Investigating Health Management Practices of Individuals with Diabetes

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ABSTRACT
Chronic diseases, endemic in the rapidly aging population, are stretching the capacity of healthcare resources. Increasingly, individuals need to adopt proactive health attitudes and contribute to the management of their own health. We investigate existing diabetes self-management practices and ways in which reflection on prior actions impacts future lifestyle choices. The findings suggest that individuals generate and evaluate hypotheses regarding health implications of their actions. Thus, health-monitoring applications can assist individuals in making educated choices by facilitating discovery of correlations between their past actions and health states. Deployment of an early prototype of a health-monitoring application demonstrated the need for careful presentation techniques to promote more robust understanding and to avoid reinforcement of biases.

Author Keywords
Elderly, Healthcare, Home, Monitoring, Qualitative Studies, Technology Probes

INTRODUCTION
The steady growth of the elderly population, evident in the recent years, is placing an unprecedented demand on the healthcare system. Chronic diseases typical for the aging individuals demand continuous care, well beyond the capacity of the traditional healthcare institutions [2]. One such disease, diabetes mellitus, affects an estimated 20% of men and women over the age of 65 and may lead to such complications as blindness, end-stage renal disease, stroke, and coronary artery disease [21]. The inadequacy of traditional healthcare necessitates that lay individuals adopt increasingly proactive roles in providing the needed care for themselves and their loved ones.

This shift in attitudes to personal health creates a host of opportunities for the emerging fields of ubiquitous and pervasive technologies. Mark Weiser [27] described a vision of computing ubiquitously embedded in the world around people, and, perhaps, within people, unobtrusively and continuously informing their judgments and actions. In the healthcare domain, pervasive computing technologies are striving to supplement human clinical observers in monitoring an individual's health and provide the necessary guidance. The first step in realizing this vision, development of capturing technologies capable of collecting the relevant data, such as sensor networks or biosensors, are a subject of intensive investigations [1,8,19]. However, the data collected is of little value, unless it informs individuals and enables educated choices. Thus, understanding of individuals' health reasoning and development of information presentation techniques that enhance and facilitate it are essential for the success of chronic self-care applications. There is a growing appreciation of human insight and sense making in the field of Information Visualization [4]. At the same time, many health monitoring applications continue to rely on a naïve assumption that once the data is collected and presented to the individuals, they will draw appropriate inferences unproblematically.

In the present work, we re-examine assumptions inherent in the emerging monitoring applications and seek answers to the following research questions:

- How do individuals with chronic diseases currently manage their health?
- How do they form judgments and reason regarding their health and diseases?
- In what ways can computing applications inform individuals' actions and assist them in managing their diseases?

Addressing these research questions demanded application of mixed research methods. Qualitative interviews of individuals with diabetes and an observational study of the diabetes support group resulted in rich insights into current diabetes management practices. To reveal health reasoning strategies, we created and deployed a technology probe – a prototype of the application incorporating state-of-the-art monitoring techniques that engaged individuals in the reflective analysis of their disease.

The three main aspects of diabetes management that emerged from the investigations are as follows:

The need to become a detective: due to considerable variability of cases, there is a need for individuals to proactively engage in analysis of their disease.

Flexible negotiation of actions: chronic nature of the disease leads to the individuals' desire to flexibly negotiate their actions based on the anticipated outcomes rather than to adopt a completely risk-free lifestyle.

Importance of motivation: difficulty of diabetes management often results in disengagement from the process and leads to astonishingly high levels of non-compliance with medical regimens or desired lifestyle.

Individuals' ability to successfully manage diabetes largely depends on their understanding of the correlations between daily activities and blood sugar levels. In this paper we propose an interpretative framework that illustrates the steps necessary to achieve such understanding. While this framework is only a rough approximation of the actual decision-making process, it highlights the barriers in the current practices and suggests ways to enhance them with computing applications.

Further analysis of the reasoning strategies demonstrates that individuals often engage in generating and evaluating hypotheses regarding possible causes of changes in blood sugar. This type of inference is subject to a number of known biases, for example the *confirmation bias* [26]: after forming a hypothesis, individuals seek evidence confirming it, and actively ignore evidence inconsistent with it.

These findings highlight a number of possible avenues for enhancing diabetes self-management. For example, monitoring applications can automate the steps of the decision-making process and help individuals draw correlations between automatically captured activities and blood sugar values. These applications create a basis for a more sophisticated form of assistance, which allows individuals to contemplate different "what if" scenarios. The success of these applications, however, will depend on such factors as ease of use and accuracy of the clinical monitoring devices, and the choice of information presentation to the users. Simple presentation of all the data captured during monitoring may be subject to confirmation bias and lead to the reinforcement of wrong assumptions. Intelligent data analysis of true correlations and careful visualization techniques that highlight true patterns can help to assuage this risk. In addition, computing applications can provide additional motivation to the individuals struggling to embrace the need for proactive disease management.

