualizing the consequences. Wide variations in self-management practices seen in people with diabetes can be understood if the process of natural analysis is followed.

The following discussion synthesizes the temporal phases of development and the definitions of the reformulated dimensions. The findings are then discussed using the explanatory matrix presented in Chapter 3.

Assimilation

Assimilation is defined as the absorption and incorporation of diabetes knowledge and skills into daily self-management efforts. The data indicate that self-regulation develops over time and is dependent on the accumulation of knowledge regarding the illness and on everyday experience integrating the regimen into daily activities. The degree of knowledge and skill assimilation becomes a context for the development of self-regulating behaviors. The first phase of development commences when the person is identified as diabetic and receives the diagnosis. In this phase, Becoming Diabetic, the person begins to learn the diabetes regimen and begins to

understand what it means to live with a chronic illness that requires continuing self-management strategies.

The learning that takes place at this time involves a series of actions, such as monitoring blood glucose levels and injecting insulin, that must be incorporated into a daily routine. The integration of this knowledge is influenced by a person's prior experience with diabetes and is continuously influenced by formal sources of medical information and by informal messages from the media and advice from family and friends. The individual's financial status, ability to attain blood glucose control, and the presence or fear of diabetic complications also influence the assimilation of diabetes treatment regimens into life activities.

Unpredictability

A transition occurs when the subjects realize that the treatment, itself, leads to untoward events that contribute to a feeling of losing control over their bodies. The illusion of being able to obtain perfectly controlled blood glucose levels is shattered as the illness and treatment experience constant fluctuations. The subjects in this study recounted experiencing severe hypo- or hyperglycemia that frightened them and led them to reconsider the value of their current regimens. In this phase of Confronting the Illusion of Promised Normality, it became clear that treatment outcomes fluctuated as a result of changes in everyday activities. The regimen needed flexibility to meet

changing circumstances or the subject would have to give up valued activities in order to continue to practice the regimen as prescribed.

Flexibility and Accountability

In the third phase of Pragmatic Sufficiency, the subjects decide what they are willing to do to balance and integrate their self-management operations and their chosen social interests. Flexibility is defined as a willingness to change the regimen when needed in order to fit diabetes care into social activities. This could be accomplished by taking more injections, taking fewer injections, increasing or decreasing the number and kinds of testing done, or modifying the diet.

Accountability is evident in how subjects choose or decide upon the course of action as well as in how they accept responsibility for the consequences of the actions: "I'm willing to do this; I'm not willing to do that; and I'll deal with the consequences of that action by self-regulating my regimen in the following way..."

One subject succinctly describes this evolution when he states: "The fact of the matter is, from a purely statistical point, I stand a better chance of getting iced on the freeway by some drunk as developing diabetic neuropathy or retinopathy. So, what am I worrying about, realistically?" (027) This point is usually reached when subjects feel they are no longer getting much help from professional care providers in solving the problems of

unpredictability and, therefore, choose to self-regulate the management based on personal analysis of the situation.

Placement of Theoretical Concepts into the Explanatory Matrix of Dimensional Analysis

Schatzman's (1986) widely applicable structure for processing natural analysis suggests that all human beings place the products of their analysis into an explanatory matrix in order to make sense of the problem under consideration and to tell the story that explains their analysis. According to his dimensional analysis matrix (Schatzman, 1986, 1988, 1991), the individual takes the attributes being considered and decides in what context and under what conditions these considerations apply, what actions will occur as a result, and what consequences are envisioned.

The researcher, using grounded theory methods, also analyzes the data and organizes it within an explanatory matrix. The dimensions abstracted from the experience of the subjects are placed in the explanatory matrix in order to give structure to the scientific analysis. Placing the products of analysis into the framework provides a means of visualizing the relationships between the identified variables and the phenomenon under consideration (see Figure 6-1).

Figure 6-1

Self-Regulation in the Explanatory Matrix

PERSPECTIVE: LIVING A NORMAL LIFE

DIMENSIONS	CONTEXT	CONDITIONS	ACTION	CONSEQUENCE
Becoming Diabetic	Assimilation	Experiencing Symptoms	Self-Managing Behaviors	Self-Regulation of Diabetes Treatment Regimen
		Learning the Regimen		
		New Meaning		
Confronting Illusion of Promised Normality	Unpredictability	Disconnectedness		
		Treatment Evaluation		
	Flexibility	Mental Olympics		
Pragmatic Sufficiency		Professional Diabetic		
	Accountability	Selective Transparency		
		Knowledge Integration		
		Food Accountability		

Placement dependent on outcome of natural analysis using Personal Meaning Schema

Choosing a Perspective

As noted in Chapter 3, once the dimensions found in the data are designated, a perspective for the analysis is chosen from the dimensions. The perspective is a dimension that explains most of the variance in the phenomenon under study and organizes the placement of dimensions in the explanatory matrix.

The single most significant finding of this study was that living a "normal life" was a central consideration in the health actions of the sample studied. This dimension became the perspective for evaluating the development of self-regulating behavior and explaining the subjects self-management choices.

Integration into the Analytic Framework

The products of the analysis are now placed into the explanatory matrix in order to demonstrate their relationships to each other (Figure 6-1). Using the perspective of living a normal life, the major dimensions in the illness chronology are designated as becoming diabetic, confronting the illusion of promised normality, and pragmatic sufficiency. The context in which these dimensions exist are designated as assimilation, unpredictability, flexibility, and accountability. Under conditions such as learning the regimen, feeling disconnected, or being selectively transparent, etc., self-management actions are carried out in a wide range of

practices. At the beginning of the diagnosis, self-management practices are carried out in a ritualistic manner and generally comply with the medically prescribed treatment plan. As the context and conditions change, self-management behaviors show wider variance from the prescription. The consequence of these events and relationships is what constitutes self-regulation in diabetes treatment regimens by people with Type I diabetes. It should be noted that self-regulation (consequences) is a fluid process and does not occur in a linear fashion. Through continuous natural analysis, actions and consequences can become the context for further actions and interactions.

Placement of the variables in the matrix helps explain variance in the actions taken by people with diabetes. The conceptualization of self-regulation in diabetes behaviors using the explanatory matrix provides a denser, more complex analysis of so called "compliance" behaviors. Further, the method presented in this analysis accounts for and integrates the interactions among biological, psychological and social concepts in the illness process and management of the illness.

Summary of Findings Chapters

Chapters 4, 5 and 6 explored the concepts abstracted from the research data. Chapter 4 indicated that people with diabetes accurately estimate the relationship between the effort expended to control blood glucose levels and the

level of control as measured by the glycosylated hemoglobin. Chapter 4 also included an introduction to the components of importance in the development of self-regulation. Chapters 5 and 6 demonstrated the phases in developing self-regulating behaviors regarding the diabetes management regimen. Chapter 6 discussed and summarized the findings using the explanatory matrix of dimensional analysis to demonstrate the relationships among the dimensions identified in the research. Chapter 7 will summarize the conclusions of the study, discuss the strengths and weaknesses of this study, and suggest implications for nursing practice.

CHAPTER 7

CONCLUSIONS AND IMPLICATIONS

The stated aim of this study was to investigate how self-regulation develops in people with insulin dependent diabetes and to determine the relationship between self-regulation, compliance with prescribed treatment regimens, and diabetes control. The study led to the development of a self-regulation model based on data gathered on the personal, social, and health explanations of individuals with insulin dependent diabetes. These explanations are defined as the contexts, conditions, actions and consequences of self-management decisions. The purposes of this chapter are to summarize the findings and conclusions of the study, and to discuss the limitations and strengths of the investigation as well as the implications of the findings for nursing practice, education, and future research.

Summary of Findings Answering the Research Questions

This section of the chapter summarizes the findings related to the development of the process of self-regulation, how self-regulation relates to earlier compliance research, and the influence of self-regulation on blood glucose control.

The Process of Self-Regulation

The research questions posed in this study asked how a person's understanding of diabetes affects the development and modification of self-regulation, what conditions and contexts affect self-regulation and the ability to comply with treatment regimens, what strategies are used in self-regulation, and how effective these strategies are in maintaining metabolic control. The implications of self-regulation for nurses trying to facilitate client self-management outcomes will be addressed in the nursing implications section of this chapter.

This study demonstrated that self-regulation of diabetes occurred over time with the illness. In the first phase of the illness (i.e., when participants felt sick), the diagnosis served as the catalyst for action and provided the hope that life would return to normal after the symptoms were controlled. Shortly after diagnosis, subjects were taught self-management actions such as monitoring and taking insulin, and were given some instructions on the diabetic diet. At that time, most subjects were willing to follow the regimen that was prescribed. Subjects felt fragile and readily accepted the help of health care professionals.

Findings indicated that during this initial phase, subjects were promised that if they followed the regimen, "everything would be alright" and they could live a "normal life." This phase was designated "Becoming Diabetic" and represented that period in which subjects were assimilated

into life with a chronic illness and in which there was little self-regulation.

The research analysis demonstrated that, as subjects began to gain experience with the illness and the treatment, they discovered that the treatment itself caused problems. While insulin kept the insulin-dependent subject alive, it also led to problems that caused incessant blood glucose fluctuations. For instance, the dose given at diagnosis frequently seemed inadequate after a period of time and needed to be changed on a periodic basis. The complexity of the treatment became more apparent and subjects became cognizant of the need to adjustment treatment. It was in this second phase that the subjects began to doubt the care provider's assurances that a normal life was, indeed, attainable. Subjects began to realize that medical science was limited in its solutions to controlling the fluctuations related to the illness.

High and low blood glucose reactions often occurred, leaving participants with the sense that the illness was unpredictable and that simply taking the insulin did not guarantee that "everything will be alright." They began to realize that the treatment required continuous intervention and did not provide total symptom stability. They discovered that insulin worked in different ways depending on a variety of factors which could change daily, such as the kinds of activity and the timing and amounts of insulin and food. In this second phase, subjects began to grow

disillusioned. This phase was designated as "Confronting the Illusion of Promised Normality".

