

Treatment of type 1 diabetes mellitus: a qualitative analysis of the impact of pharmacological and non-pharmacological treatments in children and adolescents from a city in southwestern Paraná

Tratamento do diabetes mellitus tipo 1: uma análise qualitativa do impacto do tratamento farmacológico e não farmacológico em crianças e adolescentes de uma cidade no sudoeste do Paraná

Tratamiento de la diabetes mellitus tipo 1: un análisis cualitativo del impacto del tratamiento farmacológico y no farmacológico en niños y adolescentes de una ciudad en el suroeste de Paraná

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Abstract

Introduction: Type 1 diabetes mellitus (T1DM) is defined as an absolute insulin deficiency due to the autoimmune destruction of beta cells. In Brazil, epidemiological data highlight the impact of this disease within the pediatric age group, as in 2021 the country ranked third in the international standings for children and adolescents with T1DM. Although early diagnosis is essential, it is not the most challenging stage. Living with T1DM requires shared care among the diabetic individual, their family, and a multidisciplinary team. Considering that the effectiveness of controlling such a condition is related to the interplay of various factors, the present research aims to qualitatively analyze the impact of therapeutic management on the daily lives of patients with T1DM, in order to enhance the knowledge of healthcare professionals and the academic community regarding this topic. **Objective:** To qualitatively analyze the impact of pharmacological and non-pharmacological treatments in children and adolescents aged 12 to 19 years, diagnosed with type 1 diabetes mellitus and residing in the southwestern region of Paraná, within a social and familial context. **Methods:** This is an observational study with a qualitative approach and individual analysis. The recruitment of participants followed a convenience sampling model, utilizing semi-structured interviews developed by the authors. For content analysis, categories and subthemes were delineated. **Results:** The sample consists of female patients aged 12, 18, and 16 years. At the time of diagnosis, they were 12, 13, and 12 years old, respectively. Currently, their insulin therapy regimen includes two types of medications. Regarding their history of hospitalizations related to diabetes, P1 was hospitalized twice, P2 reported not being able to specify exactly, and P3 stated that she had been hospitalized approximately five times. For them, the time dedicated to managing their condition and monitoring their blood glucose levels has never negatively impacted their lives, although the diet is somewhat inflexible. In all cases, the mothers were identified as the central figures in their care networks. Of the three caregivers, only one reported having received instructions regarding the care required for her daughter's condition. **Conclusions:** Qualitatively, there was no perception of a loss in quality of life. T1DM was understood as a chronic disease, and the impact of its management was associated with benefits such as a reduction in hospitalizations. However, there is a noted lack of health education and coordination among a multidisciplinary team.

Keywords: Diabetes mellitus, type 1; Disease management; Health strategies.

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Resumo

Introdução: Define-se o Diabetes Mellitus tipo 1 (DM1) como deficiência absoluta de insulina devido à destruição autoimune das células beta. No Brasil, dados epidemiológicos apontam o impacto dessa doença na faixa etária pediátrica, visto que em 2021 o país esteve em terceiro lugar no ranking internacional de crianças e adolescentes com DM1. Mesmo que essencial, o diagnóstico precoce não é a etapa mais desafiadora. Viver com DM1 exige o compartilhamento do cuidado entre o diabético, sua família e uma equipe multiprofissional. Considerando que a eficácia do controle de tal patologia está relacionada à articulação entre tantos fatores, a presente pesquisa busca analisar qualitativamente o impacto do manejo terapêutico no cotidiano de pacientes com DM1, para ampliar o conhecimento dos profissionais de saúde e da comunidade acadêmica sobre a temática. **Objetivo:** Analisar qualitativamente o impacto do tratamento farmacológico e não farmacológico em crianças e adolescentes de 12 a 19 anos de idade, diagnosticados com diabetes mellitus do tipo 1 e residentes no sudoeste do Paraná, no contexto social e familiar. **Métodos:** Trata-se de um estudo observacional com abordagem qualitativa e análise individual. O recrutamento dos participantes seguiu o modelo de amostragem por conveniência com entrevistas semiestruturadas elaboradas pelas autoras. Para a análise de conteúdo, foi utilizada delimitação de categorias e subtemas. **Resultados:** A amostra é composta por pacientes do sexo feminino que possuem 12, 18 e 16 anos de idade. Quando diagnosticadas, possuíam 12, 13 e 12 anos, respectivamente. Atualmente, o regime de insulino terapia conta com dois tipos de medicamentos. Ao considerar o histórico de internações relacionado ao diabetes, P1 foi internada 2 vezes, P2 relatou não saber precisar com exatidão e P3 afirmou ter sido hospitalizada cerca de 5 vezes. Para elas, o tempo dedicado ao controle de sua doença e a avaliação do seu nível glicêmico nunca interferiu negativamente em sua vida, mas a dieta é pouco flexível. Em todos os casos, as mães foram indicadas como o centro de sua rede de cuidados. Das três responsáveis, apenas uma afirmou ter recebido instruções sobre os cuidados que a doença de sua filha exige. **Conclusões:** Qualitativamente não houve percepção de perda da qualidade de vida. A DM tipo 1 foi compreendida como uma doença crônica e o impacto de seu manejo foi associado a benefícios, como redução do número de internações. Contudo, ressalta-se a carência de educação em saúde e da articulação de uma equipe multidisciplinar.

