

Self Management of Medication and Diabetes: Cognitive Control

Helen Altman Klein and Amy R. Meininger

Abstract—The healthcare industry strives to improve the technical work of healthcare providers in hospitals. In contrast, the more common home treatment tasks like managing prescription medications and complying with the complex demands of life-threatening diseases such as Type II Diabetes receive little attention. Treatment and prevention decisions are in the hands of patients and often mismanaged. Available commercial information sheets, designed to support prescription self management, are incompatible with patient perceptual and cognitive capacities. We show that material that is sensitive to the perceptual and cognitive capacities of potential users is more usable and is preferred. A review of existing training for diabetics identified compliance barriers. Many patients do not understand the dynamics that controlled their disease and so make poor decisions. Available training provides rules and procedures, but little about the dynamic demands of maintaining stability within parameters. We explored using control theory and incorporating a mental model of diabetes into rule-based training. This promises to improve the effectiveness of self management. These two naturalistic investigations confirm the importance of field studies and of using patient informants to understand the demands and opportunities that accompany medical self management.

Index Terms—Cognition, cognitive engineering, cognitive task analysis (CTA), compliance, control theory, diabetes, field studies, healthcare, medical self management.

I. INTRODUCTION

THE PURPOSE of this paper is to describe field studies of the way that patients manage their own treatment regimens, outside of the structure of hospitals and recovery centers. We view patient self management as a control task, akin to the control of petrochemical plants or manufacturing processes. We found that patients are given little by way of tools or training to prepare themselves for this self management. For a variety of reasons, the healthcare system has chosen to direct its attention to improving treatment in hospitals and recovery centers, rather than in the patients' homes.

Hospitals employ an array of complex devices and systems to deliver treatment. Technical advances help to monitor and administer medication, reduce the invasiveness of surgery, design and configure equipment for optimal use, and insure accurate records. Together these advances help safeguard patients against error and provide daily miracles. We can maintain and transplant organs and even install artificial organs. The impact of engineering extends from relatively simple monitoring devices to overarching healthcare delivery plans.

Manuscript received March 31, 2004; revised July 20, 2004. This paper was recommended by the guest editors of this special issue.

The authors are with the Department of Psychology, Wright State University, Dayton, OH 45435 USA (e-mail: Helen.klein@wright.edu).

Digital Object Identifier 10.1109/TSMCA.2004.836791

In a parallel way, the training of healthcare professionals incorporates innovative engineering solutions ranging from realistic models used for anesthesiologists, to interactive computer-based packages that allow practice with complex diagnoses, to simulation exercises. These efforts have had an enduring impact on hospital based medical treatment.

The work on self management reported here is based on a disturbing reality: while hospitals and medical training are improving exponentially, home healthcare, administered by patients and their families, is not showing this same progress. The self-managed care sector of the healthcare system has received little attention even though it is the most common and cost-effective form of treatment for many diseases and conditions. While hundreds of thousands of people undergo surgery each year, there are billions of instances of patient-administered prescription medication [1].

This paper explores two examples of self-managed care: prescription medication and blood sugar maintenance in Type II Diabetes. Medications can restore health and prevent disease. They can also cause harm if not properly administered. Each medication carries restrictions with regard to food, interactions, and side effects. Similarly, while professionals treat some diseases and conditions, others like diabetes are managed at home by patients. We discuss the compliance problems associated with medical self management and the potential offered by human factors and cognitive engineering for improving the quality of this care.

In considering problems with self management, it is customary to blame the patient or the system for compliance failures. We are told that many patients are unable or unwilling to make needed life-style changes. We are told that rushed physicians, lack of education, and patient denial contribute to failure. While this is correct, it is not the whole picture. Self-medication presents serious cognitive challenges. Diabetes self management is a complex control task. We need to consider information and decision-making demands as well as the process by which these tasks are conveyed to new "users."

First we will describe field research on prescription medication self management and then we will describe field research on diabetes self management.

II. PRESCRIPTION MEDICATION COMPLIANCE

Prescription medications are a large part of outpatient treatment in the United States. There were 3.3 billion retail prescriptions sales in 2001 and by 2004, they estimated the number to exceed 4 billion [1]. Patients may receive accurate information from pharmacies but are often noncompliant. It is estimated that half of the prescriptions written in the U.S. annually do not end

TABLE I
RECOMMENDATIONS FOR READABILITY AND UNDERSTANDABILITY

Readability		Understandability
Physical features	Cognitive features	Organizational features
Use sans serif font (Helvetica)	Present information in an explicit and familiar manner	Organize material in a standard format
Use 12 to 14 point	Use simple language	Use small, discrete sections
Limit number of sizes and styles	Avoid jargon	Use directive cues
Use high contrast	Avoid negatives	Use headings
Use of capital letters, mixed, and small letters	Avoid inferences	Space between sections
Reduce lateral masking	Use active voice	Use list format rather than prose paragraph formats
Left justify	Use short sentences	Consider graphics - mixed evidence
Color considerations	Use appropriate reading level	

up being administered correctly [2]. This misuse contributes to many medical problems.

