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Abstract

Aims. The aim of this study was to compare families with a child (2–12 years) with type 1 diabetes (T1D) to families which are not confronted with chronic illness, with regard to children's well-being, parental distress, and parenting behavior. In addition, differences were explored between families whose child has optimal versus suboptimal glycemic control. **Methods.** Mothers, fathers, and children of 105 families with pediatric T1D completed questionnaires assessing child well-being, parental distress and parenting. The control group consisted of 414 families without chronic illness. **Results.** With regard to child well-being, children with T1D had more adjustment difficulties (as reported by mothers) and lower quality of life (QoL) (as reported by mothers and fathers), whereas children themselves (8-12 years) reported higher QoL compared to controls. In terms of parental distress, mothers, but not fathers, of children with T1D reported more stress, anxiety symptoms, and depressive symptoms than controls. With regard to parenting behavior, parent reports revealed less protectiveness in fathers and less autonomy support and responsiveness in both parents as compared to controls. No differences were found in parent-reported psychological control between parents of children with and without T1D, but children with T1D perceived lowered parental psychological control. Lastly, secondary analyses indicated that especially families with suboptimal child glycemic control showed more maternal distress and worse child well-being (according to parents). **Conclusions.** Families confronted with pediatric T1D differ from families without chronic illness: childhood T1D impacts parental perceptions of child well-being and differentially affects mothers' and fathers' distress levels and behaviors.

Keywords: Diabetes Mellitus, Type 1; quality of life; parenting

1. Introduction

Pediatric type 1 diabetes (T1D) imposes a lifelong treatment regimen, impacting child well-being and requiring families to adjust their daily lives. Children and adolescents with T1D tend to experience more internalizing problems[1,2] and adjustment difficulties[3] than their peers without T1D (i.e. parent and child report). Furthermore, previous research showed that children and adolescents tend to worry about the possible consequences of their condition.[4] Children with suboptimal glycemic control also report a lower quality of life (QoL) than children with optimal control (i.e. child self-report).[5] However, research is inconclusive on whether QoL of children with T1D differs from peers. Several studies state that children with T1D experience a lower QoL (i.e. parent and child report), with the largest differences found in young children,[5,6] while other studies report similar QoL levels in youth with and without T1D (i.e. parent and child report).[4] Contradictory findings may be due to sample differences, and research should examine which variables (e.g., HbA1c, child age) relate to lowered QoL in children with T1D.

Raising a child with T1D can be overwhelming and can elicit psychological distress, with up to 30% of parents reporting clinically significant distress.[7] Compared to parents of children without T1D, mothers, as well as fathers of children with T1D across different developmental stages, tend to experience more parenting stress[1,2,8,9], although not all studies confirm this finding.[3] A childhood diagnosis of T1D can be considered a major life stressor.[7] The majority of parents of newly diagnosed children experience clinically significant depression (61%) and anxiety (59%)[10], and symptoms of depression and anxiety are higher in those parents compared to controls.[11] However, studies examining differences at a later stage of T1D found

similar levels of depressive symptoms in caregivers as compared to other parents.[2,12] With regard to anxiety, many parents, and mothers especially, fear hypoglycemia in their child.[13] Concerns about long-term health consequences and access to daycare are also regularly reported by mothers.[14] Two studies that evaluated anxiety levels confirm that caregivers of children with T1D experience significantly more anxiety than controls.[12,15] However, almost all studies evaluating distress in parents of children with T1D examined mainly mothers, leaving fathers largely understudied.

Stress and anxiety may motivate parents to engage in behaviors aimed at avoiding situations they fear (e.g. child sickness), because of potential harm that can be caused to their child.[16] In the context of pediatric T1D, parents may be highly protective of their child with T1D to avoid short- and long-term health complications.[17] Although such protective behaviors may be adaptive for the child's physical health, there may be adverse psychological consequences. For instance, in T1D, parental over-involvement has been shown to predict depressive symptoms in children,[18] and adolescents rated their parents as more controlling and overprotective compared to peers without T1D.[19] However, in younger children with T1D levels of protective parenting have not been extensively studied.

In addition to protective behaviors, the concepts of autonomy support, responsiveness and psychological control, which are grounded in Self-Determination Theory (SDT), have also received considerable attention during the last decades.[20,21] In pediatric T1D, being responsive and autonomy-supportive as a parent is highly relevant as those parenting behaviors are associated with better adolescent treatment adherence.[22,23] On the contrary, parental psychological control has been related to poor treatment adherence and adolescent depressed

mood,[22,24] and seems to be a parenting practice mostly used by parents who experience high caregiver burden. [25] These findings in pediatric T1D are in line with the basic tenet of SDT, an encompassing theory on human motivation. SDT posits that, by promoting volitional functioning (*autonomy support*), parents can support their child's basic need for autonomy, and general well-being. The child's need for relatedness can be endorsed through parental *responsiveness* (i.e., warmth, involvement, support).[20] In the context of pediatric T1D, parents might experience difficulties combining disease management with being responsive and autonomy supportive. For instance, as parents are often focused on achieving optimal glycemic control, they may be less inclined to allow input, dialogue, and show interest in their child's opinions concerning T1D treatment (i.e., autonomy support). Furthermore, by engaging in *psychological control*, which includes controlling, manipulative and intrusive practices such as guilt induction and love withdrawal, parents can also negatively influence their child with T1D.[26] However, research on those parenting concepts in pediatric T1D is scarce, and previous studies mainly focused on adolescents with T1D. Additionally, to our knowledge, no studies have compared levels of parental autonomy support, responsiveness and psychological control in pediatric T1D with controls.