At this stage, subjects took the illness management into their own hands, believing that the medical expert's prescription alone could not produce the desired results. They began to make adjustments to their regimens that, while counter to medical prescription, accommodated the rest of their life activities better. In the first phase of becoming diabetic, study participants devoted a great deal of time to the diabetes and attempted to change their lives to fit the diabetes regimen. At the point at which they began to experience disillusionment with the prescribed treatment, subjects decided to reverse the accommodation. They deemed it necessary to carry on normal activities at work, at school, or in relationships, and decided that the diabetes would have to begin accommodating these activities.

The third phase, "Pragmatic Sufficiency," occurred when the subjects became willing to do what was sufficient to take care of the diabetes while feeling good enough to participate in activities they chose to do. The goal of therapy became "feeling good enough," rather than complying with the prescribed regimen. At this point, subjects were willing to seek flexible regimens and to be accountable for self-management decisions. The investigation also revealed that participants experienced a continuous, natural analysis in which questions about self-management were sorted and decisions about what actions to take were made. During the

interviews, subjects described how they arrived at different solutions to the problems of self-management by first analyzing a particular situation, then considering the conditions under which the action would take place, and finally taking appropriate action based on the analysis. Subsequent actions were based on the experience of the initial action and its consequences. Participation in the study helped subjects focus on their own analytical process for diabetes control. Through the analysis, subjects explored the dimensions, contexts and conditions that guided their actions. The personal meaning schema provided a structure for describing the components of the analytic process.

The findings indicate a dramatic increase at the time of the second interview in the strength of the correlations between the glycosylated hemoglobin results and the subjects' estimates of their degree of control and efforts related to gaining glucose control. These results suggest that the investigation served as an intervention between Time 1 and Time 2 by having the subjects consciously analyze the steps in their decision making process and thereby clarify the effect of their self-management practices on current control. They verbally articulated descriptions of their personal meaning schema and related diabetes to their life situations. Strategies that promote these self-analytic procedures may provide clients with self-generated

approaches and solutions to management problems that result in greater glucose control.

It should be noted that self-regulation is not a linear model but rather an orderly progression towards the end point of pragmatic sufficiency. This progression embodies an interactive process in which persons move back and forth between the phases as health related actions become the focus of greater attention. This is most evident in those subjects facing complications or assessing the effectiveness of their actions in controlling blood glucose levels. Participants facing new complications such as kidney disease, for example, returned to the Diabetes Center to learn new regimens better able to restrain fluctuating blood glucose levels related to decreased kidney function. The identity of these subjects evolved from "becoming diabetic" to "becoming diabetic with kidney insufficiency." As in the first phase after the original diagnosis, less self-regulation is attempted and there is greater reliance on health professionals for regimen guidance.

The substantive theory revealed in this study explains how self-regulation develops in people with insulin dependent diabetes. The emergent schema focuses on the interaction between having both an illness life and a social existence. The individual's analysis of the importance of blood glucose control versus the needs of everyday existence, shapes the decisions around diabetes self-management.

Self-Regulation and Compliance

The self-regulation model revealed in this study contrasts the compliance model, (i.e., following or not following prescribed regimens) with a model depicting a complex set of negotiated actions directed toward maintaining a sense of well-being as defined by the person with the disorder. Traditional studies referred to in Chapter 2 measured compliance in relation to the strength of patient-physician relationships, the identification of patient characteristics predicting compliance, and adherence to prescribed regimens.

Compliance research assumes that health related beliefs are paramount in the patient's decisions to take health actions and that the actions needed to control diabetes are available if patients would only use them. The variables used in compliance research are health-related factors designated by researchers as indicators of self-management behaviors in the diabetic population. The current research indicates that health related variables are a part of a broader framework in which situational and personal factors modify and prioritize health practices.

The discoveries in this research suggest that insulin-dependent diabetic people actively manipulate their illness management. Patient decisions about treatment are not based solely on health related beliefs, but rather on how compatible the treatment is in the context of people's lives. The results of this study confirm the perspectives

of Strauss et al. (1986) and Zola (1981) that chronic illness is only one part of a person's life, that chronically ill people spend a small portion of their time in interaction with professionals, and that regimen strategies that patients actually follow reflect "practical practice" (Conrad, 1985, p. 35) to control symptoms in order to function socially and to gain some personal control over their conditions. The findings of this research suggest that efforts to understand and counsel clients with diabetes must assess the context of everyday life situations and the individual's analysis of the meaning of these contexts.

Compliance model research assumes that health beliefs are static in nature. The current investigation suggests that health beliefs are not fixed and that values assigned to health beliefs change over time. These results corroborate the findings of the Leventhal model of self-regulation research (Keller, Ward, Baumnan, 1989; Leventhal, 1982; Leventhal, Zimmerman, & Gutman, 1985; Meyer, Leventhal, & Gutman, 1985). In that model, illness representations are formulated through a process of integration of information from multiple sources, symptoms and body sensations, and experience over time. The Leventhal model of self-regulation further suggests that a person's goals for health care develop and reconfigure over time from illness representations, evaluation of responses needed to meet these goals, and evaluation of the level of goal attainment. The present study places these dimensions

in the context of everyday life activities and roles. It further expands the Leventhal conceptualizations by taking into account the prioritizing of illness needs in specific contexts, and accounts for changes in self-regulating behaviors over time through the use of the personal meaning schema and the explanatory matrix.

Explanation of Variance in Self-Management

The current study's use of the explanatory matrix of dimensional analysis provides a means for evaluating conditional influences on self-management actions and thereby provides an explanation for the wide variation seen in self-management practices among diabetic clients. Through continuing individual analysis, positions in time phases of the illness, and placement of analyzed dimensions in a framework, variation in self-regulating behaviors is explained and is expected. As new personal evaluations of contexts and conditions such as history of sexual abuse or family history of poor diabetes outcomes occur, placement of pertinent considerations in the matrix results in individually constructed actions that vary among subjects and change over time.

Self-Regulation and Glucose Control

Traditional compliance research has shown that compliance with the prescribed medical regimen or knowledge of what the regimen is supposed to be did not consistently result in better glucose control (Glasgow, McCaul, &

Schafer, 1987; Lowery & DuCette, 1976; Watkins, Williams, Martin, Hogan, & Anderson, 1967; Williams, Martin, Hogan, Watkins, & Ellis, 1967). Watkins et al. (1967) suggested that medical science probably had not yet developed methods to adequately control diabetes. Glasgow, McCaul, and Schafer (1987) suggested that glycemic control be considered in a context of factors such as stress, individual metabolic factors and appropriateness of regimen prescriptions. They also determined that compliance with part of the diabetes regimen did not guarantee compliance with the whole regimen prescription. Participants in their study complied more often with medication taking and glucose monitoring than with lifestyle modifications such as diet and exercise.

This investigation indicates that self-regulating behaviors that result from the participant's analysis does not necessarily lead to the best metabolic control. Subjects movement into the phase of pragmatic sufficiency and overt self-regulation does not necessarily represent an evolution to a better or higher level of diabetes control. The results of this study show that 50% of the 30 subjects had at least one glycosylated hemoglobin greater than two percentage points above the normal range. Pragmatic sufficiency and self-regulating actions represent patient driven efforts to assimilate the treatment regimen into other important life activities. The self-regulation model acknowledges the importance of the unpredictability of the illness and treatment on the subject's decisions to self-

regulate the regimen. The importance of the impact of unpredictability mirrors the earlier finding of Lowery and DuCette (1976) who suggested that the inability to gain control over blood glucose levels leads to a sense of loss of personal control over the body. This results in skepticism about the value of health care providers' suggestions and demands related to the treatment regimen.

Summary

The findings of this study on self-regulation of diabetes treatment regimens suggest that compliance with a prescribed regimen is of questionable value. More important than coercing compliance is the need for education on using the available tools to control diabetes and for supporting clients to practice the best self-regulated management procedures they can using their own self-generated goals and solutions.

Limitations and Strengths

Limitations

The purpose of a grounded theory study is to specify the contexts and conditions that result from a set of actions and consequences (Strauss & Corbin, 1990). The findings of this investigation offer a viable explanation of self-regulation in insulin dependent diabetic subjects using the dimensions, contexts, conditions, and actions derived from the study sample. The conceptualization may be limited

in that it may not be representative of all people with insulin-dependent diabetes. The limitations discussed here relate to the study sample and design.

Sample

One of the goals of the grounded theory methodology is to provide an explanation for the widest variation in the population being studied. In this study, the sample size of 30 subjects limits the generalization of the findings as this number does not account for all possible variations within the study population (Chenitz & Swanson, 1986; Strauss & Corbin, 1990). The data may be skewed because of the level of diabetes education in this particular sample. This sample was made up of subjects who had participated in structured diabetes education programs and had actively pursued intensive insulin therapy. Would self-regulating behaviors of other populations (e.g., subjects from public clinics where education is typically less rigorous or insulin therapy unavailable because of lack of resources) result in the same findings?

The first 30 people to consent to the interviews were inducted into the study. There was no way to study the differences between the sample subjects and those who declined to be interviewed. The sample had a fairly even spread between males (n=16) and females (n=14), but had only one African American and 29 Caucasian subjects. The study sample consisted of adults who had been diagnosed for not less than five years but no more than 20 years. Subjects

ranged in age from 20 to 55 years. These results could not be generalized to samples with children or elderly subjects, or to those with a new diagnosis or with an illness duration of greater than 20 years.

Method

The credibility of naturalistic studies is enhanced by prolonged engagement with the subjects (Lincoln & Guba, 1985). Based on this criteria, the study is also limited by a lack of longitudinal engagement with the subjects. The two interviews were conducted within three months of each other and represent a cross-section in time. The study design would have been improved by sampling a subgroup of participants several more times. A prospective, longitudinal study that followed subjects over a number of years starting at diagnosis would also have enhanced the credibility of this study.

Strengths

Lincoln and Guba (1985) cited a number of methods for strengthening the credibility of naturalistic studies. Among these were persistent observation, triangulation, peer debriefing, referential adequacy and member checks.

Even though persistent observation of this particular sample was not possible due to the limitations of the two interview design, the researcher has observed diabetic patients every week for up to 30 hours at a time over a period of seven years. This experience allowed the

investigator opportunities to observe multiple influences on diabetes self-management. In addition, the investigator's personal experience with diabetes contributed to an understanding of the issues under investigation.

