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MATERNAL REPRESENTATIONS IN THE CONTEXT OF HIV: FROM PREGNANCY UNTIL THE CHILD'S SECOND YEAR[1]

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ABSTRACT. This study investigated the mother-child relationship in the context of HIV, from pregnancy until the infant's second year, based on maternal representations. Four HIV-positive mothers aged between 19 and 39 years old participated and were interviewed during their pregnancy and when their babies were 3, 12 and 24 months old. Content analysis was carried out based on two categories of maternal representations: *of herself,* and *of the baby*. Results indicated that the mother-child relationship was a mix of satisfactions and challenges related to motherhood, child development and living with HIV. At first, the maternal representations showed a vulnerable infant and a guilty mother who feared the prejudice and social stigma linked to the infection. Over time, the representations indicated a healthier and stronger child, and a less anxious and more secure mother. Concerns about HIV were secondary compared with the challenges posed by child development, especially among mothers who accepted the diagnosis and actively coped with HIV.

Keywords: Human Immunodeficiency Virus; mother-child relationship; motherhood.

REPRESENTAÇÕES MATERNAS NO CONTEXTO DO HIV: GESTAÇÃO AO SEGUNDO ANO DA CRIANÇA

RESUMO. O estudo investigou a relação mãe-bebê no contexto do HIV, da gestação ao segundo ano da criança, a partir das representações maternas. Participaram quatro mães soropositivas, entre 19 e 39 anos, entrevistadas na gestação e aos 3, 12 e 24 meses da criança. Análise de conteúdo qualitativa examinou os relatos maternos com base em duas categorias de representações: *sobre si mesma* e *sobre o bebê*. Os resultados indicaram que a relação mãe-bebê foi acompanhada de satisfações e desafios associados à maternidade, ao desenvolvimento infantil e à convivência com HIV. As representações sugeriram, inicialmente, um bebê vulnerável e uma mãe com sentimentos de culpa, temendo o preconceito e o estigma associado à infecção. Ao longo do tempo, as representações indicaram uma criança fortalecida e uma mãe mais segura frente à infecção e à maternidade. Preocupações com o HIV foram menos enfatizadas diante dos desafios impostos pelo desenvolvimento infantil, sobretudo entre mães que aceitavam o diagnóstico e focavam o seu enfrentamento.

Palavras-chave: HIV; relações mãe-criança; maternidade.

REPRESENTACIONES MATERNAS EN EL CONTEXTO DEL VIH: EMBARAZO HASTA EL SEGUNDO AÑO DEL NIÑO

RESUMEN. Este estudio investigó la relación madre-hijo en el contexto del VIH desde el embarazo hasta el segundo año del niño, basado en representaciones maternas. Cuatro madres seropositivas participaron, con

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edades comprendidas entre 19 y 39 años, entrevistadas en el embarazo y en el 3, 12 y 24 meses del bebé. El análisis de contenido se llevó a cabo sobre la base de dos categorías de representaciones maternas: sobre sí misma y sobre el bebé. Los resultados indicaron la relación madre-hijo fue acompañado por las satisfacciones y desafíos relacionados con la maternidad, el desarrollo del niño y con el VIH. Inicialmente, las representaciones maternas enseñaron un bebé vulnerable y una madre culpable, que temía prejuicios y el estigma social asociado a la infección. Con el tiempo, las representaciones indicaron un niño sano y más fuerte, y una madre menos ansiosos y más segura. Preocupaciones por el VIH eran secundarios a los desafíos que plantea el desarrollo de los niños, sobre todo entre las madres que aceptan y afrontan activamente el VIH.

Palabras-clave: VIH; relaciones madre-niño; maternidad.

Introduction

The first interactions between mother and infant are of great importance for child development and require various adaptations from women and their families (Stern, 1997). The situation becomes more complex when the mother lives with HIV - a stigmatizing disease that can be transmitted to the baby - and depends on a strict compliance with the treatment (Ministério da Saúde, 2010).

Pregnancy in this context is cause for big concerns about the possibility of mother-to-child transmission of the virus. The risk of transmission can be pronouncedly reduced (from 25% to zero to 2%) when preventive measures are adopted, which are made available in the public health system, such as the use of antiretroviral drugs for mother and baby and the substitution of breast milk for infant milk formula (Ministério da Saúde, 2010). The baby will be considered uninfected when he/she presents two viral load tests with results below the detection limit, with the second one being performed after the fourth month of life. Between 12 and 18 months, anti-HIV testing is still carried out for seronegative diagnosis documentation purposes (Ministério da Saúde, 2014).

