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Adolescents' Experiences of Self-Management and Decision-Making in Type 1 Diabetes Mellitus

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ABSTRACT

Background: Adolescents with Type 1 Diabetes Mellitus (T1DM) encounter challenges in managing their condition, which may reduce their confidence and engagement in self-management. This study explored adolescents' experiences of T1DM self-management, focusing on factors influencing their engagement in self-management practices and healthcare decision-making.

Methods: A qualitative study using purposive sampling was conducted via clinical consultations and semi-structured interview. Thirty participants were recruited, comprising 12 adolescents with T1DM, 14 parents, and four healthcare professionals. Data were analysed using Braun and Clarke's six-phase thematic analysis.

Results: Three themes emerged: (a) Knowledge Deficits and Dependence, where limited understanding of diabetes management resulted in reliance on parents and healthcare professionals; (b) Complex Burden of Self-Management, highlighting difficulties in glycaemic control, dietary adherence, and the psychosocial impact of living with T1DM, including social stigma; and (c) Emerging yet Constrained Autonomy, where adolescents demonstrated varying levels of involvement in self-management and decision-making, ranging from passive dependence to increasing independence. These findings suggest that adolescents' self-management experiences are shaped by the interaction of diabetes-related knowledge, psychosocial challenges, and evolving autonomy.

Conclusion: Adolescents' engagement in T1DM self-management is influenced by their knowledge, psychosocial experiences, and developing autonomy. Developmentally appropriate diabetes education and supportive, adolescent-centred care are essential to strengthen confidence, encourage meaningful participation in decision-making, and promote effective long-term self-management.

Keywords: Adolescents; Self-management; Type 1 diabetes Mellitus; Qualitative research; Shared decision-making

INTRODUCTION

Chronic disease like Type 1 Diabetes Mellitus (T1DM) is an autoimmune disease which is characterised by deficient insulin production (1). The onset of T1DM commonly occurs in childhood and adolescence and is often characterised by symptoms such as polyuria, polydipsia and ketonemia (2). To maintain blood glucose levels in the normal range, individuals need to perform self-management. Effective T1DM self-management requires various tasks such as consistent glucose monitoring, insulin administration and dietary regulation. As T1DM is a lifelong condition, adolescents are expected to progressively assume greater responsibility for managing their own care, including participating in decisions related to their diabetes self-management.

The study focused on adolescents diagnosed with chronic illnesses, particularly T1DM. According to the World Health Organization (WHO), adolescents are individuals aged between 10 and 19 years, a developmental stage that represents a critical transition from childhood to young adulthood and is characterised by significant physical, psychological and social changes, including puberty (3).

Adolescents living with T1DM often described their experiences with self-management as a demanding and challenging process, as they are required to balance complex medical regimens with the daily life demands (4). Inadequate knowledge of diabetes management may further affect their engagement in self-management practices (5). Consequently, poor self-management can increase the risk of developing microvascular and macrovascular complications such as retinopathy, neuropathy, and cardiovascular disease (6). Despite the importance of self-management in preventing complications and improving quality of life (7), engagement in diabetes self-management among adolescents remains limited (8).

Existing studies have largely focused on clinical outcomes and participation levels, but limited attention to adolescents lived experiences in managing their condition (9). Adolescence is a complex developmental stage, and the demands of diabetes self-management often overlap with emotional, social, and behavioural challenges (5). However, there remains a lack of in-depth understanding of

how adolescents experience these challenges in their daily lives and how these factors influence their ability to manage their condition. Exploring adolescents' experience is essential to better understand the factors that shape their self-management practices and to inform more responsive and supportive care approaches.

METHODS

Study Design

This study adopted a qualitative approach to explore adolescents' experiences of self-management in T1DM. Data were gathered through non-participant observations during consultations, followed by semi-structured interviews with the participants. This method is commonly used in healthcare research to explore health behaviour patterns and patients' experiences (10). The reporting of this study was informed by the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.

