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ORIGINAL ARTICLE

HOW MOTHERS PERCEIVE THEIR CHILDREN WITH THE NEPHROTIC SYNDROME COMO AS MÃES PERCEBEM SEUS FILHOS COM A SÍNDROME NEFRÓTICA CÓMO LAS MADRES VEN A SUS HIJOS CON SÍNDROME NEFRÓTICA

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ABSTRACT

Objective: to understand the perception of the mothers with children diagnosed with Nephrotic Syndrome. **Method:** qualitative study performed at the University Hospital Professor Alberto Antunes (HUPAA). The production of data was collected through interviews recorded in mp3 with a semistructured script. For data analysis, a database in Microsoft Word was built. After this step, data analysis was performed through the technique of content Analysis in thematic mode. The research project was approved by the Ethics Committee in Research, CAAE number 17257413.2.0000.5013. **Results:** mothers understand that the nephrotic syndrome represents failure on renal filtration resulting in edema of the child, which is why mothers seek the health service. This disease is common for the child to be hospitalized several times in the same year, resulting in the delay of school life and an obstacle for mothers to work. **Conclusion:** mothers presented a regular level of basic knowledge about the disease and the treatment, and perceive the disease as something negative that prevents their children and families having a normal life. **Descriptors:** Nursing; Knowledge; Nephrotic Syndrome; Son.

RESUMO

Objetivo: compreender a percepção das mães cujos filhos têm diagnóstico de Síndrome Nefrótica. **Método:** estudo de abordagem qualitativa realizado no Hospital Universitário Professor Alberto Antunes (HUPAA). A produção dos dados foi realizada por meio de entrevistas gravadas em documento mp3 com um roteiro semiestruturado. Para a análise dos dados, foi construído um banco de dados no Microsoft Word. Após essa etapa, foi realizada a análise dos dados através da técnica de Análise de Conteúdo na modalidade temática. O projeto de pesquisa foi aprovado pelo Comitê de Ética em Pesquisa, CAAE nº 17257413.2.0000.5013. **Resultados:** as mães compreendem que a síndrome nefrótica representa falha na filtração renal que resulta no edema da criança, motivo pelo qual as mães procuram o serviço de saúde. Nesta doença, é comum que a criança seja hospitalizada várias vezes no mesmo ano, resultando no atraso da vida escolar e um obstáculo para que as mães possam trabalhar. **Conclusão:** as mães apresentaram um nível regular de conhecimentos básico sobre a doença e o tratamento, e percebem a doença como algo negativo que impede seus filhos e as famílias de terem uma vida normal. **Descritores:** Enfermagem; Conhecimento; Síndrome Nefrótica; Filho.

RESUMEN

Objetivo: comprender la percepción de las madres cuyos hijos tienen diagnóstico de síndrome nefrótico. **Método:** estudio de enfoque cualitativo realizado en el Hospital Universitario Profesor Alberto Antunes (HUPAA). La producción de los datos fue realizada por medio de entrevistas grabadas en mp3 con una guía semi-estructurada. Para análisis de los datos, fue construido un banco de datos en Microsoft Word. Luego de esa etapa, fue realizado el análisis de los datos por medio de la técnica de Análisis de contenido en la modalidad temática. El proyecto de investigación fue aprobado por el Comité de Ética en Investigación, CAAE número 17257413.2.0000.5013. **Resultados:** las madres entienden que el síndrome nefrótico representa una falla en la filtración renal que resulta en el edema del niño, motivo por el cual las madres buscan el servicio de salud. En esta enfermedad es común que el niño sea hospitalizado varias veces en el mismo año, resultando en el atraso de la vida escolar y un obstáculo para que las madres puedan trabajar. **Conclusión:** las madres presentaron un nivel regular de conocimientos básico sobre la enfermedad y tratamiento, y notaron a la enfermedad como algo negativo que impide a sus hijos y sus familias de tener una vida normal. **Descriptores:** Enfermería; Conocimiento; Síndrome Nefrótico; Hijo.

