

Healthcare Implications and Guidelines to Ensure Type 1 Diabetes Students' Well-being in Schools, Educational Facilities, and Surroundings

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Abstract.

Type 1 diabetes (T1D) has become increasingly prevalent globally, leading to a number of challenges in healthcare and educational sectors. Due to the complexity of its management, children with T1D often have a difficult time maintaining a healthy lifestyle alongside managing such lifelong disease which requires intensive treatment on a daily basis. This study, therefore, aimed to identify those difficulties Thai children with T1D encountered both in and out of their educational settings. Furthermore, it sought to propose specific ways in which schools in Thailand and their surroundings can provide support to meet the children's needs. Adopting an in-depth semi-structured interview with 7 individuals directly associated with T1D management, the result from both thematic and inductive analyses showed that despite a level of satisfaction in children with T1D's own disease management, a better balance of dependable information, inclusiveness, independence-autonomy-flexibility, and intensive care, or "The 4 Is" in short, is critical to an effective T1D management. The interviewees reported to encourage the 4 Is to be actively implemented by schools, parents, peers, and children with T1D themselves, as well as supported the collaboration between them, to achieve a holistic care of T1D and enhance children with T1D's quality of life in general.

Keywords: type 1 diabetes management, school support, parental support, peer support, self-support

1. Introduction

1.1 Type 1 Diabetes

Diabetes, whose common underlying cause is the degeneration of pancreatic β -cells, is a collection of metabolic illnesses characterized by a protracted period of untreated hyperglycemia (Tuomi et al., 2014). Diabetic ketoacidosis (DKA), one of the most dangerous clinical symptoms, can lead to dehydration, unconsciousness, and even death if proper treatment is not given. Diabetes symptoms, on the other hand, are frequently mild early on, and it can take a long time for a person to notice that he or she has the condition. To be more exact, it is believed that 30-80% of diabetes cases are undetected worldwide (Zimmet et al., 2001).

The World Health Organization (WHO) projected that there were 422 million diabetic adults worldwide in 2014. The number of individuals living with diabetes is continually increasing, with the biggest increases occurring in low- and middle-income nations (World Health Organization, 2011). In these countries, cardiovascular disease, retinopathy, renal damage, and nerve damage are all common health problems, following diabetes (Chawla et al., 2016). In 2019, WHO created a classification system that prioritizes clinical care in order to ensure that implementation is feasible and resources are available. Type 1 diabetes, type 2 diabetes, hybrid forms of diabetes, other particular types of diabetes, unclassified diabetes, and hyperglycemia found during pregnancy are all subtypes of diabetes (World Health Organization, 2019). C-peptide levels in blood or urine are being used to distinguish T1D from T2D. Furthermore, autoantibodies against β -cell components are more prevalent in T1D patients than in T2D patients (World Health Organization, 2019). For T1D, lower BMI, increased incidence of DKA, and 12-month insulin use after diagnosis are all common diagnosis markers (Thomas et al., 2018). The life expectancy of T1 diabetics is reduced by about 13 years (Livingstone et al., 2015). However, with restricted access to insulin in low-income nations, the forecast is substantially worse (Patterson et al., 2009).

1.2 Burden of T1D in Children

T1D is one of the most common chronic disorders in children, and can be difficult to manage because of various physiological features such as a delayed honeymoon phase (where individuals with T1D experience normal or near-normal blood sugar levels without taking insulin) and an increased insulin sensitivity. Furthermore, T1D management may very well be influenced by a child's cognitive, behavioral, and social-emotional development (Streisand & Monaghan, 2014).

Parents are crucial in their child's T1D management. They act as caregivers, monitoring blood glucose levels, providing insulin, and keeping track of their child's nutrition and physical activity (Streisand & Monaghan, 2014). As children grow more independent, they must rely on the child's school system to address any of the everyday T1D contingencies, particularly low blood glucose or hypoglycemia, which can cause seizures, coma, and death in extreme circumstances (McCrimmon & Frier, 1994). Although children with T1D have a variety of

issues at school, including cognitive skills, classroom attention, work completion, and day-to-day fluctuation, they should be allowed to engage in academic, nonacademic, and extracurricular activities in the same way that other students do (Wright et al., 2017). T1D's impacts are not universal and vary depending on the children's glycemic control. Children who have poor metabolic control and severe hypoglycemia experience more academic difficulties than those who have good glycemic control (McCarthy et al., 2003). T1D also has an impact on students' school attendance, let alone their ability to learn due to possible interruptions for glucose testing, insulin injections, or urgent snack consumption, as well as trips to the school nurse during class time. When compared to their healthy siblings, children with T1D miss an average of 10 school days, a loss of 10% of allocated school time (Parent et al., 2009). Educational difficulties of children with T1D could be addressed with new healthcare technologies and educational grading system modifications.

