EXPERIENCES AND PERCEPTIONS OF LIVING WITH TYPE 1 DIABETES AMONG YOUTH PATIENTS, PARENTS, AND PEERS: A QUALITATIVE STUDY

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Abstract

Background: The incidence of type 1 diabetes mellitus (T1D) among the youth is a global concern. This disease not only poses physical health challenges but also creates emotional and social stigmas.
Objectives: The present study aimed to explore the perceptions and experiences of patients with T1D, their guardians, and peers, a topic that has not been extensively investigated in this context.
Methods: Between March and July 2023, an in-depth semi-structured interview was conducted with eight T1D patients aged 10–20 at Phramongkutklao Hospital. Seven mothers and a group of close friends were chosen by the patients and were included in another in-depth interview. Additionally, six groups and one in-depth interview involving 20 participants were held with the youth unrelated to T1D patients at an international private school. The interviews covered general knowledge of T1D, perceptions, daily life experiences, relationships with individuals with T1D, and interpersonal relationships. Thematic analysis was used to analyze the data.
Results: Patients and parents viewed T1D as both severe and manageable, with significant lifestyle challenges, particularly in diet and daily activities, that influenced their life choices and financial stability. Although the patient experienced sudden adaptation to T1D, they developed effective self-care strategies and appreciated the supportive adjustments made by their family. Furthermore, despite proactive management of their condition through new treatments and enhanced knowledge, they encountered social challenges, including support mixed with misunderstandings and stigma. Meanwhile, guardians experienced stress from caregiving and advocated for better treatment access and support. Peers recognized that patients could lead everyday lives with proper management, but they often lacked a comprehensive understanding of T1D, highlighting substantial gaps in societal awareness.
Conclusion: The findings underscore the need for improved diabetes education and support systems to reduce stigma and enhance the quality of life among youth with T1D, particularly through peer and guardian engagement.

Keywords: type 1 diabetes, experiences, youth, adolescent, Thailand

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Introduction

Type 1 diabetes mellitus (T1D) is a chronic autoimmune disease characterized by insulin deficiency due to the progressive destruction of beta (β) cells in the pancreas. This condition can lead to serious complications, which can result in mortality.(1) T1D remains the most common type of young-onset diabetes in Thailand in individuals below the age of 30. A 3-4% annual increase in TID occurs in high-income countries. A similar trend also occurs in Thailand, with a rate of 5.0 per 100,000.(1,3) A nationwide study reported an increasing trend of T1D among children and adolescents aged 0–19 years, with a notable burden of diabetic ketoacidosis at diagnosis.(3) This trend may be attributed to environmental factors, such as perinatal conditions (delivery mode and maternal/childhood diet), and ecological influences like air pollution and climate, which are linked to the autoimmune destruction of β-cells that leads to T1D.(4) Additionally, the obesity epidemic, which promotes insulin resistance and lipid disorders, may accelerate T1D onset in genetically susceptible individuals.(4)

High responsibility for blood glucose monitoring is asserted from a young age. Diabetes management involves repetitive tasks, including continuous glucose monitoring, using insulin pumps, and adjusting insulin levels based on diet and exercise.(3) These tasks may foster stigmas stemming from societal views that often depict individuals with chronic illnesses as pitiable.(5) Such stigmas, which inappropriately may extend from type 2 diabetes, often arise from non-medical individuals' inability to differentiate it from T1D.(5,6) Additionally, the lifestyle adjustments required for T1D can lead to social isolation, limiting participation in social activities. Over time, these elements contribute to stigma development, particularly among teenagers who may internalize their discomfort, leading to decreased peer support and significant psychological consequences.(7,8)

Patients with T1D often employ strategies to conceal their condition, including hiding their T1D diagnosis, which is linked to severe hypoglycemia in youth.(9) This can impair blood sugar control and hinder social interactions. The associated stigma may result in inappropriate behavior, societal dishonesty, and entrenched negative self-perceptions and emotions that are challenging to overcome.(7,9) Moreover, parents may also face challenges in managing their child's condition, including the emotional toll of caring for a child with T1D and the impact on family dynamics.(10) Nevertheless, to the best of our knowledge, studies that directly address the stigma faced by parents and how they cope with these challenges are scarce.

