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VULNERABILITY TO SICKENING OF CHILDREN WITH HIV/AIDS IN TRANSITION FROM CHILDHOOD TO ADOLESCENCE[a]

Vulnerabilidade ao adoecimento de crianças com HIV/AIDS em transição da infância para a adolescência

Vulnerabilidad frente a la enfermedad de niños con VIH/SIDA en transición de la niñez para la adolescencia

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ABSTRACT

Objective: To identify situations of vulnerability to sickening of patients with HIV/AIDS during the transition from childhood to adolescence. **Methods:** Qualitative research with thematic content analysis of a database of interviews held with 11 subjects from 12 to 14 years old, infected by vertical transmission and with diagnosis disclosure. **Results:** On the individual level, the following were observed: knowing the diagnosis and not being able to talk about it; a negative reaction to the diagnosis; taking on the responsibility for self-care; and, difficulties in taking the medications. On the social plane: orphanhood and/or the falling-ill of a family member; telling other people of the diagnosis; the need for help to remember to take the medication; and, dating and beginning a sex life. **Conclusion:** The importance is highlighted of a multidisciplinary team which has been trained to meet this population's specific health needs, so as to promote autonomy in self-care and social integration.

Keywords: Child Health; Adolescent Health; Acquired Immunodeficiency Syndrome; Nursing.

RESUMO

Objetivo: Identificar situações de vulnerabilidade ao adoecimento de pacientes com HIV/AIDS durante a transição da infância para a adolescência. **Métodos:** Pesquisa qualitativa com análise de conteúdo temática de banco de entrevistas realizadas com 11 sujeitos de 12 a 14 anos, infectados por transmissão vertical e com revelação diagnóstica. **Resultados:** No plano individual, foram observados: saber do diagnóstico e não poder falar; reação negativa ao diagnóstico; assumir responsabilidades de se cuidar; dificuldades para tomar os remédios. No plano social: orfandade e/ou adoecimento de um familiar; contar para as outras pessoas o diagnóstico; necessidade de ajuda para lembrar-se de tomar o remédio; namoro e início da vida sexual. **Conclusão:** Ressalta-se a importância de uma equipe multidisciplinar capacitada para atender às demandas de saúde específicas dessa população, para promover a autonomia do cuidado de si e a inserção social.

Palavras-chave: Saúde da criança; Saúde do adolescente; Síndrome da imunodeficiência adquirida; Enfermagem.

RESUMEN

Objetivo: Identificar situaciones de vulnerabilidad a la enfermedad durante la transición de la niñez para la adolescencia con VIH/SIDA. **Métodos:** Investigación cualitativa, con análisis de contenido temático de banco de entrevistas realizadas con 11 sujetos entre 12 y 14 años, infectados por transmisión vertical y con revelación diagnóstica. **Resultados:** El plan individual contempló cuatro sub-núcleos: conocer el diagnóstico y no poder hablar; reacción negativa al diagnóstico; asumir responsabilidades de cuidar a sí; dificultades para tomar las medicinas. En el ámbito social: orfandad y/o enfermedad de un familiar; contar para otras personas eldiagnóstico; necesidad de ayuda para recordarse de las medicinas; relaciones y inicio de la vida sexual. **Conclusión:** Se destaca la importancia del equipo multidisciplinar capacitado para atender a las demandas específicas de salud de esta población, a finde promover la autonomía del cuidado y la inserción social de este individuo.

Palavras-clave: Salud del Niño; Salud del Adolescente; Síndrome de Inmunodeficiencia Adquirida; Enfermería.

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INTRODUCTION

The issue of the evolution of Acquired Immunodeficiency Syndrome (AIDS) in Brazil has been reflected in quantitative and qualitative changes in the epidemic's profile[1]. The quantitative change refers to the distribution of the notifications throughout the regions of Brazil, even though this may be in a distinct manner in each of them. The qualitative is reflected in the epidemic's profile, which started out linked to men and to certain groups, and following the insertion of women into the notifications, which has contributed to the tendency of the epidemiological feminization and juvenalization, with the increase in the distribution of the cases among women, children and adolescents. Populations which are more vulnerable socio-economically began to predominate, and, with the inclusion of seropositive women, there was the appearance of children who had been infected by Human Immunodeficiency Virus (HIV) by vertical transmission[2].

