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At Home With Data: Family Engagements With Data Involved in Type 1 Diabetes Management

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This article reports on an exploratory study of quantitative data use situated in families' management routines while taking care of a child with Type 1 diabetes (T1D). T1D treatment requires frequent measurement and recording of numerical data about blood sugar concentration, nutritional intake, and insulin dosage at the child's home, at school, and at other activities. We analyze coordination work between family members and others involved in the care of children with T1D using the lens of distributed cognition, and we introduce the notion of a data catchment to refer to the pathways of data flow and information storage within and between multiple agents and spaces. Interviews and observations reveal three main features of storage and use in data catchments: First, there

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A substantial portion of this work was completed when both authors were affiliated with Utah State University.

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is a great variability in how data move and are retained to enable communication between family members and others. Second, families tended to focus more on individual data points and less on aggregate readings despite some indications of ability to narrate through aggregate readings. Third, families engage in recurrent conversations and sometimes use novel artifacts to make numerical values meaningful to children with T1D. Implications for understanding this space of practice as constituting a data catchment are discussed.

Type 1 diabetes (T1D) is an incurable autoimmune disease that destroys the pancreas's ability to naturally produce insulin, a hormone necessary for the absorption and storage of glucose. In the United States, over a million adults live with T1D, and current estimates are that over 200,000 youth have it as well (Imperatore et al., 2012). T1D management involves frequent blood tests to measure blood sugar concentration and administration of insulin multiple times during the day. It requires frequent measurement and recording of numerical data about blood sugar levels, nutritional intake, and insulin dosage. To date, diabetes has appeared in learning sciences research as a contextual anchor for K-12 science units (Pichert, Snyder, Kinzer, & Boswell, 1994), as a context for reflection through novel computer interfaces (Smith, Frost, Albayrak, & Sudhakar, 2006), and as an object of inquiry with agent-based models (Dubovi, Levy, Dagan, Milana, & Zyckerman-Levin, 2018).

The T1D focus for this paper differs from those works in that it examines a naturalistic context where affected children and families must encounter and use data regularly. As part of this special issue on situating data science, our goal is to illustrate some of the family encounters with streams of numerical data so that we can understand how people, data, and routines are organized and enacted "in the wild." From this, we hope to inform learning scientists about the nature of knowing and learning with data outside of designed learning settings and also derive some lessons that can inform more intentional design efforts in the future. Our unit of analysis is the family. The primary questions that we ask are: What data encounters appear in the management and care of children with T1D? Who participates and how is information recorded, interpreted, and mobilized?

THEORETICAL PERSPECTIVES

In studying data usage that is taking place with families, particularly in a relatively underexplored area (for the learning sciences) of chronic illness management, we have adopted qualitative research methods that are highly descriptive and focused on documenting activity reported by and observed with a modest number of participants. As such, this is an exploratory study.

Theoretically, we view family data work with diabetes as a form of *data catchment* in which streams of data move in various directions toward an eventual

goal of managing a child's health. This is deliberate new terminology we introduce that builds on the metaphor of data as moving liquid (i.e., data streams, data deluge, data flows). Like a geological catchment, from which we borrow the term, where water from various natural sources moves through and temporarily resides in various landforms and structures as it moves toward its eventual destination, we imagine data catchments as also having temporary storage sites where data can reside or pool for varying amounts of time. These storage sites typically constitute part of the representational infrastructure (Bowker & Star, 2000; Hall, Stevens, & Torralba, 2002) that maintains and structures diabetes management practice, although our data orientation means that this infrastructure is oriented toward managing quantification. Thinking of the movement and storage of data toward a central aim provides a rough boundary for what should be included in examination. We would want to know, of all possible values that could be quantified, which are oriented toward a common, agent-identified and agent-designed terminus. We also would want to know the nature of different storage units, what purposes they serve, how they make certain behaviors immediately possible, and also how they influence data behavior "downstream".

The data catchment of T1D management involves the family as a distributed cognitive unit that does the work of propagating and acting upon information using various forms and media for representation across space, time, and actors (Hutchins, 1995a). The individuals involved in collecting and managing the data are also the agents of interest. That is, we are attending to the individuals who direct and alter the flow of data in service of its final goal. Our present use of the family as part of a distributed cognitive unit is one with an inherent developmental asymmetry; the parents are responsible for caring for the T1D child—a relative novice—who is restricted in their contributions to the cognitive work but are still central participants. Additionally, the locale of distributed cognitive work takes place largely at home but also can extend beyond a single site and involve actors beyond parents or the child. For instance, as children go to school or participate in outside activities or when one or more parents are otherwise absent from the physical location, the distributed cognitive work continues and must still be coordinated and managed. Thus, the span of the data catchment is not necessarily defined by common physical location but rather the paths and directions the data take as it moves through the distributed system. Another feature of looking at families in this arrangement is the ongoing challenge of helping children detect and recognize where to find quantities of consequence in the world around them, whether it is dosing their own insulin or reading nutrition labels.

