Vertical transmission of HIV in the health network: bioethics reflections on gender and care based on an emblematic case

Transmissão vertical do HIV na rede de saúde: reflexões bioéticas sobre gênero e cuidado a partir de um caso emblemático

Tonantzin Ribeiro Gonçalves^a

https://orcid.org/0000-0003-0249-3358 E-mail: tonanrib@yahoo.com.br

Gabriela Tavares^b

b https://orcid.org/0000-0002-4798-1921 E-mail: gabrielatavaresgt2011@hotmail.com

Nathalia Luiz Guimarães^c

https://orcid.org/0000-0002-6894-3705
E-mail: nathalialuizguimaraes@hotmail.com

José Roque Junges^d

https://orcid.org/0000-0003-4675-0993 E-mail: roquejunges@gmail.com

Laura Cecilia López^d

https://orcid.org/0000-0002-2454-063X E-mail: lauracli975@gmail.com

^aUniversidade Federal de Ciências da Saúde de Porto Alegre, Departamento de Psicologia. Porto Alegre, RS, Brasil.

^bUniversidade do Vale do Rio dos Sinos, Curso de Psicologia. São Leopoldo, RS, Brasil.

^cUniversidade do Vale do Rio dos Sinos, Curso de Fisioterapia. São Leopoldo, RS, Brasil.

^dUniversidade do Vale do Rio dos Sinos, Escola de Saúde, Programas de Pós-Graduação em Saúde Coletiva e em Ciências Sociais. São Leopoldo, RS, Brasil.

Abstract

In a still worrying epidemic scenario, the prevention of Vertical Transmission (VT) of HIV poses complex problems, due to the individual, social, and moral vulnerabilities of women living with the virus, in addition to the weaknesses of the health network. Based on an emblematic case, this study sought to understand the bioethical challenges of HIV VT prevention in the scope of the Porto Alegre/RS Committee. The analytical categories developed reflect on how the production of care is articulated, on the one hand, with relational discourses and practices based on gender and intersected by race and social class and, on the other, with programmatic vulnerabilities of health policies. A process of extreme stigmatization was revealed, in which the few offers for cisgender women were aimed toward reproductive regulation and perpetuated dynamics of structural violence. We discuss ways of building care that incorporates a decolonial perspective and seeks to produce equity and social justice by recognizing women's trajectories. Keywords: Vertical Transmission of Infectious Diseases; HIV; Bioethics; Women; Intersectionality.

Correspondence

Tonantzin Ribeiro Gonçalves Rua Sarmento Leite, 245 - sala 208. Porto Alegre, RS, Brasil. CEP 90.050-170.



Resumo

Num cenário epidêmico ainda preocupante, a prevenção da Transmissão Vertical (TV) do HIV impõe problemas complexos, devido as vulnerabilidades individual, social e moral das mulheres vivendo com o vírus, somadas às fragilidades da rede de saúde. A partir de um caso emblemático, este estudo buscou compreender os desafios bioéticos do cuidado para a prevenção da TV do HIV no âmbito do Comitê de Porto Alegre/ RS. Os eixos analíticos desenvolvidos refletem sobre como a produção do cuidado se articula, por um lado, com discursos e práticas relacionais pautadas no gênero e interseccionadas por raça e classe social e, por outro, com vulnerabilidades programáticas das políticas de saúde. Vislumbrou-se um processo de extrema estigmatização, em que as poucas ofertas para as mulheres cisgênero se dirigiam à regulação reprodutiva e perpetuavam dinâmicas de violência estrutural. Discute-se caminhos para a construção de um cuidado que incorpore a perspectiva decolonial e busque produzir equidade e justiça social ao reconhecer as trajetórias das mulheres.

Palavras-chave: Transmissão Vertical de Doenças Infecciosas;HIV;Bioética;Mulheres;Interseccionalidade.

Introduction

Preventing Vertical Transmission (VT) of HIV involves dealing with a unique bioethical complexity, as it brings to light situations of great individual, social, and moral vulnerability of cisgender women who are at risk of transmitting or have already transmitted the virus to one or more children (Azevedo; Guilhem, 2005). In addition to the layers of vulnerability that many of these women live with, there is also programmatic, as the implementation of policies and actions aimed at women's health, in general, tends to privilege the reproductive dimension based on cisheteronormative and moralizing standards (Souto, 2008). In the scenario of HIV VT prevention, studies have shown that the focus of policies remains on protecting children during the pregnancy-puerperal cycle and on offering contraception to women after childbirth (Bellenzani, 2013; Bellotto et al ., 2019; Fonseca; Iriart, 2012).

