

# Paediatric Type 1 Diabetes

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Type 1 diabetes mellitus (T1DM) is one of the most common paediatric chronic illnesses, with a prevalence of 1 in every 400 youth and preceded only by asthma and epilepsy. Paediatric T1DM involves many life-challenges, as children and adolescents are forced to follow an inflexible regimen. Insulin injections, physical activity and healthy dieting to avoid episodes of extremely high or low levels of hemoglobin A1c (HbA1c), both of which can put their life at risk. The ongoing management of T1DM can also be extremely challenging for parents, as requiring family support for both the physical and psychological care of the children.

Keywords: parental self-efficacy ; parental stress ; Paediatric Type 1 Diabetes ; parental diabetes-specific distress ; review

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## 1. Introduction

The ongoing management of T1DM can also be extremely challenging for parents, as requiring family support for both the physical and psychological care of the children<sup>[1]</sup>. Parents play a significant role in the management and in the monitoring of their children and adolescents' T1DM regimen-related tasks as continuously aimed at maintaining balanced their glycaemic levels. Indeed, some studies, line with the transactional model of parent-child interaction, in which the child's illness affects the family at different levels, then affecting back on the health of the child with diabetes, suggest that it represents a family disease <sup>[2][3]</sup>. Therefore, since parents have to adapt their approach to managing their children's chronic disease, they may experience several psychological symptoms. Anxiety, stress and/or depression related to paediatric diabetes, which in turn, influence the glycemic control of their children's diabetes<sup>[4][5]</sup>. More specifically, anxiety represents an emotion constituted of feelings of worrying thoughts, tension, and physical modifications (e.g., the increase of blood pressure)<sup>[6]</sup>; stress is a physiological or psychological response to internal or external stressors<sup>[6]</sup> while the perceived stress comprises feelings or thoughts regarding the general stressfulness of the individuals' life and their capacity to handle this stress<sup>[7]</sup>. Parental stress, instead, is defined as the parental perception of an imbalance between the requests of parenting and accessible sources<sup>[8]</sup>. Lastly, depression is characterized by a negative affective state, which ranges from unhappiness to an extreme feeling of sadness, despondency, and pessimism, as well as changes in physical, cognitive, and social aspects<sup>[6]</sup> which altogether interferes with everyday life.

## 2. Parental Stress, Anxiety and Depression Symptoms Associated with Self-Efficacy in Paediatric Type 1 Diabetes

### 2.1 Parental Depression and Anxiety Symptoms

Several studies reported that parents of children with T1DM experience higher levels of depression and anxiety symptoms, relevant as they associate with difficulty coping with the children's T1DM<sup>[9][10][11] [12]</sup>. Nonetheless, findings are not univocal, with some reporting a greater prevalence of depression symptoms<sup>[13][14]</sup> while others of anxiety symptoms<sup>[9] [15]</sup> in both mothers and fathers. A recent study highlighted that most of the parents experience paediatric-specific distress following their children's diagnosis of T1DM, then worsened by depression symptoms<sup>[16]</sup>. Indeed, the authors found that parents with depression symptoms show higher levels of daily T1DM-specific distress compared to parents without depression symptoms at baseline<sup>[16]</sup>. Moreover, parents reporting such symptoms at baseline also show a reduced improvement in T1DM-specific distress assessed at six- and twelve-month follow-up<sup>[16]</sup>. A 2012 systematic review reports a prevalence of 33.5% regarding parents' distress at the time of diagnosis and 19% 1 to 4 years after the diagnosis with a prevalence of parental psychological distress ranging from 10% to 74%<sup>[11]</sup>. Indeed, other evidence coherently observed that 74% of parents met mild depression and 61% met criteria for clinically significant depression<sup>[10]</sup>. A study also showed that 13% of parents present depression symptoms within a mild to moderate<sup>[17]</sup>. Along the same line, another study report that 33% of parents showed elevated symptoms of depression; the best predictors, assessed through hierarchical multiple regression analysis and logistic regression, were the caregivers low education levels, higher family stress, the children's older age and low levels of HbA1c<sup>[18]</sup>. For instance, parental depression had a significant indirect effect on children

