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RESEARCH ARTICLE (ORIGINAL)

Adolescents with type 1 diabetes mellitus and their process of developing autonomy for self-care

Adolescentes com diabetes mellitus tipo 1 e o seu processo de construção da autonomia para o autocuidado

Adolescentes con diabetes mellitus tipo 1 y el proceso de construcción de la autonomía para el autocuidado

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Abstract

Background: Type 1 diabetes mellitus requires adolescents' autonomy to perform self-care.
Objective: To analyze the process of developing autonomy for self-care in adolescents with type 1 diabetes mellitus.
Methodology: Descriptive-exploratory research with nine adolescents with type 1 diabetes mellitus. Data were collected through semi-structured interviews and interpreted using inductive thematic analysis.
Results: The process of developing autonomy in adolescents with diabetes begins with an interest in seeking knowledge about the disease and treatment, with the support of the social network, to gain the confidence in themselves to perform self-care. Obstacles to this process include difficulties in controlling diet, poor access to insulin therapy materials, and lack of safety in handling them.
Conclusion: It is essential to help these adolescents develop autonomy for self-care so that they can overcome difficulties in managing diabetes and prevent complications that can compromise their quality of life and put a burden on the health system.

Keywords: diabetes mellitus; adolescent; self-care; personal autonomy

Resumo

Enquadramento: A diabetes *mellitus* tipo 1 requer autonomia do adolescente para a realização do autocuidado.
Objetivo: Analisar o processo de construção da autonomia para o autocuidado de adolescentes com diabetes *mellitus* tipo 1.
Metodologia: Pesquisa descritiva-exploratória com nove adolescentes com diabetes tipo 1, através de entrevistas semiestruturadas e dados interpretados pela análise temática indutiva.
Resultados: O processo de construção da autonomia do adolescente com diabetes inicia com o interesse em procurar conhecimento sobre a doença e tratamento, aprimorado pelo apoio da rede social, potencializando a confiança em si para assumir o seu autocuidado. Dificuldades em controlar a dieta, ter acesso aos materiais para insulinoterapia e falta de segurança para manuseá-los constituem obstáculos para essa construção.
Conclusão: É fundamental apoiar esses adolescentes na construção da autonomia para o autocuidado a fim de superar as dificuldades na gestão da diabetes e prevenir complicações que podem comprometer a sua qualidade de vida e gerar custo ao sistema de saúde.

Palavras-chave: diabetes *mellitus*; adolescente; autocuidado; autonomia pessoal

Resumen

Marco contextual: La diabetes *mellitus* tipo 1 requiere la autonomía del adolescente para el autocuidado.
Objetivo: Analizar el proceso de construcción de la autonomía para el autocuidado de adolescentes con diabetes *mellitus* tipo 1.
Metodología: Investigación descriptiva-exploratoria con nueve adolescentes con diabetes tipo 1, mediante entrevistas semiestructuradas y datos interpretados por análisis temático inductivo.
Resultados: El proceso de construcción de la autonomía del adolescente con diabetes comienza con el interés por buscar conocimientos sobre la enfermedad y el tratamiento, potenciado por el apoyo de la red social, lo que aumenta la confianza en sí mismo para asumir el autocuidado. Las dificultades para controlar la dieta, el acceso a los materiales de insulinoterapia y la falta de seguridad para manejarlos son obstáculos para esta construcción.
Conclusión: Es esencial apoyar a estos adolescentes en la construcción de la autonomía para el autocuidado con el fin de superar las dificultades para gestionar la diabetes y prevenir las complicaciones que pueden comprometer su calidad de vida y generar gastos al sistema de salud.

