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Empirical Articles

Analysing the Experience of Motherhood Among Adolescents Living With HIV

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Abstract

Aim: Adolescent motherhood is considered a condition of vulnerability that can be further complicated by the presence of HIV infection, but little is known about how adolescent mothers experience this process. The aim of this study was to analyse the experience of motherhood among adolescents living with HIV.
Method: Seven mothers (15-21 years) recruited in specialized services in Porto Alegre/Brazil, whose babies' ages ranged from four to six months, were interviewed. Interviews were tape-recorded and transcribed *verbatim*.
Results: The qualitative content analysis of the interviews revealed a positive vision of motherhood, related to satisfaction with the maternal role and personal fulfilment. Pregnancy and motherhood served to these adolescents as an encouragement for self-care. The mothers' difficulties were related to HIV and to the repercussions of this clinical condition, especially feelings of frustration and incompleteness of motherhood on the impossibility of breastfeeding, as well as fear facing the risk of MTCT.
Conclusion: Future research of longitudinal design and with larger samples will be important to extend the knowledge of the specificities of this experience over time for young people of different ages and social backgrounds.

Keywords: motherhood, adolescence, HIV

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When motherhood occurs during adolescence, the demands that are typical of this event (e.g., ability to adapt to their new role as a parent) overlap with those expected for their developmental stage (DeVito, 2010). Adolescent motherhood can be further complicated when occurring simultaneously with the presence of a medical condition such as HIV infection. Adolescent motherhood in the HIV context is, however, a theme that has been underrepresented in research. Most studies examining motherhood in this context largely focused on the experiences of adult women (Kennedy et al., 2014; Sanders, 2008). Existing studies that involved adolescents with HIV has mostly focused on topics such as pregnancy incidence (Elgalib et al., 2011), contraceptive choices (Belzer et al., 2001), reproductive decision-making (Fair et al., 2013), disclosure (Gillard & Roark, 2013), health literacy (Navarra, Neu, Toussi, Nelson, & Larson, 2014) and anti-retroviral adherence (Kim, Gerver, Fidler, & Ward, 2014). To the best of our knowledge, no studies have focused the experience of

motherhood from the adolescents' point of view. Therefore, the aim of this study was to examine the experience of motherhood among adolescent mothers living with HIV.

Motherhood entails the early assumption of various responsibilities by the adolescent, assuming roles for which she may still not be prepared. In the literature, it was not possible to identify a single pattern regarding the experience of motherhood among adolescents. While for some being a mother was a positive experience, others perceived it as a cause of frustration. Santos and Schor (2003) identified these two types of experiences among Brazilian adolescents, who were both happy about the greater maturity and autonomy, but also sad and distressed due to the lack of support for caring the baby. Recently, Smith, Skinner, and Fenwick (2012) also showed that adolescents reported a vision of motherhood as a positive experience that fostered an opportunity to reduce risk behaviours (e.g., use of drugs and alcohol), to demonstrate personal growth and to become independent.

The presence of HIV can however bring additional challenges for the experience of motherhood. Being a mother with HIV often brings guilt, fears, prejudices (Carvalho & Piccinini, 2006; Pereira & Canavarro, 2012) and changes in women's reproductive choices, such as the decision not to have other children (Barnes & Murphy, 2009). One aspect that seems to cause more distress is the possibility of mother-to-child transmission (MTCT) of HIV (Pereira, Dattilio, Canavarro, & Narciso, 2011; Sanders, 2008). As one of the most important modes of HIV transmission is through breast milk, these mothers are oriented not to breastfeed, which causes distress. In studies with adult mothers, the indication of feelings of guilt, frustration and sadness resulting from this inability was common (Rigoni, Pereira, Carvalho, & Piccinini, 2008). For others, indifference related to this prohibition has been also reported, especially in the case of previous experience of non-breastfeeding (Paiva & Galvão, 2004).