metabolic control through parental monitoring<sup>[19]</sup>. Hansen and colleagues<sup>[12]</sup> report that 55% of mothers and 22% of fathers met the cut-off for an anxiety disorder, while for depression disorders the 26% of mothers and 19% of fathers fell above the cut-off. Similarly, in a 2013 study, 29.8% of parents scored within the moderate range or above the cut-off for severe anxiety disorders, while there was no significant difference in depression symptoms compared to the control group<sup>[9]</sup>. In another study, 59% of parents reported clinically significant levels of anxiety at the time of their children diabetes diagnosis<sup>[10]</sup>. Data, referred to parents of adolescents with T1DM, highlight that the relationship between the caregivers' psychological distress and the HbA1c levels is stronger for depression symptoms than anxiety symptoms<sup>[14]</sup>. Furthermore, data also show that parents' depression symptoms have a positive and significant indirect effect on their children depression symptoms when parental involvement in their children with T1DM is considered<sup>[19]</sup>.

## 2.2. Parental Stress and Parenting Stress

Helgeson and colleagues<sup>[2]</sup> distinguished between general stress, related to the areas of finances, marriage, and parenting, and parental stress or diabetes-specific stress referring to the stress experienced when caring for a child with diabetes. Indeed, general parental stress predicts an increase in parents' depression symptoms, which significantly associates with more children depression symptoms and lower glycemic control. Furthermore, high levels of general stress represent one of the risk factors for the onset of depression symptoms in parents caring for children with T1DM<sup>[20]</sup>. Parents who report their children's behaviour as more problematic, showed greater difficulties associated to paediatric parenting stress and increased child-reported critical parenting behaviours<sup>[12][21]</sup>. Moreover, maternal illness related stress associates with the children's mental state<sup>[22]</sup>. Considering the differences referred to children's age, parents of children (Mage = 10.8 years) report, overall, less paediatric parenting stress compared to parents of preadolescents (Mage = 12.9 years)<sup>[17]</sup>. Another study showed that parents of children aged between 2 to 7 years present higher levels of paediatric parenting stress frequency referred to the management of children with diabetes while paediatric parenting stress difficulties was associated with greater parental depression symptoms<sup>[16]</sup>. Regression analysis showed that parental depression symptoms explain 58% of the variance of paediatric parenting stress frequency and 68% of the variance of paediatric parenting stress difficulties<sup>[16]</sup>. Moreover, a study evaluating the validity of the Paediatric Inventory for Parents (PIP; a self-report aimed at assessing stress levels in parents with a child presenting a chronic illness) showed the positive predictive role of three domains, namely communication frequency (i.e., talking about the child illness), role function frequency (i.e., issues referred to the caregiver role as a parent, partner and person with their own need) and emotional problems frequency (i.e., negative emotionality referred to the child illness)<sup>[23]</sup>. Differently, parents' age appeared as negatively predicting anxiety<sup>[24]</sup>. Considering gender differences should be noted how studies present contrasting results since on the one hand they report that mothers show higher levels of paediatric parenting stress than fathers<sup>[24]</sup>. In contrast, a recent pilot study found that mothers and fathers seem to report comparable stress levels related to parenting a child with diabetes<sup>[25]</sup>. Of particular note is a study in which the sleep issues of children with T1DM has been investigated in association with family functioning and parental psychological symptoms<sup>[26]</sup>. This study showed that children's sleep issues and behavioural insomnia associates with increased parental stress, anxiety, and depression symptoms, influencing the intensive insulin regimen. Thus, the management of paediatric diabetes also impacts the children sleep and emotional functioning, while also affecting parents' sleep as the 79% of them reported on sleep disruption associated to diabetes-management<sup>[26]</sup>. Therefore, paediatric parenting stress is common in parents of children and adolescents with T1DM, resulting in adverse outcomes for children's health<sup>[10][14][17]</sup><sup>[27]</sup>, although further studies are needed to allow an in-depth comprehension of the considered symptoms and the role of parenting stress associated with the management of paediatric T1DM.

