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Family Caregiving for Children with Type One Diabetes and Its Impact on Family in Bahir Dar, Ethiopia

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Bahir Dar University

Faculty of Social Sciences

Department of Social Work

Family Caregiving for Children with Type One Diabetes and Its Impact on Family in Bahir Dar, Ethiopia

A Thesis Submitted to the Department of Social Work, Bahir Dar University
in Partial Fulfilment of the Requirements for the Degree of Master of Social Work
(MSW)

By Basiliel Nigusse

Advisor: Kerebih Asrese (PhD)

June, 2021

Bahir Dar, Ethiopia

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This is to certify that the thesis titled Family Caregiving for Children with Type One Diabetes and Its Impact on Family in Bahir Dar, Ethiopia is the of Basiliel Nigusse. It has been submitted in Partial Fulfilment of the Requirements for the Degree of Master of Social Work (MSW). It Complies with the Regulations of the University and Meets the Accepted Standards with Respect Originality.

Approved by the Examining Committee:

	Name	Signature
External Examiner:		________________
Internal Examiner 1:		________________
Internal Examiner 2:		________________

Declaration

I, Basiliel Nigusse, declare that this thesis titled Family Caregivers Experience of Caring for the Child Diagnosed with Type 1 Diabetes and Its’ Impact on the Health Related Quality of Life Parents and Family Members in Bahir Dar, Ethiopia is my original work and has not been presented for a degree in any other university, and all sources of materials used for the thesis have been duly acknowledged.

Name: Basiliel Nigusse Tibebe

Signature: ____________________

Place: Department of Social Work, Bahir Dar University

Date: June, 2021

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Abstract

Type 1 diabetes mellitus (T1DM) is a common childhood chronic disease that affects both the patient and the family. The aim of this study was to investigate caregiving challenges and their impact on the HRQoL of parents, family members, and caregivers parenting children with T1DM. A cross-sectional concurrent embedded mixed method inquiry was used. The family impact was assessed by parents completing the PedsQL™ Family Impact module (FIM), involving 155 parents and caregivers. The experience of caregiving was studied, in an audio-recorded interview with 15 caregivers of children with T1DM and receiving medical follow-up for their children at Felege Hiwot Specialized Comprehensive Hospital, Tibebe Gion Specialized Hospital, and Addisalem Primary Hospital in Bahir in Dar City Administration. Qualitative data were analyzed thematically and descriptive statistics and multiple linear regressions were used to analyze quantitative data. The finding of the qualitative data revealed the challenges facing caregivers with T1DM children, impacts on HRQoL of parents and family members, the available social support to the needs of caregivers, and caregivers coping mechanisms. The quantitative data indicated the overall HRQOL of parents which was 57.12 (95% CI 55.79-58.42), and their physical, emotional, cognitive, social functioning parents and family members. The sociodemographic and clinical characteristics of parents were correlated to their HRQoL at a statistically significant level ($P < 0.05$). This study indicated parents, particularly caregivers, are negatively affected when their child is diagnosed with T1DM. Family functioning needs to be an area of intervention in addition to clinical symptoms and blood glucose control to solicit the difficulty of T1DM.

Keywords: caregiver, children, experience, health related quality of life, parents, type 1 diabetes mellitus.

Acronym

ADA	American Diabetes Association
AIDS	Acquired Immune Deficiency Syndrome
DKA	Diabetic Ketoacidosis
DM	Diabetes Mellitus
GDM	Gestational Diabetes Mellitus
GDM	Gestational Diabetes Mellitus
HRQoL	Health Related Quality of Life
IDF	International Diabetes Federation
IIF	International Insulin Federation
NCDs	Non-Communicable Diseases
T1DM	Type 1 Diabetes Mellitus
T2DM	Type 2 Diabetes Mellitus

USD	United States dollar
WHO	World Health Organization

Chapter One: Introduction

Background of the Study

Diabetes mellitus, or simply called Diabetes is a serious, long-term (or ‘chronic’) disease that occurs either when the pancreas does not produce enough insulin (a hormone that regulates blood glucose), or when the body cannot effectively use the insulin it produces. Insulin deficit, if left unchecked over the long term, can cause damage to many of the body’s organs, even death (WHO, 2016).

Although other specific types of diabetes also exist, there are three main types of Diabetes. These are Type 1 Diabetes Mellitus (T1DM), Type 2 Diabetes Mellitus (T2DM), and Gestational Diabetes Mellitus (GDM) (WHO, 1999). In the case of T1DM, which is the focus of this study, people with this type of diabetes produce either little insulin or none at all. Currently, it cannot be prevented or the reason why it occurs is not fully understood and the risk factors are still being investigated (WHO, 2016).

T1DM can affect persons of any age; however it most commonly affects children and young adults in their early years. To control the amount of glucose in their blood, children with T1DM must take insulin every day. They will die if they do not have access to insulin (IDF, 2019). Patients must also adhere to a strict lifestyle and diet, as well as regularly monitor their blood sugar levels. Naturally, the young patients must rely on their caregivers and families for guidance, support, and everyday assistance in dealing with such a demanding set of requirements (Zysberg & Lang, 2015).

The number of children and adolescents (i.e. up to 19 years old) living with diabetes is increasing annually. In 2019, over one million children and adolescents; in total, 1,110,100 have T1DM globally. Each year, an estimated 98,200 children and adolescents under the age of 15 are diagnosed with T1DM (IDF, 2019). The International Insulin Foundation (2014) reported that worldwide, 3.2 million deaths are attributed to diabetes every year compared to 3.1 million for AIDS. Diabetes is one of the top ten causes of death worldwide.

Africa has the highest predicted increase of diabetes of all the IDF Regions, with a 48 percent increase by 2030 and a 143 percent increase by 2045 (IDF, 2019). Despite the limitations and with a few data available on sub-Saharan African children Majaliwa, et al. (2008) reported that the dangerous complication of diabetes in which the chemical balance of the body becomes too acidic named Diabetic Ketoacidosis (DKA) is becoming the leading cause of T1DM children death in Africa and documented to be the most common in sequence from Tunisia, Ethiopia, and Sudan.

In Ethiopia Nardos, Desalegn & Tedla, (2017) stated that currently there has been a growing magnitude of non-communicable diseases (NCDs) such as diabetes. Ethiopia is one of the top four countries in Sub-Saharan Africa with the highest adult diabetic populations. Patient attendance rates and medical admissions related to diabetes have been increasing in major hospitals.

T1DM care in children is difficult, and it necessitates the active participation and assistance of parents or caregivers, as well as healthcare providers, to effectively treat this chronic, life-threatening disease. A caregiver is someone who cares after, nourishes, supports, and cares for one or more children; the position is comparable to that of a parent, and caregivers can be parents, family members, foster parents, or other guardians. A parent is a person, as in a mother or father, who raises, cares for, and supports their child emotionally, financially, and materially (UNICEF, 2008; ADA, 2017)

Caregiving for a child with a long-lasting and life-threatening illness is very difficult and can have a negative impact on many aspects of caregiver and family life. Caregivers’ or families’ functioning, in turn, affects the disease management and adherence of the child (IIF, 2014). For example, it put a strain on financial resources, affecting parental wellbeing, and likely undermining the caregiver's physical and mental health (Helgeson et al., 2012; Mellin, Neumark-Sztainer & Patterson, 2004).

The effect of the child's disease on the parents' physical, psychological, and social well-being and functioning is captured by measuring the parents' Health Related Quality of Life (HRQoL) (FDA, 2006). T1DM is a stressor that caregivers must adapt to (i.e., learn to cope and live with). And a variety of factors influence a parent's or caregiver's capacity to adjust to their new role, including social support, coping mechanisms, stress perception, and socioeconomic status (Azar & Solomon, 2001). As a result, given the wide range of people's perceptions of their

HRQoL and how they cope, it’s important to understand parental or caregiver resources or social support schemes that could be used to enhance their physical and mental wellbeing.

Summing up, T1DM management is difficult, lifelong, and rigorous, and the caregivers' involvement in a child's adaptation to chronic disease is crucial. The functioning and well-being of caregivers/parents are also influenced by the child's circumstances. There is a lack of studies of T1DM in resource-poor countries. Despite growing recognition that T1DM is a major and pervasive health concern associated with alarmingly high rates of morbidity and mortality, neglect is particularly evident in Sub-Saharan Africa. In Ethiopia, the incidence rates in urban areas were higher than in rural areas (Alemu et.al, 2009; Bahendeka, 2017; Balcha, Phillips, & Trimble, 2018). Very little is known about Ethiopian family caregivers or parents whose child has been diagnosed with T1DM, nor the impact on the entire family. As a result, this study was conducted on the aforementioned disease in the cultural context of Bahir Dar Ethiopia and this study has shed light on family caregiving for the child diagnosed with T1DM and its impact on HRQoL parents and family members.

Information on the family caregivers of child diagnosed with T1DM and its impact on the parent allows a better understanding of children and their families while dealing with T1DM. Furthermore, it would be a valuable tool in the identification of needs for support or intervention by healthcare professionals including social workers and other concerned bodies.

Statement of the Problem

Having child with T1DM is problematic, putting a strain on financial resources, diminishing parental wellbeing, and putting the caregiver's physical and emotional health at risk.

(Helgeson et al., 2012; Mellin, Neumark-Sztainer & Patterson, 2004). There is a large body of literature on the lives of children and youth with T1DM and the factors that influence their health (Gullotta, Plant, & Evans, 2014) since T1DM is the most common chronic disease in children in western country (Dabelea, et al. 2014). However, there is much less research on the family caregivers' of a child having T1DM and its impact on HRQoL parents.

In Ethiopia, Tewodros (2020) studied Family functioning (family's ability to communicate, solve problems, carry out tasks and support each other) in households living with adult diabetic (T2DM) patients in Bahir Dar city Administration using exploratory major quantitative sequential mixed methods research design his major finding indicated that households living with diabetes patient developed unhealthy family functioning and those with better socioeconomic status were found to have better functioning. However, did not address family caregiving for the child with T1DM and the HRQol of parents. And as indicated in literatures and the finding of the study it's a common misconception that T1DM and T2DM are the same condition, but they're not. There is no cure for T1DM and no way to prevent it. In addition the nature of the disease (T1DM), the treatment regimen, its' impact on the family is different from that of T2DM which usually occur in adults.

There are also some other studies conducted on adults DM patients' cost that is the economic burden of DM patients by Samson (2015) and direct cost of hospitalization for DM patient studied by Yeweyenhareg and Fikre (2007) and the financial burden of out of pocket expenditure for DM by Aster (2018) other related researches. But all of them focus on the economic and financial burden on adult patient (with Type two Diabetes) and their family, and did not address other experiences of family caregivers for child with T1DM on the individual and family level. Samson (2015), for example, used quantitative descriptive and analytical statistics to investigate the economic impact of the two types of diabetes (T1DM and T2DM) on diabetic patients and their families attending health services in Addis Ababa, Ethiopia. His findings clearly stated how DM is a huge financial burden, but the study did not address the disease's other impact on the family. Furthermore, this study did not look at the economic costs of diabetes based on the type of diabetes; despite the fact that prior studies by Elrayah-Eliadarous (2007) and ADA (2018) found that the economic burden per person is higher for T1DM than T2DM.

Another study done by Fikrtemariam (2016) examined knowledge and associated factors of T1DM among caregivers of children attending a diabetic clinic, using a quantitative cross-sectional study on the caregivers of children with T1DM, her major finding was a majority of the caregivers are less knowledgeable about T1DM which would in turn affect the care they give to their child. Desalegn (2018) assessed Diseases Related Quality of Life (DRQoL) and Health-Related Quality of Life (HRQoL) in children and adolescents with diabetes. This study found that there was a lower score in school and emotional function of HRQoL and a lower score in treatment barriers, worry, and communication subscale score of DRQoL of children and adolescent. But the study did not address HRQoL of parents having child with T1DM.

Researches by Alemayehu and Shimelis (2017) studied the prevalence of diabetes mellitus in 7–12 years old school children attending the department of pediatrics and child health, Tikur Anbessa specialized teaching hospital, Addis Ababa and they found out there is a high prevalence of diabetes mellitus among children aged 7–12 years although parents failed to recognize that diabetes mellitus could affect children younger than 15 years. Zekewos, et al., (2016) studied the prevalence of diabetes mellitus and associated factors among middle adolescent and above (15 year of age and above) in Bona District, Sidama zone: a community-based study and the result of their study indicate the overall prevalence of diabetes high in a rural setting and the risk factors include advanced age, systolic hypertension high waist circumference.

A study done by Merhawit (2017) assessed the experience and the coping mechanisms of parents who are giving care for the children with autism by using a qualitative case study research design. The finding revealed that parents are struggling with practical caregiving, economic and psychological problems and they use different coping strategies these are spirituality, consulting doctors, and using other traditional treatments. Another qualitative case study conducted by Atsednesh (2014) on the psychosocial impact of childhood cancer on the parents with children diagnosed with cancer, revealed that parents encounter different psychological, social, and physical impacts that are interdependent on one another.

As to the researcher’s knowledge is concerned on research related to DM there is only one study conducted and accessible on the experience of parents having a child with DM using qualitative case study method by Fantu (2015) but the study failed to take into consideration or examined according to the age of the child at diagnosis, duration of the diagnosis and residence of the parents. Therefore this study did not manage to include the participant based on similar socio-demographic factors or variables which could significantly affect the finding of the study. And the finding seems to have implicitly over generalized the experience of parents having different family characteristics. But this study has included the participant based on the above characteristics; furthermore, the impact of having a child with T1DM on HRQoL the parent and family member as reported by parents is studied by using a mixed-method design. Hence this study is focused on family caregiving for the child with T1DM in addition, impacts on the parents is studied.

In overall, In Western countries, there is a growing body of literature on the family aspects of chronic childhood diseases. Although some researchers have examined into the experiences of children with diabetes in Ethiopia, there is little information or studies that have looked into family caregiving for children with T1DM and its impact on parent and family members HRQoL using a mixed-method design to gain a more comprehensive picture of the situation. The social support of caregivers and disease adaptation process in the home is also overlooked. In addition, the psychological (cognitive and emotional) and social and physical well-being of caregivers and parents of diabetic children is poorly understood in the Ethiopian context. Therefore to provide a more comprehensive description of the caregivers and parental condition in the context of a chronic childhood disease of T1DM, the challenges of caregiving, the impacts in terms of parental HRQoL, the social support, and adaptation mechanisms is studied.

The purpose of this study is to explore family caregiving, challenges of caring for the child with T1DM and the impact on the parent and family members, the available social support and coping and mechanisms. By doing so it will fill the gap and contribute to the knowledge base of healthcare social work, and it will also lay the foundation for further investigation.

The study comprises a general objective and four specific objectives: the second specific objective is studied quantitatively the rest of the objectives are achieved qualitatively.

Objectives of the Study

General objective

To investigate family caregiving for children with type one diabetes and its impact on the family in Bahir Dar City Administration.

Specific objectives

With the aim of reaching the above general objective, the study also has the following specific objectives:

- To describe the challenges of caring for the child with T1DM as experienced by the caregiver.
- To examine the impacts of having a child with T1DM iterms of HRQoL of parents and family members.
- To discuss the social support available to the needs of caregivers caring for the child with T1DM.
- To explain the caregivers coping mechanisms used in caring for the child with T1DM.

Research Question

1. What are the challenges of caring for the child with T1DM as experienced by caregivers in the study area?

2. What is the impact of having a child with T1DM intermes of HRQoL of parents and family members?

3. What are the social supports available to the needs of caregivers caring for the child with T1DM?

4. What are the caregivers' coping mechanisms used in caring for the child with T1DM?

Significance of the Study

There is scant research concerning the experience of caring for the child with T1DM, although some efforts have been made by few researchers little is known about the experience of Ethiopian family caregivers caring for the child with T1DM and its impact on the parent and family. The current study aims to add to the knowledge base of social work in health care by providing a recommendation for practice in the provision of service to caregivers, families, and individuals with childhood diabetes. Other health professionals, particularly those who work in the field of child health, would benefit from the increased awareness and evidence-based practice in areas related to the care of diabetic children. It also serves as evidence for social workers, government agencies, and nongovernmental organizations to intervene in the situation.

Finally, since there are limited published studies done around this area, to the best of my knowledge, it can be used as baseline data for other similar researches and provide some useful direction and information for conducting further research in the area. Thus, the study is important in encouraging further studies and practical actions that benefit children with diabetes and their families.

Scope of the study

This study is designed to examine the experience of caregivers caring for the child diagnosed with T1DM and its impact on the parent and family by using a mixed-method design. The targets of this study are caregivers and parents of the children having T1DM and those who had no other health complications. Caregivers who are attending diabetic clinics at governmental/ public Hospitals and living in Bahir Dar city administration are participants of the study. This study is cross-sectional research and a mixed method concurrent embedded Strategy is used. The study, therefore, provided context-based in-depth information on the caregiver's experience and its impact on HRQoL of the parent and family raising child diagnosed with T1DM.

Definition of Terms and Concepts

Parents: for the purpose of this study the concept of parents is a person or a mother or father who brings up and cares for and provides emotional, financial, and material support to their child having T1DM.

Caregiver: for this study, a caregiver is a person who primarily provides direct care and management for the child diagnosed with T1DM and who is a member of the family (related by blood, marriage, and living together with the child diagnosed with T1DM.)

Family: Family for this particular study is an entity that deals with caring for a child with T1DM and related by blood, marriage, and living together with the child diagnosed with T1DM.

A family Member: means a person who is belonging to a family and living in the same house; household.

Diabetes: The term Diabetes describes a group of metabolic diseases characterized by hyperglycemia (excess of glucose in the blood) resulting from deficits in insulin secretion, insulin resistance, or both in the absence of treatments (ADA, 2010).

T1DM: Type 1 diabetes is caused by an autoimmune reaction and requires daily administration of insulin to regulate the amount of glucose in their blood (WHO, 2016).

Child: A child for this particular study is a child who lives with his/her family and whose age is under 12.

Experience: Any perception, thought, feeling, activities, lived situations, etc. of family members who are responsible for caring for a child with T1DM.

HRQoL: An individual’s subjective understanding of the disease's and treatment's impact on physical, psychological (emotional and cognitive), and social functioning (Foundation Health Measure Report, 2015).

Chapter Two: Review of Related Literature

The Nature of Type 1 Diabetes Mellitus

Diabetes is a category of metabolic diseases characterized by high blood glucose (blood sugar) caused by insulin deficiency, insulin resistance, or a combination of the two. According to the WHO, diabetes has become a major challenge for healthcare systems around the world in the twenty-first century (ADA, 2010). Diabetes mellitus cases have been recorded as far back as ancient Egypt. Diabetes comes from the Greek word for “to pass through,” and Mellitus comes from the Latin word for “sweet”. As a result, diabetes mellitus is defined as an increase in the number of units of urine containing glucose (Mulder, 2012).

Typical symptoms of T1DM include increased thirst, urination, and hunger, as well as a loss of weight. These signs and symptoms can last from a few weeks to several months. When the patient is displaying any of the aforementioned symptoms the potential T1DM diagnosis is confirmed by conducting laboratory tests consisting of blood glucose concentrations, or an oral glucose tolerance test (Mulder, 2012; Atkinson, Eisenbarth & Michels, 2014). The disease's underlying mechanism has been widely debated. Genetic predisposition, environmental influences, vitamin D processing, and viruses have been identified as the most likely agents in the pathogenesis of T1DM (Bach & Chatenoud, 2012; Atkinson, Eisenbarth & Michels, 2014).

Treatment T1DM exerts a lot of effort and puts a big burden on caregivers of children with T1DM, particularly mothers, who are responsible for the majority of treatment management (Jaser, Whittemore, Ambrosino, Lindemann, & Grey, 2009). Naturally, the young patients must depend on their parents and family for guidance, support, and regular assistance in dealing with such a complex set of demands. As a result, the disorder may be called a “family condition,” as it affects the patient’s entire social and familial circle in a variety of ways (Zysberg et al. 2015).

The unregulated blood glucose level can have multifaceted effects. Poor blood glucose regulation can lead to acute low blood sugar, or a drop in blood sugar below normal, which can cause symptoms such as confusion, heart palpitations, shakiness, and anxiety, as well as ketoacidosis, which occurs when blood sugar is extremely high and acidic substances known as ketones build up to dangerous levels in the body. It also results in poor growth and chronic microvascular (damage to eyes, renal failure, and nerves leading to impotence and diabetic foot disorders and macrovascular (coronary artery disease, peripheral arterial disease, and stroke) complications (Tsiouli, Alexopoulos, Stefanaki, Darviri, Chrousos, 2013).

T1DM has become more prevalent and onset is occurring earlier, resulting in longer chronic conditions and a greater on formal support systems and formal caregivers, and for patients in early childhood. A diagnosis of T1DM has life-changing effects on families where a family member, most often the mother will find herself in the role of caregiver (Jaser et al., 2009).

While the medical elements of T1DM diagnosis and care are well-documented, less is known about caregivers and their social groups. The importance of family ties has been explained in the literature, but parents' caring experiences and integration into and societal context have not been adequately addressed. As the preceding research revealed, diabetes management has an equal impact on the family unit or close relationships, as it does on the individual. As a result, social and ecological perspectives on caregivers' experiences caring for children with T1DM were used to investigate the caregiver in the context of their social systems and how those systems interact.

Family caregiving for a patient with a Chronic Conditions in Ethiopian Context

Chronic diseases, according to WHO, are diseases that do not transmit from person to person. They last a long time and progress at a leisurely pace. Cardiovascular diseases (such as heart attacks and strokes), cancers, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma), and diabetes are the four primary categories (WHO, 2016).

In Ethiopia some studies done on the impact of chronic disease on the family caregivers and the whole family has shown the difficulty they face. The study by Yeweyenhareg and Fikre (2007) on the direct cost of hospitalization for DM patients found that diabetes patients' direct hospitalization costs are considerably greater than non-diabetic patients. A significant amount of the overall cost of admission is spent on treating acute and long-term problems. This study calls for more research, as well as the attention of health policymakers and professionals in the future planning of diabetes prevention, diagnosis, and treatment.

