Diabetes Self-Management: Patient Cognition and the Development of Expertise

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DIABETES SELF-MANAGEMENT: PATIENT COGNITION AND THE DEVELOPMENT OF EXPERTISE

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science

by

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Abstract


Human Factors researchers have explored decision making and the development of expertise in many complex, professional domains. Non-professionals make many equally complex decisions, yet this area has received much less attention. This study uses the case of type II diabetes to explore how Human Factors can help describe the complex decision making demanded by daily life.

Type II diabetes is a chronic health condition which can lead to disability and death. While self-management directed at maintaining safe blood glucose levels can reduce these risks, most Americans with diabetes show poor adherence. This study examined how people with diabetes understand their illness and how their understanding affects self-management.

Expert-novice differences found in other domains were used to predict the cognitive processes associated with effective self-management. It was hypothesized that participants who showed greater expertise in terms of articulating problem detection strategies, demonstrating functionally structured knowledge, and describing problem solving strategies would have also higher levels of self-management: reporting more self-management activities and lower glucose levels.

Cognitive task analysis interviews were conducted with twenty participants with Type II Diabetes. Participants were asked about their knowledge of and experiences with
diabetes, and critical incidents were elicited. Participants also completed a questionnaire concerning self-management behaviors and glycemic control over the last seven days. Interviews were transcribed and thematically coded. A combination of quantitative and qualitative techniques was used. Non-parametric statistics were used to relate statements indicative of expertise to reports of self-management behavior and glycemic control. Qualitative analyses extracted quotations from the interviews to illustrate how participants understood diabetes, ameliorated glucose imbalances, and constructed mental models of self-management. These analyses provide a detailed picture of patient cognition and illuminate the meaning of the quantitative results.

Participants who displayed expertise in their understanding of diabetes self-management tended to report higher levels of adherence to prescribed treatments and higher glycemic control. However, most participants lacked a functional understanding of the principals of self-management. While participants most identified the factors involved in glucose regulation, fewer understood the functional relationships among factors. Possibly due to this lack of understanding, less than half the participants described actively solving glucose imbalances. Comparisons of declarative knowledge and critical incident reports revealed that participants knew more about diabetes self-management than they actually applied in their daily lives.

This research suggests that proficient self-managers develop many of the same characteristics as experts in other domains. Yet, most participants failed to demonstrate this expertise. Patient education must better help patients develop a functional understanding of diabetes, create effective models for self-management, and control their blood glucose. As Human Factors has helped develop training and decision making
environments for many professional domains, the field has the potential to help patients and other laymen manage complex decision processes in daily life.
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Diabetes is a serious health problem in the United States. Every year, diabetes contributes to hundreds of thousand of deaths and leads to many other complications. Yet, people with diabetes can largely avoid these consequences by engaging in effective self-management practices. One reason that patients fail at self-management may be an inadequate understanding of the dynamics underlying glucose control. Many factors are involved in diabetic self-management and the relationship among these factors changes over time. Because each person’s diabetes functions a little differently, good control requires that the patient understand how diabetes functions in general and the specific responses of his/her own body to glucose imbalances.

Educational courses and literature has failed to help most people with diabetes develop functional models of the disease. Research is lacking that addresses how patients understand diabetes or how their understanding of diabetes changes as they become more expert at self-management. Yet extensive research has been done on expertise development in other domains. In this study, I draw on the findings from expertise research in other fields as a framework for investigating how people with type II diabetes develop self-management skills. I describe the ways in which patients understand diabetes and how understanding relates to self-management.

1.1 Problem Overview

In 2002, diabetes was the sixth leading cause of death, in the United States, contributing to 224,092 deaths (National Diabetes Statistics, 2006). Currently in the
United States, 20.6 million people over the age of 20 (9.6% of this age group) have diabetes. Prevalence is particularly high among Americans over the age of 60 years with 10.3 million people (20.9% of the population) over 60 having diabetes (National Diabetes Statistics, 2006). Worse still, the prevalence of diabetes is increasing dramatically, with approximately 1.3 million new cases per year (Rowley, 1999).

In healthy individuals, the hormone insulin helps convert the glucose consumed in food into usable energy. Diabetes occurs when there is a problem with insulin production or absorption (American Diabetes Association, 2005). Type II diabetes is the most common form of the disease. It occurs when the body continues to produce insulin, but either fails to produce a sufficient quantity or is no longer capable of using insulin effectively. Reduced insulin production and/or absorption prevents the body from processing glucose appropriately. Consequently, sugar builds up in the blood stream making the blood abnormally viscous and cells starve from lack of usable energy. Over time, this may cause complications involving the eyes, kidneys, nerves or heart.

Type II diabetes is a result of both genetic and lifestyle factors. Type II diabetes is typically treated with a combination of diet and exercise. Many people with type II diabetes also take some form of oral medication. These medications increase insulin production and/or decrease the amount of sugar in the blood stream by blocking the body’s natural glucose production and/or by preventing food from being broken down to release glucose (American Diabetes Association, 2005). In addition, some people with diabetes inject insulin to supplement their body’s natural insulin production.

Managing diabetes is extremely complicated. To minimize the risk of complications, people with diabetes need to maintain glycemic control (DCCT, 1993).
Glycemic control is assessed using both serum blood glucose measures, which assess momentary glucose levels, and hemoglobin A1c tests which indicate average glycemic control for the last three months. Serum glucose levels can be assessed using home monitoring devices called glucometers. The healthy range for serum blood glucose is between 80 and 120 mg/dl. A1c levels should remain below 6.5.

Controlling glucoses requires monitoring blood glucose levels and adjusting medication, food and exercise. Stress and illness can have a significant impact on glucose levels, further complicating this task. There is no standard answer to glycemic control, because each individual reacts slightly differently to various foods, types of exercise and stressors. Furthermore, these dynamics change with age and require constant monitoring to maintain awareness of current relationships.

According to the National Diabetes Statistics report (2004), many, perhaps even most, people with diabetes fail to adhere to adequate health regimes. Diet is crucial for treatment, but 35-75%\(^1\) of all patients fail to follow their prescribed meal plan. Similarly, 70-81% of all people with diabetes do not get enough exercise to improve glycemic control. Because glucose levels vary greatly across the day, depending upon factors such as stress, food and exercise, glucose readings should be taken and recorded frequently. This allows the physician to estimate overall glycemic control and allows the patient to see how glucose levels respond to environmental factors. Nevertheless, estimates indicate that 30-70% of patients fail to regularly and accurately monitor and/or record their glucose levels on a regular basis. In addition, medications are often administered inappropriately. Of those who use insulin, 20-80% are believed to use improper methods

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\(^1\) These percentages and those that follow represent the range of adherence found across the research studies that contribute to the National Diabetes Statistics report.
of administration. Depending on the specifics of the study 20-60% of patients fail to adhere to treatment with oral medications (Lerman, 2005).

Non-adherence increases the risk of diabetes related complications. People with diabetes have death rates from heart disease that are two to four times higher than adults without diabetes. People with diabetes are also two to four times more likely to experience strokes (National Diabetes Statistics, 2004). Diabetes is the leading cause of blindness in adults between 20 and 74 years of age, accounting for 12,000-24,000 new cases of blindness each year. In addition, 60-70% of all diabetics experience some form of nerve damage. Ultimately, nerve damage can lead to amputation. Approximately 60% of all non-traumatic amputations are due to diabetes. Uncontrolled diabetes also damages the kidneys. Forty four percent of all cases of end stage renal disease requiring dialysis or kidney transplants are due to diabetes. Taken together these statistics clearly indicate that people with diabetes are failing to adequately manage their disease.

1.2 What is Provided and What is Needed

Diabetes education materials provide a medically accurate overview of the disorder, as well as rules and procedures for glycemic control. While the factors involved in self-management are explained, the materials typically do not provide a functional, dynamic model of the system or describe the relationships among the various factors that influence glycemic control (Klein & Meininger, 2004). If the patient’s body does not respond as described by the rules, the patient has no functional model for decision making. Similarly, if patients deviate from the rules, they have no model to help maintain or regain glycemic control.
So, what does it take for a person with diabetes to successfully manage his/her disease? Klein and Meininger (2004) have suggested that this complex management process places a person with diabetes in a position similar to that of a power plant operator attempting to control plant dynamics. Just as power plant operators must coordinate plant dynamics, people with diabetes must coordinate the interrelated, constantly changing parameters of glucose regulation. Just as the power plant operator must recognize signs of a meltdown and prevent malfunction, patients need to diagnose problems with their glucose (both low and high levels) and formulate plans to correct imbalances. Yet, educational materials do not provide a functional model of glucose regulation to facilitate complex self-management behaviors. If patients are not provided with an adequate model for understanding self-management, how do people with diabetes understand their disease? And are some modes of understanding better than others? This study addressed patients’ understanding of diabetes and the relationship between understanding and self-management to provide a foundation for more effective educational interventions.

1.3 Development of Expertise

There is a strong research tradition addressing questions about the nature and development of expertise. One line of expertise research has analyzed extremely complex skill sets, which are acquired over long periods of time and lead to extraordinary performance. Dreyfus (1972), an early researcher in this area, formulated five stages of skill acquisition: novice, advanced beginner, competent, proficient and expert. As expertise increases, learners become more attuned to relevant contextual factors and more active and involved in the process of understanding the situation. Expertise development
is comes from a combination of personal experience and guidance from senior practitioners (Dreyfus, 1972; Dreyfus & Dreyfus, 1986).

Some aspects of Dreyfus’ model are not relevant to diabetes self-management. Dreyfus describes the development of professional skills, where extensive training is provided and learners receive expert advice and feedback for an extended period. By contrast, people with diabetes are usually given minimal training, are required to manage their disease immediately upon diagnosis, and are only remotely supervised by health care professionals.

However Dreyfus’ suggestion that as learners become more advanced they become more attuned to specific aspects of situations within the domain of expertise. This suggestion may be useful for understanding patient cognition. Contextual awareness is critical for effective control; people with diabetes need to be aware not only of abstract principals concerning how diabetes functions but also of particulars relating to their own body and present circumstances. Specifically, it is crucial that patients be able to detect and diagnose problems with their glucose levels.

Ericsson also worked on long-term development of expertise (Ericsson & Charness, 1994). Ericsson’s work has focused on the importance of time and deliberate practice for expertise development. Ericsson has argued that attaining expertise requires a minimum of ten years of deliberate practice (Ericsson & Charness, 1994). Deliberate practice requires motivation to attend to the task, motivation to improve performance, a task structure that accounts for previous knowledge, immediate feedback, and repeated performance of the same task (Ericsson, Krampe, & Tesch-Romer, 1993). Ericsson’s work has primarily focused on people who were not only experienced professionals, but
who had achieved a world class status (e.g., chess masters, pianists expected to become international soloists, etc.).

Not all of Ericsson’s ideas apply to people with diabetes. A patient does not need to be a world champion self-manager to effectively control his glucose levels. Yet deliberate practice is likely to be critical for developing an effective understanding of diabetes. Patients have to be motivated to control their glucose and monitor their glucose levels often enough to obtain the necessary feedback for their current self-management choices. Further, they need to maintain a commitment to continuing to engage in understanding their own self-management practices across the course of the disease.

Another research tradition is concerned with development of expertise in a much more limited sense. Most psychologists are familiar with the works of Piaget (1926/2001) and Vygotsky (1978; 1986) concerning cognitive development. For both researchers, development consists of a series of successive stages, each of which entails a qualitatively different view of the world resulting from mastering new sets of cognitive skills. Expertise researchers have utilized the work of both Piaget and Vygotsky to understand the development of domain specific skills and cognition (Campbell & Di Bello, 1996; Feldman, 1994; Feldman & Fowler, 1997; Vosniadou & Brewer, 1987). For example, Feldman (1994) focused primarily on changes in development that occur over limited periods (sometimes as little as a few months) in highly specific domains (e.g., map drawing, juggling, etc). He used an analysis of how participants progressed in a domain to postulate qualitatively different levels of task performance, with each level displaying distinct cognitive skills and understanding of domain relevant principals.
Feldman’s framework is not limited to understanding exceptional levels of performance and so provides a model for analyzing the lower levels understanding appropriate to an assessment of self-management. Since his work has focused on both amateurs and professionals, it does not assume an extensive period of training. Finally, Feldman has worked with a limited time course that may be more suited to an area like self-management that requires near immediate competence.

1.4 Expert-Novice Differences

Research on expert-novice differences examines cognition at different levels of performance. Chi, Glaser and Farr’s (1988) book, The Nature of Expertise, describes expert-novice differences. Several of these distinctions are likely to be significant for diabetes self-management. Experts have a large quantity of knowledge relevant to their domain of expertise. In the case of diabetes, this knowledge is likely to consist of an understanding of the effects of a wide variety of different foods on glucose levels, what different symptoms mean, and how various activities effect blood glucose.

An expert’s domain knowledge is structured differently from a novice’s (Chi, Feltovich & Glaser, 1981). Whereas novices tend to structure information in terms of superficial or marginally important characteristics, experts organize their knowledge around functional principals. This distinction has been called structure-behavior-function analysis or the form-function distinction (Collins & Ferguson, 1993; Hmelo-Silver & Pfeffer, 2004). Differentiation between superficial and functional knowledge structures is likely to be crucial for self-management. For example, a patient who has a superficial knowledge structure might be tempted to classify white bread and wheat bread as equivalent since they are both bread. By contrast, a patient with more functionally
structured knowledge would classify these foods as separate because the different fiber content of white versus wheat flour mean that these two foods affect glucose differently.

Experts have many, readily-accessible domain-specific problem solving strategies (Klein, 1999). These strategies allow the expert to act quickly and accurately in critical situations with minimal cognitive effort. Expert patients are likely to have management strategies that they have found to be effective and that can be tailored to different critical situations.

Experts often have difficulty articulating their knowledge and explaining their performance in critical situations. This is partially because experts perceive meaningful patterns rather than individual stimuli. Novices, on the other hand, focus on particular cues rather than the relationships among factors (Klein, 1999; Zambok & Klein, 1997). People with diabetes who are better self-managers may be more attuned to patterns of related stimuli, whereas less competent self-managers may focus on one or two cues.

Overall, the cognitive differences characterized by the expertise literature are likely to impact self-management. Patients who are more expert are likely to be more aware of situational factors (Dreyfus, 1976) and more attune to the system of diabetes self management as a whole (Klein, 1999) allowing for better detection of glucose imbalances. In addition, expert self-managers are likely to have more knowledge (Chi, Glaser, & Farr, 1988) and their knowledge will be more functionally structured (Chi, Feltovich & Glaser, 1981; Collins & Ferguson, 1993; Hmelo-Silver & Pfeffer, 2004) allowing them to more easily make sense of problems with their glucose. Finally, expert patients are likely to have more domain specific problem solving strategies (Klein, 1999) so they will be more able to respond to glucose imbalances.
1.5 Mental Models

Increasingly scientists have become concerned with the conceptual representations that people hold regarding complex domains. The term ‘mental models’ has been used to refer to these mental representations (Gentner & Stevens, 1983). Questions concerning what constitutes a mental model, how mental models are formed, and the factors that distinguish mental models from other cognitive constructs, such as schemata, have all been debated. While clearly important, the purpose of this work is not to resolve these issues. Instead, the present research examined a few theories of mental models that may be useful for understanding patient cognition.

One approach to mental models suggests that mental models consist of all of the potential relationships and states that an individual conceives of in relation to a particular domain. In this area, diSessa (1983) has considered the evolution of naïve concepts of physics among college students. Others have presented similar work concerning users’ understanding of simple devices (Young, 1983) and the development of graphing skills in young children (diSessa & Sherin, 2000). From this perspective, the entire current research project, which examined patient cognition regarding a particular disease, was devoted to describing the mental models held by people with diabetes.

Another approach suggests that mental models are situation specific. According to this perspective, people possess basic domain specific knowledge that they combine with the particulars of their current situation to create situation specific mental models (Keil, 2003; Patel & Arocha, 1995). The mental representations that matter here are patients’ models of specific incidents of self-management. Since the present research was, in part,
based upon personal narratives and critical incidents described by participants, many of the findings may be described as mental models, according to this theory.

Whereas both of the previous notions of mental models are fairly broad domain representations, a third theory of mental models is much more limited. It suggests that mental models are essentially analogies or metaphors that individuals use to structure knowledge and inferences about an unfamiliar domain, based on similarities to a more familiar domain (Gentner, Holyoak, & Kokinov, 2001). These inter-domain inferences can be direct (Forbus, 2001), or they may involve the blending of concepts from two different domains to create a unique semantic space (Fauconnier, 2001). The implication for diabetes is that patients may use their understanding of the functional dynamics of other areas of health care or system control to understand diabetes self-management. Because this third approach is more limited, for the purposes of the current study, ‘mental models’ refers to the analogical use of images, metaphors or knowledge from other domains to understand diabetes.

1.6 Diabetes Self-Management as a Dynamic System

Managing diabetes poses some of the same challenges that are faced by professionals in other domains. Blood glucose regulation requires maintaining control of a complex and dynamic system (Klein & Lippa, 2006). Diabetics have to be aware of situational dynamics, determine when a problem occurs, make sense of problems and develop strategies to regain control. Similar macrocognitive processes are required for other domains that human factors psychologists study (i.e. aviation, command and control, power plant operation, medicine) (Elstein, 2001; Lipshitz, 1993).
However, diabetes self-management poses certain difficulties not encountered in other domains (Klein & Lippa, 2006). In most complex domains, professionals are carefully selected for induction into the domain. Physicians have to undergo rigorous academic examinations and pilots must meet exacting physical standards. In almost every occupation, individuals choose to engage in activities within the domain and have some interest in the area and motivation to succeed. Diabetes, by comparison, is an equal opportunity event. Becoming diabetic does not guarantee that the patient has exceptional physical or cognitive capabilities, is interested in self-management or is motivated to engage in diet or exercise.

