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Original Article

Understanding the burden faced by families of children living with Type 1 diabetes mellitus in Indonesia: A multidimensional study on the financial, social, and psychosocial aspects

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Highlights

- Most families with children living with T1DM in Indonesia pay for various diabetes-related expenses.
- While most school experiences were reportedly positive, several children still experienced hardships, including bullying and discrimination.
- Diabetes camps provide many benefits to children and their families, including the provision of social support, educational resources, and building confidence.

Abstract. Type 1 diabetes mellitus (T1DM) is a lifelong disorder that affects all aspects of the lives of children and their families. A Health Needs Assessment (HNA) survey was conducted at two diabetes camps in Batu, East Java, and Parung, West Java, to evaluate the challenges and burdens faced by families of children living with T1DM in Indonesia. A total of forty-one respondents, comprising parents/caregivers, participated in the HNA. Most respondents had to pay for diabetes-related expenses, such as insulin (31.7%), self-monitoring blood glucose (31.7%), needles and syringes (63.4%), travel expenses (97.6%), and additional laboratory examinations (24.4%). The majority of the children in this study attended school (97.6%) and most liked going to school (95%). Diabetes camps were reported to be very helpful (95.1%) for gaining more knowledge and social support within the community. A family-centered approach focusing on community support and individualized solutions is required to strengthen support, share resources, increase knowledge, and ultimately improve the quality of life of children and families living with T1DM.

Key words: type 1 diabetes mellitus (T1DM), children, school, financial burden, psychosocial support

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Introduction

Type 1 diabetes mellitus (T1DM) is the most common type of diabetes mellitus (DM) in children and adolescents, accounting for 80–90% of T1DM in young people (1). In 2017, approximately nine million people were living with T1DM worldwide, and most of the reported cases were in high-income countries (2). The preventable mortality associated with T1DM in low- and middle-income countries (LMICs) is inequitably high, which in turn lowers the reported prevalence rate (3). Collaborative efforts are required to achieve the collective goal of reducing preventable deaths associated with T1DM by 30% by 2030, in line with the Sustainable Development Goals target 3.4 (4).

The goals of T1DM management primarily focus on reducing symptoms, preventing acute and chronic complications, promoting good physical and mental well-being, and establishing a life pattern that is not disrupted by T1DM (5). To assist children to live happy and healthy lives with T1DM, families require culturally appropriate and comprehensive educational resources to be available in their local languages. Along with educational resources and support groups, schooling is particularly important for improving the overall psychosocial well-being of children living with chronic health conditions. Schooling has the potential to improve health outcomes and reduce the financial burden in the long term (6, 7).

The literature on T1DM has highlighted the many social, psychosocial, and financial burdens placed on families. Economically vulnerable families, particularly those in LMICs, are subject to financial burdens from the management of T1DM and are therefore at a higher risk of complications of T1DM (8, 9). In Indonesia, access to pediatric endocrinologists, diabetes educators, and dieticians also varies geographically, with access to diabetes care being higher in urban areas such as Jakarta, than in rural areas (10). In 2024, there were 39 pediatric endocrinologists across 18 provinces out of 38 provinces in Indonesia (11).

The prevalence of T1DM in Indonesia increased seven-fold between 2000 and 2010, from 3.88 per 100 million people to 28.19 per 100 million people (10). The number of recorded cases has since increased, although the true burden is predicted to be higher due to high rates of underdiagnosis, misdiagnosis, and mismanagement (10). The rise in recorded cases of children living with T1DM in Indonesia, along with inequities related to the shortage of diabetes-trained health professionals and lack of support and awareness, are the main challenges affecting the financial, social, and psychological aspects of children and their families (10).

Person- and family-centered community development approaches to redressing inequities among children and young people living with diabetes and other noncommunicable diseases (NCDs) in resource-poor settings have been demonstrated to be effective and sustainable (6). Considering the various challenges and burdens experienced by families of children living with T1DM, a comprehensive Health Needs Assessment (HNA) offers an opportunity to further understand the unmet health needs and priorities that are unique to these families. This process can also facilitate rapid identification of strategic, collaborative, and critical actions to redress inequities and improve overall quality of life (QoL).