The design did provide for triangulation of methods using interviews, pen-and-pencil tests (the visual analogue scales), and laboratory findings (glycosylated hemoglobin). Some subjects shared their blood glucose log books during the interviews which added to the triangulation of sources.

The use of peer debriefing by a qualitative analysis group versed in the methodologies of grounded theory and dimensional analysis strengthened this study through consistent questioning regarding data collection and analysis. The group contributed to the rigor of this study by suggesting refinements in the conceptualization until a reasonable number of cases were accounted for and the variance in the data explained. This group also functioned to increase the dependability of the study by examining the processes as well as the products of the analysis to ensure that the data were accurately represented.

Referential adequacy and member checks further contribute to the credibility of the findings. Referential adequacy refers to raw data that can be examined after data collection is completed to confirm or reproduce the study (Lincoln & Guba, 1985; Sandelowski, Davis, Harris, 1989). Referential materials provide a means of confirming the data by producing an audit trail which, in this study, included

records on each subject, theoretical memos, tape recorded interviews, transcriptions of the interviews and process field notes.

Member checks refer to the procedure of checking with study participants to see if they agree that the researcher's analysis accurately represents their experience. This procedure provides the participants with the opportunity to validate the credibility of the research findings. In this study, the subjects were asked whether the constructions the researcher produced were recognizable to the participants and whether they felt it was a fair representation of the experiences they shared in the interviews. Member checks were completed on a subset of subjects and on other insulin-dependent people with diabetes known to the researcher. All of the persons asked to validate the constructions developed through the data analysis corroborated the existence of the developmental phases and identified with the concepts of unpredictability and the need for flexibility in particular. The concept of "Pragmatic Sufficiency" was grasped immediately by all respondents. Further, the perspective of "living a normal life" was universally recognized by the participants. The process of theoretical sampling in grounded theory methodology is similar to member checks and provides a means of validating or discarding emerging concepts through continuing subject interviews (Strauss, 1989). The use of the explanatory matrix of dimensional analysis (Schatzman,

1986) also provides a structure for organizing the data generated and allows for an analytic version of the subjects' stories to emerge from the descriptions given.

Implications

This study attempts to make a contribution to nursing research by focusing on the human responses to diabetes and its treatment in interaction with the environment (Levine, 1969; Meleis, 1985). It specifically attempts to broaden the perspective of the literature related to patient compliance with long-term and complex self-managed treatment regimens. As this is a preliminary study using a small sample of insulin dependent diabetic subjects, the conclusions drawn are considered tentative. The following implications for nursing practice, education, and research are made with this caveat.

Nursing Practice

Three of the findings from the study analysis have direct implications for nursing practice: 1) If living a normal life is the dimension explaining the greatest amount of variation in the results, how can living a normal life be translated into treatment regimens meeting the needs of the client? 2) The study findings suggest the possibility that as the subjects focused attention on how they managed their diabetes and analyzed their efforts at gaining metabolic control, their ability to accurately predict the actual

level of blood glucose control increased. This was reflected in the increase in the correlations between the subjects' assessments of control, effort expended, and the laboratory value for glycosylated hemoglobin levels obtained at the time of the second interview. How can this natural analysis be used in nursing practice to encourage better diabetes control? 3) It is clear that self-regulating behavior has a temporal element to it and changes over time with the disease. With this in mind, how can client education and intervention be continuously reassessed in order to identify the changing contexts in which decisions are made?

All three of these concerns can be addressed by nursing interventions focused on assisting the client with the analysis of their self-regulating actions and expediting problem identification and definition. Helping clients to verbally articulate their personal analysis leads to clarification of the client's understandings and meanings of the current diabetes state. Options for care can be explored in an atmosphere that is consistent with clients' perceptions of how diabetes care fits into their normal life activities. With new options available, clients can set goals better reflecting their own needs, decide on expected outcomes of management practices, and develop solutions to current problems. This type of intervention allows the provider to assist the client in developing criteria for evaluating whether the new management actions are effective

in meeting the goals. If the goals are not achieved, clients can be encouraged to use this information as part of further analysis to modify management strategies. The analysis can also assist both client and provider in identifying areas where further education and information may provide new choices related to care.

Personal Meaning Schema as Assessment Tool

Applied to practice settings, the personal meaning schema can be translated into assessment questions that uncover the client's natural analysis. Questions such as the following help to expose clients' understanding, sensitivities and tolerances: What do you think is happening right now for you to be getting these results? What bothers you the most about (whatever current problem is)? How much (of current problem) are you willing to put up with? What are the outer limits of your definition of acceptable control right now? What level or range of blood glucose levels do you define as your goal?

The findings suggest that as clients become more sensitive to consequences of the illness, such as at the onset of complications, their tolerances for uncontrolled glucose levels may narrow and more effort will go into controlling these levels. The reverse may also occur. With the onset of complications, tolerances for doing intense self care may decrease if a client feels there is no point in working for controlled blood glucose levels. Each of these understandings leads to different actions and

consequences. Treatment regimens should reflect current changes in understanding, sensitivities and tolerances.

Options for self management can be explored by asking the client directly: What other possibilities do you see for managing this problem? Have other options or methods for dealing with this problem been explored? What are the costs and benefits of taking that care option? How much risk is there in taking such actions?

Lastly, the concept of stake can be ascertained by asking: What value do you place on the outcome of this/these actions? The stakes may be very high as in the case of the pregnant diabetic woman who must make decisions that affect both her diabetes control and the health of her baby. The benefits of intensive self-management may well outweigh the inconvenience and intrusion of increased testing and strict dietary adherence.

Interventions geared toward making the client a more active problem solver change the role of the provider from that of a controller to that of an advisor or coach. The care provider becomes the feedback system helping clients evaluate the viability of the options chosen. In this role, the provider is a facilitator who functions to assist the client in analyzing progress toward stated goals. This type of nursing intervention allows greater autonomy for the client and relieves the provider of being the only problem solver or expert in the relationship.

Lastly, nursing interventions using the process of self-analysis can be facilitated in cost-effective group teaching environments. If groups of clients are taught how to analyze problems using a consistent model, group problem solving methods can increase the number of options and solutions made available to members of the group. Wallerstein and Bernstein (1988) suggest that education in groups promotes a sense of "power to act with others to effect change" (p. 380) and strengthens a person's belief in her/his ability to influence health behaviors. If these types of interventions are to proceed, nurse providers need to learn counselling techniques to help facilitate client self-assessment that can result in informed decision making related to diabetes care.

Anderson, Funnell, Barr, Dedrick, and Davis (1991) discovered two common difficulties experienced by professionals attempting to develop client centered teaching and treatment programs. First, professionals find it difficult to encourage clients to explore and express feelings and emotions related to diabetes. Second, educators have difficulty moving away from the role of problem solver and advice giver about the best way to accomplish diabetes self-management goals. "The educator should facilitate and not dominate the process of helping patients come to a decision about pursuing their own diabetes goals" (Anderson, Funnell, Barr, Dedrick, & Davis, 1991, p. 587).

Nursing Education

As nursing moves toward increased specialization and advanced practice in the clinical specialist and nurse practitioner roles, there is a growing need to be experts in the physiological aspects of health and illness. Increased nursing responsibility for diagnosis and treatment of health problems necessitates incorporating physiological and pathophysiological assessment skills into nursing education. In light of these new responsibilities, it is imperative that nursing education not lose sight of the mandate to also treat a person's responses to illness (American Nurses Association, 1980).

Nursing education for those working with diabetic clients needs to include both physiological and psychosocial assessment skills. The American Association of Diabetes Educators (AADE) program for diabetes educators has attempted to set standards for expert practice. The Core Curriculum of AADE (1988) teaches an educator what knowledge to give clients, methods for teaching clients how to perform diabetes self care activities, and how to test the client's knowledge of diabetes. This study proposes that nurses be educated in the natural analytic process in order to understand how individuals with diabetes treat and use information to make decisions about diabetes self-management. Use of the natural analytic process provides a means for nurses to overcome the problems mentioned in developing client centered treatment--allowing clients to

express feelings and emotions about diabetes and moving away from the role of sole problem solver (Funnell, Anderson, Barr, Dedrick and Davis, 1991). Further, nursing education needs to teach ways to integrate the products of this process into the content of teaching/treatment plans.

As noted in the section on implications for nursing practice, nursing interventions directed towards increasing the client's capacity to self-assess and self-generate strategies for change are an important part of the nurse educator's role. Methods for teaching professionals how to develop client centered interventions using interactive counseling models exist and offer helpful suggestions that could be integrated into nursing education curriculum (Anderson, Funnell, Barr, Dedrick, & Davis, 1991; Funnell et al., 1991; Funnell, Donnelly, Anderson, & Sheets, 1991; Tupling, 1981).

Patient Education

Recent reports in the diabetes education literature indicate a move away from knowledge testing as a means of evaluating diabetes management skills. It is clear that giving and receiving information is not the equivalent of knowing how to respond in an independent and appropriate fashion (Funnell et al., 1991; Tupling, 1981). More problem solving based education is needed to help clients work through situations requiring decision making skills (Pichert, Snyder, Kinzer, & Boswell, 1992).

Funnell et al. (1991) suggest that diabetes educators attempting to help clients gain mastery over their diabetes must provide programs using an "empowered client model." In this model, both client and professional are problem solvers and caregivers. Problems, learning needs, and goals and strategies are identified by the client and supported by the professional. The goals of the empowered client model are different than those of the traditional medical model where finding ways for the client to comply with prescribed regimens is the goal of diabetes patient education. The current study supports the client centered model as a more effective means of assisting clients in maximizing control of their diabetes.

Nursing Research

Further research is needed to refine the concepts of self-regulation presented in this investigation. Studies that replicate the patterns that evolved in this investigation are needed to further validate the concepts and to enrich the findings in relationship to the suggestions made for use in nursing practice and education.

The same study might be reproduced using other samples of insulin dependent diabetic subjects, such as groups that have not received formal diabetes education, to identify important similarities and differences. Other questions related to the use of a different sample are as follows: Does the model of self-regulation apply to people with non-

insulin dependent diabetes where treatment regimens involve oral hypoglycemic agents, dietary restriction and weight management? Does self-regulation apply to other ethnic groups in the same way as these subjects described? Does the model apply to other groups of people self-managing illnesses such as asthma, arthritis, and epilepsy?