According to Samson (2015), Diabetes mellitus was a costly illness for low-income individuals to treat and manage. The median cost of diabetes disease was directly 459 birr (about 22 USD) in this survey, and about 96 (32.6%) people spent over 40% of their monthly income on direct treatment (direct cost) of diabetes mellitus. Indirectly, patients and their families lose 6 days each 6 months per patient. Medical costs, insulin, and prescription purchases, and laboratory investigation costs (costs associated with the necessity for a small number of specialists) all contribute significantly to the direct cost of diabetes care.

A study done by Fikrtemariam (2016) on the knowledge and associated factors of T1DM among caregivers of children indicated Less than half (45%) of caregivers for children with T1DM were aware of the disease. The rest of the caregivers (55 %) are unaware of T1DM. Factors such as gender, place of residence, education level, and presence all influenced the level of knowledge and psychological issue. Attending diabetic education, seminars, and workshops were linked to a higher level of knowledge. According to the study, ongoing training and the preparation of various workshops are recommended in order to increase the knowledge of caregivers, which will help children with T1DM have a better outcome.

Desalegn (2018) investigated Disease-Related Quality of Life (DRQoL) and Health-Related Quality of Life (HRQoL) in diabetic children and adolescents. The study revealed that children and adolescents' HRQoL scores improved in the areas of social function and physical function, with a decrease in school function and emotional function. It also found that having well-controlled blood glucose levels, having a medium/high monthly income, and having diabetic health education were all significant predictors of higher scores. Having more hospital admissions in the previous six months and having a large family was both significant predictors of poor general HRQoL and DRQoL scores in children and adolescents.

Tewodros’s (2020) study of Family functioning indicated that because of the existence of T2DM, 51.43 % of households had inadequate functioning. Households, in particular, face difficulties in all family functioning aspects except affective participation. Behavior control was the least effective component, followed by communication, roles, affective responsiveness, problem solving, and possibly appropriate effective functioning was affective involvement.

Other factors that influenced family functioning included the patient's and household's highest levels of education, monthly average income, and family size.

According to the articles above, families have a variety of experiences caring for a child with a chronic condition. During the time of diagnosis and transitions, parents benefit from appropriate assistance customized to their unique needs. Parents' challenge of caring for children with chronic conditions is found to have social and emotional consequences; therefore, besides the medical aspect of the chronic disease, there is a social aspect that needs to be addressed by the social workers and paramedics who work directly with these families.

Challenges of caring for the children with T1DM

Caregiving a child with a long-lasting or life-threatening illness can harm many aspects of the caregiver’s life. Caregivers of children with T1DM often have difficulty balancing caring for their child with other responsibilities such as work, social life, finance, and other household tasks. As a result, they may experience more stress, worries, sad feelings, family arguments, and troubling child behavior (Eccleston et al. 2012).

Study has found that parents' psychological functioning is associated to their children's blood glucose control (Driscoll et al., 2010). Parental burnout was linked to psychosocial factors such as a lack of social support, leisure time, financial stress, and a presumption that diabetes had an impact on daily life (Lindström, Man, & Norberg, 2011). When compared to fathers, mothers reported a lower health-related quality of life and more worry following the diagnosis (Jonsson, Lundqvist, Tiberg, & Hallström, 2015). Parents, rather than children, reported a greater perception of diabetes' impact on their child's HRQoL.

From existing research, we know being a caregiver of a child with diabetes is associated with more stress in the area of social disruption, emotional and financial strain often compounded with fear of hyperglycemia(abnormal increase of glucose in the blood) hypoglycemia (abnormal decrease of glucose in the blood) in their children. Caregivers also may experience greater stress when managing the life and death nature of a child's illness, which requires a lot of time and energy. As there is an intensive and complex management plan that must be executed daily, which includes blood glucose monitoring, insulin administration, careful monitoring of diet and exercise. All of which potentially involve caregivers (Vicki et al., 2011: Lowes, Lesley, 2005). The information from the articles the researcher reviewed showed that caregiver stress can be caused by multiple factors and therefore interventions should target to address the bio-psychosocial needs of the caregivers.

Both paternal and maternal caregiving stress levels can spike when caring for an ill child with no significant difference (Mellitus et al., 2012). Yet, according to Bourdea, (2013), although it seems like mothers and fathers experience similar stressors when caring for an ill child, mothers tend to experience higher stress levels, perhaps because they are typically the child's primary caregiver.

The above articles noted mothers of children with diabetes reported a poorer quality of life than mothers of children without diabetes. The findings suggest that mothers of diabetic children are more likely to experience exhaustion, have fewer opportunities for social connections, have more difficulty with everyday activities as a result of emotional health, and are more tense and worried than mothers without a diabetic child.

The findings from the articles researcher examined showed that parental stress can be caused by multiple factors and can be potentially dangerous for all members of the family if not managed (Whittemore et al., 2012). This indicates that parental distress is common and an area of great need. Missing in the literature reviewed is an explicit look at caregiving challenges and how those challenges can be linked to caregivers' needs and the social support needed to mitigate the problem.

Diabetes imposes large economic burdens on national health care systems as well as affects individuals and their family's economies (Horton, 2017). Study suggests that the average economic burden per person with diabetes is larger for T1DM than for T2DM. However, because 94.3% of diagnosed diabetes cases are T2DM, the national economic burden is much greater for T2DM (ADA 2018). The effect on the family exceeds pure economic costs in sub-Saharan Africa as it is often the family members who bear the primary responsibility for care. This influences the work of caregiver's empowerment and education and decreases the income-generating capacity of the caregiver who is mostly women, this, in turn, affects the whole family. A study in Sudan identified the annual total median direct costs of T1DM care was USD 283. And one-third of it was used for insulin. In type 2 diabetic patients this cost was USD 175 including ambulatory services. Income level affects the cost directly in utilizing service area and amount of expenditure (Elrayah-Eliadarous, 2007).

The literature above on the economic burden of T1DM indicates diabetes places a significant financial burden on national healthcare systems and has an economic impact on individuals and their families. T1DM has a higher economic burden per person with diabetes than T2DM. What is missing from the above literature is a comprehensive understanding of caring for children with T1DM, including the types of social support caregivers and parents receive and their coping mechanisms.

The Impact of having a child with T1DM on the parents' HRQoL

HRQoL is a multidimensional construct that is consistent with the WHO's definition of health, which is defined as "a state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity." It assesses an individual's subjective understanding of the disease's and treatment impact on physical, psychological (emotional and cognitive), and social functioning (WHO, 1948, Foundation Health Measure Report, 2015).

Although the terms "quality of life" (QOL) and (HRQOL) are often used interchangeably, QOL is a wider concept and includes aspects of life that are not agreeable to the notion of healthcare services (e.g., the evaluation of the impact of the built environment on general wellbeing). As a result, HRQOL has emerged as the most appropriate word for health-related QOL dimensions that fall under the scope of healthcare services (FDA, 2006). Clinicians and policymakers are beginning to recognize the value of assessing health-related quality of life (HRQoL) in order to better treat patients and make policy decisions (Guyatt, et al. 2007).

Research on families with childhood chronic illnesses has established that both children and the whole family are affected by the illness. Therefore, optimal assessment of parent and family functioning is crucial. The PedsQL ^{TM} family impact module (FIM) assesses the health-related quality of life (HRQOL) and family functioning of parents. Measuring the parents' HRQOL captures the broad impact of the child‘s illness on the parents' or caregivers' physical, psychological, and social well-being and functioning (Lopez et al. 2008; Muscara et al., 2015).

The Family Impact Module uses a Likert response scale and scoring method, with higher scores indicating better functioning (less negative impact). The total scale score for the PedsQL Family Impact Module is the sum of all 36 items divided by the number of items answered. The sum of the items in the Physical, Emotional, Social, and Cognitive Functioning Scales is divided by the number of items answered in the Parent HRQOL Summary Score (20 items). The sum of the items in the Daily Activities and Family Relationships Scales is divided by the number of items answered in the Family Functioning Summary Score (8 items).

According to the articles mentioned above, parents of children with diabetes reported a lower quality of life than mothers of children without diabetes. The findings suggest that parents or caregivers of diabetic children are more likely to experience fatigue, have fewer opportunities for social interactions, have more difficulties with everyday activities as a consequence of emotional health, and are more anxious and worried than mothers without a diabetic child.

Having a child who places exceptional demands upon the parents may result in less time and energy for contacts with informal support networks, resulting in a reduction of the number of social support providers and ultimately having a negative impact on parental quality of life. This suggests that increasing the number of social support providers would likely improve quality of life, by expanding the social support network (Thorsteinsson et al. 2017).

Shame, grief, guilt, distress, anxiety, depression, and a poor quality of life are all commonly experienced by parents (Jaser, Whitemore, Ambrosino, Lindemann, Grey, 2008, Jaser, Linsky, Grey, 2014). Parents with psychological problems had a significantly lower quality of life in the physical, and psychological, domains, as well as more dysfunction in the social and cognitive domains of HRQoL (Bhadad, Grover, Kumar, Bhansali, Jaggi, 2011). All of these findings point to the fact that parents of diabetic children and adolescents are vulnerable to stressors and illnesses.

The preceding article has indicated chronic illnesses in children have an impact on both children and their families. As a result, in order to properly treat patients and make evidence based decisions, measuring health-related quality of life (HRQoL) is crucial, and measuring the parents' HRQOL captures the impact of the child's illness on their physical, psychological, and social wellbeing and functioning. HRQL is also a multifaceted construct that corresponds to the WHO's definition of health.

The challenge of Diabetic ketoacidosis (DKA)

DKA is an acute complication of diabetes that most often affects people with T1DM, but it may also affect people with T2DM. It's one of the most severe T1DM complications. According to the International Society for Pediatric and Adolescent Diabetes, DKA is described as a blood glucose level >200 mg/dl. DKA is caused by a drop in insulin levels, a reduction in glucose consumption, and an increase in counter-regulatory hormones. It is a medical emergency that necessitates medical attention, supervision, and vigilance in the face of potential complications. In children and adolescents with newly diagnosed diabetes, it is the leading cause of death and permanent disability. And it is more common in younger children and children whose families do not have easy access to medical care due to social or financial constraints (Wolfsdorf, Glaser, & Sperling, 2006; Codner, et al 2014; IDF, 2013)

When these young people are diagnosed with diabetes, up to 80% of them already have DKA. The prevalence of DKA at the onset of diabetes varies greatly across the country. In developed countries, the mortality rate for DKA is 2 to 5%, while in developing countries; it is 6 to 24 percent. The mortality rate of DKA is higher in developing countries due to higher rates of infection, protein-energy malnutrition, underdeveloped medical facilities, and a delay in seeking medical help (Van Zyl, 2008; Kitabchi, Umpierrez, Miles, & Fisher 2009; Wilson, 2010.)

Many children in Sub-Saharan Africa are only diagnosed with diabetes when they have DKA, which is often misdiagnosed. Diabetic patients in many Sub-Saharan African countries simply die because health-care facilities are overburdened by even more pressing medical needs, malaria, and other tropical diseases (Usher-Smith, Thompson, Ercole, & Walter, 2012, Murunga, & Owira 2013, Majaliwa, Mohn, Chiavaroli, Ramaiya, Swai, & Chiarelli, 2010). The risk of dying from DKA, Ethiopia is also repoted to be higher, maily due to medical facilities are less developed, and children may die before receiving care (Fantahun, & Gedlu, 2008, Ibekwe, & Ibekwe, 2011, Ibekwe, & Ibekwe, 2011.)

In summary, the literature point out DKA is one of the most serious T1DM complications. It is the leading cause of death and permanent disability in children and adolescents with newly diagnosed diabetes and it is a major source of risk and frustration for children with diabetes and their families. Yet the prevalence and condition of children with DKA and their families are not well studied in Ethiopia as they are in other countries.

Coping Strategies of Parent in context of Social Support

Studies have shown, the ways in which caregivers cope with the stress of diabetes are crucial in both caregiver and child diabetes adjustment. Mothers' difficulty in coping with diabetes is related to maternal psychological and physical well-being (Streisand, Mackey, & Herge, 2010). These, in turn, are linked to a child's quality of life, depressive symptoms, and blood sugar control. Maternal depressive symptoms have been found to be one of the most powerful predictors of a child's poor blood glucose control outcomes (Carcone, Ellis, & Naar-King, 2012). Therefore, examining the coping strategy and determining effective coping strategies for caregivers of children with T1DM may improve outcomes in both caregivers and their children.

According to one study, coping strategies such as talking to healthcare providers, reading more about the medical problem, and maintaining family stability were the most helpful to mothers of children with T1DM (Konradsdottir & Svavarsdottir, 2011). These studies provide preliminary evidence of caregivers coping mechanisms for dealing with the stress of diabetes management but the gap in the above literature is they did not investigate caregivers' coping strategies in relation to social support they have and its outcome on children's blood glucose management.

In the context of childhood diabetes, another two pieces of research also looked at coping strategies (Coetzee, 2007; Koegelenberg, 2013). These researches used a mixed-methods approach and were based on the Resiliency Model of Family Stress, Adjustment, and Adaptation. The notion of family resilience was developed based on the parents' assessment of measures assessing family traits such as resilience and communication. The biggest source of assistance for the families was defined as the parent’s acceptance of the disease by treating everyone equally and taking time away from diabetes-related activities. Spirituality, religious beliefs, and prayer were also mentioned as tools that parents could use to find meaning in their situation. Family, friends, neighbors, and associations and, in some situations, health professionals can be sources of social support (e.g physicians, nurses, or nutritionists). Emotional support, tangible/instrumental support, and informational support are common categories for social support. Improved health outcomes are linked to all three types of support (from varied sources)

The research on family coping has not taken into consideration the various interpretations that parents assign to their experiences of caring for a child with a chronic illness, nor the role of context in understanding their experiences. This context can be shaped by a variety of socio-environmental factors, such as caregivers' access to social, financial, and material resources (Giesbrecht, Wolse, Crooks, & Stajduhar, 2015). For parents, concepts like spirituality and coping may have multiple meanings that are not explored from such perspectives. As a result, understanding parental experiences in the context of a larger social and cultural context is crucial in understanding how they cope with the challenges of caring for a chronic childhood illness.

Health care social work and T1DM

Researchers have recommended more collaboration between medicine and social work in the management of diabetes in recent years (Wendt, 1990, Gross et al., 2007). There is increasing evidence that diseases like diabetes must be examined in the context of the social determinants of health, as underlined by the World Health Organization (Rowe et al 2016). Diabetes has long been understood to be a biopsychosocial illness (Decoster, 2001). Diabetes management necessitates a significant adjustment in lifestyle, including a low-sugar diet, regular exercise, daily blood sugar testing, and the use of oral medicines or insulin supplements. Individuals and families with limited resources, opportunities, and support require treatments to help them manage, adjust to, and slow the progression of diabetes. To address the emotional and social well-being of diabetic patients and their families, social work assistance is required (Bergman, 2013).

Recently, two studies that looked into the role of social work in diabetes were published. Rabovsky et al (2016) monitored 977 diabetic patients who had a social work consultation from three clinics in a retrospective analysis (two urban and one rural). The participants were 61 years old on average, with 64 % being African–American and 32 % being White. The most prevalent social determinants of health that social workers addressed were supporting patients with drug access and health insurance concerns, analyzing the patient's support system, and facilitating access to homecare support. They found that subgroups of individuals with poorly managed diabetes improved their disease management after a social work visit.

As the evidence reviewed above indicates, a chronic illness such as T1DM that develops at a young age can inflict impacts on the lives of those who suffer from it as well as their caretakers. The function of the professional's social worker has been proven to be crucial at diagnosis and following the diagnosis as part of healthcare teams. Especially In developing countries such as Ethiopia, which has Africa's second-largest population, doctors, particularly in government hospitals, may not have enough time to attend to patients' other needs aside from medical care. As a result, social workers and other paramedics can take a bigger role in patient care and overall management.

Generally, the research reviewed above has revealed that T1DM is a prevalent childhood chronic illness that affects both the patient (children) and the family. The social and emotional repercussions of parents' challenges in caring for children with chronic illnesses have been observed; hence, in addition to the medical element of the chronic disease, there is a social aspect that has to be treated by social workers and paramedics who deal directly with these families.T1DM caregivers frequently struggle to balance their child's care with other demands such as job, social life, finances, and other home activities. Caregivers may also be more stressed when dealing with the life-or-death aspect of a child's sickness. Diabetes also has a significant financial impact on national healthcare systems, as well as on the livelihoods of people and their families.

As a result, assessing health-related quality of life (HRQoL) is essential for effectively treating patients and making evidence-based decisions, and evaluating the parents' HRQOL captures the impact of the child's condition on their physical, psychological, and social well-being and functioning. Furthermore, comprehending parental experiences in the context of a wider social and cultural framework is critical to understanding how they cope with the problems of caring for a chronically sick child.

While the medical aspects of T1DM diagnosis and treatment are well understood, less is known about caregivers and social support. Parents' caring experiences and integration into social support have not been thoroughly addressed, despite the fact that T1DM management has an equal impact on the family unit or intimate relationships as it does on the individual. As a result, social views on caregivers' experiences caring for children with T1DM were conducted in order to explore the caregiver in the context of their social systems and their interactions.

Therefore challenges of caring, the consequences on parental HRQoL, social support, and coping mechanisms were examined to offer a more comprehensive picture of the caregivers and parental condition in the context of a chronic childhood disease of T1DM.

Theoretical Framework

An eclectic theoretical framework is used in this study since there is no one theory that fits best with any inquiry. And strong research often involves drawing on various different theories and combining ideas (Osanloo, & Grant, 2016). The Family Stress Theory and Family System Theory will help to guide this research.

Family system theory was employed in formulating research questions, defining the issue, framing the interview guide, describing and interpreting phenomena, and discussing findings. Family Stress Theory was used to explain elements of caregiver’s challenges as they related to life with the disease and also in discussing the finding of the study. The two theories were used here because complete assessment and eventual implementation of a concept require a mastery of and the use of multiple theories. But both theories may not be appropriate for all situations. Although this research is not designed to test either theory, these two frameworks complemented each other to provide for a deeper understanding of the topic of caregivers' experience of caring for the child having T1DM and its impact of the family.

Family system theory

Murray Bowen first proposed the family systems theory in the 1960s. Families, according to Bowen, are systems of interconnected and interdependent individuals, none of whom can be understood without the system. A family is a system in which each member has a function to fulfill and rules to follow. A family system is made up of a group of people and their interconnected relationships (Smith, Hamon, Ingolds, and Miller, 2009).

This definition includes two important aspects of the family: family structure and family functioning. The definition of family structure is who is in the system. It allows a family to develop its own identity and function as a unit. The degree of permeability of this boundary is especially important for families living with chronic illness, both in terms of the family's identity when the disease is always present and in terms of the family's relationships with the myriad of health education and social service providers with whom they must frequently interact. The second aspect of the family system is family functioning, which is important for understanding the reciprocal relationships between the chronically ill individual and his or her family. Family functioning refers to the patterns of relationships that connect family members (Patterson, & Garwick, 1994).

According to studies, the best way to promote successful adaptation to chronic illness is to focus on the family system as the intervention unit. When the rest of the family is healthy, the chronically ill person does better (Patterson, & Garwick, 1994). In conclusion, a family system theory is used as a theoretical framework in this study to understand the reciprocal relationships between a chronically ill child and the family caregivers. Furthermore this theoretical perspective was used by the researcher in developing research questions, defining the problem, determining the significance of the study, framing the interview guide, describing and interpreting the phenomena, and in discussing the findings.

Family stress theory/ the ABC-X model

Family Stress Theory is a middle-range theory that was developed by Reuben Hill, after World War II, in studying families' responses to war. It is one of the earliest theoretical explanations of how families deal with related stress, vary in their responses to stress, and determine how successfully a family manages stressful events.

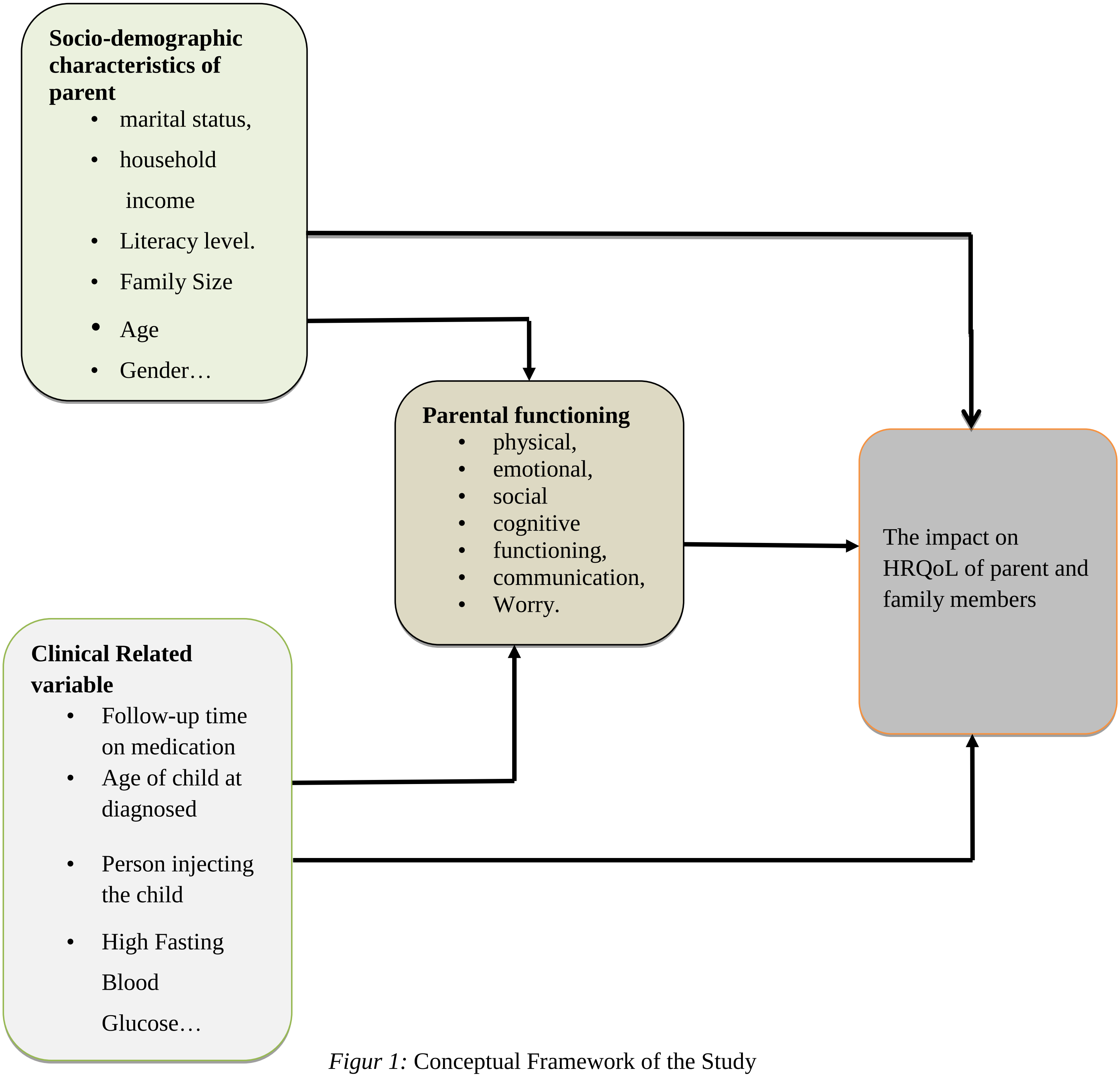
The stress and coping literature has largely been shaped by Hill's (1949) **ABC-X** model; this model expresses various aspects of stress and coping and the interaction between them. **A** represents the stressors or initial event or hardship that a family experiences. The source of stressor events can be either internal or external. External or non-volitional events which the family has no control over are more likely to increase the family's stress level, making the family more vulnerable.

