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From diagnosis to routine care in type 1 diabetes in children: Parents' experiences

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From diagnosis to routine care in type 1 diabetes in children: Parents' experiences

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Abstract

Having a child who lives with a Type 1 Diabetes (T1D) can represent a high burden for parents. The objective of our study is to identify and analyze the main challenges expressed by parents so that health care services better meet the needs of parents of T1D children. Semi-structured interviews were conducted with parents of 19 T1D children regarding detection and diagnosis, initial management at the hospital, post-discharge adaptation including daycare or school reintegration, and long-term T1D monitoring. Data analysis was performed following an inductive approach. The results showed a lack of knowledge regarding T1D in the society, especially for parents and educators. Furthermore, most parents felt overwhelmed at the hospital, and not ready for the intense self-management education (SME). They suggested it could be split over an extended period and discussed from a more practical perspective. Parents' burden is highest in the post-discharge adaptation stage especially for school reintegration, management of blood glucose levels and calculation of carbohydrates. Finally, returning to a social life was difficult, but contacts with diabetic families was a relief. In conclusion, the SME ought to be flexible and adapted to parents' needs. Spreading it over a longer period would ease families' experience. Efforts should also be made to alleviate the parents' burden on the post-discharge adaptation perceived as the most difficult stage, especially for school reintegration where training and resources on T1D should be given to key staff. Public education campaigns would raise awareness and ensure better knowledge of T1D by general population.

Keywords

Parents' experiences, Type 1 Diabetes, care trajectory, qualitative study

Introduction

An estimated 1.1 million children live with type 1 diabetes (T1D), and there are 130 thousand diagnoses each year around the world.¹ For parents, having a child diagnosed with a chronic condition can represent a significant burden.^{2,3} As such, T1D requires ongoing care and services at different life stages. For children, disease management requires support beyond the clinical setting to include the educational environment (school, daycare). It relies in large part on parents, but also, on providers in such settings, such as teachers in schools. Parents, as children's primary caregivers, play a central role throughout the whole care trajectory from the time of

diagnosis to daily diabetes management -when the routine sets in.

Different studies highlighted the burden of parents of T1D children.^{2,4-7} Difficulties faced by parents are reported at specific stages: at diagnosis,⁸ in the daily diabetes management when trying to achieve clinically recommended blood glucose levels,⁹ in the regular follow-up at home^{10,11} or by health-care providers,^{12,13} and at school.¹⁴ Researchers also focused on the psychological impact diabetes has on parents, i.e. distress, stress, depression, anxiety.^{7,15-17} Other studies reported the negative effects of stress on diabetes management and quality of life.^{2,15}

Despite the wide range of studies on parents' experiences with T1D, most of these are devoted to specific T1D populations (toddlers, young children or adolescents), specific problems (e.g., emotional impact) or specific stages of the care trajectory. There is a gap in examining parents' experience in a comprehensive way during the course of childhood, while the child grows and evolves with the condition. Also, there is a limited number of studies of parents' reflections on the trajectory as a whole, which could enable determining the difficulties faced during temporal and spatial transitions (hospital discharge, reintegration to school or daycare, routine care and return to active social life). Such an overall view would help to identify parents' needs throughout their experience with health care and educational services.

Our paper aims to fill these gaps through a descriptive qualitative study relying on semi-structured interviews with parents of T1D children. The interview guide was designed to capture parents' main concerns and challenges throughout the whole T1D trajectory in different environments and over time. Our objective is to identify and analyze the main challenges expressed by parents so that the research community, health care and social services providers, align their efforts to reduce the burden of T1D on parents of T1D children.

Methods

This research was designed as a descriptive qualitative study. We conducted semi-structured interviews with parents of T1D children who had received their child's diagnosis at least 6 months prior to the interview. It aimed to capture in-depth experiences of parents of a T1D child over time, from detection to routine care. The flexibility offered by an inductive research methodology allowed the parents to identify their most significant reflections and concerns throughout the whole T1D trajectory.

