Shared Responsibility in Collaborative Tracking for Children with Type 1 Diabetes and their Parents

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ABSTRACT

Efficient Type 1 Diabetes (T1D) management necessitates comprehensive tracking of various factors that influence blood sugar levels. However, tracking health data for children with T1D poses unique challenges, as it requires the active involvement of both children and their parents. This study aims to uncover the benefits, challenges, and strategies associated with collaborative tracking for children (ages 6-12) with T1D and their parents. Over a three-week data collection probe study with 22 child-parent pairs, we found that collaborative tracking, characterized by the shared responsibility of tracking management and data provision, yielded positive outcomes for both children and their parents. Drawing from these findings, we delineate four distinct tracking approaches: *child-independent*, *child-led*, *parent-led*, and *parent-independent*. Our study offers insights for designing health technologies that empower both children and parents in learning and encourage the sharing of different perspectives through collaborative tracking.

CCS CONCEPTS

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

KEYWORDS

child, pediatrics, type 1 diabetes, T1D, chronic illness management, probe study, health tracking, child-parent collaboration, collaborative tracking, collaborative healthcare technology

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1 INTRODUCTION

Patients with Type 1 Diabetes (T1D) need to maintain their blood glucose within a healthy range with ongoing monitoring and adjustment. Alongside tracking blood sugar levels, it is important for T1D patients to observe external factors that influence blood glucose, which are often unique to each individual. Factors such as sleep, exercise, and carbohydrate intake directly impact blood glucose, but their effects are influenced by variables such as activity intensity and duration [72]. Thus, efficient management of T1D requires tracking and monitoring various factors affecting blood sugar levels.

However, tracking the health data of children with Type 1 Diabetes (T1D) presents distinct challenges, as it necessitates active participation from both the children and their parents. Given that many T1D patients are diagnosed at a young age, they often lack the experience, knowledge, and independence needed to manage their health effectively. This creates a dependence on collaborative efforts with their parental caregivers to oversee their diabetes care [10]. Even with parental involvement, it remains crucial for children with T1D to learn how to independently monitor their data and take charge of their health management. This way, they can smoothly transition from reliance on caregivers to self-sufficiency in their management approach.

In recent years, there has been a growing focus on 'family informatics', emphasizing the importance of collaborative care within the home for patients and their family caregivers [15]. Researchers have explored how technologies can facilitate collaborative illness management for patients and their family caregivers. Their studies reveal that the involvement of family members can significantly improve illness management by distributing tasks and devising

collective strategies [13, 41, 49, 60, 74]. Recent research has also highlighted the critical role of collaboration between children and their parents in managing health through the use of tracking technologies, covering areas like sleep [48], snacking [57], and physical activities [54, 56].

However, there is a limited understanding of how young school-aged children engage in collaborative tracking with their parents to monitor their health-related data. Previous research in collaborative tracking has focused on family members tracking their own data, often concentrating on specific types of information (e.g., sleep, snacks, etc.). Moreover, these studies were more centered on guiding caregivers in working with children to establish and reinforce healthier habits. While these studies provide valuable insights into how families offer mutual support in tracking and collaborating, there remains a relatively unexplored area regarding the extent to which children can take a more active role in the collaborative tracking of health-related data, and how this involvement can be supported, particularly for children with chronic conditions like T1D. Specifically, there is a lack of understanding about how responsibilities might be shared between child and parent in their tracking process and the benefits derived from such collaborative efforts.

In this research, we investigated how children with chronic health conditions and their parents collaborated to track and manage the children's health data using a lightweight paper+digital tracking system we designed as a technical probe [25]. We conducted a three-week probe study involving children aged 6-12 with T1D and their parents (N=44). The age group of 6-12 was chosen as children in this range can begin to take some responsibility for their own care by recognizing symptoms and seeking treatment when necessary [65]. Our findings showed that collaborative tracking, characterized by shared responsibility in tracking management and data provision, had positive outcomes for both children and parents, such as increased self-care in children and improved parent-child communication. We also identified four distinct tracking approaches: *child-independent*, *child-led*, *parent-led*, and *parent-independent*. Among these, child-led and parent-led tracking required more collaboration due to increased communication and discussion between children and parents. This led to benefits like enriched learning opportunities for children and a mutual understanding of the tracked data. Even in child-independent and parent-independent tracking approaches, mutual support was valuable, as children often required assistance with reminders or validation of their logs from their parents. Data solely tracked by parents sometimes exhibited gaps or inaccuracies, which could be addressed with input from the children. Based on these findings, we propose design guidelines for collaborative health technologies tailored to children with chronic illnesses and their parents. These guidelines aim to empower both children and parents with learning and promote the sharing of different perspectives, ultimately enhancing the tracking and management of children's health-related data for better health outcomes. In summary, our contributions include:

- Identifying four types of tracking approaches between children and their parents in collaborative tracking.
- Highlighting the challenges, strategies, and benefits associated with each type, dependent on their shared responsibilities in tracking management and data provision.
- Offering design recommendations for collaborative health technologies to assist children and parents in more effectively tracking children's health-related data.

2 BACKGROUND AND RELATED WORK

2.1 Background: Type 1 Diabetes Management

Type 1 Diabetes (T1D) is one of the most common chronic disorders among children worldwide. It is typically identified and diagnosed in very young children (between the ages of 5 and 7 years old) [33]. Patients with T1D do not have pancreatic insulin production, resulting in high blood glucose levels [47]. Due to this challenge, adequate control over T1D necessitates lifetime therapy for glucose levels to remain in a healthy range. In addition to tracking blood sugar levels, it is helpful for patients of T1D to monitor external factors that can impact blood glucose and that are typically individualized to the patient. For instance, sleep, exercise, and carbohydrate intake are all directly related to blood glucose, but are also highly dependent on variables such as activity intensity or duration [72]. Adequate self-monitoring of blood glucose prior to physical activity or carbohydrate intake, and adjusting insulin doses accordingly, alleviates the risk of too high or too low blood sugar levels [36].

To properly self-monitor factors related to T1D and maintain a healthy blood glucose range, patients must continually track these factors through medical devices (e.g. glucometer or Continuous Glucose Monitor (CGM)), smartphone applications, or other mediums such as spreadsheets and paper trackers. Medical devices and applications typically contain information on current blood sugar levels and patterns throughout the day, which is information that many patients use to supplement the additional variables they choose to monitor, such as physical activity and carbohydrate intake, in order to calculate insulin dosages correctly [4] and make adjustments using insulin pens or electronic insulin pumps throughout the day [20].

However, since many patients of T1D are diagnosed at a young age, they lack the experience and understanding to ensure proper treatment of their health. This creates a reliance on collaboration with their parental caregivers when navigating their diabetes care management. Despite parental involvement, it is important for children with T1D to learn how to self-monitor their data and take responsibility for their health management to ensure an efficient transition between dependence on caregivers and independence in management [10]. Parents also often cooperate with the child's other caregivers (e.g. school teachers, nurses, and the child's siblings), to monitor the child's behaviors and health conditions to provide adequate treatments when they are not directly with their child. Thus, various stakeholders need to collaborate in order to achieve successful management of the child's T1D [31].

2.2 Collaboration for Chronic Illness Management

Informal caregiving work, extensively studied in the HCI and CSCW communities, addresses challenges in family care contexts that require collaboration and coordination among family members

[40, 68]. Parents take on extensive caregiving responsibilities for children with chronic illnesses, such as T1D, due to the child's limited self-care abilities. This is especially significant in the case of T1D, as it is often diagnosed in very young children before they have developed full physiological, developmental, and psychosocial skills [67]. The demands of handling T1D management, including careful diet control, continuous blood glucose monitoring, and insulin dosage calculations, exceed the capabilities of young children [19, 58]. Consequently, adult caregiving for these chronically ill children is essential for their illness management. Studies have examined various aspects of caregiving for hospitalized children [40], the coordination of caregiving during different phases of hospitalization [39], the responsibilities of caregivers for children with cancer [59], and psychological facets of collaboratively managing health through data [30]. Parental involvement is crucial until children reach the level of independence necessary for appropriate self-management [38, 46], and the level of this involvement must also correspond to the child's existing levels of independence [10].

Studies reveal that children's increasing involvement in self-management is largely influenced by their age. In the preadolescence period, typically spanning ages 9-14 depending on pubertal onset [17], children experience a growing sense of autonomy and independence [14]. Consequently, as these young individuals begin to take on a more significant role in disease management, the responsibility for diabetes care gradually shifts from parent to child [6, 32]. However, current research also underscores that adolescents often grapple with adherence to self-management, which can lead to a decline in glycemic control [5, 26], as they may assume responsibility for T1D management before they possess the maturity to handle it [43]. Hence, it is crucial for caregivers to transfer responsibility at appropriate times, ensuring that children have demonstrated proficiency in managing diabetes-related tasks.

The majority of previous research on pediatric patients in chronic illness management has primarily focused on adolescents. Studies have explored various aspects, including communication between pediatric patients and their caregivers [21, 22, 64], co-designing meaningful representations that support patients' communication [23], the implementation of self-care strategies [52, 53], and the potential support provided by mobile health applications for self-monitoring [18, 24, 63]. Additionally, other studies have delved into the role of parents in managing their child's chronic illness, addressing areas such as managing risk in children's health [11], adapting to illness management [51], adjusting their lifestyle [7], balancing caregiving with parenting responsibilities [59], handling various caregiving tasks [76], and facilitating effective communication with children [60, 61].

However, there is limited understanding of how young school-aged children collaborate with their parents in tracking their health-related data within informal caregiving contexts. Specifically, there is a lack of knowledge about how they share responsibilities in this tracking process and the benefits they derive from such collaborative efforts. Therefore, our study seeks to bridge this gap by investigating the benefits, challenges, and strategies employed by children with chronic health conditions and their parents as they work together to track and manage the children's health data.

2.3 Technologies for Collaborative Health Management

Recently, there has been a growing emphasis on 'family informatics', highlighting the importance of collaborative care within the home environment for patients and their family caregivers [15]. This shift is driven by the rising prevalence of chronic illnesses and a heightened interest in preventive health [16], as well as the recognized positive impact of family support on illness management [41, 50, 69, 73].

