Clinical Data in Context: Towards Sensemaking Tools for Interpreting Personal Health Data

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Clinical data augmented with contextual data can help patients with chronic conditions make sense of their disease. However, existing tools do not support interpretation of multiple data streams. To better understand how individuals make sense of clinical and contextual data, we interviewed patients with Type 1 diabetes and their caregivers using context-enhanced visualizations of patients’ data as probes to facilitate interpretation activities. We observed that our participants performed four analytical activities when interpreting their data – finding context-based trends and explaining them, triangulating multiple factors, suggesting context-specific actions, and hypothesizing about alternate contextual factors affecting outcomes. We also observed two challenges encountered during analysis – the inability to identify clear trends challenged action planning and counterintuitive insights compromised trust in data. Situating our findings within the existing sensemaking frameworks, we demonstrate that sensemaking can not only inform action but can guide the discovery of information needs for exploration. We further argue that sensemaking is a valuable approach for exploring contextual data. Informed by our findings and our reflection on existing sensemaking frameworks, we provide design guidelines for sensemaking tools to improve awareness of contextual factors affecting patients and to support patients’ agency in making sense of health data.

CCS Concepts: • Human-centered computing → Ubiquitous and mobile computing systems and tools • Human-centered computing → Empirical studies in visualization

Key Words and Additional Phrases: Personal informatics; chronic disease management; reflection; sensemaking; context; diabetes; visualizations; patient-generated data; data interpretation

ACM Reference Format:

1 INTRODUCTION

Self-monitoring is an effective approach for continuous management of chronic conditions [11]. With the availability of sensors to track relevant information, patients are increasingly supplementing data from
medical devices with contextual information from smartphones and wearable devices to inform day to day disease management [40]. Providers have also begun to realize the potential of such data in obtaining a holistic picture of a patient’s disease management context, which has the potential to inform clinical decisions such that the recommendations made by providers fit the unique needs of each of their patients [30].

Even though reflecting on one’s data to problem-solve or make sense of disease related experiences is important to inform treatment and disease management behavior, sensor-rich tracking tools provide limited support to help patients and providers reflect on data [22,42]. Specifically, while both providers and tools can support patients in interpreting standard clinical measures, interpreting contextual information (e.g., lifestyle data) is considered beyond the expertise of providers and is not yet supported by tools that patients use.

As a part of understanding chronic conditions through personally generated data, establishing associations between outcome measures and contextual factors is one of the primary reflection needs of patients [24]. However, collecting and making sense of multiple streams of contextual data affecting an outcome measure is challenging [5], more so in the absence of appropriate tools. While prior research has highlighted the need for contextual information to enable better data analysis and interpretation [5,39], it remains largely unexplored how disease-related outcome measures augmented with contextual data could be analyzed and interpreted by patients and to what extent their practices could be computationally supported.

To understand data-based sensemaking activities and how they can be supported, we conducted a multi-method study with adolescent patients with Type 1 diabetes and their caregivers to answer the following research questions:

- What are the data-based sensemaking activities that patients and caregivers engage in for using contextual and biomedical data?
- What are the challenges they face in engaging with their data?
- How can tools be designed to support data-based sensemaking activities?

We interviewed patients and their caregivers using context-enhanced visualizations of biomedical data as probes to facilitate data-based sensemaking activities. These visualizations were developed from patients’ data gathered through a three-week diary study with patients and their caregivers. While we do not claim these visualizations to be a novel contribution of this study, these displays were instrumental in facilitating data exploration and sense-making activities, which are otherwise difficult to observe in practice.

We observed four analytical activities that our participants performed when interpreting clinical data augmented with contextual data – finding context-based trends and explaining them, triangulating multiple factors, suggesting context-specific actions, and hypothesizing about alternate contextual factors affecting outcomes. In interpreting their data, we observed that they faced two challenges – the inability to identify clear trends challenged action planning and counterintuitive insights compromised trust in data. We interpret our findings using the data-frame theory of sensemaking [18] to show how our participants’ information needs evolve and emerge through various sensemaking processes. We situate our findings within the existing perspectives on sensemaking to demonstrate that sensemaking could not only result in action, as described in the sensemaking framework for diabetes management [27], but it could also result in further exploration and information needs, as shown by our findings. We argue that contextual data, which is burdensome to collect and interpret, should be explored using a sensemaking approach as sensemaking could drive information needs and hence, meaningfully guide the collection of contextual data in response to those information needs. Noting the value of sensemaking approach in exploring contextual data, we provide suggestions for designing sensemaking tools to improve awareness of contextual factors affecting patients and to support patients’ agency in making sense of data.

This study contributes in three different ways. First, our work contributes an understanding of the interpretation activities that patients engage in to derive insights from their data. Second, we inform the sensemaking framework on chronic disease self-management to identify the emergence of information needs as another outcome of sensemaking in addition to disease management action. Recognizing the complexity of collecting and interpreting contextual data, we identify a theoretical basis for understanding the use of contextual data. Specifically, we propose that the sensemaking approach should be used for guiding collection
and exploration of contextual data. Third, we contribute design knowledge for sensemaking tools to support exploration of multiple data streams including clinical and contextual data.

2 RELATED WORK
This section reviews relevant work in Ubicomp, HCI and health literature focusing on self-reflection by self-trackers and data enthusiasts, self-monitoring of chronic conditions by patients, and making sense of data.

2.1 Personal Informatics and Self-Reflection

According to Li et al.’s stage-based model of personal informatics, reflection is an important stage that helps gain insights from self-tracked data [20]. The literature on personal informatics provides a comprehensive understanding of the reflection needs of self-trackers and data enthusiasts (e.g., Status, History, Goals, Discrepancies, Context (“how other events may explain what was happening to them in the present”), and Factors (“what influences behavior over a long period of time”) [21], and details, self-reflection, trends, comparisons, correlations, and distribution (summary, outlier) [3].)

When reflecting on personal data, quantified-selfers find interpretation of self-tracked data challenging. For example, they limit the amount of data they track owing to interpretation challenges of reviewing multiple types of data [5]. To overcome these challenges, several studies have explored how reflection can be supported using visualizations and data representations. For example, systems have translated multiple types of data into stories that helped users understand what information becomes important at what time [32]. Similarly, Epstein et al. visualized several subsets of self-tracked data, which they called visual cuts, and reported that participants found value in exploring multiple cuts rather than a single view of data [9]. Although visualizations are helpful, as the amount of data increases, these could become increasingly complex for users to understand. As a result, users do not find commercially available visualizations helpful and, in some cases, resort to building their own tools for reflecting on their data [5,22].