Palabras clave: diabetes mellitus; adolescente; autocuidado; autonomía personal

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Introduction

The number of children and adolescents with type 1 diabetes mellitus (T1DM) has been increasing in many countries. Approximately 98,200 children under 15 years of age are diagnosed with T1DM every year, increasing to 128,900 in the under 20-year age group. India, the United States of America, and Brazil have the highest incidence and prevalence rates of T1DM in children and adolescents, especially in the 0-14 age group. In countries with limited access to health services, this population may face undesirable clinical outcomes and early death (International Diabetes Federation, 2019), with T1DM constituting a major public health issue.

In addition to the demands imposed by the disease, adolescents with T1DM have to cope with the physical, psychological, social, and behavioral changes inherent to this stage of the life cycle (Feitor et al., 2020). At this stage, although they begin to assume responsibility for disease self-management, this responsibility is often attributed without assessing their level of maturity to properly manage self-care, which requires behavioral, cognitive, and emotional autonomy (Jones & Foli, 2018).

Thus, the importance of this study is justified by highlighting the problems that interfere with the process of developing autonomy in adolescents with T1DM. Based on this knowledge, health professionals, especially nurses, can design proactive strategies to care for this population and facilitate this process. This study aimed to analyze the process of developing autonomy for self-care in adolescents with T1DM.

Background

T1DM is an autoimmune metabolic disease characterized by chronic hyperglycemia due to inefficient insulin production and/or action. It is subdivided into types 1A and 1B, in which the former is diagnosed on laboratory confirmation of autoantibodies that destroy β-cells and the latter when these autoantibodies are not identified, being considered idiopathic in nature (Sociedade Brasileira de Diabetes, 2019).

The World Health Organization defines adolescents as those people aged between 10 and 19 years (World Health Organization, 1986). Adolescence brings with it several psychobiological changes inherent to the transition to this life cycle, which, when added to T1DM, can have a negative impact on the process of autonomy in maintaining the necessary therapeutic regimen (Feitor et al., 2020).

In this context, it is important to assess the three interrelated dimensions of autonomy to identify the level of maturity of adolescents with T1DM to perform self-care. Cognitive autonomy refers to the adolescent's ability to make decisions based on their knowledge, values, and beliefs without the need for external validation. On the other hand, behavioral autonomy refers to the ability to make decisions and follow through with the necessary actions, such as diabetes care (blood glucose monitoring, carbohydrate counting, calculating and administering insulin doses). In turn, emotional autonomy occurs when adolescents begin to perceive their parents as people with characteristics and needs outside of the parent-child relationship. When this happens, young people begin to sever childish dependencies on their parents and to take responsibility for their own behavior (Jones & Foli, 2018). In this double transition, from childhood to adolescence and responsibilities to self-care from the parents to the adolescent, glycemic variability can occur, with hyperglycemic peaks (blood glucose above 140 mg/dL) or hypoglycemia (blood glucose below 70 mg/dL; Beck et al., 2019). This situation results from adolescents' lack of maturity to manage treatment, compromising their health (Mok et al., 2019).

Therefore, the three dimensions of autonomy and the factors that contribute to or hinder their development should be assessed on a continual basis to determine if the adolescent has reached full maturity to effectively perform the self-care activities related to T1DM (Jones & Foli, 2018). It is important to pay attention to this process of building autonomy because it directly interferes with self-care, that is, the actions performed to care for oneself. Thus, adolescents with T1DM need to be given the opportunity to express their experiences with the disease and the aspects that interfere with the development of autonomy for self-care with the purpose of identifying strategies to overcome the adversities. Cruz et al. (2018) recognize the importance of the health team in identifying the obstacles that adolescents face in their daily lives when performing self-care to plan interventions for preventing complications and improving quality of life.

Through this work, it is possible to build a care plan aimed at implementing more effective strategies to build self-efficacy and, as a result, achieve autonomy in the management of T1DM (Collet et al., 2018). Due to the impact of DM on these adolescents' lives (Zanatta et al., 2020), health professionals should seek strategies to help them minimize this impact, such as supported self-care.

Research question

How do adolescents with T1DM develop autonomy for self-care? What are the difficulties experienced in the process of developing this autonomy?

