



**College of Health Sciences  
Department of Psychiatry  
Graduate Program in Clinical Psychology**

**Exploring the lived experience of adolescents with type 1 diabetes  
receiving treatment at Tikur Anbessa Specialized hospital Addis Ababa,  
Ethiopia: A Qualitative Study**

**By  
Kaleab worku**

**September 2019  
Addis Ababa University  
Addis Ababa, Ethiopia**

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Ababa, Ethiopia: A Qualitative Study**

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## **List of Abbreviations**

**DM-** Diabetes mellitus

**EDA-** Ethiopian diabetic association

**LMIC-** Low and Middle-Income Countries

**TASH-** Tikur Anbessa Specialized Hospital

**T1DM-** type one diabetes mellitus

**WHO-** World Health Organization

# **Abstract**

## Introduction

Type 1 diabetes demands lifestyle changes including diet controlling, monitoring of blood glucose level and administering of insulin. Improved self-care and gaining positive attitudes can help to enhance better glucose management and promote long-term benefits. Moreover, understanding the lived experience of adolescents who live with type 1 diabetes from their own perspective is a significant step in improving diabetes treatment outcomes for this age group.

## Methods

This qualitative study explored the lived experience of adolescents who live with type 1 diabetic who are receiving outpatient treatment service at TASH. Data was gathered from ten participants and using Semi-structured interviews. The interviews were conducted in Amharic, transcribed and then translated in to English. The data was analyzed using thematic analysis.

## Results

All participants mentioned that they have problematic relationships with their parents regarding diabetic management and self-care. The over involvement from parents is a concern for participants for independent living and self-management of their condition. The short and long term complications of the condition, the dissatisfaction in the treatment service, lack of knowledge and understanding of parents about the condition were mentioned as challenges. Accepting their condition by developing awareness and knowledge from the training they get from the Ethiopian diabetic association as well as peer acceptance and validation about their condition were helpful for better adjusting to their condition.

## Conclusion

Finding showed type 1 diabetes is challenging for this age group. These challenges must be addressed to support adolescents in learning to manage their disease and improve health outcomes.

# CHAPTER ONE

## Introduction

### 1.1 Background

The term diabetes mellitus describes a metabolic disorder of multiple etiology characterized by chronic hyperglycemia with disturbance of carbohydrates, fats and protein metabolism resulting from defects in insulin secretion, insulin action, or both [1]. American diabetic association classifies DM into four which is type 1, type 2, gestational DM and Specific types of diabetes due to other causes [2]. Diabetes mellitus may present with characteristic symptoms such as thirst, polyuria, blurring of vision and weight loss. People with diabetes are at increased risk of cardiovascular, peripheral vascular and cerebrovascular diseases [1].

Type 2 is the most common type of diabetes is characterized by disorder of insulin action and insulin secretion either of which may be the predominantly features. Other types of diabetes like gestational hyperglycemia a carbohydrate intolerance resulting in hyperglycemia of variable severity with onset or first recognition during pregnancy [3]. The World Health Organization (WHO) (2016) indicates type 1 diabetes as a deficient insulin production which will require daily administration of insulin, and the American Diabetes Association (2014) states the difficulty of the condition demanding 'multifactorial risk reduction strategies'. Type 1 diabetes compels permanent care of the condition, with daily finger-stick blood tests, injections of insulin and seriously regulated food allowance. Blood glucose controlling is crucial to avoid occurrence of hyperglycemia or hypoglycemia as this conditions can be catastrophic. Poor treatment adherence of medications may cause difficulties and this might result mortality Type 1 diabetes is commonly occur in childhood and adolescence [4].

## **Adolescence**

Adolescence can be characterized as a stage in life where a person is in transition from childhood to adulthood. It is a process individuals undergo big physical and psychological changes. Adolescents also experience social and perceptual transitions. Physical growth and sexual maturation are often the characteristics of development of adolescents and results opposite sex relationships. The person's ability for abstract and critical thinking also develops, with understanding of self-awareness when social expectations demand emotional maturity. (WHO). As stated above, adolescents development occurs in many aspects: from puberty to sexual and reproductive growth; the development of cognition and adult identity; and the change from total socio-economic and emotional dependence to relative independence. WHO declares adolescents as people in the 10-19-year age group. Adolescents go through significant physical and neurological changes, and a phase of emotional development. Typically, they want more independence and to explore new experiences [5].

Adolescents with type 1 diabetes go through the inevitable tasks of being adolescent as well as the multiple difficulties posed by diabetes, which includes the potential for complications from this condition. Physical changes during adolescence, coupled with psychosocial factors in relation to dietary indiscretion, rebellion, and emotional liability, can lead to poor metabolic control and health status. [6]

### **1.2 Statement of the Problem**

Once considered a disease of the West and the affluent, the healthcare community is now witnessing globalization of the diabetes epidemic (The worldwide diabetes epidemic). Diabetes is a major cause of morbidity and mortality [7]. Globally more than 415 million people have diabetes and this number is projected to increase to 642 million worldwide, more than 34 million in Africa by the year 2040. In Ethiopian 1.3 million people have diabetes [8]. The prevalence of DM is higher among low and middle-income countries contributing for 77% of the total disease burden [7, 8]. According to IDF 2015 the prevalence of diabetes mellitus in Ethiopia is 2.9-3.4 % and there are 23,145 diabetes related deaths every year [7].

Unfortunately the true burden of diabetes in Africa is not clear, as there are currently very few prevalence and incidence studies, especially of T1D in children and adolescents. Only three prevalence studies [8] and five incidence surveys [7, 9, and 10] focus on T1D in this age range, and none within the last 10 years. The prevalence rates in these countries range from 27/100,000 in Algeria (for ages 0-15 years), to 95/100,000 in Sudan (for ages 7-14 years), and incidence ranges from 1.5/100,000 in Tanzania (ages 0-19 years),[8] to 10.1/100,000 in Sudan (ages 0-15 years),[7] highlighting the geographic variation in these rates. Compared to the rest of the world, where type 1 diabetes constitutes 5–10% of all diabetes cases, the proportion of type 1 diabetes among diagnosed Ethiopian diabetics is higher. In Jimma and Gondar, it was found that 45% of the patients who presented with diabetes required insulin at diagnosis.<sup>16</sup> In a study conducted in central Ethiopia, the proportion of type 1 and type 2 diabetics was 31% and 69% respectively.<sup>20</sup> The higher proportion of type 1 diabetes in Ethiopia could possibly be due to less frequently diagnosed type 2 diabetes. [11].

Adolescence is a stage of a serious of physiological and psychological changes takes place. It can also be characterized by young people's desire to establish their identity and gain independence. Teenagers with type 1 diabetes have the added burden of diabetes management.

The problems experienced by adolescents with type 1 diabetes are multidimensional. Existentially, type 1 diabetes affects their daily activities. Management of diabetes demands lifetime serious of self-care behaviors [12]. The most significant self-care behaviors are diet controlling, monitoring blood glucose, timely injection of insulin, and proper physical activity [13]. Attitude, personal beliefs, and culture of the society influence these self-care behaviors: however as young people become increasingly independent, they may undermine caregiver's supervision of their diabetes care [5]. Diabetes management is seen as a family enterprise, such caregivers' involvement in the adolescent's life is related with the creation of problems in the parent-child relationship. Psychiatric and eating disorders are reported to be more prevalent among adolescents with diabetes than among their on-diabetic peers [10]. Adolescents with diabetes are at high risk of substance abuse. This is because of their different kinds of psychological and social problems and their high demand for peer acceptance [6]. In addition, living with diabetes is related with poor school performance and employment difficulties. Living with chronic conditions is associated with educational disengagement and poor educational

outcomes Developing peer relationships and the support and acceptance of friends are vitally important in adolescence and failure to develop these relationships can lead to a sense of inferiority and feelings of not belonging. Despite constantly striving for normalcy, children and young people often report feeling different from their peers.

