

## PERCEPTION OF THE FAMILY CAREGIVER REGARDING PROBLEMS FACED BY CHILDREN IN RELATION TO THEIR DIAGNOSIS OF HIV/AIDS

Márcia Marcos de Lara<sup>1</sup>, Giovana Calcagno Gomes<sup>2</sup>, Camila Magroski Goulart Nobre<sup>3</sup>, Bianca Contreira de Jung<sup>4</sup>, Aline Rodrigues Costa<sup>3</sup>, Eloisa da Fonseca Rodrigues<sup>5</sup>

**ABSTRACT:** This study aimed to investigate the perception of the family caregiver regarding the problems faced by the child in relation to her diagnosis of Human Immunodeficiency Syndrome. A qualitative, exploratory and descriptive study was undertaken in a Day Hospital which is a center of excellence in the South of Brazil, in the second semester of 2014. The participants were 10 family caregivers of children attended in the service. The data were collected through semistructured interviews and underwent content analysis. The results emphasized the following as problems faced by the family caregiver: the need for frequent inpatient treatment, being the only person with the virus in the family, suffering prejudice within the family and at school, presenting growth delays and psychological problems. It is necessary for nurses to take responsibility for our educational role with these families so as to help them develop effective strategies for caring for the child.

**DESCRIPTORS:** Acquired Immunodeficiency Syndrome; HIV; Child; Family; Nursing.

### PERCEÇÃO DO FAMILIAR CUIDADOR ACERCA DOS PROBLEMAS ENFRENTADOS PELA CRIANÇA FRENTE O DIAGNÓSTICO DE HIV/AIDS

**RESUMO:** Objetivou-se conhecer a percepção do familiar cuidador acerca dos problemas enfrentados pela criança frente o diagnóstico de Síndrome da Imunodeficiência Humana. Realizou-se pesquisa qualitativa, exploratória e descritiva em um Hospital Dia referência do sul do país, no segundo semestre de 2014. Participaram dez familiares cuidadores de crianças atendidas no serviço. Os dados foram coletados por meio de entrevistas semiestruturadas e submetidos à análise de conteúdo. Os resultados destacaram como problemas enfrentados pelo familiar cuidador a necessidade de internações hospitalares frequentes, ser a única pessoa com o vírus na família, sofrer preconceito na família e na escola; apresentar atraso no crescimento e problemas psicológicos. É necessário que assumamos o nosso papel educativo junto a estas famílias no sentido de auxiliá-las no desenvolvimento de estratégias efetivas de cuidado à criança.

**DESCRIPTORIOS:** Síndrome de Imunodeficiência Adquirida; HIV; Criança; Família; Enfermagem.

### PERCEPCIÓN DEL FAMILIAR CUIDADOR ACERCA DE LOS PROBLEMAS DEL NIÑO DELANTE DEL DIAGNÓSTICO DE HIV/SIDA

**RESUMEN:** Estudio cuyo intuito fue conocer la percepción del familiar cuidador acerca de los problemas enfrentados por el niño delante del diagnóstico de Síndrome de la Inmunodeficiencia Humana. Se realizó investigación cualitativa, exploratoria y descriptiva en un Hospital Día referencia del sur del país, en el segundo semestre de 2014. Participaron diez familiares cuidadores de niños atendidos en el servicio. Los datos fueron obtenidos por medio de entrevistas semi estructuradas y sometidos al análisis de contenido. Los resultados destacaron como problemas enfrentados por el familiar cuidador la necesidad de internaciones hospitalarias frequentes, el hecho de ser la única persona con el virus en la familia, sufrir prejuicio en la familia y en la escuela; presentar retraso en el crecimiento y problemas psicológicos. Es necesario que nosotros enfermeros asumamos nuestro papel educativo con estas familias a fin de ayudarlas en el desarrollo de estrategias efectivas de cuidado al niño.

