SUBJETIVIDADES
e-ISSN: 2359-0777
Universidade de Fortaleza
Research Report

Type 1 Diabetes Mellitus from the Perspective of Adolescents Receiving Care in Endocrinology Units of a Referral Hospital in Southern Brazil

Diabetes Mellitus Tipo 1 sob o Olhar de Adolescentes em Tratamento nas Unidades de Endocrinologia de um Hospital de Referência no Sul do Brasil

Diabetes Mellitus Tipo 1 bajo la Mirada de Adolescentes en Tratamiento en las Unidades de Endocrinología de un Hospital de Referencia en el Sur de Brasil

Diabète Sucré de Type 1 du Point de Vue d'Adolescents en Traitement dans les Unités d'Endocrinologie d'un Hôpital de Référence du Sud du Brésil

10.5020/23590777.rs.v25i2.e16959

Larissa Rossi Silva

Holds a degree in Psychology from the Pontifical Catholic University of Paraná (PUCPR). Has experience in public policy, having worked as an intern at the Court of Justice of the State of Paraná (TJPR) and at the Specialized Reference Center for Social Assistance (CREAS) in the city of Ibiporã, Paraná.

Pricila Paveukiewicz

Holds a degree in Psychology from UFPR (2009). Completed a lato sensu specialization in Clinical Psychology with a Psychoanalytic Approach at PUCPR (2014). Holds a Master of Arts in Psychoanalytic Studies from Birkbeck, University of London (2022). Has professional experience in Psychology, Hospital Psychology, and Clinical Psychology. Currently works as a psychologist at the outpatient clinic of the Pediatric Endocrinology Unit of the Clinical Hospital Complex of UFPR (HC-UFPR), providing care to children and adolescents.

Camila Cardoso Rauen

Holds a degree in Psychology from PUCPR (2002). Completed postgraduate training at the Institute of Psychology, University of São Paulo (USP; 2004) in the Treatment and Schooling of Children with Pervasive Developmental Disorders, and a postgraduate program in Neuropsychological Assessment and Rehabilitation (2020) at the Sapiens Instituto de Psicologia. Holds a master's degree and is currently a doctoral candidate in Health Promotion in Childhood and Adolescence at HC-UFPR. Has professional experience in both private practice and public services in the fields of health and education, with a primary focus on the psychological aspects of childhood and adolescence. Currently a member of the psychology team at the Clinical Hospital Complex of UFPR, working in the outpatient clinics of Child and Adolescent Psychiatry and Neuropediatrics, as well as serving as a preceptor in the Multiprofessional Residency Program in Hospital Health Care for Children and Adolescents.

Gustavo Manoel Schier Dória

Holds a medical degree from the Evangelical Faculty of Paraná (1985), Earned a MSc in Psychiatry from USP in 1999 and a PhD in the Graduate Program in Child and Adolescent Health in the Department of Pediatrics at UFPR in 2011, with the dissertation entitled "Assessment of Psychiatric Disorders in Adolescents in Conflict with the Law.".

Abstract

Type 1 diabetes mellitus is a chronic disease that frequently manifests during adolescence. Living with a chronic condition during a life stage marked by multidimensional changes, such as adolescence, has been associated with increased psychological distress and the intensification of conflicts typical of this period. Accordingly, this study aimed to understand how adolescents diagnosed with type 1 diabetes mellitus perceive their illness. A qualitative, exploratory, and descriptive study was conducted. A total of adolescents aged 12-17 years, receiving outpatient care at the endocrinology units of a referral hospital in southern Brazil, participated in the study. Data collection instruments included a sociodemographic questionnaire and a semi-structured interview guide. The interviews were audio-recorded and fully transcribed for analysis. Data were processed using descending hierarchical classification provided by the IRaMuTeQ® software,

which organizes textual data into word classes based on statistical significance. The material was interpreted using thematic categorical analysis and a psychoanalytic theoretical framework. Six thematic categories were identified: i) being normal and being different, addressing the impact on identity construction and group belonging; ii) dealing with external control, focusing on the effects of parental control; iii) disease acceptance and the development of self-care, addressing adaptation to the diabetes care routine; iv) glycemic variability and its relationship with emotional factors, examining the influence of emotions on glycemic fluctuations; v) the process of separation from parents and the development of autonomy, addressing the transfer of care responsibility from parents to adolescents; and vi) adopting a healthier lifestyle after diabetes, addressing lifestyle changes following diagnosis. The findings indicate that the disease affects how adolescence is experienced, intensifying the challenges inherent to this developmental stage. However, its impact can be mitigated when adolescents and their families position themselves as active participants in treatment and disease management.

Keywords: adolescence, diabetes mellitus, chronic diseases, psychoanalysis.

Resumo

O diabetes mellitus tipo 1 é uma doença crônica, que se manifesta frequentemente na adolescência. A convivência com uma doença crônica em uma fase permeada por mudanças multidimensionais, como é o caso da adolescência, tem sido associada à intensificação do sofrimento psíquico e dos conflitos comuns nesse período. Desse modo, este estudo propõe compreender a percepção dos adolescentes diagnosticados com diabetes mellitus tipo 1 sobre sua doença. Para tanto, foi realizada uma pesquisa qualitativa, exploratória e descritiva. Participaram deste estudo 14 adolescentes, entre 12 e 17 anos, em tratamento ambulatorial nas unidades de endocrinologia de um hospital de referência no sul do Brasil. Como instrumentos de coleta de dados, aplicamos um questionário sociodemográfico e um roteiro de entrevista semiestruturada. As entrevistas foram gravadas e transcritas na íntegra para análise do material. Para o tratamento dos dados, utilizamos a Classificação Hierárquica Descendente (CHD), fornecida pelo software IRaMuTeQ® (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires), a qual organiza o texto por classes de palavras associadas por significância estatística. O material foi interpretado com base na Análise Categorial Temática e no referencial teórico da psicanálise, a partir das quais foram elencadas seis categorias temáticas: 1) ser normal e ser diferente, que aborda os impactos à construção da identidade e inserção nos grupos; 2) lidando com o controle externo, que aborda os efeitos do controle parental; 3) a aceitação da doença e o desenvolvimento do autocuidado, que aborda o processo de adaptação à rotina de cuidados com o diabetes; 4) variação da glicemia e sua relação o emocional, que aborda a influência de fatores emocionais na variação glicêmica; 5) o processo de separação dos pais e o desenvolvimento da autonomia, que aborda a passagem da responsabilidade pelos cuidados dos pais para os adolescentes; e 6) estilo de vida mais saudável depois do diabetes, que aborda a mudança do estilo de vida após o diagnóstico. Concluímos que a doença afeta a forma como a adolescência é vivida, acentuando as dificuldades dessa fase. No entanto, o impacto da doença pode ser minimizado quando o adolescente e seus familiares se posicionam como participantes ativos no tratamento e manejo da doença.

