Quality of life and Psychological Factors in children and adolescents with Type 1 Diabetes Mellitus (T1DM): A critical literature review

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Abstract

Type 1 diabetes mellitus (T1DM) is a chronic metabolic disease of autoimmune origin that occurs predominantly in children and adolescents, following them throughout their lives. Its treatment requires the systematic administration of insulin and the establishment of a specific lifestyle from childhood to late adulthood. Although new technologies have contributed to a better treatment approach for young people with diabetes, studies have shown that the disease continues to have a significant impact on the patients' lives. Given the complexity of the condition and the young age of the patients, the multidisciplinary treatment team should put emphasis on psychosocial interventions that will enhance self-management of the condition and contribute to improving the quality of life of patients.

Key words: Type 1 Diabetes Mellitus, quality of life, psychological factors, psychosocial interventions, Health Psychology.

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Aim of the Review

The aim of this critical review is to identify, through the current literature, the various psychological and social factors that affect children and adolescents with Type 1 Diabetes Mellitus (T1DM) and determine the possible impact on their quality of life. In this context, it is also attempted to highlight the role of the health psychologist as a member of the multidisciplinary team that should be formed in order to successfully approach the children and adolescents with T1DM.

Methods

This is a narrative review of the relevant literature, which included research articles (observational studies, systematic reviews, meta-analyses, clinical trials) published between 2002-2022 in English and Greek, retrieved from PubMed/Medline and Google Scholar databases. Due to the nature of the review, no strict selection criteria were set for the articles reviewed and included. The keywords "Type 1 Diabetes Mellitus", "Social factors", "Psychological factors", "Quality of Life" and the algorithm "Type 1 diabetes" AND "Soci*" AND "Psych*" AND "Quality of Life" were used to identify studies that correlated T1DM with psychosocial factors and quality of life.

Type 1 diabetes mellitus (T1DM) as a chronic disease

Pathogenesis of T1DM

T1DM is a chronic autoimmune disease that leads to destruction of the pancreatic cells responsible for insulin production (beta cells). Insulin is an essential anabolic hormone which plays a variety of roles in the metabolism of glucose, fats, proteins and electrolytes. More specifically, insulin pushes glucose to enter muscle and fat cells, stimulates the storage of glucose in the liver as glycogen, synthesizes fatty acids, stimulates amino acid uptake, inhibits fat breakdown in adipose tissue, and stimulates potassium uptake in cells[1].

Autoimmune beta-cell destruction lasts for months or years, leads to complete insulin deficiency and is of unknown etiology. Nevertheless, specific genetic and genomic associations have been identified, leading to the assumption that T1DM is an inherited disease. Thus, in the

case of monozygotic twins, the risk of the second twin developing T1DM is 65%, if the first twin already suffers from the disease[2].

The circulation of autoantibodies (i.e. biological macromolecules that are directed against the body's own cells) has been shown to occur in people who have or are at risk of developing T1DM. The higher the titer of these antibodies or the greater the number of different antibodies detected, the greater the risk of developing the disease[3]. In fact, in individuals with a genetic predisposition, it is believed that the factors triggering the autoimmune process of beta-cell destruction are mainly environmental, namely viral infections, environmental toxins and early exposure to dietary factors[4].

Epidemiological data on T1DM

T1DM is one of the most common chronic diseases of childhood, but it can also start later in life. There has been a steady increase in the incidence and prevalence of T1DM so that it now affects 5% to 10% of all diabetic patients. In the US, it is estimated that 1.24 million people have T1DM and this number is expected to increase to 5 million by 2050. The most common age of onset is between 4 to 6 years and in early adolescence (10 to 14 years). Worldwide, there is also considerable geographical variation in incidence. The highest incidence rates are recorded in Finland and other Northern European countries with rates around 400 times higher than those observed in China and Venezuela, where the lowest incidence is recorded [5,6].