Palavras-chave: Diabetes mellitus tipo 1; Gerenciamento clínico; Estratégias de saúde.

Resumen

Introducción: Se define la diabetes mellitus tipo 1 (DM1) como una deficiencia absoluta de insulina debido a la destrucción autoinmune de las células beta. En Brasil, los datos epidemiológicos apuntan al impacto de esta enfermedad en la franja etaria pediátrica, dado que en 2021 el país ocupó el tercer lugar en el ranking internacional de niños y adolescentes con DM1. Aunque esencial, el diagnóstico precoz no es la etapa más desafiante. Vivir con DM1 requiere el intercambio de cuidados entre el diabético, su familia y un equipo multiprofesional. Considerando que la eficacia del control de tal patología está relacionada con la articulación de numerosos factores, la presente investigación busca analizar cualitativamente el impacto del manejo terapéutico en la vida cotidiana de pacientes con DM1, con el objetivo de ampliar el conocimiento de los profesionales de la salud y de la comunidad académica sobre el tema. **Objetivo:** Analizar cualitativamente el impacto del tratamiento farmacológico y no farmacológico en niños y adolescentes de 12 a 19 años diagnosticados con diabetes mellitus tipo 1 y residentes en el suroeste de Paraná, en el contexto social y familiar. **Métodos:** Se trata de un estudio observacional con enfoque cualitativo y análisis individual. El reclutamiento de los participantes siguió el modelo de muestreo por conveniencia, utilizando entrevistas semiestruturadas elaboradas por las autoras. Para el análisis de contenido, se utilizó la delimitación de categorías y subtemas. **Resultados:** La muestra está compuesta por pacientes del sexo femenino que tienen 12, 18 y 16 años de edad. Cuando fueron diagnosticadas, tenían 12, 13 y 12 años, respectivamente. Actualmente, su régimen de insulino terapia incluye dos tipos de medicamentos. En relación con el historial de hospitalizaciones relacionadas con la diabetes, P1 fue hospitalizada dos veces, P2 informó que no podía especificar con exactitud, y P3 afirmó haber sido hospitalizada aproximadamente cinco veces. Para ellas, el tiempo dedicado al control de su enfermedad y la evaluación de su nivel glucémico nunca ha interferido negativamente en su vida, aunque la dieta es poco flexible. En todos los casos, las madres fueron identificadas como el centro de su red de cuidados. De las tres responsables, solo una afirmó haber recibido instrucciones sobre los cuidados que la enfermedad de su hija exige. **Conclusiones:** Cualitativamente, no hubo percepción de pérdida de calidad de vida. La DM tipo 1 fue comprendida como una enfermedad crónica y el impacto de su manejo se asoció a beneficios, como la reducción del número de hospitalizaciones. Sin embargo, se destaca la carencia de educación en salud y la articulación de un equipo multidisciplinario.

Palabras clave: Diabetes mellitus tipo 1; Manejo de la enfermedad; Estrategias de salud.

INTRODUCTION

Type 1 Diabetes Mellitus (T1DM) is classified as a noncommunicable disease (NCD) primarily characterized by persistent hyperglycemia.¹ In Brazil, epidemiological data from the public health department of the Brazilian Diabetes Society underscore the significant impact of T1DM, particularly among the pediatric population. In 2021, the country ranked third globally in the number of children and adolescents (ages 0 to 19) diagnosed with T1DM.² Currently, subtype 1 — an autoimmune

disorder resulting in the destruction of pancreatic islet β -cells and leading to absolute insulin deficiency — stands as one of the most prevalent chronic conditions in childhood and adolescence, with a rising incidence. Of particular concern in this age group are acute complications, especially diabetic ketoacidosis (DKA), a serious condition that often necessitates hospitalization in tertiary care facilities.³⁻⁵

While early diagnosis is essential, it does not represent the most significant challenge. Living with T1DM requires shared management involving the patient, their family, and a multidisciplinary healthcare team. It also demands an understanding of the importance of a specific dietary regimen and the ability to carry out often uncomfortable procedures, such as insulin administration.⁶ Thus, the complexity of care and the necessity for the coordinated involvement of various professionals across medical specialties and healthcare fields, along with the active participation of both the family and the patient, become evident.⁷

Given that effective management of this condition depends on the coordination among multiple stakeholders, this study aimed to qualitatively analyze the impact of both pharmacological and non-pharmacological treatments on the daily lives of patients with T1DM, aged 12 to 19 years. The analysis considers social and familial contexts, with the goal of enhancing the understanding of healthcare professionals and the academic community regarding this subject.

