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# Barriers on Diabetes Management Adherence in Children with Type 1 Diabetes Mellitus: A Literature Review

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## Abstract

**Introduction:** Managing diabetes is complex and demands daily responsibilities like regular blood glucose testing, intensive insulin treatment, careful dietary monitoring, and enhanced physical activity. These challenges make it difficult for children and their families to maintain consistent adherence to diabetes management routines. Failure to adhere to diabetes management can lead to serious complications and may even result in death. Identifying the factors that hinder treatment adherence is essential for developing effective strategies and interventions to overcome these obstacles and improve diabetes management in children. This study aimed to identify barriers on diabetes management adherence in children with Type 1 Diabetes Mellitus.
**Methods:** The research design used a systematic review following the PRISMA guidelines and utilized five databases including Proquest, Science Direct, Springer Link, Sage Journals, and Google Scholar with the keywords: "Barriers" OR "Challenges" OR "Difficulties" AND "Diabetes management" AND "Adherence" AND "Children" AND "Type 1 Diabetes Mellitus". A total of eight articles were reviewed based on the inclusion criteria. The JBI Critical Appraisal Tools were also used as a guideline to evaluate the quality of the articles.
**Results:** This review identifies various barriers to adherence in diabetes management in children with T1DM, including personal, sociocultural, interpersonal, environmental, and financial barriers.
**Conclusions:** The findings from this review suggest several strategies to address barriers to diabetes management adherence involving parents, family, school, and health services.

**Keywords**: Barriers, diabetes management, children, type 1 diabetes mellitus

## Introduction

Type 1 diabetes mellitus (T1DM) is a metabolic disorder marked by inadequate or absent insulin production due to damage to the pancreatic beta cells, typically caused by an autoimmune disease which leads to elevated blood glucose levels (Majid et al., 2022; Skyler et al., 2017). T1DM is most frequently observed in children and adolescents, though it can occur at any age. The occurrence of T1DM among children and adolescents is rising both nationally and globally (Pulungan et al., 2019). Individuals with T1DM need continuous treatment,

including multiple daily insulin injections administered regularly to keep blood sugar levels within a normal range and sugar monitoring (Craig et al., 2022). Without insulin, T1DM can lead to diabetic ketoacidosis, a condition characterized by difficulty breathing and elevated blood glucose levels that can result in unconsciousness and potentially death (Lucier & Dulebohn, 2023; Rahmayunita et al., 2023).

Type 1 diabetes mellitus (T1DM) impacts roughly 500,000 children under the age of 15 worldwide. Each year, approximately 80,000 new cases are diagnosed, with T1DM experiencing an annual increase of about 3.0% (Cho N, et al., 2015; Forouhi & Wareham, 2019). According to data from the Indonesian Pediatrician Association, there were 1,021 children with T1DM in 2014, with the highest incidence among children aged 5-6 years and 11 years (UKK, 2017). This number rose to 1,220 cases in 2018 (IDAI, 2018) and further increased to 1,645 cases by 2023, with a prevalence of 2 cases per 100,000 children. Type 1 diabetes is the most common form of diabetes among children, while Type 2 diabetes accounts for 5-10 percent of all childhood diabetes cases (Direktorat Jenderal Pelayanan Kesehatan KEMENKES, 2023).

The goals of therapy for T1DM include achieving normal blood glucose levels, preventing acute complications, reducing the risk of long-term microvascular and macrovascular complications, and providing psychological support for both children and their families (Mistry et al., 2022). Achieving and sustaining glycemic control is crucial in diabetes management, as it helps reduce the risk of future diabetes-related complications. Nevertheless, inadequate adherence to diabetes management is frequently observed, significantly affecting the health of children with type 1 diabetes mellitus (Sabbah et al., 2024). Non-adherence among patients with T1DM varied between 23% and 77%, with a higher prevalence in developing countries (Kumar, 2015). A study conducted in Egypt found that 26% of children with T1DM did not adhere to their insulin therapy (Elhenawy et al., 2022). In comparison, the level of non-adherence among children with T1DM in Singapore was reported to be even higher, ranging from 16% to 49% (Chua et al., 2019).

