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HUMAN IMMUNODEFICIENCY SYNDROME IN CHILDREN: REPERCUSSIONS FOR THE FAMILY

SÍNDROME DA IMUNODEFICIÊNCIA HUMANA NA CRIANÇA: REPERCUSSÕES PARA A FAMÍLIA

SÍNDROME DE LA INMUNODEFICIENCIA HUMANA EN EL NIÑO: REPERCUSIONES PARA LA FAMILIA

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ABSTRACT

Objective: to know the repercussions of the diagnosis of children with the human immunodeficiency virus for the family. ***Method:*** this is a qualitative and descriptive study performed with ten relatives in a Day Hospital. The data was collected through semi-structured interviews, subjecting them to the Content Analysis technique. ***Results:*** it was verified that some mothers did not know that they were carriers of the HIV virus and only discovered the contamination during prenatal and prepartum exams. Guilt was generated upon receipt of the child's diagnosis and this disclosure was difficult for the mothers. Living with the fear of death from opportunistic diseases, giving priority to food as a way of maintaining health. The concern of the mothers was reported because only the people of the nuclear family dedicate themselves to the care of the child with the objective that its diagnosis is not revealed. ***Conclusion:*** information is provided, given the main difficulties mentioned by the mothers when they receive the diagnosis, so that the health team promotes actions to be implemented as early as possible as a way to instrumentalize the family for care and encourage healthy living child. ***Descriptors***: Acquired Immunodeficiency Syndrome; HIV; Child; Family; Nursing; Pediatric Nursing.

RESUMO

Objetivo*:** conhecer as repercussões do diagnóstico de crianças com o vírus da imunodeficiência humana para a família. ***Método: trata-se de um estudo qualitativo e descritivo realizado com dez familiares, em um Hospital Dia. Coletaram-se os dados por entrevistas semiestruturadas submetendo-os à técnica de Análise de Conteúdo. ***Resultados:*** verificou-se que algumas mães não sabiam que eram portadoras do vírus HIV e só descobriram a contaminação durante a realização de exames no pré-natal e pré-parto. Gerou-se culpa diante do recebimento do diagnóstico da criança e essa revelação foi difícil para as mães. Convive-se com o medo da morte por doenças oportunistas priorizando-se a alimentação como forma de manutenção da saúde. Relatou-se preocupação das mães por apenas as pessoas da família nuclear se dedicarem ao cuidado da criança com o objetivo de que seu diagnóstico não seja revelado. ***Conclusão:*** fornecem-se informações, diante das principais dificuldades referidas pelas mães ao receberem o diagnóstico, para que a equipe de saúde promova ações a serem implementadas o mais precocemente possível como forma de instrumentalização da família para o cuidado e de incentivo ao viver saudável da criança. ***Descritores:*** Síndrome de Imunodeficiência Adquirida; HIV; Criança; Família; Enfermagem; Enfermagem Pediátrica.

RESUMEN

Objetivo: conocer las repercusiones del diagnóstico de niños con el virus de la inmunodeficiencia humana para la familia. ***Método:*** se trata de un estudio cualitativo y descriptivo realizado con diez familiares, en un Hospital Día. Los datos fueron recogidos por entrevistas semiestructuradas sometiéndolos a la técnica de Análisis de Contenido. ***Resultados:*** se verificó que algunas madres no sabían que eran portadoras del virus VIH y sólo descubrieron la contaminación durante la realización de exámenes en el prenatal y pre-parto. Se generó culpa ante la recepción del diagnóstico del niño y esa revelación fue difícil para las madres. Se convive con el miedo a la muerte por enfermedades oportunistas priorizando la alimentación como forma de mantenimiento de la salud. Se reportó preocupación de las madres por sólo las personas de la familia nuclear dedicarse al cuidado del niño con el objetivo de que su diagnóstico no sea revelado. ***Conclusión:*** se proporcionan informaciones, ante las principales dificultades referidas por las madres al recibir el diagnóstico, para que el equipo de salud promueva acciones a ser implementadas lo más precozmente posible como forma de instrumentalización de la familia para el cuidado y de incentivo a la vida saludable del niño. ***Descriptores***: Síndrome de Inmunodeficiencia Adquirida; HIV; Niño; Familia; Enfermería; Enfermería Pediátrica.

