Parenting children with type 1 diabetes

A cross-sectional study of associations between the psychological and contextual characteristics of parents, parenting behaviour and the characteristics of children in a population-based sample

Anne Haugstvedt

Dissertation for the degree of philosophiae doctor (PhD)

University of Bergen, Norway

2012

Contents

SCIENTIFIC ENVIRONMENT **5**

ACKNOWLEDGEMENTS **6**

SUMMARY **8**

LIST OF ARTICLES **10**

LIST OF APPENDIXES **11**

ABBREVIATIONS **12**

1. INTRODUCTION **13**

2. THEORETICAL BACKGROUND AND LITERATURE REVIEW **15**

2.1 CHILDHOOD-ONSET TYPE 1 DIABETES 15

2.1.1 Causation and pathogenesis *15*

2.1.2 Diagnosis *16*

2.1.3 Prevalence and incidence *16*

2.1.4 Acute and long-term complications *17*

2.1.4.1 Long-term vascular complications 17

2.1.4.2 Diabetic ketoacidosis (DKA) 18

2.1.4.3 Hypoglycaemia 19

2.1.5 Treatment and treatment goals *21*

2.1.6 Variables associated with improved treatment outcomes *22*

2.2 THE CONCEPT OF PARENTING 24

2.2.1 Parenting *24*

2.2.2 Belsky's determinants of parenting: a process model *25*

2.2.2.1 The adapted Belsky model for parenting children with diabetes 27

2.3 PARENTING CHILDREN WITH TYPE 1 DIABETES - A LITERATURE REVIEW 29

2.3.1 Diabetes and the family *29*

2.3.2 Parental fear, burden and distress during the chronic course of the disease *32*

2.3.2.1 Fear of hypoglycaemia 32

2.3.2.2 Perceived burden and emotional distress 34

2.3.2.3 Gender differences 36

2.3.3 Characteristics of parents, parenting behaviour and child HbA_{1c} *37*

2.3.3.1 The psychological and contextual characteristics of parents 37

2.3.3.2 Self-monitoring of blood glucose 38

2.3.4 Summary of the literature review *39*

3. AIM AND OBJECTIVES **41**

4. METHODS 42

4.1 STUDY POPULATION 42

4.2 CONCEPT DEFINITIONS AND OPERATIONALIZING THE CONCEPTS 43

4.3 STUDY QUESTIONNAIRE 44

4.3.1 Demographic and disease-related variables 44

4.3.2 Standardized scales 46

4.2.2.1 Hypoglycemia Fear Survey – Parent version (HFS-P) 46

4.2.2.2 Hopkins Symptom Checklist – 25 items (HSCL-25) 47

4.2.2.3 Family Burden Scale 47

4.2.2.4 Life Orientation Test 48

4.2.2.5 Oslo 3-item Social Support Scale 48

4.2.2.6 Relationship Satisfaction Scale 50

4.3.3 Additional questions included in the questionnaire 50

4.3.4 Pilot testing of the study questionnaire 51

4.3.5 The variables and scales related to the theoretical framework of the study 51

4.4 STUDY PROCEDURE 53

4.5 STATISTICAL ANALYSIS 53

4.5.1 Assessment of assumptions for the analyses 54

4.5.2 Main analyses presented in the articles 55

4.5.3 Additional analyses 56

4.6 ETHICS 58

5. RESULTS 60

5.1 ASSUMPTIONS FOR THE ANALYSES 60

5.2 CHARACTERISTICS OF THE CHILDREN AND PARENTS 61

5.3 PARENTS' FEAR OF HYPOGLYCAEMIA (ARTICLE I) 63

5.3.1 Results from additional analyses related to Article I 63

5.4 DIABETES-RELATED BURDEN AND EMOTIONAL DISTRESS (ARTICLE II) 66

5.4.1 Results from additional analyses related to Article II 67

5.5 PSYCHOSOCIAL FAMILY FACTORS ASSOCIATED WITH HbA_{1c} (ARTICLE III) 68

5.5.1 Results from additional analyses related to Article III 70

6. DISCUSSION 71

6.1 THE APPLICATION OF THE THEORETICAL FRAMEWORK IN THE STUDY 71

6.2 METHODOLOGICAL CONSIDERATIONS 73

6.2.1 The cross-sectional study design 73

6.2.2 The scales included 74

6.2.3 The sample and sample size 75

6.2.4 The statistical analyses 76

6.2.5 Biases and confounders 78

6.3 GENERAL DISCUSSION 80

6.3.1 Parents' fear of hypoglycaemia 80

6.3.2 Glycaemic control and the diabetes dilemma 82

6.3.3 Emotional distress 84

6.3.4 Mother, father and child 86

6.3.5 Parenting children with type 1 diabetes: a complex process 87

7. CONCLUSIONS AND IMPLICATIONS 89

7.1 CLINICAL IMPLICATIONS 89

7.2 IMPLICATIONS FOR FUTURE RESEARCH 90

Scientific environment

The study was performed at the Children's Clinic of Haukeland University Hospital from December 2006 to February 2007. The scientific personnel at the Clinic constituted a crucial environment, especially during the planning period and the period of data collection.

The PhD fellowship was carried out at the Department of Public Health and Primary Health Care, University of Bergen during 2008-2012 with Berit Rokne as the principal adviser. The participation at the Research School in Public Health and Primary Health Care has contributed to important theoretical and methodological discussions related to the study.

The scientific environment at the Centre for Evidence-Based Practice of Bergen University College has constituted the daily scientific network during the fellowship. The DIABEST (Diabetes for best practice) research group is one of four research groups of the Centre. During recent years, the DIABEST research group has established a strong research environment within psychosocial health and diabetes. The chair of the group is Marit Graue, Bergen University College. The collaboration in DIABEST has been of utmost importance for planning and performing the study.

The study is included in the strategic research programme for health-related research of the Western Norway Regional Health Authority headed by Monica Nortvedt at the Centre for Evidence-Based Practice of Bergen University College.

Important research collaboration with researchers at the University of Virginia in the United States has emerged during the study period. The focus on parental fear of hypoglycaemia and the use of the Hypoglycemia Fear Survey – Parent version has resulted in one joint publication during the fellowship. The research collaboration is continuing.

Acknowledgements

The study was carried out among the parents of children with type 1 diabetes in Hordaland County. I thank all the parents and the children for participating in the study. The study would not have been possible without the parents' willingness to answer quite sensitive questions regarding their experiences and emotions.

I especially thank my supervisor Berit Rokne and co-supervisor Marit Graue. To Berit I express my gratitude for her willingness to always be open and for her pleasant and kind personality. Her insight and scientific experience has given me necessary security throughout the work. To Marit I express my gratitude for challenging me to start the study, for always encouraging me and for constructive and continual guidance and support. I am very thankful for Marit's considerations and her warm personality, which has been very important to me during the work.

Warm thanks also go to my co-author Tore Wentzel-Larsen for invaluable guidance and help with the statistics and for his availability, patience and professional insight. I have always met helpfulness and kindness at the Centre for Clinical Research of Haukeland University Hospital.

In particular, I want to give my deep-felt thanks to Oddmund Søvik for his extremely important support. His kindness and scientific experience has constituted security for me throughout the work.

Further, I thank The Diabetes Research Foundation of Western Norway, the Norwegian Diabetes Association, the Norwegian Nurses' Association and the Western Norway Regional Health Authority for funding the study.

I thank the Children's Clinic of Haukeland University Hospital for enabling me to perform the study. Further, I thank Bergen University College for giving me the opportunity to be part of a supportive working environment at the Centre for Evidence-based Practice and Department of Nursing. Thanks to the University of Bergen. Thanks also to Frode Thuen, Bergen University College and Astrid Wahl, University of Oslo for important contributions

and thanks to colleagues and research fellows for valuable discussions. Special thanks to Marjolein Iversen for her availability, kindness and continuous support.

Finally, I am deeply grateful to my husband Nils-Helge and our sons Aleksander, Jakob and Ole for great support and love in everyday life.

Anne Haugstvedt
Bergen, June 2012

Summary

Background

Insulin treatment of children with type 1 diabetes requires multiple medical decisions and technical procedures every day. Although previous studies have mostly included mothers, parenting style has been associated with treatment outcomes among children and adolescents with type 1 diabetes. However, the psychological and contextual determinants for parenting among both mothers and fathers of children with type 1 diabetes, and their associations with the characteristics of the children are more rarely investigated.

Aim

The main aim of this study was to analyse associations between the psychological and contextual characteristics of parents, diabetes-related parenting behaviour and the characteristics of children with type 1 diabetes in a sample of mothers and fathers of children with type 1 diabetes of all ages up to 16 years.

Methods

Mothers (n = 103) and fathers (n = 97) of 115 children with type 1 diabetes younger than 16 years of age participated in this population-based cross-sectional survey. In addition to demographic data related to the parents and disease-specific and demographic data related to the children, the parents completed instruments measuring their fear of hypoglycaemia, perceived diabetes-related family burden, emotional distress, perceived social support and social limitation, relationship satisfaction and life orientation regarding their traits of optimism or pessimism. Regression analysis and correlation analysis were performed to analyse the associations between the variables.

Results

The children in this study had mean HbA_{1c} of 8.1%, and only 29% (n=33) of the 115 children had mean HbA_{1c} ≤7.5% as recommended by international guidelines. The parents' fear of hypoglycaemia was associated with poor glycaemic control and higher frequency of problematic hypoglycaemic events the past year among the children. The mothers reported more fear of hypoglycaemia and higher perceived burden related to the medical treatment than the fathers. The mothers' fear of hypoglycaemia and perceived diabetes-related burden

were significantly associated with emotional distress. The association between burden and distress was not significant among the fathers. The parents' fear of hypoglycaemia and perceived diabetes-related burden were not significant associated with the children's age and duration of diabetes. The parents' perceived diabetes-related burden was, however, associated with nighttime self-monitoring of blood glucose every week or more often versus every month or less. An experience of nocturnal hypoglycaemia was associated with increased symptoms of emotional distress among the parents. A higher level of education and strong perceived social limitation because of the child's diabetes among the mothers were associated with lower HbA_{1c} among the children. A higher frequency of daily self-monitoring of blood glucose was associated with improved glycaemic control and the children's HbA_{1c} increased almost linearly by age from 7 years and up.

Conclusions and implications

The study has identified significant associations between the psychological and contextual characteristics of parents, diabetes-related behaviour and the characteristics of children with type 1 diabetes. Both clinical practice and future research should be aware of the association identified between the parents' fear of hypoglycaemia and the children's glycaemic control. Further, the burden and distress related to night-time caregiving and nocturnal hypoglycaemia need attention. The association between strong perceived social limitation among the mothers and better glycaemic control among the children may indicate that achieving satisfactory treatment outcomes among children with type 1 diabetes has certain costs, especially for the mothers.

List of articles

Article I:

Haugstvedt A, Wentzel-Larsen T, Graue M, Søvik O, Rokne B. Fear of hypoglycemia in mothers and fathers of children with type 1 diabetes is associated with poor glycemic control and parental emotional distress: a population-based study. *Diabetic Medicine* 2010; 27:72-78.

Article II:

Haugstvedt A, Wentzel-Larsen T, Rokne B, Graue M. Perceived family burden and emotional distress: similarities and differences between mothers and fathers of children with type 1 diabetes in a population-based study. *Pediatric Diabetes* 2011;12:107–114.

Article III:

Haugstvedt A, Wentzel-Larsen T, Rokne B, Graue M. Psychosocial family factors and glycemic control among children aged 1-15 years with type 1 diabetes: a population-based study. *BMC Pediatrics* 2011;11:118.

List of appendixes

Appendix I: Tables related to the literature searches and the literature review

Appendix II: Tables with results from additional analyses

Appendix III: Study questionnaire

Abbreviations

CSII	continuous subcutaneous insulin infusion
DCCT	Diabetes Control and Complications Trial
DKA	diabetic ketoacidosis
GEE	generalized estimation equations
HbA_{1c}	glycated haemoglobin
HFS-P	Hypoglycemia Fear Survey – parent version
HSCL-25	Hopkins Symptom Checklist – 25 items
IDF	International Diabetes Federation
ISPAD	International Society for Pediatric and Adolescent Diabetes
MDI	Multiple daily injections

1. INTRODUCTION

Diabetes Mellitus is one of the most common non-communicable diseases globally. The International Diabetes Federation (IDF) has estimated that more than 366 million adults have diabetes, and this number is expected to increase dramatically during the coming years [1].

Further, the IDF has stated that people with type 1 diabetes account for less than 5% of the people with diabetes in most countries, but the incidence of type 1 diabetes is increasing in low-, medium- and high-income countries. Type 1 diabetes can occur at all ages, but the incidence is highest among children and adolescents. The IDF estimated that about 490 000 children younger than 15 years have type 1 diabetes globally and stated that the incidence seems to be increasing rapidly, especially among the youngest children. The incidence rates differ between regions and countries, and about 23% of the children with type 1 diabetes live in Europe. The Scandinavian countries have among the highest incidence rates of childhood-onset type 1 diabetes in the world [1].

Insulin treatment in type 1 diabetes is life-saving but requires multiple medical decisions and technical procedures every day. The people dealing with type 1 diabetes in high-income countries, however, should be aware that the most common cause of death among children with type 1 diabetes globally, is still the lack of access to insulin [2]. In addition to obvious global differences in access to insulin and equipment for monitoring blood glucose concentrations, the quality of care also differs greatly around the world [1]. To reduce these differences, the International Society for Pediatric and Adolescent Diabetes (ISPAD) has proclaimed a commitment to promote optimal health, social welfare and quality of life for all children with diabetes around the word [3]. The ISPAD Consensus Guidelines, which were first published in 1993, are an important contribution to promoting care for children with type 1 diabetes. The third edition, now called Clinical Practice Consensus Guidelines, was published in 2009 [3].

In 1994 the Diabetes Control and Complications Trial (DCCT) confirmed a significant association between poor glycaemic control and higher risk of long-term complications among adolescents with type 1 diabetes [4]. Since then, insulin treatment and technologies for insulin delivery have improved and the ISPAD guidelines have been firmly established.

Nevertheless, no unambiguous evidence indicates that technical and medical progress has substantially improved glycaemic outcomes among children and adolescents [5, 6]. Many children and adolescents do not achieve glycated haemoglobin (HbA_{1c}) concentrations of less than 7.5% as recommended by the ISPAD guidelines [7]. HbA_{1c} reflects the average blood glucose concentration during the previous 2-3 months and lower HbA_{1c} value indicates better glycaemic control [8].

According to the ISPAD guidelines, psychological care for both children and their parents is essential to reach recommended treatment goals [9]. The guidelines also state that many studies have addressed parenting style and the communication climate in the family as important in influencing treatment outcomes among children and adolescents with type 1 diabetes. Less research has addressed why parents parent and communicate the way they do. Accordingly, Jay Belsky, a psychologist and specialist in child development and family functioning at Birkbeck University of London, has claimed that there is a lack of research on the determinants for parenting [10]. Belsky emphasized the personal psychological resources, the contextual sources of stress and support and the characteristics of the child as important aspects influencing the parenting process. The ISPAD guidelines also state that few studies have explored psychological aspects among parents in the chronic course of a child's diabetes, and few studies have addressed the fathers' situation [9].

This study has focused on both mothers and fathers of children with type 1 diabetes and analysed associations between the characteristics of parents, diabetes-related behaviour and the characteristics of children to generate knowledge on 1) fear of hypoglycaemia, perceived diabetes-related family burden and emotional distress among the parents of children with type 1 diabetes in the chronic course of the disease and 2) the associations between the children's glycaemic control and the parents' life orientation, contextual resources (work, social support and the marital relationship) and diabetes-related behaviour measured by the frequency of self-monitoring of blood glucose.

2. THEORETICAL BACKGROUND AND LITERATURE REVIEW

2.1 Childhood-onset type 1 diabetes

Type 1 diabetes is one of the most common chronic diseases among children in western countries, and the disease is characterized by hyperglycaemia resulting from defects in insulin secretion [1].

2.1.1 Causation and pathogenesis

The defect in insulin secretion related to type 1 diabetes results from an autoimmune destruction of the insulin-producing pancreatic islet β-cells [11]. The autoimmune β-cell destruction starts from months to years before clinical symptoms appear and when symptoms appear, about 90% of the β-cells have been destroyed [11, 12]. About 85-90% of the people with type 1 diabetes have insulin autoantibodies at diagnosis [13].

Genetic factors explain part of the autoimmune β-cell destruction resulting in type 1 diabetes. In a meta-analysis from 2009 more than 40 genomic locations were associated with type 1 diabetes, with human leukocyte antigen (HLA) genes having the strongest association [14]. Dahlquist, Blom et al. showed, however, that genetic factors alone cannot explain the development of type 1 diabetes, and although the children of parents with type 1 diabetes have an increased risk, most children with newly detected diabetes do not have parents or siblings with diabetes [15]. The study indicated that about 1out of 10 children with newly detected type 1 diabetes had parents or siblings with diabetes. Environmental factors may play an important role in the development of type 1 diabetes, but the knowledge about these environmental initiators of the autoimmune β-cell destruction is still limited, although several studies have linked this initiation to various types of viral infections [12].

2.1.2 Diagnosis

As the ISPAD guidelines state, children and adolescents with type 1 diabetes are usually quite easy and rapidly diagnosed, normally based on blood glucose tests and the presence of symptoms. In addition to a high blood glucose concentration, the characteristic symptoms are polyuria, polydipsia, blurring of vision, weight loss and reduced general condition. Based on the characteristic symptoms and high blood glucose concentration, insulin treatment should start immediately [12].

In western countries many children are diagnosed and have started treatment before more severe symptoms of hyperglycaemia and diabetic ketoacidosis (DKA) develop. A recent study including children from Finland, Sweden and Germany found that early identification of children with a higher genetic risk of type 1 diabetes and close follow-up for the development of islet autoantibodies substantially reduced the risk of DKA [16]. Nevertheless, the incidence of DKA when type 1 diabetes is diagnosed in Europe and North America varies widely geographically. According to ISPAD guidelines, studies have indicated that between 15 and 70% of cases have DKA at diagnosis [17]. Further, in Europe, the youngest children (<5 years of age) have the highest incidence of DKA at diagnosis: 36%. When symptoms of type 1 diabetes are present the absence of insulin will cause DKA and subsequently lead to stupor, coma and death. In a global perspective, the most severe conditions are still a challenge [2].

2.1.3 Prevalence and incidence

In 2011, the IDF estimated the annual incidence of childhood-onset type 1 diabetes worldwide to be 78 000 people younger than 15 years [1]. In the western countries type 1 diabetes accounts for more than 90% of the diabetes cases among children and adolescents [12]. Although the worldwide incidence of type 2 diabetes is also increasing among younger people, type 1 diabetes will probably remain the dominant form of diabetes among children and adolescents in most European countries [18]. Norway is among the countries with the highest incidence of childhood-onset type 1 diabetes in the world [12]. The incidence in Norway increased from 1973 to 2003 despite a stable period from 1989 to 1998 [19]. During

these 30 years, the incidence rate increased from 19.1 to 28.9 per 100 000 children younger than 15 years of age. The increasing incidence seems to be continuing. Uncorrected data from 2005-2008 indicate an incidence rate of 32.4 per 100 000 children younger than 15 years [20]. In addition to the increasing incidence, evidence indicates a shift to younger age at onset of childhood-onset type 1 diabetes [18, 21-23]. An increasing incidence among children younger than 4 years means that more children are living a longer period of their childhood with type 1 diabetes.

2.1.4 Acute and long-term complications

Before insulin was discovered in 1922, most children with type 1 diabetes died within 1-2 years after symptoms emerged [24]. For people with type 1 diabetes, insulin treatment is necessary for survival. Despite of access to insulin, childhood-onset type 1 diabetes is still associated with severe adverse events and complications [25].

2.1.4.1 Long-term vascular complications

The long-term vascular complications related to type 1 diabetes include micro- and macrovascular diseases [25]. Although vascular complications are relatively rare among children and adolescents according to Donaghue, Chiarelli et al. [25], intensive treatment and education during childhood may prevent vascular complications from progressing later on [4]. The severe outcomes that may occur are visual impairment and blindness caused by retinopathy, renal failure and hypertension caused by nephropathy, pain, paraesthesia, muscle weakness and autonomic dysfunction caused by neuropathy and cardiac disease, peripheral vascular disease and stroke caused by macro vascular dysfunctioning [25]. It has previously been reported [26] that parents of children with type 1 diabetes experience the greatest diabetes-related burden related to concerns for the children's long term health.

The DCCT [27] established the important association between more intensive and better management of blood glucose regulation and lower risk of long-term micro-vascular complications among people with type 1 diabetes. The study was a randomized controlled multicentre trial performed in the United States from 1983 to 1993. Of the 1441 participants

in the study, 195 were adolescents 13-17 years old. After the DCCT study, the Epidemiology of Diabetes Interventions and Complications study continued to follow the participants from the DCCT. The Epidemiology of Diabetes Interventions and Complications study confirmed an association also between intensive insulin therapy and reduction in macro-vascular complications [28]. In the adolescent cohort of the DCCT study [4], the risk of micro-vascular complications was 53-60% lower in the intensively treated group than in the conventionally treated group. The difference in HbA_{1c} between the two groups was 1.7 percentage points (8.1% versus 9.8%). The Epidemiology of Diabetes Interventions and Complications study found an even greater risk reduction for the previously intensively treated group compared with the conventionally treated group, which indicated a memory effect of the improved glycaemic control [25].

The Oslo study [29] demonstrated an association between intensive insulin treatment (continuous subcutaneous insulin infusion (CSII) or multiple daily injections (MDI)) and the progression of micro-vascular complications even before the DCCT. The DCCT, however, is the largest study that has confirmed this important association. Although most children with type 1 diabetes in Norway are treated with either CSII or MDI [30], it has been indicated that children with type 1 diabetes have a high prevalence of cardiovascular risk factors [31]. Nevertheless, a sample of adults in Norway with childhood-onset type 1 diabetes diagnosed from 1973 to 1982 had a relatively low incidence of overt nephropathy and proliferative diabetes retinopathy [32, 33]. The incidence indicated was 7.8% for overt nephropathy after duration of diabetes of 19-30 years, and 10.9% for proliferative retinopathy within the first 25 years of diabetes. Higher HbA_{1c} significantly predicted the development of both nephropathy and proliferative retinopathy. A recent study from Australia [34] confirmed a reduction in the prevalence of early retinopathy and nephropathy among adolescents during the past 30 years. The reduction in that study was associated with a more intensive insulin regimen and a decrease in HbA_{1c}.

2.1.4.2 Diabetic ketoacidosis (DKA)

Both the long-term and the acute complications of diabetes are linked to insulin treatment and regulation of blood glucose. Insulin omission, either deliberately or undeserved, could lead to DKA among children with established type 1 diabetes. The ISPAD guidelines

indicate that poor metabolic control and/or previous DKA episodes are important risk factors for DKA. The risk of DKA in established diabetes is 1-10% per person per year [17].

2.1.4.3 Hypoglycaemia

Hypoglycaemia is one of the most common acute complications in insulin-treated diabetes [35]. Hypoglycaemia results from more insulin than the body needs in a given situation, and the cause is often a mismatch between a given insulin dose, the food consumed and recent exercise [35]. Variation in insulin sensitivity may be underestimated as a cause of the mismatches between insulin doses, food and exercise.

There is no consistent agreement on the numerical definition of hypoglycaemia. Although a blood glucose concentration <3.6 mmol/l has often been used to define hypoglycaemia among children, the ISPAD guidelines recommend blood glucose >3.9 mmol/l as a minimum blood glucose level for children with diabetes [35]. The blood glucose concentration at which symptoms develop differs between individuals and differs between hypoglycaemic events within the same individual [36].

Hypoglycaemia can be asymptomatic, mildly symptomatic or severe, and the symptoms are caused by an autonomic (adrenergic) activation and/or a neurological dysfunction (neuroglycopaenia) caused by glucose deficiency in the brain [35, 37, 38]. The most common symptoms are sweating, trembling, weakness, visual disturbance, difficulty concentrating, hunger, tiredness, confusion and anxiety [38]. The symptoms vary both between individuals and within an individual. Children have difficulty in recognizing the symptoms of hypoglycaemia more often than adults [39], and behavioural changes are more often reported as a symptom of hypoglycaemia among children than among adults [38]. Asymptomatic nocturnal hypoglycaemic episodes, which are common among intensively treated children with type 1 diabetes, are especially challenging to cope with and prevent [40].