Successful management of long term conditions in childhood and adolescence can significantly impact on condition outcomes in adulthood, however, in an effort to avoid being seen as different by their peers, young people may engage in passive coping strategies such as withdrawal, avoidance of activities and non-adherence to treatment regimens. Although much is known about the phenomenon of adolescent diabetes, little is known about Type 1 diabetes from the perspective of those who are living with it. The aim of this study is to gain an understanding of adolescent's experiences living with diabetes [14].

## **Research question**

-what are the lived experiences of adolescents with type one diabetes mellitus?

## **1.3 Objective of the study**

### **1.3.1 General objective**

The study is designed to explore the lived experiences of adolescents with type-1 diabetes.

### **1.3.2 Specific objective**

- To explore the interpersonal relationship of adolescents with T1D.
- To identify the challenges and concerns of adolescents with T1D.
- To explore the treatment adherence of adolescents with T1D.
- To identify the coping strategies of adolescents with T1D.

## **1.4 Rationale and Significance of the study**

Because adolescence as a phase of major transition period from childhood to adulthood the inevitable changes of emotions, cognitions and physical characteristics occur. Managing a chronic condition such as type 1 diabetes, while also experiencing those developmental changes, can be a major challenge for adolescents. The purpose of this study is to gain better understanding of the lived experience of adolescents with T1DM.

So this study will help health care professionals who work with Diabetes patients to have a good understanding of the lived experience of Adolescents with T1DM, which enables them to have a positive impact on their patient's diabetes management.

The study will also help patients to have better treatment adherence because they will be understood and receive standard care and diabetes education.

This study will also help policy makers to be open to the idea of participating mental health professionals who has better understanding of adolescents in standard care of diabetes management. It also help improve patients and care givers relationship and communication.

## **CHAPTER TWO**

### **REVIEW RELATED LITERATURE**

#### **BURDEN OF DIABETES**

Diabetes Mellitus (DM) is a clinical syndrome comprising a heterogeneous group of metabolic diseases that are characterized by chronic hyperglycemia and disturbances in carbohydrate, fat and protein metabolism secondary to defects in insulin secretion, insulin action or both [15].DM is one of the mounting health problems in the current era [16] and its complications have a significant economic impact on individuals, families, health systems and countries [17].

The United Nation recognized that "...diabetes is a chronic, debilitating and costly disease associated with severe complications, which poses severe risks for families, UN Member States and the entire world and serious challenges to the achievement of internationally agreed development goals including the Millennium Development Goals"[18].

The International Diabetes Federation has predicted that there will be 380 million individuals with diabetes in 2025 compared with an estimated 240 million in 2007, with a higher disease burden in low and middle income nations [19].The available evidence suggests that non communicable diseases currently contribute substantially to the burden of mortality and morbidity in adult [17].

Age-specific levels of diabetes and hypertension in many urban areas of Sub-Saharan Africa are as high as, or higher than, those in most Western European countries This situation is a result of demographic change (populations with older age structures), increasing urbanization , and associated changes in risk-factor levels, such as tobacco smoking, obesity, and physical inactivity [16]. Assessing the prevalence (the percentage of the population with diabetes) and incidence (the number of new cases) in sub-Saharan Africa is extremely difficult because of the lack of data in many countries. The limited data available shows that prevalence varies from 3- 14.5% with an overall prevalence for sub-Saharan Africa in 2010 of 3.2%, predicted to rise to 3.7% in 2030 [18].

Population-based prevalence study does not exist in Ethiopia but from hospital based studies, it can be seen that the prevalence of diabetes admission has increased. World health organization estimated the number of diabetics in Ethiopia to be about 800,000 cases by the year 2000 and the number is expected to rise to 1.8 million by 2030 Years [23].

There are three types of diabetes: type I, type II, and gestational diabetes mellitus. Each of which presents its own clinical manifestations. Type I diabetes is a condition where the body's immune system destroys beta cells in the pancreas (cells responsible for insulin production) and as a result the pancreas produces little or no insulin .

This type of diabetes is most likely to be diagnosed among children and young adults, in fact, three out of every four people with type I diabetes develop it before they reach 30 years of age. It should be noted, however, that Type 1 diabetes may be developed at any age [21]. Type 1 diabetes accounts for approximately 5-10% of diabetes cases [20].

The prevalence of T1DM differentiates between countries located in the African sub region. T1DM is frequent in African children [16], and may be a great deal number of undiagnosed cases found. The prevalence is generally less than 1/1000 and the incidence is within 1.5/100000 in Tanzania and 20/100000 in Morocco. In Ethiopia, it is estimated to be around 9.8% of patients attending Diabetes clinic in Addis Ababa [23]. These studies may be an underestimation, mainly because they were studied years ago and were hospital based studies.

## **INTERVENTION IN T1DM**

In Africa diabetes was given less attention and as a result more children pass away because of complications. The seriousness of the condition can be a risk factor for other conditions like blindness, renal failure and vascular disease. The scarcity of metabolic and clinical data in this region causes lack of early identification of the case.

The other challenge is these children with diabetes receive treatment from an adult diabetologist. Which results significant deficiencies in the delivery of information to the patients and their parents. Therefore diabetes education strategies, agreement about treatment options, utilizing flexible insulin regimens, and devices for home monitoring are necessary [19].

## **Adolescence**

Adolescence can be characterized as a stage in life where a person is in transition from childhood to adulthood. It is a process individuals undergo big physical and psychological changes.

Adolescents also experience social and perceptual transitions. Physical growth and sexual maturation are often the characteristics of development of adolescents and results opposite sex relationships.

The person's ability for abstract and critical thinking also develops, with understanding of self-awareness when social expectations demand emotional maturity. (WHO). As stated above, adolescents development occurs in many aspects: from puberty to sexual and reproductive growth; the development of cognition and adult identity; and the change from total socio-economic and emotional dependence to relative independence.

WHO declares adolescents as people in the 10-19-year age group. Adolescents go through significant physical and neurological changes, and a phase of emotional development. Typically, they want more independence and to explore new experiences [4].

## **THE PSYCHOSOCIAL IMPACT OF T1DM ON ADOLESCENTS**

### **IMPACT ON DAILY MONITORING OF DIABETIC MANEGMENT**

Adolescent is a transition period from childhood to adulthood and them experience a physical and psychological development. This age group who live with type 1 diabetes experience psychological difficulties in individual social circumstances and daily activates. [24] State the psychological impact of type 1 diabetes on the life's these age groups as an emotional struggle and a psychological burden. In his study reported that adolescents go through the experience of anxiety, especially in the way of blood testing or taking insulin in public or school. The long term negative complication of the illness is also anxiety provoking for the age group people. Adolescents living with type 1 diabetes also admitted experiencing a feeling of anxiety, discomfort and frustration with the short term complications.

### **IMPACT ON HEALTH SEEKING BEHAVIOR**

[25] studied adolescents in transition of treatment from children's to adult diabetes service and he stated that these patients suffer from anxiety as a result of lack of psychological preparation like counseling a guidance when they are in the process of transition to adult care. [25] also stated that adult service are more formal and less friendly and adolescents are usually find it difficult to adopt [26] also stated that adolescents has negative attitudes towards the health care professionals as a result.

