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# Psychological Adaptation to the Autoimmune Disease Diabetes Mellitus Type 1 in Adolescence: A Review



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#### Abstract

The improvement in living conditions and the implemented health care brought great contributions such as the reduction of acute and infectious diseases. This advance in the medical sciences allowed a reduction in the high mortality rate among the youngest and, as a result, an increase in the average life expectancy. With this developmental framework, there has been an increase in chronic diseases, including the disease Diabetes Mellitus (DM). This paper aims to highlight the contribution of psychology in adapting to autoimmune disease, whose theme is part of a broader spectrum of other goals outlined in the Portuguese national health program (NHP) of 2020. Due to the need to face and contain its impact, the NHP developed the goal of reducing premature mortality associated with DM. We present a review of literature of DM, describing its effects at the physiological, psychological and social levels, as well as at the environmental level and, in particular, focusing on its impact on the adolescent population and which intervention strategies have been triggered to better contribute to the adaptation of this specific population to the disease that is correlated with DM type 1.

Keywords: Diabetes mellitus; DM type 1 in adolescence; Cognitive behavioral therapy; Mental health in Portugal

# Introduction

The topic to be addressed is the adaptation to the autoimmune disease DM, in which a literature review will be carried out, with particular focus on DM type 1 and the need for psychological intervention in adolescent population. First, we will refer to the impact of DM in numbers both at the international and national level. We will define the problem and characterize DM taking into account the challenges it poses to different populations and the adolescent population, specific to this paper. A specific point that establishes the relationship between DM and climate change will be addressed. We will also review the state of the art involving the psychological and social effects of DM in adolescence and, finally, ways of intervening that allow mitigating these same effects.

# Methodology

This is a literature review in which several online search engines were used: PubMed, Google Scholar and Wiley, where it was possible to collect 29 documents. Inclusion criteria were: first, title that fits the theme and, second, reading the abstract and keeping the document if relevant; within the time frame between 2002 and 2022, that is, 20 years in English and Portuguese language. The exclusion criteria were abstract when it was outside the related theme or subject; out of time, that is, before 2002; languages other than English or Portuguese; there are also three additional references that were not counted as researched literature because they refer to statistical data, concerning data from World Health Organization (WHO) and National Statistics Institute (INE in Portuguese). As already mentioned, the time frame for inclusion of documents was between 2002 and 2022, but the readable documents date between 2005 and 2021. Some of the descriptors used to collect information were: "Diabetes pediatric care", "diabetes type 1 pediatric care", "psychology and diabetes type 1", "diabetes and psychology". The same descriptors were used in Portuguese. The research period was carried out between the months of September, October and November 2022.

# DM in Numbers

The improvement in living conditions and the implemented health care, advocated essentially by the development of the biomedical model, brought great contributions such as the reduction of acute and infectious diseases. This enormous advance in the medical sciences allowed a reduction in the high mortality rate among the youngest and, as a result, an increase in the average life expectancy. With this developmental milestone, there has been an increase in chronic diseases, that is, diseases that either cannot be cured or require long-term and/or lifelong treatment [1]. It is in this context that the disease DM is inserted. The WHO indicates that about 422 million people are diagnosed with DM and in 2019 about one and a half million deaths annually are directly attributed to it. In addition, 48% of deaths from diabetes occur before the beginning of the seventh decade [2]. The numbers are also substantial when referring to Portugal, as there has been a very significant increase in this disease. More than 880,000 people in the country, in a survey of people over the age of 15, have diabetes, which corresponds to about 8% of the Portuguese population [3], numbers that worry, since they are in line with the prevalence of 8,5% of the rest of the world population, over 18 years old who has diabetes [4]. Regarding the difference between the genders, in Portugal, according to INE (National Institute of Statistics, 2019), it is not very significant, with women being slightly above men (H = about 415,000, M = about 460,000).