Severe hypoglycaemia can result in loss of consciousness and/or convulsions [38]. Such episodes may frighten both the child and the parents. Hypoglycaemia is also reported to be

the cause of death in some cases of childhood-onset type 1 diabetes although hypoglycaemia is difficult to establish post-mortem [41-43].

In addition to the immediately observed outcome of hypoglycaemia, researchers in Norway have found an association between severe hypoglycaemia and decreased cognitive functioning later on [44]. Slight cognitive dysfunctioning was observed among children with early-onset diabetes (<5 years of age) who experienced severe hypoglycaemia in early childhood. Other international reports have supported this finding from Norway [45]. Follow-up of the study in Norway concludes that early severe hypoglycaemic events also may have a long term negative effect on cognition [46].

The prevalence of hypoglycaemia among children and adolescents with type 1 diabetes is difficult to assess [35]. One reason is the unclear definition. The literature defines mild hypoglycaemia as episodes in which the person (or the parents) recognizes some symptoms but can treat the episode successfully and quickly without outside help [47]. These mild episodes are described as frequent, quickly forgotten and difficult to report retrospectively. A study among 28 children (3.1-8.3 years old), using a continuous glucose monitoring system over 3 days and nights, found a higher prevalence of hypoglycaemia than expected [48]: 81 hypoglycaemic episodes. Hypoglycaemia was most prevalent at night, when the episodes were prolonged and largely asymptomatic.

Severe hypoglycaemia is either defined as an episode requiring assistance from a third part [47] or an episode with unconsciousness and/or seizures [30]. The first definition is problematic for children who continually need assistance from their caregivers. A meta-analysis indicated the prevalence of severe hypoglycaemia among children to be 36 events per 100 persons per year [49]. However, the prevalence differs between studies, and data from the Norwegian Childhood Diabetes and Quality Project (NCDQ) indicated the prevalence to be about 11 events per 100 children per year [30]. A recent large prospective study from Australia indicated a decrease in episodes of severe hypoglycaemia among children (1-18 years of age) from 17.3 per 100 children per year in 2001 to 5.8 episodes per 100 children per year in 2006 [50]. HbA_{1c} <7% was not associated with a higher risk of severe hypoglycaemia compared with HbA_{1c} of 8-9% in that study. The authors did not give any explanation for the reduction but they did speculate whether medical and technological improvements may play a role.

2.1.5 Treatment and treatment goals

Both the acute and long-term complications following childhood-onset type 1 diabetes indicate the importance of treating the disease optimally to prevent severe complications.
The main goals of diabetes treatment among children with type 1 diabetes are to achieve the best feasible blood glucose concentrations, minimizing the occurrence of hypoglycaemic events and preventing long-term complications [7]. The ISPAD guidelines emphasize that an increasing number of children with type 1 diabetes globally are receiving basal/bolus insulin regimen such as CSII or MDI to prevent long-term complications [51]. Further, the ISPAD guidelines emphasize that these intensive insulin regimens require complicated medical decisions and frequent treatment tasks every day. The guidelines also state that variations in the insulin needed, dosing inaccuracy, technical problems and pain are among the barriers for optimal glycaemic outcomes among children with type 1 diabetes despite the use of an intensive insulin regimen.

Self-monitoring of blood glucose is an invaluable tool for optimizing diabetes management. Frequent self-monitoring of blood glucose requires that the child or the parents have the monitoring equipment and spend time considering the blood glucose concentration, often many times each day. The ISPAD guidelines recommend individualized frequency and regularity of self-monitoring of blood glucose depending on the equipment available, insulin regimen and the child's ability to identify hypoglycaemia [7].

Since the DCCT, HbA_{1c} has been the gold standard for measuring glycaemic control among people with diabetes [8]. The ISPAD guidelines recommend at least one HbA_{1c} measurement per year, but ideally 4-6 measurements per year for the youngest children and 3-4 for older children [7]. Further, the guidelines recommend <7.5% as the target HbA_{1c} for children. The target is meant as a guideline, and individual targets should be determined based on overall consideration of how to best prevent both severe hypoglycaemia and long-term complications.

2.1.6 Variables associated with improved treatment outcomes

The DCCT indicated that adolescents receiving intensive insulin treatment had better glycaemic control than those receiving conventional insulin treatments [4]. The DCCT defined intensive insulin treatment as three or more insulin injections per day.

Since the DCCT, the intensive insulin regimen has been emphasized as an important tool for achieving satisfactory glycaemic control, and an increasing proportion of the children with type 1 diabetes are treated with either MDI or CSII [51]. However, the many studies comparing insulin regimens provide no evidence for a clear positive association between the intensity of the insulin regimen and improved HbA_{1c} [6]. Some studies have actually showed the opposite. In the Hvidøre Study on Childhood Diabetes, adolescents receiving two injections with pre-mixed insulin per day had a significantly lower HbA_{1c} (7.9%) than those receiving MDI (8.2%) or CSII (8.1%) [5]. In addition, the Hvidøre studies did not find that switching from twice-daily insulin regimen to MDI improved glycaemic control [52]. More than 2000 adolescents (11-18 years old) from 21 centres throughout Europe, Japan, Australia and North America participated in the Hvidøre studies, which took place in 1995, 1998 and 2005 [26]. Other studies [53] have also reported the lowest HbA_{1c} among children receiving conventional insulin treatments with less than three injections per day. Comparing these results with the results from the DCCT study, one notes that the intensive treatment in the DCCT study included, in addition to the intensive insulin regimen, at least four blood glucose measurements per day, and frequent dose adjustments according to blood glucose concentrations, food intake and exercise [27]. The treatment was generally adjusted after telephone discussions with the health care providers. In addition to frequent telephone contact, the participants visited the research centre once a month. The contact between the participants and the health care providers in the DCCT study has been described as intense and close, and potentially unstable and unmotivated participants were excluded from the study [6, 54]. Based on this, it is appropriate to question whether it was the intensive insulin regimen or the additional support that resulted in improved glycaemic control in the DCCT.

New insulin analogues have been adopted in recent decades, and new and improved technologies for insulin delivery have been developed [51]. Although the mean HbA_{1c} in Norway is reported to have declined significantly (from 8.6% to 8.1%) from 2001 to 2005

[30], no evidence indicates that new insulin regimens and improved technologies have unambiguously improved glycaemic control among children with type 1 diabetes [6]. Reports from the childhood diabetes registries in the Scandinavian countries [30, 55, 56] have shown that most children and adolescents with type 1 diabetes still do not achieve the HbA_{1c} recommended by the ISPAD guidelines.

Skinner & Cameron [6] have reviewed the literature on the benefit or impact of intensive insulin regimens, new types of insulin and insulin delivery systems and psychosocial factors such as different types of support for glycaemic control among children and adolescents with type 1 diabetes. They concluded that better insulin and better technologies and regimens for delivering insulin have limited benefit for children and adolescents, although a review of studies including both children and adults [49] has shown that people receiving CSII had better glycaemic control than people using MDI. Skinner & Cameron [6] emphasized patient support and clear goal-setting as key elements in achieving satisfactory glycaemic outcomes. They stated that family support and peer support are the most important sources of social support for children. They further claimed that optimal support, clear goal-setting and team cohesion are important factors in taking advantage of the new types of insulin and the new technologies.

The Hvidøre studies also emphasized the effects of family support. The results from the Hvidøre study in 2005 [57] indicated that both family structure and family dynamics were associated with glycaemic control among adolescents. Family factors such as parental involvement, parents' marital status, fathers' employment and discrepancies between parents and adolescents in remembering blood monitoring, had greater effects on glycaemic control than sex, age and insulin regimen.

Anderson & McKay [58] have reviewed the literature to identify important barriers to optimized glycaemic control among young people with diabetes. They also emphasized the lack of glycaemic improvements during recent decades despite pharmaceutical and technological progress. Family factors together with psychological and developmental issues are emphasized as important barriers to achieving satisfactory glycaemic outcomes. Low socioeconomic status, single-parent status, parent-child conflicts and other sources of life stress are described as aspects influencing glycaemic control among children and adolescents with diabetes.

Glycaemic control as measured by HbA_{1c} has been and still is the most central outcome variable in much of the research on childhood-onset type 1 diabetes, but the psychosocial functioning of children and parents is also emphasized as an important outcome variable in diabetes among children [9]. The association between psychosocial functioning and glycaemic control is described as bidirectional [58]. Accordingly, the ISPAD guidelines emphasize both how psychosocial functioning affects adherence to regimens and glycaemic control, and how diabetes affects psychological and psychosocial functioning [9]. Several authors within the theoretical concept of "parenting" [59] theorize about the processes of mutual influence between parental functioning (parenting) and the characteristics of the child.

2.2 The concept of parenting

Taking care of children is an activity as old as humanity. There are references to parental activities from the earliest historical eras [60]. As societies developed, parental care became increasingly integrated into religious, economic, civic and cultural contexts [59]. Although the references to parents' activities are old the noun *parenting* is quite new.

2.2.1 Parenting

After The Second World War, John Bowlby studied the effects of family disruption experienced by many families in Great Britain during the war [61, 62]. Bowlby focused on the complexity of parent-child interaction and how family disruption affects children. He conceptualized attachment as a way of understanding the relationship between parents and their children. Bowlby's attachment theory opened up a whole new field of questions regarding the process of caring for children, and during the last 30-40 years *parenting* has emerged as a new discipline.

A proposed definition of *parenting* is "purposive activities aimed at ensuring the survival and development of children" [59]. Parenting refers primarily to the process of interactions between adults and children to ensure that children develop. The adults are not necessarily

the biological parents of the child. The main objectives are the relationships, the activities and the processes [59].

Although the definition of parenting is quite simple, there has been extensive scientific enquiry on how various parenting practices affect children's development and health. The development of theories and models on the parenting process has 1) transformed from person-centred to ecologically based perspectives that consider how certain circumstances or contexts also contribute to parenting, 2) transformed from one-dimensional to multi-dimensional perspectives that consider the complex interactions between the determinants of parenting and 3) changed the focus from the parents as the sole agents to focus on the joint contributions of parents and children [63]. Urie Bronfenbrenner [64] and Jay Belsky [10, 65] are among the theorists who have included the ecologically perspective, the multi-dimensional view and the joint contributions of parents and children in their theories of human development. Bronfenbrenner's theory on the ecology of human development from 1979 [64] placed child development in an ecological perspective and laid an enduring foundation for future theories and models such as Belsky's ecological determinants of parenting model from 1984 [10].

Bronfenbrenner emphasized in his theory how the effectiveness of parenting activities depends on the parents' own relationships, economic circumstances and cultural context, and the wider social and political structures within which the parents operate. He also emphasized that the relationships between these systems and structures need to be understood to make sense of parenting practices and child development. Bronfenbrenner's main objectives were all the different systems that influence human development, whereas Jay Belsky's objectives were the near contextual and personal factors that influence parental functioning and then subsequently influence children's development [10]. At the family level, however, both Bronfenbrenner's and Belsky's theories primarily focus on interpersonal interaction between parent and child.

2.2.2 Belsky's determinants of parenting: a process model

Jay Belsky maintained that most research on parenting has investigated the characteristics of parenting style and consequences of parenting [10]. Except for studies of the effects of social

class and cultural belonging, Belsky stated that less research has emphasized why parents parent the way they do. Thus, and in accordance with Bronfenbrenner, he emphasized the importance of understanding the variables influencing the parenting process. Belsky claimed that a lack of conceptual models is the reason why much empirical knowledge within disparate parts of this field has not been used and integrated into a connected whole of the determinants of parenting. To meet this need, Belsky introduced the determinants of parenting: a process model [10].

Belsky's determinants of parenting model emphasizes the determinants of individual differences in parental functioning. The model is derived by examining research on the causation of the maltreatment of children [10]. However, Belsky argues that the determinants highlighted in the model play an important role in influencing parental functioning in general. The model presumes that parental functioning (parenting) is determined by factors from three specific domains: 1) the parents' personal psychological resources, 2) the contextual sources of stress and support and 3) the characteristics of the child. The parents' personal psychological resources are viewed as the most influential determinant of parenting by affecting parenting behaviour both directly and indirectly. The indirect effects are explained by how people's psychological resources contribute to shaping their own contextual sources (such as marital, social and job relations), which further directly influence parenting behaviour [10]. The bidirectional links between personal psychological resources and the contextual sources of stress and support illustrate the ecological view of the model.

Further, Belsky assumes the parents' contextual sources of stress and support such as the marital relationship, social network support and work to be more important for parental functioning than the characteristics of children. Finally, both parenting behaviour and the characteristics of children influence children's development directly.

Belsky's model has some indistinctness'. He does not use the concept of "personal psychological resources" consistently. Belsky [10] uses "personality", "characteristics of the parents" and "personal psychological resources" in describing this most important domain of determinants of parenting. Nevertheless, it is reasonable to interpret the concept of personal psychological resources to include both traits of personality and more unstable psychological resources influenced by contextual circumstances.

Belsky has not indicated a link between the characteristics of children and the parents' psychological resources in his model, although Belsky's previous publications have emphasized how the characteristics of children not only affect parenting behaviour but also the parents' psychological situation and marital relations. In *The Child and the Family* [65], Belsky stated that parents' initial response to a child with disabilities frequently includes depression, sadness and anxiety. In addition, he stated that individual differences between children may affect not only parenting behaviour but also the marital relationship between a mother and a father.

Several studies in various countries [66-74] have used the Belsky's determinants of parenting model as a theoretical framework in different ways. The model has guided the choice of variables included in studies, and the pathways and ranking of the determinants has been tested empirically. Both the study of Luster [70] and the study of Meyers [71] have used Belsky's model as an organizing framework, and both of them stated that Belsky's three domains of determinants (the characteristics of parents, the characteristics of children and contextual sources of stress and support) may include a broad range of operationalized variables. Further, they claimed that the variables included in a study depend on the objectives of the study and that exhaustively validating the model is therefore difficult. The study of Sherifali & Ciliska [74] is a literature review on parenting children with type 1 diabetes. The purpose of the review was to identify the strengths and limitations of Belsky's determinants of parenting model as applied to parenting children with type 1 diabetes.

2.2.2.1 The adapted Belsky model for parenting children with diabetes

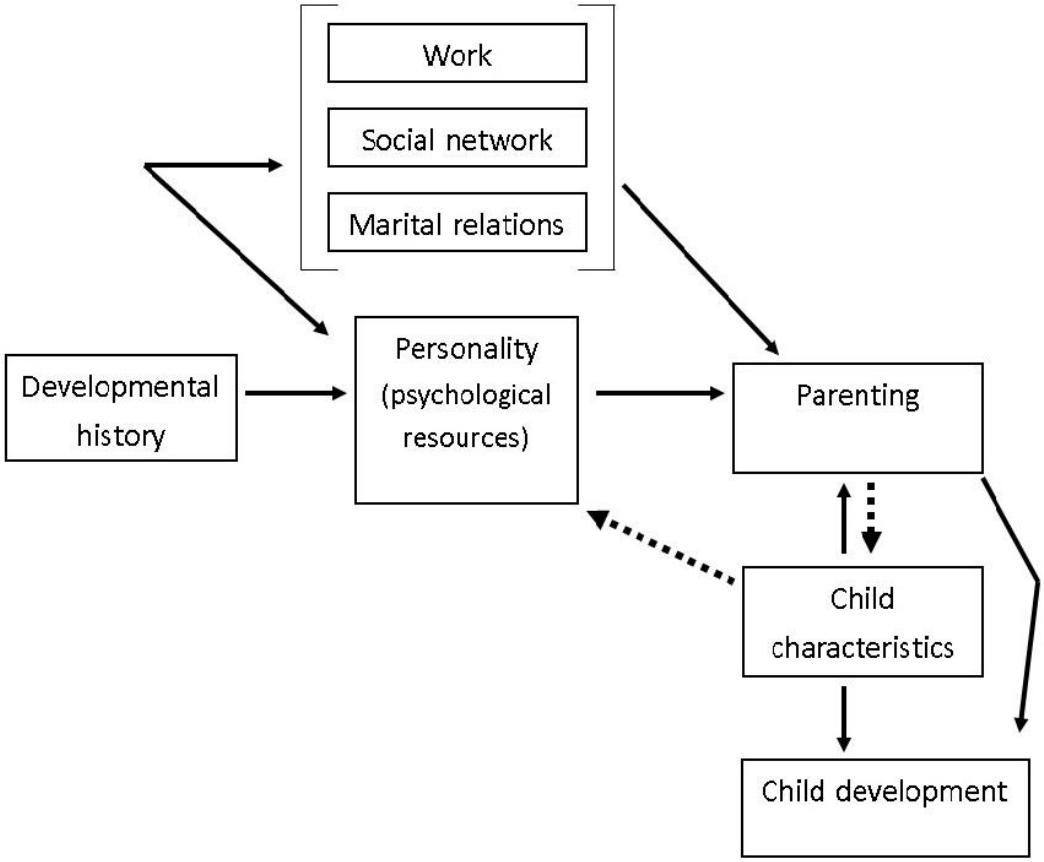
Sherifali & Ciliska [74] are the first researchers who applied Belsky's determinants of parenting model in a setting of children with maladaptive situations or chronic illness other than child abuse or maltreatment. Sherifali & Ciliska identified research literature from 1984 to 2004 focusing on the determinants of parenting and diabetes control among children 0-12 years old with type 1 diabetes. They critically appraised seven articles in relation to Belsky's determinants of parenting model. Sherifali & Ciliska noticed the lack of a conceptual framework to guide the studies and experienced Belsky's model as a tool for studies examining the determinants of parental functioning and parenting behaviour related to children with type 1 diabetes. However, they noted that the model lacks a link from the

characteristics of the children to the parents' psychological resources. In accordance with the previous reports from Belsky on the link between the characteristics of children and the parents' psychological resources [65], several studies among families of children with type 1 diabetes [75-79] have identified diabetes being diagnosed in a child resulting in psychological changes among parents. In addition, previous research has claimed both way links between parenting and characteristics of the child. As stated in Belsky's model, the characteristics of the child affect parenting. Contrary, Davis et al. [80] have shown how parenting style affects the diabetes-related characteristics of the child. Sherifali & Ciliska suggested adapting Belsky's determinants of parenting model (Fig. 1). The adapted model includes 1) a direct link from the characteristics of the child to the parents' personal psychological resources and 2) a bidirectional link between parenting and characteristics of the child. Except for these two added links (indicated by dotted lines in Fig. 1), the adapted Belsky model is similar to Belsky's original model.

Sherifali & Ciliska [74] stated that little research has investigated the determinants of parenting among the parents of children with type 1 diabetes and recommended the adapted model as a framework for further diabetes research addressing the determinants of parental functioning and the management of a child's type 1 diabetes. They suggested qualitative research to explore the phenomena of a child's diabetes and how it is associated with the characteristics of parents, they suggested longitudinal studies to reveal the effect of children's diabetes over time on parent characteristics and parenting and they suggested cross-sectional studies to examine the relationships between the determinants of parenting in the adapted model. Sherifali & Ciliska stated that cross-sectional studies could analyse and illustrate positive and negative associations between the child's diabetes, parent characteristics and parenting [74].

This dissertation has used the schematic figure of the adapted Belsky model (Fig. 1) as an organizing framework.

Fig. 1. Determinants of parenting: a process model for parenting children with diabetes adapted from Belsky's (1984) determinants of parenting model



2.3 Parenting children with type 1 diabetes - a literature review

2.3.1 Diabetes and the family

The ISPAD guidelines emphasize the importance of family factors for the management of diabetes in children [9]. Several studies [76, 79, 81] have emphasized parental psychological distress during and immediately after a child is diagnosed with diabetes. However, the parents' responsibility for a child's diabetes treatment may also be associated with mental health problems in the chronic course of the child's diabetes, and non-diabetes-related family

stress may reduce the parents' ability to manage the child's diabetes treatment. Viner, McGrath et al. [82] have emphasized this bidirectional link between family stress and the demanding treatment tasks related to the chronic course of a child's diabetes. They claimed that the bidirectional interaction may affect both the health outcomes of children and parents' mental health.

The studies focusing on family factors associated with children's health outcomes vary considerably in the instruments used and the variables included in the studies. Several studies have indicated that parenting style is associated with children's health outcomes. Perceived parent-child conflicts have been shown to be associated with poorer diabetes management [83-85]. Duke et al. [86] have more recently identified critical parenting as a risk factor for increased HbA_{1c}. Several studies have emphasized parental warmth and involvement as important for both young people's health-related quality of life [87, 88] and glycaemic control [89-92]. However, the Hvidøre study indicated that parental over-involvement could be an important predictor of poorer glycaemic control [26, 57]. In a study among younger children (4-10 years old) with type 1 diabetes, Davis et al. [80] showed that warm parenting style was associated with better glycaemic control. The authors suggested that warm parenting improves adherence by reducing family conflict and improving self-management by the child.

Lewin, Heidgerken et al. [93] noted that previous research has investigated individual facets of potentially important family factors. Based on previous studies, they aimed in a study among 109 children (8-18 years old) to more fully explore the relationships between various family variables (parental guidance and control, parental warmth and caring, critical and negative parenting, and parental responsibility for treatment) and glycaemic control. The child and one parent participated in the cross-sectional study. The study identified associations between 1) critical and negative parenting and poor glycaemic control among adolescents but not among the youngest children, 2) lack of parental responsibility and poor glycaemic control, and 3) higher levels of positive parental warmth and caring and improved glycaemic control. They showed that the family factors investigated together accounted for 34% of the variance in glycaemic control. Including also the child's age, duration of diabetes and family structure, the variables explained as much as 49% of the variance in HbA_{1c}.

In the study of Lewin, Heidgerken et al. [93], 82% of the participating parents were mothers. This applies to most of the studies we have identified within this field. Further, the ISPAD guidelinies [9] state that few studies have addressed the psychological functioning among fathers. In addition, most studies have been conducted among adolescents, and fewer studies have been carried out among younger children or among children of all ages.

It is reasonable to consider the child's age as being important in relation to family stress and the parents' responsibility for daily treatments tasks. Different ages entail different challenges. For infants, developing a trusting relationship with the caregivers is essential for development [94]. Diabetes among young children may challenges the development of this important relationship. The parents have to act as a therapist for their child in addition to being a parent. The mothers of infants and toddlers with diabetes have reported feeling diminished bond with their children and the loss of an ideal relationship with their child [75]. Children younger than 6 years depend totally on their parents' managing of their disease. Expressing emotions related to high or low blood glucose concentrations is not easy for young children. Qualitative interviews with the mothers of children with diabetes describe constant vigilance because of the child's diabetes [78].

Children 6-11 years old with type 1 diabetes also depend highly on their parents for treating the disease, although many children have learned to perform the technical procedures related to self-monitoring of blood glucose and insulin injections [9]. The parents are still responsible for the medical decisions related to insulin dosing, which also depends on food intake and activity. This may influence the children's development of autonomy and self-esteem and the development of independent initiative and creativity, which take place during these years [94, 95]. The children's developing independence may be both psychologically and practically distressing for the parents.

Special challenges arise when a child approaches adolescence [95]. Adolescents spend increasing time away from home, and the parents of children with type 1 diabetes must gradually transfer the responsibility for managing diabetes to the children. Transferring responsibility too early is associated with negative treatment outcome [89]. Appropriately transferring responsibility from the parents to adolescents with type 1 diabetes may be a great challenge for families. In addition, adolescence entails psychological, social and physical challenges related to both normal development and managing diabetes [95].

2.3.2 Parental fear, burden and distress during the chronic course of the disease

The ISPAD guidelines describe managing a child with type 1 diabetes as a source of psychological distress among the parents [9]. The next sections present reviews of the research literature addressing fear of hypoglycaemia, perceived burden and emotional distress among parents of children with type 1 diabetes during the chronic course of the disease. Sex differences related to fear, burden and emotional distress will also be emphasized. See also Appendix I, Tables 1 - 3.

2.3.2.1 Fear of hypoglycaemia

Hypoglycaemia has been stated as the most common adverse event among people with insulin-treated diabetes, and many people with diabetes perceived the fear of the unpleasant and sometimes severe consequences of hypoglycaemia as an important reason for suboptimal glycaemic control [96]. Based on research among adults with diabetes, evidence supports fear of hypoglycaemia being associated with poor glycaemic control [96]. Research among children and adolescents is less clear [97], and studies addressing the parents' fear are limited (Appendix I, Table 2).

