

Table 1. Literature searches related to the literature review (Chapter 2)*

Search terms**	Presentation of results †
Diabetes Mellitus, Type 1 OR type 1 diabetes + parent OR parenting + hypoglycemia + fear	<u>Table II</u>
Diabetes Mellitus, Type 1 OR type 1 diabetes + parent OR parenting + burden OR stress	<u>Table III</u>
Diabetes Mellitus, Type 1 OR type 1 diabetes + parent OR parenting + distress	<u>Table III</u>
Diabetes Mellitus, Type 1 OR type 1 diabetes + glycaemic control OR metabolic control OR HbA _{1c} + parent OR parenting + social support	<u>Table IV</u>
Diabetes Mellitus, Type 1 OR type 1 diabetes + glycaemic control OR metabolic control OR HbA _{1c} + parent OR parenting + marital	<u>Table IV</u>
Diabetes Mellitus, Type 1 OR type 1 diabetes + glycaemic control OR metabolic control OR HbA _{1c} + parent OR parenting + employment OR occupation OR education level	<u>Table IV</u>
Diabetes Mellitus, Type 1 OR type 1 diabetes + parent OR parenting + personality	<u>Table IV</u>
Diabetes Mellitus, Type 1 OR type 1 diabetes + glycaemic control OR metabolic control OR HbA _{1c} + blood glucose measurements OR SMBG	<u>Table IV</u>

* The primary searches were performed in September and October 2011 in the databases Medline (Ovid), Embase (Ovid), PsycInfo (Ovid) and Cinahl (Ebsco). The same terms were used in all the databases and no limitations were performed related to year of publication. Updated searches with the same terms were performed in the same databases in April 2012.

** Subheadings adapted to the terminology in the respective databases were included in the searches.

† Conference abstracts were not included and research articles addressing the diagnostic phase of a child's diabetes were also excluded.

In addition to the described searches, reference lists of articles were revised and searches on specific authors in Pubmed were performed.

The titles and abstracts of the achieved publications were revised manually regarding their relevance for the present study. The results are presented in Table II, III and IV on the following pages.

Table 2. Research publications addressing Fear of Hypoglycaemia (FOH) among parents of children with type 1 diabetes*

Authors (year) and title	Design Objectives	Sample	Instrument measuring fear	Key findings related to fear
Marrero DG et al. (1997): Fear of hypoglycaemia in the parents of children and adolescents with diabetes: maladaptive or healthy response?	-Cross-sectional survey. -To explore FOH in parents of children with or without experience of severe hypoglycaemia.	-61 primary caregivers (92% mothers) of children (5-18 yrs).	-HFS-P**	-Higher HFS-P scores in parents of children with a history of severe hypoglycaemia within the past year. -No significant associations between FOH and HbA1c.
Clarke WL et al. (1998): Maternal fear of hypoglycaemia in their children with insulin dependent diabetes mellitus.	-Cross-sectional survey. -To explore FOH in mothers and their children.	-46 mothers of children (<12 yrs).	-HFS-P	-HFS-P scores were correlated to HbA1c ($r=0.34$, $P=0.01$) -Greater FOH in mothers whose children have a history of passing out during hypoglycaemia and in mothers with higher degree of distress over hypoglycaemia that occurred when their child was asleep.
Sullivan Bolyai et al. (2002): Mothers' experiences raising young children with type 1 diabetes.	-Mixed methodology: interviews, observations and survey. -To describe mothers' experiences raising young children with type 1 diabetes.	-25 mothers of children (<4 yrs) with type 1 diabetes. -25 mothers of children without diabetes.	-Banion's Diabetes Management Concern Questionnaire	-Of 10 diabetes management variables, the mothers of children with diabetes ranked hypoglycaemia as the biggest concern. -Episodes of severe hypoglycaemia were reported as extremely stressful especially among the mothers who had experienced severe hypoglycaemia in their child.
Nordenfeldt S, Ludvigsson J (2005): Fear and other disturbances of severe hypoglycaemia in children and adolescents with type 1 diabetes mellitus.	-Cross-sectional design. -To study perceived occurrence and magnitude of fear and other disturbances of severe hypoglycaemia.	-112 children (<19 yrs) and their primary caregiver.	-Self-made empirical questions.	-Severe hypoglycaemia was identified as the most disturbing risk and the greatest cause of diabetes-related fear in children and their caregivers.
Streisand R et al. (2005): Pediatric parenting stress among parents of children with type 1 diabetes: the role of self-efficacy, responsibility and fear.	-Cross-sectional survey. -To explore parenting stress related to diabetes management.	-134 parents (86% mothers) of 134 children (9-17 yrs) with type1 diabetes.	-HFS-P	-A significant portion of variance in diabetes-related stress frequency and stress difficulty were associated with lower self-efficacy, greater responsibility and greater fear of hypoglycaemia.
Gonder-Frederick LA et al. (2006): Predictors of fear of hypoglycemia in adolescents with type 1 diabetes and their parents.	-Cross-sectional survey. -To test associations between FOH and trait anxiety, history of hypoglycaemia and clinical variables.	-39 adolescents (12-17 yrs) and one of their parents (38 mothers and 1 father).	-HFS-P and HFS-C (child version)	-FOH was not related to HbA1c. -FOH was not related to the parents' trait of anxiety or their child's history of hypoglycaemia, but by whether they believed that their child carried emergency glucose.