Palavras-chave: *adolescência, diabetes mellitus, doenças crônicas, psicanálise.*

Resumen

La diabetes mellitus tipo 1 es una enfermedad crónica que se manifiesta con frecuencia durante la adolescencia. La convivencia con una enfermedad crónica en una etapa caracterizada por transformaciones multidimensionales, como es el caso de la adolescencia, ha sido asociada a la intensificación del sufrimiento psíquico y de los conflictos propios de este período. De este modo, el presente estudio se propone comprender la percepción que tienen los adolescentes diagnosticados con diabetes mellitus tipo 1 acerca de su enfermedad. Para ello, se realizó una investigación cualitativa, exploratoria y descriptiva. Participaron en este estudio catorce adolescentes, con edades entre 12 y 17 años, en tratamiento ambulatorio en las unidades de endocrinología de un hospital de referencia en el sur de Brasil. Como instrumentos de recolección de datos, se aplicaron un cuestionario sociodemográfico y una guía de entrevista semiestructurada. Las entrevistas fueron grabadas y transcritas en su totalidad para el análisis del material. Para el tratamiento de los datos se utilizó la Clasificación Jerárquica Descendente (CJD), proporcionada por el software IRaMuTeQ® (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires), la cual organiza el texto en clases de palabras asociadas por significancia estadística. El material fue interpretado con base en el Análisis Categorial Temático y en el marco teórico del psicoanálisis, a partir de los cuales se establecieron seis categorías temáticas: 1) Ser normal y ser diferente, que aborda los impactos en la construcción de la identidad y en la inserción en los grupos; 2) Afrontando el control externo, que aborda los efectos del control parental; 3) La aceptación de la enfermedad y el desarrollo del autocuidado, que aborda el proceso de adaptación a la rutina de cuidados con la diabetes; 4) Variación de la glucemia y su relación con lo emocional, que aborda la influencia de los factores emocionales en la variación glucémica; 5) El proceso de separación de los padres y el desarrollo de la autonomía, que aborda la transferencia de la responsabilidad del cuidado de los padres hacia los adolescentes; y 6) Estilo de vida más saludable después de la diabetes, que aborda los cambios en el estilo de vida tras el diagnóstico. Se concluye que la enfermedad afecta la manera en que la adolescencia es vivida, acentuando las dificultades

propias de esta etapa. No obstante, el impacto de la enfermedad puede minimizarse cuando el adolescente y su familia se posicionan como participantes activos en el tratamiento y manejo de la enfermedad.

Palabras clave: *adolescencia, diabetes mellitus, enfermedades crónicas, psicoanálisis.*

Résumé

Le diabète sucré de type 1 est une maladie chronique, qui se manifeste fréquemment durant l'adolescence. Le fait de vivre avec une maladie chronique pendant une phase imprégnée de transformations multidimensionnelles, telle que l'adolescence, est souvent associé à une intensification de la souffrance psychique et des conflits habituels dans cette période. Ainsi, cette étude propose de comprendre la perception qu'ont les adolescents diagnostiqués avec un diabète de type 1 à l'égard de leur maladie. À cette fin, une recherche qualitative, exploratoire et descriptive a été menée. Un total de 14 adolescents âgés de 12 à 17 ans, en traitement ambulatoire dans les unités d'endocrinologie d'un hôpital de référence du sud du Brésil, a participé à cette étude. En tant qu'instruments de collecte des données, nous avons administré un questionnaire sociodémographique ainsi qu'un guide d'entretien semi-structuré. Les entretiens ont été enregistrés et transcrits dans leur intégralité pour l'analyse du matériel. Pour l'analyse des données, nous avons eu recours à la Classification Hiérarchique Descendante (CHD), proposée par le logiciel IRaMuTeQ® (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires), qui organise le texte en classes de mots associées selon leur significativité statistique. Le corpus a été interprété sur la base de l'Analyse Catégorielle Thématique et du cadre théorique de la psychanalyse, à partir de là, ces six catégories thématiques ont été dégagées: 1) être normal et être différent, qui aborde l'impact sur la construction de l'identité et l'insertion dans les groupes ; 2) faire face au contrôle externe, qui analyse les effets du contrôle parental ; 3) l'acceptation de la maladie et le développement du soin de soi, qui examine le processus d'adaptation à la routine des soins liés au diabète ; 4) variation de la glycémie et sa relation avec l'émotionnel, qui explore l'influence des facteurs émotionnels sur la variation glycémique ; 5) le processus de séparation des parents et le développement de l'autonomie, qui traite du transfert progressif de la responsabilité des soins des parents vers les adolescents ; et 6) un mode de vie plus sain après le diabète, qui aborde la transformation du mode de vie à la suite du diagnostic. Nous concluons que la maladie influence la manière dont l'adolescence est vécue, en accentuant les difficultés propres à cette période. Cependant, l'impact de la maladie peut être atténué lorsque l'adolescent et ses proches se positionnent comme participants actifs dans le traitement et la gestion de la maladie.

