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AIDS and pregnancy: meanings of risk and challenges for care

ABSTRACT

OBJECTIVE: To understand how the risk of vertical HIV transmission is perceived and interpreted by people living with HIV/AIDS, when making decisions regarding reproductive health.

METHODS: This was a qualitative study carried out at three municipal health clinics specializing in STD/AIDS, in the city of São Paulo. Semi-structured thematic interviews were conducted with eight patients (male and female), from July to December 2001. The interviewees were key informants and either they or their partners were seropositive. All of them were aged 18 or over and had been living with their partners for at least one year.

RESULTS: Among the motivations for having children, those related to the partner's expectations were highlighted, especially as a form of "recompense" for their actions. The risk of vertical transmission was used by health professionals both for discouraging pregnancy and for giving guidance on transmission prophylaxis. However, reproductive issues were not voiced at the health clinics, either by the patients or by the healthcare providers.

CONCLUSIONS: Attention should be directed not only towards controlling the infection, but also most importantly towards the wellbeing of people living with HIV/AIDS. There is a need to clarify the different points of view of users and professionals in order to achieve the most effective and appropriate solution for each specific caregiving situation.

KEYWORDS: Acquired immunodeficiency syndrome. Sexual reproductive rights. Risk. Delivery of health care.

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INTRODUCTION

Pregnancy within the context of HIV infection is a subject that often generates polemic and heated discussions, particularly among health professionals. When a woman who is known to be seropositive manifests a desire to become pregnant, or arrives pregnant at the health clinic, health professionals express feelings of indignation or incomprehension. They justify these feelings mainly on the basis of the risks of perinatal HIV transmission.

Health professionals especially use epidemiological data to justify their indignation, and healthcare programs even create reproductive health rules relating to prophylaxis for vertical transmission within the context of HIV/AIDS.²⁰

This rational scientific approach shows the risk of vertical HIV transmission. However, it does not seem to determine the reproductive decisions of seropositive individuals, according to some studies.^{1,9} Research among seropositive women in Brazil has indicated that around 30 to 40%^{15,*} of them knew of their HIV diagnosis before becoming pregnant.**

Regarding information on vertical HIV transmission, Paiva *et al*^{16,17} showed that approximately 75% of the women and 50% of the men had this information, although their desire to have children did not present any significant correlation with the level of information.

It is possible that talk regarding the risk of vertical HIV transmission is considered to be technical in nature, and this may be reinterpreted by service users.⁴ Therefore, the present paper had the objective of contributing towards gaining an understanding of the way in which this risk is perceived and interpreted by people living with HIV/AIDS. The intention was to obtain deeper knowledge of how people living with HIV/AIDS make decisions about becoming pregnant or not, and the role of the health services in this process. Identification of differences in meaning regarding pregnancy and its risks, between health professionals and patients, may help to increase the quality of reproductive health care.

METHODS

A qualitative study was carried out, based upon in-depth interviews with men and women who were being followed up at three health clinics specializing in STD/AIDS, in the city of São Paulo, between July and December 2001.

The choice of health clinics was based on the study by Oliveira & França Junior,¹⁵ which dealt with the topics of AIDS, reproductive rights and healthcare by making reference to distinct organizational types: one of them more centered on the doctor's work; another centered on a multiprofessional team; and a third that mixed these two approaches. Although these distinctions were subsequently refuted, they did suggest specific matters within healthcare practices that might have an influence on perceptions and decisions regarding pregnancy and the risk of vertical transmission.

The identification and recruitment of individuals who could make statements – all of whom seropositive, 18 years old or over, and living with a partner for at least one year – constituted an intentional process utilizing the criterion of convenience. The first author of the present study worked as a field agent in the abovementioned study,¹⁵ at the stage of observing potential participants, in situations such as pregnancy groups, waiting rooms, and consultations. These contacts not only enabled identification of seropositive individuals and their partners who expressed some desire to become pregnant, but also those who did not wish to get pregnant, and also some women who were already pregnant. The selection of seropositive individuals for the present study was therefore done by recognizing the potential of such individuals as “key informants”.

