



Original Article

ASPECTS OF SOCIAL INTERACTIONS OF HIV-POSITIVE CHILDREN FROM THE PERSPECTIVE OF THEIR CAREGIVERS

ASPECTOS DAS INTERAÇÕES SOCIAIS DE CRIANÇAS PORTADORAS DE HIV PELA ÓTICA DOS SEUS CUIDADORES

ASPECTOS DE LAS INTERACCIONES SOCIALES DE NIÑOS PORTADORAS DE HIV BAJO LA ÓPTICA DE SUS CUIDADORES

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The occurrence of HIV-infected women resulted in the birth of children exposed or infected by the virus. This research aimed to identify aspects of HIV-positive children's interactions. This exploratory and descriptive study of qualitative approach was developed at an HIV/AIDS care referral service in Fortaleza-CE, Brazil, between July and December 2009. Participants were caregivers of 13 children infected with HIV. The semi-structured interviews and content analysis enabled the creation of categories: fear of contamination by HIV in the family core; lack of confidentiality and training of health professionals in care delivery to HIV/AIDS patients; and social exclusion in the family, neighborhood and school environment. In conclusion, the social interactions of HIV-positive children are impaired. Fear, exclusion and prejudice permeate the caregivers' lives, due to the fear that the children will be discriminated against in society. This study reveals information that can support holistic nursing care.

Descriptors: HIV; Acquired Immunodeficiency Syndrome; Interpersonal Relations; Child; Nursing Care.

A ocorrência de mulheres infectadas pelo HIV resultou no nascimento de crianças expostas ou infectadas pelo vírus. O objetivo da pesquisa foi identificar aspectos das interações sociais de crianças portadoras de HIV pela ótica de seus cuidadores. Estudo exploratório-descritivo e qualitativo, realizado num serviço de referência em HIV/aids, em Fortaleza-CE, entre julho e dezembro de 2009. Participaram cuidadoras de 13 crianças infectadas pelo HIV. As entrevistas semiestruturadas e análise de conteúdo possibilitaram a elaboração das categorias: medo do contágio do HIV no seio familiar; falta de sigilo e preparo dos profissionais de saúde no atendimento aos portadores de HIV/aids e exclusão social na família, vizinhança e no ambiente escolar. Conclui-se que as interações sociais das crianças revelam-se prejudicadas. Medo, exclusão e preconceito permeiam a vida dos cuidadores, pelo receio de as crianças serem discriminadas pela sociedade. Este estudo revela informações passíveis de subsidiar atenção integral de enfermagem.

Descritores: HIV; Síndrome da Imunodeficiência Adquirida; Relações Interpessoais; Criança; Cuidados de Enfermagem.

La ocurrencia de mujeres infectadas por VIH ha resultado en nacimiento de niños expuestos o infectados por el virus. El objetivo de la investigación fue identificar aspectos de las interacciones sociales de niños portadores del VIH. Estudio exploratorio-descriptivo y cualitativo, desarrollado en servicio de referencia en VIH/sida, en Fortaleza-CE, entre julio y diciembre del 2009. Participaron cuidadoras de 13 niños infectados por VIH. Entrevistas semiestructuradas y contenidos analizados han permitido la elaboración de categorías: miedo del contagio del VIH en el seno familiar; falta de sigilo y preparo de profesionales de salud en la atención a portadores de VIH/sida, exclusión social en la familia, vecindad y ambiente escolar. En conclusión, las interacciones sociales de niños se muestran perjudicadas. Miedo, exclusión y prejuicio permean la vida de cuidadores, debido al recelo de que los niños serán discriminados por la sociedad. Este estudio revela informaciones que pueden subsidiar atención integral de enfermería.

Descritores: VIH; Síndrome de Inmunodeficiencia Adquirida; Relaciones Interpersonales; Niño; Atención de Enfermería.