Methodology

This exploratory-descriptive study with a qualitative approach was conducted in a pediatric outpatient unit of a large hospital and in homes of adolescents with T1DM in the State of Paraíba, Brazil. Data were collected between September and December 2017. The recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ) were used to ensure the validity of the results and reduce interpretation errors.

The research participants were nine adolescents who met the following inclusion criteria: having a diagnosis of T1DM, aged 10 to 19 years, and requiring regular insulin therapy. This age group was chosen because it allows analyzing the initial process of developing autonomy for self-care and the reports of those who have already achieved this autonomy. The exclusion criterion was the presence of cognitive disorders and/or communication problems. However, no potential participant was excluded.

Participants were selected through the snowball method, in which key informants, called 'seeds', nominate other potential participants who match the research profile (Costa, 2018). Thus, the seeds were first contacted in the outpatient unit and provided the phone numbers of other adolescents and their guardians so that they could be invited to participate in the research. If they accepted, the interview was scheduled to take place at their homes.

Data were collected through a semi-structured interview after the researcher had introduced herself to the participants. The following questions guided the interview: "Please tell me how your diabetes self-care is performed" and "What difficulties do you have in performing this self-care?

The interviews took place at the outpatient unit after the consultation with the specialist or at the adolescents' homes at a date and time convenient to them. Participants were interviewed individually by an experienced researcher. The interviews were audio-recorded, lasting on average 60 minutes, and transcribed in full for analysis. The criterion for ending data collection was data saturation, that is, if the purpose of the study was achieved and the repeated information already allowed understanding the phenomenon, there was no need to include new participants (Minayo, 2017).

Data were analyzed using inductive thematic analysis (Braun & Clarke, 2013) and cross-checked by two researchers. This process allowed identifying, analyzing, and identifying themes in the data. Initially, the interviews were transcribed for researchers to become more familiarized with the data. Then, the researchers individually coded and grouped the data to create pre-themes based on affinity. Their codes were revised and refined to build the themes, which were cross-checked. Lastly, the final report was prepared.

The study followed the ethical principles of the Brazilian National Health Council on research with human beings and obtained favorable opinion number 2.046.382. Adolescents aged 18 years signed the informed consent form (ICF), minors signed the assent form, and their guardians signed the ICF. As a guarantee of anonymity, the letter "A" for adolescent was used, followed by the ordinal number corresponding to the interview order and the interviewees' ages.

Results

Adolescents were aged 10 to 18 years, and most of them were male (A1, A3, A4, A6, A7, A8). Their education level ranged from the fifth year of elementary school to incomplete higher education. Their caregivers' education level ranged from incomplete elementary school to complete higher education. Four participants lived in the city where the research was carried out (A1, A6, A8, A9), two in the metropolitan region (A5, A7), and three in the interior of the state (A2, A3, A4).

Concerning the time of diagnosis, A1, A5, and A7 had been diagnosed for 7 years; A2 for 3 years; A3 for 4 years; A4 for 1 year; A6 for 12 years; A8 for 13 years; and A9 for 15 years. Participants used insulin and syringe (A1, A4), insulin pen (A2, A3, A5), insulin pump (A7, A8, A9), and insulin pump and pen (A6). Only four adolescents had health insurance (A5, A6, A7, A9), and these did not attend the family health unit (FHU). The other adolescents' frequency of visits to the FHU ranged from every week to every two months.

