

EXPERIENCES OF FAMILY MEMBERS OF ADOLESCENTS DIAGNOSED WITH TYPE 1 DIABETES *MELLITUS*: COEXISTENCE, CARE AND CHANGES

VIVÊNCIAS DE FAMILIARES DE ADOLESCENTES DIAGNOSTICADOS COM DIABETES *MELLITUS* TIPO 1: CONVIVÊNCIA, CUIDADOS E MUDANÇAS

EXPERIENCIAS DE FAMILIARES DE ADOLESCENTES DIAGNOSTICADOS DE DIABETES MELLITUS TIPO 1: CONVIVENCIA, CUIDADOS Y CAMBIOS

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Objective: to know the experiences of family members of adolescents diagnosed with Type 1 Diabetes *Mellitus*, related to coexistence, care, and changes generated by the chronic disease. **Method:** qualitative study conducted between November 2017 and May 2018 with 48 family members of adolescents with Type 1 Diabetes *Mellitus*, members of the social network Facebook. Data analyzed according to content analysis. **Results:** most participants were mothers, living in the Midwest of Brazil, aged between 41 and 60 years, with a college degree, and employed. Three categories were constructed to address family coexistence, constant care, and adaptations required by the chronic disease. **Final considerations:** family members of adolescents diagnosed with Type 1 Diabetes *Mellitus* experienced daily challenges, permeated by difficulties, fears, guilt and uncertainty about the future. Among the challenges were highlighted the changes resulting from the chronic condition in the routine, constant care, exclusive dedication to the teenager. The chronic disease enabled the adoption of healthy lifestyle habits and greater family complicity.

Descriptors: Adolescent. Diabetes Mellitus. Chronic Disease. Nursing. Family.

Objetivo: conhecer as vivências de familiares de adolescentes diagnosticados com Diabetes Mellitus tipo 1, relacionadas à convivência, cuidados e mudanças geradas pela doença crônica. **Método:** estudo qualitativo, realizado entre novembro 2017 e maio 2018 com 48 familiares de adolescentes com Diabetes Mellitus tipo 1, membros da rede social Facebook. **Dados analisados segundo análise de conteúdo.** **Resultados:** maioria de participantes eram mães, residentes no Centro-Oeste do Brasil, com idades entre 41 e 60 anos, nível superior e empregadas. Foram construídas

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três categorias para abordar a convivência familiar, cuidados constantes e adaptações requeridas pela doença crônica. Considerações finais: familiares de adolescentes diagnosticados com Diabetes Mellitus tipo 1 vivenciavam desafios diários, permeados por dificuldades, medos, culpas e incertezas quanto ao futuro. Dentre os desafios destacaram-se as mudanças decorrentes da condição crônica na rotina, cuidados constantes, dedicação exclusiva ao adolescente. A doença crônica possibilitou adoção de hábitos saudáveis de vida e maior complicitade familiar.

Descritores: Adolescentes. Diabetes Mellitus. Doença Crônica. Enfermagem. Família.

Objetivo: conocer las vivencias de los familiares de adolescentes diagnosticados con Diabetes Mellitus tipo 1, relacionadas con la convivencia, los cuidados y los cambios provocados por la enfermedad crónica. Método: estudio cualitativo, realizado entre noviembre de 2017 y mayo de 2018 con 48 familiares de adolescentes con Diabetes Mellitus tipo 1, miembros de la red social Facebook. Los datos se analizaron según el análisis de contenido. Resultados: la mayoría de las participantes eran madres, residentes en el centro-oeste de Brasil, con edades comprendidas entre los 41 y los 60 años, con un nivel de estudios superior y empleadas. Se construyeron tres categorías para abordar la convivencia familiar, los cuidados constantes y las adaptaciones requeridas por la enfermedad crónica. Consideraciones finales: los familiares de los adolescentes diagnosticados con Diabetes Mellitus Tipo 1 experimentaron desafíos diarios, permeados por las dificultades, los temores, la culpa y la incertidumbre sobre el futuro. Entre los desafíos estaban los cambios derivados de la condición crónica en la rutina, la atención constante, la dedicación exclusiva al adolescente. La enfermedad crónica permitió la adopción de hábitos de vida saludables y una mayor complicitad familiar.