Clinical features and complications of T1DM

The development of T1DM takes place in 3 stages. In stage 1 the child is asymptomatic, with normal fasting glucose, normal glucose tolerance and the presence of at least two autoantibodies in the blood. In stage 2, in addition to the autoantibodies, the child shows symptoms of dysglycaemia, i.e. impaired fasting glucose (fasting glucose 100-125 mg/dl) and/or impaired glucose tolerance (2-hour post-75 gm glucose load glucose between 140-199 mg/dl). In stage 3, signs and symptoms of diabetes appear[7].

The physical symptoms that patients, especially young people, have to deal with include polydipsia, polyuria, polyphagia and nocturnal enuresis. Patients often show catabolic symptoms, with dramatic weight loss, increased lipolysis, loss of muscle mass and muscle weakness. Insulin deficiency results in marked hyperglycaemia resulting in blurred vision, electrolyte imbalances and dehydration. If symptoms are not recognized in time, then there is a risk of diabetic ketoacidosis, a condition classified as a medical emergency and requiring immediate hospitalization and treatment as the person faces the risk of coma and death[8].

Chronic dysregulated T1DM can cause a variety of health problems due to chronic hyperglycaemia. Thus, patients have an increased risk of vascular disease, coronary artery disease and strokes, renal failure, retinopathy, neuropathy, dermatopathy and lower limb ulcers, as well as local and systemic infections. People with T1DM also have a higher risk of developing other autoimmune conditions such as autoimmune thyroiditis and gastritis[9].

Treatment and follow-up T1DM

The treatment of T1DM is based on medication and a healthy lifestyle in terms of both diet and physical activity.

T1DM is regulated by the use of insulin, which is administered parenterally, i.e. subcutaneously and intravenously, but not orally. There are several insulin categories and formulations, which differ in time of peak action and duration of action. In order to achieve tight glycaemic control and to avoid hypoglycaemia, young people with T1DM need multiple subcutaneous injections per day, often up to three, some of which are accompanied by self-monitoring of capillary glucose (6-10 times per day), using lancets. Therefore, children and adolescents with T1DM need to undergo a great number of punctures per day[10].

An alternative form of insulin administration, continuous subcutaneous insulin infusion or insulin pump therapy, is often used for children with T1DM. Large registries tracking the treatment outcomes of patients with T1DM and long-term follow-up studies suggest that children treated with continuous subcutaneous insulin infusion have lower glycosylated haemoglobin levels and lower rates of hypoglycaemia. Similarly, insulin pump studies incorporating continuous glucose monitoring devices that demonstrate significant improvement in both glycemic control and reduction in hypoglycemia in pediatric patients with suboptimal blood glucose control at baseline[9].

Lifestyle interventions are important for paediatric patients with T1DM and contribute to maintaining good health, preventing cardiovascular disease and good glycaemic control. Lifestyle modifications include healthy diet and regular exercise. Education of patients and their families on dietary approaches helps to mitigate the hypoglycaemic and hyperglycaemic effects of exercise and is part of patient self-management and support and should be provided by a qualified nutritionist, a medical exercise specialist and the paediatric endocrinologist. Education should be provided at diagnosis. Quarterly visits to the paediatric endocrinologist and involvement of the multidisciplinary team (Figure 1) ensure ongoing education throughout childhood and adolescence[9]. In terms of exercise, 60 minutes of moderate to vigorous aerobic exercise daily and muscle strengthening exercise for at least 3 times per week is recommended. At the same time, the patient should be trained to perceive and cope with exercise-induced hypoglycaemia, perform capillary blood glucose self-monitoring before exercise and

make sure to have access to carbohydrates throughout the exercise[11]. Regarding nutritional interventions, good glycaemic control requires control of carbohydrate intake and control of calorie balance. Each dietary plan must be individualised: family habits, food preferences, religious or cultural needs, schedules, physical activity and the patient's and family's self-management skills are taken into consideration. Nutritional guidelines should assess any changes in food preferences over time, access to specific foods, the patient's weight status, overall cardiovascular risk and the likelihood of other eating disorders. Adherence to dietary guidelines is associated with better glycemic control in young people with T1DM[12]. Carbohydrate measurement is fundamental as this will largely underpin the amount of insulin administered. It has been shown that a 15% or 10 gr carbohydrate deviation is unlikely to cause significant hyperglycaemia or hypoglycaemia, respectively[13].

