Designing Decision-Support Technologies for Patient-Generated Data in Type 1 Diabetes

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Abstract

People living with type 1 diabetes generate data as a byproduct of diabetes management. The development of decision support technologies can be enabled by harnessing these patient-generated data, but a major challenge is for these technologies to provide meaningful and highly personalized guidance to support individual patients' decision-making processes. In this paper, results from a year-long qualitative study were reported. Twenty-six people with type 1 diabetes were interviewed regarding the types of self-generated data they use for decision-making, their decision-making processes using self-generated data, and the difficulties they experience when attempting to use this data for decision-making. These patients' behaviors and difficulties point to new approaches to designing decision support technologies for personal use, including patient-centered and automated data entry, automated and individualized data analysis, and humanized output.

Introduction

Patients with type 1 diabetes are forced into frequent decision-making processes related to their health on a daily basis[1]. Data generated by type 1 diabetes patients (e.g., blood glucose levels, food consumption, mood, stress levels, and co-morbidity medication) can be a valuable resource for patient decision-making. This paper examines how patients with type 1 diabetes use various types of self-generated health data in their everyday decision-making processes. Understanding this issue will help improve consumer decision support technologies and enhance our capacity to use patient generated data in clinical decision support technologies.

In this paper, self-generated health data refers to health information that is collected by patients about their condition (e.g., blood glucose readings collected with a glucometer), their actions (e.g., exercise intensity), or their experiences (e.g., pain). Patients with type 1 diabetes can achieve better health outcomes by using their self-generated data to make decisions about their health, such as dietary choices spurred by frequent monitoring of their blood glucose levels[2].

However, maintaining and using self-generated health data can be challenging. An average diabetes patient spends about an hour every day on self-care[3]. Collecting and maintaining health data adds to patients' responsibilities and intensifies patients' stress[4]. Also, in many cases this patient work is invisible to health care providers[5], making it difficult or impossible to address in clinical environments.

Research on consumer-oriented technologies point to the potential value that they have in assisting patients' efforts to collect and use self-generated health data for decision making. For example, technologies that support frequent monitoring (e.g., continuous glucose monitors) may help patients to maintain better glycemic control[6]. Real-time feedback through mobile phones for diabetes patients based on their blood glucose levels, diabetes medications, and lifestyle choices may lead to improved glycated hemoglobin test results[7]. The medical informatics community is also exerting increased effort in incorporating patient-generated data in clinical information technologies (e.g., patient portal systems and electronic health records), but more research is needed to investigate the impact of this data[8] and potential approaches to facilitate the process[9].

This paper offers a patient's perspective toward self-generated health data, including its value and use by patients with type 1 diabetes for decision-making. Our purpose is to improve the usefulness and adoption rates of decision support technologies for these patients by informing technology design through naturalistic research. The research questions include: (a) What types of self-generated health data do patients with type 1 diabetes consider useful for diabetes decision support? (b) How do patients use this data for decision-making? (c) What difficulties do patients encounter when using self-generated data for decision-making?

Related Studies

Studies reporting the types of diabetes patient-generated data used in decision support technologies usually focus on health indicators and health behavior. For example, a randomized controlled trial on a community-based decision

support system, COMPLETE II, tracks patients' blood pressure, cholesterol, glycated hemoglobin, foot check results, kidney function, weight, physical activity frequency, and smoking frequency[10]. Other decision support systems reported using similar data to generate personalized decision support, including health outcome (e.g., blood glucose levels[7,11–16], Hemoglobin A1c[17], blood pressure[17], lipid[17]), diet (e.g., carbohydrate intake[7,11]), medication[7,11], and exercises[11]. One data type that is not currently well supported by these systems is the illness experience, an important aspect of decision-making processes for patients with diabetes[1].

The aforementioned decision support systems were mainly developed for shared decision-making between healthcare providers (HCP) and patients. The types of data entered are predefined, and data entry into these systems requires patient work with the help of sensor technologies. Decision support, however, is mostly directed toward HCPs, not patients. Some data that patients find useful is considered irrelevant by HCPs[18]. In other words, when using these decision support systems, diabetes patients contribute to data entry but they do not play a major role in making decisions for themselves using the generated data. For a chronic disease that involves day-to-day self-care, type 1 diabetes calls for patients' effort in daily decision-making[1]. To date, not enough research has examined patients' requirements for these technologies[19], particularly since they may use the data generated and stored in these technologies for daily self-care efforts.

Recently, the roles that patients and their self-generated data play in decision-making have been explored in several studies. This research suggests that personal preferences, values and context can shape patients' decision-making processes[1,20,21]. Disregarding these individualized requirements to pursue standardized goals may not necessarily lead to improved long-term health outcomes[19,20]. Indeed, research on various diabetes patient decision aids (e.g., cards and apps) attempts to take personal preferences into consideration[22]. Nevertheless, much remains unknown about how to design technologies that put patients at the center of the decision-making process to support their decision-making activities.

