Visualizing Health:

Imagery as data for changing personal practice

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B.A. Mathematics, Columbia College, NY, NY

Submitted to the Program in Media Arts and Sciences,
School of Architecture and Planning,
In partial fulfillment of the requirements for the degree of
Master of Science in Media Arts and Sciences
at the Massachusetts Institute of Technology

June 2001

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Abstract
This thesis is about diabetics and their theories about their health practices. Daily decisions, such as eating and exercise habits, have clear consequences for a diabetic's health, yet many of them fail to change their behavior patterns despite knowing facts about the disease. I assumed that they might change their practices if the relationship between their actions and their blood glucose levels was made explicit. To do this, I introduced photography into diabetes diagnosis, asking people to collect images of their daily activities to complement their glucose monitoring. By combining quantitative glucose measurements with qualitative portraits of action, I hoped to make the relationship between physiology and behavior an object for discussion and reflection. More so, I hoped that diabetics who viewed these data would begin to develop new interpretations of their lifestyles that would ultimately lead to healthier activities. I will discuss studies conducted in diabetes education courses and a set of visualization tools that I designed to help people see correlations between glucose data and photographs of activity. The results of these studies suggest that photographing activities may have the potential to change the ways that diabetics understand and deal with their health.

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Acknowledgements

I would like to thank my advisor Brian Smith. His insight, wit, and intelligence inspire me, his advice and support fueled this project and his editing saved it. Professor Smith has compiled an eclectic, wonderful group. I am extremely grateful to the members of Explanation Architecture for their input, support, and humor throughout the formation of this work: Tara Rosenberger-Shanker, Tim Hirzel, Jonah Peretti, Nell Breyer, Erik Blankinship, and Tamara Lackner. And to Melissa Corley who takes care of us, buys great ruebens, remembers everything and always gave me purchasing orders when I needed them.

This work would not have been possible without the help of my collaborators. Thanks to Michelle Leaf for allowing me to observe and run my study during her diabetes class in the Boston Medical Endocrine Clinic, and patiently answering all of my questions about diabetes. Hector Sobrino consistently provided encouragement, informed medical advice and the organizational skills that brought this work together. The web design is highly informed by my conversations and work with Samuel Huang. I admire his rigor and design sense. I am particularly thankful to Zach Kramer who generously shared his story, time and thoughts to strengthen this research. And to all the students and participants who agreed to participate in my study both at Boston Medical Center and in the MIT community.

I am grateful to my UROP Jackie for her well-timed enthusiasm and her resourcefulness.

I would like to thank Walter Bender for keeping his eye on this work and for his thoughtful suggestions throughout the process. And to Cameron Marlow who is always willing to dissect, critique and discuss ideas.

Urs Hirschberg helped me realize this project by introducing me to the programming tools, and design process I used to build the web site. Without his practical and theoretical knowledge, I could not have built this research project.

To my parents, who provided both technical expertise from their fields and boundless emotional support and stability during this work.

I would also like to express my deep gratitude to Stephan von Muehlen for his understanding and care during our graduate studies and my friends for listening to and thinking with me.

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1. Introduction

1.1 Diabetes

There were 15.7 diabetics in the United States as of 1997, representing 5.9% of the country's population. Diabetics have a high incidence of below the waist amputations, are two to four times as likely to suffer from a stroke than non-diabetics, and are at a significantly higher risk to develop coronary disease (Clearinghouse, 1999). Yet, diabetics can avoid most of these major complications through good blood sugar management and overall care (NIDDKD, 1998). To understand diabetes, it is helpful to understand the metabolic mechanism hindered in a diabetic.

In a non-diabetic, the pancreas produces insulin every time the stomach metabolizes food into glucose. Insulin makes the transfer of sugar from the blood stream to the cells possible. Once the sugar permeates the cell wall, the cell uses it as energy to fuel all processes. Without the presence of this hormone, sugar remains in the blood stream causing high blood sugar or hyperglycemia and cells are starved of energy. The immediate effects of high blood sugar include rapid mood swings, frequent urination, and fatigue. Overmedicating can lead to low blood sugar or hypoglycemia which has another set of symptoms: shaking, irritability, and in extreme cases, fainting. Over the years, prolonged hyperglycemia causes decreased circulation leading to damage to the nervous system and the small blood vessels especially those in the legs, the visual system, the heart and the teeth and gums. The damage to the nervous system causes decreased sensation in the limbs. Without the biofeedback of the nervous system (the sensation of pain) patients do not necessarily notice the preliminary signs of infection or damage and small problems easily develop into severe complications such as loss of vision and gangrene (NIDDKD, 1998).

Patient care therefore falls into two categories: Maintaining good blood sugar levels to reduce the chances of developing a problem, and monitoring changes in the body to identify potential problems before they escalate into a serious complication. Both of these types of care require that the patient attend to their own physiology in a new way. To control their blood sugar, diabetics must relearn how to eat, exercise, medicate

themselves and manage stress. In order to monitor changes, they must intentionally check the condition of their feet, eyes, legs and blood sugar regularly.

1.2 Dealing with Diabetes

One of the biggest hurdles for a newly diagnosed diabetic is adjusting to a new lifestyle of healthy eating and exercising. Making such changes is not easy. For one, behavioral changes are non-trivial, as old habits die hard. Giving up things like doughnuts, alcohol, and other nutritional vices are difficult because they are vices (and vices are often pleasant).

Diabetics may also create false illusions of stability to deal with their uncertainties about their health. In a sense, they may adopt a form of confirmation bias (Klayman, 1987), creating interpretations of their behaviors to confirm their health while ignoring data and information suggesting negative consequences of their actions. The human tendency is to protect hypotheses and interpretations of activities by selectively reconstructing their experiences (Erikson, 1980). For example, a diabetic may talk proudly about their aerobics courses without mentioning trips to the ice cream store after each exercise session. Placing a bias on reporting positive behaviors ultimately leads to false beliefs and practices. Unfortunately, many people only revise these beliefs after they had experienced blindness, coronary diseases, or other complications from diabetes.

The research I will describe in this thesis deals with diabetes. More specifically, it deals with the beliefs that diabetics hold about their conditions and ways to help them 1) develop better interpretations of their health practices, 2) change their beliefs about their practices to lead healthier lives. The main question is one of theory formation and revision: How do diabetics interpret (and change) their activities in light of new information? To understand this, I have explored ways to help medical patients take a more active role in their health practices. Rather than patients simply listening to advice from physicians, I have given them tools to help them become investigators of their own health practices.

There are several assumptions behind the tools that I will describe in later chapters. The first of these is that explanation is a powerful tool for revising beliefs and conceptions

about phenomena. In medical situations, physicians usually provide explanations for patients, telling them what they can and cannot do in their current conditions. On the other hand, patients may gain more from generating their own explanations of their health practices. Generating self-explanations has been correlated with increased problem-solving successes and achievement in a number of domains (Chi, 1989, 1994; Coleman, 1998; Webb, 1989). I am interested in understanding how such explanatory activities might be extended to "everyday" problem solving, where patients interpret their behaviors to understand their effects on overall health.

The second assumption is that quantitative data may not be enough to help people generate coherent explanations. Diabetics travel with monitoring devices to measure their blood glucose levels. Blood is drawn from the finger, tested with the monitor, and a single number is provided (e.g., 130 mg/dl)[1]. A collection of these glucose values provide a way for diabetics to see when their sugar is high or low, when they need to take extra insulin, and so on. Unfortunately, the numbers do little to say *why* sugar is high. It is too easy to see high numbers and to simply correct the problem with an insulin shot. In the long run, it would be much better to correct the high sugar issues with proper dieting and exercise. To do this, I have tried to help diabetics correlate quantitative glucose values with additional information that would help them explain why they see particular numbers at particular times of the day.

The best additional information may be a record of their behaviors during the course of a day. That is, high glucose levels at 1:30pm might be explained if we could see what the individual ate for lunch earlier in the day. Rather than just seeing the numbers, we would like to paint a fuller picture of health practices, combining glucose data with a "log" of eating, exercise, and other behaviors. To complement the glucose meter's data, I introduced a number of diabetics to a very different kind of sensor, a camera. I asked them to monitor and record their glucose levels, as all good diabetics should do. But I

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[1] Blood glucose is measured in milligrams per deciliter.

also asked them to photograph their meals, their exercise routines, times when they felt stressed or annoyed during the day, and other important activities that could lead to increased glucose levels.

Photographs are not the most obvious medical records, but they do facilitate three goals. First, they provide additional context for the glucose readings. The high glucose readings at 1:30pm are easily explained when accompanied by a photograph taken at 12:30pm that shows a half-eaten chocolate cake. The glucose values show the outcome of a set of behaviors; the photographs document the process of getting to that numerical outcome.

Second, photographs are also useful for helping patients through the activity of self-explanation. I ask the diabetic photographers to use their images as data, to develop "theories" about how and why the scenes they capture on film lead to the numbers that they see on their glucose meters. Photographs in this work are much more than "visual aids" to help students understand information. They are much more like previous work around imagery as data (Nardi, 1996; Smith, 2000), where learners actively create meaning by studying image content, developing theories about what they see in relation to what they know.

Third, through capturing pictures patients examine their environment with a fresh perspective. The act of shooting pictures encourages the user to step back and evaluate the otherwise familiar scene as if he were distanced from it. The discrepancy between the view through a camera and what a person sees promotes this shift in the photographer's perspective (Sontag, 1973). Patients become more cognizant of their daily actions when asked to examine what they do through the viewfinder of the camera.

1.3 The Thesis

The research in this thesis falls into two related projects. In the first one, I conducted an investigation with a group of diabetics within a self-management course held in a local hospital. I presented students in the class with disposable cameras and the mission to capture image data about their personal health practices. They shot pictures and brought them back to the class for discussion. Rather than discussing nutrition in the abstract, they studied photographs of their own meals and discussed their dietary value. Students

formed explanations of their health practices using their own images as data. These images bridged the gap between what they do in their daily routine and what they learn in the classroom. Patients formed explanations based on this data and their classmates furthered the inquiry by relating their own insights and observations on the image data in question.

But these explanations remained incomplete because, although the images describe health behavior, they do not depict the effect of the behavior on blood sugar levels. Conversely, standard logbooks show that blood sugar rose or fell but not the reason for the change. In the next phase of my work, I explored how to combine and visualize both types of data together to show correlations between behavior and subsequent changes in blood sugar. Diabetics already have a lot of blood-glucose data to comprehend and in my project I ask them to collect another type of data. To facilitate the data review, I developed ways to reduce the challenge of organizing such data. I synthesize and visualize the data to help the patient locate trends, improvements and relapses over time. In this preliminary effort, I created a website where users upload, view and supplement a record of experience. This record combines quantitative information, blood sugar, with qualitative data, images, events, and annotations. In addition to the standard log of blood sugar, I am asking them in phase 1 to collect a different type of data, images. In phase 2, I design tools to help them manage all of this information and visualize it to elucidate the connection between pattern of experience and trends in blood sugar levels.

In chapter two, I will present a case study of Zach, one of the original people who adopted photography into his existing diabetes monitoring. Zach provided a pragmatic motivation for my research; chapter three will discuss the theoretical motivations for the work. In chapter four, I present the initial testing of these ideas, and the work I did with newly diagnosed diabetics in a hospital classroom setting. Those hospital studies led to the technology designs described in chapter five.

2. Extended example

To illustrate the types of inquiry and investigation I envision promoting with this software, I will describe one diabetic's effort to use technology to monitor and learn about his disease. First, I will briefly describe the experience of one person during the onset of diabetes and his reaction to the diagnosis. I will then discuss the tools and strategies he created to track his personal health data over time and characterize the benefits of that process for him personally. Drawing from his experience, I will then explain my efforts to design tools for a general population of diabetics that may have different needs and/or levels of technical expertise.

2.1 Onset of a disease

Zach is a type I diabetic who came down with the disease at the unusually late age. His first symptoms surfaced during the end of his first semester of a graduate program in architecture. During that time, he experienced intense fatigue, thirst and blurred vision. He drank two gallons of water a day, ate an inordinate amount and could barely function. Within a week, he went to the physician. His blood sugar hovered around 500mg/dl where a normal reading would be in the range of 80-140mg/dl; the diagnosis was clearly diabetes mellitus, Type I diabetes. From that point forward, he would depend on regular doses of insulin to live.