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INTRODUCTION

In Brazil, 608,230 AIDS cases were identified from the beginning of the 1980s until the first semester of 2010⁽¹⁾. This period was marked by changes, which ranged from cases closely related to homosexuals to the current tendency of exposure of heterosexuals, young people and the increasing number of cases among women, resulting in the occurrence of children exposed to HIV before birth or already infected⁽¹⁻²⁾. According to the current national guidelines, the AIDS case definition for children, for epidemiological surveillance purposes, consists of every individual under the age of 13 who presents laboratory evidence of HIV infection and some evidence of immunodeficiency⁽²⁾.

In the context of HIV, the family emerges as a unit of care, as it can contribute to the physical and mental balance of its members. The effects on physical, mental and emotional health caused by viruses extend to family members and to those who are part of their social and affective relationships, because the uncertainty over contamination causes fear, insecurity and emotional imbalance. Regarding children born from parents with HIV, regardless of whether they are infected or not, they may experience conflicting situations, or being considered by society as victims of AIDS, since they do not practice risky behaviors⁽³⁾.

This fact transfers to parents the blame attributed to their HIV seropositivity, which can cause major disruptions to the family unit. The need for constant treatment, as well as the fear of death can cause suffering to relatives and caregivers, negatively affecting the health of these children. In the case of AIDS, there is an association between the disease and the different social groups, such as homosexuals, sex workers and drug users, suggesting multiple meanings⁽⁴⁾. Despite efforts to deconstruct this stigmatized image, AIDS is still associated with the adoption of behaviors unaccepted by society⁽⁵⁾.

HIV stands out as one of the most serious public health problems worldwide, increasingly faced by health professionals, governments and the scientific community. Thus, it is essential that nurses and other health team members understand the disease, the clinical treatment and the social aspects of these patients' experience⁽⁶⁾.

With regard to pediatric AIDS, it represents a most recent epidemiological problem, being a consequence of the profile change of people affected by HIV/AIDS and the inclusion of the term vulnerability for the implementation of protection and identification measures of new cases of the disease. This topic leads to consequences that represent the scale of the problem: orphaned children, the experience of grieving the loss of parents, and the growth and development with a chronic disease that requires specific care for the health maintenance.

Every child needs to have their rights guaranteed and be cared for by people trained to meet their needs, potentials and limitations. Furthermore, the harmonious coexistence with family and society can have positive or negative effects on a child's life, since social interactions are essential to human development, because it is in the spatiality and temporality of everyday life that the subjects build the meaning of their actions and experience the opportunities and limits of action⁽⁷⁾.

Therefore, we aimed to identify aspects of social interactions of children with HIV through the perspective of their caregivers. Studies of this nature are important when it comes to better understanding the experiences of people with HIV/AIDS, contributing as a subsidy to a holistic nursing care and addressed to the existing needs.

METHOD

This is an exploratory descriptive study with qualitative approach, carried out in a HIV/AIDS care referral service in Fortaleza, Ceará, Brazil. This service offers consultations, laboratory and radiological tests, distribution of antiretroviral drugs, condoms, and outpatient and inpatient units.

The research was conducted from July to December 2009. As inclusion criteria we used: being a mother or primary caregiver of children aged under 13 living with HIV/AIDS⁽¹⁾, regardless of the stage of infection, and being monitored in the clinical service. As exclusion criteria: having cognitive impairment or any other condition that prevented answering the questions designed by the researcher. The sample consisted of 13 caregivers of children with HIV/AIDS, who were invited to participate in the study while awaiting routine medical consultation of the child in the hospital outpatient. The interview was conducted in a private office of the service.

For data collection, we used the semi-structured interview technique, recorded on electronic device, lasting about 45 minutes, and performed by a previously trained researcher. The interview contemplated the socio-demographic profile, involving: relationship with the child, origin, age, marital status, education, occupation, and family income. Moreover, we had the following guiding question: *How is the social interaction of the HIV-positive children that you care of? How does the child relate to the family and to others, in daycare, school and neighborhood?* As for the number of participants, it was determined by theoretical saturation, due to the lack of new evidences to support the proposed objective, i.e. based on the repetition of the findings.

