Transitioning Toward Independence: Enhancing Collaborative Self-Management of Children with Type 1 Diabetes

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ABSTRACT

Although child participation is required for successful Type 1 Diabetes (T1D) management, it is challenging because the child's young age and immaturity make it difficult to perform self-care. Thus, parental caregivers are expected to be heavily involved in their child's everyday illness management. Our study aims to investigate how children and parents collaborate to manage T1D and examine how the children become more independent in their self-management through the support of their parents. Through semi-structured interviews with children with T1D and their parents (N=41), our study showed that children's *knowledge* of illness management and *motivation* for self-care were crucial for their transition towards independence. Based on these two factors, we identified four types of children's collaboration (i.e., *dependent*, *resistant*, *eager*, and *independent*) and parents' strategies for supporting their children's independence. We suggest design implications for technologies to support collaborative care by improving children's transition to independent illness management.

CCS CONCEPTS

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

KEYWORDS

child-parent collaboration, child independence, child self-care, pediatric patient, type 1 diabetes, chronic illness management, collaborative healthcare technology

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1 INTRODUCTION

Managing Type 1 Diabetes (T1D) is challenging because patients are usually diagnosed at an early age, and it requires lifelong daily treatment. Patients with T1D produce no insulin in the pancreas, which causes excessive glucose levels in the bloodstream. To keep a glucose level in the appropriate range, patients with T1D and their caregivers need to monitor blood glucose levels, adjust insulin dosages, make multiple daily insulin injections, and monitor both physical activity and carbohydrate intake 24 hours a day [19, 31]. For children, T1D management is even more challenging due to their lack of ability to engage fully in self-care or illness management, and caregivers must continuously supervise and monitor the changes in a child's ability to self-manage as they get older and become more independent to carry their self-care [9, 13]. Throughout the gradual transition toward children's independence in their T1D management, adult supervision remains important to assure appropriate illness management skills [69]. However, this transition is often marred by too much or too little parental involvement, resulting in negative health outcomes, such as higher A1C levels (average blood glucose level in past 3 months measured with blood tests) and poorer self-care skills [30, 45].

Patient independence has been a focus of HCI and medical studies on self-management [34], and prior studies have shown how a set of collaborative practices between patients and their caregivers in everyday life have been used to achieve patients' self-management [12, 48]. In pediatric care, children gain independence in illness management through a collaborative process that involves parents educating and transferring illness management skills to their child, which involves sharing and shifting responsibility for care tasks and decision-making [63]. However, the practice of transferring care from parent to child is complicated and not well studied in the literature because it involves various factors among the child, parent, and context that can impact the division of care tasks [2, 44]. Even less is known about how young children with T1D and their parental caregivers are collaboratively involved in illness management while the children become able to independently manage their condition.

In this study, we aim to 1) understand the current practices of how children with T1D and their parental caregivers are involved in their diabetes management; 2) identify challenges that they face during the collaborative care process and strategies parents developed to obtain a child's independence in self-management; and 3) provide design implications of how technology could support their collaboration toward a child's independence in illness management. To realize this goal, we conducted semi-structured interviews with children with T1D and their parental caregivers (N=41). The child participants were those aged 6-12, based on the fact that children at this age can recognize, report, seek treatment, are aware of their responsibility, and can get partially involved in their care [69].

Our findings showed that two main factors, a child's *knowledge* of illness management and their *motivation* to engage in self-care, are crucial to the child's transition towards independence in their illness management. Based on these two factors, we identified four types of children's collaboration in the parent-child illness management: *dependent*, *resistant*, *eager*, and *independent*. Based on each type, we reveal different challenges that the children and parents faced and the various strategies parents developed to handle these challenges while promoting their children's transition to self-management. Through the study, we found that process of achieving independence is not always linear and that a child's levels of knowledge and motivation are fundamental in their transitioning towards independence in collaborative care. Thus, it is crucial for parents to monitor and identify their child's states of knowledge and motivation and to respond to them by developing strategies to facilitate their collaboration. Based on these findings, we provide design implications for technologies that support collaborative care by enhancing a child's transition to independence. In sum, we make the following contributions:

- We identify four child collaboration types, the challenges of each type, and the parents' strategies to handle these challenges while working towards the child's independence.
- We highlight the importance of identifying children's knowledge and motivation levels and developing appropriate strategies to balance the involvement between parents and children in their collaborative illness management.
- We suggest specific design implications for technologies that support child-parent collaboration by facilitating the children's transition towards independence.

2 RELATED WORK

2.1 Type 1 Diabetes Management

Type 1 Diabetes (T1D) is usually diagnosed when children are very young (between 5-7 years of age), and it is one of the most common chronic childhood diseases around the world. Patients with T1D produce no insulin in the pancreas, and this causes excessive glucose levels in the bloodstream as the glucose cannot enter the body cells without the help of insulin. High blood sugar can develop complications in the kidneys and heart and can be fatal. Thus, managing T1D requires lifelong treatment to keep glucose levels in the appropriate range. T1D patients and their caregivers need to monitor blood glucose levels 24 hours a day (using a testing device like a glucometer or a Continuous Glucose Monitor (CGM) device) and make multiple daily insulin injections (using an insulin pen or an electronic insulin pump) depending upon their blood glucose level. They count carbohydrate intake in the diet and monitor physical activity to calculate the right insulin dosages. Insufficient insulin dosages can lead to high blood glucose and excessive dosages can lead to low blood glucose. Typical symptoms of high blood glucose include being thirsty, feeling sick, and urinating frequently; and of low blood glucose include feeling hungry, tired, and shaky. For children with T1D, care tasks are often imposed on their parents to assure developmentally appropriate self-management [69]. Still, child-parent collaboration on the T1D management is required for children's successful transition to independent T1D management.

2.2 Challenges in Chronic Illness Management for Child Patients

Numerous studies have explored the everyday challenges of managing health and wellness, including chronic illnesses like diabetes [23]. Managing chronic illnesses of child patients is even more challenging due to children's limited ability to self-care. Child patients often lack proper communication skills and abstract thinking when managing treatment and making decisions; consequently, they only contribute to around 10% of communication in consultations and are rarely involved in decision-making in healthcare [74]. Nevertheless, children between ages 6-12 can recognize, report, and seek treatment [69]. Those children's information needs, however, are often overlooked. Furthermore, their capacity to understand care information is misjudged by caregivers and healthcare providers [17, 18, 49].

Managing T1D could be even more challenging for children, as T1D is often diagnosed before children have enough capability in physiological, developmental, and psychosocial skills to manage their illness [72]. Since managing T1D requires careful diet management, constant blood glucose monitoring, and insulin dosage calculations, young children are not capable of managing their condition solely by themselves [29, 63]. Thus, parental involvement in T1D management is necessary throughout childhood and adolescence to manage their child's chronic health condition and assure the child's appropriate self-management [47, 52]. Parents are also expected to rapidly master and teach others about their child's T1D care, and constantly work to help the child achieve tight blood glucose control and avoid hypoglycemia while facilitating the child's normal development [7, 24, 25, 41, 80].

Previous studies have shown that children's gradual increase in involvement in their self-management is mostly influenced by their age. During the preadolescence period (a transitional phase between childhood and adolescence spanning from ages 9-14 depending on pubertal onset [26]), children develop greater autonomy and become increasingly independent [16]. The division of diabetes care responsibilities begins to shift from parent to child [6, 40], as youth take on greater responsibility for disease management. Nonetheless, studies also show that adolescent children often face challenges with adherence to self-management, which causes a decline in glycemic control [5, 37], because they take on the responsibility for T1D management when they do not have the maturity to handle it [51]. Thus, it is crucial that caregivers transfer responsibility at appropriate times when children demonstrate success in managing diabetes tasks.

However, there has been less knowledge about how much and what kind of self-management capabilities children and their caregivers are necessary at various points of illness trajectory along the developmental continuum [69]. Since the capabilities of individual children and families all vary, the transfer of self-management tasks can be very complex [44]. Aalders et al. has examined which factors impact the diabetes care responsibilities between parents and children with T1D [1] and found that the complex interplay among child, parent, and context characteristics impacted the division of care responsibilities and transfer of diabetes management tasks. Due to these intertwined associations between several factors, parents of chronically ill children experience difficulty in navigating the numerous everyday care tasks and a deficiency in support from health care providers with respect to the transfer process [2].