And **B** is the family's resources or strengths during the event or hardship. The individual members, the collective family, and the community are the potential sources for that family resources and assets that help the family prevent or buffer an event from causing a crisis state and assist the family in problem-solving to enhance the family's coping strategies. **C** is described in terms of how the family defines the event or the meaning that they give to the stressors (**A**). People, including families, are continually trying to understand, assign and form meanings about the stressor event they live in. As they are influenced by three key factors: the family's value system, previous definitions used, and previous experiences in handling crises. Families who are capable of defining an event positively and are optimistic are more likely to cope and adapt to the situation, especially useful when the event itself cannot be changed but the families' perceptions and meanings can be (Joed and Samantha, 2009).

All of these components interact together to produce **X**, which, as Hill (1949) describes it, is a crisis. When a stressor event weakens resources and family members can no longer perform their roles, the family enters a state of crisis (Joed & Samantha, 2009). The theory was later expanded to include the family's adaptation following the stressor event. Stress has a range of outcomes, from maladaptation on the negative end to bonadaptation on the positive end, depending on the interaction of the event, ABC factors, and other factors (Smith, Hamon, Ingolds & Miller, 2009). For the purposes of this study, adaptation is defined as a family unit's ability to maintain homeostasis/balance within the family system in performing their role as a family (Smith & Liehr, 2003). This model was used to explain the process and the stages the family caring for chronic disease of T1DM goes through, the possible components of caregiver's challenges. This model is used is shaping the objectives of the study and interpreting the experience of caregivers.

Conceptual Framework

The conceptual framework of the study was developed from the literature review. It shows how the concepts examined in the quantitative part of the study are related. The dependent variable in this study is the impact of having a child diagnosed with T1DM on the HRQoL of parents/caregivers and family members. Specifically the measured dependent variables are parent self-reported physical, emotional, social, and cognitive functioning, communication, and worry. Personal, social, demographic, and health-related factors of parents and their child with T1DM are the study's independent variables.



Figur 1: Conceptual Framework of the Study

Chapter Three: Research Methods

Description of the Study Area

The study is conducted in Bahir Dar City Administration, the capital of Amhara National Regional State (ANRS). The city administration has two specialized and one primary government hospitals (Tibebe Giwon, Felege Hiwot, and Adiss Alem, respectively), 11 health centers (including one private health center), 10 health posts and one family guidance association clinic, four private general hospitals, and 35 medium private clinics, according to this City Health Department. The study is undertaken in Pediatric out patient department of Felege Hiwot Specialized Comprehensive Hospital, Tibebe Gion Specialized Hospital, and Addisalem Primary Hospital. In Felege Hiwot Specialized Comprehensive Hospital A database from the Information Technology prepared excel sheet was seen and in the pediatric outpatient department, there were 246 diabetic children with type T1DM who were registered during the follow-up period. The settings were chosen because numbers of chronic disease patients were treated in these hospitals. In addition, it is believed that it is better to choose those families using public hospital which constitute a large number and rather than merging patients using private hospitals who are small in number and they might have higher economic status or income compared to those using governmental hospitals.

Research Approach

For this study, a mixed methods approach was employed. This is because a mixed research approach provides more comprehensive evidence for studying a research problem and better understanding than either quantitative or qualitative research alone (Johnson & Christensen, 2008). Therefore, the rationale behind the use of mixed method approach was because it helps to understand the problem with the use of different mechanisms or instruments. Hence, among the mixed research strategies, concurrent embedded or nested (QUAL/quan) was employed. A concurrent embedded model is a type of mixed research strategy that is used when there is a need to employ different methods to study different groups/levels or to address different research questions (Creswell, 2009). Both quantitative and qualitative data are collected simultaneously and it has a primary method that guides the study in this case qualitative and a secondary database that provides a supporting role that is quantitative. Then, mixing of the data is made to integrate, compare, or put aside information that provides a different perspective to the overall composite explanation of the research questions.

Qualitative Element

Because the focus of the qualitative element of the study is to deeply explore the meaning that the participants give to their lived experiences of caregiving, the in-depth interview method was used for this research. As a result, this method allowed for a more in-depth examination of caregivers' experiences during the caregiving process for a child with T1DM. The experience of caregiving for a child diagnosed with T1DM by the primary caregiver, parent, siblings, or family member was the research question addressed by the qualitative method, which was the primary method.

Selection of Study Participants and the Inclusion criteria

Caregivers of T1DM children, who are receiving service at Felege Hiwot Specialized Comprehensive Hospital, Tibebe Gion Specialized Hospital, and Addisalem Primary Hospital, are the source population of the study. By applying non-probability sampling method participants were selected as the study population from the source of the population using a purposive/judgmental sampling technique. The sample size is determined by the quality and richness of the data.

Inclusion criteria for the study are; the age range of the child from three months to twelve years old. The inclusion of this age group is based on the notion that the caregivers take the burden of T1DM management. Above twelve years of age, a child or adolescent can begin self-management and strive for autonomy, transitioning to full responsibility for care, resulting in change and shared decision-making and responsibility for diabetes care activities between the adolescent and parents with diabetic child (Karlsson, Arman, & Wikblad, 2008, Silverstein, et al., 2005).

The duration of caring for a child with type one diabetes or time after diagnosis is at least three months. This duration is chosen because as mentioned in the literature, following their child's T1DM diagnosis parents are in the critical transitional periods and have a different experience than those who are two or three months later (Delamater et al., 1990, Streisand, et al.2008). And also after this period, parents will have better experience explaining their situation. The age of the parent is over 18 years. parents who are above the age of 18 and who have more than 3 months of experience in caring for a child diagnosed with T1DM are believed to have enough experience to explain and express their condition, feelings, emotions, and articulate their lived experience. In addition, those who had no other health complications both the child and the caregivers are selected. Their residence is from Bahir Dar attending a diabetic clinic at selected Hospitals.

Methods of data collection and instrument development

A one-on-one in-depth interview with participants is the primary data collection method for the qualitative phase of the study. Semi-structured interviews with open-ended questions are used to describe lived experiences of caregivers. Interviewing is by far the most popular form of data collection for qualitative research among the qualitative data collection techniques.

I found that using the interview as a data collection tool advantageous, since the essence of an in-depth interview is an interest in understanding other people's lived experiences and the meaning they make of those experiences (Seidman, 2006). In addition, observation allowed me to capture the reactions and emotions in understanding a phenomenon while conducting the interviews. The researcher have used mainly an interview for this research and every word and observations to associated emotional expression that people use in telling their stories which given the researcher access to an understanding of the caregiving experience.

An interview guide with a semi-structured question is developed which combines the flexibility of the unstructured and open-ended interview for the qualitative phase of the research. Since it is an instrument for the researcher to ensure that none of the important issues to be discussed is left out of the conversation (Seidman, 2006). The topics of a semi-structured interview are pre-determined, but most of the questions are formulated by the researcher in the interview setting. Thus in-depth interview is used in this research to explore caregiving experiences of caregivers, identify parents' child diabetes-related feelings, reactions, worries, challenges, coping and adaptation mechanisms, acquired diabetes knowledge, and available social support and their need for the child and the family.

Data collection process

Parents/caregivers who come to T1DM clinics are identified in collaboration with the health care worker. After identifying parents and obtaining their consent to participate, face-to-face contacts for interview data collection was made in a place that they prefer, which is typically the hospital compound and open silent gardens in Bahir Dar city. I have tried to suggest interview place but the ultimate decision was made by them to decide where the interview will take place. The appointments are also made in consensus with the respondents. In the interview process, audiotape and interview notes are taken, and the observation during interviews is also recorded.

Data Analysis Method

Since the study is phenomenological with its general purpose to understand and describe a specific phenomenon in-depth and reach the essence of participants' lived experience, the analysis is done using the principles of Interpretive Phenomenological Analysis (IPA), which basically deals with examining how people make sense of their experiences (Smith & Osborn, 2008). Therefore data collected from the field through in-depth interviews are transcribed verbatim to create textual material. Then textual materials are repeatedly read to identify initial open codes and notes for key concepts and statements. Following that, researcher described the meaning that the concepts give and further classified the open coding. Then, the meaning statements that individual research participants give to their experiences are described and further similarities of group statements brought together into meaning units as a process of reducing the data and forming categories. Finally, researcher read and reread the identified categories thoroughly and find out themes for discussion.

Assuring the Trustworthiness of the Data

The researcher conducted the interview with the participants in such a manner that they were able to completely convey their experience of caring for a child with T1DM. It is true that a qualitative researcher will interpret the data obtained, but it might be difficult for him/her to separate his or her background, experience, or prior understanding of the issue (Creswell, 2007). Though it might be difficult to detach oneself from the data, qualitative research's credibility is still based on the researcher's effort and competence. Therefore, to keep the trustworthiness of the data, I have tried to set aside my prior information so that the data would have a minimum personal bias. Besides, the tape-recorded interviews and direct transcription, literal statements of participants, and quotations are used in the analysis of the data so that, researcher will have no chance to put personal bias in the process.

The Quantitative Element

Research design

In the quantitative element of this study, the study employed a cross-sectional survey design. Hence the data collection is at one point in time. The purpose of investigating was to assess the impacts of having a child with T1DM on the HRQL of parent and family members as reported by the parent of the child with T1DM. The question addressed by the quantitative method is the impact of having a child with T1DM on HRQoL of the parent/ caregiver and family member as reported by parents which provides supportive data for the study conducted by the qualitative method. The data was collected in the three governmental hospitals located in Bahir Dar city administration so as to generate quantifiable information, support the interpretation of qualitative findings and generalize findings to the population.

Study population and sample size determination

The entire population has been chosen for the quantitative part of this study because the well-defined population (complete sampling frame) that meets the inclusion criteria is small, totaling 154 from the three governmental hospitals, specifically, 134 from Felege Hiwot Specialized Comprehensive Hospital, 9 from Tibebe Gion Specialized Hospital, and 12 from Addisalem Hospital. Taking the entire population helps to eliminate any potential biases occurring through sampling techniques from the three hospitals.

The respondents who had been selected as participants of the quantitative part of the study are those who are caregivers and parents of a child with T1DM whose children are in treatment and follow up regularly each month or by the appointments given by health care professionals based on how they manage diabetes at the three hospitals.

Data collection Instrument

The instrument that is used (for objectives 2), the impact of having a child with T1DM on HRQoL parents and the family is the Pediatric Quality of Life Inventory™ (PedsQL™) Family Impact Module(FIM) which is a multidimensional instrument developed to assess the impact of chronic medical conditions of parents and family functioning. The PedsQL™ FIM measures parent self-reported physical, emotional, social, and cognitive functioning, communication, and worry. The Module also measures parent-reported family daily activities and family relationships.

This data collection instrument has 36-item that encompass 6 scales measuring parent self-reported functioning: 1) Physical Functioning (6 items), 2) Emotional Functioning (5 items), 3) Social Functioning (4 items), 4) Cognitive Functioning (5 items), 5) Communication (3 items), 6) Worry (5 items), and 2 scales measuring parent-reported family functioning; 7) Daily Activities (3 items) and 8) Family Relationships (5 items). The PedsQL™ Family Impact Module was developed as a parent-report instrument. A 5-point a five-point scale questionnaire ranging from response scale is utilized ranging from (0 = never a problem; 4 = always a problem).

Data Gathering Procedures

To gather the quantitative data, the researcher reviewed the outpatient department abstract register book; a document that records demographic information, card number, diagnosis, referral, and other information of the patients. Based on the information recorded in the document and according to the inclusion criteria, the researcher identified the number of patients with T1DM whose parents can be included in the study. Then the researcher contacted them when they came to the hospital on the appointment date with their health care professional and also by taking the address from the list. Before the actual use of the instrument, pilot taste was conducted and the validity and reliability of the instruments were checked. Then, with the help of intern medical practitioners, the data was collected.

The actual data collection began by introducing the purpose of the research to the respondents and by asking their willingness/consent to devote some minutes to fill the questionnaire. After getting respondents' oral informed consent data were collected by the researcher and trained data collectors and then the data was made ready for analysis. Based on the literacy level of the respondents the survey questions were administered and filled by themselves and by data collectors. The data collected at the hospitals mainly on the date of the appointment of health service.

Variables

Dependent and independent variables

The dependent variable in this study is the impact of having a child diagnosed with T1DM in terms of HRQOL of parents/caregivers and family members. Based on the literature review, researcher conducted from the existing literature written in other parts of the world, the independent variables in the study include personal, social, demographic, and health-related factors of parents and their child with T1DM. Some changes were made to these independent variables of the study after the finding of the qualitative part of the study. Thus based on works of literature the study incorporated the following independent variables: age of the child, marital status, number of children in the family, sex, educational level of parents, average family income, duration of diagnosis, age at diagnosis, and other socio-demographic clinical related variables. These variables were measured and examined to have a better understanding of the issue under study.

Data Analysis Techniques

The quantitatively collected data of the study were analyzed using Statistical Packages for Social Sciences (SPSS) version 20.00. Both descriptive and inferential statistical analyses were employed in analyzing the collected data. Descriptive statistical analysis involves using frequency counts; percentage, central tendency such as mean, median, and mode to explain the average statistical characteristics. Socio-demographic and other characteristics of parents and clinical characteristics of their child were described using descriptive statistics of median, range, and percentages. Continuous variables were summarized as mean and standard deviation, while categorical variables were stated as count and percent n (%). After the data has been transformed, a multiple linear regression analysis is used to investigate the difference in mean score and to find a significant predictor factor of parents' HRQoL.

The PedsQL™ Family Impact Module which is developed as a parent-report instrument uses a 5-point Likert scale response (0 = never a problem; 4 = always a problem). Items are reverse-scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher scores indicate better functioning (less negative impact). Scale Scores are computed as the sum of the items divided by the number of items answered by taking into accounts missing data. The Scale Score is not computed if more than half of the items on the scale are missing (Fairclough, 2010).

Validity and Reliability of the Instruments

Regarding the validity of the instrument, the researcher gets the instrument commented by his advisor and other researchers' comments were considered. Besides, a health officer working in other health care institutions commented on its content validity. Based on the comments given on the instruments; the researcher considered their comments to make appropriate revisions.

Besides internal consistency reliability alpha coefficients for the PedsQL™ Family Impact Module scales exceeded the minimum reliability standard of 0.70 (Nunnally, 1994). Most PedsQL™ Family Impact Module Scales approached or exceeded the reliability criterion of 0.70 in a study conducted in the USA, Saudi Arabia, Brazil, and Kuwait have demonstrated the validity and reliability of this instrument. In the current studies too internal consistency reliability alpha coefficient values for the PedsQL™ Family Impact Module scale done by the researcher after the pilot study exceeded the minimum reliability standard of 0.70. A pretest among a 35 subset of target respondents' Cronbach's alpha value of 8 constructs is summarized in table 1.

Table 1

Reliability Test

Variables	**No. of items**	**Cronbach's alpha**
Physical Functioning	6	0.73
Emotional Functioning	4	0.74
Social Functioning	4	0.85
Cognitive Functioning	5	0.75
Communication	3	0.77
Worry	5	0.95
Daily Activities	3	0.76
Family Relationships	5	0.88

The reliability test of the questionnaire was in the acceptable range (> 0.70). As indicated in the above table, the reliability results of the eight constructs were 0.73 (Physical Functioning), 0.74 (Emotional Functioning), 0.85 (Social Functioning), 0.75 (Cognitive Functioning), 0.77 (Communication), and 0.95 (Worry), 0.76 (Daily Activities) and 0.88 (Family Relationships).

Ethical Consideration

As Kreuger and Neuman (2006) stated social work researchers should follow proper ethical guidelines even when the study participants are negligent or unaware of it. Therefore to follow the ethical guideline support letter was obtained from Bahir Dar University Department of Social Work. Besides, the researcher took letter approval from the hospital medical directors; approached the participants with a written letter approved by the Social work Department of Bahir Dar University. The study is carried out in line with social work research ethics by following strict respect for informed consent, voluntary participation, and confidentiality. During the selection of participants as per their voluntariness, parents/caregivers were given a clear explanation about the purpose and importance of the research and their roles in the study.

Limitations of the study

The study has achieved its intended objectives. However, it does have certain limitations. Despite the fact that various chronic diseases exist, this study focused solely on caregivers having children with T1DM. Besides all of the participants were residing in Bahir Dar. As a result, the results of this study do not adequately reflect the experiences of parents of children with T1DM from various backgrounds, cultures, or ethnicities. As a result, the generalizability of a qualitative study may be reduced. Furthermore, the individuals were not chosen based on their family's household income. While this may have increased the richness of the data, it may also have influenced the outcome. The lack of a control group to compare with the study group was a limitation of the quantitative phase of the study. There are also other determinants of HRQoL that were not investigated in this study, such as family conflict and family relationships. Finally, the nonexistence of local study on HRQoL of parents and the researcher's lack of experience conducting health-related studies may impose their own limitations on the study.

Chapter Four: Finding of the Study

Qualitative Finding

An analysis of the interviews revealed a number of constructs that are discussed within the context of the challenges of caring for the child with T1DM, available social support, and coping and adaptation mechanisms as experienced by the caregivers. The first section of this chapter describes the demographic characteristics of the participants. The next section addresses a collective summary of themes. Fifteen caregivers receiving service at 3 public hospitals in Bahir Dar city administration were the participant of the study. It was composed of eight fathers and six mothers and 1 sister. The age range of caregivers is from twenty five to fifty five years. Seven of the participants were from Felege Hiwot Specialized Comprehensive Hospital, 4 from Tibebe Gion Specialized Hospital, and 4 Addisalem Hospital.

All of them were married and they reported living with 2 to 10 members in their household. Six of the participants as a family had a monthly income 4,000 and less. One caregiver did not know her monthly income (her husband was the breadwinner), and the rest made 5,000 -20,000, birr per month. Four of the mother caregiver participants reported that they did not work outside the home at the time of the interview. Concerning their educational background, 1 caregiver reported having no education at all, 4 participants had attended primary school, 3 participants have a diploma, 6 of them bachelor degree 1 have a master's degree. The ages of the child when they were first diagnosed with diabetes ranged from 1 year and 3 months to 11 years. The participants reported living with a diabetes diagnosed child from 1 to 9 years. 5 participants had poorly controlled child's Fasting Blood Glucose (FBS) level (=> 216 and < 70 milligram per deciliter (mg/dl)), 5 of them have fairly controlled diabetes (183-215) and 5 of them have good diabetic control (≥71-180). The socio-demographic and clinical related characteristics of caregiver and their children are summarized in table 2 (see Appendices 7).

The collected data from fifteenth caregivers of children with diabetes using in-depth interviews were analyzed to infer meaning. The themes were organized based on the objective of the research. Seven general themes emerged and included issues related to (a) Initial experience at the time of diagnosis (b) Facing the Caregiving Challenge at Home, (c) Distressful caregiving process (d) Hard Life with Diabetic Care (e) School Difficulty, (f) Coping (g) Social support. Within each of these themes, sub-themes were identified. The themes and sub-themes are discussed below.

Initial Experience at the Time of Diagnosis

Parents discussed how they first became aware of the symptoms and what they went through when they were diagnosed. Due to a lack of diabetes awareness, the symptoms were originally misrepresented by the parents. Their medical diagnostic did not turn out as they had hoped, and they were filled with regret for not acting sooner when they first saw the symptoms. They remained somewhat longer at home, which resulted in serious complications. During their first encounter with the symptom as well as the first diagnosis of their children with T1DM in the hospital, parents exhibited a variety of common and distinctive emotions.

Problem to identify symptoms of diabetes

Despite the fact that each participant's experience with indentifing their child's diabetes was different, they all shared some similar moments. All parents initially misinterpreted the signs of a common disease in babies and young children. They all stayed at home a little longer, hoping that their child would feel better soon. Many of the parents stated that their child has suffered dehydration and frequent urination. Tsehay, a mother of a 12-year-old boy whose child was diagnosed at the age of 4, for example, said, *"Before he was diagnosed for diabetes he was experiencing some symptoms for about 15 days like low appetite, too much urination and too much drinking water"* Selam, a mother of a 7 year and 5-month child at the time of diagnosis, expressed remorse for being inconsiderate to her child for waking her up at night for urination, saying, *"I never thought it would be diabetes… She would not be in diabetes ketoacidosis if I could have just linked it to diabetes."* Alemu who is the father of an 11 years old boy, has a degree in special needs and inclusive education has some awareness about T1DM and he was able to guess that this could be the symptom of diabetes and he immediately took his child to the hospital for laboratory examination. As he stated,

> Before we took him to the hospital he was sweating and his body was shaking, drinking a lot of water, and urinating. After that, I knew this was a symptom of low and high blood glucose so I took him to the hospital for diagnosis.

