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PERCEIVED UNCERTAINTY ASSOCIATED WITH THE MANAGEMENT TRAJECTORY OF A CHRONIC ILLNESS - DIABETES MELLITUS

by

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DEDICATION

This work is dedicated to Helen Abramson in appreciation for her unfailing support and encouragement. She has been my staunchest "cheerleader" and "cheerer-upper", offering her humor, good food, advice, and common sense during the five years of this doctoral endeavor. More importantly, she has reflected the full wisdom of her 88 years and infused me with hope when my future felt uncertain. Her friendship to me is timeless, and I thank her from the bottom of my heart.

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PERCEIVED UNCERTAINTY ASSOCIATED WITH THE MANAGEMENT TRAJECTORY OF A CHRONIC ILLNESS - DIABETES MELLITUS

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The 'unknown' is a constant companion of persons with chronic illness. Existing literature has presented uncertainty within the contexts of economics, decision-making, prediction, tolerance, control, stress, and physician/patient ambiguity. Minimal attention has been given to uncertainty as it is experienced within the context of a chronic illness situation, except as a quantifiable variable.

The purpose of this research was to explore the experience of uncertainty within a chronic illness, diabetes mellitus, and development of substantive theory of the phenomenon. Personal uncertainty was defined as: "when not knowing disrupts meaning or coherence of a personally salient situation".

Using grounded theory methodology, two in-depth interviews were conducted with a purposive volunteer sample of 19 adults, ages 24 to 53, with insulin-managed diabetes mellitus, of at least one year duration and without known complications. Interview questions pertained to areas of chronic illness described in the literature as disruptive or confusing, and special attention was given to the uncertainties identified by participants.

The central theme identified by participants was that of diabetes management. This phenomenon, termed "management trajectory", consisted of two major processes: 1) learning to manage (called "getting regulated"), and 2) maintaining management, (termed "being regulated"). Four contributing factors and their components - monitoring, cognitive strategies, control, and personal considerations - were also identified and found to vary at different points within this trajectory. Uncertainty was intricately connected with and appeared to change in intensity and focus over the course of the trajectory.

The identification by participants of a management trajectory composed of sequential phases, each with identifying characteristics, indicates the importance of acknowledging and seriously considering the patient's perspective of living with diabetes. Identification of the management trajectory may also serve to sensitize health care providers not only to the patient's experience of diabetes, but also as an organizational framework for clinical assessment of diabetes management and as a guide for content and placement of diabetes learning activities. The study has implications for descriptive and predictive research exploring the trajectory and its related components with families, with Type II diabetes, and with other chronic illnesses, as well as further explication of the monitoring strategies identified in this study - "body listening", blood/urine testing, information from health care providers, and information from significant others.

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PERCEIVED UNCERTAINTY ASSOCIATED WITH THE MANAGEMENT TRAJECTORY OF A CHRONIC ILLNESS - DIABETES MELLITUS

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PREFACE

So absolute is our soul's need of something hidden and uncertain for the maintenance of that doubt and hope and effort which are the breath of its life, that if the whole future were laid bare to us beyond to-day, the interest of all mankind would be bent on the hours that lie between; we should pant after the uncertainties of our one morning and our one afternoon; we should rush fiercely to the Exchange for our last possibility of speculation, of success, of disappointment; we should have a glut of political prophets foretelling a crisis or a no-crisis within the only twenty-four hours left open to prophecy. Conceive the condition of the human mind if all propositions whatsoever were self-evident except one, which was to become self-evident at the close of the summer's day, but in the meantime might be the subject of question, of hypothesis, of debate. Art and philosophy, literature and science, would fasten like bees on that one proposition which had the honey of probability in it, and be the more eager because of their enjoyment would end with sunset.

From George Eliot's *The Lifted Veil*

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CHAPTER ONE

Introduction

The chronic illness literature has offered anecdotal accounts of the difficulties in living with a chronic illness, and implicates uncertainty as a major component of the experience (Wiener, 1975). Medical sociologists have also described the uncertainty inherent in both providing care (Eddy, 1984; Fox, 1978; Katz, 1984; Light, 1979; and Atkinson, 1984) and in patient - doctor communications (Davis, 1963; and Mason, 1985).

Although uncertainty has been acknowledged as a major component of chronic illness (Gerson & Strauss, 1975), it has received minimal, systematic investigation within an illness context and no qualitative methodologies have been applied to explore it. The focus of this research study is on the experience of uncertainty associated with a chronic illness, specifically diabetes mellitus. This includes identifying what uncertainties exist, why, if and how they change over time, and what action, if any is taken to deal with them.

Problem Statement

The problem statement guiding this research was:

> "How do perceptions of personal uncertainty both shape and become shaped by chronic illness?"

Because uncertainty has been suggested as a major component of chronic illness, this study sought to explore the concept through qualitative methodology to identify under what conditions within a chronic illness people perceive unknowns as uncertainty and what the consequences can be.

My interest in uncertainty evolved from providing nursing care to adults with diabetes mellitus. These patients often indicated a lack of knowledge about their disease and appropriate medical management, and subsequently made seemingly inappropriate management choices. But "not knowing" was not limited to information about diabetes. There were doubts about self-esteem, self-confidence, and social acceptance. They also described a sense of body failure and not being able to trust what the body would do. They asked questions of how to cope on a daily basis, particularly when the prescribed treatment did not make sense or seemed to run counter to the expected effect.

This uncertainty was often phrased as "what does it mean?", as in "what does it mean to <u>me</u>?" (to my future, to my understanding of myself, to my commitments and responsibilities). This question according to Kreitler and Kreitler (1976) denotes a distinction between information and meaning, so that while the person may be asking "what is this disease?" they are also asking "how will I be affected personally?"

In order to address the problem statement and probe the experience of uncertainty within chronic illness, a sensitizing definition was developed to guide this research project. The word "personal" was added to uncertainty to further distinguish it as belonging to personal perceptions and responses to unknowns. Personal uncertainty specifically means to address the experience of "not knowing" and to recognize that that experience is not always amenable to justification or to direct, clear answers in informational terms from any outside source.

Personal Uncertainty

> when not knowing disrupts meaning or coherence
> of a personally salient situation.

The definition was developed after careful analysis of the existing literature and research on uncertainty, in which available definitions of uncertainty were limited to expression of probability and predictability.

The definition emphasizes significance/meaning as placed within a particular context of personal relevance. By a 'personally salient situation' is meant a situation which is significant and in which the individual is invested and has a personal stake in the course of events. Use of the word 'disruption' refers to a change or changes that require the person to reconsider the entire situation in terms of its significance or meaning for them personally. It does not carry the automatic connotation of being a negative change, since a situation of uncertainty can result in new possibilities that might not have been considered in more 'certain' circumstances.

There are many interesting questions surrounding the phenomenon of personal uncertainty in chronic illness. They include searching for causes of uncertainty and how coping occurs when the phenomenon is present. There are also questions of what relationship uncertainty has to other concepts of interest in chronic illness such as stress, adherence to medical treatment, social support, and self-efficacy. To be relevant, however, these questions must be predicated on a valid understanding of uncertainty; thus, this research was undertaken.

Significance

Chronic illness is a major health problem in the United States - an estimated 50% of the United States population has one or more chronic conditions, with 23 million of these individuals experiencing major activity limitations (Diamond, 1983) it is important to understand the chronic illness experience as fully as possible in order to plan prevention, educational, and long-term management therapeutics.

Diabetes Mellitus is a prototypical example of chronic illness. Approximately 10 million people in the United States have diabetes and the annual cost of the disease is estimated at 10 billion dollars. Diabetes is ranked among the 10 leading causes of death in the United States, accounting for 36,000 deaths per year and contributing to an additional 95,000 deaths. It is the principal or secondary diagnosis in about 2.8 million hospitalizations each year and is believed to be a major cause of blindness, renal failure, lower extremity amputations, and congenital malformations (Kovar et al., 1987). It is also a disease whose management is complex and requires daily administration, and one in which the management cannot guarantee prevention of the complications noted above. Therefore, diabetes was the prototype of chronic illness chosen for this research project.

The available literature related to uncertainty has been accounts of uncertainty and/or ambiguity's relationship to areas of control, decision-making, information processing, and sensed environmental cues. There has been little systematic exploration of the subjective account of uncertainty in illness situations. Such research would have significance for provider practice in three relevant areas: 1) an expanded view of the chronic illness experience; 2) a clearer understanding of patient-provider interactions; and 3) identifying critical components of the process of nursing care.

Chronic Illness

What is currently understood about chronic illness is its pervasive nature and potential for personal disruption. Several authors have expressed this disruption in their writings. Bury

(1982) captures the 'unreliability of the body' in his view of chronic illness as a three phase biographical disruption involving: changes in assumptions and behaviors that have been taken for granted, a rethinking of an individual's biography and self-concept, and a mobilization of resources to face one's altered circumstances. Reif (1975), too, describes the individual's concern with managing their life and lifestyle in a way that maintains active and effective functioning.

Charmaz (1983) represents a personal perspective as she depicts chronic illness as an experience of loss of self, or "a crumbling away of their former self-images with simultaneous development of equally valued new ones" (p. 169). Similarly, Moos (1977) and Cohen and Lazarus (1979) identify common areas of personal concerns and adaptive tasks within chronic illness situations as consisting of 1) tolerating and adjusting to negative events and realities; 2) maintaining a positive self-image; 3) maintaining emotional equilibrium and 4) continuing satisfying relationships.

An example of disruption prompted by uncertainty is illustrated in Weiner's (1984) anecdotal description of rheumatoid arthritis. She writes that the disease onset is insidious with ill-defined aching and stiffness, or sudden inflammation of several joints at once. Mobility and skills are unpredictably affected by alternating episodes of exacerbation and remission, and treatments may or may not be effective and may be coupled with serious side effects. The ambiguity is not limited to somatic complaints, but also includes a redefinition of the individual's self-image and social roles and a channeling of energies for 'good days' and 'bad days'. Table 1-1 highlights the distinctions between acute and chronic illnesses as based on uncertainty in the areas of diagnosis, treatment, prognosis and psycho-social interactions.

Although uncertainty has been assumed to play a role in stress and human responses, Lazarus and Folkman (1984) point out in their literature review that actually little empirical interest has been shown in personal uncertainty. Yet it may be the most important determinant in how people cope. They suggest that the role played by ambiguity in generating threat is extensively experienced in physical illness and disability. One of the ways it may do this is to pose a deleterious effect upon the process of anticipatory coping by obscuring what to expect or plan for. Jessop & Stein (1985) support this position by noting that with certain illness conditions, individuals are "...(unable) to structure his/her situation in a stable way because at any moment events could shift dangerously beyond his/her control". Further, Wright (1960) states that ... "whenever a situation occurs in which the consequences of behavior are seemingly unpredictable or uncontrollable, and which

DIMENSIONS OF DIFFERENCE BETWEEN ACUTE AND CHRONIC ILLNESSES

	ACUTE	CHRONIC
Causes	Infectious Agents	Risk factors
Time	Episodic/Short term	Long-term, uncertain duration with possible intercurrent, acute episodes
Signs and Symptoms	More easily identified and diagnosed. Usually a single body system involved.	Insidious, may produce no signs or symptoms in early phases. One or more systems often co-exist.
Outcomes:		
Pathophysiology	Mechanisms better understood; cure probable.	Uncertain but with probable progression of disease.
Psycho-social	Most likely minimal sequelae	Possible long-term alteration in self-image social relationships and employment.
Treatment	Prevention/cure Often self-limiting with short-term individual particition.	Reduce risk factors. Palliative measures. Requires long-term individual participation and coordination of many resources.
Goals	Prevention/Cure	Control of risk factors. Secondary or tertiary prevention. Emphasis on care not cure.

(Adapted from:
Gerson & Strauss, 1975
Burish & Bradley, 1983)

TABLE 1-1

benefits and harms occur in an apparently inconsistent, fortuitous, or arbitrary manner, insecurity of the deepest sort may be expected" (p. 10).

Benner (1986) has suggested that uncertainty may be experienced when a person perceives him/herself without a "situation" or "a place to stand". An example of this would be the individual awaiting a diagnosis or not knowing definitively about a diagnosis. S/he can not begin to respond or act until it becomes clearer <u>what</u> is to be responded to. Another example is a situation of an evolving cerebral vascular accident. As the loss of physical function and sensation progresses, the person is placed within a context that is completely novel and unknown. For a period of time the person is almost 'situationless' in the sense that s/he does not know what is happening in terms of their personal understanding of themselves, how it will unfold and the final outcome.

Antonovsky (1984, p.41) suggests that coping with stress is predicated upon a sense of coherence:

> "The sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one's internal and external environments are predictable (comprehensible, manageable, and meaningful) and that things will work out as well as can reasonably be expected".

One could infer from these authors that understanding or meaning of situations would be contingent upon a sense of coherence and without this coherence or "place to stand" one may experience uncertainty. This recognition of the significance of meaning and coherence is the basis for the sensitizing definition proposed to guide this research.

These views of uncertainty within chronic illness carry with them the inherent assumption that uncertainty is a negative experience and should be reduced or eliminated. An additional reason to study the concept is to explore the possibility that the uncertain experience may create new potential for new growth or functioning.

Uncertainty and the Health Care Provider

The experience of uncertainty in chronic illness is not limited to the patient. The health care provider must also contend with vague and ambiguous clinical situations. Eddy (1984) describes five ambiguous sources in medicine which may provoke uncertainty: 1) defining a disease; 2) diagnostic uncertainty; 3) selecting a diagnostic or treatment procedure; 4) observing outcomes, or deciding what critical outcome can be thought of as valid; and 5) assessing preferences or values of outcomes. The degree of ambiguity that can accompany any or all of these areas has prompted several coping strategies including specialization as a way of limiting the amount of information required to be known.

In 1978, Fox concluded that medical students were socialized or trained for certainty. Basically, she said, there are two areas of uncertainty -- 1) the first results from incomplete or imperfect mastery of available knowledge and 2) the second depends upon limitations in current medical knowledge. "There is also a third source which consists of difficulty in distinguishing between personal ignorance or ineptitude and the limitations of present medical knowledge" (Fox, 1978, p. 189). Comparing medical students' adjustment to ambiguous situations/information, Fox concluded that by the fourth year the medical student has identified specific strategies for dealing with uncertainty -- group/colleague support, social comparison of decisions and actions, and the reliability of actual experience or dogma from attending physicians.

Katz (1984), Light (1979) and Atkinson (1984) suggest that medical students are actually trained for 'certainty'. That is, rather than accepting the irrevocable ambiguity, they are encouraged to dispel ambiguity and discomfiture with uncertainty by reliance on facts, dogma and technology. The significance of their own uncertainty gets habitually suppressed to the point that significant information (the patient's personally meaningful information and possibilities), sensitivity and empathy to the patient's uncertainty becomes limited along with intervention possibilities. Such denial of awareness of uncertainty serves to make matters seem clearer, more understandable and more certain than they actually are.

That most physicians cannot even discuss the concept of uncertainty except in the most abstract, theoretical sense, Katz (1984) says, is a problem of "...not uncertainty of medical knowledge but the capacity to remain aware of, and the willingness to acknowledge, uncertainty" (p.37). This may be, in part, what Davis (1963) calls the 'function' of uncertainty. He asserts that while clinical uncertainty (ambiguity) does exist, there are times when members of the medical community use prognostic or diagnostic uncertainty to avoid interactions when the patient or family respond emotionally or with questions that cannot be readily answered.

Viewing the situation strictly from a medical perspective tends to present a conceptualization of the disease as separate from the individual. The medical model concludes that what is most valued and considered to be credible is the epistemological aspect of uncertainty, i.e., reducing or constructing information into that which can be objectified, verified and known with "certainty".

An example of the disparity that may exist between provider and patient perceptions of uncertainty was highlighted in Mason's (1985) description of 91 patients who were followed for one year. All were newly diagnosed with diabetes mellitus. Patients were found to be distressed by continuing uncertainties about the nature of the disease from which they suffered and about important aspects of self-management required of them. The 'doctor-centered' style of communication adopted by health professionals was not conducive to the resolution of these uncertainties. Assertion of a biased view of certainty, at the expense of ignoring the patient's sense of uncertainty, serves to invalidate the patient's experience. An explication of the patient's experience and understanding of personal uncertainty might serve to sensitize providers to patients concerns and to target interventions which acknowledge and validate the patients' experience. In addition, such knowledge might make it easier to consider a patient-provider cooperative stance as an alternative to the present contractual position of providing health care.

Significance of Research in Personal Uncertainty for Nursing

Traditional nursing practice, in contrast to that of medical practice, has tended to emphasize 'care delivery' rather than cure and to place less emphasis on 'certainty', and more on processes which support and maintain a level of health that is possible for the individual. Trends toward self-care have been fostered by nursing to the extent that many nursing plans of care reflect self-care outcomes as the goal of nursing interventions. This process is grounded in not only an understanding of pathophysiology, treatment, and resource utilization, but also in a recognition of the importance of individualized care, and the individual's experience and perceptions of their illness situation.

There is minimal nursing research addressing the effect of perceptions of uncertainty on chronic illness. To date, only Mishel's research (1981, 1983, 1984) has been directed towards measuring uncertainty in the illness experience. Her findings have indicated that for hospitalized patients ambiguity is a major factor in contributing to patient/family stress. In one outpatient study (Mishel, 1984), ambiguity was also shown to be the variable which explained the degree of stress experienced in an illness situation. Mishel's development of an uncertainty questionnaire and subsequent correlational research has sought to quantitatively measure uncertainty. A qualitative study could be informative to nursing practice by explicating the experience of uncertainty, particularly the conditions under which uncertainty occurs, how it is perceived and how it is managed.

Summary

Chronic illness is the major health problem of the United States today, and diabetes mellitus constitutes a major portion of the chronically ill population. It is also well acknowledged that persons with chronic illness experience more than changes in physiological functioning. Given the descriptions of Bury

(1982), Reif (1975), Charmaz (1983), Moos (1977) and Cohen & Lazarus (1979), chronic illness could best be described as the experience of a disease process within an individually meaningful psycho-social-cultural context. Chronic, permanent changes in physiological functioning may bring about an experience of "not knowing" relevant to body reliability, social functioning and the self as a person with a past, present and future. This experience of "not knowing" in relation to one's understanding of themselves and interactions with others is described as 'personal uncertainty'. The purpose of this study, as identified in the problem statement, is to explore the experience of personal uncertainty pertaining to a chronic illness, specifically diabetes mellitus. Additionally, the aim of the study is to develop substantive theory (also referred to as mid-range theory by Glaser and Strauss, 1977) of study findings.

The significance of this study pertains not only to better understanding the patient's experience with chronic illness, but also to the relevance of uncertainty in patient-provider interactions. Diagnosis, treatments and prognosis carry their own ambiguity and may be confronted by health care providers with a false sense of certainty and security. The provider's need for certainty may conflict with the patient's need for validation of their own experience of uncertainty. Theoretical development of the phenomenon of personal uncertainty could better inform providers of the relevance of considering this phenomenon in practice. Such development might also serve to guide future correlational and hypothesis testing research related to chronic illness.

CHAPTER TWO

LITERATURE REVIEW
AND THEORETICAL PERSPECTIVE

The following literature review includes scientific conceptualizations of uncertainty, research literature pertaining to uncertainty and ambiguity, and a critique of the research in relation to its use for background support of this study. The review begins with a brief discussion of the philosophical background which has guided Western culture's investigation of uncertainty. Relevant research is organized by the concepts associated with certainty/uncertainty - control, tolerance and risk, heuristics and decision-making, and perception. The limited research on uncertainty in illness situations is also included. Following the summary discussion, Section Two concludes this chapter with the theoretical perspective, Symbolic Interactionism, chosen to guide this study on personal uncertainty.

Western Philosophical View of Uncertainty

The concept of uncertainty is significantly influenced by the world view of Western philosophy, and subsequently our Western culture, which not only acknowledges 'certainty', but whose perception of good science is aimed toward explicit explanation, prediction, and control.

The question of how we can "know with certainty" has plagued philosophers for centuries. Martin Heidegger saw this quest for certainty as the origin of modern metaphysics:

> "The metaphysics of the modern age begins and has its essence in the fact that it seeks the unconditionally indubitable, the certain and assured, certainty".
> (Guignon, 1983, p.23)

Descartes could be credited with initiating the quest for certainty. From a stance of extreme skepticism, he proceeded along the lines of philosophical logic to establish all the ways in which he could 'know'. Through careful structuring of logical arguments, he concluded:

1) I exist
2) God exists (as antecedent to human existence)
3) My clear, distinct ideas are true, since God guarantees them and
4) the physical world corresponds to my clear distinct ideas of it. (Levine, 1981, p.181).

In Descartes' view, and in the view of philosophers who followed his views on Rationalism, cognitive, rational knowing is <u>the</u> key to understanding and explaining our physical and mental worlds, or, more specifically, it is through the mind that we retrieve reality. The mind is the only rational and predictable way of knowing. Descartes' legacy provided an explanation of the 'self' as 'subject/object' and an epistemologic assumption that all thinking processes and all behaviors can be organized into formal knowledge governed by causal/universal laws. By such objectification, all knowing can be verified and commensurable.

Philosophical trends since the time of Descartes have profoundly influenced a Western world view which strives for certainty, predictability, and control. This heritage easily points the way to which certainty might be accomplished, that is, via packaged information in discrete units; rational, active decision-making; and environmental control.

The research literature evolving from the Western philosophical perspective reflects attempts to identify antecedents and consequences of uncertainty. Available definitions of uncertainty have mainly considered four factors - the probability of an event, the predictability of an event, an individual's tolerance of and preference for predictability and control, and the individual's cognitive perception of an event/situation. The definitions have come from a variety of disciplines (economics, organizational management, medical sociology, psychology, nursing) which have attempted to determine the effects of uncertainty within specific areas. Table 2-1 lists definitions of uncertainty proposed from specific disciplines and their derivative concepts (see Table 2-1).

Most of these definitions of uncertainty imply (or make explicit) that uncertainty is a feeling of unease, and as such will be perceived as stress. However, as personally experienced, uncertainty may evoke several meanings and, thus, several possibilities regarding a particular situation. In this regard, uncertainty could be viewed as having a positive effect of opening up possibilities.

Common themes of these definitions reflect the premise that uncertainty is primarily faulty cognitive perception precipitated by an ambiguous event occurring in the individual's external environment. The terms 'uncertainty' and 'ambiguity' are often used interchangeably; however, in the psychological literature, Lazarus & Folkman (1984) suggest that a distinction can be made between ambiguity and uncertainty in the following way: ambiguity as associated with the event itself, and uncertainty pertaining to the individual meaning associated with the event. Norton (1975) indicates a similar point of view in his description of uncertainty as 'a state of mind' created by ambiguity, and ambiguity as a consequence of a situation, event, or interaction. These distinctions are useful distinctions between uncertainty as a human experience and uncertainty as pertaining to the environment.

Interestingly, not all cultures recognize the phenomenon of uncertainty as relevant. Wright, et al.(1977) has written of the cultural differences in probabilistic thinking and finds that

DEFINITIONS OF UNCERTAINTY

Area	Derivative Concepts
Economics/Organizational Theory	
Connolly (1980) As derived from Classical Decision Theory: "...probability of each consequence of all alternative actions are not known".	Probability
Hougland & Shepard (1980) Uncertainty reflects 1) unpredictable environmental elements; 2) inadequate perceptions of the relationships, or 3) both	Predictability Cognitive perception
Lerner (1980) Uncertainty arises from ambiguity or ignorance. Uncertainty arising from ambiguity is more pervasive and diffused than uncertainty arising from ignorance.	Adequate cues Information availability
Lorenzi (1980) Uncertainty is a general lack of predictability or precision in estimation. It can function either as threat or open up possibilities.	Predictability Probability
Starbuck (1976) Uncertainty is inevitably a characteristic of a perceiver.	Perception Personality trait
Duncan (1972) Uncertainty results from 1) lack of information regarding the environment; 2) lack of knowledge regarding consequences of a decision; and/or 3) an inability to assign probabilities.	Information processing Probability
Downey (1977) Uncertainty is any lack of sure knowledge about the course of past, present, future or hypothetical events. It may result from uncertainty regarding technical-material factors and/or perceptual uncertainty.	Information processing Cognitive perception

Table 2-1 (Table 2-1 continues)

Area	Derivatives
Psychology	
Budner (1962) Ambiguity is a cognitive state created when an event cannot be adequately structured or categorized because of lack of sufficient cues. An ambiguous situation results when there is: 1) novelty; 2) complexity; and/or 3) insolubility	Cognitive perception Event cues
Monat (1972) Temporal uncertainty is not knowing when an event will occur, but probability is known. Event uncertainty exists when probability of occurence is not known.	Event cues
Norton (1975) Ambiguity has been denoted as multiple meanings, vagueness, incompleteness, fragmented, probability, unstructured, lack of information, inconsistencies, contradictions and contraries, and unclear. Ambiguity is a consequent of a situation, event or interaction. Uncertainty is a state of mind created by ambiguity.	Affective or feeling state
McIntosh (1974) Uncertainty occurs when a decision maker is unable to assign definite values to objects and events and/or is unable to predict outcomes. Ambiguity is the inability to place an event within a comprehensive gestalt, wherein cause and effect are not discernible.	Event cues Decision making
Medical Sociology	
Davis (1960) Uncertainty can be either 'real' or 'functional'. Real uncertainty pertains to knowing little or nothing about a situation; while 'functional' refers to the use of uncertainty as a strategy to manage a situation.	Event cues

Table 2-1

(Table 2-1 continues)

Area	Deriviative
Medical Sociology, continued...	
Fox (1978) Three basic types of uncertainty: 1) lack of mastery of what is known; 2) limits of knowledge itself; 3) difficulty distinguishing between 1 and 2	Information processing
Nursing	
Mishel (1983) Uncertainty is a perceptual variable and occurs in situations where the decision maker is unable to accurately predict outcomes	Decision making Probability/ Predictability

Definitions of Uncertainty
Table 2-1

the Chinese, who are 'fate-oriented' are less likely to take a probabilistic view of the world. For example, astrology is taken seriously in Asian culture, and this type of forecasting helps to minimize any serious doubts one might have of one's life course. The research presented in this chapter, however, does correspond to the Western view that "certainty" is possible via environmental control. Our Western culture also carries the inherent value that this kind of control is desirable and preferrable.

Uncertainty Research

Various disciplines have been interested in and studied uncertainty - psychology, economics, sociology, organizational theories. Usually the research in any one field is directed towards the issues which are of central interest to that particular area. For example, psychology may be interested in how people behave in uncertain situations, while theories of organization and administration may be most interested in how people attend to information to make decisions.

Contributions from these areas have been borrowed and used across fields of interest, thus making it difficult to organize this body of literature by specific disciplines. Therefore, this literature review on uncertainty has been organized conceptually according to the variables that have been used to measure uncertainty or serve as proxy indicators of uncertainty. These concepts include 1) predictability and control; 2) tolerance and risk; 3) heuristics and decision-making; and 4) perception.

Uncertainty - Predictability and Control

Some of the earliest work on the effects of unpredictability and lack of control in situations was conducted by the discipline of psychology. Prompted by the drive/arousal model, so popular in the 1950's and 1960's, laboratory studies were conducted in which uncertainty was equated with lack of control over aversive stimuli. The major hypothesis was that persons' negative reactions (as measured by physiological indicators - heart rate, sweating, and blood pressure) could be minimized if the situation allowed for personal control/manageability or if the person had the option of escaping or avoiding the stimuli.

The aversive stimuli was most often an electric shock or loud noise varying in frequency, duration and intensity, with subjects (most often undergraduate students) randomly assigned to either a situation of control or no control. Physiological findings associated with experimental delivery of electric shock in a laboratory setting have been inconclusive in predicting any one particular, universal, physiological response. Epstein and Clarke (1982) and Evans et al. (1984) found nonsignificant variation in heart rate, and skin conductance to experimental aversive stimuli, but did notice consistent patterning during anticipatory phases suggesting an expectancy association with subsequent diminishing trends in heart rate once the stimuli and experimental conditions had been experienced.

Seminal work in these laboratory experiments on control and predicitability of aversive stimulit was conducted by Averill (1973), and Averill et al. (1972, 1977) in which they concluded that people prefer predictability when the event is aversive (i.e. electric shock with control versus electric shock with control). From a review of the control and stress literature, however, Lazarus and Folkman (1984) suggested that in real life events, people may prefer unpredictability which permits one to hope that the event will either not occur in their proximity, near future, or even in their lifetime.

Miller (1980) suggested that the variables of control and predictability were being confounded. She concluded that " controllability is preferred and less arousing because it provides the individual with additional predictability" (Miller, 1980). Miller's work is influenced by three theories - Seligman's (1968) Safety Signal view, Weiss's (1971) Relevant Feedback hypothesis, and Berlyne's (1960) Information Seeking. The Safety Signal explanation posits that when a signal (cue) reliably predicts danger, the absence of the signal reliably predicts safety and relaxation. Weiss's hypothesis is similar, in that having control reduces stress because when one is able to avoid or escape an aversive stimulus, one in effect chooses stimuli that are no longer associated with a stressor. The non-aversive stimuli are now associated with a response of avoidance or escape (Miller, 1980). Berlyne's hypothesis emphasizes the significance of having as much information as possible about the cues of an event in order to decrease uncertainty about the event and increase predictability. By having sufficient information, elements of conflict, arousal and surprise are reduced.

Miller (1979) proposed a Minimax theory of control which hypothesizes that people choose control not because it will make event cues more predictable, but because it will allow them to do something about the event/situation. She reported that there are three ways in which a person can have control in aversive events: 1) instrumental control provides the individual with actual control to the extent that s/he may even avoid or escape from the situation; 2) self- administered control which does not include the escape provision, but does allow control over the degree and duration of the aversive event; and 3) potential control concerns a belief that one can either control the event but in actuality has no control or does actually have control but chooses not to exercise it. A fourth type of control, 'actual', is proposed by Miller to denote control as distinct from predictability.

Miller (1980) and Church (1964) contend that people choose instrumental, self-administration, and potential control not because event cues are more predictable (i.e. that something is known about the event) but because control means one can actually do something about it. Their research has attempted to provide theories about why this happens and to predict what type of control individuals will choose under what conditions. Church's Internality Hypothesis explains control's function as a matching process. Using a yoked control paradigm in which persons are paired - one with control and one without - in a laboratory situation, the person with control is the first to be administered with the aversive stimuli. His/her choices form the parameters of the type and exact manner in which the stimuli will be delivered to his/her partner.

Church's findings indicated that even with known parameters (but without control) the non-control partner preferred control because, as Church posits, each person experiences the same stimuli differently and seeks to match the external stimuli to their internal state (mood, feeling, physiology). The Minimax Hypothesis proposed by Miller (1979) says it is not the matching which explains the opting for control, but rather the effect of guaranteeing an upper limit on how bad the situation can become. This is also affected by the fact that a person with control will attribute the cause of relief to his/her response. Such a response is now seen as a stable, internal source. With the addition of the attributional premise, the Minimax hypothesis predicts that when an event is perceived as personally controllable, the individual will attribute the effects (outcome) to his/herself (the reliable predictor), but when the danger is uncontrollable external attributions are made to less stable referents - luck, the experimenter, God, bureaucracy.

