Constructing Identities through Storytelling in Diabetes Management

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ABSTRACT

The continuing epidemics of diabetes and obesity create much need for information technologies that can help individuals engage in proactive health management. Yet many of these technologies focus on such pragmatic issues as collecting and presenting health information and modifying individuals' behavior. At the same time, researchers in clinical community argue that individuals' perception of their identity has dramatic consequences for their health behaviors. In this paper we discuss results of a deployment study of a mobile health monitoring application. We show how individuals with considerable diabetes experience found a unique way to adopt this health-monitoring application to construct and negotiate their identities as persons with a chronic disease. We argue that viewing health management from identity construction perspective opens new opportunities for research and design in technologies for health.

Author Keywords

Ubiquitous computing, reflection, learning, chronic disease management, diabetes

ACM Classification Keywords

J.3 Life and Medical Sciences: Medical Information Systems.

General Terms

Design

INTRODUCTION

Healthcare and health management are among the most pressing issues of the current time. Despite significant media efforts to raise individuals' awareness of the need for healthy lifestyles, epidemics of diabetes and obesity continue to grow in the US and other industrialized nations. Not surprisingly, there is a growing effort within different research communities to develop new methods and techniques to help individuals gain control over their health and wellness, manage chronic diseases, and generally adopt healthier lifestyles and habits.

Researchers in HCI have proposed a wide range of tools to help individuals manage their health. Often, these applications couple pervasive and persuasive computing techniques to encourage individuals to achieve positive changes in their behaviors and appreciate the effects of these changes [11, 26, 29]. At the same time, a growing number of applications focuses on fostering learning and sharing of experience within patient-centered communities (e.g. patientslikeme.com and tudiabetes.com).

In our own work, we investigate the potential of computing technologies to help individuals with diabetes improve diabetes management skills through reflection on their past experiences. Our research platform, MAHI (Mobile Access to Health Information), helped individuals with diabetes record free-form accounts of their diabetes experiences (voice, image, text), review these accounts against their daily blood glucose values, and reflect on the records with the help of a diabetes educator. Following the general spirit of probes [16], one of our main design goals was to build MAHI as an open and flexible application to allow individuals to develop their own patterns of engagement.

For our first study with MAHI, we recruited newly diagnosed individuals with diabetes who were attending diabetes education classes [30]. The study demonstrated that individuals engaged with MAHI primarily as a problem-solving tool that helped them to trouble-shoot such issues as problematic blood glucose (BG) values or confusing dietary choices. As a result of their engagement with the application, MAHI users were more likely to reach their diet management goals and adopt an internal locus of control than individuals in the control group.

MAHI proved to be successful in helping newly diagnosed individuals improve their approaches to diabetes management. However, these results left open the question of whether MAHI's impact was specific to this particular user group or they could generalize to a broader range of users. In order to address these questions, we deployed

CHI 2010, April 10–15, 2010, Atlanta, Georgia, USA.

MAHI with regular attendees of a diabetes support group; many of them had over 10 years of diabetes experience.

Despite the consistency of the technological platform, this new user group engaged with the application in a starkly different way. These individuals collected on average twice as many records and their average records were twice as long. At the same time, they showed little interest in using MAHI for problem solving and trouble-shooting. Instead, they embraced MAHI's free-style capture features to record rich, intensely personal stories, many of which were not exclusively related to diabetes management.

Our analysis of these stories revealed several distinct motivations. Some of these stories helped individuals address their negative emotions and reaffirm their positive attitude to health management. Other stories helped individuals re-establish their confidence in their competence and ability to manage their health. Yet others helped them to maintain a consistent sense of self, and create a link to their lives from before they were diagnosed with the disease. Researchers in social sciences argue that these three driving factors are the essential components of constructing one's *identity* [15]. As a result, we propose that the participants used MAHI as a springboard to construct and negotiate their identity as persons with diabetes.

Our findings have two important implications. On a broader level, they present additional evidence that individuals can successfully adopt a technology even if they interpret it differently than its designers. In this study, MAHI users essentially ignored its primary purpose of supporting reflection and problem-solving. Instead they embraced the flexible and open-ended nature of interactions possible with MAHI, thus addressing more relevant for them issues of identity management. Nonetheless, the intensity and consistency of their engagement with the technology is a reliable indicator that the application had a real value.

