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RESEARCH | PESQUISA

Difficulties and facilities of the family to care for children with HIV/Aids

Dificuldades e facilidades da família para cuidar a criança com HIV/Aids

Dificultades y facilidades de la familia para cuidar los niños con VIH/Sida

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Abstract

Objective: Study aimed to know the difficulties and facilities of family to care the children with acquired immunodeficiency virus. **Methods:** We conducted a descriptive study of qualitative approach, in hospital in southern Brazil, in the second half of 2014. Participants fifteen family caregivers. Data were collected through semistructured interviews and submitted to content analysis. **Results:** It found as difficulties of family for the care of children the secrecy of the child's diagnosis, administration of antiretrovirals, financial, hospitalizations, prejudice and the child's mother's death. As facilities mentioned the fact of child accept the diagnosis, obtaining benefits, support of family, neighbors and friends. **Conclusion:** It is expected sensitize the health/nursing professionals that care of children at this condition for a new look for their family caregivers, in order to guarantee him access to health services and information that enable to care for the child.

Keywords: Acquired Immunodeficiency Syndrome; Child; Family; Nursing.

Resumo

Objetivo: Conhecer as dificuldades e facilidades da família para cuidar a criança com o vírus da imunodeficiência humana. **Métodos:** Realizou-se uma pesquisa descritiva com abordagem qualitativa, em hospital no sul do Brasil, no segundo semestre de 2014. Participaram quinze familiares. Os dados foram coletados por entrevistas semiestruturadas e submetidos à análise de conteúdo. **Resultados:** Constatou-se como dificuldades da família para o cuidado à criança o sigilo do diagnóstico para a mesma, administração dos antirretrovirais, financeiras, hospitalizações, preconceitos e morte da mãe. Quanto às facilidades referiram o fato da criança aceitar o diagnóstico, obtenção de benefício, apoio da família, vizinhos e amigos. **Conclusão:** Espera-se sensibilizar aos profissionais da saúde/enfermagem que cuidam de crianças nessa condição para um novo olhar para seu familiar cuidador, garantindo-lhe acesso aos serviços de saúde e informações que os habilitem para o cuidado à criança.

Palavras-chave: Síndrome de Imunodeficiência Adquirida; Criança; Família; Enfermagem.

Resumen

Objetivo: Conocer las dificultades y facilidades de la familia para cuidar el niño con el virus de la inmunodeficiencia humana. **Métodos:** Se realizó un estudio descriptivo de naturaleza cualitativa, en hospital en el sur del Brasil, en el segundo semestre de 2014. Participaron quince familiares. Los datos fueron recolectados por entrevistas semiestructuradas y sometidos a análisis de contenido. **Resultados:** Se encontró como dificultades de la familia para el cuidado la confidencialidad del diagnóstico del niño para ello, administración de los antirretrovirales, financiera, hospitalizaciones, prejuicios y muerte de la madre. Cuanto a las facilidades referiran el niño aceptar el diagnóstico, la obtención de beneficio, apoyo familiar, vecinos y amigos. **Conclusión:** Se espera sensibilizar a los profesionales de salud/enfermería para una mirada al familiar cuidador, garantizándoles el acceso a los servicios de salud e informaciones que permitan cuidar al niño.

Palabras clave: Síndrome de Inmunodeficiencia Adquirida; Niño; Familia; Enfermería.

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INTRODUCTION

The acquired immunodeficiency syndrome (AIDS) is epidemic in Brazil, caused by the human immunodeficiency virus. In the early 80s, AIDS was linked to so-called risk groups. But with the epidemic advance, began to reach people in all age groups and belonging to different groups, including children. Currently, we find children and adolescents living with HIV/AIDS since the birth, needing antiretroviral medications for prolonged periods[1].

The global risk of vertical transmission of the HIV during the first twelve months of age is about 35% to 40%, in the absence of any intervention[2]. In resource-limited settings, half of the children who contract HIV from their mothers die. However, these deaths can be avoided by early diagnosis accompanied by antiretroviral treatment and prophylaxis of opportunistic infections[3]. The increase or decrease in cases of vertical transmission in Brazil also is controversial. In recent years, the contagion in this way is decreasing considerably[4].

