

Perception of pre- and post-HIV test counseling among patients diagnosed with aids in adolescence HIV test counseling for adolescents

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Abstract *Pre- and post-HIV test counseling has singular importance in adolescence, since it is a phase of great changes, and AIDS is an incurable chronic disease. In order to comprehend the perception of young people with AIDS diagnosed in adolescence regarding the counseling received upon testing, we conducted 39 in-depth interviews, with 23 in female patients and 16 male patients, and then analyzed the data with extensive reading, categorization and interpretation on a comprehensive basis. The results revealed that less than one third received pre-test counseling (30.8%), which often was limited to the explanation of the reason of the test, and 51.2% were counseled post-test. We found that most patients were unaccompanied when receiving the communication of their seropositivity, some of which were later informed by the adolescent's guardian. Some patients felt secure after counseling, realizing that the disease is something that would not change their lives, if they properly followed the guidelines. On the other hand, the feelings of desperation and suicide expressed by some of the patients may have been influenced by the lack of adequate counseling. We have concluded that, for the improved management of the epidemic, there is a need to enhance the communications of health professionals, especially those that are in primary care, pre-natal services, gynecology and family health strategy.*

Key words *Adolescent, Confidentiality, AIDS serodiagnosis, Counseling, Chronic disease*

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Introduction

In Brazil, the population group between 13 and 19-years-old continues to demonstrate increasing rates of AIDS incidence. The current dynamics of the epidemic in adolescents indicates a more intense feminization than in the other age groups, as well as the increase of young men who have sex with men (JHSH)^{1,2}.

Counseling upon anti-HIV testing is recommended by the Ministry of Health³ and is a procedure of active listening, individualized and patient-centered. Its main objectives are to promote a reflection that allows the perception of the one's own risks, the adoption of safer practices and adherence to treatment. The counseling process includes three components: emotional support, educational support and risk assessment. The educational support deals with the exchange of information on STDs and HIV/AIDS, as well as the means of transmission, prevention and treatment. The risk assessment provides a reflection on values, attitudes and behaviors, including the planning of strategies for risk reduction. It also contributes to a trustworthy relationship between health professional and patient, making the individual the agent in the process of prevention and self-care, as well as an important reference for disease control.

In the case of adolescents, counseling has a wider value, as it is a phase of life in which new skills and abilities are acquired that will contribute to ensure self-care in health throughout adulthood. The diagnosis of a chronic and incurable disease like AIDS in adolescence has a great impact, since it may cause several changes in the daily life, in the student life, in the process of socialization outside the family environment, among others, as imposed by the signs and symptoms of the disease and by its treatment⁴. The priority of life changes to become taking care of the disease. From the psychological point of view, adolescence comprises a phase of losses of and grief for the infant body and identity, parents, and the childhood⁵. When an adolescent has a serious illness in this period, these losses and grief will be much more painful and difficult to overcome, and the experience of the disease brings greater suffering. In this sense, the manner in which pre- and post-HIV test counseling is executed can increase or reduce the impact of diagnosis and treatment adherence.

This study aimed to understand how the pre- and post-HIV test counseling was conducted and what the impact of diagnosis was, from the

perspective of patients who were informed about their seropositivity in adolescence, in order to contribute to public health policy in the combat against the epidemic.

Methods

We chose the qualitative method due to the nature of the subject in question. The study of the target audience was composed of seropositive patients whose diagnosis occurred in adolescence and were being treated in the city of Rio de Janeiro. Data were collected in an environment of inter-subjectivity, through semi-open interviews. Interviewing allows for getting to know the system of values of their respective social groups through the words of patients; furthermore, such interviews reveal the structural conditions of the group and transmit the group representations, in specific historical, socioeconomic and cultural conditions⁶.

The Ministry of Health of Brazil provides free and universal access to treatment with antiretroviral drugs for AIDS patients. The city of Rio de Janeiro has 43 public health services and general hospitals to care for these people. The latter provide assistance to a larger and varied volume of patients, coming from various districts. For this plurality of patients, we chose to recruit potential participants for the research in the following hospitals: Pedro Ernesto University Hospital (Vila Isabel district), Gaffrée Guinle Hospital (Tijuca district), Clementino Fraga Filho University Hospital (Fundão Island) and Federal Hospital of the State Employees (Servidores do Estado) (Saúde district). These health facilities are public and serve people from various social classes, but mostly of lower socioeconomic status. Subjects were contacted by the research team and – after approval of the ethics committee and with the consent of guardians – data was collected.

The inclusion criteria were: diagnosis between 10 and 19-years-old and no more than five years prior, in order to ensure homogeneity in the group about the duration of the illness and avoid biases in the memory of the facts at the time of the HIV infection. Patients who had this profile were sent to interviewers by the health professionals who had attended them at health services. The patients recruited were informed as to the content of the research and once they had agreed to participate, they were interviewed alone in an environment of guaranteed privacy. In order to form the sample, the team visited hospitals on

average twice a week for 18 months. We closed data collection once the saturation of the information collected was observed.

