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The Meaning of Living with HIV/aids in Adolescence: a Descriptive Study

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ABSTRACT

Aim: To describe the feelings of adolescents living with HIV/aids. **Method:** a descriptive research study using a qualitative approach. Data were collected in three hospitals located in the municipality of Rio de Janeiro, between June 2011 and January 2012. Ten HIV-positive adolescents were interviewed using an audio recorder. Thematic analysis was used interpret interviews. **Results:** HIV imposes restrictions on daily activities due to treatment regimes and prejudice. Hopelessness, guilt, fear, denial and acceptance were common feelings. Most of the adolescents received family support but did not tell other about their condition. The treatment improved their quality of life but generated difficulties at work. **Discussion:** Prejudice causes feelings of social exclusion and has consequences for physical and mental health. **Conclusion:** Understanding the feelings adolescents of living with HIV may contribute improving their care by focusing on quality of life.

Descriptors: Adolescent; HIV; Acquired Immunodeficiency Syndrome; Nursing Care.

INTRODUCTION

Living with the Human Immunodeficiency Virus (HIV) in adolescence is a common reality in Brazil, due to teenagers' vulnerability to exposure and vertical transmission of the disease. Data from Epidemiological Bulletin show that in 2011 alone, 734 children and adolescents were diagnosed with HIV in Brazil. Despite declines in recent years (2006 - 919 diagnosed cases; 2007 - 850, 2008 - 900, 2009 - 800, 2010 - 752), there has been a reduction in the rate of recording of patients under 5 years old with the disease and an increase in the population aged 15 to 19⁽¹⁾. The objective of this study was to explore the feelings of adolescents living with HIV and acquired immunodeficiency syndrome (AIDS).

HIV can be contracted through both horizontal (infection by blood or unprotected sex) or vertical transmission (mother-baby). In the early days of the outbreak, infected children were resigned to the prognosis of an incurable and fatal disease. Over the years, following improvements in public health policies and access to antiretroviral (ARV) drugs, a large number of infected children have been able to survive into adolescence and adulthood⁽²⁻⁴⁾.

When entering adolescence, young people share common biopsychosocial factors such as physical transformations, exploration of their sexual identity through experimentation and diversity of partners, thoughts that lead to egocentrism and feelings of invulnerability. These changes, in addition to the instability and susceptibility to group and family influences, leads to an increase in the risk of exposure and a decrease in consideration of possible consequences⁽⁵⁻⁶⁾.

Specific factors affect young people living with HIV. Their serological status of immune impairment and vulnerability to opportunistic diseases requires continuous monitoring in specialized health centers, for laboratory and

clinical examinations and also treatments based in drugs^(3,4-5,7).

Individuals living with HIV face discrimination and stigmatization based on the disease, which can cause anguish to those living with the virus. As a result, many patients tend to keep their condition a secret or restrict knowledge to a few people, generally their guardians or family members. In adolescences, attitudes of questioning, rebellion, denial of illness, misinformation, impaired self-esteem, decreased life expectancy and fear of discrimination may all lead to problems during therapy, worsening of the health of the patient and leading to the development of more resilient strains of the virus^(4,7-9).

Adolescents living with HIV may have needs very distinct from adult patient groups. Health professionals may benefit from improved understanding of these needs in order to develop an individual treatment plan that are able to improve clinical status, increase of life expectancy and reduce treatment failures⁽⁷⁻⁸⁾.

The following guiding question was selected for this study: what are the feelings of HIV positive teenagers in relation to living with HIV/AIDS? After exploring responses to this question, the feelings of HIV positive teenagers in relation to living with HIV/AIDS can be described.

This study aims contribute to the treatment of adolescents living with HIV, given that promotion of health and the quality of life of people living with HIV/AIDS (PLWHA) are moderated by existing links between government policies, the health professionals and the patient themselves.

METHOD

The data for this study are derived from "Aids in adolescents in the city of Rio de Janeiro", a qualitative study conducted by the State University of Rio de Janeiro (UERJ). Participants

were recruited from two university and one federal hospital, located in the municipality of Rio de Janeiro, specialized in assisting PLWHA.

