Long-Term Engagement with Health-Management Technology: a Dynamic Process in Diabetes

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Abstract

Diabetes management is a complex, dynamic process that is largely incumbent on patient choices and behavior. We explore how health-management needs—and the needs for technological support—change over time for individuals with diabetes. Through interviews and a focus group, we found that after initial diagnosis, individuals face acute information needs and chiefly turn to mobile applications and Internet resources to help understand the diabetes-specific factors that affect their health. Over time their focus shifts from highly regimented routines to more flexible ones that enable them to maintain a quality of life. Our results suggest that long-term engagement with health technology does not necessarily require continuous, sustained use: routine disease management could lead to a decrease in use, until a new event occurs. Our findings point to a need for tools that help patients with diabetes to effectively manage their health as their bodies, treatment and circumstances change over time.

1. Introduction

Diabetes is a common, chronic disease that affects 346 million people worldwide, and is predicted to become the seventh leading cause of death by 2030[1]. There are two main types of diabetes: Individuals with type 1 diabetes (T1D) have a deficit in insulin, whereas those with type 2 diabetes (T2D) have an increased resistance to insulin. Diabetes leads to increased risk of cardiovascular events, is the leading cause of kidney failure and amputations, and is a major cause of blindness. Patients that can reduce their average blood glucose level (HbA1c), control their blood pressure, and treat their cholesterol can delay the onset of these complications. Yet only one in eight individuals achieves these three goals[3]. Such low rates of adequate self-management suggest that the standard model of care delivery consisting of short, infrequent visits with care providers conveys insufficient support for effective health management, including managing medications, improving diet, controlling weight, increasing physical activity, and smoking cessation[4].

In recent years, mobile technology has emerged as a promising way to provide additional support for self-management[5]. Adoption of smartphones and other mobile devices has grown exponentially in all age groups and socioeconomic classes[6] and applications for diabetes and wellness have flourished[7]. The available smartphone applications for diabetes are diverse, and allow individuals to track activities, medications, or diet, as well as to visualize the results in graphs. These types of applications offer new ways of supporting the challenge of diabetes self-management, and they have shown promise in clinical trials. A meta-analysis of 22 trials assessing the effect of mobile phone interventions on glycemic control showed a reduction of HbA1c of 0.5% over a median of 6 months' follow-up duration[11]. This effect was shown to be greater in individuals with T2D than in T1D[11]. Early work on the use of mobile phones for diabetes management studied the use of phone calls or text messaging[8, 12]. Newer studies focused on tracking applications (insulin, diet, blood glucose, and weight, for example), educational content, or integration with other systems, such as personal health records and social media[7]. Ralston et al found that the use of secure messaging with providers improved HbA1c results by 0.7%[13]. Combining mobile device and provider support, a randomized controlled trial with WellDoc Diabetes Manager[TM], a FDA-approved application that offers automated clinical coaching based on the data that patients track and supports sharing of that information with care providers, showed a 1.2% decrease in HbA1c with web- and mobile-based tools compared to usual care over a year[8]. This result suggests that mobile technology might be even more effective as a part of a comprehensive suite of technological tools.

Whether these preliminary efficacy results are an accurate picture of the benefits that mobile technology could have on diabetes self-management is unclear. In studies with a longitudinal design to assess the clinical impact of technological interventions for diabetes self-management[8, 12, 14, 15], researchers often classify irregular use of technology as a failure in use. However, the lack of use could be due to a number of factors, including a mismatch between the evaluated technology and the current stage of the patient's condition or technology design that doesn't enable patients to sufficiently adapt the application to their specific needs. For instance, Chen has found that in spite

of a similar set of self-management needs in newly diagnosed individuals, responses to these needs vary depending on the individual's physiological, social, and personal circumstances[16]. If the application that is being evaluated does not adequately match patients' current self-management needs, patients will use the system irregularly or stop using it altogether. In such cases, trial results that report average effects for the whole sample would show lower efficacy than would be found in a subsample of patients whose self-management needs were well matched by the evaluated application. Given that the large majority of current mHealth tools for diabetes rely on a single self-management strategy, tracking[7], the possibility of a mismatch between patient needs and available support cannot be ignored.

