

# Children and adolescents with diabetes: educational actions in the development of skills for self-care

**RESUMO** | Objetivo: Analisar o processo de construção de uma proposta de orientação para o cuidado em Diabetes Mellitus tipo 1, a partir de conhecimentos e habilidades em práticas de cuidado de crianças, adolescentes e suas mães. Métodos: Estudo qualitativo, convergente-assistencial, com 16 crianças e adolescentes com diagnóstico de Diabetes Mellitus tipo 1, e suas mães, atendidos em um ambulatório de endocrinologia. Resultados: identificou-se dificuldades similares entre mães e filhos, acerca do conhecimento da doença, e das ações de cuidado. Tal diagnóstico subsidiou o desenvolvimento de intervenções educativas. Conclusão: os participantes não apresentavam conhecimentos suficientes sobre a doença e os cuidados para garantir o controle adequado do diabetes. A construção de proposta educativa proporcionou uma relação horizontal e dialógica entre as pesquisadoras e os participantes.

**Descritores:** Diabetes mellitus tipo 1; Saúde da criança; Saúde do adolescente; Educação em saúde; Autocuidado.

**ABSTRACT** | Objective: To analyze the process of building an orientation proposal for the care of type 1 Diabetes Mellitus, based on knowledge and skills in care practices for children, adolescents and their mothers. Methods: Qualitative, convergent-assistance study, with 16 children and adolescents diagnosed with type 1 Diabetes Mellitus, and their mothers, attended at an endocrinology outpatient clinic. Results: similar difficulties were identified between mothers and children regarding knowledge of the disease and care actions. This diagnosis supported the development of educational interventions. Conclusion: the participants did not have sufficient knowledge about the disease and care to ensure adequate control of diabetes. The construction of an educational proposal provided a horizontal and dialogic relationship between the researchers and the participants.

**Keywords:** Type 1 diabetes mellitus; Child health; Adolescent health; Education in health; Self care.

**RESUMEN** | Objetivo: Analizar el proceso de construcción de una propuesta de orientación para el cuidado de la Diabetes Mellitus tipo 1, a partir de conocimientos y habilidades en las prácticas de cuidado a niños, adolescentes y sus madres. Métodos: Estudio cualitativo, asistencial convergente, con 16 niños y adolescentes con diagnóstico de Diabetes Mellitus tipo 1, y sus madres, atendidos en un ambulatorio de endocrinología. Resultados: se identificaron dificultades similares entre madres e hijos cuanto al conocimiento de la enfermedad y acciones de cuidado. Este diagnóstico apoyó el desarrollo de intervenciones educativas. Conclusión: los participantes no poseían conocimientos suficientes sobre la enfermedad y los cuidados para garantizar un adecuado control de la diabetes. La construcción de una propuesta educativa proporcionó una relación horizontal y dialógica entre los investigadores y los participantes.

**Palabras claves:** Diabetes mellitus tipo 1; Salud de los niños; Salud de los adolescentes; Educación para la salud; Cuidados personales.

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## INTRODUCTION

Type 1 diabetes mellitus (DM1) presents as a progressive process of beta cell destruction, leading to the stage of absolute insulin deficiency. Its presentation is abrupt and, in most cases, marked hyperglycemia rapidly progressing to diabetic ketoacidosis (DKA).<sup>(1)</sup> It mainly affects children and adolescents up to 18 years of age and has an estimated annual increase of 3% to 4% in childhood cases.<sup>(2)</sup>

To ensure the health and quality of life of patients with DM1, adequate care must



be initiated soon after diagnosis, being an ongoing process throughout life and continuously adapted to the needs of each person.<sup>(3)</sup> In addition to the use of insulin, diabetes education is an integral part of treatment and the main tool for ensuring self-care, allowing self-control.<sup>(4)</sup>

The implementation of educational programs in childhood must be planned according to the stages of child and adolescent development. The sociocultural level of families, the individual needs of the patient, family dynamics and experiences with the disease must be considered to achieve the defined objectives.<sup>(5)</sup>