#### IMPACT ON SECURE RELATIONSHIP AND CARER

In a study done on Iranian adolescent girls who are live with type 1 diabetes by[27], reported that they have concerns about forming romantic relationships, getting married and have kids. They also expressed worry of possible discrimination in their future work related issues as they are living with type 1 diabetes. They also claimed that they will be more constrained and underprivileged at home compared to their male counter parts. They felt unsafe and stated being stigmatized and bullied for having diabetes and this forced them to keep their condition secret.

#### IMPACT ON SELF STIGMA

The lack of knowledge as well as mind fullness about diabetes in the wider community like school teachers, peers and conceives is also a concern and plays its part to add psychological problems and treatment adolescent behaviors [28] studies discuss the difficulties adolescents with type 1 diabetes face when their teachers have little understanding of diabetes. Fear of negative reactions from teachers and peers lead them isolation and nondisclosure. [25] Also identified gaps adolescents' knowledge about their condition and discuss the absence of diabetes education from the day of diagnosis. [29] Also implies that adolescents is willingness to clean up doubts, upgrade their understanding and knowledge and also their self-management skills. He also states that this age group may get confused about certain area of their treatment.

#### IMPACT ON TREATMENT ADHERANCE

According to a qualitative study done by Karishma Datye on Experiences of Young Adults With Type 1 Diabetes, states that biological (hypoglycemic episodes; related to Hunger, cravings,

symptoms, time of day, and fatigue.) Psychological (knowledge, affect, cognition, motivation, and life goals), and environmental factors (school, peer relations) influence self-care behaviors. These situational influences sometimes make it harder to adhere to self-management behaviors and other times serve as motivators to self-management. Karishma Datye also states that health systems which refers to the type and quality of health care that include diabetic education influence diabetes management. [30].

## IMPACT ON DIABETES SELF CARE

In another study done by [31] describe adolescence as a transition in physiological and psychological development, risk-taking, and vulnerability. These individuals partake in various behaviors that may be vital to their wellbeing such as unsafe sex and eating disorders, Furthermore illicit drugs, alcohol, and tobacco consumption is progressive in high school students. Adolescents with chronic medical problems may be more vulnerable to participate in risky behaviors than non-diabetic adolescents.

[31] In his framework proposed for risky behaviors in adolescents, states the importance of these behaviors in adolescent's personal growth. As this activates can be a way of gaining peer acceptance and recognition; in developing independence from parents; refuse to acknowledge the expected obligations of authority; in coping with various emotional problems and stating the transition from childhood to adulthood status. This risky behaviors will increase the likelihood of poor health outcomes in chronically ill adolescents. Especially in the context of type 1 diabetes adolescents, these behaviors come with additional consequences.

## IMPACT ON FAMILY AND PEER RELATIONS

.According to [32].on his study in treatment adherence among adolescents he states that individuals with chronic illness, their environment including family plays important role from encountering to giving support for treatment associated behaviors[33].also states that diabetes management inside family should go with a developmental progression and family roles can vary in time.

Familial support in diabetes management is not enough to ensure adequate disease management as it is complex enough to occur in various settings (school home) and it should include members of family and peers. [34].states that during early childhood, children are dependent on care givers in every dimension of development.

The expansion of social relationship and increased amount of time spent outside of family is characterized by the development of middle childhood [35].Stated various similarities in relationship among children and adolescents such as sharing instrumental and emotional support, mutual liking and adaptive relationship as well as prosaically behaviors.in early adolescent's stage though peer relationship becomes more intimate and loyal.

This is especially important for adolescents with diabetes as they learn assurance in friends and share information about their illness and treatment regimen. In this stage of development parental support is undermined and this will create problematic relationship between parents and children [36].the development of new social support can be important and help individuals build autonomy and independence but risk for psychological difficulties may also occur. [37].as a result of this this adolescents with diabetes should maintain close and supportive interactions with parents and peers.

Peer relationships have high value for adolescents but according to [38] peer influence may have negative or positive impact on diabetes management.

## **CHAPTER THREE**

### **3. Methods**

#### **3.1. STUDY DESIGN**

The study seeks to explore the lived experience of adolescents with type one diabetic. It is going to be an exploratory research. Exploratory research is most useful in cases where there is a lack of sufficient information or a given information is limited.

#### **3.2. STUDY AREA**

This study was conducted at TASP in DM treatment and follow up unit. It gives both pediatric and adult outpatient diabetic treatment service. The unit serves from 2160 to 3240 outpatient adolescents with T1DM. There are different professionals in the hospital who are senior dietitians, clinical nurses and residents. The study only includes adolescents with type 1 diabetes.

#### **3.3. POPULATION AND SAMPLING TECHNIQUE**

The population of the study was adolescents with T1DM who are receiving treatment at TASP.. To select the target participant the researcher used purposive sampling technique. The researcher selects participants purposively because purposive sampling technique is preferable to use for qualitative research design. The researcher select outpatient participants who receive treatment from the Diabetic unit. The researcher uses ten samples. From those three of them were females and seven of them were males.

### 3.4. INCLUSION AND EXCLUSION CRITERIA

#### 3.4.1. Inclusion criteria for patients

- Adolescents in the age range of 10 to 19.
- Adolescents who have only type 1 diabetes.
- Adolescents who are attending their treatment at TASP.

#### 3.4.2. Exclusion criteria for patients: -

- Patients who began treatment three years back.

### 3.5. DATA COLLECTION

The data collected by using in-depth Interview. First, the socio-demographic data was collected through the structured form that is developed for this purpose. The data collection form includes age, sex, education level, and diagnosis for the patient and relationship with the patient for the family/caregivers. After collecting this data, semi-structured interviews were carried out using a topic guide to be followed by each participant. As the research goes on the topic guide was adapted. Questions were asked in a way that was easy to understand and explanations were provided many times as the participants weren't familiar with the topic. Leading questions were avoided. The topic guide questions were translated into Amharic as the interview was conducted in Amharic. The interviews lasted for 50-60 minutes on average and were all audio recorded. The interviewer conducted the interview until he reaches data saturation (10)

### 3.6. METHOD OF DATA ANALYSIS

Interviews were transcribed verbatim in to Amharic and then translated to English by the researcher. The researcher is bilingual in Amharic and English. Transcripts were coded using thematic analysis. Coding was done with open code software 4.03. Before themes/codes were identified the researcher fully read and reread interview transcripts, independently noted possible themes and codes and quotes and then pooled observations. An initial list of codes was then developed, which were grouped in to themes. Grouping related codes together generated four core categories.

1. Perceived challenges and concerns of adolescents with T1DM
2. perceived coping strategies of adolescents with T1DM
3. interpersonal relationships in adolescents with T1DM
4. perceived treatment adherence in adolescents with T1DM

### 3.7. ETHICAL CONSIDERATION

Ethical approval for the study was obtained from the Department of Psychiatry, College of Health Sciences, Addis Ababa University and permission Diabetic mellitus unit. Consent forms were given to participants prior to the interview. The purpose of the study was explained to all participants. To ensure confidentiality anonymity will be maintained and any personal information will not be included in the study. The interviews were identified only by a number code.

## **CHAPTER FOUR**

### **4. Findings:-**

#### **SOCIO-DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS**

Ten participants were interviewed; all the participants who were interviewed in this research were adolescents. All the interviewees are type 1 diabetes patients who are receiving treatment at Black Lion specialized hospital and a member of Ethiopian diabetic association.