1.3 Support for Children with T1D

1.3.1 School Support

In order to effectively manage T1D in the school environment, a collaborative effort is required. The safety, health, and educational success of T1D students are dependent on teamwork and cooperation among members of the school health team, his or her personal healthcare team outside of school, and the T1D student and family (Helping the Student with Diabetes Succeed: A Guide for School Personnel, 2016). A personalized Diabetes Medical Management Plan (DMMP) should be prepared in a school context to collect data for kids' healthcare and education programs. In addition, in conjunction with the DMMP, an Individualized Healthcare Plan (IHP) should be developed to analyze the students' management techniques and personnel required to fulfill their health goals in school (Helping the Student with Diabetes Succeed: A Guide for School Personnel, 2016). The school nurse, who is the major coordinator and care provider for students with diabetes, should establish the Emergency Care Plans for Hypoglycemia and Hyperglycemia, identifying and responding to emergencies (Wright et al., 2017).

In addition to plans, each member of the school health team including school authorities, should clearly define duties and responsibilities to help ensure the quality of diabetes care. In the United States, all school staff members should learn about T1D, understand their roles under federal and state laws affecting T1D – namely, Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act, and the Individuals with Disabilities Education Act (Schwartz et al., 2010) –, treat their T1D students just like other students, except when their medical needs or emergencies come first, and respect them. Moreover, each school health team member has specific roles which are diverse to serve as a structural system to support students with T1D (Helping the Student with Diabetes Succeed: A Guide for School Personnel, 2016). However, little emphasis has been put on developing a standard protocol for school across the globe that schools should implement. Research is thus needed to visualize how schools and

school personnel generally provide support to students with T1D, enabling the true understanding of what has and has not been done to meet T1D students' needs.

1.3.2 Peer Support

Friendships, which are an important element of adolescent life, have been demonstrated to play a significant role in improving diabetes control for students (Tolbert, 2009). Having a student who can help his/her peer with T1D, sometimes known as a "diabetic buddy," can improve the student's diabetes control and general quality of life (Wagner et al., 2006). A diabetic buddy can learn to spot diabetes emergencies like hypoglycemia, assist their diabetic friend by seeking quick medical attention, and discourage others from teasing them (Tolbert, 2009). In fact, for those with T1D, peer support can be a critical mediating component in effectively managing the disease especially in children and adolescent ages (Davidson et al., 2004). However, limited studies are being conducted regarding how peers provide support for students with T1D and their effects have not yet been thoroughly discussed.

1.3.3 Parental Support

Parent-child interactions are important in T1D care, especially for young children aged 4 to 8. They serve as caretakers for their children with roles to check blood glucose levels, administer insulin, manage appropriate nutrition in each meal, and look out for any abnormal conditions regarding T1D (Streisand & Monaghan, 2014). More negative maternal impacts are linked to lower levels of interpersonal involvement, which leads to behavioral difficulties in T1D children, and vice versa (Chisholm et al., 2014). Therefore, empathetic collaborations between adolescents with T1D, their parents, and educational and healthcare professionals are essential for an open discussion of information. This corresponds to the developmental trajectory, in which treatment management necessitates a progressive transition from early childhood parental treatment participation to adolescent self-care. As a result, from an early age, parents must assist their children in developing a sound disciplinary foundation. Further research is encouraged to understand more about the importance and ways of parent-child relationships in T1D management and the effects they entail through such relations.

1.3.4 Self Support

The diagnosis of diabetes was viewed by some T1D teenagers as the beginning of the end of their life, whilst for others, it was viewed as a crucial component that leads to fulfillment in their lives (Davidson et al., 2004). In addition, early adolescent years are a critical time for people with T1D to progressively move illness management into their own hands (Dashiff et al., 2006). Because of their physical, psychological, emotional, and social development, transitioning young adolescents to more self-care responsibilities may be difficult and confusing (Boman et al., 2015). Personality is getting more attention in the realm of health psychology, according to the Big Five paradigm (McCrae & Costa, 1987). Two of the five

personality types, emotional stability and conscientiousness, have been found to be highly linked to health behavior. Low emotional stability is linked to higher symptoms and anxiety about hypoglycemia in T1D patients (Hepburn et al., 1994). Conscientiousness, which includes attributes like self-discipline, tenacity, and dependability (McCrae & Costa, 1987), has been linked to greater self-care in the treatment of a variety of disorders, including T1D and renal dialysis (Skinner et al., 2002). Moreover, adolescents must learn to be self-sufficient in life and control their diabetes in order to make responsible decisions later in life; nevertheless, education is required beforehand (Allen et al., 2021). To have a complete idea of how crucial students with T1D's autonomy is for disease management, in-depth studies on the perception of T1D students are advised.