After being selected, novitiates in most domains undergo extensive training to insure that they acquire domain-relevant skills. Medical students and pilots undergo extensive training courses and are given opportunities to practice newly acquired skills in supervised settings. By contrast, people with diabetes do not have the luxury of an extensive training period. They are given brief instructions from a physician or nurse and may be provided with additional materials to read. Lucky patients may have the opportunity to attend a one-time training course that lasts a few weeks. People with diabetes rarely have the chance to practice self-management skills under supervision. Yet their lives depend on how well they master these skills.

Finally, even after they have finished training, most professionals belong to a community of practice (Wenger, 1998). Professional communities provide members with a forum for discussing difficulties, receiving performance feedback and hearing about new innovations. Diabetes self-management, on the other hand, is practiced privately.
People with diabetes may never have an opportunity to engage in conversation about their self-management or gain perspective on current problems.

1.7 Research Questions and Hypotheses

Little is known about how people with diabetes understand their disease. This makes it difficult for diabetes educators and physicians to help people with diabetes manage their disease. Therefore, one aim of this study was to describe how diabetics understand diabetes.

Research Question 1: How do people with diabetes understand their disease?

Given that diabetes self-management requires skill in both comprehending and manipulating multiple variables in a complex, dynamic system, I expect participants’ levels of self-management to be related to the degree of expertise that they demonstrated in their understanding of their disease. In this context, level of expertise was defined by the degree to which participants displayed the cognitive characteristics that have been found to distinguish experts in other domains (i.e. contextual awareness, functionally structured knowledge, and problem solving strategies).

H1: Greater expertise in understanding was expected to be associated with higher levels of self-management behavior.

Because glucose control depends on many factors, some of which are beyond the patient’s control, it is important that patients be able to detect glucose imbalances.

RQ 1A: What strategies and cues do people with diabetes use to detect and diagnose problems with their glucose?

Experts have more domain specific strategies for problem detection and are more attune to situational cues than are novices. Both of these differences suggest that
participants who are more expert at self-management will draw on more strategies and
cues to detect and diagnose blood glucose imbalances.

H1A: Participants who articulated more problem detection strategies and cues
were expected to have higher levels of self-management.

In order to practice effective self-management it is important that patients
understand the relationships that underlie glycemic control. Therefore, this research
pursued the question:

RQ 1B: What relationships do patients perceive among the factors affecting
glucose levels?

Compared to novices, experts have a greater level of domain relevant knowledge
and their knowledge of the domain is more functionally structured. Therefore, individuals
who are more expert at diabetes self-management will be likely to articulate more
functional relationships among the factors involved in blood glucose control.

H1B: Participants who express more functional relationships were expected to
have higher levels of self-management.

When a patient detects a blood glucose irregularity they need to restore glucose
control. Therefore it is important to know how patients cope with glucose imbalances.

RQ 1C: What strategies do people with diabetes have for correcting imbalances
in their glucose levels?

Experts are more adept than novices at solving problems within their area of
expertise. I hypothesized that this distinction will hold true in the case of diabetes self-
management.
H1C: Patients who describe more strategies for ameliorating blood glucose imbalances are expected to have higher levels of self-management.

Glucose self-regulation, like many complex domains, involves many interacting factors. Managing these factors may be difficult and cognitively demanding. Human factors research in other complex domains has suggested that expert practitioners have mental models that allow them to predict and understand events within the domain (McDougall, Curry, & de Bruijn, 2001; Langan-Fox, Anglim, & Wilson, 2004). If patients have mental models of diabetes self-management, these models may help health care professionals understand patient cognition and improve self-management.

RQ 1D: Do people with diabetes have mental models of their disease and if so what models do they use?
2. Method

2.1 Participants

A convenience sample of 20 participants was drawn from two sources. Most participants were brought in by friends and relatives, who were enrolled in introductory psychology courses. In these cases, participants’ friends/relatives received course credit. Three participants volunteered for the study after seeing a flyer posted in a local grocery store/pharmacy and received no compensation for participating. All participants were selected based on a prior diagnosis of type II diabetes mellitus.

2.2 Materials and Procedure

Participants were run in individual sessions that lasted one to one and one half hours. Eighteen sessions were conducted in the applied psychology laboratory at a Midwestern university. Two sessions were conducted in the participant’s home or office. With the participants’ consent, all sessions were audio taped. Sessions were conducted with one or two researchers present. Sessions included four components: informed consent procedures, interviews, pilot measures, and a self-report measure.

2.2.1 Informed Consent.

The participant was greeted and provided an explanation of the research and its purpose. The participant was given the opportunity to ask questions about the research and was asked to sign a consent form (Appendix A).
2.2.2 Interviews.

Semi-structured interviews were conducted in a relaxed atmosphere, at a pace that was comfortable for the participant. The interviews used an adapted method of cognitive task analysis (Gordon & Richard, 1997); see interview guide in Appendix B. While the interviews were based on a set of open-ended, guiding questions, the specific wording and order of the questions was flexible. Depending on conversational flow, the interviewer asked questions in different orders and urged participants to elaborate on points of particular interest. However, all participants were given the opportunity to address all of the areas covered by the interview guide, including the three areas of expert cognition: problem detection strategies, knowledge of functional relationships, and strategies for achieving control of glucose levels.

Interviewers began by eliciting the participant’s history with diabetes and family history of the disorder, and then addressed daily management practices and recurrent problems. Next, critical incidents were sought and explored using the critical decision method (Crandall & Getchell-Reiter, 1993; Klein, 1999). Participants were probed regarding the time course of the incident, the cues they used in making decisions, the immediate actions they chose to take, and any long-term changes made as a result of the episode. For example, “Could you describe the most recent time you had high blood sugar?” and “Why do you think it was high?” The descriptions of critical incidents provided insight into how participants applied their knowledge of self-management in daily life.

After that, participants were asked direct questions about their knowledge of diabetes self-management. For example “What things make blood sugar go up?” Direct
questions allowed participants to demonstrate declarative knowledge they possessed, but
which they could not apply to their daily lives due to a lack of opportunity or
understanding. Participants were also asked to talk about elements of their own
experience that they believed differed from the experiences of other patients or the
descriptions found in medical and self-help literature.

2.2.3 Pilot Measures.

After the interview, participants were asked to participate in three pilot tasks. The
first task involved reading scenarios about individuals experiencing high and low glucose
level and answering questions. In the second task participants were asked to sort cards
into categories according how they related to self-management. The third task involved
making concept maps of their understanding of diabetes. These measures were included
for exploratory purposes and are not analyzed here.

2.2.4 Self-Report Measure.

Participants were asked to complete the six-item, self-report Summary of Self-
Management Activities (Appendix D), which was closely derived from the Summary of
Self-Care Activities used by Glasgow and colleagues (Glasgow, McCaul and Schafer,
1987; Hampson, Glasgow & Toobert, 1990). This scale includes items regarding self-
management activities over the last week and took less than five minutes to complete.
The first three items were taken directly from Glasgow, et al.’s measure. These items
asked how often the participant took his/her medication, monitored his/her glucose and
followed his/her diet using a five point graphic rating scale. For example, participants
were asked how many of their injections or pills they took when they were supposed to:
all of them, most of them, about half of them, some of them or none of them. Item four,
taken directly from Glasgow et al.’s measure, asked the participant to write in how many
days during the last week he exercised for at least 30 continuous minutes. The last two
items were created by the researcher and asked the participant to write in their highest
and lowest glucose reading in the last week. For the items used in this study, Glasgow
and colleagues have reported validity correlations between .40 and .87 and alpha
reliability measures between .86 and .97. These correlations suggest that the Summary of
Self Care is a valid and reliable measure of self-management behavior.

2.3 Data Analysis

2.3.1 Preparation

Transcription. The taped interviews were transcribed using a literary transcription
approach designed to capture the meaningful content of the interviews (Kowal &
O’Connell, 2004). All the words spoken by the participant were transcribed using his or
her original phrasing, but no provision was made for including non-vocal features of the
conversation or utterances without semantic content.

Coding. Using Atlas.ti, a computerized qualitative analysis program, transcripts
were then divided into semantic units each encompassing a single complete idea (Chi,
1997; Kelle, 2004). Units varied in length from a few words to multiple paragraphs,
depending upon participants’ conversational styles and the complexity of the ideas being
expressed. In some cases, two or more units overlapped when a larger idea encompassed
smaller subunits. For example, in the sample passage (Figure 1) the entire passage is
considered a unit because it describes a single episode, but the passage also contains
smaller units linked to specific portions of the episode such as symptoms and presumed
causes.
Initially, transcripts for six pilot interviews were coded using the open, emergent coding principals of grounded theory (Bohm, 2004; Pidgeon & Henwood, 1997). With input from expert researchers, this code list was iteratively refined to produce a set of non-redundant codes that could capture maximal content (Flick, 1998; Mayring, 2000; Miles & Huberman, 1994). A total of 78 codes were generated and operationally defined. Operational definitions were composed of key words and concepts relevant for identifying which units to label with each code. Codes were divided into a number of categories and subcategories. Some of these categories were based on previous research in expertise (Chi, Feltovich & Glaser, 1981; Chi, Glaser, & Farr, 1988; Collins & Ferguson, 1993; Dreyfus, 1976; Hmelo-Silver & Pfeffer, 2004; Klein, 1999). For example, a functional organization of knowledge is linked to expertise (Chi, Feltovich & Glaser, 1981; Collins & Ferguson, 1993; Hmelo-Silver & Pfeffer, 2004). The ‘causes’ code, in the passage above, was one of the codes used to identify statements about the functional relationships participants’ identified. The operational definition of the ‘causes’ code was as follows: “This code is applied whenever a participant mentions the cause of
some phenomenon they are experiencing. It is expected to occur primarily in relationship
to things that raise and low blood sugar.” In this case the participant links eating to high
glucose levels. Other categories were concerned with diabetes specific content such as
symptoms that might occur during descriptions of critical incidents. A code list is
available in Appendix C.

To check for coding reliability, a subset of transcripts was coded on two separate
occasions, three months apart. No reference was made to the original coding during the
second coding. Substantial agreement was found between codings ($kappa = .78$)
indicating coding reliability. Coding was expedited by the use of the Atlas.ti software
package (Kelle, 2004).

2.3.2 Analysis

Due to the exploratory nature of the research and the range of self-management
experience among participants, quantitative data was not sufficient to address the
research question. Hence, data analysis was divided into a quantitative component
designed to address the research hypothesis and a qualitative, exploratory component.

Quantitative Data. Three kinds of coded statements were used to assess different
aspects of expertise: descriptions of functional relationships involved in managing
diabetes (e.g. statements about carbohydrates elevating glucose levels), strategies for
maintaining awareness of glucose levels (e.g. attention to symptoms), and problem
solving strategies (e.g. exercising to reduce glucose levels). The number of statements
each participant made in each category was tallied. In each category, statements related to
high glucose and low glucose were separated. Statements about problem detection and
functional relationships were also separated into responses to direct questions and statements that were part of critical incidents.

For each aspect of expertise, participants were divided into three categories according to how many statements indicative of expertise they made. In order to avoid bias in the groupings divisions were created wherever a natural break occurred in the data. Kruskal – Wallis non-parametric ANOVAs were used to compare groups with respect to self-reports of self-management behaviors and degree of glycemic control (as defined by highest reported glucose level in the last week). In addition, non-parametric, bivariate correlations were used to assess relationships between specific aspects of expertise (i.e. problem detection, functional relationships, & problem solving) and specific areas of self-management measured by the summary of self-management activities (e.g. diet, monitoring, use of medication, & exercise).

**Qualitative Data.** The qualitative analysis describes in greater detail how people with diabetes understand their disease. These descriptions are designed to complement the quantitative analysis using illustrative quotations to show how differences detected using quantitative techniques are manifested in participants’ understanding.

One of the strengths of qualitative analysis is its ability to identify emerging themes and patterns. An effort was made to note any patterns that arose in multiple interviews but that were not directly pertinent to the stated research questions. In particular, differences in locus of control and in how participants who worked in the health care field were noted. These areas are discussed in the Additional Findings section of the results.
3. Results

3.1 Who Participated in the Study?

Participants varied in their time since diagnosis (range = .66 to 35 years, mean = 10.8 years, SD = 10.0). Some participants controlled their diabetes using only diet and exercise; others required oral medications and/or insulin treatments. Participants varied in age (range = 19-76 years, mean = 53.9 years, SD = 17.3), education, and occupation. Eight participants had a high school education or less, eight had some college education and two held post graduate degrees. Four participants had worked in health care related fields. Table 1 provides a summary of participant demographics.

Table 1. Participant Demographics

<table>
<thead>
<tr>
<th>Participant #</th>
<th>Age</th>
<th>Education</th>
<th>Occupation</th>
<th>Gender</th>
<th>Years Since Diagnosis</th>
<th>Glucose High</th>
<th>A1C</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>72</td>
<td>High School</td>
<td>Plumber</td>
<td>Male</td>
<td>35</td>
<td>200</td>
<td>?</td>
</tr>
<tr>
<td>2</td>
<td>76</td>
<td>High School</td>
<td>Mechanic</td>
<td>Male</td>
<td>3</td>
<td>160</td>
<td>&lt;6.5</td>
</tr>
<tr>
<td>3</td>
<td>67</td>
<td>Grad School</td>
<td>Professor</td>
<td>Male</td>
<td>7</td>
<td>?</td>
<td>7.6</td>
</tr>
<tr>
<td>4</td>
<td>36</td>
<td>College</td>
<td>Physicist</td>
<td>Male</td>
<td>3</td>
<td>145</td>
<td>5.9</td>
</tr>
<tr>
<td>5</td>
<td>50</td>
<td>High School</td>
<td>Cook</td>
<td>Female</td>
<td>7</td>
<td>101</td>
<td>3</td>
</tr>
<tr>
<td>6</td>
<td>19</td>
<td>College</td>
<td>Student</td>
<td>Male</td>
<td>0.66</td>
<td>118</td>
<td>?</td>
</tr>
<tr>
<td>7</td>
<td>53</td>
<td>High School</td>
<td>Security Guard</td>
<td>Male</td>
<td>2</td>
<td>?</td>
<td>9</td>
</tr>
<tr>
<td>8</td>
<td>47</td>
<td>College</td>
<td>Cleric</td>
<td>Female</td>
<td>4</td>
<td>140</td>
<td>6.9</td>
</tr>
<tr>
<td>9</td>
<td>38</td>
<td>High School</td>
<td>House Wife</td>
<td>Female</td>
<td>14</td>
<td>450</td>
<td>18</td>
</tr>
<tr>
<td>10</td>
<td>62</td>
<td>High School</td>
<td>Med Tech</td>
<td>Female</td>
<td>30</td>
<td>140</td>
<td>?</td>
</tr>
<tr>
<td>11</td>
<td>19</td>
<td>College</td>
<td>Student</td>
<td>Male</td>
<td>9.5</td>
<td>137</td>
<td>?</td>
</tr>
<tr>
<td>12</td>
<td>66</td>
<td>College</td>
<td>Pilot</td>
<td>Male</td>
<td>15</td>
<td>187</td>
<td>?</td>
</tr>
<tr>
<td>13</td>
<td>50</td>
<td>College</td>
<td>Nurse</td>
<td>Female</td>
<td>4</td>
<td>141</td>
<td>6.8</td>
</tr>
<tr>
<td>14</td>
<td>59</td>
<td>High School</td>
<td>Clerical</td>
<td>Female</td>
<td>3</td>
<td>441</td>
<td>?</td>
</tr>
<tr>
<td>15</td>
<td>51</td>
<td>College</td>
<td>Pharmacist</td>
<td>Male</td>
<td>18</td>
<td>215</td>
<td>8.2</td>
</tr>
<tr>
<td>16</td>
<td>67</td>
<td>College</td>
<td>Nurse</td>
<td>Female</td>
<td>18.5</td>
<td>104</td>
<td>6.3</td>
</tr>
<tr>
<td>17</td>
<td>76</td>
<td>Grad School</td>
<td>Pilot / Teacher</td>
<td>Male</td>
<td>18</td>
<td>118</td>
<td>6.7</td>
</tr>
<tr>
<td>18</td>
<td>63</td>
<td>High School</td>
<td>Truck Driver</td>
<td>Male</td>
<td>3</td>
<td>86</td>
<td>5</td>
</tr>
</tbody>
</table>
Twelve participants were able to report their most recent A1c test result. A1c results ranged between 3 and 18, with 58% of the results falling over the recommended guideline of 6.5. Participants reported highest blood glucose readings for the last week between 86 and 450 mg/dl (mean = 180.2 mg/dl, SD = 109.4). Reported lowest blood glucose readings ranged from 65 to 130 mg/dl (mean = 90 mg/dl, SD = 23.1).

The participants’ adherence to treatment varied. Seventeen of the eighteen participants took some form of medication. Of these, 12 reported always taking their medication as prescribed and five said they usually took their medicine as directed. Adherence to recommended diets was less stringent. Only three participants said that they followed their diet all of the time, nine reported that they ‘usually’ followed their diet, four said that they did so ‘about half the time,’ and one said that he rarely followed a diet. One participant reported that she had no specific diet. All but one participant possessed a glucometer. Six participants said that they always monitored as recommended, eight that they usually did so, one that he did so half the time, three that they rarely did so and one that she never monitored. Participants reported exercising between zero and seven days a week (mean = 2.9 days, SD = 2.2).

Age, education level, and disease length were not significantly correlated with any of the measures of expertise in understanding diabetes (i.e. articulation of problem detection strategies, functional relationships, & problem solving strategies), self-management behavior, or glycemic control.

3.2 How do patients learn about their disease?

Standard care practices include educating patients about their disease upon diagnosis (ADA, 2006). Participants in this study all reported receiving education from at
least two sources and some reported up to four different educational experiences. All but two participants received at least some of their education from health professionals.

Table 2. Educational Richness Coding.

