Feelings and conflicts of women living with HIV/AIDS: A literature research

CONFLITOS E SENTIMENTOS DE MULHERES PORTADORAS DE HIV/AIDS: UM ESTUDO BIBLIOGRÁFICO

CONFLICTOS Y SENTIMIENTOS DE LAS MUJERES PORTADORAS DE VIH/SIDA: UNA INVESTIGACIÓN BIBLIOGRÁFICA

Maria Luciana Botti¹, Maria Angélica Pagliarini Waidman², Sonia Silva Marcon³, Maria José Scochi⁴

ABSTRACT
This is a literature review with the purpose to identify how the conflicts and feelings of women living with HIV/AIDS are addressed in the national literature, and the proposed pathways for an integral care approach. Data were collected in November, 2006, in the LILACS database, using the following keywords: women, feelings, HIV, AIDS, suffering, depression and fear. The inclusion criterion was that these studies should have been published in the past five years. The sample was made up of 14 studies (four dissertations, two theses and eight articles). The content analysis method allowed for the identification of three thematic categories: the researcher’s perspective, what their perspective identifies and their perspective beyond the physical body – which reveal the necessity of addressing women considering their whole context as human beings, including issues of vulnerability, social gender ideology and the promotion of self-esteem and citizenship.

RESUMO
Pesquisa bibliográfica que buscou identificar como os conflitos e sentimentos das mulheres portadoras de HIV/AIDS são abordados na literatura nacional e os caminhos propostos para uma abordagem de cuidado integral. Os dados foram coletados em novembro de 2006, na base de dados LILACS, utilizando as palavras-chave: mulheres, sentimentos, HIV, Aids, sofrimento, depressão e medo e como critério de inclusão o fato de os estudos terem sido divulgados nos últimos cinco anos. A amostra ficou constituída de catorze pesquisas (quatro teses, duas dissertações e oito artigos). O método de análise de conteúdo permitiu identificar três categorias temáticas: o olhar do pesquisador, o que seu olhar identifica e o seu olhar para além do corpo físico – as quais revelam a necessidade de abordar as mulheres considerando todo o seu contexto enquanto ser humano, incluindo questões de vulnerabilidade, ideologia social de gênero, promoção da auto-estima e exercício da cidadania.

RESUMEN
Se trata de una investigación bibliográfica que buscó identificar como los conflictos y sentimientos de las mujeres portadoras de HIV/SIDA son abordados en la literatura nacional y los caminos propuestos para un abordaje de cuidado integral. Los datos fueron recogidos en noviembre de 2006, en la base de datos LILACS, utilizando las palabras clave: mujeres, sentimientos, HIV, Sida, sufrimiento, depresión y miedo y como criterio de inclusión la divulgación del estudio en los últimos cinco años. La muestra fue constituida de catorce investigaciones (cuatro tesis, dos disertaciones y ocho artículos). El método de análisis de contenido permitió identificar tres categorías temáticas: la perspectiva del investigador, lo que su perspectiva identifica y su perspectiva más allá del cuerpo físico – las cuales revelan la necesidad de abordar a las mujeres considerando todo su contexto en cuanto ser humano, incluyendo cuestiones de vulnerabilidad, ideología social de género, promoción de la autoestima y ejercicio de la ciudadanía.

KEY WORDS
Women. Emotions. HIV. Acquired immunodeficiency syndrome. Women’s health services.

DESCRITORES

DESCRIBUTORES

¹ Nurse at the Municipal Outpatient Clinic for STD/HIV/Aids. Municipal Health Secretary of Maringá. Master in Nursing. Maringá, PR, Brazil. malumbotti@yahoo.com.br
² Nurse. PhD in Nursing Philosophy. Professor of the Nursing Department at the State University of Maringá. Maringá, PR, Brazil. angeliwaidman@hotmail.com
³ Nurse. PhD in Nursing Philosophy. Professor of the Nursing Department. Coordinator of the Nursing Masters Program, State University of Maringá. Maringá, PR, Brazil. ss.marcon@uem.br
⁴ Nurse. PhD in Public Health. Professor of the Nursing Department, State University of Maringá. Maringá, PR, Brazil. mjscochi@uem.br
INTRODUCTION

Understanding the interface between science and care means accepting the existence of possibilities in view of paradigms that are commonly treated as independent: on the one hand, science, conditioned to the positivistic standards and distant from daily nursing practice; on the other hand, care, justified by the humanistic philosophical precepts. Although proclaimed as the object of nursing actions, care is established as empiric knowledge, in a lower dimension than scientific knowledge.