Moreover, the majority of the prior works on pediatric patients are centered on adolescent patients in terms of understanding how they perform self-care in various contexts [57, 58], how mobile applications can support their self-monitoring [27, 35, 67], or how they communicate with their caregivers [32, 33, 68]. Also, many other prior works have focused on the parents' or providers' role in managing a child's chronic illness (e.g., cancer, diabetes, asthma), such as how the parents adapt to illness management [56], adjust lifestyle [8], handle different types of caregiving and technical tasks [83], balancing responsibilities between caregiving and parenting roles [64], and facilitating effective communication with children [65, 66]. However, there is very little understanding of how younger children (age 6-12) collaborate with their caregivers and participate in self-care for their illness management. To provide appropriate support and facilitate autonomy for children with chronic illnesses, it is crucial to understand their individual differences, developmental stages, and family dynamics [68, 73].

Our study thus aims to understand how children with chronic illness gradually become involved in their care and identify how they collaboratively manage their illness with their parents during the transition towards independent self-management.

2.3 Technologies to Support Children's Chronic Illness Management

Previous studies have investigated how technologies can support child patients or their parental caregivers and suggested interventions to address their challenges in various healthcare contexts. For instance, technologies can provide support for caregivers to acquire and navigate information about the children's illness [4, 28, 42], monitor a child's blood glucose levels remotely [76], and identify the needs of children with autism using wearable cameras [43]. To help gain knowledge on illness management, interactive educational games have been developed for children with diabetes [14, 38, 39]. Other tools have also been developed to enhance the communication of child patients during clinic visits, such as tools that allow children to actively participate in clinic consultations [79], or help children describe their symptoms [36].

Recently, there has been increased attention on collaborative care between patients and their family caregivers in the home setting, as the rate of chronic illness and interest in preventive health has increased [23], and awareness has grown regarding how the support of family members can positively impact illness management [48, 55, 75, 81]. Technology-mediated interventions can support this collaboration by sharing the burden of management and developing collective actions [15, 48, 54]. Studies have examined how children and their parents collaboratively track health-related information. For instance, Oygur et al. analyzed user reviews on nine trackers designed for children on how the families collaboratively use the trackers [50], and found that current tracker designs provide little agency for the children to participate. Pina et al. designed a probe 'DreamCatcher' to examine the design space of tracking sleep among family members and reported that children can be active tracking contributors [53]. Holtz et al., designed the 'MyT1DHero' app to assist adolescents with T1D by facilitating communication around diabetes management with their parents [32, 68]. Schaefbauer et al. designed a mobile application 'Snack Buddy' to help parents and children monitor their snacks together by increasing their awareness of snacking practices and promoting positive social support [62]. Tsvtatjiva and Storni developed an educational interactive eBook to support newly diagnosed T1D children and their families in learning illness management [78], and they discovered that not only the child but all the family members should be considered co-users of the educational aids because pediatric care requires the collective effort of family members.

Although these works showed an important need and potential for children's participation and collaborative care, they heavily focused on technology to support the caregiver's role to monitor or treat a child's illness management, and less attention has been paid to the children's role. Little is known about how technologies can support children's independence through collaborative care between children and their parents as children gradually gain the capability of transitioning towards independence in illness management over time. Thus, we would like to investigate how technologies can support child patients and their caregivers collaboratively managing illness and support their transition towards independence.

3 METHOD

The goal of our research project is to understand the collaborative health management practice among children with T1D and their parents and the challenges and strategies used to support the children's independence in their self-care. We conducted semi-structured interviews with pairs of children with T1D and their caregivers. This study was approved by our university's Institutional Review Board (IRB) for Medical Research.

3.1 Participants

We recruited 20 pairs of children with T1D and their caregivers. The children were between 6-12 years old and diagnosed with T1D

Table 1: Demographic information of the study participants

ID	Participants in the Interview (age of the caregiver)	Child's Age	Child's Sex	Type 1 Diabetes Diagnosis Years	CGM or Glucometer	Insulin Pump or Pen
P01	Child, Mother (39)	8	M	3	CGM	Pump
P02	Child, Mother (41)	12	M	4	CGM	Pump
P03	Child, Mother (36)	9	F	6	CGM	Pen
P04	Child, Mother (42)	8	F	2	CGM	Pump
P05	Child, Mother (40)	10	M	5	CGM	Pump
P06	Child, Mother (46)	6	M	1	CGM	Pen
P07	Child, Mother (32)	11	F	4	CGM	Pen
P08	Child, Mother (42), Father (43)	10	M	8	CGM	Pump
P09	Child, Mother (42)	10	F	6	CGM	Pump
P10	Child, Father (36)	8	M	1	CGM	Pen
P11	Child, Father (49)	7	F	2	CGM	Pump
P12	Child, Mother (39)	7	M	1	CGM	Pen
P13	Child, Mother (45)	11	M	2	CGM	Pump
P14	Child, Mother (47)	12	F	1	CGM	Pen
P15	Child, Mother (45)	9	F	7	CGM	Pump
P16	Child, Mother (21)	10	M	4	Glucometer	Pen
P17	Child, Mother (44)	9	M	1	CGM	Pen
P18	Child, Father (41)	12	M	11	CGM	Pump
P19	Child, Mother (36), Father (39)	11	F	1	CGM	Pump
P20	Mother (49)	12	F	6	CGM	Pump

at least 3 months prior to the interview, and we tried to recruit an even number of boys and girls. At least one caregiver of each child participated in the study. The caregivers were parents who identified themselves as the child's primary caregiver, therefore having the primary responsibility for managing the child's health condition. Both child and caregiver were fluent in English.

We used several online channels for recruitment, such as our University's recruiting website for healthcare researchers and the electronic newsletter for the University's diabetes clinic patients. Targeted emails were also sent to patients who were eligible for our study using the university clinic patient pool. Each child-caregiver pair received a $25 gift card for participating in the interview.

A total of 41 individuals participated in our study and their demographics are shown in Table 1. There were 14 pairs of participants that consisted of a child and a mother, 3 pairs with a child and a father, 2 groups with a child, a mother, and a father, and one single parent because the child could not join. The child patients included 11 boys and 9 girls, with an average age of 9.6 years (median: 10, SD: 1.85). The average duration they were diagnosed with T1D was 3.8 years (median: 3.5, SD: 2.84). For diabetes management, 19 out of 20 children used CGM (Continuous Glucose Monitoring) devices, and 12 out of 20 children used insulin pumps, which are automatic insulin injection devices. All the interviews were conducted virtually from February to June of 2021.

3.2 Data Collection

Before each interview, we received consent from parents and assent from children. To participate in the interview, children aged 10-12 gave written assent while ages 6-9 gave oral assent, following our institution's IRB guidelines. All the interviews were conducted virtually using Zoom due to COVID-19 precautions. During the interview, video-recording was turned on with participants' consent, and all the recordings were transcribed for analysis.

For each child-caregiver pair, the interview sessions lasted about an hour. During the session, the child and the parent were interviewed separately. We first interviewed the parents to understand their general T1D management practices. During the parent interview, we let the parent decide whether the child will be staying nearby or not, as some caregivers who have a younger child might need to carry out T1D treatment such as insulin injections for their child while participating in the interview. If the child stayed nearby the caregiver, the child was recommended to wear earphones to avoid hearing the caregiver's interview contents, since the child's presence nearby may influence the parent's answers. Interview questions focused on how diabetes is managed in daily routines, how the child does self-care and parents help the child with management, how parents try to get the child more involved in self-care, what are the challenges that they face in each context, and how they try to overcome these challenges.

