

# Type 1 diabetes mellitus: psychosocial factors and adjustment of the pediatric patient and his/her family. Review

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## ABSTRACT

Type 1 diabetes mellitus is the most common chronic endocrine disease in children, with a very low incidence in the first months of life and reaching its peak during puberty (10-15 years old is the age group with the highest incidence at the time of onset).

Based on the review of the scientific literature, our objective is to study the main psychosocial factors associated with the adjustment of these pediatric patients and their families. Research underscore the following risk factors: situational (stressful life events), personal (additional physical diseases, low self-esteem, emotional disturbances), and interpersonal (family breakdown and conflicts), and also protection factors (coping strategies, social support, fluent communication).

There is a pressing need to deal with the disturbances that affect these diabetic patients and their families, by implementing effective health care psychological interventions that take into account psychosocial factors associated with the course of type 1 diabetes mellitus.

**Key words:** type 1 diabetes mellitus, pediatrics, psychosocial impact, adjustment, family.

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## INTRODUCTION

Type 1 diabetes mellitus (T1DM) is the most common chronic endocrine disease in children,<sup>1</sup> with a very low incidence in the first months of life and reaching its peak during puberty (10-15 years old is the age group with the highest incidence at the time of onset).<sup>2</sup> During childhood and adolescence, growth is associated with psychosocial alterations; in the case of these patients, they usually have symptoms of anxiety-depression, difficulty in building their identity, a decline in self-care, and an impaired metabolic control.<sup>3-5</sup> As a result, 36% of T1DM children and adolescents will have some psychological disorder in the first year of T1DM.<sup>6</sup>

Families with infants and adolescents with T1DM find

themselves in a setting of rapid physical, psychological and social changes; T1DM may have a significant impact in their adjustment along this period of growth. As a result, many associated factors may disturb normal family functioning. The diagnosis of T1DM in this period, its later chronic course, the onset of complications and its complex treatment are a significant burden on children and their families, and result in a different personal and family functioning; apart from acquiring more knowledge on the disease and developing the necessary habits for its effective management.<sup>7</sup> Maintaining an adequate metabolic control, a good quality of life and a flexible lifestyle seem to be the main challenges for youth with T1DM and their families.<sup>8</sup>

The American Academy of Pediatrics has pointed out that a purely medical management of T1DM is not enough; besides, it is necessary to improve the child's well-being or his/her health-related quality of life, enhance his/her adaptive capacity and his/her development and transition towards a healthy and productive adulthood.<sup>9</sup>

Therefore, we deem it necessary to identify the main factors that have an impact on the adjustment to established pediatric T1DM (in this context, adjustment means the extent to which an individual responds, physiologically and psychosocially, to the stress caused by the fact of having to live with a chronic disease).

Our study stems from the need to facilitate the adequate development of children diagnosed with T1DM

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and their families. Therefore, we present an article aimed at studying the main psychosocial factors related to the adjustment of these pediatric patients and their families. To this end, between 2013 and 2014 we conducted a comprehensive review of the existing scientific literature based on strict selection criteria that ensured the scientific relevance of the different document sources included in the analysis (reference articles in the field of medicine and the most important papers published along the past 10 years by distinguished authors and supported by the empirical evidence, quality and representativeness of their results) and using the most relevant databases in the field (*TESEO, DISSERTATION ABSTRACT, ISBN, JCR, WOK, PROQUEST CENTRAL, PSYCINFO, SCOPUS, PUBMED, MEDLINE, ISOC, IME, PSICODOC, DIALNET, GOOGLE SCHOLAR and LATINDEX*). Finally, more than 90 scientific documents were selected and analyzed in depth.

### **Risk factors in the adjustment to pediatric type 1 diabetes mellitus**

A risk factor means a specific aspect of the lifestyle, an individual behavior, an environmental situation or a personal characteristic related to health related conditions, so that it is important to prevent or manage it.<sup>10</sup> Risk factors may be classified as situational, personal or interpersonal.

a. Situational risk factors include characteristics related to the environment (external to the individual) or situations that have an impact on the course of a disease.

