It's Like an Educated Guessing Game: Parents' Strategies for Collaborative Diabetes Management with Their Children

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ABSTRACT

Children with Type 1 Diabetes (T1D) face many challenges with keeping their blood glucose levels within a healthy range because they cannot manage their illness by themselves. To prevent children's blood glucose from becoming too high or too low, parents apply different strategies to avoid risky situations. To understand how parents of children with T1D manage these risks, we conducted semi-structured interviews with children with T1D (ages 6-12) and their parents (N=41). We identified four types of strategies used by parents (i.e., educated guessing game, contingency planning, experimentation, and reaching out for help) that can be categorized according to two dimensions: 1) the *cause* of risk (known or unknown) and 2) the *occurrence* of risk (predictable or unpredictable). Based on our findings, we provide design implications for collaborative health technologies that support parents in better planning for contingencies and identifying unknown causes of risks together with their children.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in HCI**; *Empirical studies in collaborative and social computing*; • **Applied computing** → *Health care information systems.*

KEYWORDS

child-parent collaboration, parent strategies for pediatric patient, type 1 diabetes, chronic illness management, collaborative healthcare technology

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1 INTRODUCTION

Managing Type 1 Diabetes (T1D) requires careful diet management, constant blood glucose (i.e., blood sugar) monitoring, and insulin dosage calculations to keep the patient's blood glucose levels in range. Keeping constant blood glucose levels is crucial for diabetes patients because having blood sugar levels that are too high (hyperglycemia) or too low (hypoglycemia) is detrimental to their health, potentially leading to fatal conditions (e.g., diabetic coma due to hypoglycemia). Managing children's T1D is even more challenging due to their lack of knowledge about illness and insufficient ability to engage in self-care, which makes children rely heavily on their caregivers in the process of managing their chronic health conditions [31, 41].

Chronic illness management in the context of pediatric care has been well-studied in HCI. A number of studies have investigated how to support parents' caregiving tasks for their child's illness management through technological supports [4, 45, 56, 69]; and some studies have focused on supporting patients, mostly adolescents, to improve their communication with their caregivers [17, 18, 60], self-care strategies [47, 49], or self-monitoring [13, 19, 59]. Recently, researchers suggest the importance of studying the family as a unit (i.e., family informatics [43]) in examining how illness management can be shared among the family members [25, 40, 68] as well as how technologies can support the ability of patients and family caregivers to collaboratively manage their illness by tracking data and monitoring their health [38, 57, 66]. However, much is still unknown about specific challenges parental caregivers encounter and how they cope with such challenges for collaborative chronic illness management with their children.

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In this study, we examine how parents cope with various challenges in managing their children's T1D in their daily lives. Specifically, we focus on identifying challenges and coping strategies to avoid potential risks (e.g., blood sugar that is too high or too low) that are harmful to children's health. To achieve this goal, we conducted semi-structured interviews with children with T1D and their parental caregivers (N=41). The child participants in our study were those aged 6-12 because children in this age group can become partially involved in their own care by recognizing and reporting their symptoms and seeking treatment when necessary [61]. Our study results showed four types of parental strategies: educated guessing game, contingency planning, experimentation, and reaching out for help. These four types were categorized along two dimensions: 1) the *cause* of risk (whether the risk factors were known or unknown to the parent) and 2) the *occurrence* of risk (whether the parent considered the risk's occurrence predictable or unpredictable). The term 'risk' indicates the situations in which children have abnormal blood glucose levels that could be detrimental to the children's health. Among the strategies identified, our analysis reveals that contingency planning and experimentation require a higher degree of collaborative work between parents and their children, as they have to work together to plan for contingent risks or detect unidentified causes of risks. Based on the findings, we provide design implications for collaborative health technologies that support parents in better planning for unpredictable risks and identifying unknown causes of risks together with their children. In sum, we make the following contributions:

- We identify four types of parental strategies for managing T1D risks in which the children's blood glucose can fluctuate significantly.
- We highlight the importance of developing parental strategies collaboratively with their child based on parents' knowledge about the cause of risks and the predictability of the occurrence of risks.
- We suggest design implications for collaborative health technologies that support parents in better planning for contingencies and identifying unknown causes of risks.

2 BACKGROUND AND RELATED WORK

2.1 Type 1 Diabetes (T1D) Management

One of the most prevalent chronic childhood disorders worldwide, Type 1 Diabetes (T1D) is typically identified in very young children (between 5-7 years of age) [23]. Patients with T1D have no pancreatic insulin production, which results in high blood glucose levels (meaning high blood sugar) since glucose cannot enter body cells without insulin [42]. Having blood sugar in the high range (hyperglycemia) can cause symptoms like thirst, feeling sick, and urinating frequently, which might cause deadly consequences for the heart and kidneys. Moreover, low blood sugar (hypoglycemia) may trigger symptoms of feeling hungry, tired, and shaky and can potentially lead to fatal conditions such as diabetic coma. As a result, controlling T1D necessitates lifetime therapy to maintain glucose levels in a healthy range.

To maintain their healthy condition, T1D patients and their caregivers must continuously check blood sugar levels using a glucometer or Continuous Glucose Monitor (CGM) device. Many CGM devices are connected to smartphone applications, which allow caregivers to track the child's blood sugar remotely. The app usually shows the current blood sugar level and patterns of blood sugar throughout the day; and it also sends push notifications for low or high blood sugar levels based on the parents' manual settings. Additionally, patients with T1D and their caregivers are expected to count carbohydrate intake in the patient's diet and monitor physical activity to calculate the right insulin dosages. Insufficient insulin dosages can lead to high blood sugar and excessive dosages can lead to low blood sugar [3], which can also lead to deadly health conditions for patients. Thus, patients and caregivers need to make numerous adjustments with insulin injections using an insulin pen or an electronic insulin pump throughout the day [16].

For managing children's T1D, parents are mostly responsible for assuring appropriate treatment and self-care for their child [2]. The parents also often cooperate with the child's other caregivers (e.g., school teachers, school nurses, parapros[1] and children's older siblings), to monitor the child's behaviors and health conditions and provide timely treatments when they are not with their children. Thus, various stakeholders such as parents, children, and other caregivers need to collaborate for children's successful T1D management [22].

2.2 Strategies in Chronic Illness Management

Patients with chronic illness often face numerous challenges due to unfamiliar problems or situations related to their illness [10]. While trying to overcome these challenges, patients try to lessen their knowledge gaps by leveraging their previous experience and developing strategies to better handle such problems in the future [37]. One of the commonly known strategies used by patients to reduce their knowledge gaps is 'sensemaking.' Sensemaking occurs when people face a problem or unfamiliar situation [11] and undergo a process of reasoning that allows them to understand and organize information to make decisions or solve problems in everyday life [50]. For patients with chronic conditions, sensemaking can support their ability to better manage their illness as it requires a thorough understanding of causal events impacting their health [28], through perceiving new data (perception), developing inferences through reflection on the situation (inference), and then carrying out appropriate activities (action) [28]. Throughout this process, patients make sense of their status and become more knowledgeable about their illness management, which can subsequently contribute to better health. While this framework provides valuable insights into how patients with chronic illnesses manage their own health, prior studies mostly have focused on how individual adult patients make sense of their own illnesses.

