Experiences of adolescents with type 1 diabetes

Vivências de adolescentes com diabetes mellitus tipo 1
Experiencias de adolescentes con diabetes mellitus tipo 1

Abstract

Background: Type 1 diabetes is a common chronic disease in adolescents and requires maturity, responsibility, acceptance, and constant care.

Objectives: To understand how adolescents live with type 1 diabetes and describe their sociodemographic profile.

Methodology: A quantitative/qualitative exploratory, descriptive research was conducted with 61 adolescents diagnosed with type 1 diabetes who followed the Facebook page Diabética tipo Ruim.

Results: The majority of the participants were male (78.68%), White (60.65%), aged 15 to 18 years (60.65%), and lived in Southeastern Brazil (40.98%). They reported feelings of fear (31.66%), sadness (22.95%), and anger (14.75%) toward the diagnosis. Qualitative data were divided into three categories: Impact of the diagnosis of diabetes on the adolescents’ lives; Accepting the disease to live better; Family, friends, and health professionals as a support network.

Conclusion: Diabetes has a major impact on the daily lives of adolescents, requiring self-care and a support network composed of family, friends, and health professionals.

Keywords: adolescent; diabetes mellitus, type 1; nursing; chronic disease

Resumo

Enquadramento: A diabetes mellitus tipo 1 é uma doença crônica que afeta frequentemente adolescentes, exigindo maturidade, responsabilidade, aceitação e cuidados constantes.

Objetivos: Compreender como é para os adolescentes viver com diabetes mellitus tipo 1 e descrever o perfil sociodemográfico dos adolescentes com diabetes mellitus tipo 1.

Metodologia: Pesquisa exploratória, descritiva, quantitativa e qualitativa, com 61 adolescentes, diagnosticados com diabetes mellitus tipo 1, seguidores da página do Facebook Diabética tipo Ruim.

Resultados: A maioria dos participantes é do sexo masculino (78,68%), cor da pele branca (60,65%), estudante (80,16%), residente na região sudeste do Brasil (40,98%), com idade entre 15 e 18 anos (60,65%). Os sentimentos em relação ao diagnóstico foram medo (31,66%), tristeza (22,95%) e revolta (14,75%). Os dados qualitativos foram discutidos em três categorias: Impacto do diagnóstico de diabetes mellitus na vida dos adolescentes; Aceitar a doença para viver melhor; Família, amigos e profissionais de saúde como rede de apoio.

Conclusão: A diabetes mellitus produz um grande impacto na rotina do adolescente, requerendo autocuidado e rede de apoio constituída por família, amigos e profissionais de saúde.

Palavras-chave: adolescente; diabetes mellitus tipo 1; enfermagem; doença crônica

Resumen

Marco contextual: La diabetes mellitus tipo 1 es una enfermedad crónica que suele afectar a los adolescentes y que requiere madurez, responsabilidad, aceptación y cuidados constantes.

Objetivos: Comprender cómo es para los adolescentes vivir con diabetes mellitus tipo 1 y describir el perfil sociodemográfico de los adolescentes con diabetes mellitus tipo 1.

Metodología: Investigación exploratoria, descriptiva y cuantitativa con 61 adolescentes diagnosticados con diabetes mellitus tipo 1, seguidores de la página de Facebook Diabética tipo Ruim.

Resultados: La mayoría de los participantes es del sexo masculino (78,68%), de piel blanca (60,65%), estudiantes (80,16%), que viven en la región sudeste de Brasil (40,98%), con edades comprendidas entre 15 y 18 años (60,65%). Los sentimientos respecto al diagnóstico fueron miedo (31,66%), tristeza (22,95%) y rabia (14,75%). Los datos cualitativos se examinaron en tres categorías: Impacto del diagnóstico de la diabetes mellitus en la vida de los adolescentes; Aceptar la enfermedad para vivir mejor; Familia, amigos y profesionales de la salud como red de apoyo.