METHODS

This study is an observational, cross-sectional cohort investigation employing a qualitative approach and individual-level analysis. Participant recruitment was conducted using a convenience sampling method. The inclusion criteria comprised children and adolescents aged 12 to 19 years, diagnosed with T1DM, and receiving treatment through the Brazilian Unified Health System (*Sistema Único de Saúde* – SUS).

Following four months of data collection conducted in primary care settings across 14 Basic Health Units (*Unidades Básicas de Saúde* – UBSs) in a municipality in southwestern Paraná, four patients were identified as meeting the study's inclusion criteria; however, only three consented to participate. Data collection was carried out through semi-structured interviews comprising both open- and closed-ended questions developed by the authors. The questionnaire gathered information on the participants' current age and age at diagnosis, duration of the disease, insulin therapy regimen, types of self-care practices — including appropriate nutrition and physical activity —, major lifestyle changes, challenges encountered in managing the treatment, and perceived quality of life. All questions were read aloud by the interviewers, and responses were transcribed verbatim using the interviewees' own words.

The same interview process was applied to caregivers, with modifications to the questions to reflect the specific objectives of this group. The aim was to gather information on topics such as family history of diabetes, the individual primarily responsible for managing the care plan following diagnosis, family adaptations related to the patient's diet, challenges faced both within and outside the family, and whether the promotion of independent self-care was encouraged. Content analysis was conducted using thematic categories and subthemes: “the diagnosis,” “treatment: insulin therapy and self-care,” “balancing diabetes and personal life in adolescence,” and “the impact of T1DM on the family environment.”

In accordance with CNS Resolution No. 466/2012, the study was approved by the Research Ethics Committee under CAAE No. 77227124.2.0000.972.

RESULTS

Three female patients with T1DM, residing in southwestern Paraná and receiving care at different UBS, participated in the study. Their ages were 12, 18, and 16 years and they are referred to as Patient 1 (P1), Patient 2 (P2), and Patient 3 (P3), respectively. No eligible candidates were excluded. The years of diagnosis were 2024, 2019, and 2020, corresponding to ages at diagnosis of 12, 13, and 12 years, respectively. The insulin therapy regimens reported by each participant are presented in Table 1. All patients indicated using insulin supplied by SUS, administered via tubes, commonly referred to as insulin pens.

Table 1. Current Therapy. Paraná, 2024.

| Patient | Insulin | Usage Regimen | Insulin | Usage Regimen |
|---------|----------|---------------|---------|---------------|
| P1 | NPH | 3 times a day | Regular | As needed |
| P2 | NPH | 3 times a day | Regular | 3 times a day |
| P3 | GLARGINE | Once a day | Regular | 3 times a day |

Source: Prepared by the authors, 2024.

With respect to non-pharmacological therapy, the variables considered included physical activity and adherence to a carbohydrate-based diet. It was observed that engagement in physical exercise was limited to weekly physical education classes at school. Among the three patients, only two reported incorporating carbohydrate counting into their dietary routines.

Regarding medical history related to diabetes, P1 has been hospitalized twice due to hyperglycemia and DKA. Her companion reported no family history of DM. P2 has lived with the disease for five years and has experienced multiple hospitalizations, although the exact number was not specified. These admissions were attributed to decompensated T1DM. A positive family history was noted, as her mother had gestational diabetes mellitus and her maternal grandmother was diagnosed with type 2 DM after age 60. P3, who has lived with T1DM for four years, reported approximately five hospitalizations for conditions including diabetic coma, T1DM symptoms, and blood acidosis — terms commonly associated with DKA. A positive family history was also present in this case, with the patient's great-grandmother having been diagnosed with DM.

To assess quality of life perception, patients were instructed to complete a questionnaire consisting of two domains:

- A – “satisfactions”; and
- B – “impact” (Table 2).

Table 2. Instrument: Self-perception of quality of life. Paraná, 2024.

| Domain | Question |
|--------|---|
| A | 1. Do you consider your diet to be flexible? |
| | 2. Are you satisfied with your diet? |
| | 3. Do you feel embarrassed managing your diabetes in public? |
| B | 1. Do you consider that the time spent managing your disease negatively affects your life? |
| | 2. Do you consider that the time spent monitoring your blood glucose level interferes with your life? |
| | 3. Do you consider that pain during insulin injection disrupts your treatment? |
| | 4. Do you consider that your disease treatment causes a loss of quality of life? |

Source: Prepared by the authors, 2024.