Figure : The multidisciplinary team required for the proper management of a child/adolescent with type 1 diabetes mellitus.
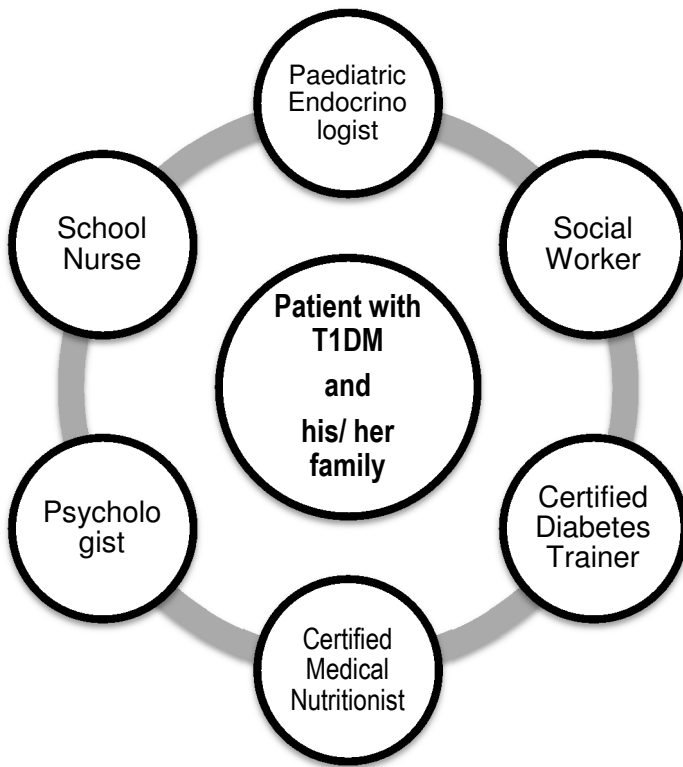
Quality of life

Introductory concepts for quality of life

There are different views on the definition and the determinants of quality of life in the literature. According to the prevailing view, quality of life is intertwined with well-being and meeting the overall needs of human beings. Thus, the World Health Organization (WHO) defines quality of life (QoL) as the sum of individuals' perceptions of their place in life, in the context of the culture and value systems in which they live and develop and in relation to their expectations, goals and concerns. It is the subjective feeling of satisfaction with life, encompassing all areas of daily life and all aspects of the individual's experience, including elements of the biopsychosocial-spiritual model. Health-related quality of life (HRQoL) is a concept that refers to the impact on one person's perceptions of life, functions and social opportunities that are affected by health-related situations such as illness, injury and treatment. The concept includes patients' perceptions of their current functional status, their satisfaction with it and their beliefs about the functional status they consider to be the ideal one. The way each individual perceives illness and treatment plays an important role and this seems to depend on personal experience. It is a multidimensional indicator, which consists of at least three broader dimensions: physical, mental and social that are affected by the illness and/or treatment of the illness[14].

The complexity of self-care needs in T1DM has been reported to have a critical impact on patients' HRQoL[15,16]. HRQoL of patients with T1DM has been widely studied in relation to other aspects such as the presence of chronic complications[17], glycemic control[18], disease duration[19] and the effect of structured educational programs[20, 21]. Determining the impact of disease on patients' lives is crucial in clinical practice because it helps clinicians to identify patients' needs, barriers to self-care as well as to make clinical decisions and improve communication with patients. Disease-specific HRQoL measurement tools have been shown to be more useful than generic tools, as they are more sensitive to changes in the specific disease and provide more detailed information about it[22]. Tools that have been used to assess HRQoL in T1DM are the PedsQL 3.0 Type 1 Diabetes Module questionnaire[23], the ViDA questionnaire for T1DM, the Diabetes Health Profile (DHP-1), the Japanese insulin dependent diabetic patient quality of life scale (JAPIDQOL), the DAWN2 Impact of Diabetes Profile (DIDP) and others[24], which are applied on a case-by-case basis.