Viewing T1D management as a data catchment and as a locus for distributed cognitive work implies that an immediate analytical step is to identify and document the key data storage sites and channels involved and describing how those are used within the system to gather, record, and share information across different

individuals. These serve as “externalized” memory for agents in the system, and as will be described below, are used in various ways. A canonical example of this from distributed cognition research involves identifying how target speeds for different aircraft weight conditions are encoded and stored in media such as speed cards and in specific positions of markers on a speed dial (Hutchins, 1995b). This is also coupled with an account of how the information moves from one storage to another and ultimately constitute forms of coordination activity between human actors. For the current work, this means that analytical attention should go to the various material artifacts and information flows within the family and the artifacts that they use to store and act upon data.

In addition to treating the family as an ensemble involved in distributed cognitive work, T1D among children is also an occasion when expansive learning takes place or has taken place within an activity system (Engeström & Sannino, 2010). Expansive learning refers to a cultural-historical perspective on learning that goes beyond knowledge acquisition and participatory shift models of learning and instead views a highly consequential disruption as the precipitate around which a new practice must be established. The learning to be done is not known by the various participants a priori. Rather, it is negotiated, and a set of practices is established outward from the site of interaction. That outward movement means that new groups and relations that are formed as new objects, in the activity theoretic sense, are established. For example, the creation of new rules or policies from administrative entities can force organizational workers to immediately establish new practices that ultimately lead to cascades of new practice within the organization. This may involve required use of a checklist or logging particular information into a software system as part of the workflow, which may ultimately yield new objects of pursuit for actors in the system (e.g., finding ways to game the system by showing deceptive numbers). The mechanisms of expansive learning are still being actively explored and articulated (Engeström, Nummijoki, & Sannino, 2012; Nummijoki, Engeström, & Sannino, 2018).

In the current project, we examine the expansive practices that have developed within a family and that continue to undergo minor modification over time following the initial disruption of T1D diagnosis. Returning to our catchment language, this is akin to understanding the pathways, landforms, and structures that have emerged as a result of data flow. To capture the formation of these as they unfold immediately would ideally involve catching the diagnosis of T1D and creation of new practices as they are negotiated within the family. However, this would have been very difficult to anticipate and raises various privacy concerns. The disruption of diagnosis happened between two and seven years prior to this study. In light of this, our approach had been to focus on retrospective accounts and the routines that emerged and have been adapting at the time of inquiry.

DATA SOURCES

The primary sources of data for this study were audio-recorded interviews and observations with families in their homes, photographs, and field notes. Recruitment was done primarily through snowball sampling within the local T1D community. The recruitment criterion was families within 30 miles of the researchers’ institution who had a child under age 12 who had been diagnosed with T1D prior to the age of 7. One family was located in a different state and participated in interviews through video chat software. In total, five families participated in the study (Table 1). Families 1–3 were visited directly in their homes twice for interviews and observations. Family 4 was interviewed by video chat at their home and recorded in a public presentation about their child’s diabetes. Family 5 was interviewed and observed in a single visit to their home. Each interview and/or visit lasted from 40 minutes to over three hours.

TABLE 1
Families Participating in the Study. The Families Represent a Range of Education Levels and Socioeconomic Backgrounds.

<i>Family No.</i>	<i>Family Surname</i>	<i>Number of Family Members</i>	<i>Parents and Occupations</i>	<i>Child With T1D</i>	<i>Prescribed Diabetes Monitoring Equipment</i>
1	Smith	5	Parent 1: University Technology Specialist Parent 2: Stay at home parent	Son: Cort, diagnosed at age 2. Visited for research at age 8.	Continuous Glucose Monitor and glucometer
2	Nelson	9	Parent 1: Disability Services Specialist Parent 2: Stay at home parent	Daughter: Phoebe, diagnosed at age 4. Visited for research at age 10.	Insulin Pump and glucometer
3	Oaks	6	Parent 1: Farmer Parent 2: Hairstylist	Son: Peter, diagnosed at age 6. Visited for research at age 12.	glucometer
4	Young	4	Parent 1: Data Scientist/ Entrepreneur Parent 2: Research Scientist	Son: Felix, diagnosed at age 3. Interviewed for research at age 10.	Continuous Glucose Monitor and glucometer
5	Merrill	3	Parent 1: Information Technology Support Parent 2: Stay at home parent	Daughter, Monica, diagnosed at age 4. Visited for research at age 6.	Continuous Glucose Monitor and glucometer

Note that the families experienced T1D diagnosis between 2 and 7 years prior to this study.