Response options included “yes,” “no,” “sometimes,” “never,” and “I don’t know.”

For P1, the time devoted to managing the disease and monitoring blood glucose levels has not negatively impacted daily life. Although dissatisfied with her diet, the patient described her eating habits as occasionally flexible. Pain experienced during insulin injections did not interfere with treatment adherence, nor was there any embarrassment reported when discussing diabetes in public.

P2 reported that the time dedicated to managing the disease and monitoring blood glucose levels does not negatively impact daily life. Although his diet was described as flexible, satisfaction with dietary habits was reported only occasionally. Pain during insulin injections sometimes interfered with treatment adherence; however, no embarrassment was expressed regarding discussing diabetes in public.

Similar to the previous patients, P3 reported that the time devoted to managing the disease and monitoring blood glucose levels does not negatively impact daily life. Her diet was described as flexible, and she currently expressed satisfaction with her dietary habits. Pain during insulin injections did not interfere with treatment adherence, nor did she report any embarrassment when discussing diabetes in public.

None of the patients reported that managing their disease resulted in a reduced quality of life. P1, P2, and P3 associated dedicated DM management with extended symptom-free periods and the absence of hospitalization due to acute diabetes complications. An additional key variable in this study involved examining patients’ support networks. In all cases, mothers were identified as the central figures within these networks.

The experience of caregiving was found to present various challenges. Among the three caregivers, only one reported having received medication administration instructions from the endocrinologist treating her daughter. Regarding nutritional guidance, two caregivers indicated receiving information from either the endocrinologist or a nutritionist affiliated with the public health system. The remaining caregiver reported having to seek such information independently through online sources.

All three families experienced changes following the T1DM diagnosis. In the case of P1, the mother reported adapting the entire household’s diet according to the nutritionist’s recommendations, ensuring that all family members consumed the same foods. Consequently, managing special dietary needs often became a concern when the family was away from home.

The situation described by P2’s mother differed notably. Few adjustments were made following the diagnosis, particularly regarding dietary changes. Challenges experienced at home included adhering to an appropriate diet, managing emotional factors, and coping with a weakened family structure. Socially, difficulties arose primarily from the need to transport insulin, as the medication requires special packaging.

For P3’s mother, shared meals were an adaptive family choice aimed at accommodating the patient’s health needs. Despite this adaptation, challenges were reported, including persistent concern for P3’s well-being. As the caregiver works outside the home, being away during a medical emergency causes significant distress. In social settings, the primary difficulty involved transporting insulin, not due to the need for special packaging, but rather because of the fear of forgetting the medication at home.

DISCUSSION

The diagnosis

In all three cases, the diagnosis was made during a hyperglycemic episode.

P2: "I was coming back from school and really wanted to eat a savory snack from the bakery. After I ate it, I went home and was super thirsty. There was always soda in the fridge, so I drank it all, but the thirst didn't go away. I was also really tired, but I thought it was just because I'd been walking home from school."

Mom 2: She looked so skinny the next day. I don't know how to explain it, but it was like she'd lost a bunch of weight all of a sudden. Then she started throwing up a lot, like, nonstop. So I figured it was best to take her to the doctor, you know?

Brazilian studies have shown a high incidence of DKA as the primary clinical manifestation prompting patients to seek medical attention, making it one of the most severe complications of untreated diabetes.^{8,9} In their study, Souza et al.⁸ reported that 58.8% of patients diagnosed with T1DM presented with symptoms such as nausea, vomiting, and altered level of consciousness, characteristic of DKA. The remaining patients exhibited classic symptoms of DM, including progressive weight loss and polydipsia.⁸ The alignment of this study's findings with existing literature is concerning, as uncontrolled hyperglycemic states are known to precipitate serious acute complications, such as cerebral edema.^{1,10}

In retrospect, T1DM was not initially suspected in the early management of the cases. Although diabetes is among the most common NCDs in this age group, its nonspecific symptoms often lead to misdiagnosis or delayed diagnosis¹¹. A study conducted in Sweden found that in 37% of cases, parents and/or guardians were initially informed of a diagnosis other than diabetes. In such instances — as observed in the case of P2 — gastroenteritis was the most frequently reported misdiagnosis.¹²

When examining the circumstances surrounding the time of diagnosis, particular attention should be given to P3. In 2020, the COVID-19 pandemic led to significant changes in the organization of health systems and in individual behaviors, particularly due to mandatory social isolation measures.¹³

Mom 3: I could tell she wasn't doing well. She lost 30 pounds in a month and was always tired, she just wanted to sleep. But since it was during COVID, I didn't think about taking her to the doctor because back then we were scared to go to the hospital unless it was really necessary. [...] They took her blood at the urgent care center [UPA] and we went home, then a few days later they called me to rush her to the hospital because she was almost slipping into a coma.

