

Children with Type 1 Diabetes in Tajikistan

A qualitative study, assessing perceptions of type 1 diabetes and the need for information and education, among affected families in Tajikistan.



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Thesis submitted as part of the Master in Philosophy Degree in International Community Health

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ABSTRACT

Title: Children with type 1 diabetes in Tajikistan – A qualitative study assessing perceptions of type 1 diabetes and the need for information and education among affected families in Tajikistan.

Supervisor: Ane Haaland

Co-Supervisor: Akhtar Hussain, Prof. Dr. med.

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Introduction: Type 1 diabetes (T1DM) is among the most common chronic childhood illnesses. Broad knowledge on complex daily management regimens including insulin injections, blood glucose monitoring, regular carbohydrate containing meals and exercise are required, to achieve normal growth and development, to prevent complications, and to promote and sustain optimal functioning for the child. If untreated, severe fluid, electrolyte and acid-base disturbances lead to dehydration, coma and death within a week. Accordingly, patient education is essential and needs to be addressed if T1DM is to be tackled, especially in developing countries. **Aim:** The aim of this study was to assess children's and parents' perceptions of T1DM and their need for information and education in Tajikistan. **Study design:** Qualitative. **Methods:** In-depth interviews with-, and focused observation of 18 diabetic children/adolescents (≤ 18 yrs: $n=15$; ≥ 18 yrs: $n=3$; age variation: 3-23 yrs, duration of disease: 20 d- 14 yrs), their parents and endocrinologists ($n=4$) provided qualitative data from three out of four regions in Tajikistan (Region of Republican Subordination, Khatlon Region, Sughd Region). Purposive- and snowball sampling were used. One focus group discussion with diabetic children and descriptive observation from three diabetes days were used to triangulate the data provided in the interviews. Data was analyzed according to Malterud's systematic text condensation. **Findings:** From discussions and observations three pertinent themes were identified: (1) *Finding out the child has diabetes*, (2) *Life with T1DM* (Responses related to (a) emotions, (b) biomedical knowledge and (c) the health system) and (3) *I would like to know more about/ I would suggest*. (1) Emotional stress and the 'evil eye' were perceived to cause T1DM. Most families had no knowledge about T1DM prior to diagnosis and medical personnel lacked awareness that diabetes could occur in children. Almost all children were severely sick at diagnosis and 11 out of 18 children had been in a coma at least once from diagnosis and onwards. (2)(a) *Responses related to emotions* were characterized by an ambiguous relationship between living with a chronic illness in reality and the uncertainty whether there was a cure that was yet unknown to them. Families experienced chronic sorrow, where coping was felt as an ongoing and spiral process by

parents, whereas diabetic children struggled emotionally and showed few adaptive coping strategies. Mocking and stigmatization, due to impaired growth and delayed pubertal development generated inordinate stress, where 8 of 16 school-aged children stopped attending school. (b) *Responses related to biomedical knowledge* included diet, where sweets, bread and 'oily food' were perceived as the worst foods for diabetic children. Only a few used glucometers as they believed to sense their blood glucose level. Further they were not able to read the English instructions and could not afford the expenses. Insulin injections were frequently left out as mothers had compassion and did not want to hurt their child. All children had experiences with hyperglycemia, but few were aware of its causality and long-term complications. Symptoms of hypoglycemia were not easily recognized. (c) *Responses related to the health system* were that families experienced insulin procurement as a main challenge. In addition, unofficial private payments often hindered families to seek professional help. (3) Diabetic children, their parents and medical doctors desired more written information targeting children with T1DM in Tajikistan. Further the value of diabetes camps was emphasized. **Conclusions:** In conclusion, this study has shown that 90 years after insulin saved the life of the first diabetic child, where the uniformly fatal disorder became a chronic illness with potential long-term survival, not much has changed for children with T1DM in Tajikistan. In this study it was found that little was known about T1DM and its treatment and that the health system had limited capacity to meet the needs of diabetic children in Tajikistan. With a globally estimated rise in incidence of T1DM, advocacy and allocation of financial resources are essential to improve diabetes care in resource constrained countries, so that children with T1DM can be empowered, preserve life quality and emotional health, and have a prolonged life expectancy.

PROLOGUE



*A flower of spring, I am very impatient
I am very discouraged, I am very sick, I want to be healthy*

*A flower of spring, I am very impatient
I ask God to give me good health*

*A flower of spring, I am very impatient
I also want to be healthy; I also want to play.*



A poem which was written by a young diabetic woman with a wonderful soft- and courageous spirit. Thank you for opening my eyes to what was yet unknown to me.

LIST OF ABBREVIATIONS

CDC	Centers for Disease Control
CDiC	Changing Diabetes in Children Programme (Novo Nordisk)
d	days
DKA	Diabetic ketoacidosis
GDP	Gross domestic product
HbA1c	Glycosylated hemoglobin A1c
HDI	Human Development Index
IDF	International Diabetes Federation
IIF	International Insulin Foundation
ISPAD	International Society for Pediatric and Adolescent Diabetes
LFCP	Life for a child programme
mmol/l	millimol per liter
n.a.	not available
NGO	Non-governmental organization
PPP	per capita at Purchasing Power Parity
rDNA	recombinant DNA
REK	Regional Ethical Committee
RAPIA	Rapid Assessment Protocol for Insulin Access
SMBG	Self-monitoring blood glucose
TDEI	Total daily energy intake
T1DM	Type 1 diabetes mellitus
T2DM	Type 2 diabetes mellitus
UiO	University of Oslo
UN	United Nations
UNDP	United Nations Development Programme
USAID	United States Agency for International Development
WHO	World Health Organization
yrs	years

1 INTRODUCTION

1.1 BACKGROUND FOR RESEARCH

1.1.1 *Type 1 diabetes mellitus*

Type 1 diabetes mellitus (T1DM) is one of the most common childhood chronic illnesses (Centers for Disease Control and Prevention, 2010). Complex daily management regimens including insulin injections, blood glucose monitoring, regular carbohydrate containing meals and exercise are required to maintain blood glucose levels within normal limits to prevent complications and to sustain optimal growth and development of the child. If untreated, elevated blood sugar levels cause severe fluid, electrolyte and acid-base disturbances, which further lead to dehydration, coma and death (Brink in Kelnar, 1995).

In 2011 the global population of children aged 0-14 years was 1.9 billion of whom 0.02% had T1DM. The International Diabetes Federation (IDF) *Diabetes Atlas* (Fifth ed. 2011) estimated the actual number of affected children to be 490.000. Of these cases 24% were accounted to the European Region, where the most up-to-date estimates and incidence rates are available (IDF, 2011).

Every year about 77.800 children are newly diagnosed with T1DM globally. This number has increased substantially in recent years, revealing a rapid increase particularly in young children (IDF, 2011). There are indications for geographic differences in trends, denoting a sharper rise in some of the low prevalence countries, particularly in Middle- and Eastern Europe. So far, neither the cause of T1DM, nor the causes of increased incidence numbers with time are known, but the rapidity of the changes and the almost universally increasing trends in younger age groups are unlikely to be explained by changes in the genetic background of the disease (Diabetes Atlas, 4th ed. 2009).

Most up-to-date epidemiological data is provided by the International Diabetes Federation. Annual incidence rates for childhood T1DM (0-14 years) worldwide are highest in the Scandinavian countries, where Finland, Sweden and Norway estimate 57.6, 43.1 and 27.9 new cases of T1DM per 100.000/year respectively. Furthermore, Saudi Arabia and the United Kingdom demonstrate high numbers with 31.4 and 24.5 new cases per 100.000/year. The lowest incidence rates globally are found in Venezuela and Papua New Guinea, both having 0.1 new cases of T1DM per 100.000/year. Tajikistan together with Uzbekistan show the lowest incident rate in the WHO European region with 1.2 new cases of T1DM per 100.000/year.

However, in many developing countries there are no numbers available due to the lack of data (IDF, *Life for a Child Programme*, 2012). The IDF estimates that there are about 80-100.000 children and youth in need of urgent assistance. Furthermore, the estimated life expectancy of a child with newly diagnosed T1DM is likely to be less than one year in some developing countries (Beran, Yudkin, & de Courten, 2005). Many die undiagnosed, others through lack of insulin, lack of expert care or other unexplored factors. This stands in sharp contrast with article 6 of the United Nations Convention of the Rights of the Child (1989), which states: '6.1 State parties recognize that every child has the inherent right to life' and '6.2 State Parties shall ensure to the maximum extent possible the survival and development of the child.' Jean Claude Mbanya, current president of the IDF, acknowledges the global inequalities in *Diabetes Research and Clinical Practice* in 2010, by stating '*Treatment and technology currently exist for people with diabetes to manage their disease successfully and enable them to lead full, productive lives. Yet, the reality is that, for millions of people, modern treatment and technology is but a dream, and the right to live a full life has been denied through ignorance, lack of resources and education, and inadequate health infrastructure*' (Mbanya, 2010).

1.1.2 Facts about treatment of type 1 diabetes mellitus

1.1.2.1 Definition of T1DM

Type 1 diabetes is a chronic autoimmune disease in which destruction or damaging of beta-cells in the pancreas results in insulin deficiency and elevated blood glucose levels, also known as hyperglycemia (Van Belle, Coppieters, & Von Herrath, 2011). Blood glucose must be regulated with insulin treatment, in combination with a balanced diet and exercise.

1.1.2.2 Symptoms

T1DM develops sudden and dramatic in most cases, where children can experience different symptoms. Such symptoms can be: frequent urination, excessive thirst, increased hunger, weight loss, tiredness, lack of interest and concentration, vomiting and stomach pain, a tingling sensation of numbness in the hands or feet, blurred vision, frequent infections and slow healing wounds (ISPAD Guidelines, 2011).

1.1.2.3 Diagnosis and treatment

Criteria for diagnosis

The World Health Organization defines the criteria for the diagnosis of diabetes mellitus as:

- Symptoms of diabetes plus casual or random plasma glucose concentration above or equal to 11.1 mmol/l. 'Casual' is defined as that measured at any time of the day, without regard to time since the last meal.

OR

- Fasting plasma glucose ≥ 7.0 mmol/l (WHO, 2006)

Treatment

Different insulins are available on the market. Ideally the type of insulin treatment is chosen according to the child's lifestyle. The treatment can include one, two or more injections per day. The aim is to match the insulin peaks with the time of food intake. Different types of insulin are: short-acting (duration 3-8 hours), intermediate/long acting (duration 10-18 hours) and new, very long acting insulins (duration up to 24 hours). Further, the choice is between fixed-ratio and combinations of different insulins (CDiC manual, 2011).

In Tajikistan Humulin 70/30, a fixed-ratio combination is used predominantly. This insulin consists of 70% intermediate/long acting insulin (Human Insulin Isophane Suspension) and 30% short-acting insulin (Human Insulin Injection, rDNA origin). The onset of action is the onset of the rapid acting component, while the duration of action is that of the long acting component. Two peaks of insulin action are present and food (carbohydrate) intake needs to be adjusted accordingly.

1.1.2.4 *Dietary advice*

Nutritional management is one of the cornerstones of diabetes care and management (Smart, Aslander-van Vliet, & Waldron, 2009). Dietary recommendations for children with T1DM are generally based on healthy eating principles, suitable for all children, with the aim of improving general health, diabetes outcomes and reducing vascular risks (ISPAD, 2011). It is therefore advised that total daily energy intake (TDEI) should be distributed accordingly: >50% carbohydrates, <35% fat (saturated fat <10%) and 10-15% protein. Sucrose can provide up to 10% of the TDEI (Association, 2008). A child with T1DM is dependent on insulin injections in order for the body to make use of the energy provided by carbohydrate containing foods. Therefore, nutritional management is focusing on the carbohydrate content in the diet especially, to make sure that insulin and diet are adapted to each other in a best possible way. Only then goals of normal blood glucose levels can be achieved and normal growth and development of the child will be assured (CDiC manual, 2011).

1.1.2.5 *Monitoring of blood glucose level*

Insulin treatment is vastly dependent on having a clear picture about fluctuations of blood glucose levels throughout the day. Furthermore, blood glucose measurements help to identify when the child is at risk for either hyperglycemia (= too high blood glucose levels) or hypoglycemia (= too low blood glucose levels). Therefore, multiple measurements per day are considered as an integral part of a successful treatment plan, aiming to keep blood glucose levels within a normal range. Thereby short- and long term complications can be prevented or delayed.

The International Society for Pediatric and Adolescent Diabetes (ISPAD) has 2011 published guidelines with targets for self-monitoring blood glucose (SMBG) levels. These figures are based on clinical studies and expert opinions, as no strict evidence based recommendations are currently available. Summarized, fasting blood glucose levels measured before breakfast should optimally range between 5-8 mmol/l. Furthermore, blood glucose levels should not exceed 14 mmol/l (= hyperglycemia) or fall below 3.9 mmol/l (= hypoglycemia) at any time of the day without appropriate steps of action being taken.

For long-term metabolic control monitoring HbA1c (glycosylated hemoglobin) has been shown to be the most useful measure. It is the only measure for which good data is available in terms of its relationship with later complications (Hanas, John, & on behalf of the International Hb, 2010). It is an excellent indicator for monitoring glycemic control the past 2-3 months. The level of HbA1c in a person with diabetes can range from normal (4-6.4%) to over 15%. Most guidelines suggest a target HbA1c of 6.5-7% for diabetic people, in an ideal situation. However in situations where resources are limited this may be unrealistic. The ISPAD target is < 7.5% for all age groups.

1.1.2.6 *Hyperglycemia and complications*

T1DM is a life-long condition that requires careful monitoring and control. Without proper management prolonged hyperglycemia can result in DKA, which is a life threatening emergency. The first symptoms of DKA develop gradually over period of hours or days. Symptoms include: drowsy feeling, flushed face, thirst, loss of appetite and fruity odor of the breath. Blood and urine tests show high amounts of glucose and ketones. More severe symptoms are heavy breathing and rapid pulse. If untreated, prolonged hyperglycemia and DKA can lead to nausea, vomiting, stomach pain, dehydration, loss of consciousness and death.

Chronically elevated blood sugar levels lead to long-term complications, which include damage of various organs and tissues. One major cause of death for patients with diabetes

is cardiovascular disease, affecting the heart and blood vessels, leading to heart attack or stroke. Kidney disease (diabetic nephropathy) can result in total kidney failure and the need for dialysis or kidney transplant. Nerve disease (diabetic neuropathy) can ultimately lead to ulceration and amputation of toes, feet and lower limbs. Loss of sensation is a particular risk as foot injuries might not be noticed and treated, leading to major infections and amputations. Eye disease (diabetic retinopathy) is characterized by damage to the retina of the eye which can lead to vision loss and total blindness (IDF, 2012).

1.1.2.7 Hypoglycemia and complications

Hypoglycemia (low blood glucose levels) is the most common acute complication of insulin treatment. Blood glucose levels $< 2.5\text{mmol/l}$ are considered too low for normal functioning of the brain. People with diabetes should aim to keep blood glucose levels $> 3.9\text{mmol/l}$.

Clinical symptoms of hyperglycemia are: trembling, rapid heart rate, pounding heart, sweating, pallor, hunger and/or nausea. More severe symptoms include difficulty in concentrating, irritability, blurred or double vision, disturbed color vision, difficulty hearing, slurred speech, tiredness, nightmares, loss of consciousness and seizures.

In cases of hypoglycemia blood glucose levels need to be elevated to a normal level. This is achieved by feeding the child with rapid-acting carbohydrates such as sweetened drinks, fruit juices and glucose-containing sweets (CDiC manual, 2011). Without appropriate steps of action hyperglycemia may have very severe consequences as it can lead to permanent damage and even death (Edge, Ford-Adams, & Dunger, 1999; Rovet & Ehrlich, 1999).

1.1.3 The Republic of Tajikistan

1.1.3.1 Geography and sociodemography

Tajikistan is a landlocked country with a territory of 143 100 km², surrounded by Uzbekistan to the West, Kyrgyzstan to the North, China to the East and Afghanistan to the South. The country is divided into four administrative provinces (Tajik: *Oblast*): Sughd, Khatlon, Region of Republican Subordination and the autonomous Region of Gorno-Badakhshan. These provinces are divided into districts (Tajik: *Raion*) and further subdivided into self-governed units on a village level (Tajik: *Jamoats*). 74% of the population is living in rural areas. This share has increased between 1990 and 2007, contrary to trends in most other developing countries (Khodjamurodov & Rechel, 2010).



Figure 1: Map of Tajikistan, Source: United Nations, 2012

Tajikistan is the poorest country in the WHO European Region and one of the 20 poorest nations in the World (European Union, 2007). This Central Asian country has a population of 6.9 million people where 38.0% are aged 0-15 years (WHO 2012). The population's ethnic background consists of 79.9% Tajiks, 15.3% Uzbeks, 1.1% Russians, 1.1% Kyrgyzs and 2.6% belonging to other nationalities (Khodjamurodov & Rechel, 2010). The main religion is Islam, followed by approximately 90% of the population, most of whom are Sunnis, while

some Pamiri Tajiks belong to the Shia branch of Islam and are followers of the Aga Khan (Khodjamurodov & Rechel, 2010). The literacy rate is 99.7% (>15 years of age) and high compared to other countries with similar levels of economic development (Khodjamurodov & Rechel, 2010).

1.1.3.2 *Economic context*

Tajikistan's gross domestic product (GDP) per capita at purchasing power parity (PPP) is estimated to be 2190 US\$ (IMF, 2010). Despite impressive GDP growth rates in recent years, Tajikistan remains one of the poorest countries (European Union, 2007). There are considerable income inequalities with the highest income quintile receiving 45% of total income and the lowest income quintile receiving only 7%, contributing to the high poverty rates (World Bank, 2007). According to the World Bank 47% of the country's population lived below the national poverty line in 2009 (poverty headcount rate), which was based on estimates from household surveys. Furthermore, 17% of Tajikistan's population was categorized within extreme poverty, defined as average daily consumption of 1.25 US\$ or less (World Bank, 2011). Tajikistan is heavily dependent on remittances, which accounted for 42% of the GDP in 2010 (World Bank, 2011). It is believed that up to two million Tajik citizens are currently working abroad, most of them in the Russian Federation (Khodjamurodov & Rechel, 2010). On the United Nation's Development Programs' (UNDP) Human Development Index (HDI), Tajikistan is with 0.607 ranked 127 out of 187 countries (UNDP, 2011).

1.1.3.3 *Health system in transition*

Historically Tajikistan declared its independence from the Soviet Union on 9 September 1991 and faced severe economic decline and collapse of the social infrastructure due to civil war, which lasted until 1997. Today, Tajikistan has still not fully recovered from the aftermaths of the war. The European Observatory on Health Systems and Policies concluded in its 2010 report that Tajikistan is lacking both human and financial resources, with little capacity to meet the health needs of its population (Khodjamurodov & Rechel, 2010).

The current health system was inherited from the Soviet Union and is described as comprehensive, highly specialized but inefficient due to its focus on curative in-patient care. The state remains the main public funder and provider of health care services, however private out-of-pocket payments are believed to exceed public revenues by far (Khodjamurodov & Rechel, 2010). Furthermore, almost all health professionals are employed by the state. In 2009 the average monthly salary for a medical doctor was 38 US\$ compared with a workforce average of 65 US\$ (Scheider, 2009). Low salaries force health personnel to pursue different strategies for income. This undermines efforts to improve the quality of

service and encourages poverty-driven corruption. In 2007 Tajikistan was ranked 150 out of 157 countries on the Corruption Index of Transparency International (European Union, 2007).

The Tajik health system is now undergoing a complex transition to a new health system, comprising new mechanisms of management, financing and functioning. Decentralization of primary health care services is playing a central role. Further, patient empowerment through health education is an important agent to increase awareness for public health concerns. So far, the population has insufficient access to health-related information and lacks awareness of the causes of ill health, particularly with regard to non-communicable diseases, with unhealthy nutrition contributing substantially to the burden of disease.

1.1.3.4 Health status and expenditure

Life expectancy at birth in years is estimated to be 66/69 for males and females respectively (WHO, 2009). Associated factors for low life expectancy are poor nutrition, polluted water supplies, and an increasing double burden of communicable diseases (malaria, tuberculosis, HIV/AIDS, sexually transmitted disease, typhoid and cholera) and non-communicable diseases (especially cardiovascular diseases). Furthermore, infant and maternal mortality rates are among the highest in the WHO European Region and respiratory as well as acute intestinal infections remain urgent health problems in Tajikistan (WHO, 2009).

WHO estimates show that in 2009 Tajikistan spent a total of 95 US\$ per person at purchasing power parity on health care, equal to 5.3% of the gross domestic product (GDP) (WHO, 2009). Based on these figures, Tajikistan was ranked 158 out of 193 WHO member countries in 2008. The United States were ranked first (7164 US\$, 15% of GDP); while North Korea, Somalia and Zimbabwe were ranked last (numbers not available).

1.1.4 Type 1 diabetes mellitus in Tajikistan

1.1.4.1 Operation Mercy

Operation Mercy is an international, non-governmental organization (NGO) which has been working in Tajikistan since 1993. Today, projects focus on disadvantaged youth, community health, education and income generation initiatives (Operation Mercy, 2012). Work within the field of T1DM started in 2008. The National Republican Endocrinology Center in Dushanbe approached the NGO asking for their assistance to conduct a diabetes camp for children with T1DM. Three diabetes camps were carried out in collaboration the following three years.

1.1.4.2 Known cases of T1DM in Tajikistan

In 2011 Operation Mercy collected data on registered cases of T1DM in Tajikistan. This was assisted by the Republican Endocrinology Center in Dushanbe and numbers were provided to the IDF's *Life for a child programme*. Registered numbers of patients are presented in Table 1.

Registered patients with T1DM in four regions and three age groups.					
Age (years)	Republican Subordination	Khatlon	Sughd	Gorno-Badakhshan	Total cases (age group):
0-14	172	33	67	n.a.	272
15-18	131	31	120	n.a.	282
19-23	152	23	n.a.	n.a.	175
Total cases (location):	455	87	187	n.a.	729
Population (million)	1.6	2.9	2.1	0.2	~ 6.9

Table 1: Epidemiological data collected by Operation Mercy and the Republican Endocrinology Center in 2011 summarizing numbers of patients with T1DM in Tajikistan

The region of The Republican Subordination has with 172 cases of T1DM in the age group 0-14 years the highest number of cases. However it needs to be mentioned that *The First Sawetzki Hospital*, considered as the in-patient hospital with the highest national competency on T1DM and the out-patient *National Republican Endocrinology Centre*, both located in the capital Dushanbe, account for many of the cases as children often are referred to these specialized institutions, especially from the Khatlon Region. This information was provided by endocrinologists, concrete numbers are however not known. Khatlon region, having the highest population with 2.9 million accounts for only 33 known cases of children with T1DM in the age group 0-14 years and Sughd Region, located in the northern part of Tajikistan has 67 cases registered respectively. There is no data available from the autonomous Region of Gorno-Badakhshan.

Epidemiological estimates from the IDF's Diabetes Atlas (5th ed. 2011) state that there are 1.2 new cases of T1DM in children aged 0-14 years per 100.000 every year, representing the lowest number in the WHO European region. In Tajikistan, having a population of 6.9 million where 38% of the population is younger than 15 years this means that there are about 31 new cases of T1DM in this age group every year, requiring life-saving insulin and comprehensive information and education. However, reliable prevalence figures do not exist at the moment and the number of unreported cases might be high.

1.1.4.3 *Personal involvement in diabetes work in Tajikistan*

Operation Mercy and the National Republican Endocrinology Center in Dushanbe organized a diabetes camp for children with T1DM once a year since 2008. The researcher's professional interest and curiosity in learning more about T1DM in a developing country was the reason for getting involved in the diabetes camp 2010. In total 20 children (16 boys and 4 girls) aged 4-17 years from the Region of Republican Subordination and the Khatlon Region attended. The aim was to enable children to meet in a safe environment where they could learn about the disease and how to live with it in a best possible way. Local endocrinologists were in charge of teaching health lessons, whereas Operation Mercy supported with the overall organization and offered fun activities for the children.

The staff was devoted, the reality however unexpected and eye-opening for the researcher. It was observed that there was a severe lack in almost every area possible. Insulin was scarce, glucometers and test strips unavailable or unaffordable in most cases and there was no diabetes education which provided children and families with life-saving information. Children confirmed that they did not have any brochures or books where they could gain understanding of the disease, symptoms of high or low blood sugar, carbohydrate containing foods etc. Furthermore, the only source of information for the attending endocrinologist was an outdated, medical textbook written in Russian. In conclusion, informative, comprehensible and culturally adapted information material for children with T1DM was not available in Tajikistan.

1.2 OBJECTIVES OF THE STUDY

1.2.1 General Objectives

The general objective was to assess perceptions of T1DM and the need for information and education among affected children and their families in Tajikistan.

1.2.2 Specific Objectives

Specific objectives that have been identified were:

- Gain insight on when and how the child was diagnosed/became diabetic and how this was experienced by the child and the parents
- Understand how being diabetic is perceived in their social environment (family, school, community, village)
- Gain insight on what affected children and their families know about T1DM, its etiology, insulin treatment, blood glucose measurements, symptoms of hypo- and hyperglycemia as well as steps of action, diet/nutrition and other illness related factors from a biomedical perspective
- Gain an understanding of challenges affected children and their families may face
- Identify helpful strategies families use to manage with the child's chronic illness
- Explore questions children and their families may have with regard to T1DM and illness-related topics
- Assess what information would be desired and perceived beneficial for diabetic children and the families to face everyday challenges, from their perspective
- Identify if there is information and education material developed for children with T1DM and their families, looking at contents and addressing apparent gaps in the material
- Explore endocrinologists' perceptions on the need for information and education for diabetic children and their families, and explore their ideas on what such materials should contain

2 LITERATURE REVIEW

The purpose of a literature review is to procure relevant literature, critically analyze the content and methods used and discover gaps, which a proposed study intends to shed light on. In this study literature from the field should have addressed childhood onset T1DM and its perception in a developing country context. As there is no published material in this field that originates from developing countries the presented articles that have been selected for the literature review are focusing on perceptions and lived experience of T1DM from the child's and/or the parents view from a developed country perspective.

2.1 LITERATURE SEARCH

Literature research was done by using the internet search engine *PubMed* and *Google Scholar*. As literature was scarce the reference list in these articles was used to find other relevant studies. Additionally the WHO, UN, CDC (Centers for Disease Control and Prevention), IDF (International Diabetes Federation), IIF (International Insulin Foundation) World Bank web sites, the curriculum from the Masters Course and resource persons were used to gain further information on the topic.

The literature review was performed during the planning phase in spring 2011. For up-date a new search was done in January 2012. As literature generally was scarce, different combinations and more general terms were used to find relevant articles. Key words that were used in the search were: perceptions type 1 diabetes, perceptions children diabetes, type 1 diabetes developing countries, lived experience children diabetes, parents' perceptions diabetes, parents living with child having diabetes.

2.2 CRITICAL REVIEW OF EXISTING KNOWLEDGE IN THE FIELD

Conclusions from the literature search were that research and literature relating to childhood diabetes is extensive, however primarily quantitative, medically focused and reflecting concerns about morbidity and mortality in the Western World. Literature on T1DM in developing countries however, is scarce and relies primarily on quantitative estimates.

Qualitative studies looking at perceptions of T1DM in developing countries are to my best knowledge not available and only a few small studies carried out in the United Kingdom, Canada, the United States and Brazil have started to address what it is like for a child and their parents to live with T1DM, using a qualitative approach. These studies are presented below.

Marshall's study *Living with type 1 diabetes: perceptions of children and their parents* (Marshall, Carter, Rose, & Brotherton, 2009) explored and described experiences of children and their parents living with T1DM from diagnosis onwards in the UK. A phenomenological

approach, using individual, conversational interviews with 10 children (aged 4-17 yrs) and their parents, was chosen. Participants originated from different ethnic backgrounds and were interviewed at differing lengths of time since diagnosis (10 months – 8 yrs), enabling maximum variation within the purposive sample. Being 'normal' was identified as being the central theme, underpinned by four subthemes: transition, attachment, loss and meaning. The findings highlighted that, despite different cultures, ages and lengths of time since diagnosis, families living with diabetes shared very similar experiences. This study was, because of its emphasis on different cultural backgrounds, of special interest to the proposed study, even though acknowledging that immigrants might have very different perceptions compared to patients physically living in a developing country. Furthermore, it was the only study looking at both the children's and the parents perspectives. However, a weakness of the study was that children's and parents' data were merged after analysis, and thus the central themes reflect their common perceptions. It would eventually have been valuable to present separate themes for children and parents.

In the following, four relevant studies are presented that focus on either the children's or the parent's perceptions regarding T1DM. Miller and Moreira have explored lived experience of children with T1DM in the UK and Brazil respectively, whereas Hatton and Smaldone are describing parent's perceptions of caring for a child with T1DM in Canada and the USA.

Miller's study *Hearing from children who have diabetes* (Miller, 1999) used a phenomenological approach to explore children's feelings about being diabetic. This methodological approach was seen as most suited, since it stresses the notion, that only those who experience the phenomenon are capable of communicating it to the outside world. In total 8 diabetic children, aged 7-12 years and who were diagnosed 4-10 months ago, participated in an in-depth interview. The conversations with the children were tape-recorded, lasted between 15 and 25 minutes and were held in the child's home. The children were asked to draw a picture of themselves in order to enable them to relax and to provide a focus for the start of the conversation, however it transpired, Miller stated, that the drawings were of limited value as children were keen to express their feelings and asking children about their 'normal day' was seen as particularly useful. Miller concluded that experiences of children aged 7-12 years, who had diabetes, could be clustered into six themes: finding out, daily discipline, being normal, good things, bad things and support. This study provided first insights into perceptions of children. However, the study used a small sample with older children and lacked insights from children which had been diagnosed for more than one year. This was however picked up ten years later in Marshall's study, discussed above.

Moreira's study *Living with diabetes – The experience as it is told by children* (Moreira & Dupas, 2006) aimed to understand the experiences of children living with T1DM in Brazil.

Symbolic interactionism and grounded theory were used as a theoretical and methodological reference framework, respectively. In total 11 children (aged 7-14 yrs) with a duration of disease between 1 and 7 years were recruited through purposive sampling from doctors offices, specialized centre's, the Pediatrics Unit of a mid-sized hospital of a city in the interior of the State of Sao Paulo, as well as snowballing through previous participants. A semi-structured interview was used where the question presented was 'what is it like for you to live with diabetes?' After the initial question, the interview was directed at comprehending the child's experience regarding different topics such as feelings related to discovering that he/she has diabetes, changes after the diagnosis, how such changes were confronted etc. Data was then grouped according to their similarity of meanings and further categorized. The interviews ended when a point of saturation was met and no new experiences emerged. In total seven themes were identified: Experiencing something unexpected, facing a harsh reality, being afraid of what is happening, living under control, trying to adapt to a new reality, maturing with this experience and looking at this illness differently. This study is of particular interest as it is the only study not originating from Western-Europe or North-America. It also has participants at different ages with a variation regarding the duration of the disease. However, from a methodological approach there is little information concerning the actual interview process, it is not clear how the analysis was performed in detail and reflexivity from the researcher is not presented and discussed. Therefore, despite the relevance for the current project the study leaves several uncertainties.

