

The Quality of Life of parents of children with Diabetes type 1

*A qualitative study of the quality of life of parents of children with
diabetes type 1 and their coping experiences*

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Abstract

Background. In Norway there are over 2500 children diagnosed with diabetes type 1 (DT1) with an annual incidence rate of 350. These children are completely dependent on insulin therapy in order to help their body function. Inconsistent care concerning the use of insulin and follow-ups on trying to meet the preferred level of glycohemoglobin (HbA1c), may lead to irreversible complications creating obstacles for leading a typical healthy life for the children as they grow up. Their parents play an important role in managing the disease and aiding these parents is essential in order to provide the children with a safe future.

Aim. The aim of this study is to explore the life quality in parents of children with DT1 and look at coping mechanisms parents have available or should have available.

Methods. This research was approached with qualitative theory where in-depth interviews with mothers lay the foundation for the results. They were conducted in a safe environment and the information was handled with respect and confidentiality. The experiences and reflections of the parents were later transcribed and categorized in order to discuss the importance of mapping how they conduct their day-to-day life and diabetes management.

Results. The findings showed that this is a group of people who live a life in unwanted isolation and loneliness. Caring for a child with DT1 demands most of their focus and attention which creates struggles at a domestic level due to sleepless nights, constant fear of managing the diagnosis wrong and contribute to potential irreversible complications. They perceive a lack of support and understanding from both health personnel, families and friends. Social support is suspected to help mothers handling such diagnosis by letting them air their thoughts and build confidence when making decisions. There seems to be very diverse and minimal care and information provided for these parents which results in a feeling of disrespect, frustration and helplessness.

Conclusion. The mothers participating in this research seemed to have several negative experiences in relation to managing the diabetes in terms of feeling isolated and ignored and they described living in a constant high stressed state. Social support is suspected to play an important role in reducing their described feeling of being closed off to society. The thesis also suggest that concrete information and care from the health personnel could contribute to creating improved quality of life for the mothers and in effect improved conditions for managing the children's diagnosis. The need for this kind of service should be further investigated and it's worrying that there has been a limited focus on this group of people up to this date.

Acknowledgements

As educational, interesting and absolutely rewarding it has been working on this thesis, it is quite a relief to finally see it come to end. The past months has been intense and at times lonely and frustrating, but it has all been worth it. Over the last few years, there has been a demanding process for development on a personal level, finishing this master thesis is the last bit of the puzzle before starting a new chapter in my life. This makes it an emotional changeover, however I am nothing but excited for what the future now may hold.

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1. Introduction

1.1 Diabetes

Diabetes is more than one single chronic disease, there are several different forms all involving insulin cells. There are two main types of diabetes: diabetes type 1 and diabetes type 2. Diabetes type 2 consists of a combination of insulin resistance and lack of insulin production due to glucose intolerance. Type 2 is the so-called lifestyle disease, which in theory can be stagnated by improvement in activity, of food choices and other factors, but relatively healthy people can also be at risk if for example both parents have the disease. The insulin producing cells in a person with diabetes type 2 are not out of function, but the body has become resistant to the insulin or the production is not big enough (Diabetesforbundet, 2016).

The unique aspect of diabetes type 1 which differs substantially from diabetes type 2, is that the production of insulin is absent throughout life (Diabetesforbundet, 2016). Diabetes type 1 is an autoimmune metabolic disorder, where the insulin producing cells in the pancreas are destroyed by the patient's body due to unknown reasons. Science still cannot say why some people get this disease despite several resources devoted to research aimed at finding a definite answer to this and hypotheses have been investigated thoroughly to find critical factors (Diabetesforbundet, 2016). In a normal person's body, the insulin is produced to give energy to muscles and tissues. As the person digest a meal the pancreas release a naturally balanced dose of insulin in order to circulate together with the sugar intake from the food and bring the blood glucose to a stable level.

When a person with diabetes type 1 consume a meal, none of the above occurs because of the lack of functioning cells and the body is unable to metabolize the sugar. When the sugar from the food are supposed to be transported to the muscles and tissues, it is built up in bundles in the person's bloodstream where it can lead to irreversible complications as explained later in the introduction.

1.2 Children's diabetes type 1

Over 95% of the children and adolescent diagnosed with diabetes has diabetes type 1, and no one is too young to have the diagnosis (Diabetesforbundet, 2016). Because of the young age

at time of diagnosis, diabetes type 1 is often referred to as juvenile onset-diabetes. Diabetes type 1 is the most common non-preventable chronic disease diagnosed in children in most of the developed world today, but the incidence rate varies from country to country. Norway is one of the top three countries with the highest incidences on the world; here there are about 32-34 per 100 000 children diagnosed with diabetes type 1 every year which is approximately 350 (figure 2), with an increased incidence rate over the last few decades, while in China there is about 0.1 per 100 000 every year.

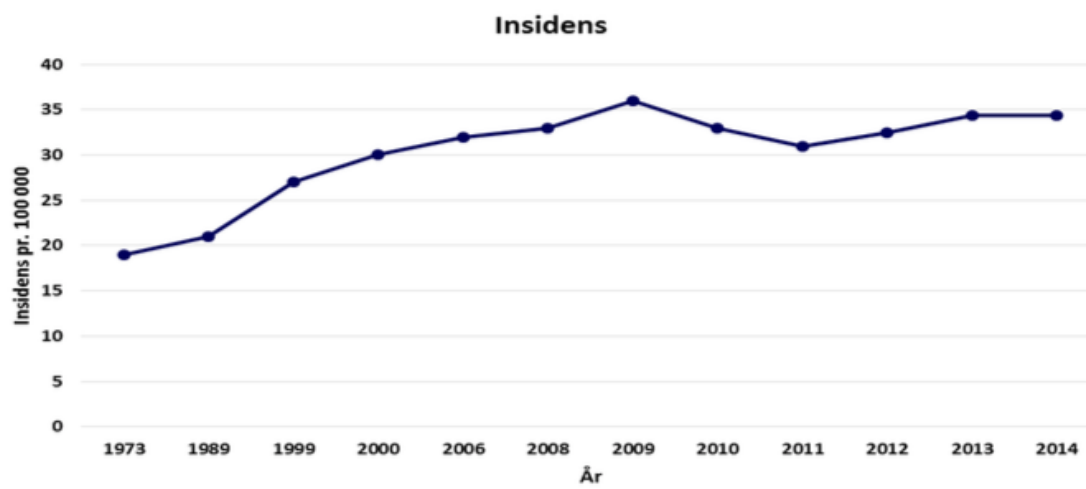


Figure 2. The incidence of diabetes type 1 from newborn to the age of 14 in Norway from 1973 to 2014. (The Norwegian Childhood Diabetes Registry 2014, p. 18)

The incidence rate increases with age (figure 3) and has its peak around the years of puberty, and it can occur for the first time at any age later on as adult though this is a lot more rare (The Norwegian Childhood Diabetes Registry).

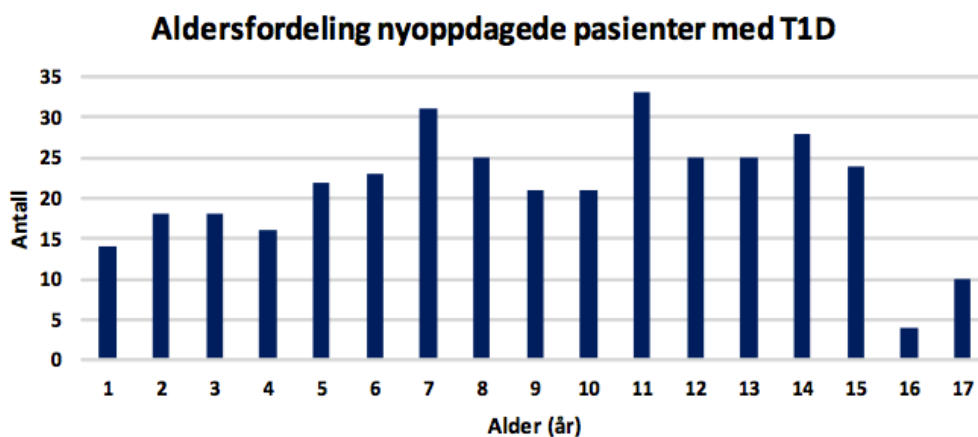


Figure 3. The number of children with recently discovered diabetes type 1 in Norway (2014), presented by age at time of diagnosis. (The Norwegian Childhood Diabetes Registry, 2014, p. 16)

Symptoms of undiagnosed diabetes in children are an extreme level of thirst and then naturally a lot more visits to the bathroom (Diabetesforbundet, 2016). Parents of children who are already potty-trained can suddenly experience the child wetting the bed at night and this may lead to frustration and creates unwanted frictions within the family before the reason is known. As will be discussed throughout the thesis, the parents struggle, guilt and decreased experience of a good life quality, and perhaps even more importantly, their work to overcome these challenges, starts already here. Children with type 1 diabetes are dependent on their parents because it is natural that they themselves can not deal with the disease themselves.

In section 1.3 a more detailed description of the treatment for children with diabetes type 1 is given, but it is necessary to mention beforehand that these children can in theory live their life as normal as any other regular kid as they can take part in activities wholeheartedly. But the work and effort put in to make this happen is a plausible interesting investigation, see 1.6 Research aim.

1.3 Treatment

1.3.1 Insulin

Before and during the 19th century, patients with diabetes type 1 faced a certain death, many due to an undiagnosed condition, but mostly because there were no cure or treatment available or known (Chase et al., 2001). Before the discovery and introduction of insulin, the only thing doctors could do for the patients was to put them on extreme diet (low/no carb and low calorie) which perhaps prolonged the lives of the patients a few years, but in theory made them twice as exposed for early death because of starvation in addition to the lack of insulin (Dahlquist and Källén, 2005). In the early 1920's, insulin injection was established as a safe clinical treatment and the survival rate increased accordingly. Nowadays, the patients still live with an increased risk of early death if the diagnose is not handled correctly and the risk of developing several acute and late side-effects and severe complications due to wrongful or inadequate treatment is relatively high (see section 1.4).

Insulin preparations can be introduced to the body in different ways, often people receive

combined treatments of the following: Short-acting, rapid-acting, intermediate-acting or long-acting. All of them with different duration and peaks, so in order to set the right dosage one has to plan the meal both in form of time of intake or what kind of intake such as what amount, does it consist of slow/fast carbohydrates, what kind of fat and/or sugar if any etc (Buyken et al. 2001). One must also foresee what to do if there is a sudden change in the meal plan, or a spontaneous meal is consumed. In addition to being affected by the different ingredients in a meal, the blood glucose level will vary during the day based on activity level, potential sickness, travelling, stress, lack of sleep and other factors. For parents with children without diabetes type 1, food and activity balance is quite challenging in itself, but when the importance of a stable glucose level is added to challenge it can at times be very frustrating and impossible to know if a correct decision is made (Lenhard and Reeves, 2001). The insulin is injected manually or automatically directly into the skin with a needle, insulin pump or an insulin pen.

1.3.2 Insulin pump therapy

Insulin pumps (continuous subcutaneous insulin infusion - CSII) give the diabetic child more flexibility in life, leading to a greater and easier involvement in everyday activities as regular children. It provides more user-friendly choices in planning meals combined with activity and insulin dosages throughout the day. Used correctly, the insulin pump helps the parents manage and control the child without a negative effect on the glycohemoglobin (see 1.5. HbA1c). Using an insulin pump, often with a continuous glucose monitor, can provide stability and lesser concern for the parents in terms of the technical aspect of the disease; a stability enables a continued typical lifestyle and potential lesser decrease in life quality for both the child and the parents (Ypsomed, 2014; Medtronic, 2016).

Studies have shown that insulin pump therapy provides a durable mean to treat children with diabetes type 1 (Wood et al., 2006, Weissberg-Benchell et al. 2003). Examples of the advantages of the insulin pump compared to needles and insulin pens are the ability to be flexible as mentioned and it is a far better hypoglycemic prevention. Children who do not use insulin pump therapy or discontinue using it after a period of time, experience a deterioration of blood glucose level and control.

Data from the annual report by the Norwegian Childhood Registry (2014) shows that 70% of the children with diabetes type 1 uses insulin pump in Norway, an increase from 9% in 2001 (figure 5).

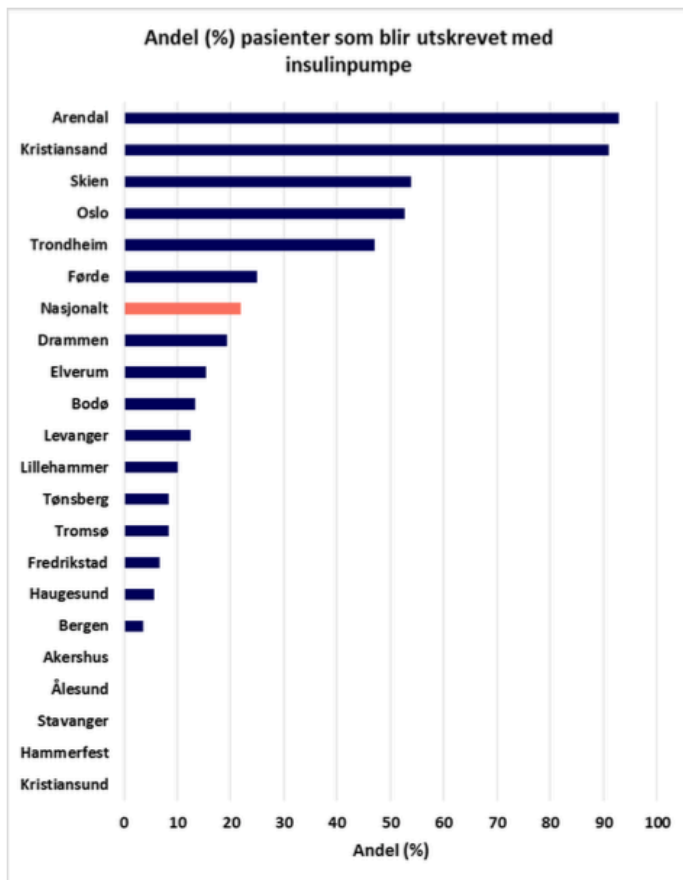


Figure 5. The number of diagnosed children starting on insulin pump therapy at the time of diagnosis (16 out of 21 children's hospitals use insulin pump therapy at the first step of treatment). (The Norwegian Childhood Diabetes Registry, 2014, p. 20)

1.4 Complications

Diabetes type 1 can pose a threat to all organs of the body, as they all need insulin to function properly. However, it is important to emphasize that the possibilities are great regards to living a good life with the diagnosis without any occurrence of complications.

