Living with the difference: the impact of serodiscordance on the affective and sexual life of HIV/AIDS patients

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RESUMO
Este estudo descritivo exploratório e qualitativo objetivou descrever e analisar o impacto da sorodiscordância na vida afetivo-sexual de indivíduos com HIV/AIDS que convivem em parceria heterossexual e soronegativa ao HIV. Foram entrevistados 11 portadores do HIV/AIDS que realizavam acompanhamento clínico ambulatorial em um hospital universitário-referência do interior de São Paulo. Os dados foram coletados através de entrevista individual gravada, e analisados segundo análise de Prosa. A vivência com a sorodiscordância ao HIV/AIDS impõe a esses casais o manejo de muitas dificuldades relacionadas à sua intimidade, dian- te da possibilidade de transmissão do HIV para o parceiro soronegativo, com impacto negativo na vivência da sexualidade entre parceros sorodiscordantes, repercutindo em alterações da resposta sexual humana, favorecendo até mesmo a abstinência sexual. Apontamos a necessidade de atendimento por equipes interdisciplinares junto aos portadores do HIV/AIDS e também de sua parceria sexual, proporcionando assistência integral, contemplando a sexualidade e as dificuldades advindas com a sorodiscordância.

KEY WORDS
HIV. Acquired Immunodeficiency Syndrome. Sexuality. Vulnerability

DESCRITORES
HIV. Síndrome da Imunodeficiência Adquirida. Sexualidade. Vulnerabilidade

RESUMEN
Este estudio descriptivo, exploratorio y cualitativo, tuvo como objetivo describir y analizar el impacto de la serodiscordancia en la vida afectivo-sexual de individuos con HIV/AIDS que conviven con pareja heterosexual seronegativa al HIV. Fueron entrevistados 11 portadores de HIV/AIDS que efectuaban seguimiento clínico ambulatorio en un hospital universitario a referencia del interior de San Pablo, Brasil. Los datos fueron recogidos a través de entrevista individual grabada, y analizados según análisis de Prosa. La convivencia con la serodiscordancia impone a tales parejas el manejo de muchas dificultades relacionadas con su intimidad, ante la posibilidad de transmisión del HIV al compañero seronegativo, con impacto negativo en la experiencia de la sexualidad entre parejas serodiscordantes, repercutiendo eso en alteraciones de la respuesta sexual humana y favorecendo hasta la propia abstinencia sexual. Se pone de manifiesto la necesidad de atención por parte de equipos interdisciplinarios para los portadores de HIV/AIDS y también de sus parejas, a fin de proporcionarles asistencia integral, contemplando la sexualidad y las dificultades derivadas de la serodiscordancia.

DESCRITORRES
VIH. Síndrome de Inmunodeficiencia Adquirida. Sexualidad. Vulnerabilidad
INTRODUCTION

Since its discovery, HIV/aids infection has been going through changes in Brazil and in the world regarding its epidemiological profile and natural history. Such feature imposes expressive challenges for its prevention and the full care for the health of infected patients. An important change that must be pointed out is the emerging HIV/aids chronic character in the last years.

Although there is no cure for aids, scientific progress regarding the diagnosis and, above all, the treatment with medication with the use of antiretroviral therapy propitiated a morbidity-mortality reduction and a significant increase in HIV/aids individuals’ survival. The disease has left the status of incurable, fatal and irreversible, and has become a potentially controllable chronic condition.

More efficient therapeutic resources availability has important implications for HIV/aids carriers, since they propitiate different life perspectives and generate new needs or enhance the existing, reinforcing the need for integral care for the health of this population.

Throughout those changes, it is possible that life projects were reconstructed after the discovery of HIV seropositivity. Some cases implicated in new love relationships with non-carriers of HIV/aids, called a serodiscordant couple.