More specifically, this research demonstrates the critical role identity can play for chronic disease management. Researchers in the clinical community argue that individuals' self-image and their ability to integrate their disease with their overall identity have dramatic impact on their ability to actively manage their health [35]. Yet the majority of computing applications that support health management focus on more utilitarian goals, such as collection and presentation of health records and behavior change. Our findings suggest that computing technologies can play an important role in helping individuals address more subtle, but perhaps more challenging aspects of diabetes management, such as constructing and maintaining an identity of a person living with a chronic disease.

MAHI

Design

MAHI [30] was designed as a mobile application developed for a Nokia N80 phone as its main interaction platform, complemented by a web-based application. To support individuals' reflection MAHI used the photo and audio capture capabilities of the phone to allow individuals record anything that was relevant for their diabetes management. This feature, an ability to make unstructured, free-form records using voice, image and written text became a critical affordance of the application in the study we discuss here; it allowed our users to adopt the application to their own needs and essentially redefine its nature. A custom-built Bluetooth attachment for a commercial glucose meter helped to integrate activity records with blood sugar values. To further assist individuals, MAHI included features to facilitate a written discussion with a diabetes educator using a discussion board.

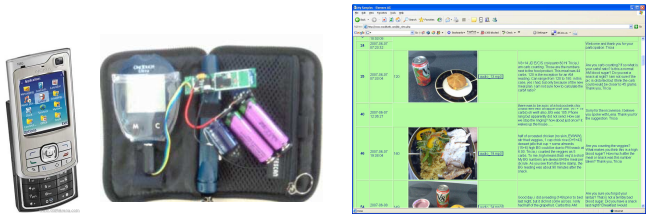

Figure 1: MAHI

Deployment study

The study we discuss in this paper was primarily designed to determine whether the results achieved in the first MAHI study were unique to the newly diagnosed individuals, or whether they would hold for a broader user base, for example for individuals with more extensive diabetes experience (over 5 years).

For this study we recruited attendees of a diabetes support group, hosted by the Diabetes Education Center in Dover, NJ. Eight individuals, all core members of the support group, volunteered to participate in a 12-week study. All individuals knew each other, and all knew the diabetes educator who was also the moderator of the support group. The members of the research team introduced MAHI in one of the group meetings; all volunteers were given a brief tutorial on MAHI features. All the participants were interviewed upon the completion of the study to assess their experience with the application.

During the study individuals collected a significant number of records (over 95 records per person on average, with the total of close to 600 records). All these records were analyzed using methods common for the Grounded Theory approach [34]. At the beginning of our analysis, we attempted to use the coding scheme developed in our earlier studies of the newly diagnosed individuals. However, it became quickly apparent that this coding scheme was not sufficient to account for the new patterns within this data. As a consequence, all the records were re-analyzed using a bottom-up, inductive analysis approach allowing for the categorization scheme to emerge from the data. As a result we identified storytelling as the main genre of individuals' interactions with MAHI and came up with 12 general

categories describing the stories. In the subsequent axial coding phase, we condensed these categories to 3 main themes.

As the results of our analysis we identified three main motivating forces behind individuals' stories. These forces included: 1) the need to maintain a positive self-image, 2) the need to reassert one's competence and 3) the need to maintain continuity in one's self-image over time. Combined, these driving factors encapsulate individuals' efforts of constructing and managing their identity. In the next section we will discuss storytelling as the most common genre that participants used for their records. We will then discuss how individuals' stories served as a vehicle for constructing their identities as persons with diabetes.

STORYTELLING AS EXPRESSION OF SELF

In the earlier studies of MAHI, the majority of the records and discussions between the individuals and the educator revolved around solving specific diabetes-related problems. They commonly started with the participant identifying a problem—a moment of confusion in an individual's routines. After some negotiation of the problem's nature, the educator asked a series of questions that helped her both refine her understanding of the problem and also demonstrate to the participants how to engage in solving problems by interrogating the data, formulating and testing hypotheses. An important note in regards to all the excerpts presented in this paper is that whenever we refer to discussions between the educator and the participants, we talk about written discussions captured on the MAHI website, rather than personal face-to-face discussions between individuals and the educator. Below is the typical sequence of messages that represent the problem-solving genre:

Blood glucose value: 165

S3 (audio record following BG reading): This is my early morning fasting reading and I don't understand why I can't seem to get this number down. My numbers during the day are between 115 and 200, but my morning ones are always high.