Descriptor: Adolescente. Diabetes Mellitus. Enfermedad Crónica. Enfermería. Familia.

Introduction

Diabetes *Mellitus* (DM) is a chronic condition caused by defects in insulin action or secretion, or both, leading to hyperglycemia⁽¹⁻²⁾. This condition, if not controlled, can cause, in the long run, several complications such as “[...] microvascular and macrovascular disorders, resulting in retinopathy, nephropathy, neuropathy, coronary heart disease, cerebrovascular disease, and peripheral arterial disease”^(2:14).

The International Diabetes Federation (IDF)⁽¹⁾ estimated a prevalence of diabetes in the world population at 9.8% in the year 2021 (537 million people), increasing by 10.8% in 2030 (643 million people), and 11.2% in 2045 (783 million people). Of these 537 million people diagnosed with Diabetes Mellitus, 2.7 million are children and adolescents. The prevalence is higher in urban areas than in rural areas, as well as in higher-income countries than in low-income countries. Among the reasons for the increased incidence of DM are urbanization, epidemiological and nutritional transition, sedentary lifestyle, overweight, population growth and aging, and also the longer survival of individuals with diabetes⁽¹⁻²⁾.

Regarding the types of DM, type 1 (T1DM) stands out, affecting 5 to 10% of the total cases, occurring mainly in children and adolescents and the second most prevalent chronic disease in this life cycle. It accounts for 90% of the cases, of which 50% are diagnosed before the age of 15⁽²⁻³⁾. According to epidemiological data from the International Diabetes Federation⁽¹⁾, Brazil is the first country in South America with the highest prevalence of people between 0 and 19 years diagnosed with T1DM, which corresponds to 92.4/1000 inhabitants.

The occurrence of T1DM in Brazil is 9,600 new cases per year in children and adolescents. The country is the third largest in the world in this age group, behind only the United States (USA) and India. Moreover, Brazil is among the 32 countries with the highest risk of developing type 2 DM, requiring carefully planned control strategies for health assessment and intervention⁽¹⁾.

The diagnosis of T1DM in adolescence brings about changes in the family's life habits, modifying its structure, since the changes are inherent to the chronic condition. The new

situation leads the family to have to understand the mechanisms of the disease in order to maintain daily care, prevent complications, and know how to intervene when interurrences occur. It requires adaptations to a chronic condition that requires permanent clinical care, complex and prolonged treatment, and sometimes hospitalizations⁽⁴⁾. In addition, it demands from health professionals and family members care that provides a satisfactory prognosis, because the treatment of T1DM requires adaptations to the new situation of daily life and implementation of coping strategies⁽⁴⁾.

From the treatment perspective, one of the consequences of chronic disease is hospitalization, when the condition worsens, or even in routine care situations. Despite the current rise in the incidence of T1DM in children and adolescents, epidemiological data are still incipient for this population. Moreover, many people remain undiagnosed for long periods of time, which can lead to complications and worsening of the disease⁽⁵⁾.

Brazil recorded between the years 2010 and 2019, 85,021 hospitalizations for T1DM, with this disease being the primary cause in individuals between 0 and 19 years old, getting a national average of hospitalizations around 8,502.10/year. From the first to the last year of the study, there was an increase of 16.12%; the year 2019 showed the highest absolute number of hospitalizations, with 9,430 notifications. In terms of mortality from T1DM in this age group, the rate was around 11.64/1,000,000 females and 6.74/1,000,000 males. The Northeast and North regions of Brazil had the highest annual mortality rate, with 1.09/1,000,000 inhabitants and 0.97/1,000,000 inhabitants, respectively. The lethality rate in this period shows that the highest rate is among females (0.74%)⁽⁵⁾.

