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## ORIGINAL ARTICLE

### TYPE 1 DIABETES MELLITUS IN ADOLESCENTS: FROM DIAGNOSIS TO THE DAILY CONTACT WITH THE ILLNESS

#### DIABETES MELLITUS TIPO 1 EM ADOLESCENTES: DO DIAGNÓSTICO AO CONVÍVIO DIÁRIO COM A ENFERMIDADE

#### DIABETES MELLITUS TIPO 1 EN ADOLESCENTES: DESDE EL DIAGNÓSTICO HASTA EL CONTACTO DIARIO CON LA ENFERMEDAD

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#### RESUMO

**Objetivo:** compreender o cotidiano de pacientes adolescentes que convivem com o Diabetes Mellitus Tipo 1. **Método:** estudo exploratório e qualitativo realizado com sete adolescentes na faixa etária dos 10 aos 19 anos de idade com diagnóstico médico de DM1, cadastrados na rede de Atenção Básica no município de Floriano (PI), Brasil, no período de março a abril de 2014. Para a produção dos dados utilizaram-se entrevistas. Os dados foram analisados e interpretados segundo a Técnica de Análise de Conteúdo. **Resultados:** como resultados emergiram quatro categorias << O momento do diagnóstico >>; << Amadurecendo com a convivência >>; << O difícil controle terapêutico >>; << A ajuda dos amigos >>. **Conclusão:** compreender o cotidiano de adolescentes que possuem DM1 se faz relevante, uma vez que a Enfermagem pode usar tais informações para traçar um cuidado humanizado e científico. **Descritores:** Diabetes Mellitus; Saúde do Adolescente; Cuidados de Enfermagem.

#### ABSTRACT

**Objective:** to understand the daily life of adolescent patients who live with Diabetes Mellitus Type 1. **Method:** an exploratory and qualitative study conducted with seven adolescents aged from 10 to 19 years old, with a diagnosis of DM1, registered in Care Network Basic in the city of Floriano (PI), Brazil, from March to April 2014. For data production there were used interviews. The data were analyzed and interpreted according to the Content Analysis Technique. **Results:** as results four categories emerged << The time of diagnosis >>; << Maturing with living >>; << The difficult therapeutic control >>; << The help of friends >>. **Conclusion:** to understand the daily life of adolescents who have DM1 is relevant, since nursing can use such information to trace a humanized and scientific care. **Descriptors:** Diabetes Mellitus; Adolescent Health; Nursing Care.

#### RESUMEN

**Objetivo:** comprender la vida diaria de los pacientes adolescentes que viven con Diabetes Mellitus Tipo 1. **Método:** un estudio cualitativo y exploratorio realizado con siete adolescentes de 10 a 19 años de edad con un diagnóstico de DM1, registrados en la Red de Atención básica en la ciudad de Floriano (PI), Brasil, entre marzo y abril de 2014. Para la producción de los datos se utilizaron entrevistas. Los datos fueron analizados e interpretados de acuerdo con la Técnica de Análisis de Contenido. **Resultados:** como resultados cuatro categorías surgieron << El momento del diagnóstico >>; << Madurez con la coexistencia >>; << El difícil control terapéutico >>; << La ayuda de amigos >>. **Conclusión:** comprender la vida cotidiana de los adolescentes que tienen DM1 se hace relevante, ya que La Enfermería puede utilizar tales informaciones para trazar una atención humanizada y científica. **Descritores:** Diabetes Mellitus; Salud del Adolescente; Atención de La Enfermería.

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INTRODUCTION

In the world, and more precisely in Brazil, we live in a change in phase of the disease profile in society, called epidemiological transition. This transition is the reduction of cases of Communicable Diseases and increased Chronic Noncommunicable Diseases (NCDs), including Diabetes Mellitus (DM). The DM has become one of the most important public health problems of the times, reaching expressive significance as it affects the population as a whole, and can occur at any age.<sup>1</sup>

One of its types, DM1, may affect different age groups; it is most commonly diagnosed in children, adolescents and young adults, corresponding to 5 -10% of cases.<sup>2</sup> The incidence of DM1 approaches 0.5 new cases 100.000 inhabitants per year, with a global trend of increase in those below 5 years old.<sup>3</sup>