Longitudinal studies of selected subjects could increase knowledge about how passage of time and changes in living patterns influence self-regulation. Additional studies looking at the impact of client centered therapy as an intervention to increase self-assessment and goal identification could be tested using both quality-of-life measures and laboratory values to measure change. The empowerment education model used by Wallerstein and Berstein (1988) could be used to investigate the impact of group education and support on diabetes self-management strategies.

Study Generated Hypotheses

A logical step in the process of knowledge generation using grounded theory methodology is the development of a theoretical model and hypotheses generation about the concepts discovered in the model development. Based on the findings in this study (i.e., how the subjects' understanding of diabetes and its care changed over time, the importance of balancing diabetes activities with life activities, and the realization that perfect control is impossible), the following hypotheses are offered as a basis

for future investigations related to self-regulation practices in subjects with insulin-dependent diabetes mellitus (IDDM):

1) Self-regulation occurs because people with diabetes are active participants in self-management decisions.

2) Self-regulation decisions by diabetic clients about diabetes control are not necessarily the same as those of their health care providers.

3) Self-regulation decisions by diabetic clients are based on valid reasoning arrived at through an individual's analysis of current life circumstances and on the degree of assessed tolerance for the current situation.

4) Self-regulation of diabetes treatment regimens in IDDM increases as the duration of the illness increases.

5) Self-regulation of diabetes treatment regimens in IDDM is preceded by acknowledgement that the illness and treatment are unpredictable and current therapies cannot completely control blood glucose fluctuations.

6) Diabetes treatment regimens are self-regulated by individuals to control the degree to which the prescribed regimens intrude on social activities.

7) Diabetes self-management actions, resulting from self-regulation, are evaluated and changed through new understandings of the illness and treatment. These actions result from analysis and integration of knowledge gathered

from people known through personal and professional interactions, illness experiences, and media input.

8) As analysis of the actions taken to self-manage diabetes increases, the capacity to accurately predict the actual level of metabolic control and to identify problem areas related to blood glucose control also increases.

9) Self-regulation occurs when a person takes charge of her/his diabetes control and is willing to be accountable for the subsequent outcomes of those decisions.

Meleis (1985) states that "nursing theory is defined as an articulated and communicated conceptualization of invented or discovered reality pertaining to nursing for the purpose of describing, explaining, predicting, or prescribing nursing care. Nursing theory is developed to answer central domain questions" (p. 96). This research has attempted to facilitate the development of theoretically guided nursing practice related to assisting clients living with chronic illness.

Summary

The theoretical model derived from this investigation attempts to describe and explain the development of self-regulating behaviors in people with insulin dependent diabetes. Self-regulation is contingent on the meaning health care practices have for the individual in relation to the demands of everyday social interactions and relationships. The model suggests that self-regulation

develops over three phases in the illness: 1) becoming diabetic, 2) confronting the illusion of promised normality, and 3) pragmatic sufficiency. The contexts of importance to self-regulating decisions are designated as assimilation, unpredictability, flexibility, and accountability.

The discoveries extend previous studies attempting to define the process of self-regulation of health actions by providing structures for analysis through use of the schema for personal meaning and the explanatory matrix of dimensional analysis. The findings challenge the assumptions of the compliance model which suggest that health beliefs are static in nature, that health beliefs are primary motivators of health behaviors, and that complete control over illness symptoms is accomplished by compliance with medically prescribed regimens. The implications of these findings were related to nursing practice, education and future research.

REFERENCES

Aitkin, R. C. B. (1969). A growing edge of measurement of feelings. Proceedings of the Royal Society of Medicine, 62, 989-993.

Allison, S. D. (1973). A framework for nursing action in a nurse-conducted diabetic management clinic. Journal of Nursing Administration, 3(4), 53-60.

Alogna, M. (1980). Perception of severity of disease and health locus of control in compliant and noncompliant diabetic patients. Diabetes Care, 3, 553-554.

American Association of Diabetes Educators (1988). Diabetes education: A core curriculum for health professionals. Chicago: American Association of Diabetes Educators.

American Diabetes Association (1986). Exchange Lists for Meal Planning. American Diabetes Association and American Dietetic Association.

American Diabetes Association (1988). The physician's guide to Type II diabetes (NIDDM): Diagnosis and treatment. Alexandria, VA: ADA.

American Diabetes Association (1991). Vital statistics. Alexandria, VA: American Diabetes Association.

American Nurses Association (1980). Nursing: A social policy statement. Kansas City, MO: American Nurses Association.

Anderson, B. J., & Auslander, W. F. (1980). Research on diabetes management and the family: A critique. Diabetes Care, 3, 696-702.

Anderson, J. W., & Gustafson, N. J. (1989). Adherence to high carbohydrate, high-fiber diets. Diabetes Educator, 15, 429-434.

Anderson, R. M. (1985). Is the problem of noncompliance all in our heads? Diabetes Educator, 11, 31-34.

Anderson, R. M., Funnell, M. M., Barr, P. A., Dedrick, R. F., & Davis, W. K. (1991). Learning to empower patients: Results of professional education program for diabetes educators. Diabetes Care, 14, 584-590.

Anderson, R. M., Nowacek, G., & Richards, F. (1987). Influencing the personal meaning of diabetes: Research and practice. Diabetes Educator, 14, 297-302.

Ary, D. V., Toobert, D., Wilson, W., & Glasgow, R. E. (1986). Patient perspective on factors contributing to nonadherence to diabetes regimen. Diabetes Care, 9, 168-172.

Backscheider, J. E. (1974). Self-care requirements, self-care capabilities, and nursing systems in the diabetic nurse management clinic. American Journal of Public Health, 64(12), 1138-1146.

Becker, M. H. (1974). The health belief model and sick role behavior. In M. H. Becker (Ed.), (pp. 82-92). Thorofare, NJ: Charles B. Slack, Inc.

Becker, M. H. (1976). Sociobehavioral determinants of compliance. In D. L. Sackett & R. B. Haynes (Eds.), Compliance with therapeutic regimens (pp. 40-50). Baltimore, MD: Johns Hopkins University Press.

Becker, M. H. (1979). Understanding patient compliance: The contributions of attitudes and other psychosocial factors. In S. J. Cohen (Ed.), New directions in patient compliance (pp. 1-19). Lexington, MA: D. C. Heath and Co.

Becker, M. H., & Janz, N. K. (1985). The health belief model applied to understanding diabetes regimen compliance. Diabetes Educator, 11, 41-47.

Blumer, H. (1969). Symbolic interactionism perspective and method. Englewood Cliffs, NJ: Prentice-hall, Inc.

Brink, P. J. (1989). Issues in reliability and validity. In J. M. Morse (Ed.), Qualitative nursing research, (pp. 151-168). Rockville, MD: Aspen Publishers, Inc.

Carver, C. S., & Scheier, M. F. (1982). Control theory: A useful conceptual framework from personality--social, clinical, and health psychology. Psychological Bulletin, 82, 111-135.

Cerkoney, K. A. B., & Hart, L. K. (1980). The relationship between the health belief model and compliance of persons with diabetes mellitus. Diabetes Care, 3, 594-598.

Charmaz, K. (1990). "Discovering" chronic illness: Using grounded theory. Social Science and Medicine, 30, 1161-1172.

Chenitz, W. C., & Swanson, J. M. (1986). From practice to grounded theory. Menlo Park, CA: Addison-Wesley Publishing Co.

Chick, N., & Meleis, A. I. (1986). Transitions: A nursing concern. In P. L. Chinn (Ed.), Nursing research methodology: Issues and implementation (pp. 237-257). Rockville, MD: Aspen Publishers, Inc.

Conrad, P. (1985). The meaning of medications: Another look at compliance. Social Science and Medicine, 20(1), 29-37.

Corbin, J., & Strauss, A. L. (1987). Accompaniments of chronic illness: Changes in body, self, biography, and biological time. In J. A. Roth & P. Conrad (Eds.), Research in the sociology of health, Vol. 6 (pp. 249-281). Greenwich, CT: JAI Press.

Correa, L. L. (Spring 1992). Running: Morale booster for staying on track. Living Well with Diabetes. Minneapolis, MN: International Diabetes Center.

Cox, D. J. (1989). Commentary on self-care behaviors and glycemic control in Type 1 diabetes by R. E. Glasgow, K. D. McCaul, & L. C. Schafer. Diabetes Spectrum, 2(1), 36-37.

Cox, D. J., Gonder-Frederick, L., & Pohl, S. (1984). Adult diabetes: Critical issues for applied research and clinical intervention. In K. A. Holroyd & T. L. Creer (Eds.), Self-management in health psychology and behavioral medicine. New York: Academic Press.

Danowski, T. S., Ohlsen, P., & Fisher, E. R. (1980). Diabetes complications and their prevention or reversal. Diabetes Care, 3, 94-99.

Daschner, B. K. (1986). Problems perceived by adults in adhering to a prescribed diet. The Diabetes Educator, 12, 113-115.

Davidson, M. B. (1986). Diabetes mellitus: Diagnosis and treatment, Vol. 2. New York: Wiley & Sons, Inc.

DCCT Research Group (1988). Reliability and validity of a diabetes quality-of-life measure for the diabetes control and complications trial (DCCT). Diabetes Care, 11, 725-732.

Di Matteo, M. R., & Di Nicola, D. D. (1982). Achieving patient compliance: The psychology of the medical practitioner's role. New York: Pergamon Press.

Dunn, S. M., & Turtle, J. R. (1981). The myth of the diabetic personality. Diabetes Care, 4, 640-646.

Etzwiler, D. D. (1967). Who's teaching the diabetic? Diabetes, 16, 111-117.

Fleury, J. (1992). The application of motivational theory to cardiovascular risk reduction. Image, 24(3), 229-239.

Funnell, M. M., Anderson, R. M., Arnold, M. S., Barr, P. A., Donnelly, M., Johnson, P. D., Taylor-Moon, D., & White, N. H. (1991). Empowerment: An idea whose time has come in diabetes education. Diabetes Educator, 17, 37-41.

