

Understanding Individual and Collaborative Problem-Solving with Patient-Generated Data: Challenges and Opportunities

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Making effective use of patient-generated data (PGD) is challenging for both patients and providers. Designing systems to support collaborative and individual use of PGD is a topic of importance in CSCW, considering the limitations of informatics tools. To inform better system design, we conducted a study including focus groups, observations and interviews with patients and providers to understand how PGD is interpreted and used. We found that while PGD is useful for identifying and solving disease-related problems, the following differences in patient-provider perceptions challenge its effective use - different perceptions about what is a problem, selecting what kinds of problems to focus on, and using different data representations. Drawing on these insights, we reflect on two specific conceptualizations of disease management behavior (*sensemaking* and *problem-solving*) as they relate to data specific activities of patients and providers and provide design suggestions for tools to support collaborative and individual use of PGD.

CCS Concepts

• **Human-centered computing~Computer supported cooperative work** • **Human-centered computing~Empirical studies in visualization** • *Human-centered computing~Information visualization*

KEYWORDS

Patient-generated data; personal informatics; chronic disease management; patient-provider collaboration; diabetes; interpreting data; reflection; problem-solving

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1 INTRODUCTION

Chronic conditions, such as diabetes, require continuous self-monitoring of one's health [13]. Advancement in technology has enabled better self-monitoring. Consequently, patients are generating large amounts of health data and sharing it with their providers to seek support in

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making sense of their data [46]. Although patient-provider collaboration in this context holds promise [25], informatics tools provide limited support in helping patients and providers reflect on health data to convert raw data into insights relevant to a patient's disease in and across different contexts – clinical and personal [5,21,40].

Specifically, in the context of diabetes, making sense of continuously generated data is important for driving disease related decisions but at the same time challenging. The insights that patients and providers draw from data are not necessarily reliable [24]. Moreover, patients and providers use different explanatory models to make sense of the disease, which could have implications for overall disease management including how patients and providers interpret patient-generated data [20]. This highlights an opportunity to further investigate how patients' personal understanding of their health comes together with clinicians' formal knowledge of the disease in the use of patient-generated data. We conducted a multi-method study involving patients with type 1 diabetes to understand the use of PGD with a focus on the following research questions:

- How is patient-generated data interpreted in individual and collaborative settings?
- What are the differences in patient and provider perceptions in interpreting data and using technology for diabetes management?

Using interviews with 14 patients and 4 providers, 12 hours of observations of clinician and diabetes educator sessions with patients, and a focus group with 4 providers, this paper addresses the above research questions by providing an understanding of the following:

- problem-solving as a central and shared purpose of interpreting patient-generated data in individual and collaborative use of data.
- differences in perceptions between patients and providers that challenge the use of patient-generated data for problem-solving.
- *problem-solving* and *sensemaking* as understood through data analysis activities of patients and providers, and collaborative sensemaking as an approach for problem-solving with data.
- design directions for informatics tools to support individual and collaborative sensemaking for problem-solving and to minimize perception differences between patients and providers to support collaboration.

In understanding how PGD is interpreted in individual and collaborative settings, we found that both patients and providers use data with the purpose of identifying and solving disease related problems. During clinic visits, this happens collaboratively between patients, providers and caregivers. In between visits, it is primarily done by patients and caregivers. Although problem-solving diabetes issues is an important goal of using data, there are differences in the use of diabetes data and technology between patients and providers, which challenge problem-solving with data. Patients and providers differ in three key ways when trying to problem-solve with patient-generated data – a) the same data gives different insights to patients and providers, b) they differ on the types of problems to focus on while reviewing data, and c) they use different representations of the data in identifying problems. We draw upon the data related activities of patients and providers to reflect on the theoretical frameworks of problem-solving and sensemaking for chronic disease management [14,26]. We propose that collaborative sensemaking as an approach to problem-solve using PGD provides a useful framework to understand the use of PGD in both individual and collaborative contexts. We provide design directions for informatics tools to support both individual and collaborative use of PGD for problem-solving and sensemaking.

2 RELATED WORK

This section reviews literature on three specific areas relevant to this study – a) collaboration between patients and providers in using patient-generated data, b) personal informatics and chronic illness management, and c) sensemaking.

2.1 Collaborative Use of Patient-Generated Data

Systems supporting patient-provider collaboration have enabled patient-provider communication over health data by having patients track and share their data to seek support for understanding their disease [25,28], by integrating home and clinical care [1], and by supporting decision-making using complex health data via tele monitoring systems [2]. Studies have also explored the use of visualizations to support patient-provider collaboration in using PGD. For example, Schroeder et al. created visualizations from food journals of IBS patients and provide an understanding of how patients and providers interpret data together using the same set of visualizations. While such visualizations are promising for collaborative interpretation of data, the current practices around use of data and challenges inherent in the clinical workflows that do already incorporate use of patients' data in clinics (e.g., diabetes) remain unexplored to a considerable extent [36].

Qualitative investigation into the use of PGD has demonstrated that collaboration over PGD happens in all the stages of the personal informatics model proposed by Li et al. [8,17]. Studies have identified the challenges of using PGD that patients and providers face, such as lack of time to review data, questions about provider expertise to review data, belief about benefits of reviewing data, and lack of support for clinicians to explore patient data [7,43], inability to transfer PGD to Electronic Medical Records, and selective sharing of information by patients based on their perception about relevance of information, consequences of sharing information and the influence on patient provider relationships [19,44]. These challenges suggest the need to improve the design of informatics tools to support collaborative use of PGD by providing visualizations and interfaces for collaboratively interpreting the data [7], by enabling creation of goals for meaningful collaboration [8] and by integrating patient-generated data in clinical workflows [44]. An important aspect of collaborative use of health data is interpreting and making sense of data to reach a common understanding of patient's health condition [10], which is largely unexplored. Designing tools for collaboration also requires understanding how collaborative reasoning happens over patient-generated data.

