

SOCIOCULTURAL CHARACTERISTICS OF ADOLESCENTS WITH TYPE 1 DIABETES MELLITUS

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ABSTRACT: The present study aimed to describe the sociocultural and clinical aspects of adolescents with type 1 Diabetes Mellitus and report group educational activity based on the needs of the target audience. Quantitative study with 38 adolescents conducted from January to June 2015, in Fortaleza, Ceará, Brazil. Descriptive statistics was used. Insight was gained to educational activities, with five adolescents intentionally selected. Most of them lived in Fortaleza: 20(52.6%), lived in their own houses: 32(84.2%), family income of one to two minimum wages: 35(92.1%). The participants had normal weight: 20(52.6%), fasting hyperglycemia: 27(71%), used two types of insulin: 18(47.3%). They reported higher difficulty in adhering to healthier eating habits to control blood glucose levels. A group educational activity focused on this obstacle was conducted. The subjects had knowledge about the disease and related care; the difficulties in treatment adherence involved sociocultural aspects that could be negotiated with the subjects and their families.

DESCRIPTORS: Nursing; type 1 Diabetes mellitus; Adolescent health.

CARACTERÍSTICAS SOCIOCULTURAIS E CLÍNICAS DE ADOLESCENTES COM DIABETES MELLITUS TIPO 1

RESUMO: Objetivou-se descrever os aspectos socioculturais e clínicos de adolescentes com Diabetes Mellitus tipo 1 e relatar atividade educativa em grupo com base nas necessidades do público-alvo. Estudo quantitativo, com 38 adolescentes, ocorreu de janeiro a junho de 2015, em Fortaleza, Ceará, Brasil. Dados descritos com frequências percentuais. Das reflexões, obteve-se insight para atividade educativa, com cinco adolescentes escolhidos, intencionalmente. Maior parte residia em Fortaleza 20 (52,6%), morava em casa própria 32 (84,2%), com renda familiar de um a dois salários mínimos 35 (92,1%). Os adolescentes pesquisados apresentaram peso adequado 20 (52,6%), hiperglicemia em jejum 27 (71%), utilizavam dois tipos de insulina 18 (47,3%). Enfatizaram maiores dificuldades no controle glicêmico relacionado à alimentação. Realizou-se prática educativa em grupo sobre este obstáculo. Os sujeitos pesquisados detinham conhecimentos sobre a doença e os cuidados; as dificuldades na adesão ao tratamento envolviam aspectos socioculturais que poderiam ser negociados com estes e familiares.

DESCRIPTORIOS: Enfermagem; Diabetes mellitus tipo 1; Saúde do adolescente.

CARACTERÍSTICAS SOCIOCULTURALES Y CLÍNICAS DE ADOLESCENTES CON DIABETES MELLITUS TIPO 1

RESUMEN: La finalidad del estudio fue describir aspectos socioculturales y clínicos de adolescentes con Diabetes Mellitus tipo 1, así como relatar actividad educativa en grupo, considerando las necesidades de ese público. Estudio cuantitativo, con 38 adolescentes, hecho de enero a junio de 2015, en Fortaleza, Ceará, Brasil. Los datos fueron descritos con frecuencias percentuales. De las reflexiones, se obtuvo insight para actividad educativa, con cinco adolescentes seleccionados de modo intencional. De los participantes, 20 vivían en Fortaleza (52,6%), 32 vivían en su vivienda (84,2%), 35 presentaban renta familiar de uno a dos sueldos mínimos (92,1%). De los adolescentes investigados, 20 presentaron peso adecuado (52,6%), 27, hiperglucemia en ayuno (71%), 18 utilizaban dos tipos de insulina (47,3%). Se constataron mayores dificultades en el control de glucemia referente a la alimentación. Hubo práctica educativa en grupo acerca de esa cuestión. Los sujetos investigados poseían conocimientos sobre la enfermedad y los cuidados; las dificultades en la adhesión al tratamiento tenían aspectos socioculturales, los cuales podrían ser negociados entre los adolescentes y sus familiares.

DESCRIPTORIOS: Enfermería; Diabetes mellitus tipo 1; Salud del adolescente.

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● INTRODUCTION

Type 1 Diabetes Mellitus (DM1) is a chronic autoimmune disease that may affect different age groups, being most commonly diagnosed in children, adolescents and young adults. Type 1 diabetes accounts for 5-10% of the total cases of diabetes. It is characterized by progressive and insidious destruction of pancreatic insulin-producing Betacells, triggering absolute insulin deficiency. It requires permanent care and health education in self-care, in order to prevent acute complications and reduce the number of chronic complications ⁽¹⁻²⁾.

