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EXPERIENCES OF ADOLESCENTS WITH TYPE-1 DIABETES AND MULTIPROFESSIONAL EDUCATIONAL INTERVENTIONS FOR CARE

Amanda Newle Sousa Silva*
Andréia Régia de Matos Rodrigues Serafim**
Caroline Magalhães de Alcântara***
Maria Veraci Oliveira Queiroz****

ABSTRACT

The present article aimed to understand the experiences of adolescents with type-1 diabetes and the multiprofessional educational interventions for care. It is a qualitative research with 16 adolescents and six professionals linked to the Integrated Diabetes and Hypertension Center in Fortaleza, Ceará, Brazil, conducted from March to October 2016, using a semi-structured interview. The data were submitted to content analysis, giving rise to the following categories: 1 Perceptions of adolescents with type 1-diabetes *mellitus* about care. Participants reported experiences of illness and treatment, difficulties and re-signification of the experience, allowing the self-management of care. 2 Educational interventions as mediators of care for adolescents with type-1 diabetes. The professionals mainlytalkedabout the moment of the consultations during their interventions and tried to help on the acceptance of the disease through learning and motivation for the adolescent to take responsibility for their own care. The experiences of adolescents with type-1 diabetes *mellitus* associated to the context of educational interventions under the multiprofessional approach articulate intersubjective realities that support clinical practice.

Keywords: Type 1 Diabetes *Mellitus*. Adolescent. Patient Care Team. Health Education.

INTRODUCTION

Type-1 diabetes *mellitus* (T1DM) is a chronic disease caused by an autoimmune disorder, that is, the progressive insulin insufficiency, characterized by the partial or total destruction of β-cells of pancreatic islets of Langerhans[1,2]. It is more prevalent in childhood and adolescence[3], representing about 5 to 10% of all types of diabetes *mellitus*, with an estimated incidence of 7.6 per 100,000 people younger than 15 years old[1]. In the United States, more than 15,000 children are diagnosed with T1DM per year[2].

Treatment is complex, involves behavioral patterns, such as physical activity, healthy eating, constant monitoring of blood glucose, medication (insulin administration) and problem solution (recognition of signs of glycemic imbalance)[2,3]. The affected people need to adopt new habits and take specific care, and the multiprofessional team must have the purpose to enable the adolescent to perform them[3].

In this transition from childhood to adult hood, adolescents experience biopsychosocial changes, feelings, problems and interpersonal conflicts and intense activities that are exacerbated by chronic illness[4]. In general, adolescents, compared to children, find it more difficult to accept the disease because they feel disadvantaged by the limits imposed by disease and treatment; they often feel sad and fearful of complications[5].

However, they gradually realize that it is possible to cope with the disease and begin to face the difficulties and to understand the treatment as normal and routine, living in a healthy way, but some need to re-signify the disease and the new experiences and to reorder their conceptions and attitudes before the lived situations[6].

A study showed that adolescents feel difficulties in managing the disease and perceive lack of empathy from the professionals assisting them[7]. However, thisposture must be modified when developing educational actions, and professionals must develop effective interaction with adolescents and pay attention to their needs. By basing educational strategies on the needs and demands of the subjects, care may be effective by achieving adherence and prevention of complications[8].

Therefore, it is necessary to establish priorities, propose exchange of experiences and facilitating instruments for teaching and learning, thus rescuing adolescents' previous knowledge and using educational strategies that are mediators of care[7-9]. Health education helps them to acquire new skills and

*Nurse. Doctoral student, State University of Ceará (UECE). Fortaleza, CE, Brasil. E-mail: amandanewle@hotmail.com
**Nurse. Master, UECE. Fortaleza, CE, Brasil. E-mail: andreiamatosrodrigues@gmail.com
***Nurse. Master Student, UECE. Fortaleza, CE, Brasil. E-mail: krouzinha_alcantara@hotmail.com
****Nurse. Doctor, UECE. Fortaleza, CE, Brasil. E-mail: veracioq@hotmail.com

knowledge to change behaviors and live with the disease[9]. In this perspective, it is important to understand that therapeutic adherence is a multidimensional phenomenon influenced by different factors, thus requiring comprehensive attention by a multiprofessional team[5].

Given these considerations, the present research sought to approximate the experiences of adolescents with T1DM by articulating them with the multiprofessional interventions for care. The results helped developing a digital educational technology (website) to adolescents T1DM. The objective was to understand the experiences of these adolescents and multiprofessional educational interventions for care.