In a series of studies Klein and Isaacson investigated an alternative explanation: patients fail because they lack understanding of proper usage and precautions [3]. When information is hard to read and understand, compliance suffers [4]. Treatment can be ineffective and the patient may experience side effects and complications. While all users benefit from clear, easy-to-use information, patients with lower reading abilities or with age-related declines particularly benefit.

Human factors and cognitive engineering both use scientific research to solve problems people face at work and at home. Like poor directions for other products, poor medication directions can interfere with correct use. This research studied the usability of prescription information provided by pharmacists and explored how this information might better be provided.

First, patients were interviewed to tap their understanding of needed self management [3]. Using cognitive task analysis (CTA) and critical decision methods procedures [5], [6], we traced each informant's experiences with one or more medications from initial prescription by the physician, to interchanges with pharmacist, and input from other sources. Finally, the interview explored anomalies, confusions, and concerns, and asked about storage and interactions.

Our interviews identified regular and potentially dangerous gaps in knowledge. We found a range of difficult decisions, including dosage, timing, interactions with food and alcohol, and reactions to missed administrations. Several interviewees reported that they were not sure if a medication to be taken every six hours required them to wake up in the middle of the night, and they commonly waited until they woke up to take the next dose. Few remembered medication interactions, many ignored information about "taking on a full" or "take on an empty" stomach. Many used nonprofessionals to help them make difficult decisions. Several interviewees reported that when the dose was a teaspoonful of the liquid medication, they paid careful attention to the first measured administration. They would try to recall what a teaspoon amount felt like when "swigging" subsequent doses from the bottle. This procedure does not insure the correct dosage.

Next, directions were collected for three medications provided by community pharmacists [3]. The material was ana-

lyzed in terms of physical, cognitive, and organizational features [7], [8]. The results showed deficiencies readily apparent to anyone trying to read the instructions packed with almost any medication. Visual features, size, font, alignment, and contrast affect readability. Poor layout posed a particular problem for older adults and for use in poor lighting. Understandability was also compromised. Based on sentence and word lengths, the material often exceeded the fourteenth grade level—a challenge particularly for people who are sick or anxious. The prose format and presentation order made it difficult to organize ideas. The material available at community pharmacies had serious gaps in matching users' needs and capacities.

The researchers, then, developed human factored sheets identical in content but consistent with the recommendations outlined (see Table I). To increase readability, a 14-point font, printing with a high-quality ink jet printer was used. This is particularly helpful for older readers. Following research guidelines, content was rewritten to an eighth-grade reading level using shorter sentences, simpler words, active rather than passive tense and positive rather than negative statements [9], [10]. Consistent with good practice, the new information used list rather than prose format with boldfaced headings and set apart bulleted possible side effects in "minor" and "serious" boxes for easy scanning [11]. A commercial sheet and the parallel "human factored" sheet are shown in Fig. 1. In the studies that follow, contrast was augmented for the commercial sheets.

Comparisons were made between the commercially available and human factored material. Sixty-two college students, aged 18 to 30 years old participated. Each participant saw one commercial- and one human-factored sheet, each for a different medication. Participants studied the sheets and answered questions while referencing the sheet as needed. Reading times were faster ($t(61) = 10.32, p < 0.001$) for the human factored (77.1 s) than for the pharmacy sheets (111.8 s). Test times were also faster ($t(61) = 4.81, p < .001$) for the human factored (122.5 s) than for the commercial sheets (150.8 s). Most important, accuracy was higher ($t(61) = 3.04, p < 0.003$) for the human factored (8.1 correct) than for the commercial sheets (7.5 correct). Finally, participants judged the human factors sheets to be "easier to remember," "easier to find information," and "easier to use" all significantly higher ($p < 0.001$). Of those