The diagnosis of T1DM also marks family life, which, after this moment, provides feelings of guilt, fear, and depression due to new care and routine changes. Children and adolescents with T1DM have physiological and emotional compromises, because they live with stressful situations throughout the treatment, affecting

their social and family life, as they start to have limitations in their activities, need to adopt a specific diet, and undergo painful procedures very often⁽⁶⁾.

Living with T1DM requires a shared attitude of the adolescent with family and friends, maintenance of self-care, as well as attention and guidance from a multiprofessional team. Self-care with chronic disease becomes complex, since the particular needs observed in this phase (social and emotional changes, growth and development, puberty) can influence the treatment of the disease and interfere with self-care. In this process, family members and health professionals can intervene with the purpose of achieving the physical, emotional, psychological, and social balance of these individuals through comprehensive care. Therefore, the family is seen as a fundamental foundation of society capable of helping the adolescent to face the new reality⁽⁶⁾.

The theme of this article is considered relevant to the nursing field, especially with regard to understanding the experiences of families and their needs, aimed at the prevention of diseases and promotion of adolescent health. By understanding the family members' experiences, it is also possible to understand how the first instance of adolescent care is adapting and how the experiences and care related to the chronic disease are, so that the health system and the professionals can improve the care and help in this process. All this also contributes to reducing the incidence of hospitalizations and mortality in this age group, contributing to a more effective care.

Most publications on this theme do not focus exclusively on adolescents, but rather on the context of the discovery of T1DM in childhood and adolescence. The publications that focus on the discovery of T1DM in adolescence portray the adolescent's own experiences, with the family members' experiences discussed in an elementary way. Thus, they offer another contribution to adolescent health.

The study was conducted by the research question: What is it like, for family members,

to live with adolescents diagnosed with type 1 DM? It aimed to know the experiences of family members of adolescents diagnosed with Type 1 *Diabetes Mellitus*, related to coexistence, care, and changes generated by the chronic disease.

Method

A descriptive, exploratory study with a qualitative approach, conducted and structured based on the Consolidation Criteria for Qualitative Research Reports (COREQ)⁽⁷⁾. A total of 48 family members of adolescents aged 12 to 19 years, the chronological definition assumed by the World Health Organization⁽⁸⁾, from November 2017 to May 2018, who were members of the Facebook page “*Diabética tipo Ruim*”, consisting of 20,485 members, participated in the study. After authorization from the page administrator for the study to be carried out, the invitation was sent to the adolescents, and expressions of interest were awaited in the form of comments below the publication.

The capture of family members occurred after the adolescent expressed interest, by sending a message to the adolescent via Messenger, requesting the name of a family member and/or legal guardian, with a Facebook profile, to enable contact. After having the Facebook profiles of those responsible, a message was sent, via Messenger, containing the invitation and information about the research objectives. To those who signaled interest, a Google Forms link was sent individually, with the Informed Consent Form. After reading and agreeing to the term, the family members had access to the questionnaire. The composition of study participants met the following inclusion criteria: being a family member of an adolescent with type 1 DM, member of the Facebook page “*Diabética tipo Ruim*”, having Messenger, and knowing how to read and write. The exclusion criteria were: not returning the answer within the given timeframe (20 days after the invitation was made) and after three contact attempts.

The questionnaire contained two parts: the first, related to the characterization of the

participating family (sex of who was answering, marital status, age, race/color, number of children, profession, income, education, and state of residence); the second part, directed to health issues and specifically in relation to T1DM (clinical health conditions of family members; sources of information used by family members of adolescents diagnosed with T1DM to better understand the chronic disease; how it is to live with an adolescent with T1DM; how the family helps adolescents to cope with the disease and what is “different” about T1DM for the family).