While research in health sciences has focused on assessing efficacy of self-management tools for diabetes, work in human-computer interaction (HCI) is exploring new approaches for technological support for behavior change, such as personalization and sense-making. For example, Mamykina et al. have focused on the development of problem-solving skills for diabetes self-management[17]. Drawing on the construct of sense-making, they developed a mobile-phone application, MAHI[18], which enables patients to collect contextual information related to their glucose measurements (e.g., what they ate, where they are, etc.). The information is uploaded to a secure website where patients can reflect on patterns in their information and discuss their data with a diabetes educator. Frost and colleagues took a similar approach: to facilitate reflection on patterns in glucose measures, the researchers used photographs to annotate glucose readings to enable patients and their providers to better understand each individual's values[19, 20].

The work in HCI and in health sciences has only begun to explore how patients' needs for self-management technologies evolve over the course of the disease and how we can design technologies to account for the evolving nature of diabetes self-management. For example, Chen has suggested that seeking of health information is cyclical rather than linear.[21] If the needs for self-management support substantially change over time, the benefits we are seeing from self-management tools might be less than they could be, in part due to the potential mismatch between the type of technology being tested and the specific needs of the patients participating in the study. To avoid such mismatches, we need to better comprehend individuals' evolving self-management needs and the ways that technology can support them over time.

In this paper, we begin to close this gap in understanding how diabetes patients' health-management needs change over the course of the disease and how they use various technologies and devices to support those changing needs, using a grounded theory approach. Our findings can inform the design of technologies that account for the shifts in self-management priorities brought about through the progression of the disease, changes in treatment, and the patients' own evolving skills and understanding of diabetes self-care.

2. Methods

2.1. Data collection

After receiving approval from the Institutional Review Board, we recruited adults with T1D or T2D through flyers in Diabetes Clinic of the University of Washington, convenience sampling, and a diabetes support group from September 2011 to October 2012. We excluded individuals with gestational diabetes because of its limited duration, as well as those on dialysis, because they see their care-providers much more frequently than other individuals. Participants received $25 for participation. We collected participants' socio-demographic characteristics, and information about their technology and healthcare use. We chose not to perform purposive sampling by disease duration, as the relationship between disease duration and disease stage is not clearly established.

We led in-depth, semi-structured, individual interviews with 11 participants. All sessions were audio-recorded and transcribed for subsequent analysis. The sessions ranged from 35-100 minutes. We asked individuals to describe their current diabetes management, their trajectory since they were diagnosed, and their use of technologies, such as their use of mobile devices and the Internet (e.g., forums, blogs, other websites). We also explored their perceived role in coordinating the care they receive. Finally, we asked them about their perceptions of barriers and motivators for diabetes self-management. We also conducted a two-hour focus group with four participants, three of whom had been interviewed individually: three individuals with T2D (diagnosed in the past two years) and one individual with T1D (diagnosed 20 years ago). During this session, participants discussed their disease, their evolving needs, barriers and motivations, and discussed their use and need for supportive technologies for diabetes.

2.2. Data analysis

Two coders each analyzed the transcripts of the individual interviews and the focus group in Atlas.ti 7 software, using open coding to establish prominent themes encountered in the data: the evolution over time of the disease and

its management; the tracked information; the comprehension, availability and usefulness of technologies such as glucose meters and their companion websites, insulin pumps, blood pressure monitors, smartphones and tablets, online forums and social networking. Codes were developed for the disease trajectory, modifications in symptoms, treatments, barriers and motivations for self-care. The two coders iteratively compared their coding schemes, revising or merging them as they discovered common and contrasting themes. We took into consideration duration and type of disease for this analysis. Reaching saturation allowed us to terminate the data collection.

3. Results

3.1 Participant characteristics

Across the interviews and focus group session, we enrolled 12 diabetes participants (six T1D and six T2D patients), who had been diagnosed for periods ranging from 6 months to over 20 years. There were five male participants, four of whom had T2D. One patient with T2D used insulin. The patient characteristics are presented in Table 1. The age range in our sample is representative of T1D and T2D demographic characteristics in the general population. Three T2D participants were Asian, one T2D participant was Black, all other participants were Caucasian.

Table 1. Participant demographics and disease characteristics.