Conclusión: La diabetes mellitus produce un gran impacto en la rutina del adolescente, ya que requiere autocuidado y una red de apoyo formada por la familia, los amigos y los profesionales de la salud.

Palabras clave: adolescente; diabetes mellitus tipo 1; enfermería; enfermedad crónica
Introduction

Type 1 diabetes (T1D) is a chronic disease characterized by high blood glucose levels that occur when the body cannot produce any or enough insulin (DeFronzo et al., 2015). According to the Brazilian Diabetes Society (Sociedade Brasileira de Diabetes, SBD), T1D accounts for 5% -10% of the total cases of diabetes, is one of the most common chronic diseases in childhood and adolescence, accounting for 90% of cases, of which 50% are diagnosed before the age of 15 (SBD, 2019).

T1D is estimated to affect around 1,106,200 children and adolescents worldwide. Brazil is the third country with the highest number of cases in this age group, totaling 88,300 cases. It is estimated that 132,600 new cases are diagnosed worldwide every year, 9,600 of them in Brazil (International Diabetes Federation, 2017).

In adolescence, the difficulties associated with T1D are more intense because the disease requires maturity, responsibility, and self-care toward chronicity. Furthermore, adolescents must understand that they need to live with some limitations and restrictions because the diagnosis of T1D involves an adaptation to new lifestyles (Silva, Amorim, Valença, & Souza, 2018). Given the diagnosis, adolescents need to change their habits and lifestyles, especially concerning blood glucose control and “acquiring healthy life habits, such as balanced diet, taking up physical exercise regularly and adhering to medicine treatment, whenever required” (Silva, Amorim, Valença, & Souza, 2018, p. 96).

This situation requires support from the family and health professionals, so it is essential to understand how adolescents live with T1D to outline strategies that can meet their needs and improve their quality of life (Cavini, Gonçalves, Cordeiro, Moreira, & Resck, 2018; Flora & Gameiro, 2016).

The search performed in databases showed that a few studies were carried out to understand how adolescents live with diabetes, and those that are available focus on epidemiology and symptomatology. Thus, this study is important because it will help guide health professionals, especially nurses, in caring for adolescents living with T1D, as well as contribute to the development of health promotion strategies for a comprehensive, humanized, and effective care delivery.

This study is part of the project DM tipo 1: ótica de adolescentes e pais and took into account the following objectives: To understand how adolescents live with T1D and to describe the sociodemographic profile of adolescents with T1D.
and accept, and subsequent access to the questionnaire. Three contact attempts were made by sending the link to the questionnaire again, after which the participants who did not answer were excluded from the study. The sample met the following inclusion criteria: aged 12 to 18 years, having T1D, and being a follower of the Diabética tipo Ruim Facebook page, consisting of 20,485 members. The exclusion criteria were not expressing interest (in the form of a comment) in the Facebook invitation within 20 days and not completing the full questionnaire. The latter criterion determined the exclusion of five participants. A convenience sampling technique was used based on the number of answers received within the deadline for data collection. Data were collected between December 2017 and April 2018 through a questionnaire with descriptive dichotomous and multiple-choice questions via Google Forms. Quantitative data were analyzed through descriptive statistics using the Epi Info™ statistical software and following the three steps of Bardin’s principles of content analysis (2011): pre-analysis, exploration of the material, and treatment, inference, and interpretation of results. In the pre-analysis, the adolescents’ answers to the questionnaire sent via Google Forms were transcribed in full. Subsequently, the transcriptions were read to obtain the first impressions of the material. Exhaustive readings followed, with emphasis on excerpts from the adolescents’ answers, using the chromatic technique. Similar ideas were grouped by color, leading to the creation of the empirical material for detailed analysis. In the phase of exploration of the material, the information highlighted in color in the empirical material was selected, and the units of meaning were created, that is, words, sentences, and expressions that gave meaning to the content in the participants’ statements. The units of meaning were grouped into categories. In the phase of treatment, inference, and interpretation of the results, the results extracted from the empirical material were compared with the national and international scientific literature to make sense of and validate the raw data discussed in three categories: Impact of the diagnosis of diabetes on the adolescents’ lives; Accepting the disease to live better; Family, friends, and health professionals as a support network. The research followed the regulations of Resolution 466/2012 of the National Health Council (CNS, 2012) for research involving human beings and the principles of bioethics, autonomy, non-maleficence, beneficence, justice, and equity. It was approved by the local Ethics Committee, under Opinion No. 2.443.357. To preserve anonymity, adolescents were identified by the letter A (adolescent), followed by an ordinal number that indicated the order in which the answers were received.