Although HIV may add difficulties to the experience of motherhood, this experience can be also positively transforming. The birth of a child may bring a new meaning for life (D'Auria, Christian, & Miles, 2006) and serve as a stimulus to self-care (Pittiglio & Hough, 2009), positively influencing the implementation and adherence to anti-retroviral treatment (ART; Sandelowski & Barroso, 2003). Hence, it is plausible that motherhood may act as a protective factor for young mothers (Barr, Simons, Simons, Gibbons, & Gerrard, 2013), including for those with HIV (Vescovi, Pereira, & Levandowski, 2014). Therefore, studying motherhood during adolescence in the context of HIV is of utmost importance, so that, along with the increase of knowledge about this theme and this specific population, strategies of health care better adapted to the context and needs of adolescent mothers may be developed and implemented.

Method

Participants

The study sample consisted of seven young mothers (15-21 years), who received an HIV diagnosis during pregnancy or childbirth. All participants were enrolled in specialized HIV services in Porto Alegre, Brazil, from February to October 2011. Participants were enrolled within a larger research project, with the purpose of assessing the mental health, adherence to HIV treatment, motherhood experience, and mother-baby relationship among adolescents living with HIV. This study was approved by the Research Ethics Committee of the Federal University of Health Sciences of Porto Alegre (Protocol 10-617) and all health institutions involved.

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Procedure

The participants' recruitment was held in health services, while they were waiting for clinical care. All participants fulfilling the inclusion criteria of the study (13 to 21 years, baby from 3 to 9 months old, diagnosis of HIV infection during pregnancy or childbirth, and nulliparity) and who agreed to participate were informed about the study's aims and provided written informed consent. A legal guardian also signed the consent form for the participants below 18 years old. In this first face-to-face contact, the participants completed a sociodemographic form and the study self-reported questionnaires. Permission for a later telephone contact was also requested, in order to schedule a face-to-face interview at least seven days later. The aim of this interview was to assess the pregnancy, birth and motherhood experience and the impact of a HIV diagnosis on these experiences. The interview was conducted individually at the health unit (on a private room), audio-recorded, and later transcribed. On average, each interview lasted between 40 and 60 minutes. Participants and their companions were provided with funds to cover transportation expenses to the health unit.

Data Analysis

A qualitative content analysis of the interviews was performed. All interviews were tape-recorded and transcribed verbatim to Portuguese. The transcripts were read while listening to the audio files to check for accuracy and to make sure no information of the interviews was missed. Content analysis identified several categories of answers related to the selected topics. However, after thoroughly reading the transcripts, some of the categories initially listed were changed, as well as thematic subcategories were organized. The mixed model of analysis proposed by Laville and Dionne (1997) was adopted. Considering the structure of thematic categories and sub-categories, two of the authors (G.C.R. and D.C.L.) allocated salient citations from the interviews separately. The two judges had several encounters to identify and discuss the central themes. Eventual doubts on categorization were solved by discussion and consensus between the two judges.

Results

Sample Characteristics

Participant characteristics are outlined in Table 1. All participants were first-time mothers and their children were between 4 and 6 months of age at the time of the study. Five participants identified themselves as single, but in romantic relationships (in all cases with the baby's biological father). One participant was employed and none was attending school at the time of data collection. Four adolescents reported to have planned the pregnancy.

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Table 1

Participants' Sociodemographic and HIV-Related Information

Characteristic	**M1**	**M2**	**M3**	**M4**	**M5**	**M6**	**M7**
Age (years)	19	17	18	18	21	15	16
Education	BEI	MEI	MEI	BEI	BEI	BEI	MEI
Socioeconomic status[a]	Middle-low	Low	Middle-low	Low	Low	Low	Low
Last occupation	Saleswoman / window dresser	Administrative assistant	Saleswoman	Sex worker	Saleswoman	NA	Student
Marital status	Single	Single	Single	Single	Married	Single	Married
Living with baby's father	Yes	Yes	No	NA	Yes	Yes	Yes
Baby's father age (years)	22	17	21	Doubt concerning fatherhood	45	24	25
Age of the baby (months)	4	6	6	4	5	6	6
Moment of HIV diagnosis (gestational age)	2	7	8	Birth	6	6	3
Mode of HIV transmission	US	US	US	Do not know	US	Do not know	US

Note. M = Mother; BEI = Basic Education Incomplete; MEI = Middle Education Incomplete; NA = Not available; US = Unprotected sex; Single = With boyfriend.