2.2 Personal Informatics and Chronic Illness Management

Personal informatics systems help people collect personal information and reflect over it. Works by Li et al. have identified different stages of tracking and understanding personal data, and the self-reflection needs of users [17,18]. Choe et al. identified the need for tools to support interpretation of self-monitored data [6]. Studies have worked to support interpretation of self-monitored data by building tools and visualizations in the form of stories from user data [30], correlational insights from multiple streams of contextual and physiological data [41], and visualizations of subsets of data collected by self-trackers [9]. In the context of chronic illness management, reflection happens in tandem with continuous data collection as chronic conditions are "actively managed" in response to immediate self-care needs, requiring a "review-as-you-go" strategy [21]. To encourage engagement with one's health data, studies have explored reflection techniques for patients, such as capturing contextual information in the form of pictures, and tags [27,39,40]. These systems do not support collaboration. Given that patients are sharing data with

providers, designing for collaboration requires understanding both individual and collaborative use of this data to extend these systems to support both types of consumers for data.

2.3 Sensemaking

Multiple conceptualizations of *sensemaking* exist in literature. Weick describes sensemaking as a retrospective process that is triggered because of a knowledge gap. This conceptualization considers sensemaking as a social process because people are affected by each other's opinions in making sense of their own world [42]. Sensemaking focused on information analysis has been defined as the way in which people try to understand complex information and create shared representations of that information to work towards a common problem [33]. In doing so, they try to understand the existence of anomalies from information and recreate information representations to accommodate those anomalies [16]. Sensemaking can be individual and collaborative. In the context of collaboratively interpreting data, collaborative sensemaking has been defined as the process of creating "mutually intelligible representations" of information [38].

For chronic illness management, Mamykina et al. introduced a framework rooted in sensemaking. This framework describes three sensemaking activities that patients engage in to continuously tackle self-care needs – perceiving new health related information signifying a gap in understanding, situating new information within one's knowledge and experiences to either construct a new model that explains the current situation or activate old models, and an action to test new models or a routine action in response to new information [26]. Because of the importance of data in managing chronic conditions and the complexity of engaging with health data, researchers have identified the need to support reasoning about one's data for both patients and providers [24]. Given the increasing prevalence of personal informatics tools, there is potential for these tools to support patients and providers in reasoning with health data. This requires understanding how patients and providers use patient-generated data to drive disease related decisions.

3 METHODS

The objective of our study was to understand how patients and providers use patient-generated data to understand and resolve disease related issues. The study used a combination of observations, interviews with patients, caregivers and providers, and a focus group with providers to gather data to understand the use of patient-generated data in both collaborative and individual settings. We chose to focus on type 1 diabetes patients because this condition requires continuous monitoring of blood glucose and contextual factors (food, physical activity, stress), and frequent regimen changes in response to the effect of these factors on the disease. Our study was conducted at a pediatric endocrinology clinic. Data from pediatric patients include both patients' and caregivers' point of view.

3.1 Interviews and Focus Groups

Patients and providers were recruited through the pediatric endocrinology clinic at a large teaching hospital using a reputational case selection method [35]. One of the lead researchers, a clinician at the facility, approached patients and clinicians. Interview and focus group data was collected by a group of researchers at the same facility. Fourteen patients and two clinicians were interviewed by this group.

3.1.1 Patient Interviews. Five interviews were conducted with the patient and the primary caregiver who accompanied the patient to clinic, one interview was conducted with only the caregiver, and eight interviews were conducted with the patient. Each interview lasted approximately an hour and followed a semi-structured interview protocol. Interviews focused on

understanding the use of technology (glucometers, continuous glucose monitors (CGM) insulin pumps, data displays) to manage diabetes, practices around collecting data, making decisions based on that data, the challenges associated with using data, and frequency of engaging with data including the use of data in clinic appointments or with diabetes educators. Patients received \$20 in compensation.

3.1.2 Clinician Interviews and Focus Group. Two clinicians were interviewed by the previously mentioned research group. The focus group consisted of four providers (different from the ones interviewed) and was conducted by the same research group. The provider interviews and focus groups elicited providers' perspectives on the utility of commercial visualizations available for interpreting diabetes data, types of information providers use to make decisions, and providers' expectations from patients in using their data. The provider interviews and focus group asked providers to walk through problem scenarios using commercial visualizations typically used during clinic appointments (e.g., [Figure 2](#)). Each provider interview was about an hour long, and the focus group lasted 90 minutes. Providers received \$25 in compensation. All interactions were audio recorded and transcribed. [Table 1](#) and [Table 2](#) provide more details on participants.

3.2 Observations

Clinicians and diabetes educators for observations were recruited through the same facility by a clinician in the research group. The observations were conducted by the first author. To understand how data is used in collaboration, 12 hours of clinic sessions and diabetes educator calls were observed, which include 5 clinic sessions and 6 phone call sessions. Each clinic session lasted about an hour (50 minutes to 70 minutes) and the duration of phone calls ranged between 7 minutes to 30 minutes. The first author took notes about the questions raised by patients and providers, the information shared by patients, and the decision reached during the session. Patients and providers were informally interviewed to request more explanation. Two diabetes educators were formally interviewed to understand the problems patients report, the data they share, the questions patients or providers ask of each other, and the challenges of working with data to make decisions.

3.3 Data Analysis

Data was analyzed using a mix of structural coding and in vivo coding [34]. Guided by interview questions, patient interview data was first analyzed to code for types of data collected and used, purpose of data use (types of problems identified from data), frequency of data use for different purposes, challenges of engaging with data (pattern extraction, understanding visualizations, aggregating data, remembering data), and data representations used for reviewing data. Similarly, provider interviews and focus group data were analyzed to code for data representations used by providers, types of information used by providers, types of problems they look for when reviewing the data, patient practices, and expectations from patients in using data (what data to use, when to use, in what format).

Coded data was further analyzed to compare and understand the differences between patients and providers with regards to the types of problems, and the ways in which they identify problems from the data. We analyzed the observation data guided by the categories that emerged from the analysis of interview data. Data from each clinic appointment and educator phone call was the unit of analysis for observation data. In the second round of analysis, coded data were grouped under themes using affinity diagrams [47]. Throughout data analysis, we tried to triangulate evidence from different sources of data – interviews, observations, and focus groups. The first author led the data analysis. The themes that emerged were continuously discussed with other

members of the research team to identify less prominent themes, which were then dropped from further analysis.

