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INTEGRATIVE REVIEW ARTICLE

PERCEPTION OF HIV-POSITIVE WOMAN ABOUT PRENATAL CARE AND PUERPERIUM: INTEGRATIVE REVIEW

PERCEPÇÃO DA MULHER HIV-POSITIVO ACERCA DO CUIDADO PRÉ-NATAL, PARTO E PUERPÉRIO: REVISÃO INTEGRATIVA

PERCEPCIÓN DE VIH-POSITIVOS DE LA MUJER SOBRE CUIDADO PRENATAL Y PUERPÉRIO: REVISIÓN INTEGRADORA

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ABSTRACT

Objective: to identify the contribution of studies in national and international level, on the perception of HIV-positive women about prenatal care, childbirth and postpartum. **Method:** integrative review with a view to answering the research question << What produced scientific knowledge is there on national and international level on the perception of HIV-positive women about prenatal care, childbirth and postpartum?>> The data was collected in MEDLINE, LILACS, BDNF and CINAHL databases in the period 2003 to 2012, 20 studies were selected and analyzed. **Results:** there are positive and negative perceptions of the care received. The care received by women is of utmost importance for the promotion of their health and protect the health of their children, as well as directly to the need for greater involvement of health professionals about the care of HIV-positive women. **Conclusion:** there is a need to conduct further studies in order to further develop these issues that can contribute to improving the quality of life of these people. **Descriptors:** Perception; Nursing Care; Prenatal Care; Childbirth; Postpartum Period.

RESUMO

Objetivo: identificar a contribuição dos estudos desenvolvidos em âmbito nacional e internacional, sobre a percepção das mulheres HIV-positivo acerca do cuidado pré-natal, parto e puerpério. **Método:** revisão integrativa com vistas a responder a questão de pesquisa << Qual o conhecimento científico produzido em âmbito nacional e internacional sobre a percepção de mulheres HIV-positivo acerca do cuidado pré-natal, parto e puerpério? >> os dados foram coletados nas bases de dados MEDLINE, LILACS, BDNF e CINAHL no período de 2003 a 2012, sendo selecionados e analisados 20 estudos. **Resultados:** evidenciam percepções positivas e negativas do cuidado recebido. O cuidado recebido pelas mulheres é de extrema importância para a promoção de sua saúde e proteção da saúde de seus filhos, bem como direcionam para a necessidade de maior envolvimento dos profissionais da saúde acerca do cuidado da mulher HIV-positivo. **Conclusão:** há necessidade de realização de novos estudos, no sentido de aprofundar estas questões que podem contribuir na melhoria da qualidade de vida destas pessoas. **Descritores:** Percepção; Cuidado de Enfermagem; Cuidado Pré-Natal; Parto; Período Pós-Parto.

RESUMEN

Objetivo: identificar la contribución de los estudios en el ámbito nacional e internacional, en la percepción de las mujeres VIH-positivas acerca de la atención prenatal, el parto y el posparto. **Método:** revisión integradora con el fin de responder a la pregunta de investigación << ¿Qué conocimiento científico hay en el ámbito nacional e internacional sobre la percepción de las mujeres VIH-positivas acerca de la atención prenatal, el parto y el posparto? >> Los datos fueron recogidos en MEDLINE, LILACS y CINAHL datos BDNF en el período de 2003 a 2012, se seleccionaron y analizaron 20 estudios. **Resultados:** muestran percepciones positivas y negativas de la asistencia recibida. La atención que reciben las mujeres es de suma importancia para la promoción de su salud y proteger la salud de sus hijos, así como directamente a la necesidad de una mayor implicación de los profesionales de la salud sobre el cuidado de la mujer VIH-positiva. **Conclusión:** existe la necesidad de realizar más estudios con el fin de desarrollar aún más estas cuestiones que pueden contribuir a mejorar la calidad de vida de estas personas. **Descriptor:** Percepción; Cuidados de Enfermería; Cuidado Prenatal; Parto; Período Postparto.

