



St. Paul Hospital Millennium Medical College

Graduate Study Program

Lived Experiences of Adolescents with Type 1 Diabetes Mellitus on follow-up at
SPHMMC

By: Genet Mulugeta (MD, Pediatric resident)



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Clinical Advisor: Dr Bereket Fantahun

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requirements for the Certificate in Pediatrics and Child Health

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ABSTRACT

Introduction: Type 1 diabetes mellitus (T1DM) is an autoimmune condition affecting children and adolescents, requiring lifelong management through insulin, monitoring, and lifestyle adjustments. Parental support is crucial for younger children, while adolescents face challenges in self-care, emotional well-being, and social stigma. Beyond medical treatment, considering the psychosocial elements help to improve health outcomes and develop targeted support strategies.

Objectives: This study was conducted to explore the lived experience of adolescents with type 1 DM on follow-up at St Paul's Hospital Millennium Medical College pediatric diabetic clinic, Addis Ababa, with on December 1, 2025, to December 30, 2025.

Methodology: A qualitative phenomenological study was conducted at the SPHMMC diabetic clinic from December 1, 2025, to December 30, 2025, to explore the lived experiences of adolescents with type 1 diabetes, focusing on psychosocial and economic perspectives. A purposive sampling method was employed to select participants. The lead investigator collected data through in-depth interviews, utilizing an audio recorder and an interview guide. Thematic analysis was used for data interpretation, facilitated by Atlas.ti software version 7.

Result and conclusion: The psychological experiences were psychological problems due to diabetes (fear, anger, stress, and giving up) and coping strategy (being alone at home, taking candy, family support, health professionals support and stick with religious activity). Identified social experiences influence social participation, disclosure status, social isolation, stigma, social support and influence on education. Further quantitative research should be conducted to describe the factor affecting adolescents with type 1 diabetic mellitus

Time frame – September 2025 to January 2026.

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Keywords – Diabetes mellitus, Adolescents, Lived Experience, SPHMMC

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Contents

ABSTRACT.....	4
ACKNOWLEDGEMENT.....	5
ABBREVIATIONS AND ACRONYMS	8
1 INTRODUCTION	1
1.1 Background of study.....	1
1.2 Statement of the problem.....	2
1.3 Significance of the study	3
2 LITERATURE REVIEW	4
3 OBJECTIVES.....	7
3.1 General Objective	7
3.2 Specific Objectives.....	7
4 METHODS AND MATERIALS	8
4.1 Study area.....	8
4.2 Study design	8
4.3 Study period	8
4.4 Source population & Study population	8
4.5 Inclusion and Exclusion criteria	9
4.6 Sample size determination & Sampling procedure.....	9
4.7 Data collection and Procedure.....	9
4.8 Data quality control.....	9
4.9 Methods of data analysis and interpretation.....	9
4.10 Ethical considerations	10
4.11 Operational definitions	10
4.12 Dissemination of results.....	10
5 Result and discussion	11
5.1 Participant characteristics	11
5.2 Psychological experience.....	12
5.2.1 Psychological problems due to diabetics.....	12
5.2.2 Coping Strategy for Psychological Problems.....	14

5.3 Social Experience Related to Diabetes mellitus	15
5.3.1 Influence on Social Participation.....	15
5.3.2 Disclosure Status, Social Isolation, and Stigma.....	15
5.3.3 Social support.....	17
5.3.4 Influence on education	17
5.4 Health facility experience.....	18
5.5 Economic experience	19
6 Discussion and conclusion.....	20
6.1 Discussion	20
6.2 Conclusion	21
6.3 Recommendation	22
7 Reference	23
8 APPENDIX	24
9 8. APPENDIX.....	27

ABBREVIATIONS AND ACRONYMS

ADA- American diabetes association

ATLAS - Archive of Technology, Life world and Language

CPMS- childhood psychopathological measurement schedule

DM – Diabetes mellitus

IDF- International Diabetes Federation

ISPAD – International society for pediatric and adolescent diabetes

PRISMA-ScR -PRISMA extension for scoping reviews

SPHMMC – St. Paul’s Hospital Millennium Medical College

SPSS – Statistical Package for Social Science

T1DM- Type one diabetes mellitus

USD – United states dollar

1 INTRODUCTION

1.1 Background of study

Type 1 diabetes mellitus (T1DM) is a prevalent chronic illness that primarily impacts children and adolescents. Over recent years, its incidence has been on the rise across the globe. Currently, an estimated 1.1 million young individuals live with this condition. While it can develop at any stage of life, it is most diagnosed during childhood or adolescence[1]. Type 1 diabetes mellitus (T1DM) is a lifelong autoimmune condition in which the body's immune system targets and destroys pancreatic beta cells. This leads to a complete deficiency of insulin, the hormone responsible for regulating blood sugar levels[2, 3].

While effective management can enable them to lead healthy and fulfilling lives, the journey beyond diagnosis presents significant challenges. Even with access to proper healthcare, T1DM remains a demanding condition that requires continuous monitoring and adherence to treatment protocols[4].

Successful glycemic control hinges on a combination of self-care measures, including regular physical activity, carefully planned meals, consistent blood glucose monitoring, and the appropriate storage, preparation, and administration of insulin. In younger children, achieving optimal blood sugar levels is strongly linked to parental support and involvement in disease management. Further, during adolescence, responsibility for diabetes management is slowly transferred from parents to the adolescent. This often causes difficult changes in intra-familial roles, potentially leading to conflicts within the family. However, adolescents with T1DM often struggle to maintain stable glycemic levels as they are a transformative stage in life, marked by significant physical, cognitive, emotional, and social development. A strong desire to fit in with peers emerges, making any perceived differences feel isolating or unwelcome[1, 4-7].

This shift often results in psychosocial challenges of anxiety, depression, and stress. studies have indicated that T1DM patients have 2–3 times more risk of depression than healthy individuals, partly attributed to maladjustment in daily routines. Stress and anxiety have been reported to decrease adherence to treatment among T1DM children and adolescents[8].