Managing T1DM is difficult and challenging, involving daily tasks such as frequent blood glucose testing to prevent both hypoglycemia and hyperglycemia, intensive insulin therapy either through multiple daily injections or by inserting insulin pump infusion sets every 2-3 days, careful monitoring on diet, and increased physical activity (American Diabetes Association, 2018). Due to these complexities, children face difficulty in consistently adhering to diet, exercise, blood glucose testing, and insulin regimens. In addition, Kusumastuty et al. (2020) revealed that the adherence of children with T1DM to their

prescribed diet varies. While outside the home, they often struggle to follow dietary guidelines because they find it difficult to decline friends' invitations to eat their favourite foods. The influence of peers plays a significant role in their food choices, as children typically spend a lot of time with friends at school and other places, leading to lapses in maintaining their required diet (Karpouzis et al., 2024).

Addressing T1DM requires a comprehensive cooperation between patients, their families, the support system, and the healthcare team (Arabiat et al., 2020). Personal and social factors can present specific challenges that affect treatment adherence in children, increasing their risk of poor glycemic control and more severe complications (Montali et al., 2022), yet research on these issues is still limited. Identifying the factors that disrupt treatment adherence is crucial for creating effective strategies and interventions to address these barriers and enhance adherence in managing diabetes among children. Consequently, conducting this research is of urgent importance. Based on the background above, this review aims to identify barriers on diabetes management adherence in children with Type 1 Diabetes Mellitus.

## Methods

### a. Design

This study used a systematic review method. The data for this study were gathered by reviewing articles from previous research using the PRISMA 2020 flow diagram (Page et al., 2021). A total of five databases were used in this review, including Proquest, Science Direct, SpringerLink, Sage Journals, and Google Scholar.

**Table 1. Electronic Databases Used**

| Database | Number of Article Found | Number of Article Selected |
|---|---|---|
| Proquest | 979 | 2 |
| Science Direct | 202 | 2 |
| SpringerLink | 348 | 1 |
| Sage Journals | 164 | 0 |
| Google Scholar | 19.100 | 3 |

### b. Searching Method

The search of articles had been conducted between June and August 2024. Keywords used in the article identification were “Barriers” OR “Challenges” OR “Difficulties” AND “Adherence” AND “Diabetes management” AND “Children” AND “Type 1 Diabetes Mellitus”.

### c. Inclusion and Exclusion Criteria

The identified articles were screened based on following inclusion and exclusion criteria: 1) The study population consists of children ≤19 years of age with Type 1 Diabetes Mellitus; 2) The research findings highlight factors that can be barriers on the implementation of diabetes management in children; 3) The study design of the article includes both quantitative and qualitative research methods; 4) The publication year are within the range of 2017 to 2024; 5) The articles should be written in English or Bahasa; 6) Free full text article. Duplicate articles and those with a review study design were excluded from this analysis.

**d. Search Outcome**

At the beginning of the article search using the specified keywords, a total of 20,793 articles were retrieved from the databases used, including Proquest (n = 979), Science Direct (n = 202), Springer Link (n = 348), Sage Journals (n = 164), and Google Scholar (n = 19,100). Sixteen duplicate articles were removed, leaving 20,308 articles whose titles did not align with the researchers' keywords. This resulted in 469 articles progressing to the screening stage to review abstracts and full content, but 327 of these were not full-text articles. Subsequently, 142 full-text articles advanced to the next screening phase, where they were thoroughly read and assessed against the inclusion and exclusion criteria set by the researchers. An additional 134 articles were excluded: 68 involved respondents over 19 years old, 52 involved respondents with type 2 diabetes, and 24 did not address factors that act as barriers or challenges in type 1 diabetes management. In total, 8 articles met the inclusion and exclusion criteria and were evaluated using The Joanna Briggs Institute (JBI) Critical Appraisal Checklist to determine article quality. All eight articles achieved a total score greater than 75% in the critical appraisal process, qualifying them in the analysis and synthesis process.