E: That is a very common question and also frustrating. What time was dinner? Did you have a chance to consume a snack? The long time span between dinner and AM often causes the increased number. Remember that after about 4 hours the liver needs fuel. A snack of 1/2c fiber cereal + 1/2 c lowfat milk will help bring this number down.

In contrast with this example, more experienced individuals enrolled in the second study demonstrated little need for joint problem solving. These individuals experienced fewer unexpected and unexplained problems, as they already had a relatively sophisticated and accurate model of the disease and required little scaffolding in solving the problems. Instead, these individuals used MAHI to record rich, intensely personal stories mixing voice notes with images and text written on the MAHI website.

The stories individuals recorded varied greatly in their structure and composition, as well as their richness and level of detail. At time these stories were carefully and purposefully crafted, had a clear narrative, and even a moral:

P (written on the website): I wanted to tell you a story: I went to a memorial service of a friend's mother last night. I had an overweight friend come with me. After they went to Charlie Brown's. I had two turkey wraps each smaller than my fist (ok) 3 potato strips with cheese (bad) celery, carrots, cucumber slice (ok) hot chicken wing, regular chicken wing and 3 mozzarella sticks (not good) and ice tea (I drove). **Moral: don't eat with bad examples.**

More often, though, the stories were not as well defined and crafted, but rather more spontaneous, and were meant to capture the spirit of the moment, or an individual's state of mind or emotion:

P: Snack at target. I only had 1/4 of the bag because I thought I lost my credit card. After searching for 2 hours, retracing my tracks I finally found it at home. I was really hot, (searching thru my messy car with a million napkins, papers and other stuff) and anxiety at thinking my card was lost. I now put my little fan on full blast right at me. Whew!

(a record made a few minutes later) My fan.

Oftentimes, individuals used stories as a wrapping to the more straightforward records of diabetes-related activities, such as meals. These records not only included all the factual details of their activities but also provided an emotional, often humorous, at times ironic context and backdrop for the activities of interest. For example, in the excerpt below the emphasis is not on the nutritional value of the meal, but on the productivity value of the evening:

P: **I accomplished nothing last night!** I ate a 100 calorie bag of Sun chips and triscuts with 3 slices of cheese while watching My Big Fat Greek Wedding.

The stories discussed so far evolved around mundane and seemingly insignificant subjects that nonetheless had

particular significance for the participants at the time when they were recorded. Other stories were more profound and deeply emotional, and referred to defining moments in individuals' lives. Below is an example of such a story. It was composed in response to a relatively innocent question from the educator regarding the age of a participant's glucose meter.

E: How long have you had the meter? It is recommended to exchange meters about every 2 years.

P: answer: I have had my meter since Nov. 04. I had my diabetes training during one of the roughest parts of my recent life. My Mom was dying of Alzheimer's and although I had a woman living with her, I was in charge of pills, finances and shopping. My daughter was expecting her second child in Florida and her doctor was considering bed rest. I was retired, but torn between the two obligations. My granddaughter was born in February and Mom turned worse and my sister put her in a nursing home when I was at my daughter's home. Mom died the end of March. Then I had to clean and sell her house. This was my life from Nov. 04 to March 05.

In contrast with the first MAHI study, the stories captured in the second study rarely generated a reciprocal discussion. More often than not, individuals' stories were constructed as monologues, with the educator contributing short sympathetic acknowledging remarks. While these stories were clearly constructed with the full awareness of the educator as the audience, they were not meant to engage her in a discussion but rather had an intrinsic value for the individuals.

These stories show the drastic difference in the way our new participants adopted the application. The participants in our earlier studies enthusiastically engaged with MAHI primarily as a problem-solving and trouble-shooting tool; they collected records as raw material to be analyzed and processed. In contrast, in our second study, individuals used MAHI like a blog, composing stories, simple or complex, mundane or profound and deeply felt, humorous or sad, with a clear narrative or without one, but all intensely personal and reflective of individuals' moods, desires and thoughts of the moment. Our bottom-up categorization of these stories aligned with theoretical framings of identity management, especially in situations of external change. In the next section we describe the three main motivating factors behind individuals' stories that suggest that these stories served as a vehicle for individuals' identity construction and management.

