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TYPE 1 DIABETES MANAGEMENT: SELF-MANAGEMENT SUPPORT NEEDS IN THE TRANSITION TO ADOLESCENCE

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ABSTRACT: To analyze the self-management support needs for the type 1 diabetes management in the transition from childhood to adolescence. This qualitative research was mediated by semi-structured interviews with nine prepubescent children attended at an outpatient clinic and Family Health Units in Paraíba between September and December 2016. The data were interpreted by thematic analysis. Prepubescent children need knowledge for the administration and management of the disease in the spaces they audit, in addition to family and social media support in the transition of care. The multidisciplinary health team has not used singular self-management support in the management of diabetes, and that of primary care has not accommodated their needs, weakening bonds with the care network. Diabetes self-management needs refer to knowledge of the disease and relationships established with social support networks such as family, multidisciplinary team, and school.

KEY WORDS: Self-management; *Diabetes Mellitus*, Type 1; Adolescence; Childhood; Nursing.

GESTÃO DO *DIABETES* TIPO 1: NECESSIDADES DE AUTOCUIDADO APOIADO NA TRANSIÇÃO PARA ADOLESCÊNCIA

RESUMO: Analisar as necessidades de autocuidado apoiado para a gestão do *diabetes* tipo 1 na transição da infância para adolescência. Pesquisa qualitativa mediada pela entrevista semiestruturada com nove pré-adolescentes atendidos em ambulatório e Unidades de Saúde da Família da Paraíba entre setembro/dezembro de 2016. Os dados foram interpretados pela análise temática. Os pré-adolescentes necessitam além do conhecimento para o manejo e a gestão da doença nos espaços que frequenta cotidianamente, do apoio da família e da rede social na transição do cuidado. A equipe multiprofissional de saúde não tem utilizado o autocuidado apoiado singular na gestão do *diabetes* e a da atenção primária não tem acolhido suas necessidades, fragilizando vínculos com a rede de cuidados. As necessidades para o autocuidado no *diabetes* versam sobre conhecimento da doença, e as relações estabelecidas com a rede de apoio social como a família, equipe multiprofissional e a escola.

PALAVRAS-CHAVE: Autocuidado; *Diabetes mellitus* tipo 1; Adolescência; Infância; Enfermagem.

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INTRODUCTION

The transition from childhood to adolescence is an important period in relation to physiological, sexual, intellectual, psychological, and social transformations, which will make individuals rebuild their ideas, thoughts, image, and perception about themselves[1]. In this phase, the experience of developing a chronic disease such as type 1 diabetes (1DM) can be a period of risk in relation to the treatment and quality of life of individuals. In addition to self-management needs, there is also transition from family-centered care to shared management with prepubescent children[2].

1DM management is characterized by the way individuals perform drug treatment, glycemic self-control, exercise, diet, hyperglycemia and hypoglycemia management, family and social support, as well as understanding what the disease is and the reason why following each orientation to achieve quality of life[3].

During the transition phase of the 1DM management by families to improve self-management of prepubescent children there are imbalance factors in the management plan such as forgetful administration or error in insulin dosage, low frequency of physical exercise and lack of knowledge about the disease. The aforementioned are closely linked to adolescence and its modifications, resulting in non-compliance of prepubescent children with the 1DM management plan, characterized by low glycemic control and, consequently, high rate of episodes of hyperglycemia and/or hypoglycemia[4].

Therefore, in this process of transferring the 1DM management between parents and children, it is necessary that the transition be made through monitoring, training, and division of responsibilities agreed between the prepubescent, the family, and the health team, which allows to identify the self-efficacy and autonomy degrees of prepubescent children[5]. This 1DM's self-efficacy refers to the set of cognitive abilities that individuals build throughout life to perform actions and achieve certain results, such as effective glycemic control[2].

