MOTHER-CHILD RELATION WITH THE HUMAN IMMUNODEFICIENCY VIRUS AND ITS PARTICULARITIES

RESUMO

Objetivo: revisar o estado atual da literatura acerca das particularidades que definem a relação mãe-filho e seropositividade. Método: trata-se de uma revisão integrativa, com busca realizada nas bases MEDLINE, LILACS e SciELO, utilizando três idiomas para o descriptor “mother-child relations HIV” de publicações do período de 2006 a 2011. 14 artigos na íntegra foram escolhidos para a análise de dados. Resultados: a transmissão vertical é a principal via de infecção do vírus da imunodeficiência humana em crianças, representando uma dificuldade para a relação mãe-filho. As pesquisas mostraram que o apoio dos pais no decorrer da vida contribui para um bom desenvolvimento dos filhos. A equipe de saúde tem grande importância no enfrentamento da doença. Entretanto, esta também estigmatiza e discrimina esse tipo de mãe, não entendendo suas necessidades e afastando-a das redes de cuidados essenciais. Conclusão: ressalta-se a relevância de um trabalho com os profissionais que lidam diretamente com esses sujeitos, oferecendo-lhes apoio médico e social necessários. Descriptores: Revisão; HIV; Relações Mãe-Filho.

RESUMEN

Objetivo: Revisar el estado actual de la literatura acerca de las particularidades que definen la relación madre-hijo y soropositividad. Método: se trata de una revisión integradora, con la búsqueda realizada en MEDLINE, LILACS y SciELO, en tres idiomas para el descriptor "relaciones madre-hijo del VIH" de publicaciones del período de 2006 a 2011. 14 artículos completos fueron seleccionados para el análisis. Resultados: la transmisión vertical es la principal vía de infección del virus de la inmunodeficiencia humana en niños, lo que representa una dificultad para la relación madre-hijo. Las investigaciones demostraron que el apoyo de los padres a lo largo de la vida contribuye al desarrollo saludable de los niños. El equipo de salud tiene una gran importancia en la lucha contra la enfermedad. Sin embargo, esto también estigmatiza y discrimina este tipo de madre, sin entender sus necesidades y quitándolas de las redes de atención esencial. Conclusión: se resalta la importancia de trabajar con los profesionales que tratan directamente con estas personas, ofreciéndolas apoyo médico y social necesario. Descriptores: Revisión, VIH, Relaciones Madre-Hijo.

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INTRODUCTION

Vertical transmission, also known as maternal-infant is the main route of HIV infection in children. Studies show that in about 65% of cases HIV transmission occurs during labor and in the childbirth itself, while intra-uterine transmission accounts for 35% of occurrences and that breastfeeding increases the risk of vertical transmission of HIV in a range that varies from 7% to 22.1

This relationship is marked by ambivalent feelings and by the need for psychic adaptation before changes and uncertainty. Since pregnancy, mothers have different feelings and expectations towards their babies, their health and the mother-child interaction in itself. Furthermore, motherhood also leads to psychosocial rearrangements, with changes in roles and alterations in the socioeconomic and relationship patterns.2

Early adolescence might also be a vulnerable period for such a mother-child relationship, due to biological, social and psychological changes. This phase is identified as a period of increased risk for the development of emotional and behavioral problems for young people, if they are inserted in a context in which it has a relative infected with HIV.3

Some studies were intended for studying the issue of mother-child relationship in the HIV positive odd context, from issues relating to the childbirth and transmission, going through the disclosure of the seropositivity, to issues of adolescence and sexual initiation of these young people. Thus, this paper aims at reviewing the current status of the literature on the particularities that define the mother-child relationship and seropositivity.

Moreover, it is aimed at understanding how they deal with the prejudice and stigma about the disease, how is their integration in society, what would be the possible factors that could positively or negatively influence with this mother-child relationship and the likely implications of these researches in the development of the knowledge about the relationship and its future directions.