In a case study aimed to investigate how schools provide support for the psychological wellbeing and disease management of T1D students, three themes, namely school characteristics, interpersonal support, and organizational support have emerged after both inductively collecting data through interviews and deductively from theory (Fried et al., 2020). For school characteristics, the participants give emphasis on knowledge, flexibility, and inclusiveness. To elaborate, school personnel must be knowledgeable on T1D and must be trained in a certified program. Students with T1D should not be restrained by stringent rules or structures. The study points out the need for negotiation and autonomy. Furthermore, schools should handle T1D management with compassion and give the students a sense of “you can do it” attitude. For interpersonal support, disease management and academic support, emotional support, and peer support should be highlighted. For students who are newly diagnosed, schools may need to make some exceptions for frequent absences due to health checkups. School personnel should empathize with the students. They should recognize that their change in behavior might come from their fluctuation of blood glucose level, and provide support as needed. Peer support is especially important emotionally rather than practically. Schools are strongly encouraged to set up a peer support system to overcome prejudices, solicit help, and tighten friendship bonds. For organizational support, roles and responsibilities must be allocated structurally to avoid any confusion. There should be one key staff member which in most cases is the school nurse. In addition, plans such as physical education plans, emergency or critical response plans, excursion plans, and camp plans, should be devised. Transitions from one meal break to another or a class year to a higher one should be prepared to match with students' emotional state. Most importantly, good communication should be developed, especially between school staff and parents. The study illustrates strong support for how schools can meet the needs of effective T1D management; nonetheless, needs to be studied further since little is known about students' autonomy, supportive practices, primary-to-secondary-level transitions, and peer support programs.

1.4 The Need to Interview Students, Parents, and Social Workers in Thailand

Effective T1D management for adolescent students is a team effort. Nevertheless, little is known about students' autonomy, supportive practices, primary-to-secondary-level transitions, and peer support programs. Therefore, this study aims to advance our current understanding by approaching the whole picture on how T1D management works, starting from school policies being established to meet the students with T1D's needs to their own T1D self-care. To elaborate, thorough interviews and discussions should be devised on different stakeholders who may be involved with the students such as parents, social workers, and the students themselves to deepen our T1D-management understanding in a holistic way.

Even though, in 1984-1985, Thailand's incidence of T1D in children aged 0-15 years old was the lowest worldwide with 0.2/100,000/year (Tuchinda et al., 1992), it has become increasingly diagnosed recently, with 17.6/100,000 of individuals less than 20 years old in 2015 and 29.5/100,000 of the same age range in 2020 (Rittiphairoj et al., 2022). Nonetheless, not much has been mentioned about students' T1D management in Thai schools. Only evidence of how Thai children improve their diabetes management is found in reports during diabetes camps (Likitmaskul, 2006; Santiprabhob et al., 2008). For instance, based on a 6-month follow-up plan, children's glycemic control, knowledge, and psychosocial state are improved by joining a 5-day diabetes camp where patients were taught diabetes self-management education (DSME). However, little is known about how students manage their T1D at schools in Thailand, what roles are specifically given to each school personnel, and what school policies or plans are established or are advised to be implemented to help students manage their disease holistically.

Research Objectives

Therefore, the objective of this study is set to explore ways in which schools in Thailand provide support for students with T1D and seek to understand what more is needed to improve their T1D control. In addition, this study aims to examine extra support that children with T1D need from their surroundings i.e., parents and peers to effectively manage their disease in addition to their own self-support.

2. Methodology

2.1 Participants

Four Thai individuals with T1D from four different institutions and ages, namely a school graduate, a university student, an upper secondary student, and a lower secondary student, were invited to participate in an in-depth interview using a semi-structured protocol. Furthermore, one of each of their parents had been approached. In sum, a total of eight people who had been involved in T1D management in their daily lives were invited to participate in the study. However, one parent did not agree to participate because she had a tight schedule during the process of data collection. Therefore, participants who were willing to be involved in this study

consisted of four individuals with T1D and three of their parents (see more detail in Appendix A).