Informal caregiving work has been well-studied in the HCI and CSCW communities. Previous studies have examined challenges in informal caregiving work within various family care contexts where collaboration and coordination among family members are necessary [36, 64]. In the context of caregiving for children, parents' informal caregiving work was done extensively due to children's limited ability to care for themselves. For instance, common chronic childhood illnesses include T1D, cancer, asthma, etc., and T1D is often diagnosed at a very young age even before children have

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[1] Paraprofessional who helps a child in school 1:1 for managing any care for diabetes

adequate physiological, developmental, and psychosocial skills [63] which makes T1D even more of a struggle for both children and their parents. Thus, child patients are usually unable to manage their condition solely by themselves, and caregiving work for such chronically ill children is essential and necessary for their illness management. For instance, studies have investigated the challenges and practices of caregiving for hospitalized children [36], the caregiving coordination journey across different phases of children's hospitalization [34], and caregivers' responsibilities for children with cancer [56]. In particular, parental involvement is imperative until children become sufficiently independent to assure appropriate self-management [32, 41], as shown in the work by Cha et al., that examined how the involvement of parental support relates to the level of the child's independence in managing their diabetes [6]. Regarding various ways to provide parental support for their children with T1D, Savarese et al., have identified four types of parental approaches for understanding their children's T1D management called 'sense of grip': dynamic, reactive, controlling, and adempitive [54]. The dynamic-type parents take the most hypothetical approach when interpreting data and are flexible about illness management. On the other hand, the adempitive-type parents have the most closed and defined interpretation of data and are rigid with illness management. While these prior studies provide valuable insights into caregivers' own approaches to supporting children, less is known about how parents can collaborate with their children and what kinds of strategies parents develop to work together with them for managing chronic illnesses. More research is needed to understand how the parents of children with chronic illnesses engage in informal caregiving work together with their children in their daily lives.

The majority of the prior work on pediatric patients in the context of chronic illness management centers on adolescent patients. They have examined how pediatric patients communicate with their caregivers [17, 18, 60], how they perform self-care strategies [47, 49], or how mobile health applications can support their self-monitoring [13, 19, 59]. Also, other prior work focuses on the parents' role in managing a child's chronic illness (e.g., cancer, diabetes, asthma), such as parents adapting to illness management [45], adjusting their lifestyle [4], balancing between caregiving and parenting responsibilities [56], and handling different types of caregiving tasks [69]. However, there is very little understanding of how young school-aged children can collaborate with their parents while the parents face unique challenges due to the child's young age and develop strategies to cope with such challenges in their illness management. Our study thus aims to extend prior work by understanding specific challenges parents of children with chronic health conditions face and what types of strategies the parents develop to cope with such challenges and collaborate with their child to better manage their child's health and illness.

2.3 Technologies for Collaborative Illness Management

Researchers in the HCI field have investigated how technologies can support patients and their family caregivers to collaboratively manage illness, revealing that family members' support can positively impact illness management through sharing tasks and developing collective actions together [38, 57, 66]. For instance, for diet management, a mobile food journaling tool called Table Chat was designed to facilitate family support for healthy eating [25]. Panicker et al., investigated how sharing of eating experiences between older adults and their adult children could facilitate family health behaviors [40]. For mental health, Yamashita et al., showed how adult patients with depression sharing their tracked data with family caregivers can help families avoid conflicts while discussing emotionally sensitive problems [68]. Similarly, technologies that support family resilience among multiple caregivers within a family were studied, such as caregiving coordination technologies for lessening 'inter-caregiver information disparity' [35] and augmenting social support practices among family caregivers [33].

A number of recent studies have shown the important need for collaboration between children and their parents by examining how children and their parents collaboratively manage health using tracking technologies in various contexts. For instance, for sleep management, a probe called DreamCatcher was designed to examine the design space of tracking sleep among family members and reported that children can be active tracking contributors [43]. For children's snack management, a mobile application, Snack Buddy, was developed to help parents and children monitor their snacks together by increasing their awareness of snacking practices and promoting positive social support [55]. For promoting the physical activities of parents and children, the use of a mobile application, Storywell, showed that satisfying moments (i.e., bonding, discovery, and educating moments) can affect caregivers' motivation [51]. Similarly, families' experiences with 'Spaceship Launch,' an exercise game (exergame) for promoting the physical activity of parents and children, revealed that family-focused and task-mastery exergames can be helpful [53]. Similarly, another app MOBERO, which assists families in developing healthy morning and bedtime routines for children with ADHD, significantly improved children's independence and reduced parents' frustration levels [62]. For T1D management specifically, MyT1DHero app was designed to assist adolescents with T1D by facilitating communication around diabetes management with their parents [18]. While these studies highlight the importance of engaging children in tracking, current tracker designs provide little agency for the children to participate according to the analysis of the user reviews on nine trackers designed for children [39]. Also, an educational interactive eBook for newly diagnosed T1D children and their families was designed, and researchers found that not only the child but all the family members should be considered co-users of the educational aids because pediatric care requires the collective effort of family members [65].

These prior works have well shown various opportunities for how tracking and monitoring technologies can help collaborative illness management for patients and their parental caregivers. However, we believe more work still needs to be done to provide more details on what types or aspects of collaboration between the child and the parent need to be supported and how to avoid risky situations (e.g., children being in risky states in their health, such as children with T1D having too high or low blood sugar level) in their chronic illness management, beyond addressing the need of

Table 1: Demographic Information of the Study Participants

ID	Participants	Child's Age	Child's Gender	T1D (Years)	CGM or Glucometer	Pump or Pen (Insulin)	Parent's Age	Parent's Occupation
P01	Child, Mother	8	M	3	CGM	Pump	39	Nurse
P02	Child, Mother	12	M	4	CGM	Pump	41	Student
P03	Child, Mother	9	F	6	CGM	Pen	36	Homemaker
P04	Child, Mother	8	F	2	CGM	Pump	42	Homemaker
P05	Child, Mother	10	M	5	CGM	Pump	40	Surgery Scheduler Supervisor
P06	Child, Mother	6	M	1	CGM	Pen	46	CTA
P07	Child, Mother	11	F	4	CGM	Pen	32	Homemaker
P08	Child, Mother, Father	10	M	8	CGM	Pump	42, 43	Teacher (both)
P09	Child, Mother	10	F	6	CGM	Pump	42	Homemaker
P10	Child, Father	8	M	1	CGM	Pen	36	GM Supervisor
P11	Child, Father	7	F	2	CGM	Pump	49	Research Assistant Professor
P12	Child, Mother	7	M	1	CGM	Pen	39	Registered Nurse
P13	Child, Mother	11	M	2	CGM	Pump	45	Retired Air Force
P14	Child, Mother	12	F	1	CGM	Pen	47	Homemaker
P15	Child, Mother	9	F	7	CGM	Pump	45	Architectural Systems Project Manager
P16	Child, Mother	10	M	4	Glucometer	Pen	21	Student
P17	Child, Mother	9	M	1	CGM	Pen	44	School Secretary
P18	Child, Father	12	M	11	CGM	Pump	41	Production Manager
P19	Child, Mother, Father	11	F	1	CGM	Pump	36, 39	Medical Insurance, Operations Manager
P20	Mother	12	F	6	CGM	Pump	49	Self-employed

tracking and monitoring the child's health. Thus, our study aims to understand how parents of children with chronic health conditions perform illness management on behalf of their children in terms of specific challenges and coping strategies to avoid potential risks to their child's health and identify how they can collaboratively manage the illness together with their children.