The interviews followed a script with questions about demographic and family information, history of sex life and infection/diagnosis of the disease, questions about pre- and post-HIV test counseling and the impact it caused in the patient and his/her family. The authors audio recorded and transcribed the interviews in full. From the beginning and throughout the study, we analyzed the textual data coming from the transcripts. This analysis included the following steps: reading and re-reading of the texts to produce a unique view of each interview, as well as cross-reading of all interviews to identify the similarities and differences in the narratives, in order to ascertain the most relevant content. Then we sought to identify the meanings attributed by the subjects on the issues raised, trying to understand the internal logic of this group through a comparative dialogue with literature. In the end, we developed classification categories that represented an interpretive synthesis of the findings to answer the objective of the study.

The study was approved by the Research Ethics Committee of the Municipal Health Department of Rio de Janeiro in 2009. All interviewees, or legal guardians of patients under 18 years old, duly signed the Consent Form.

Results and discussion

Characterization of the group

Data were collected between July 2010 and December 2011. The sample consisted of 39 patients, 23 female and 16 male. An interview with each patient was concluded, resulting in 1904 hours of recording, with average duration of 48 minutes. We highlight the following features of respondents: low socioeconomic status, with average household income ranging from 1/2 to 10 minimum wages (82% with lower or equal to 5 minimum wages income); the primary cause of exposure was sexual, among women it was heterosexual, except in two cases (one of caused by blood exposure, and the other unknown); and among men, 75% of cases were homosexual and 25% heterosexual; race was self-reported as non-white by 66.6% of patients (half or which self-reported black and the other half, mixed-race), and white by 33.4% (no one self-reported Indigenous or Asian); and an education delay of

more than two years was observed in more than half of them.

HIVtest advice and ethical aspects

Patients had difficulty in remembering the dialogue and/or guidance received at the time the HIV test was requisitioned and its result. This data may indicate that counseling was not conducted or was not significant. Less than a third of respondents (12 patients, 30.8%) said they had realized there were recommendations in the pretest, which were limited to the clarification of the reason for the exam. In the post-test upon diagnosis, counseling had been recognized by 20 (51.2%) interlocutors. A small percentage of patients who reported having received counseling was also observed in cross-sectional survey conducted by Goldani et al.⁷ in Porto Alegre - RS, with 1603 women tested during pregnancy, from which only 39.2% reported having been counselled about the test. The authors found that there was a greater chance of not receiving counseling among low-income pregnant women and who initiated prenatal tests belatedly. Similar results were reported by Passos et al.⁸ in a study of 955 mothers in a collective housing who had done rapid HIV tests in which only 26.9% received counseling. There was a significant association between lack of counseling and lower education of mothers (less than eight years of study) and the low number of prenatal visits. Another Brazilian study with 435 pregnant women followed up in prenatal service in Paraná showed an even lower percentage of pre-test counseling, only 13.6%.⁹

Less than half of the diagnoses was given in the presence of companions (18 patients, 46.1%), usually the mother or a close relative (aunt, cousin, godmother). In 3 cases (7.7%) of female patients, the partner was present. Only 4 male patients had companions upon diagnosis, all of them accompanied by their mothers. The presence of a companion upon diagnosis occurred more often among girls (14 to 23) than boys (4 of 16).

The percentage data on the counseling can be seen in Tables 1 (male respondents) and Table 2 (female respondents).

The Statute of Children and Adolescents (ECA)¹⁰ and the ethical standards of care for adolescents guarantee the right to autonomy, confidentiality and secrecy of medical appointments, without the participation of guardians^{11,12}. However, in certain situations where it is considered that the adolescent health is at risk, maintaining

Table 1. Distribution of the boys in relation to the availability of counseling and the presence of a companion upon diagnosis.

Counseling	Yes	%	No	%	Total	%
Pre-test	7	43.8	9	56.2	16	100
Post-test	10	62.5	6	37.5	16	100
Companion	4	25	12	75	16	100

Table 2. Distribution of the girls in relation to the availability of counseling and the presence of a companion upon diagnosis.

Counseling	Yes	%	No	%	Total	%
Pre-test	5	21.7	18	78.2	23	100
Post-test	10	43.5	13	56.5	23	100
Companion	14	60.9	9	39.1	23	100

secrecy is questioned¹³ and often not recommended for the protection of the patient. The health professional should assess to what extent the adolescent is able to exercise self-care. The disclosure of a positive HIV test result is one such situation. Thus, it is advisable that this news is given in the presence of a family member who can give emotional support and aid at this difficult time of life¹⁴. It is a delicate situation of professional performance, as postulated by some authors who offer guides to help professionals in this task^{15,16}. We found that in most cases the diagnosis was given to the adolescent alone, especially the boys.