Subjects and setting

The study took place in Quebec City, in Canada. Canada has a universal public health system in which all medical and hospital care is provided free at the point of service. A convenience sample was recruited among parents of a T1D child followed at the academic health center affiliated with Université Laval (CHUL), which is the only healthcare entity managing pediatric T1D in Quebec City. At the CHUL, upon receiving a T1D diagnosis, children are admitted and hospitalized for 3 to 5 days. During that time, insulin therapy and self-management education (SME) are initiated by a multidisciplinary team specialized in pediatric diabetes care. The team consists of a pediatric endocrinologist, a diabetes nurse, a dietician, and a social worker. Upon discharge, follow-up is ensured by the diabetes nurse through daily phone calls for a week. The calls are then spaced out until the follow-up appointments with the diabetes care team. Follow-up appointments are

planned every three months with the endocrinologist, as well as with other healthcare providers when needed. Parents were interviewed on the main stages of the care trajectory: detection and diagnosis, the initial management at the hospital, the post-discharge adaptation, and the regular monitoring of T1D.

Recruitment

Purposeful sampling was conducted through the CHUL, at the time of follow up appointments as well as through posters in the waiting room and hallways of the diabetes clinic. Parents who expressed interest in participating met a research team member or sent an e-mail to the principal investigator, who explained the study and its implications in details. The association *Les diabétiques de Québec* also advertised the project on their website. Parents could contact the research team by email to obtain additional information.

Interviews were conducted with parents of 19 T1D children in person at a location of their choice, by phone or via Skype. Because of time constraints and since additional interested parents did not add to the sample diversity (children's age at diagnosis and at interview, as well as parents' level of education - see Table 1), the recruitment was stopped.

Data collection and analysis

Before each interview, the researcher explained the study, the confidentiality of the collected data and obtained the parents' consent. For each stage, the interviewer let the parents speak openly about their experience and asked a few more questions, when needed, following the interview guide to ensure all topics were covered. At the end of the interview, parents were invited to identify the most stressful, the most difficult and the least efficient stage(s). Interviews lasted about an hour, were recorded and transcribed in full.

The interviews were analyzed following a general inductive approach.^{16,17} Each parents' interview was first listened and read in full to identify preliminary themes. Using the qualitative software application Nvivo, two researchers independently coded the transcriptions and their results were examined for concordance. An iterative and recursive process between data and analysis allowed the researchers to identify recurrent themes and sub-themes, as identified by bolded and italic headings in the next section. Research ethics approval was received from the Research Ethics Board of the CHU de Québec-Université Laval (N° Project 2017-3020).

Table 1. Child and parents' demographics

Characteristic	n (N=19)	mean ± standard deviation
Child's gender		
Female	13 (68%)	
Male	6 (32%)	
Child's age at diagnosis		(5,4 ± 4,0)
< 5 years old	10 (53%)	
5 – 9 years old	4 (21%)	
10 – 13 years old	5 (26%)	
Child's age at interview		(9,2 ± 4,9)
< 5 years old	6 (32%)	
5 – 9 years old	4 (21%)	
12 – 16 years old	9 (47%)	
Mothers and fathers' level of education	Asked for both parents (n=36)	
High school	9 (47%)	
Postsecondary school	18 (47%)	
Higher education	11 (58%)	

Results

Delayed detection and diagnosis

About a third of patients needed intensive care at the hospital. Parents' lack of knowledge of T1D symptoms, resulted in a delayed detection. In several other cases, detection was delayed because of misdiagnosis in primary care: "They were about to do a lumbar puncture. They had ordered many tests, but none related to diabetes, even though we told them she had lost a lot of weight and drank a lot. They thought of leukemia or of a virus" (P16).