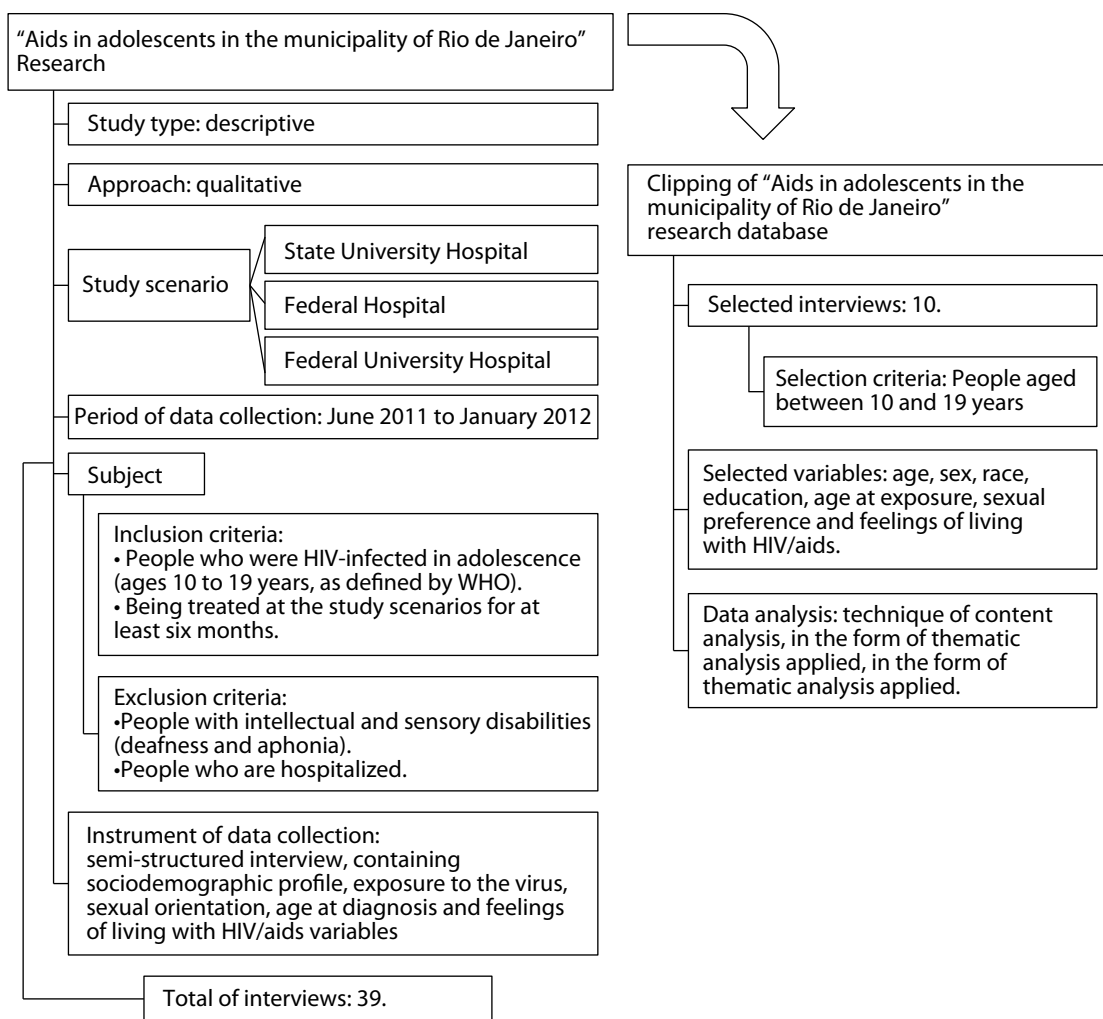
Eligible patients were all individuals who had received outpatient treatment for HIV/aids infected by the virus in adolescence, i.e. aged 10 to 19 years, as defined by the World Health Organization (WHO)⁽¹⁰⁾. Adolescents with intellectual and sensory disabilities (deafness and aphonia) and who were hospitalized at the time were excluded from the study.

Data collection occurred between June 2011 and January 2012, using a convenience sample, in which the subjects were selected

when attending routine appointments. In-depth interviews were conducted using a semi-structured script containing questions probing socio-demographic profile, exposure to the virus, sexual orientation, age at diagnosis and feelings about living with HIV/aids. The average duration of each interview was 60 minutes.

This research contains a subset of interviews from the database of a larger research project. We considered saturation of themes when deciding on sample size, which amounted to 39 respondents in the age group 15-31 years. After applying the eligibility criteria, 10 adolescents were selected for interviews.

Figure 1: Flowchart of selection of subjects and methodological approach. Riode Janeiro, 2011-2012.