While achieving biomedical targets is a crucial aspect of management, it is equally important to consider the psychosocial elements that influence self-care. Emotional well-being, social support, and personal coping mechanisms play a significant role in ensuring consistent disease

management. Additionally, research has documented the presence of diabetes-related stigma in various parts of the world, which can negatively impact individuals' confidence in managing their condition. While shared responsibility between parents and teens is associated with increased metabolic control and more positive health outcomes[4, 9].

Recognizing the complexities of living with T1D during adolescence, efforts should be made to gain nuanced information from adolescents so that comprehensive support strategies can be developed to meet the changing needs of this population. Qualitative inquiry is a valuable tool for exploring the lived experiences and coping mechanisms of adolescents with T1D, and provides insights that inform the development of targeted interventions and support services[10].

1.2 Statement of the problem

Type 1 diabetes mellitus (T1DM) is a growing global concern, with a prevalence of 12.12% among children and adolescents worldwide, 4.5% in South Africa and 2.4% in Ethiopia, according to the International Diabetes Federation (IDF) 2021 report.

The disease significantly impacts life expectancy, quality of life, and socioeconomic stability, particularly in low- and middle-income countries. In 2015, diabetes accounted for 1.5 million deaths globally, including 321,100 fatalities across Africa.

Managing T1DM presents medical, emotional, and financial challenges. Affected individuals often experience stigmatization, limited healthcare access, and reduced social participation, all of which contribute to lower education levels, higher unemployment rates, and overall economic burden. In 2021, global diabetes-related costs reached \$966 billion, with projections indicating an increase to \$1.03 trillion by 2030. Ethiopia faces additional challenges due to non-adherence to treatment, poor dietary habits, and physical inactivity[11].

While various quantitative studies have examined T1DM in Ethiopia, there remains a lack of qualitative research exploring the psychological and socioeconomic experiences of patients. This study aims to address that gap by documenting the lived experiences of adolescent with T1DM on follow-up at a pediatric diabetic clinic in SPHMMC, providing valuable insights for improving disease management, reducing stigma, enhancing caregiver support, and informing healthcare policies.

1.3 Significance of the study

Type 1 Diabetes Mellitus (DM) is one of the most common chronic diseases in adolescence posing a threat to health and potentially endangering life. However, there is currently no study that highlights their life experiences in Addis Ababa

This study had helped us to Understand the lived experience of an adolescent with type 1 DM in terms of the psychological, social and emotional experience. This had a crucial role in improving healthcare services by gaining insights into daily struggles and needs; healthcare providers can develop tailored interventions that address both the medical and psychological aspects of diabetes care. These interventions can lead to more personalized treatment plans, enhanced patient education, and better overall management strategies that empower adolescents to take control of their health

2 LITERATURE REVIEW

Adolescence is a transitional phase between childhood and adulthood that involves physical, cognitive, social, and emotional changes leading toward independence. It officially defines adolescents as people in the 10–19-year age group.

Type 1 DM in adolescents has negative impacts on their daily activities, personal aspirations, and psychological well-being[7].

Scoping review is reported in line with the PRISMA ScR checklist and Database searches were conducted from a total of 12 studies. The adolescents experienced negative emotions, such as fear, anxiety, irritation, sadness and feeling different from their peers, which disrupted their lives. Adapted support from parents, friends and healthcare professionals is crucial for adolescents coping with T1DM[1].

Meta-aggregate analysis of 14 qualitative studies was performed on the disease experience of adolescent patients with T1DM were obtained from Cochrane, PubMed, Web of Science, CINAHL, Embase, Wan fang, CNKI, and VIP, and the search period was from 1995 to 2024. The 3 overarching findings: (1) experiencing psychological distress and developing coping mechanisms following adjustment; (2) acknowledging self-management shortcomings and actively seeking support; and (3) overcoming challenges and growing through experiences. The findings illuminate that adolescents with T1DM often experience negative physical and emotional challenges during their illness. Transitioning from dependency to independence poses numerous obstacles that can be overcome by improving both internal and external support, cultivating self-management skills, strengthening coping mechanisms, and achieving control over the disease while fostering personal growth[3]

Another database search identified studies conducted between 2004 and 2014, from 5 different countries. Most participants in the studies were adolescents between the ages of 13-17 .Key findings identified were striving for autonomy, parental conflicts, yearning for social acceptance and concerns regarding diabetes education[12].

Qualitative study which was done by Kathryn M. King, Philip J. King, et al, after In-depth interviews were conducted with 20 patients diagnosed with type 1 diabetes in their adolescent years to elicit their views, perceptions, and concerns regarding living with diabetes. The problems experienced by adolescents with type 1 diabetes are multifactorial. Existentially, type 1 diabetes affects their daily activities and impinges on their academic achievement and personal aspirations. Their major fear is of hypoglycemia, resulting in their subsequent focus of preventing hypoglycemic episodes[2].

A qualitative interview study with a hermeneutic approach done in Sweden, between January and September 2017. Research showed that Young peoples' everyday lives were transformed and re-organized by their illness and they paradoxically live a double-edged everyday life[13].

A cross-sectional questionnaire-based study was undertaken to determine the prevalence and spectrum of psychosocial morbidities among 39 pediatric T1DM patients and factors associated with psychosocial distress. Anxiety, conduct disorder, and depression were the most common problems identified. The study revealed a very high prevalence (53.85%) of psychosocial morbidity among T1DM patients[14].

A qualitative exploratory design was employed in three study sites: Mulago National Referral Hospital, Wakiso HCIV, and St Francis Nsambya Hospital in Uganda. Twenty in-depth interviews were conducted. The analysis found that young people living with diabetes experience a new world of adjustments, including insulin therapy, routine blood glucose monitoring, and dietary changes that are often difficult to deal with, especially in the first year after diagnosis. The findings have demonstrated the mixed experiences of newly diagnosed young children and adolescents living with diabetes, from anxiety and stigmatization to independence[9].

