SELF-PERCEPTION OF **PSYCHOLOGICAL FUNCTIONING** AND COPING ABILITY **OF ADOLESCENTS** WITH TYPE 1 DIABETES **AND THEIR PARENTS**

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SELF-PERCEPTION OF **PSYCHOLOGICAL FUNCTIONING** AND COPING ABILITY **OF ADOLESCENTS** WITH TYPE 1 DIABETES **AND THEIR PARENTS**

ZELFPERCEPTIE VAN PSYCHOLOGISCH FUNCTIONEREN EN COPING VAARDIG-HEDEN VAN JONGEREN MET TYPE 1 DIABETES EN HUN OUDERS

(Met een samenvatting in het Nederlands)

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PROMOTOR:

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> **CHOOSE A JOB YOU LOVE,**
> **AND YOU WILL NEVER HAVE TO WORK**
> **A DAY IN YOUR LIFE.**
>
> Confucius

> **BEING DEEPLY LOVED BY SOMEONE**
> **GIVES YOU STRENGTH,**
> **WHILE LOVING SOMEONE DEEPLY**
> **GIVES YOU COURAGE.**
>
> Lao Tzu

CONTENTS

CHAPTER 1.
GENERAL INTRODUCTION

1.1 INTRODUCTION

This thesis focuses on psychological functioning and coping of adolescents with type 1 diabetes mellitus (T1DM) and their parents for a better understanding of the problems they have, in order to improve pediatric psychological care.

A major goal in diabetes treatment is, next to optimal physical functioning, psychological well-being (World Health Organization, 2012; Grey & Bolland, 1996; Nederlandse Diabetes Federatie, 2009). Both treatment goals are often not reached in adolescents with T1DM (e.g. Bryden, Dunger, Mayou, Peveler, & Neil, 2003; Faulkner, 2003). Despite increased knowledge of the relationship between diabetes and psychosocial problems, health care professionals tend to focus on the physical aspects of the disease. Glycated hemoglobin concentrations, the HbA1c values, provide a quick impression of metabolic control, reflecting physical functioning. Lack of such a quick screening tool for psychological well-being makes it difficult for health care professionals to recognize psychological problems. Nevertheless, both physical and emotional problems are seen in many adolescents with T1DM, therefore their success or failure in dealing with these problems is a particularly important domain of study. Even when psychological difficulties are identified, the optimal intervention to reach both physical and psychological treatment goals is difficult to determine as yet.

Therefore is examined in this thesis which psychological problems in Dutch adolescents with T1DM as perceived by the adolescents themselves and as perceived by their parents, may need extra attention in pediatric psychological care. As identity maturation (Meeus, Van de Schoot, Keijsers, Schwartz, & Branje, 2010) and becoming more autonomous (Erikson, 1968) are central developmental tasks in adolescence, we were specifically interested in the evaluations of adolescents themselves of their own life and their perception of their own coping abilities in dealing with the demanding aspects of the disease.

In this introductory chapter, a short description is given of adolescence as developmental phase, and of diabetes and the disease management it requires. Specific characteristics of diabetes during adolescence and the consequences for the family are also described. A transactional model is presented that is assumed to underlie the complex relationship between physical and psychological functioning. This model also guided the design and perspective of the studies in this thesis. This chapter will end with a description of the aims of the thesis and an outline of the following chapters.

1.2 BACKGROUND

1.2.1 Adolescence

Important developmental changes occur during the adolescent years, the transition period between childhood and adulthood. It is a vulnerable period, characterized by rapid, substantial biological and psychological changes occurring in a dynamic social context. From a biological point of view adolescence is a period of hormonal changes and increased brain development. Recent studies have shown that in this period the maturation of the brain continues (Jolles, van Buchem, Crone, & Rombouts, 2010; Van den Bos, van Dijk, Westenberg, Rombouts, & Crone, 2011; Toga, Thompson, & Sowell, 2006; Paus, 2005), In this developmental phase higher-order association areas integrate functions of lower-order regions that mature first (Gogtay et al., 2004). Especially the beginning of adolescence is characterized by large hormonal and physical changes (Coleman & Hendry, 1991; Feldman & Elliot, 1990). However, no direct effect

of puberty on the development of behavior problems has been found (Susman & Rogall, 2004). Often, serious psychological problems in adolescence find their origin in childhood (Sameroff, Lewis & Miller, 2000).

From a psychological point of view two primary goals of adolescence have been identified (Whitmire, 2000). The first goal is consolidation of self and personal identity, which is accomplished through the establishment of peer relations and the restructuring of family relationships. The second goal is to develop complex cognitive abilities that lead to an understanding of self in relation to others and serve as tools for lifelong learning need to develop. Slot & Van Aken (2010) describe seven developmental tasks that adolescents are expected to reach: adapting to the changing family relationships, take care for health and appearance, organizing free time activities, develop intimacy and sexuality, participating in education or work, maintain friendships and social relationships and deal with authority. As a result adolescence also is a critical period for the establishment of lifelong positive as well as risky health behaviors (Holmbeck, 2002).

Although most adolescents reach adulthood without too many problems, internalizing and externalizing behavior problems are common in adolescence, but the number of adolescents with serious emotional or behavior problems does not reach 15% (Junger, Mesman & Meeus, 2003). Rule-breaking behaviors tend to increase in adolescence, until the age of 17 years, after which it decreases (Bongers, Koot, Van der Ende & Verhulst, 2003). Also internalizing problems are increasing in this developmental phase and 12-20% of adolescent boys and girls are experiencing depressive feelings (Junger et al., 2003).

A broader framework is necessary to understand development and the occurrence of these problems. The transactional model (Sameroff & Fiese, 2000) accounts for the complexity of psychological development and explains the influence of psychosocial context on health-related phenomena. Neurological, social, and psychological development are regarded as dynamic processes that result from the complex interaction between the child and the care giving environment. This includes attention for genetic vulnerability for psychological problems and the interaction with the (social) environment from a developmental perspective (Olsen & Sameroff, 2009).

1.2.2 Diabetes Mellitus

Diabetes mellitus is a chronic metabolic disease, in which the pancreas is not able to make (enough) insulin (Craig, Hattersley, & Donaghue, 2009). The hormone insulin is responsible for the regulation of the blood glucose level and it enables the cells in our body to transmute glucose in energy. This defect in insulin secretion and/or absorption is characterized by chronic hyperglycemia. Several types of diabetes are classified (Craig et al., 2009). Type 1 diabetes mellitus (T1DM) is the result of an auto-immune reaction in which β-cells are destructed and must be distinguished from type 2 diabetes mellitus (T2DM), which is the result of insulin resistance with/without relative insulin deficiency. T1DM presents with sudden characteristic symptoms such as polyuria, polydipsia and weight loss and usually occurs before adulthood. T2DM develops more gradually and is associated with obesity, age and heredity. Other, less frequent, types of diabetes that can be distinguished are gestational diabetes (diabetes in pregnancy) and specific types (like monogenetic diabetes).

Type 1 diabetes mellitus accounts for over 90% of childhood and adolescent diabetes in most western countries (Craig et al., 2009), although the incidence of childhood type 2 diabetes is rising (Silverstein et al., 2005). Besides Asthma, T1DM is the most common chronic disease in childhood. Recent estimates suggest that approximately 70,000 children per year are

diagnosed with T1DM worldwide (International Diabetes Federation, 2006). The incidence rates of childhood onset T1DM (under the age of 14) are almost universally increasing across the world (The DIAMOND project group, 2006; Patterson, Dahlquist, Gyurus, Green, & Soltesz, 2009) but the etiology of the disease remains largely unknown. However, the increases within genetically stable populations suggest that environmental influences play an important role in the etiology of T1DM.

In the Netherlands the incidence of T1DM in children under 19 years is estimated at 0,2 per 1000; around 700 children are newly diagnosed each year (Jacobs-van der Bruggen, Baan, Feskens & Gijsen, 2004). Approximately 6.000 children and adolescents in the age of 0 to 18 in the Netherlands have T1DM (Nederlandse Diabetes Federatie, 2009). The exact number is not known, because a national registration lacks.

Current standards for diabetes management reflect the need to maintain blood glucose levels as normal as possible, in order to prevent acute problems (hypoglycemia and hyperglycemia / diabetic ketoacidosis) and long term micro vascular and macro vascular complications (e.g. nephropathy, hypertension, cardiovascular diseases), while also avoiding the sequence of acute hypoglycemia (Silverstein et al., 2005). To reach this goal, diabetes management requires a demanding, multi component and daily regimen. This regimen consists of external administration of insulin, which can be done by injections, several times per day, or by insulin pump. In addition also dietary control is necessary, paying special attention to carbohydrate intake, as well as regular exercise. Frequent blood glucose monitoring, is also necessary, several times per day. Glycated hemoglobin concentrations (most common hemoglobin A1c; HbA1c) reflect time-averaged blood glucose during the previous 2–3 months. Age-specific glycemic goals are available for different age groups (Silverstein et al., 2005).

Besides achievement of metabolic treatment goals and minimizing complications in physical health, the current treatment policy of T1DM, also focuses on maximizing quality of life and the promotion of normal psychosocial development (WHO, 2012; Grey & Bolland, 1996; Nederlandse Diabetes Federatie, 2009).

1.2.3 Adolescents and type 1 diabetes mellitus

Adolescents and T1DM form a challenging combination. The complex disease management tasks make diabetes difficult to fit into everyday life and this may influence social emotional functioning of the adolescents. Compliance with the medical regime, which requires a lot of self-discipline, may actually interfere with age-specific developmental tasks like the development of psychological autonomy. The ideal level of HbA1c in adolescents as yet, is identical to that for adults (<7%) (Canadian Diabetes Association, 2003; Diabetes Control and Complications Trial Research Group, 1994). In real life however, this level of metabolic control cannot be achieved by most adolescents. Several studies (Bryden et al., 2003; Chase et al., 2003; Diabetes Control and Complications Trial Research Group, 1994; Mortensen et al., 1998) found that HbA1c levels in adolescents are generally >8.0%. In addition, with reduction of HbA1c levels, the risk of hypoglycemia increases. Therefore the American Diabetes Association (ADA) (Silverstein et al., 2005) and the International Society for Pediatric and Adolescent Diabetes (Rewers et al. 2009) recommend HbA1c levels of <7.5% as metabolic treatment goal in adolescents, slightly higher than the recommended level for adults. Motivation in adolescents to reach this level of HbA1c might be low, as their primary focus may well be more in the present and in fulfilling immediate needs, rather than think about health risk in the long-term. In addition when an optimal blood glucose level is not reached, the consequences are small, as the body is adjusting to high blood glucose levels. Besides that, a positive side-effect

of high blood glucose levels forms a decreasing risk for hypoglycemia. Nevertheless even when the adolescent is motivated for the treatment goals, insulin resistance due to puberty, makes optimal metabolic control difficult to reach (Hamilton & Daneman, 2002).

The relationship between the more objective indices of physical health and the more subjective indications of psychological wellbeing is complex and not straight forward. Some studies found that a lower level of HbA1c, indicating a better metabolic control, was associated with better quality of life (The Hvidore Study Group, 2001). Other studies found no association between the quality of glycemic control and quality of life (Hestketh, Wake & Cameron, 2004; Laffel, Connell, Vangness, Goebel-Fabri, Mansfield, & Anderson, 2003). Faulkner (2003) found that adolescents with T1DM report a lower (health-related) quality of life compared to healthy adolescents.

T1DM is also a risk factor for psychiatric disorders in adolescents (Blanz, Rensch-Riemann, Fritz-Sigmund, Schmidt, 1993; Kovacs 1997a), especially depression Kovacs 1997b). Several studies found that T1DM and depression frequently co-occur in adolescents (Lawrence et al., 2006; Lin et al., 2005). They suggest that, especially female, adolescents with T1DM have a two to threefold increased risk for developing a Major Depressive Disorder compared to healthy adolescents. Hood and colleagues (2006) found that nearly one in seven youth with T1DM, met the clinical cut-off for depression by their own report. Adherence, anxiety for complications, child-parent conflicts, a low self-esteem and changing body perception are risk factors for developing depression (Kanner, Hamrin & Grey, 2003). Depression is negatively related to quality of life, which affects management, the risk for complications and hospitalization (Stewart, Rao, & White, 2005). Depressive symptoms are also found to be strongly associated with diabetes complications. Garrison, Katon & Richardson (2005) found that internalizing disorders are associated with increases in repeated hospitalizations for diabetes among adolescents. These studies emphasize that a co-morbid stress related psychiatric disorder is a serious complication in T1DM and diabetes management. The results of a recent meta-analysis (Reynolds & Helgeson, 2011) suggest that children with diabetes experience somewhat elevated levels of depression, anxiety, and psychological distress. However, the differences between children with diabetes

and comparison groups were smaller in more recent studies, probably due to substantial technological changes in diabetes management, like the introduction of pump treatment and new clinical standards over the past 15 years.

A possible explanation for increased psychological stress in this specific group is that with the growing knowledge of the adolescent the awareness of the disease increases, perhaps accompanied by increased worries and anxiety about short term and long term consequences of the disease. An alternative explanation is that the strong demands of the treatment regimen may lead to depressive feelings because the goal of achieving (near) normal blood glucose levels is so difficult to reach in view of the regulation problems of the blood glucose levels during adolescence.

1.2.4 Adolescents with T1DM and their families

Type 1 diabetes mellitus is often characterized as a family disease, because of the parents' contribution to diabetes management by interactions, communication, and their supervising role (Williams, Laffel & Hood, 2009; Anderson, Ho, Brackett & Laffel, 1997; La Greca et al., 1995). Consequently, diabetes has widespread implications for the psychological wellbeing of the parents, as the demanding aspects of diabetes influence family functioning and parenting as well. Indeed, the level of parenting stress is found to be higher in families dealing

with diabetes compared to families affected by severe diseases with less daily demands in treatment, like cystic fibrosis and cancer (Hullmann et al., 2010). The greatest diabetes related burden parents perceived, was their concern about the future health of their child, which was especially related to emotional distress in the mothers (Haugstveldt, Wentzel-Larsen, Rokne & Graue, 2011). During adolescence, diabetes management tasks shift from parents to adolescents. During this shift in responsibility of care blood glucose monitoring declines and HbA1c increases (Ingerski, Anderson, Dolan, & Hood, 2010). While parental monitoring is more directly associated with better adherence and metabolic control, higher quality of the parent-adolescent relationship was found to have a more indirect effect though lowering externalizing behavior problems and increasing feelings of self-efficacy (Berg, Butler, Pham, Palmer & Wiebe, 2011). Continued involvement and support of the parents is therefore needed in the adolescent's care. Nevertheless, when the parent is experiencing emotional problems, this effect is less beneficial (Wiebe et al., 2011; Eckshtain, Ellis, Kolmodin & Naar-King, 2010). From a transactional perspective parent functioning and child functioning are seen as influencing each other in a reciprocal way (Chaney et al., 1997; Cameron, Northam, Ambler, & Daneman, 2007). Indeed, higher levels of parenting stress are found to be associated with increased behavior problems in children with T1DM (Hilliard, Monaghan, Cogen & Streisand, 2010; Lewin et al., 2005; DeVet, & Ireys, 1998; Mullins et al., 2004; Mitchell et al., 2009). Stress in parents of adolescents with T1DM is multifaceted and related to both physical and emotional aspects of the adolescents functioning. Furthermore, based on their different roles within their family, differences in parenting stress among fathers and mothers may appear. The different roles and responsibilities of mothers and fathers in medical and psychological disease characteristics emphasize the need to study both parents separately (Haugstvedt et al., 2011; Dashiff, Morrison & Rowe, 2008).

1.2.5 A transactional perspective
In 2010, Sameroff described a multilevel bio psychosocial ecological systems model. In this new transactional model, earlier views that individual behavior is controlled by unidirectional biological or sociological circumstances are replaced by multidirectional perspectives Individual behavior reciprocally changes biological and social circumstances, and development comes about both from self-regulation processes, as well as through co regulation processes by others. The transactional model looks at development as a result of a complex interplay between the child with its natural personality and traits, and family experiences with economic, social and community resources.
Studying the wellbeing of adolescents with T1DM from this model is helpful in understanding the complex relationship between physiological and psychological functioning in the social context. The multilevel bio psychosocial ecological systems model integrates four different models regarding developmental change: the personal change model, the contextual change model, the regulation model and the representational model. In the personal change model the development of personality is seen as a stage process. This implies that there is a period of stability in functioning followed by a transition to a structurally different period of stability presumed to reflect a higher level of cognitive and social functioning. In the development of health related behavior adolescence forms an essential phase (Holmbeck, 2002). Adolescents with T1DM are at risk to develop both physical and psychological problems in this transition period from childhood to adulthood, which tend to continue in early adulthood (Insabella, Grey, Knafl & Tamborlane, 2007). Development however, cannot be separated from the social context. In the contextual change model the influence of the child's experiences on development

are addressed, focusing on caregivers and other sources of socialization. In adolescence a transition to independence is taking place, accomplished through the establishment of peer relations and the restructuring of family relationship. The switch in responsibility in diabetes management during adolescence makes the redefinition of the parent-adolescent relationship especially complex.

The regulation model adds a dynamic element in this relation between the adolescents functioning and the context. Actions of others regulate development and functioning of adolescents, but it also refers to the self-regulatory capacities and opportunities of the individual to adapt to the external world. As diabetes is a family disease and parents are involved in diabetes management (Williams et al., 2009; Anderson et al., 1997; La Greca et al., 1995) regulation of diabetes related behavior of the child is affected strongly through the parent-child relationship.

The last model is the representation model, that indicates that here and now experiences are recoded into abstract levels of thinking and are being internalized. These representations provide a sense of self and the other and could result in the core self-evaluation personality trait as described by Judge and colleagues (2004). They see the core self-evaluation as a higher order personality trait that is related to the general evaluation that people make about themselves and their functioning. Therefore these representations determine the eventual wellbeing of an individual. In line with this perspective the representations of adolescents with T1DM should be taken in account when studying their psychosocial functioning.

Figure 1 visualizes the conceptual model concerning physical and psychological functioning of adolescents and their parents, as studied in this thesis.

Figure 1. The concepts underlying the studies in this thesis.
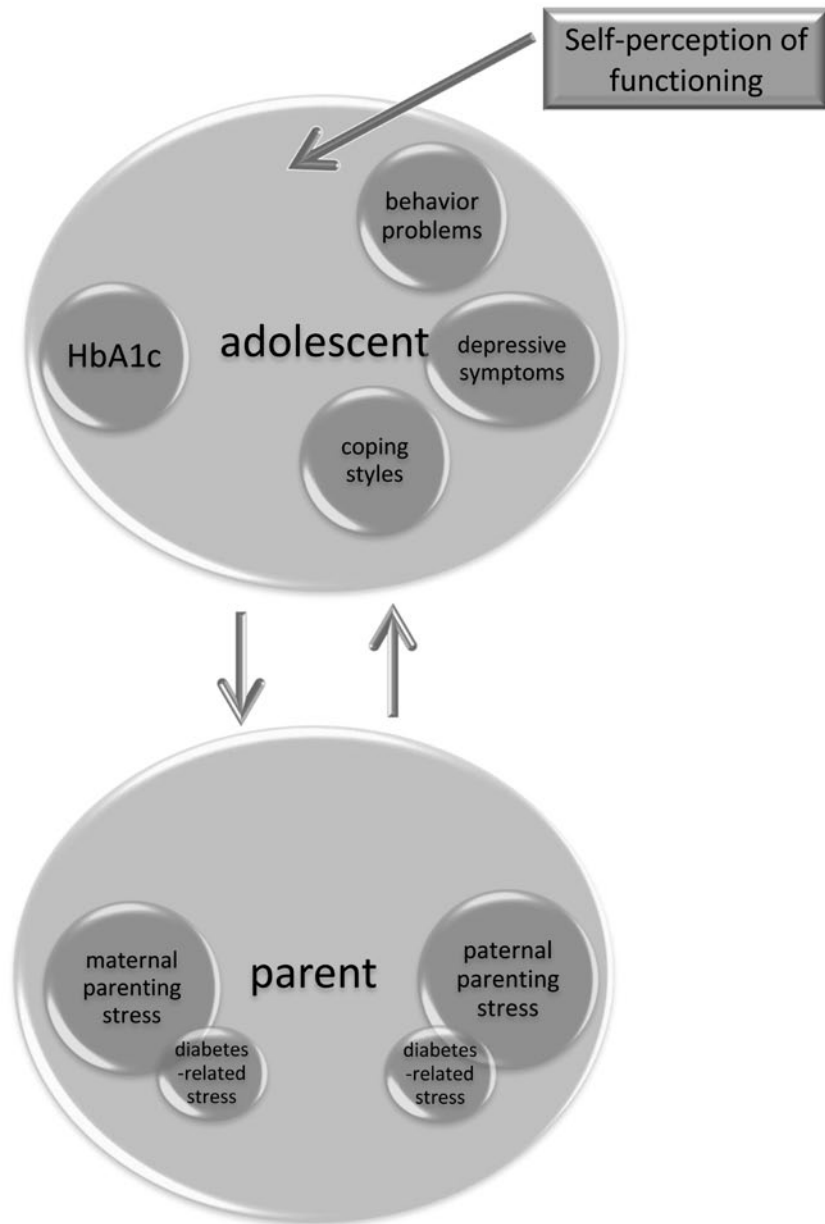
1.3 THE CURRENT THESIS

1.3.1 Perspectives and goals

The aim of this thesis is to learn how pediatric psychological care for (Dutch) adolescents and their parents may be optimized. To answer this question we investigate which psychological problems are seen in Dutch adolescents with T1DM and if these differ from the psychological problems that their healthy peers experience. Psychological functioning in adolescents (specifically depression and behavior problems) is studied while taking into account biological (gender, age, HbA1c) characteristics. In addition their social context is studied as well, by examining parenting stress. How the adolescents internalize their experiences is studied by explicitly asking them to provide their representations about their life and if they are satisfied with the way they cope with diabetes. In addition a systematic review of the literature is done to investigate the type and success rate of existing psychological interventions to support adolescents with T1DM and their parents.

The objectives of this thesis are:
1. To asses which emotional and behavioral problems occur in adolescents with T1DM from their own perspective and from the perspective of their parents, and to compare this to those of healthy peers and their parents.
2. To asses how the adolescents value their own life and how this is related to psychological and physical functioning.
3. To evaluate which coping styles adolescents with T1DM use to deal with their disease, how satisfied they are with their coping abilities, and how this relates to physical and psychological functioning.
4. To asses if parenting adolescents with T1DM is more stressful than parenting healthy peers and to examine how this relates to the physical and psychological functioning of the adolescent.
5. To describe and evaluate the literature concerning strengths and weaknesses of pediatric psychological interventions for adolescents with T1DM.

1.4 DESIGN

1.4.1 Procedure and participants

A cross-sectional study is done in a large group of Dutch adolescents with T1DM, receiving care from different hospitals. Both their fathers and mothers are also invited to participate. A comparison group of healthy peers and their parents, matched for age, gender and type of school to the adolescents with T1DM, is invited too. Both the adolescents and their parents are studied with standardized measurements for behavior problems, depression, coping abilities and parental stress that are often used in regular care. Specifically the perception of the adolescents themselves is studied; how do they value their own life and their own coping abilities?

The adolescents with T1DM and their parents were recruited from nine hospitals in The Netherlands. They were eligible to participate if they were between 12 and 18 years of age, were in secondary school, had been diagnosed for diabetes for > 6 months, and did not have comorbid medical or psychiatric conditions.

Adolescents with T1DM and their parents were approached to participate by telephone. The adolescents with T1DM and their parents were both sent a letter in which they were separately informed of the study. When they both agreed to cooperate and completed an informed consent form, an appointment for the adolescent and his parent(s) was made to answer the questionnaires when they visited the diabetes team, or at home. The parents were sent questionnaires by mail.

Schools were approached for cooperation in the same time period for the comparison group, and healthy adolescents without T1DM and their parents were invited to participate, matching school type, age and gender to that of the adolescents with T1DM. For the control group the questionnaires were sent to the adolescents and their parents at home.

The study was approved by the Medical ethical committees of the Catharina hospital in Eindhoven and the local committees of all participating hospitals.

1.4.2 Measures
Adolescents' depressive symptoms

Self-reported depressive symptoms were measured with the Children's Depression Inventory (CDI) (Kovacs, 1992). The questions refer to cognitive, affective and behavioral depressive symptoms for children and adolescents in the age of 7 to 17. The questionnaire consists of 27 Likert-type items answered on a 3-point scale, varying from zero (absence of symptom) to two (clear symptom). Total scores from 0 to 54 can be achieved. The overall scale gives an indication for the extent of depressive feelings with a mean (sd) of 7.69 (4.9) for boys and 10.46 (6.5) for girls in the norm groups. Higher scores reflect more depressive feelings. A cut-off score of 13 was used to indicate a serious level of depressive complaints, at risk for a clinical depression (Kovacs, 1992; Timbremont, & Braet, 2002). Psychometric characteristics of the CDI are sufficient (Evers, Vliet-Mulder & Groot, 2000).

Behavioral problems

The Youth self-report (YSR) measures behavior problems and competencies of adolescents in the age of 11 to 18 as reported by the adolescents themselves (Achenbach & Rescorla, 2001). The questionnaire consists of 113 Likert-type items answered on a 3-point scale, varying from zero (absence of symptom) to two (clear symptom). The overall score provides an indication for the extent of behavior problems. The subscales refer to anxious/depressed and withdrawn/depressed behaviors, somatic complaints, social problems, thought problems, attention problems, rule-breaking behavior and aggressive behavior. Psychometric characteristics are good (Evers et al., 2000).

Coping style

Coping style was measured with the CODI coping questionnaire for children and adolescents, which is based on children's and adolescents' perceptions of their illness and their views concerning their ability to deal with the disease (Petersen, Schmidt & Bullinger, 2004). The CODI consists of six domains with reliabilities that were reported as follows: acceptance (α= .83), (emotional) avoidance (α= .72), cognitive–palliative (α= .69), distance (α= .70), emotional reaction (α= .82), and wishful thinking (α=.81). Higher scores reflect more usage of the specific coping style. The questionnaire consists of 29 items, answered on 5-point scale, varying from 1 (never) to 5 (always). A separate last item 'Satisfaction, how well do you think you cope with your illness?' measures the participants'

own assessment and satisfaction of the way (s)he copes with the disease, also answered on 5-point scale, varying from 1 (not at all) to 5 (very successful).

Representation of overall functioning

We asked adolescents how they rate their life on a ten point scale 'The Rate your Life Scale', varying from zero (worst life possible) to ten (best life possible). The adolescents were asked to put a cross at the number on a Visual Analogue Scale that best represented their feelings at that moment.

Parenting Stress

The Parenting stress index (PSI) short version (Dutch version: The Nijmeegse Parenting Stress Index Short index; NOSI-K) was used to measure stress due to parenting (Brock, Vermulst, Gerris, & Abidin, 1992) in parents. The questionnaire consists of 25 items, rated on 1 (strongly disagree) to 6 (strongly agree) frequency scale. A total parenting stress score is computed as the sum of the items, resulting in higher scores for more parenting stress. The range of possible scores varies between 25 and 150. Reliability (α = 0.93) and validity of the questionnaire are shown to be good (Brock et al., 1992).

For the parents of adolescents with T1DM 5 questions were added concerning diabetes related stress: (1) stress related to diabetes specific medical interventions, (2) diabetes related disturbances in normal family life, (3) diabetes related physical and emotional problems in the child that require extra attention, (4) diabetes related restrictions in the social life of the child, and (5) worries about future health of the child. The answers required a rating from 1 (substantial burden) to 5 (no burden).

These questions were constructed by the Hvidore Study Group on Childhood Diabetes (Hoey et al., 2006).

Metabolic control

Metabolic control was obtained by glycosylated hemoglobin (HbA1c) from medical records. HbA1c is the medical standard for evaluating the quality of diabetes control, and reflects average blood glucose levels over the past 2-3 months. Higher values represent poorer control. Most recent HbA1c measures were used as reported one week before or after questionnaire completion. HbA1c was analyzed with similar assays in the different hospitals, as confirmed by the clinical chemists from different hospitals. HbA1c values are reported in % as data collection started in 2006. Since April 2010 HbA1c is reported in mmol/mol. Therefore a conversion table is shown in appendix 1.