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INTRODUCTION

Seropositivity for Human Immunodeficiency Syndrome (AIDS) and / or acquired immunodeficiency virus (HIV) is considered, although it emerged in the 1980s and generated a large outbreak of contamination, one of the alarming health problems that have affected also children. However, after the emergence of antiretroviral therapies (ART) and the adequate follow-up, the quality of life of the infected persons was improved, allowing a greater survival. It is explained that, after the free distribution of HAART, HIV / AIDS became a chronic disease, since patients diagnosed as of 1998 received the treatment obtaining greater longevity. There have been some difficulties in the treatment for the chronicity of the disease, even with all these advances, due to the corporal changes that it entails to the patient.[1]

In Brazil, the National Program on Sexually Transmitted Diseases (STDs) and AIDS was created to reduce the occurrence of HIV / AIDS and other infections, improve the quality of diagnosis, treatment and care for people with HIV / AIDS and other diseases and guarantee access to the public and private institutions responsible for its control.[2] 39,185 AIDS cases were reported in Brazil in the year, a figure that has remained stable in the last five years, with the rate of national detection rate was 20.2 cases per 100,000 inhabitants. It was observed the highest detection rate in the South region, 30.9 / 100 thousand inhabitants, followed by the North region (21.0), the Southeast region (20.1), the Central-West region (19.5) and the Northeast region (14.8).[3]

It is revealed that, in the country, the rate of detection of cases of AIDS in children under five years was 3.4 / 100 thousand inhabitants in 2012, which corresponds to a reduction of 35.8% compared to 2003. It adds in the range of five to nine years, the rate was 0.7 / 100 thousand (71% reduction in relation to 2003) and, in the range of ten to 14 years, it was 0.9 / 100 thousand.[3] Another study was conducted in a hospital in the South of the country, identifying that the Vertical Transmission (TV) rates obtained between 1998 and 2004 and 2005 and 2011 dropped significantly, from 11.8% to 3.2% , respectively.4 The study authors consider that this decline is related to adherence to antiretroviral therapy (ART) in the gestational period, performed by 69.7% of pregnant women. It is reported that, between 1998 and 2004, 60.7% of pregnant women adhered to highly active antiretroviral therapy (HAART) and, between 2005 and 2011, the adherence rate was 73.3%.[4]

It is known that AIDS is the most serious and advanced manifestation of HIV infection, which can alter the number and function of CD4 + T lymphocytes, inducing immunosuppression and resulting in the development of recurrent infections, including opportunistic infections. It is observed that opportunistic infections in children generally occur in the advanced stages of immunosuppression and are considered the main causes of death in HIV-infected patients in the pre-HAART era. It is emphasized that Pneumocystis jiroveci pneumonia is the opportunistic infection that most commonly affects children.[5]

The care provided to the child diagnosed with HIV is varied, requiring the attention and availability of the caregiver. In a study carried out at a South Day Hospital in Brazil, caregivers were given facilities and difficulties in providing care for the child: facilities related to their acceptance in the diagnosis, to obtaining a judicial benefit for assisting the care and support of the family and also of neighbors and friends, expanding the support network of the caregiver.[6]

Awareness raising about HIV prevention and care is needed through diagnostic and tactical testing for management with children, including the third line and available salvage schemes in resource-limited settings. It is noted that ART for HIV treatment is only a successful aspect for HIV-infected children, the other equally crucial aspect being the continued successful treatment of concomitant nutritional deficiencies and comorbidities, which are often common manifestations in these children.[7]

The child is accompanied, despite the difficulties encountered by the family, throughout their growth and development, with experiences and experiences that enable the family to build care that helps them live with quality. It is important, therefore, that Nursing commit itself to provide assistance and stay with these families, acting and assisting in the construction of child care, so that it permeates the human dimensions according to the context and way of life of these people.[8]

It is important to note that nurses are the first professionals to come into contact with patients with HIV/AIDS, so it is important that they use the knowledge learned during their practice in order to create strategies that help them to minimize difficulties and weaknesses that can be faced by patients. For this type of action, the creation of a bond and trust by the professional is opportune to approach the patient and accompany him /

her by encouraging the prevention and treatment of HIV/AIDS.[9]

It is believed that the study will enable the construction of knowledge to subsidize health professionals, who work with families and seropositive children, to develop more effective strategies of care, reducing the impact of their diagnosis.

OBJECTIVE

- To know the repercussions of the diagnosis of children with the human immunodeficiency virus for the family.

METHOD

This study was conducted through a qualitative, exploratory and descriptive approach.[10] It was developed with ten family caregivers who met the following inclusion criteria: being the main family caregiver of the child with HIV / AIDS, accompanying the child periodically in the Hospital treatment Day AIDS and be 18 years or older. Family members who accompany the child in the sector were excluded from the study only eventually.