Sample Size and Sampling

A total of 30 participants were recruited using purposive sampling, comprising 12 adolescents diagnosed with T1DM, 14 parents and 4 healthcare professionals. Adolescents were eligible for participation if they were aged between 10 and 18 years old and were receiving either outpatient or inpatient service for T1DM. Parents or guardians were included if they lived with the adolescent and were actively involved in their diabetes management. Healthcare professionals were selected based on their direct involvement in managing adolescents with T1DM. Parents and healthcare professionals were included to provide contextual perspectives and support data triangulation, while adolescents remained the primary focus of the study. Participant recruitment continued until data saturation was achieved across the overall dataset. Saturation was determined when no new themes or meaningful insights relevant to adolescents' experiences emerged from the integrated analysis of data obtained from adolescents, parents, healthcare professionals, and non-participant observations.

Data Collection

Data collection was conducted between January and June 2025 across multiple clinical settings, including paediatric and internal

medicine clinics and wards, as well as primary healthcare clinic and dietetic services within tertiary hospitals and community health centres in Pahang, Malaysia.

Non-participant observations were conducted by the first author, a Master's student in Nursing and registered nurse, during clinical consultations involving the participants. The observations focused on adolescents' experiences of self-management, including their involvement in decision-making related to diabetes self-management and their interactions with parents and healthcare professionals. Field notes were recorded immediately after each observation in a field notebook.

Subsequently, individual face-to-face semi-structured interviews were conducted with each participant to explore their experiences in greater depth. Interviews lasted approximately 30–60 minutes and were conducted using open-ended questions, with probing and follow-up questions applied where appropriate to obtain richer and more detailed responses. Adolescents were interviewed independently, without the presence of their parents. The semi-structured interview guides were developed based on a comprehensive review of the literature on adolescent participation in shared decision-making (SDM) and were informed by established SDM frameworks to ensure alignment with the study objectives.

Separate interview guides were prepared for adolescents, parents, and healthcare professionals to capture their unique perspectives while maintaining consistency across participant groups. The interview guides were reviewed and refined by members of the research team with expertise in paediatric care, shared decision-making, and nursing to establish content validity. Prior to the main data collection, pilot interviews were conducted with two participants from each participant group (adolescents, parents, and healthcare professionals) to assess the clarity, relevance, and flow of the interview questions. Minor refinements in wording and sequencing were made based on participants' feedback to enhance the comprehensibility and effectiveness of the interview process. The data obtained from the pilot interviews were not included in the final analysis.

Data Analysis

Thematic analysis was used to analyse the data following the six-stage approach outlined by Braun and Clarke (11). The analytic process involved familiarisation with the data, generation of initial codes, searching for themes, reviewing themes, defining and naming themes and producing the final report. Codes were derived from both interview transcripts and observation notes. Although data were collected from adolescents, parents and healthcare professionals, the analysis was guided by the study aim of exploring adolescents' experiences. Themes were developed around adolescents' experiences, while data from parents and healthcare professionals were used to provide contextual understanding, support data triangulation, and enrich the interpretation of adolescents' experiences. Healthcare professionals' perspectives were used to confirm and contextualise the findings related to adolescents' self-management and decision-making, further contributing to the interpretation and refinement of the themes. Data management and analysis were facilitated using ATLAS.ti software.

To enhance the rigor and trustworthiness of the findings, peer debriefing, reflective journaling and the maintenance of an audit trail were employed throughout the process.

Ethical Consideration

Ethical approval for the study was obtained from the relevant institutional ethics committee and the Medical Research and Ethics Committee (MREC) (Reference No. NMRR ID-24-03778-05R (IIR)) prior to data collection. Written informed consent was obtained from all participants, with parental consent secured for adolescent participants. Participation was voluntary, and all participants were informed of their right to withdraw at any stage without consequence. To ensure confidentiality, all data were anonymised using unique participant identifiers and stored securely.

Trustworthiness

Trustworthiness was established according to Lincoln and Guba's criteria of credibility, dependability, confirmability and transferability. Credibility was enhanced through data triangulation and peer debriefing. Data triangulation was achieved by

integrating data from non-participant observations and interviews with adolescents, parents, and healthcare professionals. Peer debriefing was conducted with the supervisory team throughout the coding and theme development process to discuss coding decisions and refine emerging themes. Dependability and confirmability were supported by maintaining an audit trail and engaging in reflective journaling throughout the research process. The audit trail consisted of field notes and systematic documentation of coding and analytical decisions within ATLAS.ti. Reflexive journaling was used throughout data collection and analysis to document the researcher's thoughts, assumptions, and reflections, to help reduce the influence of personal bias on data interpretation and theme development. Transferability was facilitated through the provision of detailed descriptions of the research setting and participant characteristics.

