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## Children with Type 1 diabetes The initial education process and the impact on children and their parents over the first two years

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# Children with Type 1 diabetes

The initial education process and the impact on children and  
their parents over the first two years

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När man haft bråttom länge måste man stanna upp  
och vänta in sin själ.

Gammalt kinesiskt ordspråk



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# Abstract

The overall aim of this thesis was to investigate the initial diabetes education process, the impact on children and their parents and parental satisfaction with the care received one and two years subsequent to the child's diagnosis. In order to seek a deeper understanding for how the diabetes team's initial education process works from admission to discharge among families with a child newly diagnosed with type 1 diabetes, three diabetes teams from three different paediatric hospitals, two county hospitals and one university hospital were interviewed through focus groups interviews (Paper I). In Paper II, 10 mothers and 8 fathers were individually interviewed to describe their perceptions of the initial diabetes educational process when their child was diagnosed with type 1 diabetes. A qualitative method was used and the interviews were analysed with two different types of content analysis, inductive and deductive. In order to describe and compare the disease impact on parents and children respectively, data were collected focusing parents' HRQOL one and two years subsequent to the child's diagnosis (Paper III and IV) and children's experiences of diabetes-specific HRQOL (Paper III), children's experiences of diabetes-specific family support (Paper IV) and parents' satisfaction with the care received (Paper III and IV).

The results of the interviews showed that the goal for the diabetes education is to achieve self-care for the child and their parents. The education is aimed to guide the child and parents towards self-help whereby the diabetes team immediately after the child's diagnosis provides the child and their parents with knowledge and skills about the disease and how to manage the child's treatment. Furthermore, the diabetes team tries to get an overall picture on each family by focusing on their daily life before the child was diagnosed with type 1 diabetes in order to optimize the new situation for the family. Parents experienced that the educational process was overall satisfactory. However, they wanted the education to be more adapted to each individual family to help them in their everyday life. They described the education process as almost a type of knowledge overload according to a rigid schedule and that there was no time for feeling grief and sadness. Parents felt that it was a difficult task to manage the child's disease and at the same time continue their normal family life.

The results from Paper III and IV showed that both parents' HRQOL were affected at diagnosis and one and two years subsequent to their child's diagnosis. The results also showed that mothers were especially emotionally affected during the first two years after the child's diagnosis and they also had a higher degree of



worry than fathers. Both children between 5-7 years and their parents estimated a higher degree of worry after one year than the children between 8-18 years and their respective parents did. After two years there was no relationship between how children experienced parental support and their HbA1c value. Parents were overall satisfied with their child's healthcare both at diagnosis and one and two years subsequent to the child's diagnosis.

The findings from this thesis can elucidate the understanding of how it is to live with type 1 diabetes from the both the child's and their parent's perspective the first years subsequent to the child's diagnosis. By reflecting on the findings, the diabetes teams may more clearly increase the focus on each family's individual needs at diagnosis to further develop the education process to be more adapted to the individual family and thereby promote the transition to home. To further elucidate the disease effects on parents, and especially mothers, longitudinal interview studies need to be carried out with both mothers and fathers. Furthermore, it is also important to highlight children's experiences from their perspectives as well as their siblings.

# Abbreviations

ADA	American Diabetes Association
AAP	American Academy of Pediatrics
DCCT	Diabetes Control and Complications Trial
DKA	Diabetic ketoacidosis
DSP	Diabetes Specialist Paeditrician
HbA1c	Glycated haemoglobin
HLA	Human leukocyte antigen
HRQOL	Health Related Quality of Life
IDF	International Diabetes Federation
ISPAD	International Society for Pediatric and Adolescent Diabetes
OGTT	Oral Glucose Tolerance Test
PedsQL	Paediatric Quality of Life
PDSN	Paediatric Diabetes Specialist Nurse
SPSS	Statistical Package for the Social Sciences
SWEDIABKIDS	Swedish Childhood Diabetes Registry
QOL	Quality of Life
WHO	World Health Organisation

# Original Papers

This thesis for the doctoral degree is based on the following papers referred to in the text by their Roman numerals:

- I. Jönsson L, Hallström I, Lundqvist A. A multi-disciplinary education process related to the discharging of children from hospital when the child has been diagnosed with type 1 diabetes – a qualitative study. BMC Pediatrics 2010, 10:36.
- II. Jönsson L, Hallström I, Lundqvist A. “The Logic of Care” – Parents’ perceptions of the educational process when a child is newly diagnosed with type 1 diabetes BMC Pediatrics 2012, 12:65.
- III. Jönsson L, Lundqvist P, Tiberg I, Hallström I. Type 1 diabetes – Impact on children and parents at diagnosis and one year subsequent to the child’s diagnosis. (Accepted for publication in Scandinavian Journal of Caring Sciences)
- IV. Jönsson L, Lundqvist P, Tiberg I, Hallström I. Parents’ HRQOL, their satisfaction with care and children’s experiences of family support two years subsequent to the child’s diagnosis with type 1 diabetes. (Submitted)

The Papers have been reprinted with the kind permission of each respective journal.

# Background

## Introduction

Type 1 diabetes is one of the most common endocrine and metabolic conditions in childhood. The International Society for Pediatric and Adolescent Diabetes (ISPAD) describes the goals for working with children and adolescents with diabetes as follows: optimal health, social well-being and a good quality of life emphasizing the importance of age-appropriate education and the inclusion of the family, school or college in the process (Swift, 2009), also described in the Saint Vincent declaration (Diabetes care and research in Europe, 1990). When a child is diagnosed with type 1 diabetes, the parents have often sought medical care for their children in the belief that the child has a common childhood disease and they are seldom prepared for the diagnosis. The family is often told of the child's diagnosis quickly and they do not understand what is happening; their lives change dramatically from a both practical and emotional standpoint (Lowes, Gregory, & Lyne, 2005). How the child is taken care of at the diagnosis varies worldwide, depending partly on the child's medical condition but also on the different national guidelines (Clar, Waugh, & Thomas, 2007; Hirasing et al., 1996; Siminerio, Charron-Prochownik, Banion, & Schreiner, 1999). In Sweden, the procedure traditionally involves hospitalized care for about two weeks for the child and family and, during this time, they receive education and information according to the national guidelines on how to handle the illness (Sjöblad, 2008). However, during the last decades there has been a movement towards shorter lengths in hospital and/or solely outpatient management (Swift et al., 1993; Tiberg, Hallström, & Carlsson, 2010).

Education about type 1 diabetes is often given to the child and family by a multi-professional team with specialized knowledge of children with type 1 diabetes, i.e. a doctor specialized in paediatric diabetes (DSP) and a paediatric diabetes specialist nurse (PDSN), a dietician, a social worker and a psychologist. In the team the PDSN has a key role and the children and their parents are considered active members of the team (Llahana, Poulton, & Coates, 2001; Örtqvist, Forsander, & Sjöblad, 2008). The parents have the main responsibility for the child's disease but depending on the age of the child, the goal is for the child to manage the diabetes regime themselves together with their family (Sjöblad, 2008; Swift, 2009).

The disease is complex and time consuming and places high demands on children and their parents. Earlier studies show that the child's diagnosis has an impact on the family's health-related quality of life and also an impact on the family economy in terms of parental work restrictions and high medical costs (Katz, Laffel, Perrin, & Kuhlthau, 2012; Smaldone & Ritholz, 2011).

Knowledge on how the diabetes team works with families of children newly diagnosed with type 1 diabetes and how this and the disease affects the family's daily life with short and long perspectives is limited.

## Type 1 diabetes

Type 1 diabetes is classified by the American Diabetes Association (ADA) and the World Health Organisation (WHO) as an idiopathic disease with immune mediated beta-cell destruction, often leading to absolute insulin deficiency (Craig, Hattersley, & Donaghue, 2009). The disease is characterized by a relatively acute onset of polyuria, polydipsia, weight loss and fatigue. If the disease is not treated, it leads to dehydration and metabolic acidosis with ketosis, which in severe cases with a pH < 7.30 that can lead to a coma. The symptoms can be divided into mild, moderate and severe forms. In the mild form the child is abnormally thirsty and drinks a lot; in the moderate form dehydration is present and, in the severe form mild to moderate ketoacidosis may be present (Clar et al., 2007). In the case of moderate and severe forms, the child needs infusion therapy to achieve rehydration and therefore hospitalization is necessary (Hanås, Tuvemo, Gustavsson, & Sjöblad, 2008; Hürter, 2000). The diagnosis can often be confirmed by symptoms and causal plasma glucose concentration  $\geq 11.1$  mmol/L or a fasting plasma glucose  $\geq 7.0$  mmol/L or 2-hours post load glucose  $\geq 11.1$  mmol/L during an oral glucose tolerance test (OGTT), performed as described by WHO (Craig et al., 2009; Diagnosis and classification of diabetes mellitus, 2014). In Sweden, most newly diagnosed children are at an early stage and ketoacidosis has not been developed (Sjöblad, 2008). According to SWEDIABKIDS (2012) 18.7 per cent of children in Sweden had metabolic acidosis at diagnosis. However, in the US and in the Western European countries, about 30 per cent of the newly diagnosed children have developed ketoacidosis (Neu et al., 2001; Sadauskaite-Kuehne et al., 2002).

Insulin therapy using regular insulin before each main meal and one injection at night started in 1922. After 1935 new forms of insulin with an intermediate and long-term effect were developed and most patients used just one or two injections per day. Today the recommendations for children and adolescents are to use a combination of basal insulin and rapid-acting or regular insulin. This means 5-7 injections per day for the child (Bangstad et al., 2009; Ludvigsson, Sjöblad, Örtqvist, & Hanas, 2008). Another way to administer insulin to the child is

through an insulin pump. The prevalence of using insulin pumps in Sweden is increasing and about 46 per cent of the children use an insulin pump. In the last five years, the increase among children has been 9 per cent and the percentage is highest among the younger age groups (SWEDIABKIDS, 2012).

## **Prevalence and incidence**

In 2011, the total child population of the world (0-14 years) was estimated to be 1.9 billion. About 77 800 new cases of type 1 diabetes are diagnosed each year and approximately 490 100 children in the world have type 1 diabetes and about a fourth of them come from the European Region (International Diabetes Federation, 2011). Finland has the highest incidence of onset of type 1 diabetes in the world and Sweden is in fourth place after Sardinia and Canada (Craig et al., 2009). The disease has a strong association to the human leukocyte antigen (HLA) (Resic-Lindehammer et al., 2008) and in Europe the incidence rates show a close relationship with the frequency of HLA susceptibility genes in the general population (Craig et al., 2009). European studies have shown that, in relative terms, the increase of type 1 diabetes is greatest in young children and there are indications that similar trends exist in many other parts of the world (IDF & ISPAD, 2011).

The incidence in Sweden had increased dramatically during a period from 1978-2007 and many younger children are diagnosed (Berhan, Waernbaum, Lind, Mollsten, & Dahlquist, 2011), especially in the age group 0-5 years (Dahlquist & Mustonen, 2000). In the year of 2012, 744 children in Sweden under the age of 18 were diagnosed with type 1 diabetes. Of these, 86 per cent were under the age of 15 (SWEDIABKIDS, 2012). Today there is a decreasing incidence of type 1 diabetes in Sweden, but this trend needs to be confirmed in studies done over a longer period of time (Berhan et al., 2011).

## **Metabolic Control**

Maintaining blood glucose levels close to the physiologically normal range reduces the risk of long-term complications (DCCT Research Group, 1993). The aim of diabetes management is therefore to maintain optimum metabolic control from the diagnosis onwards. To reflect the development of glucose in the blood under the last 2-3 months, averaged blood glucose levels, HbA1c (glycated hemoglobin concentrations) are measured as an individual blood sample. HbA1c is the golden standard for the long-term follow up of glycemic control (Hanås & John, 2010). The value is recommended to be a maximum of 58 mmol/mol (IDF & ISPAD, 2011). The DCCT study recommends an intensive treatment with the goal of lowering HbA1c and thereby lowering the risk for long-term complications

(DCCT Research Group, 1993; Lachin, Genuth, Nathan, Zinman, & Rutledge, 2008). The Swedish recommendation for children is an HbA1c between 52-57 mmol/mol (Sjöblad, 2008). Over the years the mean HbA1c value has decreased from 64.4 in year 2008 to 62.7 in year 2012 for children in Sweden (SWEDIABKIDS, 2012).