Interviews were intentionally unstructured so that they could be highly conversational and focus on specific practices or experiences as they were mentioned. At a minimum, they involved one parent but often included both parents and multiple siblings who would come and go while chiming in information periodically. However, for each family, the researcher deliberately posed questions related to the following 1) How they first learned that their child had T1D, 2) What data they have recorded over time, how, and why, 3) and how a typical day of data tracking and diabetes management unfolds. There were also several other ad hoc questions about diabetes and data based on individual family activities that were mentioned.

With permission from the families, photographs of various objects used to manage diabetes or track data were taken, along with relevant objects or spaces around the home. In total, 229 photographs were taken for this study and analyzed. A brief overview of the families (all presented as pseudonyms) is provided below, and the list of professions alludes to differences in socioeconomic status and education levels (with the most formally educated having a data scientist as a parent and the least formally educated having a farmer as the breadwinner).

DATA ANALYSIS

Audio records were all transcribed. These transcriptions then underwent a cycle of open coding in which the data were segmented into episodes (e.g., *how T1D was discovered*). Common topics that were mentioned were tagged. A total of 56 open codes were identified with the top six most frequently appearing being related to *data tracking, coordinating blood sugar information with child's school, how a data device worked, use of a subcutaneous continuous glucose monitor (CGM), matching carbohydrate intake to insulin, and teaching the child about managing diabetes*.

After having tagged segments of data from this open coding, two additional passes were made through the data corpus. The first was to identify their current and previous data storage systems and various novel tools that they used to cope with the numerical information related to diabetes management. A canonical tool for data storage would be a mobile app where numbers were logged. A novel tool for coping with numerical information was a hanging shoe rack in the pantry that contained various pre-packaged and pre-computed snack sorted by the number of carbohydrates in a serving (see Ochs & Kremer-Sadlik, 2013 for discussion of the importance of pre-packaged snacks in structuring food consumption in middle class families). These episodes were identified, reviewed, and summarized. The goal in this analytical pass was to characterize how different storage systems in the T1D management catchment were used by family members, or what collections were established in the catchment.

The second pass through the data was done to curate live episodes of T1D management. As some management activities took place in the researcher's presence, whether it involved checking blood glucose levels or having a snack, these were examined as opportune moments to see what decision making and considerations were made in situ by family members and how various storage systems were used. We had several instances of these lasting multiple minutes each from all families except family 4. From those, we selected some demonstrative examples that we present and descriptively analyze below.

RESULTS

Family Data Storage Systems

A major goal of the study was to examine informal but necessary data collection, management, and storage. In all five families, there was some form of blood sugar and insulin tracking, although how long these records were retained varied across families. Some kept records extending for years, and some would only intentionally keep records for the day. Following from distributed cognition, in which cognitive structures such as long-term and short-term memory are re-understood within different representations and artifacts in the cognitive system, we also report on long- and short-term information storage and operations as they relate to the T1D catchment.

Short-Term Digital Storage

The most common form of short-term digital storage came from glucometer use (Figure 1 (left)). This involved the youth pricking their finger and producing

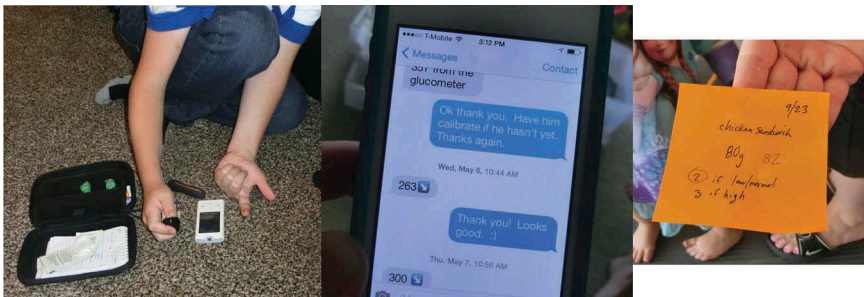


FIGURE 1 Short-term storage systems including: Glucometer usage (left), text communications (center), handwritten communications (right) between parent and school teacher about child's blood sugar level.

a drop of blood to be inserted into a glucometer, which then reported current blood-sugar concentration in terms of mg/dL. Following the disruption of diagnosis, checking current blood sugar was a new expansive practice related to the goal of monitoring diabetes. Prick tests were done several times a day for families who did not have a CGM device (a sensor that reports glucose levels in real time). For most families, this digital reading was usually shared orally and not recorded. Some exceptions to recording these numbers in a more enduring digital form took place when the child without a CGM began school and the parents needed to communicate with teachers about their child's blood sugar levels. For example, when Cort (Family 1) began 1st grade, his teacher watched while Cort checked his blood sugar levels and then texted Cort's mother with the value and awaited instructions on what to do next (Figure 1 (center)). This coordination created moments for family members to teach others who were involved in their child's care, such as teachers and school staff, about diabetes and the meanings of different numbers associated with disease management. Thus, the T1D data catchment extended beyond the home and involved the glucometer, along with text messaging, as storage and communications media.