Fear of hypoglycaemia has been emphasized as causing a lack of motivation for strict blood glucose regulation among many people with type 1 diabetes [98]. However, only two studies have found parental fear of hypoglycaemia to be significantly associated with the children's blood glucose levels [99, 100]. This may be explained by the fact that parental fear of hypoglycaemia is not clearly associated with glycaemic control, but it may also be explained by methods such as small sample sizes in previous studies. Only 4 of 13 previous publications on single studies on the parental fear of hypoglycaemia reported sample sizes exceeding 100 (Appendix I, Table 1).

Some previous publications have addressed the association between parental fear and parental distress more than the association between parental fear and children's health outcomes. Based on interviews and observations Sullivan-Bolyai [101] described the experiences of parents raising young children with type 1 diabetes. The mothers in that study reported severe hypoglycaemia as being extremely stressful, and hypoglycaemia was ranked

as the greatest concern among 10 management variables. A study in Sweden [102] has also identified severe hypoglycaemia as the most disturbing risk and the greatest cause of diabetes-related fear among children and their caregivers. Accordingly, general emotional distress, measured by symptoms of anxiety and depression, has been positively correlated with fear of hypoglycaemia among mothers of children with type 1 diabetes [103, 104]. More diabetes-related stress has also been reported to be positively associated with fear [105, 106]. Gonder-Frederick, Fisher et.al [107] identified an association between lower parental fear of hypoglycaemia and the parents' certainty that the child carries glucose in case of emergency. Two publications have highlighted distress related especially to nocturnal hypoglycaemia [99, 108]. As mentioned in section 2.1.3, nocturnal hypoglycaemia is a real problem among children with type 1 diabetes [48].

Several publications [99, 109-111] have highlighted a significant association between the parents' fear of hypoglycaemia and their experiences with severe hypoglycaemia. The most common instrument used to assess the fear of hypoglycaemia among the parents of children with type 1 diabetes is the Hypoglycemia Fear Survey – Parent version (HFS-P) [97]. The HFS-P is derived from the HFS for adults [99, 107]. Some publications have, however, used modified versions of the HFS-P [100, 106, 108, 110], which create difficulty in comparing results. Despite descriptive presentations of HFS-P values collected in the various studies, no cut-off point between an appropriate and inappropriate level of fear has been indicated [97].

Patton, Dolan et al. [110] found that mothers feared hypoglycaemia more than did fathers, but they did not identify differences in fear between the parents of children of different ages. Müller-Godeffroy, Treichel et al. [112] showed a reduced fear of hypoglycaemia among both parents and children 6 months after the transition to CSII. After reviewing the literature on fear of hypoglycaemia among children and their parents Gonder-Frederick, Nyer et al. [97] established that there is little research on fathers' fear and that there is a need for further research investigating both mothers' and fathers' fear of hypoglycaemia and how it is related to both the characteristics of the children (such as age, insulin regimen and glycaemic control) and parental emotional distress.

2.3.2.2 Perceived burden and emotional distress

The Hvidøre Study Group on Childhood Diabetes has developed an instrument for measuring parental perceived burden related to five different domains of childhood type 1 diabetes [26, 113]. The domains are 1) medical treatment, 2) family disruption, 3) the child's physical and psychological problems, 4) restrictions related to social and school activities and 5) long-term health concerns. By using the Family Burden Scale, the Hvidøre Study Group has identified the perceived burden related to the parents' concerns about a child's future health as the most burdensome domain, even more burdensome than the daily medical treatment [26]. In the first Hvidøre study, 12% of the parents reported the burden related to medical treatment as being major or large, and 57% reported the burden related to long-term health concerns as being major or large. The Hvidøre Study Group showed a decrease in total perceived burden as the age of the child increased and found that the parents of boys perceived the burden to be significantly higher than the parents of girls [113]. Finally, the Hvidøre Study Group identified a highly significant association between perceived parental burden and children's $HbA_{1c.}$ Thus, the parents of children with low HbA_{1c} reported a lower burden than those with a high $HbA_{1c.}$ Accordingly, lower perceived parental burden measured by the Problem Areas In Diabetes Scale (PAID) – parent version, has also been reported to be significantly associated with better glycaemic control [114]. In a study by Stallwood [115], a higher PAID score was associated with a higher level of parental stress as measured by the Appraisal of Diabetes Scale (ADS). Both diabetes-related caregiver stress and higher levels of home management were significantly associated with better glycaemic control in that study. Hilliard, Rohan et al. [116], however, found an association between higher paternal involvement and poorer glycaemic control. They discussed whether some fathers have increased their involvement in response to suboptimal glycaemic control.

Despite the extra daily treatment tasks related to managing a child with type 1 diabetes, no evidence supports generally higher caregiver stress among the parents of children with diabetes than among other parents. Sullivan-Bolyai, Deatrick et al. [101] did not find higher parenting stress measured by using the Parenting Stress Index (PSI) among the mothers of children with diabetes than among the mothers in a control group. Despite the same level of general caregiver stress, some mothers of children with diabetes said that the burden of care caused personal health problems such as depression, weight changes and migraines [78]. They describe constant vigilance regarding the work and responsibility for the child's

diabetes treatment. Further, managing a child's diabetes has been described as overwhelming and has been associated with emotional problems such as sadness, frustration, anger, fear and anxiety among the parents [75]. More recent studies [105, 112] have reported that the parents of children using CSII had less frequent and less difficult parenting stress than the parents of children receiving insulin injections.

Parenting stress related to children with type 1 diabetes has been reported to be linked with symptoms of anxiety and/or depression [106, 117]. Maternal stress levels have also been reported to be associated with both psychological and physical well-being [118]. In a longitudinal study Kovacs et al. [119] identified symptoms and adjustment at diagnosis as the best predictor for later symptoms of emotional distress among the parents of children with type 1 diabetes.

The reported associations between parental emotional distress and health outcomes among children with type 1 diabetes vary. One study [120] has reported that maternal trait anxiety was significantly associated with higher HbA_{1c} among children. Other studies [103, 119, 121-123] have reported no association between parental emotional distress and the children's glycaemic control. However, parental emotional distress has been associated with children finding coping with diabetes more upsetting [121], parents reporting more problematic children's behaviour and poor management skills [120, 123] and increased symptoms of depression among children [117, 124]. Subsequently, adolescent emotional distress has been linked to poor glycaemic control [122]. A path analysis found that parental emotional distress influences both depressive symptoms and poor glycaemic control among young people through problematic parenting practices such as low involvement and infrequent SMBG [125]. Accordingly, depressive symptoms among mothers have been described to undermine their caregiving effectiveness in relation to adolescents with type 1 diabetes [126].

Patton, Dolan et al. [106] found that 68% of the variance in stress difficulty among parents of young children with type 1 diabetes was associated with parental depressive symptoms and fear. In addition to the fear of hypoglycaemia the unpredictability of the diabetes treatment and the uncertainty related to ambiguity, complexity and inconsistency of information has been addressed as strong predictors for parental emotional distress [127]. Lack of systems for self-monitoring of blood glucose has also been suggested as a

distressing factor for parents [108]. To deliver appropriate support and interventions for parents of children with type 1 diabetes there is, however, a need for more evidence-based knowledge regarding factors associated with emotional distress among parents of children with type 1 diabetes.

2.3.2.3 Gender differences

Dashiff et al. [128] stated that research related to parents of children with type 1 diabetes has mostly included mothers. This review article summarized knowledge about the role of fathers in managing children with type 1 diabetes and stated that the fathers are usually not the primary caregiver of a child with type 1 diabetes but that studies have indicated that fathers' contribution to the family is important for children's health outcomes. Fathers' perceptions of family stress and resources are better correlated with children's health outcomes than mothers' perceptions. Wysocki & Gavin [129] found that fathers' involvement was associated with better adherence and better quality of life among adolescents with chronic diseases. In that study, the mothers rating of the importance of the fathers' involvement in the child's disease was higher than the fathers own rating [130]. Several studies [130, 131] have indicated that the mothers' rating of fathers' helpfulness is associated with fewer symptoms of emotional distress among mothers.

Mitchell et al. [132] addressed paternal parenting stress related to parenting young children with type 1 diabetes. The fathers in that study reported relatively mild levels of stress: lower than the stress levels reported previously by mothers. However, the fathers' level of stress was significantly associated with their level of state anxiety and with the mothers' reports of difficult behavior among children. A recent study by Hansen, Schwartz et al. [131] reported high levels of psychological distress among fathers of 89 children with type 1 diabetes (aged 7-14 years), with 44% reporting sleep problems, 23% reporting clinically significant anxiety and 19% reporting depressive symptoms in the clinical range. In this study the fathers' reports of depressive symptoms were comparable with the symptoms reported by the mothers, but the reports of anxiety symptoms were lower among the fathers than among the mothers. In a qualitative study, Sullivan-Bolyai, Rosenberg et al. [133] found that the fathers of children with type 1 diabetes described an underlying sadness at the same time as they

reported a great responsibility for being strong and for supporting their partners (the mothers), whom they described as the primary caregivers.

2.3.3 Characteristics of parents, parenting behaviour and child HbA_{1c}

The next sections present reviews of the research literature addressing associations between psychological and contextual resources among parents, self-monitoring of blood glucose and glycaemic control among children with type 1 diabetes. See also Appendix I, Tables 1 and 4.

2.3.3.1 The psychological and contextual characteristics of parents

Among the studies exploring the association between psychological aspects among parents and children's health outcomes are the Hvidøre studies. The Hvidøre study from 2005 identified an association between parental well-being and better glycaemic control among adolescents [134]. Further, well-being has been reported to be facilitated by a person's trait of optimism [135]. Nevertheless, the association between parents' optimistic or pessimistic personality and glycaemic control among children with type 1 diabetes has not been explored previously.

Previous reports have emphasized an association between parents' education and children's glycaemic control. One study published in 1998 [136] showed that the mothers' sense of empowerment and their level of education explained much of the variation in their children's glycaemic control. Later, the father's level of education was linked to better glycaemic control among children with type 1 diabetes [117, 137, 138]. Thus, higher education level among fathers was associated with better glycaemic control among children. Accordingly, higher diabetes-related knowledge among caregivers has also been correlated with better glycaemic control among children with type 1 diabetes [139-141].

Studies have shown better glycaemic control among the children of employed parents than among the children of unemployed parents [57, 142]. The parents' employment status may be a marker of social class, and lower family income has been associated with higher HbA_{1c} [143]. However, low employment status among mothers of children with type 1 diabetes has

also been considered to be a result of the children's diabetes. Sullivan-Bolyai, Deatrick et al. [101] found that only 49% of the mothers of children with type 1 diabetes reported full-time work versus 79% of the mothers in a control group. Further research is needed to investigate the associations between the mothers' and fathers' respective employment status and children's health outcomes.

Several studies [26, 57, 93, 123, 142, 144-149] have shown that single-parent status is significantly associated with poor glycaemic control. Whether this association results from limited parenting resources and more parenting stress or from a higher level of family conflicts and inappropriate communication skills is not clear. Independent of marital status, the mothers in the study of Sullivan-Bolyai, Deatrick et al. [101] reported a need for more support related to parenting young children (younger than 4 years old) with type 1 diabetes. Only 36% of the mothers of young children with type 1 diabetes reported that they could get a babysitter versus 83% of the mothers in a control group, and 52% of the mothers of young children with type 1 diabetes said that there is always someone they can call to help them versus 88% of the control mothers. The results of other studies [115, 150] support the importance of adequate parenting resources to carry out the intensive diabetes home management among young children with type 1 diabetes. Stallwood [115] reported that more meticulous home management was associated with better glycaemic control. However, a study among the mothers of adolescents with diabetes [151] found that spousal support was associated with better adherence to treatment, whereas support from other people in the social network did not predict adherence to treatment or conflicts between the mother and the adolescent. More research is needed to investigate further the association between different kinds of social support and health outcomes among children with type 1 diabetes.

2.3.3.2 Self-monitoring of blood glucose

Several studies [56, 114, 123, 125, 138, 146, 152-156] have reported an association between more frequent self-monitoring of blood glucose and better glycaemic control among children and adolescents with type 1 diabetes. Chisholm, Atkinson et al. [140] did, however, not identify any association between self-monitoring of blood glucose and glycaemic control among the children, but they identified a correlation between better general diabetes knowledge among parents and both more frequent testing and better glycaemic control

among the children. Accordingly, parental involvement in diabetes management has been reported to be associated with higher frequency of self-monitoring of blood glucose among both children and adolescents with type 1 diabetes [89]. Further, adolescents' own perception of greater responsibility-sharing with parents has been shown to be associated with higher frequency of self-monitoring [92]. These reports indicate, as suggested by the authors of the studies, that the frequency of self-monitoring of blood glucose might be marker for diabetes-related parenting behavior among both younger children and adolescents with type 1 diabetes. In addition, Hilliard, Guilfoyle et al. [123] discussed the frequency of self-monitoring of blood glucose as an indicator of adherence to diabetes management, and in a longitudinal study they identified a significant association between diabetes-related parent-adolescent conflict and decreased frequency of blood glucose tests 6 months later. Accordingly, several studies [90, 91, 125, 153, 157] have identified diabetes-related responsibility, involvement and monitoring among the parents to be associated with improved regimen adherence among children and adolescents with type 1 diabetes. Frequent self-monitoring of blood glucose is mentioned as an important part of daily diabetes management. Pattison, Moledina et al. [156] identified glycaemic control to be associated with a combination of more frequent blood glucose tests and the parents perceiving a higher age at which a child could be responsible for self-management. Urbach, LaFranchi et al. [145] found that the number of blood glucose tests performed per day was significantly associated with the marital status of the parents. Thus, married parents indicated a higher frequency of self-monitoring of blood glucose.

2.3.4 Summary of the literature review

The reviewed publications provide limited knowledge about associations between the characteristics of the children and different types of psychological stress and/or distress among the parents in the chronic course of a child's type 1 diabetes.

Research addressing the parents' fear of hypoglycaemia is limited. There has, however, been identified a relationship between the parents' fear of hypoglycaemia and the children's blood glucose regulation, but more research is needed to further explore the relationship. A possible relationship between the parents' fear of hypoglycaemia and the children's age has rarely been examined previously: most studies have included either school-aged children and

adolescents or younger children. Fathers have rarely been included in previous research addressing the parents' fear of hypoglycaemia. Also previous studies addressing parental perceived burden and/or emotional distress have mostly included mothers. Further, a possible association between the diabetes-related burden and general symptoms of emotional distress among both mothers and fathers has not been investigated previously.

Several previous studies have included contextual sources such as social support, parents' education, employment status and marital status as covariates in their studies. We have, however, not identified previous reports including all these contextual factors in the same study. We have shown that previous publications have indicated an association between frequent self-monitoring of blood glucose and improved glycaemic control among children and adolescents. The parents' diabetes-related behaviour and involvement have been reported to be associated with the frequency of self-monitoring of blood glucose among both children and adolescents.

To complement previous findings within the reviewed topics of parenting children with type 1 diabetes and to meet some of the inadequacies of previous research, further research should focus on both the mothers and fathers of children with type 1 diabetes of all ages. To compare the results with the results from previous diabetes research, further research should include some well-known diabetes-specific instruments in addition to exploring new perspectives.

3. AIM AND OBJECTIVES

The main aim of this study was to analyse associations between self-reported psychological and contextual characteristics of parents, diabetes-related behaviour and the characteristics of children with type 1 diabetes in a sample of mothers and fathers of children younger than 16 years old with type 1 diabetes.

The specific objectives of the articles were as follows.

Article I:
To explore the fear of hypoglycaemia among mothers and fathers of children with type 1 diabetes, and to analyse associations between the parental fear of hypoglycaemia and 1) the characteristics of children with type 1 diabetes and 2) parental emotional distress.

Article II:
To explore the perceived diabetes-related family burden and emotional distress among mothers and fathers of children with type 1 diabetes and 1) to analyse how mothers and fathers differ in perceived burden and emotional distress and 2) to analyse associations between parental burden and emotional distress and the characteristics of children with type 1 diabetes.

Article III:
To analyse associations between children's glycaemic control (measured using HbA_{1c}) and 1) variables related to the parents' psychological and contextual resources and 2) the frequency of blood glucose measurement as a marker of diabetes-specific behaviour.

4. METHODS

This dissertation is based on a cross-sectional, population-based study carried out as a postal survey.

4.1 Study population

The participants in the study were recruited from the outpatient clinic of the Children's Clinic of Haukeland University Hospital in Bergen, Norway. The participants were children younger than 16 years old with type 1 diabetes and their parents.

Nearly all children aged younger than 16 years with newly detected type 1 diabetes in Hordaland County are admitted to the Children's Clinic of Haukeland University Hospital. The population of Hordaland County is ethnically homogeneous and stable and included about 97 000 children (aged 0-15 years old) in 2007. In December 2006, the Children's Clinic treated 174 children with diabetes in that age group.

The inclusion criteria were 1) diagnosis of type 1 diabetes, 2) duration of diabetes of at least 3 months, 3) living with one or both biological parents and 4) no younger siblings with type 1 diabetes. Of the 174 children 9 did not meet the inclusion criteria. One child had type 2 diabetes, 1 had maturity-onset diabetes of the young, 2 lacked contact with their parents and 5 had younger siblings with diabetes. In addition, 4 children were excluded because they temporarily resided abroad. In families with more than one child with diabetes, we included the youngest child and asked the parents to answer the questionnaire with this child in mind.

Although some child-related data were collected from medical records, parents were the primary respondents in this survey, and the mothers and fathers of 161 children younger than 16 years old with type 1 diabetes were invited to participate.

4.2 Concept definitions and operationalizing the concepts

The essential concepts related to the objectives of this study are the concepts of fear, emotional distress and burden. The concepts are operationalized through the standardized scales HFS-P, measuring the parents' fear of hypoglycaemia, HSCL-25, measuring parent-reported symptoms of emotional distress and Family Burden Scale, measuring the parents' perceived diabetes-related family burden (See section 4.3).

It has previously been claimed that publications of research using scales for measuring psychosocial events and states at best roughly reflect the constructs the scales are intended to represent [158]. Accordingly, we have not identified distinct and unambiguous definitions of the concepts of fear, emotional distress and burden in the reviewed publications related to the scales. Polit & Beck [159] claim that, the more abstract a concept is, the more difficult is it to establish construct validity while what we really want to measure is unclear. Thus, in the following paragraphs, the concepts of fear, emotional distress and burden are briefly defined to clarify the interpretation of the concepts used in this study. Based on the literature review, we perceive these definitions to be in accordance with the general comprehension of the concepts measured by the chosen scales.

Bay & Algase [160] stated that fear generally is defined as a sufficiently potent, biologically driven, motivated state in which a single, salient threat guides behaviour. The definition implies recognition of a perceived risk. Further, Bay & Algase claimed that fear has much in common with anxiety except that fear is related to a specific object. They defined anxiety as a heightened state of uneasiness to a potential nonspecific threat. Thus, while the source of fear is known and specific the source of anxiety is unknown and nonspecific. In our study, the specific object related to the concept of fear is hypoglycaemia among the children with type 1 diabetes.

Anxiety and depression are the most common forms of mental disorders among non-psychiatric populations [161] and symptoms of anxiety and depression are commonly used as important manifestations of a person's level of emotional distress [162, 163]. Most types of emotional distress are accompanied by symptoms of anxiety and/or depression, and anxiety and depression are highly comorbid [164].

The concepts of “emotional distress” and “stress” are equated in some parts of the literature [163]. However, important theorists have emphasized a distinction between the two concepts. Lazarus & Folkman [165] defined stress as a process in which individuals appraise the significance of an event for their well-being and their ability to rally resources to manage its demands. The individual’s cognition of the ability to cope with stress is essential in this perspective. Lazarus [166] emphasized emotions as results of the appraisals of the significance of how an event impact the personal well-being. Accordingly, a stressful event or situation has the potential to be appraised as threatening and the potential to cause symptoms of emotional distress. Just as Lazarus & Folkman emphasized the individual’s appraisal of the situation in their definition of stress, Maurin & Boyd [167] defined subjective “burden” as an individual’s appraisal of a situation and the extent to which he or she perceives carrying a burden. The perceived burden is not necessarily associated with emotional distress but, depending on the person’s appraisal, it has the potential to be related to emotional distress.

4.3 Study questionnaire

Identical information sheets and questionnaire (Appendix II) for mothers and fathers were compiled for the study. The questionnaire included parent-reported 1) demographic variables for the parents and demographic and disease-related variables for the child, 2) standardized scales and 3) additional questions related to managing the child’s diabetes. Some information related to the child was collected from medical records. This study did not analyse all variables and scales included in the questionnaire (Appendix III) and the dissertation therefore does not comment on all the questions and scales.

4.3.1 Demographic and disease-related variables

The demographic variables of the parents included categorical variables related to the respondents’ marital status (5 categories), level of education (5 categories) and employment status (8 categories). These variables were recommended by the Norwegian Institute of Public Health (http://www.fhi.no) and have been used in previous health surveys in Norway.

Because of the sample size, the number of categories for these variables were reduced before the analyses. Marital status was recoded into two categories (married or cohabiting versus not), level of education was recoded into two categories (education at university or university college level versus not) and employment status was recoded into three categories (working full time, working part time and unemployed).

Related to the children's diabetes, the parents reported information about frequency of self-monitoring of blood glucose, night-time self-monitoring of blood glucose, frequency and occurrence of types of hypoglycaemic episodes and comorbid diseases. Because of the limited sample size, the low number of cases in some of the recorded categories and the clinical importance of the categories, we decided to recode some of these variables before performing the analysis. The frequency of self-monitoring of blood glucose was recoded from 5 to 3 categories (≤3 times/day, 4-6 times/day or ≥7 times per day), night-time blood glucose measurements was recoded from 5 to 2 categories (every week or more or every month or less) and the frequency of problematic hypoglycaemia in the past year was recoded from 5 to 4 categories (0 episodes, 1-2 episodes, 3-6 episodes or ≥7 episodes in the past year). In the descriptive analysis of the parents' reports of the frequency of self-monitoring of blood glucose, frequency of night-time blood glucose measurements, frequency and occurrence of various types of hypoglycaemic episodes and comorbid diseases in the child, we decided to use the mothers' responses if they were available. If the mothers' responses were not available, the father's answers were used. The mothers and fathers responses on these items were very highly correlated overall.

Information about the children's age, duration of diabetes, insulin regimen and HbA_{1c} were collected from both the parents and the children's medical records. Data from medical records were used in analysing these variables. Regarding the insulin regimen, reports from the parents were checked against the insulin regimen documented in medical records. The parents' reports agreed almost totally with the documentation in medical records for this variable. The insulin regimen was recorded as a four-category variable with the categories 1-3 injections per day, MDI (with short-acting insulin before meals and long-acting insulin 1-2 times per day), CSII and others. Medical records stated that all the children in the study were receiving either 3 injections per day, MDI or CSII. Because all the children receiving ≥3 injections per day used several extra doses of short acting insulin when needed, we decided to recode the variable into a two-category variable: ≥3 injections per day or CSII.

The survey included questions on the children's HbA_{1c} level to explore the parents' attention concerning the child's glycaemic control. Nevertheless, for the analysis we obtained the HbA_{1c} values from medical records and we used the measurement nearest to the date on which the questionnaire was distributed. All the HbA_{1c} values were measured within 3 months before and 2 months after distribution. HbA_{1c} was measured using the DCA-2000 (Bayer Corp. Elkhart, IN, USA). The normal range is 4.5–6.1%, and the recommended value for children and adolescents with type 1 diabetes is <7.5% [7].

4.3.2 Standardized scales

The choice of disease-specific instruments included in the questionnaire was based on the psychometric properties of the instruments described in previous reports. General instruments measuring emotional distress, social support, marital satisfaction and an optimistic or pessimistic life orientation were chosen based on validated scales used in previous studies and nationwide health surveys in Norway. The following paragraphs and Table 1 describe the scales included.