The use of an insulin pump is becoming more common in children and adolescents in many countries, but according to SWEDIABKIDS (2012), the children do not attain better metabolic control with an insulin pump. Regardless the regime chosen, it is important to have frequent blood glucose monitoring to achieve optimal treatment (Bangstad et al., 2009).

Balancing food intake, insulin and activity is a complex situation for the child and the family. The dietary recommendations for children's optimal growth and development are the same as they are for the whole family, namely a healthy diet. However, this must also be adapted to the family habits and to cultural, social and ethnic traditions. Furthermore, it is important to have regular food intake during the day with breakfast, lunch and dinner, as well as some healthy snacks in between meals depending on the child's individual needs (Samuelsson et al., 2008; Smart, Aslander-van Vliet, & Waldron, 2009). Different kinds of physical activities according to the child's interests are important in the maintenance of metabolic control. For a short physical activity an increased carbohydrate intake is normally not required, but if the activity is prolonged (> 1 hour), for example in the case of football, it is important to adjust dietary intake (carbohydrates) and insulin before, during and after the activity (Samuelsson et al., 2008).

Research in the last decade has provided a substantial amount of evidence for the relation between family factors and metabolic control. The family's situation and background as well as how they adapt to the new situation are of importance to the evolvement of the child's metabolic control (Forsander, Sundelin, & Persson, 2000; Schor, 2003; Thompson, Auslander, & White, 2001; Viner, McGrath, & Trudinger, 1996). The marital status of the child's parents has also been found to be of importance for the outcome of the metabolic control. If the child's parents lived together, the child's HbA1c was found to be lower than if there were alternative family arrangements (Swift, Chen, Hershberger, & Holmes, 2006).

#### *Short- and long term complications*

Short-term complications according to the national guidelines (Nordfeldt, 2008) are severe hypoglycaemia, defined as: an occasion of hypoglycaemia where the child has been in need of help from another person. Blood glucose levels below 3.5 mmol/L are considered to be low and even at this level, the brain is affected and functions at a lower level. Approximately one in ten children suffers from unconsciousness with or without seizures in connection with hypoglycaemia. Causes of severe hypoglycaemia can be a temporary imbalance of food, activity and insulin response. It is therefore important to adjust the insulin treatment during

increased physical activity levels (Nordfeldt, 2008). Another complication is ketoacidosis (DKA). DKA can be a result of not receiving enough insulin and usually develops slowly, but can also develop during a few hours if the person e.g. is vomiting. Early symptoms of DKA are e.g. thirst, frequent urination, high blood glucose levels or high levels of ketones in the urine (Hanås et al., 2008)

Long-term complications, related to type 1 diabetes are for example cardiovascular diseases, stroke, chronic wounds and renal insufficiency. The risk of late complications increase directly with a high HbA1c value. According to the national guidelines (Lundvigsson & Sjöblad, 2008) the recommendation for screening of long-term complication is as follows: examination of the child's ocular fundus every second year from the age of 10, examination of the child's blood pressure every year from the age of 10, and kidney injury is controlled every year by analysing albumin in urine. Simplex retinopathy is the most common diagnosis in fundoscopy and between the years 2011-2012 the incidence was 2.7 per cent in the age group 10-12 years, 8.5 per cent in age group 13-15 years and 13.2 per cent in the age group 16-17 years. The incidence increase from 4.9 per cent with a diabetes duration of 0-4 years to 30.4 per cent with a diabetes duration of 10-15 years. High blood pressure occurred in 4.3 per cent of the children who have undergone blood pressure measurement and the majority of these children are over 14 years of age. According to these guidelines, the renal dysfunction is considered permanent if two of three samples are pathological under a six month period (SWEDIABKIDS, 2012). Furthermore, at the annual examination, the children receive a check-up for signs of sensory neuropathy, thyroid disease and celiac disease (Lundvigsson & Sjöblad, 2008).

## Diabetes care

When a child is diagnosed with type 1 diabetes the care varies worldwide, partly depending on whether or not the child is acutely ill at onset. In Western Europe, and in the US, 30-50 per cent of the children have mild symptoms at diagnosis and are treated on an outpatient basis (Clar et al., 2007). There is a discussion concerning which is the best, being treated as an outpatient or inpatient basis. Admission to a hospital provides the opportunity for intensive education and this may lead to future benefits. On the other hand, hospitalization may encourage dependence on the hospital staff and does not stimulate the family's own abilities to take care of themselves in the future. When comparing these two alternative treatments no differences in metabolic control or diabetes complications were found (Clar et al., 2007). In a recent Swedish study the result showed that home-based management is a safe and effective way of providing care to children newly diagnosed with type 1 diabetes given that they are medically stable (Tiberg, Steen Carlsson, Carlsson, & Hallström, 2012). Hospitalization or home-based



management when the child is newly diagnosed is an on-going debate and more evidence is needed to determine its functionality (Clar et al., 2007).

The Swedish paediatric diabetes care is based on ISPAD's consensus guidelines and on national guidelines to ensure national care of the highest quality (IDF & ISPAD, 2011; The National Board of Health and Welfare; Sjöblad, 2008). According to the national guidelines in Sweden the goals (Larsson, 2008) include the following: the child will not have any symptoms of the disease, he/she will have a normal growth and development, treatment of both acute and long-term complications will be provided and a diabetes team specializing in children and adolescents will have the responsibility for the treatment. In Sweden, as in many other countries, education and training starts as soon as a child is diagnosed and is usually administered to the family by a multi-professional paediatric team including PSDNs, DSPs, a dietician, a social-worker and/or a psychologist (Dahlqvist, 2008; Llahana et al., 2001). The PSDN is a registered nurse with special training and expertise in paediatrics and diabetes who works as an educator, social worker, manager, communicator and innovator under his/her own responsibility (Pihoker, Forsander, Wolfsdorf, & Klingensmith, 2008). The PSDN works as a member of the team and has a key role in educating children and their parents about diabetes. He/she plays an important part in ensuring that care is co-ordinated and that the child and their parents receive information in a way that is meaningful to them (Llahana et al., 2001).

In Sweden when a child is newly diagnosed, the routine has been that hospital based care is prescribed for the child and their parents for about one to two weeks' stay according to the national guidelines (Sjöblad, 2008). During this time as well as beyond the discharge day, both children and their parents are encouraged to be active members of the care team (Kyne-Grzebalski, 1997). In Sweden after being discharged from the hospital, the child and the family have frequent contact with the diabetes team during the first six months. Contact can be in form of appointments at the hospital, telephone calls, and visits of the diabetes team in the family's home or a combination of all of these. Follow-ups are recommended every third month so as to be able to re-evaluate diabetes management and annual visits are recommended for dietetic advice, meeting psychosocial needs, blood screening and education updates (Pihoker et al., 2008; Sjöblad, 2008).

When the child is young, it is the parents who are responsible for the child's treatment, even if the child is also involved. The goal is to gradually transfer the responsibility for the management of the disease to the child, so as when the child become older, the diabetes team informs the child in an age-appropriate way (Anderson, 2009). The clinical praxis in Sweden is that the diabetes team transfers more information, training and responsibilities to the child around the time when he/she is about 10 years old (Hägglöf, 2008). At this age the child has usually reached a higher level of cognitive development and can start to adopt the knowledge and skills themselves (von Tetzchner, 2001). No child or adolescent

should be forced to learn and accept the new responsibilities. However, it is important that they have a good understanding of diabetes. Around the time of puberty they should learn the necessary skills to be more independent in their self-management (IDF & ISPAD, 2011; Berg Kelly, 2008; Swift, 2009). Parents' involvement in the child's diabetes management is still important, but is changing from that of a more controlling parental style to more of a coaching style (Anderson, 2009). Parents often succeed in managing the practical aspects of their child's diabetes, even if they have difficulties in the beginning to accept the new routines as a part of their daily lives. However, most of the parents never fully accept the diagnosis even if they appear to adapt to their situation (Bowes, Lowes, Warner, & Gregory, 2009; Lowes & Lyne, 2000). Previous research (Wennick & Hallström, 2006, 2007) showed that it was difficult for the child and family to come home from the hospital after the child was diagnosed with type 1 diabetes because the theoretical knowledge the families had received during hospitalization was no longer valid when they returned home.

## Diabetes education

When a child in a family is diagnosed with type 1 diabetes, it implies a major change for the family and they have a great need for information, education and training in order to deal with the child's disease in an optimal way. Education is found to be the key for a successful management of diabetes (Silverstein et al., 2005; Swift, 2009). Diabetes education is defined as "The process of providing the person with the knowledge and skills needed to perform diabetes self-care, manage crises and to make lifestyle changes to successfully manage the disease" (Clement, 1995). This definition is also adopted by the ISPAD (Swift, 2009). In the beginning, after diagnosis, the education is about survival, i.e. what the family must learn about the disease and the treatment before they can leave the hospital (Brink & Chiarelli, 2004). It is important that the child/adolescent and his/her family gets knowledge about how the diagnosis has been established, predisposing factors to type 1 diabetes, the need for insulin and how it works, what glucose is and what normal levels of glucose are, practical skills (insulin injections, blood/urine tests and reasons for monitoring), and basic dietetic advice. Furthermore, the family must learn about hypoglycaemia, how to prevent diabetic ketoacidosis (DKA) and how to manage the diabetes at home, at school and during physical activity. It is also necessary that the family, after diagnosis, is provided with details of emergency telephone contacts (Dahlqvist, 2008; Swift, 2009). As a complement to the verbal information, the family needs written material that is easily read and understood (Swift, 2009). The education needs to follow the specific requests of each child and family and to be continued over time, with knowledge and skills development on both an individual level and in different age

groups depending on the child's age and cognitive level (Brink & Chiarelli, 2004; Swift, 2009).

The overall recommendation in Sweden is that the child and family have continual time for information and discussions with the DSP and PDSN during the first period after the child's diagnosis. Furthermore, it is important that the information and knowledge about diabetes management is adjusted to the individual family's needs and ability to cope with the new situation. Both parents are given the opportunity to participate in training and planning about the child's disease. Practical teaching around the diabetes management, including insulin, blood glucose levels and food intake is being implemented gradually by the PDSN and dietician. After discharge, the child and their family are frequently followed up by the DSP and PDSN through both personal meetings and over the phone. High availability from the diabetes team in the beginning can mean fewer problems later on (Dahlqvist, 2008).

## Family Centred Care

There is no consensus about the definition of family centred care, but according to Institute for Patient and Family Centred Care (2010) the definition is "Patient- and family centred care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families." Also the American Academy of Pediatrics (AAP) (Schor, 2003) has a similar description of family centred care. Furthermore, the AAP describes some benefits with this type of care e.g. better understanding for the family's strengths and care capacity, improved communication among the health care members and greater child and family satisfaction with the care received. Swedish child health care is following the Nordic standard for children and adolescents in health care services (NOBAB, n.d.). This standard takes also the guidelines for family centred care into consideration and is in accordance with the UN Convention on the Rights of the Child (UNICEF, 1989). Today there are discussions about how to deliver care to children in other ways than the approach of family centred care (Shields, 2010). Söderbäck, Coyne and Harder (2011) discuss that the health care should be moving towards a more child centred care approach according to the rights of the child (UNICEF, 1989). According to a child centred care approach, the child's perspective is strengthened in meaning when both the child and the surrounding adults have a child's perspective of the situation (Söderbäck Coyne, & Harder, 2011).