Regardless, HIV/aids carriers’ sexuality understanding is still reduced. HIV carriers’ sexual behaviors have not received any attention for much time. Initially HIV infection diagnosis implicates in a death sentence. HIV/aids carriers’ sexual life seemed to be a secondary issue focused only on prevention. Studies on the sexuality of people living with HIV/aids were first carried out to find out about the factors associated with unsafe sex and to evaluate the efficiency of interventions that focus on altering that behavior. However, in comparison, little is known about the sexual experiences and adjustments of individuals living with HIV/aids.

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METHOD

This is a descriptive explanatory study, developed in a university hospital public clinic service in a city in the interior of the State of São Paulo. This study was carried out in a Specialized Care Service (SCS) with the objective to provide full care, through multidisciplinary teams for HIV/aids carriers.

Eleven HIV/aids carriers form both genders were interviewed. They were all part of the clinics and were going through medical-clinical attendance during the study. Individuals known as HIV/aids carriers participated in this study and lived with heterosexual partners with discordant serologic condition.

Considering the need for understanding and approaching sexuality in the health care context, and also the notorious lack of studies with HIV/aids carriers, especially with discordant couples, this study becomes absolutely necessary, since it has the objective of describing and analyzing the impact of serodiscordance in the sexual and affective life of HIV/aids carriers who live with heterosexual partners with discordant serologic condition.

Sexuality has very broad and diverse concept thinking. It is associated to habits, cultural behaviors, meanings and attitudes; it is related to each one’s personal history, constituting it into an inherent aspect to every individual. Sexuality is understood as the energy guiding the individual not only towards reproduction, but also towards pleasure, love and erotic feelings; it is the discovery of oneself and the other, femininity and masculinity, complementarities and the interaction between people. It is manifested throughout all individuals’ life phases, influencing all human relations, from birth till death. It is inherent to the individual and also determining of his way of being, manifesting, communicating, feeling, and expressing.

Considering that sexuality is a relevant dimension in human life, where sexual relations are connected not only to reproduction, but also to each one’s affection. It is fundamental to understand HIV/aids carriers’ sexuality in order to promote appropriate and humanized care for the health, breaking paradigms of the bio-medical care model for health and mainly focusing on biologic aspects of the care.

National literature provides studies regarding human sexuality in the nursing care context. Throughout the whole history, nursing has approached the client in general, as an “asexual” being, disregarding their sexuality and, paradoxically, it has one of the professions that have social permission to touch the body, including intimate areas, with the objective to promote basic hygienic care for individuals.

In the theoretic nursing discourse, sexuality is treated as a basic human need; however, critical and contextualized discussions are insufficient and when approached, they mainly contemplate biologic and reproductive aspects. The approach on sexuality requires enough knowledge mainly about its manifestation in the different phases of the cycle of life and the consequences resulting from infirmities, where patients deal with problems that routinely require professional help for solving them.

Considering the need for understanding and approaching sexuality in the health care context, and also the notorious lack of studies with HIV/aids carriers, especially with discordant couples, this study becomes absolutely necessary, since it has the objective of describing and analyzing the impact of serodiscordance in the sexual and affective life of HIV/aids carriers who live with heterosexual partners with discordant serologic condition.

The data collection technique used was an individual interview, recorded on tape, performed in a private office in the clinics, using a previously elaborated script with open and closed questions, performed by the researcher in this study. The data collection instrument was divided into questions about socio-demographic data identification and questions about their affective and sexual life.
Interviews were carried out on the same day as the previously booked medical appointment; the researcher would invite participants while they were waiting for the service. After their consent, the interviews were carried out after the medical or nursing appointment. Each meeting lasted in average 30 to 90 minutes. All interviews were fully transcribed and analyzed according to the discourse analysis proposal,[8] since they were pertinent for the objectives of this study.

This analysis is a way of investigating the meaning of qualitative data, a way to raise questions about the content of a certain material, including the intentional and non-intentional, explicit or implicit, verbal or non-verbal, alternative or contradictory messages. In the analysis first step, the construction of a categories system through the analysis of the material collected was used. It had the objective of identifying relevant topics, themes and patterns, featuring the topic as a subject and the theme as an idea. Themes involved a higher abstraction level than topics. After exhausting readings, the material regarding participants’ discourse were cut in discourse units and then their meanings were interpreted allowing for the construction of one Theme and four Topics, grouped by their thematic convergence.

