REVIEW

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Pediatric Type 1 Diabetes Care in Indonesia: A Review of Current Challenges and Practice

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Abstract

Type 1 diabetes mellitus (T1DM) is a chronic condition requiring lifelong management that affects a large number of children and adolescents globally. While diabetes care has improved over the years, low-middle income countries, such as Indonesia, still struggle to achieve optimal diabetes care due to limited access to healthcare professionals, insulin, diabetes technologies, and self-monitoring blood glucose (SMBG) devices. Data from the Indonesian Pediatric Society registry has reflected a stark increase in the number of children with T1DM, with the current prevalence significantly concentrated on Java island and a noticeable underreporting in rural regions. Another major challenge is the uneven distribution of pediatric endocrinologists, resulting in a low specialist-to-patient ratio. This imbalance, coupled with inadequate access to comprehensive diabetes care, complicates effective T1DM management. While the national insurance covers a portion of costs associated with T1DM care, vital aspects of T1DM management including SMBG devices are still not covered, resulting in significant financial burden to families. Access to diabetes technologies that improve glycemic control and quality of life of patients is also still largely limited. This paper evaluates the current state and future needs for insulin and SMBG in Indonesia, emphasizing the necessity of strategic interventions to improve access and quality of diabetes care.

Keywords: Pediatric, type 1 diabetes, challenges, practice

Introduction

Widely regarded as one of the most common non-communicable diseases (NCDs) in children, type 1 diabetes mellitus (T1DM) is a chronic condition that requires comprehensive and lifelong management. Insulin and self-monitoring of blood glucose are integral components of successful T1DM management. While access and availability of diabetes technologies, insulin, and self-monitoring blood glucose (SMBG) devices may be good in most high-income countries, low and middle-income countries, such as Indonesia, still struggle to provide attainable access to optimum diabetes care (1,2,3). As Indonesia works towards achieving Sustainable Development Goals target 3.4, which is to reduce premature mortality associated with NCDs, concerted efforts must be made to ensure the availability of insulin and other diabetes technologies. This paper evaluates the current situation and prospective needs for insulin and SMBG technology in Indonesia.

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Epidemiology of T1DM in Indonesia

According to Changing Diabetes in Children (CDiC) Indonesia database in January 2024, there were 1210 children and adolescents, aged 0-25 years, who have been diagnosed with T1DM (4). Based on the CDiC Indonesia registry, the highest population of T1DM in Indonesia is found on the island of Java, especially in Jakarta, and it is more prevalent in girls. However, this is probably attributable to low reporting and case finding in rural areas outside of Java Island. The population of T1DM in Indonesia up to January 2024 is shown in Figure 1. Based on the CDiC registry, the age-based population of T1DM is mainly between 11 and 15 years old (Figure 2). The data reported in this study is lower than that of most countries. This may be because the prevalence reported is hospital-based, whereby these are patients that are reported by each individual pediatric endocrinologist who manages them. Therefore, the number of children and adolescents living with T1DM is believed to be underreported.

Pediatric Endocrinologist in Indonesia

The Indonesian Pediatric Society (IPS) database shows that in 2024, there were 39 pediatric endocrinologists whose practices were located in 18 provinces (out of 38 provinces in Indonesia), reflecting the uneven distribution of pediatric endocrinologists in Indonesia (5). Figure 3 depicts the distribution of pediatric endocrinologists in Indonesia. Population data from 2023 shows that there are 84,198,626 children in Indonesia, while only 1,210 children and adolescents aged 0-25 years had been diagnosed with T1DM (6,7). This means that the ratio pediatric endocrinologists to children with T1DM is 1:134 and is 1:2,000,000 pediatric endocrinologists for the child population, indicating the low ratio of pediatric endocrinologists to the general Indonesian pediatric population. In Ethiopia, a low income country, the ratio is one pediatric endocrinologist for every 40,000,000 children (8). Along with the increase in the prevalence of children diagnosed with T1DM in Indonesia, this will increase demand for pediatric endocrine care and there is a clear need for more pediatric endocrinologists.

