

# SYSTEMATIC OR INTEGRATIVE REVIEW

## SUPPORT NETWORK FOR WOMEN LIVING WITH HIV AND ITS RELEVANCE IN PMTCT STRATEGIES: AN INTEGRATIVE REVIEW

### REDE DE APOIO A MULHERES COM HIV NA PREVENÇÃO DA TRANSMISSÃO VERTICAL: REVISÃO INTEGRATIVA

### RED DE APOYO A MUJERES CON VIH EN PREVENCIÓN DE LA TRANSMISIÓN VERTICAL: REVISIÓN INTEGRADORA

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## ABSTRACT

The rates of AIDS incidence in Brazil show signs of stabilization. Vertical transmission of the disease, still high, indicates its prevalence amongst women. The social context of women with HIV influences adherence to preventive treatment against this type of transmission. The objective of the present study was to analyse scientific production on the subject in order to identify evidences to the importance of a support network in the lives of women with HIV. It is an integrative review using Medline via PubMed and Lilacs databases. A total of 83 articles were found. Inclusion criteria was: scientific research available in full; papers written in Portuguese, English or Spanish; research published between 2008 and 2013; texts related to the subject-matter. Eleven articles were analysed. The analysis was based on reiterative readings in order to collect data and subjects. Two themes were identified: implications of support network in the vertical transmission of AIDS; and the relevance of secondary support network in decision making. The results demonstrated the significance of a support network in the adherence to prophylactic measures. Furthermore, health professionals should be aware of such network in order to consider the needs of this population in their health planning.

**Keywords:** HIV Infections; Women; Social Support; Family.

## RESUMO

A epidemia de AIDS vem sofrendo um processo de estabilização no Brasil ao mesmo tempo em que tem se apresentado de maneira especial em mulheres. E isso desperta a atenção para a transmissão vertical. O contexto social no qual a mulher com HIV está inserida influencia na adesão ao tratamento, especialmente para prevenção da transmissão vertical. Desta forma, realizou-se este estudo que teve como objetivo analisar na literatura científica as evidências relacionadas à rede de apoio na vida de mulheres portadoras de HIV. Trata-se de uma revisão integrativa que teve como bancos de dados selecionados para a pesquisa o Medline via Pubmed e o Lilacs. Foram encontrados 83 artigos e para a seleção filtrou-se artigo publicado na íntegra, nos idiomas português, inglês e espanhol, entre os anos 2008 e 2013 e que estivesse adequado à temática. Dessa forma, foram analisados 11 artigos. A análise foi baseada em leituras reiterativas para direcionar o agrupamento de dados e temas, de onde emergiram dois focos temáticos: implicações da rede de apoio na transmissão vertical e relevância da rede de apoio secundária na tomada de decisão. Observou-se a grande relevância da rede de apoio na adesão às medidas profiláticas para evitar a transmissão vertical e a importância do profissional da saúde em conhecer essa rede, a fim de incluir em seu planejamento assistencial as demandas provenientes desse contexto.

**Palavras-chave:** Infecções por HIV; Mulheres; Apoio Social; Família.

## RESUMEN

La epidemia del SIDA en Brasil está en proceso de estabilización. Se presenta, asimismo, de manera especial en las mujeres, sobre todo en lo referente a la transmisión vertical. El contexto social de las mujeres con VIH/ SIDA influye en la adherencia al tratamiento, especialmente en prevención de esta vía de transmisión. El presente estudio se llevó a cabo con el objetivo de analizar evidencias en la literatura científica sobre la red de apoyo para las mujeres con VIH/SIDA. Se trata de una revisión integradora con información recogida en los bancos de datos Medline via PubMed y Lilacs. Se encontraron 83 artículos. Los artículos seleccionados debían estar adecuados al tema, publicados en su totalidad en los idiomas portugués, inglés y español entre 2008 y 2013. Se analizaron 11 artículos. El análisis se basó en lecturas reiterativas para organizar la agrupación de datos y temas, de donde surgieron dos focos temáticos: implicaciones de la red de apoyo en la transmisión vertical y relevancia de la red de apoyo secundaria en la toma de decisiones. Se observó que la red de apoyo es importante en la adherencia a las medidas profiláticas para prevenir la transmisión vertical y que los profesionales de la salud deben conocer dicha red con miras a incluir en su planificación asistencial las demandas provenientes de este contexto.