Legend: Aids: Acquired immunodeficiency syndrome. HIV: Human immunodeficiency virus. WHO: World Health Organization. Source: elaborated by authors, 2014.

In order to acquire reports, the research objectives and possible contribution of the study to PLWHA were first defined. To adolescents willing to participate, a Statement of Consent was presented for signatures from the participant and their guardians/parents. The interviews were conducted in rooms to respect the privacy of the participant, who were asked to attend the interviews unaccompanied in order to promote trust. The proposal was accepted by all participants.

The interviews were recorded with an MP4 audio recorder. Participants verbalized their feelings and expectations in relation to HIV/aids. To preserve their identities, names were replaced by the letter (E) plus a number related to their participation in the interviews, for example, E1, E2, E3 etc.

The interviews were initially analyzed by transcribing the recorded audio and later by the reading and reviewing these reports and applying the technique of content analysis in

the form of thematic analysis. In this process we sought to capture the thematic units that were converged upon across the interviews, summarizing and categorizing the findings⁽¹¹⁾. This study was approved by the Ethics Committee of the State University of Rio de Janeiro (047/2009), the Municipal Secretariat of Health and Civil Defense (262A/2009) and the Federal Hospital of Public Workers of the State (000.442).

RESULTS

The teenagers interviewed included the following: there were six females and four males; ages varied between 15 to 19 years; adolescents had received a positive diagnosis for HIV with a mean age of 16 years; there were 7 mulatto and 3 black; 6 had incomplete primary education and 4 attended high school; 3 had sexual exposure to HIV in heterosexual relationships and 7 in male homosexual intercourses. The thematic analysis

Table 1: Structure of thematic categories of adolescents living with HIV in the city of Rio de Janeiro. Rio de Janeiro, 2011-2012. (N = 10).

Units of meaning	RU Total	RU %	Sub categories	RU Qty	RU %	Categories	Cat Qty	RU %
Limitation in relation to daily activities	8	5,2	The meaning of HIV/aids	19	12,3	Perception of HIV/aids	90	58,4
Prejudice	11	7,1						
Quality of life	10	6,5	The relevance of treatment	24	15,6	Disclosure of Diagnosis	64	41,6
Expectation of cure	14	9,1						
Despair	23	14,9	HIV diagnosis - feelings and sensations	47	30,5	Disclosure of Diagnosis	64	41,6
Fear	13	8,4						
Guilt	5	3,2						
Denial	3	2						
Acceptance	3	2						
Difficulty in disclosing the diagnosis to others	12	7,8	Disclosure of Diagnosis	64	41,6	Disclosure of Diagnosis	64	41,6
Disclosed the diagnosis to close people	24	15,6						
Received support from close people	28	18,2						
Total	154	100		154	100		154	100

Legend: Record Units (RU); categories (CAT); human immunodeficiency virus (HIV); acquired immunodeficiency syndrome (aids). Source: elaborated by authors, 2014.

revealed 154 units of significance. These were grouped into two categories and divided into four subcategories as shown in Table 1.

The Significance of HIV/aids

In adolescents' opinion, to be seropositive means living with prejudice and restrictions on daily activities. These limitations relate to acts that may predispose these individuals to acquire opportunistic disease. The testimony of one teenager who describes the difficulties associated with being a mother with HIV clarifies this, emphasizing that childbirth and child care are not equivalent to non-HIV-positive women, which creates a feeling of exclusion.

Respondents mentioned biases in romantic relationships, in their own families and in their social life. Only one respondent mentioned acceptance from their partner.

[...] right? But we are afraid to do those things, and get a chill and, for example, have a cold. You can get sick anytime [...]. (E.2)

It's something that, like, almost blocks you from living [...] you can't have a baby in a normal way, things like this. (E.3)

He [the partner] didn't like it, he didn't want to do anything with me, afraid of getting sick too. I had to come to the hospital all the time, I always came alone. (E.7)

I [the partner] like you a lot, I will not leave you because of it, we'll get through this together. (E.4)

Diagnosis of HIV – Feelings and Sensations

Feelings of hopelessness, guilt, fear, denial and acceptance were described by interviewees. One participant cited the feeling of anguish at the moment she discovered she was carrying virus and, although she had received prenatal care, transmitted the virus to her child at birth. The fear of death after diagnosis and guilty feelings emerged in the interviews, as well as the connotations of HIV as a divine punishment for transgressive acts. The feeling of denial (escape from reality to avoid suffering) was also present. Other interviewees accepted the condition, since it was discovered before acquiring any disease.