In Indonesia, T1DM patients are mainly under pediatric endocrinologist care. While in other countries, T1DM may be managed by a comprehensive team, including specialist diabetes nurses and dieticians. Low-middle income countries (LMICs) tend to approach T1DM care centered around pediatric endocrinologists, while high income countries (HICs) have dedicated interprofessional teams for T1DM care. In Pulungan et al. (1), data from 25 countries showed that only 24% of respondents reported that pediatricians were the chief healthcare professionals (HCPs) responsible for T1DM care. This study also described

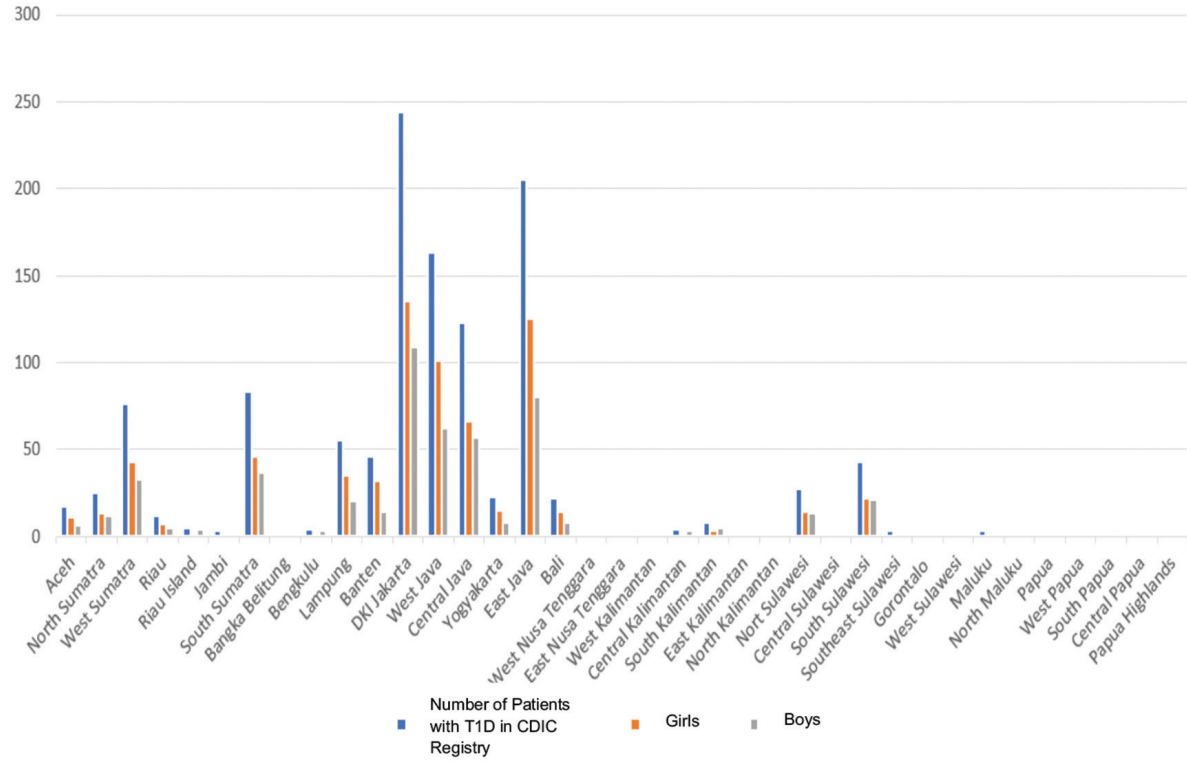

Figure 1. Distribution of type 1 diabetes mellitus in Indonesia up to January 2024