4.2.2.1 Hypoglycemia Fear Survey – Parent version (HFS-P)

The Hypoglycemia Fear Survey was originally developed to assess the fear of hypoglycaemia among adults with type 1 diabetes. Researchers at the University of Virginia in the United States are the originators of the instrument [168]. The original instrument was adapted later for measuring the fear among the parents of children with type 1 diabetes, and the HFS-P is the most widely used instrument for measuring the fear of hypoglycaemia among the parents of children with type 1 diabetes. The version used in this study consisted of 25 items divided into a 15-item worry subscale and a 10-item behaviour subscale. The items in the worry subscale measure anxiety-provoking aspects of hypoglycaemia (such as "child not recognizing that he or she is having a reaction" and "child having a reaction while asleep"), and the items in the behaviour subscale measure specific, inappropriate behaviours to avoid hypoglycaemia (such as "have my child eat large snacks at bedtime", "allow my child's blood sugar to be a little high to be on the safe side") [99, 168]. Higher scores indicate more worry or more preventive behaviour. The HFS-P was translated into

Norwegian for this study using the procedure recommended by the World Health Organization (http://www.who.int/substance_abuse/research_tools/translation/en) including 1) double forward translation, 2) a consensus meeting among the translators and experts, 3) back translation, 4) approval of the back-translated version by the original authors at the University of Virginia and 5) a pre-test of the instrument among 8 parents of children with type 1 diabetes.

4.2.2.2 Hopkins Symptom Checklist – 25 items (HSCL-25)

The HSCL-25 used in this study is a shorter version of the original HSCL [161, 169]. The HSCL-25 asks questions about the presence and intensity of anxiety and depression symptoms during the previous 2 weeks and is recommended for screening emotional distress among people without mental disorders [161, 170, 171]. A sum score is obtained as indicated in Table 1, and higher scores indicate more symptoms. The HSCL-25 has been used in several health surveys in Norway such as the Norwegian Mother and Child Cohort study [172].

4.2.2.3 Family Burden Scale

The 5-item Family Burden Scale was included in the questionnaire to assess the parents' perceived diabetes-related family burden related to 1) medical treatment, 2) family disruption, 3) the child's physical and psychological problems, 4) restrictions related to social and school activities and 5) long-term health concerns. The Hvidøre Study Group on Childhood Diabetes constructed the Scale as part of the Hvidøre Adolescent Parent Professional Instrument – Diabetes Quality of Life (HAPPI-DQOL) Protocol [26, 113]. The Children's Clinic of Haukeland University Hospital has been a participating centre in the Hvidøre studies, and the Hvidøre Study Group on Childhood Diabetes translated the Family Burden Scale into Norwegian.

4.2.2.4 Life Orientation Test

An optimistic life orientation has previously been shown to benefit a person's ability to cope with serious diseases or concerns about specific health threats [173-176]. We therefore decided to include the Life Orientation Test in this study, and we considered the parents' life orientation to be important for the parents' psychological resources, which subsequently may affect how they parent the child with type 1 diabetes. The Life Orientation Test is an 8-item self-report instrument measuring a persons' trait of optimism or pessimism [177-179]. Four items are phrased positively ("In uncertain times I usually expect the best") and 4 negatively ("I hardly ever expect things to go my way"). The negatively phrased items were reversed before analysis, with higher scores indicating a more optimistic life orientation. A sum score is obtained by summing the item scores as Table 1 indicates. In the present study, however, we used a scale from 1 to 4 instead of 0 to 4 which gives a sum score of 8-32 instead of the original sum score 0-32. Nevertheless, no mean scores were reported in Article III and no wrong information about the original scale was given. For further analyses, however, the sum scores from our study cannot be compared with those of other studies.

4.2.2.5 Oslo 3-item Social Support Scale

The Oslo 3-item Social Support Scale was included in the study to measure the parents' experience of general social network support. WHO recommends using the Oslo 3-item Social Support Scale in health surveys [180]. The items in the Scale include 1) number of confidants, 2) sense of concern or interest from other people and 3) sense of support from neighbours [180, 181]. A higher score indicates more social support. The low Cronbach's alpha for the mothers in this study caused us to exclude the Scale in analysing mother-reported data.

Table 1. Scales used in the study including number of items, internal consistency reliability[*], sum scores and response scale

	No of items	Cronbach's alpha for mothers	Cronbach's alpha for fathers	Sum scores	Response scale and scoring
HFS-P	25	0.87	0.84	25-125	5-point Likert scale (1-5).
-Worry subscale	15	0.89	0.89	15-75	The sum scores are
-Behaviour subscale	10	0.69	0.69	10-50	obtained by summing the item scores.
HSCL-25	25	0.92	0.87	1-4	4-point Likert scale (1-4).
-Anxiety subscale[**]	10				The sum scores calculated
-Depression subscale[**]	15				by summing the item scores and divided by number of items answered.
Family Burden Scale	5	0.73	0.78	5-25	5-point Likert scale (1-5). The sum score is obtained by summing the item scores.
Life Orientation Test	8	0.81	0.74	0-32	5-point Likert scale (0-4).[ǂ] The sum score is obtained by summing the item scores.
Oslo 3-item Social Support Scale	3	0.55[#]	0.71	3-14	4 and 5-point Likert scale The sum score is obtained by summing the item scores.
Relationship Satisfaction Scale	5	0.89	0.88	5-30	6-point Likert scale (1-6). The sum score is obtained by summing the item scores.

[*]The Cronbach's alpha values presented are obtained in this study

[**]Subscale analyses for the HSCL-25 were not performed in this study.

[ǂ]In the present study we performed a scale from 1-4 instead of 0-4 which give a sum score of 8-32 instead of 0-32.

[#]The mothers' scores were excluded from analysis because of the low Cronbach's alpha.

4.2.2.6 Relationship Satisfaction Scale

We used the Relationship Satisfaction Scale to assess the parents' satisfaction with the marital relationship. The scale consists of 5 statements on satisfaction with the marital relationship such as "I am very happy in my marital relationship" [182]. One item is phrased negatively ("My partner and I have problems in our relationship") and was reversed before analysis.

4.3.3 Additional questions included in the questionnaire

The originators of the HFS-P instrument recommended some additional questions for research using the HFS-P. The question concerning frequency of "problematic" hypoglycaemic episodes is such an additional question. After discussions with the originators of the scale we decided not to give the parents a definition of "problematic hypoglycaemic episodes". The purpose was to collect data about episodes perceived as problematic by the parents themselves.

Further, we included and analysed the recommended and additional questions of the HFS-P regarding the parents' experiences with hypoglycaemia while asleep, their experiences with hypoglycaemia and unconsciousness, and a question about the parents' certainty in relation to the child's carrying glucose in case of emergency. The latter question asks specifically whether the child always carries emergency glucose, and the responding categories are "yes", "no" or "don't know". The categories "no" and "don't know" were merged before the analysis. It is important to distinguish between this question and a question in the HFS-P behaviour subscale that asks how often "you" are the one who arranges emergency glucose for the child. This study tested a possible overlap between these two questions. The corresponding analysis is described in the statistical analysis section and in the results chapter.

The HFS-P also includes two additional questions regarding the parents' perceived ability to recognize and treat hypoglycaemia in their child (Appendix III, question 16 and 17, page 5

in the questionnaire). These questions are not part of the scale and were not analysed in this study.

The questionnaire for the present study also included additional questions composed for the study. Among others, the parents were asked to report the degree of social limitations experienced because of the child's diabetes and the resulting lack of access to childcare. This five-category variable was recoded into 3 categories (none or slight, somewhat or strong experience of social limitation) before analysis.

Finally, the present study questionnaire included 10 single questions derived from the Hvidøre study group regarding "who is doing what in everyday life". The seven-category questions were recoded into 4 categories (1: mother or mother and child, 2: father or father and child, 3: mother and father or mother, father and child, and 4: child) before the analysis was performed for this dissertation.

4.3.4 Pilot testing of the study questionnaire

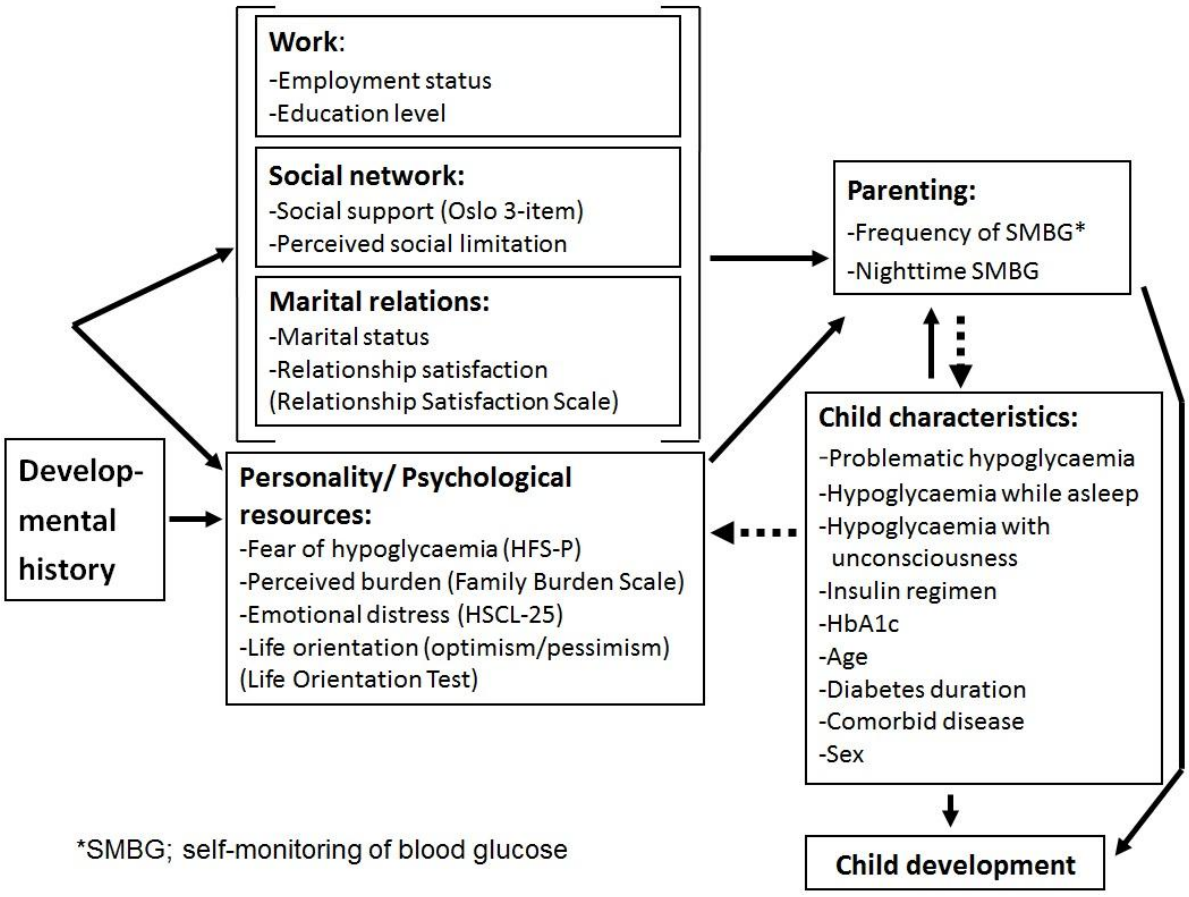
The study questionnaire was tested among 8 parents of children with type 1 diabetes before the study was carried out. The purpose of the pilot testing was to test whether the questions included in the questionnaire were clear, relevant, unambiguous and understandable, and whether the questions were perceived as reflecting the intended constructs appropriately. Based on the group's experiences and recommendations, the demographic and diabetes-related questions were changed slightly. The items in the standardized scales were perceived as clear, relevant and understandable. A pilot test like this strengthens the validity of the study [183].

4.3.5 The variables and scales related to the theoretical framework of the study

As recommended by Sherifali & Ciliska [74] we decided to use the adapted Belsky model as an organizing framework for the present study. Placing the included variables and scales into the schematic model enables a greater and more holistic view and understanding of the

different parts of the study. It also enables a better understanding of the relationship between the substudies and between this study and other studies in the field of parenting children with type 1 diabetes. The model informed the study without being tested and without being a theoretical basis for the development of the study. Fig. 2 shows the placement of the study variables and scales into the adapted Belsky model.

Fig. 2. The study-variables related to the adapted Belsky model for parenting children with diabetes



4.4 Study procedure

The data were collected from November 2006 to February 2007. The 1st of December 2006 was set as the study date for calculating the children's age and duration of diabetes. Identical requests, information sheets and questionnaires for mothers and fathers were distributed by mail to the addresses registered for the child's name. Although the posting included separate sheets and questionnaires for mothers and fathers, for ethical reasons we did not make obligations to forward the questionnaires to parents who did not share the child's address. The responsibility for distributing a questionnaire to the parents living on separate addresses was delegated to the parent living at the child's address. In accordance with the procedure recommended by the ethics committee, a reminder was sent to those who had not yet returned the questionnaire about 3 weeks after the first distribution.

The responses in the returned questionnaires were entered into the computer program SPSS (Statistical Package for the Social Sciences) version 14.0 by using the SPSS Data Entry tool, which made the process more accurate and efficient.

4.5 Statistical analysis

The statistical analysis was carried out using SPSS version 14.0 (Article I and II), version 17.0 (Article III) and version 18.0 (the additional analyses presented in the dissertation) (SPSS Inc., Chicago, IL, USA) and the statistical program R (R Foundation for Statistical Computing, Vienna, Austria) (Article I and II). The children with type 1 diabetes were considered the research units in our study. We received data from both the mothers and fathers for some children and from only one parent for others. The statistical analyses performed are listed in Table 2 and described in the following paragraphs.

4.5.1 Assessment of assumptions for the analyses

Before performing analyses using parametric techniques, the distributions of the mothers and fathers scale scores were checked by histograms. To further check the normality of the distribution of the scale scores, analyses of skewness and kurtosis [184] were performed. Scatterplots with loess curves were used to explore the linearity between the dependent variables (HFS-P worry and behaviour subscales, Family Burden Scale, HSCL-25 and HbA_{1c}) and the continuous explanatory (independent) variables (HbA_{1c}, child age and duration of diabetes) included in the analyses of the different substudies. Because the distribution of the HSCL-25 scores was skewed, the regression analyses with HSCL-25 endpoints were also investigated by a bootstrap procedure (using 10,000 bootstrap replications) [185] including bootstrap standard errors and BC_a 95% confidence intervals, to see whether the non-normal distribution of the HSCL-25 scores substantially influenced the standard errors and confidence intervals. Bootstrap standard errors and BC_a confidence intervals are constructed by using a general procedure that does not make specific distributional assumptions.

The intercorrelations between the explanatory variables included in the regression analyses presented in the three articles were analysed by using both the variance inflation factor (VIF) and Spearman's rank-order correlations. These analyses were performed separately for the mothers and the fathers. Analysis of the variance inflation factor indicates the proportion of variation in a variable that is not accounted for by other independent variables [186]. A high intercorrelation (multicollinearity) between the explanatory variables makes evaluating of results problematic, and variance inflation factors >5 and correlation coefficients >0.85 indicate problems with multicollinearity [186].

To explore the internal consistency reliability for all the scales included in the study, we analysed Cronbach's alpha for the mothers' and for the fathers' scores on the scale items. Cronbach's alpha measures the associations between the items in each scale, and the internal consistency deals with the extent to which all items of an instrument measure the same latent variable [159].

The extent of missing data was considered. As recommended [183] missing data were substituted in computing scale scores if at least half the items in a scale were answered. The missing data were substituted by inserting the mean of the non-missing items in a scale. If less than half the items in a scale were answered the respondent was excluded from the analysis including the current scale.

4.5.2 Main analyses presented in the articles

We used descriptive statistics including mean, standard deviation, range, and percentage distribution to describe the study sample (Article I, II and III). We performed analysis of variance (ANOVA) for analysing differences in HbA_{1c} between 3 age groups (Article III). We performed independent-sample *t*-tests for analysing differences between the characteristics of the children of respondents and nonrespondents.

Correlations between the parents' scores on the scales were explored by Pearson's product-moment correlations (Article I) and Spearman's rank-order correlations (Article II). Pearson's correlations were obtained for correlations between scale scores, and Spearman's correlations were used for correlations including single-item scores. Pearson's correlation is designed for continuous variables, and Spearman's correlation is recommended for use with ordinal level or ranked data [187]. We included bootstrap BC_a confidence intervals (R package boot) [188] for analysing the differences in scale score correlations (Pearson's) between the mothers and the fathers.

We performed generalized estimation equations (GEE) tests to analyse differences between mothers and fathers scale scores, and analysed differences between the mothers' and fathers' single-item scores on the Family Burden Scale by Wilcoxon matched-pairs signed-rank tests (Article II). Wilcoxon tests do not require a normal distribution of the data [189].

We performed regression analyses using the GEE procedure for regression models (R package gee) to analyse the associations between the characteristics of the participating children and the parental fear of hypoglycaemia (Article I) and parental perceived burden and emotional distress (Articles II). The GEE procedure is designed for cases in which some measures are likely to be correlated within clusters [190]. The procedure is most common for

analysing longitudinal data with repeated measures but can also be used for other studies in which some measures are likely to be correlated, such as responses from mothers and fathers concerning a common child. The method is flexible and does not require exactly the same number of assessments from each subject [183]. Using this procedure in this study allowed us to include both correlated data from the mother and the father of a common child and data from single mothers and single fathers in the same analysis. This utilization thus preserved more of the information in the data than paired-sample tests discarding data from one parent only.

We performed linear regressions to analyse associations between the children's glycaemic control (HbA_{1c}) and variables related to the parents' psychological and contextual resources and between glycaemic control (HbA_{1c}) and the frequency of self-monitoring of blood glucose (Article III). The fact that the dependent variable (HbA_{1c}) in these analyses was at the level of the child (115 cases), limited the inclusion of variables in the analysis models. We therefore decided to perform three multivariate analyses: one for variables related to the mother, one for variables related to the father and one for the frequency of blood glucose measurements and the child-related control variables. In addition, we performed bivariate analysis between each of the explanatory variables and $HbA_{1c.}$ The main reason for performing both bivariate and multiple regression analysis was to compare the results from bivariate and multiple regressions. In addition, some of the variables mutually excluded each other (marital status and relationship satisfaction) and therefore could not be included in the same multiple regression.

4.5.3 Additional analyses

Some additional analyses were performed for this dissertation to supplement the results presented in the articles, and to strengthen the validity of the results and conclusions. To supplement the HFS-P mean scores and Family Burden Scale mean scores presented in Article I and II, descriptive statistics for identifying the distributions of single-item scores were obtained. Further, paired-sample *t*-tests were performed for analysing differences between mothers' and fathers' HFS-P total scores and Wilcoxon tests for comparing the parents' single-item scores on the HFS-P worry subscale.

ANOVA, t-tests and Kruskal-Wallis and Mann-Whitney tests were performed to test differences in HFS-P worry subscale scores, Family Burden Scale scores and HSCL-25 scores between the mothers and fathers of the children in different age groups, between the mothers and fathers of the children with duration of diabetes <1 year or ≥1 year and between the mothers and fathers of boys and girls, respectively.

To supplement the GEE regression analyses (Articles I and II), we performed bivariate analyses (unadjusted analyses) between each of the explanatory variables and the dependent variables. These analyses were performed separately for the mothers and fathers. The purpose was to further explore the relationships between each of the variables and the dependent variable for the mothers and fathers, respectively.

As exploratory analyses, we performed linear regression analyses for mothers and fathers separately with the same analysis models as used in the GEE regression analyses presented in Articles I and II. When the results are interpreted, it should be taken into account that these models are somewhat larger than would have been appropriate if they had been planned as primary analyses for mothers and fathers separately.

To exclude possible overlap between one of the items in the HFS-P behaviour subscale and one of the explanatory variables, the exploratory analyses including the HFS-P behaviour subscale were also performed while excluding the current item in the scale. The exploratory regression analyses for all scales were also performed while excluding the 4 families with more than one child with type 1 diabetes.

The questions about "who is doing what in everyday life" were analysed descriptively to supplement the discussion of the mothers' and fathers' roles and responsibility related to the children's diabetes care.

As part of an international collaboration we performed a version of exploratory factor analysis with Geomin rotation to test more elaborately the psychometric properties of the Norwegian version of the HFS-P. The analysis was performed in Mplus, and polychoric correlations were used for handling the categorical nature of data. The factor analysis included only the mothers' reports on the HFS-P and was performed as part of a collaboration including a HFS-P dataset from the United States, a HFS-P dataset from Iran

and our HFS-P dataset from Norway. The results of the factor analysis were presented at the annual meeting of the European Association for the Study of Diabetes in Lisbon in September 2011 [191]. Exploratory factor analysis analyses the interrelationship among the items in a scale without any a priori hypothesis about the relationships [159]. The purpose is to investigate whether the factors displayed from the analysis support the construct of the scale.

4.6 Ethics

The study was performed according to the Declaration of Helsinki. Participation was voluntary, and the information sheet distributed to the parents stated that choosing not to participate would not affect the child's follow-up care at the clinic. The information sheet also stated that completed and returned questionnaires would be considered as consent for participating. The Western Norway Regional Medical and Health Research Ethics Committee (Ref: 06/5419, 2009/1030 and 2010/535) and the Norwegian Social Science Data Services (Project number: 14974) approved this procedure and approved an anonymous nonrespondent analysis including HbA_{1c}.

The survey included questions related to the child's physical health and sensitive questions on the parents' own life situation and mental health status. Answering the questions could be emotionally difficult for some parents. We therefore established an opportunity to refer parents with specific needs to the psychologist of the clinic's diabetes team. One mother contacted the clinic and was referred to the psychologist because of emotional problems related to the survey.

Table 2. Statistical analysis included in the study

Statistical analysis used	Article I	Article II	Article III	Dissertation
Descriptive statistics (mean, SD, percentage, range, scatterplot)	X	X	X	X
Analysis of variance (ANOVA)			X	
Independent-sample t-test	X	X	X	
Paired-sample t-test				X
Cronbach's alpha	X	X	X	
Fisher's measures of skewness and kurtosis				X
Pearson's correlation	X			
Bootstrap procedure (including bootstrap standard errors and/or BC_a 95% confidence intervals)	X			X
Spearman's rank-order correlations		X		X
Wilcoxon test		X		X
Generalized estimation equations (GEE) regression model	X	X		
Linear regression analysis			X	
Kruskal-Wallis test				X
Mann-Whitney test				X
Exploratory factor analysis				X

5. RESULTS

This chapter summarizes the main results from the three included articles in addition to the results from the additional analyses performed for this dissertation.

5.1 Assumptions for the analyses

The initial tests of the distribution of the included dependent variables in this study indicated no substantial divergence from the normal distribution for the HFS-P worry and behavior subscale scores and for the Family Burden Scale scores reported by the mothers and fathers, respectively, and for the children's HbA_{1c}. The histograms also did not identify problematic outliers. The skewness for these scales and for HbA_{1c} ranged from -0.28 to 0.68 and kurtosis from -0.49 to 1.12. The distribution of the HSCL-25 scores indicated, however, a substantial positive skewness, with low scores more common than high scores. The skewness was 1.74 and 1.93 and kurtosis 4.15 and 4.61 for the mothers' and fathers' scores, respectively.

We did not consider it necessary to transform the HSCL-25 data before the linear regression analyses were performed. Comparing the regression results with a HSCL-25 endpoint with the corresponding bootstrap results, there was mostly good agreement, although in some cases the bootstrap standard errors were somewhat higher and the bootstrap confidence intervals somewhat broader. In all cases in which the regression-based 95% confidence intervals contained the neutral value, so did the bootstrap-based confidence intervals, and vice versa. Nevertheless, the positive skewness of the mothers' and the fathers' HSCL-25 scores should be taken into account when interpreting the results of the parametric regression analyses including the HSCL-25 as dependent variable. No problematic outliers were identified among the HSCL-25 scores. Nonparametric tests were performed for comparing HSCL-25 scores between the parents of children in different age groups, between the parents of children with different duration of diabetes and between the parents of boys and girls, respectively (Appendix II, Table 1).

No substantial divergence from linearity was identified for the graphic presentation of associations between the dependent variables (HFS-P worry and behaviour subscales, Family Burden Scale, HSCL-25 and HbA_{1c}) and the continuous exploratory variables included in the various analyses (child age, duration of diabetes and HbA_{1c}).

The variance inflation factor did not indicate substantial interrelatedness between the explanatory variables included in the regression analyses performed. The variance inflation factors displayed were mostly <2. The highest value displayed was 3.29. The intercorrelations between the explanatory variables measured by Spearman's correlations also did not indicate problems with multicollinearity. The highest significant correlations identified were between child age and HbA_{1c} (r = 0.42, P < 0.001), between child age and duration of diabetes (r = 0.43, P < 0.001) and between the fathers perceived social support and life orientation (r = 0.44, P < 0.001). A few higher correlations were identified between dummy variables of the same original variable. The highest correlation between dummy variables was identified between category dummies of the variable frequency of self-monitoring of blood glucose (r = 0.76, P < 0.001).