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INTRODUCTION

Nephrotic syndrome (NS) is a set of signs and symptoms, caused by several diseases that affect the kidneys, being characterized by massive proteinuria (proteinuria over 50 mg/kg/day), Hypoalbuminemia (serum albumin lower than 3 g/dl), Hyperlipidemia (total cholesterol equal or greater than 240 mg/dL; HDL cholesterol equal or less than 60 mg/dL; triglyceride levels equal or greater than 200 mg/dL), and edema.¹⁻³

Generally, the NS is diagnosed when a child presents a variety of symptoms, including the focal edema, main reason of the consultation. The child also complains of abdominal pain, due to mesentery edema. In clinical evaluation characteristics of edema are considered, which is movable, detected on the eyelids in the morning and ankles after walking. With the evolution of this picture, accented transudates, anasarca, scrotal or vulvar edema appeared. The child may develop oliguria or even acute renal failure due to hypovolemia and decreased perfusion. It could be orthostatic hypotension or even a shock in the children. As a result, the proper behavior is a rigorous medical follow-up, the stimulus to water intake, rigid control of weight, blood pressure and fluid balance.^{1,4-6}

The diagnosis is based on clinical and laboratory criteria and the treatment initially refers to the corticosteroid therapy and should be evaluated within eight weeks to know if the child is responding to the treatment. In all cases, the responsible for the child is guided about the continuous medical follow-up in order to detect early recurrences and restart therapy minimizing complications associated with the children NS.⁷

In every relapse, the hospitalization process changes the routine of the child and the parents. Hospitalization suggests certain changes in routine, such as change in family dynamics, the interruption or delay in education, the affective deficiencies, maternal deprivation, physical and psychological aggression, among others. Thus, the child who is ill and hospitalized, becomes more fragile and sensitive emotionally.^{8,9}

In this sense, the impact of NS can be reflected in several areas of the child's life, potentially interfering on the opportunities for a healthy socio-emotional development and participation in children activities, limiting the independence of the child, since parents usually control the habits of children and contact with other children, in order to protect them, for fear that the child can get

infections. This limitation affects the understanding and acceptance of the disease by the child.^{10,11}

Nursing professionals play an important role in the care of the patient with NS, taking care of his food, water intake, and possible changes in the clinical picture with a view to their propensity to infections.¹² Also, the need for emotional support to the child, his family and health education. However, it is noticed that the multiprofessional work is essential to achieve good results.

This study was motivated by the curiosity during graduation, having the opportunity to watch children with nephrotic syndrome and their caregivers at the University Hospital Professor Alberto Antunes (HUPAA). When hearing the report of a mother, it is realized that the nephrotic syndrome does not affect just the life of the child, but the parents' routine and the way the child is treated by parents, since there is a greater care with the food, the medicine, everyday activities and interaction with children of the same age.

When searching in the literature about the disease, it is observed that nursing has a few publications on the topic. Thus, this publication contributes to the collection of nursing since the nursing professionals are those who take care of the patient most of the time during hospitalization and they need to know how to deal with the child and also with the caregiver, considering the emotional impact of the diagnosis, the daily coexistence with the sick child and the consequences of the disease.

This study aims to:

- Understand the perception of the mothers with children diagnosed with nephrotic syndrome.

METHOD

Qualitative study performed in a hospital, centre of reference in the nephrotic syndrome treatment in any age group, assisting patients in outpatient and hospital, free of charge, by the Unified Health System (SUS).

The study was conducted with parents of children diagnosed with nephrotic syndrome, hospitalized in Pediatrics of HUPAA during the period from August to October 2013, who accepted to participate in this study, by reading and signing the free and informed consent term - TCLE.

The production of the data was collected through interviews recorded in mp3 with a semi-structured script. For each individual the purpose and the form of research was explained and those who agreed to participate

was given a Free and Informed Consent Term - TCLE to be signed, in two copies, one for the researcher and the other delivered the patient at the end of the research.