In the political-organizational scope of HIV/AIDS care, despite decentralization initiatives and the adoption of care models based on comprehensive community health, the stigma related to the disease still strongly impacts access and quality of care (Parker, 2013), which indicates the low integration between HIV/AIDS and Primary Health Care (PHC) policies (Palácio; Figueiredo; Souza, 2012). In a scenario of widespread HIV epidemic in the state of Rio Grande do Sul (Pereira et al., 2018), where infection rates among pregnant women and their children in the capital, Porto Alegre, are among the highest in the country (Brasil, 2019), in 2013, the municipality established the *Comitê da* Transmissão Vertical do HIV e da Sífilis (CTVHIVS - Committee for Vertical Transmission of HIV and Syphilis) aiming to improve primary, secondary, and tertiary prevention strategies for these diseases (Porto Alegre, 2013). It is worth mentioning that the initiative was pioneering since it was only later that a regulation from Ministry of Health encouraged the creation of such committees (Brasil, 2014).

Based on the contributions of Sanitary Bioethics (Junges, 2014) and Feminist Bioethics (Diniz; Guilhem, 1999), this work seeks to understand the ethical challenges of preventing HIV VT within the scope of CTVHIVS, both in the programmatic aspect for implementing the policy and in the care relationships in the monitoring of women and their families by health professionals. From the analysis of a complex case, we discuss how different models of care in the health network are combined with discourses and relational practices guided by gender. We work with the hypothesis that there is a structural ordering of policies that amplifies vulnerability and produces the social erasure of women considered "undesirable," which overrides the possibilities of promoting autonomy and equity via health care.

A relational gender perspective is assumed (Connell, 2016) by approaching the constructions of femininity and masculinity as part of a complex social fabric that involves other dynamics and structures, such as race, class, and age (Collins; Bilge, 2021). Relational theory incorporates the dimension of gender coloniality (Lugones, 2008), understanding colonization as a long-term act of structural domination and violent suppression of the heterogeneity and humanity of colonized subjects. This framework offers us analytical keys to think about the processes of stigmatization and the production of death of certain subjects and groups, which permeate the management of lives in societies in the Global South.

Method

This is a qualitative, single-case study (Yin, 2010) arising from a larger research project that analyzes the experience of the Porto Alegre Committee for Vertical Transmission of HIV and Syphilis (CTVHIVS).

The research involved participant observations of CTVHIVS meetings throughout 2017, in-depth interviews with 14 health professionals from different levels of care, locations, and activities, as well as documentary research in the minutes of meetings, ordinances, and technical resolutions concerning prevention of VT in the municipality. A field diary was kept that included the monitoring carried out in 2017, as well as the informal insertion of one of the researchers since 2013. The research project was evaluated and approved by the Ethics Committees of the Universidade do Vale do Rio dos Sinos and the Municipal Health Secretariat of Porto Alegre. All interviewees signed a free and informed consent form.

CTVHIVS was created in 2013, as part of the strategy to decentralize HIV/AIDS care in Porto Alegre, to qualify the performance of health services in preventing HIV VT and Congenital Syphilis. Such mobilization required coordination between health and social assistance services, managers, and professionals, in addition to the dissemination of HIV/AIDS and health policy decisions in the municipality, in a scenario aggravated by poverty, stigma, and social marginalization of the population (Porto Alegre, 2013). CTVHIVS works with monthly meetings of representatives from all levels of health care, management, surveillance, social assistance, associations, and unions. Cases of HIV and Syphilis VT, non-use of antiretroviral (ARV) drugs at birth, increased risk of VT during prenatal care or loss of follow-up of the exposed child are discussed. The cases presented are proposed by professionals linked to STI/HIV surveillance and policy and the services directly involved in caring for the cases are called upon.

The case analyzed in this study was selected for the opportunity to debate the ethical challenges of preventing HIV VT since, due to its complexity, it was covered over seven CTVHIVS meetings in 2017 and mobilized a wide range of services and network devices. All material relating to the case, present in the interviews, meeting minutes, and field diary, was read exhaustively and examined by discourse analysis (Iñiguez, 2004), seeking to highlight the context of the production of both explicit and implicit meanings, in addition to the power relations involved. The reflections produced are presented below, highlighting analytical categories that bring out the ethical challenges of preventing VT and the different perspectives of care production by the actors involved.