In view of the imminence of prepubescent children taking ownership of the plan's 1DM management, there is a need of support in this process for an adequate transition of care. In this regard, the self-management support method gives the necessary support to meet this demand by advocating continued care and developing a close relationship between users and health teams. They will work together to define problems and goals, establish a care plan and monitor it so that adjustments are made when necessary[6].

This chronic disease care has five phases called 5 A's: assessment – identifying knowledge, behaviors, social life, and health history; advice - sharing constructive information and health education; agreement - joint formation of self-management plan; aid - identification of barriers, material, social resources and search for solutions to problems; assistance- definition of the most effective form of assistance according to the patient's profile[6].

Although the two transition phases, life cycle and responsibilities with care, can cause meaningful changes in the life of prepubescent children with 1DM, there are few Brazilian studies that present the needs related to this age group in relation to knowledge of the disease, parental support, family, multidisciplinary team, educational actions and acceptance in school inherent to prepubescent child care with 1DM.

In view of the above, the question was: How is the way to support the 1DM management for prepubescent children in the transition phase regarding self-management? To answer this question, the aim of this study was to analyze the self-management support needs for the 1DM management in individuals in transition from childhood to adolescence.

METHODOLOGY

This qualitative and exploratory-descriptive research was based on the Self-Management Support theoretical framework[6]. Data collection occurred between September and December 2016 in Family Health Units (FHU) belonging to each of the five Health Districts (HD) of a large city of the State of Paraíba and in the pediatric specialty outpatient clinic of a public teaching hospital, whose participants were prepubescent children with 1DM.

FHU selection occurred through random active search of the HD units, through previous contact with the local health team, which aimed to identify the register of prepubescent children with 1DM. In the respective units that

had this profile of registered users, access to participants was made possible by scheduling the interview at home by the Community Health Agent (CHA), who accompanied the researcher to the site. At the teaching hospital's outpatient clinic, prepubescent children were approached at the time of waiting for consultation, and may be registered users in the coverage area of any FHU in the State of Paraíba.

Concerning participant selection, the fundamentally biological period of developmental acceleration between 10 and 14 years old was considered prepubescent (WHO, 2015)[7]. To include prepubescent children, the following criteria were used: having a diagnosis of 1DM; being between 10 and 14 years old; being accompanied by an adult family caregiver. It should be noted that the interview was private. Participants who presented cognitive and/or communication impairment and caregivers who were not at home on the day scheduled for the interview were excluded, resulting in a total of nine participating prepubescent children.

The semi-structure interview was the technique chosen for data collection, guided by the questions: Who helped you in this process of self-management with 1DM? How was that help? To support the understanding of the participants' life context, other information involving socioeconomic and demographic conditions was also collected.

The interviews were recorded in electronic media, with an average duration of 60 minutes, being transcribed in full. The collection was ended due to theoretical saturation, so that the inclusion of new interviewees would not bring new concepts on the theme and the aim of the study had already been achieved[8].

The empirical data were interpreted by thematic analysis9, effected in three stages: pre-analysis, in which repeated and exhaustive readings of all interviews were performed until full knowledge of the content; exploration of the material, in which there is codification from the clipping of the text in record units that brought response to the objective of study, with subsequent grouping of more significant words and expressions for the construction of themes and categories to facilitate analysis; interpretation of results, obtained through the comparison of the material with the existing literature. Thus, at the end, the analysis resulted in the Nuclei of Meaning "Self-management support needs by the 1DM management plan", and its categories: Knowledge for the management plan construction; Multidisciplinary health team support to the 1dm management plan; Provision of favorable conditions for the 1DM management.

The Brazilian National Health Council (Conselho Nacional de Saúde)'s Resolution 466/12 guided the study. The Research Ethics Committee of the Center for Health Sciences of the Universidade Federal da Paraíba - REC/CHS/UFPB approved the study, under Protocol 054/14 and CAAE (Certificado de Apresentação para Apreciação Ética - Certificate of Presentation for Ethical Consideration) 27102214.6.0000.5188 of July 21, 2016. To conduct the interview, the Informed Consent Term (ICT) was signed by family caregivers, and the Consent Form by minors. To ensure participant anonymity, the acronym "PP" was used for prepubescent, followed by the chronological number of the order of the interview and the participant's age.