Methods

Study setting and design

This is a mixed-method study, action research paper with data obtained through an HNA with families of children and young people living with T1DM, informing the implementation of the Strategic Framework for Action of CLAN (Caring & Living as Neighbours), an Australia-based non-government organization (NGO) focusing on redressing inequities faced by children and families living with chronic health conditions in resource-poor settings (6). Primary data collection from respondents was performed during two offline diabetes camps organized by Changing Diabetes in Children (CDiC) Indonesia, a public-private partnership focusing on improving access to T1DM care for children and adolescents in Indonesia. These diabetes camps are costfree and open to all patients with T1DM and caregivers to attend with free transportation provided. One was conducted in Batu, East Java on June 24-25, 2023 and the other was conducted in Parung, West Java, on July 15–16, 2023. The inclusion criteria for this study were parents or caregivers of children and young people living with T1DM, aged between 10 and 18 yr, who attended either diabetes camp.

The participants were given a consent form to sign before undertaking the HNA survey, which was distributed in person, to complete on their own. Two researchers, also co-authors of this study, were present on-site for both diabetes camps to provide a presentation detailing the instructions for completing the survey and to provide further clarifications and assistance if required. Assistance provided by the researchers included interpreting questions for which the participants sought clarification. Participants were provided with a copy of a diabetes newsletter provided by CLAN. The results of the HNA were combined in an electronic datasheet. The files were de-identified after data collection and stored on password-protected computers. The quantitative and qualitative results were collected and compared with the objective of identifying the key themes. Ethical approval for this study was provided by the Faculty of Medicine, Universitas Airlangga (no. 188/EC/KEPK/FKUA/2023).

The survey

The HNA survey was developed by the research team and adapted from CLAN's 2008 HNA for the T1DM community in Vietnam (3) and the Doctor of Philosophy

research project by Armstrong (3, 7). The aim was to further understand the experiences, requirements, and challenges faced by young people and families living with T1DM. The survey consisted of quantitative and qualitative questions and took approximately 30 min to complete. There were eight sections with a total of 36 questions divided into; Demographics (six), Finances (three), Diagnosis of Diabetes (one), Management of Diabetes (five), Treatment of Diabetes (six), Management of Acute Illness (four), Diabetes and School (three), and Finding the Best Way to Help in the Future (eight). Several follow-up questions were asked depending on participant answers. This study analyzed the data collected from four of the eight sections; Demographics, Finances, Diabetes and School, and Find the Best Ways to Help in the Future.

Statistical analysis

Data were analyzed using Google Sheets (Google LLC, Menlo Park, California, CA) and SPSS Statistics (IBM, Armonk, New York, NY). Quantitative and qualitative data are presented as numbers and/or percentages. Qualitative data were analyzed using descriptive analysis to identify key themes, and answers were summarized and grouped based on their semantics. The sum of respondent answers varied in several questions, as not all surveys were completed, which was accounted for during the data analysis.

Results

Participant demographics

The total number of caregivers who attended the diabetes camps were 28 and 21 for the Batu and Parung camps, respectively. Only 41 caregivers met the inclusion criteria for the study. Eight parents/caregivers were excluded because their child was either younger or older than the age range in the inclusion criteria. The demographic profiles of the respondents are shown in **Table 1**.

The majority of respondents lived on Java Island, with 52.5% living in East Java province, 22.5% in Jakarta, 15.5% in West Java, and 7.5% in Banten. The remaining respondent (2.4%) came from Papua province. The results show that monthly family income is evenly split between those earning above their provincial minimum wage (N = 21, 51.2%) and those earning below their provincial minimum wage (N = 18, 43.9%). It is important to note that 39 out of 41 participants disclosed their financial status. At the time of this study, monthly provincial minimum wages were as follows: Rp4.901.798,00 (Jakarta), Rp2.040.244,00 (East Java), Rp1.986.670,00 (West Java), Rp2.661.280,00 (Banten), Rp3.864.696,00 (Papua).