METHODOLOGY

This is a descriptive study with qualitative approach conducted at an Integrated Diabetes and Hypertension Center, in Fortaleza-Ceará. This unit is specialized in the care of children and adolescents with T1DM; it is linked to the Unified Health System and has as team members: nurses, physicians, dentists, physiotherapists and nutritionists.

A total of 16 adolescents and 6 professionals participated in the data collection from March to October 2016, through a semi-structured interview, which took place when patients returned from the consultation with members of the multiprofessional team and after previousscheduling with the participants. The criterion adopted for the selection of adolescents was havingbeen followed-up in the service for over a year. Those who presented glycemic decompensation or other clinical/psychic alterations that prevented them from issuing information at the time of the interview were excluded.

For the professionals, the selection criterion washaving provide care for adolescents with T1DM for more than two years. It consisted, therefore of a physician, three nurses, a nutritionist and a physiotherapist. The amount of participants was set when there was repetition or redundancy of information, and the addition of other contents did not bring novelties and the objectives of the study were contemplated[10].

The adolescents' personal data, such as age, sex, diagnosis time, schooling and occupation, were raised and the guiding question for adolescents addressed their experiences with T1DM and care. Adolescents were individually approached by the researchers before the consultations, in a place without distractions that left them at ease. The interviews wereaudio recorded and had durationduration of 20 to 30 minutes. All the adolescents, with the consent of the person responsible for them,agreed with the recording. For the professionals, the semi-structured interview included time and professional experience, graduate courses and the guiding question on the care and educational interventions targeted at adolescents with T1DM.

The interviews were recorded and transcribed by the researchers who, after forming the corpus, subjected them to content analysis, following the steps: pre-analysis, explorationof the material, treatment of results/inference and interpretation. In the pre-analysis, the interviews were read repeatedly, and the recording units were identified in the context under analysis. After identification of these units of meaning, they were codified and later grouped into subcategories[11], which were regrouped by similarities, giving rise to two categories: Perceptions of adolescents with T1DM about care; and Educational interventions as mediators of care for adolescents with T1DM.

All participants agreed with the terms of the consent form, which was signed by the adolescents. The legal guardians also agreed by signing of the Informed Consent Form. The study was approved by the Research Ethics Committee of the proposing institution, under opinion no. 181,489 andapproval certificate No. 08370912.1.3001.5040, complying with the norms set forth in Resolution 466/2012 of the National Health Council. In order to guarantee the anonymity of the participants, the adolescents are identified by the letter A and the professionals by the letter P, followed by anumber referring to the order of the interviews.

RESULTS AND DISCUSSION

All the adolescents had received the diagnosis of the disease for more than three years and were between 12 and 16 years old. They were ten males and six females; the majority (n = 10) were 13 and 14 years old and accompanied by their parents; only two were with another relative (uncle). Regarding the six professionals, four had specialization/residency and three had master's degree. Regarding the time of service, it ranged from two to 37 years of experience with children and adolescents with T1DM.

The information seized subjectively with adolescents and professionals about T1DM care involves, *per si*, educational approaches permeated with meanings about thinking and doing in daily life.

Perceptions of adolescents with T1DM about care

The adolescents described the main situations experienced regarding care and health maintenance. Their speeches bring an understanding of the changes they experience in taking care of themselves. Thus, they demonstrate their perceptions about dietary restrictions.

> In order to be healthy; I am careful about the diet ... it's based on what the nutritionist recommends, types of fruits and what to avoid (A1).

> I drink a lot of water, all day, even when I don't feel like. I can only partially follow the diet, I have difficulty (...) (A5).

> I'm careful not to eat sweets, but when the blood sugar is lo, I can eat something sweet. For me, the main thing is the diet (A10).

> I do not like the diet because I cannot eat what I want (A9).

A teenager mentioned difficulty regarding the diet, but all of them recognized the importance of food choices. This issue is discussed in the literature that refers to the difficulties of adolescents in changing eating habits, the relationship with the type of food, theamount to reach glycemic goals and to stay healthy[4,8,12].

In adolescence, the preference for nutritionally inadequate foods is related to the influence of colleagues, availability of money and ease of access to unhealthy foods, besides the marketing tools that encourage the consumption of industrialized foods([13].