**DESCRIPTORIOS:** Síndrome de Inmunodeficiencia Adquirida; HIV; Niño; Familia; Enfermería.

<sup>1</sup>RN. Nurse at the Santa Casa do Rio Grande. Federal University of Rio Grande. Rio Grande, State of Rio Grande do Sul (RS), Brazil.

<sup>2</sup>RN. Ph.D in Nursing. Lecturer in Nursing and on the Postgraduate Program of the Federal University of Rio Grande. Rio Grande, RS, Brazil.

<sup>3</sup>RN. Undertaking Master's degree in Nursing. Federal University of Rio Grande. Rio Grande, RS, Brazil.

<sup>4</sup>RN. M.A in Sciences. Lecturer of the Federal University of Rio Grande. Rio Grande, RS, Brazil.

<sup>5</sup>RN. Doctoral student in Nursing. Federal University of Rio Grande. Rio Grande, RS, Brazil.

**Corresponding author:**

Camila Magroski Goulart Nobre  
Universidade Federal do Rio Grande  
R. Benjamin Constant, 480 - 96211070 - Rio Grande, RS, Brasil  
Email: kamy\_magroski@yahoo.com.br

**Received:** 23/02/2017

**Finalized:** 18/10/2017

## ● INTRODUCTION

The advance of acquired immune deficiency syndrome (AIDS) as an epidemic has reached the child population. Currently, children and adolescents live with Human Immunodeficiency Virus/Human Immunodeficiency Syndrome (HIV/AIDS) since birth, facing the disease's repercussions, including the need to take antiretroviral medications over prolonged periods<sup>(1)</sup>.

Children's contamination by the HIV virus has come to be a public health problem, with a global risk of vertical transmission of approximately 35% to 40%, in the absence of any intervention<sup>(2)</sup>. This panorama extends beyond the biological ambit and has an impact both on the family and on the relationship between the mother and child<sup>(3)</sup>.

In contexts where there are limited resources, half of all children who contract HIV from their mothers die, emphasis being placed on vulnerability for HIV/AIDS in children between zero and 12 years old, and among adolescents from 13 to 19 years old. However, these deaths are avoidable if there is early diagnosis, accompanied by antiretroviral treatment and prophylaxis for opportunistic infections<sup>(4)</sup>.

In the case of children with HIV/AIDS aged below 12 years old, the recommendation of the Brazilian Ministry of Health is to make use of Antiretroviral Therapy (ART); however, these children lack the maturity to understand the process surrounding the treatment. As a result, the presence of a family caregiver is essential in order to give support to the child's needs, and for the success of the therapy<sup>(5)</sup>.

Seropositive children have a higher probability of presenting psychological problems, due to the diagnosis being kept as a secret within the family, having their routine altered by their condition, and suffering the daily need to take medications. Feelings of frustration, rage, solitude and low self-esteem have also been identified. Accordingly, the family caregiver needs to be duly instrumentalized to overcome these routine situations, so that the child will be able to face her fears and insecurity<sup>(6)</sup>.

The interest in studying this issue arose based on the premise that if the children are aware of their diagnosis, they show understanding regarding the disease, have an active role in the treatment, and make better use of their social support network. This would make it possible to build knowledge for supporting the health professionals who work with families and seropositive children. Accordingly, the present study aimed to investigate the perception of the family caregiver regarding the problems faced by the child in relation to her diagnosis of HIV/AIDS.

## ● METHOD

A descriptive study with a qualitative approach<sup>(7)</sup>, carried out in the Pediatric AIDS Day Hospital of a Teaching Hospital in the South of Brazil, considered to be a center of excellence in attending children with AIDS. The purpose of the AIDS Day Hospital is to treat patients who are children or juveniles and who have Acquired Immune Deficiency Syndrome (AIDS). It undertakes health actions through the 'Care for AIDS Patients' Program, which has been in place since 1989.

The participants in this study were 10 family caregivers who met the inclusion criteria: to be the main family caregiver for a child with HIV/AIDS, to accompany the child periodically in the treatment at the AIDS Day Hospital of the Teaching Hospital, and to be 18 years old or over. Family members who accompanied the child in the department only occasionally were excluded.