## **Families and type 1 diabetes**

Referring to the Institute for Patient and Family Centred Care (2010), the definition of a family is two or more persons who are related in any way—biologically, legally, or emotionally. Both patients and families are the ones who define their families and who this includes. Type 1 diabetes is a chronic long term illness. A long term illness is defined as an illness which has to a considerable degree affected the child's life during at least 3 months of the last year (Berntsson & Kohler, 2001). A chronic disease in childhood is defined as a disease that has a long duration, i.e. that is expected to last, or lasts for 3 months or more or that generally has a slow progression and that can be controlled, but not cured. In most cases, a chronic disease requires a lifetime of regular treatment. The impact that the diagnosis of a chronic disease has on the family is largely dependent on the age and developmental status of the child (Perrin et al., 1993).

The diagnosis of a chronic disease in a child is a stressful event for every member of a family. The disease will probably change the family life and the relationship between family members simply because it requires the family to acclimatize (Hentinen & Kyngas, 1998; Jerrett, 1994; Lowes & Lyne, 1999; Nuutila & Salanterä, 2006). One way in which relationships between members of the family could be affected might be, for example, that parents become too occupied with the care of the diagnosed child and neglect the other children or overprotect the diagnosed child (Hentinen & Kyngas, 1998).

When a child is diagnosed with a chronic disease the family and the staff in charge of treatment start a long-lasting relationship built upon mutual confidence and equal trust (Fisher, 2001). The staff needs to address both the child and its parents in a humane manner, but a sense of humour may also be of importance for the relationship (Nuutila & Salanterä, 2006). Parents are often more self-sufficient than the staff think they are and not always aware of the help they can get from the staff during hospitalization (Shields, Kristensson-Hallström, & O'Callaghan, 2003). Parents find the huge amount of information concerning their child's disease overwhelming, even though they have a need for this information about the disease. However, if received information is contradictory, the parents felt decreasing confidence in the staff (Nuutila & Salanterä, 2006).

## **Health related quality of life**

The definition of quality of life (QOL) is, according to WHO, the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHOQOL, 1995). This definition highlights that quality of life is subjective and includes both positive and negative facets of life, as well as also

being multidimensional. Multidimensional constructs in this sense covers physical, emotional, mental, social, and behavioural components of wellbeing and functioning. The term QOL has been discussed because it seems to be too general to be used in health care. HRQOL is a broader term in relation to aspects of life and is more suitable because it includes aspects that are not generally considered as health, such as income, freedom and quality of the environment (Guyatt, Feeny, & Patrick, 1993). In a paediatric setting it is often the child's parents that report their perception of their child's HRQOL outcomes as a result of treatment. However, it is important to measure the perspectives of both child and parents because they have individual perspectives on healthcare utilization, risk factors and quality of care (Eiser & Morse, 2001; Varni, Burwinkle, & Lane, 2005). In a study by de Wit et al. (de Wit et al., 2010) it was found that it is important to include periodic assessment of HRQOL using standardized questionnaires as a routine in diabetes care.

## **The child with type 1 diabetes**

Type 1 diabetes is an ongoing condition requiring ongoing interventions. The disease also changes over time depending on the child's age and development to adulthood. Dealing with low blood glucose levels, self-care activities such as checking blood glucose and administering insulin every day was experienced as a challenge and daily trial for children and adolescents (Freeborn, Dyches, Roper, & Mandleco, 2013). Furthermore, children and adolescent also expressed feelings of being different and alone because they need to have a more regular lifestyle than their peers (Anderson, 2009; Freeborn et al., 2013; Sawyer et al., 2004). The disease also interfered when they participated in activities with friends and family (Sawyer et al., 2004). Adolescents with diabetes also described a lower life satisfaction than their peers (Faulkner, 2003). This is something the PDSN must be aware of and initiate conversations about as well as to suggest different strategies that can minimize the feeling of being different (Freeborn et al., 2013). Attending a diabetes camp or support group are strategies that give opportunities for the adolescent to meet friends in the same situation as them (Freeborn et al., 2013; Gannoni & Shute, 2010).

It has been reported that children often receive poor support in school (Anderson, 2009). In a study by Amillategui, Mora, Calle and Giralt (2009) children between 10-13 years experienced that their major concern at school regarding diabetes management was not being able to recognize a hypoglycemic episode or not being able to administrate insulin themselves. However, the children in the study reported that their greatest support came from peers and teachers. Furthermore, both children and parents expressed that teachers need more knowledge about type 1 diabetes and its management.

## **Parent's experiences of caring for a child with type 1 diabetes**

The diagnosis of a chronic disease as type 1 diabetes given to a child also affects their parents and gives rise to strong emotions. Mothers and fathers often describe feelings of sorrow and guilt (Anderson, 2009; Bowes et al., 2009; Nuutila & Salanterä, 2006) and some parents have difficulties accepting the child's diagnosis even after a longer period of time (Bowes et al., 2009; Popp, Robinson, Britner, & Blank, 2014). Parents have also described it as being on an emotional roller-coaster all the time (Gannoni & Shute, 2010).

How mothers and fathers react after their child is diagnosed with type 1 diabetes is found to be different. Mothers often react with disappointment because they experience a lack of engagement from the father in the child's diabetes management. On the other hand, fathers express that mothers do not always let them take the full responsibility for the child's diabetes care. Furthermore, fathers often need more time to grow into the new family situation (Sparud-Lundin, Hallström, & Erlandsson, 2013). In a study by Azar and Solomon (2001) it revealed that mothers used a more planning-oriented approach to their problem solving than the fathers, who instead used a distancing approach to cope with the child's disease.

## **Satisfaction with care**

Today the healthcare services are characterized as a complex and technical environment. In child health care, the child and parent's participation as well as their satisfaction with the care is essential. It is important to evaluate interventions in the care as well as the quality of care (Garratt, Bjertnaes, & Barlinn, 2007; Ygge & Arnetz, 2001) since there is evidence supporting that better satisfaction with health care yields an improved effect of treatment and this leads to better health outcomes (Garratt et al., 2007; Schmidt, Thyen, Chaplin, Mueller-Godeffroy, & Bullinger, 2008). Children have different needs depending on their situation and their parents can find it difficult to express the child's needs.

Parental satisfaction with care is due to various factors such as: feeling secure with the staff, receiving support and being involved in their child's care. Secure and well-informed parents are more likely to provide information to their children so that they also feel secure (Hallström, Runesson, & Elander, 2002). Both in earlier (Auslander, Thompson, Dreitzer, & Santiago, 1997; Lessing, Swift, Metcalfe, & Baum, 1992) and recent studies (Hays et al., 2006; Tiberg, Steen Carlsson, Carlsson, & Hallström, 2012) results show that parents are overall satisfied with their child's diabetes care. An important component in parents' satisfaction with the diabetes care was that health care workers listened and provided feedback to the parents (Fisher & Broome, 2011).

However, few studies have followed children newly diagnosed with type 1 diabetes and their parents longitudinally related to their HRQOL and their satisfaction with care. Furthermore, knowledge about how diabetes teams work with the child and family and how parents perceive the educational process in the context of the child's newly diagnosed disease are sparsely described.

# Aims

The overall aim of this thesis was to investigate the initial diabetes education process, the impact on children and their parents' and parents' satisfaction with the care received one and two years subsequent to the child's diagnosis.

Four specific aims were formulated, one for each Paper as outlined below.

- The aim of Paper I was to seek a deeper understanding of how the diabetes team's parent/child education process works, from admission to discharge, among families with a child newly diagnosed with type 1 diabetes.
- The aim of Paper II was to describe parents' perceptions of the educational process when their child is newly diagnosed with type 1 diabetes.
- The aim of Paper III was to describe and compare the disease impact on parents and children in terms of HRQOL at diagnosis and one year subsequent to the child's diagnosis with type 1 diabetes. A further aim was to describe and compare the parents' satisfaction with the care received.
- The aim of Paper IV was to describe and compare the disease impact on parents, in terms of HRQOL, parents' satisfaction with the care received and the child's experience of diabetes-specific family support two years after the child's diagnosis. A further aim was to compare mothers and fathers HRQOL and satisfaction with care over time from the child's diagnosis to follow-up two years later.



# Methods

## Overview of the samples and methods

Qualitative descriptive methods were chosen to get a deeper understanding about the educational process during hospitalization when a child is diagnosed with type 1 diabetes (Paper I and II). Quantitative methods were used to describe the impact on the families' and parents' satisfaction with the care received one and two years after the child's diagnosis, respectively (Paper III and IV). An overview of samples and methods used in the papers is provided in Table 1.

**Table 1.** Overview of the design, samples and methods used in the thesis.

Paper	Sample	Data collection	Data analysis
Paper I	Professionals in paediatric diabetes team (N=16)	Focus groups	Inductive content analysis
Paper II	Parents to children newly diagnosed with type 1 diabetes (N=18)	Open interviews	Deductive content analysis
Paper III	Children diagnosed with type 1 diabetes (N=64) and their parents (N=122)	Questionnaires at one year; PedsQL™ Family Impact Module PedsQL™ Health Care Satisfaction Generic Module PedsQL™ 3.0 Diabetes Module Scale	Statistical analysis; Independent t-test Paired t-test One-way analysis of variance (ANOVA)
Paper IV	Children diagnosed with type 1 diabetes (N=60) and their parents (N=114)	Questionnaires at two years; PedsQL™ Family Impact Module PedsQL™ Health Care Satisfaction Generic Module Diabetes Family Behavior Scale (DFBS) <sup>®</sup>	Statistical analysis; Independent t-test Paired t-test Pearson correlation

## The context of the studies

Each department involved care for a total of 20-30 children, newly diagnosed with type 1 diabetes each year. The number of children from 0-17 years in the catchment area of the hospitals is about 55,000-70,000. Each paediatric department has a diabetes team including a number of Paediatric Diabetes Specialist Nurses (PDSNs), Diabetes Specialist Paediatricians (DSPs), a dietician, a social worker and/or a psychologist. The diabetes team take care of the family during the hospitalisation when a child is newly diagnosed with type 1 diabetes and holds ongoing educational sessions with them. They also have continuous follow-ups with the child and family throughout the patient's childhood i.e. until the child is 18 years. In Paper I and II three paediatric departments were included. One of the hospitals was a university hospital and two were county hospitals. In Paper III and IV, two of the above described paediatric departments were involved, a university hospital and a county hospital.

## Study population

In Paper I, three paediatric diabetes teams were contacted about the study and were invited to participate in focus group interviews. The recruitment of the diabetes team members was conducted by the PDSN in each team. The PDSN was asked to convey information, verbal and written, about the study to members of each team as well as given a form to fill in for informed consent about participating in the study. This form was submitted by each participant to the author of this thesis. At one of the county hospitals the PDSN chose not to ask the dietician, the social worker and the psychologist to participate in the study as these were not involved in the care of the family during the initial hospital stay. The interviews were carried out between September 2008 and March 2009. For an overview of the participating professionals see Table 2.