These changes entailed investments to ensure this population's survival, as there is as yet no cure for AIDS[3]. Thus, the treatment with antiretroviral therapy (ART) altered the course of the AIDS epidemic, changing its evolution and tendencies. In the period 1980 - 2009, 5,509 cases among children below 5 years of age were notified; and 1,893 cases in the age range between 5 and 12 years of age[4].

The changes in the epidemic's pattern are also the result of actions preventing and controlling the infection, of prophylaxis, and of the clinical management of the opportunistic infections. Together, these had an impact on the morbidity and mortality of children and adolescents infected by HIV or AIDS[1,2], as well as on the shaping of specific policies ensuring free access to medications through Brazil's Unified Health System (SUS), as AIDS is considered a chronic illness[3].

Thus, these children, who were born infected through the vertical transmission of HIV, survived: they have grown, and passed into a new phase of human development. This group is known as the first generation of children with AIDS from vertical transmission to be in transition from childhood to adolescence[3,5]. This phase is characterized by a period of transformations, when sexual and cognitive maturation occur, along with the forming of identity and the exercising of experimentation with roles in society[6].

In this regard, it is the case that adolescence may be understood based on different criteria: chronological criteria, criteria of physical, sociological, or psychological development, or of any combination of these[6]. Based on the combination of these criteria, the child passing from childhood to adolescence may be vulnerable to situations which leave her health exposed[5,7].

In the light of the criticism of the concept of "risk groups", the theoretical construct of vulnerability began to be part of the discussions in the ambit of the AIDS epidemic in Brazil in the 1990's. Vulnerability examines the different situations of susceptibility which the subjects, whether they are individual or collective, experience, in three inter-related analytical planes: the individual, the social, and the programmatic[8].

On the individual plane, the evaluation of vulnerability permeates the behaviors which opportunize the infection in the situations of HIV transmission or the process of falling ill. The social plane covers the access to the information, the local authorities' investments in health, the access to and quality of the service, the population's general level of health, and the setting's socio-cultural characteristics. The connection of the individual plane with the social plane culminates in the programmatic plane, which consists of the existence of specific institutional actions for the AIDS problem[8].

This study aimed: to identify the vulnerabilities to sickening of children who had been infected by HIV/AIDS by vertical transmission and who are in the transition from childhood to adolescence.

METHODOLOGY

This is research with a qualitative approach and a descriptive nature, undertaken through re-reading through the database of a qualitative study, with the approval of the Research Ethics Committee (REC) of the UFSM/RS, in 2011, under protocol CAAE: 0371.0.243.000-11.

Regarding the research subjects, the inclusion criteria were: to be in the age range of 12 to 14 years; to know of their diagnosis, and not to be in an institution. The exclusion criteria was to have cognitive or mental limitations which made verbal expression difficult. Two parameters marked the beginning of adolescence: one legal, and the other clinical-epidemiological. The first is grounded in the Statute of the Child and Adolescent, in which childhood is chronologically delimited at 12 years of age. The second refers to the proposition of the Brazilian National Department for STD/AIDS, which considers, in regard to ART and presentation of its epidemiological data, the prolonging of childhood up to 13 years of age[4]. The number of subjects was not determined beforehand, given that the field stage showed the quantity of interviews necessary to meet the study's objective[9]. In total, there were 11 research subjects, of whom six were girls, and five, boys; three were 12 years old, five were 13, and three were 14. Two had lost their mothers, one had lost the father, and three were orphans; these six respondents were cared for by first-degree relatives.

The research setting was three university hospitals, which are centers of excellence in the attendance of children with HIV/AIDS in Rio de Janeiro. The field stage was undertaken between February and September 2007, following approval and authorization from the Research Ethics Committees (protocols EEAN/UFRJ 096/06; IPPMG/UFRJ 09/07; HUGG/UNIRIO 36/07). The family members signed the Terms of Free and Informed Consent, and the 11 children who were the research subjects signed the Consent Document.