The context of the pregnancy itself, added to this complex scenario of care of the infected mother and the social stigma still associated with HIV, may bring difficulties to the early mother-child relationship. Studies with pregnant women and mothers living with HIV have identified strong feelings of fear and guilt for a possible infection of the baby and for their own death and impossibility of seeing their children grow (Faria & Piccinini, 2010; Liamputtong & Haritavorn, 2014). Other findings include intense frustration for not being able to breastfeed, and concerns with living the stigma and prejudice (Kelly, Alderdice, Lohan, & Spence, 2013; Trocme, Courcoux, Tabone, Leverger, & Dollfus, 2013). In this scenario, finding out about HIV during pregnancy seems to be an additional stress factor (Kelly et al., 2013), and the anxiety caused by the diagnosis could darken the pregnancy experience.

Many of these feelings seem to persist in the course of the baby's first months and can lead mothers to be overprotective, making themselves entirely responsible for the care (Gonçalves & Piccinini, 2008). Depressive symptoms are also common among these mothers (Nothling, Martin, Laughton, Cotton, & Seedat, 2013), who tend to perceive the way they care for their babies more negatively (Oswalt & Biasini, 2012), and this could be a risk factor for future child behavior problems (Trocmé et al., 2013). It is understood that many feelings reported in the literature are not specific of the context of HIV and may be present among mothers who experience other conditions of risk to the baby. For instance, among mothers of premature babies the presence of intense feelings of fear, exhaustion and overprotection is common (Phillips-Pula, Pickler, McGrath, Brown, & Dusing, 2013). However, there is evidence that mothers with HIV tend to be particularly stigmatized. For example, Lawson, Bayly and Cey (2013) identified more negative judgments and social disapproval towards these mothers than towards those with other clinical conditions (obesity, lung cancer, diabetes). Thus, it could be thought that the stigma linked to HIV seems to add an important risk factor to the motherhood experience.

Aside from difficulties, studies also report many satisfactions with motherhood despite HIV. Motherhood tends to be more valued than seropositivity is and, although mothers fear the infection of the baby they also show confidence in the preventive treatment (Liamputtong & Haritavorn, 2014). Studies reveal a strong maternal affection towards children, in addition to a constant need mothers have to be close to their babies and carry out all necessary care (Gonçalves & Piccinini, 2008). In this sense, motherhood could symbolize an idea of normality in the context of HIV (Kelly et al., 2013), and the mother-child relationship would not be negatively affected by the presence of the virus, especially if

there is family support and access to treatment (Faria & Piccinini, 2010). Studies have also indicated that, as tests confirm the babies' seronegativity, maternal concerns would focus on stigma and prejudice (Shannon Kennedy, & Humphreys, 2008) and their health itself (Lazarus, Struthers, & Violari, 2009).

Despite the relevance, there are still few studies addressing the mother-child relationship in the context of HIV beyond the pregnancy and first months of life. In fact, the first two years are an important period for fighting the infection as it comprehends the process of testing and confirming the baby's diagnosis, at the same that the mother needs, increasingly, to care for herself in the face of the infection. Moreover, it is a critical period in the early relationship between mother and child, marked by rapid changes in child development and during which every interaction provides an important direction for the child's emotional development (Stern, 1985/1992).

Based on concepts from Developmental Psychology and Psychoanalysis, and considering the bidirectional nature of the mother-child relationship, Stern (1985/1992, 1997) understands this interaction as a bridge between the subjective world of mother and baby through which the latter develops his/her own ability to relate to others. The author calls *maternal representations* the way the mother experiences and interprets events of the interactive experience with the baby, and considers them a major influence on the mother-child relationship and child development. The interactive experience on which representations would be based can be real or imagined, and the mother's representational world would include, in addition to everyday experiences with the baby, fantasies, hopes, fears, dreams, memories of her own childhood, parent models and predictions for the baby's future. Among the various maternal representations, Stern (1997) highlights the *representations of herself* and *of the baby*, whose concepts will be used in this study.

A mother's representation of herself are reassessed and reorganized from the new reality with the baby, considering her as a woman, mother, wife, professional, daughter, among others (Stern, 1997). These representations are constantly transformed in the everyday interactions with the baby, and every change in the development of the baby can lead to changes in the maternal feelings of competence and self-confidence. Maternal representations of the baby, in turn, include the interactions considering him/her as to his/her temperament, personality and acquisitions, and the different places he/she occupies in the family. Such representations are present since pregnancy and follow the development of the baby. In the first two years of life, mother-child interactions, initially focused on the regulation of feeding and sleep-waking cycles, have their repertoire expanded as the baby develops in cognitive and motor terms, acquires language and learns rules (Stern, 1985/1992). Thus, maternal representations of the baby also change in the light of these new acquisitions.

As for the context of HIV, few studies appear to have specifically used Stern's ideas (1997) on maternal representations. Gonçalves and Piccinini (2008), for instance, identified that changes in maternal representations in the first months of the baby's life were crossed by specific concerns related to living with the virus and the possibility of infecting the child, leading to an overprotective care of the baby. The HIV infection seems to affect maternal representations, especially during pregnancy and the baby' first months. However, it is not known for sure how this influence occurs later in the baby's development, especially after the diagnosis, from 12 months of life. In this way, this study aimed to investigate the mother-child relationship in the context of HIV, from pregnancy until the child's second year of life, based on the concept of maternal representations by Stern (1997).