Data were analyzed following the content analysis⁽⁹⁾, organized in three steps: pre-analysis; exploration of the material; treatment of results, inference and interpretation. Pre-analysis: the literal transcription of the answers of family members in the questionnaire sent via Google Forms was performed. After that, an initial reading was performed to obtain the first impressions in relation to the transcribed material. Subsequently, exhaustive readings took place, highlighting excerpts from the family members' answers. Similar ideas were grouped by colors, and then the empirical material was constituted. Exploration of the material: the selected information was highlighted by colors in the empirical material and the nuclei of meaning were specified, that is, words, phrases and expressions that gave meaning to the content of the answers of family members were extracted, occurring the grouping of the nuclei of meaning that culminated in the constitution of categories. Treatment of the results obtained and interpretation: the results were discussed, comparing them to the national and international scientific literature, aiming to give meaning and validity to the raw data. These were classified into three categories: Living with the adolescent diagnosed with diabetes: challenges, difficulties, fears, and guilt; Constant care; What the disease brought differently to the family.

The study is part of the macro-research “Diabetes Mellitus: Parents and Adolescents' Perspective”. It followed the regulations of Resolutions n. 466/2012 and n. 510/2016, of the National Health Council, and was approved by

the Research Ethics Committee of the Universidade do Estado de Santa Catarina (UDESC), under Opinion n. 2,443,357, of 12/17/2017. To ensure anonymity, participants were identified by the letter F (family member), followed by an ordinal number assigned according to the order of return of the questionnaires.

Results

Table 1 shows the characterization data of the family members of adolescents living with Type 1 Diabetes *Mellitus*. Forty-eight family members participated in this research: 45 mothers (93.75%), 1 father (0.48%), 1 aunt (0.48%), and 1 sister (0.48%).

Table 1 – Characterization of family members of adolescents with T1DM by sex, age group, marital status, color/race, profession, origin, employment relationship and education level. Brazil – 2017-2018. (N=48) (continued)

Variables	n	%
Sex		
Male	1	68.75
Female	47	97.92
Age group		
18 to 24 years old	3	6.25
25 to 40 years old	20	41.67
41 to 60 years old	23	47.92
> 60 years old	2	4.17
Marital status		
Living with a spouse or partner	40	83.33
Single	4	8.33
Widowed or divorced	4	8.33
Race/Color		
White	32	66.68
Black	3	6.25
Brown	13	27.08
Profession		
Housewife	8	16.67
Teacher	7	14.58
Receptionist	4	8.33
Others	29	60.42
Origin		
Alagoas	1	2.08
Minas Gerais	11	22.92
Belém do Pará	2	4.17
Paraná	2	4.17
São Paulo	15	31.25
Rio de Janeiro	6	12.50
Santa Catarina	4	8.33
Piauí	1	2.08
Ceará	1	2.08
Paraíba	1	2.08
Rio Grande do Sul	3	6.25
Distrito Federal	1	2.08
Employment Relationship		
Employed	33	68.75
Not working	15	31.25

Table 1 – Characterization of family members of adolescents with T1DM by sex, age group, marital status, color/race, profession, origin, employment relationship and education level. Brazil – 2017-2018. (N=48) (conclusion)

Variables	n	%
Education level		
Did not study	4	8.33
Elementary School Complete	7	14.58
High School Complete	16	33.33
Higher Education Complete	8	16.67
Specialization/Master's/PhD	13	27.08

Source: Created by the authors.

As for the sources of information used by family members to understand the chronic disease and the ways to take care of the adolescent, the main ones were: Internet (19; 39.58%), doctor (10; 20.83%), television and magazines (7; 14.59%), families in the same condition (4; 8.33%), and support groups (8; 16.68%). The latter was also considered important by family members to help in coping with the disease.

Aiming to answer the research question, the family members answered the following questions: What is it like to live with an adolescent who has Diabetes *Mellitus*? How does the family help the adolescents to face the disease? What has Diabetes *Mellitus* brought different to the family? The answers to these questions led to the elaboration of three categories, presented in the sequence:

Living with an adolescent diagnosed with diabetes: challenges, difficulties, fears and guilt

Daily life with an adolescent diagnosed with type 1 DM is permeated by difficulties, dietary restrictions and the constant fear of all the prognoses involving a chronic disease and an uncertain future:

A constant challenge. My son doesn't accept the disease, doesn't do the daily tests to measure his glucose every day, doesn't take insulin, doesn't exercise, and eats without restriction. (F3).