The American Diabetes Association<sup>11</sup> points out that the main situational risk factors in pediatric chronic conditions include stressful life events (either physical or emotional), socioeconomic disadvantages, neglect or discrimination, and family unemployment.

b. Personal risk factors include individual endpoints of the patient that have an effect on the adjustment process.

Potential risks for the adequate evolution of patients with pediatric chronic diseases include the presence of additional physical diseases (especially, chronic and/or neurological conditions), learning difficulties, specific developmental delays, low intelligence, difficult temperaments, language and communication difficulties, repetitive academic failure, and low self-esteem.<sup>12</sup>

Besides, these young patients usually have emotional disturbances (fear, anxiety, depression,

behavior or eating disorders) which have a negative impact on their well-being.<sup>13,14</sup>

The most common concerns regarding T1DM described by these patients include<sup>15</sup> the responsibility for continuously managing or controlling T1DM, physical marks left behind by needle pricks, being constantly alert about the body response to insulin, emotional setbacks that depend on blood glucose levels, anxiety regarding the social or emotional status of their disease (especially fear of negative reactions by their friends) and, in general, the continuous thought of complications of their disease.

Pressures related to the management of T1DM may lead to major stress and psychological alterations in these children, which often result in poor metabolic control, non-compliance with treatment and, in the end, a worse adjustment.<sup>15,16</sup>

The main personal risk factors associated with a worse course of T1DM are an early diabetes onset, a longer course of T1DM, a history of severe hypoglycemia, and a worse metabolic control.<sup>8,17</sup> Another important aspect related to stress and poor adjustment to T1DM is the high hospitalization rate of these patients, which is three times higher than that of the general pediatric population.<sup>18</sup> Acute hospitalizations result in school absenteeism of patients, workplace absenteeism of family members, poor performance of all family members, a climate of family conflict, and increased morbidity and mortality.<sup>8,19</sup>

The diagnosis of T1DM is usually accompanied by a mild psychological crisis;<sup>6,20</sup> approximately 36% of patients have some sort of psychiatric disorder in the first year.<sup>6,16</sup> Although mild, these crises are usually predictors of a subsequent anxiety and/or depression event,<sup>6</sup> and a lower self-esteem.<sup>3</sup> In the second year, patients become more aware of the chronicity of their disease, its complications and the personal skills they will require to adequately manage such complications.<sup>16</sup> Diabetic children tend to develop dependency, isolation and depression.<sup>20</sup>

c. Interpersonal factors refer to the significant characteristics of an individual's relationship with his/her family and closest social environment, which have an impact on his/her adjustment to the disease.

Pediatric T1DM accounts for a major reason of stress, which affects the entire family system. T1DM may be considered a "family disease."<sup>21</sup> Patients suffer from stress and have behavioral problems and a worse functional capacity,

and as a result their families suffer from more stress and adjust poorly to the disease, and vice versa. Diagnosis and treatment of T1DM usually accounts for a traumatic event for parents, who often become angry and worried<sup>15,16</sup> (for example: they feel impotence and insecurity regarding disease-related decisions, fear professional judgment regarding family or patient habits, have a tendency towards overprotection or excessive autonomy) and have significant stress symptoms.<sup>13,15,22</sup>

General risk factors observed in families of patients with pediatric chronic diseases include other family members with physical or psychiatric conditions, physical, sexual and/or emotional abuse, parents who are criminals or abuse substances, and the death of loved ones.<sup>12,23</sup>

An adequate social and family support system (both general and specifically related to T1DM) appears as the main factor to help these patients improve their quality of life, emotional well-being (including a lower incidence of anxiety and depression), self-care, treatment and metabolic control adherence, and to feel valued and protected by others.<sup>22,24-26</sup>