With limited access to medical appointments and healthcare services overwhelmed by the high volume of infected patients, families reported fear of seeking medical care due to the perceived risk of virus exposure. Despite these challenges, data from Buenos Aires indicated that the interval between symptom onset and diagnosis was shorter during the pandemic, between 2020 and 2021, compared to the pre-pandemic period.¹³

Treatment: insulin therapy and self-care

Following the initial diagnosis, it becomes necessary to develop skills essential for daily disease management, including proper insulin storage, appropriate injection sites and techniques, and adherence to the prescribed medication regimen. This process is referred to as health education, or diabetes education.¹⁴ Effective communication among physicians, patients, and family members is recognized as a

central component of treatment.¹⁵ However, a lack of adequate training was identified as a challenge faced by caregivers.

Mom 1: [...] Everything I learned about giving insulin was from the mom of another patient who was there for the same reason as us, but her son had been dealing with it longer, so she knew a lot and taught me a lot. I also got help from my boss's husband, he's a doctor and also has a son with the same condition as hers [referring to the patient]. [...] The internet taught me a lot about diabetes.

Currently, knowledge of the pharmacotherapy of the disease is considered a predictor of effective self-management.¹⁶ Given the need for multiple daily insulin administrations, factors such as age, body weight, daily energy expenditure, including physical activity, and dietary intake are key variables in calculating appropriate insulin dosages.^{17,18} Additionally, current literature indicates that regular physical activity contributes to reductions in plasma glucose levels during or shortly after exercise and plays a role in preventing chronic complications.¹⁹

Despite these benefits, all three interviewees reported engaging in physical activity no more than twice per week. This behavioral pattern is consistent with findings in other populations, as individuals with T1DM have been shown to be less physically active than healthy adults and, in most cases, do not participate in any form of regular physical activity.²⁰

As with physical activity, nutritional therapy presents significant challenges for the participants. Currently, dietary management in type 1 diabetes is not centered on strict restrictions but rather on individualized meal planning that allows for flexibility, based on the amount of carbohydrates consumed and the corresponding type and dosage of insulin administered.²¹ A wide range of foods, such as fruits, rice, beans, and legumes, contain carbohydrates and must be accounted for in insulin dose calculations.²² Thus, it is evident that knowledge serves as the foundation for adherence. A lack of in-depth understanding regarding food types and portion sizes represents a major barrier to achieving an adequate and balanced diet.²³

Balancing diabetes and personal life in adolescence

The limitations imposed by the disease and its management can hinder socialization, as well as psychological and emotional development, among patients with T1DM²⁴, as observed in the present study.

P2: I didn't accept the illness at first, and honestly, I still haven't. [...] What really gets in the way is school. I can't bring my insulin with me to take there because they won't allow it, so whenever I feel bad without the medicine, I have to go back home.

P3: When I got the diagnosis, I was in denial, I didn't want to accept it. But now I'm pretty well adjusted; my mom helped me a lot through that process. [...] Since the new insulin [referring to glargine] doesn't need to be kept in the fridge, I just carry it in my bag to school and take it with no problem [...] I've never had any kind of restriction.

In some cases, the school environment represents the only opportunity for social interaction for these individuals, making it essential that this setting does not pose additional barriers to their daily lives.

The International Society of Pediatric and Adolescent Diabetes (ISPAD) emphasizes the need for schools to implement accommodations that support the delivery of prescribed medical care, thereby enabling students with T1DM to participate fully in educational activities alongside their peers.²⁵

Furthermore, the denial behaviors previously mentioned are supported by the literature, as both treatment adherence and glycemic control tend to decline during adolescence.²⁶ The study by Datye et al. identified the emergence of psychological disorders, such as anxiety, along with the intensification of peer relationships, as significant barriers to effective disease management.²⁷

Adolescents with T1DM are twice as likely to develop symptoms of depression and anxiety compared to their peers.²⁸ Given that individual psychological factors influence prognosis, the Brazilian Society of Pediatrics (*Sociedade Brasileira de Pediatria* – SBP) recommends comprehensive, multidisciplinary care.²⁴ However, P2 reported never having been referred to other healthcare professionals. In contrast, P3 underwent psychological treatment for one year following her diagnosis.

P2 and P3 are similar in age and duration since diagnosis but differ in their history of diabetes-related hospitalizations, with P2 experiencing a higher frequency. These findings partially contradict those of Djonou et al.,²⁹ who suggest that the number of years living with the diagnosis positively influences glycemic control, as individuals transition from denial to acceptance — an evolution observed in P3. Thus, therapeutic intervention may be considered a supportive factor in promoting treatment adherence.