After collecting the statements, the reports were transcribed in written texts, which were individually read and explored. Aiming to explore the documents, it was necessary to listen to them and read them thoroughly, one by one. For data processing, we adopted the content analysis technique⁽⁸⁾, composed of three stages: 1. Organization and systematization of ideas; 2. Material exploration and systematic transformation of the raw data of the text, by clipping, aggregation and enumeration, aiming to reach an understanding of the text and content representation; and 3. Treatment of results, inference and interpretation. We analyzed the reports and categorized them by inference of similar content, formulating the following categories: fear of HIV contamination in the family; lack of confidence and training of health professionals in the care of people with HIV/AIDS; and social exclusion in the family, neighborhood and school environment.

The project was submitted to the Ethics Committee of the hospital where the research was conducted, in accordance with Resolution No. 196/96 of the National Health Council on research involving human subjects, being approved on 06.18.2007 under Protocol No. 014/2007. The research was conducted in accordance with the ethical standards required. All participants signed the Free and Informed Consent. To present the statements and guarantee the anonymity of participants, we decided to call them by the word "caregiver" followed by Arabic numeral sequence of each interview.

RESULTS AND DISCUSSION

Of the 13 interviewees, seven were the biological mothers of the children, while the others were family members, like sister, aunt and grandmother. This is a result of maternal death due to illness by AIDS, as revealed during interviews. In such cases, who usually

supports the orphaned child is a close relative, most often female. Similar findings were observed in other researches⁽⁹⁻¹⁰⁾ whose caregivers are family members. It is worth mentioning that these women took care of children aged between three and seven years. Table 1 presents the characterization of caregivers of children with HIV/AIDS.

Table 1 - Characterization of caregivers of children with HIV, according to socio-demographic data. Fortaleza-CE, Brazil, 2009

Caregiver	Relationship	Age*	Marital status	Years of education	Occupational status	Family income**
1	Mother	35	Married	< 8	Employed	1
2	Grandmother	57	Divorced	None	Unemployed	<1
3	Grandmother	50	Married	< 8	Employed	3
4	Mother	27	Single	< 8	Unemployed	<1
5	Mother	41	Married	< 8	Employed	<1
6	Mother	33	Single	8	Unemployed	2
7	Grandmother	44	Widowed	< 8	Unemployed	<1
8	Mother	42	Married	≥ 9	Unemployed	3
9	Mother	34	Married	None	Unemployed	1
10	Sister	24	Single	≥ 9	Employed	2
11	Aunt	53	Married	8	Employed	2
12	Mother	45	Widowed	8	Unemployed	<1
13	Aunt	42	Single	≥ 9	Employed	1,5

*Age in years. Average age: 40.5 years. **Family income: measured in minimum wages. Minimum wage at the time of research: R\$ 415.00.

From these data, we verified that the age interval among mothers (27-45 years) reflects national statistics, in which women with HIV are at full reproductive age, aged from 15 to 40 years^(1-2, 11-12). As for marital status, most interviewees were married, which has also been observed in other epidemiologic studies⁽¹³⁾. Low or insufficient education level, as well as unemployment and low income levels were identified in this and other researches with people living with HIV/AIDS, demonstrating the difficulties of inserting these individuals in the labor market^(3, 6).

The statements of caregivers enabled obtaining aspects of social interactions of children with HIV, emerging the following three categories: fear of HIV contamination in the family; lack of confidentiality and

training of health professionals in the care for people with HIV/AIDS; and social exclusion in the family, neighborhood and school environment. Given below the categories are described.

Fear of HIV contamination in the family

We verified that there are difficulties of interaction between the child and the family in the home environment. Caregivers noticed the uncertainty about AIDS contamination. Such uncertainty creates fear and insecurity among family members. This fact is intensified, especially when there is the need of daily contact with a child with HIV/AIDS. The information mentioned is proven in the following statements: *In her aunt's house they separate the glass, spoon and plate, and don't get near her (Caregiver 2). When my daughter drinks at some glass, they*

wash it immediately, and when she goes to someone's house, they ask her to bring a towel and a sheet (Caregiver 9).