Training and motivation for the education of patients with diabetes and their families must be carried out by multidisciplinary teams, qualified for diabetes education. It is up to the health professional to seek information strategies that help the understanding of the disease and care, helping to overcome barriers that involve self-care and enabling them to be actors in its treatment.<sup>(5-6)</sup>

Nursing, an integral part of this team, often has difficulty in the educational-therapeutic approach to the health of children with diabetes. This difficulty contributes to an insufficient understanding of the disease and its care, causing insecurity in decision-making and in acting in the face of the disease.<sup>(4-7)</sup> Thus, in the quest to promote understanding and changes in behavior in the face of DM1, priority should be given to the use of simple information to ensure that patients assume the practices of survival in diabetes.<sup>(1)</sup>

In this context, there is a need to deepen aspects related to self-care with DM1 in childhood. Thus, the study aimed to analyze the process of building a proposal for guidance for care in type 1 Diabetes Mellitus, based on knowledge and skills in care practices for children, adolescents and their mothers.

## METHOD

This is a Convergent Care Research (PCA) with a qualitative approach<sup>(8)</sup>, using

the General Theory of Self-care as a theoretical framework.<sup>(9)</sup> In order to guarantee the methodological quality, the COREQ (Consolidated Criteria for Reporting Qualitative Research) guideline was used as a guide for its production.

The research was carried out with 16



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children and adolescents, aged between eight and 18 years, diagnosed with DM1 for at least two years, and their mothers. All patients were registered at the Pediatric Endocrinology Outpatient Service of a hospital in southern Brazil and were divi-

ded into three age subgroups (8-11 years; 12-15 years and 16-19 years), with five, nine and two participants, respectively.

The minimum age was established based on studies that indicate that, from the age of seven, children present a gradual development in their physical conditions, social and mental, with emphasis on the development of skills to solve concrete operations, master symbols and classify things, thus presenting themselves as cognitively competent for this type of design.<sup>(10)</sup> The maximum age adopted was considered from the end of adolescence.<sup>(11)</sup>

Exclusion criteria were any condition that could interfere or prevent participation in interviews or educational interventions (diagnosis of mental retardation or cognitive impairment) and individuals diagnosed with DM1 for less than two years. It was considered that, after this period, the patient would have gone through the "Honeymoon" phase, in which temporary remission of the disease may occur (lasting weeks, months and even years) and, therefore, the routine of care for DM1 can be resumed.<sup>(12)</sup>

Data were collected from April to October 2017, through semi-structured interviews, participant observation and carrying out playful and educational interventions. The collection period is justified by the time of carrying out research for a doctoral thesis.

The study was developed in two stages, in the first moment, data collection and data collection were carried out in the medical records (laboratory test results, addresses and telephone contacts). The second stage took place through home visits, which totaled three meetings with each participant, with an average interval of 55 days.

In the first meeting, sociodemographic information was collected, and an individual interview was carried out with the participants, addressing topics related to knowledge about DM1, difficulties and needs for self-care with the disease.

Instruments developed by the researchers were applied, based on the existing

literature on the subject, addressing the following issues: insulin application technique using the pen; application sites (rotation); self-monitoring of Capillary Glycemia (SMCG) and evaluation of its results; recognition of DM1 signs and symptoms and hypo and hyperglycemia correction actions; knowledge and care with food, carbohydrate counting and physical exercise.<sup>(1,3,13)</sup>

In the second meeting, educational interventions were carried out, in a participatory way, addressing the topics relevant to all the care previously described. The themes were prepared and worked with each binomial, according to the need perceived in the previous approach, respecting the age group and the ability to understand.

In the third meeting, a review of previous meetings was carried out, addressing the topics discussed and worked on in the interventions. Thus, we sought to capture the knowledge acquired by each participant and return to the necessary care guidelines that were not fully understood by the participants. The perception of each of the educational interventions carried out was also addressed in an instrument developed by the researchers for this purpose and completed by the interviewees.

In the implementation of educational actions, practical/playful activities were used, respecting the sociocultural and economic conditions of most participants. The strategies used were toys, illustrative figures, videos, PowerPoint presentations, printed materials, instruments for the use of insulin.

