

Special Article

Adolescents with Diabetes Type 1: Psychological and Behavioral Problems and Compliance with Treatment

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Abstract

Diabetes Mellitus Type 1 (T1D) is a chronic disease most common in children and adolescents so that management is a complex factor. Adolescents are trained to be autonomous. The presence of the family, especially parents, plays an important role both in the metabolic control of the disease and in the psychology of adolescents.

Children with diabetes feel different from the other children and often are ashamed. The participation of children in the self-care of T1D is quite important. However, during adolescence, various hormonal, psycho-emotional and physical changes occur that disturb the relative calm of previous years. There is usually poor glycemic control, as well as high-risk behaviors such as diabetes, increased sexuality, smoking and alcohol. Parents also experience behavioral problems such as anxiety and disclaimer.

Children and adolescents with T1D have exactly the same needs as their peers without the disease. They need to live like everyone, without deprivation but with care and consistency in their treatment program. Parents need to be informed and educated as well as their children. Good quality of life with the aim of integrating young people into social and productive life and the persuasion that they do not differ from others when they adhere to their program leads to psychosocial integrity.

Key words: diabetes type 1, adolescents, children, parents, problems, psychology, behavior, compliance

Introduction

T1D in infants, children, adolescents and parents poses serious physical, mental, social and emotional challenges (Hilliard et al., 2012).

According to the World Health Organization (WHO), compliance is defined as the extent to which a patient follows the healthcare provider's recommendations regarding medication and lifestyle change (WHO 2003).

Behavioral and compliance problems appear for a variety of reasons. There are five main factors:

patient, disease, medication, socio-economic factors and health system. Specifically, the patient's behavior affects gender, age and educational level. The disease is affected by symptoms, co-morbidity, polypharmacy and psychology factors such as depression. The type of medication, the complexity of the treatment and the side effects of medications belong to the class of medication. The socio-economic factors are the cost and the family and social environment and the health system includes the frequency of visits, accessibility and patient-therapist relationship (Frey et al., 1997, Caruso et

al., 2014, Butwicka et al. et al., 2016). Here is a description of psychological, behavioral and compliance problems in children and adolescents with AD1 and their parents.

Background

Children

Diagnosis of T1D causes shock to both parents and children themselves, and then anxiety occurs. Adaptation to the diagnosis of diabetes lasts about 6-9 months for children. Depression, social isolation and shame are feelings that most children and parents are confessing. Children feel different from the others, afraid to announce the diagnosis of the disease to their friends and their surroundings. They have the feeling that they are insulin dependent, vulnerable and feel they can not follow the schedule and life style of their friends.

The negative feelings of children lead to behavioral and compliance problems. The child with diabetes feels different from the rest of the children, ashamed and often suffocated by the overprotection of the parents (Galli-Tsinopoulou et al., 2014).

Many children record unrealistic values in the diabetes log book either because they do not measure or because the results of the measurements are not in the acceptable values.

With regard to nutrition, there are also several behavioral problems. Many children consume hidden foods and especially sweets. They eat large amounts of food uncontrollably, without following the instructions of the diabetes group or on the other hand they do not consume enough food due to decreased appetite, anger, reaction or emotional extortion (Naranjo & Hood, 2013).

Also, many children cause conscious hypoglycemia either because they do not consume enough food or because they deliver a higher insulin dose than they need (Naranjo & Hood, 2013). This behavior is intended to eat some sweet or to attract the attention of the family.

Attenuated cognitive function has been reported in children with diabetes, especially in boys, and especially in those with early diagnosis of diabetes (<5 years) (Kakleas et al., 2009).

Children also have problems at school. They feel shame about the T1D, refuse to count and give insulin because they fear the bullying from

friends. They also eat anything at school without keeping their diet because they are jealous of their friends' snacks. Finally, they exercise uncontrollably and do not observe the measurement program before, during and after exercise (Northam et al., 2005).

In the initial period after the diagnosis of diabetes, children show the difficulties in treating the disease, often presenting the feelings of sadness, withdrawal and anxiety (Northam et al., 2005). Generally, over one third of children with diabetes will develop a psychiatric disorder in the first decade of disease, with depression, anxiety, and behavioral disorders being the most common diagnoses.

