



Singular view of family care for children with the HIV / AIDS virus*

Face singular do cuidado familiar à criança portadora do vírus HIV/AIDS

Cara singular del Cuidado Familiar al niño Portador del Virus VIH/ SIDA

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ABSTRACT

Objective: To understand the lived experience of the family in caring for children with the HIV/AIDS virus. **Methods:** The study was conducted in a university hospital in the first semester of 2010. Participants included seven family caregivers. Data were collected through semi-structured interviews and analyzed using thematic analysis. **Results:** There was evidence of a silencing of the diagnosis by the family caregiver whose life function became that of caregiver for the child. In terms of difficulties for care, these included: the health conditions of the mother or her death; hospitalizations that compromised schooling and revealed the diagnosis; and fear of telling the diagnosis to the child. **Conclusion:** It is believed that health/nursing professionals need to employ strategies that enable these families to better cope with everyday life, advising them about care, providing information on HIV/AIDS to people in their social circle, and diminishing stigma and discrimination to which these children are exposed.

Keywords: Caregivers; Family; Child care; Acquired Immunodeficiency Syndrome/nursing

RESUMO

Objetivo: Conhecer as vivências da família no cuidado à criança portadora do vírus HIV/AIDS. **Métodos:** Foi realizado em um hospital universitário no primeiro semestre de 2010. Participaram sete familiares cuidadores. Os dados foram coletados por entrevistas semiestruturadas e analisados pela técnica de Análise Temática. **Resultados:** Evidenciou-se o silenciamento do diagnóstico pelo familiar cuidador que passa a viver em função do cuidado à criança. Como dificuldades para cuidar, destacam-se as condições de saúde da mãe ou sua morte, as hospitalizações como comprometedoras da escolarização e reveladoras do diagnóstico e o medo em contar o diagnóstico à criança. **Conclusão:** Acredita-se que os profissionais da saúde/enfermagem necessitam empregar estratégias que possibilitem a essas famílias melhor enfrentamento do cotidiano, assessorando-as para o cuidado, fornecendo informações sobre o HIV/AIDS às pessoas de seu círculo social, diminuindo o estigma e a discriminação a que estão expostas essas crianças.

Descritores: Cuidadores; Família; Cuidado da criança; Síndrome de imunodeficiência adquirida/enfermagem

RESUMEN

Objetivo: Conocer las vivencias de la familia en el cuidado del niño portador del virus VIH/SIDA. **Métodos:** Fue realizado en un hospital universitario en el primer semestre de 2010. Participaron siete familiares cuidadores. Los datos fueron recolectados por medio de entrevistas semiestructuradas y analizadas por la técnica de Análisis Temático. **Resultados:** Se evidenció el silenciamiento del diagnóstico por parte del familiar cuidador quien pasa a vivir en función del cuidado al niño. Como dificultades para cuidar, se destacan las condiciones de salud de la madre o su muerte, las hospitalizaciones como comprometedoras de la escolarización y reveladoras del diagnóstico y el miedo para comunicar el diagnóstico al niño. **Conclusión:** Se cree que los profesionales de la salud/enfermería necesitan emplear estrategias que possibilitem a esas familias un mejor enfrentamiento del cotidiano, asesorándolas para el cuidado, ofreciendo informaciones sobre el VIH/SIDA a las personas de su círculo social, disminuyendo el estigma y la discriminación a la que están expuestos esos niños.

Descriptores: Cuidadores; Familia; Cuidado Del niño; Síndrome de Inmunodeficiencia Adquirida/enfermería

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INTRODUCTION

The Human Immunodeficiency Syndrome (AIDS) is a disease that continues to be related to death and strong social stigma. Care of the child with aids (HIV) may cause psychic, emotional and moral suffering to the families and/or caregivers, due to the objective presence of the possibility of death in the family or of a strong process of blame, when the person responsible for transmission of the disease can be identified⁽¹⁾.

In addition to medical treatment, the child with HIV/AIDS needs follow-up by a nurse and other health professionals, due to presenting greater morbimortality than children who are not carriers of the AIDS virus. Therefore caring this child means a change in routine and dedication, and requires both emotional and physical preparation, causing change in the family dynamics. In this sense, care of the child with HIV/AIDS may cause a significant impact on its family⁽²⁾.