It is mostly when diabetes and the blood glucose level is uncontrolled or poorly controlled that the conditions described on the next few pages occur. Below, a few of the probable complications to illustrate how exposed this group of patients are and why there can never be a day off insulin and glucose focus. In addition several of the complications can be utterly

disabling over time which makes them an important part of the potential decrease in life quality for a diabetic patient.

Acute complications:

Ketoacidosis. This is a critical condition which require immediate attention and treatment. Ketoacidosis is a result from the body receiving limited or no insulin over a period of time, and prevent the body to function, releasing a mechanism that puts the body in a coma or in the worst case scenario, having a deadly outcome (Morris et al, 1997). When the body lacks insulin the sugar leaves the body quickly through the urine instead of being transported to the necessary cells, muscles and tissue. Children not yet diagnosed with diabetes type 1, can be rushed to hospital due to ketoacidosis, and the first step is often to look for sugar in the urine to determine whether or not the condition is a symptom of diabetes (Diabetesforbundet, 2016).

Hypoglycemia. Hypoglycemia can often be referred to as insulin shock or simply low blood sugar, and this is another condition due to an imbalance between insulin and glucose. In this situation, the blood sugar level decreases without any intervention, possibly due to an overdose of insulin, and it can be reversed by quickly consume something containing a significant amount of sugar or concentrated glucagon (World Health Organization, International Diabetes Federation; 2006). Because mild hypoglycemia can be quite common, diabetics often walk around with pure sugar pills in order to stagnate hypoglycemia before it escalates. Untreated hypoglycemia may result in losing conscience, cramps and more (figure 6). When the cells in the central nervous system experience a sudden and total lack of glucose they shut down immediately and the cerebral symptoms occur at the same rate. The symptoms may vary heavily from patient to patient, but every individual patient often has the same type of reaction(s) each time, which makes parents of children with diabetes type 1 experts in picking up the signs and interrupt any further development of the condition (Morris et al., 1997).

The following chart illustrates the difficulties of detecting hypoglycemia, because the symptoms are so many and different, and alone they may seem harmless or it can be tempting to connect the symptoms to common exhaustion instead of taking them seriously.

SYMPTOMS OF HYPOGLYCEMIA	
MILD HYPOGLYCEMIA	SEVERE HYPOGLYCEMIA
hunger, thirst and nausea	numbness in the lips or tongue (looses speech)
headaches and dizziness	impaired vision (seeing double)
rapid heartbeat	seizures
sleepiness	unconsciousness (coma)
sweat and chills	delirium (lack of coordination)
shakiness	
sudden, irrational moodchanges (anger, sadness)	
anxiety or impatience	

Figure 6. Various symptoms of hypoglycemia, illustrated by the author of this thesis with information from Diabetesforbundet (2016).

An important variable, which only shows itself after an incident of hypoglycemia, is the ability to register new events of the same condition (Cryer et al. 2003). This ability decreases along with the gradually slow reaction throughout all the organs in the body, which makes it crucial to inform patients with a history of hypoglycemia to make both themselves and their surrounds address more attention to alarming and/or hidden symptoms.

Serious health problems over time

Nephropathy. The kidneys are heavily exposed to damage if the blood sugar level is not stable due to poor circulation of the blood. In short; the kidneys are dependent on protein and protein needs sugar to access the kidneys; and the sugar is dependent on insulin to make its way to the correct organs. 20% to 40% of people living with diabetes type 1 and diabetes type 2 will most likely experience this kind of damage to the kidneys (Diabetesforbundet, 2016).

Retinopathy. It can be quite common for diabetics to get eye diseases due to the tiny retinal blood vessels behind the eye as studies show there is a direct connection between poor blood glucose control in diabetes type 1 and complications with vision (Hapnes and Bergrem, 1996)

Cardiovascular disease. Epidemiological studies show patients with diabetes type 1 are far more likely to get premature coronary artery disease and the mortality for young people

suffering from this condition is higher than the young non-diabetics (David et al. 2009). The same studies suggest the diagnosis works as an accelerator for developing a condition of this kind.

Diabetic foot damage - Diabetes increases the risk of severe foot damage by over 30 times. In Norway several hundred amputations are conducted on diabetic patients a year (Kapelrud, 2006).

Dental health. Research shows that diabetes type 1 patients are up to four times as exposed as non-diabetics for developing severe periodontal diseases (Grossi and Genco, 1998).

1.5 HbA1c - Glycohemoglobin

HbA1c, glycohemoglobin, is the most important variable for measuring quality at the register for children's diabetes. HbA1c reflects the blood sugar level the last few months and is the overall goal for a stable relationship with the disease and control of the handling the blood sugar level from day to day (The Norwegian Childhood Diabetes Registry, 2014) . The day to day measuring of blood sugar level will show a lot of inconsistency which can panic some parents, however they can often be reassured of their handling by a stable glycohemoglobin. These are situations that will grow on people as the time living with the disease goes by. HbA1c is the only variable that can be seen in connection with (in addition to indicate new incidents) potential challenges and developing complications, both the micro vascular and avascular I described in 1.4.

There are guidelines for the HbA1c target level for children, and this is calculated and decided in order to prevent potential complications later in life, as much as one can without drastic measures. The Norwegian guidelines for children's diabetes are set by the International Society for Pediatric and Adolescent Diabetes, who recommends a HbA1c level below 7,5 (Pediatric Diabetes, ISPAD Clinical Consensus Guidelines 2009:12:197).

However, most children does not qualify for the international HbA1c standard as Figure 7 indicates:

Alder	HbA1c (%)		Mangler HbA1c
	Mean (range)	n	n
0 - 4 år	10,3 (5,4 -13,9)	56	11
5 - 9 år	10,8 (6,6 – 16,3)	113	8
10 - 14 år	11,8 (6,8 – 17,4)	121	11
15 - 17 år	11,9 (6,5 – 16,2)	38	0
Totalt 0 - 17 år	11,2 (5,4 - 17,4)	328	30 (8 %)

Figure 7. Analyzed HbA1c level of new patients in 2014, shows the recommended level is not met by everyone (The Norwegian Childhood Diabetes Registry 2014, p. 21)

1.6 Research aim

Parents play an important role in managing their children's diabetes (Horsch and McManus, 2013; Wiebe et al., 2005), and parents in previous studies on children and adolescents state that diabetes type 1 is not the disease of the child, it is a disease of the family (Kristensen, 2004). The aim of this study is to explore the life quality in parents of children diagnosed with diabetes type 1, more specifically children between the age of 2 and 6, and how they cope with the daily challenges they are up against as individuals themselves in correlation to care for their child. In order to achieve the research aim, a qualitative approach was chosen, which includes discussing previous theories and conducting personal interviews. Combined, these will be used as sources of information for the discussion.

2. Theory

2.1 Life quality

Quality of Life (QoL) is associated with a person's experience and the individual criteria of the perceived happy life and by that definition life quality is a health state within the individual (Næss, 1998). The term life quality is quite complex and has various definitions depending on what theory behind them is sought out, but one can mention different categories within the term such as happiness, the (need for) contentment and self-realization. Commonly these categories reflect the subjective perception of the good life where one also can interpret the person's health condition is a given criteria. By this logic one can interpret further that the term consist of the physical, the psychological and the social aspect of life. The concept of health is broad and therefore one can assume that QoL can not simply use statistical data for measurement. It is quite the opposite, as stated at the beginning of this section: Quality of Life is a multidimensional concept incorporating the individual's perception of all criteria within health status, life style, life satisfaction, mental state and well-being (Mugno et al, 2007). This is consistent with the World Health Organizations definition where health is “ a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (WHO, 1948). This definition is so wide, it gets difficult saying what health is not. In addition, when stating that the term life quality is subjective, it makes the experience hard to measure.

Using QoL as a tool is important in medical practice in order to improve doctor-patient relationships, in assessing the effectiveness and relative merits of different treatments, in research and in policy making (WHO, 1998). However measuring quality of life is especially important to conditions that are chronic and to some extent impairing (Mugno et al, 2007).

The individual's life quality can be summarized within these categories based on different studies on QoL (Næss, 1994; Felce and Perry, 1995):

- Activity; to what extent does a person have a will to live, lust, interest and commitment to something outside its own sphere which is experienced as fulfilling as well as energy to conduct and live up to its own interests. In other words, not feeling tired
- Cohesion and close personal relationships with mutual respect, loyalty as well as affiliation to something greater

- Self-esteem in the way that the individual feels secure and trust him or herself regards to abilities, choices, utility and satisfaction with it's own effort and dedication towards different tasks or areas. This is also about acceptance without feeling shame or guilt which can be found to be essential within the parents and caretakers of children with any disease, chronicle or not, irreversible or not.
- The basic mood or state of happiness and joy. To what extent do the individual indulge in beautiful experiences such as connection with inner beauty, nature and not closed off to society and interaction with surrounding people. An individual's experience of life as rich and fulfilling in non-materialistic ways. In other words, an absence of melancholy, agony and/or pain.

Several of these aspects will solely be based on preferences, but one can argue that they still are essential to an individual's life quality. The individual could through own preferences value some higher than others, but the main idea is that both the daily life experiences and research show a correlation between the different areas without a complete consistency.

The categories above are quite general as well, but it could be argued they are needed in order to see the fuller picture when looking at the parents experienced quality of life. During the interviews, the respondents situations or experiences which can be related to these aspects might help prove the categories valuable for further discussion.

2.2 Family relationship and conflict

The management of diabetes type 1 is, as earlier emphasized, a complex and difficult process, hence the family as a whole needs to be addressed as well. Recognizing diabetes specific family conflicts by using management tasks helps identifying potential obstacles and triggering situations of family functions in correlation with handling the disease.

In the context of all interactions related to treating and living with a child with diabetes type 1, such as insulin administration, preparation for meals and activities as described in the introduction, diabetes specific family conflict can arise and challenge adherence and glycemic outcomes (Hood et al, 2007). Rubin et al. (1989) developed a measuring tool to put the conflicts and situations that arises on a scale in order to highlight the family-oriented nature of diabetes management, the critical nature of effective diabetes-specific

communication triggered by conflict as well as the responsiveness to change of habits. A revision of the Diabetes Family Conflict Scale (DFCS) conducted by Hood et al. (2007) emphasizes the importance of having such a tool because “whereas general family conflict is unavoidable and in fact some general conflicts is normal, diabetes-specific is counterproductive to effective diabetes management” (Hood et al., 2007, p. 1764). Their analysis revealed an association between the revised DFCS and glycemic control. The introduction illustrated in detail why good glycemic control is essential for living with diabetes type 1 without having avoidable complications.

The use and review of DFCS is based upon a survey of problem areas in diabetes, which has been shown to have a high reliability (Polonsky et al., 1995). The survey and the DFCS contribute to knowledge towards mental health functions such as general emotional distress, fear of hypoglycemia, disordered eating and it correlates measures of distress in relation to attitudes toward diabetes. Findings indicate that the family variables emerging from using such scales and surveys affect glycemic control, and their theory is that these variables play a key-role in diabetes management (Hood et al., 2007). Hood et al. (2007) also emphasize the importance of considering the well-being of parents and the family as a whole when one is looking for the best possible outcome for the HbA1c by improving the diabetes management and control.

2.3 Mental health

There is a decent amount of focus on social difficulties and psychological obstacles related to diabetes such as eating disorders and anxiety from diabetic patients (Jones, 2000; Peveler et. al, 2005). However, there is a significantly smaller amount of attention given to the parents or caretakers for the same challenges. Their mental health is just as vulnerable and has a similar critical value, in order for a diabetic child to live a good life (Wagner et al., 2005). This aspect of the diagnosis could be important knowledge for those treating the patient as well as other care-givers surrounding the family.

Mental health is mostly associated with psychology, which from the Greek origin means the study of the soul, but in the modern times it is defined as the scientific study of the human mind and its functions; why do we think what we think, why do we feel what we feel, why do we act the way we do (WHO, 2005).

It is suggested that posttraumatic stress symptoms within parents can be related to poor adherence for the child's insulin treatment and HbA1c control (Horsch and McManus, 2014), but this argument is not investigated thoroughly either. Horsch and McManus (2014) described the parents essential and complex role which strengthens the importance of this thesis' research aim:

“parents are expected to acquire a sophisticated understanding of the disease process in order to effectively respond to potentially life-threatening situations, such as hyperglycemia or hypoglycemia and ketoacidosis” (Horsch and McManus, 2014, p987)

Their study is particularly interesting as their results indicated a more positive correlation between the parents posttraumatic stress syndrome and insulin treatment of the child when the child was of young age (0 to 8 years old) compared to parents of older children (9 to 16 years old) which this thesis research has chosen for its cohort (see 3. Method).

2.3.1 Management and coping

The focus on management and coping is a central and critical aspect regards to the parental wellness in association with the child's condition. Help with coping with the emotional aspect is to be taken care of hand in hand with the practical management and coping of the disease.

When a child has been diagnosed or being examined for diabetes type 1, the parents and plausibly the closest family and surroundings will experience a steep learning curve as they come to term with the diagnosis, change of life, new daily routine and proper care (Gallo, 1991). Diabetes type 1 is often an invisible diagnosis to strangers and Gallo (1991) suspect the parents may feel like complainers if they voice their concerns or struggles with someone who can't grasp the full picture. This may reduce the life quality both in terms of both shame and tiredness as they can't get any relief of the pressure upon them.

As mentioned in the introduction, the guidelines for a good life with diabetes type 1 is to have a consistent long-term blood sugar level of $>7,5$. However, there's no guideline towards the parents minimum functionality in coping with the disease. Merely a few studies has touched upon the subject and this calls for more attention as it's the parents whom are

dealing with the disease even though it's the child who has the diagnosis (Sullivan et al., 2003). Sullivan et al. (2003) and Kristensen (2004) hypothesises that adolescent diabetics will want to take care of themselves which puts parents on the sideline, which strengthens the cohort of this thesis (see 3. Method).

2.3.2 Life crisis and depression

The Oxford Online Dictionary defined life crisis as: “1. A crucial or decisive point or situation, especially a difficult or unstable situation involving an impending change. 2. A sudden change in the course of a disease or fever, toward either improvement or deterioration. 3. An emotionally stressful event or traumatic change in a person's life” (Oxford Online Dictionary). A life crisis is connected to common events every regular person may experience throughout life, but the essence is of the kind that can be perceived as an additional strain for the person in the certain situation (Lydick and Epstein, 1993)

The strain may be a practical situation that is going through a change, but it can also be about loss and sorrow, such as a person close is diagnosed with a serious disease (Kendler et al, 2010). Other examples are hard/complicated endings to relations, economic losses, notice at work or an honor loss. Such traumas in life can be overwhelming and will potentially lead to reactions of some sorts. Previous studies have shown that when a child is diagnosed with a chronically disease feelings of fear, guilt, grief and hate arouses within the parents (Austin, 1990; Johnston and Marder 1994, Seppänen et. al, 1999) and studies like these show that the grief is not only because the child has a disease for life, but also because such a disease, like diabetes type 1, makes the child depend on its parents for much longer than a relatively healthy child.