Extremely difficult. My son was diagnosed practically as a baby, he was 1 year and 7 months[...] our life is another one, very complicated to deal with and explain that there are restrictions and times to eat. (F20).

Difficult, because I have to monitor him all day long, always explaining what he can and cannot eat. Fear takes over because of the hypo and hyperglycemia. (F45).

Painful and difficult to know that your child is living with a disease without a cure, and to imagine the after-effects if we don't take the necessary care[...] One day is different from another. (F19).

Difficult, living insecure about the future, being afraid with every hypoglycemia. (F41).

Fear also drives the family to discipline and balance to help the adolescent maintain proper glycemic levels. Daily monitoring, especially at night, makes fear of hypoglycemia a constant factor.

[...] our coexistence stands in the balance between the discipline of treatment and the care not to treat diabetes as a negative, discriminating, and limiting element. It has been a long time since we have had a full night's sleep. The early morning monitoring is very important, because of the danger of hypoglycemia. We try not to dramatize the disease: not to cry in front of her, not to treat her as an incapable or "victim", not to spoil her, and not to encourage others to discriminate against her. At social events, she eats whatever she wants. We correct it with insulin. At the same time, we try in everyday life to have a diet together with her. Sometimes it is difficult to deal with our failures. These are moments when we make mistakes in counting carbohydrates or forget to measure. Some of our failures cause us emotional distress. (F25).

Fear of complications, caused by unbalanced diet or forgetfulness of some precautions, leads family members to experience guilt when faced with blood glucose instabilities.

Constant care

The study revealed that the main caregiver of the adolescent is the mother. She is the one who constantly takes care, monitors the glycemic levels, the eating habits, applies insulin, and monitors the use of medications, which requires her to be present at all moments involving the chronic disease:

I monitor the blood glucose measurements, the application of insulin, and I also guide and prepare the food. (F1).

Being close by at the times when he needs me and making him eat every two hours, eating healthy food. (F7).

My job is to watch and control what he does basically twenty-four hours a day, seven days a week. (F3).

[...] he does the insulin applications, under my supervision, and does the glucose measurement on his own. This has been going on since the first week of diagnosis. (F10).

Other forms of care stated by family members were:

[...] monitoring in the endocrinologist, psychologists and nutritionist. (F23).

Taking to the doctor, searching the Internet for news about people with diabetes. (F12).

I give him all the support, financially, emotionally, and take care of him all the time. I am not working in order to be able to accompany him. (F33).

Always telling the truth about the disease, its consequences, and overcoming it too, we work a lot on the issue of inclusion wherever he is. (F45).

Taking blood glucose measurements, applying insulin, counting carbohydrates, teaching how to do these three things. Looking at the treatment as just another one of the not-so-pleasant everyday things [...] Do not dramatize the disease. (F25).

What the disease brought differently to the family

The diagnosis of type 1 DM caused several changes in the family routine. It brought with it anxiety, worries, financial difficulties, but also led to the adoption of healthier lifestyle habits, established new ways of living, and greater complicity.

At first, anxiety and despair. (F15).

Worries about the finitude of life, insecurity about the future. (F47).

New concerns and lifestyle, as well as spending. (F21).

It changed the routine totally; we have a schedule for everything. For meals, insulin applications. For everything we need to organize ourselves. For example: if you're going out, how long will it take, do you have to carry the supplies, something to eat. (F5).

The family members also mentioned the financial difficulties they face because they had to leave their jobs.

[...] I had to stop working to accompany my son, I'm alone with two children, so if my son is diabetic and needs support and supervision and this is not given, I'm negligent. There is this charge from doctors, nurses and

social workers from the institutions that accompany him. (F3).

Difficulty in acquiring the essential supplies for the treatment [...] (F48).

However, positive changes were also mentioned:

I believe. In my case, greater complicity between me and my daughter. (F27).

[...] a great admiration and affection for my daughter. (F25).

We started to eat healthy food, practice physical activity. Constant learning. (F32).