**Table 2.** Demographic characteristics of the diabetes teams (N=16).

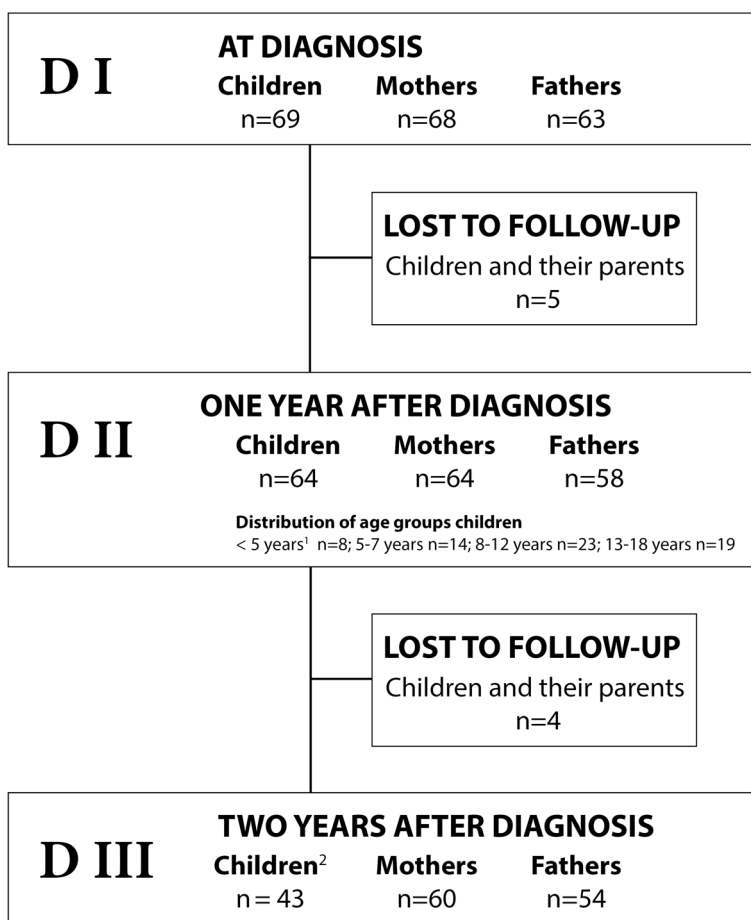
Professional	Number	Age	Experience of diabetes care (years)
Diabetes specialist paediatrician	4	45-49	16-20
Paediatric diabetes specialist nurse	6	45-49	16-20
Social worker	2	50-54	6-10
Psychologist	2	45-49	6-10
Dietician	2	45-49	6-10

In Paper II, parents of children 3 to 16 years who had been diagnosed with type 1 diabetes within the last 3 to 6 months consecutively were asked to participate in the study. Four families declined to participate. The PDSN at each hospital contacted the concerned parents who were given both verbal and written information about the study and a form for informed consent. Parents who agreed to participate sent the informed consent to the PDSN. The informed consents were subsequently handed over to the author of this thesis who, in turn, contacted the families. A total of 18 parents, 1 single mother and 17 cohabitant parents, of which one mother was not living with the father of the child were included. The interviews were carried out between April and November 2010. For an overview of the participating parents see Table 3.

**Table 3.** Demographic characteristics of parents and family (N=18).

Characteristic	n
Age (years)	
31-35	2
36-40	15
41-45	0
46-	1
Gender	
Female	10
Male	8
Education	
Elementary school	0
Secondary school	7
University	11
Child's age (years) at diagnosis	
3-6	3
7-10	3
11-14	2
15-	2
Number of siblings	
0	1
1-2	8
3-	1

In Paper III and IV, children newly diagnosed with type 1 diabetes receiving hospital care and their parents were consecutively asked to participate between March 2008 and September 2011. During this time 106 children were diagnosed with type 1 diabetes at the departments involved. The inclusion criteria were: children aged 3-15 years without any other severe chronic disease, with no siblings with type 1 diabetes, not in custody of social welfare and whose family could speak and understand the Swedish language. Seven families declined to participate in the study. The author of this thesis met all the included families in connection with the child's discharge from the hospital. One and two years after the child's diagnosis the families were contacted by phone, as agreed. Five children and their parents declined to participate at the one year follow-up and nine children and their parents at the two years follow-up, mostly because of lack of time from the parents' perspective. A flowchart showing the data collections are presented in Figure 1.



<sup>1</sup> The parents filled in the questionnaire due to their estimation of the child's estimated HRQOL

<sup>2</sup> Only children over 8 years filled in the questionnaire.

D I = Data collection at diagnosis

D II = Data collection one year after diagnosis

D III = Data collection two years after diagnosis

**Figure 1.** Flowchart of data collection.

# Data collection

## Focus groups interviews

In Paper I focus groups interviews were used. Focus group interviews imply that a group of people meet for a limited time to discuss a given topic. A moderator leads the interview and initiates the questions but allows the group to discuss the topic freely (Krueger & Casey, 2000). Members from each diabetes team constitute a focus group. Four focus group interviews were conducted with three to six participants from three different paediatric diabetes teams, two at county hospitals and one at a university hospital. At one of the county hospitals there were two focus group interviews because an emergency occurred in connection with the planned interview, so all team members could not be present at the same time. This meant that the diabetes team was divided into two groups and one diabetes nurse was involved in both corresponding focus groups interviews.

The focus group interview started with a presentation of the moderator and the assisting observer followed by an introduction, in accordance with Kreuger and Casey (2000) and Kvale and Brinkmann (2009), so as to establish a relaxed and positive environment. Each interview lasted between 60 and 80 minutes and started with the open question: "Please describe how the diabetes team members at your hospital are working with the families of a child newly diagnosed with type 1 diabetes during the time they are in the hospital". During the interview the moderator encouraged the participants to express their own perspectives and views and to respond to statements made by other team members. The moderator asked compatible follow-up questions in order to find out if there were more issues that the participants wished to emphasize. The assistant recorded the group dynamics and interactions, and added complementary follow-up questions at the end of the interview (Krueger & Casey, 2000).

## Individual interviews

In Paper II, individual interviews with parents were conducted. The research interviews intended to obtain descriptions of the interviewees' living conditions and their relationship to their situation in order to be able to interpret the described phenomena. The interviews were not a conversation between equals because it was the researcher who defined and verified the state of the situation (Kvale & Brinkmann, 2009). The perspective of the individual interviews was that of a conversation occurring between two people (Kvale & Brinkmann, 2009).

The date and place of each interview was decided in consultation with the parents. Seventeen interviews took place in the homes of the families and one at the parent's place of work, according to the parents' preferences. The interviews

were performed three to six months after a single child in the family was diagnosed with type 1 diabetes. Before the interviews started a short background and motivation for the interview was described in order to create a relaxed and open environment (Kvale & Brinkmann, 2009). The interviews started with an open ended question followed by the parent's account of their experiences of the teaching and technical training, the approaches and attentiveness of the staff concerning the understanding of the implications of diabetes, their (the parents) participation in decision-making as well as their crisis response.

After the open questions the interviewers followed up with questions such as: "What do you mean by that?", "Can you explain more about that", etc. According to Kvale and Brinkman (2009) it is important to have different types of questions after the introduction question. For example, a follow-up question can be a direct question or it can just be a nod or encouragement such as an "mm" from the interviewer so the subject feels invited to go on. It can also be a probing question; in this case the interviewer could use the content of the answer to form a question like "Could you say more about that?" Each interview lasted between 45 and 90 minutes.

## **Questionnaires**

In Paper III and IV questionnaires were completed by children and their parents at the time of discharge from the hospital and one and two years respectively subsequent to the child's diagnosis. For an overview see Table 4.

The place for each data collection was decided in accordance with the families' wishes, at the hospital or in the family's own home. Parents independently filled in the questionnaires and when necessary, the author of this thesis helped the youngest children with reading the questions so that the child could point to their answer to the question.

**Table 4.** Questionnaires used in Paper III and IV

Questionnaire	Measuring	Child	Parent	Used at
Background variables	Includes e.g. child's gender and HbA1c, siblings, parents education and income ,family situation	X (over 12 years)	X	Discharge, one and two years
The PedsQL™ Family Impact Module	The disease impact on the family		X	Discharge, one and two years
The PedsQL™ Healthcare Satisfaction Generic Module	The satisfaction with the care received		X	Discharge, one and two years
The PedsQL™ 3.0 Diabetes Module Scale	The child's HRQOL related to the type 1 diabetes	X (5-7, 8-12 or 13-18 years)	X (2-4, 5-7, 8-12 or 13-18 years)	One year
Diabetes Family Behavior Scale (DFBS)®	The diabetes-specific family support	X (over 8 years)		Two years

### *Medical records*

Values for HbA1c were collected one and two years subsequent to the diagnosis from the child's medical record-- the same value is also registered in the national quality registry, The Swedish Childhood Diabetes Registry, SWEDIABKIDS (2012).

## Instruments

### **The PedsQL™ Family Impact Module**

The PedsQL™ Family Impact Module was developed based on already existing instruments and was designed as a parent proxy-report instrument ( Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004). Parents, mostly mothers, of 46 children with complex chronic health conditions participated in developing and testing the instrument.



The instrument measured the parents' self-reported HRQOL and consisted of 36 items divided into three main scales: parental HRQOL summary score [including physical (6 items), emotional (5 items), social (4 items) and cognitive (5 items) functions], family summary score [including daily activities (3 items) and family relationships (5 items)]. It also measured communication function (3 items) and worry (5 items). A 5-point Likert scale was used (0=never a problem to 4=always a problem) and the score was transformed to a 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0), so higher scores indicate better functioning. The main scales were calculated to a sum and then divided by the number of items answered (which accounts for missing data). If more than 50 per cent of the items in a scale were missing, the scale was not computed.

The internal consistency reliability of the scale was analysed with Cronbach's alpha. Scales with alpha values of 0.70 or more are recommended (Streiner & Norman, 2008). The results for the instruments internal consistency reliability reached or exceeded the recommended limits (Varni, Sherman, et al., 2004).

The instrument was translated into Swedish and piloted tested in 103 adults, parents or relatives who accompanied the child to the diabetes clinic. The instruments total Cronbach's alpha was 0.97 with a distribution from a minimum of 0.74 to a maximum at 0.95 for the subscales (Tiberg & Hallström, 2009).

### **The PedsQL™ 3.0 Diabetes Module Scale**

The PedsQL™ 3.0 Diabetes Module Scale was developed following the methodology of Pediatric Quality of Life Inventory™ (PedsQL™) (Varni, Seid, & Rode, 1999) and was developed by reviewing literature and individual and focus groups interviews with patient and parents (Varni et al., 2003). The instrument measures diabetes-specific HRQOL and is used both as an age-specific child self-report and as a parent proxy-report, see Table 4. It consists of 28 items divided into five scales: diabetes symptoms (11 items), treatment barriers (4 items), treatment adherence (7 items), worry (3 items) and communication (3 items). The instruments are scored on a 5-point Likert scale (ranging from 0 =never to 4=almost always) except the PedsQL™ 3.0 Diabetes Module Scale for children aged 5-7 years who have a 3-point Likert scale (0=never, 2=sometimes and 4=almost always). The items are reversed and transformed to a 0-100 scale where higher scores indicate a better HRQOL.

The child self-reported and the parent proxy-report scales exceeded the reliability standard of a Cronbach's alpha of 0.70 (Varni et al., 2003).

The instrument was translated into Swedish and piloted tested in 2008 and 2009. Both the self- and proxy reports reached a satisfactory reliability with Cronbach's alpha at or above 0.70 (Sand, Kljajic, Schaller, & Forsander, 2012).

## **The PedsQL™ Healthcare Satisfaction Generic Module**

The PedsQL™ Healthcare Satisfaction Generic Module was developed following the methodology of Pediatric Quality of Life Inventory™ (PedsQL™) (Varni et al., 1999) and from literature review, focus groups interviews and individual interviews. The instrument has also been tested on staff and parents in the target populations (Varni, Burwinkle, et al., 2004; Varni, Quiggen, & Ayala, 2000).

The instrument consisted of 24 items (total score) divided into six scales: information (5 items), inclusion of family (4 items), communication (5 items), technical skills (3 items), emotional needs (4 items) and overall satisfaction (3 items). A 5-point Likert scale ranging from 0=never to 4=always and not applicable are used. The items were linearly transformed to a 0-100 scale, and higher scores indicated higher satisfaction. The scales were computed as the sum of the items divided by the number of items answered (accounts for missing data). If more than 50per cent of the items were missing respective subscales were not computed.

The internal consistency reliability, for this instrument scales, measured by Cronbach's alpha ranged from 0.82 to 0.97 with an averaging of 0.92 for parents which supports the instruments reliability (Varni, Burwinkle, et al., 2004).

The instrument was translated into Swedish by a native Swedish speaking nurse with knowledge in English and then reverse-translated by a native English speaking person. Two different versions were compared and assessed by the translators and a professor in nursing care and while some words had been changed, the meanings of the questions were the same (Törnqvist, 2010). A modified version of the instrument used in a study by Törnqvist, Månsson and Hallström (2014) was tested in a Swedish population of parents to children with brain tumours. According to the parents the instrument was easy to understand and to complete (Törnqvist, 2010).