Basically, stressful life events are commonly seen as triggers that lead to negative outcomes in a person's life (Schwarzer and Schulz, 2003). In Kendler, Karkowski, & Prescott (1999) conducted a study where they were interested to find how strong this particular link might be. Their study clarified to what degree the events would call for such a course of action that would lead to the situation where a person's quality of life would decrease and they did find that stressful life events have a substantial causal relationship with the onset of episodes of major depression.

Even though most individuals who experience stress do not develop illness, the cumulative exposure to aggravating daily hassles over a long time may have detrimental health effects (Schwarzer and Schulz, 2003). It is the irregular, but decreasing experience of the perceived good life that also concerns the aim of this thesis as it is suspected that over time it might get irreversible as well. This could call for attention in the early stages and a dedicated follow-up for the parents and care takers from the very beginning, starting at the same time as time of diagnosis and the follow-up of the child diagnosed.

2.3.3 Social support

Common for practically all the studies and theories I have been going through to create a foundation for my research, is the fact that they are based on individuals who themselves have a chronic disease. There are, as mentioned, relatively few studies where coping mechanisms and social support for the parents or caretakers of a chronically ill child is the focus. However, the studies, such as “Coping, social support, and adaptation to chronic illness” (White et al, 1992), show the importance of social support when dealing with a chronic diagnosis. Hence one can believe it is justified to assume that social support can be a crucial aspect for parents dealing with their child's chronic disease.

Social support is the individual's perception of being embraced with love and care, to be respected and valued and to belong to a social network or relationship with mutual commitments (Cobb, 1976). The effect of social support on parents with challenged children is suspected to be positive for the well-being of both parents and the children and contributes to a greater relationship between them in addition to improve the children's development (Dunst et al., 1986) and one can assume this is similar for the relationship between children with diabetes type 1 and their parents. This illustrates that a parent's need for support is affecting the chronically ill child and positive interactions with other people whether they can relate to the situation or not is encouraging, strengthening and edifying (Gibson, 1994). To the opposite, lack of support and empathy is therefore suspected to be hurtful, disappointing and frustrating.

Gibson (1995) created a conceptual model (figure 8) that reveals the mother's commitment and love for their child works as a motivator to get through the different phases of accepting

the reality to attempting to take charge of the disease. The model also shows the influencing factors I emphasize myself throughout the thesis.

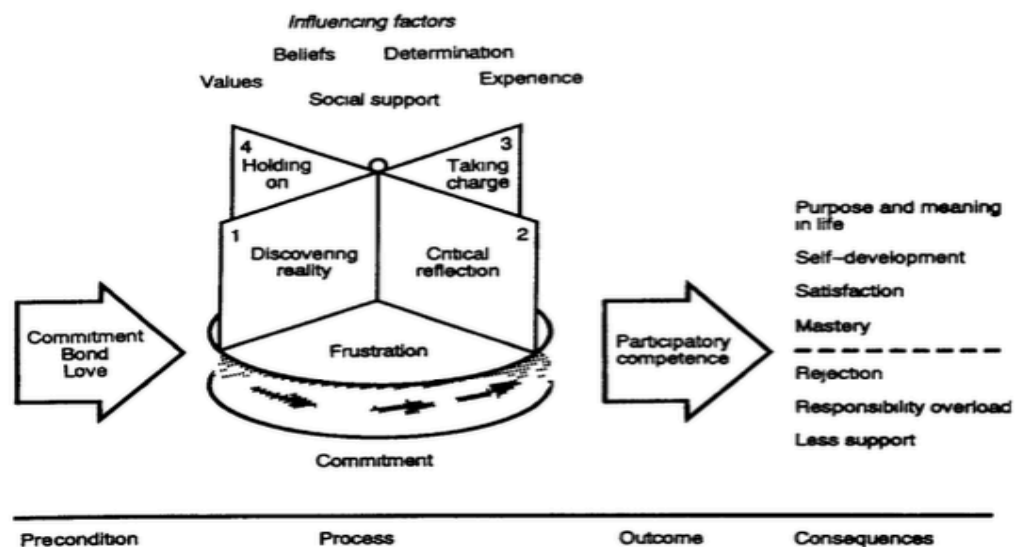


Figure 8: A conceptual model of the emotional process when coping with chronically ill children (Gibson, 1994, p. 1203).

2.3.4 Support from the family

Another aspect of coping mechanism, similar to social support is familial sources of support. It exists a demand for this type of support (Uchino et al, 1996) and it may be important to retrieve more knowledge on it. Seppänen et al. (1999) supports this, however, their results are quite weak as they only studied the first four weeks after the time of diagnosis and with two families. The developing need and family function was not taken into consideration, but one can still draw the conclusion of yielding for more research on how essential the family involvement can be in order to improve the life of the parents.

Despite devoted efforts, there were close to zero studies emerging, apart from the two mentioned above, whom looked at the importance of relatives involving themselves when a child in the family had a chronic diagnosis. Also, the two mentioned are relatively small, and this leads to a suspicion that the reason for the fact that this is all that was found at this point, is the unique aspect of a child with diabetes type 1 demands a special kind of care taking. Even if there could not be found research on the matter with other types of chronic diseases, the demand might be different, therefore the lack of research. The effect of family support will be addressed in the discussion, based on what emerges during the interviews.

2.3.5 Support from health personnel

Parents of children with a chronic disease has in small studies reported they would benefit more from the technical support and medical supervision from their respective hospitals and health personnel if the life situation of the family as well as the individual needs of the parents were taken into consideration along the way (Seppänen et. al, 1999). Thomson et al (1992) stress that the nursing staff and doctors should be aware and respect the importance of parents everyday life, and make sure they understand they do not have to sacrifice all of their own time to care for their child. This in order to minimize the disturbance of the family dynamic and to help the parents keep a acceptable energy level so they can provide the proper care, attention and excessive follow up on their chronically ill child.

A study on mothers with chronically ill children, with focus on the empowerment and coping, showed that they were frustrated with the lack of understanding from the health personnel, in particular with physicians because their concerns, whether they were rational or not, were minimized, neglected and ignored (Gibson, 1994). Gibson (1994) suggest that even though the health personnel may have acted in the child's best interest. Gibson (1994) suspects the health personnel did not acknowledge the mothers struggles to *not* transfer her fear to the child, and she explains this by suggesting they did not know this struggle was a factor influencing the mother's ability to provide decent care for her child.

As a result of advances in scientific knowledge and technology, the number of children living with chronic illness is ever increasing The burden of responsibility for the care of these children falls increasingly on the involved parents and, particularly, on mothers (Gibson, 1994; Horsch and McManus, 2014).

3. Method: The qualitative approach

Based on the theories above, I believe that by conducting qualitative interviews to gather data and information in this thesis, it will be possible to bring to light what subjects parents feel are weighing them down and they perhaps find difficult to share on their own initiative as well as where they feel they are missing information or simply what they wish they had been asked in order to open up and get help. The following pages will explain why the qualitative approach was chosen and the theory behind this method. It will also give a detailed presentation on how the research was conducted as well as all details concerning the method and collecting of known data

3.1 Gathering data

The chosen cohort consists of parents of children with diabetes type 1 ranging from the age of 2 and 6. These are children in kindergarten, and this age group was chosen because of the interesting aspect of these children are of the age where they cannot handle the disease by themselves at any point. Their coping and life quality are dependent on the people around them: parents/other family and trusted workers at their kindergartens.

Criteria for inclusion

Parents of children between the age of 2 and 6 of any ethnicity who has been diagnosed with diabetes type 1 at a Norwegian hospital minimum 12 months ago, and been attending close to all scheduled follow-ups since the day of diagnosis.

Criteria for exclusion

Children who are treated for other chronic diseases. Families who does not have acceptable Norwegian or English language proficiency in order to properly communicate (both share and receive) information on the relevant issues.

3.2 The qualitative research

At the beginning of the process of working with the master thesis, there were assumptions to how and why parents of children with diabetes type 1 were conducting their everyday life. To study this, the most natural choice was to take an qualitative approach in order capture the essences of the respondents experiences in the best possible way and present both findings

and discussion accordingly. The final choice on the method was based on Creswell (2007) who wrote:

“qualitative researchers use an emerging qualitative approach to inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is inductive and establishes patterns or themes. The final written report or presentation includes the voices of participants, the reflexivity of the researcher, and the complex description and interpretation of the problem and it extends the literature or signals a call for action.”

(Creswell, 2007, p. 37)

3.2.1 Qualitative research versus quantitative research

Both qualitative and quantitative research aims to capture the individual's point of view, however it is an acceptable logic that qualitative methods are better suited to explore individuals' experiences for example by detailed interview and time spent with the individual. Qualitative methods often focus on individual experience. Qualitative interviews consist of acquiring knowledge through dialogue with the involved parties' experience. Quantitative methods are better used on systematically and statistically gathering of information through numbers and other data. These methods rely on quantifiable data in various forms and emphasize the relationship between the data. In contrast the qualitative method investigates how the variables are created and how the social surroundings create the process and give meaning to the findings (Denzin and Lincoln, 2005).

In areas where there has been no or limited information based on in-depth research, qualitative research will be appropriate because of its ability to investigate and ask questions that will bring forth new knowledge, provided the researcher's prior knowledge of the subjects. Denzin and Lincoln (2005) describe qualitative research as involving: “... an interpretive naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them.” (Denzin and Lincoln, 2005, p.3)

As described in section 3.1, there is not much modern research on the chosen topic of this thesis hence the qualitative method is fit to investigate further. Also, the topics this thesis aims to provide more information on, are not quantifiable in a way the potential results from such a research could help achieve the answers the writer is searching for.

I borrow from and paraphrase Malterud (2001) explanation: “Medical research needs diversity. Responsible application of qualitative research methods is a promising approach to broader understanding of clinical realities. No research method will ever be able to describe people's lives, minds, and realities completely though, and medical doctors should be reminded that scientific knowledge is not always the most important or relevant type of information when dealing with people” (Malterud, 2001, p. 487), and one can then assume this is a fundamental assessment to interaction with both patients and their families.

3.3 The interviews

3.3.1 Preparing and conducting an interview

The qualitative research interview aims to see the situation from the respondents perspective as well as emphasize and expose their experiences. It is often assumed that qualitative interviews are easy to conduct because “they are similar to everyday conversations at first glance, and this assumption has probably contributed to an increase in popularity for this research method” (Kvale and Brinkman, 2009, p.34). This however, can be considered illusion. It is quite easy to conduct an interview without any form of preparation or reflections in advance, but the probability of gathering any data of value from spontaneous interviews is not particularly big.

Research in the form of qualitative interviews is a tool similar to an art form if done right and with respect for the subject and respondent. It demands a high skill level and experience with the interviewer, as well as sufficient knowledge of the subject. By choosing this research method for the thesis, it is expected to find usable material in order to conduct a proper analysis for the results and later conclusion. In addition, establishing a good relationship between the interviewer and the respondent through personal interaction is what I believe to be the most important ground rule in order to allow the relevant information to emerge.

Before meeting with the respondents a document was distributed, containing the main topics that was going to be discussed. By doing the respondents could prepare some stories they wanted to tell, and it also gave them the chance to remember, consider and write down small details they might not have remembered on the spot during the actual conversation we were to have. As the meeting with the respondents took place, a more advanced document to work

with was brought as a guideline (appendix 3). Several of the topics was followed up and explored by asking the respondents if they kindly could elaborate more when necessary.

3.3.2 Semi-structured interviews

A challenge was keeping the structure with some room for diversion as well as being able to help the respondent expressing his/her own stories and takes on different situations brought up. In addition to this one would want to be welcoming, empathic and show sensitivity towards their stories at the same time, the opportunity needed to be critical to make sure there was validity in the information that was given. This was done by either asking some simple critical questions to help them elaborate or by giving them spontaneous interpretations then and there where they could either confirm or deny these suggestions.

Active listening is every bit as important as specific comprehension of questioning techniques (Kvale and Brinkmann, 2009). Knowing this one would want to give the conversation a natural flow, therefore moments of silence was often provided if it felt right and by looking at the respondents need to have a break in order to gather thoughts, make reflections or reach conclusions of their own without me interrupting. Also it was important to pay attention to how they answered the questions and with what emotion they told their stories in order to grasp the severity of the different areas that was touched upon.

A research interview will lose its credibility if it is defined by leading questions, this is one of the reasons why using a tape recorder throughout the interview can prove it self helpful. By going through the conversation for transcription, one can also do a judgment of oneself as an interviewer in terms of how the questions were presented and therein making it open for the respondent to talk freely about the subject in focus.

Kvale and Brinkmann (2009, p. 72) define several aspects of knowledge gathered and based purely on interviews and conversations. I used these a lot in advance to reflect on the subjects I wanted to go through as well as preparing to capture the information that could possibly prove relevant for further analysis.

- Knowledge is produced. The data gathered from the interviews are not necessarily already there, one cannot simply show up and collect the information. It is produced

through the interaction between the respondent and myself, which makes the results unique and it underlines the importance of transcribing it in a way that brings forth the correct knowledge to the recipient of the study.

- Knowledge is contextual. The situational factors that occurs and forms the interview has to be considered when the information is transferred to establish the same value throughout the whole process. This is also important in order to get a good evaluation/justified critique later on.
- Knowledge is based on dialogue. The relevance of dialogue as an empirical tool in order to access new knowledge is quite valuable. Even though the world has become more and more dependent on computers and constant development of new technology, it is dependent of having a dialogue between people. Only through the spoken word can personal experience be fully understood because of phrases used (and the pauses between words, sentences and digressions) as well as body language. This is basically the human reality one should not underestimate in the modern societies.
- Knowledge is linguistic. The spoken word is quite different from the written word when it comes from an open and relaxed interview to an academic text. It is essential to be able to use all the tools to properly draw knowledge from the respondent as well as presenting the same knowledge in the results.
- Knowledge is narrative. During the interview there is access to experiences and descriptions of situations told as subjective and personal stories, and these are reported narratively in order to gather and present their relevant details.
- Knowledge is pragmatic. The pragmatic question of whether the interview produce useful knowledge is often replacing the question of whether the knowledge is true. Pragmatism insists that thoughts and preferences are legit once they enables a person to grasp and master his or her life and world.

The pragmatic aspect of the interview goes hand in hand with values and the ethical aspects which will be discussed further in 3.4.2.