Outline of the thesis

In Chapter 2 Illness characteristics of Dutch adolescents with type 1 diabetes mellitus are presented. It is studied if disease related characteristics, i.e. level of metabolic control, treatment form, age at diagnosis and duration of the disease, are related to non-disease related characteristics, i.e. gender, age, education level and family constellation in Dutch adolescents with T1DM.

Chapter 3 presents the emotional and behavioral problems in Dutch adolescents with T1DM. Different syndromes of behavioral problems, as well as depressive symptoms are compared in Dutch adolescents with T1DM and a reference group without T1DM. In adolescents with T1DM, the relationship with metabolic control (HbA1c) is also investigated.

19

The way adolescents value their own life and how this relates to psychological problems is described in chapter 4. In clinical practice the first question asked during a consultation "How are you? How do you feel?" is usually assumed to give a first and general indication of wellbeing. Therefore, adolescents are asked to rate their life on a Visual Analogue Scale, varying from zero (worst life possible) to ten (best life possible). Investigated is if the answer of this question and the way adolescents value the quality of their life, are related to standardized indices of psychosocial functioning and to HbA1c.

Chapter 5 describes to what extent the adolescents themselves are satisfied with their own disease management. It is studied to what extent satisfaction with coping ability reflects specific coping strategies and how this is related to behavioral and emotional problems and metabolic control. Specifically is studied if satisfaction with coping abilities contributes to depressive symptoms, next to different coping styles.

How parental stress is related to physical and psychological functioning of the adolescents is described in chapter 6. We study the relationship between both paternal and maternal parenting stress and indices of physical (metabolic control) and psychological (depression) and behavioral problems in adolescents with T1DM. We hypothesized that parents of adolescents with T1DM report more and different aspects of parenting stress than parents of healthy adolescents. We also expect that parenting is more stressful for parents of adolescents with suboptimal or poorly controlled diabetes (HbA1c>7.5%) and for parents of adolescents at risk for depression.

In chapter 7 the existing psychological interventions and their strengths and weaknesses to support adolescents with T1DM diabetes and their parents, are reviewed. The following questions are addressed: (1) Which psychological intervention programs are being used for adolescents with T1DM? (2) What types of intervention have shown to be effective in improving psychological wellbeing or metabolic control?

Chapter 8 presents a general discussion on the main findings of the studies included in this thesis. Strengths and limitations of the studies are discussed. The implications of the findings for the pediatric psychological care of adolescents with T1DM are elaborated, both for future scientific studies, as for clinical practice.

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CHAPTER 2.

ILLNESS CHARACTERISTICS OF THE PARTICIPATING ADOLESCENTS WITH TYPE 1 DIABETES MELLITUS

N.M. Maas-van Schaaijk, R.J. Odink & A.L. van Baar

ABSTRACT

Objective

The aim of this study was to determine if disease related characteristics, i.e. level of metabolic control, treatment form, age at diagnosis and duration of the disease, are related to non-disease related characteristics, i.e. gender, age, education level and family constellation in Dutch adolescents with type 1 diabetes mellitus (T1DM).

Methods

151 Dutch adolescents, age 12-18, with T1DM (65 males and 86 females) participated. Medical information of the adolescents with T1DM regimen was recorded from the hospital charts. The information consisted of the most recent HbA1c at the time of answering the questionnaires, duration of the disease and treatment regimen.

Results

Small significant correlations were found between metabolic control (HbA1c) and disease-related characteristics: treatment form r=.21, years T1DM r=.27, age of diagnose r=-.25. Of the non-disease-related disease characteristics only a small significant relationship was found between HbA1c and gender (r=.19). Metabolic control was better in adolescents who used multiple daily injection therapy (MDI) (mean HbA1c=8.0%, sd=1.46) than in adolescents who used continuous subcutaneous insulin infusion (CSII: insulin pump therapy) (mean HbA1c=8.6%, sd= 1.40; t(144)=-2.61, p=.01). Boys had significant better blood glucose levels (mean HbA1c=8.0%, sd=1.32) compared to girls (mean HbA1c=8.5%, sd=1.51; t(144)=-2.36, p=.02).

Conclusions

In our sample of Dutch adolescents with T1DM in the age of 12-18 years, metabolic control was better in those who used multiple daily injections and in boys. No significant difference in metabolic control was found in younger adolescents (age 12-14) when compared with older adolescents (age 15-18).

INTRODUCTION

Although the exact number of children and adolescents in the Netherlands with type 1 diabetes mellitus is not known, due to the lack of a national register, the incidence is estimated at 0,2 per 1000: around 700 children are newly diagnosed each year (Baan et al., 2009). Approximately 6.000 children and adolescents in the age of 0 to 18 in the Netherlands have T1DM (Potter van Loon et al., 2009). The prevalence of T1DM in adolescents and young adults (age 15-24) is estimated on 2.0 (boys) and 4.5 (girls) per 1000, but these numbers are based on limited data (CMR Nijmegen, 2003-2007).

The recommended target range of metabolic control is <7.5% for all age groups, as described in the ISPAD Clinical Practice Guidelines (Rewers et al., 2009). However, many adolescents experience a deterioration in metabolic control with increasing age and the metabolic treatment goal cannot be achieved by most adolescents, due to a variety of physiological and psychosocial factors. Several studies (Bryden, Dunger, Mayou, Peveler & Neil, 2003; Chase et al., 2003) found that HbA1c levels in adolescents are generally >8.0%, which is significantly higher than recommended target range (Rewers et al., 2009).

Adolescents with T1DM can be distinguished by their level of metabolic control (optimal HbA1c<7.5%, suboptimal (HbA1c 7.5-9.0% or high risk (HbA1c>9.0% (Rewers et al., 2009), but also by treatment form ((multiple) daily injection therapy (MDI) versus insulin pump therapy (CSII), age at diagnosis and duration of the disease. In the current short report we investigated if these disease-related characteristics are related to non-disease related characteristics, namely gender, age, education level and family constellation. The incidence rate does not differ in boys and girls (Wouwe, Mattiazzo, Mokadem, Reeser & Hirasing, 2004) and we expect no differences in HbA1c levels in boys and girls. All adolescents received multiple injection therapy (MDI) or pump therapy (CSII) and non used Conventional Therapy (CT). Therefore we expect no difference in HbA1c levels between these subgroups as both MDI and CSII are based on multiple administration of insulin during the day,

METHODS

Adolescents with T1DM and their parents were recruited from nine hospitals in The Netherlands. They were eligible to participate if they were between 12 and 18 years of age, were in secondary school, had been diagnosed for diabetes for >6 months, did not have co morbid medical or psychiatric conditions and were Caucasian (N=302). In the current study 151 Dutch adolescents with T1DM (65 males and 86 females) and at least one of their parents (126 mothers and 103 fathers) participated. Medical information of the adolescents with T1DM regimen was recorded from the hospital charts. The information consisted of the most recent HbA1c at the time of answering the questionnaires, duration of the disease and treatment regimen. HbA1c measurements were done by gas chromatography (GC) in all hospitals, which are considered to result in comparable values.

RESULTS

Descriptive characteristics of the adolescents included in the study are shown in table 1. The mean illness duration was 5.7 (sd = 3.9) years and mean HbA1c was 8.3% (sd =1.5). Goals for metabolic control (HbaA1c ≤ 7.5% were reached in 28% of the adolescents; 72% of the adolescents did not reach metabolic treatment goals (HbA1c > 7.5%). Of the adolescents 71 (47%) injected themselves with insulin and 80 (53%) used an insulin pump. Boys and girls did not differ in treatment form (χ^2 (1, 151) =0.021, p = 0.89). The available data about the non-participating adolescents with T1DM (N=63) showed no significant differences from the study group in mean age or in HbA1c (F(1,213)=1.46, p=.23).

Table 1. Baseline group characteristics of Dutch adolescents with T1DM.

Variable	T1DM (n=151)
Age: mean (SD)	14.9 (1.7)
Range	12-18
Gender	
male	65 (43%)
female	86 (57%)
Family constellation	
Intact family	87%
Single parent	
School level	42 (27.8%)
lower	19 (12.6%)
vocational	46 (30.5%)
higher	40 (26.5%)
pre-university	4 (2.6%)
unknown	
Treatment	71 (47%)
Injections	80 (53%)
Pump	8.3 (1.5)
HbA1c: mean (SD)	5.1-13.0
Range	9.4 (3.8)
Age at diagnose: mean (SD)	0-18
range	5.7 (3.9)
Years T1DM: mean (SD)	0-15
range	

Relationships between disease-related characteristics and non-disease-related characteristics
Small significant correlations were found between metabolic control (HbA1c) and disease-related characteristics: treatment form r=.21, years T1DM r=.27, age of diagnose r=-.25, see table 2. HbA1c was better in adolescents using MDI, who were older when there were diagnosed with T1DM or had a shorter duration of the disease. Of the non-disease-related disease characteristics (gender, age, education level and family constellation) only a small significant relationship was found between HbA1c and gender (r=.19). Metabolic control was slightly better in boys compared to girls.

Table 2. Correlations between metabolic control (HbA1c) and disease-related and non-disease-related characteristics.

	HbA1c	Treatment form	Years T1DM	Age diagnose	Gender	Age	Education level	Family constel-lation
HbA1c	-	.21**	.27**	-.25**	.19*	.08	-.04	.15
Treatment form	.21**	-	.09	-.04	.01	.00	.07	-.06
Years T1DM	.27**	.09	-	-.87**	-.01	.16	.14	.03
Age diagnose	-.25**	-.04	.87**	-	-.01	.23**	-.02	.03
Gender	.19*	.01	-.014	-.01	-	.04	.09	.02
Age	.08	.00	.16	.23**	.04	-	.38**	.04
Education level	-.04	.07	.14	-.02	.09	.38**	-	-.19*
Family constellation	.15	-.06	.03	.03	.02	.04	-.19*	-

*p<.05; ** p< 0.01 level

Differences based on treatment form, gender, and age-group
In the group adolescents with T1DM differences in metabolic control were found to depend on treatment form and gender. Metabolic control was better in adolescents who used multiple daily injection therapy (MDI) (mean HbA1c=8.0%, sd=1.5) than in adolescents who used continuous subcutaneous insulin infusion (CSII: insulin pump therapy) (mean HbA1c=8.6%, sd= 1.4; t(144)=-2.61, p=.01). Also we found that boys had significant better blood glucose levels (mean HbA1c=8.0%, sd=1.3) compared to girls (mean HbA1c=8.5%, sd=1.5; t(144)=-2.36, p=.02).
Metabolic control did not differ between the group younger adolescents age 12-14 years (mean HbA1c=8.2%, sd=1.3) and the group older adolescents age 15-18 years (mean HbA1c=8.4%, sd=1.6) this difference was not significant (F(1,146)=1.28, p=.26). No significant interaction effects were found.

DISCUSSION

In our sample of Dutch adolescents with T1DM in the age of 12-18 years, metabolic control was better in those who used multiple daily injections and boys did better than girls. Although a deterioration of metabolic control is frequently reported in adolescents (Bryden et al., 2003; Chase et al., 2003) we found no significant difference in metabolic control in younger adolescents (age 12-14) when compared with older adolescents (age 15-18). Boys were found to show better blood glucose levels than girls. This maybe due to the later onset of puberty symptoms in boys (Noordam, Rotteveer & Schroor, 2010) and differences in developmental phase may have been present between the boys and girls, despite the fact that they did not differ in chronological age.
Our finding that the level of metabolic control was better in adolescents on MDI is in contrast with the results of a meta-analysis by Weissberg-Benchell, Antisdel-Lomaglio & Seshadri (2003), who concluded that metabolic control was lower in patients using pump therapy, with

a greater benefit seen for patients using pump therapy for at least 1 year. This effect however was especially seen in patients who started with conventional therapy (CT) and it was much smaller when patients were on multiple injection therapy (MDI). Weissber-Benchell (2003) suggests that patients on MDI, had less opportunity for improvement in glycohemoglobin because they already had a more intensive therapy regimen, which can be considered a floor effect. Other studies did not found significant differences in HbA1c in adolescents on CSII versus adolescents on MDI (Phillip et al., 2007). Initial improvements in metabolic control were found not to be sustained for 2 years after commencement of continuous subcutaneous insulin infusion (Knight, Northam, Cameron & Ambler, 2011). In our sample all adolescents were on either pump therapy or on intensified multiple daily injection therapy, and none were on conventional treatment, so we expected no difference in HbA1c between both groups. To the contrary, however, we found that adolescents on MDI had a significantly better HbA1c than the adolescents on pump therapy. The improved HbA1c in the MDI subgroup might be related to the investment in planning and handling necessary to inject insulin. For the adolescents using a pump, insulin administration is done by squeezing a button and this can easily be done, without paying much attention to it. This could result in incorrect dosages. Multiple injection therapy requires that the adolescent has to do a lot of actions: getting the injection, and determine the amount of insulin. This process needs attention and probably the adolescent also pays more attention to calculate the exact insulin doses needed. Another important condition may be that Dutch adolescents are experiencing a lot of freedom in their own disease management. Treatment goals and disease management are determined in the collaboration of the diabetes professionals and the adolescent. This is different from other European countries and America, were the doctor is dictating treatment regime more. These differences in approach make it difficult to compare Dutch results with the results from other countries.

Based on the group differences found, we recommend to take both gender and therapy form into account when studying adolescents with T1DM.

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CHAPTER 3.

BEHAVIOR PROBLEMS AND DEPRESSIVE SYMPTOMS IN ADOLESCENTS WITH TYPE 1 DIABETES MELLITUS: SELF AND PARENT REPORT

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ABSTRACT

Objective

Different dimensions of behavioral problems, as well as depressive symptoms, were compared in Dutch adolescents with type 1 diabetes (T1DM) and in a comparison group without T1DM. Among adolescents with T1DM, the relationship with blood glucose regulation (HbA1c) was also investigated.

Methods

151 adolescents with T1DM (mean 14.9 ± 1.7 years) and a comparison group (CC) (N=122) reported their depressive symptoms and behavior problems. Both youngsters and parents answered questionnaires. Depressive symptoms were measured with the Children´s Depression Inventory. Behavior problems were studied with the Youth Self Report and the Child Behavior Checklist.

Results

Adolescents with T1DM did not differ from the comparison group in depressive symptoms, but they reported more behavior problems: An increased level of thought problems was found, which was corroborated by a significant difference in thought problems as perceived by their mothers and fathers. Regression analyses revealed that, in the group with T1DM, the adolescents' depressive symptoms and rule breaking behavior problems were related to higher HbA1c.

Conclusions

Thought problems are especially found among adolescents with T1DM, which need further attention in research and in clinical practice. Glycemic control needs specific attention among adolescents scoring high on depressive symptoms or on rule breaking behavior problems.

INTRODUCTION

Children and adolescents with chronic diseases are at higher risk for mental health problems. Especially in adolescence, which involves a multitude of physical, cognitive and emotional developmental changes, a chronic disease such as type 1 diabetes mellitus (T1DM) that requires daily, careful attention, may influence social and emotional functioning. Adolescents with T1DM must deal with disease-specific stressors, in addition to age-specific stressors (Reid, Dubow, Carey, & Dura, 1994). Stress, in itself, may dysregulate diabetes through psycho-physiological processes or associated changes in self-management behaviors (Snoek, 2000). Therefore, diabetic treatment guidelines include metabolic goals, as well as facilitation of normal social and emotional development (Grey & Boland, 1996). Problems in social-emotional functioning are reflected in the occurrence of internalizing or externalizing behavior problems. Diabetes has been found to form a risk factor for psychiatric disorders in adolescence, especially for internalizing behavior problems like depression Kovacs, Obrosky, Goldston & Drash, 1997; Northam, Matthews, Anderson, Cameron & Werther, 2005). Several studies have found that diabetes and depression frequently co-occur in adolescence Anderson, Freedland, Clouse & Lustman, 2001; Lin et al., 2004; Hood et al., 2006; Lawrence et al., 2006; McGrady & Hood, 2010, although this is not always the case (DeWit, 2007).

Externalizing problems may also be important among adolescents with T1DM. Externalizing behavior problems have been found to result in poorer glycemic control (Cohen, Lumley, Naar-King, Partridge & Cakan, 2004), and diagnoses of pre-existing externalizing behavior problems were associated with poorly controlled diabetes and externalizing behaviors in adolescence (Northam et al., 2005).

The kind of mental health problems experienced by adolescents with T1DM needs to be clarified, in order to improve guidelines for treatment of diabetes. To this end, researchers should rely upon both adolescent-reported measures that might be applied in regular care, as well as parent-reported measures. Comparing answers of these youths to those from healthy peers can indicate the extent to which differences exist between these groups.

We studied whether Dutch adolescents with T1DM had increased levels of behavior problems in comparison to peers without T1DM, both according to their self-reports and reports from their mothers and fathers. We studied depressive symptoms, and detailed clusters of behavioral problems. Additionally, we examined the extent to which metabolic control is related to depressive symptoms and specific behavior problems.

METHODS

Sample

Patients with T1DM between 12 and 18 years of age (n=302) and their parents were recruited for participation. They were treated by a multidisciplinary team at nine hospitals in The Netherlands. A total of 151 adolescents agreed to participate, as did their parents. Informed consent was obtained from 135 mothers and 114 fathers (see table 1). Medical information (most recent HbA1c, duration of the disease, and treatment regimen) was recorded from the hospital charts. HbA1c was analyzed with similar assays, using gas chromatography, in the different hospitals.

Schools were approached for cooperation in the same time period in order to recruit the comparison group. Healthy adolescents without T1DM and their parents were invited to participate, matching school type, age, and gender to that of the adolescents with T1DM. The comparison group comprised 122 adolescents without T1DM; In formation was also collected from 114 of these mothers and 61 of the fathers. Exclusion criteria for both groups were no participation of a parent, and comorbid medical or psychiatric illness of the adolescent. All participants in both groups were of Northern European ethnicity.

Measures

The Children's Depression Inventory

The Children's Depression Inventory (CDI) was developed to measure self-reported depressive symptoms in children and adolescents aged 7 to 17 years (Kovacs, 1992). The inventory assesses a variety of self-reported depressive symptoms, including disturbance in mood, self-evaluation, and interpersonal behaviors. The overall scale gives an indication for the extent of depressive feelings, with a mean (sd) of 7.69 (4.9) for boys and 10.46 (6.5) for girls. Higher scores reflect more depressive feelings. A cutoff score of 13 was used to indicate a serious level of depressive complaints, at risk for a clinical depression (Kovacs, 1992). Psychometric characteristics are sufficient (Evers, Vliet-Mulder & Groot, 2000).

The Child Behavior Checklist (CBCL) and Youth Self-Report (YSR)

The presence of behavior problems was studied using information from different sources, namely the adolescent themselves (YSR), and their mothers (CBCL) and fathers (CBCL). The Child Behavior Checklist (CBCL) measures behavior problems and competencies of children and adolescents between the ages of 6 to 18, as reported by their parents (Achenbach & Rescorla, 2001). The Youth Self-Report (YSR) is a self-report derivative of the CBCL for adolescents between 11 and 18 years. A detailed clustering of behavior problems is provided in the syndrome scale, which consist of anxious/depressed behaviors, withdrawn/depressed behaviors, somatic complaints, social problems, thought problems, attention problems, rule-breaking behavior, and aggressive behavior. The CBCL and YSR questionnaires have been shown to have adequate reliability and validity (Evers et al., 2000).

Procedure

The adolescents with T1DM answered the questionnaires when they visited the diabetes team, or at home. The parents were sent questionnaires by mail. For the control group, the questionnaires were sent to the adolescents and their parents at home. The study was approved by the medical ethical committees of the Catharina hospital in Eindhoven and all participating hospitals.

According to protocol, adolescents who answered in the positive to the critical item on the CDI

concerning suicidality, or who scored above the clinical range for depression on both YSR and CDI, were approached to verify whether they received psychological treatment and to offer it when necessary.

Data analyses
Potential differences in group characteristics were analyzed using chi-square or t-tests. Group differences were examined using multivariate and univariate analyses of variances. All tests were two-sided. Within the T1DM group, a regression analysis was conducted to study the relationship between HbA1c and the depressive symptoms and behavior syndrome scales.

RESULTS
Group characteristics
A description of baseline group characteristics can be found in table 1. The total group of adolescents with T1DM did not differ from the comparison group in age, gender, or education level, as expected in light of the matching procedure.

Table 1. Baseline group characteristics*.

Variable	Controls (n=122)	T1DM (n=151)
Age :mean (SD)	14.62 (1.66)	14.89 (1.71)
Range	12-18	12-18
Gender		
male	50 (41%)	65 (43%)
female	72 (59%)	86 (57%)
School level		
lower	51 (41.8%)	42 (27.8%)
vocational	12 (9.8%)	19 (12.6%)
higher	27 (22.1%)	46 (30.5%)
pre-university	32 (26.2%)	40 (26.5%)
unknown		4 (2.6%)
Treatment		
Injections		71 (47%)
Pump		80 (53%)
HbA1c: mean (SD)		8.3 (1.46)
Range		5.1-13.0
Age at diagnose: mean (SD)		9.43 (3.82)
range		0-18
Years T1DM: mean (SD)		5.74 (3.92)
range		0-15

*Group differences are not significant
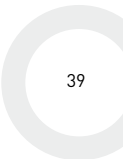
Depressive symptoms

The adolescents with T1DM (mean=7.32, sd=5.32) did not differ from the comparison group (mean=6.55, sd=5.94) in number of depressive complaints according to the CDI (F(1,265)=1.100, p=0.295). In the group with T1DM, 18 adolescents (12.4% of a total 145 with complete data) were identified as being at risk for a clinical depression, as were18 adolescents in the control group (14,8% of in total 122 with complete data). These proportions did not not differ (χ^2 (1, N =270) =0.197, p = 0.66), see figure 1.

Figure 1. Depression in adolescents with and without T1DM
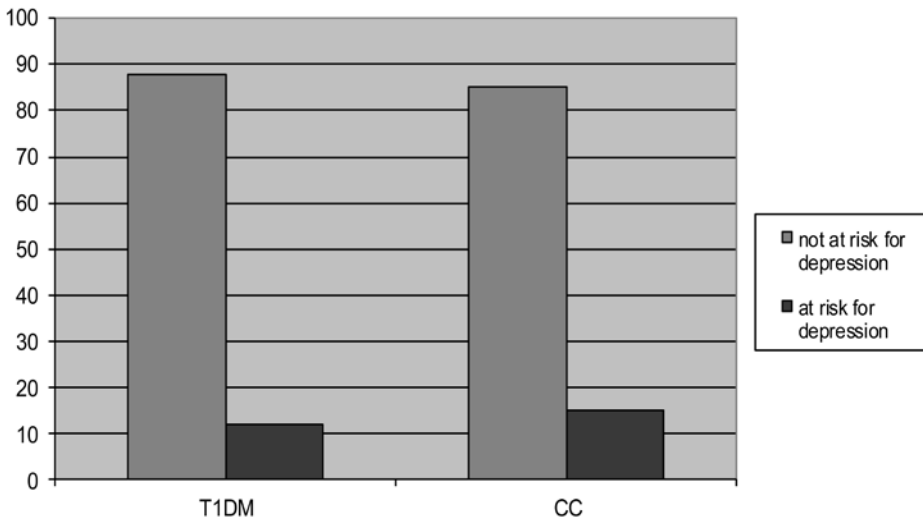
Behavior problems

Means and standard deviations for the YSR (as assessed by the adolescents) are presented in table 2, as are CBCL behavioral syndromes (as assessed by mothers and fathers). This table also indicates significant differences found with univariate analyses of variance. Mean factor scores (internalizing, externalizing, and total behavior problems,) and mean scores for the behavioral syndrome scales for adolescents with and without T1Dm, are presented in figures 2 and 3.

Table 2 Means and standard deviations for YSR (adolescents) and CBCL (mothers and fathers)

CBCL/YSR	Adolescents		Mothers		Fathers	
	Controls	T1DM	Controls	T1DM	Controls	T1DM
	N=111	N=140	N= 104	N=128	N=59	N=99
anxious/ depressed	53.11(5.50)	53.37 (9.03)	52.55 (4.61)	53.78 (7.27)	52.12 (4.12)	52.91 (8.04)
withdrawn/ depressed	53.15 (5.61)	54.84 (8.34)	53.76 (4.97)	55.58 (7.40)	52.90 (4.39)	54.52 (9.31)
somatic complaints	54.60 (5.86)	56.04 (7.59)	54.76 (5.52)	56.72 (7.53)*	53.37 (4.29)	55.18 (6.48)
social problems	54.21 (5.89)	54.37 (6.62)	53.37 (5.16)	53.22 (7.57)	53.22 (5.09)	53.61 (6.15)
thought problems	52.86 (4.47)	55.74 (8.13)**	52.76 (4.34)	54.81 (7.10)*	52.08 (3.55)	54.01 (6.79)*
attention problems	54.01 (4.98)	54.83 (6.32)	53.46 (4.23)	54.12 (5.88)	52.97 (4.08)	53.79 (5.06)
rule-breaking behav.	53.98 (4.49)	54.65 (6.65)	52.24 (4.04)	52.61 (4.79)	51.59 (3.24)	53.41 (5.18)*
aggressive behavior	52.21 (3.61)	52.87 (5.54)	52.21 (3.96)	52.94 (8.26)	51.83 (4.12)	53.11 (5.51)

Univariate analyses: * p< 0.05; ** p< 0.01

For adolescents' self-reports on the YSR for the behavioral syndromes, a multivariate analysis of variance showed a significant overall difference ($F_{(8,239)}$=2.37, p=0.018). One behavioral syndrome scale differed significantly between the groups, reflecting Thought problems, ($F_{(1,247)}$=11,63, p=0.001), see table 2. The adolescents with T1DM reported more problems than the comparison group on this subscale, which refers to questions such as: 'can't get my mind off certain thoughts'; 'have twitches'; 'have sleeping problems'. Adolescents with T1DM also reported more Thought problems in the borderline and clinical range (n=27) than did the comparison group (n=4) (χ^2(2)= 14.450, p=.001).
The difficulties concerning Thought problems were corroborated by the CBCL reports from mothers, which showed a significant difference on this syndrome scale ($F_{(1,231)}$=6.64, p=0.01). The fathers' CBCL reports also showed a significant difference for Thought problems

(F(1,155)=4.37, p=0.04). Overall, however, mothers of adolescents with T1DM did not differ significantly from mothers of healthy peers in their CBCL reports concerning behavioral syndromes (F(8,223)=1.80, p=0.08), nor did the fathers (F(8,147)=1.27, p=0.26).