Noting that DM1 has an important social impact, since it affects individuals in the youth and extended their exposure to the hyperglycemia; it anticipates the development of chronic complications.<sup>4</sup> Living with DM1 causes adolescents experience many conflicting feelings, such as fear, anxiety, fear, anger, loss, dissatisfaction and helplessness. In addition, the teen may also experience feelings of self-overcoming, and trust, acceptance and resignation; taking place, thus, an increase of maturity, given that, according to the stages of the disease, continue to live with the illness. It becomes a learning.<sup>5</sup>

Adolescence is seen as the critical time for control of DM1, due to various constraints required for processing, where often ends up in opposition to the pursuit of independence, collectivism, the idea of indestructibility, attitudes of risk between the different characteristics of this age group.<sup>6</sup>

Nursing plays a key role in assisting patients with DM1; it is at the level of primary health care, through the evaluation and its follow-up in the Family Health Strategy, with the completion of clinical history, physical examination, identification of nursing diagnoses, implementation of care, food guidance, physical exercise, assessment of glucose levels and metabolic control, either in the secondary and/or tertiary, through intensive care in the treatment of acute and chronic complications.

For the development of a committed and a humanized care, it becomes necessary to recognize the daily life of the characteristics of those subjects. It is interesting to note that these patients require a focused assistance

not only on the disease, but mainly in the biopsychosocial aspects. Thus, studies are needed to contribute to a care that goes beyond the biological requirements; however, the publication of researches that seek to understand the daily life of patients with DM1 are shy, especially when it comes to publications in the northeastern scenario, thus demonstrating the knowledge gap.

Search know how the adolescent with DM1 lives with it is relevant, because that way, the nurses will have subsidies to create assistance strategies to this clientele, as well as contribute to a reflection of all the individuals involved in this process, as ways to discover how best can contribute to care.

OBJECTIVE

- To understand the daily lives of adolescent patients living with Type 1 Diabetes Mellitus.

METHOD

It is an exploratory study of a qualitative approach developed in the home environment of adolescents who had medical diagnosis of Diabetes Mellitus Type 1, registered in the Basic Care Network of the city of Floriano-PI. Seven teenagers aged from 10 to 19 years old participated in the search. It is noteworthy that the number seven for the sample can be justified due to the saturation of the data, a procedure consistent with the qualitative approach studies.

There were adopted as inclusion criteria: to present clinical diagnosis of Diabetes Mellitus Type 1; to have experience of illness at least 1 year; to have registration and records in the Network of Primary Health Care in the city of Floriano-PI; to be classified as a teenager, according to the criteria established by the World Health Organization (WHO), that is, the individual aged between 10 and 19 years old.<sup>7</sup> The exclusion criteria were: to meet hospital and not being able physical and mentally to respond the interviews.

Data collection occurred between March and April 2014. To this end, we used the interview technique guidelines. This was recorded with the approval and consent of the interviewee. The interview included the following: characterization of the profile of the subjects, feelings after the diagnosis of DM1, changes in daily life and difficulties in engaging the treatment. It adds also that the interview method was adopted, because it enables the various aspects of social life of the adolescent with type 1 diabetes. It may be possible to analyze the behavior of the subjects facing the disease and be able to

capture the body language of the interviewee to talk a theme so attached to the physical, the emotional and the mental.

It should be noted that the interviews were conducted only after acceptance of the subjects and signatures of the Consent Term. This term ensures participants the non-maleficence, confidentiality and privacy of its statements and ensures no misuse of information and the right of individuals to disconnect at any time, research without risk of penalty or loss.

For data analysis and organization there was used the method known as Content Analysis, which is defined as a group of analysis techniques of communication and aims to message handling, in order to demonstrate the indicators to infer another fact than the message. This technique is debt in three stages, namely: pre-analysis; holding material; and finally, treating the outcomes, inference, and interpretation.<sup>8</sup>

To present the results, data were organized and presented in sociodemographic characterization of the subjects and in four categories, namely: the time of diagnosis, maturing to coexistence, difficult to control and enlisting the help of friends.

It is important to note that the content of the teenagers' speech was expressed in the results, in quotes, with the identification of fictitious names, since it must respect the anonymity of research participants.

The Municipal Health Secretariat of Floriano-PI approved the present search. In addition, it is important to note that data collection took place only after consideration and approval of the research project by the Research Ethics Committee of the Federal University of Piauí, under N° 542.524. This procedure aimed to meet the Resolution N 466, from December 12<sup>nd</sup>, 2012, governing research with humans.<sup>9</sup>

RESULTS

◆ Socio-demographic characterization of the subjects

The study included seven adolescents with a diagnosis of DM1, with a slight female predominance (4) between them.

