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CHILDREN AND FAMILIES LIVING WITH DIABETES MELLITUS TYPE 1

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ABSTRACT

Objective: To understand the perception of children and family members living with Diabetes Mellitus, Type 1. Method: Data collection by focal group, from October to December, 2016. The participants were four female children, aged between 8 and 12 years old and their parents, who were followed at the outpatient clinic of a university hospital. A structured form was used to identify the disease management, supported by the focus group. This dynamic was driven by a sensitive creative method. Data were examined and interpreted through thematic analysis. Results: According to the findings, living with diabetes is surrounded by difficulties of invasive procedures, physical and nutritional restrictions, bullying, socially and emotionally impact over family routine, which tends to be adapted to the disease demands. Conclusions: The routine of children and families experiencing the chronic disease process is noticed as a painful and difficult moment that requires daily life adaptations. The care plan should take into account this understanding, facilitating the adaptation, supported by playful group activities in order to contribute to better treatment adherence.

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INTRODUCTION

Diabetes Mellitus (DM) is one of the chronic non communicable diseases (NCDs), gradually increasing worldwide. In Brazil, 5 million people are diabetic and among them, about 300 thousand are under 15 years old (Nascimento *et al.*, 2011). As a chronic progressive disease with high complication rates, health care expenditures for DM in 2013 represented an economic impact of 11% of total health spending costs in the world. In addition, DM is considered the fifth leading cause of death in the world, representing around 5.2% of all deaths (D'amo *et al.*, 2011; SBD, 2015-2016). This chronic health condition does not only affect adults, but more and more children and adolescents are developing DM. Type 1 is responsible for more than 90% of the cases in most countries, representing about 80,000 new cases annually (ISPAD, 2014). The DM1 diagnosis in childhood affects several dimensions of the child and family's life. Since it is an unexpected and unknown episode, some feelings emerge, such

as denial, concerns, uncertainty, causing interruption in the way of living and making their future doubtful. Lack of knowledge about the disease leads to individual and familial isolation, impairing the adequate DM management (Nascimento *et al.*, 2011; Viviane *et al.*, 2016). Emotional factors have been aggravating the disease since the diagnosis, making it a continuous challenge in order to deal with chronic disease demands. It may happen due to the fact they do not know what to have DM1 means, as well as its implications in daily routine, for example, eating habits, capillary glucose monitoring, insulin application (Nascimento *et al.*, 2011). Thus, being aware of the child and family perception about their experience with DM1 is essential to plan health actions directed to the users' needs, once their adaptation to this condition could be improved the treatment adherence. The supportive and confident relation produced by the family, may influence the child behavior and improve the self-care practice. If this relation is established and added to the guidelines provided by health professionals, children increase their autonomy in specific and routine activities related to DM1, such as capillary glycaemia monitoring and insulin application (Nascimento *et al.*, 2011; Tricia *et al.*, 2013). These changes in

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habit and self-care practice influence the adherence to treatment and have an impact on glycemic control, which may affect reducing acute and chronic complications, improving the quality of life. In this context, this study aims to apprehend the perception of children and family members in the DM1 experience, based on problematization and dialogue during health education meetings. The empowering care and the user's dialogue, as the author of their existence with diabetes, must be understood taking into account their thinking and acting way. The relationship among health professionals, patients and family members may build therapeutic alliances capable of enhancing the possibilities of living with the disease (Freire, 2007).

MATERIALS AND METHODS

Qualitative research, participant type, developed in dialogical meetings among the participants mediated by the focal group. Group discussion is an important source of knowledge collective construction, consolidating a dialogical relationship among the subjects, taking into account the exchange of experiences as the substrate for the new knowledge construction (Flick, 2009). To arise discussion among children, the meetings were driven by the Sensitive Creative Method dynamic, based on the triad: observation, group discussion, and the dynamic of creativity and sensitivity (Queiroz *et al.*, 2016). Based on Freire's constructivist theory, the mentioned dynamic strengthens the dialogue among the participants, turning them active subjects in the collective construction of knowledge, through techniques that privilege creativity, using body senses and sensitivity as multiple forms of feeling expression (Soratto *et al.*, 2014). Among the children followed by the endocrinology outpatient clinic in a university hospital in Paraná, 12 of them had DM1 and were among eight to 12 years old. In this group, four had a scheduled appointment for the data collection period, from October to December, 2016. The child and the familiar responsible member were approached on the medical appointment scheduled day, receiving information and invitation to take part of the research. The four female children and their family members accepted to be engaged.