The data was collected from March to May 2018 through an individual interview with the family's primary caregiver. A first contact was created to present the research and request its permission for the research. A semi-structured interview was made up of two parts: the first with closed questions containing the subjects' identification data and the second with open guiding questions containing questions about how the child's diagnosis had repercussions on the family. Data was analyzed from the Thematic Analysis.[11]

One primary caregiver was interviewed at a time, in an individualized room at AIDS Day Hospital, shortly after the appointment or at the time of waiting for the appointment. Interviews for MP3 recordings were recorded to guarantee the reliability of the speeches, with the authorization of the subjects and, afterwards, transcribed them, and the data analysis process was started immediately. Data analysis was performed using the Content Analysis technique.[11]

Resolution 466/12 governing research involving human subjects was respected. This research proposal was submitted to the Research Ethics Committee in the Health Area - CEPAS of FURG, receiving a favorable opinion under number 29/2018. Participants signed the Free and Informed Consent Form. The family caregivers participating in the study were identified by the letter F followed by the interview number as a way to guarantee their anonymity.

RESULTS

The following are the characteristics of the study participants and the categories generated from the data analysis.

Characterization of the family caregivers participating in the study and the children

Ten family caregivers aged 23-61 years, with a mean of 42.4 years, were enrolled to participate in the study, and four were mothers as the child's relationship; two, adoptive mothers; two were parents; (four), complete elementary school (three), and complete secondary school (three). It was raised, as to the profession, that three are retired; three, home; two do general services; one is a treasurer and one, a merchant, and, in relation to the marital situation, four are single; three, married and three, separated, living with a family income between R$ 300.00 and R$ 2000.00, with an average of R$ 1,074.00.

It was observed that the children had ages between one year and nine months and 12 years, with a mean of 7.77 eight years, being six males and four females, and all acquired the HIV virus through vertical transmission.

♦ Impact of HIV diagnosis from child to family

Some mothers were unaware of HIV infection, as some were aware only during prenatal care.

> *I discovered that I had during pregnancy doing routine exams. (F4)*
>
> *I did not know I had it, it was prenatal. Only me and my son are the virus carriers. I picked up a relationship I had after I left. (F4)*
>
> *I was not even going to prenatal her, and then my mother who insisted, was not going to prenatal, for what? Do you have mothers who do not? So I will not do it. Then the mother insisted and I came to do the prenatal seven months. Then I found out. (F3)*
>
> *Her mother did not get the treatment during pregnancy, so she had this problem.* (F5)

It was noticed that one of the mothers did not perform the prenatal and only discovered to be carrier of the virus during the fast test in the maternity. The treatment of the child was started immediately and the family still hopes that the same negative tests.

> *I did not have time to do any treatment because I did not prenatal and only found out at the end of the pregnancy. I started the treatment after she was born. Doctors*

have said that until age seven, it can still be negative. She is five years and nine months old. So, there's still a little bit left. (F3)

It is noticed that, although the mothers know that they are carriers of the HIV virus, they reported not having performed the treatment during pregnancy because they did not know this possibility.

The other I did treatment, the one I did, but it did not, right. (F3)

His mother knew she had the disease, but at the time, she did not know she had treatment, that she had to take care of before, right. She did not know that, so much so that he has a sister and she knew he had treatment and his sister did not have it. It was a bar, right, but we did not know it, we were new. Not even the hospital itself at the time did not explain that she had to take care of herself. Because today the mother taking the treatment, the child has a chance of not being contaminated. (F7)

I discovered in 2007 that I have this disease. I worked on board, so I started to feel sick to my stomach. I worked until 2007, there, they compensated everyone and I came away. After a while, I began to feel sick to my stomach and to lose weight. So I came to find out that I was sick. Then I met the mother of this guria who was sick too. Then it turned out that Natasha was born. Until the three years of this guria, I lived well with her, later, she joined with a cousin of her that is of terreira, left the house. (F6)

It was considered as complicated to receive the diagnosis that the child is a carrier by the families, besides terrible, difficult and as if a bomb had fallen on the relatives. One of the families was surprised by the child's diagnosis, because she did not know that the parents were carriers of the virus. The guilty person is born with the diagnosis of the child, since the fact of having taken the medication during the gestation generated expectation in the mother of not having contaminated the child.

Terrible, terrible, it was as if they had pulled my rug for the eighth time. (F4)

It was very difficult, it was very difficult, until I accepted, it was a long time, I spent all the time crying. (F3)

Then, no, after a month, two months doing tests with him, there he gave that he had a problem with him, which he had taken from his mother. (F7)

When his father told me he was, we are so surprised because nowadays, with so much medication, condom and the person knows he has and gets pregnant. Let such a child come. We're kind of surprised, kind of puzzled. (F1)

I feel guilty, I had a normal birth. I took medication, but it did not help. (F10)

Two children were adopted and their families reported accepting their status as seropositive. It has been pointed out that HIV is not a disease and, with treatment, it can prevent the.

