The Psychosocial Support to Families of Children with Type 1 Diabetes Mellitus (T1DM) in the Diagnostic Phase of the Disease. A Concept Mapping

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ABSTRACT

The purpose of this paper was to investigate the findings of the available literature regarding the role of psychosocial support in the organic and psychosocial management of the disease for the family as a whole. To fulfill this goal, the method of reviewing the existing literature has been implemented and all the relevant necessary data were collected with the aid of two databases, namely Google Scholar and PubMed. The main criteria for selecting the appropriate scientific investigation tools were the necessary research among minors and the time of publication, especially from 2000 onwards. The later was taken into serious consideration, with a specific focus on the articles published after 2015. Psychosocial support at the stage of diagnosis can contribute to a more effective psychosocial adaptation and social work becomes of major importance. The 'crisis intervention' method can be very helpful, but it needs to be empirically substantiated through a qualitative research study.

KEYWORDS: Type 1 diabetes mellitus (T1DM), diagnosis, minors, psychosocial support, psychosocial adjustment, social work, adolenenses

INTRODUCTION

Diabetes mellitus has emerged as one of the main, most serious and frequent chronic diseases of our time causing disability, complications and reduced life expectancy (Heald et al., 2020, as cited in Sun et al., 2022). It belongs to the metabolic diseases and it is recognized as an "endogenous metabolic disorder" (Punthakee et al., 2018). According to the 10th edition of the Diabetes Atlas (IDF Diabetes Atlas, 10th edition, 2021) of the International Diabetes Federation, it affects more than 537 million people worldwide, while in the Greece, according to the data issued by the IDIKA for the year 2021, diabetes patients are over 1,000,000 (1,074,411). Taking into account ELSTAT's data regarding the last official census of the population living in Greece (2021), it is clear that diabetes patients reach 10% of the country's population.

Type 1 diabetes mellitus (T1DM) is an endocrine disease characterized by the destruction of b cells that burst from the pancreas either as the result of an autoimmune process (autoimmune diabetes) or of an unknown etiology (idiopathic diabetes), with the final consequence being the reduced or complete absence of secreted insulin. The idiopathic form of diabetes type 1 is of unknown origin, less severe than the autoimmune form of diabetes type 1 (Kharroubi & Darwish, 2015), it is inherited with high penetrance, it occurs very rarely and it usually affects patients of Asian or African background (Imagawa et al., 2000, as cited in Haak et al., 2019). However, the fact that at least one autoantibody is detected in 85% to 90% of cases (Haak et al., 2019), leads to the conclusion that the vast majority refers to the type of autoimmune diabetes and finally the term TSD1 that has prevailed identifies it. The diagnosis of diabetes mellitus is based on clinical symptoms, which are associated with metabolic imbalance and apparent hyperglycaemia (Insel et al., 2015), and it is based on laboratory methods which evaluate the venous sample. The diagnostic criteria are a random plasma glucose value ≥ 200 mg/dl accompanied by symptoms of hyperglycaemia (polyuria, polydipsia, unexplained weight loss), fasting plasma glucose ≥ 126 mg/dl, fasting is defined as no food intake for the previous 8-12 hours, 2-hour plasma glucose after a glucose tolerance test (75 g glucose loading) ≥ 200 mg/dl and glycosylated haemoglobin ≥ 6.5 (Petersmann et al., 2019). Particularly for autoimmune DM1, it is considered necessary to detect at least one autoantibody such as that of autoantibodies against
pancreatic islet cells (ICA), against insulin (IAA), against b-cell glutamate decarboxylase (GAD), against tyrosine phosphatase (IA-2/IA-2A) and against b-cell zinc transporter 8 (ZnT8) (Haak et al., 2019). In the majority of cases the diagnosis is not made at the onset of the disease as early signs are not clinically visible. In particular, autoimmune destruction of pancreatic b-cells, occurs at a variable rate. It has three distinct identifying stages, where the first two are presymptomatic and it becomes clinically symptomatic (stage three) when approximately 90% of pancreatic b-cells are destroyed (Mayer-Davis et al., 2018). Specifically, the first stage is indicated by the presence of autoantibodies and the onset of beta cell destruction, but with the individual presenting normal glucose levels. In the second stage, as self-destruction continues, dysglycaemia occurs. In the third stage, the symptomatic disease appears (Insel et al., 2015). Children usually present with symptoms of polyuria, polydipsia and weight loss, and about one third (30.2%) present with diabetic ketoacidosis (Dabelea et al., 2014). Diabetic ketoacidosis is a frequently occurring and life-threatening acute complication of newly diagnosed type 1 diabetes (Rewers et al., 2008, as cited in Duca et al., 2019) and therefore the diagnosis coincides with it. According to the research findings of this study which had a sample of 5615 young people aged up to 19 years, a higher prevalence of diabetic ketoacidosis was associated with younger age at the stage of diagnosis, minority race/ethnicity, low family income and lack of private health insurance. Similar conclusions were reached by Duca and colleagues (Duca et al., 2019), who studied 1396 young people with DMD1 under the age of 20 years. They found that in 28%, the diagnosis coincided with the presence of diabetic ketoacidosis. Based on data from various epidemiological studies, it appears that the prevalence of DMD1 is constantly increasing, with an average annual increase of 3- 4% (Norris et al., 2020), and there are approximately 96,000 new diagnoses each year globally (Mayer-Davis et al., 2018).