So far, he has demonstrated an unusual capacity to deal with his predicament. Zach repeatedly mentioned his habitual attention to detail and his affinity for numbers as helpful in monitoring his disease and managing his own care. He modified his lifestyle to suit his new needs by exchanging hurried meals in the architecture studio for balanced healthy ones at home. He also fit running and biking into his daily routine. Zach reads a lot about the mechanism of the disease, is well versed on how to prevent complications, and knows what he should be eating. His records show, and his physicians agree, that his blood sugar is under great control. As the disease progresses, it will become more difficult to manage. Zach will have to increase his insulin doses from two a day to four or five a day and may require a more complicated mixture of insulin types. Despite this, Zach has established a sustainable way of living with diabetes that ought to ensure a healthy long life.

2.2 Monitoring Health

To manage all the factors that impact his health, Zach assumed the responsibility of monitoring and analyzing his blood sugar himself. With a physician's guidance and of his own volition, Zach developed tools and strategies to monitor his health. He kept meticulous food and exercise records for six months after the diagnosis. He wrote down each gram of everything he ate and when and how he exercised. As time progressed, he developed a shorthand notation to log different food groups and tracked his consumption of each. He reviewed this data with his dietician and on his own to establish a good diet and to understand the effects of exercise on his blood sugar. After establishing a routine, Zach stopped keeping a food log; he has a sense of the composition of every meal. To manage his blood sugar data, he always keeps a standard logbook and regularly uploads his blood sugar levels from his blood sugar meter to his computer. He creates spreadsheets and graphs of these data to track changes in blood sugar over time. He analyzes these records for patterns and trends. Zach has made great efforts to collect and synthesize the information that is relevant to his health.

When he was initially learning how to manage diabetes, Zach used the graphs he made in conjunction with other records to understand the impact of exercising and eating certain foods on his blood sugar levels. In one case, he used the information to adjust his treatment. The first time he saw a dietician, she defined an austere diet for him that made him severely depressed. To solve this, Zach with her guidance slowly began to change his diet. He referred to his food log and blood sugar data to see the impact of the changes.

Zach used to review his graphs in retrospect to identify emerging patterns he did not perceive from moment to moment. For example, in Figure 2.2b, there is a clear trend towards high blood sugar in the evening. His graphs elucidate longitudinal trends that he otherwise would have overlooked. After identifying this pattern, Zach focused his attention on the values in the evenings. He began to exercise before he ate dinner to lower his evening reading. In figure 2.2c, his levels throughout the day are consistent. Now, many months later he says he barely uses these graphs. He knows what causes his blood

He still maintains his graphs out of "habit," but does not need them as much because his practice incorporates what he has learned. In Schon's terminology, Zach has become a "reflective practitioner" (Schon, 1982). He is able to analyze his personal health practice while engaged in the process itself. Zach understands his condition through understanding the data that describes it. His fascination with numbers predates his diabetes and he capitalizes on his talents to manage his disease.

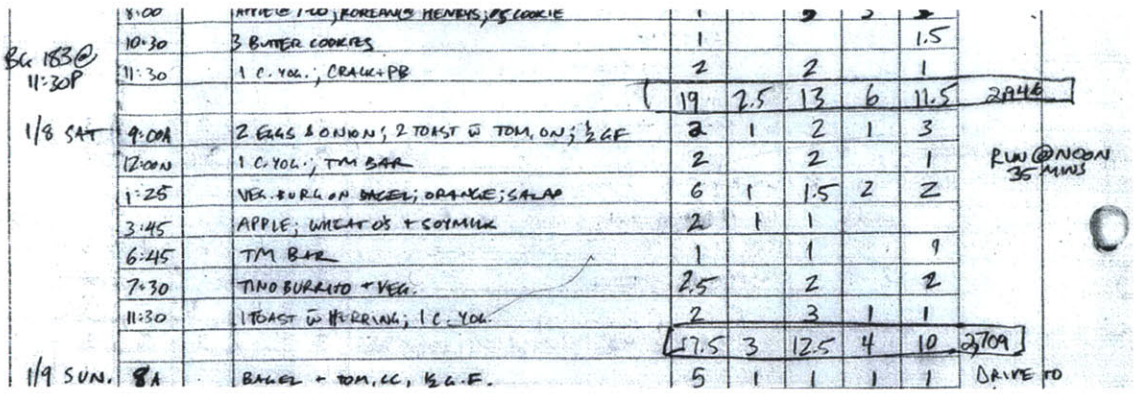


Figure 2. 1 The record of one day's worth of data from Zach's food logbook. He marked down the time he ate, what he ate, the composition of the meal in grams from five categories (starch, fruit, meat, vegetables, and fat), and when he exercised. He sums up his total calorie count from each food type and his total caloric intake for the day.

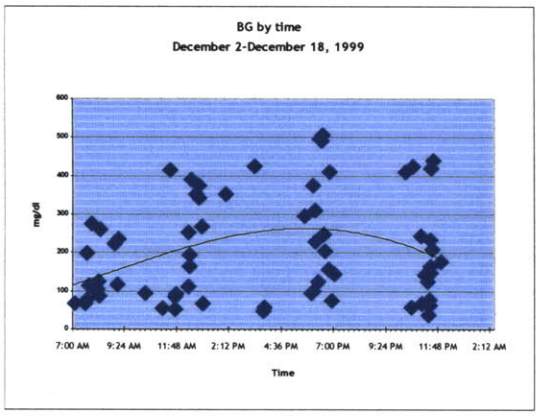


Figure 2.2a.

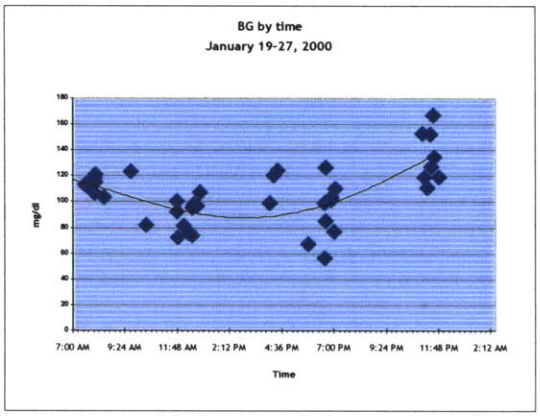
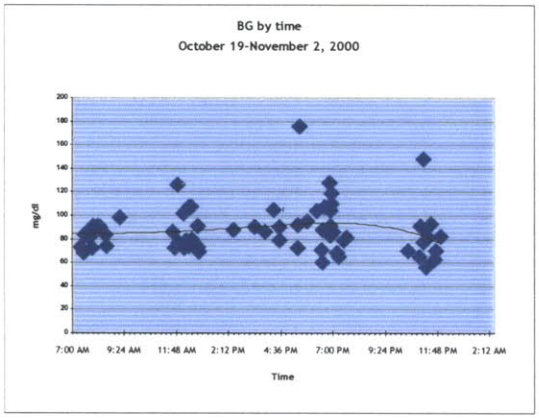


Figure 2.2b.



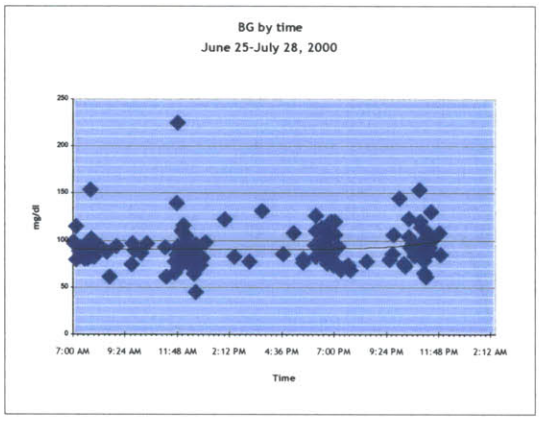


Figure 2.2c. **Figure 2.2d.**

These four graphs were taken from Zach's blood sugar record. Each graph shows at least two weeks of data and a trend line to track daily patterns. All of the blood glucose data is organized by the time of day he measured it. Figure 2a is the first graph he produced. For the first two weeks after the initial diagnosis, his blood glucose values fluctuate wildly. Note that the highest value on the y-axis in figure 2a is 600mg/dl; by figure 4b, the highest value on the y-axis is 250mg/dl. During those five weeks, figure 2a to figure 2b, he has attained better control. By figure 4d from 8 months later, his blood sugar is almost always within the target range of 80-140mg/dl.

2.3 Telling his story

Zach created an animation about his experience living with diabetes and posted it online to share with his community [2]. In it, he describes the onset of diabetes and the implications of that episode in his life. He calls his short film "Numbers." He catalogues all of the figures that now describe him: the readings off his blood glucose meter, his weight loss, the number of lancets that he will require over his lifetime, the amount of money it will cost to fund his treatment. He begins the movie with the statement "I have easily remembered numbers since I was a child…I like numbers, I like mathematics." Towards the end of the piece he states: "[diabetes] is a disease of numbers and I am comfortable with numbers." He thinks in numbers when contemplating his condition. This inclination towards mathematics and computation helps him reconcile the

[2] This site address is: http://architecture.mit.edu/~zkramer/personal/numbers.html

interaction of multiple streams of quantitative data. The records he keeps reflect this proclivity.

Before he created this animation, Zach already had a story he wanted to tell. He had an explanation about why he is competent to care for himself with diabetes. The general logic is this: for him, diabetes is about numbers, he is good with numbers; consequently, he can manage his diabetes. For Zach, this explanation appears consistent with his data and his good health. In some cases, this may not be true. After living with diabetes for over a year and a half, Zach has begun to make his practice routine. Although his health is good, I asked Zach to once again examine his own health practice, this time in images.

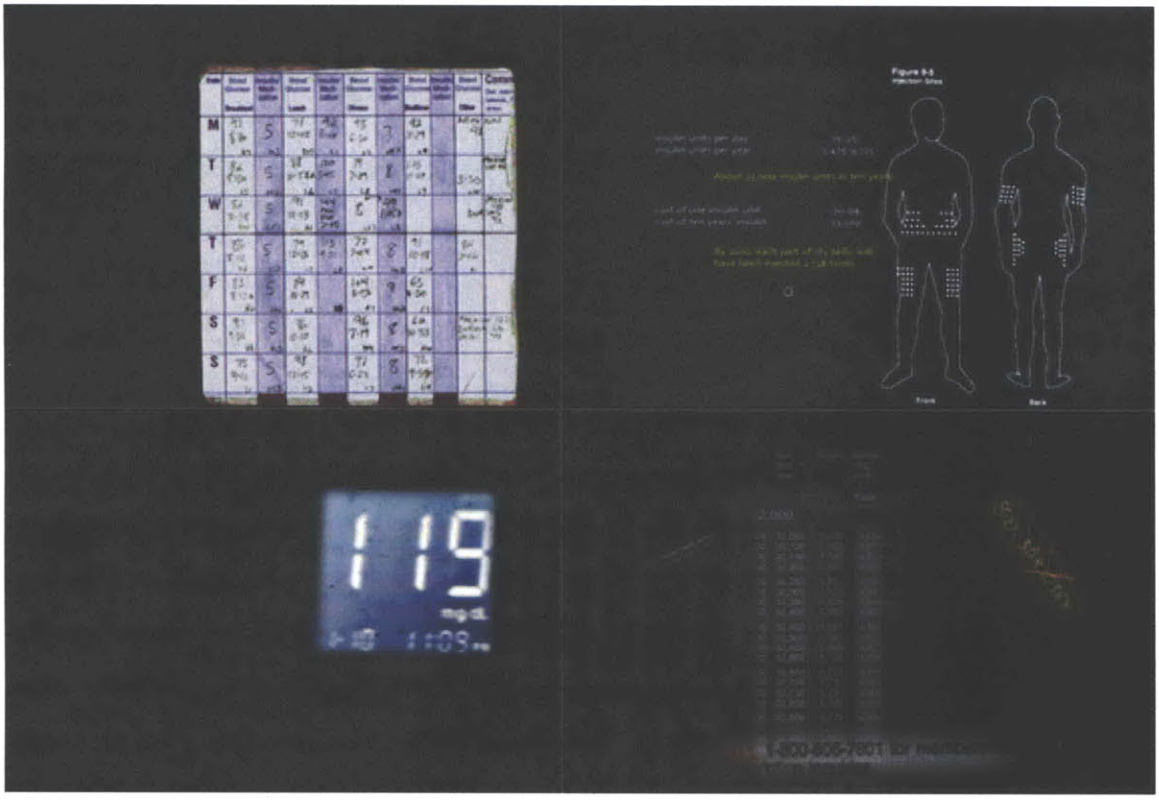


Figure 2.3 Four stills from the short film "Numbers" created by Zach to tell his story living with diabetes. In the piece he describes his personal affinity for numbers and diabetes as "a disease of numbers."