I discovered when my son was born [...] I never missed a session of my prenatal care. [...] then it was time for the examination and she said that I was HIV-positive [...] What made me upset was that my son was born sick. (E.10)

When you discover it, you already start to think you're going to die, [...] when you have no information, you only rely on some [...] like, I saw the movie about Cazusa, [...]. When you find out you have it, you can't think positive, you only think negative. (E.10)

Feels like it's a punishment, a punishment from God. [...] It's because I've done so much wrong. (E.6)

Each one has a point of view, in mine it's, like, it's nothing, a bad thing, but to me it's nothing. (E.4)

So I was kind of prepared, I picked it up, it was positive, I was ok with that, I talked a lot with her [the doctor] and everything was ok, the rates were still high, because it was in the beginning. (E.2)

Disclosure of the Diagnosis

Disclosure of the diagnosis was the most dreaded moment by adolescents living with HIV, because of prejudice associated with the disease. For this reason, most did not tell others about their condition. Many divulged their HIV status to close people only such as family members, friends and partners, avoiding exposure, criticism and abandonment.

I usually don't tell anyone, I keep it to myself, [...] unless it is a special case, [...] Someone going through this situation then I usually open myself. I like to keep it quiet since I do not know people's reaction, because of the prejudice. (E.1)

No, only he [partner], my grandmother and my aunt know about it. [...] My mother doesn't. (E.8)

Most interviewees mentioned having received family support encouraging condom use. One participant emphasized greater concern with the route of exposure to HIV rather than with the adolescent's emotional state.

My mother supports me, gives me advice, and she always talks [...] don't stop using condoms. (E.3)

My mother started crying, she said: 'How did you get that? I told you to wear a condom, you see now?'. (E.6)

My aunt was more concerned about how I got it; she didn't care about my psychological condition. (E.1)

The Significance of Treatment for the Teens

Most respondents have an optimistic view regarding treatment and emphasizes the improvements in their quality of life and their hope for a cure. One participant also added that other chronic diseases have become more severe and lethal than HIV:

Ah, sometimes I think it's a serious disease, like, it could even kill, but with the care options people have today [...] now I think it's like a normal thing. (E.3)

Today this disease is kind of normal, like, you see cancer, today it seems that HIV is better than cancer, right? Because cancer kills more than HIV. (E.5)

But I have hope, right? To find a cure. (E.6)

I'm starting to take the medicine today, it's going to be four years. It's just that, unfortunately, there's no cure yet. And I think I'll be alive, God willing. (E.10)

The difficulties that adolescents living with HIV/aids face in relation to treatment adherence, especially following initial diagnosis, is a concern that can lead to complications in maintenance up until the end. Treatment involves not only the use of medication at regular times, but also attending medical appointments and examinations. This may cause insecurity and difficulties in family and professional relationships, as the testimonials indicate:

My biggest fear is having to take this medicine. (E.3)

The worst thing in the treatment is the medicine. [...] And I always have to come to consultations, which is very annoying, [...] especially because, well, I work and I always have to give an excuse to my boss. (E.5)

DISCUSSION

The reports from adolescents living with HIV highlight the meanings that the infection has in their daily lives. Despite scientific and social advances, stigmatized views still exist, resulting from the view that HIV is an incurable and transmissible disease which requires drug dependence and constant monitoring by health services⁽⁴⁻⁵⁾.

Responses to the HIV epidemic scenario over the years has affected social representations of HIV/aids. Generalization from the first HIV-infected individuals resulted in use of the terminology "risk group", made up of homosexuals, drug users, sex workers, hemophiliacs and Haitians. This view brought a sense of security and invulnerability to individuals who did not fit into this group and reinforced discrimination of people seen as "transgressive" in relation social norms. The disease was therefore seen as a punishment against deviant behavior⁽¹²⁾.

The changes in the epidemiological profile of HIV - characterized by feminization, internalization and impoverishment - demonstrate that anyone is susceptible to infection. Leading on from this, the concept of "risk behavior" emerged, an idea that was subsequently heavily criticized for blaming the individual for failing to adopt preventive measures, as well as providing moral judgments based on disease transmission

through blood and sex⁽¹²⁾. Currently, the concept of vulnerability is proposed, seeing all people as hypothetically predisposed to infection owing to a set of individual, collective and contextual factors⁽¹²⁾.

