The Experience of Having a Child Diagnosed With Type 1diabetes: The Case of Parents and Guardians

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Thesis Approval

This is to certify the thesis prepared by Hana Fantu entitled: *The experience of having a child diagnosed with type 1 diabetes: the case of parents and guardians*. This thesis is submitted in partial fulfillment for the requirements of degree of Master of Arts in Social Work. Accordingly, we examined and approve that it is conducted according to the regulations of the University and qualifies the requirements and standards with respect to originality and quality.

Name and Signature of Examining Board

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Advisor	Signature	Date
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Acronym

DE	Diabetes Education
DKA	Diabetic Ketoacidosis
DM	Diabetes Management
EDA	Ethiopian Diabetic Association
GDM	Gestational Diabetes Mellitus
HIV	Human Immune Virus
IDF	International Diabetes Federation
IIF	International Insulin Federation
NCD	Non-Communicable Diseases
T1DM	Type 1 Diabetes Mellitus
T2DM	Type 2 Diabetes Mellitus
TB	Tuberculosis
WHO	World Health Organization

Abstract

Type 1 diabetes mellitus (T1DM), a common, chronic disease, affects the patient as well as the family. It requires daily vigilance in blood sugar monitoring, dietary management and insulin administration. It is a lifelong condition for children and their parents, the management for which imposes a vast responsibility. This research has explored the experiences of parents having a child diagnosed with T1DM. Using a qualitative exploratory design, 12 parents raising children with T1DM and who are members of Ethiopian Diabetic Association participated in audio-recorded interview. At the time of the interviews the children ranged in age from 4 to 13 years, with duration of diagnosis ranging from 1 year to 12 years. Eight major themes were identified, including issues of parental feeling and emotion, factors associated with parental distress, challenges encountered, family relationship, school and health care, diabetes education, coping and adaptation. Within each theme, numerous sub-themes were identified. The identification of challenges and unmet needs of parents implies the health care and schools systems should acknowledge the need and provide the required services and support. Psycho social, financial and emotional issues should be managed and a formal follow-up plan should be in place starting from time of hospitalization, to create access to diabetic education and raising public awareness. And, a holistic and integrated interventions at all level from policy, education, and practice and research point of view against burden of raising child with T1DM is essential.

***Keywords*: type 1 diabetes mellitus, children, parent, stress, hyperglycemia, hypoglycemia**

Table of Contents

Contents **Pages**

Chapter One

Introduction

Background of the Study

The (2014) International Diabetes Federation (IDF) Atlas (6th edition), reported 387 million people or 8.3% or 1 in 12 people of the world's population have diabetes worldwide in 2014. Of these more than 70% live in the developing countries. It further estimate an increase to 592 million by 2035 and the largest share taking place in regions found in developing countries. 1 in 2 diabetes people do not know that they have it and in every 7 seconds 1 person die from diabetes resulting in the death of 4.9 million people in 2014. Similarly, 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.

According to the (2013) International Diabetes Federation (IDF) Atlas (6th edition) there are almost 500,000 children aged less than 15 years with T1DM worldwide, the largest number being in Europe (129,000) and North America (108,700). Countries with the highest estimated numbers of new cases annually were the United States (13,000), India (10,900) and Brazil (5000).

Diabetes mellitus, or simply diabetes, is a chronic disease that occur when the pancreas (a gland organ in the digestive system) is no longer able to produces a hormone called insulin, in which the body is not able to correctly process glucose for cell energy due to either an insufficient amount of insulin or when the body cannot make good use of the available insulin. Insulin enables the body cells to absorb glucose to produce energy (IDF, 2014). Nevertheless, diabetic individuals either cannot produce this hormone properly or their body cannot appropriately use it for usual body functions (Singh, 2001).

Diabetes by itself is a long lasting and chronic disease. But people with diabetes also have an increased risk of developing a number of serious health problems. In almost high income countries, diabetes is a leading cause of cardiovascular disease, blindness, kidney failure, and lower amputation (IDF, 2014). Although other specific types of diabetes also exist, according to IDF (2014), there are three main types of diabetes. These are type 1 diabetes mellitus (T1DM), type 2 (T2DM) and gestational diabetes mellitus (GDM) (WHO, 1999).

T1DM used to be called juvenile onset diabetes or insulin dependent diabetes. In this case the bodies either produce little insulin or it cannot produce any insulin. It is usually caused by an auto immune reaction where the body's defense system attacks and distracts the beta cell that produces insulin. At present, T1DM cannot be prevented or the reason why his occurs is not fully understood and the risk factors for T1DM are still being researched (Singh, 2001).. The development of T1DM is usually sudden in previously healthy children. The disease may affect people of any age, but usually develops in children or young adults typically beginning in early life. People with this form of diabetes must replace lost insulin with daily injections of insulin otherwise many die within months if not weeks (Singh, 2001).

T2DM used to be called non- insulin dependent diabetes or adult onset diabetes, and account for at least 90% of all cases of diabetes. In this type of diabetes, the pancreas produces insulin, but it does not yield sufficient amount or the body may have difficulty in using it properly. It is often, but not always, associated with overweight and obesity which itself can cause insulin resistance of deficiency and lead to high blood glucose level (ADA, 2012).

Gestational diabetes (GDM) is a form of diabetes consisting of high blood glucose level during pregnancy. It develops in 1 in 25 pregnancies worldwide and is associated with complications of both mother and baby. Woman with GDM and their children are at an increased risk of developing diabetes later in life. Approximately half of women with a history of GDM go on to develop T2DM within 5 to 10 years after delivery (IDF, 2014).

Despite the limitations and with a few data available on sub- Saharan African children Majaliwa, Elusiyan, Adesiyun,et al.(2008) reported the prevalence of Juvenile diabetes mellitus less than 1/1000 while the incidence range between 1.5/100000 in Tanzania to 20/100000 in Morocco. The above source also reported that in Ethiopia, it is said to account for 9.8% of patients attending diabetes clinic in Addis Ababa and Gestational diabetes prevalence varied from 0% in Tanzania to 9% in Ethiopia. The report also notice that the dangerous complication of diabetes in which the chemical balance of the body becomes too acidic named diabetic ketoacidosis (DKA) and becoming the leading cause of T1DM children death in Africa and documented to be the most common form of representation in the sequence from Tunisia, Ethiopia, and Sudan. Mortality due to T1DM was found to be very high with a rate of 42.6% in Sudan (Majaliwa, Elusiyan,Adesiyun,et al, 2008).

Besides the physical and psychological problem it bring, the treatment of T1DM is also extremely costly and it is a financial burden to families and government in Africa countries where many live on less than US $1.00 per day. For example, the government of Mozambique needs to prioritize between providing insulin for 1 person for a year or essential medicine for almost 40 others (IIF, 2014).

Similarly Ethiopia, which is one of the developing nations, is at a risk of increased diabetes incidence and its diversified negative effects. In Ethiopia, the number of deaths attributed to diabetes reached over 21,000 in 2007 (Diabetes Atlas, 3rd edition). 2- 3% of the population is estimated to live with diabetes in Ethiopia and the IDF regional estimate for comparative diabetes prevalence was 5.7% for the year 2013.

This increase in the number of diabetic patient nationwide has led to the provisions of diabetes care at general outpatient clinics and hospitals. The opening of specialized diabetes clinics at Black Lion Specialized, Zeweditu and Yekatit 12 hospitals can be mentioned as an example. Several hospitals in the regions have also started diabetes care as a general outpatient service. The Gondar College of Medical Sciences has an outreach program to rural areas to provide diabetes care. The Ethiopian Diabetes Association has also tried to contribute its part in diabetes prevention, care and treatment. Currently, more than 900 children and youth are members of EDA. Almost all diagnosed with T1DM. The association supports the activities of the diabetic center found in the premise of Black Lion Specialized Hospital (EDA, 2015).

T1DM is a lifelong condition for children and their parents, the management of which imposes a vast responsibility. Parenting a child with a long lasting and life-threatening illness is very difficult and can have a negative impact on many aspects of the parent's family life. This also is the case with T1DM, as there is an intensive management plan that must be executed daily, which includes blood glucose monitoring, insulin administration, careful monitoring of diet/calories and exercise all of which potentially involve parents. Although the treatment and management of T1DM is complex, life long and demanding very little or nothing is known about the experience Ethiopian parents go through during the diagnosis of T1DM of their children. Therefore, this study is conducted to shade light from this angle. The aim of this study was to explore the experience of parents having a child diagnosed with T1DM in the cultural setting of Ethiopia, particularly the case of some selected parents who are a member of Ethiopian Diabetic Association. The study was carried out in Addis Ababa, at Tikur Anebessa Specialized diabetic center and EDA head office.

Before two years ago my little sister aged 10 was diagnosed with T1DM which was a traumatic event for the whole family. But, through time when we join the Ethiopian Diabetic Association, I realized that not only my family, but more families and parents are helplessly suffering from their child diabetes related stress and daily fighting with the countless problems. I saw and start to personally meet children living in a very heartbreaking situation. But, no one was there to be a help except the association with its limited capacity. Contrary to the fact, I recognize that the issue is not known well by the society, expected governmental and, nongovernmental organizations and even by professionals on the area. This is why I started to develop the interest not only to conduct a research on the topic but, also the reason I joined the School of Social Work from the beginning, to have a profession that can practically contribute on the area.

Statement of the problem

A number of studies have been conducted on various dimensions in relation to children with T1DM worldwide. Eccleston, Palermo, Fisher, and Law, (2012) ; Landolt, Vollrath, Laimbacher, Gnehn and Sennhauser, (2002); Vicki, Dorothy, Oscar and Linda , (2011) investigated the impact of parenting a child with T1DM. They indicated that parents of these children often have difficulty of balancing care for their children 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 behaviors. Landolt, et al., (2005) showed that the newly diagnosis of T1DM children is a traumatic and the treatment is stressful event for parents and it is likely to produce symptoms of anxiety and depression. Additionally, families with high levels of general life stress was identified for being at risk for both poor parenting and child physical and mental health outcome (Vicki ,Dorothy , Oscar and Linda,2011).

Researchers examined the relationship between parenting stress, metabolic control and depressive symptoms in adolescents with T1DM. Positive relationship were found in a more recent systematic review published by Elina, Evangelos, Alexopoulos, Charikleia , Christina , George, and Chrousos, (2014) . The finding showed that positive family functioning was strongly related to patients' glycemic control, while family conflict was adversely associated with glycemic control.

Similarly, Whitney, Rusan, Clarissa, and Anil Kumar (2012) examined the association of family organization with metabolic control in adolescents with T1DM. In the finding greater family organization and self-efficacy was associated indirectly with successful management of T1DM in adolescents. High family restrictiveness was also associated with poorer metabolic control in a study conducted by Inge, Brett, and Daniel, (2013). Whereas, other researchers indicated that changes in parent–child relation pattern or communication did not predict changes in glycemic control or treatment adherence (Jeannette, Jennifer, Jennifer, Alan ,& Dennis,2014). In line with this concept Deborah ,Chong, Debra, Jonathan, Peter, and Cynthia, (2014) exposed that declines in parental responsibility were related to deterioration in adherence and growth in self-efficacy. Ariana, Robin, Karl, Kathryn, and Margaret, (2014) and Wysocki, Taylor, Hough, Linscheid, Yeates, and Naglieri, (1996) explored a transitional pattern of self-management with a high frequency of diabetes care activities, problem solving and goals and variable amounts of collaboration with parents. Their findings revealed that transferring too much responsibility of diabetes management from parents to a child is associated with poor treatment adherence, poor diabetes knowledge and more hospitalizations.

Though, most of the above findings focus on the positive relationship between diabetes management and family support a study conducted by Kathleen ,Michael , Jame , Dennis , Linda , (2012) found out that diabetes management improved over time among emerging adults with T1DM regardless of whether youth are in high school or post-high school and whether living with parents or not. Hanson, Henggeler, Rodrigue, Burghen and Murphy, (1999) examined the health and behavior of diabetic youths living with single mothers. They demonstrated that these children are no better than diabetic children in a two-parent family. The contradictory findings from the Overstreet, Goins, San, Holmes, Greer, Dunlap and Frentz, (1995) suggested that diabetic children who live with single parents are in poorer metabolic control than those in two-parent families. However, despite such contradictory findings, Miller, Emery, Marvin, Clarke, Lovinger and Martin, (1994) concluded that greater involvement from parents of children with T1DM as compared with that of parents of children without diabetes is essential.

The psychosocial impact of diabetes in childhood is ubiquitous and involves the entire family, as well as schools and society as a whole. National Collaborating Centre for Women's and Children's Health, (2004) investigated and conformed diabetes in infants, toddlers, older children, and adolescents poses serious physical, mental, and emotional challenges. Other researchers who were interested in the area are Grey and Cameron, (1995) also reported that depression, eating, cognitive and behavioral disorders, attachment difficulties and family dysfunctions are among the major impacts of T1DM in children's psychosocial life. Specifically a study conducted by Siddharth, and Yatan, (2014) suggests that suicidal ideas and attempts are more frequent in patients with diabetes mellitus than healthy or medically ill controls.

A qualitative study was also conducted by Donna , Noshin , Shaun,(2013) to explore children's and adolescents' perspectives about diabetes self-care, their knowledge of diabetes, and their emotions associated with having the disease. And the study offered validation to emotional support, along with disease education, supportive conditions for engaging in self-care and a process of acceptance.

Factors that influence adaptation to T1DM in children and more specific parent-related factors on the health and behavioral functioning of T1DM children's has been also studied. A research conducted by Robin, Sarah , Jia and Margaret (2007) showed that, individual and family characteristics and family responses influence the level of adaptation to T1DM in children. Child's cooperation, crises and experiences, economic challenges, and parental participation in care found out to be the major mediating factors of the parental coping process with their children's T1DM (Fatemeh , Neda, and Hossein, 2013).

Aware of the existing literature it is possible to say that parenting and child T1DM is a highly researched social problem. However, when we look at the existing literature in African countries,(Majaliwa, Elusiyan, Adesiyun,et al.,2008; IIF., 2014,Sara Boseley, 2003: Makame, 1993; Hall, Thomsen , Henriksen, Lohse,2011) have conducted research mainly on the prevalence and incidence of child diabetic reveling the 'shocking' shortage of insulin, missed diagnosis and the epidemiological trends, incidence rate and public health implications of diabetes in Sub-Saharan Africa. Though, different from these dimensions

Jarova, Dube, Tivchev, and Chivengo, (2007) investigated and discussed the onset of T1DM in African children, in relation to stress and various harsh socio-economic and environmental circumstances in the case of Zimbabwean children.

When we look at the existing literature in Ethiopia, they are limited to published magazines by Ethiopian Diabetic Association and researches conducted as university thesis in the department of public health, information science and medicine. Solomon Gebremariyam, (2013) examined the prototype self-learning knowledge-based system in diagnosis and treatment of diabetic patients. Tefera Mulugeta, (2011) conducted an assessment on cognitive status of patients with T1DM. Alemu and Watkins, (2004) examined access to diabetes care in Ethiopia and Suerafealem Assefa, (2011) examined the level and the magnesium supplementation to type 2 diabetics. In general, only the prevalence, nutrition and medical treatments of diabetic patients are emphasized in all of the above local researches. The studies gave no or little attention to specific groups of T1DM children and the in-depth psychosocial aspect of the situation.

None of the studies done in Ethiopia addressed the effect of having a T1DM child on parent's, coping mechanisms used by parents and the social, psychological, and economical aspect of children with T1DM. Moreover, the studies conducted in other countries at a global level might not be valid for Ethiopian setting since there are major cultural, environmental, economic, societal and spiritual disparities between nations. Thus, this research aspires on exploring parents' experience of having a child diagnosed with T1DM in the Ethiopian context, as there is a need of a particular research to fill the gap in the existing literatures of social work domain.

Research questions

The research is designed to address the following research questions:

1. What are the acquired diabetic knowledge by the parents and social support services adapted to the needs of parents to the diagnosis TID in their children?

2. What are the feelings and reactions of parents towards having T1DM child?
3. What effects does childhood diabetic have on the life of the family?
4. What are the major psychological, social and economic challenges encountered by parents?
5. What are the parental coping and adaptation mechanisms used to the diagnosis of T1DM in their child?

Objectives of the Study

General Objective

The main objective of this study is to explore the experiences of parents living with T1DM child in Addis Ababa, Ethiopia.