Method

Participant Recruitment

Participants were recruited through snowball sampling via the researcher's personal network. The first author recruited the first group of participants among people she knows in person. Then, the first author asked the existing participants to introduce this study to people in their personal networks who were potential candidates. This process carries on through the researcher's and existing participants' networks. Snowball sampling is a recruiting method that can effectively and efficiently reach stigmatized populations, making recruitment for this study possible[23].

Twenty-six eligible participants with type 1 diabetes were recruited. Among them, 23 live in New York City and 3 are located in other cities in the East, North and Midwest regions of the United States. To protect participants' privacy, the names of the 3 cities are not reported in this paper. Participants' characteristics are presented in Table 1.

Data Collection

The data presented in this article were collected through one-on-one semi-structured interviews. The first author carried out all of the data collection using an interview guide, which was tested and revised iteratively through a pilot study with 30 diabetes patients; data from the pilot study is not reported in this paper. The major questions

Table 1 Participant characteristics

Characteristic	*n*	*%*	Characteristic	*n*	*%*
Gender			Occupation		
Male	6	23.1	Artist	6	23.1
Female	20	76.9	Business administrator	5	19.3
Age (years)			Engineer	3	11.6
19-24	1	3.8	Student	3	11.6
25-44	8	30.8	Lawyer	2	7.7
45-69	12	46.2	Accountant	1	3.8
70+	5	19.2	Doctor	1	3.8
Years of experience			Home maker	1	3.8
0.5-2	4	15.4	Journalist	1	3.8
3-19	8	30.8	Nurse	1	3.8
20-39	7	26.9	Pharmacist	1	3.8
40-49	6	23.1	Teacher	1	3.8
50+	1	3.8			

asked in the interview include: (a) What health data about yourself and generated by yourself do you collect? (b) Is this data useful for your diabetes management? If yes, in what way(s)? (c) (If participant mentioned decision making) How do you use this data to make decisions about diabetes? (d) Did you encounter difficulties in this process? (e) What kind of technologies do you think can help you overcome these difficulties?

Data Analysis

All interviews were transcribed and inductive coding was performed for each of the 5 major interview questions. The analysis follows this iterative procedure: The first author (a) coded a sample, (b) discussed the coding with colleagues, (c) revised the codebook and the coding procedure, (d) coded the old sample(s) along with a new sample, (e) repeat the previous two steps until the codebook is no longer updated, which is 8 iterations, and (f) code the other 18 interviews. A second coder coded 5 interviews with high agreement (Krippendorff's Alpha = 0.817; Cohen's Kappa = 0.818). The number of participants who mentioned each theme is not reported, as is common in research that uses semi-structured interviews for data collection[24]. Specifying the number of participants mentioning each theme may not fully represent their exact behaviors.

Table 2 Types of self-generated diabetes data used by participants for decision support

Types	Detail	Examples
Blood glucose	Blood glucose levels	120mg/dl
	Blood glucose test time	1/2/2012 11:35am (exact); before breakfast; 2h after lunch (relative)
	Blood glucose test location	L3Y (i.e., third finger from thumb on left hand, as described by a participant)
Other health indicators	Physiological	shortness of breath; fatigue; tingling in extremities
	Psychological	work-related stress; mood changes
Insulin	Insulin type	NovoLog, Humalog, and Lantis
	Insulin dosage	4 units and half a unit
	Insulin injection location	left buttock; right thigh; arm; belly
	Insulin injection time	9:00pm
Other treatments	Treatment type	metformin; medication for lupus; cancer treatments
	Treatment dosage	1 pill
	Treatment time	with dinner
Food	Carbohydrate count	"15 carbs" for a slice of apple
	Portion size	a big apple may be equal to 3 servings of apples
	Type of diet	vegan; paleo; high protein; high fat; low carb
	Types of food	red meat; fish; fruits; grains; vegetables
	Specific food	cereals; cookies; yogurt; cheese; lentil soup.
	Dining time	7:30pm
Exercise	Exercise type	running; tennis
	Exercise intensity	marathon; first run after recovery from injury
	Exercise time	3pm
	Exercise length	1 hour
Perceived environment	Seasons	winter; summer
	Weather	hot; sunny

Results

In this section, results for each of the three research questions are presented. First, the types of patient generated health data collected and used by participants for decision support are presented. Next, four decision-making patterns reported by participants are described. Finally, the difficulties that participants experience when engaging in each of the four decision-making patterns are discussed.