Eight informants were interviewed, which was sufficient for identifying and interpreting the central question of the study (Table 1). This number had not been decided at the outset, since the study did not involve statistical sampling. The idea was to focus the question on the widest possible diversity of practical situations that were potentially relevant. The intention was to identify common elements in the statements, and also elements considered to be unique, that would show significance for the understanding that was sought.¹³

The interviews were conducted using a semi-structured model (Table 2), with an average duration of two hours each. They were recorded in their entirety and then transcribed, giving a total of 146 pages. Both informants and the persons mentioned by them have been identified using fictitious names. The analysis of the material was of an interpretative nature, within the conceptual framework of epidemiological discourse² and cultural theory⁵ regarding risk. This analysis had the aim of establishing parallels between distinct perceptions regarding vertical transmission within the context of HIV/AIDS.

*Enhancing Care Initiative: AIDS Care Teams in Action. [on line]. Disponível em http://www.eci.harvard.edu/events_pubs/2004_ECI_monograph.pdf. 2004 [acesso em 13 mar 2006]

**Figueiredo R. Comportamento contraceptivo de mulheres com Aids na cidade de Santo André, 2001. Disponível em <http://www.usp.br/nepaids/ce-sa.pdf> [acesso em 29 mar 2006]

Table 1 - Individuals interviewed, according to age, number of children still living, length of time the couple had been together and serological status. São Paulo, 2001.

Individual interviewed	Age	Serological status	Children still living	Serological status of the children	Serological status of the partner	Length of time the couple had been together
Rebeca	19	HIV+	None	-	Unknown	1 year
Cleber	29	HIV+	None	-	HIV+	3 years
Nair	28	HIV-	None	-	HIV+	10 years
Paula	25	HIV+	None	-	HIV+	3 years
Marcela	33	HIV+	03	2 HIV- 1 HIV+	HIV+	18 years
Carolina	29	HIV+	02	HIV+	Unknown	1 year
Gisele	24	HIV+	01	HIV-	HIV+	10 years
Reinaldo	32	HIV+	02	HIV-	HIV-	6 years

From the interpretation of the interview content and the contextual situation of the interviewees, two core themes were highlighted for presenting and discussing the results: 1) feelings regarding maternity/paternity, HIV/AIDS and the risk of vertical transmission; and 2) reproductive issues and how these are regarded by the health services.

Ethical care was observed regarding confidentiality and privacy of the information collected. The interviewees' informed consent to their participation was also obtained before conducting the interviews.

RESULTS AND DISCUSSION

Regarding the meaning of pregnancy: children as recompense

Among the individuals who were interviewed, two were pregnant (one had three children and the other was childless), two stated that they did not want to have more children and four of them wished to have children, although with reservations.

Except for one of the interviewees, who throughout the interview expressed a very clear desire to have children, the others did not promptly express such desires. They first mentioned their worries regarding the effects of the medications on the baby, the possibility that the child would become an orphan, the financial difficulties and the chances that the baby could become ill.

Together, the statements showed that, depending on these individuals' plans for their lives, pregnancy and consequent children could make them face the likelihood of passing on their infection to the baby, and the doubts and fears regarding vertical transmission.

Even considering the reservations relating to HIV transmission, the interviewees brought out arguments to justify pregnancy. Among these, they highlighted the opportunity to experience or re-experience maternity or create a family that is so culturally rooted

as a constituent trait of female identity, from a gender-based perspective.¹⁸

Motivation to have children that was associated with the partner's expectations as a means of "recompense" for gestures or initiatives was highlighted in the group. This can be more directly related to conjugal situations within the context of HIV infection, as in Rebeca's case:

Tabela 2 - Roteiro temático das entrevistas.