Method

Participants

This study counted with the participation of four mothers who were living with HIV, followed up from pregnancy until the child's second year. During pregnancy, all of them were married, aged between 19 and 39 years old and differed in terms of number of children and time since the HIV diagnosis (Table 1). The babies, in turn, were not infected with HIV and did not present any serious

health problems. The participants were being followed-up at reference centers for HIV/Aids in the public health network in Porto Alegre-RS. They were part of a larger research project *Aspectos psicossociais, adesão ao tratamento e saúde da mulher no contexto do HIV/AIDS: Contribuições de uma intervenção psicoeducativa da gestação ao segundo ano de vida do bebê - PSICAIDS* (Piccinini et al., 2005) that followed up 90 pregnant women living with HIV until their child's second year of life, and investigated several aspects related to motherhood and child development, as well as psychosocial and health characteristics. Details of the project in terms of procedures and instruments used can be found at Piccinini et al. (2005). The selection of cases for this study prioritized heterogeneity regarding the pregnancy context (primipara/multipara) and the moment of the HIV diagnosis (before/during pregnancy).

Table 1 - Sociodemographic data about mothers.

Case	Age	Education	Occupation	Married (time)	Number of children	HIV diagnosis (time)
1	25	Complete High School	General services	3 years	0	5 months
2	19	Incomplete Elementary School	Housewife	2 years	0	1.5 years
3	39	Incomplete Elementary School	Housemaid	1 year	3	5 months
4	30	Incomplete High School	Housemaid	4 years	1	1.5 years

Design, procedures and instruments

This is a multiple case study (Stake, 2006) of longitudinal character. The participants were first contacted at the health service where they were undergoing prenatal care, when they signed an informed consent form and answered the *Family Socio-Demographic Data Interview*. In the last quarter of pregnancy they answered the *Interview on Pregnancy in Situation of HIV Infection* and the *Protocol for Assessing Compliance with HIV Treatment*. In the baby's third month, the mothers answered the *Interview on Motherhood in Situation of HIV Infection*, the *Interview on Baby Development in the Context of HIV* and the *Protocol for Assessing Compliance with HIV Treatment*. These interviews and protocol were reapplied when the children were 12 and 24 months old, using a version adapted for each age group. The interviews were conducted at the health service individually (approximately duration of 90 minutes), recorded and then transcribed. The project PSICAIDS, of which the present study is part, was approved by the Ethics Committee of the Universidade Federal do Rio Grande do Sul (Proc. 2005508).

Results and discussion

Data was analyzed through qualitative content analysis (Laville & Dione, 1999), aiming to investigate the mother-child relationship in the context of HIV, from pregnancy until the baby's second year of life, based on the concept of maternal representations by Stern (1997). For the author, maternal representations are based on interactive experiences between mother and baby, which in the present study were inferred from the mothers' reports. Two categories of maternal representations suggested by Stern were analyzed: 1) *Representations of herself*, and 2) R*epresentations of the baby*. The first category involved reports on how the participant perceived herself as a mother living with HIV. The

second category included reports on the health, development, personal and physical characteristics of the baby. The content was categorized with the aid of the qualitative analysis software NVivo (version 9). Next, each case will be presented with its particularities and illustrated with maternal reports. At the end of each case, a brief dynamic comprehension is presented with the main longitudinal aspects[3].

Case 1: Patrícia and Jonas[4]

Pregnancy: Patrícia was expecting her first child, Jonas, who had been planned. She and her husband found out they were HIV-positive during her pregnancy, and chose not to disclose the HIV diagnosis to other family members. The *representations of herself* indicated that Patrícia was happy with the pregnancy despite the initial shock after the news. In order to stay physically and emotionally well, she sought professional support and information about HIV: *"We have to lift our head and keep going as if nothing happened, without dropping the ball, for the baby; we have a son now".* Patrícia set her mind on positive aspects of reality such as her good immunologic condition, the possibility of treating the disease and preventing the baby from being infected. She had concerns about the transition moment she was experiencing, such as the upcoming childbirth and the care of the baby after she returned to work, but also specific ones regarding HIV, such as administering medication to the baby and fearing prejudice. With regard to *representations of the baby*, Patrícia could imagine him and attribute to him physical and psychological characteristics, but did not have the habit of talking to the baby. She showed concerns about his health, including the possibility of HIV infection. To deal with such distress, she idealized the baby, imagining him as handsome and healthy, whom she thanked for helping her to find out about the virus.

