

Health Seeking Behaviour and Diabetes Self-Management Among Young Adults with Type 1 Diabetes Transitioning from Paediatric to Adult Care: Evidence from the Sweetlings Program in India

Chidvilas More¹, Sonali Wagle², Monika Sawale³, Shital Bhor⁴, Dipali Ladkat⁵, Anuradha Khadilkar⁶

¹²³⁴⁵⁶Hirabai Cowasji Jehangir Medical Research Institute, Pune, India

Correspondent: dr.chidvilasmore@gmail.com¹

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ABSTRACT: Type 1 Diabetes (T1D) requires intensive diabetes self-management (DSM) and consistent engagement with healthcare services. Adherence to DSM declines during transition from paediatric to adult care. Substantial socio-financial barriers in India leads to limited health-seeking behaviour (HSB) and DSM research among young adults' post-transition. The Sweetlings program, a comprehensive paediatric T1D support initiative, provides a unique context to examine these changes. This study aimed at the assessment of the HSB, self-care practices, and barriers to DSM among young adults with T1D transitioned from Sweetlings paediatric program to adult care. Two-phased mixed-method was used. In first phase, preliminary information from 33 eligible participants identified via program database captured using Google form. Face-to-face or telephonic in-depth semi-structured interviews were conducted for them in the second phase. Data were transcribed and analysed thematically to identify patterns in DSM, adherence, and barriers after transition. Participants reported strong DSM during Sweetlings program due to structured supervision, regular reminders, provision of supplies and counselling. After transition, most of them experienced reduced glycaemic control and poorer adherence to diet, physical activity, insulin routines. Domains of decline are: supervision, self-control, counselling, occupational constraints, financial strain, discomfort about dependence on family for medical expenses. Post-transition non-adherence rose from 24.24% to 54.54% (percentages are based on 33 interviewed participants). Persistent barriers included cost of care, demanding work schedules, stigma, clinic attendance, emotional distress. Transition to adult care weakened DSM and HSB. Strengthening transitional care through structured counselling, financial-educational support, youth-friendly OPD environments, and peer mentoring may improve DSM in young adults with T1DM in India.

Keywords: Type 1 Diabetes Mellitus (T1DM), health-seeking behaviour, diabetes self-management (DSM), Sweetlings program in India, mixed method study.



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INTRODUCTION

Type 1 Diabetes Mellitus (T1DM) is an auto-immune disorder that causes insulin deficiency with serious short-term and long-term implications (1,2). It is believed to be the result of autoimmune-mediated destruction and inflammation of the insulin-producing β -cells of the pancreas and has a strong genetic component (3). Complications of T1DM can cause substantial disability and death (4). Across the globe, T1DM accounts for 5–10% of all cases of diabetes and its incidence is increasing (2). The global incidence of T1DM is increasing by 3% to 5% per year (2,5) leading to an increasing number of children transitioning from paediatric to adult care (4). T1DM commonly presents in childhood or adolescence and the International Diabetes Federation (IDF) Atlas 2021 estimates that 9.1 million people are living with T1DM in the world and over 1.2 million children and adolescents suffer from T1DM globally; of these, nearly 50% are below 15 years of age. India has 9,41,000 people living with T1DM of all ages. India has the highest number of children and adolescents under the age of 20 years (3,01,000) in the world as of 2021 (6,7).

Diabetes Self Care Management (DSM) practices of patients with T1DM are a major aspect of diabetes care. DSM is crucial for satisfactory diabetes control. When patients self-manage adequately, they can decrease the level of glycated haemoglobin by 37% (8) – it is a relative reduction as compared to their increased values. Self-care behaviour of patients with T1DM makes the management of diabetes easier for the patients as well as the caregivers. For effective DSM, patients must have a clear understanding of the disease's signs and symptoms, as well as appropriate strategies for its management and control. Self-care practices like regular self-monitoring of blood glucose levels (BSLs), adequate physical activity, diet control, healthy food adaptation, and adherence to appropriate medication practices are key factors to improve DSM and enable patients to self-manage the disease effectively. Further, the cooperation of family members and physician assistance contributes to the same. Other factors that determine diabetes self-care behaviours include diabetes education, duration of disease, presence of comorbid conditions, BMI, foot care, and smoking (9). The main objective of DSM is keeping glycaemic levels within the euglycemic range to prevent complications (10). Self-management of T1DM is thus complex and requires intensive self-monitoring of blood glucose and ketones, daily administration of insulin, regulating diet and exercise, maintaining optimal glycaemic control, frequent visits to diabetes clinics and screening services such as retinopathy (1,11,12). Factors responsible for inadequate DSM in patients with T1DM are inadequate DSM education, lack of specially trained personnel to provide psychological support and counselling, ignorance and wrong beliefs, unhealthy eating habits, inadequate physical activity, irregularity in blood glucose monitoring, clinic visits, administration of medicines, negligence of patients and various cultural barriers (9).