She is adopted. When I adopted it, I had the suspicion, but then, when her family had her brought here I came to know that she was HIV positive. The social worker at the forum asked me why I decided to adopt a child with HIV.

I replied that it was not me, she wanted me, and when you love, you do not want to know color. You do not want to know what you have. I love her for what she is. (F9)

I accepted a good one because when they were adopted I received the call that had two girls to be adopted. Only, that there was one that had an illness, that had the HIV virus. I, for me, was normal, because when I set out to adopt was one, there came two and I accepted both. If it came to me it's because it was meant to be. It is not a disease. She has only the virus. It's a normal disease. So for me it was a very natural thing because if it was my gestation and had it I could not throw it away. So this, for me, was treatable. (F5)

The fear of the death of the child due to opportunistic diseases by the family was exposed.

I do not have afraid to die. I'm afraid if anything happens to her. Afraid to happen an opportunistic illness and take my daughter away. It's just what I'm afraid of, the rest, not. (F9)

♦ Changes in living from the child's diagnosis

It was mentioned by one of the families that nothing changed in his life after the child's diagnosis. It was verified that, due to the serological condition of the child, the familiar caregiver starts to dedicate himself exclusively to his care in order to guarantee his health and well-being. Mothers are concerned that only people in the nuclear family care for the child so that their diagnosis is not revealed.

No, I did not do anything. So it has not changed much (laughs). (F3)

After I discovered this disease, it changed my life a lot. (F6)

We end up living only for the child now instead of for the people. (F3)

When God sends you something, He will not send you to perfection. God gave it to me like that. I fight, I take care of her like that for her then being a girl working there and taking care of her life. I have no prejudice with any kind of illness. (F9)

Ah, changed, first, I have to take care of him, and it's hard for anyone to keep him.

> *The only person who stays that way is my daughter. She has four children, she is married, but she stays like this a little, if not, it's always me.* (F2)

It was described by one of the families that the child's "problem" united the family to better care for it.

> *I met his father and we started dating, then, as she was with this problem and increasingly worsening her intellectual deficit, he invited me to live with him because there we were together. We came together to help each other. He wanted to have someone to take care of them, has to have, and she also has to have and she would be alone. In fact, it was good, it was quite what he said, a union to help.* (F1)

Refers to the main perceived change in family life from the diagnosis of the child. It was said that the child takes several medications and can not acquire opportunistic diseases and, therefore, needs to eat well, and food has become the family's greatest concern to the point that this aspect of living is the focus of care.

> *What changed was the family's food because he wanted to feed himself so he would not get sick, so every family has to eat the same food. He needs to feed because, first, he is a child, is in the developmental phase and, second, that the medications are very strong and need to be with food in the stomach. I stay at home with him so quietly, like the other two, always worrying about food. Food is the focus of that house, the focus of his life is for us to make him eat. He has to understand that he has to eat, he does not have to eat the whole pot of food, but he has to eat even a little.* (F1)

DISCUSSION

Prophylaxis is offered free of charge in public health services. It is pointed out that despite this, the diagnosis of the mother is not always discovered in a timely manner for the protection of the child or, in rare cases, the mothers are not oriented correctly to schedule preventive care. [12]

It is inferred that the later onset of prenatal care is due not only to the personal difficulties of pregnant women living with HIV, but also to the failures of the health system to provide early diagnosis and specialized care, despite the clear recommendations of the Ministry of Health in this respect.[13] It is recommended that health professionals be trained to offer special care to those pregnant women who start prenatal care late, as well as to those with less information about HIV during pregnancy.[14]

It helps to minimize the number of children infected with the virus by the effectiveness of chemoprophylaxis of vertical HIV transmission. Pregnancies are started earlier by pregnant women, probably with the anticipated use of antiretrovirals, and this favors the reduction of viral load in undetectable levels in the last weeks of pregnancy.[15]

The creation of strategies that enable professionals to provide good assistance to families and children living with HIV / AIDS should be considered, as they are essential. It becomes a fundamental tool and priority education so that the child diagnosed with the disease is prepared and live with quality. It is necessary to transmit this education, therefore, by the professional, in a clear and objective way to the family, the educators and the responsible ones so that this process occurs in a positive way and the child can grow and to develop well in all the sceneries of his health.[16] In this sense, through educational actions, more and more individuals are encouraged to be aware of their health responsibility, especially the young public, born in a reality where HIV / AIDS is no longer seen as tabu, teaching that the seropositive patient is a citizen like any other and that can have a normal life like the other people.[17]