<table>
<thead>
<tr>
<th>Source of Information</th>
<th>Points Assigned</th>
<th>Participants Using</th>
</tr>
</thead>
<tbody>
<tr>
<td>Word of Mouth (Advice from Non-Professionals)</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Physicians Instructions</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Consultation with Nutritionist</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Sessions with Diabetes Educator</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>One Time Independent Research</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Ongoing Independent Research</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Short Class (1 week or less)</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Long Class (more than 1 week)</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Discussion Groups</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Written Materials from Physician</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

Since no direct measure is available to compare the quality of diabetes education, exploratory coding system was devised to assess educational richness. Transcripts were scored by assigning points for each source of information that participants mentioned utilizing. More points were assigned to information that came from a health professional and to sources providing larger quantities of information; see Table 2 for details. A subset of interviews were coded by two independent coders to check for reliability; agreement was substantial (\( \kappa = 0.79 \)).

Non-parametric correlations were computed relating educational richness scores to measures of expertise (i.e. number of functional relationships articulated, number of problem detection strategies mentioned, & number of decision making strategies mentioned), locus of control (see section on additional findings), adherence and blood glucose levels. No significant relationships were found among diabetes education and either adherence or glycemic control. However, those with more diabetes education
tended to have a more internal locus of control \((\rho = .41, p<.05)\), and to display a more expert understanding of the disease in terms of problem detection strategies \((\rho = .67, p<.05)\) and decision making/planning strategies \((\rho = .54, p<.05)\); see Table 3.

**Table 3. One-Tailed, Non-Parametric Correlations with Educational Richness \((n=18)\)**

<table>
<thead>
<tr>
<th></th>
<th>Functional Relationships</th>
<th>Problem Detection</th>
<th>Decision Making/Planning Strategies</th>
<th>Internal Locus of Control</th>
<th>Educational Richness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional Relationships</td>
<td>_</td>
<td>.368</td>
<td>.315</td>
<td>.548**</td>
<td>.302</td>
</tr>
<tr>
<td>Problem Detection</td>
<td>_</td>
<td>_</td>
<td>.648**</td>
<td>.193</td>
<td>.673**</td>
</tr>
<tr>
<td>Decision Making/Planning Strategies</td>
<td>_</td>
<td>_</td>
<td>.023</td>
<td>.541*</td>
<td></td>
</tr>
<tr>
<td>Internal Locus of Control</td>
<td>_</td>
<td>_</td>
<td></td>
<td>.412*</td>
<td></td>
</tr>
<tr>
<td>Educational Richness</td>
<td>_</td>
<td>_</td>
<td></td>
<td>_</td>
<td></td>
</tr>
</tbody>
</table>

** correlation is significant at the .01 level  
* correlation is significant at the .05 level

The reasons for these correlations are uncertain. While educational experiences were related to expertise in diabetes self-management, they were not related to self-management behaviors or glycemic control. This suggests that any relationships found between expertise and self-management and glycemic control cannot simply be attributed to education.

**3.3 How Do Patients Understand Daily Self-management Practices?**

**3.3.1 Overview**

At the beginning of the interview, participants were asked how they care for their diabetes. The elements described as part of self-management indicate those factors that participants saw as related to glycemic control. A detailed list of all the factors identified is provided in Table 4.
Table 4. Factors Identified as Affecting Glycemic Control.

<table>
<thead>
<tr>
<th>Factor</th>
<th>Specific</th>
<th>Number of Mentions</th>
<th>Number of Participants Mentioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet</td>
<td>Non-specific</td>
<td>19</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Portion Control</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>High Sugar</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Carbohydrates</td>
<td>18</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Fat</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Protein</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Fiber</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>71</td>
<td>18</td>
</tr>
<tr>
<td>Exercise</td>
<td>Non-specific</td>
<td>24</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Walking</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Daily Activity</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Exer. Equipment</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>42</td>
<td>14</td>
</tr>
<tr>
<td>Medicine</td>
<td>General</td>
<td>12</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Oral</td>
<td>28</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Insulin</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>51</td>
<td>17</td>
</tr>
<tr>
<td>BG Monitoring</td>
<td>Non-specific</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Scheduled</td>
<td>23</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Sporadic</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Exploratory</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Response to symptoms</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>41</td>
<td>18</td>
</tr>
<tr>
<td>Weight</td>
<td></td>
<td>10</td>
<td>6</td>
</tr>
<tr>
<td>Stress</td>
<td></td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>Other Med. Cond.</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Alcohol</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Vitamins</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

As can be seen, participants identified a wide range of factors involved in glucose control. All participants identified at least two distinct factors. In total, participants made four to fourteen statements describing factors relating to self-management (median = 8.94).

Participants noted the six major factors that most diabetes education materials describe as influencing glycemic control: diet, exercise, medication, home glucose monitoring, weight, and stress (Becker, 2001; NDIC, 2006). Of these six factors,
descriptions of diet were by far the most complex. All participants noted that diet affected glucose levels and seventeen were able to articulate at least one specific element of their diet that might impact glucose levels. People with diabetes often are advised to control the amount of food they eat from different nutritional groups; five participants mentioned portion control (NDIC, 2006). Carbohydrates break down directly into glucose and, as such, can quickly elevate glucose levels; eleven participants mentioned controlling carbohydrate intake. Many participants (11) identified consumption of high sugar foods, those containing large numbers of simple carbohydrates, as impacting blood glucose. Proteins break down slowly and therefore have relatively little impact on glucose levels, only six participants understood this relationship. It is recommended that diabetics avoid high fat foods that can lead to obesity and poorer glycemic control; four participants mentioned controlling fats. Fiber can aid glycemic regulation by delaying glucose absorption and facilitating weight loss; three participants understood the benefits of fiber.

Fourteen participants mentioned exercise as a component of their self-management. Of these, six made comments suggesting that they had not altered their daily activities, but that since their diagnosis they had come to redefine normal activities to count as prescribed exercise. For example, when asked if she exercised, one participant answered “well I work.” It is notable that in this case, as with most of the other participants who counted daily activities as exercise, the activities they were referring to were not particularly rigorous; in the example above the participant had only a moderately physical occupation (country club cook).

Seventeen participants took medication for their diabetes. All of the participants who took medication were aware that medicine could impact glucose levels, and even the
participant who took no medicine was aware that drugs were available to lower glucose levels. As shown in Table 4, references to medications that influence glucose were divided into general references that do not specify a particular medication type, references to oral medications and specific references to insulin.

All but one participant referenced home blood glucose monitoring as part of their treatment regimen. Most of these statements simply noted occasional monitoring or instructions to monitor at specific times. Since many statements of this kind merely repeated physician’s orders, they incorporated little information about the function of glucose monitoring. Six participants used glucose testing as an exploratory mechanism to learn about how various activities affected blood glucose. For example, one woman described monitoring to help understand the situation when she suspected a glucose imbalance.

Participant #16: “If something’s starting to look like its going wrong, I take it more times during the day. I take it sometimes three or four times if things don’t seem right.”

This type of monitoring behavior shows an understanding of the role of glucose monitoring as a feedback system.

Patients with diabetes are encouraged to lose weight to help regulate their blood glucose (NDIC, 2006). Six of the participants in this study identified a connection between gaining/loosing weight and glucose control. Similarly, high levels of stress can elevate glucose; nine participants addressed this relationship. Finally, participants reported a number of other factors that they believed were related to their blood glucose: infections and other medical conditions, alcohol, and taking vitamins.
The ways in which participants thought about self-management activities differed considerably, particularly with respect to diet and glucose monitoring. The rest of this section provides a qualitative description of how participants understood the elements of self-management.

3.3.2 Diet

Lack of understanding. Some participants had only a vague understanding of dietary control. For example,

Researcher: “You said that you have a kind of diet?”

Participant #3: “Not really organized. I mean I know some things I shouldn’t eat too much of.”

Researcher: “What kind of things are you not eating too much of?”

Participant #3: “Well I shouldn’t eat too much period, which I do generally, probably. But I don’t, I don’t know, I eat less than I used to, I think and I don’t use much sugar on stuff. You know I do eat some baked goods stuff that’s got sugar in it. I don’t drink sugar soft drinks.”

This participant was typical of those with little understanding of the dietary factors influencing glucose regulation. She understood that she was supposed to be watching her diet but did not know how to do so. Participants with limited knowledge often reported one or two aspects of their diet that they attempted to regulate. These general principals, while better than nothing, were overly simplified and likely to be ineffective. For example, this participant emphasized not eating foods with refined sugar. While people with diabetes should limit sugar consumption, it is equally important to control intake of other high carbohydrate foods, such as bread and potatoes. Emphasis on not eating
refined sugars may come from the popular categorization of such foods as ‘junk foods’ or ‘desserts.’ Alternatively, participants with a limited understanding of the dynamics of glucose control may focus on refined sugars, since blood glucose is often called blood sugar.

*Rule based approach.* Most participants had been given rules for dietary control by a health professional. These rules generally included guidelines concerning appropriate portions for carbohydrates, proteins and fats. For example,

Participant #8: “I do, you know, three to four carb servings, and I’ll try to keep it, keep it equal.”

Participants often reported simplifying more complex sets of rules, in order to attain a manageable set of guidelines. For example,

Participant #5: “I knew what I was allowed to have and wasn’t allowed to have and uh you know how to exchange your starches and all that kind of stuff. I just stay away from a lot of breads and potatoes and all that.”

This participant first refers to a complicated exchange diet. This type of diet involves dividing food into groups and then allotting the patient portions from each group, which can be exchanged with one another according to a complex system of rules (American Diabetes Association & American Dietetic Association, 2003). The participant then simplifies this complex system to a simple rule, limit intake of starches. The use of simplified dietary systems, while an effective strategy for reducing cognitive workload, does not result in optimal glycemic control. Nevertheless, such diets reflect a basic understanding of dietary control.
In other cases, the number and complexity of the rules provided overwhelmed participants. For example:

Participant #12: “Most of the time if you do like a cereal and you don’t want to do a juice of course like an orange juice because its got so much of sugar in it and milk and toast with and of course the person in dietary says when we ask them a question about how do we know what butter to choose. She says you see what the first ingredient is and if it says water that’s the best type of butter... and salads if you like salads or love vegetables. Or you know fish is good. [garbled] and the oriental food they cook so fast that sometimes not as much fat’ll go into that. And you can eat those and it doesn’t hurt you as much.”

This participant had taken a five week diabetes education course, during which he was given a vast amount of information on diet. However, he was unable to integrate this information into a coherent system. Therefore, he repeatedly focused on specific pieces of information rather than articulating any understanding of the relationships that underlie the many facts he reported. Moreover, he was unable to distinguish the relative importance of the rules he had been given. Thus, he remembered more of the details about how to select a brand of butter, which is relatively insignificant, than he does the specifics of controlling his carbohydrate intake, which is vital.

Participants sometimes attempted to understand dietary control using systematic principals, but lacked the necessary information to do so. For example:

Participant #7: “Sending people to a dietician and having them try to understand how all the foods interact and what’s in everything and what you’re supposed to be looking for it gets to be a bit overwhelming when it’s condensed into just two
classes… And even eating the fruit there is a fructose in there and a sugar in there. So you are caught in a dilemma here you are trying to eat a balanced diet that’s healthy for your body but you have this underlying thing that you’re a diabetic and your supposed to do this and you’re supposed to do that especially if you have a very busy life.”

This participant was frustrated by the rules with which he had been provided. He wanted a systematic understanding of dietary control, but did not feel that his diabetes education had been sufficient to help him develop one. In addition, he reported having difficulty integrating his understanding of how he should eat as a diabetic with general principals of good nutrition and the demands of a busy lifestyle.

**Understanding of functional dynamics.** A few participants articulated a deeper understanding of dietary control that integrated cues about the specific functioning of their own body in their food choices. For example:

Participant #4: “Dieting, I try not to have more that 50 carbohydrates a meal. I noticed that I can have between 50 and 80 and not have it go up and I won’t feel sick with my sugar up. I noticed that if I have less than 50 two hours later my sugar is down, I am going to have to eat a candy bar or something to get it back up…”

This participant was typical of expert patients. Instead of using basic guidelines, he had discovered specific levels of carbohydrate intake that worked well for him. In addition, he knew the number of carbohydrates in a variety of foods. He did not rely on rough estimates for assessing the content of various foods.
3.3.3 Exercise

Participants’ perceptions of exercise were much more uniform than their understandings of diet. This may be because they did not report the same type of complex rules about exercise that they did about diet. Most participants simply noted that they engaged in particular kinds of exercises or stated that exercise decreased glucose levels. For example:

Participant #10: “If I do a lot of exercise, I know it [blood glucose] goes down faster that way.”

In a few cases, participants articulated some understanding of why exercise might affect glucose levels. One common explanation was that exercising would help rid the body of sugar. For example:

Participant #7: “So you need to burn the sugar off through exercise.”

This concept of exercise as destroying sugar may be related to popular concepts that exercise ‘burns calories’ or ‘burns fat.’ If participants already believe that exercise destroys undesirable substances in the body, it is not surprising that they would transfer this model to diabetes self management. The other mechanism that participants suggested for exercise to affect glucose levels was via an alteration of metabolic functioning. For example:

Participant #11: “Exercise helps, especially if you can do it on a regular basis. If you’re exercising, your metabolism is you know is definitely a lot higher.”

Whereas the exercise burning sugar mechanism suggests the short term effect of exercise on glucose control, the metabolic explanation links exercise to longer term benefits for glucose regulation.
Participants showed little variation in their understanding of the medication they took. Most participants simply reported what their prescriptions were:

Participant #15: “I take two different types of oral medicine. I take Glucophage twice a day, and I take glyburide twice a day, Glynase. And usually, I’ll take one of each in the morning about a half hour before [eating].”

This is typical in that most patients reported what medication they took, either by name or description (i.e. a big white pill), and their dosages, either in terms of number of pills or milligram strength. Descriptions of medication were similar for participants taking oral agents and those who took fixed dosages of insulin. Two participants reported taking variable amounts of insulin depending upon their glucose levels; both followed simple rules for increasing and decreasing insulin levels.

Understanding of drug mechanisms. Three participants tried to explain how oral medications reduce glucose levels.

Participant #3: “… at least the Actos, I think that it’s not something to increase the insulin production; I think it’s something to make the insulin. I don’t know how did he describe it to me,… there are barriers… at the cellular level it allows the insulin to work more effectively that you already have in your body, but it doesn’t stimulate you to make more insulin. Part of the type II diabetes is, I guess, poor utilization of the insulin you’ve got.”

Like the example above, all of the explanations, given by participants, centered on increasing insulin production and/or absorption. In explaining drug mechanisms, all of the participants shifted to more sophisticated vocabulary and more formal syntax,
suggesting that they were repeating explanations that they had been given by physicians. Two of the three explanations of drug mechanisms were self-contradictory; in the example above, the participant says that the drug is not involved in insulin production but then says that it is “something to make the insulin.” None of these explanations had any direct bearing on the participant’s use of their medications.

Similarly, one participant explained the role of insulin injections:

Participant #10: “… that my pancreas is not putting out the normal amount of insulin that my body needs to function. And when I take shots, that shot is putting the insulin back into my body to help my pancreas work.”

As with those participants who used oral medications, this participant’s understanding of how insulin functions did not affect the way he used his medication.

3.3.5 Glucose Monitoring

Sporadic monitoring. Some participants had little knowledge of monitoring as a feedback system. One participant never used a home glucose meter and was not aware that there was any reason for him to do so. When asked about glucose testing he said:

Participant #3: “I don’t know if I should or not. Like I say, I don’t feel the need to particularly. The doctor never suggested it.”

Other participants took glucose readings only rarely and when prompted by another person (nurse, spouse, friend).

Participant #7: “… if you’re lucky I am doing it once a week sometimes once a month. “

Researcher: “What determines when you use the monitor?”
Participant #7: “… my wife... she uh nags me a little bit as to ‘when was the last time, when was the last time.”

Participants who monitored sporadically were unable to describe any purpose for monitoring and did not use the feedback they received.

Scheduled monitoring. The majority of participants monitored on a regular schedule.

Participant #5: “I check my blood sugar three times a day. I check it when I get up in the morning, I check it just like at dinner time or just before dinner time to see whether its real high or if its up there a little bit or if its real low, and then I check it before I got to bed.”

Participants who monitored on a schedule used this feedback to keep a general watch on their glucose levels and/or to provide motivation for self-management. These participants knew their normal glycemic range and what constitutes a safe range for blood glucose.

Participant #13: “I stay below the 150, my normal range is in the 130s. I have not been able to really get it close 100 yet. But I am still much better now than I was a year from here, because then I was around 180.”

From regular monitoring, this woman knows that her blood glucose is normally in the 130s range and that it has declined some over the last year from being in the 180s. She also knows that glucose levels over 150 may be cause for particular concern. Finally, she has a general goal to lower her glucoses levels to around 100. While scheduled glucose monitoring may not provide maximal feedback, it does provide useful information.

Regular glucose monitoring can also improve motivation to engage in self-management. For example:
Participant #15: “The testing seems to keep me conscious of the fact of where I am. Because I don’t want to see if I test and it’s high. Then I’ll consciously, I’ll actually work with a conscious effort, and I’ll say to myself ‘ok watch what you’re eating and lets see if tomorrow we can do a little better.’ ”

This motivational effect may be especially strong when patients have specific goals for glucose control.

*Using monitoring as feedback.* In a few cases, participants reported using monitoring to explore specific aspects of self-management. For example,

Participant #4: “I had wings and pizza one night, and I had three pieces, and two hours later it was fine. My sugar was fine, then about two weeks later, I had four at a party, they had pizza, and I had four slices of pizza. I took my blood sugar two hours later, and it was at 225. I looked at my wife and I said ‘Hey look at this, three pieces don’t affect me, but four pieces do.’ ”

This participant used monitoring to make specific modifications to his diet. Only three participants mentioned using glucose monitoring to modify self-management.