### **Definition and Characterization**

DM is a metabolic disease in which it is characterized by a high level of glucose in the bloodstream and chronically, since its non-treatment generates serious damage to blood vessels, eyes, kidneys, nerves and to the heart itself [5,6]. Usually, the literature distinguishes two types of diabetes: type 1 and type 2. The latter is the most common, corresponding to 90 or 95% of cases, while the former accounting for 5 to 10% of cases. In both scenarios, there is a deficiency in insulin production or even none at all. In fact, insulin is a hormone released by the pancreas that directs the glucose present in the blood from food, particularly carbohydrates, the main source of energy in the body, into the cells, thus generating energy for activities of the human being. In DM, this physiological mechanism is not executed because either there is no insulin being produced, in this case DM type 1, or in insufficient quantity, as in DM type 2, to hyperglycemia. Due to the lack of sugar in the cells, the person with DM will tend to reveal a lot of tiredness and the symptoms of the 4P: polyuria (excessive desire to urinate), polyphagia (insatiable hunger), polydipsia (constant thirst), and weight loss, although they do not need to be all present. If, on one hand, the standardized values for an individual without a diagnosis of diabetes vary between 80 to 110 mg/dl of blood sugar before meals and up to 140 mg/dl after meals, on the other hand, an individual diagnosed with diabetes

may have values greater than 126 mg/dl before meals and greater than 200 mg/dl after meals. Regarding DM type 2, it is a disease that is usually associated with lifestyle, particularly sedentary lifestyle, eating habits, overweight, among others. In this sense, it is a pathology that usually appears in adults, mainly in mature ages and many already in old age when they experience more serious complications, for example, at the ocular level through diabetic retinopathy. As for DM type 1, it occurs at early ages, still in childhood or adolescence, and is associated with more genetic factors. In this clinical condition, the pancreas does not produce insulin because the immune system itself develops antibodies that attack and destroy the insulin-producing cells in the organ, that is, DM is triggered by an autoimmune reaction. Contrary to type 2 DM, failure to treat it immediately with insulin therapy after the onset of symptoms can lead the individual to enter a diabetic coma and put his life at risk. Interestingly, DM is mostly associated with Caucasian individuals, although there is an increase in the disease in all ethnic groups, and it has a higher incidence in Northern European countries, such as Sweden, Finland and Norway, as well as Italy and Northern Ireland [5,7-9].

DM is an incurable disease, in which the first-line treatment is done through glycemic self-monitoring, insulin self-administration in patients with DM type 1 or oral antidiabetics in patients with DM type 2, in addition to a balanced diet and regular physical exercise [5]. In fact, this is a disease that shortens a few years of life, since, according to Isabel Silva [6], individuals with DM tend to live 5 to 10 years less than the general population.

### Relationship between DM and Climate Change

It is true that climate changes have produced a greater increase in atmospheric temperature and, with that, harm people with DM. In fact, people with this diagnosis are more prone to dehydration and cardiovascular problems in intense heat, so the periods of the summer season will increasingly be a cause for concern for this population. Following this reasoning, it is also highlighted that heart attacks are the main cause of death in the population with DM and more frequently at high temperatures. Given the tendency to have more rigorous summers, the risk for hospitalizations is greater as a result. In addition, the more hospitalizations per year, resulting, for example, from waste produced for patient treatment using chemicals or even from common waste, the greater the contribution to global warming and the promotion of climate change. Another promoting factor for this atmospheric catastrophe concerns the individuals' lifestyles. As already mentioned, when this is combined with physical inactivity and a diet based on processed foods, it promotes DM. However, lifestyle is related to climate change, as a more sedentary individual will tend to move around in their daily lives using motorized vehicles and eating habits rich in trans-fat, which are artificially produced and have chemical additives for conservation purposes, will encourage the emission of gases into the atmosphere and, therefore,

the increase of the greenhouse effect, which is at the root of global warming and consequent destabilization of the environment [10].