What is the explanation for persons not choosing control in unpredictable/aversive situations? Ball and Vogler (1971) found that under varied experimental conditions of electrical shock stimulus, a small group of subjects chose any offered alternative, even extra shocks, in order to avoid self-administration of the stimulus. The investigators had hypothesized that the subjects would opt for self-administration over random stimulus delivery, thus indicating preference for control of aversive stimuli. Other subjects, in interviews after the experiments, indicated they were not making a choice from any personal preference of control/no control, but were trying to "outlast the experimenters" or engaging in fantasies about being a captured spy and equating the random shocks with bravery.

The Minimax hypothesis predicts that individuals will relinquish control under conditions where internal factors (own control) are construed as less stable than external factors. For example, the person traveling by car over mountainous country lanes might prefer a driver who has had more experience driving on those roads. This relinquishing hypothesis is thought to apply to situations: 1) when the individual is not certain s/he can reliably execute the response needed to produce an outcome; 2) when s/he is uncertain that the response would reliably lead to the desired outcome; and 3) when the individual has to discover what the response is that will reliably lead to an outcome (Miller 1980, p. 89). The Minimax hypothesis lags here because, as Thompson (1981) points out, Miller has not accounted for cognitive factors such as motivation and incentives which may influence an individual's choice to participate in or attempt to assume control over an event (as Ball and Vogler's subjects indicated).

From economics theory individual needs and goals enter into the control equation as choice and outcome assessments. The value of expected outcomes is called 'utilities' in economic language and 'valences' in Expectancy Theory. Such valences (+/-) are expected to vary from person to person. Tversky (1967) offers the following model of subjective expected utility:

$$\text{s.e.u. (act)} = \sum_{i=1}^{n} P_i \cdot X_i$$

P_i is one's subjective probability which may be influenced in ways described earlier by Connolly, Tversky and Kahneman, and X_i is the personally assigned value of the expected outcome (also called "utilities").

The second concept, then is that of utility (or outcome) maximization, which predicts the person will choose or try to control or manipulate the environment in such a way as to bring about the greatest return for the least amount of resources expended. While the subjective expected utility varies with individuals, the utility maximum principle is considered as nomothetic.

To summarize the literature presented thus far, uncertainty has been associated with predictability and varying degrees of control over situations. What this body of work begins to uncover is the conditions or events that may or may not evoke a control response. Although this body of research implies that not having control over a situation or not being able to predict an event is equivalent to uncertainty, the research findings from simulated laboratory situations have limited generalizabilty to actual lived situations. Folkman (1984) indicates that personal factors, such as beliefs and personal meanings of a situation, have not been considered in research questions of control. She suggests that with human behavioral research, one must also ask the question of 'control over what'? And that a person's appraisal or whether or not they have or want control is dependent upon generalized beliefs and the context of the situation.

This question of personal control has been explored as a static personality trait. A brief review of this literature is included here because uncertainty could be considered to occur when a person feels a lack of personal control over a situation or a lack of confidence about handling a situation if or when it does occur.

Locus of Control

Rotter (1966) and Bandura (1977) have taken the value expectancy theory in different directions to predict whether or not an individual will seek to control situations. From a social psychology perspective, Rotter suggests that one's 'locus of control', which is a generalized expectation of a relationship between one's acts and various rewards for punishments, will determine an individual's control behavior. Rotter's theory fits with that of the utility model and the reinforcement (behavioral link) between act and outcome.

Bandura (also from a social psychology perspective) distinguishes between expectancies and self-efficacy. Accepting the expectancy definition in utility terms, he further emphasizes one's perceived self-efficacy as a critical factor in control behavior. Self-efficacy may further explain why persons relinquish control.

Self-efficacy, a cognitive concept, is defined as the self-judgement that one either is or is not capable of organizing and executing a course of action to achieve a particular outcome. The functions of self-efficacy are considered to affect one's choice of action, how much effort will be expended to a task and the emotional and cognitive responses to a task, such as attention to, degree of stress and anxiety, and goal setting (Bandura 1986). The strength of the link between self-efficacy and action choices can be influenced by incentives (motivations and anticipated consequences), available resources, physical/social constraints and temporal disparities (the time between making a judgement and carrying it out). This cognitive behavioral model helps to explain why individuals may not choose control even though they feel capable of performing or controlling. For example, assuming personal control often increases one's burden of responsibility as well as investment of time and energy. Or to take a specific action may evoke a powerful, but unwanted, emotional response such as fear. It is conceiveable that individuals may perceive an event as unpredictable or uncertain, yet not exercise control over the event/situation even though they perceive such control as possible. They are, in effect, choosing uncertainty/ unpredictability over control.

Recent nursing research by Crabtree (1986) tested self-efficacy as a predictor of specific diabetes self-care behaviors - diet, medications, exercise and general management. Using a 30 item Diabetes Self-Efficacy Scale specifically developed, piloted and utilized for the research, her findings indicated that self-efficacy was the best predictor of self-care behaviors of diet, exercise and general management.

Tolerance for Ambiguity/Uncertainty

To continue with the theme of control and personal appraisal, it is appropriate to examine the suggestion that there are personal preference styles for tolerating ambiguity and/or risk. The psychoanalytic ego psychology has sought to classify persons according to styles (broad, encompassing ways of relating to others and situations in general) and traits (properties of persons predisposing them to react in certain ways) (Lazarus & Folkman, 1984). Research in the area of ambiguity/uncertainty searches for trait-situation combinations that will be predictive of an appraisal or behaviors of uncertainty. Extended to the concept of uncertainty, the question becomes: will persons tolerant of ambiguity react in specific ways to ambiguious situations and intolerant persons react in another? Another assumption within this view is that there are "good" and "not so good" ways of coping with ambiguity, and tolerance of ambiguity is the more desirable trait to possess.

Some of the earliest work in this area was reported by Frenkel-Brunswick (1949) on 1500 school children. When relationships between personality, perception and motivation were studied, she found that some of the children tended to consider both positive and negative factors of a situation in a "balanced" way, while others considered the situation in predominately one extreme or the other. This raised the question of whether or not tolerance of ambiguity is a factor in how situations are perceived.

Budner (1962) continued in exploration of this question and attempted to measure it by developing a Tolerance-Intolerance of Ambiguity Scale (TIAS). The final version of the scale contained 16 items, each linked to at least one of three types of ambiguity - novelty, complexity, and insolubility - and tapping one of the four postulated indicators of perceived threat: 1) phenomenological submission - anxiety and submission; 2) phenomenological denial - repression and denial; 3) operative submission - avoidance behavior; and 4) operative denial - destructive or reconstructive behavior.

Using 17 convenience samples of students in a variety of educational settings (total $n = 1005$), the TIAS was administered to all subjects and scores were correlated to three general areas: 1) socially relevant beliefs and behavior; 2) personal value systems; and 3) occupational choice. The following hypotheses were posed and supported that individuals who are intolerant of ambiguity - 1) tend to be more conventional, $r = .32$, $p <.05$; 2) express a stronger religious belief with less questioning about beliefs (mixed significance between 3 samples); and 3) are more amenable to authority ($p <.05$).

Ironically, even with the hypotheses supported at the .05

level, Budner suggested that the idea of ambiguity tolerance as a stable personality variable did not take into consideration the values, goals, resources of the individual nor the individual's conception of reality as dependent upon past experiences and intended future. He also acknowledged that correlations found in his data may have been tapping into confounded constructs, such as 'authority' confounded with perceived value of 'censorship'. He concluded that rather than being a personality variable, tolerance or intolerance of ambiguity was probably a way of evaluating reality rather than a stable trait or style of coping.

Norton (1975) indicated that Budner's instrument (TIAS) lacked adequate internal reliability and validity evidence and proposed instead the Measurement of Ambiguity Tolerance (MAT-50). Instrument items (60) were framed around a combined definition of intolerance and ambiguous "... a tendency to perceive or interpret information marked by vague, incomplete, fragmented, multiple, probable, unstructured, uncertain, insconsistent, contrary, contradictory, or unclear meanings as actual or potential sources of psychological discomfort or threat" (p.608). The implicit definition of ambiguity was derived from a content analysis of articles dealing with ambiguity as referenced in Psychological Abstracts from 1933 to 1970 in which ambiguity was used in the context of one of the following eight categories - multiple meanings; vagueness;

probability; unstructured; lack of information; uncertainty; inconsistencies; and unclear, that is, the word "unclear" was used synonymously with ambiguous.

Using 1496 undergraduate subjects the scale was administered seven times with final internal reliability (K-R 20) of r = .88, with test-retest after 10 to 12 weeks at r = .86. Content validity was assessed by an item's fit to the eight categories and its connection with phenomenological denial or submission and/or operative denial or sumission as previously described by Budner (1962). Criteria-related validity was assessed by comparison to scales of attitude rigidity, dogmatism, and Budner's instrument. The strongest relationship appeared between that of the MAT-50 and rigidity of attitudes (r = .57). In Norton's assessment of criteria-related validity, the low correlation values call this validity into question.

Construct validity of MAT-50 (that is, tolerance of ambiguity) was measured by 1) comparing the subject's willingness to volunteer for an ambiguous situation and the MAT-50 scores; 2) subjects' tolerance scores on ambiguous-unambiguous poetry compared to MAT-50 scores; 3) correlations of MAT-50 scores with language patterns from verbal interviews of 272 subjects; and 4) MAT-50 score comparison to dramatization analysis of verbal interviews. Norton reports that all four areas were positively and significantly correlated. Research by MacDonald (1970) suggested that persons having high tolerance of ambiguity seek out ambiguity and enjoy it and excel in the performance of ambiguous tasks.

Shalit proposed that ambiguity is a major factor in appraising and coping with events. His meta-analysis (1977) attempted to measure structural complexity of situations as an assessment of objective ambiguity and its effect on coping. From a review of 380 articles pertaining to psychological abstracts and medical abstracts in which coping was included as a dependent measure, 75 articles were randomly chosen then classified for coping and situational structure. Coping was rated as either poor, reduced or good, and situational structure was rated according to differentiation (number of possibilities of perception of a situation), articulation (how clearly differentiated possibilities are), and loading (the positive or negative emotion associated with the situation). The hypothesis proposed was an inverse relationship between coping effectiveness and reduced situation structure (i.e., increase ambiguity).

Using the Multidimensional Scalogram Analysis (MSA) which identifies and 'maps' similarity of patterns, Shalit (1977) analyzed the 75 articles for coping and complexity. This mapping schema supported the hypothesis, but also revealed differences in the three dimensions. Articulation was most clearly associated with failure to cope, that is, the more difficult it was to distinguish between possibilities, the more ineffective the coping. Emotional loading had the potential to interfere with effective coping and the number of possibilities in the situation had the least effect on coping. Shalit concludes that his data support the literature of ambiguity as a threat factor and that coping potential is most directly effected by whether or not situational ambiguity can be resolved.

Uncertainty as Risk

Research in the area of risk follows the earlier investigations of tolerance for ambiguity. Like MacDonald suggested, perhaps there are not only people who tolerate ambiguity well, but may actually seek out situations with unknown outcomes.

Building upon Feinkel-Brunswick's studies, Zuckerman (1960) developed the Sensation-Seeking/Risk Taking instrument which seeks to distinguish between individuals who are highly tolerant/intolerant of ambiguity and the likelihood of their engaging in risk-taking situations. He concluded that highly tolerant individuals were less likely to appraise situations as risky (as rated after reading written descriptions of situations) and were more likely to engage in risk-taking endeavors.

Lorenzi (1980) describes 'risk' as positioned midway on a certainty-uncertainty continuum. It is, he says, "...the state lying between these two extremes, where the individual has a knowledge of the probability distribution of outcomes associated with his/her choices" (p.286). This is similar to Knight's (1929) hypothesis that uncertainty is a probability continuum, ranging from subjective to mathematical probability. But is taking a risk different from feeling or being at risk?

Tversky and Kahneman's research on their Prospect Theory, an expansion of the Utility or Expectancy Theory's premise that a person will choose the prospect that offers the more valued outcome, concluded that the perceieved probability of an outcome is a major factor of whether or not a situation is considered risky (1981). This was tested in simulated gambling situations wherein subjects were told that one participant in ten would actually be "playing" (making decisions based on probability) for money. By verbally framing the probabilities and associated risk in a variety of ways, the investigators identified and numerically weighted personal variations under specific experimental conditions.

In a survey with known risk-takers (Farley, 1986), several common elements were identified: 1) preparation for the event; 2) the attention to the process of the act - preparation for it and detailed anticipation of the actual event, similar to imagining the experience and what would be required during the experience; and 3) the expression of enjoyment associated with the activity - the 'love of doing it' and 'seeing if I can'.

These characteristics support Montagna's (1980) defnition of risk as "controlled uncertainty", the degree to which is subjectively and perceptually determined.

It is apparent that the risk-takers applied a great deal of skill and preparation to their activity, but the event was not described as confusing or incoherent. The unknown was the outcome, but even that had a degree of predictability based on their perceptions of their skill and readiness. This may be quite different from those who perceived themselves "at-risk". An "at-risk" situation would be one in which the conditions for producing the situation may be unknown and there is a question of ability and resources to meet the situation. As a result, the outcome may be unknown such that all possible outcomes must be simultaneous considered. This suggests that "being at risk" is probably more akin to uncertainty than "taking a risk". This raises the question of the relationship between vulnerability and uncertainty and coping and uncertainty.

Lazarus and Folkman (1984) contend that vulnerability is closely associated with the degree of committment or involvement an individual has in a situation. Situational ambiguity can evoke or intensify a sense of vulnerability, and, subsequently, one's ability to cope with the situation. Folkman, Shaefer, and Lazarus (1979) assert that ambiguous situations can propel the person into behaviors of high vigilance (anxiety), denial, and avoidance. The authors also note that "there are a host of unresolved empirical issues linked to tolerance of ambiguity-uncertainty" and that these include understanding not only personality traits for tolerance, but also situational factors that affect tolerance, and these relationships with coping styles or choices (Folkman, et al., 1979, p. 280).

Uncertainty - Probability, Heuristics and Decision-Making

Psychology's investigation of uncertainty and ambiguity has been influenced by research in other disciplines, such as economics and organizational theory, two areas which are affected by ambiguity and uncertainty. These areas have been concerned with what people consider when making decisions or choices, under what conditions those considerations change and how, and personal actions, such as coping behaviors, that are likely to be used within a given type of situation.

George Shackle (1961), an economics theorist, defines and conceptualizes uncertainty as probability specified at two levels: 1) distributional, where statistical probability estimates can be drawn, thus uncertainty would be considered in terms of probability; and 2) nondistributional uncertainty, where the amount of knowledge is insufficient to make a decision on the basis of probability estimates. In everyday life, however, such distinctons are not so clear, and, on a more personal level, all situations have possibilities with or without probabilities.

In a conceptualization similar to Shackle's, Knight (1921) hypothesizes from the perspective of a probability continuum, with uncertainty ('subjective probability') on one end and certainty (mathematical probability), situated on the other end. This model is still employed in neoclassic economics today and assumes a maximum utility view in which "...individuals (are seen) as rational, self-interested beings selecting freely from among known alternatives of action in order to maximize their marginal productivity" (Montagna, 1980, p 18).

This view is further equated with information- processing in terms of how an environmental display gets attended to, registered, encoded and retrieved, leading perhaps to decision-making. This framework is veridical, normative and excludes emotions as a significant factor (Lazarus, 1985). This suggests that uncertainty (and ignorance) are reduced by specifying and quantifying information which can then be rationally considered. Cognitive factors of motivation, social comparison, incentives and personal goals are structured and decontextualized (and in utility theory assigned algebraic positions), while meaning and practical knowledge of skills and practices are excluded from consideration.

Expectations and predictions that people consider all probabilities in a logical, rational manner which is embedded in consistent and coherent thought (similar to a mathematical equation) is an 'assumption of human rationality' (Tversky and Kahneman, 1981). Through their research, Tversky and Kahneman (1974) declare that this is a false assumption and indicate three significant heuristics operating in 'rational decision-making', particularly when an individual is faced with complex and ambiguous events:

1) Representativeness - probabilities are evaluated by the degree to which situation A is representative of B as biased by inappropriately generalizing prior experiences to the present (e.g., stereotyping). This also includes generalizing information from a small sample size (even 1 or 2) to one's self or group and assuming that chance alone will be a self-correcting factor.

2) Availability - probabilities of an event are based on previous instances or occurences that can be brought to mind. For example, one may predict one's risk of a heart attack based on the number of people s/he has known who have had a heart attack.

3) Adjustment and Anchoring - estimates of probability are based on an intial value which is adjusted to yield or "fit" the final outcome.

The authors also suggest that decisions and choices are further biased when risk is a consideration.

Connolly (1980) posits that certainty/uncertainty is more complex than defined by classical decision theory. He explains that certainty is the case in which all consequences of all alternative actions are known, yet most real-life situations are so complex that all factors and consequences could not be known and/or rationally assessed. Connolly suggests that so-called successful decision-making may be attributable to other than rationally considered event factors or consequences. He offers some alternative suggestions for why probabilities appear to be considered beforehand, but in actuality may be considered after the event:

1) The outcome may turn out successful just by chance alone with only a few factors considered beforehand.

2) People are also prone to view the situation after the fact and then derive a rationale for a particular outcome.

3) Persons may selectively remember factors about the decision making process and emphasize those as the major contributors/antecendents.

Uncertainty - Perception

If probabilities are not always considered in a rational, consistent and coherent way, then other factors may need to be considered. Monat (1976) and Monat, et al (1972) reported that in addition to the probability of an event, the temporal aspect (when it would happen) evoked different coping behaviors in their subjects. When the laboratory event was associated with temporal uncertainty, the subjects became more vigilant. If the event was not one of "when" but "if", the attention to the situation declined. The investigators pointed out they later had difficulty in distinguishing between real avoidance behavior and subjects who were just bored.

Duncan (1972) proposed two environmental dimensions contributing to the assignment of ambiguity to an event; 1) "the static-dynamic dimension" which is the degree to which the factors of the decision unit's internal and external environment remain basically the same over time; and 2) the simple-complex dimension, which refers to the degree to which the factors in the environment are few in number and similar to one another" (p. 315). Budner (1962) also included complexity as a factor and added 'insolubility' and 'novelty'. Lazarus (1985) includes novelty, duration and temporal factors in his discussion of situation factors affecting uncertainty in stress appraisal.

In a study of perceptions of ambiguity (subjective and actual) as a factor in organizational decision-making, Lorenzi (1980) used computer simulation to engage 90 undergraduates in performing two sequential computer simulations with the second being more complex and accounting for experential learning which may have taken place in the first try. The computer simulations (except for baseline) included a stochastic error term of objective environmental uncertainty created by a random generating routine. Taking measures of individual characteristics which he speculated to be related to performance and perceived situational uncertainty, Lorenzi included seven measures:

1) Rotter's Locus of Control

2) A measure of Cognitive Complexity

3) The General Incongruity Adaptation Level developed by Driver and Struefert (1965) which is purported to measure an individual response to ambiguous and dissonant situations,

4) Need Achievement, measuring an individual's psychological need for achievement,

5) Mathematical appititude

6) Actual performance scores on both test situations

7) A Perceptions of Environmental Uncertainty Scale measuring dynamics (slow or rapid change); complexity; dominance (internal or external); need for information; unpredictability; probability fore casts to both a 5% and 10% range.

Results of the first trial strongly supported the significance of both objective environmental ambiguity and individually perceived uncertainty; however, the perceived (i.e., individual) environmental uncertainty was dominated by objective environmental uncertainty. In other words, when the environment was made highly variant, there was also higher variance in the forecast error.

Because the second trial confirmed these findings, Lorenzi concluded "...it is fair to suggest that task-related uncertainty is more critical to our understanding of uncertainty than general measures of perceived uncertainty" (Lorenzi, 1980, p. 298). An additional finding of interest was the lack of significant relationship between the individual's perceived environmental uncertainty and the actual performance. Lorenzi attributed this to the subject's ability (and confidence) and a priori beliefs about the environment. Of those who did less well in the experimental conditions, he speculated that those subjects continued to use simple operating rules and guidelines while ignoring the richness of the many possibilities offered by the computer in complex situations. In a sense, they were using the 'certainty' of more simplistic rules while ignoring the possibilities created by uncertainty. This is similar to the heuristics reported earlier by Tversky and Kahneman.

In addition to his findings that objective uncertainty was more highly correlated to performance and most influenced individual perceptions of uncertainty, Lorenzi (1980) cited Thompson's (1967) matrix of decision strategies as possible heuristics for the way in which personal appraisal of one's efficacy and goals can interact with the ambiguous environment. (See below)

Decision Strategies

	Preferences for Outcomes	
Knowledge of course/effect	Certainty	Uncertainty
Certain	Computational	Compromise
Uncertainty	Judgemental	Inspirational

Figure 2-2

Thompson's matrix depicts a utilitarian schema in which logic, arbitration, opinion and faith are neatly packaged into linear relationships accounted for by how much information one has and what one prefers the outcome to be.

Other examples of empirical research in which uncertainty is operationalized as minimal, incomplete or inconsistent perceptual cues/information, include that of Heslin et al. (1972) and Heinrichs (1984). Heslin asked undergraduate college students to describe a fictitious foreign country from limited information which was presented either positively or negatively and consistently or inconsistently. The number of alternative responses offered by the subjects were considered to be linearly associated with the degree of uncertainty experienced. Heinrichs' research was of a similar vein, in which he hypothesized that uncertainty governs aesthetic evaluations of pictures of human figures. Twenty six undergraduate students rated 36 paintings on 3 dimensions composed of 10 scales: 1) Collative - simple/complex; clear/indefinite; orderly/disorderly; familiar/unfamiliar; 2) Epistemic - interesting/uninteresting; weak/powerful; relaxed/tense; emotional/unemotional; and 3) Diversive - pleasing/displeasing; ugly/beautiful. The first four scales, considered to be the indices of uncertainty, was the sole predictor for the other ratings, but only with an r = .12.

Uncertainty Research in Relation to Illness Situations

In the arena of illness research, Merle Mishel has developed an instrument to measure uncertainty in clinical populatios and its relationship to stress and illness outcomes. Mishel's work has been seminal in nursing. Her operational definition for uncertainty is as follows:

> Uncertainty is a perceptual variable and occurs in situations where the decision maker is unable to accurately predict outcomes (Mishel 1981, p. 41).

Drawing on the work of Shalit (1977), Budner (1962), and Norton (1975), Mishel has conceived of uncertainty as having four dimensions:

1) Ambiguity - the patient's self-evaluation of the state of illness as vague and unclear;

2) Complexity - the multiple and varied cues the patient perceives about treatment and the systems of care;

3) Deficient Information - the absence of information concerning diagnosis; and

4) Unpredictability - the perceived absence of stability of the course of the illness and unpredictability of outcome.

From these dimensions Mishel has developed both the Uncertainty in Illness Scale (MUIS) and the Parents Perception of Uncertainty in Illness Scale (PUIS). Face validity of these instruments was established during piloting by review from nurses and doctors, and since its initial development, the instrument has been re-analyzed using the original data set, a 34 item, four-factor scale using a Likert-format has resulted. Reliability of the total scale has been established at a standarized alpha of .91, and reliability of the four factors are ambiguity (.91), complexity (.75), deficient information (.71) and unpredictability (.70) (Mishel, 1983).

Construct validity was initially established using 'known-groups' technique in which hypotheses differentiating between groups were supported in the expected direction. This included a group of patients awaiting diagnosis scoring higher on the MUIS than patients with a confirmed diagnosis.

Criterion-related validity was measured as the relationship between perceived uncertainty and degree of stress in a hospitalized, adult patient group. The expected directional relationship was confirmed, i.e., positively correltated, $r = .35$, $p <.001$. The hypothesis that uncertainty would be related to lack of comprehension was supported when the MUIS was converged with the Comprehension Interview adapted from the Cassileth's Recall Test, $r = -.56$, $p <.002$. The ambiguity factor showed the strongest negative correlation with the Comprehension Interview of $r = -.63$, $p <.001$.

In a correlational study of the MUIS to hospital stress (Mishel, 1984) using a sample of 268 hospitalized adults, the factor 'ambiguity' consistently explained most of the variance. In the hospital stress study, seriousness of illness, prior hospitalization, age and education accounted for 8% of the variance while entering the ambiguity factor increased the explained variance to 15%. The other MUIS factors did not add appreciably to the explained variance.

A review of MUIS's reliability and validity measures indicates that the instrument is a valid measure of uncertainty as a cognitive variable. A cluster analysis (Mishel, 1983) also reflects the instrument's sensitivity to discriminating the kinds of ambiguity, complexity, unpredictability, and information deficit with five groups of patients with different diagnostic categories. However, a quantitative measure of uncertainty determines a priori "what counts" as uncertainty. The instrument also forces a choice of pre-selected uncertainty criteria without opportunity to qualify the selection or choose another segment of the context about which the person may feel uncertain.

Summary of Literature Review

This literature review has traced the research of popular concepts associated with uncertainty - probability, predictability, control, tolerance, risk and perception - from specific disciplines (psychology, physiology, economics, nursing). The relevance of unpredictability and control as associated with uncertainty was shown to be influential on individuals' reactions in controlled laboratory situations, but predicted control responses were not consistent across studies and some subjects indicated a preference for no control, or at least preferred not to take action.

Later studies, then, turned to investigate other personal variables related to uncertainty, such as beliefs, values, motivators, traits and styles. Locus of control and the model of self-efficacy were two such examples, by addressing control as a function of beliefs regarding power and perceived ability. Literature from the areas on tolerance and risk also have contributed to discussion of whether or not persons have personality traits for ambiguity and risk tolerance. Again, these reports are from experimental designs simulating ambiguous situations. Because accounts from risk takers indicated a sense of preparedness and predictability in the risk chosen, the question arose regarding the relationship of ambiguity to feelings of vulnerability and its influence on coping choices.

The literature suggests that the more ambiguous the situation, the more person-centered coping behaviors become rather than focusing on the event. These behaviors are likely to be vigilence or avoidance. Importantly, such research draws attention to both event factors and personal factors as contributing to an appraisal of uncertainty.

The area of probability and decision making was discussed with the inclusion of research and theories which have attempted to explain how probabilities are personally assessed for problem-solving and decision-making. Risk appraisal and the preferred and most personally valued outcome are hypothesized to operate as normative, explicit equations. Yet, lived situations are too complex and interactive to permit these equations to more than limited predictive capacity.

Research on the process by which a person perceives his/her environment as uncertain/ambiguous was also included, again trying to identify explicitly those components physically and cognitively sensed and attended to. Work in this area also simulated uncertainty in classroom situations by using confusing informational clues as proxy measures of uncertainty.

The last area of research addressed was that of illness and uncertainty. Mishel's Uncertainty in Illness Scale was presented along with a critique of its limitations, and Mason's qualitative research on uncertainty in a diabetes population. Both Mishel's and Mason's work, as well as the dearth of scientific information, indicate a need for continuation of qualitative research on uncertainty in the illness experience.

Theoretical Perspective

The theoretical perspective chosen for this study is that of symbolic interactionism. This perspective was chosen for two reasons. One was the need to have a theoretical framework which acknowledges personal experience, meaning and interpretation within the illness context. The second reason was the intended use of grounded theory methodology which was developed from the princles of symbolic interactionism.

Symbolic interactionism is a theory of sociology rooted in perspectives of both phenomenology and sociology. The phenomenological representative of this perspective was Edmund Husserl (1859 - 1938), an existentialist, German philosopher. Alfred Schutz (1899-1959), an Austrian sociologist, was strongly influenced by Husserl and attempted a theoretical explanation of sociology largely integrated with Husserl's views.

As reported in Chapter Two, predominant epistemological view in the Western world has been compatible with Cartesian philosophy and the search for abstract, verifiable, universal laws of nature and human science. In contrast, Husserl and contemporaries such as Hegel, James (William), Dewey, pursued a different line of thought. These men were more concerned with lived experience, or what Husserl called the "life-world", as the starting point for inquiry. According to Husserl the person's life-world is made up of "prepredicative experiences", that is, a vague awareness of all elements in our reality or environment as a "blended field", or what he also referred to as "background horizon". This reality is taken for granted, but even more importantly, is accepted as enduring and reliable (Wagner, 1983).

Wagner (1983) goes on to describe how Husserl posited that we live in our acts, we do not reflect upon them, the 'objective' reality is taken for granted. "The 'objective' reality of the world becomes a 'subjective' certainty about the manageability of the objects in it... under similar circumstances I will be able to act similarly as I acted before, thereby bringing about similar results... this principle of pragmaticability implies readiness to cope with the unexpected... an 'empirical certainty' is plausibility, presenting a 'subjective chance' that things will be what they are thought to be and will 'behave' as expected" (p.288). These experiences make up the person's every-day 'stock of knowledge on hand'.

What mattered to Husserl and similar philosophers was everyday experience and the shared meanings of those experiences. To explore meanings and perceptions, then, one must stay within the context and look to subjective interpretation. Another concept central to Husserl's perspective was that of "typification", that an individual thing is first genuinely perceived but is then called to mind as being similar to something else from one's experience (Wagner, 1983). Schutz went on to call this the "biographically determined situation", that is, an individual's unique experiences with objects give meaning and significance to the things encountered because of subjective practicality, past use and meaning. This capacity for "typification" became a central tenet for symbolic interactionists who attempt to explain social interaction as the persons' capacity to use symbols and abstract types to create meaning and a social reality.

Schutz was intrigued by these views and sought to extrapolate them to use in the "world of working", or more specifically, to explain the connection between the micro social sphere and the macro social sphere. How sociological interactions take place is first through the subjective and situational 'logic' of daily life. The working world contains all things encountered directly by the person and follows operations of "tested recipes of action" (Wagner, 1983, p. 290).

All of this presupposes a practical intelligence based upon experiences with daily life. In part of this thinking, Schutz was influenced by Merleau-Ponty, a 20th century philosopher. Following Husserlian and Heideggerian philosophical tenets about the lived experience, Merleau-Ponty suggested that practical intelligence is possible because of the way we "know" our bodies. Embodiment is "...an inseparable sense of self" (Manning

& Fabrega, 1968). The "embodied intelligence" is part of the "stock of knowledge on hand", in that we have an experience of our bodies. This becomes a "taken for granted" understanding as part of our everyday experience. This knowing is a sense of ourselves as a physical being, and one that is experienced or grasped as a whole. For example, we often describe ourselves as "in shape" or "out of shape", and while others can readily understnad the meaning of the phrases, the experience is personally unique, since no other living creature can experience our specific "in shapeness" or "out of shapeness". For example, it would surprise most of us to wake up some morning to experience our body as that of an athelete in tip-top shape if that is not our usual experience of our body!