Data collection was undertaken in August – September 2014, through an individual interview with the child's main family caregiver. First contact was made in order to present the study and for the potential participants to report any interest they had in participating voluntarily.

The data were analyzed and interpreted using the technique of Content Analysis<sup>(7)</sup>. The stages of Content Analysis are: pre-analysis; exploration of the material; treatment of the results, inference, and interpretation. The pre-analysis involves the organization of the material, that is, the interviews were read through rapidly, seeking to visualize the specific characteristics of each subject who contributed to elaborating the initial ideas. The phase of exploration of the material consisted of carrying out the

codification of the interviews with numbers, letters or both, so that the excerpts of interest to the study could be grouped into nuclei with similar meaning, which gave rise to the categories.

In the stage of the treatment of the results, the raw results were treated in a significant and valid way, with analysis and discussion on these accounts taken from interviews with the subjects based in the framework mentioned above for this project, and in the sensitivity and experience acquired in the course of this study.

This study was submitted to the Research Ethics Committee in the Health Area, of the Federal University of Rio Grande. It was approved under Opinion N. 114/2014. The participants and their accounts were identified using the letter F, followed by the number of their interview.

## ● RESULTS

The characterization of the family caregivers and of the children who participated in the study, along with the category generated based on the analysis of the data, are presented below.

### **Characterization of the family caregivers who participated in the study – and of the children**

A total of 10 family caregivers participated in the study. They were aged between 23 and 61 years old, with a mean age of 42.4 years old. Regarding their relationship to the child, there were four mothers, two adoptive mothers, two fathers, one stepmother, and one grandmother. Regarding educational level, four had not completed primary/junior high school, three had completed primary/junior high school, and three had completed senior high school. Regarding profession, three are retired, three are housewives, two carry out general services, one piece-worker and one businessman. Regarding marital situation, four are single, three are married, and three are separated. They live on a family income ranging from R\$ 300.00 to R\$ 2,000.00, with a mean of R\$ 1,074.00.

The children were aged between one year nine months and 12 years old, with a mean age of 7.77 (8) years old. Two were male and four female. All had acquired the HIV virus through vertical transmission.

### **Problems faced by the child due to her diagnosis with HIV/AIDS**

One of the problems faced by the child is the need for frequent inpatient treatment due to opportunistic diseases.

*Quite a few times. Many, many, many times, I have even lost count. I know that it has been more than 10 times. (F3)*

*When he was only a few months old, he was hospitalized because of an opportunistic infection. (F1)*

The fact that the child is the only person in the family to have the virus becomes a problem, as the child may feel rejected, and have her self-esteem reduced.

*It is just me and my daughter who are HIV-positive. She feels different to the others (F1)*

*There are no other cases of HIV in the family, just her. (F9)*

The prejudice faced by the family is mentioned as a difficulty. They revealed that the child may suffer humiliations and prejudice from her own teachers.

*Yes, the prejudice does exist, due to the fact that people don't know how you get it. I took him out of kindergarten because the teacher was treating him differently, and he was little, he was just over one year old (F2)*

*The teachers at kindergarten know that she has it. The other parents at the kindergarten do not know – just the teachers and the headteacher. She has already experienced prejudice from her own teacher. My daughter was five years old and the teacher said that she wasn't learning because she had HIV. (F9)*

*I am not interested in what other people think or fail to think, and what they may say, I am the person who cares for her, I am the person who is bringing her up. All the same, I am worried about her, I don't want her to suffer humiliation. Even more so, because she can't even understand it yet (F5)*

*I have noticed that he really likes staying inside the house, he is a scamp. I don't know if it is just his way, or whether it is because of the virus. (F1)*

Two families revealed that their children are experiencing delays in growth. One child was born premature, and has special care needs; the other is smaller in stature than the other children his age, and – because of this – is rejected by his classmates and does not participate in their play.