Results and discussion

Case description

Carolina de Jesus (names used in the report are fictitious), 24 years old, Black, and with low education,

was diagnosed with HIV and tuberculosis and was not undergoing any treatment. Carolina's partner was a parking attendant and father of her three-monthold baby (João José). In addition to this son, Carolina had a 6-year-old boy (José Carlos), who lived with her, and two school-age girls who were in shelters. She moved house frequently and wandered around health services. Her last known home, visited by a health agent, was reported to be difficult to access, in a very poor neighborhood, dominated by drug trafficking and without basic sanitation.

The case was presented at CTVHIVS in March 2017, via an electronic alert to the health network of an exposed child when João José was three months old. Carolina de Jesus was inadvertently discharged from the hospital after giving birth and did not return for appointments at either the specialized HIV/AIDS service (SAE) or the PHC. This happened, according to the pediatrician, because she gave birth on a Friday and, therefore, the professionals on duty "were not sensitive to the indicators of risk of losing the case to follow-up," such as the fact that she had not adhered to prenatal care and had taken ARVs irregularly. The situation triggered an internal process in the service and the organization of a specific flow of care and discharge from the obstetric center for this type of case, which began to require evaluation with social work and consultation with the SAE.

The baby's first viral load test, carried out in the immediate postpartum period, in accordance with city hall ordinance for these cases (Law No. 6,259, of October 30, 1975, and Ordinance No. 33, of July 14, 2005) (Brasil, 1975, 2005), was negative. It was only after the first presentation of the case at CTVHIVS, when Carolina and the baby were taken to another consultation at the SAE accompanied by a Social Assistance Reference Center (CRAS) professional, in April 2017, that the viral load had a detectable result. The pediatrician who attended to them recognized the affectionate relationship between mother and son, as João José smiled and moved all over when his mother spoke to him.

The UBS1 nurse, who carried out the active search after the birth, reported the child's poor state of health and hygiene and, due to a report of violence, notified the Child Protection Services (CPS). According to her, neighbors reported that Carolina and her husband sold the milk that was delivered, and that the child suffered aggressions, cried nonstop, and had already been thrown against the wall. The UBS1 team thought that João José was being neglected by his parents because he had rashes all over his body. However, the reports were not confirmed in the approach taken by the CPS, with reports from Carolina's aunt and grandmother saying that she had never been violent towards the child. Furthermore, the ACS confirmed the positive mother-child bond.

After the CPS recommended taking João José in, Carolina de Jesus no longer took the child to the appointments, for fear that they would take him away from her and began to collect milk sporadically from another unit (UBS2), resisting any connection. The CPS would, maybe, shelter the two sons, José Carlos and João José, to then begin the latter's treatment for HIV; the fear was that, in the meantime, he would also become infected with his mother's untreated tuberculosis. Together with UBS2, an NGO that provided services to the municipality for the homeless population, was responsible for directing Carolina to get subdermal contraceptive implant and restart her HIV treatment at the SAE. Most professionals, however, believed that she would refuse contraception. According to reports, Carolina needed the constant presence of a child with her: "There will be another one if they take this one away from her, if she is not already pregnant" (PHC Professional; Field Diary, 06/08/17). Among side comments, people even questioned the reason for this need for having children and the repeated breaking of bonds, aspects that, however, did not become the focus of actions.

In June, the nurse at UBS2 came under a lot of pressure for not calling the CPS on the day that Carolina de Jesus presented herself for a reception consultation, since sheltering had already been determined. This professional argued that she sought to preserve the mother's bond with the service, a position that was not accepted by the other members of CTVHIVS, who highlighted the need to comply with the court decision and "save" João José, who would die "*either from the wall or from AIDS or tuberculosis*" (SAE Professional, Field Diary, 05/04/17). After that, UBS2 no longer attended meetings.

At the subsequent meeting, the CPS representative revealed that they were not informed about Carolina's diagnosis of HIV and tuberculosis when they began monitoring the case and, therefore, did not consider it a high-risk situation. Communication failures between services became evident and representatives of the CT, Public Prosecutor's Office and SAE heatedly discussed the responsibilities for the worsening of the situation, agreeing, in the end, that it was urgent to act to prevent the child's death.

At the August 2017 meeting, the CPS reported that João José's father took him to the network for shelter after learning that his son had a serious illness. The baby was then sent for HIV treatment. The other son remained with Carolina, and she refused to use contraceptive methods, with her last injection of medroxyprogesterone being given more than three months before. The case was closed at CTVHIVS and Carolina's care was taken over by UBS2. The last time the case was mentioned, the SAE professional gave news about João José, who was very cheerful and doing very well: "*He is very handsome, despite his HIV*" (Field Diary, 09/14/17).

