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ORIGINAL ARTICLE

PARENTS EXPERIENCES OF CHILDREN WITH DIABETES MELLITUS

EXPERIÊNCIAS PATERNAS DE CRIANÇAS COM DIABETES MELLITUS

EXPERIENCIAS PATERNAS DE NIÑOS CON DIABETES MELLITUS

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ABSTRACT

Objective: to investigate experiences for parents of children with diabetes mellitus. ***Method***: exploratory, descriptive study, with a qualitative approach, carried out in the municipalities of Alagoinha and Guarabira/PB, in March 2013, with the participation of 20 parents of children with diabetes mellitus, from semi-structured interviews. The data were analyzed using thematic analysis technique. ***Results***: from the speeches of the participants the categories for analysis emerged: << Feelings of sadness, worry and helplessness before the diagnosis >>; << Change routines and daily habits >>; << Watch the child before the treatment >>; << Fear of the consequences of the disease >>; << >> Suffering; << The child self-care and difficulties in support area >>. ***Conclusion***: attention to parents by health professionals is essential for diagnosis and the following treatment so that they feel more secure and able to care for a child with diabetes mellitus. ***Descriptors***: Children; Chronic Disease; Parents.

RESUMO

Objetivo: investigar experiências por pais de crianças com diabetes mellitus. ***Método:*** estudo exploratório, descritivo, com abordagem qualitativa, realizado nos municípios Alagoinha e Guarabira/PB, no mês de março de 2013, com a participação de 20 pais de crianças com diabetes mellitus, a partir de entrevistas semiestruturadas. Os dados foram analisados pela Técnica de Análise Temática. ***Resultados:*** a partir dos discursos dos participantes, emergiram as categorias para análise: << Sentimentos de tristeza, preocupação e impotência perante o diagnóstico >>; << Mudança de rotinas e hábitos cotidianos >>; << Cuidado com a criança diante do tratamento >>; << Medo das consequências decorrentes da doença >>; << Sofrimento >>; << Autocuidado do filho e dificuldades na rede de apoio >>. ***Conclusão:*** a atenção aos pais pelos profissionais de saúde é essencial no momento do diagnóstico e no seguimento do tratamento para que estes se sintam mais seguros e capazes de cuidar de uma criança com diabetes mellitus. ***Descritores***: Crianças; Doença Crônica; Pais.

RESUMEN

Objetivo: investigar experiencias por padres de niños con diabetes mellitus. ***Método***: estudio exploratorio, descriptivo, con enfoque cualitativo, realizado en los municipios Alagoinha y Guarabira/PB, en el mes de marzo de 2013, con la participación de 20 padres de niños con diabetes mellitus, a partir de entrevistas semi-estructuradas. Los datos fueron analizados por la Técnica de Análisis Temático. ***Resultados***: a partir de los discursos de los participantes, surgieron las categorías para análisis: << Sentimientos de tristeza, preocupación e impotencia frente al diagnóstico >>; << Cambios de rutinas y hábitos cotidianos >>; << Cuidado com el niño frente al tratamiento >>; << Miedo de las consecuencias decurrentes de la enfermedad >>; << Sufrimiento >>; << Autocuidado del hijo y dificultades en la red de apoyo >>. ***Conclusión***: la atención a los padres por los profesionales de salud es esencial en el momento del diagnóstico y en el seguimiento del tratamiento para que estos se sientan más seguros y capaces de cuidar de un niño con diabetes mellitus. ***Descritores***: Niños; Enfermedad Crónica; Padres.

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INTRODUCTION

Diabetes Mellitus (DM) is a metabolic disorder of multiple etiology associated with absolute or relative deficiency of insulin, whose symptomatology is characterized by metabolic and vascular and neuropathic complications.[1] Being considered a chronic disease, it requires a continuous treatment of the people affected, resulting most often in physical, psychological and social distress linked to the limitations and changes in various spheres of life of the patient and his family.[2]

DM1 or children-young diabetes is a metabolic disorder syndrome caused by lack of insulin secretion due to damage in the beta cells of the pancreas or disorders that impair insulin production, characterized by chronic hyperglycemia with carbohydrate metabolism disorders, lipid, and proteins.[3] Its incidence mainly affects children and adolescents. In the face of hyperglycemia, the patient may experience manifestations of the symptomatic triad, as polyuria, polydipsia, and polyphagia, and sudden weight loss, nausea, vomiting or abdominal pain. When the patient does not follow the recommended treatment, he may develop complications, such as neuropathy, nephropathy, among others.[4]

According to the International Diabetes Federation in recent decades, the number of people affected is growing every year in almost all age groups. Estimates for 2012 pointed to over 370 million people with diabetes worldwide; 4.8 million people are undiagnosed, and over $ 471 million was spent on health care for diabetes.

