



FROM DIAGNOSIS TO THE UNKNOWN: PERCEPTIONS OF PARENTS OF CHILDREN AND ADOLESCENTS WITH DIABETES MELLITUS

DO DIAGNÓSTICO AO DESCONHECIDO: PERCEPÇÕES DOS PAIS DE CRIANÇAS E ADOLESCENTES COM DIABETES MELLITUS

DEL DIAGNÓSTICO AL DESCONOCIDO PERCEPCIONES DE LOS PADRES DE NIÑOS Y ADOLESCENTES CON DIABETES MELLITUS

Rafael Rodrigo da Silva Pimentel¹, Thaise Targa², Márcia Glaciela da Cruz Scardoelli³

ABSTRACT

Objective: to understand the perception of parents of children and adolescents on the diagnosis of type 1 diabetes mellitus. **Method:** descriptive and exploratory study with qualitative approach carried out in a diabetes association in the city of Maringá/PR/Brazil with eleven parents of children and adolescents with type 1 diabetes mellitus. Data collection was performed by means of a semi-structured questionnaire with guiding questions. Then, collected data were submitted to content analysis on the thematic modality. **Results:** the analysis of the data gave origin to two categories: Experiencing the diagnosis; and Being transformed by the disease of the child. **Conclusion:** the diagnosis of a chronic disease generates despair, suffering and anxiety in all family members, and after this experience, life gradually changes, causing parents to adapt to something unexpected in trying to cope with their physical, emotional and social uncomfortable aspects. **Descriptors:** Chronic Disease; Diabetes Mellitus; Child; Adolescent; Family.

RESUMO

Objetivo: compreender a percepção dos pais de crianças e adolescentes diante do diagnóstico de diabetes mellitus tipo 1. **Método:** estudo descritivo e exploratório, com abordagem qualitativa, realizado em uma associação de diabéticos da cidade de Maringá/PR/Brasil, com onze pais de crianças e adolescentes portadoras de diabetes mellitus tipo 1. A coleta de dados foi realizada por meio de um questionário semiestruturado com questões norteadoras. Em seguida, os dados coletados foram submetidos à análise de conteúdo, modalidade temática. **Resultados:** da análise destes, emergiram duas categorias: Vivenciando o diagnóstico; e Sendo transformado pela doença do filho. **Conclusão:** o diagnóstico de uma doença crônica é um momento que gera desespero, sofrimento e ansiedade em todos os membros da família, e após a sua vivência, a vida tenta se transformar, levando os pais a se adaptarem com algo inesperado na tentativa de lidar com seus incômodos físicos, emocionais e sociais. **Descritores:** Doença Crônica; Diabetes Mellitus; Criança; Adolescente; Família.

RESUMEN

Objetivo: comprender la percepción de los padres de niños y adolescentes frente del diagnóstico de diabetes mellitus tipo 1. **Método:** estudio descriptivo y exploratorio, con enfoque cualitativo, realizado en una asociación de diabéticos de la ciudad de Maringá/PR/Brasil, con once padres de niños y adolescentes portadoras de diabetes mellitus tipo 1. La recolección de datos fue realizada por medio de un cuestionario semi-estructurado con preguntas guiadoras. En seguida, los datos recogidos fueron sometidos al análisis de contenido, modalidad temática. **Resultados:** de estos análisis, surgieron dos categorías: Viviendo el diagnóstico; y Siendo transformado por la enfermedad del hijo. **Conclusión:** el diagnóstico de una enfermedad crónica es un momento que genera desespero, sufrimiento y ansiedad en todos los miembros de la familia, y después de su vivencia, la vida intenta transformarse, llevando a los padres a adaptarse con algo inesperado en la tentativa de lidiar con sus incómodos físicos, emocionales y sociales. **Descriptores:** Enfermedad Crónica; Diabetes Mellitus; Niño; Adolescente; Familia.