Caruso et al. (2014) conducted a survey. Children with T1D completed a series of questionnaires and there was the category of behavioral problems. The same questionnaires were completed by children without T1D. Children with T1D had a higher incidence of problematic behaviors. In particular, they reported significantly higher rates of depression and internalizing emotions. However, the values were within normal limits but higher than those of healthy children.

A number of researchers have investigated the symptoms of depression and anxiety in children and adolescents with T1D in 14 studies. The cumulative prevalence of depressive symptoms was high. There has been an interaction of behavioral problems and HbA1c, blood glucose monitoring and anxiety and 32% of patients feel stressed. The statistic analysis confirmed a high prevalence of symptoms of depression and anxiety in young people with T1D, potentially endangering diabetes management and glycemic control. These findings support recommendations for timely assessment of psychological comorbidity and regular psychosocial assessment from the time of diagnosis of the disease (Buchberger 2016).

Adolescents

Puberty is a transition period from childhood to adulthood, ranging from the initial appearance of secondary sex characteristics to full sexual maturation by the acquisition of reproductive capacity.

In people with T1D, adolescence can cause problems, thus deteriorating metabolic control. Aggravation can be due to many reasons such as irregular meals, uncontrolled exercise, non-

compliance, risky behaviors and endocrine changes associated with puberty. Since 1989 there has been research by Caprio et al., which shows increased insulin resistance during adolescence (Caprio et al., 1989).

As mentioned, puberty is a period characterized by intense hormonal, physical and psycho-emotional changes. Then "Diabetes burnout" appears, which is the revolution and denial of adolescents in the care of the T1D.

In adolescence there is incomplete glycemic control. Counseling with peers plays an important role in the life of teenagers but often presents several problems. Teenagers are hesitant to discuss with their company the problem that they face because they fear social isolation and mockery. Adolescents have the same exploration needs as their peers but they try to fit into the new social standards without adapting and integrating diabetes into their daily lives. For example, some teenagers, especially girls, reduce the dose of insulin to control their body weight.

Boys show aggression, use of addictive substances and learning problems. On the other hand, girls have, apart from eating disorders, low self-esteem. Also, many teenagers do not accept any form of power. Instructions from healthcare givers and parents are deferred and high-risk behaviors are in place. Excessive consumption of alcohol, smoking, drugs, abstaining and schooling, obesity or anorexia, drunk driving, inappropriate behavior, and crackling are some behaviors that affect the regulation of diabetes. This poor glycemic control lasts about 5-7 years. This period depends on the duration of adolescence but increases the risk of complications for the next 6-10 years (Pompili et al., 2014, Chao et al., 2016, Goncalves et al., 2016).

According to the research by Mays et al. (2012), smoking affects adversely the management of diabetes and increases the risk of progression of adverse health effects associated with diabetes.

Researchers studied 155 adolescents with T1D aged between 10-20 years regarding to high-risk behaviors. The results showed that 39% of the sample used alcohol, 34% reported cigarette smoking, 10% reported drug use and 29% reported unprotected sex. Girls have lower rates of high-risk behaviors. The research reported the imperative need to educate and inform teenagers with and without diabetes (Frey et al., 1997).

Contrary to this risky behavior are the needs of adolescents in insulin. These are increased due to normal insulin resistance. However, omission to absence of measurements and omission of injections result in a dangerous deterioration of glycemic control. Increased eating also results in weight gain, and there is often a risk of obesity. On the other hand, reduced consumption of food for weight loss results in the occurrence of hypoglycemia (Pompili et al., 2014, Butwicka et al., 2016).

With regard to diet, many teenagers do not follow the instructions of health professionals. They are indifferent to the meal-insulin balance resulting in intense fluctuations in glucose values (Sivertsen et al., 2014, Goncalves, et al., 2016).

The research by Goncalves et al. (2016) in adolescents with T1D aged 12-19 showed that 44% of them reported a desire to maintain or increase their current weight, and 35% reported a desire to reduce the current weight.

Participants with the desire to weigh less were mostly women and this group experienced an increased incidence of eating disorders and concerns with body image. In addition, this group showed increased anxiety about physique and decreased quality of life, concerns about diabetes and life satisfaction. These emotions have led to high-risk behaviors, especially on girls' nutrition issues.

Both adolescents and children often record false measurement and insulin counts in the diabetes log book, although many do not even keep it. As mentioned earlier, teenagers want and try to join the new lifestyle to show they have age and usually duplicate negative patterns. Excessive alcohol consumption and use of drugs are for them mature indications and this behavior is confirmed by the frequent cases of hypoglycemia on Saturday and Sunday morning (Mays et al., 2012).