Stigma and gender: bioethical reflections on the care of women in situations of HIV vertical transmission

From the notion of stigma proposed by Goffman (1988) and the reflections of Veena Das (2001) in the field of anthropology, and authors such as Richard Parker (2013), Wilza Villela and Simone Monteiro (2015) in the field of studies on HIV/ AIDS, we will discuss the ethical challenges related to the health care offered by the network to Carolina de Jesus. The case in question illustrates a process of stigmatization based on gender and social inequalities, revealed throughout the entire follow-up.

For Goffman (1988), stigma refers to a social process in which an individual attribute, behavior or condition begins to be viewed negatively, depreciating the subject and generating feelings of guilt, shame, and discredit. The author describes that stigmatization, whose central element is the deterioration of identity, can occur in three ways, which involve: the abomination of the body, the deformation of the individual character, and the affiliation to a marginalized social group. The analysis of Carolina's case indicates the operation of these last two modes, in a process that unfolded from the blaming of the user for not adhering to the pregnancy treatment and for the baby's infection, as well as the systematic erasure of other aspects of her history, which could provide a more comprehensive view of the case and, therefore, of the solution courses discussed by the health network.

In this sense, attention was drawn to the fact that Carolina appeared as a character devoid of history, marked as an aggressive woman with difficulty in continuing her relationship with health units. Generally, their personal data was not retrieved when the case was discussed, as if everyone already knew who it was about and the problem it represented for the network. The total number of children was never mentioned in the meetings. The CPS reported having been called for the first time years earlier, when Carolina's eldest daughter asked a health professional for help to return to school. Then, she and her youngest daughter were sheltered, leaving the user with only one child.

The account of these events, the precise age of the daughters—who would have been between 12 and 9 years old—when the sheltering took place, whether it was before or after João José's gestation and what the repercussions were for the family were never investigated or questioned. These facts would reveal important clues about Carolina's life story, such as the reasons for not receiving prenatal care and the difficulty in accessing health services. This systematic erasure of Carolina occurred simultaneously with the highlighting of stigmatizing attributes related to HIV infection and her social condition, favoring an intense and unproductive blaming of her as a woman and mother.

Such incomplete narratives, in addition to all the situations Carolina had already experienced, led to the impression that she was much more than just 24 years old. For example, it must be considered that she was most likely had her first daughter when she was still a teenager, at the age of 13 or 14. We asked about the difficulties she experienced in her adolescence and early adult life, about the impact of the separation from her daughters on her path and mental health, not to mention her family and affective relationships. These questions reveal a poor ethical sensitivity in the production of care, which should be oriented towards guaranteeing human rights, considering the social context and the cumulative vulnerabilities experienced by women like Carolina (Ayres; Paiva; Buchala, 2012). The only attempt to rescue these elements in the discussion of the case came from PHC professionals, as described below.

The systematic blaming of Carolina de Jesus was based on distrust and disbelief in her as a mother capable of adequately caring for her child, whether by avoiding HIV infection and taking him to appointments, or by providing basic nutrition and hygiene care. Recurrently, in several of the meetings in which the case was discussed, the photo of João José's large diaper rash scar recorded on a professional's cell phone was shown to those present, which served to reinforce how questionable the user's motherhood was. There was also concern about Carolina's ability to prepare bottles, when asked during a consultation, she could not explain the exact amounts and said she put the milk and water in and shook it. The discrepancy between Carolina's speech about how to prepare the milk and the professional's view, who was probably expecting a technical description, served to disqualify her. For Carolina, mother to at least four children, perhaps this question was taken as trivial and of little importance, whereas for the professional it denoted an expected care for her child. The group derived from this the difficulty of prescribing ARV for the baby, as the mother supposedly did not even know how to prepare the bottle properly.

Carolina was seen as a "risky mother" and, therefore, needed specific interventions, as she was not expected to be responsible for raising her children. Carolina de Jesus' health history and life path placed her in a position of being the main risk factor for the child's life, in which her knowledge was disqualified, and the main threat was her inability to fulfill the ideal maternal role (Robles, 2015). In this way, maternity hospitals with different degrees of social acceptance are produced, idealized by a vision that universalizes white middle-class values (Mattar; Diniz, 2012). This is concomitant with a politicization of the feminine in public policies, which makes women targets of constant surveillance, as it is their role to guarantee and generate their children' biopsychosocial well-being, regardless of their socioeconomic status (Meyer, 2005).