Aster a mother of 7 years old described her experience of the first time seeing symptoms differently:

> when he was a little around one year old there was some form of bleeding around his genitals, but I thought since I am using a diaper it could be inflammation but after a while, it started to get worse, then we took him to a health center for examination, yet I thought it could be an infection but after laboratory examination of his urine and blood, they told me it types one diabetes.

Similarities can be established from parents' statements based on their experiences of observing T1DM symptoms in their children. All of the parents' initial interpretation of the symptoms as a common disease for children was incorrect, with the exception of one parent who had some prior knowledge of T1DM. Lack of awareness about the symptoms and the fact that the outcome of their medical diagnosis differed from their expectations has resulted in guilt for mistreatment of child for one parent.

Reaction to medical examination

During the first time of diagnosis, the majority of children were admitted to a hospital. Parents have experienced traumatic, positive, and neutral experiences. Four children have been misdiagnosed during the medical examination. One parent, Mahder, was told it is asthma, another caregiving sister of diabetic child Mahlet was told that their child’s case is a pelvic inflammatory disease; Selam was told her child was diagnosed with typhoid and typhus. And another parent, Manyazewal reported that his child was given a drug for which he had no idea what it was for. Tsehay’s son's disease was not known by a medical professional for 5 days while her child was still sleeping in the hospital. Manyazewal, a father of 12 year old daughter, described his situation as follows:

> …I took her to a private health center, but the health care professional did not know the disease so they gave us a syringe and told me to buy her a soft drink but after she drunk she got seriously ill almost close to dying then I brought her to Felege Hiwot Hospital and after laboratory test, they told me it is diabetes…at that time I was so scared I thought she was about to die.

Mahder described the situation as follow,

> The first time I knew it was diabetes I was in the hospital. It was very hard. I was shocked because I did not totally expect that at first. At first, the doctor even thought it was Asthma then he gave us some medication but she did not get better. When we came back to the doctor for the second time after a while, my husband told them one of the symptoms of our child was too much urination, then they immediately conducted a laboratory test for her glucose level then they found it was diabetes.

A more traumatic experience was witnessed by the caregiver of children admitted to another local hospital. Caregivers complained about the medical professionals' competence. For example, Melakamu the father of 2 years old child at the time of diagnosis elucidated:

> We had the most horrible hospital visit we ever had. It was a nightmare. They had to poke him three times before the thing they put on his arm [IV] could be started. And, the IV they used was not a good IV. As I stood there holding him, he moved, and it broke apart, dripping blood all over me. And then the nurses were not nice at all.

Azeb, the mother of a 3 years and 8 months old child at the time of the diagnosis, and at the local health care center were also not happy with their experience. *"Felt like we had a painful, uncomfortable experience. I think we were one of their first diabetics, so they really did not have experience."*

The parents and caregivers were faced with an acute mental crisis such as consternation, confusion, and shock when they were told their child was diagnosed with diabetes. All their attention was concentrated on their children who were ill, so they could not concentrate on other activities and problems around them. As Azeb put it, "*When someone spoke to me, I kept thinking, 'let my husband come over here and speak to you'. I kept crying all the time. I did not even pay attention to what the doctors were saying".*

The most common first-time reactions of caregivers to being told their child has diabetes were shock, anger, weeping, sorrow, and grief. Alemu remembered the moment as, "*When the doctor told me my child has diabetes I was shocked and did not know what to do.*" eight participants indicated that they had feelings of hopelessness. Tsehay said "*Well, I almost felt like my child has no future"* however some parents with little awareness of type one diabetes were not that much shocked until they knew it is lifelong.

The caregiver portrayed the innate parental instinct that comes with knowing their child have T1DM such as shock, anger, and grief. The understanding that the child's survival is entirely dependent on the parents' care also resulted in fear and anxiety. The parents' responses emphasized how critical and stressful it was to hear that their child had been diagnosed with diabetes. It represents a critical moment in one's life when new obligations and demands are introduced. Parents described how their child (new baby) experience began the moment he or she was diagnosed with T1DM, which usually occurred in the hospital. The child is no longer the healthy child to whom they had lived up, but rather the vulnerable child.

Facing the Caregiving Challenge at Home

After the diagnosis of T1DM in children is confirmed and following their discharge from the hospital, the care of these children was transferred from healthcare providers to parents or caregivers. Parents in addition to their role as a family member for example maternal and paternal roles, they had to perform a caregiver’s role; as a result, they faced several challenges. Therefore, acquiring the knowledge and skills to play this role effectively were crucial. Also, they needed the support of family and healthcare professionals.

Non-adherence with diabetic care

For most of the caregivers making lifestyle changes in their children’s lives, such as managing the children’s diet was challenging. Children’s non- adherence with the diabetic diet were common for it was inconsistent with children's demands, and they barely resist their desires for prohibited foods especially foods with high sugar content. As Aster explained it:

> My child should eat a low sugar diet, but whenever I am not around him and find the chance to eat things such as candy and biscuits, he wants to eat. He is not able to control himself, and I just do not know what to do.

Similarly, Hirut acknowledged this concern by stating:

> He needs to eat something when I inject his insulin, but he doesn't eat anything and claims he is full so that I can give him the food he likes the most which are sweet foods and other food such as white bread that should be taken in a small amount; I tell him he should only have a small amount of sweet foods but he wants more, he does not listen to me.

The control of the children's blood sugar is another duty of the caregivers after hospital discharge. Because it is influenced by reasons such as diet and stress that can alter rapidly, they are required to monitor their children's blood sugar after each meal is eaten to determine the amount of insulin. As a result, this involves a regular, uncomfortable blood sugar monitoring procedure, and children do not cooperate with it easily. As Kindu stated, "*My child does not like her blood sugar checking process. I have to persuade her to let me check her blood sugar, but I have to do it by force sometimes.*"

In order to successfully manage this disease, the children must adherence completely in all aspects. Caregivers, however, shared their concern that because this disease began in early childhood, their children do not understand the things that need to be done, they frequently face resistance from children. Manyazeals' experience clarifies this point, *"she does not remind me if I forget to inject her insulin. Occasionally she says she has injected her insulin, but she actually has not done that mainly because it is painful"*. When it was time to administer their insulin, parents reported that their children were hiding or resisting. Especially the youngest children, those diagnosed at 2, and 4 as Tizetaw and Mahder reported they would run and hide or scream while crying *'That hurts me, do not do it please!'*.

Sharing caregiving burden

Some maternal caregivers said the administration of a painful procedure such as insulin injection was very painful for them as a result; they referred to others to perform it. As Mahder stated, "…*I was shaking my hands the first time I tried to administer insulin. I was so frustrated that I was unable to do so, so I asked my brother to inject the insulin".* The mothers wanted the support of their husbands due to various responsibilities and difficulties in child care management. The majority of the mothers said their husbands were involved in the treatment and management of their children. As Hirut reported, *"My husband goes to the Diabetes Association in Bahir Dar; he gets magazines to read on the management of diabetes."*

Some caregivers said that they were not sufficiently supported by their family and friends to care for their children because they felt it was difficult to care for a diabetic child and could produce unpredictable situations for the child at any time, which would be impossible to monitor. As Tamrat stated:

> Nobody is willing for a day to take care of him. I have even tried to hire a caregiver for him. They say they are scared because if his blood sugar goes up or down, some risks could come up. The management of the disease requires somehow complicated knowledge.

Due to varied obligations and challenges in child care management, the caregivers sought the support of significant others. Although the majority of parents stated that their partners were active in their children's treatment and management, caregivers also indicated that because caring for their children was tough and necessitated a certain level of knowledge they did not receive enough assistance.

Distressful Caregiving Process

Caregiving process mentioned below further dig into the challenges, pressures, and complexities of the activities of the parents as they take care of their child with T1DM. Different emotional pressures such as guilt, shame, preoccupation, and anxiety were faced by the caregivers. Dealing with their everyday duties in the management of diabetes was very difficult for them, so they felt a heavy burden as they still had to fulfill the caring needs of their children.

Constant protectiveness

As caregivers' experience of caregiving has shown, treatment was indeed a complex process involving biological, physical, and psychosocial factors.A series of procedures are undertaken by parents in looking after their child, which "literally kept them vigilant with some difficulty" as Selam expressed it. In order to maintain blood sugar readings within the normal range, repeated blood sugar monitoring, insulin injections, and attention to diet and activity levels were involved in this day-to-day management. The experiences listed below show this management's everyday routines. Selam reported:

> …she has to take the injection [insulin] on time, twice a day; she needs to eat when she needs to eat. If I keep her with someone else she may forget the food she has to eat or she may not eat properly or when she is with other children she may mistakenly eat the food

> she is not supposed to eat. Such problems might happen. So until she grows up, I must be around her, I have to continue sticking with her.

Similarly, Tsehay stated:

> ...he gets injected every 8 hours a day, in the morning, in the afternoon, and at night if not more. We also check his blood glucose level after every meal, but now mostly in the morning and at night because he has started school. We go to the hospital once in a while, based on the appointment date given by doctors. So I have just become my child's stay-at-home doctor [laugh].

Hirut also acknowledged saying, "*It is difficult to keep them engaged. There is the whole balancing act of food, exercise, and insulin, which is always a challenge.*"

Diabetic children need a balance between food consumption, insulin injections, and movement. The above experiences show caregivers' role in ensuring activity and regulating the complex diet, activity, and medication interactions of their child.

One of the most prominent aspects of caregiving is "*clinginess*", a term mentioned by Selam to characterize the constant and demanding aspects of the condition, "*…the hardest thing for me about diabetes is the relentless constancy of it every day. You cannot take a day off, leaving her with someone else, or say I do not do this today. I have to cling to her".* This caregiver stresses the lack of options on a regular basis in managing the disease. The concept of "*clinginess*" illustrates how the diabetic body's demands are ever-present, leading to a high degree of caregiver involvement and a lack of caregiver break. Caregivers also explained how potential long-term complications, such as amputations, blindness, and even death can occur without good management, which indicate one of the reason why caregivers have to cling to their child. As Azebe stated:

> Whenever I think about the low probability of a cure for the disease, I get worried a lot, besides what frightens me the most is medical complications that could come in the future when she gets older. They say it could cause kidney failure, eye problems, and other organ failures if it is not properly managed.

The experience of caring for their child with T1DM was characterized by constant vigilance and careful management. This activity was described as requiring continuous conscious effort, active involvement, and attention, all of which can be exhausting. The way their family life revolved around diabetes was explained by one caregiver Melkamu:

> That is tough work. You are conscious of where he is, who he is with, all the time. Is it time for food? Is he all right? What is his blood sugar level? My daily routine and thoughts tended to revolve around what his blood sugar level is.

This attentiveness was portrayed as a very ongoing process. It was necessary to monitor all aspects of the daily life of their child to maintain blood sugar levels.

Parents have employed various approaches to achieve the desired outcomes. Parents tried to maintain constant doses of food, exercise, and insulin. Yet sometimes they get unpredictable outcomes. This has also left parents frustrated and struggling to make sense of the scheme. As one caregiver, Dereje, said, *"Sometimes it is really hard to figure out the things that need to be* *done to keep the blood sugar at recommended level"* referring to the difficulties of figuring out the requirements of the body. The erratic nature of diabetes has often made attempts to treat the disease appear fruitless, as Alemu mentioned below, "*sometimes, it makes no sense. When we are doing exactly the same things, eating exactly the same things, and then you give her exactly the same the next day his sugar level is high.* As illustrated the child with T1DM is described here as being within an unpredictable body; the predictable input and output patterns have become unreliable. Even with careful planning, there is no guarantee of consistent results. To make sense of this unpredictability other caregivers stated more meaningful expression, they added additional factors, such as integrating emotion control into this context, as Aster clarified:

> …but there's another thing I was informed by the doctor. I used to think it was all about activity and food, but that is not always the case. It is also about emotional reaction, stress, and which we can be aware of. For example, last time when we were in a neighbor's house a dog barked at my child suddenly then he was so scared. Then after a while when I check his sugar level it has gone high. When he also has a stressful event, like school exams it really makes his blood sugars high.

Instead of viewing the inconsistent outcomes of blood sugar as inherently unpredictable. This caregiver attempted to integrate another aspect of the life of the child, emotions, into the process of understanding the outcomes of blood sugar. This reflects how the child is more than a physical body. It incorporates connections between the body and mind (emotional state). Yet, there is still no resolution to the unpredictability. It is seen as additional influential aspects that need to be integrated into their child's careful management.

Guilt for negligence in caregiving

Often the management of the children clashed with the personal affairs of the caregivers. This caused them to care less about their children. And in the meantime, if anything happened to their children, the caregivers suffered from feelings of guilt and blamed themselves. As Selam stated “*The most difficult day for me is when my child's blood sugar rises or falls, and I believe this occurred because I was busy with other issues”* The caregivers tried to devote a large portion of their time to looking after their children, and they observed them in all facets of their lives. Some of them thought that if they left their children for a while, they had made a huge mistake because they believe that nobody could handle their children like them**.** In her own words, Mahder reported, *“I have to be there all the time; I am supposed to look after my kid. If I leave him, I feel like it is a great mistake”*

Owing to poor awareness of the initial signs of the child's illness, other caregivers faced a sense of shame. Some of them said they did not know a diabetic person in their family, relatives, or neighbors, so they did not know the symptoms. For certain others, the condition was entirely unknown. Some of the caregivers had previously experienced guilt for giving their children unhealthy diets. As Mahlet explained, *“I should confess we used to eat a lot of sweet foods including soft drinks we drank. Perhaps I feel that is why she became diabetic”.* They claimed that if they had a better way, then their children's diabetes might have been avoided. As Melkamu lamented “*when my son was getting weak, I thought it was some simple condition, so I postponed the visit to the doctor because I do not know the signs of diabetes. But staying at home made his condition worse.”*

Despite the fact that caregivers strived to spend a considerable percentage of their time caring for their children, the management of the children occasionally conflicted with the caregivers' personal life, causing them to become less concerned about their children. In addition, other caregivers felt ashamed because they were unaware of the child's illness's early indicators and the effect of eating unhealthy foods. These resulted in caregivers struggling with feelings of guilt and self-blame. This suggests that even with increased caution, caregivers were not immune to the negative repercussions of having a child with T1DM and that some of the factors affecting their well-being were unforeseen to them.

Insecure preoccupation

One of the challenges these caregivers were talking about was the fear of a bad accident or events, something that would happen to their child when they were away from them such as school. The caregivers were aware of the possible difficulties and complications of the disease and which they would not be able to monitor. The high and low episodes of blood glucose could happen either because of inappropriate carbohydrate intake, an inappropriate dose of insulin, or perhaps due to stress. Aster explained this condition as follows, *"I feel stressed when my child is not next to me; I worry that something terrible will happen to my child and no one will be able to do something."* Manyazewal reported,

> Most of the time it is hard for me to keep my attention on the things I am doing. When I am at a workplace, if I hear something happening to her I will leave whatever I am doing and come to the place my daughter is. Throughout the day all my concern is to think about her, whether she is fine or not. Even at night, I do not get enough rest.

Due to the disease's potential threats and complications, which they could not monitor if their child is not around them, caregivers' were insecure and preoccupied with the thought of a serious accident or event happening to their child were common among caregivers.

Concern about the vague future of the child

The caregivers experienced a life full of worries because of the effect of diabetes on different aspects of children's lives, recognizing that diabetes was a danger to the health of children and its complications that affect them later, and also about the social life they are going to have. They were worried about their children's presumptions of a distant and unknown future. In this regard Kindu, made this statement, "*I think a lot about his future. I am wondering what is going to happen to his health. Can he be successful in his life? I have no idea what the future holds; the future is uncertain."*

The future of their children's marriage was another area of concern for caregivers. They wonder if their children with diabetes would get married, and whether or not these children will be accepted, regarded as fit, and enough to have a good and stable marriage. This mental preoccupation upset the caregiver very much. As Tizitaw put it *"It is so hard, particularly in our society, for a girl. Will anyone be interested in her when she wants to get married? These things worry me about the future of my kids".*

Caregivers were also worried about potential unpredictability due to developmental changes. As Mahlet put it, *"you know puberty is the next major challenge. I have heard that the hormonal change that causes them to behave erratically can negatively affect blood glucose* *regulation. And I am afraid of it."* Even in the middle of current stability, future uncertainty is a source of concern. Parents were worried about such changes and how it could hinder well-planned management and monitoring strategies.

Uncontrollable Hindrance of Diabetic Care

Caregivers face different kinds of hindrance in diabetic care. The following issues are illuminated by the caregivers. For most of the caregivers using specialized care programs for their children was costly, which they claimed to be found in private hospitals. Governmental hospital coverage for drugs and other necessities was insufficient and was not always available and families must navigate the complexities of the organizations' bureaucracy to meet these needs. Sometimes even the insulin was not available in the market for those who were able to buy from the market. In addition, caregivers reported the cost of diabetic care affecting their household expenses. The experience facing diabetic complications was also discussed.

Facing economic difficulties

For families having a child with diabetes, particularly those with low household incomes, the cost of lifelong insulin treatment, constant monitoring of blood sugar, and the requirements for managing childcare along with special diets for diabetes are very difficult. This puts a heavy financial burden on them in such a way that other family expenses sometimes have to be cut to cover the costs of care. As described by Melkamu**,** *"It is too costly for the test strip and the insulin needle. We did not have these costs before, but now, for the sake of our child, we have to save by reducing family expenses."*

Many of the participants said that they really wanted to use specialized services such as advisory services to improve the health of their children, but that paying for them was difficult, if not impossible, due to the high costs of these services and low household incomes. According to Ayele:

> If I had enough money, I would monitor my child's sugar two ways a day but since the test strips are too expensive I use it occasionally once a week, I will also take her to a private hospital so that she can find a good doctor. But I cannot do so.

Similarly, Selam stated:

> The cost of the test strip is very expensive, even a lot more than the insulin, you know 50 test strips cost 350 birr. If I use it at least two ways a day it will not be enough for one month.

Most mother caregivers reported that their husbands' income was not adequate to cover their living expenses. While some of them prefer to spend their time looking after their children, others have had to work outside the home. As Azeb reported, "*some of my problems are due to the lack of sufficient wages. I want to be beside my child until he starts taking care of himself but I have to also work to cover his medical and other household expenses.*"

Facing diabetes complications

It was painful for the caregiver to encounter the complications of diabetes. The occurrence of problems with the child, such as facing the health-threatening effects of the child and hospitalization of special care facilities, placed the caregiver in a vulnerable condition. Some of participants said that they are often presented with diabetic problems amid all attempts to monitor their children's blood sugar. As Manyazewal stated, *"She felt nauseated, and could not sit on her feet. When we entered the hospital, she had lost consciousness. She was moved to the emergency room. Her blood sugar was more than 500. It was really tough."*

Diabetes complications can put the caregiver in a difficult and dangerous situation. The caregiver was put in a helpless position as a result of the child's health-threatening negative impacts and emergency room visits for special-care facilities. Despite their best attempts to keep an eye on their children's blood sugar levels, numerous caregivers reported they are routinely presented with diabetic complications such as blood glucose swings that are too high or too low. As a result, they became overwhelmed and worried, which had a significant impact on their emotional functioning.

Challenges Facing at School

This theme discussed the challenges caregivers face from the school. The sub-theme of school difficulties includes; difficulty of keeping their children safe from harm, lack of cooperation from schools.

Difficulties to keep their children safe from harm

This sub-theme revealed the difficulty of caregivers in protecting children to ensure the child's safety from harmful diabetes-related effects while their children are in school. Parents discussed how they worked hard to keep their children safe from harm. In an attempt to protect children from diabetes-related accidents or undesirable social consequences, a great deal of work was done to inform school officials and staff. This involves advocating for the child.

Many parents visited their children's schools to inform teachers and staff about the signs and effects of low and high blood glucose levels, as well as measures to be taken in case of an emergency. Other parents reported how they suggested to school officials that they should have a qualified nurse and a room for blood glucose monitoring and to put treatment material such as insulin and glucagon. Tsehay who once used to live in the USA and come back to Bahir Dar two years before, in 2019 when her child turned 10 years old stated:

> …But here in the school no one cares about his situation, they do not give him the attention he needs, though he is learning in the so-called among the best private schools in Bahir Dar. I have searched for a school that has a nurse but I cannot find one, previously he was learning at Abune Gorgorious school and there is no nurse in this school…now he learning at SOS school…there is no nurse in this school too, so he started injecting himself starting from 11 years old, for about one year I was the one injecting him in the schools going back and forth, it was hard for me. I have told the school official that the school needs nurses not only for my child but also for other children with a similar case or other emergency cases, but they did not hire one yet.

Tsehays' son also felt distressed and singled out because he had to go to the toilet to inject his insulin and missed out on time with friends*. "…he injects himself in the toilet. You know he is going to the toilet by separating himself from his friends. It is depressing."*

The caregiver who believed their children's teachers were not responding adequately demanded that changes be made at school. As Alemu said:

> When I felt like teachers weren’t aware of diabetes, they are not giving some privilege, for example eating some amount of sugar or candy when his blood sugar level gets low. I went to a school official and complained about their lack of knowledge and I told him ‘you should teach your staff.’

They believed the school was not welcoming them because they were not well-informed about diabetes as Aster also mentioned,

> when he inter to grade one there are many different teachers for different subjects… and there was a new teacher who did not know my child…one day when he experiences shakiness and tiredness [symptoms of low blood glucose level] he ate the candy and as I told him, the teacher who saw him eating candy she told him to spit what he is eating, saying ‘it is forbidden to eat candy in the classroom’ he responds to her saying ‘I have diabetes miss that is why I ate’ she thought it was a lie and she commanded him to spit the candy with irritation. When he told me this I felt so bad. How could she do not understand a child telling her such things? Is there a joke about illness? If a child tells you this you would even feel more compassionate to treat him well.

Situations like these undermine parents’ trust in teachers' knowledge of diabetes and how they respond to their child in an emergency. Caregivers have difficulties trusting a school where the staffs are not well-informed about diabetes.

Some parents were worried not only about teachers' low level of response or reactions but also about teachers' overreactions, which damage the child's self-confidence. As Hirut stipulated,

> I hate when the school personnel consider my child as if he is disabled, if it is effectively managed diabetic child can live a normal life. But Sometimes they over sympathize when they know my child has diabetes. Children need appreciation and motivation, over sympathizing can undermine their self-esteem.