In Brazil, there have been an increasing numbers of children infected with HIV/ AIDS due to the longer survival of carriers and vertical transmission, as a consequence of the increase in cases of AIDS among women, as a result of the process of feminization of the syndrome^(2,3). Mortality by AIDS in Brazil has remained at considerably elevated levels over the last few years. Data from 2004 to 2007 have shown evidence that the annual number of deaths has been around 11.000 deaths per year, showing the need for these carriers to receive special care as a way of guaranteeing an increase in their survival with quality⁽⁴⁾.

In the case of children with HIV/ AIDS, the family is shown to be their main source of care, contributing to their wellbeing. To do this the care-giving family needs to acquire competencies that qualify it for care, as it has to be sensitive to the child's demands to guarantee its healthy growth and development⁽²⁾.

The child with HIV/ AIDS needs to live with the disease and may go through confusing situations that are difficult to understand. This makes it necessary for the child to receive special care from its care-taking family. In this sense, the family has to be duly prepared to efficiently face day-to-day situations, and avoid compromising the child physically, psychologically and socially, as far as possible, so that the child itself becomes capable of facing its insecurities and fears⁽⁵⁾.

In this context, the question that directed the study was: How does the family care the child with HIV/ AIDS? From this point, the aim of the study was to learn about the family's experiences in the care of a child who carries the HIV/ AIDS virus. This knowledge may provide support for health professionals that act in conjunction with the families and seropositive children

to develop more effective care strategies that help to facilitate family care of these children, and diminish its impact.

METHODOLOGY

This was a research with a qualitative approach of the descriptive type. Qualitative research works with the meanings, motives, aspirations, beliefs, values and attitudes, enabling the researcher to observe the agents in their day-to-day lives, living and interacting with them socially⁽⁶⁾. It is descriptive because it describes the phenomenon investigated, enabling one to know the problems experienced⁽⁷⁾.

It was developed at the Pediatric AIDS Hospital of a University Hospital (UH) in the southern region of Brazil, in the first semester of 2010. The hospital is characterized as a teaching institution, receiving students from nursing, medicine, psychology, physical education, and nursing technician courses, and is a reference in attendance to carriers of HIV/ AIDS. Only nursing and medical students work in the sector holding consultations with children with HIV/ AIDS and their families. In the sector, there are two nurses responsible for the pre- and post-test-for-HIV consultations and control the administration of immunoglobulin and antiretroviral mediations of the patients. The academic nursing staff accompany these consultations.

Five mothers, a grandmother and an institutional care-giver, who followed-up the children during the monthly consultations at the Pediatric AIDS Hospital, participated as research subjects. They fulfilled the following inclusion criteria: To be the child's main home/ institutional care-giver, be lucid, oriented, and after having received explanations about the study objectives and methodology, give their Free and Informed Consent to participating. Two copies of this consent were signed, one copy being retained by each participant. They were identified in the study by the letter F followed by the interview number.

The study was conducted in compliance with the Resolution 196/96 of the National Council of Health Ethics for Research with Human Beings⁽⁸⁾. The project was submitted to the Research Ethics committee and received a favorable report, Protocol No. 067/2010.

Data was collected by means of single, semi-structured interviews with each care-giver. The interviews consisted of questions relative to the profile of the care-giving families of the child with HIV/ AIDS, about who helps the care-giver in caring for the child, the alterations that occurred in life after the diagnosis of HIV/ AIDS in the child, as regards the family member's preparation for providing this care, about the child's

special needs, the facilities and difficulties faced by the care-giver and the strategies used for providing care.

Interviews were held in the ambulatory clinic waiting room after the child's consultations with the doctor, recorded, and afterwards transcribed for analysis. They lasted around 40 minutes.

The data were analyzed by the Thematic Analysis Technique, made operational by means of pre-analysis, in which the speeches were grouped, and the registration units were prepared; exploration of the material, in which the data were coded, grouped by similarities and differences; organized into categories; treatment of the results obtained, and interpretation in which the most significant speeches were selected to illustrate the analysis. The authors were sought to provide support for the analysis⁽⁶⁾.