Short-Term Manual Storage

Short-term manual storage involved handwritten recording of diabetes-related data that was intended to be discarded not long after its use. Family 3 demonstrated this in their communications with school staff. In order to communicate and make decisions about Peter's insulin dosage in advance of school lunch, Peter's mother wrote on a sticky note each morning that went with Peter each day. That note named what the school lunch was going to be, according to the online menu. Peter's mother then determined the likely amount of carbohydrates in the lunch and recorded those values and options for insulin dosage. In Figure 1 (right), the note specified that when Peter did a manual glucometer reading, he should dose 2 units of insulin if his readings were low or normal and 3 if his readings were high. The supervising teacher would verify that Peter ate the proper school lunch (as it sometimes changed or went unfinished). That teacher would also monitor and record how many units of insulin Peter gave himself and record any modifications to the number of carbohydrates he consumed. In Figure 1 (right), Peter had consumed what the teacher estimated to be 82g of carbohydrates and received two units of insulin. The note was then returned home with Peter, and after reviewing it and his current blood sugar level, Peter's mother discarded the note. A new note was prepared the next day. While the data catchment still extended to school, this particular storage system and use of data imposed more decision making on the teacher than the one used by family 1 and prompted some daily

conversation about what the teacher had recorded, what Peter had done at school, and what actions the mother thought needed to be taken after school.

Long-Term Digital Storage

Long-term digital storage involved automatic retention of data using a digital storage system and was enabled by families in our corpus by the use of CGM devices that would upload glucose readings into the cloud and allow for the child, parents, and other permitted users to access ongoing readings of glucose data. Long-term data storage was also enabled in insulin pumps, which among other things can store blood sugar readings, carbohydrate intake, and the amount of bolus insulin doses—the amount of insulin given in preparation of increased carbohydrate intake. This information was transferred to a computer and stored in a cloud service.

Family 4, which had two parents who had extensive graduate level training in working with quantitative data, deployed a sophisticated approach for using stored data obtained from a CGM. They coupled the CGM with other data by providing their child, Felix, with two wearable activity trackers, and by logging his food consumption in a spreadsheet. Those data were then used to generate a predictive mathematical model for Felix's blood sugar that went above and beyond recommendations made by medical professionals. Their mathematical model appeared to do a better job of keeping Felix within the target range (~80-180, depending on time of day) with less fluctuation than the procedures recommended to them by Felix's physician.

Felix's mother pursued this option because she was comfortable with data and felt she had to deal with a medical establishment that was suspicious of patient data and patient-suggested treatment protocols. Indeed, a community of hackers has emerged that has advocated for more openness in CGM data so that they could create their own artificial pancreas to monitor and treat their diabetes (Lewis & Leibrand, 2016). This community, which has high visibility in the "Quantified Self" communities (Lee, 2014), feels that better access to their own health data has the potential to increase the ability of patients to make their own healthcare decisions and support improvements in precision medicine.

Using CGM data as Family 4 did—where several streams of data from multiple devices were pooled and analyzed using complex statistical procedures—was atypical in this study. Families 1 and 5 both had CGM devices and did not build mathematical models from the data. Instead, these families referred to and examined only one day's worth of data points obtained by their child's CGM even though more was stored. The challenges of this approach had been documented in Lee, Thurston, and Thurston (2017) where a family who had kept years of extensive manual records of their child's blood glucose data that was recorded in notebooks.

Several years after diagnosis, they switched to a CGM. Only several months after using the CGM and after switching to a new endocrinologist who required the family to use special report functions in the system did they realize there had been some persistent blind spots in their understanding of their child's blood sugar levels. They had been so focused on responding to immediate blood-sugar data readings from the default data view and consequently focusing on how to respond to an undesirable reading at any given moment that they had not examined multiple days' worth of digital data in aggregate. When they eventually did do so, they discovered that their child had an undetected but consistent increase in blood sugar levels at the same time each day.

This tendency to have long-term digital storage systems but leave the aggregate data reports unexamined appeared elsewhere in the data corpus. Family 2, who had data stored on their child's insulin pump, reported that they did not refer to aggregate reports of their daughter's data with regularity. Despite this, they offered to produce one and share it with the researcher during a home visit (Figure 2).

Mrs. Nelson: Here is our report (Figure 2 (left)). 2 weeks ending yesterday. So we probably should use this more. I don't. This tells us 74% high, 22% in range, and 4% low. Her high is above 140. Obviously that is going to be high. All the time she is 170, and we think that is ok. You know what I mean?

Mr. Nelson: Well, that is what they set her range at.