Table 1: Summary of patients who participated in interviews

ID	Age	Gender	CGM	Pump
P1	22	M	Yes	No
P2	23	F	No	Yes
P3	13	M	No	No
P4	29	F	Yes	Yes
P5	25	M	Yes	Yes
P6	16	F	No	No
P7	13	F	No	Yes
P8	14	F	No	Yes
P9	12	F	No	Yes
P10	15	M	No	Yes
P11	12	F	Yes	Yes
P12	16	M	Yes	Yes
P13	12	M	Yes	Yes
P14	9	M	Yes	Yes

Table 2: Summary of providers who participated in the study

ID	Gender	Title	Involvement
C1	F	Assistant Professor of Pediatrics and Communicable Diseases	Interview
C2	M	Associate Professor of Pediatrics and Communicable Diseases	Interview
C3	F	Certified Diabetes Educator	Interview and observation
C4	F	Certified Diabetes Educator	Interview and observation
C5	F	Adult Endocrinologist	Focus group
C6	M	Co-Director Diabetes Center	Focus group
C7	F	Program Director, Adult Diabetes Education	Focus group
C8	F	Pediatric and Adult Endocrinologist	Focus group

4 FINDINGS

This section first provides an overview of the data collection and reflection practices of the patients. It then describes how data was used by patients at home followed by its use in the clinic where patients and providers together used the data. It is important to understand both these use cases because health information is used in chronic care cycles that switch between individual use of information and collaborative use of information [5]. Lastly, it describes the challenges of using data that emerged by comparing the use of data by patients and by providers.

4.1 Data Collection and Reflection Practices

Out of the 14 patients that were interviewed, 8 patients made paper logs to track their data. [Figure 1](#) shows a paper log template used by patients. Out of the remaining 6 patients, 2 patients used different logging tools. P4 used Beeminder [48] and your.flowingdata [49], and P8 used an

app called Glucose Buddy [50]. The rest of the 4 patients had used paper logs previously but were not doing so at the time of the interview.

6 of the 8 patients that made paper logs had a continuous glucose monitor (CGM) or an insulin pump or both but they created paper logs despite the availability of data in these devices. Paper-based logging was preferred for multiple reasons. First, while the devices allowed for real time engagement with specific data points, accessing aggregate data from these devices was difficult because it required patients to have a technical set up that allowed downloading data to a computer. Second, most of the patients used a combination of multiple devices (CGM, pump, extra meters) that did not allow cross-device aggregation. Manually created logs helped bring all the information in one place. We did not find any substantial associations between the logging behavior and the type of patients in our sample, and the types of resources used by patients. Patients and caregivers reported writing blood sugars, insulin dose, the response of insulin dose, food, exercise, site changes for sensors, birthday parties, nights out with friends or family, and any other information that they perceived as having the potential to affect diabetes management. Table 1 shows the types of diabetes technology that patients used. Similar challenges, usefulness, and feasibility of using paper logs has also been previously noted for patients with irritable bowel syndrome [45].

All the patients reported actively reviewing their data except three of them, two of which used to review their data in the past but had given it up because they had stopped logging information. One patient (P2) using CGM did not feel the need to review her data. For her just having a mental awareness of today’s and yesterday’s data was enough for her self-care needs. Two of the adult participants had created their own visualizations to review data (P1, P4). Patients who maintained paper logs preferred to use the logs for review in combination with the CGM. Only two participants reported downloading data from devices on a regular basis (P12, P13), in addition to keeping paper logs. For all the adolescent patients, their parents reviewed the data.

During the clinic appointments, patients brought in the paper logs, glucometers and pumps to share data with the providers. During phone calls with diabetes educators, they scanned and uploaded these logs to patient portal and/or gave providers direct access to pump and CGM web dashboards by sharing the login credentials.



Figure 1: An example of a paper log template used by multiple participants

4.2 Individual Use of Data

In between clinic visits, we found that patients used their data in five typical ways – understanding trends to take corrective action, ensuring absence of problems, understanding the effect of treatment, understanding the effect of contextual factors, and responding to goals.

4.2.1 *Understanding trends.* Majority of the patients used data to identify trends in their blood glucose numbers, “P14 - *So the ones I look at the most would be patterns and daily trends.*” These

trends helped them understand the need for taking corrective actions, such as adjusting insulin dose or eating behavior. For example, one participant described the use of trends to decide if he needs to make corrections to insulin dose, *“I might correct for the numbers that I have at the moment and then check probably half an hour to an hour later and I am still going up then I will correct for that number.”* (P12)

As reported in the above quote, the patient discerned trends over short cycles of time to take insulin. Patients reported looking for trends in time windows ranging between a couple of hours in the day to a month worth of data. We also saw patients switching between different levels of engagement. For example, P7’s mother mentioned she would usually review data every couple of weeks but at times depending on the self-care need, she would review every day’s data in the evening, *“Absolutely, yeah. And sometimes it [data review] will be every evening she’ll have highs or some things.”*

4.2.2 Ensuring absence of problems. Making sure everything was going smoothly without problems was another purpose for which most of the participants reported using their data frequently. We found that participants had varying types of need to pay explicit attention to data for this purpose. For example, one of the patients who played basketball reviewed numbers from his CGM app to ensure that the sport wasn’t going to adversely affect his body, *“I would check my blood sugar during basketball and then towards the end. And if I was playing for like 3 hours maybe around hour 2 my blood sugar would start going up. High blood sugars and sports don’t go well because you start to get muscle cramps, fatigue, dehydrated”* (P5). Similarly, another patient checked her blood glucose number before disconnecting the pump for showering to ensure she wasn’t high before she disconnected her pump. (P2)

4.2.3 Understanding the effect of treatment. Patients also had to maintain an understanding of whether the treatment is working or causing issues. To develop this understanding, they engaged in reflecting over their data once they had performed changes to regimen, *“I always wrote down what did she eat, how long did the insulin last, it is an hour and a half ..., what was her sugar at that hour and a half and then what did she do afterwards”* (P8’s caregiver).