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INTRODUCTION

Acquired ImmunoDeficiency Syndrome (AIDS) is the terminology used to define an infectious, emerging, serious disease caused by the human immunodeficiency virus (HIV). Currently, HIV infection is considered one of the greatest public health problems in the world today that affects men and women equally, being that women represent 16.7 million of the worldwide epidemic.¹

Due to the increasing number of infected women at childbearing age, children are forming a group of risk also increasing for HIV infection. Annually 3 million women give birth in Brazil. According to a study conducted in 2004 on a representative sample of pregnant women between 15-49 years of age, from all regions of the country, the prevalence rate of HIV-infected women at delivery is 0.42%, which corresponds to an estimate of about 13 000 infected mothers.² Given this finding, the Brazilian Ministry of Health has implemented policies for comprehensive women's health care advocating humanized care starting from the prenatal, childbirth and postpartum periods to prevent vertical transmission (VT) of HIV from mother to child.³

These women HIV-positive, when discovering they are to become mothers, will seek health services where they will receive care for that pregnancy occurs in a healthy manner, with minimal risk both for her and for her child, and especially where they can be well hosted and treated respectfully and get individual attention.⁴ We highlight the need to consider the peculiar condition of the care that should be offered to this group of women. It is worth mentioning that the proper application of prevention is hampered by poor access and low quality of care provided in these services, the lack of information of the health team on the vertical transmission of HIV, which in turn is not prepared to provide the care so that these women can feel hosted and treated appropriately.⁵

Working with HIV-positive women becomes a great challenge because of the different dimensions involved in this condition, such as biological, emotional, economic, social, spiritual, cultural and ethical. Every woman who is in this situation should be addressed in a comprehensive and individualized way so their expectations and needs can be met appropriately.⁶ Given this context, considering the care received by HIV-positive women in prenatal care, childbirth and puerperium stages, emerges the following question: *What is the contribution of studies on national and international level, on the*

perception of HIV-positive women about prenatal care, childbirth and postpartum?

For answers to this question, this study was developed with the aim at:

- Identifying the contribution of studies on national and international level, on the perception of HIV-positive women about prenatal care, childbirth and postpartum.

METHOD

The integrative review is a research method that allows to gather knowledge on a particular topic, conducted in a systematic and orderly manner in order to contribute to the knowledge of the subject investigated. The review should follow the same criteria of methodological rigor of the original research on data collection, analysis and presentation of results, since the beginning of the study, from a research protocol previously developed and validated. That way the reader can identify the actual characteristics of the selected studies, as well as information relevant to the advancement of nursing.⁷

To accomplish this integrative literature review, we adopted the six steps indicated in the review: 1) selection of the research question; 2) defining the criteria for inclusion of studies and sample selection; 3) representation of the selected studies in tabular format, considering all the features in common; 4) reviewing the findings, identifying differences and conflicts; 5) interpretation of results; and 6) report any clear evidence found.⁷

Thus we selected the research question of the integrative review the question being defined: What produced scientific knowledge is there on national and international level on the perception of HIV-positive women about prenatal care, childbirth and postpartum?

This way the following inclusion criteria and selection of items were defined: studies published as original article, in national and international journals, in Portuguese, English or Spanish languages, that investigated the perception of HIV-positive women about prenatal care and puerperium, published in the period 2003 to 2012, regardless of method of research and articles that contained their titles and/or abstracts in the database. The exclusion criterion for these articles: studies that did not meet the inclusion criteria mentioned.

The survey was conducted by internet on articles in the databases: Medical Literature on Line (MEDLINE), Literature of Latin America and the Caribbean (LILACS), Database of Nursing (BDENF), and Cumulative Index to



Nursing and Allied Health Literature (CINAHL). For the survey of studies in LILACS and BDEF, the following terms have been selected: *gestação* (pregnancy, gestante), *pós-parto* (postpartum, posparto), HIV (VIH), *pré-natal* (prenatal), *parto* (parturition, parto), *percepção* (percepción, perception). For consulting the database of CINAHL and MEDLINE, were selected the following descriptors of Health Science (DeCS): "HIV," "pregnancy," "parturition", "postpartum", "prenatal care", "perception".

For the organization and tabulation of the data, the researchers developed an instrument that was submitted to three judges with expertise in the investigated subject. The final instrument consisted of a spreadsheet contemplates the following information: title, purpose, descriptors, journal, year of publication, country of study, study category, nature of the study, theoretical benchmark, subject of the research, analysis method, approach, in addition to identifying the main results.