Mrs. Nelson: That is what they set her range at. I wonder why it isn't showing here. But this says in two weeks that she was dosed 101 times in two weeks ... (changes the display to Figure 2 (right)) That is why I usually put 60-units [of insulin] in her pump because she uses

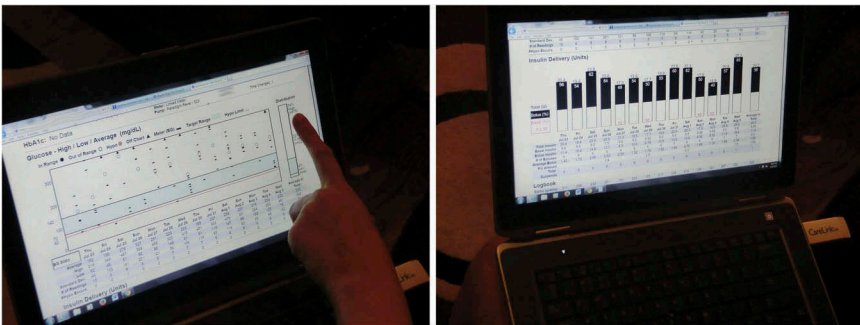


FIGURE 2 Data report from insulin pump from Family 2 showing glucose levels (left) and insulin dosage (right).

right around 20 a day so this day (*points to July 25*) my guess is we went out to dinner and she would've used more. Oh, this was the day we were in Yosemite.

Researcher: The 25th?

Mrs. Nelson: Yeah and we came back the 26th. Oh, and it tells you if she had a low. She was 52 this day 50, 50, 60 (*referring to the red values*). Yeah. And how many carbs she ate for that day. Man, what were we doing July 27? She only had 103 carbs

Mr. Nelson: All day long?

Mrs. Nelson: What was she doing on July 23rd? She had 311 carbs? That was another day in Yosemite.

Mr. Nelson: Those days you constantly eat because we were on the trail, and we didn't eat real meals hardly at all.

Mrs. Nelson: This is a good report. I should use this more. (*laughs*)

There are a few things worth noting in this transaction around the report. First, Mrs. Nelson explicitly acknowledged that she didn't use the this report very much. She stated "we probably should use this more" at the beginning of the excerpt and ends with "This is a good report. I should use this more". With the exception of Family 4, aggregate reviews of data were uncommon. Another observation from this transaction is the stance that Mrs. Nelson took with respect to how data were classified. She did not accept the device's categorization of data being "in range". According to the web tool, 140 was the cutoff value for when blood sugar levels were considered to be high. Mrs. Nelson was aware that many readings (up to 170) that she and her husband considered to be within range (up to 170) would be classified by the device as "high". This ability to question labels assigned to data speaks to her understanding of their actions as caretakers. In this way, her interpretation and trust of what the system said about Phoebe's data was tempered by her prior experience working with the data.

Second, Mrs. Nelson was moving quickly through what values she was recognizing and what inferences to make from them. Even though she did not view this report often, she was demonstrating ease with reading values from it and even making some immediate inferences. For example, she commented about the red values "Oh, and it tells you if she had a low. She was 52 this day, 50, 50, 60." Those values corresponded to what percent of her day's insulin came from the basal dosage, the amount given to her automatically throughout the day. The other unspoken amounts (48, 50, 50, 40) came from her bolus dosage. The four values were flagged as showing her basal being half or more of her overall dosage that day, which would suggest that the bolus values were lower than they should be. Mrs. Nelson's ability to recognize those as "low" even though those numbers themselves are not inherently low values, demonstrated her awareness of the various quantities and scales that were represented in the report.

A final observation demonstrated later was Mrs. Nelson’s ability to recognize and respond to unusual values. There were two incidences of this. One was when she reviewed July 25’s data and saw that the total amount was 23.8 units, making it one of the days with the highest amount of insulin being administered. Mrs. Nelson’s response to this was “my guess is we went out to dinner, and she would’ve used more”. Through this she was saying that value was higher because there had been some additional food consumption that would require additional insulin. Essentially, she was explaining why that high value existed. As another example, looking at carbs only, Mrs. Nelson also noticed that Phoebe had consumed 311 carbs on July 23. That was an unusually high number of carbs, but its appearance was something that Mrs. and Mr. Nelson were able to jointly and immediately explain (“That was another day in Yosemite.” “Those days you constantly eat”). In that case, there was a remembered change in eating behavior that they knew about and found reasonable given the circumstances.

In summary, these families all had demonstrated some ability to interpret and analyze the aggregate data that was kept in long-term digital storage systems. An exceptional use was to build a model from these logged data. A more common use was to recognize different kinds of quantities and to explain why those values were produced based on direct recall of what had transpired. However, for all but one family in this study, those reviews of aggregate data displays were rarely done even though they were available.