Interviews were used for the production of the empirical data. The guiding question was: Tell me how it is to be becoming an adolescent. The question "What is your day-to-day like, having this disease?" was only posed when the respondent spoke of his or her serological condition. The word "illness" was used, as that is how AIDS was referred to in the interviews, being referred to, but not named.

The evaluation of the empirical material was undertaken through thematic content analysis, in three stages: pre-analysis; exploration of the material; and interpretation of the results[10]. The pre-analysis was undertaken through skim reading of the empirical material in full. In this movement of listening and readings, it was sought firstly to understand the universe in which the children live. Later, it was sought to understand what it was being like to experience the phases of development from childhood into adolescence, and to have AIDS.

The exploration of the material occurred through the composition of the results of the research, based on the chromatic codification of fragments of the statements which met the objective. In order to select the empirical fragments and to structure the thematic nuclei, attention was necessary to understand the meaning of the communication, reaching - through meanings or significations, other meanings, which are related to the theoretical construct of vulnerability.

In the discussion, based on the benchmark of vulnerability, two thematic nuclei emerged, each with four sub-nuclei, which made up the description of the results and led to the discussion.

RESULTS AND DISCUSSION

The results indicate the vulnerability to sickening of the children with HIV/AIDS in the transition from childhood to adolescence: the individual and social planes.

Individual vulnerability to sickening of the children with HIV/AIDS

In the individual plane, the evaluation of vulnerability permeates the behaviors which opportunize the infection or the sickening in the situations of HIV transmission. The complexity of the individuals' actions transcends the will and incorporates the degree of awareness which the individuals have regarding the possible harms to be faced resulting from such behaviors. Thus, the effective transformation of these behaviors is considered based on the awareness acquired[8].

The individual plane of vulnerability covered four thematic sub-nuclei, these being: knowing of the diagnosis and not being able to talk about it; a negative reaction to the diagnosis; taking on the responsibility for self-care, without feeling oneself to be prepared for this; and difficulties in taking the medications.

In relation to the diagnosis, when the study subjects were children, they believed in other explanations for the need to take medications and frequently go to the hospital. They indicated that, even before somebody told them of the diagnosis, they had discovered about the illness from different sources: information in the health service, at school, and/or in the media. However, as the family and the health professionals did not speak with them directly about the diagnosis, they kept this silence, without expressing what they knew and what they had doubts about.

Knowing of the diagnosis and not being able to talk about it vulnerabilized the children, as they showed the lack of knowledge of what HIV/AIDS is, how the virus is transmitted, how they had been infected, what their treatment was like and the importance of adherence, as well as seropositivity's implications for health.

The diagnosis was revealed by the family members, sometimes with the help of health professionals from the health service where their health was monitored. This took place in the transition from childhood to adolescence.

They hardly named what they knew they had, keeping the silence imprinted and expressed by the family members, health professionals and society. They referred to AIDS with other words, such as "illness", "problem" and "problem in the blood", among other expressions.

> *[...] it was when I was 11 that my aunt told me that I had this problem [...] (C2)*

> *[...] as far as I can remember, I think I've known since I was seven or nine years old [...] there was a time when I wanted to know more about it, so I went and asked my mom what I had, and when I did, she started crying and I didn't understand a thing, I was surprised, because I thought I had got it from my dad, that he had given it to my mom, and this made me furious with my dad. But mom told me that it wasn't from my dad, that long ago she had lost several babies and had had to receive blood transfusions, so she had got it from somebody without wanting to or knowing [...] so she explained to me, 'it wasn't my fault, I didn't want you to have this virus' [...] (C3)*

> *[...] the psychologist and my grandma spoke with me [...] that was when I found out what I had, I was about nine, before that I thought it was just a heart problem [...] (C6)*

> *[...] I think I've really known since last year! It's that my mom never had the courage to tell me [...] (C9)*

> *[...] I never said anything, not even my mom ever said anything [silence] [...] I found out this year, right here in this hospital, with the psychologist. My mom couldn't tell me, so*

> *I think she (the psychologist) helped, but I knew already, because I paid attention to the papers, I paid attention in the consultations, to the information, I heard things on television, at school [...] (C11)*

For the child, the chronic disease's impact depends on her level of development, as well as when she begins to accumulate experiences with the illness. The transition from childhood to adolescence is a phase of discoveries, which makes the child vulnerable to emotional stress[6]. In this regard, the seropositivity can trigger different feelings.