	Type 1		Type 2	
n	6		6*	
Female: male	5:1		2:4	
Age range	18-34 yrs		35-64 yrs	
Duration of disease by participant	27 yrs (P3), 19 yrs (P4), 8 years (P5)	12 yrs (P6), 23 yrs (P8), 1.3 yrs (P10)	17 yrs (P1), 21 yrs (P2), 0.5 yrs (P7)	0.5yrs (P9), 1.5 yrs (P11), 1.2 yrs (P12)

*Only one individual with T2D using insulin

3.2. Evolution in health management needs

A key finding from our work is that patients' priorities and needs for self-management support change substantially over the course of the disease. In this section, we describe patients' needs and priorities in the following phases: (1) the learning phase in the initial period after diagnosis, (2) the stabilization phase, when they gained gain confidence, (3) the relearning phase, when they need to learn how to respond to changes brought about by the disease progression and adjustments in treatment, and (4) the expertise phase revealed during long-term management.

3.2.1. *Learning phase: Developing understanding after diagnosis*

Our findings indicate that the initial period after diagnosis is characterized by acute psychological distress, a need to learn about the disease, and to adopt new routines and health behaviors to control glucose levels. During this period, patients make heavy use of tracking tools and of educational websites, but find the available information insufficient.

Participants find this initial stage difficult, both at a physical and psychological level. Two participants consulted mental health professionals to help cope with their new chronic disease. Diabetes has a negative reputation, with its ban on sweets, its amputations, the painful pricks and injections and medications. Such perceptions are often buttressed by friends or family members with diabetes who have presented these complications. For one participant (P1, T2D) the moment of diagnosis was "*the branding, the shock*" and her initial thought was "*I'm a failure*." The DAWN study found that 85% of individuals reported a high level of stress (shock, guilt, anger, anxiety, depression, and helplessness) after receiving this diagnosis[22]. The difficulty of finding practical information heightened the feeling of being overwhelmed by the disease in the early stages as they tried to understand the expectations for their new lifestyle: "*I wanted something early on, I just want to know if I can eat five crackers, if that's all I have to eat, I'll eat crackers for 90 days. [...] Give me a recipe, I can follow it and not have to think about it so much.*" – FG, P7 (T2D)

In addition, a need for intensive learning characterizes this initial period as participants search for answers about diabetes and discover how to incorporate management strategies to get better and prevent complications. Self-management at this stage focuses on understanding the basics of the disease, and changing daily activities, such as nutrition. Lifestyle changes are particularly important in type 2 diabetes, where portion control, healthy food choices, and physical activity are initial steps to decrease and stabilize glucose levels. As FG, P7 (T2D) noted,

"Going back, early on, it's food. You know, you have to figure out what you can eat, and then it's exercise and then it's the combination of everything and then it's working it all in the lifestyle stuff too."

Although some information seemed difficult to find on the Internet, our subjects found comfort in its constant availability as a resource: *"It's not just "go to this class that's taught in two weeks" but "here's where you could start online tonight when you're freaking out at two o'clock in the morning"* – Intv, P5 (T1D). However, they also described how time-consuming and impractical websites were to use, particularly at early stages. This was particularly the case for a nutritional website which provides detailed breakdowns of nutrient data for an extensive selection of foods; participants described how it was difficult to utilize this data when combining several foods together. *"There's not a website that says 'eat this - you can eat this, in this proportion', none of that. And the same thing with exercise. You know, they say 'exercise' but then they don't give you – they don't just say '10 minutes per meal'."* – FG, P7 (T2D). The challenge of controlling glucose levels with food and exercise is compounded by the lack of concrete, actionable plans that new patients can adopt to get them started. Although many websites, handouts and textbooks about diabetes exist, patients expressed frustration with finding concrete information to guide daily choices. Participants found the available food plans bland, describing the need to adjust to, *"taste, lifestyle, you know, even down to the city, because [most] is tailored to the Caucasian diet right now."* – FG, P9 (T2D)

At this early stage, patients describe strategies to help adopt new routines for disease management. They integrate new behaviors like tracking, glucose testing, and they limit their food choices to those that were successful in the past: *"I was tracking down to individual ingredients I was putting into my recipes and just breaking it down to what I can. You know, we were measuring every two hours after a meal, doing exactly what they were telling us to do, wake up: check, after breakfast: check, two hours before lunch: check, two hours after lunch: check. So it was a whole routine for about the first month, two month*s." – FG, P7 (T2D)

Detailed tracking helped participants learn how different foods and routines had an impact on their blood sugar levels. However, in this early phase, participants would also simplify their lifestyle and choices to activities that they already knew how they impacted their bodies. One participant described always going to the same fast food restaurant while on the road, *"because I know exactly what that's going to do to my blood sugar"* – Intv, P6 (T1D). Restricting options is difficult, but it saves time and decreases anxiety about glucose management.