Long-Term Manual Storage

One additional storage system was one where data were recorded manually, typically in some form of paper-based log or notebook (Figure 3). Some families retained years of data, while others filled notebooks and then discarded them later. These notebooks were kept so that the family members could review data with one another and to enable some retrospective review when specific questions emerged. For example, Family 1 kept paper based logs where Cort’s mother, a stay-at-home parent, recorded all foods, carbs, blood sugar levels, and insulin dosages. At the end of the day, when Cort’s father wanted to know how Cort’s blood sugar levels had



FIGURE 3 Long-term manual data storage systems used by families 1, 3, and 5.

been, they would talk to one another briefly while reviewing that day's records. For Family 3, Peter's family was trying to get him to increase his own awareness of how many carbs he was ingesting and how many units of insulin he was taking in response. His mother required him to keep a log showing the time of day, his blood sugar, his dosing, and the number of carbs consumed. Creating this log was also another way for his parents to glimpse what he was getting at school, in addition to the sticky note that was used to communicate between parent and teacher.

One use of these logs that was shared by both Families 1 and 5 was to support purposeful information search. For Family 5, Mr. Merrill shared how he used the log when he was the primary caretaker. Most days, Mrs. Merrill oversaw T1D management. When Mrs. Merrill was away from Monica and Mr. Merrill was responsible for feeding and insulin dosing, he reported referring to the log that Mrs. Merrill maintained in order to know what steps to take.

Mr. Merrill: It [the log] let's me come back and look at the history logs and find out what she has been doing. And I can correlate the, you know, history—using historical data I can correlate and give her and determine correct dosages.

(Researcher asks for an example)

Mr. Merrill: This was last October. So let's say let's say this is today. So I come over here, yesterday, and say [Monica] was a 178 straightforward but then she did four units there. And she had a hamburger and salad. So she's 178. It's dinner time. [Mrs. Merrill] gave [Monica] four units. That means at nine o'clock [Monica] was 138 so she went down 40 points. *(scans entries in the log)* I could do a PB&J. She gave her three units to offset that, three units to offset cold cereal with almond milk. So this kind of gives me a menu.

Mr. Merrill's challenge was finding a suitable meal and suitable dosing to give to Monica. As he described it, he would look at how much Monica's blood sugar had changed and see what she was given as an insulin dosage and what she had eaten. This involved finding the difference between her blood sugar levels before and after a meal and seeing what food was given and how much insulin was administered. From looking at earlier records, one option he identified was four units of insulin if she had a hamburger and salad. Another was to do three units of insulin and feed a peanut butter and jelly sandwich or cold cereal with almond milk.

For Mrs. Merrill, the log was a source for her to perform some informal experiments. Because she included various notes at the time, she was able to not just review the numerical values but also the foods and any other annotations she made (such as if it was a new food they were trying). For instance, Mrs. Merrill had

developed some strong beliefs about what foods affected Monica's blood sugar. She was confident that different milks had different influences on her blood sugar, and so she initiated some trial and error to see if it would make a difference. According to her records in her log, it did.

Mrs. Merrill: Oh yeah, going back through the log, I've been noticing that she [Monica's blood sugar reading] was jumping so quickly. Within 40 minutes. I'm usually running up to the school and giving her another injection because she's jumping so quickly, and I'm just going "my gosh". So I decided, plus I knew it was better for her. I switched over to almond milk. And she wouldn't jump as quickly. I mean it was a huge difference.

This was reflective of a continuous process of informal experimentation to figure out acceptable foods for managing Monica's blood sugar. Together, these long-term manual storage systems played several roles. They provided a way for parents to communicate with one another about their efforts to manage their child's diabetes. These logs were seen as structured in that they required certain values to be consistently logged, but were still flexible enough to add annotations with information they thought might be useful to revisit later. When the logs were revisited, they served as individual cases that could inform current next steps, as it had been for Mr. Merrill when deciding on possible foods and dosages for Monica. They could serve as records of informal experiments to see if different food choices made a difference in blood sugar levels. They also could serve as incidental but inspectable records that could reveal why there were unexpected fluctuations in blood sugar levels, as it had been for the Smith family (Family 1). However, they were not reviewed as aggregate data. This is potentially due to an expectation that aggregate data review was the responsibility of clinicians rather than parents.

Parent-Child Conversations With Diabetes Data

Inevitably, families with a T1D child had brief conversations where parents queried young children about their blood sugar levels, what they had eaten, and what would be appropriate insulin dosages. These conversations would happen several times a day, and were an ongoing teaching and learning opportunity. In the data corpus, there were also instances or accounts of conversations where parents talked with children about the quantities that were being encountered and tried to encourage youth to reflect on those values. Two examples are presented below.