The revelation of the diagnosis of infection with HIV can be treated as a process, which begins in the first consultation, culminates in the revelation *per se*, and extends into the post-revelation monitoring. It is grounded in the link between the child, the family and the team. There is no predetermined age for the revelation, but the importance of carrying this out in childhood is discussed[11].

Thus, it is important to examine these strategies' impact and repercussion in the people's daily lives in future studies. There are, however, challenges, experienced as much by the family as by the team, which, most of the time, postpone the revelation, attributing this decision to the child being too immature to cope with the situation and keep it secret[11].

The revelation can be made because of hints from the children, who wish or need to know about their illness. Among the principal reasons which trigger the process, one finds the children's questions, the adherence to the ART, and the proximity to the beginning of life as a sexual being. Frank conversation can bring benefits for the child's life, as it makes it possible to access concrete information about their health condition, and can reduce the negative effects of the experience of having a chronic illness, minimizing fantasies and help in the adherence to the treatment and in care for health[11].

The silence transmits an unspoken message of the meaning of AIDS for the family. This contributes to the children's invisibility, as they can internalize the silence as a routine practice[12]. The imperialism of the silence self-perpetuates, and makes the child vulnerable to physical and mental health complications[13].

In relation to the negative reaction to the diagnosis, there are implications in relation to the adherence to the treatment and, consequently, to vulnerability to falling ill. The children expressed that the moment of the revelation of the diagnosis was difficult, that it caused sadness, shame, and anger. In the beginning, they did not accept that they had the illness, and saw themselves as different to other people; sometimes this resulted in being held back a year at school and impacted on their mental health.

> *[...] [silence] I didn't accept that I had this problem [silence] I didn't want to take the medication [...] I think it was when I was about 12 or 13 years old [...] I didn't accept it, I was angry about it, I even had to repeat the school year because of it, I became depressed [...] so, I discovered that I had this problem [...] when I was 12 or 13 years old I stopped taking the medication [...] (C2)*

> *[...] there was a time when we were ashamed that I had HIV, I thought I was different from other people. And that made me more and more sad, inside[...] (C3)*

The feelings experienced upon finding out about the diagnosis can have implications for how they care for their health. The facing of the revelation of the diagnosis marks a period of understanding of their perception of the illness and of themselves. This 'feeling oneself to be different' reveals feelings of anger and sadness, which can vulnerabilize the child to fall ill[5,14].

The first reaction is tears or silence, and afterwards questions appear about how the HIV was transmitted, about the illness, and about the perspectives for the future. These are followed by a long-term beneficial effect, with improvement of mood or attitude, or by not causing a negative impact on daily activities. The fact is valued that the revelation increases the possibility to dialog. At some points, one can perceive the sadness or a certain degree of non-acceptance, but the possibility of conversing about the matter can facilitate the process of development of autonomy[15].

This suffering can provoke non-adherence to the treatment, which increases the risk of physical harm, leaving the children vulnerable to immunological suppression -and, consequently, to opportunistic illnesses. It is evidenced that adolescents have greater difficulty in adhering to the treatment, due to the questioning and feelings manifested due to the seropositivity[14].

Regarding taking on responsibility for self-care without feeling themselves prepared for this, the adolescents expressed that they wanted to continue being children, as they understood that they were losing their play and gaining the responsibility of studying, helping their families, and caring for themselves. These changes are considered difficult. The vulnerability to falling ill is present especially in the acquisition of autonomy for caring for one's health, when they attend consultations without a family member accompanying them, and begin to take responsibility for the treatment, being attent to the doses and times prescribed, without another person telling them to or reminding them.

