Original Article

From Passive Observers to Active Participants: Reframing Shared Decision Making in Adolescents with Type 1 Diabetes

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ABSTRACT

OBJECTIVE: To explore the experiences and perceptions of adolescents regarding their involvement in SDM for diabetes self-management.

METHODOLOGY: A generic qualitative research design was employed to explore adolescents' experiences of SDM in T1DM care. The study was conducted at two tertiary hospitals and two community health clinics in Malaysia. Data collection was carried out between January and June 2025 across multiple clinical settings at a University Hospital and a Public Hospital, and two community health clinics in Malaysia. Data were collected through non-participant observation and semi-structured interviews with adolescents, parents, and healthcare professionals, using an interview guide. Purposive sampling was used to recruit 30 participants: 12 adolescents with T1DM (aged 10–18 years), 14 parents, and 4 healthcare professionals (paediatricians, pharmacists, and dietitians). Interviews were audio-recorded, transcribed verbatim, and analyzed thematically.

RESULTS: Three patterns of adolescent engagement were identified: (i) passive roles characterized by silence and disengagement, (ii) defensive behaviors triggered by emotional pressure or perceived blame, and (iii) active yet limited participation where adolescents expressed satisfaction with their current involvement. Despite their presence during clinical encounters, most adolescents deferred decisions to parents or clinicians. Those who actively participated did so more confidently when supported through age-appropriate education and positive reinforcement.

CONCLUSION: Adolescents showed three patterns of participation, including passive, defensive, and active but limited. Most decisions were deferred to parents or clinicians, while active engagement occurred through supportive communication and age-appropriate education.

KEYWORDS: Adolescent, self-management, shared decision-making, type-1 diabetes, participation, Malaysia

INTRODUCTION

Type 1 Diabetes Mellitus (T1DM) is a chronic metabolic condition commonly diagnosed in children and adolescents, often presenting with polyuria, polydipsia, and ketonemia. Patients diagnosed with T1DM accounted for 0.62% of all reported diabetes cases[1]. Self-management is a vital component of diabetes care, encompassing the daily actions individuals take to manage their condition. Effective self-management can reduce complications and improve quality of life[2]. However, adolescents often struggle to balance these responsibilities with academic, social, and emotional demands. Research shows that adherence to self-management remains low among adolescents[3]. This is influenced by factors such as limited health literacy, family dynamics, peer support, cost, and interactions with healthcare providers[4].

Shared decision-making (SDM) has emerged as a critical strategy to enhance adolescent engagement and foster autonomy in diabetes management. SDM involves collaboration between patients, families, and healthcare providers, fostering mutual respect, open communication, and shared responsibility in care decisions. For adolescents, SDM can promote confidence, improve clinic attendance, and strengthen self-advocacy and communication skills[5]. Joint Evaluation of decisions after SDM is also essential to ensure quality care and to strengthen adolescent–provider relationships[6]. For adolescents with T1DM, SDM is particularly important, as self-management is a lifelong requirement involving complex decisions about insulin administration, diet, physical activity, and monitoring[5]. The adolescent developmental stage,

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marked by identity formation, cognitive maturation, and increasing autonomy, offers both opportunities and challenges for active participation in healthcare decision-making.

Adolescent involvement in SDM should be viewed not merely as participation in isolated clinical choices but as a developmental and relational process that evolves with maturity, experience, and social interaction[7]. During adolescence, individuals progressively acquire cognitive and emotional capacities that enable greater autonomy, yet their participation in decision-making continues to be shaped by relationships with parents and healthcare professionals[7]. Despite this theoretical alignment between SDM and adolescent developmental needs, empirical studies indicate that adolescents' actual engagement remains limited.

Previous studies on SDM among adolescents with T1DM have primarily focused on parent and healthcare professional interactions, often overlooking adolescents' perspectives and the developmental factors that influence their participation.[8] While these studies recognize the importance of involving young patients in treatment decisions, they also reveal that adolescents frequently remain passive or peripheral during consultations, with parents and clinicians dominating discussions[7]. Moreover, limited research has explored the relational and emotional dynamics that shape how adolescents perceive their decision-making roles, particularly within family-centred Asian healthcare settings.