Situating Measurements in the Child's Body Experiences

Family 1 was unique relative to other families in this study because they had created an artifact to involve Cort in thinking about data and what the values

referred to when he was in preschool. At that age, Cort was still developing understandings of ordinality and cardinality. Because Mrs. Smith wanted Cort to gain a greater awareness of when his body felt right or uncomfortable, she devised a solution where part of a walkway in their home was repurposed to be a large numerical scale of possible blood-sugar readings increasing vertically (Figure 4). In her own words, she described how this was used before Cort began school:

Mother: This is 100– 200 was the white. It went up to 220 in the blue, that [blue] is a little high and that's [green's] really high and that's [brown] a little low and that's [orange] really low. When we checked his blood, I would have him take this little arrow and tell me where he was and was like “ok you are a little high right now, so this is how your body feels, that is how you feel like when you are high.” The “white was just right”, and “this is how you should feel between 100 and 200.”

Essentially, Cort's mother had created a new cognitive artifact (Hutchins, 1999) to mitigate against the problem of Cort's limited numeracy skills. What would be a basic computational task was adapted to become a perceptual one so that the primary concern for Cort was to identify what “color” band was associated with his current reading. The arrow (attached with a reusable



FIGURE 4 The vertical number scale that Cort's mother (Family 1) created to help Cort develop a sense of what different numerical values represented.

adhesive) had a modifiable location allowed him to see visually where on the scale his levels were. His family had also developed a special mnemonic phrase (“white was just right”) to inform him what should be his targets and what “high” and “low” looked like on the scale.

While this was in many respects simply a number line representation, Cort’s mother was trying to help him detect internally how the subjective feeling of his own body—whether he felt lethargic, distractable, hyper, uncomfortable in certain body parts, etc.—mapped onto an established numerical scale. It was a careful and developmentally appropriate tool for linking what might be called “episodic feelings” (Nemirovsky, 2011) with numerical values. In other literature related to use of self-quantification devices, this routine of mapping bodily sensation to numerical mappings has the benefit of calibrating what numbers should be expected or considered appropriate given how one’s body is feeling (Lee & Drake, 2013). Cort indeed seemed to have developed that intuitive sense, as during a home observation, Cort approached his mother while a researcher was present and said “I feel low”. This led to a check of his blood sugar to confirm he was indeed low.

Quantifying Food

Another type of conversation that appeared across four of the families during observations related to food and what quantities to consider. For example, the following is a representative conversation observed during a home visit with the Nelson family. Earlier, while the researcher was talking with the parents, Phoebe had checked her blood sugar and told her mother that it was 140, which was within the desirable range (~80-180). She decided that she wanted an apple for a snack. Her mother asked her how many carbs it had, which Phoebe reported from memory as 35. However, when Phoebe checked her blood sugar again about an hour after eating the apple, there was an immediate awareness and concern that her blood sugar level was low.

Phoebe: I am at 62 [blood sugar].

Mr. Nelson: Ok, go grab something.

Phoebe: (*Phoebe goes into pantry, then shows him a snack cake*) Can I just have this, Dad?

Mrs. Nelson: (*looks over at Phoebe*) That has 27 carbs so what do you need to stay more between? (*Phoebe does not answer*) 15. Try to find something not so high in carbs. (*pause*) How about a granola bar?

Reluctantly, Phoebe accepted the granola bar. While this brief transaction is partly a case of a child negotiating with a prepackaged snack (Ochs & Kremer-Sadlik, 2013), this conversation was representative of the conversations related to carb and

insulin matching that would transpire during the observations. These involved explicit quantification of carbs and blood sugar and then approximations of what would be appropriate numbers of carbs to raise blood sugar levels from what they were currently to the desired range.

Parents reported that having these conversations served as a recurring opportunity to get the child familiar with how many carbs were in common foods. Also, negotiating over food was an opportunity for parents to reevaluate their understandings and quantifications and do some speculating for when things differed from what they expected. In this example with Phoebe asking to eat cake, the Youngs did not expect Phoebe's blood sugar to drop so low after having eaten an apple. Right after Phoebe took her granola bar, the parents had a quick conversation with the mother saying, "(to husband) That was a big apple. I'm surprised. (*turns to researcher*). This will be a lot of what we do. 'Oh that surprises me, why did she get low?'" (*addresses both husband and researcher*) usually apples are 35 and that was a big apple too. (*turns back to husband*) It is past dinnertime so that might be part of the problem." This transaction illustrates that beyond knowing about carbohydrate counts, they had to also consider other variables, such as portion size and time of day.

Portion sizes were an important ongoing consideration for all families. Another example of portion size considerations comes from the Oaks family (Family 3). When the mother was helping her sons to get lunch ready, the first author saw computations and consideration of portion size taking place. Here, Peter was tasked with determining how many carbs he would be having for lunch and was computing how much insulin he would need to inject before eating.

Peter: What is that soda right there?

Mother: It is left over from the other night when you had a low [blood sugar] and I opened it.

Peter: Can I have some then?

Mother: Yeah. That is going to make your number, 8 oz. of root beer is 46 more. So $52 + 46$.