Individuals use intense tracking to learn how to interpret many numbers, including blood glucose results and carb counts and the effect of behaviors on their body. Patients might also start new medications and want to observe the effects of those drugs. Some participants used pen and paper or Excel spreadsheets, while others turned to their smartphones for tools to assist them, with options for averages and other analyses. They particularly appreciated the ease of data retrieval and seeing associations between trends in carbs and glucose levels: *"The nice thing about having it on the phone is I can just give [my providers] my last 90 days, without having to scroll back through a bunch of spreadsheets and paperwork and calculate the number. I can just quickly at a glance say where I am"* – FG, P7 (T2D)Even though some of our participants developed tracking strategies on their own, they wished for more guidance from their care-providers for electronic resources (websites and smartphone apps). A number of websites and apps are available for diabetes, nutrition, physical activities and weight, yet providers do not seem familiar with these resources. Patients expect their providers to suggest and advise them about these resources to ensure that patients are accessing high quality information: *"I feel like the good [providers] are also learning to go online or at least realize that there are conversations online [...] knowing good resources whether it's diabetes.org or the TuDiabetes.com network. So giving patients a starting place and not making them go to Google."* – Intv, P5 (T1D). Supplementing their interactions with providers, our participants also leveraged peer support from other individuals with diabetes, particularly at this early stage of disease. The experiences of peers can provide information not given or emphasized by care professionals*: "My friend actually was the one who told me to take my insulin earlier to offset like spikes and stuff. [...] She was the only person who said that to me, I guess. She's kind of clued me in, that's helped a lot."* – Intv, P10 (T1D)

During this initial phase, then, patients face the challenge to understand how their bodies respond to food, medication, and exercise, and, based on that knowledge, to come up with daily routines that help stabilize their blood sugar levels. Tracking tools are a key support for this process, as are online resources such as blogs and forums where patients can get advice and tips from other patients.

3.2.2. *Stabilization phase: Building confidence*

As individuals make efforts to adjust to new lifestyle choices, they progressively build skills in and confidence about diabetes self-management. They realize that they can delay the onset of complications and that their actions can bear

positive results, reflected in their HbA1c numbers or feedback from their care-provider. Patients also master the diabetes lingo, as P8 (T1D) described: *"Breakfast was one protein, two starches, one fat, one dairy, one fruit…"* After they gain initial control, patients also begin to slowly integrate new behaviors into their daily routines:

I think that initial first three months was just getting an understanding of "can we get these numbers down," "what is it going to take" and then now that we got them down, it seems like it's okay to go out and have a couple of drinks with your co-workers after work or happy hour, and do stuff. [That shift occurred] after the first A1c that went down. – PG, P7 (T2D)

During this stabilization phase, individuals gradually lose interest in tracking their diet or other activities, because they have adopted routines that generate satisfactory results. They have discovered which foods to eat in what proportion, and have developed skills at interpreting glucose results and at estimating carbs in common foods.

[I made] a master list of all the items that I could possibly eat and the glycemic load and the calories [...] For the first 60 days, [our glucose results] were always low because we knew exactly what we ate. So then after a while it was like it was the same thing we're eating every day, you know what it's going to be. So after that I just stopped [tracking]. – FG, P7 (T2D)

I can usually look at things and [...] probably 70 - 75 % of the time I get at least in the ballpark. – Intv, P8 (T1D)

Individuals gain confidence in their skills to assess carbs, or predict their response to certain activities. They might even search for ways to fine-tune their glucose results through detection of complex interactions among emotions or physical activity. They recognize that mobile technologies can provide a lot of information, but do not use them as much at this point.