Results

Table 1 shows the quantitative data about the adolescents’ sociodemographic profile. Most of the participants were male, White, students, and aged 15 to 18 years.

<table>
<thead>
<tr>
<th>Variables</th>
<th>N</th>
<th>%</th>
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<td>Gender</td>
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<tr>
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<tr>
<td>12 to 14 years</td>
<td>11</td>
<td>18.03</td>
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<tr>
<td>15 to 18 years</td>
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<tr>
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<td>21.31</td>
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<tr>
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<td>± 1.59</td>
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<tr>
<td>Weight</td>
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<td>± 61.5</td>
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<tr>
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<td>4.91</td>
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<td>2</td>
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</tr>
</tbody>
</table>

Note. SD = standard deviation.

In relation to the adolescents’ residence, the majority of them (n = 25; 40.98%) lived in the state of São Paulo, in the southeastern region. The remaining adolescents lived in 11 Brazilian states: Minas Gerais (n = 6; 9.83%), Rio Grande...
do Sul (n = 6; 9.83%), Santa Catarina (n = 6; 9.83%), Rio de Janeiro (n = 6; 9.83%), Paraná (n = 2; 3.27%), Rondônia (n = 1; 1.64%), Pernambuco (n = 1; 1.64%), Paraíba (n = 1; 1.64%), Espírito Santo (n = 1; 1.64%), and Goiás (n = 1; 1.64%). Four adolescents did not report their state of residence (n = 4; 6.55%).

Impact of the diagnosis of diabetes on adolescents’ lives
Most adolescents (n = 28; 45.90%) were diagnosed with T1D between 11 and 18 years of age and reported having sought health services due to typical symptoms such as polyuria (n = 31; 50.81%), weight loss (n = 29; 47.54%), and excessive thirst (n = 29; 47.54%). Regarding the impact of the diagnosis of the disease, the feelings of fear (n = 19; 31.14%), sadness (n = 14; 22.95%), and anger (n = 9; 14.75%) stood out. When asked about how they received the diagnosis of the disease, the adolescents answered: “At the time I didn’t know what to think. The disease was not as well known as it is today. At that moment I had no idea what my life would be like from then on” (A6, January 2018); “Fear, you feel like you don’t know what’s going on with your life!” (A36, January 2018).

The first reaction to the diagnosis was shock, followed by non-acceptance/denial of the new reality. Initially, the adolescent acts as if the disease does not exist or minimizes its severity, delaying the necessary care and refusing to manage it: “It was a shock because I didn’t know how to deal with it and what it was. I thought my life was over!” (A37, January 2018); “I still don’t accept it, which is very difficult for me on a daily basis, I won’t lie and say that I have a wonderful life” (A6, January 2018); “I don’t think I’ve accepted it yet, because I don’t do the treatment properly” (A11, January 2018). After the first moment of impact, the adolescents experienced a feeling of anger and started to question why this was happening. This situation occurred because unexpected events generate anger, revolt, and rebellion. They have an impact on disease acceptance and, consequently, on treatment adherence: “it’s not easy to be a young person and know that you have a disease that will last for the rest of your life. Sometimes I feel angry, even more in a phase of transformation like adolescence” (A36, January 2018); “I have phases of rebellion, I don’t accept it, I don’t control it, I don’t do anything right” (A23, January 2018).