Three of the participants were females, and seven of them were males. Their age is ranged from 16-19 years. All of the participants are living with their parents. Only one participant is about to join university and the rest are all attending their high school programs. None of the participants were married and their treatment period ranged from 2-19 years. Six of the participants were orthodox by religion, three of them were Protestants and one participant was Muslim.

After coding using thematic analysis 4 core themes were generated some of the core themes have sub themes: - (1) perceived challenges and concerns of adolescents with T1DM, (2) perceived coping strategies of adolescents with T1DM, (3) interpersonal relationships in adolescents with T1DM (4) perceived treatment adherence in adolescents with T1DM i.e. the participants who are quoted are identified with a number code.

#### **1. Experience of Interpersonal relationship among adolescents with T1D**

Participants in this study discussed their experience of interpersonal relationship, especially as an adolescent living with T1DM in various aspects.

### **1.1 Problematic Family relationship.**

Most of the participants mentioned that they have problematic family relationships. Participants stated parents over involvement and controlling in their diabetes management protocol as the main reason for conflict. Participants discuss they feel untrusted and suffocated by parents.

*“...I get frustrated when she orders me to take medication, tells me what to eat or not. I feel like I can take care of myself and aware of what to do and not to do. When she tells me I feel like I am a kid but I am not...” p3*

*“... ever since my diagnosis they are part of me in every aspect of my life. They are always fearful and untrusting. They keep on reminding me of medication time and my diet control. I feel it is suffocating and I know I can manage my condition without their interference...” p1*

Some participants also mentioned parents lack of knowledge about diabetes contribute for conflict. They stated that families wrongly perceive some of their actions that are not intended to breach the diabetic management protocol.

*“ ... I feel they also lack knowledge about the condition. For example, if they see me hypoglycemic and taking some sugar they blame me as if I intentionally took it to imbalance my blood glucose level. This kinds of blaming and untrusting upsets me....” p8*

Three of the participants also mentioned that they have resentments towards their parents. They stated that their parents used to tell them their condition will be cured when they grow up. And they said they hoped for that result.

*“ ...My mother used to tell me that I will be cured when I grow up and I had hoped I will be healthy just like my friends. But when I found out I have a life time disease I was really disappointed with my mother. All my hope and expectations were based on mu mothers lies. I still cold not forgive her...” p3*

Some participants also mentioned that parents give them special attention than their siblings. They stated that they feel different from their brothers and sisters and fear this treatment will make them incapable and dependent for other life challenges.

*“...because of the fear they have about my condition my family always keep an eye on me. Most of the time they cook meals only for me, remind me of my medication, always take me to school and in every part of my life they want to know and be part of it. I cannot be on my own and do whatever I want and make my own choices like a normal person. For example my mother already decided I will not be joining government university, she said she will pay for private education. I fear for myself that I cannot live independently because they are doing everything for me ....” P7*

## **1.2 Peer relationship**

Most of the participants mentioned that they have a very good relationships with their friends. They stated that their friends are understanding and supportive once they are aware of their condition. Disclosure about their condition and open communication was instrumental for the support of peers

*“... I have good friends. I am happy with our friendship. Sometimes because of my condition, I feel sad and hapless especially in exam times. So they help me study and give me encouragement. They also help me on my diet ...” p5*

Some participants also stated that they like to spend time with their friends because they feel indifferent and relief from their stress.

*“... I like to spend my time as much as possible with my friends because I like to socialize and have fun with them. When I am with them I feel normal and forget all my problems...” p4*

*“... until my friends were aware of my condition it was difficult for me. I used to experience hypoglycemia inside classroom and I was always tired so they see me as a sick person and don't want to be with me. It hurts me....” p10*

*“... There are only a few friends who know my condition. If I experience hypoglycemia or hyperglycemia they help me out. They understand me and I feel normal when I am with them....” p2*

### **1.3 Perceived Opposite sex relationship.**

Most of the participants stated that they have a healthy relationship with their opposite sex friends. They mentioned they used to have miss perceptions about these relationships but adjusted to it with experience. They said when they open up about their condition it became easier to communicate with. One participant states as follows

*“... I used to be scared of approaching girls because my assumption of them was they like active and sociable guys, which I was not at that time. I used to connect everything with my condition and it was not helping me. But recently when they see me taking injections some of*

*them were curious and that opened the door to get to know them. The more honestly I explained my situation the more supportive I found them. So I have good amount of female friends now...”p9*

Some of the participants stated that being with opposite sex friends help them to feel indifferent and accepted by others which they mentioned as a big deal for them.

*“... I have a boyfriend but my parents don’t know this. I told him about my condition and it was strange for him first but as he get to know more about me and my condition he became fine with it. He make me feel normal and accepted...” p4*

#### **1.4 relationship with teachers**

Most of the participants mentioned that they have a normal relationship with their teachers just like other students. They stated that their teachers are not aware of their condition and that is how they prefer it. Although their parents insisted letting the teachers know participants refused. They mentioned they do not want to be seen as patients in classroom in which case they fear bulling and stigmatization.

*“...my parents used to tell my teachers about my condition so that they can take care of me. But when I grow up I make that stop because I did not want to be treated differently from my friends. If the other students know my case I don’t think they want to be with me. When I was in elementary school some students used to joke with my condition as well...” p3*

Some of the participants stated that they simply do not want their teachers to know about their condition because they don’t want the special attention and care they

receive. They mentioned they want same treatment like others because they believe they can cope up with their condition.

*“...I don't want my teachers to know about my condition because what matters for me is how much do they know. I can tell them I have diabetes but I don't want them to feel sorry for me and treat me differently. If they do that it would destroy my little strength...” p10*

## **2. Perceived challenges and concerns.**

Participants discussed their challenges and concerns while living with diabetes as follows.

### **2.1 Perceived treatment service**

Most participants mentioned that they are receiving treatment below their expectations and they are unsatisfied with health care professionals. Some Participants stated that they heard about their condition from their parents. And because of lack of knowledge from parents they were not properly addressed about their condition. This resulted conflict with parents and different psychological distress to them. They claimed it would have been better the professional told them so they could have enough information and adjust themselves better.

*“...she told me I have diabetes and I am not allowed to do whatever she forbids me to do. She did not say much only I will be fine when I grow up.. When I found out I have a lifelong condition I was sad and disappointed with my mother. I blame my doctors because I had follow up every time and they never told me anything. I wish they told me earlier so that I could have understanding and more self-control. I would not feel sad and hateful to my mom as well.” p5*

*“...my parents told me my illness is called T1D. I had no idea at that moment but my parents used to tell me not to eat outside without their knowledge and every day my mom give me injection three times a day. I used to miss classes a lot because of hypoglycemia, I even fainted many times going to school. When people see you that way they feel sorry for you and that make me sad because I had no idea why I am that way. When they told me my condition I thought like any disease it would go way in a week...” p3*

Some participants also mentioned they are not happy how health care professionals broke out the news for them. They stated that the professionals did not considered their previous awareness and gave them little information about their condition. They discussed that had they been told properly, they would have adjusted easily to the complications of the condition.