Table 2 continue

<p>Patton SR et al. (2007) : Parental fear of hypoglycemia: young children treated with continuous subcutaneous insulin infusion.</p>	<p>-Cross-sectional survey. -To examine associations between parental fear and glucose control in children receiving CSII.</p>	<p>-24 families of children with type 1 diabetes (2-8 yrs). -response rate: 86%.</p>	<p>-A modified version of HFS-P for parents of young children (HFS-PYC)</p>	<p>-HFS-PYC total score was significant correlated to higher average blood glucose levels obtained by blood glucose tests. -HFS-PYC behaviour score was positive correlated with HbA1c 3 months after study enrolment ($r=0.42$, $P=0.04$). -Child's age, diabetes duration and HbA1c was not correlated with HFS-PYC total score.</p>
<p>Patton SR et al. (2008): Fear of hypoglycaemia in parents of young children with type 1 diabetes mellitus.</p>	<p>-Cross-sectional survey. -To examined FOH and to compare mothers and fathers FOH and FOH in different age groups (compare results with previous studies).</p>	<p>-81 mothers and 64 fathers of young children (2-8 yrs). -response rate: 73%</p>	<p>-HFS-PYC (modified HFS-P)</p>	<p>-A positive correlation between 1) the mothers HFS-PYC worry score and frequency of hypoglycaemia and 2) the mothers total score and a history of seizure. -Higher HFS-PYC total and behaviour scores in mothers than in fathers. -Same level of fear in mothers of young and older children. -No correlation between HFS-PYC score and age, blood glucose levels or HbA1c.</p>
<p>Jaser SS et al. (2009): Coping and psychosocial adjustment in mothers of young children with type 1 diabetes.</p>	<p>-Baseline data from a larger intervention study.</p>	<p>-67 mothers of children 2-8 yrs. (3 fathers were excluded from analysis because of the small number.)</p>	<p>-HFS-P worry subscale</p>	<p>-Mother reported symptoms of anxiety and depression were significant correlated to fear of hypoglycaemia. -The mothers' fear of hypoglycaemia accounted for respectively 7 and 6% of the variance in the anxiety and depression symptoms.</p>
<p>Monaghan MC et al. (2009) Nighttime caregiving behaviours among parents of young children with Type 1 diabetes: associations with illness characteristics and parent functioning.</p>	<p>-Cross-sectional survey and twenty-four-hour recall interviews. -To examine frequency of night-time blood glucose monitoring (NBGM) and to identify the child's illness characteristics, parents fear, anxiety and stress related to NBGM.</p>	<p>-71 parents (97% mothers) of children (2-6yrs) -response rate: 76%</p>	<p>-An 8 item modified HFS worry subscale and 1 item from a HFS-P behavior subscale.</p>	<p>-41% performed NBGM on at least 1 of the 2 nights assessed by the recall interviews. -Frequency of night-time monitoring was not associated with higher HFS-P worry score.</p>
<p>Müller-Godeffroy E et al. (2009): Investigation of quality of life and family burden issues during insulin pump therapy in children with Type 1 diabetes mellitus – Tempa large-scale multicentre pilot study.</p>	<p>-Multi-centre prospective pre-/post study. -To investigate psychosocial aspects of CSII therapy in children with type 1 diabetes.</p>	<p>-The main carer of 114 (84% mothers) of children (29 children 4-7 yrs, 25 children 8-11 yrs and 63 adolescents 12-16 yrs).</p>	<p>-HFS-P</p>	<p>-Parents of school-aged children and adolescents reported reduced HFS-P behaviour and worry subscale scores 6 months after transition to CSII compared to before the transition. Parents of younger children reported only reduced HFS-P worry subscale score.</p>

Table 2 continue

<p>Barnard K et al. (2010): Fear of hypoglycaemia in parents of young children with type 1 diabetes: a systematic review.</p>	<p>-A systematic review article. -To review studies concerning the extent and consequences of FOH in parents of children with type 1 diabetes <12 yrs.</p>	<p>-8 articles from 6 studies including parents of children < 12 yrs. -Only cross-sectional studies were included.</p>	<p>-HFS-P and some modified versions of HFS-P.</p>	<p>-HFS-P is the most common instrument to measure parental FOH. -FOH is related more to the severity than the frequency of hypoglycaemia, especially if the child has had a hypoglycaemic convulsion. -The studies did not confirm a significant association between FOH and glycaemic control in the child.</p>
<p>Nyer M B (2010): Fear of hypoglycaemia: Psychological associations and diabetes control in youth with type 1 diabetes and their parents (Dissertation).</p>	<p>-Cross-sectional design. -To study associations between FOH and frequency of severe hypoglycaemia and trait anxiety in children and parents.</p>	<p>-252 youth (6-18 yrs) and 251 parents.</p>	<p>-HFS for youth and for parents.</p>	<p>-Glycaemic control was not related to the parents FOH. -Higher parental HFS Worry score was significant associated with higher level of trait anxiety. -No association between parental HFS scores and history of severe hypoglycaemia among the youths.</p>
<p>Patton SR et al. (2011): Pediatric parenting stress and its relation to depressive symptoms and fear of hypoglycemia in parents of young children with type 1 diabetes mellitus.</p>	<p>-Cross-sectional survey. -To examine several psychological correlates of pediatric parenting stress including FOH.</p>	<p>-39 young children (<7 yrs) and a parent. -recruitment rate: 51%</p>	<p>HFS-PYC (modified HFS-P)</p>	<p>More frequent parenting stress and more difficulty with parenting stress were associated with higher HFS-PYC total scores.</p>
<p>Gonder-Frederick et al. (2011): Assessing fear of hypoglycaemia in children with Type 1 diabetes and their parents.</p>	<p>-literature review -To provide a descriptive review of the literature on FOH and presents new findings regarding the assessment of FOH</p>	<p>-24 articles addressing pediatric FOH were included (FOH among children/adolescents and/or parents).</p>	<p>Primarily CHFS (HFS for children) and HFS-P (named PHFS in this article) were used in the reviewed studies.</p>	<p>-More research is needed to increase the understanding and validity of the instruments used to assess pediatric FOH. -Given the potential importance of fear of hypoglycaemia in pediatric diabetes, there has been limited research in this area.</p>

* Table explanations:

- The selection of research articles included in the table is based on literature searches performed in the databases Medline (Ovid), Embase (Ovid), PsycInfo (Ovid) and Cinahl (Ebsco) in September 2011 and April 2012.
- The table does not include articles addressing burden and distress only in the diagnostic phase of diabetes in a child.
- In studies with multiple objectives and findings, the objectives and key findings listed in the table are adapted according to their relevance for the present study.
- The instruments listed in the fourth column of the table are only instruments of relevance for the objectives in the present study.
- Conference abstracts are not included in the table.