The shift in diabetes management responsibility from parents to the individual can be overwhelming and demanding for the youth. This study aimed to identify the perceptions and experiences of Thai youth with T1D, including those of their guardians and peers. This study could provide a comprehensive overview of the challenges and common perceptions affecting these adolescents and explore how peers, who may contribute to the stigmatization of patients with T1D, view the patients.(5,7) Additionally, navigating adolescence—a period marked by personal development and identity formation—complicates matters when a chronic disease and its associated stigmas and insecurities may overshadow management efforts.

Methods

Study Design and Subjects

We conducted a qualitative study to explore perceptions and experiences related to T1D. Participants were divided into three groups: patients with T1D aged 10-20, their guardians, and normal youth without T1D. The first group consisted of patients with T1D receiving care at the endocrinology clinic at Phramongkutklao Hospital. The closest guardian chosen by each patient was invited to participate in the second group. The third group, comprised of students unrelated to T1D from an international private school in Bangkok who were not directly involved with the patients, was interviewed using purposive sampling. In one case, a T1D patient suggested involving her close friends, who subsequently participated in a group interview. This group was analyzed separately, while the research team recruited all other peers independently. In-depth, semi-structured interviews were conducted via Zoom for the first and second groups, while the third group participated in a face-to-face group interview.

The inclusion criteria were defined for each group: patients aged 10–20 years diagnosed with T1D for at least 6 months and receiving regular care at the pediatric endocrinology clinic at Phramongkutklao Hospital. The guardians were the mothers of each participating patient. Peers were adolescents aged 13-18 years from an international school in Bangkok with no personal or family history of T1D; they were recruited to reflect general adolescent social perspectives.

Data Collection

Data were collected from March to July 2023 using in-depth or group, semi-structured interviews. These interviews included questions and probes to cover general knowledge of T1D, perceptions of T1D, daily life with T1D, experiences related to T1D, relationships with patients with T1D for guardians and peers, and relationships with others for patients with T1D themselves. The interview guide was performed by a pediatrician and a medical doctor with experience in qualitative research, and an expert in qualitative research assisted in reviewing the guide. The interviewers included two instructors from Phramongkutklao College of Medicine: a pediatrician and a medical doctor. An additional interviewer, a secondary school teacher in her twelfth year at the international private school interested in T1D, also founded a related club and T1D community at her school. A semi-structured interview guide was employed to enhance consistency and credibility, and regular team debriefings were conducted to ensure continuity.

Patients with T1D and their guardians at the endocrinology clinic were invited to participate in the interviews. For the peers, purposive sampling was used to select individuals who could provide rich information within a homogeneous character group. Interviews were scheduled at the international private school. Informed consent and insent forms were obtained before the interviews. The interviews lasted approximately 40 to 60 minutes each and were conducted in Thai. Data collection continued until content saturation was achieved, and the interviews were recorded via Zoom, which offered convenience and flexibility, allowing participants to feel more at ease. However, limitations such as reduced observation of nonverbal cues and occasional internet issues were noted. To minimize these issues, all interviews were conducted via video and followed by team debriefings.

Examples of Semi-structured interview guides

– Questions for patients with T1D: *"Can you describe how T1D has affected your daily routine, especially around meals or school activities?"* and *"What kind of support helps you feel more* *confident in managing T1D?"*

– Questions for guardians: *"What were your initial thoughts when your child was diagnosed with T1D?" "What challenges do you face in supporting your child's physical and emotional needs?" and "How has T1D affected your family life or routines?"*

– Questions for peers: *"How would you react if a close friend had to inject insulin during class or meals?" and "Do you think society understands what people with T1D go through?"*

These questions reflected the tailored focus for each group and the open-ended nature of the interviews, which allowed participants to elaborate on their personal experiences and social perceptions in more detail.

Thematic Analysis

The qualitative investigation employed a team-based, iterative thematic analysis strategy. The interview recordings were transcribed word for word and proofread by the investigators. The present research followed a six-step guide for conducting a thematic analysis.(11) First, the authors familiarized themselves with the data and generated initial codes individually. Then, they assembled and developed a coding guide based on their initial reading of interview transcripts, which was iteratively revised and refined through team discussion.(12) Both inductive and deductive coding approaches were used, and the researchers discussed observed patterns and identified key themes. The themes related to the perceptions and experiences of the three groups regarding T1D were reviewed iteratively, and all authors collectively defined and named them. The interpretation of emerging patterns in the data was refined through team discussion. The final findings were presented in the form of codes, subthemes, themes, and quotations.