2.2 Self-Monitoring and Chronic Illness Management

The data generated through self-monitoring disease-related outcome measures and contextual factors enables patients to reflect on past experiences, which helps them identify appropriate treatment and analyze the impact of past behavior on disease related outcomes. As a part of reflection, patients want different types of insights that include episodes, triggers, status and history [22]. Additionally, patients review their data to identify problems, ensure the absence of problems, or understand the effect of treatment on problems [35].

Despite the promise of data helpfully informing self-care practices, making sense of health data is challenging [10]. Several techniques have been explored to enable reflection in the literature, including capture and display of contextual data in addition to biomedical data through images; location and personally defined tags [31,41], presentation of correlations in multiple streams of context data using natural language representations and graphs [43]; collaboration with providers to learn reflective thinking skills [26]; and visualizations of symptoms and their triggers [39]. While these approaches have been found helpful, insufficient contextual data restricts critical thinking among patients [39], challenges interpretation [44], and could reinforce biases that patients have [25]. Despite the potential value of contextual data in augmenting interpretation of clinical outcome measures, there is little understanding of how patients could use such data, if made available, to reflect on their disease management behavior and what kinds of tools could support them in this process. Increased understanding of patients’ current practices can help inform the design of context-enhanced data exploration tools for patients to support making sense of disease related events and experiences.

2.3 Understanding Reflection

A review of research on reflection has noted that not enough consideration has been given to the phenomenon of reflection. Specifically, studies on reflection have identified what insights users want but have not understood different ways in which users could obtain those insights from their data [1]. A few studies have
explored how patients reflect on their data to inform action. For example, one study found that the problem-solving process (identifying a problem, devising alternate solutions, implementing a solution, and evaluating the results [14]) was a natural way of reasoning when diabetes patients reflected on their data [23]. Another study found that patients seek cause and effect relationships from their data through four phases - feature selection, hypothesis generation, feature evaluation, and goal specification [24]. To fill the phenomenological gap [1] in the understanding of reflection, techniques such as visual data exploration (exploring data through interactive visualizations [4]) and purposeful data collection for experimentation [16] have been explored. These approaches study reflection primarily for outcome measures that follow standard interpretation guidelines and disregard contextual information (e.g., location, mood, social context), as such data are often considered ambiguous and subjective. Consequently, personal informatics systems still largely remain focused on individual data streams, even though people want to connect different facets of their lives by understanding associations in different streams of data [20]. We believe understanding contextual data in addition to clinical outcome measures is important to help people connect disease management with different aspects of their lives [4]. However, the design space of tools to support interpretation of contextualized health-related information remains largely unexplored.

2.4 Sensemaking with Data

Sensemaking is another approach to understand how complex data is interpreted. Different perspectives on sensemaking have been described based on practices of knowledge workers in different domains [17,18,33,34,36]. Two of the most prominent perspectives on sensemaking include the “representation construction model of sensemaking” [33,36] and the “data-frame theory of sensemaking” [17,18]. In the HCI literature, Russel et al. articulate the representation construction model by describing sensemaking as the process of searching for external representations and encoding data in these representations to answer questions related to a specific task [36]. Building on this conceptualization, Pirolli and Card describe the sensemaking process of intelligence analysts as consisting of two interconnected loops – the information foraging loop and the sensemaking loop [33]. Information foraging involves seeking information, searching and filtering information, and reading and extracting the information into a schema. In this view, sensemaking involves iterative construction of a schema that best represents the data using the information from the foraging phase. These models of sensemaking focuses on creating external knowledge representations to enable efficient use of knowledge.

The data-frame theory of sensemaking stems from psychology and describes sensemaking as involving backward-looking mental processes to explain the past and forward-looking processes to anticipate the future [34]. This theory defines sensemaking as a natural cognitive process that involves fitting data (the “interpreted signal of events”) into a frame (an explanatory structure) or, conversely, fitting a frame around available data in an attempt to continuously improve the frame while also filtering data based on that frame [18]. Here, sensemaking is directed at performing functions including but not limited to problem detection and identification, anticipatory thinking, understanding how to act in a situation, forming associations, and projecting into the future. According to this theory, both experts and novices have the same process of reasoning, which makes the data frame model applicable to all kinds of data users irrespective of their proficiency with data and their domain of use. Unlike in the representation construction model, the focus is not on creating external knowledge representations but understanding the mental processes at play while performing functions noted above.

Various sensemaking conceptualizations have been applied to understand the execution of tasks in several domains, such as data analysis by researchers, information visualization, education, and chronic disease management [2,12,19,27]. For example, data analysis has been described as a sensemaking task wherein theory is matched against facts, discrepancies are observed, and the theory is updated accordingly [12]. Sensemaking can thus account for both exploratory and confirmatory data analysis. Exploratory analysis requires constructing schemas from data and confirmatory analysis requires collecting data based on a schema that already exists [12]. Similarly, drawing on the data-frame theory, Lee et al. characterized the cognitive activities...
of novice users of visualizations that involved seeing the visualization for the first time, constructing a frame, exploring visualization to find insights using the constructed frame, identifying abnormal data and questioning the frame, and failing to construct a frame [19].

In the case of chronic disease management, sensemaking has been described as one of the approaches to inform action by using continuously generated information and patient’s past experiences. Mamykina et al. describe sensemaking in diabetes management as a cyclic process consisting of perception, inference, and action [27]. Patients continuously perceive new information and match it against their knowledge and experiences to activate an old mental model or construct a new model explaining the situation. This is followed by a routine action dictated by the old mental model or an experimental action governed by the new mental model to tackle the situation. While Mamykina et al. provide a strong basis for the sensemaking perspective as an approach to use data to inform action for disease management, they stop short of accounting for how different steps of sensemaking can be realized using the data that the patients generate and how tools can be designed to support sensemaking through data.

3 METHODS

The objective of our study was to understand different ways in which patients engage with their data using displays of contextual and biomedical data. The study used a multi-method approach. We first interviewed patients and their caregivers to understand the current practices of collecting and reflecting on their data. We then asked our participants to collect data over 3 weeks using DReflect, a context-enhanced diary application developed by us (Fig. 1). In the 4th week of the study, we interviewed patients and caregivers using context-enhanced visualizations created from their data as probes to facilitate data analysis and interpretation activities. We chose to focus on Type 1 Diabetes patients because this condition requires continuous monitoring of several clinical factors, including blood glucose (BG), insulin dosages, and carbohydrate intake. These measures are known to be impacted by contextual factors (exercise, mood, sleep, routine, stress) [13,38], which makes it important to understand how patients interpret clinical and contextual data and how tools can be designed to help them understand the role of these factors.