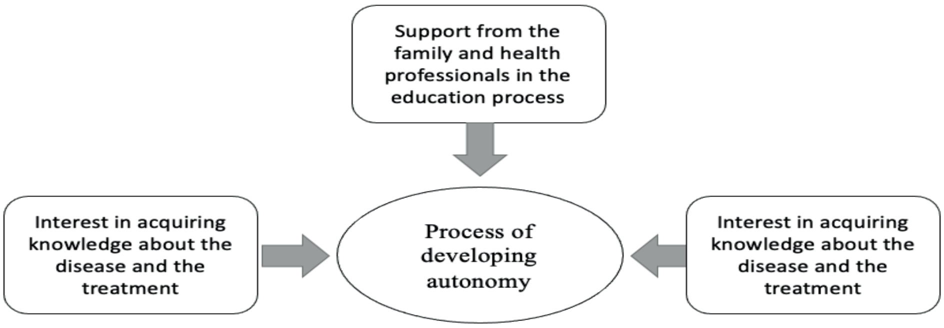
The following themes were identified after the analysis of empirical data: Process of developing autonomy for self-care in adolescents with T1DM and Difficulties experienced in the process of developing autonomy for self-care in adolescents with T1DM.

Process of developing autonomy for self-care in adolescents with T1DM

In this process of developing autonomy, adolescents need to receive external support and improve their knowledge about the disease and treatment in order for them to believe in their potential to manage care, as shown in Figure 1.

Figure 1

Interventions for developing autonomy for self-care carried out by adolescents with T1DM



Thus, this process began when the adolescent tried to gain more knowledge about T1DM to better control the disease: "I started researching about the disease and the more I researched, the more I understood . . . the more I had control over the disease. Knowing what I'm facing helps me cope with it" (A7).

The desire to learn enhances cognitive and behavioral autonomy, and the support of the family and the health professionals is essential. A type of support is the counseling and monitoring of insulin administration: "Because I saw him (father) injecting it, and I felt like it too. . . . Then he taught me and the people from the PSF (Family Health Program) helped me too. I've been injecting it ever since" (A1).

The fact that the parents agreed to let adolescents perform self-care activities contributed to their emotional autonomy: "When I was eight years old, I started injecting it. My dad said that I could already be responsible for it. He taught me . . . I like to give myself the injection and be responsible for it" (A3).

Parental support throughout the experience with T1DM was a key factor in the process of building knowledge about T1DM for cognitive autonomy, which helped them cope with the disease: "My parents helped me. As I grew older and matured, I began to understand why everything happened, what is this disease and the treatment. Today I live well with it" (A7).

The support improved this knowledge over time and helped them better identify signs and symptoms of acute situations and interventions to manage them. This improvement increased the adolescents' behavioral autonomy for self-care. "When it's low, the person becomes weak and loses balance in the legs . . . You have to do the test. If it's high, you take the correct dosage of insulin that's on the paper" (A2).

> When its low . . . I feel shaky, I check it and if it's low I correct it with something sweet. When it's high, my vision is blurred, I feel sleepy, and drink a lot of water. Then I do the test and correct it with NovoRapid. (A5).

The gradual assumption of responsibility for therapeutic management helped adolescents' achieve maturity for self-care and the desired independence.

> As I had more responsibility to take care of myself, I had more freedom. Before, my levels were very high, and I just thought 'ah, they won't let me eat sweets' and I would eat in secret. I started to understand why I couldn't eat and why it changed. And that helped me to become independent. (A6)

New treatment technologies also contributed to increasing adolescents' autonomy in performing daily self-care activities with safety.

> I felt uncomfortable with the syringe because I didn't like those big needles. With the pen, the needles are small and it's easy. I do it myself... With the syringe I had to check the unit, but with the pen I just turn the little wheel, and it already tells me the correct amount. (A2)
>
> I started to administer it with the pen... it became easier because with the syringe we had to carry around the foam cooler to preserve the temperature, and it couldn't be out of the fridge for too long. That's no longer needed with the pen, you just can't expose it to the sun. (A5)

The insulin pump helped manage the disease, triggering the perception of a normal life, with fewer dietary restrictions and better management using the carbohydrate counting technique.