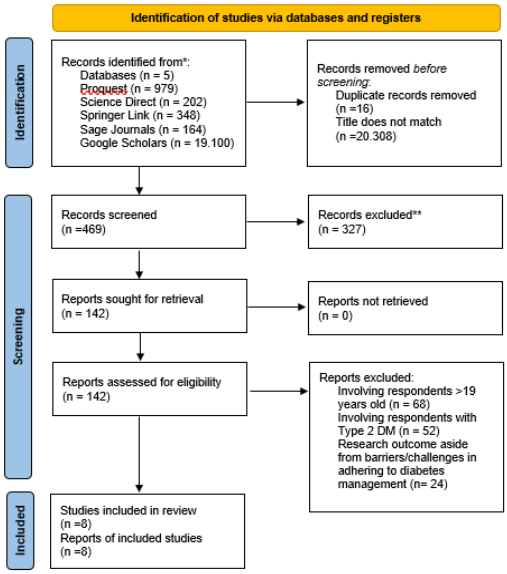


**Figure 1. PRISMA Flow 2020**

### e. Quality Appraisal

The Joanna Briggs Institute (JBI) Critical Appraisal Checklist was utilized to evaluate the quality of the articles. The JBI provides several possible responses: 'yes', 'no', 'unclear', or 'not applicable,' with a score of 1 assigned to 'yes' and 0 to other responses. We used the total score to classify the study quality into adequate and poor categories. A minimum total score of more than 75% was required for an article to be considered of eligible quality according to the critical appraisal criteria. Articles deemed of poor quality were excluded to avoid bias that could affect the validity of the study findings.

### f. Data Analysis

Articles that met the inclusion criteria and had adequate quality based on the critical appraisal process were carefully reviewed. The articles were then extracted into a table and analyzed based on the authors, year of publication, research method, and study results. A thorough review process of the abstracts and full-text articles was conducted to identify similarities and unique characteristics. The final analysis was then summarized to provide systematic findings and enhance understanding about barriers on diabetes management adherence in children with Type 1 Diabetes Mellitus.

## Results

According to the quality appraisal, eight articles were included in this literature review. The articles have been described in following table.

**Table 2. Summary of Reviewed Articles**

| No. | Title (Author, Year) | Study Method | Study Results |
|---|---|---|---|
| 1. | Barriers and facilitators to taking on diabetes self-management tasks in pre adolescent children with type 1 diabetes: a qualitative study (Rankin et al., 2018) | Qualitative design involved 24 children aged 9-12 years with type 1 DM in four Scottish pediatric diabetes centres | Children often face challenges in managing diabetes, particularly due to their heavy reliance on their parents, especially when it comes to insulin injections. They feel more secure when their parents administer the injections. Additionally, children struggle with counting the carbohydrates in their daily meals and snacks and determining the appropriate insulin dosage, further increasing their dependence on their parents. |
| 2. | Barriers and Facilitators to Involvement in Children's Diabetes Management Among Minority Parents (Butler et al., 2020) | Qualitative design involving 28 parents of 5-9- year-old children with type 1 DM at Texas Children's Hospital in Houston | **Parental distress:** Many parents experience stress when caring for children with diabetes, which hinders their ability to support their children and maintain clear expectations about their condition. Additionally, parents often feel stressed by their children's negative emotions. **Stigma:** Some parents feel ashamed of their child's illness. **Interpersonal relationship:** Some parents feel that insufficient support from family members leads to stress and limits the care they can provide for their children. They also reported that school staff and childcare are often unwilling to participate in the care of their children, causing parental burnout. **Work environment:** Parents report that limited time and lack of flexibility in the workplace present significant challenges in monitoring and providing direct |