RESULTS

Charts 1 and 2 show the characterization of the nine study participants and then the presentation of the thematic categories.

Chart 1. Characterization of prepubescent children regarding age, sex, education, time of diagnosis, and complications, João Pessoa - PB, Brazil, 2016

Participants	Age	Sex	Education	Time of diagnosis	Complications
PP1	12 years old	F	7th year of ES*	4 years	-
PP2	10 years old	M	5th year of ES*	6 years and 6 months	-
PP3	11 years old	M	Illiterate	8 years	-
PP4	14 years old	F	9th year of ES*	3 years	Abnormal renal function
PP5	14 years old	F	9th year of ES*	2 months	-
PP6	13 years old	F	8th year of ES*	4 years	-
PP7	10 years old	M	5th year of ES*	6 years	-
PP8	13 years old	M	8th year of ES*	4 months	-
PP9	11 years old	F	6th year of ES*	1 year and 5 months	-

Source: Research data, 2016

ES= elementary school.

Chart 2. Characterization of prepubescent children regarding hometown, caregiver's education, health insurance, and frequency of visit at FHU, João Pessoa - PB, Brazil, 2016

Participants	Hometown	Caregiver's education	Health insurance	Frequency at FHU
PP1	João Pessoa	Incomplete ES*	-	Once every 4 months
PP2	Pedras de Fogo	Incomplete HS*	-	Twice every 3 months
PP3	Duas estradas	Illiterate	-	Twice every 3 months
PP4	João Pessoa	Complete HS*	Yes	Do not attend
PP5	João Pessoa	Complete HS*	-	Twice every 3 months
PP6	João Pessoa	Complete HE*	-	Twice every 3 months
PP7	João Pessoa	Incomplete HS*	-	Do not attend
PP8	João Pessoa	Incomplete HS*	-	Twice every 3 months
PP9	João Pessoa	Complete HS*	-	Twice every 3 months

Source: Research data, 2016.

ES= elementary school; HS – high school; HE – higher education.

KNOWLEDGE FOR THE MANAGEMENT PLAN CONSTRUCTION

The daily life of prepubescent children begins to have new responsibilities that require, especially in this transition phase, greater participation in care.

> *When I wake up in the morning, the first thing I do is take the insulin. Before I check the glucose, because if it is too low I already decrease the dosage, but my established is 24 units of Lantus. Then, after I check the glucose and take the insulin, I go to school normally.* (PP4, 14)
> *In the morning before I go to school, I take Lantus, then I eat, and every time I eat, I fix the dosage by taking Novorapid, it's just these two. And at night, I eat and fix the dosage with Novorapid.* (PA6, 13a)

In view of these changes, daily care for glycemic control begins to be assumed by prepubescent children competent for their self-management.

> *I apply insulin in myself, I apply in the belly, in the arm, I always change places. I take the cotton with alcohol and I do not need to perform that "amount" [skinfold] to apply because the needle is already small. Then, I wait for the next dosage and 10 seconds [to apply all insulin]. If you insert it in any vessel, blood can come out, but if you don't get it right, it won't come out.* (PP4, 14)
> *I measure four fingers then I hold the skin and apply it to the leg, arm or belly. I do everything myself now. (PA5, 14a)*

This increasingly effective participation in care during the transition phase arises from the will of children with 1DM to have autonomy in relation to their parents and the need to follow the treatment correctly.

> *I have always felt the desire to learn, because who only applied the insulin at home was my mother, then when she went out, nobody would apply. Then, I wanted to learn, so when she went out I would know how to do it myself.* (PA7, 10a)

However, many prepubescent children presented fragile knowledge, little access to information or lack of understanding about the disease and its consequences.