Figure 2. Behavioral problems in adolescents with and without diabetes (YSR)
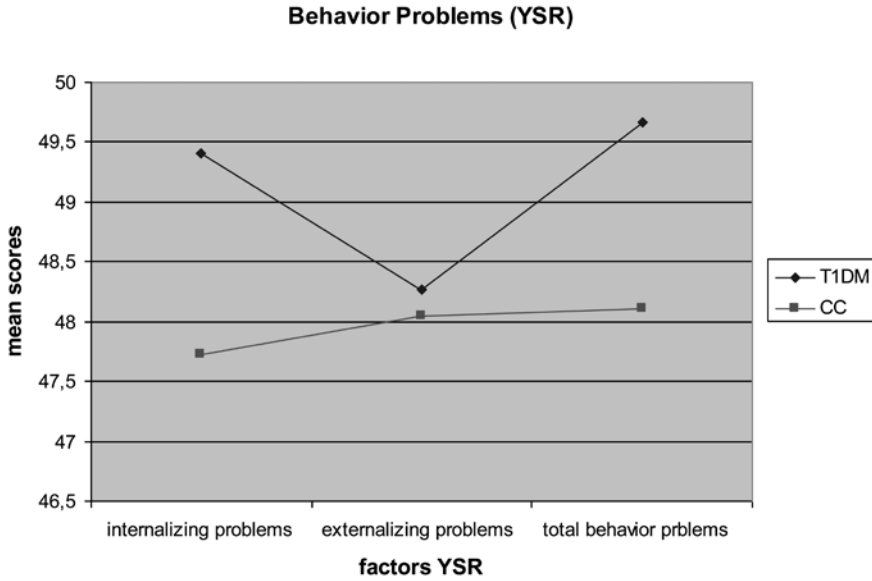
Figure 3. Specific behavioral problems in adolescents with and without diabetes (subscales YSR)
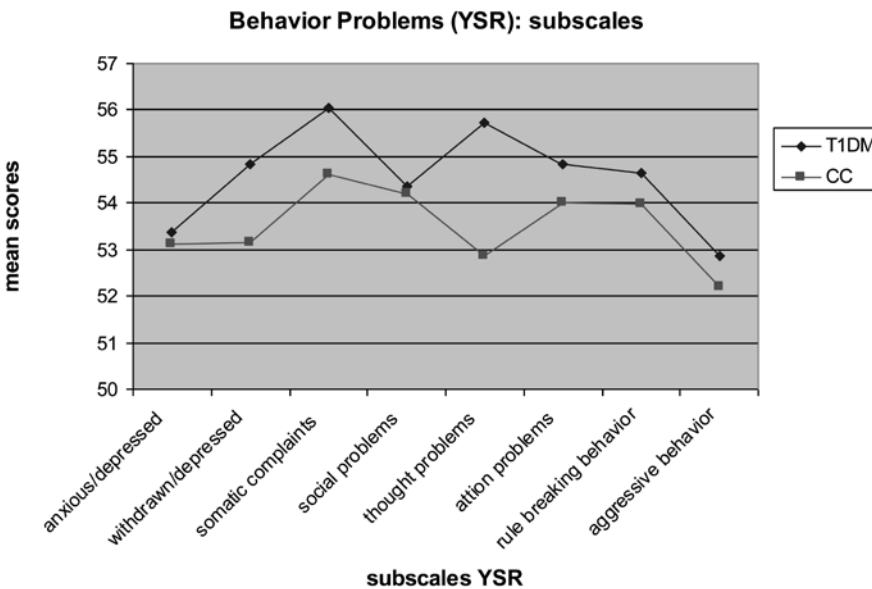
Glycemic control and social emotional functioning

A regression analysis, using the enter procedure, was conducted in order to study the relationship between glycemic control and social-emotional functioning of adolescents with T1DM, as represented by their CDI score and the scores on the eight behavioral syndromes of the YSR (see table 3). This model was significant ($F(9,121)=2.17$ $p=.029$), explaining 14% of the variance in the HbA1c levels. Children with more depressive symptoms and rule breaking behavior were found to have higher HbA1c levels.

Table 3 Relationships between depressive symptoms, behavior problems and HbA1c

	B	p
anxious/depressed	.086	.554
withdrawn/depressed	-.092	.587
somatic complaints	.214	.120
social problems	-.281	.052
thought problems	-.252	.071
attention problems	-.021	.883
rule-breaking behavior	.392	.013
CDI	.301	.009
R^2	14%	
R^2 change	14%	
F	(9,121)=2.17	.029

DISCUSSION

Our study on the types and extent of social-emotional problems among adolescents with T1DM revealed that emotional and behavior problems are related to glycemic control. Blood glucose regulation was found to be related specifically to depressive symptoms and rule breaking behavior among the adolescents with T1DM. The adolescents with poor blood glucose regulation experienced difficulties, in general, as well as problems followng rules; This likely also extends to difficulties in following the rules of their treatment for diabetes. The problems adolescents with T1DM experienced in social emotional functioning could be specifically related to diabetes and diabetes management tasks. The questionnaires used in this study were not diabetes-specific, however, so we cannot indicate diabetes-specific burdens yet.

We also found a remarkable difference, in that the adolescents with T1DM reported more thought problems than the comparison group. The results of our comparison group were in the same range as those of the original norm group of the YSR (Achenbach & Rescorla, 2001). The reports of both mothers and fathers did not show an overall significant difference, but looking univariately at the dimension, a difference in thought problems also appeared in mothers' and fathers' reports of youths' functioning, with parents of adolescents with T1DM reporting more thought problems than the parents of healthy adolescents. The fact that mothers and fathers of youths with T1DM agreed with their children regarding the higher prevalence of Thought problems may underline the importance of these kinds of behavioral difficulties. This result is not easy to interpret, however. Thought problems refer to a variety of problems in learning behavior and information processing. These adolescents more often ruminate on certain thoughts, and have twitches, strange thoughts, or sleeping problems. An explanation for such group differences may be found in subtle neuropsychological effects of diabetes. Both hypo- and hyperglycemia affect cognitive functioning, but in different ways (Periantie et al., 2006). In a recent meta-analysis, Naguib and colleagues (Naguib, Kulinskaya, Lomax & Garralda, 2009) found mild cognitive impairments in adolescents with T1DM, especially poorer visuospatial ability, motor speed, writing, and sustained attention. This was independent of a history of hypoglycemic episodes. The relationship between thought problems and blood glucose regulation was only marginally significant in our study. It is conceivable, however, that the fluctuating blood glucose levels that all patients with diabetes experience, and the high blood glucose regulation in our group (mean 8.3%), may influence thinking and perception. Our findings are also in line with Nardi (Nardi et al., 2008), who found more thought problems among adolescents in the age of 14 to 18 with T1DM, relative to a comparison group.

Another important finding is a lack of group differences in other syndromes. Further, although depressive symptoms are often associated with T1DM, we found that the incidence of depressive symptoms among adolescents with T1DM was similar to that of adolescents without T1DM. This corroborates findings of the SEARCH study (Lawrence et al., 2006). Our findings indicate that one in eight youths with T1DM met the clinical cut off for depression. This level of depressive symptoms is comparable with the results of Hood (Hood et al., 2006), who reported that one in seven adolescents with T1DM met the same criteria for depression as used in our study. Hood, however, concluded that this level nearly doubles that of the highest estimate of depression among youths in general, but this was based on prior reports and not in comparison with a control group (Fleming, Boyle & Offord, 1993; Anderson & McGee, 2006).

Clinical implications

In view of the elevated thought problems, and the important associations that blood glucose regulation held with both depressive symptoms and rule breaking behaviors, routine screening

for behavioral problems in adolescents with T1DM is recommended.

Increased attention should be devoted to the large group of adolescents who have poor metabolic control. Although strict diabetic treatment management is necessary to maintain adequate levels of HbA1c, this may indicate greater interference with daily life. Adolescents need to be stimulated by their parents and health care professionals to find intrinsic motivation for their own disease management, and to maintain their mental health. Thought problems may need special consideration, and it seems useful to investigate whether and how these problems interfere with diabetes management and daily living. To optimize glycemic levels, specific attention should be paid to adolescents reporting depressive symptoms or rule breaking behavior, in general, because they may experience the most adaptation problems when it comes to treatment rules.

Strengths, limitations, and future directions

A strength of our study is that we examined a relatively large group of 151 adolescents with T1DM. Many eligible patients refused to participate, however. Although a participation rate of 50% is comparable to other studies (Lawrence et al., 2006; Lin et al., 2004; De Wit et al., 2007), our research may have been biased in that our results reflect data of relatively well functioning adolescents. The self-selection evolving from voluntary participation may have led to an underestimation of the number of adolescents with depressive symptoms in the group with T1DM. Nevertheless, the group differences found in a behavioral syndrome like thought problems need further study, as it may be important to consider for treatment improvements.

Conclusion

One in eight Dutch youths with T1DM met the clinical cut off for depression. The adolescents with T1DM did not differ from healthy peers in their number of depressive complaints. However, the combination of depressive symptoms and rule breaking behavior was related to metabolic control. Further, elevated thought problems were found among adolescents with T1DM, in comparison to healthy peers. This finding warrants further attention in research, as well as in clinical practice.

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CHAPTER 4.

CAN ONE QUESTION BE A USEFUL INDICATOR OF PSYCHOSOCIAL PROBLEMS IN ADOLESCENTS WITH DIABETES MELLITUS?

N. M. Maas- van Schaaijk, R.J. Odink, K. Ultee & A.L. van Baar

ABSTRACT

Objective

A screening tool for psychosocial functioning of adolescents with diabetes is unavailable. We investigated if one question using a Visual Analogue Scale that indicates a rating from the worst (0) to the best possible life(10), is related to standardized indices of psychosocial functioning and wellbeing in adolescents with type 1 diabetes mellitus (T1DM).

Methods

151 adolescents with T1DM and 122 healthy peers, between 12 and 18 years of age were asked to rate their life on a scale, varying from zero to ten. Behavior problems and depressive symptoms were measured with the Youth Self Report (YSR) and the Children's depression Inventory (CDI).

Results

Adolescents with T1DM rated their life less positive in comparison to their healthy peers ($F(1,269)$= 14.01, $p=0.000$). Adolescents with T1DM who rated their life with a 6 or lower, reported more depressive symptoms and behavior problems ($F(2,131)=24.19$, $p=0.00$) compared to those with higher scores (7 or up).

Conclusions

One question, the 'rate your life scale' identified most of the adolescents at risk of internalizing behavior problems, especially depression. The results of this first step in exploring the validity of this question as a screening tool for psychological functioning are promising.

INTRODUCTION

Adolescents with T1DM often suffer from psychological disturbances (Hesketh, Wake & Cameron, 2004; Nardi et al., 2008; Varni et al., 2003). T1DM was found to be a risk factor for psychiatric disorders in adolescence (Blanz, Rensch-Riemann, Fritz-Sigmund & Schmidt, 1993; Kovacs, Goldston, Obrosky & Bonar, 1997; Northam, Matthews, Anderson, Cameron & Werher, 2005), especially for internalizing behavior problems like depression (Kovacs, Obrosky, Goldston & Drash, 1997; Lawrence et al., 2006; Lin et al., 2004). Other common psychosocial problems like externalizing behavior problems interfered with treatment adherence and were found to result in poor glycemic control (McDonnell, Northam, Donath, Werther & Cameron, 2007; Duke et al., 2008; Cohen, Lumley, Naar-King, Partridge & Cakan, 2004).

Despite increased knowledge of the relationship between diabetes and psychosocial issues, health care professionals often tend to focus on the physical aspects of the disease. Several instruments are available to measure quality of life and psychosocial problems in adolescents with T1DM, but a screening tool for psychosocial problems is unavailable. Health related quality of life (HRQoL) in adolescents with T1DM can be measured generic (e.g the Pediatric Quality of Life Inventory (PedsQL) (Varni, Seid & Kurtin, 2001), DISABKIDS (Petersen, Smidt, Power & Bullinger, 2005) and disease specific (e.g. PedsQL-DM (Varni et al., 2003), DISABKIDS-DM (Baars, Atherton, Koopman, Bullinger & Power, 2005), Diabetes Quality of Life-Youth questionnaire (Ingersoll & Marrero, 1991). Both have their strengths and weaknesses. Generic measures allow comparisons with healthy peers and disease specific HRQoL measures are more sensitive for diabetes related problems. Ideally a combination of questionnaires should be used, but it takes at least 15 minutes per patient to complete. For each consultation more time is needed when common psychosocial problems like depression and behavior problems also need to be screened. This is one of the reasons why psychosocial problems are not screened on a regular basis. In clinical practice the first question asked during a consultation (How are you? How do you feel?) is usually assumed to give a first and general indication of wellbeing. It is useful to investigate if the answer of this question and the way adolescents value the quality of their life, is related to standardized indices of psychosocial functioning. Therefore we asked how adolescents rate their life on a ten point scale, varying from zero (worst life possible) to ten (best life possible). We expected that such a rating would be a valid indicator of psychosocial problems.

METHODS

Population

All patients with T1DM between 12 and 18 years of age (n=309) treated by a multidisciplinary team at nine hospitals in The Netherlands, were asked to participate and 151 adolescents answered the questionnaires. For the comparison group, healthy adolescents without T1DM from local schools were invited to participate, matching school type, age and gender to that of the adolescents with T1DM. The comparison group comprised 122 healthy adolescents. Exclusion criterion for both groups were: a co-morbid medical or psychiatric condition. All adolescents (T1DM and controls) were of Caucasian ethnicity. Medical information (most recent HbA1c, duration of the disease, treatment regimen) was recorded from the hospital charts.

Questionnaire design and ethics consideration

Self-reported depressive symptoms were measured with the Children's Depression Inventory

(CDI) (Kovacs, 1992). The questions refer to cognitive, affective and behavioral depressive symptoms for children and adolescents in the age of 7 to 17. The questionnaire consists of 27 Likert-type items answered on a 3-point scale, varying from zero (absence of symptom) to two (clear symptom). Total scores from 0 to 54 can be achieved. The scale gives an indication for the extent of depressive feelings with a mean (sd) of 7.69 (4.9) for boys and 10.46 (6.5) for girls. Higher scores reflect more depressive feelings. Psychometric characteristics are sufficient (Evers, Vliet-Mulder & Groot, 2000).

The Youth self-report (YSR) measures behavior problems and competencies of adolescents in the age of 11 to 18 as reported by the adolescents themselves (Achenbach & Rescorla, 2001). The questionnaire consists of 113 Likert-type items answered on a 3-point scale, varying from zero (absence of symptom) to two (clear symptom). The total score provides an indication for the extent of behavior problems. The subscales refer to anxious/depressed and withdrawn/depressed behaviors, somatic complaints, social problems, thought problems, attention problems, rule-breaking behavior and aggressive behavior. Psychometric characteristics are good (Evers et al., 2000).

We asked adolescents how they rate their life on a ten point scale, varying from zero (worst life possible) to ten (best life possible). The adolescents were asked to put a cross at the number on a Visual Analogue Scale that best represented their feelings at that moment, see appendix 2.

The adolescents with T1DM and their parents were both sent a letter in which they were separately informed of the study. When they both agreed to cooperate and completed an informed consent form, an appointment for the adolescent was made to answer the questionnaires when they visited the diabetes team, or at home. For the healthy group the consent forms and questionnaires were sent to the adolescents and their parents at home.

The study was approved by the Medical ethical committees of the Catharina hospital in Eindhoven and the local committees of all participating hospitals.

Statistical analyses

Potential differences in descriptive group characteristics were analyzed using chi-square or t-tests. As the outcome variables were found to show a non-normal distribution, the results of the rating scale, the CDI and YSR total scores, as well as the results for the behavioral syndrome scales were converted to z-scores for use in parametric analyses. Group differences were analyzed using univariate and multivariate analysis of variance. A Reciever Operating Characteristic (ROC) curve analysis was done to examine the discriminative ability of the rating scale by determine the optimal cut off point of the rate your life scale. Pearson correlation coefficients were computed between HbA1c, the rating scale, the CDI, and the YSR scales. Within the T1DM group a regression analyses was done using the rating scale as the dependent variable and the variables that showed significant correlations, as the predictors.

RESULTS

The total group of adolescents with T1DM did not differ from the healthy adolescents in age, gender and education level (table 1).

Table 1. Baseline group characteristics*.

Variable	Controls (n=122)	T1DM (n=151)
Age		
mean (SD)	14.62 (1.66)	14.89 (1.71)
range	12-18	12-18
Gender		
male	50 (41%)	65 (43%)
female	72 (59%)	86 (57%)
Single parent family	Unknown	20 (13.2%)
School level[a]		
lower G. S. E. (VMBO)	51 (41.8%)	42 (27.8%)
higher G. S. E. (HAVO	27 (22.1%)	46 (30.5%)
pre-university E. (VWO)	32 (26.2%)	40 (26.5%)
vocational E. (MBO)	12 (9.8%)	19 (12.6%)
unknown		4 (2.6%)
Treatment		
Injections		71 (47%)
Pump		80 (53%)
HbA1c		
mean (SD)		8.3 (1.46)
range		5.1-13.0
Age at diagnose		
mean (SD)		9.43 (3.82)
range		0-18
Years T1DM		
mean (SD)		5.74 (3.92)
range		0-15

[a]G.=General, S.= Secondary, E.= Education; *Group differences are not significant

Overall adolescents with T1DM evaluated their life as good (M=7.4, sd=1.55). However, they rated their life significantly less positive in comparison to their healthy peers who rated their life as very good (M=8.0, sd=1.19), according to a univariate analysis of variance ($F(1,260)=13.35$, $p<.001$) corrected for gender (which had no significant effect $F(1,260)=.034$, n.s.) and age (which did show an effect $F(1,260)=4.208$, $p<.05$).

The ROC curve analyses showed that a cut off score of 6 on the rate your life scale in relation to the YSR total score had an acceptable Area Under the Curve (AUC) of .780 (CI=.682-.877), whereas 7 had an AUC of .545 (CI=.446-.623) and 5 had an AUC of .703 (CI=.559-.847).

Of the adolescents with T1DM 32 (22%) rated their lives with a 6 or lower, a significant difference with nine (7%) of the healthy controls (chi-square=10.54, p=.001). An evaluation with a seven or higher on the 10-point scale was provided by 78% (N=116) of the adolescents with T1DM, whereas this was given by 93% (n=113) of the healthy adolescents.

A multivariate analyses of variance corrected for age showed that all adolescents who rated their life with a 6 or lower, reported significantly more depressive symptoms on the CDI and the YSR total behavior problems ($F(2,237)=42.56$, $p=0.000$) and more internalizing and externalizing behavior problems ($F(2,240)=25.76$, $p=0.000$) compared to adolescents with

high scores (7 or up) on the rating scale. These groups also differed on all YSR subscales (F(8,237)=9.08, p=.000), with the higher rating group reporting less behavior problems.

For the adolescents with T1DM, a multivariate analysis, corrected for age and diabetes specific characteristics like HbA1c and form of treatment (injection or pump), showed that those who rated their life with a 6 or lower, reported significantly more depressive symptoms on the CDI and the YSR total behavior problems (F(2,121)=19.32, p=0.00) compared to adolescents with high scores (7 or up) on the rating scale. The groups differed on internalizing and externalizing behavior problems (F=2,122)=16.09, p=0.00).

The specificity of the 'rate your life scale' was .93 for depression, indicating that that 93% of the adolescents that were not depressed (CDI<13) also scored a 7 or up on the scale. For internalizing problems specificity was .88, indicating that 88% of the adolescents that reported no internalizing problems (YSR internalizing problems not within borderline or clinical range) also scored a 7 or up on the scale. The sensitivity of the scale was .58 for depression, indicating that 58% of the depressed adolescents were identified with the scale. For internalizing problems 51% of the adolescents that reported internalizing problems within the borderline or clinical range were identified with the scale.

The HbA1c, the CDI and the variables on the syndrome scales of the YSR that showed a significant correlation (table 2) with the rating score (p<0.001) were used as predictors of the answer on the rating scale in a regression analysis, employing a stepwise procedure. This resulted in a significant model, which explained 43.9% of the variance of the answer given on the rating scale, by the HbA1c, the total score of the CDI and the scores on the subscales withdrawn/depressed and anxious/depressed of the YSR together, see table 3. A worse rating of their life was given by adolescents who had a higher HbA1c and who indicated more depressive complaints as measured by the CDI and YSR. Anxiety was found to function as a suppressor variable in the regression model, as it showed a weak negative correlation with the rate your life outcome variable, but had a positive beta in relation to the other contributors to the model.

Table 2. Correlations between the rating scale, YSR, CDI and HbA1c.

	Rate your Life scale		
	T1DM (n=151)	**CC (n=119)**	**Total (n=270)**
YSR: anxious/depressed	-.271**	-.216*	-.251**
YSR: withdrawn/ depressed	-.520**	-.433**	-.504**
YSR: somatic complaints	-.348**	-.223**	-.326**
YSR: social problems	-.286**	-.301*	-.288**
YSR: thought problems	-.301**	-.198*	-.314**
YSR: attention problems	-.282**	-.158	-.256**
YSR: rule-breaking behaviour	-.069	-.373**	-.170*
YSR: aggressive behaviour	-.108	-.115	-.126
YSR: internalizing problems	-.559**	-.326**	-.478**
YSR: externalizing problems	-.164	-.280*	-.204**
YSR: total	-.378**	-.328**	-.371**
CDI (total score)	-.541**	-.500**	-.499**
HbA1c	-.216**		

*p< 0.05 level ; ** p< 0.01 level

55

Table 3. Relationships between depressive feelings, behaviour problems and the rating scale in youth with T1DM.

	Step 1	Step 2	Step 3	Step 4
	β	β	β	β
total score on the CDI	-.537***	-.359***	-.422***	-.381***
withdrawn/depressed; YSR		-.288**	-.585***	-.602***
anxious/depressed; YSR			.432***	.439***
HbA1c				-.173*
R²	28.8%	33.9%	39.6%	43.9%
R² change	.000	.002	.000	.013
F	51.45	32.37	29.02	24.29

*p<.05; **p<.01; ***p<.001

DISCUSSION

The adolescents with T1DM gave a lower rating of their life on a ten point scale than the healthy adolescents. The difference was almost 0.5 standard deviation, which is frequently considered to indicate a clinically significant effect. Of the adolescents with T1DM 22% rated their life with a 6 or lower. In contrast, this was the case for 7% of the healthy controls. Important is that a lower score on the scale was associated with more depressive symptoms and more behavior problems according to the adolescents. The low rating adolescents had more depressive feelings, more social and somatic problems and they reported more attention and thought problems compared to the adolescents who rated their life with a 7 or more. Externalizing behavior, especially aggressive behavior, was found to be less associated with the rating of their life, indicating that this acting out is not contributing to the appreciation of daily life of adolescents.

Of the adolescents who scored a 7 or more on the scale 93% were not depressed (CDI<13) and 87% reported no internalizing problems. The 'rate your life scale' was not sensitive enough to diagnose that an adolescent is depressed or not, nor does it indicate a borderline or higher level of internalizing problems. Further evaluation of psychosocial problems in low rating adolescents is necessary.

In the regression model used with the adolescents with T1DM, anxiety on the YSR was found to act as a suppressor variable. A low rating of life was explained for a large part by more depressive feelings of the adolescents and the metabolic control. This indicates that both the emotional condition, especially depressive feelings for different reasons (maybe also disease related worries) as well as the diabetes related condition reflecting health status or the disease management process, are important for the adolescents in their evaluation of their life.

Our results show that a better glucose regulation, a lower HbA1c, is accompanied by a higher rating of life and vice versa. Other studies found no relationship between metabolic control and quality of life (Laffel et al., 2003; Wagner, Müller-Godeffroy, von Sengbusch, Häger & Thyen, 2005; De Wit et al., 2007). Studies did indicate that behavior problems are associated with poor glycemic control. However, especially externalizing behavior problems have been

found to interfere with treatment compliance and result in poorer glycemic control (McDonnell et al., 2007; Duke et al., 2008; Holmes et al., 2006). It is conceivable that externalizing behavior problems have more impact on treatment compliance and glycemic control than internalizing problems.

A strength of our study is that we examined a relatively large group of 151 adolescents with T1DM. However many eligible patients refused to participate. Although a participation rate of 50% is comparable to other studies (Lawrence et al., 2006; Lin et al., 2004; De Wit et al., 2007) our study may have been biased in that our results reflect data of relatively well functioning adolescents. Another limitation was that all adolescents were of Caucasian ethnicity.

There is international consensus that a routine screening for psychosocial problems should become a standard of care (Delamater, 2009). If a standardized questionnaire like the CDI or YSR cannot be used regularly, the answer on a 10-point scale' regarding the evaluation of one's life, seems to provide an important first impression of psychosocial functioning in adolescents with T1DM. The rating scale especially showed a strong relationship with depressive feelings. The use of this simple and easy to administer measure may improve identification of these problems. Further study, e.g. of test-retest reliability of the scale and the relation between the scale and quality of life questionnaires, is necessary to investigate it's use in practice. Nevertheless the results of this first step in exploring the validity of this screening scale are promising.

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CHAPTER 5.

SATISFACTION WITH COPING ABILITY IN ADOLESCENTS WITH TYPE 1 DIABETES MELLITUS: ASSOCIATION WITH DEPRESSIVE SYMPTOMS, COPING STYLES AND METABOLIC CONTROL

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ABSTRACT

Objective

The purpose of this study was to determine whether the level of satisfaction of adolescents with type 1 diabetes with their own coping ability is related to their coping styles, as well as to behavioral or emotional problems and metabolic control.

Methods

A sample of 151 adolescents aged 12-18 years (mean 14.9 ± 1.7 years) with type 1 diabetes indicated to what extent they were satisfied with their ability to cope with their disease. They also completed questionnaires on coping styles (CODI Coping questionnaire), behavior problems (Youth Self Report) and depressive feelings (Children's Depression Inventory).

Results

A higher level of satisfaction with their coping ability was associated with an accepting coping style, less depressive feelings and a better metabolic control of the adolescents. The CDI, an accepting coping style and the level of metabolic control accounted for 43.2% of the variance in the satisfaction of the adolescents with their coping ability. In addition 40.9% of the variance in depressive symptoms was explained by an emotionally reactive coping style as well as by the adolescents' level of satisfaction with their coping ability.

Conclusions

Adolescents with type 1 diabetes, who evaluated their coping abilities as successful, showed less behavior problems and depressive feelings and a better metabolic control. The coping styles they used were based on acceptance and less on avoidance, emotional reactions and wishful thinking.

INTRODUCTION

Adolescence and diabetes form a challenging combination. The complex disease management tasks make diabetes difficult to fit in everyday life and may influence social emotional functioning of the adolescents. Compliance with the medical regime, which requires a lot of self-discipline, may actually interfere with age-specific developmental goals like the development of psychological autonomy. As a result, the adolescent has to deal with both physical and psychological stressors. Success or failure in dealing with these stressors is a particularly important domain of study because both deterioration in metabolic control and increased emotional problems are seen in many adolescents. Several studies have documented that their mean levels of metabolic control as measured by the HbA1c value, are generally >8.0%, which is considered too high and increase health related risks (Mortensen et al., 1998; Chase et al., 2003; Bryden, Dunger, Mayou, Peveler & Neil, 2003). In addition various studies have reported worse quality of life and other psychological problems (Nardi et al., 2008; Guttmann-Bauman, Flaherty, Strugger & McEvoy, 1998; Hesketh, Wake & Cameron, 2004) or even psychiatric disorders like depression in adolescents with type 1 diabetes compared to healthy peers (Blanz, Rensch-Riemann, FritzSigmund & Schmidt, 1993; Kovacs, Goldston, Obrosky & Bonar, 1997; Kovacs, Obrosky, Goldston & Drash, 1997; Northam, Matthews, Anderson, Cameron & Werther, 2005; Lawrence et al., 2006; Lin et al., 2004). The complexity of the problem is emphasized by inconsistent results concerning the relationship between metabolic control and psychosocial functioning (Hassan, Loar, Anderson & Heptulla, 2006; Graue, Wentzel-Larsen, Hanestad, Båtsvik & Søvik, 2003; Maas-van Schaaijk, Odink, Ultee & van Baar, 2011). Further study on success or failure in dealing with diabetes related stressors in adolescents is necessary to improve psychological coaching and treatment of type 1 diabetes in this developmental phase.

First, the process of managing stressors, defined by Lazarus & Folkman (1984) as coping, needs to be addressed. Several cognitive, emotional and behavioral strategies of coping are differentiated (Kammeyer-Mueller, Judge & Scott, 2009) and can be clustered in three dimensions which Kammeyer-Mueller describes as problem solving coping, emotion-focused coping and avoidance coping. Problem solving coping refers to an active behavioral coping strategy that will help to solve the problem by reducing the level of stressors and it is considered as a functional coping style. Emotion-focused coping refers to cognitive emotional coping strategies that will reduce one's intern stress level without changing the actual presence of the stressors. Avoidance coping refers to escaping from the situation that causes the stress behaviorally (distracting oneself and distancing oneself from the situation) or emotionally (by not thinking of the problem) and is generally considered to be maladaptive.

The way individuals cope with an illness was found to be associated with psychological adjustment and metabolic control (Roesch & Weiner, 2001). Seiffge-Krenke & Stemmler (2003) concluded that adolescents with stable good metabolic control experience lower levels of stressors and use a less avoiding coping style in dealing with every day stress compared to adolescents with poor metabolic control. Graue, Wentzel-Larsen, Bru, Hanestad & Søvik (2004) found that an emotion-focused coping strategy was related to poorer metabolic control and reduced quality of life. An active coping style (take action to get around the problem) had a positive and stable effect on both metabolic control and quality of life. In a longitudinal study Luyckx, Seiffge-Krenke & Hampson (2010) found that active coping styles prospectively predicted lower HbA1c levels, which in turn also

predicted an active coping style, indicating a reciprocal mechanism. These studies indicate that active, problem-focused coping styles are more adaptive than avoiding coping styles, both concerning metabolic control as well as psychosocial functioning.