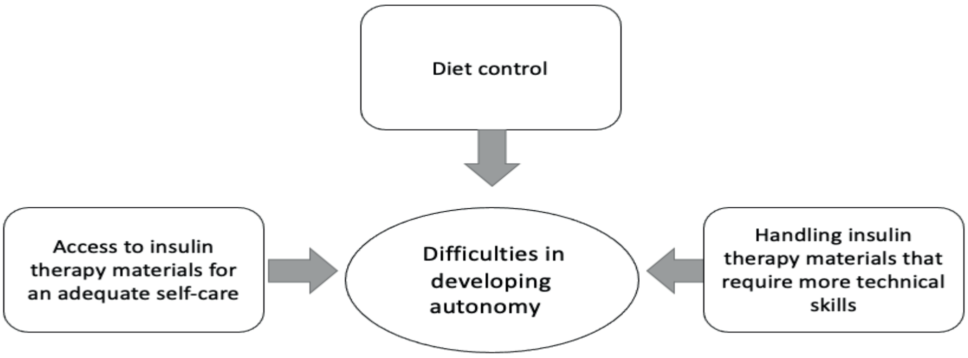
> I guess I can say that I have a normal life now because I no longer have to worry about doing the tests several times a day . . . Before, the diet was very restricted, everything light and counted. (Now) I can eat everything but in moderation. The pump and the counting give me more freedom in general. (A7)
>
> Going back to the pen was very bad. Even though I was 13, I didn't want to stick myself too often, instead of pushing two buttons and that was it. I had more freedom with the pump and counting carbohydrates, just like it was on the test . . . It gave me more freedom in eating, in sports, and in blood glucose. (A8)

Difficulties experienced in the process of developing autonomy in adolescents with T1DM

As shown in Figure 2, the factors that hinder this development process are linked to the treatment of T1DM. These factors include the diet, the access to insulin therapy materials, and the ability to handle them.

Figure 2

Difficulties experienced by adolescents with T1DM in the process of developing autonomy



Diet control is an integral part of self-care in adolescents with T1DM. However, food restriction was one of the difficulties reported by adolescents in managing the disease. “The first time was very bad (the first diet) because I was used to eating the normal everyday things . . . Now I have the diagnosis, I am more aware of what a diet is” (A4). “At the beginning of the year, I started a diet, lost weight, and then after a while I gained everything back. It had a negative impact on the treatment because my level increased, I gained more weight, the insulin also” (A5).

Self-administration of insulin is a complex activity for adolescents, requiring knowledge and technical skills. In addition, the materials used for administration were reported as factors that hinder the achievement of behavioral autonomy for self-care: “When I inject it (insulin), I get nervous and when it’s my dad I get calmer. On the thigh, I was afraid of getting some part wrong” (A1). “The pen was better, because it was bad to be always counting the lines to apply, and it also hurt less, because the needle was smaller” (A5).

A technology made available in Brazil to a few adolescents with T1DM is the insulin pump. Despite the numerous benefits described by those who use it, many still do not have access to it and yearn one day to have it in their treatment. “I wanted to use the pump because it helps regulate it (blood glucose). My father was going to ask the government to buy it because patients with diabetes need it” (A3). “I think that in the coming years things will evolve more because my name is already on the list to get the pump, but it hasn’t arrived. It (government) should invest more in patients with diabetes, the pump would bring more independence” (A5). “I think that if other people had access to the insulin pump, their control would improve . . . Because many people still undergo very outdated and painful treatments . . . It would help with acceptance” (A7).

Given these current experiences, the adolescents reported their expectations about self-care and their future with T1DM. They are specifically concerned about access to insulin therapy materials.

> The main problem is getting the inputs (insulin therapy materials) from the government and achieving our rights. Conscious patients with diabetes understand the disease and treat themselves, so the biggest problem will not be the care itself, but having access to the inputs for care. (A6)

Discussion

The onset of adolescence brings the need for the transition of the responsibility for T1DM care from parents to children (Collet et al., 2018; Jones & Foli, 2018) and the development of their autonomy. However, parental involvement in this process, through the sharing of responsibilities, is important for achieving glycemic control (Vloemans et al., 2019; Zanatta et al., 2020). Thus, the support received in the process of knowledge acquisition and development of self-care skills is essential to reaching maturity in the safe management of the disease (Collet et al., 2018).