Overall, few data were missing in the study. For each item in most of the included standardized scales, data from 0-5% of the mothers and fathers were missing. For the items in the Life Orientation Test, data from 2-7% of the fathers and 4-9% of the mothers were missing, and for the items in the HFS-P behaviour subscale, data from 3-9% of the mothers were missing. Only one father was excluded from the analyses because of too many missing items on the Family Burden Scale, one father was excluded from the analysis because of too many missing items on the Life Orientation Test and one mother and two fathers were excluded from the analysis because of too many missing items on the Relationship Satisfaction Scale. The three enclosed articles also describe the missing data and the use of missing substitution.

5.2 Characteristics of the children and parents

Among the parents of 161 children with type 1 diabetes, 103 mothers and 97 fathers representing 115 children 1-15 years old responded to the study questionnaire. The responses

from at least one parent of 115 of the children gave a response rate of 71.4%. In 86 cases both the mother and the father responded, in 18 cases only the mother and in 12 cases only the father. However, this did not indicate that the 18 mothers and 12 fathers were single parents but just that only one parent responded. Among the 115 families 4 families had more than one child younger than 16 years with type 1 diabetes.

The 115 children (57 boys and 58 girls) included had a mean age of 10.6 years (range 1.6-15.9) and mean duration of diabetes of 3.9 years (range 0.3-14.2). Of the 115 children, 17 had duration of diabetes of less than 1 year. One of these children had diabetes for 3.5 months and 5 children less than 6 months. All 115 children used an intensive insulin regimen with either ≥3 injections per day or CSII.

The children had mean HbA_{1c} of 8.1% (range 5.3-11.7%). The mean HbA_{1c} among the 98 children with ≥1 year duration of diabetes was 8.2%. Only 29% (33) of the 115 children had mean HbA_{1c} ≤7.5% as recommended by ISPAD [7], and 47% (54) had HbA_{1c} <8% as previously recommended. In total 24% (28) of the children had HbA_{1c} ≥9%. HbA_{1c} differed significantly between age groups with the lowest mean HbA_{1c} in the age group <6 years. Mean HbA_{1c} in the age group <6 years was 7.2% versus 8.0% in the age group 6-11 years and 8.4% in the age group 12-15 years. The bivariate regression analyses (Article III) indicated a significant but minor association between HbA_{1c} and the duration of diabetes in this study. HbA_{1c} increased 0.11% for every year of increased duration.

The parents of 23% of the children reported ≥7 problematic hypoglycaemic events in the past year. The parents of 69% of the children reported experiencing nocturnal hypoglycaemia at least once, and the parents of 21% experienced hypoglycaemia with unconsciousness at least once. The parents of 56% of the children reported 4-6 self-monitoring of blood glucose per day and parents of 31% reported ≥7 measurements per day. The parents of only 13% of the children reported ≤3 measurements per day.

Most of the parents (97%) included were of Norwegian ethnicity, most graduated from upper secondary school, about half had education at the university college or university level, 92% of the fathers and 37% of the mothers reported full-time employment and 45% of the mothers reported part-time work. Less than 15% of the parents reported single-parent status

(Article III). Of the responding parents, 10% (8) of the mothers and 8% (9) of the fathers reported having diabetes themselves.

5.3 Parents' fear of hypoglycaemia (Article I)

The results presented in Article I indicated that the fathers had a significantly lower HFS-P worry subscale score (regression coefficient -2.23, $P = 0.048$) and lower HFS-P behaviour subscale score (regression coefficient -2.97, $P < 0.001$) than the mothers. A key finding was the association identified between the parents' HFS-P worry score and the children's HbA_{1c} (regression coefficient 2.05, $P = 0.008$). The analysis also indicated that a higher worry score was associated with the child having a comorbid somatic disease or mental disorder (regression coefficient 3.93, $P = 0.006$) and reports of ≥7 problematic hypoglycaemic episodes in the past year versus no episodes (regression coefficient 5.06, $P = 0.005$). A lower HFS-P behaviour score was significantly associated with the use of CSII versus the use of insulin injections (regression coefficient -3.83, $P < 0.001$).

In accordance with the regression analysis for subscale scores, the additional paired-sample t-tests analysing differences between the mothers' and fathers' HFS-P total scores indicated a significant sex difference ($P = 0.002$), with the highest score among the mothers.

5.3.1 Results from additional analyses related to Article I

The additional analyses of differences in HFS-P worry subscale scores between the mothers and fathers of the children in different age groups, between the mothers and fathers of the children with duration of diabetes <1 year or ≥1 year, and between the mothers and fathers of boys and girls, respectively, did not indicate any significant difference between groups (Appendix II, Table 1).

Appendix II, Table 2a presents the analyses of bivariate associations between the explanatory variables included in the GEE analysis (Article I) and HFS-P worry and behaviour subscale scores performed separately for mothers and fathers. As did the GEE

analysis, these analyses identified a significant association between both mothers' and fathers' HFS-P worry subscale scores and a comorbid disease in the child. Further, significant associations between mothers' and fathers' HFS-P worry subscale scores and the frequency of problematic hypoglycaemic episodes in the past year were identified. The significant association between the HFS-P worry subscale score and the child's HbA_{1c} reported in Article I was only significant among the fathers in these bivariate analyses. Among the mothers, the HFS-P worry subscale score was significantly higher for self-monitoring of blood glucose at night every week or more often versus every month or less. In accordance with the results published in Article I, the bivariate analyses indicated significant associations between lower HFS-P behaviour subscale scores among both the mothers and the fathers and the use of CSII versus the use of insulin injections. In contrast to the GEE analysis, the bivariate analyses displayed a significant but minor association between lower HFS-P behaviour subscale score and higher child age. Among the mothers, a higher HFS-P behaviour subscale score was associated with higher frequency of self-monitoring of blood glucose, both daily and during the night (Appendix II, Table 2a).

The additional explorative regression analyses for mothers and fathers separately including the same explanatory variables as the GEE analysis presented in Article I did not differ substantially from the GEE analysis. The regression coefficients displayed for respectively the mothers and the fathers were mostly within the confidence interval identified in the GEE analysis. The use of CSII versus insulin injections was still associated with lower HFS-P behaviour subscale scores among both mothers (regression coefficient -3.69, $P = 0.011$) and fathers (regression coefficient -3.29, $P = 0.015$). The association between a higher HFS-P worry score and a comorbid disease in the child was only significant among the mothers (regression coefficient 5.67, $P = 0.021$) while the association between a higher HFS-P worry subscale score and ≥7 problematic hypoglycaemic events in the past year was only significant among the fathers (regression coefficient 6.30, $P = 0.035$). Accordingly, for the HFS-P worry subscale the highest standardized regression coefficient was identified among the mothers related to the variable "comorbid disease versus not" (beta 0.27, $P = 0.021$). Among the fathers, the highest standardized regression coefficient was related to the dummy variable "≥7 problematic hypoglycaemic events in the past year versus no episodes" (beta 0.29, $P = 0.035$). The highest standardized regression coefficient identified for the HFS-P behaviour subscale was for the association between lower scale scores and the use of CSII versus insulin injections among both mothers (beta -0.30, $P = 0.011$) and fathers (beta -0.28,

P = 0.015). The association between HFS-P worry subscale scores and HbA_{1c} was not statistically significant in the exploratory analyses.

The results of the exploratory analyses did not change substantially when the 4 families with more than one child younger than 16 years of age were excluded from the analysis.

The analysis related to HFS-P behaviour subscale including all 10 items or only 9 items, respectively (to test possible overlap between one of the items in the scale and one of the explanatory variables), did not indicate substantial differences between the analysis with or without the current item (Appendix II, Table 3).

The factor analysis performed for the mothers' HFS-P scores indicated the best fit for a four-factor solution (χ^2_{53} = 84.3 (P < 0.001), root mean square error of approximation = 0.008, standardized root mean square residual = 0.07, CFI = 0.94) with two factors for the HFS-P worry subscale: 1) child not having help or food available and 2) social and other negative consequences of hypoglycaemia, and two factors for the HFS-P behaviour subscale: 1) keep the child's blood glucose levels higher in some situations and 2) prevent hypoglycaemia [191].

An investigation of the mothers' and fathers' single-item scores on the HFS-P worry subscale and analyses of differences between the sexes regarding single-item scores (Appendix II, Table 4) have been published as a conference abstract [192]. As indicated in the table the highest scores among both mothers and fathers in addition to a significant difference between genders were identified on items 4, 9, 12 and 15 concerning worrying about night-time hypoglycaemia, worrying that no one would be around to help the child during a reaction, worrying about seizures or convulsions or worrying about the child having an insulin reaction. When these results are compared with the results from the factor analysis, all 4 items fit into the same factor described as the "child not having help or food available" [191].

A descriptive distribution of the mothers' and fathers' scores on items 4, 9, 12 and 15 in the HFS-P worry subscale indicated that 38% of the mothers and 20% of the fathers reported often or almost always worrying about night-time hypoglycaemia, 33% of the mothers and 23% of the fathers reported often or almost always worrying about hypoglycaemia with no

one being around to help, 23% of mothers and 14% of fathers reported often or almost always worrying about hypoglycaemia with seizures or convulsions and 37% of mothers and 29% of fathers reported often or almost always worrying about an insulin reaction in general.

5.4 Diabetes-related burden and emotional distress (Article II)

The results presented in Article II showed higher HSCL-25 scores among mothers than among fathers ($P < 0.001$). The mothers also scored significantly higher than the fathers on the item related to medical treatment in the Family Burden Scale ($P = 0.048$). The mothers' reports on all 5 items in the Family Burden Scale were significantly associated with their HSCL-25 scores (P values ≤ 0.014). None of the fathers' scores on the Family Burden Scale was associated with their HSCL-25 scores (P values ≥ 0.173). Table 3 presents the distribution of the parents' scores on the Family Burden Scale items.

Table 3. Distribution of scores on the Family Burden Scale items for the mothers (n=103) and fathers (n=97) of 115 children (1-15 years old) with type 1 diabetes

	Mothers			**Fathers**		
Family Burden Scale items:	Major or large %	Moderate %	Small or none %	Major or large %	Moderate %	Small or none %
1. Medical treatment	29.3	44.4	26.2	14.6	52.1	33.3
2. Disruption in family routine	11.4	45.4	43.3	20.9	43.8	35.4
3. Physical or psychological problems	14.1	37.4	48.5	13.7	42.1	44.2
4. Social activity and school restrictions	9.1	24.2	66.7	8.3	30.2	61.5
5. Long-term health concerns	53.5	35.4	11.1	47.9	38.3	13.9

The results from the GEE regression analysis confirmed an association between the parents' Family Burden Scale scores and their HSCL-25 scores. In addition, Family Burden Scale scores were significantly associated with ≥7 problematic hypoglycaemic episodes in the past year versus no episodes (regression coefficient 1.78, P = 0.002), and night-time self-monitoring of blood glucose every week or more versus every month or less (regression coefficient 1.42, P = 0.037). Parents who reported having experienced hypoglycaemia in the child while asleep reported higher HSCL-25 scores (regression coefficient 0.11, P = 0.012) than those who did not report experiencing nocturnal hypoglycaemia.

5.4.1 Results from additional analyses related to Article II

The additional analyses of differences in Family Burden Scale scores and HSCL-25 scores between the mothers and fathers of the children in different age groups, between the mothers and fathers of the children with duration of diabetes <1 year or ≥1 year, and between the mothers and fathers of boys and girls, respectively, did not indicate any significant differences between groups (Appendix II, Table 1).

Appendix II, Table 2b presents the analyses of bivariate associations between the explanatory variables included in the GEE analysis (Article II) and Family Burden Scale scores and HSCL-25 scores performed separately for mothers and fathers. These analyses confirmed the identified associations between higher Family Burden Scale scores and self-monitoring of blood glucose at night every week or more often versus every month or less. The significant association identified in the GEE analysis between Family Burden Scale scores and the frequency of problematic hypoglycaemic episodes was only significant among the fathers in these bivariate analyses. The association between Family Burden Scale scores and HSCL-25 scores was only significant among the mothers. The association between HSCL-25 scores and experiencing hypoglycaemia while asleep was in the bivariate analyses also only significant among the mothers, and higher HSCL-25 scores among the mothers were positively significantly associated with self-monitoring of blood glucose at night every week or more often versus every month or less. The bivariate analyses displayed some significant positive associations between the mothers' and the fathers' HSCL-25 scores and higher frequency of problematic hypoglycaemic episodes in the past year (Appendix II, Table 2b).

The additional exploratory regression analyses for mothers and fathers separately did not differ substantially from the results of the GEE analysis presented in Article II. The regression coefficients were mostly within the confidence interval identified in the GEE analysis for both Family Burden scale and HSCL-25. However, among the mothers all the associations were insignificant for both scales except for a positive significant association between the Family Burden Scale score and the HSCL-25 score (regression coefficient 3.75, $P < 0.001$). Among the father's a minor significant association was identified between higher HSCL-25 score and higher age of the child (regression coefficient 0.02, $P = 0.020$), and a significantly higher HSCL-25 score was identified among those who have experienced hypoglycaemia in the child while asleep (regression coefficient 0.12, $P = 0.042$). The results did not change substantially when excluding the 4 families with more than one child <16 years of age from the analysis.

5.5 Psychosocial family factors associated with HbA_{1c} (Article III)

The results presented in Article III related to the contextual aspects among the parents showed significant associations between the children's HbA_{1c} level and 1) the mothers' education at a university or university college level versus a lower level (regression coefficient -0.58, $P = 0.008$), and 2) strong versus none or slight experience of social limitation among the mothers (regression coefficient -0.62, $P = 0.022$) in multivariate regression analysis. The fathers' contextual sources of stress and support were not associated with the children's HbA_{1c} level. Table 4 shows the distribution of the parents' reports regarding perceived social limitation.

Table 4. Distribution of reports of perceived social limitation because of a child's diabetes among the mothers (*n*=103) and fathers (*n*=97) of 115 children (1-15 years old) with type 1 diabetes

Perceived social limitation:	Mothers %	Fathers %
Strong	20.4	16.5
Somewhat	27.6	27.8
None or slight	52.0	55.7
Total	100	100

The bivariate analyses presented in Article III indicated that the children's HbA_{1c} level was significantly associated with self-monitoring of blood glucose ≥7 versus ≤3 per day (regression coefficient -0.79, $P = 0.019$). In addition, the use of CSII versus the use of insulin injections was associated with a significantly higher HbA_{1c} (regression coefficient 0.41, $P = 0.033$). The children's age was positively associated with HbA_{1c} in both bivariate analysis (regression coefficient 0.13, $P < 0.001$) and multivariate analysis (regression coefficient 0.12, $P < 0.001$), and a scatterplot indicated a nearly linear relationship between higher age and higher HbA_{1c} between 7 and 12 years of age.

The characteristics of the children presented in Article III indicated higher frequency of self-monitoring of blood glucose among the youngest children than among the children ≥12 years of age. Among the children <6 years of age, 46% got their blood glucose measured ≥7 times per day compared with 21% of the children ≥12 years of age. All the children in the youngest age group got their blood glucose measured >3 times per day, while 19% of the children ≥12 years of age self-monitored blood glucose ≤3 times per day.

5.5.1 Results from additional analyses related to Article III

The additional descriptive analysis of the questions concerning "who is doing what in everyday life" indicated that mothers were responsible for the child's diabetes care more often than fathers (Appendix II, Table 5). In between 50% and 77% of the families, the parents reported shared responsibility between the mother and the father or between the mother, father and the child. The reports from the mothers and the fathers showed that the father or the father together with the child were responsible for the various diabetes-related tasks in less than 6% of the families. The mothers were reported to be the responsible alone or together with the child in 18-43% of the families. The reports from the mothers and the fathers differ. The fathers reported their responsibility sharing with the mothers to be higher than the mothers' reports indicated (Appendix II, Table 5).

6. DISCUSSION

6.1 The application of the theoretical framework in the study

At the point of origin, this study was not based on a specific theory. The objectives of the study were formulated based on previous research and clinical experiences. We have, however, used the schematic figure of the adapted Belsky model [74] (Fig. 1, section 2.2.2.1) as an organizing framework for the substudies described in Articles I-III. This framework has informed the study and helped us to consider the study objectives in a broader and more holistic context of determinants of parenting children. In the substudies presented in Articles I and II, we primarily investigated the link between the characteristics of children and the parents' psychological resources which is one of the links that Sherifali & Ciliska [74] missed in the original schematic model of Belsky. In the substudy presented in Article III, we also used the adapted Belsky model as organizing structure for the construction of the analysing model and the choice of variables to include. The choice of variables to include was, however, limited by the available variables in the study questionnaire.

Polit & Beck [159] distinguish between theories, conceptual models and schematic models. They claim that conceptual models and schematic models represent a less formal attempt at organizing phenomena than theories. Belsky's determinants of parenting is called "a model" [10]. In Belsky's explanation of his model, he describes, however, an abstract generalization that offers a systematic explanation about how phenomena are interrelated, which Polit & Beck describe as characteristics of a theory. Nevertheless, Polit & Beck claim that theories and models have much in common and that both theories and models can be used as framework in research.

The literature describes different ways to use theoretical or conceptual frameworks in research. Painter, Borba et al. [193] described a continuum for the varying degrees of using a theory from studies that are simply informed by theory, to studies that apply or test theory more explicitly, to studies that build and/or extend theory. The authors described being

informed by a theory as a "theoretical framework or construct identified but no or limited/partial application of theoretical framework in study components and measures". By reviewing health behaviour research in 2000-2005, Painter, Borba et al. [193] identified that most health behaviour research using a theory was informed by the theory and that a quite small proportion of the studies using a theory really tested the theory. Accordingly, Polit & and Beck [159] suppose that most nursing studies using theoretical or conceptual frameworks use them primarily to provide an interpretive context or an organizing structure for their studies, as we have done in this study.

The arrangement of the variables included in the study into the different concepts of the adapted Belsky model (Fig. 2, section 4.3.5) helped us to view our variables and our substudies in a broader context of parenting children. However, the placement of some variables into the model could be discussed, such as our interpretation of self-monitoring of blood glucose as an indicator for parenting behaviour. Based on the literature [89-92, 123, 125, 153, 157], we considered it, however, appropriate to view self-monitoring of blood glucose as a marker for diabetes-related parenting behaviour among both children and adolescents (see also section 2.3.3.2). Further, it could be discussed whether a child's HbA_{1c} should be viewed as a characteristic of the child or a marker for child development. We found it appropriate to view HbA_{1c} as a characteristic of the child, while a child's HbA_{1c} continuously changes and obviously influences and is influenced by factors related to the management of the child's diabetes in daily life.

As stated by Luster [70] and Meyers [71], many variables may be potential important when considering Belsky's determinants of parenting process model related to a specific group of parents. They further stated that the choice of variables to include in a study should be based on the sample and the objectives of the study. Accordingly, among the parents of children with type 1 diabetes in our study, other variables could have been appropriate measures of the concepts of the adapted Belsky model. The aim of the present study was, however, not to validate or test the adapted Belsky model, but to study associations between potential important determinants of parenting children with type 1 diabetes. In accordance, we did not include variables related to all the concepts in the adapted model. Variables related to the parents' developmental history and child development were not included. If the adapted Belsky model constituted the basis for the development of the study, other variables should also have been considered, such as variables related to parenting behaviour. The main

purpose of the original Belsky determinants of parenting model was, accordingly, to explain and understand the determinants of parental functioning [10].

6.2 Methodological considerations

The next sections discuss considerations related to the cross-sectional study design, the scales included in the study, the sample and sample size, the statistical analyses performed, and possible confounders and biases. The emphasized features deal with and influence the reliability and the validity of the study. The reliability of a study refers to the degree of consistency and dependability of the assessments of the attributes and validity is a quality criterion based on consideration of factors that can weaken the inferences of the study [159].

6.2.1 The cross-sectional study design

The main aim of the study was to analyse associations between the self-reported psychological and contextual characteristics of parents, diabetes-related behaviour and the characteristics of children with type 1 diabetes. Accordingly, the cross-sectional study design is considered appropriate when the purpose is to describe associations between phenomena at a fixed time [159]. The cross-sectional study design, however, has some important limitations. The design makes drawing conclusions about causality between variables impossible. Polit & Beck [159] emphasize three criteria for causality. The first is *temporal*: a cause must precede an effect in time. The second is an *empirical relationship* between the presumed cause and the presumed effect, and the third is related to *confounding variables*; the relationship cannot be explained as being caused by a third variable. Accordingly, we cannot conclude about cause and effect between variables in this study, although the direction of causation seems obvious in some cases. The data collection was performed at one fixed time which makes it impossible, for example, to clarify the direction of causality between the parents' fear of hypoglycaemia and the child's HbA_{1c} level. Nor can we exclude the association being influenced by a third confounding variable (see section 6.2.5). In the three articles enclosed, however, we have discussed possible explanations for the identified associations based on the results from previous research.

The cross-sectional design cannot provide information related to changes over time and is therefore not an appropriate design for validation of theoretical process models such as the Belsky's determinants of parenting model. In accordance with the statement of Bronfenbrenner [64] it is, however, important to understand the associations between various determinants of parenting to make sense of parenting practices, which could be appropriately investigated by a cross-sectional design.

6.2.2 The scales included

The scales included in the study are internationally acknowledged instruments that have shown good psychometric qualities in previous studies. Nevertheless, some limitations and weaknesses need to be mentioned.

The HFS-P has been used in several studies, but there is no manual for interpreting the results. Nor is there any cut-off point to indicate a serious level of fear (Article I). It has also been questioned whether the HFS-P behaviour subscale measures both inappropriate behaviour related to fear and appropriate behaviour to avoid hypoglycaemia [107, 168]. The relatively high Cronbach's alpha (0.89 for both mothers and fathers) may indicate that the number of items in the HFS-P worry subscale could be reduced. Based on a comparison of single-item scores and the factor analysis performed [191], some items related to the factor described as "social and other negative consequences of hypoglycaemia" might be excluded. Accordingly, an international study including our HFS-P data and datasets from various countries has been established to consider the composition of both the HFS-P and other versions of the Hypoglycemia Fear Survey, to countering the mentioned weaknesses of the scales and to prepare a manual for the instruments. In relation to the one item in the HFS-P behaviour subscale and the one additional item concerning both concerning the child's carrying of emergency glucose, our additional analyses did not indicate a problematic overlap between the variables (Appendix II, Table 3).

The choice of generic instruments to assess psychological resources (Life Orientation Test) and contextual resources (the Oslo 3-item Social Support Scale and Relationship Satisfaction Scale) related to the parents may have both strengths and limitations (Article III). The strength is the possibility of comparing the results from this study with the results from other

studies with other samples of parents. However, one may question whether the generic instruments really capture the disease-specific needs related to the personal and contextual resources that are important for improving the health outcomes among children with type 1 diabetes. The literature has also previously emphasized the methodological problems related to inadequate or too general measurements for revealing disease-specific needs [194-196]. Accordingly, the weak Cronbach's alpha for the mothers' scores on the Oslo 3-item Social Support Scale that caused the scale to be excluded from the analysis of the mothers' report, may result from a few items in the scale or from the mothers' mixture of perceived general social support and disease-specific social support.

6.2.3 The sample and sample size

The study included almost all children with type 1 diabetes who fulfilled the inclusion criteria in the geographically limited area of Hordaland County. Although we cannot exclude that few children on the extreme border of the county may have been followed up in the adjacent county, the sample should be considered a population-based sample of children with type 1 diabetes and their parents. This is strength. However, the parents' homogeneous ethnic background, level of education, employment status and marital status need to be taken into account when considering the generalizability of the results to other populations of children with type 1 diabetes and their parents.

Despite a population-based sample, the missing responses from a group of parents may entail a sampling bias: systematic over- or underrepresentation of members of the population with specific characteristics [159]. An approved nonresponse analysis based on limited data from the children's medical records indicated that the children of the nonrespondent parents were 1.7 years older ($P = 0.04$) and had a duration of diabetes 1.3 years longer ($P = 0.016$) than the children of the responding parents. The results, however, did not support these differences being meaningful, while no significant associations were identified between the children's age and duration of diabetes and the parents' fear of hypoglycaemia and diabetes-related burden. In addition, the children of the respondents and nonrespondents did not differ in mean $HbA_{1c.}$ In relation to other variables, we cannot exclude other social or psychological factors among parents as motives for not participating in the study and subsequently a difference between the respondents and nonrespondents on specific variables.