However, adherence to DSM practices often declines during adolescence, especially as patients transition from paediatric to adult care systems. Transitional care refers to the purposeful and planned movement of adolescents and young adults with chronic conditions from paediatric to adult healthcare systems. Emergent adulthood is a challenging period of increasing maturity, independence, and personal identity. In many settings, paediatric patients are transferred to adult care at approximately 18 years of age. Studies evaluating this transition among young adults with T1DM have highlighted the need for greater support and structured interventions during this period (13). Young adults with T1DM face the unique task of balancing DSM practices to maintain both euglycemia and optimal weight management that are often at odds with one another (9). Young adults with T1DM are at particularly high risk for poor glycaemic control, recurrent admissions due to diabetic ketoacidosis and loss to follow up (4). Suboptimal glycaemic control in young adults with T1DM increases the risk for hospitalization and diabetes-related complications and increases the burden on health care systems (13). Physiological factors in this age group such as insulin resistance and lifestyles, risk-taking behaviour, peer influence and family conflict also negatively impact DSM. Young

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adults with T1DM often struggle to adjust with the lifestyle changes such as leaving home or moving away from the family for the first time, beginning employment, starting university or college, being in intimate relationships in addition to transitioning from paediatric to adult healthcare services (1,11). These transitions are not always simple; consequently, emergent adults are at an increased risk for many physical and mental health challenges (14).

Clinical management of T1DM is generally handled at diabetes centres within hospitals by a multidisciplinary team, including endocrinologists, diabetes educators or diabetes nurse specialists and clinical dietitians (15). During the transition, patients with T1DM often struggle to adjust to the adult care services and the new levels of personal responsibilities (11). Young adults with T1DM who drop out from regular healthcare services have an increased risk for developing diabetes-related complications and emotional responses such as anxiety, depression, feelings of guilt (16). Traditional diabetes care methods may not be the most appropriate for supporting young adults' DSM (2). Appropriate support from healthcare services such as increased timing flexibility beyond traditional working hours and relevance of information for young adults with T1DM is required to ensure their continued engagement (15). Participants who continue with the same diabetes physician are less likely to face post-transition diabetes-related hospitalization (4). An Australian survey of young adults with T1DM reported the top three obstacles that prevented access to adult clinic attendance as the inconvenient times of their diabetes clinic appointment (74.4%), cost (66.3%) and distance required to travel (54.7%) (16). According to a Canadian multicentre study, as many as 30% of young adults with T1DM disengage from care during transition and 46% report difficulties with the transition process. Diabetes regimen compliance and DSM are probably negatively associated with socioeconomic status (SES) (14). Studies from China found that patients with T1DM who had low income and educational levels tend to have higher glucose levels (8). All these factors contribute to decreased clinic attendance, poorer treatment adherence and glycaemic control, and increases in hospitalization rates and acute diabetes complications for young adults with T1DM (17).

In recent years it has been acknowledged that young adults with T1DM should be recognised as having different needs and facing different challenges, compared to younger and older cohorts living with the condition (18). In the past few years there has been a growing focus on young adults with T1DM who have transitioned to adult services. During transitional turning points, a multitude of factors impact on DSM such as food literacy skills, financial stability, moving away from usual support networks and ability to take time away from study or work to attend clinical appointments (15). Several studies have estimated that there are increased chances of emergent adults with T1DM developing depression, distress, or low life satisfaction over time (14). A few examples of developed countries include Australia and Denmark where diabetes medications such as insulin are partly subsidised. In Australia, diabetes technology such as insulin pumps are only subsidised through private health insurance, while continuous glucose monitoring systems (CGMs) are subsidised for certain populations (≤ 21 years). In Denmark both insulin pumps and CGMs can be provided to the young adults with no additional cost (15). But in low- and middle-income countries (LMICs) such as India, different interventions need to be implemented for which research regarding health seeking behaviour of patients with T1DM are needed. The overall evidence about adherence to Self-Monitoring of Blood Glucose (SMBG) among T1DM patients is limited and most of it comes especially from South and South-East Asia (17,19–22). Poor adherence to prescribed protocols of long-term therapies is a pervasive and costly problem in the care of children with chronic illnesses. Studies are thus needed to explore factors related to non-adherence to treatment regimens as well as poor control of T1DM, especially with the increasing prevalence of T1DM (23).

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It is a basic human need to belong to a group and that it is a central driver of motivation to be valued and accepted by others. Such peer support can help to avoid or overcome stigma. Children with T1DM expect support for emotional problems from peers, family and especially from healthcare providers. This is crucial, considering that mental health problems double the odds of having poor glycaemic control (24). With this in mind, the ‘Sweetlings Program’ was initiated by our centre in Western India in 2010 to provide comprehensive, holistic care for children with T1DM, particularly those from socially and economically underprivileged backgrounds. The program offers free multidisciplinary support encompassing medical, nutritional, psychological, and educational services. Children up to 18 years of age with biochemically confirmed T1DM are eligible for enrolment. Regular assessments, including blood glucose and Haemoglobin A1c i.e. glycated haemoglobin (HbA1c) monitoring, diabetes education, and counselling sessions for children and caregivers, are conducted to promote optimal glycaemic control and psychosocial well-being. It helps in combating the initial shock of diabetes disclosure. The initiative emphasizes sustained engagement, empowerment, and self-management among children with T1DM and their families through a structured and compassionate care model.

The present study aims to assess the health-seeking behaviour and self-care practices of adolescents and young adults with T1DM who have transitioned from paediatric to adult care within the Sweetlings Program. It specifically examines patterns of DSM, identifies barriers affecting continuity of care, and explores psychosocial factors influencing engagement with healthcare services post-transition. The novelty lies in examining post-transition health-seeking behaviour and diabetes self-management among young adults with T1DM in an Indian LMIC setting, within the context of the Sweetlings structured paediatric support program, using a mixed-method approach. The specific objectives of the study thus are: (1) to compare self-care practices before and after transition to adult care; (2) to identify barriers to effective self-management among youth with T1DM after transitioning; and (3) to explore suggestions for improving DSM in this population.