If adolescents are aware of their own coping style and how they appraise their own abilities in disease management may form an important point of focus for psychological treatment and support. Especially, if the level of satisfaction is also related to their coping style and to their behavioral problems, depressive symptoms and metabolic control.. Perceived coping effectiveness regarding specific diabetes-related stressful events has been linked to better treatment adherence, lower depressive symptoms and higher self-efficacy (Berg et al., 2009). This suggests that an adolescent's satisfaction with his or her ability to cope with stressful disease-related situations is clinically important and influences emotional wellbeing

In the present study, we aimed to study the cognitive and emotional coping strategies adolescents with type 1 diabetes use in relation to their emotional problems and metabolic control. Therefore we used a self-report questionnaire regarding coping styles to deal with a chronic disease that informs on six separate cognitive and emotional coping strategies (Petersen, Schmidt & Bullinger, 2004). In addition, the level of satisfaction of the adolescents with their own coping ability was measured with the question: 'Satisfaction, how well do you think you cope with your illness?' The relationships between the level of satisfaction with their coping ability and the kind of coping styles used, as well as with self-reported behavioral and emotional problems and metabolic control are studied in different ways. First, to investigate to what extent satisfaction with coping ability reflects coping strategies, behavioral and emotional problems and metabolic control. In addition it is studied to what extent satisfaction with coping ability contributes to depressive symptoms, next to different coping styles.

METHODS
Participants
A total of 151 adolescents with type 1 diabetes, aged 12-18, participated in the study (65 males and 86 females). Adolescents with comorbid medical or psychiatric conditions were excluded. Medical information (most recent HbA1c, duration of the disease, treatment regimen) was recorded from the hospital charts. The mean illness duration was 5.7 (sd = 3.9) years and mean HbA1c was 8.3 (sd =1.5). The descriptive characteristics of the adolescents are shown in table 1. All participants in both groups were of Caucasian ethnicity. Of the adolescents participating in the study 13.2% lived in a single parent family, which is comparable with the number of single parent families in the Dutch population (De Jong, 2003). The available data about the non-participants showed no significant differences from the study group in mean age (14.7 years) or in HbA1c (8.4%).

Measurements
Coping style. Coping style was measured with the CODI coping questionnaire for children and adolescents, which is based on children's and adolescents' perceptions of their illness and their views concerning their ability to deal with the disease (Petersen et al., 2004). The CODI consists of six domains with reliabilities that were reported as follows: acceptance (α= .83), (emotional) avoidance (α= .72), cognitive–palliative (α= .69), distance (α= .70), emotional reaction (α= .82), and wishful thinking (α=.81). In our sample of adolescents with

type 1 diabetes reliability of the CODI as measured with Cronbach's α, was as follows: for avoidance .62, cognitive–palliative .57, distance .65, acceptance .87, emotional reaction .73, and wishful thinking .82. The last three scales show a fair or good level of reliability with clinical significance (Cicchetti, 1994).

Higher scores reflect more usage of the specific coping style. The questionnaire consists of 29 items, answered on 5-point scale, varying from 1 (never) to 5 (always). A separate last item 'Satisfaction, how well do you think you cope with your illness?' measures the participants' own assessment and satisfaction of the way (s)he copes with the disease, also answered on 5-point scale, varying from 1 (not at all) to 5 (very successful).

Depressive symptoms. Self-reported depressive symptoms were measured with the Children's Depression Inventory (CDI) (Kovacs, 1992). The questions refer to cognitive, affective and behavioral depressive symptoms for children and adolescents in the age of 7 to 17. The questionnaire consists of 27 Likert-type items answered on a 3-point scale, varying from zero (absence of symptom) to two (clear symptom). Total scores from 0 to 54 can be achieved. The satisfaction scale gives an indication for the extent of depressive feelings with a mean (sd) of 7.69 (4.9) for boys and 10.46 (6.5) for girls. Higher scores reflect more depressive feelings. Psychometric characteristics are sufficient (Evers, Vliet-Mulder & Groot, 2000). The CDI showed good reliability in our sample with a Cronbach's α of .87.

Behavior problems. The Youth self-report (YSR), the adolescent version of the Child Behavior Checklist (CBCL), measures behavior problems and competencies of adolescents in the age of 11 to 18 as reported by the adolescents themselves (Achenbach & Rescorla, 2001). The questionnaire consists of 113 Likert-type items answered on a 3-point scale, varying from zero (absence of symptom) to two (clear symptom). The satisfaction score provides an indication for the extent of behavior problems. The subscales refer to anxious/depressed and withdrawn/depressed behaviors, somatic complaints, social problems, thought problems, attention problems, rule-breaking behavior and aggressive behavior. Higher scores reflect more behavior problems. Psychometric characteristics are good (Evers et al., 2000). The YSR dimensions showed good reliability in our sample with a Cronbach's α of .91.

Metabolic control. Metabolic control was assessed by the glycosylated hemoglobin (HbA1c) values from the medical records. Most recent HbA1c measures, reported one week before or after questionnaire completion, were used. HbA1c was analyzed with similar assays, using gas chromatography, in the different hospitals. In The Netherlands these assays are considered to result in comparable values.

Procedure

A total of 309 adolescents with type 1 diabetes and their parents, treated by a multidisciplinary team at nine hospitals in The Netherlands, were approached by telephone to participate. Next a letter was sent in which adolescents and parents were informed of the study. When the adolescent and at least one parent agreed to participate and completed an informed consent form, an appointment was made for the adolescent to answer the questionnaires when they visited the diabetes team, or at home. 48 adolescents completed the questionnaire at the clinic, 103 adolescents at home: the groups did not differ significantly in any of the descriptive characteristics (data not shown).

The study was approved by the Medical ethical committees of the Catharina hospital in Eindhoven and the local committees of all participating hospitals.

Statistical analyses

Pearson correlation coefficients and stepwise regression analyses were used to examine the relationships of the coping strategies and self-perception of coping ability with metabolic control, behavior problems and depressive symptoms. Statistical significance was set at 0.05.

RESULTS

Descriptive characteristics of the adolescents are shown in table 1. Mean age of the adolescents was almost 15 years. Means and standard deviations of the results on the coping style questionnaire and the questionnaires used to measure psychosocial functioning of the adolescents are described in table 2. The mean scores of the sample of Petersen et al. (2004) with the coping questionnaire were used as a reference group. They studied a group of 188 children and adolescents with various chronic health conditions, like asthma, diabetes and arthritis. Except for the cognitive palliative coping style, the samples show similar results.

Overall the majority of adolescents perceived their coping style as effective: 71.9% of the adolescents valued their own coping ability as successful or very successful. 7.5% Of the adolescents were dissatisfied with their ability to cope with their disease. A neutral answer, neither positive nor negative about their own coping abilities, was given by 20.5% of the adolescents.

Table 1. Baseline group characteristics.

Variable	T1DM (n=151)
Age :mean (SD)	14.89 (1.71)
Range	12-18
Gender	
male	65 (43%)
female	86 (57%)
School level	
lower	42 (27.8%)
vocational	19 (12.6%)
higher	46 (30.5%)
pre-university	40 (26.5%)
unknown	4 (2.6%)
Treatment	
Injections	71 (47%)
Pump	80 (53%)
HbA1c: mean (SD)	8.3 (1.46)
Range	5.1-13.0
Age at diagnose: mean (SD)	9.43 (3.82)
range	0-18
Years T1DM: mean (SD)	5.74 (3.92)
range	0-15
Family	
Living with father and mother	130 (86.1%)
Single parent	20 (13.2%)
Missing	1 (0.7%)

Table 2. Results of the CODI, YSR and CDI of the adolescents T1DM.

CODI (N=147)	M(sd)	CODI*
Avoidance	9.34 (2.92)	12.74 (4.01)
cognitive palliative	9.99 (3.30)	13.90 (4.75)
emotional reaction	11.87 (3.57)	11.78 (4.91)
Acceptance	24.19 (4.58)	22.66 (5.15)
wishful thinking	12.07 (3.13)	12.09 (2.87)
Distance	11.26 (3.22)	11.60 (3.87)
overall item	3.82 (.81)	-
YSR (N=140)		
Total behaviour problems	49,76 (11.15)	
Internalizing problems	49,36 (11.32)	
Externalizing problems	48,39 (10.08)	
anxious/depressed	53.37 (9.03)	
withdrawn/depressed	54.84 (8.34)	
somatic complaints	56.04 (7.59)	
social problems	54.37 (6.62)	
thought problems	55.74 (8.13)	
attention problems	54.83 (6.32)	
rule-breaking behaviour	54.65 (6.65)	
aggressive behaviour	52.87 (5.54)	
CDI (N=148)		
Total score	6.55 (5.94)	
CDI>13, N (%)	18 (12)	

* mean (sd) scores on the CODI of the sample of Petersen et al. (2004)

Relationships between perception of coping ability (CODI satisfaction item) and coping styles (CODI). A strong positive correlation was found between the CODI satisfaction item and the coping style acceptance (r=.61**), see table 3. A higher level of satisfaction with their own coping ability was associated with more use of an accepting coping style. Medium negative correlations were found between the CODI satisfaction item and avoidance (r=-.47**), emotional reactions (r=-.41**) and wishful thinking (r=-.24**). A lower level of satisfaction with one's coping ability was associated with use of coping styles based on avoidance, emotional reactions and wishful thinking.

Table 3. Pearson's correlations between CODI and HbA1c,. YSR,. CDI and demographic and diabetes related information

	HbA1c	CODI avoi-dance	CODI cogn. Palliative	CODI emot reaction	CODI accep-tance	CODI wishful thinking	CODI dis-tanc	CODI satisfac item
Age	.08	.05	-.15	.05	-.00	-.08	.08	**.02**
Gender	.19	.02	-.04	.05	-.02	-.07	.05	**-.01**
Family constellation	.17	.06	.01	.12	-.28**	.16	-.22**	**-.26****
Treatment form	.25**	.12	.03	.12	.02	.07	.00	**-.02**
Years since DM diagnose	.27**	.06	.16	-.03	-.03	.04	-.09	**-.14**
HbA1c		.28**	.07	.11	-.25**	.09	-.05	**-.33****
CODI satisfaction item	-.33**	-.47**	-.12	-.41**	.61**	-.24**	.16	
YSR								
Total	.20	.26**	.13	.36**	-.30**	.09	-.07	**-.26****
Internalizing	.17	.30**	.28**	.54**	-.35**	.12	-.07	**-.29****
Externalizing	.19	.20*	-.02	.15	-.26**	.12	-.01	**-.20***
anxious/de-pressed	.10	.28**	.12	.46**	-.18	.06	-.22	**-.13**
withdrawn/ depressed	.08	.25**	.09	.41**	-.17	.06	-.13	**-.26****
somatic com-plaints	.14	.18*	.16	.31**	-.20	.06	-.01	**-.18**
social prob-lems	.00	.25**	.12	.33**	-.21	.16	-.10	**-.22**
thought prob-lems	.05	.06	.11	.16	-.10	.04	-.17	**-.14**
attention problems	.14	.18*	.01	.31**	-.25**	.07	-.08	**-.32****
rule-breaking behavior	.18	.07	-.10	.04	-.15	.05	-.02	**-.12**
aggressive behavior	.10	.21*	-.05	.13	-.19	.14	-.09	**-.17**
CDI								
Total score	.12	.41**	.16	.61**	-.47**	-.26**	-.21	**-.45****

*p<.05; ** p< 0.01 level

Relationships between the perception of coping ability (CODI satisfaction item) and psychosocial functioning (CDI, YSR).
A medium negative correlation was found between the CODI satisfaction item and reported depressive symptoms on the CDI (r=-.45**), see table 3. A lower level of satisfaction with one's coping ability was associated with more depressive symptoms. Small to moderate correlations were found between the CODI satisfaction item and the subscales of the YSR: a lower level of satisfaction with their own coping ability was associated with more behavior problems, especially for attention problems and internalizing behavior dimensions.

Relationships between depressive symptoms and coping styles
A large positive correlation was found between depressive symptoms and a coping style based on emotional reactions (r=.61**) (table 3), indicating that more depressive feelings were associated with emotional reactions as coping style. A medium negative correlation was found between depressive symptoms and an accepting coping style (r=-.47**), which reflects that less depressive feelings were associated with the coping style acceptance.

Relationships between behavior problems and coping styles
Internalizing problems (withdrawn depressed behavior and anxious depressed behavior) were associated with a coping style based on emotional reactions (r=.54**) and negatively associated with an accepting coping style (r=-.35**). In general an accepting coping style was associated with less behavior problems and a coping style based on emotional reactions with more behavior problems, see table 3.

Relationships between metabolic control (HbA1c) and coping ability and coping styles
A lower HbA1c was found to be moderately related to a higher score on the satisfaction item of the CODI (-.33**). A small relationship was found for HbA1c and an accepting coping style (r=-.25**). The better the adolescents think they are able to cope with their disease and the more they accept their disease, the better their glycemic levels are.

Regression analyses
The HbA1c, the total score of the CDI and the variables on the syndrome scales of the YSR that showed a significant correlation (see table 3) with the satisfaction item of the CODI (p<0.01) were used as predictors of the satisfaction with coping ability, in a regression analysis. Age, gender, years of DM and treatment form did not show a significant correlation with the satisfaction item of the CODI and therefore were not included in the model. Family constellation was added to the model, as it showed a significant correlation (r=-.26) with the satisfaction item, indicating that a lower score was associated with living in a single parent family. This resulted in a significant model consisting of the acceptance scale of the CODI, the total score of the CDI, and the HbA1c value, which explained 43.2% of the variance of the answer given on the satisfaction item of the CODI, see table 4. Lower levels of satisfaction with one's coping ability were indicated by adolescents who had a higher HbA1c, used a less accepting coping style and who indicated more depressive complaints (CDI).

Table 4 Regression analyses of the CODI item on satisfaction with coping ability predicted by depressive symptoms, behavior problems, metabolic control (HbA1c)

	Step 1 β	Step 2 β	Step 3 β
acceptance CODI	.606***	.560***	.468***
HbA1c		-.188**	-.188**
total score on the CDI			-.199**
R²	36.7%	40.1%	43.2%
R² change	.000	.000	.000
F	76.05	43.43	32.64

*p<.05; **p<.01; ***p<.001

Another regression analyses was done to study if satisfaction with their coping ability contributed to depressive symptoms and metabolic control (HbA1c) next to coping styles and behavior problems. None of the background variables (age, gender, years DM, treatment form and family constellation) were related to the amount of depressive symptoms, and therefore these were not added to the model. A regression analysis showed that 40.9% of the variance of depressive symptoms was explained by the emotional reaction coping style and the satisfaction item of the CODI, see table 5. Adolescents who reported more depressive symptoms, used more emotional reactions and were less satisfied with their ability to cope with there disease.

Table 5. Regression analyses of depressive symptoms predicted by coping styles and satisfaction with coping ability.

	Step 1 β	Step 2 β
Emotional reactions CODI	.605***	.511***
CODI item satisfaction with coping		-.229**
R²	36.5%	40.9%
R² change	.000	.000
F	78.33	46.73

*p<.05; **p<.01; ***p<.001

Furthermore, a regression analysis predicting HbA1c from the satisfaction item on the CODI, the CODI coping styles, YSR behavior problems and CDI depressive symptoms showed that 10.6% of the variance in HbA1c was explained solely by the score on the satisfaction item of the CODI, (F=15.35, β=-.325, p=.000) .

DISCUSSION

Overall, the majority of adolescents were satisfied with their coping ability: 72.3% of the adolescents valued their own coping ability as good or very good. Nevertheless an important part (7%) of the adolescents were not satisfied with their coping. Especially this subgroup may need attention and treatment regarding coping possibilities and disease management. The level of satisfaction of adolescents with type 1 diabetes with their own coping ability was significantly related to the coping styles they used, the amount of depressive symptoms and behavior problems experienced, as well as to the levels of metabolic control. Furthermore the cognitive and emotional coping strategies adolescents with type 1 diabetes mellitus used were related to their metabolic control and psychosocial problems, in particular behavior problems and depression. Adolescents who reported more depressive feelings used emotional reactions and avoidance as coping styles more often. Less depressive feelings were associated with an accepting coping style. Metabolic control was better in those adolescents who perceived their coping abilities as successful and who used an accepting coping style instead of an avoiding coping style. As the avoidance scale of the coping questionnaire only showed weak internal consistency, the results regarding the coping styles, specifically avoidance coping, need to be confirmed in studies using different questionnaires.

Although satisfaction with coping ability was measured with only one item, several studies have shown that one question can be specific enough to differentiate between problematic or not (Maas-van Schaaijk, Odink, Ultee & van Baar, 2011; Reme & Eriksen, 2010). In addition this item contributed in the regression analyses next to the information on coping strategies, indicating that it refers to a separate concept.

These results suggest that treatment programs in these adolescents could use such a question concerning satisfaction with disease management and that treatment may need to focus on improving the satisfaction with coping abilities. These youngsters should be taught to use an accepting coping style more often, instead of an avoiding coping style, as adolescents who evaluated their coping abilities as successful, used an accepting coping style and they used less coping styles based on avoidance, emotional reactions and wishful thinking.

Berg and colleagues (2009) have also found that perceived coping effectiveness regarding diabetes-related stressful events was associated with better adherence, lower depressive symptoms and higher self-efficacy. This suggests that a positive self-evaluation of coping in general and specifically regarding diabetes, has a positive effect on several aspects of psychosocial functioning. Such a positive effect could result from the core self-evaluation personality trait as described by Judge, Van Vianen & De Pater (2004). They see the core self-evaluation as a higher order personality trait that is related to the general evaluation that people make about themselves and their functioning. Individuals with a high core self-evaluation use less avoidance coping and more problem-solving coping, compared to individuals with low core self-evaluations (Connor-Smith & Flachsbart, 2007). Connor-Smith & Flachsbart (2007) found in a meta-analysis that specific personality traits, like neuroticism, conscientiousness and extraversion, also predicted coping styles, especially in younger samples. The role of personality in the coping process of adolescents with type 1 diabetes and how these factors interact to predict stress, needs further study and may aid designing more individualized and effective intervention programs.

Our study showed that a small part of the variance in metabolic control could be explained by the satisfaction of the adolescents with their own coping ability. Metabolic control was

better in those adolescents who perceived their coping abilities as successful and who used an accepting coping style instead of an avoiding coping style. This is in line with the research of Seiffge-Krenke & Stemmler (2003) who also found that adolescents with stable good metabolic control (HbA1c<7.6%) used less avoidance. She also suggested that a maladaptive coping style was not a characteristic of adolescents with poor metabolic control. Our study showed that the adolescents did not limit themselves to the use of a single coping style, but that they used different coping styles. When an accepting coping style was dominant and the adolescent used an avoiding coping style to a lesser degree, a positive association was found with both psychosocial well-being and metabolic control. The results confirmed our hypothesis that the adolescents who perceive their coping styles to be effective, have a better metabolic control and show less behavior problems and depressive feelings.

The use of specific coping styles was found to be related to internalizing problems, but only a weak, negative, association was found between an accepting coping style and externalizing behavior. Especially when internalizing problems occur in adolescents with type 1 diabetes, pediatric psychological treatment could be focused on their coping styles.

We were interested in the satisfaction of the adolescents with type 1 diabetes regarding their coping abilities with their chronic disease. Therefore we used a disease specific questionnaire to measure coping styles. This does not allow comparisons with more general coping styles of healthy peers. Further studies investigating coping processes in adolescents with type 1 diabetes in comparison to healthy peers may illustrate if a specific treatment to improve coping may be needed for the chronically ill youth.

Coping styles refer to preferred ways of an individual to deal with stress and therefore are not static but they reflect a process. Since this study only collected cross-sectional data, information about the stability of satisfaction with coping ability and the usage of certain coping styles in the adolescents is not available. Longitudinal studies are necessary to allow stronger conclusions regarding screening and treatment of adolescents with type 1 diabetes.

Although a relatively large group of 151 adolescents with type 1 diabetes could be studied, unfortunately many of the eligible patients refused to participate. As most important reason for not participating the adolescents indicated time investment. Although a participation rate of 50% is comparable to other studies (Lawrence et al., 2006; Lin et al., 2004; De Wit, et al., 2007) our study may have been biased in that our results reflect data of relatively well functioning adolescents. The self-selection evolving from voluntary participation may have led to an underestimation of the number of adolescents with psychosocial problems and poor metabolic control in the group with type 1 diabetes. However the mean results on the dimensions of the YSR are not particularly low. Also the mean HbA1c (8.3%) in our sample was comparable with the mean HbA1c (8.4%) of the total group of adolescents with type 1 diabetes who received care from the participating hospitals (participants and non-participants). The information on the coping styles used may also have been biased in the same way, but the mean scores of our sample are similar to the findings of Petersen et al. (2004) who studied a large group of 188 children and adolescents with a chronic disease with this coping questionnaire. Our sample less frequently showed cognitive palliative reactions, and this coping style was not found to be related to depressive symptoms and behavior problems.

To conclude, our findings suggest that the satisfaction of the adolescents with their own success or failure in coping with their disease may be an important principle guiding

counseling and treatment. Information on maladaptive coping styles may be useful to identify adolescents in need for extra support The use of screening measures on coping satisfaction and coping style may aid pediatric psychological treatment procedures. Behavioral interventions such as coping skills training could be indicated specifically for adolescents with internalizing behavior problems and low satisfaction of coping ability, in order to help adolescents achieve metabolic treatment goals, as well as goals for optimal psychosocial well-being.

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CHAPTER 6.

THE INTERRELATIONSHIPS AMONG PATERNAL AND MATERNAL PARENTING STRESS, METABOLIC CONTROL AND DEPRESSIVE SYMPTOMS IN ADOLESCENTS WITH TYPE 1 DIABETES MELLITUS

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ABSTRACT

Objective

To examine the relationship between paternal and maternal parenting stress, metabolic control, and depressive symptoms in adolescents with type 1 diabetes mellitus (T1DM).

Methods

One hundred and fifty-one adolescents with T1DM (mean age 14.9 ± 1.7 years) and a comparison group (CC) (N=122) reported their depressive symptoms and behavior problems. Mothers (T1DM N=126; CC N=106) and fathers (T1DM N=103; CC N=55) each reported parenting stress. Metabolic control was assessed by the glycosylated hemoglobin (HbA1c) values obtained from the medical records.

Results

Fathers of adolescents with T1DM reported significantly more parenting stress than fathers of the comparison group. Parenting stress was associated with depressive symptoms only in adolescents with T1DM. Parenting stress in fathers explained 25% of the variance in depressive symptoms in adolescents with T1DM and 18% of the variance in HbA1c. In mothers, this was 22% and 19%, respectively.

Conclusions

The combination of blood glucose control and depressive symptoms in adolescents with T1DM was found to be associated with both paternal and maternal parenting stress.

INTRODUCTION

Type 1 diabetes (T1DM) is a chronic illness in which both adolescents and parents are responsible for disease management and cope with multiple illness-specific daily tasks. The demanding aspects of this disease make both adolescents and their parents more vulnerable to stress. Higher levels of parenting stress were found to be associated with diabetes (Streisand et al., 2008; Streisand, Swift, Wickmark, Chen, & Holmes, 2005; Wysocki, Huxtable, Linscheid, & Wayne, 1989). Specifically, the level of parenting stress was found to be higher in families dealing with diabetes compared to families affected by severe diseases with less daily treatment demands, such as cystic fibrosis and cancer (Hullmann et al., 2010).

Stress in parents with children with T1DM is multifaceted and related to different aspects of the child's functioning. Higher levels of parenting stress are associated with increased rates of internalizing problems (Lewin et al., 2005) and depressive symptoms (Mullins et al., 2004) in the child. Studies suggest that problems like parental anxiety or depression have a direct or indirect (e.g., through parental involvement) negative impact on both metabolic control and psychosocial adjustment of adolescents with T1DM (Eckshtain, Ellis, Kolmodin, & Naar-King, 2010; Jaser & Grey, 2010). These data suggest that parenting stress is related to both physiological and psychological functioning of adolescents with T1DM. As both deterioration in metabolic control (Bryden, Dunger, Mayou, Peveler, & Neil, 2003) and increased emotional problems (Hesketh, Wake, & Cameron, 2004; Nardi et al., 2008), especially depression (Hood et al., 2006; Lawrence, et al., 2006; Lin et al., 2004; Northam, Matthews, Anderson, Cameron, & Werher, 2005) are observed in many adolescents with T1DM, the association between parenting stress and the physical and emotional functioning of children with TIDM needs to be studied.

For a conceptual framework tying together parenting stress and functioning of adolescents, a transactional perspective is taken. From this perspective, parent and child functioning is seen as influencing each other in a reciprocal way (Cameron, Northam, Ambler, & Daneman, 2007; Chaney et al., 1997). Parents who experience a lot of parenting or diabetes related stress may have difficulties in maintaining an optimal level of control concerning their children's disease management, or more generally, disciplining their children in daily life. Their children may feel that they are being overly controlled by their parents, or on the other hand, overwhelmed with responsibility for their disease management, in response to their parents' feelings and behavior. As a result, adolescents may develop behavior or emotional problems or difficulties in disease management. On the other hand, parents may experience stress in response to their children's behavior and emotional problems, or metabolic functioning. Indeed, increased behavior problems in children with diabetes have been associated with higher levels of parenting stress, especially in mothers (DeVet, & Ireys, 1998; Hilliard et al., 2010; Lewin et al., 2005; Mitchell, et al., 2009; Mullins, et al., 2004). However, the specific processes affecting parents and children in these families have been difficult to disentangle. In healthy adolescents, aggressive and rule-breaking behaviors were related to changes in overreactivity and warmth in the parents and vice versa (De Haan, Prinzie & Deković, 2012). For families in which adolescents with T1DM experience specific problems like depressive symptoms or difficulties with metabolic control, parenting stress may play an important role in the children's physical and emotional functioning.

Although it is well known that fathers play an important role in the emotional and psychological development of their children (Lamb, 2004), their role in general is still underexposed in both research and clinical practice (Dashiff, Morrison, & Rowe, 2008). Differences in parenting

stress among fathers and mothers may exist, as well as different interrelationships with functioning of their children based on the parents' different role within the family. Fathers seem to be less involved and have less responsibility in their child's diabetes management compared to mothers (Dashriff, 2003; Seiffge-Krenke, 2002). In addition, fathers' monitoring efforts are likely to be low compared to mothers (Berg et al., 2008; Waizenhofer, Buchanan, & Jackson-Newsom, 2004). Therefore, fathers may experience less parenting stress regarding child disease characteristics (Mitchell et al., 2009; Streisand et al., 2008). However, more paternal involvement with disease management was associated with less impact of the disease on the family and better family functioning (Gavin, & Wysocki, 2006; Wysocki, & Gavin, 2004). For effective diabetes management, a positive father-child relationship prior to adolescence seems necessary (Berg et al., 2008). These different roles and responsibilities of mothers and fathers in the medical and psychological aspects of disease emphasize the need to study parenting stress of both parents separately (Dashiff et al., 2008; Haugstvedt, Wentzel-Larsen, Rokne, & Graue, 2011; Streisand et al., 2008).

In the present study, we examined if mothers and fathers of adolescents with T1DM experience more stress than fathers and mothers of healthy peers, as the literature suggests that parents of children with T1DM are likely to report more parenting stress than parents of children without a chronic illness (Hauenstein, Marvin, Snyder & Clarke, 1989; Wysocki, Huxtable, Linscheid & Wayne, 1989). Next, we examined whether maternal and paternal parenting stress and diabetes specific stress are associated with emotional problems and metabolic control in adolescents with T1DM. Because the role of mothers and fathers differs in families, we expected to find different associations between parenting stress and emotional and metabolic functioning of the adolescents for mothers and fathers. In addition, we controlled for adolescent age in these analyses, as it has been found that during adolescence the parent-child relationship changes and parental responsibility of diabetes management decreases with increasing adolescent age (Palmer et al., 2011, Palmer et al., 2004). As children age and become more independent in diabetes management, the overlap in experienced stress by parents and adolescents lessens (Beveridge, Berg, Wiebe & Palmer, 2006). It was hypothesized that mothers would experience more parenting stress than fathers, especially concerning diabetes related stress. Because functioning of parents and children is viewed from a transactional perspective, it was also hypothesized that parents would report more parenting stress when the adolescent is at risk for depression. Considering the health risk of poor metabolic control for acute complications (hypoglycemia and hyperglycemia/diabetic ketoacidosis) and for long-term micro vascular and macro vascular complications (e.g., nephropathy, hypertension, cardiovascular diseases) (Silverstein et al., 2005), we hypothesized that parenting stress would be associated with metabolic control. More specifically, we expected that parents of adolescents with poorly controlled diabetes would report more parenting stress, due to daily stress concerning acute health issues (hypo- and hyperglycemia) as well as chronic concerns about long term complications.