2.4 Picturing his experience

To revisit his inquiry and augment his records, I asked Zach to gather data in images, to photograph his environment and the activities that impact his health. He took pictures of himself eating, exercising, and taking insulin (Figure 2.4). When I asked him about the process of taking pictures, he said two things. First, it made him more aware of his actions. Even though Zach does well living with diabetes he recognizes that he now automates his routine. He thought the most beneficial part about taking pictures was that it helped him step back and reevaluate what he does each day. Secondly, he said that capturing photographs seemed very much like collecting other records. It fit in well with compiling his logs.

> It's kind of amusing to look at your self from outside, from an outside perspective as if they weren't your pictures. It's sort of funny to think about what other people see in your pictures. But it's also very much like record keeping it seems to be…that to me is where it fit. It's what I am doing all the time.

I never discussed other people seeing his images, but the first thing Zach thought about was how these pictures would look to someone else. Capturing a scene and presenting it in isolation serves to remove it from the photographer's original surroundings and effectively from the photographer's original perspective. Even though the pictures were his own, Zach immediately saw them as if he were a stranger looking on. This shift in vantage point may help the diabetic review his or her own practice anew. Just as the graphs of his blood sugar data made Zach more aware of the trends in his data, shooting photographs of his environment drew his awareness to his day-to-day actions.

Figure 2.4 Three of Zach's photographs. He shot pictures of himself exercising, his meals, and injecting himself with insulin.

2.5 Learning from this case

I outline three activities through which Zach dissected and explained his situation living with diabetes – data collection, explanation through stories and photography. I draw upon aspects from each of these activities in my work. Zach collected, synthesized and visualized his blood sugar data and recorded everything he ate in his logbook. Through reviewing these logs, he learned how his system reacts to different foods and to exercise. He created a movie to articulate his personal narrative about living with diabetes. And he captured pictures and, in doing so, focused his attention and awareness on his daily practice.

The focus of my project centers on how image capture and review can inform diabetics about their own health practice. A camera is one way to simplify and enhance medical records because it captures data that is difficult to describe in numbers and increases the diabetic's awareness of daily routine. Zach experimented with taking photographs. He shot pictures of his home and his activities. Afterwards, he reevaluated the meal or event pictured from a new point of view. With that new perspective, he can reflect upon past practice and increase his awareness of what he does each day. Other diabetics may also benefit from snapshots both as a way to log food consumption and exercise schedules and as an opportunity to reexamine their environment and their daily practice.

Neither image data nor a blood glucose log can completely describe experience on their own. Blood glucose data and food logs cannot suggest why a person is in good or bad health; for this, one needs a more complete record of quantitative and qualitative data. That is, diabetics need to understand the correlation between their glucose levels and their patterns of activity. In Chapter 5, I will describe my efforts to integrate these two types of information. I consolidate quantitative records like those that Zach creates with qualitative data in the form of images into one cohesive record. I designed a single representation for both types of data to try to clarify the interconnectedness of multiple factors on the health of the diabetic. Food drives up blood sugar, exercise lowers it. Seeing descriptive and quantitative data in the same place may clarify the relative contribution of these factors especially to the newly diagnosed and or "non-compliant" patient.

3. Theory and research rationale

In this chapter, I describe the theoretical underpinnings of my research. The goal of patient education is to teach patients to manage their own health. However, patients do not necessarily change their personal practice after learning facts about diabetes (Dunn, 1990). To transform "inert" ideas into usable knowledge, educator emphasis putting ideas into practice. I describe how research from education suggests strategies to achieve this transfer of practical knowledge. Through applying new knowledge patients may decide to change their daily practice. Diabetics, like other practitioners, sometimes fall into clumsy routines without thinking about the consequences of their tacit assumptions. Practitioners, through reflecting on their own practice, examine personal biases and develop more flexible strategies to address future problems(Schon, 1982). To facilitate reflection, patients collect data on their daily routine and evaluate it. They capture information using a blood glucose monitor and a camera. In this context, images are not simply illustrations of a pre-established story as they often are. Students use photographs as data and extract evidence to formulate explanations (Mitchell, 1994; Smith, 1999; Smith, 2000). Patients articulate and reconcile explanations to increase awareness of their situation and gain strategies to approach the daily problems they encounter.

3.1 A short history of diabetes treatment

The first known reference to diabetes occurred in 1500 BC in Ancient Egypt. Technology has come a long way from the methods reported in Sanskrit literature in the 6th century AD, where diabetics were diagnosed by urinating on anthills (Bliss, 1996). Urine from untreated diabetics with an excess of sugar would attract ants. The urine of the diabetic was known to be sweet and sticky, or honey like, and in fact the word mellitus in the Latin name for type I diabetes mellitus means honey (Physiology, 2001). In a sense, ants were the first glucose monitors. The ants also foretold certain death. At that time, there was no treatment for diabetes. The most effective means of "caring" for a diabetic before the discovery of insulin was slow starvation. Elliott Joslin and his colleagues in the late 19^{th} - early 20^{th} century managed diabetes by limiting the patient's food intake to 300-400 calories a day. Diabetics on this regiment could live for up to a decade before degenerating completely and dying from of starvation. In 1922, Dr. F.G. Banting and

Charles Best, isolated insulin and succeeded in keeping dogs who had had their pancreas removed alive with injections of their own pancreatic extract. The discovery of insulin and its dramatic benefits led to great optimism in medicine, and the belief that the mystery of diabetes had been solved. Researchers did not head back to the lab until after over medicating with insulin proved to be similarly dangerous. It soon became evident that in addition to insulin dependent diabetes, what is now called type I diabetes, there are other manifestations of the disease. Cases of insulin resistant diabetics, or type II diabetics, who had less pronounced but real symptoms, were discovered and strategies to care for these people were created(Bliss, 1996). Oral medication that combats the body's autoimmune resistance to insulin was developed and treatment plans involving diet changes and exercise regiments became widely accepted for all diabetics (Physiology, 2001). Even with the advent of new medications and technologies, managing diabetes requires self-care. Patients must learn and enact good health care practices to live.

3.2 Educating diabetics to care for themselves

Diabetes self-management education is the primary way that diabetics learn to change eating habits, the way and amount they exercise, and manage emotions. Basically, patients are asked to radically alter many of the behaviors that comprise their identity. Patients do adopt better diabetes related behaviors when they perceive themselves having "control" of their disease. That is, patients who sense that they can affect change in their glycemic levels are more likely to engage in the behaviors they see contribute to that goal(Rubin, 1991), but patients will not necessarily change their practices simply because they know the facts about diabetes and its impact on health (Clement, 1995; Dunn, 1990). Educational interventions focused on skill acquisition such as problem solving and goal setting may be the most effective means to get patients to control their disease.

Diabetes education must involve the individual in his or her own care independent of educational or socioeconomic background. In the United States alone there are 800,000 new diagnoses of diabetes each year (NIDDKD, 1998). The individual differences between these people may mitigate how people cope with the disease and yet the

education they receive should attempt to resonate with all of them. Teaching diabetes self-management requires a sensitivity and awareness of the background of the student. Until a few years ago, dieticians advised patients about "*the* diabetic diet," suggesting that one way of eating would suit all people. In the past few years, an awareness of individual differences in eating habits has forced dieticians to rethink their advising, to help patients learn how to eat what they like in healthier ways. (Mensing, 2000; Molitch, Barr, & al., 1998; WebMD, 2001). The National Standards on Diabetes Self-Management curriculum stresses the importance of situating medical education into the daily life and practice of the student (Mensing, 2000). They suggest that diabetics should be exposed to the following issues in their education:

- Describing the *diabetes disease process* and treatment options
- Incorporating appropriate *nutritional management*
- Incorporating *physical activity* into lifestyle
- Utilizing *medications* (if applicable) for therapeutic effectiveness
- *Monitoring* blood glucose, urine ketones (when appropriate), and using the results to improve control
- Preventing, detecting, and treating *acute complications*
- Preventing (through *risk reduction* behavior), detecting, and treating chronic complications
- *Goal setting* to promote health, and *problem solving* for daily living
- Integrating *psychosocial adjustment* to daily life
- Promoting *preconception care*, management during *pregnancy*, and *gestational diabetes management* (if applicable)

Words like "integrating," "promoting," and "utilizing" suggest a curriculum where students are taught to actively manage their own health care. One could imagine a similar document that talked about students needing to know various facts about diabetes (e.g., "students should understand how diabetes can result in gangrene."). On the other hand, statements like "preventing, detecting, and treating acute complications" suggest that

learners be equipped with strategies for prevention, detection, and treatment. The assumption is that domain mastery is less about understanding facts and information, more about being able to perform skills (Shank, 1994). Diabetics should understand how to affect change. Unfortunately, this curriculum does not prescribe clear ways to train people to change.

3.3 Informing practice

3.3.1 Putting ideas to use

Without being put into practice, knowledge remains inert; facts and information are only useful when students understand how the ideas apply to the here and now, to current circumstances (Whitehead, 1929). In a diabetes class, this could mean having the students use information from the curriculum to solve novel problems. Rather than having doctors and educators tell patients how to act and what to eat, classes could revolve around people applying strategies to problems taken from their own lives. To learn about nutrition, people could examine their own and others' eating habits, and real cases that emerge out of students' experiences. Educators could work with students and "apprentice" them on good health practice.

In the "apprenticeship" process, health educators could engage students in conversations that promote reflection in and outside of the classroom. Seasoned practitioners, patients, may be unaware of the assumptions and biases that inform their decisions. By automating daily health practices such as preparing meals, determining dosage levels, and managing stress, patients may potentially employ dated or rigid rules erroneously (Schon, 1982). Only through dissecting a process and questioning the tacit can one begin to develop strategies dynamic enough to address the unique attributes of each situation. Patients, by reflecting on their routine and their behavioral patterns, could increase their awareness of the decision strategies and assumptions they make. Physicians and other "experts" can scaffold the patient's "reflection" by presenting alternate courses of action or pointing out implicit assumptions. Ultimately, the student begins to incorporate this "reflection" into her own practice without the aid of the expert. Schon argues that this analysis may be done in retrospect, as in the case of a class describing and analyzing a

past experience. But, the eventual goal is to integrate reflection into the execution of each action (Schon, 1982).

3.3.2 Patient awareness

Sometimes the individual may be unaware of or unwilling to see what actually exists in the environment. Looking through the external lens of the camera offers the photographer a novel perspective on the surrounding environment (Sontag, 1973). From this new perspective, students may be able to evaluate a setting without relying on their pre-existing assumptions and interests. They may be better able to engage in "reflection in action" (Schon, 1982)

In a study by Rich et al. (2000), asthmatic patients were asked to videotape their environment and daily activities. They found significant differences between what participants said about their environment and what they captured on tape. Only through the video did participants "show" the researchers that pathogens that trigger their asthma are all around them. In interviews, they rarely report that triggers and allergens are present (Rich, 2000). While the camera captured these items, the patient videographers purport not to have seen them. If explicitly confronted with these discrepancies, patients may be more willing or able to account for their presence.

3.3.3 Images as data

Within the process of forming an argument images can function in a couple of different ways. According to Mitchell (1994), images present "facts" but always have the potential to become "evidence" when some aspect of the image gains significance because of the context. Smith and Blankinship (2000) capitalize on this aspect of photographs in their design of educational technology. They see most educational uses of video and photographs as pure illustration for a predefined text or audio explanation. They design applications in which the student form the explanation themselves based on a novel of image data as evidence. In Mitchell's terminology, the student evaluates "evidence" from the "facts" presented in the visual media to construct an argument. They present images as "data" from which students pull out significant attributes.

In Rich et al.'s work (2000), researchers used video as data to answer the specific pre-established question of whether or not the asthmatics have allergens or pathogens around them. They used the presence of asthma triggers in the video to make an argument about what is taking place. Diabetics have their own set of questions. Questions arise from class content and in daily life. And when they do, images serve as evidence to formulate answers and explanations.