## **Diabetes Family Behavior Scale (DFBS)®**

This particular instrument was developed for children out of a series of pilot interviews completed with adolescents with type 1 diabetes and in the beginning it contained 60 items. DFBS measures diabetes-specific family behaviours, helping or hindering children following the diabetes medical regime (Waller & North, 1988). The 60 items measured three areas of support: guidance-control, warmth-caring, and problem-solving behaviours.

Initially the 60 item instrument was administrated to 38 persons with type 1 diabetes. Reliability, test (ranged from Cronbach's alpha 0.50 to 0.82) and retest (ranged from Cronbach's alpha 0.51 to 0.83) was acceptable and the subscales guidance-control and warmth-caring were found to relate significantly to HbA1c (Waller et al., 1986). After this the test group was expanded to 89. A significant

negative correlation was then found between HbA1c and a total score on a 15 item subset of DFBS (McKelvey et al., 1989).

The study was further expanded for testing the instrument and 321 children between 7-18 years of age attending a summer camp for children with type 1 diabetes was included (McKelvey et al., 1993). To further develop the scale, the group of children was divided into two subgroups. One group was used to examine the correlation of each item in the total DFBS score and each subscale score. In order for the item in the subscale to remain in the revised instrument the item had to pass the following: a good chance to correlation ( $p < 0.05$ ) with the subscale and have a better correlation to hypothesized subscale or with another subscale to be remained in the instrument. In the revised instrument, 47 items remained divided into two subscales: guidance-control (15 items) and warmth-caring (15 items). In the other half, the group of children was used to test the internal consistency and reliability for the revised 47 item instrument. The Cronbach's alpha was for the total DFBS score 0.86, guidance-control 0.81 and warmth-caring 0.79.

The instrument has a 5-point Likert scale (ranging from 1=all the time to 5=never) and 29 of the items are reversed as follows; 1 becomes 5, 2 becomes 4, 3 remains the same, 4 becomes 2 and 5 becomes 1. A good metabolic control is assumed to provide a higher score in diabetes-specific family support (McKelvey et al., 1993).

The instrument was translated according to the guidelines by Streiner and Norman (Streiner & Norman, 2008). A forward-backward translation was conducted by an interdisciplinary group including physicians, nurses and psychologists at the children's diabetes practice at The Queen Silvia Children's Hospital, and Sahlgrenska University Hospital, both located in Gothenburg, Sweden as well as a licensed translator. The material is not currently published.

## Data analysis

### Theoretical Framework

The theoretical framework (Paper I and II) is based on the philosophical theory "*The Logic of Care*" by Annemarie Mol (2008) from the Netherlands. The theory has a family focused perspective and is primarily, developed for adults diagnosed with type 1 diabetes, however Mol points out that the theory deserves to be tested in other contexts. According to Mol, good care has little to do with "patient choice" and infers that good care is something that grows out of collaborative attitude as well as a want to adapt knowledge and technology with respect to a sick body and complex life.

The standard of individual choice in health care, as it is advocated in health care laws in Europe and Sweden today, is to change from a formerly dominant view. This implies that when a patient meets the doctor, the doctor observes, examines and prescribes different tests to the patient without listening to him or her. In order to be able to make choices, that may have a critical effect on the patients' lives when being affected by a disease, the patients need to be heard and respected as individuals. Furthermore, Mol (2008) means that if a person has just been diagnosed with, for example diabetes, it is most likely that the person is scared and confused, and therefore, in that situation would like the healthcare staff to make the choices for him/her. According to Mol it is important that the patient immediately is involved in the practical measures of which the treatment consists. This is a concept infused with what Mol calls the "logic of choice". In healthcare practice, patients are not passive, instead patients are active in all kinds of activities. The logic of care includes the activities with which the patient is engaged. The professionals need to be open with the patient and share with them the crucial and substantive issues such as knowledge about the treatment of type 1 diabetes in order to help them create a good life in spite of their disease. Topics that are also important to address are how one can live well and learning about what can be fatal depending on the disease involved (Mol, 2008).

The theory includes terms that will guide how the logic of care and the logic of choice are to be applied in practice, i.e. patientism, doctoring, shared doctoring, activity, sensitivity and individuation. This is described and applied to children diagnosed with type 1 diabetes and their family in the descriptions below.

*Patientism* is a term that means that the professionals motivate the patients to recognize their body's signals for wellbeing and sickness. The child and their parents have to be aware of what is happening in the child's body and to respond and adapt to what is happening. Every family's lifestyle and values are taken into consideration from the professionals' views so they together with the child and family can explore ways to achieve a good life despite the child's fragile body.

*Doctoring* means that the professionals interact with the child and family, but it is the family who must control the teaching of diabetes and how the treatment will be implemented. What happens in the child's body when the body is affected by diabetes is something that the child (depending on age) and their parents must understand, as well as how diabetes is generally managed. Depending on the child's age, the child diagnosed with type 1 diabetes or their parents need e.g. to inject the insulin, measure the blood glucose level, and count the carbohydrates the child eats, as well as adjust the nutrition to the child's exercise. The professionals show the patient a great commitment by paying attention to the child and their family's emotional reactions. This requires an understanding of the difficulties that the family may feel they have in their daily live with regards to the child's diabetes. Doctoring means that the teaching is fully adapted to the both the child's and parent's needs.

*Shared doctoring* means an open and honest communication between professionals and family, where the family members communicate the stress and strains the disease brings to them in their daily lives and the professionals adapt their knowledge to the child's individual life. All persons involved (the diabetes team, the child and their parents in the care) must respect each other's experience of the child's disease, while being committed, creative as well as careful in their explorations. Through discussion and negotiation the professionals and the family try to find solutions for the individual family in need.

*Activity* characterizes the child and their parents' involvement in the care. The child and family are active, i.e. the body is active in that the child is feeling thirsty and drinks a lot. The doctor asks how much the child has drunk and the parents then give an answer such as "three litres a day". The doctor then interprets these answers as the symptoms of diabetes or not. The child is active by giving blood and urine to be tested. The child and their parents cooperate with the diabetes team by observing what is done, by asking questions, listening and performing the care needed.

*Sensitivity* means that the child and their parents must train the child to be sensitive to their body so they can actively balance the energy they need with the amount of insulin they inject. Such intro-sensing is an intriguing skill that can be taught. The sensitivity is about making the child and their parents aware of, and helping them understand, how they can appreciate the blood glucose value by learning how the child's body works at low blood glucose levels, such as with dizziness or irritation that often accompanies these phenomena as symptoms. It is also about discovering, on the child's part, how to measure so that technologies, habits, etc. are adjusted to the family's life.

*Individuation* means that a person with type 1 diabetes must learn to become a special person. In the logic of care this is about being an ordinary person yet having the personal courage to be different in this new situation. The PDSN has an important role in supporting the child diagnosed with diabetes, and encourages behaviours such as when the child or parents stand up for child's life. The family with a child with diabetes should feel unrestrained, but because a person with type 1 diabetes always must keep their food intake, activity and insulin doses in mind, they can never be completely free. It is about choosing to participate in a social life despite the disease.

## **Content analysis**

Qualitative content analysis has a focus on construed texts and is often used in behavioural science and nursing research. The method is useful for different types of texts and the interpretation can be made on different levels and is therefore useful in many research areas (Söderberg & Lundman, 2001). Content analysis can be used in both an inductive and a deductive way. When inductive analysis is used

the text is analysed without prejudice and the transcribed text is based on the individuals' experiences that emerge during the interviews. When deductive analysis is used, the analysis is based on a model or theory (Lundman & Hällgren Graneheim, 2008). The reason for using a deductive content analysis is to extend or validate a theoretical framework (Potter & Levin Donnerstein, 1999). Content analysis guided by a deductive approach is a more structured process than content analysis guided by an inductive approach (Hickey & Kipping, 1996).

## **Inductive analysis**

All interviews in Paper I were transcribed verbatim, three by the author of this thesis (LJ) and one by a secretary. The texts of the transcribed interviews were read repeatedly by all authors, in their entirety, in order to achieve an overall picture of the content and a naïve understanding. After this the text was divided into "meaning units" and later on condensed in order to capture the meaning in each unit. In the next step the condensed meaning units were coded and codes with similar content were amalgamated. After this, the codes were sorted into sub-categories and categories, based on similarities and differences. Each interview text then was read again to confirm that all texts relevant for the purpose were included in the categories and subcategories which constituted the manifest content. In the next step all the authors discussed and reflected upon the tentative categories in order to find the latent content. The latent content of the categories was finally formulated into a main theme and sub-themes (Graneheim & Lundman, 2004).

## **Deductive analysis**

The transcribed interviews in Paper II were read to get a first overall impression of the text. This step was used to make sure that all possible occurrences of the phenomenon was identified (Hsieh & Shannon, 2005) i.e. the educational process when a child in the family was newly diagnosed with type 1 diabetes. In the next step in the analysis the meaning units were condensed, and passages and the predetermined terms of Mol's (2008) philosophy in "The Logic of Care"; (patientism, doctoring, shared doctoring, activity, sensitivity and individuation) were highlighted. The encoded text from each different interview was summarized under each term and read repeatedly to make sure that the content was accurate in accordance with the meaning of Mol's terms. Two of the authors (LJ and AL) analysed the data separately and, after discussion and minor modifications, all of the authors agreed on the interpretation. Finally, the interviews were read again to confirm that all relevant texts were included.

## **Statistical analysis**

The software IBM SPSS<sup>TM</sup> for Windows (version 20.0; 21.0) was used in the statistical analysis of this study. In Paper III and IV descriptive statistics were used to present the child's and parents' demographic data and the child's HbA1c after one and two years, respectively. Data was normally distributed and therefore the independent t-test was used for comparisons between groups (mothers and fathers) and the paired t-test was used when assessing differences over time for groups (mothers and fathers). One-way analysis of variance (ANOVA) was used (Paper III) when comparing differences between more than two groups, children in different age groups and their parents. In Paper IV, Pearson correlation was used to investigate the correlation between DFBS<sup>®</sup> and HbA1c, on an individual level. P-values of <0.05 were considered statistically significant in all analysis.

# Pre-understanding

Our previous knowledge about a specific phenomenon can be referred to as our pre-understanding and it is important to be aware of this throughout the entire research process. Reflections about pre-understanding can be carried out together with others, which might prove to be useful since pre-understanding can be more obvious to other people than it is to oneself. (Nystrom & Dahlberg, 2001).

In order to minimize the risk of bias in Paper I and II, the author's pre-understanding was reflected upon and discussed throughout the whole process. The author of this thesis has more than 25 years experience as a registered paediatric nurse working with children and their families albeit not in the context of diabetes care. IH, AL and PL have all been registered paediatric nurses for more than 35 years ago and have extensive experience in research with children and their families as well as in qualitative research. IH and PL have experiences working with quantitative data.



# Ethical considerations

The studies (Paper I-IV) were conducted according to the Helsinki declaration (2013), which entailed that the participants were given information about the purpose of the study, time commitment, confidentiality, the volunteer nature of the study, as well as the right to discontinue participation at any time; informed written consent was obtained. The studies were described in Paper II, III and IV was approved by the Research Ethics Committee of the Medical Faculty, Lund University, Sweden (2007/305, 2009/371). Since professionals who are asked to answer questions related to themselves and their own profession do not fall under the Swedish Law regarding Ethical Testing in Research, referring to humans (Swedish Law about testing in Research to human beings, 2003:460), approval from the Research Ethics Committee was not applied for in Paper I. Permission to perform the studies was obtained from the chief physician at all hospitals involved.

The inclusion of children and parents in the study (Paper III and IV) were carried out at a time when children and parents were in a vulnerable life situation. The responsible DSP or PDSN gave the family verbal information about the study during the first few days after the child's diagnosis and were asked if the researcher would be allowed to come and give further information about the study. If the family agreed, the researcher came to the hospital and informed the parents and the child both verbally and in writing. The families were offered the time they needed to come to a decision to participate or not. Giving informed consent entails that the individual has the necessary information to understand the implications of participation in a study as well as the time commitment necessary and is thereby able to reflect on participating with the assurance that participation is voluntary (Beauchamp & Childress, 2013; Helsinki Declaration, 2013). All participants over the age of 12 were given written and verbal information about the study and were informed that they could terminate their participation at any time without further explanation.

