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FEAR OF HYPOGLYCEMIA IN PEDIATRIC PATIENTS WITH TYPE 1 DIABETES AND THEIR PARENTS

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Abstract. *Various medical technologies for managing insulin therapy have been registered worldwide; however, they are not equally accessible to pediatric patients with type 1 diabetes mellitus (T1DM), and the majority of children and adolescents with T1DM do not achieve the recommended therapeutic/glycemic targets. Moreover, parental fear of hypoglycemia leads to suboptimal adherence to the recommended therapeutic regimen (so-called "avoidance behavior related to hypoglycemia"), negatively impacting the metabolic control of their children. Therefore, it is crucial to understand the psychosocial characteristics of children and adolescents with T1DM and their parents in order to provide optimal patient/family-centered care. This review aimed to summarize how fear of hypoglycemia hinders children and adolescents with T1DM and their parents from optimal disease management. Available literature was assessed from the databases: PubMed, ScienceDirect, and Google Scholar. Numerous studies have examined the complexity of daily tasks in the (self-)management of T1DM (including the physical, cognitive, and emotional engagement of pediatric patients and their parents). It has also been confirmed that the occurrence of severe and nocturnal hypoglycemia represents one of the most intense fears related to acute deterioration of a child's health with T1DM. This concern can lead to maladaptive behavior and non-adherence in the form of insulin underdosing, dietary violations, and avoidance of physical activity. Therefore, it is crucial to implement educational interventions for children and adolescents with T1DM and/or their parents to reduce fear of hypoglycemia and improve self-care activities.*

Key words: *children, adolescents, type 1 diabetes, self-care activities, fear of hypoglycemia*

Introduction

Type 1 diabetes mellitus (T1DM) is typically diagnosed in pediatric patients. *The International Diabetes Federation* has projected that the global count of children and adolescents (aged 0–19 years) with T1DM was around 1.2 million in 2021, and approximately 184,100 new cases are identified each year. There is a general agreement among researchers that the T1DM incidence rates continue to increase worldwide. Moreover, T1DM stands as one of the prevalent non-infectious chronic conditions among Serbian youths (aged 0–19 years), displaying a substantial incidence rate of 16.4 per 100,000 individuals. Examination of the *National Diabetes Registry of the Republic of Serbia* (Serbia) has unveiled a considerable yearly surge in recently diagnosed pediatric patients with T1DM, notably in the age groups of 5–9 (17.1 per 100,000 individuals) and 10–14 years (29.2 per 100,000 individuals) [1]. Having T1DM in childhood and adolescence is a stressful condition for both young patients and their parents. Following the identification of newly developed T1DM in pediatric patients, there are shifts in the child's daily schedule and the entire family dynamic. Throughout this period, the essential factor becomes parental backing and engagement, as it plays a crucial role in motivating children and adolescents with T1DM to manage their care routines independently and acclimate to the challenges brought about by this demanding scenario [1].
Therefore, it is crucial to understand the psychosocial characteristics of children and adolescents with T1DM and their parents to provide optimal patient/family-centered care, reduce fear of hypoglycemia, and improve self-care activities.

American Diabetes Association and International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines recommend that glycated hemoglobin A1c (HbA1c) be kept below 7% [2]. Optimal glycemic control can reduce the occurrence and progression of diabetes-related complications. Various medical technologies for managing insulin therapy have been registered worldwide; however, they are not equally accessible to pediatric patients, and most children and adolescents with T1DM do not achieve the recommended therapeutic/glycemic targets [1,3,4]. Despite established standards of self-care, youth with T1DM are particularly at risk as they report a greater fear of hypoglycemia and have poorer glycemic control. Moreover, parental fear of hypoglycemia leads to suboptimal adherence to the recommended therapeutic regimen (so-called "*avoidance behavior related to hypoglycemia*", "*hypoglycemia avoidance behavior*"), negatively impacting the metabolic control of their children [5-8]. Studies showed that highly anxious parents engage more in generally protective behaviors such as keeping their child home from school or social activities because of the T1DM [6], and diabetes-specific protective behaviors such as maintaining blood glucose levels above recommended levels [8]. Other studies revealed that increased levels of distress and excessive worry can have negative implications for the child's psychological well-being, parents' mental health, and family functioning [9,10]. Next, the finding that parental diabetes-related worries were related to more daily protective behaviors (i.e., general protective behavior and hypoglycemia avoidance behavior) aligns with interpersonal affective–motivational theories positing that distress and worries motivate parents toward behavior aimed at

avoiding feared events [6]. Hence, this review aimed to summarize how fear of hypoglycemia hinders children and adolescents with T1DM and their parents from optimal disease management.

Materials and methods

The available literature was evaluated from databases: *PubMed, ScienceDirect, and Google Scholar*; where the following keywords and *MESH* terms were considered, as well as their derivatives, during the search: children, adolescents, type 1 diabetes mellitus, self-care activities, fear of hypoglycemia, parenting stress, parental management, pediatric. A total of 18 articles met the inclusion criteria and were included in the review.