For data analysis, a database in Microsoft Word was built. After this step, data analysis was performed through the technique of content Analysis in thematic mode. This technique allows to exploring various representations of reality based on certain theoretical methodology, because it is characterized as a technique for understanding the social dynamics and relations established between the subjects in their contexts of life.¹³

Content analysis is divided into three steps: exploration of the material, pre-analysis and processing of results, inference and interpretation. The pre-analysis is the step of organization aiming to operationalize and systematize initial ideas in such a way and to lead to a schema with research development. The step of the exploration of the material consists of analyzing the text systematically according to the categories formed earlier. The last step is the treatment of results and interpretation where raw results are used, divided into categories such as units of analysis, where they are subjected to simple or complex statistics operations depending on the case, allowing highlighting the information obtained.¹⁴⁻⁵

The research was approved by the Ethics Committee of the Federal University of Alagoas CAEE number 17257413.2.0000.5013, developed at the pediatric hospitalization in the University Hospital Professor Alberto Antunes (HUPAA), located in the city of Maceió/AL.

RESULTS AND DISCUSSION

In this study we obtained the participation of seven mothers, called M1, M2, M3, M4, M5, M6 and M7, whose children have been diagnosed with nephrotic syndrome still in early childhood with age range between 2 and 4 years, only one of the children was diagnosed at the age of 10 years old and today makes dialysis sessions.

The identification of all subjects of research be mothers still showing that studies corroborates today persists the cultural value of blaming the woman for the role of caring. Studies show that mothers even think about the possibility of other people do it for them, feel that the responsibility of care are of them and that they are the ones who do the best.¹⁶

The information obtained in this study data collection resulted in two broad categories:

perception of caregiver about the disease and knowledge about the disease and treatment.

• Mother's perception regarding the sick child

The perception that the individual has about his illness affects his behavior. However, in the case of children, especially those with chronic diseases, the perception that parents have about the disease, as well as their emotional adjustment and how they deal with the situation is what will influence negatively or positively, being of fundamental importance to the adaptation of the child regarding the disease. This way of how parents perceive cognitively the chronic disease of children is based on emotional aspects, starting from the diagnosis, daily coexistence with the sick child and the consequences of the disease.^{17.18}

Mothers interviewed perceive the NS in different ways. One of the mothers perceive the disease as a change in the life of the child, considering the everyday activities of the child are no longer as before:

It has changed his life. Because he is not like it was first, leaving the house for lunch, we leave. Now he can't be more in serene. Because if he stays in the serene he can get the flu and swell. (M1)

Most mothers see the disease as a serious problem, boring and bad that prevents the child and parents having a normal life.

I think it's a problem, very annoying, because you see the child good in a week and suddenly begins to swell [...] There is a very serious problem, I see so [...]. (M3)

I see the disease as something bad that disrupts the life of the child and parents, by excessive care he needs. But, other than that, when she's not in crisis she is a normal child as anyone else. (M6)

Although mothers see the NS as something negative, there is no way to change the health situation of the children. Thus, one of the mothers over time, began to see the disease with more naturalness, adjusting the son's condition and learning how to live with the disease.

First I thought he wouldn't resist, I was afraid of losing him, but today I see this disease with more naturalness, I know it's serious, but it doesn't bother him to live, he just have to adequate. The doctor said that is chronic, so he is learning to live with this disease. I Know that God takes care of him and nothing bad will happen. (M7)

With the disease, it is common to generate the existential questioning from the family, about the reasons he had been elected to experience that situation, especially when it is a serious disease. The explanations found in

several studies are almost linked to religion. The explanation based on divine will comfort the family, minimizing the anxiety, suffering seen as a way of growth and life lesson.^{9,19}

This perception that mothers have over the NS is largely justified by the amount of hospitalization and the essential daily care that they need to try to maintain stability in the clinical picture of children, that although they struggle, not always this condition will depend on only one action.

[...] So you try to do the best, give the medicine correctly, it's a lot of complication [...] you have to take great care to make sure I help her in the best way as possible. But, there are times I can't avoid it. M3

[...] At first it seems that nothing I did was enough, she was in crisis, even taking care of her [...]. (M6)

Mothers consider that the disease has concerning characteristics, the main one is that the kidneys stop at any time and the kid needs dialysis.