Mots-clés : *adolescence, diabète sucré, maladies chroniques, psychanalyse.*

Diabetes mellitus refers to a heterogeneous group of metabolic disorders characterized by chronic hyperglycemia resulting from dysfunction in insulin production or action (Ministério da Saúde, 2020). Most cases are classified into two broad categories: type 1 diabetes mellitus and type 2 diabetes mellitus. Type 2 diabetes is the most prevalent form in the general population and is commonly associated with sedentary lifestyle and increasing age. In contrast, type 1 diabetes is more prevalent in childhood and adolescence, accounting for 90%-95% of cases in this population. Among children and adolescents, type 1 diabetes is considered a condition with a high epidemic index and ranks third among the most common chronic diseases in this age group (Sociedade Brasileira de Diabetes [SBD], 2020).

Regarding etiological aspects, diabetes mellitus is known to be an autoimmune disease triggered by the destruction of pancreatic β (beta) cells, leading to partial or absolute loss of insulin production (SBD, 2020; Silva et al., 2024). Symptoms of type 1 diabetes include increased urinary output, excessive thirst, enuresis or nocturia, and weight loss. Other manifestations may include delayed wound healing, polyphagia, fatigue, and behavioral changes, such as decreased school performance or blurred vision (Ministério da Saúde, 2020; Rodacki et al., 2024).

Type 1 diabetes is classified as a chronic disease because it is caused by an irreversible organic alteration, has a long duration, progresses slowly, and requires rehabilitation and ongoing self-care, with monitoring and supervision over time. Once diagnosed, adequate diabetes control depends on continuous self-care to prevent disease-related complications (Victório et al., 2019), such as ketoacidosis, which results from abrupt elevations in blood glucose levels and may lead to coma or death (Ministério da Saúde, 2020).

With respect to disease control, treatment is based on five core components: diabetes education, insulin therapy, self-monitoring of blood glucose levels, an appropriate diet, and physical exercise. These measures aim to reduce symptoms, prevent acute and chronic complications, and promote normal growth and development in children and adolescents (Ministério da Saúde, 2020; Silva et al., 2024).

However, during a life stage marked by multiple changes and conflict-generating experiences, such as adolescence, the diagnosis of and coexistence with a chronic disease tend to result in stressful and restrictive situations that may generate

psychological distress. Diabetes treatment requires adolescents to maintain heightened attention to self-care, adding emotional strain to the internal and external demands inherent to this developmental phase (Aguiar et al., 2021; Vilarinho et al., 2024).

In this context, questions arise regarding adolescents' perceptions of type 1 diabetes, with the aim of investigating how the developmental changes characteristic of adolescence intersect with living with a chronic disease. The discussions generated from this inquiry may contribute to a deeper understanding among professionals who work with this population.

Adolescence: General Definitions and Subjective Aspects

Adolescence is understood as a transitional period between childhood and adulthood, marked by biopsychosocial changes that culminate in a new identity position (Guimarães, 2023). Entry into adolescence is precipitated by the bodily changes of puberty, characterized by hormonal alterations, accelerated growth, and sexual maturation. There is no strict consensus regarding the age range that defines adolescence, as its criteria vary according to cultural, social, and individual factors. In Brazil, based on the Child and Adolescent Statute (Law No. 8,069, 1990), adolescence is defined as the period between 12 and 18 years of age.

As noted by Guimarães (2023), adolescence became an object of investigation within the medical and psychopedagogical sciences only in the late 19th and early 20th centuries, when stages of life began to be studied in their specificities and conceived as phases in the progression of human development. From this perspective, adolescence came to be characterized as a period of tension determined by biological and psychological factors, which are socially expected to be overcome with the approach of adulthood.

From a psychoanalytic perspective, adolescence is conceived not merely as a chronological stage of human development but as a logical moment precipitated by pubertal transformations. These transformations trigger a series of psychic operations that remained incomplete in earlier developmental phases, the unfolding of which results in decisive changes in the adolescent's subjective position (Corso, 2002).

One of the fundamental operations of this phase is the reworking of the Oedipus complex. In childhood, the parent of the opposite sex becomes the first love object. Subsequently, puberty marks the (re)awakening of infantile sexuality, which had remained latent while libidinal energy was directed toward educational formation (Corso, 2002). According to Lima and Santiago (2010), the reworking of the Oedipus complex leads to the reaffirmation of the incest prohibition, already established in childhood. This process opens the possibility for the exercise of desire outside the family context and strengthens the adolescent's bond with the social sphere.

As highlighted by Alberti (2010), entry into adolescence has consequences for both adolescents and their parents. For adolescents, the weakening of parental knowledge entails the loss of the protection afforded by parental authority. For parents, the fantasies children hold regarding their parents' knowledge collapse, fantasies from which children previously derived a reference point. Despite the losses inherent to this process, Rassial (1997) argues that recognizing parents as non-self-sufficient subjects is precisely what authorizes adolescents to develop autonomy. Thus, separation from parents presupposes the paradoxical movement of relying on parental reference in order to eventually dispense with it.

The adolescent body's increasing resemblance to the adult body represents another aspect that signals the possibility of belonging to contexts beyond the family. Integration into peer groups facilitates the process of separation from parental knowledge and authority, insofar as aspects of family relationships are transferred to the social context (Lima & Santiago, 2010).

In light of these considerations, adolescence may be defined as a logical moment marking the exit from childhood, in which the subject is called upon to respond to the world from a position distinct from that previously occupied. This process requires the elaboration of fundamental losses, the appropriation of one's body and its new image, and the assumption of a different place within culture (Alberti, 2010; Rassial, 1997).

Diabetes Mellitus in Adolescence

Prior research (Heleno et al., 2019; Vidotti, 2019; Victório et al., 2019) indicates that being affected by a chronic disease, such as type 1 diabetes, during adolescence intensifies the difficulties and complexities inherent to this stage of life. Accordingly, it is important to understand how the combination of these two factors impacts adolescents.

Vidotti (2019) examined the impact of a recent diagnosis of type 1 diabetes in adolescents from a psychoanalytic perspective. The findings showed that, upon receiving the diagnosis, adolescents experienced feelings of fear and surprise. The restrictions imposed by treatment were perceived as punishments for excessive sugar intake, which had previously been a source of satisfaction. In addition, feelings of anger emerged in response to the need to interrupt daily activities in order to perform glycemic monitoring.

