

Designing Supportive Mobile Technology for Stable Diabetes

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Abstract. Diabetes is a complex, evolving chronic disease, with an evolving need for self-management as the disease progresses. Through patient interviews and a focus group, we explored the changing need for technological support for diabetes self-management over the course of the disease, with a particular focus on insulin users. We propose a design for supportive technology aimed at the stabilization and progression stages of diabetes, which focuses on the creation of an individualized database of how new experiences with food, physical activities and travel affect one's glucose levels. Our design supports feedback and improvement for future similar experiences, while avoiding the burden of intensive tracking. We propose a mechanism to suggest insulin doses adapted to the user, and sharing data with peers according to individual privacy wishes. Future research could allow this innovative approach to benefit non-insulin users.

Keywords: Diabetes, self-management, mobile technology, health informatics.

1 Background

Diabetes is an evolving chronic disease, and its management involves many lifestyle changes. A large part of daily disease management is incumbent on the patient, and happens in the absence of the care-provider. Mobile technology can support diabetes self-management through educational resources, data collection, data visualization, sharing results with a provider, or through encouraging feedback.

Diabetes actually represents three types of populations, characterized by their self-management and insulin needs: (1) Individuals with type 1 diabetes (T1D), who are dependent on insulin because their bodies do not produce it; (2) individuals with type 2 diabetes (T2D) *with* insulin; and (3) individuals with T2D *without* insulin, who can use diet and oral medications to treat their disease. In T2D, the body produces insulin, but its effect is decreased. Earlier stages of T2D can be treated with medications to enhance the body's response to insulin, whereas later stages of T2D require supplementation with insulin to produce an adequate glucose metabolism. Self-management needs of individuals with diabetes who use insulin differ greatly from those who only use oral medications or diet. The use of insulin requires a closer control of glucose

results, because insulin doses have to be carefully adjusted to avoid hypoglycemia. This more intense tracking of glucose results is particularly important for individuals with T1D, and has led to the development of continuous glucose monitors and insulin pumps. Individuals with T2D on insulin can control their glucose levels somewhat more leniently, as they may use a combination of oral medications and insulin to help their glycemic control. For individuals with T2D who do not use insulin, there is insufficient evidence to support routine self-monitoring of blood glucose.[4]

The most beneficial type of supportive technology for a given patient will depend on the type and stage of disease. Early in the disease, patients need to gain better understanding of the disease with the complex physiology related to glucose metabolism. For example, they need to learn how various factors such as diet and physical activity affect their glucose levels, as well as the meaning of measures such as glycated hemoglobin (HbA1c), which is commonly used to assess glucose control over the previous eight to twelve weeks.[9] Patients are also overwhelmed by all the new lifestyle behaviors they are supposed to adopt: adapting their diet, monitoring their glucose levels, and adjusting their physical activities and medications. Many mobile apps for patients with diabetes target user needs at this early stage of the disease.[2]

As they live with diabetes, patients begin to better understand their bodies' needs and responses. Patients typically learn how to make healthy choices about food, exercise and medications, which lead to better glucose control. As a result, self-tracking, which is common in early stages of the disease, is often significantly reduced. However, this stable phase is not without difficulties. As the Illness Trajectory framework notes, there are potential crises and acute episodes during the stable phase as well.[3] Some of them are caused by the patients' changing physiology, while others occur when patients attempt to change or expand their routines. Patients on insulin are particularly vulnerable to such crises, since inadequate insulin dosing can easily lead to hyper- or hypoglycemic events. In this paper, we discuss our formative work on the design of an application for self-management of stable diabetes with insulin aimed to help patients to more fully enjoy their lives by exploring new foods and activities while maintaining good glucose control and hopefully preventing acute hypoglycemic or hyperglycemic events. The application was designed based on interviews and a focus group with twelve diabetes patients. High-fidelity mockups of the application were presented to five T1D patients for feedback in an additional focus group. In what follows, we review the results from our formative study, the features of the application we designed based on those results, and the initial patient feedback on the design.