## 2.3. The Role of Parental Self-Efficacy Related to Anxiety, Stress, and Depression Symptoms

Parental stress leads to negative consequences for diabetes management as parents perceive T1DM as a complex diagnosis, which contributes to family disruption and leads to anxiety and depression symptoms<sup>[11][15]</sup>. Evidence underline a constellation of interrelated factors comprising symptoms of stress, anxiety and depression specifically related to the management of the children diabetes<sup>[11]</sup>. As such, the univocal construct of parental diabetes-specific distress. Indeed, high parental stress, anxiety and depression symptoms, altogether contribute to lowering parental self-efficacy in the context of paediatric diabetes care<sup>[10][28]</sup>. Further, findings reported parental distress or parental diabetes-specific distress indirectly relates to parents' diabetes monitoring via self-efficacy<sup>[13]</sup>. Multivariate analyses showed that parental diabetes-specific stress frequency and difficulties associates with parents psychological and behavioural functioning refers to the perception of greater responsibility and lower self-efficacy related to diabetes management<sup>[28]</sup>. Low self-efficacy was also related to anxiety and depression symptoms yet positively associated with parents' younger age. Other authors, indeed, suggest that lower distress in caregivers indirectly relates to better diabetes monitoring through higher parental self-efficacy, in turn associating with their children better adherence and HbA1c levels<sup>[13]</sup>. Of particular note is that parents' younger age brings higher parental stress, yet neither to anxiety nor depression symptoms<sup>[29]</sup>. Moreover, no

gender differences were observed for stress difficulty or self-efficacy<sup>[29]</sup>. Findings further suggest that parental negative affectivity might also negatively influence adolescents' self-efficacy. Indeed, high parental self-efficacy relates both to diabetes management and to the capacity to develop or reinforce diabetes management related skills to their children, which could positively influence children's self-efficacy regarding their diabetes self-management <sup>[29]</sup>.

## **2.4. Mothers Involvement in the Management of Children with T1DM**

Past literature mainly focused on maternal depression symptoms related to parenting children with T1DM. Specifically, after their children diagnosis, mothers report greater depression symptoms than fathers<sup>[40]</sup>. Maternal depression, related to the burden of paediatric diabetes management, results as the sole significant predictor of adolescents' glycemic control<sup>[14]</sup>. Indeed, it was reported that at baseline is associated with reduced maternal diabetes management, while predicting low glycaemic control at three-month follow-up<sup>[14]</sup>. Moreover, maternal depression symptoms also negatively associated with children's quality of life, the perception of their coping strategies, and family functioning <sup>[30]</sup>. Differently, others reported that greater maternal depression did not associate with glycaemic control, yet their adolescents and children were twice as likely to have an emergency room visit and three times more likely to be hospitalized<sup>[31]</sup>. Wiebe and colleagues<sup>[32]</sup> observed that the impact of maternal involvement varies as a function of the level of maternal depression symptoms and on the children's age, with greater caregivers' depression symptoms leading to higher levels of children and adolescents' depression symptoms<sup>[33][34]</sup>. Coherently, in a sample of mothers, 49% of them were above the clinical cut-off for mild depression symptoms, and 25% were above the cut-off for moderate depression symptoms while 26% were above the clinical cut-off for paediatric diabetes distress. As such, mothers' paediatric diabetes distress -broadly conceptualized as the sum of anxiety, depression and stress symptoms associated to having a child with diabetes- is strongly related to maternal depression symptoms and adolescents' HbA1c levels <sup>[34]</sup>although others report that maternal depression and anxiety do not associate with the children metabolic control <sup>[30]</sup>. Studies considering mothers of adolescents with T1DM show percentages ranging between 18%<sup>[35]</sup> and 26%<sup>[36]</sup> for mothers scoring above the clinical cut-off for depression and between 12.9% <sup>[36]</sup> and 13% <sup>[35]</sup> for those that have scored above the clinical cut-off for anxiety. Furthermore, highly trait-anxious mothers report holding more responsibility for diabetes management perceiving their adolescents as having less diabetes management-related capacities and as such these adolescents show stronger beliefs of their mothers' greater control over their diabetes management felt as overprotective <sup>[37]</sup>. Maternal trait-anxiety was also associated with higher HbA1c levels and greater absenteeism in preadolescents<sup>[37]</sup> while being correlated to a reduced motivation towards diabetes self-care in older adolescents <sup>[34]</sup>. Moreover, maternal stress associates to both internalizing and externalizing symptoms in children with T1DM<sup>[33]</sup> and maternal anxiety and depression symptoms associates with a decreased involvement/warmth towards their children<sup>[19]</sup>. Contradictorily, others showed that maternal involvement expectancies were related to more monitoring and less conflict, although it does not predict maternal depression symptoms <sup>[38]</sup>. Nevertheless, the greater consideration of mothers throughout the paediatric diabetes literature could be due to reports of them being more preoccupied with the internal suffering of their children with T1DM, while also showing greater feelings of sadness and anxiety compared to fathers<sup>[25]</sup>. Maternal depression and anxiety symptoms thus seem strongly interrelated, with depression resulting as the greatest predictor of adverse outcomes on children diabetes than anxiety<sup>[14][22]</sup>.