**HFS-P = Hypoglycaemia Fear Survey – Parent version.

Table 3. Research publications addressing perceived burden and/or emotional distress among mothers and fathers of children with type 1 diabetes*

Authors (year) and title	Design Objectives	Sample	Instrument measuring parental burden and/or distress	Key findings related to burden and/or distress
<p>Kovacs M et al. (1990): Psychological functioning among mothers of children with insulin-dependent diabetes mellitus: A longitudinal study.</p>	<p>-Longitudinal study design. -Interviews and questionnaire -To determine the psychological correlates of managing diabetes in a child.</p>	<p>-95 mothers of children aged 8.3-13.9 at study start.</p>	<p>-Beck Depression Inventory -HSCL- 90 item</p>	<p>-Symptoms of distress were in average below the levels generally considered to clinically significant. -Symptoms and adjustment at diagnosis were among the best predictors for later symptoms of emotional distress among the mothers. -Mothers symptoms were not related to medical aspects such as the child's HbA_{1c}.</p>
<p>Hatton DL et al. (1995): Parents' perceptions of caring for an infant or toddler with diabetes.</p>	<p>-Phenomenological design. -Interviews. -To gain knowledge and understanding of the parents' experiences.</p>	<p>-8 two-parent families of children <3 yrs.</p>		<p>-The parents described the diabetes management as overwhelming. -Sadness, frustration, anger, fear, anxiety and perceived loss of control were all described by the parents.</p>
<p>Hoey H et al. (2001): Good metabolic control is associated with better quality of life in 2101 adolescents with type 1 diabetes.</p>	<p>-Cross-sectional multicenter survey (Hvidøre). -To assess the consequences of poor glycemic control among adolescents with type 1 diabetes.</p>	<p>-2101 adolescents (10-18 yrs) and a parent from 21 centers in 17 countries.</p>	<p>-Family Burden Scale.</p>	<p>-Parents of children with good metabolic control reported lower burden than those with poor control. -Reported diabetes-related burden decreased with adolescents' age when controlling for sex, duration of diabetes.</p>
<p>Sullivan Bolyai S et al. (2002): Mothers' experiences raising young children with type 1 diabetes.</p>	<p>-Mixed methodology: interviews, observations and survey. -To describe mothers' experiences raising young children with type 1 diabetes.</p>	<p>-25 mothers of children (<4 yrs) with type 1 diabetes. -25 mothers of children without diabetes.</p>	<p>-The Parenting Stress Index (PSI)</p>	<p>-No differences in PSI scores between mothers with or without a child with diabetes. -Positive correlation between PSI score and duration of diabetes indicating that stress increased as duration increased.</p>
<p>Sullivan-Bolyai S et al.(2003): Constant vigilance: mother's work parenting young children with type 1 diabetes.</p>	<p>-Same as above.</p>	<p>-Same as above</p>		<p>-Some mothers described associations between the burden of care and personal health problems, such as depression, weight loss or gain and migraines. -The problems were partly attributed to the responsibility and the limited social support.</p>

Table 3 continue

<p>Whittermore R et al. (2003): Quality of life in school-aged children with type 1 diabetes on intensive treatment and their parents.</p>	<p>-Cross-sectional design. -To examine family factors associated with quality of life and metabolic control.</p>	<p>-56 children (8-12 yrs) and parents.</p>	<p>-CES-D measuring symptoms of depression</p>	<p>-Parents perceived the diabetes treatment regimen as moderately upsetting and bothersome. -29% of parents scored higher than the criterion score for increased depressive symptoms and were referred for further evaluation and treatment. -Increased depressive symptoms in parents were associated with increased depressive symptoms in children.</p>
<p>Mullins LL et al. (2004): 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.</p>	<p>-Cross-sectional survey. -The relationship between parental overprotection and child vulnerability and depressive symptoms and the moderating influence of parenting stress.</p>	<p>-43 mothers and children 8-12 yrs.</p>	<p>-The Parenting Stress Index (PSI)</p>	<p>-An association between parenting stress and depressive symptoms in the child was identified.</p>
<p>Stallwood L (2005): Influence of caregiver stress and coping on glycemic control of young children with diabetes.</p>	<p>-Cross-sectional survey. -To examine the influence of caregiver stress, coping and home management on glycaemic control.</p>	<p>-73 primary caregivers (predominately females) of children <9 yrs.</p>	<p>-Problem Areas in Diabetes Scale (PAID) and Appraisal of Diabetes Scale (ADS).</p>	<p>-Caregivers of younger children reported higher levels of stress. -Higher caregiver stress was associated with lower HbA_{1c}. -In addition, higher level of home management was associated with lower HbA_{1c}.</p>
<p>Streisand R et al. (2005): Pediatric parenting stress among parents of children with type 1 diabetes: the role of self-efficacy, responsibility and fear.</p>	<p>-Cross-sectional survey. -To explore parenting stress related to diabetes management.</p>	<p>-134 parents (86% mothers) of 134 children (9-17 yrs) with type 1 diabetes.</p>	<p>-The Pediatric Inventory for Parents (PIP) measuring frequency and difficulty of parenting stress.</p>	<p>-Parents of younger children and parents of children using insulin injections versus insulin pump reported more difficult parenting stress. -Increased parenting stress was associated with parents' psychological variables such as lower self-efficacy, greater responsibility for the diabetes management and greater fear of hypoglycaemia.</p>
<p>Carpentier M et al. (2006): The relationship of illness uncertainty and attributional style to long-term psychological distress in parents of children with type 1 Diabetes Mellitus.</p>	<p>-Longitudinal study design. -Follow-up study 5-6 yrs after study start. -To examine the relationship of illness uncertainty and attributional style to psychological distress.</p>	<p>-26 mothers and 4 fathers of children with illness duration ranged from 5 to 20 yrs.</p>	<p>-Brief Symptom Inventory (BSI).</p>	<p>-Illness uncertainty related to ambiguity, complexity, inconsistency of information and unpredictability was identified as a strong predictor for psychological distress among parents of children with type 1 diabetes.</p>