After the acceptance, they signed the Term of Free and Clarified Assent for children, and the Informed Consent Term for family members, followed by an interview with a structured form. The questions covered sociodemographic aspects, identification of difficulties when experiencing DM and problems identified by their relatives in the disease management. The dialogic meetings were arranged with all the participants to carry out the health education activities, which were prepared considering their experiences. This manuscript describes the content that emerged through the speaking maps constructed in the first dialogic meeting, when the participants explained their perceptions about DM1. This meeting was developed in five moments (Queiroz *et al.*, 2016; Soratto *et al.*, 2014): hosting and environment preparation to participants reception; presentation of activities; dynamic explanation for children in order to represent their living with DM1, through drawings, being supplied by white paper and crayons, under a 15-minute pre-arranged time for the task; children presentation by the individual production in the group; collective reflection based on the common characteristics and differences of the group vis-a-vis DM1. Concomitant with the dynamic, the focal group was driven by the integration of the participants through the dialogue after asking triggering questions to stimulate the

subjects' reflection: How did you feel when you received the news you had DM (child and family member)? What are the biggest limitations or difficulties of the disease in the day by day of your life? How has it been dealing with DM?. Data were recorded in audio and video, fully transcribed and analyzed by content analysis in the thematic analysis modality, which comprises the pre-analysis; material exploitation; gathered results processing and data interpretation (Cruz *et al.*, 2017). Data were performed using the NVivo software. Based on them, two thematic categories emerged: Facing the process of living as children with DM1 and Family member perceptions about DM1. Ethical aspects for the research development were attended being approved by the ethics committee by decision number 1.836.139/2016. Anonymity guarantee of the participants was obeyed through fictitious names.

RESULTS

The children were between eight and 12 years old and were in grades 3 to 7 of elementary school. They lived in the household with three to four people, with a family income of two to three Brazilian minimum wages per month (US\$548 to 822). The family members and caregivers who accompanied them, mostly, had a relationship as a mother (50%) and a grandmother (50%). The categories that have emerged for analysis reflect the creative and sensible dynamic and the information obtained in the interview form.

Facing the process of living as children with DM1

The DM1 child experience is represented by the difficulties the disease imposes as pain for insulin application and desire to eat candies, which require learning how to deal with this situation. Such difficulties are observed in the representation of children's drawings. Sara drew her body and the complications the disease can trigger, what could be observed in her speech fragments, also in Figure 1. When I discovered that I had diabetes, I learned how to take care of my feeding. I've heard that you can't eat candies because they harm organs and cause blindness. Also, you have to apply insulin daily whenever you eat. Besides, you need to take the test (from capillary glucoses), and make sure you keep the disease under control. (Sara, age 12).



Figure 1. Sara's drawing

The insulin application was noticed as the most difficult task in the treatment, followed by the changes in the daily eating

habits, she recognizes the family helps her a lot in this process. Independently of how rigorous the diabetes diet may be, she can follow it and recognize poor diets can lead to complications. In Maitê's perception, the insulin application in one of her members (Figure 2), emerges as a significant aspect, when requested to explain her drawing, she referred to pain: The (application of) insulin. Because it hurts a lot, it really hurts. (Maitê, nine years old).

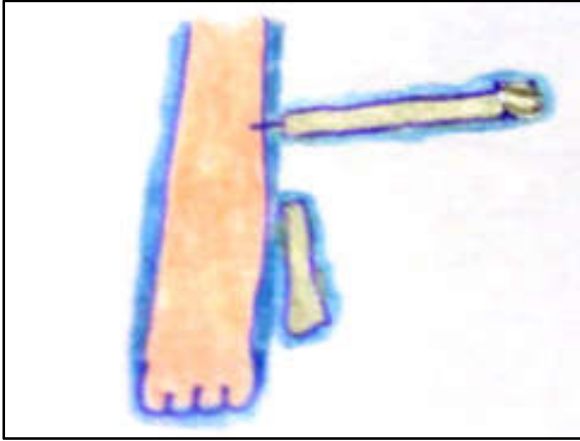


Figure 2. Maitê's drawing

Due to pain, this task is the one she considers the most difficult. She could overcome it by her family support. She did not know to answer on habit changes after being diagnosed, but reported feeding difficulties, she partially follows the indicated diet. However, she recognizes the risks of a poor diet, bringing up the DM1 complications, what may be inferred when she mentioned the possibility of losing her leg. In her drawing, Gabriela represented the disease through the application of insulin in several places of her body (Figure 3). She also said this change was the most impacting one in her daily life with the disease. Thus, she considers such activity hard due to pain, as highlighted in her speech:

The insulin application, because it hurts. (Gabriela, eight years old).