RESULTS

Sociodemographic Characteristics

A total of 30 participants were included in this study, comprising 12 adolescents with T1DM, 14 parents, and 4 healthcare professionals. The adolescents were aged between 10 and 17 years and were predominantly of Malay ethnicity. Most parents' participants were mothers that actively involved in the adolescents' diabetes care. The healthcare professionals consisted of two paediatricians, one pharmacist, and one dietician with varying levels of clinical

experience. Detailed sociodemographic characteristics of the participants are presented in **Tables 1–3**.

Themes

Following the analysis of interview transcripts and observation field notes, three main themes were identified: (1) Knowledge Deficits and Dependence, (2) Complex Burden of Self-Management, and (3) Emerging yet Constrained Autonomy. These themes represent adolescents' experiences of self-management of T1DM and their involvement in decision-making processes. The identified themes and subthemes are presented in **Table 4**.

Theme 1: Knowledge Deficits and Dependence

This theme reflects adolescents' limited understanding of diabetes management and their reliance on caregivers in managing their condition. Approximately half of the adolescents demonstrated inadequate knowledge of key aspects of diabetes care, including blood glucose monitoring, carbohydrate counting and insulin administration.

Observational data revealed that some adolescents had trouble responding to basic questions related to diabetes management during clinical consultations. They demonstrated signs of hesitation, avoiding eye contact and discomfort during the consultation, when they were asked to explain diabetes-related information or self-management practices.

Table 1: Sociodemographic Characteristics of Adolescents (N=12)

Demographic characteristic	Frequency, <i>f</i> (%)
Age	
10-12 years old	6 (50.0)
13-17 years old	6 (50.0)
Gender	
Female	12 (100.0)
Race	
Malay	11 (91.7)
Chinese	1 (8.3)
Duration since diagnosis	
1-3 years	8 (66.7)
More than 3 years	4 (33.3)
Insulin delivery modality	
Multiple Daily Injections (MDI)	12 (100.0)
Continuous Glucose Monitoring (CGM)	
Yes	1 (8.3)
No	11 (91.7)

Table 2: Sociodemographic Characteristics of Parents (N=14)

Demographic characteristic	Frequency, <i>f</i> (%)
Age	
30-40 years old	6 (42.9)
40-50 years old	8 (57.1)
Gender	
Male	3 (21.4)
Female	11 (78.6)
Race	
Malay	13 (92.9)
Chinese	1 (7.1)
Level of education	
High school	3 (21.4)
Diploma	6 (42.9)
Degree	5 (35.7)
Employment status	
Working	7 (50.0)
Unemployed	7 (50.0)
History of diabetes mellitus	
Yes	1 (7.1)
No	13 (92.9)
Has other children diagnosed with T1DM	
Yes	0 (0.0)
No	14 (100.0)

Table 3: Sociodemographic Characteristics of Healthcare Professionals (N=4)

Demographic characteristic	Frequency, <i>f</i> (%)
Age	
30-40 years old	2 (50.0)
40-50 years old	2 (50.0)
Gender	
Male	2 (50.0)
Female	2 (50.0)
Race	
Malay	3 (75.0)
Chinese	1 (25.0)
Level of education	
Degree	2 (50.0)
Master	2 (50.0)
Clinical position	
Paediatrician	2 (50.0)
Pharmacist	1 (25.0)
Dietician	1 (25.0)
Working experience	
1-5 years	2 (50.0)
More than 6 years	2 (50.0)

Table 4: Themes and subthemes

Themes	Subthemes
Knowledge Deficits and Dependence	Poor knowledge of diabetic self-management
Complex Burden of Self-Management	Difficulty in glycaemic control
	Dietary management
	Fear of Social stigma
Emerging yet Constrained Autonomy	Passive role
	Active role

“In one session, the doctor attempted to engage the adolescent by assessing her knowledge of normal blood glucose range and the principles of carbohydrate counting. The adolescent appeared uncertain and avoided eye contact. She remained silent and did not answer the question.”