Parents wished for their children to be as integrated into school as possible so that they could be cared for without feeling alone, but they did not always have confidence that this would happen.

Lack of cooperation from schools

Most of the participants reported having uncooperative school experience while a few others reported having cooperative experience**.** Some caregivers as in Kindu said they have a positive experience. *"My sons' teachers are good, they try to become responsive to his needs."* Similarly, Tiztaw, *"It is like school is now relatively fine. Fortunately, the recent teacher was helpful, have a good manners. The school is also cooperative."*

Yet, the majority of them reported they have difficulty persuading the principal or obtaining necessary cooperation and they expressed dissatisfaction with their school's support, saying things like *"When I moved my son to the school he attends now, it took some time to enroll and reach an agreement to get the necessary cooperation from the school staffs"*(Tamrat).

Ayele stated his son was not allowed to attend the school located near to their residence although he is seven years old, grown enough to attend school, in his word, *"They told us he could not come back to school until he was more aware of himself and learn to do his injection in case of emergency [e.g. low glucose level] because there is no nurse in the schools."*

A similar piece of information was given to another caregiver, Azeb said. *"They do not have anyone else willing to give her glucagon"* she reported that the kindergarten teacher refused to deal with the situation. This caregiver eventually pulled their daughter out of school. They have since moved to a different school.

Some difficulties, with the school, may vary by teacher, and the school the children with T1DM are enrolled in. As Melkamu stated, *"you may find in kindergarten where teachers are totally supportive in one year, then the following year, you will have a teacher who is careless and does not know or care."* Mahlet acknowledged this challenge by saying, *"my sisters' last year's teacher was bad. It was a hard time. Then there is this year's instructor, who has been very helpful."* Some caregivers talked about how difficult it is to address problems with the school. Aster *said, "We have had our small fights, but now I feel like we have made a change." "I have to demand and question them if they are not doing what my son needs"* also Dereje added.

The majority of those who took part in the study stated they had a difficult time in school. Some issues with school vary depending on the teacher and the school where T1DM children are enrolled. However, the majority of them have trouble persuading or receiving necessary assistance from the principal and school employees, and they have expressed unhappiness with their school's support.

Availability of Social Support

This theme discusses the social support available to needs caregivers in dealing with their difficulties. Caregivers indicated they needed social support, including psychological and practical social support. They also stated that they had unfulfilled demands. Caregivers felt that the support the diabetes association provided them was a helpful knowledge and skills. However, there was a misunderstanding in an extended family in supporting caregivers, despite their intention was treating diabetic children better; there was also a lack of community awareness about T1DM and unsupportive responses; and there was insufficient support from government and organizations in accessing medical supplies, as well as difficulty meeting treatment requirements due to high treatment costs. They also reported, and their suggestions on how could be better supported in the future.

Inadequate organizational support

Lack of sufficient support from government and organizations was another issue that was raised by caregivers. They reported that the support provided to meet the needs of children with diabetes was not adequate and the service they receive from the governmental hospital is of poor quality, because of the high cost of specialized care in the private sector they cannot afford. Only insulin is provided for free when it is available, otherwise, they have to buy from a private pharmacy. In addition glucometer, test strip, and additional insulin syringes are not provided by the hospital. As Kindu stated, *"The hospital only provides free insulin and insulin syringes and* *medical and check-up service for children less than 15 years old but we have to buy other diabetic equipment and supplies from the market."*

For all children, the share of insulin was the same, and some caregivers complained that their share of insulin, insulin syringes did not adequately meet their child's needs, so they had to buy extra insulin from the market. It was difficult for them to fulfill the treatment requirements. Ayele's experience clarifies this point further:

> The hospital exclusively provides free drugs [insulin] and syringes [insulin syringes] that can be used for a month or until the next follow-up appointment, additional insulin, insulin syringes, are not provided. Sometimes we need additional insulin and syringes because some of the syringes get broken in the process of injecting my child, as he is not always cooperative he moves his body and refuses to get injected. Even some insulin gets broken, just because we are human we make mistakes you know. The other tools like blood sugar meters, insulin pens, and test strips must be bought from the open market.

The caregiver also described how the cost of one blood glucose monitoring instrument that is a test strip which is used with a glucometer to read blood glucose level, is too expensive and to make the matter even worse one test strip is used only once. As Melakmu stated, "*The test strips are too costly and much more expensive than his drugs. There are no organizations that support us or provide us with discounts."* But for those caregivers who are a member of the diabetic association, the test strip has been provided for free. According to Aster:

> We are a member Ethiopian diabetic association Bahir Dar branch. They gave us the blood sugar measurement machine [glucometer]. Before that, I bought it by myself, it cost around 400-500 birr, but it does not work properly. And they have also given us the test strip which is too expensive. 25 pies cost from 300-400 birr on the market, plus it is used and thrown. It can have a huge economic impact and sometimes it is hard to find a test strip and the measurement machine even in Addis Ababa let alone in Bahir Dar but since he is a member of the association he gets the measurement machine the test strips from the association and each month.

As participants stated one of the concerns of caregivers was a lack of adequate organizational and government support. When insulin is available, it is offered free by government hospitals; otherwise, they must purchase it from a commercial pharmacy. Blood sugar meters, insulin pens, and test strips are among the various items that must be purchased on the open market. A test strip, which is used with a glucometer to read blood glucose levels, is far too costly, and to make matters worse, each test strip is only used once. The other issue was accessibility, it can be difficult to obtain test strips and blood sugar meters on the open market.

Acquiring knowledge and skills from the diabetic association

Caregivers reported that they had gained a better understanding of diabetes. They have to keep learning about the true meaning of their children's blood sugar levels and how it affects their functioning. Most of them said that in this respect, they had not overlooked every opportunity to increase their knowledge, because they thought that certain things they wanted to know would still exist. They wanted a trusted source as well. According to Ayele *“I go to the*

Diabetes Association each month. I need their programs for understanding. I just enjoy knowing it all". Two other caregivers, however, claimed that the information provided was not adequate and referred to various tools, such as the book and the internet, to increase their knowledge, *"It was very beneficial to obtain instruction from the association, but I gained more awareness by reading books and visiting websites on the internet"* (Melkamu). "*I prefer reading on the internet from some trusted websites than relying on the information I receive from the associations"* (Dereje).

Learning new skills and knowledge regarding T1DM has helped them better comprehend the disease. Caregivers' experiences with childhood diabetes prompted an ongoing learning process for the family, which corresponds well with parents reporting a need for more knowledge, seeking and finding support and advice, and seeking help and support from a variety of sources, including the diabetes association education, as well as from other parents and social media.

Extended family understanding and support

From extended families, there has been a misunderstanding. Several parents expressed concern about other family members' lack of knowledge about T1DM. As Kindu stated, "*I think the most difficult thing for the family is to deal with the misconception of 'it is all about the sugar'".* Dereje further clarified this point by stating:

> They would say something like, *"it only has a small amount of sugar, so it is fine".* Especially when it is his birthday every year, extended families like to provide him with

> sweet foods, they do not understand how avoiding sugar is important and my child also does not refuse to accept.

Two grandmothers find it unmanageable to refrain from offering gifts to their diabetic grandson. As Hirut puts it:

> He has a grandmother who likes to offer a bar of chocolate, cake and biscuits without asking every time we go to her home. We have attempted to speak with her, but she is unaware of the seriousness of the situation. It also leaves her in a dilemma because she needs to serve the other grandchildren as well. She does not want to put our son in a situation where he is alone. It is hard for her.

As the parent indicated, there has been a misunderstanding in extended family understanding and support due to family members' lack of awareness about T1DM, unaware of the severity of the issue, and the urge to treat diabetic children in the same manner as siblings or other children. They believe that treating a diabetic child differently in the presence of other children may harm his feelings, and they did not want to put their child in a scenario where he would be alone when they needed to serve the others as well. As a result, families find it difficult to abstain from giving gifts that were not intended for their diabetic child, especially when there is a ceremony or an event. To make matters worse, a diabetic child finds it difficult to refuse or eat the foods that are prohibited, which is attributable to the child's immaturity and natural preference for sweet foods.

Friends and community misunderstanding of T1DM

Members of the community did not realize the distinction between T1DM and T2DM. Eight caregivers expressed their experience in relation to the understanding of the community on the difference between T1DM and T2DM. Kindu said:

> I do not think people realize there are two types of diabetes, some of the people I know once told me ‘if we cared fully enough in reducing the amount of sugar my son consumed we could have prevented diabetes from happening in the first place’. And such blame-laded comments from people which come from misconceptions make me feel bad.

Another caregiver Dereje explained this concept further:

> last time when we were in the hospital a person who came to the hospital for type 2 diabetes treatment said to me ‘You know if your son does regular exercise and eat a little amount of fat and sugar, he can lose weight and through time he will heal from it and also he might do not develop diabetes at first place.’

As stated above the members of society do not differentiate the difference between T1DM and T2DM. The comments made by the others as in Derejes’ son case reflect that people assume all diabetes is the same and originates from too much consumption of sugar and fat, increase in body weight, lack of exercise and they also perceive with treatment and effective diabetes management effort it can be healed, which is not true in the case of T1DM.

Other caregivers Azeb said she was told things like, *“You gave her too much sugar, did not you?”* Some people also lack the awareness that T1DM is a lifelong disease, as it reflected in Tizitaw's report, *"some of my neighbors say to me 'when is he going to get fine?"* and *"'When is he going to heal from it?'"* Similarly Dereje, who is a father of a son with a relatively high body weight, was told, *"it's going to go away when he loses his weight, right?"* Aster expressed her desire for different names for T1DM and type T2DM, saying, *"I wish they had different names!"* And most of the participants believe that the government, Medias has not given attention to T1DM, as Alemu stated *"... I think the media should work on creating awareness about children with diabetes."* Similarly, Alemu also said:

> Apparently, the awareness of type one diabetes at a country level is low. Diabetes is not a deadly disease if it is controlled it is possible to live but since the awareness is low we are facing a lot of challenges, the media should give awareness on this issue…If there is mass testing there could be a number of people at least with type two diabetes. Recently at a funeral ceremony, when I asked how the person died they told me that "he has been drinking a lot of water 3 to 4 liters once, eat a lot then he gets tired and dies." He died without getting diagnosed but it could be due to type one diabetes.

Parents were placed under even more pressure because the general public was unaware of the differences between T1DM and T2DM. People believe that all diabetes is the same and that it is caused by excessive sugar and fat consumption, an increase in body weight, and a lack of exercise. They are also unaware that it is a lifelong condition.

Caregivers Coping Mechanisms

This theme explains how caregivers viewed certain qualities or factors as important in coping with and dealing with the challenges that come with caring for a child with T1DM.

Caregivers talked about how learning about T1DM, a supportive family unit, spirituality, as well as comparing diabetes relative to other potential childhood diseases helped them. External resources, such as social support through instrumental and emotional means, from extended family, friends, and health professionals and associations, were mentioned as helpful to positive disease adjustment.

Trust, encouragement, and a constructive attitude by a health care provider

The caregiver shared feelings about the approach the healthcare provider used. Parents wanted the use of positive reinforcement and motivation from healthcare professionals. The activities of health professionals such as conveying trust, encouragement, and a constructive attitude as soothing experiences. When they heard about others who had been successfully dealing with the disease for many years, they felt inspired. Scare tactics to increase caregiver vigilance and activities toward medication adherence, such as telling them that if they do not follow their instructions, something bad will happen to their child, were not helpful to them. The medical professional's encouragement and trust in the caregiver were also motivating and comforting to the caregivers. Dereje, whose child was diagnosed five years ago, talked about the doctor treating his child, *"the doctor we are seeing most of the time is good. He is just really optimistic. He is say thing like; 'it is possible to do it'. He points out the good things we do. This makes you feel like you are all right."* As reflected in this statement by a caregiver of a child who had a child with diabetes for several years, the caregiver wanted understanding and trust from their health care provider. Parents want to hear positive, not negative comments about diabetes as well. As one, caregiver Mahlet put it:

> Hearing the health professionals tell you the good stuff is a calming thing I would say. You know, it feels good when they tell you the story of someone who has dealt with it for sixty years and they are doing alright, instead of frightening you at first and saying that if you do not do this, and then this is going to happen. Of course, negative things might happen but with careful management, people have lived for so many years.

Another caregiver, Tsehay similarly said. "*I do not want to hear about the one who died in his sleep."*

Talking to other parents who are raising diabetic children

Many parents said that interacting with other parents who were raising kids with diabetes was one of the most helpful things. In the words of one caregiver, Mahder reported *"the associations' awareness-raising event was the most helpful thing I have ever found. The encouragement of the parents was more valuable than anything any doctor could say to me."* Another caregiver Aster also praised the advantage of talking to other parents:

> I think parents were probably also one of my best educators. They would tell us how they managed when the blood glucose got high, what worked for them and what did not. Who were their favorite doctors, how their child interacts with others in the school. I have certainly heard more helpful things from other parents.

Caregivers received valuable guidance and assistance through the diabetic association's learning platform, which allowed them to communicate with other caregivers raising children with diabetes. Reassurance, understanding they received from other caregivers on the diabetic event, a discussion about how they manage their child's blood glucose, and how they dealt with the outside obstacle were all more important elements of coping with the challenge of raising a diabetic child.

Spirituality as a Cause and coping mechanism

With respect to the cause, most participants felt that the disease had a spiritual connotation. While some respondents felt it was given by God for some reason, a few others claimed it was demonic and a few others believed it was simply a disease. Some participants could not tell where the disease was originating from. A participant who thought the state of the child was spiritual. Azeb said:

> Personally, I think it has a spiritual cause, because when she was born she was healthy, and we do not have anyone who has diabetes from me and my husband’s families, even our close ancestors. We know we do not have any of such things.

A caregiver that felt the condition was demonic, Mahder said, *“Perhaps the first person who bathed her passed on that demonic disease to her when she was born, and well, I seem to believe it.”* Another caregiver, Tsehay stated that she does not know the cause of her child’s condition. As she puts it:

> I do not know why, I have been through a lot of things. I know it is just a condition he has got. I just hope every day that whatever it is my child has possessed, God himself will take it away. He will cure it for me.

One way or the other, participants assumed something triggered the condition of the children. Most of the participants noted that the situation was spiritual. Other participants thought it was just a disease, and few respondents said they could not say exactly where the illness came from. Spirituality was also commonly mentioned by participants as one of their most important coping mechanisms.

Comparing T1DM to other diseases

As a means of dealing and coping with the stress that comes from the individual experience of caring for a child with T1DM, caregivers used social perception situated around their diabetic children to make sense of their experiences of caring for the diabetic body. By putting their child's bodily experiences relatively to other potential childhood conditions, caregivers were dealing with some of the gains and setbacks of T1DM.

These comparisons were used in two ways; to compare T1DM favorably or unfavorably by comparing T1DM with other childhood diseases. Parents concentrated on the life that could still be lived despite the presence of diabetes by stating statement such as, *"He only have diabetes,*"(Hirut), *"My daughter is in a good situation than many,"* and *"things could be a lot worse"*(Selam) and other similar descriptions of diabetes. Caregivers engaged in a social comparison process, judging their sick child to be doing better than many others. In this way, parents were able to isolate themselves and their children from these other illnesses, giving them a sense of control over their condition and strengthening their coping skills.

Parents discussed various ways in which they believed their children were in a better position than others. First, the ability of children with diabetes to socialize was emphasized. Hirut mentioned how children with diabetes can be socially integrated because they can *"read, write, and have conversations."* She went on to say that there are still some things that can be done with diabetes:

> You know, we should look at the little girl who had meningitis or the people who became disabled due to an accident a couple of years ago. I think it is good that he only has diabetes, he can still see, speak, laugh, sing, and participate.

She describes the qualities of *"still seeing, talking and laughing, speaking and being active"* to a life full of chances. This caregiver believes that being able to see, converse, and express feelings socially is an important part of living a full life.

Other caregivers stated the various ways in which diabetes can be concealed. Melkamu recalled a parent with a diabetic child saying to him, *"You should be thankful because people cannot judge or discriminate him by seeing on his face or body it is not all on display."* Because of this ability to hide diabetes, children with diabetes are spared from stigmatizing impacts of more noticeable childhood chronic conditions.

However, there are difficulties with this coping style, as it needs to compete with comparative processes with those that are perceived to be more fortunate. One caregiver said T1DM was more difficult to deal with than other diseases. Rather than treating it as a relatively favorable condition, different descriptions were used to express some of the difficult aspects of their situation that could not be overlooked. One caregiver used a common childhood situation of broken bones to explain how diabetes was more difficult due to the lack of healing, as Manyazewal puts it:

> …there is, however, the fact that it will last indefinitely unless of course, a cure can be discovered. I remember a boy who broke his arm and was brought to a hospital, we were in the same ward, and I remember thinking to myself, 'It was terrible at the time, but his arm was starting to heal,' Diabetes, on the other hand, is a long-term illness that will not go away.

These parents illustrate that there is no obvious and definitive end to the problems of living with diabetes by emphasizing how broken bones heal and contrasting this with the lack of healing in diabetes.

Quantitative Finding

Respondents' characteristics

The socio-demographic characteristics of parents and their children are presented in Table 3. The study included a total of 155 respondents. Parents' male children with T1DM accounted for 92 (59.4%), while females accounted for 63 (40.6%) of the total children. In terms of parent-child relationships, 88 (56.8%) of children had a mother-child relationship, 66 (42.6%) of children had a father-child relationship, and 1 (0.6%) of children had a grandmother-child relationship.

In terms of parental marital status, 1 (0.6%) of parents were single, 146 (94.2%) were married, 2 (1.3%) were divorced, 4 (2.6%) were separated, and 2 (1.3%) were widowed. Concerning parental education, 5 (3.2%) were not literate, 27 (17.4%) had a primary school education of grade 1-6, 37 (23.9%) of grade 7-12, 5 (3.2%) had a certificate, 33 (21.3%) had a diploma, and 48 (31.0%) had a bachelor's degree and above. In terms of parent occupation, 41 (26.5%) of parents were unemployed, 62 (40.0%) were employed by the government or private sector, and 52 (33.5%) were self-employed.

Table 3

A socio-demographic characteristic of categorical variables of children and parents

Variable	Category	Frequency	Percent
Childs' sex	Male	92	59.4
	Female	63	40.6
Relationship to child	Mother	88	56.8
	Father	66	42.6
	Grandmother	1	0.6
Marital status	Single	1	0.6
	Married	146	94.2
	Divorced	2	1.3
	Separated	4	2.6
	Windowed	2	1.3
Educational level	Illiterate	5	3.2
	Grade 1-6	27	17.4
	Grade 7-12	37	23.9
	Certificate	5	3.2
	Diploma	33	21.3
	Degree & above	48	31.0
Employment	Unemployed	41	26.5
	Government/private employee	62	40.0
	Self-employed	52	33.5

Table 4 shows the socio-demographic profiles of parents and their children of continuous variables. The mean age of the children was 6.65 ± 2.95 (mean ± SD) years. The minimum and maximum ages of children in years were 1 and 12 respectively. The mean ages of the parents were 38.13±7.43 (mean ± SD) years. The minimum and maximum ages in years were 23 and 61 respectively. The average number of children in a family was 3.07 ± 1.41 (mean ± SD). The minimum and the maximum number of children in a family were 1 and 8 respectively. The mean average family income per month was 6,932.77 ± 4,717.17 (mean ± SD) birr. The minimum and maximum average family income per month was 1,000 and 25,000 birr respectively.

Table 4

Socio-demographic characteristics of continuous variables of children and parents

Variable	Minimum	Maximum	Mean	Standard deviation (SD)
Age of the child in year	1	12	6.65	2.95
Age of parent in year	23	61	38.13	7.43
Number of children in a family	1	8	3.07	1.41
Average family income per months in birr	1,000	25,000	6,932.77	4,717.17

Table 5 (See apppedix 7) shows the clinical characteristics of respondents’ children with T1DM. Only insulin was used by the diabetic children as part of their current medication regimen. 5 (3.2%) of the children inject diabetic medications (insulin) by themselves. Note, the reason why I put large table in the appendics is that APA sixth edition (2011) does not recommend large tables to be put in the body of the research. The table is unnecessary and distracting to include in the body of the research if the table's items are discussed. It should be placed in the research's appendix section. 149(96.1%) of parents administer insulin for their children. Only 1(0.6%) of children inject diabetic drugs by the caregiver. Regarding the child’s

most recent Blood Fasting Glucose (FBG), 35 (22.6%) of children had good diabetic control, 44 (28.4%) of children had fair diabetic control, and 76 (49.0%) children had poor diabetic control.

The mean age of the child at the time of diagnosis was 3.93 ± 2.14 (mean ± SD) years. The minimum and maximum ages of the child at diagnosis were 0.49 and 11 years respectively. The mean follow-up times of treatment of diabetic children were 2.77 ± 2.17 (mean ± SD) years. The minimum and maximum follow-up times of diabetic children were 0.25 and 10.16 years respectively. The mean injection per day of diabetic children was 2.01 ± 0.11 (mean ± SD) years. The minimum and maximum injections per day of diabetic children were 2 and 3 times respectively.

HRQoL scores of the parents and family members

Table 6 shows the descriptive statistical result of the HRQoL scores of the parents and family members. The average total scale score of the impact on mothers' and fathers' HRQOL and overall family functioning as a result of having a child diagnosed with T1DM is 57.12 (95% CI 55.79-58.42). With a standard deviation of 19.20, the mean physical functioning of parents and family members was 67.50.

The average emotional function subscale score of parents and family members was 56.77, with a standard deviation of 21.00. The parents' average social functioning subscale score was 56.85, with a standard deviation of 22.26. The average score for parents' cognitive functioning was 65.48, with a standard deviation of 22.12. The average level of parental communication subscale score was 43.39, with a standard deviation of 21.34. Parents' average level of subscale score of worry about their child with T1DM was 37.58, with a standard deviation of 19.19. The average impact on a family's daily activities subscale score as a result of having a T1DM child was 66.29, with a standard deviation of 23.60. The average impact on subscale score family relationships of having a child diagnosed with T1DM was 63.06, with a standard deviation of 23.38.