Funnell, M., Donnelly, M., Anderson, R., & Sheets, K. (1991). Noncompliance with a diabetes regimen by medical students and diabetes educators. Poster presentation, 14th International Diabetes Federation Congress, Washington, D.C., June 1991.

Garrity, T. F. (1981). Medical compliance and the clinician-patient relationship: A review. Social Science and Medicine, 15E, 215-222.

Gerber, K. E., & Nehemkis, A. M. (1986). Compliance: The dilemma of the chronically ill. New York: Springer.

Glaser, B. G. (1978). Theoretical sensitivity. Mill Valley, CA: The Sociology Press.

Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory. Hawthorne, NY: Aldine Publishing Co.

Glasgow, R. E., McCaul, K. D., & Schafer, L. C. (1987). Self-care behaviors and glycemic control in Type I diabetes. Journal of Chronic Disease, 40, 399-412.

Glasgow, R. E., & Toobert, D. J. (1988). Social environment and regimen adherence among Type II diabetic patients. Diabetes Care, 11, 377-386.

Hamera, E., Cassmeyer, V., O'Connell, K. A., Weldon, G. T., Knapp, T. M., Kyner, J. L. (1988). Self-Regulation in individuals with Type II diabetes. Nursing Research, 37, 363-367.

Hayes-Bautista, D. E. (1976). Modifying the treatment: Patient compliance, patient control and medical care. Social Science and Medicine, 10, 233-238.

Hays, R. D., DeMatteo, M. R. (1981). Patient compliance assessment. Journal of Compliance in Health Care, 2, 37-53.

Hoover, J. (1980). Compliance from a patient's perspective. Diabetes Care, 6, 9-12.

Jayne, R. L. (1991). Influences on self-care practices related to compliance with diabetes treatment regimens. Poster presentation, 14th International Diabetes Federation Congress, Washington, D.C. June, 1991.

Kaufman, S. (1988). Illness, biography, and the interpretation of self following a stroke. Journal of Aging Studies, 2(3), 217-227.

Kelleher, D. (1988). Coming to terms with diabetes: Coping strategies and non-compliance. In R. Anderson & M. Bury (Eds.), Living with chronic illness: The experience of patients and their families. London: Unwin Hyman Ltd.

Keller, M. L., Ward, S., & Bauman, L. J. (1989). Processes of self-care: Monitoring sensations and symptoms. Advances in Nursing Science, 12(1), 54-66.

Kilo, C. (1982). Educating the diabetic patient. New York: Science & Medicine.

Krupp, L. B., LaRocca, N. G., Muir-Nash, J., Steinberg, A. D. (1989). The fatigue severity scale: Application to patients with multiple sclerosis and systematic erythematosus. Archives of Neurology, 46(10), 1121-1123.

Leventhal, H. (1982). Wrongheaded ideas about illness. Psychology Today, 16, 48-55; 73.

Leventhal, H., & Johnson, J. E. (1983). Laboratory and field experimentation: Development of a theory of self-regulation. In P. J. Wooldridge, M. H. Schmitt, J. K. Skipper, & R. C. Leonard (Eds.), Behavioral science & nursing theory. St. Louis: C. V. Mosby Co.

Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), Contributions to medical psychology, Vol. 2, (pp. 7-30). New York: Pergamon Press.

Leventhal, H., Singer, R., & Jones, S. (1965). Effects of fear and specificity of recommendations upon attitudes and behavior. Journal of Personality and Social Psychology, 2, 20-29.

Leventhal, H., Zimmerman, R., & Gutmann, M. (1984). Compliance: A self-regulation perspective. In D. Gentry (Ed.), Handbook of behavioral medicine (pp. 369-436). New York: Guilford Press.

Levine, M. (1969). The pursuit of wholeness. American Journal of Nursing, 69, 93-98.

Lincoln, Y. S., Guba, E. G. (1985). Naturalistic inquiry. Newbury Park, CA: Sage.

Little, R. R., McKenzie, E. M., Wiedmeyer, H. M., England, J. D., & Goldstein, D. E. (1986). Collection of blood on filter paper for measurement of glycated hemoglobin by affinity chromatography. Clinical Chemistry, 32, 869-871.

Lowery, B. J., & Ducette, J. (1976). Disease-related learning and disease control in diabetics as a function of locus of control. Nursing Research, 25, 358-362.

Mazze, R. S., Pasmantier, R., Murphy, J., & Shamoon, H. (1985). Self-monitoring of capillary blood glucose: Changing the performance of individuals with diabetes. Diabetes Care, 8, 207-213.

Mazze, R. S., Shamoon, H., Pasmantier, R., Lucido, D., Murphy, J., Hartmann, K., Kuykendall, V., & Lopatin, W. (1984). Reliability of blood glucose monitoring by patients with diabetes mellitus. American Journal of Medicine, 77, 211-217.

Mead, G. H. (1934). Mind, self, & society. Chicago: University of Chicago Press.

Meleis, A. I. (1985). Theoretical nursing: Development & Progress. Philadelphia: J. B. Lippincott Co.

Meyer, D., Leventhal, H., & Gutmann, M. (1985). Common-sense models of illness: The example of hypertension. Health Psychology, 4(2), 115-135.

National Center for Health Statistics (1990). Monthly vital statistics report, 39(8), December 17, 1990.

National Diabetes Data Group (1985). Diabetes in America. U.S. Department of Health and Human Services, NIH Publication No. 85-1468.

O'Connell, K. A., Hamera, E. K., Knapp, T. M., Cassmeyer, E.D., Eaks, G. A., Fox, M. A. (1984). Symptom use and self-regulation in Type II diabetes. Advances in Nursing Science, 6(3), 19-28.

Orr, D. P., Golden, M. P., Myers, G., & Marrero, D. G. (1983). Characteristics of adolescents with poorly controlled diabetes referred to a tertiary care center. Diabetes Care, 6, 170-175.

Pendleton, L., House, W. C., & Parker, L. E. (1987). Physicians' and patients' views of problems of compliance with diabetes regimens. Public Health Reports, 102(1), 21-26.

Peyrot, M., McMurry, Jr., J. M., & Hedges, R. (1987). Living with diabetes: The role of personal and professional knowledge in symptom and regimen management. In J. A. Roth & P. Conrad (Eds.), Research in the Sociology of Health Care, Vol. 6, (pp. 107-146). Greenwich, CT: JAI Press.

Pritchert, J. W., Snyder, G. M., Kinzer, C. K., Boswell, E. J. (1992). *Sydney Meets the Ketone Challenge*--A videodisc for teaching diabetes sick-day management through problem solving. Diabetes Educator, 18(6), 476-477, 479.

Quint, J. C. (1969). Becoming diabetic: A study of emerging identity. Unpublished doctoral dissertation, University of California, San Francisco.

Quint-Benoliel, J. C. (1970). The developing diabetic identity: A study of family influence. In M. V. Batey (Ed.), Communicating nursing research: Methodological issues (pp. 14-32). Boulder, CO: WICHE.

Rainwater, N., & Giordano, B. (1984). Improving compliance, Module #11. In AADE's Continuing Education Self-study Program, Pitman, NJ: American Association of Diabetes Educators.

Robbins, D. C. (1988). Pointing fingers (Editorial). Diabetes Care, 11, 734-744.

Rost, K. (1989). The influence of patient participation on satisfaction and compliance. Diabetes Educator, 15(2), 139-143.

Sackett, D. L. (1976). The magnitude of compliance and noncompliance. In D. L. Sackett & R. B. Haynes (Eds.), Compliance with therapeutic regimens (pp. 9-25). Baltimore, MD: The Johns Hopkins University Press.

Sackett, D. L., Becker, M. H., MacPherson, A. S., Luterback, E., & Haynes, R. B. (1974). The standardized compliance questionnaire. Hamilton, Ontario, Canada: McMaster University.

Sackett, D. L., & Haynes, R. B. (1976). Compliance with therapeutic regimens. Baltimore, MD: The Johns Hopkins University Press.

Sandelowski, M., Davis, D. H., & Harris, B. G. (1989). Artful design: Writing the proposal for research in the naturalistic paradigm. Research in Nursing & Health, 12, 77-84.

Sanson-Fisher, R. W., Campbell, E. M., Redman, S., & Hennrikus, D. J. (1989). Patient-provider interactions and patient outcomes. Diabetes Educator, 15(2), 134-138.

Schafer, A. L., McCaul, K. D., & Glasgow, R. E. (1986). Supportive and non supportive family behaviors: Relationships to adherence and metabolic control in persons with Type I diabetes. Diabetes Care, 9, 179-185.

Schafer, L. C., Glasgow, R. E., McCaul, K. D., & Dreher, M. (1983). Adherence to IDDM regimens: Relationship to psychosocial variables and metabolic control. Diabetes Care, 6, 493-498.

Schatzman, L. (1986). The structure of qualitative analysis. Paper presented at the International Sociology Conference, New Deli, India.

Schatzman, L. (1988). Anchoring grounded theory. Unpublished manuscript. University of California, San Francisco, Department of Social and Behavioral Sciences.

Schatzman, L. (1991). Dimensional analysis: Notes on an alternative approach to the grounding of theory in qualitative research. In D. Maines (Ed.), Social organization and social process: Essays in honor of Anselm Strauss. New York: Aldine de Gruyter.

Schatzman, L., & Strauss, A. L. (1973). Field Research, Englewood Cliffs, NJ: Prentice-Hall.

Schlenk, E. A., & Hart, L. K. (1984). Relationship between health locus of control, health value, and social support and compliance of persons with diabetes mellitus. Diabetes Care, 7, 566-574.

Schroeder, K. A. K. (1981). Symbolic interactionism: A conceptual framework useful for nurses working with obese persons. Image, 13(3), 78-81.

Sims, D. F., & Sims, E. A. H. (1989). Motivation, adherence, and the therapeutic alliance. Diabetes Spectrum, 2(1), 27-35.

Stensman, R. (1989). Body image among 22 persons with acquired and congenital severe mobility impairment. Paraplegia, 27(1), 27-35.

Stern, P. N. (1980). Grounded theory methodology: Its uses and processes. Image, 12(1), 20-23.

Stimson, G. V. (1974). Obeying doctor's orders: A view from the other side. Social Science and Medicine, 8, 97-104.