The non-conformist approach is also evident in the difficulties in living with individuals of the same age group who do not have restrictions imposed by the disease, making them feel different from them: “Sometimes it’s difficult to go out to eat or to parties with friends who don’t have the same problem as me” (A2, January 2018); “I don’t think I have a normal life. In fact, it is quite different from the lives of other ordinary people” (A54, January 2018).

Accepting the disease to live better
After the impact of receiving the diagnosis of T1D, adolescents face a new life situation and need to create strategies to cope with it. Acceptance is gradual, and adolescents adhere to the new lifestyle and the dietary restrictions over time, becoming more autonomous in managing the disease and facing the daily challenges: “Today I live well with it, I’ve accepted diabetes, I try to keep it under control, and I’m happy” (A12, January 2018); “I live well with it, I try to control it, but I don’t stop eating, I just eat small amounts. Some days are more difficult, but it passes!” (A19, January 2018); “Nowadays it’s more peaceful, but it’s not easy. Every day is a challenge” (A49, January 2018).

Over time, adolescents get to know more about T1D and about how to live with it by taking a few precautions. After years with the disease, I realized there are ways to live with it naturally. Today, after so many years, I’m a normal person, I live just like a normal person, and I’m happy about it. I love my insulin, I can’t live without it (A45, January 2018).

By integrating the disease, expressing their feelings, and facing the conflicts, adolescents create a new vision of themselves. Due to the need to make decisions and manage the situations imposed by adolescence and the chronic disease, adolescents find themselves in the search for a new identity, rediscovering their way of being as adolescents living with a chronic disease:

Living with a chronic disease is not easy because you know that it will always be there and that the best alternative is to control it adequately . . . this is not normal and natural for me, but it becomes part of who we are. (A23, January 2018)

“This disease has defined everything I am. My profession, the friends I choose, love. In truth, it has guided my life” (A22, January 2018).

While they accept the disease, many adolescents report insecurity about the future. As already mentioned, adolescence is a phase marked by social construction as a result of experiencing discoveries, worries, choices, and challenges, and, when associated with the chronic condition, the future becomes a constant uncertainty: “Insecurity and fear of the future. Feeling different from people my age” (A13, January 2018); “I deal well with the disease. It’s difficult to deal with possible future problems. I live haunted!” (A20, January 2018).

Adolescents’ biggest fears are associated with possible diabetes-related complications, as well as the long-term effects of the disease, which can directly compromise their quality of life. This whirlwind of emotions in adolescents with chronic disease is proportional to the changes imposed by T1D, such as food restrictions, dependence on third parties, medication use, or even fear of death, which is evident in the following interview excerpts:

It’s very difficult. I confess that it made me a better person, the idea of dying suddenly or needing other people’s help changes us dramatically. I also live with the monsters of the thoughts of the possible consequences of neuropathies. I could define it as being constantly on a roller coaster. (A22, January 2018)

“Insecurity about a healthy future, limitations imposed by food control and sadness” (A10, January 2018).

Family, friends, and health professionals as a support network
Faced with a chronic disease, the family has an important

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role in helping adolescents cope with T1D and manage their new condition, as well as provide much of the emotional, mental, and affective support. This family support promotes changes in routines and habits, especially eating habits, to facilitate treatment adherence. When asked if they received family support, 55 (90.16%) adolescents answered yes and all of them consider it to be fundamental: “Yes, because they help in my daily life and also in the case of glycemic alterations” (A1, January 2018); “Family members must support us and know how the disease works to help us if we need help and to encourage control” (A7, January 2018); “I consider this support to be very important because sometimes I’m angry and don’t want to keep caring for diabetes and they’re always there to encourage and help me” (A2, January 2018);

“It’s important, yes, because it’s not an easy thing, it’s tiring, boring, pricking your finger, injecting the insulin, eating right. I think family support is important because it doesn’t let the person be careless, there’s always someone supporting us” (A56, January 2018).