¹Student, Graduation in Nursing, Cesumar University center/UNICESUMAR. Maringá (PR), Brazil. E-mail: rdriago3@gmail.com; ²Nurse, Cesumar University center/UNICESUMAR. Maringá (PR), Brazil. E-mail: thatarga@gmail.com; ³Nurse, Master, Professor in Nursing, Nursing and Medicine Course, Cesumar University center/UNICESUMAR. Maringá (PR), Brazil. E-mail: grajcruz@gmail.com

INTRODUCTION

Chronic diseases cause important organic, emotional, and social changes that require constant care and adaptation.¹ When diabetes *mellitus* is discovered during childhood and adolescence, the family has its behavior changed and the way of dealing with the disease may instill feelings of guilt, fear and depression, threatening the routine.²

Type 1 diabetes *mellitus* is a chronic condition caused by impairment of pancreatic beta cells that are responsible for producing insulin, which has the function of lowering blood sugar levels. This problem can be the result of autoimmune factors or unknown cause, which is called idiopathic. Its incidence today is 0.5 new cases per 100,000 inhabitants/year, and mainly affects adolescents and children under 5 years.

It is noteworthy that the changes in the daily lives of kids and adolescents with diabetes *mellitus* are uncomfortable and persistent, because the treatment is permeated with dietary restrictions, insulin injections, need for regular physical activity, change in routine and the fear of possible complications.⁴⁻⁵

Faced with this experience, parents assume the roles of primary caregivers, who defend the rights of the child and the adolescent and do everything in their power to dedicate themselves fully to the search for the best care. Thus, they experience the oscillations caused by the disease and are faced with the transformations that impact the family.

Literature shows that adequate support to parents and friends helps diabetic people to better adhere to self-care attitudes, especially in relation to diet and physical exercise. Thus, it is important to involve both parents and friends in this process, seeking to encourage children and adolescents to adhere to the necessary care.^{1,7-8}

In this context, care for children and adolescents should aim at a healthy life style, going beyond knowledge about their physical and psychic changes brought by the diabetes. It is extremely important to understand the experiences of these people during the process of living with the disease.⁹

Understanding the daily experience of parents of children and adolescents with diabetes *mellitus* is important to detect the main gaps in the care routine of parents. This, in turn, can help parents to collaborate with nursing professionals to provide care with quality for such families, through actions that qualify these caregivers and provide a better

understanding of the disease that is often unknown and ends up reflecting in their daily lives. This led to the following questioning: what challenges and changes do parents experience in caring for their sick child?

In view of the above, the objective of this study is to understand the perception of parents of children and adolescents in relation to the diagnosis of type 1 diabetes *mellitus*.

METHOD

This is an exploratory, descriptive and qualitative study with eleven parents of children and adolescents who have type 1 diabetes *mellitus*. This approach was chosen because it is able of describing, recording and analyzing the reality of parents, since it allows a better understanding of the daily life experienced by family members.

The inclusion criteria were: being a parent of a child/adolescent with type 1 diabetes *mellitus*; being 18 years old or older; being conscious and oriented in time and space.

Families were found through their children's registry at a Diabetes Association located in the city of Maringá (PR), Brazil, after authorization. The first contact with the subjects of the research was made by phone call, in which the research objectives were presented. After acceptance to participate, a meeting was held at the home of the family, or in a place preferred by the family members and at the moment of the meeting the Informed Consent form (ICF) was presented and signed.

Data was produced in September 2012 in the homes of participants, according to their option, through an interview with a semi-structured script containing closed questions for characterization of the subjects and open questions to address the study objective and a field diary to grasp all feelings and expressions not verbalized in the speeches. Interviews were recorded and later transcribed in full-length to further analysis.

After producing data, we began to explore using content analysis in the thematic modality¹⁰, in order to identify the core meanings that make up the subjects' communication and that are relevant to the proposed objectives. To do so, the following steps were performed: pre-analysis; exploration of material; treatment of the obtained results, with the definition of categories of analysis, inference and interpretation. This process led to two thematic categories: "Experiencing the diagnosis" and "Being transformed by the disease".

Pimentel RRS, Targa T, Scardoelli MGC et al.

The research was submitted to evaluation and approval of the Research Ethics Committee of UniCesumar (CEP) according to Opinion 75645/2012, CAAE: 03832312.6.0000.5539, complying with the regulatory norms for the development of research with human beings in accordance with Resolution 466/12 of the National Health Council of the Ministry of Health.

It is necessary to present the parents who participated in this study with codenames of feelings recorded in the field diary during the interviews: Concern, Overcoming, Serenity, Acceptance, Attachment, Hope, Kindness, Love, Affection, Complicity and Dedication.