During the child interviews, the parent could stay nearby to cope with any unexpected situations such as network connection problems and to help facilitate the child's understanding of the questions. The parent's interventions, however, were limited to reduce the parent's influence on the child's answer. To facilitate the child's engagement in the virtual interview, we utilized six scenarios that visually demonstrated diabetes management in everyday

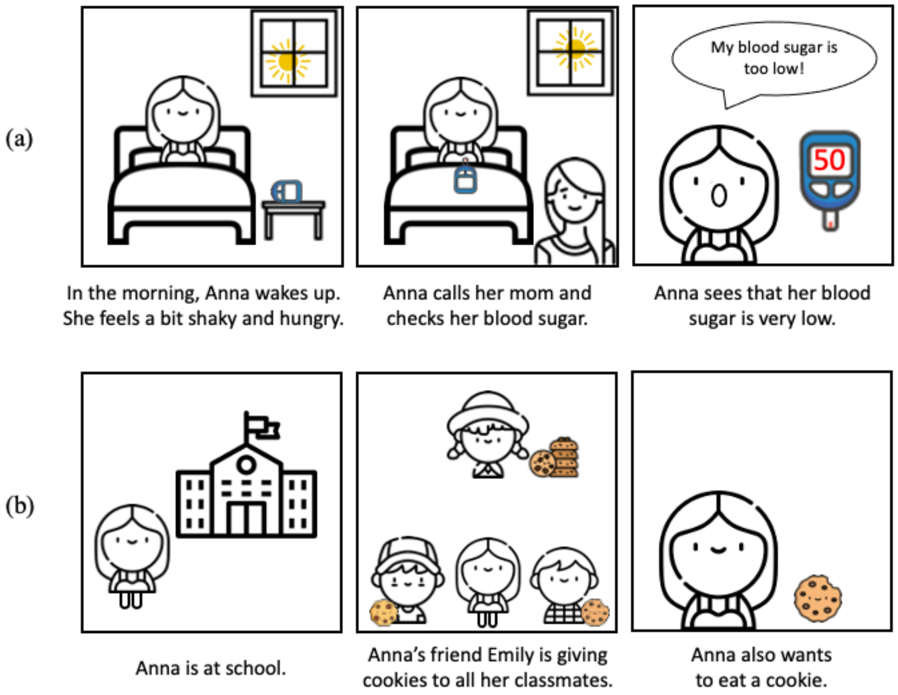

Figure 1: Scenarios used for the child interview (a: checking blood glucose level, b: eating snack in the school)

life so that the child could better recall their own experiences. The scenarios contained stories of a persona (named Anna, a child who has T1D) to depict situations that children with T1D can face at home, a friend's house, school, and the clinic. Examples of our scenarios are shown in Figure 1. Going through each story, the child was asked about Anna's situation in the story (e.g., what Anna should do and how Anna feels), and we followed up by asking the child's own experience related to each story, such as how they managed diabetes at home and school contexts, how their parents helped them with management, and if they have hard times. All the scenarios and the questionnaire were collectively designed with a child psychologist, a nurse practitioner, and a social worker who worked for more than five years with children with T1D. Participants' demographic information, T1D diagnosis date, and types of devices for diabetes management (e.g., CGM, insulin pump), and their EHR data (e.g., last clinic visit date, treatment type) were also collected. For the participant data, we removed all the personally identifiable information and assigned a unique identifier for each participant.

3.3 Data Analysis

We analyzed the transcribed interview data using inductive thematic analysis [11] to identify themes. ATLAS.ti software was used for coding the interview transcripts. First, three members of the research team individually completed open coding of the first six interview transcripts. Then we had a series of group meetings to compare and refine the codes (examples of codes: parent having a hard time doing treatment on child, parent instilling the importance of self-care to the child, child not wanting treatment). Then we categorized these codes into initial themes about challenges faced by parents (e.g., emotional challenge, treatment challenge, education challenge), challenges faced by children (i.e., emotional challenge, physical challenge, social challenge), strategies of parents (i.e., strategies for managing T1D, child adaptation), and strategies of children (i.e., strategies for receiving treatment, telling others about T1D). This helped us to focus on specific themes related to challenges and strategies related to children's self-management when we coded the rest of the transcripts. Then the same researchers coded the rest of the interview transcripts. During the process, research team members regularly discussed potential findings and any new themes that emerged during weekly meetings. The themes were revised through a series of discussions until agreement was reached: for instance, parents' challenges (i.e., difficulty of doing treatments for child, difficulty of helping child's adaptation to illness), children's challenges (i.e., not recognizing symptoms, not understanding needs of illness management), parental strategies (i.e., strategies for persuading child to do self-care, strategies for doing treatment), and children's strategies (i.e., reaching out for help, coping with treatment, doing self-care). These final themes were used to develop the four types of children's collaboration in illness management and the two factors that were crucial for child's independence in illness management (i.e., knowledge and motivation) that are presented in the findings section.

4 FINDINGS

Below we provide our findings related to child-parent collaboration in pediatric diabetes management and the child's transition towards independence in their self-care. Specifically, we describe four types of children's collaboration: *Dependent*, *Resistant*, *Eager*, and *Independent*. For each type of collaboration, we describe the observed practices of child patients and their parents and the challenges they experienced. We then illustrate strategies that the parents developed to promote their children's transition towards independent self-care. Throughout the Findings and Discussion sections, we use P# (e.g., P3, P6) to indicate the parental caregiver participant and C# (e.g., C3, C6) for the child participant.

4.1 Four types of children's collaboration in illness management

For our interview study, we analyzed how children with T1D and their parental caregivers engaged in illness management so that the children gained the independence to manage their illness themselves over time. We identified two main factors, *knowledge* and *motivation*, that were crucial to a children's transition towards independent illness management. *Knowledge* refers to the acquisition of knowledge of the illness and self-management practices, whereas *motivation* indicates the desire to perform self-care tasks for managing the illness. Based on these two factors, we identified four types of children's collaboration in illness management: *Dependent*, *Resistant*, *Eager*, and *Independent* (see Figure 2). These four types were derived from our analysis of the children's cooperation styles and their level of knowledge and motivation (high or low) in care contexts. For instance, if a child has low knowledge and low motivation, the child is categorized as a dependent type with regards to collaboration with caregivers. If a child has low knowledge and high motivation, the child is an eager type. If a child has high knowledge, but low motivation, the child is a resistant type. Lastly, if a child has high knowledge and high motivation, the child is an independent type. A child can change between the different types as they become more familiar with their health condition and/or are impacted by their parents' involvement. In the study, most children started from the *dependent* type of collaboration when they were first diagnosed because they were very young (average 5 to 6 years old for our participants); however, they gradually became more either *resistant* or *eager* to collaborate as they gained more knowledge and motivation in support of their parents.

4.1.1 Dependent Type.

Children who have both insufficient knowledge and low motivation exhibited the dependent type of collaboration. It is usually difficult for dependent type children to understand diabetes because of their lower cognitive abilities and communication skills. They have little knowledge of T1D and how to treat it. Due to this difficulty, it is challenging for them to have high motivation to self-manage the illness on their own, thus being dependent on their caregivers in collaboration. In our study, child participants were usually this type when they went to preschool (3-5) or kindergarten (5-6).

Dependent type children had difficulties understanding what the illness was as well as why their parents were giving them treatments. This often caused them to not collaborate in illness management. They frequently ran away when getting treatments, not understanding their necessity, and felt upset that their parents forced them to get painful insulin injections (P2, P3, P4, P5, P8, P9, P11, P15). For instance, C11 (7 y/o girl) was 4 years old when she was first diagnosed. During the initial days of her treatment, she was very confused and upset because she did not understand her health condition. P11 explained, *"It's difficult for a child of that age to grasp exactly what that means, but she was [still] quite stressed. I mean we had to go to the hospital in an emergency. Obviously, she knew something was wrong, but she didn't know what. And when we got there, they told her, 'Right now don't eat, don't drink anything, we need to run tests and whatnot.' And she thought that she would not be allowed to eat ever again. (P11)"*

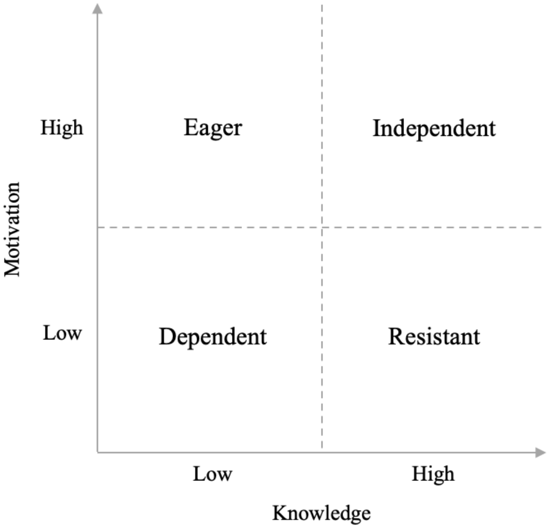

Figure 2: Four types of children's collaboration in illness management

In another example, it took C5 (10 y/o boy) two years before he began to understand the complexity of T1D after being diagnosed at 5 years old. P5 described, *"He would say a lot of things like, 'I hate my life. Why do I have to have diabetes?' Yeah, he would throw a fit any time we had to give or change a device, it was like a meltdown. So a lot of it I think was diabetes-related. It was just hitting him. Because when he was five, it was, I think it was too big and too complex for him to really understand the gravity of the situation (P5)."* Additionally, children of this type had difficulties recognizing their symptoms, which made it difficult for them to not only become motivated towards self-care, but to engage in it (P1, P3, P6, P8). For instance, among our child participants, C6 (6 y/o boy) could not identify his high or low blood glucose symptoms even when they were noticed by others, and C3 (9 y/o girl) couldn't fully recognize when she needed insulin injections until she was 7 years old, 4 years after her initial diagnosis.