Such segregation between science and care makes it difficult to comprehend complex social phenomena like the AIDS epidemic, characterized as such because it can be conceived, at the same time, as cause and effect of the social relationships, revealing prejudices and stigmas, associating the serologic condition for HIV to the incapacity and social segregation of men, women and children.

This context signals the need to involve science and care in order to cope with the problems of AIDS, because it represents an increased chance of success in the search for solutions for its prevention and control. Care, understood as respect for differences and vulnerabilities, permits the approaches needed to prevent transmission due to the notion of risk – which is culturally outlined, making most people consider themselves out of risk – as well as the acceptance of the human condition, especially regarding sexuality, necessities and weaknesses. Science, in this context, is referred to by means of scientific production, which, once published, allow for its socialization, addressing the prevention of HIV transmission and control of AIDS.

HIV and AIDS, present for nearly three decades, still cause different reactions, especially regarding the psychosocial aspects. It requires discussion, in addition to biophysiological issues, that have been widely researched and published. The scientific production about HIV and AIDS has been noted in several national and international journals.

Questions and reflections about how science and researchers have been involved in scientific production about AIDS raised our interest in developing the present article, which is justified by four considerations: a) the interests that lead the researcher to direct their work towards AIDS; b) areas with a biologist bent are closer to the theme, when compared with areas dealing with social and human sciences; c) when psychosocial aspects are addressed by studies in the healthcare field, they are usually frowned upon and are poorly received by the scientific community; d) the approximation with reality can lead the researchers away from the themes that could include them as vulnerable individuals.

The reported conflicts are subjective, they are linked to the condition of being a carrier of the virus, in a perspective beyond the existence of the virus in the blood, i.e. the serological situation goes beyond the biophysiological issues, transcending the body and involving the psyche.

Another motivation that is no less significant for this study arose from reports of women who live with HIV. When providing care to these women, it is observed that, although the reported conflicts are subjective, they are linked to the condition of being a carrier of the virus, in a perspective beyond the existence of the virus in the blood, i.e. the serological situation goes beyond the biophysiological issues, transcending the body and involving the psyche, i.e. the dynamic and energetic strength of human existence – the soul of these women.

That is the perspective surrounding the interest in verifying the existence of articles and studies which, in addition to epidemiological, physiopathological and treatment issues, address the psychosocial aspects experienced by the HIV/AIDS carriers, with the following guiding question: What support does scientific production in the healthcare area provide regarding the conflicts and feelings of women with HIV/AIDS that can offer perspectives that look beyond the physical body?

Intent on responding such a question, this study was proposed, with the following objectives: a) identifying how Brazilian scientific journals in the healthcare field deal with the conflicts and feelings of women with HIV/AIDS, in order to know the pathways that will facilitate care for these women; b) knowing theories and methods used by researchers in studies about this theme to identify the directions that could involve care beyond the physical body of women with HIV/AIDS.

METHOD

By allowing further developments in texts about the theme in a systematized and critical way, we chose to use the literature review as an investigation method to answer the guiding question. Literature reviews are usually used to explain a problem with theoretical references published in documents, attempting to know or analyze existing cultural or scientific contributions about a given topic or theme.

One of the advantages of literature reviews is that they allow researchers to cover a wider range of phenomena than by a direct research. For so, some steps are recommended: 1) searching for material in library catalogues; 2) selecting texts according to the objectives; 3) text reading; 4) taking notes only after having read the text critically; 5) transcription of the exact and useful data regarding the research theme; 6) recording any critical idea or personal conjecture that emerges during reading, to be verified and reflected upon later; 7) adequate mentions of the sources in the research report, avoiding the problem of inadequate use of material, as this characterizes violation of Brazilian and international copyright standards(7).
The selection of material was performed through a systematic search in the LILACS (Literatura Latino-Americana e do Caribe em Ciências da Saúde) database in November 2006, using the following keywords: women, feelings and AIDS; women, feelings and HIV; women, conflicts and AIDS; women, suffering and AIDS; women, depression and AIDS; women, fear and AIDS, considering that the studies should have been published in the past five years. This resulted in 419 articles.