RESULTS

Eleven relatives participated in this study; nine were represented by mothers of children/adolescents and only two were fathers. They were aged between 33 and 46 years. All were married and had one to three children.

Regarding schooling, five had completed superior education, four had completed high school and two had not completed high school. The income of the interviewees was between three and six minimum wages. The family composition was of the nuclear type, consisting of three to seven people. As for religion, six were Catholics and five, evangelicals.

The age of children and adolescents with diabetes *mellitus* type 1 was between five and 17 years. The time of living with the disease in the family context varied from one to 11 years at the time of the interview. Eight were children and three were adolescents.

◆ Experiencing the diagnosis

In this first category, it was evident that the discovery diabetes comes into the family history as something that divides life between before and after diagnosis. In the speech of Overcoming, this watershed was evident; after the discovery, the father realized that the onset of the disease modified all the conviviality; he would remember the healthy moments and would compare them with the triggering of the illness that brought the suffering of his daughter:

He (father) divided by photos, because he sees photos and says: Ah!! Here she was not sick yet, and in that one, she was already sick. And even today she suffers a lot, still needs treatment, she suffers a lot even today. (Overcoming)

Most parents described the moment of diagnosis as the most difficult of their lives, because this moment is permeated with

Do diagnóstico ao desconhecido percepções dos pais...

sadness, anguish, despair and suffering, which results in anxiety of not being able to deal with the situations that may happen in the experience of chronic diseases:

I was sad because I thought: My daughter's life is over! You see a movie in your mind. How's the birthday going to be? The food, she will not be able to eat anything! I said: My God, it's over! (Attachment)

My world fell apart, I cried for several days. At first it was very hard, the diagnosis of diabetes is very complicated because you sleep on a good day and wake up to an entirely different routine. So, you change your whole life from one minute to the next and this is very difficult. (Affectionate)

In her report, Affectionate felt judged by an attitude she had with her son, what may be the trigger of guilt:

When he was diagnosed, he was 2 years old. He was diagnosed in April, Easter was over, and there was an occasion that he received a chocolate egg and I let him eat alone, got all choked with chocolate. Then we put a photo on the social network and that was enough for everyone to start saying: "of course! He ate a lot of chocolate!!" And, I heard that a lot. (Affectionate)

Fear of the unknown in the moment of the diagnosis, treatment and prognosis resulted in difficulties in coping with unexpected situations resulting from the disease, as observed in the reports of Concern and Hope:

I had never knew anything about it, I did not know, and then he had to take insulin, to follow all that diet. So, until adapting, until today is complicated. But it was not easy, we did not know how to handle it, we were nervous in this house. (Concern)

A gente se desesperou, no início foi desesperador, a palavra que resume é desespero. (Hope)

We despaired, at first, it was hopeless, the word that describes this better is despair. (Hope)

In contrast, in Love's testimony, we perceive a better acceptance. In this case, she who soon sought to face the disease, because she had already contact with relatives and friends who experience the same situation:

Because this is hereditary, it is in the family, my cousin has it, and has that since she was five years old, this facilitated my acceptance. If this had never happened in the family before, I would be desperate, I would feel guilty about a poor diet, but the doctor told us, it's genetic. (Love)

The way the family nucleus experiences the child's disease and the understanding of the disease becomes crucial to a good acceptance, control and relationship with the

Pimentel RRS, Targa T, Scardoelli MGC et al.

person with diabetes, especially in cases of children or adolescents. The resistance to accept the disease is a feeling present in these experiences, as observed in the following statements:

My husband suffers, he is afraid of losing our kid, he gets really downhearted. (Overcoming)

My husband got worse than me, he travels, he's a trucker, and in fact he did not even want to travel any more, he did not want to stay away, he wants to stay close to be there, close. (Kindness)

However, it was found that when parents and their children are well informed about the illness, they create mechanisms to adapt and the feelings of fear, denial and despair end up transformed into acceptance:

We deal with that very naturally. For example, this episode he had of hypoglycemia in school, I went there I took care of him and I said: Bye R. (son) Mom is leaving. Then the director looked at me and said: You're going to leave him here! And I said he was going back to school and going to do the activities like a normal child. I cannot take him, shelter him, protect him and talk about my son as if he was miserable, because this is part of his life, I have to let him live life in a natural way and if I put him in a glass tube, he will be an unprotected child, afraid of everything. What I feel is that we parents make this effort, he also makes an effort, to be a normal child, the whole family does, but the community itself does not make an effort to receive it as a normal child. (Affectionate)

However, it is in the children that parents project their dreams and the guilt that they carry, what often motivates the exaggerated care typical of an affective immaturity. This is translated into a great need of protection, lack of confidence in oneself and a prolonged dependence on one or both parents:

Until then, she is seven years old now, and she was one year and eight months old when she developed diabetes and, since then, she has lived under my wing. I do not leave her go out alone. One day she wanted to sleep over her friend's house and then I asked her if that was what she really wanted, and then she said: Let us do this, if I feel bad, I'll call you. Then she went, I stayed home with my heart in the hands, and then she called, I promptly thought of the worst, and she just asked me to get her because she did not want to sleep there, I think she was afraid that something could happen. (Attachment)

In the testimony of Attachment, we saw how the child is extremely dependence on the mother, because the report makes it clear

Do diagnóstico ao desconhecido percepções dos pais...

that the daughter was not prepared to face diabetes by herself. Parents should realize that caring for the child and adolescent is not just giving the medications and supervising their feeding, but they need to help them understand the disease, the treatment and prepare the children for carrying out self-care in the future.

Another noteworthy aspect was the role of health professionals in the report of the diagnosis of the disease to the family. Desperation at receiving the report of an exacerbated prognosis was evident in the testimony of Dedication and Overcoming, as emphasized by the exaggerated signs and sequels, as well as the burden of responsibilities coming from this chronic disease:

The nurses themselves said: You have to adapt and it's going to be like this forever! The doctor also terrified me a lot, she said that I had to prepare for the worst, that destroyed me, I thought: Ok, he is dying! (Dedication)

In the unit, what they gave me of information was what I already knew. It was a very empty and very useless thing. I was would tell me that there is nothing to do about Type 1 diabetes. (Overcoming)

The triggering of a condition of infirmity enters the life of children/adolescents like something new and unknown that reflects in a tangle of feelings and emotions in the parents when they take care of their sick child. This interferes in all the familiar dynamics. Support from professionals trained to deal with the disease is necessary.

♦ Being transformed by the disease of the child

In the second category, it was observed that the families of children with the chronic condition had their daily life altered from the establishment of the diagnosis. After this impact, one of the first concerns of parents is to know what the future of the child will be like: *you change your whole life from one minute to another, it is very difficult, and it's something that you will have to deal with for the rest of your life. (Affectionate)*

Diabetes can be seen as a stressor that affects the normal development of children and adolescents and also affects social relationships within the family system. The changes of routine, with constant visits to the doctor, use of medications and hospitalizations:

Radical change, whether you like it or not, everything changes completely. (Dedication)

Pimentel RRS, Targa T, Scardoelli MGC et al.

Eating habits change. The child starts to face the day-to-day routine as something very difficult:

So, it is always a struggle. (Love)

The changes imposed by the disease also involve parents and siblings. The family, as a whole, realizes the need to adapt to the new reality: *it completely changes the routine of the house, of everyone. (Overcoming)*

Thus, the family has to start a new path, incorporating new eating and life habits, marked by the adoption of a new routine to be followed. Among the adjustments that must be made, food was cited by most parents as the most radical:

Ah! Suddenly we had to change all the food, together with her (daughter). As it was in the beginning, we changed all our habits. (Serenity)

We did not use to eat vegetables. I stopped buying biscuits. I started inserting other foods, other ways of feeding. And food is difficult. You deny cookies, tasty things, and start inserting salad instead, it was very hard, and explaining this to a child is not easy. (Complicity)

Eating habits are altered, just as it happens to the dynamics and relationships, at the same time that the disease starts to be incorporated into the routine of the family. The simple fact of going to a "birthday party" happens to be something complicated and difficult:

We go to a birthday, but before we sing happy birthday, we have to go. (Attachment)

I do everything for her, so, if the other (sister) is going to eat chocolate at the party, M. eats chocolate too, but dietetic chocolate, I bring the chocolate with us, I bring the cake, but everything dietetic, in her version. (Hope)