3.1 Patient and Caregiver Recruitment

Patients and their caregivers were recruited from a pediatric endocrinology clinic at a large teaching hospital. Patients willing to participate were screened to identify if they met the recruitment criteria in accordance with criteria-based sampling. The inclusion criteria were: Type 1 Diabetes patients that were 13-17 years of age, English speaking, willing to carry their own mobile phones or phones provided by the study team always while awake for the duration of the 3-week diary study, with adult caregivers willing to fill out diary entries for three weeks. We excluded new patients that had been diagnosed less than 6 months prior to the start of the study because they might have not yet formed stable management practices for using data. We recruited 16 patient-caregiver dyads out of which 15 completed the study (Table 1) and one dropped out after the initial interview because of time constraints. Patients and caregivers who completed the entire study received $75 in compensation. All the caregivers participating in the study were mothers of the patients.

3.2 Initial Interview

The initial interview was semi-structured in nature and lasted an hour. We first gathered demographic information and basic details about the patient’s management (devices used for management, prescribed blood glucose range, prescribed target blood glucose number, prescribed insulin regimen, insulin to carbohydrate ratio and correction factors). Next, we demonstrated the use of DReflect (Fig. 1), the android application we had developed for data collection, and explained the tasks expected of them during the 21 days of the diary study. Participants were then asked to label and save specific locations that they were going to frequently visit during the three-week study period (e.g., Home, School, Work, Grandma’s, Friend, Soccer, Horseback Riding). Additionally, patients were asked to specify their wake-up time and bedtime so that the application could
determine an appropriate time window for sending notifications. In the second half of the interview, we
followed a semi-structured interview protocol where we asked patients and their caregivers to recall the
previous day and describe their routine. We then asked them about their engagement with diabetes-related
devices and the data from those devices (how often they log data, how often they review data, and how often
they change insulin dose based on their data). This interview helped us understand the patient’s living context
and informed the exit interview questions at the end of the study.

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Sex</th>
<th>Diagnosis</th>
<th>Blood glucose monitoring</th>
<th>Insulin Administration</th>
<th>Ethnicity</th>
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<td>Pump</td>
<td>Asian</td>
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<tr>
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3.3 Diary Study

3.3.1 Patients. Patients were asked to log their meals (via captured images and estimated carbohydrates),
blood glucose number (via text input and images of glucometer), basal and bolus insulin¹ (via text input), mood
(using mood map [29]), and contextual factors affecting diabetes management and routine through hashtags
and notes (Fig. 1a). While they had the freedom to create their own tags, we also gave them ten prepopulated
tags that were developed by our study team’s clinical expert based on her knowledge of typical factors that
affect patients (#ateout, #junkfood, #exercise, #holiday, #idk, #missedbolus, #feelinghigh, #guesstimate,
#sitechange, and #stress). The data collection application, DReflect (Fig. 1), also tracked participants’ location
and, where possible, assigned location labels defined in the initial interview (Home, School). Lastly, patients

¹ In Type 1 diabetes, the pancreas stops producing insulin, which leads to abnormal blood glucose levels. As a result, managing diabetes
involves taking insulin and balancing it with food, exercise, and other factors. Insulin is administered using a combination of basal insulin
and bolus insulin. Basal insulin is the long-acting insulin that manages blood glucose throughout the day. Bolus insulin is the short-acting
insulin taken before meals to cover for carbohydrates in the food. (http://www.jdrf.org/about/what-is-t1d/facts/)
were notified to complete an end of day diary that first showed a context-enhanced summary of data reported during the day and then asked them to report critical incidents for that day (diabetes and non-diabetes related), challenges of managing diabetes for the day, and other things that they might wish to share or forgot to report during the day. To ensure compliance with self-reporting, we also notified participants if they missed entering meal logs during a day and asked them why the entries were missed. We expected three log entries from participants each day and if they did not provide any data until 5pm, they were notified. In doing so, our aim was not to assess adherence to self-care activities but to gather sufficient data each day to enable end-of-day reflection on data.

3.3.2 Caregivers. We asked caregivers to fill out diary entries for 21 days. Each day at a time of their choosing we emailed them a link to an online questionnaire. They were asked to report about their day, the routine of their family, unusual events in their day and their child’s day, and their perspective on the challenges of managing diabetes for that day.

![Fig. 1](https://tidepool.org/products/tidepool/)

3.4 Data Analysis Phase 1 and Exit Interview Documents

After the diary study phase, data (diabetes logs, diary entries, and initial interview) were analyzed to understand critical incidents, such as breakdowns in management, atypical circumstances, unusual outcome measures, and missing data for each participant. During analysis, free text diary responses from parents’ and patients’ self-reports were cross-checked to assess any discrepancies. Insights from this analysis were used to prepare exit interview documents for patients and their caregivers. The exit interview document consisted of two parts. The first part displayed data visualizations (context-enhanced biomedical measures) to participants comprising of raw and aggregate data (Fig. 2-7). The second part of the exit interview document consisted of summary of events and specific questions based on breakdowns observed in the data. The questions for patients and caregivers were mostly identical with a few variations depending on the diary responses received from each. In this section of the document, we also prompted the participants to address any mismatch in the parent and the patient responses from the diary entries in two ways – 1) we asked them to confirm if the summary of events seemed representative of the study days, and 2) we asked questions related to specific events that did not match in patient and caregiver reports. The format of visualizations remained the same for all the participants. The questions asked were specific to the events reported by the participants.

The data visualizations in the first part of the exit interview document were prepared by the research team after reviewing commercial visualizations offered by diabetes-related device companies, and by reviewing relevant literature that characterizes basic visualization insights (trends, comparisons, and distribution) [3]. Among all the visualizations we reviewed, we selected Tidepool\(^2\) formats (Fig. 2-4) to serve as a model for our

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\(^2\) https://tidepool.org/products/tidepool/
displays, given their simple design. Additionally, we adopted the classic “logbook” version (Fig. 5) of visualizations, considering their extensive use in the clinic during patient appointments and hence, the familiarity of patients with this specific format. Fig. 2, 3, 4, and 5 are modeled after existing visualizations and Fig. 6, and 7 are the novel ones developed by us. Specifically, Fig. 2 and 3 represent an adapted version of Tidepool visualizations, to which we added mood and energy labels. The scatter plot of blood glucose numbers in Fig. 4 was also borrowed from Tidepool to which we added hashtags. Our aim in developing these visualizations was not to evaluate them for their effectiveness but to present multiple representations of data for participants to have multiple opportunities to obtain insights.