# DM in Adolescence

DM is a highly disabling disease. If in older patients, therefore associated with DM type 2, nephropathies (kidney diseases), retinopathy or cataracts (eye diseases), diabetic foot, gastrointestinal tract diseases such as diarrhea, sexual dysfunctions, cardiovascular diseases such as stroke, among others, in younger patients, therefore with DM type 1, the symptomatology is much faster to generate more harmful effects, namely diabetic coma and, if

there is no early intervention, death itself [5,8]. In the case of adolescence, which is the target population of this manuscript, the chronic complications mentioned above can also occur, but they usually only appear 15 to 20 years after the diagnosis. In this sense, and in a first moment, after having already been flagged as having DM type 1 and being already under insulin treatment, it is essential to take into account the psychological aspects correlated with the pathology, whose factors may have a superb impact, not only in the course of the disease, but also in the subject's own development [6,8,9].

Adolescence, the period that goes roughly from 10-12 to 19 years old, is characterized by great changes. There is physical, cognitive and socio-emotional growth associated with development. In fact, the teenager is a "mini adult": with the hormonal changes and growth of primary and secondary sexual characteristics, he looks like an adult; at a cognitive level, he enters the period of Piaget's formal operations - he can use the ability of thought in an abstract way, manipulate symbols and mental representations of objects, plan hypothetical-deductive reasoning to solve problems, etc.; at a socio-emotional level, there is the establishment of significant relationships beyond the nuclear family, where there is a strong influence of the peer group, which can contribute to their development [11]. Indeed, at this stage, adolescents seek to establish their identity, as advocated by Erikson in his psychosocial theory of human development, in the dichotomous conflict: identity vs. identity confusion [11]. Due to this challenge, the teenager will be confronted with issues such as sexual orientation and first sexual experiences, contact with illicit substances, search for autonomy and less dependence on caregivers and decision-making needs related to their vocational orientation [12]. At this stage, despite the recognized development, the adolescent still does not have the fullness of his brain maturation, since the prefrontal cortex is not fully developed. In fact, through neuroimaging techniques, it is verified that, while in the adult brain, in the approach to situations that involve emotion management, behavioral inhibition and decision making, there is a more rational response evidenced in the prefrontal lobe, responsible for the executive functions,

in contrast to the more emotional response of the adolescent brain, which is more evident in subcortical structures such as the amygdala, an important organ for emotional and instinctive reactions in the brain. Given that the prefrontal cortical region is still underdeveloped, adolescents respond through a more primitive structure. This comes to explain the "rebellious" behaviors of adolescents from the confrontation of authority – in the relationship with parents, teachers and other superior figures, risk behaviors– experimentation and substance abuse, practice of risky sex, rigid thoughts and dichotomous beliefs – all or nothing, egocentrism, radical sense of justice [13].

# The Psychological and Social Effects of MD in Adolescence

DM type 1 often appears between the ages of 10 and 15 and at this stage motor functions and physical health in general tend to manifest themselves more vigorously and robustly, so it is crucial to take into account the psychological and social effects of the disease. It is important to point out that these aspects are the main risk predictors of mortality in DM. In this adolescent phase, where there is greater vulnerability, DM type 1 will be a great challenge. Effectively, there is great resistance to adherence to self-care for diabetes due to a combination of factors that cause stress: it is a chronic disease that, apparently, has no obvious risk. There is no immediate discomfort, and minimal compliance with its management makes it possible to reach an asymptomatic state; treatment implies changes in life habits, which adolescents often do not want to abandon because they are rewarding, namely fast food; the treatment is complicated and intrusive, as it requires being careful with the type and amount of insulin administered, in addition to what is eaten and its quantity, and this being perceived as unpleasant events that lead to a decrease in the frequency of the behavior; there is no direct supervision of behavior, that is, it is something that requires personal control and management; the objective is the treatment, not the cure, since it is only possible to prevent acute complications as previously mentioned [6,14]. In a study by Serrabulho et al. [15] with Portuguese adolescents with DM type 1, they revealed that care with food, daily management of glycemic self-monitoring and insulin administration were components with a great negative impact on their experience as carriers of this clinical condition. In fact, it is very common at this stage for young people to practice the so-called diabulimia in which they manipulate or omit the insulin values administered in order to lose weight [9]. This preoccupation of young people, particularly associated with girls, with their self-image and the stereotypes associated with physical beauty often create disturbances in eating behavior, the consequences of which will be evident in weight loss, but at the expense of high glycemic values [6]. Another common anxiety symptom in this population is the phobia of hypoglycemia. This situation appears when the patient has values equal to or less than 70mg/dl of blood sugar. This problem occurs when there is insufficient intake of carbohydrates