2 Related Work

Adoption of mobile technologies for health has grown rapidly over the past couple of years, and applications for diabetes and wellness have flourished. A recent review [2] has found that a majority of technologies for diabetes self-management have focused on tracking and data visualization, with a subset offering support for data sharing to facilitate social support from friends or care-providers. Meanwhile, educational applications have focused on diabetes literacy or insulin dose calculations. Such mobile

technologies have shown promise in clinical trials, with a meta-analysis of 22 trials showing a reduction of HbA1c of 0.5 percent over a median of 6 months' follow-up.[8] A recent randomized controlled trial showed a reduction of HbA1c of 1.2 percent over one year using a combined mobile and web-based approach.[10]

Most of the technology tested in such clinical trials focuses on the support for early stages of diabetes. Given the shock of the diagnosis and the sheer amount patients have to learn early on, this is understandable. At the time of diagnosis, 85 percent of individuals report a high level of distress, including feelings of shock, guilt, anger, anxiety and helplessness.[5] Support at this stage is clearly needed. Yet, diabetes is a progressive, chronic disease, and the need for self-management remains in the later stages of the disease as well, albeit in a different form.[11] For instance, studies find that longer duration of disease is associated with lower adherence to self-care activities, and poorer glycemic control, even though patients have a better understanding of the disease and its management.[7] It is, therefore, important to develop supportive technologies for patients with longer duration of the disease to prevent or delay the consequences of poorer glycemic control. Such technologies are currently lacking. Our work begins to address this gap in supportive technologies for diabetes.

Long-term diabetes self-management is difficult due to the incessant need to make healthy choices and constrain daily routines over many years of the disease progression. A technology aimed to help patients with such a long-term condition thus faces a challenge: how to help patients stay engaged with the self-management technology over long periods of time? The Technology Acceptance Model demonstrates that initial engagement with technology is associated with perceived usefulness and usability, [6] and is reinforced by novelty. A technology for long-term diabetes management cannot rely on novelty for its continued use, but must carefully balance the value that users get from the technology with the effort needed to use it. Given that a fourth of smartphone applications are abandoned after just one use, [12] designing such a technology is a serious challenge. Our work attempts to address this challenge by supporting intermittent use, by providing immediate value through information obtained from validated and social network sources, and by increasing the value of the application to the user the longer she continues to use it.

3 Method

For the initial study, we recruited English-speaking participants with diabetes aged 18 to 64 years. We excluded individuals on dialysis, those with cognitive impairment, and those with gestational diabetes because of their closer contact with their care-providers, more severe disease, or impairments that may hinder the adoption and use of mobile technologies. Gestational diabetes is a different form of diabetes, which is generally limited in time and is associated with different motivations for self-management. All participants were recruited in the Seattle, WA metro area.

We conducted semi-structured interviews with the participants to explore how participants' diabetes and their self-management needs evolved over time, and to discuss

their past or current use of mobile applications and Internet sites as supportive tools. We also held one focus group with four patients (three with T2D, one with T1D), three of whom also participated in individual interviews, to explore further what types of features the participants would like to see in supportive technologies. The interviews and focus group were audio-recorded, and then fully transcribed for subsequent analysis. In addition, we collected field notes of discussions with two participants (one with T1D, one with T2D) specifically about which features a technology for self-management during the stable stage should have. We analyzed the data through a modified grounded theory approach, using free codes and pre-established codes based on a literature-based conceptual model of the use of mobile technologies for diabetes self-management. Both authors coded the transcripts, then extracted themes and categories, focusing on the evolving needs for diabetes self-management over time.

Based on the results of our analyses, we created a high-fidelity mock-up of a smartphone application for unmet needs of insulin users with stable diabetes. To get feedback on the general concept and the initial design, we presented the mock-up to five patients with T1D in a two-hour focus group.

4 Results

4.1 Participant Characteristics

We recruited twelve adult individuals (>18 years old) with T1D (n=6) or T2D (n=6) for interviews and an initial focus group. We present participant characteristics in Table 1. The distribution of gender, age categories and insulin use reflects the characteristics of the disease in the population.[1] In spite of a difference in age, duration of disease was similar for both types of disease.

Table 1. Participant characteristics for the interviews and focus group

| | Type 1 | Type 2 |
|----------------------------|---------------|-----------------------|
| n | 6 | 6 ¹ |
| Female: male | 5:1 | 2:4 |
| Age range | 18-34 yrs | 35-64 yrs |
| Duration of disease | 2-27 yrs | 6 months to >20 years |

To get feedback on the design of the application, we presented the mock-up to five women with T1D, two of whom had taken part in the initial interviews. The five participants were between 20-30 years of age. Four were insulin pump users, and the fifth one used multiple daily injections of insulin.