3 METHOD

Our research effort aims to comprehend the challenges faced by parents of children with T1D and their strategies for cooperative T1D management to prevent or deal with their child's health risk. For this, we performed semi-structured interviews with the children with T1D and their parents. The university's Institutional Review Board (IRB) for Medical Research approved this study.

3.1 Participants

In total, 20 pairs of children with T1D and their caretakers were recruited (see Table 1 for the details of our study participants) and we made an effort to recruit an equal number of male and female children. The children ranged in age from 6 to 12 and each had been diagnosed at least three months before the interview. Each child who took part in the trial had at least one caregiver, and all of the caregivers were parents who declared themselves to be the child's primary caretakers, having responsibility for overseeing the child's health. Both the child and the caregiver spoke English fluently. We advertised our study on a website for healthcare researchers and emailed electronic newsletters to diabetes patients at the university clinic. Additionally, utilizing the database of patients from the university clinic, we sent targeted emails to individuals who qualified for our study. In exchange for taking part in the interview, every child-caregiver pair was given a $25 gift card.

Table 1 presents participant demographics. In total, 41 participants took part in our study. Most of our participants were patients of the university-affiliated hospital in an urban area and had employer-provided health insurance. There were 14 participant pairs with a child and a mother, three participant pairs with a child and a father, and two participant groups with a child, a mother, a father, and a parent since the child was unable to join. The average age of the 11 boys and 9 girls was 9.6 years (median: 10, SD: 1.85). They had T1D for an average of 3.8 years (median: 3.5, SD: 2.84). 12 out of 20 children utilized electronic insulin pumps, and 19 out of 20 children used continuous glucose monitors to manage their diabetes. All the interviews took place virtually using Zoom between February and June of 2021.

3.2 Data Collection

We obtained parental and child consent prior to the interviews. According to our institution's IRB policy, children aged 10 to 12 need written consent to participate in an interview, while those aged 6 to 9 need oral consent. Due to COVID-19 restrictions, all interviews were performed virtually utilizing Zoom. With the participants' permission, video recording was enabled during the interview, and all of the recordings were transcribed for analysis.

The interview sessions for each child-caregiver pair lasted around an hour. Separate interviews with the child and parent were conducted during the session. To learn about the parents' general T1D management strategies, we conducted interviews with the parents first. As some parents of younger children might need to administer T1D treatments such as insulin shots during the interview time, we allowed the parent to decide whether the child will remain nearby or not. Since the child's proximity to the caregiver could affect the parent's responses, interviewers advised that the child wear headphones if they planned to remain close to the caregiver. The focus of the parent interview questions was on how diabetes is handled in daily routines, how parents and other caregivers assist the child with management, and how children are able to engage with self-care skills. We also asked follow-up questions about the problems they experience as well as how they attempt to overcome them. The child interview questions were centered on how they manage T1D, how their parents and other caregivers help them, and what difficulties they have while managing T1D. The questionnaires were designed together with a child psychologist, a nurse practitioner, and a social worker with more than five years of experience working with children with T1D. The participants' demographic data, T1D diagnosis date, diabetes management equipment categories (such as CGM and insulin pump), and EHR data (such as last clinic visit date and diagnosis date) were also gathered. We eliminated all personally identifiable data from the participant data and gave each participant a unique identifier.

3.3 Data Analysis

For analyzing interview data, we used inductive thematic analysis [5] on the transcribed interview material. The transcripts of the interviews were coded utilizing ATLAS.ti Web qualitative data analysis software [1]. Our analysis focused on parents' data because this study, which is part of a larger project, focuses on identifying different types of parental strategies for dealing with risky situations. The first six interview transcripts were open-coded by three members of the study team independently. The codes were then compared and improved in a series of group sessions (examples of codes: parent having trouble comprehending child's fluctuating blood sugar, parent using technology to better monitor the child). We then divided these codes into initial themes about challenges for parents (e.g., emotional, treatment, and educational challenges) and strategies for parents (e.g., being knowledgeable and seeking out social support) for managing a child's illness. When we coded the remaining transcripts, this made it easier for us to concentrate on certain topics relating to the difficulties and strategies of parents. The remaining interview transcripts were then coded by the same researchers. Through weekly sessions, the five authors of this paper regularly discussed the results and any new themes that emerged over the process. The themes were altered after several review sessions until a consensus was reached: for instance, parents' difficulties (i.e., treating a child's fluctuating blood sugar, difficulty understanding the factors that affect a child's blood sugar) and parental strategies (i.e., strategies for predicting blood sugar, strategies for receiving help from others). A number of other themes were revised through a series of discussions until agreement. The difficulty of managing children's risks and the parents' coping mechanisms to reduce these risks were examined using the final themes.

4 FINDINGS

In this section, we provide our study findings on the parental strategies for collaborative diabetes management with their children. Throughout the Findings section, we use P# (e.g., P1, P2) to indicate the parent(s) in the study.

We found that each parent developed and utilized various strategies to cope with the challenges of managing their child's T1D, especially in situations that were risky and detrimental to their child's health. As shown in Table 2, our analysis showed that these strategies could be grouped into four types that varied across two dimensions: the **cause of risk** (whether the risk factors were known or unknown to the parent) and the **occurrence of risk** (whether the parent considered the risk's occurrence predictable or unpredictable). We use 'risk' to refer to situations or events in which the parents had difficulties managing their child's diabetes, leading to their blood sugar levels being too high (hyperglycemia) or too low (hypoglycemia) and potentially leading to fatal conditions (e.g., diabetic coma due to hypoglycemia).

The "cause of risk" is 'known' if the parents know how a certain factor impacts their child's blood sugar level significantly. If the parents do not know much about the factors that could lead to risk, the cause of the risk is 'unknown'. This can happen when parents observe dangerous fluctuations in their child's glucose level but do not know what is causing them. When the occurrence of a certain risk is 'predictable,' the parents can easily anticipate the risky situations that the child may face. Conversely, if the parents have difficulty predicting whether a certain risk will occur, the risk is 'unpredictable'.

4.1 Causes of Risk are Known, and the Occurrence of Risk is Predictable

After year(s) of managing their child's T1D, the parents learned a great deal about the causes and occurrences of risks associated with their child's illness. Some parents were thus quite knowledgeable about the factors that could put their child's health at risk and were able to predict the probability of risky situations. Thus, when the risky situations were predictable with known factors, parents felt fairly confident and comfortable managing their child's T1D. Parent participants frequently referred to an 'educated guessing game' in which they made guesses based on their prior knowledge and learning from illness management.