In a study by Chao et al. (2016) in Philadelphia, were adolescents aged 11-14 years old. Teens reported diabetes as the third most stressful agent. The first place occupies the school and the second place the social life.

Butwicka et al. (2016) in their study of adolescents with T1D showed that 26.6% of patients evaluated the criteria for psychiatric disorders. The most common diagnoses were anxiety (15.5%) and mood disorders (3.9%). One third of the patients (31.9%) met the criteria for

at least one psychiatric disorder during their lifetime. The presence of psychiatric disorders was associated with an increased level of HbA1c.

Greek researchers (Kakleas et al. 2009) found that adolescents with T1D have high risk of a psychiatric disorder (10-20%) or eating disorders (8-30%), and substance abuse (25-50%), resulting in the non-compliance in treatment and deterioration of metabolic control. High risk are girls teenagers with family problems and other coexisting disorders. Often, episodes of severe hypoglycaemia or prolonged hyperglycemia result in impairment of cognitive function. The T1D contributes to the development of problems in parent-child relations and negatively affects the quality of life. However, insulin pumps appear to improve metabolic control and the way patients live. Family and friends' contributions to the quality of metabolic control and emotional support are also vital. The results show and confirm other research, how high risk is the average adolescent patients with coexisting disorders and low socio-economic status.

Psychiatric disorders and behavioral disorders in adolescents with T1D are categorized either as "internal disorders" (such as depression and anxiety) or "external disorders" (such as impulsivity, hyperactivity, aggression).

Several studies have observed depression in 10-26% of adolescents with diabetes, and high rates of anxiety (9-19%) and behavioral disorders (12-20%) have also been reported (Leonard et al 2002, Dantzer et al. 2003, Northam et al 2005, Hood et al., 2006, Pompili et al., 2014). Indeed, female patients are more likely to have depression, anxiety or low self-esteem (Hood et al., 2006). Less frequent monitoring of blood glucose is an indicator of reduced compliance and the poor control of metabolism has also been associated with higher levels of depressive symptoms (Hood et al., 2006). In addition, adolescents with T1D are at increased risk of depression compared to their peers due to increased pressure, effort to gain independence from their parents and attempt to discover their identity (Grey et al., 2002, Hood et al. 2006).

Depression and other emotional disorders are associated with poor glycemic control, resulting in frequent hospital admissions due to diabetic ketoacidosis (DKA) incidents or severe hypoglycemia (Garrison et al., 2005). Poor glycemic control in adolescents with diabetes and depression can be attributed to a lack of

compliance in diet, exercise and medication (Cohen et al., 2004). In addition, there is an increased incidence of deliberate insulin omission (Pompili et al., 2014). Moreover, apathy and lack of self-care, often seen in patients with depression or anxiety disorders, can lead to eating or poor exercise habits that lead to a worsening of glycemic control.

The combination of diabetes and depression in children and adolescents has been associated with a 10-fold increase in suicide and suicidal ideation since several years ago (Kokkonen et al., 1997). In children and especially adolescents with T1D, depression may be more pronounced (some studies suggest that depression tends to be more severe, more difficult to resolve and more likely to recur) compared to young people without diabetes (Hood et al. 2006, Lawrence et al., 2006). Despite the fact that many young adolescents with diabetes admit suicidal ideation, only a few have attempted suicide, but they usually "do" by using diabetes-related methods such as insulin misuse or overdose (Boileau et al. 2006).

The risk for suicidal ideation is higher among children with longer duration of diabetes, non-compliance, coexisting psychiatric disorders and single parent families (Pompili et al., 2014). Among adolescents with T1D who were admitted to hospital for recurrent suicide attempts, there was a great prevalence of girls who had either family difficulties or fear of complications of diabetes (Boileau et al., 2006).

However, the difference is made by Sivertsen et al. (2014) research, which did not notice a difference with regard to smoking, alcohol, drug use, depression, anxiety, eating disorders, sleep disorders and physical problems (headache, dizziness, etc.). The research examined a group of 40 adolescents with T1D aged 16-19 and adolescents without diabetes.