**Palabras clave:** Infecciones por el VIH; Mujeres; Apoio Social; Família.

## INTRODUCTION

The AIDS epidemic shows signs of stabilization in Brazil. Incidence rates are, however, high: 18.7 cases per 100,000 inhabitants in 1998, and 10 cases per 100,000 inhabitants in 2008.<sup>1</sup> In the context of disease progression in Brazil the phenomenon of feminization of AIDS and the fact that a significant amount of cases are diagnosed during pregnancy stand out.<sup>2</sup>

Vertically transmitted HIV (also called mother-to-child transmission MTCT) occurs when virus goes directly from mother to embryo, foetus or baby during pregnancy, labour or delivery through contact with cervicovaginal fluids, maternal blood and breastfeeding.<sup>3</sup> As women of reproductive age are the most infected the number of infants infected through MTCT is high.<sup>1</sup>

According to the Department of Health, 0.4% of pregnant women are HIV positive, i.e. approximately 12,635 pregnant women with HIV and children exposed per year. Approximately 65% of cases of vertical transmission occur during labour and delivery; the remaining 35% occur in the womb, especially in the last weeks of pregnancy. There is still the risk of postpartum transmission through breast-feeding.<sup>2</sup>

However, MTCT can be avoided with the adoption of a series of preventive measures whose success depends on the patients and the health services. High-risk antenatal care with the prescription of antiretroviral therapy from the 14th week of pregnancy; intensive care during childbirth, no breast-feeding; and monitoring of infants until age 18 months are amongst the measures.<sup>4</sup>

Factors such as the feminization of infection, poverty, low level of education and social exclusion are growing at a faster rate and, consequently, directly influence the increase of mother-to-child transmission. All the aspects mentioned above are consequences of non-adherence to preventive measures.<sup>5</sup>

Women's social context also influences vertical transmission of HIV: the family forms the foundation of society and plays a key role in an individual's life. Family and friends are the groups able to offer security, both emotional and psychological, to the HIV patient.<sup>6</sup>

Social relations are a support network that can change a person's physical and psychological health status. It consists of a group of people, organization or social institution linked through some kind of relationship. A support network can be classified as primary or secondary. The former consists of relationships established between family members, neighbours, friends, co-workers; the latter comprises the health care professionals.<sup>7</sup>

This study aims at examining evidence in scientific literature on the importance of the support network in the lives of women living with HIV.

## METHOD

This is a descriptive literature review, a comprehensive method which motivates further research on a particular topic since it generates new ideas and approaches. Once an issue is redefined the new conceptual model inevitably suggests focus and prospects not yet fully studied.<sup>8</sup>

The research stages were as follows: elaboration of a guiding question; search in available literature; data collection; critical analysis of selected studies; discussion of results; and presentation of integrative review.<sup>9</sup>

The guiding question was: How important is a support network in the lives of HIV-positive women and which are its implications in the prevention of mother-to-child transmission (PMTCT)?

The databases selected were Medline via PubMed and Lilacs. The criteria, defined by specific descriptors, were: *HIV infections and Pregnant and Social Support and Family*. The inclusion criteria were: pertinence to the research subject; articles published in English, Portuguese or Spanish; and articles published between 2008 and 2013. The exclusion criteria were as follows: articles not available in full; dissertations or theses; papers published outside the above period of time; literature reviews.

A total of 83 articles were found: 81 in Medline and 2 in Lilacs; 19 articles matched the inclusion criteria: 17 from Medline and 2 from Lilacs (Figure 1). Next, the abstracts were read and their suitability evaluated. Eleven fulfilled the research objectives (ten from Medline and one from Lilacs). The articles left aside dealt with vertical transmission but did not mention the support network. Therefore, the integrative review was structured around 11 articles. Chart 1 details the bibliographic roadmap.

## RESULTS AND DISCUSSION

This integrative review analysed 11 articles that met the inclusion criteria previously established. Table 1 presents an outline of the selected articles. Among the publications, ten had level of evidence four and one had level of evidence three. Regarding the research origin, only two were carried out in Brazil.

Data analysis was based on reiterative readings which guided categorization of data and subjects. New readings were carried out in order to identify the regularity of relevant aspects, complementarity and coordination between existing information on each subject. Such process aimed at the development of a descriptive integrative text. This led to the identification of two main themes whose results are discussed here.