Hatton's phenomenological study *Parents' perceptions of caring for an infant or toddler with diabetes* (Hatton, Canam, Thorne, & Hughes, 1995) highlighted the inordinate stress parents experienced, resulting from factors including the criticality of the condition at diagnosis, the all-pervading nature of diabetes and being expected to manage their child's long-term care. In total 8 two-parent families with an infant or toddler were recruited by theoretical and purposive sampling through a clinic. Children were on average 18 months old and were diagnosed between 5 and 31 weeks prior to the study. A series of 14 in-depth, minimally structured, audio taped interviews of 2-3 hours each within 5 months were conducted with the parents in their homes. Findings revealed three distinct phases in the parents' experiences: the diagnosis and child's hospitalization, adjusting to care at home, and long-term adaptation. Within each of these phases, parents reported distinct stressors, responses and coping strategies. In the diagnosis and hospitalization phase parents talked about their emotional responses such as shock, anger, fear, grief and guilt, but also coping strategies such as being assertive and advocative for the child and learning to rely on the complex treatment, that must be continued, in order for their child to live. In the second phase, adjusting to care at home, themes such as blood sugar level and depression were in focus. Some of the parents even described contemplating suicide during these early weeks

following their child's diagnosis. The long-term adaptations were however more positive. Growing as a family was considered as important, especially when parents saw that their infants grew and developed normally despite their diabetes. The strength and importance of this study was in its comprehensive approach and high amount of information, at the same time reflecting insights, details and depth in the new understanding of parents being in an extremely vulnerable situation.

Smaldone's retrospective study *Perceptions of Parenting Children with Type 1 Diabetes Diagnosed in Early Childhood* (Smaldone & Ritholz), published 2011 was the most recent article addressing perceptions of T1DM in the USA. In total 14 parents of 11 children with T1DM who were diagnosed at age five or younger participated in semi-structured interviews. Purposive sampling was used. Parents were recruited from a diabetes day camp for children as well as through word of mouth from a parent who had participated in the study. Parents were interviewed separately, interviews were audio recorded, transcribed and reviewed in a multidisciplinary team including nurses, psychologists and pediatricians. Further, two parents reviewed the findings. The results were analyzed according to content analysis and dependability of the data interpretation was supported by investigator triangulation. As a result three pertinent themes were identified: diagnostic experiences: frustrations, fears, and doubts; adapting to diabetes and negotiating developmental transitions. The strength of this study was its comprehensiveness, especially in the analysis. Interesting was also that parents seemed to adjust in a similar way by going through different phases, finally leading to a long term adaptation as it was described in Hatton's previously discussed study. However, also this study was carried out in a developed country raising the question about its relevance in a very poor, Central Asian country such as Tajikistan.

2.3 IDENTIFIED GAPS IN THE LITERATURE

There was to the researcher's best knowledge no literature available that addressed *perceptions of T1DM and the need for information and education* in Tajikistan or another developing country context. This demonstrated a clear gap in knowledge. A broader literature search focusing on either *T1DM in developing countries* or *perceptions on T1DM in general* generated few articles. Published articles regarding *T1DM in developing countries* comprised first and foremost epidemiological data, particularly from sub-Saharan African states. No studies from Tajikistan, however a Rapid Assessment Protocol for Insulin Access (RAPIA) from Kyrgyzstan was published by the International Insulin Foundation in 2009, providing data from a neighboring country. Published articles focusing on *perceptions of T1DM* applied primarily a qualitative methodological approach but were based on Western culture and treatment paradigms of developed, industrialized countries. Qualitative research on T1DM in a developing country context was evidently missing.

As this study aimed to describe perceptions of T1DM and the need for information and education among affected families in Tajikistan a quantitative, positivist approach was not suitable in this case since there is no absolute truth to be found when looking at perceptions of T1DM or any other disease. Numbers could neither have described feelings and emotions nor captured lived experience of individuals with different social, cultural and moral backgrounds. Therefore a qualitative methodological approach was chosen to gain insight into the diabetic children's- and their families' situation.

3 RATIONALE OF THE STUDY

T1DM is one of the most common chronic illnesses in childhood. Insulin, its exclusive remedy and lifelong treatment was discovered in 1922 – a biomedical milestone that changed the uniformly fatal disorder to a chronic disease with a potentially long term survival. However in 2012, 90 years later, T1DM is still considered a killer disease in many developing countries where life expectancies after diagnosis in some areas are estimated to be less than one year (Beran et al., 2005).

While international initiatives have focused on the procurement of insulin to developing countries, little attention has been given to develop culturally adapted and life-saving information and education for diabetic children and their families. This is important as patients need comprehensive knowledge on insulin regimens, nutrition and blood glucose monitoring in order to sustain health and normal growth.

This is acknowledged by the International Insulin Foundation (IIF), which has suggested 11 key areas that need to be addressed if diabetes is to be tackled in developing countries: (1) organization of the health system, (2) prevention, (3) data collection, (4) diagnostic tools and infrastructure, (5) drug procurement and supply, (6) accessibility and affordability of medicines and care, (7) training and availability of health-care workers, (8) adherence issues, (9) patient education and empowerment, (10) community involved and diabetes associations and (11) positive policy environment (Beran & Yudkin, 2006). It is stated by the authors that this essential package is to be present in order to create a 'diabetes-friendly' environment. So far the emphasis has very much been on access and affordability, which are important, but cannot be seen as an exclusive solution to the problem. Beran and Yudkin further state that the issue of improving the lives of people with T1DM needs to look beyond this small part in order to create a health system able to manage all aspects of diabetes care. Furthermore it is noted that there is an urgent need for culturally adapted education material, material especially for children and illiterate patients in developing countries (Beran & Yudkin, 2010). One aspect, namely patient education and empowerment were seen as the cornerstone and long-term goal of this proposed study.

There are only few studies that have looked at how it is to live with T1DM in the Western World and no qualitative study has investigated perceptions children and their parents have about T1DM in the context of a developing country. Furthermore, there is no literature revealing that information materials for affected children, if available in developing countries, have been based on a previously performed qualitative study assessing the perceptions and needs of the patients, from their perspective. However, this is a basic requirement in order to

create culturally adapted information and education, enabling and facilitating empowerment of children and parents living with T1DM.

This study is of importance because it looks at the context in which these children live in and what culturally accepted strategies they and their families use to manage their situation. With this background, it could be possible to develop materials and strategies which address their needs, based on their understanding. Furthermore, available information and possibly increased awareness could help to identify more children with T1DM and ensure early identification and treatment of the disease.

4 METHODOLOGY AND RESEARCH DESIGN

The methodology of a study and the methods used within this frame are decided by its purpose. As the aim of this study was to assess perceptions of T1DM and the need for information and education among affected families in Tajikistan, a qualitative methodology approach was considered most suited. In qualitative research the research process is considered as important as the outcome, and the researcher's role is a tool that must be defined and described. Patton (Patton, 2002) suggests the use of 'I' in qualitative research, to communicate the inquirers self-aware role in the inquiry. The researcher's use of 'I' can state and support the subjectivity which follows the nature of a qualitative study.

How the study was planned and carried out will be described in this chapter. An introductory summary abstracts key information of respective sub-chapters, providing a brief overview over methods that were considered in the planning stage and methods that were actually used during data collection and analysis. Detailed descriptions of considerations in the working process are presented on purpose so that the reader may follow the researcher's thoughts and decisions.

4.1 THEORETICAL FRAMEWORK

Summary:

Intended theoretical framework: Holism, phenomenology

Applied theoretical framework: Holism, phenomenology, hermeneutics, constructivism

A theoretical framework can be illustrated with reading glasses that the researcher is wearing when reading the material and identifying patterns. In this way it is an integral part of the research method. A theoretical framework includes models, theories, concepts, definitions and research traditions that are utilized to understand meanings and further help to structure the understanding of the material and the findings (Malterud, 2011).

Further Malterud (2011) describes that a theoretical framework meanwhile often is developed during the course of the research process. In this way practical field work, data collection and analysis are allowed to interplay with prior theoretical positions (Malterud, 2011). This creates a dynamic process with openness to select a framework considered most suitable regarding the study's objectives and the actual material.

In this study I did consider theories at various stages during data collection and analysis. A holistic and inductive research approach, with an interpretative nature was seen as a basic element. Phenomenology inspired me predominantly in the planning stage, whereas hermeneutics broadened the view in the analysis and writing stage of the master thesis.

4.1.1 Theories and qualitative inquiries

This study was carried out with a holistic and inductive approach. Holism describes a person or a phenomenon as a whole, rather than a composition of its part. In this lies a focus on the complex interdependencies and dynamics, making the synthesis something more than just the sum of its parts (Patton, 2002). A holistic approach was intended through all stages of the project, from planning, approaching the field, gathering data, analyzing and presenting the work.

An inductive approach facilitates the necessary flexibility within qualitative research and is highly associated with the interpretivism philosophy. It has no requirement of pre-determined theory to collect data and information, and allows the researcher to provide subjective reasoning with the help of various real life examples (Newman & Benz, 1998). Inductive research means that the understanding will grow from the individual to the collective level. The learning comes through investigating specific cases and, from this, learning about the general (Malterud, 2011). Interpretivists trace their roots back to phenomenology (Schütz, 1967) and hermeneutics (Heidegger, 1962) and acknowledge the importance of the subjective human creation of meaning; however do not reject some notion of objectivity (Crabtree & Miller, 1999). It further stresses pluralism, with focus on the circular dynamic tension of subject and object (Denzin, 1989; Geertz, 1983). In practice an inductive approach was the core of this study whereas an interpretivist focus was a means of processing information, especially during field work. Different views and opinions were accepted as the informants' individual 'truth' and my own role was acknowledged in the process of developing knowledge with the subjects. Further I believe that a certain extent of objectivity was acquired as I thoroughly tried to reflect upon my own personal and professional background at every stage of the study.

Nevertheless, I was also inspired by constructivism, even though to a much lesser extent. Constructivism claims that truth is the result of perspective, meaning that it is relative. The result is that there is no true objective knowledge, as it is co-created with the researcher in every step of the process in developing new knowledge and understanding (Crabtree & Miller, 1999). Thereby, my perspective on the data gathered was constructed with the participants in a particular setting and could be different with another researcher, participants and place.

Throughout the research process different theories and concepts have influenced my thinking and will be mentioned in the following paragraphs. Reviewing existing literature in the field, the majority of articles applied a phenomenological approach to assess how children with T1DM and their parents experienced life with this chronic disease. This

encouraged the set up of the current study. Phenomenology seeks to understand the lived experience of individuals and their intentions within their 'life world' and was first introduced by the German philosopher Edmund H. Husserl (1859-1938). Phenomenology aims to search for the very nature and essence of a phenomenon. It provides answers to questions such as 'What is it like to have ea certain experience?' 'What is the essence of the lived experience of this phenomenon for this person or group of people?' To accomplish this, investigators must consciously lay aside their own preconceptions, enter into the individual's life world, and use the self as an experiencing interpreter (Crabtree & Miller, 1999). In relation to this study, I did not aim to conduct a study based purely on phenomenological philosophy, but rather to employ a general phenomenological perspective to elucidate the importance of using methods that capture children's and parents experience living with T1DM in Tajikistan.

Throughout the process of analyzing the data and studying different theoretical concepts, hermeneutics became increasingly important. Hermeneutics is a movement beyond phenomenology. The goal of hermeneutic research is to use the interpretation of lived experience to better understand the political, historical and socio-cultural context in which it occurs (Crabtree & Miller, 1999). Rundell also refers to hermeneutics as the 'critical theory of interpretation', that focuses on meanings and interpretation (Rundell in Beilharz, 1991). Hermeneutics originated in the interpretation of Biblical texts and developed for social science by philosophers such as Heidegger, Gadamer and Ricoeur. In modern usage, hermeneutics offers a perspective for interpreting legends, stories, and other texts (Patton, 2002). To make sense of and interpret a text, it is important to know what the author wanted to communicate, to understand intended meanings, and to place documents in a historical and cultural context (Palmer 1969). The implication with hermeneutical analysis is that there is never any truth independent of interpretation. Every researcher brings assumptions, a tradition of understanding to their research. These assumptions shape how the research is conducted, what is done, and what is found. In this study the importance of a hermeneutical perspective increased especially after having conducted field work, realizing that it was too ambitious to capture 'the essence' of how it is to live with diabetes in Tajikistan in three months only and without being able to communicate in their native language. As phenomenology focuses on the detail of everyday life, or the 'life-world', hermeneutics, on the other hand, takes a broader view, with a fuller analysis of both the past and the future, and broader cultural factors (Rundell in Beilharz, 1991). It was considered to be important for the understanding overall, not to limit myself to the families' description of their lived experience only. Talking with doctors and learning about the social and historical context from key informants enabled me to understand how it is to live with T1DM in Tajikistan from different angles. Therefore hermeneutics became increasingly important.

Data was analyzed according to Malterud's systematic text condensation method (Malterud, 2011). Malterud refers to Giorgi's phenomenological analysis in four steps: 1) getting a total impression, 2) identifying meaning units, 3) abstracting the contents of individual meaning units and 4) summarizing their importance. Malterud modifies Giorgi's first step. She begins the analyzing process with getting an overview over the transcribed material in its entirety by reading it without marking any details. This aims to get a picture of what the data contains as a whole. In this process she also emphasizes the importance of identifying the researcher's preconceptions and personal involvement. By starting with an intentional overview over the material, the researcher either receives a general outline for the rest of the work, a knob to hang further understanding on, or he or she gets all preconceptions and prejudices confirmed from the beginning on. In this case it is seen as difficult to work with an open mind further in the analysis process (Malterud, 2011). Knowing my limited experience as a qualitative researcher I considered Malterud's modification as especially helpful because it helped me to elucidate my own preconceptions and prejudices before continuing with further steps in analysis.

4.1.2 Professional standpoint

My professional background as a clinical dietitian/nutritionist and diabetes counselor in Western Europe has further shaped my thinking and reasoning throughout the research process. This will be elaborated on in the chapter 4.8 Reflexivity.

4.2 STUDY LOCATION

Summary:

<i>Intended study locations:</i>	Region of Republican Subordination and Khatlon Region
<i>Actual study locations:</i>	<i>Region of Republican Subordination:</i> Dushanbe, Hisor, Tusunzoda; <i>Khatlon Region:</i> Uyali, Qurghonteppa, Kolkhozobod, Faisabad; <i>Sughd Region:</i> Khujand

Field work took place in Tajikistan. The head office of Operation Mercy was located in the capital Dushanbe and functioned as the central location for coordinating the research project

Based on communication with Operation Mercy staff prior to fieldwork, families were planned to be recruited mainly from to the Central and South-Western parts of Tajikistan, namely the *Region of Republican Subordination* and *Khatlon*, as this was considered to be the most feasible. In total 11 children and adolescents with T1DM were interviewed in the cities Dushanbe, Hisor and Tursunzoda which belong to the *Region of Republican Subordination*.

In *Khatlon Region* five families were visited in Uyali, Qurghonteppa, Kolkhozobod and Faisabad. The different locations are indicated with red stars on the map in figure 2.

While being in Tajikistan opportunities emerged to conduct interviews in the northern *Sughd Region*. After I had been in contact with Operation Mercy staff in Khujand, it seemed feasible to conduct 2-3 interviews in this city as some connections had been established with the Endocrinology Center during the previous year. Parents had initiated a diabetes camp in 2010 and the Endocrinology center supported this event. Operation Mercy contributed as they donated glucometers and test strips to the children who attended the camp. I visited Khujand in November and carried out two interviews with families in the city itself.

Due to the geographical location, with mountain peaks over 7000m above sea level, the autonomous region *Gorno-Badakhshan* was considered difficult to access. However, after having been in Tajikistan for one month I wanted to explore possibilities to get access to this region, especially after having learned more about the history of the country and the period of the civil war where *Gorno-Badakhshan* was isolated from the rest of the country. I was interested to find out whether families living with T1DM in this remote area, living under extreme conditions, having a different culture and language, would have different perceptions about T1DM and the need for information and education. Connections were made with the NGO's team working in Khorugh to discuss options to conduct interviews in the region (indicated with a blue star on the map in figure 2). I planned to visit for one week in November in order to explore the area around Khorugh and to see if I could talk to any patients with T1DM. However, too many constraints emerged, so that it was not possible to follow through with my plan. One problem was that winter started earlier than normal. The safer mountain road was closed, leaving the only other option to travel in a taxi along the Afghan border, which was considered unsafe for a foreigner with very limited skills in Tajik language. Alternatively a small airplane could be taken; however it would not have been possible to book a return flight from Dushanbe as these airplanes fly on a very irregular basis, depending on weather conditions, availability of fuel and enough passengers. The second major hindrance was that I would have to apply for a separate visa for *Gorno-Badakhshan*, requiring leaving my passport at the registration office, with uncertain return-date. As I however needed the passport to travel to Khujand by plane, time constraints were setting the final limitation to follow through with the plan to visit Khorugh.

Similarly to Khorugh I also had to cancel the plan to travel to Panjakent, due to the early winter outbreak in November (location indicated with a blue star on the map in figure 2). Contacts were available to me both through the NGO but also through a local worker who originated from that city, so that it would have been possible to interview some families in

Panjakent. However, the roads were not safe and inaccessible in some areas, so I chose not to pursue this plan. Also, considering time and budget limitations, this was not a main priority.

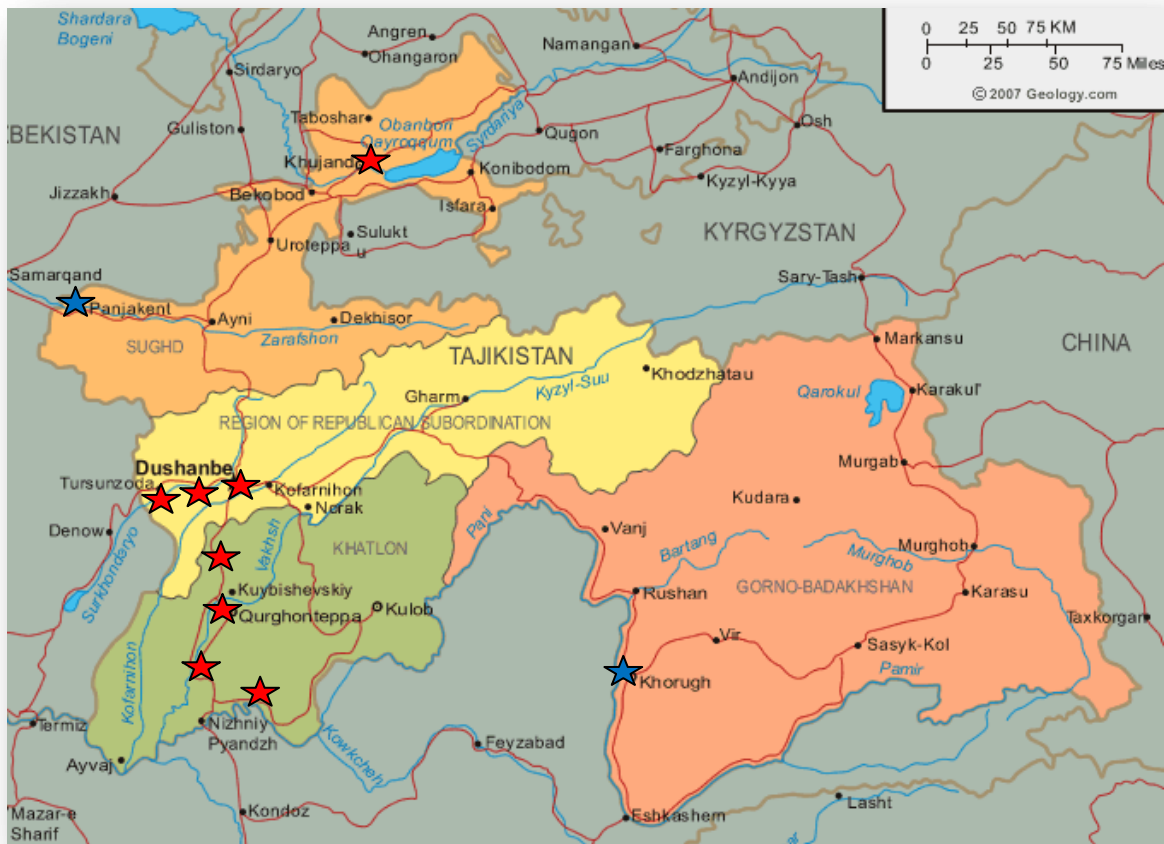


Figure 2: Map of Tajikistan indicating study locations.

Red stars indicating actual study locations: Dushanbe, Hisor, Tursunzoda (Region of Republican Subordination), Uyali, Qurghonteppa, Kolkhozobod and Faisabad (Khatlon), Khujand (Sughd). Blue stars indicating planned study locations after entering the field that were inaccessible: Khorugh (Gorno-Badakhshan) and Panjakent (Sughd).

Individual interviews with doctors were anticipated to be conducted in the Dushanbe region only, as not many contacts were established before entering the field. Parallel to options that emerged regarding interview locations with families, it also developed with medical doctors. Finally, two interviews were carried out in Dushanbe, one being a pediatric endocrinologist at one of the main inpatient hospitals in the capital, the other being a medical doctor and professor at the Medical Faculty at the University in Dushanbe. In addition, one endocrinologist from the endocrinological centers in Khujand and Qurghonteppa, located in *Sughd*- and *Khatlon Region* respectively, were interviewed.

Further, informal conversations and descriptive observations were carried out wherever possible and appropriate.

4.3 STUDY POPULATION

Summary:

Intended study population: Children and adolescents with T1DM, parents, endocrinologists

Actual study population: Children, adolescents and young adults with T1DM, parents, endocrinologists

4.3.1 Children with T1DM and their families

The central study population included children and adolescents with T1DM and their parents, as they were the ones experiencing firsthand how it is to be diabetic or taking care of a diabetic child. Furthermore it was important to hear from the families how they perceived the need for information and education, whether they would see this as something helpful or not and if so, what they would like to know and learn more about based on their own culture and biomedical understanding.

4.3.2 Medical doctors

Additionally endocrinologists were interviewed. The aim was to explore perceptions of medical doctors on the need for information and education for diabetic children and their families. Furthermore, the objective was to hear their ideas and suggestions if information- and education material would have been developed in the future.

4.3.3 Resource personnel

Informal conversations with resource personnel were further seen as a way to identify initiatives that have been undertaken to address diabetes and more specifically T1DM in Tajikistan. Such informants were mainly employees from international NGO's other than Operation Mercy.

Furthermore, contact with international experts in the field of T1DM in developing countries, were used before, throughout and after the fieldwork. Especially Graham Ogle from the IDF's *Life for a Child Programme (LFCP)* and David Beran from the *International Insulin Foundation (IIF)* have contributed with valuable insights and comments.

Two specific people have been a special resource in Tajikistan. One was an employee from Operation Mercy, who worked in the diabetes project in Dushanbe. She possessed experience working with T1DM in Tajikistan, had broad cultural understanding and spoke Tajik fluently. Furthermore, my research assistant has contributed extensively to the understanding as she added insights on cultural aspects and explanations that were

emerging in the course of the work with both families and medical personnel and that could not have been understood by the researcher alone.

4.4 STUDY SAMPLING

Summary:

Intended sample: 10 children (7-18 yrs), their parents, endocrinologists

Actual sample: 13 children (7-18 yrs), 2 children (<7 yrs), 3 young adults (18-23 yrs), their parents, 4 endocrinologists

Sampling strategies: Purposive sampling, snowball sampling

A purposive sample of 10 diabetic children, aged 7-18 years, and their parents was considered reasonable based on background knowledge from previous studies performed in the Western World (Marshall et al., 2009; Miller, 1999) and also being realistic about the limited timeframe for fieldwork in Tajikistan. This number expanded to 18 families originating from three different regions in Tajikistan, with the age variety being 3-23 years. Children below 7 years of age (2 cases) and young adults above age 18 years (3 cases) were included as it was thought to help broadening the understanding of how it is to live with T1DM in Tajikistan. The majority of participants were aged 12- 16 years (10 cases). An overview over characteristics of the diabetic children is provided in APPENDIX IV.

4.4.1 Sampling process

Purposive sampling and snowball method were used to recruit participants. As initially planned, recruitment through the NGO and the National Endocrinology Centre were important measures, even though the National Endocrinology Center was not used as extensively, since new contacts were provided through previous participants.

After arriving in Tajikistan in September, I tried to establish contact with a previous participant of the diabetes camp in 2010. She became the first respondent and connected me further with a medical student having T1DM herself. Through snowballing further, she introduced me to a professor at the Medical Faculty at the University of Dushanbe, who was leading a diabetes club predominantly for people with type 2 diabetes (T2DM). The medical student also provided contact information to an experienced endocrinologist from Dushanbe's main in-patient hospital for pediatric endocrinology. Parallel to this, the NGO provided a list with diabetic children and adolescents that had been in contact with them previously, either through participation in a camp or receiving test strips for their glucometer. Four new participants were added through this revenue.

On October 17th a diabetes day was organized in Qurghonteppa, the capital city of Khatlon region. This was initiated by Operation Mercy and the Endocrinology Center in Qurghonteppa as it had not been possible to arrange a diabetes camp in 2011 due to the severe lack of insulin in the country. Operation Mercy helped to connect with the IDF's *Life for a child programme* in order to procure life-saving insulin, which finally arrived July 2011. As insulin was available, it was possible to arrange a diabetes day. This event facilitated a natural platform to get in contact with families from the Khatlon region. Therefore, after the official program my research assistant presented the research project and asked if there were some families that would be interested in participating. Many families were interested, and during the week in Qurghonteppa five more interviews with families and one interview with an endocrinologist were added. Families were interviewed in their homes, the endocrinologist was visited at the endocrinology center.

As this proved to be a good sampling method, it was repeated when there was another diabetes day arranged by Operation Mercy in Dushanbe on November 3rd. After discussions with my research assistant, the sampling strategy was seen as positive because the families would get to know me beforehand and trust could be built. Further I could make sure nobody felt obliged to participate as the announcement was given and people could decide themselves whether they wanted to approach me or my research assistant or not. However, this sampling strategy had its limitations. First, certain families attended the diabetes day and second, the sampling was based on these families. Families which could not afford to travel to the city or were living in remote areas that were too far away were eventually not reached using the diabetes day as a platform to recruit participants. Finally, in total six families were willing to participate and arrangements were made to visit them the following weeks.

Further I was invited to participate in the International Diabetes Day on November 14th at the First Sawetzki Hospital, the main in-patient pediatric endocrinology hospital in Dushanbe. After the official event I was approached by several families asking me to come and visit them as they had heard about the project from other families that had participated previously. However, due to time constraints I decided not to focus on more interviews from the Dushanbe region but prioritized interviews in districts, such as Tursunzoda.

After having been in contact with Operation Mercy staff in Khujand in October, it was communicated that it would be possible to interview 2-3 families while visiting for four days in November. In the sampling process this was the only time where a doctor purposively selected participants for my interviews, however there were no differences in the families' answers.

4.4.2 Criteria for sampling

4.4.2.1 Prioritizing remote areas

Besides the actual sampling strategy, I had previous thoughts about the composition of the sample. In order to attain a realistic understanding of Tajik families living with a diabetic child, participants from rural areas were planned to be prioritized. This was based on my understanding from statistical data showing that 74% of the population lived in rural areas (Khodjamurodov & Rechel, 2010). Further it was thought that the availability of medical services and accessibility to food would be more challenging in rural areas. In total eight families from Dushanbe and surrounding areas, six families from other towns, and four families from rural, remote villages were interviewed.

The doctors were all affiliated to specialized centers in the capital or other bigger cities. I was interested in the endocrinologists perceptions of T1DM and the need for information and education for affected families. With this objective, I considered endocrinologists in specialized centers to be most suitable as they worked with diabetic children on a daily basis.

4.4.2.2 Representation of different regions in Tajikistan

After having started field work in Tajikistan, it seemed increasingly important to recruit families from all four regions. Especially after I had repeatedly heard local people comment that the northern part around Khujand was said to be more intellectual and educated, whereas the southern areas in Khatlon, bordering Afghanistan were seen as less developed and educated, I was interested to see whether this would be reflected in interviews with families and doctors. Measures were taken to achieve this, however, as pointed out earlier in the chapter some areas were difficult to access, especially the autonomous region or Gorno-Badakhshan. As a result, two families and one doctor from Sughd Region were interviewed, five families and one doctor from Khatlon Region and 11 families and two doctors from the Central Republican Subordination were visited.

4.4.2.3 Duration of disease

Further the lengths of time since diagnosis was thought to eventually have an influence on the families' perceptions on T1DM and the need for information and education. This was the result of previous literature research, where key articles revealed that families eventually adapted to the new situation after an initial state of shock, anger and fear (Hatton et al., 1995; Moreira & Dupas, 2006; Smaldone & Ritholz). I had originally intended to select five families, having a child with newly diagnosed T1DM, that was defined as 0-2 years and five families with a child that had been diabetic for more than two years. In reality there was a variety from 20 days since diagnosis up to 14 years, being the maximum. Four children and

adolescents had lived with diabetes for two years, 11 families for three years and more and three families reported that their child got diagnosed less than a year ago.

4.4.2.4 *Participation in a previous diabetes camp*

It was previously discussed with my supervisor whether families, where the child had participated in a diabetes camp, should be excluded from the study. They would possibly know me and my professional background but also have more biomedical knowledge about T1DM. Thereby they would eventually not represent the majority of patients and the suggestions they would have regarding information material would possibly be influenced by what they had been taught at the camp. However, after discussions and personal reflections I decided not to have it as an exclusion criteria. This was based on the following reasoning. First, I had only participated in one diabetes camp where I taught one lecture about nutrition. Secondly, I considered it to be helpful to know some children as a certain trust would have been established already. The result was that six out of 18 families had a child that had been to the diabetes camp before, of which 4 had been to the camp in 2010 and thereby knew me.

4.5 TIMEFRAME

Summary:

Timeframe fieldwork: September – December 2011

Timeframe data collection: September 14th 2011 – November 18th 2011

The study was conducted within the timeframe of the Master in Philosophy degree in International Community Health at the University of Oslo (UiO). April 2011 an abstract was submitted followed by an oral literature presentation on the current status of knowledge within the field of interest. It was applied for ethical clearance through the Regional Ethical Committee (REK) in Norway May 10th 2011. A reply was received June 24th 2011 concluding that the research project was outside of the remit of the Act on Medical and Health Research and therefore could be implemented without the approval from the Regional Committee for Medical Research Ethics in Norway. In Tajikistan, an equivalent ethics committee did currently not exist. The two most important research institutions were the Tajik Medical University and the Tajik Institute for Postgraduate Education (Khodjamurodov & Rechel, 2010). Therefore the National Republican Endocrinology Center and the Medical University was informed. The head of the National Republican Endocrinology Center affirmed their support orally, when the project was presented by the researcher September 14th 2011. Furthermore the project was registered with the Public Foundation 'Panorama' (registered in the Ministry of Justice). This foundation intends to create a database on all past and planned

research projects in Tajikistan in the period of January 1st 2009 to January 1st 2013 and was launched within the framework of the World Bank.

Field work in Tajikistan took place September – December 2011. The reason for commencing the study in September was due to the fact that Ramadan was taking place in August. Conducting a research project related to nutrition was obviously inappropriate. A preliminary action plan was provided to the NGO in Tajikistan before entering the field, to ensure enough time was calculated. In reality the actual timeframe of three full months in Tajikistan was sufficient. A detailed overview over how time was distributed can be seen in APPENDIX I. Interviews were carried out from September 21st – November 18th 2011.

4.6 DATA COLLECTION METHODS

Summary:

Intended data collection methods: Participant observation, in-depth interviews

Applied data collection methods: Observation (descriptive and focused), in-depth interviews, focus group discussion

In-depth interviews and focused observation were the main methods used to collect data with families in their homes. Furthermore, interviews with endocrinologists presented different angles regarding how it is to live with T1DM in Tajikistan. Additionally, descriptive observations from three diabetes days and one focus group discussion were used to broaden the understanding. Informal conversations were used extensively. They helped to provide insights about culture, norms and traditions and were of great beneficence in the interview settings.

These methods had been selected because they were considered most suited when exploring lived experience of T1DM and the perceived need for information and education in Tajikistan. Further the selection had been inspired by other similar studies performed in the Western World that had been critically reviewed beforehand (L. Lowes, Lyne, & Gregory, 2004; Marshall et al., 2009; Miller, 1999; Moreira & Dupas, 2006).