Peter: How many carbs would it be?

Mother: You add it. $52 + 46$.

Peter: 98. That would be like 4 or 5 units [of insulin].

Mother: We better do 5. It would be closer to $4 \frac{1}{2}$.

Peter gives himself an injection, and the twins finish preparing their lunch. Then Mother comes over to the table as they begin to eat.

Mother: Peter, you poured a little too much root beer. Remember that 8 oz. is a little bit less.

With help from his mother, Peter was being guided through some of the work involved in doing the computations, which he had computed already from looking at the nutrition facts of the bread and peanut butter he was using for his sandwich and

knowing already how many carbs were in a serving from the container of the jam. He also had added in one serving of chips (and counted out how many chips that would be), and some grapes (served in a measuring cup so he could take the right amount). With permission to have root beer, he wanted to know his total carb consumption, and rather than give him a value, her response was “you add it. $52 + 46$ ”. She then helped him determine what would be the proper amount of insulin to deliver, with some precautions included (“We better do 5”). It turned out that he had given himself more than a single serving of root beer, making such precautions prudent. This exchange served as an opportunity to review what a liquid serving size looks like—which lent itself to non-normative approximative pouring (de la Rocha, 1985)—and to practice doing computations he will need to do for the rest of his life.

DISCUSSION

From this exploratory study and the examples shared in this article, we sought to map out portions of the T1D management data catchment. We described a number of data storage systems where data flow into and some of the encounters with data that took place. From these, we observed a few qualities regarding how data were used at home. One has been that there were a multitude of data storage systems that have different lifespans that were used to serve different purposes at different times. Data storage could be used to communicate between two different individuals (e.g., parent and teacher, parent and parent) who must monitor these values and help the child to make a decision about how to respond. They could also serve as an historical record to help in current decision making. Another observation was how personal familiarity with the context that produced the data was used as a resource for talking about and interpreting data. We saw this demonstrated when a family could explain a day of high carbohydrate consumption as being related to a special meal or to continual snacking while traveling.

What was perhaps striking about these uses of data was the general lack of review and conversation around aggregate representations of data. The families and the children rarely looked at data representations that showed several dozens or hundreds of readings in some form of plot or other visual representation. They tended to focus on individual data points and specific moments in time. This is a tendency also documented in formal statistics education research, where individuals will attend to individual data points but not look for patterns and regularities across aggregate sets of data points (Ben-Zvi & Arcavi, 2001; Konold, Higgins, Russell, & Khalil, 2015). That may be something expected of clinicians more than families. However, families were adept at describing aggregates when they were ordered by time and could be situated in specific remembered encounters. While much decision-making relies on individual data points, it may be profitable to find

ways to encourage and support reviews and reflections of aggregate data in families, even when a clinician is not present. We might consider how conversations would change and how understanding about T1D management would differ if more forms of aggregate data representation were incorporated into data routines.

Theoretically, we used the lens of distributed cognition on members of families and on the data artifacts they use and create. We pushed for a view of coordinated cognitive work as extending beyond a lone site and instead being conceptualized as a T1D management data catchment which is established in response to the disruption of disease diagnosis (Engeström & Sannino, 2010). In the formation of the catchment, new pathways for data to flow are established and storage systems of different retention periods form that serve various purposes. The data flows included, but were not limited to, quantifications of servings, carbohydrates, blood sugar levels, and insulin dosages. T1D management is an exceptional case, but we believe data catchments could be articulated for areas that span multiple physical spaces as diverse as personal finance, physical training, and time tracking. It could also be extended to organizations that compile and act upon data for specific aims (e.g., meeting sales goals). It is our hope that this conceptualization of data usage in the wild is productive for the field, and other forms of storage and use may begin to appear in the literature. By documenting these, we increase our vocabulary for how data move, are retained, and are used in the wild. We position ourselves to begin to see regularities with how sociotechnical systems organically learn to manage and act upon data. For instance, a regularity we might see is *deliberation spaces* where data in a catchment are surrounded by routines that involve multiple individuals examining and sourcing collected data. Or, there may be *data bottlenecks* that exist because of limitations with a given technology or with when it is possible for data to be collected and stored. The implication for design in such cases would be that we need to identify what leads to such bottlenecks or how best to support deliberation with data. These are possibilities to be examined in the future. The core commitments one can take regarding data catchments are that they can span beyond singular places, they involve multiple possible streams of data in motion, they eventually orient toward a final goal or purpose, and they have forms of storage and retention along the way.

In terms of thinking about teaching and learning, whether it takes place formally or informally, this study serves as a reminder of the natural ingenuity and resilience people show in response to disruption. Being close to the data that are discussed and having extended histories with data appeared especially useful. In some respects, these are familiar lessons in the learning sciences but are still important enough that they bear

repetition and re-visitation as they appear in a range of settings and contexts.

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