Brazil is the fifth country with the highest absolute number of diabetics in the world, with prospects of remaining in the same position until 2030.[1] Study conducted by the Ministry of Health in collaboration with the Brazilian Society of Diabetes found that in 2012, there were in Brazil over 12 million diabetics and the incidence of type 1 DM, for the same year was in the order of one to two cases per thousand young people.[1]

With regard to the incidence of the disease in children, Eurodiab Collaborative Group published in 2008, a survey of 16,362 cases of DM at this stage and noted a 6.3% rate in children under four years of age; 3.1% for those between five and nine years and 2.4% for those between ten fourteen years.[5]

In children and adolescents, DM1 has grown 3% per year worldwide, rising to 5% among children in preschool. It is estimated that about 70,000 young people under 15 develop the disease. The Brazilian estimate provided for 2030 is that, on average, 200 young people have been diagnosed with diabetes per day.[6]

Childhood being a stage of physical, psychological and social requires special attention, since it is observed the development and infant growth, and when it presents a diagnosis of a chronic degenerative disease such as DM1, parents are almost always responsible for the care to be performed, as well as observation of clinical symptoms and/or complications arising from the clinical course of the disease.[7]

Parents of children with chronic diseases often feel powerless in the living process on limitations and suffer the new situation, changes in lifestyle and the demand for specific care that the treatment of the disease requires. Faced with these difficulties by parents and children, health professionals should reflect on their responsibility to the process of their adaptation to the disease, continually seeking strategies to provide them develop skills and knowledge, important tools for motivation to treatment adherence of the son and family reorganization.[7]

In this sense, it is essential psychological support for both the child and for the parents, because the impact of the diagnosis of a chronic disease, such as DM, hinders the acceptance of the health-disease process, and this creates family strength on the break of paradigms, especially nutritional treatment which must be performed successfully for the control of endocrine disorder. [5]

In this perspective, knowing the expectations, perceptions and experiences of parents of children with diabetes, it is extremely important for health professionals, especially those working in primary care, serving as grants to improve the quality of care for these people to help them to recognize and understand the behavior of their children; encourage them to participate in care to promote and facilitate the interaction of the child who has diabetes with their family, strengthening family ties.[7]

OBJECTIVES

● To investigate experiences for parents of children with diabetes mellitus.

● To describe the care that they provide to these children.

METHOD

Considering the study involves the pursuit of elements of the context of the experiences of parents of children with diabetes mellitus, the qualitative approach shows relevant to the scope of the proposed objective.

Descriptive and exploratory study, conducted in March 2013 with the participation of 20 parents living in two municipalities - Guarabira and Alagoinha - located in the Agreste Paraibano. To select the sample, the following inclusion criteria were adopted: being a father or mother of a child with Type I DM; of age or over 18 years; and agree to the interview in their home.

The execution of the search was authorized by the Municipal Health Department of the municipalities involved, and the research project was approved by the Ethics and Research of the University Hospital Alcides Carneiro, Campina Grande-PB under the CAAE number 06392912. 0. 0000. 5182.

Participants were selected from records obtained in Alagoinha and Guarabira Basic Health Units/PB. Then, the parents were invited to participate in the study, presenting them with the consent form to signing it. At the time, it was requested permission to interview recording, emphasizing the voluntary, anonymous participation and the possibility of leaving the research at any time and without any damages or losses for those involved.

Data collection was carried out at the homes of study participants through semi-structured interviews, recorded with MP3 device Sony, previously tested, lasting between 20 and 30 minutes. To ensure the confidentiality of the identity of the participants and their knowledge, they were used precious stones names as aliases, randomly assigned without specific criteria. At the end of the interviews, it was allowed to listen to the speeches by the respective participants. From the data saturation, there was the time communication and perception of facts by the participants begin to repeat, without imminent new facts[8] closing the data collection. Later, all the speeches were fully transcribed to form the corpus of the study material.