Despite the insistence by the health professional about the presence of a guarding, in some cases it became clear that the adolescents resisted to accept it and gave signs that they would abandon the health service if their parents' presence were mandatory. In others, the health professional put the decision of taking a companion or not to receive the test results in the hands of the adolescent. There were also some cases in which the opposite occurred: the diagnosis was given only to the parents, disregarding the right to autonomy of the adolescent, who was only later informed of his/her seropositivity.

HIV pre-test

We found that, in the perception of our respondents, the dialogue established during the consultation resulting in the request for the test

is limited to the cause of the its request, with or without risk assessment. However, for most of them, nothing was said regarding the justification of the test request. The cause informed for the request of the HIV test was signs and symptoms of STIs or opportunistic infections for some patients; for others, risky sexual activity, which includes not using condoms or the existence of HIV-positive partners. There were also test requests during the hospitalization period, when the patient was only informed that he/she had done the test only when the result was positive.

Here are some examples:

They did not say they were asking for it (the HIV test). She (the doctor) gave me a list of tests to be done ... On the day I went there to get the result I had no idea I was being tested for HIV. At no time it crossed my mind that the test would show something. (E 28)

The doctor requested the test to know about the swelling of my glands ... He explained, he said there could be something wrong with my organism. (E 04)

They did not say the reason for the request; they only said I had low immunity. (E10)

They said it was normal to request this test for anyone today who has sexual diseases. (E 38)

They said there was a great risk of having contracted because I was not using condoms with him. (E 25)

Some patients asked to the test of their own free will and others were told it was a routine examination, especially adolescent girls when sub-

jected to preventive gynecological tests or prenatal care. One of our respondents reported that the test was requested by the gynecologist in the cancer prevention tests. She was pregnant at the time and did not know. The result was communicated only after the birth of the baby, when she then was advised not to breastfeed.

No one asked me (to take the test); I went there and wanted to do that because I had been in unprotected situations. (E 027)

I did it of my own free will. (E 07)

The nurse said that this test is necessary in any prenatal care. (E 33)

The HIV test routinely recommended for all pregnant women during prenatal care; however, it is not compulsory and counseling should be offered. However, it has been observed in studies with pregnant women that this practice is already incorporated into the clinical service and the counseling has been forgotten^{17,18}.

For our respondents, the way the testing process was conducted demonstrates the predominance of biomedical focus. It may be that health professionals believe that young people cannot understand complex information about HIV, since even in the Centers for HIV Testing and Counseling (CTA), the pre- and post-test counseling has been neglected, according to Grangeiro et al.¹⁹, in a study performed in 83.6% of the CTAs in Brazil, were inadequate development of prevention and control of AIDS serodiagnosis actions were observed.

The data demonstrate a certain authoritarianism in the attitude of health professionals, who, possessing knowledge, feel themselves to be the owner of the patients' discretion to decide what is best for them. Some authors highlight the need for changing this attitude when conducting counseling²⁰. Challenging the training of the counsellors, Galindo et al observe two modes for counseling. The first one refers to the traditional posture of health practices, which is authoritarian, formal and instructive. The second professional posture is based on the symmetry of the relationship, focusing on the patient's role, allowing for a greater possibility of understanding and self-care. This view is supported by Souza et al.²¹ in a qualitative study about the view of the patients of a Testing Center about the counseling on HIV prevention.

Post-HIV test advice

We observed that, in the perception of our subjects, well-conducted counseling seems to

have contributed to the expression of positive attitudes towards the future and living with a chronic and incurable disease. In these cases, the professional welcomed and gave emotional support to the patient, explained the disease and its treatment, as well as demystified the fantasies that exist in relation to its development. As a result they engage more responsively to treatment with self-care and see their lives as normal.

They said it was not the last thing in the world. I should only take care of myself and I was going to live normally, you know? I should not be shocked, feel distressed. (E 13)

... Then she said that I had HIV. They called my parents; in this case, it was normal. They said I had to do the treatment, take medication, things like that. (E 31)

The doctors told me it has no cure, but there is a treatment; I will not die, there is medication... that nowadays no one dies of AIDS. (E 33)

I was told that I should do the treatment properly, that I would live well, that I had to treat the disease. (E 32)

This disease can even be a disease, but it does not prevent people from doing anything. (E 04).

For others, the test result was simply delivered with no guidance offered upon diagnosis. Subjects were simply informed that they were HIV positive, or that they received a prescription of conduct and duties that were meaningless to them and difficult to understand. In these cases, our respondents were insecure, fearful about the future, with a lack of prospects.