The parents of dependent type children often faced many lifestyle restrictions and a great deal of mental stress since they needed to take care of their children full time. To lessen the burden, some parents tried to get other family caregivers or school personnel to share the care tasks and responsibilities (P3, P7, P13, P14, P16). For example, when C15's (9 y/o girl) mom was too tired to change the pump, C15's older sister helped C15 instead: *"When I didn't know how to change my pod and stuff, and my mom was too tired and my dad didn't want to do it, mom and dad would tell my sister that she had to do it. (C15)"*

To summarize, children with the dependent collaboration type faced numerous struggles understanding T1D, recognizing symptoms, and even understanding the reason why they needed treatment, thus, requiring significant parental involvement to manage the illness. In particular, children below age 7 at their diagnosis were mostly in this category.

4.1.2 *Resistant Type.*

Children who are resistant to collaborate are those who know how to self-manage their T1D but do not have enough motivation to do so. These were children who gradually became knowledgeable about their illness management after a few years of experiencing treatment and learning from their caregivers. However, their low motivation often led to a passive collaboration led by their parents. For instance, they would bring the materials for treatment (e.g., insulin pen, alcohol swabs, etc.) to prepare a treatment and eat the snack that they were told to, but when there was no surveillance or specific request from their parents, their interest in engaging in self-care decreased.

The parents of resistant type children often faced conflicts with their children. This was because children were not motivated to engage in expected illness management, such as taking insulin before having snacks (P2, P5, P9, P13, P14, P16). They were not interested in self-care tasks or simply did not want to do them. This disregard for their health led to conflicts because, for example, having a snack without taking insulin could increase a child's blood sugar level significantly, which can cause life-threatening dehydration, even leading to a diabetic coma. In the following example, C13's (11 y/o boy) description of his behavior is typical of resistant type children. Although C13 knew that he should take insulin after having a snack, he did not, which led to frequent conflicts with his parents. *"Usually, I would get really hungry and just grab something from the pantry and go back up to my room. Usually, my parents figure [it] out and then I get in trouble. I get in trouble for not taking my insulin. (C13)"* In another case, P16 shared her experience when she tried resolving the issue by talking to C16 (10 y/o boy) after having a conflict with her son: *"I feel like he does that [snacking without telling] sometimes when I'm not looking, and sometimes I figure it out because I know how I put it out and how much I've put there. And if it's missing, I know somebody has done something [snacking without telling], but other times I don't realize it… until I check his levels and they're pretty high, so I know something fishy is happening here because I monitor him pretty much throughout the day nowadays. (P16)"* When a child had little motivation to properly manage the disease and refused to sufficiently communicate about snacks, parents were required to closely monitor their child's blood glucose level, and frequently had discord with the child when their glucose number went up unexpectedly. Furthermore, when the parents forced their children to perform self-care, children became more resistant to their treatment. C16 (10 y/o boy) mentioned feeling that his parents were too intrusive: *"She tells me what to do but sometimes I don't listen to her because I feel like [I'm] being controlled all the time. (C16)"*

To prevent pushback and lessen the conflicts, some parents eventually tried to allow their children to skip self-care if they did not want to do it. For instance, P5 explained why she does most of the care tasks for C5 (10 y/o boy), even though C5 knows how to do them himself: *"He can do a lot [of self-care]. But he would rather not [do those]... He doesn't like to change his devices [CGM and pump]. He can, he just doesn't like to, so we mostly do that now, and I'm okay with that because at least he knows how to do it if we weren't around… he's still a kid, and I don't want him to fully take care of all of his care. We still want him to be able to be a kid at this point. (P5)"* This quote shows that P5 knew that C5 was able to change the devices (CGM and pump) by himself; however, knowing that he wouldn't do it, P5 usually did it, in part because she wanted C5 to be like other kids who did not have to constantly manage an illness.

In addition, parents had challenges when their resistant type children started developing strategies to escape from the painful treatments as they became more knowledgeable about T1D and its treatment. C19 (11 y/o girl) was afraid of the insulin shots, so she began not eating meals to avoid them: *"But as time went on, even before the CGM, she was trying to find ways to avoid... 'Oh, I'm not hungry,' when she hadn't eaten for half the day, or she felt that the more insulin she had to give herself in a shot, it hurt more. (P19)"* As these children knew more about T1D, parents needed to work with their refusal and resistance.

In summary, since resistant type children were educated and knowledgeable of how to manage their illness, their parents naturally had high expectations for their self-care. As a result, conflict frequently arose when their child's motivation was low (regardless of age), and the child relied heavily on their parents' help for conducting self-care practices.

4.1.3 *Eager Type.*

Children who are eager to collaborate have high motivation to self-manage their T1D and are curious about learning T1D management; however, they still have limited knowledge of how to do so. In some cases, this type of child had a high motivation to learn and perform self-care shortly after the diagnosis despite their young age and was willing to carry out any part of the self-care process. For instance, C1 (8 y/o boy) was eager to learn self-care skills, so that he could still do things alone when his parents were not around: *"I'm trying to learn how to do [treatment] so when if I'm doing something. And if my mom and dad are not there I can do it myself. (C1)"* In another case, C3 (9 y/o girl) wanted to try a new pump when she saw another person using it at school: *"And then I went to school one day and I got really low so I was in the office for like an hour, but the [office] lady that had the t:slim [pump]. She showed me like a little thing [pump]... so I thought this is cool I'm gonna have to ask my mom about the [pump]. (C3)"* These children engaged in proactive learning in their illness management. However, interestingly, we found that a high enthusiasm for self-management could sometimes be challenging, even problematic, when the children did not have enough knowledge or skills for self-care. These challenges were amplified when the parents also lacked knowledge and skills because parents could not provide timely support to address the child's needs, which could cause a delay in the child's independence.

Eager children often caused their parents' anxiety when the parents were not sure if it was appropriate to let their children engage in self-management (P7, P13). For instance, C7 (11 y/o girl) wanted to do most of the treatments by herself right after being diagnosed when she was only 7 years old. Her parents worried that she was too young, and sought a consultation with her doctor to get an expert's opinion. Eventually, they decided to let C7 self-manage her T1D. Her mother recalls, *"I let her [give herself a shot], and then I remember saying to myself, 'Oh, crap. I don't think that was okay.' I followed up with her endocrinologist and everybody, and it was like, 'Yeah, Mom, that's good. If she wants to take the shots, let her.' (P7)"*

In short, eager type children lacked knowledge about their health condition and self-care skills but were highly motivated to carry out self-care despite their young age, and thus immediately sought the support of their parents to do so. However, this was challenging for the parents if they were anxious about the child engaging in self-care too quickly. But overall, we did not see significant parent-child conflicts because most children in this category were very responsive, responsible, and proactive in their illness management.

4.1.4 Independent Type. Compared to the eager type who still lacked self-care knowledge, children who are independent in collaboration were knowledgeable about their self-care and could independently self-manage T1D, although they were still under parental guidance due to their young age. Since these children had both high knowledge and high motivation to engage in self-care, we found that the level of child's cooperation was high, as children were doing most of the self-care while parents were intermittently reminding or monitoring them.