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| | | | care to their children, as well as in assisting them with diabetes-related tasks at school. **Access to technology:** Parents feel that there is no technology available that allows them to monitor their children's sugar levels remotely. **Financial resources:** Parents face financial constraints that limit their ability to provide food that maintains their children's normal blood sugar levels. **Motivation:** Parents find it challenging to refuse or restrict their children from eating certain foods, like sweets or other items that can raise blood sugar levels, especially when they lack alternative sugar-free options |
| 3. | An Analysis of Self-Reported Barriers to Type 1 Diabetes Care in a Pediatric Population in British Columbia, Canada (Ladha et al., 2021) | Quantitative design involving 197 aged 4-18 years and their caregivers at 5 regional health authorities in Canada | The most common barrier to adherence on managing diabetes reported by respondents was the distance to the clinic followed by the requirement for caregivers to take time off work. Patients residing in rural and remote areas face challenges in attending clinic appointments due to the significant distance between their homes and the clinic. Additionally, caregivers often struggle to take time off work to bring their children to the clinic. |
| 4. | British Columbian Healthcare Providers' Perspectives on Facilitators and Barriers to Adhering to Pediatric Diabetes Treatment Guidelines (McIntosh et al., 2017) | Mix-method study design involving 260 pediatric diabetes healthcare providers in British Columbia Children's Hospital | In this study, patient adherence was low due to several factors, including the preference of patients and their families to avoid venipuncture and limited resources such as funding and mental health support. Given that families and patients with Type 1 DM also require counseling and emotional support, it is crucial to integrate mental health support into every patient visit. |
| 5. | Barriers to diabetes self-management in primary care settings – Patient perspectives: Phenomenological design (Oluchina & Karanja, 2022) | Qualitative design involving 40 adolescents aged 10 to 19 years with T1DM in Thika Hospital and Kiambu Hospital | **Dynamic nature and chronic nature of T1DM:** Patients perceive diabetes as a constantly changing condition that demands frequent adjustments. What they can eat today may not be allowed tomorrow. Sometimes, patients feel reluctant to continue treatment, as they view diabetes as a lifelong disease and believe that treatment won't make a significant difference. **Personal attributes:** Patients sometimes forget or feel too lazy to inject insulin. They may also crave certain foods, especially sweets, and occasionally give in to these cravings when their family is not around. **Inadequate knowledge and skills on TIDM self-management:** The patient lacks knowledge about healthy eating, proper portion sizes, and foot care. They also believe that alternative treatments are more effective for diabetes than insulin and are unsure how to accurately calculate carbohydrate needs and insulin dosages. **Lack of motivation and support to perform T1DM self-management:** The patient feels there is insufficient time for physical activity due to a busy schedule with school assignments and household chores. Additionally, the patient believes they lack support for managing diabetes at school, and the food provided there does not align with their diabetes diet. **Emotional distress:** Patients feel stigmatized by their condition and often hide their illness from friends. They dislike their body shape due to numerous insulin injection marks and blame themselves for their illness, leading to feelings of boredom and a desire to die. Additionally, they experience significant fear at the thought of injecting insulin. |
| 6. | Challenges in achieving adequate glycemic control among children with type 1 diabetes mellitus in a resource-limited setting: A cross-sectional study from | Quantitative design involving 211 patients aged 1-18 years with T1DM at pediatric diabetes | Several barriers to adherence on diabaetes management advancing age include: Being diagnosed at an older age, coming from single-parent households, monitoring blood glucose less frequently, and having a larger number of siblings or household members |