Table 6

Descriptive statistical result of the HRQoL scores of the parents and family members

Impact of T1DM	Mean	Standard deviation (SD)	Standard error	95% CI (Lower, Upper)
Total scale score	57.12	23.90	0.69	55.79, 58.42
Physical functioning	67.50	19.20	1.54	64.60, 70.48
Emotional functioning	56.77	21.00	1.65	53.55, 60.00
Social functioning	56.85	22.26	1.74	53.55, 60.16
Cognitive functioning	65.48	22.12	1.71	61.94, 68.71
Communication	43.39	21.34	1.70	40.16, 46.94
Worry	37.58	19.19	1.50	34.68, 40.65
Daily activities	66.29	23.60	1.90	62.74, 70.00
Family relationships	63.06	23.38	1.90	59.35, 69.94

The impact T1DM on HRQoL of parents and family members

Table 7 (see Appendix 8) shows the multiple regression analysis results. Age of the child, marital status of parents, average family income, follow-up time of medication, and fasting blood glucose control had a statistically significant association with the physical functioning of parents at a 5% level of significance ($P < 0.05$). The physical functioning score of parents has a statistically positive association with the ages of the child, average family income, and medication follow-up time. Parents' marital status and fasting blood glucose control, on the other hand, were negatively associated with their physical functioning of parents ($P < 0.05$).

The emotional functioning score of parents was significantly associated with the age of the child, the age of the parents, the number of children in the family, medication follow-up time, and fasting blood glucose control ($P < 0.05$). The emotional functioning of parents was positively associated with the age of the child, average family income, number of children, and medication follow-up time. However, the emotional functioning of parents was negatively associated with the age of parents and fasting blood glucose control ($P < 0.05$).

The social functioning of parents was positively associated with their educational level and average family income ($P < 0.05$). This means that as a parent's educational level and average income rise, so does their average social functioning HRQoL score. On the other hand, fasting blood glucose was found to be negatively associated with parents' social functioning ($P < 0.05$). This means that the average social functioning of parents with poorly controlled FBG levels was lower than that of parents with well-controlled FBG levels.

The parent-child relationship and their child's fasting blood glucose control level had a statistically significant relationship with parental cognitive functioning ($P < 0.05$). There are no statistically significant variables associated with the communication functioning of parents at a 5 % level of significance. At a 5% level of significance ($P < 0.05$), the number of children in a family, average family income, and medication follow-up time were all positively associated with the worrying scores of parents. Only the number of children in a family was a statistically significant association with daily activities of parents and family members at 5% of the level of significance. The result shows that as the number of children increases by one, the score of daily activities subscale of parents and family members decreased by 3.5 ($P < 0.05$). Giving injection to a child by parents and caregivers and the level FBG control had a statistically significant positive association with family relationship subscale of parents and family members at 5% of the level of significance ($P < 0.05$).

At a 5% level of significance ($P < 0.05$), the parents' age, educational level, employment, average family income in a month, age of the child at diagnosis, person injecting the child, and fasting blood glucose control level were statistically significant association with the parents' HRQoL. When the age of parents increases by one year, the impact on HRQoL of parents’ scores also increases. Those parents who had a grade 1-6 education level reported higher HRQoL scores compared to the non-illiterate parents ($P < 0.05$). Government/private employed parents had a higher HRQoL score result compared to unemployed parents ($P < 0.05$).

As the child's age at diagnosis increased by one year, the parents' HRQoL scores increased by 1.5 ($P < 0.05$). Parents who inject insulin for their children had a higher HRQoL score ($P < 0.05$) than parents whose children self-inject insulin. Parents whose children are injected by caregivers had a higher HRQoL score than children who injected themselves ($P < 0.05$). Parents with fair diabetic control children have lower HRQoL scores than those with good diabetic control ($P < 0.05$). When compared to good diabetic control of FBG, HRQoL scores of parents with poor diabetic control scored lower ($P < 0.05$).

Chapter Five: Discussion

The aim of this study was to explore what challenges caregivers of children with T1DM face, as well as the impact on the HRQoL of the disease on the parent, caregiver, and family member. Parents were also asked about their available social support and coping mechanism. Participants discussed a variety of themes, ranging from the initial experience of finding their child's diagnosis, facing the caregiving challenge at home, distressing caregiving process, and struggle to live with diabetes, school difficulties to coping, and social support. Under these themes, a number of issues were presented ranging from the initial encounter with the symptoms of their child's disease to comparing T1DM to other diseases as a coping mechanism, including cost diabetes treatment, parenting problems, and concerns, extended family, friends, community, and school concerns, as well as the healthcare system and diabetic organizations. The quantitative data result also indicated HRQOL of parents having a child with T1DM's and family functioning are correlated to their socio-demographic and clinical characteristics. As a result, the two findings were discussed, with the quantitative results serving as a supporting role for the qualitative one. The following discussion was made based on the main findings that are important to achieving the specified research objectives.

Challenges Facing Caregiver

Parents and family members frequently wait until serious symptoms, such as diabetic ketoacidosis, appear before seeking medical help due to a lack of awareness of symptoms. This led them to believe that their children's illnesses were caused by their carelessness in raising them, and they blamed themselves. Similarly, Fikrtemariam (2016) found that parents lack sufficient knowledge of T1DM symptoms, and Smaldone and Ritholz (2011) found that caregivers were unable to recognize diabetes in their children based on their symptoms.

Confidently administering insulin during the first days after their children were released from the hospital had a significant impact on these caregivers' emotional state, and they were not sufficiently prepared for the experience. As a result, they sought assistance from those around them. These findings are in line with those of other research conducted by Smaldone and Ritholz, (2011) and Wennick, Lundqvist, and Hallstrom, (2009).

Caregivers discussed the issues of how difficult it was to persuade children to follow the recommended treatment plan. Other issues related to the child's age or actions include the child's lack of knowledge of diabetes, as well as his or her aversion to getting blood sugars tested or obtaining insulin injections. Carroll and Marrero (2006) and Bowes, Lowes, Warner, and Gregory, (2009) have previously written on this.

Children felt “annoyed” or “saddened” about blood sugar monitoring and insulin injections, which is challenging for the caregiver. This finding is also in line with the findings of Amillategui, Calle, Alvarez, Cardiel, and Barrio (2007), Antal, Wysocki, Canas, Taylor, and Edney-White (2011). In their study, they identified "insulin injection distress" which is common among children with T1DM.

The challenges of children's lack of cooperation with diabetic care and management are also consistent with findings from other studies. The problem of a child eating secretly and stealing food appears to be an old one, as it was described by Wysocki, Huxtable, Linscheid, and

Wayne (1989). Other problems previously found by other investigators included feeling "overwhelmed" and "in a daze" at the time of diagnosis (Jonsson, Hallström, & Lundqvist, 2010), concern for the child's well-being (Haugstvedt, Wentzel, Larsen, Graue, Svik, & Rokne, 2010, Wennick & Hallström, 2007, and Bowes et al., 2009). Studies have also found the need for emotional help (Bowes et al., 2009), the failure to handle the disease effectively (Smaldone & Ritholz, 2011).

Caregivers worry about the community's inappropriate attitude and understanding of their children's condition, and they believe that this problem would impact their children's future marriage prospects. Similar findings have been found in studies done by Hapunda, Abubakar, Van de Vijver, Pouwer, (2015) especially in the case of female children. And also frustration stemming from others' misconceptions about T1DM was discussed in Carroll and Marrero, study (2006).

Another component of the theme was how parents' ongoing attempts to monitor and manage the disease were followed by a commitment to constant protectiveness or vigilance. This result is consistent with prior studies by Sullivan-Bolyai et al. (2003), who found that families caring for young children with T1DM needed to be constantly vigilant. Recently, the concept of 'parallel vigilance' (Niedel et al. 2012) has been suggested, which explains parents' normal vigilance as well as a more intense vigilance for indicators of worsening diabetes.

In addition, caregivers are worried about the impact of diabetes complications on their children's health in various ways. A previous study done by Smith, Cheater, and Bekker (2015), Oskouie, Mehrdad, Ebrahimi (2013), and Wiebe, Gelfand, Butler, et al. (2011) on the same subject also showed common issues among the caregivers. Because of the unpredictability of their children's health and the incidence of acute and critical conditions, caregivers expected a challenging future for their diabetic children. Other studies done by Smaldone and Ritholz, (2011), Popp, et al. (2014), Oskouie, Mehrdad, Ebrahimi, (2013) and Usher-Smith, Thompson, Walter (2013) has backed up the results of this study finding.

Impacts on HRQoL of Parents and Family Members

The primary findings of the quantitative data of the study indicated socio-demographic and clinical factors of parents and their children with T1DM are associated with HRQOL of the parents and the family functioning. Parents, who are non-educated, with low household income, unemployed, and with poor control diabetes of their child had lower HRQOL compared to their counterparts. Those parents who had a grade 1-6 education level reported higher HRQoL scores compared to the non-illiterate parents. And being employed and having relatively higher household income increased the HRQoL of parents and the family functioning. Increases in the age of the child were also found to increase the HRQoL of the parents.

Parents or caregivers injecting insulin by themselves for their child were also found to have increased HRQoL than children injecting for themselves. One possible explanation is that as qualitative findings stipulated, children who inject themselves were more likely to skip the insulin injection due to hardship or pain of injection which in turn results in low blood glucose control which was associated with lower HRQoL in parents. From the quantitative finding, it was evident that there were complex relationships of the age of a child, blood glucose management, income, education level, employment, and HRQOL of the parents.

The age of the child was also correlated with the HRQoL of parents. This result may be due to parents becoming more physically and emotionally involved with their younger child's lives and diabetes management. Preadolescent or older children on the other hand are more self-sufficient in their caregiving process and spend more time away from their families. Similarly, Josson et al., (2015), and Holmbeck et al.,(2002) found the younger children their parents were more worried than children in older age groups because it led to overprotection and over-involvement on the part of parents in younger children. Regarding literacy level, parents who are literate and with higher education levels have the resources and knowledge to handle their diabetes and also process the information they receive from their health care providers and other sources.

In this quantitative study, parents expressed substantially more worry, this was also evident qualitative finding that they were worried about their child's regarding the danger to the health of children and its complications that affect them later, the social life they are going to have. This is in line with a study by Malerbi, Negrato, and Gomes (2012), which found that parents are concerned about their child's future in the long run and about episodes of hypoglycemia in the short run.

Social Support Available to the Needs of Caregivers

Caregivers need the assistance of others to share the burden of care. Yet except family members, others declined to help in caregiving for a diabetic child because managing him or her was frightening and difficult, particularly in emergency circumstances, which is consistent with the findings of previous studies (Smaldone & Ritholtz, 2011; usher-smith, Thompson, sharp, &

Walter, 2010). Wysock et al. (1989) also reported having trouble finding a babysitter and being worried.

Previous research by Yeweyenhareg and Fikre (2007), Tao and Taylor (2010), and Ying et al. (2010) supports the findings of this study in terms of the high cost of T1DM treatment and the financial burden that T1DM imposes on the family. The government assistance coverage was insufficient to meet the children's medical needs. Other studies done in developing countries by Higuchi (2010) have also shown the problems with insurance coverage and finances related to diabetes management are more serious.

Similar to this study, other studies on the parents with T1DM addressed the value of going to school to inform teachers and the school community (Amer, 2008; Wagner, Heapy, James, & Abbott, 2005). Parents emphasized the importance of trust and encouragement from health care providers, as well as choosing a healthcare provider with which the parents and child are comfortable, according to Jonsson et al. (2010) and Kratz et al. (2010). Parents preferred healthcare providers to be optimistic in pointing out achievements, according to Buckloh et al. (2008); pessimistic motivators and scare tactics were not valued.

In the finding of this study caregivers of diabetic children tried to increase knowledge and awareness about T1DM and there were times when the information was either incomplete or incorrect. Similarly this finding was available in other studies as well done by Smith, Cheater, and Bekker, (2015).

Caregivers Coping Mechanisms

Caregivers made comparisons with other children who were also affected by other illnesses or injury to cope with their child's condition. In the literature, this form of comparison is referred to as a “downward” social comparison (Buunk et al. 1997). People equate themselves to similar others in times of confusion, when other bases of objective measurement are missing (Leventhal et al. 1997). These procedures minimize the perception of risk. In a previous study, parents of children with T1DM explained how they used social comparisons (Gannoni and Shute 2009). Caregivers described the importance of interacting with other parents who have children with T1DM, as well as supporting the finding of Smaldone and Ritholz's (2011)'s work through involvement in diabetes-related events.

Furthermore, the caregivers discussed issues that had not been addressed in previous studies. These concerns included parenting difficulties such as blood glucose control, community misunderstanding of T1DM, and school problems that comes mainly due to lack of awareness of the school community, feelings about the healthcare system, and spirituality as a cause and coping mechanism, parents reporting the lowest score in the worry subscale of HRQoL. The parents shared their feelings, guilt, and lack of public awareness about their hardship as a result of their diabetes.

The finding that caregivers discussed about their hospital visits at the time of diagnosis was also a new issue that had not been discussed previously. Those who went to the three hospitals where the participants are selected had positive experiences, and those who went to their local health care center all had negative ones were also an emerging issue in this study.

another new finding was being filled with guilt and remorse, as are a result of caregivers especially mothers who assume that in order to reduce and prevent diabetes complications, they should devote their entire time to caring for their children.

Findings and Theoretical Perspectives

Family system theory

According to family systems theory, what happens to a target family member has an impact on other family members, and their responses in turn have an impact on the affected family members. This core assumption of the theory was best described in the lived experience of parents and in the examination of their HRQoL. Parents and caregivers discussed how their child's health status had a significant impact on their personal, family as well as day-to-day family functioning and it determined their family lifestyle, all of which again had an impact on their child's health.

This is in line with the transactional view of this theory of parent-child relationships, according to which children’s diagnosis with T1DM have an impact on their parents and parents’ functioning have also an impact on their children. It was clear that parental care for a child with diabetes had even more consequences for both the parents’ wellbeing and the health of the child with diabetes, which was consistent with the family systems theories’ perspective. Furthermore, the results revealed a strong interdependence between diabetes management and family functioning.

Family stress theory/ the ABC-X model

When faced with a traumatic situation, the ABC-X theory states that families go through four stages: crisis, disorganization, recovery, and reorganization. According to caregivers' accounts and consideration of their physical, cognitive, and emotional functioning, parents with children who have been diagnosed for four years or more appear to be in the recovery and reorganization process. On the other hand, caregivers or parents of newly diagnosed children appear to be in a state of crisis and disorganization, as the researcher observed during qualitative interviews; caregivers of newly diagnosed children's parents were clearly emotionally disturbed. However, the length of time spent in stage one can be influenced not only by the time but also by other mediator variable conditions such as family cohesion and support.

Chronic illnesses like T1DM make much more sense of the hardship on the caregivers when we consider the theory's determining factors; stressors or factor **A**, in this case being diagnosed with T1DM: what caregivers experienced was external to the family's control, leaving the family with no choice, over the stressors. Besides, these stressors the diagnosis was sudden, serious, and unpredictable, putting the entire family under immediate stress and leaving no time for the family to prepare for the stressors arrival. As a result, it is clear how strongly the family can be impacted by the stressors.

Accessing resources is one way of dealing with stressors; the **B** part of this theory stated resources in three categories: individual, family, and community. Caregivers or parents were attempting to put their personal knowledge, experience, and resources to good use by acquiring new skills and adopting a new way of life. As they faced the stressors, the majority of the caregivers tried to stay together as a family and work together to support one another emotionally and physically. They also seek the support of extended family members and associations like EDA Bahir Dar branch. Yet, some parents/caregivers have had trouble maintaining their family balance or carrying out the role they previously used to perform as a result of the stressors.

There is a difference in how the caregivers perceive or assign meaning to their situation, which is the **C** element in the theory. Some caregivers have developed a positive disposition and they were effective at dealing with it, such as by comparing T1DM relative to other serious chronic childhood illnesses. On the other hand, some caregivers tend to be in despair because they believe the stressor will not go away, they have difficulty in coping with the condition. This finding is in line with a family stress theory perspective.

The family reaches a crisis (the **X** element in the theory) when the stressor event causes the family to lose its regular stability. Despite the fact that parents have been in highly stressful situations, most of the caregivers were able to deal with it over time with the exception of Selma’s case, where the stressor acted as an immediate factor to a family crisis or divorce. The majority of caregivers had not reached a stage of crisis or a condition under which family members could no longer fulfill their duties as caregivers.

Chapter six: Conclusion and Implications

Conclusion

This study demonstrated the necessity of considering how parents, especially caregivers, are affected when their child is diagnosed with T1DM. T1DM requires complex daily care that continues throughout a child's life; these routine care demands have an impact on caregivers, parents, and the entire family. Parents and caregivers caring for children with T1DM face physical, social, and psychological challenges. Parents were overwhelmed with information and responsibilities at the time of the first diagnosis, and they needed follow-up after discharge. Parents also experienced problems in their children's schools, primarily as a result of a lack of awareness on the part of the children's teachers and school administrators. Caregivers are also often overwhelmed by their duties of T1DM management.

Many unmet needs have been identified by parents of children with T1DM, indicating service gaps. Several caregivers used phrases like "the most difficult thing," "the toughest thing," implying that different problems, such as a lack of community awareness of T1DM and support, and the hardship of follow-up treatment following hospital discharge, and the need for medical supplies by the government were given more attention.

Caregivers and children have benefited from organized events for socialization, from interaction with other caregivers and children who are in a similar position. Parents and caregivers with low household income and no literacy have a higher risk for their children to have poor blood glucose control. One approach for improving a child’s functioning is to address the challenges of parents and through assessment HRQoL, which could be a standard component of diabetes treatment or intervention. In comparison to their counterparts, parents who are uneducated, unemployed, and those having a low household income and poor management of their child's blood glucose had a lower HRQOL. Therefore to improve the physical and emotional care outcomes and decrease long-term problems and costs of T1DM, research-based interventions that promote the HRQoL of parents should be seen as part of normal treatment for families impacted by T1DM. Parents' and caregivers’ numerous needs highlight the difficulty of T1DM and indicate that more should be done to change the condition for families raising children with T1DM.

Implication for Social Work Practice

The profession of social work plays an important role in the field of public health and non-communicable diseases. Social workers can intervene to address the psychosocial difficulty of the disease on the family and their diabetic child. A social worker can home visit families may also collaborate with parents and siblings to help children develop self-management skills to decrease the burden on the caregivers. Social workers may assist the child and his or her family in developing healthy coping mechanisms. They will help the family come up with solutions to day-to-day T1DM psychosocial issues and strengthen interpersonal communication. They will link the child and family with helpful community services as needed.

The role of the social worker in reducing the myths and misconceptions that hinder T1DM care and management can also be crucial, given the lack of sufficient education and support services to enhance self-management and improve positive psychosocial results. By maintaining continuous contact with the family, a social worker will educate and inform those who play a significant role in this family life.

Implication for Social Work Education

Given the important role that social workers play in assisting patients and their families, the existing curricula must be strengthened to include content relevant to medical social work practice, and also the medical social work field practicums must be improved.

A curriculum that focuses on psychosocial support in the health sector can be included in social work education, particularly when working with families of children with chronic diseases such as T1DM. Furthermore, many people turn to or explore their spiritual and religious resources when dealing with a chronic illness. And they find meaning or purpose in it and use it as a coping mechanism; thus it is important to recognize and design the curriculum in such a way that promotes the exploration of the resources within the community's spiritual practice.

Implication for Health Policy

At the policy level, based on reviews made on Ethiopia's health policy document in relation to the current study the findings have implications for healthcare policy. The findings of the study imply that policies for children and their families could include integrating and family-focused services. T1DM's burden must be addressed, and other aspects of the disease must be considered into health policy. Because T1DM is incurable in children, the focus of childhood diabetes research could be on early detection and effective management.

Furthermore, the finding implies in order to alleviate the burden on parents and caregivers of diabetic children, the government could develop a policy that prioritizes the availability of sufficient and consistent T1DM treatments (insulin injection, blood glucose monitoring), as well as assisting diabetic families in limiting carbohydrate intake, matching exercise with diet, and in accessing other medical supplies. Because T1DM treatment medications are costly, strategies to accommodate medication provision and cost affordability by families could be devised, taking into account the socio-economic situation of families as well as the treatments' long-term viability.

Implication for Future Research

A further study out to focus on searching for data to confirm results not previously found by other studies, such as spirituality as cause and coping mechanisms, parenting difficulties such of blood glucose control management, community misunderstanding of T1DM, and school problems, feelings about the healthcare system, parents reporting lowest score in worry subscale of HRQoL.

The use of parent-reported outcome measures of HRQoL in routine care of clinical settings may need to be further investigated at the national level in order to determine their approval of using patient-reported outcome measures to enhance diabetic care and coordination. In addition, studies including people from diverse ethnic groups, family dynamics could be other prospective study areas that can be used to expand the understanding of the impact of parenting a child with T1DM and on families.

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Appendixes

Appendix 1: Informed Consent Form (English Version)

Dear Participant

My name is Basiliel Nigusse. I am a second year Social Work masters graduate student at Bahir Dar University. The Department requires every student to conduct academic research as the partial fulfillment for the degree of master of social work. Based on my area of interest, I have chosen to work on the issue of caregivers' experience of having a child diagnosed with T1DM. The main objective of this study is to explore the caregivers' experience of having a child with T1DM and its' impact on the parent and family. And I believe exploring this issue is a halfway to ameliorate challenge of caring for the child with T1DM. Thus, your response and truthful answers to questions are of great help to the study findings.

I admire your cooperation and I assure you that any information you provide will be used for academic purposes only, strictly confidential and won‘t be used for any other purpose.

There are no risks that are anticipated from your participation in the study because all professional ethics and principles will get due attention in the research. If you are not interested in giving answers, you have the right to withdraw from participating in the study at any time. Furthermore, the researcher will not continue with the interview if any difficult/ major concern arises. Thank you very much for your cooperation.

If you have any questions or concerns about this study or if any problem occurs, please let me know by dialing at 09 83481613

Researcher: Basiliel Nigusse

I have carefully read the above note and understood this agreement. Hence, I agree to participate in the study under the conditions described above.