or not eating for hours, there are errors in the administration of insulin, especially in excess, consumption of alcohol in excess or outside meals or even too much physical exercise. Contrary to hyperglycemia, the symptoms here are more evident, from excessive sweating with tremors, weakness, paleness, irritability, changes in consciousness and even coma. Because they are symptoms that can cause enormous embarrassment, adolescents often maintain hyperglycemic values in order to avoid hypoglycemic episodes. This fearful behavior leads to dichotomous behavior that can have extreme consequences [9]. Many teenagers will experience symptoms of anxiety and depression. Indeed, the anguish and frustration in relation to the differences found with peers - daily self-care, injections given, the "looks" they receive, apprehension and pessimism regarding the future - thoughts of inferiority, catastrophizing, insecurity about how it is living with the disease, irritability - maladaptive coping strategies - and social isolation - more fragile self-esteem - caused by denial and difficulty accepting the disease can lead to psychiatric illnesses. Anxiety and depression are clinical manifestations between 15 and 30% more likely in this population than in the non-diabetic population [7]. Interestingly, this prevalence is not only due to behaviors arising from thoughts and emotions, but also due to the effect of stress on the body.

When the individual is under the influence of stress, the body, in addition to releasing adrenaline and norepinephrine, essential for the flight or fight reaction, releases cortisol. Once released into the bloodstream, the pancreas will increase the level of glucagon, a hormone produced in this organ, which does the reverse job of insulin – increasing blood sugar levels. This increase in an individual with DM type 1 will be exacerbated by the fact that the pancreas itself does not produce insulin and quickly reaches a hyperglycemic level in the body [5,8].

At the family level, the literature indicates that lower socioeconomic status is related to poor glycemic control in DM in general, but there are no studies on DM type 1 [16,17]. Parents can also be a source of support [18], as it is associated with support in glycemic monitoring, greater adherence to the diet, where even the family and the patient share meals. In turn, parenting with more authoritarian styles, with stricter control, practicing constant monitoring and conferring little autonomy, can generate conflicts and challenge authority, which allows denial of the disease and poor therapeutic adherence [5,19].

Regarding the community and peers, there is a great influence of peers. At this stage of development, the more or less favorable opinion will have repercussions on adherence to treatment. In fact, a study by Storch & colleagues [20] revealed that young people who suffer from bullying and who are the target of some form of discrimination because they have DM type 1 tend to have more harmful glycemic self-monitoring and insulin therapy behaviors, that is, they tend to not adhering to treatment and particularly in public. In addition, Hains & colleagues [21] in their research study were able to identify that adolescents who have negative expectations regarding the reaction of their peers, during their self-care in the management of the disease, tend to have less glycemic control. As for the health system, there is a need for regular follow-up, as patients who attend appointments recommended by health professionals achieve better results in glycemic control than those who miss appointments [22,23]. Nuti & collaborators [24] indicated that reminders to patients via message, phone call or even e-mail can result in greater attendance at appointments. Isabel Silva [6] also talks about the importance of the relational role of the health professional. In fact, adolescents often feel unmotivated for treatment because of the style of interaction with the assigned doctor or nurse. Young people often report professionals as routine - those who always ask the same questions on every visit and ignore their concerns, as authoritarian and as negligent. Those labeled as motivators - those who ask, listen and consider their concerns and seek to make decisions together - tend to encourage better adherence to treatment. Even so, and in line with the author, Minanni & others [25] report that adolescents tend to adhere less to treatment than children. In the same vein, Wood & colleagues [26] conducted a study in which they found that only 21% of their registered clinical patients had levels of glycated hemoglobin (HbA1c), which is a percentage indicator of mean blood sugar values in the last two/three months, controlled.