In the report of daily care experiences, they also highlighted the use of insulin and expressed the achievement of autonomy:

> I pay attention to insulin; I apply it myself (A1).

> I do everything I can not to forget the daily doses of insulin (A11).

Adherence to drug therapy is one of the responsibilities that requires acceptance and learning so that patients can manage self-application. Participants demonstrated to take over insulin application. However, there is a confrontation regarding this type of care, a result similar to otherstudies[8,14], which justifies this attitude, since insulin therapy usually causes pain and suffering, aspects that may impair treatment.

In this aspect, the adolescents highlighted negative feelings regarding the application and monitoring of glycemia, referring to the repetitive and painful character of the procedures.

> The daily injections bother me. Having to punch the finger all the time (A1).

> In the treatment, I think the daily injections are bad, because they are four times a day (A3).

> I have trouble in applying (...) (A4).

> I only punch the same finger because I play the guitar (A5).

> What I do not like is to monitor the blood glucose all the time, not to decompensate (A13).

The speeches expressed the discomfort and difficulty in procedures involving pain, but the adolescents exposed the need for glycemic monitoring with the glucometer, an essential tool to immediately understand the risks of glycemic decompensation. Although they feel limited with the application of insulin, they reinforced that they are procedures inherent to daily life[14]. Thus, they said:

> My greatest worry is checking whetherit is controlled and the diet (A6).

> I take the medication right at the time and try to feed myself (A15).

> I always monitor when I eat something out of the diet (A16).

> I do not forget the injections and when I eat too much candies, I check the blood glucose to see if everything is okay (A12).

The treatment of T1DM necessarily includes a daily regimen of insulin applications and glycemic monitoring, which bring discomfort to patients. However, glycemic self-monitoring is essential for metabolic control and should be encouraged by health professionals[4]. Although it has not been reported by the participants of this research, another study presents uncomfortable situations, such as transporting the medical equipment when necessary, since they do not always have a private place to apply the medication and this was a reason that caused adolescents to delay the appropriate schedules of the applications[15].

Some adolescents view glycemic control more naturally and have learned to recognize the signs of decompensation throughout this path:

> Once, it got too low, my pressure was low; it happened two weeks ago. I was going to sleep, I had had dinner when I felt it; I felt my arm numbing (A1).

> Itfeel very bad if I do not control it right. I always have hypoglycemia (A15).

> I had hypoglycemia when I spent a day without eating (A17).

> I had hypoglycemia, the blood glucose reached 45, I was dizzy. I have already been hospitalized twice with high blood glucose (A12).

Adolescents reported signs of glycemic decompensation and, for some of them, hypoglycemia is referred to as a routine episode. This complication is dangerous for their health as it may be associated with severe cases with disorientation, loss of consciousness and convulsions, making it frightening for those who live and witness it[16]. A study shows that although they have knowledge about what to do to control blood glucose, patients adopt attitudes to maintain hyperglycemia for fear of experiencing negative experiences if hypoglycemia occurs[7].

The subjects reported practicing some physical activity routinely, since the exercise allows a better glycemic control, lowering the levels of blood glucose and bringing physical and psychological benefits[3].

> I play soccer, I take karate, I skate and my mother says shewishes I had the samededication in the diet. I do much physical activity (A4).

> I always do physical activity, ride a bike and hike (A16).

> I ride a bike (A3).

In contrast, some reported difficulties in maintaining or performing physical activity and even demotivation regarding the moment they have experienced, since they used to practice exercises.

> I am not doing physical activity, but I used to dance, I used to ride my bike. I do not do it anymore because it has been too hot and I do not feel like it anymore (A2).

> Now I am sedentary, but I used to do weight training (A5).

The more active adolescents, who practice physical activity routinely, present metabolic variables closer to that recommended, besides being a positive factor that influences the care[3]. Therefore, it is necessary to stimulate and enable these adolescents to practice physical activity.

The reports of the adolescents point out that their main worry necessarily involves healthy eating, glycemic monitoring, insulin administration, recognition of signs of glycemic decompensation and physical activity. In this context, one can perceive the challenges faced by them and the need for motivation and learning that favors effective treatment.

Educational interventions as mediators of care for adolescents with T1DM

The health team, especially physicians, nurses, nutritionists and physiotherapists, are the professionals who work directly in the care of adolescents with T1DM, especially during consultations. They discussed about their performance by referring to the educational aspects, from the update on the disease and treatment, helping to make teenagers aware and motivated to take care.