In contrast to personal informatics studies, which explore individual self-tracking tools for health data collection, family informatics advocates for digital health tools that facilitate collaborative monitoring and data sharing within families. By viewing the family network as a multi-agent system with distributed cognition, these tools address various family needs, including sensing and monitoring, communication and sharing, decision-making and action-taking, as well as treatment and prevention of illness [15]. Several studies assert that self-care technologies should empower both patients and their caregivers to participate in illness management, mirroring their everyday life dynamics [13, 41, 49]. This approach can also foster patients' independence in managing their illness, a co-constructed effort involving choices and activities within the care network, comprising patients, caregivers, and clinicians [9].

Researchers in the HCI field have investigated how technologies can facilitate collaborative illness management for patients and their family caregivers. Their findings indicate that the support of family members can significantly enhance illness management by distributing tasks and developing collective strategies together [13, 41, 49, 60, 74]. For example, a mobile food journaling tool named Table Chat was created to promote family support for healthy eating [34]. Yamashita et al. demonstrated how adult patients with depression sharing their tracked data with family caregivers could help navigate emotionally sensitive discussions and prevent conflicts [75]. Similarly, Panicker et al. investigated how the exchange of eating experiences between older adults and their adult children could foster family health behaviors [44]. Tsvyatkova et al. introduced an interactive educational eBook developed by researchers to assist newly diagnosed Type 1 Diabetes (T1D) children and their families in learning illness management. They found that all family members should be considered co-users of the educational materials, as pediatric care necessitates the collective involvement of family members [70]. To support shared illness management between adolescent patients and their caregivers, it is imperative to acknowledge physical and emotional experiences in the context of daily life. Systems should enable families to collaboratively track patients' experiences while accommodating individual tracking preferences [24]. These studies suggest that technologies tailored for patients and their families can enhance their collective knowledge and comprehension of the illness, facilitating discussions and joint decision-making among family members.

Recent studies highlight the crucial role of collaboration between children and their parents in managing health through the use of tracking technologies across various contexts. For example, in sleep management, the DreamCatcher probe was created to explore the potential of tracking sleep within families, revealing that children can actively contribute to the tracking process [48]. To monitor

children's snacking habits, the mobile application Snack Buddy was developed, encouraging parents and children to track their snacks together, fostering awareness of snacking practices, and promoting positive social support [57]. When it comes to promoting physical activities for both parents and children, the use of the Storywell mobile application demonstrated that fulfilling moments, such as bonding, discovery, and educational experiences, can impact caregivers' motivation [54]. Similarly, experiences with the 'Spaceship Launch' exergame, designed to enhance the physical activity of parents and children, revealed the efficacy of family-focused and task-oriented exergames [56]. Additionally, the MOBERO app, aiding families in establishing healthy morning and bedtime routines for children with ADHD, notably enhanced children's independence and reduced parents' frustration levels [66]. In the specific context of Type 1 Diabetes (T1D) management, the MyT1DHero app was tailored to assist adolescents with T1D in communicating about diabetes management with their parents [22].

While prior studies have demonstrated the potential of tracking and monitoring technologies in facilitating collaborative illness management for patients and their parental caregivers, there remains a need for a more in-depth exploration of how children and their parents share responsibilities in tracking children's health-related data. Previous research on collaborative tracking has largely concentrated on family members tracking their own data, often focusing on one specific type of data (e.g., sleep, snacks, etc.). Additionally, these studies were more centered on guiding caregivers in working with children to establish and reinforce healthier habits. While these studies offer valuable insights into how families provide mutual support in tracking and collaborating, there remains a relatively unexplored area concerning how children can be more actively engaged in the collaborative tracking of various types of health-related data for children, especially those with chronic conditions like T1D.

3 METHODOLOGY

The goal of this research study is to determine the benefits and challenges of collaborative tracking experienced by children with T1D and their caregivers. We conducted a three-week probe study, using a data collection probe (a lightweight paper+digital tracking system) customized for participants' tracking preferences [25]. The purpose of using a technological probe in this study was to provide a simple and flexible tracking method for children and their parents. This approach allowed us to better understand their needs and desires while tracking their data. Before tracking, participants were given the opportunity to choose their tracking topics and features during the initial interview through a 'probe customization session.' This allowed the probes to incorporate participants' varying needs based on their lifestyles and children's health conditions, facilitating improved data collection.

The study, which included a first interview before tracking and an exit interview after tracking, involved children between the ages of 6 and 12 years old and their parental caregivers. This study was approved by our university's Institutional Review Board (IRB) for Medical Research. Consent was obtained from both the parents and the children prior to conducting the interviews. In accordance with our institution's IRB policy, children between the ages of 6 to 9 provided verbal consent, and children between the ages of 10 to 12 provided written consent. All interviews took place virtually via Zoom video conferencing between July 2022 and February 2023 due to COVID-19 precautions. Given participant consent, video recordings were taken of each interview session and transcribed for analysis.

3.1 Participants

We recruited 22 pairs of children with T1D and their caregivers. Inclusion criteria for recruitment are shown below in bullet points. A gift card of $75 was offered to each participant pair as compensation for completing the study.

- Children's ages: between 6 to 12 years old
- Children's diagnosis of T1D: diagnosed at least three months prior to participating in the study
- Children's caregiver: parents who declared themselves to be the child's primary caretakers and are responsible for the child's health, and one caregiver of each child needs to participate
- Both the children and the caregivers are fluent in English
- Dexcom Continuous Glucose Monitoring (CGM) device users, which allows the research team to collect and overlay visual data of the participant's blood sugar levels with their tracked data. This is used for participants to review their data after tracking each week.

Several channels were used for participant recruitment, including our university's recruitment website for healthcare researchers, as well as electronic newsletter blasts to diabetes patients at the university clinic. Additionally, targeted emails and text messages were sent to eligible patients using the university clinic patient pool. The participant demographics are displayed in Table 1. In total, we had 44 participants (22 child-parent dyads). Out of the 22 children, 15 were male and 7 were female. The average age of the children was 9.6 years (median: 10.0, SD: 1.71). On average, the children were diagnosed with diabetes 3.4 years earlier (median: 2.0, SD: 2.38). To manage their diabetes, 15 of the 22 children used an electronic insulin pump (Omnipod or Tandem) and 7 children used an insulin pen. Five of the children were also diagnosed with additional chronic illnesses, such as ADHD or celiac disease, during the time of participation.

3.2 Our Probe Design

For the probes used in the study, we prepared a basic framework before the interview. While the probe itself did not include collaborative features, the collaborative aspect was embedded in the study design to allow observation of its emergence as a result of the study. Participants actively chose tracking methods, materials (paper vs. app), and topics through discussions. Weekly reports were provided to facilitate collective data discussions. To cater to participants' existing management styles, we prepared two versions of the probe for them to choose from: an electronic probe and a paper probe. The child and the caregiver were both allowed to select their preferred mediums. The electronic probe was designed in the Ethica application–a clinical trial and health research software platform [2]. The probes included T1D-related tracking topics, including activities, insulin, meals, moods, symptoms, and sleep, as they are known to

Table 1: Demographic information of study participants

ID	Child Age	Child Gender	T1D (Years)	Pump or Pen (Insulin)	Parent Age	Parent Gender	Parent's Occupation
P01	9	M	4	Pen	33	F	Content Writer
P02	7	M	2	Omnipod Dash	46	F	Homemaker
P03	9	M	4	Pen	40	M	School Principal
P04	12	M	7	Tandem t:slim X2	41	F	Surgery Scheduler Supervisor
P05	12	F	2	Tandem t:slim X1	37	F	Birth and Postpartum Doula
P06	11	F	6	Pen	36	F	Homemaker
P07	7	M	1	Pen	41	F	Administrative Assistant
P08	11	M	3	Omnipod 5	43	F	Director of Business Management
P09	8	F	4	Tandem t:slim X2	50	M	Research Assistant Professor
P10	9	M	2	Pen	35	F	Student
P11	9	M	1	Pen	33	M	Service Manager
P12	12	F	2	Omnipod Eros	35	F	Medical Assistant
P13	11	M	9	Tandem t:slim X2	44	F	Teacher
P14	8	F	1	Omnipod 5	37	F	Office Manager
P15	10	M	2	Tandem t:slim X0	37	F	Office Worker
P16	7	F	4	Tandem t:slim X1	42	F	Office Assistant
P17	7	F	2	Pen	44	F	Physical Therapy Assistant
P18	10	M	2	Omnipod 5	39	F	Head of Customer Success
P19	11	M	1	Omnipod 5	51	F	Homemaker
P20	10	M	2	Omnipod	31	F	Realtor
P21	10	M	8	Omnipod 5	31	F	Development Manager
P22	11	M	6	Tandem t:slim X2	47	F	Teacher

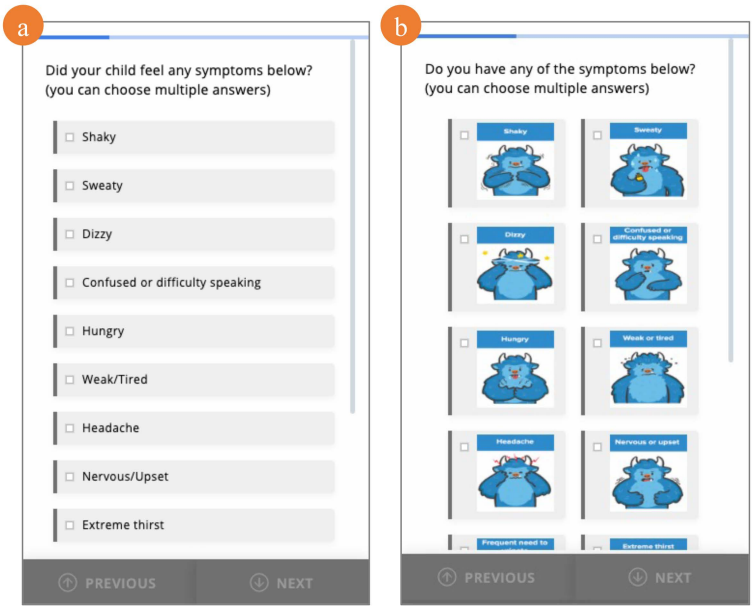

Figure 1: Symptom log in the Ethica app for (a) parents vs. (b) children – Symptoms are listed in text for parents whereas they are shown in characterized figure & texts for children