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|---|---|---|---|
| | Sudan (Ali & Alhassan, 2024) | clinic in Wad-Madani City, Sudan | |
| 7. | Living With Diabetes: Perceived Barriers of Adolescents (Gürkan & Bahar, 2020) | Qualitative design involving 18 adolescents aged 11-17 years in the training and research hospital in western region of Turkey | **Negative feeling about having diabetes:** Patients continue to struggle with accepting their diabetes, feeling bored and wishing for death. They also dislike having to carry a glucometer in their pocket while walking. **Personal barriers:** Many patients lack adequate knowledge about managing diabetes and fear complications such as hypoglycemia, hyperglycemia, and blindness. They struggle with diabetes management, often not having time for exercise and forgetting to check their blood sugar levels. Additionally, some find blood sugar monitoring to be a very distressing task. **Environmental barriers:** Constant reminders from parents or family about diabetes management can be very unsettling for patients. Conversely, parental conflict can lead to teenagers not receiving adequate attention for their diabetes care. Friends may also influence teenagers to disregard diabetes treatment, especially by encouraging them to ignore dietary restrictions. Additionally, schools can pose challenges to diabetes management, as teachers may doubt the child's illness and the food provided at school may not align with a diabetes-friendly diet. |
| 8. | Assessment of experience, fears, barriers and adherence to insulin injection among the parents of early-diagnosed children with Diabetes (Barakat et al., 2024) | Quantitative design involving 218 parents of children aged <18 years with Type 1 DM | In this study, most respondents identified several sociocultural barriers to insulin use adherence, including concerns about potential addiction, the belief that insulin is less effective than oral medications, and a preference for complementary medicine over insulin |

## Discussion

In this review, we outlined barriers to adherence to diabetes management reported by patients, parents/caregivers, and health care providers. When summarized, the barriers to adherence to diabetes management in this review encompass personal, sociocultural, interpersonal, environmental, and financial barriers. Personal barriers identified in this review include negative emotions related to having diabetes, insufficient knowledge and skills for managing the condition, emotional distress, and a lack of motivation.

Diabetes mellitus patients are one group that is vulnerable to experiencing boredom in treatment (Nduru et al., 2023). Two articles highlighted barriers to treatment adherence, namely boredom and frustration experienced by patients due to their illness. The continuous management of type 1 diabetes mellitus, which demands a high level of commitment to follow a strict schedule and guidelines consistently, frequently leads to several psychological symptoms, such as feelings of boredom, stress, and frustration. These emotional distresses affect the patient and the family members involved in the child's care. Emotional distress related to diabetes is recognized as being linked to poor treatment adherence (Hoogendoorn et al., 2024) and can have a detrimental impact on patients' health outcome (Bhaskara et al., 2022).

Considering the negative impact of emotional distress on the continuity of diabetes care and quality of life in children with T1DM, it is necessary to provide psychological support as an integral part of diabetes management. Małachowska et al. (2023) found that psychological support, not only enhances the well-being of children with T1DM and their families but also fosters more positive attitudes towards treatment, leading to improved adherence to medical advice. Additionally, according to Galler et al. (2020), psychological care such as counseling, family therapy, and behavioral interventions, was linked to stable glycemic control and a reduced occurrence of severe hypoglycemia during follow-up.

In managing type 1 diabetes, patients and parents need knowledge and independence in adjusting insulin doses, managing nutrition such as controlling the amount of carbohydrates consumed, managing exercise, and monitoring blood sugar levels. The complexity of diabetes management requires knowledge and skills for patients and families. However, three articles stated that children and adolescents have insufficient knowledge and skills in determining insulin doses and calculating appropriate carbohydrate requirements, making them highly reliant on their parents. Mariye et al. (2019) highlighted that low knowledge of self-administering insulin injection is one of the factors contributing to non-adherence to insulin therapy. Carbohydrate counting (CC) determines the carbohydrate amount in our food to calculate the correct insulin dose. It is a complex skill that is prone to errors among children, young adults with type 1 diabetes (T1DM), and their families (Khoiriani et al., 2021).

A sociocultural barrier in this study includes misconceptions about insulin therapy. An article highlights that misconceptions about diabetes treatment serve as a barrier to medication adherence, with some patients believing insulin is less effective than oral medication and opting for alternative treatments over insulin. Misconceptions about diabetes and its treatment are common among diabetes patients. A study in Taiwan found that these misconceptions frequently occur in individuals with lower educational backgrounds and those from lower-middle-income families. In the study, patients believed that insulin could harm the kidneys and lead to dialysis (Chen et al., 2020).