3.3.4 Collaborative viewing

The discrepancy in Rich et al's study (2000) between what the participants report being in their environment verses what the researchers note in the video demonstrates that the individual's perspective mediates what they "see." Participants may have intended to show one thing in the video, but they actually revealed something else entirely to researchers. Diabetics may also exhibit this tendency. Their classmates may be in a better position to extract information from an image than the photographer herself. Classmates assume mentor-like roles for one another while they examine and critique each other's images.

Patients and their families currently collaborate on health related issues on many web sites. Through these sites patients, both adults and children and their relatives, share health related information about physicians, medication, and lifestyle(Cardone, 1998; Hannemann, 1997; Parents, 2001). In one case this has led to the establishment of a mentoring program in which newly diagnosed patients pair up with people with experience living with the same chronic disease (Parents, 2001). Patients do not necessarily have the opportunity to meet other people in their situation. The Internet and hospital groups provide the chance to communicate with other people in similar situations. The nature of the patient's knowledge of the disease differs from that of a physician, so these mentoring programs may supply a type of support and information that people do not get from their health care provider. Patients attending a class on diabetes have the opportunity to benefit from the experience of other people in the class. Bringing in personal data may both help people generate meaning as they articulate stories (McAdams, 1993) and create peer-to-peer exchanges of information.

3.4 Journaling

There are many aspects of a diabetic's behavior that impact health status. These include how often they exercise, how much they eat, and their fluctuations in stress levels. To track this information, diabetics often keep logbooks where they write down their blood sugar measurements, and possibly when they exercise and what they eat. Patients working with a dietician may maintain a more complete food log temporarily. Most physicians will review their patients' logbooks with them to extract patterns or investigate problems and will adjust medication accordingly. While blood glucose monitor manufacturers as well as diabetics and others have created software tools to organize blood glucose data, food intake and exercise, from my investigation no one has tried to incorporate photographs or annotation into such a record. That combination may allow patients and physicians to better explain fluctuations in health and establish a routine that fits the patient's life.

3.5 Summary

Hospitals across the country try to teach patient how to control their disease. The most useful information an educator can provide is knowledge that the patient can fit into their daily practice immediately. Diabetics are presently taught about diabetes using general cases. Visual media obtained from their own life could supply examples for discussion within the class. These authentic examples may promote the type of reflection about practice described by Schon as "reflection in action" (Schon, 1982). Through this reflection, patients may be able to mentor one another, drawing upon their own experience as well as the information they have learned in the course.

4. Phase one: implementation and evaluation

In this chapter, I present the implementation and evaluation of the first phase of my research. My first goal was to understand how diabetes courses are currently taught, so I observed several classes run by the nutrition clinic at Boston Medical Center. The first part of the chapter describes what I learned from these observations. The second goal was to introduce new ways of learning into these classrooms, and I will describe an intervention where students photographed their daily activities and used these images to ground diabetes knowledge in personal experiences. Finally, I will discuss the impact of these interventions, examining interview data with patients and their photographs to show how the classroom dynamics changed as a result of using imagery as data.

4.1 Design Constraints

The diabetes education class at Boston Medical determined the design constraints for my preliminary research. I observed the course held during July and August 2000 to create an "intervention" appropriate for this setting. I implemented my project during October and November of the same year.

4.1.1 Patient education at Boston Medical

From conversations with diabetes educators, the class at Boston Medical seems to be a typical course. The diabetes class runs for ten sessions and is held once a week during the workday. Seven topics are covered over eight lectures. A nurse practitioner, Shelley Leaf, runs the class, teaches a few of the sessions and invites specialists to deliver talks in their respective fields. Patients from the hospital attend the class upon the recommendation of their physician or nurse practitioner.

4.1.2 Demographics

Approximately 20 people enrolled in the late summer course, although only around half attended each meeting. Of those, seven attended class regularly. About a third of the students were returnees from previous courses. In this particular hospital, over half the students are African American, about 40% are Hispanic and the remainder is Non-Hispanic Caucasian. One study examining the patient population at Boston Medical revealed that on average this group reads at a second grade level (Leaf, 1996). About half

of the students are unemployed, and many of them suffer from additional ailments such as heart disease and high blood pressure. Only one person suffered from severe diabetes complications (deteriorating vision).

4.1.3 Class Time

The class sessions follow a set routine. Participants arrive at 2:30 and have to a waiting room. If there is sufficient staff on hand, technicians weigh each student and test each person's blood pressure before they enter the classroom. There, another nurse tests the patient's blood sugar. The class is scheduled to start at 3:00. Often, there isn't enough time to test everyone within a half-hour, so students are called out of the room during the lecture. The hour lecture is often reduced by this commotion.

The classroom is located within the hospital's Nutrition Clinic. Students sit at tables set up in a U shape facing the wall. At the front of the room, there is a small whiteboard, a pull down projection screen, plastic food props in a glass food pyramid and a 20-inch TV with a VCR. Shelley sits at the upper end of one side of the U with her equipment to test blood sugar.

Session	Topic	Instructor
1	What is diabetes? Basic Facts	Nurse Practitioner
2	Basic Eating and Nutrition Information	Dietician
3	Medication: Insulin and Oral	Endocrinologist
4	Diabetes Complications	Endocrinologist
5	Diabetes Self Care: 1. Foot Care 2. Monitoring 3. Sick Days 4. Preventing Complications	Podiatrist

6	Self Care Continued	Nurse Practitioner
7	Exercise	Dietician/Trainer
8	Review and Evaluation	Nurse Practitioner

Table 4.1 Class Schedule for the course. The course runs for eight weeks and covers seven topics. The course topics closely mimic those recommended by the National Standards for Diabetes Self-Management Education reproduced in Chapter 2. One nurse practitioner runs the course. She invites specialists from the hospital to give guest lectures.

Lectures include topics such as what diabetes is, diet, holiday eating, exercise, medication, complications, and foot care. The class schedule is shown in Table 4.1. An endocrinologist, a podiatrist, a nurse practitioner and a dietician from the hospital deliver these talks. Most speakers deliver set lectures, illustrating their talks with handouts, overhead slides and/or physical props such as rubber models of food. All speakers open the floor to questions, but some elicit them genuinely. Generally, patients listen to a talk for close to an hour and ask their questions during the last few minutes. An example of a typical class follows.

Students filter into the room. People greet each other and begin to chat. One woman complains that her feet hurt, so she can't walk very far. Another man says he walks everyday for exercise. They talk about the weather, the hospital and maybe food. Meanwhile the nurse practitioner, Shelley, tests everyone's blood sugar. She asks them when they last ate and writes down the readings in each person's medical record. If the reading is exceptional in some way, she comments upon it. Ben is doing well; Arlene should come in for an appointment so that they can rethink her medication dosage. After everyone arrives, Shelley finishes testing blood sugars and begins her introductory lecture on the basic facts about diabetes. Shelley structures her talk around a set of transparencies starting with a diagram of the human circulatory system on the overhead projector.

In the first picture, sugar is represented as cubes floating throughout the blood stream. The next overhead depicts glucose receptors as triangular elements on a cell wall. Two cases follow. Without insulin, the diagram indicates, glucose cannot be delivered to the cell. With insulin, the glucose passes through the cell wall to fuel the cell. Shelley asks how many people know the difference between Type I and Type II diabetes and which

they have. Half the class does not know the difference. Because Shelley sees most of these patients, she is able to tell them which type they have. She goes on to describe the difference. Afterwards, she enumerates the typical symptoms of diabetes. Periodically, someone breaks in to ask a question. A few personalities dominate the conversation. Shelley asks the class some questions and a couple of people know all the answers. The majority of the class is quiet during the talk. At the end of the lecture, Shelley opens the class to questions. They ask factual questions like, "How much sugar is in a normal person's blood?" And they ask more personally relevant questions like, "Why do I get jittery when I have low blood sugar?" Many of the questions do not specifically apply to that day's lecture. She fields questions on a variety of topics like medications, diet, and coping with pain.

Although the blood sugar testing at the beginning of class sometimes detracts from the teacher's ability to start class on time, it gives her the chance to interact with each individual personally. She advises them on their care according to their glucose readings; this short exchange may be the most important part of attending class. For many diabetics, this may be one of the few times a week they test their blood sugar, and often the only time they receive personal advice. Shelly often asks patients to come see her, or she makes a comment about their medication when the readings are unexpectedly high or low. This short conversation seems to comfort patients who are uneasy about caring for themselves.

In week five, a podiatrist, Julie, gave an informal talk and quickly opened the floor to questions. She was casually confident with her subject matter. Unlike other speakers, she explained the biological mechanisms of phenomena without being patronizing. She could spontaneously diagram the nervous system on the white board and explain why diabetics lose feeling in their feet. She explained that it is the diabetics' choice whether or not to attend to their needs before problems emerge. Patients asked her many questions both on foot care and other topics. When she could not answer a question, she redirected them to Shelley. The patients and Shelley enjoyed this style because she both covers her material simply and addresses students' questions. Her focus on student issues made her the most popular guest instructor during the class sessions.

The most pressing issue in diabetes is what a diabetic should and should not eat. Unfortunately, the nutrition talk was one of the least helpful lectures in the series. The dietician, Jennifer, used overheads and a set of rubber food props set in a glass food pyramid to accompany her talk. While the props provided a model for the types and quantities of foods that the students could cook at home, she never explicitly made associations between home practice and class content. It was difficult for her to suggest appropriate diets without understanding people's current diets. Jennifer waved pieces of rubber vaguely resembling the size and appearance of one "serving" of different food products. There are models of steak, pork chops, broccoli, muffins, mashed potatoes, and other American standards. She discussed the relative nutritional value and acceptable portion size of each. A food with more fiber, such as most vegetables, can be eaten in larger quantities than foods with a lot of fat. Students laughed when she shows how thinly one should slice meat. Patients do not seem to relate these objects to what they cook at home. The dietician has a lot of knowledge about particular foods and their effect on health; unfortunately, she could not tailor her knowledge to the individual needs.

Several students complained about their diet — how they are not allowed to eat the foods they love. One man, Neil, repeatedly mentioned his sweet tooth and how he indulges sometimes. The nutritionist did not have the time to critique the meals that students crave or suggest substitutions. Altering favorite recipes would likely be more effective than introducing an entirely new diet. A Caribbean woman asked if a casaba is a starch or a vegetable. A short debate ensued amongst students before class continued. The dietician was at a loss. In general, the dietician listened briefly to the students' comments then persevered through her talk. The most helpful element of the talk was a diagram she showed of a "good meal," a pie chart depiction of a plate. Half of the circle was vegetable, one quarter was meat and the other was starch. The dietician tried to get people to rethink how they plan and conceive of a meal. Meat should be thought of as a side dish to accompany vegetables. Here Jennifer tried to get the students to shift their thinking about meals. She used a clear mental model that students could recall and use. Besides this moment, it seemed like the dietician had a narrow definition of a "good" diet and attempted to restrict patients to it despite its foreignness.

For the class on health complications, the physician showed a gruesome slideshow depicting everything from gangrene to sore-ridden legs to cataracts. In doing so, he tried to scare people into taking care of themselves. Other speakers attempted to quell patients' fears, like the dietician who argued that diabetics should just follow a diet that is healthy for the general population, implying that eating "right" is doable and important for everyone. These classes have a dual purpose: to present factual information and inspire patients to enact behavioral change. Although this is never stated explicitly, each teacher seems to know that motivating the patients is instrumental. Teachers adopt a variety of strategies towards this end.

4.1.4 Observations

1. People regularly talked amongst themselves before the lecture began. They articulated their difficulties living with diabetes and exchanged information on everything from healthy snack foods and packaged goods to inexpensive gyms in the area. During these casual exchanges, they demonstrated knowledge of good health practice untapped in the formal class time.

2. When the lecturers ask the class questions, one of the attendees tends to answer the majority of the time. One woman, Gail, who has lived with diabetes for 12 years, competently answers the factual questions. She knows what she should be doing and has read up on diabetes facts. But she still describes herself as having an "eating problem" and knowing what is right does not translate into choosing the best foods for her. Even though she has a lot of factual knowledge, she does not have the skills to go from "knowing" to "doing." Because there are several different lecturers, it is easy for each one to be unaware that certain personalities dominate the conversation. Many of the participants remained silent. Therefore, it was difficult to know how much most people were learning or understanding.

3. Much of the content of the course remains academic. Few of the teachers made an effort to connect class content with daily practice. For example, the dietician presented her facts without regard to what the patients currently eat. The course was centered on transmitting facts rather than usable knowledge and strategies to the students.