It is worth mentioning that during the experience of living with diabetes, Affectionate reported that she provides a healthier life for the child. This demonstrated that even with all the limitations imposed by the disease, and this resulted in a better quality of life:

Today I am aware that I offer a better life for R. (son) than what I would have offered if he did not have diabetes. He does physical activity, has good food, things that if he did not have diabetes, I would not be so much concerned about, and would not make so much effort. (Affectionate)

One of the changes that cause feelings of distress, insecurity, fear and suffering to those interviewed is the application of insulin. Most parents described this moment as the

Do diagnóstico ao desconhecido percepções dos pais...

most difficult when treating diabetes mellitus:

This was a very drastic change in the beginning. We had to deal with this (insulin) because he was very young, he was two years old, so, it was difficult for us. (Affectionate)

My husband to this day, he still does not measure, does not apply, he accompanies her, but does not do it and if I'm not at home and an application needs to be done, he calls me to do it, he does not do it at all, so that responsibility was all on me. (Attachment)

Applying insulin is a horror, it's a needle in our hearts when we apply it. (Dedication)

Also, in an attempt to reduce the suffering of seeing the child's/adolescent's pain, parents decide to feel the same as the child when inserting the needle themselves:

But I've felt so much guilt that I would pick up the needle and puncture myself. I would do it to feel the same pain as her, so she did not had to suffer alone, and it was a way to make me feel better too. (Attachment)

The issue of insulin application in the first year was difficult and I would apply it in myself to know the pain, how it feels like in the belly, the leg, the arm and it would hurt because the emotional was shaken, so I would think that it hurts a lot more in her, so the application was difficult at first. (Dedication)

On the other hand, when some parents started experiencing the suffering of the child in relation to the painful treatment, they sought to be strengthened and went after alternatives to change the lives of their children:

I would reason like this, if I will have to punch my child all the time, in a little while the leg, the arm, how will they become? There must be something different! Then we went after the bomb and the sensor. (Overcoming)

I thought, I want to use the insulin pump, but he had been recently diagnosed and I had no support from endocrinologists, they thought it was too early to get the insulin pump, because it was too recent and they did not know how to use it. Then I went after many endocrinologists until I found one that agreed with me. I found it, I placed the order and we have been using it for three years. (Affectionate)

The financial difficulties resulting from the treatment represent a significant cost in the families' budget, making them need to reorganize their budget in order to treat the sick child:

At the beginning, we were worried that everything would be so expensive, she would take a kind of milk that was super

Pimentel RRS, Targa T, Scardoelli MGC et al.

expensive and everything had to be dietary, we did not even have conditions. I would buy insulin, which was expensive, the test tape and I remember that it was very expensive, and this milk would serve seven bottles and it was R\$ 50 a can, that was hard. (Attachment)

Furthermore, there is the need, often, to leave the job to take the child to the frequent consultations and treatment:

My profession and my husband's changed a lot. I quit work, I closed the shop, today I do not work anymore, I spend more time at home because it's something that cannot be left to someone else, a paid worker, to apply the insulin, to decide what the kid is going to eat, that's for the father and the mother to do, thus, the family matter changed completely. (Dedication)

In the testimony of Affectionate, it was evident that lack of professional support has an effect on the family, causing the feeling of helplessness:

I feel that here in M. (city), clarification regarding diabetes is very much missing, support to family members of diabetic children is also missing, as well as movements, union between these people, you know. (Affectionate)

From this perspective, we believe that taking care of the family is a responsibility and commitment of the nurse. An environment of care favoring the relationship between nurses and families is very necessary, in order to build a practice that helps in coping with the difficulties experienced.

DISCUSSION

The information obtained in this research of qualitative nature, contextualized in the time and place of the realization, does not aim to a generalization of the results, but to make a significant contribution to health services in the understanding of the experience of parents who are the caregivers of children with type 1 diabetes *mellitus*.

The analysis of the perception of parents on the diagnosis of type 1 diabetes *mellitus* in their children showed that families have a negative reaction that translates into significant changes of behaviors that deconstruct the daily life. In this scenario, parents consider the diagnosis as a profound milestone. The confirmation implies establishing a new routine for the family, marked by uncertainties, negative feelings, fear and indignation towards the future of their child.