METHODS

Participants

Adolescents with T1DM and their parents were recruited from nine hospitals in The Netherlands. Adolescents were eligible to participate if they were between 12 and 18 years of age, were in secondary school, a duration of diabetes of at least six months, and did not have comorbid medical or psychiatric conditions (N=302). In the current study, 151 adolescents with T1DM (65 males and 86 females) and at least one of their parents (126 mothers and

103 fathers) participated. The available data of the non-participating adolescents with T1DM showed no significant differences from the study group in mean age or in HbA1c.

The comparison group was matched for school level, age, and gender to the group of adolescents with T1DM and was recruited from five secondary schools in the same geographic regions where the adolescents with T1DM lived in The Netherlands. The comparison group was comprised of 122 adolescents without T1DM or another medical or psychiatric condition (50 males and 72 females); 106 of their mothers and 55 of their fathers also participated.

Descriptive characteristics of all adolescents included in the study are shown in Table 1. Medical information (most recent glycosylated haemoglobin (HbA1c), duration of the disease, treatment regimen) was recorded from the hospital charts. All adolescents were of Caucasian ethnicity.

Table 1. Group characteristics*

Variable	Comparison group (n=122)	T1DM (n=151)
Age:mean (SD)	14.62 (1.66)	14.89 (1.71)
Range	12-18	12-18
Gender		
male	50 (41%)	65 (43%)
female	72 (59%)	86 (57%)
Family constellation		
Intact family	88%	87%
Single parent	12%	13%
School level		
lower	51 (41.8%)	42 (27.8%)
vocational	12 (9.8%)	19 (12.6%)
higher	27 (22.1%)	46 (30.5%)
pre-university	32 (26.2%)	40 (26.5%)
unknown		4 (2.6%)
Treatment		
Multiple Daily Injections		71 (47%)
Pump		80 (53%)
HbA1c: mean (SD)		8.3 (1.46)
Range		5.1-13.0
Age at diagnose: mean (SD)		9.43 (3.82)
range		0-18
Years T1DM: mean (SD)		5.74 (3.92)
range		0-15
Depressive symptoms, CDI: mean (SD)	7.32 (5.32)	6.59 (5.98)
Range	0-24	0-32
At risk for depression, CDI: N (%)	18 (14.8)	18 (12.4)
Total behavior problems, YSR, mean (SD)	48.11 (9.07)	49.76 (11.15)
Range	26-71	28-95
Internalizing behavior problems, YSR, mean (SD)	47.72 (10.44)	49.36 (11.32)
Range	27-73	27-96
Externalizing behaviour problems, YSR, mean (SD)	48.05 (8.21)	48.39 (10.09)
Range	29-64	29-100

*Group differences are not significant

Measures

Parenting stress

The Parenting Stress Index (PSI) short version (Dutch version: The Nijmeegse Parenting Stress Index Short index; NOSI-K) was used to measure parenting stress (Brock, Vermulst, Gerris, & Abidin, 1992) in both mothers and fathers. The self-report questionnaire consists of 25 items, rated from 1 (strongly disagree) to 6 (strongly agree). A total parenting stress score was computed as the sum of the items, with higher scores indicating more parenting stress. The range of possible scores varies between 25 and 150. Reliability ($\alpha = 0.93$) and validity of the questionnaire have been shown to be good (Brock et al., 1992).

For the parents of adolescents with T1DM, five questions were added to the PSI concerning diabetes related stress: (1) stress related to diabetes specific medical interventions, (2) diabetes related disturbances in normal family life, (3) diabetes related physical and emotional problems in the child that require extra attention, (4) diabetes related restrictions in the social life of the child, and (5) worries about future health of the child. These questions were constructed by the Hvidore Study Group on Childhood Diabetes (Hoey et al., 2006) and were rated from 1 (substantial burden) to 5 (no burden). The diabetes-related parenting stress questionnaire showed good reliability in our sample (mothers' $\alpha = .79$; fathers' $\alpha = .84$).

Adolescent depressive symptoms.

Self-reported depressive symptoms were measured using the Children's Depression Inventory (CDI; Kovacs, 1992). The questions refer to cognitive, affective, and behavioral depressive symptoms for children and adolescents ages 7 to 17. The questionnaire consists of 27 items answered on a 3-point Likert-type scale from 0 (absence of symptom) to 2 (clear symptom). Total scores range from 0 to 54. The overall scale indicates the extent of depressive feelings with a mean (standard deviation) of 7.69 (4.9) for boys and 10.46 (6.5) for girls in the normative groups. Higher scores reflect more depressive feelings. A cut-off score of 13 was used to indicate that the adolescent is at risk for clinical depression (Kovacs, 1992; Timbremont, & Braet, 2002). Psychometric characteristics of the CDI are sufficient (Evers, Vliet-Mulder, & Groot, 2000).

Adolescent behavior problems.

The Youth Self-Report (YSR) measures self-reported behavior problems and competencies of adolescents ages 11 to 18 (Achenbach, & Rescorla, 2001). The questionnaire consists of 113 items answered on a 3-point Likert-type scale from 0 (absence of symptom) to 2 (clear symptom). The overall score indicates the extent of behavior problems. The YSR is divided into two broadband dimensions that reflect internalizing (anxious/depressed and withdrawn/depressed) and externalizing (rule-breaking and aggressive) behaviors. Psychometric characteristics are good for both scales (Evers et al., 2000).

Metabolic control.

Metabolic control was assessed by the glycosylated hemoglobin (HbA1c) values obtained from the medical records. HbA1c is the medical standard for evaluating the level of diabetes control, and reflects average blood glucose levels over the past 2-3 months. Higher HbA1c values represent poorer metabolic control. The level of metabolic control of adolescents with T1DM can be considered optimal (HbA1c < 7.5%), suboptimal (HbA1c 7.5-9.0%), or poor (HbA1c **>** 9.0%) (Rewers et al., 2009). Most recent HbA1c measures, reported one week before or after questionnaire completion, were used. HbA1c was analyzed with similar assays, using gas chromatography, in the different hospitals.

Procedure

The study was approved by the medical ethical committees of the Catharina hospital in Eindhoven and the local committees of all participating hospitals. It is part of a larger study studying the self perception of psychological functioning of adolescents with type 1 diabetes (Maas-van Schaaijk, Odink, Ultee & van Baar, 2011). Adolescents with T1DM and their parents were contacted by telephone to participate. Next, adolescents with T1DM and their parents were both sent a letter in which they were separately informed of the study. After both adolescents and their parents agreed to participate and had completed an informed consent form, an appointment for the adolescents and their parent(s) was made. The adolescents answered the questionnaires when they visited the diabetes team, or in their homes. Their parents were sent questionnaires by mail. Schools were approached for cooperation in the same time period for the comparison group, and adolescents without T1DM or any other chronic illness and their parents were invited to participate. For the comparison group, the questionnaires were sent to the adolescents and their parents at home.

Adolescents who answered the critical item on the CDI concerning suicidal thoughts as positive, or who scored above the clinical range for depression on both YSR and CDI, were approached to verify if they received psychological treatment and to offer it when necessary.

Data Analysis

Potential differences in descriptive group characteristics were analysed using chi-square or t-tests. Group differences in parenting stress were analysed using univariate analyses of variance. Pearson product correlations were used to determine the relationship between parenting stress of mothers and parenting stress of fathers. Pearson product correlations were also used to evaluate the bivariate relationships between parenting stress on one hand and child demographics (age, gender, school level, and marital status), children's disease characteristics (metabolic control, treatment form, illness duration, and age of diagnosis) and psychological and behavioral measures of the adolescents on the other hand. Hierarchical regression analyses were used to evaluate the association of parenting stress (PSI) of the mothers and fathers with physical functioning as reflected in the HbA1c of the adolescents, and the association of parenting stress with depressive symptoms (CDI) of the adolescents with T1DM.

RESULTS

Descriptive characteristics of the adolescents are shown in Table 1. Adolescents varied in age from 12-18 years, with a mean age of approximately 15 years. The group of adolescents with T1DM did not differ from the comparison group on age, gender, and education level, as expected in view of the matching procedure.

Group differences between adolescents with T1DM and the comparison group

Fathers of adolescents with T1DM reported significantly more parenting stress than fathers of the comparison group (T1DM fathers mean=49.64, sd=26.34, 95% CI: 45.16-54.12; comparison fathers mean=40.65, sd=14.87, 95% CI: 34.52-46.79; $F_{(1,158)}$=5.46, p=.021; η^2=.034). Although mothers of adolescents with T1DM reported more parenting stress than mothers of the comparison group, this difference was not significant (T1DM mothers mean=44.87, sd=20.68, 95% CI: 41.39-48.34; comparison mothers mean=40.17, sd=18.69, 95% CI: 36.38-43.96; $F_{(1,232)}$=3.24, p=.073; η^2=.014). Strong correlations were found for general parenting stress between mothers and fathers (T1DM group r=.74; comparison group r=.67).

In terms of number of depressive symptoms on the CDI, the adolescents with T1DM did not

differ from the comparison group (F(1,265)=1.100, p=0.295; η²=.004). The number of adolescents identified as being at risk for a clinical depression was 18 (12.4% of 145 with complete data) in the group with T1DM and 18 in the comparison group (14.8% of 122 with complete data), which did not significantly differ (χ2 (1, 270) =0.197, p = 0.66).

In terms of the number of internalizing (INT), externalizing (EXT), and total (TOT) behavior problems, the adolescents with T1DM also did not differ from the comparison group (F(3,242)=1.095, p=0.352, η²=.013).

Adolescents with T1DM and their mothers and fathers
Strong correlations were found for diabetes specific parenting stress between mothers and fathers (r=.54). Paired sample t-tests showed that fathers and mothers of adolescents with T1DM do not differ in general parenting stress (fathers mean=46.65, sd=22.66; mothers mean=45.04, sd=20.93; 95% CI difference: -1.64-4.84, t(92)=.98, p=.33) or in diabetes specific parenting stress (fathers mean=14.19, sd=3.35; mothers mean=14.37, sd=3.05; 95% CI difference: -.43-.80, t(96)=.60, p=.55).

Adolescent age was not associated with general and diabetes specific stress for either fathers or mothers. In the adolescents with T1DM, metabolic control was significantly associated only with externalizing behavior problems (r=.19) and total behavior problems (r=.20).

Fathers of adolescents with T1DM at risk for depression (n=10) reported significantly more parenting stress (mean=75.20, sd=29.94, 95% CI: 59.49-90.92) compared to fathers of adolescents not at risk for depression (mean=46.63, sd=24.50, 95% CI: 41.42-51.84; F(1,101)=11.73, p=.001; η²=.106). Fathers of adolescents at risk for depression also reported more diabetes related parenting stress (mean=11.30, sd=3.65, 95% CI; 9.16-13.44) compared to fathers of adolescents not at risk for depression (mean=14.32, sd=3.39, 95% CI; 13.61-15.03; F(1,101)=7.04, p=.009; η²=.066).

Mothers of adolescents with T1DM at risk for depression (n= 14) also reported more general parenting stress (mean=60.43, sd=28.28, 95% CI: 50.13-70.73) than mothers of adolescents not at risk for depression (mean=42.57, sd=18.12, 95% CI:38.89-46.27; F(1,123)=10.43, p=.002; η²=.079). In addition, mothers of adolescents with T1DM at risk for depression reported more diabetes related parenting stress (mean=12.46, sd=2.33, 85% CI: 10.75-14.17) compared to mothers of adolescents not at risk (mean=14.54, sd=3.19, 95% CI: 13.95-15.12; F(1,125)=5.16, p=.025; η²=.040).

Fathers and mothers of adolescents with poorly controlled diabetes (HbA1c>9.0; n=36), suboptimally controlled diabetes (7.5-9.0%; n=69), and optimally controlled diabetes (HbA1c<7.5%; n=41) were compared. Mothers of adolescents with poorly controlled diabetes reported significantly more general parenting stress (mean=58.77, sd=29.72, 95%CI: 50.88-66.66) than mothers of adolescents with suboptimally controlled diabetes (mean=40.81, sd=17.43, 95%CI: 35.70-45.92) and mothers of adolescents with optimally controlled diabetes (mean=43,14, sd=16,37, 95% CI: 36.43-49.85; F(4,240)=7.43, p=.001, η²=.109). No significant differences in diabetes related parenting stress were found between the mothers of poorly controlled (mean=13.77, sd=3.42, 95% CI: 12.49-15.05), suboptimally controlled (mean=14.39, sd=3.51, 95% CI: 13.56-15.21), and optimally controlled adolescents (mean=14.50, sd=2.74, 95% CI: 13.42-15.59; F(4,240)=.43, p=.654, η²=.007).

No significant differences were found in general parenting stress for fathers of adolescents with poorly controlled diabetes (mean=58.74, sd=30.49, 95% CI: 47.57-69.91), suboptimally controlled diabetes (mean=48.13, sd=25.72, 95% CI: 41.38-54.89), and optimally controlled diabetes (mean=45.86, sd=16,82, 95%CI: 36.82-54.90; F(4,192)=.175, p=.180, η²=.035). In ad-

dition, no significant differences were found in diabetes related stress of fathers of poorly controlled (mean=13.42, sd=3.27, 95% CI: 11.83-15.02), suboptimally controlled (mean=14.10, sd=3.75, 95% CI: 13.13-15.06), and optimally controlled adolescents (mean=14.52, sd=3.16, 95% CI: 13.23-15.81; $F_{(4,192)}$=.56, p=.571, η^2=.011).

Table 2. Pearson's correlations between parental stress and characteristics of adolescents and their behavioral and emotional problems

	Comparison group		T1DM	
	Fathers (n=55)	Mothers (n=106)	Fathers (n=103)	Mothers (n=126)
Age	-.064	.079	-.040	.063
Gender	-.044	.017	.000	-.021
Treatment form	-	-	-.184	-.092
Years since DM diagnose	-	-	-.153	.099
HbA1c	-	-	.180	.249**
YSR				
Total	.278*	.313**	.331**	.293**
Internalizing	.256	.316**	.314**	.280**
Externalizing	.244	.258*	.331**	.293**
CDI				
Total score	.250	.276**	.500**	.493**

* p< 0.05 level ; ** p< 0.01 level
YSR Youth Self Report
CDI Children's Depression Inventory

85

Parenting stress and physical and emotional functioning of adolescents
Pearson correlation coefficients showed small to moderate associations between parenting stress and behavior problems and depressive symptoms in both groups, and for both parents, see table 2. For diabetes related characteristics only HbA1c was found to correlate significantly with maternal parenting stress.
Separate hierarchical multiple regression models were generated to examine the association between parenting stress in mothers and fathers of adolescents with T1DM and their HbA1c. Both models were conducted in steps, controlling for lower-order demographic and disease related characteristics in Step 1 (i.e. age, gender, age at diagnosis, years DM and treatment form), psychological and behavioral characteristics in Step 2 and including maternal or paternal

parenting stress in Step 3. Only independent variables with significant (p ⊼ .05) associations with the dependent variable were used. Results are presented in table 3A. For the association between Hba1c and paternal stress, the first Step, controlling for demographic and disease related variables was significant, R^2=.15, $F_{(4,95)}$=4.06, p=.00. The change in Step 2, where the total score of behavior problems (YSR) was added to the model, was also significant, R^2=.18, $F_{(5,95)}$=3.84, p=.00. Finally, paternal parenting stress was added, with the full adjusted model explaining 18% of the variance in HbA1c (R^2=.23, $F_{(6,95)}$=4.51, p=.00). The relationship of maternal parenting stress and HbA1c also remained after controlling for the variables entered in Step 1 (R^2 =.15, $F_{(4,118)}$=5.08, p=.00), and Step 2 (R^2=.18, $F_{(5,118)}$=4.82, p=.00), with the full adjusted model explaining 19% of the variance in HbA1c (R^2 =.22, $F_{(6,118)}$=5.53, p=.00).

In the same way separate hierarchical multiple regression models were generated to examine the association between parental parenting stress and depressive symptoms in adolescents with T1DM. Both models were analysed in two steps, controlling for lower-order demographic and disease related characteristics in Step 1 (i.e. age, gender, HbA1c, age at diagnosis, years DM and treatment form), and maternal or paternal parenting stress in Step 2, see table 3B. Only independent variables with significant (p ⊼ .05) associations with the dependent variable were used. For the association between depressive symptoms in the adolescent and paternal stress, the first step controlling for demographic and disease related characteristics was not significant, Step 1 R^2=.04, $F_{(6,86)}$=.54, p=.78). When paternal parenting stress was added to the model in Step 2, a significant change was found, R^2=.29, $F_{(1,85)}$=29.54, p=.00: paternal parenting stress explained 24.8% of the variance in depressive symptoms as experienced by the adolescents. Maternal parenting stress was also significantly related to depressive symptoms in the adolescent after controlling for the variables entered in Step 1 (R^2=.04, $F_{(6,109)}$=.69, p=.66, not significant), with the full adjusted model explaining 21.6% of the variance in depressive symptoms in the adolescents (R^2=.25, $F_{(1,108)}$=31.24, p=.00).

Table 3. Parenting stress and glycaemic control regression analysis

	FATHERS				MOTHERS			
Variables	b	t	p	R^2 change	b	t	p	R^2 change
Step 1				.15*				.15*
age	.06	.64	.52		.05	.58	.57	
gender	.20	2.17	.03		.20	2.35	.20	
years DM	.28	2.89	.01		.22	2.59	.01	
treatment	.23	2.42	.02		.21	2.48	.02	
Step 2				.03				.03
YSR tot	.05	.48	.63		.08	.90	.37	
Step 3				.06*				.05*
PSI	.27	2.58	.01		.24	2.76	.01	

* $p<.05$

Table 4. Parenting stress and depressive symptoms regression analysis

	FATHERS				MOTHERS			
Variables	B	t	p	R^2 change	b	t	p	R^2 change
Step 1				.04				.04
age	-.01	-.06	.96		-.08	-.58	.57	
gender	-.04	-.38	.70		-.03	-.33	.74	
HbA1c	-.03	-.32	.75		-.01	-.09	.93	
years DM	.25	.89	.38		.21	.80	.42	
age at diagnoses	.13	.44	.66		.22	.83	.41	
treatment	.10	1.05	.30		.05	.59	.56	
Step 2				.25*				.22*
PSI	.54	5.44	.00		.49	5.59	.00	

* $p<.05$

DISCUSSION

Fathers of adolescents with T1DM showed more parenting stress than fathers of adolescents without a chronic disease, which supports our hypothesis. Although depressive symptoms in adolescents with T1DM were not clinically elevated in our study, the relation between depressive symptoms and parenting stress was different for parents of adolescents with and without T1DM. While parents of adolescents with T1DM reported significantly more parenting stress when the adolescent experienced more depressive symptoms, no such relationship was found between parenting stress and depressive symptoms in the comparison group. In parents of the comparison group, parenting stress was related to aggressive behavior of the adolescents.

In the adolescents with T1DM, general parenting stress demonstrated a stronger relationship with depressive symptoms than diabetes related parenting stress. Parents of adolescents with

T1DM who were seriously at risk for depression reported significantly more general parenting stress with large effect sizes, and significantly more diabetes related parenting stress with moderate effect sizes, compared to parents of adolescents with T1DM who were not at risk for depression. Examination of the association between parenting stress and disease control in diabetes showed the greatest parental stress, with a large variation, in the parents of the poorly controlled group. Mothers of poorly controlled adolescents experienced significantly more general, but not diabetes specific, parenting stress. However, these mothers may also experience stress because they feel the need to improve disease management and to monitor their children more closely to do so, which was not addressed in our measurement of diabetes specific stress. Future studies might use improved measures of diabetes related parental stress to understand better these specific concerns related to disease management.

An especially important finding was that parenting stress in fathers and mothers of adolescents with T1DM was related to adolescent emotional functioning and to a lesser degree to physical functioning. Specifically, 25% of the variance in self-reported depressive symptoms was explained by general parenting stress of their fathers; 22% of the variance was explained by maternal parenting stress. Parenting stress was also related to physical functioning in the adolescents with T1DM, especially in fathers. Parenting stress in fathers explained 18% of the variance in HbA1c and parenting stress in the mothers accounted for 19% of the variance in HbA1c. Another important finding of this study was that parents, particularly fathers, of adolescents with T1DM were worried when their child was experiencing depressive feelings, and to a lesser degree when the metabolic control of the adolescent was worrisome. Parental worries mostly concerned general parenting issues and not diabetes related parenting issues, which may be associated with the transition in responsibility in this developmental phase. Because parents become less responsible for disease management during adolescence, they often are not faced with direct disease outcomes like the actual blood glucose level. However, when interacting with their child, they may frequently be confronted with the child's negative mood. This suggests that every day stressors play a bigger role for parents than the possibility of future problems, such as the physical complications that may result from diabetes. Even if these daily stressors of the adolescents' functioning and behavior could reflect physical problems, it appears that parents focus on the behavioral consequences and not on possible physical functioning.

This study indicates that the combination of diabetes and depressive symptoms in adolescents is associated with parenting stress. Surprisingly, this finding was independent of the age and gender of the adolescents. These findings are important for family assessment and treatment as detailed information about parenting stress for both fathers and mothers can identify risk factors for the psychological wellbeing of the adolescent. Paternal stress may influence family functioning by affecting mother and child adjustment. In addition, child behavior may be more related to paternal parenting stress than maternal parenting stress (McBride, Schoppe, & Rane, 2002). Most of the time however, healthcare professionals tend to focus on mothers of children with T1DM because mothers seem to take more responsibility in diabetes management tasks than fathers (Mitchell et al., 2009). Since paternal parenting stress was associated with psychological functioning of the adolescents, the results of this study emphasize the necessity to involve fathers in the treatment of adolescents with diabetes, and to determine ways to keep fathers engaged in clinical practice. The involvement of fathers in parenting their adolescents with T1DM was also reflected by the large number of fathers that participated in this study. It is possible that paternal involvement in the treatment can be improved by explicitly inviting fathers

to treatment appointments and by being flexible in scheduling appointments (e.g., in the evening).

The association between fathers' emotional functioning and the behavior and psychological wellbeing of their children needs further attention in research, especially during adolescence. Further, our results indicate that discussing the adolescents' psychological health with both parents instead of focusing on the physical health of their child is important for psychological wellbeing of both the adolescent and his parents.

In our study, the adolescents with T1DM did not differ in reported depressive symptoms and behavior problems from the comparison group. This finding is in contrast with studies reporting higher rates of depression in adolescents with T1DM (Hassan, Loar, Anderson, & Heptulla, 2006; Hood et al., 2008; Lawrence et al., 2006). In a recent meta-analysis, Reynolds and Helgeson (2011) found that children with diabetes experienced somewhat elevated levels of depression, anxiety, and psychological distress. However, the differences between children with diabetes and comparison groups were smaller in more recent studies, possibly due to substantial technological changes in diabetes management and new clinical standards over the past 15 years. Another study among Dutch adolescents with T1DM did not reveal an elevated level of the prevalence of depression (de Wit et al., 2007).

While the current study has clarified several facets of the relation between parenting stress in both parents and depressive symptoms in adolescents with T1DM, several limitations must be considered. A technical point is that different HbA1c values were determined in the labs of all participating hospitals, instead of one lab only. Although a similar method was used to determine HbA1c values across participants, small differences cannot be excluded. In The Netherlands, however, these assays are considered to result in comparable values. Another limitation is that although we studied a relatively large group of adolescents with T1DM and their mothers and fathers, many eligible patients refused to participate. However, a participation rate of 50% is comparable to other studies (Frøisland et al., 2012; Lawrence et al., 2006; Lin et al., 2004). Nevertheless, our study may have been biased in that our results reflect data of relatively well-functioning adolescents and parents. Although we had no reason to believe that a specific subgroup participated in this study, we could not examine this possibility in detail. Furthermore, parental psychopathology, such as anxiety and depression, was not assessed, even though several studies have shown that parental psychological functioning may be associated with parenting stress (Lewin et al., 2005; Mullins et al., 2004) and physical and emotional functioning of adolescents (Eckshtain, Ellis, Kolmodin, & Naar-King, 2010; Wiebe, et al., 2011). Another limitation is that all families were Caucasian, which represents the majority of the Dutch population; yet, these results cannot be generalized to families with another background. Finally, longitudinal studies, which follow paternal and maternal parenting stress in relation to emotional and physical functioning of adolescents with T1DM across time, are necessary to evaluate causal relationships.

In conclusion, our findings show that parenting stress of both mothers and fathers is related to depressive symptoms, as well as to metabolic control in adolescents with T1DM. Treatment guidelines for adolescents with T1DM and future longitudinal studies should address both their mothers' and fathers' parenting stress.

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CHAPTER 7.

PSYCHOLOGICAL INTERVENTION PROGRAMS FOR ADOLESCENTS WITH TYPE 1 DIABETES MELLITUS

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ABSTRACT

Objective

To evaluate strengths and weaknesses of recent psychological intervention programs for adolescents with type 1 diabetes mellitus (T1DM), specifically in relation to depressive symptoms and metabolic control.

Methods

A review of recent studies was done, evaluating psychological intervention programs performed by health care professionals, aimed at improving health and psychological wellbeing, especially depressive symptoms, of adolescents with T1DM.

Results

The 19 studies identified were heterogeneous regarding intervention, participants, settings, and reported outcomes. The intervention programs were multifaceted, focusing on general (cognitive) behavior treatment, coping skills improvement, stress management, motivation, family involvement, or peer involvement. Results varied for psychological wellbeing and metabolic control depending on the specific focus. Most psychological intervention programs only had a small (positive or negative) effect on metabolic control (HbA1c). The only large effect size of improvement of HbA1c was found after a cognitive behavioral coping intervention. Three studies reported on depressive symptoms. A decline in depressive symptoms in the treated adolescents after the intervention period, was found in two studies: one used a cognitive behavioral method focused on improving coping skills which showed a large effect size and one focused on motivation which had a medium effect size.

Conclusions

Improving the use of effective coping skills, may aid in healthy long-term adaptation to type 1 diabetes mellitus. Improvements in design of intervention programs and in evaluation studies are necessary.

INTRODUCTION

Type 1 diabetes mellitus (T1DM) is a psychologically and behaviorally demanding chronic illness. The strict diabetes regime interferes in daily life in every developmental phase, but particularly during adolescence, a period of many developmental changes. These changes involve hormonal, physical, psychological and social areas, all specifically affected in adolescents with T1DM. Adolescents with diabetes tend to ignore their vulnerability for the potential consequences of their disease in their age-appropriate preoccupation with the present. One of the difficulties for treatment compliance is their desire for more independence (Hanna & Guthrie, 2000). Research consistently demonstrated that adolescence is associated with poor metabolic control (Allen et al., 1992; Mortensen et al., 1998; Bryden et al., 2001). Many behavioral (knowledge, skills, adherence), psychological (stress, coping) and medical (complications) factors contribute to metabolic control (Wysocki, Greco & Buckloh, 2005). Further, T1DM is a risk factor for developing psychiatric disorders in adolescents (Blanz, Rensch-Riemann, Fritz-Sigmund, & Schmidt, 1993; Kovacs, Goldston, Obrosky & Bonar, 1997a), especially depression (Kovacs, Obrosky, Goldston & Drash, 1997b). Several studies found that T1DM and depression frequently co-occur in adolescents (Lawrence et al., 2006; Lin et al., 2005; Hood et al., 2006). Adherence, anxiety for complications, child-parent conflicts, a low self-esteem and changing body perception are risk factors for developing depression (Kanner, Hamrin & Grey, 2003).