Given the fact that AIDS is a chronic disease, there are constant questioning imposed on the family group living in this situation, requiring decisions about medical treatment and about the relationships in the social and spiritual level, and lifestyle⁽⁶⁾. As stated in the literature, the different situations related to changes in daily life and lifestyle, such as the difficulty of living with a chronic and incurable stigmatizing disease, the uninterrupted use of medications, the overprotective family, among other circumstances, cause feelings of fear, insecurity and anger at home⁽¹³⁾.

This behavior is mainly due to fear of HIV contamination, as well as the lack of health education, regarding the forms of virus transmission, even though these are widely available, some people, out of fear or impossibility of understanding, are just not able to assimilate this information. So, the family no longer contributes to the child wellbeing, and thus ceases to be a primary care unit and source of help for its members, as reported: *Everyone in my family is afraid of me and my son, afraid of catching our disease, so I hardly go to my relatives* (Caregiver 6).

Obviously, the family sees itself as something unique in its everyday life, composed of projects, expectations, frustrations, difficulties, reflections, losses, responsibilities assumed or not, all the experiences that exist in everyday family life. Thus, they have their everyday relationship dynamics shared by family and individual events. In this context, the physical and emotional health of the family members has an important role in its functioning. As these members are interconnected, any change that happens in the health of one affects all others and changes the family unit as a whole^(5, 10). As it was observed, families may experience difficulties or inability to perform coping actions. Personal and interpersonal factors arise and affect the

management of crisis or illness situations experienced by them.

The reactions to the diagnosis are strongly influenced by individual beliefs and values, as well as by the social group in which they are inserted. Furthermore, the dominant image of AIDS is still a consequence of the first infections, when there was no benefit from using antiretroviral drugs, and HIV/AIDS patients were more susceptible to opportunistic diseases, having a poor quality of life.

We also observed an unfair treatment to the child, as described below: *His aunts do not want us to go to their house because they say they will get infected* (Caregiver 11). *His godmother told she did not want him there because he would bring the disease to her house* (Caregiver 12). *Her grandmother said that just from being near her she would get infected; they have even spoken of killing her* (Caregiver 13).

Therefore, the cultural meanings caused by the disease interfere with the family behavior regarding the person with AIDS, who starts being discriminated from the family group and deprived of the right to have a healthy social interaction. Findings like these are not limited to children with HIV; they also extend to those who are part of their daily living, such as mothers, fathers, or caregivers, reflecting negatively on their daily social life^(10, 13).

In the face of HIV seropositivity, the reactions cause some impacts ranging from denial to rationalization, and are expressed in many ways, such as aggression to patients, family disruption and even abandonment⁽⁵⁾. This study identified that children with HIV/AIDS no longer have a good relationship with the family, because of the stigma directed to parents or main caregivers. However, this fact limits opportunities of getting support and social contacts. The prolonged silence and poor communication also hinder the adherence to treatment, and trigger behavioral disorders, self-directed stigma and higher levels of

psychological stress for people with HIV and their caregivers.

Lack of confidentiality and training of health professionals in the care for people with HIV/AIDS

As it was verified, some health professionals demonstrate behaviors of discrimination and intolerance toward patients with HIV/AIDS. Such behaviors emphasize the lack of technical or ethical training in assistance, as we can see in the statements below: *When I arrived at the health center, I saw people whispering: he is HIV positive* (Caregiver 2). *The hospital staff keeps spreading mine and my son's diagnosis* (Caregiver 4). *When she is going to be vaccinated, the nurse is afraid to put cotton in the blood that comes out* (Caregiver 10).

The exclusion from health professionals causes embarrassment to users, and at the same time causes a withdrawal from services that can provide better treatment and quality of life. According to studies, these situations result of misinformation and prejudice of health professionals, reinforcing the lack of ethical commitment and technical inexperience concerning HIV-positive patients⁽⁶⁾.

This discrimination can hinder the access of HIV/AIDS patients to services available in the health network, neglecting also the care and treatment for other medical conditions besides AIDS. Despite the increase in the number of AIDS cases being a fact confirmed by epidemiological analysis in Brazil⁽¹⁾, the following statements indicate that health professionals are not always able to welcome the patients with HIV/AIDS, even in the most basic actions: *They did not want to treat my son when he had tumors, they told us to go back to the hospital specialized in infectious diseases, but I had no money for the bus ticket* (Caregiver 12). *When my son had the flu, he had to do an X-ray of lungs and the doctor said he could not do it, that only the HIV doctor could* (Caregiver 8).