1. Living with HIV/AIDS
 - From when HIV/AIDS was diagnosed until today.
 - The news
 - Central concerns
 - Plans
 - Networks of family and friends
2. Reproductive history
 - Pregnancies
 - Abortions
 - Children
 - Contraceptive methods (how was the choice made/ why?)
3. Intentions regarding reproductive life
 - Do you intend to have children?
 - Why?
 - Do you think you should/can control your reproductive life?
 - Who have you already talked to about this? Why?
 - Have you talked to your partner? What have you talked about?
 - Who would you like to talk to about this? Why?
 - Who wouldn't you talk to about this? Why?
 - What could change your intentions?
 - Condoms
 - What has already been?
 - Who have you already talked to about the subject?
 - What does your partner think?
 - Likelihood of use
4. Love/sexual life
 - How do you assess your relationship with your partner today?
 - Is it any different to before HIV?
 - What would you need to do to improve it?
 - Have you talked about the matter?
 - Has anyone given you any tips about the relationship?
5. Relationship with the healthcare services
 - Which professionals do you usually talk to most?
 - Has anyone talked about whether you should or should not have children?
 - Which of them do you think you could talk to about this?
 - What do you think they would say if you said you wanted to have children?
 - And if you said you were pregnant or your partner was pregnant?
6. Life before HIV
 - Life before HIV

“...he had a woman... he finished with his wife and stayed with me... And I have to thank him very much, because I was using drugs, he was the one who took me away from drugs. And I drank... I quit drinking because of him... I think he's the right person for me... He says he has eight children and he doesn't have any with me... He wants to have a child with me... The thing he wanted the most in his life. He says that before he dies, he wants to have a child with me ...” (Rebeca)

For Carolina, despite having two HIV+ daughters, losing one baby due to the disease and fearing vertical transmission, her partner's desire has justified a fourth pregnancy. He had not only accepted her serological condition but also offered support to her and the baby, a gesture that contrasted with the experiences of being abandoned by other partners when she had become pregnant.

“He was wanting the pregnancy... He's crazy to know if it's a boy or a girl, so that he can buy clothes!... For me, my past was sad! ... I know it's not easy to live with someone who has this problem. But not for him! Now I'm pregnant by him. With his son or daughter, I don't know! He is the one, the only one, the one... This one I know I can trust...” (Carolina)

Perceptions regarding the risk of vertical transmission

These perceptions were present in the way the interviewees spoke, based on the way in which doctors and epidemiologists speak about the risks. They were selected, understood and often interpreted by the interviewees, according to their own contexts and/or their desires to have or not to have children.

It was possible to observe two kinds of approach among professionals regarding reproductive issues. Some professionals based their arguments on the risks in order to discourage seropositive women from the idea of having children, by emphasizing the likelihood of HIV transmission. Others, although mentioning such chances, seemed to give emphasis to prophylactic measures for preventing vertical transmission, thus already foreseeing pregnancy as a possibility.

This type of talk was taken up by the women, but there was no discussion about the alternatives as such. For example, in Rebeca's case, she was faced with differing emphasis from two doctors in the health clinic and chose to place more value on the words that represented less of an obstacle to her plans for having children:

“It's not because one says you can and the other says

you can't, that we're going to get mad and do something crazy!... it's not because you've got HIV that you can't have a child. Yes, you can! From the moment you take your medication all right, yes you can have a child. Because then, up to the second year, the child's blood can be negative...” (Rebeca).

Foreseeing the doctors' reactions towards intentions to become pregnant or pregnancy already in progress, the interviewees' words were concentrated exclusively on controlling HIV transmission, although apparently expressed differently (censure or prophylaxis of vertical transmission). The way they expressed this, without other considerations regarding their wishes and motivations, and inseparable from healthcare, was just like any other woman of reproductive age would say it. Even in the case of pregnancy that was already in progress, what the women put across was the doctor's concern for preventing infection of the child.