Current treatment programs tend to minimize the potential harmful effects of the disease and maximize psychological wellbeing for the adolescent. Several papers elucidated to what extent different psychological treatment or intervention programs succeed in this aim. Hampson (2001) reviewed the effectiveness of educational and psychosocial interventions for adolescents with type 1 diabetes until 1999. Educational and psychosocial intervention programs were found to have small to medium beneficial effects on various diabetes management outcomes and programs could be more effective when the inter-relatedness of the various aspects of diabetes management are demonstrated. Northam, Todd and Cameron (2006) concluded in their review of studies published until 2003, that most used a diabetes-specific, unstandardized intervention and none targeted a specific psychological disorder. Many studies were found to show methodological limitations. In order to improve health outcomes Savage, Farrell, McManus & Grey (2010) emphasized the need to take into account the scientific development of the interventions and not only report data about efficacy but also about the effectiveness of the interventions. The development of effective treatment programs may have to focus upon the most frequent reported problems in adolescents with T1DM, namely the decline in metabolic control and the increase of depressive symptoms. To find the best intervention program, or the most promising ingredients for designing a focused intervention program the following questions are addressed:

Which psychological intervention programs are being used for adolescents with type 1 diabetes?

What types of intervention have shown to be effective for psychological wellbeing, especially reducing depressive symptoms and internalizing behavior problems and in improving metabolic control (HbA1c)?

METHODS

Studies using different psychological treatment programs for adolescents with type 1 diabetes were searched. The core terms of the search strategy were type 1 diabetes and adolescents, then narrowed down to those studies that reported on psychological interventions. The search strategy was combined with key words regarding "diabetes", "adolescent" or "youth", "psychological" or "psychosocial", and "intervention". Medline, Picarta, ERIC, Web of Science and PsycINFO were searched for original articles published between 1999 and December 2011. Additionally, the reference lists of all relevant studies were studied. Studies were selected as being potentially relevant based on the titles and abstracts. Potentially relevant cited studies were retrieved in full text and checked concerning the inclusion criteria:

1. primary topic concerns type 1 diabetes
2. participants are non-hospitalized adolescents (12-19 years)
3. a description of a psychological or psychosocial intervention aimed at behavioral change, is presented.
4. the paper is written in English

Studies concerning intervention based on education, telecare or intensive treatment alone, were not included. For the studies that met the criteria for a Randomized Control Trial (RCT) Effect Sizes (and pearson's correlations) were calculated for metabolic control (HbA1c), depression and depression, when data were available. Individual-study effect size estimates were analyzed with SPSS 16 macros from Lipsey and Wilson (2001). A majority of the Randomized Control Trials provided the means and standard deviations needed to compute the ESs. When studies did not provide this information, t-values, F-values, and p-values were used to calculate d.

RESULTS

Twenty-six papers reporting on psychological or psychosocial intervention programs for adolescents were identified. Seventeen studies were excluded following review of abstracts. Reasons for exclusion were: a focus on type 2 diabetes or obesity (n=9), based on telephone interviews concerning health (n=3), a focus on education (n=4), not published in English (n=1) and only reporting a description of a research protocol or intervention without results (n=3). Nineteen studies met the inclusion criteria and reported results for different outcome measures, see figure 1. Different theories, but primarily cognitive behavioral principles were found to underlie these studies. All treatment programs intended to improve the quality of care through minimizing the potential harmful effects of the disease and trying to achieve a good quality of life (QoL). In addition the intervention programs intended to increase treatment adherence and improve adjustment to diabetes or to diabetic control.

Figure 1. Number of identified psychological intervention studies for adolescents with type 1 diabetes
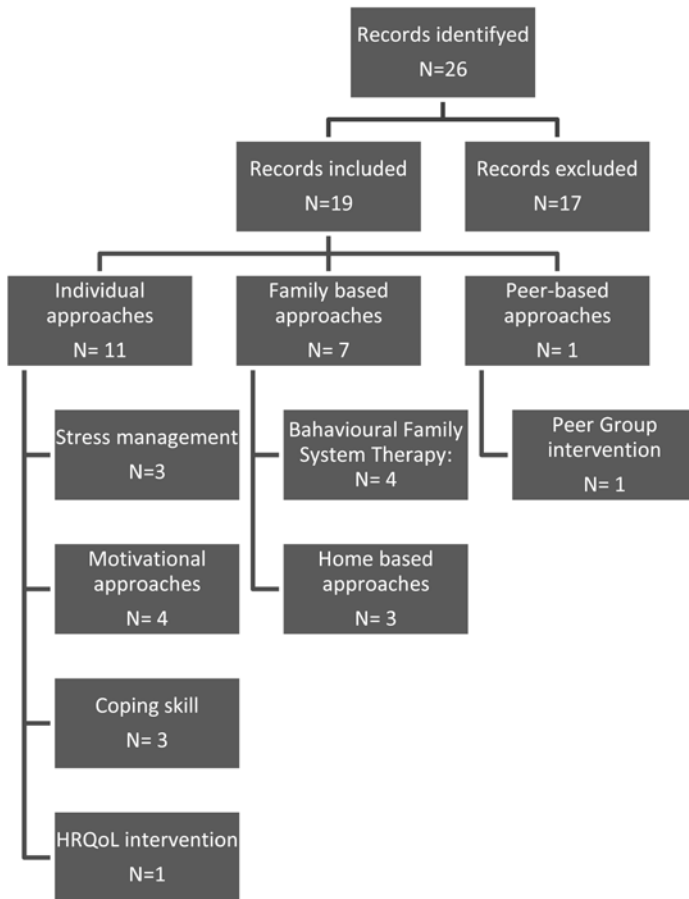
Different types of intervention programs could be distinguished, concerning individual treatment (directed at stress management, improvement of motivation or coping skills or health related QoL) or family treatment, or peer based approaches. Summary data of each study, categorized by intervention type, are presented in table 1. Study no's 1, 2, 3, 7, 13 and 18 had very small sample sizes that often precluded the finding of statistically significant effects. Descriptions of these studies are included as these provide important descriptive and qualitative information. The studies are presented according to type of intervention.

Table 1. Psychological intervention studies for adolescents with T1DM

REFERENCE	INTERVENTION	NUMBER OF PATIENTS A) EXP. GROUP B) CONTROL	MEAN ADOLES-CENT AGE	NUMBER OF SES-SIONS	FOLLOW-UP (MONTHS)	RESULTS MEDICAL		RESULTS PSYCHOLOGICAL	
Individual treatment						MEASURES	OUTCOME	MEASURES	OUTCOME
Hains (2000)	Cognitive behavioral intervention; stress management	a)8 b)6		6		HbA1c	none	DSQ KIDCOPE STAI	Improved state-anxiety, diabetes-related stress, and negative coping over time, but no group differences
Hains (2001)	Cognitive behavioral intervention; stress management	a)6 b)-		8	3	HbA1c	none	RCMAS STAXI DSQ	4 of the 6 patients showed some improvement on anxiety, anger expression and diabetes stress; 8 dropouts
Silverman (2003)	Cognitive behavioral intervention; stress management	a) 6 b) -		6	3	HBa1C Adherence interview meter	CBI had impact on at least one self-care behavior	DSQ	2 of 6 patients showed decreased diabetes related stress
Viner (2003)	Cognitive behavioral intervention ; motivation	a) 21 b) 20		6	4-6	HbA1c	Improvement of HbA1c (1.5%)*	SDQ SED Socrates stages of chabge question-naire	No improvements in psychological distress, but self efficacy improved
Channon (2003)	Cognitive behavioral intervention ; motivation	a)22	15.8	Variable		HbA1c	Improvement in HbA1c (1.1%)*	Wellbeing Questionnaire DKS-A SDSA PMDQ FACES DFBS	Reduction in fear of hypoglycaemia; Wellbeing, diabetes self-care, family behaviors, family process and diabetes knowledge did not change
Channon (2007)	Cognitive behavioral intervention ; motivation	a)38 b)28	a) 15.3±0.97 b) 15.4±1.19	Variable	24	HbA1c	a)Improvement in HbA1c (0.6%)* b) HbA1c + 0.1 ns	DQoLY CHCL HCCQ DKN SEDS WBQ DFBS PMDQ	Improved quality of life and wellbeing improvements in positive well-being and quality of life. Not all main-tained after 24 months
Knight (2003)	Cognitive behavioral intervention ; motivation	a)6 b)14		6	6	HbA1c	No improvements		Changed perception of diabetes; less threatened and more feelings of control and acceptance
Grey (2000)	cognitive-behavioral intervention; coping	a) 42 b) 35	14.2±1.9	6	12	HbA1c	Improvement of metabolic control and HbA1c (1.2%)*	SEDS CDI Issues in Coping with IDDM DQoL-Y DLS scale DIS Disease related worries scale	Improvement of QoL; rate of severe hypoglycaemic events remained unac-ceptably high and Hba1c levels remained above the normal range
Grey (2004)	cognitive-behavioral intervention; coping	a) 42 b) 35		6	12	HbA1c	Improved metabolic control and HbA1c*	SEDS CDI Issues in coping with IDDM DQoL-Y	Improved QoL
Whittemore (2010)	Internet cop-ing TEENCOPE	a)12 b)-	14.4±.90	5	3-6	HbA1c	Ns?	PedsQL PSS Coping with IDDM-child scale SDS CDI	Better self efficacy
De Wit (2008, 2010)	HRQoL-intervention	a) 41 b) 40	A) 14.8±1.1 b) 14.9±1.0	4	12	HbA1c	a) HbA1c start 8.6±1.4, eind 8.4±1.6 b) HbA1c start 8.8±1.3, eind 8.3±1.3 no sign differ-ence between the groups in decline in A1c levels (p=.54)	CHQ-CH87 CES-D DFCS	Better psychosocial health (CHQ-CH87): p=.002 Ado with HbA1c>9.5% no decrease After 12 mth decline ns ns

							groups in decline in A1c levels (p=.54)	CES-D DFCS	ns ns
Family based intervention									
Wysocki (2000)	Behavioral Family Systems Therapy	a) 38 BFST, 40 ES b) 41		10	3-6-12	HbA1c	No effects on treatment adherence Effects on diabetes outcomes depended on age and gender	TADS DRC PARQ IC IDDM treatment adherence SCI	Improvement in parent-adolescent relations and reduced diabetes-specific conflicts
Wysocki(2001)	Behavioral Family Systems Therapy	a) 28 BFST-D, 35 ES b) 29		12	6-12 (not done yet)		BFST and ES improved HbA1c (0.8%) compared to SC among those with HbA1c.>9.0%		BFST improved family conflict and adherence compared to SC and ES, especially among those with HbA1c>9.0%
Wysocki (2007)	Behavioral Family Systems Therapy	Follow up of a) 28 BFST-D, 35 ES b) 29			6, 9, 12, 15, and 18 months	HbA1c	Lower mean HbA1c of the BFST-D than the SC group and lower than the ES group Improvement in HbA1c mediated by improvement in treatment adherence.	PARQ DRC DSMP	The diabetes-related conflicts were not less in the BFST group after 6 months.
Harris (2005)	In–home Behavioral Family Systems Therapy	a) 18 b)-		10	6	HbA1c	No improvements	SCI DMQ DRC AIS DFB CBCL CBQ	No improvements
Ellis (2004, 2005)	Multisystemic therapy Home based interbention programm	a)13 b)12	13.6±1.6	Min 6 months 2/3 times a week		HbA1c Meter INSADH EATADH BGTS ER visites	Improve HbA1c 3.56% (p<.05)	DMS-A DMS-P	ns
Ellis (2007)	Multisystemic therapy	a) 64 b) 63		48	7	HbA1c Meter 24 hour recall interview	Improved HbA1c (0.8%) and frequency of blood glucose testing(p=.001)	DSQ	Diabetes-related stress was reduced.
Laffel (2003)	Family focused intervention	a) 50 b) 50	a)13.6±2.8 b)12.1±2.3	4	12	HbA1c	Glycemic control better and HbA1c lower (0.2%)	Interview PedsQL DFCS DFRQ	No decrease in diabetes-related family conflict or decrease of QoL
Peer group based approach									
Greco (2001)	Peer group intervention	a) 21	13.1±1.98	4	-	HbA1c SCI	No change in adherence	DESAT DSSI TADS DRC SPP PIR	Higher levels of knowledge, higher ratio of peer to family support. Parents reported decreased diabetes-related conflict

* significantly

Individual treatment approaches

Stress management

Hains, Davies, Parton, Totka & Amoroso-Camarata (2000) examined the effectiveness of a stress management training program in helping adolescents with diabetes to cope with stress. The experimental group and the control group (the waiting-list group) ranged in age from 12 to 15 years. The intervention involved a six weekly session training program using both cognitive-restructuring and problem-solving strategies. The program followed a

101

3-phase, cognitive-behavioral stress inoculation training: (1) the conceptualization phase, (2) the skill acquisition and rehearsal phase, (3) the application phase. No significant differences were found between the experimental and control group at post-test and follow-up. However a within-group analysis showed that the experimental group significantly improved on state-anxiety, diabetes-related stress and negative coping, compared to no improvements for the control group. The impact of this cognitive behavioral intervention was again studied with 14 adolescents (Hains, Davies, Parton & Silverman, 2001). Six adolescents, age range 12-18, participated in the whole program, but eight dropped-out before or during the intervention. The youth who did not complete the program had higher levels of HbA1c. Eight individual training-sessions in cognitive restructuring and problem solving were done, showing different responses: four of the six youngsters showed some improvement in that they showed less anxiety, anger expression and diabetes stress. These gains were maintained at follow-up. The study described above was repeated (Silverman, Hains, Davies & Parton, 2003). Six adolescents received the training in individual sessions, and self-care behavior in combination with diabetes-specific stress was studied. For two adolescents glucose checking was improved, but only one used the recommended rate of four daily checks. Overall the intervention had a beneficial impact on at least one self-care behavior for five adolescents and it reduced the diabetes-related stress in two adolescents. For part of the adolescents the stress management training program also had a positive effect on at least one aspect of psychological wellbeing. The training did not improve metabolic control. For the teenagers most at risk for complications the training was less effective.

Motivational approaches

A motivational and solution-focused therapy group intervention was done to improve metabolic control in 21 young people of 11-17 years with poorly controlled type 1 diabetes (mean annual HbA1c >8.5%) (Viner, Christie, Taylor & Hey, 2003). The aim of this therapy was to increase motivation to engage in treatment, combined with solution-focused therapy (SFT). The therapy consisted of six weekly group sessions. A group for parents was run before the beginning of therapy to facilitate parental support of change. The program produced a significant reduction of 1.5% in HbA1c in the intervention group at 4-6 months post therapy compared to no change in controls. The improvement was partly maintained at 7-12 months post intervention, but the difference between the intervention group and controls then was not significant any more. Overall psychological distress was unchanged by this intervention program, however, although self-efficacy improved significantly in the cases.

A motivational interview, that is a counseling approach to induce behavior change, was studied in a pilot (Channon, Smith & Gregory, 2003). Twenty-two adolescents aged 14-18 years participated in motivational interviewing sessions over a period of six months. The adolescents were responsible for deciding on the location and frequency of the appointments, as well as the presence of others, such as parents or peers. The sessions included: awareness building, alternatives, problem solving, making choices, goal-setting and avoidance of confrontation. A significant reduction of 1.1% in HbA1c was found during and after the intervention period. Also a significant reduction in fear of hypoglycemia and in the scores for the 'living with diabetes' scale was found, indicating that diabetes was easier to live with after participating in motivational interviewing sessions. Wellbeing, diabetes self-care, family behaviors, family process and diabetes knowledge did not change. After this pilot a multicenter trial with the same intervention was done (Channon et al., 2007). The intervention group consisted of 38 and the control group of 28 adolescents with diabetes type 1. The group who participated in motivational interviewing had a significantly lower HbA1c (by 0.6%) after intervention (with a

mean of 9.0% vs. 9.5% for controls) and this was maintained after 24 months. The intervention group also showed improvements in positive well-being and quality of life. Not all of these positive psychological changes were maintained after 24 months.

Another intervention based on motivational interviewing consisted of six weekly sessions using motivational interviewing techniques and externalizing conversations (Knight et al., 2003). After the intervention, the perception of diabetes of the adolescents was changed (N=6). They felt less threatened and had more feelings of control and acceptance. After 6 months the differences between the two groups were maintained with the control group being far more negative than the treatment group. The paper reports qualitative research, no quantitative results are presented. A motivational-focused intervention seems to improve metabolic control, but for long-term changes an extended treatment period may be necessary.

Coping skills improvement

Coping skills training forms a specific cognitive-behavioral intervention that focuses on improving competence and mastery by retraining inappropriate or non-constructive coping styles like self-blaming and patterns of self-destructing behavior into more constructive behavior, like appropriate self-care activities. Children, adolescents, and parents caring for children with type 1 diabetes demonstrated improved metabolic and psychosocial outcomes after coping skills training (Grey & Berry, 2004). The results of a study by Grey (1998) showed that adolescents who received Cognitive Skill Training (CST) had lower HbA1c than controls (7.9% ±1.0% vs. 8.4% ±1.1%) and better diabetes self-efficacy, and they were less upset about coping with diabetes than adolescents receiving intensive management alone. In addition, adolescents who received the CST found it easier to cope with diabetes and experienced less negative impact of diabetes on quality of life than those who did not receive CST. A study to determine whether the initial effects could be sustained over one year in youth by implementing intensive therapy regimens was done (Grey, Boland, Davidson, Li & Tamborlane, 2000). The adolescents in this study (N=77) were randomly assigned to one of two groups: with or without coping skills training (CST). The CST was provided in a context of intensified diabetes treatment by a diabetes team. The coping skills training occurred in six weekly group sessions, followed by monthly visits over the next 12 months. The adolescents learned to cope with their lives in the context of diabetes management; skills including social problem solving, cognitive behavior modification, and conflict resolution. HbA1c at baseline was 9.1% in de CST group and 9.2 in the control group. After 12 months HbA1c was 7.9% for the CST group versus 8.5% for the control group. Differences in HbA1c levels were statistically significant over time and between groups. The adolescents in the CST group had better metabolic control and better general self-efficacy. They reported less negative impact of diabetes on their quality of life and had fewer worries about diabetes. Coping Skills Training seemed to teach adolescents how to initiate and maintain intensive treatment of diabetes, which resulted in improved metabolic control and psychological wellbeing. Teaching the adolescents to negotiate with family members and the diabetes team over treatment responsibilities proved especially helpful. However, although HbA1c levels were significantly lower after 12 months, the rate of severe hypoglycemic events remained unacceptably high and Hba1c levels remained above the normal range. Particular attention to adolescents with poor metabolic control is essential when treatment is intensified, because these adolescents are less likely to reach treatment goals (Grey, Davidson, Boland & Tamborlane, 2001).

Increasingly important for youth these days is internet. Internet is a promising way, given its availability and attractive features, to reach adolescents with T1DM. Whittemore, Grey, Lindemann, Ambrosino & Jaser (2010) developed an internet CST named TEENCOPE. In this

study the internet intervention, TEENCOPE, was compared with an internet education program, Managing Diabetes. TEENCOPE consisted of five weekly sessions on self-talk, communication skills, social problem skills, stress management and conflict. Managing Diabetes consisted of four weekly sessions on glucose control, nutrition, exercise and sick days, and new technology. The 6 TEENCOPE participants demonstrated trends for better diabetes self-efficacy, better coping, better general T1DM treatment QoL and less perceived stress compared with the 6 participants in the education group. TEENCOPE participants engaged in the internet program more than education participants did, with twice as many log-ins over the duration of the program. Primary efficacy findings are promising and show the potential of TEENCOPE to improve health outcomes in adolescents with T1DM

Health related quality of life intervention
Monitoring and discussing health related quality of life (HRQoL) in adolescents was evaluated in an RCT (De Wit et al., 2008). Adolescents in the age range of 13-17 years (N=91) were randomly assigned to the HRQoL intervention group (N=46) and the control group (N=45). During a 12 month study period all adolescents (both HRQoL intervention group and control group) had three regular appointments at a three-month interval. The HRQoL intervention consisted of two parts: 1) monitoring HRQoL right before the the 3-month appointment with the paediatrician and 2) discussing of the HRQoL scores with the teenager during the appointment. The adolescents in the control group received care as usual. After the intervention period mean HbA1c was 8.4 ± 1.6% for the HRQoL group and 8.3 ± 1.3% for the control group, with no significant differences between the groups in decline of HbA1c levels over time. Scores of psychosocial health revealed however that the intervention group showed a significant improvement, mainly due to improvements in behavior problems and self-esteem. Also an increased participation in family activities was seen in this group. Psychosocial health remained the same in the control group. However, adolescents with poor metabolic control (HbA1c>9.5%) did not show improvements of psychosocial functioning over time. These data suggest that a relatively simple intervention, namely discussing HRQoL during regular appointments, has a positive effect on psychological functioning in adolescents with relatively good to moderate metabolic control. No effect was seen in metabolic control and in adolescents with poorly regulated diabetes.

Family-based treatment approaches
The effect of Behavioral Family Systems Therapy (BFST) was compared with an Educational and Support group (ES) and current therapy (CT) (Wysocki et al., 2000). 119 families participated and the age-range of the adolescents was 12-17 years. The CT group continued in standard therapy for type 1 diabetes. The ES group attended 10 group meetings emphasizing diabetes education and social support. The experimental group received 10 sessions of BFST. BFST consisted of four therapy components: (1) problem-solving training; (2) communication skill training; (3) cognitive restructuring; and (4) functional and structural family therapy. BFST yielded improvement in parent-adolescent relations (on extreme believes). The frequency of conflicts was not changed, but for the BFST group, the conflict intensity was reduced. The BFST group showed a significant reduction of diabetes-specific conflicts compared to ES and CT. No effects on treatment adherence were found. Psychological adjustment to diabetes and diabetic control depended on the adolescent's age and gender, indicating that boys and younger girls derived benefits of BFST. Evaluations after 6 and 12 months showed that BFST yielded lasting improvement in parent-adolescent relationships and a delayed improvement in treatment adherence (Wysocki et al., 2001).

Next a revised intervention program, BFST for diabetes (BFST-D) was evaluated (Wysocki et al., 2006). The SC group continued standard care for diabetes; the ES families attended 12 multifamily meetings within 6 months for diabetes education and social support. Session content followed an American Diabetes Association curriculum for teens (Johnson, 2000). The BFST-D consisted of the same components as BFST, but also included diabetes-specific adaptations, using SMBG data to modify insulin. The BFST-D group improved on diabetes related conflict only for the adolescents with the poorest diabetic control at baseline. BFST-D yielded greater improvement in treatment adherence. Among those with poor metabolic control (HbA1c>9.0%) improvement of Hba1c (by 0.8%) was significant for both BFST-D and ES. A follow-up study (Wysocky et al., 2007) showed that the mean HbA1c of the BFST-D group was significantly lower than the SC group at 6, 9, 12, 15, and 18 months and significantly lower than the ES group at months 9, 15, and 18. Improvement in HbA1c appeared to be mediated by improvements in treatment adherence. The diabetes-related conflicts were not less in the BFST group after 6 months.

Home based approaches

The effectiveness of in-home BFST for adolescents with poorly controlled diabetes and a history of missed clinic appointments was also examined (Harris, Harris & Mertlich, 2005). In-home BFST performs intervention sessions in the context in which the behavior occurs. The families (N=18) received ten sessions of in-home BFST over a periods of approximately 5-6 weeks. The therapy components were the same as for regular BFST. Although the initial follow-up indicated decreases in general family conflict, diabetes-related family conflict and behavior problems, the 6-month follow-up demonstrated that the improvements were no longer present. HbA1c remained unchanged both initial and post treatment levels as well as at 6 month follow-up.

The effectiveness of another home–based intervention, multisystemic therapy (MST), was studied too (Ellis et al., 2005a). MST is an intensive, family–centered, community–based treatment originally designed for use with adolescents with antisocial behavior. MST interventions targeted adherence–related problems within the family system, peer network, and the broader community systems in which the family was embedded. Intervention techniques used were cognitive–behavioral therapy, parent training, and behavioral family systems therapy. The mean number of sessions was 48 (SD 19) for treatment completers, with a mean length of treatment of 5.7 months. The adolescents of the families who participated in MST (N=64) showed significant improvements in the frequency of blood glucose testing and HbA1c (by 0.8%). A reduced number of hospital admissions was found when the participants were compared to a standard care group (N=63). The MST also reduced diabetes/related stress among these adolescents (Ellis et al., 2005b). The improvements of HbA1c were however lost at follow-up (Ellis et al., 2007). Improvements with in-home MST were demonstrated by Ellis (2005a; 2005b) but not by Harris (2005). These findings suggest that home-based interventions can be beneficial, especially in poorly controlled adolescents, if the intensity is high and the intervention period is long enough. For maintenance of improvements it may be necessary to continue the intervention sessions.

To evaluate a family focused-intervention Laffel and colleagues (2003) examined the effect of a family-focused teamwork intervention compared to standard multidisciplinary diabetes care. Their group consisted of 100 children and adolescents, age range 8-17 years: 50 in the experimental group and 50 in the control group. The intervention for families in the teamwork condition focused on the importance of parent-child responsibility-sharing for diabetes tasks

and ways to avoid conflicts that undermine such teamwork. At each visit a responsibility-sharing plan was negotiated. Four areas were addressed in four modules: (1) communication about diabetes; (2) meaning of HbA1c and explaining the need for parent-child teamwork during the adolescent period; (3) response to good blood sugars and avoiding the "blame and shame cycle"; (4) sharing the burden of diabetes tasks with family members and using a logbook to solve problems with out-of-range values. In the teamwork group the HbA1c did not deteriorate as did the standard care group after one year of follow-up. Despite the increased family involvement in the teamwork group, no difference in diabetes-related family conflict or improvement of quality of life was reported.

Peer-based approaches
Greco, Pendley, McDonell & Reeves (2001) evaluated a structured intervention program that integrated peers into diabetes care in a healthy and adaptive manner. Adolescents, age between 10 and 18, with diabetes (n = 21) and their best friends (n = 21) participated in a group intervention aimed at increasing diabetes knowledge and social support of diabetes care. The intervention consisted of four 2-hour education and support group sessions. Following the intervention, adolescents and their friends demonstrated higher levels of knowledge about diabetes and support, as well as a higher ratio of peer to family support, and friends demonstrated improved self-perception. Parents reported decreased diabetes-related conflict. However no significant change in adherence was noted and the adolescents with type 1 diabetes reported no changes in diabetes-related conflict, adjustment and self-perception.

Effect Sizes
For the studies that met the criteria for a Randomized Control Trial (RCT) Effect Sizes (and pearson's correlations) were calculated for metabolic control (HbA1c), depression and quality of life, when data were available, see table 2. Because of the limited data available, it was not possible to perform a meta-analysis.
Most psychological intervention programs only had a small (positive or negative) effect on metabolic control (HbA1c). Ellis (2004; 2005; 2007) found a medium effect of Multisystemic Therapy on HbA1c in adolescents with poorly controlled diabetes; metabolic control was better after the intensive treatment period. The only large effect size of improvement of HbA1c was found after Cognitive Skill Training (Grey et al., 2000). Very divers measures were used to assess psychological functioning. Only three studies reported data about depression in the adolescents treated, one study reported behavior problems and three studies reported on Quality of Life. Both Grey (2000), a cognitive behavioral intervention focused on improving coping skills, and Channon (2007), a cognitive behavioral intervention focusing on motivation, found a decline, with a large and medium effect size respectively, in depressive symptoms in adolescents after the intervention period. In line with this, these studies found comparable improvements of quality of life in the adolescents.

Table 2. Effect Sizes concerning metabolic level and psychosocial outcomes

Study	HbA1c		Depression		Behavior problems		Quality of Life	
	ES(d)	r	ES(d)	r	ES(d)	r	ES(d)	r
Channon, 2007	-0.28*	-0.14*	-0.85***	-0.39**			-0.75***	-0.47**
de Wit, 2008	0.07*	0.03*	0.20*	0.10*	0.43**	0.21*		
Ellis, 2004,2005	-0.70**	-0.33**						
Ellis 2005, 2007	0.64**							
Grey, 2000	-0.80***	-0.37*	0.70**	0.33**			0.61**	0.29**
Hains, 2000	0.35*	0.17*						
Laffel, 2003	-0.38*	-0.19*					0.04*	0.02*
Viner, 2003	-0.31*	-0.84***						
Wysocki, 2001	0.20*	0.10*						

* small effect size
** medium effect size
*** large effect size

DISCUSSION

To promote health and prevent psychological or physical harm, pediatric psychologists need to use effective, accessible and affordable intervention programs (Rae, 1998). The intervention programs reviewed, all aimed to reach these goals: (1) improving metabolic control (HbA1c); (2) improving Quality of Life or related aspects of psychological wellbeing and; (3) maintenance of improvements after completion of the intervention.