Lack of communication just after the diagnosis

Some parents reported improper communication with the medical staff, and not fully understanding the function of each care team member. When the diagnosis occurred during a weekend or holiday, the pediatric T1D team was not accessible, thereby delaying receiving comprehensive health education. In the meantime, they received minimal information from the medical staff, which they mentioned causing high levels of stress. Some parents - who reside far from the city - were also disappointed not being told of available dedicated facility for family members of hospitalized children next to the hospital.

Overwhelmed parents after the diagnosis

During their stay in the hospital, parents met with T1D care team members. They felt overwhelmed by the quantity of new information they had to learn in a short time: "It didn't go well at the hospital because they give you tons of information [...] It goes so fast that you don't have time to understand. You don't have time to react that they've already brought you to another room" (P15). Most parents reported they were not ready for such intense SME: "The emotions are so intense that we listen, but we

don't really hear. We try to process the info but we don't get it all" (P12). They felt they did not have time to process the fact that their child has a chronic illness: "Everyone wanted to show us everything at the same time. When you learn such bad news, I think you're not even able, at the beginning, to hear that" (P15). Some parents would have liked a provider to explain T1D to their child: "You have your son to whom you have to explain what is going on, and at same time, understand yourself" (P1).

SME should be adapted to parents' needs

Several parents suggested splitting the SME over time, after experiencing it at home: "It would have been nice to have some training later, after you are back home and it sinks in. You give a short training when you're in a calm state" (P15); "After we take back control over our emotions and we understand a little bit better the disease, after we lived with it at home and know better what that means, we are ready to take in more information from the dietitian, maybe a month or so later" (P18).

Several parents would have preferred a more practical SME, especially with regards to dietary restrictions: "It would be interesting if, in the training, they could show practical tips for when we'll return home instead of just the theory around calculating carbohydrates" (P18). Some parents also mentioned they would have liked refresh SME sessions about notions they use less often: "There are so many things that you forget [...]. Ketones, we had just forgotten what we are supposed to do in such a situation [...] It would be worthwhile to do a refresh on these things a year later, or something like that" (P18).

Expected but difficult post-discharge at home

Lack of self-confidence when returning home. Although the majority of parents found the post-discharge very stressful, none mentioned they would have liked to stay longer at the hospital. Some expressed lack of self-confidence and worried: "You have to trust yourself, but you have your son's life in your hands" (P1). "When you are left alone, by yourself, you feel lost" (P10). They appreciated the follow-up care offered after discharge. Parents all had phone numbers and emails to reach the T1D care team, if needed, which reassured them: "You know that you can call whenever, there is a good support. That is reassuring" (P1).

Constant stress regarding meal adaptation. Dietary restrictions stressed most parents: "It's all we think about. We prepare the next meal, the next snack" (P1). While setting strict meal schedules was not so difficult for well-organized parents, establishing additional snacks was harder. Several parents also mentioned facing difficulties in counting carbohydrates or giving specific amounts of carbohydrates, especially for toddlers. They felt nervous, especially about hypoglycemia risks, since toddlers cannot express themselves well: "She couldn't say: I need sugar. At some point, she said « me, dizzy, mom ». And [her blood sugar level] was around two" (P5).

Effect on parental workforce participation. Several parents indicated taking a medical leave. While some family doctors or employers were rather comprehensive, some parents reported difficulties obtaining paid extended leave: "As an independent worker, if I wanted to stop [working], there is no financial support. I had to be sick to be entitled to sick leave and get paid [...]. There was nothing [at the government level]" (P5).

Effect on siblings. The majority of parents mentioned that siblings were emotionally affected by the new situation: "[The sister] was afraid that [the T1D child] dies, especially while she was in the hospital" (P8). Other parents mentioned that siblings received less attention: "Of course, we have less attention for them. We care a lot about [the T1D child]" (P4). Siblings have no choice to adapt to the new nutrition rules: "We eliminated a lot of things from the grocery store like granola bars and things like that. We try not to let them eat in front of her" (P4).

