Difficulties in Adherence to Treatment of Adolescents With Type I Diabetes Mellitus

RESUMO

Avaliar as dificuldades dos adolescentes com diabetes mellitus tipo I na adesão ao tratamento. Estudo do tipo transversal e descritivo de abordagem quantitativa, realizado por meio de um questionário que avaliou características sociodemográficas, clínicas e hábitos. Foi utilizada a estatística descritiva e o software *Statistical Package for the Social Science for Windows*, versão 22.0 para análise dos dados. Dos 70 participantes, 58,6% eram do sexo masculino, com renda familiar de até um salário-mínimo 78,5%, seguiam o tratamento 92,9%, entretanto com dificuldades para manter a adesão 71,4%, para seguir a dieta orientada pelo médico 58,6% e para realizar a contagem de carboidratos 61,4%. Entre as dificuldades referidas pelos adolescentes estão a adesão ao tratamento, o seguimento da dieta orientada pelo médico e a contagem de carboidratos, fatores que podem favorecer a necessidade de intensificar a implementação da educação contínua sobre a doença, de forma a otimizar o controle e prevenir complicações. Este estudo contribui para a prática ao destacar a necessidade de estratégias educativas mais eficazes e personalizadas para adolescentes com diabetes tipo 1, além de sugerir melhorias no acompanhamento médico e maior envolvimento familiar**.**

DESCRITORES: Diabetes Mellitus tipo 1; Doença Crônica; Saúde do Adolescente; Serviços de Saúde; Cooperação e Adesão ao Tratamento**.**

ABSTRACT

To assess the difficulties adolescents with type I diabetes mellitus, have in adhering to treatment. This is a cross-sectional, descriptive study with a quantitative approach, conducted using a questionnaire that assessed sociodemographic, clinical characteristics, and habits. Descriptive statistics and the Statistical Package for the Social Sciences for Windows, version 22.0, were used for data analysis. Of the 70 participants, 58.6% were male, 78.5% had a family income of up to one minimum wage, 92.9% were following treatment, but 71.4% had difficulty maintaining adherence, 58.6% had difficulty following the diet recommended by their physician, and 61.4% had difficulty counting carbohydrates. The difficulties reported by adolescents include adherence to treatment, following the diet recommended by their physician, and counting carbohydrates, factors that may favor the need to intensify the implementation of ongoing education about the disease in order to optimize control and prevent complications. This study contributes to practice by highlighting the need for more effective and personalized educational strategies for adolescents with type 1 diabetes, in addition to suggesting improvements in medical monitoring and greater family involvement.

DESCRIPTORS: Diabetes Mellitus, type 1; Chronic Disease; Adolescent Health; Health Services; Treatment Compliance and Adherence.

RESUMEN

Evaluar las dificultades de los adolescentes con diabetes mellitus tipo 1 para adherirse al tratamiento. Estudio transversal y descriptivo con enfoque cuantitativo, realizado mediante cuestionario que evaluó características sociodemográficas, clínicas y hábitos. Para el análisis de los datos se utilizó estadística descriptiva y el software Statistical Package for the Social Science para Windows, versión 22.0. De los 70 participantes, el 58,6% eran varones, con ingreso familiar de hasta un salario mínimo (78,5%), el 92,9% seguía el tratamiento, pero tenía dificultad para mantener la adherencia (71,4%), seguir la dieta recomendada por el médico (58,6%) y contabilizar los carbohidratos (61,4%). Entre las dificultades reportadas por los adolescentes están la adherencia al tratamiento, el seguimiento de la dieta recomendada por el médico y el conteo de carbohidratos, factores que pueden favorecer la necesidad de intensificar la implementación de la educación continua sobre la enfermedad, con el fin de optimizar el control y prevenir complicaciones. Este estudio contribuye a la práctica al destacar la necesidad de estrategias educativas más efectivas y personalizadas para adolescentes con diabetes tipo 1, además de sugerir mejoras en el seguimiento médico y una mayor participación familiar.