CONSTRUCTING IDENTITIES THROUGH STORYTELLING IN DIABETES MANAGEMENT

Asserting Positive Self-Image

The first step to asserting a positive self-image is removing obstacles to creation of such an image and acknowledging and addressing negative aspects of individuals' perception of self [15] In our deployment study, addressing negative emotions was one of the most prominent themes of the records made by the participants and their conversations with the educator. The excerpt below is indicative of many such records saturated with frustration and bitter acceptance of what it means to be perceived as somebody with diabetes:

(a conversation about an inflamed cut on a foot written on MAHI website)

P: He (MD) said it was infection, which made the cells inflamed. Apparently this is common. **He has another patient with the same thing and asked me what we had in common. I said "Diabetes" and he said "Bingo!"**

Sometimes, these sentiments took the form of irony and self-deprecating humor:

P: After class, I had a glass of wine, turkey on a Martins whole wheat roll, 1 cheese not bad but then 2 sticks of string cheese w. turkey and 4 Triscuits. **I went to bed rather than devour the kitchen.**

Another step in constructing a positive self-image is in contextualizing, explaining, and justifying behaviors that are not consistent with this image. From this perspective, many records of sub-optimal choices were accompanied by remarks that either provided mitigating context, or other explanations for these uncharacteristic decisions. Poor dietary choices were not consistent with our participants' perceptions of themselves as responsible and knowledgeable individuals in control of their disease; clearly they knew better, however, external circumstances forced them to temporarily lower their standards:

P: Yesterday Tim ended up is the emergency room with kidney stones… so it was a bit stressful and dinner was cheese and crackers last night.

P (next morning): **Dinner was very unorthodox last night; I was embarrassed to take a picture.** Tom wanted Chef-Boy-Ardee pasta and meatballs. I had about ½ cup of that, corn on the cob and cantaloupe as a snack.

Often, these comments were made in anticipation of the educator's critical judgment of individuals' choices:

P (voice record taken together with a picture of a meal): **Don't get up there,** I am not eating this by myself, I am sharing it with a friend.

Erez and Earley [15] argue that much of identity construction is driven by the basic need of individuals to maintain a positive self-conception. "One manifestation of the need for self-enhancement is the general tendency to distort reality, through selective perception and bias in attribution, in the service of maintaining a positive self-conception [15]. In our study, whether the participants were

directly talking through their negative emotions, or were justifying and explaining their sub-optimal choices, their main concern appeared to be in maintaining that positive image of self as able, confident and competent. This last attribute, competence was another salient theme in the individuals' interactions with MAHI, which we discuss in the next section.

Reaffirming Competence

Not all individuals' interactions with MAHI took the form of storytelling; some records were more straightforward and familiar to us as indications of problems or challenges that individuals experienced. However, and in contrast with our earlier studies, in an overwhelming majority of cases, these participants were able to immediately offer probable and often correct explanations of underlying causes:

P: I just tested my sugar two hours after eating breakfast and this is something I never understand. It's still pretty high. I think it was 200. And I thought I ate… had a bowl of cereal, had some milk, didn't overdo it. I didn't start out that high. You would have thought that it would have gone down 2 hours later a little. **Now, I know I've been sipping coffee around 7:15 or so, but I don't know if this could have made that much of a difference.**

Similarly, even when these participants asked questions, they quickly transformed these questions into a form of reassurance of one's competence and efficacy:

Participant: I am a little confused though if it's 2 hours after you start eating, or 2 hours after you've stopped eating (laughs).

Educator: Two hours from when you start eating.

Participant: **Thank you, that's what I thought.**

This finding is perhaps not surprising; after all, these individuals seasoned in diabetes management possessed the necessary knowledge and problem-solving skills. At the same time, the way they proposed their explanations suggests that they took some comfort and pride in reaffirming their competence, for example their ability to convert even a very unhealthy meal into a rather healthy version:

P: **This Chinese was not as "Chinesy" as a regular Chinese restaurant.** If you pick the baked/poached salmon, spinach with cheese (I scrape most of the cheese off), mushrooms (with as little sauce as possible from mushrooms and chicken), the string beans (extra sauce shaken off), the wontons from wonton soup and add the hot and sour soup with the tofu. Sometimes I have the ice-cream instead of the fruit (depends on the fruit.

Albert Bandura [2] proposed the term "self-efficacy" to describe a phenomenon similar to what we observed in our study. In his definition, self-efficacy is "a judgment of one's capability to accomplish a certain level of performance". The records of individuals' interactions with MAHI showed that it was important for the participants to constantly reaffirm their competence in managing their disease and their ability to maintain the desired level of control over their lifestyles choices and, as a result, their health.