METHOD

This is an integrative review of the current status of the literature on the cited topic. The search was conducted in the MEDLINE, LILACS and SCIELO electronic databases, being that we listed the papers identified as suitable to the objectives of this literature review. After identification, we selected the papers that met the following inclusion/exclusion criteria: (a) papers that addressed the mother-child relationship, being that at least one of these subjects was HIV positive; (b) papers available in their full version; (c) one of the pairs had to be the mother; (d) not including the relationships among fathers, siblings or caregivers; (e) review articles were not included; (f) publications between 2006 and 2011; and (g) theses, dissertations and monographs were not included.

The selection of the descriptors used in the review process was conducted in accordance with the query in the MESH (Medical Subject Headings of the BIREME - Virtual Health Library).

In the MEDLINE and LILACS databases, we made searches by using three languages for the descriptors. In English, we typed “mother-child relations HIV”; for the Spanish, “relaciones madre-hijo VIH” and in Portuguese “relações mãe-filho HIV”, using the option of “integrated search method”. Nonetheless, we did not find any new data on the changes among the above mentioned languages.

In the survey in the SCIELO, we used the descriptor “mother-child relations HIV” and the result was the same as found in other databases already mentioned. So, we put the keywords “mãe-filho AIDS” (in Portuguese). Only papers that were fully available for query were selected. It was also determined the specification of the publication year of these papers, being that we selected only papers published in the last five years, covering, therefore, the period between 2006 and 2011, in view of the need to consider a more recent and updated literature period and in the face of the amount of existing publications, and it was necessary to delimit the publication time for performing a better data analysis.

In MEDLINE, 130 results were found without year delimitation. Pausing awhile in the period from 2006 to 2011, 62 articles were identified. But, only 18 full texts were available in the cited database. Due to the low number of available full articles, we have appealed to journals and periodicals websites so that we could have access to such papers in their full versions. This search the journal websites was repeated in other databases when necessary. Thus, from the 62 results found in the last five years of publication of the bibliographic material researched in MEDLINE, we obtained 42 full papers.

Regarding the LILACS, 10 results were found without year delimitation. Being restricted to the period from 2006 to 2011, six
results were found. However, only five full texts were available: one thesis and four papers. From the papers, one had already been selected in MEDLINE, remaining three full papers.

In research conducted in the SCIELO, in the period from 2006 to 2011, five articles were found, of which one article was repeated on the same page, counting twice, and another had already been selected in other databases, remaining three full papers.

On the whole, 48 full papers were initially identified. Next, we identified papers that met the subsequently cited inclusion/exclusion criteria.

After the research phase and initial selection, the reading the abstracts of the 48 selected papers was done. Hence, the studies that met the inclusion criteria were read in their entirety. Finally, 14 papers were chosen that met the inclusion criteria.

When assessing the papers, we observed the following aspects: 1 - title, authors, journal, publication year, and database; 2 - objectives; 3 - participants (criterion for sample selection, sample type); 4 - intervention (used procedures); 5 - used tools; 6 - obtained results; 7 - limitations / difficulties; 8 - conclusions / final considerations.

### RESULTS

Preliminary data were raised with respect to publication year, journal, as well as study and subjects characteristics (Figure 1). It should be highlighted the concentration of publications in the last two years, showing an impressive growth of studies on this matter in question. It is also noticed a concentration of studies in undeveloped or developing countries. Regarding the methods, the majority of them made use of qualitative methods to achieve the objectives of exploring the perceptions and needs and, thus, offering descriptive information about the subjects and demands, by employing inventories, scales and interviews.

<table>
<thead>
<tr>
<th>First Author</th>
<th>Year</th>
<th>Journal</th>
<th>N</th>
<th>Location</th>
<th>Method Characterization</th>
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<td>43</td>
<td>Florianopolis-SC (Brazil)</td>
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<td>57</td>
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<td>Palin 11</td>
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<td>103</td>
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Figure 1. General characteristics of the studies. Source: MEDLINE, LILACS and SCIELO databases.