Results

Characteristics of Participants

Eight participants with T1D comprised four males and four females, aged between 10 and 19 years (mean age, 15.8 years; **Table 1**). Each participant had been diagnosed with T1D for a duration ranging from 4 to 10 years. In the second group, all guardians were the patients' mothers, and one patient selected peers to participate in a group interview. The mothers' ages ranged from 35 to 45 (mean age: 41.2 years). Among the third group, six group interviews were conducted among peers aged between 13 and 18, comprising 10 females and 6 males, and one in-depth interview with a female participant interested in T1D (total n = 17; mean age: 15.2 years). A patient invited 4 close friends to participate in a group interview as her guardians; this subgroup was analyzed separately.

Table 1. Demographic characteristics of respondents

Respondent identification	Sex	Age (years)	Years since diagnosis	Relationship with patient
Type 1 diabetes patients				
ID1	F	15	6	N/A
ID2	M	15	8	N/A
ID3	F	14	4	N/A
ID4	F	12	6	N/A
ID5	F	14	7	N/A
ID6	M	19	10	N/A
ID7	M	10	8	N/A
ID8	M	16	5	N/A

Table 1. Demographic characteristics of respondents

Respondent identification	Sex	Age (years)	Years since diagnosis	Relationship with patient
Guardians				
G_1	F	41	N/A	Mother
G_2	F	35	N/A	Mother
G_3	F	35	N/A	Mother
ID4_P (n=4)	F = 4	12	N/A	Close friends
G_5	F	40	N/A	Mother
G_6	F	42	N/A	Mother
G_7	F	45	N/A	Mother
G_8	F	44	N/A	Mother
Peers*				
Group 1 (n=2)	F=2	Year 12	N/A	Peers
Group 2 (n=2)	M=2	Year 12	N/A	Peers
Group 3 (n=3)	F=2, M=1	Year 11	N/A	Peers
Group 4 (n=3)	F=3	Year 10	N/A	Peers
Group 5 (n=3)	M=3	Year 10	N/A	Peers
Group 6 (n=3)	F=3	Year 8	N/A	Peers
ID_P	F=1	Year 12	N/A	Peers

ID; Indepth, G; Guardian,s P; Peers, F; Female, M; Male, * The peers were grouped by their years of study

Perceptions and Experiences of T1D Patients

Four themes were identified: perceptions of T1D, lifestyle, and future differences, coping with the responsibility of management, and social aspects. **Table 2** shows sixteen subthemes. Individuals with T1D view their condition as severe but manageable, recognizing the significant lifestyle and daily challenges it has. Adapting to T1D involves an initial learning curve, especially when it comes to making dietary adjustments. Over time, many develop effective self-care strategies and experience personal growth while strengthening their relationship within the family. For example, one patient expressed gratitude towards family efforts to avoid sweets to prevent feelings of jealousy, highlighting the supportive adjustments made by loved ones (ID 4).

Lifestyle and prospects are significant concerns for T1D patients, who experience limitations in sports, reduced time for daily activities, and financial strain from treatment costs. These factors impact their life choices and quality of life. Frequent insulin injections disrupt daily routines, causing physical, psychological, and social discomfort. For instance, one student noted restrictions on sports participation at school due to teachers' concerns about potential health risks despite the student's willingness to engage (ID 2). Moreover, a patient noted a need for a government-related job to access a better healthcare scheme (ID6).

Regarding their management responsibility, patients with T1D proactively manage their condition by adopting new treatments and acquiring improved knowledge for effective blood sugar control, striving to maintain normalcy. However, social interactions are mixed; while broad support exists, misconceptions and stigma exist. Patients seek a better understanding of their social circles to avoid alienation and undue attention. Informed and empathetic social support is crucial in lessening the psychological impacts of T1D, highlighting the need for greater

Table 2. Thematic analysis of type 1 diabetes (T1D) patient's perception and experiences

