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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. © 2026, Liaquat University of Medical and Health Sciences. All rights reserved.

Author keywords

Adolescent; Malaysia; participation; self-management; shared decision-making; type-1 diabetes

Indexed keywords

EMTREE medical terms

adolescent; Article; blame (psychology); child; conceptual framework; defensive behavior; dietitian; disengagement; education; emotional stress; engagement; ethnography; experience; female; follow up; grounded theory; health care personnel; human; human experiment; insulin dependent diabetes mellitus; Malaysia; male; non participant observation; pediatrician; perception; pharmacist; phenomenology; positive reinforcement; public hospital; qualitative research; satisfaction; semi structured interview; shared decision making; tertiary care center; triangulation; trustworthiness; university hospital

Device trade names

Commercial names given to devices, used for branding and differentiation in the market, commonly referenced in scientific and clinical research.

NVivo 15

Funding details

Details about financial support for research, including funding sources and grant numbers as provided in academic publications.

Funding sponsor	Funding number	Acronym
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