A recent IDF study estimates that approximately 108,300 children and adolescents “under 15 years of age” will be diagnosed in 2021, and this number increases to 149,500 when the age range is extended to “under 20 years of age” (IDF Diabetes Atlas, 10th edition, 2021). These figures do not represent the total number of patients with T1DM due to its high incidence (new diagnoses) in people over 19 years of age and its prevalence. The prevalence refers to all cases, newly diagnosed and not, however, as shown by Mobasseri et al., (2020), there is no epidemiologically accurate information in the world. To that end, research findings suggest that T1DM occurs at any age, with the highest concentration of cases being in the 10-14 years age group (Rogers et al., 2017; Forga et al., 2015, as cited in DiMeglio et al., 2018). According to Atkinson et al., (2014) peaks of high case concentration occur between 5-7 years or close to puberty, while according to Katsarou et al., (2017), the incidence shows a peak at the age of 12-14 years, although this may be a result of early diagnosis, particularly in high prevalence countries. In contrast, incidence declines after age 14 years and this downward trend continues in adulthood (Xia et al., 2019). Similar observations were made in the meta-analysis study on the prevalence of SDT1 among people aged 15 years and older by Diaz-Valencia and colleagues (2015), which concluded that in 23 of 35 countries, the incidence of T1DM was higher in the age range 0-14 years compared to 15-19 years, with a steady decline in diagnoses after the age of 14 years. As information on T1DM in adulthood is relatively scarce (Xia et al., 2019), a population-based study in China was able to cover all age groups and confirmed the above findings of age-based variation in incidence. Specifically, in the study by Weng et al., (2018), the highest incidence was in the 0-14 age group (1.90), followed by the 15-29 age group (1.02), and then the over-30 age group (0.51). Specific analyses within the 0-14 age group show a peak of incidence in the group of 10-14 years (2.68), followed by that of 5-9 years (1.98) and 1.10 in the 0-4 age group. In addition, for age groups above 15 years, the incidence of type 1 diabetes decreased steadily with age. Finally, the same study showed that 65.3% of newly diagnosed cases were participants older than 20 years of age, demonstrating that T1DM is not ultimately a disease with a juvenile onset, but a disease that can occur and affect all age groups of the global population (Table 1).
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In terms of gender, T1DM appears to affect both sexes equally with a slight predominance in the male gender. In contrast, when the focus is on juvenility, girls show a slight predominance, which may be a result of the association of T1DM with age, as biologically, girls enter the developmental stage of puberty earlier than boys (Weng et al., 2018). Good adaptation to the disease is associated with an effective adjustment to the psychosocial state that the disease creates. According to Kulzer et al., (2021), psychosocial factors central to adaptation are identified as emotional and cognitive acceptance of diabetes, acquisition of knowledge and skills in daily life, identification and modification of behavioral patterns for self-management and, finally, successful coping with disease-related problems. To that end, an effective psychosocial adaptation involves a wide range of emotional and behavioral responses focusing on self-management while maintaining quality of life. However, the diagnosis of a chronic disease causes a wide range of negative psychological reactions, such as uncertainty about the future (Kwakkenbos, 2014, as cited in Dekker & de Groot, 2018), anxiety and depressive disorders (Dekker, 2015, cited in Dekker & de Groot, 2018) in the family system. In this regard, Simms et al, (2016), report that at the time of diagnosis, young people and their parents often report high levels of anxiety, shock, fear and distress, with the most common stressors being a sense of loss of the child's health, fear of short- or long-term complications (e.g., hypoglycaemia, shortened life expectancy), information overload and the realization of intense daily management responsibilities.

It is important to note that, the family plays a key role in the children's adjustment to the disease (Sahithya et al., 2019). Parental adjustment difficulties have been found to be associated with both lower parental effectiveness in managing the child's diabetes and greater child behavioral problems (Lohan, et. al., 2017). Parents are prone to high rates of depression, especially around the time of the diagnosis (Hessler, et al., 2016) and this is associated with poorer diabetes adjustment and management, particularly in younger children (Ducat, 2015, as cited in Young- Hyman, 2016). The existence of diabetes mellitus requires significant lifestyle changes and these necessary management behaviors impose a significant burden on the patient and their family environment. This creates challenges, especially for a developing child (Fritsch et al., 2011, as cited in Sahithya, & Raman, 2019), thus setting the scene for the potential creation of mental disorganization. Furthermore, since most of these tasks are too complex for children to undertake independently, as their intellectual maturity does not enable them to adequately cope with them, parents/caregivers usually take over the supervision of these responsibilities. Therefore, caring for a young child with diabetes can be overwhelming, stressful for parents, and can ultimately affect wider family life (Whittemore et al., 2012 as cited in Kimbell, et al., 2021).