Themes	Subthemes	Codes
Perception toward T1D	*T1D is severe, yet patients with T1D can still lead a normal life*	Can lead everyday lives; preferable to other serious conditions; unbothered by having diabetes; lives proceed as usual; no shame in injection marks; comfortable injecting publicly
	Although it requires time, patients with T1D can adapt to life with the condition.	Initially struggled to adjust; time was needed to adapt; initially struggled with dietary changes; eventually adapted to living with diabetes; the adaptation took time.
	T1D has led to self-improvement and awareness of their flaws	Led to better self-care; fostered greater discipline; identified personal flaws; understood personal capabilities
	Scares about the disease itself and its impacts	Visited a psychiatrist; concerned about future health; worried about the disease; fears diabetic shock; can be severe.
Lifestyle and future difference	*Necessary to avoid foods one craves*	Same types of food; affected eating habits; restraint in food choices; control eating at some meals
	Cannot play sports as well as peers of the same age group	Missed sports opportunities; impacted sports performance; teachers concerned about sports participation; carried snacks for exercise; teachers feared hypoglycemia during exercise
	Having less time during the day compared to others	Not being able to sleep in; affects daily routine; add on routines; dislikes doctor visits due to time loss; frequent hospital visits
	T1D treatment affects expenses, limiting the ability to choose the desired future	T1D impacts expenses; chose disliked career for treatment coverage; hinders studying abroad; forced to study in the disliked field for expense coverage; argued with the parent over study choices
	Insulin injections disrupt daily life.	Injection pain; Worried about pre-meal blood tests; Carries insulin everywhere; Careful with insulin when traveling abroad; Wishes for assistance with insulin injections; Injections for life.
Coping responsibility to management	*Can self-adjust treatment independently to lead an everyday life*	More injections to adjust poor control; proper medication allows sweet food consumption; can eat anything if food is calculated properly
	Ready to gain knowledge and improve to control sugar levels effectively	Always open to new treatments; interested in better sugar control methods; skilled in continuous glucose monitoring; tests blood before meals; precise in food calculation; knows repeated injections hinder absorption
Social	*People still mock diabetes patients, but it is not taken seriously and bearable.*	Does not dwell on being mocked; people still tease about diabetes; does not resent those who misunderstand and mock the condition.
	Wants those around to have an accurate understanding of the potential of people with diabetes	Wants others to know diabetics can play sports; desires societal knowledge about diabetes; some still think obesity necessarily leads to diabetes; friends misunderstand T1D
	Wants to be seen as the same as everyone else, not the center of attention	Doesn't want to be the center of attention; Embarrassed about injecting in public; Injecting draws others' attention; Doesn't want pity for diabetics; Embarrassment delays injections; Empathizes with fellow diabetics
	People around are ready to care for and show interest in the patient's condition	No impact on friendship closeness; open to answering friends' questions; friends express concern; Friends interested in T1D; teachers always supportive; Good relationship with mother; empathy among diabetics

societal awareness and sensitivity. “After injecting insulin, I sometimes feel self-conscious, especially in public places. I worry that people might stare or wonder what I am doing. So, I tend to inject discreetly at a table, or if I cannot hide, I might ask my mom or dad to sit beside me to provide a little cover” (ID1).

Perceptions and Experiences of T1D Guardians

Table 3 demonstrates the themes, subthemes, and codes for the T1D guardians. Similarly, four themes were identified: perception of T1D, perceived relationship with the patient, coping and responsibility for management, and social aspects. Like the patients, T1D is regarded as severe yet manageable and is often preferred over other serious conditions. There is a call for broader, more effective national access to standardized treatment. Concerns highlight the difficulties T1D patients face in living similar lives to their peers, prompting discussions about the need for improved healthcare access and more attentive care. *“The public health system is not very developed for those living in rural provinces; there is a big difference between doctors and nurses there compared to Bangkok. In Bangkok, doctors and nurses are very caring and provide good care, but they feel less considerate of patients in the provinces. It is particularly noticeable for nurses. I do not understand why there is such a disparity” (G3).*

Regarding the perceived relationship with the patient. Guardians often experience guilt and over-responsibility, which can lead to conflicts stemming from their deep concern for the patient’s well-being. Understanding the patient’s mindset, particularly during adolescence, is crucial for enhancing care and alleviating family tensions. “I feel like I might be depressed. The sugar levels will not decrease despite taking every measure to keep things normal and avoiding any unusual foods. It feels like a vicious cycle, making me want to cry” (G7).