Table 3 continue

<p>Hoey H et al. (2006): Parent and health professional perspectives in the management of adolescents with diabetes: Development of assessment instruments for international studies.</p>	<p>-Cross-sectional multicentre study (The Hvidøre study, 1998). -To describe psychometric validity and clinical applicability of questionnaires measuring family burden.</p>	<p>-2101 adolescents (10-18 yrs) and a parent; and health providers from 21 centres in 17 different countries in Europe, Japan and North America participated</p>	<p>-The Family Burden Scale measuring 5 domains of diabetes-related burden.</p>	<p>-The Family Burden Scale for both parents and health providers showed good psychometric properties. -The greatest burden, as perceived by both parents and health professionals, is related to long term health concerns. -More than half of the parents reported the burden of long term concerns to be major.</p>
<p>Sullivan Bolyai S et al. (2006): Fathers- reflections on parenting young children with type 1 diabetes.</p>	<p>-Qualitative descriptive study design with interviews. -To describe fathers' experiences in parenting and managing the care of their young children with type 1 diabetes.</p>	<p>-14 fathers of 15 children <10 yrs with diabetes.</p>		<p>-The fathers described an underlying sadness but a great responsibility for being strong and "to stay in the loop" to maintain managing skills and support their partners (the mothers) who were described as most often the primary caregiver.</p>
<p>Cameron LD et al. (2007): Maternal trait anxiety and diabetes control in adolescents with type 1 diabetes.</p>	<p>-Cross-sectional survey. -To examine the relationship of maternal trait anxiety with diabetes regulation among adolescents with type 1 diabetes.</p>	<p>-47 adolescents (13-18 yrs) and their mothers.</p>	<p>-The trait subscale of the State-Trait Anxiety Inventory (STAI). -The emotional representation subscale of the Illness Perceptions Scale-Revised.</p>	<p>-For younger adolescents, maternal trait anxiety was associated with higher HbA_{1c} -Trait-anxious mothers reported more responsibility for diabetes management tasks and perceived their adolescents as having poorer management skills.</p>
<p>Butler DA et al. (2008): The impact of modifiable family factors on glycemic control among youth with type 1 diabetes</p>	<p>-Cross-sectional design. -Structured interviews and questionnaire. -To identify modifiable family factors impacting glycaemic control in youth with type 1 diabetes.</p>	<p>-153 youth (8-16 yrs) and a parent.</p>	<p>-To measure diabetes-related burden the PAID (Problem Areas in Diabetes)-Parent version was used.</p>	<p>-More perceived burden was associated with higher youth HbA_{1c}. (r=0.27, P<0.001). -Parents who reported negative affects related to high and low blood glucose values reported higher levels of parental burden.</p>

Table 3 continue

<p>Jaser SS et al. (2008): Mediators of depressive symptoms in children with type 1 diabetes and their mothers.</p>	<p>-Baseline data as part of an RCT. -To examine the relationships among maternal and child depressive symptoms and child and family psychosocial factors.</p>	<p>-108 school-aged children (8-12 yrs) and their mothers.</p>	<p>-The Center for Epidemiologic Depression Scale (CES-D)</p>	<p>-An association between higher levels of maternal depressive symptoms and child depressive symptoms was identified. -Despite no significant relation between maternal depressive symptoms and the child's HbA_{1c}, poorer HbA_{1c} was associated with children finding it more upsetting to cope with diabetes which further on was significant associated with higher maternal depressive symptoms.</p>
<p>Bowes S et al. (2009): Chronic sorrow in parents of children with type 1 diabetes.</p>	<p>Qualitative study design with in-depth interviews. -To explore parents' longer-term experiences of having a child with type 1 diabetes.</p>	<p>-10 mothers and 7 fathers of children with type 1 diabetes 7-10 yrs after diagnosis.</p>		<p>-Continuing feelings associated with grief were expressed by both mothers and fathers. -The described a resurgence of grief at critical times. -Mothers elaborated more on their emotions than fathers.</p>
<p>Jaser SS et al. (2009): Coping and psychosocial adjustment in mothers of young children with type 1 diabetes.</p>	<p>-Baseline data from a larger intervention study. -To examine symptoms of anxiety and depression in mothers of young children with type 1 diabetes.</p>	<p>-67 mothers of children 2-8 yrs.</p>	<p>-The Center for Epidemiologic Depression Scale (CES-D). - The state subscale of the State-Trait Anxiety Inventory (STAI).</p>	<p>-21% of the mothers reported clinically significant levels of symptoms of anxiety. -24% reported clinically significant levels of depression. -Mothers symptoms were not related to children's metabolic control.</p>
<p>Mitchell SJ et al. (2009): Stress among fathers of young children with type 1 diabetes. FOH is related more to the severity of hypoglycaemia than the frequency</p>	<p>-Sub study of a larger descriptive survey. -To study correlates of fathers' pediatric parenting stress related to diabetes in a child.</p>	<p>-43 fathers of children 2-6 yrs.</p>	<p>-The Pediatric Inventory for Parents (PIP).</p>	<p>-Fathers parenting stress is positively associated with his state anxiety and mother-reported difficult child behaviour.</p>
<p>Monaghan MC et al. (2009) Nighttime caregiving behaviours among parents of young children with Type 1 diabetes: associations with illness characteristics and parent functioning.</p>	<p>-Cross-sectional survey and twenty-four-hour recall interviews. -To examine frequency of night-time blood glucose monitoring (NBGM) and to identify the child's illness characteristics, parents fear, anxiety and stress related to NBGM.</p>	<p>-71 parents (97% mothers) of children (2-6yrs) -response rate: 76%</p>	<p>-The state subscale of the State-Trait Anxiety Inventory (STAI). -The Pediatric Inventory for Parents (PIP)</p>	<p>-Parents who performed night-time blood glucose measurements (NBGM) sometimes reported higher state anxiety than those performed NBGM rarely/never. -The same association was not found between parents who performed NBGM often/always. -The authors concluded that lack of a system for BGM may be distressing.</p>