(Observation note 06, 8th May 2025)

Similarly, observations during clinical consultation revealed that some adolescents experienced difficulties with proper insulin administration, which contributed to issues such as bruising at injection sites.

“During a routine consultation, the doctor assessed an adolescent’s injection site and noticed some bruising on the abdominal area. When asked whether the bruises were painful, she stated that she could not remember and appeared visibly anxious. The doctor reassured the adolescent. The parents further explained that they caught adolescents rushing the procedure and failed to rotate injection sites properly, which may have contributed to the bruising.”

(Observation note 08, 12th June 2025)

This pattern was also reflected in interview data, where adolescents described reliance on others in managing their care. One adolescent reported relying on her mother to calculate insulin dosage and resorting to estimation when her mother was unavailable:

“Most of the time my mom does calculate the dosage for me and if my mom is not around, I just estimate it.”

(Interview, A07, 13 years old, 26th May 2025)

These findings suggest that adolescents have limited knowledge of diabetes care and it is often accompanied by reliance on caregivers, which influenced adolescents’ ability to independently manage their condition.

Theme 2: Complex Burden of Self-Management

This theme reflects the multifaceted challenges adolescents encountered in managing T1DM. These challenges were evident across several aspects of self-management, including glycaemic control, dietary management and experiences of social stigma.

Difficulties in achieving glycaemic stability were commonly reported among adolescents, with frequent episodes of both hyperglycaemic

and hypoglycaemia affecting their daily functioning and overall well-being. Observation data indicated that fluctuations in blood glucose levels remained a recurring challenge despite ongoing self-management efforts.

“During a routine consultation, the doctor reviewed adolescent’s glucometer log and noticed significant fluctuations, including a spike reaching 30 mmol/L. The parent explained that this occurred during the recent Raya celebration, when the adolescent consumed large amounts of festive food and engaged in prolonged physical activity.”

(Observation notes 08, 12th June 2025)

Other parents also described cases of recurrent hypoglycaemic episode that affected adolescents’ ability to participate in daily activities.

“She usually experienced hyperglycaemic but when she has hypoglycaemic, she became tired and doesn’t want to go to school.”

(Interview, Parent 01, 21st December 2025)

Similar concerns were reported by other parents in which the adolescents frequently experienced episode of hyperglycaemia that led to multiple hospital admission over the past year:

“She rarely experienced hypoglycaemic but most of the time is hyperglycaemic. She was even admitted to the hospital five times last year.”

(Interview, Parent 04, 7th January 2025)

These findings show that achieving glycaemic stability remains a significant challenge for many adolescents with T1DM.

Dietary management also emerged as another major challenge, particularly in relation to regulating food intake, maintaining healthy eating habits, and adhering to dietary recommendations. Parents frequently reported difficulties monitoring adolescents’ eating behaviours, especially when food choices occurred outside direct supervision.

One observation highlighted an incident in which a parent discovered sweet wrappers in the adolescent’s pocket, indicating the purchase of sweets at school.

“During the consultation, the parent informed the doctor that she found sweet wrappers in

adolescent's pocket, suggesting that the adolescent had purchased sweets at KAFA (school). When asked by doctor how many she bought, the adolescent replied, 'around three to four pieces only'. The doctor then continued to advise the adolescents' and parents on the sugar intake. The adolescents started to appear defensive and fidgeting with her nails.

(Observation notes 06, 8th May 2025)

This behaviour made it difficult for the parents to enforce dietary restrictions at home, which are further complicated by peer influence. Parent shared that her daughter's preference to eat the same food as her peers, making it difficult to maintain healthy dietary choices.

"It is difficult to take care of the food and eating habits, especially when she sees her friend eating. She also wants the same thing."

(Interview, P04, 7th January 2025)

These excerpts highlight that dietary management remained a persistent challenge for adolescents with T1DM.