Regardless of their self-direction, some independent types were still worried about their ability to properly manage their illness or forgetting to do so (P9, P16, P19). For instance, C16 (10 y/o boy) knew that he could check his blood glucose level by himself using a glucometer, but did not feel confident doing it alone when a parent was not around, like a school setting. In another case, C19 (11 y/o girl) occasionally had emotional struggles about missing her blood glucose check even though she was usually diligent with most of her self-care tasks: *"Sometimes I feel bad because I wasn't responsible enough to check my blood sugar every hour, every two hours. I'm like, 'Okay, now I need to go check my blood sugar and I'll try not to do it again,' and if I do it again, I feel a little angry at myself. (C19)"*

Some parents also did not fully trust their children, which led to them placing restrictions on their child's self-management even after the child had already become quite independent. For instance, some children were not allowed to go to sleepovers or use their own digital devices (e.g., smart phone, smart watch) because the parents did not fully trust that they would carry out their self-care practices (P3, P5, P9). A few parents even used technological devices of their own to monitor their children (P3, P5, P13, P18), helping them feel more secure and allowing their children more autonomy. C18's (12 y/o boy) dad mentioned: *"But having the Dexcom Follow app [tracking app connected to the CGM device] just made that, at least our emotional comfort level, a lot higher. A lot more trusting and able to let [C18] have a little more autonomy, so. (P18)"*

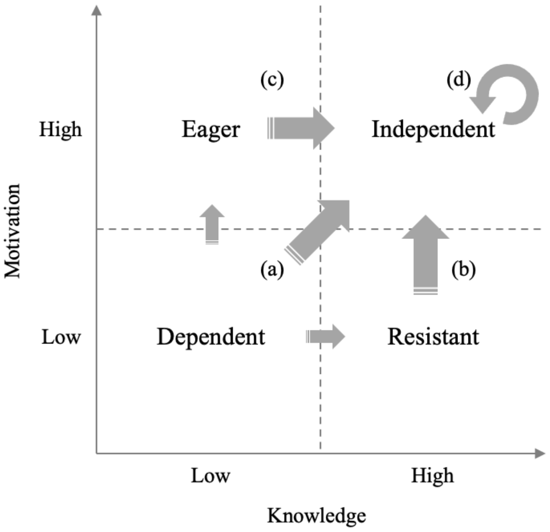

Figure 3: Different transition pathways toward children's independence depending on parent's strategy: (a) dependent to independent, (b) resistant to independent, (c) eager to independent, (d) maintaining independence

In summary, independent type children were highly involved in their self-management but sometimes faced emotional struggles if they did not feel confident about their self-care. Also, parents who had less trust toward their child's self-care were still involved in monitoring their child frequently and gave certain restrictions to ensure the child's self-care practice.

4.2 Parents' Strategies for Children's Transition to Independence

In addition to the four types of children's collaboration on how they engaged in the treatment of their T1D with their parents, we recognized various strategies the parents developed to help their children progress towards independent self-care. While the ultimate goal was for their child to become the independent type (i.e., high motivation and high knowledge), the intended transitions occurred differently depending on the child's current state (i.e., whether the child was motivated or knowledgeable) as shown in Figure 3. These transitions were also impacted by other factors such as the child's developmental stage and parental involvement. In our study, most children started from the *dependent* type when they were first diagnosed because they were very young and had less ability to do self-care. But they gradually became either *resistant* or *eager*, or eventually *independent*, as they gained more knowledge and motivation through the support of their parents. For instance, parental involvement such as giving rewards or inviting children into decision-making that could make children more motivated in self-care was crucial for the *resistant* type of children, whereas parents' educational and informative support that could facilitate the knowledge of *eager* type of children in self-care was important for children's successful transition to independence. We describe

Table 2: Summary of the parental strategies for children's independence in self-management

Child's Transition	Transition Goal	Main Parental Strategies
Dependent to Independent	Increasing the child's knowledge and motivation	- Teaching urgent parts of self-care skills (e.g., seeking help from others) - Emphasizing the importance and necessity of self-care
Resistant to Independent	Increasing the child's motivation while the child has high knowledge	- Giving rewards to boost the child's engagement - Involving the child in the decision-making process - Creating a comfortable environment for the child's self-care
Eager to Independent	Increasing the child's knowledge while the child has high motivation	- Quickly learning about T1D and transferring knowledge - Reaching out for outside help (e.g., health professionals) to better handle their child's curiosity and demands
Maintaining Independence	Supporting the child continuously motivated and learning to do self-care	- Supporting the child to feel safer with doing self-care by double-checking and reminding treatments - Adjusting the child's engagement level in self-care

each of these children's transitions and the different strategies the parents used, as summarized in Table 2.

4.2.1 Dependent to Independent Type: Increasing the child's knowledge and motivation. To help a child with low motivation and little knowledge, parents tried to make their child more knowledgeable and motivated to participate in self-care. As mentioned earlier, timely communication between children and caregivers is crucial for conducting T1D treatments, however, this was difficult for dependent type children because they were sometimes unable to understand T1D and why they needed treatments.

Most parents wanted their children to learn skills specific to the more urgent parts of self-care, such as seeking help from others when the parents were not available. For instance, when C15 (9 y/o girl) started kindergarten, P15 taught her to inform other adults about what she ate so that someone at the school could help with carb counting. As COVID-19 hit, P15 also had to teach her how to enter things in the pump by herself for when no parapros[1] were there: *"I think it's more what she needed at that time. When she started kindergarten, I needed her to understand that she had to have insulin after each meal, so that she could advocate that, 'I just ate, here is what it is.' I knew she couldn't count her carbs, I knew she couldn't give herself insulin, but [it was] enough to know that she needed to look for somebody to do that. Then as it started looking like we were getting into the COVID time period, then I was starting to go, 'Okay, we may not have parapros, we may not have this.' So it's more about how to be a little bit more independent by being able to enter things into her pump. (P15)"*

Some parents also tried to motivate their children by consistently emphasizing the importance and necessity of self-care, although they found it challenging to make their children understand without also making them feel bad about being a T1D patient (P3, P5, P9, P18). Since the children had difficulties understanding the importance of self-care, parents persistently tried to instill it into their children by frequently talking with them about their thoughts. C3's (9 y/o girl) mom mentioned, *"I think what helped her is [that] I told her, everybody has to do something to take care of themselves. You know everybody has to watch what they eat, to exercise. Everybody has to take vitamins or go to the child checkups once a year. Everybody has to go to the eye doctor. This is what you do. (P3)"* Some parents also taught their children about the importance of recognizing symptoms by paying attention to their body (P1, P3, P8, P17). For instance, C17's (9 y/o boy) mom explained, *"One thing we try to get him to do is just pay attention to his body and what his own body needs, and how to work on correcting that. (P17)"* Still, some children were not able to recognize their symptoms. In this case, parents tried to quickly adopt a CGM or pump so that the child could better understand their blood glucose levels by looking at the colored numbers and icons displayed on the device (P3, P4, P13, P18).

In short, the transition from the dependent to the independent type involved various strategies to make the children become more knowledgeable about their health condition and the most important self-care skills, and more motivated to do self-care by instilling its importance into the children.

4.2.2 Resistant to Independent Type: Increasing the child's motivation while the child has high knowledge. Resistant type children had more conflicts with their parents due to a lack of motivation to get involved in self-care. To mitigate the conflicts, parents used several strategies to get their child more motivated and engaged in self-care. The most common strategy used by parents was giving rewards. These children already had enough knowledge to carry out self-care but did not have enough motivation, so rewards were a direct and quick way to boost the children's engagement. Several types of rewards were mentioned during the interviews: screen time (P8), playing with parents (P15), dying hair a favorite color (P15), new books (P16), and stuffed animals (P4). C15 (9 y/o girl) described how she liked the rewards for performing self-care: *"I like it because I normally dye my hair blue and I have it bleached right now since the last time, so I already decided the color that I wanted. I want my hair in the summer to be pink, and my hair in the school time to be blue, and then I'm trying to talk them into getting a puppy if they're lower and better. (C15)"* While P15 was happy that C15 was more involved in self-care by getting rewards, she was also worried that C15 may want bigger rewards (i.e., getting a puppy). Though rewards worked effectively most of the time, parents also

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[1] paraprofessionals who help children manage diabetes 1:1 at school

found that they came with certain limitations. They were frequently unsustainable (e.g., some children kept changing their mind about what kind of reward they wanted); or even at times inappropriate (e.g., giving food as rewards).