Regarding age, the average was of 15.6 years old. Regarding the time of diagnosis, four subjects had the disease between 1 and 3 years, two between 5 and 8 years and for over 10 years.

Considering the religion, four were Catholics, two evangelical and one not positioned. Considering housing, six said they live with their parents and with grandparents.

Regarding the level of education, it was found that five said they have not completed secondary school and two had incomplete primary school. Considering family income, those who received 2-3 monthly minimum wages prevailed, which is considered to be R\$ 724,00 at the time of data collection.

To contemplate and achieve the proposed objectives, from that time, the data is presented in categories. The four categories listed were: the time of diagnosis; maturing to coexistence; the difficult therapeutic control; and the help of friends.

◆ The moment of the diagnosis

In this category the subjects express in their statements it was difficult for them to find out the diagnosis of DM, as well as the various feelings that surfaced the new reality, the main being sadness, fear and anger about the unknown. Here are some testimonials:

*Well, at first I was very sad, right? I do not know why. It seemed to change everything in my life. Really changed. (Francisco)*  
*At first, I felt sadness. Because I do not know much about the disease, right? [...] Then, I felt cold in the stomach with fear. My God! And now, what will become of me? I felt very scared, even! (Joseph)*  
*I already feel like [...] why it was me? It could not have been with someone else? (Margaret)*

Notable are also the speeches of adolescents, the vision that they have about the disease. This condition is seen by some as something complicated and this is evidenced by reports of the presence of signs and symptoms that manifest in their body. There are also consequences arising from the DM1, such as loss of vision, which ends up creating feelings of fear to recognize people who have gone through the same experience and were not successful under treatment. These manifestations can be evidenced in the following lines:

*[...] Diabetes is not that usually so one has. And also the people who have said that goes through problems like the problems I felt. I was almost blind, could not see ahead. (Joseph)*  
*[...] When I found out was peeing a lot and losing weight. I ate and still hungry and still eating a lot. I did not know what it was. (Anne)*

It is also possible to identify in the speeches that some teenagers said they had not suffered much with the diagnosis of DM1, as can be seen in the following excerpts:

*So when I had diabetes, I was only eight, right? [...] I think the task of age; it was not much shock to me. I did not feel much difference, no. I was kind of normal. (Rose)*

*At the time, I was only four. I did not quite understand what it was, but I knew that a lot would change in my life. Then I didn't take into account as a matter of age. (John)*

#### ◆ Maturing with the coexistence

This category expresses the maturation of the idea of having DM1, from the continuous living with the disease. At first, what appeared to be something upsetting, unknown and limiting their impulses and desires, becomes something more palliative. Teens learn gradually the nuances of the disease and begin to seek, always, to information about you. Realize that gives to live normally with it. Thus, each day there is a new discovery and, gradually, teens will get used to the new routine of life. The statements below can prove the statement above:

*[...] It also changed my thinking [...] I knew nothing about diabetes; then I also was interested about it. But over time, I realized I would give to live, usually [...] it cannot exist normally [...] with you. (Francisco)*

*[...] I do not know much about the disease, right? Then I googled, I talked to my doctor and saw the risks I ran if I could not do treatment properly if I did not take the medicine properly and not to eat things properly. I learned to do the right treatment, to eat things right? Then today it's controlled' re normal. [...] I keep doing the same things, with respect to my own body, right? (Joseph)*

#### ◆ The difficult therapeutic control

It can be seen in this category, how hard it is for teens adjust to the new reality, the changes in relation to daily routines such as insulin, the limitations imposed by the power, the need to do tests and the responsibility for self-care, which is not always fulfilled by them. Initially, one can see in the reports issues of responsibility for self-care, the difficulties regarding adherence, expressed in the use of medications, and especially the difficulties in following a diet with dietary restrictions. Here is the testimony:

*Ah! It is very complicated! There are times that it seems like you will die. Reaches certain times of diabetes that the glucose levels will come very high; very low [...] Then, I go into situations that it seems that I will not leave, severe problems and symptoms that come too heavy for me. My impression is that I'm not leaving this time. It is not easy to live with that, no. It must always be regulated life. Always have to be okay [...] policing. To have no error. Not to have more serious problems later. (John)*  
*[...] It's a little difficult, both for the sake of being type 1, which must be all the time following, sticking, taking insulin, it is also*