Specific Objectives

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

- explore feelings and reactions of parents towards having T1DM child;
- Explore the effects of childhood diabetic on the life of the family; major psychological, social and economic challenges and changes encountered by parents having T1DM child.
- Explore the parental coping and adaptation mechanisms used to the diagnosis of T1DM in their child.
- Explore if and what, social support services are available to the needs of parents with TID child and needed support.

Significance of the Study

There was no previous significant study conducted on the situation of T1DM children and their parents in Ethiopia specifically. Therefore, this study will provide some useful direction and information for conducting further researches in the area. Additionally, it provides evidence for social workers, governmental organizations and civil societies to intervene in the situation. Thus, the study is important in encouraging further studies and practical actions that benefit the children with diabetes and their families specially who are a member of Ethiopian Diabetes Association.

Theoretical Approach

Social theories are general frameworks or tools of empirical evidence used to study, understand and describe the world and interpret social phenomena. It is an explanation of observations that can show us how to intervene, predict behavior, guide research, answer questions about particular phenomena and understand data in an organized way (Smith, Hamon, Ingolds, and Miller, 2009 ; Joed, and Samantha, 2009).

In social sciences, it is unrealistic to find only one way or a single theory to understand social phenomena, particularly those as complicated as individuals and families. Thus, the selection and usefulness of a theory is measured by its ability to describe or predict some event or behavior (Babbie, E, 2004). Therefore, in this part of the paper I will present theories and a model that are used for guiding and directing my research. More than one framework is used here because complete assessment and eventual implementation of a concept requires a mastery of and the use of multiple theories. No single theory is appropriate for all members of an audience.

A growing interest has been on the topic of family and parenting worldwide, family stress theory and the ABCX model has been accepted as an appropriate theory beginning from the 1930s which guides most contemporary family researches and laid the foundation for most empirical researches on the area (Joed and Samantha, 2009: Suzanna, 1984). In addition, family system theory is used to guide this research as it is as an overarching framework, and the emphasis of this research is on the interaction and interrelatedness of family members and their affects in turn.

Family system theory

It is generally believed that family systems theory emerged primarily in the 1960s.

The family systems theory is a theory introduced by Dr. Murray Bowen that suggests that individuals cannot be understood in isolation from one another, but rather as a part of their family, as the family is an emotional unit. Families are systems of interconnected and interdependent individuals, none of whom can be understood in isolation from the system. In family systems theory, a family is much more than a collection of individuals who live together and are related to each other. Rather, as a natural social system, it has a holistic quality possessing its own rule, characters, communication patterns and power structures (Smith, Hamon, Ingoldsand Miller, 2009).

According to Bowen, a family is a system in which each member had a role to play and rules to respect. Members of the system are expected to respond to each other in a certain way according to their role, which is determined by relationship agreements. Within the boundaries of the system, patterns develop as certain family member's behavior is caused by and causes other family member's behaviors in predictable ways. Maintaining the same pattern of behaviors within a system may lead to balance in the family system, but also to dysfunction (Smith, Hamon, Ingolds and Miller, 2009).

This theory believes that, no behavior can be understood in isolation and if a person shows symptomatic behavior, it is seen as representing a dysfunctional system. They also believe in circular causality which states: in human social interaction, there are a number of forces moving in many directions simultaneously and in the process, there is a repetitive pattern of interaction which has a mutual influence. This will guide the behavior of a person, not a liner cause or one event (Smith, Hamon, Ingolds and Miller, 2009).

I used these two theoretical perspectives in analyzing the research. Framing the interview guide, understanding, describing and interpreting the phenomena and disusing the findings.

Family Stress Theory

Throughout history, families have dealt with stress and crises (Joed and

Samantha,2009). Although its widespread use comes later, through modified, family stress theory, which looks at how the family as a system deals with challenging situations, stress or events, was developed while professor Reuben Hill (1949) studied family reactions to the depression of the 1930s and later to wartime during World War II (Smith, Hamon, Ingolds, and Miller, 2009: Joan, 2002).

Hill, as a result theorized that there are two complex variables which act to buffer the family from acute stressors and reduce the direct correlation between multiple stressors and family crisis. These were formulated into what he called his ABCX theory of family stress or crises model which was 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 (Joed and Samantha,2009). Family Stress Theory is a developmental theory borrowed from family science, which explores why some family systems adapt and even grow and thrive when faced with situational stressors or transitional events, while other family units deteriorate and disintegrate under similar circumstances (Cynthia, 2000).

Both positive and negative events can cause stress. A crisis is reached when the family is no longer able to maintain its usual balance because of the stressor event or when it can no longer maintain the status quo using their existing individual or collective family resources (Smith, Hamon, Ingoldsby, and Miller, 2009). Generally, family stress becomes problematic when the level of stress causes a disturbance within the family system or on individual family members (Suzanna, 1984: Joed and Samantha, 2009).

Surviving family crises is not all bad news there are some possible positives. Families often function better and become more cohesive after a crisis than they were before. (Smith, Hamon, Ingoldsby, and Miller 2009). In fact, researchers and theorists have generalized about the positive outcome of crises. Hardship may increase family functioning and solidarity (Joan M. Patterson, 2002).

According to Smith, Hamon, Ingoldsby, and Miller (2009) the impact of such positive or negative change on the family depends upon two things, how easily and adequately a family able to adapt their family roles to meet the needs of the situation and how cohesive prior to the stress the family were. Therefore, according to the theory families who were organized and cohesive prior to the stress were best able to deal with economic losses, whereas disorganized families faced further breakdown (Joan, 2002).

Family stress theory sets forward acute stressors, which could lead to family crises, including physical, emotional, or relational crises. Families go through four stages when faced with such stressful situation: crisis, disorganization, recovery, and reorganization (Smith, Hamon, Ingoldsby, and Miller 2009). These costs not only affect the stressed individual but also the family and the surrounding community (Joed and Samantha, 2009).

The ABC-X model of family stress theory

Hill's model of family stress helps consists of three variables, A, B, and C, which interact to bring about a product, X (Joed and Samantha, 2009). A being the stressor (the event), interacting with B (the family's crisis-meeting resources or strengths), interacting with C (the definition/perception or attribute meaning the family makes of the event). If the family cannot immediately figure out how to solve the problem, this will lead to crisis and produce, the X (the crisis) component of the model (Smith, Hamon, Ingoldsby, and Miller, 2009; Joed and Samantha,2009).

The model is comprised of two distinct parts: the adjustment Phase and the adaptation Phase. Each phase describes the family's ability to cope with illness, or stressors looking at family strengths, resources, and coping/problem-solving abilities.

Stressor Events (The A Factor):

Borrowing the definition of Boos, 2000, Joed & Samantha, (2009) defined the stressor event as an occurrence, positive or negative, that either changes or has the potential to change the family system. The source of stressor events can be either internal or external. External or non volitional events which the family has no control, are more likely to increase the family's stress level, making the family more vulnerable to crisis (Joed & Samantha, 2009).

In relation to the above concept Cynthia (2000) identified four basic assumptions within the original family stress model developed by Rueben Hill in 1949. These were: - (1) Unexpected/ non normative/ unpredictable, or unplanned events are usually perceived as stressful. (2) Events within the families, such as serious illness, are more disruptive than stressors that occur outside the family, such as war, flood, or depression. (3) Lack of previous experience with stressor events leads to increased perceptions of stress. (4) Ambiguous stressor or events which the family is unable to clarify what is happening, to whom, and for how long, are more stressful than non-ambiguous events.

A chronic stressor often persist over time, leads to a crisis since the family probably will experience additional stressors throughout its duration, causing more strain on resources because the situation is resistant to change. In addition, events or stress that accumulate or occur at or about the same time or stress together with other events rather than any one isolated stressor event is more likely to increase family stress, decrease the family's coping abilities, and cause a family crisis (Joed and Samantha, 2009).

Resources (The B Factor):

According to Joan,2002 Hill theorized that 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.

Individual resources include intelligence, education and acquired skills, personality characteristics, physical and psychological health, self-esteem, and allocation of time. The family's resources are family cohesion, which is the interconnectedness of family members through the sharing of interests, values, affection, positive family bonds, effective communication, and support (Cynthia, 2000). Community resources also are effective in helping families deal with stress. These resources are defined as those resources available from outside the family unit, such as religious institutions, government agencies, social support, as well as across family variables: is viewed as a primary buffer for preventing family breakdown due to stress (Cynthia, 2000: Joed and Samantha, 2009).

Meanings (The C Factor):

Perceptions (C Factor) include the range in cognitions and attitudes between hope and personal effectiveness vs. despair, and helplessness. These two complex factors relate together with the acute stressors and ongoing social context of chronic stressors, to predict family crises (Cynthia, 2000). 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).

Outcomes to stress occur on a continuum, from maladaptation/ the negative end to bonadaptation/ on the positive end, depending on the interaction of the event, ABC factors (Smith, Hamon, Ingolds & Miller, 2009). When the family is unable to balance demands and capabilities and a stressor event weakens resources and family members can no longer perform their roles, the family enters a state of crisis (Joed & Samantha, 2009).

Cynthia, 2000 identified nine aspects of resilient families dealing with a chronic illness situation. These include: balancing the illness with other family needs, maintaining clear family boundaries, developing communication competence, attributing positive meanings to the situation, maintaining family flexibility, maintaining a commitment to the family as a unit, engaging in active coping efforts, maintaining social integration, and developing collaborative relationships with professionals.

Chapter Two

Literature Review

This chapter summarizes a systematic review of the literature conducted to examine the experience of parents of children who have T1DM, major contributors to parent's distress, suggested intervention mechanisms and the intermediary coping mechanisms and concerns, the relation between care, management of diabetes and parenting and family relationships, the social and psychological impacts and challenges. The collection of literature here provided an important perspective on the issue of parenting a child with diabetes.

Experiences and perceptions of parents

T1DMis a growing concern worldwide and there has been a great improvement in the clinical knowledge, epidemiology and management of the condition (Majaliwa et al., 2008). However, physical survival is not the only part of the battle in life with this kind of chronic illness; there are also emotional and psychological challenges that accompany the disease. Living with diabetes is not simply a matter of knowing how to manage your diabetes, or your child's diabetes, sometimes the stresses are just too much and other supports are needed (Insulin Dependent Diabetes Trust, 2010).

Parenting a child with a long lasting or life-threatening illness can have a negative impact on many aspects of the parent's life. Parents of these children often have difficulty of 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).

The majority of articles (insulin Dependent Diabetes Trust, 2010: Vicki S., 2011 :Lowes, Lesley, 2005; Eccleston et al., 2012: National Collaborating Centre for Women's and Children's Health, 2004) noted psychological distress, fear, depression or depressive states, family conflict, adherence issues/diabetes management, and the responsibility/burden of diabetes as contributors to parent distress. From existing research, we know being a parent 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 hypoglycemia. Parents also may experience greater stress when managing the life and death nature of 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 parents (Vicki et al., 2011: Lowes, Lesley, 2005). Therefore, the information from the articles examined showed that parental stress can because by multiple factors not a single reason and interventions should target parents.

The evidence from twenty quantitative and fourteen qualitative studies indicates that parents of children with T1DM show significant levels of psychological distress including symptoms of depression, anxiety, and posttraumatic stress (Lesley, 2005). Also, a study of newly diagnosed children with diabetes showed that the diagnosis is a stressful event for youth and families and it is likely to produce symptoms of anxiety and depression. Symptoms of Post-Traumatic Stress Disorder occurring in 22% of mothers and 16% of fathers 6 weeks after diagnosis (Landolt et al., 2002). Again, Parents' response to a diagnosis of childhood diabetes was corresponds to the grief reaction normally associated with bereavement experiencing an intense, stress, sadness about the diagnosis, which represented a number of losses (Lowes, Lesley, 2005).

Both paternal and maternal parenting 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, but mothers tend to experience higher stress levels, perhaps because they're typically the child's primary caregiver.

According to Teri (2013) when a child is diagnosed with chronic illness, it is ordinary for parents to feel guilt and sadness. Anger is also common. They may feel angry toward their partner, the world at large or even, at times, toward their child. Also Parents may feel guilty for having transmitted the genetic components of diabetes to their child and worried that they have not done enough to manage the disease. In addition, Parents of children with diabetes are extremely concerned about how poor glycemic control has influenced their child's growth and development specially, the fear that their child will experience severe hypoglycemia particularly when it is associated with seizures or a loss of consciousness. (Diana et al., 2000) lack of control may also be the most stressful aspect of care giving parents can feel a loss of control when, they are unable to help their child feel better, or are uncertain about the future prognosis (Teri, 2013).

Having a child diagnosed with T1DM is believed to be an anxious and distressing time particularly challenging as it includes Parallel vigilance: the delicate balance between the parent being the life support for the child with diabetes and the parent learning to let go of the same child in the maturation process. Parents face difficulties knowing how to assist their child proactively without creating a negative family dynamic (Selaine, Michael, Martin and Margaret, 2013). Since, one of the critical issues facing parents of children with diabetes is when and how to transfer primary responsibility for diabetes management to their child. Specially, it is difficult for parents to set boundaries and diabetes care expectations as their children are maturing (Vicki et al, Deborah et al. 2010; Mellitus et al., 2012).

Wysocki and associates in 1996 examined the psychosocial predictors of when diabetes management is typically transferred from parents to children and the outcomes resulting from this transfer. Their findings revealed that transferring too much responsibility for diabetes management to a child is associated with poor treatment adherence, poor diabetes knowledge and more hospitalizations. These finding suggest that, appropriately transferring diabetes care from parents to child requires consideration of the child's level of diabetes knowledge, chronological age, cognitive level and socio-emotional functioning. This indicated the opportunity for health professionals to intervene in the family.

Some argue that, depression, anxiety and psychological problem should not be viewed as exclusive to diabetes. Since living with any chronic conditions incurs the same problem. They also argue that general strains of everyday life and specific stress of managing diabetes shouldn't be mix up (Insulin Dependent Diabetes Trust, 2010). In relation to this idea a longitudinal research which conducted a 5-year long study on 132 children with T1DM, who were enrolled when they were 12 years old on average, examined the relation between general stresses related to finances, marriage, parenting and diabetes-specific stress related to caring for a child with T1DM. The Result reviled that greater general parents stress was associated with poorer child outcomes, whereas greater parent diabetes-specific stress was associated with better child outcomes (Vicki et al., 2011).

However, the experience of having a child with diabetes on parent's life is not uniformly negative. Some positive aspects of having a child with diabetes can be mentioned, ranging from increased family closeness, family cohesion, to improved family health habits, to improvements in the child's psychosocial profile (Mellin et al., 2004; Leehu, Tally & Anna, 2012).

Parenting stress and a child health outcome

Another associations drawn in the literatures was between parents stress and a child health, Consistent with the family systems theory perspective, Although it is clear that parental involvement in diabetes management benefits the health of the child with diabetes, caring for a child with diabetes has implications for both parents health and the health of the child with diabetes.

Parents who are stressed may become overwhelmed by their responsibilities and withdraw from helping the child. Conversely, Parents often go to extremes in parenting, exerting more control over the child's diabetes care because of the fear associated with negative diabetes outcomes or as a response to their distress. Both extremes may undermine the care-giving effectiveness (Vicki. Et al,. Deborah. et al., 2011; Mellitus et al., 2012). Researchers have examined the relation of parent stress to child health outcomes, but findings are not clear. A cross-sectional study found no link between parent stress and child health or glycemic control (Mitchell et al., 2009). Wells, Kristen, 2006 also did not support any of the three relationship between stress, depression, and glycemic control. In the finding stressful life events and depression were not related.

Whereas a longitudinal research conducted by Vicki et al., (2011) supported the positive relationship between high levels of Parental general stress, poorer mental health and children poor diabetes management. Again, depressive and stress symptoms of family have been shown to have negative effects on parenting, child quality of life, and child’s metabolic control as well as poor child outcomes and poor disease management (Lowes, 2005;Djarova, 2007). In these articles the need for parental screening and interventions focused on the parents themselves, in addition to family interventions. And therapeutic psychological interventions and educational programs were recommended as a help to alleviate family diabetes-related stress and improve glycemic control.

In addition, a research which reviewed 6 cohort studies, 3 cross-sectional studies, and 1 qualitative study on the way family stress influences glycemic control among patients with diabetes who are younger than 18 years of age. All the reviewed studies support the fact that dysfunctional family interactions, authoritarian parenting and diabetes related family stress are related to worse glycemic control. Stress leads to problematic child behavior and deterioration of glycemic control, even though a few studies suggest otherwise. This review confirms the dominant principle that specific factors of family function influence glycemic control in young patients with T1DM. (Elina et al., 2014).