The content of the materials used for the educational activities was equivalent for all participants, but with age-appropriate language. For children aged up to 11 years, the resources used were in the form of toys and games, while for adolescents aged 16 to 18 years, videos, pictures and printed material were presented. For participants aged between 12 and 15 years old, both types of approaches were used, according to the understanding of each one, evaluated by the researcher at

the time of the activities. The printed materials used in the interventions were compiled into a personalized handout, delivered to each child and adolescent at the end of the study.

The interviews and all the moments of the meetings were recorded in a digital file and later transcribed in full. At each meeting, notes relevant to the investigation were made in a field diary.

Data analysis was performed following the steps of the qualitative analysis suggested by PCA, which are apprehension; synthesis; theorization and transfer, aiming at the future socialization of the results.<sup>(8)</sup> All material collected, at all times with the participants, was transcribed and went through phases of intense reading, which later gave rise to the units of meaning that supported the coding process.

For the presentation of the study results, the participants were identified as E (school children - 8 to 11 years old), AJ (young adolescent - 12 to 15 years old) and A (teenager - 16 to 18 years old), followed by the number representing their age in ascending order, among the other participants in their age subgroup. Mothers were identified by C (caregiver), followed by the letter and number corresponding to their child. The study was approved by the Institutional Standing Committee on Ethics in Research with Human Beings (COPEP), under CAAE: 17652413.8.0000.0104, and approval opinion no. 2,364,261/2017.

## RESULTS

In the group of schoolchildren, three were female and two were male, the average time of diagnosis discovery was 4.6 years, and they had an average of 3.6 years of outpatient follow-up. In the group of young adolescents, five were female and four were male, the average time to discover the diagnosis was 4.9 years and they had 4.7 years of outpatient follow-up. In the group of adolescents, there were two boys with a mean time of diagnosis and outpatient follow-up of seven years.

After the data analysis process, two

thematic axes were arrived at: "The knowledge of children, adolescents and their mothers about DM1"; and "Care actions with DM1 and the difficulties faced in managing the disease". Based on each of the categories, the educational interventions carried out with the participants were developed.

### The knowledge of children, adolescents and their mothers about DM1

The first thematic axis demonstrated the participants' perception in relation to DM1. It was supported by the following categories: "Limited knowledge about DM1" and "Restricted perception of damage caused by DM1 in the long term".

The category "Limited knowledge about DM1" emerged in the first interview with the participants, when they were asked about their understanding of the disease. Among the schoolchildren's mothers and the two groups of adolescents, most had difficulty talking about the disease, denoting a superficial knowledge about DM1, its causes and consequences, while the others (adolescents) had a slightly clearer understanding. About the subject:

I know it's his pancreas that can't capture the sugar he sends to the body, it doesn't dissolve the sugar, his pancreas is stopped, and that's why the insulin stops digesting this sugar. (CAJ3)

Regarding the category "Restricted perception of damage caused by DM1 in the long term", when participants were asked about adverse situations of the disease, despite reporting that uncontrolled diabetes can produce damage, they demonstrated not having sufficient knowledge about its complications.

You can go blind, have your kidneys damaged, give something to an injured person. (A2)

Faced with the perception of the par-

participants' lack of information about DM1 and its complications, an educational material was developed that sought to meet the objective of guidance on these topics. For this activity, a playful explanatory material was used, enabling the manipulation of the instrument and the active participation of children and adolescents during the interventions, in addition to a presentation aimed at the three age groups, with illustrations and guidelines.

### Care actions with DM1 and the difficulties faced in managing the disease

The second axis was supported by five categories that represent the care needed to maintain the health of patients with DM1: "Hypoglycemia and hyperglycemia: prevention, recognition and management"; "Use of the pen and the rotation in insulin applications"; "SMCG: importance of technique and data recording"; "Recognizing healthy foods and understanding carbohydrate counting"; "Physical activity and its importance in diabetes management".