*“...I had many questions about my condition and even if I go to hospital every time nobody gave me answer. Some of my friends told me diabetes is an old person disease and I ask myself why it happens to me. What bothered me the most was I did not know how to take injections and I used to inject in the same area around my amblicored which has caused me complications. I was always sad and irritable. I connect everything with my condition and fight a lot ...” p2*

*“Had he gave us information about my condition, my family and I would not have suffered the next two years. The first two years of my life with diabetes was the worst time I had in my life and I describe it as ‘ I was born for the second time with bad luck’ ...” p9*

Most participants also stated that professionals are not addressing their needs with participant’s expectations like more time for discussions about their condition, their stage of treatment and other difficulties they are facing in relation to diabetes.

*“You can say I am going for follow up only for prescription. I give them my fasting result and if it’s fine no more discussion will happen. It will be good if they give us additional information’s about our condition and involve our parents to teach them about our condition ...” p3*

Some participants also stated they don’t find the same doctors in there follow ups and they feel uncomfortable talking about their condition again and again.

*“I come for my follow up and the doctors are always different. If we can find the same doctor who knows us it will be good because it is tiring to tell and remind about your condition every time...” p6*

## **2.2 complications of diabetes (short term and long term)**

All participants mentioned that experiencing short term diabetes complication such as hypoglycemia and hyperglycemia as painful and managing this complication as a very challenging part of their lives.

*“The challenges are when you have hypoglycemia and hypoglycemia. Managing to stabilize these situations is very painful. There is also tiredness and loss of energy ...”p10*

Most participants also stated that the long term complications of type one diabetes, such as heart attack and problems with kidneys, eyes and nerves is a concern for them. They mentioned that they feel anxious when they think about these complications.

*“I worry what this disease will do to me in the long term. I hear it affects different parts of our body and thinking about this make me feel anxious...” p8*

### 2.3 Living independently.

All participants mentioned that they are convinced that it will be difficult to live by themselves without family support. High family involvement and over protection creates a sense of dependency and lack of confidence for self-management of their condition.

Some of them stated that they may experience unexpected complications from their condition and they fear they cannot cope up by themselves.

*“...but I always anticipate what if something unexpected happens to me and this stressed me out. Without my family I don't think I can survive. Everything was done for me by my parents...”*  
p7

Some participants mentioned that although they can handle their diabetes management protocol by themselves, the material and emotional support they get from family make it difficult to live independently.

*“I don't think I can live by myself. Despite their limitations my family help me in every aspect of my life. They support me financially, with cooking, giving me advice...”* p2

Some of the participants mentioned that they are unsure of themselves to adopt new situations because their families do all things for them.

*“I think this will be difficult. We are a tight family and they will not allow me to be by myself. They are more anxious than me they feel I cannot be able to adopt anywhere new. Interims of controlling my diabetes I can do it independently but other factors like financial issues and situational challenges scare me to live my family and live alone...”* p5

#### **2.4. Difficult treatment regimen.**

All participants mentioned that their treatment regimen is very hard to follow and limiting in many aspects of their life. They stated that they should always be conscious about this treatment regimen like dietary control, exercise and taking medications on time. Otherwise complications will occur.

*“You cannot eat and drink whatever and however you want to just like a normal person. As long as I have diabetes my life is limited it is exhausting and stressful ...” p6*

Most of them also stated that these treatment regimens are affecting them in their social life. Because they have the condition they must be reserved from certain things like drinking alcohol and eating sugary foods.

*“I am always concerned about my diabetes. When I am with my friends for example, if they want to chill while drinking alcohol I cannot do that because of my condition so I will isolate myself and it hurts. I cannot eat with my friends as well. I am always taking insulin twice a day but a normal person would get up and do whatever he wants. You cannot stay outside home for long because of medication and even if it is late you cannot take insulin in public places as some people may think it as a drug ...” p1*

Some of the participants also mentioned that financial issues of the family influence their dietary control.

*“It kind of difficult to follow my dietary program because we are poor. I eat what is served and I don't have the privilege to choose diet that support my condition. ...” p3*

## **2.5 family anxiety**

Most participants discuss that family stress about deteriorating metabolic control and engage in intrusive parenting behaviors such as nagging which results disagreement and conflict about diabetes management.

*“I think I am the one who is ill. They act like they care more than me about my condition. Every time we argue about my medication and diabetic self-care ...” p2*

Other participants stated that they believe family support in their life, including diabetes management is important. But they mentioned that they feel saddened and self-blame when they see their parents and family members worry excessively because of their condition.

*“My mom worries about me very much. She always say she should be sick instead of me. Watching and listening her like that I hate my condition. It make me feel sad and hopeless ...” p7*

## **2.6 Spiritual Life**

Some participants stated that living with type 1 diabetes affects their spiritual life where some practices of their religion like fasting may affect their diabetes treatment in a negative way.

*“Fasting has a big part in my religion and because of my condition I cannot do it and I feel guilty of betraying my God and sinful. ...”p3*

While some of them mentioned they are in dilemma and confusion about their spirituality and their medical problem. Spirituality preaches anything can be healed, but their condition is a lifelong.

*“I believe with praying and holy water God can heal anyone from any problem but biologically my disease is not curable and I am becoming confused and doubting my religion which is very distressing because I love God ...” p10*

### **3 Coping Strategies**

Participants in this study mentioned some thoughts and behaviors that they use to adjust to the emotional and physical challenges of their condition.

#### **3.1. Accepting the new normal.**

Most participants stated that they integrate their condition in to the background of their daily life activates by learning diabetes as part of living. They mentioned that this attitude help them to view their condition as manageable by shifting their negative emotions to positive directions.

*“...living with diabetes is challenging for me but I consider it as a friend like we have good moments, bad moments and it will always live with me. This helped me to learn that I am strong enough to live with a difficult disease and I feel like if I can do this i can resist any thing in life...” p5*

Some participants discuss that accepting the reality of their condition as part of their life and knowing its consequences help them to consider their diabetic management seriously and to be more treatment adherent.

*“ ... I know I need to take my injection every day. Because if I don't take it I will dye.so taking medication is one part of my life. ...” p2*

*“ ... I don't see injection as a bad thing, in fact I see it as a special thing that keeps my life going. ... ” p5*

Other participants also stated that accepting their condition helped them to improve their relationship with parents. Because they agree in the diabetes management protocol which increases trust and avoid conflict.

*“ ... no one orders me to do or not to do anything in my family regarding my diabetes management. They gave me the responsibility and they trust me now. But it was not always like that. We used to argue a lot ... ” p9*

Some participants mentioned that recognizing about their condition helps them to enhance their self-esteem. They acknowledge that everyone has limitations and strengths.

*“ ... I am becoming used to my problems and limitations so I enjoy my time with them instead of thinking what I lost. All of us have weakness and strengths. So they have their own issues just like mine is diabetes ... ” p1*

*“ ... but now I know my diabetes only limits me from some things and make me focus on my body more. That is only the difference between me and my non diabetic friends. Everyone has a limitation I feel this way now ... ” p9*

### **3.2 positive coping.**

Most participants discussed that changing their perspective about diabetes and view it from the positive side of the condition is helpful for better adjustment. They stated regular exercise, choosing diet, continuous medical checkups, free from substance abuse and change in optimist personality as positives of living with the condition because normal people will be negligent and not give focus as such.

*“ ... living with diabetes made me to be more conscious about my health. I choose my diet and exercise regularly. I also check up my medical status and I am more positive person...” p5*

Some participants discussed that living with diabetes makes them stronger and resilient for other life challenges including academic related and relationship issues. They stated that the ability of taking care of themselves shows they can be trusted for any responsibility. And proves they have strong personality.