RELATED WORK

Exploratory studies of individuals' health attitudes in the field of Human Computer Interaction have mostly focused on understanding needs of the aging adults who desire to remain independent and "age in place". For example, Mynatt et al [20] found that the transition to the assisted living was often initiated by the adult children who desired peace of mind regarding the well-being of their aging parents. Morris [18] et al focused their investigations on aging adults coping with cognitive decline and suggested a number of design directions to reinforce social connectedness of such individuals. In addition, there is a considerable body of research in the field of biomedical informatics documenting the difficulties lay people experience in comprehending medical information [22] and making sense of their own data [16].

The ability to automatically monitor individuals' health and activities became one of the necessary components of health-related or aging-related applications. However, the design, implementation and deployment of such systems remain a significant challenge. Many projects taking advantage of monitoring utilized "Wizard of Oz" techniques [20], relatively simple monitoring [25], or focused on comparatively well-defined and easily recognizable activities, such as medication taking [8]. Recognizing more complex, but also more typical human activities remains non-trivial [19]. In addition to the inherent computational complexities, such systems present considerable challenges for deployment and installation in domestic environments [1].

These new monitoring capabilities allowed researchers to propose a number of creative solutions in the home healthcare space. In some of these applications, automated capture techniques assist human observers as is the case with monitoring of children with autism [11]. Others, such as the Digital Family Portrait [20] or the CareNet display [5], focus on supporting adult children in their care for the remote or collocated parents. Yet others target the aging individuals themselves. For example, Mihailidis [17] proposed systems that provide cognitive assistance to aging individuals with dementia.

A somewhat different class of computing applications utilizes data captured by sensors to explicitly change individuals' health behavior. Intille [14] argues that providing relevant information at the time of decision making may influence individuals' health choices. Jafarinaimi [15] utilizes *persuasive computing* techniques to maintain individuals' awareness of their posture.

While these and many other explorations inspired and motivated our work, the research questions regarding disease self-management postulated at the beginning of this paper remained unanswered. The findings presented here extend the existing work in the field by focusing on the disease self-management strategies, health reasoning involved in the management, the limitations of the current practices and opportunities to address them with ubiquitous or pervasive computing applications.

THREE APPROACHES TO INVESTIGATION

In the past three decades, the focus on augmenting working environments led to the emergence of research methodologies inspired by ethnography and anthropology, such as ethnomethodology [6]. A related approach, cognitive ethnography [12], was applied to studies of human cognition as it occurs in the natural work settings.

In recent years, however, the research community has begun to examine the everyday lives of the individuals. This transition challenged appropriateness of conventional ethnography-oriented techniques for investigating domestic environments. Concerns regarding privacy and the sensitive nature of such settings render ethnographic observations problematic and often impossible. For the same reasons, the utility of cognitive ethnography for investigation of reasoning in domestic environments and everyday situations is uncertain.

The challenges of domestic environments inspired development of a new set of techniques, called cultural probes [9]. Cultural probes are carefully designed sets of provocative materials intended to inspire emotional responses from people that reveal motivational forces shaping individuals' lives. Technology probes [7, 13] further extend the concept of cultural probes: they serve as instruments to investigate unknown environments and as initial prototypes of the applications.

Until now, the focus of cultural or technology probes was on highlighting individuals' cultural or social biases, attitudes and deep motivational forces that drive their behavior. In the current work, however, one of the main research questions was to understand judgments and reasoning involved in diabetes self-management. Thus, the goal of the probe was to engage individuals in reflective reasoning about their health and highlight strategies, biases or misconceptions. It was necessary then to design a special type of the technology probe that would provoke such response, which we call a *cognitive probe*. We hope that cognitive probes extend and continue the tradition of cognitive ethnography in a way that cultural and technology probes extended ethnographic traditions as applied to domestic settings.

Interviews

The first phase of the study included interviews of 15 individuals with diabetes. The participants of the interviews varied in age (from 40 to 60 years old) and in diabetes history (from pre-diabetes to 20 years of experience) but could be considered from a relatively homogeneous social group – middle class professionals with college to PhD level education. The participants were recruited among research personnel of Siemens Corporate Research, Inc. and from the attendees of the diabetes education center located in Dover, NJ. The interviews were videotaped and coded for further analysis.

Observation of Diabetes Support Group

The support group observed during this study was sponsored by the American Diabetes Association certified Diabetes Education Centre in Dover, NJ. The centre provides a variety of services for individuals with diabetes, including educational courses or consultations with dieticians, in addition to the opportunity to attend meetings of support groups. The number of people in the group varied between 8 and 15, all participants above the age of 40, most above 50, with a relatively even male/female split. The length of participation in the group varied widely, with the most senior tenure of over 8 years, and several newcomers present at every group meeting. The group was facilitated by an expert dietician. The group met every other week during the 6 months of the study. Due to the sensitive nature of the discussions, no video or audio capture was used. Field notes taken to capture observations were annotated and coded.

Cognitive Probe

The probe used in the study was of a dual nature. Most importantly, it was meant to heighten individuals' awareness of their health behavior and engage them in reflective analysis. At the same time, it served as an early prototype of a health monitoring solution. The application, Continuous Health Awareness Program (*CHAP*), utilized sensing and self-report techniques to capture individuals' actions and daily blood sugar trends; the deployment study allowed the research team to observe participants' reasoning about the captured data. The technologies used were inspired by the previous explorations of activity capture in context of the Digital Family Portrait studies [20].