Interviewer: *And if you went to your doctor and said: 'Doctor, I want to get pregnant', what do you think he'd say?*

Marcela: *I think he'd say: 'No!'*

Interviewer: *Why?*

Marcela: *Ah, because I have this... that the baby could be born ill again, right? I think this is risky!*

Interviewer: *And if you went and said: 'Doctor, I'm pregnant!'*

Marcela: *Ah, I think he'd say: 'So let's start the treatment to see if we can save the baby (laughing).'* (Marcela)

Considering that a planned pregnancy may diminish the risk of vertical transmission, inasmuch as some laboratory markers are under control (viral load, CD-4 and CD-8, among others), it can be supposed that this situation is more favorable than an unplanned pregnancy.

However, in hypothetical situations, it was foreseen that, when faced with an *intention* to become pregnant, the doctor would emphasize the risks of vertical transmission, in a way that implied an objection to the pregnancy, without mentioning the possibilities of prophylaxis and conditions that would decrease such risks. If the pregnancy was already *in progress*, this “threat” (according to the interviewee) would be attenuated by the professional, who would be busy trying to save the baby.

Finally, another way of expressing the risk of vertical

HIV transmission was mentioned by Gisele. After receiving information from her doctor regarding the chances of transmission with and without prophylactic treatment, she placed equal value on them, without distinction, thus putting together the probabilistic objectivity of the risk with her desire to become pregnant by classifying the chances of infection as “minimal” or “very small”.

“...My deliveries are all cesarean, I’m nervous, I have high blood pressure... It’s very little to do with HIV... the chance of contaminating the baby is minimal... I’ve already asked once... about how to have a child. Curiosity, right? Then, she (the doctor) said there was an 8% chance of it happening, if I was taking the medication... And 20% if I wasn’t. So, the possibility is small”. (Gisele)

Gisele’s interpretation of the risk of vertical transmission took place within a context in which she was trying to weigh up the possible hazards of the HIV seropositivity with her broader plans for the future:

“... Ah, I have a lot: I’m thinking of buying an apartment, setting up a kiosk, doing things without a boss. I’m always thinking about setting things up, doing things... In short: I don’t even remember I have HIV. Only when I come here!... when I go to get medications... but it’s very much a passing memory. It’s not that fixed thing: ‘ah, I’m going to die!’...” (Gisele)

The statement revealed situations in which the health service users made their reproductive issues clear to the health professionals. The responses they received had the aims of giving information, discouraging pregnancy or giving guidance about the possibility of prophylaxis for vertical transmission. They provided choices or even a repertoire of arguments in justification. However, questions relating to reproductive health, and in particular conception and contraception, did not always seem to be clear, both for users and for health service professionals.

Silent preclusion of reproductive issues in health clinics

Some practices by health professionals seemed to contribute towards service users’ reproductive issues not being spelled out, particularly regarding pregnancy. Furthermore, the fact that these users did not take the initiative to talk about the subject seemed to “exempt” the professional from promoting such dialogue.

In Cleber’s case, although he felt welcomed by the health clinic, the health professionals’ continual prescribing of the use of condoms worked indirectly as

“silent preclusion” of talk about the possibility of having children.

Interviewer: *“And with a doctor here in the clinic, did you talk about it?”* (about pregnancy)

Cleber: *“No. We never talked.... Because they always advise us to use condoms. They say we need to use condoms because one person’s HIV isn’t like someone else’s. So you’ve got to use them even though you’ve both got it. That’s what they said. So we didn’t even make any comments. We always use condoms”* (Cleber)

The information that he and his wife (also HIV+) had on the subject was restricted to the content of the printed information slips that accompany the medications:

“We already thought (of having children), but the slips that come with the medications, they don’t recommend it. None of them, including the medication I got here. They don’t recommend it...because they don’t know what might happen” (Cleber)

Although it should be expected that health clinics are aware of the issues relating to prevention, they may inhibit initiatives that go against such prescription or their actions may lead to “clandestine transgression” of the guidance. This occurs when clinics are restricted to repeating the recommendations, without seeing the problems in the possible difficulties or conflicts of interests regarding condom use, such as the desire to have children.