This study, therefore, addresses this gap by providing an in-depth exploration of how adolescents with T1DM perceive and enact their roles in SDM, and how their attitudes, behaviors, and relationships with parents and healthcare professionals influence their engagement. The findings offer practical insights to inform the design of age-appropriate and family-inclusive interventions that strengthen adolescents' confidence and meaningful participation in chronic disease management.

METHODOLOGY

Study Design

A generic qualitative research design was employed to capture the nuanced perspectives of adolescents, parents, and healthcare professionals regarding adolescent engagement in SDM. This methodological orientation focuses on understanding participants' subjective experiences and meanings in their natural context, without strict adherence to a particular qualitative tradition, such as phenomenology, grounded theory, or ethnography. It allows the researcher to explore "what" and "how" questions about a phenomenon, emphasizing descriptive interpretation rather than theory generation.[9] The approach was selected for its flexibility and pragmatic orientation, enabling the exploration of lived experiences of SDM while remaining grounded in participants' accounts rather than in any predetermined theoretical framework.

Setting and Participants

The study was conducted at two tertiary hospitals with specialized pediatric diabetes clinics. Purposive sampling was used to select participants who could provide rich, relevant insights into adolescents' experiences with SDM. Inclusion criteria for adolescents were those aged 10–18 years, diagnosed with T1DM for at least 1 year, and attending regular follow-up appointments. Parents and healthcare professionals directly involved in adolescents' care, such as paediatricians, pharmacists, and dietitians, were also recruited.

A total of 30 participants took part in the study, comprising 12 adolescents with T1DM, 14 parents, and 4 healthcare professionals. Semi-structured interviews were conducted individually with one participant per session in private consultation rooms within the hospital and clinic settings to ensure confidentiality and comfort. Each interview lasted approximately 30–60 minutes and followed an interview guide that explored experiences, perceptions, and interactions related to SDM. Interviews were audio-recorded with prior consent, conducted primarily in Malay or English, depending on the participant's preference, and later transcribed verbatim for analysis.

Data Collection

Data collection was carried out between January and June 2025 across multiple clinical settings, including the pediatric and internal medicine clinics and wards at a University Hospital and a Public Hospital, and two community health clinics in Malaysia. Non-participant observations were conducted during clinical consultation sessions, focusing on verbal and non-verbal interactions, turn-taking in discussions, and decision-making dynamics. Semi-structured interviews were conducted separately with adolescents, parents, and healthcare professionals, lasting 30–60 minutes. Interview guides explored experiences, perceptions of SDM, barriers, and enablers of participation. All interviews were audio-recorded with consent and transcribed verbatim. Observational field notes were integrated into the data.

The research team consisted of three members with complementary expertise. The principal researcher, a registered nurse and senior academic with extensive experience in pediatric and family nursing research, conducted the majority of interviews and observations. She has undergone formal training in qualitative methodology and has previously published qualitative studies in the areas of family decision-making and child health. Her professional background in pediatric care facilitated rapport-building with participants and fostered a comfortable environment for sharing personal experiences. To minimize potential bias, she had no direct clinical involvement in the participants' ongoing care. One research assistant, with master's-level training in nursing and prior exposure to qualitative research, supported transcription accuracy

and initial coding under the supervision of the principal researcher. All team members participated in regular analytic meetings to ensure consistency and rigor throughout the coding process.

Data Analysis

Data were analyzed thematically following Braun and Clarke's[10] six-step process, including familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report.10 Coding was conducted using NVivo 15 to manage and organize data.