3.3.3 The ethical aspect of the interview

Amongst several ethical challenges that can emerge during a qualitative research, in which is already mentioned, challenges after the interview where transcription and analysis can be a critical situation for ethical judgment. There is a few aspects to this that is given more focus on than others because of the respect one should have for other individuals as well as parents as a unique group of people. Emotional trauma can be an individual side effect as the role of a parent to a chronically ill child can be challenging and exhausting, though this most likely occurs whether or not they participate in this study, and at this point there is no follow-up study where these respondents would need to be contacted again.

Consent and confidentiality was important to emphasize on beforehand out of respect for the participants and their children. All information and details emerging before, during and after the interviews are presented anonymously. The Norwegian Centre for Research Data (NSD) was applied in order to get approval for conducting these kinds of personal interviews as well as storing the information for a certain amount of time. This application was accepted (appendix 1).

3.3.4 The process

After having prepared a draft of the interview guide, this was sent to a mother of a diabetic child to get feedback on the subjects and relevance. There were some comments and together with the thesis supervisor, better and final guidelines were developed for the following interviews. A pilot interview was also conducted and accordingly some structure was adjusted. Using a mother as a preliminary resource person made the interviews better prepared as well as making the interviews feel comfortable for both parts from start.

Parents of children with diabetes type 1 was approached through closed forums after asking permission to join by stating the thesis intentions to the administrative people. By posting a general inquiry, a decent amount of interest was received from the members and this let me elaborate more on the project in private conversations and make the final recruitment after giving the potential participants time to digest and conclude whether they wanted to take part in this or not. In addition there came a lot of positive feedback from parents across the country, but due to the limitations of resources the inquiry had to be limited to recruit parents

in a acceptable travel distance, but still, the feedback was positive and parents acted grateful for learning that such a research was going to be conducted.

The aim was to find parents of up to 10 children who had been diagnosed with diabetes type 1 while in the relevant age interval. The cohort ended up consisting with 7 of these, including the pilot interview, and due to time limit and geographical challenges, it was decided in dialogue with the thesis supervisor that this was an acceptable size of the cohort. Intentionally there was no preference to whether it was going to interviews with only mothers, only fathers or both parents combined, but the outcome of the recruitment was only mothers and with such a small cohort this can be found acceptable. However, in the discussion later (5.2 Methodological reflections) it is argued for why it would also be beneficial to include fathers, in addition to elaborating on why mothers can be the primary study objects.

To make it easy for the respondents to find time to participate in my research they were offered house visits at their time of choosing, which they all agreed to except one case where it was beneficial to meet in the middle at a café with a relaxed atmosphere. This might have made opening up more comfortable as well. The interviews took between 90 and 150 minutes, which was longer than anticipated, but definitely necessary because the respondents had a lot to share, and cutting time would mean missing out on information.

Before the meeting with the respondents at our arranged time and place, they were sent the overhead document as mentioned earlier so they could prepare some for what was going to be discussed. Again, they were informed that the interviews would be tape-recorded and they had every right to withdraw either before or during the interviews. At the time of the meeting, they were once again asked if they were comfortable with the recording of the conversation in which they agreed. In addition, everyone signed the consent for use of their shared experiences for research purposes.

Each interview was transcribed immediately the following days before conducting the next. By doing this there could be evaluation of the flow of information and questions with the thesis supervisor and adjustments were made along the way to make sure the relevant details would emerge for each interview.

The analysis of the interviews were inspired by systemic text condensation (Malterud, 2012). This approach follows four steps: 1. Reading all of the data material to form an overall impression (i.e. identify preliminary themes); 2. identifying units of meaning in the material (i.e. coding); 3. condensing and summarizing the contents of the codes into categories; and 4. generalizing concepts related to the specific theme of the study. I transcribed the interviews alone, and this allowed me to get myself re-acquainted with the respondents stories which proved to be valuable and at the same time quite an emotional task. However, it helped me work with step 2 and identify the topics that most commonly affected the respondents and which topics each respondent held closest to their hearts. I used this to create categories and codes in compliance with step 3, initially by my own interpretation, then later in discussion with my supervisor, in order to structure the presentation of findings in a sensible and relevant form.

After having transcribed every interview, the recordings were deleted and the report was written consisting of results based on the systematization of the transcriptions. An additional resource person, also a mother of a diabetic child, was contacted and she had not been part of the interviews. Nor did she know anything about this thesis before she was approach which after having conducted and transcribed the other interviews. The intention was to find out whether she would recognize the initial results, and to explore alternative experiences and interpretations, and the result of this will be presented in the discussion rather than with the rest of the findings.

4. Findings

4.1 Presenting the results

The material extracted from the in-depth interviews can be described as life stories, because even though I went there as a researcher with prepared subjects and questions, it was the respondents who themselves choose which stories they wanted to include and what details they wanted to share. In this way, the interviews became biographical.

During the interviews we went back and forth in time, but I have chosen to present them according to a timeline (figure 9) beginning with the early stages of symptoms and discovery of the disease, then I will be going through relevant changes and development in handling the disease, conflicts and personal struggles. To end the presentation of the results with the respondents thoughts for the future and some additional takes on ongoing situations within the family and home are in focus.

This way of looking at the final material makes the interviews unique, in terms of both content and presentation, compared to listing statistics from quantitative research or only using numeric scales as a qualitative measurement.

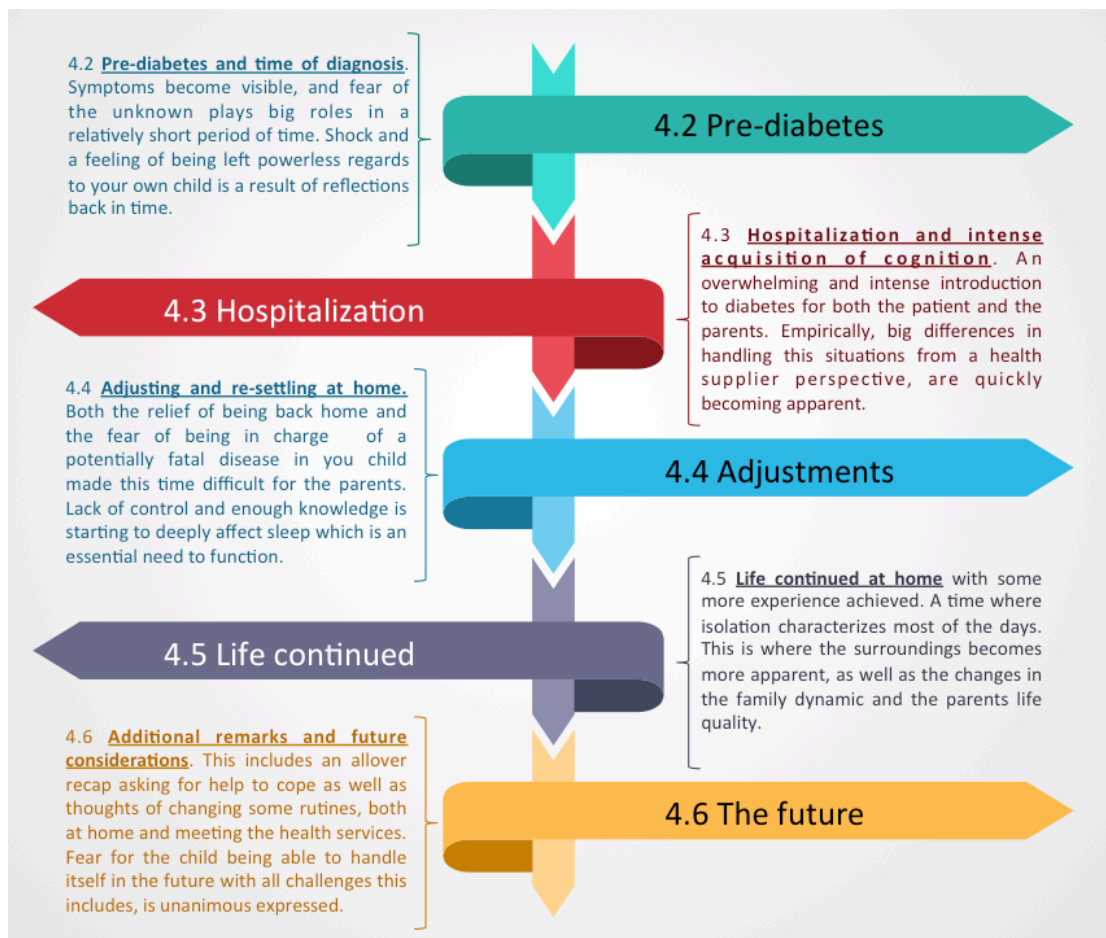


Figure 9. Timeline created by the author of the thesis, following the parents from shortly before the diagnosis, through the time of diagnosis and the following years.

As figure 9 shows, there are five superior time periods that will be present chronologically according with what was mentioned at the start of this section. Within each of these time periods I have also tried to divide them into two main categories in order to best follow the development of the parents, the disease and family dynamic over time. By going through the transcriptions thoroughly, I have gone with: *a) knowledge* and *b) life quality*. A short description of them is as follows: *a) knowledge* (and hereby also lack of it) will include both the competence offered by the health services and knowledge within the family, friends and society involved as well as the effect knowledge seem to have. Using *b) life quality* as a category is a result of touching upon so many terms like isolation, sleep deprivation, partner conflict and more. As one can see, both of these categories are quite broad and intertwining, but it was necessary to not make them to limited and specific because there were many aspects combined which will describe and lead to these two main categories. These categories will also play a significant role when discussing the results in chapter 5.

When presenting the material, I am including various quotes I saw best fit for describing the different situations within these categories. Some quotes, no matter how perfectly describing they were, have been excluded in order to avoid identification based on the unique situations that have occurred to some of these families which can be quite recognizable by characterization.

4.2 Pre-diabetes and time of diagnosis

I let the respondents reflect back in time and tell their stories on how they first noticed the (then unexplainable) symptoms. To most of them the classical symptoms of drinking gallons of water and then going from a potty-trained child to wetting the bed at night, were waved off at start as strange changes in their child. But as they continued, the parents remember being worried, but still completely unaware of the severity of this situation. Common for the children were also unexplainable weight loss and reduction in energy levels, which is known to spike some fear in every parent.

“She downed two bottles of water during the night and when we had to change both her night clothing’s and her bedding, we started being suspicious. In addition she seemed quite drained from energy”

Two of the respondents had somewhat knowledge themselves to what the symptoms meant, or had a close person who set the idea, but still there was denial and again the severity of the situation was not properly thought of.

”When she turned three, she started losing a lot of weight. We assumed it was only natural due to her baby fat at this point, but then she became worryingly skinny and had no energy. She was drinking heavily and wet herself a lot. And I remember saying: the way she is drinking, you would think she had diabetes. But in my head there was no way she could ACTUALLY have it. So I was naive maybe..”

”..and then out of nowhere my brother-in-law said: you sure she does not have diabetes , and I was like: where on earth did that come from. But we went away for a week and she kept on drinking and drinking, peeing and peeing..”

“..and that health secretary barely dipped the stick in the glass before the stick turned completely dark. And she looked at me like - get your kid. I’m barely a nurse, but this is diabetes -. And was thinking - no, no, no, that makes no sense -, but the lady insisted. I still didn’t understand anything because my girl was healthy. There was nothing wrong with her.”

Some of the respondents was confronted with diabetes at their general practitioner after several tests because they were told diabetes type 1 would be highly unlikely. The diagnosis resulted mostly in feelings of shock without a dramatic scene otherwise. At the time of event, they reported that they kept their cool, but in retrospect they describe themselves in a state of paralyzation. In addition, their own knowledge of diabetes type 1 was quite limited and as with the first symptoms, the severity and complexity of the disease had not sunk in.

For the ones who called or went to the emergency room, quite some frustration occurred throughout the process. Two of the respondents were turned down by the nurse on watch, either by perceived eye rolling and refusing to take tests, or told to come back when the blood sugar level was above 20. They were told anything below that level was not something to worry about, even if the parent in question emphasized on the pre-occurring situation leading to the call.

”..I let them use one of our sticks to check their two-year old, and there was no doubt. And then they call the emergency room and was told off with – no, just call your general practitioner on Monday..”

“They told me not to bother getting in touch again unless he is above 20, but I call back when he was at 18 and explain I am worried about him and his safety at this point. But I think I met the same person and got the same answer. She finally said she would have the doctor call me if she could find him available. HE was in no doubt - pack your bags and get here asap! -”

I asked the respondents how they felt about this reception of them and in retrospect towards the disease. They all made clear that even though they had limited or no knowledge of diabetes type 1 themselves at that point, they wished they had been met with more confident and respect from the health personnel at the primary service.

“I remember thinking it was a good thing we have been leading a pretty healthy life up until now, we probably have not made anything worse at least..but it would not have made any difference, I did not realize a carb is a carb no matter where it originates”

4.3 Hospitalization and intense acquisition of cognition

After receiving the initial notice of diagnosis the life of the families took a dramatic turn of events. And stayed that way. They are shipped off to the hospitals they belong to by county and with barely one of the parents given time to stop by their house for a bag with essentials, they are at the hospital for 10 to 14 days. The respondents describe the first few days, especially the first day, as an overwhelming and intense day in their life. They had no control of the situation, neither were they getting any acceptance towards the diagnosis. Two of the respondents remember being surprisingly calm and having a hands-on approach to the whole situation at first, but after the first night they started reading about the disease through various websites and studies online. One respondent, though they all looked for cures that are not there, went to desperate lengths as her first initiative.

“..googled everything about diabetes, not to mention switching organs.. That was me, thinking I could find one single hospital in the world that could switch my pancreas with hers, so she could have mine..and I could get hers and the disease. That was like..my first thought, that was my solution. This is something we have to fix. We just have to.”

This is where they wished they had been told *not* to read and google everything on their own at night, in a fragile state. They wish they had been met with some alone time with a competent doctor, without the child present where they could actually air and ask about all these frightening thoughts. They expect this would prevent some scares in the future as well. After a few days, the fear and the first grasping around the new reality started kicking in.

“Well, one thing was the fact that we had to stay at the hospital for a while, but the worst part was the fact that she was going to live with this for the rest of her life. It was not just two weeks at the hospital and then home and we are done. God, it was so awful, and it is still painful to think about it. It is horrible when your kid is chronically ill.”

They parents reported the same situation and frustration at the learning stage. They were getting quite a good introduction to the diabetes type 1 itself, though in a reportedly hasty manner, and the technicalities concerning the therapy at the choice of *the hospital*. The respondents tell of different levels of knowledge, but the subjects are the same and the manner in which they are taught. They felt safe in terms of being taught to treat the diabetes correctly. They are trained in reading and calculating carbohydrates, and most of them are told to live their lives exactly like before. This is another aspect to building confidence to their new life. None of the respondents felt any warning or preparation on handling the emotional aspect of living with diabetes type 1. Not for the child and not for them. I asked them straight out at this point if anyone at the hospital or elsewhere in the health service, had ever asked them - the parents - how they were doing. The unanimous answer was no.