In selecting aggregate data insights to be displayed in the visualizations, we were guided by Choe et al.’s research characterizing basic visualization insights, such as time trends, averages for data summary, and comparisons [3]. Additionally, the use of contextual data (location and type of day) was inspired by Epstein et al.’s concept of visual cuts where an outcome measure is profiled by different contextual parameters (e.g., amount of physical activity against commute time, and location) [9].

In deciding the low-level features of our visualizations (e.g., bars, lines, solid color or gradient), we created multiple versions of displays using pilot data and obtained feedback from our pilot study participants (two patient-caregiver dyads). Based on this feedback, we selected vertical bar charts, scatter plots, solid colors, and abstract keywords and symbols for mood and energy, such as high and low, to represent the data. The options evaluated by pilot participants included line charts, horizontal and vertical bar charts, combination of line and bar charts, scatter plots with solid colors and gradient, and scatter plot combined with bar charts.

Although we collected data from Continuous Glucose Monitors (CGM) and insulin pumps for the three weeks by having patients download data from these devices, we did not use that data for two reasons. First, not all participants used a CGM or an insulin pump. Second, for participants who used the CGM and/or the pump, their use of these devices was discontinuous because of accuracy issues, device failures, and preference to not wear CGM and/or pump, for example during family vacations. As a result, we could not obtain data consistently across participants. Additionally, although we gave participants the option to log basal insulin in addition to bolus insulin, the majority of the participants did not log this information. Consequently, we dropped it from our analysis and from the data visualizations.

3.5 Exit Interview

After the diary study, we conducted an hour-long exit interview with the patient and the caregiver separately. The aim was to understand how they use context-enhanced displays to make sense of their experiences from the 21 days. To maximize recall, all the interviews except two (P10 and P12) were conducted within a week from when the participant ended the diary study phase. Participants were sent their exit interview documents that contained visualizations and questions (described above) a day or two, prior to their exit interview to review them. All the participants confirmed in the exit interview that they were able to review their data prior to the interview.

During the interview, we asked participants to walk through the data representations while thinking aloud. Additionally, when needed, we probed them by asking what they learned from the visualizations and how the data displays helped or didn’t help them understand diabetes. Next, we asked them the questions from the second part of the exit interview document. These questions focused on days that were unusual or that involved a critical incident as identified from the diary data. These questions were supplemented with day-wise displays of their data to enable recall and reflective conversation [41]. Some participants printed out the exit interview documents for use during the interview. Other participants accessed the PDF file on their computers. They walked through the visualizations one by one as directed by the interviewer.

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3 https://www.medtronicdiabetes.com/CareLinkPDF/Logbook/
4 https://support.tidepool.org/article/29-viewing-your-data-daily-view
5 https://support.tidepool.org/article/89-viewing-your-data-weekly-view

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3.6 Data Analysis Phase 2

In this phase, the exit interviews from caregivers and patients were analyzed focusing on their analytical activities during the interview. The first iteration of data analysis was primarily guided by the interview questions and data was coded using in vivo and descriptive coding [37] to label the insights or findings patients gathered from their data, how they came up with those findings, what is challenging about using data to generate insights, and what other information could be useful. Next, the codes were iteratively reviewed to
merge similar codes and disregard less prominent codes. The codes and associated interview quotes were then analyzed to group them into meaningful themes using affinity diagrams [45]. These were discussed within the research team to further develop them.

4 FINDINGS

This section first describes data-based analytical activities that patients and caregivers engaged in while exploring their data during the exit interviews. Next, it describes the challenges that patients and caregivers faced while exploring and analyzing data. Lastly, it demonstrates how these analytical activities and challenges relate to the different sensemaking processes described in the data-frame theory of sensemaking to facilitate the emergence of information needs [18].

4.1 Data-Based Analytical Activities

When interpreting their data, we observed that participants engaged in a range of analytical activities, including four distinguishable activities that emerged as themes from the data — they observed context-based trends and explained them, they triangulated information from multiple factors, they generated context-specific self-care actions and anticipated the consequences of those actions, and they hypothesized about additional factors to explain their data.

4.1.1 Patients Found Context-based Trends in Outcome Measures and Explained Them. In analyzing their data, most of the patients and caregivers sought to understand trends in BG numbers in combination with other factors. While exploring time-based trends, patients and caregivers perceived the variation of BG numbers with time in different ways, such as trends in specific time periods of the day, “mostly I think of it [trends] in time periods.” (P02 Mother), trends related to a specific time of the day over multiple days, “A time of day, for me, has been my go to, ‘Okay, let’s hone in on a problem here because it’s happening at the same time every day.’” (P11 Mother), and trends within a day, “A trend for me is when he has two to three highs right in a row.” (P13 mother)

Participants also found trends using a combination of the primary outcome measure (BG number) and specific factors other than time, such as mood, food, insulin, sleep, type of day (e.g., weekend/weekday/vacation), location, physical activity, flu, travel, and other factors unique to each participant. For example, P12 spotted a trend relating to sleep (using the label #sleep), “And I can also see a trend ... for example, when I wake up, it was mostly two or three hundreds [i.e., higher than recommended] and it was all #sleep so I know it was sleep”. Similarly, P06 and his mother noted that every BG number associated with “#running” was above range.

Investigating context-based trends in outcome measures prompted patients and caregivers to generate explanations when they noticed something obvious or unusual. For example, noticing a trend of difference in numbers between the first half and the second half of the day, “When he comes home from school he doesn’t immediately look at his [Continuous Glucose Monitor] and say, oh, I better give myself the correction right now so that I don’t end up high at dinner.” Similarly, seeing how BG numbers remained steady with location, P15’s mother explained why there was no variation in BG numbers or food across different locations, “going to grandma’s cottage wasn’t that different than being at home on the weekend. You still have consistent meals and snacks. I might see a bigger difference if it’s her being away at camp or, you know, a trip to the amusement park like I said, versus a normal day at home.” She further projected that locations unlike home that are associated with more activity could affect management in a more noticeable way.