In their secondary research Rechenberg et al., (2017) indicated that past research had concluded that 13% - 21.3% of young people with SDT1 develop symptoms of anxiety (Bernstein, Stockwell, Gallagher, Rosenthal, & Soren, 2013; Herzer & Hood, 2009; Kovacs et al., 1997, as cited in Rechenberg et al., 2017), which are more prevalent in pre-adolescence in boys and in adolescence in girls (Zahn-Waxler et al., 2008, as cited in Rechenberg et al., 2017), and 18.4% (Silverstein et al., 2005, as cited in Rechenberg et al., 2017) are diagnosed with an anxiety disorder during childhood or adolescence. The SEARCH study in the United States found that 14% of the young with diabetes reported mild depression and 8.6% reported moderate to severe depression (Lawrence et al., 2006, as cited in Sahithya & Raman, 2019). Girls reported more symptoms of depression than boys and depression was associated with poorer glycemic control (Lawrence, et. al., 2006, as cited in Delamater, et. al., 2018). Also, the prevalence of depressive symptoms was associated with an increased risk of severe hypoglycaemia, hospital admission with diabetes-related complications and lower

Table 1. Prevalence of SDT1 based on age group

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Prevalence of SDT1</th>
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<tbody>
<tr>
<td>0-4</td>
<td>0.00</td>
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<tr>
<td>5-9</td>
<td>0.50</td>
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<tr>
<td>10-14</td>
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<tr>
<td>15-19</td>
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<tr>
<td>20-24</td>
<td>2.00</td>
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<td>25-29</td>
<td>2.50</td>
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<td>30-34</td>
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Corresponding Author: Georgia Konstantopoulou
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quality of life (Kristensen et al., 2014). The high comorbidity between depression and diabetes lead to the emergence of the new term “diabetes dysphoria”, which is defined as an emotional state that causes significant emotional distress but does not meet the criteria for Major Depressive Disorder (Kreider, 2017). In particular, diabetes dysphoria refers to the negative emotions that result from living with diabetes, which relate to feelings of frustration, hopelessness, anger, guilt, and fear (Esbitt, et al., 2013, as cited in Hagger, et al., 2016).

The Psychosocial support to families

The quality of life, i.e., the personal and social well-being and life satisfaction of young people and their families is at risk. However, Nieuwesteeg et al., (2012, as cited in Delamater, et al., 2018) report that children with DM1 rate their quality of life as similar to that of their peers. This indicates that children do not perceive their condition as limiting, possibly because they learn to socialize from an early age with the condition of diabetes and therefore they cannot compare their lives before and after this condition. In contrast, according to Yi-Frazier et al., (2016) parents rate their children's quality of life as lower than that of their peers. Also, Yi-Frazier et al., (2016) indicated that compared to their parents, the majority of young people with T1DM reported higher general and specific scores on the PedsQL, which is a validated instrument measuring health-related quality of life (Pintus, & Ng, 2019). This fact can possibly be explained by parents taking a more emotional approach to their child's health status, bringing to the fore the new concept of psychosocial quality of life, which is defined as an individual's feelings about their health and well-being, relating to physical, psychological and social functioning, as well as feelings of satisfaction and happiness (Suurmeijer et al., 2001, as cited in Nasirin, 2020).

The link between quality of life and glycemic control was demonstrated by the global TEENs study, which aimed to characterize diabetes-related quality of life (D-HRQOL) considering a global sample of 5,887 young and young adults from 20 countries classified in the age groups of 8–12, 13–18 and 19–25 years. In particular, Anderson et al., (2017) showed that there is a linear relationship between quality of life and glycemic control, namely the lower the glycated hemoglobin, the better quality of life the research participants had. In addition, this research showed that the lower quality of life was seen in the female gender in all age groups and the young adults of the 19-25 group. Nieuwesteeg, et al., (2016) in their research on whether parental stress and the interaction between parents and children 0-7 years is related to their quality of life, showed that the child's self-management ability and quality of life affect parental stress and parents' quality of life. This finding is evidence that T1DM is a family affair and that potentially the empowerment of the child's mental factors will positively influence the child's ability to self-manage, which in turn will positively influence the quality of life of the family system. Clearly, young people with DMD1 are at risk for emotional and behavioral problems, yet the psychological aspect of the disease is often lost as the focus seems to be on the medical aspect, namely achieving glycaemic control (Sahithya, & Raman, 2019). According to the study by Teixeira De Domenico & Chiaradia Mendes-Castillo, (2017) regarding the social support received by adolescents with T1DM and their families, they identified nuclear family, friends, school, religion, health personnel and social media groups as sources of social support. Indeed, family, friends and religion as agents of socialization have an important role in transmitting values, but also in providing emotional support through the personal bonds they create with the individual.