The aim of the current study is to compare families with and without pediatric T1D on child well-being (adjustment and QoL), parental distress (anxiety symptoms, depressive symptoms and stress) and parenting (protective behavior, autonomy support, responsiveness, and psychological control). Additionally, we examined whether differences between families with and without pediatric T1D were present for children with suboptimal (HbA1c ≥7.5% (58 mmol/mol)) versus optimal glycemic control (HbA1c <7.5%).[27] Based upon previous

research, we hypothesized that children with T1D would experience more adjustment difficulties[3] and lower QoL than children without T1D[5,6], and that parents of children with T1D would report more stress[2,9], anxiety symptoms[12], and possibly more depressive symptoms,[11] compared to controls. Furthermore, we expected that parents of children with T1D would engage in more protective behaviors[19], provide less autonomy support, and less responsiveness as compared to controls. The largest differences between the clinical sample and the control group were expected to be present between the general sample and families with children with suboptimal metabolic control. Additionally, we explored whether parents of children with T1D were more psychologically controlling. To take into account the understudied group of fathers, all hypotheses were examined for mothers and fathers separately.

2. Methods

The current cross-sectional study is part of the Interpersonal Risk and Resilience in Childhood Diabetes project (IRRiCD; for protocol details: http://hdl.handle.net/1854/LU-8535160). This manuscript reports on the first wave (T1) of the prospective study of IRRiCD. The study was approved by ethical committees of all participating hospitals and is in accordance with the Declaration of Helsinki.

2.1 Subjects

Families were recruited through six hospitals in Flanders, Belgium. To be included, children had to (a) be diagnosed with T1D for at least 6 months, (b) be aged 2-12 years and (c) have at least one Dutch-speaking parent. All families who met the inclusion criteria and had a routine clinical visit between July 2016 and December 2017 received information about

the project. Families who gave consent (*N*=152) were contacted, of which 122 agreed to participate. Sixteen families later withdrew, due to various reasons (see http://hdl.handle.net/1854/LU-8535160). One family was excluded as mother and father completed the questionnaires together. The focus of this study was on mothers and fathers, therefore grandmothers (*N*=2) were excluded, and in a family with two mothers, one mother was randomly selected. Only children of 8 years or older completed questionnaires themselves. The final sample consisted of 105 families (43 mother-father-child families, 23 mother-child dyads, 3 father-child dyads, 18 mother-father dyads, 16 mothers only, 2 fathers only).

A control group of families from the general population was recruited through schools in urban areas in Flanders, Belgium. A flow-chart of the recruitment procedure can be found in the protocol (http://hdl.handle.net/1854/LU-8535160). Children (a) aged 2-12 years, (b) who had at least one participating Dutch-speaking parent were included. Children with T1D (*N=1)* or other chronic diseases (i.e. asthma, *N*=4) were excluded, as well as participants with too much missing data (*N*=8). Again, only children of 8 years or older completed questionnaires, resulting in a total control group of 414 families (234 mother-father-child families, 2 mother-father-two children families, 75 mother-child dyads, 19 father-child dyads, 15 mother-father dyads, 55 mothers only, 14 fathers only).

Differences in demographic characteristics between the clinical and control group were examined through independent sample t-tests for continuous variables (i.e., child and parent age) and Pearson χ^2 test for categorical variables (i.e. child sex, parent marital status, and parent education). The clinical group differed from the control group on maternal

education level solely, with mothers from the control group having a slightly higher educational background (χ^2=10.729, p<.05). Demographic information is presented in Table 1.

- Insert Table 1 here -

2.2 Procedure

All parents of children with T1D were sent an e-mail containing a secured weblink to the questionnaires and a personal code. Parents completed all questionnaires at home (±50 minutes). Children with T1D (≥ 8 y.) who were willing to participate, provided written assent and completed the questionnaires under supervision of a researcher at the hospital or at home (±20 minutes). The control group was recruited through nine schools. All parents received an invitation letter. Parents of the youngest children (2,5-7 y.) who agreed to participate were sent an e-mail containing a secured weblink to the questionnaires and a personal code, and completed the questionnaires at home (±20 minutes). In the oldest age group (8-12 y.), parents were asked to return the letter to school if they did not want their child to participate in the study (passive informed consent for child participation). Children completed the questionnaires in the classroom, under the supervision of a researcher (±40 minutes). Each participating child received paper versions of the questionnaires for their parents, who were asked to complete the questionnaires at home and return them by mail (±45 minutes). All parents provided informed consent for themselves and their child. All children provided written assent.

2.3 Questionnaires

As the current study is part of a larger project (IRRiCD project), only the questionnaires used in the current study are described.