> *[...] It's being difficult! [silence] [...] When I was still little, I played with my best friends, with toy cars, with dolls [pause in the account] now I can't, I'm big. If I play like that, the others will mock, you know, 'baby, baby'. [...] so, I have to take more responsibility for my life, care for myself more, forget what I have left behind [...] I'm an adolescent, but I wish I weren't [silence] [...] (C6)*

> *[...] it's change, isn't it? You have to take responsibility for things [...] change in how you are, it's not just playing now. Now, I have to be responsible for school, for the medications I take [...] not fail to do what has to be done [...] (C8)*

The desire to be a child shows vulnerability to the sickening in the transition, imposing autonomy on the children in relation to self-care, sometimes without their feeling prepared for this. The need to become autonomous is considered difficult. This can influence the daily routine of the child who needs help, as she becomes dependent on the other in order to adhere to the treatment[5,7,16].

In this regard, it is important to help this child in the health service, with the objective of offering support for the development of autonomy in line with each person's own pace[5].

In relation to the difficulties in taking the medications, there is the parents' non-adherence, the physical characteristics of the medications, the doses, the times, and the challenge of keeping up the routine of taking medications indefinitely, this being a chronic illness with no cure at the time of writing. To this one may add the need for continuous and permanent monitoring of health, which interferes in their daily life, especially in relation to school.

> *[...] my mom always said this: 'my love, if somebody gives you medication to take, don't take it!' because my mom was like that, she pretended to take the medication but threw it away [...] my grandma gave it to her [...] when I was 12 or 13 years old, I stopped taking the medications [...] I had what my mom told me in my head, for me not to take medications, when I didn't have any illness, that if anybody gave me medication I was to throw it away, if they sent me to the doctor, I wasn't to go [silence] later, I actually understood that I should take the medication [silence, looks at the interviewer] that that medication meant life to me! [...] My day-to-day is difficult because of the medication, I have to take it every day, and it's those big capsules three capsules, plus another two and one more a week, and there's the Bactrin. It's horrible! Will I be able to stop taking medications one day? I stop and think, why is it that I take medication each and every day? (C2)*

> *[...] I love my school, but now I can't go to school, because the doctor didn't authorize it. [...] In the beginning, I didn't like [going to hospital], I had to miss school, there's that business of taking the medication [...] my friends don't take it, and I have to [pause in the account]so it's irritating!(C7)*

In relation to the difficulties found in taking the medications, the parents' influence in the adherence stands out, due to the character of dependence which is related to the difficulty in continuing with the treatment, because of its complexity or its permanent character; the dependence may be partial or total. As the parents, most of the time, also have HIV/AIDS, they have the experience of adherence or not, which can impact on the attitude of the children. This points to the need to assess the level of autonomy of their commitment to the treatment. This being the case, both need support for adherence, and autonomy in the taking of medications must gradually be made possible for the child, in the transition to adolescence[17].

The chronic nature of the illness is revealed as one of the determinant factors for the difficulty in taking the medications. The change in the children's routine as a result of this health requirement, concurrently with the transformations inherent to the phase of development of adolescence, is shown to be challenging[7].

Social vulnerability to sickening of the children with HIV/AIDS

The social plane encompasses the access to information, the local authorities' investments in health, the access to and quality of the service, the population's general level of health and each setting's and each individual's socio-cultural specific characteristics, such as housing, level of education, access to consumer goods, the degree of political and economic priority given to health and even the degree of freedom of thought and expression[8].

The social plane of vulnerability encompassed four thematic sub-nuclei, which are: orphanhood and/or the falling-ill of a family member; telling other people of the diagnosis; the need for help in remembering to take the medication; and dating and the start of life as a sexual being.

Orphanhood and/or the falling-ill of a family member was identified as vulnerability to falling-ill when the interviewees reported the lack of a responsible person to accompany them to the health services and, because of this, feeling alone due to the lack of a maternal and/or paternal presence.