In the search for literature sources, it was not possible to identify different domestic protocols that include the psychosocial dimension of diabetes mellitus, as these may not exist or may not be published. Instead, the study sought for information in the form of guidelines that have been published by the International Society for Pediatric and Adolescent Diabetes (ISPAD) and the American Diabetes Association (ADA). These guidelines are not binding and they are given in the form of recommendations. However they reflect the general philosophy of each of these organizations and the importance of psychosocial support. According to Delamater et al., (2018), the International Association for Pediatric and Adolescent Diabetes (ISPAD) recommends that mental health professionals and experts in the management of diabetes mellitus be included in the multidisciplinary health team care. This is because children and young people with T1DM have a higher incidence of emotional and mental disorders compared to their peers, while children and young people with poor metabolic control are more likely to have psychosocial problems and psychiatric disorders than children with good metabolic control. ISPAD recommends assessment of the developmental progress in all areas of functioning focusing on physical, academic, emotional and social development, referral and maintenance. A psychoeducational or neuropsychological assessment will determine if learning disabilities are present. It also urges the use of regular assessment of the developmental adjustment and the understanding of diabetes management, which will include detection of autonomy and self-management ability. According to Young-Hyman, et al., (2016), the American Diabetes Association (ADA) emphasizes that environmental, social, emotional and behavioral factors (psychosocial factors) affect patients' living, quality of life and their ability to achieve satisfactory medical results. For this reason, he recommends the provision of psychosocial support to all people with diabetes and not exclusively to those with T1DM, as this optimizes health outcomes and health-related quality of life. The ADA makes special reference to the self-care skills taught at diagnosis and specifically to the education that
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occurs during initial hospitalization. Specifically, as Chiang et al., (2018) report, the ADA suggests that people with diabetes should be assessed and receive education until they become competent in diabetes self-management skills. In the De Wit et al., (2014) research sample, it was evident that psychosocial care is available to many adolescents worldwide, yet 30% of them do not have access to a mental health professional. The timing of diagnosis, which disrupts the mental balance of families, is not always accompanied by support interventions, and any interventions that are carried out do not include an initial assessment of psychosocial functioning. At the same time, according to the report of the Association of Children’s Diabetes Clinicians (ACDC) in the UK, access to mental health care and psychological support is not consistent (Ng, et al., 2020), which was also evident in the study by De Wit, et al., (2014). Ng, et al., (2022) suggested that clinicians should be able to use psychological assessment tools to help detect early psychological distress. Hence, if necessary, immediate referral to psychological services will be available to enable intervention. They report that psychological interventions such as solution-focused therapy, coping skills training, cognitive behavioral therapy or family-focused interventions aimed at supporting the emotional well-being and mental health of people with T1DM have shown significant improvements in patients' quality of life and overall diabetes management (Ng, et al., 2022). The research by Rankin et al., (2016) investigated the information and support needs of parents when their child is diagnosed with T1DM, with the ultimate aim of finding appropriate ways to provide a framework for future improvement of the support provided. To this end, with 54 parents of children aged 2-12 years from four pediatric clinics in Scotland, UK, they conducted a qualitative social research study through semi-structured in-depth interviews, thus ensuring the flexibility required for parents to share their own perceptions and experiences. According to parents' experiences during their hospital stay, they experienced challenges and difficulties regarding the wealth of information delivered using unfamiliar terminology (e.g., ketones) that they could neither fully understand nor naturally assimilate (Rankin et al., 2016). Table 2