To assess the quality of articles, we used a structured assessment instrument of the level of evidence according to Agency for Healthcare Research and Quality (AHRQ), which considers the production of scientific knowledge of evidence-based practices and the placement in hierarchical levels, namely, at level I: evidence is made through a systematic review or meta-analysis of all relevant randomized controlled trials, or from clinical guidelines based on systematic reviews of randomized controlled trials; at level II, evidence is derived from at least one randomized controlled trial and well designed; at level III, these are obtained from well-designed clinical trials without randomization. The level IV has evidence of cohort and case-control well defined. While the V level corresponds to systematic reviews of descriptive and qualitative studies; level VI has evidence of a single descriptive or qualitative study. Finally, level VII has evidence of opinion of authorities and/or an expert committee report. Thus, all 20

selected studies possessed Level of Evidence (LoE), Level VI referring to descriptive studies with low power and inferential association. 8

The studies were subjected to thorough reading of each complete article, highlighting those that corresponded to the proposed objective and in order to organize and tabulate the data, of which 20 met the inclusion criteria.

After the analysis of the selected studies, assessed content was analyzed by simple descriptive statistics and synthesized text. For further analysis of synthesis of the articles that met the inclusion criteria, a summary table specially built for this purpose that specifies aspects was used: title of the article; identify the authors; Goal(s) of the study; year and level of evidence.

At the end of the review, the concepts covered in each article of interest and researchers were extracted, and were constructed a total of three categories for analysis, specified as the first category this way was: Care received in prenatal care: positive and negative perceptions of prenatal care. The second category was care after childbirth: perceptions of HIV-positive women and the third category: the postpartum care: perceptions of HIV-positive women.

RESULT AND DISCUSSION

It was observed that 19 (95%) articles were published in national journals and 1 (5%) were published in international journals.

The countries of origin of the studies were as follows: Brazil 19 (95%) and India 1 (5%) of the studies.

The selected studies were classified according to their category as specified by the publishing journals, and 20 (100%) were original research.

For a better understanding of the study, we developed a summary table with the relevant data for each item found, as in figure 1.



Title	Author	Objective	Year	Level of Evidence
Perception of HIV-positive postpartum women compared to pre-natal	Plas TO, et al. ^{13th}	Knowing the experiences of puerperal women of the human immunodeficiency virus (HIV) on the care of prenatal care.	2007	VI
Advice on anti-HIV testing in the puerperal cycle: the look of integrity	Carneiro AJS, et al. ¹⁹	Analyze the professional care to women to whom positive HIV was acknowledged during labor or postpartum.	2010	VI
Life in the world of the woman who has HIV / AIDS in everyday (IM) possibility of breastfeeding	Paoin S et al. ²⁰	Presenting the world's understanding of the life of the woman who has the human immunodeficiency virus in everyday (im) possibility of breastfeeding.	2011	VI
AIDS and pregnancy: meanings of risk and the challenge of care	Smith C et al. ²¹	Understanding how risk of vertical transmission of HIV is perceived and interpreted by people living with HIV / AIDS in their reproductive decisions.	2006	VI
Experiences of pregnant and postpartum women with a diagnosis of HIV	CB Araújo et al. ¹⁷	Identify the experiences of pregnant and postpartum HIV carrying women with quimiprofilaxis for prevention of vertical transmission.	2008	VI
Experiencing the adversity of binomial pregnancy and HIV / AIDS.	Preussler GMI et al. ⁹	To identify adversities experienced by mothers when faced with binomial pregnancy and HIV / AIDS.	2007	VI
Vertical transmission of HIV: Expectations and actions of HIV-positive pregnant women	El Moro et al. ¹⁰	Identify the expectations and actions of HIV positive pregnant in view of the pregnancy and the fetus.	2006	VI
Dilemmas and conflicts of being a mother in the presence of HIV / AIDS	MTG Galvão et al. ¹¹	To learn the dilemmas and conflicts revealed by women who become pregnant in the presence of infection by HIV / AIDS.	2010	VI
Problems with puerperal breast revealed by seropositive mothers	MMT Machado et al.	To learn experienced and revealed situations of non-breastfeeding.	2010	VI
Maternity in a HIV situation: a study on the feelings of the pregnant.	FT Carvalho et al. ¹²	Knowing the feelings of pregnant women with HIV / AIDS about the infection itself, maternity and baby.	2006	VI
HIV positive mothers and non-breastfeeding	Moreno C et al. ²⁷	Understand the meaning of the experience of not giving breastfeeding and the reasons why mothers follow this recommendation.	2006	VI
Feelings of HIV-seropositive women given the inability to breastfeed	M Batista et al. ²⁶	Analyze the feelings of postpartum HIV seropositive women, in a ward, given the inability to breastfeed.	2007	VI
Breastfeeding: impact caused on pregnant HIV-Positive women	DCS Vines et al., ²³	Identify HIV-positive pregnant women with major concerns about the prevention of breastfeeding and assess the needs of individual educational activities as an alternative form to psycho-emotional and emotional support to pregnant women.	2004	VI
Being pregnant and seropositive for Human Immunodeficiency Virus: a reading in the light of Symbolic Interactionism	EL Moor et al. ¹⁶	Describe the everyday context experienced by pregnant and HIV-positive women for human immunodeficiency virus (HIV), focusing on the experience of being pregnant and accept this state.	2010	VI
Adherence to prenatal HIV + women who did not take prophylaxis of vertical transmission: a behavioral and social access to health care study.	Darmont MOR et al. ¹⁸	Identify the behavioral factors and those of the health system that, in the view of the women, hinder or prevent access to prenatal care, and as a result, to the prophylactic measures	2010	VI