This reflection happened at varying time spans and with varying frequency. The above quote describes a caregiver assessing the impact of insulin in the frame of a couple of hours. Another patient described his engagement over a day to understand the correctness of treatment, *“I fast for a day to see what my blood levels looked like to make sure my basal levels were correct”* (P5). Similarly, one of the caregivers described how her frequency of downloading the meter numbers became higher around the time when a change in treatment was made, P14’s mother *“I’ll download it more when we’ve made a recent basal adjustment [changes in insulin] to see how we did”*

4.2.4 Understanding contextual factors. Being aware of the problematic contextual factors affecting diabetes was an important objective of engaging with one’s data for both patients and their caregivers. For example, one caregiver explained how she looked at the data to understand different contextual factors, such as food and activity, that could be affecting blood glucose numbers, *“I’ll look at the trends on the CGM against the paper and then I can see like, oh, today, he had soccer or he went climbing at the rock climbing gym or whatever, or I can see his carbs or sometimes if he spikes after breakfast, I’ll go, oh, he had a bagel.”* (P14’s caregiver)

4.2.5 Responding to goals. Goals triggered engagement with data in different ways. Patients reviewed data specific to a goal to work towards that goal, *“From my perspective, I look at it primarily because I know that [he] has an issue at night, because we’ve really gotten it down to where we focus around the night time”* (P8’s caregiver). At times, not meeting the goal was a problem and it prompted them to review their data, *“When I do review is when I derail on one of those goals and then I’ll be like ‘oh so what happened in the last week that made my blood sugar average or whatever I’m using at the time”* (P5).

4.3 Collaborative Use of Data

Data was used by providers in collaboration with the patients with the purpose of identifying and understanding problems. During clinic appointments that happened once every three months, we observed that patients and providers co-constructed the meaning of patient's data by interpreting and reinterpreting data shared by patient. This helped them crystallize the insight or the problems signified by the data. This process of meaning construction in the clinic was described by one of the patients as follows, *"My doctor always sits down with a stack of printouts of some of the Ping [51] software and she kind of pages through them and I mean occasionally she will say 'it looks like you are having a bunch of lows' and so we'll talk about that. Or sometimes I'll be like 'oh no that was just last week why don't you look a couple weeks back.' She'll look a couple weeks back and be like 'okay you're right that was just last week what happened?' I'll be like 'I started running again so I had to change my basal but I didn't really catch on until I had a few days of lows and then I changed my basal.'"* (P4)

As described in the above quote, the clinician extracted critical events from patient's data, which she wanted to discuss further with the patient to identify potential problems. Next, the patient plays her role in invalidating provider's concern by categorizing the occurrence of that incident as short term, thereby dismissing the need to have a discussion around that data. Additionally, they discuss the potential cause of problems. In reaching a conclusion, patients and providers use information from multiple sources (glucometer, data visualizations from the device, patient's lived experiences, and clinician's domain knowledge). We encountered similar instances of problem-solving in patient phone calls with certified diabetes educators. These problems include physiological issues related to diabetes, treatment adjustments, understanding causes of problems, operating medical devices, and getting supplies.

4.4 Frequency of Engagement with Data

The description of different ways in which patients used their data reflects two types of engagement with data based on how often and for what purpose patients engaged with their data.

4.4.1 Planned engagement. Planned data review sessions included data review in the clinic and individual review sessions at the patient's home. Data review during clinic appointments was planned wherein providers downloaded data from the patient's devices and either printed them or used the computer screen to see visualizations. Patients also brought paper logs, which they shared with the providers. Such reviews happened approximately every three months, which was the standard follow up period for patients. Patients planned and performed individual data review sessions with varying frequency at home. While most of the patients mentioned attempting to review their data every couple of weeks, three patients (P1, P3, P5) reviewed their data every day. Only one patient (P2) did not review her data at all until the clinic visit. Instances of planned data review involved both goal directed data review (looking for trends, understanding factors that might be causing the trends, and understanding if the treatment worked), and general use of data to understand how the patient was doing overall and if something needed attention. While it might seem obvious that patients with CGMs would review their data more frequently because of real time access to data, it is worth noting that not all patients who had a CGM were reviewing data every day or even every week.

4.4.2 Unplanned engagement. At times, engagement with data was incidental or context-based to meet an immediate self-care need. For example, activities such as playing a sport, or driving a car called for a quick review of one's numbers before the activity to ensure safety. Not meeting a goal prompted a closer data review, and a consistent undesirable trend in numbers called for a review to understand corrective treatment changes. Seeking support from diabetes educators is another case of unplanned data review wherein depending on the kind of problem patients faced, they shared their data with the educators to go over it. Considering the different frequencies with

which patients needed to engage with data for varying purposes, patients also reported switching between different frequencies for data review, sometimes reviewing every day and sometimes every week. It is this type of engagement where data collection and reflection happened together, as identified by prior work [6].

4.5 Challenges of Using Data for Problem-Solving

As reflected by the above use cases, identifying and solving problems was an important aspect of engaging with patient-generated data in both individual and clinical settings. We further analyzed the data to understand the challenges of using data for problem-solving and found that patients and providers differed in perceptions over three aspects –defining a problem, types of problems, and use of data representations. This challenged communication during collaborative use of data.

4.5.1 Data gives different insights to patients and providers. Although patients and providers use the same data, we found that they differ in how they interpret the data for defining problems. We found several instances when the same data was interpreted differently by patients and providers. For example, during observation of a patient call with one of the educators, a patient’s caregiver called with a concern of high blood sugar trends during the night and the morning. The following vignette further describes the call:

CDE logged in to the pump dashboard and starts looking at the data. After some time, she mentions, “it is not that bad, overall we want 50% of the readings in range.” She further explains “we use this to check patterns.” She then thinks aloud trying to make sense of the patterns seen, “It isn’t that bad. I will call her to see what is she worried about.” (C3)

In the above case, while the patient’s caregiver thought that the patient was high and needed some medication (insulin dose) changes, the educator did not think that the situation was as bad. In another instance, a patient, her caregiver and the clinician were discussing patient’s data during a clinic appointment. The patient had brought in paper logs with two weeks of data (blood sugar numbers, carbohydrates, and insulin) and annotations related to her menstrual periods. The following vignette describes what happened,

The patient was concerned about running high the week before her periods started and had brought in paper logs to the appointment. The clinician arranged the paper logs sequentially on the examination chair and asked the patient to circle all the high numbers in the log. When patient was done, the clinician tried to assess the pattern of high numbers around the week that was annotated with details on patient’s periods, pointing to different places on the paper log. The clinician was unable to spot a trend as claimed by the patient and asked her, “So you said you were high during the periods or going into it?” The patient had a puzzled expression on her face while looking at the logs and was unsure about her earlier claim. She did not answer the question that clinician asked. After a moment of silence, the clinician mentioned, “it seems like you are high 2 to 3 days into your periods. So, should we adjust the Lantus [insulin]?”