¹ One T2D individual on insulin.

4.2 Changing Self-Management Needs

At the time of diagnosis, participants describe the onset of disease as an intense learning experience. They needed to rapidly comprehend the essentials of disease management and apply their knowledge to their behaviors. For example, they had to learn which foods to choose and what quantities were appropriate:

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. You know, it doesn't mean just food and exercise, it's also plenty of rest. – FG, P7 (T2D)

Early in the disease, participants used a range of solutions to collect and organize data, from handwritten charts to websites, Excel spreadsheets, and mobile applications. They tracked glucose levels, carb consumption, diet, insulin or weight. They appreciated food diary apps for their large nutrition databases. Visualization of the data helped participants understand the relationships among the exercise, food and glucose results. They liked having reminders to test for blood glucose, and kept fixed schedules for meals and testing:

I became really, really religious about [tracking foods and glucose], really quite strict about what I was eating and almost too strict. – FG, P11 (T2D)

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 months – FG, P7

As participants gained control over their disease, they progressively decreased self-tracking, often supported by the improved health status. Tracking is effortful and time-consuming, and the perceived benefit at the point of stabilized disease was much smaller than during the initial phase. They did not want to track meticulously for the rest of their lives. As they often restricted their food choices to predefined amounts of selected diabetes-compatible foods to stay within a satisfactory range of glucose results, they did not find tracking to be necessary for their usual foods and routines. They also acquire skills in assessing what they ate and predicting insulin needs.

[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)

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

As they gained control of their diabetes, the participants' priorities changed. They discussed the importance of quality of life, and the desire to try new foods and have the freedom to change their routines. For these new behaviors, tracking retained its usefulness. As during the initial learning phase, tracking allowed adjustment and improvement for repeated behaviors. Rather than needing to do it constantly, though, participants in later stages only tracked intermittently, when a particular need arose:

I want to be able to eat food. Like I want to be able to try food and not be really scared of everything I put in my mouth [...] I've had [diabetes for] almost 20 years now, it's crazy. But, I'm still learning every day just what I can and cannot eat - FG, P4 (T1D)

I don't really track much unless I am specifically looking for a pattern. – Intv, P4 (T1D)

Evolving disease and management led to evolving needs for supportive technology. After the initial stage of the disease, participants wanted to be able to test new foods while maintaining their health. To accomplish this, they wanted an individualized, continuously growing database of how foods, activities or events affected their health. As FG-P9 said, “*the most important is knowing the consequence on the glucose of whatever you're doing.*” Available food diary apps lack data on ethnic and homemade foods. Trying out new foods or physical activities requires an estimation of physiological responses, taking many factors into consideration (amount and composition of food, physical activities, hydration, stress, etc.). Our participants wanted a customized diary with personal notes about the accuracy of their estimations for new foods or activities. They emphasized the importance of these narratives to interpret glucose results. They described how care-providers were sometimes quick to comment on abnormal results because they did not know the context behind the numbers:

The chart of all my blood sugars, it's, like, each number has a story behind it. And it's like, I remember, you know, that meal or I was sick or, you know, there's so much more than just numbers that goes into it. – Intv, P4 (T1D)

Furthermore, they wanted these notes to be easily retrievable to be able to remember, adjust and improve their estimation the next time they found themselves in a similar situation. Such an app would allow the creation of a highly personalized database of the effects of food, physical activities and insulin needs on the user's body.

Participants also found social support to be very useful for diabetes self-management. Most participants belonged to a peer network, either in person or online. They explained how different it was to receive advice from a peer, someone who “got it,” than from a healthcare provider. They emphasized that sharing experiences with peers could fill gaps in the advice received from health 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)

4.3 Designing IDiDit: Integrated Diary for Diabetes

Our results show how useful tracking and educational apps are, particularly early after diagnosis. But we also found a need for supportive technology for the more experienced individuals who have reached a point where intensive tracking is no longer perceived as useful. At this stage of stabilization, individuals have adopted routines for foods and activities, but they do not want to restrict themselves to these routines. They want to maintain a “high quality of life.” By this, they mean that they would like to maintain good glycemic control while being able to have some degree of flexibility, to keep experiencing new foods and adventures. Although they have acquired

sufficient diabetes self-management skills to get by many unexpected situations by performing additional glucose checks or by learning how to “eye-ball” the insulin requirements, supportive technology could help by suggesting individualized insulin doses, keeping track of these novel experiences, and providing feedback for future improvement in similar situations. Based on these results, we created a high-fidelity interactive mock-up of a diary application aimed at the needs of patients with stable diabetes. Key features of the application, Integrated Diary for Diabetes (IDiDit), are shown in Figure 1.