A qualitative project on T1DM lived experiences in southern Ghana. The study participants were young persons living with T1DM (n=28) and their caregivers (n=12). Study shows T1DM impacted the schooling of young people living with the disease. The mechanisms of these impacts, and young peoples lived experiences are not art factual, but rather support discourses on health selection and inadequate social support for young people living with the disease. The results call for the need to develop educational and social interventions to address these

barriers[15].

A phenomenological study was conducted among adolescents living with type 1 DM who received medical follow-up in Bahir Dar. This study revealed that adolescents with DM were experienced social, emotional, spiritual and psychological challenges. They also faced issues related to adherence, sleep and insulin availability, as well as a lack of coping strategies. They relied on support from family, friends, school teachers, healthcare providers, and the community. Coping mechanisms such as avoidance, adaptation, and acceptance were utilized to manage their emotional challenges[16]

A descriptive phenomenological study was conducted to explore the lived experience of people with type 1 diabetes in North East Ethiopia, Kemissie General Hospital, A total of 13 participants were enrolled in this study. Fear was one of the psychological experiences felt by people with type 1 diabetes. Being diabetic has a great influence on social participation, as reported by the majority of the respondents. The most common reasons mentioned by respondents were fear of hypoglycemia, feeling tired during the journey, and the food prepared for those special events not being suitable for them. Some of the respondents did not disclose their status to another person except their family, and they performed selective disclosure depending on the situation. The reported reasons for not disclosing their status were fear of stigma, isolation, and dissemination of their diabetic status as secret information to another person[11].

A qualitative study was conducted to explore the lived experience of people with type 1 diabetic in South Africa, Pretoria exploring adolescents' subjective personal, family, school and hospital lived experiences. The study showed that living with type 1 diabetic had negative psychological, school and social impacts[16].

3 OBJECTIVES

3.1 General Objective

- To explore the lived experience of adolescents with type 1 DM at diabetic follow up clinic in SPHMMC, Addis Ababa, Ethiopia, from September 2025 to January 2026

3.2 Specific Objectives

1. To explore psychological experience and coping strategies in the adolescents' daily life and gain an understanding of how these facets are impacted by T1DM in SPHMMC diabetic follow up clinic.
2. To explore social experience including in the adolescents' daily life and to gain an understanding of how these facets are impacted by T1DM in SPHMMC diabetic follow up clinic.
3. To explore economic experiences of the adolescents' daily life and to gain an understanding of how these facets are impacted by T1DM. in SPHMMC diabetic follow up clinic.
4. To explore health facility experience of the adolescents' daily life and to gain an understanding of how these facets are impacted by T1DM. in SPHMMC diabetic follow up clinic.

4 METHODS AND MATERIALS

4.1 Study area

This study was conducted in St. Paul's Millennium Medical College. SPHMMC is the second largest hospital in the capital Addis Ababa with a catchment population of more than 5 million. The hospital was established in 1969 GC by the Late Emperor Haile Selassie and is currently governed by a board under the federal ministry of health. In addition to an inpatient capacity of more than 700 beds, on average 1200 emergencies and outpatient clients are seen daily in the hospital.

The college has clinical, academic and administrative staff that provide medical specialty service including diabetic care to the patients who are referred from all over the country. Pediatric endocrine and diabetic clinic give service throughout the year with two pediatric endocrinologist sub specialists in collaboration with residents and nurses.

4.2 Study design

A qualitative phenomenological design was used to explore the lived experiences of adolescents with type 1 DM on follow-up at SPHMMC

4.3 Study period

This study was conducted from December 1, 2025, to December 30, 2025 G.C.

4.4 Source population & Study population

The source population were all adolescents type 1 DM patients who are on follow-up at diabetic clinic at SPHMMC.

The study population was all adolescents who were diagnosed with type 1 DM and on follow-up during data collection period at SPHMMC.

4.5 Inclusion and Exclusion criteria

Inclusion criteria –

- All type 1 diabetic patients aged between 12-19 years who are on follow-up at SPHMMC diabetic clinic at least for the past 6 months

Exclusion Criteria –

1. Seriously ill people with type 1 diabetes who are unable to communicate at the time of data collection

4.6 Sample size determination & Sampling procedure

Purposive sampling was used to select participants for this study. The sample size was determined based on data saturation, which was evaluated using criteria, like the research questions need to adequately address, complete answers which do not require further clarification and no new information emerging from subsequent interviews

4.7 Data collection and Procedure

Data collection was through face-to-face in-depth interviews using semi-structured guiding questions. The interview guide after developed in English which comprises of socio-demographic, psychological, social, emotional, and economic impact and diabetic follow up clinic visit experience then was translated into Amharic and Afan oromo for better understanding

The principal investigator (PI) conducted all the interviews. Meetings were scheduled at times convenient for participants once they agreed to participate in the study.

4.8 Data quality control

To ensure the quality of the research findings, the PI was considering different sets of criteria focusing on the credibility, dependability, transferability, and conformability of the study using various techniques based on Lincoln and Guba's criteria

4.9 Methods of data analysis and interpretation

Thematic analysis was used to analyze the data. Initial and line-byline coding systems as well as value-coding methods were used. Based on the relationship between the codes, sub- themes were

developed. Then, the main themes were constructed by combining the subthemes. The analysis of data were facilitated by the usage of Atlas.ti software version 7.

The generated data was compiled by frequency tables.

4.10 Ethical considerations

Participants were informed about the study and confidentiality was maintained. Participation in the study was completely voluntary and Informed consent before interview was taken. The thesis was submitted and clearance was sought from the ethical committee of SPHMMC.