4. Patients attend class to learn how to live with diabetes, but typically non-diabetics who do not know first hand the challenges of living with the disease teach patients. I am not claiming that a teacher has to have diabetes to teach about diabetes, living with diabetes is different than simply knowing what one ought to do. Relating stories about diabetics' experiences and diabetics telling personal stories may be a better way to communicate how one can live with the disease than just relating facts. One instructor empathized with the students saying she could never live with diabetes. Although she had good intentions, this attitude does not help the class. The students could benefit from mentors with or example stories of diabetics who manage diabetes well.

4.2 Intervention

Based on my class experience, I defined a set of goals for my intervention.

1. Explicitly connect factual course content with implementing change in daily personal practice.
2. Incorporate self-explanation and knowledge sharing into the class discussion.
3. Increase awareness of personal health practices by helping students reflect on their daily routine and examine the health care decisions they make each day.

I structured my preliminary investigation to fit within the time constraints of the class and to be useful to a population with a varying level of technical expertise and educational background. I decided, along with the nurse practitioner/educator, Shelley, on appropriate technologies for these users. We chose disposable film cameras and paper-based logbooks as promising tools to deploy to this class.

4.2.1 Implementing the work

My goal for the project was to incorporate (self) explanation and knowledge sharing into the classroom activities. I introduced the task with a description of my objectives that people would share their experiences, coping strategies and challenges with the class. I presented my impressions gathered during my initial observations. Diabetes does not occur in a vacuum. The personal and cultural history of the individual affects how they

cope with this disease. Also, while living with the disease, many of the seasoned diabetics seem to have acquired skills and strategies that may benefit other people. I asked them to share their stories in the interest of helping everyone present. I then introduced the idea of creating a photo-documentary of their lives. I asked subjects to record anything they felt impacted their health. I made general suggestions such as photograph what you eat, where you exercise, and where you spend time with your family. It was not intended to be a comprehensive record, but rather, a window into whatever aspect of their lives they wished to investigate and reflect upon. I brought images captured by members of my research group depicting meals, bar scenes, and people swimming as examples.

I asked participants to capture images and record their blood glucose readings in a logbook that I designed. They brought in their film and records each week. I developed and printed the film and returned the prints the next week when we tried to synchronize the blood sugar and co-occurring images.

Each week, I led discussions on salient actions captured in the images. When applicable, we highlighted connections between the content depicted and the topic of that session and revisited relevant images from previous weeks. Our conversations took place before and after the scheduled lecture.

4.3 Discussion of results

Several observations emerged from class discussions and interviews. First, participants often demonstrated and reinforced their understanding of the material covered in class through describing the photographs. Secondly, participants often "saw" different objects and identified different activities than the photographer herself. Thirdly, the tone and the way information was shared changed. The pictures facilitated conversations about particular topics, but even when people are not sharing their pictures, people began to be more vocal and share their stories within class discussions.

4.3.1 Knowledge reinforced

Participants draw on source content when describing the images and incorporate the logic of their teachers into these descriptions. When one participant, Emmanuel, showed a photograph of a large portion of grilled meat, rice, coleslaw and fried dough in a Styrofoam container (Figure 4.3) Gail, volunteered her analysis. She playfully chastised him about the portion size of his meat. She went on to critique the meal with great specificity. The meat was grilled, that was good, but then he was eating fried dough. He has to cut down on the fat. These comments resonated with the lecture the dietician had presented the week before. But unlike that lecture, this exchange prompted a pragmatic discussion between the two of them. Emmanuel discussed how he has trouble eating properly because he does not like to cook She suggested alternatives like ordering a salad or trying to make something simple and healthy at least once a week.

In this exchange, Gail used the analytic tools she had learned from the dietician. She made comparisons between the ideal meal and her fellow student's. Both students explicitly connected what they had learned in class with how they could integrate that information into future practice. While I still do not know if this will motivate change, acknowledging that there are other possible choices may make change more probable.

Figure 4.1 Image captured by one student of his dinner. This photograph prompted a conversation between two students about portion sizes, food preparation, and balancing food groups.

4.3.2 Alternate points of view

Each person views the images with their own "filter". Participants describe some features of their photographs and omit others. Seemingly unintentionally, participants photographed "unhealthy" objects in their environment. They do not comment on the presence of these objects or even perhaps see them. Winston professed to be shooting a picture of his dinner salad in one picture and an innocuous shot of his refrigerator in another (Figure 4.2), yet other people in the class note a variety of evocative objects in the compositions. One student pointed out the ashtray next to the salad plate on the kitchen table. Another person noticed the empty potato chip bag in the bin under the table. In the photograph of the refrigerator, Winston captures both his diet Pepsi and the regular Pepsi with sugar in one shot. Other students notice the six packs of beer that he has neglected to mention. In an unrelated conversation, the nurse practitioner tells me that this particular patient has a fear of loading his own syringes and relies on other people to prepare them, hence the cup of needles seen in the image. In the all too familiar setting of one's home, participants did not seem to take notice of all the information the environment contained.

4.2.a **4.2.b**

Figure 4.2 Two photographs from one student's collection. While Winston claimed to be photographing his salad plate and just his refrigerator in these shots, some students noticed elements in the scene that he had not described such as the ashtray in figure 4.2.b and the "real" Pepsi and beer in figure 4.2.a.

Although these students shot photographs with a certain intention (for example to take a picture of a salad), these "everyday" photographers frame their pictures in such a way

that they are open to other interpretations. An expert may compose a picture with greater attention to the content and aesthetic balance than these participants. But in these pictures, there is almost an element of surprise when patients capture objects that they do not recognize on a conscious level. Other viewers note the presence of these "unhealthy" things. The discrepancy between the photographer's interpretation and the stranger's interpretation of the image initiates conversation about health care practice. This interaction encourages the patient to reflect upon past experience to understand what really took place. As I discussed in chapter 3, analyzing these images of past actions along with their fellow students may help patients think more carefully about their health practices.

4.3.3 Lecture vs. Conversation

The most dramatic change I observed with the introduction of the photo-journal activity was in the general tenor of the class. We encouraged participants to share and use their personal experiences to explain their health practices. With this shift came the transfer of authority from the lecturers to the students. The knowledge transfer became more fluid as students began to articulate their knowledge more frequently. Shelley began inviting input from students more often.

In one instance, a student who was particularly well read about diabetes began interjecting more factual information into the discussions. This shift in the class structure was appealing enough that, during one session when one visiting lecturer had to cancel, Shelley held an impromptu discussion with the students. Instead of addressing the class from the front of the room, she took a seat at one of the tables and asked people to discuss their questions. We talked about eating with family and non-diabetics. We discussed ways to cope with pain and create alternate exercise regimes. At the end of the session, Shelley remarked how interesting the hour had been. The students integrated their experiential knowledge into this previously formal educational setting. The photographs functioned as artifacts around which people could explain personal practice. After integrating conversations about personal issues through the photography activity, it became easier to talk about personal issues in general. More people participated in the

conversations than before, and they were more likely to include references to what they do daily.

4.3.4 Camera as alternate lens

One student, Arlene, employed a more proactive strategy in photographing her environment. She used the camera to guide her attention to the parts of environment that are relevant to her health. She shot pictures of her staircase, her porch, and her couch (Figure 4.3). When I interviewed her about these photographs, she implied that taking photographs made her see items in her house differently. She said she began to look at her staircase as an affordable way to exercise. Her porch looks like an attractive spot to relax when she felt stressed. And she discussed how she tries to avoid sitting on the couch too long watching television now that she has diabetes. Currently, she doesn't sit on her porch often, and she only climbs the stairs to get in and out, but in taking the pictures, she seemed to notice that she could do things differently.

Figure 4.3 Arlene took pictures of her house. She used this activity to examine how she could live differently in her familiar surroundings. She contemplated using the stairs to exercise, sitting outside on her porch more, and avoiding the couch and watching TV. These photographs remind her of these observations.

In a few images, Arlene set up "still lives" of objects in her kitchen (Figure 4.4). She composed one picture with a triad of objects: a bottle of olive oil, a canister of cooking spray and a stick of butter. She explained that those three foods define the decision she makes at each meal of how and what to cook. She likes the butter but knows she should use the cooking spray. Similarly, she took a picture of honey and sugar, two items she is not supposed to eat, and then another shot of her spices. In our discussion, she said that looking at the spices made her realize she could use these (healthy alternatives) instead of

the sweeteners she craves. At every juncture, a diabetic has a choice between temptation and compliance. In these photographs, Arlene highlighted this fact. When I asked if taking these pictures changed anything for her, she said:

> Yeah I think it made me more aware of you know … I have lots of spices in the house and I try not to use the salt and stuff, but it made me more aware of …ya know, what I need to be doing and the positive things I could do. I have an eating problem you know, and in order to be half way successful I need to be aware to think about it before I do it.

Her awareness of her environment increased as she re-viewed it with the camera in hand. She reports that this activity changed how she views her decisions. Even within the confines of the diabetes treatment, patients have options. The first step is to be aware of what these choices are and their consequences and the next step is to be able to implement good practice. In this short study, this participant seemed to use the activity to become more conscious of her options, whether or not she makes any changes is still to be determined.

4.4a **4.4b** **4.4c**

Figure 4.4 Arlene's decisions — her pictures of sources of fat, spices, and sweeteners.

4.3.5 Anticipating the next move: Practical Problems with pen and paper

While film cameras worked well for this population, there are clear improvements that could facilitate the inquiry. Because the images are small (3x5"), they are difficult to use in whole-class discussions. Students shared photographs by passing them around the room. Therefore, the class conversation often deteriorated into disparate discussions situated around images. If we had projected or enlarged the images, we may have been

better able to maintain a coherent class-wide discussion. Alternatively, we could have organized small group discussions that may have been just as effective.

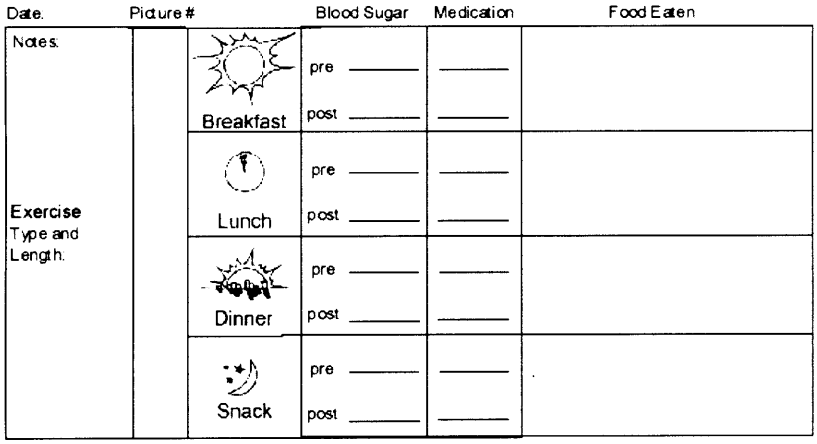


Figure 4.5: One page from the logbook that I designed and distributed to the class. The images were borrowed from another logbook designed at Boston Medical. This logbook incorporates both quantitative data (blood sugar, and dosage levels) with other descriptive information (exercise, food intake) and qualitative data (photographs). Taking medication and testing blood glucose usually occurs before or after meals. Therefore, I organized the data collection around when people eat. The hope was that once we had this information, we could see how the quantitative data correlates with patterns of behavior.

This format also limited the types of data I could include and the time frame I could work in. Because we were using disposable film cameras, we were never able to track other events that co-occurred with the images. I wanted to use time as the organizing principle for the data. I had hoped that if there was a way to track the time the photograph was taken, we would be able to synchronize the images with other pertinent information such as the blood sugar levels, exercise schedules and meals. I designed a paper logbook and label scheme for the disposable cameras to encourage people to attach temporal and other information. A sample from the logbook appears in Figure 4.5. During one class, I distributed these materials and asked participants to note the date the photograph was taken and/or the event pictured for each exposure and to record several categories of events in the logbook. While a few people used the logbook and others shot photographs, none did both. A partial solution, which may be adequate for this population, might be distributing film cameras with a timestamp feature. Another issue with using film is the time it takes to process and print the exposures. Patients may be more motivated to take pictures if they can see them immediately, and they could take more pictures within the duration of the course. These two issues, our inability to synchronize photographs with

other data and the processing time required, led me to investigate the potential of using digital cameras and data capture devices.