Like the patient, parents proactively embrace new treatments and enhance their knowledge of effective glucose management. They express a need to adjust their lifestyles to manage T1D-related dietary and insulin needs, which can impact their finances and employment. Socially, while support is generally positive, misunderstandings persist. Nevertheless, T1D parent groups can facilitate sharing experiences, reduce anxiety, and improve emotional and practical support. “There is a group for parents of children with diabetes; it consists only of guardians, not the children themselves. They constantly share information within the group” (G5). Patients and families advocate for greater societal under-

Table 3. Thematic analysis of type 1 diabetes (T1D) guardians’ perception and experiences

Themes	Subthemes	Codes
Perception toward T1D	*T1D is severe, yet individuals can still lead an everyday life*	Open about T1D; adjusts to diabetes over time; sees T1D as preferable to cancer; Sees T1D as better than cerebral palsy; can live like other children; worries about diabetes-related dangers
	Desires genuine nationwide access to standard treatment for T1D patients	Biased against older doctors as outdated; fewer specialists in provinces than Bangkok; aims for normal HbA1C levels; praises hospitals for teaching food calculation; values pre-discharge psychiatrist consultations
Perceived relationship with the patient	*Concerned for patients who cannot live like other children*	Upset patients cannot live normally; distressed by complications; struggle with diabetes acceptance; pities dietary restrictions; note embarrassment in public testing; fears injection pain; patients overly fret about diet; concerned about injections and eating
	Desire patients to be more closely watched and cared for than normal children.	Needs more care than peers; moved schools for sugar level management; changed schools for constant maternal supervision.

Table 3. Thematic analysis of type 1 diabetes (T1D) guardians' perception and experiences

Themes	Subthemes	Codes
Perceived relationship with the patient	*Feels guilty for contributing to the patient's diabetes*	Manages stress through T1D research; fears having another child with diabetes; believes nursing does not smooth patient care; feels guilty for giving child sweets; believes they contribute to T1D
	Concern for the patient is so great that it leads to conflict	Argued about diabetes management; disagreed on educational paths; reminded patient of mistakes; did not give in when patient cried against injections; always reminded about testing and insulin; depression from patient's diabetes; vigilant about treatment compliance
	It necessitates the guardian to self-improve in order to understand the teenager's mindset better.	Knows patient's weaknesses in T1D management; maintains a good relationship with the patient; understands teenage behavior; recognizes patient's strengths; Teaches resilience during vulnerability; Adapts to diabetes
Coping with responsibility to management	*Ready to self-improve for better sugar level control*	Always open to new treatments; seeks better sugar control methods; practices food calculations for school; aware repeated injections reduce effectiveness; mother researched diabetes; knows various insulin types; keeps up with diabetes research; believes in solutions to manage sugar spikes
	Families with T1D can independently adjust their treatment to enable a normal lifestyle.	Can eat anything if food is calculated; knows emergency treatment for complications; understands how to calculate food intake; smooth patient care depends on perspective adjustment.
	Diabetes treatment impacts the guardian's work and finances	Necessity to resign from job; affects current employment; travel costs for treatment impact; no impact on job; financial impact; high treatment costs
	Carrying equipment to store insulin makes life more difficult	Challenges include storing insulin; challenges in carrying insulin; and hopes for non-injection treatments; traveling abroad affects medication dosing
Social	*People around are ready to care for and take an interest in what the patient is going through*	Family provides strong support; friends always offer help; acquaintances are aware of the complications; close people around them understand diabetes; friends and teachers comprehend the condition; the family understands and cares for the patient.
	Forming support groups for guardians of diabetes patients offers better care and emotional support.	Meeting many patients reduces worry; attending diabetes camps improves disease perception; grouping patients lowers insulin costs; and a positive environment decreases anxiety.
	Desires those around to have accurate knowledge and understanding of the potential of people with diabetes	Dislikes mocking of people with diabetes; views society as unaware of T1D; wishes for greater T1D awareness; some teachers lack T1D understanding; family members lack knowledge; blamed for patient's diabetes.
	Understands and is eager to share knowledge and experiences about diabetes with others	Understands the challenges faced by T1D; believes their family is prepared to care for T1D; is ready to share with others; is open to advice from others; and welcomes support from others.

standing of T1D to reduce stigma and strengthen community support.