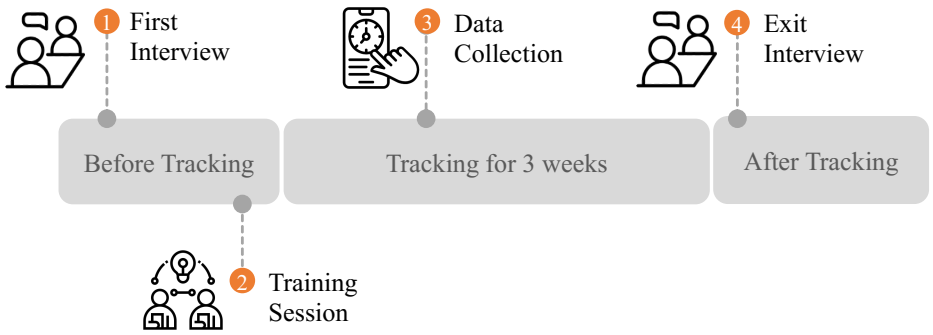

Figure 2: Study procedure in four phases – (1) first interview (1 hour), (2) training session a day before tracking (30 minutes), (3) data collection for three weeks, (4) exit interview (1 hour)

be directly related to blood sugar levels [37, 71]. We also provided basic components for each topic. For instance, the activity tracker included a list of activities that the child frequently engages in and the start and end time of the activity. The insulin tracker contained the time, dosage, and type of insulin (basal or bolus). The meal tracker contained time and the number of grams of carbs for each meal. The mood tracker contained time and eight types of moods (e.g., happy, sad, nervous, etc.). The symptom tracker contained time and a list of common symptoms (seven symptoms related to high blood sugar levels and eight symptoms related to low blood sugar levels). The sleep tracker contained times for when the child went to sleep and when they woke up, and a rating for the quality of their sleep on a five-point Likert scale from 'very bad' to 'excellent'.

To track data in Ethica, participants answered a series of questions per topic. For instance, if a child chose to track their symptoms, they would need to specify the symptom they felt, providing the time of day they experienced the symptom. The questionnaires also had the option of providing additional context via a text box, image attachment, or audio messages. In order to facilitate engagement in the children, their probes were designed to be more child-friendly (Figure 1), including images with characters to visually demonstrate certain terms used in the probes (e.g. a character exemplifying the symptom shaky, sweaty, etc.). Ethica sent out three notifications a day to the participants reminding them to track (once in the morning, once in the afternoon, and once in the evenings). The times that these notifications were delivered were customizable to cater to participants' daily schedules. The paper probe gathered the same information but lacked the notification, audio message, and image attachment features.

3.3 Study Procedure

The study procedure included four main phases (Figure 2). The first interview (one hour) was divided into three parts: the parent interview, the child interview, and the probe customization session. After the first interview, members of the study team created the probes, either in the Ethica application or as a printed PDF file, and scheduled a 'training session' with the participants. The training session lasted approximately 30 minutes and helped prepare participants to track for three weeks. Once this was completed, participants began the three-week data collection period. During their final week of tracking, the study team scheduled the exit interview (one hour), which was divided into a parent interview, a child interview, and a weekly report review session.

3.3.1 First Interview. The first interview consisted of a parent interview (20 minutes), a child interview (10 minutes), and a probe customization session (30 minutes). After an introduction to the study, we interviewed the caregivers for 20 minutes. As some parents needed to administer T1D treatments such as insulin shots during the interview session, we allowed the participants to decide whether the child would remain present during the parent's interview. We asked the caregivers questions to better understand the family's past and current diabetes-related data-tracking practices and challenges they experience while tracking this information. Questions included "What kind of information do you collect for managing your child's health?" and "Who is involved in tracking this data?". Next, we interviewed the children for ten minutes to gauge their level of involvement and comfort with T1D management and their tracking practices for diabetes-related information. Questions included "Have you used a journal before?" and "How do you track your blood sugar level?".

After the interviews, we used the remaining 30 minutes to introduce the probe study and help participants customize their probes. To facilitate the child's understanding of the probe study and the benefits of tracking diabetes-related information, we provided a fictional scenario that visually demonstrated probe usage and data tracking. The scenario involved a persona (a character named Anna) to depict a situation in which a child with T1D experiences daily difficulties related to diabetes and uses a probe to overcome them (Figure 3). Participants were then directed to choose either the paper probe or electronic probe and to select three to four topics to track with at least one shared topic between the parent and the child based on their preferences. To help them with this process, we provided the following default options: activities, symptoms, sleep, meals, insulin, and moods. Participants were allowed to adjust the topics to fit their learning desires, for instance, in addition to tracking insulin, one participant tracked irritation of insulin sites as well. In total, there were seven caregiver-child pairs that selected to both use the paper probe, 11 pairs who selected to both use the electronic probe, and four pairs where the parent selected the electronic probe and the child selected the paper probe (Table 2).

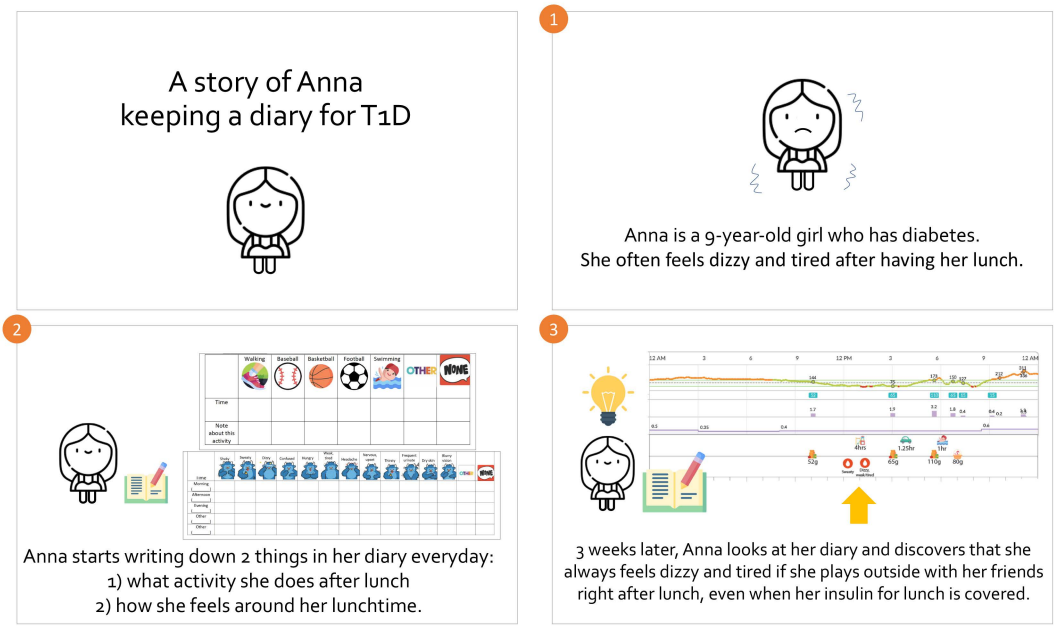

Figure 3: Three scenes from the scenario shown to children during the probe customization session: (1) introduction of a character Anna, (2) Anna starts using her diary, (3) Anna reviews her data and finds out new insights about her symptoms

Table 2: Choices of the probe format (paper or app) and the tracking topics for children and their parents

ID	Child probe	Parent probe	Child topic	Shared topic	Parent topic
P01	Paper	Paper	Activity	Symptom	Sleep
P02	Paper	App	Activity	Meal	Symptom
P03	Paper	App	Activity	Meal	Insulin
P04	App	App	Mood	Meal	Sleep
P05	App	App	Symptom	Meal	Moods, Pump Site
P06	App	App	Symptom	Meal, Insulin	Sleep
P07	App	App	Sleep	Meal, Mood, Insulin & Site, Mood	NA
P08	App	App	Sleep	Mood	Meal
P09	Paper	App	Activity	Symptom	Sleep
P10	Paper	App	Mood	Insulin Site	Symptom
P11	App	App	Activity	Mood	Meal, Symptom
P12	Paper	Paper	Activity	Sleep	Meal
P13	Paper	Paper	Moods	Meal	Sleep
P14	Paper	Paper	Moods	Meal	Pump site
P15	App	App	Symptom	Mood	Sleep
P16	App	App	Pump Site & Issues	Meal	Sleep
P17	Paper	Paper	Meal	Insulin & Site	Symptom
P18	App	App	Activity	Mood	Meal, Pump Site
P19	Paper	Paper	Activity	Meal	Sleep
P20	App	App	Activity	Symptom	Meal
P21	App	App	Activity	Pump Site & Issues	Moods
P22	Paper	Paper	Mood	Activity	Meal

3.3.2 Training Session. After the probes were created, the study team scheduled the training session for the participants. This was a 30-minute long meeting where the study team walked each parent and child through their respective probes. We first had the participants install the Ethica app using a registration code and participant ID to access their unique trackers. Next, we provided hypothetical scenarios to both the parent and the child to walk them through an example of one full day of logging. For the child, the scenario guided them through a hypothetical occurrence of their tracked topic, prompting them to log a given time of day and information about the topic (e.g. "Let's say you felt sad at 9 AM. Please fill out the mood tracker"). A similar scenario was provided for the caregiver to walk them through each topic as well as the end-of-the-day survey. If either the child or the parent chose the paper diary, parents were also guided through a paper tracker submission process, as they were responsible for providing photos of the paper tracker via Ethica.