Results and discussion

Self-care

"Self-care can be defined as the execution of essential tasks concerning the well-being and health of children diagnosed with T1DM". These tasks are carried out either autonomously by the pediatric patients themselves or with the assistance of their parents or guardians, particularly when the child's capabilities are insufficient [1]. *Chieng and colleagues* [11] have deduced that the degree of self-care among pediatric T1DM patients is closely intertwined with their developmental stage and chronological age. Additionally, T1DM is linked with a multitude of risks and more than 600 intricate responsibilities that are imperative for the effective management of this chronic ailment [1,12]. These responsibilities encompass not only the physical undertakings crucial for maintaining glycemic levels but also the emotional adaptation to living with a chronic medical condition [1,13]. Hence, using advanced diabetes technologies may be an effort to temper fears about hypoglycemia.

Hypoglycemia

Hypoglycemia, or abnormally low blood glucose (i.e., blood glucose level < 3.9 mmol/L (< 70 mg/dl) is an acute complication of T1DM that results in unpleasant and potentially dangerous symptoms such as shaking, confusion, lethargy, loss of consciousness, seizures, and even death. However, symptoms of hypoglycemia also may occur with higher blood glucose levels, especially if a rapid decrease in blood glucose has occurred. Clinically significant hypoglycemia is diagnosed when the blood glucose level is lower than 3.0 mmol/L (< 54 mg/dl). Severe hypoglycemia is an episode requiring the help of another person, regardless of blood glucose level [14].

Consequently, fear of hypoglycemia is a major problem for many parents of pediatric patients with T1DM, including parents whose children have never experienced severe hypoglycemia, due to concerns about the acute and chronic neurologic effects of hypoglycemia. A disproportionate share of hypoglycemia occurs at night, making nocturnal hypoglycemia a particularly important issue. In the large continuous

glucose monitoring (CGM) *Juvenile Diabetes Research Foundation* study, biochemical hypoglycemia ((CGM glucose concentration lower than 3.3 mmol/l (< 60 mg/dl)) occurred during 8.5% of nights, with 23% of these events lasting more than 2 h [14, 15].

It has been confirmed that the occurrence of severe and nocturnal hypoglycemia represents one of the most intense fears related to acute deterioration of a child's health with T1DM. This concern can lead to maladaptive behavior and dietary violations, avoidance of physical activity, and non-adherence in the form of insulin underdosing [5,7,8].

Day-to-day fluctuation in daily parental and pediatric patients' worries

It is well known that children younger than age six are at an increased risk for hypoglycemia due to high insulin sensitivity, unpredictable eating and physical activity patterns, and difficulty recognizing or communicating symptoms of low blood glucose. Parents with a higher level of responsibility for child management often describe having negative experiences involving struggle, frustration and worry about their child's self-management [8,10,16,17]. Previous research has emphasized that a greater parental fear of hypoglycemia is associated with higher HbA1c levels [8,17,18]. Most studies noted that fear of hypoglycemia was higher in mothers than in fathers [8,10,19]. Moreover, mothers who worry most about hypoglycemia compensate by maintaining their child's blood glucose levels above recommended levels [8]. An explanation could be that mothers are the primary caregivers and more often have the central role in managing the child's routine day-to-day diabetes care. In Serbia, pediatric patients with T1DM gradually acquire the skills to independently manage their condition, often starting in childhood. Initial self-care steps often encompass tasks like glucose monitoring and insulin injections [1].

However, important components of self-care include following a healthy diet, regular physical activity, adherence to insulin therapy, monitoring blood glucose, and having healthy coping and problem-solving skills related to diabetes self-management, particularly problem-solving during episodes of hypoglycemia [1]. Hypoglycemia should be prevented on time because fear of hypoglycemia is often associated with significant psychosocial dysfunction and suboptimal diabetes self-management.

Non-adherence to diet

Non-adherence to the prescribed dietary regimen is quite high. Studies found that parents of children aged 8 to 12 take more actions (changing dietary intake) to avoid hypoglycemia than parents of adolescents. Furthermore, worries about hypoglycemia predicted hypoglycemia avoidance behavior [6,10]. It's in line with our findings [1] that showed that children had less adherence to the prescribed dietary regimen and faced more challenges in managing T1DM during their time in school, which concurs with a Serbian study from 2016. [20]. This suboptimal dietary adherence can have repercussions on metabolic control.

Non-adherence to physical activity

Fear of hypoglycemia has been reported to be a major barrier to engaging in a regular physical activity/exercise program. However, physical activity plays a vital role in the self-management of T1DM. Riaz et al. [21] found that adherence to physical activity advice as the dependent variable shows a significant association with and fear of hypoglycemia.