In this case, the patient had come to clinic with a specific concern about running high. Even though both the patient and provider were looking at two weeks of data from the logs that patient brought, the clinician was unable to see the same blood sugar trend as the patient. Moreover, when the clinician asked for clarification, the patient was unable to communicate her concern effectively perhaps because realizing that the provider had a different perception of the problem made her submit to provider authority. The patient left the appointment without getting her original concerns addressed, since the clinician did not look at the problem in the same way as the patient did.

At times, patients disagreed with providers regarding a problem “*She had sort of altered consciousness and we weren’t quite sure what was going on. So, it wasn’t really a seizure, but her*

endocrinologist thinks it probably was. Interestingly, [during] neither of her seizures could we measure her to be particularly low” (P14’s mother).

We found two reasons for this difference in perception of problems. First, the data interpretation criteria used by patients are different from that of providers. For example, when we asked P10’s mother if she uses “bolus to basal ratio” (a metric used by providers to tailor insulin dose) for making changes to basal insulin, she described that it was hard to do so, “*Well, it’s hard to look at that [bolus to basal] with him because of the way that he eats. He doesn’t eat consistently.*” Owing to the difficulties in applying guidelines for interpreting the data, patients develop their own criteria for evaluation of data. For instance, one patient recalled, “*I remember reading somewhere that they say you should think about adjusting your basal if you’re doing more than 10% of your total daily insulin from correction boluses*” (P4). Moreover, even for riskier situations such as ketones that could lead to an emergency room visit, patients did not apply the guidelines for identifying problems, as described by one of the clinicians, “*they are already supposed to check for ketones at 300 [BG number] and a lot of families will say oh they never have ketones so they kind of never check them*” (C1). As described in the quote, “300” does not get perceived as an indicator to check for ketones, even though providers would recommend that. Thus, patients and providers have different perceptions of risk.

Second, patients might be unaware about the evaluation criteria that providers use to extract instances of problems from the data and vice versa. For example, as mentioned by providers in the interviews, they use rules, such as “more than twice a week is too many lows”, and “50% or more highs denote trends,” to check for trends in the data. When we asked patients, we obtained diverse responses about the criteria for classifying a series of numbers as a trend. For some patients five or six days of similar numbers constituted a trend, whereas for some a month long of consistent data was what constituted trends.

Such differences in perceiving data could be problematic because it might lead to a case where patients are overly concerned even when there is no problem or it might also lead them to ignore a problem when there is one. Additionally, collaboration over patient data is affected, as patients might perceive differences in perception as a mistake on their part, affecting their confidence to deal with their data and communicate with the provider.

4.5.2 Patients and providers differ on the type of problem to focus on. We found that all our participants typically worked through the data to figure out trends to take corrective actions, such as a dose change that would fix the trend, and to evaluate the effect of the dose change on the existing trends. For example, one of the patients explicitly stressed the importance of looking at the trends, “*Trending, knowing what direction your blood sugar is trending, is really important. Basically, I check my blood sugar every once in a while: when I wake up, before meals, before sleep. Here [showing the CGM] you can look at 3 hour trends, 6 hour trends, and 24 hour trends*” (P5). As a part of understanding their data to manage diabetes, just knowing trends in data was good enough for them.

While providers want patients to get into the habit of reviewing their data to identify trends, they also want patients to focus on individual data points that are problematic, such as high or low blood glucose numbers, to figure out the causal behavior responsible for that data. For example, one of the clinicians shared the advice he gives families, “*What I tell families is, you have to get to the point where you can explain the outliers. You have to solve the problem when it’s happening or it’s never going to register in your brain. I say look, any time your sugar is above X, I need you to spend at least a minute thinking about how it got there. Did you bolus for your snack? Did you undercount your last meal? Because you are going to remember at that moment in time exactly what happened*” (C2). As mentioned in this quote, the clinician specifically wants the patients to pay attention to the outliers, that is the blood glucose numbers that are not typical.

Additionally, he wants the patients to solve the problem at a time when it happens to understand the cause behind the problem.

We also found that providers look at the information related to CGM and insulin pump alerts to understand atypical events and how the patient is responding to them, as mentioned by an endocrinologist, *“Sometimes we will pay attention to some of the alerts and alarms they have going off. Sometimes they don’t have enough and other times they have so many that they just ignore all of them”* (C7). Going by this expectation to understand atypical events, we observed that clinicians also ask patients about these specific events during clinic appointments. However, in their day to day engagement with data, patients might be selectively attending to these events, or even if they did attend to all the events, they might not remember details of each event. For example, one of the patients who was actively monitoring his data daily found it difficult to bring up details related to critical events that clinicians asked about, *“One thing that really frustrated me was that I would go to my endocrinologist and then 3 months later go to another one and it’s hard to tell what’s happening in-between there. They would look at my charts and be like you were high and then low and what happened and I don’t know what happened”* (P5).

We also found that amongst our patient participants, most of the adolescent patients tended not to pay attention to individual events of atypical blood glucose numbers. For example, even though they set alarms on their insulin pump and continuous glucose monitor to make them aware of unusually high or low numbers, they usually turn these off and ignore the atypical lows and highs of blood glucose numbers. This could happen because the patient’s perception of risk or problem might depend on how they feel and not entirely on the interpretation of physiological numbers, as described by the caregiver of P13, *“P13 is having trouble like the CGM will alarm him but he won’t feel it or hear it and then he will be in the 300s for several hours and I will look at it and say you’ve been in the 300s for 4 hours, what’s going on? And he says I didn’t feel it.”*

In another case, the patient’s mother took care of these alerts as long as she could. But every time the patient was in school, she disliked the alarms going off so she stopped using those alarms completely, as described by P8’s mother, *“When I was in control, I did like those alerts. But then when she was at school, she doesn’t like having it go off all the time. So, that was what caused her to cease using that.”*

This further demonstrates that most patients do not make use of problem-solving opportunities (i.e., atypical events) because they might not be in a situation to do so, or they might not perceive enough risk associated with the problem. Working with trends in their data is good enough for them. Moreover, even if they do pay attention to discreet events in addition to trends as expected by the providers, they are unable to recall information associated with specific events. When it comes to sharing information with the providers about specific instances, they fail to do so.

