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# Invisibility of drug use and support for professionals of the AIDS services

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## ABSTRACT

**OBJECTIVE:** To describe the influence of conceptions of health professionals on the care given to HIV/AIDS patients using drugs.

**METHODS:** Qualitative study based on semi-structured interviews with 22 professionals of different levels from two specialized STD/AIDS public services of the city of São Paulo was conducted in 2002. The interviews were recorded and submitted to a thematic analysis.

**RESULTS:** Professionals reported difficulties in identifying drug users among their patients, indicating the invisibility of the issue. They find drug users more difficult to treat, because they disturb the service and do not comply with treatment. Although they acknowledge the special needs of users, and that it is important to deal with drug use, health professionals believe that these issues are not their responsibility. Professionals showed personal and technical limits in handling these cases, showing the importance of their lack of specific capacity building. Thus, they recommend the creation of specialized services for this care, recognizing their own services as inappropriate. Although they were aware of the harm reduction project, there was a little participation in it.

**CONCLUSIONS:** Technical, ideological and personal elements such as beliefs, values and affective/emotional dimensions were relevant to enhance or refuse to develop more specific bonds with drug user patients. The conceptions on drug use may interfere in the development of a better care and equity in health care.

**KEY WORDS:** Acquired immunodeficiency syndrome. Patient care team. Patient care. Cost of illness. Prejudice. Health services, manpower. Health knowledge, attitudes, practice. Qualitative research.

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## INTRODUCTION

Drug use is one of the many challenges that had to be incorporated by health professionals working with people living with HIV/AIDS.<sup>8</sup> Between 2001 and 2002, in specialized services on DST/AIDS of the city of São Paulo, the Harm Reduction Project (HRP) was introduced, aiming at decreasing transmission and reinfection to HIV and Hepatitis C virus among injection drug users (IDU). Then, it was believed that drug use was being discussed in the routine of care.

However, some professionals had complaints regarding drug users (DU). They were seen as responsible for conflicting relations with professionals and services, with impact on the success of care.

Thus, there could be a hierarchy of patients in the routine of services, with discrimination of those considered as “difficult”. This discrimination was

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inspired by studies on the help of women in violence situations,<sup>15,16,18,19,\*</sup> where health professionals have to deal with a sociocultural issue that they do not consider as a health issue. These professionals refer to the subject as an unpleasant and problematic issue: taking care of the violence suffered was like opening “Pandora’s box”, the bearer of human disgraces and misfortunes.<sup>18</sup> Thus, they see themselves having to deal with several problems and suffering due to violence, but they account the attitudes of these women for the difficulty in this care. Studies<sup>15,16</sup> have constructed the notion of “difficult patients” on the care point of view, adopted in the present study. Such patients represent discouraging situations for professionals and are considered by them as the product of certain characteristics of the patients: the “difficult” case becomes the “difficult person”.

Likewise, drug use means a greater complexity of care. The analogy here is done in terms of the common understanding of drug use as a sociocultural issue, more than a demand of the health area, even though, just as violence, it has several repercussions on this area.

For professionals, drug use, either in therapy, or compliance with antiretroviral treatment, implies considerable changes in their work with AIDS, because it is added to its difficulties, those difficulties related to getting sick due to drug use.

This new complexity in care may be approached by analysis of the dimensions of the process of health work that are traditionally studied: the technical scientific dimension and the organizational.<sup>17</sup> These dimensions deal with diagnostic and therapy rules and the modalities that structure care in health services that should be specifically thought for patients with AIDS using drugs. However, another dimension little studied is also present on the process of work in health care. It is the investigation of the personal/moral dimension that together with the other two, form the behavior of the professional in their routine. As a singular *colloquio* of the technique in health work, has an important room in clinic-care decision making for beliefs, values, and even prejudice of the professionals.<sup>11,13,\*\*,\*\*\*,\*\*\*\*</sup> This occurs especially when there is a void in the definition of the other two dimensions. In the present study, this personal/moral dimension was valued based on the comprehension that the stereotyped understanding with its consequent stigmatization, may explain the behavior,

conscious or unconscious of the professional regarding these “difficult patients”.

Such procedure, if revealed, may be dealt with to ensure care of patients and not their exclusion. This approach of the way professionals act aims at contributing with this critical reflection, creating proposals that may avoid discriminatory practices, as well as refusal to reorient professional action regarding care of DUs living with AIDS.