The way they were overloaded with information was also too much at once. They had no chance to getting a good overview of it all. Especially being taught it all at the bedside in front of the kid and in a room almost suffocating them with “insulinart” as one mother said it with a brief gallows humor to lighten the subject. Another told me she felt both she and the staff were violating her child by conducting all the necessary controls of the blood sugar level. The idea of hurting the child with needles before overcoming the fear and the pain for them was difficult and devastating. Using force in the beginning made them question the development of the relationship between them, and it is a barrier hard to get by.

”There were a lot of controls and tests the first days of our hospital stay and she was scared. There were a lot of different doctors conducting them, but we HAD to go through each one no matter how much it sucked for both her and us..it was hard to pretend everything was ok in front of her”

”I remember thinking – what is this going to do with the trust – between him and myself..the fact that we have to use needles on him all the time from now on..”

”In the beginning it was...awful. Inserting needles into that little body, and even if it gets easier, there are times we hit a more sensitive place. And sometimes we had to hold her down, it was not ok for any of us..”

None of the respondents were particularly dissatisfied with the stay at the hospital, but when I asked what they missed it was a proper psychological team. A real need of someone who could help them to understand and prepare for the new life and help them to gather and vent their thoughts from the start.

”The thing we really missed at her debut was some alone time with the doctors. And I have said we, the parents, should have one, two, three hours at least with a psychiatric nurse who also know diabetes. So you can vent your thoughts and feelings. Because who else is can handle it? Your friends does not understand s*** about what you are talking about”

They were consistently told not to worry about the nights and they should continue sleeping like before. As it shows later, this was one of the worst advices they received. None of the respondents are sleeping through the night. The staff was controlling the child at all hours of the day, so telling the parents not to do so was quite confusing for most. In addition, the parents felt like failures in the beginning when they got up all night despite what the hospital said. After some time they did however come to terms with the advice being wrong.

”Well, you do not have to get up at night and measure if it seems stable before bedtime. But that fear..the fear of waking up in the morning and find your kid critically low”

”I heard all the other hospitals tell the parents not to get up at night, just sleep through. That is nonsense! At least at start! So why make the parents even more anxious?”

One respondent had the opposite experience, and she claimed the hospital they used ought to be a standard for the other hospitals to look to. Even though she told of some less good situations at this place as well, overall it was a decent experience compared to all the other respondents’ way of being introduced to the disease. She was also the only one who was prepared for the reality of the night watch.

”Everything was so thorough, so they did not have to be bothered more than necessary you know..by providing us with such a solid introduction and training. And I KNOW, as you might have heard from others, that NO OTHER hospital works like this.”

”And at my hospital they were neutral and said you will probably be up a lot at night..”

At one point, the perceived care for the families coming in at the time of diagnosis had been so worrying that it resulted in a filing a report to the county doctor. There was no case per se as there were no fatal consequences of the situation at this particular hospital, but the report resulted in a written recommendation in favor of the one who reported it. In this report, the county doctor advised the hospital to improve their routines and ask for aid. They were also advised to get in touch with the hospital mentioned earlier who has set quite a good standard. Allegedly this was not followed up.

”They have such a horrible system of training. They know how to inject the needles, calculate dosages and such, but that is it. They do not know the disease!”

4.4 Adjusting and re-settling down at home

I was interested in how they felt coming home after two weeks of life-changing experiences. They left the house one day to do a check at the doctor and when they returned their lives would never be the same. Suddenly the house felt both safe and unfamiliar.

”The day we were signed out was a great relief, it felt good returning back home. I cried a lot from relief, sorrow and a feeling of being completely different than before. It was still so much to learn, but it was nice to get started and taking charge at home. We thought that as soon as we got the routines in place it would be ok. But the routines were difficult to establish. Impossible really..”

”After being taught to inject insulin, calculate and count carbs and whatnot, we sat with the feeling: ok, we have the answer. And then we got home and reality punched us right in the face. The first week home we had three situations where he was as low as 1,5 and 1,8 and such. So we were quite cocky leaving the hospital thinking this is easy! But no...”

They told me the reality kicked in and the more they learned and read, the more fear they felt. And the complexity of diabetes became bigger and more obvious. Even if they knew it during the hospital stay, it was in these first weeks and months at home, where they began to realize and feel the pressure of having to deal with the unique type of disease diabetes is, and the fact that it is a job 24/7 for the rest of their lives.

“Nah..it was rough. We have always said - no matter what, at least our kids are healthy -, but we cannot use this anymore..”

All things considered, this period of time is remembered as mostly confusing and with a steep learning curve. The stories varied some depending on what kind of introduction they had at the hospital, and all but one are saying, when reflecting back, that they were not prepared for the challenges dealing with the diabetes alone. The respondents had no time to themselves, but did not think about it at the time, because it basically was no time to think. One described it as having a newborn, the firstborn, were you live in some kind of a bubble, and the others I mentioned this illustration to, could confirm that this was quite accurate. No sleep, no clue on what was going on and no way to predict what was going to happen next.

4.5 The continued life

“I felt trapped, and I still do.”

4.5.1 Acceptance

After some time at home, adjusting and getting better at managing the disease, the constant pain was let go to some extent and the fear and worry became a habit rather than a plague. The respondents told me they had somewhat come to terms with never being able to predict the outcome of a meal, an injection of insulin, a fever or activity. Realizing this made it easier for them to cope with their and their child's life with diabetes type 1.

”Fear and hurt are still the two things that hit me first every day. The grief has become part of me I think. I find myself in despair, getting mad and pissed off really at the fact that it has to be this way.”

However, the strain from being stressed and always on a high alert as well as continuously lacking sleep night after night for months and years was taking its toll on the family and on the parents. Even if they had adjusted somewhat to dealing with diabetes, a good sleeping pattern did not return to several of the respondents.

”I was terrified of the fact that she was going to die at night. And it took over a year after we returned home for me to enter her room without holding my breath because I was so scared I was going to find her dead. I felt that fear every day and every night...”

”And that self-allegation revisits when I sometimes is just too tired at night. I can see him being too high, but I just can not get myself out of bed. And then I fall asleep. And he wakes up higher than the roof.. Makes me feel like the worst mom.. And then if the HbA1c is high at the next control I get furious with myself. The guilt never leaves me.”

In the beginning they required leave of absence from work in order to stay at the hospital, adjust and train employees in the respective kindergartens. After this all but two of the respondents had sick leave over periods of time. Due to depression, difficulties coping, pure exhaustion amongst other triggers, they had not been able to function at home or at work. At this day they are not sure it has been the best way of dealing with the underlying problem, but it is the only solution they knew back then.

”The first time he had cramps because he was too low he was conscious, and he was so scared. Terrified..he was shaking so badly. At that point I managed to stay calm on the outside, but I was being torn apart on the inside and we were rushed off with an ambulance. In the following weeks I had severe cases of anxiety, I could be at work and have an attack and imagine him dyeing in the kindergarten.”

4.5.2 Being parents and partners

the respondents constantly live on the edge, and the energy level is like a roller coaster and it affects the ability to be nice to each other as partners. They admit they need talk to each other more, but they become sick of the whole subject sometimes as well. They emphasize that the energy and the time simply is not there anymore. Time to sit down and simply have a conversation about important subjects and sometimes conversations like they used to have were the talk just made itself and they did not focus on diabetes or the negative things in their lives. They say like before, and by that they are not quite sure themselves whether before is the time before children or the time before diagnosis of diabetes. But again, time flies and they sometimes avoid it because it is either hard to talk about or they know there will not be

any point to it. Here also, they admit that's a dangerous path, because they fear they create a wall towards each other which can be painful to break down the more thick it gets.

“So, I think there is a lot of unnecessary edges and stepping on each others toes, without anyone to blame really. Without the diabetes, being married to each other would be easier..”

Being sick and tired of having frustrating conversations over and over is mentioned by all the respondents. A few of them concludes while speaking on this subject that it might be better if it was not on a non-talking subject level, because they feel angry and frustrated but it is not because of the partner which they know they should say out loud. They also feel the need to air frustration. One respondent described herself and her husband as colleagues and logistic partners more than anything in the middle of difficult times.

“It is mostly taken out on us as partners. For a long time, we had a routine where we just fought as soon as the kids went to bed every time he was home from work”

“..I can not tell if it is the toddler years or the diabetes, but obviously..we barely sleep, we just walk around as zombies and annoyed. We have no time together, to just sit and relax as the couple we used to be..”

However, despite the struggles mentioned above that the parents go through as partners, they also experience unique aspects of life together. They describe each other as dependent of each other in the way that it is only them who can understand each other. They have gone through, and survived a trauma in their lives, and kept meeting this trauma together.

“In a way you can say it brings us closer and connects us, it is only him and me who knows this life.”

4.5.3 The family dynamic

After talking for a while about the relationship between the parents, we expanded to looking at how the family as a whole had changed. All the families had one or more children in addition to the child with diabetes, so it was natural to see how the disease affected the family dynamic and what kind of conflicts, if any, was suspected to be explained by the time

consuming disease. In the families where the siblings were younger or very close in age, the parents could not tell if the children were treated differently because of the diabetes or because they were just different children by personality. They said they obviously had to focus more on the child with diabetes, but was not sure if it was more to it, and the sibling was too small anyway to notice or express anything regarding this anyway.

The mothers who had older children were starting to realize that the extreme focus on the disease was becoming a loss for the siblings. And realizing this is described by them all as painful and it made them feel guilty, but without any solution on how to fix it. They explain they have not been doing a good enough job regarding conversing with them on how the diabetes has affected them. They have not been able to catch the siblings feelings, which in most of the cases turned out to be great amounts of fear more than anything. Two of the sibling from different families has had anxiety regards to fearing that too low blood sugar levels will kill their younger sister or brother.

“But one or two nights after the incident (severe ketoacidosis), my husband put her to bed and she says: Dad, I know there are tears in my eyes, but it just happens sometimes, right?, where my husband says its ok to be to be sad when your little brother is at the hospital and you might be fearing for him..and then the waterfall just opened up. She completely broke down. So we’ve been talking to the school nurse, to help us look after her.”

This is something they have been told by the nurse at school..and this again has made them realize that they perhaps has misjudged the siblings need for attention, because when one of the parents has been alone with the older sibling, their original thinking was that the sibling was going to have time off from dealing with the diabetes, but instead the respondents has started thinking this is wrong in some cases. Instead of not talking about it at all, they want to let the sibling communicate how they feel if needed, all though they describe doing that is also difficult. They do not want to force a conversation, and in addition the respondent themselves wants to focus on something completely different than the diabetes when they have the chance. These thoughts has made them feel guilty both in the moment and in retrospect.

“And it is so painful when the eldest says she wishes I did things with her as well, so we try to make it happen, but it’s never as often as we would want. And it will never compensate for

the fact that she still always have to wait. She probably feels unjust treated because her sibling HAS to get our attention no matter how tired we are. So she feels that we provide different attention on purpose, but we do not..how do I explain it to her who is a child herself..”

“And when the teacher said to me: oh, I can tell this one is used to waiting.. God, it was like a knife stabbing me in the heart.”

The respondents are quite clear when they say this is something that other people does not understand. Several times the sentence “she/he should be glad she does not have diabetes” has been heard, but the fact is that the siblings has in some cases expressed the opposite. That they wished they had diabetes, in order to receive the same attention and care.

4.5.4 Relatives and friends

These reflections made me ask them how they felt about their outer family and other people in their surroundings. How were they treating them and if there was any significant difference from before the child became a diabetes type 1 patient. First of all every single one of the respondents shook their head when we entered this subject. A few had one or two relatives who they could say definitely made an effort in involving themselves in the new diabetes life and helping the parents by unloading a few hours now and then or a night or two. Concerning the rest, the involvement was absent. One thing is the level of knowledge towards the disease, as one respondent described it: Diabetes is a disease everyone have heard of, but nobody knows of. But it is the lack of willingness to learn that bothers these respondents. It makes them feel disappointed, isolated, sad and angry. One explained it as a downwards going spiral as the longer it took for someone to “care”, the further she isolated herself, until the door was closed both ways.

They also feel there is little or no understanding to how complex the disease actually is or struggling with the daily life surrounding diabetes can be. They meet people who ask or comment on the disease with presumptions in the lines of “have you given your child too much sugar” or “oh, so they can never eat sugar again”.

They feel the society do not realize how much energy and focus it takes. To them the general impression seems to be “is diabetes not just - give some insulin and it is all good?”, and meeting these reactions from friends are described as quite hurtful. This also leads to them not being able to talk properly with their friends and other mothers with relatively healthy children, because they feel they are whining even though diabetes and all the fear and exhaustion in relation with this is something they really feel the need to vent. When people they used to consider as close friends suddenly are not there anymore, they feel it has created an additional strain to their life.

“People do not understand a thing! They think its just inserting a dosage and all is well, but on the other hand I didn’t know much more either at start, but at least I shut up about it. And they do not understand the difference between type 1 and 2, asking if she will outgrow it and such..”

The situation and relationship is described as similar concerning grandparents on both sides. As mentioned a few immediately came “to the rescue”, but for the rest they felt the grandparents, in other words their own parents, suddenly disappear. This hurt even more, some of the respondent say, because your own parents are someone who you had thought you could count on no matter what. In addition, some relatives and grandparents discriminate between siblings. In some families only the sibling without diabetes is invited for sleepovers and play dates without the parents.

“We are so incredible disappointed and hurt by how little support we have received from family and friends..”

“Often I feel like a failure, because we DO fail at times, and that feeling sucks so bad.. Nobody knows about this feeling, or are able to understand it..”

“Like yesterday, when they called me about her, I could hear a loud sigh from my co-worker around the corner.”

The children have had diabetes a few years already, so the fact that the situation with relatives and friends is unchanged from the time of diagnosis and up until the time of conducted interviews made the respondents realize this situation is not going to change,

unless they managed to change it themselves. But when confronted with these speculations they reacted with an exhausting expression. It is all too much sometimes and they do not know where to find the energy to cope, to be efficient and to make an effort on all levels.

4.5.5 Interaction with health personnel

We spoke briefly previously about depressions and sick leave, but I revisited the subject because I was interested in finding out if they could point out any specific reason to why it went as far as sick leave, some had it multiple times and some never went back to working full time. The respondents had difficulties answering this as they were not sure how it could have been prevented, apart from sending diabetes back to hell as one described it.