Vargas et al. (2020) also sought to understand the emotional state of adolescents with type 1 diabetes and their family members based on psychoanalytic theory. The diagnosis was found to trigger a mourning process related to the loss of health. For this reason, the authors emphasize the importance of a humanized approach at the time of diagnosis and during hospitalization.

In further studies grounded in psychoanalytic theory, Marcelino and Carvalho (2005) reported that emotional aspects, such as traumatic experiences, may influence the etiology of diabetes, conceptualizing it as a psychosomatic disease. Conversely, emotional states are also influenced by the disease itself, characterizing diabetes as a somatopsychic condition. From this perspective, adolescents' reactions to diabetes depend on their internal resources and individual life histories.

From a psychological standpoint, particularly within resilience theory, Cassarino-Perez and Dell'Anglio (2015) observed that adolescents' personal characteristics may function either as protective or as disorganizing factors. The main protective factors identified included engagement in self-care activities, the establishment of bonds, and social skills. Disorganizing factors included difficulties in impulse and emotion regulation, denial, and apathy.

According to Victório et al. (2019), type 1 diabetes during adolescence triggers several stressors. The primary stressors reported by adolescents were related to glycemic monitoring and the consequences of not adhering to professional recommendations, which generated feelings of guilt and incompetence. As a result of the illness, adolescents also expressed feelings of anger, fear, and sadness, which were considered secondary stressors in coping with the disease.

Heleno et al. (2019), from a psychological perspective, described how children and adolescents participating in a vacation camp perceived their diabetic condition and its treatment. Difficulties in adapting to the new condition and adhering to treatment were observed, particularly at the beginning; however, greater adaptation was noted over time. Participants reported feelings such as tension, fear of death, and guilt related to their family members' emotional reactions. In their relationships with parents, adolescents expressed ambivalent feelings: on the one hand, they felt supported; on the other, they perceived excessive control.

In the field of nursing, Zanatta et al. (2020) aimed to understand adolescents' experiences of living with type 1 diabetes. The study found that both the diagnosis and the limitations imposed by the disease elicited different emotional responses, including sadness and anger at the time of diagnosis, fear of prejudice or discrimination due to a distinguishing characteristic, and frustration when adolescents felt misunderstood by their families and health professionals.

Taken together, these findings indicate that type 1 diabetes has a significant emotional impact on adolescents' lives. However, there is a paucity of studies addressing this topic from psychological and psychoanalytic perspectives, and the available research is largely more than 5 years old. Therefore, the present study was developed to investigate adolescents' perceptions of type 1 diabetes and their experience of living with the disease. This study is expected to contribute updated evidence to the scientific literature and to support health professionals in understanding the subjective aspects of this population.

Method

This study adopted a qualitative approach with an exploratory and descriptive design. Data collection was conducted through the administration of a sociodemographic questionnaire to outline the adolescents' profiles, followed by semi-structured interviews.

The research was performed at the Pediatric Endocrinology Unit (UEP for short, in Portuguese) and the Endocrinology and Metabolism Service (SEMPR for short, in Portuguese), both integrated into the Clinical Hospital Complex of the Universidade Federal do Paraná (CHC-UFPR), located in Curitiba, Paraná, Brazil. A convenience sample was therefore selected. Inclusion criteria were i) adolescents diagnosed with type 1 diabetes; ii) aged between 12 and 17 years, in accordance with the age range defined by the Brazilian Child and Adolescent Statute (Law No. 8,069, 1990); iii) receiving outpatient follow-up care at the UEP or SEMPR; iv) present at the outpatient units on pre-established days and times for data collection; and v) having provided informed assent, with informed consent obtained from a legal guardian. The exclusion criterion was the presence of cognitive conditions that could compromise understanding of the informed assent process.

The study was submitted to and approved by the Research Ethics Committee of the CHC-UFPR (Approval No. 4,928,734). After obtaining authorization from the aforementioned units, recruitment visits were conducted, resulting in a sample of 14 adolescents. Table 1 presents the participants' characteristics based on data obtained from the sociodemographic questionnaire. For confidentiality, adolescents were identified by the letter "A" followed by a number corresponding to the order of participation in the study.

Table 1

Participant characteristic

Participant	Age	Sex	Race	School grade	Time since diagnosis	Previous hospitalization
A1	12	M	White	7th grade (elementary school)	2 years	None
A2	12	F	Black	7th grade (elementary school)	1 year	One
A3	15	F	White	1st year (high school)	5 years	One
A4	13	F	White	8th grade (elementary school)	10 years	Two
A5	12	M	White	7th grade (elementary school)	7 years	One
A6	16	M	White	3rd year (high school)	15 years	One
A7	14	M	White	9th grade (elementary school)	2 years	One
A8	13	F	White	8th grade (elementary school)	5 years	Five
A9	14	F	White	8th grade (elementary school)	9 years	Eight
A10	14	M	White	9th grade (elementary school)	2 years	Three
A11	17	M	White	Higher education (incomplete)	12 years	Two
A12	17	M	White	2nd year (high school)	2 months	None
A13	13	F	White	9th grade (elementary school)	3 years	One
A14	15	M	White	7th grade (elementary school)	7 years	Five

Individual interviews were then conducted with the adolescents. A semi-structured interview guide was used, developed based on a prior literature review and consisting of seven questions. These questions addressed what it is like to live with diabetes, the experience of receiving the diagnosis, self-care practices, daily life with the disease, and perceived influences on relationships with parents, social relationships, and self-image. The interviews were audio-recorded, transcribed verbatim, and entered into the IRaMuTeQ® software, which supported the qualitative analysis. According to Souza et al. (2018), the use of software in qualitative analysis offers advantages by facilitating the organization and segmentation of information, allowing text segments to be identified and associations between them to be established more efficiently.