3.3.3 Data Collection. Throughout the three-week-long period, each caregiver and child tracked and submitted their chosen topics each day via Ethica. If the participant chose to log electronically, they would fill out the logs sent to them via Ethica. If they chose to log on paper, they would manually write down their responses, and at the end of the day, the caregivers would upload photos of each paper log to Ethica. In addition to this, the study team collected information on how each day of tracking went for the participants (if they learned anything new or experienced any challenges) through the end-of-the-day survey in Ethica. In situations where either the parent or child forgot to log up to two days in a row, a study team member reached out to them via email to remind them to track daily and to mitigate any technical difficulties they may have encountered. At the end of each week of the study, a study team member created a weekly report based on the participants' tracked data using Adobe Illustrator to help the participants visualize their tracked data and pinpoint patterns (Appendix A). These reports were mailed electronically to the participants and made available via Ethica, along with a weekly report survey designed to gauge whether the participants viewed and discussed the report.

3.3.4 Exit Interview. Following the completion of the data tracking period, each participant pair took part in a final exit interview, which lasted one hour. We first interviewed the parent for 30 minutes, then the child for 15 minutes, and used the remaining 15 minutes to review each weekly report with both the parent and child. During the parent interview portion, children were once again allowed to remain in the room at the choice of the parent to accommodate T1D care needs. We asked the caregivers questions to gather information regarding their overall experience with collaborative tracking. Questions included, "Did your child ask for help while recording their own data?", "How did you and your child work together?" and "Did you notice any differences between your tracked data and your child's tracked data?". During the child interview, we asked questions to understand their level of involvement with and understanding of the tracking process. Questions included, "Were you able to use it alone or did you prefer to get help from your parents?" and "Did you have any difficulty while tracking any of the topics?" Questions focusing on challenges experienced, benefits gained, and lessons learned were also asked to both participants.

In the weekly report review session, the study team members walked the participants through each week of their tracked data using the weekly reports. During this time, we asked participants questions to learn how they utilized the reports and if they learned anything new about the child's diabetes. For example, "Did you have any discussions with your child about the data?", "Did you notice any patterns from looking at the data?", etc. If there were notable disparities between the child's and parent's tracked data, we also asked them to explain why this may have occurred.

3.4 Data Analysis

We analyzed the transcribed first and exit interview data using inductive thematic analysis [8] to identify themes among the responses. These transcriptions, as well as other additional data such as weekly reports and data collected through the survey answers from the end-of-the-day survey and the weekly report survey, were coded using ATLAS.ti computer-assisted qualitative analysis software [1]. The first 6 participant pairs' interview transcripts and supplementary data were open-coded by three authors of this paper independently. These codes were discussed and adjusted through an interactive process between the three researchers, as well as the other study team members. We then developed a codebook to categorize each code into a broader theme, such as tracking effort, tracking strategy, child independence level during tracking, tracking motivation, etc. The remaining 16 participant pairs' transcripts and data were divided among the same three researchers and coded using the finalized codebook. Through weekly sessions, the five authors of this paper regularly discussed the results and any new themes that emerged throughout the coding process before finalizing the codebook. Once all thematic coding was completed and the themes were finalized, the researchers used these themes to develop the framework for the different types of tracking between children with T1D and their parents. These are presented in the findings section. The summary of the analysis of participants' log data (e.g., number of days logged and log entries) is shown in Appendix B.

4 FINDINGS

The collaborative tracking of children's Type 1 Diabetes (T1D) yielded several benefits for both children and parents, such as improved self-care in children, increased T1D knowledge, and enhanced communication skills. As children received help from their parents for tracking, they acquired specific T1D management skills (e.g., symptom recognition, carb calculation) and demonstrated increased awareness of T1D management. As parents acquired data from children, parents found value in gaining deeper insights into their children's subjective data (e.g., mood, symptoms, sleep quality), which provided new perspectives on children's abnormal blood sugar levels.

During the study, parents and children shared responsibility for tracking in different ways, resulting in unique challenges, strategies, and benefits associated with different tracking configurations. These collaborative arrangements varied across two dimensions:

Table 3: Four types of tracking based on the responsibility for tracking management and data provision

		Responsibility for Data Provision	
		Child	Parent
Responsibility for Tracking Management	Child	Child-independent	Child-led
	Parent	Parent-led	Parent-independent

1) **responsibility for tracking management**, and 2) **responsibility for data provision** (Table 3). Firstly, either the child or the parent took responsibility for managing tracking overall, including maintaining the log and performing the actual recording. Secondly, either the child or the parent was responsible for providing data, since the individual responsible for tracking might not have had all the answers independently. The necessity for shared responsibility in tracking data between children and parents arose from the age range of the children in our study, which spanned from 6 to 12 years. In this cohort, children needed parental support in data collection, while parents required their children's input for accurate tracking. In the paper, we use identifiers such as P# (e.g., P1, P2) to refer to specific parents and C# (e.g., C1, C2) to indicate children in the study.

4.1 Child-independent Tracking

When children had the skills and knowledge to independently log their health-related information, they took responsibility for tracking management and filled in the information in the tracker by themselves. This was typically observed among older children who exhibited greater self-confidence in tracking. Parents of these children had a high level of trust in their children's ability to manage their own data, and they often tried to encourage their children's independence in tracking without imposing pressure on them. Children of this type demonstrated confidence in their tracking abilities, without requiring assistance from their parents. For instance, C15 remarked, *"I do it by myself. I didn't really need any help"* (C15), and C20 mentioned, *"I prefer to do it by myself because it's quick, easy, and not really difficult. I don't think I need my parents to help me with that"* (C20).

Parents also supported their children in carrying out independent tracking, as they observed their children's competence and diligence in recording data. For example, P20 mentioned, *"Whenever I heard the sound [from the Ethica push notification], I noticed how responsive he was, and he talked about it all the time. So, I didn't need to inquire because he was consistently providing feedback that he was doing it"* (P20). Parents generally had high trust in their children for tracking and keeping their data.

Some parents intentionally allowed their children to be independent in tracking because they wished to foster their children's independence through the tracking experience and encourage their honest responses. P4 mentioned her desire for C4 to become more independent through the study: *"I gave him full trust in that, that was his to do and I wanted him to put it in without me hovering over-correcting him or saying, 'No, that's not how you feel'. And because the goal again is to get him to be more independent. So him doing that work I think was helpful in that"* (P4). P22 noted that she wanted C22 to provide honest answers, refraining from checking his responses: *"I wanted C22 to feel like he could be completely honest and so I would hand him the paper. He would take care of it and I didn't try to adjust anything because that's how he felt. That was his response and I wanted to respect what he said"* (P22). Thus, children had less parental control and experienced fewer feelings of surveillance, as parents willingly entrusted tracking and data retention responsibilities to the child.

4.1.1 Challenges. Despite their independence in tracking, some children frequently forgot to log their data or made mistakes while recording information such as incorrect or missing data. For instance, C6 acknowledged, *"I'm not that good at remembering stuff"* (C6). C18 mentioned that he struggled to differentiate between noon and midnight, saying, *"I sometimes made mistakes because I accidentally made the app say that I logged my activities all day because I didn't know if it was 12:00 PM or 12:00 AM"* (C18). P9 noted that C9 did not understand the need to add timestamps to the symptom tracker, explaining, *"So she at first didn't quite get that she was supposed to put the time on it"* (P9).

Several parents expressed concerns about their children's overconfidence or their own inability to assess whether their children were tracking accurately, especially if there were discrepancies in data recorded between the child and the parent. C4 learned to estimate carbohydrate counts during our study and displayed confidence in his own estimates, stating, *"I'm not too bad at estimating food carbs, so I just put in what I thought it was"* (C4); however, P4 noticed discrepancies between the child's estimation and hers, believing that the child's estimations could be inaccurate. Additionally, C6 thought her blood sugar levels were better because she experienced fewer symptoms, even though P6 perceived her numbers as unfavorable. C6 explained, *"Oh I just kind of took a second. And how am I feeling right now? I usually probably 95% I had no symptoms because I've been having better numbers I guess"* (C6). P11 and P18 were also uncertain about whether their children tracked accurately during the study: *"He says that he did well, but I'm not 100% sure"* (P11); *"So he just did it on his own whenever he felt like it, and hopefully did it well"* (P18).

4.1.2 Strategies. Parents employed several strategies to overcome challenges associated with child-independent tracking while maintaining support for their children's tracking efforts. Some parents tried to remind their children to track throughout the day

or checked-in with them at the end of the day. P21 explained, *"I would do reminders throughout the time period to make sure that C21 was getting it done when it needed to be done, and he was pretty responsive to that whenever he needed those reminders"* (P21). We also observed that some parents gradually reduced their reminders as their children demonstrated competence. One parent noted, *"I reminded him throughout the day, but towards the end I just gradually stopped asking him knowing that he knew what to do"* (P8).

Instead of constant reminders, some other parents established routines to check if their children tracked during the day. For example, P15 said, *"I'd ask him, 'Hey, did you do it today?' and he'd respond, 'Oh yep, I did it'"* (P15). Another parent, P18, shared, *"At the end of the day, we always have a checklist we run through right before bed. It's like, 'Is your homework done? Did you study for your test? Did you brush your teeth?' [...] We added to that, 'Did you log your information?'"* (P18).

A few parents were more involved in ensuring that their children collected information accurately by reviewing the logs to identify any missing parts. For example, C13 would receive reminders from P13 due to incomplete meal logs: *"Yes, because most of the time, I sometimes forget smaller parts of a meal, and then my mom will remind me, like, 'Oh wait, you had an apple with lunch' or whatever"* (C13). P9 also reviewed the child's log at the end of the day and prompted the child to complete any missing sections: *"Some of it she wrote after the fact because I reminded her that she had forgotten to log it"* (P9).

4.1.3 Benefits. When children were responsible for their own tracking, they experienced several benefits. They developed an increased awareness of T1D management, gained self-confidence in their management abilities, and felt comfortable about being entirely independent throughout the study, experiencing less strict parental control or surveillance. In some cases, children developed improved sleep and eating habits and became more knowledgeable about the various factors influencing blood sugar levels.