It would have been an advantage for the study to have some psychosocial information about the nonrespondent parents. We did, however, not have such information and we did not consider it as justifiable to ask additional questions to parents who declined to participate in the study. A response rate above 70% is normally viewed as satisfactory, although the possible sampling bias related to nonrespondent parents should be kept in mind when interpreting the results.

Strengths of the study include the sample size compared with other studies in the field and the inclusion of both mothers and fathers of children of all ages between 1 and 15 years old. Nevertheless, the sample size limited the ability to include all possible relevant variables in the analysis models. For example, based on the literature review on parental fear of hypoglycaemia we excluded the children's sex as a covariate in the regression analyses. Based on the results of the Hvidøre study in 1998 [113], which indicated higher perceived diabetes-related family burden among parents of boys than among parents of girls, sex should perhaps have been considered as a possible important covariate to include in the analyses related to the three articles. However, in the additional analyses of differences between parents of boys and girls (Appendix II, Table 1) and in the bivariate regression analyses (Appendix II, Table 2a and 2b) we did not identify the parents' fear, burden or emotional distress as differing significantly between the parents of boys and girls.

The sample size limited subgroup analysis. To overcome the challenges related to the limited degrees of freedom when designing analysis models, we recoded and reduced the categories for some categorical variables, as described in the results section. In addition, using Belsky's determinants of parenting model made selecting variables to include in the analysis model reported in Article III more structured. Using the GEE procedures for regression models (Article I and II) also maximized the use of the data from all the participating parents.

6.2.4 The statistical analyses

The choice of using the GEE procedure for regression models for the analyses in Articles I and II was primarily based on the correlated structure that exist between the mother and father of a common child. The dependent variables in these analyses were on the parents' level, which included 200 (103 mother and 97 fathers) respondents. The GEE regression

analyses maximized the use of the data from all the participating parents and allowed us to include some more explanatory variables in the analysis models compared with what a normal linear regression model separately for the mothers and fathers would allow. Separate normal linear regression models would, however, display more clearly how each explanatory variable was related to the dependent variable among the mothers and fathers, respectively. We therefore performed exploratory additional regression analyses in this dissertation separately for the mothers and the fathers. There is, however, uncertainty related to these exploratory analyses because of the somewhat larger models than would have been appropriate if they had been planned as primary analyses for mothers and fathers separately. Accordingly, we did not perform further additional analysis in other and smaller subgroups based on the same model as the GEE regression analyses in Articles I and II. The results from the comparison of mean scale scores in subgroups of parents indicated no significant differences in mean scale scores between subgroups of parents (Appendix II, Table 1),

The bivariate (uncorrected) analyses performed separately for mothers and fathers (as additional analyses to the GEE regression analyses presented in Articles I and II) gave some additional information about differences between the parents despite the limitation of not correcting for other important explanatory variables. However, the purpose of the regression analyses presented in Articles I and II was not mainly to analyse differences between mothers and fathers but to analyse associations between the characteristics of children and the psychological characteristics of parents in general. The discussion of differences between mothers and fathers presented in Articles I and II was primarily based on the correlational analyses and comparison of mean scale scores.

Based on the literature review, we considered it appropriate to compare the mean scale scores between the parents of children in the age groups 1-5, 6-11 and ≥12 years, between the parents of children with duration of diabetes <1 year or ≥1 year, and between the parents of boys and girls (Appendix II, Table 1). We decided not to compare the parents of children above and below the mean age and above and below the mean duration of diabetes. In the literature there exists some resistance against forking appeared from the data itself [197].

The choice of using a linear regression model for analysing the HSCL-25 despite the positive skewness of this variable could be discussed. The variable may have been transformed

before analysis, or nonparametric analysis could have been performed. Walters & Campbell [185] have, however, concluded that linear models such as multiple regression analysis and t-test seems to be robust to the violation of assumptions that some health-related scales are likely to cause (that is, skewness and non-normality). Like in this study, they compared the results from analyses using linear models with results from analyses using the computer intensive nonparametric method, the bootstrap. Their comparison was performed in four data sets, all including health-related quality of life data measured using the SF-36 Health Survey. As in this study, standard error and confidence intervals did not differ significantly between the ordinary linear regression and the bootstraps.

The results from the GEE analyses presented in Articles I and II, the results from the additional bivariate analyses for mothers and fathers separately and the results from the exploratory multivariate regression analyses for mothers and fathers separately differ somewhat, as expected. The separation between the mothers' and fathers' results causes obviously some different results. Accordingly, the results of bivariate uncorrected analyses differ from those of corrected multivariate models. The exploratory multivariate analyses performed separately for mothers and fathers entail high uncertainty because many variables are included in the analyses in such small samples. All the results from the various regression analyses did, however, display important similarities and significant associations between the characteristics of children with type 1 diabetes and psychological aspects among mothers and/or fathers, and the general discussion of the dissertation emphasizes this (section 6.3).

6.2.5 Biases and confounders

A common problem in behavioural research is an occurrence of interrelatedness of the independent variables; multicollinearity [186]. As indicated in the results section, this was not a problem in our study, which contributes to strengthening the validity of the study conclusions. Further, the identified linearity between the dependent variables and the continuous explanatory variables strengthens the validity of the study results. When interpreting the results of a cross-sectional study, one should, however, be aware of the possibility that any covariation identified between two variables could be caused by a

common underlying variable. Such a confounding bias is defined as a bias of the estimated effect of an exposure variable on an outcome variable caused by the presence of a common cause of the exposure and the outcome [198]. A confounding variable is defined as an extraneous variable that confounds or obscures the association between two variables [159]. The multiple regression analysis performed (Article I, II and III) included several explanatory variables and control variables to control presumed confounding variables. Such control is viewed as a critical tool for managing bias and enhancing the validity of the study conclusions [159]. However, all feasible confounders cannot be controlled for when studying psychosocial variables and human behaviour, as in this study. Thus, confounding bias should be accounted for when discussing and interpreting results, such as the possibility that an underlying family factor affects for example both the parents' fear of hypoglycaemia and the child's glycaemic control (Article I). The correlation coefficients often achieved when correlating psychosocial or behavioural variables show the complexity of variables influencing human emotions and human behaviour. Correlation coefficients are typically between 0.2 and 0.4 [159], as obtained in this study (Articles I and II).

Possible mediating variables should be considered in interpreting the associations identified between variables in this study. A mediating variable is a variable that "goes between" variables in a causal chain linking other variables [159]. It is reasonable to interpret, for example, the association between higher perceived social limitation among mothers because of the child's diabetes and the child's HbA_{1c} level as being mediated by, for example, mothers' high ambition (as discussed in Article III) or more meticulous home management, as indicated in a previous study [115].

Further, possible self-report biases should be considered in this study as in all surveys. The variable "problematic hypoglycaemic episodes" may cause self-report bias because of the lack of a clear definition of "problematic episodes". Even with a clear definition, there is uncertainty related to self-reports of hypoglycaemic events regarding both the self-report bias and recall bias. This problem is emphasized in the literature [199], and the prevalence of hypoglycemic events is reported to vary greatly between studies. Underestimation is presumed also for the severe episodes with unconsciousness and/or convulsion because of the challenges related to both self-report and recall.

Differential item functioning, which arises when one or more items in a scale behave differently in various subgroups of the sample [183], might also be a problem in this study. We have questioned (Article III) whether some mothers mixed perceived general social support and disease-specific social support when responding to the Oslo 3-item Social Support Scale. In addition, factors such as age, socioeconomic status or the characteristics of the child's diabetes may cause respondents to interpret items in a scale differently.

Although we encouraged the mothers and the fathers to answer the questionnaire separately in the information sheet, we have no control over the circumstances related to the response situation. The potential effects of such biases should be kept in mind when discussing and interpreting the results.

6.3 General discussion

The study has identified significant associations between the self-reported psychological and contextual characteristics of parents, diabetes-related behaviour and the characteristics of children with type 1 diabetes.

6.3.1 Parents' fear of hypoglycaemia

The association identified between increased parental fear of hypoglycaemia and increased HbA_{1c} values among the children (Article I) is important and needs further attention. The results from the additional bivariate analyses in this study indicated, however, that this association was only significant among the fathers. Nevertheless, it is important to explore further whether parental fear of hypoglycaemia could cause lower insulin doses and subsequently higher HbA_{1c} levels among children with type 1 diabetes. Based on this study, we cannot draw any conclusion about this. In relation to the association identified, we cannot exclude a confounding variable causing both increased fear among parents and poor glycaemic control among the children. The question of whether parents' short-term concern can cause poor long-term health outcomes among their children needs to be treated seriously. For further cross-sectional studies, the sample size seems to be a critical point. The quite

small sample sizes in many previous studies may explain the divergent results achieved. In addition to our study, only two previous studies have significantly associated more parental fear and increased blood glucose levels among the children [99, 100]. Larger multicentre studies including national and/or international collaboration are recommended.

Evidence from our study and previous reports [99, 109-111] indicates that parents' experiences with hypoglycaemia in their child are correlated with their fear of hypoglycaemia. Thus, more problematic or severe experiences are associated with more fear. Further, we identified important differences between mothers' and fathers' levels of fear. The mothers reported both more hypoglycaemia-related worrying and more preventive behaviour to avoid hypoglycaemia than the fathers. Various explanations for the sex differences could be suggested. The explanation for elevated worrying among the mothers compared with the fathers may be that women often report higher levels of distress than men, but other explanations may also be possible. As indicated in this study (Appendix II, Table 5) and in previous reports, mothers are more often than fathers the ones who manage diabetes in everyday life [128, 133]. This may explain both the increased worrying and the increased use of preventive behaviour among the mothers versus the fathers. Health care professionals should consider the differences between the parents when discussing roles and responsibilities related to parenting a child with type 1 diabetes in consultations. In some cases, suggesting that fathers become more involved in managing the child's diabetes may be appropriate to lessen the strain on and worrying of the mothers.

For single-item scores on the HFS-P worry subscale, mothers and fathers reported the highest scores on approximately the same items. Both mothers and fathers reported most worrying related to night-time hypoglycaemia, hypoglycaemia when no one is around to help and hypoglycaemia resulting in seizures or convulsions (Appendix II, Table 4). Although both mothers and fathers had the highest scores on these specific items, the mothers reported significantly more worrying than the fathers on these items. The mothers seem to be more worried than the fathers about both severe hypoglycaemia occurring and about the risk that the child will not receive suitable treatment when hypoglycaemia occurs. Health care professionals supporting the families of children with type 1 diabetes should be aware of these sex differences. In addition to discussing the mothers' and fathers' roles and responsibilities, offering different support for mothers and fathers may be appropriate. However, more research is needed to further explore the differences we have identified.

It is reasonable to claim some fear of hypoglycaemia as being appropriate for the parents' awareness and prevention of severe hypoglycaemic episodes among their children, but worrying resulting in emotional distress may be inappropriate and could be associated with inappropriate behaviour. The lack of HFS-P cut-off points for serious worrying and inappropriate preventive behaviour make the division between appropriate and inappropriate action complicated. Despite the lack of cut-off points, previous reports have stated that the parents of children with type 1 diabetes significantly fear hypoglycaemia [99, 100, 111]. In our opinion, drawing this conclusion based solely on the mean HFS-P subscale scores alone is problematic. Nevertheless, although the mean subscale scores in our study were not remarkable, the descriptive distribution of the scores for single items of the HFS-P worry subscale indicated that 20-40% of the parents reported often or almost always worrying about night-time hypoglycaemia, hypoglycaemia with no one being around to help, hypoglycaemia with seizures or convulsions and insulin reactions in general. Based on these results, it is reasonable to conclude that many parents have significant fear related to hypoglycaemia. Suggesting regularly assessing the parents' fear of hypoglycaemia may be appropriate to avoid negative outcomes for children with type 1 diabetes and their parents.

6.3.2 Glycaemic control and the diabetes dilemma

For most chronic conditions, treating and preventing the immediate symptoms are correlated with promoting long-term health. This is not the case in diabetes. Preventing the immediately hypoglycaemic episodes involves keeping blood glucose levels higher, which subsequently increases the risk of long-term complications. This study has shown significant fear of hypoglycaemia among the parents. Nevertheless, more than half of the parents reported a major or large burden related to concerns about long-term complications (Table 4). This conflict between the immediate and long-term interests can be called the "diabetes dilemma" and may be an important factor why only 29% of the children in this study reach treatment goals for blood glucose regulation with $HbA_{1c} \leq 7.5\%$ as recommended by the ISPAD guidelines [7].

Optimally balancing preventing hypoglycaemia and preventing long-term complications is a great challenge for the parents of children with type 1 diabetes. Some parents have described

this balance as walking on a tight rope. Frequent self-monitoring of blood glucose has been shown to be important in managing the balance between hypoglycaemia and hyperglycaemia [56, 114, 123, 125, 138, 146, 152-155]. The parents in our study reported many daily measurements. Thus, the parents of 87% of the children reported ≥4 measurements per day, and the parents of 31% of the children reported ≥7 measurements per day. The blood glucose measurements need to be followed by a decision related to a need for action in administering insulin or food. Keeping a child's blood glucose in balance is demanding. The parents seem to perceive the night-time measurements as extra burdensome. The association identified between the use of CSII and less preventive behaviour among the parents may indicate a more predictable blood glucose concentration and/or fewer experiences of problematic hypoglycaemic episodes among children using CSII than among children receiving insulin injections. Maybe the use of CSII could be recommended for the children of parents perceiving burden and emotional distress related to night-time measurements and nocturnal hypoglycaemia. However, the children using CSII in the study did not have an overall better glycaemic control as measured by HbA_{1c} than those receiving insulin injections.

In accordance with the Hvidøre studies [5, 52] this study did not support with any statistical significance using the most intensive insulin regimen such as CSII to achieve optimal glycaemic control among children (Article III). However, frequent self-monitoring of blood glucose seems to contribute significantly to optimal glycaemic control. The association between high frequency of self-monitoring of blood glucose and better glycaemic control and the association between strong perceived social limitation and better glycaemic control may indicate strict and ambitious parenting, which has some costs for the mothers. High ambition may also create difficulty in transferring the responsibility for the child to someone else occasionally. The association between a higher level of education among mothers and better glycaemic control among children may be related to the complicated and demanding disease treatment and the fact that "it costs to be among the best". This study cannot conclude about the causality between the mentioned variables, but diabetes teams and health care providers should create treatment plans and develop interventions for all types of families with diverse types of social background. Today's insulin regimens and diabetes management plans may be too complicated and demanding for some families. In a recent study in Sweden, 252 parents of children with type 1 diabetes (<18 years of age) reported significantly more symptoms of burnout than the parents in a control group [200]. Of the parents of children with diabetes, 44% of the mothers and 28% of the fathers scored as

having clinical burnout [201]. The reported burnout was associated with low social support, lack of leisure time, financial concerns and a perception that the child's diabetes affects everyday life.

6.3.3 Emotional distress

This study has found that fear of hypoglycaemia is correlated with emotional distress among parents of children with type 1 diabetes (Article I). Among the mothers, we have also found that the diabetes-related family burden is correlated with emotional distress as measured by symptoms of anxiety and depression (Article II). Although we cannot conclude about the causality between variables, it is reasonable to assume that childhood type 1 diabetes is a risk factor for increased emotional distress, as expressed by symptoms of anxiety and depression, especially among mothers. In our study, 11% of the mothers and 5% of the fathers reported considerable symptomatic emotional distress, with HSCL-25 scores ≥1.75 (Article II). We did not include a control group of parents in this study and cannot therefore conclude about the rates of emotional distress in this population compared with the general population of parents in Norway. Data from Statistics Norway (http://www.ssb.no/english) did not indicate significantly different levels of emotional distress between the general population of Norway and our population of mothers and fathers. Accordingly, Sullivan-Bolyai, Deatrick et al. [101] found that the mothers of children with diabetes and the mothers in a control group had similar levels of general stress as measured by the Parenting Stress Index. They concluded that the mothers over time adapt to the challenges related to managing diabetes and that managing diabetes drew the mothers' attention away from other parenting tasks that mothers in general reported as being stressful.

Night-time caregiving is one task that seems to increase the stress levels among the parents of children with type 1 diabetes and the parents of children with other chronic diseases [108, 202, 203]. The significant fear of night-time hypoglycaemia and the association between nocturnal hypoglycaemia and emotional distress identified in this study support this conclusion. Our study (Article II) also correlated frequent night-time measurements with increased perceived diabetes-related burden. Although mothers reported more fear of nocturnal hypoglycaemia than did fathers, we do not know anything about sex differences related to the burden of night-time caregiving. Nor do we know which parent carried out the

night-time measurements reported in our study. Nevertheless, it may be important to discuss with the families more in detail how they can manage treatment tasks in the evening to prevent nocturnal hypoglycaemia and further increase the parents' feeling of security at night without frequent night-time measurements. Clear guidelines for night-time tasks may contribute to reducing the stress of parenting while inconsistent routines for night-time blood glucose measurements have been related to increased parenting stress [108].

Both clear guidelines and a sense of security around the treatment of hypoglycaemia may be important in reducing the parents' levels of perceived stress and symptoms of emotional distress. The parents in our study are concerned that no one might be around to treat an episode of hypoglycaemia. The significant association between increased worrying about hypoglycaemia and a comorbid disease in the child (Article I) may result from the same lack of security related to the treatment of a possible episode of hypoglycaemia. The reason parents lack security may differ between the parents of children with, for example, coeliac disease and the parents of children with hyperactivity disorder. The increased worrying among the parents of children with an additional disease could, however, also be explained by the overall increased responsibility for the child's health.

Although most parents seem to adapt well to a child's diabetes, health care providers should not ignore the parents who experience considerable fear, burden and emotional distress because of a child's diabetes. In addition to the 11% of mothers and 5% of fathers with considerable symptomatic emotional distress, 20-40% of the parents in our study reported significant fear of hypoglycaemia and 50% reported a major or large burden related to their concern about the child's future health. Of the mothers, 30% reported a major or large burden related to the medical treatment and 20% reported strong social limitation because of the child's diabetes. The results may indicate a need for arenas and interventions in which these groups of parents can raise and discuss their concerns without the child being around. Help may also be needed to educate and build a network around the families: a network of people that the parents easily can trust to manage the diabetes dilemma related to hypo- and hyperglycaemia when the parents are not present.

6.3.4 Mother, father and child

One of the most significant changes in society during recent decades is the increasing frequency at which families and established relationships break up. It has been well documented that such break-ups have psychosocial and health-related consequences both for the couple and for any children [204]. The burden of having a child with a chronic disease may be a risk factor in developing relational problems within a family. However, most children in our study lived together with both parents, and only 15% of the mothers and 12% of the fathers reported being single parents. We did not find any association between single-parent status and children's health outcome as measured by HbA_{1c} (Article III), although many previous studies have reported that the children of single parents have poorer glycaemic control than the children from two-parent households [26, 57, 93, 123, 142, 144-149].

An unequal distribution of care giving and a lack of appreciation of the partners' role may result in conflict in a family [205, 206]. Accordingly, the differences between the parents' fear, perceived burden and emotional distress identified in this study may cause conflicts between the parents. Preventing conflicts may require discussing the differences with the parents to achieve mutual appreciation of the partners' roles and emotions. In accordance with the results of this study (Appendix II, Table 5), also previous studies have shown that the parents often perceive the division of the responsibility for managing the child's diabetes differently [207, 208]. Thus, fathers reported taking more responsibility for the diabetes management than mothers reported them to do. In our study between 51 and 64% of the mothers and between 62 and 77% of the fathers reported shared responsibility for the various diabetes-related tasks in everyday life (Appendix II, Table 5). Although the results indicated that the mothers more often than the fathers are the responsible for the management of a child's type 1 diabetes, the fathers' involvement in managing children's chronic diseases has been reported as being important for both reducing emotional distress among mothers and improving family functioning [128, 130].

The associations between the children's HbA_{1c} and the mothers' level of education and perceived social limitation may also support the interpretation of the mothers as most often being the primary caregiver. Accordingly, a group of fathers of children with type 1 diabetes

have described distancing as a conscious coping strategy [209]. The fathers described their purpose as a conscious distancing from disease-related issues to lessen the anxiety of the mothers. Further, they described a focus on the child's strengths. Without a clarifying discussion, the partner is likely to view distancing as a coping strategy negatively, and this may subsequently contribute to conflict.

Unexpectedly, we did not find that the children's age or the duration of diabetes were significant associated with parental fear, burden or emotional distress (Article I and II), but the children's age was significantly associated with their glycaemic control (Article III). It is well known that HbA_{1c} is higher among adolescents than among younger children. Hormonal changes and reduced insulin sensitivity may be reasons for the increasing HbA_{1c} during this period, but social and psychological factors may also play a role. However, to our knowledge, previous publications have barely discussed the explanation for the increasing HbA_{1c} found among children in the period between 7 and 12 years old. The reasons for the increased HbA_{1c} may be other than physical ones. Our study could not identify the explanation for this association, but based on previous literature, we suggested that the transfer of responsibility from parents to children might be an important issue (Article III). As a child grows, the roles change, and parents should gradually transfer the responsibility for the daily treatment tasks to the child. Too early transfer of responsibility has been reported to be associated with poor glycaemic control [89]. Accordingly, the parents may need to receive adjusted guidance in the process of transferring responsibility and motivation for treatment tasks to their child with type 1 diabetes.

6.3.5 Parenting children with type 1 diabetes: a complex process

The adapted Belsky determinants of parenting model indicates that the process of parenting children is a complex process. The variation in the objectives, instruments used and results presented in previously published diabetes parenting research supports this complexity. Accordingly, our study has identified various significant associations between the characteristics of the children with type 1 diabetes and fear of hypoglycaemia, emotional distress and perceived diabetes-related family burden among the parents in the chronic course of the children's type 1 diabetes. Further, the study has identified significant associations between contextual factors related to the mothers and glycaemic control among

the children. Finally, significant associations have been identified between the action of measuring the children's blood glucose and both the characteristics of the children and the psychological characteristics of the parents. The associations identified should be taken into account both in clinical practice and future research, although our study's contribution to exhaustive understanding of the parenting process related to children with type 1 diabetes is limited. We perceived the adapted Belsky model as an appropriate organizing framework that places the variables and objectives of the study into a broader context of parenting children, although the model inherently enables many other variables to be included than those included in our study.

7. CONCLUSIONS AND IMPLICATIONS

This study has identified significant associations between the psychological and contextual characteristics of parents, diabetes-related parenting behaviour and the characteristics of children with type 1 diabetes. Parental fear of hypoglycaemia was associated with a comorbid somatic disease or mental disorder in the child, high frequency of problematic hypoglycaemic events and poor glycaemic control. Higher parental perceived burden was associated with ≥7 problematic hypoglycaemic events in the past year and self-monitoring of blood glucose at night every week or more often. Mothers' higher education and higher perceived social limitation were associated with better glycaemic control among the children, and the youngest children and those with the best glycaemic control as measured by HbA_{1c} had the highest frequency of self-monitoring of blood glucose. The children's age and duration of diabetes were not significant associated with the parents' fear of hypoglycaemia and perceived diabetes-related burden, but the study showed that achieving satisfactory treatment outcomes among children with type 1 diabetes has some costs, especially for the mothers. Mothers reported more fear of hypoglycaemia, higher burden related to the medical treatment of the child's diabetes and more emotional distress than did the fathers. The results may have implications for both clinical practice and further research.

7.1 Clinical implications

Although most parents seem to adapt well to a child's diabetes, one should be aware that 20-40% of the parents in this study reported often or almost always worrying about their child's night-time hypoglycaemia, hypoglycaemia while no one is around to help or severe episodes of hypoglycaemia. The parents' fear of hypoglycaemia should be addressed in interventions and consultations. Accordingly, health care providers should be aware of the possible association between parental fear of hypoglycaemia and reduced glycaemic control among children, although this association needs to be investigated further. Night-time hypoglycaemia and night-time blood glucose measurements require special attention in consultations with families. It seems to be important to increase the parents' security at night

and reduce their perceived burden and emotional distress related to the night-time activities and night-time hypoglycaemia.