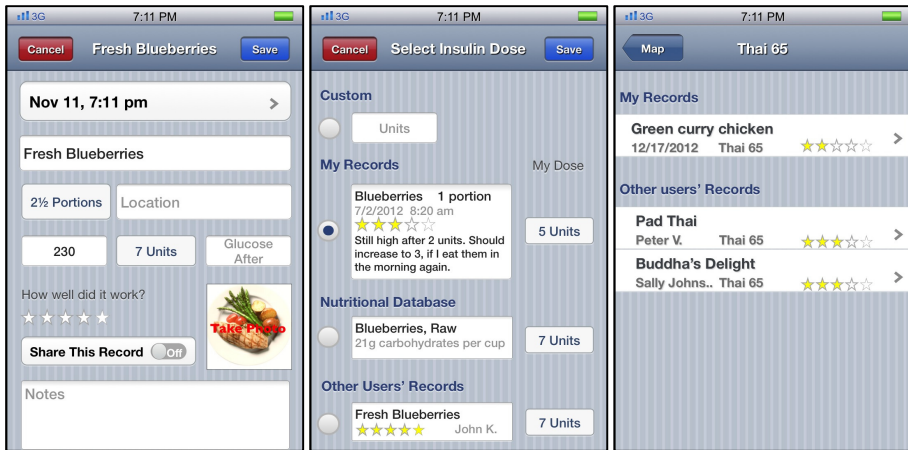


Fig. 1. Mock-ups of IDiDit: food entry; insulin selection based on user’s previous records, a nutritional database, and records from other users; user’s own and other users’ records for a local restaurant.

We are designing IDiDit to be a personalized diary application intended to help diabetes patients who use insulin to explore new foods and activities while maintaining good glucose control. The application’s basic function is to track how food, physical activity, and travel affect the user’s glucose levels and the insulin adjustments that the user makes to compensate for those activities. When entering foods and physical activities, the user can record before and after glucose levels, insulin adjustment, and a rating of how well the adjustment worked to bring—or keep—glucose level in the normal range. The user can also enter any addition information, in the form of a free-text note, which can help make sense of the recorded glucose change. For example, the user might note that she substituted brown rice for white rice in a restaurant meal or that she had a mild fever (left panel, Figure 1). For travel, the user enters any time change and free-text notes about how glucose management was affected by the trip.

At the most basic level, then, IDiDit provides the user with a history of her glucose management around food, physical activity, and travel that can be searched whenever the user needs to make a similar food or activity choice. To make this functionality more robust, however, IDiDit is being designed to provide several unique features. First, all data in IDiDit is fully searchable, including any free-text comments. If a user searches for “fever,” for example, she would get all results that contain the word

“fever,” enabling her to better understand how being sick affects her glucose metabolism. In this way, IDiDit is not only a repository of knowledge about foods and activities, but also about a variety of contextual factors that affect the user’s glucose management. The richer the data that the user enters in the application—and the longer she uses it—the more IDiDit can support discovery of highly personal patterns.

Second, to leverage experience of other patients and to make IDiDit useful before the user has much data of her own in the system, IDiDit is being designed to have a robust social component. Social functionality enhances the application in two ways: by providing suggestions for insulin dosing based on other users’ experiences, and by reducing uncertainty inherent in trying new foods at restaurants without nutrition fact information. In terms of insulin dosing, a fundamental feature of IDiDit is automatic suggestion of customized insulin adjustments for new foods and activities (middle panel, Figure 1). Any time the user enters a food or an activity, she is presented with several suggestions for the insulin adjustment: based on the user’s own highest rated prior record of the same food or activity (this suggestion, adjusted for the correct portion size or activity duration, is the default choice); based on the information available in the built-in nutritional database, if any; and based on other users’ highly-rated records of the same food or activity. In the latter case, the suggested insulin dose would be automatically calculated based on the difference in insulin sensitivity between the two users. By leveraging social data, IDiDit would thus be able to provide ballpark insulin doses even for activities and foods that the user has never tried before and for which no standardized information exists.