4.1.2 Patients Triangulated Information from Multiple Factors. In addition to understanding the effect of individual factors on a certain measure (amount of carbs consumed, or BG number), patients connected multiple factors to obtain a more comprehensive understanding. This helped them discover new insights and validate existing knowledge (confirm or deny). For example, when looking at the variation of numbers across different
locations (Fig. 7: home, grandparents’ house, church/youth group, others) and different types of days (Fig. 6: weekdays and weekends), P01’s mother noted, “It reaffirms what I knew about her grandparents’ house. It doesn’t surprise me at all that her sugars are really high over the weekends and yet she doesn’t eat many carbs, because I don’t know that my parents are generally telling her, hey did you shoot [insulin] for that? Do you know how many carbs that is?” The caregiver in this case saw that the patient has high BG numbers on weekends (type of day) and is also at her grandparents’ house (location) for weekends. She triangulated information from these two contextual factors to confirm her suspicion that diabetes management does not happen as expected over the weekends at the grandparents’ house, resulting in high BG numbers.

Similarly, P03’s mother discovered that P03 did better when they were both away from home together. This led to the conclusion that being together during the time away from home afforded more supervision and better control, “She was getting better control when she was not at home. [laughs] I’m thinking a lot of the ‘unknown location’ [locations not labeled during the initial interview] was when we were on vacation. And I was with her so I was, like, on top of her all the time making sure things were checked and things were done more accurately. I realized it when I looked at this [data], I didn’t really realize it before.” They both got more time together when they were out of home for vacation, or family dinners because P03’s mother was at work most of the time otherwise.

As a part of triangulation, a few patients and caregivers (P03 Parent, P11 Patient and Parent, P12 Parent) moved between displays to compile the inferences they obtained and confirm their understanding, “I looked at graph one and I could see ... as I would go down and looked at the others, it just kind of confirmed where I was at.” (P03 Parent)

4.1.3 Patients Generated Suggestions for Context-based Self-care Actions and Their Consequences. Patients suggested actions that could help them change insulin dose, eating behavior, and adherence to self-care activities to obtain better control over their BG numbers. For example, while understanding the time-based trends in BG numbers, P03’s mother broke down the day into three parts (breakfast, lunch, and dinner) to identify the time windows for which insulin dose could be adjusted in response to food intake. Similarly, P12’s mother investigated three types of data streams together (BG numbers, carbs, and insulin) and compared the existing patterns with what the expected patterns in these streams should be to identify corrective action, “if the carbs pattern matches the blood glucose pattern then the insulin needs to be higher to bring the blood glucose down. What it tells me when I look at it that way is that his carb ratio [a patient-specific value that determines how much bolus insulin to give based on carbohydrates consumed] is not high enough.” She concluded that the similarity between carb pattern and glucose pattern implies that the carb ratio should change to keep the BG numbers steady.

While the action suggestions in the abovementioned cases naturally followed from the observation of trends and aimed at fixing only the current problem, there were other, more intricate suggestions that also considered the interaction between multiple factors and the potential impact on the anticipated consequences of a self-suggested action. For example, P06’s mother pointed out that P06 was often high after running and explained how a temporary dose of insulin might help bring down the numbers but she also had to be cautious about the additive effects of insulin and physical activity to avoid low BG numbers, “We’ve talked about maybe doing that temp basal after he gets done running, but typically he comes right down after running. He’ll do a correction and he comes down. So, running a temp basal makes me a little nervous because I don’t want him going [too] low later.”

4.1.4 Patients Hypothesized About Alternate Contextual Factors to Explain the Data. When participants could not explain the outcome measures (BG numbers) using factors present in the displays, they generated ideas about alternate factors. For example, P08’s mother noted the need to understand sleep patterns with the BG number patterns, especially during a trip in the summer vacation when the sleep schedule was unusual, “on [the trip], he slept a lot, he slept late in the day, he was high. So, I’m wondering what impact that has. Similarly, P02 thought of physical activity to consider as a factor to explain his numbers for a given day, “I think one of the things that would be helpful for me because I have such an erratic schedule would be like activity level. That would probably be helpful for myself because I am not consistently being active.” Another factor that was considered
was specific food choices, “I would love to see this with food choices, like... Somethinng that would help to really hone in on, ‘Does that really have a major impact on the numbers?’.” (P11 parent)

4.2 Data Exploration Challenges

Even though patients and their caregivers meaningfully engaged with patients’ data, they faced two challenges – the inability to identify clear trends and counterintuitive insights were hard to explain and compromised trust in data.

4.2.1 Inability to Identify Clear Trends Challenged Action Planning. Particular characteristics of the data patients generated influenced whether participants were able to identify any trends. For example, caregivers of P02 and P08 were unable to find trends in the data, which made it difficult to obtain any insights, “considering most of the boxes are red, it’s hard to really see a clear pattern because he’s high, like, what? 85–90 percent of the time here so it’s really hard to glean anything from that other than he’s high a lot.” (P08 Mother). While having high numbers most of the times can be seen as a “pattern” in itself, participants and caregivers did not perceive such general tendencies of the data as useful for action planning. As a result, participants were unable to think of the next steps, “It was so hard to figure out what to do next because it was just all over the place, so random.” (P11 Mother). In such cases, patients and caregivers felt the need to call the clinic to make dose changes or understand the next steps, “so what we would do is when it’s random like that we call the clinic and we say, ‘Tell me the first place to start because there’s nothing clear for me to do’” (P12 Mother).

Similarly, when a contextual factor resulted in both desirable and undesirable trends, patients found it difficult to understand its true effect and needed more information. For example, P04’s mom could not understand the effect of eating out (#ateout) and guessing carbs (#guessimate) on P04’s BG numbers (Fig. 4), “I’m just looking at the red [numbers] talking about guessing and eating out. But then even [for] her green ones [number], there’s guessing and eating out and she was green.” She felt the need for more information to quantify the effect of the same factor on in range and out of range BG numbers and the accuracy of guesses with different types of food eaten outside home.

4.2.2 Counterintuitive Insights Were Hard to Explain and Compromised Trust in Data. When engagement with data resulted in counterintuitive insights, participants found it difficult to explain those. For example, P06’s mother was surprised to observe that the patient was not so well controlled at home, as she thought that the home environment provided an ideal set of self-management “tools.” “I think I would have expected him to have better numbers at home so I’m kind of surprised. Only because we have the tools at home.” (P06 parent).

In another case, P04 and her mother found it difficult to convince themselves of the truthfulness of a counterintuitive insight that they got from the data when they saw that P04’s weekday averages were higher than weekend averages, “I don’t think this is a completely accurate representation of... you would think that the BG would be higher on the weekend, but it was actually lower. But I think maybe if you were to do the next 21 days, things could be flipped, you know, the weekday would be lower and the weekend higher.” (P04 Mother).