Several children noted that they became more aware of their T1D management needs as they logged independently, as exemplified by C4: *"I'm more focused. I'm reminding myself, well I got to change my pump and stuff earlier. I was able to change my Dexcom [CGM device] by myself"* (C4). Parents also observed their children becoming more self-aware about their care throughout the study. P18 noted, *"I think what I observed was he became a lot more articulate about remembering to turn on activity mode [in the insulin pump], remembering to eat some snacks before going to practice. I think that the act of tracking just made him subconsciously more aware of the control he has over his diabetes management. And I saw him taking more ownership, he was checking in with me to make sure I was doing things. So I started doing less and giving him more responsibility. So I think that was an outcome"* (P18).

Some parents mentioned that complete independence is quite rare for children with T1D, as parental involvement is needed in most aspects of daily care. Therefore, the feeling of independence and confidence toward self-care during this study was a significant benefit for the children. P20 expressed, *"This [tracking] was something that he can do completely independent and by himself and I can tell that he really enjoyed that. It was his own thing and so that was a really positive outcome. I wasn't expecting, I felt good about that"* (P20). C11 echoed this sentiment: *"I like doing it by myself"* (C11), and C22 appreciated his mom's non-invasive approach to tracking: *"I feel more independent, so I'm not forced to do it. It's on my own will, around when we usually go to bed. [...] I wasn't under that much pressure"* (C22).

Through their experience of tracking independently, some children also developed better sleep and eating habits. P4 observed that C4 was making efforts to eat healthier, noting, *"He would say, 'I need to eat healthier' or 'I need to drink more water' or 'I don't think I covered that right,' and stuff like that because previous to tracking, he would just like, 'I'm eating.' [...] So, I think it helped him slow down and look at what he's eating. I don't think he ever really paid attention to his mood, so that was also helpful for him"* (P4). P8 noticed that C8's sleep habits had improved during the study, stating, *"I got to say that C8's sleep habits have been improving. I would say a marked difference, absolutely"* (P8).

4.2 Child-led Tracking

Children in the child-led tracking approach were responsible for managing the overall tracking process, taking the lead in tracking while receiving support from their parents for data sourcing. Child participants, particularly younger ones, often lacked the necessary functional skills for tracking diabetes-related data, such as math skills for counting carbs or telling the time/duration. Thus, these children frequently sought help from their parents for collecting and recording data that they couldn't determine on their own. In the case of C1 as an example, C1 actively asked for P1's help on counting and remembering the time/duration for activities and sleep. C1 mentioned, *"I asked my mom how long I did those [activities]"* (C1); and P1 also explained, *"Even with the activities he's recording, he's relying on us to record the time to know when he's doing something. So he's going to have to come to us for that kind of guidance"* (P1). Some children could identify the times but in contextual terms (e.g., 'right after recess'), rather than in precise hours (e.g., '1:00 PM'), as one parent (P18) noted, *"He seemed to do a lot better with those sort of context times as opposed to the hour time. He couldn't tell me that it was 1:00 PM, but he could say it was right after recess"* (P18). In this type of tracking, the child's active management, along with parental support for data sourcing, resulted in a collaborative tracking effort primarily led by the children. As children sought assistance from their parents and remained the primary lead in the tracking, rather than the parents imposing on the process, they didn't feel much pressure from their parents.

4.2.1 Challenges. Although these children showed motivation to record comprehensive data with the help of their parents, sometimes their parents did not possess all the answers to their questions. In our study, parents reported that they might not be aware of the exact duration of their child's activities. Additionally, some parents felt challenged when seeking a balance between giving their child precise answers and not allowing the child to become fully reliant on their answers. For instance, P1 recalled how C1 relied entirely on P1 to keep track of the times, which wasn't ideal because C1 didn't try to make an effort to remember the times independently: *"It's not always great because he's relying on one of the adults around him to keep track of the time, and then he has to remember to ask, 'Can you tell me what time we did this?'"* (P1). C18 also mentioned

that he didn't pay much attention to the activities because he knew his parents could assist with that data: *"Yeah, it was based on my mom's answer because I don't pay much attention to how much time is left [for activities]"* (C18).

4.2.2 Strategies. As children often sought assistance from their parents during child-led tracking, the parents made efforts to become more proficient at gathering data themselves or teaching their child skills to acquire the data themselves. To better respond to children's requests for data, such as timestamps or duration, some parents maintained a separate log of that information in order to provide answers when their children inquired. When parents were with their children, they often used devices like fitness watches to track time. P1 explained, *"When we go for an intentional exercise or we're going for an intentional activity, we will start the activity in our watch. And so then we keep track of the times and we're able to tell him, this is what time you did a hike or this is what time you did this"* (P1).

Parents also estimated certain data or sought information from others, particularly when they were not directly with their child. For example, when C1 went outside or returned from activities, his parent would note the time: *"Usually if I know he's going outside and I will ask what he's doing during that time, I will just mark the time and say, okay, this is the time he's doing this. And then when he comes back in, I'll say, okay, this is the time he stopped doing this'"* (P1). If the child was with others, such as their siblings, parents would also seek information from them: *"I ask his sisters a lot too cause they're nine and ten and they're a little bit more, they can read well and they can tell time and they have a better sense of time at all. [...] The girls, so his sisters are actually more helpful in some of those details"* (P2).

To prevent children from becoming overly reliant on their parents for tracking data, some parents chose to engage in discussions with children rather than providing direct answers. For example, P6 assisted C6 in the carb-counting process so that she could eventually determine the carb amount on her own: *"Mostly, I would prepare what she ate, or if she was making her own breakfast if she was having cereal or a bagel or something in the morning that she could make herself. She would just say, 'How many carbs are in this?' and we would just talk together"* (P6). P17 also mentioned that she didn't offer a direct answer to C17 when it came to categorizing foods in the meal tracker; instead, she initiated discussions to encourage the child to think about the answer: *"It's more with her kind of discussing the food pyramid, kind of what one is this, and so I didn't see green, so it was like, okay, that's other, and then it's like, well let's put this under this one and stuff. And then the sweets and stuff, it's kind of like, well, it's almond, so is it really protein or is it sweet? So those kinds of things"* (P17).

4.2.3 Benefits. In child-led tracking, children managed their tracking while receiving support from their parents, and the discussions between children and parents about learning skills (e.g., math skills for carb counting or telling time/duration) fostered a sense of collaboration. In this style of tracking, children would identify the specific information they needed assistance with and approach their parents for this information. In turn, parents guided their child through processes such as time telling or carbohydrate counting to help the child determine the answer themselves. The parents also frequently double-checked the children's responses to verify their accuracy. As a result, children improved their abilities with these self-care skills and processes, increasing their involvement with T1D care.

P3 mentioned how he was able to engage C3 in carb counting through the daily conversations that occurred during their collaborative tracking efforts: *"C3 and I worked on adding up his total carbs. So that's one change I would say. We started having him do a lot of the math, oh himself, after recognizing how many carbs are in certain foods and with him getting a little older, starting to add it up on his own. We started that last couple of weeks through this. So he would add up, I would tell him the amount, or I'd have him look at the nutrition label of whatever he was eating and add it up. I would double-check his addition. He would enter it into his pump and then I would double-check that he entered it correctly and then we'd hit the button"* (P3).

Similarly, P6 described how child-led tracking encouraged conversations that eventually helped C6 become more involved with her care: *"I think it was great for C6's learning about how to count carbs because that's something that we wanted to do. So it definitely opened up those lines of communication for her to learn how to count the carbohydrates, how to track what she's eating, and how much insulin dose. But we did definitely discuss whatever she was eating together because she was not able to just guess on her own"* (P6).

C6 also expressed satisfaction with her improved carb counting skills: *"I feel like I got somewhat better on carbohydrates and this counting stuff. And actually, I felt like it was good to actually pay attention on how I was feeling with the symptoms and learning how much insulin I usually get so I can use that knowledge in the future too. I have a sixth-grade camping trip at the end of the year, so I feel like this is really helping with my knowledge and stuff"* (C6).

4.3 Parent-led Tracking

In parent-led tracking, parents took charge of the overall management of tracking, while requesting data from their child. This style of tracking was particularly prevalent when parents selected to track subjective data topics such as moods and symptoms and valued their children's perspectives on these matters. Some parents considered their own observations in addition to the child's responses about these data in order to make a better-informed decision about what to record.

These parents strongly believed that subjective data, such as mood, symptoms, and sleep quality, could only be accurately obtained by the child and directly requested this information from their child. For example, P1 and P13 always asked their child about sleep quality: *"I don't know how he feels when he wakes up. We have to have that conversation together"* (P1); *"I had a good idea usually of when he went to bed and when he got up. But in terms of how he had slept the previous night, that was always him telling me and all me circling the data point for it"* (P13). In another situation, to track issues regarding the insulin pump, P21 regularly asked C21 for this information: *"Yeah, whenever we were doing his insulin pump site, just because there were different things on there. If it was itching or leaking or that's something that I have, you can see if it's leaking, if the adhesive is wet, but I don't know how his body's reacting to it, so whenever it was the insulin site if it was usually the day that we were*

changing it, I would get his input on it to make sure that I knew how he was feeling with it and everything like that" (P21).

On the other hand, some parents used a combination of their own observations and their child's answers to achieve more accurate data recording. For instance, P6 considered both her observations and C6's responses for logging sleep time because the child might have slept later than she assumed: *"I asked her, I mean, her room's right across from mine and we don't sleep with our doors closed, so I pretty much know about when she's sleeping. However, I did ask her and confirm and say, 'What time did you go to sleep last night?' And she'd say at 11 or 10:30 or midnight or whatever. So I did confirm that with her. I didn't just try to guess"* (P6). For tracking mood, P1 utilized her observations as well as C1's responses: *"We would try to ask him questions about how he was feeling and we would try to use what we could see versus what he said he was feeling and cause there are some times when we know that he's going to be in a bad mood"* (P1).