Maintaining Consistency

Diabetes introduces a major disruption to daily routines and activities. Once diagnosed, individuals need to make, at times, significant adjustments to their lifestyles, questioning and analyzing such routine activities as grocery shopping, cooking and eating meals. Perhaps because of the disruptive nature of the disease, it becomes important for individuals to maintain a strong sense of connection with their habits and preferences before they were diagnosed with the disease and coherence in their sense of self.

In many of the records and discussions captured with MAHI, the participants talked about their old routines and things they like to do. The few excerpts below are very typical of this type of record:

P: Hi Pam, this is Sally and Tim. We are having breakfast/lunch. As you can see it's pretty late. **We tend to be late on weekends.**

P: **I tend to eat differently on weekends.** I usually eat a larger breakfast and dinner. We are usually off doing something and only eat 2 meals on the weekend. Sometimes we will have something light in-between breakfast and dinner but not always.

Similarly, oftentimes the participants insisted on maintaining some of the more cherished family traditions, however unhealthy or whatever their impact may be. For example, in the excerpt below, the participant is happy to indulge in fresh, bakery-baked bread, regardless of its content of carbohydrates:

E: Is that bakery wheat? Nothing to eat until now? Is the time right when you checked you sugar this AM?

P: Yes, it is from the bakery. **We usually never buy bread from the store. It's a bit heavier on carbs, but it's worth it (laughs).**

Below is another, perhaps even more typical example of individuals' conscious choice of a clearly unhealthy meal that is a part of the individual's long-established routine.

P (voice recording): This is about a couple of hours after lunch, and about an hour or 40 minutes after eating a bag of popcorn, which I had after lunch. It was good too(chuckles).

E: What kind of popcorn that it was so good? Did you have enough carbs at lunch In other words, were you hungry or just saw the popcorn and decided to eat?

P: **I had enough carbs at lunch, but I always get this popcorn from Target. It has all the bad oils, is more salty than I like, but tastes good when it is fresh, which it was at this time.**

Many records taken by the participants, as in the excerpt below, may look somewhat odd and perhaps meaningless, given the purpose of MAHI as a tool for health monitoring and management. However, these records of simple activities with no connection to the disease, helped individuals to re-establish some normalcy, rhythm and order in their lives and create a continuity in their perception of self:

P: These are from my wild raspberry bushes. I had them on Sunday. I have lots more to pick up when they ripen more – but I'll have to remember to wear long pants and shirt, so I don't get more scratches.

One of the main aspects of individuals' identity is this sense of continuity over time. "The sense of continuity and consistency helps individuals to connect events in their current social life to past experiences and to maintain a coherent view that enables them to operate effectively in the environment [15]." This continuity of identity and self-image persists even through major events, such as marriage and changed jobs, and, as our study shows, through diagnosis of diabetes. Our participants took some effort to hold onto routines and practices that reminded them of their lives before diabetes and helped them to maintain the coherent sense of self.

Assessment of MAHI impact

To assess MAHI's impact of MAHI on individuals' health management practices we deployed a number of qualitative and quantitative measures. Our goal was to asses its impact along several different directions including: 1) individuals' cognitive state, for which we used a diabetes understanding questionnaire developed by the Diabetes Education Center; and 2) their attitude towards the disease, for which we utilized the Health Locus of Control questionnaire. Both questionnaires were deployed twice, before the study began and upon its completion. These measures were consistent with the ones utilized in our first study. We complemented these quantitative measures with qualitative open-ended interviews with the participants upon the completion of the study. The interviews were meant to assess individuals' overall experience with the application.

Neither of our quantitative measures returned statistically significant results. The review of the data suggested that our measures, while appropriate for the newly diagnosed individuals, were not sensitive enough to capture any changes for the more experienced individuals. Both measures for participants in the second study produced a ceiling effect: the majority of them achieved a perfect score on the diabetes understanding questionnaire prior to enrolling into the study, and the majority of them already had an internal locus of control.

The qualitative interviews, however, revealed that most of the participants had come to rely on MAHI as a source of comfort and reassurance. They became attached to the possibility of "talking through things" with the application, although few of them felt that they were talking directly to the educator:

I knew she was there and that she read everything, but I think sometimes I was just talking to myself.

These comments from the closing interviews further confirm our conclusion that individuals' stories and storytelling had an intrinsic value for the participants in helping them address some of the more pressing aspects of constructing their self-image as a person with diabetes.