Although many services are not specialized in the treatment and monitoring of people with HIV/AIDS, the professionals cannot refuse to treat the sick person, especially given the social and financial difficulties experienced daily by these patients. This finding reveals the lack of humanization and lack of knowledge on basic healthcare. About this subject, studies report that the transformation of health professionals is expected and essential, since the limited look on human beings devalues the influence of socioeconomic and cultural structures, and disregards the comprehensive care, which should go beyond the treatment of the physical body⁽¹⁰⁾.

Furthermore, studies with approach anchored in the relationship between health communication and care for HIV patients are unanimous in asserting the lack of training of the multidisciplinary health team in establishing an effective communication with these clients. The main reason for this deficiency concerns the occurrence of feelings of insecurity and anxiety arising from the risk of HIV contamination⁽¹⁴⁾, as identified in one of the mothers' statement: *Some people there in the health center told they did not study to perform the treatment of patients with AIDS, so they did not even want to talk to me, they did not help me, or my son, who did nothing wrong, he just had the flu* (Caregiver 1).

Discrimination against people with HIV is still a social reality and, paradoxically, in health services, in which a multidisciplinary team needs to treat all kinds of problems of service users, without distinction. Despite the lack of specialized services in the healthcare for people with HIV/AIDS, often there are problems that can be solved in primary health care institutions. As we verified, many professionals create barriers to the initiation and continuation of treatment, or always refer the patient to another health service. Conflicts of this kind persist as the main problem in providing healthcare to individuals with HIV/AIDS. Therefore, there is an

urgent need for training and information strategies capable of reaching the professionals and users of health services across the country.

Social exclusion in the family, neighborhood and school environment

According to caregivers, the child is often excluded in the family, neighborhood and school or daycare center. This fact determines certain forced reaction behaviors, for example, hiding the condition of HIV seropositivity. This strategy can sometimes prevent situations of discrimination and stigmatization processes.

Thus, as one of the caregivers reported, the HIV seropositivity was highly secret in the neighborhood. Usually, the mothers fear that the neighbors find out about the diagnosis of their children and start to exclude them, or that they suffer reprisals, as described: *If I told the neighbors that we were HIV positive, certainly there would be prejudice, and no one would like him* (Caregiver 1).

Revealing the diagnosis and living with a disease still seen as fatal and socially unacceptable constitutes a real drama, so that caregivers use the most different arguments. To prevent or postpone the confrontation with their own vulnerability situation, studies report that when experiencing fear, which is a common feeling in the face of the revelation of HIV seropositivity, the people infected and even their caregivers begin to lie or omit issues related to the disease^(9, 14).

When the community suspects the child diagnosis, the mothers reported suffering discrimination, even from family members, as seen in the speeches: *The neighbors keep talking that we're sick, that we have a very serious disease* (Caregiver 3). *Some women in the village do not let their children play with mine, nor come near him; my son has virtually no friends, he lives alone* (Caregiver 6). *His aunts do not let him play with their children; preferably not even get near them* (Caregiver 7).

The statements described how hard it is living with AIDS, especially for seropositive mothers, which often feel blamed for the discrimination directed toward

the child. However, such situations are common in society. They happen due to the lack of clarity about what the disease is and how it is transmitted, as we can see: *I feel guilty that he lives alone, it's my fault, I brought him to the world; I have to protect this child, because sometimes people do not like him because of me* (Caregiver 12).

In general, the imagery built around the AIDS epidemic throughout the 1980s and the associations of the virus to certain groups contributed to that, even when knowing some information, people remain stuck in the paradigm of "risk groups" and therefore become vulnerable to infection⁽⁶⁾. These events influenced the behavior of other people regarding HIV patients and their families, creating feelings of anxiety, motivated by fear of social rejection. These stigmatizing feelings are often identified in other studies on HIV/AIDS. As assumed, there seems to be in the family, or in the social environment, no understanding of AIDS as a chronic disease capable of normal living⁽¹⁵⁻¹⁶⁾.