4.3.1 Challenges. In parent-led tracking, since parents requested information often from children, children had increased feelings of surveillance. Oftentimes, challenges arose when children did not like being questioned or felt uncomfortable answering. We observed that older, more independent children were bothered by their parents' questions, which resulted in parents asking less frequently during the tracking process. For example, P8 mentioned that she decided to rely on her observation when tracking C8's mood because he found the constant questioning annoying: *"I think I asked a little bit more frequently in the beginning. I think maybe the last week it was just more of my observation. He was getting annoyed with me constantly asking"* (P8). C18 stated that he initially felt somewhat uncomfortable sharing his moods but eventually became more open to discussing them with his parent: *"When I first started doing them, I felt a little uncomfortable cause I never really talked to her about it. I would always talk to a counselor about it, but then we got more and more in-depth with each other, and now it just doesn't really make me nervous. So it used to, but then you just kind of don't feel"* (C18).

Some parents noted discrepancies between their child's answers and their own observations during tracking, which led parents to place less trust in their child's responses. For instance, P6 explained that C6 consistently reported sleeping well, although the parent noticed that C6 woke up multiple times during the night: *"C6 pretty much says I slept good every time. I'm like, well, nah, maybe not so much. [...] I would say if she woke up during the night, then I would bump that down [to lower score for sleep quality]. Even though if she said she still slept good, I had to wake up and give her a [insulin] shot two times, then I would've put a bad or a lower score, even if she said a higher score. Cause I was like, well that's not really good sleep if you're waking up two times"* (P6).

P10 highlighted an instance where her observation of C10's mood differed drastically from his response, leading to a discrepancy in their tracked data: *"I would check in with him during that 8:30 bedtime discussion of what's going on, and I'd say, 'Hey, it seemed to me like you were pretty happy tonight,' and he'd be like, 'Yeah, I was really happy tonight.' [...] so we did discuss those feelings before I put it in. Only once did he disagree with me. He was like, 'I was happy, everything was fine.' And I was like, 'You're clearly angry. That is not right.' So there was once where I just made my own choice separate from him"* (P10).

4.3.2 Strategies. To foster better communication with their children for tracking purposes, some parents created strategies to encourage openness in discussions, which can also alleviate feelings of increased parental surveillance or distrust. For example, P18 discovered that it was more effective to inquire about C18's moods after C18 had improved his emotional state: *"C18 could not have the discussion [about his mood] while he still felt bad. So at first, our first couple of discussions about it and didn't go as well as I would like. But when finally there was a day that he was having trouble at school and felt really lonely and left out from his group of friends. Because it was several hours later that we talked about it, that became a lot more useful"* (P18). Parents also established routines for discussing these matters when their children were more available. P3 preferred to engage in discussions when picking up C3 from grandma's house: *"Just what we would pick about. Just when it would be a discussion upon picking him up, 'Hey, what'd you do at grandma's today?'"* (P3).

When parents' observations and their child's responses diverged, they endeavored to arrive at a consensus through negotiation. For instance, P18 and C18 discussed C18's moods and attempted to reach a mutual understanding: *"In most of the time, what it would be is I would say, 'You didn't feel like you were happy or you seemed like you were upset earlier. Could you describe how you were feeling?' And then he would tell me the story of what happened and describe the trigger. And then I would say, I'd suggest a word, and then he would tell me, 'Yeah, that sounds right' or 'No, actually I would call it just sad because da da da.' And so I was like, 'All right, well, I'll go with that then'"* (P18). In C21's case, he wanted to review what his parent had logged regarding his moods because it might differ from his own perceptions: *"I just want to see what she said for my mood and stuff. She can, sometimes she'll think I'm mad or something, but I'm really not. So that'd also be another reason I would want to see if she said I was sad or something but I was just really tired or something, I would want to see what she said"* (C21).

4.3.3 Benefits. Through conversations initiated by parents who actively sought out their child's input, parents and children improved their ability to ask and answer specific questions regarding subjective topics, creating more open and detailed communication. For instance, P2 recalled that she previously didn't inquire about specific symptoms when C2 was feeling low, but through active discussions with C2, she learned to ask more precisely and found that C2 also started sharing more details: *"The symptoms, that was good because I don't always ask him very specifically when he feels low. [...] So that was really good to say, 'How exactly did you feel when you were low?' And to have him tell me like, 'Oh I feel kind of dizzy' or 'I feel just tired.' So that was helpful to me because it's not a question I normally was asking him in the past. So I think that's probably the biggest gain there. That's like a difference from before could kind of improve how he communicates to us, how he feels. Definitely"* (P2).

Similarly, C18 improved his ability to describe and share his moods with his parent: *"I thought this [tracking mood] would be a productive way for him to learn to use those words more frequently to name his feelings if we talked about what I saw and how he felt he was feeling. So I just thought it was a good conversation, a catalyst for*

some growth between him and me. [...] So I thought that was really good because I think at ten he's still learning how to describe how he's feeling other than just good or bad. So it was valuable that way" (P18).

Regular tracking discussions also led to improved general communication between parents and children in their daily lives and increased bonding opportunities with children. P18 noted that even when they couldn't track activities, C18 would share his feelings, which led to valuable conversations: *"What was neat was even when we weren't able to track, he would tell me, 'Oh, here were the feelings that I had today' and 'Here's where I would've gone in to track my activities'. So even though it wasn't recorded, there was still kind of a lot of benefit from opening that conversation, which I hope will continue in the future"* (P18). P16 highlighted that this experience was a bonding opportunity for them, as they didn't get to spend much time together due to their busy schedules: *"We don't get to spend a lot of time because we're always running and it was just nice to be able to sit down and do something together. It was a bonding, a little bit of experience"* (P16).

4.4 Parent-independent tracking

Parent-independent tracking occurred when parents took on the responsibility of managing their children's health data by collecting it themselves. This approach was primarily used for gathering objective data topics, such as the amount of carbohydrates in meals and insulin dosages. Parents found it convenient to oversee this type of data collection in their daily care management for children with T1D and chose to track this information independently because they had confidence in their own observations.

These parents also relied on estimations or observations to track data such as sleep time/quality or moods, especially if they were physically with their child throughout the day. For example, for tracking mood, P5 stated, *"Evening, obviously I'm with him directly. So then at that one was a little easier to know exactly what his moods were like and stuff like that. Usually, I can tell by being around him"* (P5). To monitor sleep, P15 typically checked on C15 during the night and in the morning, allowing her to assess his sleep quality: *"I check on him usually in the middle of the night and again in the morning. So I kind of based it on that, the way he was sleeping, because if he was rolling around or if he woke up when I came in the room, if he was really dead asleep and I rolled him over and looked at his pump and everything and he didn't wake up, then I'm like, okay, he slept good and I'd ask him to some of the time, but usually I could tell by that if he was, or this morning he got up and went to, got up and went to the bathroom before I left for work. So I knew he was like, he didn't sleep as good"* (P15).

4.4.1 Challenges. While parents' direct observations were valuable for tracking information about their children, there are limitations in this tracking practice due to observation and estimation inaccuracies. P9 highlighted that there were occasions when C9 went to bed later than expected, indicating that her estimated sleep time might not always be accurate: *"Sometimes you put her to bed, and within five minutes, she's asleep. But sometimes you can hear them chit-chatting or something happens and whatnot. So, I know the time going to bed doesn't necessarily match the time going to sleep. So I reported the time going to sleep, at least to the best of my knowledge"* (P9).

Furthermore, when parents were not physically with their child and unable to observe or estimate their child's state, they were only able to collect partial data. For instance, P7 primarily tracked moods in the morning when she could observe C7 at home: *"Well it was hard, because a lot of the times I wasn't with him throughout the whole day, so I would track in the morning whether he felt happy, you know if it seemed like we were having a good morning and he seemed happy, then I would say that he's happy"* (P7).

4.4.2 Strategies. To gather comprehensive data and information, parents often relied on external sources of information, such as other caregivers who possessed relevant data, particularly when direct observation of their child was not feasible. For instance, to log C5's mood, P5 often asked for information from her husband, cousin, and others who interacted with C5: *"So I really only saw her, I don't know, maybe an hour a day. So I rely on everybody else around me to make sure I track the correct mood. So I observed when I was around her, and then I had my husband. I asked him how she was, and then I have my cousin who lives with us right now. I asked her, and then I asked C5 how she was and then that's how I logged it"* (P5). When children were at school, parents gathered information from teachers or school nurses: *"The hardest part was when she was at school. Thankfully, since I pack her lunch, I know everything that she eats and stuff, but just to make sure the time that her teacher gave her the injection and then which arm and stuff"* (P17). Similarly, P20 explained, *"Breakfast was like 60, 70% my husband telling me what it was, lunch is always the school nurse telling me what he had"* (P20).

4.4.3 Benefits. Tracking independently allowed parents to have flexibility and collect data in a more timely manner. The process of recording data became more convenient when these parents did not seek input from their child. We found that these parents felt confident in their ability to discern their children's different moods or sleep quality. P8 mentioned using direct observation to track C8's mood, since it was quick and easy to gauge the child's mood through her observation alone: *"There was just an innate thing about if he wasn't seemingly happy or in a good mood I was able to tell. But for the most part, it kind of came after when I picked him up from school every day and he just bounces in the car and he is all smiles and school was good, and when he is with me and he is running around playing with the cats happy. So I think just by his actions alone, I was kind of safe in my observations"* (P8). For data that these parents considered more important, they even felt reassured by capturing the data themselves to be sure of its accuracy. For example, P14 assumed that different pump sites could impact C14's blood sugar level differently before tracking, which he could confirm by tracking it by herself: *"I think it just proved that the theory that I had about her pump sites, so it was good from that aspect"* (P14).

Parents utilized their preferred strategies, allowing them to handle the responsibility of tracking management and recording with little interference. Consequently, the tracking behaviors of parents did not impact or influence those of the children, as they respected their child's individual approach: *"Yeah, normally when he was logging, he would log by himself. We wouldn't do it at the same time. I would do mine at the end of the day, and I don't think I ever once*

watched him log his information. He did that all on his own at whatever time made sense to him. He is more of a do everything in this moment, impulsive sort of executor of tasks, if you will. Whereas I think I am more of a plan it all out in advance and then do it all in the future sort of person" (P18).