Design

CHAP included the following components: 1) the GlucoWatch G2 Biographer™ [28] – a commercially available glucose monitoring device worn as a wrist-watch that non-invasively samples blood sugar every 10 minutes; the Analyzer software allows viewing the captured records; 2) X10 motion detection sensors positioned in places of usual activity, unique for each household; 3) a computer-based diary application allowing individuals to report on their activities, composition of meals or medications as well as their emotional state; 4) a webcam for free-form comments or notes for the research team. The main purpose of the motion detection sensors was to provide an additional reference for the research team and help assess accuracy of self-reports.

The diary was available from a laptop screen augmented with a touch-sensitive MagicTouch cover to simplify user interaction. Participants could either select from offered lists or enter free-form text. The list of activities was developed with reference to the taxonomy of Activities of Daily Living [26], and refined based on the findings of field trials with the Digital Family Portrait [20]. The list of meal types was created based on the food pyramid developed by the Food and Drug Administration [30]. The participants were encouraged to record activities as they occur, however they could also make entries retrospectively. To allow participants to assess their emotional state, we employed the Self-Assessment Manikin (SAM) [3].

Figure 1: Components of CHAP

Deployment study

CHAP was deployed in two households for two weeks each. The participants for the study were recruited via recommendations of physicians consulted in the course of the project. The candidate subjects participated in 30 minute interviews to determine their suitability for the study. Subject selection decisions were made in consultation with their primary care physicians. Participants received $500 reimbursement.

In addition to the monitoring activities described above, the study included daily 30 minute interviews with the participants at their home. The interviews utilized the following structure: the interviewer reviewed the daily records in the diary, asking the participant to elaborate on them or to fill in the gaps. After that, the GlucoWatch was taken off of the participant's arm and the data was uploaded onto the laptop. The participant then was asked to review the readings and comment on them. All the sessions were video and audio taped, transcribed and analyzed.

Figure 2: Participant at home

DETAILED FINDINGS

In this section we discuss detailed findings as discovered by the interviews and observations, and the case-studies of deploying the cognitive probe.

Interviews and Observations

The analysis of qualitative findings was performed in accordance with Grounded Theory [10]. All the transcripts were coded by the first author with respect to the patterns emerging from the data, rather than applying a predefined coding scheme. The most prominent themes that emerged from the investigations are presented in Table 1.

Diagnosing diabetes	**Quotes**
Diabetes is often diagnosed late because the symptoms are difficult to observe.	*"You are dehydrated, a bit more tired or fatigued, or hungry, but if you work 16-hour days, and it's summer, that's how you feel most of the time anyway".*
Often, individuals are diagnosed by accident.	*"I had a rash, actually, and I thought it was a poison ivy, because I am very allergic to poison ivy… And I couldn't stand the itch actually, it wouldn't stop, and they took a few blood tests and told me – oh by the way, you are diabetic, and my sugar levels were above 400 at the time."*
The first reaction to the diagnosis is usually quite stressful, especially for those with a family history of diabetes.	*"When I just got diagnosed, we were all scared [my wife and kids] and we started exercising, we bought bicycles, we went around for a few months, yeah, I think we all joined." … "My father-in-law for a long time had a diabetes, and eventually… (shaking his head) … very horrible end of … last few years of his life because of diabetes. Yeah. We've seen it first hand that it's not a fun disease when it progresses to the point that you start losing limbs and people lose their eye-sight, so it's a pretty horrible disease."*
Patients often blame doctors for not stressing the seriousness of the disease early on when they were most anxious to address it.	*"I also know now that had I started doing this (controlled diet and exercise) before, I could have prevented this. Or at least pushed it off until later on. And I wish my doctor told me this, it would give me a strong motivation for doing this".*
Monitoring and management	
Diabetes challenges individuals' passive attitude to health and demands a proactive management.	*"I mean it's a big change to your life, it is a food change, it's a way of life change. You have to be more active, you HAVE TO be more active. You know, sometimes people are just not able to be active. And it just makes it difficult, you rather it wasn't happening to you than to know…so you deny it…and the more you deny it… the worse it gets."*