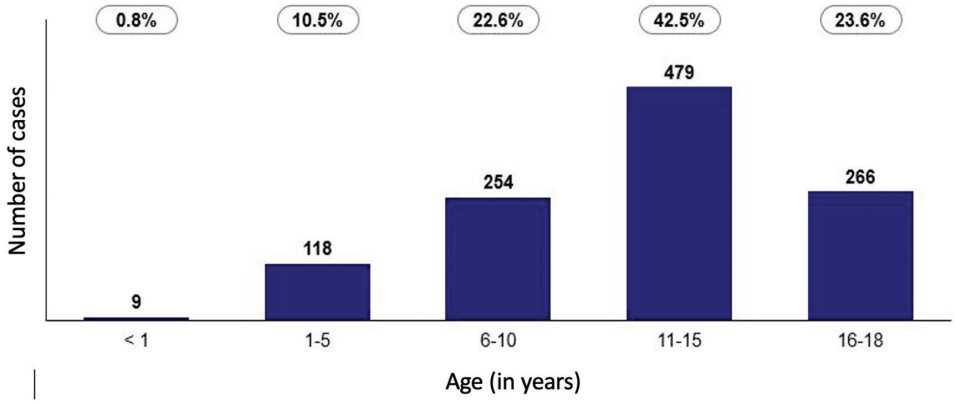

Figure 2. Distribution of type 1 diabetes mellitus in 1,126 young patients based on age as of January 2024

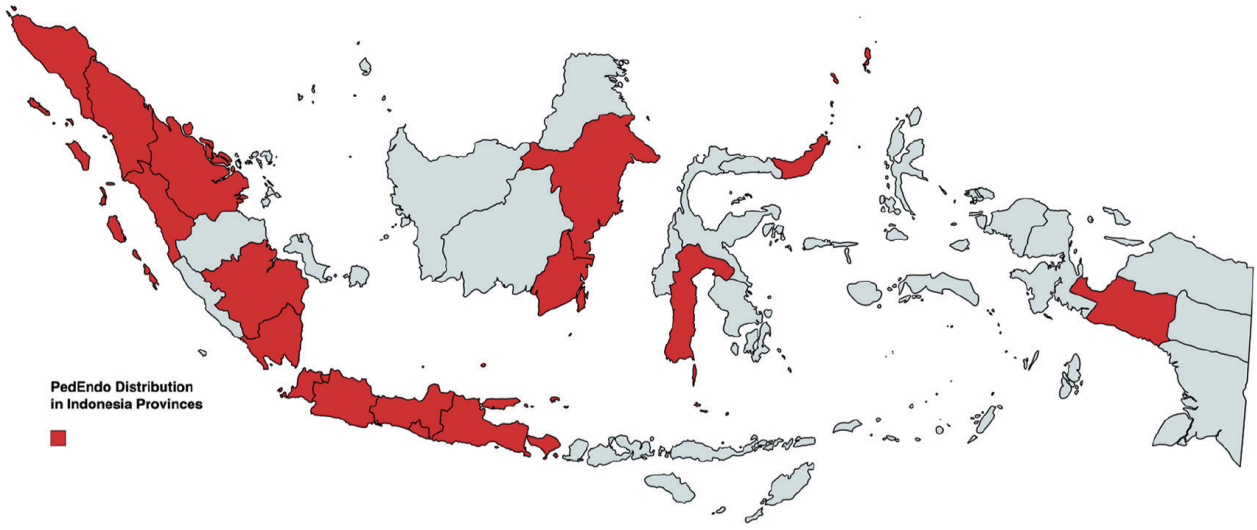

Figure 3. Distribution of pediatric endocrinologists in Indonesia

the need for a comprehensive team providing medical care for T1DM, which was mentioned by 36% of respondents (1). A persistent issue in LMIC is the insufficient number and uneven distribution of qualified HCPs. The absence of adequate technical guidance, training initiatives, and financial support for these programs exacerbates this challenge (9).

Pediatric endocrinologists often advocate for their patients, particularly in environments lacking universal healthcare coverage. The Think Tank Group outlined a 7-step cascade to assist these professionals in their advocacy role. The cascade begins with identifying the target population and progresses through ensuring service contact coverage, assessing input-adjusted coverage, intervention coverage, and quality-adjusted coverage. It further evaluates user adherence and outcome-adjusted coverage to ensure optimal care and desired health outcomes. This framework provides a structured approach for pediatric endocrinologists to optimize support for patients and families dealing with T1DM, and it can be adapted to various patient groups (10).