*a disease that few people have. So where I come I will not find someone like me. [...] It's that there're always watching all the time, going to doctor, undergoing tests before I was once in a year or so and now have to do every three months. Then it changed. (Margaret)*

Another issue observed in the reports of the adolescents refers to the difficulty of non-medication acceptance and the need to conduct periodic exams. Often they do not believe that the use of drugs and the completion of laboratory tests are required, these teenagers end up leaving aside the follow-up treatment, although understand and recognize the consequences of not following the treatment regimen, which can be seen in the lines below:

*[...] Sometimes you do not want to take insulin. It has happened a few times, I did not want to take insulin. Then leave once without taking, occasionally try to leave one week [...] But it does not work. Then you feel bad. (Francisco)*

*[...] The matter, now, I'm having trouble with insulin, because sometimes sites that we apply are hurting, becomes swollen, begins to leave blood. Then, donate a lot. (Margaret)*

*[...] For a long time I have diabetes, right? And the person, routine, just sometimes relaxing. To meet a little with some of the obligations, sometimes us for a little bit, but always have to go back and continue again. (Rose)*

In addition to insulin therapy being mentioned as a major obstacle in the treatment of DM1, teens refer also to the problematic in control with food. The speeches below include these nuances:

*The difficulties are to follow the diet. It's a bit difficult. I do not know, because when you want but [...] you feel kind attraction hum hum [...] for sugar. I think it is the need that you cannot eat; it seems that gives more desire to eat, yet. Then sometimes ends up falling into temptation, too. (Francisco)*

*[...] I feel very, very hungry all the time. In fact, hunger may be because of glycemic rates. As I'm not too able to control very well [...] then, live only hungry, wanting to eat all the time. I cannot understand, because I do everything at the right time, but it continues in this disorder. So, have' re ruling me, all the time. It's a bit complicated. (John)*

*Follow the diet is bad because he sees people eating [...] (laughs) and cannot eat. See people eating makes you want to eat and not power. Then, it is bad. (Anne)*

*Ah! It's bad because you see your friends eating things and you cannot eat. It is [...]*



*because I cannot eat things like that. You have the right things. (Mary)*

#### ♦ The help of friends

This category sets out how important it is for young teenagers the support and the help of friends following the treatment of DM1. There are friends who spend most of the time with adolescents, especially in the school environment, exchange of ideas and recognize as part of their peer groups. Many times teenagers realize that their friends show concern and care for them, as shown by the statements below:

*[...] Everyone was always good friend. My colleagues are very helpful. Often when I feel bad they will already asking what it is, what do I need, what they can do to help me. They are very friendly. (John)*

*[...] Always have those friends that leaves not take soft drinks, nothing! No, this here is diabetic. My God! Do not give it to him, not. (Joseph)*

*My colleagues say you cannot eat anything sweet. They avoid eating near me. (Anne)*

### DISCUSSION

There was found in the reports of adolescents, in the first category, that the diagnosis of DM1 brought many conflicting feelings and, gradually, these young people were noticing the changes that the disease would involve in their lives. It can also be noted that some teenagers have not suffered much from the impact of the diagnosis of DM1, believing they are children when at the time of the discovery, and reporting not recognizing the implications of such a discovery would cause.

The feelings in this study were also reported in another study. Scholars say that DM1 can cause many feelings inside the teenager, such as inferiority, low self-esteem, sadness, fear, anger, anxiety, regression, denial of illness, hopelessness, failure to love and relate well with people, the idea of suicide and depression. However, the presence or absence of these feelings, will depend on the internal resources of the personality of each level of knowledge, the way it was given the news of the disease, as well as the support they receive from their family and friends.<sup>10</sup> Thus, in seeking to understand the teen before experiencing the process of living with diabetes, it is clear that fear is part of this universe, not only because of having a chronic disease, but also for being something unknown and the need for a daily and a continuous care, these relevant to your control.<sup>11</sup>

The time of diagnosis is considered the most difficult for teenagers because they realize the need to change their life style and routine. Thus, health professionals, including nursing, need of support and support to this group and its families to better conduct treatment. The priority given to nursing professionals is in fact the knowledge that the essence of the profession is the care for the human being in an attempt to maintain, recover, rehabilitate and promote the health of individuals, in addition to actions to prevent diseases and disorders to human health.<sup>12-3</sup>