For analysis, it was chosen the thematic analysis and grasp the core meanings that compose communication, considering the frequency of data that give significance to the analyzed object, the pre-analysis steps, material exploration and treatment results were observed obtained and interpretation.[8]

RESULTS AND DISCUSSION

The study included 19 mothers and a father of children with Diabetes Mellitus. A predominance of parents aged between 31 and 40 years was observed, representing 10 parents (50%), followed by 21 and 30 years and 41 and 50 years, equivalent to four (20%) parents respectively, and 51 or older, corresponding to two (10%) parents participating in the survey.

As for education, 11 (55%) parents reported having an elementary school, eight (40%) high school and only one (5%) participants declared no education. concerning family income in terms of the monthly minimum wage, 11 (55%) parents reported income of a minimum wage, followed by three (15%) with less than a minimum wage, two (10%) with two minimum wages, three (15%) receive three minimum wages and only one (5%) have a monthly income of eight minimum wages.

The above data shows that about the socioeconomic aspects of the study participants most are families with low education and low monthly income, which can contribute to poor support in the daily lives of these families living the experience of a child with a disease chronic and limiting in many aspects of life.

♦ Presentation and characterization of categories

The speeches of parents, obtained in the recorded interviews were transcribed and proceeded several readings with the aim of the authors to appropriate the essence of their speech and allow the inference of the themes for analysis, emerging the following categories of analysis: 1 - Feelings of sadness, worry, helplessness before the diagnosis; 2 - Change of routines and daily habits; 3 - Fear of the consequences of the disease; 4 - Suffering; 5 - The child self-care and 6 - Difficulties in support network.

The thematic category 2 - Change of routines and daily habits adds a subcategory entitled: Care of the child before the treatment.

♦ Category 1 - Feelings of sadness, worry, helplessness facing the diagnosis

The discovery of the diagnosis of a child with diabetes can be the framework of a new lifestyle, this time, characterized by fears, uncertainties, limitations and concern.[9] These feelings are shown as ways of coping significant situations that threaten individuals observed in the following lines:

> *It was a big shock [...] because it is diabetes and be a child (Amber).*
>
> *I cried a lot, and I was worried. I felt terrible! (Crystal).*
>
> *My feeling was helplessness! You cannot do anything at that time (Amethyst).*
>
> *Very sad huh ?! Because we think, have healthy children, and when it comes to a disease [...] we suffer a lot (Quartz).*

It is natural that parents always expect healthy children, so there may be frustrations and disappointments to find that the child is carrying a chronic disease by changing the dreams of a future without interference in the child's development and living conditions.

Given this situation, the parents plans for this child are modified, and the future becomes doubtful. During discovery of the diagnosis, it is evident that the emotional aspect becomes embrittled by changes in dreams and design expectations that mothers for their child. Fear and anxiety remain even after diagnosis, though the situation requires emotional balance so that these feelings do not affect the care.[10]

In this context, the feelings and concerns go beyond the immediate; they are concerned about the new style of living of the son, limitations, and new types that care that will certainly affect the whole family. Parents experience negative feelings, leaving them plagued by the inability to meet the demands imposed by the disease, even with the assistance received and dedication dispensed in the course of treatment.[11]

The fact of not having generated a perfect child and doubts about the future of their child can provide feelings of guilt, anxiety, fear and even grief, which ultimately interfering with the family routine.[12] Thus, having the family close is one of the keys to success in the treatment of people with diabetes; however, the family must be emotional balance and can help to satisfactorily in the treatment and thus overcome the conflicts.[13]

Study of mothers of children with Type 1 Diabetes Mellitus allowed increasing knowledge about the perception of these mothers before the diagnosis of their sons, showing despair, anguish, and fear as feelings experienced at the time of diagnosis.[14]

♦ Category 2 - Change of routines and daily habits

Chronic illness can be seen as a stressor that affects the normal development of the child and also affects social relationships within the family system. The routine family changes with constant doctor visits, medications, and hospitalizations.[2] The change in family life, especially the changes related to eating habits, is evident in the following statements:

> *It is difficult because you have to have rules. Time to food must be every three hours. You have to practice sport (Chalcedon).*
>
> *The way of life has also changed. He does not eat a lot of pasta, soda, sweets, cake, getting enough exercise (Pearl).*
>
> *We had to totally change the menu, even to keep it in power. Then thinking about the welfare of her, everyone lives today, by her situation (Quartz).*
>
> *I do not like to go to parties for her not to see the children eating because he sees children eating ice cream, she wants. Popcorn, she wants. So to not see her suffering so much, so I prefer more at home, leaving only the place that she did not see those kids eating whatever she wants (Galena).*

Starting a new way in the lives of these families means incorporating new eating and living habits, introducing a new routine to follow. The adaptation of family life to the child´s illness and the consequences it entails have implications for everyone involved, on the one hand depriving some habits that were regular, and secondly by introducing a healthier way of life, but that was not part every day. Among these habits, the food is what most affects the family in this context.[9]

The participants stressed that the specific power was one of the most complicated items following the diabetes treatment because there was a significant change in supply. The diet compliance can become even more difficult due to some aspects: to be restricted, continuous and low glycemic products encumber the family ordinary expenses.

In this perspective, food control is always a question of conflict between the family and the carriers of the disease, creating difficulties and distress due to the parents insist on a strict diet control and thus reducing the frequent use of insulin. This difficulty encountered by parents after the discovery of the disease about food is also included the financial side of buying new and specific foods to the pathology.[7,12]

In this regard, the correct treatment of diabetes requires good nutrition, regular control of blood glucose, insulin delivery, and financial difficulties may hinder or hamper the control of the disease. Another aspect that should be highlighted is that often the family in an attempt to prevent the child consume foods with high glycemic content limits their social life, excluding events that are considered important to the development of the child.[18]

Adding to the challenges already posed by DM, negative attitudes of friends also occur due to lack of knowledge about the diagnosis and, even when they know, such attitudes are influenced by the lack of knowledge about the functioning of the disease and the care needed with the same for this food plan is essential to the successful management of DM1. The reports show that this may result in behaviors not always desirable to the child, especially when it involves candy offering to them.[19]

♦ Subcategory 1 - Beware of the child before treatment

Living with the fear understands the feelings of fear that parents have about the future of the child and unfavorable situations that may arise in the short and long term, lived in moments of unexpected decompensation.[11] It is experiencing these fears when the child is with more severe hypoglycemia or hyperglycemia. It does not have tranquility, always worried about something that can happen at any time:

It is very complicated because when he has any virus, immunity it already low and there have diabetes changes (Opal).

Have to be very careful with hypoglycemia, then you have to make her eat sugar (calcite).

Then suddenly I find myself having to stick three or four times, on the little finger of her, bailing in the case of hypoglycemia (Pyrite).

Survey participants emphasize the difficulties encountered by the continued coexistence of treatment, which requires discipline, patience, attention and care. In this sense, it is noteworthy that following all team health guidance becomes an arduous task due to continued care.

According to the adaptation of parents and the information they receive about the care in the treatment of children, they realize what changes should be made, such as changes in feeding times, the practice of physical exercise, insulin application at the correct times and concern for the child to get sick and cannot eat certain foods, in addition to disproportion care of the child, concerning injury for fear of not healing.[9]

♦ Category 3 - Fear of the consequences of disease

Both children and parents have difficulty living with the disease, being prone to feelings of worry and fear and permanent sense of threat to the physical integrity of the patient for the consequences that may arise:

> *Living in fear as it may aggravate the situation (Jade).*
>
> *I felt very worried because diabetes we know that the person is blind and lose members [...] and that kills when it is not treated (Rubi).*
>
> *And he for being child gets hurt a lot and takes to heal (Quartz).*
>
> *You have to be careful with hygiene. Be careful not to cut at her feet, to see if it's cracked (Larimar).*

For parents' research, diabetes was as a propellant for care. The awareness of the importance of care is based on common sense that the child having this disease will be changes in their lives as a daily reordering is required. This condition requires direct care for avoiding complications inherent to the disease to the child, such as hygiene with their feet, be careful not to cut or hurt your feet, check if it is not to crack, do not allow the child to stay barefoot and others.