# Psychological Intervention in Adolescents with DM Type 1

Since adolescence is a critical phase for its normative development, programs and protocols that seek to intervene with this population and help them to better adapt to their clinical condition are important, whose condition, as already noted, has strong implications beyond of physical symptoms. In this sense, there have been some studies that have evaluated the impact of some intervention programs in this population. In a study by Channon & colleagues [27] in a group of 66 adolescents between 14 and 17 years of age, using the motivational interview technique, it was possible to verify a decrease in glycated hemoglobin (HbA1c) compared to the control group, which received the usual care in routine consultations. This approach made it possible to understand, in the follow-up, an improvement in self-care in the experimental group compared to the control group and then, after 24 months, the maintenance of these same results. The authors concluded that the discrepancy generated in the adolescents allowed a change of perspective, insofar as self-care can make a difference in the results of the patient with diabetes. Therefore, it produces long-term results in glycemic control, well-being and quality of life. In another study by Nansel & colleagues [28] in a group of 81 adolescents between 11 and 16 years old, using selfregulation techniques, through self-monitoring, setting goals and solving problems, allowed the experimental group to significantly reduce HbA1c when compared to the control group. This was a

24-month longitudinal study, in which an improvement in selfcare over time was found, as the effects of the treatment only started to appear in the 12<sup>th</sup> month. The authors believe that the exponential effect from the first year is due to the cumulative effect of exposure to the experiment and refinement of problemsolving skills. In a study by Maranda & colleagues [29] in a group of 28 adolescents between 10 and 17 years old using a behavioral technique in the experimental group – having a pet, an aquarium fish, and a control group that was not the target of this treatment allowed to reduce HbA1c more significantly in the first compared to the second group. The strategy consisted of measuring glucose whenever the teenager fed the fish, bringing an added motivational component and a more pleasant association with the patients' self-care process. Lansing & colleagues [30] carried out an intervention study in 15 adolescents between 13 and 17 years of age in rural areas with uncontrolled glycemic control. The techniques consisted of training cognitive-behavioral skills, executive functions through stimulation of working memory and motivational positive reinforcement. This was an innovative project since its intervention is online. The young people completed the skills training that lasted one hour and then at the end there was a game. Furthermore, the more they carried out the plan and reported their glycemic values, the more monetary incentive they would have. Parents were also included and would have access to online sessions to encourage therapeutic adherence, as well as its maintenance. Just like the children, the more daily reports the parents reported would also be monetarily incentivized. During this process, young people and families would be able to be accompanied by health professionals, whom they could turn to whenever necessary. The results were encouraging there was an increase in blood glucose monitoring, there was a decrease in HbA1c values, and there were improvements in the inhibitory capacity of behavior and in working memory through executive functions.

## Conclusion

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The studies reveal that there has been a growing interest in supporting young people with DM type 1. Even so, and according to the findings, there is greater scientific support for intervening with people with DM type 2. Due to the more accentuated disease in numbers, according to the general objectives of the WHO and the 2020 Portuguese NHP, already mentioned, this greater focus is understandable. It is also possible to note that the intervention strategies used are mostly derived from the cognitive-behavioral approach. In fact, the Psychological Portuguese Order [31] states that cognitive-behavioral therapy (CBT) is the therapy with the most studies carried out and has proven to be an approach that has great advantages in terms of cost-benefit because it is of a brief and with a high recovery rate. In addition, the document mentions that this intervention strategy is of great importance in chronic diseases such as DM, as it allows to reduce the health costs of these patients in the order of 18% to 31%.

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