		recommended by Ministry of Health for the control and reduction of vertical transmission of HIV.		
Repeated pregnancy among women with known HIV status in Pune, India.	Suryavanshia N et al. ²⁴	Analyzing repeated pregnancies among women with HIV status	2008	III
Measures to prevent vertical transmission by HIV employed by the mothers of seropositive children	AF Leal et al. ¹⁵	Examine measures to prevent vertical transmission of HIV employed by mothers of HIV positive children who were accompanied by Specialized Care Service (SAE) of the municipality of Pelotas.	2012	VI
The experience of motherhood for a HIV seropositive woman: a case study	Bazani AC et al., ²²	Understanding the experience of motherhood for a woman seropositive for HIV.	2011	VI
Being a HIV-positive mother: significance for HIV positive women and for nursing	Monticelli M et al. ²⁵	Understanding the meaning of being a HIV-positive mother: significance for HIV positive women and nursing ward unit and to identify the similarities and contrasts present in these meanings.	2007	VI
The realization of anti-HIV testing in prenatal care: meanings for pregnant women	RMO Silva et al. ⁵	Understand and analyze the significance of testing for HIV during antenatal care for pregnant women.	(2008)	VI

Figure 1. Summary of articles included in the Integrative review.

In the classification of the studies, as to the context in which they performed the environment of specialized service or referrals for HIV/AIDS, the following was highlighted by concentrating 14 studies (70%), hospitals and maternities with four articles (20%); and basic health service and non-governmental organization with two articles (10%), being one study for each environment.

The articles were categorized by the methodological nature of the study, as follows: 18 (90%) developed an approach with qualitative studies and two (10%) with a quantitative approach.

Regarding the theoretical framework used in the study, 9 (45%) did not specify in the text, and/or had not adopted a theoretical framework; 7 (35%) are based on the comprehensive woman care policies; and 4 (20%) on phenomenology.

The most used descriptors were: Prenatal woman, HIV/AIDS, Lactation. In the collection of the data, and to assess the perception of HIV-positive women about the care received in prenatal, childbirth and postpartum, 17 (85%) studies with semi-structured interviews were identified, two (10%) that used structured questionnaires and one (5%) with study with focus groups.

With respect to research subjects of the studies, there was the participation of 604 HIV-positive mothers, in which 341 (56.45%) were multigravid; 62 (10.26%) were primigravid; 17 (2.81%) were multiparous; (13) (2.15%) were nulliparous and 171 (28.31%) of

women without further description in the studies.