According to Merleau-Ponty (1962), embodied intelligence gives not only an understanding or sense of being as a physical entity, it also provides us with an avenue of cultural expression that is understood (grasped intuitively) and is not a reflective process. For example, we know how to walk down a crowded street without bumping into others, how close to stand to another when we talk to them. In these and other ways, we physically understand and express ourselves culturally.

Alfred Schutz's perspective on development of sociological theory was influenced by philosophers of his time, including Husserl and Merleau-Ponty. Following in Schutz's sociological views and concern with the interaction between the individual and society, were proponents of what became known as the "interactionist" perspective - George Simmel, Max Weber, George H. Mead. This perspective placed strong emphasis on subjectivism, i.e., how the basic mental processes of the individual shapes the nature of the social world. Mead suggested that society could be viewed as a constructed phenomenon arising out of adjustive interactions among individuals. The human mind was thought to be unique in its ability to use symbols to designate objects in the environment and, thereby, construct meaning of the social world, thus the term 'symbolic interactionism' (Turner, 1982). The interactionist perspective sets out three critical points: 1) a focus on the interaction between the actor and the world; 2) a view of both the actor and the world as dynamic processes; and 3) the actor has the ability to interpret the social world.

"Ethnomethodology" emerged in anthropology from this rich background of symbolic interactionism and placed emphasis on how the individual and social world interact to establish a sense of a factual world, a consensus among individuals of a shared reality. While the interactionist would be concerned with the conditions under which definitions, norms and values occur, the ethnomethodologist would focus on how members come to agree upon an impression that there are such things as rules, definitions and values (Psathas, 1968).

Herbert Blumer, a student of George Mead, is credited with joining the interactionist perspective and ethnomethodology towards understanding how individuals can re-define situations and share social meanings (Turner, 1982). Blumer placed emphasis on the interaction as process and the preferred sociological methodology of inductive theory development. Manfred Kuhn, however, offered an alternative view of symbolic interactionism with an more structured, positivist approach and a preferred methodology of deductive theory development. He formed what is known today as the "Iowa school" (State University of Iowa), while Blumer's school of thought continued at the University of Chicago. There are points of convergence of the two schools which retain the distinctive theoretical perspective of symbolic interactionism in general (Turner, 1982):

1) Humans have the capacity to create and use symbols
2) Humans use these symbols to communicate with each other via agreed upon meaning of vocal and bodily gestures.
3) By interpreting these gestures, humans are mutually able to anticipate each other responses and adjust to each other, i.e. it is by 'role-taking' that interaction occurs, which is imaginatively assuming the position or point of view of another person.
4) These interactions form the basis of society.

Blumer and Kuhn differ, however, in five areas: 1) the nature of the individual 2) the nature of the interaction; 3) the nature of social organization; 4) method for studying humans and society; and 5) how to develop social theory.

That Blumer views the self in terms of possibilities of interactions within the context of the lived experience is evident in his statement regarding inductive theory development: "No theorizing, however, ingenious, and no observance of scientific protocol, however meticulous, are ever substitutes for developing familiarity with what is actually going on in the sphere of life under study" (Blumer, 1969).

As an outgrowth of Blumer's interpretation of symbolic interactionism and his influence on the "Chicago School", Barney Glaser and Anselm Strauss, both students of Blumer, developed an approach to theory building for sociology known as grounded theory. Grounded theory is most appropriately applied in areas in which little research has been done, i.e. for preliminary, exploratory and descriptive studies (Glaser & Strauss, 1966). Its specific focus is theory generation by linking thoroughly analyzed concepts and propositions about the phenomenon being investigated.

Grounded threory as a methodology uses the technique of constant comparative analysis to compare data by coding and categorization processes. Validity and reliability are measured not by traditional management of threats as in hypothetico-deductive research, but rather by the rigorous, faithful description of the phenomenon, how well the developed framework fits both the data and outside contexts, and by how clearly the investigator's decision trail can be followed by other researchers (Sandlowski, 1986). The resultant substantive theory developed from grounded theory methedology can then provide a direction for theory testing or further inductive research.

Summary of the Theoretical Perspective

In order to understand why and how persons perceive uncertainty in their illness experience, it is necessary to explore the historical-socio-cultural perspective of the person and their chronic illness. This area has been under-represented in symbolic interactionist thought. It is important, then, to explore personal uncertainty from a theoretical perspective which permits ready access to meaning from personal and social transaction, i.e. the micro (individual) and macro (larger socio-cultural context) merging. The symbolic interactionist approach with its connection to a phenomenological underpinning is an appropriate framework to guide the proposed research.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

Introduction

The problem statement posed for this study was stated as "how do perceptions of personal uncertainty both shape and become shaped by chronic illness?". The question pertains to the personally salient unknowns experienced by those with a chronic illness and the aim of the study is to explore this phenomenon and propose a substantive theory from the findings.

Both the significance and literature review sections of this document suggest that perceptions of personal uncertainty are probably constituted by not only the diagnosis of chronic illness (i.e., the specific disease), but also the inherent understanding of one's self as well as the understanding (coherence and saliency) of the situation. The nature of the question and the aim of the study, then, requires a naturalistic mode of inquiry and a methodological approach which permit access to an in-depth exploration of the subjects' experience with chronic illness and the associated unknowns. The methodology chosen for this study was grounded theory, which is itself based in the philosophical perspective of symbolic interactionism as proposed by Blumer

(1969). Grounded theory is an inductive approach to theory development through naturalisitc inquiry and, as a specific methodology, directs sampling techniques, data collection methods and analytic procedures to be used.

Procedure

Study Sample

Because diabetes is a complex, heterogeneous syndrome, one could expect subjects' histories (i.e., their recall of their diabetes experiences) about their disease and illness experiences to differ based on severity of disease, complexity of treatment regimens and presence/absence of complications. The desired sample was one that could uncover the broad scope of unknowns associated with diabetes as self-managed on a day to day basis. This exploration of uncertainty associated with chronic illness required a sample of participants who shared a diagnosis with similar treatment without having experienced the circumstances and, thus, the rather particular uncertainties associated with debilitating complications.

The purposive sample was recruited from an adult age range (24 to 53), based upon the criteria that they be employed, with a diabetes mellitus diagnosis for at least one year, insulin managed, and currently without diabetes complications. Subjects were chosen from those who were directing and managing their own diabetes care on a day to day basis. This purposive sample was intended to be representative of a general, 'normal' diabetic population rather than a more seriously ill population found in tertiary care settings. Subjects were recruited from an outpatient settings to provide an analysis of uncertainty unrelated to the ambiguity or unknowns inherent to in-patient institutional settings, routines and treatments.

Nineteen adult volunteers who met the previously stated criteria comprised the group of participants for this study. All were residents of the San Francisco Bay Area (residents of San Francisco or one of three surrounding counties - Marin, Alameda, Contra Costa). All participants had been diagnosed for at least one year with diabetes mellitus, the average being 7.3 years and the range from 1 to 22 years. Two participants had had a diagnosis of detected retinopathy which did not require treatment, but the group was otherwise without diagnosed, pathophysiological complications from diabetes. Three of the women participants had a diagnosis of concurrent thyroid disturbance and were treated with oral medication. One woman had been diagnosed with breast cancer three months following the diabetes diagnosis. At the time of the interview she was 9 years post-cancer treatment.

All participants were insulin-managed. Eighteen of the group were insulin-requiring, and the remaining participant, diagnosed as Type II and obese, required insulin because of unsuccessful trials of oral agents. All participants, with the exception of the subject who had Type II-obese diabetes, were using self testing of blood for glucose determinations and 17 of the sample had initially used only urine testing after being diagnosed. The subject with Type II diabetes was in the process of learning to do self testing of blood for glucose.

Seven of the participants were men, and 12 were female. This is similar to the population patterns of diabetes mellitus, in which women are more likely than men to be diabetic at younger ages (20 - 55). Seven subjects were single, four were divorced and single at the time of the interviews, and eight were married. Of the eight who were married, five had children. Four had their children prior to diagnosis and one male participant had had a child after diagnosis. All but four participants had a college education or graduate degree, and all but 3 had secure employment placement with accompanying medical benefits. Of the remaining 3, one was self-employed and having difficulty finding work; one was in the process of leaving a domestic job with no new prospects in sight; and the third had just returned to a job as delivery person but anticipated leaving that job in near future. Sample characteristics are summarized and available in Appendix A.

Recruitment Process

The initial, purposive sample for this study was recruited in three ways. One recruitment strategy involved placing ads in Bay Area American Diabetes Association chapters' newsletters which briefly described the study and the criteria for participation. (See Appendix B) Recruitment also took place through two private physician practices and one psychotherapist who conducts a diabetes support group, and through a university-based diabetes teaching program.

Each physician or agency was provided with 10 recruitment letters which they could distribute to patients meeting the recruitment criteria. Persons notified could respond directly to the project investigator and thus maintain anonymity, since the physician would notify qualified persons but would not know who did or did not decide to participate. One of the two physicians elected to post notice of the study in his waiting room with the result that two persons responded. There is no way, unfortunately, of knowing the number of persons who were eligible but chose not to respond. The other physician mailed out only one of the recruitment letters. The psychotherapist announced the study her group of approximately 12, and left fliers describing the study and directions for participation in the waiting room. Five responses, and subsequently 3 participants, were obtained from that source. (Copies of the recruitment communications can be found in Appendix C).

The newsletter approach was by far the most fruitful with a total of 16 responding, and 11 eligible for and enrolled in the study. Of the five not eligible, two had had gestational diabetes and were not now on treatment; two were not insulin-managed; and one had a duration of over 30 years and an onset in early pre-school years. Although only two subjects were directly recruited from the university diabetes teaching center, 8 of the newsletter or private support group recruits had attended that particular education class and 3 had attended an education class at their health maintenance organization. Seven of the 19 had or were continuing to attend a diabetes support group.

In sum, of the 19 participants in the study, 11 of the subjects were respondents to the newsletters, two from private physician offices, three from a private diabetes support group, and 2 from the university diabetes education program.

Data Collection Methods

After a subject was enrolled and had signed the required informed consent, s/he was interviewed twice for approximately 2 hours each time. (Informed consent is provided in Appendix D) Each interview session was tape-recorded. These interviews most often took place in the subject's home at a date and time convenient for them. Three subjects who lived in outlying areas but commuted to the city for work elected to meet in a quiet setting within the university.

The interview "program" was prepared and guided by both the sensitizing definition of uncertainty developed when preparing for this study - "when not knowing disrupts meaning or coherence of a personally salient situation" - and the disease and illness trajectories described by Strauss, et al. (1975). The disease trajectory has identified points of possible unknowns - diagnosis, treatment, and prognosis - and the illness trajectory is concerned with the manner in which an individual organizes the disease experience personally and socially. (The interview questions are provided in Appendices E)

The first set of interview questions was based on both the definition of personal uncertainty and information from the chronic illness literature. The definition of personal uncertainty used for this study suggested that uncertainty might be present when an unknown would be disruptive to individual in some personal way. In addition, the chronic illness literature suggests that the disease can be can be disruptive or problematic for the individual in several ways. These areas include 1) personal concerns associated with the time leading to diagnosis, 2) the time of diagnosis, 3) the prescribed treatment or management, 4) body changes over time, and 5) management and body experiences over time; and 6) personal and social situations. The basic interview questions changed slightly after approximately 5 or 6 first-time interviews in order to recast the questions in the common vernacular of the subjects and to probe responses offered in the first session. For example, in the first interview there were questions asked about "body trust". Since this question brought puzzled looks, the terms were changed to "body responses" or "being able to rely on their body feelings".

The second interview session involved further probing in specific areas of difficulties and unknowns related to diabetes as identified by the individual in the first interview. The questions were then asked within the context of a specific management concern, such as being able to know all the ways they seem to respond to an insulin reaction. (Both interview questionnaires and examples of "uncertainty" comments are provided in Appendix E).

The first interview also included a demographic profile which, when presented in an open-ended manner, provided a personal profile of the participant as well. During the second interview, the personal profile of each respondent broadened and sharpened. In addition, the second interview provided not only an opportunity to probe into areas presented at time one, but also reflected a repetitive pattern such that much of the initial information could be substantiated and confirmed for meaning and interpretation, thus contributing to the validity of the study. In a sense, the participants validated and reflected upon their own stories and thus identified areas of diabetes concerns. For example one woman who had repeatedly used the word "hard" in the first interview, reflected on the word at our second meeting and described in detail when diabetes was "hard" and when it was "easier" throughout her 9 year history with the disease.

In all, approximately 68 hours of interview were conducted, including time spent in follow-up phone calls to some participants in order to clarify certain categories or to verify information.

Data Analysis

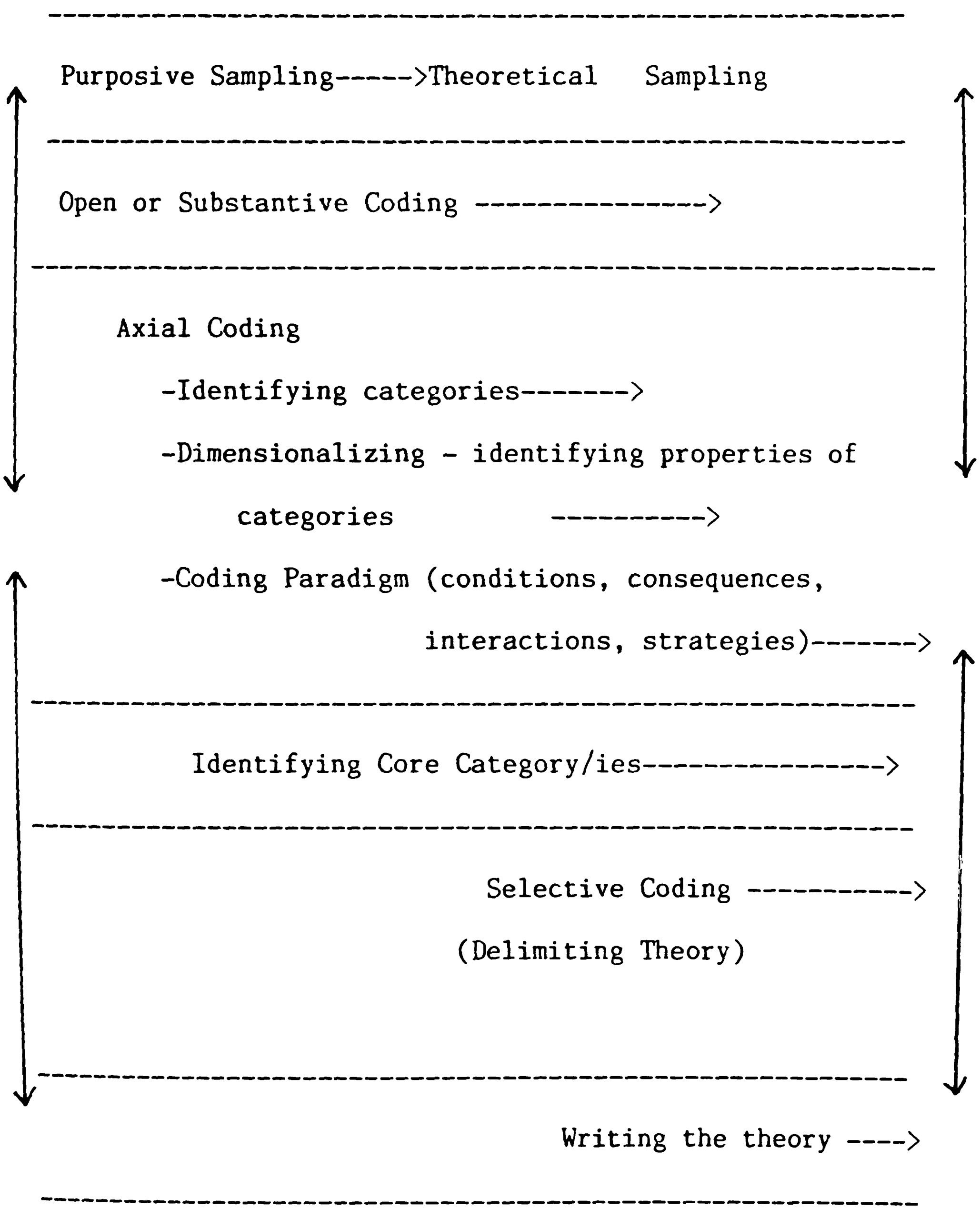
Interview data were analyzed using the primary technique of constant comparative analysis and associated processes consistent with grounded theory methodology (Glaser & Strauss, 1967). Unlike a hypothetico-deductive approach which places the major analysis at the end of data collection, analysis for retroductive theory building begins with onset of data collection and continues via specific processes throughout the inquiry. As a methodological process, grounded theory uses simultaneous collection, coding, categorizing and conceptualization (Field and Morse, 1986, p. 109). Processes utilized within this overriding framework of constant comparative analysis included simultaneous data collection, open or substantive coding, axial coding, coding paradigm, theoretical and methodological memos, selective coding, theoretical sampling and theoretical saturation. The final step in analysis is the proposed substantive theory reflecting core concepts and interrelationships as interpreted from analysis grounded in the data. These analytical processes are depicted in Figure 3-1 and are discussed in the following sections with examples from this study's data.

Open Coding

The first coding process used was that of open coding, also called substantive coding, which occurs as the researcher does line-by-line analysis of the data. Two examples from the study data of this open coding process are as follows. The first example had to do with monitoring body responses and sensations..."I trust my body about 90% of the time. I feel like I am fairly well tuned in to my body. I am always listening; running checks on how I feel. I ask myself that a lot every day. There is never a time that I am not thinking about it." This statement received the code of "tuning in" and "body listening".

The second example was related to management. "But I know more than he (doctor) does. Right after I was diagnosed I gained 20 pounds in one week. He didn't know about multiple injections and I didn't really get regulated until I went to the DTC." This statement prompted the code of "getting regulated", which this informant went on to describe as the early part of the management process.

GROUNDED THEORY OPERATIONS



Purposive Sampling----->Theoretical Sampling

Open or Substantive Coding --------------->

Axial Coding

-Identifying categories------->

-Dimensionalizing - identifying properties of categories ---------->

-Coding Paradigm (conditions, consequences, interactions, strategies)------->

Identifying Core Category/ies---------------->

Selective Coding ----------->

(Delimiting Theory)

Writing the theory ---->

Figure 3-1

Axial Coding

Axial coding is described by Strauss (1987, p.64) as

> ..."build(ing) up a dense texture of relationships around the 'axis' of the category being focused upon. This is done, first, by laying out properties of the category, mainly by explicitly or implicitly dimensionalizing it. Secondly, the analyst hypothesizes about and increasingly can specify varieties of conditions and consequences, interactions, strategies, and consequences (the coding paradigm) that are associated with the appearance of the phenomenon referenced by the category. Third, the latter becomes increasingly related to other categories" .

Concurrent with substantive coding, data of each participant were again perused and compared. This constant comparative analysis yielded the identification of broad, general themes or categories. Early on, the study data revealed approximately 11 general categories of information being described: 1) Personal profile; 2) Personal meaning of the disease; 3) Social comparison - self to self; self to normal others; self to diabetic others; 4) Etiology and pre-diabetes; 5) Self as diabetes manager; 6) Accepting the diabetes "self"; 7) Body experiences - reliability and predictability; 8) Controlling diabetes; 9) Uncertainty with health care providers and health systems; 10) Family responses and 11) Ongoing uncertainty about the future, "down the road uncertainty".

Dimensionalizing

In a process Strauss (1987) and Schatzman (in progress) call "dimensionalizing", the researcher makes inquiries about properties of each category. When categories are analyzed with such questions as "what is distinctive about this piece of the phenomenon?", "is it always the same?", "does it change over time?" then one begins to see relationships between categories. An example of the dimensionalizing process used in this study concerned the category of "self as manager", that is, the kinds of things people did to manage diabetes. Almost all of data examples reflected self-managing as gathering and using information, a category which became known as "monitoring". Monitoring was noted to occur in several ways, or to have several dimensions - testing body fluids (blood or urine); having physicians test body fluids and provide interpretations of diabetes status; noting comments, advice and opinions of others about their diabetes status/health; and by "listening" to their own "body talk". The data also reflected that use of monitoring sources could change over time and was contingent upon experience, diabetes knowledge and social context.

Coding Paradigm

Another process of analysis involved use of "coding paradigm" (Strauss, 1987). The "coding paradigm" includes examination of each category or sub-category for a) conditions; b) interactions; c) strategies; and d) consequences. For example, why and when would a person use "body listening"? How (strategies) would they accomplish body listening? Did interactions with others or environmental elements, such as blood testing results, change how one listened or interpreted their body? What were the consequences of "listening" ? From use of the coding paradigm and dimensional analysis, inter-relationships among categories could be discerned. Specifically those of health care provider interactions, social comparison, family responses and body experiences subsequently became known as avenues for monitoring and related to choices of management strategies at specific points in the management trajectory.

Memos

Throughout these analytical processes, the researcher notes ideas, thoughts and reflections about the data. These "memos" are written and become incorporated into the comparative process, as they are organized, sifted through and reorganized as new questions or coded areas/categories emerge. In addition to analyzing codes and categories, the written memos become the "map" for finding one's direction around and through the data. The memos document connections, or relationships, and are critical in linking the data conceptually. An example from this study concerned the process of learning how the body responds or can respond to different management strategies. One participant had discovered that it was the intermediate-acting insulin that had been at the root of some of his "sneakier" insulin reactions, but he had always attributed those reactions to the quick-acting insulin. After participating in an education program where he was placed solely on the quick-acting insulin he recalled how surprised he had been. A memo written at this time focused on how body response patterns are attributed to specific strategies and that body responses influence whether or not a specific strategy will be tried; also that a strategy's usefulness is assessed by the way the body responds and determines if the new strategy will be used again or discarded. Another memo noted that insulin reactions could be disruptive, scary and frightening, and subsequent interviewing focused on what made the reaction scary or frightening and whether there were insulin reactions that were not associated with negative emotional responses. These examples demonstrate that the memos both guide the early processes and data collection and assist with directing one towards theoretical sampling and eventually form the "text" of the phenomenon under study.

Theoretical Sampling

Analysis and data collection are further linked by a technique called "theoretical sampling". Strauss (1987) defines theoretical sampling as ..."a sampling of incidents, events, activities, populations, etc. It is harnessed to the making of comparisons between and among those samples of activities, populations, etc. It is sampling directed by the evolving theory" (p.21). In this study, an example of theoretical sampling was that of conducting interview questions towards gathering specific information about the management process that participants described. The need for this showed up early in the study in that some participants described their diabetes career as beginning with education and guidance using the most up-to-date information and technical advances. Other participants did not have these resources or came upon them late. This raised the question and prompted interview questions to determine whether or not there were differences in their descriptions of a management trajectory or in monitoring activities or skill in "listening" to "body talk".

Theoretical Saturation

Simultaneous data collection, coding and conceptualization also moves the researcher towards theoretical saturation which Strauss describes as ..."when additional analysis no longer contributes to discovering anything new about a category" (1987, p. 21). Using the study example of "monitoring", the data from all informants were reviewed several times for ways in which monitoring occurred, that is, what information was used and where did it come from? The data showed four sources of this information - 1) information or an understanding of their bodies "body listening" that could be generated and interpreted by themselves alone; 2) testing body fluids (urine/blood) that could be conducted alone or by others (doctor or health care provider) generated; 3) other people's comments or behaviors towards their diabetes status; and 4) interpretations of their diabetes status from their physicians. Interview probes and exploration of the data did not turn up any new category or dimension of monitoring.

Selective Coding, Core Categories and Delimiting Theory

At some point into analysis the investigator must ask "What question does this data answer?", that is, what is the central theme that ties this phenomenon together? This requires identifying the core category or core categories. Strauss (1987) describes core categories as those categories to which most other categories are related and it " 'accounts for most of the variation in a pattern of behavior'" (p. 34). The "core" being referred to is the core or central category around which all others are organized. In some studies, as in this one, there may be more than one core category. This study had two core categories - monitoring and management.

Selective coding, described by Strauss as ..."when all other subordinate categories and subcategories become systematically linked with the core" (1987, p. 69), is both a process used to identify core categories and to further analyze the remaining categories for their relationship to the central phenomenon. With relationships identified, categories and respective properties are further reviewed and analyzed and possibly merged into fewer categories until the resulting structure retains both requirements of theory - parsimony and scope (Glaser & Strauss, 1967). Through this process, the emerging theory can also be "delimited". Delimiting means to intentionally exclude categories which do not contribute to the theoretical explication of the core categories. For example, most of the participants discussed personal meanings related to diabetes, but as a category it contributed indirectly to the understanding of monitoring and management phenomenon. Therefore, it was acknowledged in the substantive theory as a part of one's personal considerations which influence one's management choices

Development of Substantive Theory

Glaser and Strauss (1967) distinguish between two types of theories which can be generated through the use of constant comparative analysis - formal theory and substantive theory. Formal theory is "developed for a formal, or conceptual, area of inquiry such as stigma, formal organization, or socialization" (Strauss, 1987, p.242). Substantive theory, on the other hand, is developed to explain a discrete, empirical area of inquiry, such as a particular phenomenon about patient care or professional education. In her discussion of model building in nursing, Stember (1986) states that models vary in their abstractness and testability, but the basic function of any model is to diagrammatically communicate "some aspect of reality" (p.104). The substantive theory proposed from this study, then, is an initial framework of associations of the findings. This framework will depend on further research for construction of directional or causal relationships. It is anticipated that the immediate utility of the conceptual rendering proposed from this study will be in providing understanding of the phenomenon and to sensitize the nurse or other health care provider to its existance (Knafl & Howard, 1984).

Early on in data collection and analysis it became clear that participants were describing a process that occurred over time. The process being learned was that of managing diabetes. The unknowns and uncertainties expressed were presented within the context of this learning process, and were noted to change over time. Some uncertainties could be ameliorated or changed by information, some by experience and some unknowns that were distressing initially remained unknown but did not always evoke the feeling of uncertainty.

The resultant development of the substantive theory of the management process is a culmination of all of the analytical steps. (See Chapter Five for complete discussion of the proposed substantive theory) The conceptual schema was presented to and discussed with three of the participants and four persons with diabetes who did not participate in the study. This was done to establish both credibility and fit which is comparable to internal validity determinations required by hypothetico-deductive research. All participants queried in this review were able to recognize their own diabetes experiences within the proposed management framework.

CHAPTER FOUR

FINDINGS AND ANALYSIS

The central phenomenon identified from the study data was "management". All participants described learning diabetes management and being guided by monitoring activities, cognitive strategies, and personal considerations. Learning to manage diabetes occurred over time, and participants described specific phases that they had been through in this process. The experienced uncertainty was described within the context of learning and/or maintaining diabetes management, and, more specifically, the uncertainty was related to the phases identified within these processes.

Participants described "management" as being comprised of two major processes - learning to manage diabetes and maintaining management of diabetes. The two processes were futher described as consisting of phases. For this reason, the central phenomenon of management was labelled "the management trajectory" (trajectory) to denote all of the diabetes learning and maintenance processes described by the informants. This trajectory assumes major importance because participants' reported diabetes experiences were organized around it.

Uncertainty did not emerge as the central theme in the data, but the data indicated that uncertainty was associated with every phase of the trajectory and strongly influenced the management process. In fact, the four factors necessary to diabetes management - 1) personal considerations; 2) cognitive strategies; 3) monitoring; and 4) control - had to be either learned or recognized as having specific interactions and effects on diabetes. Because uncertainty was described within the context of learning about diabetes management and specific situations of management, it is discussed in accordance with phase of the management trajectory.

This chapter is divided into two sections. The first section identifies and describes the management trajectory processes - "getting regulated" and "being regulated" and their associated phases (see Figure 4-1, page 91). Informants gave the process of learning to manage diabetes the overarching label of "getting regulated" - a process of learning which pertained not only to knowing and incorporating specific diabetes tasks, but also finding "what works for me". As indicated in Figure 4-1, (page 91) "getting regulated" has four identifiable phases which ideally culminate in the recognition and use of a basic routine which incorporates not only diabetes management principles but also reflects the individualization of these principles into a plan that "usually works for me". Several informants described pausing (sometimes for several years) at a particular phase and continuing to use the associated management strategies. Why they paused and why they discontinued a particular phase is discussed in Section One of this chapter.

Section One also describes the process of "maintaining" management once the basic routine is identified. This maintenance process was identified by the informants as "being regulated". "Being regulated" describes a phase of diabetes that is accomplished almost entirely from one's basic routine and using that routine to broaden the scope of management in order to participate in more situations - travel, pregnancy, sports, etc. "Being regulated" is shown in Figure 4-1 (page 91) as consisting of both "basic routine" and "trial and error", as characteristics of both are used to manage new situations.

Discussion of each phase of the trajectory incorporates and specifically identifies the four factors inherent in the trajectory. Two of these factors are the priniciple activities within the trajectory - monitoring activities and cognitives strategies. Another, that of "personal considerations", is a modifying factor, in that any management strategy is influenced by personal choice or interpretation. The fourth factor is the intention of management which is "control". Control is a term common to diabetes and often used interchangeably with the word "management". It was used frequently by participants, but their data indicate that how control is perceived, and thus defined, differs at particular points along the trajectory. Section Two provides a more explicit discussion of these four important factors of management and their relationship to the management trajectory.

The following discussion of diabetes management assumes the reader has a familiarity with both diabetes and its treatment. A brief review of current, standard medical management of diabetes is provided in Appendix F.

Section One - The Management Trajectory

All nineteen informants described a process that occurred over time and began with the recognition of symptoms they now associate with the disease of diabetes. They frequently used phrases such as "the way I do it now is to..." or ... "the way I did it before was to...", or "finally I found that what works best for me is...", and "In the beginning I...". One woman remarked, "I hope you are talking to people in the middle." By "in the middle", she was referring to people who were still learning about how to find a management routine that would work for them.

Participants varied from one another in their choices of management strategies, knowledge of the disease of diabetes, personal resources and personal meanings ascribed to the disease experience. However, the patterns of their management experiences were strikingly similar, if not exact. The repetition of the process in every personal account indicated that such a framework or trajectory exists.

The use of the term "management trajectory" (trajectory) is borrowed from the process proposed by Strauss, et al. (1975), in their description of an "illness trajectory". This includes the "total organization of work done over that (illness) course, plus the impact on those involved with that work and its organization" (p.64). The findings of this study revealed a pattern of processes of management "work" that occured over time and included others besides the participant, such that, and taken in total, it could be aptly identified by the use of the word "trajectory".

The use of the word "trajectory" is offered cautiously and with awareness that when a phenomenon is a process consisting of both overt and subtle transitions, there may be a tendency to focus solely on the overt, explicit changes. Furthermore, these changes may identified as distinct, fixed and hierarchical steps. The abstract, artificial boundaries designated by a trajectory may also imply a linear relationship between contextual elements. The processes and experiences described by the participants indicated that learning management occurs in a sequence, but they also indicated that there is not a prescribed amount of time alloted to any particular phase, nor can duration of diabetes diagnosis be equated with being at a specific skill level of diabetes management. There are also conditions when an individual may choose to go back to a certain point in the trajectory, and being at any particular point can not be equated with "good" or "right" management. Instead, participants described maintaining management at a specific point because "it works for me", and, likewise moving to a different phase of management because what they were doing "didn't work".