Types of Self-Generated Health Data that Patients Collect and Use in Decision Making

Participants in this study report collecting, maintaining, and using a wide range of self-generated health data for making health-related decisions. A list of the various types of self-generated health data that participants use to support decision-making processes is presented in **Table 2**. Note that not all participants report using all types of data. In other words, participants may use a subset of the types listed in Table 2. Also, participants' preferences for different data used in decision-making processes may develop and change over time. For example, P19 was diagnosed with lupus shortly before the interview and her new procedure for diabetes decision-making takes into consideration the ways in which lupus treatments would impact her diabetes-related routine.

The types of self-generated health data used by participants for decision-making cover many aspects of their health condition, related treatments, regimens, and personal contexts. The scope of this data sometimes extends beyond that advised by participants' HCPs. Some participants recall their HCPs asked them to collect blood sugar levels and test time and date. Others add that food diaries detailing the types of food and corresponding portion size are recommended by their HCPs. However, participants were not required to keep records on other types of data that they use for decision making or keep uninterrupted records of the types of data preferred by their HCPs.

Use of Self-Generated Health Data in Decision Making

Participants report four patterns of decision-making processes that rely on the use of self-generated data related to diabetes. These four patterns include: (a) connecting causes and effects – "What caused these health outcomes?", (b) establishing priorities – "What should I do next?", (c) negotiating outcomes – "What may I give up?", and (d) setting visibilities – "What do I want to see?". In the rest of this section, each of these four patterns will be introduced with detailed descriptions and examples.

Pattern 1: Connecting Causes and Effects

Participants make decisions about future actions by identifying specific factors, based on the data they collect, that positively or negatively impact their health outcomes. In Table 2, blood glucose and other health indicators are considered health outcomes by participants and the other types of self-generated health data (e.g., insulin, food and exercise) are considered causes that may affect health outcomes. Three approaches were taken by participants to connect cause and effect, including observation, statistic testing, and experimentation.

Observation. In all cases of observation, participants observe changes in their self-generated health data by using time-stamps, which allow them to solve problems related to diabetes management. Some of these observations occur over short periods of time. For example, all participants test their blood sugar levels before and after meals. When their test results are unexpected, they estimate or check the carbohydrate content in their meals to find out which items are responsible for causing specific test results. Likewise, for participants who perform a variety of exercises and experience various treatments, they tend to associate unexpected health outcomes with changes in their exercises and treatments occurring immediately before the observed changes in their health outcomes. Participants who observe immediate health outcome changes following activities they perform tend to adjust their activities to amplify positive outcomes and temper negative ones. For example, consuming food with high carbohydrate levels (e.g., orange and potato chips) lead to spikes in some participants' blood glucose levels immediately afterwards, which makes them reconsider similar food options in the future.

However, not all cause and effect connections are easily observable in the short term. For example, participants complain that injecting insulin at the same site on the body can affect the effectiveness of the insulin, potentially because of the building up of scar tissues. This phenomenon cannot be observed in the short term, and participants often suspect other factors that can have a more direct impact on blood glucose levels (e.g., food consumption and exercise) before moving on to the less obvious factors (e.g., insulin injection site and temperature). In this circumstance, keeping long term records of self-generated health data is a necessity. For example, P2 keeps paper records of his blood sugar levels over the long term and he color-codes these records according to how high the blood sugar levels are when measured. He keeps a large board and pins his records on it so he can easily observe

patterns of codes and colors in his records. When he observes a cluster of certain color, he reads the annotations in these records on the contexts of these records (e.g., food intake, insulin injection location, and finger used for a blood sample) to find out what may have caused these clusters of certain blood sugar levels. Participants who observe cause and effect connections over the long term tend to approach behavior change decisions more cautiously. Some participants reported consulting other sources (e.g., HCPs, support groups, online communities, and medical and health articles) for reassurance before taking actions.

Statistical analysis. Participants who maintain electronic records of their self-generated health data sometimes conduct statistical analyses with their observations in order to locate potential problems. For example, P18 built annotated records of his blood sugar levels with Microsoft Excel spreadsheets. He describes how he uses statistical analysis to identify issues of importance in these records, "*I noticed the clustering, I noticed the change on weekends, I noticed the changes on the seasons, because my overall requirements are a little higher in the summertime, and down a little bit in the winter time. Took me years of charts to try to work that out. ...In an effect, it speaks to me. Also in terms of time series. I go back, and then look at it month before, I look at it years before, around this time of year, and I know I'm having a seasonal change. ...This is why a data driven approach was for me.*" P18 was confident with his findings because they were based on models using longitudinal data. These findings alleviated P18's concerns about unexpected changes in his blood glucose levels during the winter and prompted him to monitor his condition more closely and make necessary adjustments to his insulin intake during the same period.