There are significant individual variations in diabetes.	*"... not everybody's diabetes works the same way, you are going to find out as you speak to other people. And everybody has their own method, or a plan and you have to figure it out with your doctor"*
Figuring out the optimal lifestyle is difficult due to high complexity of interrelations between actions and blood sugar values.	*"...it's definitely tied to your food, you know. Except that it's not, it does not correlate exactly. So you try all sorts of things, you eat later or you have a snack before going to bed. My (blood sugar) was a little high, so I would have a snack... and that didn't work...and then I tried eating dinner at a different hour... and that didn't work. So you don't know what works and doesn't work sometimes."*
Medication can ease the problem, but is a double-edged sword: it may have long-term consequences, and proactive self-management may seem unnecessary.	*"... some of the oral medications make you gain weight too, they make you retain a lot of water, which affects the function of your liver and your kidneys, and everything else, and eventually your heart..." "At the beginning we really paid attention to it...but after a while (after taking medication), I realized that I could have that bowl of pasta at the Italian restaurant and it wasn't a big deal."*
Identifying the optimal medication regimen is just as difficult, even for clinicians.	*"I was on insulin for about 11 years, back and forth, trying different combinations of insulin and oral medication...it wasn't working...and then I found the right mix of orals that worked without the insulin...There are different strategies we could try, we tried different medications, taking them in a different order, and you always try them for a few months and see how it goes."*
Patients often try to negotiate the compromise between the health and the desired actions.	*"Listen, I'll tell you, when I was young, and I would go on vacation, and if I didn't have my periods and I was on birth-control pills, I would just manipulate my birth-control pills. And if you have really done that, you know what I am talking about. And I think we all do that. Well, diabetics that are on insulin they can do that, and if they know that they are going to a wedding where they are going to eat everything they want, they are just going to manipulate their insulin."*
Individuals desire an intensive and frequent engagement of their physician in analysis and reasoning regarding their case.	*"In order for me to manage I would have to see him once every week or be able to speak to him once a week and say: these are my numbers right now, what should I do to change the way these numbers look?"*
Motivation and denial	
Deprivation of favorite activities may lead to emotional distress	*"My doctor tells me: boy, you are a trooper... you need to manage it and you need to not feel deprived. Because once you feel deprived you can sit in the corner and cry. And you can't allow that, because it is self-defeating."*
Visual records of monitoring can encourage individuals to at least keep taking the samples	*"I think it also helps me to check, because I hate to see a hole in the table, so I force myself to take it so that it's not discontinued. Because it's a pain in the neck if I skip a day – I have to make a lot of changes and manually change things, so in the morning I think – yeah, I need to go and poke my finger."*

Table 1: Emerging themes from diabetes interviews and observations

Deployment Case Studies

In this section we describe in detail the findings from the deployment of the cognitive probe.

Case study 1

For the purposes of this paper we will call our first participant Mary. Mary was a native of Georgia in her 80s, who spent most of her life in Atlanta where she worked as a secretary. She had 3 children, a son and a daughter still in Atlanta and a daughter in New York City, where Mary lived in an independent-living retirement community on Upper East Side. For many years Mary had served as a president of the tenants' social committee: her main responsibilities were in greeting new tenants and helping them to integrate with the community. She no longer served as a president but remained very engaged. Last fall she started taking photography classes.

Mary's diabetes was considered border-line: her blood sugar was generally well-controlled and she took minimum amount of medication. Mary followed a sliding blood sugar measurement schedule (varying the sampling time between different days); however her records were fragmented due to difficulties with the glucometer. Mary had never enrolled in diabetes education classes or consulted a dietician; her main clinical contact was her primary physician.

Mary had been using a personal computer for several years, mostly to exchange emails with her grandchildren in the South.

Mary's participation in the study was due to her daughter, who convinced Mary to give it a try. Mary, however, adopted a relatively skeptical attitude. She remained very guarded about her life; refused to reveal her exact age, and was careful in sharing any personal details. She also refused to accept the distribution of roles as researchers – study participant. Daily interviews quickly transformed into conversations, covering topics of general interest as much as questions pertaining to the study. In addition, the interviewers needed to be prepared to share just as much personal information as they were inquiring about.

Despite her high sensitivity to privacy, Mary did not have reservations about installing motion detection sensors wherever the research team suggested. The single exception declared off-limits was the bathroom. The final configuration of sensors was as follows: front door; kitchen: counter, by the microwave, by the cat feeder; living room: entertainment unit (by the TV), working table (with all the correspondence), coffee table; bedroom: working table (with a PC) and the night stand. After installation, the sensors integrated in the household without much difficulty. Initial humorous comments regarding the sensors' friendly blinking (the red light goes on when the sensor detects the motion) stopped after the first few days and there was no mention of the sensors after that.

The first few days of the study demonstrated that the research team had grossly underestimated the complexity of the GlucoWatch. Physical assembly of all the device parts necessary to put it on presented a barrier that Mary was only able to overcome during the last few days of the study. After several unsuccessful attempts, Mary requested that one of the researchers be present during the assembly, and one during the calibration, 2 hours after the assembly. Only in the last 3 days of the study, both the assembly and the calibration were performed independently and successfully.

Findings – case study 2

The second participant, Paul, was an 80-year old New Yorker, still only semi-retired, as he continued to manage an investment portfolio and real estate leased to various businesses in the greater New York area. He lived with his second wife, Monica, who was retired as well. Paul had two children from his first marriage, a son and a daughter, both living remotely, and five grandchildren.

Paul became an avid computer user about 3 years ago, was managing his investment portfolio online and had an extensive email exchange with like-minded individuals, often regarding prominent political or social issues.

Paul, in his own words, had a very elaborate medical history, including experience with triple bypass and prostate cancer. He followed a rather strict medication routine, using medication dispensers to organize his pills and vitamins on a weekly basis.