Participants identified two major processes associated with management - learning to manage diabetes and maintaining management of diabetes. In their words these two processes were described as "getting regulated" and "being regulated". "Getting regulated" encompasses the period of time it takes to try out the doctor's prescribed management regimen, make modifications, and then find out what personally works best. "Being regulated" means having a knowledge and understanding about diabetes that is grounded in one's own basic routine which can be used for daily diabetes planning or under unusual or novel circumstances. The following section discusses these two processes more fully, and Figure 4-1 reflects the entire trajectory (see Figure 4-1).

"Getting Regulated"

When the participants talked about "getting regulated", they were referring to the effort put in to implementing a medically prescribed treatment regimen and towards making that regimen "fit" or make sense for them. Learning how to manage begins once the diagnosis is made and a treatment regimen is prescribed. This prescription is then tried out at home and attempts are made to both follow the regimen <u>and</u> to incorporate the regimen

THE PHASES OF THE DIABETES MANAGEMENT TRAJECTORY

__Process One__: "Getting Regulated"
This process consists of four phases of learning to manage diabetes. The individual can stop and continue with any one particular phase based on experienced body responses and personal considerations.
"Getting Regulated" begins with the diagnosis and receiving the medical treatment prescription:

Phase 1 - "Trying it Out"

Phase 2 - "Figuring it Out"

Phase 3 - "Trial and Error"

Phase 4 - A Basic Routine

__Process Two__: "Being Regulated"

This second process concerns maintaining management based on the established basic routine. This process used the basic routine, and sometimes trial and error activities, to participate in new situations and to expand the repertoire of diabetes managment.
Phase 4 - A Basic Routine

Phase 3 - "Trial and Error"

Management Trajectory

__Figure 4-1__

into a particular lifestyle. Participants call this phase of learning how to manage, "trying it out". For some individuals this may not require too much adjustment or personal change, but others find that they must begin to search for a compromise between the regimen and "what works for me". To find this compromise, the individual must increase effort and attention to diabetes management strategies, a phase the informants called "trial and error". The aim is to find the "fit"/"what works for me" which is an individualized basic routine that works most of the time to get the person through an ordinary day without experiencing difficulties with diabetes management. Once a basic routine is found, the person may then consider themselves "regulated" but must then maintain the diabetes management. The discussion of the trajectory and "getting regulated" begins with "trying it out".

"Trying It Out"

"Trying it out" refers to actually implementing the prescribed medical regimen in daily life, trying to do exactly as instructed and fit each task in on time and/or in a precise way. Planning management is superficial in this first phase, and is accomplished by trying out the received medical plan, but not from the point of individualizing one's own care. This phase of learning entails experiencing the diet, which may be anything from merely restricting sweets, to a carefully calculated and measured number of calories eaten at specified times. The prescription may also include a dose and schedule for either insulin or an oral agent for diabetes, as well as and testing either blood or urine and keeping a record of results.

"Trying it out" is remembered as a time of effort, of being "hard", even compulsive. Trying to remember everything that needs to be done. A woman in her early 50's described it as ...

"In the beginning I was very compulsive about measuring and timing...I was a wreck! I thought if I didn't do everything I would have a high or low reaction.. it was hard to remember everything and also hard to accept. My family said I was capable of dealing with it, but what choice did I have?" Another young woman responded ..."In the beginning I measured everything, tested urine and recorded everything". This compulsiveness may be generalized at first to all areas of management and then may shift to selective areas...

> "I stuck with the diet for about a year before I got more relaxed. I would go in cycles with the urine testing, though. At first I was real good about it."

Part of this compulsion is associated with a fear that if one deviates from the received regimen then one is doing something wrong. Even when experiencing negative physical effects, there is reluctance to make changes on one's own in this early stage. This is due, in part, to the fact that in the beginning people do not know what to expect or what to expect if they did make a change. One woman said that she rapidly gained weight right after she came home from the hospital because her insulin dose was high and she had been prescribed 1800 KCal. She thought she <u>had</u> to eat that much because it was prescribed and because she was experiencing so many insulin reactions. She recalled that she was frequently on the phone to the doctor about the reactions and he would prescribe changes in the insulin dose.

It is during this time that new psychomotor skills must be learned. These include learning to prepare and administer an insulin injection and learning the technique of either blood or urine testing. Persons using insulin therapy and doing blood testing must use needles for both procedures. Fear and anxiety vary among patients for this part of the management but can range from an annoyance and disruption of daily activities to extreme fear such that the person will travel to the doctor's office or hospital daily for the injections. However, insulin administration was recounted by some as the "easiest" part of management during this first phase because dose adjustment was not even contemplated, therefore it required little effort beyond preparation and administration at the prescribed time/s. The difficulty came for some in remembering to take the insulin or making time to test and administer insulin.

Another part of urine and/or blood testing is determining when to do the test. In this phase of "trying it out", the participants talked about following the schedule set by the physician, if indeed one was suggested. None of the informants in this study knew what to do with this testing information in this phase of "trying it out", but did indicate that "those numbers bring the diabetes back into reality". Common to this phase of learning, the participant would perform the test but not know "where" they were supposed to be or exactly what to do about it.

Records of results in this phase are likely to be considered as information for the doctor, not as information upon which to base independent or autonomous management changes. There is heavy reliance on the physician to interpret blood or urine test results, body symptoms and diabetes status in general. The doctor is also consulted before any changes are made in the prescribed management routine, with the possible exception of diet. Dependence upon physician advice is a hallmark of this early time, as is the assumption that the doctor has clear-cut answers about diabetes. This reinforces the idea that control <u>over</u> diabetes is possible, or as one subject put it, "I thought I'd eventually get control over <u>it</u>". Others related the following comments; "They (doctor and nurses) told me that this is diabetes, and it will take a while to control"... "I had the impression from the doctor that if I tested enough and did everything I was supposed to that I could control it". One young man even thought that by doing everything as prescribed he could actually cure himself.

Experiencing insulin reactions and, alternately, high blood sugars, are perceived as novel body experiences. It is during this early stage that one becomes aware of the body in this new way. As the prescribed regimen is "tried out", with little or no basis of comparison or knowledge of what to expect, new body sensations are sometimes questioned:

"At first I was on the pills and no one had explained to me about the reactions, when it did happen I wasn't sure what I was feeling. I had read about the symptoms but actually feeling the shaking, that really bothered me." Informants describe this retrospectively as the beginning of "listening to my body" or "becoming tuned in" to their bodies, thus begins an important monitoring activity which can only be accomplished by the individual with diabetes. In this phase of "trying it out", however, it is not information they can act on, but only react to. The reaction is usually emotional - fear, confusion, anger, a sense of loss (particularly of spontaneity). Part of the reaction to the experienced physical changes is the association with coming to understand that diabetes is a life-threatening and life-long, permanent disease. Emotions fluctuate from relief at having a diagnosis "at least I am still alive!" and "at least it isn't cancer", to disbelief.. "It took a while to realize that I really had it. It was like a bad dream. I thought if I followed the diet it would go away and that is why I was so obsessive in the beginning."

Family and friends' reactions are clearly remembered in this stage, and informants described feelings of "being alone", having to deal with family members who were frightened, expressed feelings of guilt and were generally non-supportive, as well as family members or close friends who were solicitous and concerned. All informants recalled being told, by either friends or family, anecdotes about someone else with diabetes, and these were most often extreme cases involving blindness and loss of a limb, with a quickly added "but that won't happen to you".

Temporally, this stage is briefer than the others. It is usually experienced quickly, within weeks or a few months, and culminates with the recognition of the difficulty of adhering faithfully to a rigid routine. This may become an emerging attitude about the routine, and commonly it is one of "too much structure", "too rigid", "I can't do this (follow this regimen) if I have to do it this way". Also, there is a growing suspicion that the received regimen does not "fit" or is not working for them personally...

"I had always known how to regulate diet and exercise, but now there were all these new things to consider, and I was doing the right things, but my body wasn't reacting the way it used to and I didn't know how it was going to respond."

In summary, "trying it out" is the first learning phase of the larger process of "getting regulated". It is a time which begins with diagnosis and prescription of a management regimen, and ends when that no longer works. "Not working" can indicate several things, the most common of which is the experience of physical discomfort or confusion about what is physically occuring, particularly with insulin reactions and unexpected (and unexplained) urine and blood test results. "Not working" can also mean that not all aspects of the received routine fit into their job, their social activities or the way they see themselves.

The unknowns of this phase pertain to several areas. There are questions about the diagnosis - "am I going to die?"; "will I be sick?"; "do I have to change my life?"; - and about managing diabetes - "what do I have to change?"; "what do I have to do?"; how am I supposed to do it?" The uncertainty in this phase is directed more towards trying to find out what the disease 'diabetes' is and what kind of impact it will make on one's life, particularly in terms of life expectancy, quality of life and the kinds of tasks that must be undertaken.

There are also questions about how others, especially family, close friends and co-workers will respond. These uncertainties, because as unknowns they are personally disruptive, have strong emotional components of fear and lonliness. Several participants described receiving the diagnosis and then waiting until they were alone to cry..."On the second day I began to cry and I couldn't stop. I thought 'oh, ___!' my life is over!! and I'm going to be different'" ..."I felt so totally alone"... "I think it was about facing my own mortality". There is also an expression of "certainty" about what the physician can do, thinking that s/he is the key or the answer about how to "control" diabetes.

The typical outcomes of this phase are experiences of novel and probably negative body responses, such as insulin reaction/s, weight gain or continued weight loss and symptoms of hyperglycemia (headache, fatigue, visual changes). Trying to incorporate the prescribed treatment may be disruptive to the daily routine or socially embarrassing. Trying to "do everything right" may be considered to be too much effort or "it was driving me crazy". This phase commonly ends in confusion and frustration, and a recognition that adjustments need to be made. It is the consequences of this first stage that prompts the transition into the next phase which is "figuring it out".

"Figuring it Out"

The consequences of "trying it out" are the conditions which bring about this next phase of learning, termed by the participants as "figuring it out". The distinctive characteristic of this phase is that the individual begins to modify the plan that was prescribed for them. Along with the modifications comes an accompanying awareness that these adjustments can be made without significant negative results.

Most likely the first regimen adjustment will occur in the strategy of diet - adjusting food amounts, including a favorite food, or eating out. One woman described this process ...

> "In the beginning I had to think about the diet and weigh and measure and I was frantic. I was worried, too, about trying alcohol, but I did try it and found that it didn't bother me, so I began to try foods like Chinese food and Italian food and different salad dressings."

Diet adjustment seems to be a strategy that has a margin of safety. For people taking insulin the major caveat is "You <u>must</u> eat!". Eating is also an activity and experience that has become individualized over many years. People know what they like or do not like and they know how they respond physically and emotionally to particular foods. For these reasons, food is a familiar and known part of one's adult life. Also, by the time they come to "figuring it out", those on insulin will have experienced an insulin reaction, mild or severe, and will likely choose the "certainty" of a higher blood glucose to avoid the possibility of a repeated reaction, particularly if the reaction/s was/have been severe or socially embarrassing. Because they have had experience with blood glucose levels that were above normal and were able to still function for a time before diagnosis, the message translates that self-adjustment of diet is relatively safe and even necessary.

As with "trying it out", the "figuring it out" phase does not usually include self-adjustment of insulin. Insulin is perceived as a medicine and under the doctor's jurisdiction. Therefore, this phase continues to be characterized by heavy reliance upon the physician. A young woman who was experiencing frequent and distressing insulin reactions recalled...

> "The doctor was the first to adjust the insulin dose. He said it should have been cut way down when I left the hospital, but he cut it back when I told him I was having all those insulin reactions when I exercised."

Control at this point is considered as a state of being, that one can <u>have</u> or be in control. This control status is based upon one's urine or blood test results and/or the laboratory determinations made by the physician. If the person understands that s/he is to fall within a particular range when self-testing and the result fails to fall within this range, there is a strong emotional response of guilt, anger and frustration. Likewise, the physician's test result is also seen as a judgement on how "good" they are as a diabetes manager. The acceptable range for blood glucose, just like the insulin dose and schedule, is that range set by the doctor, and the strategies prescribed at the time of diagnosis are still viewed as the way to have control <u>over</u> diabetes. One school teacher described it as...

> "In the beginning they prescribed a certain amount of

insulin in the hospital and when I came home I had reactions, reactions, reactions. The doctor kept cutting back my insulin, but I stopped taking the regular altogether because I thought I had gotten to where I needed to be. I wanted to believe that if I got myself to a certain place where I was ok I'd never have to change or adjust. I thought that if I had to adjust the insulin so often then I wasn't doing something right."

"Figuring it out" can be a difficult phase of "getting regulated". What can make it "hard" is the conflict between what one has been told to do, what one actually experiences when applying the regimen. The prescribed treatment is considered to be the best one to follow but they just can't figure it out. A participant, a physician, recounted...

> " I thought that when I couldn't see very well [this was after a few weeks on insulin when the lens of the eye was readjusting from the prolonged hyperglycemic state] that it must be part of the disease. I thought it might stop, but I never thought that it could be from the treatment. I thought it was just part of the disease."

Another young woman, a physical therapist, recalled...

> "When the doctor changed my insulin around, I thought that this wasn't working. Then I realized that this is a game! And that you have to play around with it, but

> he didn't give me the freedom to change it around at first. I thought his word was law and that he knew what he was doing."

The conflict in this phase is not merely a matter of <u>wanting</u> to alter the prescribed regimen because it might be tedious or inconvenient. The major discrepancy is the experienced body responses. The responses may not be the ones they have desired (to feel well again) or the ones they have been told to expect. How one feels at this time may be assumed to be due to the "nature of diabetes" or that diabetes has its own character, so that you can never really expect to feel well again. A young man remembered ...

> "It took a little while just to process all of the information, and to learn new information... before the educational course, I just thought that what I was experiencing was the nature of the disease. I just couldn't get a good handle on this thing."

And a participant who is a registered nurse recalled ...

> "After about 4 or 6 months I went to the education course, but prior to that I thought I was supposed to feel like that, but what I was doing wasn't really working and even though I was feeling better I was not really healthy".

Testing blood or urine at this point may continue or continue but be less frequent. Unless one is adjusting insulin or planning to see the doctor in the near future, testing of blood or urine may seem irrelevant. Testing is described as carried out in cycles..."I was testing urine, but infrequently, but I wasn't getting a very good read that way. I went by what I thought was best". And ..."I did do urine testing but I wasn't real consistent. I was pretty good when I was first diagnosed but after a couple of years I did it infrequently, and then I would start getting more concerned about it and test urine every day." Blood or urine testing may also be discontinued during this phase of "figuring it out" because they do not know what to do with the information or they see no correlation between management strategies and test results.

Informants also described "not wanting to know" because the test results are may seem frightening if they have been told that high blood glucose levels are likely to lead to blindness, kidney disease, etc. Such results may be even more frightening when they do not know what action to take, i.e. what strategy changes to make. A woman diagnosed in 1985 recalled...

> "I felt so vulnerable, lapping up every piece of information they gave me. I had to learn to put all these fruits and vegetables in my diet, but even as I started getting better regulated my blood sugar still wasn't regulated and even after I got my insulin regulated I wasn't sure how to handle the diet with my insulin...I was doing the right thing but my body wasn't reacting the way it used to and I didn't know how it was going to respond."

The "body listening" described in the phase of "trying it out" continues and there may be some associations made between blood or urine tests and perceived body responses. The "listening" at this time is more or less a gross estimate of "everything is fine" or "everything is not fine". Those who have experienced insulin reactions may begin to discern onset and how to respond, but they may not necessarily pinpoint why it occurred. There may be an understanding that the way to manage a reaction is to eat, but selecting the right foods in the right amounts may not be known.

There is also a continuing, powerful need to not have diabetes. One woman described it this way ... "In the first few months I said I didn't have it yet because I could take insulin only once every three days. By the third day, tho, I would be so sick that I would have to take the shot." And another woman told me ..."for the first 8 years I pretended I wasn't diabetic, but then things started falling apart (her health)." And a recent college graduate recalled ..."for 6 or 7 years after the diagnosis I compensated for having the diabetes by drinking more than anybody else and being wilder than any one". And the fellow who managed on diet alone for 5 years remarked... "I told myself that I only had a touch of diabetes".

There is a curiosity at this point to know how others have managed their diabetes. A business woman described it as ...

"I wanted to know how others were coping...the textbooks told me what was appropriate but it never worked...the urine was information that was two hours old, so I tried memorizing symptoms (of high and low blood glucose), but to keep from going through the anxiety of a low blood sugar I overate because it was so damn scary!"

An overweight woman in her early 40's described how the information she has now about diabetes and its management doesn't make sense to her..."maybe in time it gets better and it all fits into place. I'm going back to the education class because I really didn't pay attention before when they were talking to the patients on insulin, but I need to know it now."

As noted earlier, the distinguishing characteristic of "figuring it out" is that the person begins to discern the need to modify the prescribed regimen in some way to make it more manageable or a better fit into their lifestyle. The emphasis is not so much on having a routine that incorporates the best blood glucose control activities into a daily routine, as it is on external factors such as being able to fit in most or some of the prescribed regimen into a convenient work schedule or daily routine without too much disruption. It may even be that modifications have to be made <u>because of</u> the received regimen. For example, one woman described having to eat "all the time" to keep from having insulin reactions since, then she later found out, she was on too large doses of insulin.

"Figuring out" these modifications may provoke confusion and frustration if the person feels nothing seems to be working right. The regimen and figuring process may seem to be a great deal of effort. There is a strong curiosity now about how other people with diabetes manage, and several participants described wanting a support group or seeking out a support group at this time.

Although this phase of "figuring it out" is primarily a learning phase, individuals may maintain management at this point by attending to as few of the diabetes tasks as possible. This is more likely to occur if the individual is not experiencing disrupting or confusing physical responses, and if what they are doing seems to work for them socially as well. One man described it as "...well, it didn't seem to be getting any worse. It just stayed about the same, and I could deal with it. I mean I didn't have to deal with it very often. Mostly I ignored it and it pretty much stayed the same." They may also be willing to put up with a certain level of physical discomfort if it means less effort or attention to the diabetes. This may be more prevalent in persons who have either endogenous insulin function remaining or Type II diabetes, and experience their diabetes as being "stable".

The person may continue in this phase for weeks, months or even years. If the body responses "seem ok", that is, no or minimal discomfort, then this level of management may be sufficient, and the prescribed treatment with a few personal adjustments may suffice. This was reflected in the following comments: ..."It was enough for me to know to get by and to answer questions semi-intelligently, and getting by for me were the things I needed to do to keep the urine test within acceptable standards"..."The only time I had to deal with diabetes was once a day, when I took my insulin". If diabetes is thought to have its own "nature" or way of making one feel a certain way physically, then this plateau may be accepted even if it is somewhat physically uncomfortable.

The uncertainties of this phase center around the realization that the prescribed management doesn't work or fit for them, but they don't know what other choices they have. A significant question at this point which indicates the broadening use of "body listening" is ..."why don't I feel better?" They may be 'certain' that diabetes has its own 'nature' and, must therefore adjust to that.

There are questions about how other people with diabetes manage, and learning that others may have different insulin or dietary prescriptions can evoke a lot of uncertainty - "does that mean my diabetes is better or worse than their's?"; "should I be doing something differently?"; "is my doctor right about this diabetes and the insulin, or is their doctor wrong?".

There is also the unpredictability of insulin reactions and/or "bad days" or how long it will take to recover from a reaction ..."I can be wiped out for hours!". There are also questions about modifying the prescribed regimen - "what can I safely change?"; "should I tell my doctor that I want to change/have changed?"; "am I doing it right?". And, of course, there are questions about what to do with test results - "am I supposed to change something when I see these numbers?"; "which numbers are bad?"; "where does the doctor want the numbers to be?". For those who can't "figure it out" or can't find a management routine/regimen that seems to work, there is movement into the third phase, which they call "trial and error". One woman called it "by guess and by golly!".

"Trial and Error"

This may be the most critical phase within the trajectory because there is a great deal of effort expended. It may be that the person had it "figured it out" for a while and had a routine that was "good enough", but physical symptoms eventually become apparent and disturbing - symptoms get worse, reactions are more frequent or more severe, relationships or interactions with others become a major problem. The following are comments reflective of this turning point...

> "The reason I was concerned is that I was having problems with reactions in the middle of the nite, and my wife was developing sleep disorders. She was always afraid of me passing out."

> "I had gotten sick when we were traveling in Europe on tour (with the band), and I thought it was time I came back and tried to get my diabetes under control again."

When this direction towards management changes occur, it is with the awareness that what was "ok" or "good enough" before is no longer adequate and "something" needs to be changed.

The "trial and error" phase is similar to "figuring it out", but there is a greater intensity of attention to connecting management strategies to specific body responses, and attempting to manipulate strategies to evoke a particular body response. The period of time spent in this phase of learning to manage diabetes is described as quite complex and "hard". There is an increased search for answers and for strategies that work, meaning those which not only fit into a lifestyle, but which works best to bring about predictable and positive physical reponses and keeps blood glucose levels within a determined range. This phase requires a great deal of effort as described by the young man whose wife was terrified of his night time reactions. He finally enrolled in a four day education class and talked about that particular period of time...

> " It took me about 6 weeks to figure it out and it was

> terrible! I was just going up and down and up and down. I finally said I can't live this way, we can't do this. I was monitoring 6 to 8 times a day and not knowing when the insulin reaction was going to hit. What I realized was that I am very sensitive to regular insulin and that I had to back off."

Characteristics of this man's story were also to be found in the phase of "figuring it out", but with movement into "trial and error", all characteristics assumed a stronger intensitity. For example, there appears to be an acknowledgement that more help is necessary. Individual participants handled this need for more information in different ways. Some returned to the doctor, or changed doctors; found and signed up for an educational class; and/or did lots of reading about diabetes or talking with other diabetics. The common similarity, however, was "getting serious" about diabetes management.

Planning diabetes management changed, too. Whereas in the phase of "figuring it out" the planning was done from a prescription with attention to a "fit" with personal preferences, planning in the "trial and error" phase assumes a new dimension towards individualizing strategies towards a better diabetes outcome. The individual also described trying to find out the "why" of diabetes related outcomes. They talk about this as "pinpointing what it was that made the difference". Much of the "pinpointing", a thinking back over events, becomes integrated with body responses, particularly blood glucose responses..." when I did that, my blood sugar went sky high", or "when I exercise without eating something first, I always spill ketones in my urine". Planning strategies and pinpointing outcomes are the central focus of this phase.

Part of the intensity of pinpointing is associated with an increased use of testing, either blood or urine. All the informants who had originally used urine testing described switching over entirely to blood testing when they "got serious" about management. They deduced that urine results was not a valid indicator of what is actually going on at the moment and that it was very difficult to plan management strategies by these results.

Blood values, on the other hand, "are magic". These test results are powerful and indicate whether or not management choices were "right" or "wrong". It may even be that the blood test results prompt the transition to the trial and error phase. One woman describes such an experience...

> "I went to a diabetes fair that was held in this area. I thought I was doing pretty good for the last three years until the woman took a drop of my blood and tested it on the machine. It read 400 and something! I was shocked! I went out the very next day and bought my own machine."

Because this "trial and error" phase has such intensity and effort, the testing results, more than ever, seem to carry with them a qualitative judgement about whether they, as diabetes managers have been "good" or "bad". The question posed of testing is not merely a quantitative one, i.e. "what is my actual blood glucose?" but is also a qualitative one - "how well am I succeeding as a manager of this disease?". So much importance is attached to the test results in this phase that some informants describe actually "taking on" the physical responses usually associated with a particular number, for example if the physical response at 250mg/dl is fatigue, thirst and irritability, then the person who felt fine before testing might convince him/herself that they actually did not feel all right. Even if the person does not take on "high glucose symptoms", the contradictory information between machine and body may reduce the trust one has in "reading" or "hearing" the body correctly. As one informant described it ..."there was a period of time where I was relying on the machine to determine my mood!" The dialogue that takes place between the person and the glucose machine and the emotional response that can be evoked by the test result is a phenomenon I have termed as "monitor talk", or what one participant called "facing the monitor!". This is described as a dialogue which occurs every time a blood test is done. In the "trial and error" phase, the dialogue can be harsh and punitive... "You're stupid, stupid, stupid!", or, disheartening and depressing... "I hate seeing those numbers. Sometimes there is no reason why [meaning why the test result was different from what was expected]."

Seeing unexpected high numbers can bring about a tremendous sense of guilt and frustration, even anger. Also, the guilt may not be limited to a judgement of having let one's self down, but extended to having let down family members. For one young man who had been started on an oral hypoglycemic agent (OHA) at the time of diagnosis and then switched to insulin, the higher numbers were associated with a great deal of guilt because he and his family thought that if he was really "good" for a sufficient period of time on the insulin, he would be able to return to the pills or be off medication altogether. The high numbers meant he was doing it wrong and that he was cheating his young family.

It is during this phase of learning that diabetes control now becomes associated with personal management choices, and not as control by following a prescribed regimen. They see the connection between choices and outcomes - what they did or did not eat; how much or what kind of exercise they were doing; how long the insulin lasts; the times they have insulin reactions, etc.

In this "trial and error" phase, there may still be strong reliance on the doctor or health care provider to set the blood glucose ranges for them, but there is also increased attention and awareness of body responses in both the higher and lower blood glucose ranges. They may even begin to decide what is "high" for themselves, with varying determinations to indicate mild, moderate or very high blood glucose levels. There is also a greater awareness of insulin reactions, possibly of when, different types, ways to respond to them, etc.

The person may seek permission to make self-adjustments in insulin dose and schedule. Those who attend comprehensive educational programs are more likely to be guided towards making such changes. Without formal education, self-adjustments are likely to be relatively cautious, a few units at a time, and getting regulated on insulin seems to take a longer time.

The dependence upon physician usually begins to wane at this point unless s/he is actively involved in guiding this new phase of diabetes learning. One of the consequenses of this phase, however, is that there may be a straddling the fence of who is responsible for the diabetes management, meaning that the physician is still expected to have the answers, but the person also recognizes their day to day involvement in and impact on management.

In summary, the "trial and error" phase is a time of increased uncertainty and intense effort. Previous strategies seem to no longer work and the individual is not clear how to proceed. Emotional reactions to management outcomes, particularly the "machine talk", is most intense. Having the educational resources and personal capacity for learning diabetes management appears to be crucial. If body response patterns and associated management behaviors can be discerned, there is likely to be continued movement towards the development and understanding of one's basic routine which occurs as the next phase of "getting regulated" and one begins to "get a handle on it" [the diabetes management].

The common outcomes of "trial and error" do not always end with the person recognizing a need for a basic routine and going on to further develop in that phase. The degree of effort required in "trial and error", along with unexpected outcomes, can lead to frustration, anger and abandonment of the process. The "obsessiveness" of this phase as it was characterized by some informants, may seem futile if somewhat predictable patterns are not discerned. A person may opt for a return to "loose control" if they consider that too much effort is required, or that the effort expended does not bring about the desired results. Or they may still be confused about what they can realistically expect in terms of diabetes outcomes. If patterns cannot be discerned or all trials seem to end in confusion, the person may discontinue progress and return to a modified version of the earlier phase, "figuring it out". An example is a middle-aged informant who has attended an education class three times and was planning a fourth at the time of our interview. She still feels that the information she has doesn't make sense and she is waiting for someone at the class to pull together everything that everyone (doctors and nurses) has told her together. In the meantime she has gone back to strategies that "worked ok", but still has this sense that she could do better.

Uncertainty in this phase is focused on "what can I do?" or "what do I need to do?" to be in glucose control. Questions center around the intense effort - "how often should I test my blood?"; "when should I test my blood?"; "what do I do with that information?"; "can I adjust the insulin? How?"; "what all do I need to consider?"; "why can't I find a reason for the test result?"; "<u>is</u> there a reason for the test result?"; "what kind of diabetes manager am I?"; "what am I capable of as far as managing my diabetes?"; "what effect will this choice of action have on me now? later?". These questions reflect the work of this phase which is trying out various management strategies and trying to make sense of how an action relates to an outcome.

Movement through the "trial and error" phase and style is movement away from the prescribed treatment and towards an individual basic diabetes routine. This basic routine appears to be predicated on having an intense period of concentrated effort to coordinate blood test results with what strategies have been applied and with how one feels. If continuation is perceived as possible and desirable, the person moves on to the next, and last, phase of "getting regulated", which is that of establishing an individualized basic routine.

"Basic Routine"

Once the prescribed treatment plan has been "tried out", adjustments made in an effort to "figure it out", and an intensification of "trial and error" problem solving, the next phase has been termed "getting a handle on it", or "what I usually do". I have given this phase the label of "basic routine" to include both the sense of understanding about management that is apparent at this time and the recognition of "what usually works for me" which is used as the foundation for other management choices or decisions.

This is perhaps the most exciting phase in the management trajectory. During this phase the individual's management becomes grounded in a "knowing" that is based not only in cognitive information about diabetes as a disease, but also an understanding of body response patterns. In fact, there may be little indication of cognitive knowledge about diabetes as a disease and its associated treatment, but there is an attention to outcomes of management choices. This means that management actions and body responses are beginning to become integrated into patterns that are discernible and, for the most part, coherent. The patterns permit one to plan for a daily diabetes routine and to plan ahead for out-of-the-ordinary circumstances, such as eating out; going to a brunch; traveling; making a change in the usual daily routine.

The attention to "body listening" becomes an acknowledged and credible, even indispensable, source of information, and is very much integrated with assessing other information. One man described it as ...

> "I'm always listening to my body. Are you hungry? Are you all right in there? I never stop thinking about it or at least being aware of it."

Another woman described an encounter with her husband when he appeared quite annoyed and asked her to stop asking him how he was! She said that up until that moment she had not realized she was asking the question so often, but she recognized that she was asking it of herself all of the time!

When transition is made through this phase, the person has his/her own individual core routine. If new situations are encountered, the person can use this core to plot new strategies, because at this point they have found and they know what works for them. Phrases such as "I've gotten a handle on it", or "I'm putting it all together" are used to describe their situation during this phase.

There is increased attention to and confidence in body listening and reduced reliance on physician interpretation of day-to-day management. The increased body listening is also extended to a broader scope of body-related diabetes experiences. Not only does one know what the blood glucose range should be, but they can also discern "high high's" and "medium high's", as well as the test results requiring their immediate attention. For example, ..."When I see an 80 I know I'm ok and have a little time, but when I see a 70 I know I better do something right then because at that point I seem to drop fast if I'm dropping. At 40 and 50? It's Uh, Oh!!" Most participants could articulate what their individual glucose ranges should be and what they wanted them to be. They had their own glucose "goals". In addition, several had a time limit on how long they were willing to tolerate being outside of that range. Also, they described an awareness of types of insulin reactions and the effects of various insulin schedules.