A cognitive behavioral treatment with a focus on coping skills (Grey & Berry, 2004; Grey et al., 2000; Grey *et al.* 2001) best reached the treatment goals described. For health related treatment goals the only large effect size of improvement of HbA1c was found after Cognitive Skill Training (Grey et al., 2000). Depressive symptoms were not measured in most studies. When depressive symptoms were taken into account, both Grey (2000) and Channon (2007) found a decline, with a large and medium effect size respectively, in depressive symptoms in adolescents after the intervention period. Promoting use of effective coping skills might aid in healthy long-term adaptation to diabetes mellitus. Learning to cope with family conflicts around diabetes is one important aspect of this intervention program, and the use of internet to help adolescents to cope with T1DM seems promising. Intervention programs that focus on support by family or peers alone, are not found to be sufficient for adolescents. These programs showed that diabetes-related conflict decreased and knowledge increased, but they had little or no effect on treatment adherence and diabetic control. Hence, a focus on improvement of coping skills of the individual adolescents from a cognitive behavioral perspective is justified and even necessary. These results are in line with earlier conclusions drawn by Hampson (2001) and Northam (2006). They both concluded that behavioral interventions can have beneficial effects on both psychological, and, to a lesser extent, metabolic control outcomes.

A number of limitations of the reviewed studies need to be mentioned. First, the groups were very heterogenic concerning age, gender and the level of metabolic control at the start of the intervention program. Socioeconomic status of the families was generally not mentioned and its impact could not be evaluated, while SES is associated both with metabolic control and QoL (Hassan, Loar, Anderson & Heptulla, 2006). Furthermore, most sample sizes were quite small varying from 6 to 64 patients and most of the time sample sizes were not based on a priori power calculations. In addition most studies were not randomized controlled evaluations. Finally, the studies used different ranges of HbA1c. Therefore the effects of the reviewed intervention programs could not be compared in detail.

Many cognitive-behavioral (knowledge, skills, adherence), affective-psychological (stress, coping, depression) and medical (complications) factors contribute to the metabolic status of patients with T1DM (Silverstein et al., 2005). Theoretical models relating psychological treatment to those factors and including potential mediating factors still need further development. Changes in metabolic control (HbA1c) are often seen as a primary outcome of intervention. Psychological factors like depressive feelings and a poor QoL, however could even be more important than improvements in HbA1c at certain ages. Changes in behavioral and psychological outcomes can also mediate effects on health. At least, it is necessary to realize that improving quality of life and metabolic control must be separate treatment goals, because the relationship between these two important outcome measures remains unclear.

A complicating factor for coping skills and adaptation to T1DM is depression (Grey et al., 2001). Depressive feelings and a bad quality of life prior to treatment may have a negative impact on treatment goals. The programs studied are combined with intensive treatment by the medical team. Intensity of treatment may have a paradoxical effect because intensifying treatment can have a negative impact on perceived stress and emotional problems (Wysocki et al., 2005). The group of adolescents with diabetes and co morbid depressive symptoms need special care and specific intervention that also focus on depressive feelings, instead of offering them the same treatment as adolescents who do not experience these feelings. A special cognitive-behavioral group therapy might reduce depressive symptoms and improved self-concept and self-efficacy (Rosello & Jimenez-Chafey, 2007).

Special attention must be given to adolescents with poor metabolic control. The dropout rate in the studies is very high for this group (if they actually participated in the first place) and these adolescents are less likely to reach treatment goals. The results indicate that it is necessary to involve parents in the treatment for this group. Involving peers, as yet did not prove to be successful, but attention should be paid to potential reactions of friends and peers as these are associated with diabetes-related stress (Hains et al., 2007).

A final consideration relates to the fact that recent intervention programs focus on treatment instead of prevention. Problems in non-compliance especially appear in mid-adolescence (Kovacs et al., 1992). Instead of relatively short, intensive intervention sessions, less frequent meetings offered over a longer time period may be better in view of prevention targets. Such meetings could be started already in early adolescence or before when hormones have yet to interfere with metabolic control. In this way the adolescents may better anticipate that they have to cope with problems that may appear in a later developmental phase.

Although the results of some of the evaluated intervention programs are promising, the conclusions drawn from this review should be interpreted with care, because of many methodological limitations as mentioned. Improving designs of intervention programs is necessary, as is evaluation of their feasibility and success with adolescents with T1DM. Focus upon improvement of coping skills as method for intervention seems most promising.

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CHAPTER 8.

## SUMMARY AND DISCUSSION

SUMMARY AND DISCUSSION

The aims of this thesis were to examine self-perception of psychological wellbeing and coping ability of adolescents with T1DM and their parents and compare them to healthy peers and their parents in order to learn how pediatric psychological care for (Dutch) adolescents with T1DM and their parents may be optimized. As described in chapter 1 the objectives of these thesis were: (1) to asses which emotional and behavioral problems occur in adolescents with type 1 diabetes mellitus from their own perspective and from the perspective of their parents, and to asses if this is different in adolescents with T1DM compared with healthy peers; (2) to assess how the adolescents value their own life and how this is related to psychological and physical functioning; (3) to evaluate which coping styles adolescents with T1DM use, to deal with the disease, how satisfied they are with their coping abilities, and how this relates to physical and psychological functioning; (4) to asses if parenting adolescents with T1DM is more stressful than parenting healthy peers and examine how this relates to the physical and psychological functioning of the adolescents; (5) to describe and evaluate the literature concerning pediatric psychological interventions for adolescents with T1DM.

In this concluding chapter the results regarding these key issues and the implications for pediatric psychological care will be discussed. Additionally, the strengths and limitations of the studies presented in this thesis are discussed, recommendations for future research are made and clinical implications are presented.

Behavioral and psychological problems in adolescents with T1DM

In chapter 2 the emotional and behavioral problems in Dutch adolescents with diabetes were compared to the emotional and behavior problems of healthy peers, see figure 1.

Figure 1. Visualizing the conceptual model studied in chapter 3: 'Behavior problems and depressive symptoms in adolescents with type 1 diabetes mellitus: self and parent report'.
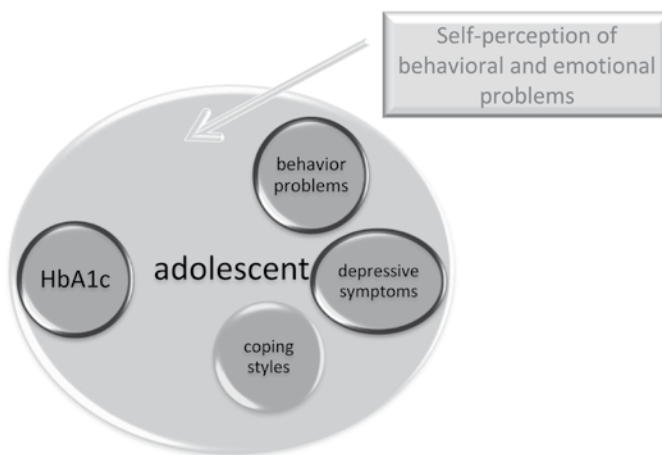
Emotional and behavior problems in adolescents with T1DM were found to be related to metabolic control. Specifically the combination of depressive symptoms and rule breaking behavior was related to metabolic control, in that adolescents who reported both depressive

symptoms and rule breaking behavior had poor metabolic control. This indicates that adolescents with poor metabolic control are experiencing difficulties not only to follow the rules of their diabetes treatment difficulties, but they show difficulties to follow rules in general.

Based on prior studies (Lawrence et al., 2006; Lin et al., 2005, Hood et al., 2006) higher levels of depressive symptoms were expected in adolescents with T1DM when compared to healthy peers. However, in our study the adolescents with T1DM did not differ from the reference group in the number of depressive complaints according to the CDI. Neither we found more adolescents at risk for depression in the group of adolescents with T1DM: in the group with T1DM 12.4% of the adolescents had a score above the cut-off compared with 14,8% in the group of healthy peers. Recently Reynolds & Helgeson (2011) presented a meta-analysis that indicated that children with diabetes experienced somewhat elevated levels of depression, anxiety, and psychological distress. However, the differences between children with diabetes and comparison groups were smaller in more recent studies, possibly due to substantial technological changes in diabetes management and new clinical standards over the past 15 years.

As pre-existing externalizing behavior problems have been associated with poorly controlled diabetes (Northam, Matthews, Anderson, Cameron & Werther, 2005), externalizing behavior problems were studied too. Dutch adolescents with T1DM were found to report more behavior problems than healthy peers. The adolescents with T1DM specifically reported more thought problems than the reference group. Mothers and fathers also reported more thought problems of their children. The fact that mothers and fathers agree with their children may underline the importance of this kind of behavior problems, like *can't get their mind off certain thoughts*, *have twitches*, *strange thoughts* or *sleeping problems*. A possible explanation for an increase in thought problems in adolescents with T1DM may be found in subtle neuropsychological effects of diabetes. Mild cognitive impairments are associated with T1DM in adolescence (Naguib, Kulinskaya, Lomax & Garralda, 2009). Recent studies have shown that in adolescence the maturation of the brain still continues (Van den Bos, van Dijk, Westenberg, Rombouts, & Crone, 2011; Toga, Thompson, & Sowell, 2006; Paus, 2005). The impact of diabetes on the developing brain may result in these thought problems.

Representation of overall functioning

There is international consensus that a routine screening for psychosocial problems should become a standard of care (Cameron, Northam, Ambler & Daneman, 2007; Delamater, 2009). The current standard of care for children and adolescents with T1DM in the Netherlands (Potter van Loon et al., 2009) states that psychological functioning should be integrated into regular care. This standard does not describe in detail how this should be done. Our findings about behavior problems and depressive symptoms indicate that adolescents with T1DM should (at least) be screened for psychological problems. Several instruments are available to measure quality of life and psychosocial problems in adolescents with T1DM, but these questionnaires are time-consuming and a screening tool for psychosocial problems in adolescents with T1DM is unavailable as yet. We investigated if the answer on the first question usually asked during a consultation (How are you? How do you feel?) provided through a rating on a Visual analogue scale (the 'Rate your life scale'), varying from zero (worst life possible) to ten (best life possible), gives information about psychological functioning of adolescents with T1DM. The conceptual model guiding this chapter is shown in figure 2.

Figure 2. Visualizing the conceptual model studied in chapter 4: 'Can one question be a useful indicator of psychosocial problems in adolescents with diabetes mellitus?'.
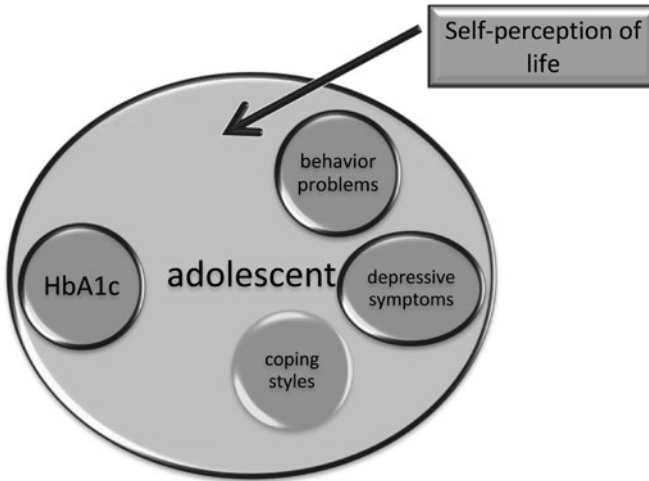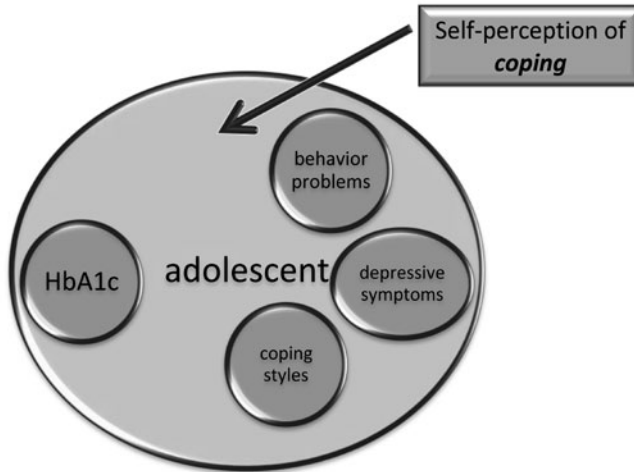
Adolescents with T1DM were found to have a positive representation of their overall functioning. Despite this positive finding, the adolescents with T1DM were also found to be less positive about their overall functioning than their healthy peers. More adolescents with T1DM than healthy peers evaluated their life as unsatisfactory. A lower score on the scale was associated with more depressive symptoms and more behavior problems according to the adolescents. Our study suggests that when adolescents experience psychological and behavioral problems, they value their life as less positive, independent of the kind of problems they experience. The answer on the 10-point 'Rate your life Scale' regarding the evaluation of one's life, seems to provide an important first impression of psychosocial functioning in adolescents with T1DM. Especially depressive feelings were found to be related to the 'Rate your life Scale'. Another study among young adolescent students, aged 11-14 years, also concluded that a self-perception score from zero to ten can be used as a simple and accurate indicator of their general mental health status, especially of their depressive symptoms and feelings of anxiety (O'Dea, 2009). Identification of psychological problems in adolescents may be improved with the use of this simple and easy to administer measure. The 'Rate your life Scale' can be a substitute for the first question usually asked during a consultation (How are you? How do you feel?'). However it is premature and incorrect yet to conclude that the 'Rate your life Scale' can be used as a complete screening tool for psychosocial problems in adolescents with T1DM.

Satisfaction with coping ability
Because glucose regulation of Dutch adolescents with T1DM in general is poor (mean HbA1c>8%), and psychological and behavioral problems are frequently seen in combination with a less positive representation of their overall functioning when compared with healthy peers (Maas-van Schaaijk, Odink, Ultee & van Baar, 2011), success or failure in coping with the stressors of diabetes is a particularly important domain of study. The representation of the adolescents themselves about their own ability to deal with the disease may play an important role in these processes. Besides evaluating which coping styles adolescents with T1DM use to deal with the disease, it was also studied how satisfied the adolescents were with their coping abilities, and if this was related to physical and psychological functioning, as described in chapter 5.

Figure 3. Visualizing the conceptual model studied in chapter 5: 'Satisfaction with coping ability in adolescents with type 1 diabetes mellitus: association with depressive symptoms, coping styles and metabolic control'.

The majority of adolescents with T1DM had a positive representation of their coping style regarding their disease. The adolescent's satisfaction with his or her ability to cope with diabetes was found to be related to both their physical and psychological functioning. Adolescents that value their coping style as more satisfying reported less depressive feeling and less (particularly internalizing) behavior problems and they had a better metabolic control (lower HbA1c). Furthermore the coping strategies adolescents with T1DM used, were related to their metabolic control and psychosocial problems. Metabolic control was better in those adolescents who used an accepting coping style instead of an avoiding coping style. Adolescents who reported more depressive feelings used coping styles based on emotional reactions and avoidance more often. Less depressive feelings were associated with an accepting coping style.

Berg and colleagues (2009) also found that perceived coping effectiveness regarding specific diabetes-related stressful events was linked to better treatment adherence, lower depressive symptoms and higher self-efficacy. In combination with our results this suggests that a positive self-evaluation of coping in general and specifically regarding diabetes has a positive effect on physical and psychosocial functioning. Such a positive effect could also result from an overall positive representation of self, which Judge, Van Vianen & De Pater (2004) described as the personality trait, core self-evaluation. They see the core self-evaluation as a higher order personality trait that is related to the general evaluation that people make about themselves and their functioning. The way adolescents perceived their overall functioning and their overall ability to cope with diabetes may form a part of the expression of the representation of the self of these adolescents.

The relation of parenting stress and physical and psychological functioning of adolescents with T1DM

The demanding aspects of diabetes not only influence psychological functioning of the adolescent, but family functioning and parenting as well. The daily demands in treatment make parenting even more stressful than parenting a child with a severe disease with less daily demands in treatment, like cystic fibrosis and cancer (Hullmann et al., 2010). From a

transactional perspective it is expected that functioning of parents is related to functioning of children and vice versa. The gradual transition in responsibility in diabetes management during adolescence might be an extra stressor in this process. In chapter 6 was studied if parenting adolescents with T1DM is more stressful than parenting healthy peers and examined how parenting stress in both fathers and mothers is related to the physiological and psychological functioning of the adolescent, see figure 4.

Figure 4. The conceptual model visualizing chapter 6: 'The interrelationships among paternal and maternal parenting stress, metabolic control and depressive symptoms in adolescents with type 1 diabetes mellitus'.
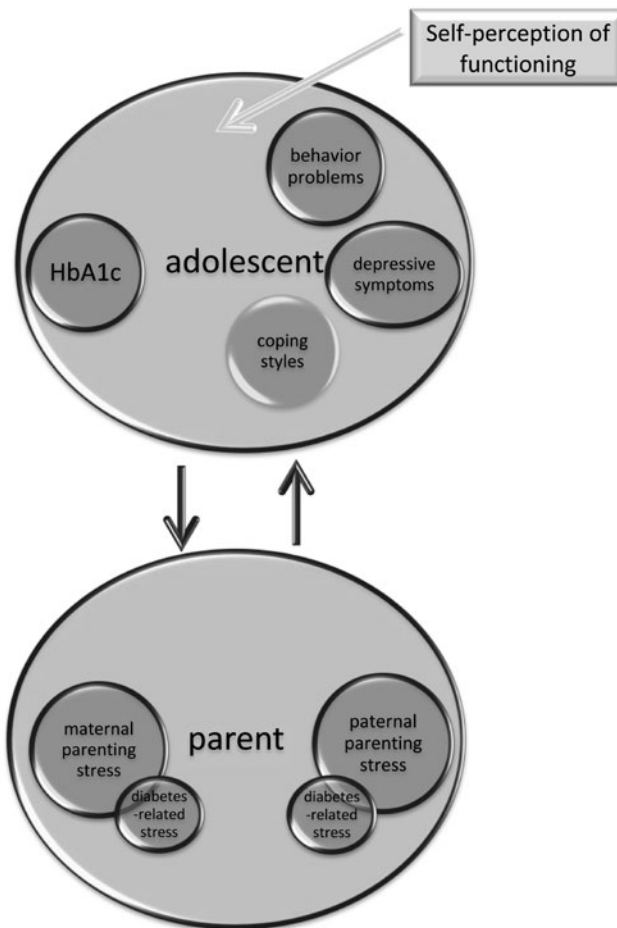
Especially fathers of adolescents with T1DM showed more parenting stress than fathers of adolescents without a chronic disease. Important is that parenting stress in both fathers and mothers of adolescents with T1DM was found to be related to emotional functioning in adolescents with T1DM, and to a lesser degree to physical functioning: only in adolescents with T1DM parenting stress was associated with more depressive symptoms. The relationship of parenting stress with either a worrisome or good level of HbA1c was limited. Specifically the combination of diabetes and depressive symptoms in the adolescents with T1DM was found to be associated with both paternal and maternal parenting stress. No relationship was found between parenting stress and depressive symptoms in the comparison group. Haugstveldt, Wentzel-Larsen, Rokne & Graue, 2011) found that the greatest diabetes related burden parents perceive, is their concern about the future health of their child. Parents of Dutch adolescents with T1DM were especially worried about the depressive feelings of their children and to a much lesser degree about the metabolic control of their child. Thus their worries concerned general parenting issues and not diabetic related parenting issues. Every day stressors probably predominate in the stress perception of parents, not future worries, like the risk for complications. It seems that parents are focusing on the behavioral effects of the disease, even if the cause of these stressors, like the mood swings in the adolescent, could be a physical problem, like the fluctuating blood glucose levels.

Although fathers seem to have less responsibility in diabetes management compared to mothers (Dashriff, 2003) the impact of paternal parenting stress on psychological functioning of the adolescent was at least as large as the impact of maternal parenting stress. Perhaps fathers are more involved when their child has diabetes. When fathers experience high levels of stress, this may have a great impact on family functioning.

Pediatric psychological interventions for adolescents with T1DM
Current treatment programs tend to minimize the potential harmful effects of the disease and maximize psychological wellbeing for adolescent with T1DM. In recent years several efforts were made to improve treatment programs to promote better physical health as well as psychological health in this age group. Therefore the recent literature evaluating psychological intervention programs was systematically reviewed, as described in chapter 7. Given the most frequently reported problems in adolescents with T1DM, namely the decline in metabolic control and the increase of depressive symptoms, we specifically addressed intervention focusing on these parameters. The intervention programs reviewed, all aimed to reach three goals: (1) improving metabolic control (HbA1c); (2) improving Quality of Life or related aspects of psychological wellbeing and; (3) maintenance of improvements after completion of the intervention.

A cognitive behavioral treatment with a focus on coping (Grey & Berry, 2004; Grey, Boland, Davidson, Li & Tamborlane, 2000; Grey, Davidson, Boland & Tamborlane, 2001) best reached the treatment goals described. Promoting use of effective coping skills might aid in healthy long-term adaptation to diabetes mellitus. Learning to cope with family conflicts around diabetes is one important aspect of this treatment, and the use of internet to help adolescents to cope with T1DM seems promising. Intervention programs that focus on support by family or peers alone are not found to be sufficient for adolescents.

Further it seems necessary to realize that improving quality of life and metabolic control must be separate treatment goals, because the relationship between these two important outcome measures is found to be inconsistent.

Strengths of the study

The study has a number of strengths, such as the relatively large number of adolescents with T1DM that could be studied. Also the use of a control group, the availability of both adolescent-reports and parent-reports and the high participant rate of fathers of adolescents with T1DM form strong points of the studies reported in this thesis.

Limitations of the study

The first limitation of the study that needs to be discussed, regards the response rate. Although a participation rate of 50% is comparable to other studies with adolescents (Lin et al., 2004; Lawrence et al., 2006; De Wit et al., 2007; Frøisland et al., 2012), our study may have been biased, in that our results reflect data of relatively well functioning adolescents with T1DM. As most important reason for not participating the adolescents indicated time investment – in the letter asking for participation we indicated that it would take 60 minutes to answer all questionnaires. The response rate varied per hospital, possibly also depending on the skills (like enthusiasm, persuasive power) of the person who approached the adolescents and the parents. The limited data available about the non-participating adolescents with T1DM revealed no differences in mean age and in HbA1c. Therefore we had no reason to think that a specific subgroup participated in this study, but this could not be studied in detail. Data of non-participants could not be collected systematically.

Because time investment was an important reason for declining participation we offered the adolescents the opportunity to fill in the questionnaires at home. Consequently, the self-report questionnaires were completed in a variety of manners, including in the hospital (before clinic appointments) and at home (received by mail). This inconsistency is problematic in that adolescents may have been influenced differentially by the hospital setting or they may have had assistance when completing the questionnaires at home. Nevertheless, we found no differences between adolescents who completed the questionnaires at home and the adolescents who completed the questionnaires at the clinic. In addition we collected most data using questionnaires. A self-serving response bias (Van Dorsselaer et al., 2010), that indicates that people tend to present matters better than they are, cannot be excluded.

Further, only a few aspects of physical and psychological functioning could be studied. To get an indication of physical wellbeing, glycated hemoglobin concentrations (most common hemoglobin A1c; HbA1c) was used, which is seen as the golden standard for long-term follow-up of glycemic control (Hanas & John, 2010). As HbA1c reflects time-averaged blood glucose during the previous 2–3 months, it does not provide information if blood glucose levels are fluctuating or relatively stable during that period of time. For optimal interpretation this information would be needed too as both hypoglycemia (low blood glucose level) and hyperglycemia (high blood glucose level) affect functioning (Periantie et al., 2008). We also could not collect information about self-management behavior, such as the number of times self-monitoring of blood glucose (SMBG) was done. For an indication of psychological well-being we used two important parameters: behavior problems and depression. We used standardized indices of psychosocial functioning that are used regularly in pediatric psychological care. Interviews may result in more qualitative and detailed information concerning the relationship between disease management and psychological wellbeing.

Furthermore, psychopathology like anxiety and depression in parents was not assessed, while several studies have shown that this may influence the experienced parenting stress (Lewin et al., 2005, Mullins et al., 2004) and the relationship with physical and emotional functioning in the adolescents (Wiebe et al., 2011; Eckshtain, Ellis, Kolmodin & Naar-King, 2010).

Another limitation was that all adolescents were of Caucasian ethnicity, so the results of these studies cannot be generalized to families with another background.

Finally the cross sectional nature of our study prevents study of causal relationships and developmental trajectories over time that may be especially important during the transition phase during adolescence.

Future directions in scientific investigations

Longitudinal studies, following self-perception of functioning, coping and parenting stress in relation to emotional and physical functioning of adolescents with T1DM, are necessary to evaluate developmental trajectories over time and study causal relationships. Based on our study findings we suggest that future research should address the following issues.

As both adolescents and their parents report elevated levels of thought problems, future research should address this topic more thoroughly. To what extent and in what way confused thinking and other difficulties in cognitive functioning might be related to diabetes type 1 and disease management seems important to study. Our results indicate that self-perception and satisfaction in adolescents with T1DM also need attention in further research. The concept of Core Self Evaluations (CSE) as described by Judge (Judge & Erez, 2003; Judge et al., 2004) may be useful for this purpose. Core Self Evaluations consist of four specific core traits (Judge et al., 2004), (1) self-esteem, the overall value that one places on oneself as a person; (2) generalized self-efficacy, an evaluation how well one can perform across a variety of situations; (3) neuroticism, the tendency to have a negativistic cognitive/explanatory style and to focus on negative aspects of the self; and (4) locus of control, beliefs about the causes of events in one's life - an internal locus of control indicates that individuals see events as being contingent on their own behavior. Together, these core self-evaluations are a basic, fundamental appraisal of one's worthiness, efficacy, and capability as a person. The role of personality in the way adolescents with T1DM cope with (disease-related) stressors and how this interacts with psychological and physical functioning needs further study and may aid designing more individualized and effective intervention programs.

The role of fathers in physical and psychological functioning of adolescents with T1DM appeared to be important. Further study is indicated regarding the effect of fathers' emotional functioning and behavior on psychological wellbeing of their children and family functioning. For designing intervention programs it is important to study if fathers' emotional wellbeing is the result of the adolescents' functioning or the other way around and how fathers' and adolescents' functioning are influencing each other in a reciprocal way.

Further study, e.g. of test-retest reliability of the 'Rate of your life scale' is necessary, as well as on the relation between the scale and quality of life questionnaires and other psychosocial problems. And finally randomized controlled trials evaluating intervention programs are needed. Few studies evaluating intervention programs have been done as yet. Intervention aimed at active coping strategies for adolescents may be useful. Such interventions programs may need to be adjusted for specific subgroups. In addition such intervention programs could make use of the 'Rate your life scale' ad of the satisfaction with their coping ability, guiding specific trajectories of screening and counseling. The content of these intervention programs could make use of the clinical implication of this study.

Clinical implications

The aim of this thesis was to get a better understanding of the problems adolescents with T1DM and their parents experience, in order to improve pediatric psychological care. As

intensive pediatric psychological care is not available for all adolescents with T1DM, nor is it necessary, a stepped care model is suggested, see figure 5.

The first step is that health care professionals use the 10-point 'Rate your life scale' regarding the evaluation of one's life, to get an impression of psychosocial functioning in adolescents with T1DM. The 'Rate your life Scale' can be added to the first question usually asked during a consultation (How are you? How do you feel?'). Next, the answers and commentary as given by the adolescents need to be discussed in the team for diabetes care, and adolescents who rate their life with a 6 or lower should be referred to the pediatric psychologist.

Additionally, as was found that an adolescent's satisfaction with his or her ability to cope with diabetes is related to both their physical and psychological functioning it seems relevant to address coping ability and specifically ask adolescents how well they think that they are able to cope with their disease on a regular basis. If the adolescent thinks that he or she is not able to cope satisfactorily with the disease, a pediatric psychologist should be consulted.