Therefore, the objective of the present study was to understand the influence of the conceptions, beliefs, and values of health professionals regarding drug use in their routine practices in specialized services of DST/AIDS.

## METHODOLOGICAL PROCEDURES

The survey was conducted in 2002 in two units of the public sector, one outpatient specialized service in DST/AIDS, and a reference center on DST/AIDS, hereafter called units 1 and 2. They were selected because they presented greater reported cases of AIDS, according to the exposure category: injection drug use,<sup>\*\*\*\*\*</sup> and the professionals had more contact and experience in the care of these cases.

Professionals of different categories were invited to take part in the study, some of them had finished high school and some had graduated from college, and they had been working in the place for at least one year, this was the minimum amount of time in the service that enable to match professional life with the care of the user population.

This was a qualitative research, conducted through a semi-structured interview, with a written statement of the interviewees in the end with “advice to their peers”. The methodology used on a previous study<sup>14</sup> was adopted to collect and assess statements of professionals on the routine of work regarding: recording, transcribing, and checking reliability of interviews; the way interviews were conducted and how they were assessed. Interviews were based on pre-defined scripts and lasted for one hour on average. This methodology was chosen because it favored the expression of beliefs, values, conceptions, and feelings regarding the study object.<sup>14,\*\*\*\*\*</sup>

\* Kiss LB. Temas médico-sociais e a intervenção em saúde: a violência contra mulheres no discurso dos profissionais [dissertação de mestrado]. São Paulo: Faculdade de Medicina da USP; 2004.

\*\* Peduzzi M. Equipe multiprofissional de saúde: a interface entre trabalho e integração [doctorate thesis] Campinas: Faculdade de Ciências Médicas da Unicamp; 1998.

\*\*\* Ribeiro JM. Trabalho médico: ciência, arte e ação na conformação da técnica [doctorate thesis]. Rio de Janeiro: Escola Nacional de Saúde Pública da Fiocruz; 1995.

\*\*\*\* Schraiber LB. Medicina tecnológica e prática profissional contemporânea: novos dilemas, outros desafios [tese de livre-docência]. São Paulo: Faculdade de Medicina da USP; 1997.

\*\*\*\*\* Coordenação Municipal DST/AIDS. Município de São Paulo, 1º. Semestre/2002, dados preliminares. São Paulo; 2002

\*\*\*\*\* Nemes MIB, organizador. Aderência ao tratamento por anti-retrovirais em serviços públicos de saúde no Estado de São Paulo. Brasília: Ministério da Saúde; 2000.

The script for interview was formed by two items: 1) description of the care job, reports of action of the professional routine from the beginning of participation on the service, characterizing professional life and their perception on the difficulties and possibilities of care; 2) relation noticed between adherence to treatment and drug use; 3) personal and/or family experience with drug use, as well as their overall opinion on the use as a social and health issue; 4) perceptions and representation on health work in the context of the combination AIDS/drug use.

For data analysis, the following reference pictures were used: process of work in health,<sup>7,11,13</sup> stigma and discrimination,<sup>4,10</sup> and invisibility of social and cultural issues in health.<sup>15,16</sup>

The first reference picture was used as a basis to discuss the interfaces between professionals and their jobs, regarding technical and scientific skills, and personal/moral dimension. References on stigma and discrimination were used to discuss conceptions on drug use and within this issue, the invisibility of care as its major problematic, based on studies on similar invisibilities.<sup>15,16</sup>

Assessment of the empirical material was thematic and was conducted from the reading of each individual report, within the assimilation technique, followed by cross sectional reading of the set of statements.<sup>14</sup> Findings were treated according to four thematic areas: work with HIV/AIDS; perception on the patients with HIV/AIDS; drug use: conceptions and values; work with HIV/AIDS patients using drugs. The last two will be the main target of the article.

The study was approved by the Research Ethical Committee of the Municipal Health Secretariat and all respondents were ensured confidentiality and anonymity of their statements.

## ANALYSIS OF RESULTS

The 22 professionals interviewed had been in the services for six years, and were in work teams (Table).

Patients cared for in the services studied that did not present as a category for HIV exposure the use of injection drugs, were 12.5% and 14.4%, respectively in units 1 and 2. Thus, we could not estimate drug use among patients.