Insulin Supply in Indonesia and its Importance

Since its discovery in 1921, insulin has been the core life-saving treatment for T1DM. It is the cornerstone of optimal blood sugar control in countries with limited resources (11). Approaching normoglycemia is the goal of T1DM therapy, and this may only be achieved by using insulin in the majority of pediatric patients diagnosed with diabetes. Clinical use of insulin is remarkably complex, and optimal glycemic control can be challenging to achieve and maintain. There is rarely a treatment regimen that is applicable to all people because of the dynamic nature of growth, development, and hormonal changes during childhood and adolescence (12).

Insulin therapy plays a crucial role in the management of T1DM. A solid understanding of current insulin therapy methods is essential for effective management. Studies conducted by Sow et al. (11) have highlighted several shortcomings, including a low level of knowledge regarding insulin therapy. Sow et al. (11) recommended enhancing and monitoring T1DM management training for healthcare providers across various sectors.Children and adolescents with T1DM require multiple insulin injections every single day and often use a combination of fast-acting, short-acting, medium-acting, or long-acting insulin to achieve optimal blood sugar control. New insulin analogs and diabetes technology tools have transformed insulin treatment during the past few decades. Insulin pens have become a popular insulin delivery modality in young people with diabetes due to their ease of use and increased dosing accuracy compared to insulin delivery. In some countries, there are insulin pens connected with smart phone applications and continuous glucose monitoring (CGM) devices, allowing pen users access to benefits such as data collection, alerts and reminders, and dosing calculators that take insulin on board into account (13).According to the PrimaKu and CDiC database in January 2024, children and adolescents with T1DM use three groups of insulin: basal, bolus, and premix (14). The types of basal insulin used by patients are Levemir®, Lantus®, Ezelin®, and Sansulin®. The types of insulin bolus used in Indonesia are Apidra®, Novorapid®, Humalog®, and Lispro®. Premix insulin used in Indonesia is Humalog mix 25®, Humalog mix 50®, and Novomix®.

Based on the CDiC Indonesia registry, more than 50% of the 1,210 patients used Novorapid® in their daily blood sugar management (14). Novorapid® is commonly used in blood sugar management settings, often combined with basal and premix insulin therapies. The most frequently used insulin combination is the basal bolus combination.

The daily insulin dose for patients with T1DM is empirically recommended to be between 0.7 and 1.2 units per kilogram of body weight per day (12). The estimated national insulin requirement for children with T1DM is calculated based on the average daily dose and the average body weight of registered patients, who average 12.3 years old. Therefore, age limits of 12 and 13 years are utilized. The lower limit corresponds to the two-digit P50 rounding of the weight curve for 12-years-old boys, which is 35 kg (rounded up from 34.81 kg). The upper limit is based on the two-digit P50 rounding of the weight curve for 13-year-old girls, resulting in 40 kg (rounded up from 39.51 kg). The national growth curve used for this calculation is the Indonesian National Synthetic Growth Chart developed by Pulungan et al. (15) in 2018.

The calculation of the national insulin adequacy requirement involves estimating twice the number of patients currently registered in the IPS Endocrinology Working Group-CDiC Indonesia joint registry, which is almost 20% of the number reported by the International Diabetes Federation in 2022 (16). Calculation of the national insulin requirement can be seen in Table 1. Most patients use a basal bolus regimen with proportion 50:50. This proportion varies from what is generally used in other countries as children in Indonesia tend not to inject insulin whilst at school. Therefore, most pediatric endocrinologists opt to increase the basal insulin dose to compensate for not injecting during school hours. This highlights an existing need for greater support from schools as well. Insulin availability is generally in pen and cartridge form with a strength of 1 mL containing 100 insulin

Table 1. Calculation of national insulin needs

Body weight (kg)	Individual daily dose (unit/KgBW)		Number of patients	Monthly needs		Yearly needs	
	0.7	1.2		Minimal (unit)	Maximal (unit)	Minimal (unit)	Maximal (unit)
35	24.5	42	2204	1,766,940	3,029,040	21,203,280	36,348,480
40	28	48		2,019,360	3,461,760	24,232,320	41,541,120

Kg: kilograms, KgBW: kilogram body weight

Table 2. Forecast of national T1DM insulin cartridge requirement

Insulin	Monthly needs (cartridge)		Yearly needs (cartridge)	
	Minimal	Maximal	Minimal	Maximal
Basal	2,944.9	5,769.6	35,338.8	69,235.2
Bolus	2,944.9	5,769.6	35,338.8	69,235.2
Total	**5,889.8**	**11,539.2**	**70,677.6**	**138,470.4**

T1DM: type 1 diabetes mellitus

units, 300 units per-cartridge. Based on Table 1 with minimal and maximal insulin dose, calculation of the national insulin requirement for children and adolescents with T1DM in cartridges can be simplified, as shown in Table 2.