Other participants report benefitting from statistical analysis provided by applications for diabetes management, such as those that work with their continuous glucose monitors. Participants note that these applications usually help identify patterns of changes in health outcomes (e.g., blood glucose levels), but do not associate these outcomes with a wide variety of potential causes (e.g., exercises, stress and temperature), although some connect carbohydrate intake with blood glucose levels. Also, participants complain that these applications require manual entry of nearly all of their self-generated health data, except for blood glucose levels, which are automatically measured and documented by their continuous glucose monitors and related applications. Due to the lack of functionality and the efforts required for manual data entry, participants who report using such applications find their data entry incomplete (e.g., P7 had interim blood glucose records on her continuous glucose monitor) or that their usage declines and stops after a few months. These participants explain that these applications were not very useful for them, but their HCPs can help them with decision-making after reviewing the blood glucose levels they collected over 10 days to 2 weeks before their clinical visits, depending on their HCP's requirements.

Experimentation. Some participants experiment on themselves to extract the causes of certain health outcomes. Experimentation is usually employed by participants who do not identify relationships between causes and their effects through observation and statistical analysis. An experimentation method reported by participants is to establish a routine of daily activities and test the effect of new behaviors (e.g., eating a new type of food, performing a new physical exercise, changing insulin injection schedule, mixing different types of insulin, using expired insulin, and switching medical devices) on specific health outcomes. Participants also voice that diabetes management is a "noisy system", and they usually repeat the same experiment multiple times before making a conclusion if they do not consider the changes in their health outcomes large enough to justify the necessary behavior changes.

Pattern 2: Establishing Health Priorities

When cause and effect connections are established, participants plan the steps they will take for future behavior changes. While some changes may be perceived by participants as straightforward (e.g., reducing carbohydrate intake to an amount recommended by HCPs), others may involve multiple processes when the cause and effect relationships are intricate.

Take P16's treatment of chronic fatigue as an example. P16 was living with cancer and type 1 diabetes, and one of the treatments for cancer made her suffer from chronic fatigue. The symptoms of the fatigue were so severe that she struggled to get out of bed every morning. Every time when she attempted to test her blood sugar, she falls asleep without realizing it. This fatigue, coupled with her unstable blood sugar levels, became dangerous because it increased the risk of her inability to react during a hypoglycemia episode.[1] To treat the fatigue, P16 had three options, and could choose any of the options or a combination of the options: (a) change her cancer treatment, (b) change her diabetes treatment (e.g., adjust insulin dosages and dosing methods), (c) change her diabetes regimen (e.g., increase exercises

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[1] Hypoglycemia: Situations of blood glucose levels dropping below a certain threshold. Hypoglycemia may be more difficult to recover in patients with type 1 diabetes that use insulin. If left untreated, hypoglycemia can worsen and lead to severe health consequences, such as seizures, unconsciousness [25].

and reduce carbohydrate intake). P16's health care team offered her a wide range of choices for potential treatments and regimens, but they did not have a clear sense of how effective these changes would be for P16 as an individual patient. She decided to immediately change her cancer treatment; then, she joined a physical training class in the same hospital where her health care team was located. Finally, she changed her diabetes treatments by acquiring a continuous glucose monitor. These changes took course over a 2-year period, and P16's fatigue was largely reduced.

P16's decision-making process involves considerations for cause, convenience and cost; she prioritizes different considerations for different reasons, at different times during her decision-making and her resultant behavioral changes. First, she removes the cause of negative health outcomes (e.g., fatigue-inducing cancer treatment). Then, she increases positive health outcomes by participating in convenient behaviors (e.g., exercising). Later, she aims for less convenient and costlier causes of positive health outcomes (e.g., a continuous glucose monitor).

Other participants also report considering cause, convenience and cost, but with different priorities. For example, P13 acquired a continuous glucose monitor shortly after her diagnosis because being able to monitor her blood glucose levels in real time helps her make decisions on micro-adjustments and maintain constantly in-range blood glucose readings. In this case, P13 prioritizes cause and convenience over cost.

Pattern 3: Negotiating Outcomes

Participants report that they have specific goals in mind when they make connections between causes and effects and they negotiate between these goals to decide what actions to take. Some of these goals are straightforward health outcomes, such as achieving stable blood glucose levels and not experiencing diabetes complications. While many health outcomes pursued by participants require similar actions (e.g., timely insulin injection around meal time can help type 1 diabetes patients avoid symptoms of hyperglycemia and also reduce the chances of complications in the long run), some health outcomes have competing requirements. For example, P22 describes her fears of hypoglycemic episodes, "*I'm not aggressive enough with it* [i.e., carbohydrate counting]. *I always underestimate. It goes back to my fear of lows.*" In this case, P22 believes that maintaining an in-range average blood glucose level increases the chance of hypoglycemia. She negotiates between the immediate and potentially devastating effects of the acute hypoglycemic episodes and the relatively mild but degenerative effects of hyperglycemia. To reduce the chances of the acute episodes, P22 decides to loosen her standards for carbohydrate counting and maintain a relatively high average blood glucose level.