The AIDS chronicity implies accession process to a complex and prolonged drug regime. In this sense, the adhesion of the people who have HIV/AIDS does not depend on the disposal and the free supply of antiretroviral drugs, especially when it comes to children. Among factors that complicate the therapy adherence in infantile public are: taste and unpleasant odor of the drugs, changes in lifestyle, excessive number of doses and drugs, forgetfulness of medication and/or its doses, the drug administration outside the home and timetables[5]. As factors that facilitate the adhesion have the disappearance of the symptoms of the disease with the use of medication, ingestion of drugs with liquids, the use of adhesives to identify drugs, the association of ingestion with the routine activities of everyday life, recreational activities in order to clarify questions concerning the accession and strengthening the relationship between health care professionals, children and family[6].

The child who has HIV/AIDS and need to make use of antiretroviral drugs can not understand the process involving therapy, the need to use the medication, the progression of the disease and its consequences. Thereto, they need special care owing to the psychological and physical impact that this fact entails. The family presents itself as the main source of help and care, contributing to their well-being[5].

Since the birth of a child, the family plays the role of a caregiver. Children with HIV/AIDS need to have family support for their social and emotional development[7]. The nurse/health team has to understand the needs of family caregivers, helping them to obtain early diagnosis and access to treatment and the child, the effective family planning and orientation for to qualify to care for her and take care[8]. The family caregivers need to be aware of the conditions and needs of the child and mainly the importance of adherence to therapeutic success. Most of the time, is a family who performs these actions, and their fundamental in the care of health needs, growth and development of children[6].

To assist the family to play this role is necessary to know their experiences in caring for these children. In this sense the question that guided this study was: what are the difficulties and the facilities presented by the family to care for the child with HIV/AIDS? From that objective was to know the difficulties and family facilities to care for children with HIV/AIDS.

METHODS

It is a descriptive, exploratory study with a qualitative approach. It is descriptive and exploratory as it observes and records the incidence of the phenomenon to explore their size the way it manifests and factors to which it relates[9]. The qualitative approach considered as a source of study, the perspective of individuals who experienced certain phenomenon and their meanings[9].

The study was conducted in the second half of 2014 in the hospital Dia Aids Pediátrico at a hospital in south Brazil. This is a reference hospital in the care of children with AIDS since 1989. It is a large public hospital that only attends patients insured by the National Health System. In the Hospital Dia monthly scheduled appointments and drug administration for effecting the treatment are realized. Currently, there are 40 children under attendance.

Fifteen family caregivers participated that attend the inclusion criteria: be the main caregiver of children with HIV/AIDS, accompany the child periodically at the Hospital Dia and be 18 years or older. Excluded from the study were families accompanying the child only occasionally.

The data were collected by one of the study researchers through unique semi-structured interviews with each participant. They were questioned about how difficulties and easy were caring for HIV/AIDS children. These were carried out in the waiting room of the Program Hospital Amigo da Criança (Baby Friendly Hospital Program), the comfort, privacy, and being annex to Unity Hospital Pediatrics study. The interview data were subjected to content analysis[10]. This method operates through three stages: pre-analysis, exploration of material and finally the treatment of results, inference and interpretation. The pre-analysis phase is the organization that goals to make operational and systematize the initial ideas, choose the documents, perform the initial reading that enabled a corpus that is the set of documents analyzed.

In the exploration of the material are determined the text cuts in categorizing units for analysis and coding of data. After this step, goes to the processing of results in which the encoded material comes to be represented by the registration units, forming units and categories[10].

The ethical principles were respected, according to Resolution Nº 466, of December 12, 2012, the National Health Council[11]. The research project was submitted to the Ethics Committee of the Federal University of Rio Grande/FURG and approved following the opinion nº 114/2014. The speeches of the participants were identified by the letter F for family all followed by the interview number.

RESULTS

Presented the characterization of study participants and the categories generated from the content analysis: family difficulties to take care of the child with HIV/AIDS and family facilities to care for children with HIV/AIDS.

Characterization of family caregivers in the study and children

The participants of the study were fifteen family caregivers aged 23 and 61, with an average of 42.4 years. They have as degree of kinship of the child, mother (six), adoptive mother (three), father (three), stepmother (one) and grandmother (two). Having as educational background, incomplete primary education (nine), complete elementary education (three) and complete high school (three).