4.1.1 *Strategy: Educated guessing game.*

To maintain or keep predictable risks under control, parents tried to monitor their child's behaviors on as many occasions as possible. They also communicated with other caregivers, such as teachers and paraprofessionals, by asking for school schedules and detailed information on their child's activities or snacks at school. Using their child's class timetable as well as smartphone applications connected to the child's CGM, parents would remotely monitor their child's blood sugar and try to anticipate any fluctuations in the blood levels. For example, P12 used a schedule to monitor her child's risk, more closely looking out for low blood sugar before and after any activities, which was

Table 2: Four Types of Parental Strategies for Managing Children's T1D

	Cause of Risk: Known	**Cause of Risk: Unknown**
Occurrence of Risk: Predictable	**An educated guessing game** The parents feel knowledgeable and comfortable with the illness management (e.g., constantly monitoring and predicting their child's blood sugar).	**Experimentation** The parents conduct experimentation with their child to discover the risk factors (e.g., restricting their child's meals & activities or exploring more about the possible causes).
Occurrence of Risk: Unpredictable	**Contingency planning** The parents try to plan out their children's diet or behaviors that can impact blood sugar in advance of the risk situations (e.g., planning meals & activities with children, working on action plans with caregivers).	**Reaching out for help** The parents try to figure out the factors of unpredictable risk situations by consulting with experts who are more knowledgeable (e.g., consulting with the clinic or asking T1D communities).

a cause of risk when the child was in school. P12 explained, *"the teacher emailed me [C12's] schedule for his class, so all the specials and all of the lunch schedules and the recess schedule, and then I took that schedule and I put in any time that [C12's] blood sugar would need to be checked, and what the range should be before he could have an activity."* (P12)

Parents also constantly updated their knowledge of predictable risks. For instance, in addition to tracking his daughter's activities based on the school schedule, P11 started to track her mood after realizing that her activity during recess differed daily based on her energy level, which in turn, was determined by her mood. For example, when C11 was happy, she more actively played with her friends, lowering her blood sugar more quickly. Thus, P11 usually asked the school teacher about C11's mood to more accurately calculate the insulin dosage for lunch which was followed by recess. *"The only solution was to communicate with her teaching assistant at school by text and ask her before pre-bolus [giving bolus insulin prior to a meal or a snack] saying how active she was and what kind of mood she was in, and try to make decisions based on that,"* (P11) he explained.

By actively monitoring their child's individual causes of risk, such as activities and moods that are known to impact blood sugar, the parents became more skilled at predicting their child's blood sugar fluctuations. Some parents referred to this practice as an 'educated guessing game,' because they were able to feel confident in their "guesses" in certain circumstances based on knowledge gathered from months to years of illness management. These guessing games were more frequent and more successful among the more experienced parents; we also noticed that these parents continued to constantly update their knowledge because it was not possible to perfectly predict every risk all the time. As P5 said, *"We're never going to be perfect, because we're not [pancreas] and there's no way I can completely think and act like [one]. So yeah, we do our best in educating ourselves and calculating things, and researching stuff and being knowledgeable, but when it comes down to it, it's an educated guessing game."* (P5)

4.2 Causes of the Risk are Known, but the Occurrence of Risk is Unpredictable

Even though the parents were already familiar with the causes of risk that could significantly impact their child's blood sugar, they were sometimes unable to predict whether a certain risk would occur or not. This was because the child's activities or diet were easily influenced by other situational or external factors, or the child simply changed their mind without telling their parents, which made causal events, such as eating sugar or being very active, unpredictable. Thus, the parents would sometimes have difficulties pre-adjusting the blood sugar levels prior to the child's activities, such as exercising. For instance, P11 mentioned that because C11 was very active and frequently changed her mind about what she wanted to do, it was difficult for him and other caregivers to figure out the right insulin dosage. If C11 wanted to be active after her insulin dose, this could lead to low blood sugar. P11 stated, *"You can see that she's not doing anything, and then give her insulin [and] two minutes later, she might decide that it's a good time to go and do jumping jacks. She's an active seven-year-old."* (P11) Thus, for P11, the most challenging part of diabetes management was guessing whether his daughter would be highly active because it could lead to low blood sugar: *"The challenge for us is whether or not she's going to be active. She has some recess and some PE, but it doesn't necessarily mean the activity is going to be intense. So, there's a little bit of a guessing game in this regard to figuring out whether her numbers are too high or too low, and blousing accordingly if she's going a little too high, and making adjustments, and things like that."* (P11)

The unreliable and spontaneous nature of children made predicting risks challenging. *"It's not quite the same as an adult where you know what you feel like; you know what you are going to do, and over time, you have a pretty good idea of how it will affect you"* (P11), P11 noted. *"[I] don't know whether she's going to be in a mood of sitting down and reading a book or in a mood of running around like crazy with her brother."* (P11) Similar to the spontaneous activities described by P11, children often changed their minds about how much and what types of food they wanted to eat during mealtime.

For instance, P9 said that sometimes C9 still felt hungry after eating or didn't want to eat all her food during a meal, which made it difficult to accurately foresee and adjust the insulin dosage for the meal times: *"What [the endocrinology team] wanted us to do with her injections was to give her an injection before she ate so that the insulin could work along with her food. So that became very tough, too. If [C9] was still hungry after a meal, I'd be trying to figure out, well, what can you have at zero carbs? And help her eat more if she was hungry. Or if we gave her too much insulin, and she didn't want to eat, it would be like, I'd be chasing carbs then with something."* (P9)

4.2.1 Strategy: Contingency planning. To deal with unpredictable risks when the risk causes are known, parents developed collaborative contingency plans, such as planning meals and activities together with their children. This involved parents proactively asking their children about what activity they wanted to do or what they wanted to eat and making shared decisions. For instance, before each mealtime, P12 always tried to confirm with her child what he wanted to eat and how much in order to make a proper adjustment to their meal plan: *"We do the carb count and give him the insulin based on the food he's going to eat. So we have to confirm with him that, okay, you're going to eat this ham and cheese sandwich, grapes, your cucumber, and your yogurt, right? If he says he's not going to eat all of that, then we don't want to give him all that insulin. So that's why we have to ask him."* (P12) Some parents also provided options so that their child could make their own choices and would be more willing to stick with them: *"We asked him in the morning if he wants that or if he wants something else with his food, his breakfast. Then he chose and said, 'Mommy I want the apple juice or I want a one-half cup orange or I want that.'"* (P6)

This contingency planning worked better when it was done carefully and in consideration of possible alternative causal events (e.g., the sudden change of the child's behavior or a device failure). In the example of planning a school lunch—one of the most representative parental contingency planning scenarios—children sometimes ended up eating only one item or a smaller portion of the lunch prepared by parents. This could lead to low blood sugar if they calculated insulin dosage based on the total carbs in the prepared meal. To resolve this issue, some parents prepared tools that could help their child with counting the carbs of each item in the lunchbox, so that the child could add the number of carbs in the part of the meal that they wanted to eat and adjust the bolus insulin dosage accordingly. For instance, some created a slip that contained a sliding scale and a breakdown of the carbs in the lunch items. This helped the child more easily calculate the carbs they actually ate. As P20 described, *"We have a slip that I actually had created back when she was in elementary school that I will write on the back what she's having for lunch, a breakdown of the carbs per item in case she changes her mind and that way they can eliminate that carb number. We do a carb count for her and the slip also has her sliding scale on it. So in the event, say, her pump failed and [the caregivers in the school] had to give her a shot of insulin instead, they would know how to handle that for units and things like that."* (P20)

Parents also proactively set up action plans with other caregivers, including the child's teacher, school nurse, or paraprofessional, to better prepare for any risks that might occur. They held regular meetings with them, such as right before the beginning of the school year, to develop an action plan on how to handle risk situations that their child might encounter at school. Additionally, family friends or other parents were sometimes involved in carrying out the plans parents developed. For instance, for sleepovers, some parents trained other parents how to use a smartphone application that tracks their child's blood sugar during the night, so that they could help ensure the contingency plans worked. P13 said, *"We have a couple of friends that have regular sleepovers with him, and so I've added them to his Follow app [Dexcom Follow smartphone application that's connected to Dexcom CGM]. [My friends] can turn on notifications when he's staying the night at their house. Then when he's not there, they just turn the notifications off so they're not getting the notifications all the time. But yeah, we've been very fortunate that our friends have been so supportive."* (P13)

Overall, to manage any unpredictable risk that may occur, parents developed contingency plans collaboratively with their child and other caregivers to better plan ahead for the child's activities or meals. These involved parents confirming the child's plan for meals or activities, or setting concrete action plans for risk situations with other caregivers.