4.5.3 Patients and providers use different representations of data to identify problems. For patients, reviewing one’s data is the key to maintaining control in diabetes, as mentioned by one of the clinicians, *“I think reviewing data is a key to success whether you are familiar with that or not you unfortunately have to become familiar with it, you know, since it’s your life”* (C1). However, patients struggle in reviewing their data to draw insights because of the unsuitability of commercially available data visualizations, even though they are the primary users of the devices that are the source of these visualizations. When we asked P11’s mother about the use of commercially available graphs, she mentioned that finding patterns is difficult and she did not think that the graphs helped much: *“I feel the patterns are very hard to identify. I feel like there’s no rhyme or reason [for using the graphs]. I feel like they’re just a bunch of just scatter plots everywhere, lines up, lines down. I don’t know how he [clinician] makes heads or tails of it.”*

Most patients relied on manually compiled paper logs to understand their data, and they also brought these to clinic. One of the patients who expressed dislike for the commercially available graphs had created her own visualizations for getting a more accurate reflection of blood glucose numbers over multiple days, *“I hate the Dexcom Moday Day graph. It’s the one where they overlay*

all your days but the dots just stack up on each other. For me the heat maps that I've done are a vast improvement on that because they actually show you. When the dots are just overlapping each other you can't get an accurate picture of the density at any given point" (P4).

On the contrary, we found that clinicians found these commercial graphs useful, *"The stats are very helpful, that is one of the things I use the logbook for but going back to the daily strips, its useful to help find quick trends. I like different views for different reason depending on what I am doing with the patient"* (C8). As observed in clinic sessions and as reported by all providers in the focus group, these graphs were frequently used by clinicians during patient appointments. For example, Figure 2 is a visualization that shows an overview of data from the insulin pump [52]. Some providers liked seeing such visualizations as a printout during patient appointments while some preferred an electronic version on the computer screen. The visualizations offered multiple perspectives over the data and helped the providers explore trends over multiple days, data from individual days, and behavioral data such as "how often they are checking (BG numbers)" and "how often they are disconnecting from their pump".

While providers agreed that these dashboards are useful for them, they also acknowledged that families might not be looking at them, and engaging with them as needed,

"I think that these kind of things are really nice for us to look at but sometimes it prevents the family from writing down and looking at blood sugar numbers. I think that would be easier for people to see if they have it in this kind of form but this is a lot of information. Or these other sheets are a lot of information, so I don't know how easy it is for people, you know to look at them or not" (C1).

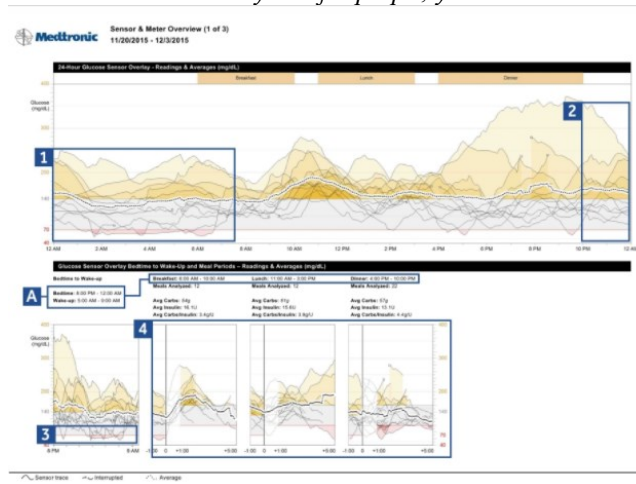


Figure 2: © Medtronic MiniMed, Inc. Example of a visualization used by providers. This is taken from a Medtronic insulin pump.

As expressed in the above quote, the clinician appreciated all the information in the graphs but also understood that there was a lot of information in the graphs, which would make the visualizations cognitively burdensome for patients, discouraging them from engaging with their data. However, there was also an expectation from the providers for patients to use these visualizations, as mentioned by one of the educators in the focus group, *"I want them to see what I am seeing so that when I do want to talk to them on the phone in between they have a good idea of the way my brain is working"* (C7).

The educator wanted patients to understand these visualizations so that patient was on the same page as her, which would make communication easier. However, patients have their own ways of

obtaining insights from their data (e.g., paper logs, self-created visualizations) instead of using the visualizations providers want them to use. Patients and providers rely on different representations of the same data for extracting insights, which restricts development of an initial common ground for communication.

5 DISCUSSION

This study found that both patients and providers use patient-generated data to identify problems and understand those problems to reach a decision about the next step. However, in interpreting data, they have different perceptions around problem-solving: they used different data representations, they had different understanding of what is a problem and there were differences in selecting the types of problems that need attention. This makes collaboration effortful as it leads to differences in how they perceive risk of problems and the associated response to problems. While such perception differences remain unacknowledged during patient-provider interactions, they do govern what problems get discussed during such encounters. Consequently, there is an immediate impact on decisions regarding patients' treatment and behavior.

Although prior studies have acknowledged the existence of perception differences between patients and providers about patient-generated data in terms of the type of data that is useful and the overall value of data [43,44], little is known about how differences in perception affect the interpretation of patient-generated data in making disease related decisions. Our study builds upon prior work to provide an understanding of *what* are the differences in patient-provider perceptions in interpreting patient-generated data and *how* they affect collaborative reflection for identifying and solving disease related problems. While a recent study demonstrated that the same set of visualizations were helpful for both patients and providers and that collaborative review of these visualizations was promising [36], our study found that this was not the case. Commercially available visualizations that are built using clinical guidelines were useful for providers but not for patients. Instead, patients had their own ways of creating representations of the same data to draw insights.

Prior work to understand collaboration with patient-generated data has identified the creation of boundary negotiating artifacts as a basis to understand and support collaborative use of PGD [8]. We propose that another basis for supporting collaborative use of PGD is problem-solving as understood through the framework of collaborative sensemaking. This approach to understand the use of PGD provides a way to not only understand collaborative use, but it consolidates both individual and collaborative practices of using PGD, as sensemaking and problem-solving can and do happen individually and collaboratively across the chronic care cycle. Sensemaking in health care has been primarily discussed as an approach for patients to take [26] or as an approach that facilitates collaboration amongst providers for information seeking activities [29]. In this study, we found that patients and providers seek to engage in collaborative sensemaking with data to problem-solve. In this discussion, we reflect on Hill-Briggs' problem-solving model and Mamykina et al.'s framework of sensemaking for diabetes management as understood through our findings. Considering the usefulness of both these frameworks, we present collaborative sensemaking as an approach to problem-solving in diabetes and provide design suggestions for tools to support problem-solving and sensemaking among patients and providers.