The silence regarding reproductive issues may also be shared between patients and health professionals. Carolina had three daughters, all of them HIV+. One of them died because of the disease, and therefore would have deserved more active attention from the health services. However, neither she, because of alleged “lack of opportunity”, nor the services when faced with this history, took the initiative of talking about pregnancy or contraception until she informed the infectious diseases doctor about her menstrual delay, which triggered a request for testing and subsequent confirmation of the pregnancy.

Interviewer: *Did he (the doctor) ever, before you got pregnant, talk about pregnancy, about having or not having children?*

Carolina: *No, he still hasn’t gotten to that point with me... he’s never talked about that, no!*

Interviewer: *Never talked?*

Carolina: *Never. He hasn’t had this opportunity yet...*

The desire to have children does not come down to just a personal wish or individual decision, but is modeled by broader social rules. As could be seen from some of the statements by the female interviewees, for them this desire was especially associated with their partners' expectations.

The insistence by Rebeca's partner that he wanted to have children with her, despite already having eight, each one with a different woman, may be a way of marking his virility, which is "a recurrent substantive theme and also a moral value in the expression of what it is to be a man".¹¹ Likewise, Paiva *et al*,¹⁷ recorded conversations among men in which they said that to have children "is an obligation" or "it makes me feel more of a man".

In turn, by living up to their partners' expectations, the women in some way regarded pregnancy as a form of "recompense". In the anthropological perspective provided by Mauss,¹⁴ pregnancy can be thought of within the "triple obligation of giving, receiving and recompensing", thereby reinforcing the conjugal alliance.

According to Knauth,¹⁰ "the maintenance of reproductive activity is an important strategy used by women (...) that is activated especially in the case of those are still in the phase of consolidating the alliance and are seeking, through maternity, to strengthen this relationship". Moreover, gaining a descendant through maternity reinforces the relationships with the consanguineous family.

Thus, these rules and social values, when they form part of and guiding the plans that people with HIV/AIDS have, may take precedence in their reproductive decisions, when they are weighed up against the risk of vertical transmission, as was identified in the statements by some of the interviewees.

The same history of life that made Carolina worried about the health of the baby she was expecting – since all her children were HIV+ – also made it acceptable to take the risk of vertical transmission in pregnancy, given her opportunity to change the story line of her sad past through the experience of a unique conjugal relationship.

Therefore, even if it is fundamentally important that health policies and practices regard the risk of vertical transmission as a concern, through providing information and access to prophylactic measures for this manner of transmission, they cannot ignore people's wider aspirations and their plans for their lives. Otherwise, there would even be a risk that the effectiveness of these policies and practices could be compromised.

The rejection of pregnancy by health professionals, within the context of AIDS, as foreseen in the interviewees' statements and corroborated by other studies,^{14,17} follows the lines of the predominant role of the notion of epidemiological risk in healthcare practice. Such notions often "limit the possibilities for opening up medical and hygiene practices to the various socially constructed subjective characteristics, the different needs, and the dynamism of human realities".²

Even when considering some changes and restrictions in the daily lives of people with HIV/AIDS, like those imposed by the use of medications, these people's lives cannot be reduced or restricted to their serological condition. Nor can it be assumed that, because of their seropositivity, they do not have plans or aspirations, as was seen from Gisele's words. She said that she did not even remember she had HIV, except when she came for consultations. Through this strategy, she places her plans for her life above the possible limitations due to her serological condition.

In the decision to have children, this kind of "forgetfulness" about HIV may be seen by the health services as a lack of consideration for the risk of vertical transmission. However, for people who are seropositive, it can be a way of activating what Douglas⁵ called "subjective immunity", which allows people to get on with their lives and, even when facing danger, allows them to "dare to experiment and not become unstable in the event of failure".