The primary caregiver, while dealing with the child's/adolescent's illness, faces guilt because the children are in their care,

Do diagnóstico ao desconhecido percepções dos pais...

thereby feeling responsible for the onset of the illness and believing that they did something wrong or failed to do what was needed to avoid the disease. It is evident that the feeling of guilt is elapsed from the appearance of the disease, and thus this brings a negative meaning to this experience.

The lack of knowledge about the child's illness has repercussions on the difficulties faced, the treatment and the eating habits. It is important to adapt the new situation in the routine of the family.

An important point presented in the study is the role of health professionals, particularly nurses, in the monitoring of these families from the moment of diagnosis onwards. They need to assist the provision of care and guidelines. However, the study identified the absence of support from nursing professionals. Lack of communication between health professionals interferes with the care given to children and adolescents with diabetes *mellitus*, since parents reported the lack of effective follow-up by these professionals.^{2,12}

Another event to be highlighted is that parents project their dreams in their children and they plan their future, but when faced with a chronic condition, the guilt that comes over them ends up having implications that exaggerate the care they give to their children. This overprotection invades the autonomy of the children and can affect the feelings of dependence. They feel coerced to accept the decisions taken by their families and can also generate clashes of opinions because children may not accept the impositions.¹³⁻¹⁴

When investigating the changes brought by the child's illness, it was verified that adaptation to the new reality is necessary. This includes hospitalizations, change in life styles and eating habits. According to the results found in this study, research indicates that the daily life of the main caregivers has changed and this has taken place with struggle, battle and sacrifice.⁷

Among the changes experienced by parents in their daily life, it was possible to see that feeding was cited as the most drastic. Studies show that eating is the most difficult change, as it is accompanied by suffering, as children are charged with the need to resist eating what they like and the in amount they desire. Parents end up playing a fundamental role in the effectiveness of this diet, because their support makes the child and the adolescent face the disease more adequately and with less suffering.¹⁵⁻¹⁷

Pimentel RRS, Targa T, Scardoelli MGC et al.

Some parents avoid participating in festive meetings, for fear of losing control over their children. This could result in their exclusion from social coexistence, sometimes failing to attend the festive meetings. This is a factor that can cause the social isolation of the family.¹⁸

With the advent of the disease, new care practices are inserted into the routine and the implementation of procedures for the control and application of insulin are situations of suffering for both parents and children. In the quest to reduce the suffering of the child, parents decide to feel the same pain, performing in themselves the painful procedures. This situation shows how the treatment is surrounded by anxieties and fear of the unknown, since children are submitted to various procedures, including the application of insulin that always involves pain.¹⁹

Financial problems faced by parents also interfere with the care given to the sick child. New food and the expense with medicines cause that family to reorganize itself to focus on the treatment of the sick child/adolescent.²⁰

The results show that there is still much to be done in favor of families of children and adolescents with type 1 diabetes *mellitus*. Thus, this study contributes to the elaboration of strategies and to the adequacy and provision of a more humanized care from health professionals.²¹

Among the limitations of this study is the lack of choice regarding a theoretical reference to subsidize the analysis and the discussion of the speeches presenting their social and emotional aspects, what could contribute to deepening the analysis.

Also, the composition of the study subjects, which were only fathers or mothers, can be considered a limitation. It is necessary to include grandparents and other relatives who also assume the role of main caregivers. This would result in more diverse perspectives, since the inclusion of other family members should also be considered essential for the progress of the treatment of children/adolescents with type 1 diabetes *mellitus*.

CONCLUSION

The study made it possible to understand how chronic diseases, in this case diabetes *mellitus*, significantly alter biological, psychological, emotional and, especially, social aspects of the lives of parents of diabetic patients. Furthermore, it was noted

Do diagnóstico ao desconhecido percepções dos pais...

that the involvement of people close to them influences the control and the prevention of the disease, either positively or negatively. The emergence of a disease such as diabetes *mellitus* can give rise to different feelings, but this mostly generates hope of healing. The initial moments, the discovery of the disease, considerably interferes in the way of life of the family and of the diabetic person.

The initial approach of health professionals is important. Especially nurses, who are the professionals who are, historically, close to families and to the reality into which these are inserted, have an important role.