Again, another research also indicated that greater parental involvement in adolescent diabetes management is associated with better adherence to blood glucose monitoring, which in turn results in better metabolic control and that shared responsibility for diabetes management is associated with better psychological adjustment and self-management in adolescents. Since, greater involvement from parents of children with diabetes is imperative because of the additional demands of diabetes treatment regimens (Robin et al., ND; Deborah. et al., 2010) .

Even more importantly, frequencies of stressful life events during the year prior to the clinical onset of T1DM that occurred within the family were recorded as risk indicating factors for the onset of T1DM in African children that precipitate severe emotional stress, increasing consequent risk of later development of T1DM (Djarova., 2007).They reported that the frequency and structure of the stressful life events occurred within family are risks for the onset of T1DMin life events involving actual or threatened losses within the family, such as serious illness or death of the mother, death of brother or sister, or hospitalization of mother or father, the report showed significantly increased frequencies in the diabetic group (range 10–30%) than in controlled children (range 4–10%).

Parenting and management of diabetes

Another dominant them throughout the literature was the connection between parenting and the care and management of diabetes. The care and management of diabetes is a huge and a very difficult task, particularly caring for children who have been diagnosed with T1DM which involves the entire family, as well as schools and society as a whole. Which has been shown to contribute to grater parental distress, owing to the chronic nature of the condition (Elaine & Sinead, 2013;Diana, Christos,Przemysluawa&Maia,2000).

The psychosocial impact of diabetes in childhood is everywhere and striking a balance among hypoglycemia/hyperglycemia, growth/development, and other life factors is not easy for health care providers, patients, or families. In addition, personal, family, or environmental conditions present before the onset of diabetes may compound the delicate balance needed to maintain good glycemic control (Diana, Christos, Przemyslawa & Maia, 2000) .

Diabetes care tends to focus on clinical outcomes, with blood glucose readings and

HbA1c or A1c (HbA1c or A1c: is a lab test that shows the average level of blood sugar over the previous 3 months and it is used as an indicator of diabetes control.*)* values as the measures of success, likewise, the person with diabetes is not the only person who may require care and attention: family members and caregivers are also part of the formula (Elaine & Sinead, 2013). In recent years, social support groups have been established to provide parents with an environment in which to share their experiences and advice of the experiences of parents outside of the hospital setting, and the significance of these social support groups in diabetes care delivery (Elaine & Sinead, 2013). For People living with diabetes there is much more to the creation of a successful life with diabetes than clinical measures (Bridget, Eleanor, & Randi, 2011).

Research suggests that to achieve success in managing diabetes and the psychosocial issues associated with youth, especially adolescents with type 1 diabetes, health professionals should promote self-efficacy, interpersonal support, depression prevention, and effective coping strategies (Nathan et al., 2012; Deborah et al., 2010). In strengthening the above idea Siddharth, and Yatan, (2014) reported that suicidal ideas and attempts are more frequent in patients with diabetes mellitus than healthy or medically ill controls. Psychological morbidity, including depression, precedes suicidal ideas and attempts; a common method of suicide attempt in patients with diabetes includes uses of high doses of insulin and its congeners or medications to treat the disease.

Although, diabetes management improved over time for these emerging adults with T1DM. Diabetes-specific self-efficacy is important for diabetes management regardless of whether youth are in high school or post-high school and whether living with parents or not (Kathleen et al., 2012). Diabetes-specific self-efficacy may also play an important role in successful diabetes management among youth with lower impulse control (Nathan et al., 2012).

Family relationship and diabetes management

Family relationship was also another common area considered in the reviewed literature, family relationships is important in managing chronic illness; the management of diabetes in children is highly under the control of the patient and their surroundings. Yet, family has not been fully integrated into current clinical practice. And here, the literature demonstrated how the family system, social unit or intimate relationships are equally necessary as is the individual's own emotional well being in the course of diabetes management and how those systems impact health behaviors.

A study conducted by Seiffge et al., (2013) investigated the longitudinal interplay between supportive relationships with parents and metabolic control in families that differ in parents' restrictiveness. The results showed that family restrictiveness moderated longitudinal associations between metabolic control and perceived social support. For adolescents reporting high family restrictiveness, poorer initial metabolic control predicted greater subsequent declines in perceived parent social support, and lower initial perceived parental social support predicted greater subsequent deterioration in metabolic control. Similarly, in a study conducted to examine the association of family organization with metabolic control in adolescents with type 1 diabetes through the mechanisms of family self-efficacy for diabetes and disease management, family organization is associated with metabolic control (Whitney et al., 2012).

In addition to the above studies that have focused on family dynamics, organization, parental behavior and restrictiveness. Findings indicate that families with open communication patterns and supportive and containing behavioral patterns typically raise children with better managed T1DM. The evidence suggests a general association between family function, communication and the child's compliance with various aspects of care, ranging from dietary restrictions to more frequent testing and better care adherence (Bridget, Eleanor, Randi, 2011). Also, the relationship of family communication to subsequent adherence suggests the need to assess family communication concerning diabetes-related management during preadolescence since, during the transition to adolescence family communication changed in unexpected ways (Jeannette, Jennifer, Jennifer, Alan, & Dennis, 2014).

Literature addressing the general psychosocial and behavioral functioning of children and adolescents suggests that living with a single parent places children at risk for numerous problems (Lanahan et al., 1994). Research specific to diabetes has been less conclusive about the impact of living in a single-parent home. A study examining the health and behavior of diabetic youths living with single mothers have demonstrated that these youths are no worse off than diabetic young people in a two-parent family (Hanson et al., 1999). Other suggests that diabetic youths who live with single parents are in poorer metabolic control than those in two-parent families (Overstreet et al., 1995).

Although a great deal methods of parenting are available, a child-centered, high-demand approach appears to result in the most favorable behavioral and psychosocial outcomes for children. Key issues for parents of children with diabetes include avoidance of punishment when dealing with diabetes issues, arrangement of nontraditional households to better facilitate diabetes management, awareness of the potential negative effects of parental overinvestment in helping children with diabetes, and the appropriate transference of diabetes management from parents to older children (Wysocki, et al., 1996).

In general we can say that greater involvement from parents of children with diabetes compared with that of parents of children without diabetes is imperative because of the additional demands of diabetes treatment regimens. In the case of diabetes, younger children may need a great deal of parental involvement in the physical aspects of caring for their diabetes (e.g., giving shots, drawing up insulin), whereas older children may need a great deal of parental involvement in the form of verbal prompts and cues to facilitate self-management behaviors (Miller et al,.1994).

Major contributors to parental distress and coping concerns

When we consider another point of discussion raised in the literature it was parental coping concern on T1DM child, the mediating factors of the parental coping process with their child's diabetes consist of four main categories: patient's cooperation, crises and experiences, economic challenges, and parental participation in care (Fatemeh, Neda, & Hossein, 2013). A research conducted by Robin, Sarah , Jia and Margaret (2007) also showed that, individual and family characteristics, such as age, socioeconomic status, treatment modality, psychosocial responses, depressive symptoms and anxiety and individual and family responses (self-management, coping, self-efficacy, family functioning, social competence) influence the level of adaptation to T1DM in children.

It seems that reinforcing positive features, such as support, warmth, and good relationships among family members, are highly important in facilitating cooperation between the patient and his/her family. Parents' coping process with their child's diabetes can be eased by psychological support such as psychological counseling, especially during situational crises; involvement of charities and the strengthening of insurance systems by the governmental sector in order to reduce the costs associated with juvenile diabetes; strengthening family confidence, positive attitudes, ability to manage stress, and accountability; and participation of both parents in managing the situation (Fatemeh, Neda, & Hossein, 2013).

A research team that has used, 11 school-aged children and 12 parents of youth with T1DM over the years, identified individual and family characteristics, such as age, socioeconomic status, treatment modality (pump vs. injections), psychosocial responses (depressive symptoms and anxiety), and individual and family responses (self-management, coping, self-efficacy, family functioning, social competence) as major factors that influence the level of adaptation to chronic illness in children. Socioeconomic status (SES) and family structure (single parent vs. two parents), family dynamics, communication, and emotional regulation with families of higher SES and consisting of two parents are also associated with better diabetic indicators in children (Leehu, Tally & Anna, 2012; Robin et al,. nd).

The ways in which children and adolescents cope with stress are important mediators of the emotional and behavioral outcomes of stressful situations, such as living with T1DM. A study which explores the mediating factors that affect Iranian parents' coping processes with their children's type 1 diabetes using the grounded theory method consist of the child's cooperation, crises and experiences, economic challenges, and parental participation in care (Fatemeh, Neda, & Hossein, 2013).

And psychological problems, such as depression, behavior disorders, and eating disordered behavior, have been recognized as potential negative responses over time and ineffective coping, poor family functioning, lack of social competence, particularly during adolescence and/or longer duration of T1DM can increase the risk for the development of depression (Robin et al., n.d.).

Findings indicate parents cope chronic illness by changing their expectations, becoming knowledgeable about the disease, dealing with social isolation, handling discipline, working with professionals, connecting with peers, and caring for personal needs using the family system, a stressful event requiring adaptation, familial knowledge, skills and resources, and use of coping strategies including family-to-family networks, community based family support, Fatemeh, Neda & Hossein (2013). Behavioral family systems therapy, teamwork intervention, attention control, education and support groups. Glycaemic control, diabetes-related conflict, parental involvement in management, children's and young people's adjustment to diabetes care, and parents' anxiety levels (Leehu, Tally & Anna, 2012). Although many parents find ways to effectively manage this stress, such as developing routines and finding sources of support, a longitudinal qualitative study exploring the experience of parents of newly diagnosed children reveled that parents coped initially by focusing on the practical skills and gaining knowledge about diabetes. A fear of hypoglycemia dominated their thoughts and affected many aspects of their life. They experienced a loss of spontaneity but established new routines to accommodate their child's needs. Professional support was important to parental coping, particularly accessibility to advice via an on-call phone (Lowes, Lesley, & Madeline 2005).

Suggested intervention mechanisms

The above literatures in broadly suggests diabetes educational programs should provide self-management, diabetes-specific self-efficacy skill and support to patients, develop programs in executing this type of care including education for friends and family. Education that are related to attitudes and behaviors associated with the young person's diabetes, and depression/distress assessment for the person with diabetes, family relationships, as well as for the support team surrounding that person.

Patient-centered communication of adolescents' and parents' the physician was also associated with greater perceptions of control and competence for both adolescents and parents and highly related to subsequent adherence and metabolic control and competence in diabetes management (Deborah, 2010). Moreover, In line with the above ideas, psychological therapies have been developed for parents of children and adolescents with a chronic illness. Such therapies include parent only or parent and child/adolescent, and are designed to treat parent behavior, parent mental health, child behavior, child mental health, child symptoms and/or family functioning (Eccleston et al., 2012). In conclusions the management of T1DM need for developmentally appropriate family support and health care professional guidance. Identification of specific and remediable challenges and barriers unique to each child with diabetes requires persistent vigilance and an understanding of how these challenges may manifest themselves (William, 2011).

In conclusion, the overall burden of the emotional and physical stress that can plague parent's depression and stress was discussed frequently from the perspective and also how parent behaviors impacted youth perspectives of disease and psychological and physical state.

Likewise, responsive parenting and cohesive family organization was closely linked to positive youth health perceptions and optimism. It is understandable that depression and depressive symptoms might accompany the diagnosis of a life threatening childhood illness. Moreover, the literatures pointed to many recommendations for interventions aimed at the family unit. It seemed that addressing challenges regarding psychological stress and role strain in particular might aid in the reduction of the end result in addition to the other positive coping mechanism identified. Psychological stress and negative coping mechanisms was also considered in the context of family as they could lead to negative diabetes outcomes and family engagement in diabetes is the opposite.

Chapter Three

Method

Philosophical stance

Professionally as a researcher my stance about reality is subjective. I believe in social science academics, inquiries should be subjective rather than analyzing reality in a time and context free perspective, objectively, and by just considering what has been said by the majority as a reality. Especially, given the objectives of this research to explore parents' experiences in raising T1DM child, a constructivist philosophical epistemology fits it best (Morris, 2006). The guiding principle of constructivist research is that data are unique to their time and place. It proposes that human experience can only be understood as a subjective reality. Constructivist paradigm does not assume an objective reality (Morris, 2006). The best way to understand human phenomena is to completely and thoroughly understand the perceptions or constructions of those people who are engaged in that human phenomenon. To do this, they collaborate with those involved in a particular human experience to create a valid, authentic, shared construction of the experience being researched (Morris, 2006).

Research Design

The purpose of this study is to explore the parental experience and the meaning of having a child diagnosed with T1DM as to their context through using qualitative research approach. An exploratory case study research design was used to see what parents experienced and how they view their experiences.

This study was exploratory qualitative case study research. It was exploratory in a sense that no prior studies have examined the lived experience of parents raising T1DM child in Ethiopia. Cherry (2000) explains that exploratory research is very useful when we know little about a new phenomenon or will be needed to explore the lived experiences of people with similar service need. Kreuger and Neuman, (2006) stated that exploratory research answers “what” questions whose aims are to become familiar with basic facts, setting and concerns about an issue. This form of research helps in understanding perceptions of the respondents and how and why certain outcomes were achieved or not. The goal is to capture what is happening and present people from their own perspectives and views (Hancock, 2002).

Qualitative research approach would be used if it is sought to identify recurrent themes, clearly answer the research questions of the inquiry by going directly to the social phenomenon under the study and observing it as completely as possible (Cherry, 2000). Moreover, qualitative case study will help to understand complex social phenomena and allows the researcher to retain holistic and meaningful characteristics of real life as people's behavior becomes meaningful and understandable when placed in the context of their lives and the lives of those around them (Yin, 2003). Moreover, the research the data was collected and the phenomena also were examined at one point in time.

Study setting

The study is conducted in Addis Ababa, at EDA head office and Diabetic center found in the premises of Black Lion Specialized Hospital. Addis Ababa is the capital city of Ethiopia with a population of 3,384,569 according to the 2007 population census it has an estimated area of 530.14 square kilometers (CSA, 2008).

The Ethiopian Diabetes Association was established on January 23, 1976 for the purpose of providing a forum to diabetes patients so that they can discuss ways of prevention, the provision of information and treatment for all affected by diabetes. The initiative came from Ethiopian Medical Association, health care professionals and people who live with diabetes at the time. It is the first patient based association in the country (EDA, 2014). Currently, the Ethiopian Diabetes Association is registered as a non-governmental organization and the membership at the association has reached 20,000 with 27 branches spread over major cities of the country. Children with diabetes are also members of the association and membership reached more than 900. The association wishes to support children in terms of education and treatment. However, its limited capacity doesn't allow it to engage in activities (EDA, 2014).

Tikur Anebessa Specialized hospital is one of the famous national teaching hospitals, which provides multi-dimensional aspects of care to clients who need health care service. The hospital diabetic center was inaugurated by the International Association of Lions Club on November 1994. EDA supports the activities of the diabetic center found in the premises of Black Lion Specialized Hospital. This special center for diabetic patients gives a screening service for diabetic retinopathy (eye problem) However, it has no capacity to perform additional treatment only confined to screening (EDA, 2014).

The activity that brings many members to the head office is the free blood glucose test (Hb1C) since few patients afford to make self-blood test regularly. A private laboratory supports the association by giving free coupons so that members can have a blood glucose test for free. Moreover, the association celebrates November 14 every year as the United Nations Diabetes Day as major way of crating awareness about diabetes (EDA, 2014).

Selections of participants

Twelve Parents of T1DM children and who are member of EDA, are the source population of the study. By Applying non probability sampling method participants were selected as study population from the source of population using purposive/judgmental sampling technique.

Inclusion criteria

Participants in this study did fulfill the following condition to be the participant in the study. First and for most, participation was based on their willingness. Inclusion criteria for the study were age range of the child (ages 0-15), age of the parent (over 18 years) and duration of T1DM (living with diabetes for at least 1 year). As noted above, the research selection allowed only an age range of 0-15 years for the children with diabetes. The rationale for inclusion of this age span is based on the assumption that the above mentioned age group reflects the prevalence mid age (12-14) of diabetes in adolescents and emerging adults. Moreover, parents who are above the age of 18 and who have more than 1 year of experience living with a T1DM child is believed to better explain the situation, express their feelings, emotions, and articulate their lived experience.