Three months: The *representations of herself* portrayed a confident and fulfilled mother who was consolidating her own way of caring for her son. She felt it was easy to understand her baby and meet his needs. Regarding HIV, she seemed more concerned about her health and appealed to thoughts like "there are worse diseases" to stay emotionally well. She was still keeping the diagnosis a secret for fearing prejudice. As for the *representations of the baby*, Jonas was developing well and was described as joyful, calm and easy to handle. Patrícia saw him healthier and stronger despite the virus: *"Now I am more confident. I had to put in my head that he is safe because I complied with the whole treatment".*

12 months: The *representations of herself* showed that Patrícia was happy with motherhood, but also tired due to the routine with her son, in addition to having trouble setting limits. She was consistent in her treatment, without mentioning greater concerns about her health. The *representations of the baby*, in turn, emphasized the restless and energetic behavior of her son, but also his pleasant temper. Although HIV-negative and developing well, Patrícia considered that he had a potential risk of being infected in the daily interaction with his parents, for instance through contact with blood and wounds. Nevertheless, she said she did not deprive herself of moments with her son, but ensured that possible wounds of hers were well protected with bandages.

24 months: The *maternal representations of herself* showed a woman happy with motherhood, but distressed for having to balance the time with her son with her job away from home. Patrícia felt tired and struggled to set limits to him. She had even sought psychological support to deal with it. As for HIV, although in good health conditions, she considered that the concern about the infection would always be present, and kept using positive thinking as a coping strategy. She also continued to hide the diagnosis from her family. About *representations of the baby*, Patrícia saw Jonas as a healthy, good-natured child who was constantly learning, but he was also restless and had trouble accepting limits. She understood that her son behaves like that to have her attention, since she spent little time with him. Patrícia again mentioned the risk of Jonas contracting HIV in the daily life with his parents, being one more reason for her to care of herself, preventing wounds or protecting them well: *"I try not to think about it, but then he*

[3] The thesis entitled *Relação mãe-bebê no contexto do HIV: Investigando as representações maternas da gestação ao segundo ano de vida da criança*, written by the first author of this article, available at www.lume.ufrgs.br, on which this article is based, contains several reports of each case that could not be presented herein due to space limitations. For this reason, the transcriptions were edited so their length could be reduced, but without loss of their essence.

[4] All names are fictitious, preserving the identity of the indivbiduals involved.

gets sick and 'oh my God, what if that is it?' I do not think this risk is real, but it worries me because he is a child living with parents who have the virus".

The longitudinal analysis of maternal representations indicates that the *representations of herself* initially denoted a maternal identity under construction, with positive expectations that remained even before the HIV diagnosis. Throughout the period investigated, Patrícia consolidated her maternal identity and materialized her positive expectations in the everyday life with her son, but with some difficulties associated with the transition moment experienced. The HIV infection seemed to be accepted by the mother over the period, and she coped with it by attempting to stay emotionally well; in this way, the HIV did not seem to interfere heavily with motherhood. The reports associated with the *representations of the baby*, in turn, were about a baby covered by his parents' affection, but potentially vulnerable due to the infection. Such vulnerability was gradually replaced by the representation of a healthy baby with good development, though inserted in a context of vulnerability due to his parents' diagnosis. Jonas lived with the challenge of reconciling his constant acquisitions and the learning of limits. In general, the relationship between Patrícia and Jonas was marked by affection and care, but also by challenges inherent to motherhood and child development. The HIV infection, always present and acknowledged, did not prevent the exercise of motherhood by Patrícia, neither seemed to affect the child's development directly.

Case 2: Regina and Paulo

Pregnancy: Regina was expecting her first child, Paulo. She knew of the diagnosis since a year and a half ago and disclosed it only to her husband, who was HIV-negative. The *representations of herself* showed a quite ambivalent expectant mother: she spoke of her desire to get pregnant, but also said that pregnancy was not in her plans because she had the virus. She felt happy but also worried about the baby. She envisioned a good relationship with him, but also felt insecurity and frustration for not breastfeeding and guilt because her baby would have to take medicines: *"Every mother dreams of leaving the recovery room, holding her baby and breastfeeding him"; "A child taking medicines without even knowing why… it is my entire fault".* The r*epresentations of the baby* involved concerns about his health and nutrition, since he would not be fed with breast milk. She talked to her baby and explained to him about using the bottle so he understood why he would not breastfeed him.

Three months: The *representations of herself* indicate a happy mother positively surprised with her performance in the care of her baby. However, Regina felt quite uncomfortable with him being on medication as well as with her inability to breastfeed him, although she complied with all the required care: *"Every mother wants to protect her child, breastfeed her. Being a HIV positive already changes everything; you have to give them a bottle"; "If one day they find the cure for the virus, the first thing I will think about is having a child, only to breastfeed her".* As for the *representations of the baby*, Regina mentioned his good development, growth and health. Despite the fear for her baby's infection being still present, she was more confident after the good results of his exams. Paulo was seen as calm, cheerful, affectionate, but also demanding. Regina was concerned about his nutrition because he had not been fed breast milk. According to her, he was a 'glutton'; so that he was satiated, she would give him a greater amount of milk than that recommended by the nutritionist. She also reported that Paulo did not accept the medication well and was reluctant when he had to take it.

