

Vânia de Souza Souza<sup>1</sup>Dina Czeresnia<sup>II</sup>

# Demands and expectations of users of HIV testing and counseling centers

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## ABSTRACT

**OBJECTIVE:** To analyze the characteristics, demands and expectations of users of an HIV testing and counseling center.

**METHODOLOGICAL PROCEDURES:** Qualitative research carried out with 32 users of a testing and counseling center in the state of Minas Gerais (southeastern Brazil), from November 2005 to March 2006. The open semi-structured interview technique was used, as well as an adaptation of the content analysis method. Thematic modality was employed.

**ANALYSIS OF RESULTS:** Lack of knowledge regarding the service, difficulty in perceiving oneself as vulnerable to infection, justifications of not belonging to risk groups, fear of embarrassment and of precarious care emerged as important limitations to the access to the testing and counseling center.

**CONCLUSIONS:** A paradox was identified in the users' discourse between the participative aspect in overcoming vulnerability and the search for pragmatic solutions for excluding risk. Their demands signaled strategies that should contain: high-quality information and access to the service and to prevention and health promotion discourses.

**DESCRIPTORS:** Acquired Immunodeficiency Syndrome, prevention & control. HIV Seropositivity. Health Services Needs and Demand. Health Vulnerability. Qualitative Research.

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## INTRODUCTION

Since 1997, with the implementation of the first *Centro de Testagem e Aconselhamento anti-HIV* (CTA - HIV Testing and Counseling Center) in Brazil and the consolidation of counseling as a decisive practice in the prevention of sexually transmitted diseases (STD), HIV and AIDS, research into testing services has indicated the relevance of its capacity to provide information and shelter for users.<sup>7,8,14</sup> On the other hand, failures in communication and in the form of approach have been indicated. The latter has been considered as compliance with a protocol to deliver examination results, limited to the prescriptive aspect and with a poorly defined objective.<sup>17</sup> In many moments, listening was replaced by an approach that was merely informative,<sup>8</sup> investigative and normative, which can be summarized as instructions for condom use.<sup>17</sup>

To the team of counselors, occasionally formed by nurses, psychologists, doctors and social workers,<sup>1,13,14</sup> the main obstacles to user assistance are related to the following aspects: short assistance period, mainly the individual post-test counseling; inadequate place; lack of dynamism in the collective assistance; difficulty in establishing an interaction with user; and unprepared professionals to deal with the subjective issues related to STD/HIV/AIDS prevention.<sup>3,11,14</sup>

<sup>1</sup> Departamento de Enfermagem Materno Infantil e Saúde Pública. Escola de Enfermagem. Universidade Federal de Minas Gerais. Belo Horizonte, MG, Brasil

<sup>II</sup> Departamento de Epidemiologia. Escola Nacional de Saúde Pública Sérgio Arouca. Fundação Oswaldo Cruz. Rio de Janeiro, RJ, Brasil

### Correspondence:

Vânia de Souza Souza  
Escola de Enfermagem - UFMG  
Av. Alfredo Balena, 190 - Santa Efigênia  
30130-100 Belo Horizonte, MG, Brasil  
E-mail: vaniassouza@yahoo.com.br

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Counseling proposes practice that is related to integral care and health promotion, through interventions based on the singularity of the subjects' worldview and on shared social experiences.<sup>11,16</sup> Its efficacy depends on a health policy that is sensitive to the sociocultural context and to sexual identity questions.<sup>11</sup> In addition, preventive approaches are targeted at personal and collective themes, like gender relations, prejudice and civil rights, and they cannot be regulated by general orientations.<sup>7</sup>

At the CTA, actions are developed in two stages: pre- and post-test counseling, aiming to help the subject in the evaluation of and reduction in his/her vulnerability to STD/HIV/AIDS. To achieve this, learning about this clientele's characteristics is fundamental, in order to adequately meet their demands and expectations. Such information is also important to subsidize strategies aiming at the collectivity.

In a study<sup>17</sup> that investigated the meanings users attribute to pre- and post-test counseling, it was concluded that certain limitations in the concretization of the counseling proposal result from the professional's difficulty in interacting with the user. This fact indicates the existence of difficulties also in the response to the demands and expectations of the population assisted by the service, as well as in the recognition of its diversity and specificity. Continuing that investigation, the objective of the present study was to analyze the characteristics, demands, and expectations of users of an HIV testing and counseling center.

## METHODOLOGICAL PROCEDURES

Qualitative and exploratory study with analytical-descriptive orientation, conducted in two stages: the first was developed when the users arrived at the CTA, before the pre-test counseling; the second was carried out at the end of the post-test counseling, with the same users who had been previously interviewed.<sup>17</sup> In this paper, the results of the first stage were analyzed.