5.1 Data-Driven Problem-Solving

Problem-solving is an important skill that patients are expected to develop to tackle everyday challenges of diabetes management and adjust self-care practices in response to barriers to adherence [12]. The problem-solving model as proposed by Hill-Briggs accounts for how patients

inform their actions to maintain adherence to prescribed regimens by identifying and overcoming barriers to self-management. According to this model, problem-solving for successful chronic disease management includes four components: a) problem-solving process, b) problem-solving orientation, c) disease specific knowledge, and d) transfer of past experiences [14]. In managing diabetes, as we have seen, an important aspect of problem-solving is the ability to engage with one's data to reflect on one's experiences using disease specific knowledge. While several interpersonal interventions have aimed to train patients in problem-solving skills [11], tools do not currently support problem-solving through engagement with data [23]. In managing their diabetes, we found that patients make use of data in different ways with the aim of identifying problems from the data (trends, contextual factors), understanding the cause of problem (contextual factors), evaluating effectiveness of their solution to problems (treatment changes), and managing in anticipation to avoid problems and minimize risks (ensuring the absence of problems, and responding to goals). Since considerable use of data, if not all, is centered around identifying and solving problems, it presents the need to support problem-identification and problem-solving through data analysis activities.

5.2 Data-Driven Sensemaking

In addition to problem-solving, *sensemaking* is another framework that has been considered useful in understanding how patients might inform their actions in managing diabetes based on information and experiences. Mamykina et al.'s sensemaking framework describes diabetes management as consisting of two modes: habitual mode and sensemaking mode [26]. According to this framework, both modes include three activities - perception, inference and action. Patients operate in habitual mode when information and experiences fit into already existing mental models of disease management. When new information and new experiences create gaps in understanding, patients operate in sensemaking mode to adjust their mental models. While both problem-solving and sensemaking describe a set of activities that patients perform or should perform to address self-care issues, and can be considered as complementary, they emphasize different aspects of disease management. Sensemaking focuses on informing action by generating explanatory models for breakdowns or unusual experiences during self-care, and problem-solving focuses on identifying problems or barriers to inform action in terms of selecting a solution for the problem, acting on it and evaluating the effect of the action on the problem. Both require the ability to identify problems or gaps in one's understanding before an action can be taken.

5.2.1 Sensemaking versus Satisficing. In this study, we found that in using their data to problem-solve diabetes issues, patients did not necessarily engage in sensemaking right when problems (e.g., unusual blood sugar readings) happened. That is, patients did not necessarily make use of what Mamykina et al. refer to as "teachable moments" (e.g., unusual highs or lows of blood sugar), as much as providers wanted them to. Instead, our patients satisficed to handle atypical situations by doing what they perceive to be necessary to quickly fix the problems and perhaps to avoid the burden of explicit sensemaking, which could result in diabetes burnout [31]. For example, to handle unusual blood sugars, it is easier and more imperative for patients to take corrective action (i.e. take insulin or consume carbohydrates), than to also understand why did those numbers happen. Thus, problem-solving in real time involved using data to the extent that was good enough to resolve the immediate symptoms (unusual blood sugars) without engaging in sensemaking to find probable explanations for the problem.

5.2.2 Sensemaking in Retrospect. Once patients have the time or an opportunity to go through their data, it was then that they might try to retrospectively engage in sensemaking with data to understand what factors might be causing the problem, and what that means for patients' disease management. This mostly happened during planned engagement sessions that involved the retrospective use of data at home or in clinic, as shown in the study. Understanding this episodic

nature of sensemaking is important to inform the design of tools to support it because patients might not always be receptive to opportunities to perceive gaps in their understanding and to bridge those gaps because of the burden that sensemaking entails. This further demonstrates that patients might not necessarily experience or practice different activities of sensemaking (perception-inference-action [26]) distinctly or in that order. For example, perception and inference could happen retrospectively through data analysis activities. This observation echoes the lived informatics critique of the stage-based model of personal informatics, which claims that the steps of the stage-based model are not distinctly and rationally experienced in real life [32]. Similarly, the steps of sensemaking (proposed in the framework in [26]) might not necessarily be descriptive of natural behavior, but rather prescriptive of ideal behavior. Considering the burden that sensemaking entails, it is important for tools to provide support for data analysis activities for sensemaking in ways that are concordant with people's actual practices.

5.2.3 Data-Driven Collaborative Sensemaking. Another aspect that the findings from our paper bring to light is that sensemaking for self-management of diabetes might not only happen individually, but patients also engage in collaborative sensemaking with their providers throughout the chronic care cycle. That is, patients switch between individual and collaborative sensemaking. While Mamykina et al.'s framework accounts for individual sensemaking by patients, it does not consider the role of caregivers and providers in sensemaking for guiding and supporting self-management of diabetes. For caregivers and providers who are considerably removed from patients' lived experiences, patient-generated data is the basis for understanding patients' experiences and supporting management [15]. Hence, sensemaking through data analysis and reflection, that is understanding the data before acting on the data, becomes crucial not only for patients individually, but also for caregivers and providers if they are to support the patient. Our study further unpacks the complexity that multiple stakeholders bring when engaging with patient data. Above, we reported the differences in stakeholder perceptions that challenge collaborative interpretation of data. Considering that collaboration happens in all stages of PGD use [8], there is a need to extend this framework to incorporate collaborative processes in the use of data.

Both problem-solving and sensemaking are useful frameworks to understand diabetes management, and they have mostly been considered separately. There is a potential to integrate these two frameworks as both require considerable engagement with one's data. That is, data analysis activities are a part of both problem-solving and sensemaking in the management of diabetes. We further elaborate our proposal of supporting data analysis activities for problem-solving through collaborative sensemaking.