4.11 Operational definitions

Lived Experience – The personal subjective experiences, perceptions, and emotions of adolescents managing Type 1 Diabetes Mellitus (T1DM) in their daily lives, including medical, psychological, social, and economic aspects

Adolescent -All individuals aged from 12 to 19 years old.

4.12 Dissemination of results

After the data is analyzed, the results of the research were presented to SPHMMC's department of pediatrics and child health. The findings were sent for publication in relevant scientific journals so that they can be useful for other academic researchers and clinical practitioners. They might also be presented on different conferences and professional society meetings like Ethiopian Society of pediatrics and child health. The data can also serve as a base line for future studies

5 Result and discussion

5.1 Participant characteristics

From 16 participants 9 were females and the rest 7 participants were males. The mean and median ages of participants were 15.81 and 15 years respectively. The educational statuses of the participants ranged from grade 6 to grade 12. The mean and median duration of diagnosis of diabetics in years was 7.2 years and 7 years respectively. Depth interviews were conducted at silent areas with adolescent participants. Some of economic experience interviews were conducted with their parents/caregivers.

Table 1 Participants demographic and economic characteristics of living experience of type 1 diabetic mellitus at SPHMMC 2026G.C

Cod e	Sex	Ag e	Reside nce	Religion	Educatio nal status	Education al status of mother	Education al status of father	Occupation of father	Occupatio n of mother	Averag e monthly income	Duratio n of diagnos is
01	Femal e	17	Urban	Muslim	10	8	10	Private	Privat	4000	14
02	Male	16	Urban	orthodox	9	8	12	Pension	Housewif e	10000	4
03	Femal e	18	Urban	Protestant	11	Diploma	12	Driver	Teacher	40,000	12
04	Male	15	Urban	Orthodox	10	10	8	Merchant	Merchant	3000	3
05	Femal e	18	Urban	Orthodox	12	4	Read and write	Merchant	Merchant	50000	6
06	Male	18	Urban	Orthodox	12	8	12	Driver	Housewif e	25000	6
07	Femal e	14	Urban	Protestant	8	Read and write	Can't read and write	–	Housewif e	7000	6
08	Male	13	Urban	የዩኒ ቨክስቲያን	7	12	12	Driver	Private	12000	4
09	Femal e	16	Urban	Orthodox	11	6	6	Governmen tal	Out of country	10000	8
10	Femal e	14	Urban	Protestant	8	5	Degree	Governmen tal	Governm ental	15000	10

11	Female	14	Urban	Orthodox	8	12	12	Merchant	Merchant	20000	5
12	Male	12	Urban	Muslim	6	5	5	Merchant	Housewife	25000	10
13	Female	18	Urban	Orthodox	12	12	12	–	Housewife	5000	6
14	Male	15	Urban	Protestant	9	Degree	Masters	Governmental	Teacher	60000	5
15	Male	17	Urban	Orthodox	10	6	8	Merchant	Housewife	25000	4
16	Female	18	Urban	Orthodox	12	Masters	12	Daily labor	Teacher	7000	10

The findings from in-depth interviews were organized and presented through themes, sub-themes, and categories. Analysis of the data identified different interrelated themes that reflect the lived experiences of adolescents with type 1 diabetes mellitus.

These themes include:

Psychological experience, encompassing two sub-themes psychological challenges associated with diabetes and coping mechanisms for these challenges, healthcare service experience, economic experience and social experience, which is divided into four categories: effects on social participation, experiences of isolation and stigma, availability of social support, and influence on educational opportunities.

5.2 Psychological experience

5.2.1 Psychological problems due to diabetics

Majority of respondents felt nothing or no reaction when they said that they have diabetes mellitus because they were little children who did not know about the disease and were not considered it as a lifelong illness. But when they knew that it was not curable, some of them felt angry and stressed.

“When I was first diagnosed with diabetes mellitus, I didn't feel anything because I was a child. I didn't know anything about diabetes, so I didn't know that it would be with me for the rest of my life. But as I had known about the disease and started taking medication, I had started to feel a little bad when I stopped eating sweets.”

Code 1 female respondent

“During initial diagnosis I felt nothing when the doctor said that I had diabetes mellitus, because I was little child who did not know about diabetes mellitus and were not considered it as a lifelong disease. When I knew that was an incurable disease, I felt angry and stressed.” Code 3 female respondent

“When the doctor told me that I had diabetes, I did not feel bad because my family told me it is curable, but when some foods are restricted and knew it is lifelong disease, I had felt bad and during this time I became careless, start to take sweet foods carelessly.” Code 8 female respondent

Negative emotion was one of the psychological problems felt by some of the respondents during their first diagnosis of diabetes mellitus. Some of them felt shocked, cried, and scared during the initial diagnosis. The reasons for negative emotions reported by some of the respondents were that they considered the disease as a killer which had make them felt like they were going to die soon and that they couldn't live. Assuming that felt like they were dependent on their family for injections every day. However, few of the respondents had history of diabetics' mellitus in their family and they had known challenged life in their family. They considered diabetes is a serious disease that prevented them from daily activity.

“Initially I knew that I had diabetic when went to health facility for other medical care, when the physician had told me I shouted, stressed and angry, because it has incidentally occurred. The reason to went to health facility was abdominal discomfort at the time tested and had diabetic.” Code 4 male respondent

“When I was first told that I had diabetes, I was very scared. I felt like I was dependent on my family and I thought that injectable drugs had given every day. But when I saw the syringe, I calmed down because syringe was smaller in size.” Code 15 male respondent

“When the doctors told me that I had diabetes and could only be treated with injectable drug, I felt like I was going to die soon and that I couldn't live.” Code 16 female respondent

Some adolescent thought that they had diabetes because their family did not protect them from the things that can cause it. They had said that our family were accountable to this illness. In addition, they also thought that their diabetics come from family related.