Fear of social stigma emerged as an important challenge influencing adolescents' self-management practices. The fear was reflected in both adolescents' accounts and parental observations and were often associated with concerns about negative perceptions from others.

For instance, an adolescent reported feeling discomfort in administering insulin injection in public settings:

"I think it's difficult when I am outside. I don't want to inject at public."

(Interview, A07, 26th May 2025)

Alongside adolescents' reluctance to inject in public, some parents reported advising the adolescents to limit disclosure of their condition at school.

"Even her secondary school teacher does not know about her condition. I always told her not to tell people that you have diabetes, just say your pancreas is broken or not working."

(Interview, P09, 26th May 2025)

Other parents also shared that her daughter had become increasingly reluctant to discuss her condition after entering secondary school.

"At school, she is a bit shy. During primary school, she was fine with it, but since she is a teenager now, she is more hesitant to talk about her condition."

(Interview, P04, 7th January 2025)

These examples reflect fear of negative peer perception and stigma leads adolescents to conceal their condition, limiting their ability to perform diabetes self-management, particularly in school or public settings.

Theme 3: Emerging yet Constrained Autonomy

This theme reflects adolescents' varying levels of involvement in managing T1DM, particularly in relation to self-care practices and participation in decision-making processes. Adolescents' involvement ranged from passive reliance on parents to more active engagement during clinical interactions.

Passive role was the predominant pattern observed and was characterized by minimal verbal participation, hesitation and reliance on parents during clinical consultations. Adolescents often remained quiet, avoided responding to questions, or deferred communication to their parents.

"During one consultation, the doctor initiated a discussion by asking the adolescent about her condition. She responded with a brief smile but did not speak, maintaining eye contact without engaging verbally. The parent then explained that the adolescent occasionally experienced stomach tightness and internal discomfort. When the doctor redirected the question to the adolescent, she remained silent and turned towards her parents, indicating reliance on her caregiver to respond on her behalf."

(Observation note 05, 12th June 2025)

This pattern is further supported by interview data, where one parent acknowledged that decisions during clinical consultations are primarily made by the parents, with limited input from the adolescent.

"Usually, the mother is the one who made decision with doctor. She just listens and follows the decision."

(Interview, P04, 7th January 2025)

These findings show that adolescents often assumed a passive role in decision-making and self-management, characterized by minimal verbal participation and dependence on adults.

In contrast, some adolescents demonstrated active involvement in their care, particularly when they felt comfortable interacting with healthcare professionals. This was reflected through asking questions, seeking clarification, and participating in discussions related to their condition.

Observational data showed that certain adolescents took initiative in seeking information to better understand their diabetes management. For example, during a consultation with pharmacist, an adolescent asked about the appropriate storage of insulin:

“During a consultation with the pharmacist, an adolescent asked about the appropriate storage of the insulin, inquiring whether it could be kept in a hot place. She appeared attentive and eager to learn while listening to the pharmacist’s explanation. The pharmacist then clarified that insulin should be stored in a cool environment to maintain effectiveness and prevent degradation.”

(Observation notes 02, 21st January 2025)

Similarly, active participation was observed during a session with the dietician involving a food pyramid activity:

“During the activity, the adolescent asked about ‘tempe’ as she was unsure of its classification within the food pyramid. The dietician responded by providing several clues before explaining that ‘tempe’ is a source of protein. Following the explanation, the adolescent was able to place the food item in the appropriate section of the food pyramid diagram. The dietician then continued to explain the food pyramid and balanced nutrition in diabetes management.”

(Observation notes 01, 21st January 2025)

Active involvement is also evident in adolescents’ attempts to perform diabetes related self-management tasks independently. During one clinical consultation, the parents explained that the adolescent occasionally attempted to self-inject, although she appeared fearful:

“During the consultation, the parent explained that the adolescent preferred to inject herself and had made several attempts under their supervision, although she appeared fearful.”

(Observation notes 08, 12th June 2025)

These findings indicates that although many adolescents relied on parental support, some actively participated in discussion and self-management activities. Such involvement suggests an emerging sense of autonomy that developed within the context of ongoing guidance and support from parents and healthcare professionals.