Parents

Parents play an important role in children's and adolescent's life with diabetes. They also exhibit behavioral problems such as anxiety, excessive rigidity, depression, overprotection and on the other hand indifference, non-compliance with the guidelines and the given program by health professionals.

Parents often go through excessive measurements due to anxiety. These may well exceed 50 per day. A hypoglycaemia or

hyperglycemia can lead parents to this movement. The uncertainty and lack of knowledge and education to deal with an acute complication can have negative consequences for the adolescent. Adolescents accept with difficulty the necessary of daily measurements and the pressure from parents exacerbates their relationships (Galli-Tsinopoulou et al., 2014).

Parents also want a lower HbA1c. They seek it in any way, either by giving less food to children or by overdosing or reducing the insulin dose resulting complications (Gilli-Tsinopoulou et al., 2014).

With regard to diet, parents may not prepare suitable foods for children with T1D for a variety of reasons. The limitation of time, the minimum preferences of children in the food, the higher cost of healthy food, and the influence of children's friends are some of the reasons (Patton et al., 2015, Patton et al., 2016). All these obstacles create anxiety for parents, which is transmitted to children or to fight each other.

On the other hand there are parents who reluctant to give insulin to children. They think that insulin can cause hypoglycemia or gain weight and follow their own ways of treatment.

Many parents do not follow instructions of doctors and health professionals. They find new ways of treatment, by avoiding medication and giving children medicines or formulations that will cure diabetes. Non-insulin can lead to significant problems in adolescents' development and lead to stagnation (Galli-Tsinopoulou et al., 2014).

Many mothers are in constant vigilance with concerns, responsibility and lack of support as a result of some having physical and / or emotional problems. These problems are not externalized in the appropriate way and the result is the intensification of the relationship between her and the child (Sullivan-Bolyai et al., 2003).

In a survey, 102 parents with children with T1D were involved. Parents reported depression, anxiety, stress and problems in caring of diabetes within 4 weeks of their child's diagnosis. Women showed higher rates of anxiety (Streisand et al., 2008).

Parents of young children with T1D describe their day-to-day management. Night care appears to increase parental anxiety and stress. The aim of this study was to examine the frequency of

nighttime measurements (NBGM) from parents to children. The parents (N = 71) of the children completed questionnaires to assess the frequency of NBGM and maternal anxiety. About one-third of parents reported regular blood glucose levels of their child when the last was sleeping. The result was increased parental anxiety for children's breeding ($p < .05$) (Monaghan et al., 2009).

The emergence of anxiety confirms one more research. Parents of 132 children with T1D with an average age of 12 years are generally stressed in their lives but also specifically on the issue of diabetes, resulting their poorer mental health. Generalized anxiety was associated with the poorer metabolic control of children (Helgeson et al., 2012).

In addition, many parents do not trust adolescents to manage their diabetes. They think they make many mistakes, have risky behavior, ignore dangers and do not know how to deal with a complication. Parents also fear to manage diabetes by the children themselves at school. These were the results of the survey of 28 parents with children with 13-18 years of age and T1D (Carroll & Marrero 2006).

Whittemore et al. (2012) proceeded to a review study of 34 articles on the psychological experience of parents with children with T1D. The prevalence of parental psychological discomfort in all studies ranged from 10% to 74%, with an average of 33.5% of parents reporting anxiety at diagnosis and 19% of parents 1 to 4 years after diagnosis.

This behavior of parents has led children to self-exposure to stress and reduced quality of life for the whole family. Parental psychological stress had also a negative impact on the management of diabetes.

The negative results of metabolic control can cause problems among family members. A high value of HbA1c causes anxiety for parents. Furthermore, parents blame the teenager for reduced effectiveness in managing of T1D. This situation disturbs the relationship between family members (Law et al., 2013).

Conclusion

The common goals for treating T1D are good metabolic control, avoid complications and ensure quality of life.

The achieve to euglycemia of children and adolescents with T1D, a group of scientists is need and the understanding of the family. Educating not only the patient but also the family members or friends is probably the biggest part that can lead to autonomy and then to the better outcome of the disease.

The demands of the disease and the patients' pressure are increasing and more effort is needed and also urgent and frequent adoption of new self-care behaviors.

Education and information is the key to diabetes treatment. There are indications that educational interventions in children and adolescents with diabetes have a beneficial effect both on glycemic control and on the psychology of their own and their social environment (Lange et al., 2014).

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