PATIENT INFORMATION LEAFLET DRUG NAME: SUNIX 5MG TABLET	Patient's Name																						
ACE INHIBITORS - ORAL																							
<p>USES: ACE inhibitors prevent certain enzymes in the body from constricting blood vessels. This helps to lower blood pressure and makes the heart beat stronger. This medication is used to treat hypertension (high blood pressure) and heart failure.</p> <p>HOW TO TAKE THIS MEDICATION: This medication may be taken without regard to meals. Take it exactly as prescribed and try to take it at the same time each day. Do not stop taking this medication without consulting your doctor. Some conditions may become worse when the drug is abruptly stopped. Your dose may need to be gradually decreased.</p> <p>It is important to continue taking this medication even if you feel well. Most people with high blood pressure do not feel sick.</p> <p>SIDE EFFECTS: Dizziness, headache, diarrhea, constipation, nausea, fatigue, or dry cough may occur the first several days as your body adjusts to the medication. To avoid dizziness and lightheadedness when rising from a seated or lying position, get up slowly.</p> <p>Inform your doctor immediately if you develop chest pain, difficult breathing, skin rash, tingling of the hands or feet, swelling of the face, lips or tongue or yellowing of the skin or eyes while taking this medication.</p> <p>PRECAUTIONS: Avoid "stimulant" drugs that may increase your heart rate such as decongestants or caffeine. Decongestants are commonly found in over-the-counter cough and cold medicine.</p> <p>Consult your doctor before using salt substitutes.</p> <p>Limit your intake of alcohol and use caution when exercising or during hot weather as these can aggravate dizziness and lightheadedness.</p> <p>Be sure your doctor or dentist knows your complete medical history especially if you are planning to undergo any medical or dental procedures.</p> <p>This medication has been known to cause fetal injury and possibly death when used during the second and third trimesters. If pregnancy is suspected, stop taking the drug immediately and notify your doctor. Since this drug appears in breast milk breast-feeding is not recommended.</p> <p>NOTES: It is important to have your blood pressure checked regularly while taking this medication. Learn how to monitor your blood pressure. Discuss this with your doctor.</p> <p>MISSED DOSE: If you miss a dose, take as soon as remembered; do not take it if it is almost time for the next dose, instead, skip the missed dose and resume your usual dosing schedule. Do not "double-up" the dose to catch up.</p> <p>STORAGE: Store at room temperature away from sunlight and moisture. Do not store in the bathroom.</p>	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="padding: 2px;">SUNIX 5 mg Caplets</td> <td style="padding: 2px;"></td> </tr> <tr> <td colspan="2" style="padding: 2px;">Instructions: Take x pills x times a day.</td> </tr> </table> <p>Uses: An Ace Inhibitor Drug. (ACE) Lowers blood pressure and strengthens heartbeat. Used to treat high blood pressure and heart failure.</p> <p>How to Take: Can be taken with or without food. Take at the same time each day. Keep taking until the prescription is used up, even if you feel well. Most people with high blood pressure do not feel sick. You may get sicker if you abruptly stop taking the drug.</p> <p>Missed Dose: Take as soon as you remember. If it's almost time for your next dose skip the missed dose. DO NOT take two doses to catch up.</p> <p>Storage: Room temperature away from moisture and sunlight. DO NOT store in the bathroom.</p> <p>Possible Side Effects:</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td colspan="2" style="padding: 2px;">Serious- contact your doctor for:</td> </tr> <tr> <td style="padding: 2px;">• Chest Pain</td> <td style="padding: 2px;">• Skin rash</td> </tr> <tr> <td style="padding: 2px;">• Difficulty Breathing</td> <td style="padding: 2px;">• Tingling hands or feet</td> </tr> <tr> <td style="padding: 2px;">• Swollen face, lips, or tongue</td> <td style="padding: 2px;">• Yellowing of the skin or eyes</td> </tr> </table> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td colspan="2" style="padding: 2px;">Minor- contact your doctor if these do not go away:</td> </tr> <tr> <td style="padding: 2px;">• Upset Stomach</td> <td style="padding: 2px;">• Dry Cough</td> </tr> <tr> <td style="padding: 2px;">• Headache</td> <td style="padding: 2px;">• Constipation</td> </tr> <tr> <td style="padding: 2px;">• Fatigue</td> <td style="padding: 2px;">• Diarrhea</td> </tr> <tr> <td colspan="2" style="padding: 2px;">• Dizziness If you get dizzy when rising, get up more slowly.</td> </tr> </table> <p>Warnings: Avoid Stimulants such as CAFFEINE or DECONGESTANTS (found in many cough and cold medicines). Do not use SALT SUBSTITUTES without doctor's permission. ALCOHOL may make you dizzy. Limit drinking. Be careful exercising and in hot weather- you may get dizzy. DO NOT take while PREGNANT. May harm fetus. Do not BREAST FEED. This drug will appear in breast milk.</p> <p>Check your blood pressure regularly while taking this drug. Be sure your doctor and dentist know your complete medical history and ALL medications you are taking.</p>	SUNIX 5 mg Caplets		Instructions: Take x pills x times a day.		Serious- contact your doctor for:		• Chest Pain	• Skin rash	• Difficulty Breathing	• Tingling hands or feet	• Swollen face, lips, or tongue	• Yellowing of the skin or eyes	Minor- contact your doctor if these do not go away:		• Upset Stomach	• Dry Cough	• Headache	• Constipation	• Fatigue	• Diarrhea	• Dizziness If you get dizzy when rising, get up more slowly.	
SUNIX 5 mg Caplets																							
Instructions: Take x pills x times a day.																							
Serious- contact your doctor for:																							
• Chest Pain	• Skin rash																						
• Difficulty Breathing	• Tingling hands or feet																						
• Swollen face, lips, or tongue	• Yellowing of the skin or eyes																						
Minor- contact your doctor if these do not go away:																							
• Upset Stomach	• Dry Cough																						
• Headache	• Constipation																						
• Fatigue	• Diarrhea																						
• Dizziness If you get dizzy when rising, get up more slowly.																							