The families are worried and fearful about the immediate and late complications that may be affected due to not correct adhesion of the child's treatment. The morbidity associated with long-term diabetes results in certain complications such as microangiopathy, retinopathy, nephropathy, and neuropatia4. The absence of correct metabolic control may contribute to long-term complications compromising thus the quality of life of these persons.[4-15]

Study of 1009 children and adolescents found that the prevalence of retinopathy was 1.4% and 6.4% nephropathy. It showed that this representative sample of type 1 diabetes had poor control metabólico16. Another survey conducted with 71 adolescents with type 1 diabetes showed that of the total group, only 13 patients (18.3%) were classified as adequate glycemic control and patients with poor glycemic control had a lower age at diagnosis and longer duration of the disease.[17]

Thus, treatment recommendations for the control of DM1 in children and adolescents are based on insulin replacement, nutritional adequacy and physical activity for the prevention of acute and chronic complications and promote growth and development. In planning and implementing the recommendations, patient characteristics must be known for accuracy of actions and control.1

♦ Category 4 - Suffering

The experience of seeing her son suffer from the disease causes great suffering to the parents, who try not to expose the child. This pain is also experienced with distress at the time of monitoring of blood glucose and insulin administration, even arranged to do whatever it takes to reduce the aversion that the child feels the procedimentos.[11]

> *My daughter takes four insulin a day, four punches. She makes three times blood glucose test; there are times when she cries because it hurts. This is only suffering! (Pearl)*
>
> *She is saying. "I'd rather die than live like this, without being able to eat things" That's difficult, it's very painful to hear it! (Larimar)*
>
> *She says, "Mainha, when I'll be good" is not easy to hear that (Calcite)*

> *Then, every time I applied the insulin, I'd go to the room, crying very well, and sometimes I applied wrong, and bleeding, there was that was sad (Chalcedon).*

Survey parents reveal that the achievement of blood glucose testing and insulin application are difficult moments to experience because often feel tortured by the knowledge that this is the only option to help the child.

This health condition that requires dietary restriction, daily application of insulin and strict control of blood glucose levels, requires adaptation to change, not only the child but also the family. The insulin therapy limits the child´s life with diabetes and their families on schedules, control, and application. Parents feel tortured, as in most they carry out the parenteral administration of medication. In addition to these aspects, it is noteworthy that the maintenance of regular physical activity and adherence to psychosocial treatment is required.[7,9,11,20]

Chronic degenerative diseases such as type 1 DM need treatment for life and during this journey the family members go through difficult times, knowing that dedication to the care of children requires time and energy.[6]

♦ Category 5 - The child self-care

Chronic disease imposes changes in the child's life and his family, requiring retrofits in the face of the new situation and coping strategies. It is recommended that parents and health staff promote learning opportunities for the child to develop skills for self-administration of insulin and home control and recognize the foods that are allowed aiming at their independence.[9]

This fact is evident in the speeches below, in reporting on their own children experience in relation to self-care:

> *Once we start to get along with others and participate in lectures, we have a quieter life and see that [...] it is a disease that is treatable and we can have a normal life (Opal).*
>
> *Today, he is very aware, he know you cannot eat sweet things (Tourmaline)*
>
> *The doctor said: "You are who will apply your shots!" In a moment she learned, is the one who applies the arms, belly and thigh (Turquoise).*
>
> *She arrived in a place, the staff offered: either a bullet? She: "I cannot, I'm diabetic." Someone gave a glass of soda to her, then she: "No, I can only take if zero [...] because I'm diabetic!" (Galena).*
>
> *Once we start to get along with others and participate in lectures, we have a quieter life and see that [...] is a disease that is treatable and it can have a normal life (Opal).*

By studying the coping strategies of adolescents with DM1, researchers found that support and social support are strategies used by young people as a positive factor to face the unwanted effect of stress of disease.[15] They seek to talk with family members in an attempt to accept the realization of a daily and repetitive treatment because often feel exhausted by having to always do the same things every day, but at the same time remember the care and family care that drive to advance and face difficulties.