DISCUSSION

This study explored adolescents’ experiences of self-management in T1DM. The findings revealed that adolescents demonstrated limited knowledge of diabetes care, while facing practical challenges related to glycaemic control, dietary management and fear of social stigma. Adolescents also demonstrated varying levels of autonomy in self-management and decision-making processes. These results highlight the complexity of fostering adolescents’ autonomy in T1DM self-management. The themes are interrelated and illustrates how adolescents’ self-management experiences are influenced by their understanding of diabetes care, the practical and psychosocial challenges they encounter, and their evolving role in managing their condition and participating in healthcare decisions.

Adolescents in this study demonstrated limited knowledge of essential aspects of diabetes management, including carbohydrate counting, blood glucose monitoring and insulin administration. These knowledge deficits appeared to influence their confidence in performing self-management tasks and contributed to reliance on parents and healthcare professionals. Adolescents who lacked adequate understanding of their condition often experienced uncertainty when making decisions related to their daily care, limiting their ability to engage independently in self-management activities.

These findings are consistent with previous studies reporting that inadequate knowledge and self-management skills as significant barriers to effective self-management among adolescents (12,13). Adolescents may struggle to fully comprehend the complexity of T1DM, which can affect their ability to interpret symptoms, evaluate health-related information, and make appropriate decisions regarding their care (14). As a result, knowledge deficits may restrict adolescents’ participation in self-management and reinforce dependence on adults. Furthermore, limited understanding of

diabetes management may reduce adolescents' confidence in performing self-care tasks, making them more likely to seek guidance from parents and healthcare professionals.

Thus, providing age-appropriate information helps reduce decisional conflict and improve adolescents' engagement to diabetes self-management (15). Structured diabetes education tailored to adolescent developmental stages is essential to strengthen their self-care and autonomy (16). These findings emphasize the importance of integrating consistent, age-appropriate diabetes education into routine clinical practice.

In contrast, some adolescents demonstrated curiosity and willingness to learn about their condition. They actively participate in discussions by asking questions and seeking clarification regarding aspects of their self-management during consultations. Although their knowledge remained limited, this behaviour suggests that supportive interactions with healthcare professionals can encourage adolescents to engage more actively in self-management. Previous research indicates that increased diabetes knowledge is strongly associated with higher self-efficacy among adolescents, which enhances adolescents' confidence in managing their condition (17). Therefore, fostering an environment that encourages adolescents to express their concerns and seek information may facilitate more effective self-management behaviours.

The findings indicate that adolescents faced various self-management challenges, including glycaemic instability, dietary restrictions and fear of social stigma. These challenges illustrate the complex demands of diabetes management during adolescence and may hinder adolescents' ability to manage their condition effectively. When adolescents feel overwhelmed by these difficulties, their engagement in diabetes self-management may decline, reducing their ability to manage their condition consistently. Previous studies have highlighted challenges in adhering to dietary restrictions and maintaining consistent self-management, as adolescents often struggle to perform carbohydrate counting and calculate the insulin dosage (18). Such challenges may increase reliance on healthcare providers and parents for guidance and support in diabetes management.

Adolescents with T1DM have also reported fear of social stigma, particularly when self-management practices attract unwanted attention from peers (19). Concerns about negative judgment may discourage adolescents from openly discussing their condition or performing self-management activities in public settings. In addition, the continuous demand of diabetes self-management, which requires frequent health-related decisions, may contribute to decision fatigue. This fatigue can affect adolescents' motivation and reduce their engagement in managing their condition (14).

Besides that, adolescents in this study demonstrated varying levels of autonomy in managing their condition, with many continuing to rely on adults for support. Most adolescents were found to generally assume a passive role during the self-management and decision-making process. This passive participation may be influenced by limited knowledge and the burden of self-management, which can lead adolescents to rely more heavily on adults when discussing treatment decisions. Such dependence may also reflect the transitional nature of adolescence, during which responsibility for disease management is gradually transferred from parents to adolescents.

In some cases, adolescents appeared passive during consultations and self-management activities, which may reflect uncertainty, low confidence or discomfort in handling their condition (12). Such responses suggest that adolescents may not yet feel adequately prepared to take full responsibility for their care, particularly when they lack sufficient understanding or experience (4).