We even take turns at night. This is a joint fight. I always tell him that today I take care of him so that tomorrow he can take care of me, in my old age. (F4).

A change in diet. And the whole family learned to use the glucose meter and insulin pens, and also to recognize episodes of hypoglycemia. (F23).

Discussion

The age range of the participating family members was between 41 and 60 years, which evidences that the person responsible for the adolescent is in the adult phase and, possibly, has more responsibility to take care of the daily routine, show affection and attention, and has greater ability to talk/dialogue and understand the adolescent. In relation to this finding, a study⁽¹⁰⁾ reveals that the age of the family members makes them better able to help the adolescent to live better with the chronic condition and face complications, suffering and difficulties.

Most of the family members completed high school and a large portion of them have post-graduate degrees at the *lato* and *stricto sensu* levels. It is believed that this higher level of education helped family members to better understand this chronic disease, its particularities, and the need for lifestyle changes, especially regarding the adoption of healthy diets recommended for adolescents living with T1DM.

Thus, the findings of this study corroborate those of a study⁽¹¹⁾ that identified increased education, access to professional training, and sometimes increased income as subsidies for the adoption of healthy lifestyle habits, as well as a greater ability to receive health information, reflect on it, and how to incorporate it into their daily lives. The study participants affirmed that,

despite all the difficulties, the diagnosis of T1DM gave the family the opportunity to adopt healthier life habits, led them to new ways of living, and encouraged the search for new knowledge to act in face of the different situations that arise, such as, for example, the handling of specific devices for the chronic disease, like the glycometer, to measure blood glucose.

In this line of thought, it is worth noting that the diagnosis becomes a watershed, since, after the discovery, the family restructures itself to, as a priority, meet the adolescent's needs. Family life starts to revolve around care, and the family members change their behavior, turning to a common point, working towards the same goal, and leaving the rest of the daily concerns in the background. The adolescent often does not feel motivated and willing to practice self-care. Thus, family members need to extend support and affection to help him face the new way of living. In this study, it was observed that family members became responsible not only for their son, but for his disease. In face of this, they faced difficulties to sustain the routine they were used to, to keep their jobs, and to take care of their well-being, because most of the time they needed to dedicate themselves exclusively to the care of their son.

In relation to these considerations, a study⁽¹²⁾ discusses that the family starts to feel secure when they learn to deal with T1DM and realize that they are providing good care, evidenced by the improvement in the clinical picture. As a result, they become more united and stronger to live with and support this chronic condition, being able to deal better with daily situations. The other trend is to preserve the integrity of the family unit, uniting and avoiding conflicts, to be able to offer support to each other⁽¹²⁾.

Another change caused by the chronic disease highlighted by family members is related to the high cost of acquiring foods that help maintain proper glycemic levels, because these are of high commercial value and difficult to be obtained in some locations, making the diet an obstacle in maintaining the stability of the chronic condition. In this context, in this study,

32 adolescents' family members highlighted the application of insulin and proper nutrition as the main difficulties/changes in daily life. The Brazilian Diabetes Society⁽¹³⁾ preconizes that, with all the advances in the treatment of T1DM, the intake of carbohydrates should not be restricted, but adequate to the nutritional needs. The carbohydrate counting method allows this macronutrient to be ingested, with correct adjustment of the insulin dose to be administered, without affecting blood glucose control.

Therefore, adolescents and family members should be advised by health professionals about possible strategies to optimize postprandial glycemia, maintaining a balanced diet and a variety of foods, which will make the cost of food manageable. The key is that the nutritional adequacy is done individually, according to the nutritional needs and specificities of each patient, ensuring better glycemic control, adequate growth and development in children and adolescents with T1DM, without the need for restrictive diets⁽¹³⁾.

Another challenge reported was the high cost of inputs, purchased privately by 17 (35.42%) study participants. This data corroborates the study⁽¹⁴⁾ that also found the need for families to acquire the inputs privately, because only part is funded by the Brazilian Unified Health System (SUS). The latter offers free distribution of medicines and necessary materials to DM patients enrolled in education programs. This fact should be advised and informed to the family members by the professionals responsible for the management of the adolescent's health conditions⁽¹⁴⁾.