Figure 3. Gabriela's drawing

The school was cited as a relevant environment related to the living difficulty with DM1, which was reported in Adriana's speech and drawing (Figure 4):

There are a lot of people who keep judging just by the person you are. For example, if you are very thin, look like a

toothpick, or very chubby, like a whale. You are judged by having a disease, everyone can have a disease. (I feel) very embarrassed because they (school classmates) joked for nothing, they kept cursing all the time. Then, I talked to my principal, but it did not work. (I would like) they respected the disease, instead of making fun of that. (Adriana, 11 years old).



Figure 4. Adriana's drawing

Depression associated with bullying may contribute to poor adherence to treatment and restrict the self-care. Despite her psychological distress, Adriana also acknowledges the insulin application and glucose tests are difficult activities due to the pain. Moreover, the deprivation to "stuffs" was a significant change after the disease discovery. Even knowing the risks of a poor diet, while stating she could be hospitalized, she admits not following the diet and ingests candies daily. The children perceptions about their illness, as well as, feelings and understanding about how others see them are issues that interfere with DM1 proper management. When children have family and social support, the DM1 representation drawings are focused on the pain from invasive procedures and food restriction. When the same support was not found, the representation was perceived by psychological overlapping physical pain. Living with DM1 and maintaining its adequate management constitute challenges that must be faced daily by children and their family.

Relatives perceptions about DM1

The negative impact of DM1 diagnosis generated in mothers and grandmother's feelings of sadness and commotion, mainly due to the disease discovery to be in childhood and, consequently, the restrictions to be imposed on the child's life. Such feelings emerge because DM1 is a chronic condition, which will require lifelong follow-up, breaking the paradigm of growing and developing healthily, making the future uncertain.

At first it was a shock [...] because we felt sorry for her, and she (Sara) used to say: stop crying mom, I'm a person that who understood, I'm with this stuff (DM1), I have to take care and it will be all right (Fernanda, Sara's mother).

I stopped crying a little while ago, only after I went to the psychologist, because I was very anxious. When we discovered, it was a huge shock [...] She was hospitalized, I only cried. Every time I was applying insulin, I cried desperately [...]. (Evelin, Gabriela's mother).

I needed a psychologist and psychiatrist to give the first ones (insulin) and even then the first time I passed out, I was not courageous. (Maria2, Adriana's grandmother).

Fernanda and Sara presented a harmonic relationship, although the disease discovery to be a shock for them, which changed all the family routine. Sara was the one who supported her mother the most to face the whole process. The mother emphasizes that the insulin application is difficult in the diabetes treatment, and associates it with sorrow when she sees her daughter feeling pain. Sara's mother said she is a determined girl, follows the guidelines, control the feeding and perform the insulin application by herself.

Nowadays, (the most difficult) is the insulin application, she does it in several places: in the leg, thigh[...] she exercises, she makes insulin and the tests right (blood glucose test strips). Then, she is well controlled. I will not say she doesn't eat snacks, not because she has diabetes she will not be able to eat, but at the right time [...] the insulin hurts, it hurts, but Sara has been applying on her own since the day she started using it. She learned to apply, she does not let anybody to do that, she does everything right. I just thank God for that. (Fernanda, Sara's mother).

Because of the difficulties they face due to the limitations that the disease brings and because their treatment is predominantly invasive, family members feel guilty and tend to question the onset disease.

Every time I was going to apply insulin I thought *my God*, how it will be? Why does it happens to a child? For me, it's something an adult did, I did, my husband did, got it? That was my thought, mine, not his, man is more levelheaded and calmer. I was already very anxious, today I'm less. (Evelin, Gabriela's mother).

Evelin was moved by this speech, mainly exposing the disease discovery process, when reporting Gabriela had the first incorrect diagnoses, leading to the worsening of the disease, requiring hospitalization:

She (Gabriela) received the blessed worm medicine, (in the first diagnosis they said) it was worms. She started losing weight, she even ate and ate a lot. She was trembling like that, and from that moment, she started losing weight from day to night. [...] Gabriela started drinking lots of water, going to bathroom all night. She was barely sleeping. Then we took (to the doctor), and (we said): doctor, in my husband's family, they are all diabetic. Thus, by the symptoms, we think she has diabetes. Next, the doctor requested exams [...]. My husband went to the health basic unit, brought the exams, then I said: I think there is no time anymore (her voice was trembled), and from there, we took her to the emergency service. In this unit, she was already with 430 (glucose test). The doctor said: Gabriela goes to the hospital straight to the ICU, because she has a lack of potassium and high diabetes (Evelin, Gabriela's mother).