Insulin is a critical part of T1DM care. First introduced in 1962, insulin pumps have been largely instrumental in improving glycemic control in pediatric T1DM patients, with early studies demonstrating a clear benefit towards improving glycemic control with less fluctuations in glucose levels and lower incidence of hypoglycemia (17). As technology rapidly progresses, new hybrid closed loop system integrate CGM systems with an insulin pump and offer automated insulin delivery in response to blood glucose trends. Studies conducted in HICs have shown increased time-in-range, improved hemoglobin A1c (HbA1c) levels and a decrease in hypoglycemic events. Currently, insulin pumps are only available to a handful of those capable of paying personally or have access to private insurance that provides coverage. They are not provided by most insurance providers including the national health insurance. Our data estimates that insulin pumps are used by less than 2% of T1DM pediatric patients in Indonesia.

SMBG in Indonesia

Routine SMBG helps patients to adjust their insulin dose with food intake. Therefore, it also enables patients to correct their blood glucose when it is out of the target range when not associated with meals. Well-controlled SMBG further contributes to improved HbA1c levels. SMBG is also important for patients with T1DM when performing sports to adjust insulin dose before, during, and after physical activity to avoid the risk of hypoglycemia. Monitoring SMBG when patients are sick is also crucial (18).

The frequency of SMBG varies according to individuals and the availability of testing devices and strips. It also depends on patients' and caregivers' ability to recognize early signs of T1DM emergencies and conduct a blood glucose check. To optimize glycemic control, SMBG is recommended to be performed 6-10 times a day (19). There is no study from Indonesia that compiles the mean HbA1c levels for children nationally and data are limited to each center. As in Jakarta, the average HbA1c level is around 12.5%, whereas in Surabaya, the average HbA1c level is 10.7% (20).In Indonesia, finger stick blood glucose monitoring is the most widely used method to check patients' glucose levels periodically. Similar to the global data, this method is widely used in most countries, while CGM is only available in around a third of respondent countries (1). Data has shown that CGM is superior to the finger stick method for several reasons: 1) CGM is associated with lower HbA1c; and 2) the finger stick method requires patients' compliance and awareness (21,22). CDiC data indicated that 53% of registered patients regularly check their SMBG, with half of them infrequently checking their SMBG. Studies have shown that CGM is cost-effective in decreasing short-term and long-term complications and yields lower HbA1c levels compared to finger stick testing (21,22,23). Unfortunately, SMBG devices and glucometer strips are again not covered by the national health insurance, therefore making this a challenge for Indonesian children with T1DM.

CGM systems are more flexible than conventional finger-prick glucose tests and are especially beneficial for patients on intensive insulin therapy, reducing discomfort and allowing for easier glucose monitoring. Despite being registered in the Food and Drug Supervisory Agency, the use of CGM has not been widely established in Indonesia as payment has to be made personally, either by private insurance or out of pocket. It is not covered in the national insurance scheme, which the majority of T1DM patients in Indonesia rely on. While there are some private and company insurances that cover CGM, it is important to note that access to such insurance may be limited to those who can afford private insurance. Current efforts to improve diabetes care in Indonesia have yet to achieve an improvement in general access to diabetes technologies, as efforts are currently being directed towards the training of HCPs and expansion of access and availability to basic diabetes care, such as insulins and conventional SMBG technologies such as test strips and readers.