In relation to the second stressor identified by Datye et al.,²⁷ the findings of this study were also contradictory. When asked, all three patients denied experiencing embarrassment when managing their diabetes in social settings. Despite the complexities associated with living with a chronic condition, the interviewees reported that treatment does not result in a reduced quality of life. They acknowledged that, without medication, the clinical manifestations of glycemic decompensation are harmful. These accounts underscore the importance of patient education, ensuring that, even when perceived as unpleasant, treatment measures are understood and valued as essential to health and well-being.

The impact of T1DM on the family environment

Mom 1: I'm the one who takes care of her food and gives her insulin, but only sometimes. [...] I've always encouraged her to do it on her own, even though she's still young, because I'm not with her all the time; she needs to learn to handle things by herself so she doesn't get sick when I'm not around.

Mom 2: Since I don't work and I'm a stay-at-home mom, I'm the one who cooks for everyone here [referring to the house], so I end up making her food too. But she knows how to cook and take care of herself pretty well; she already knows what she can and can't eat. [...] Now she's 18, so she takes care of herself, but she's been doing that for a long time, since she was 14. You just get used to it.

Mom 3: I was the one taking care of everything most of the time, but when she goes to her dad's place [referring to the patient's father], he takes care of her. Now that she's older, she can take care of herself too [...] she cooks her own food and manages her diabetes.

Initially, the role of caregiver was assumed by the mothers; however, in all three cases, they emphasized the importance of their daughters' education and involvement in managing their own care.

Recognizing the value of family participation, Mansour et al.³⁰ identified significant differences in treatment adherence among patients who received diabetes education alongside their families. According to the authors, such involvement enhances well-being and motivation to maintain treatment, contributing to laboratory results within recommended parameters.³⁰

However, Goethals et al.³¹ caution that intrusive parental involvement may be counterproductive. In their investigation of autonomy *versus* control as motivators for self-management, autonomy-supportive behaviors were positively associated with adherence motivation, in contrast to controlling approaches.³¹ Accordingly, health professionals should encourage parents to involve their children in treatment-related decision-making and promote supportive communication.³²

Furthermore, in all reported hospitalizations, mothers served as the primary companions. Consistent with the findings of this study, Barichello et al. observed that the responsibility for continuous care typically falls to the mother.³³ Family stress and caregiver burden are recognized as significant risk factors for poor metabolic control.³⁴ For healthcare professionals, acknowledging caregivers' feelings of exhaustion, frustration, and concern enables the development of tailored interventions. Flexibility in the treatment plan has been shown to positively impact the continuity of care and patient follow-up.

CONCLUSION

The initial contact with the disease occurred through episodes of hyperglycemia requiring hospitalization, a common event in the patients' lives. Despite the complexity of the condition, most patients reported receiving no formal instruction on pharmacological or non-pharmacological treatment, leading them to seek information from sources outside the healthcare system. Additionally, follow-up with nutritionists and psychologists varied among patients, which may have influenced their current relationship with the disease and their approach to management.

Within the family environment, paternal involvement was reported as minimal, with dietary adjustments cited as the most significant impact. A perception of nutritional therapy as restriction-based remained prevalent. Despite these factors, no qualitative loss of quality of life was reported. Type 1 DM was recognized as an NCD, and its management was associated with perceived benefits, including fewer hospitalizations and longer symptom-free periods. However, the lack of structured health education and insufficient coordination of multidisciplinary care teams remain important concerns.

The small sample size constituted the main limitation of this study, restricting the understanding of the broader reality of patients at the municipal level. Consequently, further research is needed to complement and expand upon the data collected.

CONFLICT OF INTERESTS

Nothing to declare.

AUTHORS' CONTRIBUTIONS

MDF: Writing – original draft, Writing – review & editing, Investigation, Methodology, Resources, Software. TNG: Writing – original draft, Investigation, Methodology, Resources, Software. GBS: Project administration, Formal analysis, Conceptualization, Data curation, Supervision, Validation, Visualization.