> *I know that diabetes is a disease that makes people feel stuff. Then, afterwards, I don't know anymore.* (PP3, 11)
> *I wanted to know how to eat right, what diabetes can cause. I think. I think if I had more knowledge, it would be more controlled.* (PP8, 11)
> *When I'm feeling sick, I don't know what's happening to me, I know it's because of diabetes.* (PA1, 12a)

The knowledge of prepubescent children in relation to complications was constructed based on previous experiences.

> *When the glucose is low, I keep shaking, then I check the blood glucose and I eat a candy. When it's high, I have a headache, then I check too and I take insulin.* (PA9, 11a)

The superficial understanding of some prepubescent children about the importance of diet for glycemic control evidences the need for support for the development of self-management.

> *I know that eating wrong things can increase diabetes, but I know that the disease is not only related to sweets. I can't quite explain, but it has to do with food.* (PA8, 11a)

FAMILY SUPPORT IN THE TRANSITION PHASE OF CARE

In the transition of care initial phase, mothers are generally recognized as the main support of the prepubescent. Mothers bring safety to the performance and teaching of practices, leaving them confident to develop their responsibilities with the management plan.

> *My mother helped me a lot with my nervousness when I went from syringe to pen [...] my mother taught me mainly because she is with me always and I saw her doing it.* (PP8, 11)
> *My mother helped me by explaining how to do it... the times and doses so I can go out and do it myself. She is also instructing not to apply too much insulin or too little, always pay good attention to the dose.* (PA6, 13a)

Nevertheless, the transition phase to self-management can also be influenced by several factors that surround the family environment, such as socioeconomic situation, low level of education of caregivers and deficit of cognitive ability of family members.

> *My mother doesn't know what diabetes is. She doesn't know how to apply [insulin]. I feel bad [...] then my mother takes me to her friend's house to take insulin.* (PA3, 11a)

In this sense, there are determinants that concern family control such as the financial difficulty to buy specific foods for diabetics, constituting an obstacle that weakens family support.

> *[...] 100 bucks to buy food for those who are diabetic is nothing. (PP4, 14)*
> *Sometimes my mother is unable to buy the things for me that I want, my vegetables, fruits.* (PA1, 12a)

The family plays a fundamental role in food restructuring and in creating ways to reduce the desire to eat sweets, supporting prepubescent children in controlling their eating habits.

> *My mother helps me a lot in feeding. She puts everything in the right amount [...]. My aunt helps me too. When my food is missing, she comes and buys it.* (PP9, 11)
> *My father is picky, keeps an eye on my food 24 hours. He eats along with me and keeps saying that lasagna-like foods are sour [laughs]. Then I end up accepting and even having other options, I eat only what I can.* (PP4, 14)

However, sometimes excessive demands of the family in relation to sugary foods, whose consumption was previously commonplace and now represent a prohibition, can cause the prepubescent to omit some facts involving their food, especially when they have been living with the disease for some time and have acquired prior knowledge to prevent complications and awareness that are co-responsible for their self-management.

> *I ate once hidden, because my mother wouldn't let me eat candy so I had the opportunity to buy, I ate and corrected. But I've never been sick because of it.* (PP6, 13)

To overcome the daily desires in relation to diet, strategies are created by both the prepubescent and the family.

> *Sometimes I feel uncontrollable desire to eat candy, sometimes it's not a candy, it's a popcorn. Then, I leave not to feel like eating it anymore, I come out the house and eat a fruit I like.* (PP9, 11)
> *When I go to a party, my mother always takes crackers so I don't eat sweet things*. (PP1, 12)

MULTIDISCIPLINARY HEALTH TEAM SUPPORT TO THE 1DM MANAGEMENT PLAN

The support provided by professionals together with families favored a greater and better understanding of the disease.