Participant‟s signature: ______________________

Date: ______________________________________

Name of the Researcher: _________________________

The Researcher‟s signature: ______________________

Date: ____

Appendix 2: Informed Consent Form (Amharic Version)

ውድ ተሳታፊ

ስሜ ባስልኤል ንጉሴ እባላለሁ ፡፡ በባህር ዳር ዩኒቨርሲቲ የሁለተኛ ዓመት የሶሻል ወርክ የማስተርስ ተመራቂ ተማሪ ነኝ ፡፡ የትምህርት ክፍሉ እያንዳንዱ ተማሪ ለሶሻል ወርክ ማስተር ዲግሪ በከፊል ማሟያ ይውል ዘንድ ምርምር እንዲያደርግ ይጠይቃል ፡፡ እኔም በህጻናት የስኳር ህመም የአስታማሚ/ተንከባካቢዎች ተሞክሮ ላይ ምርምር ለማድረግ እየሰራሁ እገኛለሁ ፡፡ የዚህ ጥናት ዋና ዓላማ የስኳር ህመም የአስታማሚ/ተንከባካቢዎች የማስታምመ ተሞክሮ እና በወላጅ እና በቤተሰብ ላይ የሚያሳድረውን ተጽዕኖ ማጥናት ነው ፡፡ እናም ይህንን ጉዳይ ማጥናት ልጆን የማስታምመ ተግዳሮትን ለማሻሻል ግማሽ መንገድ ነው ብዬ አምናለሁ ፡፡ ስለሆነም ለጥያቄዎች የሚሰጡት እውነተኛ መልሶች ለጥናቱ ግኝት ትልቅ

እገዛ ያደርጋሉ ።

ስለትብብርዎን አመሰግናለሁ እናም እርስዎ ያቀረቡት ማንኛውም መረጃ ለትምህርታዊ ዓላማ ብቻ ጥቅም ላይ የሚውል፣በጥብቅ ሚስጥራዊ እና ለሌላ ዓላማ እንደማይውል አረጋግጥልዎታለሁ።

ከጥናቱ ተሳትፎዎ የሚጠበቁ አደጋዎች የሉም ምክንያቱም ሁሉም የሙያ ስነምግባር እና መርሆዎች በጥናት ላይ ተገቢውን ትኩረት ያገኛሉ ። መልሶችን የመስጠት ፍላጎት ከሌለዎት በማንኛውም ጊዜ በጥናቱ ከመሳተፍ የመተው መብት አለዎት ። ከዚህ በተጨማሪም ተመራማሪው ማንኛውም ችግር /ስጋት ከተፈጠረ በቃለ መጠይቁ አይቀጥልም ። ስለ ትብብርዎ በጣም አመሰግናለሁ ።

ስለዚህ ጥናት ማንኛውም ጥያቄ ወይም ሥጋት ካለ ወይም ችግር ከተከሰተ እባክዎን በ 09 83481613 በመደወል ያሳውቁኝ

ተመራማሪ ባስልኤየል ንጉሴ

እኔ ከላይ ያለውን ማስታወሻ በጥንቃቄ አንብቤ ይህንን ስምምነት ተረድቻለሁ ።

ከላይ በተገለጹት ሁኔታዎች ውስጥ በጥናቱ ለመሳተፍ እስማማለሁ።

የተሳታፊ ፊርማ ________________________

ቀን ____

የተመራማሪው ስም ____________________________

የተመራማሪው ፊርማ ________________________

ቀን ____

Appendix 3: In-depth Interview Guide for the Caregivers (English Version)

This tool is designed to collect data about the experience of caring for the child diagnosed with type 1 diabetes the data collected will be used for the purpose of this research only being kept merely in the hands of the researcher. Moreover, your actual name will not be mentioned in the paper. I hereby request you to be open and honest while responding so that the research could succeed and achieve the intended goal. Please give your answer in detail for each question below.

Section One: Background Information

I. About child with diabetes:

1. Child's age in years?
2. Child's gender?
3. Child's current grade level in school?
4. How old was the child when first diagnosed?
5. How many very low or high blood sugar episodes in this year has the child had?
6. How many days of school in this year did the child miss because of Diabetes?
7. In your estimation, how worried is the child about his being diabetes?
8. Did your teen have been diagnosed with any psychological problems? By whom?

II, about you and your family:

1. Your age in years?
2. Your gender?
3. Your marital status?
4. Family income monthly?

5. Does the child live with you?

6. How many other family members in the home and what are their ages?

Section Two: The following questions explore about how you have been experiencing as a care giver of a child with diabetes:

1. Tell me about your feelings and reactions with the first diagnosis of child with diabetes? Probe- How did you know at first? How was the first diagnosis? How was it is managed at first?

2. How were the chills' school and teachers, friends and family members' reaction?

3. Talk about some challenges you have experienced while caring for the child with Diabetes, pro- challenges psychological, social, economic, physical, work and health related with diabetes management. If you checked any of the above problems, how difficult have these problems made it for you to do your work, get along with other people? Handle child school, situations with friends, etc.

4. Tell me how you have been feeling as a care giver of a child with diabetes? Probe diabetes related worries, about health complications, diabetes management burden and psychological stress.

5. Talk about how diabetes has impacted your family;
siblings, finance, Work, Marital or other relationship?

6. Do you share responsibility for child's diabetes with a spouse/partner or other family members? Probe- Any disagreement on the management, how is familial communication and relationship in managing child diabetes and after the diagnosis.

7. Tell me about child's school life in relation to his diabetes

8. What coping and adaptation mechanisms' was used? Probe- Who was there providing support? Such as friends and family members, from health care professionals, from other social support systems, from civil organizations....?

9. How confident are you about your overall knowledge of diabetes, and your ability to manage your child diabetes? Where and how did you gate the education? What would be your preferred method of receiving information that could be helpful in managing your child diabetes?

11 Tell me about how caring for a child with diabetes should be? Probe- restrictiveness, transferring the responsibility, or limit independent activity?

12 Is there any kind of help and support you are receiving? Probe- Is there any support network, care givers support group, organization or community support, or from government? What kind of help would be most helpful? What should be done at the family, government, community, civil organizations and level to address the problem?

13 What scares you the most about child diabetes? Is there anything else you would like to share with me about caring for the child with diabetes?

Appendix 4: In-depth Interview Guide for the Caregivers (Amharic version)

ይህ መሣሪያ በአይነት 1 የስኳር በሽታ የተያዘውን ልጅ የመንከባከብ ልምድን ለመሰብሰብ የታሰበ ነው የተሰበሰበው መረጃ ለዚህ ጥናት ዓላማ የሚደረገው በተመራማሪው እጅ ብቻ ነው ፡ በተጨማሪም ፣ ትክክለኛ ስምዎ በወረቀቱ ውስጥ አይጠቀስም ። ምርምሩ እንዲሳካ እና የታሰበውን ግብ እንዲያሳካ ምላሽ በሚሰጥበት ጊዜ ግልጽ እና ታማኝ እንድትሆኑ እጠይቃለሁ ። እባክዎን ከዚህ በታች ላሉት እያንዳንዱ ጥያቄዎች መልስዎን በዝርዝር ይስጡ ።

ክፍሌ አንድ፡- መነሻ መረጃዎች

I. ስለ ልጅዎ የስኳር በሽታ በተመለከተ የተዘጋጁ ጥያቄዎች :

1. የልጁ ዕድሜ?

2. የልጁ ፆታ?

3. በትምህርት ቤት ውስጥ የልጁ ወቅታዊ የክፍል ደረጃ?

4. በመጀመሪያ ሲመረመር የልጁ ዕድሜ ስንት ነበር?

5. በዚህ ዓመት ስንት በጣም ከፍተኛ እና ዝቅተኛ የስኮር መጠን ልጆት አጋጥሞታል? ምን አደጋ አስከትሎበታል?

6. በዚህ አመት ውስጥ ልጆት በስኳር በሽታ ምክንያት ስንት ጊዜ ከየትምህርትብት ቀረ?

7. በእርሶ ግምት ልጆት ስለ ስኳሩ ህመሙ ምን ያህል ይጨነቃል?

9. ልጆት በ ስኳሩ ህመም የተነሳ ለ ስነልቦና ችግር ተጋልጦ ያውቃል?

II. የግል እና የቤተሰብ ሁኔታ:

1. ዓመታት ውስጥ የእርስዎ እድሜ?

2. የእርስዎ ፆታ?

3. የጋብቻ ሁኔታዎ?

4. የቤተሰብ ገቢ በየወሩ?

5. የልጁ/ቷ ወላጅ ወይስ አሳዳጊ ኖት?

6. በቤት ውስጥ ስንት ሌሎች የቤተሰብ አባላት እና ዕድሜያቸው ስንት ነው?

ክፍል ሁለት: የሚከተሉት ጥያቄዎች እንደ አስታማሚ ከ ልጆት የስኮር ህመም ጋር በተያያዘ ያሎትን የህይወት ተሞክሮ የሚመለከቱ ናቸው።

1. ለመጀመሪያ ግዜ ልጆት ስኳር እንደለበት እንዴት አወቁ? ስሜቱስ እንዴት ነበር? ምን ተስማዎት?

ህክምናው እንዴት ነበር?

2. ሌሎች የቤተሰቡ አባላት፣ጎረቤቶች፣ አስተማሪዎች እና ጓደኞች ስሜት፣አስተያየት እና ምላሽ እንዴት ነበር?   ?

3. የስኳር ህመምተኛውን ልጅ በሚንከባከቡበት ሂደት ላይ ያጋጠሞት ችግሮች አሉ? ካሉ ምንድን ናቸው? ከ ስነልቦና፣ ከማህበራዊ ህይወት እና ግንኙነቶ፤ከ ኢኮኖሚ፣ ከስራዎት እና ከጤና አንጻር ይግለፁልኝ?

4. የስኳር ህመም ላለበት ልጅ እንክብካቤ ሰጭ በመሆኖ የተሰማዎት ስሜት ምን እንደሆነ ንገረኝ? ከታማሚው የስኳር በሽታ ጋር የተያያዙ ጭንቀቶች ፣ ስለ ጤና ችግሮች ፣ የስኳር በሽታ አያያዝ ውጥረት/ሸክም እና ሥነልቦናዊ ጭንቀት ይንገሩኝ ።

5. ፋይናንስን ፣ ሥራን ፣ ጋብቻን ወይም ሌላ ግንኙነትን ጨምሮ የስኳር በሽታ በቤተሰብዎ ላይ ምን ያህል ተጽዕኖ እንዳሳደረ ይነጋገሩ?, የእርስዎ ቤተሰብ ተጽዕኖ እንዴት ያዩታል

6. ለልጅ የስኳር ህመም የማስታመም ሃላፊነትን ከትዳር ጓደኛ / አጋር ወይም ከሌሎች የቤተሰብ አባላት ጋር ይጋራሉ ? ልጆ የስኳር ህመም ከተገኘበት በሁላ የልጆች የስኳር በሽታን ለመቆጣጠር እና ከምርመራው በኋላ የቤተሰብ እና ግንኙነት እንዴት ነው ፡

7. የስኳር ህመም ጋር በተያያዘ ስለ ልጆ የት / ቤት ሕይወት ይንገሩ

8. ምን ዓይነት የመቋቋም እና የማላመድ ዘዴዎች 'ጥቅም ላይ ውለው ነበር? ድጋፍ የሚሰጠው ማን ነበር? እንደ ጓደኞች እና የቤተሰብ አባላት ያሉ ፣ ከጤና እንክብካቤ ባለሙያዎች ፣ ከሌሎች ማህበራዊ ድጋፍ ስርዓቶች ፣ ከሲቪል ድርጅቶች ....?

9. ስለ አጠቃላይ የስኳር በሽታ ዕውቀትዎ እና ስለ ልጅዎ የስኳር በሽታ የመቆጣጠር ችሎታዎ ምን ያህል እምነት አሎት? የስኳር ህማም ትምህርቱን የት እና እንዴት አገኙ፤ ለልጅዎ የስኳር በሽታ ለመቆጣጠር ጠቃሚ ሊሆን የሚችል መረጃ ለመቀበል የእርስዎ ተመራጭ ዘዴ ምን ሊሆን ይችላል ?

11. የስኳር በሽታ ያለበትን ልጅ መንከባከብ ምን ያህል መሆን እንዳለበት ንገረኝ? መገደብ ፣ ኃላፊነቱን ማስተላለፍ ወይም ገለልተኛ እንቅስቃሴን መገደብ?

12. ምን ዓይነት የሚያገኙት ድጋፍ አለ? - ማንኛውም የድጋፍ ትስስር ፣ ለተንከባካቢዎች ድጋፍ ሰጪ ቡድን ፣ አደረጃጀት ወይም የማህበረሰብ ድጋፍ አለ ወይንስ ከመንግስት? ምን ዓይነት እርዳታ ጠቃሚ ይሆናል? ችግሩን ለመቅረፍ በቤተሰብ ፣ በመንግሥት ፣ በሕብረተሰብ ፣ በሲቪል ድርጅቶችና በየደረጃው ምን መደረግ አለበት ?

13. ስለ ህፃን የስኳር ህመም በጣም የሚያስፈራዎት ነገር ምንድነው? የስኳር በሽታ ያለበትን ልጅ ስለ መንከባከብ ከእኔ ሊያጋሩኝ የሚፈልጉት የቀር ነግር አለ?

Appendix 5: Impact on the HRQoL Parents and family Questionnaires (English version)

Part One. Socio-Demographic and clinical related questioners

These questionnaires have been prepared to gather information about socio-demographic and clinical related characteristics of your family and your child with T1DM. So, there is no need to write your name. Your genuine responses to all items of this questionnaire contribute a lot to the successful completion of this study. You are, therefore, kindly requested to provide genuine information. The information you give will be used only for research purpose and it will be kept confidential. I thank you very much for taking your time in filling in this questionnaire.

Direction: please check and/, circle fill in the blank spaces of the following socio-demographic and medial related questioners.

A. Socio-demographic Questioner

No	Question	Coding Categories
1	What is your relationship to the child (please check and/or circle)?	1. Mother, 2.Father, 3.Grandmother 4. Grandfather 5.Guardian 5.Other ______
2	What is the age of the child (Enter in the space)	________________ year
3	The child sex?	1. Male 2. Female
4	Marital Status	1.Single 2. Married 3.Divorced 4.Separated 5.Widowed
5	Number of children in family (enter	________________

	space)	number
6	Educational level?	1. Not illiterate 2. Grade 1-6 3. Grade 7-12 4. certificate 5. Diploma 6. Degree & above
7	Occupation Or Job Title:	1. Unemployed 2. Government/private employee 3. Self-employed 4. Other specify(________________)
8	What is the average family income per months?	________________ birr

B. Clinical Related Questioners

9	At what age was the child diagnosed?	________________year or/month
10	How long has he/she been on medication/follow up	________________year or month
11	Which drug regimen you are following currently for your Diabetes?	1. Oral anti diabetic medications only 2. Insulin only 3. Insulin and oral anti diabetic medications
12	Who injects the child?	1.self 2.parent 3.care giver
13	How many time do you inject per day?(Enter space)	________________ times/day
14	What is the child’s most recent HbA1c (HbA1c or A1c) (Reviewed from card)	1. _______% date taken__________

Part Two: Questionnaire on the Impact of T1DM Parent and Family

DIRECTIONS

Families of children sometimes have special concerns or difficulties because of the child's health. On the following page is a list of things that might be a problem for **you**. Please tell us **how much of a problem** each one has been for **you** during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.

In the past *ONE month*, as a result of your child's health, how much of a problem have *you* had with…

PHYSICAL FUNCTIONING *(problems with…)*	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. I feel tired during the day	0	1		3	4
2. I feel tired when I wake up in the morning	0	1		3	4
3. I feel too tired to do the things I like to do	0	1		3	4
4. I get headaches	0	1		3	4
5. I feel physically weak	0	1		3	4
6. I feel sick to my stomach	0	1		3	4

EMOTIONAL FUNCTIONING ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**ften**	**Almost Always**
1. I feel anxious	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I feel frustrated	0	1	2	3	4
5. I feel helpless or hopeless	0	1	2	3	4

SOCIAL FUNCTIONING ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**ften**	**Almost Always**
1. I feel isolated from others	0	1	2	3	4
2. I have trouble getting support from others	0	1	2	3	4
3. It is hard to find time for social activities	0	1	2	3	4
4. I do not have enough energy for social activities	0	1	2	3	4

COGNITIVE FUNCTIONING ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard for me to keep my attention on things	0	1	2	3	4
2. It is hard for me to remember what people tell me	0	1	2	3	4
3. It is hard for me to remember what I just heard	0	1	2	3	4
4. It is hard for me to think quickly	0	1	2	3	4
5. I have trouble remembering what I was just thinking	0	1	2	3	4

COMMUNICATION ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**ften**	**Almost**

					Always
1. I feel that others do not understand my family's Situation	0	1	2	3	4
2. It is hard for me to talk about my child's health with others	0	1	2	3	4
3. It is hard for me to tell doctors and nurses how I feel	0	1	2	3	4

WORRY ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1.I worry about whether or not my child's medical treatments are working	0	1	2	3	4
2. I worry about the side effects of my child's medications/medical treatments	0	1	2	3	4
3. I worry about how others will react to my child's condition	0	1	2	3	4
4. I worry about how my child's illness is affecting other family members	0	1	2	3	4
5. I worry about my child's future	0	1	2	3	4

DIRECTIONS

Below is a list of things that might be a problem for **your family**. Please tell us **how much of a problem** each one has been for **your family** during the **past ONE month.**

In the past ONE month, as a result of your child's health, how much of a problem has your family *had with…*

DAILY ACTIVITIES ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**often**	**Almost Always**
1. Family activities taking more time and effort	0	1	2	3	4
2. Difficulty finding time to finish household tasks	0	1	2	3	4
3. Feeling too tired to finish household tasks	0	1	2	3	4

FAMILY RELATIONSHIPS ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. Lack of communication between family members	0	1	2	3	4
2. Conflicts between family members	0	1	2	3	4
3. Difficulty making decisions together as a family	0	1	2	3	4
4. Difficulty solving family problems together	0	1	2	3	4
5. Stress or tension between family members	0	1	2	3	4

Appendix 6: Impact on the Parents and family Questionnaires (Amharic version)

ክፍል አንድ: ማህበረሰባዊ፣ ግላዊ እና የህክምና ሁኔታን በተመለከተ የሚጠየቁ ጥያቄዎች

ይህ መጠይቅ የተዘጋጀው ማህበረሰባዊ፣ ግላዊ እና የልጆን የህክምና ሁኔታን መረጃ ለመሰብሰብ ነው። ስለሆነም ስምዎትን መፃፍ አያስፈልግም። ለነዚህ ጥያቄዎች ትክክለኛ መልሶችዎን መስጠትዎ ለዚህ ጥናት ወጤታማነት ብዙ አስተፃኦ ያደርጋል። ስለሆነም ትክክሌኛውን መልስ እንዲስጡ በአክብሮት እጠይቃለሁ። የሚስጡት መረጃ ለጥናት አገሌግልት ብቻ የሚውል ሲሆን ሚስጥራዊንቱም ይጠብቃሌ። ጊዜዎትን ሰውተው ይህን መጠይቅ ስለሞሉልኝ በጣም አመሰግናለሁ።

መመረያ: እባክዎ ምርጫዎን የሚዎክለውን አማራጭ በመክበብ ወይም በባዶ ቦታ በመሙላት ያመላክቱ።

ሀ. ማህበረሰባዊ እና ግላዊ ጥያቄዎች

ተ/ቁ	ጥያቄ	አማራጮች
1	የእርስዎን ግንኙነት ከታማሚው ጋር ምንድን ነው (እባኮ ያመላከቱ ወይም ይክበቡ)	1. እናት 2. አባት 3. ሴት አያት 4. ወንድ አያት 5. ሞግዚት 5. ሌላ _______
2	የልጆት ዕድሜ ስንት ነው (በባዶው ቦታ ውስጥ ያስገቡ)	_________________ አመት
3	የህጻኑ/ኗ ፆታ	1. ወንድ 2. ሴት
4	የጋብቻ ሁኔታ	1. ያላገባ/ች 2. ያገባ/ች 3. የፈታ/ች 4. ተነጣጥለው የሚኖሩ 5. የትዳር አጋር በሞት የተለየ/ች
5	በቤተሰብ ውስጥ የልጆች ብዛት	_________________ ቁጥር
6	የትምህርት ደረጃ?	1. ያልተማረ/ች 2. 1ኛ-6ኛየተማረ/ች 3. ከ7ኛ-12ኛየተማረ/ች 4. ሰርተፉኬት 5. ዲፕልማ 5. ዲግሪና ከዚያ በሊይ
7	የመተዳደሪያ ስራዎት ምንድ ነው?	1. ስራ ዓጥ 2. የመንግስት/የግል ድርጅት ሰራተኛ 3. የግል ስራ 4. ሌላ ካለ ይጥቀሱ___________
8	በወር አማካይ የቤተሰብ ገቢ ምን ያህል ነው?	_________________ ብር

ለ. የህክምና ሁኔታን በተመለከተ የሚጠየቁ ጥያቄዎች

9	ልጆ ለመጀመሪያ ጊዜ የስኳር ሕመም ተገኘበት/ባት? በስንት ዓመቱ/ቷ ነበር?	________________ አመት ወይም / ወር
10	ልጆ ምን ያህል ጊዜ መድሃኒት / ክትትል ሲያደርግ/ ስታደርግ ቆየ/ች	________________ አመት ወይም ወር
11	በአሁኑ ጊዜ ልጆ ለስኳር ህመምዎ የሚከተሉት የትኛውን የመድኃኒት ስርዓት ነው ?	1. በአፍ የሚወሰድ የስኳር በሽታ መድሃኒቶች ብቻ 2. ኢንሱሊን ብቻ 3. ኢንሱሊን እና በአፍ የሚወሰድ የፀረ ስኳር ህመም መድሃኒቶች
12	ልጆን ማን ኢንሱሊን ይወጋል ?	1. ራሱ/ሷ 2. ወላጅ 3. እንክብካቤ ሰጪ
13	በቀን ስንት ጊዜ ኢንሱሊን ይወጋሉ	________________ በቀን
14	የሆሞግሎቢን ኤልሲ (HBA1C) ውጤትን (ከካርድ ላይ በማየት የሚሞላ)	1. ________% የተወሰደበት ቀን __________