### 3.3.6 Weight

There was little variation in how participants understood the effects of weight loss. Most noted attempts to lose weight, or that weight loss could help glycemic control. For example:

Participant #17: “But I’ve noticed through the years that losing weight is important. I mean you can be way overweight or obese, but if you’re losing weight your blood sugar is going down.”
Most participants did not know why weight loss aided glucose control. Two participants suggested that reduced caloric intake associated with weight loss led to increased glycemic control.

3.4 Problem Detection: How do I know Some Thing is Wrong?

Complex systems in real world settings are affected by many factors. These disturbances mean that inevitably unanticipated problems will occur in the system. Skilled practitioners need to be able to detect these problems so they can begin procedures to compensate. Pilots have to be sensitive to problematic pressure systems, nurses must be alert for signs of sepsis, and firefighters need to watch for indications of structural collapse in a flaming building. Similarly, patients need to be able to detect abnormal glucose levels.

Participant #4: “It was 1:30, quarter till 2. I hadn’t eaten lunch. So I was sitting there and I started feeling shaky, it’s almost like an anxiety attack. Again you have to pay attention to your body. I knew that my blood sugar was low, so I tested it and it was 77, so I knew that I had to do something.”

To detect problems with their glucose, patients have to parse complex cues and combine different sources of information to determine that their glucose has moved outside the normal range. Patients who are in tune with their bodies may draw on somatic cues, such as the shakiness that the participant above described. Or, patients can use a home blood glucose monitors, to objectively assess their current blood glucose levels. The following section describes how people with diabetes identify problems, and how problem identification contributes to self-management and glucose control.
3.4.1 Overview

Participants were asked about their problem detection strategies in two ways, through descriptions of critical incidents to understand real life care practices and direct questioning to probe declarative knowledge. Participants reported two common strategies: attending to somatic cues and monitoring. And one less common strategy: being informed by others, for problem detection. Each strategy had different manifestations. Table 5 describes the frequency with which strategies were reported.

Table 5. Number of Mentions of General Strategies and Specific Cues Used for Problem Detection in Critical Incidents and Declarative Statements

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Cue</th>
<th>High BG Critical Incidents</th>
<th>High BG Declarative Statements</th>
<th>Low BG Critical Incidents</th>
<th>Low BG Declarative Statements</th>
<th>Total - Critical Incidents</th>
<th>Total Declarative Statements</th>
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<td>Blurry Vision</td>
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<td>0</td>
<td>1</td>
<td>1</td>
<td>5</td>
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<td>0</td>
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<td>2</td>
<td>2</td>
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<tr>
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<td>2</td>
<td>1</td>
<td>4</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
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<td>4</td>
<td>4</td>
<td>1</td>
<td>9</td>
<td>5</td>
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<td>3</td>
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<td></td>
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<tr>
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<td>1</td>
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<td>12</td>
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<td>1</td>
<td>1</td>
<td>6</td>
<td>1</td>
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<td>5</td>
<td>0</td>
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<td>1</td>
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<tr>
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<td>0</td>
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<td>0</td>
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<td>1</td>
<td>11</td>
<td>1</td>
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<td>2</td>
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<tr>
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<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Others</td>
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<td>0</td>
<td>0</td>
<td>0</td>
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<td>1</td>
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</table>

40
While looking at Table 5, it is also important to note that while most people with diabetes experience symptoms when their glucose levels are too high or too low, some patients do not experience symptoms. This insensitivity may either be due to individual differences or to loss of sensitivity over the course of the disease. Similarly, while somatic cues provide important information, many of the most frequent cues can indicate both high and low glucose levels reducing their value as signals of particular glucose level.

*Somatic cues.* While most of the items in Table 5 are self explanatory, a few require explanation. The coma/fainting category in Table 5 refers to incidents where a participant describes losing consciousness due to a severe glucose imbalance. During a mild episode, the patient can be revived easily. In other cases, medical attention is required. For example, one person said she knew when her glucose was low because “you get dizziness and if its too low you pass out. You go into what they call a diabetic coma.” Since the participant was unconscious during these episodes, she could not use this cue for problem detection. However, participants still viewed fainting as a diagnostic, because it was easily detected by others and prompted action to ameliorate the problem.

Foggy thinking was one of the most frequently cited cues to a blood glucose imbalance. Foggy thinking refers to any sensation the participant experienced that involved some form of cognitive impairment. For example,

Participant #5: It is kind of I don’t want to say an out of body experience, but you know, you know that you’re confused, you know why ,and so you’re like, I’ve gotta do something to get this blood sugar back up.
Difficulty articulating this symptom was common. Other descriptions referred to confusion, disorientation, difficulty concentrating, light-headedness and clouded thinking.

Shaking was another commonly reported symptom. Most participants merely referred to feeling ‘shaky,’ but two participants explicitly mentioned vestibular instability, as opposed to a tremor. For example:

Participant # 2: Well not drunk, but you feel uneasiness and my balance is just off.

The last of the ambiguous somatic cues is tingling. This sensation is caused when elevated blood glucose levels lead to restricted circulation in the extremities, and is similar to the sensation of ‘pins and needles,’ which is experienced when circulation is cut off due to poor posture.

Glucose Monitoring. Participants described using glucose monitors to detect problems in three ways. In some cases, monitoring results were the first indication that the participant had of abnormal glucose levels. This is classified as ‘initial,’ because the participant experienced no prior indication of a problem. In other cases, the participants reported somatic cues indicative of a glucose imbalance, but were unable to define the problem until taking a glucose reading. This type of monitoring is labeled ‘accompanying.’ Finally, occasionally participants reported completely diagnosing a problem based only on somatic cues, but chose to take a glucose reading to ‘confirm’ their diagnosis.
3.4.2 Quantitative Analysis: Does Problem Detection Affect Treatment Adherence and Blood Glucose Levels?

Experts are better at using environmental cues to detect problems than are novices (Dreyfus & Dreyfus, 1986). Similarly, people with diabetes need to be aware of their glucose levels and prepared to detect glucose imbalances. Participants use many cues to detect glucose imbalance (see Table 5). Are these strategies effective?

To test whether greater expertise, as characterized by more problem detection strategies, was linked to superior self-management, participants were divided into three groups based on the number of problem detection strategies mentioned. Groups consisted of those who mentioned 0 to 2 strategies, 4 to 8 strategies and 10 or more strategies.

A Kruskal-Wallis non-parametric ANOVA indicated that the groups differed significantly in terms of highest reported blood glucose levels ($H = 9.93, p < .05$). While the small sample size precluded paired comparisons, differences between group averages suggest that those who articulated more problem detection strategies generally reported lower glucose levels.

Similarly, a second Kruskal-Wallis test indicated significant group differences in adherence to treatment ($H = 7.13, p < .05$). Again, although no paired comparisons were performed, group differences suggest that individuals who mentioned more problem detection strategies had higher levels of self-management. In particular, non-parametric, bivariate correlations revealed a significant, positive relationship between the number of problem detections strategies articulated and adherence to dietary restrictions ($rho = .50, p < .05$). No significant bivariate relationships were found between the number of problem
detection strategies articulated and adherence to medication, exercise, or blood glucose monitoring.²

Taken together, these results support hypothesis H1A. Knowledge of problem detection strategies is related to self-management, both in terms of adherence and glucose control.

3.4.3 Qualitative Analysis: Declarative Knowledge

Somatic Cues. Participants generated more somatic cues for problem detection when asked directly how they could tell if their glucose was high/low than they reported when asked how they knew their glucose was imbalanced during specific episodes of hyper/hypoglycemia. In some cases, the symptoms reported when directly asked appear to be memorized during diabetes education classes. For example,

Researcher: “How do you know if your blood sugar is high?”

Participant #12: “If you have, you’re light headed, you’re hyperactive, you get tired easy, you’re thirsty…I think that’s about all.”

² In this, and later sections of the quantitative analysis, there is an apparent disconnect between the results of the ANOVAs and the bivariate correlations. There are two reasons for this divergence. First, the ANOVAs use composite assessments of self-management behaviors and glycemic control, but the bivariate correlations use individual item measures. Second, many of the measures were skewed and/or included extreme outliers. This skewness was not corrected because it corresponded to observed trends in the population, however it does impact upon the results of the correlations. Outliers were not excluded different participants were outliers on different measures and their exclusion would have further diminished the already small sample size.
In this case, the participant listed symptoms associated with high glucose. However, she stated them as being removed from herself by using the second person. She also added the phrase “I think that’s about all” suggesting that she was attempting to recall a learned set of items rather than drawing on personal experience.

Similarly, in some cases, participants were aware of symptoms of abnormal glucose that they had never experienced themselves and therefore did not have the opportunity to relate in anecdotal form.

Researcher: “How would you know if your blood sugar was high?”

Participant #13: “Well for me, I mean I know what the symptoms of high blood sugar is but I’ve never really had those symptoms.”

Researcher: “What would those symptoms be for somebody else?”

Participant #13: “Well the symptoms would be you get kind of dizzy, light-headed, kind of hot feeling, um, you just get disoriented.”

For participants who experienced few symptoms, direct queries allowed them to demonstrate problem detection strategies that they had never used. Whether participants could use these cues to detect problems should the opportunity arise is uncertain.

Blood Glucose Testing: There were fewer reports of using monitoring as a way to detect glucose imbalances when asked directly (N = 2) then when describing particular episodes (N = 21). This difference is somewhat surprising since glucose testing is the most direct way to identify problems. A closer look at how patients think about glucose monitoring helps to provide explanations for this discrepancy.

The majority of participants took glucose readings on a fixed schedule. For these participants, glucose testing became a daily ritual.
Participant #10: “Sure, you know I check my blood sugar every morning when I get up. More or less that’s how I go through my day you know.”

Participants, such as the one above, who have integrated glucose monitoring into their daily lives may be less likely to consider glucose monitoring as a strategy for problem detection, because it is simply part of their daily routine. Nevertheless, these participants used glucose testing to help detect problems. Several participants reported monitoring more often when they were concerned that their blood glucose might be elevated or depressed.

Participant #17: “If something’s starting to look like its going wrong I take it [blood glucose readings] more times during the day. I take it sometimes three or four times if things don’t seem to be right.”

In this case, glucose testing appears to have become so natural that it lost salience as a problem detection strategy.

Other participants did not seem to view glucose readings as an information source. Instead, they saw glucose test results as something their physicians’ used to check adherence and monitor progress.

Participant #16: “But I could always tell when my blood sugar was getting too low, but it had to be confirmed with the Accucheck. And that was for the doctor’s benefit. I guess there are some people who lie, and I wasn’t one of them. But you know it had to be proved to him.”

This participant viewed her symptoms as providing her with information, while seeing glucose readings as being for her physician’s benefit. This view may be reinforced by social norms of physician-patient relationships. In most cases, patient experiences
symptoms and seeks medical attention. The physician then runs diagnostic tests. In many cases, the patient is not even informed of the numerical outcome of the tests, only of the physician’s diagnosis. Blood tests are typically part of physician problem detection rather than a strategy being used by a laymen. This may make it more difficult for patients to adjust to using home blood glucose monitoring for problem detection. Moreover, patients’ with this mindset may resent testing, because they believe the physician is checking the veracity of their statements.

3.4.4 Qualitative Analysis: Critical Incidents

Participants described 32 critical incidents (14 high glucose; 18 low glucose) that included specific strategies for problem detection. These incidents depict how participants used somatic cues and monitoring for problem detection in natural settings.

Learning to Use Somatic Cues. Participants most often reported detecting abnormal glucose levels via somatic cues (see Table 5). However, learning to identify and interpret these cues is a complex and potentially dangerous process. Most diabetes education classes and self-help manuals include lists of symptoms for high and low glucose. However, the interviews suggest that it takes more than a list of cues for patients to effectively use somatic feedback. Patients’ skill at monitoring and interpreting somatic cues varied tremendously. Many participants reported that the first time they experienced hyper or hypoglycemia they were unable to interpret the symptoms.

Participant #16: “The first time I had no idea what was going on. The second time I knew immediately, because I call it a brain fart. I had a problem pulling a word out that I wanted to say right then. And I called the doctor. I said you know
there’s something going on. I have no idea what it is…I went in and he did an
accucheck and it was like 170 and he said ‘yeah that’s what it is.’

Although this woman was trained as a nurse and was aware that distorted cognition is a
symptom of high blood glucose, when she first experienced this sensation she did not
understand its significance. She had to go to her physician’s office and have him interpret
her symptoms in light of objective glucose. After she made this connection, she could use
the cue to detect and diagnose her elevated blood glucose.

Over time, people with diabetes become adept at interpreting somatic cues.

Participant #2: “I was out mowing and it was hot. And I got the front yard done
and I was in the back yard and I could feel this, like this [makes a shaky hand
gesture]. So, I shut the mower off and went in and checked it and took my orange
juice.”

This participant was attuned to symptoms of hypoglycemia, and thus able to recognize
what he was feeling and take appropriate action.

Similarly, sometimes relatives and friends of a patient can tell when the patient
has abnormal glucose levels. This type of problem detection is based on recognition of
abnormal behavioral patterns. For example:

Participant #5: “It dropped real low and I started getting really confused and then
that’s when J-, my fiancé, he said ‘you’ve got to, you know, you’ve gotta eat.’”

It is particularly useful for friends and relatives to help with problem detection in cases,
like the one above, where symptoms may make it difficult for the patient to think clearly.
Similarly, as patients age, they may become increasingly dependent upon significant
others to help cope with the challenges of controlling diabetes.
In addition, over time they may become accustomed to unusual sensations indicating potential glucose imbalances.

Participant #17: “You know when I was teaching math, it would get to the end of the teaching day, and you just wanted to collapse you know. You just felt that way. And so suddenly I realized, maybe its my blood sugar level.”

Participant #8: “I went to bed at like 10:30 and woke up at 4:00 in the morning with a really bad headache. And diabetes was the first thing that came into my head.”

These examples show how patients look to diabetes as an explanation for novel symptoms. In both these cases, there were impediments to realizing the symptom was related to diabetes. Exhaustion is considered natural at the end of the day, as is disorientation upon waking in the middle of the night. Yet, these participants recognized their glucose imbalances. Increased sensitivity to physical sensations indicating possible hypo- or hyperglycemia is important, since patients must learn to identify new cues as the disease progresses.

Some people with diabetes develop taxonomies of somatic cues that allow them to determine precisely how far from normal their glucose level is.

Participant #4: “About an hour after I ate, I felt sleepy, sick to my stomach. When you pay attention to your body, you know what your blood sugar is doing. As soon as I started to feel sleepy, I knew that my blood sugar was above 180. When I started to fee sick to my stomach I knew that I had to test it. When I did test it, it was 258.”
Though only two participants displayed this level of specificity in diagnosing somatic cues, the high level of control that these participants had over their blood glucose levels demonstrates the utility of such great sensitivity (A1cs of 5.9 and 6.3).

While the use of somatic cues to detect problems is a common and effective strategy, it can also be dangerous. If a person misdiagnoses a glucose imbalance, they can exacerbate an extant problem or cause a problem where none existed. Somatic cues are particularly susceptible to misinterpretation since they are subjective and may be ambiguous.

Participant #11: “I had high blood sugar. I felt like I had it probably last week, about Wednesday. My lunch wasn’t exactly lunch. It was before; it was around 11. And then I didn’t eat anything before I went to work, since I was in a hurry. And then after work, I came back at about 5:00. I was just you know dead tired.”

Researcher: “And you thought your blood sugar was high?”

Participant #11: “Well, that time it was low. I don’t know if it jumped up to high after I ate, because I got really tired again.”

This participant reported experiencing fatigue, which she attributed to abnormal glucose levels. However, she was confused about the interpretation of this symptom. Initially, she attributed the fatigue to high glucose. But after reporting that she had not eaten much during the day, making it unlikely that her glucose would be high, she switched to interpreting the symptom as indicating low glucose. Finally, after she had eaten dinner and was still fatigued, she attributed this feeling to high glucose again. At no time during the episode did she test to confirm her interpretations. This patient’s difficulty appears to lie in that fatigue is one of a number of symptoms that can be due to either high or low
glucose. When patients rely on somatic cues that can signal either hypo- or hyperglycemia, it is easy to misdiagnose and exacerbate the problem.

*Home Blood Glucose Testing.* Participants reported using blood glucose monitors in problem detection in three ways. In some cases, the first indication that a patient is experiencing a blood glucose imbalance is when they take a routine blood glucose reading.

Participant #9: “When I met my real mom she had sugar. So, she’s like, one day she’s like ‘let’s take your sugar.’ And my sugar was 300 and something. And she’s like ‘you gotta get to the doctor quick.’”

Participant #10: “I took my blood sugar this morning it was 66… boy was I scrambling for that orange juice.”

Regular monitoring is particularly important for patients who are not sensitive to somatic cues and during unusual events. For example, infections, diseases and the prescription medications for other conditions can all impact glucose levels. Accordingly, a number of participants emphasized glucose monitoring during illness.

Participant #5: “I got bronchitis really bad… And it was fluctuating, it was going up and down, up and down and I had to check it like every 3 hours to make sure that it wasn’t going up really high.”

During unusual events, such as illness, it is especially important to have reliable cues for detecting problems.

Participants often reported using glucose monitors and somatic cues together to help with problem detection. In some cases, participants used somatic cues as an
indicator that something was wrong and then followed up with a blood glucose test to figure out the exact nature of the problem.

Participant #12: “One time, I was shopping at the grocery store, and I felt funny, a little funny, so I came home. I took my blood sugar and it was low…”

For patients who have less robust symptoms, or who find it difficult to interpret somatic cues, combining somatic cues and monitoring can be an effective strategy. This strategy is labeled ‘accompanying’ in Table 5.