Children are also victims of discrimination by school professionals and by their own colleagues, as revealed: *My daughter says that classmates keep saying she is sick; they do not want to play with her, nor drink water from the same glass* (Caregiver 1). *When the principal knew I had AIDS, she took my son to take the exam without consulting me and now everyone in the neighborhood knows about it, and she wants me to take my son out of the school, I do not know what to do, because I have no money to pay for a private school* (Caregiver 4). *The mothers of the other children say that my son has to study in a school exclusive for AIDS patients* (Caregiver 5).

When children with HIV are discriminated at school, there is a violation of their dignity and freedom of transit in collective spaces, which consist of civil rights. The discrimination experienced at school results in exclusion, a fact that hinders or restricts the access to vocational education. Faced with the stigma related to HIV/AIDS, the school community seems to fear accepting these children in school, which was also identified in other studies⁽¹⁶⁻¹⁷⁾.

In general, studies affirm the existence of difficulties in enrolling children and adolescents with HIV/AIDS in regular schools, which represents important consequences of prejudice directed towards these individuals^(14, 17). Such episodes involving HIV/AIDS patients and schools have had major repercussions, and thus made it possible for this issue, initially restricted to the educational sphere, to be treated publicly. One of the proposals developed to try to solve this serious problem was the creation of the Interministerial Ordinance 769, from 05.29.1992, by the Ministries of Health and Education, which ensures the access to education and the preservation of confidentiality of seropositivity condition of children and adolescents with HIV/AIDS⁽¹⁷⁾.

As observed, the change of AIDS from aggravation with high mortality rate to chronic illness affects the physical and psychological development of HIV seropositive children, especially those infected by vertical transmission. With the advent of antiretroviral therapy and access to treatment, there was an improvement in quality of life. Thus, the psychosocial needs now have a new meaning and relevance, especially when considering the inclusion of these children. We emphasize that these children live in families with multiple difficulties, such as the stigma caused by the disease brought by parents, death of one of the parents and financial problems. All these factors hinder their appropriate healthcare treatment.

FINAL CONSIDERATIONS

This study verified that HIV infection interferes with the interaction of the child with family members and society. Fear, exclusion and prejudice permeate the lives of caregivers, given the fear that their children get rejected or discriminated. The findings of the everyday

life of these children sometimes go beyond the boundaries of human understanding. They are starting their process of social interaction and knowledge of the world they live, and end up having deep trouble to fit in a society unable to be welcoming and live with differences. Although children can feel, they are not yet able to judge and understand the situation they are exposed to. Therefore, when designing this study, we were based on interviews with caregivers of the children.

We confirmed AIDS as a stigmatizing disease, which brings with itself a great challenge to family members, health professionals and society. With regard to caregivers of children with HIV/AIDS, they start having to live with many events in the same period, such as assimilating the fact of being a carrier of an incurable virus, which was transmitted to their child, or taking care of a child from someone who died of AIDS, dealing with feelings originated on social prejudice related to this disease.

In order to approach the limitations caused by this condition in the best way possible, caregivers need to feel safe and find support from health professionals. Likewise, the family and the community should be guided on the proportions taken by HIV in general population, as well as about the aspects of the disease, either by health services or through the media. Strategies like these could make the everyday life of people living with HIV/AIDS less traumatic and help to maintain a social support network.

There were difficulties in the development of this research, mainly because pediatric AIDS is a complex issue and difficult to approach. As limitation, we emphasize that the interview had to be conducted on the same day of the consultation; thus, the participants were greatly concerned about losing their turn due to the interview.

Finally, this study showed the extent of the needs of social interactions of children infected with HIV/AIDS, presenting situations where we can intervene in order to meet the human needs of these children and their families. We also highlight the need for more studies that address the topic of pediatric AIDS, so we can perform assistance according to the unique care needs of this group, in order to promote a better quality of life.

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