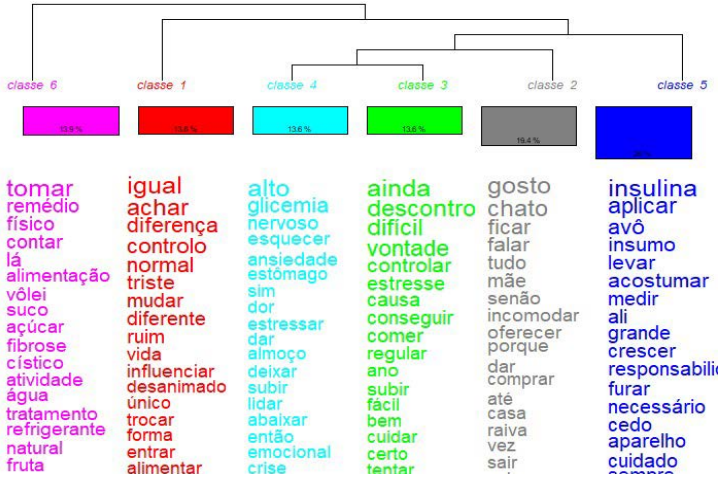
In this study, descending hierarchical classification (DHC), one of the analytical procedures provided by IRaMuTeQ®, was employed. DHC organizes the textual corpus into classes of words associated through statistical significance, based on the total frequency of word occurrences across the analyzed texts. Subsequently, a qualitative analysis was conducted using thematic categorical analysis (Bardin, 1977) and grounded in the psychoanalytic theoretical framework.

Results

The collected material was processed using IRaMuTeQ®, which generated a dendrogram composed of six word classes. These classes were derived from a total of 11,776 word occurrences distributed across 14 texts, corresponding to the 14 interviews conducted. The resulting dendrogram is illustrated in Figure 1.

Figure 1

Dendrogram generated by the IRaMuTeQ® software based on descending hierarchical classification (2021).



The reading and textual analysis of the interviews made it possible to translate the word classes into the following thematic categories: i) being normal and being different: impacts on identity construction and group belonging; ii) dealing with external control; iii) acceptance of diabetes and the development of self-care; iv) glycemic variability and its relationship with emotional factors; v) the process of separation from parents and the development of autonomy; and vi) adopting a healthier lifestyle after diabetes. To illustrate these categories, excerpts from participants' narratives are presented. The adolescents' accounts are described below, followed by a discussion of these findings.

1) Being normal and being different: impacts on identity construction and group belonging

A division was observed between participants who reported feeling "normal" or "like everyone else" despite having diabetes and those who perceived the condition as a "difference" in relation to others: "I think it's the same as a person who doesn't have diabetes, because I can talk, hear, see, and play" (A13, female, 13 years); "I felt very sad because I didn't know other people who had diabetes. When I found out, I thought I would be excluded, especially at school" (A8, female, 13 years).

These narratives reveal issues related to identity construction and questions about the possibility of belonging to a peer group. In this context, "normality" appears to be associated either with the ability to perform the same activities as people without diabetes or with discovering that the diagnosis is shared by others. Regarding difference, A8's account reflects fear of not fitting into social relationships. However, this concern tends to be mitigated when adolescents find groups that accept their differences and help them cope with the difficulties associated with their condition, as illustrated in the following account: "My friends even treat me a little differently, but it's with care. They worry about me for my own good" (A9, female, 13 years).

Other participants reported difficulties participating in group activities with friends due to diabetes-related restrictions: "They go out somewhere and then go to an all-you-can-eat brigadeiro place, and I have to say I can't go. Sometimes that's kind of annoying, you know?" (A7, male, 14 years). Dietary limitations were found to affect adolescents' relationships with peer groups, as eating often represents a shared social activity. As a result, adolescents may experience difficulties or losses in establishing bonds with their peers.

2) Dealing with external control

Self-care is often supported by family members and the health care team during follow-up visits. However, external demands are frequently perceived as excessive, generating feelings of anger, guilt, stress, and family conflict: "It stresses me out, it makes me angry, because I don't like people controlling me (…). When I get here [to the outpatient clinic], they tell my mother that she has to do something to make the diabetes go down" (A3, female, 15 years); "When the diabetes goes up, we [the participant and her father] start arguing because 'it's my fault, I'm the one who ate things, I'm the one who made it go up'" (A4, female, 13 years).

Other participants indicated that family supervision and control were beneficial for maintaining consistent and effective care: "Now [after the diagnosis] my parents argue a little more because they have to take care of the diabetes. It's annoying, but it's good, because otherwise I don't measure my blood sugar or apply insulin, and then my glucose is always high" (A7, male, 14 years); "Sometimes we might think they're being too strict, but it's so we take better care of ourselves, really just for our own good" (A8, female, 13 years).

These accounts show that, in some situations, parental supervision provides a sense of security regarding adherence to self-care, without which adolescents might not attend to treatment with the same level of commitment. One factor that may explain this perception of external control, as illustrated by A7 and A8, is awareness of the health and life risks associated with poor adherence to care. In such cases, external control functions as a source of support and facilitates adequate disease management.

3) Acceptance of diabetes and the development of self-care

Blood glucose monitoring, insulin administration, and dietary restrictions, particularly regarding sweets, were widely reported as difficulties by participants: "It's hard to accept having this, it's hard to apply insulin because it hurts, not being able to eat things. Sometimes I forget that I have to do this" (A2, female, 12 years); "I always thought measuring blood sugar and applying insulin was annoying, and with my grandmother I managed to fool her, so I wasn't doing [self-care]" (A9, female, 13 years).

The limitations and care routines imposed by diabetes treatment generate distress for adolescents, as they involve physical pain and discomfort while simultaneously reducing sources of daily gratification. These factors directly influence acceptance of the diagnosis and adherence to treatment. As a result, some participants reported consciously or unconsciously circumventing diabetes control, for example, through forgetfulness.

Such difficulties indicate that self-control and self-care are not innate capacities but rather skills that must be developed. In this regard, several factors were mentioned as facilitating the development of self-care: "In the first years after the

diagnosis it was hard, because I was diagnosed very young. Then, over time, I got used to it" (A13, female, 13 years); "There are people who have cancer, diseases that aren't easily cured. Diabetes, you just have to control it, and then you can live with it" (A5, male, 12 years).