Quality of life in patients with T1DM

The presence of T1DM alone implies a reduced HRQoL, when compared to the corresponding quality of life of people without T1DM[25]. More specifically, a recent meta-analysis of 31 qualitative study prototypes by Vanstone et al[26] showed that the long-term and short-term negative consequences of uncontrolled T1DM affect all aspects of patients' lives: physical, emotional and social. The effect in each domain is extensive and the effects interact across domains. Uncontrolled blood sugar levels lead to significant psychological distress, negative mood, cognitive difficulties, irritable or aggressive behavior and related problems with relationships, self-image and self-confidence. Emotional

distress is widespread and often not adequately addressed by healthcare providers. Patients live in fear of complications from diabetes in the long term, as well as in the short term, they worry about the personal, social and occupational consequences of hypoglycaemic episodes and may limit normal activities such as driving or socialising.

The onset of T1DM in childhood implies a lifelong health problem. Given the long-term exposure to the detrimental effects of dysglycemia and the risk of developing diabetes-related complications, intensification of treatment options is critical. Thus, increased treatment demands and the pursuit of optimal glycemic targets disrupt the normal activities of children and their families[9].

Classic intensified insulin therapy regimens involve multiple subcutaneous injections daily in order to administer insulin and several capillary glucose measurements after fingertip pricking with special scalpels. In fact, many times, adolescent patients and parents of children with T1DM are asked to make complex decisions about the dosage of insulin to be administered based on capillary blood glucose values. In recent years, advances in therapeutic technology in diabetes have introduced continuous insulin infusion devices that are placed subcutaneously and, as a result, patients avoid self-administration of insulin which are accompanied by multiple injections. More and more studies show that the use of these devices improves the quality of life of patients with DM1[27]. The adherence to treatment for young patients therefore requires painstaking compliance to a daily routine of medication as well as dietary and physical. The role of lifestyle modification in improving patients' HRQoL is poorly understood. Some studies have shown that lifestyle factors such as proper leisure time physical activity, healthy diet and adequate sleep and work time are associated with better HRQoL among people with and without diabetes, despite the fact that many young people find it quite difficult to follow the rules required to adhere to treatment guidelines, especially under peer pressure[28].

Accumulating research data suggest that the duration of T1DM is inversely related to HRQoL, although some small population studies have failed to demonstrate the same. In contrast, the presence of diabetes-related complications appeared to be associated with symptoms of anxiety and depression and low HRQoL. Regarding glycaemic control, it appeared that patients with poor control, as expressed by glycosylated haemoglobin, had lower HRQoL. Female gender and older age of patients were also associated with lower HRQoL. Patients' perceptions of the condition, namely that it is a stressful, distressing or difficult condition to manage and that it may have adverse health effects, are associated with low HRQoL and depression[29].

Finally, T1DM also has an impact on the quality of life of the parents-caregivers of diabetic persons. Increased caregiving burden has been found to be associated with poorer HRQoL in mothers of patients with T1DM[30], at a time when parents report that it is difficult to bear the emotional burden of diabetes for themselves and their children as well

as the burden of finding suitable diabetes specialists to assist their children to manage their diabetes [31].

Psychological and psychosocial factors in DM1

The impact of psychological and psychosocial factors on the lives of patients with T1DM is particularly important. A recent systematic review and meta-analysis showed that patients with T1DM have a much higher relative risk of suicidal behavior, a finding that can be attributed to either co-existing depression, other mental disorders or physical symptoms that often co-exist with T1DM[32].