Ethical Considerations

Ethical approval was obtained from the IIUM Research Ethics Committee (IREC 2024-322) and the Medical Research and Ethics Committee (MREC), Ministry of Health Malaysia (MOH) (NMRR ID-24-03778-05R). Before data collection, written informed consent was obtained from parents, and assent was secured from adolescents aged 18 years or younger. The researcher first approached parents during clinic visits at participating sites, including the pediatric and internal medicine clinics of the hospital and the community health clinics. The researcher met with parents in a private consultation room to explain the study's purpose, procedures, the voluntary nature of participation, potential risks and benefits, and measures taken to ensure confidentiality and anonymity. Parents were also informed that participation or refusal would not affect their child's medical care. Information sheets and consent forms written in both Malay and English were provided and reviewed together with the researcher to ensure understanding. Adequate time was given for parents to ask questions before signing the consent form. Copies of the signed documents were provided to parents for their records. Participation was entirely voluntary, and all identifying information was removed from transcripts and reports to maintain confidentiality.

Trustworthiness

The rigor of this study was established using the criteria for trustworthiness encompassing credibility, transferability, dependability, and confirmability.[11] Credibility was enhanced through prolonged engagement with participants, in which the researcher maintained continuous interaction with participants and the study setting over a six-month data-collection period. This included multiple interviews and follow-up communications with adolescents, parents, and healthcare professionals at the pediatric diabetes clinics. Data triangulation was achieved through numerous sources, including adolescents, parents, healthcare professionals, and observational notes, which provided comprehensive perspectives on shared decision-making experiences. Member checking was conducted after preliminary data analysis, during which selected participants were contacted by telephone or via follow-up clinic visits to review summarised interpretations of their interview data. This process allowed participants to verify the accuracy of the researcher's understanding and provide clarification or additional input where necessary. Peer debriefing was carried out throughout the analysis phase, during regular meetings with co-researchers and academic peers who were not directly involved in the data collection. These sessions served to critically review coding decisions, challenge potential researcher bias, and refine theme development, thereby strengthening the credibility and confirmability of the findings. Transferability was supported by providing rich, thick descriptions of the study setting, participant demographics, and contextual details, which enable readers to judge the applicability of findings to other contexts. Dependability was maintained through an audit trail documenting methodological decisions, coding processes, and theme development, ensuring transparency and allowing for external review of the research process. Confirmability was reinforced through reflexive journaling and systematic documentation of analytic decisions, demonstrating that findings were grounded in participants' accounts rather than the researcher's preconceptions.

RESULTS

Sociodemographic Characteristics of the participants

The data on the characteristics of the respondents in this study are:

Table I: Characteristic Respondents

Demographic characteristic	Frequency	Percentage
Age		
9-12 years old	6	50.0
13-17 years old	6	50.0
Gender		
Female	12	100
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

Table I indicates that 12 female adolescents with T1DM were observed and interviewed in the study. Half of the participants were aged 9-12 years (50.0%), while the other half were aged 13-17 years (50.0%). Most of the participants were Malay (91.7%), with only one Chinese participant (8.3%). In terms of diagnosis duration, the majority were considered newly diagnosed, with 66.7% having been diagnosed within the past 1 to 3 years. Among parents, the majority were mothers (72.7%), aged 40–50 years, predominantly Malay (91.0%), and nearly half held a diploma. Over half were unemployed, and only one reported having diabetes. The four healthcare

professionals comprised two paediatricians, one pharmacist, and one dietitian, with equal gender distribution, mainly Malay (75.0%), and with between one and five years of clinical experience.

Data from participant observations and semi-structured interviews were analyzed thematically, producing three predominant patterns of adolescent engagement in SDM: (i) passive roles characterized by silence and disengagement, (ii) defensive behaviours triggered by emotional pressure or perceived blame, and (iii) active yet limited participation where adolescents expressed satisfaction with their current involvement. These patterns represent a continuum of involvement, with adolescents shifting between roles depending on the clinical context, the nature of the decision, and the level of support received.

Theme 1: Passive roles characterized by silence and disengagement.