Although family support is positive, adolescents expect health professionals to integrate their support network, to help, to understand, and to guide them in managing the disease and the difficulties imposed along the way. However, in the interviews, the adolescents emphasized the need for these professionals not to judge them, to be patient, and to understand how this process of acceptance, adaptation, and change of habits occurs.

Don’t criticize. Don’t judge. Don’t question. Just let us talk! We have no one to share this with, and it’s not just anyone who understands it. I lost count of how many times I went to vent and even cry with friends and heard: who told you to eat so many candies? Now you’re going to be sick forever. It’s hard to explain that it’s not your fault. (A20, January 2018)

I hope you are patient! We really know what we have to do, but we’re not always in the mood for it. Diabetes is a tiring disease, and you must understand that sometimes we need to give it a break. We need to do the things that ordinary teenagers experience. It is the health professionals’ role to clarify us, show us the paths, the possible sequelae. But if they don’t understand that we won’t always do everything to the letter, they’ll never be able to truly help us. We want professionals who are our friends. (A23, January 2018)

“They shouldn’t impose treatment conditions. They should talk to the patient and, together, define the best ways and options for a better treatment. No teenager likes to be forced to do things.” (A26, January 2018)

Restrictions and care needs create the need to build new values as well as for changes in identity formation and interpersonal relationships, leading adolescents to draw closer to other groups with whom they identify and support them. These results demonstrate the need and the importance of sharing things with their peers. Contacting with other diabetic adolescents allows them to feel more comfortable exposing their needs, doubts, and worries while realizing that they are not the only ones to have to cope with the situations imposed by the disease and its management.

“It’s always good to have support from those who also have the disease because they understand what it’s like to live with diabetes” (A12, January 2018).

It’s important to talk to someone in the same situation to ask questions, receive tips and feel free to talk about your day to day with people who will understand what you go through and help you deal with your doubts and insecurity. (A2, January 2018)

Similarly, A8 and A10 also expressed a desire that their family members, friends, and health professionals have diabetes because if they experienced the disease, its routines, and the need to maintain daily care, they would better understand the difficulties that they have to face in their everyday life.

I wish health professionals or their children had diabetes so they could see what it’s like because what they recommend us to do is difficult to do in our everyday lives, I try, but it’s very annoying and very bad to live like this, so to demand that much from me doesn’t help me because they don’t know what it’s like (A8, January 2018)

“Theory helps a lot in treatment, but only daily coexistence provides a real knowledge of the disease” (A10, January 2018).

Discussion

This study revealed that the impact of the diagnosis of T1D triggers feelings of fear, sadness, and anger, and that adolescents begin to experience difficult moments and struggle with these feelings, especially fear and insecurity, because it is an unexpected situation and they have little knowledge about this disease. Thus, they experience non-conformity, denial, and the need to change habits. These limitations and the impact of the chronic disease might also make them not adhere to treatment, which may cause the treatment to fail and turn the management of the chronic disease into a slow and painful process (Gomes et al., 2019; Conte & Riveros, 2018).

Adolescents seem to have difficulties in accepting T1D because it deprives them of pleasurable activities due to the amount of time spent on caring for the disease and the associated restrictions, which have a direct impact on their social life and make them feel different from other individuals of the same age group. Flora and Gameiro (2016, p. 33) argue that this moment requires “adolescents and their families to have an autonomous and responsible attitude in disease management” because several difficulties will arise throughout the adaptation process. These difficulties can be minimized and overcome if the adolescents engage in disease control and adopt the necessary care, taking into account that changes in life habits are crucial for controlling the disease.