The initial result was analyzed and selected, removing items that were not specifically scientific studies or that were repeated in the different keyword groups researched. Later, a database was organized with the bibliographic references and abstracts of each article, according to their availability in LILACS.

This material was again selected, through reading and analysis, considering the following inclusion criteria of the scientific production: a) addressing the theme: conflicts and feelings of women with HIV and AIDS; being a study produced in Brazil; b) being an article published in an indexed journal, a master’s thesis or a doctoral dissertation.

The final sample, after successive selections, consisted of fourteen studies. Four of them were doctoral dissertations, two were master’s theses and eight were articles published in Brazilian journals. In order to organize the results, a spreadsheet was elaborated with the information, objectives, theoretical references, methodological framework, situation found, associated factors and answers, as shown in Chart 1 (Annex), which later helped for the content analysis.

Reading, classification and recording of the information and contents regarded: a) identification data: title, author(s), the school where the study was presented or the journal where the material was published and the year of presentation or publication; b) objectives; c) theoretical frameworks; d) methodological frameworks; e) contextualization, meaning situations experienced by the women and factors associated with these experiences; f) answers to the guiding question.

Since content analysis is characterized as a group of methodological instruments that can be applied to very different communication elements, it was used to handle messages to evidence references, which would in turn allow for inferences about other realities than that of the message(3).

This type of analysis has two functions, which may (or may not) dissociate when put into practice. The first regards the heuristic function, i.e. content analysis makes the exploratory attempt richer and increases the likelihood of discoveries; and the second refers to the administration of the proof, in which hypotheses worded as provisory questions or statements serve as guidelines, appealing to the method of analysis of confirmation or information(3).

In this article, content analysis uses both functions, because they are both presented as the exploratory process of the bibliographic research and establish assumptions for the guiding question of the study.

RESULTS AND DISCUSSION

Data analysis permitted finding relevant themes that support the elaboration of the thematic categories: the researcher’s perspective, how the researcher observes, what the researcher’s perspective identifies, and looking beyond the physical body.

The researcher’s perspective

• First aspect – Vulnerability related to women with HIV/AIDS from the gender perspective.

Female vulnerability has been marked by the subordination of women to male desires, determined by conflicting relationships with their own sexuality. The female identity is built from cultural and social determiners that reinforce love as a sort of protection, establishing risks for sexually transmissible diseases and AIDS. As such, the researchers’ concerns in understanding the vulnerability of women can be observed, illustrated by the objectives of a few studies: Describing how women with HIV perceive their vulnerability at the probable time of infection and understanding the difficulties to prevent the sexual transmission of HIV before and after diagnosis(4); Characterizing individual vulnerability in relation to practices and attitudes about the sexuality of female students in the first year of courses at a university in Rio de Janeiro, aiming to support preventive interventions related to HIV transmission(5); Perception of risk of infection in women infected by HIV(6).

Gender relations and social roles, in a way, determine the health and disease of women, since they influence their behavior regarding self-care. Motherhood, for example, stated as a very strong element of female identity and culture due to its link with the body and nature, in times of AIDS, is characterized by fear and guilt. Several women ignore their serologic status for HIV, as well as possibilities of vertical transmission. It is not rare to find women who discover about their seropositivity in the pre-natal, delivery and post-partum periods.

Investigating the social and cultural derivations regarding gender and presence of HIV in the life of women is a topic of interest, according to the objectives of certain studies: Comprehending the impact that HIV infection has on the lives of thousands of women, especially regarding such a fundamental aspect of the lives of women as HIV motherhood(8); Identifying attitudes and feelings among HIV-positive pregnant women(9); Studying, among HIV-positive women, the feelings associated to motherhood and orphanhood, when they became aware of their serologic condition.

• Second aspect: The programmatic organization

The analysis of the vulnerability to HIV infection addresses three dimensions: individual, social and programmatic vulnerabilities(10). The programmatic vulnerability, in turn, is defined by the three main elements of prevention identified by the WHO: 1) information and education; 2)
social and healthcare services; 3) non-discrimination of people with HIV/AIDS.