4.3 Causes of Risk are Unknown, although the Occurrence of Risk is Predictable

Sometimes, parents could predict risky situations that might occur based on their general knowledge of diabetes or by recognizing patterns in the blood sugar levels in certain contexts (e.g., a certain time of the day, a certain activity, etc.) although they didn't have enough knowledge to identify the specific causes of the blood sugar change. For instance, P15 explained that since C15'd blood sugar fluctuates a lot during nighttime. P15 was able to predict the night crashes in managing C15's blood sugar despite not knowing the exact cause of the risk: *"[C15's] blood sugars look like a rollercoaster, and it just happens to be that because the night is a longer time period that she goes without being checked, also at this time, she tends to crash more."* (P15) Many parents also mentioned that they expected more fluctuations in the child's blood sugar level when the child played a certain sports activity although they were unsure of how exactly the combination of factors like the duration of exercise, activity level, weather, etc. would impact the child's blood sugar. P12 mentioned, *"Because activity can cause changes in your blood sugar, and it definitely affects C12's. Like when he plays outside for long periods of time, or swimming, or when he plays baseball, bike riding, things like that."* (P12) Thus, even though the parents could generally predict that the child's blood sugar will fluctuate significantly, it was challenging to calculate insulin and correct the blood sugar level because the combinations of factors can impact their blood sugar differently.

Moreover, as children are continuously growing, the parents knew that various changes related to the child's development (e.g., puberty) were causes of risks that can impact blood sugar. Although these were predictable risks, it was challenging for parents to understand how these causes (e.g., changes in hormones, moods, or the body) could actually affect blood sugar. Parents complained about how difficult it was to deal with various changes during the child's growth. P20 said, *"she's grown almost an inch every three months for the last two and a half years. So that's been a big factor for us because* *she's growing so quickly."* (P20) Similarly, P5 noted, *"[T]ake all of the great calculations you've done with your endocrinologist and throw them out the window because that's how things work during puberty. Nothing makes sense. During growth spurts, it's like, I don't know. We just had to recalculate all of his stuff because he got older and bigger and he's growing."* (P5) As C5 was going through puberty, his established T1D management practice no longer worked, as some of the factors known to cause risks were now different. Thus, the child's growth and hormonal and physical changes required the parents to explore and identify the new, unknown causes that could impact their child's health. Also, even with the same recognized causes, the parents had to readjust their insulin calculations because their child's body would react differently than it used to. Thus, parents were able to anticipate situations that would be a general risk to their child while still trying to figure out the actual causes leading to the situation and how to respond to them. This was particularly difficult for parents of children who were growing fast, like C20.

4.3.1 Strategy: Experimentation. To cope with the unknown causes of risk and their child's individual differences, parents performed their own experiments, such as restricting choices and sticking to what works, making small adjustments, and trial and error, in order to decrease the uncertainty until they gained more knowledge. Some would intentionally restrict their child's diet and activities to minimize the risks as much as possible. For example, P13 created a list of foods that did not make her child's blood sugar fluctuate much: *"[The food list] helps us know what foods work, like what he likes that's low carb, whether it's the Cappello's pasta or the Magic Spoon cereal. And then we've started getting him Fairlife Milk instead of regular milk because it's only six carbs a cup as opposed to twelve. Once we find something that works, we just stick with it."* (P13) We also found that some parents were more restrictive with their child's activities, such as limiting play dates, to reduce potentially risky situations. As P18 said, *"We were [sometimes] more restrictive in his activities because we just didn't know how his diabetes was going to affect a particular event."* (P18)

At the same time, other parents tried to keep things simple and make small adjustments as needed, especially when the occurrence of risks was predictable, like with playing sports. For instance, once P13 noticed the high fluctuations of C13's blood sugar during sports, she tried to keep dinners low-carb to lessen the impact of meals on her son's blood sugar, even though she had no idea about the actual cause. Another predictably risky situation was the shift to summer since many new changes could be expected, including daily routines. For example, P19 was planning to adjust the correction level during the summer season because it was predictable that C19 will be much more active during the summer: *"Summer, we're a lot more active. We own a boat that we're out on the water pretty much every weekend and she's swimming and lots more friends and running around. So we're just getting into that part of the season, so already we started doing this whole all right, minus 10 carbs. If it's 45 for dinner, we're only doing 35 to try to offset so that we don't go to lows."* (P19) Like this case, parents were expected to better manage their child's blood sugar by making small, simple adjustments because the risk was predictable, even though they had no idea about what the exact cause might be.

Similarly, parents were also careful not to make too many changes in insulin in a short time, because it could make things more complex due to increased sources of causes that could lead to risks and make decisions on treatment harder. P20 noted, *"I like to try to watch and see, okay, if she's rounding, let's see if she's going to humpback over and come down. [We are] not changing too much all at once because then you don't know if you change a correction factor and a basal rate, which thing didn't work or which thing worked where you're going, 'Okay. Well, I changed two things but I don't know which thing to change back.'"* (P20) By lessening changes in the insulin adjustments, parents and children could figure out the trend of blood sugar better without added complexity from the insulin change.

As parents gained more experience with T1D management, they actively sought a better solution by employing trial-and-error to explore new causes (e.g., foods and activities). This led parents to explore the unknown causes in collaboration with their children to seek a better, more workable solution. P17 explained how much effort it took for her and C17 to figure out the right treatment for C17 to play hockey. Since the risk of low blood sugar during hockey practice was predictable, they tried to find out how exactly his blood sugar would change as a result of the sport. During practice, C17 was willing to continuously check in with his mother to test and adjust his blood sugar whenever needed. She said *"we had to test him like every 20 or 30 minutes. It took us a couple of weeks. We had to stop during his practice, check where he was, and adjust. And then after a couple of weeks of doing that, we started to see patterns that we noticed right away that he [his blood sugar] drops very quickly in hockey. So we learned that we've got to get his blood sugar up before he even goes out on the ice. And we only knew that from doing it. We have to just keep an eye on him and adjust it as needed."* (P17) Through several rounds of their experimentation, C17 and P17 figured out how hockey impacted C17's blood sugar in detail. She also noted how trial and error required the active involvement of C17 because it was a long-term effort and that parent and child both needed to cooperate to find out the most optimal, workable solution: *"So that's a little bit tricky. That's something that we just have to trial and error. And different sports are different. He plays soccer right now, but that doesn't take as much out of him as hockey."* (P17)

4.4 Unknown Causes of Risks when the Occurrence of Risk is Unpredictable

Even though the parents tried their best to manage their children's diabetes, there were always times when things did not make any sense for either the parents or child, and they had no idea about the potential causes of risk, and thus were unable to predict the risk at all. This was more common for those whose children were in the early stages of their T1D diagnosis, but even experienced caregivers often felt confused since their child's blood sugar could fluctuate due to many different factors, including activity level, stress level, diet, and mood, making it difficult to predict risk. Several parents mentioned that they sometimes felt that their child's levels spiked or plunged without reason (P5, P12, P13, P15, P17, P19). P12 said, *"He can have the same food, the same activity, and his blood sugars will be completely different on two different days."* (P12) Additionally, varying combinations of the different factors made it even more challenging for parents to figure out the actual cause of their child's blood sugar change, as seen in the case of C13 whose levels sometimes went high in the morning. P13 noted, *"There's been a few times, like I said, for whatever reason, his numbers in the morning are always high [. . .] I don't know if it's the combination of breakfast, the morning time, the gym class, the time to get to school. I don't know. If I knew what it was, I would fix it so it wouldn't be high all the time."* (P13) P13 suspected those morning highs could be due to the combination of contextual factors such as time, breakfast, and school in the morning but was not sure how exactly the activities impacted the sugar level or how to treat it.