Selection and size determination

Cherry (2000) states that qualitative studies typically use small numbers of participants partly because so much in-depth data are collected in qualitative studies; hence, data from small samples are manageable. In qualitative research, sample size is not the key; rather it is the richness of the data that is vital. Hence, twelve individuals were taken as participants of this research. Data collection was, actually, finalized due to saturation of information. That is, when the interviewees began repeating, concerns, and the researcher obtains adequate topic information and no longer gain new insight (Anthony, Nancy, 2010). Participants were recruited using purposive sampling technique. In the concept of purposeful sampling the inquirer selects individuals because they can purposefully inform an understanding of the research problem and central phenomenon in the study (Creswell, 2007).

Methods of data collection

I used a semi-structured in-depth interview and observation to guide the data collection. Among the qualitative data collection techniques interview is by far the most commonly used method of data gathering for qualitative studies. I found using interview as a data collection method advantageous while the root of in-depth interview is an interest in understanding the lived experience of other people and the meaning they make of that experience (Seidman, 2006). Observation is useful to collect more information regarding interaction, way of life and visible challenge. Beside it will allow the researcher to capture the reactions and emotions in understanding a phenomenon.

I used an interview and observation for this research because every word and associated emotional expressions that people use in telling their stories can give access to understanding the most complicated social issues, because social issues are abstractions based on the concrete experience of people.

Instrument development

The interview guide 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). Beside, the format of the interview itself is that of a semi-structured interview as semi-structured interviews combine the flexibility of the unstructured and open-ended interview. The topics of a semi structured interview are pre-determined, but most of the questions are formulated by the researcher in the interview setting. This in-depth interviewee was recruited in this research just to explore lived experience of parents, identify parents child diabetes related feelings, reactions, worries and challenges, coping and adaptation mechanisms, acquired diabetes knowledge and available support for the child and the family. In addition, demographic and basic information data was collected about each participant's family. This researcher is attentive to what the interviewee says, and responds with follow-up question and probes (Willems, Roos ,Timmerman, Christiane, Carling, and Jorgen, 2011).

Concurrently, here, during the face to face contact the parent and I have had, and as I went to six of the participants' home the emotional reactions of the parents like crying and other expressions are critically looked and analyzed. In the pilot test interview, three participants gave favorable feedback that encouraged the use of the interview guide. The participant verbalized that the interview was appropriate and inclusive. Those individuals participated in the pre-test of data collection instruments were excluded from the main study.

Data collection process

Parents are identified in collaboration with staff members of EDA and people who work with them in the Black Lion Diabetic Care Center. After the identification of parents, and getting their willingness to participate, the face to face contacts for the interview data collection were held in the place of their preference. Six of them were interviewed at their respective home and for others at the hospital and association offices. The appointments with each participant were set in consensus with the respondents. In the interview process audiotape and interview notes were taken, and the interview is transcribed subsequently. The interviews lasted approximately 40- 60 minutes. As we could notice from the above explanations the interview in this study was conducted in a face to face and one-to-one contact by me.

Data Analysis Method

After the successful completion of data collection the next task was analyzing the collected data strictly following the data analysis steps. The data was analyzed manually. Transcribing, translating, coding, categorizing, identifying themes, presenting the findings and discussions were key steps in the process of the analysis The central purpose of qualitative data analysis is to organize the masses of data acquired during the data collection phase in such a way that the themes and interpretations that emerge from the process accurately address the original research questions (Creswell, 2007).

The recorded interviews were transcribed verbatim (all words, silences, laughter, and utterances) and transcripts were reviewed for accuracy, I transcribed all of the cases in to 132 pages and listened to each informant’s stories 2 times. Hearing the recorded tape and reading the field notes gave me the chance to increase my understanding of the informants’ stories. I did the translation of each transcript from Amharic to English and I typed it. I prepared field notes/memos which addressed what happened in the interview, how I felt in the interview, my perception of the informant, and personal observation.

The major task of analyzing qualitative interviews is data reduction because the amount of qualitative data is large. The data might seem unmanageable in the early stages of organization (Cherry, 2000). During analysis I gave due attention to identifying potential implications and answers for my research questions. In the process I followed the thematic approach of qualitative data analysis technique. Data were coded well to categorize and sort what is obtained after a thorough sensitizing of it.

Coding is a key step in the process of analyzing. The purpose of coding is to structure the collected data and to make sense out of it (Creswell, 2007). And, which provides the researcher the link between data and the conceptualization. Then, after developing 126 codes, concepts have been developed which were grouped into 8 themes and 34 subthemes.

Assuring the trustworthiness of the Data

As a qualitative researcher, it is true the researcher will make interpretation of the data collected, which is a bit hard for the researcher to separate his/her background, history or prior understanding of the issue (Creswell, 2007). Though it is hard to separate oneself from the data, the credibility of qualitative research is still in the effort and ability of the researcher. 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. In addition using multiple data sources (direct observation and in-depth interview) can raise the credibility of the data collected as is insure the trustworthiness of the information.

Trustworthiness of the information can also be assured through data triangulation. Confirming the information collected from an in-depth interview through observation. In addition, I tape recorded the interviews and directly transcribed it, literal statements of participants and quotation are used in the analysis of the data. so that, I will have no chance to put my personal bias in the process.

Ethical consideration

Ethical clearance was obtained from Addis Ababa University School of Social Work. The study was indisputably 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 have been given a clear explanation about the purpose and importance of the research and their roles on it too. Likewise, they were also assured about confidentiality and anonymity as well. They have been told that in the report there will not be incorporation of name or any information that indentifies privacy. The names indicated in the analysis of this study are not real names. Participant weren't asked question that could identify them as well as their family. I have also promised them that the raw data from all tools will be kept in a private baggage till properly discarded. The agreement for use of tapes to record data during interviews was also made in advance of data collection.

The respondent's verbal consent was obtained after explanation about the extent, procedures, duration, purpose, confidentiality, anonymity and about the voluntary nature of the research. Real names of participants are not included when they are quoted in this report. The willingness of each participant was obtained for the tape recording and note taking of the interview and privacy was maintained. In regard to the issue of ethics in social work research, Kreuger and Neuman (2006) states that social work researchers should follow proper ethical guideline even when the study participants are negligent or unaware of that.

Because, I went to some of participants home and set appointments with other participants to meet on the days that they came to hospital or the association for their own purpose to minimize the possible additional cost on them. Therefore, on the data collection process no financial, refreshment or other compensation was given to participants.

Limitation of the study

This study was designed to examine the lived experience of parents having a child diagnosed with T1DM in a qualitative way. However, there are certain limitations to this study. The sample participants may not accurately represent parents from different backgrounds, cultures or ethnicities raising children with T1DM. Findings were not examined according to age of the child at diagnosis, duration of the diagnosis, level of parents' involvement, or household income. In the process of the interview most of them were very emotional talking about their traumatic experience and crying. In this case, I was obliged to stop the interview and calm down them till they feel relaxed which challenged me in controlling my emotion and demanded extra time. But I believe that their emotion, pauses and facial expression supported me to understand the situation of these parents. Moreover, participants were only willing and comfortable to give verbal consent than signed and written consent.

Chapter Four

Finding

An analysis of the interviews revealed a number of construct which can be discussed within the context of parental experience of having T1DM child. The first section of this chapter describes the demographic characteristics of the participants. The next section addresses a collective summary of themes.

The sample consisted of 12 members of EDA. The sample was composed of 4 fathers, 7mothers, and 1 sibling. Their ages ranged from 26 to 48 years. 2 of the participants were from rural area and 10 of them from Addis Ababa. 8 of them were married, 3 were divorced, and 1 were single (the sibling). All reported living with 2 to 11 members in their household.5 of the participants as a family had a monthly income less than 1,000 birr. 2 parents did not know their monthly income (those from rural area), and the rest make 3,000 -10, 000 birr a month. All the mothers' participants reported that they did not work outside the home at the time of interview. Concerning their educational background, 3 parents reported having no education at all, 2 participants were only able to read and write, 1 participant had attended primary school, 1parent completed a high school,1 participant have diploma and 4 bachelor degree. The ages of the child when they were first diagnosed with diabetes ranged from 14month to 12 years. The participants reported living with a diagnosis of child diabetes from 1 to 9 years. 3 bad hb1c (>14) conditions were found among the 12 participants child. 3 of the participants had multiple chronic ill members in the family.

Table 1

socio-demographic/economic status of research participants

No	Pseudonym	Age	Marital status	No of household	Educational level	Monthly family Income	Child age at diagnosis	Child age	Recent Child Hb1c result	Living place
1	Lemeleme	38	Marred	5	Read and write	<1,000	9	13	Good	Addis Ababa
2	Abeba	32	Divorced	4	Grade 8 complete	<1,000	18 month	10	Good	Addis Ababa
3	Teferi	42	Marred	5	Degree	>10,000	8	10	Good	Addis Ababa
4	Hiewot	42	Marred	6	Grade 12 complete	>10,000	2	9	Good	Addis Ababa
5	Emebete	34	Marred	6	Degree	>10,000	6	8	Good	Addis Ababa
6	Solomon	48	Marred	5	Degree	6,000	7	8	Good	Addis Ababa
7	Diriba	40	Marred	5	Illiterate	Don’t know	12	10	Bad	Rural area
8	Helen	26	Single	8	Degree	3,000	12	15	Good	Addis Ababa
9	Mulugata	48	Marred	11	Read and write	Don’t know	7	10	Bad	Rural area
10	Zenashe	32	Marred	4	Illiterate	<1,000	6	8	Good	Addis Ababa
11	Mulu	34	Divorced	4	Illiterate	<1,000	3	15	Bad	Addis Ababa
12	Aberashe	30	Divorced	2	Diploma	<1,000	14 month	4	Good	Addis Ababa

An analysis of the interviews revealed a number of themes which mainly reflected a sense of being overwhelmed because of the diabetes management (DM) and related life experiences. From a total of 132 pages of 12 verbatim transcripts, numerous significant statements were extracted. 126 codes, 8 themes and 32 subthemes were identified in the answers obtained from the parents' interviews. The findings in relation to the research questions are presented in this section answering the feelings and reactions of parents towards having T1DM child, effects of childhood diabetes on the life of the family, major psychological, social and economic challenges encountered by parents and parental coping and adaptation mechanisms used to the diagnosis of T1DM in their child.

The finings in relation to each other are presented (1) Parental feeling and emotion, (2) factors associated with parental distress, (3) challenges encountered, (4) Family communication and relationship, (5) school issues, (6) health care issues, (7) diabetes education, (8) coping and adaptation. Within each of these themes, sub-themes were identified. The themes and sub-themes are discussed below.

Parental feeling and emotion

Under this theme two major Sub themes; (a) How Parents knew about their Children's Diabetes Status and (b) parental distresses were identified.

How Parents knew about their Children's Diabetes Status

Although all of the participants had different experience concerning how they knew their child is diabetes for the first time, they still share some common moments. At first all parents consider the symptoms as a common illness for infants and small children. They all have waited a little longer at home hoping their child would start feeling better soon. All parents said their child has been through symptom of dehydration and frequent urination. For example one mother, Mulu, a mother of 15 years old boy, whose child has been diagnosed at the age of 3 said,

> *"…My son has been urinating more than usual for about a week, not only in frequency but volume. I attributed this to as he was drinking 9 litter water a day and it just seemed to make sense, I was tired of bringing him a glass of water; so, I sat 3 litter jar water near to his bed."*

Another interviewee, Helen, a sister of a child who was 12 year at the time of diagnosis regretted, for being impolite to her sister as she wake her up at night for urination and said, "*I never thought of it..… If I could have just connected it to diabetes, she wouldn't be in DK.*" Another parent, Hiewot, a parents of a 9 years old daughter, diagnosed 7 years ago, remembered the time as it was yesterday and said, "*She began complaining of being hungry and thirsty all the time, requesting drinks in the middle of the night and wetting the bed. But, her weight wasn't increasing.*" Diriba, who lives far from Addis given referral urgently to Tikur Anbessa Hospital, was also challenged by the situation on his way to the Hospital at night. He remembered a moment and said, "*The driver was complaining as we stopped him so many times on the way because the child was urinating frequently.*"

Through the process ten parents children have been miss- diagnosed. Two parents namely, Mulu and Abeba reported that their children have been suspected for being HIV positive; another two parents, Solomon and Hiewot, children for developing infection and the other's children were given a drug which they don't know what it for was. Here is the case of one mother, Mulu, said,

> *"First I took my son to health care center and they gave him some drugs but there was no change. I took him to another three private hospitals they gave him a lot of medicines saying this and that. But, still he was sick even worse, the situation was hopeless…. But one day while cleaning a house and listening to a radio I heard about the symptoms of diabetes on children. It was exactly the same as my child…I ran out of a house and told my land*

> *lord …she said, ' I was crazy and commenting diabetes is for rich people not for those who are poor like me …she then gossiped my son is HIV positive…. But, her relative sad about my situation took me to another hospital…I was afraid to tell the doctor about what I suspected. Anyway, he got it and immediately referred me to Tikure Anbessa Hospital."*

Crying, frustrations, sadness, grieving and hopelessness were the major reactions of parents for being told their child has diabetes. One father, Solomon recalled the moment as, "*When the doctor told me…. I sat on the floor and cried like a little child…*" All twelve participants reported that they had feelings of hopelessness. Zenashe,said, "Well, I almost felt like it was the end of the road."

However, most of the parents at first thought it had cure and will go away so easily Abeba, where child was diagnosed at 18 month, said, "*I was frustrated but, I was ok until I heard it can't be cured, that was when everything goes down feeling the world was over.*" Another mother, Mulu, said, "*I thought he will be cured and we will live the hospital soon. So, when the nurses showed me how to inject I didn't care at all. I was busy doing my hand crafts...It was later that I understood it is my everyday life.*"

The participants described feelings of anxiety during the moment. Lemelem, said, "*I felt like I was destroyed, I was confused………it felt like the walls were closing on me.*" Some parents reaction was like a parent of child diagnosed at a very young age (ages at diagnosis were 14 months) who said, "*To be honest I didn't remember how it was like, I lost myself, I was doing things unconsciously in between the crying and staring in my daughter.*" Helen's way of knowing about her sister's condition was a little different as she told it,

> *"No one was willing to tell me what was going on and why? Accidentally I met someone at the hospital gate and we start talking, later I found out the guy was an internship medical student … he looked at the libratory*

> *prescription in my hand and asked me the case…. and then he simply said, ' OH its T1DM! Type 1 diabetes' … I thought being type 1 is better than 2 as it is a lower number…but he continued and said 'type one is the bad one... it has complications ….' he keeps talking… he even talks about pancreases' transplantation. But, after some point I wasn't listening, I was lost and sick, it seems like everything is rolling fast. ….. I went to the internet café and goggled, He was right….. (Crying)…..when I went back to the hospital I couldn't face my sister…..how am I going to tell this little girl the fact… she was very sure that it will be cured and we leave the hospital soon…I wished I could be lost, I felt the world come over, I felt helpless and powerless."*

Most parents also thought that the medical diagnosis was wrong and the doctors had made a mistake. Emebet , said,

> *"I thought that it was wrong, I was full of disbelief and hoped that someone would walk into the hospital room and say they had made a mistake and we could all go home safe…..I felt that at sudden my life was taken, it was unexpected twist and I did not know what to do."*

Parental distress

The most common verbalized comments concerning parental distress were sadness, anger, depression, and anxiety that they relate to their child diagnosis of T1DM. It was viewed by the participants as a result of child diabetes and consistent stress. Ten participants reported that diabetes had a major impact on their lives. Their responses often revealed feelings of anger. Aberashe said, "*Sometimes I can't believe diabetes as lifelong sickness and this happen to my little kid!*" Emebet was like, "*I didn't like it*". Some parents are angry about the misunderstanding and the comment people give to them. Helen said "*I get real upset over that.*"

A sense of fate and defeat was expressed by Zenashe, 32 year old women, who's another daughter also, has chronic disease and suffers from it. Her son was diagnosed with diabetes at age 6. She cried during the interview and expressed with sorrow "*Most of the time I am depressed and sad …I just don't get excited with things anymore.*" She further explains that she get really anxious, "*I really try hard not to lose my mind.*" Moreover, most Parents expressed feelings of fatigue and fear in their day-to-day life.

Following their child diabetes and its management some parents are experiencing health problems beside the overwhelmed feelings. Two fathers, Solomon and Diriba reported that they are suffering from regular headache that started at the moment of being told of its incurability, and two mothers Mulu and Zenashe are experiencing hypertension and gastric.