Paul's diabetes was discovered by an accident after an adverse reaction to a medication. Physicians involved with diagnosis did not stress the importance of immediate lifestyle adjustment, and Paul continued consuming juices and sweets, which aggravated his state. At the time of the study, however, he was "eating sensibly and carefully" and exercised religiously, either at a gym or at home. He followed a strict daily blood sugar sampling schedule and had several years' worth of written logs. His latest glucose meter stored the records electronically, thus eliminating the need to maintain logs.

From the first introduction, Paul was enthusiastic about the study and immediately connected with the idea of learning about the consequences of actions with the assistance of computerized tools.

> *"My feeling is that with a healthcare provider the vocabulary and the way different people measure pain… so I don't know sometimes that I am communicating adequately about what's really happening. And if you have mechanical devices that are absolute in their measurements, the better you can be at solving the problems"*

Neither Paul, nor Monica had much reservation in regards to capturing and sharing data collected by the sensors during the pre-study interview. However, during the installation of the probe they requested a detailed description of the sensors' capturing capabilities, with a particular concern about capture of conversations. Aesthetic considerations led to suggestions that sensors are positioned in discrete places, and not on visible surfaces. A few places declared off-limits included the bathroom and private areas in the bedroom. The final configuration of sensors was as follows: front entrance: by the door, and by the mirror; living room: entertainment unit, exercise bike; kitchen: by the microwave; bedroom: by the bed, by the computer, by the working table.

Even for somebody as intelligent and experienced with computers and technology as Paul, the GlucoWatch presented considerable difficulties. The first demonstration of the device inspired a shower of sarcastic remarks from his wife: "Before you start a patient, do you give them some sort of IQ test? I think this requires a high IQ." "Yeah, it's like watching a monkey in a zoo" agreed Paul while going through the steps of the assembly. Several steps demanded a very high level of manual dexterity – pulling out one of the protective layers required a tight grip and could only be accomplished using pliers. However, Paul was eager to solve the puzzle; after carefully reviewing the instructions he was able to assemble and calibrate the device without any assistance on the second day of the study.

DISCUSSION

In the introduction of this paper, we presented a number of research questions. Below we generalize our findings to address these questions:

Current management practices

A more detailed account of themes that emerged from the qualitative study are summarized in Table 1. The three recurrent aspects of diabetes management were as follows:

The need to become a detective

The main goal of all diabetes management activities is to keep patients' blood sugar at a consistent level as close to the "normal" as possible. The management techniques usually involve a diet low on carbohydrates and sugars, regular exercise and appropriate medication. While there are general guidelines regarding management strategies, developing a well-suited care plan remains a significant challenge for each newly diagnosed individual.

> *"I am looking for answers to my questions, and I want them to be definitive, and nobody can give me any."*

These words of a frustrated new patient are exemplary of numerous similar comments. Great individual variability of diabetes prevents physicians from devising precise guidelines that are applicable to all patients. Instead, individuals are taught to become increasingly sensitive to their health, recognize symptoms of low or high blood sugar and become more attuned to individual reactions to different types of foods, exercise and medication. "We try to teach them to become detectives" commented a nurse at the education center, and indeed it takes the mental acuteness of a detective to discern the patterns that lead to the successful management. Unfortunately, the current way of tuning management practices comes down to a trial and error process:

> *"You try something and you keep your fingers crossed, and then you see that it doesn't work, and you try something else."*

Flexible negotiation of actions

One of the recurrent themes in the discussion of the diabetes support group stressed the importance of the balanced lifestyle for individuals with diabetes. Drastic changes, common for the newly diagnosed patients, quickly lead to the feeling of deprivation and often prevent long-term adoption of the necessary restrictions.

To ensure enduring lifestyle change, the facilitators of the group stress the need for intelligent moderation or compensation, rather than full exclusion.

> *"I try to tell them – if you are going to a party and you know you will want that piece of cake, that's ok, go ahead and have it. But then have something really light for breakfast. Or dance at the party for a couple of hours."*

Assisting individuals in flexibly negotiating their actions and finding the right balance between pleasurable activities and the desired state of health was seen as one of the main targets of the diabetes education.

Importance of motivation

Introduction of restrictions in the lifestyle can be a painful process for individuals with diabetes. The need to follow a particular diet makes travel, corporate, or family functions problematic:

> *"We went to my husband's family function, and there was nothing there I could eat. She (sister-in-law) didn't even have a tossed salad. Sitting with an empty plate is embarrassing."*

Moreover, the necessary restrictions need to be persistent throughout the life of the individual. The commitment to the low-risk lifestyle is influenced by a variety of factors that can provide both motivation and discouragement:

> *"Actually, if I have a string of a few days of low numbers, I feel more encouraged to keep it up. Yeah, but then the numbers would come up and then you feel – ah, well, if its up already ..."*

Health reasoning

Decision Cycle

Individuals' ability to successfully manage diabetes largely depends on their understanding of the correlations between daily activities and blood sugar levels. We propose the following framework to illustrate the steps necessary to achieve such understanding. While this framework is only a rough approximation of the actual decision-making process, it highlights the barriers in the current practices and suggests ways to enhance them with computing applications.