DESCRIPTORES: Diabetes Mellitus Tipo 1; Enfermedad crónica; Salud del adolescente; Servicios de Salud; Cooperación y adherencia al tratamiento.

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INTRODUCTION

Diabetes Mellitus (DM) is a chronic disease of multiple origin, resulting from the absence of insulin in the body or the inability of its effective action and is characterized by permanently high blood sugar levels[1,2].

According to the International Diabetes Federation (IDF), in 2022, around 8.75 million people had diabetes and 1.52 million were under the age of 20. IDF projections indicate that by 2045 one in eight adults, approximately 783 million, will be living with diabetes, representing an increase of 46%[1].

In Brazil, more than 30,000 Brazilians are affected, corresponding to between 5 and 10% of children and adolescents with DM1, with short and long-term acute complications when the disease is not controlled. Among the countries with the highest number of DM1 cases, Brazil ranks third in prevalence worldwide, behind only the United States and India[1,3].

As a chronic disease, it is directly associated with complications and repercussions on the patient's quality of life, as well as high mortality rates. It is considered to be a disease that is difficult to control, as it requires changes in lifestyle, guidance to promote acceptance of the disease and adherence to treatment, especially in adolescents[3].

Family support contributes to the recovery of the patient's clinical condition, but it is stressful for the adolescent and his or her family to face the changes in the daily routine, due to the frequent number of appointments, hospitalizations and restrictions, affecting not only the adolescent with DM1, but all family members, which makes it important for multidisciplinary teams to intervene in terms of guidance and patient care [4].

Adhering to the treatment of DM1 and following the guidelines of health professionals contributes to effective control of the disease, reducing possible complications that may arise. It is therefore necessary to understand and accept them in such a way as to be able to learn about the disease and accept its restrictions [6].

In this context, the aim of this study was to assess the difficulties that adolescents with type I diabetes mellitus may have that compromise adherence to treatment.

METHODOLOGY

This is a cross-sectional, descriptive study with a quantitative approach carried out between March and June 2019 in the endocrinology outpatient department of the University Hospital located in the city of Campina Grande, Paraíba.

The municipality of Campina Grande is located in the state of Paraíba with an estimated population in 2017 of 410,332 inhabitants and a demographic density of 648.31 inhab./km according to data from the Brazilian Institute of Geography and Statistics [24].

This service, where the research was carried out, was inaugurated on December 20, 1950. Since it was founded, it has become a reference center for teaching, research and medical care in the Northeast, providing patients with care tailored to their specific needs [25].

According to the study's dimensions of care, the endocrinology outpatient department, like other specialties, was created with the aim of providing assistance to patients registered at the unit who require follow-up care. Since its creation, due to its public nature, and later its status as a teaching hospital, it has taken on a regional scope, so that the clientele it seeks comes from Campina Grande, different municipalities in the state of Paraíba and other states [25].

The population of this study was made up of registered adolescents with DM1 who were being monitored at the service.

Participants were selected on the basis of convenience sampling, comprising 70 adolescents aged between 10 and 19 living in the city of Campina Grande - PB, some municipalities in the state of Paraíba and other states, such as Pernambuco. The inclusion criteria were: adolescents aged between 10 and 19 who had been followed up at the clinic, with a confirmed diagnosis of the disease for over a year, so that they could answer questions about possible changes caused by the disease. Exclusion criteria were adolescents with neurological, hearing or cognitive disorders, due to the difficulty/limitation of communicating the questions proposed in the instrument.

Data collection took place in the outpatient department of the University Hospital of Endocrinology, on Wednesday and Thursday mornings from 08:00 to 11:00. According to the data from the outpatient department, the number of patients registered and seen in all age groups during the research period totaled 791.

Residents of the municipalities that agreed on services with Campina Grande in all age groups amounted to 494 and residents of Campina Grande to 297. Appointments were scheduled every Friday at the outpatient clinic, and care was provided on Wednesdays and Thursdays from 8am. When patients had satisfactory glycemic control, they were assessed on average ev-

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ery three months by the nursing, nutritionist and endocrinology teams. Now, when glycemic control was irregular, the appointments were weekly, monthly or fortnightly. Therefore, depending on glycemic control, appointments were rescheduled.