Excessive parents' involvement needed in daycare centers and schools

Parents need to find new daycare centers. Some private daycare centers found T1D too complex to manage and no longer accepted the child. Public daycare centers were generally prompt to accept them. A parent emphasized the importance of being informed about the government's available programs for daycare centers welcoming T1D children: "We should've known from the start, the daycare centre could receive special needs entitlement for her [...]" (P3). Daycare centers and schools that had already

accommodated T1D children were more prepared and positive about it.

Parents left to themselves to manage their child's reintegration. In most cases, educators had no to limited knowledge of T1D. Most parents had to train them for weeks, and only a few received help from a nurse: "They don't know what diabetes is. It was the first case in the school. I had to explain everything [...] we had endless meetings" (P15). Some parents mentioned the presence of a part-time school nurse. Parents had to prepare educational tools themselves without necessarily having the skills to support educators. Parents often wrote documents and protocols to facilitate their child's supervision. They also had to assist staff during the first weeks of their child's reintegration, spending several days or sometimes months at the daycare or school.

Educators insecure and parents constantly called. Despite having a detailed protocol, educators frequently contacted parents, mostly because fear, panic or insecurity: "They panic all the time. I wasn't going every day, but they were calling all the time" (P15). At the beginning of each school year, the parents have to train and assist the staff again: "For 2-3 months, we get called more" (P1). Several parents mentioned having to stay available for the daycare or school at any time made working difficult: "I have my cell all the time, at work, I have it, all the time, I can't not have it. I have to advise at work, if I am in training, if my phone rings, I need to answer. I have to be reachable at all times" (P10). Several parents indicated the disruptions led to taking a medical leave, to change or quit work for a while: "Six months later, I had a sick leave. It was for me. I was too burned because they called me all the time at school. I was stressed, it was crazy" (P4).

Difficult return to pre-diagnosis social life

The T1D diagnosis changed social life for both children and parents.

Outside activities require much more effort. Several parents found doing anything outside the usual routine very complex, particularly because they had to train every person they wanted to leave their child with. T1D could represent a barrier for a child to attend day camps during the summer: "Where we have difficulty is with day camps [...]. We have to make a request [for special needs], which may not be granted. [...] I wonder why there is such a great monitoring at school but as soon as summer comes, we are on our own and have to fight [for services]" (P1).

Society misunderstanding and judgment. Some parents mentioned ignorance in the general population which yields judgment and unfounded remarks: "In society, I find that there may be a lack [of knowledge]. People say 'Ha you are diabetic, you have to pay attention to sugar'. But this is not what it is at all!" (P12). Parents and their T1D

child occasionally received negative comments in public: “You get told that you gave him too much junk food. They’ll accuse you. [...] He ate too much, he’s fat [...] We went once to [a restaurant], he took out his kit very delicately, a lady said “well another who pricks himself, he should do it at home [...] There is still a lot of prejudice. It’s a not a well-known disease” (P15).

Burden of follow-up care

Some parents reported that the delay of three months between follow-ups, explicitly specified by the care team, was not always respected, that the appointment scheduling process with the T1D care team was not flexible or did not adapt to parents’ availabilities. Some also mentioned communication problems with health care providers. They felt judged, incompetent and guilty: “What I find difficult also with the doctor at the appointments level, is to get a slap on the wrist [...] I have all the time this feeling of guilt. I find it harsh to be reprimanded by the doctor!” (P10). Some parents felt uncomfortable to ask questions for fear of being judged: “Sometimes I asked a question, I feel like I’m being a bitch. I was not comfortable, and even now, I’m not still not comfortable asking all the questions.” (P19). A parent reported that the appointment was too short when parents wanted to meet all the providers of the care team. “Basically, we see the endocrinologist and that’s all. No, I do not have all the support and time during scheduled appointments.” (P2). Some parents also wished that the care team kept their family doctor informed of their child’s diabetes results.