4.3.5 Summary

After the introduction of the photo-journal activity, the class changed in a number of ways. Students began to discuss diabetes with one another rather than simply addressing their questions to the teacher. They used the language and skills of the lecturers to analyze personal data. And some participants explicitly stated that documenting their familiar environment with a camera helped them view it with a new perspective. They became more aware of their personal practice and environment. The overarching theme is that we began to collapse the distinction between what people do to manage their disease each day and what they learn in the class. Patients incorporated their personal stories and examples from their lives into the class discussions. They applied their new knowledge to how they could change practice. This may help them revise how they make their decisions on a day-to-day basis. Still, the limits of these tools became apparent quickly. It was difficult to integrate the use of more than one type of data at a time, and the time lag that the film processing necessitated meant that people's images were less current and seemed less relevant by the time we looked at them. These issues motivated me to create software that may expedite the process.

5. Phase two: implementation and evaluation

In the previous chapter, I described diabetics using photography as a tool for reflection and learning. In addition to image data, diabetics already measure and record their blood glucose readings regularly. Although I tried to create paper-based tools to link images with blood sugar data, synchronizing that data with pen and paper was difficult. In this chapter, I explore how different types of data (blood sugar, images and annotations) could be consolidated into a single view. I created a web database that provides visualizations of quantitative and qualitative data for people to look at relationships between glucose values and behavior.

I describe my preliminary efforts and an evaluation of my tools with one diabetic. The first section discusses the structure of the web site, its functionality and the design rationale. In the second section, I describe one diabetic's history, the artifacts he produced with my tools and his reaction to using the site.

5.1 Implementation

I designed a database to navigate, visualize and add personal health related data. Patients capture images with a digital camera, test blood sugars with a glucose meter, and upload their data to a server. The web application organizes and visualizes the data according to the time they were captured. In this section, I describe the data capture devices, the infrastructure and design of the site and the way that data are retrieved and augmented through the site.

5.1.1 Data Capture Devices

We standardized the input into the system by providing users with a glucose meter and a digital camera. Additional information is entered by the user through an interface on the website. We chose the LifeScan FastTake meter to collect blood glucose data because of its compact size, popularity, and data storage, and data upload features. . Because many patients already use this model, we do not have to impose any additional changes to their

routine or retrain them to use a new meter. Patients can retrieve past readings by scrolling through the values on the meter itself or by uploading the data to a desktop machine through a serial port. For this project, patients upload and save their values into a default text file format specified by the manufacturer. Once the data is uploaded to a desktop machine with an Internet connection, the patient logs into the site and uploads the file. The text file is parsed, and the data is placed into a database and associated with the user's unique id and the time the measurement was taken. Users capture digital images. These images are uploaded to the user's directory on the server, and a link to each image, the time it was taken, and the user's ID is placed in the database. The user also adds other supplementary information through the website, as I describe below.

5.1.2 Site Infrastructure

For the site, I designed a MySQL database and an interface to it using PHP, a server side scripting language. The server scripts generate code that a client web browser can read or load. I used PHP to generate GIF image files, HTML and Javascript code. Javascript was used to handle client-side events and interactions. We hosted the site on a server running the beta version of Apple Computer's Mac OS X operating system.

I defined a table in the database for each type of information: user ID, blood sugar level, exercise, mood, and photographs. A unique timestamp and user ID define each entry in the database, besides those in the user table. This is the same user ID that the participant uses to login into the site.

5.1.3 Journal Visualization

The journal visualization represents the separate streams of data in a single interface. I created different views onto the data depending on the granularity of time Users see an overall view of their blood sugar data, and they can choose specific days to focus in on. The day representation includes a record of two factors that are thought to have an impact on blood sugar: exercise (time and duration) and food (as portrayed in photographs). I also included a gross measure of mood, as low blood pressure can cause irritability and mood swings. There is space to enter comments on for each day and each individual

photograph. Through this integrated representation of quantitative and qualitative data, patients can examine how different variables affect one another.

Figure 5.1 depicts an overall view of one diabetic's blood sugar data for one month. Days unfold from left to right; hours progress from top to bottom. Blood sugar tests appear as rectangles. The red rectangles are high readings, the gray readings are in the ideal target range and the blue ones are low values — the brighter the color, the higher the reading. The lower left of the screen displays the legend for interpreting the visualization, and the gray lettering below reports the overall statistics on the data set. This view emphasizes daily patterns in blood sugar fluctuations. In this case, high readings occur in the evening, low readings occur primarily in the morning. This representation can be compared to those in Chapter 2 (Figure 2.2.b) where Zach graphed some of the same data. Once the user views this representation, he or she can investigate a day of interest by pointing to it with the mouse. In figure 5.1, the 12th is selected.

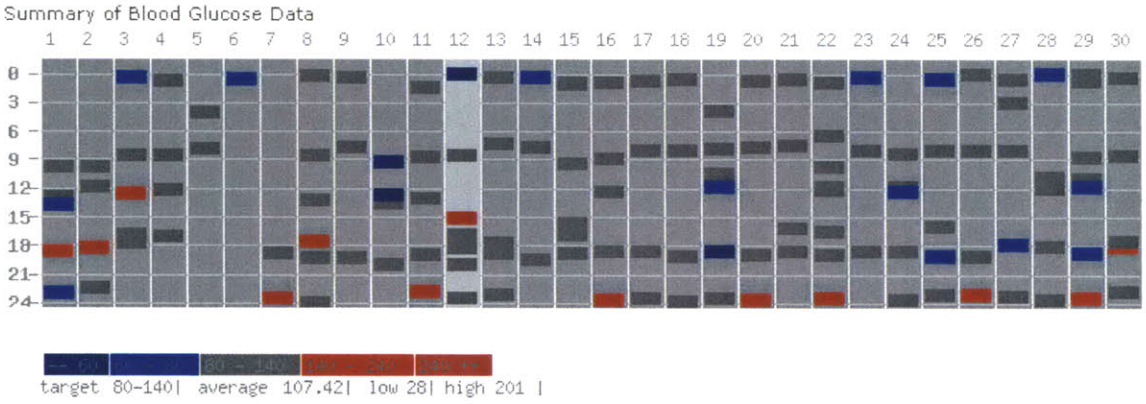


Figure 5.1 The overview of the blood sugar data. The days are represented by the vertical gray bar with hours of the day progressing from top to bottom. Each blood glucose test is represented by a rectangle. Blue rectangles denote low blood sugar; red ones are high. The mouse is currently over the 12th. Clicking on the day will show the corresponding day view.

I borrowed the main organizing principle of this visualization from standard logbook design. Meter manufacturers and physicians distribute logbooks to diabetics to record their values (Figure 5.2). Standard logbooks arrange data according to the time the

readings were captured. Specifically, each value links to a meal, assuming that glucose tests occur at eating time. This visualization shows daily patterns that emerge around mealtime. A row contains a day's worth of data; a column shows how blood sugar at one mealtime varies across days. Similarly, in my overview (figure 5.1) a column shows the day's data and a horizontal slice shows the values for a single time of day over multiple days.

This log differs from my representation in that it contains fields for insulin dosages. I chose not to include insulin to facilitate data capture. By limiting myself to blood sugar data (and images), I could access information directly from the meter (and the camera).

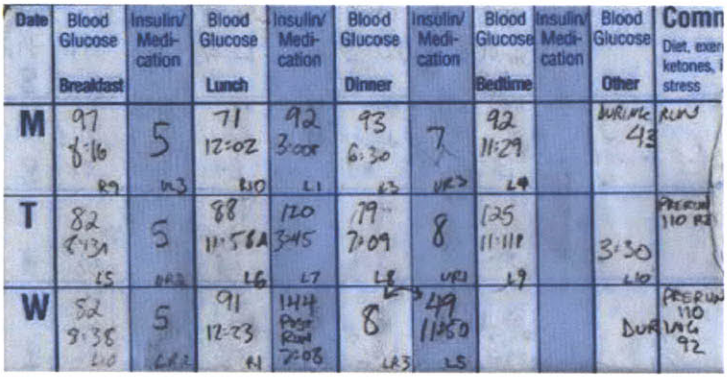


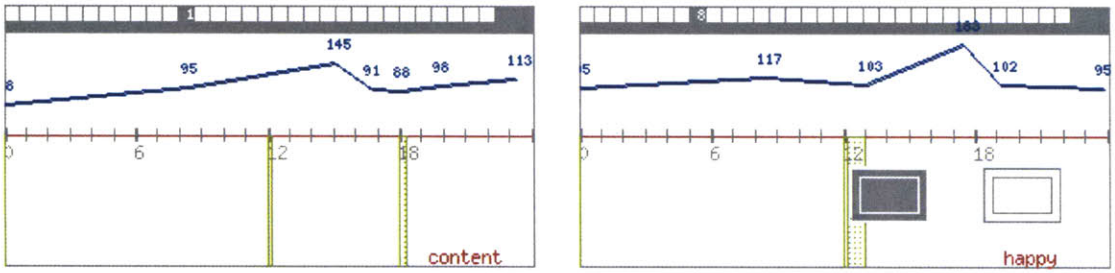
Figure 5. 2 A sample from a standard blood glucose logbook distributed by LifeScan with all meters. Each value is recorded in the field that corresponds to the current meal.

With fewer variables to visualize, I was free to be more specific about the time. I used a 24-hour clock to increase the flexibility of the visualization for two reasons. Firstly, patients do not only test at meals and other readings suggest baseline values for blood sugar. Secondly, diabetics do not necessarily eat at the same time each day, although doing so helps to minimize variation in glucose levels. This view onto the data describes the patient's routine and departure from it.

This representation also highlights when people tend to test their glucose. Physicians tell patients to vary the time of day they measure their glucose to ensure that they understand the entire day's fluctuations. For example, patients may experience dramatic drops in blood sugar at night but never know it because they do not test at the appropriate times.

This view points out holes in data collection as clearly as it shows the data present. Patients point and click their mouse on the day (column) to access more information.

The mouse rollover triggers the corresponding day view to appear on screen. Hours run along the x-axis on the horizontal line in the center of the graph. The blood sugar data is on the y-axis. Icons representing photographs appear along the bottom half of the graph according to the time associated with the picture. Users view the photographs by moving their mouse over the photo icon. Users can add more information to the day representation, such as mood or when they exercise, by inputting values into a form on the same screen. Exercise events show up as a green backdrop in the bottom half of the graph and mood is displayed in the lower right hand corner. Figure 5.3 shows two days. For the day on the left, the user did not take any photographs. On the day to the right, he shot two pictures. The photo icon on the left is highlighted to reflect that it has been selected. Once the user selects an image, it appears directly below. For both days in Figure 5.3, the user has entered two brief exercise events.



5.3a **5.3b**

Figure 5.3: Each of these two views represents one day's worth of data. Time runs along the x-axis, blood sugar run along the y-axis. An icon representing photographs appears in the appropriate spot on the time line depending on when the user shot the photograph. The user shot two photographs on the day represented in figure 5.3b; the one on the left is selected. Users augment the record with information about when they exercised which then appears as green rectangles, and a gross measure of how they felt that day is displayed in the lower right hand corner.

Within the day view, I place the image icons and blood glucose data on the same timeline. The highlighted image in figure 5.2b, for example, could be a picture of the

lunch that caused blood sugar rise graphed above it. This portion of the visualization highlights the connection between the quantitative and the qualitative data.

Figure 5.4 shows the journal interface. The user scans the overall view (a); selects a panel of interest with a mouse click; and chooses a photograph to view by "mousing over" a photo icon (b); the chosen photograph appears below (d). Once the user selects a day, she can add exercise events, annotations, or a description of mood through the text boxes and menus in (c). The day's annotations appear within the text window in (c) each time the user accesses that day. All other additional information becomes part of the day view.

The combination of photographs and blood sugar data in a single representation shows events that may impact the fluctuations in blood sugars. And the combination of blood sugar levels and the photographs may cue the recall of other co-occurring events. For example, a photograph of a volleyball court may trigger the recall of a picnic on that day or a sharp drop in blood sugar might remind the user about an afternoon run. If so, the user adds the appropriate annotation or event. The representation for each day updates as the user adds more information.