This study revealed that over time adolescents become more familiarized with diabetes and how to live with it; they go through the adaptation process and learn to live
with the disease and its limitations, accepting it as part of their life. Awareness and acceptance are essential for adolescents and families to cope with the difficulties and achieve a better quality of life (Primer, Afonso, Lima, & Abe, 2018).

The results demonstrate the importance of stimulating the adolescent’s interaction with other individuals and groups who experience the same concerns. It is believed that spending time with friends is essential to help adolescents face their disease and live with it because sharing experiences allows them to understand that their fears and difficulties are not unique. Furthermore, sharing experiences will help adolescents to accept the disease and promote the resignification of the chronic disease (Primer et al., 2018; Nass et al., 2019).

The involvement of friends and family in the therapeutic process increases adolescents’ self-confidence and understanding of the need for treatment adherence. However, the study puts forward the need to move from a focus on impositions regarding T1D care and disapproval of attitudes from family, friends, and health professionals to a focus on seeing the adolescent as a human being undergoing a transformation and someone who is learning to live with the limitations and care needs imposed by the disease.

For adolescents with T1D, disease management is directly related to how they interpret their health condition and the treatment-related obligations from their family, friends, and, included here, health professionals. Especially concerning the nurse’s intervention, Malaquias et al. (2016) and Cruz et al. (2018) highlight the importance of knowing the meaning of becoming an adolescent with a chronic disease to provide appropriate care while focusing on coping with the difficulties and challenges imposed by the chronic disease and considering the adolescents’ needs and expectations.

The results of this study on how adolescents live with T1D are in line with those found by Malaquias et al. (2016), Cruz et al. (2018), and Gomes et al. (2019) regarding the affirmation that the performance of the nurses and health teams improves when they are aware of each adolescent has received the diagnosis and accepted the disease. This understanding will promote the creation of affectional bonds that can contribute to planning strategies capable of responding to the needs and changes imposed by T1D. In this line of thought, Cruz et al. (2018) and Collet, Batista, Nóbrega, Souza, and Fernandes (2018) emphasize the importance of strengthening adolescents’ support networks composed of family, friends, and health professionals for the creation of a welcoming environment where they share knowledge and experiences and feel comfortable with expressing their needs. This approach favors the adolescents’ empowerment for self-care maintenance and highlights their responsibility in controlling their treatment.

In addition, health professionals must show interest in the needs, anxieties, and fears of adolescents and their families and establish a relationship of trust that will contribute to disease management and therapeutic efficacy. Health professionals’ reprisals based on the possible consequences of unsuccessful treatment adherence have low effectiveness because they discourage the adolescent (Amado, Leal, & Saito, 2014).

Moreover, this research revealed that adolescents, even at the height of their uncertainties and sometimes rebelliousness and fear, especially fear of death, caused by the diagnosis of T1D, recognize that the chronic disease requires changes that influence their routine. They express the need to have a support network consisting of family, friends, and health professionals. Still, they emphasize the need to be understood without judgment because they understand that the actions of this support network will benefit their self-care, help them overcome the difficulties imposed by the chronic disease, and guide them in diabetes care.

**Conclusion**

The results of this study indicate that the diagnosis of T1D has a significant impact on the adolescents’ routine, making the entry into adolescence even more turbulent, requiring the adolescents to be mature and responsible given the self-care needs and the limitations imposed by this chronic disease.

By accepting T1D, adolescents understand the importance of self-care and the support network composed of family, friends, and health professionals because they help them to face the difficulties of everyday life, better understand the chronic disease, and adhere to treatment.

This study provided an understanding of how adolescents live with T1D, offering the scientific community and the health professionals information to better plan interventions for helping adolescents in their self-care process. Throughout the study, some limitations influenced the results, such as the difficulty in making adolescents aware of the importance of their participation in the research. The low adherence might have prevented the identification of other aspects intrinsic to the disease that could be useful in the elaboration of care strategies. Therefore, other studies should be conducted using different types of approaches.

**Author contributions**

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