According to the adolescents' accounts, age, time since diagnosis, and the support network surrounding the adolescent were factors that favored adaptation to routines and limitations and, consequently, acceptance of the disease. In addition, as highlighted by A5, the limitations imposed by diabetes may be minimized by the perception that the disease course is "under the patient's control," as the individual is responsible for managing their own care routine.

4) Glycemic variability and its relationship with emotional factors

Some participants identified the influence of emotional factors both in triggering diabetes and in the emotional manifestations resulting from the disease, as illustrated by the following reports: "When I found out I had diabetes, my anxiety increased, I got very nervous" (A2, female, 12 years); "Sometimes my blood sugar is normal at lunch, then something happens that makes me nervous or anxious, and when I check my glucose, it's high" (A3, female, 15 years); "At the beginning, I realized that this [diabetes control] affected my mood. When my blood sugar changed, I got a little irritated" (A14, male, 15 years).

These findings indicate that living with diabetes can lead to mood changes and emotional symptoms, such as anxiety. Conversely, emotional factors also appear to influence fluctuations in blood glucose levels, constituting a psychosomatic component. Thus, a bidirectional relationship between emotional changes and glycemic variability is evident.

5) The process of separation from parents and the development of autonomy

Participants reported feeling responsible, either on their own initiative or encouraged by family members, for managing their disease. In this respect, adolescents' attitudes varied, with some feeling calm and confident in performing self-care, while others experienced difficulties assuming full responsibility: "Now that I'm growing up, I'm taking care of it myself. I always check my glucose on my own. When I go to a friend's house, I also apply insulin" (A5, male, 12 years); "I end up not doing the care on time, and that irritates me" (A14, male, 15 years); "I forget to apply insulin. My mother says I'm responsible, but I'm lazy, so I'm afraid of disappointing her" (A2, female, 12 years).

When participants reported difficulties managing diabetes care independently, feelings such as frustration, irritability, and fear of losing parental trust emerged, potentially leading to significant self-pressure. Due to these emotional implications, parental supervision of the care routine, although sometimes perceived as controlling, conveys a sense of security and protection to adolescents: "Parents need to keep an eye on it, because not every adolescent or child has that responsibility" (A14, male, 15 years); "Over time, I learned [how to take care of the diabetes], and my mother taught me. Now I can do it on my own" (A9, female, 13 years).

Thus, from the adolescents' perspective, the development of autonomy in managing diabetes care is grounded in the reference of care, protection, and security provided by parents.

6) Adopting a healthier lifestyle after diabetes

The diagnosis of diabetes led to lifestyle changes among participants, which they perceived as beneficial to health, quality of life, and self-image, as illustrated by the following examples: "I'm actually healthier now, because before, when I went running, I could only run a little and I was already short of breath" (A7, male, 14 years); "I used to eat everything. I think that's even why I got diabetes. Now I started drinking more juice and eating more fruit, and I think that even helped me" (A12, male, 12 years).

These participants perceived that consuming sweets provided a form of gratification experienced as excessive and lacking self-control. Notably, A12 attributed responsibility for developing diabetes to himself, referring to the disease as something that had been acquired.

Discussion

The participants' narratives indicate that living with diabetes during a phase marked by multiple transformations, such as adolescence, introduces additional challenges that overlap with those already inherent to this developmental stage. This finding is consistent with the study by Heleno et al. (2009), which highlights that the changes experienced during adolescence generate conflicts for both adolescents and their parents and that, when accompanied by a chronic disease such as type 1 diabetes, these conflicts tend to intensify.

During this period, both adolescents and their parents lose the idealized positions they once held for each other. As a result, adolescents seek new ideals and construct an identity outside the family context (Alberti, 2010). Therefore, adolescents' desire to feel accepted by a group of peers is understandable (Lima & Santiago, 2010).

However, the adolescents' accounts also reveal that when a medical diagnosis such as diabetes is present, it becomes incorporated into the identity under construction, leading adolescents to perceive themselves as marked by difference in relation to their peers. As noted by Zanatta et al. (2020), adolescents often fear discrimination and exclusion due to characteristics that distinguish them from others. Conversely, when they are included in social circles that demonstrate acceptance and openness toward their condition, tension and fear tend to be alleviated. As shown by Heleno et al. (2009), peer groups can function as a source of support, enabling adolescents to receive encouragement and to relate to others with whom they can talk openly about the disease.

With regard to self-care, the adolescents interviewed reported discomfort with external demands, primarily from family members, which were sometimes experienced as invalidating the autonomy so highly valued at this stage of life. Other participants, however, perceived their parents as sources of support and protection, without whom treatment would become even more difficult. These differences in adolescents' accounts may be explained by the degree of psychological elaboration achieved by each individual. In addition, factors such as age, time since diagnosis, and the available support network appear to facilitate the processing of these issues.

Another difficulty reported by adolescents concerns the demands and restrictions imposed on daily routines. Adolescents expressed distress related to interrupting pleasurable activities to perform glycemic monitoring, the physical pain associated with insulin administration, and especially dietary restrictions, particularly regarding sweets. In line with Vidotti (2019), these treatment-related limitations may be understood as symbolic representations of castration, given the chronic and irreversible nature of the disease. This perspective helps explain adolescents' reports of diminished satisfaction following diagnosis.

Interruptions in routine, glycemic control, and dietary restrictions appear to remind adolescents, as noted by Rassial (1997), that satisfaction cannot be fully attained but only partially experienced. It is therefore understandable that adolescents show some resistance to acknowledging this limitation, particularly when it is reinforced by a chronic illness. This resistance is reflected in difficulties accepting the diagnosis, expressed through complaints about treatment-related limitations and attempts, conscious or unconscious, to transgress them. Faced with the reality of the disease, adolescents are required to construct singular responses that allow them to endure and manage their condition. This process entails mourning the loss of health and accepting the identity of being diabetic.