Adolescents in this category were physically present during consultations but contributed minimally. They often remain silent, avoiding eye contact and allowing parents or healthcare professionals to speak on their behalf. The adolescents responded only with brief answers or non-verbal gestures despite repeated prompts.

This behavior was observed in multiple clinical encounters:

During a routine ward round, the doctor started by asking about the adolescent's condition and reviewed her morning glucose reading of 18 mmol/L. The doctor then inquired about the adolescent's pre-bedtime intake. The parents replied that she had only eaten a sandwich. The doctor attempts to engage the adolescent by asking about her daily food intake at school. Initially, she responded with brief answers, but eventually limited her responses to nodding and smiling. Throughout the consultation, however, she appears distracted and avoids eye contact. The adolescent seems to be listening, but shows little interest. (Observation note 04, 7th January 2025)

A similar situation was observed during another clinical consultation, where adolescents responded briefly.

During one consultation, the physician was reviewing the latest HbA1c result, which was 7.2mmol/L, slightly higher than the previous reading of 6 mmol/L. The physician reassured them that the result remained within the normal range and then discussed the adolescent's diet and physical activity. When asked whether she participated in any sports, the adolescent replied, "No". The physician continues to make several attempts to engage her by asking questions, but she responds only with brief answers such as "Yes" or "No". - (Observation note 07, 26th May 2025)

These patterns can be supported with an interview with a parent, who acknowledged that the decisions during clinical consultations were primarily made by the parents, with limited input from the adolescent.

"Usually, I'm the one who decides with the doctor. She just listens and follows the instructions" (Parent 04, 7 January 2025).

This reliance on others to make decisions reflects a pattern where adolescents perceive decision-making as the responsibility of adults, reinforcing their passive role. While many adolescents maintained silence, others responded when feeling pressured, often shifting from passive disengagement to defensive self-protection when they perceived criticism. This shift from silence to self-protective responses is explored in the next theme.

Theme 2: Defensive behaviours triggered by emotional pressure or perceived blame.

In this pattern, adolescents reacted with guarded or resistant behaviours when discussions highlighted perceived shortcomings in their diabetes self-management. Emotional triggers often arose during reviews of high glucose readings, missed injections, or dietary lapses.

During one consultation, a physician noted a spike in an adolescent's glucose readings. The parent, attempting to prompt honesty, warned that the doctor might contact the school to restrict sports activities. The adolescent responded by raising her voice defensively while playing on her phone. She eventually admitted to buying sweets at school. The physician later shifts to a calm, supportive tone; however, her body language remained tense (Observation note 06, 8 May 2025).

Parents recognized that such defensiveness often emerged when adolescents felt blamed. One parent described how her daughter became less communicative when confronted about dietary lapses:

"When she sees her friends eating something she can't have, she also wants the same thing… and when we tell her no, sometimes we fight a lot because of that" (Parent 09, 7 January 2025).

These behaviours appeared to protect the adolescent's self-esteem but, at the same time, reduced openness in discussion. The emotional tone of the encounter, particularly whether it felt judgmental, played a critical role in determining whether adolescents engaged or withdrew. When emotional safety was established, some adolescents moved beyond defensiveness, engaging more constructively, even if their role remained limited.

Theme 3: Active yet limited participation.

A smaller subset of adolescents participated more actively when directly addressed by clinicians, provided with age-appropriate explanations, and given opportunities to demonstrate skills. For instance:

In a consultation with a pharmacist, an adolescent asked about insulin storage and participated in a return demonstration of injection techniques. She appeared focused and engaged, prompting the pharmacist to provide additional tips for reducing injection discomfort (Observation note 02, 21 December 2024).

When asked regarding SDM, one adolescent described it as a shared process between herself, her

parent, and the doctor:

"Making decisions with other people is like…with me, my mom and doctor? And I think I have enough and I'm okay with it" (Adolescent 07, 13 years old, 26 April 2025).

Interestingly, despite their limited role in final decision-making, these adolescents often expressed satisfaction with their involvement, suggesting they equated being consulted occasionally with full participation. This indicates that some may equate occasional consultation with full participation, potentially creating a gap between perceived and actual decision-making power.