Given the amount of psychological and behavioral problems in adolescents with T1DM as indicated in our study (Maas-van Schaaijk et al., 2012) and previous research (e.g. Reynolds & Helgeson, 2011; Hood et al., 2006), a regular psychological screening procedure should be done on a yearly base, even when adolescents rate their life positive and are also positive about their ability cope with the disease, in order to identify adolescents at risk for psychological problems. Especially since these psychological problems are associated with diabetes-specific health behaviors in the future. More anxiety symptoms have been found to predict higher HbA1c values after one year, while depressive symptoms predicted less frequent blood glucose monitoring (BGM) and poorer quality of life after one year (Hilliard, Monaghan, Cogen & Streisand, 2011:McGrady & Hood, 2010). Our findings indicated that one in eight youth with T1DM met the clinical cut off for depression. Although the depression rate does not seem to be elevated in adolescents with T1DM, the substantial number of adolescents at risk for depression, justify regular screening for depression in pediatric psychological care. The weak relation between glycemic control and psychosocial functioning indicates that this screening should not be limited to adolescents with poor glycemic control.

Screening should further include diabetes related problems. Screening for a broad range of psychological problems with regular questionnaires (De Boer, et al., 2008) is time consuming for both the adolescents and health care professionals and expensive. Therefore a specific screenings instrument containing several aspects of psychological functioning (e.g. depressive symptoms, quality of life, and other aspect such as eating behavior, family functioning and diabetes related stress) is now being developed by The Dutch Quality of Life Team. Furthermore, as De Wit (2007) pointed out, it is not only necessary to screen for psychological problems, but also to discuss them with the adolescents. Given the rapid changes seen during adolescence, such a screening procedure and discussion of psychological functioning should be done on a yearly base. As our results were independent of gender or age of the adolescents, it does not seem to be necessary to distinguish different approaches for boys or girls and for young adolescents or older adolescents.

When the adolescent is found to be at risk for psychological problems and the pediatric psychologist is introduced, a more detailed analysis of psychological functioning should be done, which can indicate the direction of the following psychological treatment.

Based on medical and psychological screening roughly five groups can be distinguished, requiring different approaches: (1) adolescents with good physical and mental health (who do not need an intervention): (2) adolescents with physical problems (poor metabolic control) and no psychological problems, (3) adolescents with only psychological problems related

to having a chronic illness, (4) adolescents with only psychological problems not related to having a chronic illness and (5) adolescents with both physical and psychological problems. Intervention programs should be adjusted to the underlying problems and focus on the perceptions of the adolescent in order to motivate them to reach treatment goals. When specific psychological problems (such as depression or specific behavior problems) are the primary symptoms, the intervention should be targeted to these problems. The work field of pediatric psychologists should focus on adolescents in the groups mentioned under point 3 and 5.   A specific cognitive-behavioral group therapy might reduce depressive symptoms and improve self-concept and self-efficacy for the adolescents in group 3 and 5. Also special attention must be given to adolescents with poor metabolic control (group 2), as the dropout rate in this group is very high (if they actually participate) and these adolescents are less likely to reach treatment goals.

Given the association between parent and adolescent functioning, parenting stress, parental psychopathology and family functioning should be integrated in pediatric psychological care as well. It could already form a component of the screenings measure. As the impact of paternal parenting stress on psychological functioning of the adolescent was at least as large as the impact of maternal parenting stress, health care professionals and pediatric psychologists in particular should actively engage fathers in treatment programs.

Finally, besides attention for emotional psychological problems, pediatric psychologists should pay attention to even subtle symptoms of cognitive psychological dysfunction. As both adolescents and their parents reported elevated levels of thought problems, it seems appropriate to discuss cognitive functioning and learning in detail with the adolescent and his parents. Neuropsychological assessment is needed when (even subtle) problems in this area are reported.

Figure 5. Model stepped care: Psychological care for adolescents with T1DM
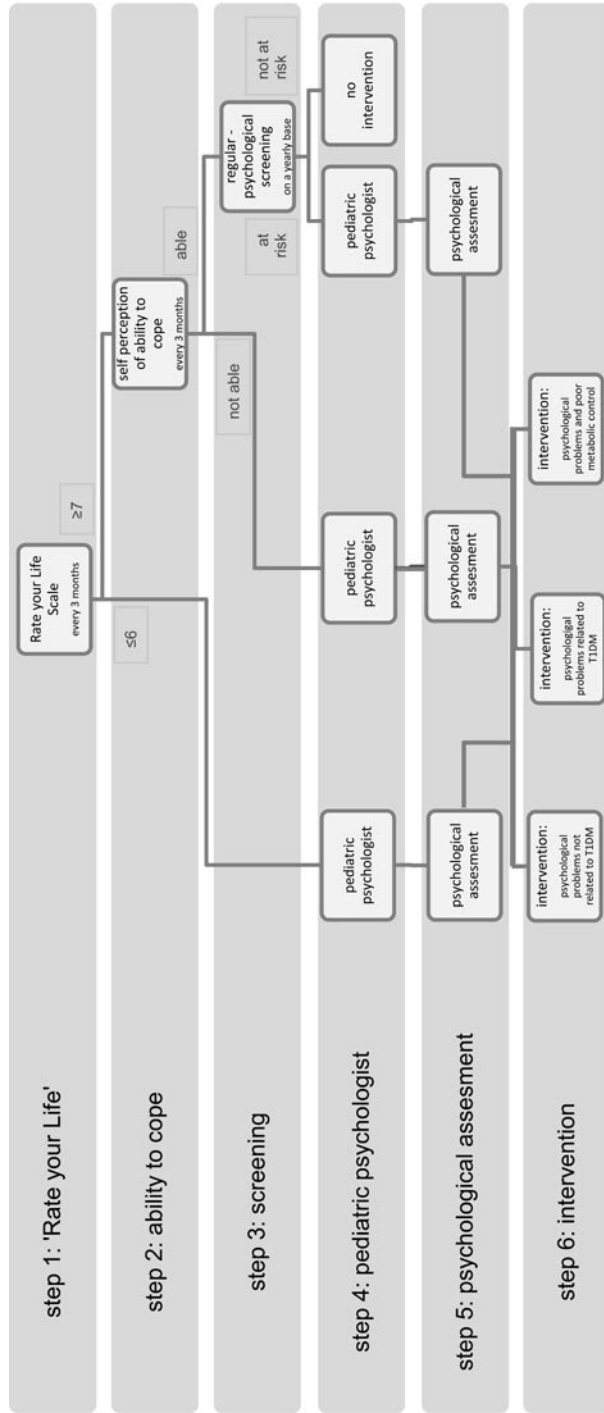
Main conclusions from this thesis:

- One in eight youth with T1DM met the clinical cut off for depression
- The adolescents with T1DM did not differ from healthy peers in number of depressive complaints
- Specifically the combination of depressive symptoms and rule breaking behavior was related to metabolic control
- Adolescents with T1DM reported more thought problems than healthy peers
- Adolescents with T1DM have a positive representation of their overall functioning. They rated their life with a mean of 7.4 on a 10 point scale, but they rated their life less positive in comparison to their healthy peers
- Adolescents who rated their life with a 6 or lower, reported more depressive symptoms and more internalizing and externalizing behavior problems than adolescents who valued their life with a 7 or up
- An important first impression of psychosocial functioning in adolescents with T1DM can be provided by the answer on the 10-point 'Rate your life Scale' regarding the evaluation of one's life
- The majority of adolescents had a positive representation of their coping style: 71.9% of the adolescents valued their own coping ability as successful or very successful
- Satisfaction with their own coping ability was related to both physical and psychological functioning. Adolescents that value their coping style as more satisfying, reported less depressive feelings and less (particularly internalizing) behavior problems and had a better metabolic control (lower HbA1c)
- Metabolic control was better in those adolescents who perceived their coping abilities as successful and who used an accepting coping style, instead of an avoiding coping style.
- Especially fathers of Dutch adolescents with T1DM reported significantly more parenting stress than fathers of healthy peers
- Parents of Dutch adolescents with T1DM were especially worried when their child was experiencing depressive feelings; not when the physical functioning of the adolescent was worrisome. Also their worries concerned general parenting issues and to a much lesser degree diabetic related parenting issues
- The association of paternal parenting stress was at least as large as the association of maternal parenting stress with psychological functioning of the adolescent
- Fathers need to be involved in treatment, especially when the adolescent had depressive symptoms

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127

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SAMENVATTING

(SUMMARY IN DUTCH)

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In deze thesis is de zelfperceptie van psychisch welzijn en coping vaardigheden van jongeren met type 1 diabetes mellitus (T1DM) onderzocht en vergeleken met die van gezonde leeftijdsgenoten. Ook hun ouders hebben informatie gegeven over hun eigen opvoedingsstress en over het welzijn van hun kinderen. De informatie werd verzameld om de pediatrische psychologische zorg voor (Nederlandse) jongeren met T1DM en hun ouders te kunnen optimaliseren.

De doelstellingen van deze thesis waren:

(1) onderzoeken welke emotionele en gedragsproblemen zich voordoen bij adolescenten met T1DM, vanuit hun eigen perspectief en vanuit het perspectief van hun ouders, en na te gaan of dit verschilt van gezonde leeftijdgenoten,

(2) onderzoeken hoe de jongeren hun eigen leven waarderen en hoe dit gerelateerd is aan psychische en lichamelijk functioneren,

(3) evalueren hoe tevreden adolescenten met T1DM zijn over hun coping vaardigheden, en hoe dit zich verhoudt tot hun lichamelijk en psychisch functioneren,

(4) onderzoeken of ouderschap van adolescenten met T1DM stressvoller is dan ouderschap van gezonde tieners en hoe zich dit verhoudt tot het fysieke en psychologische functioneren van de adolescenten,

(5) beschrijven en evalueren van de literatuur over psychologische interventies voor adolescenten met T1DM.

Gedrags- en psychische problemen bij adolescenten met T1DM

De jongeren met T1DM rapporteerden meer gedragsproblemen dan hun gezonde leeftijdsgenoten. Opvallend was dat de adolescenten met T1DM specifiek meer denkproblemen (thought problems) rapporteerden, zoals 'kan bepaalde gedachten niet uit zijn /haar hoofd zetten', 'obsessies', en 'slaapproblemen'. Ook moeders en vaders van adolescenten met T1DM rapporteerden meer denkproblemen bij hun kinderen. Het feit dat moeders en vaders het met hun kinderen eens zijn, zou kunnen wijzen op het belang van dit soort gedragsproblemen. Een mogelijke verklaring voor meer denkproblemen bij adolescenten met T1DM kan worden gezocht in subtiele neuropsychologische effecten van diabetes. De impact van diabetes op de zich ontwikkelende hersenen zou kunnen leiden tot deze denkproblemen.

Hoewel 1 de op 8 jongeren met diabetes at risk bleek te zijn voor depressie, verschilden de adolescenten met T1DM niet van de controle groep in het aantal depressieve klachten, zoals gerapporteerd op de CDI. Ook vonden we geen verhoogd risico op depressie bij adolescenten met T1DM, mogelijk als gevolg van aanzienlijke technologische veranderingen in de behandeling van diabetes in de afgelopen 15 jaar.

De hoeveelheid en aard van de emotionele en gedragsproblemen bij jongeren met T1DM bleek samen te hangen met hun metabole controle, de HbA1c waarde. Met name de combinatie van depressieve symptomen en grensoverschrijdend gedrag bleek gerelateerd te zijn aan metabole controle: adolescenten met meer depressieve symptomen en meer grensoverschrijdend gedrag hadden een slechtere metabole controle, dat wil zeggen een hoger HbA1c. Dit geeft aan dat adolescenten met een slechte metabole controle niet alleen problemen hebben om zich aan de regels van hun diabetesbehandeling te houden, maar ook in het algemeen moeilijkheden ervaren om zich aan regels te houden.

Representatie van algeheel functioneren

De eerste vraag die gesteld wordt tijdens een consult is meestal: Hoe gaat het? Hoe voel je je? Onderzocht is of het antwoord op deze vraag informatie geeft over het psychische functioneren van adolescenten met T1DM. Dit is gedaan door de adolescenten een cijfer te laten geven dat weergeeft hoe zij hun leven waarderen, op een visueel analoge schaal (VAS), variërend van nul (slechtste leven mogelijk) tot tien (beste leven mogelijk).

Adolescenten met T1DM bleken over het algemeen een positieve representatie te hebben van hun algeheel functioneren met een gemiddelde waardering van een 7,4. Ondanks deze positieve bevinding, waren adolescenten met T1DM echter minder positief dan hun gezonde leeftijdsgenoten: zij waardeerden hun leven gemiddeld met een 8.0 Meer jongeren met T1DM dan gezonde leeftijdgenoten hadden hun leven met een 6 of lager geëvalueerd. Een lagere score op de schaal was geassocieerd met meer depressieve symptomen en meer gedragsproblemen volgens de adolescenten zelf. Het antwoord op de 10-punt schaal 'Geef je leven een Cijfer', lijkt hiermee een belangrijke eerste indruk te geven van het psychosociaal functioneren van adolescenten met T1DM.

Tevredenheid met coping

De meerderheid van de adolescenten met T1DM (71,9%) had een positieve representatie van hun vermogen om te gaan met hun ziekte. Deze tevredenheid van de adolescenten over hun vermogen om te gaan met diabetes bleek samen te hangen met zowel het fysieke als het psychische functioneren. Jongeren die van mening waren dat ze voldoende tot goed in staat waren om te gaan met hun ziekte rapporteerden minder depressieve gevoelens en minder gedragsproblemen. Ook hadden ze een betere metabole controle (lager HbA1c) dan jongeren die van mening waren dat ze onvoldoende in staat waren om te gaan met hun ziekte. Verder was de metabole controle beter bij de adolescenten die een accepterende copingstijl gebruikten, in plaats van een vermijdende copingstijl. Adolescenten die aangaven meer depressieve gevoelens te ervaren, gebruikten vaker coping stijlen op basis van emotionele reacties en vermijding. Minder depressieve gevoelens waren geassocieerd met een accepterende copingstijl.

Onze resultaten laten zien dat een positieve evaluatie, waarbij de adolescenten met T1DM aangeven dat zij tevreden zijn over de manier waarop zij in staat zijn om te gaan met hun ziekte, samenhangt met beter lichamelijk en psychosociaal functioneren.

Algemene en diabetes gerelateerde ouderlijke stress

De veeleisende ziekte diabetes kan niet alleen het psychisch functioneren van de adolescent beïnvloeden, maar ook het functioneren van het gezin en de opvoeding.

Vaders van adolescenten met T1DM bleken meer ouderlijke stress te rapporteren dan vaders van adolescenten zonder een chronische ziekte. Belangrijk is dat ouderlijke stress bij zowel vaders als moeders van adolescenten met T1DM bleek samen te hangen met het emotioneel functioneren van de adolescenten, en in mindere mate met het lichamelijk functioneren. Met name de combinatie van diabetes en depressieve symptomen bij de adolescenten met T1DM bleek samen te hangen met ouderlijke stress van zowel vaders als moeders. In de controle groep werd geen verband gevonden tussen ouderlijke stress en depressieve symptomen.

Psychologische interventies voor adolescenten met T1DM

De recente literatuur over psychologische interventie-programma's werd systematisch geëvalueerd. Aangezien de meest frequent gerapporteerde problemen bij adolescenten

met T1DM een verslechtering van de metabole controle en een toename van depressieve symptomen zijn, hebben we specifiek gekeken naar het effect van interventies op deze twee parameters.

Een cognitief gedragsmatige behandeling met de focus op het omgaan met de ziekte bleek het beste de behandeldoelen te kunnen bereiken. Het bevorderen van het gebruik van effectieve coping vaardigheden kan helpen bij een gezonde aanpassing aan diabetes mellitus op de lange termijn. Leren omgaan met diabetes gerelateerde gezinsconflicten lijkt een belangrijk aspect van de behandeling te zijn.

Het gebruik van internet om jongeren te helpen om te gaan met T1DM lijkt veelbelovend. Interventieprogramma's die enkel gericht zijn op het verbeteren van het gezinsfunctioneren lijken onvoldoende effectief te zijn.

Sterke punten en beperkingen van de studie
Het onderzoek heeft verschillende sterke punten, zoals het relatief grote aantal adolescenten met T1DM dat geparticipeerd heeft. Ook het gebruik van een controlegroep, de beschikbaarheid van zowel adolescenten-rapportages als ouder-rapportages en de hoge deelnemersaantallen van vaders van adolescenten met T1DM vormen sterke punten van de studies in dit proefschrift. De voornaamste beperking van dit onderzoek is het responspercentage, aangezien slechts 50% van de adolescenten en ouders die benaderd zijn om mee te werken, ook daadwerkelijk hebben geparticipeerd. De beperkte gegevens die beschikbaar zijn over de niet-deelnemende jongeren met T1DM toonden geen verschillen in de gemiddelde leeftijd en in HbA1c. Daarom hadden we geen reden om te denken dat slechts een specifieke subgroep heeft deelgenomen aan deze studie.

Toekomstig wetenschappelijk onderzoek
Longitudinale studies zijn noodzakelijk om mogelijke causale verbanden te onderzoeken tussen de eigen inzichten van de adolescenten met betrekking tot hun functioneren, hun coping vaardigheden en de stress van hun ouders in relatie tot de emotionele en fysieke problemen van adolescenten met T1DM.

Aangezien zowel de adolescenten als hun ouders verhoogde niveaus van denkproblemen bij de jongeren rapporteerden, verdient dit onderwerp in toekomstig onderzoek extra aandacht. Onze resultaten geven aan dat zelfperceptie en tevredenheid over eigen mogelijkheden bij jongeren met T1DM ook aandacht in verder onderzoek verdienen. De rol van de persoonlijkheid in de manier waarop jongeren met T1DM omgaan met (ziekte-gerelateerde) stressoren en hoe dit samenhangt met psychologisch en fysiek functioneren zou verder onderzocht moeten worden om na te gaan hoe deze informatie zou kunnen bijdragen aan het ontwerpen van meer geïndividualiseerde en effectieve interventieprogramma's.

De rol van de vaders in het fysieke en psychische functioneren van adolescenten met T1DM bleek belangrijk te zijn. Verdere studie is nodig over het effect van het emotioneel functioneren van vaders op het psychisch welzijn van hun kinderen en het functioneren van het gezin.

Daarnaast is ook nader onderzoek nodig van de 'Geef je leven een cijfer' schaal: bijvoorbeeld van de test-hertest betrouwbaarheid en onderzoek naar de relatie tussen deze schaal en kwaliteit van leven en andere psychosociale problemen.

En tot slot is duidelijk geworden dat gerandomiseerde studies naar interventieprogramma's nodig zijn. Interventie programma's moeten mogelijk worden aangepast voor specifieke subgroepen, zoals adolescenten met T1DM en een comorbide depressie.

Klinische implicaties

Het overkoepelende doel van dit proefschrift was om een beter begrip te krijgen van de problemen die Nederlandse jongeren met T1DM en hun ouders ervaren, om de pediatrische psychologische zorg te verbeteren. Omdat intensieve pediatrische psychologische zorg niet voor alle jongeren met T1DM nodig is, wordt een stepped care model voorgesteld.

De eerste stap zou screening voor psychologische problemen moeten zijn als een geïntegreerd onderdeel van pediatrische zorg. Hoewel het aantal depressieve symptomen niet verhoogd is bij jongeren met T1DM rechtvaardigt de hoeveelheid jongeren at risk voor een depressie in het algemeen en de samenhang van grensoverschrijdend gedrag met de hoeveelheid depressieve klachten zoals gerapporteerd in hoofdstuk 3, de toevoeging van een depressie vragenlijst in deze screening. Om een eerste indruk te krijgen van het psychische welzijn van de adolescenten zouden professionals gebruik kunnen maken van de 10-punts VAS schaal 'Geef je leven een cijfer'. Omdat is gebleken dat de tevredenheid van adolescenten over hun vermogen om te gaan met diabetes samenhangt met zowel het fysieke als het psychische functioneren, lijkt het relevant om op regelmatige momenten aan de jongeren te vragen hoe goed ze denken in staat te zijn met hun ziekte om te gaan. Gezien de grote fysieke, emotionele en sociale veranderingen gedurende de adolescentiefase zal deze screening en het bespreken van de resultaten jaarlijks gedaan moeten worden.

De volgende stap in het stepped care model is het persoonlijk introduceren van de pediatrisch psycholoog bij de adolescent en zijn ouders, voor die adolescenten waarbij uit de screening is gebleken dat ze een verhoogd risico lopen op psychologische problemen. Een meer gedetailleerde analyse van het psychologisch functioneren kan dan door de psycholoog gedaan worden, die richting moet geven aan de daarop volgende psychologische behandeling. Op basis van medische en psychologische screening kunnen grofweg vijf groepen onderscheiden worden, die verschillende benaderingen vragen: (1) jongeren met een goede lichamelijke en geestelijke gezondheid (geen behoefte aan een interventie): (2) jongeren met fysieke problemen (slechte metabole controle) en geen psychische problemen, (3) adolescenten met alleen psychische problemen gerelateerd aan de chronische ziekte, (4) adolescenten met alleen psychische problemen niet gerelateerd aan de chronische ziekte en (5) adolescenten met zowel fysieke als psychische problemen. Interventie programma's moeten worden aangepast aan de onderliggende problemen en zich richten op de perceptie van de adolescent, om hen te motiveren voor behandeling. Wanneer specifieke psychologische problemen (zoals depressie of specifieke gedragsproblemen) de belangrijkste problemen zijn, moet de interventie ook gericht zijn op deze problemen. Naast aandacht voor de emotionele psychische problemen, moeten pediatrisch psychologen aandacht besteden aan zelfs subtiele symptomen van cognitieve dysfuncties. Neuropsychologisch onderzoek is nodig wanneer (ook subtiele) problemen op dit gebied worden gerapporteerd.

Gezien de relatie tussen het functioneren van de adolescenten en de ouderlijke stress lijkt het tenslotte zinvol ook aandacht te besteden aan het functioneren van de ouders en hun opvoedingsstress in zowel de screening als de behandeling.

133

Belangrijkste conclusies van dit onderzoek:

- Een op de acht jongeren met T1DM voldoet aan de klinische cut-off score voor een depressie
- De adolescenten met T1DM verschilden niet van gezonde leeftijdsgenoten in het aantal depressieve klachten
- Met name de combinatie van depressieve symptomen en grensoverschrijdend gedrag bleek samen te hangen met de metabole controle
- Jongeren met T1DM rapporteerden meer denkproblemen dan gezonde leeftijdsgenoten
- Jongeren met T1DM hebben over het algemeen een positieve representatie van hun algeheel functioneren. Desondanks waardeerden zij hun leven minder positief in vergelijking met hun gezonde leeftijdsgenoten
- Jongeren die hun leven met een 6 of lager waardeerden, rapporteerden meer depressieve symptomen en meer internaliserende en externaliserende gedragsproblemen dan jongeren die hun leven waardeerden met een 7 of hoger
- Een belangrijke eerste indruk van het psychosociaal functioneren van jongeren met T1DM kan worden verkregen door het antwoord op de 10-puntsschaal 'Geef je leven een cijfer'
- De meerderheid van de jongeren had een positieve representatie van hun coping vaardigheden: 71,9% van de jongeren waardeerden hun vermogen om te gaan met de ziekte als succesvol of zeer succesvol
- Tevredenheid met het vermogen om te gaan met de ziekte was gerelateerd aan zowel fysiek als psychisch functioneren. Jongeren die meer tevreden waren over hun coping vaardigheden rapporteerden minder depressieve gevoelens en minder gedragsproblemen. Bovendien hadden zij een betere metabole controle
- De metabole controle was beter bij adolescenten die hun coping vaardigheden als succesvol zagen en die een accepterende copingstijl gebruikten, in plaats van een vermijdende coping stijl
- Met name vaders van adolescenten met T1DM ervoeren meer ouderlijke stress dan vaders van gezonde leeftijdsgenoten. Hun ouderlijke stress was algemeen van aard en niet duidelijk diabetes gerelateerd
- Ouders van Nederlandse adolescenten met T1DM ervoeren vooral veel ouderlijke stress als hun kind naast diabetes ook depressieve gevoelens had en niet zozeer wanneer het fysiek functioneren van de adolescent zorgwekkend was. Hun ouderlijke stress bleek vooral algemeen van aard te zijn en in veel mindere mate diabetes gerelateerd
- De rol van ouderlijke stress op het psychisch functioneren van de adolescent was bij de vaders minstens zo sterk als bij de moeders
- Vaders moeten meer betrokken worden bij de behandeling, met name wanneer de adolescent met T1DM depressieve symptomen ervaart

DANKWOORD

ACKNOWLEDGEMENTS

DANKWOORD

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CURRICULUM VITAE

CURRICULUM VITAE

Nienke Maas-van Schaaijk werd geboren op 31 oktober 1976 te Geldrop. Na het behalen van haar VWO diploma aan het Strabrecht College te Geldrop ging zij in 1995 psychologie studeren aan de Katholieke Universiteit van Nijmegen (de huidige Radboud Universiteit), met als afstudeerrichting Neuro- en revalidatiepsychologie. Daarnaast volgde zij de afstudeerrichting Kinder- en Jeugdpsychologie aan de Katholieke Universiteit Brabant (huidige Universiteit van Tilburg). Na diverse stages en werkervaringsplekken in het Sint Anna ziekenhuis in Geldrop, Zonhove te Son en Breugel, Praktijk Neuropsychologie te Waalre en een wetenschappelijke stage bij de Hondsberg te Oisterwijk, behaalde zij in 2000 haar diploma.
Aansluitend werd zij als gezondheid§szorgpsycholoog in opleiding aangesteld bij Stichting SWZ (Zonhove) en behandelcentrum De Wendel (Nieuw Spraeland) en behaalde 2002 haar diploma. Vervolgens is zij in 2003 in het Catharina ziekenhuis te Eindhoven gestart met de opleiding tot klinisch psycholoog, differentiatie kinderen en jeugdigen. Vanaf dat moment is zij ook als psycholoog betrokken bij de diabeteszorg aan kinderen en jeugdigen en hun gezinnen. De opleiding tot klinisch psycholoog rondde zij eind 2006 af, waarna zij werd aangenomen als klinisch psycholoog op de afdeling Medische Psychologie binnen het Catharina ziekenhuis, waar zij nog altijd werkzaam is, met als speciaal aandachtsgebied de diabeteszorg. Daarnaast is zij hoofddocent voor de GZ opleiding bij RINO Zuid. Tevens is zij actief betrokken bij de implementatie van kwaliteit van leven in de routine zorg voor kinderen en jeugdigen met type 1 diabetes mellitus vanuit de werkgroep Dawn Youth/ Kwaliteit van Leven.

Appendix 1: Conversion table HbA1c*

HbA1c-values		HbA1c-values	
Old (NGSP) %	New (IFCC) mmol/mol	Old (NGSP) %	New (IFCC) mmol/mol
4.0	20	8.0	64
4.1	21	8.1	65
4.2	22	8.2	66
4.3	23	8.3	67
4.4	25	8.4	68
4.5	26	8.5	69
4.6	27	8.6	70
4.7	28	8.7	72
4.8	29	8.8	73
4.9	30	8.9	74
5.0	31	9.0	75
5.1	32	9.1	76
5.2	33	9.2	77
5.3	34	9.3	78
5.4	36	9.4	79
5.5	37	9.5	80
5.6	38	9.6	81
5.7	39	9.7	83
5.8	40	9.8	84
5.9	41	9.9	85
6.0	42	10.0	86
6.1	43	10.1	87
6.2	44	10.2	88
6.3	45	10.3	89
6.4	46	10.4	90
6.5	48	10.5	91
6.6	49	10.6	92
6.7	50	10.7	93
6.8	41	10.8	95
6.9	52	10.9	96
7.0	53	11.0	97
7.1	54	11.1	98
7.2	55	11.2	99
7.3	56	11.3	100
7.4	57	11.4	101
7.5	58	11.5	102
7.6	60	11.6	103
7.7	61	11.7	104
7.8	62	11.8	105
7.9	63	11.9	107

* Hoelzel, W., Weykamp, C., Jeppsson, J.O., Miedema, K., Barr, J., Goodall, I., et al. (2004). IFCC Reference System for measurement of hemoglobin A1c in human blood and the National Standardization Schemes in the United States, Japan, and Sweden: a method-comparison study. Clinical Chemistry, 50, 166-74.

Appendix 2: Visual Analogue Scale 'Rate your life'

Below is a picture of a ladder. The top step indicates the best possible life, and the bottom indicates the worst possible life: where on this ladder would you place your life?

10   **Best life possible**

9

8

7

6

5

4

3

2

1

0   **Worst life possible**

143