I was told quite a few stories where they had struggled over the years since the time of diagnosis, and after we spoke more about these and the respondents took breaks to reflect, it became clear that they were never looked after. They were always on their own and there was no follow-up from the hospital's staff on how the parents and the family were coping with the diabetes. The hospitals were relatively satisfying with regards to continuous treatment of the actual disease, but not at all involved in the psychic health of the family. Not the child's or the parents. Not a single one of the respondents, or their partners, had been asked once how they were doing. When we entered this matter, it was obvious that it was sore never to have been asked this and it became clear to me as an interviewer that being given the opportunity to open up was badly needed. The respondents had trembling voices at this point and to some a break was needed in order to dry up the tears, which made quite an impact. They themselves were never in focus, and it felt strange for both them and myself that during these interviews were the first time they were in this position.

“After this many years, the first time I am being asked it by a student.. I can see now how messed up that is.”

“The importance of having someone to talk to who actually understand is more relevant than I thought.”

“What we see with the health personnel we meet, is that they, probably not on purpose, make me feel more guilty than I already do if the HbA1c is not satisfying. And it is such a negative

experience, lots of finger pointing.. And we walk out of there thinking oh my god, we have to pay even more attention.”

The respondents have experienced no support from the health care system on this matter, no supply of a competent psychologist. Three of the respondents had contacted professionals by their own initiative, in order to improve their fragile life quality, but they have not felt properly met there either. They believe the reason for this is the fact that there is no available psychological team who also knows the life involving diabetes as a disease as only one of influential factor. No diabetes psychologist exist to their knowledge, as there are with diabetes nurses.

“I was feeling quite down last year, depressed..and well, they try I guess, but all they do is provide equipment that can make him more stabile.”

“..if I had been asked I would tell them I was bloody tired. I want to throw the s*** out from a mountain top.”

Also, one parent explained her perception of this situation with a theory which concluded with saying there probably is not a compliance between what they (the health personnel) and what we (parents) experience as dramatic, struggling and challenging. Both this respondent and others admit that it would be easier to be asked and followed up rather than starting to ask for this help themselves, because it takes both energy and pride. They wish not only to be asked once, because it can be at the wrong time. For example in the middle of a hectic situation and they might not have time to answer anything else but a quick “yes, it’s fine”. In addition, if they are asked, and they want to explain how difficult it actually is, they believe they want to be followed up on this. One respondent suggested, perhaps the health personnel they meet in reality is afraid to ask, or do not have the time.

“Because, I am like if I am in shock and someone ask, I just tell them fine, fine..and wave them off. And then I break down seconds after, but then nobody is there.”

“Just knowing it is someone out there with an understanding who I could call, might do so we do not need it as much. It is just..having a safety net, or someone to turn to for support if

there is an emergency or something. If we are exhausted by comforting and carrying the disease on behalf of our girl..”

The parents express exhaustion in terms of feeling that they always have to fight for attention, both for themselves and for their child. On several occasions, a respondent described the annual checkups and HbA1c-control at the hospital as nothing but frustrating. She brought notes and questions to these appointments, asking what is the proper way to handle the different situations that occur at home with regards to the diabetes. She felt she was waved off with a non-enthusiastic answer “well, just try what you feel like, I am sure you will manage”. They never got to speak to a doctor at these appointments, only once was one available, the other times it was only the nurse even though they asked for more. The respondent in this situation used this treatment as one of the several reasons for complaining about this institution to the county doctor. When I spoke to the other respondents about this, several confirmed they had had similar experiences at their hospitals.

“We have only been with the diabetes nurses, but we have noticed a diverse knowledge from them..”

When some has taken their child to the doctor for other reasons, such as a twisted arm or a virus infection and so on, they always mention that their child has diabetes type 1 in case it will affect anything. Most of these times they are only met with strange comments as they have called it such as “poor kid, you cannot eat ice cream” or “I see, is she very dependent on the insulin?”

“Even when I meet health personnel I have to say - yes, of course he gets insulin, he cannot survive without it.” They don’t seem to know his disease compared to type 2. They do not know the difference...so when you met a doctor or a nurse who do, you never let them go!”

Two of the respondents had their diabetic child at the hospital for two other independent, and in theory harmless, operations. Both of them experienced obstacles in convincing the staff with reference to the respective operations. First of all they had to work hard to convince them that using a Continuous Glucose Monitor (CGM) during the operation was essential for the child's health. Hours under anesthesia with no way to know how the situation was affecting the blood sugar level would make it impossible to give the right amount of insulin

and/or glucose. One of these children was out for more than 24 hours because of pain related to the operation, and was without insulin for all this time as well. The mother in this situation had only been familiar with the diabetes diagnoses for three weeks and was afraid to stand up to the health personnel. She says if this had happened now, a few years later, there is no way it would be in the same manner. She is quite worried the child had a ketoacidosis, and is worried about how this will affect the child later in life in terms of complications.

In addition these two mothers felt they were not met with respect, as if diabetes was not a disease worth making an effort towards. The problem here, they believe, is that it was health personnel from completely different departments who was dealing with their child at this point. And the competence in dealing with diabetes was absent. When thinking back, they can't understand why someone with knowledge was contacted or referred with before hand. If these situations was going to be recurring for their child and the parents wasn't going to be heard, the complications later in life due to bad insulin control would be critical.

“To this day I still believe, and I am being completely honest, it is pure luck they did not kill him. They really had no idea. They had put him in ICU, and he stayed there throughout the day and in the evening I had to fight for him to get pain medication despite the fact that he was newly operated, so I use a lot of energy on this fight. Here is my kid, he cannot move at all, eyes barely flickering, and all this because of his level of pain. He came to quite quickly when he got meds, so I am glad I stood up for him. And through all of this, he was without insulin, almost 48 hours, and all they said was they would get back to it. It was only three weeks after learning of the diabetes, so I trusted them, but we know now in retrospect, that this was a huge trigger for complications, and I worry about this today.”

“And it is terrifying that there are doctors and nurses around here who are supposed to take care of him if something happens, and then they do not really grasp what the disease implies!”

4.6 Additional remarks and the respondents future considerations

As mentioned, having diabetes type 1 and being the parent or caretaker of a diabetic child demands a focus 24/7, and some parents described themselves as being in a anxious mode and on the alert all the time. Several of them mentioned their cellphones about as much as

they mention sleepless nights. They keep having to check it, both consciously and unconsciously. They never relax without it and if they for some reason leave it, it is with a panicking feeling they find and check it after two hours. In other words, they describe a continuous state where they never relax. Even if they want to leave it, they cannot manage. One said she longed for long walks in the woods without being disturbed as an example, but she never dares to leave her phone and she is afraid to go far, in case she is needed immediately.

“I can never have a resting pulse, it is obviously exhausting and an extra strain on me”

During the interviews the respondents seemed to always know where their phones were, I observed them checking it quickly while talking. Even in the middle of one interview, there was a call from the kindergarten asking for guidance because they were having trouble correcting the child's high blood sugar level pre food-intake, and this respondent confirmed what the others said about never being able to “turn off”.

“I constantly look at my phone, checking the sound hundreds of times”

Before we finished the interviews, I let the respondents gather their thoughts to see if they had more they felt relevant to our conversation or if they simply had something they wanted to get off their chests. Most of them did have stories and feelings they wanted to air, which again confirmed the need for having someone to speak to about the ups and downs of their life surrounding a child with diabetes. Several also mentioned worries about the future, which lead to the additional and final aspect I wish to present as a result.

They started out fearing for their child, the fear grew stronger the more they learned and they find the thought of the children taking care of themselves without the parent being there, terrifying. They have been asking themselves, is it possible to just follow the child around forever? They wish to, but know they have to prepare for the day when the child needs to detach itself, and some of the respondents have already started to create a proper foundation in order to help the child provide itself with a good insulin and HbA1c-control and avoid complications at all costs.

“Some day he is supposed to take care of himself..and there are so many dangerous aspects to it all, what if he goes low in a situation he is unable to do something about it? I mean, we have all been young and naive once, but for him it can be life threatening.”

“If I see her start giving rats ass about herself, like other teenagers do, others with diabetes can do..and I am not allowed to help? It is going to be so hard..and I know parents experience this..that the kids do not give a s***.”

The ones with female children worry particularly about the weight loss effect of not taking insulin, and they fear even if they do everything in their power to prevent this, the pressure they read about in today's society will be bigger than their effort.

“We are trying to create a solid foundation now, explain why it is important to pay attention to this disease. And we pray she never learns, or she probably will though, about the most effective diet..to lose weight by avoiding the insulin.. I am completely terrified of that situation. Because I know how focused girls are at these things..”

5. Discussion

The aim of this master thesis' research was to explore the quality of life for parents of children with diabetes type 1.

My main findings after having conducted the interviews, followed up by e-mail for necessary additional requires and thoroughly going through the results are as follows:

1. Feelings of isolation, loneliness and domestic struggles are present and demanding for the mothers:

They eliminate themselves from the outside world when they first learn about the diagnosis. They let it demand all of their attention and focus which affects siblings as well as creating mutual frustration between the parents as partners. They continue to be isolated because of lack of support from both friends and families and are often left with no one to turn to when they feel weighed down by their worries.

2. Diverse knowledge and treatment in communication with the health service:

While all of the respondents had different stories, most of them had the same experiences. They felt ignored as for their individual psychological needs and request for additional knowledge on the disease. Often they were met with incompetence from staff they had interaction with at various stages of the development of the diagnosis and additional situations, where knowledge of diabetes treatment was essential, but absent.

The result and discussion is not to conclude on any reality, but an effort to communicate in the most accurate way how the respondents experiences surrounding the diagnosis and their own evaluation of their quality of life can be interpreted:

“There is no consistency to what others regard as “dramatic” in a diabetes related situation, and what we experience as dramatic”.

As with most of the topics I have touched upon during this thesis, the following discussion show that even if I have tried to group my findings separately, they will affect each other several times.

5.1 Theoretical reflections

The theoretical discussion is divided into three parts. The first addresses the undefined role of the health personnel at the first phase after the time of diagnosis. After going through the results from the interviews, it is presumed that this is the most critical phase with regards to being met with competence, understanding, health related support and safety. The second part discusses the following phase, when the family is back home and are trying to continue their life in adjustment with diabetes. In this phase it is suspected the social support plays the most important part, and reflections based on previous studies and theories with regards to this type of support will be presented. The third part is the outcome of the two previous parts, how is this all connected and what are the consequences in terms of the parents quality of life.

5.1.1 The role of health personnel - are they providing a service or is it just a job?

The following discussion regarding health personnel is based on a subject all the respondents had strong opinions about; the importance of creating a diabetes environment with knowledge beyond just the technical aspects.

Concerning what knowledge is demanded and what's expected from the health care system are two different sides to the situation. During the thesis, it is pointed out the fact that parents, in particular mothers, are left with the impression that they are not met with sustainable care. Care in this case goes beyond the technical follow-ups in relation to the disease, it is the psychological care as well as being met with respect and time when there are interactions with the health care system. Even though the health personnel have the necessary competences for treating diabetes, the pedagogic way of sharing it is quite diverse. Instead of learning from each other, the parents got the impression that the different hospitals had an attitude along the lines of “the child is doing well with regards to his or her HbA1c, so our work here is done”. This is quite an edgy statement, but it is included here to reflect the feelings of the respondents. There is a belief that the understanding on the subject is varies from hospital to hospital based on staff experience and resources mostly. This again makes the process of training and introducing to treating the diabetes is carried out differentiate, and this concerns what is emphasized on the various hospitals as well.

The reason for this might be the focus on diabetes type 2 in the national guidelines for diabetes, and only a small section devoted to diabetes type 1. The last hearing for the latest revised National Guidelines for Diabetes is clear on the need for universal competence. The general practitioners and other health personnel employed in the counties health and care services as well as decision makers both countywide and regional are the main object they are meant to reach. They have emphasized on creating coordination routines with the specialist health service in order to improve the general practitioners competence and confidence in dealing with an increasing number of patients with diabetes and other chronic diseases (Helsedirektoratet, 2016). These limitations indicate that the recommendations mainly apply to patients with diabetes type 2.

The focus on management and coping is a central and critical aspect regards to the parental wellness in association with the child's condition. Both the acute and the long-term complications are difficult and sensitive subjects, which should be brought up and properly informed with the affected parents or others. As a source of information the health personnel may be the most important, as well as support for the parents' management at the first phase in life after the time of diagnosis (Canam, 1993). Amongst other reasons, this is important because in the next move, if there is no support from the health personnel, or adequate information, the parents will outsource the search for information and turn to the internet. Here, they reportedly find a lot of studies and theories to why diabetes develops in some, and they are not equipped to read it critically in this phase. In addition, they read about stories, the worst-case scenarios and more, which makes them irrationally frightened. I suspect this can be avoided if there was devoted extra time to conversate with the parents, let them ask everything they wonder and provide reasonable and trustworthy answers. This is somewhat strengthened by Canam (1993) when he says that one of the most important needs is that the health personnel tries to understand their problems and provide support, both informal and emotional, in a respectful manner. Parents in a previous study on adolescents with diabetes type 1 have stated that even despite the quality of the service as long as time is provided by health personnel (Kristensen, 2004). In addition, these parents point out that this is an opportunity to meet other parents in the same situation if the service is provided as group sessions as well.

In the study by Seppänen et al. (1999) some of the results were similar in context where the parents reported that they needed more informational support to cope with the new situation

and their feelings and they stressed how valuable the conversations with the health personnel were. However, Seppänen et al. (1999) only interviewed two sets of parents and they only looked at the first 4 weeks after the time of diagnosis and they have not given any attention to the following time, nor do they mention how the situations can develop. I am not sure they can claim a solid result based on such a limited research in both time and cohort, but alas, their indications are consistent with mine in this phase.

5.1.1.1 Research to improve the relationship between parents and health personnel

All the everyday energy cost and effort to keep the child on a stable blood sugar level and the continuous fight when it is so often unstable and unpredictable. One could investigate if some of the situations that have been described are consequences of misunderstandings. Still, a researcher who can only watch diabetes from the outside will probably never know about these situations, but when working closely with someone who is living in the middle of it, research aimed to create an insight to these aspect could prove themselves valuable and beneficial for both the parents, the child and the health personnel whom only get even better at receiving new cases and introducing the next family to their new life.

For the struggling parents there might be several solutions such as cognitive therapy, but they have to be presented for them. A doctor will be able to explain that their child has an incredibly small chance of dying during the night and they could be reassured and calmed by this information, even if they have to hear it more than once. As my respondents said, they sometimes do not have the energy to pay attention one hundred percent on what they are being told, in addition, fear overcome their rational thought. In order to help them with their thoughts and feelings, the doctor needs to know about them. He or she will only know by asking, and the doctor ought to know that the question is worth devoting time, because the benefit will come to those who need it.

Perhaps it should be discussed for the next revision of the National Guidelines for Diabetes whether diabetes type 1 should be given a bigger part of the this strategic plan. If it then would lead to more research on more than the efficiency and technicalities of the disease, I predict it would be beneficial due to all the difficult thoughts and feelings that arises with the unpredictable task it is to live with diabetes or be the parent of a child with diabetes.