Data collection took place between March and June 2019 and the interviews took place in a private room in the endocrinology department. A structured form was used to obtain sociodemographic data and data related to the follow-up of the patient's treatment. The first part provided a sociodemographic characterization of the participants, including the following independent variables: biological sex (male; female), age group (in completed years: 10 to 19 years), self-reported race/color (white; brown; black), marital status (of the adolescent: single; married), parents' marital status (single; married; stable union; divorced), schooling (incomplete elementary school; incomplete high school; complete high school), family income in reais (no fixed income; up to 1 minimum wage; more than 1 to 2 minimum wages; 3 to 4 minimum wages; over 4 minimum wages), with whom the adolescent lives (father; mother; alone) adolescent's city (municipalities in the state of Paraíba; Campina Grande; other states).

Behavioral factors in terms of monitoring the treatment of the disease were analyzed using the following variables: frequent monitoring of type I diabetes mellitus (yes; no), time interval for monitoring (every month; every 2 months; every 3 months; over 4 months; not at all), reason for not monitoring (difficulty making an appointment; carelessness; other), following treatment on a daily basis (yes; no), being satisfied with treatment (yes; no), having difficulty adhering to treatment (yes; no), has difficulty regularly following the diet instructed by the doctor (yes; no), understands the doctor's instructions (yes; no), tries to clarify doubts with the doctor (yes; no), reason for not clarifying doubts with the doctor (shyness and only the mother or guardian asks; has no doubts; has no interest), carbohydrate counting (yes; no); has doubts about carbohydrate counting (yes; no).

The survey was based on self-reported information subject to information bias. Another bias that hindered the participation of adolescents was the lack of transportation for some living in other municipalities in Paraíba and the inadequate communication when making appointments (the families didn't know that appointments were being made at the service itself, because previously they had been made by the municipality's Health Department), and they were patients with chronic illnesses who had self-care deficits. In addition, attempts were made to minimize the damage caused by the biased scenario, with an early pilot test, training for the person responsible for data collection and a form with confidential data.

Participants were selected on the basis of convenience sampling, consisting of 70 adolescents who were interviewed according to their availability and presence at the institution during data collection.

The data collected was processed by reviewing the forms for legibility, quality of information, organization, filing and typing. The data was stored in a structured Microsoft Excel spreadsheet and then processed using the Statistical Package for the Social Science (SPSS) for Windows, version 22.0, analyzed using descriptive statistics and discussed in accordance with the relevant literature.

The study followed ethical precepts in accordance with Resolution 466/2012 of the National Health Council, which regulates research involving human beings. The project was submitted to the Research Ethics Committee of the Alcides Carneiro/PB University Hospital (HUAC) of the Federal University of Campina Grande - PB and was approved under opinion no. 3.398.694 and certificate of submission for ethical appraisal no. 04259018.20000.5182. All participants over the age of 18 signed the Free and Informed Consent Form (FICF), the adolescents signed the Free and Informed Assent Form (FASF) and the adolescent's legal guardian signed the Responsible Person's Consent Form, once the confidentiality of the answers, voluntary participation and the possibility of leaving the study at any time had been guaranteed.

RESULTS

From the sample of 70 adolescents with DM1 in the service, Table 1 shows that the highest percentage of adolescents was male (58.6%), aged between 16 and 19 (35.7%), brown (52.9%), single (98.6%) and living with their parents (65.7%). The predominant level of schooling was incomplete primary education (60.0%), with a family income of up to one minimum wage (68.6%). Most of the adolescents lived in municipalities in the state of Paraíba (54.3%) and in Campina Grande (44.3%).

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Table 1 - Social and demographic data of adolescents with type 1 diabetes mellitus seen in the endocrinology department of a University Hospital, Campina Grande, 2019.