Participants who had reached this phase of "getting regulated" were all adjusting their own insulin. There were individual differences in how they had come to learn this adjustment, but all saw it as absolutely necessary and crucial to being able to manage diabetes. This was a contrast to the earlier phases where insulin adjustment or change was left up to the physician.

There is development in this phase of a recognized "certainty" to specific strategies, such as "if I eat I know my blood glucose goes up" and "if I eat certain foods like red sauce on my pasta I know there is sugar in there and my blood sugar will go up," or, "I know if I take more insulin that my blood glucose will drop". They become aware of how sensitive or insensitive they are to insulin and if that varies at particular times of the day..."usually I am very sensitive to insulin, even raising it by one unit of regular can be too much, but if I am high in the mornings before breakfast I know I can take more regular insulin and not have a reaction".

Persons in this phase also have a sense of their own progress through the management trajectory, a sense of a past stage/s or phase/s of diabetes management. They can recall where they have been in relation to their management and what has or has not worked. They will recall the times they were figuring it out and denying or ignoring being diabetic. They recall the frustration. By recalling their experiences over time, they have an opportunity to recognize their progress and to compare management of diabetes <u>now</u> to the management of diabetes <u>then</u>.

Interestingly, at this phase, there is less concern with why one's diabetes differs from others'. Questions more likely center around how others specifically handle a particular situation or aspect of management. Descriptions from others are then compared to one's basic routine/management strategies. This is not to imply that informants who were or had experienced this phase were doing everything "right" or "by the book"; rather they could recognize and had familiarity with the management choices that worked for them.

The difference between this basic routine and the quasi-routine of the "figuring it out" phase is that management in this phase takes into account many more of the variables which may affect diabetes. For some variables they may have an explanation, for others, such as for why they are less sensitive to insulin the morning hours, there may just be a recognition of the effect.

Another person expressed that the difference between this phase and the earlier phases is that the individual takes on an accountability for managing diabetes, and makes choices about the level of and type of glucose control they want. They describe their own responsibility for making diabetes management work for them, and for finding what works for them. Ironically, they may still express doubt about the diabetes diagnosis, but the difference at this point is that they do not stop doing the activities that work for them. Modifications are made because of the situation or preference at the moment, not because they don't really have the disease.

In summary, the "basic routine" is the last phase within the process of "getting regulated". It follows "trial and error" and expresses management which has a degree of reliability. Also, specific strategy combinations/sets can be recognized as "ok" or "safe" and used as one's baseline or usual repretoire for managing diabetes. Which patterns are acceptable are individually determined and control may be described as "steady control", that is, recognized as both process and outcome. One young woman summed it up ...

> "Diabetes is a game. Like walking down the white line on a Nevada highway, but you don't know how wide the road

> is... you are never sure... on one side is high blood sugar and on the other is low blood sugar. What I've learned is to make my own little off-white line and it may fall somewhere near the definite highway mark and sometimes it doesn't, but you have to be comfortable either way. I believe somebody has to feel as rotten or as good as they can before they can come right out in the middle."

Developing a basic routine does not mean that one has attained a stationary point of equilibrium and that management is now a fixed, individualized recipe. What it does indicate is that the person has tried out various management strategies with attention to testing results and body responses and has a basic understanding of what works for them in terms of management. For example, they may now understand how sensitive they are to insulin, what usually happens when they exercise, what foods drive up the glucose levels, how long a high blood glucose will take to come down, what different insulin reactions feel like and which ones they can "catch" and which ones may still remain unpredictable.

The significance of uncertainty shifts in this phase from the many unknowns associated with earlier phases. In fact, there are now more knowns - body responses, effects of insulin, effects of exercise, ways of handling social situations and comments of others, one's own ability to manage diabetes, identification of what is not known. The pressing questions in this phase are those uncertainties which have dogged the entire diabetes career, and they are also the ones which cannot be answered now or at any point with any certainty - "am I doing the best that I can?"; "should I be doing something else?"; "is what I am doing good enough to prevent complications in the future?"; "what is ahead?"; "can I handle pregnancy?"; "should we try to have a baby?".

There is also recognition of the 'certainty' of the continuance and unpredictability of diabetes. Subjects described this as "acceptance of diabetes", not just of the diagnosis, but of the personal effort towards management that will be required for a life time. The term "routine" in the label for this phase does not imply sameness, it instead refers to what <u>usually</u> works on a typical day. There is never assurance that any two days will be alike in terms of blood glucose response even if everything is done the same and events occur with a similarity. One man noted..."The day may seem the same, but, you know, something as simple as no mail today may evoke a different emotional response and it may show up in my blood test."

Without this development and understanding of what basically works and why, the individual cannot move on to the second major process within the trajectory, "being regulated". Instead, s/he will most likely revert back to some modified version of "figuring it out" and staying at "good enough" control, or, as it may now be perceived, "as good as I can get it".

Summary - "Getting Regulated"

"Getting regulated" is one of two major processes identified by the participants as comprising the overall diabetes management trajectory. It is specifically concerned with learning to manage diabetes. It begins at the time of diagnosis with the first phase of "trying it out", wherein the person tries out the prescribed treatment regimen. For most of the informants, this phase was brief as they experienced the need to modify the prescribed regimen. By modifying the regimen, they were trying to "figure it out" for themselves and how they could make the management fit their lifestyles and preferences.

Some described remaining in the second phase for a long time, even years, until some event, usually a worsening physical condition, would prompt their efforts towards better glucose control. At this point they moved into the third phase, "trial and error", and intensified diet adherence, blood testing and attention to diabetes management principles. The positive consequence of this phase was the development and recognition of patterns of body response associated with specific management choices, resulting in what the individual could identify as his/her "basic routine", or what "usually works for me".

Overall, the characteristics of "getting regulated" include recall of experiences that were remembered as "hard", "frustrating" and "confusing". Reliance on the physician changed from near total dependence at the beginning, to occasional contact after the basic routine was identified. Learning to test blood included not only psycho-motor skills, but also experiencing "monitor talk" and the emotional reaction to feeling "judged" and "guilty" when unwanted numbers appeared on the machine. The characteristics of all four phases of the "getting regulated" process are summarized in Table 4-1.

For those who persist through the process of "getting regulated", there can be recognition of learning and understanding one's own individual management patterns. Experience with one's basic routine can then bring about a sense of "being regulated", the second major process of the trajectory, which is the ability to maintain diabetes management.

Uncertainties associated with "getting regulated" pertain not only to learning the principles of diabetes management and the psycho-motor skills required for administering insulin and doing blood testing, but also to questions of confidence in one's ability to do these things and to learn how to do them "right". In the later phases of "getting regulated" there are questions of whether or not one is doing enough and doing in a way that is best for them. After establishing a basic routine that works best, most uncertainty is directed towards the diabetes future, such as diabetes complications and child-bearing issues.

CHARACTERISTICS OF THE LEARNING PHASES

TRAJECTORY PHASE	CHARACTERISTICS:
Trying it Out	-Upset that body has failed. -Heavy reliance on doctor for management direction. -Rigid adherence to prescribed management. -Experiences novel body responses - high and low blood glucose. -Describes control as control over diabetes. -Experiences aspects of prescribed management as restrictive or not working.
Figuring it Out	-Begins "body listening" specific to diabetes. -Begins to modify prescribed management. - Describes management as "hard", requiring lots of effort. -Wonders how other people with diabetes manage. -Looks for the "right way".
Trial and Error	-Begins to identify aspects of treatment that do not work. -Increases use of blood testing. -Strong emotional response to test results. -Begins to acknowledge "body listening". -Begins to associate body listening with management experiences. -Begins to describe body experiences related specifically to diabetes. -Tries to integrate doctor's information with own diabetes experience.

Table 4-1

(Table 4-1 continues)

Summary - "Getting Regulated"

TRAJECTORY PHASE	CHARACTERISTICS
	-Wonders why other diabetic people have different regimens.
Basic ("Usual) Routine	-Less use of word "hard" as management descriptor. -Talks about what "usually" works. -Identifies patterns in body responses. -Identifies larger scope of body responses: e.g. types of insulin reactions. -Describes how to incorporate basic management principles into daily routine. Plan for new situations from this style..."what usually works for me is...".
Being Regulated	-Less emotional response to blood test results. -Increased confidence in self to make management decisions. -Description of management encompasses wide body of complex, interactive diabetes variables. -Management adjustments made basis of basic routine. -Takes breaks from basic routine. -Incorporates diabetes management into new situations, does not ignore management needs except selectively.

Trajectory Characteristics
Table 4-1

Being Regulated"

In order to maintain the diabetes management that one has learned, the individual uses the basic routine as a pivotal point to expand the scope and flexibility of lifestyle activities. "Being regulated" also reveals an awareness and appreciation of the complexity of diabetes management but without the accompanying anxiety so prevalent in "figuring it out" and "trial and error". One of the characteristics of this process is that, while managing diabetes will always require a great deal of attention at any time, the participants describe this process as requiring less cognitive effort. They also note their increased confidence in their own ability to manage diabetes according to their choice of control.

One woman referred to "being regulated" as "diabetically knowing", indicating that she now understood so many more aspects about diabetes and the management. She meant she could consider diabetes situations with less effort than before she had established what worked for her. "Being regulated" is a continuation of exploring and experiencing one's basic routine.

Descriptive charactericstics of the process of "being regulated" (see Table 4-2) included knowing "what works best for me" and yet an ongoing, continuous effort required to maintain the management. "Being regulated" is not considered as an arrival point where the learned activites can stop, but rather as a broader understanding of a process they must continue for the rest of their lives.

In this process, blood testing is the test of choice and none of the participants were willing to even consider giving up their glucometers. They were able to describe how they would attempt to manage without it, and the descriptions were of carefully following their basic routine. Testing also improves body listening when the person is not sure of the body talk - "It doesn't happen too often now, but once in a while I'll be fooled. I'll think my blood sugar is ok and it will be in the 200's."

In this process, there is still an emotional response to the test results, but they are less intense and of shorter duration. This is not to imply that the high glucose readings are unemotionally encountered, but there is an attitudinal difference based on several factors. For instance, there is now some idea of what usually works to bring down the blood glucose and about how long it will take. Further, there is an understanding that control _over_ diabetes is not possible, at least not in the sense of making every single test result end up within a narrow range. Also, there is an acceptance that not every blood glucose test result can be explained. Sometimes trying to pinpoint "why" ends up as a question mark. In these cases, what the person relates is a reliance on their own ability to take appropriate action (not necessarily _the right_ or absolutely predictable action).

Blood testing becomes a guide to the control process, not the means to control as may have been imagined in the earlier stages.

There is also less anxiety associated with high glucose readings because there are more strategy choices possible. It is interesting that the choices were always available, but only become possible for that individual when a certain level of knowing and understanding is reached. This level of expertise is difficult to capture as explicit components and is perhaps best revealed by the story of a young woman who was asked by a friend how she decided how much insulin to take. The young woman replied,...

> "I make incredible calculations all of the time. There is a constant back burner going about how everything is going to affect (me) diabetically. I usually give a pat answer to a question like hers, but instead I gave her a specific answer to what I was doing now. I said 'well, today I swam this much, and I knew we were not going to have dinner until late, but I didn't want to have my blood sugar go up, so I took a couple of units then,... and now I think I am going to eat about this much, and we'll be in the car this many hours driving ... and tomorrow I want to be doing this, so I want to make sure when I go on this camping trip that I don't have a

reaction in the middle of the night..' and she just looked at me and said 'oh, my God! And I said, 'I'm always going through these calculations'".

Cognitive efforts seem directed towards two kinds of activities, i.e. "making sure" or verifying that the basic routine being used is adequate in terms of keeping blood glucose within acceptable ranges, and that of planning ahead when new or not-routine situations come up. This indicates that the person can include and participate in more situations and still manage diabetes, and even continue to increase the scope and skill of management.

Also, within the phase of "basic routine" and its extension, "being regulated", persons describe being able to "take a break" from diabetes. This is a different venacular than is used in phases of "getting regulated". In those phases, the person was more likely to describe any chosen change in management as "cheating". Taking a break, however, implies a conscious choice to stop or alter management actions. It is done in a variety of ways, but usually by testing less or not at all and sticking with the basic routine diet and insulin schedule. Or they may test, but not make insulin adjustments unless the blood glucose goes up to a certain point. One woman remarked that she might test but not take any action unless the blood glucose was 250mg/dl or more. Another woman described taking "diet holidays" and not testing blood at all. Then, she said, she would correct any out of range blood glucose the next day.

No matter how the breaks are taken, they are assumed with an understanding of the risks involved and the likely consequences. Most often the break strategies shift back to the basic routine, to the place where they know what works. They have determined that the fluctuation can possibly be corrected with a particular action or that it may be self-correcting over time. The action may also be known but not implemented if it does not "fit" with what is going on at the time or with one's emotional state.

Self-adjustment of insulin, which was initially taboo and/or frightening or even perceived as poor management, is now viewed as a necessary management option. Informants who practice management at this level tell me they would be suspicious of any physician who told them how much insulin to take as a matter of a fixed daily dose since ..."every day is different. Even if you do exactly the same thing, eat the same, exercise the same... it will be different blood glucose wise". By knowing how they respond to insulin and how to make their own adjustments they still consider every day as different, but express a greater reliance in themselves to handle any differences that come up. The reliance on physicians is relegated to a position of consultation and the doctor's information is considered rather than followed.

There is also a comparison to other diabetics that is summarized as a recognition that every one's diabetes is different, and what is looked for in terms of support from friend's and family can be fairly well articulated. One unmarried man responded ...

> I don't want people's advice. It is nice to have their concern, but how they express their concern is a tough line. I try to take it into account and say I am appreciative of that person, but an ideal relationship would be where they ask me very little about it. But I love it when friends ask me how things are going. The ideal would be someone who is supportive, follows the diet with me and doesn't give advice or admonishments. I don't want them questioning how I administer my diabetes. Probably an ideal relationship would be with another diabetic."

The kind of diabetic control discussed in "being regulated" is that which is "flexible". Not only does the person make a choice of blood glucose ranges and when and how long to be out of range, there is also an understanding that there is no such thing as control. One young woman remarked...

> "I don't think there is a perfect anymore. I look back or I hear others talk about how hard it is, and now they sound like complaints, but I have to stop and remember the different adjustments and relationships you go through with any kind of illness like this. I hope you are talking to people who are in the middle, who are

going through the stages."

Sometimes persons in this stage will engage in "tight" or "steady" control and sometimes they "take a break". They make choices to eat favorite or high sugar foods, but with less guilt and less of "beating myself up". The young woman quoted above continued ...

> "The off-white line is always moving and bouncing, like a reflection from the sun in a mirror. I think it is almost entirely experience (finding the white line), because I can't make you feel these things and I can't tell you what you shouldn't feel comfortable with, and I don't think there is any book that can tell you the key. It is crazy because I can do the same thing two days in a row and my blood sugars can be all over the board. It is never the same and that is not a real encouraging thing to somebody that wants the white line."

The cognitive effort is applied only at those times during the day when an insulin or dietary adjustment is required, or when the situation encountered is either novel or has seldom been experienced. The rest of the time the diabetes is kept "on the back burner". In fact, most persons in this stage do not keep records of blood glucose test results, but hold the information in their heads, just as they can "eyeball" the right food portions or "automatically" chose foods appropriate to their diet.

Informants describe movement back and forth between "being regulated" and "basic routine", and even "trial and error", if illness or a novel situations occurs, such as pregnancy or a job change. Under these conditions, the person may have to go back to "figuring it out" or "trial and error". However, they can never truly regress to a former naive position because their awareness of "knowing diabetically" has been established.

The unknowns associated with "being regulated" have, in part, changed from those experienced while "getting regulated". What has become more 'certain' is the patterns of body responses that are now seen as familiar, even though the response cannot be predicted 100% of the time. There is a better understanding of effects of different management strategies on them individually. Responses of friends and family are also known, and one's "criteria" for telling others about diabetes or discussing diabetes is clearer. Such criteria can be used to plan for or anticipate social situations. Participants also describe knowing when and where to seek out more information about managing diabetes, and they have learned what they can or cannot expect from the physician or their health care system. Further, they have different expectations regarding "diabetes control", because they now <u>know</u> control to be an ongoing process and a matter of their personal choice.

The uncertainty that prevails is the "down the road" uncertainty. When queried, participants who had experienced "being regulated" expressed less uncertainty about what to do day to day with diabetes and more concern over the future. When asked point blank about uncertainty and diabetes, they answered with the unknowns of the future or what they called "down the road" uncertainty. This included decisions of whether or not to have children; concerns about entering into a partnering relationship; questions of being a burden; questions of finances; questions of complications. However, those who experiencing "being regulated" seemed hopeful that they are doing everything that they can now, and that that is a positive indicator for the future. Ironically, the uncertainty and unpredictability about the diabetes future helps to maintain hope. One man summed it up... "It's pretty nice to look back and realize where you came from, and that is a pretty good motivator!".

Section Two - Influencing Factors of the Management Trajectory

This section discusses in more detail the four factors of "management" which directly influenced learning and progress through the management trajectory. These include the two activities of management 1) monitoring and 2) cognitive strategies; the modifying factor of management 3) personal considerations; and the intention of management 4) control. How these factors may be linked as a theoretical framework to explain how people learn and maintain diabetes management, is described in Chapter Five. Uncertainty is integrated into these factors such that perceptions of uncertainty are related not only to the particular learning phase of the trajectory, but also the specific factor/s of management at any given time.

Activity Factor - Monitoring

This study identified four sources for diabetes monitoring activities. These included 1) "body listening", which is paying attention to body responses and response patterns; 2) self-testing of urine for a glucose and/or ketones measurement; and self-testing of blood for glucose. These first two sources are direct determinations made by the person themselves. The third and fourth sources are noted as secondary, or indirect, sources of information coming from other people, which, in these data, were identified as 3) secondary/indirect from health care provider and 4) secondary/indirect from family or significant others. These sources are more fully defined and described in the following discussion.

"Body Listening"

"Body listening" is an example of the concept of embodied intelligence described in Chapter Two under Theoretical Perspective - a source of "knowing" that comes from experiencing the body. Participants in this study described experiencing phenomena they called "listening to my body"; "being in tune with my body"; or "understanding the signals". This monitoring activity was not always perceived as an objective, cognitive process, but rather as an ongoing process of awareness that enabled them to call cognition (problem-solving and decision-making) into play if necessary. The word "symptom" was rarely used by the informants, and was avoided as a descriptor unless referring specifically to indicate diabetes as a disease.

It seems, then that this process of "body listening" is not part of the disease process, nor is it an abnormal process. Rather, it appears to be an example of embodied intelligence and is experienced as a continuous, going awareness. Perhaps it can be thought of as a continuous, automatic scanning such as radar screening. In the context of diabetes it may assume an extended compensatory function for the loss of automatic glucose control.

"Body listening" for the participants in this study was specific to that of the diabetes context. Within the diabetes context, it appears that this "listening" begins with experienced body changes from diabetes leading to diagnosis. These changes disrupt the body understanding or knowing that was present prior to the onset of disease symptoms. With diagnosis and prescribed management, the person is required to acquire a new understanding of his/her body experience which now includes both the disease process and the response to management strategies employed to control the disease.

Until the person can experience particular body phenomenon over time, such as an insulin reaction, and discern patterns, the phenomenon itself may not seem credible or reliable. For example, persons with high blood glucose may describe a feeling of mental dullness and the same person may describe mental confusion at the onset of an insulin reaction from an intermediate insulin. However, over time the person may come to describe the high blood glucose dullness as associated with a feeling of depression that persists for hours or days, whereas the dullness and confusion from too much insulin occurs within minutes or over the previous hours and is associated with repetitious behavior or thoughts. As one person described her insulin reaction, "when I have a reaction from NPH it can sneak up and I'll feel foggy and out of it. Then I'll notice that I'll keep doing the same thing over and over."

Informants in this study gave examples of becoming acutely sensitive to body responses of glucose fluctuation or management changes. One woman described "knowing" how to inject insulin away from capillaries because she could feel, "knew", where the capillaries were.

The skilled "body listeners" identified not only usual patterns associated with minimally high, moderately high and very high blood sugars, but also distinguished between types of insulin reactions as well. However, even the most skilled and experienced "listener" was quick to point out that they are not correct 100% of the time in their interpretation, but usually "right most of the time", and "most of the time I come close to predicting what will show up on the machine".

In addition to discerning body sounds to distinguish between high and low blood glucose situations, body listening was also used to determine if physical sensations are or are not diabetes related. For example, a headache may be associated with either high or low blood glucose, the onset of flu, a worsening of the diabetes in general (maybe an impending stroke or progressive involvement of the eyes) or "just a headache". This involves a "checking out" process which requires a mental rundown of all diabetes related activities over the past few hours or day, and maybe even a reflection back over several days or weeks of activities, depending on the symptom being checked out. "Checking it out" for this group of participants was always augmented with blood testing.

Skill in "body listening" was described as developing over time and in conjunction with diabetes experiences and acquired knowledge about diabetes. Awareness of this monitoring activity was uncovered by participants as they recalled pre-diabetes and post-diagnosis experiences. Relating diabetes events over time provided not only with a sense of progress in management and acceptance of diabetes, but also the relationship of "body listening" to their choice of management action (or no action).

Body responses are present, of course, whether or not a person recognizes them or understands diabetes as a disease; however, as one participant put it, in order "to know diabetically" all body patterns, cognitive information and management experience must be integrated into a whole. This becomes what another called "the ultimate awareness", and another, using the analogy of a bullseye with the rings representing all the aspects of diabetes and the self, called "being on the mark". This last informant's example also included the following remark, "It isn't just about knowing the right thing to do. It is knowing the difference between whether you are having a good or bad day. A friend of mine has AIDS and he understands immediately what I mean by this. If it was just a matter of following the book, it would all be so easy, but it isn't!"

In summary, the major characteristics of this type of monitoring are 1) it is internal; 2) it cannot be experienced directly by others; 3) it is continuous, that is, it always going on; and 4) consciousness of it can range from minimal/vague awareness to a remarkably astute sense or understanding of the experience of the body.

Testing - Urine/Blood

Both blood and urine testing have similar characteristics as a monitoring source. The tests 1) are "internal" in the sense that they are a measure of the person's own body fluid; 2) are an objective determination which can be administered by someone other than the person with diabetes; 3) are episodic determinations; and 4) can influence personal perceptions of ability to manage diabetes. Because 18 or the 19 informants used blood testing exclusively to make management decisions, and because the remaining informant was in the process of learning this skill, the discussion of testing in this study will refer primarily to blood.

Blood testing requires equipment, time and a needle stick. Over time it can be painful, cause callouses and decreased sensitivity on the pads of the fingers. One young man described deciding which fingers to use...

"This hand is too valuable to stick pins in, so it can only be these 3 fingers, and sometimes the drop of blood isn't sufficient and then you have to start again! I can really dread that penlet! After a whole bunch of times you build up callouses and then you have to decide which fingers you will sacrifice up to the Needle Gods!"

Blood and urine tests are characterized as "episodic" because they are not done continually. How often they are carried out can be either a function of the doctor's prescribed frequency or, as is more likely, the convenience and discomfort experienced by the person. When the experience is similar to the one described in the quote above, the person may decide to "take a break". This may be part of the "taking a break" behavior which was described in the process of "being regulated". From one participant ...

> "There was a period of time that I just stopped testing altogether because I didn't like what was happening. I wasn't controlling myself the way I should and I did not want to make any more changes in what I was doing. As soon as I started testing again, I got back in control. As soon as you start looking at those numbers, they pretty much tie your diabetes back into reality!"

This statement, which was corroborated by other informants, indicates that blood testing has accompanying functions in addition to providing a number value. One is that the number can reconfirm the diagnosis, and secondly that obtaining a number means an action needs to be taken. Another woman remarked, "There are just some days that I don't want to know because I don't want to have to deal with it, so if I'm feeling okay I'll just take a break."

As described in Section One, the process of "getting regulated" is likely to include the experience of "monitor talk". The number value is not only an objective measure of blood glucose level, but is also a source for making a judgement about one's own abilities to manage diabetes. This phenomenon of reacting to the test results was described by this man as "I depend on the machine but the longer I live with it it doesn't set me off as when I first started using it." Another woman described the difficulty of getting over this reactive attitude..." I kept thinking that it must be my fault, and then I would decide that I didn't even want to know! Finally, my therapist gave me this mantra to "chant" each time I did the blood test... 'even if my blood sugar is high I am still a good and lovable person'".

The data indicated that the association between "body listening" and blood testing becomes increasingly integrated, such that blood testing becomes a way of "checking it out", meaning checking out what they "hear" when listening to their bodies. This association is borne out by the responses of the informants when asked how they thought they would get along if the machine was not available to them anymore...

"Without the machine it would be a lot harder, because I

> can feel the sensation but I am not always accurate"...
>
> "Not testing would be like shooting from the hip, and taking multiple doses of insulin a day would be very difficult"...
>
> "I'd go crazy! Well, let me think about that. I did forget it once and did pretty well, BUT your guesses are wrong lots of times!"

It appears that testing, in conjunction with "body listening" helps to guide the individual through "trial and error" into establishing a "basic routine". The following quote is from a young man who describes such a situation...

> "No, I couldn't do without the machine because I can't tell where I am. I do know, though, exactly what the ranges are, like at 65mg/dl or 40mg/dl I may feel bad, and I don't get the shakes until I am real low. And my upper number is about 250mg/dl. So the glucometer tells you where you are at, but you can get into that whole thing and it is a real syndrome [he was referring to the intensity and attention to testing during the "trial and error" period], and you have to back off from that. I could finally back off when I got control of the whole thing... when I got my baseline insulin to cover me... when I saw those numbers smoothing out, then I knew everything was going to be alright! I mean I still know

that I am very sensitive to insulin and that I have to do the sliding scale, but that insures me that if there is a change I will pick it up."

To summarize, testing is measuring body glucose levels through the medium of a body fluid, urine or blood. Besides being an objective, quantitative (or, as in the case of urine, semi-quantitative) measure, the "numbers" are associated with individual judgements about management skills. The test results are also used to determine when one has achieved a baseline/basic routine, and help to confirm or "amplify" body listening.

Secondary Source of Monitoring by Health Care Provider

The health care provider, usually the physician, serves as an information source by proffering an interpretation of the patient's diabetes status from medical assessments and from episodic laboratory determinations (blood glucose, hemoglobin Alc, urinanalysis, and other diagnostic tests related to diabetes).

Characteristics of this monitoring source are that it is 1) indirect, meaning it is an intermediary source of information and a source which the person must seek apart from themselves; 2) external, meaning an interpretation made by someone other than the person with diabetes; 3) is episodic; and 4) is solicited in the sense that the appointment is made, testing or examination is done, and interpretation is sought from the physician. Reliance on this secondary and indirect source of monitoring can dampen attention to body listening, particularly if the "sounds" seem vague or in conflict with the provider's interpretation, or receive little validation from the health care provider. An example from the data was described as ...

> "In the beginning I was having a lot of headaches and I was worried about them. When I tried to tell my doctor he said 'I'm not worried about eh headache, we need to look at how to adjust your insulin!' I thought the headaches might be from the blood sugar. I just needed to have them acknowledged as part of me...just acknowledgement, that is the word!"

Participants who rely on these measurements and secondary assessments may also take on the label ascribed to them and call themselves a "good" or "poor manager", etc. One man with a six year history of diabetes described a good lab value given to him by his doctor..."I actually hadn't been feeling very well, but when he told me the test was okay and that he was pleased, then I was pleased, too."

On the other hand, the experience of being acknowledged and heard by the health care provider was described as ...

> "He made me feel so good about myself and he made me feel like 'keep trying!'... just by recognizing the effort I was making."

Use of this monitoring source appears to change as one learns more about diabetes management. A woman related these changes by this example ...

> "At the beginning my doctor got me through it (taking injections) and he was willing to treat me as an outpatient because I had no money or insurance. I know now that he didn't know much about diabetes, but he was really supportive. I see him about once a year now, but I know more about diabetes than he does. He didn't know about multiple injections, and I didn't really get regulated until I went to the teaching program. At this point I don't believe it is possible to manage diabetes by having your doctor control it."

This example and others suggest that information from the health care provider is sought and relied upon more heavily in the early phases of "getting regulated", but that this reliance wanes as one "gets a handle" on their own basic routine.

Secondary Source of Monitoring by Family and Significant Others

The fourth source for monitoring, that of family or significant others, provides both verbal and non-verbal information to the person with diabetes about others' perceptions of diabetes and how well or poorly they think things are going. Characteristics of this monitoring source are 1) external to the person with diabetes; 2) usually episodic; 3) may be either solicted or unsolicited; and 4) can provide a basis for comparison - of diabetic-self to diabetic others and/or diabetes-self to non-diabetic others.

This secondary source of monitoring by others includes instances of other people noticing an insulin reaction, possibly before the person with diabetes realizes it. A physician who participated in the study remarked ...

> "I'm just not aware of them, but I am starting to recognize them on my own. My wife picks it up at night, and at work others pick it up before I do. Before I go in for surgery, usually one of the residents will ask me if I had anything to eat... no, that doesn't upset me. I'm glad they're aware."

Another man who is responsible for supervising others in his office division said ...

"Yeah, everybody at work knows... I don't make a big issue out of it. I make sure somebody knows 'just in case'. It would be stupid not to tell somebody."

Family members, friends, co-workers and even strangers can comprise this secondary source. These people can be chosen or invited to participate in observing body responses, to respond to testing values, and even to make suggestions about choices of management. A young woman in business described her secretary as ...

"a real doll. She seems to know right away what is going on and she will stay around for a while because she knows that these reactions upset me and that it takes a little while for me to get back to being myself."

Others may also make unsolicited statements about the diabetes, such as telling "diabetes stories", or make judgemental comments, suggestions - "Are you alright?!" "Diabetics aren't supposed to eat that, are they?"

What qualifies this as a monitoring source is the fact that the diabetic person attends to the information and applies their own personal interpretation to it. It further qualifies as a source of information because it has the potential to alter the person's diabetes related behavior or personal attitudes about diabetes and its management. Descriptions within the data indicated that this monitoring source was manifested as an interactive process capable of influencing the person's management routine, disclosure about the diabetes to others and perceptions of themselves personally and socially.

Monitoring activities associated with this source included two major type of comparisons made by the person with diabetes. Comparing one's diabetes-self with other diabetics is an activity that assumes subtle but distinct changes over time. Initially, soon after diagnosis, people wanted to know how others are or have coped with diabetes. Later they wanted to know if others' diabetes regimens are the same or different, and if different, why? Does a difference in regimens mean that their own diabetes is better or worse?

Those persons describing themselves in later phases of the Trajectory wanted to compare notes with others "like myself", in terms of age, type of diabetes, similar diabetes events, etc. And this later comparison seemed to take on the tone, not of "why isn't their regimen like mine?", but more within the context of "I wonder if they have found an easier or better way to do _X_". Several participants recalled listening to others' serious or frightening diabetes experiences and thinking about why that could or could not happen to them. They could also articulate the precautions they now included in their basic routine to prevent such unwanted experiences.