Acceptance of the diagnosis involves both conscious and unconscious factors. When the diagnosis is not sufficiently accepted at the psychic level, disease control may be compromised, which may account for the variability in participants' responses. In this sense, the findings align with Marcelino and Carvalho (2005), who argue that coping with diabetes is related to each individual's psychic constitution and mental functioning. Although the elaboration of health loss constitutes a psychic process, it does not depend solely on adolescents. Families and health professionals can facilitate this process by creating spaces for dialogue and attentive listening to adolescents' real needs regarding their health condition and treatment.

From this perspective, parents emerged in participants' accounts as the primary sources of support in diabetes care, corroborating findings from previous studies (Heleno et al., 2009; Vidotti, 2019). Family involvement in disease management served as a foundation upon which adolescents could develop autonomy and self-care. As Alberti (2010) emphasizes, contrary to common assumptions, parents remain highly important figures for adolescents. Without their presence, adolescents cannot effectively separate from them, as they must be able to choose whether or not to draw upon the guidance and models provided by their parents. Thus, parental presence enables adolescents to exercise judgment, which supports the development of autonomy.

Autonomy, as perceived by the adolescents, was closely related to the exercise of desire, as it depended on the possibility of separating from parental knowledge and constructing personal knowledge that would allow them to manage their diabetic condition. However, as noted by Lima and Santiago (2010), the reaffirmation of the impossibility of complete satisfaction, reiterated during the second Oedipal moment, is a necessary condition for adolescents to appropriate their desire and act more autonomously.

Thus, participants' narratives suggest that the restrictions imposed by diabetes care routines functioned as limits that enabled adolescents to regulate forms of satisfaction experienced as excessive and lacking self-control. Paradoxically, these restrictions provided adolescents with a sense of freedom, as they reported gains in health, quality of life, and self-esteem that they had not achieved prior to diagnosis.

Final Considerations

This study demonstrates that type 1 diabetes has significant implications for how adolescence is experienced. Coping with type 1 diabetes, like coping with adolescence itself, requires a process of psychological elaboration that allows both the reality of the disease and the reality of puberty to be symbolized. Although this constitutes a psychic process, families and health professionals can facilitate it. Adolescents reported feeling more supported when adult supervision and guidance were present in diabetes care. For this reason, self-care should be assumed gradually, considering adolescents' level of awareness regarding the importance of glycemic control and their motivation to adhere to treatment.

It is also important to reflect on the involvement of families and health professionals in disease management. As recommended by the Brazilian Diabetes Society (SBD, 2020), both patients and their families should position themselves as active participants in treatment, and the gradual transfer of care responsibilities to adolescents should be encouraged. The effectiveness of this process also depends on a multidisciplinary team capable of providing the knowledge, skills, and psychosocial support necessary for disease control (Almeida et al., 2024).

This study focused on investigating adolescents' perceptions of type 1 diabetes mellitus through an exploratory and descriptive design, using thematic categorical analysis and IRaMuTeQ® software to support data analysis. The findings allowed for an examination of subjective aspects of type 1 diabetes mellitus in adolescence from a psychoanalytic perspective. Nevertheless, considering the emphasis on multidisciplinary care, future studies should explore the effects of ongoing follow-up, including psychological support, for adolescents diagnosed with diabetes.

References

Aguiar, G. B., Machado, M. E. D., Silva, L. F., Aguiar, R. C. B., & Christoffel, M. M. (2021). A criança com diabetes mellitus tipo 1: A vivência do adoecimento. *Revista da Escola de Enfermagem da USP, 55,* 1-8. https://www.scielo.br/j/reeusp/a/gjsMrG6Fm8cxpGPrVJnJMmj/?lang=pt

Alberti, S. (2010). *O adolescente e o outro* (3a ed.). Zahar.

Almeida, A. M. R. M., Santos, B. L., Delmaschio, C. R., Mascarenhas, C. S., Souto, G. S., Oliveira, H. M., Ribeiro, I. R. F., Ribeiro, J. L. C., Monteiro, L. N., Sampaio, L. M. C., Leal, M. V. S., Baptista, M. M., Magalhães, M. R. M., Pascholino, M. G. S., & Scapim, S. N. (2024). Diabetes mellitus tipo 1: Uma revisão de literatura. *Brazilian Journal of Health and Biological Science, 1*(1), 1-18. https://bjhbs.com.br/index.php/bjhbs/article/view/29

Silva, F. R. A., Oliveira, P. L., Araujo, L. M., Alencar, W. G. D., Oliveira, G. L., Silva, A. P. O., Monteiro, E. L. T., Paulino, R. K. F., Ribeiro, R. L. B., Silva, B. R., Silva, M. A., & Bomfim, D. S. (2024). Diabetes mellitus tipo 1 na adolescência: Adesão ao tratamento e qualidade de vida. *Brazilian Journal of Implantology and Health Sciences, 6*(5), 1162–1175. https://doi.org/10.36557/2674-8169.2024v6n5p1162-1175

Bardin, L. (1977). *Análise de conteúdo*. Edições 70.

Lei n.º 8.069, de 13 de julho de 1990. (1990, 13 de julho). Dispõe sobre o Estatuto da Criança e do Adolescente e dá outras providências. Presidência da República. https://www.planalto.gov.br/ccivil_03/leis/l8069.htm

Cassarino-Perez, L., & Dell'Aglio, D. D. (2015). Processos de resiliência em adolescentes com diabetes mellitus tipo 1. *Psicologia em Estudo, 20*(1), 45–56. https://www.redalyc.org/journal/2871/287142227006/

Corso, D. M. L. (2002). Édipo, latência e puberdade: A construção da adolescência. *Revista da Associação Psicanalítica de Porto Alegre, 23*(10), 18–30. https://appoa.org.br/uploads/arquivos/revistas/revista23.pdf

Guimarães, J. (2023). "Abriu minha mente": Transitando entre a infância e a adolescência. *Etnográfica*, *27*(2), 341–364. https://doi.org/10.4000/etnografica.13629