Feelings like anxiety and sadness dominated the family, requiring psychological follow-up. They also considered difficult the required food restrictions in order to have a good glycemic control for Gabriela.

The greatest difficulty is feeding herself, she is so hungry. I told the doctor, my God, don't you have some medicine to stop her eating so much? [...]. She goes to school and there are some parties there. For example, at this year's country party, we did the (carbohydrate) accounts, what she was going to have at the party, to feed herself, not to stay out, not to be excluded. (Evelin, Gabriela's mother).

Maria1, Maite's grandmother, also mentioned the granddaughter's difficulty at applying insulin, as well as following rules, such as insulin application and food control, which brings stress for all of them.

She does not like to apply insulin, we help her, however, most of the times her mother does that [...]. For her, it is difficult to follow rules, the time to make the insulin, glucose test. She wants someone to do it, then, we have to argue, to talk, what causes stress. (Maria1, Maite's grandmother).

Over time, the daily care needs, the family care involvement and get along with the diabetic child, replaced guilty feelings for acceptance of the condition, and then, reverting itself into family support. This support is essential for the child to overcome the difficulties encountered along the process.

I used to stop to think and then I said: no, I can't cry, I need to be strong to help her (Gabriela), she will need me and and her family. (Evelin, Gabriela's mother).

The family is very important in this and I was very strict, my husband too. And so, she was a girl who used to listen to us, everything we informed her. Thanks God, Sara has ever been a determined girl, (if she says so) she will do, she does, she never complains about taking (insulin) or anything. (Fernanda, Sara's mother).

The family should be incorporated into the disease care process, considering conflicting environments, with low family DM1-relative issues involvement, result in poor treatment adherence, contributing to inappropriate self-care, poor glycemic control, and increased complications. In Maria2 and Adriana's case, the grandmother is legally responsible for her granddaughter. In the dialogical encounters, they demonstrated a conflictive relationship, the grandmother criticized her granddaughter by being impatient and regarding Adriana's difficulties in assuming self-care, resulting in inappropriate disease management.

[...] I have the definite legal guard, my daughter was not prepared when she delivered, she was a child mother caring another child [...]. I stopped working because she (Adriana). For Adriana to take insulin I need to punish her (physically), because if I just say, she doesn't get it. That's complicated ... She doesn't help herself, all she eats is in large amounts (Maria2, Adriana's grandmother).

The difficulty of following the guidelines and controlling feeding is so intense that Maria2, as pointed out in her speech, doesn't know how to deal with this situation, requesting a medical prescription for feeding restriction. The grandmother can't understand DM1 from her granddaughter's point of view, which turns get along with difficult and avoids the child support. The change in family routine regarding feeding was also reported by mothers and other family responsible

members, evidencing the necessity to be adapted to this condition.

In our daily routine, we have changed our eating habits. Now, we eat more salad and fruits. Barbecue was almost every day, but now we have cut. And so, are we going to eat a snack? Yes, we are! Once a week, every twice a month, alright, we rarely eat pizza [...]. (Fernanda, Sara's mother).

Everything was changed, about our feeding routine... When it was increasing (glycaemia) at night, we changed the white rice for whole grain rice. Then, it stopped increasing [...]. (Evelin, Gabriela's mother).

In my refrigerator, I have only fruit and water. I can't make any dessert. Even the fruit, which is controlled, she doesn't control. She isn't pleased with little. [...] She is headed by the food [...] The doctor said that it is caused by disease (hunger), the brain doesn't send the information properly, informing the body that is was enough. (Maria2, Adriana's grandmother).

To cope with the chronic disease, families gradually adapt their needs, triggered by the disease, facing the children's daily activities. Families sometimes adjust and deal with children chronic diseases by putting themselves close to them. On the other hand, preexistent problems can be potentialize promoting a conflictive life way. Consequently, caring and living with the diabetic children require gathered efforts, which are not always possible in certain family arrangements.