Participants also have other considerations that may compete with their pursuit for better health outcomes. Such considerations reported by participants include quality of life, time, and social life. Participants complain that not being able to enjoy their favorite food affects an important aspect of their quality of life. For example, P6 enjoys a small portion of ice cream every day, but her blood glucose is sensitive to the sugar in the ice cream. In order to manage diabetes, P6 has to cut back on her daily ice cream portion and take extra insulin to cover for the blood glucose spikes. Also, participants found the lack of time due to factors such as the pursuit of a career, caring for family, and traveling a major reason that may compromise their diabetes management endeavor. P8 attempts to maintain the best blood glucose levels with a busy graduate school schedule. Because of her busy schedule, she is not able to guarantee timely food intake, so she keeps snacks at her desk and micro-manages her insulin injection through a pump to obtain the best possible outcomes. Further, participants find that their social lives impact their decision-making processes as well. For example, P17 explains his struggles to negotiate between diabetes management and a normal social life: "*...to let down, let's say a friend or not make it to a social arrangement because of a hectic diabetic disruption. It's difficult for someone else to understand, because, in a lot of ways, it's an unreasonable disease. ... I think I have trouble with those moments saying to friends, you know like, it's a long, hard day and I know were aren't right words, but I think it's a psychological weight to kind of carry for this irrational disease that can disrupt at any moment.*" Other participants also mention social eating and religious fasting as difficult moments where they must balance healthy social relations and the temptation of food with the possibility of negative health outcomes.

When negotiating between aspects of their lives that compete with health outcomes, rather than giving up or reducing the frequency and intensity of certain actions, participants in this study also report seeking alternative actions that have less impact on their health outcomes. For example, P9 enjoys sweet foods and drinks and finds them to be an important aspect of her quality of life, but they usually create spikes in her blood glucose levels and require a greater insulin dosage. To achieve a balance between quality of life and stable, in-range blood glucose levels, P9 stockpiles Glucerna, a sweet beverage that she discovered would not create sugar spikes that were as severe, and she uses it to substitute her usual breakfast.

Pattern 4: Setting Visibilities

When participants use their self-generated health data to make decisions, they have different preferences regarding

the type of data they want to see in different circumstances; they also have different preferences for the quantity and timing of such data.

Data selection. All participants do not use all types of data listed in Table 2 for decision-making. Some participants follow their HCPs' recommendations such as using carbohydrate counting and food consumption to determine insulin dosages, while other participants use other types of data for the process, depending on their daily activities and preferences. For example, P2 performs the same moderate exercises on a daily basis, so he does not consider exercise-related data relevant for decision-making. On the other hand, P12 is a marathon runner with varying exercise schedule, and exercise-related data is a major input for her to make treatment and regimen decisions.

Quantity and timing. Participants have different preferences regarding the quantity of data they use for decision-making. Some participants prefer large quantities of self-generated health data because more data means greater possibilities of discovering recurring patterns and hidden connections. On the other hand, participants who do not keep records of their health data (e.g., blood glucose levels) but use it for real time decision support (e.g., test blood glucose to determine the next insulin dosage) tend to prefer smaller quantities of data collected shortly before or during the decision-making episode. The reasons participants give for these preferences are that too much data is overwhelming, and data collected too long before the decision-making episode has little bearing on their ever-changing health statuses (e.g., blood glucose readings).

Decision-Making Difficulties

Participants in this study identify various difficulties that they experience with their current decision-making processes and supporting technologies. These findings are reported in **Table 3**.

The difficulties reported by participants point to three disconnections between their decision-making processes and the support they receive, including: (a) data entry does not reflect data used for decision making, (b) data analysis is difficult to carry out and results are hard to comprehend, and (c) output of analysis is difficult to understand and put to practice. The four decision-making patterns are influenced by different disconnections, with (a) *connecting causes and effects* and *negotiating outcomes* mainly caused by data entry and analysis problems, and (b) *establishing priorities* and *setting visibilities* mainly related to issues with data output. Decision support technologies that address these three disconnections will offer better utilities and experiences for patients with type 1 diabetes. The next section details some of the ways that these disconnections can be addressed in decision-support technology design.