Strauss, A. L. (1987). Qualitative analysis for social scientists. New York: Cambridge University Press.

Strauss, A. L., & Corbin, J. (1990). Basics of qualitative research. Newbury Park, CA: Sage Publications, Inc.

Strauss, A. L., Corbin, J., Fagerhaugh, S., Glaser, B. G., Maines, D., Suczhet, B., & Weiner, C. L. (1984). Chronic illness and the quality of life (2nd Ed.). St. Louis: C. V. Mosby.

Trostle, J. A. (1988). Medical compliance as an ideology. Social Science and Medicine, 27, 1299-1308.

Tupling, H. (1981). You've got to get through the outside layer: A handbook for health educators, using diabetes as a model. Diabetes Education & Assessment Programme of the Royal North Shore Hospital of Sydney and the Northern Metropolitan Health Region of the Health Commission of New South Wales.

Turner, J. H. (1986). The structure of sociology theory, 4th Edition. Chicago: The Dorsey Press.

U. S. Bureau of Census (1990). National health interview survey. National databook: Statistical abstracts of the U. S. (110th edition). U. S. Department of Commerce.

Wallerstein, N., & Bernstein, E. (1988). Empowerment education: Freire's ideas adapted to health education. Health Education Quarterly, 15(4), 379-394.

Watkins, J. P., Williams, T. F., Martin, D. A., Hogan, M. D., & Anderson, E. (1967). A study of diabetic patients at home. American Journal of Public Health, 57, 452-459.

Williams, T. F., Martin, D. A., Hogan, M. D., Watkins, J. D., & Ellis, E. V. (1967). The clinical picture of diabetic control studies in four settings. American Journal of Public Health, 57, 441-451.

Wilson, R. C., & Jones, P. W. (1989). A comparison of the visual analogue scale and modified Borg scale for the measurement of dyspnoea during exercise. Clinical Science, 76(3), 277-282.

Wysocki, T., Green, L., & Huxtable, K. (1989). Blood glucose monitoring by diabetic adolescents: Compliance and metabolic control. Health Psychology, 8(3), 267-284.

Ziegler, O., Kolopp, M., Got, I., Genton, P., Derby, G., Drouin, P. (1989). Reliability of self-monitoring of blood glucose by CSII-treated patients with type 1 diabetes. Diabetes Care, 12(3), 184-188.

APPENDIX A

Indices of Blood Glucose Control

American Diabetes Association (1988)

Biochemical Indices of Metabolic Control: Top Limits

Biochemical Index	Normal	Acceptable	Fair	Poor
Fasting plasma glucose	115	140	200	>200 mg/dL
Postprandial plasma glucose	140	175	235	>235 mg/dL
Glycosylated	6	8	10	> 10%

Adjust for normal values of laboratory, and increase limits for elderly patients.
Any change of insulin should be made cautiously and only under medical supervision.

APPENDIX B

Letter to Potential Subjects

RAE L. JAYNE, R.N., M.S., C.D.E
DIABETES RESEARCH STUDY
415-563-5658

Date

Subject's Name
Subject's Address

Dear:

I am writing to you as a former participant in the UCSF Diabetes Center education course to see if you would be interested in being part of a study I am now conducting.

The study is to help health professionals understand the process people go through in fitting their diabetes treatment plan into their everyday activities. I am interested in finding out how you manage your diabetes, what events or people influence how you take care of your diabetes, and what level of blood sugar control you feel you have. It is hoped that this information will help health professionals better understand the experience of living with long-term treatment plans for diabetes and help them to better assist in diabetes care.

What you will be asked to do if you participate in the study is to spend an hour to an hour and half talking with me on two occasions. These sessions will be about two to three months apart. At the first interview you will be asked some questions about yourself, you will be asked to estimate your level of blood sugar control, and a finger stick will be done to collect a glycosylated hemoglobin level. The second interview will also have you estimating your blood sugar control and having a finger stick done for another glycosylated hemoglobin level. These test results will be shared with you when the results are available. The interviews will be scheduled at a time and place that you choose. I am more than willing to meet you at a time or place that is convenient for you.

Participation in this study will have no influence on your care at UCSF, and you are free to decline to be in this study, or to withdraw from it at any point.

If you are NOT interested in having me call you to set up an appointment, please sign the enclosed card and return it to me. If I do not receive the card from you in two weeks time, I will be calling to set up an interview time. Thank-you for your consideration.

Sincerely,

Rae L. Jayne, R.N., M.S., C.D.E.
Doctoral Candidate, School of Nursing
University of California, San Francisco

APPENDIX C

Consent Form

UNIVERSITY OF CALIFORNIA
CONSENT TO BE A RESEARCH SUBJECT

A. Purpose and Background

Dr. Sally Rankin, Ph.D., R.N. and Rae Jayne, M.S., R.N., are doing a study looking at how adults with Type I diabetes incorporate the management of diabetes into their daily activities. The purpose of this study is to generate knowledge about diabetes that will enable health care professionals to assist clients with their diabetes management.

B. Procedures

If I agree to be in the study, I will be asked to participate in the following procedures on two occasions, two to three months apart:

1. I will be asked to meet with the researcher to answer a series of questions about my understanding of what diabetes is and how I manage the care of this illness. I will be asked about events, people, and situations that influence the decisions I make about my diabetes management.

2. The interviews where the questions will be asked will be audio tape recorded.

3. I will be asked to make an estimate of the level of metabolic control I have attained with my current management practices.

4. A blood sample will be drawn from a finger puncture at each interview (two times). The sample will be one drop of blood each time.

These procedures will take place at a time and place determined by the researcher and myself, and will take a total time of about three hours.

C. Risks/Discomforts

1. Some of the questions may make me feel uncomfortable, angry, or upset, but I am free to decline to answer any questions I do not wish to, or to stop the interviews at any time.

2. Study records will be kept confidential as is possible. No individual identities will be used in any reports or publications resulting from the study. Study information will be coded, identified by number only, and kept in locked files. The audio tapes of the interviews will be destroyed after transcription and coding is completed.

3. The blood test will be collected through a finger puncture, may be uncomfortable, and could possibly lead to skin infection. Procedures to minimize this risk will include thorough hand washing with soap and water prior to the puncture and the use of a disposable, single use lancet for obtaining the blood drop.

D. Benefits

There will be no direct benefits to me from participating in this study. The anticipated benefit is the better understanding on the part of health professionals of patients' experiences in dealing with the long-term treatment plans required to care for diabetes mellitus.

E. Alternatives

I am free to choose not to participate in this study. If I do not sign this consent, I am declining to be in this study.

F. Costs

There will be no costs to me as a result of taking part in this study.

G. Reimbursement

There will be no financial reimbursement to me for participating in this study. I will be given a copy of the results of the glycosylated hemoglobin test.

H. Questions

I have talked to the investigator, Rae Jayne, about this study, and have had my questions answered. If I have any further questions about the study, I may call her at (415) 476-5029 or (415) 563-5658.

If I have any questions or comments about participation in this study, I should first talk with the investigator. If for some reason, I do not wish to do this, I may contact the Committee on Human Research, which is concerned with protection of volunteers in research projects.

I. Consent

I have been given copies of this consent form and of the Experimental Subject's Bill of Rights to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on my own present or future status as a patient, student or employee at UCSF.

_____ _____

Date Subject's Signature

_____

Signature of Person Obtaining Consent

APPENDIX D

Interview Guide

INTERVIEW GUIDE

FIRST INTERVIEW-TIME ONE

Explanation of study: confidentiality; use of tape recorder. Explanation of procedure: filling out demographic information at beginning of the interview; interview format.

DEMOGRAPHIC DATA

Date: _____ Code Number: _____

Age: _____

Age at diagnosis: _____ Sex: _____

Occupation: _____

Source of insurance payment for health care:

Private Insurance _____
Medical ___
Medicare ____
Out of pocket ____

Complications of diabetes:

Retinopathy (eye) _____

Nephropathy (kidney) _____

Cardiovascular (heart) _____

Neuropathy (nerve problems) _____

Diabetes regimen:

One shot/day _____
Two shots/day _____
Three shots/day _____
Four or more shots/day _____ (if more than four, how many? _____)
Insulin pump _____

Ethnic Identity: White____ Afro-American____ Chinese/Chinese American___ Japanese/Japanese-American___ Fillipino/Philipino___ Pakistani/East Indian____ Other Asian____ American Indian or Alaskan Native___ Mexican/Mexican-American/Chicano___ Latin-American/Latino___ Other Spanish/Spanish American___ Arabic/Middle Eastern___

Questions related to history of diagnosis and understanding of what diabetes is.

1. When did you first learn about your diagnosis of diabetes?

2. What was that experience like for you?

3. How did you feel being told you had a chronic illness?

4. What was your understanding of the diagnosis?

5. What did you think diabetes was? How did you know this information?

6. What did you think caused the diabetes?

7. What kind of experience had you had with diabetes or other illnesses before that time?

8. What kinds of practices did you have to start doing then that you had not done before? What regimen was prescribed?

9. How difficult was it to follow?

10. What was the hardest part?

11. What made it hard for you?

12. How did the diagnosis affect those around you?

13. How did the diagnosis change your relationship with your family, friends, co-workers? (Probe about what these groups consisted of; what kind of work were they doing; in what ways did the diagnosis change relationships, if in any way?)

14. What did these people do that was helpful to you in terms of your diabetes care? Unhelpful?

15. VAS will be given and subject asked to complete it. Finger puncture will be done and blood sample collected.

Interview one will close by asking for any additional comments the participant might want to add to what we have talked about; give sheet entitled Diabetes Research Study to note any thoughts on interview or questions that come up before next interview; set approximate time for next interview.

DIABETES RESEARCH STUDY
Rae L. Jayne, RN
563-5658

If there are any questions you would like to ask at our next meeting that you forgot to ask today, please write them on this paper and we will talk about them next time. Also, if you think of anything you would like to add to our last discussion, put those thoughts down on this paper also.

SECOND INTERVIEW - TIME TWO

Go over sheet entitled Diabetes Research Study for any details subject added since last interview; summarize data from first interview and clarify any issues raised in transcription of first interview tape; explain procedures for this interview.