Meanwhile, certain adolescents demonstrated a more active role in this study. These adolescents engaged in behaviours such as asking questions, seeking clarification and attempting aspects of self-management independently. This active engagement may reflect a higher level of readiness, confidence, and familiarity with their condition. These findings suggest that autonomy in self-management exists along a spectrum and develops progressively over time. Adolescents require appropriate support, guidance, and opportunities to build their confidence to transition from passive reliance to more active and independent self-management.

Overall, this study highlights that adolescents' ability to manage their condition is shaped by the interaction between knowledge, self-management challenges, and the role that they adopt in performing self-management. Strengthening developmentally appropriate education and fostering supportive care environments are essential to enhance adolescents' confidence, promote independence, and support effective long-term self-management.

CONCLUSION

This study explored adolescents' experience of their involvement in the self-management of T1DM. The findings demonstrated that adolescents' engagement in self-management was shaped by knowledge deficits, the complex burden of managing their condition, and varying levels of autonomy in self-care and decision-making. While some adolescents demonstrated active involvement, many adopted a more passive role, reflecting limited confidence and readiness to participate in decision-making processes.

These findings underscore the importance of addressing adolescents' developmental, educational, and psychosocial needs within chronic disease care. Creating supportive and responsive care environments, where caregivers and healthcare professionals actively facilitate adolescents' understanding and involvement, is essential to promote meaningful participation in their own care.

LIMITATIONS AND RECOMMENDATIONS

This study has several limitations. The relatively small sample size and recruitment from selected healthcare facilities in the East Coast region may limit the transferability of the findings. In addition, the hospital-based recruitment approach may have reduced socio-economic diversity that potentially influences participants' perspectives and experiences. To enhance the trustworthiness of the study, purposive sampling, peer debriefing and maintaining an audit trail were employed.

In terms of clinical practice, education should be tailored to adolescents' developmental stage to enhance their understanding and engagement in their care. At the policy level, the development of guidelines that emphasize adolescent-focused involvement in care should

be considered for integration into national diabetes management frameworks.

Future research should explore these care practices across more diverse socioeconomic, cultural, and religious contexts to enhance inclusivity and broaden the applicability of findings.

CONFLICT OF INTEREST

The authors have no conflict of interest to declare about this work.

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AUTHOR CONTRIBUTIONS

KA: Analysed and interpreted the data, drafted the manuscript, supported administrative and logistical tasks, and collected and assembled the data.

LSP: Conceptualised and designed the study, analysed and interpreted the data, critically revised the manuscript, obtained funding, and approved the final version.

MAMH: Conceptualised and designed the study, provided study materials or patients, supported administrative and logistical tasks, and approved the final version.

WSHWMA: Analysed and interpreted the data, drafted the manuscript, collected and assembled the data, and approved the final version.

AA: Drafted the manuscript, critically revised it for important intellectual content, and approved the final version.

SLFS: Conceptualised and designed the study, critically revised the manuscript, provided study materials or patients, supported administrative and logistical tasks, and approved the final version.

US: Drafted the manuscript, critically revised it for important intellectual content, and approved the final version.