> *At first my mother and I researched a lot about diabetes. The doctors and nurses [from the referral outpatient clinic] also helped my mother to know about it. Nowadays, she knows everything she does, how to treat, the risks [...] and she teaches me, the doctor helps me with doses and monitoring of blood glucose. Nurses help me to monitor blood glucose, how to control it, always showing how important it is to control blood glucose.* (PP6, 13)

The health professional in the Self-Management Support agreement phase can collaborate by creating strategies for compliance with the 1DM management plan.

> *My mother said the doctor said that when I wanted to eat the candy, she'd take a piece of nothing for me to eat, then I feel happy.* (PP1, 12)

However, care and guidance provided by FHU professionals for some prepubescent children were not sufficient to meet their needs.

> *At the FHU they do not give information about food [...]. I tell my mother that I wanted better guidance of what I can and can't eat to get better from diabetes.* (PP1, 12)
> *When I go to the FHU, almost no one helps. I would like someone from FHU to help me more in feeding, guiding me even in what I can and cannot eat.* (PP9, 11)

Moreover, the fragility in carrying out home visits and in the resolution of demands reflect negatively in the maintenance of the bond with the health unit and with the care network.

> *When I go to the health care center [FHU], there is no care, doctors do not come or do not attend people. They leave it for another day, then when there is, they would say they had to talk to my doctor from the hospital. And no one goes to my house either.* (PP1, 12)

SCHOOL IN THE PROVISION OF FAVORABLE CONDITIONS FOR THE 1DM MANAGEMENT

In the transition phase, children still have no safety of management in the face of complications. Schools should offer favorable conditions for management, in view of being the place where children spend time of their day living with people and situations different from those that occur in the family nucleus.

> *My mother has often been asking at school to send natural snacks, but she never did. It's really hard that way.* (PP4, 14)

The presence of people at school who know that the prepubescent child has 1DM is essential to avoid future damage to their health.

> *When I feel bad at school, when it is low or high, they do not know how to do anything, so they tell me to call my mother and give me medicine for headache. Once the principal did not believe me, then I was drinking water to feel better, because she did not let me go home. When I arrived, blood glucose was high.* (PP9, 11)

In this sense, strategies were indicated by prepubescent children to solve these problems of the fragile knowledge of people at school about the disease.

> *I would like the nurse [from FHU] to come to my school to talk about diabetes and rearrange the food there. At my friend's school, the nurse went there and helped her a lot.* (PP9, 11)

In relation to diet, it is influenced by friendships built at school, whether they are through support or not in carrying out health maintenance actions.

> *My friends don't know what diabetes is, but they don't give me candy because they know it's bad for me.* (PP2, 10)
>
> *My friend helps me always being careful to go to the cafeteria to see what I can and cannot eat.* (PP9, 11)
>
> *My friends offer candy even knowing I have diabetes, but I do not accept [...] it is very hard to control.* (PP8, 11)

DISCUSSION

Self-management support needs by prepubescent children to develop an effective 1DM management plan were related to knowledge about disease management, family support and its implications for self-management development, in addition to support of the multidisciplinary team and support network, including schools, because it is an environment where prepubescent children spend much of the day.

In this transition phase, the family plays an important role in the co-responsibility of the DM1 management plan of prepubescent children, since it will need long-term care, which will modify their daily life and that of their family, such as the incorporation of recurrent consultations, hospitalizations, medication schedules, specific care, and changes in daily conducts[10].

The management plan for insulin-dependent people is complex, both in children and adolescents, as it requires constant monitoring of blood glucose level, knowledge of signs and symptoms of hypoglycemia and hyperglycemia, and daily application of insulin with support for this self-management from the family, close people, and professionals through health education[11].

Given the need to manage their own care in the 1DM management plan, prepubescent children had to introduce new activities and responsibilities in their daily lives such as knowing the correct times of insulin application, different types and dosages, how to apply them and how to perform the blood glucose test, in addition to food control.

In this process, self-management support is fundamental. When the blood glucose test and insulin application begin to be part of the daily activities of prepubescent children, it is necessary to assess through observation the performance of the procedure to later advise them to feel safe in these activities, establishing

an agreement with care actions and accompanying them until they have autonomy to perform it.