Adolescence is the transition period from childhood to adulthood, characterized by physical and biopsychosocial development. It can be a difficult and challenging period, particularly because of the peculiarities involved in self-assertion and in asserting their autonomy and opinions in their relationships with families, peers and society. However, it can be even more difficult when adolescents have chronic diseases, such as DM1⁽³⁾.

Adolescents diagnosed with DM1 face a conflictive situation because illness requires permanent changes in daily life. Chronic diseases impose patient adaptation to limitations. These impact of these changes is greater for children and/or adolescents usually expected to be in good health conditions to grow and develop to their full potential⁽⁴⁾.

In view of the aforementioned, family's support to youngsters with diabetes may help them cope with this disease. Health professionals, including nurses, are expected to provide guidance on diabetes and its treatment to these young patients and their families ⁽⁵⁾.

Nurses are also responsible for providing counseling on healthy habits to adolescents, seeking to reduce the harm caused by DM1⁽⁶⁾.

Therefore, health professionals must identify the needs of these patients, empowering them so that they feel capable of taking care of themselves. This process involves a group educational activity targeted to the adolescents and their families, knowledge of the sociocultural context and clinical aspects of the users assisted under the Unified health system.

The following question was then posed: what are the sociocultural and clinical aspects of adolescents with type 1 Diabetes Mellitus that may be useful in group educational activity?

Therefore, the present study aimed to describe the sociocultural and clinical aspects of adolescents with type 1 Diabetes Mellitus and report group educational activity based on the needs of this target audience.

● METHODS

Exploratory and descriptive study with two steps of data collection. The first data collection mostly involved quantitative data obtained in individual semi-structured interviews. The second step concerned an educational activity with the adolescents that participated in the first step.

The total study population was 86 adolescents, and convenience sampling was used to select 38 subjects who met the following inclusion criteria: aged 10-19 years, monitored at the Center of Diabetes and Hypertension (CIDH), diagnosed with type 1 diabetes for at least six months, and whose records were available during the study period. Adolescents with clinical interurrences such as symptoms of hypoglycemia or hyperglycemia were excluded.

Information was obtained with the use of a semi-structured interview guide that included sociocultural and clinical aspects, as well as an open-ended question on the care needed to maintain glycemic control. The study was conducted from January to June 2015. Contacts with the subjects and data collection occurred in April-May 2015. Data was entered and subjected to descriptive analysis using Statistical Package for the Social Sciences (SPSS), 20.0.

The adolescents that participated in the first step of the study were personally contacted and later contacted again by a reminder telephone call. The first scheduled meeting did not occur due to non-

attendance. Five subjects attended the second meeting. The communications were recorded with audio-visual resources.

In the second step, a group educational activity was performed with some of the adolescents intentionally selected for this purpose who were present at the health center. The educational activity prepared by the researchers aimed to encourage dialogues and reflections on healthy eating habits among youngsters with Diabetes Mellitus. The strategies developed included invitation and reception; rounds of conversation about eating and diabetes: application of dynamics: recommended and not recommended food; discussion and reflection. The material resources used were pictures/images.

Regarding the interaction with the adolescents, after the participants were received and informed on the group dynamics, guidance on eating habits during consultations with health professionals; motivations and difficulties in choosing the foods to be included in the diet were encouraged. Subsequently, identification and classification of the pictures of recommended and not recommended foods began.

The participants produced two tables representing these foods; observance of three-hour intervals, increased water intake and spontaneously talked about the different insulin injection sites, hand washing before medication application and care with the feet. After compilation of the ideas based on these tables and on the conversations between the participants, the researchers stimulated the subjects to report their daily habits, and possible doubts were clarified through a language accessible to the adolescents. Also, the benefits of some foods were emphasized, and the adolescents were reminded of the importance of diet for a better glycemic control, as well as on medications and physical activity.

The assessment was made through observation of the adolescents during the activities and by the doubts and questions generated by each participant.

The study complied with the ethical precepts for human research of Resolution no 466, of December 12, 2012⁽⁷⁾. The project was approved by the Research Ethics Committee of Universidade Estadual do Ceará (181.489). Confidentiality and anonymity, as well as the right to withdraw from the research were ensured to the subjects.

● RESULTS

After analysis of the social and cultural aspects of the adolescents with DM1 who participated in the study, the following results were obtained.

Of the 38 adolescents interviewed, 20(52.6%) were male and 18(47.3%) were female. Regarding their origin, 21(55.2%) lived in the capital Fortaleza, nine(23.7%) lived in the inland of the state and eight (21%) lived in the metropolitan area. Regarding schooling, 37 (97.3%) were enrolled in schools, 20(52.6%) were attending elementary school, 14(36.8%) were attending secondary school, and three(7.9%) were attending higher school. Concerning the age range of the participants (10-19 years), it was found to be consistent with their educational level.