About the profession, three are retired, six homes, three general services, two workers and a trader. About the marital status, six were single, married five and four separate. Living with a family income between R$ 300.00 and R$ 2,000.00, with an average of R$ 1,074.00, the minimum wage at the time R$ 724.00.

Children have aged between one year and nine months and 12 years, with an average of eight years, six males and four females. All they acquired HIV infection by vertical transmission.

Family difficulties to care for children with HIV/AIDS

Family members reported difficulties in maintaining secrecy about the diagnosis of the child to the same, because they want to choose the right moment to reveal her diagnosis.

> *It has no facility! It's not easy! (F1)*
>
> *It is more difficult, yes! (F4)*
>
> *When she enters in the clinic, the nurses do not speak HIV or she carries. I asked, because she is very smart, she knows everything. I want to pick the best time to tell her what she has (F9).*

They find it difficult to administer antiretroviral drugs to the child because they are medications that often cause gastric reactions such as stomach pain, nausea and vomiting, making it difficult for the child to eat them. Their biggest concern is that the medication should be used for a lifetime.

> *Take care for him is normal is more difficult is to give the medicine, the timetable is twice a day, every twelve hours (F2).*
>
> *He takes medicine every day, at the same times. Every day for the rest of his life. This is it, is pretty complicated (F7).*
>
> *At first it was very difficult to make her take the drugs. Now she is more accustomed, complains but takes. Sometimes she gets a little sick. Sometimes throws up. She says that the stomach hurts, but are the drugs (F6).*

Considering the amount of medications they take, children have difficulty feeding, causing great concern in the family caregiver.

> *His alimentation makes me very worried, me and his father. Sometimes he comes home, just like yesterday. I invited him to eat and he said he was not hungry. Thing you know you care because you have to eat (F8).*
>
> *The greatest difficulty is to make her feed. I think it will be malnourished, but I'm always trying some food such as juices and fruit (F11).*

One of the families reported having great financial difficulties to pay for the care demands with the child.

> *With what I earn I am not able to support my daughter. I tried to get a benefit for her and the INSS denied. With R$ 507.00 I pay water, electricity, supermarket, the land, property tax and gas. I have no money for the rest of the month (F13)*
>
> *I don't have money to buy diapers for her. I will ask for help from her father and from my mother (F14).*

Child care is permeated by fear that it will hurt and bleed during play with other children. Therefore, they provide the child to play indoors with the brothers and under his supervision, preventing play with other children, imposing limitations as a form of protection that does not get hurt.

> *If he gets hurt, I'll clean up. But there is the risk of some little friend or someone else try to help without knowing what he has. I avoid letting him play in his little friends' houses. He plays more with his brother (F12).*
>
> *My fear is if she falls, gets hurt and someone having contact with blood. She did not play with anyone, only at school. At home only with my little grandson. I let her stay more on her computer (F15).*
>
> *My son does not go to friend's house. If the little friend want to come play here at home. This is already a thing of my system, because it has no limits, just take care of her at the time that it hurts (F5).*

Another reported difficulty was to prevent the child get opportunistic infections and has a decreased immunity.

> *Hard thing is to attack these opportune diseases, because of his body, depending on how are his defenses. All this worries me (F7).*
>
> *If he is lying we become already worried. He's a normal kid, just a kid who has a disease. Luck is the CD4 it is very well, but it happens that we are afraid because of other diseases that can get into his body (F8).*

They referred to as difficulty faced by the family the need for hospitalization for the child.

> *When he was little, he was hospitalized because of AIDS. It was a shock! (F12)*
>
> *When she was in the shelter, she was already lowered into the hospital, she had to go to ICU because of infection that appeared. After it came to me not (F5).*

One of the caregiving families revealed that child care is lonely. They complained that they can not disclose the meaning of caring to society. Society does not want to know of the disease, do not give voice to caregivers.

> *I do not see much to be done for children who have HIV, society does not do much. I feel lonely (F5).*
>
> *At the hospital they teach us just taking medication and has to be careful to avoid diseases. No one ever gave voice to the adoptive mothers or mothers who also have passed to see what they think. We need to have psychological counseling and social assistance (F9).*

They denounced the prejudice suffered within the family and the others. Including one of the family said that the hospital feels stigmatized by health professionals who assist them.