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<tr>
<th>RESEARCH</th>
<th>TITLE</th>
<th>THEME</th>
<th>QUESTIONS</th>
<th>CONCLUSIONS</th>
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<tbody>
<tr>
<td>Yi-Frazier, J. P., Hilliard, M. E., Fino, N. F., Naughton, M. J., Liese, A. D., Hockett, C. W., ... &amp; Lawrence, J. M. (2016)</td>
<td>«Whose quality of life is it anyway? Discrepancies between youth and parent health-related quality of life ratings in type 1 and type 2 diabetes».</td>
<td>Health-related quality of life (HRQOL) is a critical diabetes outcome, yet differences between youth and parent-proxy ratings can make interpretation difficult. This study aims to explore potential differences between self- and parent-reports of Pediatric Quality of Life Inventory (PedsQL) scores from youth with type 1 (T1D) or type 2 diabetes (T2D) and to evaluate associations between discrepancies, PedsQL scores, and glycemic control (HbA1c).</td>
<td>Discrepancy existed between youth and parent-proxy reports of generic and diabetes PedsQL scores in T1D and T2D (all p values &lt; 0.01). Higher (more favorable) ratings were reported by youth except for those 5-7-years old, where parents' scores were higher. When parent-proxy scores were higher, discrepancies were largest when the child reported low PedsQL scores. Higher HbA1c was associated with larger discrepancies (youth scores higher) for adolescents with T1D.</td>
<td>Discrepant PedsQL ratings suggest that parents may often underestimate youths' HRQOL except in the youngest children. Although examining both reports is optimal, the youth report should be prioritized, particularly for young children with T1D and for adolescents with either T1D or T2D.</td>
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<td>Pintus, D., &amp; Ng, S. M. (2019)</td>
<td>«Freestyle liberal flash glucose monitoring improves patient quality of life measures in children with Type 1 diabetes»</td>
<td>In 2017 the UK's Association of Children's Diabetes Clinicians (ACDC) launched a national educational package to</td>
<td>52 children (33 M,19 F) with a mean age of 11.6 yrs (range 4 m-17.2 yrs) were evaluated. Mean HbA1c 3 months post Freestyle Flash GM Freestyle Flash GM technology associated with appropriate education and regular support by healthcare professionals improves</td>
<td>Freestyle Flash GM technology associated with appropriate education and regular support by healthcare professionals improves</td>
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<td>mellitus (T1DM) with appropriate provision of education and support by healthcare professionals.</td>
<td>provide training in the use of Freestyle Flash glucose monitoring (GM) to healthcare professionals. To evaluate metabolic outcomes and quality of life (QoL) of children with T1DM trained in the use of the Freestyle Flash GM system adopting the ACDC guidelines.</td>
<td>showed a significant improvement when compared with HbA1c values at 12-, 6- and 3-months pre-Freestyle (p-value 0.040, 0.040, 0.012 respectively). This improvement was not sustained at 6 and 12 months (p-value 0.15, 0.50). The PedsQL3.2 diabetes scores demonstrated significant improvement in patient QoL, reduction of diabetes symptoms and treatment barriers following the use of the new technology.</td>
<td>patient quality of life measures in children with T1DM.</td>
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<td>Saoji, N., Palta, M., Young, H. N., Moreno, M. A., Rajamanickam, V., &amp; Cox, E. D. (2018) « The relationship of type 1 diabetes self-management barriers to child and parent quality of life: a US cross-sectional study».</td>
<td>Families of children and adolescents with Type 1 diabetes experience self-management challenges that negatively impact diabetes control. This study assesses whether self-management challenges are also associated with quality of life (QoL) for children and adolescents with Type 1 diabetes and their parents.</td>
<td>Children aged 8-12 years (n = 135), adolescents aged 13-16 years (n = 132) and their parents completed QOL assessments (diabetes-specific QOL from the PedsQL Diabetes Module or the Family Impact Module, both scaled 0-100) and a validated survey of up to six self-management barriers [PRISM; scaled 1 (low) to 5 (high)]. Regression coefficients were calculated to assess the association of self-management barriers with child and adolescent diabetes-specific QOL or parent QOL, including interaction effects to assess the stability of the associations.</td>
<td>Single-unit differences in self-management barrier scores are associated with clinically meaningful differences in QOL for children and parents. Interventions specifically tailored to address individual self-management barriers may improve both diabetes control and QOL.</td>
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<th>«Factors associated with diabetes-specific health-related quality of life in youth with type 1 diabetes: the Global TEENs Study»</th>
<th>The objective was to characterize diabetes-specific health-related quality of life (D-HRQOL) in a global sample of youth and young adults with type 1 diabetes (T1D) and to identify the main factors associated with quality of life.</th>
<th>The TEENs study was an international, cross-sectional study of youth, 8–25 years of age, with T1D. Participants (N = 5,887) were seen in clinical sites in 20 countries across 5 continents enrolled for 3 predetermined age groups: 8–12, 13–18, and 19–25 years of age. To assess D-HRQOL, participants completed the PedsQL Diabetes Module 3.0 and were interviewed about family-related factors. Specifics about treatment regimen and self-management behaviors were collected from medical records.</th>
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<tbody>
<tr>
<td>Nieuwesteeg, et al. (2016)</td>
<td>“The relationship between parenting stress and parent–child interaction with health outcomes in the youngest patients with type 1 diabetes (0–7 years)”</td>
<td>What is the relationship between parental stress and parent–child interaction and health outcomes in younger patients with type 1 diabetes (0–7 years)</td>
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<td>The results support the notion that diabetes does not only affect the child with T1DM: T1DM is a family disease, as parenting factors (like stress and parent–child interactions) are associated with important child outcomes. Therefore, it is important for healthcare providers to not only focus on the child with T1DM, but also on the family system.</td>
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<td>Author(s)</td>
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<tr>
<td>Sahithya, &amp; Raman, 2019</td>
<td>‘Psychosocial issues in Type 1 Diabetes Mellitus - A review and proposal of a model for evaluation and management in the Indian context’</td>
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<tr>
<td>Teixeira De Domenico &amp; Chiaradia Mendes-Castillo, (2017)</td>
<td>“Social support for the child with type 1 diabetes and their family”</td>
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It was possible to collect evidence in the literature on social support for children with type 1 diabetes mellitus and their families. One of the main sources of social support was the groups formed in social media. This should arouse the interest of the professionals in a special way, given the impact and the ease in the interactions that they can provoke. In addition, due to the greater number of international papers, it is desirable to publish more articles in the national context, better characterizing the country's reality and resulting in more appropriate interventions.
Young-Hyman, et al. (2016) | “Psychosocial care for people with diabetes: a position statement of the American Diabetes Association” | This article provides diabetes care providers with evidence-based guidelines for psychosocial assessment and care of PWD and their families | Thus, individuals with diabetes and their families are challenged with complex, multifaceted issues when integrating diabetes care into daily life. To promote optimal medical outcomes and psychological well-being, patient-centered care is essential, defined as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” | Complex environmental, social, behavioral, and emotional factors, known as psychosocial factors, influence living with diabetes, both type 1 and type 2, and achieving satisfactory medical outcomes and psychological well-being. 