4.6.1 Descriptive observation and informal conversations

The term *descriptive observation* was invented by Spradley (Spradley, 1980) and denotes one of three 'types' of observation. These are: descriptive-, focused- and selective observation. Descriptive observations are explained to occur early in the study and are classified the least systematic. They are guided by the general question, '*What is going on here?*' where every attempt is made to observe as much as possible (Crabtree & Miller, 1999).

The first two weeks were used to explore the new culture, meeting with the research assistant and organizing the first interviews. Being especially sensible for visual impressions, sounds and smells in the beginning when entering a new culture, this was made use of by writing down observations in a diary and discussing them with a co-worker in the NGO who had lived in Tajikistan for five years and was familiar with the local language and the culture. When starting to work with my research assistant I also explored and discussed observations that I had made with her to gain a broader understanding of the culture in general from a local Tajik. Observations were made especially about general everyday life such as how people related to each other, how different age-groups or people of opposite sex interacted, how people were dressed, how public transport was used, how sellers and buyers interacted at the local markets, how they related to me as a foreigner and also how I was expected to interact in social settings such as being invited for dinner to a neighbor.

Further it was used to gain insight into aspects of the health system, especially by observing public hospitals when visiting a friend's relative or when I was invited to the First Sawetzki Hospital in Dushanbe to participate in the International Diabetes Day on November 14th 2011. Descriptive observation was also used at two different diabetes days for children with T1DM and their families in Qurghonteppa and Dushanbe. Further I joined a few visits to the Ministry of Health, which again added new insights.

4.6.2 Methods used with children

In-depth interviews supported by focused observations were the most helpful methods that were used to assess children's perceptions of T1DM and the need for information and education material.

4.6.2.1 Setting the scene

The children were all visited in their homes, as it facilitated a relaxed and natural environment, creating safety for the child, where he/she was familiar with the surroundings and customs. It was generally perceived that this generated a comfortable atmosphere both for the participants but also for me as the researcher to ask questions about their daily life.

In most cases the families were visited during a working day. The time depended upon whether the children had to go to school in the morning or in the afternoon, which could be different depending on the child's age and the school itself. My research assistant always called beforehand informing them one more time that we were planning to come and to ask which public transportation we could take, to reach to their home, in the cases where the interviews were in Dushanbe and surroundings. I wanted to demonstrate that I tried to adjust to the culture as much as possible even though using public transport was more time

consuming and less convenient, than taking a taxi. Another way I tried to adjust to the culture was by wearing local clothes, and if perceived necessary in the villages I intended to cover my hair. My impression was that this was seen as positive even though I was hesitant in the beginning whether this would make me 'stand out' even more. I generally received positive comments. Further elaborations on how I tried to access the new culture are given in chapter *4.8 Reflexivity*.

Almost exclusively I and my research assistant were warmly welcomed and often I sensed that it was seen as a special day for the diabetic child, having someone explicitly visiting them. Often the mothers had prepared food and after we greeted and did the first small talk, they guided us into the room where guests were received. Usually one room in the apartment or house was decorated and cleaned in such a way that guests could be received at any time of the day. As I knew basic phrases and sentences in Tajik, which I had learned with my language helper, I tried my best to use them. This helped to break down the barrier in many cases, equalizing the power balance in the relationship between the informants and me as the researcher.

Further I was very intentional where I would seat myself around the table placed on the floor. I knew that the seats, farthest away from the door, opposite of the table was reserved for the most honored guest. I was usually requested to sit in this particular spot unless the mother in law or another older lady was present. However, whenever possible I tried to place myself on one of the sides, trying to demonstrate clearly that I was humble, however without offending the hosts by sitting next to the door, which would be the considered as the lowest rank. My research assistant was generally sitting next to me, so that I could place the recorder between us being visible but not intrusive.

Before starting the official interview my research assistant always explained the project one more time to make sure the participants had understood what they would consent to. After the families gave oral consent and agreed to be recorded I started the interview by asking about how it all started. Focused observation was generally used within the interview setting.

4.6.2.2 Focused observation

The term focused observation is described by Spradley (Spradley, 1980) and represents the second of three types of observation (descriptive, focused, selective) that were described earlier. They can be compared with a funnel, where descriptive observation is the broadest level. Focused observation is more selective than descriptive observation but more general than selective observation. By definition it represents choices the researcher has made to filter out areas of interest and what has been learned from being in the setting.

Prior to field work participant observation was considered the main method besides in-depth interviews. These methods were seen as the most valuable and feasible to construct data together with the children about how it is to live with T1DM. The reason why participant observation had been selected in particular was based on the following reasoning. It was thought to be essential to engage with children as their language and capability to express their thoughts and feelings might not be fully developed. Furthermore it was considered as helpful to construct data with shy and introverted children. It was planned to spend two half days with each family in order to establish trust and confidence and take part in their everyday life. However, due to several reasons participant observations was changed to focused observation.

4.6.2.3 *The need to change to focused observation*

I experienced that it was challenging to carry out participant observation to the extent desired, so that I felt the need to change the approach to focused observation. One reason was that most families were extremely hospitable and in many cases had prepared food, so that we would sit on traditional cushions on the floor around a square-shaped tablecloth that was filled with the best dishes they had to offer. Therefore, it became the natural place to construct data, sitting eating together and talking. This however narrowed down my options to actively participate in the observation. Another limitation with using participant observation was that I was not able to communicate with the children in their native language, which took away some of the dynamics that the method could have generated. I could for instance not start doing something actively to get the child involved before the research assistant had translated what I was about to do.

After trying out different approaches and repeatedly seeing that the interview setting was similar in most cases, I decided to use what was available more actively rather than pursuing participant observation. As the setting was not entirely new for me anymore I felt that descriptive observation according to Spradley (1980) was too broad, whereas selective observation was too narrow as every family was different and the interview setting was varying. This led me to the decision to use focused observation, where I wanted to gain a deeper understanding about the relationship between the parent and the diabetic child but also about food choices. Conversations were held sitting around a table. This led to questions about what he or she would usually eat, pointing out what was considered 'good' or 'bad' foods for diabetes. Then I could explore their reasoning and rationality. It was seen as especially insightful listening to what they considered to be good or bad foods and then observing to what extent they followed their own recommendations.

4.6.2.4 *In-depth interviews*

Liamputtong and Ezzy (2005) describe a good interview as follows: *'A good interview is like a good conversation. Good conversation is a two-way affair. One person talks, while the other listens, responds and encourages. In a good interview, the person who does most of the talking is the interviewee. While the interviewer asks questions and may talk a little about themselves, most of the time the interviewer listens, and the focus of the observation is the experience of the interviewee'* (Liamputtong & Ezzy, 2005). Based on the described nature of in-depth interviews the aim of using this method was to shed light on how it is to live with T1DM in Tajikistan. Furthermore, it was assumed to be a helpful method to gain insight into present biomedical knowledge on T1DM, insulin treatment, nutrition and other disease related factors.

There is no general recipe on how to conduct a good in-depth interview, however there are some useful skills and practical guidelines that the researcher could have in mind (Kvale & Brinkmann, 2009). A practical approach that was applied in this setting was to identify general topics that were wished to be addressed during the interview. A thematic guide was constructed. Further, possible questions that could be utilized were formulated. The original thematic guide that was used during field work is provided in APPENDIX II. In general I wanted to explore three areas:

1. The story of how the child became diabetic (when and how did the child become diabetic and how was this experienced)
2. How it is to live with T1DM in Tajikistan
3. What would they want to know more about regarding T1DM and about how to live with this chronic illness? What are suggestions they would have for other families with a diabetic child?

This provided a guideline for me as the interviewer but left the required flexibility in a qualitative method to change direction of the dialogue, or explore a certain area more than others, if this was considered as helpful. This is also pointed out by Anderson and Goolishian who argue that understanding is best gained through *'questions born of a genuine curiosity for that which is 'not-known' about that which has just been said'* (H. Anderson, Goolishian, & Hopstadius, 1992). Mostly I started a conversation with asking about their story of becoming diabetic as it was personal and enabled me to connect with the child before I started to explore into different directions. Their story also always generated new questions that I was interested in learning more about and could be brought up at a later stage of the interview. During the first interviews I asked if they could tell me about how it was when they became sick. Getting to know more about Tajik culture and the importance of storytelling and the

richness in poetry I rephrased the question asking about their story, as I thought this would suit better. This was received very well and transpired to be a door opener for a good interview. Also it is more objective and neutral, not using the word 'sick' generally having a negative connotation.

Furthermore, probing was used extensively in the interview. *'A probe is a follow-up question that aims to elicit information to fill in the blanks in a participant's first response to a question'* (Liamputtong & Ezzy, 2005). Rubin and Rubin propose six different types of probes: elaboration (ask more detail), continuation (encourages talking), clarification (resolves confusions), attention (interviewer shows attention), completion (encourages participant finishing a thought) and evidence probes (asks how sure participant is of his/her interpretation) (Rubin & Rubin, 1995).

I planned to interview children individually, providing space and using methods such as drawing and storytelling that would make it natural for them 'to tell how it really is to be diabetic'. I thought that this would show them respect as being experts about their disease, feelings and experiences. Furthermore, as described by Miller, an individual conversation was thought to enable me as the researcher to accommodate the specific needs of the child, as they were at different stages of their development (Miller, 1999). In-depth interviews were therefore tried to match the child's cognitive level by using additional prompts, changes in pacing, using child-oriented language and adapting the question style as indicated previously (Marshall et al., 2009).

Reality demonstrated that my highly organized and well thought through approach had to be adjusted to the actual setting. As described earlier, I was an anticipated guest that was interested in the family and their child with T1DM. As many conversations revolved around sharing a meal together it quickly became evident that interviewing the child by itself would be ideal but not feasible, unless I wanted to offend the parents. Also, being sick was in general much less of a private matter in Tajik culture compared to my own culture. Therefore, sometimes a sister, an uncle or a grandmother was present during the interview. In such a case I decided not to exclude the family member but viewed him or her as a resource to get a different perspective. I did know however, that this decision could affect the desired depth in the conversations with the child.

Interviews lasted from 30 minutes up to two hours and were all tape-recorded after explaining the study thoroughly and asking for oral consent as well as for permission to record the interviews. After the interview, I and my research assistant spent some time with the children making sure they felt comfortable with what they had said.

4.6.2.5 *Drawing*

Drawing is considered an important and child-friendly method to elicit children's everyday experiences. It can facilitate as an icebreaker or a warm-up activity to build trust and to create a common focus. Further it can help quiet and shy children to feel more comfortable and engaged with a research situation as it provides time to reflect on the topic or question, not being pushed to give an immediate answer. Therefore, drawing becomes a means through which the child can communicate experiences which are too complex to describe verbally, but which are being perceived and integrated into a child's organization or reality (McNiff, 1982). Drawings are seen especially valuable when combined with additional explanations and interpretation provided by children as '*art throws off the covers that hide the expressiveness of experienced things*' described by Dewey (Dewey, 2005).

In practice, I thought that drawings could be helpful in the beginning of the interview asking the child to draw a picture of him- or herself with 'their diabetes' or ask if the child could draw some good and bad things with having diabetes. As explained previously the interview often started with gathering around a meal, therefore it was not seen as a natural setting to use drawing at that point. However, as I knew from previous camps the children loved to color, I prepared some printouts with different motives that I brought along and used when it was perceived appropriate. This was used mostly in the beginning of fieldwork, however I felt that it became too much of a distraction causing the mothers to talk more and the children to talk less. This method was therefore used to a very limited extent.

Not trying to neglect the method entirely, it was tried out in a focus group discussion, where children painted what they considered to be good and bad foods for diabetes. This will be elaborated further under point 4.6.2.7 *Focus group discussion*.

4.6.2.6 *Storytelling*

Every story a child tells contributes to a self-portrait – a portrait that others can use to develop an understanding of the storyteller. Each time children describe an experience about them or someone else, they construct part of their past, adding to their sense of who they are and conveying that sense to others (Engel, 1995).

Storytelling is another unique method to engage with children and facilitate an environment where they can share their feelings about how it is to be diabetic. Children tend to have a very limited vocabulary to express their feelings (sad, cross, not fair, bored, happy, scared) (Sunderland, 2000), and still they feel a hundred other feelings that are not included in this list. With such a restricted verbal vocabulary, they tend to select a feeling word that may seem like the feeling they are having, but which in reality might be quite another one.

Therefore, it is extremely important to engage with the children with empathy, trying to live oneself into the language the child is familiar and comfortable with, namely stories. *'The right language of expression frees the child. The wrong language imprisons him'* (Sunderland, 2000). Without having access to imaginative modes of expression, the deeply rich inner world of the child may remain unshared. If a child tells a story, he/she can express many different feelings and meanings about an experience, in this case being diabetic, and captures a fuller picture of the child's perceptual reality (Sunderland, 2000).

In practice, storytelling similar to drawing was used to a much lesser extent than planned. In a broader sense the method was used, the first question intentionally being 'what is your story?' The answer was however a description of actual incidents and not a fictive story with an underlying message. In one interview one participant shared a poem that she had composed, talking about how it is to live with diabetes.

4.6.2.7 *Focus group discussion*

Focus group discussion is a particular method using group discussion as platform to gain new knowledge and understanding. Typically a facilitator leads the group through topics of questions of interest and the participants express their views via discussing the issue in a group (Liamputtong & Ezzy, 2005). Another definition is given by Khan and Manderson (1992) who describe focus group discussion as a qualitative research method *'with the primary aim of describing and understanding perceptions, interpretations, and beliefs of a selected population to gain understanding of a particular issue from the perspective of the group's participants'* (Khan & Manderson, 1992).

Based on this understanding one focus group discussion was conducted in connection with the diabetes day that was carried out in Qurghonteppa in October. This method was initially not planned to be used but the opportunity presented itself and was considered of value as several children from the district would be gathered in one place. Furthermore I wanted to explore more with regards to what they thought about diet and good food choices. This was an area that I wanted to learn more about. Both the attending medical personnel and the children and parents were informed and agreed to have a focus group discussion at the end of the program of the diabetes day. My personal involvement prior to the focus group discussion was limited to descriptive observation.

In total 16 children and adolescents were present with a variety in age from 6 years up to 18 years. The topic of discussion was 'food choices'. Krueger and Casey recommend six to ten participants as an ideal group size (Krueger & Casey, 2000). As the group was too large for a focus group discussion, the children were divided into two groups, one being asked to draw considered 'good foods' for diabetes and the other group drawing perceived 'bad foods' for

diabetes. After 10 minutes of drawing activity the groups were asked to present and comment on each other's choices, trying to facilitate a discussion. The children were however tired, the temperature was about 30° Celsius and the only room available was dark, had an extremely low ceiling and only very few small windows, so that an intended group discussion ended as a group interview, where only limited new knowledge was gained. After 10 minutes I personally decided to set an end to the focus group discussion as I felt it was unethical to keep the children just to get some data.

4.6.3 Methods used with parents

In order to generate an understanding of the parent's perceptions about T1DM and their need for information and education the main methods were considered to be focused observation and in-depth interviews in the families' homes.

In the majority of the interviews only the mother was present. The reason for this was generally that the husband was working, in many cases in Russia, where he could be staying several months at the time. The mothers were welcoming and friendly, in some cases skeptical and in other cases they showed emotions.

4.6.3.1 Focused observation

I planned participant observation to be a main method to be used with parents. The focus was thought to be centered on buying food from the local market and thereby getting into discussion about what they usually would eat and why they would do so. Furthermore I considered the option to help the mother preparing a meal. I could actively have helped to prepare the food, observing and asking the mother about how she prepared food, and if she did it differently for the child with diabetes.

Participant observation was difficult to carry out in reality. The mothers usually had prepared food before I visited them and also I was unsure about whether it would be appropriate and polite to follow the mother into the kitchen after only a few minutes with them, knowing that it is important to them to welcome guests into their nicest room. Therefore I decided to replace participant observation with focused observation. In combination with in-depth interviews this was used extensively and generated important information about the relationship between the mother and the child as well as their food habits. As I was working with a research assistant that translated the interviews, I intentionally used the time where they were talking to observe and discreetly capture impressions and notes in a small notebook that I had with me at all times.

4.6.3.2 *In-depth interviews*

The interviews were generally carried out according to the description given in chapter 4.6.2 *Methods used with children*, as in-depth interviews with parents and children were conducted together. The thematic guide was used as explained previously.

Generally mothers were very talkative, willing to share about life with their child's illness. It sometimes seemed that talking and verbalizing emotions and thoughts for them was experienced as helpful, especially when someone was genuinely interested. Their willingness to talk was of course appreciated, however after the first interviews I needed to evaluate the situation thoroughly to make sure the child received 'enough space' and options to talk about his/her experience. Especially when children became diabetic at a young age it was natural for them to ask their mother to tell the story, as they did not remember the details themselves.

Further, mothers were often much occupied with getting a cure, leading me into the pitfall wanting to teach- rather than listening to them. As I got more experienced with the interviews, I learned how to answer or not answer certain questions. This is further discussed in chapter 4.8 *Reflexivity* and chapter 5 *Ethical Considerations*.

It was obvious that the parents deeply cared about their child. Many showed emotions and started to cry during the course of the interview. Others reacted more neutral. For the interview setting it meant that I was able to connect with the parents on a deeper level, as it felt natural for me to show that I was affected when they told me about situations that had been difficult, or how much compassion they have for their child. Throughout the course of the fieldwork I learned more about how to react in such, for me, challenging situations. For instance I intentionally let there be silence when the parents were crying, not trying to respond quickly with the first, not well resonated comment that came into my mind. Words are powerful tools and once they are released there is no possible way to erase what I had said. Therefore I learned that to be present but quiet demonstrated respect that could not have been achieved through words.

After sharing and talking about emotions, I intentionally moved the conversation up some levels, meaning I steered the conversation into a less emotional topic, eventually something more practical. This was done out of two reasons. First I considered it as important to continue with the interview in a way that would not give the participants the impression that I was only interested dwelling in their sorrow, but that I was interested in learning as much as possible about all facets of their everyday life. The second and even more important consideration was that the child was present.

Parents themselves were hesitant when talking about their child and showing their own emotions. In many interviews the child left the room at some point. This gave the parent a unique opportunity to condense what she thought was most important in two minutes, something that she maybe had held back previously during the interview because she did not want to tell this in the presence of the child. Had interviews been performed individually from the start, this information would maybe not have been revealed. As I realized the importance of these moments and the depth they opened, I was especially aware of these situations and what the mothers would share.

4.6.4 *Interviews with endocrinologists*

In total four endocrinologists from different geographical areas and institutions were interviewed. Interviews were conducted in the respective hospitals and lasted 30 minutes – 1 hour. Topics that I wanted to explore in the interviews were similar to the topics that the families were asked about, however different angles were explored as the participants all were endocrinologists, currently working in the field of diabetes. The original thematic guide is provided in APPENDIX III.

4.7 RESEARCH ASSISTANT AND TRANSLATOR

Summary:

Female research assistant: Assisted with planning and carrying out 16 interviews with families and 3 interviews with endocrinologists in the Central Republican Subordination and Khatlon Region

Female translator: Translated 2 interviews with families and 1 interview with an endocrinologist in Khujand (Sughd Region)

As I did not speak Tajik there was an obvious need for a translator or a research assistant. I needed help with both translating the interviews but also contacting and organizing meetings with participants. Therefore I preferred to hire one research assistant for the duration of field work, and that she would be compensated for an approximate 50% position, funded through my research budget. I also hoped and anticipated that working with only one person would facilitate a closer cooperation, which again could have a positive effect, when discussing and interpreting the results gained through the interviews.

4.7.1 *Finding and working with a research assistant*

As I had been in contact with Operation Mercy throughout my planning process, they assisted me with finding a research assistant. My requirements were that it should be a

woman, that she would speak both Tajik and English fluently and that she would have good skills when interacting with children. A female research assistant was preferred out of several reasons. First, it was considered more culturally appropriate, since a close working relationship between opposite sex's might be perceived as improper and would shed a negative light on my personality, which again would influence trust and openness in the interviews with participants. On the other hand, I was not sure to what extent Tajik women would work outside of their home. This was therefore discussed with the staff from the NGO supporting my choice for a female research assistant. Another reason for prioritizing a female research assistant was that it was thought that women, often being mothers themselves, would connect with children more easily than men, especially in a gender divided society. In Tajikistan women are usually the ones taking care of the house and the children, while men are employed outside the home or even work as labor workers in Russia for extended periods of time. Therefore it was seen as especially important to connect well with women and the children.

Operation Mercy provided me with the contact information of a possible research assistant after arriving in Tajikistan. We arranged two initial meetings to get to know each other and for me to decide whether she would be a suitable candidate. In the first meeting I introduced her to the research topic and her possible role. I provided her with a copy of my research protocol and asked her for comments and feedback regarding the cultural appropriateness. She had valuable insights, spoke English fluently and we connected very well on a personal level. Therefore I decided to work with her.

The research assistant did not have a medical background; however she had been involved in work affiliated to another NGO before, working on topics like HIV prevention in the southern part of Tajikistan, being considered the most conservative religious area in the country. Thereby she had some background knowledge on health issues and practical experience in communicating sensitive topics. However, as her mother was a general practitioner I could sense that her comments after the interview sometimes could be influenced by her own preconceptions. This was noticed especially when talking about adherence to treatment. When talking to her I understood that she was aware of her preconceptions and I did not notice that it had any influence on the interviews.

I decided our first interview to be with a girl that I got to know through the diabetes camp. As it would be the first interview for both of us I considered it to be helpful to conduct an interview with a girl I had known from the last year. Trust would more likely be present and this was thought to facilitate a more relaxed atmosphere. In all the interviews she small talked with the families when we arrived, inviting trust and confidence. Also, I observed that her interaction with the mothers was natural, open, relaxed and friendly, giving me the

impression that she was accepted by them, even though she was dressed as a professional with a black skirt and a blouse.

The interviews were conducted in a way where the research assistant translated my questions and then translated to me what the participant had said before I posed the next question. As we got to know each other better and as she also was familiar with the thematic guide and what questions I was interested in, she had the freedom to elaborate or probe if she perceived there was a need for further exploration. After every interview we talked and reflected upon what has been experienced, heard and seen to enhance internal validity. I did intentionally ask the research assistant about her thoughts first to make sure her perception was not influenced by my comments. Further it was also seen as helpful to verbalize feelings and impressions, especially after having carried out emotionally challenging interviews.

Interviews were conducted mostly in Tajik, but also in Russian and Uzbek when needed. As I got to know in the field, medical professionals that were trained during the Soviet times often still preferred to speak Russian, especially when medical terms were needed. Also 15.3% of Tajikistan's population originates from Uzbekistan (Khodjamurodov & Rechel, 2010). Therefore Uzbek was the preferred language in some rural areas in the South and the West of the country. My research assistant spoke Tajik and Russian fluently, according to her own opinion, and could communicate well in Uzbek as her mother was from Uzbekistan originally.

In general, having a research assistant has added more to the work than it has set limitations. She contributed with insights and comments. This enriched the data and provided important information that otherwise would have been missed, as I was not familiar with their way of thinking. The limitation is that situations of probing have been missed out and 'reading between the lines' was only possible based on what the research assistant had translated.

4.7.2 Translator in Khujand

As I travelled to Khujand in November, my research assistant did not have the chance to join as she had a one-year old son. Therefore I used a translator for the three interviews that were conducted there. Staff from Operation Mercy in Khujand recommended me a young student with good English skills. We connected well, but I felt her age was to some extent a limitation to connect with the families. This was demonstrated through clothing, but also the fact that she was a student, unmarried and not having children, which limited how much she could identify herself with the families or their situation. She did not have any prior knowledge about T1DM but was generally interested and invited trust and confidence. The disadvantage was that she sometimes got so consumed that she only translated a summary of what the participants had said. Therefore the interview setting was in general more challenging.

4.8 REFLEXIVITY

The researcher's background and position affects what he or she chooses to investigate, from which angle the investigation was approached, which methods were considered most suitable, which findings were seen as most appropriate and how conclusions were framed and communicated (Malterud, 2001). Therefore, a qualitative researcher needs to be capable to grasp his or her own role in the research process as well as considering its consequences for the findings, interpretations, and conclusions (Crabtree & Miller, 1999). This process of constant and conscious evaluation is referred to as reflexivity. It starts by identifying preconceptions that have been brought into the project by the researcher, such as previous personal and professional experiences, pre-study beliefs about how things are and what is to be investigated, motivation and qualifications for exploration of the field, and perspectives and theoretical foundations related to education and interests (Malterud, 2001). The aim of reflexivity is to create transparency for the reader to follow the researcher's thinking and reasoning (Sandelowski, 1986).

4.8.1 *Preconceptions and prejudices*

My education and work experience has influenced my thinking and reasoning prior-, during- and after the fieldwork in Tajikistan. My educational background is in nutrition, having studied and graduated in Germany. After graduation I have worked as a registered dietitian in a hospital in Germany, where I further acquired the certificate for diabetes counseling, authorized by the German Diabetes Association. Part of my work was to teach, train and empower newly diagnosed patients with diabetes, so they could handle their disease in everyday life with confidence and know-how. Having broad knowledge about treatment of diabetes in a Western World context led me regularly into the pitfall to confuse my role as a researcher with my earlier role as diabetes counselor. This became evident in the way I would ask leading questions about their situation from a biomedical perspective such as insulin treatment or blood glucose measurements. Sometimes this was surely appropriate, but often it was done without being aware of my own reason for asking. This tendency I could see again when transcribing the interviews. I jumped sometimes too fast from one biomedical topic to another rather than exploring or probing further, in hindsight thinking to myself '*why did I not ask more about that?*'

A second challenge, in my dual role as a professional in the field that I was conducting research in, was the question about how much I would allow myself to be a source of information for the families. In one of the first interviews the mother of a participant was a doctor. They had an internet connection at home and access to more information than the average patient. It felt as I was the one who was interviewed by the mother during the one hour interview. She viewed me as a resource person and took the opportunity to gain

answers to things that she was wondering about. As a researcher I learned an important lesson in this interview. I needed to find an ethically sound way to answer their questions, but not becoming their diabetes counselor. After reflecting and discussing the situation with my research assistant, I told her that she could tell about my previous participation in the diabetes camp but not emphasize my professional background and working experience. Furthermore I decided for myself that I would answer question that I was directly asked about but not offer information voluntarily. These decisions improved the interview setting and information was exchanged in a natural way. Therefore I followed my strategy, of course being open for exceptions when I felt it was needed. When a child did not know that drinking lemonade or juice would elevate their blood sugar, it would have been ethically wrong not to explain that this was almost the same as giving an intravenous glucose infusion. When such information was given, families showed appreciation and this further strengthened trust.

Connected to my last point was also a prejudice that I became conscious of while doing research. Summer 2010, about one year before I commenced fieldwork, I attended the diabetes camp, conducted by Operation Mercy and the Republican Endocrinology Center in Dushanbe. At that point I was working clinically with diabetes patients in Germany and wanted to attend the camp in Tajikistan out of my own interest. The contrasts could not have been bigger. The first impression of the diabetic children's situation was shocking and eye opening. Insulin was accessible, but not on an uninterrupted basis and information was not available at all. As I knew from my own practical experience training and information is extremely important. I felt distressed knowing that I had biomedical knowledge they did not have. Additionally I felt guilty because I was not in a position to share biomedical knowledge with them working as a researcher. At first, it was difficult to handle because I did not have any experience with shifting my dual role as a diabetes counselor and researcher. Having received insight into how they live with T1DM, what they struggle with and what questions they have, I offered some information at the end, which I considered to be valuable for them from the standpoint of a diabetes counselor. Thereby I consciously shifted my role. In several cases I explained the child and the parent how to use the glucometer or summed up what was good to eat, based on the foods we had talked about previously. Thereby I did not confuse my role but offered some information at the end, stepping out of my role as a researcher. This was appreciated very much by the families and helped me to use my bad consciousness in a constructive way.

In general, as I got more experienced in conducting interviews I became more aware of my own way of thinking and reasoning. Therefore I increasingly tried to doubt impressions and conclusions I had made, questioning whether this really was what was communicated. In this process discussions with my research assistant were of great importance and benefit.

4.8.2 Cultural barriers and opportunities

Being a foreign researcher working in a very different culture compared to my own presented both challenges and opportunities. In the following sub-chapters I will explain how these challenges and opportunities were experienced, reflected- and acted upon and how they influenced my findings.

4.8.2.1 Accessing a new culture

When entering the field I had limited experience concerning Tajik culture and no prior experience with qualitative research. Therefore my cultural understanding and skills developed while being in the field. I was eager to learn about the country and tried to find ways to gain access to the new culture in an intentional but natural way.

As I had lived in different countries before, my experience was that language and the willingness to learn were the most important determinants to whether I was invited into the scene behind the curtain. Therefore I was determined to learn some Tajik, even though knowing that what I would learn within three months would be very limited. A young woman, barely speaking English was willing to teach me Tajik once or twice a week. I learned and practiced basic words and simple conversations. My personal aim was to be able to introduce myself, saying something about my family, telling how old I was, that I was married for five years and that I did not have any children. From my previous visit in 2010 I learned through key informants that these questions would be of interest to the families. I also aspired to be able to briefly tell what my project was about, which I managed more or less towards the end of my field work. One way I broke the ice was by applying my almost non-existent and broken Tajik language skills. Trust was built, as I was not firm and formal, but was able to laugh about myself. This was especially helpful when meeting the families the first time. It created a shift in power positions, demonstrating that they were the experts and I was not. It was an intentional decision to use this approach consistently, even though it required me to step out of my comfort zone many times. But, it seemed to be successful and as I noticed the positive effect of it, I continued to talk Tajik. My personal impression was further that the willingness to learn Tajik rather than Russian, often being the preferred language of educated people in Tajikistan, was acknowledged positively and many parents smiled with a surprised and puzzled look on their face.

The main religion in Tajikistan is Islam, followed by approximately 90% of the population (Khodjamurodov & Rechel, 2010). As part of their religious and cultural heritage, hospitality was valued highly. I was often invited and treated as a special guest. This was experienced as a benefit. The advantage was that I gained access to locals, learning how to interact, how to greet, how to small talk, where to sit in a formal setting etc. Further I was able to practice

my language skills. Therefore I valued the hospitality of friends and acquaintances and tried to learn as much as I could while being in the field, instead of being busy working on my computer. Experiencing the culture from the inside rather than looking at it from the outside helped me to understand and interpret observations and comments from the interviews with the families.

Initially I was unsure about how I as a foreigner would be perceived by both the families and the doctors. Being in Tajikistan I experienced it as a benefit in certain areas. The fact that I was an outsider to their cultural norms allowed me to ask simple and eventually 'stupid' questions. They were the experts and could teach me how life in Tajikistan was like. As I however was aware of also, I could miss important points since I was dependent on my translator. I tried to be especially aware with my other senses, mainly observing the facial expressions of the respondent. Thereby I tried to critically review what was translated to me to see whether it made sense according to how I had observed their behavior. I am however aware that body language to a large extent depends on the respective culture and its traditions, and that facial expressions and body language could have been misinterpreted during the interviews.

Further I thought it might be challenging to be a female researcher in a Muslim culture. By observing the culture and talking to different people I learned that many women had high positions. This was inherited from the former Soviet system. Many mothers in the urban areas worked outside of their home. In the villages I was told that it would be more conservative. Asking other people with cultural insight about what to wear and whether I should cover my hair or not, helped me to find a solution that I felt comfortable representing. I chose to always wear Tajik clothing when conducting interviews as most women were wearing traditional clothes. This helped me to fit more into the culture. The families generally made positive comments, so that I felt that my clothing was appropriate. I was told that people living in the South were more conservative Muslims than in the Central part and in the North. Therefore I was advised to cover my hair and I thought I would not have any problem doing so. Being in the situation however it seemed hypocritical to me only to cover my hair when conducting the interview, so I dismissed my initial plan. I did not experience any negative consequences and families did not behave differently. However, due to the limiting language skills and possible misinterpretations of body language I might have interpreted the situation wrong.