Comparisons with non-diabetic persons were also described. The data in this areas were concerned primarily with the difficulties of being diabetic in social situations with others who are not diabetic. They remarked that non-diabetics do not have to eat on a particular schedule, or maybe not eat at all, and that they (the participants) have to go through a great deal of effort to carry out their basic routines in social circumstances. The most difficulty centered around situations in which non-diabetic others were controlling the when and what of eating, or the activity schedule.

Family and others may also indicate verbally or non-verbally whether or not it is convenient for the person with diabetes to "be diabetic". One young woman was traveling with her parents in Europe, and the parents was to eat dinner late in the evening, "Sometimes," she said, "it was okay for me to be diabetic, but other times they didn't want me to be diabetic because it bothered what they wanted to do. This is the same Mother who is all the time telling me, 'it would be okay if you would just follow the book!'."

Another reason why this monitoring source can be so important is the potential for shared diabetes activities. Some informants described spouses or close friends who shared the cognitive burden of diabetes. While no one else can actually experience the diabetes for the person, what can be shared are the planning activities - scheduling and planning meals; "making sure" that food or insulin or supplies are readily available; sharing in decision making about insulin doses, exercise, or pinpointing what went wrong with the management strategy. Most importantly, perhaps, is that the person feels validated from this sharing and that others acknowledge the effort and attention demanded by diabetes management. These cognitive activities, which are described next, are persistently required of the diabetic and do become burdensome and tiring. As one man stated in this regard "diabetes gets on you. It's always there demanding your attention".

To summarize, this source of monitoring information comes from others besides the health care provider/s. It is information that informs the diabetic about how others are reacting to the diabetes and to them as a diabetic. The information has the potential to influence diabetes behaviors and how the person with diabetes feels about her/himself as a diabetic. The influence, use of and changes in specific monitoring activities at specific points within the trajectory is depicted in Figure 4-2, which follows the discuss on cognitive strategies.

Activity Factor - Cognitive Strategies

According to participants, managing with a chronic illness such as diabetes requires that one learn three cognitive strategies - planning, pinpointing and plotting. "Planning" is knowing and doing or preparing to do those activities which will most likely produce a certain outcome. Planning in regards to management means that the person plans to do those things which they have come to know will "cause" blood glucose variation or body responses to happen as they have before. Planning is used to "make sure", to make management as certain as possible. For example, if a person is anticipating a long car ride over several hours, s/he will take food along "to make sure" that if it is needed it will be there. This planning is necessarily based on an understanding of the principles of management as well as experience in applying management strategies to themselves.

Before planning can be approached from a more autonomous, self-management position, the person must engage in "pinpointing". This begins early in management and involves thinking back to what things have brought the person to the present point. This is evaluating after the fact what went wrong or right, deciding what it was that made a difference. A common example is that of trying to pinpoint why an insulin reaction occurred - did I take too much insulin? did I eat enough? was I more active today than usual? Pinpointing, also, requires an understanding of factors that can affect blood glucose levels.

The third cognitive strategy, "plotting", requires both the ability to plan and to pinpoint. Whereas planning is used for ordinary, everyday situations or those circumstances frequently encountered, plotting is a form of planning for less familiar situations. To do it requires that one knows principles of management, what usually works for them under routine circumstances, and then taking that information and modifying it to implement strategies which they hope will have the desired effect. Plotting will also take place if the person has had an unpleasant situation with diabetes and wants to prevent its recurrence or if pinpointing over time reveals a trend in blood glucose fluctuation. Pinpointing and plotting, then, can be done for short term management changes or to make overall management changes.

All three cognitive activities require grounding in an assessment of monitoring information as well as knowledge about diabetes and management principles. These activities are acquired and refined through monitoring and emerge and evolve at particular points in the trajectory. This is depicted in Figure 4-2.

The Goal Factor of Management - Control

Control is word often used when discussing diabetes. It is inherent to managing diabetes since the point of doing any of the management activities is aimed at controlling the disease. Most commonly, the term "diabetes control" refers to having blood glucose levels remain within a specified range, and this was the most frequent response from participants when they were asked what the word meant to them. However, use of the word "control" was usually preceded by an action modifier ("under control"; "out of control"; "taking control"; "being controlled") indicating that the experience of control is somewhat different than an abstract definition of the term. Indeed, the data regarding control could be grouped according to three connotations - control as status or a blood glucose number; control as process or the things one does to manage to achieve a specific level of

CHANGES IN MONITORING AND COGNITIVE ACTIVITIES
THROUGHOUT THE MANAGEMENT TRAJECTORY

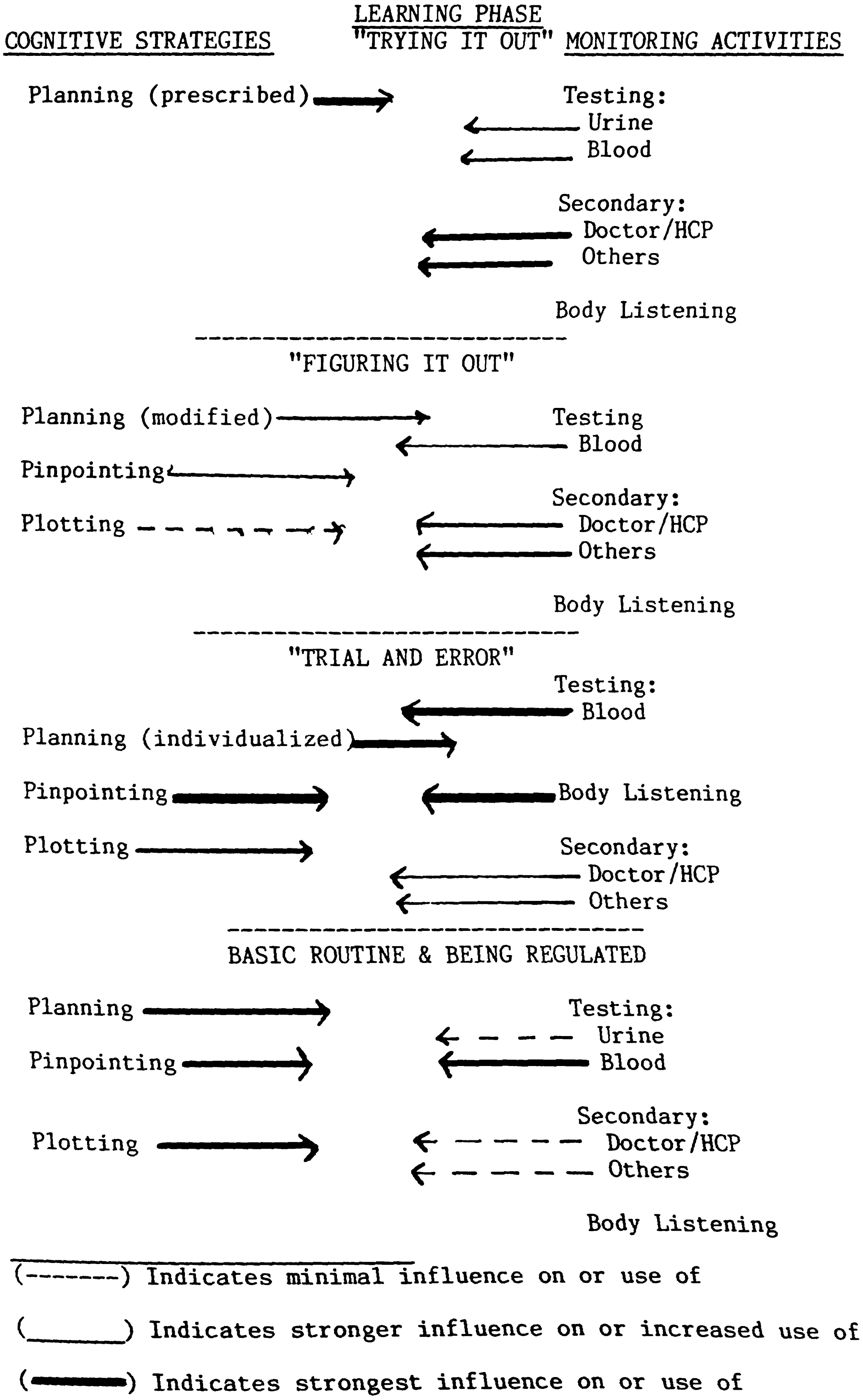


Figure 4-2

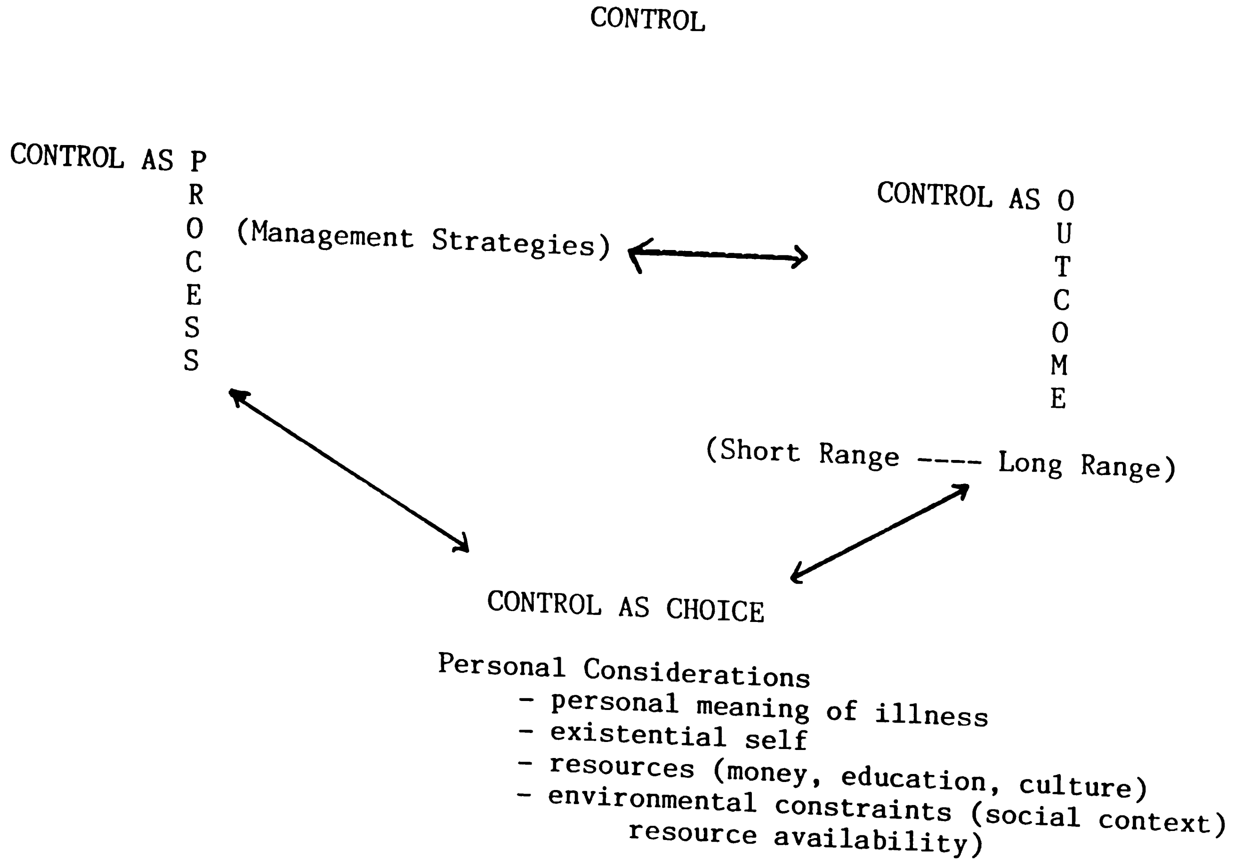
control; and control as a choice about what management strategies to use and what status/blood glucose value one desires (see Figure 4-3).

Descriptions of control as status included "He is in good control" or "poor control", in reference to blood glucose numbers. Status could be futher delineated as short term, the blood glucose value right now, or as long term, as an overall outcome of the trends of blood glucose values over time

In reference to control as process, one young informant described himself in "loose control" indicating the intensity and accuracy with which he attends to management strategies. In this regard, control is what one does and may also include knowledge about where one is with one's blood glucose numbers.

The third aspect of control is that of choice. Informants talk about choosing a certain level of control, that is they choose a particular process of management and the ranges of blood glucose levels that they can accept. When asked about how long she would allow a blood glucose level of 200mg/dl to persist, one woman replied...

> "Oh, I might not jump on that right away. It depends on what else is going on. But if it was, say 220 or 250,



The Functions of the Factor of Control

Figure 4-3

> I wouldn't let that go. Sometimes, though, I've done everything I can, and then I just have to say to myself that it's going to be high for a while, but it will come down in a few hours."

In this study, a description of control as status, process or choice was very much reflective of where one was with the process of learning to manage. In the later phases glucose control within a specific range is a goal which must be achieved by choosing specific activities (taking control) and both are determined by personal choice at any given time.

Most participants described knowing what environmental or personal aspects needed attention in order to bring about a desired glucose response, but also stressed how important it was to be able to "kick back" sometimes when control became "too intense" or too much of a burden. Those in or having experienced earlier phases of learning described "cheating" as a deviation from activities required to stay in glucose control; whereas those in later phases talked about "taking a break" from "tight control". This was futher indication that the concept of control changes with movement in the trajectory.

Additionally, participants describing the early phases of learning to manage talked about control as a point of achievement as if it were actually an absolute, that is, once control is achieved, no further effort is required, and diabetes may even be cured. Later in the trajectory, informants talked about management as a realization of needing to individualize their management to fit themselves and that it would be an ongoing process. Those who have experienced "being regulated" had difficulty talking about control in abstract terms. They provided examples of why absolute control over diabetes is not possible, and then discussed what control is possible for them. This comparison of control as described by the informants to the research on control as outlined in Chapter Two is discussed further in Chapter Six under the Discussion section.

Modifying Factor - Personal Considerations

Personal considerations encompass components of personal preference and personal logic or reasoning which modify learning and management choices. Monitoring and management activities cannot be viewed apart from personal preferences, patterns of coping, emotional responses, situational appraisal, one's perspective of self, educational background, life experiences (both the past and those hoped for). These considerations, along with personal meanings associated with the disease and experiences in social contexts, are all part of the illness experience.

As a factor affecting the management trajectory, personal considerations have to be recognized and included, but descriptive data in this study are sparse. What is available from these data and from impressions of the informants during the interviews are the characteristics noted above. These appeared to influence the amount of time taken to progress through the trajectory as well as the individual's choice of management style at any given point. These considerations were apparent in the young musician's story when he described all the things he felt he needed to do to achieve control of his blood glucose most of the time. He clearly identified everything he needed to do to achieve the high level of glucose control but expressed an unwillingness to give the consistent time and attention required. "That is not 'me' right now", he said.

Another informant with a 12 year history of diabetes had only recently identified a routine that works best for her. Part of the delay, she said, came from an enormous underlying fear that had nearly immobilized her management of diabetes for all of these years ...

> "There is a fear that the high numbers means your arms and legs are going to fall off; and there is not being in sync with what you are told to do and how you feel. I go through cycles, a string of bad days and a string of good days. That used to scare me, but now there is a comfort

> in the changes, because I know the blood sugar will come down in a few hours or by tomorrow."

"Being perfect", that is, always having perfect blood glucose readings, was not worth it to some of the informants. One older, and quite knowledgeable woman stated:

> "Diabetes control is feeling ok and not being sick. It means paying attention to what you are doing. Perfect means that all you do is pay attention to diabetes all day, but you realistically have to decide how much attention you want to pay."

Several participants described having the knowledge and know how to manage but sometimes experienced fatigue at the end of a day, or as one man said:

> "Do you realize what a drag it is to not be able to just fall into bed at night when you are exhausted? No! You can't go to sleep, you have to test and maybe take more insulin, or maybe go prepare a larger snack. It's a pain."

Sometimes, he said, he just ignores what he knows would be the "diabetically correct" thing to do just because he doesn't feel like doing it.

Another woman described the difficulty she runs into if she tries to "give myself a day off and take it easy". She said if she did that, "like one day I took off and decided to watch old movies and relax. My blood sugars shot way up because I was just sitting around!". At other times, however, she has opted for "a day off" from diabetes and "caught up" the next day.

There are two important reasons for recognizing and including personal considerations as a significant component of the trajectory. One is that the data suggests personal confidence (efficacy) in managing diabetes may improve as one learns not only about diabetes but how to manage with diabetes. The second is that the possibility of choice is always open for an individual. Personal considerations determine what the possibilities are for any given individual. This is crucial, since not all persons are capable of or even want to go through the learning and effort required for "being regulated" or even developing a basic routine based on sound management principles. Also, there is the choice to switch the level of management, as with those who want to "take a break".

Summary of Chapter Four

Findings have been presented and organized to provide a full description of the core category, "management" as a trajectory comprised of two major processes - "getting regulated" and "being regulated". "Getting regulated" was described by informants as a process having four phases, all concerned with learning how to manage diabetes and culminating in an overall, individualized basic routine that they identified as stable and reliable for making management decisions and planning their days. "Being regulated" referred to the ongoing process, a way of "being", of maintaining diabetes management. "Being regulated" as a part of the trajectory, followed the learning phases of "getting regulated". In actuality, however, there are informants who have not identified a basic routine but would describe themselves as maintaining management. The distinguishing feature is the scope and attention to the myriad of variables which can influence diabetes glucose control. Participants currently involved in "being regulated" provide examples of management that subsume a broad comprehension and understanding of the complexity of diabetes within any given situation. Other participants give attention to very few variables, but because of a feeling of physical stability, would say they are "in control".

There were many unknowns associated with each process and phase of the trajectory description. Participants' venacular was rich with indicators of questions, confusion, and wondering. These indicators were associated with specific phenomenon or situations that were and/or remained puzzling or not entirely clear. However, unknowns experienced as uncertainty in the beginning because of their disruptive nature or potential for disruption, did show change over time. For example, a question about how to manage in the beginning, changed by the time an individual had learned a basic routine. At the point of basic routine, the future was still unknown and some management skills were still unknown, but there was a confidence in one's own ability to manage whatever situation might come up.

Uncertainty was also associated with the management factors - monitoring, cognitive strategies, personal considerations and control - and changed in response to changes in these factors. An example was learning to manage diabetes in social situations. In the early learning phases there was uncertainty about both how to manage in general and what to do in social situations, such as having dinner at a friend's home. Later, as the person learned how long they could delay dinner and what insulin adjustments they could and were willing to make, they could be more verbal and specific with their host/ess or choose the strategy most appropriate for them.

An interesting finding about uncertainty was its association with "body listening". Although there was body awareness before diabetes, after diagnosis body responses in relation to diabetes was something that had to be learned. Conscious attention to body responses and improved skill in "body listening" were described by participants as a necessary requisite for being able to establish a basic routine. They also indicated that this awareness was unknown in the beginning of management and integrating "body listening" with management strategies and outcomes required a great deal of effort.

Section Two described the factors important to "management". These factors were defined from informants' descriptions and priniciple characteristics were highlighted. The proposed links between these factors and development of the diabetes management trajectory is discussed in Chapter Five as the substantive theory of this study's phenomenon.

CHAPTER 5

SUBSTANTIVE THEORY DEVELOPMENT

The central process described by study participants in Chapter Four was how they manage diabetes mellitus, more specificially, learning to manage and maintaining management. This broad, core category of "management" was further described as a "management trajectory". The description from the participants indicated that the trajectory evolved over time and was predominately influenced by the factors of 1) monitoring; 2) personal considerations; 3) cognitive strategies; and 4) control. Uncertainty was associated with each trajectory phase and with the influencing factors.

The purpose of this chapter is to propose a framework for the development of substantive theory of this management phenomenon. This is not to be construed as formal theory, but rather a conceptual rendering of the associations between the influencing factors and the trajectory. The diagramatic schemas (Figures 5-1 through 5-4) reflect the findings' associations at each phase of the trajectory. The relationship of personal uncertainty to the trajectory and the influencing factors is discussed and summarized at the end of this chapter.

The propositional links offered in the following discussion are based on three major theses:

1. Persons with diabetes mellitus acquire skills of management and choose management styles based on information from monitoring sources, of which the most influential and significant is that of "body listening".
2. Uncertainty associated with learning to manage diabetes is dependent upon the interaction between situational context and personal considerations and upon the particular phase of learning to manage diabetes.
3. To achieve "being regulated", the learning phases of "getting regulated" must be sequentially experienced.

There are several important, supportive premises to these theses:

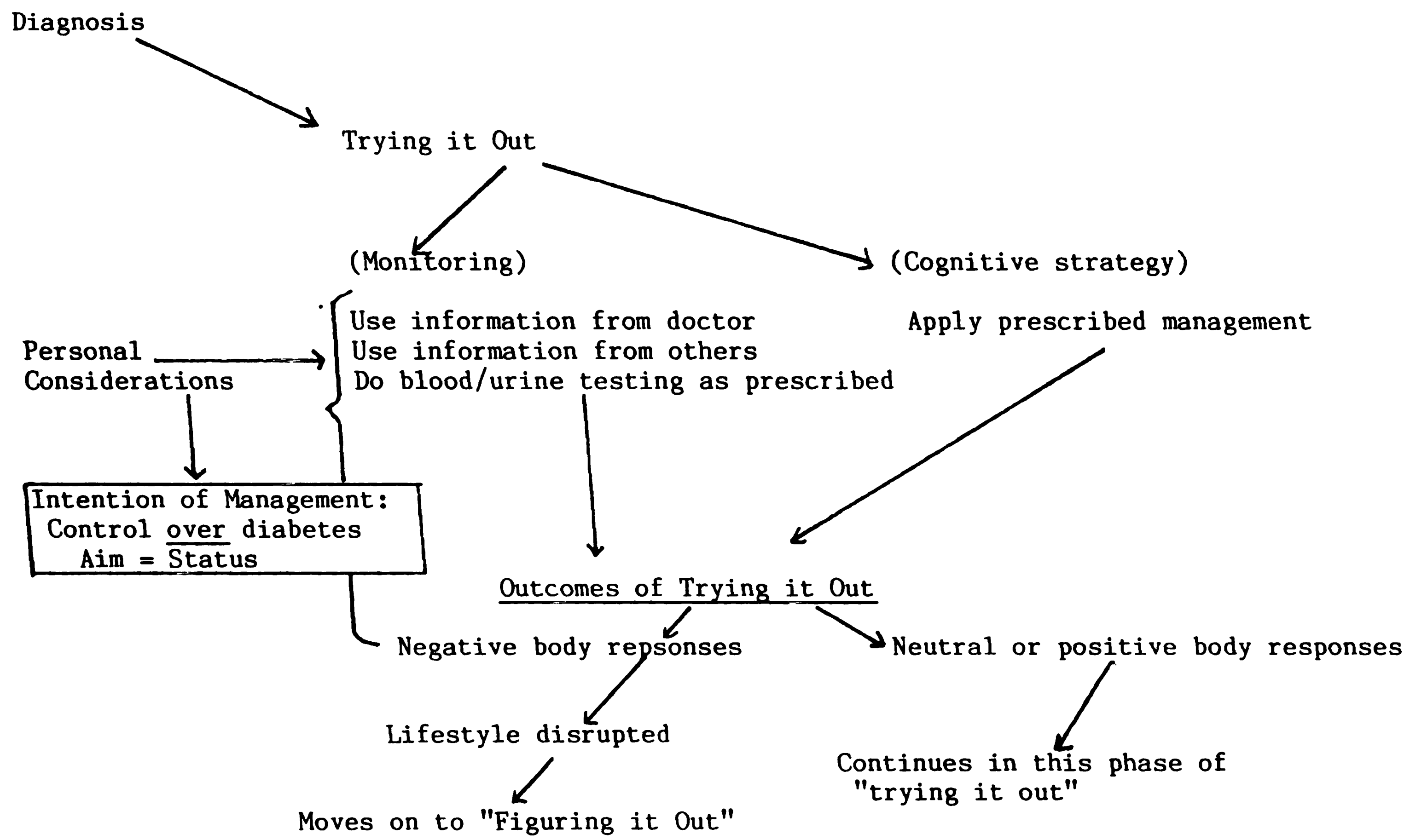
1. Monitoring activities in relation to diabetes occur over time and concurrently with experiences of employing management strategies.
2. Monitoring activities inform cognitive strategies and, thus, direct choices of management strategies.
3. Personal considerations can modify any monitoring activity, and, therefore, cognitive strategies at any given time.
4. "Body listening" related to diabetes and associated management choices must be learned.
5. "Body listening" is experienced wholistically, and is not limited to symptom detection.
6. "Body listening" can be developed to a highly skilled level.
7. "Body listening" will directly influence the status, process and choice of diabetes control.

Relationships between these theses and premises are proposed in the following discussion. The discussion is organized by phases of the management trajectory and diagrams of the links between management factors at each phase are offered. The links are represented by lines and arrows. These are not offered as "causal" relationships, but rather as associated phenomenon. Stronger relationships (indicated by the solid lines) occur over time as one progresses through the trajectory, but this temporal dimension is not meant to be represented in these figures as "temporally ordered" as might be proposed in an empirically tested, causal model. The dotted lines suggest weak associations between factors. At each phase the modifying factor of "personal considerations" is thought to be a prevalent and influencing factor, and its potential as a modifying influence is indicated by the bracketing of the entire process in each diagram. Likewise, the factor, "control" is denoted as the "intention of management", and is indicated and enclosed at each phase in the lower left hand corner.

"Trying it Out"

The conditions which initiate "trying it out" are the declaration of a diagnosis and an assigned, medical treatment prescription. Figure 5-1 denotes that this as a fairly straight-forward process. The diagram also indicates that there is little integration between monitoring activities and cognitive strategies.

PHASE ONE OF "GETTING REGULATED"
Trying It Out



"Trying it Out"
Figure 5-1

Management activities are more veridical at this stage, with little, if any, incorporation of feedback of outcomes to alter management strategies. The intention of management in this phase is control "over" diabetes. Control is viewed as an absolute status to be achieved. The predominant monitoring activities are those which are assigned by the physician and the cognitive strategy employed is that of planning to incorporate the assigned tasks.

Possible outcomes of this phase, "trying it out", include experiences of novel, and probably negative, body responses (insulin reaction/s, headache, fatigue, visual changes). There are also emotional sequelae - embarrassment, fear, anger, and frustration - as the person tries to do the "right" thing at the "right time" in the "right" way. When there is an experienced lack of "fit" between the prescribed regimen and personal preferences for lifestyle, the individual may be prompted towards movement into the next phase of "figuring it out". However, some individuals may experience little difficulty or disruption from implementing the diabetes regimen and may continue to follow with prescribed medical plan without modification. It may be assumed that if the diabetes changes and results in changes in body response, then the individual will then move on to the next learning phase.

For the majority of participants in this study, this phase of "trying it out" was of short duration, and the impetus for movement into the next learning phase, "figuring it out", was the perceived rigidity of the prescribed treatment and the experienced negative body responses.

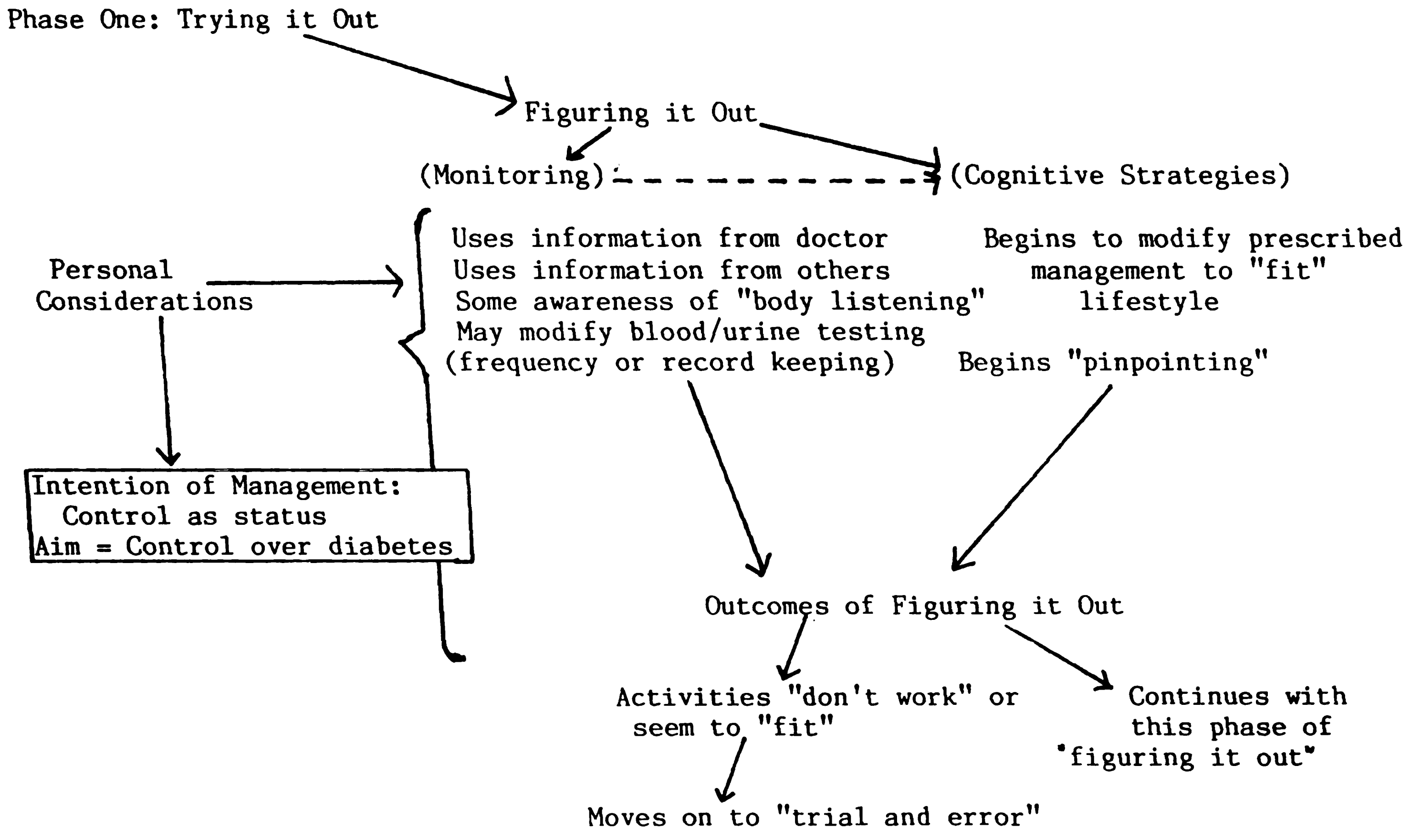
"Figuring it Out"

The disruptive outcomes of "trying it out", that is, the confusing, unpredictable and negative body responses, the difficulty of incorporating the tasks into their usual lifestyle, questions about management, are the conditions which set up the possibility for movement into "figuring it out". In Figure 5-1 "body listening" was not included in the monitoring activities; however, this source of monitoring receives more attention in the phase of "figuring it out" as the individual begins to modify the prescribed treatment in accordance with personal preferences and body responses. (See Figure 5-2)

Although there is a continued reliance on the secondary monitoring sources of the physician and others, the modifications in management are assessed for "fit" with both personal considerations and the information gained through monitoring. If the "fit" is not there, the person will move into "trial and error" which is an intensification of the search to find a management style that meets personal requirements.