The three patterns identified, passive silence, defensive resistance, and active but limited participation, represent a fluid continuum of engagement. Adolescents moved between these roles depending on consultation dynamics and opportunities for meaningful input. Supportive communication and inclusive practices encouraged movement toward greater participation, while judgmental or adult-dominated exchanges reinforced passivity or defensiveness.

DISCUSSION

This study examined the behavioural patterns and perceptions of adolescents with T1DM regarding their participation in SDM, identifying three interrelated themes along a continuum of engagement: (i) passive roles, (ii) defensive behaviours, and (iii) active yet limited participation where adolescents expressed satisfaction with their current involvement. Together, these patterns illustrate how adolescent participation is shaped not only by individual knowledge and skills but also by relational dynamics, consultation styles, and the emotional climate of clinical interactions[12].

Adolescents who adopted a passive role tended to rely on parents and healthcare professionals to speak and make decisions on their behalf, often making minimal verbal contributions. This finding aligns with earlier studies showing that young patients are frequently positioned as recipients of decisions rather than active contributors, especially in family-centred cultures where parental authority is emphasized[12]. In this study, adolescents often deferred to parents or healthcare professionals, offering minimal verbal input and relying on adults to interpret or respond on their behalf. This behaviour may stem from developmental, cultural, and clinical factors. Developmentally, younger adolescents may lack the cognitive maturity to grasp complex treatment decisions fully[13]. However, the persistence of such patterns in older participants suggests that clinical norms and family communication habits also reinforce passivity[14v]

Defensive responses emerged when adolescents felt blamed or judged for lapses in self-management. As in previous research, perceived judgment in healthcare interactions has been shown to reduce adolescents' openness and willingness to participate in SDM[15,16]. In this study, defensive behaviours were often triggered during discussions of elevated blood glucose levels, missed doses, or dietary lapses, mainly when parental frustration was expressed in front of healthcare professionals. Defensiveness may function as a self-protective mechanism, allowing adolescents to avoid uncomfortable topics or perceived loss of face[17]. However, it also interrupts information exchange and limits collaborative problem -solving. The findings highlight the need for psychological safety within the consultation setting, where adolescents can discuss challenges without fear of blame or reprimand.

The findings of the study found that a smaller group of adolescents demonstrated greater engagement, particularly when consultations included direct questions, age-appropriate explanations, and opportunities for hands-on participation. However, their decision-making authority remained limited, with final choices often made by parents or clinicians. Interestingly, these adolescents frequently expressed satisfaction with their current involvement, suggesting that occasional consultation may be perceived as full participation. These findings aligned with a previous study, in which young patients equated occasional consultation with active involvement, suggesting a potential mismatch between perceived and actual agency[5]. While such participation is encouraging, the gap between expressed satisfaction and meaningful engagement raises questions about the adequacy of current involvement. Adolescents may not recognize the full scope of decisions they could participate in, or they may be content to defer final choices to adults while still feeling included[18].

Cultural and familial norms may also shape adolescents' participation in SDM. In the Asian context, including Malaysia, healthcare decision-making is often influenced by hierarchical family structures and a respect for authority figures[19]. For most situations, this pattern of adults' dominance in decision-making is often justified under the pretext of respecting authority or older adults[19-20]. These cultural expectations may contribute to adolescents' reluctance to assert their opinions or take an active role in discussions. Therefore, there is a need to strengthen adolescent involvement in culturally sensitive SDM that includes family-oriented strategies that clearly maintain both boundaries and values.

The findings of the study highlighted that the three patterns observed in this study are not rigid categories but fluid states, with adolescents moving between them based on situational and relational factors. A previously passive adolescent might engage actively when given clear explanations and emotional support, while a typically engaged adolescent might withdraw defensively when feeling judged. Recognizing this fluidity can help healthcare teams adapt their communication dynamically, adjusting their approach according to the adolescent's cues and readiness.