BACKGROUND

Even with an initial cursory look at our data it became apparent that this study was not about reflection, reasoning and problem solving as we originally expected. The rich stories we were finding in the data, expressing individuals' concerns about their positive self-image, their competence and self-efficacy, and the coherence and consistency of their self overtime brought to our attention the issues of identity construction and management. In this section we discuss some of the relevant concepts in regards to identity management and relate our findings to the existing body of work in this area.

Explorations In Identity

In the 1960s, psychologist Erik Erikson popularized the term 'identity' to describe the formation and continuing development of a 'sense of self' or 'self-concept,' most active in adolescents but continually refined throughout life. For Erikson, identity construction was the mechanism by which people move through life stages, continually "fitting self to context." [14].

For Erikson, a unitary sense of identity is constructed after a successful search for who one is. However, other perspectives of adolescent development view the construction of self as one that involves multiple "public" selves, which are presented according to the demands and constraints of particular situations [20]. In a way, one could distinguish two different but tightly interrelated views of identity: individuals' self-perception, *ego-identity*, shapes their projected social image, *social identity*, which in turn affects their perception of self.

Since Erikson, the term 'identity' has taken on many new shades of meaning as it has been adopted by the social sciences. Increasingly, it is the social aspect of identity that dominated the more self-centered view. Foucault [19] represents possibly the most extreme version of the 'social identity' spectrum, asserting that "nothing in man—not even his body—is sufficiently stable to serve as a basis for self-recognition or for understanding other men." [19]

The notion of self-image constructed and negotiated with the perception of others can be traced back even earlier than the concept of identity, to the writings of Cooley [12], who introduced the idea of a "looking-glass self". In the looking-glass self a person views himself or herself through others' perceptions in society and in turn gains identity. This idea is further and rather dramatically developed by Goffman [17], who described individuals' identity management as theatrical performance in which individuals actively construct the image that will help them achieve their goals.

We argue that in a way, MAHI served as a springboard, or as Cooley's looking glass, thus helping individuals rehearse and practice their projected self-image. It provided them with an audience, albeit a very limited one; only the diabetes educator could view and respond to individuals' stories. However, the monologue-like nature of the records leads us to argue that the stories had an intrinsic value, even given the limited audience. The process of reflecting on their experiences, and talking through some of their pressing concerns was helping individuals negotiate their self-image as persons with diabetes.

Constructing Identities with Technology

Much of what is written about identity management places particular importance on managing impressions through bodies. These issues became particularly intriguing with the introduction of computing technologies. "While physical constraints such as the body, biological sex, race, or age can have a profound effect on self-definition and self-presentation [10], many of these attributes become flexible in online environments." [25] The potential of online environments to redefine individuals' self-expression, and as a consequence, construction of self, attracted much attention in computer-mediated communication environments such as chat rooms, newsgroups, MUDs, and blogs [5, 13, 18, 22, 36].

Sherry Turkle was one of the first to examine individuals' expression of self in the digital domain. In 1984, Turkle introduced issues of identity and the 'looking glass self' to the HCI community [36]. For Turkle, the 'second self' was the vision we form of ourselves as we "catch sight of our images in the mirror of the machine." [ref, 36. p. 9]. Turkle argued that the Internet can facilitate multiple identities, allowing people to 'cycle' through different selves, erasing hard boundaries between real and digital, life and fiction.

More recently, the issues of identity construction have been actively explored in the domain of Social Network Sites. (SNS) Several of the defining characteristics of SNS, such as public profiles and publicly visible social networks are essential components of identity management. In her account of teenagers' use of MySpace, danah boyd discusses how teenagers "write their identities and communities into being." [4] In MySpace, boyd argues, "teens are inclined to present the side of themselves that they believe will be well received by their peers." Because the same social structures and views that regulate "coolness" in the physical world also exist online, their behavior online is subject to the same standards that exist in the real world.

Another area where identity issues are at the forefront of researchers' attention is online support communities. Høybye at al [24] found that storytelling was a common interaction genre in online support communities. They examined the motivations of participants in the breast cancer support group and found that the women felt empowered by the exchanges of knowledge and experience within the support group. Likewise, Hayes et. al [21] reports on the deeply personal nature of the "journey of chronic cancer care" and the sometimes very public discussions of successful and unsuccessful cancer treatments.