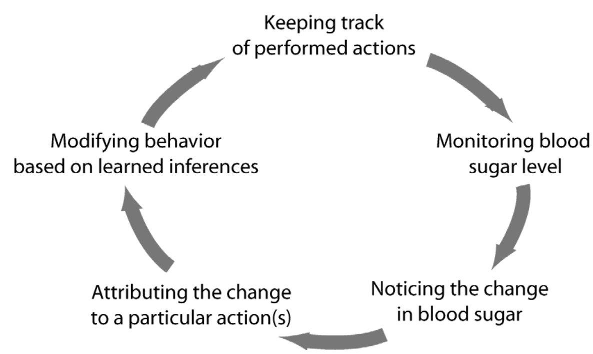

Figure 3: Diabetes decision cycle

The cycle begins with individuals keeping track of their actions. There are two types of actions: interventions are intended to modify conditions, such as medications or exercise; nominal actions may still lead to a change in conditions, but without such intention. Careful monitoring of the blood sugar level allows individuals to notice changes in blood sugar during the day. Once a particular pattern of change is recognized, it needs to be attributed to a particular action, either nominal or interventional. Establishing such correlations enables individuals to modify behavior based on learned inferences – reinforce actions that lead to positive outcomes, and inhibit actions that lead to negative outcomes.

While successful management requires tight connection between these steps, there are numerous gaps, disconnects and break-downs that force individuals to engage in a lengthy and laborious trial and error process.

Keeping track of one's actions is notoriously difficult. Meal diaries, often suggested in diabetes, are rarely strictly followed and are usually recommended for short periods of time or in special cases. Painful fingerstick blood sugar sampling techniques prohibit probing beyond a few times a day. Such infrequent sampling may highlight longitudinal trends, but does not reveal the daily patterns. Consequently, attributing change in the blood sugar to a particular action is non-trivial. The last step of this cycle, action modification, presents a significant challenge in itself: full understanding of the negative consequences of certain actions may not guarantee the necessary change in the health behavior. In fact, this last step, individuals' ability to modify their behavior given full understanding of consequences, was challenged by the many physicians consulted in the course of the project.

Hypothesis-based reasoning

We introduced the cognitive probe to engage the participants in reflective explorations of and reasoning about the possible correlations between their activities and changes in the blood sugar readings. As different as our two participants were, daily interviews pointed to the similarity in their reasoning approaches. In both cases, within the first few days of the study, the participants formed a hypothesis regarding a particular causal relationship. Once the hypothesis was formed, they carefully monitored the data seeking evidence confirming their hypothesis.

Despite all the difficulties with the technology, the participation in the study heightened Mary's awareness of her daily readings, taken with both the GlucoWatch and the regular glucose meter. During one of the first days of the study days, her attention fell on a somewhat higher reading after eating a breakfast cereal containing raisins.

> *"You know, I am starting to notice that every time I have this new cereal, my blood sugar goes up; can it be possibly true?"*

Any negative consequence of raisins, as a natural product, seemed counterintuitive to Mary; however, this suspicion required further investigation. Each subsequent day's readings increased Mary's confidence in her conclusion. By the end of the study she was convinced that raisins led to the rise in the blood sugar. Dieticians consulted during the study confirmed the suspicion – due to their high glycemic index, raisins, as well as grapes, lead to a quick rise in blood sugar value. This discovery changed Mary's skeptical attitude to health monitoring; by the end of the study she was contemplating extending her participation.

Paul took a structured scientific approach: he spent the first day of the study keeping a close watch of the GlucoWatch readings while experimenting with actions (how quickly would my blood sugar change if I had a glass of orange juice?). He also sampled his blood sugar with a conventional glucose meter 5 times in one day to assess the accuracy of the GlucoWatch readings. The first event that drew his attention was a considerable jump in the values captured within a half an hour period:

> *"Could there? Does that make sense? Because other than the orange juice as a trial, I didn't eat anything. But I did have some excitement. I wasn't too excited, but may be I was because I was raising my voice more or less. Is that emotional involvement, is that possible?"*

Thus the first hypothesis was created. When discussing this event during the daily interview, Paul already presented it as his first discovery:

> *"Ok, so what I did was frustration with staff in setting up appointments for an MRI and consultation with neurosurgery. And that may have been, that may have affected the glucose inside."*

During the subsequent days of the study, Paul paid close attention to his emotional state, going through SAM [3] questionnaires, and even noting all agitated conversations in notes. All the subsequent readings seemed to confirm the suspected relationship between the emotional state and the high readings. Interestingly enough, he formed no new hypotheses, at least in the duration of the study.

These findings demonstrate the success of the cognitive probe: for the first time in their lives, our participants had access to such extensive retrospective records and could engage in reflective analysis. At the same time, the process of discovery the participants engaged in, alerted us to a potential danger. In the decision-making literature, hypothesis based reasoning is associated with a number of biases, for example the confirmation bias, or individuals' tendency to proactively search for evidence confirming their hypotheses, and simultaneously ignoring or discounting negative evidence [26]. Monitoring applications that simply visually present the captured data may inadvertently reinforce individuals' preconceived notions and biases, rather than facilitate genuine discoveries.