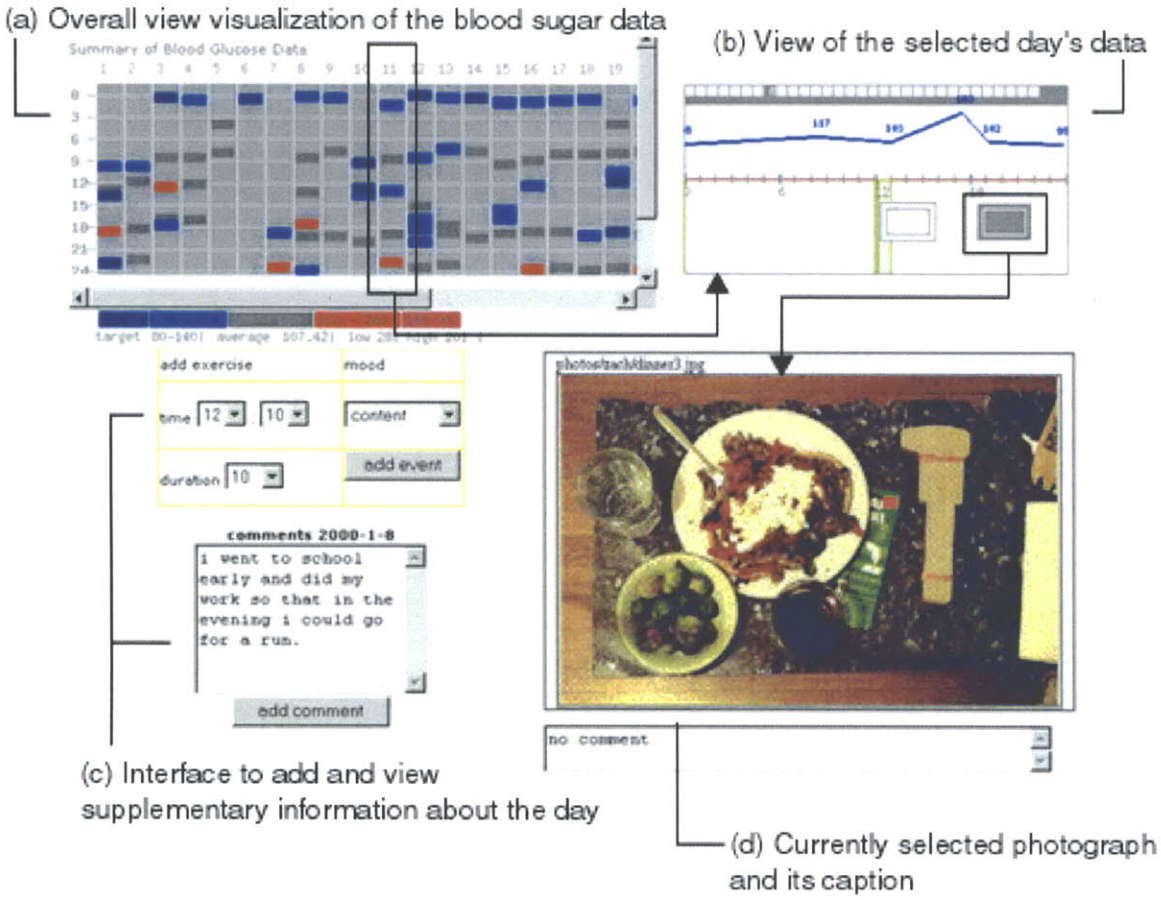


Figure 5.4 The journal page in its entirety; (a) Depicts the blood sugar levels over time; (b) is the day view currently selected; (c) the text fields and menus where users add data; (d) the currently selected photograph.

5.2 Evaluation

After finishing the web site, I evaluated the tool with a type I diabetic who I will call Dan. In this section, I describe Dan's background, his data, what he created with the web tools and his reactions to using the software.

5.2.1 Method

Dan shot pictures over a two-week period and uploaded five weeks of blood sugar data from his meter. We conducted two interviews, one before and one following his participation. In the following sections, I will describe some of the content of those interviews, present his data, discuss his reaction to the project and to the visualization of

his blood glucose values, and show the pictures he took and how they juxtaposed with his blood sugar data.

5.2.2 Brief biography of the subject

Dan is a type I diabetic. He is now 20 years old and has been diabetic for 10 years. Ever since he was diagnosed at the age of ten, he has administered his own insulin and helped manage his blood sugars. For the last two years, Dan has been on a pump that delivers insulin according to a set schedule through a small needle attached to the abdomen. Dan tests his blood sugar often, 4 or 5 times a day. He says that sometimes his values are high, but his blood sugars have improved since going on the pump. In his own mind, Dan is a fairly responsible diabetic, but from his data and his other comments, Dan clearly does not have "control" over his blood glucose levels.

5.2.2 Initial interview

Both Dan's data and his comments during an interview indicate that he is not managing his diabetes as well as he thinks he is. A test measuring his average blood sugar over a 6 – 8 week period indicates that he has sustained high blood sugars[3]. From this short evaluation, Dan seems to have some misconceptions about how he should care for himself.

Dan's does not perceive himself being "out of control" partially because of the way he defines good glycemic control. While doctors at Boston Medical define 80-140 mg/dl as the ideal target range for blood sugar, Dan's personal target range is 120 – 150 mg/dl, and

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[3] In addition to the blood sugar test diabetics administer themselves throughout the day, periodically their physicians will order a hemoglobin A1c (HbA1c) test. The HbA1c indicates the average blood glucose levels over the last 60-90 days (MiniMed, 2001). Below 7.2 % is considered ideal to avoid long-term complications; 7-8 % indicates good control. Over 8% and physicians should take action (Wong, 1999). Before going on the pump Dan's test results were in the low "9's." Over the last 2 years the level has decreased to high sevens – low eights; the most recent reading was 8.2.

he states that he is satisfied if his blood sugar is below 200. Dan also said that he can and does consume 300 calories a day. Although I argue in chapter 4 that there is no one set diet for a diabetic, there are clear guidelines about how *much* a diabetic should consume. Physicians stipulate that a man of Dan's weight should consume about 2560 calories a day (EndocrineWeb.com, 2001). If his estimate is close, Dan eats an excess of at least 440 calories a day. When asked if he conforms to a good diet, he replies that he does and that his diet works for him both physically and personally. The discrepancy between what he thinks is a suitable diet and what research claims is appropriate for a type I diabetic his size may account for some of his difficulties. He reported that even when he did exercise and follow a good diet during high school, his sugars did not reflect it. But what it means to him to follow a good diet is unclear.

To control his disease, Dan makes changes based on measurements of the moment without regard to long-term trends. He likes the pump because it allows him to make fast adjustments that seem to have an immediate effect. He stated:

> Since the pump it's been a lot better, just because when [blood sugar] does get high I can do something about it more quickly. But, I think it's just been the pump. Like seeing it, seeing what I do has more of an effect positively, it makes me feel a little better.

Dan seems to change his insulin dosage level and his care on a point-by-point basis without a sense of long-term patterns, changes, or trends. If his blood sugar is high or he is about to eat a large meal, he takes more insulin. Dan's strategy seems to "work" in his mind because of some small short-term changes he can affect, but his system is detrimental to his long-term health. Instead of thinking about how his behaviors affect his glucose levels, he uses insulin to counteract his "unhealthy" behavior. Visualizing data over time and examining the factors that influence blood sugar may help him revise his care strategy.

5.2.2 Study Results

Dan used this opportunity to investigate how everyday situations affect his blood sugar. Even before I asked him anything, Dan stated that participating in this project made him more "aware of certain things." He told me that he was curious about a particular

situation: He wanted to know whether dancing is strenuous enough to lower his sugars. After being at a party and dancing, he took a picture and recorded his blood sugar to see if there was any effect. It turns out he did not see a change.

He also "measured" how particular foods affect his blood glucose. He took a picture of leftover pizza because he has noticed that pizza typically raises his blood sugar. Sure enough, he took the picture at a moment where his levels were particularly low, and during the next four hours, his blood sugar shot up by 200mg/dl. He explained that he did not know how many grams of carbohydrates are in pizza, so he could not account for them with the correct insulin dosage.

Dan was surprised by his blood sugar data plotted over time after he uploaded his values to the site. The measurements were organized in the data visualization described in section 5.1. The visualization shows five weeks worth of values (figure 5.4). He commented on what he saw.

> There definitely seem to be more of the really high numbers than I thought. Because sometimes there will be a couple in a row, or a few in a day, but I never realized there were quite so many.

The extremity of the data genuinely shocked him. At first he had no explanation, but when pressed, he said he wasn't taking enough insulin. Before we reviewed the data, I had asked him to characterize his daily patterns and overall data trends. He predicted that his blood sugar is high at night and in the early morning and lower during the day. The visualization revealed that about 1/3 of measurements are quite high (240 or above), and these values appear throughout the day in addition to the morning. Still, Dan stuck with his original theory. When asked how his prediction matched up with the data visualization, Dan replied, "I definitely see it." He pointed out that blood sugar is usually high in the morning. He neglected to comment on the other high readings.

Unfortunately, he failed to investigate the only late evening reading that was within the target range. On one day, Dan took a picture of himself right before he went running. After he exercised, his blood sugar dropped from 231 (a high level) to 104 mg/dl (a level within the target range). This serves as a counter example to his theory that blood sugars

were always high in the evening. The presence of this anomaly demonstrates how much exercise affects blood sugar.

Dan usually monitors his sugars on a point-to-point basis; he does not review his long-term data. He stated that he is more likely to consciously raise his blood sugar to avoid risk of fainting in the short-term than to be nervous about high readings. He knows that hyperglycemia is damaging eventually, but he remains more concerned with his present state. He has grown accustomed to seeing high readings, but it is still surprising to see the high readings cumulatively.

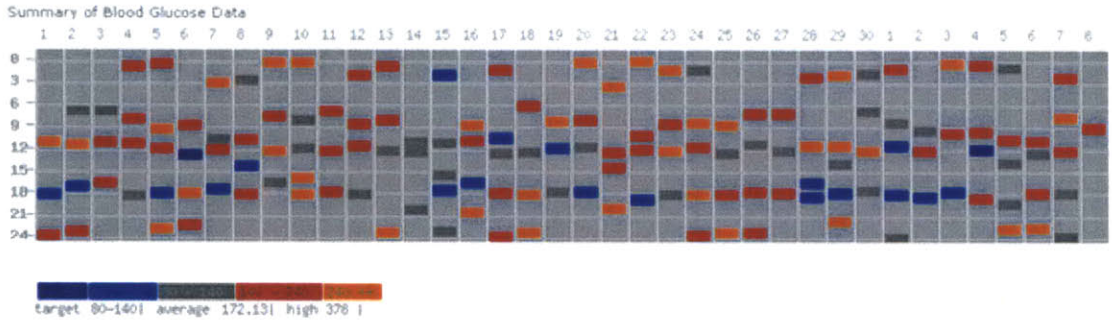
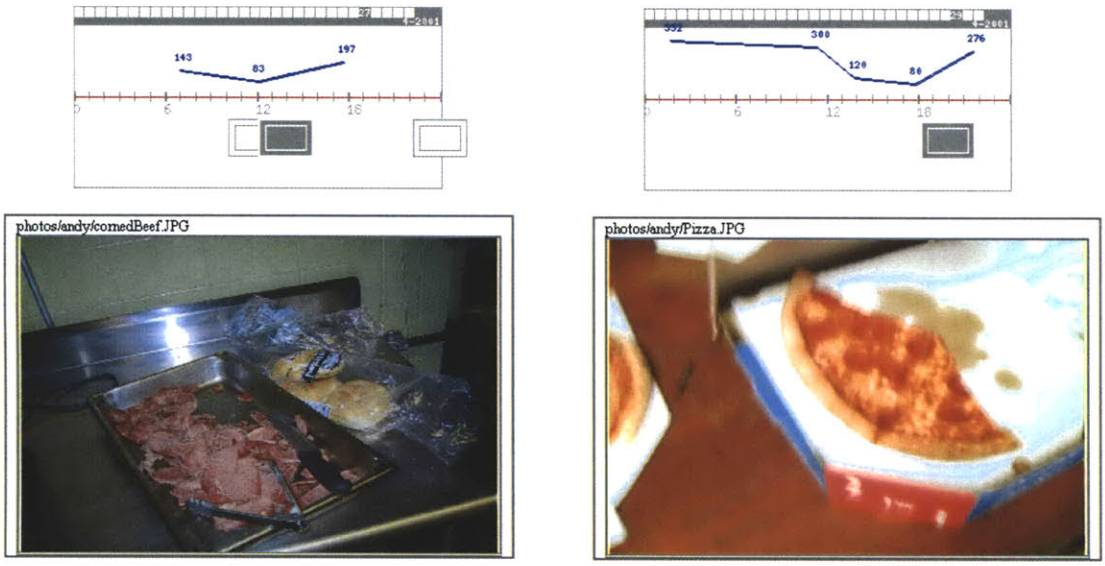


Figure 5.5 Dan's data for a five-week period. Dan's levels are high throughout the month. The visualization discounts his theory that his levels rise at night and in the early morning and fall during the day.