Current Situation and Challenges in Indonesia

"Children are not little adults" is a view stressed by the American Diabetes Association in their 2018 position statement on Type 1 Diabetes in Children and Adolescents (24). With its distinctive pathophysiology, epidemiology, psychosocial challenges, and developmental considerations, diabetes in children is very different from diabetes in adults (25). The pediatric and adolescent period comprise years of rapid growth and formative development. Coupled with the challenges that naturally occur during those years, children and adolescents living with T1DM have the added challenge of accommodating T1DM as part of their day-to-day lives (24). This includes regular insulin injections, blood glucose monitoring, nutritional planning, physical activity and concerns about high/low blood glucose (26). The importance of good T1DM management cannot be overstated, with its direct association with glycemic control, improvement in quality of life and protection from long-term diabetes-associated complications (27).To achieve optimal T1DM management, patients and families must be supported with

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adequate means to attain access to treatment, including various forms of insulin, SMBG devices and monitoring examinations, comprehensive education and psychosocial support. Introduced in 2014, the main health insurance scheme available to Indonesian citizens is Jaminan Kesehatan Nasional (JKN) (28). Under this scheme, T1DM patients are able to access a monthly supply of basal and prandial insulin, based on the indicated doses, 90 pieces of needle and alcohol swab, as well as an HbA1c examination every three months. Insulin is available in all hospitals but not primary health centers. Therefore, most patients diagnosed with T1DM are able to access this basic care if they are enrolled in the national health insurance. However, SMBG devices, such as glucometers and glucose strips are not covered by the national insurance. Examination of diabetes-related autoantibodies are not routinely conducted in Indonesia, either in academic medical institutes or private practice. These tests are only available in a limited selection of centers. However, in 2024, pediatric endocrinologists were advocating for the examination of diabetes-related antibodies. These diagnostic tests for autoantibodies are equivalent with examinations, such as C-peptide. However, insulin autoantibodies are not routinely conducted but are available if paid out-of-pocket in several major health centers. Essential treatment in T1DM emergency, such as glucagon, is currently not under the coverage of JKN. Devices like insulin pumps and CGM are known to improve diabetes management. However, access and availability to such devices in Indonesia still needs to be improved, even in academic medical institutes, because even in these centers most patients rely on the national insurance.

The cost of SMBG devices in Indonesia range from Rp 300,000 to Rp 600,000 (19.21-38.40 USD), with a pack of 25 glucose strips ranging from Rp 60,000 to Rp 120,000 (3.84-7.68 USD). With a minimum requirement of four glucose tests a day and a recommended number of six tests per day, this totals up to Rp. 600,000 (38.40 USD) per month if families were forced to pay out of pocket. In a country where the monthly average household income is Rp. 3,178,227 (203.52 USD) in 2023, this places significant additional financial burden on patients and families (29). While insulin is generally covered by the national health insurance, there are still patients who have to pay out-of-pocket for insulin. It is not uncommon for patients to purchase insulin out-of-pocket as they found that the supply covered by the national health insurance is insufficient or with the intention of reducing the need for monthly visits, and thus the associated transportation costs and inconvenience associated with hospital visits, such as days off from work/school and having other children to take care of. When access to insulin and SMBG devices are threatened, so is overall management and glycemic control. Patients are also at higher risk of experiencing life-threatening complications (30,31).

One of the efforts to alleviate the challenges of equity of T1DM care is CDiC Indonesia. CDiC Indonesia is a public-private partnership focused on improving access to T1DM care (31). One of the programs includes providing blood glucose strips to patients registered in the program. T1DM patients between the age of 0 to 25 years old are eligible to receive four glucose strips a day and monthly supplies of glucose strips are delivered to patients' homes.

Another prominent multisectoral partnership is between the existing national health mobile application and information systems, namely PrimaKu and SatuSehat. PrimaKu is an application developed in collaboration with the Ministry of Health, the IPS, and the National Population and Family Planning Board. PrimaKu is a mobile application used by parents across Indonesia to monitor their children's growth and development (32). In 2023, PrimaKu was updated to include a Diabetes Diary feature, allowing T1DM patients to either connect their glucometers to PrimaKu for automatic syncing or manually input their SMBG results, which sync directly with a glucometer. The Diabetes Diary is not limited for use by only pediatric T1DM patients. As of November 2024, there are 1,408 people registered to use the diabetes diary.As part of an effort to integrate health information systems and to improve efficiency, PrimaKu has since launched a collaboration with SatuSehat. SatuSehat is a national initiative by the Ministry of Health that integrates patient medical record data at health facilities into one Indonesia Health Services (33). While Indonesia has seen substantial growth towards digitalization, not all patients are able to benefit from this, as there are still patients with limited access to mobile devices and the internet. For these patients, SMBG is recorded manually using pen and paper.