REFERENCES

1. Kahanovitz L, Sluss PM, Russell SJ. Type 1 diabetes-a clinical perspective. *Point Care* 2017;16:37–40. <https://doi.org/10.1097/POC.0000000000000125>.
2. Chiang JL, Kirkman MS, Laffel LMB, Peters AL. Type 1 diabetes through the life span: A position statement of the American Diabetes Association. *Diabetes Care* 2014;37:2034–54. <https://doi.org/10.2337/dc14-1140>.
3. Datye KA, Moore DJ, Russell WE, Jaser SS. A Review of Adolescent Adherence in Type 1 Diabetes and the Untapped Potential of Diabetes Providers to Improve Outcomes. *Curr Diab Rep* 2015;15. <https://doi.org/10.1007/s11892-015-0621-6>.
4. Kim JE. Illness Experiences of Adolescents with Type 1 Diabetes. *J Diabetes Res* 2022;2022. <https://doi.org/10.1155/2022/3117253>.
5. Karlsson A, Arman M, Wikblad K. Teenagers with type 1 diabetes-a phenomenological study of the transition towards autonomy in self-management. *Int J Nurs Stud* 2008;45:562–70. <https://doi.org/10.1016/j.ijnurstu.2006.08.022>.
6. Melendez-Ramirez LY, Richards RJ, Cefalu WT. Complications of type 1 diabetes. *Endocrinol Metab Clin North Am* 2010;39:625–40. <https://doi.org/10.1016/j.ecl.2010.05.009>.
7. Modi AC, Pai AL, Hommel KA, Hood KK, Cortina S, Hilliard ME, et al. Pediatric self-management: A framework for research, practice, and policy. *Pediatrics* 2012;129. <https://doi.org/10.1542/peds.2011-1635>.
8. Geneti Y, Wondwossen K, Adimasu M, Deressa D, Lami FAM, Abdisa L, et al. Adherence to Diabetes Self-Management and Its Associated Factors Among Adolescents Living with Type 1 Diabetes at Public Hospitals in Addis Ababa, Ethiopia: A Cross-Sectional Study. *Diabetes, Metabolic Syndrome and Obesity* 2022;15:659–70. <https://doi.org/10.2147/DMSO.S350168>.
9. Sun Z, Zhang W, Wang J, Zhang Y, Wu Y. The Illness Experiences of Adolescents with Type 1 Diabetes Mellitus: A Qualitative Meta-synthesis. *Asian Nurs Res (Korean Soc Nurs Sci)* 2024;18:313–21. <https://doi.org/10.1016/j.anr.2024.07.004>.
10. Renjith V, Yesodharan R, Noronha J, Ladd E, George A. Qualitative methods in health care research. *Int J Prev Med* 2021;12. https://doi.org/10.4103/ijpvm.IJPVM_321_19.
11. Braun V, Clarke V. What can “thematic analysis” offer health and wellbeing researchers? *Int J Qual Stud Health Well-Being* 2014;9. <https://doi.org/10.3402/qhw.v9.26152>.
12. Oluchina S, Karanja S. Barriers to diabetes self-management in primary care settings – Patient perspectives: Phenomenological design. *Int J Afr Nurs Sci* 2022;17. <https://doi.org/10.1016/j.ijans.2022.100465>.
13. Pınar Gürkan K, Bahar Z. Living With Diabetes: Perceived Barriers of Adolescents. 2019.
14. Montali L, Zulato E, Cornara M, Ausili D, Luciani M. Barriers and facilitators of type 1 diabetes self-care in adolescents and young adults. *J Pediatr Nurs* 2022;62:136–43. <https://doi.org/10.1016/j.pedn.2021.09.014>.
15. Wijngaarde RO, Hein I, Daams J, Van Goudoever JB, Ubbink & DT. Chronically ill children’s participation and health outcomes in shared decision-making: a scoping review 2020. <https://doi.org/10.1007/s00431-021-04055-6>/Published.
16. Cho MK, Kim MY. Educational needs of people with type 1 diabetes mellitus and their parents: A cross-sectional study. *Nurs Open* 2023;10:4849–58. <https://doi.org/10.1002/nop2.1737>.
17. Marshall A, Bui NH, Nilsen A, Lim L, Burke G, Christie A, et al. Knowledge and Self-Efficacy as Key Determinants of Transition Readiness in Adolescents with Type 1 Diabetes: Insights from Adolescents, Parents, and Clinicians. *Diabetology* 2025;6. <https://doi.org/10.3390/diabetology6120159>.
18. Qi Y, Xia L, Chen Y, Hu Y, Xie Z, Yi T, et al. Self-management needs of adolescents with type 1 diabetes on transition to adult health care: a qualitative study. *Eur J Pediatr* 2025;184. <https://doi.org/10.1007/s00431-025-06373-5>.
19. Joiner KL, DeJonckheere M, Whittemore R, Grey M. Perceptions and experiences of living with type 1 diabetes among Latino adolescents and parents with limited English proficiency. *Res Nurs Health* 2020;43:263–73. <https://doi.org/10.1002/nur.22019>.