4.8.2.2 *Being from a rich country with comprehensive treatment options*

It was at times challenging during the interviews to face the reality that treatment options and care are more advanced in a biomedical sense in my country of origin. Children rarely end up

in a diabetic coma and certainly have not experienced all possible long-term consequences including stroke at the age of 18.

Even though they knew I was from a presumably rich country, I was never directly asked for money during an interview, so that I did not perceive it to be a big problem compared to other countries that I have travelled and worked in. However, a few times I noticed that my research assistant commented in Tajik that I did not have any money and as I understood these words I do think in hindsight, that my research assistant probably sometimes answered the question for me. What was asked about more often was however how diabetic children would be treated in Norway, jokingly saying about their son or daughter '*he/she wants to come with you*'. Some parents were desperately looking for a cure and thought in Norway everything would be different. I knew that it would, however, not because there is a different treatment but because there is a more comprehensive support system for families with a diabetic child. During the first interviews I explained that insulin is the exclusive remedy and that the only difference was that children in Norway would receive a different kind of insulin. Thereafter many questions aroused, asking about the difference, whether it was superior to theirs and if they could buy it in Tajikistan as well. I therefore decided after the first four interviews not to mention details about the other types of insulin that are used in Norway. Explaining differences of various types of insulin would only make sense if the participant had prior biomedical knowledge about the mechanism action of insulin and how it affected the blood sugar. Explaining that children in Norway needed daily injections of insulin also, was accepted and the conversation could then focus on an area that was different, namely that comprehensive information and education is available in Norway. Children and families could then be asked about their impression of whether information was needed and if so, what they would like to know more about.

4.8.2.3 Taking on responsibility for the child during the interview

A cultural challenge that was experienced concerned interviews where mothers were very engaged and talkative. I paid much attention to what was, according to my ethical standards, justifiable talking about during the interview, when the diabetic child was present. For instance I perceived it to be wrong to discuss treatment costs when the child was present as I was afraid to place an additional emotional burden on the child, anticipating that he or she maybe would feel guilty for the family's financial problems. However, there might be a chance that I acted overprotective, assuming that I knew more about what the child would be capable of hearing and bearing, than the mother knew. Maybe I should have let the mothers decide what was right and what was not, especially as I did not know the culture very well and did not know how much the child knew about these aspects, or how much he/she was usually involved in discussions about e.g. costs of treatment. As I reflected upon this

situation I came to the conclusion that it was right to take responsibility in the interview situation. I did not want to jeopardize the child's emotional well-being, and I could possibly have done so if I had let the mothers talk about their worries and concerns. Also, after only a few interviews I realized that children struggled emotionally. This factor was the most prominent in my decision to rather risk the chance to appear overprotective than to cause any additional harm to the child. Practically, I tried to steer the conversation in a different direction or towards a more superficial and practical level, when I was concerned about a certain topic, and felt that it was experienced as a natural part of the interview and that mothers did not seem to feel offended.

4.8.2.4 *Reactions to hospitality, poverty and corruption*

One particular challenge that I experienced when entering the new culture was related to their hospitality. It was very difficult for me to accept and appreciate their generosity, not thinking '*how will they survive the next weeks, having spent so much money only because of my visit*'. This burdened me often. Poverty was less visible compared to other parts of the World where I had travelled to before, in a sense that families had small, simple houses or apartments which were very clean and tidy. However not having water and electricity might not be a vast challenge in countries where the climate is warm throughout the year; however it was very difficult in Tajikistan where temperatures during the winter months reach -10° down to -20° Celsius. It was challenging as I met poverty in a way that I had not seen it before. The hidden, subtle poverty that was not visible judging from the first impression became more and more evident the longer I was in Tajikistan. As an incentive I provided some coloring materials for the child, a glucometer or test strips, depending on whether they had a glucometer already. I did consider bringing some food also, showing my appreciation for their hospitality. Taking into consideration though that glucometers and test strips were very expensive in Tajikistan, I thought it would become too much. The gift was well received, and parents were especially thankful if I took some time after the interview to explain to them how they had to use the glucometer.

A definite challenge was when I realized how endemic out of pocket payments were within the health care system and the effects it had on the families having a child with T1DM. They had to decide carefully whether they would take their child to a hospital or not, never knowing how much the cost would be at the end. This made me angry and frustrated, realizing that the problem was rooted much deeper than just providing insulin and information. This was a challenge especially when meeting doctors. As I was very conscious about being objective and non-judgmental in all interviews, my decision was not to confront doctors with this issue. The interviews with the four endocrinologists were generally friendly and informative, but I did not gain any information about their standpoint regarding out of pocket payments. A second

reason why I was cautious addressing this topic was that I wanted to protect the families' anonymity. Many of the diabetic children were patients in the respective institutions where the doctors worked at. However, I wanted to understand the underlying reason as I did not perceive the doctors I met to be cruel and selfish people. Reading literature and talking to key informants I realized that doctors had extremely low salaries. In 2009 the average monthly salary for a medical doctor was 38 US\$ compared with a workforce average of 65 US\$ (Scheider, 2009). This explained to me to some extent the 'need' for out of pocket payments from their patients.

4.8.2.5 *Being affiliated with Operation Mercy*

Operation Mercy has assisted with diabetes camps since 2008 and further helped with insulin provision earlier in 2011, when there was a severe insulin shortage in Tajikistan. Many of the families were therefore familiar with the NGO or members of the staff. Due to their help in a severe crisis the NGO was perceived positively both by the families and the doctors who were very thankful for their assistance. Operation Mercy staff assisted me as door openers and provided initial contacts. Since the NGO was well liked, this might have influenced how I was perceived by the families also. Therefore I paid attention that participants were not only recruited through them. After initial interviews with families, participants were preferably enrolled through snowballing method from various sources, to depend less on contacts from the NGO only.

My colleague who coordinated the diabetes project in Operation Mercy in Dushanbe had a vital influence on my experience in Tajikistan. She helped me to get as much authentic adventures throughout my field work as possible. This contributed vastly to my cultural understanding and maturation as a researcher. There was surely also a certain pitfall in interacting closely with a colleague that worked within the diabetes project. Her experiences and views did influence my thinking, especially in the beginning of the research, when I was not as familiar with the actual circumstances yet. I tried to find a balance by actively processing and reflecting about experiences and observations on my own first, so that I had views that were clearly defined by what I had experienced. Thereby I thought to be less susceptible to other opinions, keeping my professional distance to the field and rather acknowledging her thoughts and insights as valuable information from a key informant. I further discussed most of the findings and experiences with my research assistant, providing a counterbalance to both my perceptions and the ones of my colleague.

The research assistant was affiliated with Operation Mercy through previous projects, did at the time when the study was commenced however not work for the NGO. The possible

influence of the research assistant's background and preconceptions were acknowledged and reflected upon in chapter 4.7 *Research assistant and translator*.

4.9 DATA ANALYSIS

Summary:

Data analysis: Systematic text condensation according to Malterud

Software: Nvivo9 data analysis program

4.9.1 Management of the data

All interviews with families were tape-recorded and immediately transferred to my personal laptop. The laptop was secured with a password and encrypted in addition. The computer was kept in my suitcase, which was locked in my room. Before starting the analysis, names were replaced with abbreviations. Since both the diabetic child/adolescent and the parents were present during interviews, the quotations were later on referred to as 'Diabetic child number 1 to 18' (D1-18), 'Mother of the diabetic child number 1 to 18' (M1-18), 'Father of the diabetic child number 1 to 18' (F-18) and 'Relative of the diabetic child number 1 to 18' (R1-18). A personal notebook with observations and comments as well as coded material, were kept at a secure place.

The endocrinologists were purposely sampled according to their positions in key hospitals and endocrinology centers. Due to the small sample of specialists in the country full anonymity was neither possible nor targeted. After transferring interviews to the laptop their actual names were replaced with 'Doctor number 1 to 4' (DO1-4).

The focus group discussion was tape-recorded with permission of the participants and transferred to my personal laptop. Drawings children provided during the focus group discussion were kept with their permission and observations were noted in a personal notebook.

Descriptive observations from three diabetes days (Qurghonteppa October 17th; Dushanbe November 2nd; First Sawetzki Hospital, Dushanbe November 14th) were captured in a personal notebook.

4.9.2 Transcription

Interviews with families and doctors were tape-recorded. Transcription of the material was performed by myself as soon as possible after the interviews. Due to limited time in Tajikistan it was only possible to transcribe a few interviews in the field, especially since the average recording time was one to two hours. The majority was transcribed as soon as I returned to

Norway, during December 2011. However, for every interview two documents were created, one being the verbatim transcript of the interview, the second one being a document where I noted general impression about the interview, questions that came up, thoughts that I wanted to explore, how consent was gained for the interview and the recording, specific observations that I had made and what we talked about before and after the interview. This second document was created immediately after every interview to enable me to remember the setting and atmosphere when transcription would be done some weeks later.

Thorough reflection after the first four interviews, transcribed in the field, allowed evaluating the thematic guide and rephrasing questions such as asking about 'their story' rather than 'how was it when you became sick'. Further, new themes such as emotional stress being perceived as a cause of diabetes and economic challenges with insulin procurement, were explored further.

Back-translation of the interviews to Tajik was not possible due to time constraints and the research assistant's limited access to computer and internet. However, through thorough discussions with my research assistant after every interview, possible misunderstandings were identified. Also, as she translated what I had said and then translated the participant's response before I would probe or ask another question, I recorded both my questions and the corresponding answer which made the transcription process uncomplicated.

Interviews with doctors were transcribed verbatim. One interview was transcribed while being in Tajikistan; three were transcribed in Norway December 2011. A second document was created and included impressions, observations and thoughts. This was done immediately after every interview.

The focus group discussion was transcribed verbatim by me, based on the tape-recorded material. Descriptive observations from three diabetes days were transferred from the notebook into a word-document.

4.9.3 Steps of analysis

Data was analyzed according to Malterud's systematic text condensation method (Malterud 2011) referred to in chapter 4.1 *Theoretical framework*. Accordingly four steps of analysis were followed: 1) getting a total impression, 2) identifying meaning units, 3) abstracting the contents of individual meaning units and 4) summarizing their importance. Malterud modifies Giorgi's first step and suggests beginning the analysis with acquiring an overview over the transcribed material in its entirety by reading it without highlighting any details.

Due to the time limitations the focus needed to be narrow enough to be comprehensible in the scope of the Master in Philosophy program. Systematic text condensation was used to

analyze all data material; however the themes emerging from the interviews with the families were determining the findings, as the focal point of the study was to shed light on their perceptions and experiences of living with T1DM. Interviews with four medical doctors, observations at three diabetes days and one focus group discussion were included primarily to triangulate or to emphasize different angles to the perceptions of the families.

As transcription had not been completed before returning to Norway, the first step, getting an overview over the material by reading through the transcribed information in its entirety, was done in Norway. I perceived this as positive, as I could relate to the material in a new way, providing enough personal distance to the participants and the material. This enabled me to work with an open mind and I identified new aspects which I had not thought about in the field. I further used my own field notes and diary to identify preconceptions and prejudices throughout the entire analysis process but especially in the initial step of analysis where I wanted to get an overview of the material as a whole. This helped to 'bracket' my own involvement before continuing with further steps of analysis.

In the second step, meaning units from the interviews were identified. These segments and phrases were then subsequently grouped under different themes, forming descriptive and meaningful clusters. Coding and grouping was assisted by the software Nvivo9, which helped to organize and systematize the data material. Throughout the second step visual illustrations with comments and arrows helped to structure and crystallize core themes.

Throughout the third step, contents of individual meaning units were summarized, each having several sub-themes. Finally, meaning and essence of the coded material was synthesized in the fourth step.

4.10 DISCUSSION OF METHODOLOGY

Karp writes in Grey et al. (2007) *'The ultimate test of a study's worth is that the findings ring true to people and let them see things in new ways'* (Gray, 2007). In order to be able to meet this goal the researcher needs to evaluate and discuss how he or she has reached to his or her findings and how the choice of methods have affected the findings that were gathered. In this process validity and reliability play a central role. Kvale sais *'to validate is to question'* (Kvale & Brinkmann, 2009). In all research we should ask ourselves whether the selected methods have been relevant to acquire knowledge that highlight our objectives (Malterud, 2011). If we have failed to choose appropriate methodological paths, findings from our material will not generate valid answers. In other words, validity and reliability state something about how trustworthy and useful our findings are. As validity and reliability derive from experimental and quantitative research, trustworthiness or rigor are sometimes preferred terms in qualitative research (Liamputtong & Ezzy, 2005).

Maxwell emphasizes in Miles and Huberman (1994) that there are no defined measures or perfect decision-making rules to establish validity of qualitative research. They do however point out strategies that can be helpful. These are: checking for representativeness and for researcher effects, triangulating, weighing the evidence, checking the meaning of outliers, using extreme cases, following up on surprises, looking for negative evidence, making if-then tests, ruling out unauthentic relations, replicating a finding, checking out opposite explanations, and getting feedback from informants (Miles & Huberman, 1994).

This study provided information about perceptions and experiences from different persons who were affected by- or treated patients with a particular chronic illness. The data presented and discussed was based on the objectives from one perspective primarily, namely the diabetic children and their families. However, triangulation with information from endocrinologists, one focus group discussion, discussions with key informants and resource personnel provided important information and added to the validity, in the sense of a broader understanding. As the analysis and discussion focused on the diabetic children and their parents' perspective through their own experiences, the knowledge gained more depth and became more nuanced.

The findings from this study are from a small sample and during a specific time. Different sampling methods (purposive sampling and snowball sampling) and clearly defined sampling criteria were used to enroll participants. Sampling criteria were: focusing on remote areas, including different regions of Tajikistan, selecting children with various duration of disease and limiting participants who had prior experience from a diabetes camp.

Even though findings from qualitative research cannot be generalized, the variation of study locations, including eight cities and villages in three out of four regions in Tajikistan enabled a broader understanding of diabetic children and their families' experiences. This study can thereby say something about what was common among these families, living with the illness in various parts of the country. Furthermore, also different settings were used to collect data, namely families' homes and diabetes days.

In qualitative research, the process is considered equally important as the outcome (Patton, 2002). In this study, all steps of action were thoroughly described in the methods chapter, demonstrating transparency and allowing the reader to follow the researcher's reasoning and rationality whenever changes and adjustments were considered necessary. The validity was also strengthened through triangulating data, which was gained by using different methods. These were: in-depth interviews, descriptive- and focused observation and focus group discussion.

As part of the qualitative nature of the study, the sample included only few participants. Thereby, certain subjectivity of the data was implied, as the experience of truth is individual and a subjective. Clear descriptions of the participants' experiences and views are given in the findings- and discussion chapter. As the subjectivity of the researcher inevitably led to interpretation of the material, discussion of reflexivity, including the researcher's preconceptions and prejudices, was essential to validate the data.

One research assistant translated nearly all interviews, increasing the internal validity of the study. Furthermore, it was considered important to limit the influence the researcher's and the research assistant's preconceptions. Therefore, the interviews and the interview guide were discussed and evaluated consistently. This allowed new themes and questions to be included, as they emerged during the interviews. Thereby the views and experiences of the participants were central and the data collection process was dynamic. Further, seemingly obvious answers were not taken for granted but doubted, probed, questioned and reaffirmed, trying to leave as few opportunities for the researcher to interpret, what was said by the families, as possible.

The findings of this study are primarily valid for the participants in this study. However, as the context, the research setting, methods used and the study population were described in detail, some extent of transferability might be possible to other similar settings. More specifically, some findings might be transferable or relevant to diabetic children in other parts of Tajikistan, and possibly to other developing countries. As the International Insulin Foundation has conducted a Rapid Assessment Protocol of Insulin Access in the neighboring country Kyrgyzstan (Abdraimova & Beran, 2009), some findings might be of interest and value.

4.10.1 Strengths of the study

- No information was available stating that this or a similar study, assessing perceptions of T1DM and the need for information and education among affected families, was performed in Tajikistan or any other developing country before. Therefore the knowledge that was gained through this study will possibly contribute to new knowledge in the field of T1DM.
- The triangulation of data collection methods (interviews with diabetic children and their families, interviews with doctors, observations at three different diabetes days, one focus group discussion) presented different perspectives and provided comprehensive descriptions of how it is to live with T1DM in Tajikistan.

- The variety in the characteristics of the participants having T1DM (age 3-23 years, duration disease 20days – 14 years, different socio-economic classes) covered the diversity of conditions.
- Interviews with families and endocrinologists from different cities and villages showed that perceptions and experiences were common in various parts of the country.
- All interviews were performed in close collaboration with a local research assistant and transcribed by the researcher herself. This maintained closeness to the field and increased internal validity.
- Having a competent and locally known research assistant increased the quality of the interviews as new insights were added. Further she participated in discussions regarding the appropriateness of questions asked, which allowed adjusting the questions based on what was learned in the first interviews. As she was from the area where research was conducted, she could introduce the researcher to the families in a professional and culturally appropriate manner.
- As the researcher was from a different culture, this provided a potential neutral arena for the families to voice their experiences and what was important to them, without being judged. This resulted in thick descriptions about their lived experience with T1DM.
- The biomedical knowledge of the researcher and experience as a diabetes counselor benefited to the understanding of the information provided by the families and the doctors and also strengthened her credibility with the medical personnel.
- Previous participation in a diabetes camp in Tajikistan provided the researcher with basic information and experience about what kind of challenges children with T1DM face. It further provided insights for developing and adjusting the research tools.
- Support from Operation Mercy, the only NGO working with T1DM in Tajikistan, provided access to information and contacts when entering the field.

4.10.2 *Limitations of the study*

- The researcher had no prior skills in Tajik or Russian language and was therefore greatly dependent on local assistance both with translations and organization of interviews. In the interviews some information was most likely lost through the translation process.
- Data collection was limited by time and weather conditions in the field. It was wished to conduct interviews also in the autonomous region Gorno-Badakhshan, however this was restricted by the early winter outbreak and time limitations as a separate visa was needed.
- Data could possibly be biased due to the researcher's affiliation to the NGO that has arranged summer camps for children with T1DM in Tajikistan since 2008.
- The researcher had biomedical knowledge and experience as a diabetes counselor. Therefore, preconceptions and fast drawn conclusions could have affected the interviews and therefore the findings.
- The research assistant's preconceptions through her mother's work as a medical practitioner could have affected how questions were asked and translated, and thereby have influenced the findings of the study.
- Children were interviewed with their mother or both parents being present. Hearing what their parents thought, often before they offered any opinion themselves, could have affected their own perceptions and thoughts, and therefore the findings.
- In one city, the endocrinologist selected two participants for the study. Such selection could have affected data and thus the findings.

4.11 DISSEMINATION OF FINDINGS

After the thesis is completed and submitted, a presentation of the work will be given with public access at the University of Oslo. The thesis will later be available in the University's library.

Furthermore, a summary will be translated to Tajik and distributed to participants and main stakeholders involved in diabetes work in Tajikistan in August 2012. Also it is planned to present the findings to these groups in Tajikistan in August 2012.

The information and insights gained through the project will further be used by Operation Mercy to develop an information booklet for families living with T1DM in Tajik. This booklet will be developed and pretested with the involvement of the researcher in August 2012 and will eventually be launched at the International Diabetes Day November 14th 2012.

5 ETHICAL CONSIDERATIONS

This study was carried out according to the principles stated in the World Medical Association Declaration of Helsinki (World Medical Association, 2008), the International Ethical Guidelines for Biomedical Research Involving Human Subjects from the Council for International Organizations of Medical Sciences (CIOMS) (CIOMS, 2002), the Universal Declaration of the Human Rights (United Nations, 2007) and the UN Convention on the Rights of the Child (1989). Specific ethical challenges related to this study are identified in the following paragraphs.

5.1 APPROVALS

In Norway ethical approval was obtained from the Norwegian Research Ethics Committee (REK) June 24th 2011. It was concluded that the research project was outside of the remit of the Act on Medical and Health Research and therefore could be implemented without the approval from the Regional Committee for Medical Research Ethics in Norway.

In Tajikistan, an equivalent ethics committee did currently not exist. The two most important research institutions are the Tajik Medical University and the Tajik Institute for Postgraduate Education (Khodjamurodov & Rechel, 2010). A lack of coordination has been described as the main weakness of the current Tajik health research system (Iskhakova & De Haan, 2006). Based on this information, ethical clearance was obtained through the Tajik Medical University, in particular through the National Endocrinology Centre located in Dushanbe. The head of the institution affirmed their support orally, when the project was presented September 14th 2011. Furthermore the project was registered with the Public Foundation 'Panorama' (registered in the Ministry of Justice) as described in *4.5 Timeframe*.

5.2 INFORMED CONSENT

The declaration of Helsinki (World Medical Association, 2008) states, that the researcher has an obligation to ensure that the person participating in the research understands what is implied by their participation, and that such a person's consent to participate is obtained without coercion. Thus, informed consent is an important ethical consideration in any research involving human subject. Basic elements of it include: brief description of the study and its procedures, full identification of the researcher's identity, and assurance that participation is voluntary and that the respondent has the right to withdraw at any point without penalty, an assurance of confidentiality, and benefits and risks associated with participation in the study.

According to this background, a fully informed and voluntarily given consent was obtained from participants prior to any data collection. Parents were planned to consent for their own

participation and for the child's, if the child was below 16 years. Children below 16 were planned to give their assent, whereas those above 16 years should have given written consent. This attempt was mainly based on Marshall et al.'s (2009) study, which provided a very similar set-up, and used 16 years as a threshold for a written, informed consent. In general there is no consensus stating clear rules about at which age to involve children in the informed consent process.

In the planning phase it was noted that a written consent might present itself to be challenging. Tajik people, who have been suppressed by a corrupt and strictly monitored system under the governance of the Soviet Union, were generally hesitant to sign formal documents. The previously prepared written consent form was translated into Tajik. After reviewing the written and oral consent options, my research assistant, the Head of the National Endocrinology Center and other key informants suggested the use of oral consent as it was considered to be more culturally appropriate and would not create suspicion from the participants to whether I could use the document to their disadvantage. Therefore oral consent was used consistently, following the standards described above. A written version of the oral consent used with the parents and the children >16 years of age is provided in APPENDIX V. Information provided to children <16 years of age was adjusted according to the child's age and its cognitive abilities.

5.3 CONFIDENTIALITY

To ensure confidentiality and anonymity, only the child's first name and age was used when the interviews were transcribed. The reason why the child's name was preferred during the transcription was to help me to recapture and remember the interview setting. After coding meaningful clusters, the names were replaced with acronyms 'Diabetic' (D1-18). The parents were coded with 'Mother' (M1-18), 'Father' (F1-18). Relatives, which in some cases were present during the interview, were named 'Relative' (R1-18).

Additional information about the participants was kept in a personal notebook and was only read and used by myself. This notebook was stored in a secure place.

As doctors were purposely sampled according to their positions in key hospitals and endocrinology centers, their anonymity was neither possible nor target. Their actual names were replaced with the acronym 'Doctor' (DO1-4).

Information about the participants, raw materials as well as audio recordings will be destroyed after the completion of the master thesis.

5.4 TO WORK WITH A VULNERABLE GROUP

5.4.1 *Meeting with the families*

Families having a diabetic child were considered as a vulnerable group. T1DM is an illness that is rarely known by the general public in Tajikistan. In many cases families therefore preferred to keep secrecy about their child's illness as they feared consequences. In some cases the families explained that the child was mocked after peers got to know that he or she was diabetic.

It was experienced that families were appreciative and benefited from the interview. They were able to express their feelings and experiences to me as a culturally neutral person, who would neither judge, nor accuse them. Their appreciation was demonstrated in the interview. Many families said that they were thankful that someone would return to Tajikistan because they cared about their diabetic child, the family's wellbeing and was interested in listening to their experiences.

5.4.2 *Children as informants*

Children were viewed as a vulnerable group throughout the research process and their wellbeing was considered the highest priority when interacting with the families. This was based on my understanding that children have less competence, compared to adults, when deciding whether they want to participate in research. One reason that is extensively discussed in literature is, whether informed consent is sufficiently understood. Therefore I paid special attention to that information regarding participation and what it entailed was explained in a child friendly- and understandable way to the children.

As interviews were carried out with both parents and the child, it was important to guard the child's wellbeing. During the interviews the openness of the mothers was positive as it created a relaxed atmosphere and lively discussions. However, their willingness to share also created a need to take active responsibility in every step of the interview, reflecting on the child's role in the current setting. I tried to protect the child by consciously not addressing certain topics. Furthermore, I often directed the conversation to a more superficial level. This was done in order to protect the child from emotional harm. Two examples are given below.

For instance, I was especially aware when the parents addressed information regarding cost of treatment. Even though further probing could possibly have generated valuable information, I considered it as unethical with the child being present. I did therefore try to intentionally guide the conversation in a different direction and eventually addressing the topic again when the child was not present.

Similarly, I paid attention to how much depth was ethically justifiable, first and foremost to protect the child. As described earlier, mothers did often not have anyone that understood their situation. Therefore, as I showed interest in them, they provided descriptions of great depth. To protect the child in such situations two steps of action were taken in particular. One was to steer the conversation to a more superficial level, the other was to let the mother voice her own thoughts but not talking for the child.

After the interview I spent enough time to engage and interact with the child, making sure that he/she was comfortable. It was experienced that children felt comfortable with what they had said as they usually stayed in the room and continued to talk or engage with me in one way or another.

5.4.3 Identifying injustice

When carrying out this study one injustice in particular was experienced. Families were in many cases required to pay for treatment and care or even for life saving insulin. However this was provided to the health system through Project Hope and the IDF's *Life for a child programme*, free of cost. This was especially challenging for poor families as described in the findings chapter. One could ask whether the doctors should have been confronted directly. This was after careful considerations not done due to different reasons. First, the families' anonymity could have been jeopardized as most doctors knew some families which had participated in the study. Furthermore the NGO's reputation could have been affected negatively as I, despite being an independent researcher, often was connected with the NGO. This could have affected future work permissions in the country, and thereby have a negative effect on the families situation, as Operation Mercy was the only organization assisting families living with T1DM in Tajikistan. Also, as I intended to be involved in diabetes work in Tajikistan in the future, I did not want to risk my own established position in the country. Finally, to act on the identified injustice would neither be the objective of the project, nor would it be an adequate or well thought through contribution to counteract injustice and corruption.

5.5 BENEFICIANCE AND USEFULNESS

Furthermore, the balance between the beneficence and usefulness needed to be addressed. Even though no physical risk was involved in the study, there was a possibility of emotional distress as a result of in-depth interviews. Constant awareness and critical reflection, especially when interviewing children, was a key quality that I used consciously in order to prevent children and their parents from harm. A support system for families that were interviewed was available through Operation Mercy and the National Endocrinology Centre, where children attended for regular health checks. Even though some families lived further

away, they all possessed mobile phones. Phone numbers between a colleague in the Operation Mercy diabetes project and the families were exchanged. Thereby she could be contacted in case support was needed.

A possible benefit for the parents and the children was pointed out previously, namely the possibility to voice their experiences and thoughts. Also, I provided answers to some of the questions they had, after finishing the interview. When families were visited in more remote villages especially they did receive attention from their community, where people curiously asked how this family could be so important that a foreigner would come to visit them. This attention may be positive as it could create awareness and increase acceptance of T1DM in the community. It needs to be mentioned also, that the attention could have created unwanted disclosure of the child's illness eventually. However, as families agreed to be visited in their home, they were most likely aware of the possibility to get attention from the community.

6 FINDINGS

The aim of this qualitative study was to assess perceptions of T1DM and the need for information and education among diabetic children and their parents in Tajikistan. Information was gained through in-depth interviews and focused observation during the interviews.

Ongoing analysis of collected data with 18 families throughout field work and the writing process led to three distinctive themes: (1) *'Finding out the child has diabetes'*, (2) *'Life with type 1 diabetes'* and (3) *'I would like to know more about' and 'I would suggest'*.

To further broaden the understanding of how it is to live with T1DM in Tajikistan, four endocrinologists from different geographical areas and specialized institutions were interviewed. Also, observations at three diabetes days, one focus group discussion and informal conversations with resource personnel helped to view the data from different angles.

The first theme **'Finding out the child has diabetes'** includes core themes such as: *How it started, perceptions about causes of diabetes, experienced symptoms of being sick, experiences with doctors diagnosing T1DM and parents immediate reaction to diagnosis.*

'Life with T1DM' is divided into three sub-topics: *responses related to emotions, responses related to biomedical knowledge and responses related to the health care system.* The sub-topics are each having respective core themes. In the chapter describing *responses related to emotions* themes from parents and children are described separately as they differed considerably from each other.

The third theme **'I would like to know more about' and 'I would suggest'** describes the families' and endocrinologists' responses related to the need for information and education. It further comprises suggestions from children with T1DM, their parents and the doctors about topics that should be included in an information booklet for affected families.

Finally, a **summary** abstracts challenges families face, divided into *challenges that can be met by giving information and challenges that need solutions from the health care system.*

The findings are based on data from interviews with families primarily. Therefore, these are referred to if not stated otherwise.

6.1 INTRODUCTION - PRESENTING THE CASE OF A YOUNG MAN

D. is a 23 year old man who was diagnosed with T1DM at the age of 11. His story describes how he has experienced to live with this illness for the past 12 years. Diagnosed as a child, he is now a young adult living of disability pension. He is suffering from all long-term

complications, thus affecting his daily life. His story is told because it captures the severe consequences T1DM can have, if consistent insulin procurement and appropriate information and education, are not provided.

D. started his account with telling how his family reacted when he was diagnosed with T1DM at the age of 11 and how he lived with this chronic illness from that time onwards.

'My family didn't believe that I had diabetes, so we went to another clinic and there they also said that I had diabetes. I stayed in that hospital for one and a half month. They said that children are not allowed to take other medicines, but that I should only get insulin. It smelled acetone from my mouth.

When I was discharged from the hospital I didn't have a diet because I was very young. I used to eat everything, like cake and RC Cola, and in 2003 on February 3rd there was Korvon holiday and I had difficulties breathing, I had problems with my heart and I went into a coma. I was in a coma for almost one month. Then, when I became better, I was taken to the second floor, to another department of the hospital and I was overdosed by insulin.'

S: So, what happened then?

'I have been in a coma again. It was the second coma and I was in the coma for almost two months. When I was in the coma I dreamed about a tunnel and it was very white and bright and I had to pass this tunnel, but I didn't pass it because I thought that if I pass this tunnel, maybe I will die. Then I woke up again. It was winter when I was in the coma but I felt my legs were burning. My legs were covered with a blanket and when I took of the blanket I saw blisters on my feet. The doctor said it was because of my diabetes. It was like sugar came out of my feet.

Then I was taken to the city hospital and there they didn't accept me and they said that I was burned by hot water. They sent me to the skin hospital (dermatology). When I came in the car I said to my mom 'maybe I will die, bring me back home'. I was back in our city then and we went to the hospital and one more scientist there said 'you have gangrene and puss and you have to rub alcohol on it'. Then at that time I used to rub two big bottles of alcohol every day and it dried.'

S: Did it hurt?

'Yes! To tell it briefly, I suffered a lot during that time. And besides my legs I also had problems with cataract, anemia and they had to give me treatment for constipation. I lost lots of blood [...] As I was in the hospital for a long time I became very impatient and the doctors said to my sister, my legs would be amputated. My sister refused and said that they would take me back home and treat me. Then I was home again and I used to bandage my legs by myself.'

S: How old were you when you were in that coma?

'14 years old. [...] When I was back home, one doctor came and they opened the blisters and he said 'his cells are dying'. And my legs became dark and blue and my veins were very big. I bandaged the legs with my sister. When I looked at my feet I was very shocked and I was very afraid. [...] Every time when nurses came to bandage my feet, I didn't let them, I said to my family 'No, I don't want them to do it, I will do it for myself. Make tea for them, but I will do the bandage for myself.' Lots of blood

used to come of my feet and the doctors said that I had to put down my legs to get a good circulation. I suffered with my legs for a long time.