It is added that the mother's sense of guilt, apprehension and fear of being responsible for transmitting the disease to the child may interfere with her relationship with the child and, in some situations, cause her physical distancing.[18] She observed In another study, too, the fear of transmitting the virus or other diseases to the children led the mothers to adopt positions of overprotection and distancing.[19]

It is estimated that hospital admissions for opportunistic diseases may occur, especially when the child is diagnosed late with HIV / AIDS. A case study of hospitalized children was presented in a study conducted in Vitória, Espírito Santo, and the most frequent diagnosis was chronic anemia. Children were also hospitalized for episodes of invasive bacterial infection, acute otitis media or recurrent sinusitis, dermatitis, prolonged diarrhea or gastroenteritis, candidiasis, and tuberculosis.[20] It is therefore recommended that health professionals attend to the rapid diagnosis of HIV so that the rates of hospitalizations due to opportunistic diseases decrease and the children have a higher expectation and quality of life.

The behavior of the child is negatively influenced by the omission of the diagnosis by the family member. It is argued that the caregivers' omission regarding the true reason for the use of the medication may be seen by

children as deception and betrayal, and they may consider the prolonged silence about their true health condition.[21]

There is also evidence of rejection or differential treatment of the child due to their diagnosis, which causes many mothers to isolate their relationship with other children or people in day-care centers, at school or in other social spaces. [22] Thus, it is necessary that the emotional aspects of these mothers be worked out, together with the professionals, so that there is no imbalance in the relation between the mother-child pair and the socialization of the child.

Care is taken by the family caregiver and they are present at all times in the life of the child and the adolescent, and in some situations, it may feel stressed and overwhelmed by the experience of caring, presenting a feeling of impotence. It is necessary, therefore, that the Nursing team take care of this situation and stimulate the confidence and capacity of the family caregiver in knowing what to do, reducing these stressful moments so that the walk next to the child and the adolescent is the best possible.[23]

Benefits are provided for the dissemination of the diagnosis of the child's illness, since the patient has the support to share their anguish and difficult moments. However, this revelation is not always seen as a benefit because, although close friends or relatives know about the condition of the child or adolescent, the disease and its aggravations are rarely discussed. [24] Communication of caregivers and recognition of children's efforts to learn how to manage information about their condition by health professionals should be encouraged. It is necessary to sharpen the perception that children's questions and expressions of their feelings provide openings for communication so that they have the chance to grow and live with quality despite the illness.[21]

Regarding the adherence to the drug treatment, the study carried out with children with HIV showed that some did not adhere to the practice due to the bad taste of the medication and the side effects caused. In relation to daily activities, the same study showed that the children interviewed stated that they did not change their routines and were able to exercise them normally.[25]

It is understood, in this sense, that the child living with the diagnosis of the disease experiences a series of experiences of which it needs specific care for the maintenance of its health. In this regard, the family is the main provider of child care that requires adequate guidance and information from health professionals and the media to live and develop health.[12]

CONCLUSION

The objective was to know the repercussions of the diagnosis of HIV / AIDS in the child for the family. It was found that some mothers did not know that they were carrying the HIV virus and only found the contamination during prenatal examinations or during the rapid test in the maternity before delivery. It is noticed that the majority did not carry out the treatment during the gestation and the receipt of the diagnosis of the child was difficult generating the feeling of guilt.

Mothers are united for care by living with the fear of the child's death from opportunistic diseases and prioritizing food as a way of maintaining their health and well-being. The concern of the mothers was mentioned because only the people of the nuclear family dedicate themselves to the care of the child with the objective that its diagnosis is not revealed.

It is possible to conclude from the data that the health / nursing professionals need to work together with the families, from the time of receipt of the child's diagnosis, in the learning of care, acting in the basic and hospital networks, during their hospitalizations hospitals, and also to schools to receive these children without prejudice by building, with the family, a network of social support around the child with HIV / AIDS.

Among the limitations of the study, it is possible to point out the lack of research carried out by nurses with children with HIV / AIDS and the issues surrounding their living. Thus, it reveals a vast field of action for nurses who have, in health education, one of the pillars of their work. It is hoped that this study will serve as a reference for other research that addresses the theme of family care and the child with HIV / AIDS, from the perspective of Nursing professionals, making possible new looks on the subject.

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