Factors associated to distress

Dealing with the management of diabetes created challenges in various forms of participant's life. Parents identified three factors (a) childhood, (b) child's diabetes management willingness, and (c) child diabetes worry.

Onset of the disease

Being diagnosed at early childhood stage is identified as an issue by all parents as a major factor associated with parental distress. Aberashe, a parent of child diagnosed at 14 months and now age 4, explained. "*It is the worst thing that could happen to a mother*" she said, "*There is no way that people can teach a child about insulin at so young age.*" she reported that her daughter used to hide and cry when it was time to test blood sugar or administer insulin….Aberashe cried while saying, "*one day when I was about to give her a shot she asked me, when I was going to stop injecting her with this needle?'* Also Abeba, a parent of child who was diagnosed at 18 month, when talking about injection remembered her son crying and saying "*No! mom don't do it*" Hiewote, a parents of a 9 years old daughter, diagnosed 7 years ago, stated " *she mostly yells ,'that hurt me ' I feel so bad when* *she cries and my I eyes gets full of tears and sometimes I couldn't even see the needle and count the insulin right.*"

On the other hand, Aberashe identified the positive side of being diagnosed at childhood and explained, "a lot of people say ʽoh, it so hard that she got diabetes at such a young age' but, sometimes I will look at it in the positive way. She is growing up with it." she continues explaining, "Sometimes I meet parents of children diagnosed at older age and who complain about their child resistance to accept diabetes and to make change in their way of life."

Child diabetes management responsibility

It's believed that as the children got older they assumed more responsibility for self-care. However, this transition was not without problem as mentioned by the parents. An example of a 15-year-old girl who didn't want to be worried is described by her sister Helen, "*now a days she start to refuse to monitor her blood glucose levels, go on food restriction and be elusive about test results*" she further stated "*she got so tired,…..I knew this would happen but it just happened too fast.*"

Although some children would forget or not want to be bothered, ten parents said that as their children got older they were making an effort to be more responsible even becoming more matured compared to their age mates. As she talked about her 13 years old daughter Lemeleme said, "*I am very proud of her for how well she is responsible*."

Child worries of diabetes

Parents described their children emotional responses to having diabetes as mostly silence, some acceptance and positive attitudes. Helen indicated, her sister often express anger and frustration with having diabetes. A 15-year-old boy, who has had diabetes for 12 years, complained to his mom 'am so sick of diabetes' as told by his mother Mulu. In contrast, two parents, Lemelem and Teferi, stated their children had maintained positive attitudes toward their disease as they have been coached by their parents well on how to handle the physical and psychological baggage of the disease.

Challenges parents encountered

Parent's responses during the interview are sub categorized in to nine sub-themes under 3 main categories of physical, psychological, economical and social challenges.

Physical Management of Diabetes

Meal planning

Identifying the right meal

Those who receive insulin injections need to consume carbohydrates in the right quantity and at the right time to prevent their blood sugar from dropping seriously low or going up. Everyday parents need to match insulin, food intake and be watchful of the child's physical activity. Because of this, meal and snack times are strictly adhered to. This issue was addressed by all parents. The mother of an 8-years-old boy, Emebet, stated, "*my son eats 6 times a day and I should know what and how much he eats all day*." Some parents find hard to differentiate the type of meals as carbohydrate, protein, minerals….and the like.

Children eating without the knowledge of parents

In addition, many children eat food without their parent's knowledge. The mother of a 9 years old child Hiewot, stated "*I tell her gently when she wants some food, she should come and tell me. But my daughter sneak food and when I measure the glucose the numbers goes up and I feel bad….it's a child's thing*". Another mother Abeba acknowledge that her child has been through the whole sneaking food type of things too. She said "*he used to steal money from my wallet and when I went to his school looking for the stolen money, I always find him eating all biscuit and candy*."

Another concern mentioned by the parents was about trying to maintain the balance between glycemic control and letting a child to be like his normal friends. Aberashe being a single mother said, “*Sometimes I prefer to let my daughter eat whatever her friends are eating and give her more insulin shot later.*” Parents sometimes made conscious decisions to ignore the rules. Teferi said, “*after all he is a child.*”

Administering insulin outside home

Administering insulin outside home was mentioned by two parents as a challenge. They found it difficult to find a place where they feel comfortable giving the child an insulin injection, Helen, said “*whenever we go out we usually inject insulin at restaurant toilets.*”

Children inability to recognize symptoms

Parents of four children said their children were not able to recognize symptoms of hypoglycemia (low blood sugar level) and suffered from it. Zenashe, once found her son laid down on bed being in hypoglycemia situation but couldn’t tell the symptom, she said, “*he just slept until I returned from church and I immediately gave him sugar and he became fine, later on he told me that he was playing football with his friends and had much exercise*.”

Pressure of related illness on diabetes management

Illness and stress can also make it difficult to maintain an appropriate blood sugar. This was mentioned by several parents. One father, Solomon, whose child was hospitalized before three month for ‘tonsil’ treatment commented, “*her sugar level is so much more fragile…..actually she has never been free from disease, earlier she has been diagnosed for intestine infection…… we are having horrible time*.” Another mother, Aberashe, noted flu is a challenge for her child and Helen, mentioned, “*School exam stress*” as a challenge for making it difficult to control blood sugar.

Fearing health complication

Ten parents expressed feelings of fear related to health complications that diabetes potentially can bring. One mother, Hiewot, expressed her concern saying, “*although the diabetes educators said if we took care of it, they are going to live a healthy life as anyone* *else" but, it is still very scary! Especially as you watch 11 years old kid gone blind because of diabetes*." Similarly Helen, witnessed,

> "*When we (she and her diabetes sister) went to Tikure Anbesa for follow-up, we saw a 10 years old diabetic kid starting to have kidney problem…..the very thing that make me sick is thinking about diabetes related health complication diabetes is not only about your present, it's also about your future...Actually we are doing our best to control it. But, it seems hard to avoid…. In the long run it may injure her heart, kidney, and nerve, take her leg or eyesight….that is one of the reasons that I always say pediatrics should be differentiated from the adult one. Because when children's see older people with the complication at the hospital they may feel hopeless and may say this is my destiny."*

Asked about what worried her most about her child? Emebet replied,

> *"Thinking about the complications kills me, my son is 8 years old, I have may be only 10 more years to decide on his everyday life ….but when he gets 18 and grow up I will have no power so, I am worried that he might get in to complication by being careless or tired of the diabetes management."*

Most Parents didn't find it emotionally easy to talk with their child about the heath complication. Hiewote is one of the parents who find it difficult. As she said,

> *"My daughter used to eat sweets at school hiding from me. So she was having hyperglycemia frequently. Whenever I get bad number on the gelucometry the complication come to my mind and gets me frustrated. One day I asked her, to close her eye and tell me what she see… she replied, 'noting, it's all dark' then I told her this is what will happen to her if she*

> *don't stop taking sweets and hide from me. After then she brings all the chocolate and candy that she gets at her school to me …it was hard I was even crying telling her this."*

One guardian, Helen, said, "*because I have no guts to tell her about the complications, I always put the magazine that has this kind of messages just in front of the table so that, she could read*" although another parent, Solomon, find the magazines scary for a child to read.

Parents not only were concerned about their child developing complications, seven parents acknowledged the possibility that their child could die suddenly of the diabetes. Most parents always wake up and check their kids at mid night and even some share a bed with their child. Hiewote said,

> *"Especially at first I was worried that I might not find my daughter alive in the morning. So, I don't even fall asleep, I just sat and watch her. When she gets up in the morning that was my happiness, starting that time I don't sleep much and still we are sharing the same bed room."*

Psychological challenges

Lack of emotional support

With the initial diagnosis all were heart-broken and felt sadness. In relation to this the need for emotional support were recognized by all parents. These feelings are demonstrated in the comments, "*it just comes unexpectedly and shake up your life", "you imagine of how life will be and ask why me?*", "*How am I going to handle it?*" (Aberashe) Emebet said, "*I have never been and will not be in such crises ever. That was my climax!*" Helen was like, "*what is life after all, I lost all the sense.*"

Parents expressed that they wish they had someone who knows about the situation and be with them after the diagnosis. Hiewote, said, "*You see me fine now after managing* *diabetes for 7years. There were many years where I sat in my living room and cried. I felt like I will never be able to do it.*" Another parent, Solomon, mentioned that his wife still cry day and night after 1 year diagnosis of their 8 years old daughter and need some kind of emotional and psychological support.

All participants reported to have been in need of some emotional and psychological support at the time of their child's diagnosis, and immediately after they knew about the status. But, most of them were not able to get the support they longed for. Emebet, pointed out the disparity between help and information regarding physical management and emotional management with her statement,

> they just tell you that it is a chronic illness, something that could cause your child to die at any moment and just only show you how to do the injection, what to do with glucometry and the like, and there is no therapist, someone at least who has the experience…………. No Support, there is no emotional, mental support for it.

Similarly, Helen, said, "*I didn't want to leave the hospital, I was scared of going home, I was frustrated, they tell you it is life threatening and the next thing you know they let you go home, you can imagine how it feels.*"

Child misbehaving

Many parents interviewed indicated the change in their child behavior as they became angry, aggressive, isolated, offended, very emotional, and careless and start a fight with siblings. Parents were found to be intertwined between managing the diabetes, disciplining child behavior and allowing the child to have a childhood time. And face difficulty determining if the mood swing is the result of an abnormal blood sugar or something else. These concerns were voiced in two parents, Solomon and Teferi, Further described by, Solomon, said,

> *"I think the most challenging thing when parents deal with diabetes child is adapting to their behavioral change….at the beginning we as a family were confused. But, now the first thing I do is I measure her sugar level and if it's normal ……oky, it's all about her mood and we just leave her."*

Most parents were concerned about disciplining of a child whose moods could be affected by blood sugar changes. All mothers admitted that they don't go hard on punishing their diabetes child. Mulu with a 15-year-old boy who has had diabetes for 12 years, complained,

> *"It's hard for me as a parent because, I will get mad at him for doing things wrong…but at the same time I wonder if he is misbehaving like this because of his sugar level. He is always angry about his diabetes… You may keep the blood sugar well, but how do you correct the behavior? I am having a very tough time, he is becoming out of control, I was hoping he will help me some day…….but not anymore, he drop out school……"*

4.3.2.1 Experiencing burnout

When asked about challenges experienced, one mother responded saying, "*You know, I sometimes hate my son's insulin and hate the whole thing.*" (Emebet) These feelings were shared by the mother of a 10-year-old boy diagnosed for 9 years

> *"… I often, have that day where I am like I can't do it anymore, most of the time I cry …..I am also with chronic illness taking pills every day, when my child get sick I spend sleepless nights feeling no one is there for my poor child excsept me… anyway this is my destiny, so, I can't help it, just only accept it (crying). (Abeba)"*

Social challenges

Misunderstanding of T1D

All parents observed a lack of understanding of the difference between type 1 and type 2 diabetes by the community. Such comments as, Helen, said, “The first thing is people don’t know there are two different type of diabetes” she also encounter “*people and relatives saying the child could probably go to gym, lose weight and won’t have diabetes anymore.*” Most mother participants (Hiewote, Emebet, Lemeleme,Zenashe) in this research reported receiving comments even from their husband such as, “*it is because you feed the child too much sugar and sweets*” and “*when your child grows up its goanna go away.*” Actually, none of the interviewee knew about child diabetes before their child has been diagnosed for it; they thought it was all about aging and being overweight. Mulugata, a father of a 12 years old daughter, who lives in rural area, and whose child has been diagnosed at age 10 the first time, said,

> *“At the first time when the doctors told me and my wife our daughter is diabetes we didn’t believe them, I hoped that it might be some kind of paper error, how can a child at this age has diabetes? I heard that it only caught older and fat people who live in luxury. But, our daughter was very skinny who lives in poverty and in a farmer’s family ….. When we went back to our community they didn’t accept the fact. They thought it is a bad sprit. I replied to them by saying ‘we don’t know more than the doctors.’ But, we took her to almost all spiritual places for cure and tried our best. Even, once a guy from Addis took me to an organization and convinced me that there is a medication that is newly imported from foreign country that can cure the disease quickly, I was very optimistic that I immediately sold my cow and bought the medicine with 3,000 birr and I paid 340 birr for registration at the organization. But, now I have all the medicine and the cartons being thrown away in my home. Because, after two days of taking the drug my child became more ill and she*

> *stopped taking it. She doesn't want even to see it now. For the rural family like me selling a caw was a big loss and the money was too much."*

Zeritu indicated one of the major challenges she faced related to her child diabetes was discrimination as she said,

> *"Whenever my son goes out to play foot ball with other kids there was women who let her child get out of the play immediately…despite that I tried to tell her that it is not communicable. But, she was very arrogant to me. One day when my son asked me why this women is doing this and said, 'is this because of me' I went to the association crying even not wearing a scarf, they gave me a medical paper that declares diabetes is not communicable, I waited late at night until her husband came and gave him the paper".*

Erosion in social interaction

Concerning challenges related to social interaction, many participants reported that although, lots of friends, families and other social circles understand what they are going through and does not make an extra effort. Aberashe noticed her social relationship being gradually eroded. One participant, Helen, verbalize that she lost interest in social life saying, "*Because most of my social circle doesn't know about the situation I just don't feel like they know me*."

Economical challenges

Financial cost of diabetes:

The cost of managing diabetes was an issue identified by most families. Solomon, the father of a recently diagnosed child complaining about the cost of diabetes care saying, "*I paid too much money at a hospital. I paid 10,000 birr for a week and I was tired of finding glucometer. But, now I am having free service from the association including the medical* *equipment*. ”Abeba and Mulu as single poor parents are worried about what would happen to their child if something happens. Those two parents who are from rural area, Diriba and Mulugata are financially challenged for paying their transportation, restaurant and motel service whenever they come to Addis Ababa for follow-up on regular base.

The cost of balanced diet needed for the child is also additional cost for parents who are underprivileged. Zenashe said, “*I am renting milk for my son, I pay 300 birr a month…. this is too much for us.*” On the other hand, there are financially well done families like Emebet and Hiewote. These two parents want to contribute something for the association and help poor families. Emebet described the situation,

> *“… I was a women who was selfishly living, I buy everything that my child asks for, I have no problem of paying my child medical care, or I never worried about what to feed him, but one day this question crossed my mind ‘ what will happen to the poor women with diabetes child?’……I came to the association and start working with them. I am now one of the parent support group committee established recently….after then I hear a lot of related problems, there are diabetes children who get in to hypoglycemia and fall down at school every day for not having food/ a lunch box, even there are diabetes children who lives in the street and hardily eat.”*

Some participants mention that it’s hard for them to get better care at private or at specialized pediatrician clinic as they can’t afford the expense.

Employment change

In addition to the above challenges all mother respondents experienced the effect of child diabetes management related to their employment. Including quitting jobs outside the home, changing the type and place of work, as most of them puts it ‘*my child is my job*.’ Most of the mother’s quit job so they would better be able to monitor their child, insulin, diet and hospital follow ups. But, two parents Mulu and Zenashe got fired for missing work frequently, attending their child hospital. This employment change off course affected their income negatively.

Concerning the type of job, three parents are making a living by baking and selling injera, Abeba wash closes for the neighborhood, Emebet and Aberashe stay at home and Hiewote sells kids clothing, playing materials at the gate of her home. All of them believed that their previous job was much better than the present. They are just settling for less, prioritizing their child care. In relation to mothers employment change Hiewote told her experience,

> *"I used to have a big super market, and it was full of sweet things and I always bring my daughter with me at work place. After she got sick I never leave her home. So, whenever parents come and buy sweets for their kids she starts to cry. So, I felt so bad that my child can't have it. I don't want her to suffer seeing other kids enjoying … so I gave the shop for rent."*

On the other hand, the situation gave Emebet a stay home mom a chance to go out and actively participate in the association program and advocate for child diabetes.

Family communication and relationship

Family and marriage issues addressed during the interviews included (a) parental disagreement, (b) siblings and extended family and (c) family misunderstanding of T1DM.