Regarding family income, 20 participants (52.6%) lived on the minimum wage, followed by 15(39.5%) whose family income was two to three minimum wages and four (10.5%) whose family income was four or more minimum wages. Housing conditions were adequate: 32(84.2%), or else, most respondents lived in their own houses. Besides, 17(44.7%) reported living with five or more people, followed by 11(28.9%) who lived with three other people and eight (21%) who lived with four other people. Regarding family interaction, 26(68.4%) lived with their parents, which indicated that they were both dependent on their parents and received help from them.

Participation in social groups obtained a percentage of 35(92.1%), indicating overcoming of social anxiety and embarrassment, since only three (7.9%) did not participate in social groups.

Regarding the health aspects reported in the clinical findings of the adolescents, most of them, 20(52.6%) had normal BMI (18.5 – 24.9), six (15.8%) were below the ideal weight and two (5.3%) were above the ideal weight. Fasting capillary glucose tests of most adolescents, 27 (71%) indicated hyperglycemia (over100mg/dl) and eight (21%) had normal fasting blood glucose levels. Regarding the

time elapsed since the initial diagnosis of DM1, 20(52.6%) of the participants reported more than four years, 14(36.8%) reported two to four years and four (10.5%) approximately six months.

The main symptoms of the patients at the initial diagnosis were polyuria, polyphagia and polydipsia, weight loss, hyper and hypoglycemia, 16(42.1%); polyuria, polydipsia and polyphagia, 11(28.9%) and weight loss, signs of hyper and hypoglycemia, nine (23.7%).

Regarding drug therapy, 18(47.4%) used Neutral Protamine Hagedorn (NPH) insulin and regular human insulin, while 16(42.1%) used long-acting insulin analogues and three (7.9%) used a combination of analogues with NPH and/or regular insulin. Regarding insulin therapy, 37(97.3%) of the adolescents gave themselves insulin injections, seven (18.4%) said that insulin was injected by their mothers or other relatives.

Regarding physical activity, 30(78.9%) reported routine physical activity and eight (21%) of them did not perform physical exercises. Of those who performed physical activity, the most frequent activities were collective sports, (42.1%), such as soccer, basketball, volleyball, and the weekly amount of physical activities in physical education classes. Five (13.1%) participants reported practicing more than one sport.

Regarding self-care and attitudes to control the disease, the adolescents reported daily practice as an inherent condition of life. The most frequent self-care measures were balanced food intake, regular physical activity, correct medication intake, regular consultations with health professionals and proper skin and foot care. It was found that 17(44.7%) implemented four or more of these measures, with focus on glycemic control.

In the second step, analysis of the data collected in the interviews identified that dietary adherence was the main problem experienced by the adolescents, especially in social situations. Therefore, the group educational activity focused on the eating habits of adolescents with DM1. Although all the subjects who participated in the first step were invited to the subsequent step, only five of them attended the second step and discussed eating habits.

● DISCUSSION

The findings of this study showed that the living conditions and income of the respondents did not favor healthy habits, since most of them lived on the minimum wage and faced other difficulties. This situation is aggravated when the individual is affected by chronic disease that requires specialized care, technologies and continuous care.

Corroborating the literature, type 1 diabetes is a chronic and serious disease that impairs the quality of life, especially of children and adolescents, with impact on the whole family⁽⁸⁾. Life history, income and educational level of the adolescents and their parents may influence glycemic control⁽⁹⁾.

The context in which the adolescents are inserted often makes it difficult for them to adhere to the treatment of diabetes. Adherence/adequacy to this process involve the goals and objectives of self-control, the environment, developmental milestones, cognitive progression, among other elements⁽¹⁰⁾.

The treatment of type 1 diabetes is a complex combination of drug and non-drug therapies that causes emotional and mental impact in the adolescents, generating negative emotions such as anger, concern, embarrassment, anxiety about their daily lives and possible occurrences^(8,11).

Most participants in this study reported that the drug treatment consisted in a mix regimen of NPH and regular insulin because these drugs reduce chronic complications, although other therapies are more effective, though more expensive^(2,12).

The type 1 diabetes self-management practices reported by the adolescents indicated that the treatment involved drug and non-drug approaches. Self-management is complex, requires continuous monitoring of blood insulin levels, dietary adjustment, daily insulin doses, practice of physical activity, which generates stress for the adolescents and their families and difficult metabolic control⁽¹³⁻¹⁴⁾.