Some apps will tell you like if say, you know, three strawberries, or whatever, they will tell you how many carbs that is. But I kind of just eyeball it and you know, from experience, just sort of trial and error with different things – Intv, P4 (T1D)

There have been a couple of times where I come out of the pool and been really low – it was at the beginning when I didn't know exactly how it would affect me but I feel like, generally, at least now, I'm able to kind of predict what's going to happen and I take glucose tablets with me when I run and bike and that kind of stuff. – Intv, P10 (T1D)

The key feature of the stabilization stage, then, is that patients have managed to internalize knowledge that previously required them to use external tools. By better understanding their bodies and the ways in which factors that affect their sugar levels interact, they are able to "eyeball" different types of foods and predict the effects that eating something will have on them. Consequently, intensive tracking technology became less useful at this point.

3.2.3. Relearning phase: Responding to changes

Some participants described feelings of guilt when their glucose results were less satisfactory. Consideration about staying healthy for their loved ones only compounds this feeling: *"I think I just start feeling guilty because [...] I was not managing my diabetes the way that I should. [...] And it's unfair to my husband to be so nonchalant about it. So there's that guilt that kicks you into action in a positive way."* – Intv, P6 (T1D)

Glucose levels can start reacting differently over time for various reasons. Even though individuals have learned how life choices affect glucose results, how various factors affect a person's body can change over time. Our participants described a continuous need to re-evaluate their lifestyle in order to understand changes in glucose patterns.

Some changes in glycemic control are necessitated by the changes in the body itself, often as a result of the disease progression: *"It's [been] two years now that I've had diabetes; it's changing pretty significantly now. And so I'm having to like re-learn things that I thought I kind of at least had a feel for the last couple of years, [...] But I've noticed that I need more insulin for any of the carbs that I do eat. I need to take them earlier, like 15 minutes before. [...] Generally speaking, I need more insulin, so any of the numbers I did learn for the foods that I typically eat, I'm kind of relearning now, how it affects me now"* – Intv, P10 (T1D)

The need for relearn glucose control can also be brought about by changes in treatment such as new treatment regimens or a new device, such as a continuous glucose monitor (CGM) or insulin pump, which can drastically alter diabetes self-management. *"Before I got my CGM, it was really a guessing game. It was very much like, you think that you know what's going on and what's happening.[With a CGM,] you have this meal every single morning and this is what your blood sugar did every single morning. What was the difference with this morning versus others,*

you know, because everything else is the same?" - Intv, P4 (T1D). Finally, relearning can be necessitated by changes in the patients' lives, such as travels or a new job: *"To try to eat on a regular schedule, to try to eat foods that are appropriate on a regular schedule are not simple on the road"* – Intv, P2 (T2D).

Whenever patients notice that their bodies are responding in unexpected ways, they must determine whether the change in glucose response is a one-time event or a pattern that would require an adjustment of diet or insulin regimen. Individuals adopt different strategies to answer that question: some will look at previous days, others rely on their memory, and yet others will again start tracking their food, glucose, insulin, and activities more closely: *"I don't really track much unless I am specifically looking for a pattern."* – Intv, P4 (T1D)

To monitor changes in glucose patters, providers may ask individuals to track their diet and glucose in preparation for visits. This helps assess if there is any gradual change in trends, and provides concrete points for feedback if abnormal results are found. Although care-providers can provide insight into some abnormal results, they might not have the contextual and lifestyle information needed to interpret all results. Tracked results without context can lead to misunderstandings and frustration for the patients, while limiting the provider's ability to provide feedback... As P4 noted, *"The chart of all my blood sugars, it's, like, each number has a story behind it. And it's like, I remember that meal or I was sick or, you know, there's so much more than just numbers that goes into it."* – Intv, P4 (T1D)Learning to manage diabetes is not a one-time shot, but rather a continuous process. As the circumstances change, patients have to relearn how their bodies react to different factors that were once a known quantity. The need for external support often goes up in these situations. Patients will turn to their clinicians as well as technology to regain control of their glucose levels.

3.2.4. *Expertise phase: Managing for the long-term*

Long-term management of diabetes is important, because effective diabetes management can reduce complications. Yet, the disease does not remain patients' main focus and instead they begin to prioritize quality of life. Over time, patients develop a nuanced and detailed understanding of their illness that leads to balancing glucose management with the desire to explore new foods and activities.