*She was born at eight months. I only did the prenatal consultation when I was seven months pregnant, which was when I found out, so I only did one month of treatment. And that means that she is a special child, everything is different, all the care is different. She does not sit, and she does not walk. And if you leave her lying down all the time she gets sores, you have to take care of her. (F3)*

*He isn't growing, he has delays in his growth. He is 12 years old, you would think he is eight. All the other children his age are bigger. He says that he cannot play with anyone, because nobody wants to play with him, because he is little. He cannot play football, he can't go to school parties, he can't do anything. (F8)*

They mentioned that the child may present psychological problems due to anger at her diagnosis, and because of the possibility of her death.

*It is the psychological side of all this that is giving him the most problems. There are days when he is really angry, he says he is going to stop taking the medicine because he is going to die any time so he doesn't need to take it anymore. When he does that, I tell him that this is not how it is, because otherwise I would have already died. (F8)*

The family caregivers mentioned difficulties in arranging help to care for the child, bearing in mind that the child is seropositive, and that people are scared of catching the disease.

*I find it difficult to get help to care for her. My brothers and sisters help me with money sometimes, but only them. (F3)*

Another obstacle mentioned by the families is the arrival of adolescence, and the child's experience of sexuality. They mention the fear of never being able to find love or being able to have sex.

*He thinks that because of what he has, he will never be able to have a girlfriend. And I tell him that it is not that he cannot – just that he will have to be more careful. (F8)*

One of the inconveniences faced by the family caregiver is the need for the child to take a cocktail of antiretroviral medications on a daily basis, and at the same times.

*She takes the medication every day, and at the same times. (F9)*

*Yes, every day, and at the same times. (F10)*

*He takes the medications every day, at the same times. Seven and seven. (F4)*

*He makes use of the medications every day, at the same times. (F8)*

*I make use of the medication twice a day, at 12 hourly intervals, always at the same times. (F2)*

*He takes the drugs every day, and at the same time. It is just that he doesn't even remember that he has the drugs which he has to take. He is quite aware, he knows that he has to take everything properly, he just doesn't remember the times. (F1)*

## ● DISCUSSION

One of the problems faced by the child is the need for frequent inpatient treatment due to opportunistic infections. One study undertaken in a hospital in South Africa revealed the prevalence of

diseases such as pneumonia and urinary tract infections associated with HIV in children who required inpatient treatment<sup>(4)</sup>.

One study undertaken with children in Malawi, in Africa, demonstrated the multiple instances of inpatient treatment in patients aged less than two years old. This high demand for inpatient treatment suggests the need for continuous improvement in early diagnosis<sup>(8)</sup>. It is worth emphasizing how strange the child finds the environment, and that the prolonged periods of inpatient treatment can result in the child's perception of the hospital as a place characterized by prohibition and infantilization, a cause of indignation, solitude and homesickness. The child may also perceive the disease as a punishment, which will lead to death. The fact that the child is the only child in the family who has the virus becomes a problem, as this aspect is associated with the strong presence of stigma, and feeling oneself to be rejected accompanies the fear of revealing the diagnosis – and as a result of this, there is exclusion, prejudice and rejection<sup>(9)</sup>.

Accordingly, studies which have sought to identify the prevalence of discriminatory attitudes in relation to people with HIV/AIDS have shown that a considerable number of people continue to believe that AIDS can be transmitted through simple social coexistence<sup>(10-11)</sup>. Because of this fact, in the silence which results from the disease, people hide the word of HIV/AIDS as a protection strategy – and this happens when the child needs to take the antiretrovirals.

Another problem faced by the family is prejudice. According to this study's results, the child may suffer humiliations and prejudice from her own teachers. The inclusion of health education activities in school could be a transformative tool for promoting dialogue and critical reflection regarding the stigma of AIDS, so that these individuals may be comprehensively integrated into the community in which they live, minimizing the discrimination and prejudice<sup>(12)</sup>. It is necessary, therefore, to develop in each person the ability to interpret the routine and act in such a way as to incorporate appropriate attitudes and behaviors for improving these children's quality of life.