5 DISCUSSION AND DESIGN IMPLICATIONS

Our findings uncovered the various dynamics of collaborative data tracking between parents and children, highlighting distinct challenges, strategies, and benefits contingent on their shared responsibilities in tracking management and data provision. Through the use of probes, parents and children collaboratively tracked children's health-related data, by engaging in discussions and communication about illness. Collaborative tracking among family members was studied similarly but in a different context by Pina et al.'s work. They designed DreamCatcher as a probe to examine family members' tracking sleep [48]. They found that during child-parent collaborative tracking, children could be active tracking contributors and it encouraged them to work together. Extending this work, our paper highlights how family members collaborate to manage children's health by distinguishing their roles by identifying their distinct responsibilities (i.e., who is leading the tracking management and/or responsible for providing data), which yielded four types of collaborative tracking. Each type had unique challenges, strategies, and benefits for collaboration, which should be further considered for designing collaborative health-tracking technologies for children and their parents.

Notably, collaborative efforts were more prominent in child-led and parent-led tracking compared to child-independent or parent-independent tracking, which can be attributed to the more frequent communication between children and parents, yielding benefits such as enriched learning opportunities for children and a mutual understanding of the tracked data. Even in child-independent and parent-independent tracking approaches, mutual support was found to be beneficial, as children often needed assistance through reminders or verification of their logs from their parents. Data solely tracked by parents exhibited potential incompleteness or inaccuracy, which could be rectified with children's input. Thus, it's crucial to identify challenges in each tracking approach and encourage effective collaboration between children and their parents.

These findings show that collaboration extends beyond helping each other collect more thorough and accurate data. The collaborative efforts created space between children and their parents to have more conversations about learning skills related to illness management, understanding illness, and sharing emotions. Drawing from these findings, this section presents design guidelines for collaborative health technologies catering to children with chronic illnesses and their parents. These guidelines aim to empower children and parents in learning and encourage the sharing of different perspectives, ultimately improving the management of children's health-related data for better health outcomes.

5.1 Empowering children and parents through collaborative tracking and learning

In a prior study by Saksono et al., family interactions around physical activity (PA) data tracking were limited, and the PA trackers did not sufficiently enhance the value derived by families from their data [55]. Caregivers' beliefs, specifically regarding illness susceptibility and education, prompted deeper reflections on PA data with their children. The authors suggested that health apps should extend their goals beyond health, incorporating educational objectives for families such as improved performance in math and reading. Similarly, our study revealed that collaborative tracking held educational value for both children and parents through active discussions around data collection. Our findings further imply that technologies should accommodate varying educational needs, recognizing different levels of involvement between children and parents in managing tracking and providing data.

In child-led tracking, younger children in particular, benefited significantly from their parents' guidance in recording data that required specific skills, like calculations for carbohydrate counting or time telling. We found that the learning curve for these processes during tracking, especially when supplemented with meaningful discussions, went beyond mere data collection and held educational value. Notably, children showed deeper learning outcomes when parents facilitated discussions rather than providing answers directly. This also allowed parents the opportunity to gauge their child's abilities and determine what skills to teach the child to help them become more involved in their care. This was evident in C6's case in which she got better at carb counting skills with P6's support through discussion. This approach played a significant role in preventing potential over-reliance on parental assistance throughout the tracking process. Through a collaborative effort, children could become better at tracking, gain increased awareness of T1D management, and develop greater self-confidence in their abilities. This aligns with previous studies emphasizing that children can be active participants in tracking their own health data [3, 48]. Children's participation not only encourages their engagement in tracking routines but also enhances their awareness of health, fostering positive social support between children and their parents [48, 57].

Meanwhile, parents also benefited from learning about their children's state of understanding of different types of data and tracking abilities. Throughout the three-week tracking period, parents adapted their communication styles to meet their children's needs, adjusting their involvement level as their children improved their tracking skills. In the previous example of child-led tracking, P6 discovered C6's enthusiasm for learning carb counting, which was valuable for learning to provide the appropriate support for the child. In the case of C3, P3 gradually involved C3 more in adding up the total carbs independently with confirmation checks from P3 rather than providing answers. Even in cases where children demonstrated a high degree of independence in their tracking efforts, parents could still learn whether their children were diligent in tracking by monitoring the progress and gradually reduce reminders if needed (e.g., C8).

Building on the MyT1DHero app designed to support communication about diabetes management between children and parents via in-app messages [22], we suggest incorporating features that empower both children and parents to initiate conversations while tracking data. For children, the app could suggest sending messages related to specific data types (e.g., carbs, time) to their parents if

children are unsure about such data. Parents could also send messages to their children if they have any questions about logged data (e.g., possible inaccurate carbs or missing time) while reviewing children's data. Furthermore, the system could track patterns in these conversations and suggest more in-depth discussions about such data between parents and their children. For instance, if a child consistently asks questions about carbs, the system can provide learning sessions about calculating carbs for the child and parent pairs.

The educational aspect of tracking for children can be amplified through the implementation of a chat-based tracking system. Recent research on a health data recording chatbot demonstrated the benefits of clear, guided questions for children [3]. We propose incorporating this approach into children's tracking systems by offering detailed follow-up questions to guide them in recording data effectively while interacting with the system. For instance, if a child logs "during recess" as the time of an activity, the system could prompt them to specify when the recess took place. This could support children in gradually developing skills such as understanding timeframes and recalling time naturally, rather than seeking this information from their parents. If it continues to be a challenge for the child, the system can suggest that they ask their parents for support with those specific data points while providing the parent with a description of the child's current state of understanding.

The in-app chat feature can be further enhanced by providing parents with guidelines on how to effectively engage their child in overcoming these challenges. This would be crucial in fostering a more independent and educational tracking experience for children. Previous studies have shown that systems offering guidance for tracking health-related data were beneficial for both children and parents [62, 66]. Building upon these features, the system could provide suggested questions for parents to use during discussions, tailored to each child's specific needs, rather than supplying direct answers. For example, in the previous scenario where the child noted "during recess" and asked their parent for the time, the system could guide the parent to ask the child about the timing of their lunch and when they had recess (e.g., before or after the lunch), encouraging the child to think about timeframes more actively.

Our findings suggest that many parents and children progressively developed collaborative strategies and practices. Several children in our study became more knowledgeable and independent in tracking data with their parents' assistance. Consequently, the systems could adapt to changes in their collaborative learning process over time. For instance, while the system would focus on helping the parents teach their children practical skills (e.g., calculations) for collecting data, the system can also directly help older children with challenges in recalling times or missing data through reminders. As children enhance these skills, the system could gradually reduce these suggestions.

5.2 Sharing different perspectives while minimizing tensions

Our findings highlight the importance of sharing different perspectives through collaborative tracking between children and their parents. In parent-led tracking, parents often cross-referenced their observations to children's thoughts and opinions, particularly in the realm of subjective data like symptoms, mood, and sleep quality. Parent-independent tracking, however, revealed potential limitations when relying solely on parents' observations, especially in subjective data categories where children may have differing perspectives. Such limitations of data mismatches or inaccuracies were more prevalent in parent-led and parent-independent tracking, given parents' active involvement in comparing their observations with children's reports. This aligns with a previous study on collaborative tracking of smartphone usage by adolescents, where parents focused on discrepancies between the child's self-report and the parent's observation [12]. Parents tended to trust their own observations more, based on their prior knowledge of the child, and only raised questions when the data was unexpectedly different. However, in our study, when discrepancies arose between the data logged by children and parents, the process of negotiating and reconciling these differences emerged as a valuable strategy. For instance, P18 and C18 actively engaged in discussions about C18's moods, aiming to reach a consensus. This collaborative effort not only fostered shared understanding between them but also strengthened their relationships, ultimately leading to improved communication.

As previous studies have shown how children can contribute to more reliable tracking data [3, 42, 52], considering children's thoughts and opinions becomes critical in the collaborative tracking context. Recognizing and addressing these differences is essential for data accuracy. While our findings focused on child-parent collaborative tracking in the T1D context, some of these insights may also apply to other populations, including adults, with chronic health conditions, cognitive impairments, or psychological conditions affecting tracking abilities. Prior studies emphasized the benefits of the family members tracking on behalf of users, particularly when facing physical or cognitive limitations, resulting in more comprehensive data [28, 29, 45]. Our findings also suggest that collaborative tracking between patients and their caregivers could be beneficial for cross-checking and sharing perspectives, especially for subjective data like symptoms or moods.

Despite several benefits of collaborative tracking and sharing data, previous studies have also raised concerns around privacy issues of sharing children's data with other family members [49], parents' surveillance of children's data [27], and surveillance issues of self-monitoring technology use [35]. A prior study by Jorgensen et al. found that parents' surveillance of children's physical activity and sleep data reduced children's information disclosure [27]. Similarly, in our study, some children felt uncomfortable sharing their thoughts, especially in parent-led tracking, where requests for information disclosure heightened feelings of surveillance and decreased privacy (e.g., C8, C18), so it was crucial for parents to adopt strategies promoting open discussions to alleviate these concerns. However, children in child-led and child-independent tracking experienced less feelings of surveillance as they actively sought and appreciated their parents' help, such as providing data or reminding them to log. This allowed them to be more willing to share thoughts or data with their parents.

To alleviate tensions related to surveillance and agency issues between children and their parents, technologies should be carefully designed to foster perspective sharing and effective discussions. We propose a more thoughtful implementation of privacy settings in

tracking for dual logging, capturing both children's thoughts and parents' observations. Building on the work of Chen et al., who visualized children's self-reports and parents' observations of smartphone usage for comparison [12], we suggest that the system also tracks child-parent collaboration types and offers corresponding privacy features. For example, in child-led and child-independent tracking, where children take the lead in collecting data, children could have more control over managing their data. Children and parents could log their data completely separately, but children could still have the option to check their parents' data when seeking assistance or validating the accuracy and completeness of their own data.

Such a system could also enhance child-parent collaboration in parent-led and parent-independent tracking by allowing children to specify the extent of data sharing with their parents. As parent-led tracking could impose increased feelings of surveillance on children, the system could offer choices for children to indicate which data component and how much of that data they wish to share with their parents. For instance, the system could assist children in selecting the data topics (e.g., symptoms, meals), components (e.g., all the records except for the notes section), or the duration (e.g., during a certain period of time) they want to share with their parents. If children are unwilling to share their data altogether, the system could suggest the parents start with parent-independent tracking and gradually involve their child by guiding the parents to engage in effective discussions with their child. As children and parents gradually change their level of involvement in managing or providing data, the system could dynamically capture these shifts and suggest corresponding changes in the privacy settings.