After full reading of the papers, highlighting the objectives, results and final considerations, the publications were classified and quantified into thematic categories and grouped by the publication year. These categories were selected to better represent the obtained, studied and discussed results, with a view to achieving the papers objectives (Figure 2). From Figure 2, it might be observed that the categories are not mutually exclusive, since a same paper might be classified into more than one category, as it includes several factors of the binomial relationship. However, the categories that better characterized the study were chosen.
In Figure 2, it can be seen that all papers include, in their discussions and results, the mother-child interaction, since this is the purpose of this review. However, each paper addresses this issue in a particular way. Some of them emphasize the need to establish a strong bond and attachment on the part of the pairs, from the childbirth until the adolescence, as it helps to fight against with the disease, facilitates the disclosure of the diagnosis, by decreasing the risk of developing depressive or aggressive symptoms, as well as valuing the quality of life and of the relationship. Mothers of newborns use the non-verbal communication as a means of interaction and establishment of bond with their babies and to realize abnormalities and immediate desires thereof.

Studies, intended for approaching the development and behavior of children, found that the pairs who have developed a greater attachment between themselves had as result children with higher degrees of autonomy and self-esteem. Parental support throughout life favors the development of more resilient children and, thus, children with higher self-esteem and self-efficacy. Mothers with greater physical impairment level provide the growth of children with greater responsibilities and, therefore, they will be more autonomous adolescents.

The disclosure of the seropositivity diagnosis is also an important objective for some surveyed papers. The results show that mothers play an important role, and they wish to assume it, in the disclosure of diagnosis to their children and ground their communication decision on the child’s ability to understand and assimilate the information. These mothers report that the most common behaviors of their children after the disclosure of the diagnosis are feelings of sadness and concern. Widows and married mothers are more likely to disclose the diagnosis to their children than single mothers. Some researches show that mothers have to deal with the tension between the secrecy which surrounds the disease and the concern of when to reveal to their children, as well as the consequences of this decision-making on the part thereof. As mothers live afraid of the disclosure, they have to develop strategies for masking the treatment and the disease nature from their children. On the other hand, some mothers share their secrecy with healthcare team members, relatives or their children, in order to win social support - something crucial at that time.

Studies disclose that, often, the healthcare team becomes a strong bond of support, because it knows about the diagnosis. Accordingly, there is no need to disclose to other people, avoiding the spread of knowledge in relation to their diagnosis with others and, thereby, protecting their children. Nevertheless, the lack of adequate psychosocial support is a pretty reticent data in the papers. Besides the secrecy imposed by society, most times, the mother is isolated It was found that this binomial (mother-child) needs assistance and guidance to properly deal with the issues that emerge, because many bonds are broken after the discovery of the contamination, further inhibiting the communication the decision of the diagnosis and accentuating the social isolation as a form of protecting their children. Nonetheless, some bonds are strengthened and mothers emphasize the importance of a support network, which might be small, but well-structured.6,13

Discrimination from the healthcare team is seen as a major factor for the withdrawal of the mothers in relation to the treatment necessary for children, which decreases the quality of care. Some studies highlight the importance of a healthcare team that values women. Two surveys have investigated the participation and involvement of healthcare team in the relationship between the mother-child binomial and AIDS.6,13 Such studies showed the relevance of these professionals regarding the care for the binomial in question and also the burden of stigma and prejudice that they carry in themselves, directly affecting the mothers, since the professionals themselves do not understand their support needs. Therefore, the team
should be focused on the issues raised by mothers, as a way of preventing depressive symptoms. This need for attention on the part of the healthcare team towards the mother is proven in some studies when they claim that maternal depression hinders the mother/child interaction, being that the physical instability of the mother is a triggering factor for childish depression. Furthermore, mothers of medically fragile infants are more likely to develop depressive symptoms than the ones of healthier newborns, taking into account that these subjects, usually, are under intense medical care.

**DISCUSSION**

This current study aimed at producing an integrative review on the minutiae that characterize the mother-child relationship and seropositivity. From the analysis of the 14 selected papers, it should be highlighted some important points. For example, most of the researches make use of qualitative methods to obtain data, such as interviews, scales and inventories, in pursuing to achieve their objectives of describing, deepening and understanding of the particularities of this binomial relationship.