[a]Socioeconomic status was obtained from the integration of the following information: education, neighbourhood of residence, present occupation, last occupation, and forms of aid received. Moreover, the location in which the participants were selected (public health service) constituted, by itself, an indicator of socioeconomic status, considering the current context of Brazil.

The content analysis of interviews revealed five key themes, which are presented in Table 2 along with illustrative quotes.

Table 2

Major Themes, Sub-Themes and Illustrative Quotes of the Participants

Major theme	**Sub-theme**	**Illustrative quotes**
Feelings about motherhood	*Happiness and fulfilment*	"A fulfilled woman, a happy woman! Even with all the difficulties, all, with obstacles... a fulfilled woman!" (M5)
	Non-incorporation of the maternal role	"I still cannot believe. I take care [of the baby] and all, but sometimes it comes to my mind like this: 'My God, I'm a mother!', it seems like I didn't get it yet. I still can't believe I'm a mom!" (M4)
Description as mother	*Positive descriptions*	"I think I'm a good mother, because I can do anything to please him, everything he needs, even too much sometimes" (M1) "Oh, I'm pretty thoughtful, I like giving him affection, like playing with him, I do not like to see him crying and stuff like that" (M6)
	Difficulty to describe as mothers	"Well, I do not know how to tell you [how I am as a mother]" (M7)

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Major theme	Sub-theme	Illustrative quotes
Personal changes after the baby's birth	*Happiness*	"Now I cannot go without laughing, I just look at her and already start laughing, playing with her. It has changed quite a lot" (M2)
	Personal maturing	"Ah, I feel more mature, more able to do various things and much happier with him" (M1) "Really, I had no patience with any child (…) I thought it was going to be different. 'Oh, I am just going to have [the baby], and I am going back to work, I'm going to drop my kids off at day care, I do not care'. To tell you the truth, I thought so before. But after he was born it has changed ... it is very different. My thinking has changed a lot" (M5)
	Increased self-care	"It changed, I quieted down, I stopped using drugs, I became more responsible, I became more adult" (M4) "When I discovered that I was..., I had HIV, I thought I was going to die, that everything would end, that nothing else would matter. And after he was born, I saw that I could fight, I had someone to worry about" (M6)
	Romantic relationships	"Every couple has their arguments, right? It is normal, but before it was too much. It was like... any reason and there was an argument between the two of us. (...) Now we talk more than argue" (M5) "He gives me more attention" (M7)
	Family relationships	"What is better is that my family has come to me more, because before they did not come, did not even care about me... Now everything has changed, right, because everyone is around, they want to stay near" (M3) "We ended up getting a lot closer, you know? It is not like... 'What if they call me?'. 'If they do not call me, I am calling [them]. If they do not come to my house, I am going there' like this, you know?" (M5)
Challenges and difficulties associated with the maternal role	*Maternal role*	"Not now, we already know what he wants, what he does not want. At the beginning, it is more difficult, because we do not know; we had never been through that. The other people's kid is cute, but when it is ours, that we have to wake up every three hours and then it is a lot harder. But now he is stabilized, well behaved" (M1) "Just at the beginning [I had difficulty]. I was afraid to bathe, but it was quick to learn. I was afraid of being alone, I was afraid she would drown and I would not handle it, several things" (M7)
	Separation from the baby	"I cannot leave her. I left her with her godmother one day, but I could not stop calling a minute. I do not know, I think nobody will ever take care as a mother!" (M2) "Oh, it is bad, because I miss her so much. Because when I am with her, it is like this the whole day [baby does something cute]" (M3) "I always take her along when I go out. Only when I have to come early, for a doctor's appointment, then I have to leave her. If I do not, she suffers and so do I, huh? It becomes more difficult." (M7)
	Caregiving tasks	"Ah, the only difficulty that I have with her is to carry, because she is kind of heavy [laughs]" (M2) "Waking up every day at dawn" (M4)
	HIV-related: MTCT transmission, breastfeeding, and social impact of non-breastfeeding	"The main [concern] is that he contracts [HIV]. It is the main; the one that gives me more headaches (...) HIV is for life" (M5) "I thought it was going to influence his size, his development" (M1) "Like I always say: I'm a mother, but I am not a complete mother, because something is missing, something that we know what it is (...) It is not the same thing!" (M5) "Well, at the beginning I was pretty ... it is something pretty boring, is not it, that thing 'Ah, why do not you breastfeed?'. Then I say I had hepatitis, I am not going to go and tell the whole world, huh?" (M1) "Oh, it is kind of bad, because everywhere I go, I have to be taking the milk, water and bottle. Sometimes people ask 'Oh, he is not breastfed? Why?', so I lie, saying 'I did not have milk' or 'He had a problem and I had to stop giving', I invent something" (M6)
	Fear of prejudice	"Oh, because, for example (...) If he puts the blame on me, saying I did not do the treatment right, that it was because of me that he was infected, or it was because I was not careful enough, a few things like that, because his father did not have ... Then he will say 'OK, so you got it from another person or otherwise, it was not from my dad, you could have taken more care" (M6)
	Future family planning	"I wanted to have another child (...). Only then there is the whole HIV issue again, so I do not know ... I think it's going to be just F. [the daughter]" (M7)