In terms of restaurant foods, we envision that IDiDit would have a Yelp-like map-based display of the nearby restaurants. The record for each restaurant would contain information about foods that are present either in the user’s own diary or that have been logged by other IDiDit users (right panel, Figure 1). In this way, the user would get access to insulin dosing information that would help her make an informed insulin adjustment even for foods that the user might not be able to correctly eye-ball.

Finally, to make these functions to work well, IDiDit needs to have both robust privacy settings and sufficient information about users’ insulin sensitivity to be able to automatically calculate insulin doses for different people. In regards to privacy, our initial plan was to make diary records private by default, but to enable users to override the sharing setting for any individual record either at creation time or later on.

4.4 Feedback on IDiDit

To get feedback on the concept and design of IDiDit, we presented an interactive, high-fidelity mock-up of the application in a focus group with five T1D patients. Their reactions on the concept were very positive, and they thought that an application like IDiDit could effectively support glucose management. More concretely, the participants had several insightful comments about IDiDit’s functionality that are relevant not only to IDiDit but to other diabetes self-management applications as well.

To track food amounts, we proposed to log food in terms of “portions,” which people seem to relate to easily based on their “eye-balling” skills. Participants expressed concern, however, about the uncertainty of what a portion meant from one

person to the next, and how that could affect reliability of data entry and insulin dosing suggestions. They suggested that portion size be logged in terms different-sized balls, as participants did not commonly use units such as cup, tsp or Tbsp. They thought that a golf ball or tennis ball were better standardized units that most people could imagine.

This idea is intriguing but it is not without its own problems. While a tennis ball worth of rice or beans is easy to visualize, it is not clear that such units would work for all foods. For instance, measuring liquids such as soup in tennis balls seems rather unintuitive. This comment does point to the importance of a thoughtful choice of measures in applications like IDiDit, and that finding a right measure that works across a broad range of foods or activities can be difficult.

Also in relation to logging food, we envisioned that users would be able to take a picture of the food to better jog their memories. This functionality was perceived to be more important than we originally thought, however. Participants thought that pictures would be key for helping understand portion sizes or to have a better idea of the composition of the eaten meal in relation to the administered insulin dose. The use of pictures before and after a meal was suggested as a way to address the portion variability: participants all agreed that seeing a sequence of pictures would help make data from peers more helpful, allowing them to compare other users' data with their own usual estimations. Moreover, pictures could document substitutions (e.g., brown rice instead of white rice), and food combinations (e.g., avoiding starches). In addition to supporting before and after pictures to address these comments, we will be introducing structured prompts in the notes for substitutions for those who do not take pictures.

Privacy is an important issue to users when recording personal events, particularly when an application offers options for sharing this personal data with peers. Our study results revealed how easily our participants felt judged about their glucose results or other data. At the same time, our focus group participants clearly understood the value of data sharing in an application like IDiDit. To balance these two sentiments, they emphasized the importance of granular privacy settings. In addition to being able to override a global sharing setting, participants thought that what was needed was to allow control over which parts of the dataset are shared. For instance, they wanted to be able to share glucose results and insulin doses, while keeping private personal notes, or name and demographics. This is an important point but also one that does not have an easy solution. How exactly such settings should be implemented is not clear. Should there only be global settings that apply to all records in the same way? If per-record overrides are provided—as we originally intended—would these need to be granular as well or should they merely switch sharing of the current record on and off? Answers to such questions are not obvious but designing privacy settings correctly is an essential condition for acceptance of social applications such as IDiDit.

Feedback on IDiDit mock-ups reinforced the point that when it comes to patient technologies, design details matter hugely. How data entry or privacy is designed can make or break an application. Iteration and early feedback are thus invaluable.

5 Conclusion

As diabetes changes over time, so does the patients' need for technological support. Based on interviews and focus groups, we described features of one type of application that can support patients in stable stage of the disease: an individualized database for estimation of glucose trends or insulin needs personal history, commercial food datasets, and peer experiences. Such an application could enable patients to experiment with new foods and activities while maintaining health and living their lives to the fullest.

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