Parental disagreement

Another point mentioned by participants was disagreement between parents and family members. Emebet said,

> *"At first my relationship with my husband became different my husband was always in to counting numbers, number of insulin dosage, carbohydrate counting, sugar level…..and me I was busy with getting to*

> *know mothers with diabetes child, finding people who made it with diabetes …the other issue of conflict was that, my husband used to blame me for every hyperglycemia (high blood sugar level) and hypoglycemia (low blood sugar level) our child had in the day…..we are still working on that"*

Another mother, Hiewote, said,

> *"My husband blames me for ignoring him and being too emotional with our diabetes child. He thinks I should pass the responsibility to our child but she is only 8.We also had a big fight once as I really wanted to join college and study nursing. He said, 'the knowledge you have is enough for your child' but I want to have the opportunity to help people like myself who sometimes feel that life and their health is far out of their control, I want to own a child diabetes clinic and education center, just to help more children with diabetes and teach parents…..anyway one day I hope I will make it true."*

Similarly, diabetes was a turning point for Mulu's divorce she said,

> *"… Off course we had a long story of unhappy marriage, but it came to an end when my husband started blaming me for having an affair with doctors, he thought I spend all day and night at a hospital for other dirty reason …the guy was very jealous anyway."*

Siblings and Extended Family Support and communication

In response to the question about issues regarding siblings or other family members the vast majority of parents said the siblings of the child with diabetes are very cooperative physically and emotionally. One Mother, Emebet, indicating a negative experience said, "*the younger siblings want all the diabetes care* (laughing)…..*at some moment they wished they could be like the diabetes child just to be the center of attention*." Similarly Hiewote, said, "*the other older siblings always complain that I am in favor of her (the diabetes child), I hope they will understand me*". On the other side, in discussing a positive outcomes, Helen, said, "*I think our sister diabetes has made all the family members to become more responsible even the very younger sibling care about her*."

Change in family lifestyle

Helen, Hiewot, Teferi, Solomon and Embet are parents who said their family life style has changed concerning healthy eating because of the child with diabetes in the family. One mother, Hiewote, expressed the change as "*we stopped shopping soda and carbohydrate foods, although it is not easy to persuade other family members. ….We just don't want her to feel isolated*" in relation to this concern, Helen told her traumatic experience saying:

> Amazingly before I knew it I stopped using sugar, I get disgusted when people put sugar in their coffee, once I almost vomited when I saw a man …chomp mouthful of sugar in a café…..I know sweet is possible for diabetes in limited amount ….but I still hate it and I don't like people who puts many spoon of sugar in their drinks.

Extended Family member misunderstanding of T1DM

Several parents commented on the lack of understanding of other family members regarding T1D. One father, Teferi, stated, " *I think the hardest part of getting used to it for the family is that there is a misconception that it is all about high usage of sugar or high level of sugar in a body. They would say 'eat its ok.*" As one participants, Helen, puts, "*whenever we go to relatives home they give her sweets and say, 'let her eat it's once in a blue moon' off course it's with good will, they don't want to isolate her…. they just don't realize how it can affect her*."

The positive side of child diabetes

Beside participants issue of disagreements and other family issues all parents agreed that their family intimacy and communication support and care has increased. As they started doing thing as a family following their child diagnosis. For example, Solomon said, "*I was a very out looking father and arrogant to my wife but not anymore! My wife has also a sickness and she is emotionally hurt, this is my time to be there for my family.*" Embet, also said, "*At some point the family was detached but later we became more allied*".

School related Issues

In response to the question about issues regarding child with diabetes and school life, (a) School cooperation, (b) creating awareness for the school, and (c) friends at school were discussed by parents.

Cooperation from schools

Parents reported both positive and negative experiences with their children's school experience. Some (Emebet,Teferi,) were satisfied with support they receive from schools, yet other parents had difficulty getting the needed cooperation. One mother, Aberashe, whose child has been diagnosed at the age of 14 month described her problem in finding a school who is willing to accept her child and even one school administrator recommend her to let her daughter stay home until she was able to do her injection and be in control of her glucose level. At that time the mother was challenged by the administrator question "*who is going to be responsible if she get in to comma*."

Another mother, Zenashe, pointed out that problems with the school vary in regards to teacher's willingness. As she put,

> *"You may find teachers with good heart and then the next year you will have teacher who could care less, but I am lucky that this year my child has a teacher who herself has diabetes. She is so kind to my child."*

In concern with the issue most parents mention that teachers did not want to deal with the mood swings associated with the diagnoses. Helen, relate this to her little sister experience, “*she was placed as if she became behaviorally challenging student.*” This parent further discussed the challenge of working through problems with the school, “*we have had a big fight with the school, when one teacher confronted my sister what she is diagnosed for….just in the middle of the class and when she returned home she told me that she felt so bad.*”

Only two parents, Abeba and Solomon, reported, their child missed class frequently because of diabetes sickness. Solomon, said, “*She missed a lot of class this school year because as she been in DK the highs and lows made it impossible to stay in class and learn. She found it hard to catch up at school*.”

Creating awareness for the school

All parents talks with the school about their child health status and explained what T1DM is; some parents do it every year to create awareness and the school to take into consideration when dealing with children in this kind of situation. Particularly one mother, Hiewote, shared her hobby during the interviewee about going into the school at the end of each year to educate and give flyers about diabetes on the yearly parent’s day celebration organized by the school. She also gives flyers to every clinic she could reach.

Support from the children’s friends

All parents said some child friends know about their child diabetes. Children are naturally curious, to know what their friend is doing with the diabetes management and the medical staff he brings at school like, needles, glucometer…and the like. Regarding this one father, Solomon, had an experience,

> Three months before my child who is a grade 2 student check her friend sugar level with her glucometer and strip at school…the next morning I had a call from the school….. The child’s parents came and appealed… that was a shock for everyone.

Challenges associated with school lunch

Another common issue raised was regarding lunch at school. One mother, Hiewote, a mother of 8 years old, described the case,

> *"One day my daughter came home being very weak, sweaty and tired. She was totally in hypoglycemia, when I ask her what happened she said, 'I shared my lunch with friends', starting from that day I changed my schedules to be able to give her insulin shots at lunch because the school did not have a nurse. I go to her school every day at lunch time, to feed, check the sugar level and give her a shot….I decided to give her a shot at lunch, meaning, three time a day because her doctor said,' it's very advisable if you have the energy' …its very challenging but worthy…I will do whatever it takes, I prefer to suffer now than regretting later on."*

This parent, Helen, has only good thing to say about her sister lunch time at school. She said, "*Her friends are amazing; because she eat her lunch sharing with them, they always bring foods that fit with her sugar, they are also very cooperative in accompanying her home when she feels sick.*"

Health care services

Health care service issues including, (a) hospital experience, (b) health care providers approach, (c) information at the hospital and (d), hospital discharge were raised by participants during the interviews.

Hospital experiences at the time of diagnosis

Few (Solomon, Hiewotee, Emebet, Tesfaye) parents had only good things to say about their hospital experiences. Four parents said the doctors and the service was good. The parents of children admitted at governmental hospital they had a more negative experience. Some Parents complained about the competency of the medical professionals. For example, the mother of a child who was 14 month at the time of diagnosis, Aberashe, claimed,

> *“It was horrible! There was no one who tells you what is exactly going on, the doctors change every time and the new doctor starts from scratch again. Since they don’t have a single guluconetry, I used to go to the laboratory outside the hospital every four hour including the night time. You can tell how it is scary with all that gangsters standing around. It is all because, the big governmental referral hospital don’t have a simple laboratory test machine that detect a Ketoacidosis level (a laboratory test that should be administered very frequently when a child is in DK/comma condition), but every single private laboratories own that…..it’s a shame for the hospital.”*

Similarly another parent, Helen, who were at the same referral hospital at the time of diagnosis, were not happy with the experience either. Saying,

> *“Nurses were not nice at all and competent, my sister was admitted in DK condition for 15 days. One day I was the one who detected nurse is giving her the wrong IV, running….I informed the doctors who were in shock about the error, she could have died.”*

Emebet, also recently met a pharmacist who doesn’t know what child diabetes is, she said,

> *“We went to the pharmacy looking for artificial sugar, when I talk to my son the pharmacist listened that my son is diabetes and she asked me 'are you sure? Did you take him to a hospital? Did the doctors said that?’ she was all amazed to here he is diabetes and I was amazed that she didn’t know.”*

Healthcare providers approach

Most parents state that they wanted healthcare providers to use positive reinforcement and encouragement during their hospital stay although only some obtain that. The mother of a boy diagnosed at the age three has liked her doctor and said, "*She was very sociable, she was like a friend she gave me advice to the entire problem I have, even concerning my marriage and family, she encourages me, she makes my son feel like he is ok, meeting her was a relief.*" Parents feels it is important to find a healthcare provider with whom they are comfortable with and who is regular. Concerning this, one mother, Lemlem, reported that every time she goes to the hospital she finds a new doctor and wish if there were common doctors who follow only children with diabetes and who knows how to deal with child psychology.

Hospital discharge

Despite the dissatisfaction at the health care service several parents reported the need for support after hospital discharge and they felt scared of going home all alone taking all the new responsibility. Helen, said, "*I wish we could stay in the hospital forever at least there is doctors nearby you*" another parent, Solomon reported, " *we were scared of going home"* and another parent, Lemelem, said, "*it was just overwhelming task while you are leaving the hospital*" One mother, Aberashe, expressed the feeling, " *I thought I am out of everything…… it would have been great at list to get to know some parents raising children with diabetes*" she further described how she felt, "*just a call to see how you are doing from someone who knows about it would have been so helpful to me……I wasn't sure about what I was doing* "

Information at the hospital

Many parents felt overwhelmed with the information given during their hospital stay. Information's were vague and too much of shocking and parents missed to hear positive things about diabetes. As one father, Teferi, put it, "*I would suggest having the health professionals that tell you the good things too*". Helen also claimed,

> *"They could have told you both sides, rather than scaring you by saying she is going to lose her leg like this guy….naming famous musician who died after diabetes. …sometimes they are ignorant… They forget that they*

> *are talking about your child and you are a parent… I don't think they know how it feels…I read on a magazine that there are people who live more than 40 years with T1DM they should tell you this too.*"

Two parents Abeba and Diriba reported the healthcare providers were defensive when questioned. One father described this happening during their hospital admission, "*nurses were getting mad at us for questioning, but we come from a rural community we have no information about T1DM we know nothing.*" One Mother, Emebet, described this, "*we are on the defense already; you know we are hesitating, so we took our baby to another hospital which the doctors don't like it and they were very angry*"

Diabetes education

Concerning the diabetes education, parents talked about, (a), limited knowledge of diabetes, (b) access to diabetes education, (c) importance of diabetes education and (d) preferred method of receiving education.

Limited Knowledge about diabetes management/DM

Two participants were unable to describe what hypoglycemia is. The participant's child had been diagnosed for the past two and three years. One of the parents, Diriba, who came from rural area for follow up at Tikure Anbessa Hospital was with his kid who seem like a 9 years old but later I found out he is 12. He answered in response to the question about his knowledge of diabetes by saying "*I know well! Yes off course, how dare you it's my son life*" but later in the interview he didn't tell if his son ever fell for being hypoglycemia he rather said, "*No! My child disease is about high sugar level not low*" the child HB1C result was also very bad, high > 14 the machine even couldn't read it. The advisable range for a diabetes child is between 7 and 8.

Mulugeta, who is a father of a child aged 12, came from rural area to take insulin and other equipment. The child HB1C result was very bad, > 14. The staffs at the organization were curious to know what was wrong. Because, the number of insulin dosage his daughter is taking was much higher than her weight. So, her HB1C result was estimated to be very low with frequent hypoglycemic experience. However the truth was the opposite. Latter on when the father was asked how he is preserving the insulin, he demonstrated in the wrong way which make the insulin work less effectively. Note that, families at the rural area keep the insulin cold in the sand traditionally since they don't have refrigerator and electric power. Also while the girl was physically examined it was known that she is injecting herself only at one body part which also hinders the effectiveness of insulin distribution in the body.

Emebet, one of the participants and who is active at the parent support committee in the association witnessed her experience of meeting a child, who suffers from limited knowledge of diabetes in the family, saying,

> *"I went to the hospital just for observation and collected data for our new project. There was a poor 7 years old child who seems in Dk condition. He was so dizzy and there is an old woman with him (his aunt). I went to the doctor room with them, and I was shocked to hear he is the one who injects himself and doesn't know numbers clearly that he dose himself insulin as he likes. The woman said, 'I brought him from rural area when he was sick but I couldn't be a help because I am very old, uneducated and poor'. The doctor hospitalized the child immediately for being in DK….(crying)….I saw my son in his eyes they are almost in the same age…I tried to find someone close to the family at list to teach how to inject. But, no one was there the old women told me that, the shop keeper in their neighborhood is the only help as he let them keep the insulin in his refrigerator. When I called him he was busy to come….. I also have met children aged only 10 and 11 coming to the hospital and to the association all alone….not only*

> *because of the shortage of diabetes education, but having parents who are educated and well done but very negligent and ignorant. Some of them didn't care at all."*

Diabetes education

Two participants, Mulugeta and Diriba believed that there is lack of access to diabetic education. Verbalized that they had no access to a diabetes educator or educational program. Mulugeta said,

> *"We are coming here from the country side only for follow up, we are always in rush, they told us there is education program every week. But, we have no time to stay here for the education, the hotel cost is also too much that I didn't attend the program except once."*

All Parents stated they had some access to medical care. This medical care included access to medical equipment but not always access to a medical doctor. However, all participants agreed on the importance of education. One mother, Aberashe stated it, "*Diabetes management require your knowledge as equal as being a doctor.*" And, most parents suggest parent's group discussion. Some suggested internet, media and home to home education would be the preferred method of receiving information about diabetes.

Coping and adaptation

Different parents used different coping and adaptation mechanism to cope up with the situation (A) developing a positive attitude, (b) Increasing diabetes management knowledge, (c) meeting other children's with T1DM, (d) talking with other parents raising children with T1DM and (e) participating in activities hosted by the association were identified by participants as means to get along with it.

Developing a positive attitude

In spite of the many problems faced by the parents, several of them maintain a positive attitude. They expressed the importance of being positive and of recognize things are could but can be worse. In the words of one mother, "*I am always trying to be positive because there is nothing you can do about it. It's better to accept it*" Her positive attitude came from her experience in the hospital when her friend relative was diagnosed with cancer and died later. As she put it,

> *"We were in the pediatric ward with my friend and there I saw kids with the worst situation, diagnosed with leukemia and other. May be its rude to say…. but it was a good thing to go up there and see all of the other kids that have so much more to deal with. It makes you grateful that it is diabetes."*

Zenashe, who is a mother of two chronically ill children, adapted to diabetes positively as she found it better than her older daughter brains disease which she think is the worst and doesn't go away. She said, "*She does try almost every drug of Amanual Hospital (a mental health hospital)….no change"* (Crying). *"So, comparing to this insulin is almost a cure*." Telling how she cops up with it, Helen used the expression "*at list it is manageable*."

On the other hand, denial was also one of the negative adaptations that some parents used. Helen, who is responsible for parenting her sister said, "*my mother still deny it is a life time thing she believes it will go away some day…I mean… it's ok at least it helped her*." Hiewote, also witnessed that there are a family members that she knows and who even don't call the name diabetes not to give it a recognition.

Increasing diabetes management knowledge

All parents indicated as more year goes by and as they increase in their ability to manage their child diabetes, they adapted it and make it a habit. A mother of a child diagnosed for 4 years, Lemlem, said.

> "*It was definitely a lot harder in the beginning through time you just start knowing what to do, time solve everything*". Another mother Hiewote said, "*it is*

> *now 7 years at some point it became your habit.…especially as you increase your knowledge it calms you down…. you know, now many parents calls me and ask me for medical advice….. As if I am a doctor… "* (Laughing*).*

Meeting other children with T1DM

Most parents feel strongly that their children meeting other children's with diabetes helped them through all the way and find it very important. In the words of four parents, Emebet,

> "*for our child and the family it was the best thing to be able to see that there are other kids attending similar activities*." Helen, "*I think the hardest thing for a child is to think 'I am the only person that has diabetes*." Solomon, "*you know, they (children) may not believe you telling them there are other people out there that do have diabetes.*" And, Hiewote, "*it make them not feel alone*" all parents believed there was value for their child with diabetes to interact with children who also have diabetes. One mother, Helen, said, "*it is the best thing for your child to be able to see there are other kids just like him and they can do normal stuff, just like everybody else can do.*"

Talking with other parents and participating in activities hosted by the association

Many parents said one of the most helpful things was talking with other parents who were raising diabetes child and meeting those people who live with diabetes. Hiewote, said,

> *"It was the first day that I was told my child it is diabetes and the doctor suggested me to contact the association; it was on Saturday I reached to the office almost when the staffs were leaving, I was crying like it is the end of the world. This woman start to talk to me, when she told me she is diabetes herself beginning from her childhood I immediately cool*

> *down…..she was a happy pregnant woman almost having her second baby, that was the most helpful thing I ever found."*

Emebet, encourages meeting parents for the emotional support she gets. She said, "*Doctors could not ever give you this*" Another parents, Solomon and Zenashe, magnified the benefit of letting a child meet successful people with diabetes. Zenashe, she further said, "*my child wants to work at the association when he grows up, and he was inspired by a diabetes young man who works in the association.*"

Four Parents namely, Helen, Emebet, Hiewote and Aberashe participating in organized diabetes activities was valuable for their child and for themselves. It gave opportunity for the children to see other children with diabetes and for parents.