Justice considered, all families that spoke and understood some Swedish were asked to participate (Paper II-IV). When the interview study regarding the parents was designed, an access to a professional interpreter was provided if needed (Paper II). However, there were no parents eligible for recruitment that did not speak or understand Swedish. In Papers III and IV some parents had a non-Swedish background and when necessary, the author of this thesis helped the parents explain the meaning of a word or questions found in the questionnaires.

Children under the age of 12 were verbally given age specific information and gave their assent according to the Helsinki Declaration (2013) (Paper III and IV). Parents were reassured that if they chose not to participate or even interrupted their participation that this would not affect their child's care and treatment (Paper II-IV). All participants were guaranteed confidentiality. No identification was included in the transcribed interviews (Paper I and II) to minimize any possible connection to any one person. Questionnaires (Paper III and IV) were coded and linked together. The author of this thesis who was not involved in the child's care distributed all questionnaires and kept the code lists separate from all material. All material (Paper I-IV) was kept in a safe and locked place and the code lists were only available to the researchers.

# Findings

The findings are presented under the following headings: *The education process at diagnosis* (Paper I and II), and *The disease impact on the family* (Paper III and IV).

## The education process at diagnosis

### **At admission**

The diabetes teams, consisting of DSPs, PDSNs, a dietician, a social worker and/or a psychologist described that the educational process started as soon as the family was admitted to the hospital. Their aim with the educational process was to prepare the family for leaving the hospital, described as the overarching theme, achieving adherence to self-care (Paper I). The focus was on teaching the child and family about monitoring blood glucose levels, administering insulin and in what ways diet and activities could affect the body.

The parents felt that the professionals were knowledgeable and calm and immediately took care of the child when they entered the paediatric hospital (Paper II). The parents described that they were in shock and usually had no previous experiences of type 1 diabetes. They expressed a feeling that everything happened suddenly; the therapy was initiated and appointments were made with the diabetes team. This was a source of confusion for the parents but it also gave them a sense of security as described by Mol as *patientism* (Paper II).

### **During hospitalization**

By creating knowledge through practice, the DSP and the PDSN described that they tried to get the family members to focus on the diabetes management education by taking an active part in the child's care. The PDSN tried to strengthen the family and deepen their understanding of the disease based on the family's own questions. The professionals used a checklist for information, teaching and demonstration, as well as for the practical skills children and parents needed to learn (Paper I).

The diabetes teams described that the goal of the DSP and the PDSN was to establish a relationship based on a two-way communication with parents and the child in the early stage of the disease to create a desire among the parents and children to become cooperative partners. Both parents and siblings were encouraged to stay at the hospital to acquire knowledge and to learn about type 1 diabetes. The diabetes team members described that it was regarded as important to establish a trusting and long-lasting relationship between the family, the DSP and the PDSN. They described that the family often had shorter or longer appointments with the social-worker, psychologist and dietician who informed about help and support during the hospitalization and if needed in the future. For example, the parents described that they appreciated that the dietician accompanied them to the grocery store to discuss the family's food habits and give them suggestions on foods that suited their particular family. (Paper I).

The diabetes teams believed that the instructions about type 1 diabetes was to some extent tailored to each family's individual needs and to the child's age with the aim of capturing the diversity of the whole family (Paper I). They described that there was no fine line for when the child was able to participate in his/her own care, but most children around the age of ten years wished to take part in their own care. For teenagers the focus of training was on themselves but the parents still had the primary responsibility. For the non-Swedish speaking immigrant families, it could sometimes be difficult to give the knowledge and skills about the disease that they needed because the time available with an interpreter was sometimes described by the diabetes teams as too short for the families to learn at their own pace.

The education was experienced by the parents as "intense with almost an overload of knowledge", especially when the child was not present (Paper II). The parents felt that the DSP and PDSN had knowledge, extensive experience in diabetes care and a strong commitment in teaching the family what had happened in the child's body and what the body needed, precisely described by Mol as *doctoring*.

The parents experienced that the professionals at the ward and the PDSN taught them and their child to take care of practical things, such as taking blood glucose and giving/taking insulin injections (Paper II). The professionals injected the child with insulin either until the time he/she felt ready to inject him/herself or the parents were ready to give the child the injections. Parents often took the blood glucose and injected insulin to younger children as described as *activity* by Mol (Paper II).

Parents described that they felt that compassion and caring permeated their hospital stay but they were shocked and saddened by the news that their child had a chronic disease (Paper II). There was no time for grief and the parents only let their tears come when they were alone. Both mothers and fathers expressed disappointment that there was no time allotted for the grief and shock during hospitalization. This is described as *sensitivity* by Mol.

## Transition to home

Achieving practical knowledge and skills by the medically unskilled family was described by the diabetes team as a challenge. The family, having thorough information and instruction, gained an insight into situations that could arise for a child suffering from type 1 diabetes and had learn to apply their knowledge even when they did not fully understand the ramifications of what they were doing (Paper I). In order to let the family test the new knowledge, they went home for shorter and longer leaves, first for only a few hours at home to be successively extended to a weekend at home. To try to obtain an overall picture of the family, the diabetes teams described that the DSP and the PDSN observed the family's non-verbal communication, i.e. the parents' body language and how secure the parents and the child appeared to be in using the knowledge and skills they had been taught. The PDSN prepared the parents for discharge and informed them that she was available on the phone during daytime and the staff on the ward could be reached nights and during weekends if any problems arose. Parents described that after having been in hospital for approximately a week they longed to go home. Even if they did not feel that they had the child's diabetes care totally under control they felt ready for discharge (Paper II). This is described as *shared doctoring* by Mol.

Parents expressed that it was important to regularly keep the times and procedures decided upon with regards to diet, insulin and different activities, so they brought the routines they learned at hospital home with them (Paper II). This implied an immense change in the social situation of the families. The parents also experienced a sorrow that they could no longer do things spontaneously in their family because everything had to be planned in advance. The parents expressed that they wished for more active advice about how to live their lives at home. They all struggled with the idea of being a good parent, both in terms of managing the child's diabetes but also with regards to helping the child to continue with a normal life as much as possible, in spite of the diabetes. This could be described as *individuation* according to Mol.

## The disease impact on the family

Parents' HRQOL were significantly different both at the time for the child's diagnosis ( $p=0.003$ ) and one year later ( $p=0.041$ ). Mothers reported a lower HRQOL than fathers at both occasions (Paper III). After two years mothers still reported a lower HRQOL (69.13) than fathers (74.93) (Paper IV). Mothers reported significantly more problems in physical ( $p=0.022$ ), emotional ( $p=0.001$ ), social ( $p=0.035$ ) and cognitive ( $p=0.013$ ) functions than fathers at the time of their child's diagnosis. Problems in emotional functioning still remained for mothers

compared with fathers after one ( $p=0.007$ ) (Paper III) and two years ( $p=0.011$ ) (Paper IV) respectively. At the time for diagnosis and after two years, mothers reported significantly more worry than fathers,  $p=0.004$  respectively  $p=0.035$  (Paper III-IV). Mothers also estimated a higher degree of problems with the family daily activities at diagnosis ( $p=0.004$ ) and during the first year after the child's diagnosis ( $p=0.007$ ) than fathers (Paper III). However, two years later, no significant differences were reported between the parents (Paper IV). One year after the child's diagnosis, mothers reported a higher degree of communication problems compared to fathers,, such as talking to others about the child's disease ( $p=0.010$ ). Mothers also estimated a higher impact on the family than fathers during the first year after their child's diagnosis ( $p=0.033$ ) (Paper III).

Children over the age of five and their parents experienced the child's HRQOL differently according to diabetes-specific questions one year subsequent to the child's diagnosis. For children under the age of five, mothers experienced their child's HRQOL lower than fathers with a significant difference surrounding the child's diabetes symptoms ( $p=0.006$ ), the treatment adherence ( $p=0.022$ ) and the overall diabetes-specific HRQOL ( $p=0.003$ ). No other significant differences were reported between the parents. Fathers reported a significant higher degree of worry ( $p=0.008$ ) than the children in the age group between 5-7 years. In the two oldest age groups (8-12 and 13-18 years), children estimated a significant higher degree of treatment adherence than their mothers ( $p=0.011$  respectively  $p=0.039$ ). Children aged 8-12 years estimated their diabetes-specific HRQOL lower than their fathers (0.028). Both children between 5-7 years and their parents estimated a higher degree of worry than children and parents in the other age groups ( $p=0.037$ ) (Paper III).

Two years subsequent to the diagnosis there were no significant correlations between the HbA1c and how children over the age of eight experienced diabetes-specific family support (DFBS total score) ( $r=-0.19$ ,  $p=0.24$ ). There were also no correlations between children's HbA1c and family support, neither in the subscales guidance-control ( $r=-0.19$ ,  $p=0.23$ ) nor warmth-caring ( $r=-0.22$ ,  $p=0.18$ ). However, in the results there was a clear outlier found and when this was removed, a significant correlation between HbA1c and warmth-caring was found ( $p=0.031$ ) (Paper IV).

Parents were satisfied with the child's healthcare both at diagnosis and after one and two years subsequent to the child's diagnosis. There was no significant difference between mothers and fathers overall satisfaction (Paper III-IV). However, mothers reported significant lower satisfaction than fathers concerning emotional needs both after one year ( $p=0.039$ ) (Paper III) and after two years ( $p=0.012$ ) (Paper IV).

# Discussion

## Methodological Considerations

There are two different research methods to structure a study and to analyse the information – a qualitative or a quantitative approach. In both approaches the quality of the study needs to be evaluated. In qualitative research the quality is often evaluated by trustworthiness including: credibility, dependability, confirmability and transferability (Lincoln & Guba, 1985). Corresponding terms in quantitative research are validity and reliability (Polit & Beck, 2012).

### Trustworthiness

*Credibility* refers to confidence in the truth of data and the interpretation of the data. This includes how credible the data and conclusions are by considering how the contexts and participants have been chosen, and also how the analysis is carried out (Polit & Beck, 2012). Three different paediatric hospitals, one university hospital and two county hospitals in the southern part of Sweden were included to obtain variation in the selection in Paper I and II. The recruitment of members to the focus group interviews with each diabetes team was conducted by one of the PDSNs in each team. This could have affected the interview situation since team members might have felt obliged to attend when they were asked to participate by some colleagues in the team. However, the professionals that participated in the focus groups interviews all have had long or very long experience within the area and working in teams. This anticipates that they have been able to speak freely about the initial educational process when a child is diagnosed with type 1 diabetes. In order to obtain a variation all parents of children who were diagnosed with type 1 diabetes during the interview period were consecutively asked to participate (Paper II). A total of 14 families were asked, and 18 parents in 10 families accepted, to be interviewed. The families come from both rural and urban areas; 16 parents were cohabiting and 17 parents lived in their own homes; this heterogeneity in the group supports the credibility.

It is important to investigate everything in a timely manner in an interview to build up a trust between the interviewer and the interviewee (Fontana & Frey, 1994). Before each interview started there was time allotted for some “small talk”

in order to overcome any form of discomfort that can occur for both interviewer and respondents.

In order to create a more dynamic interaction, the recommendation when using focus groups should be that the participants do not know each other prior to the first interview (Krueger & Casey, 2000). In the everyday work of diabetes teams the members are used to sharing their experiences and to be influenced by each other, and so the group interviews (Paper II) seemed to be a natural way of establishing a communication built on trust. However, it also raised a challenge during the interviews since they already knew each other well. Another challenge was the number of participants in the groups. There was a variation between three to six persons in the different focus groups compared to the recommendation by Krueger and Casey (2000) which was five to ten participants. In smaller groups it can be easier to share ideas but it can also be a smaller pool of ideas (Krueger & Casey, 2000). During the interviews the moderator was observant of both verbal and non-verbal communication in order to make sure that everyone in the group was able to express his/her own opinion (Krueger & Casey, 2000). Furthermore, a small group that already know each other can limit the group dynamics (Reed & Payton, 1997) and that was sometimes obvious (Paper I) when each profession described their work with the child and family while the others were more or less silent.