2.2 Data Collection

Each participant was asked to take part in semi-structured interviews to express his or her opinions on managing T1D and illustrating how support from those around them can affect such management. All interviews ranged from 17-44 minutes in duration for each participant (average 31.6 minutes), varying based on their length of answers and pace of speaking. Participants were encouraged to speak freely without interruption about their experiences. Their audios were digitally recorded with the participants' permission and transcribed. The transcribed sections where participants' responses were found to address the research questions significantly contributed to possible themes according to thematic analysis. Consistency and dependability were ensured by taking field notes after each interview and using a semi-structured interview guide with questions and prompts (Kvale, 2006). For parents and students with T1D, specific guides have been created. Students were asked questions such as: How do you take care of yourself? Any difficulties you face regarding your daily management with T1D? In what ways does your school provide support for you and what do you think you need from your school? In what ways do your parents provide support for you and what support do you think you need from them? Parents were asked questions such as: How do you feel when your child was diagnosed with T1D? In what ways do you provide support for your own child? What do you think he/she needs from you? In what ways does the school provide support for you and what do you think you need from your school?

Researchers informed the purpose and method of the study to all participants prior to the interviews. They decided to participate in this study without any pressure and were free to withdraw at any time during the study. To prevent direct identification, names of participants were coded by pseudonym as shown in Appendix A.

2.2 Data Analysis

To analyze the collected data, the thematic analysis approached was adopted. First of all, all interview tapes were listened to and transcribed several times for the researchers to familiarize with the narratives. Second, all transcripts were critically studied and analyzed for possible themes to emerge using comparing and contrasting methods. The data was analyzed both inductively and deductively, based on the data itself and pre-existing theory, although the former approach was more emphasized. The participants' narratives were used to extract common and contrasting opinions on each subject. Third, similar statements made by the participants were divided into groups in order to uncover common themes. In addition, in order to detail the diversity of impressions of the connection, the researchers looked for descriptions by people who tend to narrate experiences differently. Finally, in this written report, the common themes and noteworthy individual distinctions were explored.

3. Results and Discussion

According to the thematic analysis, the participants' narratives were classified into four main categories: information, inclusiveness, independence-autonomy-flexibility, intensive care (The 4 Is), which can be a guideline for T1D management as summarized in Table 1.

For **information**, evidence to the school is required to prove that the student's disease is authentic. Prior to the student's diagnosis, the majority of school personnel had no idea what T1D was. The terms T1D and T2D are often used interchangeably. Therefore, there should be courses for school personnel to get educated about T1D. Moreover, the school nurse or the person in charge of the school's nursing room should be the most knowledgeable and capable of handling T1D situations, especially in health emergencies where effective plans are advisable. Not only school staff but also peers are encouraged to learn about T1D. Peers, with appropriate information and understanding of T1D, can help in emergencies. Despite having little or no information about T1D before their child diagnosis, parents are found to acquire in-depth information just after the diagnosis which significantly contribute to good T1D management. Most importantly, the child with T1D him- or herself should possess sufficient knowledge about T1D and apply it correctly to maintain a healthy lifestyle (see more detail in Appendix B).

Being **inclusive** is a crucial factor for a supportive environment for students with T1D. It is critical to have a supportive health care team in school and outside of school, as well as cooperation between them. Some participants reported to receive sufficient amount of support from the school; however, some mentioned they were looked down on because of their disease by both school personnel and peers. The effects of bullying and disparaging words on students with T1D can be damaging to their disease management and mental health. Some participants reported to feel terrible about having T1D and were afraid to ask for help. Parents pointed out the importance of cheering their T1D child up with encouraging words and treating them just like any other healthy child are treated (see more detail in Appendix C).

According to the respondents' experiences, flexible class rules and extra aid from the school and school personnel led to fewer emergencies and better T1D management. However, in other cases, the student's adaptability outweighs their T1D needs, preventing them from properly absorbing the curriculums. To prevent school staff from making assumptions, the school should provide an adequate amount of flexibility. Also, more attention should be paid to the implementation of instruments to deal with T1D emergencies. Most importantly, school staff and parents should have a level of trust in children with T1D on their disease management and give them **independence** to choose their health care options as appropriate. Apart from the school setting, as children with T1D become more mature, parents reported to respect their decisions more, and trust their children with their own management to a higher level (see more detail in Appendix D).