This quality of life: like I know that I can spend so much time and be so diligent and write everything down and do what you were doing in the beginning. But is that really worth it in the long run? [...] I test on average 10 times a day. [...] But that's seven seconds out of my life, the tracking. So that's definitely a goal of mine, [...] finding that balance a little bit better and maybe doing a little less work, but still getting the good results – FG, P4 (T1D)

I mean, you're not going to live your whole life watching, counting calories, every grape that you eat. I mean I'm getting really close to that point now where [...] I'm not thinking about my meals every day. I'm content with like, if I miss a snack so, I'll make it up at dinner – FG, P7 (T2D)

As individuals grow to live with diabetes, there is a point when they understand enough about what behaviors they should adhere to, but also realize that they are not enjoying life as much as they would like to.

Individuals discover over time that the metabolism of glucose can be intricate and sensitive to a range of factors*: "I've had [diabetes for] almost 20 years now, it's crazy. But, I'm still learning everyday just what I can and cannot eat and – because even if you go straight off carbs, fiber, glycemic index, like there's other things that go into it. [...] And glycemic load is a little bit dependent on the meal. So like if you eat like grapes by themselves, they might have a certain glycemic load but if you eat them with cheese, it'll change it."* – FG, P4 (T1D). In addition, Type 2 patients not on insulin therapy frequently taper their glucose monitoring to avoid the unpleasant finger pricks required. Although this can be patient-initiated, providers also encourage this when results are satisfactory*: "Since I've been a diabetic for over 20 years, I just do it in the morning. I don't watch it other times of the day that usually ends up being a good reflection about how things are being handled.* – Intv, P1 (T2D)

As individuals loosen their dietary restrictions, they may wonder how this affects their glucose and initiate a short period of glucose tracking to see if they are still on track: "*I check [my blood glucose] once in a while when I do try something different, when I eat something different or, you know, if I'm feeling awkward or something."* – Intv, P7 (T2D). While some individuals used electronic spreadsheets or handwritten notes, others used smartphone weight-tracking applications that provided detailed information about the breakdown of foods.

3.3. Social and emotional impacts across phases

Diabetes, like many chronic conditions, can lead to a variety of different emotions. The pressure of handling food choices, calculating carbs and insulin doses, and testing glucose on a daily basis can lead to anxiety in some

individuals: *"I want to be able to eat food. Like I want to able to try food and not be really scared of everything I put in my mouth"* – FG, P4 (T1D). These emotions also occur in T2D individuals, even without insulin therapy: *"There's really a mental pressure. You're talking about the constant thing. It's a constant mental pressure on me to always keep track of what I eat, how much I eat, when I eat, and on and on"* – FG, P11 (T2D)

For many, the motivation to keep up with the many daily requirements of one's regimen is to stay healthy and delay the onset of complications or need for new medications. Many individuals are influenced by a parent or relative who has experienced, or even succumbed to these complications. Fear of consequences can drive motivation for self-management: *"The negative aspect would be knowing that eventually, [diabetes] will catch up. It's a non-stopping disease and eventually it will catch up with me and I don't know why, I don't know what will happen to my bones or my eyes or skin or heart or something will eventually go. [...] And that knowing is sometimes hard to handle, that knowing. So my own father passed away because of complications of diabetes."* – FG, P11 (T2D)

The balance between highly controlled self-management and spontaneous activities is a fine line. Individuals can push themselves by setting high standards with the risk of being too demanding, or they can feel pressure from their care-providers to improve numbers. Performance in disease management can be a sensitive topic, as P8 (T1D) describes: *"While I'm willing – able and willing to talk about my diabetes, I'm not – I don't want to have any perception of being judged."* This may be why some individuals feel a particular affinity with peers, particularly care-providers who also have diabetes. There is a shared understanding that behaviors cannot be perfect all the time and less than ideal results do not invite critical judgment.

This doctor, who is a type 1 diabetic that I met at diabetes camp, [...] she was the only doctor I've ever met that like I felt like really understood and really just made it okay to eat ice cream if you knew what to do and… It's okay if you have high blood sugar every once in a while, just keep on going, and keep figuring out. – FG, P4 (T1D)

To an outsider, diabetes appears to be a burdensome disease with many requirements for testing, medications, lifestyle changes and restrictions in diet. Yet our participants had a very positive approach and expressed an acceptance with having to live with this condition. Individuals with T1D tended to describe the disease as the way their body was, whereas T2D participants considered it as a wake-up call because they had become so unhealthy.