“When I look at my childhood photos, I was very fat; I was the only child in the family, so they Care and maintain me and didn't stop me from eating whatever I want. And because of that, I became diabetic; there is also another reason, which is there are diabetics in our family, namely my uncle and my grandmother. If my family had known about diabetics, I wouldn't have diabetes mellitus.” Code 1 female respondent

Majority of respondents had feared of diabetic complication and lifelong medication.

“I am afraid of the things that can cause me to worry, such as blindness, kidney disease, heart disease and leg amputation.” Code 13 female respondent

5.2.2 Coping Strategy for Psychological Problems

To cope with psychological problems, some of the respondents take prescribed drugs to live harmoniously with the disease and taking traditional medicines like ‘abish’ but a few respondents did not do anything to manage negative feelings.

Some of respondents keep kermila/candy in their bag and they took it when symptom of hypoglycaemia had seen.

“I take it from keremila when my blood sugar levels drop. During the holidays, there are a lot of cakes and other sweets, so I don't eat these foods.” Code 12 male respondent

Other respondents tried to manage the situation by playing with friends, being alone at home, and seeking support from family and health professionals.

“When I am getting angry, my mother reassure me to keep quiet about what is going on, and she says why I am worried since she and my brothers are here for me.” male respondent

“I have learned at governmental school, which the governments provide breakfast and lunch service, but some restricted food is given to us. This challenged me. I had not eaten the school food.” Code 6 male respondent

“Every person does not want to have the disease, but it is forced on by the will of God, so I accept and tolerate it. I perform spiritual activities and praying to cope with those negative feelings.” Code 10 female respondent

5.3 Social Experience Related to Diabetes mellitus

5.3.1 Influence on Social Participation

Being diabetic has a great influence on social participation, as reported by the majority of the respondents. They did not attend social gatherings such as wedding ceremonies, birthday ceremonies, holiday ceremonies and other ceremonies at home. The most common reasons mentioned by respondents were fear of hypoglycemia, fear of trauma this leads to foot ulcers, feeling tired during playing, and the food prepared for those events not suitable for them.

“I eat alone at school because my friends can eat sweet foods, so I don't have to eat with them. Even though I take keremila when my blood sugar levels drop. But during the holidays and other ceremonies even if so much sweets are available, I don't eat these foods. My family helps me a lot to study, to do my best and by eating same food which is allowed for me” Code 12 male respondent

“I didn't play much with my friends and had easily fatigability. Living with diabetes affects personal feelings. When I went to other places like visiting relatives or any other programs I must held my insulin injections, this gave me the discomfort because I didn't want to show it to others.” Code 4 male respondent

“I eat sweets during holidays and when I have programs at home. I had known it was a fault, and the consequences would be seen next week, i.e. my blood sugar level will increase. During this time, I am taking right medicine and avoiding forbidden foods. The food prepared during the holidays also leads to increase blood sugar and other diseases. During the holidays, I often get intestinal diseases, amoeba, and giardia.” Code 1 Female respondent

5.3.2 Disclosure Status, Social Isolation, and Stigma

Majority of respondents disclosed their diabetes status to their relatives, friends, and neighbors. Disclosing their status was beneficial for some respondents to get social support.

“My school friends and the people in the neighborhood know that I have diabetes, and no one has ever

discriminated me. Being diabetic has no special impact on me. I am afraid of the things that can cause me to worry, such as blindness, kidney disease, and leg amputation.” Code 13 female respondent

“My friends know about the illness and during illness my friends take me to clinic and give support. My family supports me by remembering medication time and preparing good foods at home. At time of holiday and wedding I hadn’t taken sweet and fatty foods.” Code 2 male respondent

Few of the respondents did not disclose their status to another person except their family, and they performed selective disclosure depending on the situation. The reported reasons for not disclosing their status were fear of stigma, isolation, and dissemination of their diabetic status as secret information to another person.

“Except for one of my classmates, my classmates don't know that I have diabetes, and I don't want them to know about my illness. I don't tell them because I afraid of that they might criticize me if they know. I often get sick, but even if they insist on asking me why, I don't tell them.” Code 11 female respondent

“My friends don't know that I had diabetes. Because if I disclose it, they may stigmatize me. But the school doctor knows. I am at the same school with my brother, so he will help me if something wrong happens .” Code 15 male respondent

Social isolation and stigma were among the reported social problems of participants. Few participants faced social isolation imposed by others. The major reasons for social isolation are reported by participants being unable to drink and eat food together, being unable to work together, and even not being able to discuss things with them.

“My friends think that I am not equal to others. They think as if I am not doing anything, not working, not able to learn because of diabetics. Living with diabetics affects my personal feeling; some people think it is a transmitting disease from person to person. They don’t understand it. Some people don’t want to get closer to me. But Some friends are understanding and support me in the case of illness. My family is supportive, especially my grandmother she remembers me every things about the follow up, medication timing and what to eat and not to eat. “Code 8 male respondent

Social stigma was another problem faced by participants. Some participants verbalized that they kept their diagnosis a secret from neighbors and friends to avoid diabetes-related stigma. Participants were very secretive about their health. They told only the closest family members whom they could trust. The participants feared that disclosure would result in losing friends or becoming socially isolated. They just wanted to be alone to avoid being confronted with stigma.

“I had felt like I was different from my friends in the first time. When my mother had told my teachers that I had diabetes, I suddenly felt sad. And I would be very angry, saying that if my friends knew about my illness. When my friends first heard about it, they stigmatized me. The reason was that they thought diabetes can transmitted from person to person, but after a few days they have started to know about disease. Now they are very supportive to me.” Code 1 female respondent

5.3.3 Social support

Majority of respondents had supportive family members who knew about diabetic illness. Majority of respondents said that support from family members plays a crucial role in managing diabetic illness. Because of support from family members and friends they had eaten appropriate food, took medicine at appropriate time and controlled diabetic mellitus.

Majority of the patients claimed that receiving social support inspired them to lead healthy lifestyles and reduce psychological issues. In addition to the family, some respondents received support from friends, teachers' neighbors, and health professionals.