> *If the own family turned away from us when we knew, I imagine people outside what they will not do (F11).*
>
> *When I arrive at the hospital and say that I'm caregiver of a child with HIV/AIDS, the first thing they tell you is for you place gloves, not touching that patient without gloves because she has AIDS. I think that's a crime (F13).*

The child's mother's death causes the number of caregivers is reduced. They worry about who will stay with the child if they die because, in some cases, are also carriers of the virus.

> *His mother died of cancer. Not that AIDS is not involved. As she was the low immunity died faster. He was six when his mother died. Now it's me and a mate I have to take care of him (F7).*
>
> *I went to the lawyer and took custody of it, not to let her fall in life. I want to see if sell my house and walk away from Rio Grande. My relatives live in Santa Catarina. If I die due to the disease they would have to take care of she for me (F6).*

Family facilities to care for children with HIV/AIDS

One of the family referred to as the facility that the child accept his diagnosis. However, he guided the child not to talk at school and for others that it have the virus.

> *[...] At school I ask to her not to reveal to anyone (F3).*
>
> *He accepted well, isn't discriminated against. We always talk that did not need to speak to anyone that he has the disease. If your friends know will be your friends anyway. Who are friends will not only be because of illness (F1).*
>
> *Another referred facility was to obtain a judicial benefit, achieving the caregiver to retire, so beneficiary, making had more time to care for the child.*
>
> *I looked forward to try a benefit, but they took me. I had to put a lawyer to be able to retire. It is best to take care of her (F6).*
>
> *The money earned from the INSS helps me to spend the entire time taking care of her. There are times I lose the benefit but do new examination and gain again (F3).*

Consider as easily family support in child-care provision. Data from the study show that mothers, husbands and brothers are organized to assist the family in care.

> *My mother and my brother are the only people to whom I trust the care of my daughter. When I have to leave the house they are who care (P10).*
>
> *My husband helps me in care at the hospital. He shares the care with me. When he is working I take care of our daughter when he comes to rest at home (P9).*

Besides the family, some neighbors and friends approach the family of the child with HIV/AIDS in order to organize a social support network to assist it. The aid was manifested by offering clothes, diapers and milk for the child as well as emotional support to the family.

> *My friend and godmother joins the youngest son's clothes for me. All her friends are joining and helping too (P13).*
>
> *I have some neighbors who donates diaper and formula milk. They said that get them at church wherein They go. It is helping me to care for her. (F10).*

DISCUSSION

Family members referred to as difficulty disclose the diagnosis to the child. An Australian study that studied how is the disclosure of diagnosis to the children about their HIV status by the family found that disclosure can traumatize the child, causing a sensation of fear and abandonment and discrimination from family and friends[12]. Prejudice directed to parents extends to children. The misinformation among family, neighbors and friends related to virus transmission routes leads to the isolation of the family and child[13].

The family's difficulties in administering antiretroviral drugs in children cause family fear due to gastric reactions and, consequently, nutrition problems. An American study that assessed the main barriers to medication adherence for HIV showed that they are motivated by discomfort of the physiological side effects related to loss of appetite, abdominal pain, nausea and vomiting, causing acquired resistance of the organism and low effectiveness of medication[12].

Families of children with HIV/AIDS generally are in socially vulnerable and therefore have financial difficulties in the care of children. The improvement in the financial situation of households is due thanks to government support, through the benefit of continued provision. This contributes to a national minimum wage of R$ 724.00 per month, the caregivers responsible for children with HIV/AIDS, and important role in building new meanings for the disease and recovery of self-esteem by mothers and/or caregivers[14].

The difficulty facing the family the child's limitations with HIV/AIDS makes it blamed and fear of future hospitalizations. The blood is presented as the objectification of HIV, reminding the caregiver the child's HIV status. American study on children affected by HIV/AIDS reveals that playing the run and express themselves due to the consequences of physical weakness caused by opportunistic diseases, can promote overprotective or discriminatory attitudes of people of their surroundings and those to them dispense care, especially mothers, since about them bears the weight coordinate treatment and everyday activities[15].