Despite these changes, stigma and discrimination remain present in the lives of PLWHA. The young population has been the target of scientific studies given increases in the number of infections by horizontal transmission (blood and sex) in this age group and the increased survival of infected children (from vertical transmission) that survive into adolescence^(2-4,13). Adolescence is described in this context as the stage of human development between childhood and adulthood, characterized by physical and psychosocial changes supported by puberty and the environment. Thus, an adolescent with HIV combines common dilemmas of adolescence itself with dealing with the condition of HIV⁽¹³⁾.

Studies^(5,7,13) conducted in São Paulo, Rio de Janeiro and Rio Grande do Sul describe the daily lives of young people living with HIV, revealing common experiences during this specific stage of development. Young people enjoy hanging out at night, having their freedom and privacy, they use the internet, establish friendship bonds and affection and start to recognize the need for responsibility and maturity. They may realize that they are growing and their body is changing, including their way of being.

For respondents, their own dilemmas associated with adolescence assume significantly greater importance. Young people refuse to (or "do not care" about) acknowledging life with HIV. Thus, they develop a sense of fear and refusal to talk publicly about the infection for fear of prejudice. They believe that, by sharing their diagnosis, they may be excluded from social spaces^(2,7,13). In their quest for acceptance, they assume an impersonal identity, because being identified as "different" exposes them to judg-

ments and causes problems in interactions with others. And thus, adolescents may feel that they need to present an identity that is considered common and expected by everyone^(5,13).

An investigation⁽¹⁴⁾ conducted in Rio de Janeiro with 630 people identified that the living with PLWHA at work and at school led to greater acceptance than in romantic (sexual) relationships. These findings reinforce the idea that adolescents fear sharing their condition with partners.

Life in school is, however, still perceived by adolescents as an embarrassing situation, in which some report that they do not participate in activities and have problems in relationships, fearing discrimination⁽⁷⁾. It is known that living with HIV/aids does not prevent the completion of daily activities; however, discriminatory conceptions and stigma barriers are still present in social life.

So, teens with HIV face at the same time two different perspectives on their lives: the individual experiences of being a "normal" and an "abnormal" adolescent, coping with being infected with a stigmatizing disease with no cure⁽¹³⁾. Studies^(15,16) indicate that young people do not fully accept living with HIV and they oscillate between periods of acceptance and understanding of the situation, with moments of absolute distress for not being able to adapt.

Being diagnosed with HIV represents a challenge for those infected because of prejudice still present in society, which may lead to devastating consequences such as abandonment, loss of employment, low self-esteem and lack of motivation⁽¹⁵⁾. In this context, studies have shown the stigma against PLWHA can lead to development of depression⁽¹⁷⁻¹⁸⁾.

The disbelief experienced by PLWHA can occur as a result of two situations: when the person is afraid or even anticipates the rejection of others and expresses feelings of shame, and

at the moment they experience a discriminatory experience. Both lead teens to alter their behavior to avoid stigmatizing situations⁽¹⁵⁾.

In the reports of study participants, we observe the influence of the media in constructing the ideas of an HIV-infected-person in the minds of teenagers. Given its ability to spread information, it can shape understanding of the illnesses without the required reflection on what is right or wrong or useful or not to communicate, especially to children and adolescents who are into the knowledge construction process and may consider the information they are present with as absolute truths⁽¹⁶⁾.

The concept of the disease as a punishment from God (reported by one respondent) can be justified both by the historical construction of the epidemic, associated with the idea of violation of social norms, and associated religious philosophies. In many situations, the search for a better future motivates individuals to find faith and spirituality. Religion can arouse in people feelings of belief, protection and support against the fragility of living with HIV⁽¹⁶⁾.

Disclosure of a diagnosis has been a dilemma for HIV-positive young people due to prejudice, mentioned in several investigations^(5,7,16). This is usually restricted to a small group of people, often family members. Despite realizing they are being seen differently, due to possible changes in physical appearance, the decision to not tell because of the fear of rejection remains^(5,7). The fear of being "discovered" even influences adherence to drug therapy and access to health care for fear of doubts and suspicion in their social circle^(7,15).

The lack of understanding of aids as a chronic disease and the patient as capable of living in society leads to behavior change for both the teens themselves and their families, who keep secret about seropositivity and remain protective over the teenager in relation to prejudice

and the representations the infection raises in family^(4,15-16).