“When I'm with my friends, I don't feel anything. I feel like I can live like them. My friends know that I have diabetes. They support me, they know that I have it, they help me and advise me. They don't isolate me.” Code 12 male respondent

5.3.4 Influence on education

Few respondents reported that diabetics had influence on their education. Few respondents reported that they drop out from school because of diabetics; the reasons were hospitalization, frequent complication and frequent absence from school.

“Living with diabetes affects my education, in the past two weeks I went to school only two days.” Code 8 male respondent

“Living with diabetes affects my education. I had doubling grade seven and grade eight because I had been admitted to hospital for a long time. ” Code 7 female respondent

Some respondents reported that diabetes had no influence on education. Living with diabetes has no influence on education, the reason is that the teachers, classmates and family members support them during missing classes. They reported that they read books and classmates notes during diabetic follow up day.

“When I came to hospital, I was very disappointed because I missed class. But I am trying to study by reading books and so far, I have not had any problems with my education. ” Code 12 male respondent

“Living with diabetes did not affect my education. I did not show my problem to others; the reason is not clear. In school time no problem happens.” Code 5 female respondent

5.4 Health facility experience

Majority of respondents had reported that they liked health facility service, doctors’ behavior, ways of understanding and even the health professionals had helped financially.

Few respondents had negative experiences with health facilities. They think that the long waiting time at service point, system interruption, lack of communication of physicians and they don’t listen appropriately.

“The health professional didn’t give medication appropriately; the drugs are not available at health facility. System interruption. The doctors said the drug had been sent to pharmacy via the system, but the pharmacist responded that it was not sent.” Code 4 male respondents

“I understood what the doctors told me, but I felt the doctors didn’t understand me. I didn’t want to take insulin injections at school, because I thought that my classmates would stigmatize me if they knew about my condition. So even though insulin is prescribed as 3 times per day, but I only took the morning and evening doses, because of school time. I have missed one times every day.” Code 4 male respondent

“Some doctors don’t understand even when I tell them my feelings. The time given to us with doctors is too short.” Code 6 male respondent

5.5 Economic experience

All respondents were in adolescent age group, and they were dependent on their family income. Majority of economic experience responses were received from family members. Majority of respondents had no economic influence for their diabetic care. The reason is that they had community-based health insurance and a member of diabetic society, and they reported that diabetic medication and testing cost, for monitoring glucometer and strips cost had been covered by community-based health insurance and diabetic association.

“The Community based Health Insurance and the Diabetes Association provide sufficient assistance, so it has not put any strain on our family economy. In particular, the Diabetes Association is helping us financially and by providing awareness about diabetes once a month.” Code 10 female respondent

Few respondents were reported that diabetic had influence on their family income, the reason is the high cost of testing and medications. In addition, caregivers must take time off to manage repeated hospital admissions, which often leads to job loss. As a result, the family has experienced significant financial strain.

“Living with diabetics affects my family income and it affects my mothers work time”. Code 7 female respondent

6 Discussion and conclusion

6.1 Discussion

In this study, adolescents living with type 1 diabetes were afraid, which arises from fear of complications such as amputation, kidney disease, heart disease and blindness. Fear also arises from acute complications, such as the fear of hypoglycemic episodes. This result is similar to studies conducted in Denmark that the major fear is hypoglycemia, resulting in their subsequent focus of preventing hypoglycemic episodes[2]. This might be due to the proper understanding of diabetic patients about the complications of diabetes, which may restrict their social participation and limit routine activities that can reduce the quality of life of adolescents living with diabetes.

In this study negative emotions were one of the psychological problems felt by some of the respondents during their first diagnosis of diabetes. Some of them felt shocked, cried, and scared during the initial diagnosis. The reasons for negative emotions reported by some respondents were felt that they had been dependent on their family, fear of diabetics, fear of complication, fear of drug by injection, fear of social isolation and fear of stigma by their friends. This study was similar to the study conducted in western countries the adolescents experienced negative emotions, such as fear, anxiety, irritation, sadness and feeling different from their peers, which disrupted their lives[1, 4-7]. This study was also similar to a study conducted among adolescents living with type 1 DM in Bahir Dar showed that adolescents with DM experienced social, emotional, spiritual and psychological challenges. They relied on support from family, friends, school teachers, healthcare providers, and the community[7].

In this study respondents did not attend social gatherings such as wedding ceremonies, birthday ceremonies, holiday ceremonies and other ceremonies at home. The most common reasons mentioned by respondents were fear of hypoglycemia, fear of trauma this leads to foot ulcers, feeling tired during playing, and the food prepared for those events not suitable for them. This study similar to the study conducted in England, being diabetic has a great influence on social participation. The most common reasons mentioned by respondents were fear of hypoglycemia, feeling tired during the journey, and the food prepared for those special events not being suitable for them[11]. This might be due to fear of isolation, stigma, and the fact that the food prepared for the special social events was not suitable for diabetic patients, which inhibits their participation in the social events.

In this study majority of respondents disclosed their diabetes status to their relatives, friends, and neighbors. Disclosing their status was beneficial for some respondents to get social support. Even if few respondents did not disclose their status to their illness this study contradicts the study conducted in England, they did not

disclose it to their friends and their neighbors. The reported reasons for not disclosing their status were fear of stigma, isolation, and dissemination of their diabetic status as secret information to another person[11]. This might be due to their interest in protecting themselves and their families from stigmatization by either isolating themselves or not disclosing their diabetes status to society.

In this study few respondents reported that diabetics had influence on education. Few respondents reported that they had school drop out because of diabetics; the reasons were hospitalization, frequent complication and frequent missing of classes. This study was similar to study conducted in Ghana shows that living with diabetics influenced the schooling of young people living with the disease[15].