The next strategy parents used to motivate their children to engage in self-care was to involve them in the decision-making of their treatments (P2, P4, P10, P15, P19). For instance, P2 let C2 (12 y/o boy) choose the pump that he wanted: *"So [C2] was able to see different kids who had different pumps and kind of talked to them a little bit and then I think his, his friend and Oklahoma had the same pump. And that was part of what kind of led us to this one [pump], because I did want him to kind of take most of that. Like having the choice, mainly be his, and I would support whatever he wants to do because again, this is going to be on his body, it's not on mine. (P2)"* When a child and a parent had differing opinions, they would negotiate, as in C19's (11 y/o girl) example: *"Well, I think if we had our choice, maybe we would've gone with t:slim [pump], because of the closed-loop to the Dexcom option that at least is available currently. But she was very adamant about not wanting to, so the negotiation came into play where okay, it's not the slick system that we would like, but you're comfortable with it. It's an improvement. (P19)"*

Other strategies to increase resistant type children's motivation include creating a comfortable environment in which the child could participate in a self-care task by waiting patiently until the child becomes more comfortable with self-care, using devices like a CGM and a pump, and letting the child engage in fun, active activities that might have a similar effect as self-care, such as dancing. For instance, P2 encouraged C2 (12 y/o boy) to minimally participate until he felt comfortable: *"So I would encourage him to do what he was comfortable with but told him that I would do everything else and that's kind of how it's been. (P2)"* Another parent P11 motivated C11 (7 y/o girl) to be active when she has a high blood glucose level by playing music to dance: *"If you know she needs to be active, you can try to motivate her to do some activities or put music on so that she can dance and things like that. (P11)"* Also, other parents purchased and used devices like a CGM and a pump for children to have an easier time with treatment. C19 (11 y/o girl) described how using a pump made her more comfortable with care: *"In the beginning, I just got sick of stuff after like the first three weeks. I would act like I didn't want to eat anything. And then after the pump, I feel like I can have snacks whenever I want and I'm really excited about it. It's been a real lifesaver for me. (C19)"*

The transition from resistant to independent was supported by different styles of parental involvement to increase the child's motivation. While some parents used more direct strategies, such as giving rewards, others took a more inviting and gentle approach, such as including the child in the treatment's decision-making process or creating an environment in which the child felt empowered to do self-care.

4.2.3 Eager to Independent Type: Increasing the child's knowledge while the child has high motivation.

For an eager type child (i.e., high motivation for self-management but low knowledge), parents tried to quickly learn and become more knowledgeable about T1D and its management practices so that they could transfer the knowledge to their child in a timely manner. Since these children tended to be curious and interested in learning and trying new things, the parents frequently reached out for outside help, such as to health professionals or educators, to better handle their child's curiosity and demands, with the hope that the child could safely learn about their illness and become independent. For instance, when C13 (11 y/o boy) wanted to get a pump immediately after his diagnosis, his parents had to persuade him to wait while they did their own research so that they could make a more appropriate decision about the pump and teach him how to use it accurately: *"Oh, he wanted a pump before we even left the hospital once he found out what that was... He was like, "I want a pump, mom. I want this."... I still told him that we were going to have to wait and look into it... We did a lot of research, yeah. Talked with a lot of people, did a lot of research before we chose which pump we chose. (P13)."*

Many parents used diabetes camps for getting their children more knowledgeable about T1D because these camps have professionals to teach their children (P11, P13, P15, P18). For instance, C18 (12 y/o boy) has gone to the American Diabetes Camp every summer since he was five years old: *"Yeah, so he goes to the American Diabetes Camp every summer, and has been going since he was five I think. I think he did maybe three years of day camp and then maybe since he's eight he started doing sleepover camp for a week. It's structured with nurses and doctors all over the place, basically parapros, so it's definitely a diabetes camp, so I think that was our comfort level there. (P18)"* Similarly, P15 sent C15 (9 y/o girl) so that she could learn new skills every year: *"Prior to the whole COVID thing, she would go to camp every year and they would teach her a new skill each year, and I knew she lost that because there was no camp last year, and there's no camp this year. Kind of took that over. (P15)"*

For eager type children, their transition to independence required an appropriate and timely education. Thus, parents needed to become informative, knowledgeable, and skillful shortly after their children's diagnosis, actively seeking outside help to provide the necessary and appropriate information.

4.2.4 Maintaining Independent Type: Supporting the child continuously motivated and learning to do self-care.

Although independent type children had both high levels of knowledge and motivation, they could still transition back to the resistant or eager types over time due to changes in their life circumstances or their feelings about carrying self-care. For example, some children did not always feel safe about doing self-care and neglected their self-care when they were not with their parents. To prevent this, parents tried to help their children feel safer and confident at carrying out their self-care by helping with treatments, such as double-checking their insulin and infusion sites (P9, P13, C19), remotely monitoring their blood glucose levels (P5, P15), and intermittently reminding them to check their insulin (P5, P9, P13). Most parents had their children adopt technological devices, such as CGMs or insulin pumps so that it would be easier for them to manage the illness on their own (P3, P13, P19). For instance, C19 (11 y/o girl) felt safer and worried less after getting a CGM: *"I felt a lot more safe because before I had my CGM, I felt like I was going to pass out in the middle of the night and not notice, and then I would be passed out all night. But now I feel like I'm much better and I can run around more and I feel more free than I did when I had to poke my finger. (C19)"*

Some parents and children would make a collaborative decision to have full freedom during specific periods, for example, a cheat day, particularly when illness management became too tiresome (P1, P5, P13, P20). This allowed the child to feel some freedom from the 24/7 self-care. For example, P20 explained that although her daughter was pretty independent in her treatment, they sometimes found that she wanted a break from looking at her devices. They agreed to allow C20 (12 y/o girl) to take off the CGM once a month: *"And then she will ask, about once a month, to have 24 hours off of her pump where she knows we're doing injections and she knows she has to be the one that does most of them and she seems to be fine with that. So we try to pick a weekend so it's not during the school day because that's a lot harder because then she's running to the office all the time for correction shots and stuff like that. (P20)"* Although letting children have too much freedom could be risky, the parents respected and trusted their children's self-management enough to allow them to have small breaks and reduce their burden from self-care.

In short, independent children required much less of their parents' involvement than the other types. Nevertheless, parents tried to help their children feel safer while doing self-care and minimize the child's mental stress. If parents had enough trust in their child's self-care performance, the parent and the child made self-care rules and decisions flexibly together, so that the self-care would not be too burdensome but sustainable.

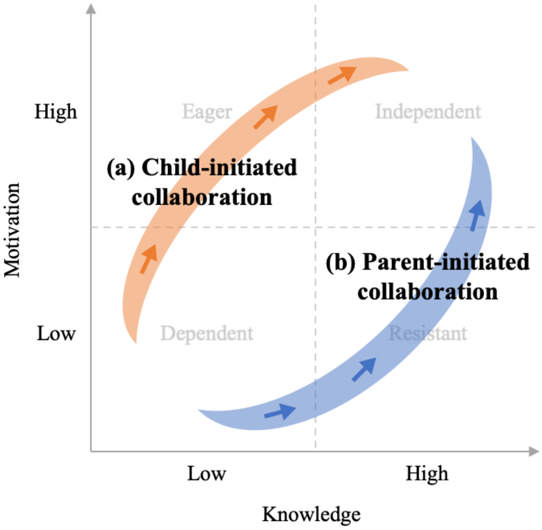

Figure 4: Overall transition pathways from the dependent to the independent type: (a) child-initiated collaboration, (b) parent-initiated collaboration

5 DISCUSSION

5.1 Identifying Knowledge and Motivation as Key Factors for Children's Independent Self-Management

Self-management (or self-care) is the cornerstone of diabetes management because daily care tasks, such as monitoring blood glucose and adjusting insulin, are required of patients to maintain their health condition without any life-threatening risk [61]. Existing literature on pediatric diabetes has reported that a child's responsibility for their T1D tasks directly correlates with their age [6, 40]. According to this prior finding, children's participation in self-management varies and occurs based on different developmental stages, including the level of motor development, cognitive ability, and emotional maturation, [69] that largely progress as they get older. Preschoolers and early school-aged children (3-7 years) often lack motor control and cognitive development but can gain confidence by participating in simple tasks, such as testing blood glucose or helping to keep records. School-aged children (8-11 years) have more developed cognitive and social skills and, under the supervision of an adult, can get involved in additional tasks, such as counting carbohydrates and insulin injections. During pre-adolescence, children are able to develop greater autonomy and become increasingly independent [16] since they have the fine motor control to perform most self-management activities, although they still might need help with decision-making about insulin adjustments [21]. Our study findings support this prior understanding that age influences the level of children's engagement in self-care, especially for the dependent type children in our study. Child participants fell into the dependent type when they were in preschool (3-5) or kindergarten (5-6) because they had insufficient cognitive abilities and communication skills to fully understand T1D. Some of these children gradually made the transition to the independent type as they got older and became more aware of their diagnosis and better understood how to manage their T1D.