Child Quality of Life (QoL) was measured via the Dutch Pediatric Quality of Life Inventory – 4.0 Generic Core Scales (PedsQL), parent-proxy report for toddlers (2-4 y.), young children (5-7 y.) and children (8-12 y.), and child self-report (8-12 y.).[28,29] The PedsQL consists of 21-23 items, assessing child physical, emotional, social and school functioning, and has been validated in a pediatric T1D population.[30] Respondents report on how much of a problem each described situation has been over the past month (0=never a problem, 4=almost always a problem). All items are linearly transformed to a 0-100 scale. The total score consists of the mean of all item scores, and ranges from 0 to 100. Higher scores indicate better QoL.

Child adjustment difficulties were assessed via Dutch parent-proxy reports for toddler (2-3 y.) and child/teen (4-16 y.) of the Strengths and Difficulties Questionnaire (SDQ).[31,32] The SDQ contains 5 subscales of 5 items assessing child hyperactivity, conduct problems, peer problems, emotional symptoms, and prosocial behavior. The current study used the total difficulty scale (range 0-40), which includes all subscales except prosocial behavior. Higher scores indicate more child adjustment difficulties. Parents reported on their child's behavior over the past 6 months (0=not true; 1=somewhat true; 2=definitely true).

Parental stress was assessed via the 10-item Perceived Stress Scale (PSS) assessing the extent to which parents experienced their daily life as unpredictable, uncontrollable and overloaded.[33,34] Parents reported how often certain distressing thoughts or feelings were present during the past month (0=never, 4=very often) (total scale range 0-40). Higher scores indicate more parental stress.

Parental anxiety symptoms *and depressive symptoms* were measured by Dutch versions of the Patient-Reported Outcomes Measurement Information System (PROMIS) for anxiety and depression.[35,36] Both scales include 6 items and measure the presence of feelings of anxiety and depression during the past 7 days (1=never, 5=always) (total scale range 6-30). Higher scores indicate more symptoms of anxiety and depression.

Parental protective behavior was assessed via the Dutch translation[37] of the 19-item Parental Overprotection Measure (OP), which asks parents how often the described protective behaviors are the norm for them (0=not at all, 4=very often).[38] Higher scores indicate more protective behaviors (total scale range 0-76).

Parental autonomy support was measured in both parents and children (≥ 8 y.) by 7 items of the Dutch version of the Autonomy Support Scale of the Perceptions of Parents Scale (POPS).[39,40] To assess *parental responsiveness*, 7 items from the Dutch version of the Child Report of Parent Behavior Inventory (CRPBI) were used.[41,42] *Parental psychological control* was assessed in both parents and children (≥ 8 y.) by the 8-item Dutch version of the Psychological Control Scale – Youth Self-Report (PCS-YSR)[43,44]. For parent reports, the 8-item parent version was used.[42] In these three parenting scales, items were answered on a 5-point Likert scale (1=not applicable, 5=totally applicable); higher scores indicate more autonomy supportive behavior (total scale range: 0-35), more responsiveness (total scale range 0-35) and more psychological control (total scale range 0-40) respectively."

Cronbach's alphas of the questionnaires were acceptable and are provided in the Appendix (supplementary material online).

2.4. Glycemic control

Two HbA1c-values were obtained from the child's medical record: the most recent value before (days before questionnaire completion: *M*=59.91) and the first value obtained after questionnaire completion (days after questionnaire completion: *M*=34.06). The mean difference between both values was .37 (range: 0.00-1.80). As HbA1c is an indication of the average blood glucose level during the past three months, the following rule was used: when the most recent HbA1c value was obtained longer than 120 days before (i.e., four months), or 182 days after (i.e., six months) questionnaire completion, the HbA1c value was counted as missing (*N*=3). When both HbA1c values (before and after questionnaire completions) were available, the mean of both values was used as an indicator of glycemic control at each wave. Otherwise, the one available value was used instead.

2.5. Statistical analyses

Analyses were conducted using SPSS 25.0. Analyses of covariance (ANCOVA) were used to examine mean level differences between the clinical and control group on child well-being (QoL and adjustment difficulties), parental distress (stress, anxiety symptoms, depressive symptoms), and parental behavior (protective behavior, psychological control, autonomy support, responsiveness). Secondary ANCOVA analyses were conducted to explore whether mean-level differences between patients and controls varied among families of children with optimal versus suboptimal glycemic control. Two patient groups were created based upon the ISPAD guidelines: HbA1c<7.5% (optimal glycemic control) and a HbA1c≥7.5% (suboptimal glycemic control).[27] As data were collected between 2016-2017, a target HbA1c of 7.5% as recommended at that time, was used in the current study, instead of

the new ISPAD-2018 recommendation of 7%.[27] Planned contrast analyses were conducted to estimate the differences between the control group and both clinical groups. All analyses controlled for child age (standardized) and child sex, and effect sizes were calculated (i.e. ηp^2: partial eta-squared). Cohens[45] guidelines were used to interpret the effect sizes (small: ηp^2=0.01; medium: ηp^2=0.06; and large: ηp^2=0.14). Analyses of parent-reported variables were conducted for mothers and fathers separately.