Table 3 Participants' difficulties with using self-generated health data for decision-making

Decision-making patterns	Difficulties	Detail
Connecting causes and effects	Identify causal factors	Unable to locate causes of certain health outcomes.
	Identify intensity of causal factors	Difficult to determine how much influence each causal factor have on certain health outcomes.
	Identify solutions	Unable to find viable ways to address the causal factors for negative health outcomes.
Establishing priorities	Stay accountable	Difficult to stick to the plan.
Negotiating outcomes	Identify current trends	Unable to monitor the trending of current health outcome indicators.
	Estimate individualized outcomes	Difficult to predict health outcomes based on personal health history and actions taken.
Setting visibilities	Too much information	Irrelevant information causes fatigue to notifications and negative emotions.
	Inconvenient access	Medical terms that are difficult to understand, tools that have awkward displays, not sure how to interpret the data, not sure what questions to ask.

Discussion and Implication

This paper describes the multiple types of self-generated data that type 1 diabetes patients use in their everyday decision-making processes, the ways in which they use this data to make decisions, and the difficulties they experience in these processes. These results point to multiple venues for the design and redesign of decision support technologies for patients with type 1 diabetes that will not only provide direct support for patients, but will also harness patient generated data for clinical use. In the clinical environment, individual patients' longitudinal data that is used by patients in their decision-making processes can enrich and enhance the data used by clinicians for medical decision making in clinical care. Collections of this data, gathered as part of patients' daily routines, may also enable the identification of cause and effect connections not commonly considered in clinical settings, as well as potential treatments and regimen recommendations used by patients.

Patient-Centered Data Entry

People living with type 1 diabetes use a wide range of self-generated health data for decision-making. The different types of data they generate, collect, store, and use extends beyond HCPs' requirements[10]. Some of this data is patients' perception of themselves and their environment, such as mood and weather. The nuances of health data captured by patients and used by them in everyday settings for decision-making are usually not incorporated in the design of decision support systems. To facilitate using patient generated data to support patients' decision making, allowing patients to define the types of data to enter into their decision support technologies is necessary. For example, P2 considers blood glucose testing location and insulin injection location important for him to interpret his blood sugar readings, especially when he compares his readings across testing and injection locations. In contrast, P11 believes that stress is a major cause of her diabetes and is highly conscientious about work-related stress levels. Considering these highly specialized needs, it is not sufficient to offer these two participants a standard diabetes decision support application that allows them to document their carbohydrate counts and insulin dosages. A better, more flexible solution is to allow patients to define data types that are beyond the standard setup, enabling them to name new data entries (e.g., variables), their measurements (e.g., categorical or continuous), and their entry method (e.g., choose from preset options or enter free text) as well as incorporate this data to support their decision-making processes.

Furthermore, the larger amount of data collected by patients in the home points to the insufficiency of patient data routinely collected in the clinical setting. If patient-generated data is incorporated into clinical records, it may be useful for improving patient-provider communication and clinical care by offering HCPs data-driven approaches from patients' perspective, rationales of patients' activities, and possibilities of discovering new working regimen initiated and tested by patients.

Automated Data Entry and Analysis

Participants in this study expressed their needs for decision support systems that can automatically identify potential causes for changes in their health outcomes. Some participants also experienced difficulties with identifying solutions for certain health-related problems and desire decision support technologies that will aid them in finding solutions for these problems. Some participants mentioned that existing technologies (e.g., continuous glucose monitors) can address some of their needs, but others complained that the automated functionalities of these technologies are limited to blood glucose related tracking and recommendations. There is currently not enough support to automate the collection of other types of self-generated data (e.g., diet and exercise). When possible, incorporating existing self-generated data from other devices using open APIs, such as step-tracking software on many mobile phones or weight data collected by smart scales, may be one way to aggregate and store self-generated data for patient use.

In an effort to automate the data entry and decision-making processes, the medical informatics community has made recent developments in consumer-oriented technologies, such as a diabetes wound management app based on image recognition technologies[26] and a meal-camera system used in telemedicine for diabetes patients[27]. More research is needed to facilitate communication between applications that automate the entry and analysis of different data to offer more coherent and meaningful consumer experiences.

Individualize Data Analysis

Findings in this paper demonstrate that type 1 diabetes patients' decision-making processes are highly personal. Some decisions are made within the participants' resource constraints and their personal preferences. These constraints and preferences differ between patients and may change over time. This issue points to the need to not only use patients' personal health data for individualized care, but also to allow patients to shape the underlying logic of how this data can be viewed, analyzed, and used. For example, a piece of decision support technology that

models a type 1 diabetes patient's blood glucose levels on weekly, monthly, and yearly basis may not clearly show patterns for all three time intervals, particularly if the patient has a non-standard work schedule. In this case, allowing the patient to set her preferred time interval to match her specific schedule may help the technology determine if the patient's work schedule plays a significant role in affecting her blood glucose levels.