Even with a small set of image data, plausible correlations between activity and glucose level begin to emerge. Dan only took a small number of photographs, but each of the pictures of food and exercise link directly to a change in blood sugar. He photographed meals of pizza and corned beef, both of which were followed by increases in blood glucose (figure 5.5). Likewise, his photograph of going running corresponded to a dramatic drop in blood glucose level.

Dan is on the pump that ideally helps reduce large fluctuation in blood sugar. His sugar level should remain within the range of 70-140 before and two hours after meals (WebMD, 2001). But Dan's data visualizations suggest that his behavioral choices (what he eats, when he exercises) impact his blood sugar. Eating certain foods drive blood sugar

levels out of normal range. The relationship between behavior and blood sugar points to the problems in Dan's care.



5.6.a **5.6.b**

Figure 5.6 Two pieces from Dan's record. Each figure, 5.6a and 5.6b, shows an image Dan captured along with the graph from that day of blood sugar values. In both cases, eating (the meal pictured) resulted in blood glucose increases. In 5.6a blood sugar rose 115 mg/dl, in 5.6b, blood sugar shot up 195 mg/dl. Although the time lag between testing differs, the user could infer that pizza had a larger effect on blood sugar than the corned beef.

5.2.3 Discussion

Even from Dan's small data sample emerged experiences of note. Dan used the tools to examine particular aspects of his environment and he freely reported his results. He formed hypotheses and investigated them. Through this inquiry, he formed some explanations for fluctuations in his blood sugar.

The artifacts themselves suggest that qualitative data could suggest explanations for the changes in quantitative data. Images of food synchronized with rises in blood sugar and photos of exercise corresponded to drops in blood sugar. The images and data jointly

suggest that behavioral choices impact Dan's blood sugars, despite being on a an automated insulin regiment.

Even with this evidence, Dan rigidly resisted thinking about how his behavior impacts health. He attributes his high blood sugars to a lack of insulin when, in fact, he is probably overeating. When asked how he manages his blood sugar, he says he compensates overeating with higher doses of insulin. At one point, he did acknowledge that this might be risky behavior but remains unwilling to give up his lifestyle. Still, viewing his data over time did give him a sense of how high his levels are. We only had one opportunity to meet after Dan input his data. In that single conversation, Dan did not revise his story entirely.

Capturing and visualization data is only the beginning of a process. In our first conversation, Dan said he is doing pretty well living with diabetes and his physician generally agrees. The visualization pointed out that his difficulties are real. To get Dan to incorporate this information into his self-explanation requires further conversation and introspection. A system like this could lead towards increased communication between patient and physician. Physicians look at glucose readings now, try to give feedback. Supplementing those data with illustrations of activity, physicians could possibly get a better understanding of lifestyle, and make more informed recommendations to patients. The tools increased Dan's awareness of his practice, but he did not take the next step toward implementing what he saw. Without the social support of a class or a physician, Dan did not shift his understanding of his current behavior.

6. Conclusion

6.1 Summary

In this thesis, I focus on how diabetics form and revise theories about health practice. I created tools for patients to develop self-explanations based on data captured from their lives. Often times, people proceed through their day without any conscious awareness about how actions affect general well being. In the case of diabetics, daily decisions have clear consequences for health; blood sugar changes calibrate those consequences. In this work, I assume that patients will be more likely to adopt responsibility for managing diabetes if they see correlations between their actions and blood sugar fluctuations.

Currently almost 6 percent of America's population has diabetes and the number is continuing to grow (Clearinghouse, 1999). For most of these cases, diabetes could be avoided or controlled by implementing healthy daily behaviors (Uusitupa M., 2000). Unfortunately, most patients resist changing their diet, exercising, or attending to health needs. Diabetics who sustain high blood sugar levels risk increased rate of heart attacks, strokes and amputations.

Typically when diabetics struggle with blood glucose control, physicians and specialists intervene with the "right explanation." Both in classroom settings and individually, health care providers lecture diabetics on appropriate behavior and the "reason" for their difficulty. In this work, I created tools for diabetics to construct and reevaluate their own explanations about their current health. Through examining daily activity and the effect of their actions on overall health, patients may be more willing to implement behavior changes. During this project, patients collect information on their own situation and by extracted evidence from personal data archives they formulate explanations and theories about health practice.

I introduced diabetics to an unusual data capture device, the camera. Through shooting photographs and reviewing these images, diabetics individually increased their "awareness" of what is in their environment, the scope of their daily choices, and the decisions they make each day. Within a class on diabetes, students reinforced what they

learned in the course and mentored one another drawing from personal experience. They effectively bridged the divide between the facts they learned in the course and their daily practice.

As an effort to elucidate the correlations between blood sugar and concurrent activities, I designed tools that link photographic evidence with blood sugar data, annotations, and health related events. To explore this idea, I consolidated different streams of data into one web-based data visualization. Users navigate through their blood sugar levels, images, and add other events they recall. From this view, they investigate the long-term effects of their actions, as well as the immediate implications of each choice they make (every meal they ate, every breath they take).

6.3 Interpreting the results

Recent theories of situated cognition suggest that learning is much more than having knowledge in one's head; Learning is about activity, about increasing one's abilities to use tools and negotiate with others (Brown, Collins, & Duguid, 1990; Lave & Wenger, 1991; Rogoff, 1990).. Moving to new levels of performance often requires assistance from others (Vygotsky, 1978); in our case, this additional support could be from a parent, physician, fellow diabetic, or other expert. Tool use may also increase performance; just as a calculator helps one perform mathematics more competently, a glucose monitor gives diabetics access to new materials to think with.

Diabetics are often taught about their disease through classroom lectures. Simultaneously, they use glucose meters as tools to collect physiological data. I changed the current situation in two ways. First, I introduced a new tool to collect personal data, the camera. Second, I increased communication between people to provide opportunities for argument, discussion and possible conceptual change. Within a diabetes classroom, photographs functioned as new artifacts for reflection. In this setting, people began to revisit and revise theories about their own personal practices. Although I do not have enough data to claim that collecting and reflecting on image and other data makes people healthier, my study does suggest that self-explanation and reflection in the classroom changes the class dynamics and conversations in informative and useful ways. Patients

solidified their understanding of course content, they mentored one another on health practice and they articulated ways to alter their routines.

In the web version of my project, I preserved the basic set of tools — cameras, images, and logbooks — and created more efficient ways to synchronize and display information. Butthe collaborative aspect of the project was missing during this phase of the research. The web tools provide the means to analyze behavior and blood sugar values in conjunction with one another. Although this may present more compelling evidence for the impact of actions on blood sugar fluctuations than photographs alone, the tools are not enough. The diabetic reported feeling more "aware" of his actions than he had before the project. But without other people to interject their analysis, he never reworked his explanations of his situation. Unlike the patients at the hospital, Dan's "awareness" did not lead him to reinterpret the significance of his actions.

While phase 1 and phase 2 of my work differed in many ways, there is some basis for comparison. Both the students in the class and Dan captured images and analyzed them. The students in the class seemed more open to rethinking their conditions than he was. One reason is that their assumptions were continually being questioned and challenged by others in the class and by the instructor. They were challenged to respond to other people's critiques. Dan, working alone, did not have the resources to become more critical and more responsible. Dan holds to his original hypotheses, despite contradictory evidence seen in his data visualizations. In a sense, he is a classic case of confirmation bias (Klayman & Ha, 1987), only seeking evidence to support his original theory while ignoring disconfirming evidence. Dan's hypotheses are resistant to change, but a doctor or other expert may have been able to challenge his views, providing the social scaffolds necessary for him to rethink his behaviors. Through social interactions like those described in Chapter 4, Dan might be able to reconsider and update his own analyses and interpretations

6.3 Future work

The web tools pointed out the correlations between action and blood sugar change, but this evidence was insufficient to enact modifications by the isolated user. In the future,

these tools could be accompanied by collaborative learning opportunities like those in the classroom. To get patients to make the leap from "awareness" to reevaluating theories seems to require a social intervention. In my future work, I will explore that scenario.

I began the design of a systematic analysis of these web tools with a physician, Dr. Hector Sobrino. Through organizing a class or group, similar to the one held at Boston Medical, we would reintroduce the collaborative, mentorship element into this project. Patients could collect digital images and blood sugar data over time and meet regularly to discuss data and results. A diabetes instructor would suggest as well as address questions that arise from the data collection process. In an extended study, we could evaluate if reflection and self-explanation effect how patients make daily decisions, and, if so, what impact it has on physical health. The hospital study suggested that images as data function to increase awareness and explanations of practice. A longitudinal study could examine the long-term benefits of such an inquiry.

Appendix A
Interview outline during part 1

The interview will cover three topics:

1. Compliance
2. Community
3. Reaction to pictures

Compliance:

What's the most difficult thing that you have to do to care for yourself?
Do you do it anyway? If so, always?
Why?
Does monitoring your blood sugar, diet and exercise affect your health?
How?
Is there anything that you or others have done or said that has made you change how you care for yourself?

Community/Communication:
Do you talk about diabetes?
Who is involved in your care?
What aspects?
Who do you talk to about your problems?
Who do you discuss diabetes with?
How much time do you spent discussing diabetes?
Does your family/friends understand your diabetes?
Would you like them to?
What issues in particular?
Who is the most helpful?
What type of support is the most helpful to you?
Are there any issues regarding your diabetes which are hard to communicate?
To your doctor?
To family or friends?
Would increasing your communication with others help you manage your disease?
Do you have friends or family with diabetes?
If so, are they a source of information?

Photo-journal:

What type of technologies do you use now to record your values?
Have you ever considered using or used any other technology?

What did you think about recording your actions with a camera?
Did taking pictures of your behavior have any effect on you?
Do you feel the same way about your actions now that you have taken these pictures?

Did you feel comfortable sharing your pictures with other people?
Did people react the way you expected?
Did the pictures affect the way you talk about your experience living with diabetes?

Appendix B
Introductory Questionnaire for part 2

Name_____
Weight _____lbs.
Age _____
Race _____
Years of education _____
What type of diabetes do you have? _____
When were you diagnosed? _____
When did you begin treatment _____?

Personal Care

On average how many times a day do you test your blood sugar?
_____

If you are on insulin, do you change you insulin level according to blood sugar fluctuations?

Do you exercise? Yes☐ No☐
If so, circle the type of exercise you do and state how often you do it.
Strengthening _____
Aerobic _____

Do you now follow a diet that you think is appropriate for diabetes? Yes☐ No☐
Do you discuss you diet with a dietician or other health care professional? Yes☐ ☐
No
Is your current diet working for you in terms of your health and for you personally? Yes☐ ☐
No

Medication

Insulin Yes ☐ No ☐
Dosage:
_____Oral
medication
Which one(s) and at what
dosage?_____
Has your dosage changed during the last 2 months? Yes☐ No ☐ If so, could you please explain why it changed and to what new drug?
_____

Have you had a HA1C test recently? Yes☐ No☐ If so, do you know the result?_____ Date:_____

Appendix C
Final Questionnaire for part 2

Blood Sugar Control

What is your target range for your blood sugar?

_____

Without reviewing your log book, what would you say was the range of your blood sugar levels over the last week?

_____

How many times did you have high readings this week?

_____

How many times did you have low readings?_____

Did you know the cause of these fluctuations? Yes ☐ No ☐ Could you please explain those causes?

_____

_____

_____

Did these high or low events routinely happen during one part of the day? Ye☐ N☐

When?

_____

Study

Why are you interested in participating in this project?_____

What's your objective?_____

Are there any areas of your personal care that you would like to improve, like your diet, your exercise schedule, your weight, or just generally controlling you blood sugar levels? Please list them._____

Is there anything else you are interested in exploring/learning about?

_____

Technology

Do you have access to a computer on the internet? Yes☐ No ☐

Do you work with computers or use them daily? Yes☐ No ☐

Do you use the web? Yes ☐ No ☐

Have you ever uploaded your values from your glucose monitor to a computer?

Yes☐ No ☐ How often? _____

Have you ever used a digital camera?

Yes☐ No ☐

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