The programmatic plan refers to the existence of institutional actions that are specifically focused on the AIDS problem, covering aspects like: a) commitment of local authorities to face the problem; b) actions effectively proposed by said authorities; c) inter-institutional and inter-sector coalition (healthcare, education, social welfare, labor) for specific actions; d) planning actions; e) management of said actions; f) involved institutions being able to respond; g) adequate and stable financing of the proposed programs; h) continuity of the programs; i) assessment and feedback for the programs, etc. The studies addressing programmatic vulnerability have the following objectives: Understanding the necessities of care regarding reproductive health in the perspective of the carriers and describing the stigmatization and consequent violation of their rights, present in the attitudes of the healthcare professionals and standardization of healthcare models (12); Identifying, in reports of HIV-seropositive women who abuse drugs, elements to support the development of Prevention and Orientation Programs for DST/AIDS focused on this social group (12).

• Third aspect: The daily life of women with HIV/AIDS

With the evolution of treatment and the availability of anti-retroviral therapies, people with HIV are able to maintain their health for years. However, the existence of misconceptions in society about HIV/AIDS and the forms of transmission result in a life surrounded by stigmas, usually becoming stressful and difficult.

Women with HIV/AIDS can be faced with hostility and rejection, even from those who are closest to them. They are still at risk of losing their jobs, their families or important social relationships; immersed in this context, the difficulty to speak about the diagnosis and express sexuality becomes constant.

With the experiences of women with HIV/AIDS, the studies analyzed provided support that allows for reflections about the need for social and cultural transformations in relation to coping with the stigma, which can be observed in the objectives: categorizing and describing daily sources of stress of women who carry the HIV virus (13); Assessing the quality of life of women with HIV/AIDS (14); Identifying and describing coping strategies for women with HIV/AIDS (15).

How the researcher observes

• First aspect: Methodological approaches

The methodological choice to perform a given study can demonstrate how the researcher attempts to explain a given phenomenon. Through the pathways chosen for the explanation, it is possible to recognize the comprehension of the method used and the coherence in its application, in order to achieve the proposed objectives. As such, a method is justified and established as the objects are achieved by means of said method, by highlighting one or more of its aspects, an approach that permits a better apprehension of the studied reality, even to the extent of producing knowledge that is capable of transforming it (16).

By definition, qualitative and quantitative approaches in research contain groups of interpretative practices named methods, which, in theory, are not bound to a single field of knowledge, understood as the border area for the manifestation of scientific production processes (17).

Out of the 14 studies analyzed, seven used a qualitative approach (10, 12-13, 15, 20), five were quanti-qualitative (10, 12-13, 15, 20) and two studies were quantitative (15, 14).

Quantitative studies are meant to bring observable data, indexes and tendencies to light. They must be used to cover, from a social point of view, a great amount of data, such as demographic groups for example, classifying them and making them intelligible through variables (14).

In the context of the qualitative approach applied to the Healthcare Sciences, the conception that is usually employed comes from the Human Sciences, i.e. the researcher attempts to understand the individual or the collective meaning of the phenomenon, instead of studying the phenomenon itself. By transferring the conception to the healthcare areas, it is indispensable to know what certain phenomena, such as diseases and life, represent for people.

For the context of the Human and Healthcare Sciences, a generic definition of qualitative methods presented by two sociologists is transcribed and usually quoted in literature: Qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them (19). Qualitative analysis might not quantify. On the other hand, there is nothing in quantitative analysis that would eliminate the need for new qualitative analyses. The opposition of quality and quantity becomes a fact, and integration is unavoidable (17).

• Second aspect: The theories that support the discourse

The theories should involve principles and concepts that are coherent with the research or study they support. As such, the theoretical framework should be compatible with the treatment given to the problem and the reasoning developed. Distinct theories were found in the studies, aiming to clarify the research themes, which could be grouped in two main approaches.

The first of these is linked to the research theme – beyond the physical body. It was identified that the theoretical frameworks used come from the human sciences, such as social psychology, psychoanalysis and sociology, and these were: Theory of crisis and process of solving problems; Stressful events; Ways of coping with problems; Mechanisms of defense; Post-structuralist perspective of the cultural studies, supported in the contributions of Michel Foucault – using the allegory of the blanket and Sexuality (20).
The second approach refers to gender issues, especially regarding women’s vulnerability in relation to HIV transmission and falling ill from AIDS. For so, the references used were: Women’s subjectivities; Gender and stigmatization; Gender and vulnerability approaches; the historical dialectic materialistic concept and Marxist feminism; Quality of life and women with HIV/AIDS and The concept of vulnerability to HIV infection.