These situations above highlight the importance of providing diabetes education to both children and their families. Education plays a crucial role in diabetes management by enabling personalized care, enhancing treatment adherence, decreasing misconceptions about the illness and its treatment, and preventing diabetes-related complications, ultimately resulting in more effective management. Ainiyah et al. (2023) mentioned that educational programs, such as family coaching, can enhance patients' and their families' knowledge and abilities in managing diabetes independently. Diabetes education programs can also be offered through

individualized sessions, webinars, group classes, and clinics that provide customized treatments proven to enhance glycemic control and improve family relationships (Alzawahreh & Ozturk, 2024). Additionally, a study indicates that nutrition education programs improve teenagers' ability to independently calculate the carbohydrate content in their meals and improve their skills in determining insulin doses without relying on their parents (Gabriel et al., 2016).

Interpersonal barriers include a lack of support from family members, as well as school and daycare staff, in assisting patients and their families dealing with diabetes management, which ultimately results in parental stress. Two articles in this review highlighted the insufficient support provided by schools for children with type 1 diabetes mellitus (T1DM). The lack of adequate school support for children and adolescents with type 1 diabetes mellitus (T1DM) is further demonstrated by the absence of food options that are appropriate for a diabetes-friendly diet. Children and adolescents with type 1 diabetes (T1DM) spend the majority of their time at school, so they need access to suitable and secure care for managing their condition during their time at the school (Fried et al., 2018). However, a study indicates that schools feel unprepared to offer support to children with diabetes and do not allocate additional time for this assistance, as it may place a burden on teachers who must provide support during their regular teaching hours (Nannsen et al., 2023).

Schools' limited involvement in managing diabetes among children may be due to a lack of knowledge among the school staff. Gutzweiler et al. (2020) showed insufficient knowledge about diabetes and diabetes management for teachers, along with poor Communication between teachers and parents, were identified as the primary obstacles to providing adequate support for children with type 1 diabetes in kindergarten and school. Therefore, not only patients and parents but teachers and staff at schools also need to be provided with diabetes education programs so they can be involved in caring for children with T1DM while at school, considering that they spend quite a long time at school. Bassi et al. (2023) proved that a training program consisting of education and skills related to glucometer use, managing hypoglycemia and hyperglycemia, glucose monitoring, and insulin pump usage, effectively increased school staff's understanding of T1DM and boosted their confidence in managing diabetes.

In this study, parents and caregivers of children with T1DM primarily experienced environmental and financial barriers. Two articles indicated that the long distance between home and the clinic, combined with inflexible work schedules, made it challenging for parents to take their children to appointments, provide direct care, and monitor their children's health.

In families with single parents or multiple children, parents often struggle to provide food that helps regulate normal blood glucose levels. This finding aligns with Azimi et al. (2024) that parents often face difficulties balancing work responsibilities with managing T1DM, resulting in career compromises and financial sacrifices. Our findings highlight the need to develop technology that enables parents to manage their children's diabetes care remotely or consult with health services online, thereby reducing the need for frequent clinic visits.

## Conclusion

This review identifies various barriers to adherence in diabetes management in children with T1DM, including personal, sociocultural, interpersonal, environmental, and financial barriers. The findings from this review suggest several strategies to address barriers to diabetes management adherence, such as providing educational programs on diabetes for children, parents, and schools to enhance knowledge, skill, and confidence to gain proper care and increase school involvement in managing diabetes care for children during school hours. Additionally, psychological support is crucial for families of children with T1DM to help prevent parental stress, frustration, and other emotional distress among children and their families. Technology is needed to allow parents of children with T1DM to consult with healthcare providers remotely and monitor their children’s blood glucose levels from a distance.

## Author Contributions

First author: formulating the research concept, conducting article searches and reviews, and writing the manuscript

Second author: Conducting article searches and reviews

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None

## Conflict of Interest

The author declares no conflicts of interest related to this research.

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