In the category "Hypoglycemia and hyperglycemia: prevention, recognition and management", all the mothers of the schoolchildren mentioned their children's difficulty in recognizing the symptoms of hyper and hypoglycemia, reporting, on average, two symptoms for each occurrence. Two children did not report symptoms of hyperglycemia, according to their mothers' reports.

Young adolescents and adolescents reported recognizing, on average, three symptoms for both hypo and hyperglycemia, namely sweating (50%), tremors (43.7%) and skin pallor (25%) for cases of hypoglycemia and polyuria (50%), polydipsia (37.5%) and tiredness (25%), associated with cases of hyperglycemia.

I've already had a blood glucose level of twenty something, but I don't feel anything very strong, just dizziness and I'm shaking [...]. (AJ3)

Most of the schoolchildren's mothers (80%) reported that, for the correction of hypoglycemia, sweetened solid foods, dairy products and chocolate were offered. Only one mother referred to the correction of blood glucose with water and sugar, but she was not able to specify the amounts used. For the correction of hyperglycemia, they used pre-defined doses of insulin, according to the blood glucose values.

As for blood glucose corrections, performed by young adolescents and adolescents, 54.5% said they corrected hypoglycemia through the consumption of sugar water and soft drinks, but only one used the recommended amount. In hyperglycemia, the majority (54.5%) used insulin for correction, according to the values defined by the carbohydrate calculations, 18.2% followed a pre-established table for blood glucose values and 27.3% of them applied insulin without performing any type of calculation, using their experience in corrections as a basis.

When it's low (glycemia) I eat fruit, honey, milk, chocolate. I don't even need to measure it before, I already know it's low and when it's high I take insulin, when it's more than 350. (AJ7)

The omission in the application of insulin, during the school period, proved to be a common habit among the participants of the present study, reported by 80% of the mothers of schoolchildren and by 82% of the adolescents of both age groups who also stated that they omitted insulin at other times besides the school period.

I sometimes forget to take insulin. My mother says this is going to be a problem. I forget sometimes in the afternoon. When it's nighttime, at dinner, it's usually high. (AJ1)

In the interventions and guidance on

acute complications, pictures and written materials were developed for the two groups of adolescents, which were read and discussed with the participants, enabling guidance on glycemic changes.

In the category "Use of the pen and the rotation in insulin applications", the participants performed only some of the standardized actions for the application of insulin with the use of the pen.

I use the needle a couple of times... I don't count to ten, just a lot sometimes... I find it difficult for me to wash my hands to make the insulin. (A2)

As for the rotation of insulin application points, for most participants (94%), there was no prior planning for its execution and, although 32% stated that they performed the rotation, they did not establish a sequence for this action.

The locations of choice were determined according to situations such as practicality, location preference or the amount and characteristics of insulin. In order of preference, they were reported as follows: abdomen, arms and thighs. Application to the buttocks was cited as an option in cases of higher doses. Lipohypertrophy was reported by 75% of participants, in different parts of the body.

Her arm is even atrophied, stiff, dry from doing so much in the same place. Before changing doctors, no one had ever told me that I had to change the place. It was seven years in the arm alone. Now I try to change places, but I do it my way. (CAE2)

For the educational approach on this topic, an instrument developed by the researchers was applied, containing the steps common to the use of insulin pens. In the interventions with the students, a doll and the materials necessary for the application of insulin were used. For the two groups of adolescents, an instrument



was also developed to mark the preferred locations for applications and a tool to help guide the relay and understand the application locations.

In the category "SMCG: importance of technique and data recording", although the performance of this care was reported by all participants, difficulties were observed in its conduct, both on the part of children and adolescents, as well as mothers.

The average SMGC was 5.4 tests a day among schoolchildren, 4.2 for young adolescents and 4 times a day among adolescents. During school hours, tests were performed by only 25% of participants (1 school, 2 young adolescents and 1 adolescent).