*“ ...I am strong enough to live with such a difficult disease and I feel like if I can do this I can cope with other challenges. ...” p6*

*“ ...living with diabetes makes me realize that I am strong enough to pass through difficult situations. Because nothing can be difficult than my condition ...” p1*

Others stated that living with the condition gives them a purpose and a goal to achieve. They discussed that they want to show others that they can perform and achieve just like there non diabetic friends.

*“...I know if it was not for diabetes I would not be a good student. I want to show I can cope with diabetes and be successful in my education. I want to show others that diabetes cannot hold them back from achieving what they want. So for me it gives me a purpose to live...” p1*

### **3.3. Peer Support**

Most participants in this study mentioned that disclosing about their condition to friends and open communication were helpful to the adjustment of their problems.

*“...I used to have rogue assumptions about diabetes but after I met my friends in diabetic association, it becomes easier. We become inseparable and talk a lot about our condition. it helped me to understand and accept my condition ...” p10*

Some participants stated that downward social comparison with friends’ especially diabetic friends is helpful for them to feel good about themselves and their condition.

*“...I visited some peers who have the same problem and I felt like I am not alone or the only victim. There were kids who were in bad shape than I was ...”p3*

Others mentioned that when they are with their friends they feel indifferently treated and accepted regardless of their condition.

*“...my friends are aware of my condition and they are supportive.so I feel good. Nobody cares about my condition we just have fun ...”p6*

### **3.4. Diabetes management education**

All participants mentioned that they are participating in diabetes education programs and discussed how the knowledge and awareness they get from the education is helping them to cope up and adhere to their treatment.

*“...I participate in the association and they facilitate diabetes education programs. It is very satisfying. It creates awareness and bond among ourselves. ...” p4*

Most of the participants stated that the education includes awareness about the condition, the treatment options and the effects and the consequences of the condition. They mentioned that doctors and nutrition professionals are invited to teach.

*“...my mother told me my diabetes was caused by the side effect of the drug I was given for my asthma. That was my knowledge until a year ago. I now know about my condition and nobody is to blame. It is a biological disease and I am taking medication for it. ...” p5*

Some of them mentioned that even if the condition is difficult to treat, they strongly believe they need to take medication without second thought.

*“...it is a must to take medication... It is not negotiable or you do it by preference. Either I take it and live or die. So I feel totally obligated to take my medication. ...” p1*

#### **4. Treatment Adherence**

Most participants stated that they are adherent to their medication. They discussed that their adherence to the medications is associated with balanced glycemic control and optimal benefits from their prescribed medications, which can lead to improved medical condition. They also mentioned that they are adherent to the strict diabetic self-care protocols. With good self-management like diet control and exercise, participants mentioned they can reduce the risk of developing complications.

*“...there are situations I experience hypoglycemia and in this case I try to drink water and exercise. If I experience hypoglycemia I will have sugary snacks but overall I try to manage my condition by taking my medication ...” p7*

Other participants mentioned that they avoid participating in risky behaviors which can affect their condition like illicit drug use, alcohol, smoking, unprotected sexual activities and skipping medications. They stated that the awareness about diabetes and the involvement of good social support as protective factors.

*“...I never participated in risky behaviors because after I grew up I have knowledge about the consequence. In the early days of my treatment my parents were involved more so there was no way I could practice those things ...” p9*

Some participants stated that for conformity with friends they sometimes use alcohol and eat cake in social events like birthdays.

*“...I eat some forbidden food materials and drink alcohol when I am friends. It is hard to say no when they are all doing it. But not always, I stop right away...” p2*

Some participants also stated that they used to skip medication because of the pain and because of over parental involvement. But with the awareness they have now they don't practice in risky behaviors now.

*“...yes I intentionally used to skip my medications and use alcohol and cigarette. There were conflicts with my family and I feel like it was a revenge for me. But I know now I was only hurting myself...” p4*

## CHAPTER FIVE

### 5.1. DISCUSSION

This study finds out that family relationship as problematic. Parents are described as over involving and over controlling in diabetic management. Family involvement in diabetic tasks such as persistently ordering to take injections and reminding them about dietary control are associated with diabetic related conflicts. Participants in this study also discussed their fear of living independently. Because of over parental involvement participants developed anxiety and lack of confidence for self-management of their condition. They also stated they want to be let the responsibility of managing their condition by themselves. This finding is supported by the study of [26] discussed that adolescents want the right level of familial involvement and choose shared management of their condition. But, they admitted that too much familial involvement and supervision leads to sadness, conflict, embarrassment and anger which creates lack of motivation and non-adherence to treatment.

The other finding that was emerged from our study is parent's lack of knowledge about diabetic also a factor for conflict. Parents give miss information about the condition and miss perceive some of the actions of the adolescents as attention seeking or negligent self-care treatment. This finding is consistent with [28]. In this study the lack of knowledge and awareness from the family members and parents of the patients regarding the condition has a negative impact on the relationship of the patients and family.

This study also identified, because of their condition adolescents pass through difficult treatment regimen and self-care behaviors which forces families to focus more on them but participants don't want to be given special attention and unique treatment from their siblings by their parents. The study done by [27] support this finding. The study identifies the serious restrictions lay on these adolescents and the persistent reminders that they are shows significant influence on self-management of the condition.

Another finding in this study shows, participants Opening up and disclosing about their condition to friends resulted validation about their condition and acceptance. Participants feel indifferent and are open to the emotional support and encouragement they gain from friends. This finding is similar [39] study in which it's mentioned adolescents desire for friends acceptance and seeking validation from their peers about their diabetes management protocols. It is also stated that adolescents feeling of motivation, sense of belonging and confident to treatment adherence in the case of peer acceptance about their condition.

In contrast to this finding there were some participants who preferred to hide about their condition from teachers and friends by the fear of stigmatization and bullying. [27] Similarly stated adolescent's perceived view about the negative reactions of peers, teachers and community when they hear about the condition due to this lack of knowledge.

The other finding from our study that needs further exploration is participant's dissatisfaction on the treatment service they are receiving from the diabetic clinic. The way of disclosure about their condition, interchangeability of professionals and the lack of understanding of the psychological needs of adolescents by professionals stated as challenges by participants. This finding is supported by the study of [25]. He explains adolescents in transition of treatment from children's to adult diabetes treatment clinic and he stated that these patients suffer from anxiety as a result of lack of psychological readiness like counseling and guidance when they are in the process of transition to adult care. [25] Also stated that adult service are more formal and less friendly and adolescents are usually find it difficult to adopt. [26] Also stated that adolescents has negative attitudes towards the health care professionals as a result. This study also find that participants distress and concerns with the short term and long term complications of the condition. Managing to stabilize hypoglycemia and hyperglycemia as well as fear of the negative long term complications stated as challenges. This result is consistent with [24]. In his study adolescents experience anxiety, especially in the way of blood testing or taking insulin in public or school. The long term negative complication of the condition is also anxiety provoking for these age group people. Adolescents living with type 1 diabetes also admitted experiencing a feeling of anxiety, discomfort and frustration with the short term complications.

The finding that participants accept their condition as the new normal and integrate diabetic self-care and management in their daily activities may be counterproductive a lot for the prognosis of the illness. This coping strategy helped them to shift the negative emotions associated with diabetes to positive directions which results better management of their condition and adherence to medications. This finding is supported by the study of [40]. Strickland. In this study Accepting Diabetes is defined as recognizing diabetes is part of you and having diabetes is normal. As adolescents pass through the grief, anger, sadness, denial, and rebellion of being diabetic, they understand that diabetes is not going away and should be accepted. They realize the negative consequences of not taking care of diabetes and believe that they are able dealing with diabetes and feeling normal. Adolescents shared the process of coping and accepting that diabetes “is” their new normal.