3. Results

3.1. Child well-being

As reported in Table 2, mothers of children with T1D perceived more child adjustment difficulties (F(1,474)=16.10, p<.001) than controls. No group differences in child adjustment difficulties were found in father reports. Further, both parents of children with T1D reported lower child QoL than controls (mothers: F(1,474)=7.72, p<.01; fathers: F(1,343)=4.17, p<.05). In contrast, self-reports of children with T1D (8-12 y.) showed higher QoL than peers without T1D (F(1,395)=12.62, p<.001). Secondary contrast analyses revealed that one of the group differences between patients and controls differed according to patients' HbA1c-level. More specifically, as perceived by mothers, only children with suboptimal glycemic control had lowered QoL compared to controls (p<.01).

Ancillary analyses of parent proxy-report of only the oldest children (8-12y.) were conducted for clarification and revealed no significant group differences in child QoL between patients and controls (mothers: F(1,396)=3.66, ns, ηp^2=.009; fathers: F(1,314)=2.14, ns, ηp^2=.007).

- Insert Table 2 here -

3.2. Parental distress

As presented in Table 3, mothers of children with T1D reported significantly more stress ($F(1,475)=8.43$, $p<.01$), depressive symptoms ($F(1,477)=6.46$, $p<.05$), and anxiety symptoms ($F(1,476)=21.90$, $p<.001$) than controls. In fathers, no significant group differences were found in parental distress. Secondary contrast analyses revealed that the difference in stress and depressive symptoms between mothers of children with T1D and controls differed according to child HbA1c. Only mothers of children with suboptimal glycemic control reported heightened symptoms of stress ($p<.01$) and depression ($p<.01$), whereas mothers of children with optimal HbA1c experienced similar levels of stress and depressive symptoms compared to controls.

- Insert Table 3 here -

3.3. Parenting behavior

As summarized in Table 4, no significant differences were observed in protective behavior between mothers of patients versus controls. Fathers of children with T1D reported less protective behaviors compared to controls ($F(1,344)=6.02$, $p<.05$). However, secondary contrast analyses indicated that this difference was only present for fathers of children with optimal glycemic control ($p<.05$).

Both mothers and fathers of children with T1D reported significantly less autonomy support (mothers: $F(1,474)=9.54$, $p<.01$; fathers: $F(1,343)=6.06$, $p<.05$) and responsiveness (mothers: $F(1,475)=5.53$, $p<.05$; fathers: $F(1,343)=14.49$, $p<.001$) than controls. However, for

fathers, secondary contrast analyses revealed that lowered autonomy support (p<.05) and responsiveness (p<.01) was only present in fathers of children with optimal metabolic control. For mothers, lowered responsiveness (p<.05) was only present in mothers of children with suboptimal metabolic control. With regard to psychological control, no significant differences were found between parents of children with and without T1D (parent report). However, secondary contrast analyses revealed that mothers of children with suboptimal metabolic control reported to engage in more psychologically controlling behavior than mothers of children without T1D (p<.05)

In child reports, no group differences were found in parental autonomy support and responsiveness. In contrast with parent reports, children with T1D perceived both parents as less psychologically controlling compared to controls (mothers: $F(1,389)=4.64$, p<.05*;* fathers: $F(1,378)=4.68$, p<.05).

- Insert Table 4 here -

4. Discussion

This multi-informant study including children, as well as fathers and mothers, compares families with pediatric T1D with families without pediatric chronic illness in terms of child well-being, parental distress and parenting behavior. Additionally, the study explores whether differences between families with and without pediatric T1D differ according to the child's optimal versus suboptimal glycemic control.

4.1. Child well-being

In line with our hypotheses and previous research,[3] mothers of children with T1D perceived their children as having more adjustment difficulties than controls. However, fathers did not report differences in child adjustment, which may suggest that mothers perceive the behavior of their child with T1D as more problematic than fathers. This difference in perception may be related to the elevated maternal stress levels observed in the current sample. Indeed, stress can increase parents' sensitivity to behavior problems in children with T1D, even to misbehaviors that are considered as normative at a certain age.[46]

As expected, our results indicate that parents of children with T1D perceive their children to have lower QoL than controls. It is possible that a feeling of compassion for their child who has to stick to many treatment recommendations, as well as their own experience of diabetes burden, and increased distress, may influence their perception of their child's QoL. However, mothers only perceived lowered QoL for children with suboptimal glycemic control. These results are in line with previous findings indicating that higher HbA1c-levels are related to lower child QoL.[5,47] Consequences of suboptimal glycemic control (e.g., ketoacidosis, increased parental distress), rather than T1D per se, may negatively influence parents' perceptions of child QoL. Alternatively, as the current study is cross-sectional, child QoL may also influence child glycemic control. Children with better QoL, and their parents, may find more ease in dealing with the T1D management, resulting in better glycemic control.[47] In contrast with our hypotheses, children with T1D (8-12 y.) reported higher QoL than controls. This, however, corresponds with findings of a systematic review concluding that QoL of children having T1D of 8 years and older is not impaired.[4] However, knowledge of self-reported QoL of younger children is largely lacking. Relatedly, the contrasting results