Fig. 1. Pharmacy- and human-factored instruction sheets.

who expressed a preference, 54 of 60 preferred the human factored sheets. Those who selected the commercial sheets incorrectly assumed that they had more information. In this young sample, the human factored sheets were more effective and they were preferred.

Next, 41 healthy older adults aged 58 to 87 years old and living independently in the community participated. Each saw one commercial formatted and one human factored sheet, for different "fake" medications. The research materials described factitious, not actual, medication descriptions. Participants followed the same procedure as described above. The human factored material took less time (83.9 s) to study than did the pharmacy material (118.3 s). The difference was significant ($t(32) = 6.04, p < 0.001$). Testing times and accuracy scores were not significantly different in the older sample, probably because of great variability in performance. Participants reported the human factored material to be "easier to find information," "easier to remember," and "easier to use," all differences were highly significant. For those expressing a preference, 35 of 39 older participants preferred the human-factored information. The results suggest that more attention needs to be given to adapting instructional material to the variability of older users.

Finally, a field comparison was made with a convenience sample of 39 pharmacy customers for any of three prescription medications: Claritin, Entex LA, or Amoxicillin. On receiving the medication, each customer was given the human-factored sheet along with the usual commercial sheet. Some were taking

the medication themselves and others were supervising the medications for others. About one week after receiving the medication, we queried preferences for the two instruction formats during phone interviews. The customers judged the human-factored sheets to be better on nine dimensions (see Table II for results). Of those expressing a preference, 32 of 37 preferred the human factors instructions.

Prescription medications promise medical benefits, but are often used inappropriately. While physicians and pharmacists may counsel patients, take-home instructions have the potential to help patients use medications properly. To be effective, information must be read, understood, and referenced when necessary. This requires that the instructions match the users' perceptual and cognitive capacities. These studies confirm difficulties associated with available material. Human factors and cognitive engineering can use the knowledge gained in interface design and cognition to develop better medication descriptions. If patients are to be partners in their own medical treatment, we must change the system that currently generates often difficult and sometimes incomprehensible material.

III. TYPE II DIABETES SELF MANAGEMENT

We turn next to the challenges of Type II Diabetes. If self management of prescription medications, a "simple" problem, can tax-user capacity, we can appreciate the challenge of managing a disorder as complex as Type II Diabetes. Diabetes mirrors the complexity of other complex disorders including asthma

TABLE II
PREFERENCES FOR PHARACY AND HUMAN FACTORED (HF) SHEETS

Question	Commercial	HF	χ^2
Which sheet is easier to use?	2	16	10.89
Which sheet is better?	5	34	21.56
Which is easier to read?	1	37	34.11
On which is it easier to find information?	1	31	28.13
Which sheet has information that is easier to remember?	1	20	17.19
Which has the better organization?	2	21	15.70
On which is important information the most prominent?	0	34	34.00
On which is the writing most understandable?	3	25	17.29
Which sheet would you prefer for future prescriptions?	5	32	19.70

and so may model the management of a broad range of disorders.

This disease currently ranks as the seventh leading cause of death in the United States. The estimated sixteen million Americans with Type II Diabetes are at risk for developing serious complications such as eye disease, kidney disease, nerve damage, and heart disease. The costs of medical care average three times greater for patients with diabetes than without [12]. Most of the added expense is spent on managing late complications. There is compelling evidence that good control of blood sugar reduces the damage that diabetes inflicts over the years to the heart, retina, kidneys, nerves, and connective tissue. Poor compliance is a major contribution to mortality rates and complications [12].

A. What is the Patient's Task?

The first step in understanding the technical challenge facing a diabetic was to review the medical literature. We looked at the formidable task demands of Type II Diabetes self management. With diabetes, the cells either do not respond normally to insulin or the pancreas does not produce enough insulin, or both. If the cells do not accept glucose, it accumulates in the bloodstream and leads to adverse effects.

Patients can dramatically reduce their risks of developing long-term complications and of premature death by maintaining safe blood sugar levels. Illness and stress alter requirements for food and medication. In order to detect imbalances, patients must monitor blood sugar level and remain aware of changes in their physiological state reflective of high or low blood sugar. There are devices that allow patients to monitor blood sugar, there are effective medications, and there is good documentation of the role of exercise.