Variables	N	%
Sex		
Male	41	58,6
Female	29	41,4
Age group		
10 - 12 years	22	31,4
13 - 15 years	23	32,9
16 - 19 years	25	35,7
Color		
Brown	37	52,9
White	26	37,1
Black	07	10,0
Adolescent's marital status		
Single	69	98,6
Married	01	1,4
Parents' marital status		
Married	36	51,5
Divorced	15	21,4
Stable union	10	14,3
Singles	05	7,1
Others	04	5,7
Education		
Elementary school incomplete	42	60,0
High school incomplete	21	30,0
Complete high school	07	10,0
Family income		
No fixed income	05	7,1
Up to 1 minimum wage	48	68,6
More than 1 to 2 minimum wages	10	14,3
From 3 to 4 minimum wages	06	8,6
Above 4 minimum wages	01	1,4
Which individuals do you live with?		
Dad	46	65,7
Mother	16	22,9
Living Alone	08	11,4
City		
Municipalities in the State of Paraíba	38	54,3
Campina Grande	31	44,3
Other States	01	1,4
Total	70	100,0

Source: Prepared by the author, 2024.

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Table 2 shows that most of the adolescents (94.3%) had frequent outpatient monitoring of their illness, with the majority of this being done every three months (55.7%), due to difficulties in scheduling appointments, carelessness or lack of time on the part of their parents. A smaller percentage (14.3%) went every one month.

It was also found that the majority followed their treatment daily (92.9%) and were satisfied (94.3%). However, they had difficulty adhering (71.4%) and had difficulty following the diet recommended by their doctor (58.6%).

Tabela 2 – Acompanhamento do diabetes mellitus tipo 1 em adolescentes atendidos no setor de endocrinologia de um Hospital Universitário. Campina Grande, 2019.

Variables	N	%
Frequent monitoring of DM1		
Yes	66	94,3
No	04	5,7
Follow-up time interval		
Every month	10	14,3
2/2 months	11	15,7
3/3 months	39	55,7
Over 4 months	06	8,6
It doesn't	04	5,7
Reason for not following up		
Difficulty making an appointment	02	2,9
Carelessness	01	1,4
Others	01	1,4
Follow the treatment daily		
Yes	65	92,9
No	05	7,1
Satisfaction with treatment		
Yes	66	94,3
No	04	5,7
Difficulty in adhering to treatment		
Yes	50	71,4
No	20	28,6
Difficulty in regularly following the diet advised by the doctor		
Yes	41	58,6
No	29	41,4
Understands medical guidelines		
Yes	67	95,7
No	03	4,3
Seek clarification from the doctor		
Yes	46	65,7
No	24	34,3
Reason for not clarifying doubts with the doctor		
Shyness and only the mother or guardian asks questions	16	22,9
You have no doubts	06	8,6
No interest	02	2,9

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Carbohydrate counting		
No	43	61,4
Yes	27	38,6
Are you unsure of your carbohydrate count?		
Yes	43	61,4
No	27	38,6
Total	70	100,0

Source: Prepared by the author, 2024.

With regard to understanding the doctor's instructions, the adolescents said that they did (95.7%), but only (65.7%) tried to clarify their doubts with the professional. Of the adolescents who didn't clarify their doubts with the doctor (34.3%), the reasons were shyness, lack of interest or because the mother was the one who took the initiative. Carbohydrate counting was not carried out by the majority of adolescents (61.4%) and the reason given was difficulty in learning the method or lack of interest.

DISCUSSION

In studies carried out in Brazil, the percentage of adolescents with DM1 is higher among females [9,10] diverging from the data identified in this study, in which there was a greater predominance of male adolescents. In addition, 52.9% of the group were brown.

The marital status of the parents in the study, predominantly married or in a stable union, can be considered a protective factor, considering the chance of follow-up and support that the adolescent can receive in coping with the disease when the parents are close [11].

Among the participants in the study, more than half earned up to one minimum wage, a condition that can have an unfavorable impact on the treatment of the disease, since the costs of supplies and diet are high, becoming a factor that has a direct influence on adherence and the treatment of diabetes [11].