The higher levels of fear and emotional distress and the greater perceived burden related to medical treatment among the mothers than among the fathers should be discussed in diabetes-teams and with families. Further, it seems important to build and educate networks around the families of children with type 1 diabetes to manage the perceived strong social limitation experienced by 20% of the mothers and 17% of the fathers. The associations identified between better glycaemic control among the children and mothers' higher level of education and strong perceived social limitation because of the child's diabetes may indicate that achieving satisfactory treatment goals is demanding. Health care providers should design interventions and support adapted for all types of families based on their resources and sociodemographic background.

7.2 Implications for future research

The results of our study have created questions and suggestions for future research. A core is a recommendation of larger studies including multicentre studies with national and/or international collaboration to compensate for the weaknesses related to the relatively small sample sizes of our study and many other studies on parenting children with type 1 diabetes. Accordingly, our study has shown a need for further work exploring both mothers' and fathers' fear of hypoglycaemia and its relations with children's glycaemic control in larger samples of children with type 1 diabetes of all ages and their parents. Recognized instruments to assess both the parental fear of hypoglycaemia and the diabetes-related burden are recommended for future research so that results can be compared between studies and manuals for interpretation of results can be prepared. For comparisons between studies and for viewing the relationships between studies on parenting children with type 1 diabetes, the adapted Belsky's determinants of parenting model could be recommended as an organizing framework.

Various study designs are suggested for future research to achieve a more integrated comprehension of parenting children with type 1 diabetes. Longitudinal studies are

recommended to clarify the causality between the variables in the parenting process. Focus-group interviews or in-depth interviews are recommended to gain more in-depth insight into the meaning of the parents' experiences of fear of hypoglycaemia, diabetes-related family burden and emotional distress. For further analyses of cross-sectional data, analyses to explore how the included variables are related to each other through mediators and causality chains are also suggested.

REFERENCES

1. International Diabetes Federation: **IDF Diabetes Atlas**. 5th edn; 2011.
2. Gale EA: **Dying of diabetes**. *The Lancet* 2006, **368**:1626-1628.
3. Hanas R, Donaghue K, Klingensmith G, Swift PG: **ISPAD Clinical Practice Consensus Guidelines 2009 Compendium**. *Pediatric Diabetes* 2009, **10**(Suppl. 12):1-2.
4. Diabetes Control and Complications Trial Research Group: **Effect of intensive diabetes treatment on the development and progression of long-term complications in adolescents with insulin-dependent diabetes mellitus: Diabetes Control and Complications Trial**. *The Journal of Pediatrics* 1994, **125**(2):177-188.
5. De Beaufort CE, Swift PGF, Skinner CT, Aanstoot HJ, Aman J, Cameron F, Martul P, Chiarelli F, Daneman D, Danne T *et al*: **Continuing stability of center differences in pediatric diabetes care: Do advances in diabetes treatment improve outcome?** *Diabetes Care* 2007, **30**(9):2245-2250.
6. Skinner CT, Cameron FJ: **Improving glycaemic control in children and adolescents: which aspects of therapy really matter?** *Diabetic Medicine* 2010, **27**:369-375.
7. Rewers M, Pihoker C, Donaghue K, Hanas R, Swift P, Klingensmith GJ: **Assessment and monitoring of glycemic control in children and adolescents with diabetes. ISPAD Clinical Practice Consensus Guidelines 2009 Compendium**. *Pediatric Diabetes* 2009, **10**(Suppl. 12):71-81.
8. Hanas R, John G: **2010 consensus statement on the worldwide standardization of the Hemoglobin A1c measurements**. *Pediatric Diabetes* 2010, **11**:209-211.
9. Delamater AM: **Psychological care of children and adolescents with diabetes. ISPAD Clinical Practice Consensus Guidelines 2009 Compendium**. *Pediatric Diabetes* 2009, **10**(Suppl. 12):175-184.
10. Belsky J: **The determinants of parenting: A process model.** *Child Development* 1984, **55**:83-96.
11. Gepts W: **Pathologic anatomy of the pancreas in juvenile Diabetes Mellitus**. *Diabetes* 1965, **14**(10):619-633.
12. Craig ME, Hattersley A, Donaghue KC: **Definition, epidemiology and classification of diabetes in children and adolescents. ISPAD Clinical Practice Consensus Guidelines 2009 Compendium**. *Pediatric Diabetes* 2009, **10**(Suppl. 12):3-12.
13. Sabbah E, Savola K, Ebeling T, Kulmala P, Vähäsalo P, Ilonen J, Salmela PI, Knip M: **Genetic, autoimmune, and clinical characteristics of childhood- and adult-onset type 1 diabetes**. *Diabetes Care* 2000, **23**(9):1326-1332.
14. Barret JC, Clayton DG, Concannon P, Akolkar B, Cooper JD, Erlich HA *et al.* & The Type 1 Diabetes Genetics Consortium: **Genome-wide association study and meta-analysis find that 40 loci affect risk of type 1 diabetes**. *Nature Genetics* 2009, **41**(6):703-707.
15. Dahlquist G, Blom L, Holmgren G, Hägglöf B, Wall S: **Epidemoiology of diabetes in Sweedish children 0-14 years of age. A six year prospective study.** *Diabetologia* 1985, **28**:802-808.
16. Larsson HE, Vehik K, Bell R, Dabelea D, Dolan LM, Pihoker C, Group TTS: **Reduced prevalence of diabetic ketoacidosis at diagnosis of type 1 diabetes in young children participating in longitudinal follow-up**. *Diabetes Care* 2011, **34**:2347-2352.
17. Wolfsdorf J, Craig ME, Daneman D, Dunger DB, Edge JA, Lee W, Rosenblom A, Sperling M, Hanas R: **Diabetic ketoacidosis in children and adolescents with diabetes. ISPAD Clinical Practice Consensus Guidelines 2009 Compendium**. *Pediatric Diabetes* 2009, **10**(Suppl 12):118-133.
18. Patterson CC, Dahlquist GG, Gyürüs E, Green A, Soltész G: **Incidence trends of childhood type 1 diabetes in Europe during 1989-2003 and predicted new cases 2005-20: a multicentre prospective registration study**. *The Lancet* 2009, **373**:2027-2033.
19. Aamodt G, Stene LC, Njølstad PR, Søvik O, Joner G, The Norwegian Childhood Diabetes Study Group: **Spatiotemporal trends and age-period-cohort modeling of the incidence of**

type 1 diabetes among children aged < 15 years in Norway 1973-1982 and 1989-2003. *Diabetes Care* 2007, **30**(4):884-889.

20. Skrivarhaug T, Stene L, Strøm H, Drivvoll A, Njølstad P, Joner G, Norwegian Childhood Diabetes Study Group: **The incidence of childhood onset type 1 diabetes in Norway is steadily increasing for both sexes.** *Pediatric Diabetes* 2010, **11** (Suppl 14):24.
21. Svensson J, Carstensen B, Molbak A, Christau B, Mortensen HB, Nerup J, Borch-Johnsen K: **Increased risk of childhood type 1 diabetes in children born after 1985**. *Diabetes Care* 2002, **25**(12):2197-2201.
22. Harjutsalo V, Sjöberg L, Tuomilehto J: **Time trends in the incidence of type 1 diabetes in Finnish children: a cohort study**. *The Lancet* 2008, **371**(May 24):1777-1782.
23. Dahlquist G, Nyström L, Patterson CC, The Swedish Childhood Diabetes Study Group, The Diabetes Incidence in Sweden Study Group: **Incidence of type 1 diabetes in Sweden among individuals aged 0-34 years, 1983-2007**. *Diabetes Care* 2011, **34**:1754-1759.
24. Marks H: **Longevity and mortality of diabetics.** *Am J Public Health* 1965, **55**:416-423.
25. Donaghue K, Chiarelli F, Trotta D, Allgrove J, Dahl-Jørgensen K: **Microvascular and macrovascular complications associated with diabetes in children and adolescents. ISPAD Clinical Practice Consensus Guidelines 2009 Compendium**. *Pediatric Diabetes* 2009, **10**(Suppl. 12):195-203.
26. Hoey H, McGee HM, Fitzgerald M, Mortensen HB, Hougaard P, Lynggaard H, Skovlund S, Aanstoot H, Chiarelli F, Daneman D *et al*: **Parent and health professional perspectives in the management of adolescents with diabetes: Development of assessment instruments for international studies**. *Quality of Life Research* 2006(15):1033-1042.
27. Diabetes Control and Complications Trial Research Group: **Diabetes Control and Complications Trial (DCCT): the effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus.** *New England Journal of Medicine* 1993, **329**:977-986.
28. Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications (DCCT/EDIC) Study Research Group: **Intensive diabetes treatment and cardiovascular disease in patients with type 1 diabetes.** *New England Journal of Medicine* 2005, **353**(25):2643-2653.
29. Dahl-Jørgensen K, Brinchmann-Hansen O, Hanssen KF, Ganes T, Kierulf P, Smeland E, Sandvik L, Aagenaes Ø: **Effect of near normoglycaemia for two years on progression of early diabetic retinopathy, nephropathy, and neuropathy: the Oslo study**. *British Medical Journal* 1986, **293**:1195-1199.
30. Margeirsdottir HD, Larsen JR, Kummernes SJ, Brunborg C, Dahl-Jørgensen K: **The establishment of a new national network leads to quality improvement in childhood diabetes: Implementation of the ISPAD Guidelines**. *Pediatric Diabetes* 2010, **11**(2):88-95.
31. Margeirsdottir HD, Larsen JR, Brunborg C, Øverby NC, Dahl-Jørgensen K, The Norwegian Study Group on Childhood Diabetes: **High prevalence of cardiovascular risk factors in children and adolescents with type 1 diabetes: a population-based study**. *Diabetologia* 2008, **51**:554-561.
32. Skrivarhaug T, Bangstad H-J, Stene LC, Sandvik L, Hanssen KF, Joner G: **Low risk of overt nephropathy after 24 yr of childhood-onset type 1 diabetes mellitus (T1DM) in Norway**. *Pediatric Diabetes* 2006, **7**:239-246.
33. Skrivarhaug T, Fosmark DS, Stene LC, Bangstad H-J, Sandvik L, Hanssen KF, Joner G: **Low cumulative incidence of proliferative retinopathy in childhood-onset type 1 diabetes: a 24-year follow-up study**. *Diabetologia* 2006, **49**:2281-2290.
34. Downie E, Craig ME, Hing S, Cusumano J, Chan AKF, Donaghue KC: **Continued reduction in the prevalence of Retinopathy in adolescents with type 1 diabetes**. *Diabetes Care* 2011, **34**:2368-2373.
35. Clarke W, Jones T, Rewers A, Dunger D, Klingensmith GJ: **Assessment and management of hypoglycemia in children and adolescents with diabetes. ISPAD Clinical Practice Consensus Guidelines 2009 Compendium**. *Pediatric Diabetes* 2009, **10**(Suppl. 12):134-145.

36. Cox D, Gonder-Frederick L, Antoun B, Cryer P, Clarke W: **Perceived symptoms in the recognition of hypoglycaemia.** *Diabetes Care* 1993, **16**:519-527.
37. Cryer PE, Davis SN, Shamoon H: **Hypoglycemia in Diabetes**. *Diabetes Care* 2003, **26**(6):1902-1912.
38. Deary I: **Symptoms of hypoglycaemia and effects on mental performance and emotions.** In: *Hypoglycaemia in clinical diabetes.* 2 edn. Edited by Frier B, Fisher M. England: Wiley 2007: 25-48.
39. Gonder-Frederick LA, Snyder AL, Clarke WL: **Accuracy of blood glucose estimation by children with IDDM and their parents**. *Diabetes Care* 1991, **14**(7):565-570.
40. Raju B, Arbelaez AM, Breckenridge SM, Cryer PE: **Nocturnal hypoglycemia in type 1 diabetes: An assessment of preventive bedtime treatments**. *The Journal of Clinical Endocrinology & Metabolism* 2006, **91**(6):2087-2092.
41. Dahlquist G, Källén B: **Mortality in childhood-onset type 1 diabetes**. *Diabetes Care* 2005, **28**(10):2384-2387.
42. Skrivarhaug T, Bangstad H-J, Stene LC, Sandvik L, Hanssen KF, Joner G: **Long-term mortality in a nationwide cohort of childhood-onset type 1 diabetic patients in Norway**. *Diabetologia* 2006, **49**:298-305.
43. Patterson C, Dahlquist G, Harjutsalo V, Joner G, Feltbower R, Svensson J, Schober E, Gyürüs E, Castell C, Urbonaité B *et al*: **Early mortality in EURODIAB population-based cohorts of type 1 diabetes diagnosed in childhood since 1989**. *Diabetologia* 2007, **50**:2439-2442.
44. Bjørgaas M, Gimse R, Vik T, Sand T: **Cognitive function in type 1 diabetic children with and without episodes of severe hypoglycaemia**. *Acta Pædiatrica* 1997, **86**:148-153.
45. Desrocher M, Rovet J: **Neurocognitive correlates of type 1 diabetes mellitus in childhood**. *Child Neuropsychology* 2004, **10**(1):36-52.
46. Åsvold BO, Sand T, Hestad K, Bjørgaas MR: **Cognitive function in type 1 diabetic adults with early exposure to severe hypoglycemia**. *Diabetes Care* 2010, **33**(9):1945-1947.
47. Strachan M: **Frequency, causes and risk factors for hypoglycaemia in type 1 diabetes**. In: *Hypoglycaemia in clinical diabetes.* second edn. Edited by Frier B, Fisher M. England: Wiley; 2007: 49-82.
48. Amin R, Ross K, Acerini CL, Edge JA, Warner J, Dunger DB: **Hypoglycemia prevalence in prepubertal children with type 1 diabetes on standard insulin regimen: Use of continuous glucose monitoring system**. *Diabetes Care* 2003, **26**(3):662-667.
49. Pickup JC, Sutton AJ: **Severe hypoglycaemia and glycaemic control in Type 1 diabetes: meta-analysis of multiple daily insulin injections compared with continuous subcutaneous insulin infusion**. *Diabetic Medicine* 2008, **25**:765-774.
50. O'Connell SM, Cooper M, Bulsara MK, Davis EA, Jones TW: **Reducing rates of severe hypoglycemia in a population-based cohort of children and adolescents with type 1 diabetes over the decade 2000-2009**. *Diabetes Care* 2011, **34**:2379-2380.
51. Bangstad H-J, Danne T, Deeb LC, Jarosz-Chobot P, Urakami T, Hanas R: **Insulin treatment. ISPAD Clinical Practice Consensus Guidelines 2009 Compendium**. *Pediatric Diabetes* 2009, **10**(Suppl 12):82-99.
52. Holl RW, Swift PGF, Mortensen HB, Lynggaard H, Hougaard P, Aanstoot H-J, Chiarelli F, Daneman D, Danne T, Dorchy H *et al*: **Insulin injection regimens and metabolic control in an international survey of adolescents with type 1 diabetes over 3 years: results from the Hvidore study group**. *Eur J Pediatr* 2003, **162**:22-29.
53. Nordly S, Mortensen HB, Andreasen AH, Hermann N, Jørgensen T: **Factors associated with glycaemic outcomes of childhood diabetes care in Denmark**. *Diabetic Medicine* 2005, **22**:1566-1573.
54. American Diabetes Association: **Implications of the Diabetes Control and Complication Trial**. *Diabetes Care* 2003, **26**(Suppl. 1):25-27.
55. Hanberger L, Samuelsson U, Lindblad B, Ludvigsson J: **A1C in children and adolescents with diabetes in relation to certain clinical parameters. The Swedish Childhood Diabetes Registry SWEDIABKIDS**. *Diabetes Care* 2008, **31**(5):927-929.

56. Svensson J, Johannesen J, Mortensen H, Nordly S: **Improved metabolic outcome in a Danish diabetic paediatric population aged 0-18 yr: results from a nationwide continuous Registration**. *Pediatric Diabetes* 2009, **10**:461-467.
57. Cameron FJ, Skinner TC, de Beaufort CE, Hoey H, Swift PGF, Aanstoot H, Aman J, Martul P, Chiarelli F, Daneman D *et al*: **Are family factors universally related to metabolic outcomes in adolescents with Type 1 diabetes?** *Diabetic Medicine* 2008, **25**(4):463-468.
58. Anderson B, McKay S: **Barriers to glycemic control in youth with type 1 diabetes and type 2 diabetes**. *Pediatric Diabetes* 2011, **12**:197-205.
59. Hoghughi M: **Parenting - An introduction**. In: *Handbook of parenting theory and research for practice.* 1 edn. Edited by Hoghughi M, Long N. London: SAGE Publications Ltd; 2004: 1-19.
60. French V: **History of parenting**. In: *Handbook of parenting.* edn. Edited by Bornstein M. Mahwah, NJ: Lawrence Erlbaum; 1995.
61. Bowlby J: **Maternal care and mental health**. London: HMSO; 1951.
62. Bowlby J: **Attachment and loss**. Harmondsworth: Penguin; 1980.
63. Conley CS, Caldwell MS, Flynn M, Dupre AJ, Rudolph KD: **Parenting and mental health**. In: *Handbook of parenting theory and research practice.* edn. Edited by Hoghughi M, Long N. London: SAGE Publications Ltd.; 2004.
64. Bronfenbrenner U: **The ecology of human development: Experiments by nature and design**. Cambridge, MA: Harvard University Press; 1979.
65. Belsky J, Lerner RM, Spanier GB: **The child in the family**. US: Addison-Wesley Publishing Company; 1984.
66. Belsky J, Fish M, R I: **Continuity and disconinuity in infant negative and positive emotionality: family antecedents and attachment consequences**. *Developmental Psychology* 1991, **27**(3):421-431.
67. Volling B, Belsky J: **Multiple determinants of father involvement durning infancy in dual-earner and single-earner families**. *Journal of Marriage and the Family* 1991, **53**(2):461-474.
68. Woodworth S, Belsky J, Crnic K: **The determinants of fathering during the child's second and third year of life: a developmental analysis**. *Journal of Marriage and the Family* 1996, **58**(3):679-692.
69. Borgenschneider K, Small S, Tsay J: **Child, parent and contextual influences on perceived parenting competence among parents of adolescents**. *Journal of Marriage and the Family* 1997, **59**:345/362.
70. Luster T: **Individual differences in the caregiving behavior of teenage mothers: An ecological perspective.** *Clinical Child Psychology and Psychiatry* 1998, **3**(3):341-360.
71. Meyers SA: **Mothering in context: Ecological determinants of parent behavior** *Merrill-Palmer Quarterly* 1999, **45**(2):332-357.
72. Sadler L, Anderson S, Sabatilli R: **Parental competence among African American adolescent mothers and grandmothers**. *Journal of Pediatric Nursing* 2001, **16**(4):217-233.
73. Van Bakel H, Riksen-Walraven M: **Parenting and development of one- year olds: Links with parental, contextual, and child characteristics**. *Child Development* 2002, **73**(1):256-273.
74. Sherifali D, Ciliska D: **Parenting children with diabetes and Belsky's Determinants of Parenting Model: literature review**. *Journal of Advanced Nursing* 2006, **55**(5):636-642.
75. Hatton DL, Canam C, Thorne S, Hughes A-M: **Parents' perceptions of caring for an infant or toddler with diabetes**. *Journal of Advanced Nursing* 1995, **22**:569-577.
76. Lowes L, Lyne P: **Chronic sorrow in parents of children with newly diagnosed diabetes: a review of the literature and discussion of the implications for nursing pracitce**. *Journal of Advanced Nursing* 2000, **21**(1):41-48.
77. Landolt MA, Ribi K, Laimbacher J, Vollrath M, Gnehm HE, Sennhauser FH: **Posttreumatic Stress Disorder in Parents of Children With Newly Diagnosed Type 1 Diabetes**. *Journal of Pediatric Psychology* 2002, **27**(7):647-652.

78. Sullivan-Bolyai S, Deatrick J, Gruppuso P, Tamborlane W, Grey M: **Constant Vigilance: Mothers' Work Parenting Young Children With Type 1 Diabetes**. *Journal of Pediatric Nursing* 2003, **18**(1):21-29.
79. Streisand R, Mackey ER, Elliot BM, Mednick L, Slaughter IM, Turek J, Austin A: **Parental anxiety and depression associated with caring for a child newly diagnosed with type 1 diabetes: Opportunities for education and counseling**. *Patient Education & Counseling* 2008, **73**:333-338.
80. Davis CL, Delamater AM, Shaw KH, La Greca AM, Eidson MS, Perez-Rodriguez JE, Nemery R: **Parenting styles, regimen adherence, and glycemic control in 4- to 10-year-old children with diabetes**. *Journal of Pediatric Psychology* 2001, **26**(2):123-129.
81. Landolt MA, Vollrath M, Laimbacher J, Gnehm HE, Sennhauser FH: **Prospective study of posttraumatic stress disorder in parents of children with newly diagnosed type 1 diabetes**. *Journal Am Acad Child Adolesc Psychiatry* 2005, **44**(7):682-689.
82. Viner R, McGrath M, Trudinger P: **Family stress and metabolic control in diabetes**. *Archives of Disease in Childhood* 1996, **74**:418-421.
83. Hauser ST, Jacobsen AM, Lavori P, Wolfsdorf JI, Herskowitz RD, Milley JE, Bliss R: **Adherence among children and adolescents with insulin-dependent diabetes mellitus over a four-year longitudinal follow-up: Immediate and long-term linkages with the family milieu**. *Journal of Pediatric Psychology* 1990, **15**(4):527-542.
84. Wysocki T: **Associations among teen-parent relationships, metabolic control, and adjustment to diabetes in adolescents**. *Journal of Pediatric Psychology* 1993, **18**(4):441-452.
85. Miller-Johnson S, Emery RE, Marvin RS, Clarke W, Lovinger R, Martin M: **Parent-child relationships and the management of insulin-dependent diabetes mellitus**. *Journal of Consulting and Clinical Psychology* 1994, **62**(1):603-610.
86. Duke DC, Geffken GR, Lewin A, Williams LB, Storch EA, Silverstein JH: **Glycemic control in youth with type 1 diabetes: Family predictors and mediators**. *Journal of Pediatric Psychology* 2008, **33**(7):719-727.
87. Graue M, Wentzel-Larsen T, Hanestad BR, Sovik O: **Health-related quality of life and metabolic control in adolescents with diabetes: the role of parental care, control, and involvement**. *Journal of Pediatric Nursing* 2005, **20**(5):373-382.
88. Botello-Harbaum M, Nansel T, Haynie D, Iannotti R, Simons-Morton B: **Responsive parenting is associated with improved type 1 diabetes-related quality of life**. *Child: care, health and development* 2008, **34**(5):675-681.
89. Anderson B, Ho J, Brackett J, Finkelstein D, Laffel L: **Parental involvement in diabetes management tasks: relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus.** *Journal of Pediatrics* 1997, **130**(2):257-265.
90. Ellis DA, Podolski C-L, Frey MA, Naar-King S, Wang B, Moltz K: **The role of parental monitoring in adolescent health outcomes: Impact on regimen adherence in youth with type 1 diabetes**. *Journal of Pediatric Psychology* 2007, **32**(8):907-917.
91. Wiebe DJ, Berg CA, Korbel C, Palmer DL, Beveridge RM, Upchurch R, Lindsay R, Swinyard MT, Donaldson DL: **Children's appraisals of maternal involvement in coping with diabetes: Enhancing our understanding of adherence, metabolic control, and quality of life across adolescence**. *Journal of Pediatric Psychology* 2005, **30**(2):167-178.
92. Vesco A, Anderson B, Laffel L, Dolan L, Ingerski L, Hood K: **Responsibility sharing between adolescent with type 1 diabets and their caregivers: importance of adolescent perceptions on diabetes management and control**. *Journal of Pediatric Psychology* 2010, **35**(10):1168-1177.
93. Lewin AB, Heidgerken AD, Geffken GR, Williams LB, Storch EA, Gelfand KM, Silverstein JH: **The relation between family factors and metabolic control: the role of diabetes adherence**. *Journal of Pediatric Psychology* 2006, **31**(2):174-183.
94. Erikson E: **Childhood and society**, 2 edn. New York: Norton; 1963.