RESULTS

The data showed two categories: The experience of family care of the child with HIV/AIDS and difficulties faced by the family to provide care.

The experience of family care of the child with HIV/ AIDS

The study showed evidence that the care-giver families of the child organize themselves to provide care. The mothers were the children's main care-givers, keeping secret their serological condition and that of their children.

"My mother-in-law takes care when I need to go out. The child lives only with me and its father. I am afraid others will get to know that we have HIV". (F1)

"My mother helps when I need it. I don't ask anyone strange into the house. I don't want them to know it is HIV". (F6)

The mothers in this study said that they had discovered they were carriers of the virus during the pre-natal exams. Nevertheless, it was also found that mothers who knew they were seropositive were falling pregnant. After learning of the diagnosis of HIV in the mother and child, the family shows evidence of stress.

"I fell into depression during the first days. I found out about the diagnosis when I was in the eighth month". (F2)

"It was difficult for everyone. He has a younger brother that also has the disease.. But it was terribly sad". (F5)

Contamination of the child by HIV may be difficult for the family to accept, in view of its frailty, and the family is able to understand that it depends entirely on the family's care to maintain its quality of life. In this sense, the family care-giver begins to live a life devoted entirely to care of the child in the hope of achieving its cure.

"I took care of the child. Did everything that was possible. I abdicated from everything else in my life. The pediatrician told

me that right from the first exam he did, it was undetectable. He said that it would probably continue giving this result. It was a blessing!" (F2)

When they were asked about the special care the child requires, the families were almost unanimous in saying that they received the same care given to children who were non carriers of HIV/ AIDS. Many of them even mentioned that they hardly remembered that the child has the virus.

"I look after him just as I cared for my other daughters. He is so healthy that I forget the fact". (F2)

"I treat him the same ways as I treat his brothers, only [...] I try not to think about this". (F4)

In this sense, one of the main types of care for the child is to follow-up his health.

"We don't wait. We attend consultations correctly". (F4)

It was observed that the family takes greater care of the child when it hurts itself and there is bleeding.

"When the child hurts or cuts itself, we take a little extra care. I don't want to touch anyone else? It is blood? It has the virus". (F7)

Difficulties faced by the family in providing care

As the child's mother, generally its main care-giver, is also seropositive, she may present health problems. Depending on these problems, the child's care may be compromised.

"I have tuberculosis, and he could catch it. Right at the beginning of pregnancy I discovered I was a carrier". (F2)

"I underwent surgery for an aneurism and have sequelae". (F3)

It was noted that in some cases, the mother's death due to AIDS leads to the child being cared for by another family member. Members outside of the family nucleus get together in order to help with caring for the child.

"Their mother died and they were left with their father, but he works and has no time. So I live with them so I can take care of them". (F5)

When the mother dies, the child who carries the virus may end up in an institution for lack of a family structure that is able to cope with caring for it.

"She is the eldest, lives in a Home for Girls. I cannot manage the two. She has a problem in her head...wants to hit everybody. I already take care of him and the little one. She has even been in a psychiatric hospital". (F5)

Another problem faced by the care-giving family is with regard to revealing the child's diagnosis to it. They say they are afraid because the child might not understand sufficiently well to be able to deal with the news, thereby justifying why they hide it from the child.

"He does not understand what happens, but he gets very irritated when he gets sick. I don't know how to tell him, and I don't want him to suffer". (F5)

"I don't think he has much idea about what the disease is. I am afraid of his reaction, that is why I hide it from him". (F7)

Another concern in taking care of the child is with regard to its schooling, because many face interruption or delay in their studies because of the disease, or learn in special classes.

"She is in the second grade, but it is a special class. She has difficulty with learning and her brother has the same problem. She has failed three times because of hospitalizations". (F7)

"I didn't tell them at school, I was afraid they might not accept her there". (F2)

DISCUSSION

The data revealed that the family members organized themselves in caring for the child, keeping secret their and the child's serological condition. The mothers were the children's main care-givers. A grandmother and an institutional care-giver were also found. It was verified that when faced with the diagnosis of HIV/ AIDS, the family organizes itself to take care, creating an intrafamily social support network formed by the members of the family in the home itself and others that join with this intention.