> I talk about the disease so that they can understand about the treatment. There must be updates on the use of insulin, about the latest available on the market. Knowing the disease, becoming aware and thus accepting the deficiency of insulin so that they can adopt new habits (P3).

> The actions begin at the base, explaining what diabetes is, why the treatment has to be with insulin, in the case of T1DM. Wehave to talk about the disease and what diabetes is, and what it may entail in the future for them, if they do not take proper care. Explaining the complications of the disease, the risksat the short, medium and long term (P6).

Knowledge about the disease is seen as a tool that will improve the self-management of care, thus promoting patient autonomy[15]. Therefore, education on diabetes can minimize doubts in order to change risk behaviors, clarify the guidelines provided[9] and promote the adolescents and their families'abilities to be active and reach treatment goals, guaranteeing self-care and self-controland integrating the clinical interventions of the multidisciplinary team[1,4]. Nevertheless, when patients have knowledge of the chronic condition and the professionals prioritize participatory strategies, thisfavors learning and motivates the subjects to adopt healthy attitudes.

On the communication with adolescents, professionals highlight the importance to treat them in a natural way, not differentiating them from the other adolescents with regard to choosing healthy attitudes. Thus, they bring in their speeches the pathwayof follow-up during consultations and educational care.

> I like to treat them as a regular adolescent, using terms such as dietary re-education instead of diet. I realize they feel very different. To stimulate self-care, we have to talk about the possible complications, I like to show figures, images and comprehensive guidelines, talking about lipodystrophy, but I do not like to traumatize the patient (P1).

> Awareness. First, we have to educate, because I often start saying that their diet is what should be the ideal for all adolescents, because there is no different diet for the diabetic patient (P2).

The professionals' speeches indicated the education actions targeted at the adolescents are aimed to improve knowledge and autonomy in the care. A study discusses that caregivers should use educational strategies with the objective of improving patients' health, enabling them to take care of their health[9]. However, this requires a critical and objective approach, raising knowledge that facilitates the implementation of guidelines and makes them the subject of their own care[7].

Authors have pointed out that in adolescence food choices are influenced by subjective aspects related to knowledge and perceptions, but also by economic, social and cultural factors. In this aspect, there is highlight to the influence of colleagues, mainlyof classmates, where they have the majority of the meals[13]. Unsurprisingly, the diet is the most worrisome item for adolescents with T1DM[4,5,7].

The eating aspects are crucial for the treatment, especially in the glycemic control. Therefore, it must be a routinetheme to be discussed with the adolescents. In this research,the professionals discussed the food groups (regulators, energetic and builders), showing the variety that should make up the menu and the stimulus for a healthy diet.

> One of the main aspects that should be addressed is about diet (P1).
>
> Dividing the diet into three main and three intermediate groups, including the regulators, energetic and builders. Stimulating the consumption of fruit and salads (P2).
>
> We should explain what healthy eating is (P6).
>
> Their dietshould be followed byeverybody;the ones who do it differently are wrong. Insulin-dependent diabetics are mandatorily subject to fractionation, to bring the main focus of healthy eating (P2)

This is corroborated by some authors[4,5,7], when professionals reported that adhering to the diet is one of the main actions of care for adolescents with T1DM, reinforced in their education. This action should be understood as an empowerment process so that teenagers can consciously adopt healthy attitudes with planning of their self-care[4].

Healthy eating was pointed out by adolescents and professionals as an important action for glycemic control, associated with other therapeutic behaviors. There is evidence of the need for nutritional monitoring and encouragement of healthy eating, since dietary behavior is a complex dimension that must be continuously explored in educational interventions.

> I provide guidance on self-care, physical activity, healthy eating, drug adherence, proper use of footwear and postural reeducation (P5).
>
> For their self-care, they should receive guidelines on what the disease is,the rotation application techniques, asking what they know and what they do not know about care, making blood glucose tests, which they do not often do (P6).

Essentially, in the care for adolescents with T1DM, the literature shows that it is necessary to have food education with a variety of nutrients in order to maintain the ideal for the glycemic profile[1].The elaboration of a care plan taking into account the demands of the adolescents aims at a comprehensive care of the subjects and adherence to the treatment, in order to prevent possible complications associated with the disease[8].