The individual differences of each child also led to confusion in identifying the cause of the risk since the impact of a particular factor on blood sugar is different for everybody. That is, even though there could be a general rule of thumb about how things work universally, the actual impact might vary from person to person. For this reason, many parents could not rely on what others said about the impact of different activities and food. For example, P20 described her child's certain reactions at odd times, which she was unable to relate to any specific cause: *"I did have to do it myself manually and give her a little bit of insulin because she also is one of those kids that about four hours after she eats dinner sometimes, we will just get this weird jump. And I don't know if it's that her body's just taking that long to process her food, and then, whether it's a protein that drives her up four hours later because it is always so weird to me, 'Why four hours after she's eating are we seeing this spike in blood sugar? It doesn't make any sense to me.' So the only thing we're coming up with is that it's a reaction to either, say, her body's still breaking down some of that part or it's a reaction from the protein."* (P20) In this case, P20 noticed an unusual jump in C20's blood sugar level four hours after dinner. She thought that either C20's digestive process or the food's protein might have caused this weird spike but was unsure because these do not normally impact the levels of other children.

4.4.1 Strategies: Reaching out for help. To better prepare for unpredictable risks due to unknown causes, parents consulted with their clinicians or sought help from online communities to learn more. A consultation with an endocrinology team was the most common strategy to cope with risk when the blood sugar was frequently out of range. For instance, P20 was also unable to find the exact causes of C20's low levels in the morning which were unpredictable, and thus, consulted with an endocrinology team routinely. She said, *"One thing that we find is that if I correct [C20's blood sugar] too much in the morning then she drops low by lunchtime. So we've been working on her numbers with her endocrinology team to try to determine how to kind of get her through the day. So we have it set up."* (P20)

Even with the consultations, it was sometimes difficult for the parents to find out the exact causes of risk and when it will happen because it varies by each individual and there are so many contextual factors involved. To overcome these challenges, some parents actively sought advice/answers in Facebook groups that included parents of children with T1D in order to deal with their child's challenges with unpredictable risks. For example, C20 ran cross country, but the exercise setting in the pump did not work because the child frequently went low during the workouts in unpredictable ways. To better understand the causes of the low level and how to treat it, she asked Facebook communities for parents of children with T1D: *"I wanted [C20] to be able to complete a meet without me having to run alongside her and embarrass her or anything like that. I belong to three different Type 1 diabetic parent Facebook groups and I just sent a message out on each one and said, 'Any of you that have middle schoolers who are in cross country, would you be willing to share with me how you handle blood sugars during their practices and meets?' I got great feedback from a lot of them."* (P20) With several different suggestions from other parents, P20 could better understand the causes of C20's lows during cross country and work towards optimizing treatment for her child.

5 DISCUSSION

5.1 Making Sense of Risk in Collaborative T1D Management

In the findings, we uncovered four types of parents' strategies for managing various risky situations in which a child's blood sugar might fluctuate: an educated guessing game, contingency planning, experimentation, and reaching out for help. Through these strategies, we found that parents tried to explore unknown causes, anticipate risks, and develop plans to mitigate the impacts of unforeseen risks. In chronic illness management, patients' efforts and learning processes of understanding the cause and impact of the illness have been well studied in the prior literature through the lens of sensemaking. Sensemaking is a theoretical domain that seeks to identify cognitive processes that people use to organize information for making decisions and/or solving problems [50]. In the area of sensemaking for chronic illness management, Mamykina et al. distinguish between the sensemaking mode and the habitual mode of self-management [28]: the sensemaking mode occurs when it is difficult to manage the circumstance with the current level of knowledge, whereas the habitual mode is characterized by routine behavior wherein people can make decisions based on their knowledge and experience. In our study, we observed that parents engaged in the habitual mode as they became more knowledgeable about risks. By performing an 'educated guessing game' described by our participants, they were better aware of the causes and the occurrences of the risks. When they became more comfortable with T1D management, they eventually were better prepared for contingent risks based on their knowledge of the factors that impact blood sugar.

Our study findings also show how parents make sense of their child's chronic illness in a collaborative context. Compared to adult patients who engage in sensemaking to deal with their own diabetes management [12, 28], in our study, parents of children with T1D transition between sensemaking and habitual modes on behalf of their child due to the child's young age and insufficient ability to self-care [31, 41]. Moreover, the fact that children are easily influenced by situations and change their minds about what they are going to do (activities) or what they are going to eat (diet), can impact their blood sugar levels in unexpected ways. Thus, collaboration with their children is necessary and crucial for parents. In particular, 'contingency planning' and 'experimentation' require extensive collaborative work between children and their parents, as those strategies cannot be carried out by parents themselves but need their children's involvement to plan for contingent risks or discover unidentified risk causes. As seen in our study, parents and children collaborate to explore the unknown causes of risks through experimentation with the potential causes that could impact the child's blood sugar (e.g., sports and foods). During experimentation, parents mostly relied on their own (general) reasoning to determine how the causal factors impacted blood sugar. This is because children may have difficulties understanding the mechanisms at play and the reasoning required. Rather, children were involved more as proxies because carrying out treatment requires the actual involvement of the child. Children's engagement throughout the experimentation was especially crucial because oftentimes, the process involved several rounds of trial-and-error to find out the optimal action plan. Comparatively, even during their habitual mode in which the causes of risks are (generally) known and the occurrence of risks are (generally) predictable, maintaining the educated guessing game for managing T1D requires the least, but still some amount of collaborative work between children and their parents.

The majority of sensemaking literature focuses on past events because sensemaking largely involves reflection on past experiences. However, some studies suggest that dealing with future events is crucial for better managing chronic illness [14] and argued for the aspect of anticipatory thinking and projecting into the future within sensemaking [44]. For instance, Katz et al. introduced the concept of Fluid Contextual Reasoning (FCR), which is a combination of sensemaking and habitual modes [21]. In FCR mode, patients make in-the-moment decisions with increased awareness of how factors that impact their illness relate to the past, present, and future and navigate through a time continuum. Our study analysis also indicates that parents are heavily engaged in FCR mode in predicting certain risks that may happen in the future and developing contingency plans together with their child, even though they are not completely sure when those risks will happen. Developing plans for contingencies collaboratively with their children is essential for parents to deal with unpredictable occurrences of risks, even when the causal factors are known because children are often unpredictable and easily influenced. As seen in our study's examples of collaborative meal planning (e.g., giving the child options to choose what they will eat and how much they will eat, providing guidance on how to count their carbs in case the child ended up eating differently), active involvement of the child is imperative to collaboratively work on contingency planning and needs to be maintained throughout the entire planning process.