The research was conducted between November 2005 and March 2006 at a CTA located in an easily accessible area, near the central region of one of the municipalities with the highest number of AIDS cases of the state of Minas Gerais (southeast of Brazil).<sup>14,15</sup> The place was chosen due to the history of the CTA, which provides services for approximately 300 users per month, with daily assistance and in two shifts.

The CTA meets the spontaneous demand of the population of the metropolitan region and neighboring areas, and the demand deriving from referrals from other health institutions, such as blood centers, military institutions, companies, governmental and non-governmental organizations. The CTA offers collective pre-test counseling,

individual post-test counseling, ELISA anti-HIV laboratory exams, hepatitis B and C tests, and also the Venereal Disease Research Laboratory (VDRL), for detection of infection caused by syphilis.

Pre-test counseling lasts between 60 and 90 minutes. Post-test counseling, with delivery of the exam's result, lasts approximately 20 minutes. In the period when the research was conducted, the team of counselors was composed of six psychologists and two nurses.

The study had the participation of 32 individuals of both sexes, older than 18 years, who were attending the CTA for the first time and were not aware of the service's work process. Pregnant women were excluded because their reason for going to the service could have been exclusively related to prenatal exams. Only one interviewee was selected per shift, due to lack of time to perform more than one interview before the beginning of pre-test counseling. Thus, the choice occurred for the sake of convenience: the chosen individual was the first one who arrived at the service, fulfilled the inclusion criteria and agreed to participate in the study, which was extended until the saturation of information.

The interviews were recorded and integrally transcribed by a single researcher and the participants were identified by pseudonym and age.

As part of the corpus referring to pre-counseling, the open and semi-structured interview allowed to verify the user's previous knowledge of the service and his/her motivation to attend the CTA. To investigate this, the following guiding questions were used: "how did you arrive at this service?", "had you heard about it previously?", "what do you know about it?", "what do you expect from this service?" (concerning assistance), "what reasons made you look for this service?"

To systematize the material, the thematic modality<sup>2</sup> of the content analysis method was used. It has the following stages: identification of a thematic structure; application of the thematic structure to the data; identification of the themes with the cases, mapping; and data interpretation.

The use of the software NUDIS-T (N4),<sup>a</sup> designed for qualitative information processing, favored the in-depth analysis when it enabled strategies like: verification of segments that were common to two categories (*intersect*); demonstration of a theme that is inside a certain context (*if-insight*); facilitated intersection of the information with certain categories.

The analytical categories that were used to systematize the reports were: self-recognition of the vulnerability condition; lack of knowledge of the vulnerability condition; positive and negative expectations; restricted and amplified demand regarding assistance/counseling.

<sup>a</sup> software NUDIS-T (N4) NUDIS-T (N4) (QSR International Pty. Ltd., Melbourne, Austrália; <http://www.qsrinternational.com>)

The research was approved by the research ethics committees of *Escola Nacional de Saúde Pública Sérgio Arouca da Fundação Oswaldo Cruz* (opinion 101/05) and of the Municipal Health Department (opinion 054/2006).

## ANALYSIS OF RESULTS AND DISCUSSION

The participants showed that they did not know beforehand about the fact that the set of exams anti-HIV, VDRL and hepatitis B and C is available for free at the CTA, as recommended by *Sistema Único de Saúde* (SUS – National Health System). The discovery of this service was related, as well as the encouragement to search for assistance, to referrals made by blood centers or suggestions made by sexual partners, relatives, friends and neighbors who had already been assisted by the service:

*"Look, I arrived here through my boyfriend, see? (...) He said: 'Look, go there, it's a good exam. You need to do it to know if everything is fine with you.'"* (Gabriel, 24 years old)

The fact that the main means of dissemination of the service are constituted by the network of friends and by blood centers was confirmed by other studies.<sup>7,13</sup> Professionals of the area state that the dissemination of this assistance is mainly performed by people who already use the service.<sup>7,13</sup> However, word of mouth propaganda is slow and limited to specific groups, and it may remain restricted to people who are already used to attending public healthcare services. The discourses also revealed a small participation of the media in the dissemination of the service.

It was found that, even in situations of unprotected sexual intercourse, with fixed or occasional partners, users went to the CTA for other reasons. One of the justifications was the obtention of an HIV-positive result, through the immunoenzyme method known as ELISA, after the interviewee or his/her partner donated blood at a blood center:

*"I surely wouldn't come and I'm telling you the truth. I came mainly because of this problem of my wife's positive Elisa".* (Sandro, 65 years old)

Other reasons for going to the service were related to the interviewee's refusal to be a donor in a blood center, the pressure exerted from the partner, due to marriage or to the partner's pregnancy.