For some caregivers provided care to children with HIV/AIDS becomes solitary, whereas refers to a disease known previously as being exclusive of the groups of excluded, marginalized and discriminated against in society. Study confirmed that family and responsible caregivers can become overwhelmed because they have the daily task of facing the challenges related to the treatment of AIDS. The constant trips to the clinic, detection of different signs and symptoms of AIDS and medical care, encouraging caregivers that abandon drug therapy or reduce your time as an escort across social exclusion[16].

The family prejudice, social and health professionals makes AIDS a stigmatized disease. An indian study proves that prejudice and discrimination contribute to the vicious circle between family, society and health workers, as the AIDS reports to an illness perceived as lethal, being a disease that can put others at risk, be a condition apparent to others and be a disease whose causes are perceived as only responsibility of the individual[17].

Maternal death makes the child with HIV/AIDS vulnerable to abuse and bad treatment their future caregivers. American study showed that mothers of children with HIV/AIDS are afraid that their children suffer from violence, for staying to family care or persons unknown to adopt them, and may generate future behavioral and psychological trauma in child[18]. Complementing these findings a Brazilian study shows that orphan hood, institutionalization, passing through various structures and family organizations and the impossibility of family care, may interfere with the child's healthy development and stable family relationships[8].

As facilities for the care of family members revealed the acceptance of the child with HIV/AIDS in relation to diagnosis. According to studies there are children who become accustomed to living with the virus, and the fear of death attenuated. AIDS is now seen as a chronic disease that can be kept under control[13]. When the child accepts without resistance to antiretroviral therapy caregivers begin to cope better with the disease and with the act of administering medication[6]. However, the study shows that even a child accepting your diagnosis shows up with no real idea of the importance of therapy, forgetting to administer the doses in their proper times outside the home[14,19].

The financial vulnerability of families of children with HIV/AIDS leads them to require government benefits they are entitled to. In Brazilian literature the Continuous Cash Benefit contributes to improved quality of families who have no other source of income that would interfere with adherence to treatment, both mother and child, it depends financially on parental care, caregivers or legal guardians[14].

Family support, neighbors and friends in the care to children with HIV/AIDS contributes to family care. With the need for assistance to adapt to the care the family uses a network of social support that mobilizing financial and personal resources, contributes to the family coping in the face of feelings of fear, helplessness and discrimination in child care[7].

FINAL CONSIDERATIONS

The study allowed to know the difficulties and family facilities to care for children with HIV/AIDS. It was verified as family difficulties for the care of children with HIV/AIDS confidentiality about the child's diagnosis for it, administration of antiretroviral drugs for children, financial issues, need for hospitalization for the child, experience of prejudices in the family, by others and by health professionals who assist them and the child's mother's death. As for the family to care facilities mentioned the fact that the children accept their diagnosis, obtaining benefit you are entitled to and the support of family, neighbors and friends.

As study limitation presented not allow generalizations, although it was not this goal, because it is qualitative research. Another limitation was the theme just by the direct perspective of family caregivers. It is hoped that this study will serve as a reference for other research that addresses the issue of family care and children with HIV/AIDS from the perspective of nursing professionals providing new perspectives on the theme.

The study provides evidence how complex family care to children with HIV/AIDS. It is expected for sensitize of health/nursing professionals who care for children in this condition for a new look to family caregivers in order to guarantee you access to health services and information to enable them to care for children. Thus, we will be contributing to the emergence of a new family, where children with HIV/AIDS are welcomed and cared for more instrumentalized form.

Furthermore, it is necessary that we take our educational role with these families in order to assist them in the development of child care effective strategies. Health professionals/nurses must work together with families from the time of receipt of the child's diagnosis, care learning, working in basic and hospital network during their hospitalizations, together with the schools to receive these children without prejudice, building together with family a social support network around the child with HIV/AIDS. The actions developed by health professionals and/or nurses should be implemented as early as possible as a means of family instrumentation for the care and encouragement to live healthy child.

It was concluded that knowledge of the difficulties and family facilities to care for children with HIV/AIDS subsidizes the practice of health professionals, especially nurses, because they enhance health education as proposed prevention, promotion and recovery of the real health needs of individuals and social groups in search of integrality of care

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