Although diagnosis and treatment are provided by the Ministry of Health, dependence on public health services, which often lack a satisfactory supply of medicines and supplies, can be detrimental to the treatment of diabetes. In addition, the high demand for specialized services often compromises the scheduling of the ideal period for re-evaluations and return appointments [8].

In the sample, the presence of adolescents from other municipalities in the service is due to the fact that there are no other reference units nearby for treatment, assistance and care for patients with DM1, generating a significant demand for referrals from the interior to the state capital or to cities that have reference treatment [6,11].

Most of the adolescents were aware of the importance of medical advice, followed the treatment and were satisfied. However, they had difficulties maintaining adherence and following the diet recommended by their doctor. Adherence to treatment and self-care for diabetes is more difficult for adolescents and is influenced by their level of development, family interaction and social pressures [17]. Among the many difficulties are doubts, insecurity, dietary restrictions and uncertainties that cause changes in the lifestyle of adolescents, favoring discomfort, especially for those who are not used to so many changes in their routine [17,18].

Accepting new eating habits and maintaining self-care is a challenge, as family demands for control of the disease lead to difficulties in adhering to the therapy proposed by the doctor, directly influencing glycemic indices and disease management[12].

Another issue to consider is that adolescents don't accept food restrictions because they can't resist foods that are outside the diet prescribed by the doctor, such as sweets, pasta and soft drinks. Coupled with the family's financial situation, which can limit them from following a diet that requires higher costs, coupled with the adolescent's insistence on eating what is not allowed, this ends up interfering with adherence to treatment [13].

As for the guidelines provided by the doctor, most of the group followed them, which can have a satisfactory impact on the progress of treatment and the reduction of complications. Continuous assessment and routine consultations are strategies for monitoring and controlling DM1 in adolescents[19].

Allied to medical and nutritional guidelines, one resource that can help control diabetes is carbohydrate counting. The majority of the group did not use carbohydrate counting (61.4%). However, if the use of a diet low in carbohydrates makes counting complex and difficult in clinical practice, for adolescents with DM1 it becomes a challenge due to the necessary guidelines and precautions [2],even though it is an important therapeutic tool [20, 21].

It's worth pointing out that carbohydrate counting is an effective meth-

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od that requires guidance from a nutritionist, and during the research we didn't see that this was offered. This strategy stands out from the others, mainly because it improves quality of life and offers various dietary options for patients with DM1. Nutritionists play a fundamental role in dietary and nutritional monitoring to control the disease [23].

The Brazilian Diabetes Society recommends that DM1, being a disease that requires continuous care, requires health education with educational techniques based on patients' prior knowledge, with a view to jointly developing a care plan. Guidelines that make them feel safe and aim to ensure the autonomy of patients, family members and caregivers[2, 22].

Among the difficulties mentioned by the adolescents are adherence to treatment, following the diet recommended by the doctor and counting carbohydrates, factors that may favor the need to intensify multidisciplinary actions aimed at attending to and resolving the issues identified and the implementation of continuous education about the disease, in order to optimize control and prevent complications.

CONCLUSION

This study made it possible to identify the main difficulties faced by adolescents with type 1 diabetes mellitus in adhering to treatment, highlighting aspects such as the difficulty in following the doctor's diet, counting carbohydrates and maintaining constant adherence to the therapeutic regimen. Although most of the adolescents reported satisfaction with their treatment and understanding of the medical guidelines, barriers related to sociodemographic factors, such as family income and family support, and behavioral difficulties, such as shyness and lack of interest, were determining factors for non-adherence to treatment. In addition, the lack of adequate resources in the public health system, together with the overload of services and shortage of supplies, can aggravate the situation of non-adherence.

These results point to the need to step up efforts to educate patients and their families, as well as to improve access to and the quality of outpatient care. Psychological support strategies and the creation of more efficient communication channels with the healthcare team could be key to overcoming the barriers identified.

We conclude that adherence to treatment for type 1 diabetes in adolescents is a multifaceted challenge that requires a holistic approach, involving both the medical team and the patient's family and social environment, to promote better management of the disease and prevent future complications.

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