Opportunity space for computing applications

The three methods of investigation employed in the study outlined a number of directions for the design of computing applications that assist individuals in diabetes self-management. The limitations of the current self-management process, illustrated within the decision framework, provide ample opportunities for the ubiquitous and pervasive computing. The emerging sensor networks coupled with machine learning and data analysis tools can help individuals keep track of their actions in an unobtrusive way. New clinical monitoring devices can increase blood sugar sampling rate with non-invasive techniques revealing daily trends. The analysis of these data either by the individuals, or by data analysis algorithms could bring certain correlations to the individuals' attention and provide a basis for *informed action*.

The success of such applications, however, will depend on a number of factors. It became clear that the complex assembly and operation of the currently available clinical monitoring devices, such as the GlucoWatch, may render them inaccessible for untrained individuals. In addition, individuals' trust in such devices will depend on their accuracy. For example, one of Paul's questions that remained unresolved was in reference to the accuracy of the readings. Checking each GlucoWatch reading with a finger stick sample was impractical, if not impossible. Thus each new unusual or unexpected reading could be an indicator of an important trend, or a sampling error. At the same time, simple presentation of all the data captured during such monitoring may lead to the reinforcement of wrong assumptions and be subject to the "confirmation bias". Intelligent data analysis of true correlations and careful visualization techniques that highlight true patterns will help to avoid this potential limitation of monitoring applications.

While monitoring applications can help individuals learn about their disease, informing their actions may not always be sufficient to secure the desired change in the health behavior. Theories of behavioral change, such as Transtheoretical Model [23], argue that knowledge and information can best serve those who have reached a certain state of acceptance and readiness for change. Until then, individuals need for additional motivation may be addressed by *affective* or *persuasive* computing techniques such as those explored in [14] or [15].

CONCLUSION AND FUTURE WORK

In this paper we discussed opportunities to enhance self-management of diabetes identified by applying three research methods: qualitative interviews, observational study and a cognitive probe. While interviews and observations provided rich insights into current diabetes management practices, deployment of the probe highlighted judgments and reasoning involved in self-care.

These investigations demonstrate that individuals need to proactively engage in investigation of their disease, rather than merely relying on existing guidelines. Understanding the consequences of daily activities allows flexible negotiation of the balance between the desired lifestyle and health state. Lack of such balance may lead to feelings of deprivation and disengagement from the necessary self-care. The interpretive framework presented in Figure 3 helps to illustrate limitations of current diabetes management practices. While confirmation bias is a well-known psychological phenomenon, the deployment of CHAP exposed its potential implications for the design of the health monitoring applications.

These findings highlight a number of possible avenues for enhancing diabetes self-management. Monitoring applications can automate the steps of the decision-making process and help individuals draw correlations between automatically captured activities and blood sugar values. The success of such applications, however, will depend on such factors as ease of use and accuracy of the clinical monitoring devices and the choice of presentation of information to the users. Simple presentation of all the data captured during monitoring may be subject to the confirmation and other biases and lead to the reinforcement of wrong assumptions. Intelligent data analysis of correlations and careful visualization techniques that highlight evident patterns will help to avoid this potential limitation of monitoring applications. Additionally, computing applications can provide additional motivational factors to the individuals struggling to embrace the need for proactive disease management.

While our investigations shed light on our initial research questions they uncovered many others. In the current work we focused exclusively on *reflective* analysis of past activities. It is our belief that such analysis can contribute to individuals' general understanding of factors influencing their health. At the same time, the impact of this understanding on individuals' daily choices requires additional investigations. Simple daily activities such as cooking, grocery shopping or ordering a meal in a restaurant are subject to continuous and intricate interplay of health concerns, personal preferences and desires, social pressures, or self-image considerations. Computing applications that attempt to inform or influence daily activities need to account for these various factors.

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REFERENCES

1. Beckmann, C., Consolvo, S., LaMarca, A., 2004, Some assembly required: Supporting end-user sensor installation in domestic ubiquitous computing environments. *Proceedings of the Sixth International Conference on Ubiquitous Computing (Ubicomp 2004).* 6-10 September 2004. Nottingham, UK.
2. Bodenheimer, T., et al. 2002. "Patient self-management of chronic disease in primary care." *JAMA* 288(19): 2469-75.
3. Bradley MM, Lang PJ., 1994, Measuring emotion: the Self-Assessment Manikin and the Semantic Differential, *J Behav Ther Exp Psychiatry*. 1994 Mar;25(1):49-59
4. Card, S., Keynote Address: From Information Visualization to Sensemaking: Connecting the Mind's Eye to the Mind's Muscle, in Proceedings of the IEEE Symposium on Information Visualization (InfoVis'04) pp.: xii- xii
5. Consolvo, S. and Towle, J., 2005, Evaluating an ambient display for the home. In *CHI '05 Extended Abstracts on Human Factors in Computing Systems*

(Portland, OR, USA, April 02 - 07, 2005). CHI '05, pp.1304-1307.