[...] When I was 16 years old I suffered a lot with my legs and the 1st August, it was my birthday, I was sitting on the sofa and I was doing the bandage and my mom was sitting near me and my nephew was giving me alcohol not to faint. I was very impatient and was watching TV and I started to turn my toes and I just cut and, when I had cut all of my five toes to an end, I fainted. It hurt a lot and there was lots of puss in my leg. Until 2008 I wasn't able to walk. I was always at home and I even crawled to go out somewhere. I told my mom 'please find me crutches' and until 2008 I used to use crutches. Then I stopped using them and from that time I started walking by myself. And when I stopped using my crutches, they didn't believe how I could possibly walk again. You know, I wasn't discouraged; I had hope, that's why I was able to walk again. Some people that have diabetes, they say that 'I have diabetes, what shall I do?' and I say that 'please don't be discouraged'.

[...] So, when my legs were better again my vision started being impaired. I wanted to become a surgeon but when my sight became very bad I said 'There is no way I will become a surgeon'. When my sight was very good, I used to go out. I don't want to tell a lie, it is almost seven or eight months ago I have been out, not even outside around our district. When my blood sugar is very high (> 30 mmol/l) I usually ask my sister to follow me out. But I saw that my sister was very busy today that is why I went out by myself to meet you. Otherwise they help me to go out.

[...] In 2010 I had pancreatitis and I used to throw up. I had to go to the emergency room but the doctors said that I should go to the hospital in Dushanbe. I was taken to the Sawetzki Hospital in Dushanbe and I had to stay there for one week. When I was discharged I became worse again. I was taken back to the hospital in Dushanbe and at that time I became much worse. The doctors said 'There is no hope, he is going to die' and they called my sister who is in Russia. In this hospital I was laying in my bed with my mother very close to me. Two nights I dreamed about my two dead friends who asked me to give them my hands, but I didn't. I told the doctors about my dream and they said if you had given the hand to your dead friends, you might have died. I was so weak and I said to my mother 'I am going to die' and they cried; they cried a lot. Then I became hopeful again, hopeful for the future, and from that time, I am living. After I was discharged from that hospital, I used to take medicine as I was very weak, my legs were very weak. I couldn't walk. I started to have a diet and then I slowly became stronger but my eyes became worse and I stopped going out. At the moment I have problems with my kidneys, with my liver, my heart, my vision, so the whole body is weak.'

(Participant D-02)

6.2 FINDING OUT THE CHILD HAS DIABETES

One objective was to gain an understanding of when and how the child got diabetic and how this was experienced by the child and the parents. Families all provided a rich description of a very personal story. This shed light on important key aspects regarding how T1DM was perceived.

6.2.1 How it started

Each family presented a unique and detailed story about how the child became diabetic. The mother of an 18 year old girl, who had been diagnosed when she was 4,5 years old, still remembered the details of the story and told it vividly as if it would have happened only a short time ago.

'When she was 4,5 years old, she was playing, and there was hot water in the bowl and so she was burned. She put her leg in the bowl and she got burned. Two legs were burned and her stomach and we took her to the hospital. When she was back home she started urinating often and a lot. We didn't know how it started but she started urinating a lot and very often and she even didn't know that she needed to urinate.' (M-01)

The actual stories were very different from one another. A 23 year old young man that had been diagnosed 11 years ago was telling about an event where he was punished by his teacher for a minor incident.

'When I was in the 5th grade in school, one day when we had a drawing lesson I forgot to bring the painting materials like pencils and that teacher punished me that I didn't bring the materials. He punished me and wanted me to stand up and sit down 250 times. Then when I came back home I was very tired and it was a very heavy burden for me. And from that time I started urinating every night and then we went to the hospital to have a test and there they found out that I had diabetes. The level was 17 mmol/l.' (D-02)

Another example demonstrates the heterogeneity of their personal encounters even further. The mother of a young diabetic woman told how her daughter got diabetic at the age of 12 after her sister had unexpectedly died.

'When my daughter got diabetes, it happened after her sister died. Her sister was six years old and she was sick for three days and died. After that my other daughter got sick. She was in the Pamir (mountainous area in the East) with her older sister on vacation, and her younger sister was in Dushanbe. She died while they were gone. They didn't see her because they didn't have the chance to come back for the funeral. After that she got diabetes.' (M-04)

Data showed that the duration of the disease did not influence how well their stories were remembered or how many details were given.

6.2.2 Perceptions about causes of diabetes

The families had distinctive thoughts about why the child got diabetes. More precisely, topics such as fear, leading to emotional stress, and the 'evil eye' were given as possible explanations for why the child became sick.

The mother of a 16 year old diabetic girl explained what she had heard from other people: *'Many people say that they get this disease when they were afraid of something or if*

someone was scared.' (M-10) This was also confirmed by another parent, saying that many diseases would come from fear and that her daughter had experienced a situation of great fear at her aunt's house once. (M-05) A 14 year old diabetic boy told about an earthquake, and how this had provoked fear and emotional stress.

'In 2008 when there was an earthquake I was very much scared and after two days we went to the hospital to find out what was wrong with me.' (D-14)

The doctors had a biomedical explanation for the cause of T1DM and acknowledged inordinate stress as one possible cause for developing this disease. One doctor elucidated his thoughts in more details telling:

'As we are doing research also we have found out in the last years that the first reason for getting diabetes is that it is heritable, the second one is to be poor. Many children coming to our hospital are from poor regions where they grow vegetables and they put fertilizer on the vegetables and we found out that fertilizer also influences to get this disease. And another reason is also that children from areas of civil war are affected more as they have experienced a lot of severe stress.' (DO-01)

That stress played a role in developing diabetes was further elaborated when the doctor explained that diabetes had risen notably especially after the civil war, which took place in the Central and Southern regions of Tajikistan, and lasted from 1991 – 1997.

Key informants provided information about the all pervading nature of the evil eye in the culture and everyday life of the people. A few interviews provided examples. One mother mentioned the evil eye as the reason for why her 13 year old daughter got diabetes three years ago. She explained:

'Some people say, because she is a very smart and beautiful girl she is given by the evil eye [...]. Whatever is beautiful or pretty, people give more attention to. For example some children they don't speak well even they are 4 or 5 years old, but my daughter started speaking when she was 3 years old, she could speak very well, maybe that is why she got the evil eye. She was very pretty, very smart and very nice. Everyone likes her.' (M-05)

Another mother of a 13 year old boy had a similar perception. Key informants explained that if someone was possessed by the evil eye this person could be taken to a religious leader (Mullah). Through prayers and drinking water that was prayed for, the evil eye could be cast out. The mother explained that her son usually got better after having been taken to the Mullah. Therefore she considered this as proof that the disease was given by the evil eye. (M-08)

6.2.3 Experienced symptoms of being sick

Classical symptoms such as 'having to go to the toilet all the time', 'being thirsty' 'feeling weak', 'weight loss', 'having dry skin' and 'constipation' were described by most families in the interview and followed a specific incident described previously. 'Urinating' and 'being thirsty' were named the most.

A mother of a 14 year old diabetic girl explained how she first realized that something was wrong with her daughter before she received the diagnosis two years ago.

'She drank a lot and she was urinating a lot. When she ate sweets she threw up and she became very thin. Then we went to the hospital where they diagnosed her.' (M-12)

Another mother of a 16 year old boy noticed similar symptoms when her son first got diabetes, however also pointed out that he lost weight and urinated predominantly during the night, when he wet his bed. (M-18)

6.2.4 Experiences with doctors diagnosing T1DM

Prior to diagnosis only a few families told that they did seek help from sources outside of the health sector. It was perceived that most families consulted doctors and medical personnel when symptoms were physically evident. However as religion was an all pervading part of their life, a few families also described that they sought help from religious leaders (Mullah's). When help was sought in the health system, several families explained that medical personnel were not aware of that also children could be affected by diabetes. This challenge was supported an endocrinologist who said:

'Doctors and nurses usually are well informed about diabetes but not so well, because usually when children get sick and are in a coma they don't think about diabetes. They don't think that children may have this disease[...] Doctors do everything but think about diabetes at the last.' (DO-03)

Medical doctors' lacking awareness of- and biomedical knowledge about T1DM and its treatment had severe consequences for the child. This was pictured, in detail, by five families. Parents of one girl described the helplessness and despair they experienced when taking their child from one clinic to another, trying to find an explanation for what was wrong with her. She received treatment for various diseases such as measles, food allergy, intestinal worms, typhoid fever and malaria and was transferred from one institution to another, the result being that she ended in a coma.

'Wherever we had been, the hospital, the diagnostic centre and some other places, nobody found out what was going on [...] When we went to this other hospital they said that they

had to 'wash and clean' her stomach and she got glucose infusion. After that she went into a coma.' (F-05)

Despite the extremes of maltreatment, there were however also several families who voiced that their child got diagnosed without delay. Analyzing the interviews according to their geographical location, there was no trend showing that urban institutions had less severe cases of maltreatment compared to rural areas. It was perceived that the diagnostic outcome predominantly depended on the skills and biomedical knowledge of the individual attending doctor.

6.2.5 Parent's immediate reaction to diagnosis

The parent's immediate reaction to diagnosis was described in various ways and with different terms by many families during the interview. 'Shock', 'rejection' and 'anger' were used to describe their instant response. Facing the reality of having to live with a chronic disease was perceived to be a key issue.

One mother explained her immediate reaction when her four and a half year old daughter got diagnosed, responding with refusal, helplessness and withdrawal.

'Then from there she was sent to the hospital and there they prescribed her insulin, but I didn't want insulin, so I refused to do this. When I found out that it is diabetes and it is forever I got very upset and I was in the bed all the time.' (M-01)

Another family described their reaction differently, telling that they sought help from other sources such as folk medicine and religious healers when their daughter got diagnosed at the age of 10.

'In our family no one has this disease. We didn't know anything about diabetes and when we heard about insulin we thought that maybe we will do it temporarily. Then, we found out that this disease is forever we tried to do other things. We used folk medicine to heal her. We went to Mullahs and other religious healers. It didn't work, so then we continued with insulin.' (M-05)

In the worst cases the initial response of the parents had severe consequences for the diabetic child. A young man, diagnosed at the age of 11, explained the families' reaction consecutively resulting in a diabetic coma.

'My family didn't believe that I had diabetes, so we went to another clinic and they also said that I had diabetes and I stayed in that hospital for 1 ½ month. [...] First we didn't face it, we didn't understand but after I was in the coma we were stressed.' (D-02)

Looking at the responses as whole, families reacted differently and sought help in different places; however, they all found out through personal experience that insulin seemed to be the only remedy that guaranteed help.

The parents' reaction was furthermore voiced by two doctors who expressed that the most challenging part of their work was to inform the families about that their child will have to live with a life-long illness.

'This is the most difficult thing for us. It is very difficult to talk to them the first time because they get very upset. Some of them just don't believe it and they go to some traditional healers or religious healers. It is very difficult to say that they have to take insulin for the rest of their lives, but I also try to say that it is not the end of the world, but you must get insulin all the time!' (DO-01)

Another doctor explained that the families often did not believe in them, and quickly went to a Mullah or would do something else. Further he said *'If they don't get well and have complications, then they come back to see us.'* (DO-03)

6.3 LIFE WITH TYPE 1 DIABETES

As a life-long chronic illness, T1DM affected the families' everyday life. Several objectives aimed to assess current biomedical knowledge of diabetic children and their parents, as the overall general objective was to find out if they perceived there to be a need for more information and education. During data collection extensive information about emotional responses and responses concerning the health system emerged. The findings are therefore presented according to these three sub-themes: responses related to emotions, responses related to biomedical knowledge and responses related to the health system.

6.3.1 Responses related to emotions

Life revolved around an ambiguous relationship between living with a chronic disease in reality and the uncertainty about whether there is a cure that was yet unknown to them. Affected children and their parents expressed different ways of living with this discrepancy.

6.3.1.1 The children's perspective

Finding out how children managed their daily life with diabetes often presented itself as a difficult task. Therefore observation became an important instrument to collect data and parents contributed with comments. In several interviews the child left the room at some point. The limited minutes with the mothers or the parents also generated data with great depth. They often described aspects of the child's emotional life, which they did not voice while the child was present.

The children's reaction to being sick

A few mothers described the child's emotional release of anger and frustration, mostly expressed in a physical way, varying in its degree.

One mother explained how her 14 year old teenage boy, usually being a hesitant, polite and shy boy expressed frustration about the never-ending nature of the illness.

'Sometimes he shouts, 'How long will I do injections'' (M-03)

Another mother of a four year old boy, who had been diagnosed 20 days ago, expressed the boy's physical reaction, saying: *'When he gets angry he bites me.'* (M-07) Observations during the interview confirmed the mothers account. The little boy did bite his mother, screamed and pulled her hair several times.

Other reactions named by a few families were refusal to take insulin and acting capricious. One mother even voiced that her 13 years old son got so angry that she asked the doctor to prescribe some medicine for his emotions. (M-09)

Identifying with T1DM

Only in one interview the mother described explicitly that the child identified with the illness. However, this was viewed as a special case as the child was very young.

The mother of a newly diagnosed four year old boy expressed how her son, after having been diabetic for not even a month showed how he clearly identified himself with the disease. She pictured a situation where they were eating together, explaining:

'For example I gave him a little of this bread (white bread) today, but he did not eat it. He asks me to give him his bread (whole grain bread). He says 'I am diabetic' [...] When we had 'Shakkarobh' (national dish with fresh bread) he said 'I am going to eat my food, not this one.' (M-07)

Another situation was connected to insulin injections. The mother told:

'This morning, when he was playing with his brothers and I was calling him to get his injection he said to his brother 'please wait for me, I will just get my injection and I will come right back to play with you again'. He is quiet and does not cry when he gets his injection.' (M-07)

Only two children who participated were at such a young age. Despite this description being unique it sheds light on an important aspect. It indicates that even very young children can have an understanding of being diabetic. Even if the concept of living with a chronic disease may not be understood yet, this incident indicates that he understood the practical implications of being diabetic on a day to day basis.

Wanting to compensate

Many of the children tried to compensate for being diabetic in different ways. The most evident was being outstanding in school, proving to others and themselves that it is no drawback to have diabetes. The mother of a 14 year old diabetic boy complimented her son's abilities in school, accentuating that he was the best student in his class. *'He doesn't have any shortcomings'* she said.

One student having T1DM also described another facet. She did not want to be a financial burden to her family as they had spent much money on her treatment throughout the years already. She wanted to be independent, managing on her own. Further, she explained that students usually paid to get accepted at university, except if the applicant was exceptionally intelligent and hard working. Therefore she studied extremely hard and managed to receive a coveted spot in the medical program. Furthermore, her stamina and hard work also rewarded her in gaining respect from others, as she pointed out in the interview:

'In the secondary school I did very well and my classmates asked me 'How did you get in? How much did you pay?' And I said, I didn't pay any money. I was a little bit offended when they asked me how much I had paid because they knew me and they knew that I did well at school, so it hurt me a little bit. At the medical university I am doing very well also, I am usually one of the best students and I get awards for my work.' (D-04)

In contrast, other children stopped going to school. Many helped in the everyday life in the household, a secure, familiar place. At the Operation Mercy diabetes day in Dushanbe a 15 year old girl stated that her favorite leisure activity was to help her mother clean the house. When the girl was interviewed at a later point this was explored further, and the girl said that she liked to watch TV, clean the house and now she was cooking food. Her sister, also being present voiced that it was difficult for her sister to go outside the house as she got tired very quickly and people would make comments. Therefore the diabetic girl helped and supported the family in other areas, such as completing household tasks. Through her engagement in the household she would be considered as a commendable young woman and a potentially excellent future wife.

Children's perceptions of benefits having T1DM

None of the children did specifically state benefits of having diabetes when they were asked during the interviews. Rather a puzzled and shocked facial expression was shown. The answer was obvious to them as the older sister of a 15 year old diabetic girl answered *'No! It is suffering.'* (R-13)

When asked for further explanations why she thought it was suffering for her sister she explained:

'For example if you get sad your blood sugar gets high or for example you should not eat any sugar and sweets. If you eat one candy your blood sugar can get high. She is always sick. She is not like other children. They are always active, but she is not like them. And she is not interested in going to school; she does not have any interests.' (R-13)

Despite the clear statements that there were no benefits of having T1DM some important positive aspects were described at various stages of the interview. The circumstances could be many, in school, in the family setting or in society.

One young man explained that he was well-known and respected in his city, that everybody knew him and greeted him very respectfully saying 'aka', meaning 'big brother'. (D-02) This term was often used to demonstrate respect to a male person, normally to someone being older. In this case this was said to a young man, demonstrating the degree of respect they expressed.

This young man also described the benefits of being well-known and respected in the city. Living of a marginal disability pension, insulin procurement was extremely challenging for him when insulin was not provided free of cost. However, as everyone knew and respected him, he could always obtain insulin in one or another way. (D-02)

Benefits were also mentioned in relation to school. The mother described in an interview how her daughter, after having been away from school for an extended period of time attended the 'last bell', being the last official school day before graduating from secondary school. The daughter then added eagerly:

'And the principle said to me. I will take a picture of you. I want to have a picture of me and of you he said.' (D-01)

The mother further commented that her daughter had advantages in her class. *'At school she could do what she wanted, the teacher let her do as she wanted'* (M-01) she said.

Another mother of a 16 year old diabetic boy described that her son was respected by everyone in school and that he was allowed to study at home. She explained:

'Everyone knows everyone and they respect him. The teachers also know. He doesn't go to school so much. [...]The teachers know and understand because I have explained them. They say that he should attend the school maybe 2 or 3 times a month, just to be familiar with the curriculum. He studies at home.' (M-18)

In the family household benefits were mentioned in a few cases. When asking a boy about whether he as a boy helped to work in the field, he responded with a smile on his face that

he did not. The mother commented thereafter *'I don't know why he doesn't. I think maybe it is because he is spoiled.'* (M-08)

Physical signs of diabetic complications caused mobbing, exclusion and isolation

Mobbing due to long-term complications of high blood sugar

Many parents described that it became evident to the public that the child was sick when they entered puberty. Many children reported that they were mocked by peers in school because they were too short or too thin and that they therefore had stopped attending classes. A 14 year old boy who had lived with T1DM for almost three years described his everyday life at school.

'Everyone in my class knows and they mock me. They say 'You are very thin. You are very sick. You will die soon; you will not have a long life'' (D-14)

He was mocked and excluded by his peers. Another 15 year old girl told that she stopped attending school because she was embarrassed about herself, saying *'I was very small among them. They are strong and I am very small.'* (D-10)

Furthermore, a 15 year old diabetic girl, who had stopped growing at about 1.30m of height, explained an everyday situation she faced when being out in public, and how the family had dealt with the challenge.

'Usually when I go out and people ask which grade I am and I say I am in the 10th grade they just cannot believe it. My mother said that when people ask to tell them that I am in the 4th grade. [...] When I do it like that they don't ask any more questions.' (D-13)

Mobbing due to acute complications of high blood sugar

Other children mentioned that they needed to go to the toilet often and did not want peers to make comments. Therefore they would either not attend school or leave early as a 12 year old diabetic girl described during the interview.

'I don't know what they think about me but maybe they say something about me when I am absent. I usually try to leave early to go right back home after school. Then they ask 'why do you leave so early?' It's because I don't want to go to the toilet at school and as I need to go often I try to go back home early. Maybe our teacher explains them that I have a problem.' (D-16)

One mother further described an incident that affected her son. Other children who did not know anything about T1DM had mocked her 13 year old boy. She explained:

'In the summer when he goes swimming children sometimes laugh at him and they say that 'Why is your stomach so big?' and he said to me that he wouldn't go there anymore because children would laugh at him. I said, 'Go, it's ok, don't be embarrassed.' (M-09)

Consequences of being mocked

The result of being mocked or being made fun of was that children withdrew from school or other social settings, often feeling sad and lonely. One mother described the everyday situation of her 11 year old son:

'He does not go out very much. He only goes to school and when he comes back he just sits at home. If we have electricity, he watches TV.' (M-08)

Several families described how isolation led to a circle of negative and destructive thoughts. One mother recaptured what her 13 year old son was thinking of.

'He says 'I'm afraid to die. I just want to get hope, rather than to die.' He says: 'I just don't want to be in a graveyard, I want to be somewhere close to my family'' (M-09)

Thoughts about death were not described by the children themselves, but by a few mothers and one sister. These thoughts were told in situations during the interview where the affected child was not present. One sister explained why her diabetic sister never forgot to take her insulin. A seemingly simple explanation revealed a deeper meaning, namely that she was afraid to die.

'One of our relatives also had diabetes. He was in Russia and he forgot to take his insulin two or three times and then he was in a coma and he died. They sent his body from Russia and my sister got very sad and upset. She doesn't forget to take her insulin. She does it always!' (R-13)

Coping with feeling sad and lonely

Some children described what they did when they felt sad and lonely. Different answers were given. A 12 year old girl explained that she would go outside or read a book; whilst a 13 year old boy described that he would go and feed his rabbits and his chickens in the backyard of the house. An 18 year old girl, who had lived with diabetes since she was four and a half years old, expressed her feelings and thoughts through poetry. In the interview she cited her poem about how she experienced to live with diabetes.

'A flower of spring, I am very impatient

I am very discouraged, I am very sick, I want to be healthy

A flower of spring, I am very impatient

I ask God to give me good health

A flower of spring, I am very impatient

I also want to be healthy; I also want to play' (D-01)

This poem captured some of the essence of the children's emotional responses. A life between what is, and what could be; and an alluring amount of hope in between.

6.3.1.2 *The parents' perspective*

Families showed compassion and love

The families all voiced a strong compassion and love for their diabetic child. The mother and other women in the household were in most cases the ones that were involved in the child's life the most. Compassion and love was shown especially through focused observation during the interviews. Many mothers gazed at their child with a concerned look while talking, or sometimes just were quiet with tears in their eyes. It showed compassion and at the same time helplessness. The family of a newly diagnosed four year old boy voiced what many families expressed during the course of the interview. The mother told that she sometimes said to her son *'It would be much better if I would have the disease, because I am much older than you and you are so young.'* (M-07)

The grandmother, who was present during in the interview told that the child's father, forced to work in Russia to provide money for the family, was returning to Tajikistan only to be with his son. His mother also showed that her husband had sent special sweets for diabetics for their son from Russia. When asked about how the father reacted when he got to know his son was diabetic the grandmother responded:

'He (the father) cried for two days. Every time when I call him he cries and says that I have to take care of him well and he says 'I will come back to Tajikistan. I don't want to stay in Russia anymore; I want to be with my son'. He already has a ticket and will be coming soon.' (R-07)

The mother further retold a conversation she had overheard between the little boy and his older siblings showing how much they cared for and loved their brother.

"Maybe if we could take your disease that would be better, maybe if we could share it'. They love him very much and they have compassion with him. I have heard what they said to him, but they don't say those things in front of me'. (M-07)

These descriptions demonstrated how parents and close family felt deep compassion and love for the diabetic child and would have offered their own health if it would help their child, brother or sister.

How parents related to the diabetic child

Parents had different ways of relating to their diabetic child. A few parents tried to protect their child by observing them closely whilst others gave their child more freedom in handling

everyday life with the disease. The mother of a 14 year old diabetic boy described how his father tried to make sure that his son was in good health and did not have any shortcomings.

'We are trying to do the best we can. His dad is paying attention to him very much; he checks his body every day to see he has any wounds or sores. He also measures his clothes.' (M-03)

Another mother of a 12 year old diabetic girl voiced that she understood that she had to look after her daughter like a baby. *'You have to give them much more attention'*, she said (M-05). A similar meaning was given when a mother was asked why she did approve her son go to the diabetes camp previously. She expressed that she was afraid of what could happen to him when he was away from her and said:

'I just didn't want him to be far from myself and I would think a lot about him if he's not with me. I will get sick if he is far from me.' (M-09)

In cases where the parents stated that they observed their diabetic child closely, children did not respond directly to how their parents' behavior made them feel. However, one young woman said that she appreciated her families support, noting especially her mother who did not refuse her anything, but let her decide what was good for her. (D-04)

Perception of fate

Families experienced a discrepancy between living with a chronic illness and at the same time hoping that there might be a cure that they had not heard about yet. A third dimension was that of fate, where a few parents expressed to have found a way to accept the situation.

Descriptive observation and discussions with key informants showed that in Tajikistan the concept of fate is strong and prevailing. God is in charge, he gives and he takes and there is little the individual can contribute. God's sovereignty however also seemed to give families hope, believing that God could change their destiny. Most families shared this mindset in the way they responded to questions in the interview and one mother of a 12 year old girl explained:

'People are not able to do what God does. Who knows, what will happen. Everything is in God's hands. Maybe it was already written in her fate.' (M-05)

She concluded by saying *'It is in our fate and God gave this disease and maybe he will give a cure.'* (M-05), demonstrating the hope she had as she believed that only God could change their fate.

Parents considered other chronic diseases to be worse

In two interviews with families the mothers voiced that there were chronic diseases that are considered 'worse' than having T1DM. Physical disability was named as such a condition.

The reason was that it was more visible to others and that the children were thought to be even more dependent on their parents. One of these mothers voiced that she thought that her daughter was not as severely disabled that she needed to sit in a wheelchair. She expressed her gratitude by saying *'I am so thankful to God that our child isn't disabled. Maybe she will have a long life.'* (M-05)

A similar statement was made after an interview with a mother who had participated in the diabetes day, conducted by Operation Mercy in Dushanbe. The diabetes day took place at the NGO's local facilities in November 2011. While the children gathered in the conference room for training and fun activities the mothers accompanying the children were gathered separately in the kitchen/dining area to facilitate a forum where they could exchange experiences and information. Observations from this day demonstrated that these ten mothers eagerly discussed and shared their situation about being a parent of a diabetic child. One mother was at a later point interviewed in her home and asked about her perception of the diabetes day and how she experienced meeting other mothers of diabetic children. She described that she felt encouraged and voiced a general consensus from the mothers that they were thankful that their child was not 'severely sick'.

'We parents are very thankful to God that our children are not so seriously sick like being disabled or completely dependent on other people. We are very thankful that our children are not like them.' (M-17)

Another diabetes day was organized by Operation Mercy and the regional Endocrinology Center in Qurghonteppa, the regional capital of the Khatlon region in the South of the country. One mother was asked in a consecutive interview later during the week about her impressions from the diabetes day. She described that she found the experience to be helpful, especially as she previously often felt alone in her situation, living in a small and remote village. She explained during the interview that she somehow felt relief and encouragement seeing other families where the child was diagnosed at a much younger age compared to her own child. She explained:

'When I saw other parents with very young children it was, how to say, a little encouragement. Even if the doctor told me 'Don't be so sad, there are many children with this disease' I wanted to see that myself. I even said to him: when there are other families coming with diabetes, call me, I want to see it with my own eyes. At that time I didn't know of any child with diabetes, only a girl who was in 11th grade, but no younger children.' (M-09)

Most parents, who had attended at a diabetes day and participated in an interview at a later stage, voiced that they perceived an exchange between families as positive and encouraging. It helped to see their own situation in a new and different light, realizing that they were not the only ones being affected.

Parents' concerns about their child's future

Some parents expressed during the interview that they were worried about the future of their diabetic child. One mother voiced that it was easier when her daughter was younger as she did not understand the social consequences diabetes would have in her later life.

'When she was small she didn't understand a lot about the disease but now she understands everything and she gets sad often.' (M-01)

Conversations with key informants and descriptive observations concerning cultural values highlighted distinctive gender specific roles and issues. This affected how consequences of having diabetes were perceived and described. A few mothers were afraid that their daughters would not get married because of diabetes and one mother verbalized very specifically in an interview:

'I got 4 children, but I pay more attention to her. The doctor said, don't worry, it's ok, she can have children. But in our culture when you finish the secondary school a girl should marry. How will I tell the people that will come to ask my daughter to marry someone? How will I tell them my daughter is sick? That is why I think a lot about her.' (M-05)

The same kind of concerns were voiced by another mother who recaptured how her diabetic son's older sister got divorced after she had been diagnosed with T1DM.

'When she was at that hospital they diagnosed her with diabetes. She stayed in her husband's house for 6 months, then she was brought back to her parents house. She was very sick. They got divorced that time.' (M-08)

Through informal conversations with key informants it was understood that being healthy and able to bear children is one of the most important determinants for a young woman be married. Infertility is seen as a reason for divorce or marrying a second wife.

When looking at boys, the concerns were related to whether he could provide for a family. Through informal conversations with key informants and observations it was understood that the sons stay with their family of origin when a marriage is arranged, whereas the wives move in with their husbands and their parents in law. Therefore, households often consist of two to three generations and provision of food and other essentialities can be a great challenge. When the family exceeds the capacity of the housing the youngest son and his family is responsible for staying with the parents to provide for their living. Therefore the youngest son has a special position. Based on this cultural understanding I was able to understand the underlying meaning when one mother said with tears in her eyes that the diabetic child was her youngest son. (M-03)

Whether it was their son or daughter who was affected by diabetes parents were worried about their child's future. How this came to be evident in their lives depended on gender specific roles in society.

6.3.2 Responses related to biomedical knowledge

Families' biomedical knowledge about T1DM varied. Specific questions were asked as an entry point and further explored according to the responses given. Topics of exploration were: sources of information, nutrition, insulin and its application, blood glucose measurements, symptoms about hypo- and hyperglycemia. Topics that emerged were herbs, acetone and coma.

The topics were generally not asked in a schematic and sequenced way, but raised and explored when natural and appropriate during the course of the interview.

6.3.2.1 Information available on T1DM

Almost all families said that they did not know what diabetes was before their child got affected by it. Most families stated that their attending doctor, in most cases an endocrinologist, was their exclusive source or information. Only very few families had books about diabetes, and all of them were in Russian. They did not think that these books were suited for Tajik culture and would very much wish that there would be information available in Tajik. Recipes were often perceived to be too advanced with foods either not being available in Tajikistan or far too expensive to be purchased by an average Tajik citizen. (M-03)

Only three families said that they had access to internet. They did use it extensively to find out whether there were new ways of treatment or even a possible cure. One mother said *'Almost every day we look at the internet and look for new information.'* (M-03) The increased biomedical knowledge of these families was reflected in the questions they posed.

Internet was available in Tajikistan but not accessible by most people and computer skills were limited. One doctor explained his way of using 'Google' to find information, saying that *'We don't have a special site we just ask a question on Google and we get some answers.'* (DO-03)

Further, it was observed in hospitals and endocrinology centers that doctors had very limited printed information. Some had a few posters from international organizations such as WHO or USAID, however targeting patients with type 2 diabetes, not type 1. Some medical textbooks in Russian were available, however not suited for patients, and sometimes outdated.

6.3.2.2 *Perceptions about a good diet*

'Diet' was the favored word used by the families in interviews to make statements about their food habits. This was a topic all families had biomedical knowledge about. Most families perceived that the worst things for a diabetic child were sweets and bread, followed by 'oily food'.

The concept of 'good foods' and 'bad foods' was also explored at the diabetes day in Qurghonteppa where a focus group discussion was conducted. Children painted pictures of what they considered 'good foods' and 'bad foods' for diabetes and choices were discussed thereafter. Despite the methodological challenges (see chapter 4.6.2.7 *Focus group discussion*) the following drawings were provided by the children, aged 6 – 18 years.