In view of the above, this study contributed to identify the gaps in the care provided to the parents of children and adolescents with type 1 diabetes *mellitus*. The study showed that when parents assume the function of caregivers, they adopt several modifications in their routine, they make sacrifices, and provide support. When they discover the child's diagnosis, they go through a whirlwind of feelings triggered by a chronic, painful and unknown disease.

Thus, it is necessary that health professionals, especially nurses, recognize the obstacles faced by caregivers of patients with chronic diseases. They must plan actions involving parents in the care of the children/adolescents with type 1 diabetes *mellitus*, in order to prepare them for the challenges and limitations that are imposed by the disease and promote the autonomy of the child to perform self-care supported by the parents. They must also provide psychological and emotional support so that these people may have a better quality of life.

REFERENCES

1. Souza IVB, Marques DKA, Lacerda ORM, Collet N. Percepção das mães frente ao diagnóstico do filho com diabetes mellitus tipo 1. Cogitare Enferm [internet]. 2011 [cited 2016 Mar 22]; 16(1):43-8. Available from: <http://revistas.ufpr.br/cogitare/article/view/21110/13936>.

2. Júnior PCTC, Pereira SMPD, Almeida VCF, Saraiva ARB, Alencar AMPG. Assimilating the impact of diabetes mellitus in children under the perspective of mothers. Rev Rene [Internet]. 2014 [cited 2016 May 10];15(1):60-9. Available from: http://www.revistarene.ufc.br/revista/index.php/revista/article/view/1368/pdf_1.

3. Sociedade Brasileira de Diabetes. Diretrizes da Sociedade Brasileira de Diabetes 2014-2015. São Paulo: AC Farmacêutica; 2015. 390 p.

Pimentel RRS, Targa T, Scardoelli MGC et al.

Do diagnóstico ao desconhecido percepções dos pais...

4. Pennafort VPS, Silva ANS, Queiroz MVO. The perception of nurses regarding educational practices for children with diabetes in hospital care. *Rev Gaúch Enferm* [Internet]. 2014 [cited 2016 Apr 11]; 35(3):130-6. Available from:

http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1983-14472014000300130.

5. Cavini F, Gonçalves K, Cordeiro S, Moreira D, Resck Z. Vivências de adolescentes com diabetes: uma abordagem fenomenológica. *J Nurs UFPE On line* [Internet]. 2016 [cited 2016 Sept 12];10(2):805-13. Available from: http://www.revista.ufpe.br/revistaenfermage/index.php/revista/article/view/8375/pdf_9721.

6. Baltor MRR, Matos APK, Wernet M, Ferreira NMLA, Dupas G. The perceptions of families with children having chronic diseases and their relationships with healthcare professionals. *Rev Esc Enferm USP* [Internet]. 2013 [cited 2016 May 22];47(4):808-14. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0080-62342013000400808.

7. Silva MAS, Collet N, Silva KL, Moura FM. Cotidiano da família no enfrentamento da condição crônica na infância. *Acta Paul Enferm* [Internet]. 2010 [cited 2016 June 13];23(3):359-65. Available from: <http://www.scielo.br/pdf/ape/v23n3/v23n3a08.pdf>.

8. Sparapani VC, Borges ALV, Dantas IRO, Pan R, Nascimento LC. Children with Type 1 Diabetes Mellitus and their friends: the influence of this interaction in the management of the disease. *Rev Latinoam Enferm* [Internet]. 2012 [cited 2016 June 13];20(1):117-25. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-11692012000100016.

9. Fragoso LVC, Araújo MFM, Lima AKG, Freitas RWJF, Damasceno MMC. Vivências cotidianas de adolescentes com diabetes mellitus tipo 1. *Texto & Contexto Enferm* [Internet]. 2010 [cited 2016 July 15]; 19(3):443-51. Available from: <http://www.scielo.br/pdf/tce/v19n3/a05v19n3>.

10. Minayo MCS. *Pesquisa Social: teoria, método e criatividade*. 33 ed. Petrópolis: Vozes; 2013.

11. Leal DT, Fialho FA, Dias IMAV, Nascimento L, Arruda WC. A vivência dos familiares de crianças e adolescentes portadores de diabetes mellitus tipo 1. *Rev Eletrônica Enferm* [Internet]. 2012 [cited 2015 Aug 20]; 14(1):189-96. Available from:

https://www.fen.ufg.br/fen_revista/v14/n1/pdf/v14n1a22.pdf.