Table 3 continue

<p>Müller-Godeffroy E et al. (2009): Investigation of quality of life and family burden issues during insulin pump therapy in children with Type 1 diabetes mellitus – Tempa large-scale multicentre pilot study.</p>	<p>-Multi-centre prospective pre-/post study. -To investigate psychosocial aspects of CSII therapy in children with type 1 diabetes.</p>	<p>-The main carer of 114 (84% mothers) of children (29 children 4-7 yrs, 25 children 8-11 yrs and 63 adolescents 12-16 yrs).</p>	<p>-The Pediatric Inventory for Parents (PIP) measuring frequency and difficulty of parenting stress.</p>	<p>-Six months after transition to CSII parents of school-aged children and younger children reported significant less frequent parenting stress, less difficulty with parenting stress and lower overall burden of diabetes.</p>
<p>Stewart SM et al. (2009): Patient- versus parent-reported psychological symptoms as predictors of type 1 diabetes management in adolescents.</p>	<p>-Longitudinal study design. -To study whether psychological symptoms were among others related to adherence and metabolic control.</p>	<p>-231 adolescents (11-18 yrs) and a parent.</p>	<p>-Personal Adjustment and Role Skills Scale – III (PARS-III).</p>	<p>-Adolescent- but not parent-reported symptoms of anxiety and depression were correlated with poor metabolic control.</p>
<p>Streisand R et al. (2009): Associations of parent coping, stress and well-being in mothers of children with diabetes: Examination of data from a national sample.</p>	<p>-Cross-sectional survey with telephone interviews. -To determine the associations of parental coping, stress and psychological and physical well-being.</p>	<p>-Mothers of 278 children (<1 -17 yrs) with type 1 or type 2 diabetes.</p>	<p>-4 item measuring parent stress. -1 item measuring psychological well-being and 1 item measuring physical well-being.</p>	<p>-Maternal coping and stress levels were related to both psychological and physical well-being. -Mothers in single-parent homes indicated significantly poorer well-being, both psychologically and physically.</p>
<p>Eckshtain D et al. (2010): The effects of parental depression and parenting practices on depressive symptoms and metabolic control in urban youth with insulin dependent diabetes.</p>	<p>-Cross-sectional survey -To examine relationships between parental depressive symptoms, parenting, youth depressive symptoms and glycaemic control.</p>	<p>-61 parents of children 10-17 yrs.</p>	<p>-The Brief Symptom Inventory 18 (BSI 18).</p>	<p>-The presence of parental depressive symptoms influences both youth depression and poor glycaemic control through problematic parenting practices such as low involvement and monitoring (Path analysis)</p>
<p>Cunningham NR et al. (2011): From caregiver psychological distress to adolescent glycaemic control: The mediating role of perceived burden around diabetes management.</p>	<p>-Cross-sectional design. -To examine whether perceived diabetes-related caregiver burden mediated the relationship between caregivers' psychological distress and adolescents' glycaemic control.</p>	<p>-147 adolescents (13-18 yrs) and their primary caregiver.</p>	<p>-The State-Trait Anxiety Inventory (STAI) -PAID-P (for measuring diabetes-related burden)</p>	<p>-Perceived burden mediated the relationship between caregiver symptoms of anxiety and depression and adolescents' glycaemic control.</p>

Table 3 continue

<p>Patton SR et al. (2011): Pediatric parenting stress and its relation to depressive symptoms and fear of hypoglycemia in parents of young children with type 1 diabetes mellitus.</p>	<p>-Cross-sectional survey. -To examine several psychological correlates of pediatric parenting stress.</p>	<p>-39 young children (<7 yrs) and a parent. -recruitment rate: 51%</p>	<p>-The Pediatric Inventory for Parents (PIP) -Beck Depression Inventory II</p>	<p>-Higher stress frequency and difficulty were associated with higher parental depressive symptoms.</p>
<p>Hilliard ME et al. (2011): Parent stress and child behaviour among young children with type 1 diabetes.</p>	<p>-Cross-sectional survey and twenty-four-hour recall interviews. -To examine associations between parenting stress and parent reported child behaviour problems</p>	<p>-73 parents of children 2-6 yrs (97% mothers).</p>	<p>-The state subscale of the State-Trait Anxiety Inventory (STAI). -The Paediatric Inventory for Parents (PIP)</p>	<p>-Structural equation modelling indicated that greater general anxiety and parenting stress were associated with parent report of more problematic child behaviour. -Parenting stress was not associated with metabolic control or blood glucose variability.</p>
<p>Hilliard ME et al. (2011): Fathers' involvement in preadolescents' diabetes adherence and glycaemic control.</p>	<p>-To examine the relationship of paternal involvement in diabetes care with adherence and glycaemic control.</p>	<p>-136 mothers and fathers of preadolescents (9-12 yrs).</p>	<p>-Interviews on adherence and blood glucose meter downloads.</p>	<p>-Mothers and fathers reported similar amount of paternal involvement, yet mothers rated paternal involvement as more helpful. -An association between increased paternal involvement and poor glycaemic control was identified. An interpretation of increased involvement as response to suboptimal outcomes was suggested.</p>
<p>Wiebe DJ et al. (2011): Longitudinal associations of maternal depressive symptoms, maternal involvement, and diabetes management across adolescence.</p>	<p>- Longitudinal design. -To examine whether maternal depressive symptoms predicted level of maternal involvement in diabetes management.</p>	<p>-82 youth (10-15yrs) and their mothers</p>	<p>-The Centre for Epidemiological Studies of Depression Scale.</p>	<p>-Maternal involvement was associated with lower adolescent depression and better glycaemic control, but this association was stronger when mothers reported fewer depressive symptoms. -Mothers' depressive symptoms may undermine her care-giving effectiveness during adolescence.</p>
<p>Hansen JA et al. (2012) Paternal involvement in pediatric type 1 diabetes: Fathers' and mothers' psychological functioning and disease management.</p>	<p>-Cross-sectional design. -To examine the constructs of parenting stress and marital satisfaction among mothers and fathers. -To examine the impact of paternal involvement on regimen adherence and glycaemic control in children.</p>	<p>-82 mothers and 43 fathers (36 mother/ father dyads).</p>	<p>-The Pediatric Inventory for Parents (PIP) -Hospital Anxiety and Depression Scale (HADS) -Dyadic Adjustment Scale (DAS)</p>	<p>-Maternal perception of father helpfulness was associated with decreased maternal depressive symptoms. - Maternal perception of paternal helpfulness and higher amount of involvement was associated with improved marital satisfaction.</p>