Control of diabetes requires that the patient maintain their blood sugar level in the optimal range from 80 to 120 mg/dl [13]. Both elevated and depressed levels are health risks. In Type II Diabetes, patients are more likely to encounter problems with high blood sugar. Because food increases blood, attention to diet

is important. Too many carbohydrates can increase blood sugar; too few will lower it below safe levels. Diabetics need a diet that balances carbohydrates, proteins, and fats. Simply cutting out sugar is not enough. Exercise can reduce blood sugar level, but too much can lower blood sugar to dangerous levels. Adding to the difficulty, exercise can be dangerous when blood sugar goes over 240 mg/dl. When blood sugar is high, patients should check their urine for ketones. If ketones are high, they should not exercise as it can increase blood sugar level. An imbalance can place the patient in danger.

The day-to-day management of diabetes also varies because normal life stressors and illness alters the way the body functions, changing blood sugar. This means that each episode of stress or illness requires a recalibration of diet, medication, and exercise. Even though patients may not be able to control factors such as stress and illness, they need to make adjustments in diet, exercise, and medication to adapt to their impact.

Maintaining blood glucose within the desirable range is critical. There can be subjective warnings of glucose imbalance. Extreme thirst, frequent urination, or drowsiness can be symptoms of high blood sugar. Shakiness and sweating often mark the presence of low blood sugar. These signs can be subtle and difficult to interpret. Well-designed monitoring devices are available but the patient still has to check the data regularly and make accurate interpretations. Continual attention is needed for appropriate adjustments.

Finally, the human body undergoes age-related changes in functioning that influence blood sugar use. While the direction of these changes is known, their timing and pattern are not. Therefore, the lessons learned years earlier might no longer apply. This can create negative transfer to go along with all of the other complications.

B. How Do Diabetics Understand Their Task?

To understand the vulnerability of this complex self management process, we interviewed Type II Diabetics. The interviewees were all under the care of a physician and had received

some information about diabetes. Most had attended at least one set of classes offered by a hospital and many had received personal training from a dietitian or diabetes educator. Their symptoms and disease cycle varied in time from onset, severity, and training. We were particularly interested in differences in time from onset because we want to see how rules and perceptual recognition change over duration. We looked at the disease history as well as at self management activities and approaches.

Our interviews used CTA and critical incident methods to assay the patients' understanding of the demands of diabetes self management [5], [6]. We looked for specific incidents that presented self management challenges. These included holiday dinners, travel, and stress at work. We explored patient mental models of the disease and its regulation. To understand diabetes self management within a control-system framework, we need to understand the cognitive processes and decision making of practitioners—in this case, the patients. We need to know how patients search for information, and how they use it. We need to understand the options considered and the decision rules used to understand options. We expected some reasonable level of performance competence. What we found was disheartening.

Some interviewees had a good sense of the basic rules. One ate the same breakfast every morning because she knew it met her glucose requirements. Many of our interviewees, however, lacked even a reasonable set of rules for self management. They did not know how to count carbohydrates, read food labels, or identify food groups. One patient, for example, would go without food to lower his blood sugar. He knew that he wanted to keep control of his blood sugar, but he had no idea of the problems associated with this approach.

One interviewee articulated how it felt to have high blood sugar and what to do to combat it. However, we found many difficulties in detecting problems and responding to subjective indicators. Patients often misapplied the rules that they had been taught. One diabetic, for example, always ate something sweet when she felt "funny." She did not know if she was experiencing high or low blood sugar and did not know that it made a difference.

There are two ways to find blood sugar level. One is to test your blood, which can be inconvenient and painful. Many patients have trouble keeping up a schedule of testing. They reported that the procedure is both physically and psychologically aversive. The second way to gauge blood sugar level is to "feel" it when blood sugar is too high or too low. Some people can detect the physiological changes associated with blood sugar extremes. They have been able to use feedback from their initial blood tests to confirm their "feel" for departures from a normal range. Most of the interviewees did not report an ability to sense departures from normal, and did not even know to try. They were entirely dependent on the results from blood tests.

Many patients do not know what to do with the glucose-level information. In the interviews, we heard repeatedly that the purpose of testing was to bring the numbers to the physician. A better use, rarely articulated, would be to use the information to see what is affecting blood sugar. For example, the few patients who were skilled at self management reported discoveries such as "I wondered why my blood sugar was so high. Then I remembered that Big Mac. I guess that wasn't a good idea." or

"When my blood sugar shot up every time I visited the kids, I realized how anxious they made me" or "Boy, I ate a lot on Thanksgiving but my blood sugar didn't really go up that much. I realized it must have been the walk we all took after dinner." These interviewees were actively engaged in this sense making and demonstrated how to use test results. Most patients, however, were not engaged in learning to control their blood sugar levels.