Thematic Analysis of Perceptions and Experiences of T1D Peers

Among peers, three themes were raised, including perceptions of T1D patients, societal awareness about T1D, and perceived lifestyle and future differences. It is acknowledged that T1D patients can lead lives similar to those of their peers with effective management. *"I wonder if they can still just go about their life normally, like they might not have to change. (Group 3)"* There is a strong call for increased societal education about T1D, promoting online and school-based learning to enhance empathy and care. Nonetheless, T1D patients are often perceived as fragile, facing distinct challenges that require a compassionate and flexible approach from family and society.

Peers agree that there are significant knowledge gaps and misconceptions about T1D, especially in differentiating it from Type 2 diabetes. Common misconceptions include oversimplified links between diet and exercise, as well as misunderstandings about the causes and risk factors of T1D. *"But I think that adults usually associate diabetes with a threat to kids, not with eating sugary foods. Moreover, do not eat this or you will get diabetes sort of thing (Group 3)."* This lack of understanding affects the public's perception of T1D management, shaping attitudes and promoting misconceptions about how the disease is managed and treated.

Similarly, peers view living with T1D as significantly impacting their lifestyle, especially in areas such as exercise, sports, and daily routines, including meal planning and insulin management. Patients engage in meticulous meal planning and constant insulin management, which is considered both challenging and vital for maintaining good health. *"Like the people around them, we treat them to eat less or within their carbon-to-insulin ratio, eat a certain*

Table 4. Thematic analysis of type 1 diabetes (T1D) peers' perception and experiences

Themes	Subthemes	Codes
Perception toward patients with T1D	*Believes that eventually, T1D patients can live a life indistinguishable from that of their peers*	Patients with type T1D can lead an everyday life, manage their daily activities, and adapt to their condition.
	Friends and society should be ready to learn and update their knowledge about T1D.	Learn more about T1D online; learn through discussions with experts; desire for serious T1D education in curricula; classroom education on T1D; believe youth are studying T1D.
	Shows empathy and readiness to care for patients with T1D closely	Empathizes with T1D patients; admires adaptable diabetics; ready to care for people with diabetes; accepts people with diabetes close to them; Saddened by loved ones' diagnoses; sees people with diabetes as fragile; worried about diabetics' life challenges
	Believes that patients with diabetes should be treated equally to other children	Treat diabetics like anyone else; dislike mockery of T1D eating habits; dislike weight-related teasing of people with diabetes; obese diabetics may face ridicule.
Perceptions of societal awareness about T1D	*Believes society still lacks knowledge and understanding of T1D compared to Type 2*	A society less familiar with T1D than Type 2; struggles to distinguish between T1D and Type 2; links T1D to diet and exercise; needs more T1D education; seeks a better understanding of T1D; teenagers lack T1D awareness; confuses insulin injections with drug use.

Table 4. Thematic analysis of type 1 diabetes (T1D) peers' perception and experiences

Themes	Subthemes	Codes
Perceptions of societal awareness about T1D	*Society may have misconceptions about T1D behavior and treatment*	T1D motivates sports involvement; people with diabetes experience fatigue and constant hunger; insulin injections are required before meals; distinction between Type 1 and 2 is unnecessary; public insulin use may seem like drug abuse; sweets pose risks to diabetics; exercise manages blood sugar
	Peers may harbor misconceptions about the causes and risk factors of T1D.	Believes a virus causes T1D; thinks all T1D is Type 2; misunderstands T1D pathology; assumes sweets cause T1D; thinks age is the only difference between Type 1 and 2; adults suspect sweet consumption in children could lead to T1D.
Lifestyle and future differences	*Having T1D affects exercise and sports participation*	T1D impacts sports competition; adapting to T1D allows for sports participation; exercise requires special attention
	Additional complicated steps are required before eating each meal	Must pay special attention to diet; healthier food choices necessitate careful eating; calculate food; calculate insulin dosing before meals; people with diabetes must test blood before every meal
	Insulin injection is a challenge for those with T1D	T1D need guardians for insulin injections; people with diabetes must adapt to injecting medication; insulin injections pose challenges; patients fear injections
	It is necessary to adjust to a more delicate and cautious lifestyle than the general population.	People with diabetes need major lifestyle adjustments; T1D alters daily routines; diabetic care demands meticulousness; early-diagnosed individuals struggle more with adaptation; T1D care is particularly challenging.

number of carbohydrates, and perhaps even restrict them from consuming too much glucose. (Group 1)"

Discussion

This study successfully gathered detailed data on the perceptions and experiences of patients with T1D, their guardians, and peers. It reveals that while patients manage their condition and adapt personally despite social and lifestyle challenges, guardians face stress from caregiving, advocating for greater treatment access and support. Peers acknowledge that patients can lead everyday lives with proper management, but they lack a complete understanding of T1D, indicating significant gaps in societal awareness. These perspectives underscore the need for enhanced knowledge and education to reduce stigma and improve the quality of life for individuals affected by T1D, highlighting the importance of a comprehensive healthcare and community support approach.