95. Anderson BJ: **Children with Diabetes Mellitus and family functioning: Translating research into practice**. *Journal of Pediatric Endocrinology and Metabolism* 2001, **14**:645-652.
96. Wild D, von Maltzahn R, Brohan E, Christensen T, Clauson P, Gonder-Frederick L: **A critical review of the literature on fear of hypoglycemia in diabetes: Implications for diabetes management and patient education**. *Patient Education & Counseling* 2007, **68**(1):10-15.
97. Gonder-Frederick L, Nyer M, Shepard JA, Vajda K, Clarke W: **Assessing fear of hypoglycemia in children with type 1 diabetes and their parents.** *Diabetes Manag (London)* 2011, **1**(6):627-639.
98. Frier B: **Living with hypoglycaemia**. In: *Hypoglycaemia in clinical diabetes.* 2nd edn. Edited by Frier B, Fisher M. England: John Wiley & Sons, Ltd; 2007.
99. Clarke WL, Gonder-Frederick A, Snyder AL, Cox DJ: **Maternal fear of hypoglycemia in their children with insulin dependent diabetes mellitus**. *Journal of Pediatric Endocrinology* 1998, **11 Suppl 1**:189-194.
100. Patton S, Dolan L, Henry R, Powers S: **Parental fear of hypoglycemia: young children treated with continuous subcutaneous insulin infusion**. *Pediatric Diabetes* 2007(8):362-368.
101. Sullivan-Bolyai S, Deatrick J, Gruppuso P, Tamborlane W, Grey M: **Mothers' experiences raising young children with type 1 diabetes**. *J Spec Pediatr Nurs* 2002, **7**(3):93-103.
102. Nordenfeldt S, Ludvigsson J: **Fear and other disturbances of severe hypoglycaemia in children and adolescents with type 1 Diabetes Mellitus**. *Journal of Pediatric Endocrinology and Metabolism* 2005, **18**:83-91.
103. Jaser SS, Whittemore R, Ambrosino JM, Lindemann E, Grey M: **Coping and psychosocial adjustment in mothers of young children with type 1 diabetes**. *Children's Health Care* 2009, **38**:91-106.
104. Nyer M: **Fear of hypoglycamia: Psychological associations and diabetes control in youth with type 1 diabetes and their parents**. US: University of Virginia; 2010.
105. Streisand R, Swift E, Wickmark T, Chen R, Holmes CS: **Pediatric parenting stress among parents of children with type 1 diabetes: the role of self-efficacy, responsibility, and fear**. *Journal of Pediatric Psychology* 2005, **30**(6):513-521.
106. Patton SR, Dolan LM, Smith LB, Thomas IH, Powers SW: **Pediatric parenting stress and its relation to depressive symptoms and fear of hypoglycemia in parents of young children with type 1 diabetes mellitus.** *J Clin Psychol Med Settings* 2011, **18**:345-352.
107. Gonder-Frederick LA, Fisher CD, Ritterband LM, Cox DJ, Hou L, DasGupta AA, Clarke WL: **Predictors of fear of hypoglycemia in adolescents with type 1 diabetes and their parents**. *Pediatric Diabetes* 2006, **7**(4):215-222.
108. Monaghan MC, Hilliard ME, Cogen FR, Streisand R: **Nighttime caregiving behaviors among parents of young children with type 1 diabetes: Associations with illness characteristics and parent functioning**. *Families, Systems & Health* 2009, **27**(1):28-38.
109. Marrero D: **Fear of hypoglycemia in the parents of children and adolescents with diabetes: maladaptive or healthy response?** *Diabetes Educator* 1997, **23**(3):281-286.
110. Patton SR, Dolan LM, Henry R, Powers SW: **Fear of hypoglycemia in parents of young children with type 1 Diabetes Mellitus**. *J Clin Psychol* 2008, **15**:252-259.
111. Barnard K, Thomas S, Royle P, Noyes K, Waugh N: **Fear of hypoglycaemia in parents of young children with type 1 diabetes: a systematic review**. *BMC Pediatrics* 2010, **10**(50).
112. Müller-Godeffroy E, Treichel S, Wagner VM: **Investigation of quality of life and family burden issues during insulin pump therapy in children with type 1 diabetes mellitus - a large-scale multicenter pilot study**. *Diabetic Medicine* 2009, **26**:493-501.
113. Hoey H, Aanstoot HJ, Chiarelli F, Daneman D, Danne T, Dorchy H, Fitzgerald M, Garandeau P, Greene S, Holl R *et al*: **Good metabolic control is associated with better quality of life in 2,101 adolescents with type 1 diabetes**. *Diabetes Care* 2001, **24**(11):1923-1928.

114. Butler D, Zuehlke J, Tovar A, Volkening L, Anderson B, Laffel LM: **The impact of modifiable family factors on glycemic control among youth with type 1 diabetes**. *Pediatric Diabetes* 2008, **9**(Part II):373-381.
115. Stallwood L: **Influence of caregiver stress and coping on glycemic control of young children with diabetes**. *Journal of Pediatric Health Care* 2005, **19**(5):293-300.
116. Hilliard ME, Rohan J, Carle AC, Pendley JS, Delamater AM, Drotar D: **Father's involvement in preadolescents' diabetes adherence and glycemic control**. *Journal of Pediatric Psychology* 2011, **36**(8):911-922.
117. Whittermore R, Urban AD, Tamborlane WV, Grey M: **Quality of life in shool-aged children with type 1 diabetes on itensive treatment and their parents**. *The Diabetes Educator* 2003, **29**(5):847-854.
118. Streisand R, Mackey ER: **Associations of parent coping, stress, and well-being in mothers of children with diabetes: examination of data from a national sample**. *Matern Child Health J* 2010, **14**(612-617).
119. Kovacs M, Iyengar S, Goldston D, Obrovsky SD, Stewart J, Marsh J: **Psychological functioning among mothers of children with insulin-dependent Diabetes Mellitus: A longitudinal study**. *Journal of Consulting and Clinical Psychology* 1990, **58**(2):189-195.
120. Cameron LD, Young MJ, Wiebe DJ: **Maternal Trait Anxiety and Diabetes Control in Adolescents with Type 1 Diabetes**. *Journal of Pediatric Psychology* 2007, **32**(7):733-744.
121. Jaser SS, Whittemore R, Ambrosino JM, Lindemann E, Grey M: **Mediators of depressive symptoms in children with type 1 diabetes and their mothers**. *Journal of Pediatric Psychology* 2008, **33**(5):509-519.
122. Stewart SM, Wang JT, Wang Y-C, White PC: **Patient- versus parent-reported psychological symptoms as predictors of type 1 diabetes management in adolescents**. *Children's Health Care* 2009, **38**:200-212.
123. Hilliard ME, Guilfoyle SM, Dolan LM, Hood KK: **Prediction of adolescents' glycemic control 1 year after diabetes-specific family conflict**. *Arch Pediatr Adolesc Med* 2011, **165**(7):624-629.
124. Mullins LL, Fuemmeler BF, Hoff A, Chaney JM, Van Pelt J, Ewing CA: **The relationship of parental overprotection and perceived child vulnerability to depressive symptomatology in children with type 1 Diabetes Mellitus: The moderating influence of parenting stress**. *Children's Health Care* 2004, **33**(1):21-34.
125. Eckshtain D, Ellis D, Kolmodin K, Naar-King S: **The effects of parental depression and parenting practices on depressive symptoms and metabolic control in urban youth with insulin dependent diabetes**. *Journal of Pediatric Psychology* 2010, **35**(4):426-435.
126. Wiebe D, Gelfand D, Butler J, Korbel C, Fortenberry K, McCabe J, Berge C: **Longitudinal associations of maternal depressive symptoms, maternal involvement, and diabetes management across adolescence.** *Journal of Pediatric Psychology* 2011, **36**(7):837-846.
127. Carpentier MY, Mullins LL, Chaney JM, Wagner JL: **The relationship of illness uncertainty and attributional style to long-term psychological distress in parents of children with type 1 Diabetes Mellitus**. *Children's Health Care* 2006, **35**(2):141-154.
128. Dashiff C, Morrison S, Rowe J: **Fathers of children and adolescents with diabetes: what do we know?** *Journal of Pediatric Nursing* 2008, **23**(2):101-119.
129. Wysocki T, Gavin L: **Paternal involvement in the management of pediatric chronic diseases: Associations with adherence, quality of life and health status**. *Journal of Pediatric Psychology* 2006, **31**(5):501-511.
130. Gavin L, Wysocki T: **Associations of paternal involvement in disease management with maternal and family outcomes in families with children with chronic illness**. *Journal of Pediatric Psychology* 2006, **31**(5):481-489.
131. Hansen JA, Schwartz DD, Weissbrod C, Taylor PW: **Paternal involvement in pediatric type 1 diabetes: Fathers' and mothers' psychological functioning and disease management.** *Families, Systems & Health* 2012, **30**(1):47-59.
132. Mitchell SJ, Hilliard ME, Mednick L, Henderson C, Cogen FR, Streisand R: **Stress among fathers of young children with type 1 diabetes**. *Families, Systems & Health* 2009, **27**(4):314-324.

133. Sullivan-Bolyai S, Rosenberg R, Bayard M: **Fathers' reflections on parenting young children with type 1 diabetes**. *MCN Am J Matern Child Nurs* 2006, **31**(1):24-31.
134. Hoey H: **Psychosocial factors are associated with metabolic control in adolescents: research from the Hvidoere Study Group on Childhood Diabetes**. *Pediatric Diabetes* 2009, **10** (Suppl. 13):9-14.
135. Wrosch C, Scheier MF: **Personality and quality of life: The importance of optimism and goal adjustment**. *Quality of Life Research* 2003, **12**(Suppl. 1):59-72.
136. Florian V, Elad D: **The impact of mothers' sense of empowerment on the metabolic control of their children with juvenile diabetes**. *Journal of Pediatric Psychology* 1998, **23**(4):239-247.
137. Faulkner MS: **Family influence on self-care, quality of life, and metabolic control in school-age children and adolescents with type 1 diabetes**. *Journal of Pediatric Nursing* 2007, **22**(1):59-68.
138. Johns C, Faulkner MS, Quinn L: **Characteristics of adolescents with type 1 diabetes who exhibit adverse outcomes**. *The Diabetes Educator* 2008, **34**(5):874-885.
139. Stallwood L: **Relationship between caregiver knowledge and socioeconomic factors on glycemic outcomes of young children with diabetes**. *Journal of Specialists in Pediatric Nursing* 2006, **11**(3):158-165.
140. Chisholm V, Atkinson L, Donaldson C, Noyes K, Payne A, Kelnar C: **Predictors of treatment adherence in young children with type 1 diabetes**. *Journal of Advanced Nursing* 2007, **57**(5):482-493.
141. Tahirovic H, Toromanovic A: **Glycemic control in diabetic children: role of mother's knowledge and socioeconomic status.** *Eur J Pediatr* 2010, **169**:961-964.
142. Meunier J, Dorchy H, Luminet O: **Does family cohesiveness and parental alexithymia predict glycaemic control in children and adolescents with diabetes?** *Diabetes & Metabolism* 2008, **34**:473-481.
143. Drew LM, Verdant C, Butler J, Berg C, King P, Griffith K, Wiebe DJ: **Depleted parental psychological resources as mediators of the associations of income with adherence and metabolic control.** *Journal of Family Psychology* 2011, **25**(5):751-758.
144. Kaufman FR, Halvorsen M, Carpenter S: **Association between diabetes control and visits to a multidiciplinary pediatric diabetes clinic**. *Pediatrics* 1999, **103**(5):948-951.
145. Urbach S, LaFranchi S, Lambert L, Lapidus J, Daneman D, Becker T: **Predictors of glucose control in children and adolescents with type 1 diabetes**. *Pediatric Diabetes* 2005(6):69-74.
146. Swift E, Chen R, Hershberger A, Holmes CS: **Demographic risk factors, mediators, and moderators in youths' diabetes metabolic control**. *Annals of Behavioral Medicine* 2006, **32**(1):39-49.
147. Frey M, Templin T, Ellis D, Gutai J, Podolski C: **Predicting metabolic control in the first 5 yr after diagnosis for youths with type 1 diabetes: the role of ethnicity and family structure**. *Pediatric Diabetes* 2007, **8**:220-227.
148. Grabill KM, Geffken GR, Duke D, Lewin A, Williams L, Storch E, Silverstein J: **Family functioning and adherence in youth with type 1 diabetes: a latent growth model of glycemic control**. *Children's Health Care* 2010, **39**:279-295.
149. Hansen AJ: **Paternal contribution to disease care in parenting a child with type 1 diabetes**. Washington: American University; 2010.
150. Frey MA, Ellis D, Templing T, Naar-King S, Gutai JP: **Diabetes mnagement and metabolic control in school-age children with type 1 diabetes**. *Children's Health Care* 2006, **35**(4):349-363.
151. Lewandowski A, Drotar D: **The relationship between parent-reported social support and adherence to medical treatment in fmilies of adolescents with type 1 diabetes**. *Journal of Pediatric Psychology* 2007, **32**(4):427-436.
152. Marvicsin D: **School-age children with diabetes: Role of maternal self-efficacy, environment, and management behaviors**. *The Diabetes Educator* 2008, **34**(3):477-483.

153. Berg C, King P, Butler J, Pham P, Palmer D, Wiebe D: **Parental involvement and adolescents' diabetes management: the mediating role of self-efficacy and externalizing and internalizing behaviors**. *Journal of Pediatric Psychology* 2011, **36**(3):329-339.
154. Helgeson V, Honcharuk E, Becker D, Escobar O, Siminerio L: **A focus on blood glucose monitoring: relation to glycemic control and determinants of frequency**. *Pediatric Diabetes* 2011, **12**:25-30.
155. Ziegler R, Heidtmann B, Hilgard D, Hofer S, Rosenbauer J, Holl R, the DPV-Wiss-Initiative: **Frequency of SMBG correlates with HbA1c and acute complications in children and adolescents with type 1 diabetes**. *Pediatric Diabetes* 2011, **12**:11-17.
156. Pattison HM, Moledina S, Barrett T: **The relationship between parental perceptions of diabetes and glycaemic control**. *Arch Dis Child* 2006(91):487-490.
157. Palmer DL, Berg CA, Butler JM, Fortenberry KT, Murray M, Lindsay R, Donaldson D, Swinyard M, Foster C, Wiebe DJ: **Mothers', fathers', and children's perceptions of parental diabetes responsibility in adolescence: Examining the role of age, pubertal status, and efficacy.** *Journal of Pediatric Psychology* 2009, **34**(2):195-204.
158. McGrath RE: **Conceptual complexity and construct validity.** *Journal of Personality Assessment* 2005, **85**(2):112-124.
159. Polit DF, Beck CT: **Nursing research. Generationg and assessing evidence for nursing practice**, 8 edn. US: Lippincott Williams & Wilkins; 2008.
160. Bay EJ, Algase DL: **Fear and anxiety: A simultaneous concept analysis.** *Nursing Diagnosis* 1999, **10**(3):103-111.
161. Winokur A, Winokur D, Rickels K: **Symptoms of emotional stress in family planning service: stability over four-week period**. *British Journal of Psychiatry* 1984, **144**:395-399.
162. Garrido MM, Hash-Converse JM, Leventhal H, Leventhal EA: **Stress and chronic disease management.** In: *The handbook of stress science: Biology, psychology, and health.* edn. Edited by Contrada RJ, Baum A. New York, NY, US: Springer Publishing Co; 2011.
163. Lobel M, Dunkel-Schetter: **Conceptualizing stress to study effects on health: Environmental, perceptual, and emontional components.** *Anxiety Research* 1990, **3**:213-230.
164. Nærde A, Tambs K, Mathiesen KS, Dalgard OS, Samuelsen SO: **Symptoms of anxiety and depression among mothers of pre-school children: effect of chronic strain related to children and child care-taking**. *Journal of Affective Disorders* 2000, **58**:181-199.
165. Lazarus R, Folkman S: **Stress, appraisal, and coping.** NY: Springer; 1984.
166. Lazarus R: **Cognition and motivation in emotion.** *American Psychologist* 1991, **46**(4):352-367.
167. Maurin JT, Boyd CB: **Burden of mental illness on the family: A critical review.** *Archives of Psychiatric Nursing* 1990, **4**(2):99-107.
168. Irvine A: **The fear of hypoglycemia scale** In: *Handbook of Psychology and Diabetes.* edn. Edited by Bradley C. Switzerland: Harwood Academic; 1994: 133–155.
169. Derogratis LR, Lipman RS, Rickels K, Uhlenhuth EH, Covi L: **The Hopkins Symptom Checklist (HSCL): a self-report symptom inventory**. *Behav Sci* 1974, **19**:1-15.
170. Sandanger I, Moum T, Ingebrigtsen G, Dalgard OS, Sørensen T, Bruusgaard D: **Concordance between symptom screening and diagnostic procedure: the Hopkins Symptom Checklist-25 and the Composite International Diagnostic Interview.** *Soc Psychiatr Epidemiol* 1998, **33**:345-354.
171. Nærde A, Tambs K, Mathiesen KS: **Child related strain and maternal mental health: a longitudinell study**. *Acta Psychiatr Scand* 2002, **105**:301-309.
172. Magnus P, Irgens LM, Haug K, Nystad W, Skjærven R, Stoltenberg C, The Moba Study Group: **Cohort profile: The Norwegian mother and child cohort study (MoBa)**. *International Journal of Epidemiology* 2006, **35**:1146-1150.
173. Friedman L, Nelson D, Baer P, Lane M, Smith F, Dworkin R: **The relationship of dispositional optimism, daily life stress, and domestic environment to coping methods used by cancer patients**. *Journal of Behavioural Medicine* 1992, **15**:127-142.
174. Taylor S, Kemeny M, Aspinwall L, Schneider S, Rodriquez R, Herbert M: **Optimism, coping, psychological distress, and high-risk sexual behavior among men at risk for**

Acquired Immunodeficiency Syndrome (AIDS). *Journal of Personality and Social Psychology* 1992, **63**:460-473.
175. Carver C, Pozo C, Harris S, Noriega C, Scheier M, Robinson D, Ketcham A, Moffat F, Clark K: **How coping mediates the effects of optimism on distress: A study of women with early stage breast cancer**. *Journal of Personality and Social Psychology* 1993, **65**:375-390.
176. Stanton A, Snider P: **Coping with a breast cancer diagnosis**. *Health Psychology* 1993, **12**:16-23.
177. Scheier MF, Carver CS: **Optimism, coping and health: Assessment and iImplications of generalized outcome expectancies**. *Health Psychology* 1985, **4**(3):219-247.
178. Scheier M, Carver C, Bridges M: **Distinguishing optimism from neroticism (and trait anxiety, self-mastery, and self-esteem): A reevaluation of the Life Orientation Test**. *Journal of Personality and Social Psychology* 1994, **67**(6):1063-1078.
179. Thuen F, Rise J: **Psychological adaptation after marital disruption: The effect of optimism and perceived control**. *Scandinavian Journal of Psychology* 2006, **47**:121-128.
180. Meltzer H: **Development of a commom instrument for mental health. In: Nosikow & Gudex (eds). EUROHIS: Developing Common Instruments for Health Surveys.** In: *EUROHIS Devloping Common Instruments for Health Surveys.* edn. Edited by Nosikov A, Gudex C. Amsterdam: IOS Press (on behalf of WHO); 2003.
181. Dalgard OS, Dowrick C, Lethinen V, Vazquez-Barquero JL, Casey P, Wilkinson G, Ayuso-Mateos JL, Page H, Dunn G, Group TO *et al*: **Negative life events, social support and gender differences in depression**. *Soc Psychiatr Epidemiol* 2006, **41**:444-451.
182. Dyrdal GM, Røysamb E, Nes RB, Vittersø J: **Can a happy relationship predict a happy life? A population-based study of maternal well-being during the life transition of pregnancy, infancy and toddlerhood.** *Journal of Happiness Studies* 2010, **12**(6):947-962.
183. Fayers PM, Machin D: **Quality of life. The assessment, analysis and interpretation of patient-reported outcomes**, 2 edn. England: Wiley; 2007.
184. Duffy ME, Jacobsen BS: **Univariate descriptive statistics**. In: *Statistical methods for health care research.* 5th edn. Edited by Munro BH. London: Lippincott Williams & Wilkins; 2005.
185. Walters SJ, Campbell MJ: **The use of bootstrap methods for analysing health-related quality of life outcomes (particularly the SF-36)**. *BMC Health and Quality of Life Outcomes* 2004, **2**:70.
186. Munro BH: **Regression Diagnostics and canonical correlation**. In: *Statistical methods for health care research.* 5th edn. Edited by Munro BH. London: Lippincot Williams & Wilkins; 2005.
187. Pallant J: **SPSS survival manual**. England: Open University Press; 2007.
188. Efron B, Tibshirani R: **An introduction to Bootstrap Boca Raton**: Chapman & Hall/CRC; 1993.
189. Altman DG: **Practical statistics for medical research**. London: Chapman & Hall/CRC; 1999.
190. Davis CS (ed.): **Statistical Methods for the Analysis of Repeated Measurements.** New York: Springer-Verlag; 2002.
191. Gonder-Frederick L, Vajda K, Shepard J, Amira F, Vafa MR, Haugstvedt A, Graue M: **Parental fear of hypoglycaemia in mothers of children with type 1 Diabetes Mellitus: a cultural comparison.** In: *Annual Meeting of the European Association for the Study of Diabetes (EASD).* Lisbon, Portugal; 2011.
192. Haugstvedt A, Rokne B, Wentzel-Larsen T, Graue M: **The Hypoglycemia Fear Survey – Parent version: Comparison of mothers' and fathers' reports on the worry subscale items in a population-based study**. In: *15th Annual FEND (Federation of European Nurses in Diabetes) Conference.* Stockholm, Sweden; 2010.
193. Painter JE, Borba CP, Hynes M, Mays D, Glanz K: **The use of theory in health behavior research from 2000 to 2005: A systematic review**. *Ann Behav Med* 2008, **35**:358-362.
194. Kovacs M, Kass RE, Schnell TM, Goldston D, Marsh J: **Family functioning and metabolic control of school-aged children with IDDM**. *Diabetes Care* 1989, **12**(6):409-414.

195. Quittner AL: **Re-examining research on stress and social support: The importance of contextual factors**. In: *Stress and coping in child health.* edn. Edited by La Greca A, Siegel LJ, Wallander JL, Walker EC. New York: The Guilford Press; 1992.
196. Anderson BJ, Brackett J: **Diabetes in children**. In: *Psychology in diabetes care.* 2 edn. Edited by Snoek FJ, Skinner CT. England: Wiley; 2005.
197. Harrell FE: **Regression modeling strategies with applications to linear models, logistic regression, and survival analysis**. New York: Springer; 2001.
198. Porta M: **A dictionary of epidemiology**. England: Oxford University Press; 2008.
199. Matyka KA: **Hypoglycaemia in children with diabetes**. In: *Hypoglycaemia in clinical diabetes.* Second edn. Edited by Frier B, Fisher M. England: John Wiley & Sons Ltd.; 2007.
200. Lindström C, Åman J, Norberg AL: **Increased prevalence of burnout symptoms in parents of chronically ill children**. *Acta Pædiatrica* 2010, **99**:427-432.
201. Lindström C, Åman J, Norberg AL: **Parental burnout in relation to sociodemographic, psychosocial and personality factors as well as disease duration and glycaemic control in children with Type 1 diabetes mellitus**. *Acta Pædiatrica* 2011, **100**:1011-1017.
202. Cottrell L, Khan A: **Impact of childhood epilepsy on maternal sleep and socioemotional functioning**. *Clinical Pediatrics* 2005, **44**:613-616.
203. Meltzer LJ, Mindell JA: **Impact of a child's chronic illness on maternal sleep and daytime functioning**. *Arch Intern Med* 2006, **166**:1749-1755.
204. Amato PR: **The consequences of divorce for adults and children.** *Journal of the Marriage and the Family* 2000, **62**:1269-1287.
205. Pelchat D, Lefebvre H, Perreault M: **Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability**. *Journal of Child Health Care* 2003, **7**(4):231-247.
206. Pelchat D, Lefebvre H, Levert M-J: **Gender defferences and similarities in the experience of parenting a child with a health problem: current state of knowledge**. *Journal of Child Health Care* 2007 **11**(2):112-131.
207. Dashiff C: **Self- and dependent-care responsibility of adolescents with IDDM and their parents**. *Journal of Family Nursing* 2003, **9**:166-183.
208. Wysocki T, Gavin L: **Psychometric properties of a new measure of fathers' involvement in the management of pediatric chronic diseases**. *Journal of Pediatric Psychology* 2004, **29**:231-240.
209. Dashiff C: **Parents' perceptions of diabetes in adolescent daughters and its impact on the family**. *Journal of Pediatric Nursing* 1993, **8**(6):361-369.