> *My mom can't bring me to the consultation or to pick up the medications any more [...] she became ill after having my little brother [...] she ended up in hospital for four months [...] (C1)*

> *[...] my mom died [silence, looks down...] [...] I couldn't accept why my mom had died, my dad too [...] I am very alone [...] it's becoming more and more difficult, [...] So, I come on my own [to the consultations], [...] And I have to*

> *take more responsibility for this too. [...] it's very hard [silence and looks back at the interviewer, crying] my mom isn't here with me [silence] not my mom, nor my dad [wipes her hand across her face to remove tears] [...] (C2)*

> *[...] it was one year and eight months after I was born [that the mother died]. [silence] it's bad [silence] sometimes I miss her [silence] mainly when my stepmother argues with me (C8)*

Because they are in a transition between phases of human development, these children are still dependent on their parents[5,6]. Thus, their orphanhood has an impact on their development and health, due to the helplessness resulting from the loss of one or both parents and the destructuring of the family. The lack of a parental role model can mean objective and subjective voids; objective, when they express that they have nobody to take them to the consultations; and subjective, in the sentiments which surround the parental figure.

In relation to their serological condition, the lack of support from the parent(s) can have negative results in the adherence to the treatment, as the child needs help to take the medications and to keep attending the consultations with accompaniment from a responsible adult[16].

One can add to this the stigma and discrimination related to the serological condition, which configure a critical element in the promotion and protection of their rights[18]. This can also result in problems related to the children's mental health.

Telling other people about the diagnosis can prejudice the relationships and the adherence to the treatment, indicating vulnerability to falling ill. The study subjects expressed the treatment's influence on routine relationships; so as not to fail to take the medications, for example, sometimes they didnot participate in daily activities with their peers, so as to avoid questions which might lead to their diagnosis being revealed. They did not tell other people about the illness, keeping the silence recommended by their families, so as to avoid the discrimination which results from the epidemic's stigma. Only family members and specialized health service professionals knew of the diagnosis.

> *[...] when you have to go to somebody's house, you have to take the medication with you, so I don't even go! If someone tells me that I have to go to somebody's house, I don't even go! Because it's also like this, they're going to ask you: 'why are you taking medication?' and then what am I going to say? Understand?[...] (C2)*

> *[...] when they told me I was still a child, and they asked me not to tell anybody, because if I did, other people would be disgusted by me or not want to get near me. So, this doesn't happen, because I don't tell anyone, so nobody knows. (C6)*

The silence recommended by the family internalizes the stigma regarding HIV. Stigmatization is a social process in which one builds a social identity which is considered normal[5,20]. In this regard, the seropositive children can alter the meaning of normality when they are among their peers who do not present the same health condition. They consider themselves to be normal, as they are experiencing a routine of transition like all the children, and express that what is different is having to be always taking medicines[5].

This feeling of inadequacy can provoke self-hate, isolation, depression and/or hostility, such that the people who are stigmatized find support among others who experience the same condition of stigmatization. This socialization creates an atmosphere in which the subjects feel themselves to be normal, and in which they exchange experiences on what each is going through[20].

The need for help to remember to take medications restricts autonomy, makes independence difficult in self-care, and influences adherence to treatment, indicating vulnerability to falling ill.

> *[...] I'm taking the medication correctly, but, sometimes, [puts hands on face] I forget. [...] and my mom says 'go take the medication' and I'm like,'in a minute' then, a little later, 'I will' and 'I will' and then, when I notice, the time has gone, and I realize that I forgot. (C3)*

> *[...] I still don't take it on my own, she [the mother] has to remind me (C9)*

> *[...] what's bad is taking the medication, I already take it on my own, sometimes my mom reminds me [of the time to take the medication]. She reminds me often [...] (C10)*

The need for help with adherence to treatment makes the figure of the caregiver extremely important, as it is his or her responsibility to control the child's adherence to the treatment[15]. This dependence on care from another person entails strengthening or minimizing the situation of social vulnerability, as having the support of family members strengthens adherence, helping the child to remember the times for taking the medications. It can, however, restrict the child's autonomy[14].