The two thematic categories are: influences of support network in MTCT; and relevance of a secondary support network in decision making.

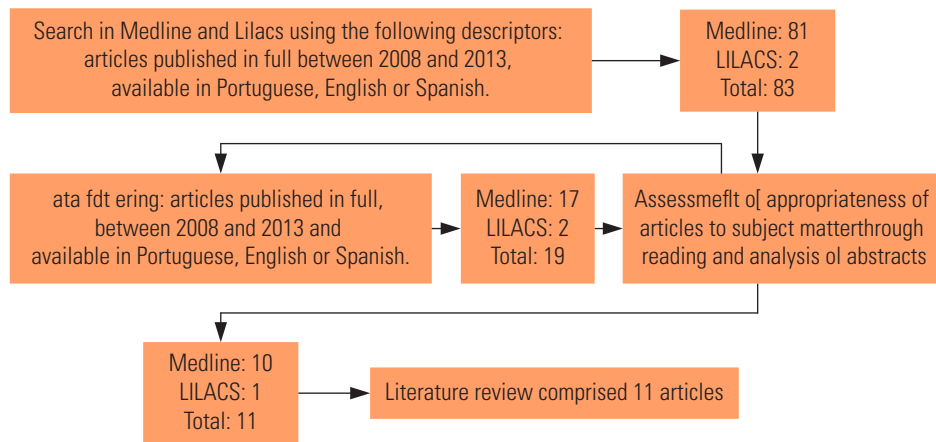


Figure 1 - Flowchart of bibliographic roadmap.

Table 1 - Characterization of academic production according to title, year of publication, journal, authors, country, and level of evidence, Teresina – 2014

Nº.	Title of the article	Year	Journal	Authors	Country	Level of Evidence
1	Mother to mother (M2M) peer support for women in prevention of mother to child transmission (PMTCT) programmes: a qualitative study	2013	PLOS ONE	Shroufi A, <i>et al.</i>	Zimbabwe	4
2	A qualitative study exploring attitudes and perceptions of HIV positive women who stopped breastfeeding at six months to prevent transmission of HIV to their children	2013	Malawi Medical Journal	Mataya R, <i>et al.</i>	Malawi	4
3	Social context and drivers of intimate partner violence in rural Kenya: implications for the health of pregnant women	2013	Culture, Health & Sexuality	Hatcher AM, <i>et al.</i>	Kenya	4
4	The Role of HIV-Related Stigma in Utilization of Skilled Childbirth Services in Rural Kenya: A Prospective Mixed-Methods Study	2012	PLOS ONE	Turan JM, <i>et al.</i>	Kenya	4
5	Factors Associated with Pregnant Women’s Anticipations and Experiences of HIV-related Stigma in Rural Keny	2012	AIDS Care	Cuca YP, <i>et al.</i>	Kenya	4
6	Adherence to Combination Prophylaxis for Prevention of Mother-to-Child-Transmission of HIV in Tanzania	2011	PLOS ONE	Kirsten I, <i>et al.</i>	Tanzânia	3
7	Adesão ao pré-natal de mulheres HIV+ que não fizeram profilaxia da transmissão vertical: um estudo sociocomportamental e de acesso ao sistema de saúde (Adherence to antenatal of HIV+ women who did not prevent MTCT and access to health care: a social and behavioural study)	2010	Cadernos de Saúde Pública	Darmont MQR, <i>et al.</i>	Brazil	4
8	Dilemas e conflitos de ser mãe na vigência do HIV/AIDS (Dilemmas and conflicts of being a mother with HIV/AIDS)	2010	Revista Brasileira de Enfermagem	Galvão MTG, <i>et al.</i>	Brazil	4
9	Stigma as experienced by women accessing prevention of parent-to-child transmission of HIV services in Karnataka, India	2010	AIDS Care	Rahangdale L, <i>et al.</i>	India	4
10	Community, Family, and Partner-Related Stigma Experienced by Pregnant and Postpartum Women with HIV in Ho Chi Minh City, Vietnam	2009	AIDS and Behavior	Brickley DB, <i>et al.</i>	Vietnam	4
11	Rede de apoio de mulheres que têm HIV: implicações na profilaxia da transmissão vertical (Support network for women with HIV: implications for prevention of MTCT)	2011	Jornal Brasileiro de Doenças Sexualmente Transmis-síveis	Langendorf TF, <i>et al.</i>	Brazil	4

## INFLUENCES OF SUPPORT NETWORK IN MTCT

Most of the articles demonstrated to what extent a support network influences HIV-positive women in seeking advice during pregnancy or in carrying out PMTCT measures.