5.2 Parental Approaches for Strategies in Collaborative T1D Management

Previous studies on informal caregiving suggest that patient care involving multiple caregivers is often challenging due to the complexity of maintaining awareness, coordinating handoffs among the caregivers [64], and inter-caregiver information disparity [35]. While studies revealed the main challenges among caregivers, our findings revealed challenges parents faced when taking care of their chronically ill children. One of the biggest challenges for parents was finding out the causes of high or low blood sugar levels. It was often challenging for parents to accurately pinpoint what factors (e.g., child's diet, activities, mood, etc.) caused the child's blood sugar to go up or down, and how much those factors impacted it. To overcome this challenge, parents conducted experimentation that involved children throughout the process. Interestingly, this experimentation ranged from limiting changes of the potential causes (restrictive) to exploring more about the unknown factors (exploratory).

According to the regulatory focus theory, there are two approaches to performing tasks to achieve a certain goal [15]. One is prevention focus, which is characterized by the motivation to accomplish goals through the avoidance of failure. Another is promotion focus, which is characterized by the motivation to accomplish goals through achieving a certain gain. In our study, some parents tried to accomplish the goal of lessening fluctuations in their child's blood sugar by restricting the child's activities (e.g., playing with friends) and foods (e.g., high-carb snacks) to avoid the causes of risks as much as possible. These practices were closer to the prevention focus since they were trying not to face risk by reducing potential causes. On the other hand, others tried to further explore the unknown causes by trying out new foods or monitoring the child's blood sugar during the child's sports practice. These practices were closer to the promotion focus, as parents attempted to better adjust and make changes to the child's activities or diet.

We also noticed that parents were more promotion-focused as they became more knowledgeable about their children. In the beginning, it was challenging for parents to explore new causes due to a lack of knowledge about the regimen and their child's uniqueness. However, as they became more skilled through the trial-and-error processes, parents were better prepared to leverage their additional knowledge to try new methods. Mamykina et al. showed that patients can also abandon the habitual mode to construct new inferences [27]. Likewise, in our study, parents became more experimental when they tried to explore or anticipate more causes that could impact blood sugar. Through this process, parents could better provide treatments for their own children by finding out unique causes that impact the child's blood sugar. Still, they were cautious about changing things too much because it could increase the complexity of interpretation. That is, exploring more factors by experimentation could potentially lead to more risk if they were not ready to interpret situations well or if other factors could add complexity. Thus, when parents perform experimentation to identify unknown factors, they also try to avoid making too many changes because it could be harmful to the child. Thus, balancing between exploratory and restrictive strategies was also crucial for maintaining children's health.

Apart from how parents' motivations and goals relate to parental strategies, other studies identified how parents take different approaches to describe their child's illness. Savarese et al., identified four types of parental approaches for children with T1D, or the 'sense of grip' in four levels: dynamic, reactive, controlling, and adempitive [54]. The dynamic-type parents take the most hypothetical approach when interpreting data and are flexible about illness management. On the other hand, the adempitive-type parents have the most closed and defined interpretation of data and are rigid with illness management. Our study showed that parents who are closer to dynamic-type tend to explore unknown factors and prepare for risk with contingency plans. Moreover, even though the parents became fairly knowledgeable, they remained motivated to identify more causes and occurrences of risks by doing an educated guessing game. Thus, the parents attempted to keep their children actively involved throughout the management process.

Recently, an increasing body of literature highlights how 'self-experimentation' can help patients be more knowledgeable about and better manage their illness [7, 20, 24]. While prior studies on self-experimentation focused on the individual work of carrying out experiments and exploring more factors that may impact the outcome, our study extends these investigations by examining how parents do so in a collaborative setting, as parents need to conduct experiments with their children to derive an optimal treatment. As children are generally too young to carry out their own experiments, they were mostly involved in these experiments as proxies, by following their parents' instructions about what to do in the practice. However, as they became more independent, they were more aware of what was happening in the experimentation and recognized that they should support their parents. A previous study on dyadic collaboration in illness management [6] showed that children gradually transition toward a higher level of independence as they became more knowledgeable of and motivated to perform self-care. Most of the children started with a lower level of involvement as a proxy in experimentation because of their young age and fewer self-care skills. This suggests that as children become more independent through greater knowledge and parental help, they will gradually become more involved in understanding how the experimentation is conducted and actively seek better action plans.

5.3 Design implications for Technologies Supporting Collaborative T1D Management

5.3.1 Supporting collaborative contingency plans. For developing these contingency plans, one of the biggest limitations of current diabetes self-tracking tools is providing actionable information that could help future decision-making rather than showing historical data [21]. That is, the diabetes tools should be both informative and actionable [46]. Thus, by utilizing contingency plans that are already in place and shared by caregivers, technologies can be designed to better support developing new contingency plans with more actionable guidelines. For instance, parents could upload their contingency plans represented by a set of action plans (e.g., if something happens, then this should be done) for probable risk situations. Then they could also share those plans with other parents of children with T1D, and compare those plans with their own if there are any missing parts or other aspects which require further consideration. As the child's data accumulates, the system could also provide more personalized suggestions for developing better contingency plans.

In our findings, developing contingency plans was mainly led by parents, as understanding the whole process of risk could be challenging for children. However, in order to better manage their health, children must also become more knowledgeable about contingency plans as they become older and more independent. Thus, education tools for collaborative illness management can support this gradual transition of children's participation in the process. For instance, based on the child's self-care level, the system could recommend steps for the parents on how children might help them plan for any contingencies. When children are young and lack self-care abilities, the system could start by teaching habitual practices, which are easier for children to learn and understand. Then as children become more involved in their T1D management, the system could support children as they learn about contingency plans by providing possible risk situations and suggesting ways to resolve those issues. A prior study developed a web-based educational tool to provide coping interventions for the parents of T1D children [67]. However, we argue that children's involvement is also crucial for making both better use of such coping strategies and a better sense of risky situations. A study conducted by Saksono et al. examined how a parent-child storytelling tool can encourage families to reflect on their physical activity and help lead to family behavior change [52]. Applying this concept of family-based intervention to collaborative contingency planning, a storytelling tool could enable children to engage in learning different types of coping interventions and help children share their thoughts and emotions with their parents to develop their own contingency plans together.

To develop a shared understanding of the contingency plans among the child's caregivers, parents remotely communicated throughout the day with other caregivers (e.g., school teacher, nurse, parapro, etc.) about the child's T1D management. By sharing the child's school schedule, moods, activities, etc. with each other, they tried to prepare for any unpredictable occurrences of risks. Existing studies have suggested that systems designed to help contingency plan sharing could enable efficient communication among caregivers. For instance, Shin et al. showed how a mobile application could support caregiver collaboration by increasing mutual understanding of strategies [58]. Similarly, Neustaedter and Brush designed a linkable family calendar, 'LINC', through a participatory design process with families. They found that awareness of the family members' activities and changes in their tasks while working on the calendar enable coordination among the family members [29]. Building upon these prior studies, we suggest that a coordination tool for caregiver groups can be designed to better support relevant coordination processes and mutual awareness in developing and following contingency plans. For instance, the tool could suggest several scenarios of potential risk situations (e.g., a child's pump not working, or the parapro not being able to help the child in the school) based on the child's background information (e.g., whether the child is using the pump, and whether the parapro is helping the child in the school) so that they could better envision risk situations and plan for them. Then, the group of caregivers in the network could brainstorm possible ways to resolve these issues and come up with potential solutions. Later, when the relevant risk situation occurs, the group of caregivers for the child can send out a notification to other caregivers so that they could better be aware of those situations and act together promptly according to the pre-set contingency plans. By doing so, parents and other caregivers could effectively communicate and carry out treatment in any contingent risk situations.