- Good foods that were drawn were: apple, pear, pomegranate, watermelon, cucumber, tomatoes, cabbage, cheese, yoghurt
- Bad foods that were drawn were: grapes, banana, melon, chocolate, small melon, bread

Information regarding food habits and good diet for diabetic patients was also looked into extensively by focused observation during the interviews. As we were sitting and eating in many cases, it was observed if the children would eat something and if, what they would eat. A discrepancy between what the child said to be a 'good' diet and what was actually eaten was observed often. Some children did not eat anything, but got 'their' food before they left to go to school. In most cases this was a bouillon soup with some carrots, potatoes or rice and eventually some meat. Others did eat, but were very hesitant. Others again ate whatever they desired, including foods that they previously had stated were bad for diabetes. A 16 year old diabetic boy told how important it was to have a good diet but throughout the interview he was eating white bread with cheese. (D-18) Another 14 year old boy stated that white bread was particularly bad for diabetes, but kept eating crackers, containing comparable amounts of white flour and therefore carbohydrates. (D-14)

One family lacked important biomedical knowledge about diet despite living in the North, by several key informants described as the more educated and modern area of Tajikistan. While talking about their food habits the mother asked whether it was ok that her 12 year old daughter, who had lived with diabetes for 4 years, could drink lemonades. When answered that this was not recommended, the following question was whether she could drink juices then. In contrast the same mother stated very clearly that doctors didn't allow her daughter to eat candies, sweets and fried meat. (M-12)

Most families stated during the interview that their source of information regarding diet was their attending doctor. Therefore doctors at specialized centers were asked about their

perceptions on a good diet for children with T1DM. As shown in the answer from an endocrinologist, similar foods to what the families had stated were named.

'The first thing is not to eat sweet things and the second thing is not to eat bread. As you know our culture and people they just can't live without bread, it is their main food. They can eat fruits but not all of them, for example they don't have to eat melon or grapes, persimmon, banana, but they can eat other fruits.' (DO-03)

Another doctor was giving out printed sheets with information about diet for diabetics that she had found on the internet. One table listed carbohydrate units with respective foods; the other table illustrated the glycemic index of different foods. She explained that she normally provided both lists to the patients and that the families did not like the list with the carbohydrate units. The reason why people preferred the glycemic index was that they were given more freedom and less restriction regarding their diet as the doctor's statement highlights.

'For example our doctors say that you are not allowed to eat melon but you can eat water melon. [...]For example doctors say that they are not allowed to eat grapes at all, but here it says that they can eat 3 grapes. That is why people like this.' (DO-02)

6.3.2.3 *Families did not use carbohydrate units*

One doctor explained how their hospital carried out monthly trainings for diabetic children and their families. Parents were informed about carbohydrate units and doctors instructed them how much they could eat of different foods. When the doctor was asked if families thought it was difficult to weigh foods and calculate carbohydrate units, the response was that the doctors in practice were performing the calculations and the parents were writing down a list of numbers only (DO-01). When interviewing families, carbohydrate units were not used by any as a measurement and only a few mentioned that they had heard about it previously.

6.3.2.4 *Insulin treatment: application and prejudices*

Biomedical knowledge about insulin and how it affects the blood sugar was rather limited. Most families used Humulin 70/30, which they injected twice a day. Insulin R (regular) and Insulin N (insulin isophane) were also used by a few children. Injections were mainly done in the upper arm and in the leg. In a few interviews with families it was discovered that the child used the same injection spot exclusively.

'You know the needle does not go very deep but we have been doing it for two years and her arm gets very hard.' (M-15)

This quote was given by a mother of a 10 year old diabetic girl explaining that her daughter refused insulin injections persistently. Many families knew that insulin was life-saving.

Nevertheless, injections were skipped regularly. This was done for different reason, one being the instant physical pain, mentioned above and expressed by many children. Intertwined with the physical pain the child was experiencing, was the parent's reaction. Many parents used the Tajik expression '*dil mesuzad*', meaning '*my heart burns*', when explaining why they did not want to force their children to take insulin. Through key informants it was learned that this term was often used when someone was experiencing pain and you felt with them. It could almost interchangeably be used with the English word '*compassion*' it was said. Furthermore it was learned through key informants that Tajik people often were concerned more with the present than the future, in order that the immediately felt pain of insulin injections was considered as more important than long-term complications, which few families had biomedical knowledge about. The mother of a 16 year old diabetic boy verbalized the dilemma she had experienced, saying:

'For almost one month he did not get insulin injections because we just didn't want to hurt him anymore, but then he got very, very sick. Then we started to do injections again. Every time we did injections he cried. Now he does it by himself. Of course I understand how difficult it is for him to take insulin every day and he has been doing it for 4 years. It is easy to say that he has to do it, but it is really difficult to take it all the time.' (M-18)

The challenge was more intricate with young children. One mother of an 18 year old girl, who was diagnosed at the age of four, described the challenge of knowing intellectually that she needed to inject insulin, at the same time however not overcoming the emotional hindrance of having to hurt her little daughter.

'My daughter cried when I gave her injections. She cried and said 'don't do that, don't do that'. Because I had compassion, I couldn't do the insulin injections.' (M-01)

It was shown that none of the children injected insulin at school. It was in most cases done before and after, so that other students would not make any comments. In the majority of cases their peers did also not know that they were diabetic either. A 12 year old diabetic girl said:

'Before I did it at school, but when my class mates looked at me I didn't like it. Then I changed it and now I do it at home before I go to school. I do it at 11am, go to school and when I come back from school I do it at home at 3 or 4.30pm after reading my 'namos' (prayers)'(D-16)

Limited biomedical knowledge and judgments about injections in the general public was described by one 14 year old diabetic boy. He was observed injecting insulin and judged to be a drug user.

'One day when I was doing my injection when I was on the balcony, one boy saw me from the distance and he thought I was a drug user. Even when I told him that I have diabetes he did not really believe me.' (D-14)

Drug abuse and smuggling of drugs is a problem in Tajikistan as the major drug route is passing from Afghanistan through Tajikistan to Russia and other countries in the West. Therefore drug use is, even if rarely visible in everyday street life, an increasing problem. Preconceptions led to judgmental behavior and exclusion of diabetics who needed to inject insulin with syringes several times per day.

6.3.2.5 *Glucometers: cost, availability, awareness and application*

Glucometers and test strips were scarce and expensive, and an average Tajik family could not afford to buy either one of them. According to doctors, Accu-Check from Roche and new Chinese brands could be purchased at pharmacies. Also a Russian brand 'Elta Satellite' was suggested in an interview with a doctor as a cheaper option, the costs being about 250 Somoni (~54 US\$). Test strips (50 strips) would cost approximately 150 Somoni (~36 US\$). Glycosylated hemoglobin (HbA1c), which is used to identify the average plasma glucose concentration over prolonged periods of time, was at the point of investigation not available in Tajikistan. This was stated by a doctor working at one of the central endocrinological institutions in the capital. The reason was explained to be that reactants were too expensive to be purchased.

Two of four doctors also mentioned that they thought that more training was needed because families did not understand the value of testing their blood sugar. This was frequently observed when visiting families. Even though they had received a glucometer including test strips free of cost as well as training at the diabetes camp, it was often nicely wrapped and placed on the top shelf in the cupboard. Asking a doctor about her thoughts on the use of glucometers she said:

'I think if their parents see how it works and would experience how it helps them when the blood sugar of the child for example falls; I think they would use it. They should also know that they should not only use it in the camps but explain to them to use it regularly.

Sometimes the parents just keep it and think it is a gift, so they just keep it but don't use it. I sometimes see that they just wrap it and keep it.' (DO-02)

The doctors' opinion was supported by an interview with a young educated woman with T1DM who had biomedical knowledge above the average participant. She said that she did not need to measure her blood sugar because she could feel how high it was. She felt safe, because even if her blood sugar was as high as 18 or 20mmol/l, she did not feel terribly sick. (D-04)

Another important reason why glucometers were not used at home was voiced by a mother who said:

'Both the glucometers and the instructions are in English. We have got two glucometers, but they are both in English. We understand Russian but not English.' (M-05)

Parents wanted to read instructions in order to understand what they had to do and what the glucometer was good for. A few families also stated that they were confused about how to use the glucometer and therefore had stopped using it. One participant mentioned that he did not know what to do when the letters 'IO' instead of a number appeared on the display. He did not understand the meaning of these letters. When helping to read and understand the English instruction, it was evident that letters on the display meant that the blood sugar was above the upper detection limit of 30mmol/l. He read the letters according to the Cyrillic alphabet, meaning that the letters on the screen in the Greek alphabet were 'NO'. Instructions in Russian were not provided. (D-02)

Most children explained that they measured their blood sugar once a month at a diagnostic center or when visiting their doctor. However, there were a few cases where regular blood glucose measurements were carried out 2-3 days a week. These children had comprehensive support by the parents or another important family member. In one case the mother was a medical doctor who was knowledgeable about T1DM and its treatment. Another girl had a very active grandmother who had T2DM and attended a diabetes club for patients with T2DM.

In hospitals doctors told that they would measure the blood sugar both as part of diagnosis but also to find an adequate insulin dosage. One doctor said:

'We usually measure the blood sugar before every insulin injection. Sometimes we maybe measure the blood sugar 8 times a day.' (DO-03)

The challenge for doctors was that families did not continue to measure their blood sugar at home, which in turn made it difficult for doctors to find an adequate amount of insulin, so the child would neither get hypo- or hyperglycemic. It was explained by one doctor that their practical solution was to find a middle way, prescribing a fixed approximate dosage, aimed to first of all prevent hypoglycemia (DO-02).

6.3.2.6 *Experiences with high- and low blood sugar and consequent steps of action*

Interviews with families showed that symptoms of hypo- and hyperglycemia were not easily recognized.

When the children were asked about their experiences of having a low blood sugar, and which bodily symptoms they had experienced, the answers varied. A 16 year old diabetic girl said that she had experienced hypoglycemia and described the bodily reactions correctly.

'Yes, sometimes I have a very low blood sugar. When it gets low I feel very hungry and my arms and legs are shaking.' (D-10)

An 11 year old diabetic boy described his preference of having a hypoglycemic blood sugar level saying *'When it is 3mmol/l I feel very good. Once it was very low, it was 1mmol/l. [...] I was healthy and didn't feel bad when it was 1mmol/l.'* (D-08)

Further in one case the participant described which actions he would take to increase the blood sugar if he felt hypoglycemic.

'When it gets low I drink tea with sugar. Then I eat food. Then it gets higher. When it gets too high, there is one fruit it is called 'dolona', it is a mountainous food. We make compote of that. But now, nothing helps me. Now it is so high, that I don't know how to make it lower. I tried everything, but I have felt that nothing is helping anymore.' (D-02)

However, what became evident also in his description is, that he knew what to do when the blood sugar got too low, but was not sure how he could lower the blood sugar if it was felt to be high. Few families thought of the option to increase the insulin, rather they experimented with different foods and herbal teas that they anticipated would help.

Also, in a few cases symptoms of hyperglycemia were mistaken with symptoms of hypoglycemia as demonstrated in an answer from a 13 year old diabetic boy when he was asked about his experienced symptoms having a low blood sugar:

'When it gets low I have a headache and I have to vomit.' (D-09)

Biomedical knowledge about their blood sugar level was diverse and was based on their personal experience. One young man also stated that he was not familiar with symptoms of hypoglycemia since he did not have experience with it, saying:

'When my blood sugar gets high I become very weak and I want to drink a lot. But my blood sugar does not get low, so I don't know how this feels like. Usually it gets too high.' (D-06)

Symptoms of high blood sugar were described in many cases and included being tired, weak, having headache and sleeping. One 11 year old diabetic boy explained how he sat at home, feeling tired and weak.

I become very weak and I just don't want to walk. I just sit in one place and I always watch cartoons. (D-08)

Children all had experience with hyperglycemia in particular, to what extent they were aware and had biomedical knowledge to identify their condition correctly were however diverging.

6.3.2.7 *Experiences with elevated acetone and coma*

Acetone and coma were topics that emerged in the interviews with families. At least 11 out of 18 children and adolescents had experiences with high acetone and diabetic coma, caused subsequently by chronic high blood sugar levels.

Parents had different information about how they could recognize when the acetone was elevated. An experienced mother of a daughter who was diagnosed 14 years ago explained:

'I already know when it is high. I know it from her urine smell. It smells acetone, it is like foam and it gets white. And I already know the symptoms. She also gets constipated. She also throws up and has headache.' (M-01)

Another mother pointed out further symptoms that she had both learned from the doctor but also observed herself:

'The doctors told me that you will know it from the smell. His mouth can smell acetone. Another thing is that he gets very weak and always wants to sleep. He gets very thin.' (M-14)

Asking about why they thought acetone increased, many families were aware of the connection between prolonged high blood sugar, elevated acetone and coma.

Various approaches were described by families on how elevated acetone could be treated. A few had received specific advice from their doctors on how to 'wash out' the acetone as described by one mother:

'I give her water mixed with soda. I put 2 full spoons of soda in 2l of boiled water and dissolve it and give it when it happens. I also give her yoghurt. But, I don't give her oily food. She eats boiled food, not oily food. When it happens I try to give her the first aid myself. And when I take her to the hospital they give her infusion.' (M-01)

Besides dietary adjustments and using a self-made soda mixture, herbs were used by many families as well. This is described in the following chapter.

Diabetic children were asked how they perceived being in a coma. One 16 year old diabetic boy recalled very specifically when he was in a coma but was not able to remember specific details. He said *'I only remember that it was snowing that day. It was January 2008, the 12th or the 13th when I was in the coma.'* (D-18)

Another young man who had been diabetic for 11 years described a very unique encounter when he was in a coma for a prolonged time.

'I have been in a coma again. It was the second coma and I was in the coma for almost 2 months. When I was in the coma I dreamed about a tunnel and it was very white and bright

and I had to pass this tunnel, but I didn't pass it because I thought that if I pass this tunnel, maybe I will die. Then I woke up again.' (D-02)

Coma was experienced by many and feared by most as they knew, that their life or the life of their child would be dangling on a string.

6.3.2.8 *Perceptions about- and experiences with herbs*

The use of herbs was mentioned in a few interviews with families. Specific herbs were used and perceived as an appropriate remedy to reduce symptoms. The most frequently named herb was walnut leaves. Others herbs that were referred to by a few families were chicory, rhubarb, bay- and beans leaves, corn silk and 'khatsch'. A 20 year old medical student who was trained as a pharmacist explained how she used the different herbs to prepare teas when she had symptoms of high blood sugar and felt sick. She explained:

'I make tea from walnut leaves that I drink. I also make tea from another herb. As I am a pharmacist I know what kinds of herbs are good for diabetes. This is walnut leaves, and this is 'khatsch', I boil it in water and then I drink it. This is chicory and it has purple flowers. When you break the stem there is a milky liquid coming out. They grow it in Varzob (geographical area outside of Dushanbe).'' (D-04)

A mother explained further that they did not use the leaves of the chicory, but made tea from the stem (M-18). When asked whether they did experience any improvements in the child's condition after using herbs a mother replied that it helped a little, but not so much (M-17).

Observations from group discussions at the diabetes day in Dushanbe, with about 10 families, showed that there were different opinions about to what extent herbs were helpful. A few hoped for an alternative treatment to insulin, others viewed it as an additional remedy that could be helpful when the child got sick of hyperglycemia, whilst others again were persistent in telling that only insulin was able to reduce the blood sugar. The vivid discussions demonstrated that this was a topic of interest. It was explained by the participants that herbs were easily accessible to most families and free of cost.

Asking one doctor about his opinion on the use of herbs, as a treatment or an additional remedy, he clearly stated that *'Without insulin we cannot save the children's lives.'* (DO-04)

6.3.3 *Responses related to the health care system*

Assessing perceptions about the health system was initially not planned, however as this was closely intertwined with the challenges families faced, key aspects related to insulin procurement, cost of treatment, as well as how T1DM was perceived in the health care system are described in the following paragraphs.

6.3.3.1 *Experiences with- and concerns about insulin procurement*

Experiences and concerns related to insulin procurement were mentioned by most families during the course of the interview. Observations of group discussions at the Operation Mercy diabetes day in Dushanbe broadened the understanding further.

Insulin was provided by Project Hope, an organization which had worked in Tajikistan since 2002. March 2011 a severe insulin shortage occurred as a result of unstable insulin provision. The consequence was that families had to buy insulin themselves before the International Diabetes Federations *Life for a child programme* was able to procure life-saving insulin to Tajikistan. In cases where families had to buy insulin themselves, it was reported that the cost of one vial (10ml) of Humulin 70/30 would range between 120-150 Somoni (~26 US\$ - 33 US\$). These numbers were based on information from interviews with both families and medical doctors. One doctor estimated that one vial would last for about one month, depending on how much the individual child needed (DO-03). This was supported by one participant who stated that he generally managed with one vial (10ml) per month (D-14). The comparably high cost for buying insulin caused severe problems and was reported by most families. A father described his despair in the situation saying:

'The most difficult is to take my daughter to the hospital and to get insulin to treat her. I got insulin for free from the hospital, but now when I had to buy it twice I don't have any more money to spend. I have three children, I don't have work.' (F-12)

This description was the reality for many of the families visited. A few families reported how they found alternative ways to procure insulin. They explained that they received insulin through family members who worked in Russia. In such cases insulin was transported with relatives or a trusted person either by plane or car.

The consequences of unstable insulin provision were also described by the doctors. They all portrayed the situation as serious and challenging. One doctor described that patients had suffered severely due to the lack of insulin earlier in 2011. Especially children originating from poor families were seen as vulnerable, as they did not have the financial means to purchase insulin. In such circumstances families had to take up loans. The doctor further explained that they sometimes helped them and did not charge any money for the treatment. (DO-03) These statements were made from doctors in different geographical areas, indicating that the insulin scarcity was not limited to one region. One doctor from the South said *'When there was an insulin shortage they (children) were seriously sick because they could not afford to buy insulin'* (DO-03). A doctor from the North said, when asked about whether many children had been in a coma due to the insulin shortage, *'Yes, many! Even now we don't have enough insulin left.'* (DO-04) That insulin was becoming scarce again was

also confirmed by one of his patients' family, where the mother explained that the doctor could not provide insulin anymore.

'First the doctor gave us two vials of insulin and some syringes but then he said that they had many other children they had to provide with insulin as well, so from that time my husband had to buy it.' (M-11)

At the Operation Mercy Diabetes day in Dushanbe several of the ten families attending told that they currently were struggling with insulin provision. As a consequence several children had been admitted to the hospital due to very high blood sugar levels. A few also reported that they had been in a coma.

Discussions with key informants pinpointed the need for sustainable solutions to procure insulin on an uninterrupted basis. It was further mentioned that both the Ministry of Health and international actors needed to be involved in finding a sound solution for Tajikistan.

6.3.3.2 *Managing cost of treatment*

Families did mention cost of treatment in relation to insulin procurement, but also in connection with treatment and care in hospitals.

Both families and key informants explained that it was normal to pay money for treatment at the hospital. This included medicines and infusions. In 2009 the average monthly salary for a medical doctor was 38 US\$ compared with a workforce average of 65 US\$ (Scheider, 2009). Therefore other revenues of income needed to be pursued to provide income for their own family. As a result, out of pocket payments were endemic in the medical system. This was voiced clearly by several families. One mother described *'Wherever you go, you have to pay some money.'* (M-05) When asked why they were offering money the following description was given by one father:

'We give the money just to get better treatment and not to make them angry. If we give them money it is better and we get treated better. If you don't give money it does not work. There are some people who can't give money and then the staff gets very angry and they just don't look after them.' (F-12)

Few families gave explicit numbers of how much they would pay to receive better treatment, but one father said: *'50 Somoni (~11 US\$) for the doctors, 20 Somoni (~4 US\$) for the nurses and for others 10 Somoni (~2 US\$)'* (F-12) A mother described how they managed, knowing that hospital treatment was necessary at some point: *'We need to collect money and when we have enough we go to the hospital again.'* (M-15)

One family described that there had been instances where it was difficult to obtain free insulin, when asked if they received insulin free of cost.

'Yes, we do, but it is very difficult to get free insulin. In order to get insulin we have to go to maybe 10 rooms and I think we have to give some money to them to get insulin, because they look at you very strangely when you get it free. It is easier to buy it at the pharmacy.' (F-05)

Some families described on the other hand that not all doctors required bribes for 'better' treatment and care. One grandmother stated:

'I am so thankful for doctors that have done such a great job with my grandchild. They did not ask any money from me. I thought my grandchild is going to die. And the head doctor at the hospital was very nice and said that we did not have to pay money and he did not ask for anything.' (R-07)

Another mother said *'But our doctor is a very good doctor, he has a very good heart and he also has good knowledge. He is very humble'* (M-04).

Families described the relationship between themselves as patients and the health personnel as ambivalent. In practice most families had to carefully consider whether it was really needed to take their child to the hospital, as the actual expense for receiving treatment was unpredictable due to the endemic nature of out of pocket payments.

6.3.3.3 *T1DM in a transitioning health system*

Interviews with families and doctors showed how T1DM was perceived in the health system and how it had changed after the fall of the Soviet Union. A mother and nurse by profession expressed her thoughts about societal- and health system changes as followed:

'Life has changed after the Soviet times. We had a very different life in the Soviet Union; we didn't have so many problems. We have many problems now days. There were not so many people with diabetes that time. Maybe that is why this disease is increasing so much because now we have so many problems. Wherever we go we have to pay money and people are burdened, stressed and angry. Maybe this is why this disease is increasing. You can see that even youth have high blood pressure and heart problems.' (M-14)

A medical doctor on the other hand pointed out his opinion saying that medical care was deficient in remote areas in the past, but that after independence things had developed and that many people were more skilled. (DO-01)

However, it was acknowledged that epidemiological data regarding actual numbers of cases with T1DM were inadequate and lacking, as patients only were registered if they were admitted to an endocrinology ward. One doctor explained:

'Because of many reasons, we don't know the exact number of cases in Tajikistan. If we say there are 200 or 300 people with diabetes in Tajikistan that is not the exact number. For example a child can be in the surgical department, having some operation, but maybe he or she also has diabetes.' (DO-02)

The main pediatric hospital for diabetic patients had republican status, meaning that children from the entire country could be referred to this hospital. The doctor explained that children coming from Dushanbe were mostly migrants, originating from other regions of the country; especially parts that were affected by the civil war 1991-1997. (DO-01) He explained further that cases of diabetes have risen in the past 20 years, the time he had worked as a specialist in this area.

'First, when I started working in this area 20 years ago, I can say that there were very few people with diabetes, maybe there were about 100 people in the whole of Tajikistan. Every year we register 50-60 people that come to our hospital. These people come from Khatlon region and the Central Region.' (DO-01)

Key institutions for treating T1DM were located in the capital Dushanbe, in the northern city of Khujand (Sughd region) and in the southern city of Qurghonteppa (Khatlon region). Case numbers of children and young adults living with T1DM show that the Republican Subordination, the Khatlon Region and the Sughd Region accounted for 455, 87 and 187 known cases respectively (detailed information is provided in *Table 1: Epidemiological data, Chapter 1 Background for Research*). One doctor commented that the autonomous region of Gorno-Badakhshan was supported by the Aga Khan Foundation, which was perceived to provide good medical care. Actual cases of T1DM were however not available.

6.4 'I WOULD LIKE TO KNOW MORE ABOUT' AND 'I WOULD SUGGEST'

All participants were asked two specific questions during the interview. The first question was *'Do you think that more information about T1DM is needed from your point of view?'* The second question was *'If an information booklet for diabetic children and their families would be developed, is there a topic that you would like more about?'* *Do you have any questions or suggestions?* The questions were posed to the diabetic child, the parents and the endocrinologists and were generally asked towards the end of the interview.

Families and doctors all stated that there was a need for more information for families living with the T1DM. A few families who had lived with a diabetic child did however say that they felt they knew everything already, but thought it would be of great benefit for newly-diagnosed children and parents. One doctor stated that *'I think if we have this booklet, we can use it to work with them because you know doctors don't have much time to develop and write material'*. Further she said *'I think it is because people are not educated, that is why many people die from this disease.'* (DO-02) pointing out the need for patient information.

A doctor from the endocrinology ward in the republican hospital in Dushanbe explained that they arranged trainings once a month with about 25 participants at a time. Despite his initial conviction that children and families, who had attended the training, were well informed, he

responded very positively later in the interview, when asked whether he thought more information material was needed.

'It would be a very good work! The children need this booklet, so I would be very glad if you would make such a booklet! You know, the patients we have often ask us about if we have some information, but the booklets we have we don't have them all the time. It would be very good if they have a good knowledge about diabetes and if they know about complications they can get. We would be very thankful for your work!' (DO-01)

The most profound reaction pointing out that information would be desired and appreciated was experienced at the International Diabetes Day, held at the First Sawetzki Hospital in Dushanbe. Being invited as a guest, I used this opportunity as a platform for observation. However, five minutes after arrival I was asked to give a speech without any prior notice. The most recognized endocrinologists in the country were present as well as many families with their diabetic child. I talked about my reason for coming back to Tajikistan, wanting to learn more about families living with a diabetic child. I explained that their information would be used to hopefully create a booklet about T1DM in Tajik. The response was overwhelming as everyone unexpectedly started clapping. This was a definite statement from both the families as well as the doctors that information was very much needed and would hopefully be used and supported by them.

6.4.1 Suggestions from families

Children and their parents were asked during the interview which topics they would suggest to be in a booklet for patients with T1DM. Learning about a good diet for diabetics was the main topic that was suggested by children and parents in 15 out of 18 families. Within this group, there were varieties of suggestions, most saying not to eat sugar, sweets, bread and oily food.

Families also had questions about fundamental biomedical knowledge regarding diabetes, namely how it is defined (named four times) and how it is treated (named five times).

Looking beyond the questions that were named more than once, a great variety of highly relevant suggestions were made by the families. An extensive list of suggestions is provided below:

- Have a good diet (15x)
- Treatment of diabetes / Is it curable? / Can I take pills instead of insulin? (5x)
- What causes diabetes? / What is diabetes? (4x)
- See the doctor and get everything checked (3x)
- Protect your sight, gum and stomach (2x)

- Take insulin on time! (2x)
- What makes my blood sugar go high? (2x)
- Be careful with sores - they heal slowly
- Don't drink alcohol!
- Free special centers for diabetes
- Recopies with affordable local foods
- How to communicate with society to prevent isolation and depression
- How to look after myself in daily life
- What are symptoms of diabetes?
- Test urine to diagnose diabetes – it tastes sweet
- Why do I feel weak when I get sick?
- Why is diabetes increasing so much in Tajikistan?
- Information in one book- not a little here and there
- Which herbs are good for diabetes?
- Physical exercises – How can I be more active? / What am I allowed to do?
- I want to read about something encouraging
- Tell children not to be discouraged!
- What to do when you just have been diagnosed

6.4.2 Suggestions from endocrinologists

Endocrinologists had similar suggestions, regarding the content of a booklet targeting diabetic children and their families, but different focal points. Doctors suggested topics such as describing what diabetes is, how children could look after themselves to prevent complications and to write or illustrate how glucometers should be used, preferably in combination with training. A full list of their suggestions is provided below.

- What is diabetes? (2x)
- Look after yourselves to prevent complications (2x)
- Teach about glucometers and how to use them (combination with training) (2x)
- Nutrition / Diet
- What is insulin? / How does it work in your body?
- Statistics about how many people have diabetes in general and in Tajikistan – show children that they are not the only ones with this disease
- Give hope – give examples from other countries or famous people (athletes, stars)
- Explain that having diabetes does not mean that you cannot get education
- Make colorful books that are child friendly including pictures

6.4.3 *Diabetes camps were experienced as encouraging*

Besides mentioning information material many families and doctors pointed out the need of diabetes camps for the children. When children were asked about whether they had been to a diabetes camp their eyes lit up and a smile appeared. When asked about what they liked, most said that they liked the games and playing with others. One girl also said she liked the regular meals. This positive experience was also described by most mothers, who had a child that had been to a diabetes camp. The mother of a diabetic 18 old girl said *'My daughter got so happy when she got to go to the camp. [...] If there are these kind of places, if they organize these kind of things, it would be so good because they are always at home, they don't go out. It would be so good if camps would continue.'* (M-01)

A doctor mentioned that his patients were very impatient to go to the camp. They had called him frequently, asking when it finally would take place. As there was an insulin shortage in 2011, there was not diabetes camp. The doctor stated that some children got very upset and sad when they were told that they could not go to the camp. When he explained to them why it was not possible to conduct a training they responded *'It's ok, we can buy insulin ourselves if we can go to the camp'* showing the willingness to somehow make it possible to go to the camp, even though the financial constraints would have been severe for the rest of the family.

6.5 SUMMARY OF CHALLENGES FAMILIES FACE

A final summary is presented, aiming to abstract challenges families face, distinguishing between *challenges that can be met by giving information* and *challenges that need solutions from the health system*. This was considered of support, having in mind the overall future goal to develop information material, based on the findings of this research project.

6.4.1 *Challenges that can be met by giving information*

The following points will highlight which challenges families faced and how information material could improve their situation.

Information about T1DM and its treatment

- As most families did not possess written material about T1DM and how it is treated, a booklet developed with them and for them would fill this gap, offering support in their everyday life.
- As life revolved around an ambiguous relationship between living with a chronic disease in reality and the uncertainty about whether there is a cure that was yet unknown to them, providing information at an early stage would add to clarification.

- As most children experienced chronic hyperglycemia, information about blood sugar regulation through food, insulin and exercise might help to a life with less symptoms, feeling healthier in general.

Cause of T1DM

- As most families experienced that emotional stress and evil eye caused diabetes, information about the biomedical standpoint might help to realize that is not their fault.

Acute complications

- As some families initially did not recognize insulin as the life-saving remedy, the provision of an information booklet immediately after diagnosis could help to prevent delayed action, and possibly life-threatening situations.
- As initial symptoms of having T1DM were not recognized in most cases, providing basic information about symptoms could create an increased awareness, contributing to rapid diagnosis.
- As some families did not recognize symptoms of hyper- and hypoglycemia correctly, information about symptoms, possible causes and consequent steps of action could help to prevent acute high- and low blood glucose level.
- As most families were well acquainted with elevated acetone levels and diabetic coma, information about steps of action and first aid could help to prevent life-threatening situations.

Long-term complications

- As some parents described it to be challenging to enforce insulin injections when their child refused persistently, information about long-term consequences and how they can be prevented could help to internalize that insulin injections are in the best interest of the child.

Emotional support

- As many families felt alone in their situation, information about actual cases of diabetic children worldwide as well as in Tajikistan could be of emotional support for the families.

- As some parents voiced concerns about their diabetic child's future, information about successful people living with T1DM could be an encouragement to the families.
- As many children experienced exclusion and loneliness, information could lead to more self-confidence in identifying with T1DM, facilitating openness rather than withdrawal.

Food and herbs

- As most families had limited biomedical knowledge about the effect of different foods on the blood sugar, information about locally available and affordable foods could contribute to a better understanding of a healthy diet for diabetic children, and result in better long term blood glucose levels.
- As many families had experience with the use herbs, information about their usefulness but also limitations could provide guidance.

Insulin and glucometers

- As most families had limited biomedical knowledge about insulin, information about its mode of action, how it should be administered and stored could help the families to manage their daily life in a better way.
- As most families had marginal knowledge about glucometers, information concerning its administration and its usefulness in conjunction with insulin therapy could help to gain a better controlled and more consistent blood glucose level.

6.4.2 Challenges that need solutions from the health system

The following points need be addressed by the government in Tajikistan in order to meet the challenges the families face.

- Insulin was not available on an uninterrupted basis, causing severe acute complications such as coma and potential death.
- Insulin was not affordable by poor families in cases where free insulin was not provided, causing chronic hyperglycemia, consequently leading to long-term complications.
- General awareness about the existence of T1DM in Tajikistan was scarce, causing families to experience prejudices and exclusion from society.