To increase the credibility in Paper II, two interviewers collected individual data from both parents in the family at the same time. The parents were interviewed separately so as to minimize the influence of the partner's experiences. Earlier studies (Dashiff, 2003; Hatton, Canam, Thorne, & Hughes, 1995; Leonard, Kratz, Skay, & Rheinberger, 1997) showed that there are different opinions about fathers' engagement in their child's diabetes management. Fathers are usually not the primary caregiver of the child's daily care. Their contributions to the family are often based on their knowledge and views on the diabetes management. This behaviour may be associated with the disease management outcomes (Dashiff, Morrison, & Rowe, 2008).

To increase credibility in the analysis process in Paper I and II, one experienced researcher and also a co-author (who did not take part in the interviews) participated in the entire analysis process. Furthermore, to get validation by experts (Lincoln & Guba, 1985), the article manuscripts were discussed and reviewed in a research group consisting of doctoral students, and junior and senior researchers in different areas of research.

*Dependability* refers to the stability of data over time and across conditions (Polit & Beck, 2012) and is achieved by others examining the materials to see whether the research process can be followed (Tobin & Begley, 2004). Therefore, the research process in Papers I and II are described as precisely as possible. During the interviews probing questions were used by the interviewer for clarification to ensure an understanding of the experiences described. In order to increase dependability, the findings in both Paper I and Paper II have been



discussed during several collaborative meetings with the co-authors and also in research seminars with both junior and senior researchers.

*Confirmability* refers to the objectivity of data and interpretations (Polit & Beck, 2012) rather than the researchers own construction. This risk was reduced in the studies (Paper I and II) by the fact that several researchers with different backgrounds participated in the analysis process. Furthermore, the results are presented with quotations from the diabetes team (Paper I) and from both mothers and fathers in Paper II to reveal the interpretations of the text.

The theory by Mol (2008) used during the analysis in Paper II is grounded in the idea of outpatient care for adults with type 1 diabetes and has, to our knowledge, not previously been used in a paediatric setting. However, the theory is discussed by Alftberg and Hansson (2012) in the context of self-care within the healthcare system as a whole. Mol points out that even if the theory is used in one context, it can be used in others. When shifting to other sites and situations, the theory can be translated, some aspects can remain the same while others will change. The theory is to be used actively and can be used in order to explain the educational process and make it more easily understood by the involved professionals when a child is diagnosed with type 1 diabetes. According to Hsieh and Shannon (2005), there is a risk using a theory through the whole research process because it might increase the risk to find evidence that only supports rather than detracts from the theory. Furthermore, the researcher can ask questions in a way that the participants only answer in a certain way to please the researcher. Another potential risk is that the researcher becomes blinded by the theory and cannot see the contextual data. The interview questions in Paper II are not based on Mol's theory; they are rather based on earlier results from focus groups interviews with paediatric diabetes teams (Paper I). This can increase the confirmability (Lincoln & Guba, 1985). However, more research is needed in order to know whether or not it is beneficial to use this theory in a paediatric setting.

*Transferability* refers to whether or not the findings can be transferred to other groups or settings than those studied (Polit & Beck, 2012). Parents of children who had received the diagnosis of type 1 diabetes were interviewed in Paper II. Most of these parents were Swedes living in private houses in smaller or larger cities. Since geographical and cultural constraints, as well as socioeconomic statuses affect the parenting of a child with a chronic disease (Singer & Ryff, 1999), our results might need to be further discussed before they could be transferred to another context. Also in Paper I, the transferability can be further discussed because of different treatment regimes, as in or outpatient care associated with the initial education process can be experienced differently by the various professionals.

## Validity

Different diabetes-specific instruments were used to investigate the impact on the child and their parents after the child was diagnosed with type 1 diabetes at three different time points, at discharge from the hospital, and after one and two years subsequent to the child's diagnosis (Paper III and IV). Because of an error in the study protocol, the first ten families at the two year follow-up were not given the opportunity to fill in the diabetes-specific questionnaire (The PedsQL™ 3.0 Diabetes Module Scale). This was taken into consideration, and after some discussion, it was decided not to use the data from the PedsQL™ 3.0 Diabetes Module Scale questionnaire in Paper IV. This management can of course be discussed further. Perhaps it would have been better to use the reduced data since it provided a comparison between one and the two year follow-ups.

The internal validity refers to whether the conclusion that is reached in a quantitative study is credible or not, and also to aspects regarding instrument choice and attrition (Polit & Beck, 2012). Selection bias is the most common threat to internal validity. It refers to whether the study population is representative or not (Kazdin, 2010). In Paper III and IV parents of children under the age of three and over the age of 16 were excluded. This can be discussed, especially concerning parents to the youngest age group (between 0-5 years) because type 1 diabetes is still increasing in this age group (Dahlquist & Mustonen, 2000). It is also a limitation that only parents that could speak and understand the Swedish language have been included because an early study showed that immigrant children and their parents require special approaches to bridge the gap owing to culture and tradition differences and the management of diabetes (Povlsen, 2008).

Internal validity can be threatened by the issue of instrument choice and attrition (Kazdin, 2010; Polit & Beck, 2012). Polit and Beck (2012) express that a change in the measuring instrument or the measurement procedure over time could bias the results. In both Paper III and IV the instrument and the structure over time were decided in advance to minimize the risk for bias in instrumentation (Kazdin, 2010).

There was a long inclusion period for Paper III and IV and there is a risk that the diabetes management changed a bit during this time and this unfortunately was out of our control (Polit & Beck, 2012). According to Kazdin (2010) and Polit and Beck (2012) attrition, otherwise known as loss of subjects, is a risk especially when the period between data collection points is long. A follow-up after 12 months of participants implies a higher risk of attrition than a one month follow-up (Polit & Gillespie, 2009). In both Paper III and IV the internal and external dropouts at the one and two year follow-up were relatively small. The internal dropouts varied from four to eight per cent amongst the different instruments. The external dropouts included five children and their parents between the time of diagnosis to the one year follow-up and four children and their parents between the one and two year follow-ups. One reason for the small internal and external

dropout in Paper III and IV could be that the author of this thesis met almost all children and their parents at all three data collection time points and was available for questions if any arose. Furthermore, if the children needed help with reading the questions the researcher facilitated them.

The choice of instrument was based on literature and earlier experiences of using some of the instruments in a Swedish context. Instruments can be evaluated for the internal consistency and the most used method for evaluating this is Cronbach's alpha (Polit & Beck, 2012). All instruments were psychometrically tested with satisfactory values and that increase the reliability. One of the instruments, Diabetes Family Behavior Scale (DFBS)<sup>®</sup> (McKelvey et al., 1993), was psychometrically tested (unpublished data), but to our knowledge the instrument has not earlier been used in a Swedish context. However, children over eight years of age who filled in this questionnaire had no problems to complete the questionnaire which indicates that the questionnaire was understandable and easy to complete (Paper IV).

The external validity in quantitative studies refers to what extent the results of a study can be generalized to another population and setting. The external validity can be affected by the internal validity (Kazdin, 2010). In Paper III and IV children between 3-15 years of age newly diagnosed with type 1 diabetes and their parents were asked consecutively to participate at two different paediatric settings in the southern part of Sweden during approximately three and a half years. A consecutive sample reduced the risk of bias, even if the data collection period was longer and reflected seasonal fluctuations. The variation of, for example, education levels, ethnic and socioeconomic backgrounds rises when the participants come from multiple sites (Polit & Beck, 2012). In this longitudinally completed study, two different hospitals with different catchment area were used and therefore a better representation of the population has been obtained and this increased the possibility of variation in the data (Paper III and IV).

## General Discussion

The overall aim of this thesis was to contribute to the knowledge of the initial diabetes education process, to illuminate the impact on children and their parents' and parents' satisfaction with the care received at the time of diagnosis, one and two years subsequent to the child's diagnosis.

Both the diabetes teams (Paper I) and the parents (Paper II) described the time after a child is diagnosed with type 1 diabetes as intense. Parents need to learn, in a relatively short period of time, how to handle both the knowledge and skills surrounding how type 1 diabetes affects the child's body and life. According to Mol (2008) (Paper II) it is important to meet the parent at his/her level of knowledge and experience of the disease. This is also the intention of the diabetes

teams (Paper I). The diabetes teams described how they asked questions about the families' lives and how they tried to be engaged in every family on an individual level. In the period after their child's diagnosis, parents described (Paper II) that they were in shock and found that the diabetes team followed the diabetes checklist and ticked off both theoretical and practical skills in a predetermined order which was not according to the family's needs and questions. Using a diabetes checklist is entirely in line with both national and international guidelines (Dahlqvist, 2008; Swift, 2009). However, the recommendation is that the families are to be given written information and a schedule that should be updated on a daily basis (Lemanek, Kamps, & Chung, 2001; Swift, 2009). If the families have access to the checklist, and the planning schedule is discussed and planned in co-operation with the family, the interdependence may increase.

The parents described (Paper II) that they were given a good reception and care during the hospitalization. They also felt that they could rely on the professionals' knowledge and experience in diabetes care. This is in line with an earlier Swedish study by Wennick and Hallström (2006). Also Mol (2008) describes that this is important since the motivation to acquire knowledge starts when the patients feel a commitment on the part of the professionals. Parents described (Paper II) that during the time at the hospital there was no time for them to express the sorrow they felt. Mol (2008) also describes that the sorrow must be put aside since the parents need to focus on how to learn about taking care of the sick child. The sadness the parents describe they experienced had to be kept inside since they did not want to cry and feel sad in front of their child (Paper II). Furthermore, mothers reported more emotional problems than fathers at the time of the child's diagnosis and also at the one and two year follow-ups (Paper III and IV). This might be a result of that the parents must put their sorrow and sadness aside at the time of the child's diagnosis. In this time of psychosocial transition it seems to be especially the mothers that are in need of increased emotional support. These results are in line with a qualitative study by Lowes, Gregory and Lyne (2005) who interviewed parents 10 days after their child's diagnosis and four and 12 months subsequent to the child's diagnosis. As a result the diabetes teams not only have to take care of the child but they also have to be aware of and look for symptoms of anxiety among the parents (Landolt et al., 2002; Streisand et al., 2008).

Interviews with the parents revealed that going to the grocery store with the dietician was a positive experience because the dietician discussed the family's food habits with them and guided them to different alternatives that suited them (Paper II). This is an example of when, according to Mol (2008), the family has an opportunity to open up and discuss their food habits with the dietician and together they can find alternative food that the family feels they can use in their daily family life. However, this was not discussed by the diabetes teams during the focus group interviews (Paper I).

The diabetes teams experienced that parents during hospitalization gained knowledge and insight about how they needed to take care of their child also in particular situations that could arise with a child suffering from type 1 diabetes, such as hypoglycaemia (Paper I). The parents often learned how to apply their knowledge without always fully understanding the consequences of what they were doing. To do, and to understand what one is doing, are two different things and this is fully understood by the diabetes team (Paper I). Before discharge the diabetes team checked the parents' skills regarding the child's disease by, for example, talking about the families' plans for the first week at home or by giving the parents a questionnaire to fill in and then having them talk through the answers with the PDSN (Paper I). The parents experienced that they saw this evaluation as being a good way of gaining insight into the development of their own thoughts and knowledge about type 1 diabetes (Paper II). This is also in line with other studies (Murphy, Rayman, & Skinner, 2006; Northam, Todd, & Cameron, 2006; Winkley, Ismail, Landau, & Eisler, 2006) that describe that it is important to evaluate the education with a focus on the goal of self-control, psychosocial adaptation and glycaemic control.