Questions related to how person takes care of diabetes; what kinds of regimens are used; how did they decide to follow these plans?

1. What do you do now to take care of your diabetes? (Probe use of diet, self-monitoring of blood glucose, exercise, relaxation therapy, people who help them with care).

2. What is your insulin regimen now?

3. Is this what your health care professional asked you to do? (Probe for differences).

4. Is the regimen you use now different than what you have done in the past?

5. If there are differences, why have changes been made?

6. How much time does it take each day to care for your diabetes? Does the care interfere with other activities?

7. Describe a typical day's activities, include how your diabetes care fits into your schedule? (Probe for work activities and responsibilities).

8. How does your diabetes care fit into your life goals and plans?

9. How well do you feel your diabetes care activities help you stay healthy? (Probe relationship of activities and complications either those present or thoughts on how metabolic control impacts the occurrence of complications).

10. How do you get feed-back on how well your diabetes management is working? (Probe for who gives feedback, what symptoms give information about metabolic control, what tests are done to confirm control).

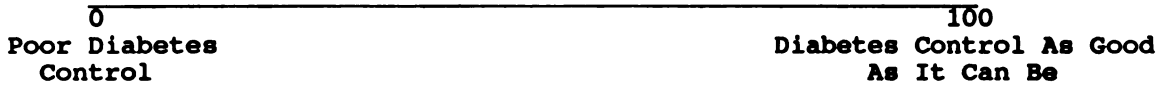
11. VAS will be given and subject will be asked to complete it. Finger puncture will be done and blood sample collected.

12. After the VAS and GHB are collected, subject will asked: Is there anything else you would like to add that I have not asked you about that you feel is important to this study?

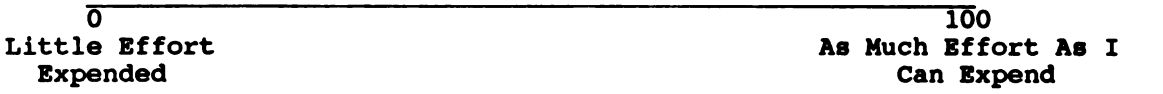
APPENDIX E

Visual Analogue Scales

ESTIMATE OF DIABETES CONTROL
VISUAL ANALOGUE SCALE



ESTIMATE OF EFFORT EXPENDED TO ATTAIN DIABETES CONTROL
VISUAL ANALOGUE SCALE

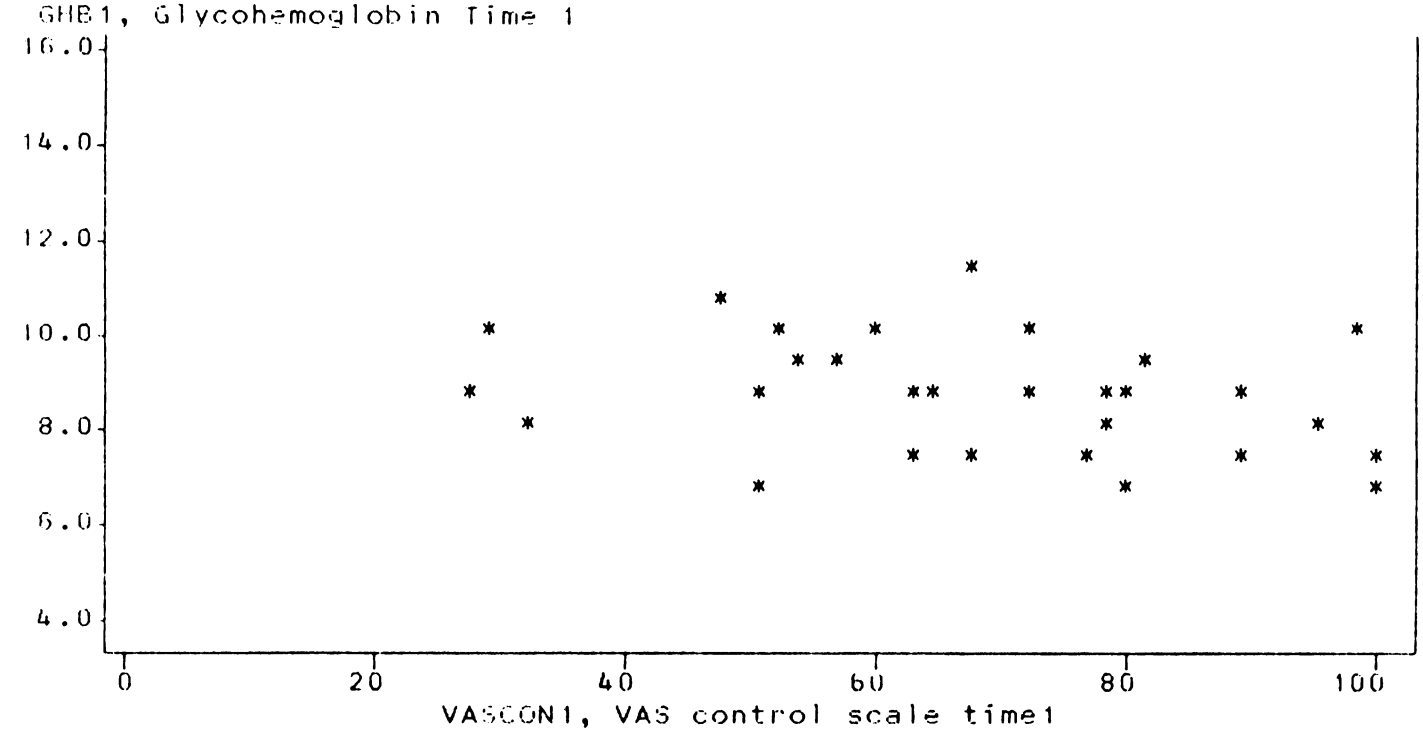


APPENDIX F

Scatterplots of VAS Scores/GHb Levels

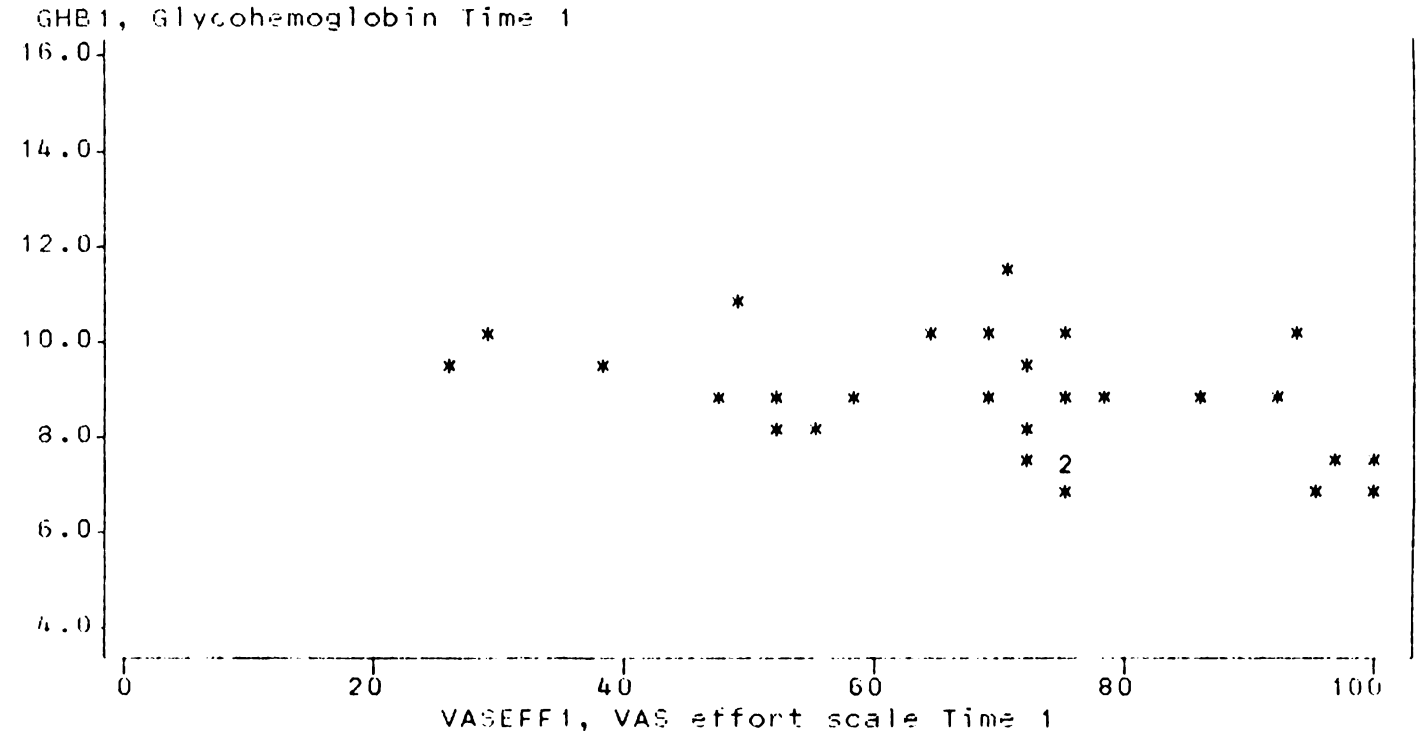
Module: SCATTER, Scatterplot 06-24-1992 Page: 1
File: RAE1, Demographic and Data file- Dissertation