4.3 Understanding the Emergence of Information Needs from the Data-Frame Perspective

As we conducted our data analysis, we were struck by the connections between our findings and the processes described in the data-frame theory of sensemaking [18]. While we did not set out to apply this theory to analyze our data, the synergy between our findings and the data-frame theory of sensemaking inspired us to further interpret our findings from the perspective of this theory. Doing so helped us reflect on and add to the existing perspective on sensemaking for disease self-management [27]. It also helped us demonstrate the value of the sensemaking approach for exploring contextual data, considering that such data is hard to capture and analyze computationally. We discuss these points in section 5. In what follows, we first describe the important aspects of the data-frame theory and then demonstrate its relevance to our findings.

The data-frame theory describes sensemaking in terms of two entities: data and frames. Data is defined as the “interpreted signal of events”. Frames are “explanatory structures” that describe the relationship between
different data elements. A frame could be a story describing events in a chronological sequence, a map showing spatial layout, a script describing the steps of a routine job, or a plan showing the sequence of future actions.

In this theory, sensemaking has been defined as the process of fitting data into a frame to establish relationships between different data elements and, hence, explain the data [18]. It is these relationships that, in turn, assign relevance to different data elements. In addition to identifying a frame, sensemaking also involves defining what counts as data based on the emerging frame. The process of constructing a frame begins with a few salient data elements called “anchors”. Multiple anchors can be compiled to create a frame that explains an event. If new data not fitting into the frame are perceived, the sensemaking process modifies the frame or creates a new frame to fit the new data element(s). In the course of constructing a frame, different lower-level sensemaking processes may occur, relating to how the data and the frame mutually inform each other. These include seeking a frame, elaborating the frame, preserving the frame, questioning the frame, re-framing, and comparing frames [18].

From the perspective of this theory, our findings show how the information needs of patients emerge and evolve through these sensemaking processes, as they refine their understanding and awareness. With regards to disease management, the majority of the “frames” that we refer to here are cause-effect relationships and conditions in which these relationships manifest, leading to narratives describing when and how one or more factors (either clinical or contextual) affected an outcome measure. Here, contextual factors (e.g., location, mood, hashtags and notes), and clinical factors (e.g., insulin, carbohydrates) served as anchors to create a frame (i.e. an explanatory structure) describing different ways in which the factors affect or could affect the outcome measures (i.e. the BG numbers).

4.3.1 Seeking a Frame. Seeking or constructing a frame involves deriving a frame from the data by identifying plausible anchors (factors likely to affect BG numbers) and then filtering the data based on the emerging frame. In this study, patients and caregivers constructed frames by identifying context-based trends and then seeking information to explain those trends, i.e., by using one or more factors as anchors to explain the variations in outcome measures. For example, P04 considered sleep to be an anchor to explain high numbers after waking up but she could not find consistent data to support this frame and eventually rejected it, “sometimes if I like wake up later than usual, then like my blood sugar might run like a little bit high, but it’s not really consistent, so there’s not really any consistent difference.” In another instance, P11 recalled one of the days from the study to understand a set of BG number variations wherein she considered multiple anchors to explain what affected the numbers on that day, “On August 5th, I was on a road trip so I was sitting in the car and eating a lot. And it was earlier in the morning so, like, tired mood, plus also sitting and eating made my number go really high.”

4.3.2 Elaborating the Frame. According to the data-frame theory, once sensemakers have a frame, they try to extend or strengthen this frame by seeking and inferring more data to fit the frame. In this study, our participants started with frames based on their lived experiences with diabetes. For example, as previously described, P01’s caregiver held the frame that P01 tends to have poor control when she is visiting grandparents’ because nobody reminds her to take care of herself. Seeing data coherent with her diabetes is poorly managed at grandparents’ house is associated with poor management of diabetes to “her diabetes is poorly managed at grandparents’ house and on weekends. P01 is at grandparents’ house on weekends.”

4.3.3 Preserving the Frame. At times, sensemakers commit to a frame and then, when they encounter data that does not fit the frame, they distort the data to fit the frame or find an explanation to discard the data while keeping the frame. For example, P04 and her caregiver believed that she tends to go higher on weekends.
However, her data from three weeks showed otherwise (i.e. higher on weekdays). On seeing the data, P04 questioned the calculation of averages, “I feel like it might just be the, like, imbalance between how many weekdays there are and how many days there are in the weekend”. P04’s caregiver did not think it was a true representation, “I don’t think [the difference between weekdays and weekends] has much to do with anything.” The caregiver and the patient explained away the data that did not align with their frame of how weekends and weekdays affected BG numbers.

4.3.4 Comparing Frames. Another form of sensemaking is identifying alternate frames or sharpening differences between two frames. In reviewing their data, patients and caregivers came up with alternate frames using hypothetical anchors (not present in the displays). For example, as described above patients and caregivers hypothesized and sought information about multiple factors not present in the display to explain the data (sleep, physical activity, and type of food). In addition to identifying alternate frames, they also compared frames to make explicit the distinction between them. For example, observing less difference in numbers between weekdays and weekends, P08’s caregiver considered two frames, one based on summer vacation and the other on school routine. During summer vacation, the variation between weekend and weekday numbers was less because every day was the same. But during the school year, she projected that this difference was going to be higher because weekdays were different from weekends. Similarly, P15 compared two different locations for similar effect in summer vacation, as described previously.

4.3.5 Re-framing. Reframing could involve establishing new anchors, looking at discarded data, or reinterpreting the data. For understanding changes to BG numbers in patients with type 1 diabetes, the two most salient anchors to explain fluctuations in BG numbers are the amount of insulin taken and the amount of carbohydrates consumed. However, other factors, such as physical activity, or the specific type of food could also affect BG numbers. P11’s caregiver looked at the patient’s BG numbers along with carbohydrates and insulin data. In contrast to general beliefs about the determinants of BG changes, the caregiver concluded that the low BG numbers were not caused by insulin or by carbohydrate consumption, “It seems like when she had the lows it didn’t necessarily mean, like, over-bolusing or, like, a high carb consumption.” She then thought of other factors (exercise and food type) that could be causing such variations in the BG numbers to re-frame the data using other anchors, “I’m assuming it’s the exercise thing. Or perhaps the food choices that I’m not sure, probably both play into it.”