It was observed (Table 1) that nine of the fourteen papers were conducted in undeveloped or developing countries. This finding deserves to be emphasized due to the fact that HIV infection occurs in all continents, because it is a pandemic with far reaching for individuals in several countries, without distinction of class, breed or economic power. The concentration of researches in this specific population hinders knowledge about the issue at stake, since the disease affects individuals inserted in the most varied contexts and cultures, and might reveal specific characteristics of this relationship.

Most HIV + mothers report they had a wanted pregnancy. Generally, in the contemporary society, motherhood is reinforced by the social role that the woman represents. Aspiring to have children is an innate desire, to give meaning to the life, because of the standards in which they had been socialized, or by the construction of their feminine or virile identity. But, while motherhood, is for non-infected women, socially desired and encouraged, the right to desire to have children is denied to the seropositive women, being that those who get pregnant in this situation are, usually, considered reckless and cruel for exposing children to the risk of becoming infected.

Discrimination, prejudice and stigma are situations that go through various stages in the life and relationship between mothers and children with HIV. Besides the disease, these mothers have to face the prejudice on the part of society. Nowadays, the acquired immunodeficiency syndrome is still synonymous with social exclusion. These mothers daily live with feelings of fear, guilt and awe of the social judgment, i.e., there is the fear of humiliation and shame. The individual with this disease is stigmatized by society, whether in developing countries or in developed countries. But, the experience of HIV-related stigma affects not only mothers and/or children, since it incisively also affects family and emotional relationships and, even, the social life of women with HIV.

In fact, being a mother in this situation is a paradox, because it simultaneously represents the expected and the censored, i.e., something that is socially stimulated and condemnable. They know they have the virus, but are reluctant to get in touch with this reality that, besides being painful, imposes a new directioning in their lives. Thus, the contextual complexity of the syndrome, full of contradictions and inconsistencies becomes clarified. The family is the main source of support for women to overcome the challenges imposed by the HIV infection, being that the family bonds might be narrowed or reinforced depending on the child and on the mother's health status. With these, there is no need of revealing, thus preventing the spread of knowledge of the diagnosis with other people, in view of protecting the child.

The revelation of the disease from parents to their children puts into play the maintenance of secrecy and might rekindle the feelings of guilt and anger related to the family infection history. A form of infection can bring up painful situations for parents, such as extramarital affairs and drug use history. Added to this the desire from the parents to protect the children from the stigma, from death possibility, and to prevent the child might be a victim of social isolation. For many mothers, the cost-benefit of the mother reveals her illness needs to be relativized. For other mothers, the lie becomes justifiable, especially when it involves the protection of children in the school environment, for example. Mothers report that the most common behaviors of their children after the disclosure of the diagnosis are related to sadness and concern.
As discussed above, the situation of HIV infection in women is enhanced by social issues related to the gender and the restrictions imposed on the reproductive aspects, bringing them a particular psychological burden, including the depression. Mothers report that depression is immediately related to think in an excessive way about a situation, in this case, the disease. Hence, this act of thinking about the disease is identified as the main source of individual distresses.\textsuperscript{19-20}

For married mothers, the rates of depression were associated with worsening in the health conditions of their husbands and children. Nevertheless, it should be considered that poverty and lack of socioeconomic resources, alone, constitute psychosocial risks. The caregiver role that women play in society makes that most of them think that the first responsibility is linked to the health of their children and partners and, therefore, often, do not realize the risk. They neglect the proper care of their own health, but they do everything to take care of their children and prevent that they might become infected or worsen their health status. Thus, there is a dual role for these mothers to meet: dealing with the virus and being a caregiver. Moreover, studies have emphasized the concern of parents with the emotional and psychological impact of the disease itself and the stigma on the children, because of their negative reactions or from the other people. Concerning the families where children also have HIV, the parents might experience feelings of loss and early bereavement, since they think that the final outcome of the disease could be the death. With that, they experience strong emotional burden and suffering.\textsuperscript{19-20}

Checking the quality of life is important to conduct treatment strategies and healthcare programs, which, in turn, might favor not only the physical aspects of the clientele, but also those related to the psychic and social dimensions, by enabling the healthcare team to plan a comprehensive care. Practitioners should always be prepared to establish a differentiated listening to the seropositive women for identifying whether the fact they do not think about HIV is a positive attitude, as a way of survival, or negative, as a form of detachment from the reality.\textsuperscript{20}