for child self-report (8-12 y.) versus parent-proxy report (2-12 y.) may be partially explained by the difference in child age range, as especially QoL of young children with T1D might be perceived as lower compared to controls.[6] When only parent-proxy reports of the oldest children (8-12 y.) were taken into account, additional analyses showed no significant group differences in QoL. Notably, in the clinical sample, parent-proxy reports (*M*=79.50-80.96) and child self-reports (*M*=80.89) of QoL were comparable, whereas in the control sample children reported remarkably lower QoL scores (*M*=74.97) compared to parent-proxy reports (*M*=83.14–84.10). These results are in line with other observations that, compared to general samples, there is a higher parent-child agreement in clinical populations, which might be related to higher parental involvement in health-related domains.[48] Furthermore, in clinical populations, children tend to report slightly higher child QoL than parents, whereas in non-clinical populations, it is the other way around.[48,49] A closer investigation of variables that impact levels of parent-child (dis)agreement in different populations is warranted.

4.2. Parental distress

As hypothesized, mothers of children having T1D experienced more stress, anxiety symptoms and depressive symptoms as compared to controls. Increased maternal anxiety symptoms were present regardless of child glycemic control, which is in line with previous research[12,15]. Interestingly, higher symptoms of stress and depression were only observed in mothers of children with suboptimal HbA1c. This might explain why previous research that did not take into account HbA1c-levels when comparing caregivers of children with and without T1D, could not always confirm differences in depressive symptoms.[2,12] Again, suboptimal child glycemic control and its consequences, rather than T1D itself, may elicit

maternal stress and depressive symptoms. Alternatively, maternal stress and depressive symptoms may (indirectly) predict child HbA1c,[50,51] or the associations between child HbA1c and maternal stress and depressive symptoms may be influenced by other variables, such as socioeconomic status.[52,53] Future longitudinal research is warranted to examine the directionality of these effects.

No differences were found in stress, anxiety symptoms and depressive symptoms between fathers of patients versus controls, which was rather unexpected as previous research demonstrated increased parenting stress (i.e., stress specifically related to parenting) in fathers of children with T1D.[9] The current study is, however, one of the first to examine group differences in general stress, and symptoms of anxiety and depression for fathers separately. Consistent with previous research, our results suggest that fathers' affective well-being may be less influenced by their child's T1D compared to mothers.[54] Further, only 3.6% of parents appointed father as primary T1D caretaker (see Table 1). This suggests that fathers may be less often involved in the disease care of their child, and almost never solely responsible, which might partially explain their less affected well-being.

4.3. Parenting behavior

Comparable levels of protective parenting were reported by mothers of children with and without T1D, which is in contrast with our hypotheses based on previous research in adolescents.[19] Differences in parental protectiveness between patients and controls may specifically arise during adolescence.[19] Parents may find it particularly difficult to relinquish T1D responsibilities at that age, and may be more cautious in 'letting go' of their adolescent with T1D compared to siblings.[55] Surprisingly, fathers from patients were less protective as

compared to controls, although this difference was only observed for fathers of children with optimal glycemic control. There is some indication that fathers may only get actively involved in T1D care as a need arises (e.g., high HbA1c).[54] When their child reaches optimal glycemic control, fathers might not feel the need to intervene, and even be more permissive. However, future research should examine this hypothesis.

As expected, parents reported being less autonomy supportive and less responsive towards their child with T1D compared to controls. A high focus on optimal disease management might interfere with attending to their child's needs for autonomy and relatedness. Furthermore, lowered responsiveness may be more common for parents of young children with T1D compared to adolescents, which may be related to higher disease demands placed on parents of younger children.[56] No differences in psychological control were observed between parents of children with T1D and controls. However, when taking into account HbA1c levels, mothers of children with suboptimal glycemic control were found to be more psychologically controlling than controls. This is in line with previous research relating psychological control to worse treatment adherence in adolescents with T1D.[22] Our results suggest that also in younger children psychological control might be associated with worse T1D outcomes. However, it has to be noted that this relation is likely reciprocal. Furthermore, the observed elevated distress in mothers of children with suboptimal HbA1c may further explain the current result, as heightened caregiver burden is known to be related to elevated psychological control.[25]

In contrast to parent reports, children with T1D reported comparable parental autonomy supportive and responsive behaviors, and perceived their parents as less

psychologically controlling as compared to controls. As a variety of factors such as age and subjective interpretation of items can influence the accuracy of children's reports, it is important to discriminate between parental *behaviors* and children's *perceptions* of those behaviors.[57] The current study suggests that children with T1D perceive their parents' behavior as similar or even more adaptive than their peers without T1D do, whereas parents themselves are more critical about their parenting. As suggested in previous research, children may perceive their parents as having legitimate authority to express expectations concerning their health.[58] Consequently children with T1D may interpret their parents' behavior as an expression of care, and thus less psychologically controlling compared to controls.