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- The table does not include articles addressing burden and distress only in the diagnostic phase of diabetes in a child.
- In studies with multiple objectives and findings, the objectives and key findings listed in the table are adapted according to their relevance for the present study.
- The instruments listed in the fourth column of the table are only instruments of relevance for the objectives in the present study.
- Conference abstracts are not included in the table.

Table 4. Research publications addressing glycemic control (HbA_{1c}) among children with type 1 diabetes and 1) the parents personal psychological and contextual resources and 2) blood glucose measurements as a marker for diabetes-specific parenting behavior*

Authors (year) and title	Design Objectives	Participants	Relevant instruments used	Key findings related to the
Anderson B et al. (1997): Parental involvement in diabetes management tasks: relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus.	-Cross-sectional design. -Questionnaire and interviews. -To identify parental behaviours that relate to adherence and metabolic control.	-89 youth (10-15 yrs).		-Parental involvement in Self-Monitoring of Blood Glucose (SMBG) was associated with more frequent SMBG. -Increased frequency of SMBG was associated with lower HbA _{1c} .
Florian V, Elad D (1998): The impact of mothers' sense of empowerment on the metabolic control of their children with juvenile diabetes.	-Cross-sectional design -Questionnaire -To examine the mothers' sense of empowerment.	-88 mothers of children (12-17 yrs)		-Mother's sense of empowerment and their education explain a significant proportion of the variance in their children's metabolic control.
Kaufman FR, Halvorsen M, Carpenter S (1999): Association between diabetes control and visits to a multidisciplinary pediatric diabetes clinic.	-Cross-sectional design. -To measure associations between number of visits to the clinic and HbA _{1c} and demographic variables.	-360 children with a mean age of 11.6 yrs.		-Children from single-parent households had fewer visits to the clinic than children from two-parent families. -A significant association was identified between more frequent visits and lower HbA _{1c} .
Sullivan Bolyai S et al. (2002): Mothers' experiences raising young children with type 1 diabetes.	-Mixed methodology: -Survey (and interviews + observations). -To describe mothers' experiences raising young children with type 1 diabetes.	-25 mothers of children (<4 yrs) with type 1 diabetes. -25 mothers of children without diabetes.	-The Home Care Resource Inventory (HCRI). -The Coping Health Inventory for Parents (CHIP).	-49% of the mothers worked full-time compared to 79% of the control mothers. -36% of the mothers versus 83% of the controls reported "I can get a babysitter". -52% of the mothers versus 88% of the controls responded "yes" to "there is always someone I can call to help me".
Whittermore R et al. (2003): Quality of life in school-aged children with type 1 diabetes on intensive treatment and their parents.	-Cross-sectional design. -To examine family factors associated with quality of life and metabolic control.	-56 children (8-12 yrs) and a parent.		- HbA _{1c} was associated with the fathers' education level; thus youths in families with higher education had lower HbA _{1c} .
Stallwood L (2005): Influence of caregiver stress and coping on glycemic control of young children with diabetes.	-Cross-sectional survey. -To examine the influence of caregiver stress, coping and home management on glycaemic control.	-73 primary caregivers (predominately females) of children <9 yrs.	-Diabetes Self-Management Profile (DSMP) assessing home management.	-Higher DSMP score, which indicated more meticulous home management, was correlated with lower HbA _{1c} .

Table 4 continue

<p>Urbach SL et al. (2005): Predictors of glucose control in children and adolescents with type 1 diabetes.</p>	<p>-Cross-sectional design. -Data collected from medical records. -To evaluate HbA_{1c} and factors associated with HbA_{1c}.</p>	<p>-155 children and adolescents (2-18 yrs).</p>		<p>-Younger age in the child and married parents were associated with better glycemic control. -A significant association was identified between higher number of blood glucose measurements per day and married parents. -Those visiting the clinic 3-4 times/yrs had lower HbA_{1c} than those visiting the clinic <2 or ≥5 times/yr.</p>
<p>Frey MA et al. (2006): Diabetes management and metabolic control in school-age children with type 1 diabetes.</p>	<p>-Descriptive cross-sectional study. -To study the effect of mother's coping resources, cognitive resources, family stress and demographic variables on metabolic control.</p>	<p>-59 mothers of children (6-13 yrs) with type 1 diabetes.</p>	<p>-The Coping Resources Inventory (CRI). -The Diabetes Management Scale – Parent Report (DMS-PR)</p>	<p>-A significant association between HbA_{1c} and the mothers' reports of better diabetes management measured by DMS-PR score was identified. -The study did not identify any significant associations between children's HbA_{1c} and cognitive resources, coping resources and family stress.</p>
<p>Hoey H et al. (2006): Parent and health professional perspectives in the management of adolescents with diabetes: Development of assessment instruments for international studies.</p>	<p>-Cross-sectional multicentre study (The Hvidøre study, 1998). -To describe psychometric validity and clinical applicability of questionnaires measuring family burden.</p>	<p>-2101 adolescents (10-18 yrs) and a parent; and health providers from 21 centres in 17 different countries in Europe, Japan and North America participated</p>		<p>-A significant higher HbA_{1c} was identified in one-parent families compared to two-parent families.</p>
<p>Lewin AB et al. (2006): The relation between family factors and metabolic control: the role of diabetes adherence.</p>	<p>-Cross-sectional design. -To examine family factors as predictors for metabolic control.</p>	<p>-109 children (8-18 yrs) and one caregiver (82% mothers).</p>		<p>- Higher HbA_{1c} in children from single-parent. - HbA_{1c} was weakly positive associated with child age and diabetes duration. -A median analysis showed demographic variables combined with family functioning and adherence to predict 49% of the variance in HbA_{1c}.</p>
<p>Pattison HM et al. (2006): The relationship between parental perception of diabetes and glycemic control.</p>	<p>-Cross-sectional survey. -To measure the relationship between child competences, parental self-efficacy and children's glycaemic control.</p>	<p>-51 parents (82% mothers) of children (6-12 yrs)</p>		<p>-More frequent self-monitoring of blood glucose (SMBG) and higher perceived age at which a child could be responsible for self-management, were associated with better glycaemic control.</p>