In view of the aforementioned, parents must provide social and emotional support and counsel to their children to help them effectively manage the disease independently. Constant surveillance may cause suffering, but learning to cope with the situations will make the adolescent a spiritually, emotionally and mentally healthy adult⁽¹⁵⁻¹⁶⁾. The adolescents showed adequate self-management of diabetes, injecting insulin by themselves .

On the other hand, most of them reported eating unsuitable foods such as savoury snacks and soda at school. A few reported eating fruits brought from home. However, it is known that lower-income families are at higher risk of eating more caloric and less nutritious food, because these items are cheaper than fruits, vegetables or other low-calorie nutrients, Therefore, the schools must provide physical, material and human resources that ensure the appropriate conducts in the management of DM1. This requires that teachers are well informed about diabetes, its management, as well as on school health aspects⁽¹⁷⁾.

It is necessary to increase nutritional monitoring of diabetic patients to ensure greater adherence to dietary restrictions, improving glycemic control. This can be obtained by offering a wide variety of foods and planning with the patient a more balanced diet, to favor metabolic control⁽⁹⁾.

Regulation of blood glucose in DM1 is very difficult, particularly for adolescents who experience physical and mental development, which has greater impact on metabolic control.

The present study found that most subjects had fasting hyperglycemia because of an unhealthy diet, particularly at night. Although parents encourage self-management of diabetes by children and adolescents, they also play a significant role in monitoring self-management activities that involve adaptation to a healthy lifestyle, adoption of a healthy diet, practice of physical activity and administration of insulin injections by the patients⁽⁸⁾.

Most subjects performed physical activity to improve metabolic response and control glycemic levels. Sedentary lifestyle is one of the main factors contributing to difficult metabolic control of blood glucose in patients with DM1. Therefore, physical activity should always be encouraged⁽¹⁸⁻¹⁹⁾.

Creative and participatory approaches are needed. Participatory strategies that favored interaction among the adolescents were developed in this study, enabling them to expose their condition and learn about the disease and treatment, in a dynamic way.

The group educational activities contribute to the development of skills and abilities that stimulate participation and self-management of the disease. However, to ensure changes in the lifestyle of these patients and in their attitudes toward treatment, other strategies e.g. multi-site interventions should be implemented to impact the management of diabetes and glycemic control, allowing that diabetes sufferers share their experiences and learn more about the disease^(8,16,20).

Therefore, a dynamic group educational activity that involved the sharing of experiences was developed in this study.

The health professionals stimulated the participation of the adolescents in educational activities, by inviting them to discuss their views on the disease⁽¹⁶⁾. The results suggested that the adolescents are adhering to the recommendations of the health professionals.

Thus, group activities mediated by nurses is a key strategy for the encouragement of adherence to self-management of diabetes^(8,21).

The interaction with diabetic adolescents showed that they most of them were well informed on the treatment, but found it difficult to adhere to it, which resulted in poor dietary control and fasting hyperglycemia. The educational intervention and the group dynamics favored the exchange of experiences regarding management of healthy habits and coping with diabetes among the participants, contributing to positive changes in their lifestyles.

● FINAL CONSIDERATIONS

Sociocultural and clinical aspects of adolescents with type 1 diabetes mellitus were described, and a group educational activity focused on the needs of the target audience was implemented, providing insight on the difficulties of the subjects regarding treatment adherence.

The development of an educational intervention based on information provided by the adolescents with diabetes stimulated the debate, and consequently the problematization of daily issues such as the selection and amount of foods in the diet; association of diet and glycemic control and prevention of complications. The adolescents said they disliked the foods prescribed in the diets, and usually had bread with butter and milk for breakfast. Another aspect stressed by the respondents was their difficulty in adhering to the recommended diet at school because their peers usually had savoury snacks and drink soda. Two adolescents reported eating fruits brought from home at school. Also, one adolescent ate a porridge of wheat flour available at school and another one usually ate biscuits brought from home.

After the interaction with the adolescents with diabetes, the healthcare team became aware of the general and individual characteristics of this population. They also perceived the needs for educational activities that favor the dissemination of knowledge on the disease, the importance of self-management in order to prevent possible complications and provide well-being. Although the adolescents were aware of the treatment and of the complications of diabetes, many of them did not adhere to the treatment and, thus, an educational intervention was necessary.

This intervention resulted in the exchange of experiences with the adolescents, allowing them to talk about diabetes and related aspects such as self-management, adherence to treatment, as well as clarify their doubts.

The present study demonstrated the importance of educational activities that involve the active participation of adolescents with diabetes, their families and the health staff. However, one limitation concerns the small size of the sample.

Therefore, further studies on how to implement effective nursing interventions that meet the unique needs of adolescents are required to ensure effective treatment, reduce health problems and improve the quality of life of these individuals.

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