[...] the doctor said that at any moment he can go for hemodialysis and he also can die. (M1)

[...] This last time she swelled she spent a lot of time swollen and we know that when she is swollen, kidneys are not working well and if it is not working well, all flamed, with that big belly in pain, we know also he can paralyze [...]. (M3)

Some mothers are afraid that the kidneys stop and his son go to obit.

[...] I worry a lot that this kidney stop anytime and I miss her. (M4)

[...] My biggest concern is that the kidney doesn't work anymore and he doesn't resist. (M6)

However, mothers do not consider that their children have normal lives, if compared with other children and their routine.

I don't think so because it's not so similar to the others who can play, they can do anything, eat everything. (M1)

More or less. I try to do it, but there are things I cannot change, as in the case of food and medications every day. (M5)

Only two mothers consider that the children have normal life, but they do not hide the disease brings changes in the child's life.

She has a normal life when she is not in crisis, she has her limitations, but that doesn't stop her from being a happy child, to play, to smile and to be a mischievous girl. (M6)

I Consider. He plays and does everything a child does, he talks, walks and goes to school. Like I tell him, just do the diet and

take medication that he won't have to go to the hospital. (M7)

The NS does not affect just the routine of the children, but also parents, primarily mothers, who are usually those who assume the role of caregiver of the child, both in hospitals as at home.

The changes that occur in people's lives when they play the role of caregivers make the women to share the roles of mother and worker. Many times, when dealing with the need to take care of the sick child, it causes they leave in the background the work outside the home, having to negotiate more flexible schedules with employers or even abandon the job.²⁰⁻¹

Although, in the lines of two mothers interviewed so far, there were no sudden changes in routine. This is justified because they are housewives, devoted more to family and home, and by nature they already have a larger care while the child is small.

I didn't work, I'm a housewife. It has changed a bit because I need to be here, I have other children. (M1)

NO. I don't work, I just study, but only what the teacher sends me, the work and everything, my mom brings me, I do, then she takes it back, I ask for a certificate and I take it. So far, I'm not also here a long time. (M2)

However, most mothers stated that their routine has quite changed, because they work or worked outside the home, they had to learn to do a differentiated food and in everything they do put the child as a priority.

My life has changed a lot because then all I'll do I'm thinking about her [...] The food at home, we have changed after we found [...] I basically buy different food for her. (M3)

In any aspect. I'm a housekeeper, I can no longer work. When she fell sick I had to leave work to stay here with her. Because nobody can stay with her. I have no help from her father [...]. (M4)

It interferes, because I do everything thinking on her, food, leisure, everything. Even if I go out I recommend many things to people who will stay with her and still care about to know how is going. The work is also complicated when she gets ill, because I need to stay with her and I'm missing to work. I guess I just can work because there are those who stay with her. (M6)

Despite the health status of children changing the routine of the family, especially the mothers, over time they learn to cope with the disease.

The routine of the child and family are changed, not only for hospitalizations, but by diet changes, medication timetables,

frequency of visits and tests, and care as social interaction due to low immunity during some stages of the disease.

With regard to food, it is noticed that mothers follow the guidelines of health professionals, especially the nutritionist, preparing food separately to the child without salt and buying food given to the low sodium diet.

I take care in food [...]. I just take things that nutritionist gave us [...]. (M2)

With food I take great care at home and do the food separated, without salt, everything correct [...]. (M3)

In addition, some of these mothers monitor their children every day in the games and in schools, in order to prevent them from improperly feed according to their pathological condition.

If she goes to school I wonder if she will eat the snack of her classmates, I am afraid, then I tell always to the teachers. (M6)

I keep an eye when he is playing and I go direct to the school to know how he's behaving to not eat what he should not eat. (M7)

One mother reported the difficulty of having a daughter with NS, unable to work due to constant hospitalizations and she sees her daughter get sick for lack of basic nutrients.