Table 4 continue

<p>Stallwood L (2006): Relationship between caregiver knowledge and socioeconomic factors on glycemic outcomes of young children with diabetes.</p>	<p>-Cross-sectional, correlational design. -To describe the relationship between caregiver knowledge, socioeconomic factors and glycaemic control.</p>	<p>-73 caregivers of children < 9 yrs.</p>		<p>-Higher caregiver knowledge was associated with lower HbA_{1c} levels, higher income and being married.</p>
<p>Swift EE et al. (2006): Demographic risk factors, mediators, and moderators in youths' diabetes metabolic control.</p>	<p>-Cross sectional design. -Path analysis. -To examine key demographic risk factors for poorer metabolic control.</p>	<p>-211 children (9-16 yrs) and one parent each (84% mothers).</p>		<p>-When socioeconomic status, ethnicity and marital status were considered simultaneously with path analysis, living with married parents was the sole predictor of better glycaemic control in children. More frequent meals and more frequent SMBG mediated this effect.</p>
<p>Chisholm V et al. (2007): Predictors of treatment adherence in young children with type 1 diabetes.</p>	<p>-Cross-sectional survey. -To investigate whether diabetes-specific, demographic and psychosocial variables predict adherence.</p>	<p>-Mothers of 65 children (2-8 yrs).</p>		<p>- HbA_{1c} was not correlated to frequency of SMBG. -However, better general diabetes knowledge was correlated with both more frequent tests and better glycemic control.</p>
<p>Faulkner MS, Chang L (2007): Family influence on self-care, quality of life, and metabolic control in school-age children and adolescents with type 1 diabetes.</p>	<p>-Descriptive, correlational study design. -To assess associations among demographic variables, family behaviours, self-care, QOL and glycaemic control.</p>	<p>-99 children and adolescents (10-18 yrs).</p>	<p>-A parental demographic data sheet.</p>	<p>-The father's educational level was the only significant predictor of HbA_{1c}. -Age, sex, race, duration of diabetes and mother's educational level were not significant predictors of HbA_{1c}.</p>
<p>Frey MA et al. (2007): Predicting metabolic control in the first 5 yr after diagnosis for youths with type 1 diabetes: the role of ethnicity and family structure.</p>	<p>-Accelerated longitudinal design. -To explore differences in glycaemic control between ethnicity and sociodemographic variables.</p>	<p>-71 children (>10 yrs) and parents with at least 3 yrs duration of diabetes.</p>		<p>-Higher HbA_{1c} levels were identified in single-parent families compared to two-parent families.</p>

Table 4 continue

<p>Lewandowski A, Drotar D (2007): The relationship between parent-reported social support and adherence to medical treatment in families of adolescents with type 1 diabetes.</p>	<p>-Cross-sectional survey. -To investigate relationships between mother-reported spousal and network support, mother-adolescent diabetes-related conflicts and adherence to treatment.</p>	<p>-51 mother-adolescent (13-18 yrs) dyads.</p>	<p>-The Social Provisions Scale – Spousal Version. -The Social Support Questionnaire.</p>	<p>-In this sample higher levels of perceived spousal support were associated with less maternal-adolescent conflict and better adherence to diabetes treatment. -Support from the social network did not predict maternal-adolescent conflict or adherence to treatment.</p>
<p>Butler DA et al. (2008): The impact of modifiable family factors on glycemic control among youth with type 1 diabetes</p>	<p>-Cross-sectional design. -Structured interviews and questionnaire. -To identify modifiable family factors impacting glycaemic control in youth with type 1 diabetes.</p>	<p>-153 youth (8-16 yrs) and a parent.</p>		<p>- HbA_{1c} was significantly lower in youth monitoring blood glucose ≥ 4 times/day compared with youth monitoring < 3 times/day. -Those monitoring ≥ 4 were younger than those monitoring < 3 times/day. -Number of injections was not associated with HbA_{1c}.</p>
<p>Cameron FJ et al. (2008): Are family factors universally related to metabolic control in adolescents with Type 1 diabetes?</p>	<p>-Cross-sectional multicentre study (Hvidøre). -To assess the importance of family factors on metabolic outcomes in adolescents.</p>	<p>-2062 adolescents (11-18 yrs) from 19 countries and parents.</p>		<p>-Adolescents with parents living together had significant lower HbA_{1c} than adolescents from single-parent families. -Adolescents with employed fathers had lower HbA_{1c} than adolescents with unemployed fathers.</p>
<p>Johns C, Faulkner MS, Quinn L (2008): Characteristics of adolescents with type 1 diabetes who exhibit adverse outcomes.</p>	<p>-Cross-sectional descriptive study design. -To identify characteristics of adolescents with type 1 diabetes who exhibit poor outcomes.</p>	<p>-108 adolescents (mean age 15.3 yrs).</p>		<p>-Those with HbA_{1c} $< 8\%$ had a higher frequency of SMBG /day and higher father's education level than those with HbA_{1c} $> 8\%$.</p>
<p>Marvicsin D (2008): School-age children with diabetes: role of maternal self-efficacy, environment, and management behaviors.</p>	<p>-Descriptive cross-sectional design. -To identify the role of maternal self-efficacy, maternal environment and management behaviour for glycaemic control.</p>	<p>-41 mothers of children 6-10 yrs.</p>		<p>-Children with more SMBG had a lower HbA_{1c}.</p>