Knowing about the disease and seeing the positive results obtained through it encourages adolescents to seek more knowledge to better manage their condition. In addition, it helps them develop coping and acceptance skills for achieving behavioral autonomy.

A Norwegian study reports that adequate knowledge about the disease and treatment in adolescents with T1DM is extremely relevant to strengthening self-care skills. In this way, they can perform daily procedures and observe and respond to signs and symptoms experienced in their daily lives (Strand et al., 2019).

Knowing the signs and symptoms of hyperglycemia and hypoglycemia will help identify and resolve decompensated glycemic values, dietary variations, and incorrect insulin doses. These changes can result in coma, vascular complications, and diabetic ketoacidosis. To avoid them, adolescents and their caregivers should be familiar with the definition of hyperglycemia and hypoglycemia, recognize early signs and symptoms of each situation, the treatment, and the prevention (American Diabetes Association, 2020).

This knowledge is usually built from lived experiences and the guidance of health professionals who are part of their social support network. A study (Cruz et al., 2018) emphasizes the importance of support from professionals and parents for adolescents with T1DM to perform their self-care activities better, which positively impacts their quality of life.

This support enhances the success of the implementation of these actions in a manner consistent with the situation experienced. Therefore, professionals can provide health education to address issues identified in this study as interfering with adolescents' autonomy. Thus, the care offered is improved and proper management is ensured, which also prevents future complications.

Adolescents with T1DM experience numerous changes in their daily lives, requiring willpower, behavioral change, and adaptation. In this process, the support provided by social support networks helps them acquire autonomy to manage their life with the disease with quality (Collet et al., 2018).

This process is enhanced when the adolescent is interested in developing the necessary skills and the parents are receptive to letting them perform self-care activities, such as insulin therapy and glycemic testing. Thus, the fears about the procedure are overcome, and the adolescents' emotional and behavioral autonomy is increases, boosting their maturity. Nevertheless, health professionals' assessment of adolescents' level of maturity for self-care is a key aspect in this transition and essential for proper self-care management.

As for insulin therapy, these adolescents' experiences with using the syringe to administer insulin were reported as difficult, painful, and outdated, which can hinder the development of autonomy. On the other hand, the insulin pen, by having a smaller needle and being easier to calibrate the dosage, increases adolescents' interest in learning how to perform this self-care as they feel safer and more confident. Thus, this study concluded that technology increases adherence to the established protocol by facilitating transportation, handling, and administration and promotes the development of emotional and behavioral autonomy.

In line with these results, a study conducted in São Paulo, Brazil, found that the materials used in insulin therapy are related to therapeutic compliance and that insulin pens are an excellent alternative to facilitate adherence. Conversely, there may be barriers to insulin administration when it requires different materials for storage and transportation or when feelings such as fear, insecurity, and pain are aroused by the route of administration (Dias & Junqueira, 2020). Bariya and Nayberg (2017) from the University of California also emphasized the benefits of replacing the syringe with the insulin pen to minimize the burden on management and enable better performance, given that syringes are associated with pain, inconvenience, and social stigma.

In this study, even greater benefits were observed when using the continuous insulin infusion pump (CIIP), which was synonymous with better quality of life for adolescents. This technology facilitates therapeutic management, contributing to better glycemic control, less glycemic variability, and the freedom to manage their routine without much intervention from third parties. The satisfaction in using this technology encourages therapeutic compliance by promoting greater autonomy.

CIIP therapy involves the release of long-acting basal insulin, usually once or twice a day, and fast-acting insulin after meals. When comparing the use of this therapy with multiple daily injections of insulin, one study pointed out the beneficial effect in reducing glycated hemoglobin concentrations and in cases of hypoglycemia (American Diabetes Association, 2020). In addition, satisfaction with treatment, food freedom, reduction of daily complications, and parental stress were also reported as benefits, positively impacting the quality of life of adolescents with T1DM (Beck et al., 2019) and their families.