In this phase it is surmised that personal considerations have a stronger influence at this point, both in initiating this

PHASE TWO OF "GETTING REGULATED"
Figuring It Out



"Figuring it Out"
Figure 5-2

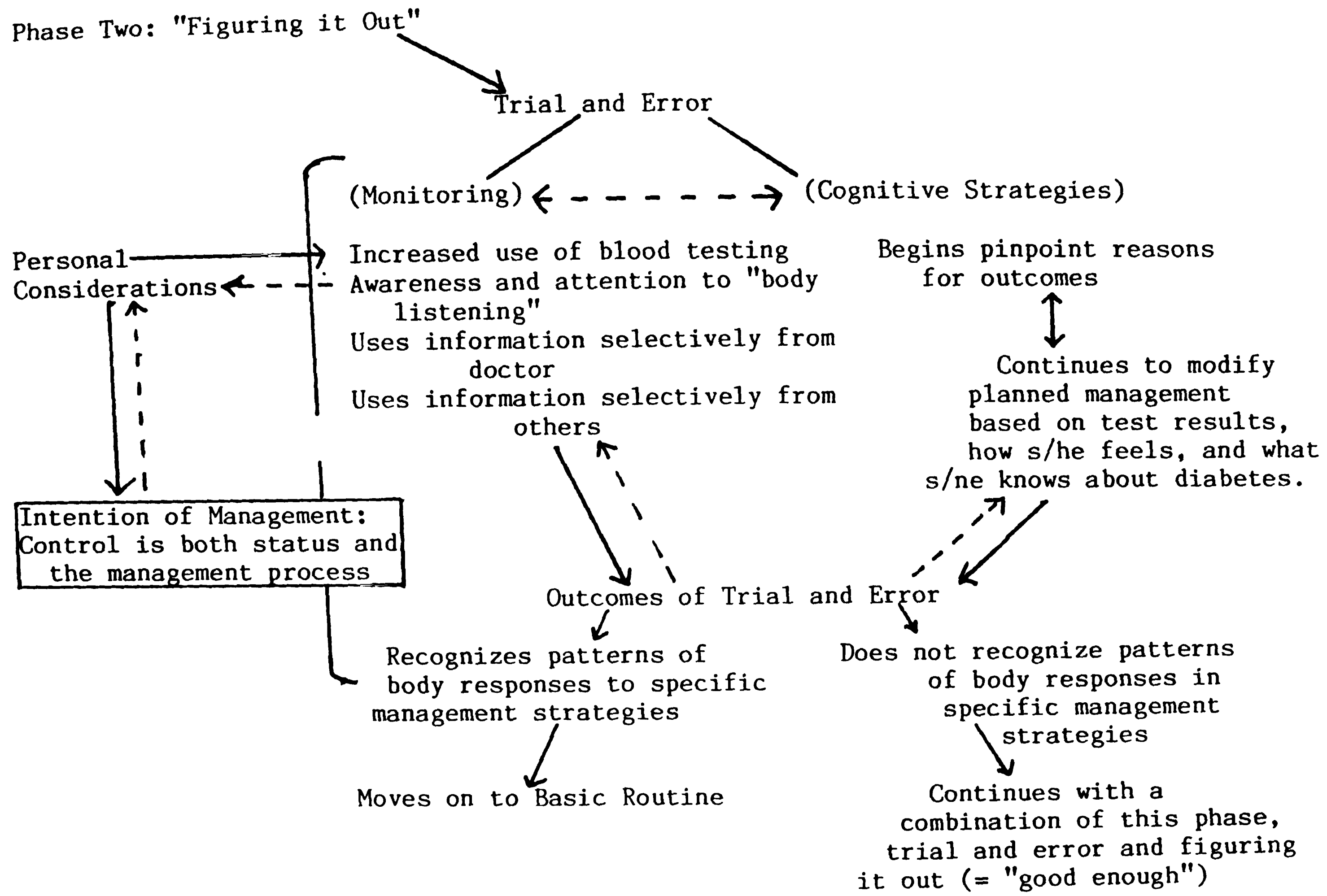
phase and in deciding if the management style "fits". How one usually problem solves health situations and what resources are available and considered possible will influence whether or not there is continued dependence on the health care provider as a monitoring source.

In addition, the findings suggest that the cognitive strategy of pinpointing begins at this time and is used to modify the prescribed treatment regimen. In Figure 5-2, the broken line between monitoring and cognitive strategies indicate a beginning, though weak, connection being made between monitoring information and cognitive choices about management. Control is still perceived as "control over" diabetes.

"Trial and Error"

An assessment that the management regimen is still not working or "fitting", will prompt the style of "trial and error". The processes at work here are an intensification of monitoring and management efforts. There is greater attention to, and very likely an increase in frequency of blood testing and to "body listening". As shown in Figure 5-3, a bi-directional relationship begins to emerge between the specific monitoring attentions and the evolvement of cognitive strategies (see Figure 5-3). Cognitive strategies expand now to include more pinpointing and individual planning, which, in turn, affect management choices. At this point, there is also an affect of

PHASE THREE OF "GETTING REGULATED"
Trial and Error



Trial and Error
Figure 5-3

management strategies on monitoring, as the individual makes a choice and then checks to see the blood glucose effects. In this way, the association between choice of management strategy and monitoring assessments is made. As this repertoire expands, so too can the skills of pinpointing and planning.

During this phase of management, personal considerations become more integrated with diabetes management such that the management goal is not so much scheduling diabetes tasks for minimal disruption of usual activities, but more of integrating the two simultaneously. The diabetes is not so set apart from living as it was in "figuring it out".

This phase may require the most intensive interpretation and support from the health care provider, both in providing accurate information to assist with pinpointing and in recognition of body response patterns. This would include soliciting and utilizing information from "body listening". Information from a secondary source, particularly the physician, will now be "screened" for coherence with experiences of body responses in relation to diabetes.

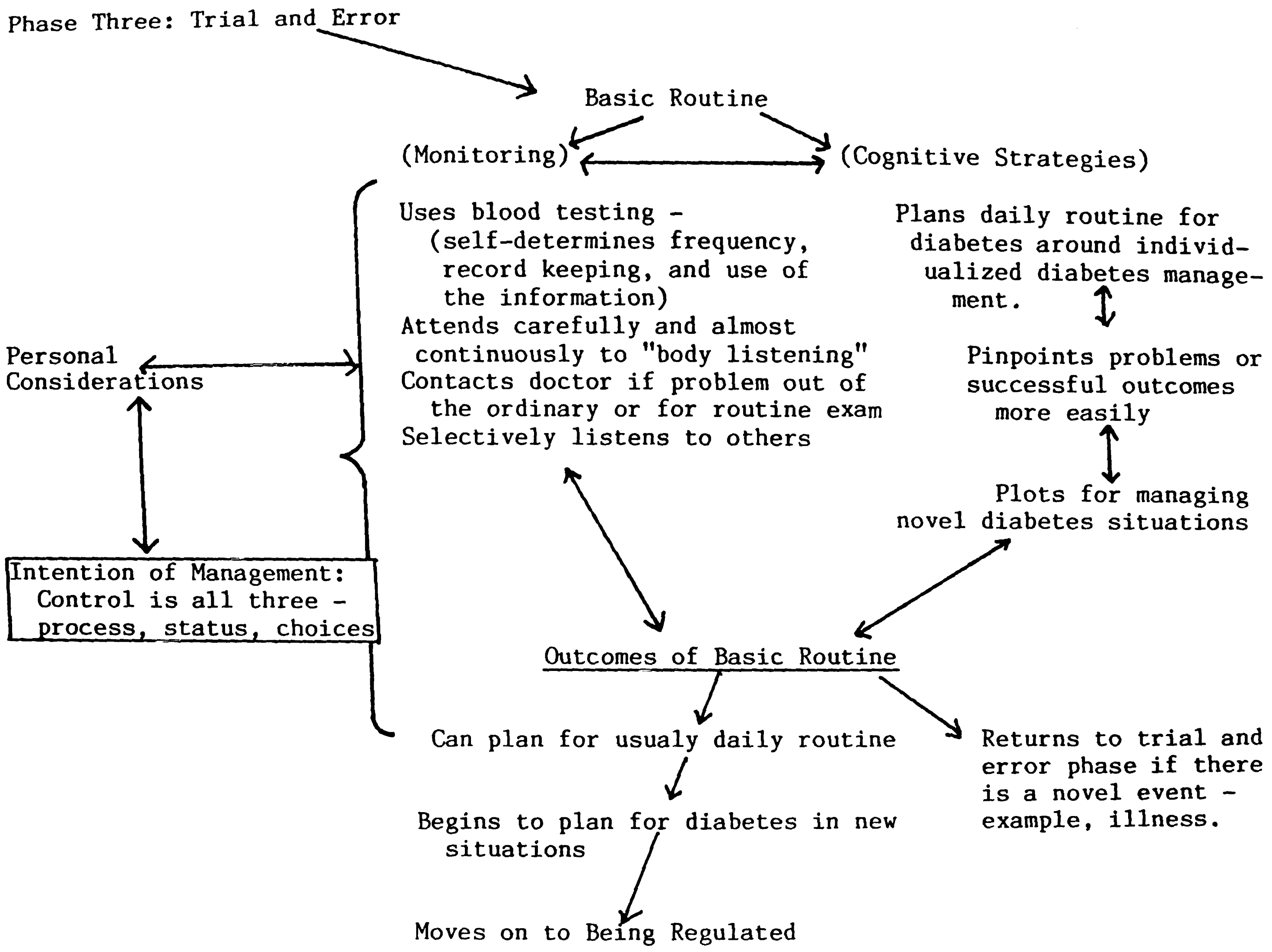
Control in this phase of the trajectory becomes associated with the process of management. Thus it may be that the person may opt for "loose control" rather than progress on to the "basic routine". Or the person may revert back to periods of "loose control" even after establishing the basic routine, if personal considerations determine it to be necessary. It would seem that more cognitive knowledge about diabetes is essential at this point, particularly basic management principles and interaction effects between management components. This appears to be necessary to make the choices that will help develop the preferred physical responses.

Basic Routine

The "basic routine" is depicted in Figure 5-4. The conditions for this phase of management are sufficient experience with "trial and error" to discern patterns in body response associated with particular management strategies. This phase takes into account more of the variables which influence the diabetes under usual situations, such as planning for a typical day at work.

The major hypothesis of this phase of management is that "basic routine" cannot occur without progression through the other prior learning phases. Further, plotting cannot take place until a person understands what basically works for them. It seems possible that the term "basic routine" may not apply equally well to all aspects of management. For example, a person may have a very good idea of his/her response to insulin, his/her best administration schedule, and be very knowledgeable about how certain foods affect their blood glucose, but they may have very little understanding about the effects of exercise on this regimen.

PHASE FOUR OF "GETTING REGULATED"
Basic Routine



Basic Routine
Figure 5-4

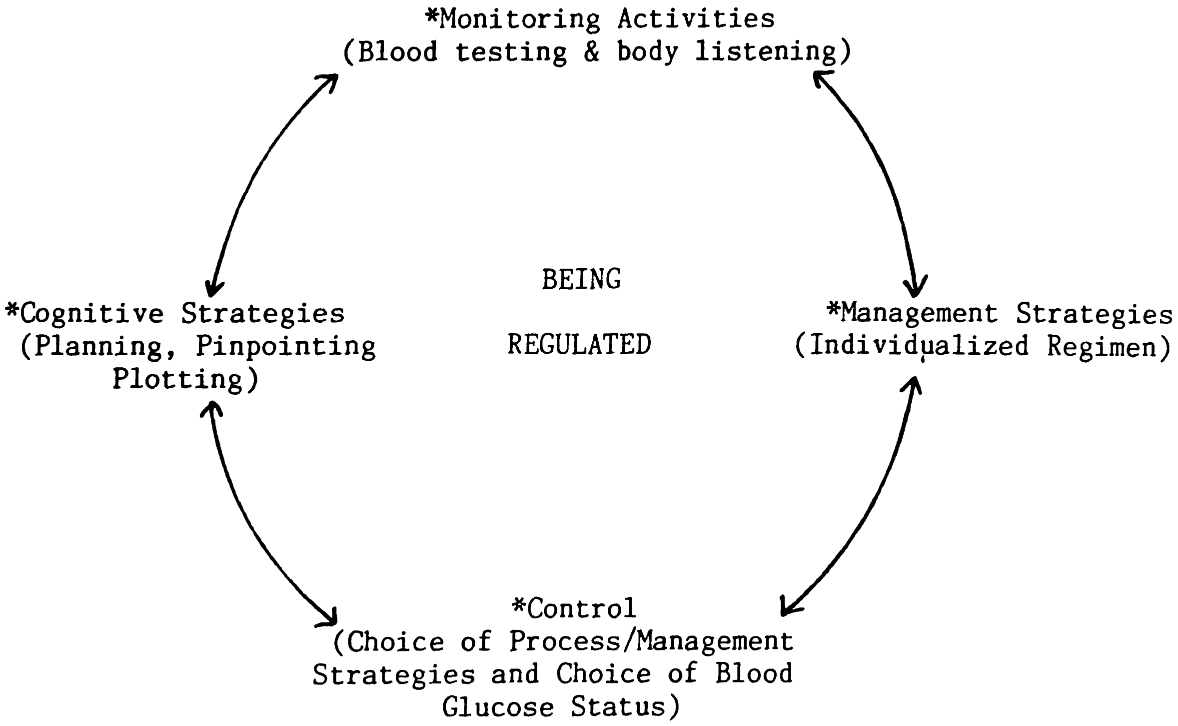
Cognitive strategies now include pinpointing from a wider scope of diabetes knowledge and experience, and planning has assumed an individualized approach while retaining basic management principles. It appears that plotting activities can be carried out at this point with some real grounding in personal experience and confidence. This is the significant outcome of this phase of learning to manage diabetes, in that there is now a developed baseline for management which can be used for plotting diabetes management in new situations.

"Being Regulated"

Figure 5-5 indicates the bidirectional relationships and total integration between management choices, cognitive strategies, and monitoring activities. The major changes are the near exclusive attention to monitoring sources of "body listening" and blood testing, and the use of all three cognitive strategies - planning, pinpointing and plotting.

Positive experiences of this process are perceived flexibility in one's daily routine, greater possibilities for participation in one's interests (so said the scuba diver, the frequent world traveler, and the rock climber), and a sense of confidence in one's ability to manage diabetes no matter what the situation may be.

The Process of "Being Regulated



*Integrated with Personal Considerations

"Being Regulated"
Figure 5-5

The Substantive Theory and Uncertainty

The sensitizing definition developed to guide this study, was:

> When not knowing disrupts meaning or coherency of a personally salient situation.

The findings supported this definition as participants described situations and related unknowns which either disrupted their understanding of the situation or required some immediate decision or action along with a degree of unpredictability in outcome.

Descriptions also suggest that learning to manage diabetes is prompted or at least influenced by personal uncertainty. Unknowns became personal uncertainty when the context or situation was unclear, yet a personal choice or decision had to be made about the diabetes management. The context could refer to either the external environment, such as a social situation, or to "listening " to and understanding one's body responses.

In the beginning, after diagnosis and with the implementation of management, there are many unknowns and much experienced personal uncertainty, particularly with regard to affect of one's actions on the his/her body - food, insulin, exercise, stress. In fact, in the beginning the individual may not even know what it is s/he needs to know, and later they may form the question but not know if an answer is available or where or how to look for it.

The unknowns associated with the phase of "trying it out" included - learning what diabetes is; learning about principles of diabetes management; learning new psychomotor skills; and wondering what body responses to expect as well as what to expect from prescribed management. There is also not knowing how or what to expect from trying out the treatment regimen. There are also the questions that will remain unanswered, i.e., about their future and diabetes - complications, illness, financial worries. Until one has experience with treatment application, there is no basis of comparison.

After "trying out" the medically prescribed treatment, the individual may try making modifications in this plan that better suit his/her lifestyle or make changes to ameliorate negative body responses. Unknowns of this phase, "figuring it out", are similar to "trying it out", but there are additional questions about why the prescribed treatment does not work. This may prompt questions about the accuracy of the diagnosis and whether or not the diabetes is more or less serious than was first described. There are also questions about why one's treatment regimen may differ from someone else with the "same diabetes"; is insulin really necessary?; can insulin eventually be discontinued?; will the diabetes improve? And there are questions about "who" has the answers and a growing suspicion that the physician may not have the answers. Questions of how much a regimen can be modified and for how long may arise, as demonstrated by the woman who would take insulin every three days because she was relatively symptom-free in the interim.

The "trial and error" phase of learning how to manage diabetes is a time of increased experienced uncertainty. The individual is progressing from a management plan that is not working well to a time of intensified trial and error with what may, at first, seem like erratic results. The old strategies didn't work well, but new management combinations may also be interpreted as not working. The person is caught between two phases of management, neither of which works. Uncertainty in this phase centers on wondering <u>if</u> a successful management regimen can be found. There is an intensive search for cause of physical effects, and associated frustration and anger if the cause cannot be found (or if blood test results appear illogical).

A major portion of this frustration stems from the fact the body response may seem incongruent with choices of management strategies. While patterns may emerge between some strategy choices and body response, other outcomes may never be explained. This eventually becomes a "certainty", that no two days will ever be alike and that some blood glucose values and body response cannot be directly attributed to a specific cause.

Also, even with experience of specific patterns, no body response is ever absolutely predictable.

Uncertainty can be handled in one of two ways at this point. The person may elect to return to old strategies, or, if they can discern coherence between tried strategies and body responses, they will most likely continue with the trial and error until they have a "handle on it". Ironically, there are still unknowns to contend with, but with "trial and error" phase there are more reliable strategies which have been experienced as working and from which the person can determine the patterns emerging for him/her.

In the last phase of "getting regulated", as with "being regulated", unknowns about the future are sometimes experienced as uncertainties when the person tries to project him/herself into a future situation. In fact, participants who had experienced this phase of management spoke of daily unknowns as more of an accepted fact of life which no longer evoked feelings of uncertainty. Unknowns were expressed as uncertainty and had an air of urgency to them if the situation was novel or unfamiliar and had the potential to affect diabetes status. At these times, participants described going back to the basic routine that they had established for themselves and starting trial and error activities once again. Participants experiencing this phase of management also described going back to some variation of the basic routine not only during times of unfamiliar circumstances but in order to take a break from the demanding schedule of management.

Emotional and attitudinal responses to uncertainty appeared to change over time. In fact, a significant characteristic of "being regulated", is the acknowledgement of the unpredictability of diabetes and acceptance of the fact that there will always be unknowns. However, what has become more predictable by that phase is the confidence they have in themselves to handle whatever situations occur.

Several participants talked about losing "spontaneity" as a result of having diabetes. One 24 year old woman expressed it as losing the "wonderful uncertainty of life". By this she meant having to always plan days and activities around diabetes and not being able to take advantage of an opportunity that might come up on the spur of the moment. She went on to describe that unplanned-for activities could be incorporated but not without a lot of juggling of management strategies and increased decision making. She noted, however, that with establishing her own basic routine, some of this lost spontaneity was returning because now she was better at knowing her own limits and body responses to a variety of situations.

In summary, the findings presented in Chapter Four indicated that there is a management trajectory within which people learn to manage diabetes and find what works for them. This trajectory is influenced and modified by specific factors of monitoring, cognitive strategies, personal considerations and management intention/goals of control. This chapter suggested a temporal sequencing and associated relationships among the factors in the management trajectory. Uncertainty associated with learning to manage diabetes was also discussed within this framework, and was shown to change focus as one progressed through the trajectory. A summary table of the described uncertainties associated with each phase of the trajectory is provided in Table 5-1. As indicated by Table 5-1, there are shared uncertainties among the participants of this study which vary across the management trajectory; however, individually perceived uncertainty and/or responses to uncertainty vary. Although these particular uncertainties cannot be circumscribed and predicted, the rich description of the diabetes experience provides sensitization to and understanding of uncertainty's significance in the illness experience.

PERSONAL UNCERTAINTIES ASSOCIATED WITH SPECIFIC PHASES OF THE MANAGEMENT TRAJECTORY

TRYING IT OUT	What is diabetes? What does the diagnosis mean for my life? What do I have to do? Change? How do I do it? (what is prescribed) Will I die? What physical feelings are diabetes? Which aren't? What if I can't do what I am told? (e.g. take insulin shot) Can I still work? Should I change careers? How will this affect my family? my relationships? My social life?
FIGURING IT OUT	Why don't I feel better? Am I doing the regimen right? How *should* I feel? Are insulin reactions normal? Are *my* insulin reactions normal? How do I make sure I don't have insulin reactions? What if I pass out? What do the test results mean? Should I do something based on the test results? What? Can I make changes without asking the dr.? Why is my insulin dose/diet/insulin reactions different than "so and so's"? How do other people do this? How can I still socialize? Travel? What will be future be like with diabetes?
TRIAL AND ERROR	Why don't I feel better? Is it possible to feel any better? What works for other people with diabetes? What do I have to do to get normal blood sugars? Why doesn't the blood test turn out right when I do the right things? *Are* there answers? *How* do I find what will work for me? What are these blood sugars doing to me? What will prevent complications? Is what I'm doing good enough to prevent complications? What *is* "good" control? What will the future be like?

Table 5-1

(Table continues)

Personal Uncertainties,... continued

BASIC ROUTINE	[Many of the uncertainties pertaining to trial and error persist into this phase, particularly those concerns regarding the adequacy of their management. Questions also come up regarding whether or not there is a better way to handle a specific situation] How do others handle (X)? (specific situation) Is what I'm doing good enough to prevent complications? What will the future be like?
BEING REGULATED	[Many of the same uncertainties of basic routine pertain to this phase, and questions about the future persist]

CHAPTER SIX

Discussion

This study began from an interest in uncertainty specifically related to the context of a chronic illness, diabetes mellitus. From available literature on chronic illness, it was anticipated that uncertainty would be a salient part of the illness experience. The findings supported this assumption, and, in addition, disclosed two related aspects of living with a chronic illness, i.e., the trajectory of learning to manage diabetes and the uncertainty associated with each phase of the trajectory. This description supports earlier work of Strauss et al. (1984) regarding the development of a "career" of chronic illness management as a trajectory which unfolds over time and makes a unique impact on the person.

The evidence provided by the subjects in this study indicated that there are uncertainties associated with diabetes management and that these uncertainties change over time with experience. In fact, in the earlier phases of learning to mange diabetes the unknowns are associated with attempting to achieve control <u>over</u>

diabetes, whereas in later learning phases absolute diabetes control is perceived as not possible. This perception takes into consideration the constant flux of blood glucose, the myriad of factors influencing it, and the effort required to attend to all possibilities (even if they could be known) all the time. In fact, some participants expressed relief when they recounted making this discovery about diabetes control. Without the pressure of looking for that absolute "right" way of managing for control, more attention could be directed towards actual experiences and adjustment of management to "fit" preferred life styles, strategies and body responses at any given moment.

The issue of control may have relevance in relation to the management trajectory from two perspectives, that of self-efficacy and skill acquisition. Bandura presents self-efficacy as an expectation that an individual can successfully execute the behavior required to produce an expected outcome (Bandura, 1977). He further states that efficacy expectations are based on four major sources of information: performance accomplishments, vicarious experience, verbal persuasion, and emotional arousal. Certainly, evolution of the management trajectory involves all of these areas, plus the additional information source of "body listening", and it is likely that as the person experiences more of the monitoring and management activities and moves through the stages, self-efficacy will change as well. Benner (1984) and Dreyfus (1980) suggest a different perspective for skill acquisition, and Dreyfus' Skill Acquisition Model is discussed later in this section.

Unlike the early researchers of control who equated certainty with the ability to manipulate and predict external stimuli (Averill 1973; Averill et al. 1972, 1977; Ball & Vogler, 1971; Seligman (1968), informants of this study reported the importance of internal responses or "listening" to body sounds. Although Church's Internality Hypothesis acknowledges that individuals perceive stimuli differently, and Miller's Minimax Hypothesis posits that an individual will try to control the degree of and duration of aversive stimuli, the emphasis is on control of "aversive" stimuli. Individuals did talk about efforts to avoid negative physical outcomes, such as insulin reactions, but these behaviors were person-and situation-dependent and were not consistently predictive across informants. Nor were informant's descriptions of "body listening" limited to aversive stimuli or negative body cues (symptoms). "Body listening" was experienced and described as wholistic, or a general sense of self and health at any given moment.

This grasp of context and meaning was absent in citations on uncertainty as a fixed personality trait of intolerance of ambiguity reviewed in Chapter 2 (Frenkel-Brunswick, 1949; Budner, 1962; Norton, 1975; Zuckerman, 1960). Findings in this study not only related tolerance of ambiguity to personal preferences, but also to the particular learning phase of management. All informants described the need for structure and routine in the beginning, which suggests that disease management in and of itself is ambiguous initially and requires steps to be performed consistently, almost rigidly, in order to create some coherent pattern of management. Informants did not present themselves as "tolerant" or "intolerant" personalities. However, they individually articulated situations and conditions under which they preferred to manage diabetes and those situations in which they perceived themselves to be more at risk. These situations varied according to personal experiences, and did not exist as an "all or none" personality trait, but more as a repertoire of possibilities for that particular individual. In fact, tolerance seemed to be more of an issue associated with continuing or maintaining management strategies over a period of time, since in all phases, informants described ways of "kicking back" or "taking breaks". An interesting question would be whether or not tolerance is a factor for continuing in a particular phase of management.

The significance of recognizing "body listening" as a credible and important monitoring source by people with insulin requiring diabetes is perhaps the most exciting finding. Although "embodied intelligence", as discussed in the

"Theoretical Perspective" of Chapter 2, is considered by some philosophers to be a shared, human capacity, coming to know one's physical self in terms of diabetes is something that must be experienced and learned as it is initially and unknown and novel body experience. That this happens and how it happens has implications for understanding the scope of uncertainty faced by persons with diabetes, and perhaps other chronic illnesses. It also has implications for understanding "compliance" or adherence behaviors associated with complex medical treatment regimens, in that prescribed treatments must fit or be altered to fit both personal preferences <u>and</u> "body sounds". Persons who are quite skilled at diabetes management pay attention to more than symptoms. They come to understand their body response patterns so well that they may sometimes choose negative body responses in order to engage in a desired activity, knowing and attending all the while to the quality of the body response. For example, some informants take "breaks" and allow blood glucose in the low 200's, but are "tuned" into to an overall "sense of" the body at any given moment. Additionally, there is a great deal of effort expended towards learning to "body listen" and interpret patterns. This effort is seldom included in educational and clinical assessments of clients with diabetes.

Recent research in the area of understanding body patterns has approached this arena of body response from the standpoint of recognizing symptoms and taking action. Carter et al. (1983) have attempted to determine how effective people are at subjectively determining their blood glucose status without the aid of a testing device. They found no significant correlation between the ability to associate symptoms with accurate blood glucose measures, but did find consistent intra-subject reliability. In other words, individuals can tell whether they are experiencing high or low blood sugar symptoms most of the time. This is consistent with the descriptions from this study, in that most of the subjects have an understanding of individual body responses for high and low glucose, but they were also quick to point out that these estimations can never be accurate 100% of the time. A similar study by O'Connell (1984) concluded that all 38 Type II diabetic patients studies in her research use symptoms to monitor blood glucose levels and to guide diabetes-related activities.

Merging the concepts of embodied intelligence and experience, Dreyfus (1980) and Benner (1984) offer an alternative basis for development of expertise which appears applicable to findings in this study. The Skill Acquisition Model (Dreyfus, 1980) incorporates not only cognitive skills but also the concept of embodied intelligence and the cultural influence. The model also addresses perception not as identifying properties or components of situations, but wholistically grasped or attended to with the informant identifying the critical or salient elements.

The model has five stages - novice, advanced beginner, competent, proficient and expert. These stages very nearly approximate the trajectory set forth in this study. The novice is described as the beginner with no knowledge or experience, similar to the person with diabetes at the time of diagnosis. As the person "tries out" the prescribed treatment plan, s/he moves into the stage of advanced beginner, someone who now has beginning familiarity with diabetes and its management. Through "figuring it out" and "trial and error", the person may reach a point of competence, still attending to the "rules" of diabetes, but incorporating experiences into the management planning.

With the development of a "usual" routine, the individual can become proficient at managing day-to-day activities while attending less and less to specific step-by-step rules and more and more to the context of diabetes as a whole. In this stage, Benner points out that the person spends less time deciding the right thing to do, rather s/he seems to intuitively attend to the salient issues. The term "intuition" is used in the sense of being based on a great deal of experience and awareness. The final stage of expertise could be likened to that of "being regulated". The initial fear and angst associated with doing all the right things and doing them in just the right order, has given way to "knowing what works" and "keeping tabs". The nature of the effort associated with diabetes changes from "the things I had to do" to "working around it". One person described it as having more options, but still never really knowing the absolutely right thing to do: "the only thing I can really trust at this point is my adaptability...whatever happens I'm going to be able to roll with them. That makes a big difference...I'm able to take it with a little more lightness because it seems like it is going to be ok whatever it is."

Comparing findings of this research to the work of Mishel (1981 - 1984), as discussed in Chapter Two, there is evidence to support that uncertainty, as factored by Mishel (ambiguity, complexity, information deficit, and unpredictability) is prevalent in the diabetes experience. A quantitative measure of uncertainty, however, fails to capture the dynamics of uncertainty as it is experienced. Some unknowns which are initially of great concern (future complications, daily management) continue as unknowns but are altered by experience and context.

Informants also describe the later management phases as having much more complexity and ambiguity, but associated perceived uncertainty has diminished because of experiences of successful management and increased personal confidence. There is also an associated acceptance of the acknowledged unpredictability of diabetes and/or external situations.

Mishel's more recent correlational research (1987) concerning the effect of social support on perceived uncertainty and adjustment in gynecological cancer patients collected data at three time points - diagnosis, during treatment and post treatment. Her findings support findings of this study that perceived uncertainty changes over time.

Ironically, according to the participants, there is a "certainty" that the course of diabetes is uncertain and subject to change with little or no warning, and the only reliability comes form trusting one's self to respond to each situation as well as possible. Reviewing the definition developed for this study, i.e., when not knowing disrupts the meaning or coherency of a personally salient situation, new information could apply to uncertainty in terms of its function and outcome. Participants did describe unknowns as uncertain and threatening when they felt that personally salient situations were disrupted, and that they could be adversely affected by not knowing particular information or knowing exactly what to do. However, they also described the buffering effect of not knowing information which they thought might be upsetting, such as their chances for developing kidney disease, or maybe not wanting to know a blood sugar at a particular moment because they did not want to deal with diabetes right then.