4.4. Clinical Implications

All significant group differences found in the current study display medium to large effect sizes (i.e. $\eta p^2 > .06$)[45], pointing out possible clinically relevant differences. Provided that the present findings are replicated, the current study may have important clinical implications. In addition to the well-established clinical care for children with T1D, targeted psychosocial support for children and families at risk may be beneficial. First, with regard to child well-being, our findings point to the clinical importance of targeted interventions for children with type 1 diabetes, and especially for those at risk of lowered well-being. Parents of children with suboptimal glycemic control reported mean child QoL scores below the clinically relevant cut-off of 79 (mothers, M=74.26; fathers, M=78.75)[59]. It may be beneficial to integrate an assessment of quality of life and overall child well-being into routine clinical care. Integrating well-validated instruments such as the Pediatric Quality of Life Inventory 3.2 Diabetes Module[60] or the Pediatric Quality of Life Inventory 4.0 Generic Core Scales[28] into

routine clinical diabetes care seems timely. By identifying children at risk, health care providers may intervene in an individually tailored manner, responding to each child's and family's specific needs. Further, although replication is needed, the finding in our study that children with T1D (8-12 y.) report higher QoL is a promising finding that points to the importance of being aware of, and supporting the resilience many children and families display when confronted with chronic illness. Second, in line with previous research[2,8,12], mothers of children with T1D, especially children with suboptimal glycemic control, reported elevated distress, and their mean scores for anxiety were above the clinically relevant cut-off (i.e. 55) for mild anxiety (*M*=56.27-58.04). Therefore, additional support for parents seems meaningful, especially as previous research demonstrated that parental distress is related to parent and child functioning, glycemic control, and parental behavior[7,61]. Diabetes healthcare teams may opt to integrate screening for parental distress into clinical care, and choose to make a clinical assessment of parents in general, and of mothers of children with suboptimal glycemic control more specifically. In order to do so, it is important that health care teams are well prepared (e.g. have knowledge of good screening instruments and appropriate adult referrals) and assessments are preferably done by a mental or behavioral health specialist (i.e. psychologist, social worker, or psychiatrist) who is part of the healthcare team. Whether subsequent support for parents who score high on screenings for distress should be provided by the health care team, or health care teams should refer to specialist care depends on the resources of the team, the seriousness of the distress symptoms, and the willingness of the parent to engage in psychological care. Third, with regard to parenting behavior, empowering autonomy supportive and responsive parenting behaviors is recommended, especially in

families with suboptimal child glycemic control. The diabetes health care team can serve as a model for parents through their supportive and guiding communication style[62], offering encouragement, and positive feedback. Further, health care teams can opt to involve behavioral health specialists who are trained in providing evidence-based interventions to families when problems arise in the domains of parenting and communication.

4.5. Strengths, Limitations, and Suggestions for Future Research

The current study was one of the first to examine levels of parental distress and parenting behavior in the context of pediatric T1D for mothers and fathers separately. The multi-informant approach allowed for examining differences between parent and child perspectives. An additional strength of the study is the comparison made between families of children with and without T1D, according to glycemic control (optimal/suboptimal). As several group differences were only observed for children with suboptimal metabolic control, we recommend future studies to consider metabolic control when examining differences between families with and without pediatric T1D.

Several limitations provide directions for future research. First, findings are based on cross-sectional data, precluding examination of evolution over time and causal inferences. Future longitudinal research is warranted to replicate current findings. Second, children with and without T1D completed questionnaires in a different context, which may have differentially impacted item comprehension and social desirability. Third, the current study included a large child age range (3-12 years). Future research may opt to recruit larger samples that allow to investigate possible differences due to child age or developmental stage. Fourth, multiple hypotheses were tested, increasing the risk for type one error. However, as

suggested by Rothman[63] and Perneger[64], we decided against correction for multiple testing because we had specific a priori hypotheses. Furthermore, we preferred type-one errors (i.e., false positives) above type-two errors (i.e., false negatives), that way ensuring to detect all group differences. Finally, the majority of the parents were married/cohabiting and were highly educated, and the children with T1D had a mean HbA1c of 7.07%, which is slightly lower than the international average (i.e., 7.5%; 0-10y.)[65]. Consequently, the present sample may represent a selective highly functioning sample, but as no socio-demographic data of families who declined participation were available, a comparison with decliners was not possible. Furthermore, mothers in the control group were slightly higher educated than mothers in the pediatric T1D sample. As socioeconomic status is known to influence parent and child functioning,[52,53] future studies should target more heterogeneous samples to examine the generalizability of the current findings.

4.6 Conclusion

The current findings highlight interesting psychosocial differences between families dealing with pediatric T1D and control families. Children with T1D reported no impaired QoL, which is a promising finding. However, parents, in particular of children with suboptimal glycemic control, did perceive lowered child well-being and mothers reported increased maternal distress. Furthermore, both mothers and fathers of children with T1D reported less autonomy support and responsiveness as compared to controls. These findings suggest that, in addition to the well-established clinical care for children with T1D, parents of these children may also benefit from targeted psychosocial support (e.g., by screening for parental distress).

5. Conflict of Interest

There are no conflicts of interest to report.