In this study majority of respondents had no economic influence on their diabetic care. The reason is that they had community-based health insurance and a member of diabetic society, and they reported that diabetic medication and testing cost had been covered by community-based health insurance and diabetic association. This study was contradict to study conducted in south Africa showed that living with diabetic had influenced on family income[16]. This might be due to community-based health insurance, and a member of diabetic society had started currently in Ethiopia.

In this study majority of respondents had reported that they liked health facility service, doctors' behavior, ways of understanding and even the health professionals had helped financially. But few respondents had negative experiences with health facilities. They think that the long waiting time at service point, system interruption, lack of communication of physicians and they don't listen appropriately. This study had a little contradicting study conducted in Europe that have great difficulty coping with their health status and highlight a lack of empathy from health care professionals[2].

6.2 Conclusion

In this study, the lived experience of adolescents with Diabetes in Saint Paul's Hospital Millennium Medical College was addressed in terms of the psychological, social and economic experience of adolescent with Diabetes. The psychological experiences were psychological problems due to diabetes (fear, anger, stress, and giving up) and coping strategy (being alone at home, taking candy, family support, health professionals' support and stick with religious activity). Identified social experiences were influence on social participation, disclosure status, social isolation, stigma, social support and influence on education (dropping out of school and repeated absences from school). Identified economic experiences were for majority did not significantly affect their family income. This was largely attributed to the availability of community-based health insurance and support from the Diabetes Association .However, some experienced financial strain due to diabetes-related care (costs

of medications and testing,difficulty in participating income generating work).Identified health facility experience were majority had positive experiences with appreciated(the quality of services, the behavior and understanding of doctors, and the financial support) and challenges identified were (long waiting time, interruptions in service, poor communication from physicians).

While type 1 diabetes is primarily a biomedical condition, it also brings significant psychosocial and economic challenges that demand a comprehensive approach. Therefore, healthcare professionals should enhance programs for disseminating health information.

6.3 Recommendation

Health professionals should strengthen health education to reduce negative emotions of adolescents living with diabetic mellitus.

Further quantitative research should be conducted in order to describe the factor affecting adolescents with type 1 diabetic mellitus.

7 Reference

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8 APPENDIX

Appendix 1. Information sheet

The purpose of this data collection tool is to capture data regarding the lived experience of adolescents with type 1 DM at diabetic follow up clinic in at SPHMMC. This structured data collection tool will use primary data from the participants of this study and it will take 40-60 minutes to complete the data collection process on each interview and it will be collected by the primary investigator using a semi structured, in-depth interview guide .The information gathered from the patients will be very important in the realization of this study. The name of the patient will not be recorded. Honest report from the patient valuable and it is very important to ensure quality of data collection since it will be used for appropriate measures that will be taken.

Data collector name

Name of supervisor

Signature

Annex II: Data collection checklist**Table 1**

Background characteristics of the participants of the research of lived experience of adolescents living with T1DM, SPMMC, 2025

1.	Sex	A. Female B. Male
2.	Age in year	_____ Yrs.
3	Residence	A. Urban B. Rural
4	Religion	A. Orthodox B. Muslim C. Protestant D. Catholic E. Others
5	Ethnicity	A Oromo B. Amhara C. Tigrian D. Others
6	Educational Status level	_____
7	Parental educational level	A. College graduate B. Completed High school C. Less than high school D. Can read and write E. Illiterate
8	Parental Current occupation	A. Unemployed B. Farmer C. Government employee D. Daily laborer E. Merchant

		F. Others
10	Monthly income of the family	_____ birr
11	Time Since Diagnosis	_____ years

1. How did you react when diagnosis as Diabetic mellitus?
2. What challenges do you face in sticking to your treatment plan?

Emotional & Psychological Impact

1. How has living with diabetes affected your feelings or mood?
2. Are there times you feel different from your peers because of your condition?
3. What helps you cope during difficult moments?

Social Relationships & Support

1. How do your friends and classmates respond to your condition?
2. Do you feel supported by your family in managing your diabetes?
3. Have you ever felt stigmatized or misunderstood because of your condition?

Healthcare Experience

1. Can you describe your experience with follow-up care
2. What do you like or dislike about the services provided?
3. Do you feel listened to and understood by your healthcare providers?

8. APPENDIX

Appendix 1. Information sheet

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[illegible]

□ □ □ □ _____

Table 1 : Background characteristics of the participants of the research of lived experience of adolescents living with T1DM, SPMMC, 2025

1.	ፆታ	ሀ. □□ ለ. ወንድ
2.	ዕድሜ	
3	መኖሪያ	ሀ. ከተማ ለ. ገበር
4	ሀይማኖት	ሀ. ኦርቶዶክስ ለ.ሙስሊም ሐ.ፕሮቴስታንት መ. ካቶሊክ ሠ. ሌሎች
5	□□□	ሀ. ኦሮሞ ለ. አማራ ሐ. ትግራይ መ. ሌሎች
6	የርስዎ የትምህርት ደረጃ	□□
7	የወላጅ ትምህርት ደረጃ	ሀ. የኮሌጅ መምረቂያ ያላቸው ለ. ከፍተኛ ትምህርት ያጠናቀቁ ሐ. ከፍተኛ ትምህርት አልጨረሱም መ. ማንበብና መጻፍ የሚችሉ ሠ. ማንበብና መጻፍ የማይችሉ
8	የወላጅ አሁን ያሉበት ሥራ	ሀ. ሥራ አጣ ለ. ገበሬ ሐ. የመንግስት ሰራተኛ መ. ቀን ሰራተኛ ሠ. ነጋዴ

		ሸ. ሌሎች
10	የቤተሰቡ ወርሃዊ ገቢ	_____
11	ከተመረመሩ ስንት ጊዜ ሆነ;	_____

የህመም ምርመራ በኋላ ምላሽ

1. እርስዎ ተመርምረዉ ስኳር እንዳለብዎት ሲነገርዎ እንዴት ተቀበላችሁ?
2. የስድር በሽታዉን ለመቆጣጠር በየቀኑ የሚገጥምዎ ፈተና/challenge/ ምንድን ነው?