METHOD

This was a mixed-method descriptive study with a predominant qualitative component conducted in 2023–2024. Ethics approval was obtained on 10th November 2023 from Ethics Committee Jehangir Clinical Development Centre, Pune, India. In order to assess health-seeking behaviour and diabetes self-management of individuals transitioned to adult care, a structured methodology was employed with purposive sampling. A Google Form comprising closed-ended questions was developed to capture initial insights of the participants. Data from these forms was used for development and refinement of the interview guides. A purposive sampling approach was used to recruit participants who had transitioned from paediatric to adult care within the Sweetlings Program. Participants who had transitioned from paediatric to adult care within the Sweetlings Program were eligible for inclusion in the study. A total of 38 eligible participants were identified through the project database. Each participant was contacted via phone, during which the purpose, aims, and objectives of the study were explained to ensure informed participation. Of the 38 eligible participants, 33 consented to participate and were included in the study. Two declined the participation, while three could not be contacted due to invalid or unavailable updated contact information. Thus, participants who could not be contacted or who declined consent were excluded from participation. Upon obtaining consent, the identified participants were requested to complete the Google Form. Sociodemographic questions (such as gender, age, education, occupation, family size); financial questions (such as income, expenditure on diabetes management), clinical and transition questions (such as dates of enrolment and transition, BSL readings); and questions related to DSM (such as regular

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BSL checking, injecting insulin etc.) were asked in the form. The responses collected through the form were systematically compiled and exported into an Excel spreadsheet for analysis.

This analysis provided an overview of common trends and patterns, which served as the foundation for designing an in-depth semi-structured interview guide. The guide aimed to explore in greater depth the themes that emerged from the quantitative responses such as their regime and types of support they received when they were at Sweetlings program, instructions and support provided at the time of transition to adult care, reasons for irregular doctor visits, irregular BSL checking and non-adherence to the instructions after the transition along with the basic personal and family information and suggestions to improve the program. Questions related to the identified themes were incorporated into a semi-structured interview guide consisting of both closed-ended and open-ended questions. All 33 participants who completed the Google Forms were invited for follow-up in-depth qualitative interviews. While face-to-face interviews were preferred for richer interaction and better observation of non-verbal cues, logistic constraints prevented some participants from traveling to the hospital. In such cases, interviews were conducted via telephone to ensure inclusivity. The average duration of each interview was approximately 45 minutes. Coding and thematic interpretation were performed by an experienced qualitative health researcher, and no major disagreements emerged during data interpretation. Data saturation was considered to have been achieved at approximately 25 interviews, as no substantially new themes emerged thereafter. Quantitative findings from the Google Forms and qualitative interview themes were integrated during analysis to provide a more comprehensive understanding of post-transition health-seeking behaviour and DSM practices. The study was conducted at Jehangir Hospital, Pune city, Maharashtra state, India.

Data collection and entry into Microsoft Excel occurred simultaneously to maintain accuracy and timeliness. All interviews were audio-recorded (where consent was given), transcribed verbatim, and reviewed meticulously by the research team. The transcribed data underwent thematic analysis—a method that involves coding, categorizing, and interpreting qualitative data to identify recurring themes and patterns. Coding was conducted by a single experienced qualitative researcher using thematic analysis. Codes were developed around major themes including diabetes self-management (DSM), psychosocial and family support, supervision during paediatric care, occupational and financial barriers after transition, post-transition non-adherence, dependence on family for medical expenses, doctor visits, and BSL monitoring practices. The in-depth thematic analysis provided nuanced insights into the health-seeking behaviours, barriers, and facilitators experienced by the respondents during their transition to adult care.

RESULT AND DISCUSSION

Out of 38 participants, 33 agreed to give the in-depth interviews. 17 out of these 33 were females and 16 were males. Two males are married and 14 are unmarried while three females are married while 14 are unmarried. Mean age of the participants at the time of the study was 24.4 ± 2.8 years and mean age at the diagnosis of diabetes was 10.3 ± 4.4 years. Denominators to the percentages are 100. Participant information is mentioned in Table 1: Participant Description.

One participant mentioned that “children with T1DM receive good treatment and support at Sweetlings program. My health really improved due to this support. I learned how to manage BSLs. My family was also unaware about T1DM as nobody in the family had this condition. They used to worry a lot - nobody knew anything. Due to this program, family members also learned about

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what T1DM is, how to deal with a child with T1DM and how to live a normal life with T1DM with much ease.”