Furthermore, to facilitate children's sharing of different perspectives on their parents' observation, even in situations where parents independently log their children's data, children could be provided with an objection feature to their parents' data. This feature would enable children to articulate their differing thoughts regarding the data recorded by their parents. For instance, if a child perceives that their sleep quality, noted by the parent as 'good,' was in fact 'bad,' the child could initiate an objection through the system, prompting a notification to the parent. Subsequently, the parent would be alerted to the child's objection. To complement this, the system could also offer suggestions for discussions aimed at further exploring and comprehending the diverse viewpoints of children and their parents.

5.3 Limitations and Future Work

Our study's findings regarding the collaborative tracking approaches for children and their parents may not be universally applicable to all aspects of children with chronic illnesses. Further investigation is required to assess children with different chronic conditions, such as cancer and asthma, to ascertain if similar approaches for tracking are observed. It is important to note that our study's outcomes are specific to children aged 6 to 12, as we exclusively included pediatric patients within this age range. While this focus provided valuable insights into the collaborative tracking practices of children and their parents within this cohort, it is conceivable that older children (adolescents and young adults) or very young children (under 6 years old) may exhibit distinct dynamics, which should be explored in future studies.

Moreover, our participant pool predominantly comprised individuals from the urban clinic associated with the university, many of whom possessed a relatively high level of education and medium to high incomes. The participants also used a CGM (Continuous Glucose Monitoring) device to monitor their blood glucose levels. While this allowed us to gain insights into how families gather several types of data collaboratively with the support of technical devices, our findings may not fully capture the unique challenges faced by families of low-socioeconomic status (SES), who may encounter additional hurdles in health management, including financial constraints and limited healthcare devices. Consequently, further research is needed to gain a more comprehensive understanding of diverse family demographics, including those from low-SES backgrounds.

The management of children's illnesses entails not only parents, who serve as the primary caregivers, but also a broader network of caregivers within the family, school, and other settings. Parents actively collaborate with other caregivers within the household (such as siblings), at school (including teachers, paraprofessionals, and school nurses), and in clinical settings (such as doctors and nurses) for collecting children's health-related data. Thus, future research endeavors should explore diverse collaboration approaches, encompassing these varied stakeholders.

6 CONCLUSION

Managing health data for children with Type 1 Diabetes (T1D) is a collaborative effort involving both children and parents. This study investigated how children with chronic conditions, particularly those aged 6-12 with T1D, and their parents worked together to track children's health data. Our three-week probe study with 22 child-parent pairs revealed four distinct tracking approaches (i.e., child-independent, child-led, parent-led, and parent-independent), characterized by shared responsibility in tracking management and data provision. Each of these approaches yielded unique challenges, strategies, and benefits. From these findings, we propose design implications for collaborative health technologies tailored to children with chronic illnesses and their parents. These guidelines seek to encourage learning opportunities and facilitate the exchange of perspectives between children and parents, ultimately improving the tracking and management of children's health-related data for better health outcomes.

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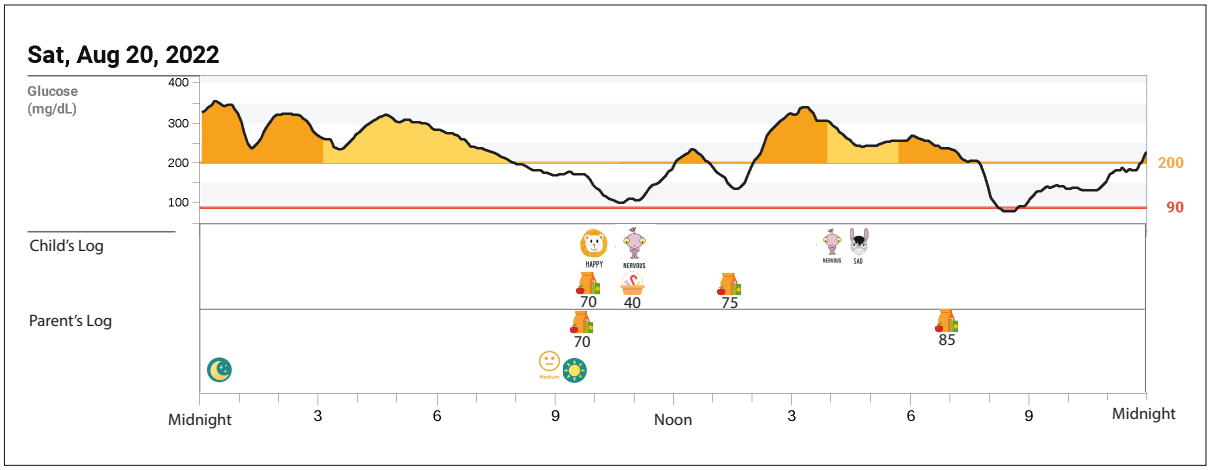
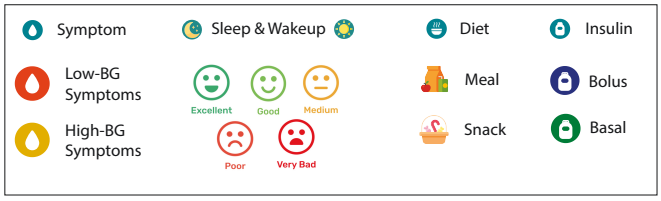
A WEEKLY REPORTS PROVIDED TO THE PARTICIPANTS: ONE-DAY EXAMPLE

At the end of each week of the study, participants were provided with a weekly report based on their tracked data to help them review their tracked data and pinpoint patterns. These reports included an index (to indicate how each tracking topic is visualized) and the 7 days of their tracking results. The images below illustrate examples of weekly reports provided to the participants (P4 and P6): (a) Index for indicating how P4's tracking topics, (b) Day 1 tracking result for P4, (c) Index for P6's tracking topics, (d) Day 1 tracking result of P6

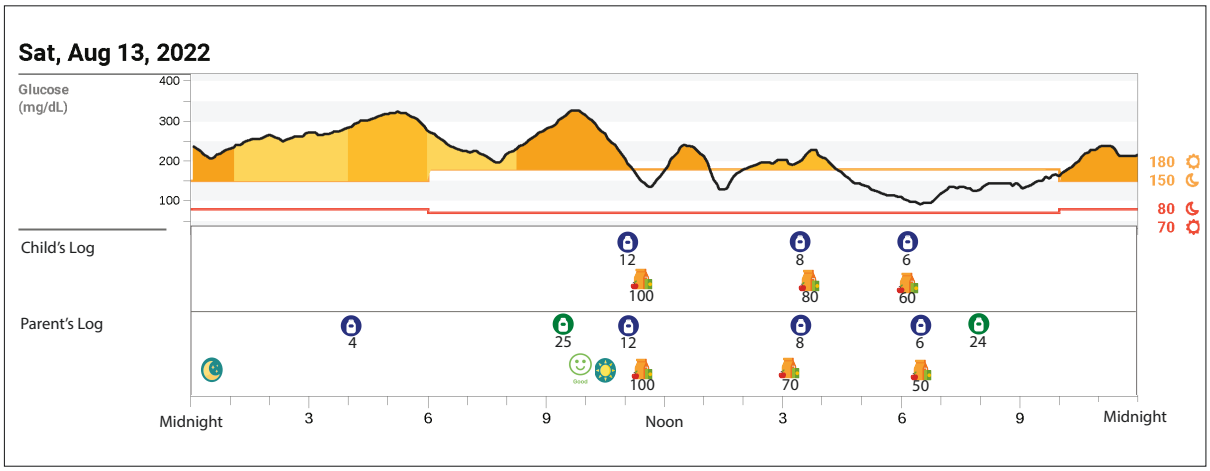
a

b





d



B SUMMARY OF THE PARTICIPANTS' LOG DATA ANALYSIS

The summary of the participants' log data analysis is shown in the table below, including: (A) Number of days logged, (B) Number of logs submitted, (C) Number of log entries per day – Out of the three-week tracking period (21 days in total), the average number of days that children participated (data submitted) was 15.73 days (median=18.00, SD=5.59), and 17.23 days (median=19.50, SD=5.24) for parents. The average number of the total log entries for children was 71.45 entries (median=55.50, SD=49.10), and 79.18 entries (median=73.00, SD=52.64) for parents. The average number of log entries per day (total number of log entries divided by total number of days for each participant) was 4.18 entries (median=3.45, SD=2.13) for children and 4.47 entries (Median=3.96, SD=2.34) for parents.

ID	Number of days logged (A)		Number of log entries (B)		Number of log entries per day (C=B/A)	
	Child	Parent	Child	Parent	Child	Parent
P01	21	21	53	47	2.52	2.24
P02	21	21	141	11	6.71	0.52
P03	17	17	116	103	6.82	6.06
P04	10	19	35	43	3.50	2.26
P05	16	10	55	49	3.44	4.90
P06	18	21	111	167	6.17	7.95
P07	10	21	43	225	4.30	10.71
P08	20	17	56	69	2.80	4.06
P09	18	21	62	48	3.44	2.29
P10	19	18	139	52	7.32	2.89
P11	6	7	10	23	1.67	3.29
P12	20	20	42	77	2.10	3.85
P13	20	20	124	90	6.20	4.50
P14	20	20	161	135	8.05	6.75
P15	20	21	69	81	3.45	3.86
P16	3	9	5	28	1.67	3.11
P17	21	21	133	126	6.33	6.00
P18	7	15	24	102	3.43	6.80
P19	19	19	118	114	6.21	6.00
P20	14	3	23	7	1.64	2.33
P21	9	21	20	54	2.22	2.57
P22	17	17	32	91	1.88	5.35
Mean	15.73	17.23	71.45	79.18	4.18	4.47
Median	18.00	19.50	55.50	73.00	3.45	3.96
SD	5.59	5.24	49.10	52.64	2.13	2.34