To reiterate, it is highly likely that the prevalence of T1DM reported in this study only reflects the tip of the iceberg. National databases are based on hospital-based data reported to CDiC or the Endocrinology Working Group of the IPS. With the false perception that the prevalence of T1DM in Indonesia is low, this contributes to the poor understanding and awareness of the general public, as well as health care professionals in Indonesia. In turn, the lack of awareness and knowledge of health care professionals also leads to cases being underdiagnosed and misdiagnosed. However, in recent years, through advocacy and public campaigns conducted by organizations like CDiC and the Endocrinology Working Group of the IPS, this has started to change. One campaign has been to initiate a national training programme in collaboration with the Ministry of

Health, to train HCPs on how to diagnose and manage diabetes in both children and adults.While several major government hospitals are working towards establishing diabetes clinics, these are still widely unavailable in Indonesia. International recommendations have highlighted the importance of a multidisciplinary diabetes team consisting of a pediatric endocrinologist, dietitian, a diabetes nurse educator and a mental health professional (34). Multidisciplinary care is hampered as Indonesia lacks the number and quality of training of HCPs (35,36). While several major hospitals may conduct in house training, training of HCPs in Indonesia is largely supported by organizations like CDiC Indonesia. CDiC Indonesia routinely conducts basic and advanced training regarding the diagnosis and management of T1DM in children and adolescents free-of-charge and open to HCPs nationally. As access to a multidisciplinary team in Indonesia is still limited, a lot of the burden of diabetes education is placed on pediatric endocrinologists, pediatricians or residents working in the endocrinology clinic of government teaching hospitals. The limited number of HCPs supporting the clinical management of children with T1DM will translate to less guidance provided to patients and their families, including support for insulin dose adjustments or management of acute conditions. This contrasts with the care available in the majority of HICs, such as the provision of 24-hour emergency call centers, a help center that answers queries and provides suggestions via email or telephone, as well as a diabetes clinic systems that link CGM data to diabetes clinics, enabling remote monitoring by the diabetes team (36).

Conclusion

The landscape of T1DM management in Indonesia reveals a multifaceted challenge requiring comprehensive strategies to address. Despite the concerted efforts of organizations like CDiC Indonesia and advances in insulin therapy and diabetes technology, significant gaps persist in access to care and resources. The epidemiological data underscores the growing burden of T1DM among children and adolescents, with many new cases probably being missed entirely, magnified by the uneven distribution of pediatric endocrinologists and limited access to insulin and SMBG devices. The current reliance on pediatric endocrinologists for T1DM care underscores the need for a more comprehensive, multidisciplinary approach to management, as seen in high-income countries. Furthermore, while the national health insurance provides some coverage for insulin, essential SMBG devices remain largely uncovered, posing major financial burdens on many families or threatening poorer overall glycemic control. Addressing these challenges necessitates not only improvements in healthcare infrastructure and access but also comprehensive education and support for patients and families. Collaboration between public and private sectors, along with expanded training programs for HCPs, will be pivotal in enhancing T1DM management and improving outcomes for affected individuals in Indonesia.

Ethics

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Footnotes

Authorship Contributions

Concept: Muhammad Faizi, Aman B. Pulungan, Design: Muhammad Faizi, Aman B. Pulungan, Data Collection or Processing: Muhammad Faizi, Ghaisani Fadiana, Dhiya Nadira, Angela Angela, Helena Arnetta Puteri, Aman B. Pulungan, Analysis or Interpretation: Muhammad Faizi, Ghaisani Fadiana, Dhiya Nadira, Angela Angela, Helena Arnetta Puteri, Aman B. Pulungan, Literature Search: Muhammad Faizi, Ghaisani Fadiana, Dhiya Nadira, Angela Angela, Helena Arnetta Puteri, Aman B. Pulungan, Writing: Muhammad Faizi, Ghaisani Fadiana, Dhiya Nadira, Angela Angela, Helena Arnetta Puteri, Aman B. Pulungan.

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