The management of this need is influenced by the maturity and understanding of this process that varies according to current age, time of diagnosis, intellectual level of prepubescent children and their family[12]. Nevertheless, these factors will significantly influence their degree of autonomy. On the other hand, the possible or necessary changes in habits, in order to reach maturity and understanding this care, should be worked on in the assistance phase.

However, it is worth highlighting the need for this process to be initiated from the moment the children can develop their cognitive skills (self-efficacy) and care for the 1DM management plan[13]. In other words, prepubescent children will take over their self-management according to their individual conditions to manage and develop it.

In most families, mothers play a very important role in supporting self-management, especially in insulin application and blood glucose testing[14]. Corroborating this assertion, they were identified as a source of confidence for prepubescent children, leaving them safe to perform procedures for monitoring and glycemic control, developing the necessary responsibility for self-management. Another study[15], conducted with adolescents, also points out that issues related to relationship with parents, family dynamics and social support offered to adolescents with 1DM can influence the process of complying with treatment as well as the construction of autonomy. In this sense, health professionals need to focus their actions on the principle of co-responsibility in the face of self-management support by prepubescent children with 1DM and their families.

These actions consist of observing the family dynamics and knowledge about the 1DM management in the assessment phase. They promote health education through constructive information in the advice phase, establish an agreement that helps mothers and children in this transition of care, provide assistance whenever necessary and follow-up to monitor the success of this dynamic amid the challenges of 1DM according to the uniqueness in each specific situation or meeting of care.

The confidence and independence achieved by participants to perform care started from the need imposed by the disease and from the family demand in the daily construction of this process according to the maturity of prepubescent children.

Although the dependence on family help is still present in the transition from childhood to adolescence, through support and follow-up to the management of care inherent to the 1DM management plan, it decreases over time and builds an empowerment of individuals that tend to generate autonomy for self-management. In this sense, autonomy construction is not related to the time of diagnosis of 1DM, but with the appropriation of the disease management by prepubescent children.

Additionally, it was evidenced that the 1DM management plan can also be influenced by socioeconomic factors that surround the family environment. Corroborating this finding, studies[16,17] state that the socioeconomic situation of the family, caregivers' low education level, and the deficit of cognitive ability of family members and people close to children with 1DM influence and sometimes hinder the establishment of an effective self-management.

In this study, low education level of mothers was an obstacle to the acquisition of knowledge and skills necessary to understand the disease, demands of care and treatment, hindering the process of understanding self-management by prepubescent children. This situation greatly influences the management of emergencies and may interfere in future with complications resulting from the disease.

A study states that the cultural capital of prepubescent children suffers strong domination of their parents, being built, in general, according to the encouragement received from them[18]. In this study, many interviewees presented evidence of fragile knowledge, little access to information or lack of understanding about the disease and its consequences. It was evidenced the need for self-management support by health education strengthening in the advice phase for a more solid construction of this knowledge and follow-up to monitor self-management actions.

As for diet, families often have economic difficulties in accessing adequate food. A study conducted in Brazil revealed that foods diets or lights are expensive

and this can become problematic for the family nucleus, limiting the purchase of these products, especially in low-income families[19]. In this context, this study shows that financial difficulties in purchasing these foods constitute stress for prepubescent children and their families, both in their homes and in other environments such as school. Thus, through self-management support it is possible to adapt the possibilities of treatment to the socioeconomic reality of the families in the agreement phase so that the actions of the 1DM management plan are effective.

Another relevant factor in relation to care refers to knowledge about the signs and symptoms of hyperglycemia and hypoglycemia. In the United States, the American Diabetes Association[20] states that blood glucose variation can be identified when at low levels by weakness, irritability, fainting, sweating, and weak pulse, and at high levels by headache, polyuria, polyphagia, and polydipsia. These clinical manifestations may be caused by decompensated glycemia, dietary variations and erroneous use of insulin dosage, contributing to generate coma, vascular complications and diabetic ketoacidosis. Individuals with 1DM and their caregivers should know the definition of hyperglycemia and hypoglycemia, be able to identify early signs and symptoms of each situation, and have the ability to intervene and prevent.