Financial burden of T1DM on families

Although most respondents did not incur extra expenses on insulin, 13 (31.7%) paid for additional insulin. The range of monthly expenses for diabetesrelated expenditures reported by those paying additional out-of-pocket expenses ranged from Rp72.500,00 to Rp1.500.000,00 (4.77-98.60 USD). In addition to the National Health Insurance (NHI) and out-of-pocket payments, patients with T1DM rely on support from NGOs, such as CDiC, for glucometer devices and strips. Thirteen patients paid for additional self-monitoring blood glucose devices and strips (31.7%), ranging from Rp130.000,00 to Rp4.000.000,00 (8.34-262.92 USD). In comparison to self-monitoring blood glucose (SMBG) devices and insulin, more patients paid for needles and syringes (N = 26, 63.4%) and travel expenses for hospital appointments (N = 40, 97.6%). Some patients paid for additional laboratory examinations (N = 10, 24.4%). The mean amounts patients paid for insulin, SMBG devices, needles and transportation costs were Rp479.038,00 (30.85 USD), Rp713.461,00 (45.94 USD), Rp206.057,00 (13.27 USD), and Rp131.250,00 (8.45 USD), respectively. Perceived financial burden associated with T1DM care is shown in Fig. 1.

School experience with T1DM

The majority of the children with T1DM in this study attended school (N = 40, 97.6%), with only one respondent reporting that their child did not attend school, citing repeated hospitalization as the reason. Generally, most participants reported that their child coped well academically (N = 19, 47.5%) and very well (N = 10, 25%) with schoolwork. Similar results were reported for coping well socially (N = 17, 43.6%) and very well in school (N = 15, 38.5%). Regarding physical activity, 32 respondents (82.1%) reported that their child fully participated in all sports at school.

The study explored parental perceptions of the social experiences at school of children living with T1DM. Although most respondents have spoken to their child's teachers about diabetes (N = 36, 92.3%), several parents hesitated to inform the school of their child's condition (N = 3, 7.7%). Two respondents expressed concerns about their child being bullied or discriminated against (66.6%), while one did not feel the need to inform teachers because they felt that diabetes did not affect their child's life (33.3%). Those who had conversations with teachers generally reported positive and supportive attitudes from the teachers, whereas others were surprised and expressed concerns that something would happen to the child at school. Some respondents reported that their child had been the subject of rumors and faced discrimination at school (N = 4, 10.3%). Some comments directed at these children included remarks like, "How can a child get diabetes?" or questions about many sweets the child consumes. The results are summarized in Table 2.

Characteristics $(N = 41)$	Number of responses (%)
Which province do you live in? (41)	
Banten	3 (7.3)
East Java	21 (51.2)
Jakarta	9 (21.9)
Papua	1 (2.4)
West Java	6 (14.6)
No responses	1 (2.4)
Do you live in a rural or urban area? (41)	
Rural	11 (26.8)
Urban	30 (73.2)
What is the average income for your household each month? (41)	
Equal to or above the provincial minimum wage *	21 (51.2)
Below the provincial minimum wage *	18 (43.9)
No responses	2 (4.9)

Table 1. Demographic profile of the participants

Data are presented as the number of responses and percentages in parentheses. * Provincial minimum wage in Jakarta: Rp. 4.901.798, East Java: Rp. 2.040.244, West Java: Rp. 1.986.670, Banten: Rp. 2.661.280, Papua: Rp. 3.864.696.

Perceived Financial Burden Associated with T1DM Care of Families Living with T1DM in Indonesia



Fig. 1. The perceived financial burden experienced by respondents. T1DM, type 1 diabetes mellitus.

Resources and support

This study aimed to identify the best approach to assist children and young people living with T1DM in the future. When asked about reading materials on T1DM, all respondents (N = 41, 100%) reported that the available educational resources were helpful and expressed their desire for more materials.

All respondents reported the diabetes camp was "very helpful" (N = 39, 95.1%) or "quite helpful" (N = 2, 4.9%). Feedback on how the support group meetings assisted them is presented in **Table 3**. Families were asked whether they would attend diabetes support group events in the future. The majority answered yes (N = 37,

90.2%) and expressed interest in having an active role in the diabetes support group (N = 35, 85.4%).