Psychological factors and T1DM

The daily life of a child and adolescent suffering from T1DM is anything but simple as there are many issues that both the person and his/her family have to deal with. There are therefore many points where the disease interacts with psychology. Data from relevant studies demonstrate that adolescents with depressive symptoms report less frequent self-monitoring of capillary glucose. Social anxiety appeared to be negatively associated with both compliance with insulin therapy and adherence to dietary guidelines especially in male patients[33, 34]. A recent meta-analysis of 14 studies confirms an increased incidence of anxiety and depression in children with T1DM and correlates them with poor glycemic regulation[35]. Fear of hypoglycaemia has been associated with non-compliance with insulin dosing instructions, but has also been associated to a lesser extent with non-compliance with exercise and dietary instructions[36].

Psychosocial factors and T1DM

Self-efficacy has been positively correlated with both adherence to nutritional guidelines[37] and frequency of capillary glucose measurements. In addition, supporting the autonomy of adolescents from both parents and caregivers appeared to be positively associated with self-care related to nutrition [38]. Children's and adolescents' representations of illness have also been studied. It was found that the perception of diabetes as a health threat was negatively associated with the frequency of capillary glucose measurements. Regarding patients' perceptions of the effectiveness of T1DM treatment, it was found that positive perceptions were positively correlated with the frequency of self-monitoring of capillary glucose as well as self-care in diet[39].

With regard to the impact of T1DM on patients' lives, it was found that self-care in nutrition was inversely correlated to

the importance of the perceptions concerning the impact that the disease may have on the patients[37]. Indeed, it was shown that altering the perceptions of the treatment effectiveness was in turn associated with more faithful adherence to nutritional guidelines[39]. Similar data have been documented for the relationship between positive representations of T1DM and exercise adherence and the relationship between psychological adjustment and exercise adherence[40].

The mental characteristics of adolescents with T1DM

Managing diabetes in the adolescent age group presents a more complex set of challenges given the range of physiological, social and emotional changes that occur between childhood and adulthood, including puberty, peer pressure, the desire to be 'normal', the identity formation process and, often, the willing to control the "boundaries" set by health professionals, parents and caregivers[41].

The role of the health psychologist

Effective management of diabetes requires complex, ongoing and demanding self-care behavior. Given the importance of psychosocial factors in the management and the progression of diabetes, there is a need to develop and implement effective, well-evaluated psychosocial interventions to help patients cope with the daily demands of diabetes[42]. Interventions have focused on supporting self-management. This effort has taken the form of educational programs aiming at teaching specific diabetes management skills and enhancing the patient's independence so that they can actively participate in their own treatment through carbohydrate measurement or blood glucose monitoring. Psychosocial interventions aiming at addressing emotional difficulties through a variety of problem-solving and emotion-focused techniques also play an important role[43]. A meta-analysis performed by Pillay et al[44] showed that behavioral programs applied to patients with T1DM have a benefit on patients' glycaemic control for at least the first six months of intervention.

Most clinicians believe that psychological problems are associated with worse clinical outcomes and have led to the establishment of guidelines to ensure that psychological support is provided to patients and that negative emotions that arise as a consequence of having diabetes are successfully managed [45]. Psychosocial interventions such as cognitive behavioral therapy, problem-solving therapy, coping skills training and and family therapy have been shown to be effective in improving the quality of life of patients with T1DM 46. All in all, psychosocial interventions have been recognized as an integral part of diabetes care. Such interventions are very useful in improving glycaemic control and self-care behavior, reducing the risk of complications and improving the quality of life of the patient with T1DM.

Conclusions

T1DM is a chronic health problem in youths, with significant physical, mental and social consequences which often go both ways and are interrelated. All these parameters contribute to shaping the quality of life of patients and therefore need to be treated as a whole by the multidisciplinary team. The role of the health psychologist is important in this context, both in terms of prevention and interventions.

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