- The lack of information among health personnel about diabetes in children lead to delayed diagnosis and maltreatment.
- Medical personnel had limited up-to-date information about treatment and care of T1DM in Russian language and no information was available in Tajik.
- The limited availability of health centers with competent endocrinologists in remote areas forced families to travel several hours. The limited accessibility led to considerable travelling expenses for the families.
- Out of pocket payments in the health sector have been described to be a major hindrance for poor families to seek help.
- Salaries of medical doctors were described to be very low, cultivating out of pocket payments to be an integral part of the health care system.

7 DISCUSSION OF FINDINGS

In this study, interviews with 18 diabetic children, their parents and four medical doctors provided qualitative data on how T1DM is perceived in Tajikistan. Furthermore, perceptions about the need for information and education, from their perspective, were described.

From discussions and observations, three pertinent themes were identified and described in the previous chapter. These themes were (1) *Finding out the child has diabetes*, (2) *Life with type 1 diabetes* and, (3) *'I would like to know more about'* and *'I would suggest'*. Key findings of respective themes will be subject of discussion in the following sub-chapters.

7.1 FINDING OUT (OR NOT FINDING OUT) THE CHILD HAS DIABETES

In Tajikistan, public awareness regarding T1DM was marginal. Furthermore, biomedical knowledge of affected families and hospital staff, regarding the causation and its treatment, was limited. This affected perceptions families had, regarding the etiology of T1DM, and led to severe consequences regarding treatment, especially when the child presented first symptoms and medical advice was sought.

7.1.1 *The families' perception of illness causation*

The parents shared detailed encounters of how they experienced their child to become diabetic. Common for most families was that they had very distinctive thoughts about the cause of the illness. The outbreak of diabetes was linked to an emotionally stressful event. A few families also viewed the 'evil eye' as the source of the child's disease.

According to the lay model on illness causation by Helman (2007) illness can be perceived as caused by factors related to the individual, nature, social relations or the supernatural sphere. In this model individual factors include lifestyle, behavior, personality, bacterial invasion, inheritance, physical constitution and organ function, whereas natural factors focus on chemical or natural substances (e.g. drugs, climate, the influence of sun, moon and planets) and environmental factors (poisons, smoke, pollution, exhaust fumes). Social relations may include relations between people (e.g. evil eye), interpersonal conflicts, people considered to possess evil forces and the supernatural sphere emphasizes factors such as fate, spirits and God/gods (Helman, 2007).

Based on this model, Tajik families in this study explained the causation of the illness mainly through the individual, through factors including social relations and through the supernatural sphere. An unexpected and emotionally burdening event released stress and fear, and is most closely related to an individual factor. However, as such events were varied, including natural disasters (e.g. earthquake), personal loss (e.g. unexpected death of a sister) or a difficult interpersonal situation (e.g. punishment by a teacher) the findings also indicate that

there are several layers of perceived causality, all related to an event that caused emotional stress. In this study an event caused stress which thereafter caused diabetes, so the question may rise, if a theoretical model can hold the complex interdependencies of human reasoning. The second explanation, namely that diabetes is caused by the evil eye, is more obvious to be placed in the category of factors including social relations and the supernatural sphere.

7.1.1.1 *Emotional stress*

Regarding emotional stress being a cause of diabetes, a few other studies report a similar finding (Dechamp-Le Roux, Valensi, Assad, Sislian, & Attali, 1990; Garro, 1995; Greenhalgh, Helman, & Chowdhury, 1998; Hjelm, Bard, Nyberg, & Apelqvist, 2003; Hunt, Valenzuela, & Pugh, 1998; Thompson & Gifford, 2000). A comparative study carried out in France, stated that Europeans cite various explanations regarding causes of diabetes mellitus whereas North Africans primarily cited stress or fate to be the cause (Dechamp-Le Roux et al., 1990). A similar comparative study was conducted by Hjelm et al. (2003), who explored the influence of cultural distance on health and illness beliefs in women from various cultural backgrounds (Arabic, ex-Yugoslavian, Swedish) with T2DM living in Sweden. The findings demonstrated that women from Arabic countries, and to a minor extent ex-Yugoslavia, discussed sorrow and emotional stress (as part of the migratory experiences) to be the cause of the disease (Hjelm et al., 2003). Another finding which is congruent with the findings of the current study is that even though participants explained their illness to be 'the will of Allah/God', they actively searched for information about management of diabetes. This was noticed in particular as questions were posed to the investigator during the interview, Hjelm states. Tajik families in this study behaved likewise, indicating a discrepancy between acknowledging and respecting God's sovereignty but experiencing at the same time the human desire to understand and find an explanation for their disease.

Stress as a cause was also a minor finding in a few other studies. A study in the UK explored British Bangladeshis' health beliefs and folk models about diabetes and described that the participants perceived sugar, Western diet, as well as emotional stress to be a cause of the illness (Greenhalgh et al., 1998). Hunt et al. (1998) explored Mexican American diabetes patients' causal stories and found that patients' causal explanations of their illness often were driven by an effort to connect the illness to their personal history. As an example one patient believed that his diabetes was provoked by the suicide of his brother, which caused him a lot of emotional stress (Hunt et al., 1998). This example is very similar to the one explained by a young diabetic woman in this study, who became diabetic after the inordinate stress she experienced as a consequence of her sister's unexpected death.

Even though none of the studies have focused on diabetic children in particular, there are indications however, that the perception of emotional stress being a possible cause of diabetes mellitus is relevant to diabetic patients, independent of age, culture and whether they have T1DM or T2DM. It may be asked if this perception is much more widely spread than anticipated, but not acknowledged as qualitative research on diabetes has not focused much on developing countries so far. Taking into account, that the highest increase in diabetes is expected to affect these populations in the coming years in particular, it might be argued that more attention should be drawn to understand their perceptions on the etiology of diabetes, helping to refine and adjust educational programs and interventions to strengthen the individuals' understanding of the disease and what they can do to live well with diabetes both physically and emotionally.

7.1.1.2 *The evil eye*

In this study a few families also explained the evil eye to have caused diabetes. Literature on the evil eye is considerable, does however focus on descriptive encounters with few attempts to explain the evil eye in theory (Dundes, 1992). Dundes explains in his book *The evil eye: a casebook* (1992) that the evil eye is a fairly consistent and uniform folk belief which is based upon the idea that an individual has the power to cause harm to another individual or his property, merely by looking at or praising that person or property. The harm may consist of illness, or even death or destruction. Typically he states, the victim's good fortune, good health, or good looks – or unguarded comments about them – invite or provoke an attack by someone with the evil eye. As a consequence physical symptoms can include loss of appetite, excessive yawning, hiccups, vomiting, and fever (Dundes, 1992).

In Tajikistan religious beliefs are strong and part of everyday life. As explained by Patai (1951) in an anthropological study on nomadism in Middle Eastern and Central Asia, there were numerous popular pre-Islamic customs, traditions and rituals, including the evil eye, which either had been incorporated into official Islam, or at least were tolerated (Patai, 1951). In Tajikistan Muslim culture and folk beliefs interacted and coexisted ambiguously with unclear distinguishing lines. What was right and honorable, and wrong and shameful behavior was clearly defined in the culture, however often without clear reference to the source defining the norm. For example, having a sick child sometimes was experienced as a curse from God for wrong behavior, attitudes or thoughts. Other times good fortune, good health or good looks were seen as a reason for someone to get jealous or envious, thereby placing the evil eye on the other person. This was for example demonstrated in the encounter from a 13 year old diabetic girl's mother saying that her daughter was exceptionally beautiful and smart and perceived this to be the reason why she was captured by the evil eye and became sick.

Loss of appetite and vomiting are among the symptoms a person can experience once captured by the evil eye (Dundes, 1992). These are also classical symptoms of acute hyperglycemia, which very likely have occurred between the onset and the diagnosis of T1DM. Therefore, it may be natural and understandable that parents connect the child's onset of the illness with the evil eye as a cause of diabetes.

7.1.2 Seeking help in the health system

Prior to diagnosis, very few families were aware of- or had knowledge about diabetes, so that no foundation was provided to connect the child's physical symptoms with the illness. As a consequence the children became worse, lost appetite and weight, had to vomit and became increasingly lethargic. When parents sought help in the medical sector, their experiences varied considerably, where in the worst cases children ended in a diabetic coma due to maltreatment. However, there were also several families who voiced that their child got diagnosed without delay.

7.1.2.1 Health seeking behavior

Most families explained that they sought help at hospitals and diagnostic centers. However, some also mentioned that they had consulted family members or went to a religious leader to receive prayer for the child. With persisting physical symptoms, they sought help at medical centers or hospitals. Kleinman (1980) describes in his model on health care seeking behavior that health care may be sought in the popular, folk or professional sector. The popular sector comprises non-professionals in the family, friends and relatives. The folk sector includes folk-healers, who are specialized in different forms of healing, sacred or secular. Finally, the professional sector is the organized, legally sanctioned healing professions, such as modern Western scientific medicine and biomedicine (Kleinman, 1980). In Tajikistan religious- and folk beliefs (e.g. evil eye) are a central part of everyday life. However, this did not seem to be reflected in the families' initial health seeking behavior, as described in the interviews. Some stated how they looked for help in the popular and folk sector, however most described how they sought advice in the professional sector. A similar behavior was also shown by Hjelm, who described that Arab women, who are similar in culture to Tajik's, had a lower threshold for seeking support from nurses and physicians than Ex-Yugoslavians and Swedes (Hjelm et al., 2003). However, as I most likely was identified with the professional sector, this could have influenced their willingness to describe their contact with folk healers or religious leaders. After the diagnosis, when the parents in this study got to know that T1DM is a life-long chronic illness, some clearly stated that they went to the folk sector to seek help. Finally, they all returned to the hospital, realizing that insulin was the only effective treatment. Jobling (1988) refers to this behavior as 'Sisyphus syndrome' in Anderson & Bury (1988) where

Sisyphus, condemned by the gods, rolled a boulder up to the top of a hill, only to see it roll back down again (R. Anderson & Bury, 1988). Similarly, patients went through rituals of treatment, only to find out that the condition had changed very little. This finding was important as it demonstrated that families, after seeking help elsewhere, realized themselves that insulin was the only life-saving remedy. This made them open and receptive for information and education, the challenge was however, that there was no child-friendly information available in Tajik language.

7.1.2.2 *Doctors lacking awareness of- and biomedical knowledge about T1DM*

Parents' pre-diagnostic memories were characterized by inordinate stress, helplessness and despair. The degree varied according to how well they experienced to be taken care of by the health system.

Regarding their pre-diagnostic experience families described two main problems. First, attending doctors' and health personnel's lacking biomedical knowledge, about symptoms and diagnosis of T1DM, caused a delay in diagnosis and treatment; second, children were subject to maltreatment in hospitals. Consequences of both were that many children became ketoacidotic, a life-threatening situation, leading to coma and death if untreated. It is known that the frequency of diabetic ketoacidosis (DKA) at clinical onset of diabetes varies widely by geographical region from approximately 15% to 75% (ISPAD, 2011). Dunger et al. (2004) further estimate the overall mortality rate in pediatric patients with DKA to be between 0.15% and 0.3% (Dunger et al., 2004). However, it is claimed that this rate almost certainly is significantly higher in underserved populations with inadequate medical services (ISPAD, 2011). This could be supported by the findings of the current study in Tajikistan. Almost all diabetic children experienced DKA at clinical onset of the disease and 11 out of 18 diabetic children had been in a diabetic coma at least once since diagnosis. One patient recorded how he encountered his experiences of almost dying. Furthermore one participant explained that his sister, who also was diabetic, died a few years ago, at the age of 21 years.

It seems highly likely that the main reason for such high numbers of children with DKA at diagnosis was closely linked to the limited awareness of- and biomedical knowledge about T1DM among medical doctors and health personnel, treating the patients coming to-, and staying at the hospital to seek help and to be treated. This phenomenon has been described in other studies from similar settings in sub-Saharan African countries (Elamin, Ghalib, Eltayeb, & Tuvemo, 1997; Monabeka, Mbika-Cardorelle, & Moyen, 2003; Rwiza, Swai, & McLarty, 1986). Majaliwa and colleagues (2008) stated, that the high prevalence of DKA (diabetic ketoacidosis) in newly diagnosed patients with T1DM in Africa is attributed to the lack of awareness among health workers and the community at large (Majaliwa et al., 2008).

As a consequence limited awareness of- and biomedical knowledge about T1DM may result in maltreatment, as shown in a study from Tanzania, where 21 out of 199 patients were diagnosed having cerebral malaria, however presenting symptoms of severe DKA or coma (Makani et al., 2003).

Furthermore, the lack of awareness about T1DM has not only been reported in developing- but also in developed countries, as it was shown in Hatton's study (1995), describing that some young children had been misdiagnosed initially as having meningitis, leukemia or another devastating illness (Hatton et al., 1995). On a positive note it has been shown in an Italian study by Vanelli that the frequency of DKA at onset of diabetes was reduced sustainably when vigorous efforts were made to educate the medical community and school personnel concerning the classical symptoms of diabetes and, in particular, the significance of bedwetting during the night (nocturnal enuresis) (M Vanelli et al., 1999; Maurizio Vanelli, Chiari, Lacava, & Iovane, 2007). Despite these results being from a European country, they indicate that simple and most basic information on classical symptoms may have a considerable effect to prevent the child from life-threatening situations. They further highlight the importance of not only educating health personnel, but also targeting teachers. In the current study 8 out of 16 school-aged children stopped going to school. It might be imaginable that teachers, if they had information about T1DM, would be able to support diabetic children in a better way, encouraging them to stay in school. Furthermore, they could contribute to the emotional well-being of the diabetic child by educating co-students about the need to understand and support, rather than to stigmatize and isolate the child.

7.2 LIFE WITH TYPE 1 DIABETES

7.2.1 The consequences of lacking information and education on diabetic children and their families' emotional well-being

Emotional responses were characterized by an ambiguous relationship between living with a chronic disease in reality and the uncertainty about whether there is a cure that was yet unknown to them. This experience was maintained, one reason being that children and their families did not have any information, providing answers to their questions. This affected life with T1DM in various ways. Furthermore, public awareness was limited and affected how diabetic children and their parents were perceived in society. These aspects will be discussed in the following sections.

7.2.1.1 Biographical disruption

Chronic illness is by definition a long-term, and perhaps permanent, event in a person's life (Bury, 1991). It is acknowledged that the onset of chronic illness represents an assault to a person's physical self. However, equally important, it also affects a person's sense of

identity, where he or she doubts his or her self-worth (Charmaz, 1983). As a consequence, loss of confidence in the body results in loss of confidence in social interaction. This description of how a person experiences the onset of chronic illness, is what Bury (1982) refers to as 'biographical disruption' (Bury, 1982).

Diabetic children were faced with an abrupt onset of the disease and a trajectory of a life-time chronic condition. Becoming diabetic was most likely experienced a biographical disruption. Physically, the pancreas stopped producing insulin, leading in most cases to DKA and coma at diagnosis. But, children were also deprived of their identity as a healthy child, facing a life-long disease which requires a strict regimen including in particular frequent insulin injections and a well-regulated diet. In addition, almost none of the families had heard about T1DM before, creating confusion, disbelief, rejection, shock, fear, anxiety, anger and helplessness. After an initial shock and immediate reactions, a process of grieving started.

7.2.1.2 *Chronic sorrow*

Initial feelings that children and their parents experienced were very similar to those of a normal grief reaction. Worden noted that disbelief, confusion, sadness and relief are all normal manifestations of grief (Worden, 2009). As Miller described in *Hearing from children who have diabetes*, an actual death had not occurred. However, in many ways a death of part of the body might also require a process of grief with acceptance of loss and adjustment to a new life (Miller, 1999).

Grief reactions were not only experienced by the affected, diabetic child, but also by his or her parents. Hatton found that parents reported feelings such as shock, anger, denial, sadness and frustration in response to the diagnosis (Hatton et al., 1995). Lowes and Lyne stated that this might well be described as grief reactions to the loss of the healthy child (Lesley Lowes & Lyne, 2000).

In the literature there are at least two major streams concerning what is considered to be a 'normal' grieving process, following bereavement or significant loss (Lesley Lowes & Lyne, 2000). These are grouped into *time-bound theories* and *theory of chronic sorrow*. Time-bound theories were first described by Kübler-Ross (1970) and are based on a linear model. She identified five stages of emotional response to death of a significant person. These were: denial, anger, bargaining, depression and acceptance (Kübler-Ross, 1970) and are suggested to be sequential by some. Time-bound theories have been developed through research with bereaved persons predominantly; describe similar patterns and imply that each person follows a similar trajectory in the grieving process. Worden (2009) claimed however, that experiences of grief are unique and individual, implying that each person does not move through stages of grief in a predetermined order (Worden, 2009). Worden further explained

that the bereaved person has to actively work on his grief, coming to a point where the reality of the loss is accepted, where the pain of grief is worked through, where the environment is adjusted according to the new situation, and where the bereaved person has emotionally relocated to move on with life (Worden, 2009). Unless these four tasks are achieved, the grieving process will not be complete.

In contrast, *theory of chronic sorrow* emphasizes that the grief process is not necessarily terminated when a stage of resolution or acceptance is reached. Rather grief can be perpetual with periods of remission and intensification (Hayes, 2001; Tinlin, 1996). A variety of perspectives have been described, most of which are based on work involving parents of children with severe disabilities. In developed countries T1DM does in most cases not lead to severe, physical disabilities, so it may be questioned to what extent a seemingly invisible chronic disease can lead to chronic sorrow. However, in this study in Tajikistan, where many children had clearly visible impairments, it is imaginable that a constant reminder caused a circular pattern of chronic sorrow. There may be events or situations that bring the child's condition to the forefront, thus reawakening feelings that were present when the child was diagnosed initially. In this study, triggering situations described by the families were for example that the child often was sick and lethargic due to poorly adjusted blood glucose levels, repeated admissions to the hospital, stunting of growth and delayed pubertal development, leading to mocking and exclusion by peers, dropping out of school as children could not bear the 'shame' of being different anymore, having a child that was sad and lonely and that the child had visible complications such as paralysis after a stroke, or amputations. Families in this study, living with a diabetic child in Tajikistan, were more likely experiencing sorrow as a chronic state rather than time-bound. Whether the child had been diagnosed few weeks- or many years ago, the mothers often showed emotions during interviews, silently crying when talking about their child.

Triggers might have led to emotional turmoil and eruption of recurrent grief more easily as families had very little information about the disease and its treatment. Life revolved around an ambiguous relationship between living with a chronic condition in reality and the uncertainty about whether there is a cure that was not known to them yet. Therefore, the gap between reality and hope might be much wider and deeper compared to families living with T1DM in a developed country, where information and support are provided and where diabetic children can thus live a close to normal life. As a consequence, the lack of biomedical knowledge in the families, community, schools and in the health system may cause children and parents in resource-poor settings to experience frustration, fear, anger, helplessness and depression both more frequent and for extended periods of time than well-

informed patients in developed countries. Diabetic children are denied to live a full and productive life and are instead faced with a life characterized by sorrow and sadness.

7.2.1.3 *Long-term adaption to life with T1DM*

For long-term adaption to chronic illness Bury (1991) suggested the use of 'coping', 'strategy' and 'style'. 'Coping' as it is used in the chronic illness literature, refers to the cognitive process whereby the individual learns how to tolerate or put up with the effects of illness. 'Strategy' in contrast to 'coping', directs attention to the actions people take, or what people do in the face of illness, rather than the attitudes people develop. 'Style' in the context of chronic illness refers to the way people respond to, and present important features of their illness or treatment regimens (Bury, 1991).

Parents: Coping, strategy and style

Coping, described by Bury (1991), was experienced as a spiral and dynamic process among the families in Tajikistan. Coping strategies that were used by the parents were to find a cause, to be assertive, protective and to show deep compassion for the diabetic child, seeking help and support at hospitals (if affordable and if the doctors were trusted) and seeking contact to other affected families. Finding a cause or an explanation seemed especially important to parents in this study, in order to be able to cope with the chronic nature of the disease. This was for example shown in the way families told a very specific and detailed encounter about how the child became sick and how this was linked directly to an event which had caused emotional stress or a situation that provoked the evil eye to cast spell on the child. These explanations seemed to be more detailed the longer the child had been diabetic. For example, while the mother of a newly diagnosed (20 days ago) boy had no thoughts about the etiology of T1DM yet, other parents who had lived with a diabetic child for years had very detailed explanations about what had caused the outbreak of the illness.

Coping strategies in the current study were similar to the ones described by Hatton, exploring perceptions of parents caring for an infant or toddler with T1DM within the first months after diagnosis (Hatton et al., 1995). In Hatton's study, coping strategies which parents developed shortly after diagnosis included being assertive and being an advocate for the child, dealing with the child's needs, realizing that the complex regimen must be continued in order for their child to live, seeking support, particularly among hospital staff, accepting a lack of support from fearful families and friends, looking for a cause, considering alternatives and clinging to hope for an early cure. Among the coping strategies in the adaption phase were tactics such as taking charge of the situation, trusting others and building support systems (Hatton et al., 1995). Parents learned to cope with the situation as they *'had no choice in the matter'*, Hatton states. They understood that their child's future health was entirely dependent on how

well they would cope and manage the child's condition. The overwhelming feeling of responsibility was furthermore intermingled with hope and optimism for a future cure. One mother explained *'at the hospital they told us all about research. They gave us faith and hope. That's what we needed. It's what kept us going and sustained us.'* Hope was perceived as a motivator, providing the strength to focus on the child's needs both during hospitalization, but also after returning home.

Parents in the current study further compared their child's disease with other chronic illnesses, concluding that it was better to have diabetes than to be physically and mentally disabled as their child would be even more dependent on them. Similarly parents in Hatton's study developed this strategy. One father told *'[...] but I thought diabetes, it's better than leukemia, maybe our baby won't die'* (Hatton et al., 1995). Whilst this account was the result of an immediate reaction to the diagnosis, parents in the study seemed to use this coping strategy to accept the child's ongoing health struggles in a long-term perspective. It was not a statement about whether the child would survive, but more on how to best live with the limitations of the disease in everyday life.

Duration of the disease also seemed to affect how parents coped and which strategies were used. For instance, if the child had been sick for only one or two years, their strategy was very much concerned with obtaining information about a possible cure. Even though this strategy did not diminish as diseased years went by, it seemed though that it was replaced gradually by getting to peace with that their child got sick because it was in the families fate. Religious belief helped to cope with the chronic disease, a phenomenon which has been described by other authors such as Gordon and colleagues where women with different chronic illnesses were interviewed about which role religious believes played in their experience and the way they coped with their illnesses. The majority of women reported that religious beliefs were important in living with a chronic disease. Furthermore, more women, who were identified as coping well reported strong religious beliefs (Gordon et al., 2002). However, similarly to the experiences of the parents in Hatton's study (1995) constant stressors evoked emotional responses, which again required new coping strategies. Coping was therefore both in Hatton's study (1995) and the current study perceived as an ongoing, spiral process constantly requiring new adjustments.

Diabetic children: Coping, strategy and style

Children in the study struggled emotionally. They were often subject to mocking and stigmatization and had limited coping strategies. This led to self-determined withdrawal, in particular from school. Many showed signs of resignation and 8 out of 16 school-aged children stopped attending school, leading to feelings of loneliness and sadness. Whereas

the parents experienced a spiral process, with a frequent shift between coping well and triggers causing emotional stress anew, the children's situation could be described as more vulnerable. For example, when the child was mocked at school, he or she did often not have strategies to cope with the situation, therefore quitting school. Mothers had compassion and did not force pressure on their child to continue attending school. Once the child had abandoned school, it was difficult emotionally because they were excluded and lonely, but also regarding their future, because it would be difficult to continue with education at a later point. Marshall identified in her study *Living with type 1 diabetes: perceptions of children and their parents* that diabetic children experienced transition to be a natural and normal part of growing up, thereby coping better than their parents. She described that parents experienced new concerns and fears as they saw their child becoming increasingly independent in his or her choices and decisions (Marshall et al., 2009). In some ways it seemed to be the opposite to the findings of this study. Diabetic children often experienced difficulties to develop adequate coping strategies as there was marginal awareness and understanding of the disease in public, leading to preconceptions and exclusion; transition was difficult for them. It could therefore be claimed that whilst parents in developed countries see their diabetic children grow up and becoming more independent, families in this study, and possibly other developing countries, experience that their children become more dependent the older they get and the more physical complications and impairments they acquire, because of inadequate treatment and management of the illness.

Kelleher (1988) suggested in Anderson and Bury that a generally low level of knowledge about the mechanisms of diabetes could be the reason why so few people coped and were in control of their diabetes. He found that people who coped needed a certain level of knowledge about diabetes in order to make adjustments to their treatment (R. Anderson & Bury, 1988). Transferred to the current study, Kelleher's findings word the essence of what had been observed, namely that children had difficulties to cope with diabetes, as they and their families lacked understanding of their condition. It is claimed that culturally adapted information and education might be the key component to help children cope with their illness in a developing country such as Tajikistan.

Some children did develop coping strategies such as being outstanding at school, identifying with the disease, getting special attention, being respected, being angry, reading books, writing poetry and taking care of their animals. Being outstanding at school was named most frequent as a coping strategy. A few other studies from developed countries have studied coping strategies in diabetic children. Kovacs and colleagues (1986) described the most prevalent coping strategies in children with T1DM to be wishful thinking, thoughts of forbidden foods, and resentful thoughts. Further, behavioral coping strategies, including

information seeking, were evident from the beginning (Kovacs, Brent, Steinberg, Paulauskas, & Reid, 1986). Schur and colleagues (1999) also proposed that it is possible that denial, if used in a positive and adaptive way, described by Lazarus in Breznitz (Breznitz, 1983), might be fundamental in how diabetic children and youth manage living and coping with diabetes (Schur, Gamsu, & Barley, 1999). Grey showed that preadolescents and adolescents differed considerably in the manner in which they coped with the illness. Younger children were more likely to cope by ventilating feelings through yelling, arguing, and the like, whereas older children were more likely to cope with avoidance behaviors of drinking, smoking or staying away from home (Grey, Cameron, & Thurber, 1991). They further reported in a later study (1997), determining coping behaviors one year after diagnosis, that coping behaviors were stable. Self-worth was associated with the use of less spirituality, more use of humor and more positive self-care (Grey, Lipman, Cameron, & Thurber, 1997). It may be seen that ventilating anger through yelling was similar to some of the descriptions in this study, other coping strategies have however differed, indicating that coping needs to be seen in light of the cultural context and that more information from resource limited countries is needed.

Diabetes camps and diabetes days facilitated temporary active coping style

Diabetes camps and diabetes days were experienced very positively by all the children and parents who had participated in such an arrangement previously. Children's eyes lit up when they told about their experience, and mothers reported how their child got encouraged spending time with other children in the same situation, realizing that he or she was not the only one having T1DM. This positive experience was congruent with findings in other studies, which have been carried out in developed countries. McCraw and Travis reported that self-esteem increased in all children (McCraw & Travis, 1973) whereas Zimmerman et al. described that self-concept of children with diabetes improved after a one week diabetes camp (Zimmerman et al., 1987). Furthermore Briery and Rabian reported a notable decrease in anxiety levels from pre-camp to post-camp (Briery & Rabian, 1999).

Furthermore, a child's coping style can be active and problem-focused, leading to adaptation or passive and detachment-focused, being associated with maladaptive behavior (Smith, Schreiner, Brouhard, & Travis, 1991). Diabetic children in this study demonstrated a predominantly passive coping style; however after the camp or participation in a diabetes day, mothers reported that their child was encouraged for some weeks or months, eventually showing temporary active coping strategies. With no further follow-up though, many children finally returned to the passiveness with little hope for the future. In the study by Smith and colleagues (1991) adolescents endorsed the use of fewer detachment-focused strategies post-camp.

Based on the findings of this study, it may be suggested that the importance of diabetes camps, especially in a cultural context where little is known about T1DM, cannot be overemphasized, as this may be the only occasion where diabetic children get to enjoy, share and receive encouragement from other children, who are in the same situation.

7.2.1.4 *Stigma*

'The term 'stigma' originates from the Greeks and was referred to bodily signs designed to expose something unusual and bad about the moral status of this particular person' (Goffman, 1989). Today it is applied more to the disgrace itself than to the bodily evidence of it. Goffman (1989) describes three different types of stigma. First, there are various physical deformities of the body which can be perceived as abnormal. Second, there are character flaws which can cause a person to be perceived in a certain and unfortunate way. Such perceptions can include: having a weak will, being domineering, having unnatural passions, having treacherous or rigid beliefs, or being dishonest. If these interfere with a known record of, for example, a mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, or radical political behavior, this leads to stigmatization. Finally there is stigma of race, nation and religion. The common social reaction for all three types of stigma is that an individual, who might have been received easily in ordinary social settings, is turned away as he or she possesses a trait which leads to inevitable attention. The person possesses a stigma, an undesired differentness from what we had anticipated (Goffman, 1989).

Based on the findings from the interviews with families diabetic children were mainly affected by the first category of stigma, namely stigma as a result of physical symptoms caused by elevated blood glucose levels. These will be discussed in the following paragraphs.

Stigma related to hyperglycemic symptoms

Most children lived with chronically elevated blood glucose levels, leading to physical symptoms. The renal threshold for glucose in children is approximately 10-11 mmol/l (ISPAD, 2011). Therefore, if blood glucose levels exceed this threshold, excess glucose is excreted through the urine. Due to the osmotic effect of glucose, large amounts of water in the body get lost as a result (osmotic diuresis) and children experience the physical symptom of having to go to the toilet often.

A qualitative study by Rajaram (1997) explored the biographical disruption that occurred as a result of hypoglycemic episodes and found out that people with diabetes may attempt to hide or minimize their symptoms because they do not want to be regarded as 'disabled' or unable to take part in everyday activities (Rajaram, 1997). Even though most diabetic

children in this study did not have much experience with hypoglycemic episodes leading to trembling, pounding heart, dizziness, slurred speech, it can be argued that whether children disappear often to go to the toilet or behave strangely, it might be perceived by people in a similar way, namely that something is wrong with them. Children experienced stigmatization as a consequence of frequent urination especially in their everyday life at school. One girl left early from school to avoid exposure of her illness, knowing that her peers would talk about her in her absence. Others stopped going to school. In this study half of the diabetic children at school-age (8 out of 16) stopped attending school or participated rarely.

Stigmatization led in many cases to exclusion and isolation as children were not able to cope with this challenge. Research on stigma in chronically ill epileptic patients showed that an individual's self-image was threatened only when the person accepted the social devaluation of his or her condition (Jacoby, 1994; McLin & de Boer, 1995; Scambler & Hopkins, 1990). A patient felt stigmatized when he or she believed the communities inappropriate ideas. Subsequently, if people started to believe that they were different from others because of their condition, the stigma was internalized. Once this took place, behavior changed and psycho-social difficulties such as shame, insecurity and withdrawal started to become visible (Fernandes et al., 2007). These observations seem to be similar for children with T1DM in this study. In several cases the mothers commented that their child would only stay home and watch TV, not wanting to play with other children anymore, being sad often, and voicing thoughts of wanting to give up.

Stigma related to impaired growth and delayed pubertal development

Whilst families were able to keep secrecy about their child's disease at a young age eventually, long-term physical complications became evident in adolescence. This added new layers of stigma. Many adolescents stopped growing in height and pubertal development was delayed. Again, children experienced that they were mocked and not understood by friends and peers, particularly in relation to school. Also, teachers sometimes were not able to meet the children's needs. These experiences have also been described elsewhere. Maslakpak's study (2010) on diabetic Iranian adolescent girls' quality of life, demonstrated that teachers' and classmates' knowledge about T1DM was not experienced as sufficient, and that some teachers had a negative attitude towards them (Maslakpak, Anoosheh, Fazlollah, & Ebrahim, 2010). Furthermore, a British survey about diabetes showed that many teachers did not have adequate understanding of diabetes, and were unable to recognize the medical and educational needs of these students (Mukherjee, Lightfoot, & Sloper, 2000).