Exchanging with other diabetic families is a relief

More than half of parents indicated it took them from six months to two years to adapt to and accept the diagnosis: “it is a complex condition on a daily basis, even if it’s been years. There are always hard-to-manage situations” (P10). Several parents joined diabetes groups to chat or do activities together: “We all share our struggles, give information, or comfort others” (P14). They greatly appreciated these groups and wished they had been

informed about them by the T1D care team: “The camp was really where I got most support, as a parent” (P5). A few parents met other families with a T1D child followed at the same hospital, during either the initial stay or a follow-up appointment. A parent mentioned that having an education session with another family comforted them: “It gives the impression that you’re not alone. There is someone else going through the same thing” (P7). Another parent found it reassuring for their 2-year old daughter to have her insulin pump installed with another 6-year old girl: “She could see that there was someone else who had a pump and she wasn’t alone. I found it reassuring for her” (P18).

Most “stressful”, “difficult” and “inefficient” stages as perceived by parents

After recalling their experiences with their child’s illness through the whole T1D trajectory, parents were asked to point out what seemed to be the most stressful, the most inefficient and the most difficult stages over the whole trajectory, while leaving open the interpretation of these qualifiers. Table 2 summarizes the results obtained with the frequency of the stages identified. Four participants did not report any “inefficiency” over the whole T1D trajectory when formally asked the question.

Discussion

Our study points out the difficulties, challenges and the emotions experienced by parents of a T1D child over time and in different contexts throughout the T1D care trajectory from the diagnosis stage to T1D routine care. Our results align with those reported in the literature⁸ with regards to the diagnosis stage. Rankin et al.⁸ identified a ‘delayed pathway’ to diagnosis due to parents’ attribution of T1D symptoms to other conditions or to the child’s development stage, or sometimes to a general practitioner’s misdiagnosis. Our results indicate that parents, educators in schools and daycare centers, and sometimes family doctors have insufficient knowledge of

Table 2. Summary perceptions of the most stressful, inefficient and difficult stages

	Stage	Number of patients
Most “stressful”	Post-discharge adaptation	8
	Diagnosis	7
	Initial management at the hospital	4
Most “inefficient”	Initial management at the hospital	7
	Detection	6
	Post-discharge adaptation	1
Most “difficult”	Regular monitoring	1
	Post-discharge adaptation	16
	Diagnosis	3

T1D's main symptoms. Our study further points out that such a misunderstanding of T1D concerns the society in general and is likely to yield to judgment and rejection, making it difficult and sometimes impossible for parents and the child to return to the social life they had before the diabetes diagnosis. Rankin et al.⁸ suggested national campaigns to raise awareness and promote better knowledge of signs of T1D. We recommend such public education campaigns about T1D not only to promote early detection but also to reduce inappropriate judgment of T1D children from the general population.

Most parents felt very distressed and shaken at the hospital right after the diagnosis. The information overload and feeling of being overwhelmed are in line with the literature which highlighted the importance of reassuring parents before teaching them complex information about T1D management^{6,18}. Parents and children need a grieving time and must be listened to. Parents may benefit from psychological support by the appropriate health care providers, who can help them to accept their child's diagnosis.^{6,19} Additional efforts should be made to help parents understand the role of each member of the T1D diabetes team. Parents need to know all the services they are entitled to and could access during their stay in the hospital and later. This could reduce the emotional impact they experience after the diagnosis. The resources available can support them in their efforts to adapt to their child's new situation, including adaptations required for the reintegration of their child in daycare centers or schools, or in day camps.

Our results suggest that the training program that was provided while the child was hospitalized, following the diagnosis, ought to be more flexible to adapt to the parents' needs, to their initial knowledge of T1D, their emotional state and their capacity to assimilate the information. These results are in line with those of a previous study conducted in Sweden.¹⁸ For some parents, spreading the SME over a longer period would contribute to ease the families' experience and help them adapt progressively to T1D. Whenever possible, several families could receive the SME together, reducing the care team's workload and enhancing contact between T1D families.