Health and education professionals must adopt a permanent attitude of empowerment regarding the basic principles of health promotion among those undertaking educational activities, teachers, and staff of the schools. Schools are spaces in which children, besides learning cognitive skills, develop and establish diverse social links<sup>(13)</sup>.

Another problem reported is delay in growth. It is mentioned that because of this, the child is rejected by classmates and does not participate in their games. One study on the impact of antiretroviral therapy on the growth of children with HIV reveals that its use may be associated with changes in bodily composition and in the metabolism. It follows that these children's growth needs monitoring<sup>(14)</sup>.

A further problem faced by the child is the possibility of presenting psychological problems due to her anger in relation to her diagnosis and the possibility of death. These children, from the very beginning of their childhood, already have a representation of death; however, the concept of death is consolidated gradually, in parallel with their cognitive development. Only in adolescence is this concept fully consolidated<sup>(15)</sup>.

There is also the fact that the family members fail to help to take care of the child, due to the child being sero-positive and people being scared of acquiring the disease. Besides sharing the care for the child who has HIV, family support is important for the mother or family caregiver. Situations of prejudice, stimulated by disinformation regarding the modes of transmission, may be directed towards the parents and the child, revealing the lack of support from family members, neighbors and friends<sup>(16)</sup>.

One study undertaken regarding the routine life of people with HIV showed that prejudice is experienced not only in the community, but also within the family<sup>(17)</sup>. In some cases, the disinformation regarding forms of infection can lead to clothes and utensils being separated in the home, due to the fear of transmission of HIV<sup>(18)</sup>.

One challenge faced by the child is the arrival of adolescence, and the experience of sexuality. The children reveal the fear of never being able to have boyfriends or girlfriends, or being able to have sex. There seems to be a tendency for some family members to correct behaviors, associated with an absence of preparation on the part of these family members to deal with topics related to adolescence, such as those involving sexuality.

One study on vulnerability to illness in children with HIV/AIDS during the transition from childhood to adolescence revealed that frank conversations and access to concrete information on health conditions can minimize their doubts – which are characteristic of this phase – and assist in the care they take with their health<sup>(12)</sup>. In this regard, family dialogue is a space for exchange, which can make it possible for there to be discussion and understanding of guidance which can support the adolescent<sup>(19)</sup>. In one study undertaken with sero-positive adolescents, these expressed the need to want to undertake the treatment and to receive help from family members in coping with the different situations posed by the disease<sup>(20)</sup>.

Finally, the child's need to make use of a cocktail of antiretroviral drugs on a daily basis and at the same times is also reported as a problem. Adherence to the treatment for HIV/AIDS must be addressed in a broader way – as being much more than the simple ingestion of medications. The link between children and adolescents with their parents/caregivers and the healthcare team is of supreme importance for appropriate adherence<sup>(21)</sup>.

As a result of the appearance of antiretroviral therapy, the mortality rate from HIV/AIDS among sero-positive adolescents and children has reduced considerably, and the quality of life of these patients and their family members has consequently improved. Accordingly, the family members – in particular the caregivers –, tend to face new challenges – such as the revealing of the diagnosis, the beginning and continuation of attendance at school, and adherence to complex and long-term drug treatment, besides the arrival of puberty and the initiation of a sex life<sup>(21)</sup>.

Among this study's limitations, one can indicate the lack of studies undertaken by nurses with children with HIV/AIDS, and the issues involved in their lives. As a result, there is a vast field of work for nurses for whom education in health is one of the pillars of what they do. We hope that this study will serve as a reference for other studies which address the topic of family care and of the child with HIV/AIDS, from the perspective of nursing professionals, allowing new perspectives on this issue.

## ● FINAL CONSIDERATIONS

This study aimed to investigate the perception of the family caregiver regarding the problems faced by the child in relation to her diagnosis of HIV/AIDS. As problems faced by the child, due to her diagnosis with HIV/AIDS, the family caregivers mentioned the need for frequent inpatient treatment due to opportunistic infections; being the only child with the virus in the family, possibly feeling rejected and having her self-esteem reduced, suffering prejudice in the family and at school; presenting growth delays; psychological problems due to feeling angry with her diagnosis and the possibility of her death; and the fear of never being able to have a boyfriend/girlfriend or have sex.