When asked about the difference of when they had begun working with AIDS compared to the time interview was conducted, they reported generically that they felt the services were more structured, with systematic care, availability of treatment and capacity building to deal with issues regarding HIV/AIDS. Also in general terms, they considered the performance of the service as

good. Difficulties mentioned were related to: physical area, referral and counter-referral to other services for some specialties and compliance with anti-retroviral treatment.

Next, physicians' statements are highlighted because they express more significantly the issues assessed.

### Use of drugs: conceptions, values and stereotypes

Regarding drug use, different conceptions were found among the interviewees. Some professionals stated that drug use is always bad, "the worst thing in the world", but it is referred as individual choice, highlighting the harm for the individual. Others related it to pursuit of pleasure, and this pursuit was seen as valued nowadays, placing the problem of drug use in the sociocultural field.

For some, drug use is due to personal and affective experiences, such as needy, despair, ruptured families, and experiencing violence. For others, it was due to social structural aspects, such as poverty, unemployment and lack of opportunities. A few, however, established connections between personal and social experiences in the life of users. Frequently drug use was seen as a

**Table.** Number of professionals interviewed by categories and research unit. São Paulo, 2002.

Field/Professional category	Number
Unit 1	
Physician	3
Nurse	1
Social worker	2
Psychologist	1
Nurse assistant	3
Laboratory assistant	1
Managing technician assistant*	1
Sub-total	12
Unit 2	
Physician	3
Nurse	1
Social worker	1
Psychologist	1
Nutritionist	1
Occupational therapist	1
Nurse assistant	1
Office boy-doorman*	1
Sub-total	10
Total	22

\* managing professionals that were working in another position, working directly with the care-reception of patients

“disease”, and it was not considered as having a personal or social origin.

Professionals reported that the most commonly used drugs by their patients were alcohol, marijuana, snorted cocaine and crack. A few of them reported injection drug user patients.

Most interviewees reported having no personal experience with drugs, not even among relatives or friends. Both these cases and those who reported having such experiences, reported they adopted the same behavior: advise use interruption and start treatment. Professionals reported that drug users, especially those using alcohol and crack are considered as the most “difficult”. According to the result of interviews, this is due to lower compliance with antiretroviral treatment and because these patients present undesirable behaviors: they are undisciplined, disturb, and cause problems in the services. Pediatricians also point out that DU patients, such as parents of patients, are difficult because they abandon their treatment, and also interfere on the treatment of their children exposed to HIV.

*“I believe that those causing most problems are drug dependent patients, you see? They really stop, I, at least, have had many patients abandoning treatment...they cannot comply with treatment”.* (Physician)

When they were asked about “easier” patients, interviewee reported women, and overall all those who comply with treatment, and who follow guidelines; and those who do not cause trouble during care.

*“... there are those women, married women who got the disease through their husbands...so they follow treatment properly...”.* (Nurse assistant)

### **Work with HIV/AIDS patients using drugs**

Several difficulties had been reported by health professionals in dealing with patients using drugs. Some justified them due to the prejudice of people in general, and to the difficulty of patients themselves in revealing their drug problem.

*“... Not approaching too much the issue of drugs... there is still to much prejudice regarding the issue of drugs, although we think it is more liberal to provide guidance, to talk about the use... there is still prejudice, this barrier between professionals and users still exists.”* (Nurse assistant)

Some professionals said they could not notice DUs among their patients and they felt they should preserve themselves with everything involving drug use. That is, they did not ask, or care. Others believed that the greater the bond with the patient, the easier it is for them to say it; even so, this was always the patient’s initiative.

*“... sometimes it depended a lot on the opening and how the appointment is going at the time... but it is not routine to approach.. when I realize patients want to say something, then I have to be opened, but this is not something that I ask”.* (Physician)

Professionals reported that DU patients cannot comply properly with treatment, but they always returned to the service. When they were asked, some were surprised they had never wondered why these patients returned to the services. When reflecting about it, most of them believed that patients looked for attention, support, and listening, because many of them lived alone, or were not supported by their families.

Notwithstanding the great importance given to compliance with medical treatment, some interviewees remembered that this treatment is not always the greatest demand of DU patients, indicating perhaps, that due to fear of dying, some patients returned to the services for love and care, whereas other returned for benefits due to their socioeconomic difficulties. Thus, for professionals, health services would also be seen as a place for social living or for attention to poverty.