ክፍል ሁለት፡ የወላጅ እና የቤተሰብ ተጽዕኖ መጠይቅ

መመሪያ

በልጁ ጤንነት ምክንያት የልጆች ቤተሰቦች አንዳንድ ጊዜ ልዩ ስጋቶች ወይም ችግሮች ያጋጥሟቸዋል ። በሚቀጥለው ገጽ ላይ ለእርስዎ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር አለ ። እባክዎን ባለፈው አንድ ወር ውስጥ እያንዳንዳቸው ለእርስዎ ምን ያህል ችግር እንደነበሩ ከሚከተሉት አንዱን በመክበብ ይንገሩን ።

0 ችግሩ **ፈጽሞ ከሌለ**

1 ችግሩ **በዝቅተኛ ደረጃ** ካለ

2 ችግሩ **አንዳንድ ጊዜ** ካለ

3 ችግሩ **ብዙ ጊዜ** ካለ

4 ችግሩ **ሁል ጊዜ** ካለ

ትክክለኛ ወይም የተሳሳቱ መልሶች የሉም ። ጥያቄውን ካልተረዱ እባክዎን ለእርዳታ ይጠይቁ ።

ባለፈው አንድ ወር በልጅዎ ጤንነት ምክንያት ምን ያህል ችግር አጋጥሞዎታል…

ስለአካላዊ ደህንነት (ያለው ችግር…)	ችግሩ **ፈጽሞ የለም**	ችግሩ **በዝቅተኛ ደረጃ** አለ	ችግሩ **አንዳንድ ጊዜ** አለ	ችግሩ **ብዙ ጊዜ** አለ	ችግሩ **ሁል ጊዜ** አለ
1. በቀን ውስጥ ድካም ይሰማኛል	0	1	2	3	4
2. ጠዋት ከእንቅልፌ ስነቃ የድካም ስሜት ይሰማኛል	0	1	2	3	4

3. ማድረግ የምወደውን ነገር ለማድረግ በጣም ደክሞኛል	0	1	2	3	4
4. ራስ ምታት ይሰማኛል	0	1	2	3	4
5. በአካል ደካማ እንደሆንኩ ይሰማኛል	0	1	2	3	4
6. የሆድ ህመም ይሰማኛል	0	1	2	3	4

ስለ ስሜት ደህንነት (ያለው ችግር…	ች ግሩ **ፈጽሞ የለም**	ችግሩ **በዝቅተኛ ደረጃ** አለ	ችግሩ **አንዳንድ ጊዜ** አለ	ችግሩ **ብዙ ጊዜ** አለ	ችግሩ **ሁል ጊዜ** አለ
1. ጭንቀት ይሰማኛል	0	1	2	3	4
2. ሀዘን ይሰማኛል	0	1	2	3	4
3. ቁጣ ይሰማኛል	0	1	2	3	4
4. ብስጭት ይሰማኛል	0	1	2	3	4
5. አቅም እንደሌለኝ ወይም ተስፋ እንደሌለኝ ይሰማኛል	0	1	2	3	4

ስለ ማህበራዊ ደህንነት/ መስተጋብር(ያለው ችግር…	ች ግሩ **ፈጽሞ የለም**	ችግሩ **በዝቅተኛ ደረጃ** አለ	ችግሩ **አንዳንድ ጊዜ** አለ	ችግሩ **ብዙ ጊዜ** አለ	ችግሩ **ሁል ጊዜ** አለ
1. ከሌሎች እንደተገለልኩ ይሰማኛል	0	1	2	3	4
2. ከሌሎች ድጋፍ ለማግኘት ችግር አለብኝ	0	1	2	3	4
3. ለማህበራዊ እንቅስቃሴዎች ጊዜ ማግኘት ከባድ ነው	0	1	2	3	4
4. ለማህበራዊ እንቅስቃሴዎች በቂ ኃይል የለኝም	0	1	2	3	4

ስለ አእምሮ ደህንነት (ያለው ችግር…)	ችግሩ **ፈጽሞ የለም**	ችግሩ **በዝቅተኛ ደረጃ** አለ	ችግሩ **አንዳንድ ጊዜ** አለ	ችግሩ **ብዙ ጊዜ** አለ	ችግሩ **ሁል ጊዜ** አለ
1. ትኩረቴን በነገሮች ላይ ማድረጉ ለእኔ ከባድ ነው	0	1	2	3	4
2. ሰዎች የሚነግሩኝን ማስታወሱ ለእኔ ከባድ ነው	0	1	2	3	4
3. የሰማሁትን ለማስታወስ ለእኔ ከባድ ነው	0	1	2	3	4
4. በፍጥነት ማሰብ ለእኔ ከባድ ነው	0	1	2	3	4
5. እያሰብኩ የነበረውን ለማስታወስ ተቸግሬያለሁ	0	1	2	3	4

ስለ ተግባቦት (ያለው ችግር…)	ችግሩ **ፈጽሞ የለም**	ችግሩ **በዝቅተኛ ደረጃ** አለ	ችግሩ **አንዳንድ ጊዜ** አለ	ችግሩ **ብዙ ጊዜ** አለ	ችግሩ **ሁል ጊዜ** አለ
1. ሌሎች የእኔን የቤተሰብሁኔታ እንደማይረዱ ይሰማኛል	0	1	2	3	4
ስለልጄ ጤና ከሌሎች ጋር ማውራት ለእኔ ከባድ ነው	0	1	2	3	4
3. ለዶክተሮች እና ለነርሶች ምን እንደሚሰማኝ መንገር ለእኔ ከባድ ነው	0	1	2	3	4

ስለ ጭንቀት/ስጋት(ያለው	ችግሩ **ፈጽሞ የለም**	ችግሩ **በዝቅተኛ ደረጃ** አለ	ችግሩ **አንዳንድ ጊዜ** አለ	ችግሩ **ብዙ ጊዜ** አለ	ችግሩ **ሁል ጊዜ** አለ

ችግር…)					
1. የልጄ የህክምና እየሠራ ስለመሆን አለመሆን እጨነቃለሁ	0	1	2	3	4
2. ስለልጄ መድሃኒቶች / የህክምና የጎንዮሽ ጉዳቶች እጨነቃለሁ	0	1	2	3	4
3. ሌሎች በልጄ ሁኔታ ላይ ምን እንደሚሰማቸው እጨነቃለሁ	0	1	2	3	4
4. የልጄን ሕመም ሌሎች የቤተሰብ አባላት ላይ ስላለው ተጽዕኖ እጨነቃለሁ	0	1	2	3	4
5. ስለልጄ የወደፊት እጨነቃለሁ	0	1	2	3	4

ከዚህ በታች ለቤተሰብዎ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር ነው። ባለፈው አንድ ወር

ውስጥ እያንዳንዱ ለቤተሰብዎ ምን ያህል ችግር እንደነበረ እባክዎን ይንገሩን።

*ባለፈው **አንድ ወር ስጥ** በልጅዎ ጤንነት ምክንያት **ቤተሰቦችዎ** ምን ያህል ችግር* ገጥሞአቸዋለል…

ሰለ የእለተለት እንቅስቃሰሴ ጭንቀት/ስጋት **(ያለው ችግር…)**	ችግሩ **ፈጽሞ የለም**	ችግሩ **በዝቅተኛ ደረጃ** አለ	ችግሩ **አንዳንድ ጊዜ** አለ	ችግሩ **ብዙ ጊዜ** አለ	ችግሩ **ሁል ጊዜ** አለ
1. የቤተሰብ እንቅስቃሴዎች የበለጠ ጊዜ እና ጥረት መውሰድ	0	1	2	3	4
2. የቤት ውስጥ ሥራዎችን ለመጨረስ ጊዜ የማግኘት ችግር	0	1	2	3	4

3. የቤት ውስጥ ሥራዎችን ለመጨረስ ከፍትኛ የድካም ስሜት	0	1	2	3	4

ስለ ቤተሰባዊ ግንኙነት (ያለው ችግር…)	ችግሩ **ፈጽሞ የለም**	ችግሩ **በዝቅተኛ ደረጃ** አለ	ችግሩ **አንዳንድ ጊዜ** አለ	ችግሩ **ብዙ ጊዜ** አለ	ችግሩ **ሁል ጊዜ** አለ
1. በቤተሰብ አባላት መካከል መግባባት አለመኖሩ	0	1	2	3	4
2. በቤተሰብ አባላት መካከል ግጭቶች	0	1	2	3	4
3. እንደቤተሰብ በጋራ ውሳኔ የማድረግ ችግር	0	1	2	3	4
4. የቤተሰብ ችግሮችን በጋራ ለመፍታት ችግር	0	1	2	3	4
5. በቤተሰብ አባላት መካከል ውጥረት ወይም ጭንቀት	0	1	2	3	4

Appendix 7: The Socio-Demographic and Clinical Related Characteristics of Caregiver

Table 2

The socio-demographic and clinical related characteristics of caregiver

No	Pseudonym	Relationship to child	Age of caregiver	Age of child	Marital status	Sex of the child	No of household	Caregivers' Education level	Monthly income	Child's age at diagnosis	FBG result
1	Manyazewal	Father	42	12	Married	F	6	Grade 5	3500	7	Poor
2	Maheder	Mother	29	2 year and 8 month	Married	F	4	Diploma	6000	2	Poor
3	Aster	Mother	36	7	Married	M	2	Masters	13,000	1 year 3 month	Poor
4	Tsehay	Mother	39	12	Married	M	5	Diploma	Don't know	4	Faire
5	Selam	Mother	37	8	Married	F	4	Grade 7	2000	7 year & 5 month	Faire
6	Ayele	Father	47	7	Married	M	10	Grade 6	3000	1 year & month	Good
7	Alemu	Father	40	9	Married	M	6	Degree	6446	8 year & 4 month	Good
8	Hirut	Mother	32	12	Married	M	4	Degree	20,000	8	Good
9	Melkamu	Father	29	4	Married	M	4	Degree	4000	2	Faire
10	Tamrat	Father	41	9	Married	M	8	grade 5	5000	8 year & one month	Faire

11	Kindu	Father	55	8	Married	M	6	Diploma	3000	6	Poor
12	Dereje	Father	39	10	Married	F	7	Degree	9,000	5	Poor
13	Tezitaw	Father	63	7	Married	F	8	Non literate	3,000	4	Faire
14	Azeb	mother	33	3 year and 8 month	Married	M	1	degree	7000	1	Good
15	Mahlet	sister	25	4 year and 3 month	single	F	4	degree	12000	2 year and 6 month	Good

Appendix 8: Clinical Characteristics of Children with Diabetes

Table 5

Variable	Category	Frequency		Percent
Current drug regimen	Insulin only	155		100
Person injecting the child	Self	5		3.2
	Parent	149		96.1
	Caregiver	1		0.6
Child's most recent blood fasting glucose	Good diabetic control	35		22.6
	Fair diabetic control	44		28.4
	Poor diabetic control	76		49.0
Variable	Minimum	Maximum	Mean	Standard deviation (SD)
Age of child at diagnosed in year	0.49	11	3.93	2.14
Follow-up time on medication in year	0.25	10.16	2.77	2.17
Injection per day	2	3	2.01	0.11

Appendix 9: Multiple Linear Regression Analysis on HRQoL of Parent

Table 7

Multiple linear regression analysis of predictor of impact of having a child diagnosed with T1DM on HRQoL of the parents and family members and its β coefficients with 95% confidence interval

Variable	Physical functioning	Emotional functioning	Social functioning	Cognitive functioning
Relationship to child				
Ref = Mother				
Father	6.85 (-0.26, 13.95)	6.18 (-1.51, 13.87)	2.35 (-6.03, 10.73)	-1.44 (-10.30, 7.42)
Grandmother	-48.55 (-101.22, 4.12)	-13.06 (-70.07, 43.94)	14.32 (-47.78, 76.41)	67.56 (1.90, 133.21) *
Age of the child in year	0.88 (0.28, 1.48) *	1.34 (1.10, 1.58) *	1.05 (-2.14, 4.23)	-2.47 (-5.84, 0.89)
Age of parent in year	0.11 (-0.45, 0.66)	-0.75 (-1.36, -0.15) *	0.17 (-0.49, 0.83)	0.59 (-0.11, 1.29)
Child sex (Ref = Male)				
Female	-4.39 (-10.40, 1.61)	2.33 (-4.16, 8.83)	-6.59 (-13.67, 0.49)	-3.13 (-10.62, 4.35)
Marital status of parents				
Ref = Single				
Married	26.24 (-9.01, 61.49)	-6.98 (-45.13, 31.16)	20.43 (-21.13, 61.98)	-24.39 (-68.33, 19.55)
Divorced	33.71 (-8.09, 75.50)	8.18 (-37.05, 53.42)	35.82 (-13.46, 85.10)	-15.20 (-67.30, 36.90)
Separated	20.48 (-20.28, 61.24)	-30.23 (-74.35, 13.88)	15.45 (-32.60, 63.51)	-25.14 (-75.95, 25.67)
Windowed	-63.44 (-113.90,-12.98) *	-8.13 (-62.74, 46.48)	22.91 (-36.58, 82.40)	8.97 (-53.93, 71.87)
Number of children in a family	-0.69 (-3.16, 1.78)	3.37 (0.70, 6.05) *	2.16 (-0.75, 5.08)	-3.04 (-6.13, 0.04)
Educational level				
Ref = Illiterate				
Grade 1-6	-11.29 (-29.09, 6.51)	-2.34 (-21.60, 16.93)	-20.12 (-41.10, 0.87)	-0.24 (-22.43, 21.95)
Grade 7-12	-14.58 (-31.81, 2.65)	-5.99 (-24.64, 12.65)	12.87 (7.44, 18.30) *	2.85 (-18.63, 24.32)

Certificate	0.54 (-22.39, 23.46)	-11.96 (-36.77, 12.85)	8.99 (6.75, 11.23) *	5.59 (-22.98, 34.16)
Diploma	-9.54 (-27.27, 8.19)	-4.82 (-24.01, 14.37)	8.68 (5.14, 12.22) *	-2.73 (-24.83, 19.37)
Degree & above	-8.36 (-26.74, 10.01)	0.62 (-19.27, 20.50)	7.2 (4.8, 9.6) *	5.86 (-17.05, 28.77)
employment				
Ref = Unemployed				
Government/private employee	-5.21 (-14.31, 3.88)	-6.36 (-16.21, 3.48)	-10.53 (-21.25, 0.20)	-1.20 (-12.54, 10.14)
Self-employed	-0.52 (-9.41, 8.37)	-7.14 (-16.76, 2.48)	-4.73 (-15.21, 5.75)	-2.56 (-13.64, 8.52)
Average family income per months in birr	0.01 (0.001, 0.017) *	0.001 (0.0002, 0.002)*	0.001(0.0001, 0.002) *	0.0003 (-0.0008, 0.001)
Age of child at diagnosed in year	-0.70 (-3.51, 2.11)	-2.27 (-5.31, 0.77)	-1.99 (-5.30, 1.33)	1.54 (-1.96, 5.05)
Follow-up time on medication in year	1.84 (0.81, 2.88) *	0.34 (0.21, 0.47)*	-0.97 (-4.35, 2.41)	3.24 (-0.33, 6.82)
Injects the child				
Ref = Self				
Parent	-16.87 (-35.02, 1.28)	-7.23 (-26.87, 12.41)	-7.29 (-28.68, 14.11)	-21.02 (-43.64, 1.61)
Caregiver	-27.61 (-72.99, 17.76)	22.10 (-27.00, 71.21)	-17.61 (-71.11, 35.88)	-39.48 (-96.04, 17.09)
Injection per day	5.80 (-23.40, 34.99)	-12.16 (-43.76, 19.44)	2.51 (-31.92, 36.93)	13.80 (-22.60, 50.20)
FBG (Ref = Good diabetic control)				
Fair diabetic control	-9.45 (-17.88, -1.01,) *	-15.14 (-24.27, -6.02) *	7.38 (2.56, 17.32)	-13.81 (-24.32, -3.30) *
Poor diabetic control	-14.19 (-22.15, -6.23) *	-13.29 (-21.90, -4.67) *	-12.84 (-22.23, -3.46) *	-9.20 (-19.12, 0.72)
Adjusted R-square	0.34	0.36	0.32	0.23

Variable	Communication	Worry	Daily activities	Family relationship	Total
Relationship to child					
Ref = Mother					
Father	2.76 (-5.96, 11.48)	-1.86 (-9.71, 5.98)	-2.56 (-12.2, 7.1)	-3.21 (-12.15, 5.74)	1.13 (-2.2, 4.5)
Grandmother	14.4 (-50.2, 79.1)	-6.1 (-64.3, 52.0)	-16.5 (-88.2, 55.3)	-51.5 (-117.8, 14.8)	-21.8 (-46.4, 2.8)

Age of child in year	1.58 (-1.74, 4.89)	1.9 (1.0, 4.9) *	1.49 (-2.18, 5.17)	2.80 (-0.60, 6.20)	0.9 (-0.4, 2.1)
Age of parent in year	-0.06 (-0.75, 0.62)	0.47 (-0.15, 1.08)	0.75 (-0.01, 1.51)	0.28 (-0.43, 0.98)	-0.4 (-0.6, -0.1) *
Child sex (Ref = Male)					
Female	-7.00 (-14.36, 0.36)	-6.39 (-13.0, 0.2)	4.83 (-3.34, 13.01)	3.12 (-4.44, 10.67)	-2.2 (-5.0, 0.7)
Marital status of parents					
Ref = Single					
Married					
Divorced	2.19 (-41.05, 45.42)	-5.21 (-44.1, 33.7)	11.2 (-36.8, 59.2)	-2.4(-46.9, 41.9)	
Separated	5.98 (-45.29, 57.24)	-3.50 (-49.6, 42.6)	25.9 (-31.1, 82.8)	39.6 (-12.96, 92.3)	2.6 (-13.8, 19.1)
Windowed	-0.83 (-50.83, 49.2)	-13.4 (-58.4, 31.6)	2.6 (-52.9, 58.1)	-7.89 (-59.19, 43.41)	16.3 (-3.2, 35.8)
	-12.49 (-74.4, 49.4)	-18.2 (-73.9, 37.5)	-20.0 (-88.7, 48.7)	21.6 (-41.87, 85.14)	-4.9 (-23.9, 14.2)
					7.3 (-16.3, 30.8)
Number of children in a family	-0.85 (-3.88, 2.18)	4.0 (1.3, 6.7) *	3.5 (0.14, 6.9) *	-1.61 (-4.72, 1.50)	-1.9 (-3.0, -0.7)
Educational level					
Ref = Illiterate					
Grade 1-6	7.6 (-14.2, 29.4)	-16.6 (-36.2, 3.1)	-16.0 (-40.3, 8.2)	-18.13 (-40.53, 4.28)	9.6 (1.3, 18) *
Grade 7-12	12.1 (-9.1, 33.2)	-10.4 (-29.4, 8.6)	-17.9 (-41.4, 5.6)	-7.00 (-28.68, 14.68)	-6.7 (-14.8, 1.3)
Certificate	14.1 (-14.0, 42.2)	-1.28 (-26.6, 24.0)	-9.1 (-40.3, 22.1)	-10.21 (-39.1, 18.6)	-2.7 (-13.4, 8.0)
Diploma	13.98 (-7.8, 35.7)	-7.2 (-26.7, 12.4)	-20.1 (-44.3, 4.0)	-17.99 (-40.31, 4.33)	-7.1 (-15.4, 1.2)
Degree & above	11.68 (-10.9, 34.2)	-11.4 (-31.6, 8.9)	-19.8 (-44.8, 5.2)	-7.12 (-30.25, 16.01)	-3.7 (-12.2, 4.9)
Occupation					
Ref = Unemployed					
Government/private employee	-4.42 (-15.58, 6.74)	-5.18 (-15.2, 4.9)	-1.88 (-14.3, 10.5)	-5.57 (-17.0, 5.9)	-5.0 (-9.3, -0.8) *
Self-employed	-4.36 (-15.26, 6.55)	-5.35 (-15.2, 4.5)	4.18 (-7.9, 16.3)	2.92 (-8.3, 14.1)	-2.2 (-6.3, 1.9)
Average family income per months in birr	0.0004 (-0.0007, 0.002)	0.006 (0.004, 0.02,) *	-0.0002 (-0.001, 0.001)	0.00003 (-0.001, 0.001)	0.001 (0.0001, 0.001) *
Age of child at diagnosed in year	-2.50 (-5.95, 0.95)	-1.79 (-4.89, 1.31)	-2.05 (-5.87, 1.78)	-2.20 (-5.73, 1.34)	1.5 (0.2, 2.8) *
Follow-up time on medication in year	1.22 (-2.30, 4.74)	0.5 (0.4, 0.7) *	-0.77 (-4.68, 3.13)	-0.95 (-4.55, 2.66)	0.3 (-1.1, 1.6)
Person Injects the child					

Ref = Self					
Parent	-9.6 (-31.8, 12.7)	-9.49 (-29.5, 10.5)	-9.7 (-34.5, 14.98)	-12.5 (-35.4, 10.3)	11.7 (3.2, 20.2) *
Caregiver	-8.7 (-64.4, 46.9)	3.78 (-46.3, 53.9)	-51.8 (-113.6, 10)	65.9 (8.8, 123.0) *	23.2 (2.0, 44.4) *
Injection per day	16.6 (-19.2, 52.4)	-16.8 (-49.0, 15.4)	31.0 (-8.7, 70.8)	4.4 (-32.3, 41.1)	5.6 (-8.0, 19.3)
FBG (Ref = Good diabetic control)					
Fair diabetic control	-0.25 (-10.59, 10.1)	5.14 (-4.2, 14.4)	-5.25 (-16.7, 6.23)	-5.6 (-16.24, 4.98)	-6.5 (-10.4, -2.5)
Poor diabetic control	-7.33 (-17.09, 2.43)	0.42 (-8.37, 9.20)	-4.16 (-14.99, 6.7)	-14.5 (-24.47, -4.4) *	9.4 (5.7, 13.1) *
Adjusted R-square	0.20	0.20	0.19	0.30	0.12

Note. Items are reverse scored, higher score indicates better functioning and vice versa. *= significant at $p<0.05$, Ref: indicates a reference category, FBG: fasting blood glucose.