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Major theme	Sub-theme	Illustrative quotes
Concerns related to the baby	*Fear of contamination*	“Only in relation to infection, but I do not think she is going to be [infected]. But it is this, that's all for now” (M7)
	Prejudice	“Although I have not suffered [prejudice], he, being a kid, could suffer” (M4)
	Health	“When she gets sick, then I get really worried. I am afraid” (M3)
	Future	“If I will know how to educate him, that's my concern. And if he will be a good person” (M4)

Note. M = Mother

Content Analysis

Feelings About Motherhood

The first category was associated with the different feelings related to motherhood. Feelings of happiness and personal fulfilment, along with feelings of non-incorporation of the maternal role were identified. The participants reported a sense of greater happiness and fulfilment as a woman and a greater motivation to carry out the caregiving tasks. However, reports of non-incorporation of the maternal role were also found, even when performing the tasks related to baby care.

Description as a Mother

The participants described themselves in a positive way, and considered to be good mothers. Among these positive descriptions were worrying about the baby, being attentive, striving to meet their baby’s needs and spoil them. In contrast, difficulties to describe themselves as mothers were also identified in the participants’ narratives.

Personal Changes After the Baby’s Birth

This category includes the participants’ reports concerning personal changes perceived after the baby’s birth. Positive life changes were identified, such as a feeling of greater happiness, maturing, increased self-care and improvement in romantic and family relationships. The main change identified was the feeling of greater happiness due to motherhood. However, changes indicative of a personal maturing process and of better self-care after the baby was born have also been mentioned.

Changes in the romantic relationship were also found, in the sense of an improvement, highlighting feelings of greater union, reduced arguments, and greater attention from the partners towards the young mothers. Similarly, it was noticed improvements in the relationship with families of origin, particularly associated with an increased support for baby care.

Challenges and Difficulties Associated With the Maternal Role

This category included all the participants’ reports regarding the difficulties and challenges encountered in performing the maternal role. They reported the fear of being unable to perform properly the maternal role, especially regarding the caregiving tasks soon after the baby’s birth. The difficulty of separating from the baby, even if for brief moments, was also mentioned. For most mothers, these moments were not common, since only one participant had a steady job. However, adolescents revealed some distress about leaving their children in the care of others, often preferring to take them along, mostly because they did not feel safe with the care provided by others. Still, difficulties regarding caregiving tasks have emerged, mainly of practical order, as carrying the baby (because of the weight) and waking up early in the morning to feed the baby.

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Participants also mentioned as difficulties of motherhood those arising from the presence of HIV. Anxiety feelings about the possibility of MTCT were present. The impossibility of breastfeeding was also mentioned as a difficulty, for different reasons, such as not feeling the completeness of motherhood, fears related to the quality of the mother-child bond and the appropriate growth of the baby. The social impact of non-breastfeed was an additional aspect for this difficulty, since this generated curiosity in people and mothers' discomfort. They often turned out to hide the real reasons of this impossibility due to fear of prejudice.

Additionally, mothers have shown a fear of suffering prejudice by their children in the future, as a result of HIV. The presence of HIV has presented itself as a difficulty also to future motherhood, reflecting in the mothers' family planning, by fear of MTCT and through repetition of experiences of distress already felt during pregnancy.