4.3.6 Questioning the Frame. Sensemakers question a frame when they encounter inconsistent data or detect an anomaly, or when their expectations in the context of a particular frame are violated. When patients and caregivers derived counterintuitive insights as described above, they questioned the anchors they were considering. For example, P04’s caregiver wanted to understand if eating out and guessing the amount of carbohydrates in food was affecting the patient’s numbers. Looking at the days associated with #ateout #guesstimate, she could see both red (out of range) numbers and green (within range) numbers. She was left questioning if eating out and guessing were relevant anchors to explain the numbers, “so it’s like, it didn’t even matter whether she was guessing or eating out.” She sought more information on how the distribution of BG numbers is affected by these events of eating out and guessing carbs.

5 DISCUSSION
In this study, we explored how patients and caregivers made sense of multiple streams of data collected by the patients. While prior work identifies insights that patients want from their data, we provide an understanding of the interpretation activities that result in these insights. We observed four analytical activities in which our participants engaged while interpreting their data – finding context-based trends and explaining them, triangulating multiple factors, suggesting context-specific actions, and hypothesizing about alternate contextual factors affecting outcomes. In pursuing these analyses, our participants faced two challenges – inability to identify clear trends challenged action planning and counterintuitive insights compromised trust in data. We interpret our findings using the data-frame theory of sensemaking [18] to show how our participants’
information needs emerge and evolve through different sensemaking processes described in this theory (e.g., seeking a frame by identifying trends and factors causing them, elaborating a frame by triangulating multiple factors).

In this section, we compare sensemaking as observed in this study with prior conceptualizations to demonstrate that sensemaking can not only inform disease-management action, but it can also result in the identification of new information needs and drive further exploration (as described in the interpretation of our findings through the data-frame theory of sensemaking). This makes sensemaking a valuable approach for facilitating the emergence and discovery of patients’ information needs, which can guide the collection of further data that are relevant to fulfill those information needs. We thus argue that contextual information should be explored using a sensemaking approach. Such data, which come with their own challenges of capture and analysis, need not all be collected upfront, as sensemaking could drive information needs and hence, guide the collection of data that would be needed to fulfill those information needs.

5.1 Sensemaking for Guiding Action

Existing sensemaking perspectives on chronic disease self-management describe disease management behavior in terms of continuously perceiving and inferring information and experiences to inform action [27]. For example, in the “sensemaking” mode of diabetes management described by Mamykina et al., patients may construct new explanatory models and take an experimental action instead of a routine action to accommodate new experiences. Here, developing explanatory models is essential for action. In a similar direction, our findings show that when participants were able to explain their data, they were more easily able to identify the need for an action (i.e., if a self-care action was required or not). Additionally, in a few cases, they were also able to identify the action they should take.

5.2 Sensemaking to Identify Information Needs for Guiding Data Collection and Exploration

There were also instances when the participants were not entirely able to explain their data (i.e. construct a frame) and finish their exploration. For example, the challenges that participants faced while reviewing their data exemplify cases when they were unable to understand or explain the data. While this did not result in a suggestion for action, it prompted them to think of alternate anchors not present in the data display that could meaningfully explain the data. Because one of the key aspects of sensemaking is to identify and define relevant data, even when such data is not available, sensemaking can proceed with access to limited data (p. 122) [18]. For health-related tracking, this could suggest an episodic approach to the collection of contextual data. That is, contextual data might not need to be tracked and reflected upon continuously (e.g., tracking needs are governed by patient condition [31]) and patients might not always know what data to collect. Instead, the need for more relevant data could emerge as and when patients make sense of the available data. Thus, sensemaking could help patients understand the collection and use of contextual data for health-related tracking without necessitating the availability of comprehensive data upfront.

This also highlights that a possible outcome of sensemaking is exploration by identifying information needs, as also described in the data-frame theory of sensemaking (i.e. when data-frame congruence does not happen [18]). This observation differs from Mamykina, et al.’s, sensemaking-based disease management model that considers action as a necessary outcome of sensemaking in the perception-inference-action cycle [27]. Instead, our observations align with the data-frame theory of sensemaking to suggest that in addition to action, sensemaking could drive information needs for meaningful exploration. These information needs are continuously shaped and reshaped through the iterative application of several sensemaking processes described above that include seeking a frame, elaborating a frame, preserving a frame, comparing frames, re-framing, and questioning a frame. The identification and refinement of information needs in turn can potentially help patients identify the data they need to collect in response to the information needs.

6 DESIGNING TOOLS TO SUPPORT SENSEMAKING

Our findings and our reflection on different sensemaking perspectives are suggestive of design implications for sensemaking tools to improve patients’ awareness of factors affecting outcomes and to support their agency as sensemakers.

6.1 Improving Awareness of Factors Affecting Outcomes

A recent body of work has explored the use of self-experimentation tools that help patients collect relevant data to test self-generated hypotheses and establish associations between factors and outcomes (e.g., dairy worsens irritable bowel symptoms). To form hypotheses, such tools rely on patient’s own knowledge of what factors are affecting their symptoms or on clinicians to guide patients in selecting independent and dependent variables for the experiment. While disease specific outcome measures can be universal, we cannot assume that all the factors affecting these measures are necessarily universal among patients. Additionally, there could be factors or combination of factors unique to each patient that the patient or their clinicians might not be entirely aware of. This suggests the need to support a pre-experimentation step to explore the factors that are worth testing. In the pre-experimentation phase, patients could gain an improved understanding of the relevant factors or information needs through retrospective sensemaking, similar to what we observed in this study. Our findings show that when patients engaged in sensemaking, they identified information needs to continue the exploration in order to eventually explain their data, as described above. They hypothesized about alternate factors not present in the data displays to explain their data. In this way, sensemaking resulted in better awareness of relevant factors affecting outcomes and the understanding of data that needs to be collected in response to an emerging hypothesis and information needs. Existing tools do not entirely support an informed selection of factors to test among the many that could be affecting patients’ condition [15]. These tools can be extended by including a pre-experimentation phase where patients collect multiple streams of data including factors and outcome measures, rank these factors through retrospective analysis and sensemaking, and conduct experiments based on the prominence of the factors. Additionally, the system can suggest potential factors to the patient to collect data on and further explore that factor.

6.2 Supporting the Sensemaker’s Agency

Automation undermining individual agency is of growing concern in the field of personal informatics [7]. While computational support is necessary when dealing with multiple streams of data as it is challenging for the users to make sense of it [5], it is also important to understand the nuanced role of human intelligence and cognitive processes that need to be scaffolded. Our findings are suggestive of three ways to support the sensemaker’s agency.