On the other hand, some secondary accounts at the meetings reported that João José was within the expected weight and height for his age, meaning that he was fed adequately. Some professionals highlighted the presence of a positive emotional bond between mother and child, which was consistent with the fact that Carolina often stopped seeking health services out of fear of losing custody of her children. However, such contradictions disappeared in the construction of a narrative in which the versions of Carolina as irresponsible and incapable of performing the maternal role prevailed. This dynamic of silencing and denunciations was linked to the intense depreciation of her as a young, black woman, a mother living with HIV and socially vulnerable. In this sense, Villela and Monteiro (2015) discuss how stigma violates the right to health of women who engage in prostitution, have abortions, or are infected with HIV, increasing their vulnerability to illness and death. For the authors, stigma hides power struggles regarding women's autonomy, hindering access to the right to health and social support.

These contradictions indicate that the view regarding Carolina de Jesus could also be the result of a generalization about women like her, pregnant women with HIV, black, and poor, treated in services, which reveals the network's difficulty in ethically problematizing the social markers of difference in their actions. For example, we cite the health network's moralization and fear about Carolina's possible desire to have new children, as if this right were not legitimate to her, or at the very least questionable, as it implied the risk of her children contracting HIV. The issue of her ability to take care of herself and her parenting conditions in the context of poverty in which she lived was never brought up as an object of action or reflection, as if poverty were an irremovable fatality, displaced from health work. Situations like this revealed the institutional racism that guides the practices and organization of health

institutions in their daily work, contributing to the naturalization of racial inequality and culminating in the precariousness of the black population's access to their rights (López, 2012).

As a social process, stigma operates from power relations that perpetuate vulnerability, social exclusion, and discrimination (Parker, 2013). It is no coincidence that the same people who suffer HIV-related stigma are also those who live on the margins of social and health policies and do not have their citizenship recognized. Therefore, although stigma tends to manifest itself more clearly in face-to-face relationships, this process necessarily reflects power structures that generate social inequalities (Parker, 2013). Therefore, there is greater difficulty in accessing material and symbolic goods, intersecting inequalities of gender, race/ethnicity and social class with stigmatized characteristics or behaviors in specific contexts (Villela; Monteiro, 2015). Thus, state and international programs and policies are involved both in the production and in confronting stigma, which reveals itself as a long-lasting process of "debilitation" that occurs not only in individuals, but through the network of family and community relationships (Das, 2001).

In this sense, the figure of the baby's father only appeared in the accounts as the one who "resolved" the follow-up of the case, highlighting the rationality of his act, in contrast to the apparent irrationality of Carolina's escape and wandering around the network, as perceived in the words of a professional: "I thought this was beautiful, because our entire network, all the information that we circulated, reached the father and it wasn't the CPS that sheltered, the PHC that didn't need to be activated" (Field diary, 03/08/2017). The professional's account during the meeting in which the case was "discharged" by the Committee reveals that the figure of the father seems to have resolved, for the network, even the impasse created by the PHC's opposing position on sheltering. On the other hand, it is worth highlighting that Carolina's partner was never tested for HIV and João José was already his second child with her. In this case, it is clear that gender inequalities, intersected by the social conditions of families, penalize not only women, but also the health of their companions. A recent analysis of the National Policy for Comprehensive Attention to

Men's Health highlighted the presence of discourses about men as supporting figures and the fragility of the idea of co-responsibility in reproductive and parenting issues, as well as the lack of harmony with inequalities and existing diversity (Dantas; Couto, 2018). In the context of the right to HIV prevention, the case illustrates that the invisibility of cis heterosexual men in the daily actions of the health service (Leal; Knauth; Couto, 2015) is linked to the process of stigmatization and moral vulnerability of women living with HIV (WLHIV).

The dimensions analyzed lead us to ask about autonomy as a bioethical issue. It seems that the only health devices that attempted to promote Carolina's autonomy as a woman and mother were those linked to PHC, proposing actions situated in her life context. Feminist bioethics reconfigures the principle of autonomy (dear to classical bioethics) to think of it, in contexts of profound inequality, as a situationallity to be achieved, remaining linked to the need to produce social justice (Diniz; Guilhem, 1999). As will be discussed in the analytical axis below, the structural ordering of policies amplifies vulnerabilities, in social erasure and the production of death, overriding the promotion of autonomy and equity as human rights.