12 months: The *representations of herself* indicated that Regina was happy with motherhood and her child, and more acquiescent to not having breastfed him. She felt difficulties in setting limits, and found in the day care center a way to organize her son's routine, which she tried to keep at home. As for HIV, Regina had a metabolic change due to the use of antiretroviral drugs, was hospitalized and felt afraid to die and leave her son. Her medication was substituted and she was already home and better, but because all this was recent, she was still insecure about staying alone with him. Given this situation, she chose to disclose the diagnosis to her mother and grandmother, who supported her, *"If I knew it, I had told them long before".* The *representations of the baby,* in turn, showed the good development and health of her child, considered uninfected by his mother: *"Whatever you teach him he pays attention;*

then you turn your back and he is doing it. He plays games, can already separate the right colors". Paulo was referred to as affectionate, calm and cheerful, but also a glutton, and adapted well to new routines.

24 months: The *maternal representations of herself* described a competent and fulfilled mother in the exercise of motherhood, who valued the dialogue with her child and shared his discoveries: "He is always calling me: *'Mom, come see it!'. It is amazing! Each day a new thing"; "I thought it would be way harder, but I am doing quite well".* Regina was more confident about how to handle the setting of limits to her son and balance the work and care routines. Her tests indicated that the infection had been controlled; however, Regina would have to undergo a hysterectomy because of a severe uterine injury, whose rapid progression could be associated with the HIV presence. Thus, she could not get pregnant anymore. To deal with this grief, she found comfort in the feeling of fulfillment about the relationship with her son: *"I am sad about the surgery itself, but just the thought of knowing I already have a child… I always wanted a little boy. I am happy already; it was worth it all".* About the *representations of the baby*, Regina described Paulo as active, communicative and adaptable, and said he was learning to deal with limits. He was a healthy child, and Regina no longer considered him likely to be infected.

The longitudinal analysis indicates that the *representations of herself* initially denoted a mother insecure about the arrival of her first child, with a number of concerns related to motherhood and the HIV presence. An intense frustration with her inability to breastfeed was present, in addition to guilt for her child needing medication, which seemed to impact her relationship with the baby during pregnancy and the first months of life, for instance when it comes to her overfeeding him and explaining about the use of the bottle. Gradually the reports showed a mother who was more confident and secure about motherhood and seemed to have elaborated the initial grief caused by the presence of HIV, especially with regard to her inability to breastfeed, which allowed her to turn to this relationship with her son in a smoother way. She acknowledged the limitations arising from living with HIV and the grief she needed to elaborate in the face of the possibility of not gestating anymore, without this seeming to weaken her in the maternal role she had been playing. The *representations of the baby* at first indicated a fragile baby threatened by the infection and lack of breast milk. Increasingly, his good development, learning and various adaptations were evidenced, and he was no longer considered threatened by HIV. Given the above, it is found that, although the HIV diagnosis had caused an initial tension, present in the mother-child interactions, the virus gradually took a secondary place in the relationship between Regina and Paulo. Although present and manifested in the mother's health, the infection no longer seemed to affect the mother-child relationship negatively.

Case 3: Mara and Denis

Pregnancy: Mara became pregnant with her fourth son, Denis, in an unplanned way. She found out about HIV during her pregnancy and, until then, with little knowledge about the virus, only understood it as a fatal and incurable disease. She received support from her children and husband, all HIV-negative. Regarding the *representations of herself*, Mara was very involved with her baby, with whom she envisioned a good relationship. She believed she would be even more caring with this child because of the virus, which added worries as well as sadness for not breastfeeding: *"All of them were breastfed… and now this one… knowing that I will have milk but will not be able to breastfeed him… It is hard but I know I cannot… no way".* Despite the initial shock, she claimed to be less worried about the virus in that final moment of her pregnancy. She was undergoing the treatment prescribed but avoided thinking about the infection. She tried to keep the same routine as before and did not like when others worried about her health. As for the reports associated with the *representations of the baby*, although Mara feared that he would be infected, she said she did not consider this possibility for being complying with the preventive treatment. She imagined her baby would be smart and look like her other children. Mara assigned him the role of 'savior': "*This baby came to prevent something worse from happening. I think this baby came to save me. If it was not for this pregnancy I would have not found that out. So I began*

to accept, and now I am so close to him!; Feeling his movements was the best thing because I really felt he was a living being, that it was for him that I had to fight".