Chapter Five

Discussion

The main objective of this research was to explore the experiences of parents raising children with T1DM regarding challenges, the impact of the disease on the family, and difficult situations parents encounter, explore feelings and reactions of parents towards the situation and explore the parental coping and adaptation mechanisms used to the diagnosis of their child. Also, parents were asked to identify if and what, social support services are available and their preferred means of support.

Participants addressed various issues, physical, financial, social and psychological burden of child diabetes management, including cost, problems and worries of parenting, concerns with extended family, friends, community and the school, the healthcare system and also about the used coping and adaptation means.

This chapter includes a discussion of the finding from the data analysis, in this study, participants focused on feelings of stress caused by the daily management of diabetes. For these participants, diabetes was mentally, emotionally, and physically challenging being overwhelmed with its complexity and management. Others reported being frustrated with the uncertainty of the disease and the loss of control. Some participants focused on the social isolation. Many participants reported suffering from stress, depression, and anxiety. In an effort to control the negative emotions, participants looked for psycho social support beside the medical treatment. This section of the paper presents the major findings of the research in relation with other researches done on similar study area. Some of them are supported by pervious researches and others are not well discussed in the literature reviewed for this research.

A number of findings in this research supported previous research. For example, regarding parental issues, all participants' response to the diagnosis of childhood diabetes corresponds to the intense, frustration, stress and sadness about the diagnosis. Most parents also in the long run developed a feeling of, anger, depression, and anxiety that they relate to their child diagnosis of T1DM. This findings collaborate to those of other researchers as it showed that the newly diagnosis of T1DM in children is a traumatic and the treatment is stressful event for parents and it is likely to produce symptoms of anxiety and depression, stress, worries, sad feelings, symptoms of depression, psychological distress, anger, fear, feeling of loss and grief, and posttraumatic stress (Landolt, et al., 2005: insulin Dependent Diabetes Trust, 2010: Vicki S., 2011 :Lowes, Lesley, 2005 :Eccleston et al., 2012 : National Collaborating Centre for Women's and Children's Health, 2004).

As identified in this research finding dealing with the management of diabetes created challenges in various forms of participant's life. The known multiple factors by parents were being a child , child diabetes management willingness, and their level of worry which directly support the pervious researches (Vicki et al., 2011 :Lowes, Lesley , 2005) that stated child adherence issues, diabetes management, and the responsibility and burden of diabetes as contributors to parental distress. They further showed parental stress are cause by multiple factors not a single reason.

Participants were concerned about their child developing complications, the possibility that their child could die suddenly of the diabetes. This confirms results of researcher reported by Diana et al. (2000) & Teri. Bourdeau et al. (2013). The researcher in their earlier finding reported that parents of children with diabetes are extremely concerned about how poor glycemic control has influenced their child's growth and fear that their child will experience severe hypoglycemia which may cause death and feel uncertain about the future prognosis.

As presented in the finding section all participants were in need of some emotional and psychological support at the time of their child diagnosis, and immediately after the time of hospital discharge, supporting the finding of Insulin Dependent Diabetes Trust, (2010). The research discovered the need of social and psychological supports as stated physical survival is not the only part of the battle in life of family with T1DM but also emotional and psychological challenges that accompany the disease.

The value of talking with other parents as emotional support as described by participants supports the previous studies conducted by Elaine,(2013), who discussed the significance of social support groups and the value of sharing experiences of parents outside of the hospital setting. And they believed for people living with diabetes there is much more to the creation of a successful life with diabetes than clinical measures.

Several parents complained of difficulty in distinguishing when bad behavior needs to be disciplined or when it results from an abnormal blood sugar and all participants admitted that they don't go hard on punishing their diabetes child. Selaine Niedel, Michael Traynor, Martin McKee and Margaret Grey (2013) reported a similar mess that parents face in knowing how to assist their child on the right way without creating a negative family dynamic.

One of the critical issues facing parents of children with diabetes is transferring primary responsibility for diabetes management to their child. It was mentioned by participants as it was not without problem as mentioned by the pervious researcher Vicki S. et al, and Deborah J. et al.(2011) Further explained, it is difficult for parents to set boundaries and meet diabetes care expectations as their children are maturing.

The feelings of burn out were shared by participants during the interview. As Vicki S. et al,. Deborah J. et al. (2011) and Mellitus et al. (2012) reported parents who are stressed by DM may become overwhelmed by their responsibilities and may experience feeling of burn out from helping the child.

As clarified by the participant in addition to the psychological challenges DM has financial and social burden including additional diet cost and the need for the mother to make changes to her employment. The mass research (insulin Dependent Diabetes Trust, 2010: Vicki S., 2011: Lowes, Lesley, 2005: Eccleston et al., 2012: National Collaborating Centre for Women's and Children's Health, 2004) associated, parents with diabetes child with more stress in the area of social disruption, emotional and financial strain. And the above researches conformed that parents have difficulty of balancing caring for their child to other responsibilities such as work, social life, finance and other household tasks.

For questions related to family communication and relationship the issues mentioned by participants were family argument, sibling's reaction and supports from extended family members in child diabetes management. In general this findings were reported by earlier research findings as Elaine., 2013, and Diana W et al., 2000 conformed, care and management of diabetes involves the entire family and the connection between parents. Some stated disagreement between parents and family members and child misbehaver is also supported by the findings of the f Landolt, et al., (2002) finding. In his work he investigated the impact of parenting a child with T1DM and conformed that, as a result of DM stress parents may experience family arguments and troubling child behavior.

However, as in the current findings, Mellin et al., (2004) and Leehu Zysberg, Tally Lang and Anna Zisberg, (2012) found some positive aspects of having a child with diabetes, ranging from increased family closeness, family cohesion, improved family health habits to improvements in the child's psychosocial profile.

The issue raised by participants in relation to lack of knowledge and help at school setting and challenges discussed at the hospital settings confirms results reported by William, (2011), Elaine et al. (2013) & Diana W et al. (2000). T1DM management need developmentally appropriate health care professional guidance, health care providers, and well established support at schools and society as a whole. As in the current findings, in

2013, Fatemeh, Oskouie, Neda Mehrdad and Hossein Ebrahimi, reported developing a positive attitude, increased diabetes management confidence, informal psychological support and counseling as coping and adaptation mechanism as some of the parents raised.

Participants in this study also addressed issues not identified in the literature reviewed for this research. Some part or some of them may be not significantly addressed in pervious researches. These issues including: General misunderstanding of T1DM in a family and extended family members, issues concerning school life, school friend's cooperation and lunch time associated problems. Problems of discrimination and misunderstanding of T1DM in a society, specific concerns like, limited Knowledge about DM, access to medical education, illiteracy about DM in a family especially from the angle of rural community were not found in the literature review. And also problems associated with health care providers, feelings about the healthcare system, misdiagnosis and incompetency of health care professionals in child diabetes diagnosis were not discussed. Therefore, further research on the area may perhaps aim to see the above issues.

Relating findings with theoretical perspectives

Family system theory

Generally, According to family systems theory, what happens to a target member of the family affects other family members and their response in turn affects the target family members. This main assumption of the theory was better described in the lived experience of parents participated in this research, parents mentioned how their child health status totally affected their personal, family and marriage life, day to day activity in the family and how it defined their family habit, which in response affects the child health. This is consistent with the transactional model of parent–child interactions, in which children affect parents and parents affect children. Another associations drawn in the finding was between parents involvement in diabetes management and a child health benefits, Consistent with the family systems theory perspective, it was clear that parental caring for a child with diabetes has much more implications for both parents health and the health of the child with diabetes.

In addition, most of the above findings witnessed the strong interdependent relationship between diabetes management and family support. As most participants put, “my child diabetes affects the whole family.”

Stress theory

This section will focus on discussing the findings with the basic assumptions of family system theory and family stress theory which revolve around the central components of the ABC-X model. The basic assumption of family stress theory is based on two things: integration and adaptability. Accordingly, most parents’ families were integrated, organized and cohesive prior to the stress. So that they were best able to deal with the losses and became most capable of dealing with the stress. Whereas, the actual stress put one parent, Mulu’s, family in to further breakdown (divorce) as there was prior disorganization in the family.

The theory assumes that, families go through four stages when faced with a stressful situation: crisis, disorganization, recovery, and reorganization. Based on participant’s story, my observation and considering the participants emotional and psychological state, parents with longer duration of diagnosis, likely 3 years and more seems to be in recovery and reorganization phase. Whereas, parents of newly diagnosed child looks still in crisis and disorganization phase. They were crying and very emotional during the interview. Though, the time to stay in stage one and move to the next can not only be affected by duration of the stress but also with other mediating factors.

Stressor events are neither positive nor negative prior to our interpretation. But, chronic illness like T1DM diabetes make more sense of stressing as we consider the following determining factors set by the theory: what participants faced is external to the family control and it is natural which left the family with no option, control or decision over the stressor. Beside, this stressor need all family members to deal with it and disrupts a family in general, no family participated in this research has prior experience of the stressor, the diagnosis was sudden, sever and unexpected which put the entire family in immediate stress, giving no time for a family to anticipate the stressors arrival. On the top of this most participants' perception towards the situation was hopeless. Thus, it is clear to see how severely the family is affected by the stressor and is dealing with high degree of stress. Specially, considering the fact that chronic stressor often persists over time and is resistance to change which likely create other related stressor at the same time.

One way of dealing with stress is by accessing resources, the B component of this model: stated that we should think of resources as falling within three categories: individual, family, and community. In the case of participants, all parents are trying to use their personal knowledge, experience and potential they acquired, by learning new skills and way of life. Most of them stick together as a cohesive unit facing a crisis and pull together to help one another emotionally and financially. They are also using a help from extended family member and EDA. In fact, in the process there are some who faced family disagreements also difficulty in retaining their balance in a family.

When we see how the participants interpret the situation there is disparity. Some parents are optimistic and developed positive attitude. On the other hand, some parents seem to believe this stress will not go away and despair. Related to stress theory individuals and families who believe that a stressor cannot be solved are dooming themselves to failure. By contrast, those who can cognitively reframe the problem as being something they can handle are better able to manage the stressor. Especially, useful when the event itself cannot be changed but the parents perceptions and meanings can be.

Whether or not a family will enter a state of crisis is determined by the previously discussed components of the ABC-X model (stressor event, mediating resource and definition of the stressor). A crisis is reached when the family is no longer able to maintain its usual balance because of the stressor event. Even though parents has been in to big stressful situations no parents (Except, Mulu) in the research reach to crisis or no participants family is broken apart. On the opposite, most participants do function better and become more cohesive after a stressor event than they were before.

Chapter Six

Conclusion and Implication

Conclusion

In conclusion, eight major themes were identified from interviews of twelve participants who have T1DM child and who are a member of Ethiopian Diabetic Association. The lived experiences of the parents regarding their child chronic illness, health, and well-being are included, experiences involving sadness, fear, and anxiety. Although, participants felt the need for physical, emotional, financial, social, family and psychological support, programs were not available except the very limited help they get from the association. Some did not have diabetes education and felt that there is a limited access to diabetes education. Most participants have challenging child school life and health care service experience which need to be addressed with holistic, integrated and multi leveled approach. On the other hand, the stressful situation helps families to pull available resources that are internal and external to the family, enhances their cooperation and cohesiveness, enable function better and found some positive aspects of having a child with diabetes and it also creates change in the structure of the family; roles, rules and boundaries.

Implications

This study implies that many challenging emotions are common in parents raising T1DM child. In order to make this perceptions and lived experiences more positive, holistic and integrated interventions at all level from policy, education, practice and research angle against burden of raising child with T1DM is essential.

Implications for policy

Government at the Macro level should give attention to diabetes care in general and child diabetes in particular. Although, there is a national strategic action plan for prevention and control of non-communicable disease (NCD) for the year 2014-2016 no significant programs and activities have been implemented or even announced by the government so far. Because NCD are not one of the thematic areas of the New Millennium Development Goal (NMDG) most international or local donors are not interested in working towards child diabetes. Only the Ethiopian Diabetic Association is working for all the diabetes people in Ethiopia. So, the Ministry of Health should do a lot more than having an action plan. The Ministry should be proactive in advocating on behalf of Ethiopian diabetes children, securing funds and creating access to free insulin. Seeing that the number of diabetes children is increasing worldwide and Ethiopia is sharing the part, the provision of insulin, needless, stripe, glocumatry, and other expensive medical equipment for free, strengthening healthcare services, equipping laboratories and creating access to quality health care, creating awareness and advocating children to be tested for their sugar level should be a concern of the government.

Basically the notion that government should work towards diabetes is related to the prevention of the complications of diabetes. As working on diabetes is working on many non-communicable dieses at the same time. If we control diabetes as a national level we can minimize the risk of future generation developing heart and kidney failure, amputation and nerve damage and blindness in a country.

A public awareness campaign delivered by way of multi-media regarding type1 diabetes and how it differs from type 2 diabetes may help dispel some misunderstandings among the public and also health care professionals. Such a campaign may begin with coverage by news media.

Advocacy work should be done by professional societies, influential people, civil society organizations and government agencies. This may result in increased national funding, grant awards and/or fund raising for diabetes care and research.

Implications for social work practice and education

Social work practice should be integrated with schools and health care services providers. In addressing psychosocial needs health care and school system should follow a holistic approach counting social workers at the center. Family relationship and strong family system, social unit or intimate relationships are equally necessary as is the individual's own emotional wellbeing in the course of diabetes management and those systems impact health behaviors. Therefore, at a Micro level family should be fully integrated into current social work practice.

Emotional supports should be provided during the initial hospital stay and hospital discharge as a regular part of follow-up visits to help parents address negative emotions. Also, a program that puts parents of newly diagnosed children with in contact with experienced parents may calm some apprehension as well as supply practical advice.

This research implies that diabetes education and other programs should target and provide support to parents, friends and family as well as for the support team surrounding that person including school and community.

Diabetes self-management programs are the cornerstone of diabetes care, teaching children the survival skills with diabetes can prevent disease complications and appropriate diabetes education may reduce the fears of diabetes complication by parents. The fundamental assumption here is that behaviors and feeling can be changed through appropriate diabetes education.

Additionally, Clinicians need to review their approach and requires using motivational strategies that enhance parents and these child psychosocial heaths.

Equally, help in obtaining financial assistance dealing with additional diabetes costs is basic. Including, obtaining nutritional support for the child and the family, free medical care, and economical support which may reduce the financial burden of diabetes for the family.

Such an effort would likely require cooperation by, other third party and the association.

Mothers changing employment was also one of the challenge mentioned which has a direct effect on the family financial power. Some families wished if their where a diabetes day care center to their child with professional attendant.

A problem related to child school life implies a need to educate teachers and at list one other school official about child diabetes. Learning materials need to be available for the child family to take to school for educational purposes. The importance of putting the topic of diabetes in the subject matter of biology like that of HIV AIDS, Tuberculosis/TB/ and Meningitis which would require support by government.

The availability of school nurses or clinic should be increased and be a must for all primary schools, serving not only children with T1DM, but also those with other health needs.

From the findings of this study, it is implicated that small clinics in rural area and extension health care workers should be trained in diabetes management. Distance learning educational programs could also be a possibility. One to one teaching method may allow the illiterate parents practice the new learned skills and return demonstrations of concepts. Information needs to be provided through discussions, videotapes, and booklets.

Implications for research

Implications for research would include looking more detail findings on the life experience of children and youth with diabetes and their families in Ethiopian context. Further research could also aim to see the experience of family having more than one T1DM children, identify differences between parents maintaining positive attitudes and those with more negative responses, see if there is a relationship between parents who have positive attitudes and children who are accepting of the disease; if their is differences in life experience between mother who are working outside of home and who don’t and find out if age of a child creates difficulty in maintaining appropriate glycemic control. Additionally, research involving participants from various socio cultural groups and family structures may be useful in increasing our understanding of the impact of raising a child with T1DM on families. Moreover, Social work researches must continue to move towards interventional programs that can be easily implemented.