Professionals had problems answering if they met the needs of these patients, because they realized this during the interview. However, they believed they were welcoming, established bonds, and encouraged compliance, although it was hindered by poverty and social issues.

Professionals also emphasized they treated all patients equally, without distinctions. Thus, they see they acted the same for all patients. However, they recognized that some of the patients’ needs were not met.

*“I see this was, as a doctor, it does not matter if the patient is a prostitute, or a homosexual, or a transvestite, we have all kinds of people here..., they are all patients, and you as a person, a doctor, a human being, cannot question anything you see...”* (Physician)

Thus, although all interviewees thought that drug use hindered compliance with AIDS treatment, this would not be an impediment. However, overall, professionals admitted they were not trained enough and did not have information enough on drug use and its relation with AIDS treatment.

*“I think our lack of knowledge is a limitation, I am complete ignorant regarding this, ok,... drug use together with AIDS and with medication, what can occur..., I have no idea...”* (Pediatrician)

Regarding the limits and possibilities to deal with drugs in the services, most of them answered that, although DUs were part of the patients, they believed they should be referred to specific services. Drug users would not be their professional responsibility.

Professionals reported the feeling of impotency due to the absence of resources for referring patients and pointed institutional limits related to the lack of equipment and agreements with other services to refer examinations and admissions. Some of them reported personal/emotional limits to deal with the use of drugs and they reported that they “did not have the profile” to care for DUs. Although they have not exactly explained what would be that profile, at first, they mentioned personal and emotional qualities. Social conditions of the patients were considered as important aspects concerning the difficulties to follow up their needs.

Technical ignorance was considered as a professional limit, and to deal with the use of drugs was a “distressing and limiting factor” to their actions, and to any kind of dialog that related to it. Even if they identified a fail to treat DU, interviewees did not show interest in being trained.

*“... the drug is very present in the life of the patient, that is the greatest secret... we will see, because we cannot interfere, so we live passively with that... we do not approach because we cannot do anything...we are kind of abstracted”.* (Nurse)

Among the possibilities of improvement of care in the services, some mentioned the creation of patient groups conducted by specialized professionals; others, the improvement in social conditions of the patients, which could result in greater compliance with treatment; and the improvement in welcome in the unit, even if this was the responsibility of another professional.

Externally to services, interviewees referred to two possibilities: the need for specialized health services in the care of DUs for referral of patients in general; and the creation of a service specific to deal with drug users living with HIV/AIDS. Professionals acknowledged their own services as unsuitable for this purpose.

*“... if we placed a drug service within the service of AIDS, it would get absurd dimension, we wouldn't be able to absorb, right?... we would have to have specialized services and many services... to place all these dependents in the service for AIDS would be dangerous, because I think a structure just for this purpose would be necessary...I believe that more complex than dealing with HIV is dealing with drugs”.* (Nurse)

Regarding the HRP as an institutional policy to approach drug use, introduced in the services of AIDS in 2001 and 2002, most professionals referred they knew about the “project”. Some of them believed that the effectiveness of the program was incipient and others considered that, at that time, there was great engage-

ment for the success of this activity. Only one of the interviewees was involved in the program. The others justified not getting involved because they considered that they “didn't have the profile”, saying that “someone” should take the responsibility, not seeing this activity as a routine in everybody's work.

*“... this program had been developed by this group, I think they are reaching their goals...”* (Nutritionist)

The view of professionals regarding HR was split, although a few of them could explain how it worked in their unit. Many place the issue as a “*historical mistake*”, since the “*IDU population would not be significant at the time to justify the dimension proposed*”.

*“... I am not completely favorable, I believe the moment is gone! The impression I get is that the time for this work has elapsed...”* (Physician)

Going through the items of the script “advice that I would give to peers”, our attention was caught by the use of terms that can lead to stigma of these patients and fear of dealing with them, even if some of them offered to listen and welcome.

*“I have no specific advice, but what is most important, is not being afraid, but not take risks when dealing with drug addicts. When it is difficult to deal with them, always share care with another professional. And if you can't, refer the case to a more skilled professional”.* (Anonymous statement)

## FINAL CONSIDERATIONS

The present survey enabled to detect some conceptions and values of professionals regarding patients using drugs in the services studied. The findings reinforced the outcomes of studies on the perspective of health professionals on the use of drugs, and the approach of patients specifically with AIDS.<sup>3,9,12</sup> The approach of health professionals on drug use recorded in the present study also has similarities with that of violence against women.<sup>18,19,\*</sup> Because of the mentioned sociocultural characteristic of drug use and violence against women, efforts to approach them as a health issue reinforce the professional perception that these issues would not be the responsibility of health professionals. When they continuously state that the determinants of these situations are, sometimes individual and personal, and sometimes due to the social structure, these professionals express feeling and representations that, in the health service level, little can be done about them. Drug use, thus, becomes a health issue only because of its consequences, which should be treated regardless of the fact that they were caused by drug use.