Even for people who are expert at reading somatic cues, blood glucose monitoring provides more exact information and prevents misinterpretation. Accordingly, some participants reported using home blood glucose monitors to confirm and improve information already obtained from somatic cues. For example:

Participant #5: “With my diabetes I feel it more when it drops real, real low…some mornings, when I get up, it’s like real light headedness and dizzy. And I’ll check my sugar and it’s at like 40 something.”

Even though this man was aware that his blood glucose levels were low, he still checked his glucose levels to confirm his initial diagnosis. In Table 5, this strategy is labeled ‘confirmatory.’

3.5 Functional Relationships: How do I Understand What is Happening to My Blood Glucose?

In controlling a complex domain, practitioners have to be aware of the factors that affect domain dynamics. Pilots have to understand weather patterns and aerodynamics. Military commanders have to understand troop movements. And, diabetics have to
understand diet, exercise, medication, and so forth. If patients fail to understand the
dynamics behind glucose control they will be unable to explain glycemic imbalances and
predict how their actions will affect blood glucose levels.

When asked to explain why his glucose was low one participant commented:

Participant 4: Well, I didn’t have a whole lot of breakfast. I’ve walked here and
I’ve walked back to work and the vitamin B6. Ever since I’ve started taking
vitamin B6, I’ve noticed that my blood sugar will drop a lot quicker.

Patients explain aberrant blood glucose readings by drawing on a variety of factors. In
this example, the participant identified two of the major areas involved in glycemic
control, diet and exercise, as contributing to his low glucose. He focused on how these
factors affect his blood glucose over a few hours. He also looked for more long-term
influences on the dynamics of his blood glucose, identifying a new vitamin supplement as
possibly leading to lower glucose levels. These factors may help explain this episode of
hypoglycemia, to correct the imbalance, and to prevent future episodes.

3.5.1 Overview

Explanations of critical incidents and direct questions showed what factors and
relationships participants thought of as being involved in glycemic control. After
describing each critical incident, participants were asked what they believed caused the
imbalance. At the end of the interviews, participants were asked directly what they
thought made glucose go up or down. Direct questions allowed participants to express
functional relationships that they knew existed, but which they could not apply to their
daily lives due to a lack of opportunity or understanding. A detailed list of all of the
relationships identified is provided in Table 6. Relationships identified during general
descriptions of treatment regimens, elicited in response to direct questions, are also included for the sake of comparison.

Table 6. *Functional Relationships that Patients Believe Affect their Glucose Levels.*

<table>
<thead>
<tr>
<th>Factor</th>
<th>Specific Aspect</th>
<th>Treatment Regimens</th>
<th>Raising Blood Glucose</th>
<th>Lowering Blood Glucose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Portion Control</td>
<td></td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>High Sugar</td>
<td></td>
<td>13</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Carbohydrates</td>
<td></td>
<td>18</td>
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<td>6</td>
</tr>
<tr>
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<td></td>
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<td>2</td>
</tr>
<tr>
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<td></td>
<td>7</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Fiber</td>
<td></td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Not Eating</td>
<td></td>
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<td>3</td>
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<td>General</td>
<td>24</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Walking</td>
<td>7</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Daily Activity</td>
<td>9</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Exer. Equipment</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Not Exercising</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Medicine</td>
<td>General</td>
<td>12</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Oral</td>
<td>28</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Insulin</td>
<td>11</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Non-Adherence</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>BG Monitoring</td>
<td>General</td>
<td>5</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Scheduled</td>
<td>23</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Sporadic</td>
<td>6</td>
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<td>0</td>
</tr>
<tr>
<td></td>
<td>Exploratory</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Response to symptoms</td>
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<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Non-Adherence</td>
<td>0</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>Weight</td>
<td></td>
<td>10</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Stress</td>
<td></td>
<td>4</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>Heat</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Other Med. Cond.</td>
<td>7</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Alcohol</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Vitamins</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Water</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Many relationships were mentioned with respect to general treatment, rather than being connected to high or low glucose levels. For example, portion control was often described as being an integral part of treatment but was never explicitly related to either lowering or raising glucose levels. This suggests that while participants generally understand the factors involved in glycemic control, they are uncertain about how these
factors alter glucose levels. As with problem detection strategies, the functional relationships participants identified when directly questioned varied considerable from those identified during critical incidents. Participants were more likely to mention diet and medication in response to direct questions but were more likely to discuss glucose monitoring and other factors as part of critical incidents.

3.5.2 *Quantitative Analysis: Is knowledge of functional relationships related to self-management and glucose levels?*

Kruskal-Wallis non-parametric ANOVAs were used to test whether there were any differences in adherence or blood glucose levels based upon the number of functional relationships participants identified as causing high or low blood glucose levels. Participants were divided into three groups based upon the number of functional relationships identified (1 to 2 relationships, 4 to 9 relationships and 11 or more relationships). Significant differences were found among groups in terms of adherence to treatment ($H = 6.085, p < .05$). In particular, non-parametric, bivariate correlations indicated that those who mentioned more functional relationships were more adherent to medication prescriptions ($\rho = .479, p < .05$). Although, the small sample size precluded paired comparisons, differences in means suggest that those who articulated more functional relationships generally had higher levels of adherence. There were no significant differences between groups in terms of glycemic control.

3.5.3 *Qualitative Analysis: Declarative Knowledge.*

When asked what factors elevate or reduce glucose levels, most participants simply listed the elements in their treatment regimens. The following exemplify responses to queries about things that raise glucose levels.
Participant #8: “Stress, overeating, if I don’t take my medicine.”

Participant #5: “Sweets, well you know like cookies, candies, regular soda, and stuff, breads, pastas, all that kind of stuff that turns into sugar.”

Participant #12: “Eating something that is not in your diet or eating too much of something.”

Many participants, like those in the examples given above, largely attributed high glucose levels to eating carbohydrates, not adhering to self-management recommendations, and stress. Low glucose was associated with adhering to treatment regimens, medicine, weight loss, and exercise. Rather than seeing glucose control as a unified system, most participants divided the factors affecting glucose regulation in half and inaccurately connected one half with high glucose and the other with low blood glucose.

Two participants, both professional nurses, provided explanations of low glucose that centered on relationships among factors rather than lists of factors. For example:

Participant #13: “…if you’re diabetic taking your medication and not eating enough; taking too much of your medication, especially if you’re on insulin; and taking your medication and not being active as you usually are cause that can bring down your blood sugar. Or, taking your medication and then deciding that you’re gonna watch what you eat and do what you should do, but you’re on a high dose and continue to take that high dose even though you’ve changed your life style.”

This participant emphasized the relationships among factors and how those relationships can lead to low glucose. However, the primary focus is on medication in concert with other factors, suggesting that this more systematic understanding is specifically related to
professional knowledge rather than to an understanding of the participant’s own self-management.

3.5.4 Qualitative Analysis: Critical Incidents.

During the interviews, participants were first asked to describe the most recent time that they had high/low glucose and then to describe other memorable incidents of hypo/hyperglycemia. A total of 53 critical incidents (22 low, 31 high) included attributions of specific causal factors. These incidents provide insight into how participants use functional dynamics to understand their experiences with glucose regulation.

When asked about their most recent episode of high/low glucose, many participants described fairly small (50-80 point) fluctuations in their glucose levels. These variances were most often ascribed to lapses from normal self-management behaviors and were related to diet, exercise, and medicine. For example:

Participant #10: “Why do I think mine was low? I was up and down quite a bit yesterday. I did my laundry and cleaned the house. I forgot to eat. That was why.”

Participant #3: “Some of that [high glucose levels] might have been because I wasn’t exercising as much. And maybe, I was eating a little more carelessly.”

Other critical incidents from daily life attributed glucose irregularities to stress. For example:

Participant #2: “Like well today, my son was having a problem and his wife wanted to divorce him… You don’t think you get that shook up about something, but that’ll raise your level too, getting nervous and all that.”
Participant #4: “Well last week at work I felt, I have a supervisor, and I felt like I was being micromanaged. I noticed that it wasn’t high, but it was higher than usual. Again it is the stress.”

Stress can impact glucose levels and is more difficult to control than some of the other factors involved in self-management.

When asked to relate particularly memorable incidents, participants often described unusual events that did not fit their understanding of self-management. These episodes were often severe and required medical intervention. In some cases, participants had atypical reactions to elements of their treatment regimen. For example:

Participant #16: “I got in trouble one time with a medicine I was on where I actually blacked out and my blood sugar was less than 25, and they had a terrible time elevating it… So, they took me off that medication and put me on a lighter medicine.”

Participant #4: “It was probably 6 months ago, I would go to bed and it would be 120. When I woke up in the morning, after fasting, it would be 140, that kind of stressed me out because I wanted it between 80 and 120. So, I spoke to the doctor. One of the things that I learned about diabetes is that the liver produces sugar and mine produces too much.”

The examples above are typical of incidents where the participant reacted in unusual ways to normal treatment. In each case, the participant noticed the irregularity and consulted a physician to make sense of the problem and come up with a solution.
Many participants related episodes regarding the effects of other medical conditions on glucose control. In some cases, the other illness directly affected glucose levels. For example:

Participant #12: “Like if you have a cold or a sinus infection or anything like that it’ll cause it to elevate. The last time it was really high like 500 was when I had the infection in my leg.”

Participants often described infections as leading to elevated glucose levels. In other incidents, the medical condition itself did not cause irregular glucose levels, but the drugs used to treat the other condition affected glucose levels. For example:

Participant #10: “I got bronchitis really bad….They put me on some kind of medication that affected my sugar. And it was fluctuating, it was going up and down, up and down and I had to check it like every 3 hours to make sure that it wasn’t like going up really high.”

In cases such as the example above, participants had been warned that they would experience increased glucose fluctuations. But in other instances, the participant was unaware that medication would affect their glucose and only discovered the problem when their glucose rose or dropped dramatically.

3.6 Problem Solving: How do I Correct Glucose Irregularities?

To effectively control a complex domain, practitioners need to respond effectively to problems and correct system imbalances. Aviators need procedures for responding to equipment malfunctions. Fire fighters need to control a fire before it spreads. And people with diabetes need to be able to restore control when their glucose is outside of the safe
range. This section will describe the strategies that participants use to solve problems with their blood glucose levels.

In the previous two sections, we looked at how Participant 4 detected an episode of hypoglycemia (using somatic and monitoring cues) and then made sense of that episode (by connecting it to exercise, insufficient food intake, and use of vitamins). The following quotation describes the strategy this participant then used to ameliorate the problem:

Participant 4: “I knew that my blood sugar was low, so I tested it and it was 77. So, I knew that I had to do something. So, what I do is I keep some lifesaver’s cream savers in my desk, because I knew that that would up my blood sugar real quick. It is just a quick fix until you can get some other food in your body. Orange juice is better for it, but I don’t have OJ at work. I started heating up my frozen lunch then.”

In order to prevent severe hypoglycemia, this participant ate a candy containing substantial amounts of simple carbohydrates. Simple carbohydrates quickly raise glucose levels, but do not elevate glucose levels over an extended period. In order to prevent his glucose levels from dropping again, he then prepared other food that would maintain his glucose at a higher level for several hours.

3.6.1 Overview

As participants described critical incidents, they were asked what actions they took to solve the problem. Table 7 summarizes strategy use.
In order to solve a problem, the problem must first be detected and understood in terms of functional relationships. This dependence may explain why participants articulated many fewer problem solving strategies than problem detection strategies (Table 5) and functional relationships (Table 6). Participants who did not detect a problem and achieve some understanding of why it might be occurring would have difficulty solving the problem. This interpretation is supported by the finding that only 10 of the 18 participants offered any problem solving strategies at all.

Most of the labels in Table 7 are self-explanatory, but a word of explanation may be necessary for problem solving strategies related to medication. Some participants reported they resolved an episode of hypo- or hyperglycemia by changing their prescription medications. Physicians were always the primary decision makers in modifying prescriptions. Thus, while the participant did solve the problem, they did not decide how to restore glycemic control. Similarly, in four of the six cases where a

<table>
<thead>
<tr>
<th>Eating</th>
<th>General</th>
<th>High Sugar</th>
<th>High BG</th>
<th>Total Mentions</th>
<th>People Mentioning</th>
<th>Low BG</th>
<th>Total Mentions</th>
<th>People Mentioning</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td>0</td>
<td>3</td>
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<td></td>
</tr>
<tr>
<td>Exercise</td>
<td>General</td>
<td></td>
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<td>1</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Walking</td>
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<td></td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Calming Down</td>
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<td></td>
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<td>0</td>
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<td></td>
</tr>
<tr>
<td>Drinking Water</td>
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<td></td>
<td></td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Medicine</td>
<td>Perscrip. Modif.</td>
<td></td>
<td></td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Additional Dose</td>
<td></td>
<td></td>
<td>6</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Incr. Adherence</td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

Table 7. Strategies for Ameliorating Glucose Imbalances.
participant took an additional dose, a physician was responsible for administering that additional dose of insulin. In the other two incidents, the same insulin dependent participant elected to take an unusually high dose of insulin. In one case, a participant reported deciding to be more careful about adhering to her prescription in order to ameliorate hyperglycemia. This is a preventative effort rather than an immediate solution.

3.6.2 Quantitative Analysis: Do Problem Solving Strategies Matter?

To assess the relationship between articulation of problem solving strategies and self-management, participants were divided into three groups based upon the number of expressed problem solving strategies (0 problem solving strategies, 1 to 2 strategies and 3 to 7 strategies). Kruskal-Wallis non-parametric ANOVAs compared groups with regards to adherence to treatment and glycemic control. Significant differences were found among groups in terms of adherence ($H = 6.70, p<.05$). Group means suggest that those who articulated no problem detection strategies (mean adherence$^3 = 7.9$) showed less adherent than those who articulated either 1 to 2 (mean adherence = 10.5) or 3 to 7 (mean adherence = 9.667) strategies. In particular, non-parametric bivariate correlations revealed a significant relationship between problem solving strategies and glucose monitoring ($\rho = -.451, p<.05$). Those who articulated more problem detection strategies were more adherent with regard to glucose monitoring. There were no significant differences among groups in terms of glycemic control.

3.6.3 Qualitative Analysis: Resolving Episodes of High Glucose

Self-Help. Only three participants, in a total of six different episodes, described themselves as primary decision makers for remediating high glucose levels. This means

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$^3$ Higher numbers indicate greater adherence to prescribed self-management regimens.
that only one sixth of the sample described taking independent action to help control high glucose.

Even those participants who took independent action did not always make effective decisions. One participant described drinking orange juice during an episode of high glucose. Since orange juice has a very high sugar content, people with diabetes are frequently advised to drink orange juice to help with low glucose levels. Therefore, it seems likely that this participant may have generalized this recommendation to apply to high glucose as well, even though orange juice would exacerbate this situation.

Another participant, in two separate incidents, described exercising in order to help lower glucose levels.

Participant 4: “I can’t have it that high. So I went and took a walk and everything.”

While exercising reduces glucose level, only one participant reported using this strategy. As a group, the participants did not use exercise in glucose self-regulation.

The same participant also reported reducing stress as a way to reduce glucose levels.

Participant #4: “Again it is the stress. I have noticed that my blood sugar will go up high if I am stressed. Especially if I put stress on myself, I have this thing where I say I’d like to be a duck, water off my back.”

This participant directly linked the cause of the high glucose levels, stress, with the solution of trying to remain calm. This is the only incident of high glucose where a participant mentioned solving the problem by eliminating the source of the problem.
In two cases, participants mentioned drinking water as a way to reduce glucose levels. In one incident, the participant drank water, because a family member had given it to her. But in the other incident, the participant articulated a specific belief that water would reduce his glucose levels.

Participant #11: “I drank a pretty good sized glass of water before I went to bed. But besides that no.”

Researcher: “What does the water do?”

Participant #11: “…it just you know, like anything else dilutes it a little bit bring the sugar down a little…for me it seems like drinking water will kind of flush some of that sugar out with it.”

The participant apparently has not been told that drinking water would lower his glucose levels. Rather, he believed that high glucose meant he too much sugar in his blood. He presumed that diluting the sugar would reduce his glucose levels. Although the participants understanding of the physiological cause of his elevated glucose levels was overly simplified, his causal understanding helped him select an effective intervention. This incident illustrates how patients’ beliefs can affect self-management problem solving.

Seeking Professional Help. Many more participants (9) used problem solving strategies that centered on health care professionals. Twelve of the fifteen incidents involved changes in medication. In five of these incidents, glucose levels were reduced via a change in prescription. For example,
Participant #5: “I’ve been on insulin for just a little over a year, because they had me on the oral medication and, you know, it wasn’t working. And so they ended up putting me on the Lantus.”

In most of these incidents, the participant made a general statement that their glucose levels were not under control, as in the statement above that the medication was not working. Then, the participant provided a description of actions that the physician, or other health care provider, had taken to ameliorate the situation. In all of these incidents, the participants never reported being actively involved in solving the problem with the physician.

The patient’s passivity was even more evident in instances where the participant described seeking professional help for a problem but did not specify how the problem was solved. For example:

Participant #9: “It was a thousand one time... and I went to good Samaritan Hospital. And that’s why they was keeping me because of the sugar they was just trying to get it down.”

This participant could not describe what actions were taken to reduce her glucose levels. Even with prompting, the only details she remembered about being in the hospital were that her glucose level was 1000 mg/dl and that she stayed there for three days. Despite the fact that she was conscious, she was disengaged from treatment decision making.

3.6.4 Qualitative Analysis: Resolving Episodes of Low Glucose

Unlike incidents of high glucose, participants were more likely to make decisions about managing low glucose. Several factors may have contributed to this difference. First, while many people experience few symptoms of high glucose levels, hypoglycemia
is generally accompanied by quite salient physical symptoms (such as extreme weakness). Thus, people may be more inclined to take action to remediate their low glucose levels in order to relieve unpleasant symptoms. Similarly, hyperglycemia is not exacerbated by inaction, but hypoglycemia intensifies until the patient ingests something containing glucose. Participants may feel a greater need to act in the face of hypoglycemia in order to prevent the situation from deteriorating. Finally, although many participants connected exercise to lower glucose levels (see section on functional relationships) this relationship may be less salient than the relationship between eating and higher glucose levels. Most diabetes education focuses heavily on diet. This may lead participants to see dietary solutions (i.e. eating when glucose is low) as being more salient options for problem solving. In addition, unlike exercise which requires taking time out of daily activities, eating is easily integrated with other obligations.