When listening to the respondents elaborating their experiences during the first period of time after the diagnosis, which was in great deals related to feelings of shock, I tried to catch whether these experiences were fading. Because if they were not fading, one could suggest that the shock lead to posttraumatic stress syndrome. A few of the respondents used these words themselves, and as with the theory on connecting parents posttraumatic stress syndrome to HbA1c-control, it could be an indication that there might be something to it. Looking at the Horsch and McManus (2014) study where they claim to have found a correlation between parents posttraumatic stress symptoms and the child's insulin treatment and HbA1c-control, my findings can be used to underline their statements and add to the importance of dealing with this matter. I emphasize on their description of the role of the parents:

“parents are expected to acquire a sophisticated understanding of the disease process in order to effectively respond to potentially life-threatening situations, such as hyperglycaemia or hypoglycemia and ketoacidosis”. (Horsch and McManus, 2014, p987)

With this quote at hand, I suggest what my respondents have felt and continue to feel concerning this situation, are quite common outside my cohort as well. There is a big responsibility they are expected to handle without any wrongdoings. This pressure seemed almost unbearable to some, which calls for assistance from others in relation to the family, whether it is friends, relatives or health personnel. The parents are always fearing for their children and these thoughts and worrying feelings leads them into situations such to getting up several times at night check, and perhaps not trusting others to take care of them during the day yet. This is too big a task to deal with and handle alone, and the need to air these emotions and worries are quite present. Some of the mothers who were interviewed, did not even realize how much they missed a resource person for their mental health until they were confronted with some of my topics and questions. In addition, feelings and certain thoughts are quite personal, and not necessarily something one would want to share with anyone.

If there were ongoing or future studies with a greater cohort over time, it would be interesting to see the consequences of this. Not only for the child's complications, but also for the economic status of the parents and the family, and whether an upgraded care provided from the health service can prevent such situations or intervene so it will not develop further. The

feeling of the lack of respect in most of the respondents cases is worrying, as it does not give the unexpected new life a good start. My respondents were receptive to the idea of having a devoted resource person within the healthcare system who they could turn to, such as a psychologist who had experience, or specialization, in both the emotions and the practical situations concerning living and caring for a child with diabetes type 1.

5.1.2 Social support

When bringing a newly diagnosed child home from the initial hospital stay, a parent's stress level is rapidly increasing (Gallo, 1991). In the study by White et al. (1992) parents reported issues similar to the experiences of the parents in my own study. In addition it is the fear of doing something wrong due to the lack of the needed skill and knowledge when managing the diabetes without the supervision of health personnel, which is elaborated in 5.1.1. Studies like these show that in order to cope the parents need their own everyday life routines to be in balance in order to care sufficiently for their child. The effect of social support in this matter is assumed to be significant (White et al., 1992; Thompson et al., 1992), and therefore one can draw the assumption that the effect in lack of social support is the opposite. My findings indicate this when the respondents report feelings of isolation and difficulties coping partly because they have no one to turn to for help or support. Their social life has decreased noticeably since the disease and they are left with a feeling of being avoided and hurt. It is important to mention the limitation to this situation as all of the respondents have two children or more, and being parents to small children often compromise the social life in any case.

I can only speculate to why this is the situation, because in this thesis only one side of the story is researched and presented. Fear of the unknown can affect the people around them and lead to avoidance, in addition not all of the respondents asked for help either, so it is uncertain what outcome it would give. However, being constantly exhausted drained energy from the parents, and the experienced lack of energy to approach and ask for help, they expressed a longing for someone to approach them. Seppänen et al. (1999) found that parents experienced social support as meaningful to able to cope and that they frequently sought emotional support from their relatives and friends and were able to discuss the child's diabetes type 1 with them. They have described the situation my respondents' aims to be in, which is why I believe it is a decent theory presented. Yet as mentioned in 5.1.1, their study involves only two sets of parents and only the first four weeks after the time of diagnosis,

hence I am not taking their results for granted. In addition though, as I have discussed above, the parent's ability to cope as partners is challenging with their child's diagnosis. Ultimately it is the parents who have the responsibility for the child, this means they are not given the chance to take a break from caring for their child because they take turns giving each other “time off” and sharing the responsibility. Furthermore this means they do not have the opportunity to take this said time together without their children, which could provide room for maintain their relationship as well as discussing their feelings towards the situation they both live in and support each other emotionally while not being in the middle of managing the day-to-day life.

Sullivan et al. (2003) looked at similar aspects as I did, and was left with the same impression on how little is known about the experiences of the parents, and in particular the mothers, raising children with diabetes type 1. Their study was mainly about describing the everyday life, but they do mention social support as a next step in research and implicate nursing practices introduced where it could be beneficial. My findings confirm their findings when the results from interviewing mothers are presented on how complex the role of the parents are in the day-to-day life (figure 10). These findings indicate there should be more research identifying the trigger factors throughout the timeline presented in 4. Method.

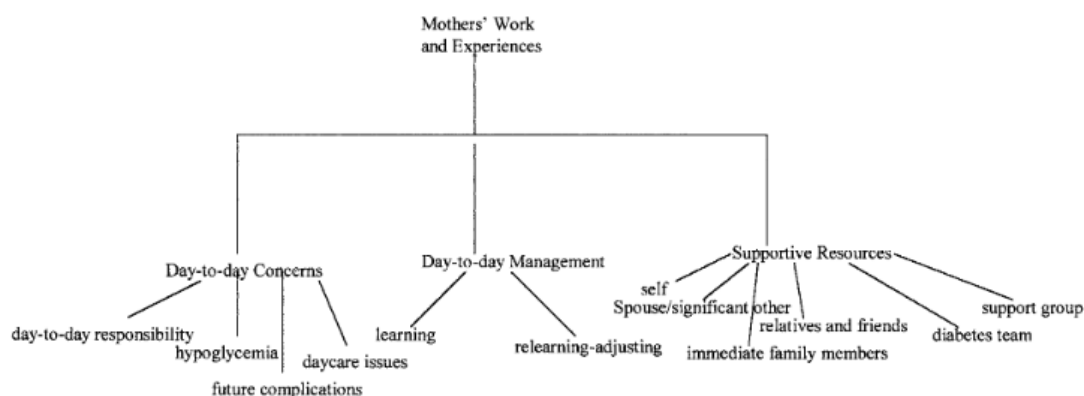


Figure 10. The overall connections of experiences for a mother of a child with diabetes type 1 (Sullivan et al., 2003, p. 24)

Gibson (1995) found that mothers of chronically ill children benefited in great deal from social support in order to cope and feel empowerment when dealing with their child's illness and adjusting towards the day-today life. The support came from friends, relatives and partners which substantiates the findings in my research where these types of support came into the conversations I had with the respondents. But on the contrary, Gibson (1995) only found that they *did* receive this support, hence the study did not take into consideration the consequences of *not* receiving such support. Yet, I interpret the studies findings in relation to my own in the most logic and correlating way by turning the theory the other way around. When the parents, in this case the mother's, lack any sort of social support, they experience a loss and additional obstacles in order to manage the life with a chronically ill child. I believe all the aspects needs to be fulfilled, in order to properly feel somewhat at ease with their life. This belief is based on the respondents experiences with only one or two types of support, and in some cases none, but they still felt isolated because they had the impression that people, whether it was friends or relatives, in their surroundings were not there for them.

However, what I did not investigate further was whether the support actually existed, but the respondents were not capable of receiving it. By this I suspect some mothers can isolate themselves in order to maintain full control and are unable to let the diabetes go and be open to support. This is consistent with Canam's (1993) theory where it is suggested that for parents who cares for a child with a chronic diagnosis, there are difficulties reaching out to others in the community or utilize any alternatives that might already be present. This due to the demanding domestic tasks where the parents time and energy are practically fully used. This coupled with negative attitude from the society, as my respondents have felt upon in terms of lack of understanding and knowledge, leads to said isolation and the barrier to break this pattern is perceived impossible at times (Canam 1993). If the parents are not able to establish a network despite such conditions themselves, I suggest their respective municipalities could benefit from conducting research on this matter and provide a decent communication platform for families similar to these.

5.1.3 Life quality

As mentioned in the result section, I found that Mugno et al. (2007) did a study to evaluate the Quality of Life (QoL) in parents with challenged children and emphasizes beforehand that assessment of QoL is especially relevant to conditions that are chronic and impairing. The

interesting design of this study is their method using control groups of parents. It gives them the ability to compare and one can assume if such a study was done with parents of children with diabetes, similar results could occur. They concluded that parents of these children showed impairment of QoL compared to other groups, and the transferability is present as I hypothesize children with diabetes demands additional energy and focus from their parents based on the information my respondents provided.

In section 2 of the thesis, categories for assessing an individual's life quality was presented. Shortly they can be summarized as follows: *not feeling tired, relationships with mutual respects, security and satisfaction with own decisions, not being closed off to society and absence of agony and pain* (Næss, Siri, 1994; Felce, David & Perry, Jonathan, 1995). This goes hand in hand with the general definition made by WHO (1948) where health is “ a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”.

Going through this literature, it is more clear how essential the situations the respondents have described contains critical aspects. Based on all the information I was given during the interviews and the presentation of some of the most relevant findings, these definitions became quite important. The experiences and stories of my respondents all involve one or more aspects of these categories, but in the opposite side. They *do* feel tired, they *miss or have lost* social relationships with mutual respect, they feel *insecure and are dissatisfied* with results based on their decisions, they feel *isolated and closed off* and there is clearly a presence of *both agony and pain*. All of these combined certainly affect their health and therefore their quality of life. Again, this would be more appropriately mapped with a bigger cohort and with control groups. One can insist it is needed to do so, in order to identify specifically what reduces each of these categories and provide the already mentioned improvement of help and care.

My findings in terms of quality of life are established in earlier studies as well if the transferability is taken into consideration. Parents of children with a chronic illness experience more stress than parents of typically healthy children (Rodrigue et al. 1990; Allik et al., 2005). As Schwarzer et al. (2003) found in their study, traumatic events in life can be seen as triggers that lead to negative outcomes such as stress related syndromes or

depression. This is in accordance with the perceived quality of life for the parents of this study, and how they have coped with life after the time of diagnosis. The importance of choosing the right action is stressed by Kendler et al. (1999) where they found a link, in which a certain course of action would lead to a decrease in the quality of life of an individual and eventually trigger a casual relationship with depression. The responsibility of taking care of themselves in addition to their child is now illustrated throughout the thesis to be overwhelming and a unbearable task for an individual, which calls for support, preferable preventive to avoid the negative outcome all together.

5.2 Methodological reflections

5.2.1 Validity and reflexivity

I chose to do a qualitative study using semi-structured interviews for investigating my research question and gathering data for my thesis. It was preferred compared to focus groups or quantitative research, because of the advantages these types of interviews can give. Numbers alone would not be able to say anything about the individual's preferences, reflections or experiences, and a qualitative in-depth interview makes it more comfortable for the respondent to reflect at his or her own pace and I had the opportunity to observe body language during the conversation. Having it semi-structured with prepared guidelines for the questions, strengthens the ability to keep track of the relevant subjects, but it gives space and welcomes spontaneity from the respondents to share more than expected. A weakness I spent time considering and made an effort to avoid, was the fact that I could unknowingly or unwillingly affect or lead the respondent in directions he or she would not think of if my presence was not there, which could question the validity of the results.

To test and potentially strengthen the results, I gave as I mentioned at the end of 3. Methods, the final draft of 4: Findings, to an independent respondent. She acknowledged the reflections of the others and my understanding of their experiences to quite a great extent. Situations such as the constant fear of failure, fear of death at night, loneliness and frustration, the struggle of maintaining a good partnership, difficulties dividing attention between the siblings were recognizable for her, in addition to the matter of *never* have been asked how *she* was doing. This made me confident in my choice of focus at the result section as well as how I conducted the research in order to extract exactly these situations and feelings.

As for the matter of reflexivity, I can first of all say I did feel welcome when I met with my respondents and got the impression that they felt safe and together we friendly conversation rather than an interview. Even though I sometimes steered the conversations in a certain direction in order to get information of the respondents experience or thoughts on the subject, I believe the respondent chose when and what to share. As they opened up, a lot of emotion emerged. It might be because I came there first of all as a student who already had a basic understanding of diabetes care. It made them relax in terms of not having to explain everything they spoke of, because as it turned out, this was one of the things they were quite tired of: the lack of knowledge on diabetes type 1 and the ability to differentiate between type 1 and 2. In addition I went there as a mother of two young children and could easily relate to the fuller picture of upbringing and the challenges it involves without adding diabetes management into the mix. The same concerns the guilt when dividing attention between siblings, as well as having to make an effort to take care of oneself. I believe it lightened the mood when we were able to share stories and laugh at heavy obstacles together with a type of humor only mothers can if I dare say it.

This thesis has included a more extensive focus on findings than the typical thesis, however not all of the mentioned findings re-occur in the discussion. This can be argued with the fact that in order to give a broader picture of the parents situation, one needs to be aware of how many existing factors there are which influences their quality of life. In addition, based on the interviews done for this thesis, one can insist on expand the findings to contain even more than was presented here.

5.2.2 Limitations and suggestions for future research

While I successfully interviewed mothers of diabetic children, I did not add aspects from the fathers point of view. The fathers play a unique role in the family and for the development even if the mothers seems to be the overseer of the insulin control and diabetic follow-ups (Holmbeck et al., 2002; Seiffge-Krenke, 2002), so even if I have used the word “parents” several times during the thesis, the results are purely based on the mother's. Fathers tend to have a more academic approach and put the “child first, diabetes second” (Sullivan et al., 2007) which makes for different experiences and reflections from the same situation. Yet one can argue that the results are strong as they are presented because the burden of responsibility for the care of chronically ill children fall particularly on mothers (Gibson 1995) and these

mothers tend to have a lower self-evaluated QoL compared to fathers (Mugno et al., 2007). In a bigger study, it would definitely be of value to have both parents involved. Also all of the cohort was made up of Norwegian, married women of families with a steady income. Without doubt this limits the ability to say anything about universal results as families of ethnic minority or single parents. It would be beneficial to have these taken into consideration as well in order to get a broader picture.

An important reason for limiting my cohort to the specific age group, is because one can suspect that as the age increases and children start school/become adolescents their needs change, their experience and awareness of the disease and its (side) effects are more obvious and pose a different intruder to their everyday life, both social and physical. This assumption confirmed by the respondents when they spoke about the future and the worrying when the children were going to take care of themselves. The parents of children at the adolescent ages will probably have new experiences, and perhaps different kinds of struggles. Especially in puberty the treatment meets more unique challenges than in any other stage of life, where they are in a process of becoming independent human beings, where involvement from parents mostly is an unwelcome factor in their life (Silverstein et al., 2005). As the responsibility increases and the child/adolescent are left alone with controlling and maintaining a decent stability for the disease, the challenges are increasing as well. The hormones run wild through the years of puberty and this results in a growing demand from the patient's body and a bigger need for insulin in order to function as it should. This is quite a dangerous combination with a low insulin intake because of reduced compliance (Boland et al., 1999). This is illustrated with data from NCDR which shows an increase of HbA1c level connected with the increased age (see figure 7).