MAHI was not designed to support identity construction; its design emphasized reflection and problem-solving. It did not include any established features for the management of digital identities, such as public profiles or visible social networks. Nor did it provide individuals with the rich and diverse audience for their stories, as would have been the case if MAHI was designed as an online community. Yet we saw that MAHI's affordance of attaching unstructured notes allowed the participants to go beyond mere cataloguing of experiences to recording stories, anecdotes and other rich expressions of self. This unexpected appropriation of the application opens a question regarding the role of technology in helping individuals construct their identities in context of chronic disease management.

Diabetes as Identity Crisis

The issues of identity management have a special relevance for those living with chronic conditions such as diabetes. Identity construction involves maintaining a delicate balance between one's body and surroundings, within a social and cultural context. Loss of control over individuals' bodies, whether impaired motor function or dramatic weight fluctuation, upsets this balance and requires a re-evaluation of their identities.

Researchers argue that identity issues may be a major contributing factor to the variations in self-care behaviors for such diseases as asthma [1] and diabetes [27]. They find significant differences in self-care between individuals who "accepted their chronic condition as part of their identity and those who rejected their illness in both a personal and

social sense and would ignore or only partially adhere to treatment" [35].

In extreme cases, a chronic disease may even cause what Erikson termed an 'identity crisis.' [14] For Erikson, an identity crisis was a signal of a shift in life stages, most often associated with adolescence, but not limited to young people: "Identity involves a sense of continuity of self images over time, a continuity that may be disrupted when puberty creates radical alterations in one's physical appearance." [14] In a similar, and sometimes similarly dramatic matter, chronic diseases such as diabetes disrupt continuity in individuals' sense of identity and force them to redefine their perception of self and their social interactions. As a consequence, they lead to what Charmaz describes as a "diminished self-concept" (9, p.168), referring to it as a "fundamental form of suffering." Charman describes a dramatic case of an identity crisis in a 26-year old female with type 1 diabetes, who was unable to integrate her new diabetic self with her overall personality. As a result, her illness became the prevailing feature of her life and her identity. As an act of rebellion and rejection of her new identity she refused treatment and developed severe complications at a very young age.

The stories individuals recorded with MAHI resonate well with the loss of continuity and diminished self-image. As we showed in the previous sections, continuity and coherence in individuals' sense of self and, specifically, the connection to their selves before the disease was of utmost importance. In their stories, individuals often returned to their most cherished practices that were worth preserving regardless of their health impact. They found many opportunities to remind their audience, and to themselves, of their competence and mastery in managing their disease. And they used their stories to talk through their negative emotions regarding the disease, their frustration of being perceived as somebody with diabetes and their constant struggle to not be defined by it.

DISCUSSION

The findings we discussed in this paper have two broad implications. On one hand they once again show that given the opportunity, individuals engage with technology in unique and personally meaningful ways that may not match the expectations of technology designers. However, this disagreement does not necessarily preclude individuals from adopting the technology. At the same time it raises the attention of the research community to the importance of identity in chronic disease management and a question of whether and how it could be addressed in applications for health management.

Designing for Flexible Appropriation

The issues of adoption and appropriation of computing technologies by their users are an integral part of the ongoing discourse within the HCI community. Many researchers argue that multiple interpretations of technological artifacts by their users are inevitable, particularly in the area of non-professional use. For example, Nardi et al describe the use of instant messaging for "outeraction" [32] and Voida et al describe the use of iTunes as an ad-hoc awareness mechanism [37].

As a consequence, HCI researchers suggest that open implementation and flexible design should be considered as mechanisms to support flexible appropriation [33].

Our study provides additional evidence and further contributes to this ongoing discussion. Because MAHI was designed as a probe, it included considerable flexibility in the interaction styles. The participants of the two MAHI studies were given the opportunity to record combinations of voice notes, photographs and written text about anything they viewed as relevant to their health. As a consequence, some of them focused on solving diabetes-related problems that created continuous interruptions in their daily routines. Other individuals chose to record intensely rich personal stories that helped them construct and negotiate their self-image as persons with diabetes.

The study showed that designing MAHI as a probe was a successful strategy for designing MAHI as an application. Instead of trying to cluster potential users of diabetes management applications (as we had done in our studies, separating novices and individuals with considerable diabetes experience) and target each group with particular design features, MAHI allowed each subgroup to find their own way to appropriate the same basic functionality. At the same time, the consistency of low-level interactions (all participants took pictures, recorded voice notes, and engaged in written discussions with a diabetes educator) opened a possibility of bringing together different user groups who may have different expectations and as a result interpretations of the same technology. More research is needed to determine whether exposing individuals to different interpretations and interaction styles will enrich their own engagement with technology or will lead to a clash of values and interpretations.