The study was approved by the Research Ethics Committee of the hospital (protocol number 7656/2002). All participants were informed of the objective of this study and they signed a free and informed consent form. In addition, they all agreed to record interviews. When approaching the participant, their secrecy and anonymous feature was ensured in the study; therefore, all names presented in this study are fictional.

RESULTS AND DISCUSSION

In order to organize results, data were distributed as from speeches under a certain Theme: sexuality after HIV/aids infection between serodiscordant couples, and four Topics articulated to the theme: Fear of Sexual Transmission to the Partner, Sexual Response Alterations, Sexual Abstinence and Sexual Life Maintenance.

Theme 1 – Sexuality after HIV/AIDS infection between serodiscordant couples

Particularities of the HIV infection as transmissible and yet incurable, impose changes and adjustments in the relationship between serodiscordant couples. These changes impact the relationship and the couple’s affective and sexual behavior, leading them from sexual abstinence between them to denial attitudes regarding HIV/aids acquisition and transmission risks.

It is important to point out that these changes and adjustments impose many challenges to those couples and, even for those with more time of knowledge about the diagnosis and experience in a serodiscordant relationship, conflicts, fears, guilt feelings can arise, negatively impacting on living their sexuality.

Although aids is considered a chronic disease, with important possibilities for the carrier to enhance physical and emotional condition, they still face many challenges in the psycho-social scope, as stigma and prejudice, since its discovery has always been associated to deviant sexual practices according to social rules, compromising sexuality.

Parting from this theme, discourse analyses were grouped into four topics as follows.

Topic I – Fear of HIV transmission for the partner

One of the issues mentioned quite frequently by serodiscordance and that negatively impacts on sexuality between partners with different serology, regards the HIV infection transmission fear for the seronegative partner.

After the discovery of serodiscordance, couples experience difficulties related to sexual practice evidenced by fear and distancing since, in this situation, there is an infection risk through sexual intercourse.[7]

After HIV positive diagnosis, serodiscordant couples need to develop dealing strategies for sexual risk decreasing the tension between worrying about a possible infection and the desire to keep sexually active. Such strategies comprise from denial and rationalization (believing that they are immune to the virus) to very strict behavioral rules (using more than one preservative), leading to full sexual abstinence[9].

Every time we have sex, I tell him to stop so I can check; I have to squeeze it to be sure, then I see; I even tell him to change the condom. Every time the sex is over, I have to check and squeeze it to see if it something came out (Solange).

[...] I don’t feel comfortable with my wife, not the way I felt before, I feel like a stranger, not as a husband (Sandro).

[...] you get used to the condom, but the fear is always there… (Cláudio).

Acknowledging the possibility of HIV transmission is one of the questions that arose from serodiscordance, which is frequently present in the routine of carriers who live with different serology partners.

Being perceived as someone that brings danger for the sexual partner can generate great distress in the infected partner, in addition to feelings of guilt and anxiety. These emotional aspects have great importance and they negatively impact living sexuality. The following speeches emphasize this aspect:

[...] I got this woman from her family and then I will send her back with HIV, a disease… In my mind, things don’t match, my ignorance is huge, I am very afraid (Pedro).

I am afraid of transmitting it, afraid of passing it on to her, I will feel guilty, it is awful the way I felt, I already tried to leave him because of this (sex), he became very rebellious, sometimes I don’t even feel like having sex with him because
I worry, my mind is somewhere else, it is not where it should be, I worry about not harming him, he is a very good person (Solang).

[...] I am scared to death, can you imagine if I pass it on, how awful it is to go out with a person that is not a carrier...it is really weird. Imagine if I force him or convince him to do it and then he is infected, it has to be a spontaneous thing, then he will contract the virus and will hate me for the rest of his life (Antônia).