Humanize Decision Support Output

Some participants voice their frustration and confusion when engaging in their existing decision support aids for their lack of intuitive interfaces (e.g., continuous glucose monitors and their corresponding applications and carbohydrate counting books). Participants report that they prefer decision support technologies designed for laypeople, who do not have specialized knowledge in medicine or expertise with using search engines. Participants would prefer to communicate with decision support technologies as if they were human (e.g., both the patient and the technology can use and understand plain, natural language), and would like these technologies to help hold them accountable for their health-related decisions (e.g., recording blood glucose test results and maintaining diet) like HCPs would.

These requirements point to three potentially useful aspects of decision support technologies for patients with type 1 diabetes: (a) the ability to translate between natural language and search queries; (b) the ability to translate between medical terms and lay terms; and (c) the ability to socialize with the patient at checkpoints (e.g., making sure that the patient keeps her daily carbohydrate count at under 200 grams). This study does not yield enough information on how to determine what incidents qualify as checkpoints or how frequent these checkpoints should be. The literature on using telemedicine reminders to support self-management and promote adherence in people with chronic conditions does not agree on how frequently reminders should be sent, and there is not enough research on the detection and determination of checkpoints to date. For example, Tao and colleagues argued that the frequency of electronic reminders does not seem to moderate medication adherence[28]. Eleches and colleagues found that the frequency of reminders has an impact on patients' adherence to antiretroviral therapy (i.e., an HIV treatment) and that weekly reminders seem to have a more significant positive impact than daily reminders[29]. Research also suggests that allowing teenage asthma patients to set the frequency of reminder text messages may enhance patients' self-management[30]. Therefore, a future direction for this work is to determine when and how to build checkpoints in to these technologies. It is possible that, like the recommendation to individualize data analysis, checkpoints should also be a setting that patients can customize to their own preferences.

Conclusion

This qualitative study explores type 1 diabetes patients' decision-making behaviors and designs that can support these behaviors with a focus on patient generated data. The findings have implications for decision support for patients in their everyday lives, and may also extend to the clinical space. As this is a qualitative study with a purposive sample, the results are not generalizable but may be transferrable to other patient populations where decision-making is frequent (e.g. coronary heart disease, lung cancer) or when patients may generate and track data beyond their HCPs' requirements (e.g., pregnancy)[18]. More research is needed to investigate the effects of the design recommendations and explore certain aspects of decision support technology design (e.g., the timing of checkpoints to promote adherence).

References

1. Jull J, Witteman HO, Ferne J, Yoganathan M, Stacey D. Adult-Onset Type 1 Diabetes: A Qualitative Study of Decision-Making Needs. Can J Diabetes. 2016 Apr;40(2):164–9.
2. Haller MJ, Stalvey MS, Silverstein JH. Predictors of control of diabetes: Monitoring may be the key. J Pediatr. 2004 May;144(5):660–1.
3. Safford MM, Russell L, Suh D-C, Roman S, Pogach L. How much time do patients with diabetes spend on self-care? J Am Board Fam Pract. 2005 Aug;18(4):262–70.
4. Sun S, Belkin NJ. Managing Personal Information over the Long-term, Or Not? Experiences by Type 1 Diabetes Patients. In: ASIS&T '16. Copenhagen, Denmark; 2016.
5. Ancker JS, Witteman HO, Hafeez B, Provencher T, Van de Graaf M, Wei E. The Invisible Work of Personal Health Information Management Among People With Multiple Chronic Conditions: Qualitative Interview Study Among Patients and Providers. J Med Internet Res. 2015;17(6):e137.
6. Deiss D, Bolinder J, Riveline J-P, Battelino T, Bosi E, Tubiana-Rufi N, et al. Improved Glycemic Control in Poorly Controlled Patients with Type 1 Diabetes Using Real-Time Continuous Glucose Monitoring. Diabetes Care. 2006 Dec 1;29(12):2730–2.
7. Quinn CC, Shardell MD, Terrin ML, Barr EA, Ballew SH, Gruber-Baldini AL. Cluster-Randomized Trial of a Mobile Phone Personalized Behavioral Intervention for Blood Glucose Control. Diabetes Care. 2011 Sep

1;34(9):1934–42.

8. Hsueh P-YS, Martin-Sanchez F, Kim K, Peterson S, Dey S, Yang B, et al. Secondary use of Patient Generated Health Data (PGHD). IMIA Yearb Rev 2017.

9. Elhadad N, Mamykina L, Zhu X, Chen C-H. Patient generated data: the missing link in patient-centered care? In: AMIA '16. 2016.

10. Holbrook A, Thabane L, Keshavjee K, Dolovich L, Bernstein B, Chan D, et al. Individualized electronic decision support and reminders to improve diabetes care in the community: COMPETE II randomized trial. Can Med Assoc J. 2009 Jul 7;181(1–2):37–44.