For girls at this age body complexes also plays a part as low or no dosage of insulin reduces weight. The research project Co-morbid Diabetes and Eating Disorders was recently conducted by the University Hospital of Oslo shows a large percentage of children and adolescents with diabetes type 1 has difficulties dealing with eating and discontinued use of insulin (Jones et al., 2000). Living in this situation for years or even just a short period of time increases the chances of blindness heavily as well as speeding up the process of reaching other complications described earlier in the thesis. This is a period of time which is extremely challenging for the both the patient and his or her family, as well as for the health personnel whom may be forced to play a bigger patriarchal part in order to inform and give treatment.

Many of the complications are permanent and at some points deadly. In line with Kristensen (2004) I would find more studies following parents of adolescents with diabetes type 1, looking into these challenges to be interesting and it could show other aspects of the mothers' struggles.

5.3 Conclusion

Mothers of children with diabetes type 1 seems to experience several challenges related to their own life quality and coping with their children's diabetes. It seems that loneliness in terms of not being understood, supported or heard is an important aspect of these experiences. Within this thesis cohort, several described high levels of stress which can be interpreted as post stress syndromes as they have been through a life turning and traumatic event in their life. This thesis' findings should be further investigated to identify and map the critical factors and situations in order to draw more attention to them. This will in turn provide health personnel more information to act and provide more specific support. More focus will be beneficial to aim at the parent's needs. Perhaps first of all the mothers, but secondly the fathers who is just as important, but it is likely they demand different attention.

This study suggests a worrying pattern in how little help is provided and sometimes how little knowledge is present in some cases. Supplying good management conditions is critical in order for both parents, the diabetic child and the family as a whole to function well.

References

Allik, H., Larsson, J-O, and Smedje, H., (2006): "*Health-related quality of life in parents of school-age children with Asperger syndrome or high-functioning autism.*" Health and quality of life outcomes 4.1

Boland, E. A., et al. (1999): "*Continuous subcutaneous insulin infusion. A new way to lower risk of severe hypoglycemia, improve metabolic control, and enhance coping in adolescents with type 1 diabetes.*" Diabetes care 22.11: 1779-1784.

Buyken, A. E., et al. (2001): "*Glycemic index in the diet of European outpatients with type 1 diabetes: relations to glycosylated hemoglobin and serum lipids.*" The American journal of clinical nutrition 73.3: 574-581.

Canam, C., (1993) "*Common adaptive tasks facing parents of children with chronic conditions.*" Journal of Advanced Nursing 18.1: 46-53.

Chase, H. P., Kim, L. M., Owen, S. L., MacKenzie, T. A., Klingensmith, G. J., Murtfeldt, R., & Garg, S. K. (2001). "*Continuous subcutaneous glucose monitoring in children with type 1 diabetes.*" Pediatrics, 107(2), 222-226.

Creswell, J. W. (2013). "*Research design: Qualitative, quantitative, and mixed methods approaches.*" Sage publications.

Cobb, S., (1976): "*Social support as a moderator of life stress.*" Psychosomatic medicine 38.5: 300-314.

Cryer, P. E., Davis, S. N. and Shamoon, H., (2003): "*Hypoglycemia in diabetes.*" Diabetes care 26.6: 1902-1912.

Dahlquist, G. and Källén, B. (2005). "*Mortality in Childhood-Onset Type 1 Diabetes A population-based study.*" Diabetes care 28.10: 2384-2387.

Denzin, N. K. And Lincoln, Y. S. (2009). *The SAGE Handbook of Qualitative Research*. London: Sage Publications

Diabetesforbundet (2016). About diabetes. <http://diabetes.no/om-diabetes/diabetes-type-1/> [accessed 28.11.2015]

Felce, D. and Perry, J., (1995): "*Quality of life: Its definition and measurement.*" Research in developmental disabilities 16.1: 51-74.

Hapnes R, Bergrem H. (1996): "*Diabetic eye complications in a medium sized municipality in southwest Norway*". Acta Ophthalmol; 74: 497-500.

Helsedirektoratet (2016). *Nasjonal faglig retningslinje for diabetes (report)*. <https://helsedirektoratet.no/Documents/H%C3%B8ringer/Diabetes-nfr-h%C3%B8ringsversjon-laget-260516.pdf> [accessed 20.04.2016]

Gallo, A. M. (1991): "*Family adaptation in childhood chronic illness: A case report.*" Journal of Pediatric Health Care 5.2: 78-85.

Gibson, C. H. (1995): "*The process of empowerment in mothers of chronically ill children.*" Journal of advanced nursing 21.6: 1201-1210.

Grossi, S. G., and Genco, R. (1998): "*Periodontal Disease and Diabetes Mellitus: A Two-Way Relationship**." Annuals of periodontology 3.1:51-61.

Jones, J. M., et al. (2000): "*Eating disorders in adolescent females with and without type 1 diabetes: cross sectional study.*" Bmj 320.7249: 1563-1566.

Kapelrud, H. (2006): "*Lower-limb amputations and diabetes.*" Tidsskrift for den Norske laegeforening: tidsskrift for praktisk medicin, ny raekke 126.17: 2261-2263.

Kendler, K. S., Karkowski, L. M., and Prescott, C. A., (1999): "*Causal relationship between stressful life events and the onset of major depression.*" American Journal of Psychiatry.

Kendler, K. S., Kessler, R. C., Walters, E. E., MacLean, C., Neale, M. C., Heath, A. C., & Eaves, L. J. (2010). Stressful life events, genetic liability, and onset of an episode of major depression in women. *Focus*.

Kristensen, F. (2004): *Mellom tiltro og frihet - bekymring og kontroll*. Sykepleievitenskap, 24: 31-35.

Kvale, S. And Brinkmann, S. (2009). *InterViews: Learning the Craft of Qualitative Interviewing*. London: Sage Publications

Lenhard, M. J., & Reeves, G. D. (2001): *Continuous subcutaneous insulin infusion: a comprehensive review of insulin pump therapy*. Archives of Internal Medicine, 161(19), 2293-2300.

Lydick, E., and Epstein, R. S. (1993): "*Interpretation of quality of life changes*." Quality of life Research 2.3: 221-226.

Malterud, K. (2001): "*Qualitative research: standards, challenges, and guidelines*." The lancet 358.9280: 483-488.

Malterud, K. (2012): *Systematic text condensation: a strategy for qualitative analysis*, Scandinavian Journal of Public Health, 40(8), 795-805.

Medtronic (2016). *About MiniMed*. <https://www.medtronic-diabetes.se/minimed-systemet/minimed-640g-systemet> [accessed 10.12.2015]

Morris, A. D., et al. (1997): "*Adherence to insulin treatment, glycaemic control, and ketoacidosis in insulin-dependent diabetes mellitus*." The Lancet 350.9090: 1505-1510.

Mugno, D, et al. (2007): "*Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder*." Health and quality of life outcomes 5.1

Næss, S (1987). *Quality of life research. Concepts, methods and applications(report)*. Oslo: Institute of Applied Social Research

Næss S. (1994) *Yrkeskvinne – husmor, kvinners livskvalitet*. Oslo: Institutt for anvendt sosialvitenskapelig forskning

Peveler, R. C., et al.(2005): "*The relationship of disordered eating habits and attitudes to clinical outcomes in young adult females with type 1 diabetes.*" *Diabetes Care* 28.1: 84-88.

Polonsky, W. H., et al. (1995): "*Assessment of diabetes-related distress.*" *Diabetes care* 18.6: 754-760.

Rodrigue, R. Morgan, S. B., Geffken G.R. (1990): "*Families of autistic children: psychological functioning of mothers*". *Child Psychology*, 19:371-379

Schwarzer, R. and Schulz, U. (2003). *Handbook of psychology*. Published online: Wiley Online Library

Silverstein, J, et al. (2005): "*Care of children and adolescents with type 1 diabetes a statement of the American Diabetes Association.*" *Diabetes care* 28.1: 186-212.

Sullivan-Bolyai, S., et al.(2003): "*Constant vigilance: mothers' work parenting young children with type 1 diabetes.*" *Journal of pediatric nursing* 18.1: 21-29.

Sullivan-Bolyai S (2006): "*Fathers' reflections on parenting young children with type 1 diabetes*", *American Journal of Maternal Child Nursing*, vol 31, 24-31

The Norwegian Childhood Diabetes Registry (2014). *Annual report 2014*. Oslo University Hospital

Thompson, R. J., et al. (1992) "*Stress, coping, and family functioning in the psychological adjustment of mothers of children and adolescents with cystic fibrosis.*" *Journal of Pediatric Psychology* 17.5: 573-585.

Uchino, B. N., Cacioppo, J. T., and Kiecolt-Glaser, J. K. (1996): "*The relationship between social support and physiological processes: a review with emphasis on underlying mechanisms and implications for health.*" *Psychological bulletin* 119.3: 488.

Weissberg-Benchell, J., Antisdel-Lomaglio, J., and Seshadri, R. (2003): "*Insulin pump therapy a meta-analysis.*" *Diabetes care* 26.4: 1079-1087.

White, N. E., Richter, J. M, and Fry, C. (1992): "*Coping, social support, and adaptation to chronic illness.*" *Western Journal of Nursing Research*

Wood, J. R., et al. (2006): "*Durability of insulin pump use in pediatric patients with type 1 diabetes.*" *Diabetes Care* 29.11: 2355-2360.

World Health Organization. (2005): *Mental health atlas 2005: report of a WHO consultation.* World Health Organization.

World Health Organization. (2006): *Definition and diagnosis of diabetes mellitus and intermediate hyperglycemia: report of a WHO/IDF consultation.* Geneva:, International Diabetes Federation

Ypsomed (2014). *About Ominpod.* <http://www.mylife-diabetescare.no/mylife-omnipod-pod-en.html> [accessed. 10.12.2015]

Appendicies

1. Approval from NSD
2. Request to participate/ Information letter (translated to English)
3. Questionnaire guidelines (in Norwegian)



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Vår dato: 30.03.2016

Vår ref: 47510 / 3 / STM

Deres dato:

Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 19.02.2016. Meldingen gjelder prosjektet:

47510	<i>Foreldres håndtering av barnehagebarn med diabetes type 1</i>
<i>Behandlingsansvarlig</i>	<i>Universitetet i Oslo, ved institusjonens øverste leder</i>
<i>Daglig ansvarlig</i>	<i>Ivan Spehar</i>
<i>Student</i>	<i>Eleni Xiros</i>

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/meldeplikt/skjema.html>. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://pvo.nsd.no/prosjekt>.

Personvernombudet vil ved prosjektets avslutning, 22.12.2016, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Vigdis Namtvedt Kvalheim

Siri Tenden Myklebust

Kontaktperson: Siri Tenden Myklebust tlf: 55 58 22 68

Vedlegg: Prosjektvurdering

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Avdelingskontorer / District Offices:

0220 NSD, Helsevitenskapelig fakultet, 4055 Rosendalsgt. 1, 0316 OSLO, TEL: 4755 58 21, FAX: 4755 58 96

Information letter to parents of children with type 1 diabetes

Life quality of children

Request to your participation in a questionnaire/interview in connection with a master thesis at the University of Oslo

Background and intentions

I'm a master student of the program Health policy, economics and management at the Faculty of Medicine at UiO. I intent to contribute to a better understanding of the life quality of children living with diabetes type 1 in connection with insulin pump therapy. I intend to do this by focusing on the child's and its parents experience with Omnipod and MiniMed.

What this study asks of your involvement

It's voluntary to participate and you can withdraw from the interview at any time. In order to get information on your child's everyday life, I invite you to an interview/informal conversation with me where I'll ask open ended questions. Proposed subjects will be sent by email before the meeting. The meeting will be arranged on your conditions, but it's necessary to do it in person.

What happens to the information

The conversation will be recorded for transcription, then later deleted. All the information provided from you can only be used as described in the background and intention section above. It will be handled as anonymous answers, but it's necessary to sign a consent form which gives me permission to use the answers for research.

If there is any questions to the study, feel free to contact me at any time by phone: 95 87 50 52, or by email: e.s.xiros@studmed.uio.no

The study is approved by the **Norwegian Social Science Data Services**.

Best regards,
Eleni Xiros
master student

Spørsmålsguide for samtale med foreldre

1. Introduksjon:

- Referere til informasjonsskjema – si litt om hva studien går ut på, hva målet er og hvorfor den gjennomføres
- Demografi; kjønn, alder, status, antall barn, utdanning, inntektsintervall. Dette kun for statistisk opplysning dersom det kan ha noe påvirkning ift forskjell på svar fra respondenter

2. Barnet:

- Hvordan vil du beskrive barnets (ved navn) allmenne helse?
- Merker du noen forskjell i sosiale sammenhenger eller aktivitetsdeltagelse for ditt barn kontra andre barn? (evt eksempler på merkbare hindringer/begrensninger)
- Opplevs barnets humør som “normalt” eller en side av diagnosen ved blodsukkerendringer?
- Hvis flere barn: noe forskjell i aktivitetsnivå, matinntak, søvnmønster o.l.?

3. Forelder: (eksempler der det passer)

- Hvordan opplevde du tiden rundt oppdagelsen av diabetes? Husker du noen spesifikke tanker eller følelser? (på godt og vondt)
- Har du noe inntrykk av hvordan samfunnet eller andre mennesker ser på diabetes eller hva de generelt kan om sykdommen?
- Har dere endret hva slags aktiviteter/ferier/utflukter dere begir dere ut på siden diagnosen? Planleggingsfasen? Må det justeringer til underveis? (ikke insulindosejusteringer)
- Merker du om det går mer tid til barnet nå enn om det ikke hadde diabetes? Er det evt noe forskjell i tidsbruk ovenfor søsken? Kan du evt si noe om hva du velger å prioritere bort av din egen tid? (trening, betalt arbeid, sosialisering o.l.)
- Har dynamikken innad i familien gått gjennom noen endring? Forholdet de voksne imellom?

- Føler du at du får den hjelpen og/eller avlastningen du har behov for? (fra helsepersonell, familie, andre i omgivelsene) Hva ønsker du deg eventuelt mer av eller noe annerledes?

4. Annet:

- Er det noe du vil tilføye? Noe du føler preger/påvirker deg og dere?
- *Bekreft/avkreft tolkninger, godkjenning av eventuell oppfølging per mail/telefon.
Forsikre om fortrolighet.*