6. References

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Table 1. *Demographic characteristics of the sample.*

		Clinical sample			**Control Group**		
		N (%)	M (SD)	range	*N* (%)	M (SD)	range
Child		**N=105**			**N=416***		
Age			8.98 (2.39)	3-12		9.47 (2.32)	2-12
2-4y.		5 (5)			24 (6)		
5-7y.		23 (22)			39 (9)		
8-12y.		77 (73)			353 (85)		
Months since diagnosis			41.82 (32.12)	6-200		/	
HbA1c			7.07 (.78)	5.60-9.65		/	
<7.5%		78 (74)					
≥7.5%		27 (26)					
Sex	Female	50 (47.6)			201 (48.3)		
	Male	55 (52.4)			215 (51.7)		
Treatment	Daily injections	78 (74.3)			/		
	Pump	24 (22.9)			/		
Nationality (Belgian)		101 (96.2)			411 (99)		
Parent		**N=166**			**N=665**		
Age			40.96 (6.32)	28-68		41.22 (4.91)	29-67
	Missing				3 (.5)		
Sex	Mother / stepmother	100 (60.2)			381 (57.3)		
	Father / stepfather	66 (39.8)			284 (42.7)		
Marital status	Married/cohabiting	144 (86.7)			563 (84.7)		
	Divorced	10 (6)			38 (5.7)		
	Single parent / widow	8 (4.8)			28 (4.2)		
	Blended family	4 (2.4)			32 (4.8)		
Education	Higher education (>18y)	105 (63.3)			489 (73.5)		
	High school	53 (31.9)			148 (22.3)		

	Middle school	5 (3)	20 (3)
	Primary school	3 (1.8)	3 (.5)
	Missing		5 (.8)
Most involved in diabetes care – as reported by each parent	Mother	78 (47.0)	/
	Father	6 (3.6)	
	Both equally involved	82 (49.4)	

Note. M=mean, SD=standard deviation. When both parents participated demographic information of the child was based on the information given by one of both parents. * In two of the 414 families, mother and father reported about another child (= 2 siblings).

Table 2

ANCOVA comparison for child well-being across T1D and controls

					Glycemic control							
							Controls VS suboptimal glycemic control			Controls VS optimal glycemic control		
	T1D	**Controls**	**Group difference ANCOVA**		**Group difference ANCOVA**		**HbA1c ≥7.5%**	**Group difference**		**HbA1c <7.5%**	**Group difference**	
variable	*M (SD)*	*M (SD) sample size*	*F*	*ηp²*	*F*	*ηp²*	*M (SD) sample size*	*Contrast estimate*	*ηp²*	*M (SD) sample size*	*Contrast estimate*	*ηp²*
C. adjustment difficulties MR	10.52 (5.87) *N*=99	7.84 (5.70) *N*=379	16.10***	.033	12.97***	.052	13.41 (6.31) *N*=27	5.46***	.047	9.44 (5.35) *N*=72	1.51*	.009
C. adjustment difficulties FR	8.86 (5.37) *N*=64	7.68 (5.49) *N*=283	2.03	.006	1.45	.008	10.21 (5.48) *N*=14	/		8.50 (5.72) *N*=50	/	
C. QoL MR	79.50 (12.56) *N*=99	83.14 (11.49) *N*=379	7.72**	.016	7.56**	.031	74.26 (13.16) *N*=27	-8.86**	.030	81.46 (11.83) *N*=72	-1.73	.003
C. QoL FR	80.96 (12.36) *N*=64	84.10 (10.61) *N*=283	4.17*	.012	2.44	.014	78.75 (8.37) *N*=14	/		81.58 (13.27) *N*=50	/	
C. QoL CR	80.89 (9.92)	74.97 (14.07)	12.62***	.031	6.30**	.031	82.66 (7.73)	6.56*	.012	80.16 (10.67)	6.06**	.022

N=69	*N*=330	*N*=20	*N*=49

Note. M=mean, SD=standard deviation; QoL: Quality of life; C.=Child, MR=Mother report; FR=Father report; CR=Child report; ηp^2=partial eta squared effect size; All models controlled for child age and sex.
* p<.05; ** p<.01; *** p<.001

Table 3
ANCOVA comparison for parental distress across T1D and controls

					Glycemic control							
							Controls VS suboptimal glycemic control			Controls VS optimal glycemic control		
	T1D	**Controls**	**Group difference ANCOVA**		**Group difference ANCOVA**		**HbA1c ≥ 7.5%**	**Group difference**		**HbA1c <7.5%**	**Group difference**	
variable	*M (SD)*	*M (SD)*	*F*	*ηp²*	*F*	*ηp²*	*M (SD)*	*Contrast estimate*	*ηp²*	*M (SD)*	*Contrast estimate*	*ηp²*
Stress M	24.70 (6.14) *N*=100	22.67 (5.95) *N*=379	8.43**	.017	5.59**	.023	26.30 (5.25) *N*=27	3.59**	.019	24.11 (6.37) *N*=73	1.35	.006
Stress F	22.52 (5.74) *N*=66	21.29 (5.47) *N*=283	3.03	.009	1.64	.009	23.36 (4.62) *N*=14	/		22.29 (6.03) *N*=52	/	
Depressive symptoms M	10.17 (4.42) *N*=100	8.98 (4.05) *N*=381	6.46*	.013	5.92**	.024	11.74 (4.94) *N*=27	2.75**	.023	9.59 (4.10) *N*=73	.60	.003
Depressive symptoms F	8.48 (3.40) *N*=66	8.15 (3.18) *N*=283	.83	.002	.67	.004	8.00 (2.88) *N*=14	/		8.62 (3.54) *N*=52	/	
Anxiety symptoms M	13.51 (4.70) *N*=100	11.21 (4.23) *N*=380	21.90***	.044	12.08***	.048	14.59 (5.25) *N*=27	3.35***	.031	13.11 (4.45) *N*=73	1.90**	.024
Anxiety symptoms F	10.60 (4.09) *N*=66	10.15 (3.31) *N*=282	.58	.002	1.39	.008	9.36 (2.62) *N*=14	/		10.94 (4.36) *N*=52	/	