I am afraid of bursting the condom, of infecting my partner, it is a life. If I infect a person, it is a life that I am putting through suffering (Pedro).

Emotional aspects are factors that interfere in the pleasure and in living the sexuality. In face of that, how is the sexual intercourse quality between serodiscordant couples, since HIV transmission risk for the loved person is always present during the sexual relationship, in addition to negative feelings experienced in this serodiscordant relationship?

In order to deal with HIV sexual transmission, many strategies are used, as the use of two preservatives with the purpose to prevent HIV sexual transmission to the sexual partner. These strategies, even knowing they are not recommended, they can be observed between those who intend to keep sexually active, .

About tranquility, I use the preservative; actually I use two preservatives, because I worry about it bursting, because I have been through that, so I use two preservatives. My wife doesn’t like that I use two preservatives, but I am very categorical. It is not recommended, but I feel safer, because I have been through bursting a preservative, then I think, if one bursts, the other is beneath it, because then she is safe, because I am not the problem, the problem is if I pass it on to her, because I care for her, I love her and I don’t ever want this to happen (Marcelo).

The use of two preservatives is not recommended; actually it has been pointed out as a risk factor for bursting due to the friction between them, exposing couples to the risk of being infected by HIV. Between serodiscordant couples, a difficulty in the systematic use of condoms is demonstrated, whether for the trust in the device as a safe method for HIV sexual transmission prevention, whether for the alteration in the sexual satisfaction resulting from the mandatory use and also for the difference in acceptance between men and women related by gender relationships asymmetry[9,10], those questions demonstrate the limit of rationality in the preventive discourse and its limitation in the couple’s subjective scope[10].

Another question to consider is that the fear of HIV sexual transmission can be related to the lack of knowledge on the ways HIV can be transmitted, contributing for the fear of transmitting HIV to the seronegative partner while sexual intercourse, as reported below:

The fear is always there, because we don’t have knowledge like doctors do, in the beginning, for me, if my organs (genital) were wet, I would get worried (Claudio).

In face of these questions brought by serodiscordance, health services should also extend services to the seronegative partner, since the impact of seropositivity directly reflects in both their lives.

**Topic II – Sexual Response Alterations**

Sexual desire reduction can be caused by organic processes or psycho-social factors[11]. It tends to be a sexual problem when there is a high discrepancy between sexual interests levels between two people involved in the relationship. Moreover, any chronic disease can potentially inhibit sexual desire, impacting sexuality depending on the psychosocial adjustments of the disease. Among HIV/aids infection carriers, other studies point the negative dealing with sexual life due to both biologic alterations as tiredness, fatigue, diarrhea and emotional alterations that cause anxiety, major depressive disorder, isolation, tension, fear of rejection, insecurity and apathy[12-13].

Sexuality is quite compromised by HIV seropositivity impact and physical, emotional and social consequences associated to it, mainly among women carriers of HIV/aids[12], who after discovering about the HIV diagnosis, experience uncertainty, insecurity feelings characterized as a moment of crisis[12-13].

Being HIV/aids seropositive with a seronegative partner implies in protection care strategies. These care strategies can be perceived in the reports, showing that serodiscordance interferes in the sexual and affective relation, introducing fear in the sexual relation that is now seen as dangerous, blocking the joyful and satisfying sexual activity.

Among the investigated individuals, alterations in the sexual response was identified, manifested by desire and sexual stimulus inhibition, in addition to the reduction and absence of orgasmic sensations, as we can observe in the following speeches:

With the preservative she (the partner) never reaches an orgasm, on the contrary. Sometimes not even me, because of the sensibility, sometimes it is delayed and I already have had times when I don’t reach it (Rogério).

We had never used it (condom) before; it upsets me to use a preservative. So, to tell you the truth, I don’t feel at ease with my wife. Ok I will use it, but sometimes I put it on and then I cannot keep the sexual intercourse (Sandro).