*Eating*. Eating carbohydrates is the easiest way to raise glucose levels. Four participants in this sample reported using this strategy. For example:

Participant #10: “I took my sugar this morning it was 66…boy I was scrambling for the orange juice.”

Of the four participants who mentioned consuming simple carbohydrates to raise glucose, three reported drinking orange juice. In cases of extreme hypoglycemia, there is an advantage to drinking rather than eating sugar, because the glucose is processed faster. However, none of these participants had glucose levels low enough to make the difference in processing time significant. Rather these participants seem to have chosen orange juice as a remedy for hypoglycemia because it is often used as an example in diabetes education materials.
Three participants either mentioned eating in general or eating food that was not exclusively composed of carbohydrates. For example:

Researcher: “So what did you do?”

Participant #11: “…went and got myself a peanut butter sandwich and got on with that.”

Both participants who offered details about what they ate chose foods composed of simple carbohydrates (i.e. jelly and bread) along with protein and/or fats (i.e. peanut butter). This is desirable combination because the simple carbohydrates raise glucose levels quickly while protein and fat help maintain glucose at a higher level. Participant who used this combined carbohydrate/protein approach seemed to have a more sophisticated understanding of how different foods affect glucose levels.

Seeking Professional Help. Problem solving strategies involving changing medications or seeking professional help were very similar for episodes of high and low glucose. However, fewer participants sought professional assistance in dealing with low glucose levels than high levels. The one participant, who received medical care for low glucose, received professional help because he lost consciousness and his wife called an emergency medical team.

3.7 Mental Models: How Do Patients Understand the Self-Management System as a Whole

In many complex domains, practitioners employ mental models to help understand systems on a holistic level (Gentner & Stevens, 1983). While many definitions of mental models have been offered, the term mental models is used here to
refer to the analogical use of images, metaphors, or knowledge structures from other domains to understand diabetes. In these interviews, four basic categories of mental models were uncovered. All of these models helped participants to do one or more of the following: assess responsibility for self-management, organize the factors involved in glycemic control, take action to ameliorate problems, and predict future glucose levels. Model descriptions are ordered from the least sophisticated to most sophisticated. While the small number of participants prevented formal evaluation of the models, each description is followed by an initial assessment of the model’s implications and efficacy.

3.7.1 The Addiction Model

Model Description. One participant described diabetes using alcoholism as a metaphor.

Participant #1: “I don’t know if you just don’t believe it because it doesn’t hurt you so bad, or whether you think that you’re smarter than they are. I don’t know. What makes a drunk do it? … It is addictive; there’s no question about it. And like I say, your body adjusts to it. You function so much better when you’re drinking then when you’re not drinking. And diabetes is that way. You feel better when you’re abusing yourself than you would be. Like I said it would keep a bird alive if you eat just exactly what you’re supposed to and the cravings for things.”

Using this addiction model, a poor life style is seen as being akin to the use of an addictive substance, such as alcohol or tobacco. The unpleasant physical sensations, hunger and aching muscles, associated with healthy changes in lifestyle are equated with the withdrawal symptoms experienced by addicts. Although this model was only
articulated by one participant, organizations such as overeaters anonymous attest to the popularity of the notion of poor nutrition as an addiction (www.oa.org).

**Model Implications.** Addictions are notoriously difficult to overcome and success rates are low. By framing diabetes self-management within an addiction model, the participant emphasizes the difficulty involved in self-management and abrogates responsibility for poor health choices. The addiction model also draws attention to the need for social support as opposed to knowledge as an aide to self-management. This participant explicitly stated that his knowledge of self-management was irrelevant. Until patients with this model believe that they have the ability to effect change in their behavior they are unlikely to adhere to any form of self-management regimen.

**Model Efficacy.** For this participant, this model did not provide an effective way to view self-management. He had already lost a leg and was on kidney dialysis. In addition, his glucose levels were in the least controlled third of the group and were outside of the safe range.

3.7.2 The Recipe Model

**Model Description.** The recipe model was the most common model expressed. Two thirds of the participants (12) made some reference to it, though the degree to which participants had internalized this framework for self-management varied.

Participant #5: “I knew what I was allowed to have and wasn’t allowed to have and, you know, how to exchange your starches and all that kind of stuff. I just stay away from a lot of breads and potatoes and all that.”

Participant # 10: “They tell you to walk and through the exercising that keeps it in shape. I don’t do that much walking.”
These quotations illustrate the notion that there is a ‘right way’ to care for diabetes. Health care professionals communicate this ‘right way’ to the patient, and the patients’ job is to follow their physicians/nurses’ instructions. This is the model that most diabetes education materials provide.

*Model Implications.* This model is pervasive and its implications for self-management decision making have been enumerated in the earlier sections on problem detection, functional relationships and problem solving. The basic implication of this model is that health professionals provide rules and procedures. The physician has primary responsibility for decision making, but the patient is responsible for implementing the physician’s decisions. Since patients are provided with rules rather than functional relationships, few participants with this model understood how the elements of self-management were related. The procedures in this model provide a guide to routine self-management. However since glucose regulation is a dynamic system, no set of rules and procedures can cover all of the situations that a patient encounters in daily life. As such, this model is only partially effective as a guide for action and prediction of future events.

*Model Efficacy.* This model is useful for routine self-management but cannot accommodate the full range of events that may affect glucose. The efficacy of this model depends upon the quality of the rules provided, the patient’s understanding of those rules, the patient’s ability to fit rules into daily life, and the patient’s motivation to follow prescribed procedures. In this sample, some participants were given rules that addressed only the most basic situations. For example, prescribed rules typically ignored other medical conditions:
Participant #12: “And it’s really hard sometimes because all of the ones for the heart and the ones for sugar and all that they don’t all mesh so you have to work in between it.”

While participants sometimes received highly detailed rules they often had only a vague understanding of how to implement these rules or were overwhelmed by their number and complexity.

Participant #7: “Sending people to a dietician and having them try to understand how all the foods interact and what’s in everything and what you’re supposed to be looking for it gets to be a bit overwhelming when it’s condensed into just two classes…”

Other participants found the rules were incompatible with time constraints and financial pressures.

Participant #15: “It’s just hard to get that lunch when I need the lunch and then sometimes by the time I get the lunch I’m so hungry that I go over board with that… It’s rather difficult to get a regimen in.”

Finally, some participants simply did not wish to follow the rules they were given. Overall, the efficacy of this model was fairly patient specific. In some cases, the recipe model worked well for daily self-management, however in unusual situations or cases where participants were given poor procedures this model was ineffective.

3.7.3 Model of Sugary Blood

Model Description. Blood glucose is often referred to as blood sugar. Accordingly, two participants thought of blood glucose levels as the concentration of
sucrose (i.e. table sugar) in the blood stream. For one participant, this model was just a simple image that he used to understand the problem of diabetes.

Participant #7: “The thought is just the blood in my body carrying sugar, there’s just too much blood sugar in my blood.”

This participant did not connect his model to self-management decisions.

The second participant with a sugary blood model had a much more elaborate model.

Participant #11: “It will pick up on that sugar [from eating simple carbohydrates] pretty good. And, that sugar’s not really filtered out very good and it, my sugar level, will go up to start with and then it will go down it’ll kind of…”

Researcher: “Ok so that’s what happens if you eat simple carbohydrates are there other kinds of carbohydrates?”

Participant #11: “There are, I don’t really have to worry about those too much its pretty much fats. See they break down into simple carbs in the long run but they’re kind of like a complex carbohydrate when they’re starting out.”

During the first part of the exchange above, this participant described the physiology of diabetes as a problem of filtration. The participant believes that in healthy individuals, sugars are filtered out of the blood stream so glucose levels remain stable. For people with diabetes, he believes sugars, which he equates with substances containing simple carbohydrates, are not filtered properly. This participant drew a picture of how he perceives this filtration mechanism. Figure 2 is a replica of his drawing.
The participant extended his model to explain the effects of different types of food on glucose levels. He described how other foods (complex carbohydrates and fats) slowly break down into the simple carbohydrates that he believes are the sugar in his blood. He believes that these substances do not have the same impact on his glucose as simple carbohydrates because of the longer digestion period caused by the breakdown.

*Model Implications.* Since this model presents blood glucose as a type of sugar solution, it may be useful in interpreting glucose readings. The one to one correspondence between dietary sugar and blood glucose may prompt patients to control their intake of high sugar foods and help predict the effects of certain foods on glucose levels. On the other hand, participant 11’s model did not include a mechanism for lowering glucose levels and has no way to account for the role of exercise, illness or stress. Thus its utility as a functional model is somewhat limited.
Model Efficacy. Participant seven’s version of this model is quite sparse and has no direct links to self-management actions. Thus, it is not surprising that this model was not particularly useful in terms of aiding self-management. He had the second worst level of adherence and the third highest glucose level (A1c = 9). By contrast, participant 11’s more detailed version of this model with its direct implications for self-management was more successful. He was ranked in the top third in terms of adherence and the bottom third in terms of glucose control.

3.7.4 Control Model

Model Description. Two participants viewed diabetes as a manual control problem. Both of these participants had extensive exposure to control systems; one was a physicist and the other had worked both as an air force pilot and engineer. These professional experiences probably facilitated their model development.

Participant 17 equated diabetes with a number of feedback control systems including an airplane autopilot and a thermostat. In each of these systems, he described a sensor that monitors critical parameters and then automatically triggers appropriate actions when the system varies outside of a specified range. Participant 4 equated self-management to the manual control involved in driving a car.

Participant #17: “You know your body comes with an automatic control of your blood sugar, and it takes care of that and did for years. But now you’ve lost the automatic control. So now, you must manually take care of yourself. That’s what diabetes is no automatic control…It’s a feedback control. That’s the way I see the disease of diabetes. And when the body gets where it can’t react, whether it senses
the need, you know the sensors can get bad or its ability to act to those sensors can get bad. Either one of them can cause high or low ... blood sugar.”

Participant #4: “With controlling the diabetes, though, the process of controlling it was hard at first. But then, I realized that it got easier because it’s like driving a truck. Every now and then you drive off of the road, but then you just put yourself back on the road.”

In each of these models, there is an explicit understanding that glycemic control is a dynamic system that responds to multiple factors in the environment. In addition, each model implies that there is a safe range within which the system must be maintained, with the necessity for corrective action when glucose deviates too far from this range.

*Model Implications.* This model is more sophisticated than those described previously. It acknowledges a variety of influences on glycemic control and the influences of multiple factors. Airplane and truck navigation are affected by a wide variety of environmental influences, some of which the driver can control (i.e. navigation) and some of which are purely environmental (i.e. weather conditions). Diabetes self-management is similarly subject to controllable (i.e. diet) and uncontrollable (i.e. aging effects) influences.

This model highlights the importance of feedback. An airplane autopilot cannot function without sensors (speedometers, altimeters, etc.) to provide feedback on the plane’s location. A truck driver cannot navigate without a clear view of the road. Similarly, diabetes self-management requires that the patient monitor their glucose levels in order to maintain an awareness of their current situation. With this emphasis on
feedback, it is not surprising that the two participants with a control model were among those who made the most detailed use of glucose monitoring to understand how specific actions affect their glucose levels.

Both of these participants saw a person with diabetes as a human agent responsible for exerting manual control over a dynamic system. Like the pilot of a manually controlled airplane who cannot depend on an autopilot to make course corrections. The patient has to be an active decision maker and problem solver. Just as the pilot has to be aware of flight conditions and decide when to make adjustments, the patient has to be aware of their glycemic status and alter their behaviors accordingly.

*Model Efficacy.* It is not clear how effective a control model is for diabetes self-management. Participant four was one of four participants tied for reporting the second highest levels of self-management behavior. But, participant 17 was the third least adherent. These radical differences in adherence may be because of the way the questions about self-management activities were phrased. Participants were asked how reliably they performed certain activities in the way in which they were ‘supposed to.’ This wording implies that the patient is following external rules. By contrast, the control model emphasizes active decision-making. The incompatibility of these two models may have led participant 17 to report lower levels of adherence because he had substituted personal decision making for following physician’s instructions. Similarly, it is not clear how this model is connected to objective glycemic control. Participant 17 had the fifth best control over his glucose levels; during the week prior to the interview his glucose levels never varied outside of the normal range. Participant four’s glycemic control was ranked tenth
in terms of the highest glucose reading in the last week. But, his long term glycemic control was well within the safe range (A1c = 5.9).

3.8 Additional Research Findings

3.8.1 Locus of Control

In reviewing interview transcripts, it appeared that the degree to which patients felt capable of and responsible for controlling their diabetes varied tremendously. This suggested that participants’ loci of control may be related to self-management behavior. Locus of control describes the degree to which individuals believe that they have the ability to control their lives (Judge & Bono, 2001). Research has demonstrated that locus of control is important for patient self-management (O’hea, Grothe, Bodenlos, Boudreaux, White & Brantley, 2005; Surgenor, Horn, Hudson, Lunt, & Tennet, 2000). In order to explore these differences systematically, interview transcripts were coded for locus of control and post hoc analyses were performed.

Method. A coding system was created for locus of control. Selected transcripts were initially coded and the coding system was iteratively refined until it covered all statements indicative of locus of control. For example, “references to third persons as being responsible for care” (i.e. spouses, children) was coded as indicating an external locus of control, and statements about “experimentation with food, exercise, etc” in order to understand the specific effects of various actions were coded as indicative of internal locus of control. See appendix E for the full coding criteria. Two raters independently coded a subset of transcripts; substantial agreement between raters indicated reliability of the coding scheme (kappa = .79). To accommodate differences in the number of
statements made, the ratio of internal to external statements was computed for each participant to summarize their locus of control with regard to diabetes.

**Results.** Participants were divided into three groups: those who made more external statements (i.e. ratios less than 1), those who made marginally more internal than external control statement (i.e. ratios between 1 and 2), and those who made substantially more internal than external control statements (i.e. ratios greater than 2). A Kruskal-Wallis non-parametric ANOVA revealed significant differences among groups with respect to highest glucose level in the last week ($H = 7.221$, $p<.05$). Differences between group means suggest that those with a more internal locus of control tended to have lower glucose levels. The relationship between glucose levels and locus of control was also confirmed with non-parametric, one-tailed, bivariate correlations. Internal locus of control was associated with healthier glucose readings in the last week ($rho = - .555$, $p<.05$) and lower A1c readings ($rho = - .594$, $p<.05$).

Similarly, a Kruskal-Wallis ANOVA revealed significant differences between groups in adherence to self-management regimens ($H = 9.378$, $p<.05$). Differences between group means suggest that those with more internal loci of control tended to report higher levels of self-management behavior. In particular, non-parametric, one-tailed, bivariate correlations indicate that those with more internal loci of control tended to be more adherent in terms of diet ($rho = - .501$, $p<.05$) and glucose monitoring ($rho = - .405$, $p<.05$). Locus of control was not significantly correlated with any of the aspects of expert understanding explored in this research.

3.8.2 Health Professionals
This sample included several health care professionals (1 pharmacist, 2 nurses, & 1 phlebotomist). A review of their transcripts revealed contrasts between these participants’ thinking as professionals versus their personal experiences with diabetes.

Thinking as professionals. The healthcare professionals all had exposure to diabetes in their professional roles. Both nurses had worked with people with diabetes, and one had served in a hospital as a diabetes educator. The pharmacist routinely worked with patients managing medication and the phlebotomist had been responsible for glucose testing in a hospital setting. It is not surprising that these participants, who had served in the health care field, were conversant with technical jargon and applied it to their own treatment. For example, when asked about his self-management, the pharmacist responded:

Participant #15 (pharmacist): “I take two different types of oral medicine. I take Glucophage twice a day and I take glyburide twice a day, Glynase.”

Only after describing his medication in detail did he discuss diet and exercise. By contrast, most participants in the sample began by discussing diet. It is not surprising that a pharmacist would be particularly concerned with medication, and that professional considerations appeared to influence his own self-management. Similarly, most participants had difficulty identifying what medications they took. This participant readily identified both of his medications and added the generic for one medicine. The other participants who had worked in health care provided similarly detailed descriptions of their medications.

These participants were also more aware of the rules presented in diabetes education classes. For example,
Participant #13 (nurse/diabetes educator): “Some vegetables are not bad like the broccoli and the cauliflower. And fruit, you can eat strawberries and blueberries but that’s it... And in the vegetables you cannot eat corn, you cannot eat potatoes, you cannot eat peas.”

Participant #16(nurse): “I have, always have protein of some kind. I have at least 2 vegetables, sometimes 3 depending on what I’m eating. I have a serving of fruit and I have some kind of a starch...”

Both of these quotations describe rules that participants are typically given but which are rarely understood. Participant 13 explains that some fruits and vegetables are good for people with diabetes while others are harmful. Most participants have difficulty understanding that one category of foods (e.g. fruits) can contain both helpful and harmful items. Similarly, many participants are advised to control their diet by consuming fixed portions of different food groups. Most of the participants in this study simplified these rules; participant 16 describes using this portion system with no difficulty.

Thinking as patients: Reflections on dual roles. Three of these healthcare professionals commented on differences between their theoretical understanding of the disease and their own experiences.

Participant 13 was surprised by the emotional and motivational problems associated with self-management.

Participant #13 (nurse/diabetes educator): “I used to think that well now this is it I’ll tell you you’re diabetic and these are the things that you should do and can do to help have a more normal life and they would say ‘well, I feel ok, I’m doing ok.’
And I would think well you know but you’ve gotta…Well when I was diagnosed I had no symptoms so I basically I continued to do the same things I had always done. It’s like you’re in denial until it affects you actually physically.”