Table 1. Participant Description

S.N.	Age	Sex	Marital Status	Education	Occupation	Income (INR)	Age at diagnosis	Years since transition	DSM expenditure (INR)
1	22	F	Unmarried	B.A.L.L.B. last year	Education	NA	18	2	3000
2	24	M	Unmarried	B.Tech. Biotechnology	Business	30000	11	3	2500
3	22	M	Unmarried	B.Sc. Microbiology	Education	NA	13	1	3500
4	22	M	Unmarried	Business Administration and Comp. Application	Education	NA	5	2	4000
5	25	M	Unmarried	12th Pass	Agriculture	7000	12	4	2500
6	24	M	Unmarried	Dip. in ENTC.	Service	20000	12	5	1500
7	24	F	Married	S.Y.B.Com.	Housewife	NA	12	4	3000
8	22	F	Unmarried	F.Y.B. Com.	Unemployed	NA	13	1	3000
9	23	F	Unmarried	GNM	Service	15000	12	2	1500
10	22	M	Unmarried	B.C.A.	Service	10000	13	1	1800
11	22	F	Unmarried	B.Com.	Education + Service	6000	7	1	2200
12	23	M	Unmarried	M.Pharm.	Agriculture	5000	12	2	4000
13	25	F	Unmarried	B.A.	Unemployed	NA	9	3	2000
14	24	F	Unmarried	B.Com. LLB	Education	NA	8	2	3400
15	27	M	Unmarried	11th pass	Unemployed	NA	17	4	2000
16	27	M	Unmarried	B.A.	Preparation for Police Recruitment	NA	20	4	3800
17	35	F	Unmarried	B.Sc. Chemistry	Service	18000	2	5	2500
18	23	M	Unmarried	12th Pass	Service	8000	7	5	5000
19	22	M	Unmarried	B.Com. M.B.A. (2nd year)	Education	NA	2	5	4200
20	26	F	Unmarried	B.E. Comp. Science	Service	35000	8	4	3000
21	26	M	Married	B.Sc. Microbiology	Service	40000	12	6	6000
22	20	F	Unmarried	B.B.A.	Education	NA	10	3	5100
23	25	M	Unmarried	M.Com	Service	8000	3	2	3000
24	23	F	Unmarried	B.Com	NA	10000	12	5	3000
25	24	F	Unmarried	M.A. Clinical Psychology	Unemployed	NA	3	3	4300
26	24	M	Unmarried	B.Tech 3rd Year	Education + Service	9000	13	2	3000
27	23	F	Unmarried	Hotel Management	Service	18000	10	3	3000
28	31	M	Married	M.Sc. Nursing	Service	56000	13	6	5500
29	24	F	Unmarried	B.A.	Unemployed	NA	15	2	4000
30	25	F	Married	10 th	Housewife	NA	10	4	1800
31	25	F	Married	Mechanical Engineering	Service	25000	4	4	2500

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S.N.	Age	Sex	Marital Status	Education	Occupation	Income (INR)	Age at diagnosis	Years since transition	DSM expenditure (INR)
32	25	M	Unmarried	Software development	Service	10000	12	3	3500
33	27	F	Unmarried	Dip. ENTIC. BCA	Education + Service	26000	11	6	3800

Differences in Self-Care Before and After Transition to Adult Care

Self-Care and Management During the Sweetlings Program

Participants consistently described receiving comprehensive, structured support during the Sweetlings Program. They were provided with essential diabetes-management materials, including glucometers, glucose strips, insulin vials or cartridges/ insulin pens, needles, and storage pouches. Children without refrigeration at home were given small refrigerators for insulin storage. Participants described the Sweetlings Program as helping children with T1DM become more confident, independent, and socially comfortable. One participant mentioned that “Team Sweetlings does 100% efforts to manage our T1DM; we are like a family. The team took our care as if we are their children.” She further stated that “Sweetlings Participants only have to follow all the instructions - rest is taken care by Sweetlings team.”

All participants reported that their BSLs were generally well controlled during the program, supported by regular laboratory tests such as HbA1c, thyroid assessments, and annual check-ups. Adherence to DSM tasks was described as relatively easy, largely because the Sweetlings team offered clear instructions, close supervision, and routine reminder calls for tests and appointments. Participants recalled the team as caring, attentive, and consistently available.

Doctor visits during the program were structured and convenient. Participants visited the clinic, where Sweetlings physicians were always present. Social and psychological counselling was described as an essential component of care. Counsellors supported children and parents and sometimes visited schools to explain T1DM to teachers and peers, contributing to reduced stigma and improved self-esteem. One participant quoted – “I am very much satisfied with the support provided by Sweetlings team. My diabetes was very much in control and I was called twice a year to do the full body check-up.”

Self-Care and Management After Transition to Adult Care

Following transition, participants experienced a significant decline in their ability to maintain glycaemic control. Of the 33 participants, 21 (63.63%) attributed this decline to reduced supervision, loss of reminder systems, and the need to independently manage appointments and finances. 17 out of 33 (51.51%) participants reported difficulty in sustaining the level of lifestyle discipline required for optimal DSM, and 16 (48.49%) were able to maintain a regular diet or insulin regimen but they also mentioned that it is very difficult to do so.

Doctor visits became irregular for 17 out of 33 (51.51%) participants after transition. 10 of 33 participants (30.30%) had not visited a doctor for almost a year due to inconvenient clinic timings,

the need to coordinate schedules, consultation fees, or limited access to endocrinologists. Those who did seek care typically visited general physicians or diabetologists.

Loss of counselling emerged as a major concern. It has been emphasised by the participants that – “parents should be counselled - they should be made aware about the diabetes of their child. They should be told that it’s just like another disease and there is nothing to get feared about it.” Also, in the schools – “class teachers and class mates of a child with T1DM should be made aware about what T1DM is and how to take care of a T1DM child - social stigma can be overcome by talking about it.”

Participants found it difficult to access counselling services comparable to those offered in Sweetlings. A participant said “Teenage psychological counselling, marriage counselling are required for explaining the relation between T1DM and reproductive health, T1DM and offsprings - whether T1DM is hereditary.”

According to one participant – “T1DM awareness among common people is necessary – it will help create empathy.”

One of them underlined the fact that “Social, psychological and family counselling provided by the team proved immensely helpful to me while dealing with my T1DM.”

Many continued to rely on the Sweetlings helpline or clinics for emotional and social support. One of the participants said that “Me and a few other participants transitioned to adult care were trained to train other children with T1DM regarding how to operate the diabetes syringes, finger pricker, how to maintain BSLs etc.”