I still have diabetes, and I still have to do this every day. [...] That's the way I am as a person – Intv, P4 (T1D)

I always tell the doctor that being diagnosed with diabetes was the best thing that ever happened to me, because it stopped me in my tracks. I wish I did that I'd been diagnosed twenty years ago because I would not be in the same health situation as I am now. – Intv, P12 (T2D).

4. Discussion and design implications

Our finding that self-management needs change over time aligns well with the Corbin and Strauss's Chronic Illness Trajectory[24] and suggests that technology will play different roles at different stages of the disease. In particular, based on our studies, we identified four functions where technology could play a supportive role: understanding the new disease, responding to changes in times of stability, improving communication, and tailoring to individual motivations and needs.

4.1. Understanding the new disease

Supportive technologies can play a particularly useful role at the onset of disease, as patients create their mental model of the disease and its management. Mobile technologies can guide initial lifestyle choices of nutrition, physical activity, glucose monitoring or medication in three ways: (1) Tools can *facilitate tracking* by guiding patients to easily capture a full range of factors that affect glucose levels. By taking advantage of sensing and lightweight self-report, a new generation of tracking apps could enable patients to log, with little burden, not only glucose levels and food intake, but also sleep, stress, physical activity, and other potentially relevant influences on glucose variations. (2) Applications can *support learning* by enabling patients to understand the interactions among the factors they are tracking. This data interpretation could be achieved through the use of visualizations, coaching (e.g.,[17]), games, and through the use of machine learning algorithms for automatic pattern detection. For instance, a tracking application could not only visualize patterns in historical data, but also use logged data to provide visualizations of likely glucose changes over the next couple of hours—visualizations that could help the user understand and make more informed choices about different foods, activities, or types of insulin. Such visualizations could help the user to get an intuitive understanding of, for example, why foods with the same amount of carbohydrates can affect their bodies so differently or on the duration and effect of the different types of insulin. (3)

Finally, mobile applications can *support skill development* through the use of video clips, for instance, to teach patients how to perform a foot exam.

4.2. Responding to changes in times of stability

Participants indicated that intense tracking and diet restriction occurred mainly in the early stages of disease. As individuals grasp how to make healthy choices and adopt healthier behaviors, the perceived benefits of intensive tracking are surpassed by the cost in time and effort. While ongoing glucose tracking is recommended for insulin use, it might not be necessary for those who do not need insulin[25]. In addition, as patients learn to estimate content of different types of foods, regular carb tracking becomes less useful. At this stage, the burden of tracking could be decreased for insulin users by switching to a lower-intensity mode for routine tracking, where information is added to the patient's log automatically (via the glucose meter and sensors), while maintaining enough data to enable the system to detect significant pattern changes that need to be brought to the patient's attention.

As the disease stabilizes and the concerns about quality of life take front stage again, individuals begin to break out of strict routines and experiment with new foods and activities. One role supportive technology can play at this stage is to support such experimentation while helping individuals to maintain good glucose control. One way to do this is through the creation of a personal knowledge base that patients can use to track their glucose responses and insulin use when they try new foods or activities. Such a system could help improve future decisions through rapid retrieval of prior personal experiences and may help reduce the anxiety of decision-making under uncertainty (P4, T1D and P11, T2D). This is also an area where a large-scale, patient-reported repository could be particularly useful. If a system knew insulin sensitivity parameters for different users, it could automatically use one user's data to recommend insulin dosages for the same food or activity to other users. Practical applications of this crowdsourcing framework include insulin recommendations for areas with inadequate standardized information available such as restaurant menus, athletic activities, travel, and other activities that affect patients' glucose levels.

Finally, one challenge in the period of stability is how to detect and communicate abnormal test results. Not all abnormal results require changes in behavior. Machine learning could help detect repeated anomalous events over a short period of time and prompt the user to make an appropriate change, such as changing the basal insulin rate. In our study, we found that the way to communicate a need for change is important. Warning alerts in response to a missing or abnormal glucose measurement may aggravate an individual's feelings of guilt or may be perceived as a judgment. Future research could explore the use of more subtle cues such as changing the color of the phone's wallpaper to provide a gentle indication to examine potentially concerning changes in glucose values.