Concerns Related to the Baby

This category comprised all reports related to concerns about the children. Concerns associated with the presence of HIV emerged, such as the fear of contamination and the prejudice arising from this condition, and worries about the possibility that the baby would contract HIV, even when the exams had presented a contrary result.

Concerns not related to HIV emerged too, such as those relative to childhood diseases and about the future of the baby, in the latter case, of the child being able to achieve what he/she wishes and becoming a good person.

Discussion

In this study examining the experience of motherhood among adolescents living with HIV, the main findings highlight positive perceptions of motherhood, concurrently with difficulties with the maternal role and relevant concerns related to the presence of HIV. The vision of motherhood as positively transforming presented by adolescent mothers may be related to a pregnancy planning or even the desire to be a mother prior to the discovery of pregnancy. Indeed, the preponderant factor for planning pregnancy was these adolescents' desire to be mothers, being motherhood linked to happiness and personal fulfilment.

The view of motherhood as meaningful may be linked to life changes arising from this condition, such as an increased feeling of maturity, empowerment and change of status brought by the pregnancy, particularly because the adolescent starts to be seen and to feel like a woman, and needs to be addressed as an adult who wants the best for their child (Aujoulat, Libbion, Berrewaerts, Noirhomme-Renard, & Deccache, 2010; Silva, Nakano, Gomes, & Stefanello, 2009). In this study, the adolescent mothers mention as significant changes a greater maturity and an improvement in the romantic and family relationships, which can contribute to this change of status. This is consistent with the suggestion that the positive vision of motherhood by adolescents could be due to the understanding of social ascension through pregnancy and motherhood, taken as a life project, which sometimes drives the adolescents in searching for better opportunities for the future of their own and of their children (Pantoja, 2003). However, difficulties of appropriation of the maternal role and self-description as a mother were also found. These difficulties can be derived, among other factors, from the lack of a positive maternal role model in their lives (despite becoming closer to the family of origin after pregnancy).

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Similarly, the surprise from early pregnancy and consequent maturity required could also exacerbate this difficulty.

According to the adolescents' narratives, pregnancy and motherhood seemed to be positive events in their lives despite the presence of HIV. For some, motherhood has acted protectively, serving as a stimulus to self-care, especially to prevent MTCT of HIV, but also for the treatment itself. These findings are in agreement with prior works conducted in Brazil (Carvalho & Piccinini, 2006; Vescovi et al., 2014) and United States (D'Auria et al., 2006). As noted by Carvalho and Piccinini (2006), pregnancy serves as a stimulus to treatment, due to the fear of MTCT, but also because of their own health and to ensure the possibility to see their children grow up.

It is interesting to note that even in the presence of HIV, the adolescent mothers generally declared not noticing a significant impact of HIV on their daily life with the baby. This was also reported by Nelms (2005) in a study with HIV-infected adult mothers from different ethnicities, particularly among those who did not present clinical complications related to HIV. These mothers reported as the only interference factor of HIV the need to keep in secret their health condition. Nevertheless, also in line with Nelms (2005) findings, the need of adopting some specific measures of caregiving has emerged as an interference of HIV on motherhood. Particularly, and consistent with other studies (Ngarina et al., 2014; Treisman, Jones, & Shaw, 2014), the most stressed aspect was their inability to breastfeed, which is an important aspect to the Brazilian culture identity as mothers. This inhibition led to feelings of sadness and frustration, even though the participants cared about the child's well-being. Participants expressed a feeling of incompleteness of motherhood and fear regarding the quality of the bond established with the baby, eventually compromising his development. Adolescent mothers also reported feelings of discomfort because people in their midst noticed this restriction, which served as a potential disclosure of the presence of HIV. However, other adolescents reported not worrying about being unable to breastfeed, perhaps as a result of the information and recommendations received from the health team, as well as of their personal acceptance. These adolescent mothers have demonstrated resignation and calmness for doing what was the best for their child.

Corroborating prior findings reported by adult mothers (Carvalho & Piccinini, 2006; Rigoni et al., 2008), this study showed the possibility of MTCT as one of the central issues in the relationship established between these mothers and their babies. This was their main concern in relation to their children, as many mothers feel responsible for putting the baby's life at risk. According to Rigoni et al. (2008), adult mothers demonstrated intense fear of transmitting HIV to their babies, engaging in careful measures to avoid it, mainly through a correct completion of ART. Moreover, the concern demonstrated by the adolescents of this study may be intensified by their own behaviours, i.e., the mode they were infected (sexually). The possible contamination of the child would be related to lack of self-care, increasing their guilt and, consequently, their concerns with MTCT.