Table 4 continue

<p>Meunier J, Dorchy H, Luminet O (2008): Does family cohesiveness and parental alexithymia predict glycaemic control in children and adolescents with diabetes?</p>	<p>-Cross-sectional design. -To examine the relationship between family cohesiveness and parental alexithymia and glycaemic control.</p>	<p>-45 families of children and adolescents (6-18 yrs).</p>		<p>-Unemployed parents and single-parent status were significant associated with higher HbA_{1c}.</p>
<p>Svensson J et al. (2008): Improved metabolic outcome in a Danish diabetic paediatric population aged 0-18 yr: results from a nationwide continuous registration.</p>	<p>-Prospective study design. -To describe changes in glycaemic control over a period of 10 yrs (1996-2006).</p>	<p>-2705 children and adolescents (0-18 yrs) in the Danish National Diabetes Registry.</p>		<p>-A reduction in HbA_{1c} between 1996 and 2006 was related to an increased number of SMBG during the period.</p>
<p>Eckshtain D et al. (2010): The effects of parental depression and parenting practices on depressive symptoms and metabolic control in urban youth with insulin dependent diabetes.</p>	<p>-Cross-sectional survey -To examine relationships between parental depressive symptoms, parenting, youth depressive symptoms and glycaemic control.</p>	<p>-61 parents of children 10-17 yrs.</p>		<p>-Less SMBG was significantly correlated with worse metabolic control as measured by HbA_{1c}.</p>
<p>Grabill K M et al. (2010): Family functioning and adherence in youth with type 1 diabetes: A latent growth model of glycemic control</p>	<p>-Longitudinal study design. -To determine the impact of family variables on HbA_{1c} changes during two year of following up.</p>	<p>-109 children (8-18 yrs) and one caregiver (82% mothers). (see Lewin 2006)</p>		<p>-One-parent households were related to worse parent- and child rated adherence and to higher baseline and 2-year HbA_{1c}. -Family income was not related to HbA_{1c}.</p>
<p>Vesco AT et al. (2010): Responsibility sharing between adolescents with type 1 diabetes and their caregivers: importance of adolescent perception on diabetes management and control</p>	<p>-Cross-sectional study design. -To analyse associations between caregiver responsibility and glycaemic control and frequency of SMBG.</p>	<p>-261 adolescents (13-18 yrs) and their caregivers.</p>	<p>-Diabetes Family Responsibility Questionnaire.</p>	<p>-Adolescents perception of greater responsibility sharing with caregivers on management tasks was associated with higher frequency of blood glucose measurements.</p>
<p>Tahirovic H & Toromanovic A (2010): Glycemic control in diabetic children: role of mother's knowledge and socioeconomic status.</p>	<p>-Cross-sectional design. -To investigate the role of mother's knowledge and socioeconomic status on glycaemic control in diabetic children.</p>	<p>-50 mothers of children (5-15 yrs).</p>		<p>-Higher mothers' diabetes knowledge and higher socioeconomic status were associated with lower HbA_{1c}.</p>

Table 4 continue

<p>Berg CA et al. (2011): Parental involvement and adolescents' diabetes management: the mediating role of self-efficacy and externalizing and internalizing behaviours.</p>	<p>-Cross-sectional design. -To examine mediating processes linking parental involvement to diabetes management and glycaemic control.</p>	<p>-252 young adolescents (mean age: 12.5 yr) with type 1 diabetes.</p>		<p>-A direct association between mothers' monitoring and adherence, and father's monitoring and adherence and glycaemic control.</p>
<p>Helgeson VS et al. (2011): A focus on blood glucose monitoring: Relation to glycemic control and determinants of frequency.</p>	<p>-Cross-sectional design. -To examine the relation of blood glucose monitoring to glycaemic control.</p>	<p>-132 adolescents (mean age: 12 yr) with type 1 diabetes.</p>		<p>-More frequent SMBG was related to better glycaemic control. -Age-related declines in measurements occurred among adolescents with low self-esteem, high stressful life events and lower parental support.</p>
<p>Drew L et al. (2011): Depleted parental psychological resources as mediators of the association of income with adherence and metabolic control.</p>	<p>-Cross-sectional design. -to examine by SEM analysis whether the income to HbA1c link was mediated by parental depressive symptoms, parental acceptance, and less treatment adherence.</p>	<p>-252 adolescents (10-14 yrs), their mothers and 188 fathers.</p>	<p>-The Center for Epidemiological Studies of Depression Scale.</p>	<p>Lower family income was associated with higher HbA1c, more depressive symptoms in mothers and fathers and less acceptance from the parents. -The relationship between lower income and HbA1c was mediated by parental acceptance and lower adherence.</p>
<p>Hilliard ME (2011): Prediction of adolescents' glycemic control 1 year after diabetes-specific family conflict: the mediating role of blood glucose monitoring adherence.</p>	<p>-Prospective study design. -To test adherence to blood glucose monitoring as a mediator between diabetes-specific family conflict and glycemic control.</p>	<p>145 adolescents (13-18 yrs) and a parent.</p>	<p>-Diabetes Family Conflict Scale</p>	<p>-Higher adolescent-rated family conflict scores as baseline predicted less frequent blood glucose measurements at 6 months and higher HbA1c levels at 12 months.</p>

* Table explanations:

- The selection of research articles included in the table is based on literature searches performed in the databases Medline (Ovid), Embase (Ovid), PsycInfo (Ovid) and Cinahl (Ebsco) in October 2011 and April 2012.
- In studies with multiple objectives and findings, the objectives and key findings listed in the table are adapted according to their relevance for the present study.
- The instruments listed in the fourth column of the table are only instruments of some relevance for the objectives in the present study.
- Conference abstracts are not included in the table.