5.3 Collaborative Sensemaking as an Approach to Problem-Solving with Data

As described in the findings, during clinic sessions, patients and providers worked through the data to identify critical events from the data, classify those events as problems or non-problems and generate explanations for the cause of problems to decide appropriate response. Sensemaking thus, primarily happened through data analysis activities. In analyzing data to first identify relevant information and then co-construct what that data means for patients' disease, providers employ and attempt to convey disease specific knowledge, which is the third component of problem-solving model [14]. Patients contribute their experiential knowledge to validate or invalidate the meaningfulness of the data in question, which relates to the past experiences component of the problem-solving model [14]. In this way patients' personal understanding of their health comes together with clinicians' formal knowledge to problem-solve using sensemaking with data. Problem-solving as understood through collaborative data-based sensemaking thus provides a useful lens to understand the practices of interpreting PGD to make disease related decisions.

5.4 Design Implications

The insights from this study point to design suggestions for computer-supported cooperative systems to support both individual and collaborative problem-solving with data as understood through the framework of *sensemaking*.

5.4.1 Promote mutual intelligibility of individual sensemaking efforts. Sensemaking in the clinic, which is a case of collaborative sensemaking, was fraught with three challenges as this study found: patients and providers used different data representations, they had different understanding of problems, and they prioritized different types of problems that needed attention. In collaborative sensemaking, every individual engages in sensemaking effort based on their experience and knowledge, which may be conflicting with the worldviews of others involved in collaborative sensemaking [37]. As shown by this study, conflicts in problem-solving challenged collaboration between patients and providers in sensemaking with patient data. This points to the need to better understand how such conflicts can be resolved.

One of the ways to resolve this conflict follows from our findings. We found that patients often use criteria developed based on their experiences to understand their diabetes data. These criteria might not entirely align with clinical guidelines but are still used by the patients for their own benefit. Consequently, misunderstandings and disagreements arise when they engage in collaborative sensemaking with their providers. Such disagreements could be resolved by making them aware of each other's ways of looking at the data. Tools to support awareness of each other's data-related work (findings, hypothesis, evidence) have been studied for data analysts [22]. Such tools could potentially be adapted to support mutual understanding of sensemaking efforts between patients and providers. Moreover, effective collaboration requires both patients and providers to trust each other's use of patient data [36]. For this to happen, each party needs to know how the other is using the data throughout the care cycle so that differences in perceptions can be minimized. Such tools can bring to the foreground the tacit knowledge used by both parties in interpreting patient-generated data, thereby promoting trust.

5.4.2 Support problem identification for sensemaking. We found that not being able to assertively identify problems from the data discouraged patients while communicating with clinicians. This can also affect patient's problem-solving orientation [14]. Patients capture considerable amounts of data that cannot possibly be comprehensively explored, given the short time of clinic visits. It becomes important to help patients and providers retrieve meaningful and useful information sooner and without putting in more effort. To support sensemaking with information, as a first step, tools need to support identification and selection of relevant problems or gaps. Patient generated data, such as physiological numbers, can be used to computationally identify problems in a simple manner [3]. Machine learning approaches, such as anomaly detection [4], are more advanced techniques that could help.

5.4.3 Use problems as a basis for goal-setting. We found that patients and providers collaborated in clinic to identify problems from the data, and those problems became the basis for further use of data to understand causal factors behind the problem, the current state of treatment, and the potential treatment changes that might help. Prior work has identified the need to create goals for collaborative use of PGD by having goal-based data collection, curation and visualization [8]. This study suggests that problems identified from the data can be used as goals for data review during clinic sessions. Systems can support patients in selecting problems that they might want to discuss in the clinic visit. For example, a system that can identify possible problems, could prompt the patient to bookmark relevant events for review in the clinic and gather more data related to those events. A bookmarking feature supplemented with annotations and context data can augment clinical communication by helping the patient recall the problem and the context in which that problem happened. Because problem-solving is an ongoing process throughout the chronic care cycle, systems can also involve providers, specially diabetes educators, to guide patients in

selecting the problems that they need to focus on in between clinic visits. This would further streamline patients' efforts in collecting and using their data for sensemaking and problem-solving activities.

5.4.4 Support need driven sensemaking with data. Patients engaged with their data in planned and unplanned ways, as reported in our findings. In trying to make sense of their data, they needed to access and review data from varying time windows (e.g., data for a day, data for a month) for varying needs. For example, sensemaking with data was prompted by the need to understand the effect of treatment or by the realization of not meeting a goal. Such needs to review one's data could arise multiple times during the day or could happen over a larger frame of time. Informatics tools should support tailoring the amount of data (e.g., time range) that patients want to explore and the frequency with which they want to review this data.

6 CONCLUSION

In understanding how patient-generated data is interpreted individually by patients and collaboratively between patients and providers, this study found that patients and providers use patient-generated data for the shared purpose of identifying and understanding disease related problems. In exploring differences in the interpretation of data and use of diabetes technology, our study found three differences in patient-provider perceptions that challenge collaborative use of patient-generated data for problem-solving – differences in understanding what is a problem, what types of problems to focus on, and differences in the use of data representations. Drawing on these insights, we reflect on two specific conceptualizations of disease management behavior (frameworks of *sensemaking* and *problem-solving*) as they relate to data analysis activities of patients and providers and suggest opportunities for extending these frameworks. We propose collaborative *sensemaking* as an approach to problem-solving with patient-generated data. This provides a framework to understand both individual and collaborative use of data. Given the perception differences between patients and providers, this study suggests that informatics tools need to support mutual intelligibility of sensemaking efforts with data to facilitate effective collaboration, and they need to support problem-identification for effective sensemaking.

This study contributes in three important ways. First, while prior studies provide individual accounts of data use by patients or by providers, this study contributes knowledge of nuanced challenges in the collaborative use of data by comparing patient and provider perspectives. Second, it reflects on theoretical frameworks of *problem-solving* and *sensemaking* to uncover opportunities for extension and integration of these frameworks for chronic disease management. Third, it offers practical guidelines for designing systems to support patient-provider collaboration in using data to drive disease-related decisions.

As the ability to gather data improves, it becomes increasingly important for systems to support both individual and collaborative use of data among patients, caregivers, and providers, especially for patients with chronic conditions that require lifelong management and collaboration with providers. Systems need to be designed with the aim of promoting efficient use of data concordant with people's practices, without introducing additional overhead to the burden of disease management.

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