Studies have described a lower level of autonomy and more strictness as common characteristics of families with adolescents who suffer from diabetes.<sup>22</sup> Excess family blending or cohesion, overprotection, strict rules and coping strategies, and difficulties to solve conflicts should be taken into account when aiming at enhancing families' capacity to adjust to complications typical of T1DM (for example, metabolic crises), together with the causes of stress distinctive of adolescence.<sup>27-29</sup>

Adolescents with T1DM who come from a broken or dysfunctional home or single parents have more depression and lower levels of general well-being. The presence of rejection or aggressive relationships and the sense of little emotional support are risk factors that hinder the adequate course of the disease.<sup>25,30</sup> These patients have a higher chance of experiencing depression when they perceive a low level of specific family support.<sup>22</sup> As a result, the most important risk factors for this population include intense, long-lasting and/or frequent conflicts between parents or among family members, family breakdown, incoherent or unclear parenting styles, excessive strictness or lack of family flexibility to adjust to the changing needs typical of childhood/adolescence or to the different

situations related to the disease (nutrition and exercise recommendations, outpatient visits, hospital stays, etc.).<sup>27</sup>

### **Protection factors in adjustment to pediatric type 1 diabetes mellitus**

Protection factors refer to those aspects that may safeguard individuals with a specific disease or that, ultimately, may reduce or mitigate its negative consequences. Overall, we should point out the following:<sup>10</sup>

- a. Coping strategies (losses associated with chronic diseases are considered stressors that require coping with both the problem and emotions at different times. The first type of coping may serve better in situations that can be modified; while the second type, may be exercised in irreversible situations. Therefore, when adjusting to a disease, these two components play a differential role at different times, from anticipating a loss to overcoming it); or
- b. Protection factors that originate from the study of risk factors (many risk factors may be considered inversely as protection factors: family support, employment, no financial difficulties, no previous pathologies, etc.); or
- c. Factors detected based on the clinical experience (communication fluency, self-efficacy, feeling capable of caring for oneself and for the sick, ability to plan and solve problems, mental flexibility, finding sense in experiences).

The main protection factors that may help a child with diabetes adjust to his/her disease include a positive feeling of self-efficacy, feeling useful, being capable of self-care, adequate coping strategies, decision-making and problem-solving when dealing with the stress of a chronic disease, communication and planning skills, a good sense of humor, and the capacity for reflection.<sup>23,31</sup> In addition, overall self-esteem and social support have demonstrated a positive association with adjustment and a negative association with stress;<sup>26</sup> therefore, both variables help to reduce stress and thus increase the chance of an optimal adjustment to T1DM during childhood. In turn, child and adolescent resilience appears to function as a buffer regarding the lack of glycemic control and self-care behavior in relation to T1DM.<sup>32</sup>

The main protection factors in pediatric T1DM are the presence and perception of family support.<sup>12</sup> Patients with greater well-being are those who perceive that their families have a

better capacity to adjust to T1DM consequences and to their growth, who are more cohesive and organized and, therefore, have fewer conflicts.<sup>22</sup> A balanced family cohesion (which enables a stable and safe relationship with certain autonomy among family members) and a balanced family organization (without too much autonomy and excessive personal recommendations regarding personal objectives or goals) appear as related to a greater well-being, a lower level of anxiety and depression, more energy, a better diabetes management and less intergenerational conflicts.<sup>12,22,27,33</sup>

Finally, an adequate glycemic control since the onset of diabetes is associated with a favorable disease course, which helps to enhance patients' academic skills.<sup>34</sup> In addition, a sense of control by patients and their families has been identified as a protection factor which increases their adjustment and functioning mechanisms in the case of diabetes.<sup>35</sup>

## CONCLUSIONS

Our study shows that there is a pressing need to deal with the psychosocial aspects that affect children and adolescents with diabetes and their families, with a focus on what should become a public health priority. Thus, improving the health status of these patients should not be the only objective; it is also necessary to deal with these factors so that the costs incurred by these patients and their families are also reduced. For health care psychological interventions to be effective, psychosocial factors associated with T1DM should also be promoted by means of adequate campaigns. ■

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