DISCUSSION

In child health care, it is necessary to consider not only the technical aspects of the disease management, but also its physical, emotional and social needs, using strategies to identify and minimize the pressure caused by the interventions. This will have repercussions on better disease management, habits and self-care changes, but mainly on the well-being of the child and his/her relatives (Viviane *et al.*, 2016). Negative emotions towards the disease and the treatment could be noticed, considering the children's point of view. These feelings overcame other daily life alterations after the DM1 diagnosis. The health professional's attention is often given to the biological aspects, without noticing the psychological elements significantly affect the child and her family, resulting in less treatment adherence. The children's drawings emphasized the repercussions of coping with the disease in their bodies, sometimes sacrificed by multiple needle punctures, as illustrated in insulin administration and blood glucose test, painful experiences that mark their daily lives. Nevertheless, in most of the drawings landscapes are not observed, what refers to the child not to be inserted in the social context. When there were other people, as in Adriana's representation, the emotional suffering, due to the social exclusion, was emphasized, overcoming the physical pain from the treatment.

Playful interactions among children and health professionals can promote proximity and trust for both of them, which contribute to the treatment adherence (Queiroz *et al.*, 2016; Soratto *et al.*, 2014). As identified, the chronic disease diagnosis and the limitations discovery, the modifications in the daily life and the possible sequels, impact emotionally over the families and result in stressful situations. This triggers a rejection phase in which family members feel guilty, tend to

question the disease discovery, which result in family conflicts influencing the patient's daily life (Leal *et al.*, 2012). The health team needs to understand that health care planning should consider all aspects involved, also sadness and despair feelings. In addition, the prospect of a painful life and uncertainty, related to an incurable disease, requires frequent treatment and follow-up (Cruz *et al.*, 2017). The change in family daily life also generates stress and difficulties in the disease management, mainly related to eating habits, as reported by the American Diabetes Association (ADA, 2015). Meals should be planned, involving the whole family in changes, such as sharing meals and acquiring healthy eating habits, goals to be encouraged in order to implement a new successful routine.

Thus, in order to assist the decision making, the health team actions should have established a horizontal dialogue in their relationship with families. As in our study, other studies point out to questions about the intensive routine of insulin application, difficulties with self-application, insulin correction of hypo and hyperglycemia (Prado *et al.*, 2014; Venancio *et al.*, 2017). Few studies bring pain as a significant factor for non-adherence to the treatment (Nascimento *et al.*, 2011). They reveal the necessity to address these painful experiences that mark these children daily lives. The primary health care team, with more frequent contact with the child and his/her family, should use the dialogue conducted by the ludic as a tool to approach the child. This strategy should be used for the disease diagnosis and throughout the treatment, which to develop the necessary team confidence and to allow children to express their emotions facing the problem, facilitate the disease understanding and its repercussions in the short, medium and long term.

In addition to the family and the health professionals' support, the school and friends are fundamental components to cope with the disease, since children want to feel accepted in social environments, independently of their condition (Nascimento *et al.*, 2011). A child's closer friend is essential to help him/her with the daily difficulties imposed by the disease management. The way they label or treat diabetic children results in sadness and depressive moods, making them feel different from others. In our study, the child who was bullied by her colleagues was the one with the greatest difficulty with the disease management and to remain herself normoglycemic. Significant correlation was detected between behavioral difficulties and depressive disorders with altered metabolic control and reduced self-care capacity (Moore *et al.*, 2013). The health team should value the school network and leisure sites members, so that, based on the disease understanding, the prejudices are transformed into support and empowerment for its management. The care and intervention planning support based on the family will empower the home care, which must be composed by the children and family experience throughout the chronic disease, such as the DM1. Besides, the support should consider an interdisciplinary perspective of the comprehensive and resolute care, as well as, dialogue, trust and co-responsibility (Cheraghi *et al.*, 2015). According to this conception, attention practices based on comprehensiveness and resolution are essential for bonding and trustworthy establishment among child, family and professionals, providing better attention to their demands, difficulties and expectations perception. Going beyond biological disease necessities, which reach dimensions related to the way families face the chronic condition problem.

Conclusions

Children perceive their painful chronic condition as restrictive, impacting on their daily routine. In addition, the family DM1 perception implies feelings, such as guilt, anguish, sorrow for the child pain, resulting from invasive procedures and disease care demands. The use of playful activities, dialogue and horizontality relationship among team, family and child are effective tools to support identification and understanding of experiences and perceptions of children and families, living with DM1. These strategies may transform them into protagonist actors, dealing with a chronic disease. Consequently, they are strengthened and then adhere to the proposed care, achieving metabolic control, acute and chronic complications reduction, as well as quality of life and health improvement.

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