Only the cases of unprotected sexual contact with multiple partners or suspicion regarding the partner's infidelity were understood as vulnerability and proved to be capable of mobilizing the interviewee's initiative to go to the CTA:

*"I had a guilty conscience about these relations I had without using condoms. It wasn't only one, there were many."* (Nonato, 29 years old)

The perception of vulnerability was also awakened by rumors of the partner's serum positivity or due to receiving an HIV-positive result, which needs diagnostic confirmation by means of a second blood collection called second sample or confirmatory test:

*"I wasn't even thinking about it (...) I was invited: 'My grandmother is at the ICU and she needs blood, can you donate some?' 'Of course.' Then I went there. (...) I didn't use condoms during the entire relationship with my boyfriend (...) That is the mistake that is now crystal clear to me. Sometimes, you think you have a risk-free life and we're at risk all the time."* (Otávio, 35 years old)

The study also revealed that, in the interviewees' mental imagery, the possibility of an HIV-positive diagnosis, the main reason for going to the CTA, is considered remote, due to the justification that they do not belong to the "risk group". Even nowadays, after 30 years have elapsed since the emergence of AIDS, the discourse of risk groups is still strong, commonly associated with sex professionals, people with multiple sexual partners, drug users and ill people who need blood transfusions. Having "reliable" partners or partners considered to be stable, even during a short relationship, were arguments presented for not belonging to this group:

*"I've already have five boyfriends after I separated. And I've always had relations without condoms. (...) I had been dating all of them for a while. And they're people (...) of high social level, (...) none of them were promiscuous. They were reliable (...) people, of good background."* (Desirré, 42 years old).

These results corroborate other studies, in which people with fixed or stable partners do not perceive themselves as being vulnerable and, therefore, do not see the need to use condoms nor to perform the HIV test. When they perform it, they do not consider likely that they will obtain a positive result because they recognize themselves as belonging to a "low risk group".<sup>5,6</sup> However, according to Szwarcwald et al,<sup>18</sup> the Brazilian epidemic seems to be at a 'second' stage today, through its expansion to a wide set of people with behavioral patterns viewed as 'low risk patterns', according to the traditional indicators of individual vulnerability evaluation.

In the interviewees' discourse, lack of knowledge regarding the service, difficulty in perceiving oneself as vulnerable, justifications of not belonging to "risk groups", fear of embarrassment and of precarious care emerged as important limitations to the access to this modality of assistance.

As for users' expectations, negative aspects were associated with prejudice concerning a poor assistance, derived from a history of precarious assistance provided by SUS. Mentions were made to long queues, bureaucracy, slow service, lack of attention and of space for questions. Participants showed no interest in the assistance proposal focusing on the educational-preventive aspect, which regarded as important only the result of the exam.

The interviewees also manifested fear of being stigmatized, mistreated or of having their intimacy exposed. The fact that the CTA is located in a medical assistance unit, which services several clinics and not specifically AIDS, was mentioned as fundamental for choosing the service:

*"Because I live in the country. If I go there, I know the nurse. So, no way. Then, I'd better do it here. And also, it's a place that almost no one knows about (...) It's safer [she laughs]." (Adelaide, 23 years old)*

Among the positive expectations regarding the assistance, the users referred to confidence in a good care, based on information provided by people who had been previously assisted, and on the prestige of the Brazilian AIDS program. The expectation of receiving information, a safe and responsible assistance based on the accuracy of the diagnosis, as well as professionals prepared to help them in case "something goes wrong" (a positive result), were also factors they mentioned.

If, on the one hand, there were expectations of precarious assistance, on the other hand, it was considered an opportunity to express their fears and feelings, as they felt guilt, regret, shame of exposing themselves to friends or relatives and being reprimanded:

*"To support me because there's no one I can talk to, you know? (...) I've already tried talking to a friend, but she'll condemn me, see? So, I expect to receive psychological support because I'm very upset." (Ana, 18 years old)*

The need to express themselves and to be sheltered can be interpreted, according to Foucault's conception,<sup>9</sup> as the effect of confession. Confession is a discourse ritual in which the act of speaking produces a feeling of purification, consolation and forgiveness for one's failures. Besides, the author considers that the discourse of truth, in the examination of oneself, began to be imposed on people from so many different points that it was already incorporated by subjects not as an effect of a power that coerces, but as something that liberates them and "promises salvation", as observed in the discourse below:

*"It is a contextualized exposure for a certain end. They aren't here to spy on my life, to gossip. The aim*

*is to take me to treatment, so, if the person doesn't understand this, he is really playing against himself. I think it's inevitable to be exposed like this." (Otávio, 42 years old)*

In the Foucaultian view, the party that listens does not occupy simply the place of judge who condemns or exempts. The party's role is also hermeneutic, because its power is scientifically validated when it uses revelation, to decode it and transform it into a discourse of truth that is completed only in the one who collects it and can intervene in a therapeutic form: "Truth heals when it is said in time, when it is said to whom it should be said and by the one who is, at the same time, its owner and the person responsible for it."<sup>9</sup>