11. Augstein P, Vogt L, Kohnert K-D, Heinke P, Salzsieder E. Translation of Personalized Decision Support into Routine Diabetes Care. J Diabetes Sci Technol. 2010 Nov;4(6):1532–9.

12. Rodbard D, Vigersky RA. Design of a Decision Support System to Help Clinicians Manage Glycemia in Patients with Type 2 Diabetes Mellitus. J Diabetes Sci Technol. 2011 Mar;5(2):402–11.

13. Bergenstal RM, Ahmann AJ, Bailey T, Beck RW, Bissen J, Buckingham B, et al. Recommendations for Standardizing Glucose Reporting and Analysis to Optimize Clinical Decision Making in Diabetes: The Ambulatory Glucose Profile. J Diabetes Sci Technol. 2013 Mar;7(2):562–78.

14. Mahmoudi Z, Johansen MD, Nørgaard HH, Andersen S, Pedersen-Bjergaard U, Tarnow L, et al. Effect of Continuous Glucose Monitoring Accuracy on Clinicians' Retrospective Decision Making in Diabetes: A Pilot Study. J Diabetes Sci Technol. 2015 Apr 16;9(5):1092–102.

15. Vettoretti M, Facchinetti A, Sparacino G, Cobelli C. Patient decision-making of CGM sensor driven insulin therapies in type 1 diabetes: In silico assessment. In IEEE; 2015. p. 2363–6.

16. Al-Taee MA, Abood SN, Al-Nuaimy W, Al-Taee AM. Blood-glucose pattern mining algorithm for decision support in diabetes management. In IEEE; 2014. p. 1–7.

17. O'Connor PJ, Sperl-Hillen JM, Rush WA, Johnson PE, Amundson GH, Asche SE, et al. Impact of electronic health record clinical decision support on diabetes care: a randomized trial. Ann Fam Med. 2011 Feb;9(1):12–21.

18. Zhu H, Colgan J, Reddy M, Choe EK. Sharing patient-generated data in clinical practices: An interview study. In: AMIA '16. 2016.

19. Wilkinson MJ, Nathan AG, Huang ES. Personalized Decision Support in Type 2 Diabetes Mellitus: Current Evidence and Future Directions. Curr Diab Rep. 2013 Apr;13(2):205–12.

20. Tamhane S, Rodriguez-Gutierrez R, Hargraves I, Montori VM. Shared Decision-Making in Diabetes Care. Curr Diab Rep [Internet]. 2015 Dec;15(12).

21. Kalra B, Gupta Y, Kalra S. Timing of Delivery in Gestational Diabetes Mellitus: Need for Person-Centered, Shared Decision-Making. Diabetes Ther. 2016 Jun;7(2):169–74.

22. Shillington A, Col N, Bailey R, Jewell M. Development of a patient decision aid for type 2 diabetes mellitus for patients not achieving glycemic control on metformin alone. Patient Prefer Adherence. 2015 Apr;609.

23. Atkinson R, Flint J. Accessing Hidden and Hard-to-Reach Populations: Snowball Research Strategies. Soc Res Update. 2001;28(1):93–108.

24. Morgan DL. Qualitative Content Analysis: A Guide to Paths not Taken. Qual Health Res. 1993 Feb 1;3(1):112–21.

25. National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). Low Blood Glucose (Hypoglycemia). 2016 Aug; Available from: https://www.niddk.nih.gov/health-information/diabetes/overview/preventing-problems/low-blood-glucose-hypoglycemia

26. Strong D, Agu E, Pedersen P, Tulu B, He S, Wang L, et al. Sugar: A mobile phone app for diabetes and diabetic wound management. In: AMIA '13. 2013.

27. Hashimoto M, Nakamura U, Akiyama M, Takebayashi T, Oshima M, Kumegawa T, et al. Meal-camera system to support nutritional tele-consultation for diabetics. In: AMIA '15. 2015.

28. Tao D, Xie L, Wang T, Wang T. A meta-analysis of the use of electronic reminders for patient adherence to medication in chronic disease care. J Telemed Telecare. 2015 Jan;21(1):3–13.

29. Pop-Eleches C, Thirumurthy H, Habyarimana JP, Zivin JG, Goldstein MP, de Walque D, et al. Mobile phone technologies improve adherence to antiretroviral treatment in a resource-limited setting: a randomized controlled trial of text message reminders: AIDS. 2011 Mar;25(6):825–34.

30. Britto MT, Munafo JK, Schoettker PJ, Vockell A-LB, Wimberg JA, Yi MS. Pilot and Feasibility Test of Adolescent-Controlled Text Messaging Reminders. Clin Pediatr (Phila). 2012 Feb;51(2):114–21.