The construction of health knowledge among adolescents with T1DM actively includes knowledge of their needs and health promotion through effective care[17]. It should be noted that self-care is a modality of construction of the therapeutic project and is mainly composed of evaluation, counseling, agreement, assistance and follow-up, aiming at recovering health. Also,so that the health professional can achieve an effective follow-up, they should use active strategies in the care for the adolescent and theirfamily[18].

Sincethe care for the adolescent with T1DM1 goes beyond food control, the adequate management of insulin therapy includes the correct application of insulin and other procedures, such as rotation and its technique.

> I see they misapply the insulin, in the wrong places. I think it is important to teach about the use of insulin. So I always like to show how to do the rotation; I try to guide as much as possible (P1).
>
> One of the aspects that I deem asmost important is the application of insulin. They should have basic supplies, such as tape, syringe, needle, insulin and being able to handle the tools (P4).
>
> I emphasize the correct way and the insulin-application technique (P6).

Complementing the reported experiences, professionals emphasized that one of the significant procedures in the treatment and maintenance of positive responses to the health of adolescents with T1DM is the use of insulin to achieve a metabolic control; observing the application sites, the rotation and the application technique. In addition, they clarified the necessary inputs and the handling, such as tape, syringe and needle. The location and proper form of

application deserve attention, as they are peculiarities related to educational actions, essentially during the nursing consultation with the adolescent.

Another study indicates that the knowledge and the mastery of insulin administration have been insufficient. Also, there has been inadequate storage and management of inputs, such as lancets, and these erroneous concepts impair the care and increase the risk of long-term complications[12].

In the interlocution of thepreviously reported experiences of adolescents and the meanings of educational activities for professionals in relation to glycemic monitoring, we can highlight:

> [...] doing the monitoring, seeing what is wrong and trying to correct it. Providing guidance in the cases of hyper and hypoglycemia and the conducts to be performed in these cases (P1).

> Showing an example of glycemic mapping (P3).

> [...] they do not know what they do with that figure; they do not know the goals. And what to do in case of hypoglycemia and hyperglycemia. They are very afraid of having hypoglycemia and do everything not to have it, but when they realize they feel good with blood glucose at 200, 300 and do not feel many things, they get more comfortable. We have to talk about the complications of not taking care (P6).

In reporting their guidelines for adolescents, practitioners pointed out the main aspects they address and how they identify situations of hypoglycemia or hyperglycemia, raising their awareness to care to correct and maintain glycemic levels and record them on the glycemic map. A study showed that when adolescents do not maintain metabolic control, there is a tendency to worsening when age increases[19]. Thus, it is an indispensable point to be discussed and monitored by professionals so that these adolescents can change their attitudes.

Another aspect discussed by the professional team was the insertion of physical activity in the treatment, that is, the adoption of this habit by the adolescent with T1DM.

> Talking about physical activity. They must follow the steps of physical activity and healthy habits (P4).

> The practice of physical activity in health education programs has been developed by the institution. A need aimed at improving the functionality of lower and upper limbs, the body as a whole. For their self-care, they must be aware and motivated to adopt these measures (P5).

This professional recommendation may have individual meanings and guidelines. A study showed that physical activity is among the main concerns of adolescents, as they are afraid of the occurrence of hypoglycemia during the practice or at the end thereof. In order to avoid this, they should be individually guided regarding the type of activity, intensity and duration, as well as the measure of reducing 10 to 20% of the insulin dose in the previous meal, in addition to monitoring it before, during and after exercise[12].

Other types of care inherent to daily life were highlighted, such as body and dental hygiene, skin and foot care, among other everyday habits.

> Specifying on the website the age of the public for which it has been designed, hygiene control, bathing, toothbrushing, foot care, glycemic control (P3).

> Body hygiene, foot and skin care, proper use of footwear, health education workshops (P5).

In order to reduce the undesirable effects of diabetes treatment, it is necessary for the health team to encourage adolescents to recognize their individual needs so that they can be independent in their own care[4]. Professionals should communicate to be multipliers of knowledge and promote health promotion[17].

Experiences are re-signified for both the adolescent and the professionals when they experience this chronic condition that requires support and learning before the demand for care. From these findings, we can infer that the participation of the multiprofessional team in the adolescent outpatient follow-up involves continuous care and education, providing the integration of knowledge and the autonomy of these subjects.

FINAL CONSIDERATIONS

By listening to the experiences of adolescents with T1DM and the educational interventions of the multiprofessional team during the consultations, we could partially understand the meanings of this reality configured in the research objectives.