The experience of caring for a child with HIV/ AIDS may be the factor that reveals the carer's own infection to the persons around her in daily social life. Having an infected child who, from an early age, must face the revelation of the situation, could expose her and her family members to discrimination and prejudices, which they all fear, and that is why the family omits revealing this condition⁽¹⁰⁾.

In spite of the efforts to dismantle a stigmatized image, the cause of AIDS infection is still associated with the adoption of socially unacceptable behaviors, such as promiscuity, homosexuality and the use of drugs⁽⁹⁾. In this sense, revealing the diagnosis of HIV/ AIDS is a painful process of confrontation, considering that the greatest fear is of social isolation and loss of support of important persons, in addition to the risk of having to live with discriminatory attitudes⁽¹¹⁾.

Revealing themselves as carriers means being exposed to judgments and exclusion, with the first threat perhaps not being the disease, as a physiopathologic process, but disease as the cause of a pathological social condition, generating fear of the consequences impacting on day-to-day family, social and working life relationships^(12,13). This fact shows the uniqueness of family care-giving to the child with HIV/ AIDS because, in addition to the normal demands of care, one has to avoid others in order to keep the secret⁽¹⁴⁾.

Receiving the diagnosis of infection by HIV is one of the most critical events, awaken diverse feeling in individuals, ranging from surprise, disappointment,

sadness, despair, fear of the unknown and of what may happen⁽¹³⁾. For women who discover they are seropositive during pregnancy, or even for those who fall pregnant knowing of their diagnosis, facing this condition has taken place as a unique moment in their lives⁽¹⁵⁾. Therefore, women with HIV/ AIDS, experience two extremely complex processes: That of being the carrier of a sexually transmittable disease, in this case, infection by HIV, and that of being the mother of a seropositive child⁽¹⁶⁾.

It was verified that from the time of diagnosis of HIV/ AIDS in the child, taking care of it gains and outstanding place and begins to mean the existence of the care-giving family for the purpose of seeing the child in good health, and it is common for them to abdicate from questions that used to form part of the world they lived in⁽¹⁾. The presence of a feeling of confidence, satisfaction and relief has been shown when a negative diagnosis is given.

Not perceiving the child as being different by virtue of its serological condition shows that after the impact of the diagnosis, the care-giving family adapts itself to its new mode of living, re-dimensioning the significance of HIV when the child's conditions of health are shown to be good. This meaning is revealed from the time it is understood that being a child is unique and singular in its existence and appreciating its potentialities⁽¹⁾.

The care-giving family of the child with HIV/ AIDS may not perceive it as being different from the other non seropositive children, when comparing HIV/ AIDS with other types of diseases, considered by them as being more serious and life-limiting. They showed that if the child's physical conditions did not show signs of disease, it did not need any special care⁽¹⁾.

The maintenance of health and physical integrity today allows the seropositive individual to live in a manner close to normality. Slowly, AIDS has been acquiring the characteristics of a chronic disease and some myths are being diluted and transformed, which are signs that the experience of living with HIV has progressively been changing⁽¹³⁾.

In this case, it was verified that blood was presented as the objectification of HIV, reminding the care-giver of the child's serological state. The stereotype of the person with AIDS is in the contaminated blood, as a living element, affecting the imagination of individuals⁽¹³⁾. HIV transmission via blood is one of the best known form of contagion. Thus, the care taken to avoid contact with the blood of a seropositive child is disseminated by health professionals to the care-giving family, causing the family to be reluctant that transmission of the virus to another person occurs via the blood from injuries.

As a consequence of AIDS, many children are orphans, needing to be cared for by family members

who are not always willing to undertake this sacrifice⁽¹⁷⁾. After the mother's death, they end up in institutions where the children will have specific care as regards their health and antiretroviral treatment, protection against violence and maltreatment, guarantee of access to health services and schooling. However, this does not stop it from being a place that is stigmatized in the eyes of society, and in some cases, deprives the children of family and social life⁽¹⁷⁾.

The existence of affection, care, communication and a stable family structure are important in minimizing the feelings of abandonment, loneliness and the threat of death, the fruit of living with this disease⁽¹⁸⁾. Therefore questions such as orphanhood and consequent institutionalization, the various family structures and organizations and the impossibility of receiving family care-giving are difficulties sometimes experienced by seropositive children, and may interfere with their development in a healthy manner.