[...] We had a reduction in the frequency, pleasure, we both reduced part of the care, in a way, we sometimes avoid having sex (Rogério).

[...] Sometimes we go through three, four days without that pleasure, that desire, we don’t have the same intimacy as before (Sandro).

I don’t even like to have sex with him, I do it worried about the condom, if it will burst or not (Solang).

[...] I don’t feel at ease with the wife, not the way we were before, I feel like a stranger, not like a husband (Sandro).
...) We use to do it more often, maybe it's because of the shock, because in the past, we use to do it (sex) with all that freedom and now, knowing about this problem, sometimes we accumulate that in our head, I don't know, it's psychological too (João).

We can identify the emotional aspects that contribute for these alterations, as the negative feelings related to a possible transmission to the loved person, emotional aspects originated from seropositivity, in addition to distancing the couples and of the affection ties between them.

Those changes occur mostly due to difficulties in adjustment both for seropositive and seronegative partners due to that new reality experienced by the establishment of a serodiscordant relationship.

Sexual desire is marked by a low level of sexual receptivity, which may generate problems in the relationship, since not being receptive to the partners’ sexual needs makes the partner feels frustrated, rejected, isolated and, the non-receptive partner, on the other hand, feels guilty for not feeling up to satisfy the other's needs.

Among factors that are directly involved with these alterations, we can mention the mandatory use of preservatives, the fear of HIV transmission, since it regards a relationship with a person with a different HIV serology. Moreover, low self-esteem and devaluing stand out, the distress of living with the possibility of an HIV transmission to the loved person, and the guilty feelings as the negative impact aspects that interfere with living the sexuality.

Although the use of preservatives is seen as necessary to avoid HIV sexual transmission to the seronegative partner, the investigated individuals point to its use as one of the interfering factors on sexual satisfaction. It is seen as a barrier for the couples’ intimacy, interfering in the pleasure and sexual satisfaction, making acceptance difficult.

Those couples who were built before the discovery of HIV show more difficulty in using the preservative, mainly when it is not even experienced anymore (14).

In a study carried out in the city of São Paulo that investigated the sexuality of women carriers of HIV/aids also points to avoid sexual intercourse. The feeling of rejection among HIV carriers is common along with the fear of getting infected by the partner. These facts interfere in the intimacy, affection and sexual activity.

In the past, it was normal, just like every couple. Now, I don’t have sexual relations with my husband, it is the craziest relationship I’ve ever seen in my life, because it is perfect during the day; at night, we watch TV (Antonia).

We have no sexual relationship at all…we have distanced because of HIV, I don’t go after her and she doesn’t come after me anymore. Sometimes, I have tried with her, I cherish her, care for her, but her coldness hurts me even more, you feel no married life anymore (Pedro).

After the discovery of HIV serodiscordance, the relationship is filled with care to protect the other, and the fear of being infected by the disease in each sexual act is a feeling experienced by couples that brings distress and suffering.

[...] sometimes we are at the high point of the relation and she (the wife) looks 4-5 times, scared that it might burst or tear. It like that every second, she is looking at it, she has no trust, she uses the preservative, but she has no trust that she is not in danger, not at risk (Sandro).

[...] She is really scared, we used to discuss watch it if it bursts (preservative), but it is not the same, you are there, but your mind is somewhere else, it’s not the same thing, any motive is a reason for worrying her (Pedro).

[...] He (the husband) is totally afraid of being infected, I think it’s funny, because he says he isn’t, he doesn’t like to talk, he doesn’t show it, but he is really scared… a scared person 24 hours next to you (Antonia).

In a study carried out in the city of São Paulo that investigated the sexuality of women carriers of HIV/aids also points
out that the fear for HIV transmission is one of the main reasons reported to worsen sexual life(14). Another study with 148 women living with HIV/aids also pointed that more than half of the women interviewed were in sexual abstinence since they found out about HIV seropositivity(16).