12. Rankin D, Harden J, Waugh N, Noyes K, Barnard KD, Lawton J. Parents' information and support needs when their child is diagnosed with type 1 diabetes: a qualitative study. *Health Expect* [Internet]. 2016 [cited 2016 May 22]; 19:580-91. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/hex.12244/abstract;jsessionid=623E9B467C6F996EFA8809FF82809D6D.f04t04>.

13. Oliveira APL, Sarmento SS, Mistura C, Jacobi CS, Girardon-Pernili NMO, Lira MOSC et al. Experiências de familiares no cuidado a adolescentes com diabetes mellitus tipo 1. *Rev Enferm UFSM* [Internet]. 2013 [cited 2016 July 10];3(1):133-4. Available from: <http://periodicos.ufsm.br/reufsm/article/view/8074/pdf>.

14. Araújo YB, Collet N, Gomes IP, Nóbrega RD. Enfrentamento do adolescente em condição crônica: importância da rede social. *Rev Bras Enferm* [Internet]. 2011 [cited 2016 May 15]; 64(2): 281-6. Available from: <http://www.scielo.br/pdf/reben/v64n2/a10v64n2.pdf>.

15. Schneider KKL, Martini JG. Cotidiano do adolescente com doença crônica. *Texto & Contexto Enferm* [Internet]. 2011 [cited 2016 May 15];20(spe):194-204. Available from: <http://www.scielo.br/pdf/tce/v20nspe/v20nspea25.pdf>.

16. Malaquias TSM, Marques CDC, Faria ACP, Pupulim JSL, Marcon SS, Higarashi IH. A criança e o adolescente com diabetes mellitus tipo 1: desdobrar do cuidado familiar. *Cogitare Enferm* [Internet]. 2016 [cited 2016 Aug 23];21(1):1-7. Available from: <http://revistas.ufpr.br/cogitare/article/view/42010/27251>.

17. Sweenie R, Mackey ER, Streisand R. Parent-child relationships in type 1 diabetes: Associations among child behavior, parenting behavior, and pediatric parenting stress. *Fam Syst Health* [Internet]. 2014 [cited 2016 Aug 22];32(1):31-42. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3950351/>.

18. Valentim SA, Haddad MCL, Rossaneis MA. Dificuldades vivenciadas pelo portador de diabetes mellitus residente em distrito rural. *J Nurs UFPE On line* [Internet]. 2015 [cited 2016 Aug 15];9(4):7330-7. Available from: http://www.revista.ufpe.br/revistaenfermage/index.php/revista/article/view/5649/pdf_7525.

19. Silva MEA, Gomes IP, Machado AN, Vaz EMC, Reichert APS, Collet N. Implicações da condição crônica da criança para sua família.

Pimentel RRS, Targa T, Scardoelli MGC et al.

Do diagnóstico ao desconhecido percepções dos pais...

Ciênc Cuid Saúde [Internet]. 2014 [cited 2016 May 22];13(4):697-04. Available from: http://www.periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/20816/pdf_251

20. Nóbrega VM, Reichert APS, Silva KL, Coutinho SEID, Collet N. Imposições e conflitos no cotidiano das famílias de crianças com doença crônica. Esc Anna Nery Rev Enferm [Internet]. 2012 [cited 2016 May 22];16(4):781-8. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1414-81452012000400020.

21. Lawton J, Waugh N, Noyes K, Barnard K, Harden J, Bath L et al. Improving communication and recall of information in paediatric diabetes consultations: a qualitative study of parents' experiences and views. BMC Pediatr. 2015; 15(67):e9. doi: 10.1186/s12887-015-0388-6. PubMed PMID: 26054649; PubMed Central PMCID: PMC4460975.

Submission: 2015/09/05

Accepted: 2016/08/06

Publishing: 2017/03/01

Corresponding Address

Rafael Rodrigo da Silva Pimentel
Rua Londrina, 298, Ap. 07
CEP: 87050-500 – Maringá (PR), Brazil