Summary of Key Differences

Participants identified six major categories of differences in self-care before and after transition:

1. Supervision – highly structured during Sweetlings; minimal after transition to adult care
2. Self-control – supported during Sweetlings; difficult to sustain independently after transition to adult care
3. Counselling – readily available during Sweetlings; scarce after transition to adult care
4. Occupation – work demands interfered with DSM after transition to adult care
5. Financial status – affordability issues emerged after transition to adult care
6. Awkwardness about medical expenditure – dependence on family after transition to adult care created discomfort

These differences were consistently experienced as major contributors to reduced DSM after transition. These categories emerged from closed-ended as well as thematic coding of interviews.

Barriers to Diabetes Self-Management (DSM) After Transition

Adherence to Instructions During the Sweetlings Program

While 24 (72.72%) participants reported adherence to all the instructions during the program, 9 (27.27%) did not comply fully. Reasons for non-compliance included occupational/ school constraints, financial limitations, unhealthy diet consumption at social events, lack of physical activity, tiredness, laziness, and lack of interest or motivation. Physical barriers, such as thyroid-related discomfort or breathing difficulties, were also cited. It has been quoted by the participants that – “participants transitioned to adult care tend to skip insulin doses due to lack of money and then face serious health complications.”

Adherence to Instructions After Transition

After transitioning to adult care, non-compliance increased substantially, with 17 (51.51%) of participants reporting that they did not adhere to the instructions provided at transition.

Barriers included (Figure 1):

- Occupational factors (inconvenient work hours, unstable employment)
- Financial dependence and inability to afford doctor fees [Quote: I feel ashamed that my father pays for my medicines] [Quote: Children with T1DM primarily need financial help] [Quote: Participants transitioned to adult care tend to skip insulin doses due to lack of money and then face serious health complications]
- Dietary factors: frequently consumed food purchased outside the home during social interactions, packed meals often get spoiled due to long travel times, and the healthy options available were perceived as tasteless and monotonous [Quote: I would ask children with T1DM to follow their meal timings, to take care of themselves and not to be dependent on others]
- Lack of interest in education [Quote: Children with T1DM should complete their education] [Quote: Vocational job training helps for quick financial independence]
- Inconsistent exercise routines [Quote: Weight management is crucial in DSM]
- Pain associated with BSL monitoring [Quote: Checking BSLs for 3-4 times in a day is really painful]
- Forgetting scheduled check-ups due to daily responsibilities
- Clinics located far from home [Quote: Children with T1DM need to visit endocrinologist and diabetologist as they provide thorough treatment and should avoid going to a general physician] [Quote: It is difficult to find cost-effective adult diabetologist or endocrinologist]
- Heavy family responsibilities
- Presence of immediate health problems, leading some to deprioritize DSM

- Fatigue from demanding work, lack of energy at the end of the day, low motivation, and boredom with the strictness of the instructions made it difficult for them to follow guidelines
- Others: Not enough material/ equipment to comply with these instructions.

BSL Monitoring Patterns

24 (72.72%) participants reported checking their BSLs regularly. 21 (87.5%) of them checked daily and remaining checked either weekly or 4-5 times per week. 10 (30.30%) participants did not check their BSLs regularly. Reasons for irregular monitoring included:

- Inconvenient work hours
- High cost of strips
- Social stigma
- Reluctance due to pain from multiple pricks

One of the participants said “I check BSLs for 3-4 times in a day - almost after every meal.”

BSL Control Status

20 (60.61%) participants reported controlled BSLs (i.e. between 80-130mg/dL before meals and under 180 mg/dL 1-2 hours after meals), while 13 (39.39%) participants reported uncontrolled BSLs. Additional responses included:

- One participant reported high morning and night BSLs
- One participant was depending on physical symptoms instead of monitoring
- Two participants did not respond

Glycaemic control is self-reported and cannot be verified clinically.

Barriers associated with uncontrolled BSLs included (Figure 2):

- Irregular meal timings
- Occupational strain and unstable working hours
- Peer or colleague pressure to consume unhealthy foods
- Laziness or lack of exercise
- Distrust in “healthy” food products
- Stress due to family issues
- Painful pricking or swelling
- Other illnesses

Doctor Visit Patterns

24 (72.72%) participants reported regular doctor visits, while 9 (27.28%) participants did not report regular doctor visit. Those visiting regularly varied in frequency: monthly, bi-monthly, tri-monthly, or six-monthly.