Three months: The *representations of herself* portrayed a loving mother who was competent in the care of her baby, but also sad for not having breastfed. Feeling calmer with motherhood, she could speak about some fears that she had not addressed during pregnancy, as the fear of not feeling affection for her son, or having this relationship shaken by the presence of the virus. She took entire responsibility for the care of her baby and had difficulty accepting any help. Mara said she did not worry about the virus because she had good immunological conditions and did not notice any limitations in her routine: *"It is like I did not have the virus. I work, I clean the house, I walk barefoot, I wash the house with a hose, and I do not feel sick. It is no problem having it. I think there are things more serious than having the virus".* However, she reported fearing that her children were left alone if she happened to fall ill, and discomfort for having to answer questions about why she was not breastfeeding. The *representations of the baby* showed a healthy baby who was developing well. Mara was confident that her child had not been infected, supported by preliminary tests indicating his seronegativity. Denis was seen as affectionate and smiling, and very dependent and close to her. Mara was ambivalence about that: she was happy for having her son's preference, but felt tired and overburdened for always having to be with him, since he would not accept to be cared for by other people.

12 months: The *representations of herself* evidenced a responsible and caring mother. Mara reported with pride how much she tried to satisfy the desires of her son, but also felt tired in this routine, to which she was fully devoted. She said little about HIV. She only said that she was alright but afraid of infecting her children in everyday situations, such as contact with wounds and dishes, and, for this reason, was careful not to get hurt. In the *representations of the baby*, Mara referred Denis as a healthy baby who was developing well and no longer ran the risk of being infected with HIV. According to her he was restless, demanding and easily irritated when paid no attention: *"He is good-natured, but there are days when he is cranky, only cries. It is hard, but ... sometimes any little thing annoys him; you have to walk with him all the time, he is restless".* He resisted being taken care of by other people or sleeping away from Mara, which ended up burdening her.

24 months: Mara became depressed, and the *representations of herself* were affected by this depressive state. She associated depression with the assimilation of her HIV diagnosis ("the penny has dropped") which, until then, had been somehow denied: *"I do not think being a mother has been hard so far; hard it is to live with the virus; I do not even like to talk about it much".* Although depressed she showed satisfaction with the relationship with her child, felt him close to her and tried to keep herself involved in care activities, even if at a slower pace. Mara was aware of her limitations at that time and could finally accept support from her family with the care of her son. The *representations of the baby* showed a healthy child with good development, calm and cheerful but very dependent of his mother. In this sense, Mara was concerned because she saw that her son did not eat and suffered during her absence: *"He cannot see me leaving; you have to hide him, otherwise he cries and keeps crying until I get back. When I arrive he does not let go of me, fearing that I will leave".*

The longitudinal analysis indicates that the *representations of herself*, crossed by the news of HIV, initially showed a loving mother who dealt with the distress mobilized by the knowledge of the diagnosis and waiting for the baby by using strategies based on the avoidance of the diagnosis and maternal omnipotence, shown by an overprotective care towards the baby, for which the mother was fully responsible. Such strategies, however, were insufficient in the long term, denouncing the mother's fatigue due to having to care for the child and the impact caused by the diagnosis, culminating in a picture of depression. The reports associated with *representations of the baby*, in turn, initially revealed intense maternal projections, including that of him having come into the world to reveal the HIV diagnosis. In this way, Denis should have his needs met promptly, and felt angry and demanding when that did not happen. He also seemed to suffer the impact of HIV when living with Mara's depression, and appeared insecure when away from her. With that said, it is considered that the relationship between Mara and Denis, in general, was marked by affection, but also dependence, anxiety and insecurity. Although all these feelings are present to some degree in any mother-child relationship, their persistence and intensity can cross the line separating health and psychopathology. In the case of Mara and Denis, the impact in the face of HIV, the distress and the activated coping strategies seem to have

intensified those feelings, contributing to depression. Fortunately, Mara was being treated and recovering, now having assimilated the reality of the presence of the infection.

Case 4: Flavia and Carol

Pregnancy: Flavia was the mother of a boy and was expecting a girl, Carol. She knew of the HIV diagnosis before pregnancy, and was already on medication. Some family members and her husband, who was HIV-negative, also knew of her condition. However, the reports associated with the *representations of herself* were crossed by the anxiety mobilized by the infection. Flavia had a positive perception of herself as a mother, wanted another child and was happy about carrying a girl. However, having HIV filled her with guilt, fear and anxiety: *"I cannot get it out of my head… since I knew I was pregnant. My fear is bigger than everything".* She was afraid of being judged for being pregnant and HIV-positive. For this reason, Flavia sought to isolate herself from her social circle: *"The day I give birth to her no one will know [for fearing that somebody finds out about the HIV at the hospital], and when I tell everyone, I will be already home".* The *representations of the baby* were also crossed by anxieties due to HIV. She feared that her daughter was HIV-positive, died or had malformations. Flavia felt guilty and thought that her daughter might need extra care after birth. Given all that, it was hard for Flavia to imagine how her daughter would be in terms of appearance or personality.