## **2.5. Fathers Involvement in the Management of Children with T1DM**

As regards fathers' involvement in their children's chronic illness, few studies have addressed this research question. Yet, fathers' involvement in diabetes care seems to associate with higher parental stress, depression, and anxiety symptoms <sup>[12]</sup>. Fathers' paediatric parenting stress positively associates with state-anxiety, although they report greater hope and self-efficacy<sup>[39]</sup>, thus suggesting that fathers may differently experience parenting stress compared to mothers. A recent study showed that poor metabolic control, mediated by the fathers' perception of their children's behavioural problems, influences on father-and-child's dysfunctional interaction as associated to parenting stress <sup>[25]</sup>. These different experiences may have implications for their level of anxiety and depression and the children's behaviour<sup>[39]</sup>. Fathers of adolescents with T1DM report greater parenting stress<sup>[27]</sup>, yet it was observed that decreasing paediatric parenting stress by increasing the perceived social support prompts a decrease in depression and anxiety symptoms. The study showed that paediatric parenting stress explained 25% of the variance in the depression symptoms variance and 18% of their HbA1c levels<sup>[27]</sup>. Moreover, fathers report relatively high self-efficacy and hope concerning their children with T1DM, although their stress showed no association with the children's glycemic control<sup>[39]</sup>. More specifically, fathers' beliefs and perception of efficacy relate to adolescent's self-efficacy<sup>[40]</sup>. Nevertheless, finding of fathers' psychological symptoms and their involvement in managing children with diabetes need further explorations.

### 3. Discussion

The present paper was to review past literature regarding the impact of children and adolescents' T1DM on parents' well-being. The variables considered regarding paediatric diabetes management were parental self-efficacy, parental stress, anxiety, and depression symptoms. In line with the transactional model of parent-child interaction, in which both parties bi-directionally influence each other, parents' management of their children diabetes and the potentially associated family conflicts, indeed, show consequences upon children's physical and mental health<sup>[2]</sup>. Such interactional perspective is particularly important for clinical interventions, as psychological and behavioural variables, directly and indirectly, parents' and children's well-being. For this reason, the understanding of how parents are affected by their children diabetes cannot be neglected<sup>[2]</sup>, especially considering parental self-efficacy as a protective factor towards the whole family well-being.