In the light of this, it becomes necessary to allow the children to take a more active role in their treatment during the transition from childhood to adolescence. This process must be gradual in accordance with the uniqueness of each child and family, making it not an imposition, but a conquest, based on cognitive development, in accordance with the child's age and maturity, so that she can understand the information made available[5].

One strategy is to carry out play activities from childhood onward, so as to promote the child's empowerment in the face of the diagnosis[12] and, thus, to support the process of transition to adolescence.

Dating, and starting life as a sexual being, were indicated as characteristics of adolescence because they are part of a phase of discoveries -but are prohibited by the family because of the serological condition. The limits imposed result, once again, in the silence within the family and are added to what is not said outside the family so as not to reveal the diagnosis. This restricts having dialogs to clear up doubts and strengthens the vulnerability to falling ill, especially the possibility of reinfection and/or transmission of the virus in sexual relations.

> *[...] and I get embarrassed [to speak about sex], I know I haven't done anything wrong yet, but an adolescent always wants to discover things, I already almost tried to discover, but whenever I'm going to discover something, I get scared, I don't know why so I nearly [...] (C3)*

> *[...] sometimes, if I like a guy, they [the father and grandfather] intervene and say I can't. [...] So I say to her [the grandmother] say that it's not like that, if I'm going to have a boyfriend, I'll tell them! (C7)*

> *[...] I am ashamed [silence] I don't like to talk about it [silence] I did actually have a boyfriend, a while back, but I don't any more. It was okay! (C11)*

In the transition to adolescence, they think of dating, as they recognize that it is part of this phase of development. They are experiencing discoveries in the relationships with their peers, such as liking, kissing and dating. There are doubts, however, about whether they should talk about the illness, as they are worried about the other person's reaction. The family says that they cannot date, and this is seen as interference in their lives[5].

The family prohibits them from becoming emotionally or sexually involved with the other. This contributes to this population's invisibility in society, as the space for dialog is restricted[7].

FINAL CONSIDERATIONS

Evidence was found of situations of vulnerability to falling ill in children with HIV/AIDS in the transition from childhood to adolescence, on both the individual and social planes. Vulnerability on the programmatic plane did not emerge in these interviews, which emphasizes the importance of investing in studies to explore this conceptual plane.

In the light of these situations, emphasis is placed on the importance of the communication between the health team, the child and the caregiver during the process of revealing the diagnosis, so as to construct an atmosphere of dialog and freedom.

It is fundamental to indicate guidelines for an ethical conduct in carrying out the process of revealing the HIV diagnosis, which ensure the assistance and protection of these children and their families, such that it may be a shared and continued decision. It is stressed that the revelation entails clinical and psychosocial consequences. In this way, it is essential to identify when and how this process should be undertaken, and who should do so.

A support network must be promoted for the individual needs of each family, considering the process of revelation, discovery and coexistence with seropositivity. This process begins in infancy and needs to encompass the monitoring of the consequences of the revelation *per se*, so as to minimize negative reactions. This experience can be monitored as much in the specialized service as in the health center, depending on the link developed. In this regard, it is necessary to be attent to what the child knows of her illness, breaking the silence, the silencing, and the concealment, so as to include the child in the care for her health, respecting the limits imposed by the family, at the same time as supporting and encouraging the process of the revelation of the diagnosis.

In relation to the treatment, the children indicated the difficulty found in taking the medications, which points to the importance of the health professional highlighting the benefits of the treatment, considering its complexity, so as to adjust the therapy to the day-to-day experienced by the child and her family.

There is the need for the social support of the child who is in the situation of having lost a parent and/or of having a family member fall ill. The recognition of a role model in the family is essential for the development of a social network for health support. This helps in the process of psychosocial maturation necessary for handling questions which are characteristic of this phase of life, such as dating and the beginning of life as a sexual being.

The insertion of health education activities at school can be a transformative tool for promoting dialog and critical reflection on the stigma surrounding the illness, so as to integrate the individuals comprehensively in the community in which they live, minimizing the discrimination and prejudice.

The importance is emphasized, therefore, of a multidisciplinary team which is trained to meet this population's specific health needs, promoting autonomy in self-care, in a gradual and non-imposing way.

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