Gender can be understood as a form of ideology. Its conceptions are built throughout society, occurring in the different narratives experienced. Concerns about gender-related processes are justified because they influence behavior, thoughts and feelings of the individuals, affect their social interactions and help to determine the structure of the social institutions.

What the researcher’s perspective identifies

Above all, researching means to become disquiet; it means questioning reality, searching for answers that are often temporary. With these answers, new disquieting thoughts emerge and become established. Consequently, it is necessary to search for new answers and explanations. In this process, the researcher seeks, at first, intellectual and theoretical partnerships, highlighting the theory; however, the object is only unveiled in the interface between the theoretical framework and the reality found in the research field.

The many problems found in the world of women seem even more numerous when AIDS is considered. Some studies describe the context of this encounter as: crises; stress; exclusions; being abandoned by the family; damaged quality of life.

In addition to several problems present in the reality experienced by the women with AIDS, the concern of the researchers in verifying the social function of the women changed by AIDS should be noted, either by the coping strategies of women with HIV/AIDS; the attitudes and feelings of HIV-positive pregnant women, influenced by deep issues in relation to being a mother and not being able to breastfeed, the possibility of bearing a seropositive child or even the necessity of planning the orphanhood of the child.

Looking beyond the physical body

The support offered by literature in the healthcare area regarding the conflicts and feelings of the women with HIV/AIDS that can take the research beyond the physical body of these women point to the perspective of integral care: offering care that integrates all healthcare moments; pregnancy and HIV demand integral care for seropositive women: incorporating sexuality with a gender perspective and the promotion of human rights, such as sexual and reproductive rights.

As such, care is regarded as a means for social maintenance or re-inclusion, adopting citizenship as a guiding axis. The notion of social care is presented as a form of healthcare, countering the mechanisms of exclusion and stigmatization. Encouraging emotional support groups; Creating support groups for relatives and partners: Discussing projects that will bring income; Ethical and constitutional obligation to promote reproductive rights.

With the involvement of the families from the moment the patient is informed of the diagnosis, the compliance of those women with treatment and the reduction of the prejudice related to the problem become easier. When we associate the patient, their relatives and the healthcare team, it results in a therapeutic process, where everybody takes responsibility for monitoring these women.

Integral care also involves prevention, i.e. the programs, campaigns and information should be able to reach the singularity of the individuals. The experiences with prevention that have been occurring in centers specialized in care delivery to HIV carriers rarely incorporate the comprehension of the sociocultural aspects that can increase vulnerability to HIV and to falling ill. Services are still organized to cover biomedical and educational facts centered on the ways of transmission and promotion of protective instruments (condoms, abstinence, single-use needles, etc) or the clinical control of infection and compliance.

Intent on reviewing the forms of the programmatic approaches, some researchers highlighted the importance of prevention as a form of care and development of citizenship: HIV prevention among women should also include, in addition to strategies to pass on information and reproductive and sexual healthcare, strategies that will strengthen the individual, reinforce self-esteem and stimulate autonomy in general.

With a view to differentiated and responsible coping regarding sexual and reproductive healthcare, the researchers highlight the need for healthcare professionals to understand gender issues.

The dimension of gender relations and respect for diversity in the many sexual orientations has been incorporated in several prevention actions, but gender is still regarded as something singular, with female as a synonym of oppression to women; preventive actions do not further the issues of the impact of gender relations in the increased vulnerability of men. Dissolving the myths of the image of the new woman and unveiling how gender ideologies cloud, in the capitalist model, the increasing exploitation of the productive and reproductive work of the working-class women. Denaturalizing the experience of maternity, showing how the conditions to have and raise children are socially different and unequal.

The transformation of healthcare professionals is expected and indispensable. A limited look defines actions that devalue the influence of socioeconomic and cultural structures. The consensuses about how to mediate patients, quickly taught in a prescribing attitude of ready-made
models of behavior, or the marketing campaigns of condom use financed with public money (instead of the industry that profits from it) have not been enough to produce the changes that are necessary to attain significant results in relation to integral care beyond the physical body[24].