REFERENCES

- Costa BB, Moreira TA. Principais aspectos fisiopatológicos e clínicos presentes no Diabetes mellitus tipo I (autoimune). *Res Soc Dev*. 2021;10(14):e153101421773. <https://doi.org/10.33448/rsd-v10i14.21773>
- Pititto BA, Bahia L, Melo K. Dados epidemiológicos do diabetes mellitus no Brasil [Internet]. 2023 [cited on Nov 28, 2024]. Available at: https://profissional.diabetes.org.br/wp-content/uploads/2023/06/Dados-Epidemiologicos-SBD_comT1Dindex.pdf
- Rodacki M, Teles M, Gabbay M, Lamounier R. Classificação do diabetes. *Diretriz Oficial da Sociedade Brasileira de Diabetes*; 2023. <https://doi.org/10.29327/557753.2022-1>
- Oliveira YCD, Almeida LM, Costa MAA, Cavalcante JC, Gomes RU. Perfil clínico-epidemiológico dos pacientes portadores de diabetes mellitus tipo 1 atendidos no Ambulatório de Endocrinologia Pediátrica do Hospital Universitário Professor Alberto Antunes. *GepNews*. 2021;4(2):10-8.
- Vargas DM, Andrade BB, Bork B. Perfil clínico e epidemiológico de crianças e adolescentes com diabetes mellitus 1 atendidos na atenção secundária em Blumenau -SC. *Arq Catarin Med*. 2016;45(3):58-70.
- Souza MMC, Alves TCHS. Caracterização da vivência familiar de crianças e adolescentes portadores de Diabetes mellitus tipo 1: uma revisão narrativa. *Res Soc Dev*. 2022;11(2):e6011225313. <https://doi.org/10.33448/rsd-v11i2.25313>
- Marques ELV, Almeida NM, Canuto FVS, Nascimento MAB, Rodrigues D, Avendano RMO. Perfil clínico e epidemiológico de crianças e adolescentes com diabetes mellitus tipo 1. *Com Ciências Saúde*. 2021;32 Suppl 1:11-5. <https://doi.org/10.51723/ccs.v32iSuppl1.990>
- Souza LCVF, Kraemer GC, Koliski A, Carreiro JE, Cat MNL, Lacerda L, et al. Diabetic ketoacidosis as the initial presentation of type 1 diabetes in children and adolescents: epidemiological study in southern Brazil. *Rev Paul Pediatr*. 2019;38:e2018204. <https://doi.org/10.1590/1984-0462/2020/38/2018204>
- Ramos TTO, Noronha JAF, Lins BS, Santos MCQ, Santos SMP, Cantalice ASC. Cetoacidose diabética em crianças e adolescentes com diabetes mellitus tipo 1 e fatores de risco associados. *Cogitare Enferm*. 2022;27:e82388. <https://doi.org/10.5380/ce.v27i0.82388>
- Pannia PG, Balboa R, Navarro R, Nocita MF, Ferraro M, Mannucci C. Prevalence of cerebral edema among diabetic ketoacidosis patients. *Arch Argent Pediatr*. 2020;118(5):332-6. <https://doi.org/10.5546/aap.2020.eng.332>
- Muñoz C, Floreen A, Garey C, Karlya T, Jelley D, Alonso GT, et al. Misdiagnosis and diabetic ketoacidosis at diagnosis of type 1 diabetes: patient and caregiver perspectives. *Clin Diabetes*. 2019;37(3):276-81. <https://doi.org/10.2337/CD18-0088>
- Wersäll JH, Adolfsson P, Forsander G, Ricksten S, Hanas R. Delayed referral is common even when new-onset diabetes is suspected in children. A Swedish prospective observational study of diabetic ketoacidosis at onset of type 1 diabetes. *Pediatr Diabetes*. 2021;22(6):900-8. <https://doi.org/10.1111/pedi.13229>
- Andrés ME, Grimberg N, Torres F, Ferraro M, Jiménez V, Linari MA. Type 1 diabetes in pediatrics during the COVID-19 pandemic: Time from symptom onset and forms of presentation at a referral hospital. *Arch Argent Pediatr*. 2024;122(4) :e202310291. <https://doi.org/10.5546/aap.2023-10291>
- La Banca RO, Sparapani VC, Bueno M, Costa T, Carvalho EC, Nascimento LC. Strategies to educate young people with type 1 diabetes mellitus on insulin therapy: systematic review. *Texto Contexto Enferm*. 2020;29:e20180338. <https://doi.org/10.1590/1980-265X-TCE-2018-0338>
- Caccavale LJ, Corona R, LaRose JG, Mazzeo SE, Sova AR, Bean MK. Exploring the role of motivational interviewing in adolescent patient-provider communication about type 1 diabetes. *Pediatr Diabetes*. 2019;20(2):217-25. <https://doi.org/10.1111/pedi.12810>
- Hamdan S, Taybeh E, Alsous MM. Determinants of self-care among Jordanian children with type 1 diabetes mellitus. *J Egypt Public Health Assoc*. 2024;99(1):19. <https://doi.org/10.1186/S42506-024-00166-8>
- Brasil. Ministério da Saúde. Secretaria de Ciência, Tecnologia, Inovação e Insumos Estratégicos em Saúde. Departamento de Gestão e Incorporação de Tecnologia e Inovação em Saúde. Protocolo clínico e diretrizes terapêuticas do diabetes mellito tipo 1. Brasília: Ministério da Saúde; 2020.
- Melo KFS, Almeida-Pititto B, Pedrosa HC. Tratamento do diabetes mellitus tipo 1 no SUS. *Diretriz Oficial da Sociedade Brasileira de Diabetes*; 2023. <https://doi.org/10.29327/5238993.2023-12>
- Pereira WVC, Vancea DMM, Oliveira RA, Freitas YGPC, Lamounier RN, Zagury RL. Atividade física e exercício no DM1. *Diretriz Oficial da Sociedade Brasileira de Diabetes*; 2023. <https://doi.org/10.29327/557753.2022-6>
- Cockcroft EJ, Narendran P, Andrews RC. Exercise-induced hypoglycaemia in type 1 diabetes. *Exp Physiol*. 2020;105(4):590-9. <https://doi.org/10.1113/EP088219>
- Campos TF, Ramos S, Campos LF, Guimarães DB, Baptista DR, Gomes DL, et al. Terapia nutricional no diabetes tipo 1. *Diretriz da Sociedade Brasileira de Diabetes*; 2024. <https://doi.org/10.29327/5412848.2024-4>
- Bohnen D, Souto D, Fenner N, Campos TF. Manual de contagem de carboidratos para pessoas com diabetes. São Paulo: Departamento de Nutrição da Sociedade Brasileira de Diabetes; 2023.
- Ait-Taleb Lahsen H, El Amine Ragala M, El Abed H, Hajjaj S, El Makhtari R, Benani S, et al. Educational needs of type 1 diabetes mellitus T1DM children and adolescents in Morocco: a qualitative study. *J Educ Health Promot*. 2023;12:114. https://doi.org/10.4103/jehp.jehp_54_23
- Azevedo AEBI, Goldberg TBL, Bonetto DVS, Fernandes EC, Cesconetto G, Oliveira HF, et al. Adolescência: doença crônicas e ambulatórios de transição. São Paulo: Sociedade Brasileira de Pediatria; 2020 [Internet]. 2020 [cited on Nov 28, 2024]. Available at: https://www.sbp.com.br/fileadmin/user_upload/22641c-ManOrient_-_Adoles_-_doencas_cronicas_e_ambulat_de_transicao.pdf