Chiang et al. (2018) | “Type 1 diabetes in children and adolescents: a position statement by the American Diabetes Association” | Diabetes management for children must not be extrapolated from adult diabetes care. In caring for children and adolescents, clinicians need to be mindful of the child’s evolving developmental stages and must adapt care to the child’s needs and circumstances. | pediatric-onset diabetes is different from adult diabetes because of its distinct epidemiology, pathophysiology, developmental considerations, and response to therapy | Timely anticipatory guidance and care coordination will enable a seamless child/adolescent/young adult transition for both the developing patient and his or her family. 

Ng, et al., (2022) | “Managing the psychosocial impact of type 1 diabetes in young people” | Managing the psychosocial impact (Depression and anxiety, Disordered eating and diabulimia) of type 1 diabetes in young people | They conducted a systematic review using the search terms “children,” “Adolescents,” “type 1 diabetes,” “psychological,” “psychology,” “mental health,” “well-being,” “anxiety,” and “depression” in PubMed, Scopus, CINAHL, Clinical Evidence, the Cochrane Collaboration, and PsychInfo from 2000 to January 2022. We reviewed the reference lists of publications. | Work with young people using specific and measurable goals to develop ways to manage their diabetes in a sustainable way, asking and understanding what is important to them when prioritising their diabetes management. Encourage them to engage with peer support. Identify what is important to the patient and work towards this.
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| Rankin et al. (2016) | “Parents' information and support needs when their child is diagnosed with type 1 diabetes: a qualitative study” | The aim of this study was to describe and explore parents' information and support needs when their child is diagnosed with type 1 diabetes, including their views about the timing and chronology of current support provision. | The objective was to identify ways in which parents could be better supported in the future. | They suggest that professionals should consider the timing and chronology of support provision to ensure that parents' emotional and informational needs are addressed when their child is diagnosed and that practical advice and further emotional support are provided thereafter, which takes account of their day-to-day experiences of caring for their child. |

Psychosocial interventions in the diagnosis phase of the disease

The psychosocial adaptation of minors and their families can be facilitated through support programs. Rearick et al., (2011) explored the experiences of parents with children up to 12 years of age who had recently been diagnosed with T1DM following twelve months of peer-based social support that they themselves received based on the Social Support to Empower Parents (STEP) intervention. In this program, parent mentors, who were selected by STEP organizers through the criteria of successful disease management in their own children, provided support to parents of newly diagnosed children through home visits and telephone conversations. Their strategy focused on establishing a good collaboration with STEP team members and educating parents on how to support their children, actively listen, and identify the community resources. The goal of the program, was to establish and maintain a supportive mentoring relationship with each participating parent, communicate about key issues related to daily living, assist parents to identify and address their unmet needs, and finally, assist mothers on how to identify and utilize existing social support resources both in their family and in the community. Findings showed that the STEP intervention was useful, providing participants with emotional and informative social support that led to improved parental psychosocial functioning, which included a better perception of the social support and of the impact of the child's diagnosis on daily life.