Although prepubescent children reported knowing and identifying signs and symptoms of these complications through their experiences, they did not show safety in decision-making for the implementation of appropriate measures to solve the problem.

A study states that it is common to make a mistake about the symptoms of hyperglycemia or hypoglycemia among prepubescent children, generating doubt about what is really happening in their body, a dangerous situation for the proper management of glycemic levels, due to the lack of knowledge of children with 1DM and their family[21].

Not infrequently, in the transition of self-management, prepubescent children still do not have safety in the management of possible complications. To cope with this situation during their stay in school, a study conducted in Canada explained that the School needs to have a competent and trained team to support students with 1DM and reduce barriers so that they can actively participate in any school activity[22]. Therefore, health professionals should support education professionals.

However, it was evidenced that, in schools, there was no people prepared to attend the complications of the disease, urgencies that can endanger the lives of these students or the development of activities that promote learning about 1DM among the school staff members. Moreover, there is no interaction between the FHU team and the School to equip them for the proper management and support of prepubescent children in their daily difficulties with the 1DM management plan at school.

This need must be worked together by health and education team professionals in the assistance phase, which aims to investigate barriers, difficulties, connect the support network and empower it on a given subject so that there is adequate support for prepubescent children with 1DM.

According to a Brazilian study, the educational institution is considered a member of the social support network for children in transition to adolescence and their families. This support must be effective in order to list her needs in the control of 1DM, in the correction of problems, overcoming obstacles and prevention of injuries[23].

Health professionals have a primary role with prepubescent children so that they have an understanding about the 1DM management plan throughout life, especially in the transitions between phases when there are doubts, fears and challenges.

A Brazilian study shows that health education contributes to a preventive, individual and adaptive approach to individuals in the community[24]. Furthermore, to achieve this goal, the home visit is considered a strategy of the aid phase in self-management support, especially for people with 1DM who need continuous and longitudinal care.

It is understood that home visits are the responsibility of all members of the health team, but, in general, it is performed by CHAs, who are the bond between the FHU and the user. CHAs have the function of monitoring, together with nurses and doctors of the activities directed to children, as well as being articulators of social control of health and education. They assist nursing in educational follow-up with prepubescent

children, provide other members of the health team with information about the needs concerning the transfer of responsibility and, thus, also promote autonomy for self-management[12, 25]. However, there was a low frequency of home visits by CHAs, weakening the bond between prepubescent children, their family and the FHU.

The fragility in the bond between the FHU and prepubescent children-family results in the transfer of responsibility by the FHU team to the care with the specialist, which may lead to a rupture of the bond between both in the follow-up of treatment and other needs, weakening the entire cycle of the self-management support method.

To the extent that these users are not adequately monitored in the FHU, the assistance and aid phases of self-management support are vulnerable, because the team has not understood the complexity of this situation as well as has not adequately performed its role as care coordinator and orderof the health care network, especially in situations of chronic illness such as 1DM.

Prepubescent children with 1DM reported difficulties in dealing with the limitations imposed by the disease and this has negatively impacted their ability to change life habits. To overcome this adversity, the development of joint actions between family-child/adolescent-professional of different levels of care favor the 1DM management plan by adapting the guidelines to the reality of the family nucleus, reducing the stress caused by change and promoting a more effective adherence[26].

Although the concepts of adherence to treatment and self-management are intertwined in the management of 1DM, a study conducted in Portugal points out differences between both: the first term covers the second, but goes beyond, being a process that encompasses factors ranging from compliance with the procedures to obtaining the desired results. While self-management would be more limited to daily behaviors and practices, being linked to the patient's autonomy[27]. The authors emphasize that differentiating these two concepts allows to promote improvements in the health monitoring of these young people, because the engagement in their self-management favors their adherence to treatment.