Impaired growth and delayed pubertal development also had implications on the families' perception about the diabetic child's future, in particular whether they would get married, in cases where the diabetic child was a girl. This concern was also described in other studies where it was reported that diabetic adolescent girls felt distress when their disease was disclosed to their fiancés and the fiancés parents (Maslampak et al., 2010; Sato et al., 2003; Sullivan, 1979). In particular, Maslampak's study (2010), conducted in Iran, a country with a culture very familiar to Tajikistan, was congruent with the current study, stating that diabetes may afflict men and women equally, but that the suffering associated with the disease has a more tremendous effect on a girl's life. Jovanovic (2004) further described that young diabetic women's ability to bear a healthy child may be poor or impossible (Jovanovic, 2004), having severe consequences for these young women in certain cultures and parts of the World. Tajikistan could be described as a country with a similar culture.

7.2.2 Some consequences of families' lacking biomedical knowledge on the diabetic child's physical health

7.2.2.1 What is a good diet for a diabetic child?

The most frequently named topic regarding biomedical knowledge was 'diet', where sweets, bread and 'oily food' were perceived to be the worst foods for a diabetic child.

Nutritional management is one of the cornerstones of diabetes care and management (Smart et al., 2009). This opinion was also represented by families in Tajikistan, as diet was the biomedical topic most had some knowledge about and requested and/or suggested further information on, if a booklet for diabetic children would be developed. In total 'having a good diet' was suggested 15 times in 18 interviews with families.

The families' perception of a good diet for a diabetic child did however deviate from standard guidelines in one particular point, namely that 'oily food' should be avoided. This opinion was shared by most endocrinologists and families. In the ISPAD guidelines it is broadly stated that dietary recommendations for children with T1DM should be based on healthy eating principles, suitable for all children, with the aim of improving general health, diabetes outcomes and reducing vascular risks (ISPAD, 2011). As children with T1DM are dependent on insulin injections in order for the body to make use of the energy provided by carbohydrate containing foods, dietary advice does predominantly concentrate on the carbohydrate content of the diet. Only when there is a balance between dietary intake of carbohydrates and administered insulin, goals of normal blood glucose levels can be achieved and normal growth and development of the child will be assured (CDiC manual, 2011).

No clear answer was found, to why 'oily food' was not recommended to children with T1DM. Without claiming an ultimate answer to why oily food was so central in their dietary recommendations, two possible explanations may be discussed. The first reason may be that the only available printed information on diabetes in Tajikistan concerned T2DM. It seemed that doctors', and thereby families' biomedical knowledge relied on information which was provided for patients with T2DM. This could explain the focus on oily and fatty food, as this is the food group with the highest caloric value per gram. An initial step in treatment of T2DM focuses on life-style changes, including weight reduction. Weight reduction is most easily achieved by reducing the food group with the most calories, namely fats. Further, animal fat is seen as dietary risk factor for developing arteriosclerosis and emphasized especially for patients with T2DM. It is proposed that the families 'oily' food concept most likely was derived from recommendations which targeted patients with T2DM.

The second explanation for the families 'oily' food concept was rooted in the fact that children were experiencing hyperglycemic symptoms frequently. In such cases, they felt sick with loss of appetite, they experienced headache, felt constipated and had to vomit. It was said by some children that they did not want to eat and if, only a watery soup. It may be that the dietary recommendation was based on their personal experiences. If feeling sick, it is plausible that there might be a natural tendency towards avoiding fatty/oily foods that generally are less easily digested. An additional factor may be that diabetic children explained to have problems with their digestion in general. Thereby, the doctor's answer did eventually reflect their practical experience on what was best tolerated by the patients.

It is suggested that the misconception that children with T1DM should not eat 'oily' food, is not only wrong, but limited the already restricted food choices diabetic children were having. It is further claimed that information material, focusing on carbohydrate intake rather than fat content, is severely needed for children with diabetes in Tajikistan.

7.2.2.2 *Compassion versus long-term diabetic complications*

Families had compassion with their diabetic child and mothers often struggled to inject insulin when the child refused persistently. This constant struggle was also described by parents of diabetic children in Hatton's study (1995), outlined in the literature review. In this study, families did however have little biomedical knowledge about physical long-term consequences of poorly regulated blood glucose levels.

The mother's compassion in combination with lacking biomedical knowledge, regarding complications, was unfortunate for the diabetic child. Whilst it was understood that passing over an insulin injection led to acute symptoms, many families did not connect chronically

elevated blood glucose levels, which were a consequence of skipping insulin injections, with long-term complications.

T1DM is associated with long-term complications affecting the micro- and macrovascular system. Microvascular complications can affect the eyes (diabetic retinopathy), kidneys (diabetic nephropathy) and the peripheral and vascular nervous systems (diabetic neuropathy) (Nathan, 1993). Macrovascular complications may lead to stroke, heart failure and amputation of the limbs. Although the underlying causation of these complications is not understood in its detail yet, hyperglycemia seems to play a central role (Klein, Klein, Moss, Davis, & DeMets, 1988; Nathan et al., 2005).

Retinopathy causes visual loss and blindness and is prevalent in 34.6% of all patients with diabetes (Yau et al., 2012). In the current study, many children reported to have impaired vision. Even though it was not an aim of the study to investigate whether there was a direct linkage between poorly regulated blood glucose levels and impaired vision, it may be imaginable that a chronically elevated blood sugar was at least a contributing factor.

Diabetic neuropathy affects the nerve system and causes pain, paresthesiae, muscle weakness and autonomic dysfunction. According to the EURODIAB IDDM Complications study the prevalence of diabetic neuropathy in all diabetic patients is 28% in Europe with no significant geographical differences (Tesfaye et al., 1996). In the current study some children explained that they experienced severe pain in their feet and legs, in particular at night, indicating the possible presence of diabetic neuropathy. However this was not clinically examined in this study and the researcher's interpretations are solely based on information from the patients.

Diabetic nephropathy causes hypertension and renal failure and is prevalent in 21% of patients with T1DM after 20-25 years duration of disease (Andersen, Christiansen, Andersen, Kreiner, & Deckert, 1983). End-stage renal failure was the primary cause of death in 66% of patients before hypertensive therapy was introduced (Krolewski, Warram, Christlieb, Busick, & Kahn, 1985). However, hypertensive therapy was not available to- or affordable by most diabetic children in Tajikistan, and dialysis only existed in very costly private clinics. Therefore, even though we do not know what the figures are, it is likely that renal failure might still be a major cause of death in resource constrained countries.

Patients with T1DM furthermore have an increased risk to develop macrovascular complications, including coronary artery disease, peripheral arterial disease, and stroke (Fowler, 2008). Cardiovascular disease is the primary cause of death of people with either T1DM or T2DM (Laing et al., 2003; Paterson, Rutledge, Cleary, Lachin, & Crow, 2007). In the current study macrovascular events were described and affirmed by an endocrinologist in

to cases. An 18 year old girl had a stroke with partial paralysis of her right arm after 10 years duration of disease. Another participant had an amputated foot. Despite that there were only two cases, it did indicate that macrovascular diseases might be likely to occur after fewer years with T1DM, compared to developed countries.

Medical facts highlight the importance of coherent medical treatment with insulin and long-term consequences, chronically elevated blood glucose levels, have. It is imaginable that mothers may have carried through with a more strict insulin regimen, if they had biomedical knowledge about, and thus were aware of, the long-term consequences poorly adjusted blood glucose levels had on their child's health. They could eventually have looked beyond their instant feelings of not wanting to hurt the child, knowing that insulin injections were in the best interest of their child, both short- and in particular long-term.

7.2.2.3 *Limited awareness on monitoring the child's blood glucose level*

Self-monitoring of blood glucose (SMBG) is ideally an integral part of optimal care of diabetes as it provides essential information about whether insulin dosage is adjusted correctly to the child's age, physical activity, diet patterns etc. Without SBGM treating patients with insulin is a guessing game, consequently leading to poorly adjusted blood glucose levels with a high risk of hyperglycemic- and hypoglycemic episodes and complications.

However, SMBG was rarely used by diabetic children in this study. The reasons explained by the families were threefold. First, a few children claimed that they could feel how high their blood sugar was. Second, families who wanted to use the glucometer were often unable to read the instructions, as they were provided in English and not in Tajik or Russian. Third, the cost of purchasing a glucometer and test strips was a barrier to inform and advice patients to use this device.

The first aspect was closely linked to the families' lack of available biomedical knowledge regarding SMBG. Consequently, instead of measuring their blood sugar, children based their interpretation concerning how high their blood glucose level was on whether they felt physical symptoms or not. Even though there has been found a certain correlation between patients experienced symptoms and its accuracy, it was recommended by Gonder-Frederick et al. (1986) that patients need to be informed that their symptom beliefs may be inaccurate and that they need to be systematically tested with SMBG (Gonder-Frederick, Cox, Bobbitt, & Pennebaker, 1986). Sagarduy (2004) further demonstrated that children with T1DM showed a great variability in the accuracy of estimating their blood glucose level. Regarding hyperglycemia they had false beliefs regarding indicative symptoms and perceived the

absence of symptoms as an indicator for a normal blood sugar level (Ybarra Sagarduy, 2004), a finding which was congruent with this study.

As many diabetic children had received a glucometer and a supply of test strips through Operation Mercy, provided by private, international donors, it was asked why the devices were not used. Reasons were, that they did not remember how to use it after having been explained in the diabetes camp, and that they did not understand the English instructions that were provided. This was an essential finding, as it demonstrated that some families were eager to learn and interested in understanding how they could use the device. However, as such information was not available, they resigned.

Some families consulted their attending doctor for advice. Based on the findings it may be suggested that health professionals presented a deficit in appropriate communication skills to facilitate interactive learning. Ideally, children need to be taught how to use the glucometer first, but then trying it themselves with supervision, positive feedback and encouragement. This should be practiced until the child feels comfortable and safe to manage the device him- or herself (ISPAD, 2011). As medical doctors eventually are trained to mainly impart knowledge on their patients, children were only receiving instructions, but were not empowered in their abilities to measure their blood sugar themselves. Also, a key would be to tailor the information to what the patient wants to know (Maguire & Pitceathly, 2002). This implies that the skilled person needs to communicate in such a way that the patient becomes aware, that certain information could be of interest for him or her (Casey, Murphy, Lawton, White, & Dineen, 2011). If children with diabetes and their families do not understand the overall picture of why SMBG is important, they will not see the need to learn more about it either. It might be of a discouragement instead, to be confronted with poor blood glucose levels, not having any biological knowledge about how to affect them through diet, exercise and small insulin dosage adjustments. If it would be communicated that SMBG is a tool to help them improve their blood glucose levels and thereby physical wellbeing, adherence might be likely to improve. Endocrinologists who were interviewed acknowledged the challenge regarding SMBG and suggested explaining how to use glucometers in a possible booklet for children with diabetes in Tajikistan, whereas none of the families named this as their preferred topic of interest.

A third reason why awareness on the importance of SMBG was limited may be to the fact that glucometers and test strips were expensive, so that medical doctors did not emphasize its importance. The cost-factor is also acknowledged in the ISPAD guidelines, which state that costs for SMBG relative to the cost of living make this technology unavailable in many parts of the world (ISPAD, 2011).

7.2.2.4 *Recognizing symptoms of hyper- and hypoglycemia*

All children had experienced symptoms of high blood glucose levels, were however often not aware of its causality as they had no biomedical information. Furthermore, symptoms of too high- or too low blood glucose levels were not easily recognized and in a few cases mistaken. This may be especially dangerous in cases where the child is hyperglycemic.

According to the ISPAD guidelines '*Hypoglycemia is a result of a mismatch between insulin dose, food consumed, and recent exercise and is rarely, if ever, a spontaneous event. A careful review of blood glucose records will yield a retrospective prediction of the hypoglycemic event for at least 50% of the events*' (ISPAD, 2011). This statement claims that hypoglycemia is predictable in most cases, *if the patient is aware of insulin administration including its mode of action, if the child has biomedical knowledge about foods and how they affect the blood glucose level, if the child is knowledgeable about that physical exercise lowers the blood glucose level and if the child possesses equipment to measure- and is able to keep record blood glucose levels.* These are all key aspects of a comprehensive diabetes management and taken for granted in developed countries with comprehensive education and training regarding T1DM and its treatment. However, all of these aspects were present only to a very limited extent among Tajik diabetic children in this study.

In the current study, one adolescent boy stated that he did not experience any physical symptoms of hypoglycemia despite his blood sugar being 1mmol/l, indicating the lack of biomedical knowledge that was present. In such a case, this boy would most likely be in a life-threatening situation. Limited biomedical knowledge and awareness about hypoglycemia may have very severe consequences as it can lead to permanent damage and even death if appropriate steps of action are not taken (Edge et al., 1999; Hannonen, Tupola, Ahonen, & Riikonen, 2003; Rovet & Ehrlich, 1999). Hypoglycemia is a significant factor contributing to excess mortality in patients with diabetes (Nishimura et al., 2001) and data from developed countries, stating that nocturnal death appears to be responsible for about 6% of death in diabetic patients aged below 40 years (Tanenberg, Newton, & Drake, 2010; Thordarson & Søvik, 1995), lets one only imagine what the situation might be in developing countries such as Tajikistan. Therefore, understanding how insulin, food and exercise must be balanced, in order to reduce the risk of hypoglycemia in particular, is essential for all patients and families living with diabetes to avoid life-threatening acute incidents.

7.2.3 Two main complicating factors families experienced with regard to the health system in Tajikistan

As the findings of this study highlight, the challenges in relation to T1DM in Tajikistan were many, they were complex and they included facts about the health system. In regard to the health system two main challenges were experienced by the families. First, insulin was not available on an uninterrupted basis. Second, unofficial private payments in the health system hindered families to seek help. These focal points will be addressed in the following sub-chapters.

7.2.3.1 Insulin procurement

In 2012, 90 years after insulin saved the life of the first patient, 14 year old Lenard Thomson, creating a paradigm shift, where the uniformly fatal disorder became a chronic disease with potential long-term survival, not much has changed for children with T1DM in developing countries such as Tajikistan. For this population T1DM is still as a killer disease.

In Tajikistan insulin was supplied through international donors and provided to patients free of cost. However, insulin was not available on an uninterrupted basis due to different reasons. In such cases families struggled severely as they had to purchase insulin privately. The cost for one vial (10ml) of insulin, lasting for maximum one months, varied from 26-33 US\$. In a World Food Programme (WFP) survey, based on 300 rural households in the Khatlon region 2011, it was calculated that a minimum food basket for one person was 30 US\$ per month and an average household size consisted of nine people. Yet, households spent on average only 87 US\$ for the entire household on food. For at least 60% of the households in the Khatlon region, the minimum food basket was unaffordable (World Food Programme, 2011). Relating these figures to the cost of insulin, it shows that one third of the financial means on food, for a family household of nine, would be spent on insulin. It is plausible that families had no choice in the matter than to prioritize the survival of the household, rather than sustaining the health of one child.

Similar data has also been reported from other resource-limited countries such as Tanzania for instance, where the average monthly cost for insulin treatment equaled to 25% of the minimal wage (Neuhann, Warter-Neuhann, Lyaruu, & Msuya, 2002). Daneman (2009) concluded in a *review on the state of the world's children with diabetes*, that families in developing countries often must choose between insulin for the child and starvation for the other children, or inevitable death of the child with diabetes so that the rest of the family can survive (Daneman, 2009). He further suggested, in regard to insulin procurement, that International donors and NGO's must recognize T1DM as a health problem in resource constrained countries and allocate and advocate appropriately. Furthermore a special focus

should be placed on increasing insulin and testing equipment to those who cannot afford it. It was also suggested that the private sector should control costs of insulin and other necessary equipment for the world's poorest (Daneman, 2009). The fact that the most common cause of death, in children with diabetes worldwide, still simply is the lack of access to insulin, demonstrates that there still is a long way to go to change the destiny of diabetic children in resource limited countries around the World.

7.2.3.2 *Unofficial private payments*

Unofficial private payments in the health system were reported by many families and presented a major barrier to seek help. Bribery is well known in Tajikistan and has been described previously. Tajikistan was for instance ranked 150 out of 157 countries on the Corruption Index of Transparency International (European Union, 2007). Further, recent results from the Corruption Perception Survey, carried out by the Presidential Centre for Strategic Research in Tajikistan, and supported by the Organization of Security and Cooperation in Europe (OSCE), gave reaffirmation. In total 1000 people from the six largest cities in Tajikistan were asked about their perceptions regarding corruption in the country. Some 55% perceived that corruption had risen notably in the past five years. Traffic police were perceived as the most corrupt public servants by 84% of the respondents. The police in general came very close with 83%. Ranked third was the public health sector with 80%, and prosecutor's offices with 71.6%. Furthermore the census found that practically all various forms of corruption were practiced, with bribery leading (86%), followed by the abuse of power (78%), and nepotism (70%) (Asia Plus, 2011).

As the actual cost for treatment was unpredictable for families before seeking help, the decision needed to be well thought through beforehand. As mentioned in the previous chapter, the choice between helping their diabetic child and sustaining the survival of the rest of the family was as choosing between pest and cholera. Therefore, if the child was not severely sick, meaning being ketoacidotic, the parents tried to use other remedies such as herbal teas, to alleviate symptoms of hyperglycemia. Medical doctors on the other hand pledged their patients to contact them before they were pre-comatose, as they were aware that the child's life in such a case could be dangling on a string.

The problem is clearly much more complex and interwoven than what this study was able to capture. However, one aspect which was recorded was that medical doctors had to cope with a very low income. From a previous assessment by Scheider (2009) it is known that a monthly salary is 38 US\$ for a fully qualified medical doctor compared with a workforce average of 65 US\$ (Schneider, 2009). Comparing 38 US\$ with 30 US\$, being the estimated cost for a minimum food basket per person per month in the Khatlon region, it is not

surprising that medical doctors may struggled equally much for their daily survival as the patients they were treating. Not aiming to justify out of pocket payments, the low salaries do however to some extent explain why anti-corruption initiatives may not be successful in eradicating the problem.

8 CONCLUSION

In conclusion, this study showed that 90 years after insulin saved the life of the first diabetic child, creating a paradigm shift, where the uniformly fatal disorder became a chronic illness with a potential long-term survival, not much has changed for children with T1DM in Tajikistan, and possibly other developing countries. For this population, T1DM is still often a killer disease. This study clearly demonstrated the profound consequences of lacking public awareness and limited biomedical knowledge among health personnel, regarding T1DM and its treatment, on the diabetic child's physical health and emotional well-being.

A few global initiatives have taken steps of action, aiming to provide insulin to the poorest nations. However, facing the reality that the most common cause of death in diabetic children worldwide still simply is the lack of access to insulin, demonstrates that there is a long way to go to change the destiny of this population in resource limited countries. It is plausible that Tajik families in this study often had no choice in the matter than to prioritize the survival of the household rather than sustaining the health of one child, as cost of treatment and care were considerable and unpredictable.

Further, it has been stated in previous literature that initiatives need to look beyond the insulin dilemma. This study has clearly shown that, even though insulin had changed the fatal nature of the disease to a chronic illness, the quality of life for these children with T1DM was still very poor. This could have been different. Whilst insulin is a profound necessity for the survival of a diabetic child and ought to be available free of cost at all times, implying the need for solutions from the health system, diabetic children and their parents in this study had very limited opportunity to gain understanding of their condition or to be empowered to look after their child in a way that would ensure a good quality of life for them, as no culturally adapted and child-friendly information and education about T1DM was available. Therefore they had little biomedical knowledge regarding the etiology of T1DM, its treatment and most importantly how to live a good life with this chronic illness. In its essence, the consequence of inadequate treatment in conjunction with lacking awareness and biomedical knowledge about the management of the illness is, that parents of a diabetic child in a resource constrained country such as Tajikistan witness their child becoming more dependent, the older- and the more physical complications and impairments he or she acquires. In contrast, parents in developed countries, with access to comprehensible treatment options, support and care, see their diabetic child grow up, with perspective of a long and close to normal life.

Sadly, because the disease hits comparably few, it is not considered a public health tragedy that, in 2012, children in developing countries such as Tajikistan do not even have access to life-saving insulin on an uninterrupted basis. With a globally estimated rise in incidence of

T1DM, advocacy and allocation of financial resources are essential to improve diabetes care in resource constrained countries, so that children with T1DM can be empowered, preserve life quality and have a prolonged life expectancy.

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EPILOGUE

“Sometimes the first duty of intelligent men is the restatement of the obvious.”

~ *George Orwell* ~

May this work have contributed to restate the obvious.

~ *Severina Haugvik* ~

APPENDIX

APPENDIX I: DETAILED TIMEFRAME SEPTEMBER – DECEMBER 2011

Calendar week	FAMILIES <i>In-depth interviews, observations, focus group discussion</i>	KEY INFORMANTS <i>Interviews, informal conversations</i>
Week 36 (05.- 11.09.2011)	<i>Arrival Dushanbe: Sunday 4th of September</i> - Translation of written consent form - Meeting with NGO staff – inform about the project - Meet the head of the National Endocrinology Centre in Dushanbe – inform about the project – gain consent	
Week 37 (12.09.- 18.09.2011)	- Meeting and training with research assistant - Finalized thematic guide and discussed it with research assistant - Organizing a driver	
Week 38- 41 (19.09.- 16.10.2011)	DUSHANBE AREA Interviews with 5 families from Dushanbe and surrounding areas in the Region of Republican Subordination	<i>Interviews:</i> one doctor from the First Sawetzki Hospital in Dushanbe, one professor from the medical university in Dushanbe <i>Informal conversation:</i> USAID representative
Week 42 (17.10.- 23.10.2011)	QUORGHONTEPPA Observation and focus group discussion at diabetes day October 17 th in Quorghonteppa Interviews with 5 families from Khatlon region	<i>Interview:</i> one doctor from the Endocrinology centre in Quorghonteppa <i>Informal conversations:</i> Minister of Health in Khatlon
Week 43 (24.10.- 30.10.2011)	DUSHANBE Transcribing, reflection and planning of further interviews	<i>E-mail contact with:</i> <i>Graham Ogle</i> – Life for a child programme, IDF <i>David Beran</i> – International Insulin Foundation (IIF) <i>Prof. Thomas Danne</i> – former president of ISPAD
Week 44- 45 (31.10.- 13.11.2011)	DUSHANBE Observation Operation Mercy diabetes day November 2 nd KHUJAND Interviews with 2 families from Sughd region DUSHANBE Interviews with 2 families in Dushanbe	<i>Interview:</i> one doctor from the Endocrinology center in Khujand

<p>Week 46 (14.11.- 20.11.2011)</p>	<p><i>DUSHANBE</i> Observation at the International Diabetes Day at the First Sawetzki Hospital</p> <p>Interviews with 4 families in Dushanbe and Tursunzoda</p>	
<p>Week 47 (21.11.- 27.11.2011)</p>	<p><i>Final week in Tajikistan</i> Meeting with Operation Mercy – presentation of preliminary findings to the ones working in the diabetes project</p> <p>Meeting with newly established national diabetes NGO – discussion of preliminary research findings and further support/collaboration</p> <p><i>Departure Tajikistan November 26st</i></p>	
<p>Week 48 (28.11.- 04.12.2011)</p>	<p><i>GERMANY</i> Meeting with possible donors to help with procurement of glucometers and test strips</p>	

APPENDIX II: QUESTION GUIDE FOR INTERVIEWS WITH FAMILIES

Overall aim

Assess perceptions of T1DM and the need for information and education among affected families in Tajikistan.

Information for the research assistant

This is not a fixed list of topics and questions that all have to be answered consecutively, but more like a guide for questions we want to address. The list might be refined as we go along and see what people find to be important and place emphasis on.

- Gain insight into **when and how** the child became diabetic (**the story**)
 - When did you get diabetes/ for how long have you had diabetes? Can you tell me something about that?
 - How did it start? Did you experience any symptoms?
 - Did you go to the hospital? How was that? Can you tell me something about what they did there? Have you been in a coma? How long did you have to stay at the hospital?
 - How did the parents feel when their child got sick? Can they tell something about that? What did they do and where did they seek help (hospital, traditional healer, other)? What was their immediate reaction when the child got diagnosed?
 - Had the family heard about diabetes before? (either T1DM or T2DM)

- Gain insight into their **biomedical knowledge** about **T1DM, insulin treatment, nutrition/diet, blood glucose measurements** etc.
 - When you got diagnosed, who has helped you to learn about diabetes? (doctors, nurses, others)
 - Did they teach you how to do the insulin injections? Can you teach me how to do it? Is it difficult?
 - Do you also inject insulin at school? (probe reasoning for action) Do peers know that you have diabetes? Have you told them? How do they react?
 - How do you usually know how much insulin you need?
 - What is good for you to eat / not so good to eat? Do you have to eat something different than the rest of your family? How is that?
 - Do you measure your blood sugar? (at the hospital or at home). Would you like to teach me how to use a glucometer? Is it difficult?

- Who has thought you how to use the glucometer? How often do you have to do it? What do the numbers look like?
- Do you have any information or books about T1DM? If yes, what do you like/do not like with it? Do you have any suggestions what would make it better to be used in Tajikistan?
- Gain an understanding about **challenges** affected children and their families face in relation to coping with T1DM in Tajikistan
 - What is the hardest part about having diabetes? (Is there anything positive/are there any benefits with having diabetes?)
 - Do people know that you have diabetes? (why/why not) What is their reaction?
 - Who helps you to manage with diabetes in your everyday life?
 - What is most difficult for the parents? (caution when the child is present)
- Identify **helpful strategies** families use to cope with the child's T1DM
 - What do you do when you feel that you are getting sick from the diabetes (hypo- or hyperglycemia)
 - Is there something that you usually eat or drink that makes you feel better?
 - What has helped you? E.g. how did you overcome the barrier of injecting insulin? How did you learn what is good for a child with diabetes to eat? Is there anything that you maybe would like to share with other parents in the same situation?
- Explore **questions** that children and their families may have with regard to T1DM and illness-related topics?
 - If there would be made a special booklet for children with T1DM in Tajikistan.
 - Are there topics that you have found to be important and that you think would be helpful for other children of parents in your situation?
 - Is there a topic that you would like to learn more about?
- **How** should **information** be made available from their point of view?
 - What kind of material? (Book, video, drawing material, diabetes camp etc.)
 - Have you been to a diabetes camp before? How did you like that?
 - Would be helpful to meet other families with a diabetic child regularly for exchange and training?

APPENDIX III: QUESTION GUIDE FOR INTERVIEWS WITH DOCTORS

- How do doctors treating diabetic children consider the **situation in Tajikistan**
 - What is the biggest challenge for families with a diabetic child in Tajikistan from your perspective?
 - What is the biggest challenge for you as an endocrinologist treating children with T1DM?
 - How has the insulin shortage in 2011 affected the diabetic children? (have many been in a coma?)

- **Identify** if there is **information** and **education** material developed for children with T1DM
 - How do patients learn about how to live with T1DM (training?)
 - Do you have any information- or education material that you use? How do you use it? What do you like with it /what do you not like with it?
 - Is there a need for other material from your point of view? If so, what kind of material?
 - What topics would you suggest for an information booklet targeting diabetic children and their families?

APPENDIX IV: CHARACTERISTICS OF DIABETIC CHILDREN

Characteristics children with T1DM	N	%
Age distribution	18	100
≤ 18 yrs	15	83
<i>0 - ≤ 14 yrs</i>	11	
<i>15 - ≤ 18 yrs</i>	4	
≥ 18 yrs	3	17
Gender distribution		
Boys	9	50
Girls	9	50
Geographical distribution		
<i>Central Republican Subordination</i>	11	61
<i>Khatlon Region</i>	5	28
<i>Sughd Region</i>	2	11
<i>Autonomous Region of Gorno- Badakhshan</i>	0	0
Summary		
Age variation	3 yrs - 23 yrs	
Diabetes duration	20 d - 14 yrs	
Known cases of T1DM in 1st or 2nd line fam. history	2	11
Coma (≥ 1 time)	11	61
Participated in diabetes camp 2010	4	22

APPENDIX V: ORAL CONSENT

Consent was given orally with one witness present

My name is Severina Haugvik, and I am a student. At the moment I am doing research for my master degree in 'International Community Health' for the University of Oslo in Norway. I want to learn more about how it is to live with T1DM / care for a child with T1DM in Tajikistan. I would like to ask you questions about your life, what challenges you face, but also if there are things you have found to be helpful in your everyday life with diabetes that other families in your situation maybe could learn from. I would also like to hear if you have any information and education material such as books or pamphlets where you can learn about diabetes. Maybe you could also help me with suggestions on what would be helpful for you and other families in the same situation to know about or maybe you have some specific questions about diabetes that you would like to have an answer to? I am an independent researcher and doing this out of my own interest. I do not work for any organization and I am not paid by anyone to do this research.

The interview may take up to one hour. I have a professional and personal interest in how it is for you to live with T1DM / having to take care of a child with T1DM. No staff or other individuals will be able to know your thoughts and opinions on how you experience life. It will therefore have no consequences for the health care you receive. I am interested in you telling me your story, and I respect what you know. I hope that you will look at me as someone who knows very little about how you experience life as a person with T1DM or parent taking care of a child with T1DM. I will listen and learn from you.

As our conversation may address private matters, you should not feel pressured to discuss issues that you want to keep private. You can end this interview at anytime without telling me why you chose to do so. There will be no consequences of this. If you do not wish to use a tape recorder, you can refuse this, and I will take some notes instead.

Lastly, I would like you to know that your identity will be confidential and your name and exact age will not be written anywhere and will never be used in relation to the information you tell me. The recordings will be deleted once my research report is finished. The information you tell me will be used for purposes of this study and publications in academic journals only. If you have any questions or requests to me about the research and you part in it, I encourage you to ask me at any time before, throughout or after the interview.

APPENDIX VI: RESPONSE FROM ETHICAL COMMITTEE IN NORWAY (REK)



Region: REK sør-øst A
Saksbehandler: Jørgen Hardang
Telefon: 22845516

Vår dato: 24.06.2011
Vår referanse: 2011/1108
Deres dato:
Deres referanse:

Ane Haaland
Universitetet i Oslo
Oslo

2011/1108a Barn med type-1 diabetes i Tadsjikistan: Oppfatninger av sykdommen og behov for informasjon blant rammede barn og deres familier

Children with Type-1 Diabetes in Tajikistan. A qualitative study assessing perceptions of Type-1 Diabetes and the Need for Information- and Education among affected Families in Tajikistan.

Project manager: Ane Haaland, University of Oslo

We received the application on 10 May 2011 with the following enclosures: research protocol, information letters for children and parents, declaration of consent, and CV for project manager.

The Regional Ethics Committee reviewed the project application during the meeting on 9 June 2011.

The project was assessed by the Committee in accordance with the Norwegian Research Ethics Act of 30 June 2006 and Act on Medical and Health Research (the Health Research Act) of 20 June 2008.

The project addresses problems concerning type 1 diabetes in children in Tajikistan. The disease is a serious disorder in developing countries which may lead to death within a week in an untreated child. The aim of this project "is to assess parents' and children's perceptions of T1DM and their need for information and education in Tajikistan." Study sample is 10 diabetic children aged 7-18 and their parents. Triangulation of methods: in-depths interviews, informal conversations and participant observation.

There seems to be no evidence of registration of medical information on the patients, only of what they know and what kind of questions they may have.

The committee find the aim of the project is to gain knowledge about the experiences or perceptions of the parents and children concerning of T1DM both the parents and the patients) as well as the health personnel. The project does not include patients and does not collect any medical information about them.

The Committee concluded that they consider the research project to be outside the remit of the Act on Medical and Health Research and therefore can be implemented without the approval from the Regional Committee for Medical Research Ethics.

Med vennlig hilsen

Gunnar Nicolaysen
professor dr. med.
leder


Jørgen Hardang
seniorrådgiver

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Vi ber om at alle henvendelser sendes inn via vår saksportal eller på e-post. Vennligst oppgi vårt referansenummer i korrespondansen.