They gave me a paper saying I was HIV positive. They did not say anything, just gave me the paper. During two weeks I spent all the money I had, because I was going to kill myself. (E 27)

He came, he said a bunch of stuff and I did not understand anything. (E 29)

It was as if someone said to you that a loved one had died. The first idea is not to believe, you know? ... And now, what is going to happen to me? Am I going to die? A teenager, alone ... (E 01)

When you find it out, you think you will die, you will not last five years. Today I know that it is not exactly like that, because I see many people sitting here who have been sick for over 20 years. But when you do not have any information you cannot think positive. (E 39).

Delivering the diagnosis of a chronic and incurable disease is not an easy task, besides involving ethical dilemmas. On the other hand, medical education in most schools still focuses on technology, not giving much attention to other issues, such as communication skills. Our study shows

that the procedure for communicating diagnosis done in an erroneous or insufficient manner may have negative consequences, which can interfere in treatment adherence. A study based on interviews with doctors who treat adolescents with chronic diseases showed similar results. Respondents demonstrate that the information of the diagnosis to the adolescent patient is the most difficult task, especially in relation to the ethical issues²². This difficulty in revealing a diagnosis was also observed in a survey with nursing students conducted by Cappi et al.²³ in a *CTA*. The authors point out the lack of preparation to deal with aspects of sexuality and exiguous time to establish bonds. The recognition of the lack of training and the demand for qualification in the counseling practice was also verified by Filgueiras and Deslandes²⁴ and in a investigation developed in STD, SAE (Specialized Care Service) and *CTA* services.

An investigation carried out with American women corroborates our findings to show that the way in which the results of HIV tests are reported and the supply or lack of pre- and post-test counseling can determine the adherence to treatment and the prevention of the transmission of the virus to others²⁵. On the other hand, an unsatisfactory counseling may have serious consequences, such as a case mentioned in a qualitative analysis by Fonseca and Iriart¹⁸ with pregnant women. One of the new mothers, after the post-positive HIV test advice, was caught breastfeeding her son, even though she was theoretically oriented to interrupt breastfeeding. The authors also point out that counseling with no interaction and that is not patient-centered may damage the adherence to treatment or delay its initiation.

It was demonstrated that 240 young South Africans participants of a study in focus groups on the voluntary HIV testing were afraid to know if they are infected; subjects thought the test should only be applied to those with symptoms of the disease, and they feared being discriminated. More than half of the investigated young people mentioned suicide upon confirmation of seropositivity. The study recommends the voluntary testing services be friendlier to young people²⁶. The risk of suicide among HIV-positive patients was also found in another South African study with 190 patients, volunteers in an HIV-testing hospital in Durban. Thoughts of suicide were more frequent in males at young age, under 30 years old. The authors note that

the pre- and post-HIV test can track the risk of suicide in patients with depressive behaviors and create intervention strategies to avoid it²⁷.

It is noteworthy that many HIV test requests are not made in *CTAs*, but by primary care doctors, during consultation regarding some health problem. These professionals are often not trained to give counseling and are even sometimes unaware of the technical standards of the Ministry of Health. It is necessary to make an effort so that these Ministry guidelines are disseminated and known by all professionals who work directly in the clinical service and not only those working in Testing Centers.

In summary, our results show that the advice on the anti HIV testing recommended by the Ministry of Health is not being conducted satisfactorily in the perception of patients whose diagnosis occurred in adolescence. Few acknowledge the availability of counseling, and most cases post-test diagnoses have been conducted in the absence of a guardian, which is contrary to the ethical standards of care for adolescents. On the other hand, the narratives showed that a well-conducted counseling contributes to adherence to treatment and to the perception that it is possible to have a normal life even with the diagnosis of a chronic and incurable disease at this stage of life.

We would like to emphasize that the qualitative approach used in our study allowed for knowledge acquisition of important and unique elements about giving counseling on HIV-AIDS, which is crucial in the clinical practice for the continuity and adherence to treatment. Just as with AIDS, other chronic diseases in patients of this age group may also be better conducted by an improved, friendlier, and more ethical, person-centered counseling.

Our study leaves open questions to be investigated, since it was limited to the HIV patient on treatment perspective, without considering those who did not participate in the study or those who had tested negative for HIV. Our study also does not focus on the other side of this relationship: health professionals who serve the public with communicational difficulties in the work process of the Public Health Units. However, our findings show that the training of those who exercise the counseling role in the *CTAs* or in service at units of the Family Health Strategy, Prenatal and Gynecology should provide a positive impact on the dynamics of the epidemic.

Collaborations

SR Taquette participated in the study design, collection and analysis of data and writing of the manuscript. AO Rodrigues and LR Bortolotti took part in the collection and analysis of data and final revision of the manuscript.

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