FILTER: Reject if id=12



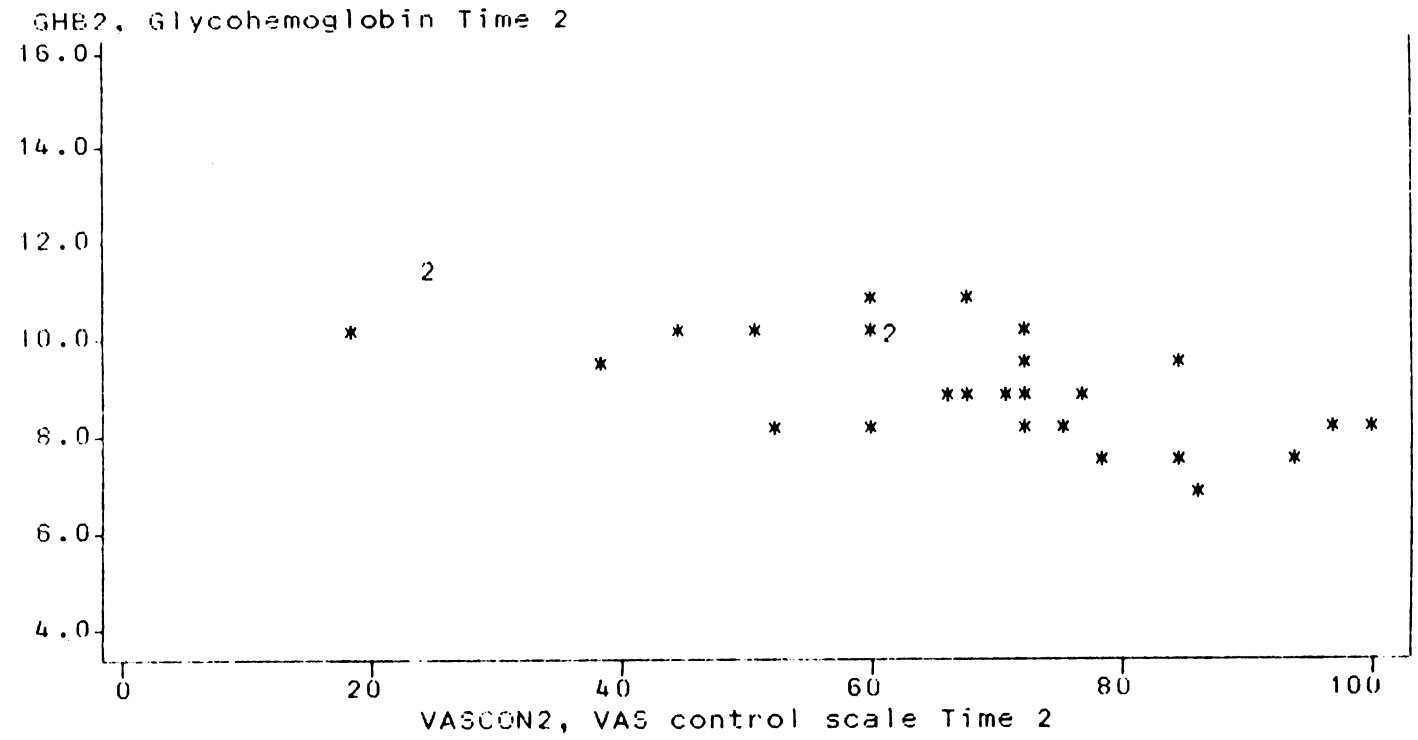
Note: VASCON1 x GHB1 plotting symbol: *

FILTER: Reject if id=12



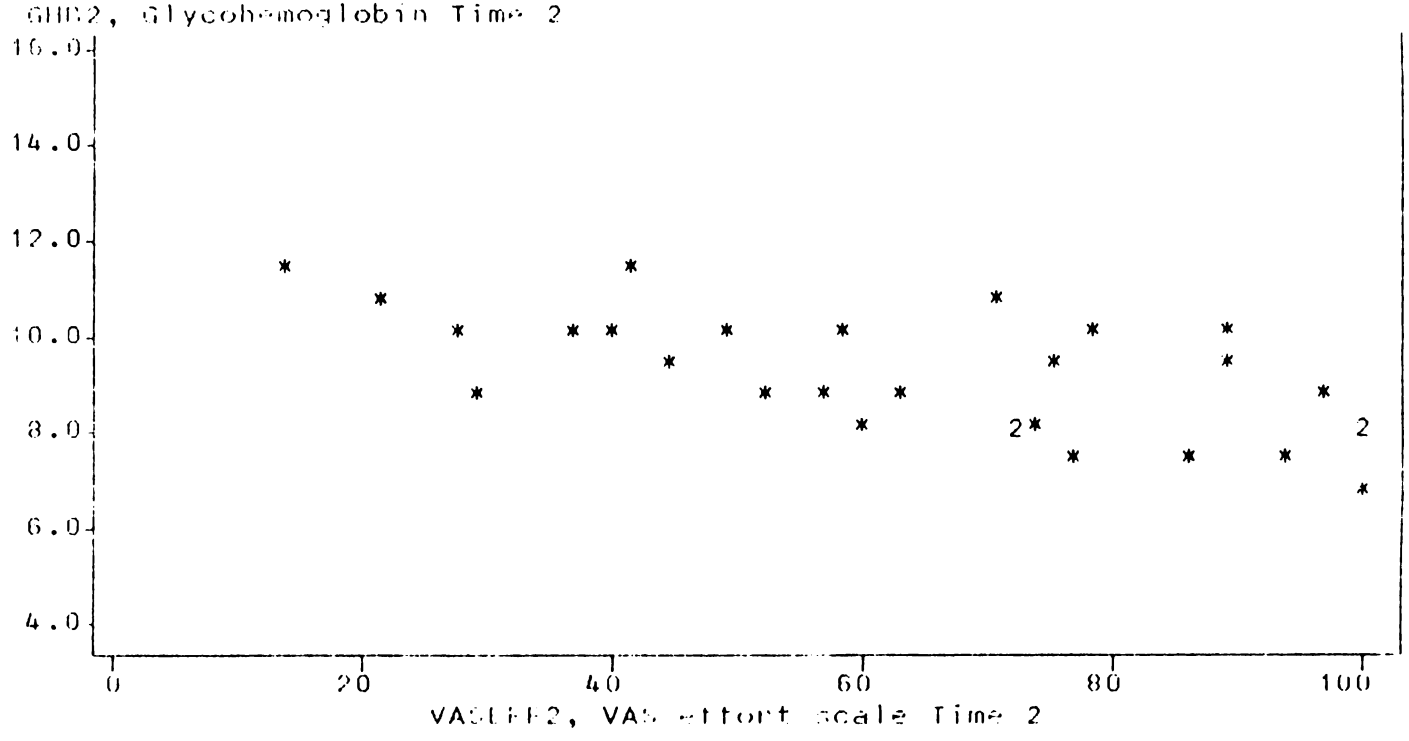
Note: VASEFF1 x GHB1 plotting symbol: *

FILTER: Reject if id=12

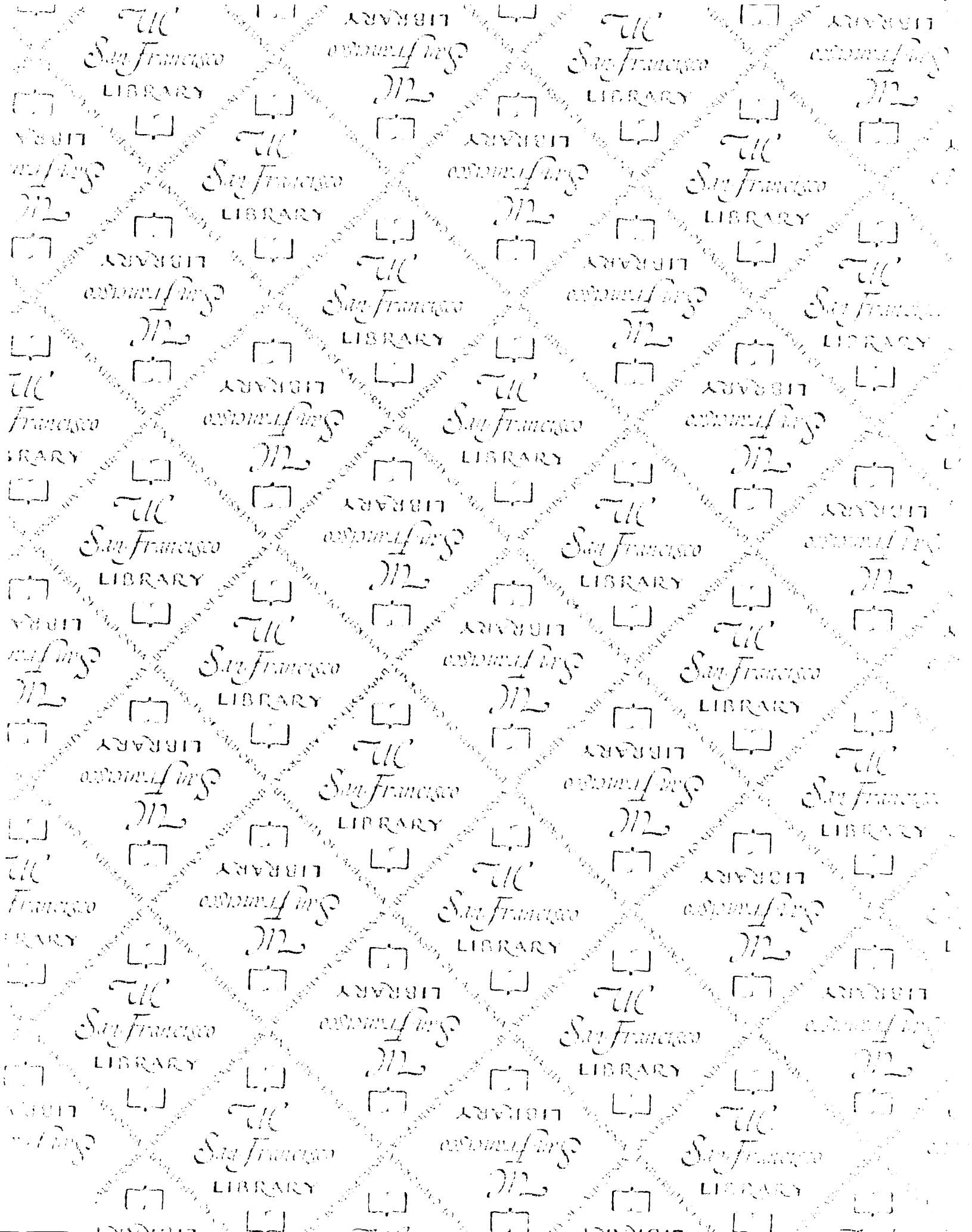


Note: VASCON2 x GHB2 plotting symbol: *

FILTER: Reject if id=12



Note: VASEFF2 x GHB2 plotting symbol: *


The
San Francisco
LIBRARY