Regarding the source of information for the care of adolescents diagnosed with T1DM, it was observed that family members built their knowledge, reinforced their conducts and clarified doubts, most of the time, in non-scientific means, such as the Internet, television and magazines. This is a worrisome fact, because family members are less frequently accessing health care professionals, who are prepared and have the technical and scientific knowledge to adequately support them in

relation to the doubts and the care they need to have regarding treatment and conduct. This search is being carried out through means that are not always reliable, such as the Internet, which has been on the rise for years and is increasingly consolidating itself as a fast source for the search for information.

Thus, the Internet, the most accessed means of searching for information about T1DM care for the participants and used for data collection in this research, should be a field explored by Nursing to promote Health Education actions. Through the Internet, it is possible to disseminate knowledge and information about health more quickly and easily, thus reaching a larger audience. Studies have proven the effectiveness of this virtual medium for greater dissemination and speed of information, due to the ease of access, either through blogs, flowcharts, conversation circles, and virtual pamphlets⁽¹⁵⁻¹⁷⁾.

Another result that deserves comment is that, among many professionals able to provide care to adolescents with T1DM, only the physician was cited as the health professional who is accessed to help the family in the search for information and guidance. In this sense, the health care developed in Primary Health Care (PHC), which is one of the means accessible to the treatment of people with chronic diseases, has fragilities in SUS⁽¹⁸⁾, especially in the actions performed that are still guided by the biomedical model, leading to a great distance from the necessary and contemplated practices to people living with chronic diseases. This condition further burdens the family, which needs to seek its own means to understand the disease and know how to intervene.

This situation of fragility in the public health system repeats itself in different places of the Brazilian reality⁽¹⁹⁾. The increased prevalence of DM in recent years has brought with it the need for health professionals to be qualified to care for this population, because good quality care implies better health outcomes, especially with regard to disease control, prevention of complications, and health system costs. This improvement in qualification also contributes to a re-dimensioning of health care and means taking

the attention of health professionals beyond the biological dimension of care. With this, they will be able to understand the adolescent as an integral being, who has frustrations, difficulties, uncertainties, and all the other feelings related to his biological age⁽²⁰⁾.

The findings of this research also reinforced the need and importance for family members to learn about T1DM, not only to prevent complications or intervene in the face of complications, but to share knowledge with the adolescent, always telling the truth, avoiding giving a negative and/or dramatic connotation to the disease, in order to assist in their adaptation and search for an identity permeated by daily limitations and restrictions. In this context, it is essential that the family establish a healthy environment, find a balance and a solution to difficult and stressful issues, such as nightly glucose monitoring⁽²¹⁾. To think of a healthy environment is to perceive the family exploring the possibilities to face the chronic condition in its complexity.

In search of this empowerment and the need to relearn how to live and, especially, learn to live with an adolescent diagnosed with a chronic disease, the family members cited the support groups as essential for sharing experiences. They declared that the experiences shared in the groups helped other families to better face the situations that could occur. However, they drew attention to the importance of disseminating information about adolescent T1DM in all segments of society, so that the prejudice that many suffer can be softened and so that adolescents can be understood in the environments where they live.

A study⁽²²⁾ affirms the family members' need for help when they discover that their children have T1DM, because they are faced with doubts, uncertainties, anger and despair. Therefore, they seek explanations to understand the disease and find solutions to minimize the suffering and the negative effects that the chronic disease can bring. Faced with the diagnosis of a chronic disease such as DM, the family goes through a reorganization process, for it will experience constant movements between order and

disorder, which will demand from each family member patience and responsibility to deal with the different situations⁽²³⁾. However, the stronger the bonds, the lower the tensions and the greater the organization of the family system for the development of a collaborative, permanent and continuous care for the adolescent⁽²³⁾.