Heleno, M. G. V., Vizzotto, M. M., Mazzotti, T., Cressoni-Gomes, R., & Modesto, S. E. F. (2009). Acampamento de férias para jovens com diabetes mellitus tipo 1: Achados da abordagem psicológica. *Boletim de Psicologia*, *59*(130), 77–90. http://pepsic.bvsalud.org/pdf/bolpsi/v59n130/v59n130a07.pdf

Lima, N. L., & Santiago, A. L. B. (2010). Por que os adolescentes escrevem diários na rede? A escrita de si no universo virtual. *Revista Pesquisas e Práticas Psicossociais*, *5*(1), 53-64. https://pesquisa.bvsalud.org/portal/resource/pt/lil-617540

Marcelino, D. B., & Carvalho, M. D. B. (2005). Reflexões sobre o diabetes tipo 1 e sua relação com o emocional. *Psicologia Reflexão e Crítica*, *18*(1), 72–77. https://www.scielo.br/pdf/prc/v18n1/24819.pdf

Ministério da Saúde. (2020). *Protocolo clínico e diretrizes terapêuticas do diabete melito tipo 1.* Secretaria de Ciência, Tecnologia, Inovação e Insumos Estratégicos em Saúde, Departamento de Gestão e Incorporação de Tecnologias e Inovação em Saúde. http://bvsms.saude.gov.br/bvs/publicacoes/protocolo_clinico_terapeuticas_diabete_melito.pdf

Pereira, M. E. V., Oliveira, N. G., Ribeiro, P. R. F., Silva, T. M. C., & Dias, C. J. M. (2023). Definições e classificações da adolescência. In C. J. M. Dias, C. A. A. Dias Filho, C. T. Mostarda, & H. A. Costa (Orgs.), *Exercício físico e saúde do adolescente* (Cap. 1, pp. 1-10). Atena. https://atenaeditora.com.br/catalogo/post/definicoes-e-classificacao-da-adolescencia

Rassial, J.-J. (1997). *A passagem adolescente: Da família ao laço social.* Artes e Ofícios Editora.

Rodacki, M., Cobas, R. A., Zajdenverg, L., Silva Jr., W. S., Giacaglia, L., Calliari, L. E., Noronha, R. M., Valeiro, C., Custódio, J., Scharf, M., Barcellos, C. R. G., Tomarchio, M. P., Silva, M. E. R., Santos, R. F., Almeida-Pitito, B., Negrato, C. A., Gabbay, M., & Bertoluci, M. (2024). *Diagnóstico de diabetes mellitus.* Diretriz Oficial da Sociedade Brasileira de Diabetes. https://doi.org/10.29327/5412848.2024-1

Sampaio, V. V. L., Ayres, J. C. Z., Borges, L. M., Cruz, N. S., & Sabino, I. M. O. (2023). Diabetes Mellitus tipo 1 - uma revisão abrangente sobre a etiologia, epidemiologia, fisiopatologia, diagnóstico e tratamento. *Revista Brasileira de Revisão de Saúde*, *6*(5), 24239–24249. https://doi.org/10.34119/bjhrv6n5-474

Sociedade Brasileira de Diabetes. (2020). *Diretrizes Sociedade Brasileira de Diabetes 2019–2020*. Clanad Editora Científica. https://www.diabetes.org.br/profissionais/images/DIRETRIZES-COMPLETA-2019-2020.pdf

Souza, M. A. R., Wall, M. L., Thuler, A. C. M. C., Lowen, I. M. V., & Peres, A. M. (2018). O uso do software IRAMUTEQ na análise dos dados em pesquisas qualitativas. *Revista da Escola de Enfermagem*, *52*, 1–7. https://doi.org/10.1590/S1980-220X2017015003353

Vargas, D. M., Barbaresco, A. C., Stainer, O., & Silva, C. G. L. D. (2020). Um olhar psicanalítico sobre crianças e adolescentes com diabetes mellitus tipo 1 e seus familiares. *Revista Psicologia e Saúde*, *12*(1), 87–100. https://doi.org/10.20435/pssa.v12i1.858

Victório, V. M. G., Andrade, A. L. M., Silva, A. M. B., Machado, W. L., & Enumo, S. R. F. (2019). Adolescentes com Diabetes Mellitus tipo 1: Estresse, coping e adesão ao tratamento. *Saúde e Pesquisa*, *12*(1), 63–75. https://repositorio.pucrs.br/dspace/handle/10923/16304

Vidotti, T. C. (2019). *O diagnóstico de diabetes mellitus tipo 1 na adolescência: Uma discussão à luz da psicanálise* [Dissertação de Mestrado, Universidade de São Paulo]. Biblioteca Digital de Teses e Dissertações da USP. . https://doi.org/10.11606/D.47.2019.tde-11112019-175703

Vilarinho, A. V. S., Silva, T. D., & Barroso, W. A. (2024). Efeitos psicossociais do diabetes mellitus tipo 1 em crianças e adolescentes. *Revista Eletrônica Acervo Saúde*, *24*(4), 1-8. https://doi.org/10.25248/reas.e16548.2024

Zanatta, E. A., Scaratti, M., Argenata, C., & Barichello, A. (2020). Vivências de adolescentes com diabetes mellitus tipo 1. *Revista de Enfermagem Referência*, *5*(4), 1-7. https://doi.org/10.12707/RV20044

How to cite:

Silva, L. R., Paveukiewics, P., Rauen, C. C., & Dória, G. M. S. (2025). Type 1 Diabetes Mellitus from the Perspective of Adolescents Receiving Care in Endocrinology Units of a Referral Hospital in Southern Brazil. *Revista Subjetividades, 25*(2), e16959. https//doi.org/10.5020/23590777.rs.v25i2.e16959

Correspondence address:

Larissa Rossi Silva
E-mail: silva.larissarossi@gmail.com

Pricila Paveukiewicz
E-mail: Pricila.pav@gmail.com

Camila Cardoso Rauen
E-mail: camila.rauen@gmail.com

Gustavo Manoel Schier Dória
E-mail: gustavomsdoria@gmail.com

Received on: *01/24/2024.*
Accepted on: *05/08/2025.*