Three months: The *representations of herself* described a mother who was more confident and secure about the care of her daughter, and less guilty because she believed that she had not transmitted the virus to her: *"I thought it would be harder. I even thought she could have the disease and it would be harder to take care of her".* Her concerns were focused on reconciling her return to work and the care of her daughter, although she counted on family support. As for the infection, she was less anxious about judgments and more concerned about her own health due to a decrease in her immunity. She felt anxious when she thought she could die and have little time with her children. With respect to the *representations of the baby*, health and the first result of the test assured her that her daughter would not have the virus. The strong anxiety during pregnancy seemed to have been reduced. He considered her daughter good-natured, sometimes angry, but easy to handle.

12 months: The *representations of herself* portrayed a careful and competent mother in the routine with her daughter: "*I am a real doting mom, very caring, attentive, a super mom".* About the HIV, she claimed she was calmer, was complying with the treatment, kept herself healthy and resumed social situations from which she had isolated herself: *"I am normal. My doctor said, 'you have to take care of yourself, but you have to live a normal life, otherwise you will get depressed', so that is what I am doing".* The *representations of the baby* were marked by the good development of her daughter and the test results indicating seronegativity. She felt afraid when her daughter fell ill, but the feeling did not seem strong, since the child was in good health. According to her, Carol had a temper and was pretty sociable; she was also close to other family members, which calmed Flavia down, as she though that her daughter would be fine if she fell ill.

24 months: The *maternal representations of herself* evidence a loving and caring mother with her daughter, who knew to set limits, though feeling tired because of work. As for HIV, she perceived she was coping better with the infection and managed to talk more openly about the issue. She kept good health habits and knew that she should do so for the rest of her life in order to strengthen herself against the virus. She felt an urgency to leave everything ready for her children, especially financially, in case she died. About the reports associated with *representations of the baby*, Carol was in full development, healthy and cheerful. Flavia's concern revolved around her daughter falling ill, because she always thought of the possibility of it being a sign of HIV infection, despite the seronegativity diagnosis having been confirmed: *"She got sick the other day; you think about all kinds of things. The tests came back negative but you never know…".*

The longitudinal analysis of the *representations of herself* initially denoted a distressed mother, whose guilt for the possibility of infecting her daughter threatened her self-perception as a good mother. The fear of suffering prejudice and the fear of death were quite intense during pregnancy and led her to

have isolation attitudes. Gradually, the reports associated with the representations showed a more confident mother who had adapted to the reality of living with the infection, whose anxiety had been accommodated and given way to a more peaceful experience of motherhood. The *representations of the baby*, in turn, initially indicated a fragile baby threatened by the virus, but who, after birth, developed well and bonded with Flavia. The risk of infecting her daughter did not disappear completely and was perceived when the child would fall ill, although less intensely. With that said, it is considered that the relationship between Flavia and Carol, initially crossed by intense anxiety and maternal guilt, gradually came to be marked by a strong emotional bond and many satisfactions with motherhood. This relationship conceived the presence of HIV and the finitude perspective mobilized by the life with a chronic disease without, however, appearing to impair the child's development.

General discussion

The present study investigated the mother-child relationship in the context of HIV, from pregnancy until the child's second year of life, based on maternal representations. Considering the similarities between the cases presented, it was clear that the influence of HIV was always present but in different ways throughout the period investigated. Thus, despite the infection, the mother-child relationship in the course of two years in the child's life was accompanied by several satisfactions and joys, in addition to challenges associated with motherhood performance and child development.

In the initial period involving the pregnancy and the first three months of life there was a prevalence of representations of a mother quite guilty for a possible infection of her baby, afraid of being judged and suffering prejudice for having a stigmatized disease and being gestating in this context. Such representations were accompanied by intense anxiety, and these findings agree with previous studies conducted with pregnant women and mothers living with HIV (Faria & Piccinini, 2010; Liamputtong & Haritavorn, 2014; Trocme et al., 2013.). A very interesting aspect evidenced in the literature, and which was present here, was the frustration for the inability to breastfeed. Such frustration proved present both in the representations of herself, since the mother needs to elaborate the grief for an aspect that culturally makes motherhood concrete (Liamputtong & Haritavorn, 2014), and in the representations of the baby, who is deprived of breast milk (Faria & Piccinini, 2010). Thus, the representations of the baby during this early period were also greatly influenced by the context of HIV, since the possibility of infection and the lack of breast milk seemed to make him/her more vulnerable for these mothers. Based on Stern's conceptions (1997), according to which maternal representations influence the mother-child relationship, it was possible to see that they were staged in the interactions in different ways from mother to mother, including emptying or idealizations about the imaginary baby, maternal isolation and excessive care with the baby. The presence of overprotective care had already been evidenced in the literature (Gonçalves & Piccinini, 2008) and associated with the fear of infecting the baby, as well as more avoidant attitudes on the part of mothers towards their children, which, if persistent, can impair child development (Nothling et al., 2013;. Trocme et al., 2013).