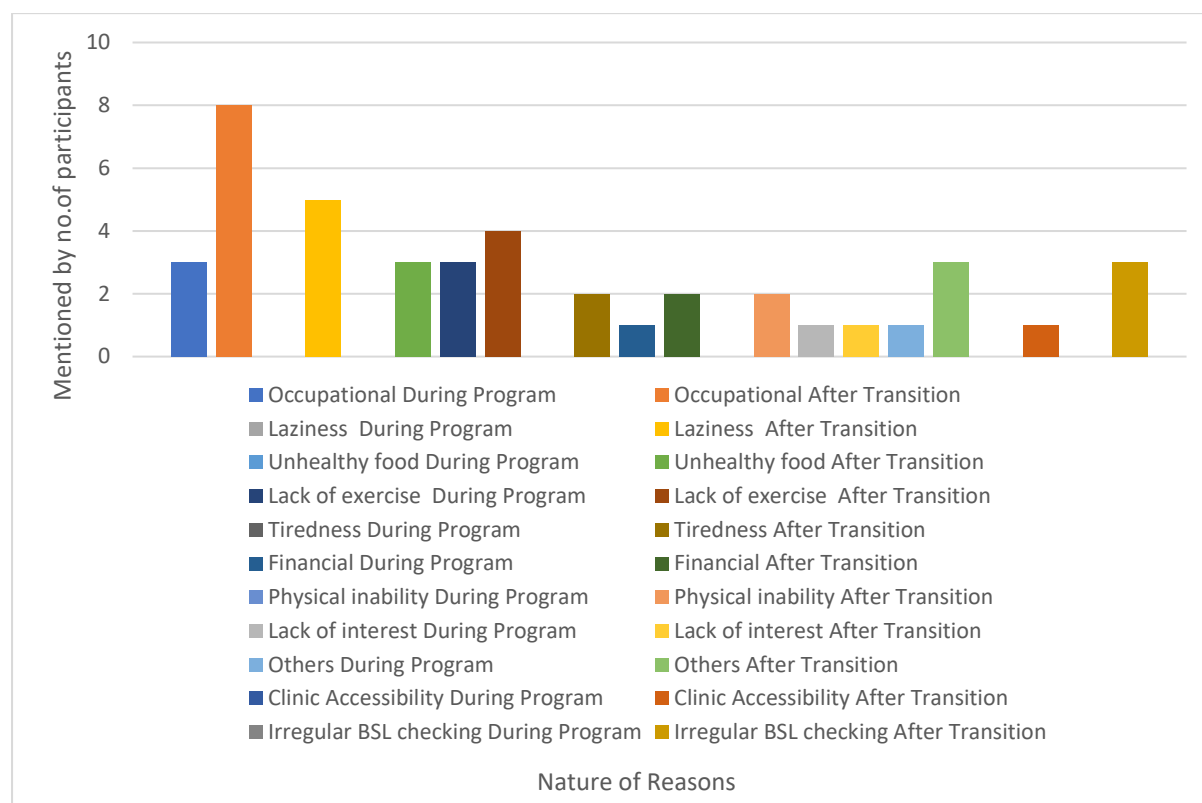


Figure 1. Reasons for non-adherence to the instructions given during the program and after the transition

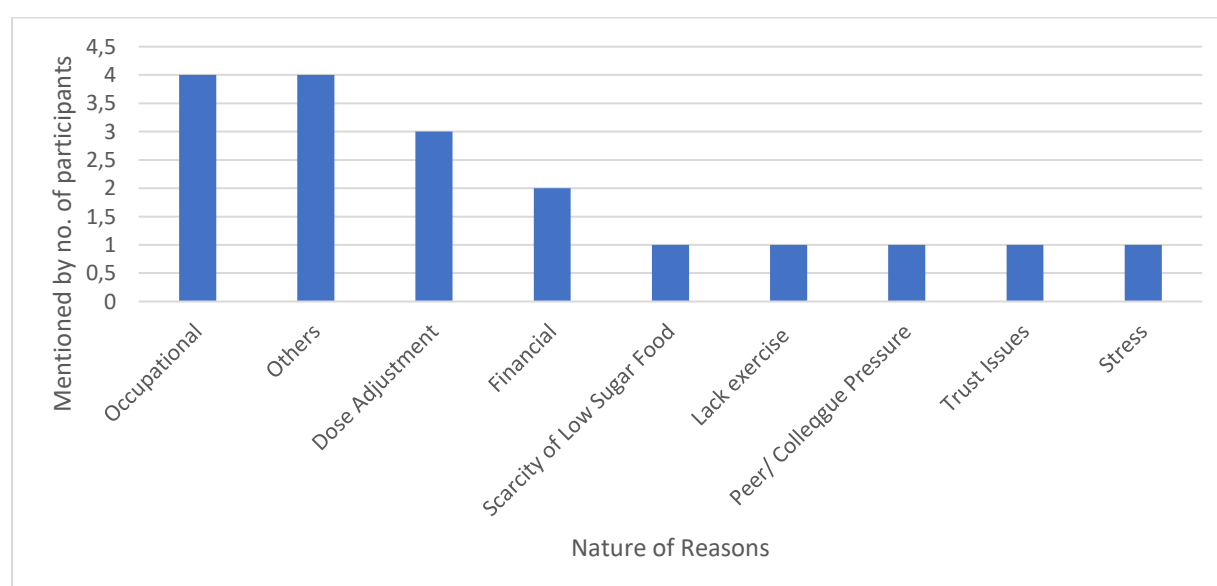


Figure 2. Reasons for Uncontrolled BSLs

Barriers for irregular doctor visits included

- Busy schedules
- High consultation and medication costs
- Long travel distances and poor transportation
- Inconvenient clinic timings
- Social stigma and desire to hide T1DM
- Lack of trust in non-Sweetlings doctors
- Pregnancy, childcare duties
- Absence of recent test reports

Responsibility for Medical Expenditure

Only 12 (36.36%) participants paid for their own medical expenses; 21 (63.64%) participants depended either on family members or on an employer. Financial dependence has direct correlation with reduced DSM. It results in reduced strip use, skipped visits, insulin adjustment, consuming cheap and unhealthy food etc. Feelings of awkwardness about dependence influenced some participants to:

- Reduce BSL checking to save strips
- Avoid doctor visits
- Use less insulin or adjust doses
- Avoid requesting healthy food at home

Patterns of Health-Seeking Behaviour

- 52% did not follow instructions after transition → indicating reduced adherence.
- 61% reported controlled BSLs → indicating awareness of the importance of monitoring.
- 70% regularly visited doctors → suggesting moderate health-seeking behaviour.

Overall, participants remained relatively consistent in BSL checking and doctor visits but showed reduced adherence to dietary, exercise, and lifestyle instructions. One of the participants transitioned to adult care mentioned “sometimes a participant transitioned to adult care is asked to visit the OPD and explain a particular patient about T1DM management. This usually works - the one with poor maintenance is motivated seeing participants of the same age who are successfully maintaining their health.”