ስሜታዊና አእምሮ ተጽእኖ

1. ከስኳር በሽታ ጋር መኖር ስሜትዎን ወይም አመለካከትዎን ይጎዳል?
2. በአንዳንድ ጊዜ ከጓደኞችዎ የተለየ መሆን ተስምትዎ ያወቃል?
3. በአስቸጋሪ ጊዜዎች ምን ያደርጋሉ?

ማህበራዊ ግንኙነቶችና ድጋፍ

1. ጓደኛዎ ሁኔታዎን እንዴት ይመለከታሉ?
2. የስኳር በሽታን ለመቆጣጠር የቤተሰብዎ ድጋፍ እንዴት ያዩታል?
3. በሕመምዎ ምክንያት ተገፍተዉ (stigmatization) ወይም በትክክል ያልተረዳችሁ አለ?

የጤና አገልግሎት ተሞክሮ

1. በህክምና ተቋማት የሚደረግልዎን የህክምና ክትትል ልምድ(expeiriance) ቢገልጹልኝ;
2. በሚሰጡት አገልግሎቶች ውስጥ የምትወዱት ወይም የማትወዱት ምንድን ነው?
3. ህክምና በሚሰጥዎ የጤና ባለሙያ የሚያዳምጧችሁ እና የሚረዷችሁ ይመስሏችኋል?

8. APPENDIX
Appendix 1. Information sheet

Kaayyoon meeshaa walitti qabinsa odeeffannoo kanaa muuxannoo jireenyaa dargaggoota dhibee sukkaaraa gosa 1ffaa (Type 1 DM) qaban, kan kilinika hordoffii sukkaaraa SPHMMC keessatti tajaajila argatan, odeeffannoo walitti qabuu dha. Meeshaan walitti qabinsa odeeffannoo qindaa’aa kun odeeffannoo jalqabaa hirmaattota qorannoo kanaa irraa fayyadama. Adeemsi walitti qabinsa odeeffannoo nama tokkoof tokko gaaffii fi deebii keessatti daqiiqaa 40–60 fudhata. Odeeffannoon kun qorataa ijoo ta’een, qajeelfama gaaffii fi deebii walakkaa-qindaa’aa fi gadi fageenya qabuun ni walitti qabama.

Odeeffannoon dhukkubsattoota irraa argamu milkaa'ina qorannoo kanaaf baay'ee murteessaa dha. Maqaan dhukkubsataa hin galmeeffamu. Dhukkubsattoonni odeeffannoo dhugaa kennuun baay'ee barbaachisaa fi gatii guddaa qaba. Akkasumas, qulqullina walitti qabinsa odeeffannoo mirkaneessuun baay'ee barbaachisaa dha, sababiin isaas odeeffannoon kun tarkaanfii sirrii fudhachuuf ni fayyada.

Maqaa walitti qabaa odeeffannoo

Maqaa hoogganaa qorannoo (supervisor)

Mallattoo (Signature)

Table 1 : Background characteristics of the participants of the research of lived experience of adolescents living with T1DM, SPMMC, 2025

1.	Saala	A. Dhalaa B.. Dhiira
----	-------	-------------------------

2.	umurii	_____
3	Mana jireenyaa	A. Magaalaa B. Baadiyyaa
4	amantaa	Amantaa: A.. Ortodooksii B. Muslima C. Pirootestaantii D. Kaatolikii E. Kan biroo
5	Saba (Sabummaa)	A. Oromoo B. Amaara C. Tigraayi D. Kan biroo
6	Sadarkaa Barumsaa Keessan	_____
7	Sadarkaa Barumsaa Warraa (Maatii)	A.Eebbifamaa Kolleejjii kan qaban B.Barumsa olaanaa kan xumuran C. Barumsa olaanaa kan hin xumurre D. Dubbisuu fi barreessuu kan danda'an E.. Dubbisuu fi barreessuu kan hin dandeenye

8	Hojii maatiin (warri) amma irratti argaman: .	A. Hojii kan hin qabne B. Qonnaan bulaa C. Hojjettoota mootummaa D. Hojjetaa guyyaa E. Nagaddee (Daldalaa) B. F.. Kan biroo
10.	Galii baatii maatii	_____Birr
11	Qorannoo erga gootee yeroo hammamiiti?	

Deebii qorannoo dhukkubaa booda:

1. Yeroo qorannoon godhamee sukkaarri si keessa jiraachuu sitti himamu haala akkamiin fudhatte?
2. Dhukkuba sukkaaraa to'achuuf qorumsi (challenge) guyyaa guyyaan si mudatu maali?

Dhiibbaa Miiraa fi Sammuu:

1. Dhukkuba sukkaaraa waliin jiraachuun miira keessan ykn ilaalcha keessan ni miidhaa?
2. Yeroo tokko tokko hiriyaan keessan irraa adda akka taatan isinitti dhaga'amee beekaa?
3. Yeroo dhiphuu ykn yeroo rakkisaatti maal gootu?

Walitti dhufeenya hawaasummaa fi Deeggarsa:

1. Hiriyaan keessan haala keessan akkamitti ilalu?
2. Dhukkuba sukkaaraa to'achuuf deeggarsa maatii keessanii akkamitti argitu?
3. Dhukkuba keessan kanaan kan ka'e qofatti baafamuun (stigmatization) ykn sirriitti hubatamuu dhabuun isin mudatee beekaa?

Muuxannoo Tajaajila Fayyaa:

1. To'annoo fayyaa dhaabbilee fayyaa keessatti isiniif godhamu muuxannoo keessan (experience) yoo nuuf ibsitan;
2. Tajaajila isiniif kennamu keessaa kan jaallattan yookaan kan hin jaallanne maalidha?
3. Ogeessi fayyaa isin yaalu kan isin dhaggeeffatuufi kan isin hubatu isinitti fakkataa?