[...] I try not to give fat and salt to her and give the diet foods, but I do not have many conditions to give her what she needs, such as fruit and meat [...] In fact she gets sick more because I am unable to give the right food, we are poor, she runs out of food, she gets weak and need to come here. My mother helps a lot, I do not know what would become without her. The medicine makes her hungry, but she seeks at home and have nothing to eat. The doctor asks why she is so weak, the exams see that there are lack of nutrients, but I'm ashamed to say. Here they are trying to get money but it has been denied several times, but the hospital is running because of her situation. (M4)

The food still interferes in the experience of the child in society, since a mother prefers not to take her daughter to birthdays not seeing her daughter crying for food she cannot eat, since the child is difficult to understand the limitations imposed by her parents.

[...] Often I only take to birthdays when is from the family when it is not, if there is a lot of intimacy I do not take her because she wants to eat chocolate cake, chocolate and soda, then I do not take her to not seeing her crying. I get invitations and often do not show her, not to harm her. (M3)

Mothers also limit children according to the health of others around them.

[...] I am so watching this rainy season, children coughing, with the flu, then I speak to the teacher I will not take her because now she is taking this strong medication, she has low defense and get sick [...]. (M3)

I keep an eye on him when he is playing to not be around someone sick [...]. (M7)

These limitations happen due to the child's fear to get some disease that happens when the child is immunocompromised due to proteinuria.

• Knowledge of the disease and treatment

The moment that the family is notified of diagnosis is stressful, tense, covered with uncertainties, bringing fear of the unknown and often painful. They start thinking how it will be living with the disease and its meanings. In addition to concerns about an uncertain future and the fear of death, determining significant change in the dynamics and family relations, including external dimensions to family.^{19,22-3}

The chronically ill children need their parents to clarify about the disease, the established therapy and restrictions, so that the family exerts an important role in the care, not only as basic care providers, but mainly in aspects related to the pathology helping the child throughout the process.²³⁻⁴

Basic knowledge of the disease is perceived by the speeches of other mothers, where the central idea about nephrotic syndrome is related also to impaired glomerular filtration:

I know this is a problem in the kidney, it does not work right and so there is a swollen body. (M5)

I know it is a syndrome where the kidneys are not working right, they should filter the blood and eliminate all the urine, but rather than that it does not filter the water going to the body and therefore it is swollen. (M6).

I know it's a disease that damages the kidneys and it does not eliminate the water the body should eliminate, getting swollen [...]. (M7)

Thus, we can understand that these mothers understand that the nephrotic syndrome is a failure in renal filtration resulting in the child's edema.

With regard to clinical aspects, the appearance of generalized edema was the motivation to mothers to seek health services:

[...] He woke up swollen [...]. (M2)

At first it was swelling [...]. (M3)

He was all swollen, not opening the right eyes. (M5)

NS causes fear in mothers due to complications that can occur, progressing to chronic renal failure, which can result in the need for renal replacement therapy (hemodialysis and kidney transplantation), clearly being expressed in the speeches of mothers:

[...] The disease is very serious, you have to be very careful with him and that at any moment he can go for hemodialysis. M1

The doctor said he can do hemodialysis, but I do everything not going, but I know that it is not up to me. (M7)

Patients with nephrotic syndrome should be evaluated periodically for effectiveness of treatment and development of acute or chronic toxicity, and the dose adjusted as necessary and to control adverse effects of medications. The monitoring of the disease should be carried out through clinical and laboratory evaluations.

Based on the collected data, it is seen that mothers follow the correct guidelines as the regularity of consultations, a fact that becomes essential in the child's life maintenance. In addition, it is noticed that mothers are well advised to return to the reference service where the child begins to show signs of the disease at home, even if it is not a selected day for consultation.

I come to the consultations on the right days, I don't let it pass [...] And if I realize that she's with any symptoms, that she will go into a crisis, I come to the hospital. (M6)

When there is a consultation, I come, when he swells or gets an infection. I give medications on time, take him to take the exams and do everything that the doctor asks. (M7)

In nephrotic syndrome, it is common for children to be hospitalized for several times in the same year due to changes in routine examinations, infections and disease signs. In the interviews, mothers reported large amount of hospitalizations experienced by the children, which results in losses in school life by absence in essential activities that the school demands.²⁵