It is necessary for the nurse to have a basic theoretical knowledge of the process of illness and treatment in HIV/AIDS, in order to be able to help and teach the family caregiver and the child to live with the disease – and in this way, to take on an educational role with these families so as to help them develop effective strategies for caring for the child.

Health/nursing professionals need to work in conjunction with the families right from the moment when they receive the child's diagnosis, helping them learn to provide the care, working in the primary health care and hospital networks, during their inpatient treatment, and with the school so that they may receive these children without prejudice – thus constructing, in conjunction with the family, a social support network around the child with HIV/AIDS.

The actions undertaken by the health professionals and/or nurses must be implemented as early as possible, as a means of instrumentalizing the family for the care, and encouraging the child to be able to live a healthy life.

## ● REFERENCES

1. Botene DZA, Pedro ENR. Implicações do uso da terapia antirretroviral no modo de viver de crianças com Aids. *Rev. esc. enferm. USP*. [Internet] 2011;45(1) [acesso em 23 fev 2017]. Disponível: <http://dx.doi.org/10.1590/S0080->

62342011000100015.

2. Ministério da Saúde (BR). Boletim epidemiológico HIV/Aids. Brasília (DF): Ministério da Saúde; 2014.
3. Borges JMC, Pinto JA, Ricas J. Mães e crianças vivendo com hiv/aids: medo, angústia e silêncio levando a infância à invisibilidade. *Estud. psicanal.* [Internet] 2009;(32) [acesso em 13 jan 2017]. Disponível: [http://pepsic.bvsalud.org/scielo.php?script=sci\\_arttext&pid=S0100-34372009000100008](http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S0100-34372009000100008).
4. Liotta G, Marazzi MC, Mothibi KE, Zimba I, Amangoua EE, Bonje EK, et al. Elimination of mother-to-child transmission of HIV infection: the drug resource enhancement against AIDS and malnutrition model. *Int J Environ Res Public Health.* [Internet] 2015;12(10) [acesso em 12 jan 2017]. Disponível: <https://dx.doi.org/10.3390/ijerph121013224>.
5. Potrich T, de Paula CC, Padoin SMM, da Silva CL. Cuidado familiar na adesão à terapia antirretroviral em crianças com HIV/AIDS. *Cogitare Enferm.* [Internet] 2013;18(2) [acesso em 26 dez 2016]. Disponível: <http://dx.doi.org/10.5380/ce.v18i2.32589>.
6. Gomes GC, Pintanel AC, Strasburg AC, Xavier DM. Face singular do cuidado familiar à criança portadora do vírus HIV/AIDS. *Acta paul. enferm.* [Internet] 2012;25(5) [acesso em 21 jan 2017]. Disponível: <http://dx.doi.org/10.1590/S0103-21002012000500016>.
7. Bardin L. Análise de conteúdo. Lisboa: Edições 70; 1979.
8. Nosek CA, Buck WC, Caviness AC, Foust A, Nyondo Y, Bottomani H, et al. Hospital admissions from a pediatric HIV care and treatment program in Malawi. *BMC Pediatr.* [Internet] 2016;16(22) [acesso em 22 jan 2017]. Disponível: <http://dx.doi.org/10.1186/s12887-016-0556-3>.
9. da Motta MGC, Pedro ENR, Neves ET, Issi HB, Ribeiro NRR, Wachholz NIR, et al. Criança com HIV/AIDS: percepção do tratamento antirretroviral. *Rev. Gaúcha Enferm.* [Internet] 2012;33(4) [acesso em 18 jan 2017]. Disponível: <http://dx.doi.org/10.1590/S1983-14472012000400006>.
10. Garcia S, Koyama MAH, Grupo de Estudos em População, Sexualidade e Aids. Estigma, discriminação e HIV/AIDS no contexto brasileiro, 1998 e 2005. *Rev. Saúde Pública.* [Internet] 2008;42(Suppl. 1) [acesso em 4 dez 2016]. Disponível: <http://dx.doi.org/10.1590/S0034-89102008000800010>.
11. Guerra CPP, Seidl EMF. Crianças e adolescentes com HIV/AIDS: revisão de estudos sobre revelação do diagnóstico, adesão e estigma. *Paidéia (Ribeirão Preto).* [Internet] 2009;19(42) [acesso em 21 dez 2016]. Disponível: <http://dx.doi.org/10.1590/S0103-863X2009000100008>.
12. Bubadué RM, de Paula CC, Carnevale F, Marín SCO, de Brum CN, Padoin SMM. Vulnerabilidade ao adoecimento de crianças com hiv/aids em transição da infância para a adolescência. *Esc. Anna Nery.* [Internet] 2013;17(4) [acesso em 20 fev 2017]. Disponível: <http://dx.doi.org/10.5935/1414-8145.20130015>.
13. de Holanda ER, Collet N. As dificuldades da escolarização da criança com doença crônica no contexto hospitalar. *Rev. esc. enferm. USP.* [Internet] 2011;45(2) [acesso em 17 jan 2017]. Disponível: <http://dx.doi.org/10.1590/S0080-62342011000200012>.
14. Kim RJ, Rutstein RM. Impact of antiretroviral therapy on growth, body composition and metabolism in pediatric HIV patients. *Paediatr Drugs.* [Internet] 2010;12(3) [acesso em 17 jan 2017]. Disponível: <https://dx.doi.org/10.2165/11532520-000000000-00000>.
15. Torres WC. Psicologia da cultura: o conceito da morte na criança. *Arq. bras. Psic.* [Internet] 1979;31(4) [acesso em 21 dez 2016]. Disponível: <http://docplayer.com.br/38243788-O-conceito-de-morte-na-crianca.html>.
16. Galvão MTG, Lima ICV, da Cunha GH, Santos VF, Mindêllo MIA. Estratégias de mães com filhos portadores de HIV para conviverem com a doença. *Cogitare Enferm.* [Internet] 2013;18(2) [acesso em 20 fev 2017]. Disponível: <http://dx.doi.org/10.5380/ce.v18i2.27630>.
17. da Silva LMS, Moura MAV, Pereira MLD. The daily life of women after HIV/aids infection: guidelines for nursing care. *Texto Contexto Enferm.* [Internet] 2013;22(2) [acesso em 21 dez 2016] Disponível: <http://dx.doi.org/10.1590/S0104-07072013000200009>.
18. Liamputtong P, Haritavorn N, Kiatying-Angsulee N. HIV and AIDS, stigma and AIDS support groups:

Perspectives from women living with HIV and AIDS in central Thailand. *Soc Sci Med.* [Internet] 2009;69(6) [acesso em 17 fev 2017]. Disponível: <http://dx.doi.org/10.1016/j.socscimed.2009.05.040>.

19. Ressel LB, Junges CF, Sehnem GD, Sanfelice C. A influência da famíliana vivência da sexualidade de mulheres adolescentes. *Esc. Anna Nery.* [Internet] 2011;15(2) [acesso em 17 fev 2017]. Disponível: <http://dx.doi.org/10.1590/S1414-81452011000200005>.

20. de Paula CC, Padoin SMM, de Albuquerque PVC, Bubadué RM, da Silva CB, de Brum CN. Cotidiano de adolescentes com o vírus da imunodeficiência humana em tratamento. *Rev Enferm UFSM.* [Internet] 2013;3(3) [acesso em 21 dez 2017]. Disponível: <http://dx.doi.org/10.5902/217976929862>.

21. Cardim MG, Norte MS, Moreira MCN. Adesão de crianças e adolescentes à terapia antirretroviral: estratégias para o cuidado. *Rev. pesqui. cuid. fundam. (Online).* [Internet] 2013;5(5) [acesso em 17 dez 2016]. Disponível: [http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/1624/pdf\\_1002](http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/1624/pdf_1002).