Among serodiscordant couples, this question is even more marked, since it became evident that fear is shared between partners, generating conflicts in the relationship when the need for sexual satisfaction is different between partners, implicating in a lack of trust.

[... ] I tried to talk to her many times, because she is different, why is she acting like that with me, I am aware that a women cannot be two years without having sex with a men… (Pedro).

It is important to mention the risk of sexual transmission in penetrating sexual practices. Moreover sexuality goes beyond genitality; it is only one of its aspects. Other ways of sexual expression can be motivated between serodiscordant couples(5).

Therefore, regarding serodiscordant couples, it is not enough for them to have access to high quality preservatives, it is evident that health professionals must be prepared to help people who live and experience serodiscordance, considering its psychosocial aspects originated from its presence in the personal life and in the sexual and affective relationship.

The way to deal with sexuality will depend on the support and counseling that carriers receive in the process. An approach based on dialogue about the clients’ decisions is fundamental(15).

Changes must occur in professional practice to provide that so that they can affectively act in an interdisciplinary work, going beyond not only the biologic sphere of the disease and medication adherence, but also its impact and psychosocial implications(10). Interdisciplinary service for serodiscordant partners promotes the integration between the team and patients, favoring the link and the support, both fundamental for therapeutic success(17).

**Topic IV – Sexual life maintenance**

Sexual and affective life ending or restriction can be occasional or everlasting, because the serodiscordant couples’ relationship goes through difficulties and fears. Regardless, after difficulties are experienced with the discovery of HIV seropositivity, many individuals are able to rebuild their professional life and also their sexual and affective life.

Even with distress coming from the seropositive diagnosis and the experience of a serodiscordant relationship, some HIV/aids carriers search for keeping the affective and sexual life.

The diagnosis is not going to keep me from having a sexual life, my life will still be normal, both mine and hers, this problem we have will not get in the way of our relationship (João).

I have a normal life, it’s not because of this problem that my life will end, my life is still the same, I must have my pleasures the same way I had before (Mário).

How do we live with someone without a sexual life? (Cláudio).

With aids chronic characteristics growing, it is even more common to see serodiscordant couples. The discovery of seropositivity made couples develop strategies to deal with the sexual risk in order to reduce the tension between worrying about a possible transmission and the desire of keeping sexually active(10); however, we found only a few studies carried out about the theme and the lack of specific specialized services for this population, when a lack of continuous preventive/educational actions and counseling guided to the full care for HIV/aids carriers and their partners is observed with a view to enhance the quality of life of those individuals. However, it must be a compound search both for the people living with HIV/aids and health professionals with the objective of providing care appropriately covering the sexuality aspect.

**FINAL CONSIDERATIONS**

Discovering that one of the partners is an HIV/aids carrier imposes the couple to handle many difficulties regarding their intimacy, mainly derived from the possibility of HIV transmission to the seronegative partner. For those couples who intend to keep sexually active, the question of risk and protection of the seronegative partner regarding the HIV infection experienced by serodiscordant couples is a problem. Therefore, health professionals must be prepared to help those individuals face their problems.

In order to provide a full approach for the needs of serodiscordant couples, the health team must be prepared to help them overcome difficulties in the sexual scope. The team must work the emotional aspects that interfere in the sexual pleasure quality, searching for demystifying the meaning attributed to aids, working with the guilt that many carriers feel regarding sexuality, helping them to deal with the fear of sexual transmission and HIV infection, facilitating the dialogue between couples by creating opportunities for the discussion between the team and the couples.

For those couples who choose sexual abstinence, health professionals must respect their decision, focusing on the fact that sexuality goes beyond the genital aspect, and that other ways of pleasure that offer no risk of being infected by HIV can be sought.

Understanding the difficulties of serodiscordant couples in the sexual and affective scope and help them to deal with them is to respect the individual going beyond his se-rologic condition and the HIV sexual prevention question, considering them as human beings with individual and subjective needs for living sexuality.
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