In the National Guide of Good Clinical Practice for Diagnosing and Treating Diabetes Mellitus, it is recommended to do normal physical activity by the child's age, participate in physical education classes, as well as play sports, except sports in which sudden hypoglycemia can endanger the patient's life (jumping, diving, etc.). In adolescence, active but moderate physical work at home or in the field is advised [22]. The usual recommendations for physical activity include the performance of aerobic physical exercises of moderate intensity, lasting 150 minutes per week - divided into three training sessions; or 75 minutes per week of intense aerobic physical activities; with the possibility of combining moderate and intensive training [22,23]. Despite the benefits and clinical recommendations, studies suggest that children and adolescents with T1DM are not meeting the recommended 60 minutes of moderate to vigorous physical activity per day [1, 22-24].

Non-adherence to the prescribed insulin regimen

Similarly, a factor found to be significantly associated with suboptimal diabetes self-management is fear of insulin [20]. Noncompliance with prescribed treatment schedules is a serious problem worldwide. *Van Name et al.* [25] reported that parents who used insulin pumps were more concerned about their children developing hypoglycemia. *Abitbol* and *Palmert* [26] concluded that parental fear of hypoglycemia is also associated with reluctance to follow insulin dosing recommendations. Consistent with these data, Smudja et al. [1] found that 89.56% of children and adolescents with T1DM were non-adherent to self-care activities. However, compliance with a prescribed insulin therapy regimen, medical nutrition therapy, and engagement in physical activity, constitute essential facets of diabetes self-management.

Glycemic control adherence

Daily glycemic control and diabetes management are complex for children and their caregivers and can lead to stress among all members of a family. Parents often report fear of nocturnal hypoglycemia as a major problem [25]. *Glocker et al.* [27] have estimated that parents are more likely to perceive higher levels of psychosocial burden related to their child’s disease than children and adolescents with T1DM, especially parents of younger children.

In CGM users, a higher parental fear of hypoglycemia correlates with a higher scanning frequency [7,27]. *Smudja et al*. [1] and *Tully et al*. [17] confirm the context

of diabetes-specific functioning among parents of newly diagnosed children; parents of these pediatric patients monitor their children's glucose levels more frequently due to concerns about hypoglycemia. This is a major problem for children who do not have access to CGMs and are afraid of needle sticks. This can lead to family conflicts that can deteriorate suboptimal glycemic control.

Conclusion

Fear of hypoglycemia is an important clinical problem. The greatest worries of parents of children and adolescents with T1DM are related to hypoglycemia during sleep and circumstances during which it would be difficult to detect hypoglycemia. Both manifest hypoglycemia and fear of hypoglycemia remain the major limiting factors for optimal disease management in pediatric patients with T1DM, especially during the night time. Therefore, it is crucial to implement educational interventions for children and adolescents with T1DM and their parents to reduce fear of hypoglycemia and improve self-care activities.

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STRAH OD HIPOGLIKEMIJE KOD PEDIJATRIJSKIH PACIJENATA SA DIJABETESOM TIP 1 I NJIHOVIH RODITELJA

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Sažetak. *Različite medicinske tehnologije za upravljanje inzulinskom terapijom su registrovane širom svijeta; međutim, nisu podjednako dostupne pedijatrijskim pacijentima sa dijabetesom melitus tip 1 (T1DM), a većina djece i adolescenata sa T1DM ne postiže preporučene terapijske/glikemijske ciljeve. Štaviše, roditeljski strah od hipoglikemije uzrokuje suboptimalno pridržavanje preporučenom terapijskom režimu (tzv. "ponašanje u vezi s izbjegavanjem hipoglikemije"), što negativno utječe na metaboličku kontrolu njihove djece. Stoga je ključno razumjeti psihosocijalne karakteristike djece i adolescenata sa T1DM i njihovih roditelja kako bi se pružila optimalna njega usmjerena na pacijenta/porodicu. Ovaj pregledni rad imao je za cilj sumirati kako strah od hipoglikemije onemogućava djecu i adolescente sa T1DM i njihove roditelje za optimalno upravljanje bolešću. Dostupna literatura procijenjena je iz baza podataka: PubMed, ScienceDirect i Google Scholar. Mnogobrojne studije sagledale su složenost svakodnevnih zadataka u (samo)kontroli T1DM (uključujući fizički, kognitivni i emocionalni angažman pedijatrijskih pacijenata i njihovih roditelja). Također, potvrđeno je da pojava teške i noćne hipoglikemije predstavlja jedan od najintenzivnijih strahova vezanih za akutno pogoršanje zdravlja djeteta sa T1DM. Ova zabrinutost može dovesti do maladaptivnog ponašanja i neadherentnosti u vidu subdoziranosti inzulina, prekršaja u ishrani i izbjegavanja fizičke aktivnosti. Stoga je ključno provoditi edukativne intervencije za djecu i adolescente sa T1DM i/ili njihove roditelje kako bi se smanjio strah od hipoglikemije i poboljšale aktivnosti samozbrinjavanja.*

Ključne riječi: *djeca, adolescenti, dijabetes tip 1, aktivnosti samonjege, strah od hipoglikemije*