Suggestions for improving self-care and diabetes management in this population

17(51.51%) participants mentioned that Sweetlings Program does not need any changes and that they are very satisfied with the program while 16 (48.49%) participants provided their suggestions. These are –

- Psychological and financial counselling should be arranged for the participants especially for those who are going to face the major lifetime shifts such as marriage, child birth etc. Relationship and reproductive counselling sessions are required to address issues related to diabetes, reproductive health, potential risks to offspring, and the hereditary nature of T1DM. Career management and guidance for job search should be provided.
- Support should be decided on financial independence and not on the age. The needy ones should keep getting insulin even after transitioning out as they tend to skip insulin doses due to lack of money and then face serious health complications. Support should be stopped once the participant gets financially independent.
- Help should be provided to finish education.
- Proper guidelines on diet should be given at the time of transition.
- Guidance for overall health management is required at the time of transition.
- Psychological counselling should be provided to overcome various fears related to diabetes. Teenage psychological counselling is also required for lifestyle and diabetes management as this is age where major hormonal changes occur in the body.
- Names of endocrinologists and diabetologists should be suggested for further treatment. Area-wise references of cost-effective adult diabetologist or endocrinologist should be given to those who are transitioned to adult care. Importance of endocrinologists and diabetologists should be described.
- Personality grooming sessions are required to make the children more confident.
- Regular direct communication with children is more important.
- Social stigma about T1DM can be overcome by talking about it. Class teachers and class mates of a child with T1DM should be made aware about what T1DM is and how to take care of a child with T1DM. General awareness of people surrounding the child with T1DM is also important for social acceptance. Awareness sessions should be arranged to explain the difference between T1 and T2 diabetes. Such awareness will help others to create empathy. Also, preventive measures and emergency actions shall be taught through these sessions, it might save someone's life.
- Support children in developing acceptance of their T1DM and confidence in discussing their condition openly.
- Provide counselling to parents to encourage supportive, non-stigmatising behaviours and to strengthen their capacity to assist their child's long-term development. Parents should be

reassured about the nature and management of T1DM to reduce fear and anxiety following diagnosis.

- T1DM creates problems in education, occupation, service and marriage. Teach children and their parents to manage the condition without stress.
- Bone density of transitioned adults, at least for spine, should be done for free once in every year.
- Every transitioned adult should be provided with unique diet and medicine plan as not all of them have a fixed routine – some live in hostels, some travel a lot, some work in shifts etc. So, all these conditions should be considered before giving diet plan and medicines.
- Incorporate age-appropriate recreational or engagement activities within the OPD setting to create a child-friendly environment. Such initiatives may help reduce anxiety and stress associated with T1DM and routine clinic visits for both children and their parents.

This study explored the experiences of Sweetlings participants as they transitioned from a structured paediatric T1DM program to adult care, with particular focus on changes in self-care, adherence patterns, and barriers to DSM. It also explored suggestions for improving self-care and diabetes management in this population. The integrated findings show a clear and consistent pattern: while participants demonstrated relatively strong DSM during the Sweetlings Program, the transition to adult care was accompanied by a substantial decline in supervision, support, and routine, leading to poorer adherence and increased difficulty maintaining glycaemic control. These findings closely mirror national and international evidence, which consistently reports deterioration in glycaemic control, clinic attendance, and DSM behaviours following transition to adult care (25–27). However, the present study extends existing evidence by providing insight into the lived experiences of young adults with T1DM transitioning from a structured paediatric support program within an Indian LMIC.

A key finding relates to the profound difference in supervision between the two care settings. During the structured paediatric support program, intensive monitoring, reminder calls, accessible physicians, and ready availability of supplies created a highly organised environment that reinforced DSM. After transition, participants were required to independently schedule appointments, remember tests, and manage their own supplies. This shift reflects a broader challenge seen in other T1DM transition studies, where the sudden withdrawal of structured supervision contributes to disengagement, irregular follow-up, and disrupted routines. Research from India and other LMIC contexts similarly reports that reduced provider engagement and abrupt autonomy are major contributors to poor transition outcomes (28). The results also highlight the importance of self-control and structured routines. Participants described self-control about diet, insulin timing, and lifestyle behaviours as highly dependent on the external structure provided by the support program. Once this structure was removed, many struggled with irregular meal timings, unhealthy food consumption (often linked to work demands or peer pressure), and inconsistent exercise. These findings suggest that successful DSM during adolescence may depend substantially on external reinforcement systems, which may become difficult to sustain once young adults transition into more independent and demanding social and occupational roles. These

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behavioural challenges combined with occupational constraints such as busy shifts, long travel times, and fatigue emerged as dominant barriers to DSM in adult care. Such behavioural disruptions have been similarly documented internationally, where adolescents frequently report difficulty maintaining dietary discipline, exercise routines, and insulin adherence in unsupervised adult care environments (29,30).