Mackey et al., (2016, as cited in Simms et. al., 2016) conducted a pilot intervention with a target group of parents of newly diagnosed children aged 1-6 years using trained telephone counsellors and peer parents. Findings showed that providing an intervention within the first year of diagnosis provided some protection against worsening glycaemic control in children whose mothers had increased symptoms of depression at the time of initial diagnosis. A parent-focused program is the Triple P - Positive Parenting Program. The theoretical background of this program is social learning principles, cognitive-behavioral and developmental theory and its aim is to prevent behavioral and emotional difficulties in the minor by providing psychoeducation to parents to increase their knowledge, skills and confidence (Lohan et al., 2016). The types of this programme appear to be effective in terms of family functioning, as shown by Westruppet et al., (2014, as cited in Lohan et al. 2016) who evaluated Standard Triple P for parents of children with T1DM aged 4-12. Similar were the findings of Doherty, Calam and Sanders (2019, as cited in Lohan et al., 2016) who evaluated the Self-Directed Teen Triple P work- book having as a target group parents of adolescents aged 11-17 years with T1DM. Positive Parenting for Healthy Living is an intervention program that uses positive language, emphasizing on improving family functioning rather than correcting deficits (Morawska et al., 2020). According to Lohan, et al., (2016) Positive Parenting for Healthy Living is a new approach that focuses on shifting the focus of diabetes management from a purely traditional medical approach to a more holistic one that includes parental intervention as a component of the disease management plan. Morawska et al., (2020) evaluating this program with parents of children with T1DM aged 2-10 years in Australia, highlighted that the majority of parents reported that the program had helped them to effectively deal with their child's behavior and the problems that arose in their family.

Another intervention program which is both of educational and psychosocial nature, is the “Type 1, Year 1” (T1y1) program implemented in Philadelphia, USA. This program is the result of an effort to improve the quality of care and support that young people and their families receive during the first year following a diagnosis of SDT1 (Hawkes et al., 2019). Indeed, to evaluate its effectiveness in glycaemic control and effective disease management Hawkes et al., (2019) conducted a study comparing children who had received the standard diabetes education provided and those who had been enrolled in the 'Type 1, Year 1' (T1y1). Hawkes...
et al., (2019) found that glycaemic control, as reflected by the glycosylated haemoglobin levels of the children in the program, was improved compared to the control group at 6, 12 and 18 months after diagnosis, yet this improvement was not statistically significant at 24 months. Nevertheless, this study was evaluating the success of this intervention based on glycaemic control and it was not designed to assess whether it had an impact on psychosocial issues related to the disease, such as quality of life or diabetes distress. They also noted that the impact of the program was more significant in children aged 5-12 years, possibly because parents play a more active role in diabetes care in children than in adolescents.

CONCLUSIONS

T1DM is an endogenous metabolic disorder that has been on the rise in recent years, resulting in an increase in its global incidence and prevalence. The highest incidence is found in the minority age group, specifically in the 10-14 years age group, although T1DM can occur at any age of human life. At this age, and generally in minors, children are an integral part of the family, whatever its structure or dynamics. Consequently, any events that influence children also influence the family system through the interaction of its members. For this reason, minors were chosen for the diagnosis, as in the majority of cases the diabetes patients live in the family environment and the care is provided entirely or partially by the parents. The timing of diagnosis and the subsequent first year of living with T1DM trigger a series of adjustment reactions characterized by adverse emotions and reminiscent of the stages of mourning. It was found that these initial reactions are often resolved within the first year, but maladaptation in this initial phase puts minors at risk for subsequent high prevalence of psychosocial and medical difficulties, i.e. co-existing psychiatric disorders, treatment regimen compliance, stigma and social isolation. Thus, emphasis was placed on psychosocial comorbidity and how it affects adaptation and disease management. To this effect, the focus was on analyzing anxiety disorders, depressive disorders and food intake disorders, while identifying disorders exclusive to people with diabetes mellitus, such as fear of hypoglycaemia, needle phobia, diabetes dysphoria and diabetes mellitus. The presence of psychological comorbidities and high rates of psychological decline in young people showed that these are of particular concern not only because of the burden and the challenges they present to the daily life and social functioning of the young, but also because of their potentially detrimental impact on the medical dimension of diabetes mellitus. Indeed, such problems may increase the risk of poor self-management and contribute to poorer glycaemic control and quality of life, as they are interdependent.