One interviewee could describe how food, stress, exercise, and medications worked together in her body. Most interviewees reported that they really did not know what was happening. This meant that when anomalies occurred, they had no way to think out possible solutions. So, eating out, extra stress, or changes in activity level all posed real health risks. Overall, most patients lacked a mental model that would allow them to manage the complex system involved in glucose regulation.

C. How Are Patients Now Prepared for Self Management?

In response to advances in medication, monitoring technology, and food science, professionals provide self management instructional material for diabetics. The material, grounded in dietary needs and medication characteristics, is widely available. Newly diagnosed patients with health insurance also typically receive classroom training or individual counseling offered under the auspices of hospitals. Training includes one or more group sessions or individual sessions with a diabetes educator.

At initial diagnosis, all of our interviewees had been given printed material outlining self management goals, rules, and procedures. The American Diabetes Association prepares most of the material given to diabetics. We reviewed this material in terms of principles of traditional instructional technology.

The material is medically accurate and revised as new scientific information becomes available. Recent material reviews features of the disorder in an upbeat tone—"You can protect your future health." and "...congratulations on being the kind of person who cares enough about health and well-being to learn what you can do to live well with diabetes." It is geared toward life-long change. Both accuracy and the tone of the materials support and encourage learning.

The training material provides an overview of the important ideas building heavily on classical learning approaches. Initial abstracts provide a structure for each unit. The patient learns about diet, weight control, exercise, testing, and medication. They learn about preventive care, illness, and sexuality. They receive information about resources. There are lists to reinforce rules and procedures and for later reference. Topics covered in the lists include "common sources of stress," "treating low blood sugar," and "sick day foods and drinks." Emphasis is given to continuity of care: the role of family support and the help available through the American Diabetes Association. There are places to record meal planning, exercise choices, and medication schedules. Chapters have quizzes to check understanding and end with a "Final Check" that provides review. The presentation of these materials is attractive. Important ideas are highlighted with colored and sometimes bulleted text. The booklet is illustrated with realistic people. The text structure is appropriate and the print is large enough for most older adults.

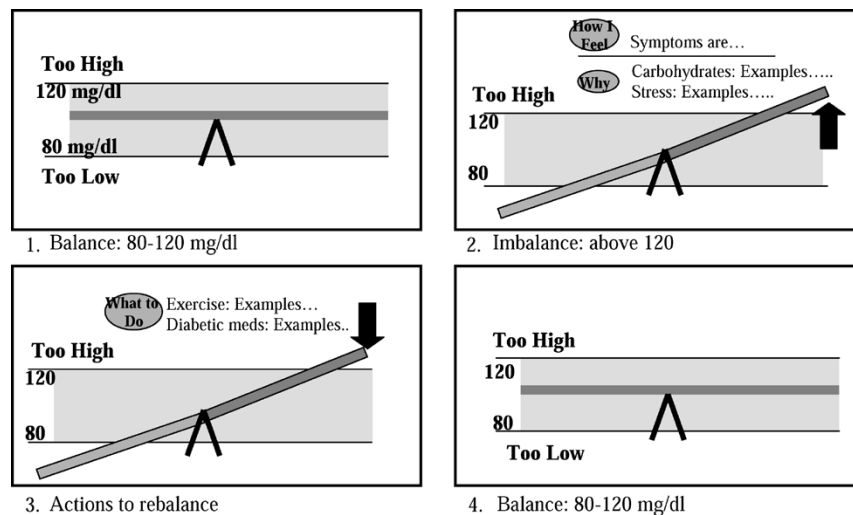


Fig. 2. Balancing blood sugar.

This content analysis confirms that the most readily available instructional material presents rules and procedures in a way that is consistent with good instructional practices. The presentation is at a level appropriate for older adults who constitute the majority of those suffering from the disorder.

The training materials have high medical accuracy and instructional sophistication, but that is not enough. The material aims to provide rules and procedures. Rules and procedures are necessary, but not sufficient for effective self management. The patients need a conceptual model that enables them to accomplish the complex blood sugar balancing act. They need to know how the various factors (e.g., diet, exercise, stress, insulin dose) together govern blood sugar level. Patients are not guided in using the results of blood tests to learn how to self-regulate. There is little about detecting when blood sugar goes outside safe levels.

The complex decision making required of Type II Diabetes goes beyond rules and procedures. The interviewees had little understanding of the complex control relationships among diet, stress, exercise, and medication. They did not generally use the blood sugar monitoring information to alter their eating or exercise. In short, they were following static rules not controlling a dynamic system. We believe that without adequate mental models, and without an attitude of self-efficacy to master the control task, diabetics cannot be active partners with healthcare professionals in managing their disease.