However, our study also shows that a child's progression towards independence is not always linear nor temporal, or determined by their age or by the time since diagnosis. In other words, being older or having more experience with T1D does not always mean that children are capable of more independently carrying out self-care. In our study, a child's level of knowledge and motivation were found to be critical factors when transitioning to independence. Crucial to building self-management skills are knowing accurate T1D treatment information and having enough motivation to participate in self-care. In addition, knowledge and motivation are especially important in the children's collaboration with their parents, since these factors tend to determine whether the collaboration is child-initiated or parent-initiated, with child-initiated collaborations leading to a quicker and more successful transition to independence. For instance, eager type children were more proactive in learning how to do management, which sparked 'child-initiated collaboration' in T1D management (pathway (a) in Figure 4). This often facilitated the child's rapid transition into independence and led to successful collaboration between the parents and the child. On the other hand, resistant type children who were slow in gaining motivation and were relatively passive in their cooperation for T1D management, leading to 'parent-initiated collaboration' since the children passively learned self-care due to their low motivation and interest despite their older age or longer duration of diagnosis (pathway (b) in Figure 4). We also want to note that the amount of knowledge and motivation a child has can also change, can either increase or decrease, in response to the amount of work and effort put in by their parental caregivers (although some children were highly motivated just because of their character). A child's knowledge and motivation are essential to achieving an independent self-management practice and should be well-supported. How promptly parents identify a child's lack of motivation or knowledge and respond with effective strategies can determine how well a child is able to gain the necessary independence for self-management.

Knowledge and motivation have been covered in prior studies as key factors for successful self-care. In the HCI community, personal informatics literature has discussed them primarily for the use of self-tracking tools that collect data such as symptoms, physical activity, and dietary habits [20, 46, 62]. Knowledge plays a role in the understanding of health information, i.e., data, and motivation act like an intention, relating closely to user engagement with health applications (e.g., user engagement may decline if they feel that mHealth tools are difficult to use or the tools cannot meet their expectations [20]). While these studies have mostly looked at knowledge and motivation separately in the context of self-care tool use, our finding suggests that knowledge and motivation are both necessary for successful child-parent collaboration in illness management. In addition, social psychology studies on health and illness have presented the Information-Motivation-Behavioral skills model (IMB model) that illustrates how information and motivation lead to building better behavioral skills and performing more self-care [22]. In other words, when a patient has enough information (i.e., relevant knowledge of their illness and medication) and motivation (i.e., a personal desire to carry out self-care), they can develop sufficient illness management skills and maintain self-care with continuous effort. While this model was widely based on adult [3, 60] and adolescent [59] patients, extending on these previous studies, we have found that a child's independence in illness management also requires both sufficient knowledge and motivation for the collaboration with their caregivers.

5.2 Developing Appropriate Parental Strategies for Collaborative Illness Management

In pediatric care, adult or parental supervision is necessary to assure the children's appropriate self-management as the care responsibilities are transferred to the children as they grow up [69]. Educating and transferring illness management skills from the parent to the child is a proactive process that involves sharing and shifting responsibility for care tasks and decision-making [63]. However, the practice of transferring care from parent to child is complicated and not well studied in the literature; the transition is often difficult due to over- or under- parental involvement, often resulting in negative health outcomes for children with T1D, such as higher A1C levels and poorer self-care skills [30, 45].

Existing research has also discussed the impact of various parenting styles in relation to children's adaptation and performance on achieving independence and their psychological well-being while gaining independence [10, 70, 84], and has presented four typical parenting patterns: authoritarian (communication is unidirectional and enforcing); authoritative (communication is bidirectional but the parents make the final decision); permissive (parents advise and inform their children to make better decisions); and neglectful (parents show little to no interest in their child and minimize their involvement) [10]. Prior research's most common results suggest that an authoritative parenting style is most effective for establishing a child's independence [70].

According to our analysis, however, the optimal level of parental involvement differs depending on the child's collaborative care type (i.e., dependent, resistant, eager, and independent types of collaboration and different transition pathways in our study). That is, one parenting style, like authoritative, may not be effective for all types of children because each child's knowledge of T1D and level of motivation is different. Specifically, our study indicates that the most involved child-parent collaboration efforts occur with the 'eager' and 'resistant' types. The dependent and independent types require either high parental involvement (because the children lack sufficient abilities) or low (because the children can manage their own treatment). For the eager and the resistant types, parents must extend more of an effort to work with a child who lacks either motivation or knowledge. While parents of the resistant type needed to compensate for their child's lack of motivation in order to maintain the child's health, the parents' timely involvement with the eager type children hastened their transition to independence. Thus, it is important that parental involvement is carefully designed according to the child's type and transition pathway.

Likewise, the appropriate level of parental involvement needs to be flexible to the changes in a child's type and pathway over time. In our study, some parents actively developed and used different strategies to better adjust their involvement and cope with their child's changes in self-care. For example, when the child showed signs of transitioning back to being more resistant from independence, parents needed to adjust their involvement in their child's illness management by imposing restrictions, such as a more regulated diet or no sleepovers. Here, the parent strategies were used to become more authoritative. On the other hand, to prevent the child from being overburdened by self-care, even if they were highly motivated, parental involvement may become more permissive by using strategies that allow the child some freedom (e.g., turning the CGM off for a day and instead of using a glucometer, having a snack freely while taking insulin). Thus, parental strategies need to be developed to balance the parental involvement level but also they should be flexibly deployed in response to how the child reacts and behaves in their self-care.

Therefore, how quickly parents can identify their child's current states of knowledge and motivation as well as any change in the child's self-care behavior and then develop appropriate strategies is necessary to facilitate an optimal parent-child illness management collaboration. This is because diabetes is not a disease that can be managed by the caregivers' work and effort alone, but requires a significant amount of the child's cooperation in the form of independent self-care. By tracking and identifying the child's knowledge and motivation levels, parents can properly transfer responsibility when the child demonstrates success in managing diabetes tasks, and they can also prevent the child from taking on more responsibility for their diabetes management than they have the capability or motivation to handle. This practice can help avoid burdening the child and putting risk on their health outcome. In the next section, we discuss how health technologies can support more effective collaboration between child patients and their parents.

5.3 Design Implications for Technologies to Support Collaborative Care

Based on our study insights, we suggest three main design implications for technologies to support child-parent collaboration in chronic illness management: identifying the child's knowledge and motivation levels, developing strategies for collaborative T1D management, and adjusting the child-parent involvement accordingly.

5.3.1 Identifying Child's Knowledge and Motivation Level. While many existing health education tools that support T1D management have been developed primarily focusing on a child's age and developmental phase [69], our findings showed that levels of knowledge and motivation mattered more in the transition of children with T1D to independent self-care. Thus, identifying the child's current states of knowledge and motivation (i.e., their collaboration type) is crucial to the parents' development of an effective transition strategy to help their child become independent in their self-care. We believe that a more personalized system can be developed to support the different levels of children's self-management knowledge and motivation. For instance, a self-tracking tool connected to diabetes devices (e.g., CGM and pump) can recognize how much the child knows about illness management and track their engagement in self-care. Also, diabetes education tools can include features that track a child's knowledge and motivation levels to identify a child's ability to engage in self-management.