The literature repeatedly mentioned the stigma of the disease. Moreover, some studies sustain that stigma is one of

the most important factors influencing women’s adherence to HIV treatment and their following vertical transmission control programmes.<sup>9,10</sup> Pregnant women HIV+ status generates in them the fear of prejudice; such feeling influences negatively their adherence to preventive measures. Fear of discrimination, abuse and rejection of health services led women to cite stigma as a hindrance to HIV testing. In addition, access to antena-

tal care and diagnosis of HIV-positive status at delivery are often insufficient. Thus, despite being aware of the importance of preventive measures, many women have no access to them<sup>11,12</sup> They are less likely to seek a health care service, even knowing the unit and its professionals.<sup>10</sup>

Although stigma is a major influence in women's decision making, many of them develop coping strategies, such as religion and family and/or partner support,<sup>9</sup> i.e. a primary support network.

The lack of a primary support network influences care seeking by HIV-positive women. The lack of support from a partner (in cases in which he does not participate actively with their partners in pregnancy or labour) influences the way women face pregnancy. In some studies, women said that such support was denied as soon as the partners were told about their condition. Some women believed that they would change their minds over time. The absence of the baby's father causes depression and a feeling of vulnerability, lived as an abandonment omen. The researchers found that the couple often refuses testing or does not accept the results and stops attending the health unit altogether.<sup>13-15</sup>

Another possible scenario: prevention is carried out without the partner's consent, causing conflicts that often lead to domestic violence. The pregnant woman is in a particularly vulnerable position and economic dependence shapes her decision to seek strategies to prevent vertical transmission. Pregnant women with HIV are especially reluctant to disclose the care they receive; however, her partner's refusal also means that she and the unborn baby will suffer.<sup>16</sup>

Support is fundamental to established relations, since it helps the individual not to feel isolated and to overcome family adversity. The family is the main source of support for these women. There are cases of family breakdown after diagnosis of one of its members. Such disruption in family relationships is still due to lack of information about the disease, in addition to prejudice and discrimination.<sup>7</sup>

Living with a family member with HIV/AIDS is an experience filled with loneliness and isolation by the patient, demonstrating the importance of family support in the process of adaptation to living with the disease. In the selected studies the following feelings were listed: loneliness, loss of meaning in life and hopelessness, uncertainty whether to tell or not about the disease and whom to tell about it.<sup>17</sup>

Health team interventions provide women with information about HIV transmission, prevention and actions that could help them to cope better with the challenges of living with HIV. Such interventions require health professionals trained in counselling in order to encourage men to be HIV tested and to support their partners if they are diagnosed as HIV positive.<sup>15-18</sup>

Lack of information about the disease and its mode of transmission makes social disintegration stronger. Furthermore,

prejudice and discrimination are sometimes determining factors in family relationships.<sup>7</sup>

## RELEVANCE OF THE SECONDARY SUPPORT NETWORK IN DECISION MAKING

Health services where women receive antenatal care, monitoring and training on new-born care comprise the secondary support network. This network is sometimes the only support such women have, since very often health care professionals are the only people aware of their diagnosis.<sup>7</sup>

Motherhood and health services can be a source of frustration to women living with HIV/AIDS, once the welcoming provided by the health team proves unsatisfactory. In this context, some people described motherhood as "wrapped up in prejudice" after reports of women living with HIV who had suffered prejudice and discrimination during activities involving nursing procedures such as perinatal monitoring.<sup>18</sup>

Among other irregularities, carelessness, lack of confidentiality and no observance of protocols related to HIV testing were found. Researchers came by the case of a woman who was tested without consent. In the same study, another breach of confidentiality was found when the results of a HIV testing were revealed by a health professional.<sup>19</sup> Such facts show that some health professionals still need to be more cautious as to HIV testing and respect ethical aspects required before diagnosis.