The major obstacle to accessing CIIP is the lack of governmental investment in treatment technologies for people with diabetes. Based on these adolescents' reports, it can be concluded that the forms of treatment made available by the government influence acceptance, management, and self-care. This relevant aspect should be considered by health professionals when caring for this population and requires significant changes in public policies.

The adolescents mentioned that diet was another difficulty in performing self-care. Different behaviors were identified because, for some, understanding the purpose of following the diet is enough to motivate them to follow it, and for others, controlling the diet goes beyond understanding and awareness, and the desire to eat something forbidden increases. The awareness of responsibilities is positive, but the motivations and barriers need to be considered in the supported self-care assessment stage and worked on in the agreement and assistance stages, refining the autonomy for diet control.

A study conducted in the state of Ceará, Brazil, corroborates the findings of this study. The authors found that the dilemma between following the diet and falling into the temptation of eating foods considered inappropriate by health professionals and/or parents is part of the daily lives of adolescents with T1DM. This happens due to the difficulty in facing internal desires and appeals to external stimuli around food, which interferes with their self-control (Fragoso et al., 2019).

Therefore, carbohydrate counting combined with the insulin pump provides a greater sense of food freedom, encouraging glycemic control. This method is used to ensure that 45 to 65% of the total daily calories come from carbohydrates, which helps determine insulin doses (American Diabetes Association, 2020).

As for disease management, the good expectations for the future among adolescents with T1DM are linked to the use of the CIIP. However, access to this technology is dependent on the government. The government should support them by providing the necessary materials because, no matter how satisfactorily the adolescent performs self-care, without the support of the government and the care network, the expected outcomes for disease management may not be achieved due to lack of favorable conditions.

The health team needs to improve attitudes that are already part of daily life, guiding adolescents to take care of themselves and encouraging them to make the necessary changes to their lifestyle, thus empowering them to self-manage their health condition with more autonomy (Fragoso et al., 2019). Nevertheless, given the complexity of the daily care required by the treatment, the support of health professionals, including nurses, to adolescents with T1DM and their families is very important in the process of developing autonomy. Through this support, they will understand the disease better and adopt appropriate attitudes to self-manage their own health.

This study has some limitations, such as the selection of adolescents in only one outpatient unit of reference in the capital city of northeastern Brazil and the small number of participants. Despite this, the qualitative approach used here does not seek to generalize the findings but rather grasp the singularity in the reports of those who participated in the study. In turn, it will bring important contributions related to the factors that may facilitate or interfere with the development of autonomy for self-care in adolescents with T1DM, adding content for the construction of new knowledge about the subject under analysis.

Conclusion

The process of developing the autonomy of adolescents with T1DM begins with their desire to have more knowledge about the disease and treatment to perform their daily care activities. The family and the health professionals play a key role in this construction of health care, helping adolescents achieve cognitive, behavioral, and emotional autonomy and gain confidence in their potential to perform self-care, overcoming the challenges to reach maturity.

These results show that facilitating adolescents' access to technological resources for therapeutic administration promotes behavioral and emotional autonomy. The cost-benefit analysis of the insulin pump - a technology not yet made available to all by the government because of its high costs - shows that its use may translate into savings for the government by increasing adherence to treatment and preventing clinical complications that will put a greater burden on the health system and interfere with the quality of life of these adolescents and their families.

This study helps nurses to better understand what can facilitate or hinder the process of developing autonomy in adolescents with T1DM, and this new knowledge can support the proactive action towards the singularities. Nevertheless, future studies should be developed to identify more promising strategies in supported self-care, which nurses can use to help these adolescents in the process of building their autonomy and resilience mechanisms.

Author contributions

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