6.2.1 Enable Feedback on Computational Insights. The data analysis activities of patients revealed that when they obtained counterintuitive insights, they did not always believe them, rather questioning how the data was analyzed or how the results might change if they collected another data sample. This shows that even simple computational insights gathered from data might not reflect the lived experiences of patients, which was also demonstrated by prior research on self-experimentation (patients did not entirely believe the conclusion reached by the self-experimentation application [15]). This could happen because of reasons such as, data was collected over a short period of time, or the data collection happened over a time that was not representative of typical days.

The possibility that these insights might not resonate with patients’ lived experiences suggests that tools that provide insights drawn from patient-generated data need to support manual assessment of the insights. One way in which this could be accomplished is by giving patients the ability to provide feedback on the system-generated insights. For example, participants could rate the insights on a scale of 1 to 10 to indicate how representative of their experiences an insight is. Similarly, tools that generate and test health recommendations, such as the sleep recommendations generated by SleepCoacher [8], can be extended by letting users prioritize system-generated recommendations for implementation and experimentation. Obtaining user feedback on
system-generated information can help researchers understand the performance of experimentation or analysis techniques over time to assess if the techniques need to change to provide better recommendations or there are genuine variations in data that the user is unaware of.

6.2.2 Support Insight Validation Through Triangulation. Our findings show that patients and caregivers triangulated insights from multiple factors. While it is important and perhaps easier to understand the effect of single factors on an outcome measure, multiple factors operate together in everyday context of disease management, as reflected by our participants’ experiences. Hence, it becomes important to understand the cumulative effect of these factors in several combinations that they manifest. Cross verification between factors is one way in which our participants increased their understanding of the cumulative and nuanced effect of these factors on both the outcome measure and the disease management behavior. Tools that help patients collect multiple streams of data need to provide ways in which triangulation can be performed as it could potentially increase users’ confidence in self-generated insights. For example, self-experimentation tools [16] could be extended to use multiple experiments to cross verify insights from each of them instead of relying on one experiment for a conclusion.

6.2.3 Support Anticipation of Future Conditions and Consequences. Some of our participants not only wanted to understand the past and the present from their data, they also projected insights for different contextual conditions and anticipated the consequences of self-care actions. Tools should support simulation to enable users in understanding the impact of a different contextual condition that is less apparent in a data snapshot. For example, context prediction algorithms can be used to infer future contexts from the past contexts [28]. Additionally, such prediction could be supplemented with information about uncertainty for users to exercise discretion in assigning relevance to these predictions.

6.2.4 Enabling Clinician Involvement. When understanding self-care actions and their consequences, it will be essential for tools to enable patients to involve clinicians when needed. For example, patients could invite clinicians to review a self-care action that resulted from a patient’s analysis of their data. Clinicians could then validate the self-care action suggested by the patient while also providing information about what consequences should the patient be aware of, what other data could help them make a better decision or recommending other self-care actions. Such information can also be automatically sourced from disease-specific knowledge repositories built over time in collaboration with clinicians (e.g., diabetes [6]) and made available to patients through standard templates if they do not wish to seek clinician support [23].

7 LIMITATIONS

Our study participants were adults and adolescents. In the exit interviews, both these participants separately engaged in sensemaking with patients’ data. While the simpler analytical activities (e.g., finding a trend) could be generalized for both these populations as we saw both patients and caregivers engage in these activities, the complex analytical activities (e.g., triangulation, hypothesizing, suggesting action) would perhaps be more natural for adults than adolescents because of differences in education and cognitive abilities. Additionally, one of the factors affecting data interpretation could be data literacy, which we did not assess in this study. However, we used simple representations of data, which is perhaps why we did not find any of our participants struggling to engage with their data.

We acknowledge that the granularity of data collected by our self-tracking tool, DReflect, was less than what could have been obtained by continuous glucose monitors (CGM). However, our aim in this study was to obtain a volume of self-reports sufficient to engage participants in self-reflection at the end of each day during the diary study phase. Additionally, the variety of CGMs used by our participants posed a technical challenge in obtaining this data because it would have required introducing participants to a new tool suite (e.g., Tidepool6) that they were unfamiliar with.

6 https://tidepool.org/products/tidepool/
Regarding the visualizations we presented to participants, we want to note that having granular data could have resulted in more informative visualizations. However, our aim in this study was to present simple visualizations to participants, considering that we were working with adolescents. Some of our visualizations are a lot simpler than the others. For example, the aggregate visualizations (Fig. 6 and 7) show simple insights, such as comparison of BG numbers between weekends and weekdays, and comparison of BG numbers across locations. While these displays might seem simple, they provide a contextual profile of patient’s disease control and aim at improving awareness of the contexts in which the patient needs to improve disease management. The majority of our participants found these displays useful for improving awareness.

8 CONCLUSION

Given the limited understanding of how patients could interpret clinical data with contextual data, we explored interpretation activities of patients with Type 1 diabetes and their caregivers using context-enhanced visualizations of patient data collected through a three-week diary study. We observed four different analytical activities performed by participants as they interpreted contextual and clinical data - finding context-based trends and explaining them, triangulating multiple factors, suggesting context-specific actions, and hypothesizing about alternate contextual factors affecting outcomes. We also noted two challenges that participants faced in engaging with their data— inability to identify clear trends challenged action planning and counterintuitive insights compromised trust in data. Interpreting our findings using the data-frame theory of sensemaking [18] shows how information needs of our participants were shaped by the various sensemaking processes, which we elaborate. Situating our findings within two existing perspectives on sensemaking (the data-frame theory and Mamykina et al.’s sensemaking framework for chronic disease self-management), we show that sensemaking could not only result in action as described by Mamykina et al.’s sensemaking model for chronic disease self-management [27], but it could also generate new information needs and guide exploration. Considering the challenges of capturing and computationally analyzing different types of contextual data, we argue that the sensemaking approach should be used for exploring contextual data as it can result in information needs that could further guide the collection of relevant data in response to those needs. Lastly, noting the value of sensemaking approach for using contextual data, we provide design suggestions for sensemaking tools to improve awareness of contextual factors affecting patients and to support patients’ agency in making sense of data.

This study contributes in three different ways. First, while prior research shows the types of insights patients want from their data, our work contributes an understanding of the interpretation activities that lead to those insights. Second, we inform the current sensemaking perspective on chronic disease self-management by comparing it with the data-frame theory of sensemaking. Recognizing the complexity of interpreting contextual data, we identify a theoretical basis for understanding the use of contextual data by proposing that the sensemaking approach should be used for exploring contextual data. Third, we contribute design knowledge for sensemaking tools to support exploration of multiple data streams including clinical and contextual data.

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