◆ Received prenatal care: positive perceptions

In studies about the perception of HIV-positive women on the received prenatal care, it was found that women perceive care as an expression of love and protection for their children. They report that the support received is valuable for the prevention of disease in their babies.⁹ They refer that with the prenatal control they had the opportunity to clarify their doubts regarding the diagnosis of HIV, and to take preventive measures and perform the treatments in an attempt to free the babies of future suffering caused by HIV infection, also avoiding guilt, responsibility and the ability to be the bearer of an incurable, and especially not accepted by society, infection.^{5,10-12}

For HIV-positive women, the received prenatal care played a key role since they were informed about HIV and how to prevent transmission to the baby, and received support for adherence to antiretroviral treatment, and had the opportunity to interact with other women in a similar condition to theirs.¹²⁻¹⁴ For these women, their health is being put in the background, being at that moment their greatest wish and priority to protect and prevent contamination of the child that is being generated, make every effort to follow all the recommendations mentioned in prenatal care, not miss appointments, adhere to treatment



correctly, so as to prevent their child getting infected with HIV.^{6,15}

Prenatal control was an experience of emotional support and counseling to their demands, which helped a lot in overcoming the difficulties they were experiencing at that moment, as pain, fear, anguish, doubt for the child while it was maternal commitment protect you against HIV.^{9,15 to 17}

Studies on the perceptions of some HIV-positive women who attended all prenatal appointments throughout the period, were reported satisfactory, they felt supported by members of the healthcare team in prenatal care, and were concerned for their welfare, without prejudice, they listened with complicity and privacy, which was highly valued by them.¹⁸ Moreover, when prenatal care is provided by the same professionals, they feel more secure and have confidence to express their problems, doubts and fears during pregnancy.¹³

◆ Received prenatal care: negative perceptions

Among the negative perceptions of prenatal care, there is a lack of information or superficial guidance by some health professionals, with respect to the importance of HIV serologic testing. Many of them became aware of the requested tests through the reading of the examination requisition, causing concern regarding the protection of their children.¹⁸ Besides this, women expressed that the impact of the result could be lesser if they knew that they were being subjected to that test.¹⁸⁻¹⁹

Other women expressed they felt lost, recalcitrant, indignant and disappointed by the coldness shown by some health professionals while informing them of the results of a HIV-positive test, going through frightening and desperate experiences, for not receiving guidance on the care needed.^{10,14,20}

Among the negative perceptions related to care provided by health professionals, were highlighted the lack of acceptance, dialogue, attention of professionals, who appear hurried, inattentive and aggressive, demonstrating discrimination for some women, because they have many children, and becoming pregnant while being infected by HIV.^{11,13,18} Moreover, the use of highly technical terminologies made it difficult to understand the recommendations for these women, and therefore could not be complied; and also the lack of human resources and rotativity of health workers in basic health units that perform prenatal care, contribute to the difficulty of access to these services.⁹⁻¹⁸

◆ Received care at childbirth: perceptions of HIV-positive women

The analyzed studies show that perceptions of HIV-positive women in relation to the care received at delivery were translated by fear and concern of HIV transmission to the baby.¹³⁻²³ They have fears about the transmissibility of HIV in childbirth, especially regarding childbirth that will have to occur in the presence of HIV, they will have to take the injectable zidovudine, and go through the response to treatment, the possible need for caesarean section, and with fears about the risks to their own health.^{14,24} Apart from, the questions regarding contamination of the baby with the virus is a reason for great anguish and fear of losing the baby even before it is born, apart from fear for their own lives. Some mothers reported the support and the importance of some health professionals at that point in their lives, they even mentioned a favorable reception and an enabling environment at birth.¹³⁻¹⁴

To other HIV-positive mothers, perceptions of care received at birth is marked by dehumanization, poor reception, isolation, poor dialogue ratio, and detachment from the professional who is caring for them, experiencing inadequate care, such as lack of guidelines on anti-HIV serological test and without preserving the confidentiality of the diagnosis in the delivery room, experiencing shame associated to sadness.^{11,17,19}

◆ Care received in the puerperium: Perceptions of HIV-positive women

With regard to perceptions of HIV-positive women in relation to the care received in the puerperium, they refer: experienced isolation, insecurity, suffering shame that someone discovered their diagnosis of serum positivity and fear of experiencing prejudice, discrimination and indifference on the part of those around him, such as families, friends and companions.^{21,23 to 24}

The mothers together in an accommodation room plus the experience of all the situations mentioned above, also have to face the experience of not being able to breastfeed her child. They express to have received guidelines to avoid breastfeeding after childbirth, during prenatal consultations, especially those who already know their serologic *status* for HIV. Some said they were informed only after the baby's birth.^{11,25}

They reported a lot of suffering for not breastfeeding, because this act is a form of interaction in which the mother has the ability to convey warmth, love, protection and health of your baby, and this practice is encouraged.