D. Mental Model for System Control

Human factors includes a rich body of theory and data on control systems and the training of personnel to manage such systems [15]. It is time that we tap this knowledge to support patients in this medical self management task. We must be able to provide a mental model of the disease that can support effective self management of this dynamic system. To be effective, a model must be within the parameters of the operator's capacity. It is necessary but not sufficient to teach rules that maximize functioning in routine situations. We must also cultivate a model useful for long-term flexibility and adaptability. We need to go

beyond blame to a solution that taps the extensive human factors literature on control.

Despite the complexity of the diabetes self management task, there is little time for prolonged training and graduated practice. Further, diabetics are not selected for their aptitude or skill. They tend to be older and include many who are uncomfortable with technology. Most have spent decades developing incompatible eating patterns. Unlike many complex skills, diabetes self management uses unskilled operators, disallows start up time, and demands proficient performance.

Accordingly, we are using the interview data collected with diabetics to develop a model to capture the complex relationships of diabetes. The model is based on the medical demands of diabetic self management. Patients need a model that explains the impact of diet, stress, exercise, and medication on blood sugar. They must be able to use blood sugar monitoring information, both subjective and objective, to diagnose problems. They need to develop and implement corrective actions when an imbalance is identified. They must respond appropriately to unexpected deviations, anomalies, stress, and health changes.

A simplified version of the conceptual model of self management is shown in Fig. 2. The model first presents the concept of a balance between "too high and too low." The first frame is a representation of the balance point showing the safe (80–120 mg/dl) and unsafe ranges. The model next introduces the subjective feeling or symptom associated with high blood sugar. It presents the possible contributions, the "whys" of high blood sugar. The third frame introduces possible actions that can return the system to a balanced state. A final frame shows the result of effective self management, a return to balance. Actual training would introduce a great deal of information in graduated steps. In future work, we envision an online version that would be able to display the impact and time course of specific remedial actions. For example, what would be the impact of 6 oz of orange juice or a 20-min walk? Work on this representation has been initiated [16].

We are now formalizing and testing the model that is represented. We have conducted some interviews with diabetics and

responses are very positive. The next step is to measure the effect on the performance of successful blood sugar management.

E. Diabetes and Complex Control Demands

Type II Diabetes requires the control that is characteristic of other complex systems designed to maintain stability within parameters. System control is necessary for many dynamic and interdependent operations. A power plant, for example, may need to maintain fairly constant pressure even as demand shifts over the 24-h day and over seasons. Differences in the temperature of water change functional patterns. We provide power plant operators with some simple rules for control but also with sophisticated training in the dynamic physical and technological nature of the operation. We provide physical artifacts to illustrate control imbalances systems [14]. By understanding how the system works, the power plant operator can better manage anomalies and handle emergencies under time pressure. Even in the face of great potential danger, these plants have excellent safety records because they operate within specified parameters.

As we better understand the parallels between the task of the power plant operator and the diabetic, we will be able to improve performance on the task of maintaining glucose within the desired range. The development of this model for training is informed by the way diabetes maps onto a complex control model.

Amateurs are not put in charge of a power plant, but a diabetic is expected to be in charge from initial diagnosis. The interactions of diet, medications, exercise, and stress change blood sugar levels daily. Because of the need for rapid patient compliance with a dynamic regimen, healthcare professionals have resorted to teaching rules. Rules are a good starting place, but they can be disastrous in the long-term. While rules work for simple control systems they are not sufficient for dynamic tasks. Rules are limited to simplistic situations that are invariant. When diabetics are given simple rules and shortcuts without considering the dynamic and progressive nature of diabetes, long-term complications are inevitable. A better approach is to provide diabetics with a functional understanding of the disorder.

A mental model can capture the complex interactions of glucose maintenance. Patients can use a mental model as a basis for self management decision making. Mental models allow more adaptability, flexibility, and ultimately more control. This control can slow the long-term complications of the disease. While rules may be a starting point, a functional mental model of the disease mechanisms appears necessary for effective control.

IV. CONCLUSION

Self management is critical for the treatment of many diseases and health conditions. Appropriate self medication can cure disease, relieve pain, and extend human life. Good self management of diabetes means short-term health and long-term survival. It is inexpensive and the most effective approach to care. self-managed care is challenging because it occurs in the natural setting of daily life rather than in a professional healthcare setting. It depends on untrained patients rather than on skilled healthcare personnel. Even with these constraints, patient self management sometimes requires much more than adherence to

stable rules and the application of fixed procedures. Control of a complex biological system demands the same judgment and decision making, as does the control of other complex systems.