Among patients with T1D, most had a positive perception of their condition, viewing it as severe but still manageable. Similar to a previous related study in South Africa, initially, patients with T1D adjusted to the reality of living with diabetes, took time to adapt and eventually accepted their situation.(13,14) Patients with T1D have to avoid their favorite foods or face restrictions in sports, where teachers may express concerns about their participation.(15,16) Despite these challenges, patients with T1D are ready to mainly leverage new technologies, such as insulin pumps, to effectively manage their condition, appreciating the fewer adverse outcomes associated with such advancements.(14,17) In addition, although patients with T1D are ready to adopt treatments, they do not want to stand out because of their condition, feel anxious about injecting insulin in public, and prefer to do so discreetly or with their parents providing some cover.(13,14) Therefore, technologies such as insulin pumps and continuous glucose monitoring devices, which can be discreetly worn under clothing, might be beneficial.(18)

Similar to findings from related studies, guardians of patients with T1D, predominantly mothers, generally have a positive outlook on the disease.(19–21) Both patients with T1D and their parents view T1D as severe but manageable, noting that daily life can proceed almost normally with just a few additional steps during mealtime.(19) However, some guardians express concerns about their child's ability to lead a typical life, especially regarding food consumption and insulin injections, particularly during the transition to university, where greater privacy is desired.(13,19,20) Interestingly, these concerns often lead to conflicts with patients driven by the guardians' worries.(22) Therefore, a middle ground should be established between parents and their children to foster a comfortable relationship.

Some parents feel guilty for thinking that their child's condition is entirely inherited from them, which causes significant stress and concern.(19, 22) Although T1D is considered genetically inheritable, it is not a single-gene disease with a high chance of inheritance. Instead, it is a complex trait where the disease mode of inheritance is considered multifactorial. Hence, providing education and holistic care to parents is essential to help them reduce self-blame and improve their overall well-being.

The guardians also noted a disparity in care standards between rural areas and urban cities, such as Bangkok, which adds to the stress and difficulty of traveling; this may increase the resources required for diabetes care, causing guardians to face employment and financial challenges, sometimes leading them to leave their jobs to manage emergency conditions.(19,21,22) Despite these challenges, T1D guardians remain informed and supportive, willing to share their knowledge and experience with others, and find strength in participating in a T1D parent support group.(19, 22)

Similar to related studies among T1D friends, peers generally perceive the condition positively, believing patients can live similar lives.(24) Nevertheless, studies on peers unrelated to T1D are scarce, and direct comparisons of the perceptions are challenging. The present study emphasizes the need for friends and society to be better informed about T1D to enhance the care provided to patients with T1D. Previous studies in the Netherlands also noted that T1D friends are concerned that misconceptions about the causes and risk factors of T1D persist, such as the oversimplified link between sugar consumption and the development of diabetes, leading to uncomfortable feelings among the patients.(24, 25) Hence, this highlights the need to integrate basic knowledge about childhood diseases, such as T1D, into school curricula.

Based on these findings, school peer education programs should be developed to improve understanding of T1D and reduce adolescent stigma. Structured support for guardians, both emotional and practical, may help reduce stress and strengthen family relationships. Public health efforts such as awareness campaigns and youth-friendly diabetes services can promote more equitable and effective care. Future research should investigate the long-term effects and adaptability of these strategies across various settings.