\* Kiss LB. Temas médico-sociais e a intervenção em saúde: a violência contra mulheres no discurso dos profissionais [master's dissertation]. São Paulo: Faculdade de Medicina da USP; 2004.

Drug use was an issue that caused tension on patients' health care. Drug use in HIV/AIDS patients was considered one of the main difficulties in patients' follow-up, bringing up the issue of lack of technical issue of professionals, since it was pointed out as a specific situation outside the care of patients with HIV/AIDS.

Therefore, the perception of interviewees was contradictory regarding what to do with the fact that DU patients return constantly to the services although they do not comply with the treatment, because they acknowledge and refuse at the same time specific demands of these patients.

The findings of the present study confirm those of Castanheira et al\* (2000), that verified the difficulty of professionals to deal with stories of life of patients regarding drug abuse, because they often were in conflict with their conceptions and values, leading to a break of their relationship with these patients.

Nemes \*\* (2000) and other authors<sup>1,2</sup> showed that conditions such as: unemployment, prison, lack of permanent address, little experience of physicians regarding care of these cases, and the age of IDU interfered in their treatment, more than the use of drugs in itself.

Drug users have always been considered, beforehand, as "difficult" people. Turning difficult cases into difficult people, results in "bad patients". This situation may be considered as one of the ideologies building the stereotypes of cases that are refused because of principles, and that are not dependent on particular and concrete situations, becoming the mechanism for labeling people that end up defining individuals as marginalized. Thus, the power of excluding people who present the "markers" of these labels,<sup>4</sup> such as DUs is used, because they are always difficult people.

As part of this ideological construction, we have also observed that only the patients were made accountable for having difficulties in talking about drug use, and they have not acknowledged difficulties of the

professionals. The fact that this discussion should not be started by professionals reinforces the invisibility of DUs in the services, and the silences that are present in the relationship between professionals and users. Such as other complex and sensitive issues, the accountability for making the problem explicit is only given to those with the problem.<sup>5</sup>

Interviewees justified not managing the cases due to lack of technical expertise. Although technical inability to deal with drugs<sup>3,6</sup> was mentioned as one of the major limits to professional action, there was little interest in capacity building and when it was mentioned, it was seen as an overall improvement of the services, not including the interviewees. Therefore, if on one hand the possibilities of better care were projected for future achievements, and as someone else's responsibility, they put in check if capacity building of professionals already working in these services would be efficient for improving the care given.

HRP appeared as a strategy to deal with the complexity of the issue, presenting resources as such. Nevertheless, it was always referred with a peculiarity: it was very important, but for other people to work with it.

Drug use, through the issues of invisibility, silence, stereotypes, and refusals to act, is possibly an issue that can highlight unrevealed demands of patients that are hardly ever dealt with in the routine of care. Because of that, it enables to rescue essential elements of equality, among them the relevance of a policy and aid proposals that improve health care in these situations.

Thus, discussing presence of AIDS/drug use has proven to be important as a critical reflection that offers arguments for other studies and for proposals of improvement of the quality of specialized services. The present study revealed the need for rethinking issues regarding rights in patients' care, because it showed how culture in health, as well as some aspects of professional acting, may interfere in the development and consolidation of policies for care equity.

\* Castanheira ERL, Capozzolo AA, Nemes MIB. Características tecnológicas do processo de trabalho em serviços de saúde selecionados. In: Nemes MIB, organizador. Avaliação da aderência ao tratamento por anti-retrovirais em usuários de ambulatórios do sistema público de assistência à AIDS no Estado de São Paulo. Brasília: Coordenação Nacional DST/AIDS. Ministério da Saúde; 2000. p. 133-69.

\*\* Nemes MIB, organizador. Aderência ao tratamento por anti-retrovirais em serviços públicos de saúde no Estado de São Paulo. Brasília: Ministério da Saúde; 2000.

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