Perspectives of the families on the future and wellbeing of their children

The perspectives of the families on the future of their children were mostly positive. The majority of respondents "completely agree" that their child will: have a happy family in the future (N = 38, 92.7%); attend university (N=35, 85.4%); have a job that they like (N = 37, 90.2%); have opportunity to do what they want (N=37, 90.2%); and a good income to live comfortably (N = 34, 82.9%). The remaining respondents answered

Characteristics (Responses)	Number of responses (%), Median (Min–Max)
Does your child with Diabetes attend school? (41)	
Yes	40 (97.6)
No	1 (2.4)
If no, why not? (1) In and out of the hospital	1
If yes, what grade is your child in at school? (40)	
Elementary school	15 (37.5)
Middle school	15 (37.5)
High school	10 (25)
Does your child like going to school? (40)	
Yes	38 (95)
Sometimes	1 (2.5)
No	1 (2.5)
How does your child cope academically with schoolwork? (40)	
Very well	10 (25)
Well	19 (47.5)
Good enough	10 (25)
Poor	1 (2.5)
Very poor	0 (0)
How is your child coping socially with school? (40)	
Very well	15 (38.5)
Well	17 (43.6)
Good enough	5 (12.8)
Poor	2 (5.1)
Very poor	0 (0)
No response	1 (2.5)
Have you talked with your child's teachers about Diabetes? (40)	
Yes	36 (90)
No	3 (7.5)
No response	1 (2.5)
If not, please explain why not. (3)	
Diabetes does not affect my child's life	1 (33.3)
Concerns of my child being bullied/discriminated	2 (66.6)
If yes, how did your child's teachers respond? (36)	
Well	7 (19.4)
Just normal	1 (2.8)
Willing to provide additional support, care, and supervision	15 (41.7)
Providing a room for the child to inject insulin or check glucose levels	1 (2.8)
Try to understand and ask questions	3 (8.3)
Surprised	5 (13.9)
Afraid that something would happen	1(2.8)
No response	3 (0.3)
Does your child participate fully in all sports at school? (40)	00/00)
Yes No	32 (80)
INO No vocnonco	1(17.5) 1(9.5)
no response	1 (2.0)
Does your child become the subject of rumors and face discrimination at school	? (40)
Yes	4 (10)
NO	35 (87.5)
No response	1 (2.5)
II yes, what sort of things are said? (4)	0 (70)
now can a child get diabetes?	Z (50) 1 (95)
They eat too many sweets. "They are always ill"	1 (20)
1110 Y ALC ALWAYS III.	1 (40)

 Table 2.
 School experience and type 1 diabetes mellitus

Table 3.	General feedback on the diabetes camps and the community support group meetings where the
	Health Needs Assessment was conducted

How has this Diabetes Support Group Meeting helped you? (N = 41)	n (%)
My child gets knowledge on his/her condition	5 (12.2)
My child learns to be more independent and gains confident to do his/her diabetes care	17(41.5)
My child learns self-control with food and understands the importance of physical activity	3(7.3)
My child is able to socialize, gain new friends, and realize he/she is not alone	25 (61)
My child feels happy, entertained, and excited	10 (24.4)
Parents get to know other parents and realize they are not alone	20 (48.8)
Parents get knowledge on diabetes	31 (75.6)
Parents learn how to deal with children when they are sad and happy	2(4.9)
Opportunity to ask and consult with doctors/experts	5(12.2)
Learn about calorie counting and diet management	7 (17.1)
Gain new experiences	4 (9.8)

"agree" to the statements above.

At the end, the participants were given an opportunity to ask any questions or write about any concerns they may have for their child with T1DM, and the responses (N = 7) varied by topic. Three questions were related to the progression of diabetes research and whether there were any available treatments to cure T1DM. Concerns surrounding the independence of the child in managing their diabetes were featured, as well as taking care of their future family. Families showed clear appreciation and passion for community events, such as the diabetes camp, so they could support one another and continue to make informed decisions for their child:

"It's been a very useful event, because it helped us parents' become more knowledgeable about our kids' condition."

"Hopefully, we always have events like this because they help both us parents and children with diabetes not feel alone and give us confidence to face different situations."

"The event was very useful, and it'll be interesting to have further follow-up sessions, like developing an active community to discuss more educational material regarding diabetes in next year's session and share updates on the medical world regarding diabetes."

Discussion

Holistically understanding the experiences and needs of families of children and young people living with T1DM facilitates collaborative approaches to practical actions that redress inequities and optimize overall QoL. In the study by Pulungan *et al.*, patients were still either partially or completely responsible for payments of essential diabetes care, such as insulin, HbA1c, C-peptide, antibody testing for diagnosis, and lack of government support for more advanced diabetes-related technology (12). The out-of-pocket diabetes-related expenditure of all participants in this study reflects inequitable universal health coverage and a lack of support for families and children living with T1DM in Indonesia.