Some participants described uncertainty as "wonderful". This was not the uncertainty of diabetes, but rather the uncertainty of life which carries new opportunities and hope. This uncertainty was discussed as spontaniety, and some participants identified it as a loss of spontaneity incurred because of diabetes. However, informants who had acquired a large repertoire of diabetes skills and expertise of "body listening" noted some return of spontaneity occuring as a result of the relative "certainty" of body response patterns and self-reliance. Together, pattern recognition and self-confidence suggested new opportunities and possibilities for the individual in the face of continuing unknowns about diabetes.

Limitations

The focus of this study was limited to only one chronic illness, diabetes mellitus, therefore, generalizations about the theory can not be made to other chronically ill populations. It is probable that chronic illnesses share some areas of uncertainty in common, but that the specific disease process may carry with it unique uncertainties that may not be identified when the research is limited to one population. Participants in this study were also interviewed at a time when they were not experiencing exacerbations or worsening or their disease condition. None of the participants had experienced complications of diabetes that required ongoing treatment; therefore, the data presented does not explicitly capture the possible areas of uncertainty or unknowns that may be associated with acute illness situations. An additional limitation of the study is that the subjects, with exception of one participant, were all insulin-required diabetes. For this reason, the findings may not be reflective of the experience of monitoring and management associated with Type II or non-insulin requiring diabetics.

The study sample was also limited in that family members or "significant others" were not included in the interview process. The personal accounts given involving situations with family or friends did indicate that family monitoring may be a significant factor in learning and trusting one's own management, and that these people who interact frequently with the diabetic individual have their own monitoring and management skills to learn.

Some of the participants described the mental strategies of diabetes, those of pinpointing, planning and plotting, as "getting on you", meaning that it becomes a cognitive burden. This is the part of diabetes they want to share and can share with others if another is willing to participate with them. These are considerations for future research projects.

Strengths of the Study

The sample chosen for the study was taken from a population experiencing a chronic illness that is time-consuming in its daily management and carries with it the potential for life-threatening, socially isolating and costly complications. Diabetes is representative of a chronic disease that brings with it many unknowns. Therefore, results of this study have the potential for application to other chronic illnesses.

The participants of this study varied in their experience and expertise of diabetes management, yet all participants confirmed the characteristics of the management style of "trying it out", while those who had experienced the processes of "getting regulated" actually described experiences similar to those who were in these processes at the time of the interviews. In this way, there was validation of the management trajectory even though not all participants had experienced "being regulated".

Additional confirmation came from participants during the second interview when they were asked to expand or develop areas expressed in the first interview. Much of the content in the second interview for each participant was repetitive in story themes and descriptions.

Implications for Nursing Practice

The conclusions of this study suggest that insulin-requiring diabetics go through a process of learning how to manage their diabetes. This has implications for nursing in both patient education and clinical management. Recognizing the existence of a management trajectory which is directed by monitoring activities suggests that direct nursing care/guidance would be particularly important during "trying it out" and "getting regulated". It also means recognizing that nursing care strategies for an individual who is "getting regulated" may need to be particularly intensive in terms of time and focused on assessing the individual's progress with recognizing body responses and body response patterns. Certainly, nursing activities for the person "being regulated" would be expected to be more of a collaborative and consultative nature.

Educational content for diabetes programs may need to be reevaluated to include more practical information and individual variation, but most importantly to include recognition of the use of "body listening" as a valid monitoring technique. Educational content should also include the existence of "machine talk" or the dialogue that goes on between the person and the blood test result, as well as how to move towards the point of making that information more objectively useful and less of a personal judgement.

The findings also reveal a need for the individual to be able to tell of their experience with diabetes, not just to report back medically important information. There is a need for the person to have the unpredictable nature of blood glucose fluctuation confirmed, as well as the frustration that comes of trying very hard to follow a regimen and not having the body "do what it is supposed to!"

The study has implications for the content of nursing assessments administered to clients during clinic or education appointments. In clinic situations, the questions must be broader than those limited to medical concern. A medically focused question might be "how much insulin are you taking and when?" Nursing questions would be reflective of and focused on the person's experience with insulin, for example "what does it feel like when you take insulin?" "how do you know that an insulin reaction is coming on?" "what kind of reactions do you think are scary or hard to deal with?" These questions indicate nursing's concern for "care" issues, both nursing care interventions, i.e. professional suggestions for management, and self-care strategies.

The study further suggests that people "take breaks" from diabetes. They do this in a variety of ways, but everyone does it. "Taking a break" sounds markedly different from "cheating" or "non-compliance" or "non-adherence". "Taking a break" patterns could be easily assessed during nurse and patient interactions and this information used to plan nursing interventions.

On a broader level, the study has implications for nursing in general. It provides us with a picture of illness experience that is not routinely solicited in medical settings and, therefore, is seldom acknowledged or used in any systematic way. The Social

Policy Statement of the American Nurses' Association states that nursing is concerned with ..."responses to illness" (American Nurses' Association, 1980). Individuals' experiences are their responses, and nursing must pursue in practice and in research those questions which pertain to experience and process.

Implications for Future Research

This study suggests that insulin-dependent diabetics can learn to understand body response patterns in conjunction with particular management strategies. Questions remain regarding whether persons with diabetes who do not require insulin or persons with other chronic illnesses experience such patterns and stages of management.

The study also raises questions about the kinds of uncertainty or unknowns are experienced by family members or close friends of persons with diabetes, and in what ways they then respond to the chronically ill individual. Research activities similar to the one reported here could shed light on that experience and perhaps further inform this study's findings.

The study also has implications for research in diabetes education to evaluate content and outcomes of specific types of programs and content of programs. A comparison of self-care management outcomes between persons who have participated in a didactic educational program and those participating in a program of both didactic and practical information with client follow-up could yield useful information. Additionally, educational programs planned according to the management trajectory could be implemented and evaluated.

The concept of a specific management trajectory based on specific monitoring skills could be useful as a clinical concept to assess where patients are in the management trajectory in order for appropriate nursing guidance and education to be prescribed. The tool would necessarily require a qualitative measure of verbal descriptions of management experiences which would reflect both the understanding of management complexity and recognition of personal body response patterns as well as emotional reactions/responses to diabetes situations.

Conclusion

This study began as an exploration of uncertainty, a concept thought to be inherent in chronic illness. What emerged was the centrality of the experience of learning to manage a chronic illness (diabetes mellitus), of which uncertainty was a major part. Participants identified many unknowns in the descriptions of their experiences with diabetes, but these unknowns only took on the personal significance of uncertainty when the process of management or learning to manage was disrupted in some way.

Many of the unknowns described by informants were anticipated before this study began. But the findings revealed an unexpected unknown which seemed central to learning to manage diabetes, and that was that people with diabetes have to recognize and acknowledge body response patterns in order to make any coherent sense out of management activities. This information seems to be common-sense understanding, but it is not reflected in the chronic illness literature except as identifying symptoms of disease. Toombs (1987), in writing about patient - physician differences in communicating and conceptualizing the illness experience, notes that it is often assumed to be simply a matter of a difference in levels of knowledge; however, she suggests, knowing the experience of illness is not about the differences in knowledge, it is about the difference in understanding.

The inductive theory building approach used in this study permitted retention of context, meaning and significance, and uncovered another level of understanding the reality of what it means to live with diabetes....

> "What does uncertainty mean?" echoed S. "It means that something comes up that I don't understand, and it is usually with specific instances. Right now it is fairly rare, but if you had asked me last November [when he enrolled in a diabetes education class after 19 years duration of diabetes] I would have said there is a lot of uncertainty! You see, the key to dealing with uncertainty is to make it not uncertain! (laughed) The key is understanding ...being able to manage everything. Being able to manage blood sugar is the key to that uncertainty for me. And if you can't change it, well then you just have to accept it and take care of the problems as they arise. That is the way you live with it, by being aware and alert so that if the opportunity comes up for doing, you will do it!"

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APPENDICES

APPENDIX A

SAMPLE CHARACTERISTICS

SAMPLE SIZE:
N = 19

GENDER:
FEMALES = 12 *(5 M; 6 NM; 1 D)
MALES = 7 *(3 M; 3 NM; 1 D)

AGE:
RANGE 24 - 53 years
MEAN 36 years
FREQUENCY: 5 IN 20'S
9 IN 30'S
3 IN 40'S
2 IN 50°S

SOCIO-ECONOMIC
UPPER INCOME LEVEL = 4
MIDDLE INCOME LEVEL = 11
LOWER INCOME LEVEL = 4

EDUCATION
HIGH SCHOOL EDUCATION = ALL
COLLEGE EXPERIENCE or GRADUATE DEGREE = 15

*M = Married
NM = Not Married
D = Divorced

DURATION OF D.M.
RANGE 1 TO 22 YRS
MEAN 7.3 YEARS

# INJECTIONS/DAY
0 = 1/DAY
8 = 2/DAY
11 = 3 OR >/DAY

SMBG = 18

URINE TESTING
NO = 16
OCCASIONAL = 5

DM EDUCATION CLASS
YES = 13
10 = UCSF
3 = KAISER

SUPPORT GROUP
NEVER = 12
YES = 7

APPENDIX B

!!!! VOLUNTEERS NEEDED FOR RESEARCH STUDY !!!!!

AN OPPORTUNITY TO DESCRIBE THE DIABETES EXPERIENCE FROM THE PATIENT'S POINT OF VIEW!! AN R.N. WHO IS WORKING ON HER DOCTORAL DISSERTATION IS VERY MUCH INTERESTED IN INTERVIEWING PEOPLE ABOUT THE "UNCERTAINTY" AND "UNKNOWNS" THEY HAVE EXPERIENCED SINCE BEING DIAGNOSED WITH DIABETES.

IF YOU:

- ARE BETWEEN AGES 25 - 55
- HAVE HAD DIABETES MELLITUS FOR AT LEAST ONE YEAR
- HAVE NO COMPLICATIONS (HIGH BLOOD PRESSURE IS THE EXCEPTION)
- ARE MANAGED ON INSULIN INJECTIONS
- AND WOULD BE WILLING TO PARTICIPATE IN TWO INTERVIEW SESSIONS (ABOUT 1½ HOURS A PIECE. AT YOUR HOME OR ANOTHER CONVENIENT, PRIVATE AREA)

THEN......

PLEASE CONTACT MARTHA AT (415) 333-9950 for additional information or an appointment.

THANK YOU!!!

APPENDIX C

From: , M.D.
Miller Avenue
Mill Valley, California
94132

Dear

I am contacting you on behalf of Martha Price, a registered nurse, who is presently working on her research for her doctoral degree at the University of California, San Francisco. Her research efforts are directed to the study of persons with diabetes mellitus, and are specifically concerned with the many uncertainties and unknowns a chronic illness like diabetes can provoke.

My office is one of several sites Ms. Price has contacted to help her reach people who would be appropriate for her research study. Although I am neither conducting the study nor assuming any responsibility for the study, I have agreed to support Ms. Price's recruitement efforts. Ms. Price informed me that she would very much like to interview adult persons like yourself who have diabetes, in order to understand what kinds of uncertainty you have experienced as a result of having diabetes and what it has been like for you to live with those experiences. This letter is the only time I will be contacting you about the research study.

Ms Price has explained that each person who chooses to participate in the study will be interviewed at two different times at either the person's home or at another location convenient for them. Each interview will last about 1 1/2 to 2 hours. For all information discussed in the interviews, confidentiality will be maintained as far as possible. Persons who do decide to participate will not be known to anyone except Ms. Price. Neither myself nor any of my office staff will know whether or not you decide to participate. This letter from me to you merely informs you that this study is currently going on and that you are in the category of person Ms. Price is seeking to interview. Your continued medical care through me will in no way be altered or changed by whether or not you decide to participate in Ms. Price's research study.

Ms. Price believes that the results of her research could be helpful to physicians and nurses by providing them with a better understanding of their diabetic patients' day to day experiences, and even, perhaps, to find improved ways of assisting persons who must adjust to a chronic and complex disease such as diabetes.

You can let Ms. Price know whether or not you are interested in participating in the research study by filling out the enclosed form and mailing it back to her in the stamped envelope provided. You may also contact Ms. Price by phone at (415) 333-9950.

Thank you for your consideration.

Sincerely,

Dr. ______________

Enc: (2) reply form and
stamped envelope for return

REPLY TO REQUEST FOR PARTICIPATION IN RESEARCH PROJECT

_____Yes, I am interested in participating in this study and would like more information about it. I am listing my name, address and phone number below so that I may be contacted by Ms. Price.*

____No, I am not interested in participating in this research study. I am listing my name below so that I will not be contacted regarding this research again.

NAME: ______________________________

ADDRESS: ____

____

PHONE: Area code:_______ Number: ____________________

*The best time of day to contact me at the above telephone number is ______________________________. If there is an alternate number where you could be contacted, please list it and the times you are available at that number: Area code: __ Phone # __________________, between the hours of ___________.

When you have filled out the form, please place it in the envelope provided and put it in the mail as soon as possible. Thank you.

Additional information about the research study can be obtained from Ms. Price by using either the address on the envelope provided or at phone # (415) 333-9950.

APPENDIX D

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

CONSENT TO BE A RESEARCH SUBJECT

Martha Price, RN, is doing a research study to learn about the personal experience of uncertainty associated with diabetes mellitus. She is interested in knowing how the experience of having diabetes has influenced my feelings of uncertainty and what that means to me.

If I agree to participate in this study, the following will occur: I will be interviewed at two separate times for approximately 1 to 2 hours each time. The interviews will take place in either my home or some other place that is convenient and maintains my privacy and is acceptable to me. The interview questions will consist of questions about my experiences with diabetes in general and about the areas of uncertainty I am currently experiencing and/or can recall from the past. I understand that these interviews will be tape recorded.

Written records and the recorded tapes will be handled as confidentially as possible. Tapes will be coded numerically and not by my name. Interview information will not be made available to any personal physician or clinic personnel, nor will any personal physician or clinic personnel have access to this information. No identities will be used in any reports or publications resulting from this study. The tape recordings will be erased at the end of the study.

There are some possible risks or discomforts from being in this study. Answering some of the questions may make me uncomfortable or upset by bringing into my awareness anxiety-producing issues about the nature of my diabetes and my management of diabetes. I am free to refuse to answer any questions.

There may be no benefit to me from participating in this study. It is hoped that this study will result in improved understanding of how uncertainty influences the lives of persons with a chronic illness such as diabetes. This information will be useful to clinicians in planning programs and treatments for persons with diabetes mellitus.

This information has been explained to me by Martha Price, RN, who has offered to answer any questions I may have. She can be reached at (415) 333-9950 if I have any questions.

In addition, I may contact the Committee on Human Research, which is concerned with protection of volunteers in research projects. I may reach the committee by calling (415) 476-1814 from 8:00 am to 5:00 pm, Monday through Friday, or by writing to the Committee on Human Research, University of California, San Francisco, CA 94143.

I have been given a copy of this form to keep.

Participation in research is voluntary. I have the right to decline to participate or withdraw at any point in this study without jeopardy to my medical care. If I wish to particpate I should sign this form.

Date

Subject's Signature

Investigator's Signature

APPENDIX E

DEMOGRAPHIC INFORMATION

1. Age____________

2. Sex____________

3. Marital status __________________

4. Children (number of children and their ages)
____

5. Occupation ____
____

6. Who do you live with and what are the relationships to you? ________________________________
Are you financially or otherwise responsible for those who live with you?

7. How far have you gone in school? ___________________

8. Do you have health insurance that covers the cost of diabetes supplies, medications, hospitalizations, etc?___________________

9. When was diabetes mellitus diagnosed?_______________

10. Does or has anyone in your family had diabetes? ____
If they are still living, what is the quality of their life at this time? ________________________
Do you have close friends who have diabetes? _______
and what is the quality of their life at this time? ____________________________________

11. Do you take medication for diabetes? What kind and how often? ______________________________________
____

12. If you are taking medication for diabetes, do you ever experience low blood sugars or "reactions"?
_________________. If yes, how often per week? ___

13. Was a diet prescribed for you? __________________

14. Was an exercise program prescribed for you? _______

15. Do you have an exercise routine that you follow?

16. Do you have only one doctor/nurse/other that you see for the diabetes? ____________
Do you see other doctors/nurses/other regularly? ______________________________

17. Have you ever attended an education class on diabetes mellitus?________________If yes, how long ago?

18. Have you ever attended or been part of a diabetes support group? __________________________________

19. Have you ever experienced complications from diabetes?_______ If "yes", what complications are they?

INTERVIEW GUIDE
(First)

To start the interview the investigator will ask the demographic questions of the informant. (See Demographic Information sheet).

Section I

1. Tell me a little bit about yourself. (Prompts can be from the Demographic Sheet. The aim is to be very general to put the subject at ease and to begin the personal profile upon which to frame the remaining interview time.

2. How do you spend your free time? How would you like to spend your free time?

3. Describe this particular time in your life (Prompts: What is going on? Is it stressful now or has it been recently? Are there periods of time in your past that seemed really difficult to dieal with? How do/does those times compare to now?

4. Are there things you would like to be doing with your life that are different than those you are doing now? If so, what keeps you from doing some or all of those things? (can use the words they have given as response).

Section II

Prompt: Now I would like to talk with you specificially about your life with diabetes. There are no right or wrong answers .... I really want <u>your</u> story, not the answers you think a doctor or nurse would want to hear or be interested in. This may seem awkward at first, but I will guide you and I want you to tell me if any question is too hard to answer right now.

1. What do you think precipitated your diabetes?
   What was going on in your life at that time?

2. What did it mean to you when you heard the diagnosis?
   Can you recall the feeling you had at the time of diagnosis and describe it to me?
   How about that period of time soon after the diagnosis, what was that like?

3. How would you say diabetes has affected your life?
   That is how has you life changed? What things in particular changed?

4. What still remains confusing or 'unknown' about living with diabetes? Do you think these things (what subject describes) is pretty common among all diabetics? (If they think their confusions are unique...why do you think your situation might be different?)
   Can you describe how that confused feeling actually feels for you?
   What affects the feeling? (Prompt: When does it get better, go away, come back?)

5. What do you find yourself worrying most about? Do you think this is what most diabetics worry about or do you think your worries might be different...if so, how? (If prompt is needed: "Some people with diabetes have told me that what they worry about most is going unconscious, other have told me that they worry most about getting a complication such as kidney disease; some worry about keeping their jobs")

6. Do you ever experience body sensations that you think are directly related to or caused by the diabetes? What are these and what do they feel like? What do you think about when you experience these sensations? What do you do?

7. You have lived with diabetes now for ____ years.
   What have you come to "trust" or know about your experience with diabetes?
   What don't you trust even at this point?
   How does the trust you have in the diabetes experience thus far differ (or is the same as) the trust you may experience with the medical personnel you come in contact with?
   Do you "trust" your body? (in relation to diabetes)

8. This is a question I'd like you to think about a bit before you answer, and I will come back to it if you prefer. What does the term or statement "diabetes control" mean to you? (Prompt: as compared to what you think your doctor means by it)

9. What kind of things have your done to try to understand diabetes and the management of it?

10. When you imagine your future, what do you see ahead for yourself?
    Is it hard to see ahead? What makes it hard to see the future?

11. Are there still areas related to the diabetes that we haven't talked about that still seem like °pockets' of confusion for you, or puzzlement? Or maybe your have your own word for it, if so tell me about these 'unknowns' that remain.

EXAMPLES OF "UNCERTAINTY LANGUAGE" USED BY THE PARTICIPANTS

These words and phrases were interspersed throughout the informants' responses. At the end of every first interview, the tapes and transcripts were reviewed for these phrases or words and a list was made along with the specific area of context in which they occurred. At the time of the second interview, these bits of the previous interview were then shared with the participant and the particular contexts of uncertainty were discussed further.

"<u>still</u> not controlling it!"

"kinda not sure"

"had to learn"

"even with (x).., it still wasn't working"

"couldn't understand it"

"for no reason at all"

"I can't feel it creeping up"

"I wonder if..."

"just all of a sudden"

"who knows why?"

"don't know and no one can tell me"

"what <u>is</u> it?"

"not in sync"

"losing control"

"wasn't really sure"

"what if I didn't?"

"don't know how others do it"

"didn't know what to ask"

"you don't want to know"

"not aware"

"not quite right"

REVISED INTERVIEW GUIDE

1. What do you think caused the diabetes?
What was going on in your life at the time of diagnosis?

2. What did it mean to you to hear the diagnosis?

3. Did you wonder if you could really manage? What were some of your thoughts at that time?

4. Compared to how you manage now, do you see a difference or experience the management differently from when you were first diagnosed?

5. How much time did it take to get where you are now? Are there times that you feel like you're back at the beginning? What is going on at those times?

6. Did you always know what insulin to give? When did you start to adjust it? Under what conditions do you adjust it yourself?

7. Did you always know what to eat? When did you start to be more flexible in your diet?

8. Did you always know how exercise would affect your diabetes? How did you learn, and what do the conditions have to be for you to exercise? or not exercise? Does it always work for you?

9. How effortful is the management for you now? (Scale of 1 to 10) and how would you have rated it at the beginning?

10. What areas about having a chronic illness like diabetes still remain puzzling or confusing? Are those situations <u>always</u> confusing, or does it fluctuate? What about these situations make them puzzling?

11. Have you compared how you felt or thought about yourself prior to the diagnosis and now...is there a difference or a change?

12. Do you think other diabetics experience these same puzzlements? Do you think that other diabetics experience their diabetes the same way you do... i.e. do you think you experience insulin reactions, or high blood sugars the same? Do you think others have the same vague symptoms that you have or have had? Do you attribute most of your body feelings, sensations, cues to diabetes?

13. How well do you think a person can know their body's response to diabetes? What do you think of when someone says "diabetes control". What does the word control mean to you in general? Personally? Do you think you and your physician are talking about exactly the same thing when either of you use the term "diabetes control"?

14. Do you ever experience confusion about your interaction with your physician/nurse/health care provider? When does that confusion occur? What makes things clearer?

15. Do you find yourself worrying about the diabetes? What worries you the most?

16. What do you see ahead for your future? Are there goals you want to accomplish? Do you think you will be able to? What would stop you?

17. Are there still areas of uncertainty or unknowns that you often have to deal with that we haven't talked about?

18. What were some of your reactions to the interview? Any surpising questions? Areas that we didn't talk about that you wanted to talk about?

APPENDIX F

Standard Medical Management in Diabetes Mellitus

The hallmark sign of diabetes mellitus is an elevated blood glucose. The non-diabetic person has a fluctuation in blood glucose of approximately 70 - 120. This range varies slightly for women, who tend to have a lower range point of approximately 60. The cause of abnormal blood glucose fluctuation due to diabetes mellitus is attributed to either a lack of insulin, a reduction in the amount of insulin produced, or a target cell defect which prevents insulin from being utilized properly. Even in the non-diabetic person, various factors affect blood glucose metabolism - food, amount and consistency of exercise, normal circadian patterns such as cortisol release in the early morning hours, menstrual cycles, and physiological stress responses such as illness and emotional stress. Some factors are more accessible to direct measurement, such as diet, while other factors remain somewhat elusive in their affect on blood glucose, for example, emotional stress. These factors present no problem to blood glucose fluctuation for the non-diabetic. The person with diabetes, however, not only has lost the automatic blood glucose control function but also shares the loss of normal function, to varying degrees, of counterregulatory hormones of glucagon, growth hormone and somatostatin. The complex interaction of the hormones is only beginning to be understood within the scientific community.

Persons with diabetes experience most glucose excursions with accompanying body responses or signals. Headaches, fatigue, mood swings, sweating, trembling, anxiety, confusion, parasthesia of a body part, as well as other individual responses can be associated with blood glucose levels that fluctuate outside a normal range, and the signals vary from being subtle and vague to observable phenomena. These body experiences can also be associated with non-diabetic events, too, but in the case of a chronic disease like diabetes these are largely subjective determinations and distinctions that must be made over time. Too, glucose fluctuations can be promulgated from either the disease itself or from aspects of treatment prescribed to keep blood glucose levels within a certain range. Again, these are distinctions predicated on monitoring body responses and individual interpretations can determine whether or not a treatment strategy is continued, modified or stopped altogether.

Treatment of diabetes mellitus is aimed towards lowering blood glucose and maintaining it within a normal range. The standard treatment includes diet, medication and exercise, and blood or urine self-testing. Treatment must also be coordinated with the cause of the diabetes. If little or no insulin is being produced, then daily insulin replacement is required. If insulin target cells do not respond to insulin, then weight loss is suggested for the obese diabetic and perhaps an oral hypoglycemic agent will be used in conjunction with dietary management. When weight loss is unsuccessful or if insulin production becomes compromised, then daily insulin administration may become necessary. Because an accurate diagnosis beyond the label of diabetes mellitus is difficult, costly and time consuming, persons are initially assigned to the broad categories of Type I (insulin-dependent) or Type II (non-insulin dependent) obese or non-obese. The diagnostic uncertainty persists in a sense throughout the person's lifetime because the pathology itself may change. For example, what began as a insulin-receptor defect on a target cell may later be followed by insulin depletion in the pancreatic beta cell. Even a Type I (insulin-requiring) individual may begin management on low doses of insulin, but as beta cell destruction worsens they may require increasingly higher doses insulin.

For the uninformed person with diabetes, this diagnostic uncertainty may be perceived as verification that their disease is something other than diabetes, perhaps a heretofore undetected or little known disease, but not diabetes. Too, prescribed changes in medication may also be perceived erroneously as a worsening or improvement of the diabetes, when in fact the change is actually a situational adjustment, such as an accomodation to a new exercise routine, travel or an illness. This has implications for whether or not treatment is seen as necessary.

If medications - insulin or oral agents - are used to control the blood glucose level, a side effect may be a lowering of blood glucose below the acceptable range, thus producing associated body symptoms of hypoglycemia. As noted above, not only is blood glucose fluctuation in diabetes mellitus erratic, but also the counterregulatory hormones, such as glucagon and epinephrine, may have an impaired response to counterbalancing hypoglycemic episodes. Symptoms associated with elevated or too low blood glucose are commonly listed in textbooks and educational pamphlets as discrete and specific phenomena, however, actual individual experience with high or low blood glucose levels may vary, and similar symptoms may occur with both high and low glucose. Because health care providers tend to rely on the textbook symptoms, they may make diagnostic determinations solely from that information and try to convince the patient that s/he is misreading body responses.

Patterns of blood glucose fluctuation can become discernible over time, but can never be totally predictable. The fluctuations are considered to be medically important from the standpoint that persistently elevated blood glucose levels are thought to be associated with progressive, degenerative pathology of the eye, kidney, heart, blood vessels, nerves, genito-urinary, joints and skin. Conversely, repeated, markedly low blood glucose values have been associated with varying degrees of loss of mental functioning, injury during loss of consciousness and are, in general, psychologically frightening and socially embarrassing. Blood glucose measurements are, therefore, considered to be the preferred self-testing method for current blood glucose status and as proxy measures of actual disease progression, although data available has not confirmed the probability of this latter relationship.

The first available self-testing method for blood glucose was a test for glycosuria. This test is a semi-quantitative measure and is considered to be an indirect measure of blood glucose at any given point in time because it is reflecting the level of blood glucose as it was at least two hours ago. There is a great deal of variation in test results because of individual renal glucose thresholds, the direct influence of medications on test results and because of the time lag between blood glucose elevation and detection of glucose in the urine. Semi-quantitative in this test means that results show only presence or absence of glucose, not how much or how little. There is no way to determine if a low blood glucose situation is pending if the test result is "negative"; therefore insulin or diet adjustments made from these urine self-testing results are usually gross, not precise changes, and there is less likelihood that urine test results will be coherently linked to strategies. One person described his early diabetes management and urine testing as "I would try to be negative before dinner, and if I was then I assumed everything I was doing was alright". Although inaccurate in providing indication of blood glucose, urine can be tested for presence of ketones and this information can be a valuable adjunct in the presence of high blood glucose values to indicate the severity of abnormal metabolism in situations such as illness, surgery, or insulin depletion.

In 1975, a direct measure of blood glucose using capillary blood was made available here in the United States. In the past 12 years this process has been refined and today gives an accurate measure of the current status of blood glucose (± 10%; and ± 20% at very high - >300 mg/dl - and very low < 70 mg/dl - values). Techniques for this test require that a sufficient drop of blood be obtained by pricking the skin with a needle, usually on a finger pad, and placed on a litmus strip. The drop is left for a prescribed period of time, then blotted and either the strip itself is "read" or is placed in a machine, called a glucometer, to be "read" as a digital number which shows up on the glucometer screen. Both a visual litmus reading or a glucometer reading indicate a blood glucose range, but the direct litmus value requires an additional visual discrimination, a determination in which one may err "in favor of" a more normal value range. (need citation)

Blood glucose measurement is an assessment of a moving target. Blood glucose levels are never stationary, even in the absence of food intake or activity, so the testing captures a reading that will within minutes be a higher or lower number. Frequency and timing of blood testing can be either provider or patient determined, but commences with the prescribed management routine or is prescribed later in the diabetes career. No matter the number of tests prescribed, there are consequences of frequent finger sticks. Frequent testing often results in development of callouses on finger pads, and each test requires a minimum of about five minutes to perform.

Another part of learning how to do self-testing of blood (also called Self-Monitoring of Blood Glucose - SMBG) is learning when to do the test. This schedule varies on several factors. If the physician prescribes or the person desires a firm control of the blood glucose range, then SMBG must be done frequently. Sometimes patients are given algorithms to follow indicating specific insulin dose and timing for certain blood glucose ranges. They may also be algorithms of diet to use, also. However, if the physician determines that control cannot be tight or that people in general do not want to stick their fingers frequently, then the testing schedule may be as few as two or three times a week. Also, if the person does not know what to do with the information, or they feel that they are collecting this information only for the occasional doctor's visit, then there may seem to be no point in doing frequent measurements.

Once the reading is obtained it becomes a piece of information that can be used in a variety of ways - either to change a management strategy (insulin adjustment or diet adjustment) at the moment or to detect trends in blood glucose fluctuations such that more permanent changes are made in the overall management plan. The information can also not be used at all, but perhaps merely recorded and reported to the health care provider at a later time. There is also variation in whether or not the information is recorded at all, with newly diagnosed persons recording faithfully and persons with long duration of diabetes and blood testing perhaps not recording at all but rather "keeping a running trend in my head."

An indicator of blood glucose levels over a period of 6 to 8 weeks is accomplished via a blood test called hemoglobin Alc or hemoglobin Al, in which the glucose "coating" of the hemoglobin molecule on a red blood cell is measured. Persons who do not have diabetes have values within a certain low % range (4 - 7%). Persons with diabetes may also be in this low range, but it is assumed that this is accomplished only with good blood glucose control, i.e. that the patient is doing all the "right" things. However, intervening variables such as anemia, pregnancy, low hematocrits or any red blood cell abnormality will influence the accuracy of this test. Also, if a person with diabetes experiences wide glucose swings - extremes highs and lows - this has an accumulative effect and can result in a high % value. Likewise, if the person has varied his/her diet to include items normally not on the prescribed diet, for example a weekend of holiday eating, the value of the HgbAl may be elevated and give a false impression of dietary non-compliance.

References for this section on diabetes management:

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