Some of the analyzed studies demonstrated concern with this scenario, as shown by the following excerpts:

[...] Identifying the updates in medical ideology in the reproductive field; in the case of HIV+ pregnancy, this is evident in the mission of saving babies, reproducing the gender ideology that naturalizes women in their maternal role[7];

[...] using different professional instruments and methodologies is necessary to allow for different approaches to the study object, favoring professional practice and the production of knowledge[27];

Furthering questions, crossing mirrors, walk among the spaces, break binary patterns, the rigidity of identities, crossing the power/knowledge/truth games[10];

Identifying contradictions and conflicts... which enables the social subjects to give new meanings to their representations, experiences and practices, both professional and in life, pointing to the possibility of transformations in the healthcare model and practices related to health[7].

The social representations of seropositive men and women are dimensioned in two axes: objective and subjective. This characteristic can be explained by the gender differences, which influence the perception and behavior when one is faced with life[26]. For example: among men, there is a predominance of objective elements, i.e. AIDS is shown as a disease that causes fear, brings limitations and demands a new beginning in life, needing help. For women, there is a predominance of subjective elements, with AIDS being represented as a disease wrapped in prejudice, which brings suffering and for which a hope of health is sought. Death is seen as terrible, pre-planned, slow, fearful and discriminating by women[26].

In general, suffering involving fear, prejudice, abandonment, gender differences, guilt and exclusion is still constant among people with HIV/AIDS. As such, it is necessary to find strategies to help them and their families in their processes of coping, acceptance and naturalization of the situation. Professionals need to show concern with the non-biological aspects that interfere in the transmission chain and in life with the disease, since the mental, emotional and social aspects of the epidemic are sources of great suffering for the carrier. Surely, the benefits obtained from the control and extension of life change the carrier’s perspective, showing the need to search and find strategies that will provide these people with more quality of life, because emotional and mental aspects influence the quality of their health[11]. In spite of the therapeutic evolution and its direct reflex in the reinterpretation of AIDS, it can be observed today that, ever since its discovery, it has been associated with death and all the pertinent suffering.

**FINAL CONSIDERATIONS**

This article identified respectable contributions of scientific production in the healthcare area about the conflicts and feelings of women with HIV/AIDS, which may support a perspective that looks beyond the physical body.

Although the studies found are scarce, they showed coherent concerns, especially when dealing with the ethical, reproductive health and human right dimensions. They note the necessity of sociocultural approaches that consider indispensable themes for the social gender ideology, promotion of self-esteem and citizenship.

By reflecting on the findings, it was verified that the scientific paradigm based on the biologist approaches, looking only at the physical body, is not capable of covering the complexity of the social phenomenon of AIDS. As such, its connection with the paradigm of care is noteworthy, since both paradigms seem to be complementary.

**REFERENCES**


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**ANEXO**

**Chart 1 – Aspects analyzed in the studies included in the study - Maringá, PR - 2006**

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<td>Objectives</td>
<td>Describing how women with HIV perceive their vulnerability at the likely time of infection and understanding the difficulties of preventing the sexual transmission of HIV before and after the diagnosis.</td>
<td>Perception of the risk of infection in HIV-infected women.</td>
<td>Studying the feelings associated to motherhood and orphanhood in HIV-positive women when they became aware of their serologic condition.</td>
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<tr>
<td>Theoretical Framework</td>
<td>Female subjectivity and seropositivity (Knauth, 1999)</td>
<td>Sexuality (Foucault e and post-structuralist authors).</td>
<td>Defense mechanisms of the ego against painful or unbearable ideas or feelings (Anna Freud, 1974).</td>
</tr>
<tr>
<td>Situation found</td>
<td>Exclusions</td>
<td>Faithfulness, trust and belief.</td>
<td>Motherhood and orphanhood</td>
</tr>
<tr>
<td>Associated Factors</td>
<td>Personal difficulties, symbolic difficulties and economic difficulties.</td>
<td>Loving relationships.</td>
<td>Motherhood: Right and feeling of being a mother, not being able to breastfeed and delivering a seropositive baby. Orphanhood: Planning for situations of disease or disease and feelings in relation to the child's orphanhood.</td>
</tr>
<tr>
<td>Answers</td>
<td>HIV prevention programs must consider psychological, socioeconomic and cultural aspects. Using psychoeducational approaches.</td>
<td>Although the pacts between couples are fluid and with the possibility of changes, women try to give meaning to their amorous territory by believing in and trusting their partner's faithfulness.</td>
<td>Mechanisms, such as compensation, denial, rationalization and projection, acted to minimize unconscious feelings of guilt.</td>
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