I don't take the device to school because it's embarrassing. [...] everyone will see it. (AJ9)

The results of the glycemic monitoring tests were not recorded in the "record map", immediately after they were performed, by any of the participants. Most of the schoolchildren's mothers reported taking notes at the end of the day (80%), 55.5% of the young adolescents took them daily and one of the adolescents stated that they filled in the record map only close to the appointment, consulting the values stored in the glucometer.

In the last few months I think I've only done about three checkups a day. I don't mark anything on my map. I only schedule before going to the doctor. (A2)

During the interventions that addressed the importance and technique of SMCG, the lancing pen and other materials for hand antisepsis were used as educational materials, in addition to some drawings printed on paper.

In the category "Recognizing healthy foods and understanding carbohydrate counting", it was found that the control of the schoolchildren's diet was carried out exclusively by the mothers and 80% of

them mentioned difficulty in controlling the child's food. As for the carbohydrate calculation, 40% reported not knowing how to count.

Among young adolescents, 55.5% reported knowing how to count carbohydrates and, in the case of adolescents, food control and carbohydrate counting were performed by only one of them (50%).

I don't do carb control. I've heard of it, but I don't know how to do it. You have to see it on the internet, but not here. I had to find a way to know how to do it. (CE2)

My mother does the carbohydrate calculation for me. I don't even remember how she does it, there's so much counting that needs to be done! Do you think I will remember? (AJ8)

Among the study participants, 81.2% reported difficulties in controlling the diet, exceeding daily carbohydrate doses stipulated for meals, resulting in hyperglycemia throughout the day.

The educational activities were carried out with the students in a playful way, with toys and figures that referred to food and kitchen instruments. With adolescents of both age groups and their mothers, the intervention took place through discussions about healthy eating and the use of a table for counting carbohydrates. A food diary was developed and used in the interventions for 31.2% of the participants.

In the category "Physical activity and its importance in controlling diabetes", it was observed that, among the participants of each age group addressed, only 37.5% practiced some type of physical activity with a defined routine, as follows: 20% of students; 44% of young adolescents; and 50% of adolescents.

He [...] does Muay Thai three times a week. Runs, plays all day. (CE1)

In the interventions on the subject, discussions were held with the adolescents, highlighting its importance. The material used presented guidelines for the proper execution of activities, avoiding hypoglycemia due to the exercises.

In order to get to know the participants' perception of the educational interventions carried out, all were asked to answer the questions referring to the topics addressed. The interventions highlighted as positive were presented as follows: insulin application and rotation (93.8%); guidance on DM1 (75%); SMCG and records (68.7%); feeding and counting carbohydrates (56.2%); physical activity (43.7%); recognition of signs and symptoms and correction of hypo and hyperglycemia (31.2%).

I'm now pricking my finger and I've already started injecting my leg with insulin. I will make you (researcher) and my mother proud. (E2)

I understood that rice and beans is a spoon and salad can eat a lot. (E5)

I think that everything you explained to me, [...] every time I apply insulin, it seems like I imagine it going [...] until today, every time I apply it, it seems like I feel the insulin working. (AJ3)

## DISCUSSION

The participants of the present study had limitations in their knowledge about the disease, as observed in other studies and, although they claim to have already sought information about the disease, they were not able to discuss it.<sup>(14-15)</sup>

The acute complications of diabetes are responsible for a large part of the mortality of these patients and for the poor quality of life.<sup>(3-4)</sup> The maintenance of high blood glucose levels can lead to chronic complications such as diabetic retinopa-

thy, nephropathy and neuropathy, which are micro and macrovascular implications, developed due to disease. <sup>(1)</sup>

Recognition of blood glucose fluctuations is important as they require prompt treatment. Severe hypoglycemia can trigger seizures and lead to death, and hyperglycemia is directly related to the incidence of acute and chronic complications. Therefore, glycemic control becomes fundamental in diabetes care. <sup>(16)</sup>

Higher blood glucose targets are accepted for adolescents than for adults. This occurs for this age group because adolescents have greater difficulty in controlling their glycemic levels, both because of their physiology and the behavioral challenges inherent to age. <sup>(3, 16-17)</sup>

Lipohypertrophy was reported by 75% of participants. This result is quite significant, especially considering that data on this complication, which is the most common complication of insulin therapy, occurs in approximately 50% of all patients with diabetes. <sup>(17)</sup>

Although there have been advances in technology with the use of insulin delivery pens and the use of increasingly thinner and shorter needles <sup>(17)</sup>, it was observed that the participants face situations that hinder the correct technique for care.