Beyond HIV, it is interesting to highlight the resumption of the relationship with the family of origin (particularly with their mother) and the improvement of marital and family relations from the pregnancy and the child's birth. As indicated by DeVito (2010), although prior conflicts may have existed in their relationship with their mother, when the adolescents became a mother, these conflicts may be disregarded because now they had something in common. The return of adolescent girls to the family of origin also seems to relate to their insecurity and doubts about their capacity to raise and take care of the baby. Nevertheless, this initial insecurity is also common among adult mothers, who often seek support next to their own mothers (Stern, 1997).

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Despite the available support to take care of the baby, adolescents showed an inability to spend a few moments away from their child. This may be related to the adolescents' positive self-description as mothers. Participants efforts to match what is socially expected from a good mother was observed, namely providing child's needs, being available, responsive, and a source of warmth and affection. There seems to be, amid these adolescents, a concern in perfectly performing the maternal role. This is consistent with findings suggesting that the mothers' exclusive dedication to their children is a necessary condition to be considered a good mother, thus promoting the mothers' effort in proving their competence (Silva et al., 2009). This need of being a good mother could be concealing the fear of not being a good mother, the vision of incompetence facing the great responsibility required by taking care of a child, but also their own guilt related to the possibility of MTCT.

Based on our findings, we can see the relevance of HIV to the experience of motherhood, generating feelings of guilt, worries and fears, probably linked to the social representation of seropositivity. At the same time, it was found that motherhood in adolescence can be seen as positively transforming, and the baby can be perceived as a new opportunity, encouraging self-care. The diagnosis of HIV, although not directly examined in this study, carries numerous concerns and uncertainties. Yet, when simultaneous to experience of pregnancy, these concerns seem to be mitigated, highlighting the notion of the paradoxical effects of motherhood in the context of HIV (Sandelowski & Barroso, 2003). Although the negative feelings are noteworthy, such feelings seem to be secondary facing the joy of motherhood, associated with positive feelings, the importance of continuity of life and motivation for self-care. This may suggest that mothers are, to some extent, coping well with the HIV diagnosis. It is possible that pregnancy and motherhood may have a protective effect for psychological well-being, i.e., pregnancy and early motherhood might have buffered the negative effects of the HIV diagnosis (Pereira & Canavarro, 2012; Vescovi et al., 2014). Moreover, it is plausible that these adolescents could be in denial, which is a common defense mechanism used in such situations (Bedimo, Bessinger, & Kissinger, 1998). Future studies, particularly of longitudinal design, are warranted to clarify this issue.

Some limitations should be considered. A convenience sampling method was used, and the small number of available participants may not be representative of this population. As these adolescents have mostly reported a more positive experience of motherhood, we cannot assume that these findings reflect the whole experiences of young mothers living with HIV in Brazil or elsewhere. As well, the sample size is smaller than that normally required to reach saturation of themes. Data were collected through an interview, and did not involve a longitudinal follow-up, in which any changes in the motherhood experience throughout the development of the adolescents and the babies could be observed. Additional studies, of longitudinal design, comprising larger samples and adolescents of different social backgrounds are warranted, in order to deepen the current knowledge about this theme.

Despite these limitations, this study offers an important contribution to the literature. This study, while focusing the experience of motherhood of a group of adolescents with HIV from their own perspective, provided an in-depth knowledge of this phenomenon, which has been examined predominantly among adult women. This study contributes therefore to the literature by allowing an expansion of the existing knowledge, particularly in a population that is still underrepresented in research in Brazil, but also in the international context. Furthermore, these findings are important for the development of more accurate strategies of attention and clinical care of adolescents and to promote the health of the mother-baby dyad. It is necessary that health teams (in both primary healthcare and obstetric care) know this population and how they experience motherhood and HIV, so

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they can better guide them, mainly regarding not only the adherence to ART by their own, but also of the baby in the first months after birth.

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Competing Interests

The authors have declared that no competing interests exist.

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