In 2014, Indonesia established the BPJS Kesehatan, a social security agency that provides NHI (13). As of March 2023, over 252 million Indonesians have gained access to health services through BPJS Kesehatan. Although insulin is covered by this health insurance scheme, there are limitations to what is covered (10). BPJS Kesehatan covers claims based on a package system called the Indonesia Case-Based Groups (INA-CBGs), where spending limits on services provided to patients are no longer charged, based on the details of the service itself, but on the disease-related group codes, diagnosis of the patient, and the healthcare facility level (14). Under this system, healthcare providers are allocated a specific amount based on the diagnosis of the patient regardless of the services that the patient requires. This system forces pediatric endocrinologists and pediatricians responsible for T1DM care to adjust the medications, examinations, and services prescribed and provided to these patients according to the package limited by the INA-CBGs.

Thirteen participants in this study (31.7%) paid for additional insulin. Participants elaborated that they were only provided with exactly one month of insulin supply, without accounting for any extra for emergencies. Furthermore, patients are required to visit healthcare providers to gain access to this monthly supply. With existing health disparities in Indonesia and a limited number of pediatric endocrinologists, T1DM centers are still located only in major cities, adding an extra burden on families who are required to travel long distances. This was reflected by the vast majority of participants (97.6%) who had to pay travel expenses. As a lifelong condition, ensuring sustainable access to healthcare services relies not only on coverage of essential medicines through the NHI, but also on the additional burden associated with T1DM care, including travel costs and allocating time to visit healthcare facilities each month.

In addition to insulin administration, SMBG is another critical pillar of T1DM care and plays a pivotal role in preventing diabetes-related complications. The International Society of Pediatric and Adolescent Diabetes recommends testing 6 to 10 times a day to optimize glycemia with fingerstick SMBG. Despite numerous studies highlighting the importance of SMBG, challenges such as access and affordability still prevail because BPJS *Kesehatan* does not cover the costs of glucometers and strips. The patients in our study relied on the support of NGOs to provide these glucometer strips. One such NGO, CDiC Indonesia, provides registered patients with glucometers and strips for four daily tests. Prior to the establishment of NGOs, such as the CDiC, patients opted not to undergo SMBG, compromising glycemic control and future health outcomes.

In a study by Ogle *et al.* that analyzed the financial costs of T1DM for families in 15 low-income countries, glucometer strips were found to be the most expensive diabetes-related consumable (9). In addition to diabetes-related consumable costs, there are high costs associated with travel, laboratory examinations, and consultations (9). Ogle *et al.* reported that annual diabetes-related expenditures varied between 255 USD and 1,185 USD, equating to a median of 56% of the annual gross income (9). The current study found that, on average, families spent 31.49 USD per month on diabetes-related expenses, which equates to 377.88 USD per year. With existing economic and social disparities in Indonesia, such expenses were viewed as significant sources of financial burden, with 9.8% and 17.1% of the respondents citing "lots of stress" and "quite a bit of stress," respectively, when asked about the perceived financial burden associated with T1DM care.

Schools are an important part of the lives of children and adolescents living with T1DM. Acknowledging the differences in academic standards between provinces in Indonesia, this study did not gather objective data on academic performance. However, academic performance, social interactions, and participation in physical activity at school were perceived well by families in the present study. Although the vast majority of respondents in the study did not complain of declining academic performance, prior studies have reported that poor glycemic control can negatively impact academic performance (15). Therefore, appropriate care and monitoring must be provided for any complications or challenges experienced by schoolchildren with T1DM.

While families reported positive and supportive responses from their child's teacher, educating school staff on diabetes will improve diabetes management so that the child may fully participate in school to their highest ability. The social stigma and discrimination faced by families and children with T1DM in this study (10.3%) may affect diabetes management. Two families expressed hesitancy to inform the school of their child's condition because of concerns about being bullied and discriminated against. Other studies have shown a link between stigma and compliance to diabetes care in children (16). A qualitative study by Elissa *et al.*, which sought to explore the social impact experienced by children with T1DM, reported that a sense of isolation forces the children to compromise their diabetes self51

management and even keep their condition a secret so that they could "fit in" (16). A lack of understanding of T1DM in society can lead to misconceptions and, thus, negative stereotypes that affect the capacity of families and children to participate fully in diabetes care (10, 16). One such example in this study involved a child who was a subject of rumors and faced discrimination at school by fellow peers, saying, *"they eat too many sweets"* as a cause of their condition. Two other families also reported comments from their peers saying, *"How can a child get diabetes?"*. There is generally low awareness in society regarding the distinction between T1DM and T2DM, and that children can have diabetes (10).