A cross-theme comparison showed both shared and differing perspectives. All groups viewed T1D as serious but manageable and believed patients could live nearly everyday lives. However, guardians were more concerned about long-term care, patients emphasized coping and peer acceptance, and peers had limited understanding. These differences reveal gaps in awareness and support. Although most participants reported positive adaptation, the study also revealed emotional burdens, including parental anxiety, self-consciousness in public, and internalized pressure to appear strong consistently. These findings underscore the need for more comprehensive emotional support in daily life.The present study reveals that all groups generally view the patients in a positive light. They believe that patients with T1D can lead everyday lives, a perspective supported by similar previous literature.(14, 24) However, guardians often worry more about the patient's daily activities, such as calculating food intake, maintaining healthy eating habits, and administering insulin injections, which can lead to misunderstandings and conflicts.(13, 19) Interestingly, mothers are typically the primary guardians, more aware of the day-to-day issues faced by the patients than fathers.(19) This often leads to conflicts, with mothers bearing the brunt of daily care responsibilities while fathers provide support and mediation. In which mothers are more involved in hands-on management, fathers often engage more when technology is involved, providing crucial emotional support and relief. This dynamic sometimes leads to conflicts, but it also fosters deeper communication about managing the child's diabetes effectively.(19)

The findings underscore the urgent need for policy-level interventions to bridge the gaps in societal understanding and support for individuals with T1D. Notably, this study is among the first to comprehensively explore the perspectives of patients with T1D, their guardians, and peers regarding public diabetes awareness. Participants frequently observed that societal familiarity tends to center on Type 2 Diabetes, leading to confusion between the two types and perpetuating misconceptions, such as the erroneous association of obesity with T1D or the misidentification of insulin administration in public as illicit drug use.(5, 6) These misconceptions reflect a broader lack of awareness, highlighting the importance of integrating T1D education into school curricula to foster peer understanding and empathy.(24) In addition, implementing structured peer support programs, caregiver training, and targeted public health messaging could help correct these misunderstandings.(21)

Equally important is addressing structural inequities in healthcare access, particularly in rural areas. The study highlights disparities in care quality driven by geographic location, with fewer diabetes specialists and adolescent-friendly services available in rural hospitals.(26) These gaps may adversely affect treatment outcomes and overall disease management. Therefore, enhancing healthcare infrastructure and ensuring consistent access to specialized care across regions is essential for promoting equitable and effective T1D support nationwide.

The present study had several noteworthy limitations. First, it utilized single-center data, and selection bias may also be present due to recruitment from a single hospital and one international school, which could potentially limit generalizability. Second, the interviewers were primarily doctors, which could lead to interviewer bias. Nevertheless, a semi-structured guide was utilized, and all authors iteratively finalized the codes, increasing the validity. Third, future research should consider including peers with close ties to individuals with T1D to gain deeper contextual insight. Mixed methods and longitudinal designs may better capture evolving perceptions. Volunteer bias should also be acknowledged as a potential limitation, especially among peers with positive attitudes. Finally, the interviews were conducted online, which might have resulted in some details being missed. However, we conducted the interviews via the Zoom application, which allowed us to both see and hear the participants, creating a more realistic interaction. Despite these limitations, our research was the first to study in-depth perceptions and experiences among not only T1D patients but also T1D parents and peers in Thailand.

Conclusion

This study offers in-depth insights into the perceptions and experiences of patients with T1D, their guardians, and peers, highlighting the challenges and necessary adaptations for managing the condition holistically. Patients and their guardians show resilience in adapting to societal norms. Nevertheless, guardians, mainly mothers, may experience significant stress from advocating for better treatment access and managing daily care, often resulting in conflicts. Peers are supportive but display a limited understanding of T1D, underscoring significant societal awareness gaps and prevalent misconceptions. The study emphasizes the urgent need for improved education and stronger support systems to enhance the quality of life for those affected by T1D and advocates for equitable healthcare access across all regions. However, the findings may not generalize to youth from public schools, rural settings, or lower-income backgrounds. Future longitudinal qualitative research is recommended to explore how perceptions and experiences change over time.

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Ethics approval and consent to participate

The study was approved by the Medical Department Ethics Review Committee for Research in Human Subjects, Institutional Review Board, Royal Thai Army (Approval no. S057q/65), according to the international guidelines, including the Declaration of Helsinki, the Belmont Report, CIOMS Guidelines, and the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use - Good Clinical Practice (ICH-GCP). Documentation of informed consent was used, and the Institutional Review Board, Royal Thai Army Medical, granted permission.

Availability of data and materials

The datasets generated and/or analyzed during the current study are not publicly available because they contain sensitive identifying information. However, due to ethical restrictions, the data sets are available from the author upon reasonable request (contact Sethapong Lertsakulbunlue via Sethapong.ler@pcm.ac.th).

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