The loss of psychological and social counselling surfaced as one of the most significant changes affecting participants. Counselling during the Sweetlings program served multiple functions: helping children cope with diagnosis, addressing fear of pricking, supporting parents, and reducing school-based stigma through teacher and peer engagement. After transition, participants found it difficult to access comparable counselling services and continued to rely informally on Sweetlings counsellors. This finding highlights the possibility that continuity of emotional support and trusted provider relationships may play an important role in sustaining long-term engagement with DSM behaviours. This reflects the critical role of psychosocial support in sustaining long-term DSM behaviours, especially during adolescence and young adulthood when emotional and social pressures are high. International studies have reported that structured psychosocial support significantly reduces diabetes distress and improves glycaemic outcomes during transition (31,32). The findings further illustrate the strong influence of occupational and financial barriers. Irregular working hours, unstable employment, heavy workload, and long commutes directly disrupted dietary routines, BSL monitoring, and clinic attendance. Financial dependence and the high cost of doctor consultations, insulin, strips, and “healthy” foods caused participants to consciously reduce BSL checks or adjust insulin doses to save resources. National studies similarly highlight ‘cost’ as one of the largest barriers to T1DM management in India, where families often face catastrophic health expenditure for insulin and monitoring supplies (33,34). Many financially poor families have to compromise with the insulin over food for family. Feelings of embarrassment or awkwardness about family members bearing medical expenses further influenced DSM decisions. These patterns are consistent with evidence from other LMIC contexts, where financial strain frequently leads to reduced adherence in chronic disease management. Social stigma also emerged as a meaningful barrier. Some participants avoided doctor visits or BSL monitoring to hide their condition due to past experiences of teasing or exclusion. Trust issues with non-Sweetlings doctors further hindered healthcare utilization, suggesting that continuity of relationships — rather than mere transfer of care — is vital in maintaining engagement with adult services. This finding echoes studies from India, the Middle East, and parts of Africa, where stigma continues to play a major role in diabetes concealment and delays in care-seeking (35,36). The quantitative patterns reinforce these qualitative findings. The proportion of participants not following instructions increased from 24.24% (8 participants) during the program to 54.54% (18 participants) after transition, indicating diminished adherence. Despite this, 60.60% (20 participants) reported their BSLs as controlled and 69.70% (23 participants) reported regular doctor visits, suggesting that certain DSM behaviours — especially those central to immediate health — were retained more successfully than others. Participants were more likely to maintain BSL monitoring and doctor visits than dietary adherence, exercise, or other lifestyle practices, indicating an uneven pattern of health-seeking behaviour. Similar selective adherence patterns have been reported in Canadian, UK, and

Australian cohorts, where blood glucose monitoring was better maintained than lifestyle behaviours post-transition (37,38).

Overall, the findings demonstrate that transition to adult care represents a period of vulnerability for young adults with T1DM, particularly in contexts where adult services are less integrated, less supervised, and less psychosocially supportive than paediatric programs. The themes that emerged — supervision, self-control, counselling, occupation, financial status, and discomfort about expenditure — collectively shape DSM behaviours and must be considered when designing transition support systems. This aligns with global recommendations calling for structured transition programs that include multidisciplinary coordination, psychosocial support, and extended transitional follow-up (29,39). Strengthening transitional care requires addressing these multi-level barriers, recognising that DSM is deeply influenced by structural, emotional, social, and economic contexts rather than individual motivation alone.

Participants suggested several strategies to improve DSM after transition, largely aimed at reducing the financial, occupational, and educational barriers they face. They recommended support in completing education, securing jobs, and achieving financial independence, along with partial assistance for strips, insulin, or tests to ease the cost burden that affects adherence. They also expressed a need for continued dietary guidance and structured diabetes related education to help them maintain consistent routines. Similar priorities for financial and educational support have been highlighted in national and international studies on T1DM transition (27,33). Psychosocial support was the most frequently emphasised need. Participants stressed the importance of counselling to address stigma, confidence, fear of pricking, and major life decisions, and suggested increasing public and school awareness to reduce discrimination. They also valued continuity with caring healthcare providers and recommended youth-friendly OPD environments, referrals to affordable diabetologists, and opportunities for peer mentoring from past Sweetlings participants. These suggestions align with global evidence showing that psychosocial care, supportive clinical environments, and peer support improve DSM in emerging adults (30,31,39).

Strengths and Limitations

Strengths of this study include its in-depth qualitative approach, which allowed for a rich understanding of lived experiences across multiple domains, including supervision, counselling, occupational demands, financial strain, and stigma. The inclusion of detailed participant narratives provided nuanced insights into the complex realities of DSM after transition — an area with limited empirical literature in the Indian context. Additionally, the study uniquely examined the role of a structured paediatric support program, offering valuable evidence on how such models influence long-term self-management.

However, a few limitations must be acknowledged. The study involved participants from a single program, which may limit generalisability to other regions or healthcare systems. Self-reported data may also be subject to recall bias or social desirability bias. Objective clinical measures (such as HbA1c values) could not be collected alongside qualitative narratives, which could have strengthened the interpretation of DSM patterns. Glycaemic control is self-reported and cannot

be verified clinically. Finally, the cross-sectional nature of the study does not allow assessment of how DSM behaviours evolve over longer periods after transition.

CONCLUSION

The findings of this study suggest that young adults with T1DM experienced stronger DSM and health-seeking behaviour during participation in a structured paediatric support program that provided supervision, reminders, and psychosocial support. Following transition to adult care, many participants described difficulties maintaining self-care routines due to reduced supervision, occupational demands, financial strain, stigma, and limited access to counselling and specialist care.

Participants highlighted several strategies that may help strengthen transition care, including continued psychosocial support, financial and educational guidance, youth-friendly clinical services, peer mentoring, and improved referral systems for adult diabetes care. While the findings are based on experiences from a single structured support program and self-reported participant perspectives, they provide important insight into the challenges faced by young adults with T1DM transitioning to adult care in an Indian LMIC context. These findings may help inform the development of more supportive and context-sensitive transition-care models for young adults with T1DM.

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