Parents of children with T1DM seem to be at greater risk for mental health issues<sup>[9]</sup>. Indeed, studies report parents to show higher levels of depressive as opposed to anxious symptoms compared to the general population<sup>[2][18][22]</sup> while others observed mothers, in particular, to be often above the clinical cut-off for both depression and anxiety symptoms<sup>[13][18]</sup>. Moreover, trait-anxious mothers appear as particularly over-protective toward their adolescents and children with T1DM, as they perceived them to be less capable in dealing with their disease<sup>[42]</sup>. Maternal trait-anxiety was also associated with preadolescents higher HbA1c levels and internalizing problems<sup>[36]</sup>. Contrarily, fathers tend to experience more state-anxiety<sup>[39]</sup>, yet not much knowledge is present about fathers' depression symptoms in the context of paediatric T1DM. Furthermore, maternal depression and parental stress were also strongly associated with subsequent negative effects on children's self-management and lower glycemic control<sup>[19]</sup>. This is not surprising considering the relation between maternal depression symptoms and reduced child-centred parenting behaviours<sup>[35]</sup>, as well as a reduced parental monitoring, thus resulting in low metabolic control<sup>[36]</sup>. Moreover, high parental self-efficacy permits better monitoring, which in turn allows better adherence and better HbA1c levels of their children by buffering the impact of parents' diabetes specific distress upon their psychological well-being. Indeed, parental stress, depression, and anxiety symptoms associate with lower parental self-efficacy<sup>[10]</sup>. As such, implications for clinical interventions should be thoughtfully considered and addressed to improve parental self-efficacy. It is relevant for better managing children's chronic disease, especially conceptualizing diabetes management within the transactional model of child-parents interaction<sup>[2]</sup>. Indeed, high family general stress represents one of the risk factors for developing depression symptoms in caregivers of children with T1DM<sup>[20]</sup>, with parental diabetes-specific distress negatively impacting on family cohesion<sup>[11][41][15]</sup> and vice versa<sup>[15]</sup>. Parental anxiety and depression symptoms and diabetes-specific stress may also contribute to the worsening of parental functioning, impacting diabetes management<sup>[2]</sup>. For instance, a five-year study highlighted that parental general stress predicted a decrease in HbA1c levels, while parental diabetes-specific stress predicted an increase in children depression symptoms and better diabetes management<sup>[2]</sup>, which could be due to a greater fastidiousness in dealing with the tasks imposed by the disease. On the same line, maternal symptoms of anxiety and depression are related to reduced child-centred parenting, with anxiety further increasing hostility toward the child, thus jeopardizing mothers' capacity for disease management while lowering their child's quality of life. Besides, other studies showed that parental distress related to paediatric diabetes management and comprising only depressive and anxiety symptoms negatively correlates with the HbA1c of their adolescent and children with T1DM<sup>[14]</sup>. Another relevant aspect is that parents need to adapt their behaviours and parenting to the changing necessities as associated to social, emotional, and physical changes. This is relevant for parents' capacity to manage their children diabetes and to favour adolescents' capacity to self-manage their disease, which is particularly low during adolescence<sup>[14]</sup>. Based on these observations, we hypothesized that adolescents' lower diabetes self-management might be associated with their level of self-efficacy, which could, in turn, be influenced by parental self-efficacy towards diabetes management. For example, results suggest that parental negative affectivity may negatively affect adolescents' efficacy and self-efficacy<sup>[40]</sup>. Keeping this in mind, understanding how children's age and the specific necessities associates with a particular developmental period needs to be further explored, allowing to better tailor clinical care planning. Lastly, it is worth of note that parents can experience other types of stress, which can add up to the management of their children with T1DM. Indeed, parents who showed worries about their financial incomes and their marriage present limited time to support and assist their children with a chronic disease<sup>[2]</sup>. More specifically, a lower social economic status (SES) contributes to inadequate adherence to the clinical recommendations and to higher parental distress<sup>[13]</sup>, in particular, in parents of younger children and of a non-Caucasian race. Moreover, higher SES was related to better glycaemic control<sup>[13]</sup> and a lower SES was shown to be a significant predictor of higher maternal anxiety symptoms<sup>[30]</sup>. Similarly, parents of children with T1DM who show lower education levels were more prone to display depressive symptoms<sup>[18]</sup>. In this regard, maternal depression was negatively associated with family cohesion<sup>[20]</sup>; indeed, higher levels of family cohesion were related to a better quality of life and lower levels of parental stress, anxiety and depression symptoms<sup>[9]</sup>. However, single, or divorced mothers reported to use more maladaptive coping skills compared to married or accompanied mothers<sup>[35]</sup>.

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