Our results regarding preferred locations for insulin application corroborate another study on the health of adolescents with diabetes <sup>(14)</sup>, and follow the standards recommended by the Brazilian Society of Diabetes, which determines the abdomen, flanks, buttocks and thighs as suitable places, and should be away from joints, bones, large blood vessels and nerves. <sup>(12)</sup>

In the results of the present study, it was observed that all the interviewees reported performing the SMCG throughout the day, unlike previous research with adolescents, in which 12.3% of them reported not performing the tests. <sup>(14)</sup> However, the daily frequency of our participants' checks was lower.

The person with DM1 and their caregivers must understand the importance of this care to monitor and prevent asympto-

matic hypoglycemia and hyperglycemia. Tests should be done frequently throughout the day, and some patients may need six to ten tests in this period. <sup>(12)</sup>

In the case of children, control should



[...] the process of building an educational proposal with the setting of the home itself provided a horizontal and dialogic relationship between the researchers and the participants, valuing the listening and the knowledge of the caregiver and the patient.



be more frequent due to their glycemic instability and difficulty in recognizing and reporting symptoms. With the evolution of cognitive and physical development in childhood, they become more cooperative and, although they still need constant supervision from the caregiver,

they should already be included in this care. <sup>(3)</sup>

Although in adolescence the young person is already capable of self-care, due to the behavior of cognitive and physical development, it is a phase of greater risk of severe glycemic fluctuations or DKA, since they occur more frequently, the neglect of care and the greater lack of control of these levels. However, it is important to note that improved glycemic control decreases long-term complications of diabetes in adolescents. <sup>(10)</sup>

Difficulty in food control in childhood and adolescence has also been reported in previous studies, interfering and impairing the control of DM1. <sup>(13,18)</sup> To obtain glycemic levels closer to the goals, the nutritional approach must be individualized, with a food plan based on food preferences and the type of activity performed by the individual.

Although physical exercise brings many benefits to patients with DM1, it represents a challenge due to the increased risk of hypoglycemia <sup>(16)</sup>, that can occur during and after the activity, or even have a late effect that can last several hours. <sup>(19)</sup> Therefore, care guidelines to avoid the undesirable effects of physical exercises in patients with DM1 are extremely important. <sup>(15,20)</sup>

Using interactivity and the practice of care activities in a playful way, it is possible to assess the significance that the child gives to the topic related to diabetes. <sup>(3)</sup> In the case of adolescents, communication should be based on the use of more recent technologies, which have shown, in addition to expanding knowledge about DM1, greater acceptance of aspects related to self-care and psychosocial well-being. <sup>(13)</sup>

#### STUDY LIMITATION

The fact that it was carried out in only one reference outpatient clinic and the collection took place in 2017 induced limitations to the study, however, it exposes important information about knowledge and skills in the management of DM1,

strengthening knowledge on the subject, in addition to equipping the participants for the autonomy of childhood care through knowledge.

#### CONTRIBUTIONS TO PRACTICE

The study contributes to nursing practice by supporting strategies that facilitate these children and adolescents and their caregivers to take care of themselves and others, in an efficient and individualized way, respecting the different stages of

child development, characteristics of their own environment, and encouraging adaptations of the health education process to the conditions of each family.

#### CONCLUSION

Most of the participants did not have sufficient knowledge about the disease and the care that could guarantee adequate control of diabetes. The main difficulties were related to insulin injections and rotation at the application sites. Most parti-

cipants did not perform daily insulin and SMCG records.

It was found that the educational actions carried out were perceived as positive for most participants. It was also observed that the process of building an educational proposal with the setting of the home itself provided a horizontal and dialogic relationship between the researchers and the participants, valuing the listening and the knowledge of the caregiver and the patient.

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