Cognitive engineering research can help identify the decision requirements and cognitive challenges that confront patients seeking to follow medical regimens. Our field observations, CTA interviews, and critical incident interviews provide understanding of how the technical demands of the tasks are understood by patients and how suitable material and instruction might be provided. If all that is required is adherence to rules and procedures, there is an established literature on instructional design to tap. We have shown that both in the relatively simple case of following a medication regimen, and the relatively complex case of self managing blood sugar levels, patients face unexpected complexities and challenges. When healthcare professionals formulate a treatment plan, they may believe that all the patient has to do is follow the steps and the procedures. Several decades of research in cognitive systems engineering and related disciplines should disabuse us of this notion. Miller and Woods have described how procedural approaches to complex skills are inherently limited and insufficient [15]. That is why we believe that effective self management by patients will require cognitive field studies to understand the real barriers to following treatment plans. Field studies can also help develop the necessary tools and training to enable patients to succeed.

ACKNOWLEDGMENT

The authors thank J. J. Isaacson for her initial efforts and M.-H. Lin for her technical support.

REFERENCES

- [1] National Council on Patient Information and Education [Online]. Available: <http://www.talkaboutrx.org/compliance.html#problem>
- [2] H. R. Manasse, "Medication use in an imperfect world: Drug misadventuring as an issue of public policy," ASHP Research and Education Foundation, 1989.
- [3] H. A. Klein and J. J. Isaacson, "Making medication instructions usable," *Ergon. Design*, vol. 11, pp. 7–11, 2003.
- [4] D. C. Park and T. R. Jones, "Medication adherence and aging," in *Handbook of Human Factors and the Older Adult*, A. D. Fisk and W. Rogers, Eds. San Diego, CA: Academic, 1997, pp. 257–287.
- [5] R. R. Hoffman, B. W. Crandall, and N. R. Shadbolt, "A case study in cognitive task analysis methodology: The critical decision method for the elicitation of expert knowledge," *Human Factors*, vol. 40, no. 2, pp. 254–276, 1998.
- [6] H. W. Gordon and R. T. Gill, "Knowledge acquisition with question probes and conceptual graph structure," in *Questions and Information Systems*, T. Lauren, E. Peacock, and A. Graesser, Eds. Mahwah, NJ: Erlbaum, 1992, pp. 29–46.
- [7] R. W. Morrell and K. V. Echt, "Designing written instructions for older adults: Learning to use computers," in *Handbook of Human Factors and the Older Adult*, A. D. Fisk and W. Rogers, Eds. San Diego, CA: Academic, 1997, pp. 335–361.
- [8] J. Hartley, "Eighty ways of improving instructional text," *IEEE Trans. Profess. Commun.*, vol. PC–24, pp. 17–27, Mar. 1981.
- [9] T. C. Davis, M. A. Crouch, G. Wills, S. Miller, and D. M. Abdehou, "The gap between patient reading comprehension and the readability of patient education materials," *J. Family Prac.*, vol. 31, pp. 533–538, 1990.
- [10] D. G. Morrow, V. O. Leirer, and J. Sheikh, "Adherence and medication instruction: Review and recommendations," *J. Amer. Geriatric Soc.*, vol. 36, pp. 1147–1160, 1988.
- [11] D. G. Morrow, V. O. Leirer, and P. Altieri, "List formats improve medication instructions for older adults," *Educ. Gerontol.*, vol. 21, pp. 163–178, 1995.
- [12] P. Hogan, T. Dall, and P. Nikolov, "Economic costs of diabetes in the U.S. in 2002," *Diabetes Care*, vol. 26, no. 3, p. 917, 2003.

- [13] *Right from the Start: Type 2 Diabetes*, Amer. Diabetes Assoc., 1993.
- [14] K. B. Bennett, "Representation aiding: Complementary decision support for a complex, dynamic control task," *IEEE Contr. Syst. Technol.*, vol. 12, no. 4, pp. 19–24, 1992.
- [15] T. E. Miller and D. D. Woods, "Key issues for naturalistic decision making researchers in system design," in *Natural. Dec. Making*, C. E. Zsombok and G. Klein, Eds., 1997, pp. 141–149.
- [16] L. Woods, personal communication, Apr., 22 2004.



Amy R. Meininger received the B.F.A. degree from Columbus College of Art and Design, Columbus, OH, in 1987 and the B.A. in psychology in 2001 from Wright State University, Dayton, OH, where she is currently pursuing the M.S. degree in human factors and industrial/organizational psychology.

Her interests include applied cognition, medical self management, and also cross cultural differences in cognition and decision making.



Helen Altman Klein received the B.S. degree from Michigan State University, East Lansing, MI, and the M.S. and Ph.D. degrees in experimental psychology from the University of Pittsburgh, Pittsburgh, PA, in 1967 and 1969, respectively.

She is a Professor of psychology and a Member of the Graduate Faculty in the Human Factors and Industrial/Organizational Psychology Program, Wright State University, Dayton, OH. She has written over 100 papers. Her research in applied cognition has explored domains including civil aviation, military

command and control, driving, and architecture as well as medical compliance. Her recent research has emphasized natural field settings and also cross cultural differences in cognition and decision making.