Parents in this study explained how several members of the care team called them daily after the hospital discharge. While this confirms the importance of constant access to the diabetes team for practical and emotional support as reported by Rankin et al. and by Whittemore et al.,^{6,7} it also highlights parents' needs for several members of the multidisciplinary care team to initiate the contact and call them frequently, especially during the post-discharge adaptation.

Most parents emphasized the lack of diabetes knowledge of educators as well as the absence of a specialized nurse at

daycare centers and schools. This is in line with an international study²⁰ indicating that only three of 21 countries had adequate numbers of nurses in elementary schools. The lack of knowledge about T1D in schools was also mentioned in other studies.²¹⁻²⁴ This affects parents who had to train and assist the daycare or school staff by themselves and personally ensure the safety and well-being of their child^{21,25} by being continuously available. Our study reveals that this would have an additional impact on parents' professional life. Giving basic training on T1D to key persons in schools and daycare centers (specialized educators, for example) would ensure that when a new T1D case is diagnosed, the daycare or school staff is able to manage diabetes more quickly and reintegration of the T1D child is much easier. This echoes training approach recommendations in Spain²⁶ and in the United States,²³ which recommend that school nurses and teachers receive training on hypo- and hyperglycemia symptoms so that they could seek appropriate help when needed²³.

After daycare or school reintegration, the parents' solicitation emphasized in this study and others^{21,25} could possibly be reduced by providing shared resources specialized in T1D to a group of schools. Such resources among groups of daycare centers or schools would reduce parents' burden and provide an experiential learning of successful diabetes management practices in daycare centers and schools. In Boogerd's study,²⁷ parents report wanting local peer support that could be organized online. Parents suggested that such support groups be initiated and moderated by the diabetes teams in local clinics. Additionally, online material could be developed for educators in schools and daycare centers. It would be adapted to educators' needs and give them the necessary information they should know to manage diabetes in schools. The purpose of such a tool would be to decrease calls to parents, and hence to limit referring to parents only for urgent matters.

Parents appreciated connecting with other parents of T1D children who lived a similar experience. Sharing represented emotional support and they also reported receiving informational support. Without necessarily taking ownership of such groups, health care providers could suggest contacting such resources for parents of a newly diagnosed child, including diabetes associations⁷ or blogs.¹³ A challenge, however, is that many of such groups are not being monitored by providers and the information made available could be incorrect. Having a health care provider doing some monitoring could be helpful. This aligns with the results reported in Boogerd et al.²⁷ where parents expressed they had difficulties assessing the reliability of general information they found on the internet and required their health care providers to guide them.

It appears from our results that parents' burden is highest in the post-discharge adaptation stage, especially for school reintegration, management of blood glucose levels and calculation of carbohydrates. There is a need to strengthen services of psychological support in both the post-discharge and the diagnosis stages, as these were reported as the most stressful stages. Finally, the efficiency of services delivered during the detection and the initial management at the hospital stages should be improved especially with regard to the dissemination of relevant and useful information to parents, health providers not involved in diabetes, and in educational services (daycare centres and schools).

Conclusion

Our study examined the experience of parents of children living with T1D, from the initial diagnosis to the chronic disease management. Learning about their child's diagnosis was a shock. Parents felt overwhelmed by the diagnosis and all the information that they were being given. They had to accept that their child had a chronic condition that will change not only the child's life but also the life of the family. Post-discharge adaptation was the most difficult, especially for school reintegration, management of blood glucose levels and calculation of carbohydrates. As they adapted, parents acknowledged that society viewed their child differently, and that ignorance of the T1D disease can lead to judgement.

One of their main suggestion was to make services more flexible to adapt to their needs, and specifically providing self-management education over time to enable a better absorption of the new information. The hospital took this recommendation seriously and has gradually transformed this phase of the care after this study. Future research could evaluate the effects of the changes on patients' experiences.

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