6. Dourish, P., and Buttoon, G. 1998, On "Technomethodology": Foundational Relationships between Ethnomethodology and System Design. *Human-Computer Interaction*, 13(4), 395-432.
7. Fitton, D, Chevherst, K., Rouncefield, M., Dix, A. and Crabtree, A., 2004 Probing Technology with Technology Probes. Paper presented at the *Equator Workshop on Record and Replay Technologies*, February 12-13, London: Equator IRC.
8. Fishkin, K.P., Wang, M., Borriello, G. "A Ubiquitous System for Medication Monitoring," Pervasive 2004.
9. Gaver, B., Dunne, T., and Pacenti, E. 1999. Design: Cultural probes. *interactions* 6, 1 (Jan. 1999), 21-29.
10. Glaser, Barney G. Theoretical Sensitivity: Advances in the Methodology of Grounded Theory. Mill Valley, CA: The Sociology Press, 1978.
11. Hayes, G.R., Kientz, J.A., Truong, K.N., White, D.R., Abowd, G.D., Pering, T. Designing Capture Applications to Support the Education of Children with Autism. *Proceedings of UBICOMP 2004: The 6th International Conference on Ubiquitous Computing* (September 7-10, Nottingham, England), 2004.
12. Hollan, J., Hutchins, E., and Kirsh, D. 2000. Distributed cognition: toward a new foundation for human-computer interaction research. *ACM Trans. Comput.-Hum. Interact.* 7, 2 (Jun. 2000), 174-196.
13. Hutchinson, H., Mackay, W., Westerlund, B., Bederson, B. B., Druin, A., Plaisant, C., Beaudouin-Lafon, M., Conversy, S., Evans, H., Hansen, H., Roussel, N., and Eiderbäck, B. 2003. Technology probes: inspiring design for and with families. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (Ft. Lauderdale, Florida, USA, April 05 - 10, 2003). CHI '03, pp.17-24.
14. Intille, S. S., "Ubiquitous Computing Technology for Just-in-Time Motivation of Behavior Change (Position Paper)," in *Proceedings of the UbiHealth Workshop*, 2003.
15. Jafarinaimi, N., Forlizzi, J., Hurst, A., and Zimmerman, J. 2005. Breakaway: an ambient display designed to change human behavior. In *CHI '05 Extended Abstracts on Human Factors in Computing Systems* (Portland, OR, USA, April 02 - 07, 2005). CHI '05, 1945-1948.
16. Kaufman, D.R., Starren, J, Patel, V.L., Morin, P.C., Hilliman, C., Pevzner, J, Weinstock, Goland, R. & Shea, S. (2003). A cognitive framework for understanding barriers to the productive use of a diabetes home telemedicine system. In M. A. Musen, C. P. Friedman and J. M. Teich (eds.) *Proceedings of the American Medical Informatics Association Symposium*, Fall 2003 (pp. 356-360)
17. Mihailidis, A. (2002, November 9 - 12). Intelligent supportive home environments for older adults with dementia: Current and future Research. *Gerontechnology* 2002. The International Society for Gerontechnology Conference, Miami Beach, FL, Gerontechnology (Congress Issue), 2 (1), 133.
18. Morris, M., Lundell, J., Dishman, E., Catalyzing social interaction with ubiquitous computing: a needs assessment of elders coping with cognitive decline. *CHI Extended Abstracts* 2004: 1151-1154
19. Munguia Tapia, E., Intille S. S., Larson, K., "Activity recognition in the home setting using simple and ubiquitous sensors," in *Proceedings of PERVASIVE 2004*, pp. 158-175
20. Mynatt, E. D., Rowan, J., Craighill, S., and Jacobs, A. 2001. Digital family portraits: supporting peace of mind for extended family members. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (Seattle, Washington, United States). CHI '01, pp.333-340.
21. National Diabetes Association Facts and Figures Sheet, www.diabetes.org
22. Patel, V.L., Branch, T., & Arocha, J. (2002). Errors in interpreting quantities as procedures: The case of pharmaceutical labeling. *International Journal of Medical Informatics*, 65, 193-211.
23. Prochaska, J.O., Prochaska, J.M., Why Don't Continents Move? Why Don't People Change? *Journal of Psychotherapy Intergration*, Vol.9, No. 1, 1999, pp.83-101.
24. Rowan, J. and Mynatt, E. D. 2005. Digital Family Portrait Field Trial: Support for Aging in Place. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '05. pp.521-530
25. Wagner, E., & Groves, T. (2002). Care for chronic diseases. *British Medical Journal*; 325: 913-914.
26. Wason, P.C. (1960). On the failure to eliminate hypotheses in a conceptual task. *Quarterly Journal of Experimental Psychology*, 12, 129-140
27. Weiser, M., "Open House". in *Review*, the web magazine of the Interactive Telecommunications Program of New York University. March 1996, ITP Review 2.0.
28. http://www.glucowatch.com/
29. http://aspe.hhs.gov/daltcp/reports/meacmpes.htm
30. http://www.fda.gov/