¹⁷ However, when infected with HIV, breastfeeding becomes impossible for the additional risk posed upon it, with them feeling a sense of guilt, sadness, loss of female and maternal identity, impotence, inferiority, pain, discrimination and humiliation.^{9,14,20} It is a painful and exhausting, not to breastfeed her child and still stop lactation through bandaging. Reported feelings of patients are: malaise, anguish, anxiety, suffocation, physical discomfort, feeling of inferiority, violence, pain, sense of pruning.^{24,26}

The perception of the care received in relation to the breasts after childbirth highlights the lack of guidelines resulting in the experience of pain, fever and breast engorgement.^{27th} Mothers told that they, being unable to breastfeed, invented several excuses such as anemia "I am using medicine", "I have no milk," Hepatitis C, diabetes, strong medicines, "I have no beak".^{19,26-27} These justifications, they attributed to the fear of prejudice and discrimination from others to discover their serology *status* for HIV infection, because of the inability to breastfeed.^{25th} Most women claim to have a great desire to breastfeed their children, but the sacrificing is more than worth it for their children, so they do not feel guilty later.^{22 26}

This way specialist care is of utmost importance for these women, to improve quality of care levels: prevention, health promotion, and prevention of vertical transmission of HIV / AIDS in children²⁷.

FINAL REMARKS

This integrative review on perceptions of HIV-positive women about the received prenatal, childbirth and postpartum care, reaffirms the importance of care in these stages of their lives, deeply marking their life stories, with different perceptions and opinions about the care received.

The synthesis of the analyzed studies allows us to identify the production of scientific knowledge that demonstrates positive and negative perceptions of the received prenatal, childbirth and postpartum care. Such perceptions need to be considered since they constitute valuable subsidies of qualification of the care provided to this specific population.

Regarding the positive perceptions of received prenatal care, women report that it was an experience and opportunity to answer their questions about the diagnosis and receive information and guidance to overcome difficulties they were experiencing at that

moment and that way save their children from an incurable and not accepted by society disease. It was also the opportunity to interact with other women in similar condition to theirs.

As for the negative perceptions of received prenatal care, the studies highlight the lack of acceptance, lack of information or superficial guidance on the importance of the HIV serologic test and sometimes show discrimination for having many children, for becoming pregnant and being infected by HIV, as well as the use of technical terminology that hinder understanding and follow-up care for women.

With regard to perceptions about the care received at birth, the analyzed studies also highlight on one hand, positive aspects, such as the reception and an enabling environment by professionals, giving support against the fears and concerns of women at that time. On the other hand, some women have negative perceptions about the care received at childbirth such as dehumanization, poor reception, isolation, loneliness and even lack of advice about the test to be performed in the delivery room, and lack of privacy when they get their result.

With regard to perceptions of care received in the postpartum period, the studies reviewed show as negative aspects: isolation, insecurity, suffering, shame that someone may discover their diagnosis, for fear of prejudice, discrimination and indifference on the part of those who are to around them. The experience of not being able to breastfeed her son and stopping lactation by strapping of the breasts, are also highlighted as negatives, causing suffering, sorrow, anguish, loss of feminine and maternal identity, impotence, inferiority feeling, pain, discrimination and humiliation, affecting the physical and emotional dimensions of women. Further in relation to the care of the breasts after childbirth, they refer to lack of guidelines, resulting in pain, fever and breast engorgement. Unable to breastfeed, invent various excuses for fear of prejudice and discrimination on finding out their serologic *status* on HIV infection. Among the positive aspects, there is the guidance received by all women on the contraindication of breastfeeding as a way to prevent the additional risks of vertical transmission from mother/child through this practice.

We conclude that the synthesis of the knowledge produced about the care received in prenatal, childbirth and postpartum periods, confirms the importance of using research findings to support the care provided



to HIV-positive women, as well as directs the need for greater involvement of professionals in humanized health care for HIV-positive women in these moments. The realization of new studies on the care received by HIV-positive women in the antenatal, childbirth and postpartum periods in different contexts, is recommended to deepen these issues which can contribute to promoting health and improving the quality of life of these people.

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