It is widely acknowledged that educational resources are a vital part of the holistic management of NCDs, including T1DM. One hundred percent of the respondents reported that they had access to educational resources that are helpful for diabetes management but expressed their desire for more material. Culturally appropriate educational materials, tools, and other resources in local languages are important for health literacy so that families can make informed decisions about the health of their child (10, 17–19).

This study was conducted during two diabetes camps in Java, Indonesia. Feedback on both diabetes camps was mostly positive, with common feedback related to the opportunity for parents and children to gain more knowledge and confidence in diabetes management, as well as a sense of mutual support among parents and children living with the same condition. Surveys from other support group meetings within the diabetes and congenital adrenal hyperplasia communities in Vietnam highlighted the positive effect of such events on the QoL of children (20). Families in the diabetes community reported increased confidence in medical management, improved blood glucose control, and sought help from healthcare professionals more often (20). Increasing social support is an integral part of support group events and leads to an improved QoL. Cutrona and Suhr categorized social support into five main areas: informational, emotional, esteem, social network, and tangible support (21). These five areas conceive the value of educational resources, empathy felt, increasing self-confidence and abilities, mutual understanding, and access to quality resources (22). Families often experience emotional stress from the pressure of daily diabetes care, which is required throughout their lifetime; therefore, there is a broader requirement for social support and resources (16, 17, 23). A study of adults living with T1DM in Australia highlighted the interconnection between low social support, challenges in diabetes management, low health literacy, and low self-esteem (24). Adults living with T1DM who had strong social support while growing up showed mastery in their self-management as adults (24). The overall benefits and effectiveness of support group events are an important part of social support and serve as conduits for information sharing. Furthermore, a study by Soenggono et al. that followed up with patients having T1DM three months after a diabetes camp found a significant improvement in glycemic control, supporting the idea that the positive impacts of such events also extend to clinical improvements (25).

Diabetes requires lifelong care and attention, and understanding the perspectives of the families of the independent future and well-being of their child provides further insights into the experiences of families. The majority of those surveyed in this study strongly believed that their child will have a bright future in terms of their personal lives, as well as academic and professional opportunities. However, one parent expressed concern about the ability of their child to care for their own family in the future. In a country such as Indonesia, where family and religion are core to the culture, it can play an important role in providing support within the community, and therefore develop a sense of resilience (26).

Limitations

The self-reported survey used in this study had limitations, including response bias, response fatigue, misinterpretation of questions, and recall bias. However, this was minimized by the availability of research assistants to answer and clarify questions during data collection. The research assistants and participants received specific guidelines on how to fill in the HNA survey, but the participants were given freedom to answer. While the survey was adapted from CLAN's 2008 HNA for the T1DM community in Vietnam (3) and the Doctor of Philosophy research project by Armstrong (7), a locally validated tool has yet to be developed. Additionally, confounding variables, such as the education and occupation of other caregivers, parental marital status, and primary caregiver identification were not collected in this study. These omitted variables limited the ability of the current study to further explore the possible causal relationship between the socioeconomic status and diabetes care burden of the families. Furthermore, objective information regarding the academic performance of children and young people, as well as their subjective school experience and details regarding school absences, were not collected in the study. Finally, as the survey was conducted at offline diabetes camps, the respondents may not represent the entire cohort of children with T1DM in Indonesia.

Conclusion

A comprehensive HNA that identified the experiences, needs, and priorities of families of children living with T1DM in Indonesia broadens the understanding of the unique challenges and burdens faced. In this study, financial burdens and school experiences varied among families, and the individual families that experienced hardship suggest that there is a requirement to continually and collectively support families and the community so that all children have their needs met. Additionally, families expressed the value of community support group events as opportunities to strengthen social support, share resources, increase their knowledge of holistic approaches to diabetes management, and build confidence. Through a person- and family-centered approach to community development, collaborative and practical actions can redress inequities so that all children and young people living with T1DM and their families can live with the highest QoL attainable.

Conflict of interests: The authors have no conflicts of interest to declare.

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