Note. M=mean, SD=standard deviation; M=Mother; F=Father; *ηp²*=partial eta squared effect size; All models controlled for child age and sex.
* p<.05; ** p<.01; *** p<.001

Table 4
ANCOVA comparison for parenting behavior across T1D and controls

					Glycemic control							
							Controls VS suboptimal glycemic control			Controls VS optimal glycemic control		
	T1D	**Controls**	**Group difference ANCOVA**		**Group difference ANCOVA**		**HbA1c ≥7.5%**	**Group difference**		**HbA1c <7.5%**	**Group difference**	
variable	*M (SD)*	*M (SD)*	*F*	*ηp²*	*F*	*ηp²*	*M (SD)*	*Contrast estimate*	*ηp²*	*M (SD)*	*Contrast estimate*	*ηp²*
Parent report												
Protective parenting M	30.54 (13.83) *N*=99	30.20 (12.00) *N*=381	.002	.000	.14	.001	31.22 (13.12) *N*=27	/		30.29 (14.17) *N*=72	/	
Protective parenting F	27.20 (10.93) *N*=64	30.46 (10.43) *N*=284	6.02*	.017	3.36*	.019	29.29 (8.69) *N*=14	-1.58	.001	26.62 (11.48) *N*=50	-4.25*	.019
Autonomy support M	26.02 (3.92) *N*=99	27.33 (3.39) *N*=379	9.54**	.020	5.57**	.023	25.37 (4.30) *N*=27	-1.95**	.016	26.26 (3.78) *N*=72	-.95*	.009
Autonomy support F	25.70 (3.47) *N*=64	27.03 (3.19) *N*=283	6.06*	.017	3.08*	.018	25.50 (3.20) *N*=14	-1.38	.007	25.76 (3.57) *N*=50	-1.06*	.012
Responsiveness M	30.31 (3.27) *N*=99	30.99 (2.87) *N*=380	5.53*	.011	3.17*	.013	29.78 (3.80) *N*=27	-1.22*	.009	30.51 (3.05) *N*=72	-.62	.006
Responsiveness F	28.31 (3.20) *N*=64	29.86 (3.00) *N*=283	14.49***	.041	7.23**	.041	28.29 (2.84) *N*=14	-1.64	.011	28.32 (3.32) *N*=50	-1.65**	.033
Psychological control M	16.32 (4.49) *N*=99	16.64 (4.10) *N*=380	.29	.001	4.65*	.019	18.41 (5.29) *N*=27	1.79*	.010	15.54 (3.91) *N*=72	-.1.03	.008

Psychological control F	16.45 (4.29) *N*=64	17.21 (4.10) *N*=283	.75	.002	.42	.002	16.86 (3.86) *N*=14	/	16.34 (4.43) *N*=50	/
Child report										
Autonomy support M	25.57 (4.72) *N*=69	24.84 (4.18) *N*=319	2.13	.006	2.11	.011	24.80 (3.87) *N*=20	/	25.88 (5.03) *N*=49	/
Autonomy support F	26.09 (4.82) *N*=68	25.34 (4.64) *N*=310	1.74	.005	1.38	.007	25.42 (4.72) *N*=19	/	26.35 (4.88) *N*=49	/
Responsiveness M	29.94 (3.87) *N*=69	29.66 (4.65) *N*=321	.18	.000	.09	.000	29.75 (4.13) *N*=20	/	30.02 (3.80) *N*=49	/
Responsiveness F	28.82 (5.58) *N*=68	28.48 (5.41) *N*=314	.15	.000	1.17	.006	26.95 (7.62) *N*=19	/	29.55 (4.45) *N*=49	/
Psychological control M	15.90 (5.29) *N*=69	17.42 (5.53) *N*=324	4.64*	.012	2.88	.015	16.80 (5.31) *N*=20	/	15.53 (5.30) *N*=49	/
Psychological control F	14.94 (5.25) *N*=68	16.59 (5.96) *N*=382	4.68*	.012	2.48	.013	15.68 (5.56) *N*=19	/	14.65 (5.15) *N*=49	/

Note. M=Mother; F=Father; ηp^2=partial eta squared effect size; All models controlled for child age and sex.
* p<.05; ** p<.01; *** p<.001

5. Appendix

Supplementary data can be found at: - *insert URL* -