Finally, children with T1D should be conscious of their conditions consistently on a daily basis. They should be able to handle their T1D daily routines, including correctly counting carbohydrate portions, monitoring blood glucose, and administering insulin. For younger children, peers, parents and school staff (particularly the latter two) should provide **intensive care** by closely monitoring their conditions to avoid risks of frequent emergencies. A good mindset is also pivotal to effective T1D management. The majority of participants mentioned having a positive outlook as they grew accustomed to T1D management throughout the years. However, some still did not feel an improvement. School staff, peers, and parents should provide sufficient emotional support and comfort to the children should it be necessary (see more detail in Appendix E).

The results clearly show that effective T1D management for children is a team effort, emphasizing on the solidarity of many individuals. Support needed for students with T1D comes from both interpersonal and intrapersonal entities, including schools, peers, parents, hospitals, and the child with T1D him or herself. Although many participants showed an overall satisfaction with the support they received, there is still capacity to improve. In this study, those areas can be categorized into the “4 Is”, namely, information, inclusiveness, independence-autonomy-flexibility, and intensive care.

Table 1: Guidelines for Effective T1D Management in Children

	Information	Inclusiveness	Independence, Autonomy & Flexibility	Intensive Care
Schools	T1D education (levels of depth depends on each personnel role) Distinguish two types of DM Emergency plans preparation	Cooperation between health team members Communicate with parents about the children’s conditions (levels of consistency depends on the child maturity and condition) Showing support and understanding through assistance Avoid insulting statements Monitor students’ conversation	Adjustable schedule Flexible deadlines Adjustable class rules Trust T1D children on T1D management Let T1D children decide to participate or not participate in sports activities that may affect their health	Look out for T1D emergencies by being attentive towards abnormal signs Provide an appropriate space to store T1D devices Rigorously on-time meal (lunch) schedule
Peers	Fundamental T1D education	Avoid bullying and understand its implications		Look out for T1D emergencies by

		Support their T1D friend in activities both associated and not associated with T1D		being attentive towards abnormal signs
Parents	In-depth T1D education	Encourage T1D children in times of need	Let T1D children choose who to tell about T1D	Monitor young T1D children's blood glucose level
	Present diagnosis evidence to the school	Give T1D children emotional support when needed	Let T1D children choose their T1D devices	Administer young T1D children insulin
	Inform the school authority about the diagnosis, conditions, and ways of assisting	Communicate with teachers about T1D	Trust T1D children on T1D management	Calculate carbohydrate portions for young children with T1D
		Avoid insulting statements		Look out for T1D emergencies by being attentive towards abnormal signs
				Take T1D children to consistent health checkups
				Ensure enough T1D supplies
				Financial support
				Rigorously on-time meal schedules
				Ask T1D children of how their T1D condition is
Self	Know as much T1D information as possible		Choose who to tell about T1D	Count carbohydrate portions
	Know how to treat themselves in T1D emergencies		Choose their T1D devices	Monitor blood glucose
				Administer insulin

Be aware of
activities that may
affect their health

Be alert of
abnormal
conditions

4. Conclusion

The 4 Is (information, inclusiveness, independence-autonomy-flexibility, and intensive care) are a set of comprehensive principles for ensuring high-quality T1D management in children, enhancing not only physical, but mental, emotional, and social aspects of living with a lifelong disease. For information, evidence to the school is required to prove that the student's disease is authentic, and school personnel are encouraged to learn more about T1D. Being inclusive is essential for a supportive atmosphere for students with T1D. It is essential to have a helpful health care team in and out of school, as well as their cooperation. In addition, the school staff and parents of children with T1D should trust in the children's ability to manage their disease and provide them the autonomy to choose their health care alternatives independently and flexibly. Lastly, children with T1D should be aware of their situations and should be able to manage their daily routines, including carbohydrate portion counting, blood glucose monitoring, and insulin administration. Peers, parents, and school personnel (especially the latter two) should provide intensive care for younger children by closely monitoring their circumstances to reduce the danger of frequent emergencies. It is believed that if children with T1D have a good balance of dependable information, inclusiveness, independence-autonomy-flexibility, and intensive care, they can lead a meaningful and enjoyable life with as little difficulty as possible.

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APPENDICES

Readers interested in detailed descriptions given by the participants in this study can access the analyzed data via this QR code or the link attached below



<https://drive.google.com/file/d/1epOaO8h2yeedbAPppADRZBkqyotwX7Oh/view?usp=sharing>