Participant 15 commented that the medical model of diabetes self-management did not account sufficiently for lifestyle factors and personal commitments.

Participant #15 (pharmacist): “They say you know you have to eat this, this and this. Well a person’s life style, it’s kind of hard to adapt your lifestyle to the disease or the disease to the lifestyle.”

Participant 16 had recently developed arthritis and was having trouble accommodating her diabetes self-management practices to the physical limitations imposed by this new condition.

Participant #16: “I think where the education is lacking is that things change as you grow older. You know and that really wasn’t the focus of the information in nursing.”

Does being a medical professional help? If current medical models of diabetes are adequate, professionals who have extensive exposure to those models should be able to totally control their glucose levels. For the four participants in this study who were health professionals, medical training did not seem to be sufficient to insure glycemic control. Three of the four participants in this group reported glucose levels above 120 mg/dl in the last week: two reported glucose levels in the 140s and one reported a high glucose reading of 215 mg/dl (well beyond the safe range). These healthcare professionals (average adherence = 1.91) did not appear to differ from the group as a whole (average
adherence = 1.97) in self management behaviors. At least in this sample, those with medical training were not better than the sample at managing their diabetes.
4. Discussion

The prevalence of type II diabetes mellitus population is increasing. Currently, most people with diabetes fail to manage their disorder, leading to high rates of death and disability (National Diabetes Statistics, 2004). A large body of research has addressed potential causes of this failure (Gonder-Frederick, Cox, & Ritterband, 2002; Hampson, Glasgow, & Foster, 1995; Senecal, Nouwen, & White, 2000; Williams & Bond, 2002). However, none of this research has considered how patients understand diabetes or the relationship between cognitive conceptions and self-management.

The goal of this research was to describe how people with diabetes understand their disease and how understanding affects self-management. The literature on expert-novice differences was tapped to see how cognitive differences affect performance in other domains (Dreyfus & Dreyfus, 1986; Chi, Feltovich, & Glaser, 1981; Chi, Glaser, & Farr, 1988; Klein, 1999). This framework helped generate hypotheses about the possible relationship between cognitive understanding and self-management. In particular, three types of statements were used to define expert cognition: awareness of situational cues, functionally structured domain knowledge, and readily available problem solving strategies.

Naturalistic Decision Making is one approach that has been used to study expert performance and cognition in real world domains (Klein, 1999). This approach provides flexible interviewing and observational techniques that are suitable for exploring the complexity of real world domains (Gordon & Richard, 1997; Crandall & Getchell-Reiter,
Since this study was focused on exploring how participants understood diabetes and applied that understanding to self-management practices, the semi-structured interviewing techniques of Naturalistic Decision Making were well suited to this type of research.

Because of the exploratory nature of this work, extensive interviews with a small sample size were conducted and intensive qualitative analysis was undertaken. In addition quantitative analyses were used in hypothesis testing. The specific findings of these analyses are provided in the previous section. Therefore, this discussion will interpret the findings and suggest possible implications and directions for future research.

4.1 Overview

4.1.1 Hypotheses

The degree to which participants demonstrated expertise in understanding diabetes self-management was hypothesized to be related to self-management behaviors. In particular, participants who used more problem detection strategies (H1A), expressed more functional relationships (H1B), and articulated more strategies for correcting blood glucose imbalances (H1C) were expected to have higher reported levels of adherence to treatment demands and of glycemic control. All segments of hypothesis one were tested using self-report measures of adherence to treatment and highest glucose level in the last week as criteria for assessing self-management. The overall hypothesis was supported with respect to self-reports of adherence and partially supported with regard to blood glucose levels.
Problem detection was significantly associated with better glycemic control and greater adherence to self-management behaviors. Hypothesis H1A was completely supported. Articulation of functional relationships was significantly associated with greater adherence to self-management behaviors. Hypothesis H1B was partially supported. Finally, articulation of decision making strategies was significantly associated with adherence to self-management but was not related to glycemic control. Hypothesis H1C was partially supported.

These results suggest that patients’ understanding of the cognitive processes demanded for successful diabetes self-management is related to health behaviors and outcomes.

4.1.2 Patients’ Understanding of Self-Management

The qualitative component of the study, described below, provides greater detail regarding the specific differences in understanding that differentiate successful from unsuccessful self-managers. Participants differed in their awareness of the factors required for effective glycemic control. Most participants described four major factors affecting diabetes: diet - 100%, exercise - 78%, medication - 94%, & monitoring - 100%. Participant understanding of the roles of exercise and medication was fairly uniform. However, participants’ understanding of diet and glucose monitoring varied considerably. For both diet and monitoring, participants ranged from those who had only a vague knowledge of the factor’s importance, to those with a detailed understanding of dietary control and monitoring.

Many fewer participants, three and six respectively understood the more subtle effects of stress and weight loss. While these factors can have an immediate impact on
glucose levels, their strongest effects are seen over the long term. This extended time course may contribute to difficulty in perceiving relationships among stress, weight loss, and glucose regulation.

In terms of problem detection and the use of functional relationships, there were important differences between participant’s declarative and functional knowledge. Direct questions tapped declarative knowledge and questions eliciting critical incidents tapped application of this knowledge to their own life. In both these areas, participants mentioned different factors when asked directly about their knowledge than when describing critical incidents (see Table 5 & Table 6). Participants described more somatic cues for problem detection when asked directly than when describing critical incidents, but were much more likely to mention glucose monitoring during critical incidents. Similarly, participants described more functional relationships involving diet and medication when directly asked but were more likely to mention exercise and glucose monitoring during critical episodes.

Currently, most research and diabetes education programs test patients’ understanding by looking at declarative knowledge. The results of this research suggest that insuring that patients have information does not insure that they will apply that information to make self-management decisions. Research and educational programs need to assess functional knowledge not just declarative knowledge. Future research should consider what determines whether patients apply their declarative knowledge to self-management practices and how to insure that knowledge communicated during diabetes training is transferred to actual self-management.
4.1.3 Mental Models

Many definitions of mental models have been offered (Gentner & Stevens, 1983). This study used the term mental models to reference the analogical use of images, metaphors, or knowledge structures from other domains in understanding diabetes (Gentner, Holyoak, & Kokinov, 2001). Participants in this study described four distinct models of diabetes self-management: addiction, recipe, sugary blood, and control. These models helped define locus of responsibility for diabetes management, guide actions, explain glucose levels, and predict future events.

One participant saw diabetes as being akin to alcoholism. This model allowed him to abdicate responsibility for self-management. But it was not useful as a guide to action, as an explanatory model, or as a method for prediction. Twelve participants saw diabetes self-management as akin to using a recipe, a formulaic task that if executed correctly would produce the desired result. They saw health professionals as primarily responsible for making decisions and saw their role as following physicians’ instructions. This model was superior to the addiction model in that it guided action in many routine situations. However, it did not provide an explanatory mechanism or a means for prediction. This limited its usefulness in the face of anomalous outcomes or unusual events. Two participants conceived of diabetes in terms of sucrose concentration in the blood stream. This model made the patient responsible for controlling the sugar concentration in their blood and provided a rough guide to action in terms of diet. As a mechanistic model, it also provided an explanatory mechanism. However, it was limited in that it focused on diet and omitted other influences. Finally, two participants conceived of diabetes in terms of a manual control model. In this model, the patient was responsible
for controlling the system. This model also helped guide behavior, provided an explanatory mechanism and allowed for prediction of future events. Unlike the sugary blood model this model accommodated the multiple factors involved in self-management.

Mental models can impact on how patients learn about newly diagnosed conditions and engage in health behaviors. Models help patients define responsibility for health maintenance, decide what behaviors are appropriate to maintain/regain health, and explain episodes of illness. More research is needed to explore how patients form mental models of chronic illnesses, how these models impact health behavior, and how medical professionals can promote the development of efficacious models.

4.2 Study Limitations

Participants in this study were somewhat younger than the population of people with diabetes as a whole. Over 57.9% of people with diabetes are over the age of 60 (Cowie & Eberhardt, 1995), while only 44% of participants were over 60. Older individuals may conceive of diabetes differently from this sample. However, within the sample there were no discernable age dependant differences and all other participant demographic were similar to the patient population as a whole.

Intensive interviewing and transcript analysis facilitate detailed description and allows for exploration of topics that emerge during the course of research (i.e. mental models & locus of control). However the use of these techniques limited precluded the use of a large sample so that many groups of interest, such as those possessing particular mental models of the disease, were too small for quantitative analysis. The research suggests important cognitive factors that require further research such as the effect of
specific types of diabetes education on self-management, the use and development of patients’ mental models, and how patient-provider interactions affect self-management behavior.

Finally, the data collected in this study was self-report. Since this study aims to understand how patients think about the disease, self-reports of cognition and descriptions of experiences were appropriate. However, the self-report measures of glycemic control and adherence to treatment regimens were more problematic. Issues of self-presentation may have prompted some participants to report inflated levels of self-management and glycemic control. Even though the measure used in this study was based on a validated questionnaire, it is possible that participants’ self-reports were inaccurate. Future work should use patient records in order to confirm glucose levels.

Similarly, while the interview techniques used were appropriate to the aims of the research, the flexible nature of the interviews meant that interviewer biased and inadvertently leading questions might have affected statements by participants (Garza, 2005). In particular, questions designed to elicit participants’ declarative knowledge on specific topics may have prompted retrieval of particular kinds of information. If such retrieval effects occurred, they could provide an alternative explanation for why participants’ declarative knowledge did not always match the strategies they used during critical episodes.
4.3 Theoretical Implications and Future Research

4.3.1 Expert-Novice Differences

*Relationships among cognitive indicators of expertise.* At the beginning of this study, no specific connections among the three aspects of expertise targeted were posited. However, the data suggests that these elements are functionally related, at least in the area of patient self-management. Self-management requires the development of several cognitive processes akin to those required for expert practitioners in other domains. Research on expert novice differences indicates that expertise leads to greater sensitivity to domain specific situational variables (Dreyfus, 1972). For people with diabetes, this means that those with greater expertise are more attuned to cues regarding their glucose levels and consequently are more able to detect problems. Since problem detection is the first step to problem solving, this situational sensitivity is crucial. Experts also organize knowledge around functional relationships rather than superficial features (Hmelo-Silver & Pfeffer, 2004; Collins & Ferguson, 1993; Chi, Feltovich & Glaser, 1981). This means that patients with greater expertise should be more sensitive to the relationships among factors controlling glucose levels. More expert patients therefore are better equipped to understand why their glucose levels are at a particular level and to identify potential problems. Finally, experts have many domain specific problem solving strategies that allow for quick responses to critical situations (Klein, 1999; Chi, Glaser, & Farr, 1988). Thus, more expert self-managers are more likely to have the skills to solve problems and make decisions about their self-management.
The interviews illustrated that these aspects of expertise are not isolated. For effective decision making, each aspect of expertise is a pre-requisite for the next. The incident used in introducing each section exemplifies this process:

Participant #4: “I had a pop tart, I had class here … sat through the class, walked back. It was 1:30 quarter till 2 I hadn’t eaten lunch [Functional Relationships]. I was sitting there and I started feeling shaky, it’s almost like an anxiety attack. Again you have to pay attention to your body. I knew that my blood sugar was low, so I tested it and it was 77 [Problem Detection], so I knew that I had to do something. So what I do is I keep some lifesaver’s cream savers in my desk because I knew that that would up my blood sugar real quick. It is just a quick fix until you can get some other food in your body [problem solving strategies]… I didn’t have a whole lot for breakfast. I’ve walked here and I’ve back to work and the vitamin b6. Ever since I’ve started taking vitamin b6 I’ve noticed that my blood sugar will drop a lot quicker [functional relationships].”

This participant describes diagnosing a problem with his glucose using somatic and objective cues; he is sensitive to domain specific situational cues. He then takes immediate action to remedy the problem, showing knowledge of domain specific problem solving strategies. Notably at both ends of the episode he describes the key activities that contributed to the episode. The use of these functional relationships as bookends points to their importance in the decision making process.

The cumulative nature of these component processes was supported for this participant population. Figure 3 illustrates this funneling.
At each stage of the decision making process fewer patients were able to accomplish necessary tasks. Thus participants provided a rich and varied set of descriptions of problem detection cues. Knowledge of functional relationships was more limited. And by the time participants had to select actions to solve glucose imbalances, less than two thirds of patients took any action at all and many of those who responded did so either by following rote procedures or turning the problem over to medical professionals.

Currently, research frequently treats the various cognitive skills that distinguish experts from novices as independent processes (Chi, Glaser, & Farr, 1988). These findings suggest that these factors are in fact interrelated and that the development of some cognitive skills may be prerequisite for the development of others. Future research should consider how the cognitive skills indicative of expertise are interrelated and how these relationships may affect training and performance.
How are cognition and the development of expertise related? Much of the literature on expertise has emphasized the role of longevity and education in defining expertise (Dreyfus, 1972; Ericsson & Charness, 1994). Traditionally expertise researchers separate experts and novices based on some a priori criterion (i.e. possession of a professional degree, tenure in the field, etc.) and then compare differences between experts and novices in terms of cognition (Chi, Feltovich, & Glaser, 1981).

This study took the opposite approach. Rather than defining expertise at the beginning of the study and searching for differences in cognition, this study began by analyzing the cognitive differences between experts and novices in other domains and using these differences to define expertise. These criteria proved useful for predicting performance in the domain both in terms of behavior (adherence to self-management regimens) and objective results (blood glucose levels). Thus rather than starting with groups of experts and novices and examining their cognitive difference, this study started with differences in cognition and looked at how these differences affect domain performance. These results suggest that instead of considering expertise simply as a phenomenon that evolves over time, it may be appropriate to consider it as a particular type of cognition. Future research should consider whether expertise is best defined in terms of external criteria (i.e. professional certification, tenure in the field) or in terms of cognitive characteristics (Chi, 2000).

The cognitive characteristics indicative of expertise are more than the result of formal education and/or experience in self-management. This was suggested in the examination of those participants who were both health care professionals and suffering from diabetes. This group had the most formal education with regard to diabetes and had
had experience with the disease prior to diagnosis. Yet, these participants, while possessing more technical knowledge, had similar levels of understanding and self-management as the rest of the sample. Formal education does not appear to be enough to create an expert self-manager.

If expert understanding, at least in this domain, is not linked to formal training and seniority, what does it mean to be an expert self-manager? Rather, than internalizing a medical rule based perspective, the key to expert self-management seems to be actively learning to perceive the dynamic relationships between glycemic control and the specific reactions of the patients’ own body. Further research should address exactly what factors determine which patients engage in this active, dynamic learning process and how to facilitate such learning.

4.3.2 Naturalistic Decision Making

The Naturalistic Decision Making movement (NDM) has techniques for studying decision making and other complex cognitive processes outside of the confines of a laboratory (Gordon & Richard, 1997). To date, NDM has focused on analyzing the decision processes of professional decision makers, such as field commanders, fire fighters, and air force pilots. However, people make many complex decisions during the course of daily life. By analyzing patient self-management decisions, this study has shown that NDM techniques can be profitably applied to complex decision-making in daily life.

Because managing complex areas within daily life is the responsibility of lay individuals, it is important to use NDM techniques to understand the complex decision-making of non-professionals in real world settings. For example, the Americans with
Disabilities Act of 1990 made it illegal to discriminate against people with disabilities in a variety of domains including education and employment. As this act has come into effect, thousands of Americans with disabilities have gained admittance to opportunities and environments that were previously inaccessible. These individuals are faced with many challenges as they try to interact effectively with new and complex environments, while coping with the limitations of their disability. NDM has the potential for exploring how individuals cope with these challenges and for providing new ways to improve accessibility and success for the disabled.

4.3.3 Mental Models

In the introduction, three approaches to mental models were described. One research tradition sees mental models as encompassing all of an individual’s cognition in a given domain (diSessa, 1983; Young, 1983; diSessa & Sherin, 2000). This perspective suggests that all of an individual’s domain knowledge is equally accessible and integrated into a coherent picture. This argument is contradicted by the finding that participants’ declarative knowledge regarding self-management differed from the knowledge they reported using in daily life. Rather the disparity between these two types of knowledge supports the view that peoples’ mental models are situationally specific (Patel & Arocha, 1995; Keil, 2003). Future research should address the stability of mental models across time and situations.

The third notion of mental models as the analogical use of knowledge from other domains has been the primary focus of this study. This study has suggested that these models can be effective as ways to organize information and guide action within a complex and novel domain. However, it has also demonstrated that analogical models
may constrain the cues that people attend to in the novel domain and lead to impaired performance. For example, this was the case for the sugary blood model that led participants to focus on diet while excluding other critical aspects of self-management. Future research should explore how people select domains for comparison in creating mental models and the ways in which concepts from other domains can be transformed when taken into a novel domain.

4.4 Practical Implications and Future Directions

Patient cognition matters. This study suggests that patients vary in their understanding of diabetes and that these differences are reflected in their self-management practices. Differences in patient cognition must be considered when planning diabetes education courses, creating educational materials, preparing individual treatment regimens, and shaping physician-patient communication.

Patients differ in their locus of control with respect to diabetes management. Some of the patients in this study were very passive with regard to diabetes management. They expected their health care team to take primary responsibility for glucose control and to provide simple and effective rules. These participants were not active partners in making decisions about healthcare and did not take responsibility for solving glucose imbalances. Other participants were deeply involved in making decisions and solving self-management problems. They wanted their physicians to provide the information that they needed to make effective decisions, but did not want strict rules. Physicians should consider patient cognition in communication and making decisions about treatment. Rule
specificity and degree of patient involvement in decision making should be moderated by
the patient’s locus of control.