The families' experiences (Paper II) were that they took the hospital routines home with them. These routines were based on how often blood glucose testing should be done, and which doses of insulin and food should be given without taking into consideration the lifestyle of the families. Those families having difficulties adapting their daily lives to the child's disease (type 1 diabetes) after coming home have also been described in other studies (Eiser & Morse, 2001; Lowes et al., 2005; Wennick & Hallström, 2006). The families expressed a desire for the professionals to teach them how to live their lives at home in a way which embraced their new circumstances (Paper II). According to Mol (2008) this would mean that the parents should have raised this question with the diabetes team in an open manner so that they, together with the professionals, could have discussed the family's problems and reached a satisfactory solution for everyone included.

One year subsequent to the diagnosis, the group of children between 5-7 years and their parents felt a higher degree of worry in diabetes-specific HRQOL than the group of parents and children from 8-18 years (Paper III). This result differs from earlier results that showed that children between 13-18 years have a higher degree of worry in diabetes-specific HRQOL than younger children (Sand et al., 2012). However, in general, the parents estimated their child's diabetes-specific HRQOL was lower one year subsequent to the diagnosis than the children themselves (Paper III). These findings are consistent with other studies (Eiser & Morse, 2001; Kalyva, Malakonaki, Eiser, & Mamoulakis, 2011; Nansel, Weisberg-Benchell, Wysocki, Laffel, & Anderson, 2008; Sand et al., 2012). This disagreement in self-report and proxy-reports underlines the importance of collecting material directly from children and not relying only on proxy informants whenever possible.

At the time of the child's diagnosis and at a follow-up two years later, mothers reported significantly more worry than the fathers (Paper III and IV). What this worry among mothers manifests itself as is different for each individual mother, but it can come from an intensive mothering (Hays, 1996) in which mothers have the primary responsibility for the child's wellbeing and development. That mothers are more involved in their child's disease is also described in other studies (Azar & Solomon, 2001; Wennick & Hallström, 2007) and that fathers often use distancing as a coping strategy (Azar & Solomon, 2001). Earlier studies have showed that parents are frequently worried about hypoglycaemic episodes and long-term health problems (Bowes et al., 2009; Malerbi, Negrato, & Gomes, 2012; Peyrot, 2009).

Parents were overall satisfied with their child's healthcare both at the time of the child's diagnosis and at follow-up after one and two years after the child's diagnosis (Paper III and IV). Today there is increased evidence that greater satisfaction with health care services results in better treatment adherence and this leads to better health outcomes (Garratt et al., 2007; Schmidt et al., 2008). In a survey of 3299 families by Marino and Marino (2000) families reported that the most predictive signs of overall satisfaction were questions about the collaboration between nurses and parents. However, mothers estimated a lower satisfaction with emotional needs than fathers both one and two years subsequent to the child's diagnosis (Paper III and IV). Some earlier studies (Coyne, 2006; Coyne & Cowley, 2007; Lam, Chang, & Morrissey, 2006) have shown that honest, truthful and frequent communication from health care professionals means often being emotional support for parents.

# Clinical implications and future perspectives

The findings of this thesis gave insights in that both children and parents are affected, but in different ways when a child in the family is diagnosed with type 1 diabetes. Healthcare professionals may need to have more regular individual appointments to meet both the children and their parents' individual experiences and emotional needs during the years after the child's diagnosis. Another way to meet this need could be parental groups in which parents can connect and create networks with other parents who have had shorter or longer experiences of having a child diagnosed with type 1 diabetes.

To further explore mothers' emotional needs during the first years after their child is diagnosed with type 1 diabetes, more longitudinal studies are needed, especially qualitative studies. Today we have knowledge that mothers are emotionally affected at the time for their child's diagnosis and at one and two years subsequent to the diagnosis, but we do not know what it specifically consists of. Qualitative interviews might be one way to reveal what affects the parents emotionally and thereby providing knowledge to further individualize the care of the parents since their emotions and needs have an impact on the whole family.

Parents are overall satisfied with the child's care. However, they still experienced that they took the routines from the hospital back home with them, regardless of whether it fit the family's lifestyle or living conditions. This can perhaps be overcome through home-based care grounded in each family's individual needs. It is important to ask children and their parents early in the process about what skills and experience they have about type 1 diabetes, and to be able to continue building on their unique viewpoint of and knowledge of the disease. Home-based care has been evaluated to be equally safe as hospital based care at the onset of type 1 diabetes. This change in the initial care can also change how all family members are involved in the sick child's care in a more natural way. In further research it would be interesting to use mixed methods in a longitudinally perspective in order to get a more thorough understanding of the composition of how the diagnosis of type 1 diabetes in a child of the family impacted the other family members individually.

Currently when the hospitalizations at diagnosis are decreasing, home based care can be thought of as an alternative after a few days at the hospital. This is important to evaluate this change of care on an on-going basis. This change is not

only affecting children diagnosed with type 1 diabetes but it also affects their siblings and parents. Both qualitative and quantitative studies are needed to further develop this management style of diabetes care.

Last but not least it is important to ask the children and adolescents themselves to further elucidate how they experienced the received care at the time of diagnosis and the management of the disease during the first years after. Today few studies involve younger children, so it is especially important to ask children between 5-7 years about how they would like to be informed and involved in the diabetes education process.



# Summary in Swedish

## Svensk sammanfattning

Diabetes typ 1 är en av de vanligaste ämnesomsättningssjukdomarna i barndomen. I Skandinavien finns cirka 94 000 barn och ungdomar med diabetes typ 1 och år 2020 förväntas antalet vara cirka 160 000. Det övergripande målet för vården av barn och ungdomar med diabetes typ 1 är att de ska ha en god hälsa, ett socialt välbefinnande och en god livskvalité. När ett barn i Sverige insjuknar får barnet och närstående utbildning om sjukdomen under en till två veckors sjukhusvistelse i samband med barnets insjuknande.

Det övergripande syftet med avhandlingen var att belysa den inledande utbildningsprocessen när ett barn insjuknar i diabetes typ 1 utifrån både diabetes teamet och föräldrarnas perspektiv samt att beskriva hur sjukdomen påverkar barn och föräldrars välbefinnande över en två-års period. Ett ytterligare syfte var att undersöka föräldrars tillfredsställelse med barnets vård ett respektive två år efter barnets diagnos.

I den första delstudien genomfördes fokusgruppsintervjuer med diabetes team vid tre olika barnkliniker i södra Sverige. Analysen genomfördes med kvalitativ innehållsanalys. Diabetes teamen beskrev att familjens utbildning startar direkt efter att barnets diagnos är ställd med målsättningen att familjen ska vara väl förberedd för att kunna ta hand om och sköta barnets sjukdom vid utskrivning från sjukhuset. För att nå målet egenvård utgår diabetes teamet och personal på barnavdelningen från en checklista fokuserande områden som t.ex. hur och hur ofta blodsocker skall mätas, injektionsteknik samt hur mat och olika aktiviteter påverkar barnets välbefinnande. Inför utskrivning får familjen prova på att vara hemma genom permission från avdelningen, först under några timmar, sedan under en dag för att till slut sova hemma. Innan utskrivning utvärderas familjens kunskaper och behov av ytterligare kunskap samt hur de kan nå diabetes teamet för frågor efter utskrivning.

För att få kunskap om hur utbildningsprocessen i samband med barnets diagnos upplevdes utifrån föräldrarnas perspektiv (delstudie 2) intervjuades 18 föräldrar, tio mödrar och åtta fäder, vars barn insjuknat i diabetes typ 1. Föräldrarnas berättelser analyserades men en kvalitativ innehållsanalys utifrån de begrepp som Annemarie Mol från Nederländerna beskriver i sin teoretiska referensram, "The Logic of Care" fokuserande samarbetet mellan patient, familj

och vårdpersonal. Den första tiden efter barnets diagnos upplevdes av föräldrarna som mycket intensiv då familjen skulle ta in en mängd kunskap, både teoretisk och praktisk. Samtidigt upplevde föräldrarna att de var i chock och kände en sorg över att deras barn hade fått en kronisk sjukdom. Familjerna upplevde att de fått ett gott bemötande och en god vård under sjukhusvistelsen och de kände en trygghet i att diabetes teamet hade en stor kunskap och erfarenhet av att ta hand om barn med diabetes och deras familjer. De uppskattade när utbildningen anpassades efter deras familjs förutsättningar och individuella behov. Den checklista som användes för att säkerställa teoretiska och praktiska områden upplevdes inte alltid sammanfalla med den förståelse föräldrarna hade för tillfället. Föräldrarna tog rutiner som de lärt sig på sjukhuset med sig hem efter utskrivningen och var inte förberedda på hur de skulle förhålla sig till barnets sjukdom i förhållande till familjens dagliga liv.

För att undersöka hur barn och föräldrars välbefinnande påverkas under de två första åren efter att ett barn i familjen insjuknat i diabetes typ 1 genomfördes två studier (delstudie 3 och 4) där 69 barn och deras föräldrar inkluderades. De besvarade frågeformulär om hur de upplevde sin och familjens välbefinnande. Föräldrarna besvarade även ett frågeformulär angående deras tillfredsställelse med barnets vård i samband med diagnos, och ett respektive två år därefter. Resultatet visade att mödrar upplevde en lägre hälsorelaterad livskvalité än fäder i samband med barnets insjuknande och ett år efter barnets diagnos, dock visade resultatet att bådask livskvalité förbättrades under det första året. Vidare upplevde mödrarna signifikant mer känslomässiga problem och oro i samband med att sjukdomen debuterade än fäderna. Efter ett år kvarstod de känslomässiga problemen för mödrarna och de upplevde då också problem med att prata med andra om sitt barns sjukdom. Vidare upplevde de, jämfört med fäderna, att familjen hade påverkats signifikant, speciellt vad gällde familjens dagliga aktiviteter. Både barn i den yngre åldersgruppen, 5-7 år och föräldrarna upplevde mer oro relaterat till diabetes specifika frågor jämfört med barn och föräldrar i de äldre åldersgrupperna. I de två äldre åldersgrupperna (8-12 år och 13-18 år) upplevde barnen att de hade en högre grad av följsamhet till behandlingen än vad deras mödrar upplevde att de hade och barn mellan 8-12 år upplevde en sämre hälsorelaterad livskvalité än vad deras fäder beskrev. Föräldrarna var nöjda med barnets vård både när de insjuknade och efter ett år, dock upplevde mödrar efter ett år att de i mindre grad hade fått sina känslomässiga behov tillfredsställda. Två år efter barnets diagnos var mödrarna fortfarande signifikant mer oroliga och mer känslomässigt påverkade än fäderna. Båda föräldrarna var nöjda med barnets vård, men mödrarna upplevde fortfarande en mindre grad av tillfredsställelse gällande deras känslomässiga behov. När barnets upplevelse av familjens stöd sattes i relation till deras HbA1c värde framkom inget samband mellan deras HbA1c värde och om de upplevde familjens stöd som omtänksamt och vägledande eller mer kontrollerande.

Sammanfattningsvis framkom det i denna avhandling att mödrarna är mer känslomässigt påverkade de två första åren efter barnets diagnos än fäderna. Vidare att de yngsta barnen och deras föräldrar känner mer oro kring frågor som handlar om barnets sjukdom och behandling ett år efter barnets diagnos jämförbart med äldre barn och deras föräldrar. Det framkom inte något samband mellan barnens upplevelse av familjens stöd och deras HbA1c värde efter två år. Angående utbildningsprocessen är det viktigt att anpassa den initiala utbildningen efter barnets diagnos utifrån varje familjs individuella behov genom att tydligare kombinera familjens behov med den checklista som används av diabetes teamet.

Genom att lyfta fram barnens och föräldrarnas egna beskrivningar av hur deras välbefinnande och livskvalité påverkas kan mer riktade insatser från hälso- och sjukvården ges. En ökad förståelse för den initiala utbildningsprocessen och hur vardagen upplevs av barn och föräldrar kan öka hälso- och sjukvårdens möjligheter avseende förebyggande insatser och behandling av barn med diabetes typ 1 och graden av ohälsa i den framtida vuxna befolkningen.

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