REFRAMING SDM IN ADOLESCENT T1DM CARE

Reframing SDM for adolescents with T1DM requires a thoughtful approach that accounts for the unique developmental needs of this age group. First, communication practices within the clinical encounter must shift from adult-directed information delivery to genuine two-way dialogue. Adolescents benefit when clinicians address them directly, use youth-friendly language, and provide time for reflection and questions, rather than speaking primarily to parents[21]. Consistent evidence shows that when adolescents perceive consultations as respectful and inclusive, they disclose more accurate information and demonstrate stronger adherence to treatment plans[22]. Second, family involvement must balance guidance with autonomy. Parents remain crucial partners in diabetes care, particularly for tasks that require attention, such as insulin dosing and monitoring[23]. Excessive parental control can unintentionally reinforce passivity or trigger resistance, while too little involvement risks lapse in management[24]. Thus, gradually transferring responsibility from parents to adolescents for specific self-care tasks as the adolescents' competence develops has been shown to enhance both confidence and glycemic stability[25]. Third, adolescents need sustained opportunities to build competence and confidence in self-management and SDM. Age-appropriate diabetes education covering carbohydrate counting, insulin titration, and recognition of the signs of hypoglycemia and hyperglycemia, combined with hands-on practice and feedback, equips young people to participate as informed partners[26]. Decision aids tailored to adolescents, peer-led workshops, and digital tools such as interactive apps have been associated with improved knowledge and self-efficacy.[27] Taken together, these elements create an ecosystem in which young people can move from passive observers to confident collaborators in their own care. Implementing such a reframed approach has the potential to improve treatment adherence, optimize glycemic outcomes, and lay the foundation for lifelong self-management.

IMPLICATIONS FOR PRACTICE

The study's findings, highlighting passive, defensive, and active yet limited patterns of adolescent participation, emphasize the need for interventions that are both developmentally responsive and relationally supportive. For adolescents who remain passive, healthcare professionals should intentionally engage them by addressing questions directly, providing time to respond, and validating their input to enhance confidence. For those showing defensive behaviors, healthcare professionals and parents should use non-judgmental communication to reduce perceived blame and anxiety. Among adolescents who are already actively participating, opportunities should be expanded to include more complex aspects of diabetes management, with continuous guidance.

CONCLUSION

This study explored how adolescents with T1DM engage in shared decision-making, revealing three distinct yet fluid patterns of participation: passive roles characterized by silence and disengagement, defensive behaviours triggered by emotional pressure or perceived blame, and active yet limited participation in which adolescents expressed satisfaction with their current involvement. These patterns demonstrate that adolescent participation in SDM is influenced by more than just individual knowledge; it is shaped by relational dynamics, communication styles, emotional safety, and the opportunities they are given to contribute. Moving adolescents from passive or defensive positions toward more confident and informed engagement requires deliberate, multi-layered efforts that address how consultations are conducted, how parents support autonomy, and how self-management skills are built. By promoting open communication, creating supportive family and clinical environments, and equipping adolescents with the knowledge and confidence to contribute meaningfully, we can finally improve both self-management outcomes and the quality of care.

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AUTHOR CONTRIBUTION

Pien LS: Conceptualized the study design, data analysis, and manuscript writing.
Alias K: Involved in data collection coordination, data analysis, manuscript review and editing.
Mohd Annuar WSHbW: Contributed to validation, literature review, and manuscript editing.
Atan AB: Involved in the data collection and interpretation of results.
Muhd Helmi MAb: Contribute to data analysis support and critical review.
Seong SLF: Contributed to participant recruitment, data collection and manuscript revision for intellectual content.
Ahmad N: Contributed to Literature review, data verification, and manuscript proofreading.
Shariff NM: Contributed to project administration, data

management, and review of the final manuscript.
Solikhah U: Contributed to the conceptual input and manuscript critical revision.
All authors reviewed the results and made contributions to the final manuscript.

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