5.3.2 Supporting collaborative identification of the causes. Identifying the causes of risk was challenging for parents because there are several factors (e.g., activity, diet, mood, etc.) that can impact blood sugar, and the extent to which these factors impact blood sugar levels varies by person. In practice, the children were mostly engaged as proxies for providing their data to their parents, especially when they were young and less knowledgeable about T1D. To lessen the burden on parents and enable more effective identification of causes of risks, a system could support children in tracking their moods or activities to make better projections about blood sugar levels. For instance, Pina et al. showed that children could actively collaborate with their parents in tracking their moods [43]. If the children are too young to track their own data, the system could alternatively support remote caregivers (e.g., teachers, parapros) in tracking data. Furthermore, technology could utilize historical data collected from other devices (e.g., Fitbit, dietary logs) or contextual resources (e.g., weather, school schedule) to help parents more accurately identify factors that may significantly affect the child's blood sugar. This could help to overcome current limitations in insufficient contextual information in current diabetes self-tracking tools [21, 48, 49]. For example, let's say the system analyzed that the child's blood sugar became elevated during school recess when it was rainy because the child felt gloomy. Thereafter, when the child is at school and it starts to rain before recess time, the system could warn the parent that the child's blood sugar may go up, so that the parent could keep their eyes on monitoring or adjusting blood sugar level. Furthermore, the system could also make suggestions by comparing the child's data with that of other children in similar conditions (e.g., age, weight, personality, etc.). For instance, in the cases of children who just started going to school, some of them may have higher blood sugar due to the higher level of stress, while others may have lower blood sugar due to higher activity levels. By comparing a child's data with that of other children, the system could better recognize and suggest factors that are more meaningfully related to the individual child.

As parents became more confident about their diabetes management and knowledgeable about potential risks, they explored more factors that may significantly impact the child's blood sugar by conducting experimentation. To support this, technologies could recommend possible guidelines for conducting such experiments, especially for those with little to no personal analytics experience who may not be able to analyze data or run self-experiments on their own [8]. For instance, 'SleepCoacher' was developed by Daskalova et al. to support people's self-experimentation by providing personalized automated sleep recommendations [9]. For diabetes management, Mamykina et al. developed a system to recommend a list of behavioral triggers that users can experiment with [26]. As users become more knowledgeable, a system can support them with self-experimentation by creating their own personalized behavior-change plans [24]. Karkar et al., developed 'TummyTrials' to support patients with irritable bowel syndrome (IBS) in designing, executing, and analyzing self-experiments to evaluate whether a specific food triggers their symptoms [20].

While these previous works have focused on individual adult patients carrying out self-experiments, for the context of pediatric illness management, children's involvement is crucial yet challenging because experimentations need to be collaboratively conducted by children and their parents. As children are young, it could be challenging for them to engage in the experimentations properly because they may not fully understand how the experiments should be done or why such experiments are needed. Thus, collaborative experimentation is necessary between children and parents so that parents can help their children get involved in experimentation, and a system can support their collaboration to lessen the challenges. Building on the prior work by Neustaedter et al. that investigated how families used calendars for coordinating tasks with each other [30], we suggest that the system could be designed like a collaborative experimentation tool. Since it could be difficult or unsafe for children to engage alone in the experiments or design their own experiments when they are still young, the tool could first start with recommending easier and age-appropriate experiments based on children's temporal blood sugar patterns. For example, if the system recognizes that the child's blood sugar is sometimes high after breakfast on Saturdays, it could recommend a simple experiment for Saturday morning, such as having a less heavy breakfast or waking up at a regular weekday time. These recommendations could be first reviewed by the parents to see if they are appropriate for their child's ability and applicable to the family's daily routines. Such recommendations already screened by parents then could be shared so that the child could choose the option that they would like to try out. Then, the system could provide relevant step-by-step guidelines for the parents and their child to follow together. This way can help increase the child's engagement since the recommendations are more suitable for the child's level of understanding and preference. Furthermore, we suggest the system could create concrete guidelines at different levels for child-parent pairs, especially for younger children who might have insufficient knowledge about their illness. For instance, younger children could be guided with less involvement in the experiment, while older children could be involved more. As children grow familiar with these experiments, the system could help them understand why such options were being recommended so that they could learn and even try designing their own experiments eventually. After the children have carried out the suggested actions, they could input the results of these experiments, helping the system provide more optimal suggestions. As their data accumulates, the system would be able to provide increasingly personalized and actionable solutions.

5.4 Limitation and Future Work

Our study results on the parents' strategies for handling the risks of children with T1D might not apply to all facets of children with chronic illnesses. Further study is required to examine parents of children with other chronic illnesses (such as cancer and asthma) to see if they exhibit similar strategies for illness management. The results of this study are based on children aged 6 to 12 because we only included pediatric patients in this age range. While studying this age group provided valuable insights into how parents carry out various strategies for children of this age range, older children (adolescents and young adults) or very young children (under 6 years old) may show differences through future studies. In addition, we recruited most of our participants from the urban clinic at the university, and most were fairly well-educated with medium-high incomes. While this allowed us to understand how the families utilized various resources for collaboration, our findings may not capture other challenges faced by families of low-socioeconomic (SES) status who may have additional barriers to health management such as financial constraints and limited access to healthcare.

Thus, further research is needed to understand more diverse family types, including those of low-SES.

Management of children's illnesses involves not only parents who are the children's primary caregivers, but also other caregivers from the family, the school, and other locations. This is because parents collaborate actively with other caregivers in the household (such as siblings), at school (such as teachers, paraprofessionals, and school nurses), or in the clinic (such as doctors and nurses). Thus, these individuals' strategies might differ from that of the parents.

Finally, COVID-19 caused most outside activities and in-person school schedules to be disrupted between February and June of 2021, when our data was collected. The participants' responses to questions about different strategies they performed to manage risks or the methods used when parents were away from their children may have been influenced by these circumstances, even though our study focused on parents' strategies in daily activities.

6 CONCLUSION

Keeping blood sugar levels within a healthy range is difficult yet crucial for diabetes patients because abnormally high or low blood sugar can be detrimental to their health. Managing children's T1D is even more challenging because they cannot manage their illness by themselves, which causes them to face more risks when their blood sugar levels fluctuate significantly. To investigate how parents of children with T1D try to avoid these risky situations, we conducted semi-structured interviews with children with T1D (ages 6-12) and their parental caregivers (N=41). Our research revealed two dimensions that are significant for categorizing parental strategies: 1) the cause of risk (known or unknown) and 2) the occurrence of risk (predictable or unpredictable). Based on these two dimensions, we identified four types of parental strategies: educated guessing game, contingency planning, experimentation, and reaching out for help. Of these strategies, contingency planning and experimentation require more collaboration, as they involve planning for potential risks or uncovering the causes of unknown risks. Our findings provide design considerations for collaborative health technologies that can support parents in better planning for contingencies and identifying unknown causes of risks with their children.

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