It was evident that psychosocial adaptation, which refers to processes of accepting the new reality and seeking new ways of managing the disease, is divided into effective or good adaptation, which contributes to good health, and detrimental or bad adaptation, which leads to adverse health outcomes. Regional components of psychosocial adaptation are emotional and cognitive acceptance of diabetes, acquisition of knowledge and skills in daily life, identification and modification of behavioral patterns with the aim of self-management and, finally, successful coping with disease-related problems (Kulzer et al., 2021). However, due to the complex nature of the disease, which requires multiple daily self-management behaviors, additional challenges arise in the form of emotional difficulties faced by people with diabetes and their caregivers. Since the ultimate goal is to achieve beneficial psychosocial adjustment, as a preventive factor of psychosocial and medical problems, it was considered necessary to involve psychosocial support in the diagnosis phase. Effective psychosocial adaptation includes a wide range of emotional and behavioral responses with a focus on self-management, as it enhances the autonomy and self-esteem of the T1DM patient, while maintaining a good quality of life. Psychosocial support to the family living with diabetes is not exclusively focused on relieving the mental distress brought about by the diagnosis, namely psychological support, but is also a helpful means of preventing social isolation and maintaining pre-diagnosis functioning. The diabetic team was identified as an important provider of psychosocial support, since it is the one that interacts with the family at the moment of diagnosis, which is possibly the most critical moment as they come into first contact with the complex condition of T1DM and experience the shock of the diagnosis. Due to the fact that health care providers follow service protocols, one of the initial objectives of the study was to make a comparison between them, as the theoretical assumption was that psychosocial support differs according to the prevalence of the disease and the social policy model followed by each country. Unfortunately, the collection of such protocols was not achieved, possibly because they do not exist or are not published in scientific journals which were the source of information on which the writing of this paper was based. This fact constitutes a limitation of the study. Nevertheless, instead, we retrieved the inventory of the recommendations of the International Society for Pediatric and Adolescent Diabetes (ISPAD) and the American Diabetes Association (ADA) and carried out a summary, which reflects the philosophy of the relevant international bodies in the context of psychosocial care. The adherence to their recommendations was evaluated through the global study by De Wit et al., (2014). The research showed that the timing of the diagnosis was not always accompanied by support interventions that could help avoid the potential development of symptoms of psychological distress, particularly for caregivers who perceive the impact of the diagnosis more immediately than children, while any interventions that do
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take place are overwhelmingly devoid of the necessary psychosocial assessment material. Psychosocial support interventions are appropriate to complement medical management interventions, so that there is multilevel and holistic support for the person with DMD1 and their family context. Thus, research on the literature was conducted and we identified the factors which address management more broadly. These included psychoeducational activities such as Social Support to Empower Parents (STEP), Triple P - Positive Parenting Program, Positive Parenting for Healthy Living and Type 1, Year 1 (T1y1). These interventions, although not entirely focused on the time of diagnosis which this paper considers important, showed good results regarding parental psychosocial functioning, family functioning, children's behavior and emotions, hypoglycaemia-related anxiety and glycaemic control, which confirms the theoretical hypothesis. However, early interventions during the diagnosis, even of short duration, are considered to contribute a lot to psychosocial adjustment, as they provide emotional support to the minor and his or her caregivers, they teach positive parenting practices that enhance autonomy rather than overprotectiveness and they help to link the family to community resources. T1DM is a disease that affects the whole family, so any interventions should target both the patient and the family. For this reason, this paper considers such interventions constructive and proposes their relevant design and implementation through the participation of social workers as part of the diabetic team. Family is one of the domains in which social work science is directly involved, having even developed a specific method of intervention, “Social Work with Families”. The diagnosis of a chronic disease in a family member upsets the family's equilibrium, its homeostasis and it may lead to a crisis. The rapid invasion of T1DM in a child is a traumatic event for the family, as there is an immediate awareness of mortality, since, as previously mentioned, one third of new diagnoses follows the diabetic ketoacidosis diagnosis, which is a life-threatening acute complication of T1DM. Nevertheless, even in cases where the diagnosis is not made after diabetic ketoacidosis, the visible risk of direct and indirect complications is a threat in itself. According to the study of Landolt et al., (2002, as cited in Simms, & Monaghan, 2016) the family often perceives the diagnosis as a cause of dissolution. The findings of their study showed that 51% of mothers and 42% of fathers experienced clinically significant symptoms of PTSD 1 year after diagnosis. Still the family often fails to cope with this situation and implement the usual problem solving mechanisms which were successful in the past. This fact combined with the traumatic or threatening event of the diagnosis, make up a crisis situation and therefore the social work method of "crisis intervention" can be effective. "Crisis intervention" as a method which aims to reduce the risk inherent in the crisis situation and restore balance.

Caregivers should immediately overcome the shock of diagnosis, recover their strengths and provide an environment that reinforces safe disease management, as T1DM is a condition of daily and demanding vigilance. Crisis intervention, as a model of psychosocial support in T1DM, involves carrying out direct and indirect actions to shape the appropriate conditions to avoid crisis and enhance good adaptation. The direct actions are focused on releasing the unfavorable emotions, reassuring the patient and the family and helping minors and parents identify and activate defense mechanisms in order to develop effective coping strategies that will not only prevent the crisis from developing, but also contribute to an effective and beneficial psychosocial adaptation. At the same time, the implementation of indirect interventions with the wider family environment will have a catalytic effect, as it will activate the community network through which social support flows. Motivating the family and linking them with peer groups of parents and children will contribute to the task by providing emotional support and information and creating bonds between them that will facilitate the path of living with diabetes mellitus.

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