Many mothers report their anxieties with regard to members of the professional team in the search for social support. The discrimination from the healthcare team is a major factor for the withdrawal of the mothers in relation to the treatment necessary for children, which decreases the quality of care. Often, women living with HIV find an unsatisfactory welcoming by the healthcare team. It is very common to hear reports of the little assistance of healthcare services and the lack of openness to psychological issues that underlie this delicate moment in the lives of these women. There seems to be an unpreparedness on the part of healthcare professionals for caring of these patients, often, due to the lack of knowledge, skill or technique in the area.\textsuperscript{6,13}

For women, the main meaning of being a mother with seropositivity is to be a “super-mom”; as for the healthcare team, these mothers are seen like “resistant”.\textsuperscript{6} Situations like this are the result of misinformation and moral and ethical prejudice. They show a lack of humanization from the professionals in the healthcare services intended for this population, as well as lack of guidance on the appropriate management for HIV-positive patients. These facts might generate constraint on the part of healthcare services users. In the everyday life, these issues permeate the lives of patients and are extended to the family scope and to the society at large to consider.\textsuperscript{18}

Although HIV infection is still incurable, the idea of being a chronic and treatable sickness is widely accepted today. In large part, this concept was promoted by the effects of the medicinal drugs, which have dramatically improved the quality of life of patients, by reducing mortality indexes and the occurrence of opportunistic diseases. Despite the evolution in treatment forms, which increased patient survival and turned it (HIV) into a chronic disease, in popular representations, the association between AIDS and death is very striking. Some studies work with the perception and fear of death by mothers and children.\textsuperscript{19,20} However, from the 14 papers selected for this review, none of these focuses on this specific issue of death and dying.

Other papers address this issue in the following way: the association that the infected women make with the death is mainly expressed at the time of the disclosure of the diagnosis. Subsequently, when they are going to make contact with healthcare professionals and other people in the same situation, when they are not with exacerbated symptoms and compare themselves with the other patients, they believe that death is not as immediate as they thought. Thus, the invisibility of the disease also allows the invisibility of death itself. The perception of death is also unequally manifested in different social groups. The actual threat of death is

Melo KS, Ferreira CL, Maia EC.

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much more present in the less favored social classes of the population, who live exposed to situations of everyday violence and poor living conditions. 4,10,1,20

When this relationship between mother and child reaches the adolescence, it raises other particular issues of this stage of the human development. The most delicate moment regarding the relationships of these young people is in the time to establish relationships outside the family scope, by fear of prejudice and discrimination, especially in affective relationships, which might be expressed in the form of contamination and guilt.21-2

CONCLUSION

Throughout the history of human civilizations, the relationship between mother and son had always an important aspect in the educational formation and, mainly, affective and social for both of them. And when this relationship is coupled with the transmission of a virus like HIV, it becomes critical to understand this relationship loaded of prejudice, guilt and stigma of a sexually transmitted and chronic disease, both from the perspective of that mother who transmitted it, and from the contemporary society that condemns and do not accepts the differences.

This is a relationship based on the confrontation of difficulties, such as facing discrimination from those people who have been trained to care for others. The healthcare team, in several studies, is positioned as one of the main agents of prejudice and, in addition, is the main factor for the disengagement of patients from the critical care for the treatment insertion and maintenance.

This open space for communication and patient dissatisfaction towards the healthcare team is something new in the studies. This can be verified in this review, since researches dedicated to this issue are more recent publications. Thus, we have opened pathways for raising a reflection on the part of those healthcare professionals, so that they might perceive the need for a careful physical and psychological approach, not only for these specific patients, but also across the support healthcare network.

Finally, it should be highlighted the affective and supportive value that prevails in this relationship. When there is a strong and well established bond, when the heart-to-heart dialogue and communication are prevalent, the possibility of holding a good confrontation of difficulties reveals itself as something available to the reality of the binomial, which is no different from other relationships among non-infected mothers and children.

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