Since discovering that he is hospitalized. I was admitted many times. It was more than three times a year. There are months I'm going home, stay fifteen days and come back, and fifteen days here and fifteen at home. Even taking the medication, very carefully. Because of that he's late at school, two years. (M1)

When it was discovered, I came here almost every month, now the medication is making effect and we almost only come here to consultations. I'm not sure how many times, but there were several [...] she lost the

year at school because we had to come here several times. (M6)

Hospitalization is seen negatively due to unusual situations, such as the accumulation of information transmitted as soon as they arrive, the experience of unpleasant situations and witnessing scenes of suffering in the hospital everyday, including his own son, feeling helpless for not make him free from that suffering. Another negative factor that generates a lot of anxiety is the need to bring the child to many tests, often invasive, and the result demands a long wait.^{19,25-6}

The experience of hospitalization takes the family to have many feelings that originate in real or imaginary facts, and are manifested through feelings, actions and thoughts that show the difficulty parents have in dealing with situations such as: nervousness, crying, loss of appetite, and other behavioral changes.²⁶

Nursing has the important role of giving emotional support both the child and the family that they may better understand the situation and reduce the fears and insecurities. In addition, the nurse must accompany the family, guide when feeding, water intake, be aware to changes in the clinical picture. It is necessary to develop research in nursing aimed at patients with nephrotic syndrome, in order to better intervene in such cases and provide growth in scientific records of the area.^{12,27-8}

CONCLUSION

It is noticed that the mothers had a regular level of basic knowledge about the disease and treatment and they related them to nephrotic syndrome and renal changes resulting in failure of glomerular filtration causing an edema in the children when they enter the so-called "crisis". However, in some cases it is seen that mothers only reproduce the information from the professionals without, however, understand them. This indicates the need to improve communication between nursing staff and family, since some professionals explain superficially employing incoherent scientific language for the mother understanding. The use of terms accessible to the understanding of the parents to talk about the child's health status can reduce anxiety, concerns and fears.

Mothers perceive the edema as the main sign of the disease, seeking the health service. They also cite the abdominal pains and hyperthermia, which are usually in infectious processes, common in children with NS due to proteinuria resulting in decreased immunity.

NS causes insecurity due to the instability of the clinical picture and fear because of the complications that can occur. In the interviews, the fear that has been faced with a poor prognosis was reported, with penalization of renal function and the children need of renal replacement therapy, hemodialysis, to survive.

Due to this fear of the disease, mothers interviewed say assiduously attend consultations, conduct examinations requested to monitor the condition and when necessary they go in search of the reference service to decrease the risk of complications. In this way, it is observed that mothers are well advised to return the service if the children show some characteristic of recurrence or infection, which causes multiple hospitalizations during the same year. The impact of these hospitalizations in child's life reflect the delay in school life, where most of them are in different grades not compatible with their age.

With regard to child's, daily life and family it is shown that there were significant changes since the discovery of the disease. There was a change in the child's eating habits and even some families, with the intention of promoting the child's acceptance to the new lifestyle. Mothers report that these adjustments are not easy, but health professionals of the HU guided them.

The food problem did not bring changes only at home but reflected in the life of the child in society. It was found that mothers in an attempt to protect the child, they limit and control the children most of the time, whether at school, when playing or in proximity situations with other individuals who expose their children to risk factors for the disease. In addition, NS interfered significantly in the routine of mothers. However, for mothers who work or worked, this fact reflected more intensely due to absence from work because of the constant hospitalizations and long periods, resulting in the loss or abandonment of employment for some of them. Despite the change in the routine of mothers in many ways, when getting confidence in caring for the chronically ill child, they realize that it is also possible to live with the disease and its limitations.

Based on the collected data, it is suggested the formation of groups with mothers of children with NS in the days of consultations to clarify more and more about the aspects of the disease and the importance of actions in their child's daily life. It would be important to strengthen, at the time of the meetings of

this group and in hospitalizations, the guidance to food and teach mothers ways of preparing food without salt, but that even pleasant to the child's taste.

It is expected that this study will serve as an incentive for new nursing studies, focused on patients with nephrotic syndrome, since the research literature in the area is scarce.

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