In experiencing illness and care, the adolescents reported their difficulties, the various feelings and the physical pain associated with glycemic control and insulin therapy. However, they have overcome and taken responsibility for their health. This autonomy has beencertainly achieved by the support received from the multiprofessional team that has provided continuous follow-up with guidelines and encouragement on specific treatment and care.

The present study had as limitation the individual interview conducted in a short time, because group

interviews were planned to approach common experiences, in order tobroaden discussions and reflections between the adolescents. It was difficult to collect the data due to the disagreements among the adolescents in the consultation space. However, other points of the studied reality were amplified by associating adolescents'experiences and learning with the professionals'speeches, which allowed observing intersections in the care of these subjects.

The re-signification of their experiences mediated in the multiprofessional educational guidelines allows a significant therapeutic support to the health of the adolescent with T1DM.

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EXPERIÊNCIAS DE ADOLESCENTES COM DIABETES TIPO 1 E INTERVENÇÕES EDUCATIVAS MULTIPROFISSIONAIS PARA O CUIDADO

RESUMO

O artigo teve como objetivo compreender experiências dos adolescentes com diabetes *mellitus* tipo 1 e as intervenções educativas multiprofissionais para o cuidado. Pesquisa qualitativa realizada com 16 adolescentes e seis profissionais vinculados ao Centro Integrado de Diabetes e Hipertensão em Fortaleza, Ceará, Brasil. Realizada de março a outubro de 2016 utilizando entrevista semiestruturada cujas informações foram submetidas à análise de conteúdo originando as categorias: 1 Percepções de adolescentes com diabetes *mellitus* tipo 1 acerca do cuidado. Os participantes relataram vivências do adoecimento e do tratamento, as dificuldades e a ressignificação da experiência possibilitando o autogerenciamento do cuidado. 2 Intervenções educativas como mediadoras do cuidado aos adolescentes com diabetes *mellitus* tipo 1. Os profissionais, discorrem, principalmente, o momento das consultas quando em suas intervenções, intentam colaborar na aceitação da doença, aprendizados e motivação para que o adolescente assuma o seu cuidado. As experiências dos adolescentes com diabetes *mellitus* tipo 1 associadas ao contexto de intervenções educativas sob o olhar multiprofissional articulam realidades intersubjetivas que subsidiam a prática clínica.

Palavras-chave: Diabetes *Mellitus* Tipo 1. Adolescente. Equipe de assistência ao paciente. Educação em Saúde.

EXPERIENCIAS DE ADOLESCENTES CON DIABETES TIPO 1 E INTERVENCIONES EDUCATIVAS MULTIPROFESIONALES PARA EL CUIDADO

RESUMEN

El artículo tuvo como objetivo comprender las experiencias de los adolescentes con diabetes *mellitus* tipo 1 y las intervenciones educativas multiprofesionales para el cuidado. Investigación cualitativa realizada con 16 adolescentes y seis profesionales vinculados al Centro Integrado de Diabetes e Hipertensão em Fortaleza, Ceará, Brasil. Realizada de marzo a octubre de 2016 utilizando entrevista semiestructurada, cuyas informaciones fueron sometidas al análisis de contenido originando las categorías: 1. Percepciones de adolescentes con diabetes *mellitus* tipo 1 acerca del cuidado. Los participantes relataron experiencias de enfermedad y del tratamiento, las dificultades y la resignificación de la experiencia posibilitando la autogestión del cuidado. 2. Intervenciones educativas como mediadoras del cuidado a los adolescentes con diabetes *mellitus* tipo 1. Los profesionales describen, principalmente, el momento de las consultas cuando, en sus intervenciones, intentan colaborar en la aceptación de la enfermedad, los aprendizajes y la motivación para que el adolescente asuma su cuidado. Las experiencias de los adolescentes con diabetes *mellitus* tipo 1 asociadas al contexto de intervenciones educativas bajo la mirada multiprofesional articulan realidades intersubjetivas que ayudan la práctica clínica.

Palabras clave: Diabetes *Mellitus* Tipo 1. Adolescente. Equipo de atención al paciente. Educación en Salud.

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Corresponding author: Amanda Newle Sousa Silva. Avenida Torres de Melo, 370, Fortaleza - CE. Bairro: Centro. CEP: 61.700-00. E-mail: amandanewle@hotmail.com

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