It is important to mention that DM1 brings with it the need for changes in daily life, particularly in adolescence, which is a coated phase of intense changes and modifications are the biological or psychosocial field. Such modifications, biological, psychological and physical, are now clearly described in the literature.<sup>14</sup>

The speeches of the second category reveal that every day for adolescents with DM1 is a new learning, a discovery and, above all, recognition of continuous adaptation. About it, study of 14 adolescents diagnosed with DM1 in the city of Fortaleza-CE, found that, with time, the teens learn to live normally with the disease and start to get used to the new lifestyle, developing skills through experience.<sup>15</sup>

Gradually, teenagers will adapt to this new reality, becoming subject more active in the health / disease control, at first, acute complications such as hypoglycemia and hyperglycemia. This fact becomes important, since student already reported that, in that adolescents are acquiring more knowledge about the disease, the treatment becomes more effective.<sup>16</sup>

It is very significant that professionals involved in the care of this group, especially nursing, can recognize the most difficult times and situations experienced by these adolescents and also understand the feelings and experiences that can contribute to comprehensive care and technical necessary for the management of DM1.<sup>11</sup>

In the speech of adolescents in the third category were identified that adolescents with T1DM face numerous challenges and obstacles along the therapeutic treatment, such as complications arising from the disease itself, the need to readjust their schedules to meet the therapeutic demands and responsibility for self-care and self-control.

The literature supports the findings of the third category, since scholars, while researching the experience of young women in

contact with the DM1, identified that the greatest difficulties and obstacles are in relation to the therapeutic control, issues such as glucose monitoring, and the presence of hypoglycemic and dietary restrictions. They found, too, that such restrictions attributed to illness are seen as a factor that limits and hinders the daily care.<sup>17</sup>

In another study, focuses on one of the biggest challenges to maintain a treatment and a good control of chronic diseases, especially DM1 is the adherence to the treatment plan of the subjects.<sup>8</sup>

Data from a study of a group of people assisted by a multidisciplinary team of a research center and university extension of Ribeirão Preto, it was found that participants with diabetes face the food control with despair, in that many feelings such as anger and dissatisfaction are part of everyday life.<sup>19</sup>

In the testimonies of adolescents in the fourth category, it was realized how important the support and the help they receive from friends, to continue the treatment compliance. Studies support the findings of this research, mention to rely on the help not only from the family, but friends also are strong links, very important, to encourage them and support them in carrying out the treatment.<sup>15-20</sup> Not by fact that adolescent diabetic, that this fact will influence their friendship relationships. For, they are close friends with whom they talk and vent about their illness.<sup>14</sup>

It was noticed in the adolescents with T1DM reports that none of them reported having been the victim of any kind of prejudice or discrimination because of having this disease. However, in another study it was found that adolescents who have been victims of such negative feelings, live with fear.<sup>11</sup>

## CONCLUSION

The Type 1 Diabetes is affecting, increasingly, a large number of younger patients worldwide. This fact is also present in the city of Florianópolis. Thus, when it sought to understand how the adolescent living with T1D, the authors knew that this task would not be easy. The constant search of subjects who could participate was arduous task, as it was to have their consent to participate.

Before the seven teenagers who were studied, it was found that the crucial points revealed in the interview were the time of diagnosis, living with the disease, therapeutic control and the help of friends.

Upon receiving the diagnosis, the teenager is driven by many conflicting feelings such as

fear, sadness and revolt. So each young expressed different feelings, depending on the socioeconomic and family background inserted. And yet, over the living with the disease, adolescents expressed the ability to keep their lives within a certain pattern of self-care responsibilities and acceptance as required for therapeutic control.

In addition, the subjects enunciated the great challenges and difficulties to adapt to the new reality and to the therapeutic regimen, the main changes in daily life: the need to make periodic checks, the use of medications, adopting healthy eating habits and responsibility for self-care.

The teenagers said how important it is to understand, support, participate and help friends to get the desired therapeutic control. In this context nursing that can be seen as a science that seeks the integral and holistic care of its customers. It emphasizes the importance of nurses in the care of this group, to form the value that be (the teenager) in its multiple dimensions in order to achieve the expected therapeutic control.

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