However, we anticipate that these tracking tools might be more effective for eager or independent type children who have the high motivation to engage in learning and performing self-management since the dependent or resistant types may not be willing to use such tools. Thus, we suggest that these tools should also provide collaborative tracking by incorporating parental involvement and support. Previously, self-tracking has been primarily used by individuals, but some recent studies have shown that self-care technologies should enable both patients and their caregivers to collaborate in illness management, as they do in everyday life [15, 48, 54]. This is because independence in illness management is co-constructed by the choices and activities of the care network, including the patients, caregivers, and clinicians [12]. This view becomes even more crucial for child patients who can't yet manage their illness by themselves. Thus, we suggest collaborative tracking technologies that enhance parent-child collaborative efforts and facilitate parents' assistance of the child in the transition to self-care. For instance, a system can monitor how much the child is involved in these tracking activities (e.g., checking blood glucose level, helping with carb counting), and share the data of the children's involvement with the parents. Based on the child's current involvement level, the system can recommend if parents need to be involved in tracking collaboratively with the child and give suggestions on how to improve collaborative tracking.

In addition, our study showed that independence was achieved when both motivation and knowledge were high and there was a critical need to balance between motivation and knowledge in the process of their child's gaining independence. In prior research, a too quick transfer of responsibility to the child in diabetes management was associated with poor outcomes [82]. To help parents decide the appropriate level of care tasks and responsibility and whether their child is ready to learn a new skill, a system could track whether the child has enough motivation and suggest the right timing. This could help parents more safely transfer responsibility to their children when they demonstrate enough motivation to manage their diabetes tasks and prevent them from taking on more care responsibilities than they can handle.

5.3.2 Developing Strategies for Collaborative T1D management. In our study, when parents identified their child's collaborative type, the parents often responded to it by developing different strategies that could more efficiently facilitate the parent-child illness management collaboration. The study also showed that child-parent collaboration was more active among pairs with eager or resistant type children because the work between the child-parent pair intensified when either knowledge or motivation was missing. Consequently, as discussed earlier, their collaboration was often manifested in either child-initiated collaboration among children who gained more motivation compared to knowledge (pathway (a) in Figure 4), or parent-initiated collaboration among children who gained more knowledge compared to motivation (pathway (b) in Figure 4). Thus, we suggest that developing optimal strategies to help the child gain independence should be designed collaboratively between children and their parents considering these collaborative pathways.

For child-initiated collaboration (in Figure 4), diabetes education tools could be designed to support what a child wants to learn or know about T1D, since children who initiate the collaboration have enough motivation to learn and their curiosity is more centered on specific topics, such as self-care devices. For instance, in the case of C13, who was so eager to use a pump and learn about it, the system can provide specific information, such as what type of pumps are used and how to use them. At the same time, the same content can also be provided to the parents or other caregivers, since the challenge with the eager type children can worsen when their caregivers also lack knowledge. While existing education tools are more focused on teaching only the child, parents also need to learn the skills. This is crucial, particularly for the case of newly diagnosed children, where both the child and parents, or the entire family, need to get educated immediately after the initial diagnosis [77].

For parent-initiated collaboration (in Figure 4), a recommendation system could suggest different parental interventions and strategies for parents based on the child's current knowledge and motivation levels as well as the urgency of the content. For example, parents may have a hard time figuring out what skills need to be taught to the child first when they try to help their dependent type child gain more self-care skills and knowledge. In this case, the system could recommend which strategies should be implemented first to expedite the child's process of gaining more independence. For instance, 'recognizing T1D symptoms' and 'understanding the importance of timely treatment' should be taught and understood by the child earlier on since these skills are needed for the child to be able to reach out for help when needed. If such recommendations were made by the system, it could ease the burden in cases in which the parents initiate and lead the collaborative efforts as some may struggle with knowing the appropriate level of parental control and involvement in their child's T1D self-care, as we saw in our study.

5.3.3 Adjusting Child-Parent Involvement Level. As mentioned in the discussion, it is necessary that both the parent's and child's involvement levels in their collaboration should be balanced and adjusted according to the child's capacity and willingness to engage in self-care. Even with independent type children, our parent participants still occasionally monitored and checked up on their child's health status because they worried about overburdening the child with responsibilities and thus decreasing their motivation.

The parents' efforts to balance between the need to keep the child free from stress and the need to ensure that their child was engaging in appropriate self-care became even more crucial as the children became more independent and were expected to feel confident enough to carry out their self-care [71]. To address this concern, we argue that a system could regularly check and track a child's feelings and confidence level to figure out whether the child is overburdened with excessive self-care tasks. If the system recognizes any noticeable concern, it can notify the parents with recommended strategies to help the child feel less burdened (e.g., finding a good time to take a break). Also, by recording specific recommendations/strategies that worked for the child, the system can learn from the data and suggest more timely and personalized strategies, thereby preventing the child from losing motivation when he/she may not have enough motivation to handle more care responsibilities yet. We acknowledge the potential privacy issues of such a system in which the data regarding a child's emotion is shared, so any data that could be shared with the parents should be discussed between the child and parents prior to data collection and its privacy setting should be also adjusted at any time throughout the system usage.

We also found that many parents faced substantial lifestyle restrictions and mental stress, especially with dependent type children, since the parents had to manage almost all of these children's diabetes care. To support this burden on parents, a virtual agent on a smart device could take on some of the caregiving roles to assist parents to balance their involvement level in self-care duties. For instance, when parents are apart from their child or are too busy at work (a situation that gives more anxiety to our parent participants), a virtual agent integrated with a CGM or pump could monitor the child and help motivate them and instill the importance of self-care by saying encouraging words to the child (e.g., quotes from famous people who have T1D). By facilitating and advancing the adjustment of the children's and the parents' involvement levels, we expect more efficient and sustainable child-parent collaborations, which could eventually enable children to better achieve and maintain their independence.

5.4 Limitation and Future Work

Our study focused on the self-management of children with T1D, and the results may not cover all aspects of children with chronic illnesses. While T1D management requires a lot of care practices both by children and their parents, further research is necessary to explore child patients with other chronic illnesses (e.g., cancer and asthma) to see if they show a similar transition to independence in illness management.

Though the children's current state of knowledge and motivation levels significantly affect their transition pathways from the dependent to the independent type, their transition can be also impacted by other factors, such as developmental factors and parenting styles, as we discussed. Future research with a larger sample size that includes diverse parenting styles with children in different developmental stages is required to identify other influencing factors and further explain their association to the transition pathway model in detail.

Because we recruited child patients between the ages of 6 to 12, the findings of this study are specific to this age group. While focusing on this age group derived rich insights on a child's transition to independence, very young children (less than 6 years old) and older children (adolescent and young adults) should also be examined. Future research can explore if there are any similarities or discrepancies to our findings for different age groups.

Additionally, although we only interviewed parental caregivers (the primary caregivers), there are also other caregivers in the family, school, and other places, involved in the children's illness management. The children's collaboration with other caregivers in the family (e.g., siblings), in the school (e.g., teacher, paraprofessional, school nurse), or in the clinic (e.g., doctor, nurse) can have characteristics that are different from that of the child-parent dyad.

Lastly, our data was collected from February to June of 2021, when most outside activities and in-person school schedules were interrupted because of the COVID-19 pandemic. Although we focused on the child-parent collaboration in the home setting, these specific circumstances could have influenced the participants' answers related to self-care challenges or the strategies employed when parents were apart from their children.

6 CONCLUSION

Children with T1D and their parents collaborate toward the children's independence in illness management. However, less had been known on how children collaborate with their caregivers as they gain independence in self-management. To investigate how children and their parents collaboratively manage T1D, we conducted semi-structured interviews with child-parent dyads. Our study showed that independence is not always a linear process but the level of knowledge and motivation matters in transitioning to independence. Thus, how parents quickly identify a child's current state of knowledge and motivation and respond to it by developing strategies can be necessary to facilitate their collaboration with children. Based on these findings, we suggested design implications for technologies to support collaborative illness management for children's transition to independence.

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