"Subjective immunity" would not mean denial that they have the disease or denial of the risk of vertical transmission but, rather, would mean what Douglas⁵ – taking risk as a culturally constructed notion – called "acceptability of the risk". From this perspective, the desire or the decision to have children, depending on the normative concepts in which this takes place, may deserve different "levels of acceptability", even if there is an awareness of the risk of vertical HIV transmission. This could be seen from the modulations in the meanings of such risk that the interviewees presented, and it is in accordance with the studies by Paiva *et al*.^{16,17}

In the light of the foregoing, a certain degree of polarization was demonstrated between the search for "technical control" over the disease, through emphasis on the epidemiological risk of vertical transmission, and people's plans for their lives, which included the assertion of identities and the strengthening of conjugal alliances by means of maternity and paternity.

On the one hand, it is expected and desired that health professionals deal with the question of the risk of ver-

tical transmission. On the other hand, it was observed that developing this topic, if centered only on technical control, may work as a way of discouraging or even censuring pregnancy within the context of HIV/AIDS.

It is a cause for concern that, because health professionals' stance regarding pregnancy is foreseen, the subject is not brought up at consultations, as pointed out by one of the interviewees. Through fear of the reaction from the health professional, discouragement or condemnation of pregnancy, it could happen that Cleber and his wife have a child without prior counseling and guidance. They would return to the health clinic only after the pregnancy was confirmed, on the basis of the hypothesis that, once the pregnancy was in progress, the doctor would accept the situation without further discussion.

It is important to emphasize that, if explicit censure can "shut out" reproductive issues, the professionals' silence – with their authority (and power) that is bestowed by society – will preclude, or at least create an obstacle to dialogue within the scope of the health services.

If it were not for the hegemony of technical discourse, the question that would arise is whether men and women living with HIV would feel more at ease to make clear their reproductive issues to the health services. It also has to be asked why health professionals somehow conform to such silence.

Taking Douglas's reflections,⁵ it is possible to point out that the perceptions of both patients and health professionals are permeated by moral and social presuppositions that usually originate from their experiences, and which respond to different rationales.⁷

To treat the distinct positions of users and healthcare professionals as different rationales is totally different from taking this situation as indicative of a lack of rationality among the users in their perception of the risk of vertical transmission.

By supporting the existence of distinct rationales between individuals regarding the perception of risk, it becomes essential to understand the communication strategies and the negotiations between these individuals, instead of reducing the problem to a pedagogical one that can be solved by appropriate transmission of "technical" thought from the professionals to the "lay" users.

The search for technical success, such as HIV control, points to horizons on which any healthcare proposals are based. But users do not seek health services to obtain "technical success". What individuals seek is

practical success, i.e. the means to accomplish their broader plans for their lives.² This is why it is fundamentally important to create the possibility of sharing these two horizons within the space of healthcare. By continuing as parallel or contrary perspectives, in the way that was reported by some of the interviewees, the aspirations for both technical and practical success lose their best possibilities for full realization. Technical horizons lose the opportunity to achieve solid form as a type of discourse with meaning and interest for users, while practical horizons fail to benefit from the advantages that could be brought about by technical resources available.

By treating this question as a conflict within the plane of morality, it seems pertinent to mention Freitag,⁶ regarding the tragedy of Antigone. At the end of the book, some "ways out" from the conflicting situations are presented, based mainly on the discursive ethics of Habermas.⁸ The book makes it clear that it is important to understand the validity of rules by means of discussion and argument. It says that it is not "by hiding the true reasons for our actions that they become justifiable, but by exposing them, making them transparent for us and for others".⁶

The idea of care³ in its most radical sense seems to bring together the search for technical success by health professionals and the realization of practical success sought by users. However, putting together technical success by means of prophylaxis for vertical HIV transmission with people's plans for their lives and their reproductive plans when they are living with HIV depends upon dialogue interactions that will promote an efficient meeting point for these two true individuals: professionals and users.

In this sense, people's plans for their lives would be taken into consideration and would not be exclusively conditional on controlling the disease. Discourse regarding the risk of vertical HIV transmission or the prescribing of condoms might guide and not simply "shut off" reproductive issues. This would also provide an open dialogue about people's plans for their lives and happiness, in the search for ways to construct reproductive decisions involving greater solidarity, democracy and emancipation.

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