Thus, it can be seen that the social network formed by family members, relatives and friends is essential for the formation of a bond with the individual who lives with a chronic disease, reflecting in the process of education for self-care and knowledge of adolescents about their condition⁽²⁴⁾. In this network, nurses have a fundamental task when it comes to humanizing technical health care, since they are in charge of providing care focused on the sick individual exposed to risks and in need of curative measures and his family, in order to preserve his health. This care must be extended to the family⁽²⁴⁾.

Professional nurses care for a diversity of morbidities, especially chronic conditions, as is the case of T1DM. Therefore, they must be attentive to the development of a holistic care, which provides, through dialogue, the protagonism of the person in their rehabilitation and the search for a better quality of life. For this, it is essential to develop a relationship of trust with the adolescent, helping them to express feelings and promote positive thoughts, in addition to providing a safe and supportive environment⁽²⁵⁾.

In this context, the importance of health education is highlighted as a pedagogical process that requires the development of critical-reflexive thinking among participants. Thus, reality can be unveiled in a collective way, the emancipation and autonomy of adolescents can be enabled in their life trajectory, besides being trained to make health decisions for self-care⁽¹⁵⁾. The nursing consultation is an extremely important intervention to implement the process of health education, essential for both the adolescent and their family members to understand and become aware of the importance of complying with the treatment and the proposed activities to improve their quality of life⁽²⁵⁾.

With the discovery of the disease, daily challenges became present, marked by fear, guilt, and uncertainty about the future. However, the major challenge for the family members was to adopt the necessary changes with the diet, lifestyle, besides the exclusive dedication to the adolescent. However, parallel to the difficulties, the chronic disease provided greater complicity and support among the family members who cared for the adolescent.

The limitation of the study was the lack of face-to-face contact with the participating family members, which usually occurs in research focused on interviews/statements. The research brought contributions to the nursing field, evidencing the confrontations of some Brazilian families regarding the daily challenge of living with adolescents diagnosed with T1DM, requiring knowledge about how to help and care for the adolescent, especially in virtual networks. The study brought data from a national level, viable by the use of a method still little used, which is the Internet, both for the participants and for the information collection, enabling different evaluations according to each family member and the specific region where they lived and corroborating information about care, changes and challenges that were present in the families that lived with adolescents with T1DM.

The results of this study corroborate the available literature, bringing advances to scientific knowledge by allowing a better understanding of the family role in the care of adolescents living with T1DM, since most of the available literature presents the context of childhood/adolescence and not only the experiences of the adolescent public. It also contributes to reveal the difficulties experienced by families in the daily living with an adolescent diagnosed with a chronic disease and alerts health professionals to the need for a more present action with these families.

Final Considerations

The family members of adolescents diagnosed with Type 1 Diabetes *Mellitus* experienced daily challenges, permeated by difficulties, fears, guilt and uncertainty about the future. Among the

challenges they highlighted the changes resulting from the chronic condition in the routine, the constant care, the exclusive dedication to the teenager. However, the chronic disease enabled the adoption of healthy living habits and greater family complicity.

It also highlights the need to implement health care actions for adolescents with chronic disease, based on their needs, the reception and bonding. In this scenario, nurses need to be present and compose the network of support to families, so that professional practices contribute to a comprehensive and effective care to these adolescents and their families who seek health care services.

The innovation of the method is noteworthy, since the Internet allows people to interact at a distance and has provided a comprehensive nationwide study on the experience of family members. Still, it is the main source of information for adolescent care and should be explored by health professionals in terms of health education and correct information for handling the chronic disease.

Collaborations:

1 – project conception and planning: Ângela Barichello, Carla Argenta and Elisângela Argenta Zanatta;

2 – data analysis and interpretation: Ângela Barichello, Maira Scaratti, Carla Argenta and Elisângela Argenta Zanatta;

3 – writing and/or critical review: Ângela Barichello, Maira Scaratti, Carla Argenta and Elisângela Argenta Zanatta;

4 – approval of the final version: Ângela Barichello, Maira Scaratti, Carla Argenta and Elisângela Argenta Zanatta.

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