Likewise, the interviewees' demand for guidance and awareness-raising so as to promote change in view of the risk of HIV infection was marked by a passive positioning that did not involve much reflection during counseling, mainly regarding the capacity to act as agent in the constitution of a practice of prevention against infection. A power to change was granted to the fear deriving from the assistance experience, to the normative character of preventive conducts or exclusively related to the opportunity of obtaining information on the clinical-epidemiological aspects of the infection:

*"This is what I'd like to hear in the lectures, something that shocked, even scared, so that the person becomes afraid of it. So that the person starts following the rules. The rules must be obeyed." (Juan, 47 years old)*

In these conditions, the user seems to attribute a certain status to the counselor, due to the institutional and technical place from which this professional speaks, situating him/her "as the subject who perceives, observes, describes and teaches."<sup>9</sup> Counseling, in this case, may be characterized as a resource of potential control, which combines hierarchy techniques with the sanction that normalizes.<sup>4,10,16</sup> Thus, counseling can be seen as a strategy of disciplinary power,<sup>14</sup> "as it is ruled by basic guidelines and procedures, established by the National STD/AIDS Program, founded by the Federal Government, and as it challenges subjects in many moments, with the use of regulating and corrective mechanisms."<sup>16</sup>

Unlike the restricted demand with a passive positioning during counseling, the interviewees also revealed more participative and reflective postures regarding assistance. An example was the demand for guidance and explanations aiming at a subsequent definition of viable strategies, in accordance with the participant's beliefs and life conditions:

*"Because I think that using condoms isn't a satisfactory attitude. If I found someone, I'd say, aren't we going to*

*do all the tests to see if we're immune? I think that it's possible to have a healthy relationship, one respecting the other.” (Jordano, 44 years old)*

In Fairclough's<sup>4</sup> view, counseling, as a technology of the discourse of modernity that is frequently applied to the areas of teaching, health and publicity, is part of a change in contemporary discourse which, in an ambiguous way, presents a democratic-emancipatory and disciplinary-regulating tendency. Counseling emerges as a resource of potential control as it enables to take, in a subtle or explicit way, aspects of people's private life to the domain of power.<sup>4</sup> In the democratizing aspect, it is configured as a way of talking to people about themselves and their problems, showing empathy with their accounts. Therefore, there is a distance from the affirmation of authority and explicit competence, moving from formality towards informality.<sup>4</sup>

In view of this aspect, which Fairclough<sup>4</sup> calls conversational, the opportunity of dialog and the exchange of information seem to be directed at a broader view of the conditions of vulnerability to HIV/AIDS. In this context, the user's discourse is compatible with a more inclusive and dialogic format of counseling. In it, the weakening of control is observed, aiming at a more autonomous and self-motivated “self”, to whom capacity and the will to choose are attributed.<sup>4</sup>

The ambiguity pointed by Fairclough<sup>4</sup> in the counseling practice was equally identified in the interviewees' demands and expectations. This aspect leads to the idea of plural stakeholder,<sup>12</sup> that is, the manifestation of a plurality of action schemes (or habits) in the same subject, as illustrated below:

*“At the moment, with what I've been through, I think it'd be better to do the test instead of attending lectures, talking. I keep remembering that mistake I made all the time, you know? (...) But now I think it's very good. It relaxes me. Talking is good. I need to learn about myself, you know what I mean? So that I can take care of myself better in the future. (...) I want the service to shelter me, if the result of the test is positive.” (Ana, 18 years old)*

In this perspective, the stakeholder's trajectory depends on the sanctions – positive and negative –, indicating limits that are frequently blurred.<sup>18</sup> In this scope, the institutional discourse of counseling may be related to an ambiguity that is typical of a society that is fragmented and, therefore, complex, in the sense of its non-homogeneity or contradiction. As a contemporary discourse practice, it reflects or represents social entities and relations, positioning people in several ways as social subjects, under a discourse of contradictory instructions for domination and emancipation.<sup>4</sup>

## CONCLUSIONS

A paradox was identified in the users' discourse between the participative aspect in overcoming vulnerability and the search for pragmatic solutions for excluding risk. There is a circular logic that makes counseling become a practice that is conditioned to the form of interaction, of the interpretation of the individual, circumscribed by a correlation of forces. A certain strategy can be accepted, rejected or modified by the subject.

Counseling work at a CTA consists of helping in the (re)construction of the other person's know-how with the aim of establishing autonomy in relation to HIV/AIDS prevention, using models that make more sense to the user's perspective. In this context, the demands pointed by the interviewees indicate the need for strategies that encompass improved information quality, better access to the service and to prevention and health promotion discourses.

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