The participants in this study suffered prejudice from their families, corroborating the findings of other studies that show that family members do not always offer proper emotional support to HIV positive adolescents^(2,8). Health care professionals, in the context of HIV/aids, must act as facilitators to demystify taboos and help the family structure if teenagers want to disclose the diagnosis or express discomfort about prejudice episodes.

Despite the fact that disclosure of a diagnosis can be associated with negative feelings, a study has shown that adolescents who experience high levels of disclosure (when most people were aware of their condition) were more competent in their interpersonal relationships. The open and frank attitude about the disease was associated with better family relationships, psychosocial adjustment and coping and less anxiety regarding caregivers^(7,15).

The disclosure, however, is not always easy and involves many factors, including the time of diagnosis. Research indicates that adolescents with recently revealed seropositivity have more difficulties than those who have been living with the infection since childhood. However, all of them showed signs of anxiety regarding modified daily life due to the disease^(3,7).

Study participants had an optimistic view regarding their treatment. Although stated less frequently than in other investigations, the teens were aware that treatment adherence contributes to the maintenance of their health and quality of life, avoiding death and consequently, the suffering of the people around them^(3,16).

In the routine treatment experienced by the teens interviewed, drug therapy is often depicted as difficult in various assessments^(7-8,13). For treatment adherence to be considered satisfactory, the patient must take at least 95% of the

prescribed pills; when not followed properly, it promotes increased viral load and resistance, reduction of TCD4+ lymphocytes and increased risk of opportunistic infections⁽⁸⁾.

Young people demonstrate difficulties following medication prescription due to an attitude of rebellion and questioning the disease, their treatment and caregivers' monitoring. The chronicity of the disease and the need for continuous drug therapy, even without the presence of symptoms, is a deterrent. The rigidity of schedules, the quantity and flavor of tablets, the alteration in daily tasks and side effects of medication were also discussed as factors that compromise therapy^(3,7,13).

The fragility of the access to health facilities for adolescents living with HIV/aids was also considered in a study⁽⁴⁾. The results point to limitations in the structure of the service, regarding appropriate space to this population, distance from it, their bonds with the team and preparation of professionals to give comprehensive, holistic and effective care based on all the patients' needs. In general, facilities are usually university hospitals, which have a large influx of students and professionals, making it difficult to build relationships and establish good continuity in good treatment.

The systematization of nursing care for people affected by HIV has shown good results. An investigation was carried out in a hospital in the city of Goiânia showed that the training nurses in HIV diagnoses promoted beneficial changes in leisure, self-care, self-esteem and anxiety⁽⁹⁾.

The multidisciplinary and nursing teams have a significant role in improving the quality of life for PLWHA. Considering the representations of living with HIV/aids presented to adolescents, it is important that professionals carefully listen and are sensitive to the development of strategies that include family therapies to help over-

come social stigma and are not restricted only given on drug treatment without additional care. It takes sensitivity to understand what is not spoken, other nuances and enable externalization of emotions that will assist in promoting self-care of HIV-positive teenager.

CONCLUSION

Living with HIV is associated with a multiplicity of meanings for adolescents with HIV. This study helps to understand the perceptions and meaning of HIV/aids for participants. In their reports, they describe prejudice, a sense of exclusion in the social environment, insecurity and difficulties relating to treatment follow-up and in interpersonal and professional relationships.

Disclosure of the diagnosis still causes fear as a result of prejudice, and so is limited to a few people, usually family members. The family and social support appears to enable higher treatment compliance, improves quality of life and promotes motivation for a better future. Accordingly, health professionals must try to engage in educational activities, especially ones with a large impact (internet, radio, television and newspapers) for the deconstruction of prejudices and stigmas.

Nursing contributes to provision of care for HIV-positive adolescents, assisting them via empathy and holistic vision, understanding the demands of the health and psychosocial issues involved, making care plans, guiding treatment follow-up and promoting autonomy.

Despite the limitation of geographical area, the result of this research is consistent with other investigations that describe the experiences of HIV-positive adolescents nationally. It is known that PLWHA have limita-

tions in their daily lives, in social contexts and in relation to health care services. However, it is imperative that attention on the health of this group respects the individual and the subjective experiences of each adolescent.

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Lívia Rocha Bortolotti : Data interpretation and analysis

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Stella Regina Taquette: Project conception and relevant critical review of intellectual content

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