As described in the introduction, most current diabetes education materials
provide rules and procedures for self-management. This study found that while many
participants have been exposed to a rule based approach, they rarely followed the rules
exactly as provided. Often, participants found the rules too complex and confusing to
apply in their daily lives. They did not have the time or resources to follow the rules that
had been given. Consequently, many participants followed simplified or adapted versions
of the procedures provided. In most cases, these adaptations were better than nothing, but
they usually excluded key elements of diabetes self-management such as exercise. In
many cases the adaptations were ineffective and/or maladaptive.

One way that some participants were able to synthesize diabetes self-management
information was by using analogical mental models. These models (the addiction model,
recipe model, sugary blood model, & control model) each compared diabetes self-
management to a more familiar and/or easily understood image or system. These
comparisons allowed participants to organize their understanding of diabetes and to make
predictions. While none of the participants were explicitly trained to use these models, at
least two of these models (sugary blood & control) were effective. Given the utility of
spontaneously generated models by non-professions, further work is needed to see if
explicitly developed analogical models may provide a useful guide for self-management.
If this is confirmed, future educational efforts should consider incorporating analogical
models and explicitly training patients in their use.
In sum, as research in diabetes education and self-management should address the processes and determinates by which patients transform educational communications into actual self-management practices. Important questions include the appropriate levels of procedural specificity for different patient groups, the development and use of mental models, the relationships between particular kinds of self-management and differing life styles, and determinants of patients’ preferences for active versus passive health care decision making. From an applied perspective, future diabetes education should focus on providing patients with the information and skills they need to become active self-managers in addition to offering pre-packaged formulas. One way to do this would be to provide opportunities to practice diagnosing and correcting glucose imbalances.
5. Conclusion

Diabetes is a growing health concern in the United States. It is important that people with this disease effectively control their glucose levels in order to prevent serious health complications. This study suggests that how participants’ understanding of diabetes in general, and self-management in particular, can affect self-management and glycemic control. Participants who had a more expert understanding of the disease, as indicated by discussion of problem detection strategies, use of functional relationships and problem solving strategies, reported higher levels of treatment adherence and better glycemic control. Some participants also effectively used mental models to organize knowledge and predict future glucose levels. This research suggests that future efforts at patient education should focus more on helping patients to take control of their disease, understand the functional dynamics of glycemic control, and develop effective mental models.
Appendix A

CONSENT TO PARTICIPATE IN RESEARCH
Department of Psychology
Wright State University
Dayton, OH 45435

Title of Study
Everyday Decision Making

Purpose of Research
The purpose of this study is to gain a better understanding of how people think about chronic illness and make decisions about self-management.

Activities
During the study, I will be interviewed for between one and two hours. If I agree to do so, I may be asked to keep a tape diary of my self-management decisions for 10 days.

Compensation
If applicable, in exchange for my participation, I will receive one research credit, for each half-hour or part thereof, for a maximum of six credits.

Confidentiality
I understand that any information about me obtained from this study will be kept strictly confidential and that I will not be identified in any report or publication.

Recordings
I understand that, if I give permission for the investigator to do so, the interview will be recorded on an audio tape. After completion of the interview all tapes will be locked in a secure location.; at the end of the study all tapes will be destroyed.

Risks/Benefits
There are no known risks. The benefits of this study include an increased understanding of decision making processes.

Freedom to Withdraw
I realize that my participation in this research study is completely voluntary.

I understand that I am free to refuse to participate in this study or withdraw at any time and that I am free to refuse to answer any question. There is no penalty of any kind for either participation, non-participation, or withdrawal.

Availability of Results
A summary of these results may be requested by contacting the researchers listed below.

The summary will show only aggregated (i.e., combined) data for the entire sample. No individual results will be available. The results of this study will be available on approximately May 15, 2005.

Investigator
The research investigator is listed below and if you have concerns or questions about the research,
Availability

she can be reached at Wright State University's Department of Psychology (775-2391). If you have any questions or concerns you may also contact Helen Klein Ph.D., Professor, Department of Psychology, 447 Fawcett (937-775-2391). If you have questions about your rights as a subject in this study, you may contact the Wright State University Institutional Review Board at 937-775-2425.

Katherine Lippa
Principal Investigator

_________________________    Date
Signature                  

Consent

My signature below indicates that I consent to participate in this research study.

_________________________    Date
Signed                      

Appendix B

Interview Guide

- Personal History
  - Story of Diagnosis
    - When were you diagnosed?
    - What led up to your diagnosis? (symptoms, incidents, etc.)
    - What information have you received about diabetes? (classes, literature, physician instructions, dietician, etc.)
  - Family History
    - Do you have any family members who have diabetes?
      - Who?
      - How long have they had diabetes?
      - How much contact have you had with their diabetes (before and after your own diagnosis)? Has this contact helped you understand diabetes? How?
      - Ways that you’ve noticed their diabetes is different from yours?
  - Major fluctuations and Changes since First Diagnosis
    - Have there been times since you were first diagnosed when you noticed major changes in the way your diabetes worked, in terms of symptoms, how much control you had, etc.?
    - Since you’ve had diabetes would you say that you have gotten better overtime at understanding your diabetes and managing the disease? Could you describe your growth in terms of how you manage diabetes?

- Daily Activities
  - How do you control you diabetes (get descriptions that are as detailed as possible, be sure to clarify whether the Participant thinks they do what they should or whether they have two models one of what they ought to do and one of what they actually do)?
    - What is your control range?
    - Diet?
    - Exercise?
    - Medications?
    - Other?
  - Could you describe a typical day…(get the subject to talk through what they do from waking up until going to sleep be sure to get a sense of when they exercise, when they monitor bg and when and what they eat)
    - During the work week?
    - On the weekend?
    - When there is a holiday or you’re on vacation?
• Critical Incidents
  o Could you describe the most recent time you had high blood sugar?
    ▪ When did you notice it was high?
    ▪ Symptoms?
    ▪ Did you take a reading?
    ▪ Why do you think it was high?
    ▪ Did you do anything to help bring down your blood sugar?
  o Could you describe the most recent time you had low blood sugar?
    ▪ When did you notice it was low?
    ▪ Symptoms?
    ▪ Did you take a reading?
    ▪ Why do you think it was low?
    ▪ What actions did you take to help raise you blood sugar?
  o Are there any other times that stand out in your mind when you had particularly high or low blood sugar or when you were confused for some reason about what to do about your diabetes?

• Declarative Knowledge
  o Functional Model
    ▪ In general terms could you describe to me controlling you diabetes works?
    ▪ What’s the goal?
    ▪ What things make you blood sugar go up?
    ▪ How do you know when your blood sugar is high?
    ▪ What things make it go down?
    ▪ How do you know when your blood sugar is low?
    ▪ Do different foods effect your blood sugar in different ways? How?
  o Physical Model
    ▪ Could you describe to me how you think that diabetes works in your body?
    ▪ What happens if you don’t control your blood sugar well enough?

• Personal Issues and Problems
  o Have you found anything that is particularly helpful to you in controlling you diabetes?
  o Are there things that you think may it particularly difficult to control you diabetes?
  o Do you feel like you are able to control you diabetes if you make an effort?
  Do you have any advice that you would give a newly diagnosed diabetic?
Appendix C

Code List

Consequences

Cardiovascular – This code is used to refer to cardiovascular problems resulting from diabetes including heart attack, stroke, etc. Maybe applied to narrative episodes and direct statements.

Kidneys - This code is used any time the participants mentions kidney dysfunction whether as part of a narrative episode or an acknowledged negative outcome.

neurology - This code is used any time the participants mentions neurological damage, including reduced sensation in the extremities, whether as part of a narrative episode or an acknowledged negative outcome.

pregnancy complications – applied to any mention of pregnancy problems resulting from diabetes.

Vision – applied to any mention of long term visual impairment associated with diabetes.

Education

classes – applied whenever the participant mentions attending any form of diabetic management and nutrition classes.

Initial learning experiences – applied to narrative descriptions of how the participant gained knowledge of the disease and their initial experiences trying to care for their diabetes.

Oral instructions – applied whenever the participants mentions directly being told about diabetes self-management by a medical professional.

written materials – used any time a participant refers to attaining information from written materials either paper or online.

Functional Statements

Causes - This code is applied whenever a participant mentions the cause of some phenomenon they are experiencing. It is expected to occur primarily in relationship to things that raise and low blood sugar.
change over time – applied to statements about long term changes in level of control, self-management behaviors, or dynamics of the disease.

Lowering BG – this code is attached to actions that are taken to lower blood glucose levels.

Not eating – applied to statements where participants attribute their level of glycemic control to not eating enough

personal theory – This code is used to label any notion about factors that affect diabetes that are not part of traditional notions of the dynamics of the disease. (For example, a participant mentioning that they believe being a Christian helps them control their diabetes).

raising BG – This code is attached to actions that are taken to raise blood sugar levels.

General Content

BG monitoring – This code is applied anytime a participant mentions taking their blood sugar. It may occur in a description of the treatment regime, as part of a critical incident, etc.

Control – applied to statements about actual level of control that participants have over their BG.

Critical Incident – applied to narrative descriptions of particular memorable experiences involving diabetes.

Declarative Knowledge – This code is applied to any statement that is generated in response to questions about the participants’ abstract understanding of the disease. (ex: how does diabetes work in the body? What things make blood sugar go up?)

Fluctuations – applied to mentions of the general patterns of increase and decrease s in BG level both across the day (such as somebody saying that their BG tends to vary by 200 point across the day) and over the general course of the disease (such as going from periods of frequent hypoglycemia soon after diagnosis to periods of frequent hyperglycemia later on).

goals– this code is applied to statements participants make regarding their general goals for the overall self-management process, such as long life, balance, good health, high quality of life. It is NOT applied to descriptions of participants goals in terms of specific element s of self management , such as exercise four times a week or keeping their BG under 150.

high BG – this code is applied to any statements connected to high blood sugar such as critical incidents, symptoms, control strategies, putative causes, etc.
Initial Diagnosis – This code is attached to descriptions of the whole experience leading up to and including diagnosis. This code may include precipitating symptoms, critical incidents, tests, etc.

Insulin – this code is attached to any mention of insulin use either as a description of a treatment regime, as a part of a critical incident or as a strategy for combating high blood sugar.

low BG - this code is applied to any statements connected to high blood sugar such as critical incidents, symptoms, control strategies, putative causes, etc.

Oral agents – this code is used anytime that a participant mentions using oral medication to help control their blood sugar. It is NOT used if other oral medicines such as vitamins or Tylenol are brought up.

other people w/ diabetes – this is used any time a participant describes someone else they know who has diabetes.

social events – code applied anytime a participant mentions involvement in a social event. This code can be used either in relation to narratives such as somebody mentioning eating out when describing a critical incident, or as a barrier to self-management such as somebody mentioning that they have difficulty with sticking to their diet at parties.

social influences – This code is attached to case where the participant mentions family and friends facilitating or denigrating self-management actions either by directly action or indirect influence

Stress – this code is attached to any mention of stress or high stress events (ex: car accident, family tension). It is expected to occur primarily in critical incidents and as an attributed cause of high BG.

Weight – used anytime a participant mentions their weight as a factor in controlling their diabetes.

**Barriers**

Practical Barriers – applied to any statement where the participant felt their self-management practices were impinged by technical problems including: time, equipment failure, other role responsibilities, etc.

Psychological Barriers – applied to any mention of emotional experiences that limit patients ability or motivation to engage in self management

Uncertainty – used anytime a participant mentions particular difficulty with knowing what they should do about their diabetes. This code is expected to be used both for
difficulty determining BG levels and for difficulty knowing how to respond to BG.

**Diet**

Alcohol – This code is used any time the participant mentions that they consume/d alcohol. It may occur in description of critical incidents, as a factor cited for increasing or decreasing BG, as a source of uncertainty, as a barrier to good self-management, in reference to dietary restrictions, etc.

Carbohydrates – This code is used any time a person mentions either consumption of carbohydrates (for example mentioning eating a lot of pasta as a catalyst for a critical incident) or controlling carbohydrates as a part of a diet. It can be applied either when the abstract carbohydrates is mentioned or when examples of high carb food are provided (ex. A participant saying they have to cut down on bread and potatoes).

drinking water – code applied to mentions of increased water consumption as part of a treatment program.

Eating – This code is attached to cases where a participant mentions eating in a critical incident or describes eating as strategy for coping with low bg or a cause of high bg.

Fats– This code is used any time a person mentions either consumption of high fat foods (for example mentioning eating a lot of bacon as a part of a critical incident) or controlling fat intake as a part of a diet. It can be applied either when the abstract fats is mentioned or when examples of high fat food are provided (ex. A participant saying they have to cut down on eating chick en skins).

Fiber – This code is applied anytime a participant mentions increased fiber consumption either in the abstract or in terms of specific dietary changes such as switching from white bread to wheat bread.

High Sugar- applied to mention of food items that have extremely high sugar content (candy, soda, ice cream, cake, etc). This code can occur either as part of a description of a diet plan if the participant specifically mentions cutting out deserts, as part of a critical incident where the participant consumed high sugar items , as a strategy for dealing with hypoglycemia if the participant mentions eating high sugar items as a way to cope with this problem, etc.

Other medical condition – applied to any discussion of the relationship between diabetes/glycemic control and other medical problems

Portion control – description of dietary self-management based on limiting intake of specific types of foods.

Protein – This code is used any time a person mentions either consumption of high
protein foods (for example mentioning eating chicken as a part of a critical incident) or manipulating protein intake as a part of a diet. It can be applied either when the abstract ‘protein’ is mentioned or when examples of high protein food are provided (ex. A participant saying they now eat more fish as opposed to bread).

**Physiology**

filtration of excess glucose – mention of the problems associated with removing excess glucose from the blood stream. Expected to occur as part of a description of the physiology behind diabetes.

glucose breakdown – mention of the bodies difficulty breaking down glucose into useable energy. Expected to occur as part of a description of the physiology behind diabetes.

lack of insulin – This code is used in connection with descriptions of the physiology behind diabetes. In particular it is connected to descriptions of the bodies lack of production of sufficient insulin.

Pancreas – used anytime a participant mentions the pancreas

**Situational Qualifiers**

personal differences – This code is used in connection with statements about how the participant sees their diabetes as different from the experiences or functional dynamics seen by other diabetics. This code can either be used if the participant is directly contrasting their experience to those of an acquaintance or if they are taking in the abstract about variation in individuals experiences. Finally if a participant mentions the need to pay attention to the specific functioning of their own body then this code can be used.

knowing your body – This code is attached to any statement emphasizing the importance of being aware of the state of the patients body and the way that the dynamics of the disease function on a personal level.

**Strategies**

calming down – this is used anytime a participant mentions stress reduction. It is expected to occur primarily as a strategy for countering the effects of stress on BG, but it could occur elsewhere.

Compensating – used whenever a strategy of using a some element of self-management to counteract particular difficulties. (ex exercising more before a party)

Estimation – this code is attached to mention of estimation of the effects of various factor that effect diabetes as a strategy for helping to control self-management. (ex: estimation of carbohydrate content of food in a restaurant)
Professional help – this code is used to refer to any statement by a participant where they seek the services of a medical professional to help cope with a glycemic imbalance

Symptoms

blurry vision – This code is used whenever a participant mentions experiencing temporary visual deterioration. This is essentially a symptom and can occur in symptom lists, critical incidents, etc.

coma – mention of losing consciousness as a symptom

Constipation – mention of constipation as a symptom

dizzy – mention as a symptom.

Fatigue – mention of tiredness as a symptom.

Flushed – mentions of feeling flushed or feverish as a symptom

foggy thinking – mention of cognitive impairment as a symptom.

frequent urination – mention as a symptom.

headache – mention of headaches as a symptom.

hunger – mention of unusual hunger as a symptom.

Hyperactivity – mention of excess energy as a symptom

irritability – mention of irritability as a symptom.

nausea – mention of nausea as a symptom.

Shaky – mention of feeling shaky as a symptom.

slow healing – this code is attached to cases where a person mentions unusual difficulties in healing from routine injuries /illness. This code is expected to occur primarily as part of critical incidents but it may also be mentioned as a symptom or complication.

sweating – mention of sweating as a symptom.

thirst – mention of unusual thirst as a symptom.

tingling – mention of tingling (also, feeling of pins and needles, prickling, etc) as a
symptom.

Weakness – mention of feeling weak as a symptom
Appendix D

Summary of Self-Management Activities

Please think about the last week and choose the answer that best describes how often you performed each activity.

1. How many of your injections or pills did you take when you were supposed to?
   1. ___ All of Them
   2. ___ Most of Them
   3. ___ About Half of Them
   4. ___ Some of Them
   5. ___ None of Them

2. How often did you test your glucose levels at the time of day you were supposed to (no more than 30 minutes early or late)?
   1. ___ Always
   2. ___ Usually
   3. ___ About Half the Time
   4. ___ Rarely
   5. ___ Never

3. How often did you follow your recommended diet over the last seven days?
   1. ___ Always
   2. ___ Usually
   3. ___ About Half the Time
   4. ___ Rarely
   5. ___ Never

4. How many days during the last week have you exercised for at least 30 continuous minutes? _______ Days

5. During the past week, what was your highest blood glucose reading? _____ mg/dl.

6. During the past week, what was your lowest blood glucose reading? _____ mg/dl.
Appendix E

Criteria for Analyzing Locus of Control

**External Control**

References to a third person as being responsible for care
Statements of externally derived rules
References to physicians – excluding initial diagnosis
Direct Statements: ex “I don’t have control”
Statements that medication is primarily responsible for controlling the disease
Statements about monitoring being from at third party (i.e. physician/ nutritionist)

**Internal Control**

Episodes of decision making based on symptoms
Experimentation with food, exercise, etc.
Statements about learning over time
Statements about taking responsibility for treatment
Direct Statements: ex “I can control my diabetes if I try”
Statements about being strong
Using monitoring to guide action

**Excluded from Coding**

Statements about other people
Statements about other medical conditions
General nutritional theories
Statements that simply answer a direct question from the interviewer
References


Medicine, 7, 127-141.