Although some participants knew the importance of following the diet for glycemic control, knowledge was superficial, focusing on the restriction of sugar foods. This type of misunderstanding can be overcome in the assistance phase. A study emphasizes the importance of helping prepubescent children to understand the need for a specific diet during the transition, avoiding problems of adherence to new eating habits[28].

Guidance regarding the intake of sweets should be in the sense of moderation, and not of strict prohibition. For this, it is necessary to adopt some care such as carbohydrate counting and corrections with insulin, contributing so that it is not consummated hidden[26]. Affirming this reality, it was observed that the removal of sweets from the daily life of prepubescent children is challenging. Some of them developed mechanisms for the acquisition of new habits, in order to satisfy their desire to consume it, but in a moderate and controlled way, which make them happy.

In addition to this support and guidance in relation to sweets, the family plays a fundamental role in food restructuring, supporting prepubescent children in the control of eating habits, guiding the type of food, as well as in the acquisition, in the acceptance of the diet and avoiding food frustrations[19,23,29]. The present study shows that prepubescent children have their parents as a reference regarding the foods to be consumed when the family actively participates in the process of food reeducation.

Schools were identified as the most difficult environment to maintain the diet due to the food influence of friends and the little variety of healthy food provided at snack time. Food sold in schools has become a major problem in the control of 1DM. This is affirmed by a Brazilian study that claims to be in school the place where problems related to the adaptation of the diet become clearer, evidencing the need for a food rearrangement as a form of support[19].

Exposure to sweets, snacks, fried foods and soft drinks in schools reveals the little importance given by schools to healthy eating, even when requested by the family. Nevertheless, schools are not able and have not sought to meet the special needs of their students, compromising the 1DM management plan.

Interpersonal relationships of prepubescent children also interfere, positively or negatively, in the

maintenance of the diet. A study corroborates these findings by stating that contact with friends can generate positive support when characterized as companionship or can be negative when related to diet without support or understanding on the part of colleagues[29]. In this study, positive support was configured in the help and understanding, although minimal, of the need for food restriction, providing prepubescent children with motivation to stay in the diet. However, when there is no such stimulus, internal conflicts are triggered because they need to resist food preferences to the detriment of health maintenance, generating a negative attitude towards the execution of the 1DM management plan.

In view of the above, support to prepubescent children in the 1DM management plan, including glycemic testing, insulin application, diet control, as well as the understanding of complications and signs and symptoms of exacerbation of the disease can be satisfactorily worked on by the family through continuous health education with the participation of the multidisciplinary team and social support networks such as school. Feeling supported in their needs in this process, prepubescent children can develop a degree of self-efficacy that will provide them with security to perform self-management with autonomy.

FINAL CONSIDERATIONS

This study analyzed the self-management support needs by the 1DM management plan of prepubescent children, including the transition of self-management, the fragility of knowledge about the disease, the self-efficacy and maturity in performing the necessary managements for treatment, the influence of the external environment for the maintenance of the diet and daily life with chronic disease in the transition from childhood to adolescence.

The responsibility of prepubescent children with the new daily tasks, the fragile support of the family, the superficial knowledge about the disease, its consequences and possible complications can lead to an emotional overload, impairing their self-management at this moment of the transition.

Health professional support presented weaknesses, with a transfer of responsibility to the PHC follow-up. This way of producing care has triggered barriers in the acquisition of knowledge and management of children and families, interfering in the quality of self-management and distancing them from the PHC team.

It is pointed out that the limitation of this study was carried out in a single city. However, self-management support, through its phases, can bring an expanded look to the needs of prepubescent children with 1DM in the transition from childhood to adolescence. This may allow adequate follow-up, reducing the impacts caused by the disease and by this phase of life on the transfer of self-management from family to children.

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