In general Interventions designed to satisfy needs identified by parents should be implemented with appropriate evaluation of their effectiveness. Therefore, researches in the area are suggested as it helps ideas and recommendations to be implemented in a cost effective way and essential to the well-being of society.

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Appendices

Appendices A

Informed consent

Researcher: Hana Fantu

Title of the research: the experience of having a child diagnosed with type 1 diabetes: - the case of parents in Addis Ababa

Objective of the study:

The main objective of this study is to explore the experience of parents of living with T1DM.

Procedures

If you take part in this study, you will be asked to: Participate in individual interview. All interviews will be audio recorded. All recordings and transcripts will be kept in a locked location. Tapes will be destroyed upon transcript completion.

Alternatives

You have the alternative to choose not to participate in this research study, Voluntary Participation; you should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time of the process without negative consequences or with any information being published or disclosed. Moreover, you will have Access to the results of the research, if you so desire.

Risks and discomforts:

This research is considered to be minimal risk. The only discomfort that the researcher expects is the discomfort or stress that may arise from talking about the experience of the child diagnosis and the challenges they are facing. There are no known additional risks to those who take part in this study. Furthermore, the researcher will not continue with the interview if any difficult/ major concern arises.

Benefit of this study:

The benefit of this research is that it will provide some useful direction and information for conducting further researches in the area; it may also provide evidence for social workers, public health and clinical professionals, governmental organization and civil societies to intervene in the situation as a family unit. Moreover, the research will suggest better policy implications that guide appropriate policy interventions for the country at large. But, I don't know if you will get any benefits by taking part in this study. Or there are no plans to provide you with financial compensation.

Confidentiality and anonymity:

The researcher will keep your study records as confidential as possible, allocate pseudonyms for you and your child to ensure that after the data has been collected no one will be able to identify who you are. The researcher will also destroy all evidences that link you to the research after the research process completed. With regard to privacy, the researcher will respect your privacy and only collect information that is relevant to the research study.

If at any stage you feel that yours or your child's privacy is being violated the researcher will reorganize, the study to ensure that you are in no way compromised. The researcher is working under the supervision of advisor (DebebeEro, PhD) from the School of Social Work, Addis Ababa University, to ensure that the researcher does not do anything unethical. The researcher can be contacted by telephone, mail or e-mail if desired.

Cell phone: +251912118488

E-mail:- hanafantu@gmail.com

If you have any questions, concerns or complaints about this study, call DebebeEro, PhD at Cell Phone +251911639236

Consent to Take Part in this Research Study

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

I freely give my consent to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form.

Signature of Person Taking Part in Study Date

____

Name of Person Taking Part in Study

____

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect. I hereby certify that when this person signs this form, to the best of my knowledge, he or she understands:

- What the study is about.
- What procedures /investigational devices will be used
- What the potential benefits might be.
- What the known risks might be.

Signature of Person Obtaining Informed Consent Date

____

Name of Person Obtaining Informed Consent

Appendices B

In Depth Interview Guide

This tool is designed to collect data about the experience of having a 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, you do not need to mention your name on the questionnaire. 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.

Interview questionnaire

1. about your child with diabetes:
   1. Your child's age in years?
   2. Your child's gender?
   3. Your child's current grade level in school?
   4. How old was your child when first diagnosed?
   5. What is your child's most recent HbA1c *(HbA1c or A1c: is a lab test that shows the average level of blood sugar over the previous 3 months and it is used as an indicator of diabetes control.),* What did your child's doctor tell you about what your child HbA1c level should be?
   6. How many very low or high blood sugar episodes in this year has your childhad?
   7. How many days of school in this year did your child miss because of Diabetes?
   8. In your estimation, how worried is your child about his being diabetes?
   9. Did your teen have been diagnosed with any psychological problems? By whom?

2, about you and your family:

1. Your age in years?
2. Your gender?

3. Your marital status?
4. Family income monthly?
5. Does your child live with you?
6. How many other family members in the home and what are their ages?

3, the following questions ask about how you have been feeling and experiencing as a parent of a child with diabetes:

1. Tell me about your feelings and reactions with the first diagnosis of your 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 child school and teachers, friends and family members' reaction?
3. Talk about some challenges you have experienced while raising your 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 parent 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, including extended family, siblings, finance, Work, Marital or other relationship?
6. Do you share responsibility for your 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 your child 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 parenting 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, parents 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 your child diabetes? Is there anything else you would like to share with me about raising your child with diabetes?

Appendices B

Amharic Version of Informed Consent Form

ለጥናቱ ተሳታፊዎች

የዚህ ጥናት አጥኚ የጥናቱን አላማ፣ ሂደት እንዲሁም እዚህ ጥናት ላይ ብሳተፍ የሚገጥሙኝ ችግሮች በሚገባ አሳውቆኛል፡፡ በቂ መረጃዎችን ያገኝሁኝ ሲሆን ያልገቡኝ ነገሮች ለመረዳትም ጥያቄ የመጠየቅ ዕድልም አግኝቻለው፡፡በተጨማሪም በቃለ መጠይቁ ወቅት ማቋረጥ ከፈለኩ እንደምችል እና ይህም እኔ ላይ ምንም ችግር እንደማያስከትል ተረድቻለው፡፡ስለዚህ እዚህ ጥናት ላይ የመሳተፉ ፍላጎት እንዳለኝ እና የጥናቱ አጥኚ ርእሱን በተመለከተ ትክክለኛ መረጃ ለመስጠት ያለኝን ፈቃደኝነት በፊርማዬ አረጋግቸጫለው፡፡

የተሳታፊውስም፡ ____________________

የተሳታፊውፊርማ፡ ___________________

ቀን፡ ________________________________

ለጥናቱ አጥኚ

እኔ ሃና ፋንቱ በአዲስ አበባ ዩኒቨርስቲ በሶሻል ወርክ ትምህርት ቤት ውስጥ የማስተርስ ተማሪ ስሆን በአሁኑ ወቅት የመመረቂያ ጥናታዊ ጽሁፍ በማዘጋጀት ላይ እገኛለሁ፡፡ከላይ የተገለጸውን የጥናቱን ተሳታፊ፣ ስለጥናቱ አላማ፣ ሂደት እና ጉዳቶች በሚገባ አስረድቼዋለው፡፡የሚኖረውንም ሙያዊ ስነምግባር በሚገባ ገልጬለታለው፡፡የተሳታፊውን ሚስጥር መጠበቅ፣ስሙን ሚስጥራዊ ማድረግ እና በጉዳዮች ላይ ተሳታፊው የመወሰን መብቱ በሚገባ አጽንኦት ተሰቶባቸዋል፡፡ከታችያስቀመጥኩት ፊርማ የሚያመለክተው ሁለንም አስፈላጊ መረጃ ለጥናቱ ተሳታፊ አስቀድሜ መስጠቴን ይሆናል፡፡

የጥናቱ አጥኚ ስም፡____________________

የጥናቱ አጥኚ ፊርማ፡ __________________

ቀን፡ ________________________________

አዲስ አበባ ዩኒቨርስቲ፣የሶሻል ወርክ የድህረ ምረቃ ት/ቤት

የጥናቱ ርዕስ - ወላጆች የስኳር ህመም 1 ያለባቸውን ልጆች በማሳደግ ዙሪያ ያላቸው የህይወት ተሞክሮ

ስሜ ሃና ፋንቱ ሲሆን በአሁኑ ወቅት የማስተርስ ትምህርቴን በአዲስ አበባ ዩኒቨርስቲ፣በሶሻል ወርክ ትምህርት ክፍል ውስጥ እየተከታተልኩ እገኛለው፡፡የሶሻል ወርክ ትምህርት ቤት፣የማስተርሰ ተማሪዎች ከመመረቃቸው በፊት ጥናታዊ ጽሁፍ እንዲያቀርቡ ይጠይቃል፡፡እኔም በዚሁ ምክንያት ከላይ በተጠቀሰው የጥናት ዕርዕስ ላይ ለመስራት መርጫለው፡፡ይህ መጠይቅ የተዘጋጀው ወላጆች የስኳር ህመም 1 ያለባቸውን ልጆች በማሳደግ ዙሪያ ያለቸውን የህይወት ተሞክሮ በተመለከተ መረጃ ለማሰባሰብ ነው፡፡

የዚህ ጥናት አላማ ወላጆች እና ቤተሰቦች ከ ልጃቸው የስኳር ህመም ጋር በ ተየያዘ ያጋጠሞቸውን ችግሮች፣የወሰዱትን እርምጃ፣ እያገኙት ያለውን እና የሚያስፈልጋቸውን ድጋፍ ማወቅ ነው፡፡ ይህ ጥናት ወደፊት ለሚሰሩ ጥናቶች እና የመንግሰት ፖሊሲ አቅጣጫዎችን ለማሳየት ይጠቅማል፡፡በ መንግስት፣ በባለሞያዎች እና ማህበራዊ ተቋማት መሰራት ያለባቸውን ነገሮች ያሳያል ብዬአምናለው፡፡

በዚህ ጥናት ላይ ሲሳተፉ ከእርሶ ጋር ለአንድ ሰአት የሚቆይ ቃለ መጠይቅ ይኖረናል፡፡እዚህ ጥናት ላይ በመሳተፎ የሚገጥሞት ችግር አይኖርም፡፡ምናልባት ያሳለፉት አሳዘኝ ነገሮች ካሉ በ ቃለ መጠይቁ ወቅት ስሜቶ ሊነካ ይችል ይሆናል፡፡ ግላዊ የሆነ የገንዘብ ወይም ሌላ የሚያገኙትም ጥቅም አይኖርም፡፡ ፡፡ ሁሉም የሚሰበሰበው መረጃዎች በዋናነት ለትምህርት ጉዳይ ሲውል በርግጥ በርዕሱ ዙሪያ የሚሰሩ ድርጅቶች ወይም ግለሰቦች ሊጠቀሙበት ይችላሉ፡፡ጠቃሚ መረጃዎች እንዳያልፉኝ በቃለመጠይቁ ወቅት ድምጽ መቅጃ እጠቀማለው፡፡ነገር ግን በድምጽ መቅጃም ሆነ በጽሁፍ የምይዘው መረጃ ሚስጥራዊነቱ ተጠብቆ ይቀመጣል፡፡መረጃው ወደ ወረቀት ከተገለበጠ በኋላም ካሴቶች

ይቃጠላሉ፡፡በማንኛውም በሚሰበሰብ መረጃ ላይ የእርሶ ሆነ የልጆት ስም አይገለጽም፡፡የእርሶን ስም በሌላ የውሸት ስሞች ይተካሉ፡፡ በቃለመጠይቅ ወቅት ምቾት ካልተሰማዎት የማቋረጥ መብቶ የተጠበቀ ነው፡፡ከላይ የተጠቀሱትን ሙያዊ ሥነ-ምግባሮች ከግምት ውስጥ በማስገባ እና ጥናቱ የፈለገውን ግብ እንዲመታመጠይቁን በግፅነት እና ታማኝነት እንዲመልሱልኝ እጠይቃለሁ፡፡ አመሰግናለሁ፡፡ ሌላ በ ጥናቱ ላይ የሚያነሱት ጥያቄዎች ወይም ቅሬታ ካሎት የሚከተሉት የስልክ ቁጥሮች መጠቀም ይችላሉ፤

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ልጆትን በተመለከቱ የተዘጋጁ ጥያቄዎች

1. ያታ ?
2. እድሜ ?
3. የትምህርት ደረጃ ?
4. በስኳር ህመም መያዙ/ዞ ከታወቀ ስንት ግዜ ነው ?
5. የልጆት አማካኝ የ 3 ወር ውጤት ስንት ነበር ? በዶክተሮች ስለውጤቱ ምን አይነት አስተያት ተሰጥቶታል ?
6. በዚህ ዓመት ስንት በጣም ከፍተኛ እና ዝቅተኛ የስኮር መጠን ልጆት አጋጥሞታል? ምን አደጋ አስከትሎበታል?
7. በእርሶ ግምት ልጆት ስለ ስኳሩ ህመሙ ምን ያህል ይጨነቃል?
8. ልጆት በ ስኳሩ ህመም የተነሳ ለ ስነልቦና ችግር ተጋልጦ ያውቃል?

የግል እና የቤተሰብሁኔታ

1. ያታ?
2. እድሜ ?

3.የጋብቻ ሁኔታ ?

4.የትምህርት ደረጃ ?

5.ወርሃዊ የቤተሰቡ ገቢ ?

6.የልጁ/ቷ ወላጅ ወይስ አሳዳጊ ኖት?

7.በአሁኑ ሰዓት ልጃት ከማን ጋር ነው እየኖረ ያለው/ችው ?

8.የቤተሰብ አባል ብዛት? እድሜ ?

የሚከተሉት ጥያቄዎች እንደወላጅ ከ ልጆት የስኮር ህመም ጋር በተያያዘ ያሎትን ስሜት እና 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 ህመም ያለበትን/ባትን ልጆት በማሳደግ ሂደት ላይ ያጋጠሞት ችግሮች አሉ? ካሉ ምንድን ናቸው? ከ ስነልቦና፣ ከማህበራዊ ህይወት እና ግንኙነቶ፤ከ ኢኮኖሚ፣ ከስራዎት እና ከጤና አንጻር ይግለፁልኝ?

4 በየቀኑ የሚያደርጉት የስኳር ቁጥጥር እና እንክብካቤ ከግል እና በቤተሰቦ ህይወት አንፃር እንዴት ይገልጹታል? የመጡ ለውጦች ወይም ችግሮች አሉ? በትዳሮ እና በሌሎች ልጆቾ ላይ ያስከተለው ተፅኖ አለ? በጤና በኩልስ?

5 ከ ልጆት የስኳር ቁጥጥር ጋር በተያያዘ ያለቦት ጭንቀት አለ? ወደፊት ተያይዘው ሊመጡ ስለሚችሉ የጤና እና ሌሎች ችግሮች ምን ይሰማዎታል?

6 ከ ልጆት የስኳር ቁጥጥር ጋር በተያያዘ የቤተሰቡ ሃላፊነት ክፍፍል እንዴት ነው? በዚህ ሁሪያ

የሚነሱ አለመግባባቶች አሉ? በአጠቃላይ ከስኳር ህመሙ መከሰት በኃላ የቤተሰቡ ግንኙነት እንዴት ይገልጹታል?

7 ልጆት ካለበት የስኳር ህመም ጋር ተያይዞ የትምህርት ቤት ህይወቱ ምን ይመስላል?

8 ስለ ሰኳር እንክብካቤ እና ቁጥጥር ያሎት እውቀት ምን ያህል ነው? በቂ እውቀት ነው ያለኝ ብለው ያሰባሉ? ትምህርቱን ከ የት እና እንዴት አገኙ? ይህን በተመለከተ መረጃዎች እና ትምህርቶች በ ምን መልኩ መሰጠት አለባቸው ብለው ያስባሉ?

9 የስኳር ህመም ያለቸውን ልጆች ከማሳደግ አንጻር ወላጆች ምን አይነት የልጆች አስተዳደግ ቢከተሉ ያመክራሉ? ከፍተኛ ድጋፍ እና ቁጥጥር ከ ወላጅ ቢደረግላቸው ወይሰ ሃላፊነት ቢሰጣቸው የተሻለ ነው ብለው ያስባሉ?

10 በእነዚህ ግዚያቶች ውስጥ ያሉትን ተጽኖዎች እና ችግሮች ለመቋቋም እንዴት ቻሉ? ያደረጓቸው ጥረቶች ምን ነበሩ? ከማን ድጋፍ እና እርዳታዎች አገኙ? ለምሳሌ ከጓደኞች ፣ ቤተሰቦች ከ ጤና ባለሞያዎች፣ ከ መንግስት እና ማህበራዊ ተቋማት…

11 በ ልጆች የስኳር ህመም ዙሪያ ለወላጆች ምን አይነት ድጋፎች ቢኖሩ መልካም ነወ ብለው ያስባሉ? ይህንን ችግር ለመፍታት ከ መንግስት እና ማህበረሰብ ምን ይጠበቃ?

12 ከ ልጆት ህመም ጋር በተያያዘ ከ ሁሉም ይበልጥ መጣም የሚያስጨንቆት ምንድ ነው? ሌላ ሊነግሩኝ የምፈልጉት ነገር አለ?