Lack of women's adherence to the prevention of MTCT may be partially explained by the poor professional performance to monitor these women. Poor quality of care is generally associated with excessive workload that decreases the team's levels of motivation and commitment resulting in inadequate care. Furthermore, job rotation between departments often affects negatively continuity of care. Reducing change of duties and ensuring supervision of the activities may be important to reduce shortage of well trained staff and contribute considerably to improve rates of adherence to treatment during pregnancy and childbirth.<sup>20</sup>

Non-adherence to treatment may be associated as well to the lack of qualification of professionals to answer questions, solve complaints and sooth these patients' worries.<sup>10</sup> Health professionals must receive training in counselling, since the encouragement and guidance they provide are of great importance in decision making regarding treatment with antiretroviral drugs and adherence to no breastfeeding.<sup>12-15</sup>

Apparently, women who suffer some form of HIV-related stigma are less likely to seek health care facilities with qualified professionals. Even after encouragement from people close to them, they are still reluctant to seek treatment.<sup>10</sup>

A study carried out in Brazil revealed that some women tried to hide diagnosis even in health units for fear of be-

ing discriminated against by health professionals or of having HIV+ diagnosis exposed in the local community. A health professional even encouraged one of them not to seek antenatal care. Issues relating to access and lack of professional support hinder the seeking of health care and, particularly, the performance of antenatal care.<sup>13</sup>

Shortage of human resources in basic health units contributes to delay the population's access to units that perform antenatal care. The discourse of the respondents in the above article mentioned that current antenatal services are worse if compared to those of previous pregnancies. Increased formalities to getting antenatal started, a high turnover of professionals, the shortage of laboratory resources, the lack of integrated working between the units, the health units being closed and the mobilization of health personnel to fight epidemics like dengue were mentioned as barriers in the interviews.<sup>13</sup>

Lack of understanding of health professionals about the social reality and the difficulties women experience contributes to non-adherence to antenatal care. This is the result of the lack of information and moral and ethical prejudice; it reveals the lack of a humanistic approach of professionals in referral services, as well as lack of appropriate guidance on how to deal with HIV positive patients. These factors make service users feel embarrassed.<sup>19</sup>

HIV-positive pregnant women deserve specific care. Mode and place of communicating diagnosis results can influence how women experience their condition and its impact on their life and family. The lack of understanding and professional ethics in the health units is noticeable.<sup>19</sup> There are no welcoming services offered to the patients and this influences their decision to withdrawal from MTCT prevention programme. The irritable attitude of health professionals, the lack of dialogue with the doctor and the general lack of attention are also considered negative aspects of the secondary support network.<sup>13</sup>

Another relevant aspect was women not knowing when precisely during antenatal, delivery and postnatal care HIV should be controlled. Such issues need to be emphasized or explored during follow-ups.<sup>13</sup>

The research confirmed that in this context pre-test and post-test counselling are likely to raise awareness about self-care. Advice to this population group should emphasize probable scenarios involving their babies and their role as the most important care providers.<sup>19</sup>

This type of approach includes the following: actions that acknowledge cultural and institutional origins of the problem by examining laws and policies related to HIV, HIV testing, improvement of services, better training of health professionals in ethics and professional strategies and community education as well as the expansion of specialized care services including mul-

tidisciplinary teams with an interdisciplinary approach in order to meet the needs of these clients.<sup>19</sup>

An optimal organization of the health facilities could improve welcoming and advice services, implementing stigma-reducing interventions and increasing the offer of programmes to prevent MTCT.<sup>10</sup>

## CONCLUSION

Support networks for pregnant women living with HIV/AIDS play a central role in improving adherence to prophylactic measures. Health professionals should be aware of their importance in order to include them in the care planning process. Health professionals make up the secondary support network. They emphasize the need to increase and maintain the primary support network. They also provide a starting point based on information and shared knowledge. Such backup promotes women's health and enables them to make decisions in order to break away from the inequality and oppression they experience in their daily lives with their partners and family members.

None of the articles analysed mentions multidisciplinary teams or non-governmental organizations as support groups. The secondary support network is deficient and such situation could be improved through the organization of multidisciplinary teams, approaching especially educational practices. The authors highlight the relevance of the nurse whose humanistic training considers not only biological questions, but also guidance, counselling, emotional support and psychological monitoring of patients and families.

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