Being in hospitals, making use of antiretroviral medications, as well as having clinical and laboratory exams performed, may cause discomfort and irritability in the life shared between care-givers and carriers, in addition to emotional wear in both, and may lead to revealing the child's seropositivity, making it difficult to live in its social medium⁽¹⁹⁾.

Revealing the diagnosis to the child may present an important source of stress to the family. This can be delayed but not avoided indefinitely. Tell the child about its diagnosis makes the paradox of life and death become part of the life of HIV positive women, causing them anguish. Unconsciously, these two representations cohabit, making the image of the donor of life could, in the eyes of the child, be transformed into the image of the donor of death⁽²⁰⁾.

The difficulty in revealing the diagnosis to the child unbalances the emotional state of mothers, causing them anguish. Thus, hiding it has three faces: the non exteriorization of HIV/ AIDS, the seropositivity of the mother and child. All with consequences that are difficult to face, demanding care⁽²¹⁾.

The time and manner in which the mother and/ or other family member will reveal the diagnosis to the child is of great importance, since the traumas in infancy may compromise its future. In this sense, once perceives that hiding the diagnosis and silence in the face of the child's questions are part of the day-to-day life of the family and are shown to be defense mechanisms in the sense of protecting the child from prejudices and social isolation⁽²²⁾.

The difficulties of schools, when they are faced with the reality of HIV/ AIDS, arise around routine questions: How to act when injuries occur, exchange of objects among the children, and manifestations of

affection, such as kissing and embraces, in addition to the difficulty of acceptance of the seropositive child by the parents of children not infected by the virus, due to the fear of contagion by a disease that is still incurable. In this sense, the care-giving families prefer not to inform the school of the child's condition, so as not to expose it to prejudices.

The limitation of this study was the number of participants. From this aspect, the need for further studies about family care-giving to the child with HIV/ AIDS was considered, particularly as regards the reproductive right of seropositive mothers in order to support the work of health professionals.

FINAL CONSIDERATIONS

The data obtained in this study revealed the experiences of the family in care of the child with HIV/ AIDS. With regard to the experience of family care-giving to the child it was verified that mothers were the main care-givers and were concerned about keeping secret their seropositive condition and that of their children. The positive serology of the child is the cause of stress for the family, whose hope for a cure lies in the care they give. As special care, the concern about following up the child's health and the fear of HIV virus transmission when the child has an injury that bleeds, was evident.

The following were shown to be difficulties faced by the family in taking care of the child: illness or death of the child's main care-giver, also seropositive; the need for institutionalizing the child due to lack of a family care-giver; hiding the HIV/AIDS diagnosis from the child; and the need to interrupt or delay schooling because of health problems.

It was concluded that public policies and health services are necessary, adherent to the needs of the family care-givers of children with HIV/ AIDS, helping them to obtain early diagnoses and access to their treatment and that of the children, to effective family planning and guidance that qualify them to take care of the children and of themselves.

Nurses and other health professionals should provide support for seropositive pregnant women to face the day-to-day adversities they will encounter. As regards follow-up of these women and their children, it is of the utmost importance to provide humanized post-partum assistance and amplification of the networks of attention and social support to care for seropositive children and their family care-givers.

It is necessary to understand that infection by the HIV/ AIDS virus does not diminish a woman's desire to be a mother. Therefore, her serological status may not be considered at the time of taking the decision to fall

pregnant, and whether or not to use contraceptive methods. The study revealed that silence on the reproductive rights of HIV/AIDS carriers continues and are sources of social stigma. In spite of seropositive women being independent citizens as regards their sexual health, they are still vulnerable to unprotected sexual relationships and their desire to fall pregnant is criticized.

In this sense, the goal of nursing care is to qualify persons to be the protagonists of their lives and the aim

is to equip them to make responsible decisions. Thus, the nurse must provide support, adequate advisory services to families and all those who care for children with HIV/AIDS, with the purpose of offering answers to their doubts and fears, providing pertinent information about HIV/AIDS to the persons within the social circle of these families. Thereby one will create appropriate environments for diminishing the stigma and discrimination to which these families and children are exposed.

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