25. Bratina N, Forsander G, Annan F, Wysocki T, Pierce J, Calliari LE, et al. ISPAD Clinical Practice Consensus Guidelines 2018: management and support of children and adolescents with type 1 diabetes in school. *Pediatr Diabetes*. 2018;19 Suppl 27:287-301. <https://doi.org/10.1111/pedi.12743>
26. Silva K, Miller VA. The role of cognitive and psychosocial maturity in type 1 diabetes management. *J Adolesc Health*. 2019;64(5):622-30. <https://doi.org/10.1016/j.jadohealth.2018.10.294>
27. Datye K, Bonnet K, Schlundt D, Jaser S. Experiences of adolescents and emerging adults living with type 1 diabetes. *Diabetes Educ*. 2019;45(2):194-202. <https://doi.org/10.1177/0145721718825342>
28. Versloot J, Saab H, Minotti SC, Ali A, Ma J, Reid RJ, et al. An integrated care model to support adolescents with diabetes-related quality-of-life concerns: an intervention study. *Can J Diabetes*. 2023;47(1):3-10. <https://doi.org/10.1016/j.jcjd.2022.05.004>
29. Djonou C, Tankeu AT, Dehayem MY, Tcheutchoua DN, Mbanya JC, Sobngwi E. Glycemic control and correlates in a group of sub Saharan type 1 diabetes adolescents. *BMC Res Notes*. 2019;12(1):50. <https://doi.org/10.1186/S13104-019-4054-1>
30. Mansour M, Parizad N, Maslakkpak MH. Does family-centred education improve treatment adherence, glycosylated haemoglobin and blood glucose level in patients with type 1 diabetes? A randomized clinical trial. *Nurs Open*. 2023;10(4):2621-30. <https://doi.org/10.1002/nop2.1522>
31. Goethals ER, Soenens B, Wit M, Vansteenkiste M, Laffel LM, Casteels K, et al. The role of parental communication in adolescents' motivation to adhere to treatment recommendations for type 1 diabetes. *Pediatr Diabetes*. 2019;20(7):1025-34. <https://doi.org/10.1111/pedi.12901>
32. Miller VA, Jawad AF. Decision-making involvement and prediction of adherence in youth with type 1 diabetes: a cohort sequential study. *J Pediatr Psychol*. 2019;44(1):61-71. <https://doi.org/10.1093/jpepsy/jsy032>
33. Barichello A, Scaratti M, Argenta C, Zanatta EA. Vivências de familiares de adolescentes diagnosticados com diabetes mellitus tipo 1: convivência, cuidados e mudanças. *Rev Baiana Enferm*. 2022;36:e46696. <https://doi.org/10.18471/rbe.v36.46696>
34. Mahler FL, Konrad D, Landolt MA. Perceived family stress predicts poor metabolic control in pediatric patients with type 1 diabetes: a novel triadic approach. *J Diabetes Res*. 2022;2022:3809775. <https://doi.org/10.1155/2022/3809775>