Constructing Identity with Technologies for Health Management

MAHI enabled identity management by its flexible design and free-form nature of interactions. At the same time, there are a number of known mechanisms that can more explicitly help individuals address these issues.

Health-monitoring applications can borrow techniques from Social Network Sites. In particular creating publicly viewable profiles can help individuals to bring to the forefront the most salient aspects of their selves. In a similar way, constructing individuals' social networks can help to reinforce their social identity by highlighting their affiliation with particular individuals and groups.

In addition, health management technologies could take lessons from educational technology research into virtual worlds and immersive environments, or what Bers calls

"Identity Construction Environments." [3] In Bers' 3D virtual world, Zora, adolescents and teens create ad modify private and public places and objects, and, more importantly for identity construction, attach stories to these objects in a way that helps them formulate personal interpretations of the virtual world.

Consistently with Bers, our own study showed the potential of storytelling to assist individuals with constructing and managing their identities. In a similar vein, Holland et al [23] discuss a compelling case of identity construction through socially mediated storytelling using the example of Alcoholics Anonymous. In their analysis they show how personal stories of alcohol abuse told by the more senior members of the group provide a prototype and example of an alcoholic's life. Storytelling has been recognized as a powerful technique in diabetes education. According to Carter at al: "stories can allow the positive power of words to create a new empowering vision of the future and reshape the way one thinks about disease." [6]. Computing applications could provide sophisticated mechanisms to support and nurture these practices. For example, the iTell application by Landry and Guzdial helps individuals compose stories about personal experiences using digital photographs [28]. iTell walks its users through the steps of the narrative composition process, such as Brainstorm, Organize, Writing and Add Personal Media. The application encourages its users to think of a storyline, the characters and other necessary components of a narrative in a more systematic way. Similarly, health management applications could help individuals compose more compelling personal stories by suggesting their elements and guiding users through the composition process.

Supporting identity construction and in particular storytelling, may lead to new challenges. First of all, they may present new demands on the diabetes educators or other clinical professionals who facilitate individuals' interaction with health management applications. The increased intensity of individuals' interactions with the application, their longer and more intense records required the educator to dedicate more time addressing individuals' concerns. Furthermore, issues of identity construction may require a different type of expertise than dealing with more straightforward aspects of diabetes management.

CONCLUSIONS

In this paper we presented an extension of our earlier research in investigating computing applications that help individuals with diabetes manage their health. In these earlier studies, we deployed a mobile health monitoring application, MAHI, with newly diagnosed individuals with diabetes. During the study these individuals enthusiastically engaged with MAHI as a problem-solving and trouble-shooting tool to address the many diabetes-related challenges they faced on a daily basis. In our second study, we deployed the same application with individuals with considerable experience managing diabetes. The study showed that despite the consistency of the technological platform, our new participants engaged with the application in a very different way. Instead of using it as a problem-solving tool, they utilized free-form capture capabilities of MAHI to record rich, intensely personal stories. Our analysis of these stories revealed that they were motivated by three main drives: the need to maintain a positive self-image, the need to re-affirm individuals' competency in managing the disease, and the need to maintain a continuity in one's self-image and a link with their self before the disease. These themes lead us to propose that individuals used MAHI as a springboard to construct their identities as persons with diabetes.

MAHI was not designed to support identity construction. The flexibility of the capture mechanisms allowed individuals to adopt the application to their own needs and essentially redefine its nature. However, computing technologies for health management can more specifically and explicitly address individuals' need for identity management. Following social computing applications, such as Social Network Sites, they can offer more explicit features for identity management, such as public profiles and friend lists. In addition, they could offer richer support for storytelling for example by helping individuals construct narratives using text or other digital media. The efficacy of supporting identity management for creating positive outcomes remains an open question. Future research will show whether and how to incorporate identity construction into the design of computing technologies that create positive impact on individuals' health.

ACKNOWLEDGMENTS

We would like to thank Patricia Davidson and the personnel of the Diabetes Education Center, Dover, NJ for their invaluable assistance in running this study, OIT GT for their generous donation of the cell phones, and ECL lab and Mike Terry for assistance in writing and editing this paper.

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