Researchers studying diabetic adolescents, it was noted in their speeches that they are able to analyze their initial experiences with diabetes as difficult, but to relate how they cope in this with their treatment, concluding that today are more instrumented, therefore more easy to get along in daily life with all the requirements that diabetes needs.[15]

similar meanings were found in speeches of teenagers of a study[13], to verbalize they had to get used to the changes, which felt like normal people seeking harmony with chronic illness and being diabetic would face and face treatment, that is, have brave spirit.[13]

There are ways to combat the chronic health condition, for example, search for information, acquire skills, use features such as monitoring and adherence to therapy and incorporation of the new situation to lifestyle familiar.[11] With regard to emotions and feelings of uncertainty , ambiguity and uncertainty, it is recommended to use strategies such as explanations for what is happening, considering the causes and results of the condition you are experiencing, use defense mechanisms to keep hope, keep the communication process and relationship to accept offer and refuse support.[9]

♦ Category 6 - Difficulties in the support network

The social network has fundamental importance because it is an essential resource in helping the family at different times in the course of chronic disease. Thus, health professionals must recognize their importance and work on it in order to strengthen coping mechanisms and help in adapting this journey.[12]

During the stages of chronic disease, the participants of this research go through many difficult times, including the difficulty of supporting the network of public service does not provide necessary materials continuously for diabetes control.

> *It is quite complicated, because unfortunately the health of Brazil bad and does not offer nearly feature [...] if I had this health plan (Pyrite).*

> *The greatest difficulty is financial, because it has the exams, the ribbons that we purchase; It is all difficult (Pearl).*
>
> *Her doctor insisted so much that we had to resort to the Ministry of Health and get the insulin it free, then we went to court and managed to get by the city (Quartz).*
>
> *We get the SUS straight: the tapes, insulin. But there are moments missing, then we have to replace buying and everything is very expensive (Agate).*

Lack of host connection and accountability at the primary level of health care have triggered difficulties in coping with the chronic condition in childhood families of this study. There is no reception as the availability of material resources is committed, directly affecting the health of children. Actions of this nature make it impossible to provide care guided by the dialogic dimension in the encounter between professionals and families of children with chronic conditions, restricting the social network that already shows fragile. Therefore, it is necessary to think about this method of organizing work process so that these families feel welcomed in their health needs.

There is still long way to go in this regard, since the child and family need to be pursued and be accompanied by professionals from Basic Health Units that should act concurrently with the Health Departments of the municipalities cited in this study to give adequate support to children.

FINAL REMARKS

It is shocking for parents the diagnosis of their child with a chronic degenerative disease such as diabetes mellitus type 1, which is expected healthy and suddenly children are facing a pathology which will face throughout their lives.

The participants emphasized that sadness, worry and helplessness are the feelings arising at the time of the child's diagnosis of discovery with DM1 because it is a chronic disease of unknown etiology and possible future complications. Therefore, monitoring of health professionals is essential, not only at the time of diagnosis as well as for the continuity of treatment for parents to feel more secure and able to care for a diabetic child.

The study makes us understand that the change in lifestyle and routine of children with DM and the family is inevitable and radical. The results showed that the change in eating habits is one of the most difficult activities recommended treatment from the perspective of parents, because there are many dietary restrictions imposed by the disease and those changes, most of the time, are followed not only by children but also by his family in order to facilitate the adaptation of the child to the new food menu.

In addition to changes in diet, treatment requires them an important rigor, as regards the intervals of meals, testing blood glucose, the insulin injections and symptoms of hypoglycemia. Other parents fear is related to food in school, and in children's parties, due to the high glycemic foods that are offered on these occasions. These situations difficulties indicate that parents need support and support to deal with diabetic children. The family begins to live with the sick child and ends up involved with the daily care. Thus, feelings of fear, denial and despair can lead to acceptance.

Limitations of this study focus on the fact, because it is a qualitative study, we have a small sample, restricted to a single geographic location, does not confer significant statistical consistency and the results; however, our findings may give rise to reflections for the multidisciplinary team and be a stimulus reason for new studies to prove or disprove these findings, as the purpose of strengthening our knowledge of the problem that permeates families have in their midst a child with diabetes, requiring respectful, dignified and ethical care and can promote better quality of life.

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