This study also found that participants receive satisfactory diabetic management education from the Ethiopian diabetic association. They stated that they gain knowledge and awareness about their condition. The treatment options for diabetes, the complications of the condition and its management, the consequences and diet control are some of the trainings given by the association. This training has a big effect on the participants on their treatment adherence. This finding is strongly supported by the study of [30], diabetes education enhances self-care behavior. Diabetes educators help patients in delivering the knowledge and skills they need to manage their condition. High-quality diabetes education can have positive influences on self-care behaviors and treatment adherence. Some participants in contrary mentioned the need for more education from specialists and professionals to clarify confusions and improve knowledge. This finding also supported by [29] reported adolescents’ willingness to clarify doubts, update knowledge and enhance their self-management skills. Participants also stated being confused about certain areas of their treatment and suggested need for a skill-based education system to improve knowledge and promote autonomy.

## **5.2. LIMITATION**

Some of the limitations of this study includes failure of including adolescent patient participants who did not take diabetic education and also are not a member of Ethiopian diabetic association who could have unique experience living with the condition because of unwillingness to participate in the data collection time. The study also failed to include involve parents of adolescent participants in our study as it would have helped in understanding their perspective of the same experience. The serious limitation of the study is that the participants included in this study may not be representatives of adolescents with T1DM in this setting. Because we could only involve those who were attending in the treatment as an outpatient in the hospital. Those who were not engaged in the study for several reasons like who developed other physical illness or long term complications are likely to have been missed.

## **5.3. RECOMMENDATIONS**

- In our study Diabetic education was found out to be effective for creating awareness and improve knowledge about the condition as a result it is recommended to involve parents as well.
- Professionals who work in diabetic clinic should be trained better ways of breaking the bad news for adolescent patients.
- Adolescents who live with T1DM should get proper psycho education about T1DM.
- The Diabetes mellitus clinic should work in collaboration with mental health professionals to better understand and address the developmental needs of adolescents with T1DM.
- The Diabetes Mellitus clinic should also establish a guideline for professionals and parents. How to deal with adolescent patients with T1DM.

#### **5.4. CONCLUSION**

Our finding suggest that adolescents who live with T1DM experience challenges because of parental lack of knowledge and failure to recognize their developmental changes by professionals and health system. Taking our findings in to consideration, improving the knowledge of parents with diabetic education and the capacity of professionals as well as helping adolescents strengthen their peer relationship and support would improve the treatment adherence and quality of their lives.

## Appendixes

### Appendix I

#### Data collection form

|                       |
|-----------------------|
| 1. Code has given     |
| 2. Age                |
| 3. Level of education |
| 4. Employment status  |
| 5. Religion           |
| 6. Place of residence |
| 7. Gender             |

## Appendix II

### Topic guide questions

1. How did you find out you have T1D?
  - how did you react to the news?
  - were the doctors gentle enough letting you know the news?
  - Did you get counseling before and after you are told?
  - are you happy about the way you knew the news?
  - what do you think of that caused you diabetes?
  - is there anybody to blame for your illness?
  
2. What is your experience of living with T1D? (Negative and positive)
  - how is it different, living with diabetes from your previous experience?
  - what did you learn about yourself and others living with T1D?
  - what do you feel when medication time approaches?
  - how do feel when you see injection?
  
3. What are your concerns in terms of living with T1D?
  - what do you think of making opposite sex relationship?
  - do you have concern of living independently?
  - what is your expectation of the outcome of your treatment?
  
4. How satisfied are you with the treatment service you are receiving?
  - what do you do to control and manage your illness?
  - do you receive diabetes management education from your clinic?

-how satisfied are you with the education?

5. How is your interpersonal relationship? (Family, Peer, opposite sex, School teachers).

-how do you describe your parents involvement in relation to diabetes management protocol?

-do they give you more attention than your siblings? (How do you feel about it?)

-does your family involvement in diabetic management include corporal punishment?

6. How do you feel about yourself when you are with your non friends?

-do you enjoy being with friends or prefer to be alone?

-when you see other peers are you preoccupied with the thought of what you are

Missing than what you have?

-what do you want to achieve?

7. What do you think of taking medication every day?

-have you ever participated in a risky behavior that could affect your diabetes management?(Intentional or unintentional).

-have you ever skipped dosage of your medication or took sugary foods?

8. How do you cope up when you are in difficult situations?

## Appendix III

### **Participant Information Sheet**

I am conducting a research project that will require me to collect data from the adolescents who live with type one diabetes. It is a mental health research study that explores the lived experience of adolescents with type one diabetic experience.

The purpose of the study is to explore adolescents lived experience from their own perspective.

This will be done by conducting an interview using a certain amount of questions to be covered with each participant. The interview will take up to 50-60 minutes but the structure and duration will primarily be led by your responses. If you agree the interview will be audio recorded. Your confidentiality will be strictly protected; no names will be recorded during the interviewing process or when stored. After the data is transcribed it will be stored in password-protected folders with restricted access.

Your personal information that could lead to your identification will never be disclosed in either oral or written form. I will need to hear your true feelings about the issues that will be discussed and your real experiences (not just about good aspects of services) as it is the only way we can improve the care we are currently delivering. Apart from the time required for the interview, there will be no risk associated with the study. You will be compensated for the time you spend with us. You have the right of free choice to participate in the study without any obligation. During the interview, we might come across sensitive issues.

If there is any question you don't want to answer, you can miss out that question. You have full right to ask for a break, to reschedule or even to withdraw from the research anytime during the interview. You have the option to withdraw from the study or choose not to participate at any time without penalty or repercussions. This will have no effect on the diabetic service that you are receiving.

I would also like to inform you that this study is approved by the ethical committees of the Department of Psychiatry, Addis Ababa University, and Tikur Anbessa Specialized Hospital.

The principal investigator is KALEAB WORKU, Department of Psychiatry, and AAU.

Email: kaleab.w@yahoo.com

TEL; +251912234415

Based on the information provided about the study, Are you willing to participate in the study?

**YES**

**NO**

If the answer is YES please continue to the informed consent form below.

Informed Consent Form

I understand the information I provide is confidential

*Yes*

*No*

I agree to the interview being audio-recorded

*Yes*

*No*

I agreed to voluntarily participate in this study after fully understand the procedures that will be conducted.

Participant

**Signature**\_\_\_\_\_ **Date**\_\_\_\_\_

## Amharic Translation Appendixes

### 1. የስኳር ህመም (አይነት 1 ) እንዳለበዎት እንዴት ነበር ያወቁት?

- በሽታው እንደለብዎት ሲሰሙ ምን ተሰማዎት?
- የምክር አገልግሎት ስለበሽታው ከተነገሮት በፊትና በኋላ አግኝተው ነበር?
- ስለህመምዎ ያወቁበትን መንገድ ደስተኛ ነበሩ ?
- የስኳር ህመሙ በምን መንስኤ መጣብኝ ብለው ብለው ያስባሉ?
- በበሽታው በመያዝ የሚወቅሱት ሰው አለ?