4.3. Improving communication

When individuals have a better understanding of diabetes and its management, they can select relevant information to report for in-depth discussions and useful feedback with their providers. P4 explains how there is a "story behind each [glucose] number", a lens through which to interpret abnormal results. Self-management technologies should allow individuals to easily capture contextual information that might be relevant for interpreting their glucose results. Smith et al.'s work on photo annotation of glucose data is a step in the right direction [20]. Easily connecting information about location, recent sleep history, workload, stress levels, etc. with specific glucose readings would further support learning and sense-making that can occur in discussions with healthcare providers.

Our findings showed a gap between patient expectations and provider guidance for websites and apps related to diabetes. Participants' providers welcomed various formats (paper, email or apps) for patient-reported data and appreciated patients' technological expertise, but they were not a good resource of technical information themselves. Creating a well-maintained database of diabetes-related resources and their reliability could improve patient care.

Sharing with and learning from peers is important. Individuals with a disease become experts in that disease[26]. Our participants readily turned to peers for practical information, such as food recipes or management of insulin with a new type of sport. Peers bring in a different type of information than the providers, because they "get it", and grasp the challenge of having to always be on top of the disease management. Future technologies could make peer exchange of actionable information and social support easier by integrating a social component with tracking tools and enabling patients to seek support (e.g., on understanding why their glucose responded in a certain way to a particular food or activity) in the context of the information that prompted the need for support. How such social functionality can be designed in a privacy-sensitive and unobtrusive way is an open research challenge.

4.4. Tailoring to individual motivations and needs

Motivations for diabetes self-management vary: for some people delaying the onset of complications is a motivator, whereas for others that same thought creates anxiety. Likewise, for some, the mental burden of disease is increased with tedious data entry and tracking, or bothersome alerts, whereas for others, technology simplifies data retrieval and reminders serve their purpose, allowing patients to concentrate on other activities. Such differences can lead one patient to abandon the same technology that another patient finds invaluable. For these reasons, technologies intended for long-term not only need to support simple customizations—enabling or disabling of reminders, for example—but may need personalization at a much more fundamental level. An application that had a robust user profile that included user's goals, motivational orientation (e.g., whether the user is promotion- or prevention-focused[27]), attitudes toward illness, and other similar factors, could adapt its behavior to the user's need at a deep level—employing motivational strategies to which the user would be most receptive, framing glucose results in terms that would not be discouraging, and using personalized content (e.g., user's professional goals) to support health behaviors.[28] How to construct such rich profiles with minimal user burden is an important research question.

Just as patients' motivations vary, so do the situations in which they have to perform health activities. Such situations—locations, people patients are with, etc.—can act both as facilitators of and barriers to effective health management. Technology can further support patients' self-management by helping them create implementation intentions[29]—plans when, where and how they will perform health-promoting activities or resist activities that hurt their health. Given enough data from sensors and the information that the patients themselves log, technologies could both help patients to discover situations that influence their health-related activities and incorporate those situations into effective implementation intentions that can strengthen their health practices.

By taking into account how self-care needs change over time and the individual differences that shape diabetes management, future technologies could help patients with diabetes to manage their disease effectively over the long-term, contributing both to their health and quality of life.

4.5 Limitations

Although our participants are representative of the two types of diabetes, a limitation of our study is the small size of our sample. Due to disease type-related and individual differences in approaches to diabetes self-management, the full range of needs for supportive technologies may not be entirely covered in our sample. Self-selection to participate in studies can be a bias, particularly as most of our participants had outstanding diabetes management.

5. Conclusion

With several short-term studies showing promising results for mobile technologies in chronic disease management and in particular diabetes[8, 9, 11], we need to explore how to establish long-term engagement with these technologies. Where self-management evolves over time alongside disease trajectories, engagement with technology also becomes a dynamic process. Our findings suggest that the design of tools for diabetes that support long-term engagement should allow periods where the individuals can suspend use of one or more features of the application. A tool that can accommodate intermittent use raises questions of how to reengage the user at timely moments when repeatedly abnormal results or new trends are detected. If designed properly and flexibly, such technologies could provide patients with the support that is most important to them at their own stage of illness, communicate with their providers more effectively, and maximize the technology's effectiveness in helping patients improve their self-management and their health.

Acknowledgments

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