However, over the first and second years of life, changes have been noticed in these maternal representations, which portrayed a stronger child in the face of HIV, and a more confident mother despite the infection and motherhood. While anxieties related to the infection seemed to decrease, since the babies' tests did not confirm their infection, satisfactions and fulfillment concerning motherhood, child development and the mother-child relationship became even more manifest, and these aspects seemed to be more valued than the presence of HIV, corroborating previous findings (Gonçalves & Piccinini, 2008; Kelly et al., 2013.). The main difficulties reported by the mothers with respect to the mother-child relationship were the setting of limits, and fatigue resulting from their work routine and care of their children. However, said difficulties appear to be proper of the child's development period, marked by a significant increase in the child's autonomy, which requires great adaptation from parents (Stern, 1985/1992), more than any specific trend associated with the HIV context.

In the child's first and second years, the mothers reported concerns about the possibility of their children being infected in the everyday life with their HIV-positive parents through contact with blood and wounds, which were also present in the study by Faria and Piccinini (2010). However, such concerns did not seem to have a direct influence on the mothers' interactions with their children, but emphasized the mother's self-care. It was also possible to identify that the concerns of mothers in general switched from the baby's health to their own health, just as found in studies by Lazarus et al. (2009) and Shannon et al. (2008). This is because the maternal infection was still active and, in some cases described here, brought consequences to the mothers' health. On the other hand, it was also found that mothers who acknowledged the limitations of living with HIV and spoke of their distresses did not report overprotective care with their babies at the end of the first and second years. It seems that the possibility of connecting with their pain and grief helped them elaborate these feelings, making the latter less likely to affect the mother-child relationship. Thus, it is possible to think that the persistence of overprotective care with the baby after his/her first years of life would be more present among mothers who attempt to avoid contact with the anxieties caused by the diagnosis, which may cause them to feel a strong need to protect their babies.

In this study, one of the mothers (Case 3) exemplified these findings in a more specific manner. She showed some avoidance of the HIV diagnosis, as well as a need to overprotect her baby, which seemed to give her the idea that her son would also be protected from the infection threat. This mother stimulated the maintenance of dependent behavior in her son, even when his development called for greater autonomy (Stern, 1992). Given the prevalence of maternal anxiety, it is understood that the adaptive capacities and singularities of the babies seemed to be left in the background, which can jeopardize their emotional development (Stern, 1997). Thus, it is worth stressing the importance of being attentive to the process of acceptance and living with an HIV diagnosis on the part of mothers, which can last many months after birth, even after the baby's diagnosis has been defined. In this sense, helping mothers to express and experience the anxiety mobilized by the virus, bringing the reality of the infection closer rather than avoiding it, appears to be a way to prevent maternal anxieties from intervening in mother-child interactions.

Another aspect that deserves attention is the association between maternal depression and HIV, already evidenced in the literature (Nothling et al, 2013; Oswalt & Biasini, 2012; Trocme et al., 2013) and in the present study as well. In the case which it was most present (Case 3), maternal depression proved more intense in the child's second year, after the diagnosis was acknowledged by the mother from an emotional point of view. Considering that maternal depression poses a potential risk to the mother-child relationship and child development (Nothling et al., 2013), it is worth reinforcing the need to be mindful of the impact of HIV on the mother's emotional health and assist these mothers.

In short, the findings of this study indicate that the influence of HIV on the mother-child relationship gradually gave way to aspects proper of motherhood and child development, including satisfactions and challenges over the babies' first two years. The presence of HIV was conceived by mothers as an ever-present vulnerability but less valued in the face of the experiences enabled in their relationship with their children. However, this process seems more possible when mothers manage to accept limitations and possibilities to face the infection, focusing on coping.

Final considerations

The findings of this study highlight the importance of expanding the focus of healthcare to beyond the mother-child HIV prevention, paying special attention to the mother's mental health so that the developing child is protected too. Such attention also consists of understanding the social and still stigmatizing components surrounding HIV to which these mothers are subject. Welcoming them, encouraging them to go after their rights and helping them find effective social and family support are key aspects in the service for these mothers.

It is worth highlighting herein some methodological limitations of the study. Data based on reports about a few cases may not have contemplated other relevant aspects of the mother-child relationship,

and aimed at understanding the cases without pretension of generalization. Thus, studies involving a larger number of participants and which resort to various instruments in the same investigation, including direct observation of the mother-child interaction, should be further conducted, allowing the triangulation of findings (Stake, 2006). It is also important to consider that the data of this study can only be validated within the social context of the participants, who had family support, had no major physical limitations resulting from Aids, had access to specialized health follow-up, and whose babies were seronegative. Finally, it is emphasized that, given the objectives of this study, many important points have not been deepened herein (e.g. disclosure of the diagnosis, marital relationship, reproductive rights, social stigma and prejudice, inability to breastfeed) and deserve further studies due to their relevance. Aside from these eventual limitations, this longitudinal study involving two years of follow-up broadens the findings in the literature for showing the articulation between the context of HIV, motherhood and the mother-child relationship during the early period of child development, especially after the baby's diagnosis has been defined.

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