### 2. ከስኳር ህመም (አይነት 1) ጋር የመኖር ልምድዎ ምን

#### ይመስላል(አሉታዊ/አዎንታዊ)?

- በፊት ከነበረዎ ልምድ ጋር ሲነጻጸር ከስኳር በሽታ ጋር መኖር በምን ይለያል?
- ከራስዎ እና ከሌሎች በስኳር ህመም ጋር ከሚኖሩ ሰዎች ምን የተማሩት ነገር አለ?
- የመድሃኒት መወሰጃዎ ሰዓት ሲደርስ ምን ይሰማዎታል?
- በመርፌ የሚሰጥ መድሃኒት በሚያዩ ጊዜ ምን ይሰማዎታል ?

### 3. ከስኳር ህመም (አይነት 1) ጋር በመኖር ውስጥ ምን ያሳስብዎታል?

- ከተቃራኒ ጾታ ጋር ግንኙነት መመስረት ላይ ምን ያስባሉ?
- ያለ አጋዥ ብቻዎን የመኖር ጉዳይ ያስስባዎታል ?
- ከሀክምናዎ እርዳታ ውጤት ምን ይጠብቃሉ ?

### 4. እየወሰዱ ባሉት የህክምና እርዳታ ምን ያህል ረክተዋል ?

- በሽታዎን ለመቆጣጠር ምን ያደርጋሉ ?
- የስኳር በሽታን በመቆጣጠር ዙርያ ያለ ትምህርት በክሊኒኩ ይማራሉ ?
- በትምህርቱ ምን ያህል ረክተዋል ?

**4.ከሰዎች ጋር ያሉት ግንኙነት ምን ይመስላል (ከቤተሰብ፣ከአቻ ጓደኛ ከጤና ባለሙያዎች፣ከተቃራኒ ፆታና ከትምህርት ቤት መምህራን) ?**

- ከስኳር ህመም አያያዝ ጋር የወላጆችን ተሳትፎ እንዴት ይገልጹታል ?
- ከቅርብ ከዘመዶች በበለጠ ወላጆች ትኩረት ይሰጡታል( በዚህስ ምን ይሰማዎታል) ?
- ከስኳር ህመም ጋር በተያያዘ ቤተሰብዎ ያለው ተሳትፎ አካላዊ ቅጣትን ያካትታል ?

**5.ከጓደኞች ጋር በሚሆኑበት ጊዜ ስለራስዎ ምን ይሰማዎታል ?**

- ከጓደኛ ጋር ወይም ብቻዎን ከመሆን የቱን ይመርጣሉ ?
- ሌሎች የእድሜ አቻዎችን ሲያዩ እርሶ ካሎት ነገር ይልቅ ያጡትን ነገር ሲያስቡ ይጨነቃሉ ?
- ማሳካት የሚፈልጉት ነገር ምንድን ነው ?

**6.በየቀኑ መድሀኒት ስለመውስድ ምን ያስባሉ ?**

- የስኳር ህክምናዎን ሊጎዳ በሚችል መልኩ አስጊ እና አደገኛ ባህሪዎች ላይ ተሳትፈው ያውቃሉ(በማወቅ/ባለማወቅ)?
- የመድሀኒት አወሳሰደዎን አልፈው/ዘለው/ ወይም ጣፋጭ ምግቦች ወስደው ያውቃሉ?

**7.ከባድና አስቸጋሪ ሁኔታ ሲገጥሞ በምን ይቋቋሙታል?**

# የተሳታፊ የስምምነት ወረቀት

ከወጣት የስኪር ህምምተኞች(አይነት 1) አጠቃላይ የኑሮ ልምድ አካባቢያዊ ግንኙነት ፈተናዎች እና መቋቋሚያ መንገዶችን በተመለከተ መረጃ ለመሰብሰብ የሚያስችለኝን የምርምር ፕሮጀክት እየሰራሁ ነው።ይህ የሚካሄደው እያንዳንዱ ተሳታፊ የተወሰኑ ጥያቄዎችን ቃለ ምልልስ በማካሄድ ነው።ቃለ መጠይቁ ከ50 እስከ 60 ደቂቃዎችን ይወስዳል።ግን አወቃቀፍና ቆይታው በዋናነት በእርሶ ምላሾች ይመራል።ቃለመጠይቁን ከተስማሙ በድምጽ ይቀዳል፤ሚስጥራዊነቱ በጥብቅ ይጠበቃል። በቃለ መጠይቁ ሂደት ወይም በሚመዘገብበት ጊዜ ምንም ስሞች አይመዘገቡም፤ጥናቱ ከተጻፈ በኋላ በይላ ፍቃድ በተጠበቁ አቃፊዎች ይቀመጣል፤ማንነትዎን ሊጠቁም የሚችል የግል መረጃዎ በቃል ወይም በፅሁፍ አይገለጽም። ይህ ጥናታዊ ፅሁፍ አገልግሎት ለማሻሻል የምንችልበት ብቸኛው መንገድ ስለሆነ ስለ እውነተኛ ልምድዎ እና እውነተኛውን ስሜትዎን መስማት እፈልጋለሁ። ለቃለ መጠይቁ ከሚጠየቀው ጊዜ በተጨማሪ ከጥናቱ ጋር ምንም አይነት አደጋ አይኖርም። ከኛ ጋር ለሚያሳልፉት ጊዜ ይካሳሉ። ያለምንም ግዴታ በጥናቱ ውስጥ ለመሳተፍ ነጻ ምርጫ የማድረግ መብት አለዎት። በቃለ መጠይቁ ምልልሱ ወቅት ስሜታዊ ጉዳዮች ሊያጋጥሙን ይችላል።

መልስ መስጠት የማይፈልጉት ማንኛውም ጥያቄ ካለ ጥያቄውን ሊያልፉት ይችላሉ።

በቃለ መጠይቁ ወቅት በማንኛውም ጊዜ ረፍትን ለመጠየቅ፣ለሌላ ጊዜ እንዲቀጥሉ ወይም ከቃለ መጠይቁ የማቋረጥ መብት አለዎት። ከጥናቱ ሙሉ ለሙሉ ለመውጣትም አማራጭ አለዎት ወይም በማንኛውም ጊዜ ያለ ቅጣት ለመሳተፍ ምርጫ አለዎት። ይህም በሚቀበሉት የስኪር ህምም ህክምና አገልግሎት ላይ ምንም ተፅዕኖ አይኖረውም በተጨማሪም ይህ ጥናት በጥቁር አንበሳ ስፔሻላይዝድ ሆስፒታል በስኪር ህክምና ክፍል የፀደቀ መሆኑን ለረጋግጥላችሁ እወዳለሁ።

ዋና መርማሪ - ቃለአብ ወርቁ

ኢሜል ሐሻበቁሻሽ.ቾ፣ጋሻቁበዐ.ሾበባ

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ስለ ጥናቱ በተሰጡት መረጃዎች ላይ በመመርኮዝ በጥናቱ ለመሳተፍ ፍቃደኛ ነዎት

አዎ

አይ

መልሱ አዎ ከሆነ እባክዎን ከዚህ በታች ባለው መረጃ ላይ ከተስማሙ ቅፅ ይቀጥሉ።

የተረጋገጠ የፍቃድ ቅጽ

እኔ የሰጠሁት መረጃ ሚስጥራዊ እንደሆነ ተረድቻለሁ።

አዎ

አይ

በቃለ መጠይቅ በተቀረፀው ቃለ መጠይቅ እስማማለሁ።

አዎ

አይ

የሚከናወኑትን ሂደቶች በሚገባ ከተረዳሁ በኋላ በዚህ ጥናት ውስጥ በፍቃደኝነት ለመሳተፍ ተስማምቻለሁ።

ተሳታፊ

ፊርማ

ቀን

## Appendix IV

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