Programmatic and necropolitical vulnerability: fragility of bonds and reproductive regulation

In this analytical axis, we will discuss the case in light of the concepts of programmatic vulnerability and necropolitics, arguing that the articulation between the social and subjective vulnerabilities of WLHIV and the weakening of the health network and the work of professionals testifies to the operation of a process of State violence, historically rooted against women, especially black and poor women.

Carolina de Jesus' itinerancy was intertwined with urgent disruptions in the professionals' discussion of the case, making her story erratic and clouded. It was clear that it was difficult to articulate interdisciplinary work that included women's health as a way of also impacting on the child's whole health. The strict focus of the actions on the baby in the face of virus infection, reproducing a biomedical logic, relegated Carolina to a secondary position, in which her health and well-being were not the object of attention, as seen in another study dealing with the pregnancy and childbirth of WLHIV (Bellotto et al., 2019). For example, care alternatives focusing on Carolina's mental health were not discussed at any time. As a result, by taking contraception as the only possible offer, feelings of disappointment and failure were produced in the network, given her evasions.

There was no perceived opening to address particular issues in Carolina de Jesus' story that would help to develop care strategies that made sense for her and promoted ways to increase autonomy in her life and, consequently, regarding her health care. Reflecting on care from the perspective of who she was would also imply recognizing Carolina as a subject of rights and a citizen to be served in her singularities, aiming to promote equity and social justice. Violations of rights has a fundamental impact on people's lives that, consequently, make it impossible to achieve autonomy in health due to the lack of a social structure that supports individual care and avoids basic mortality risks (Junges, 2014), as the history of the fight against AIDS in Brazil has taught us so much (Ayres; Paiva; Buchalla, 2012). For Carolina, these violations were present from the few educational opportunities she had throughout her life, the lack of decent housing and food, to the lack of basic sanitation in the region where she lived.

Here we evoke the notion of necropolitics (Mbembe, 2017) to think about contemporary forms of subjugation of life to the power of death as a continuity of colonial relations. Starting from the concept of biopower developed by Foucault, Mbembe argues that, today, in addition to managing life (making people live), the State operates the management of death (how and who should die). The central mark of necropolitics is the presence of a constant risk of death, personified through violent and cruel actions that loom over certain groups and populations, which are subjected to extreme conditions of social existence, as if they were "living dead." Carolina's life trajectory and how her case was treated by the network demonstrate the presence not only of indirect elimination strategies (due to the structural deficiencies that surrounded her existence and the symbolic violence directed at her), but of apparatuses that constantly exposed her to

risk of direct violence, such as threats of eviction in the territories where she lived, of starvation, death due to exposure to drug trafficking-related violence, and the removal of her children. Even though Carolina did not die, as far as we could follow, death is actually produced among these women, and during the research, two poor black WLHIV and one of their children, monitored by the network, died from HIV/AIDS-related causes. Therefore, it is up to us to ask, on a daily basis, about ways to prevent the maintenance of the State's necropolitical power.

It is in this scenario that we understand the extreme fragility of the bond between the network, Carolina, and her family, with relationships based on mutual distrust and threats. For example, Carolina's attendance at her baby's appointment shortly after giving birth was only possible after a great deal of pressure from the UBS1 team, with the threat that if she failed to show up, she would no longer receive powdered milk at the unit, although the team itself admitted that it was not possible to impose this condition.

In another instance, the UBS2 nurse was pressured by the CTVHIVS because she did not contact the Public Prosecutor's Office or the CPS on the day that Carolina de Jesus went to the unit for a reception appointment, as the baby's sheltering had already been determined. The nurse stated that she did not deny the actual risk to the child's life, but admitted that there was love in the relationship between him and his mother. For her, Carolina ended up leaving the territory because she was being threatened by people linked to drug trafficking. UBS2 stated that it did not feel comfortable contacting the CPS, as the immediate consequence would be the loss of the link between the service and the user, this being one of the few times that she was the focus of care. The professional reported that, on that occasion, João José was fine, although dirty, which was no different from how other children from the same community showed up at the UBS. Faced with this, another professional warned: "Dirty, with a viral load of more than 100 thousand!" (Field diary, 06/08/17), highlighting the risk of death for the child.

After this meeting, UBS2 no longer attended CTVHIVS. In an informal conversation with an NGO worker who worked with UBS2 to provide care to Carolina's family, the service chose not to call the CPS because it prioritized delivering cans of milk so that João José could eat, as the family was starving. Furthermore, they lived in a plywood cubicle in which eight people slept in total. In a nearby cubicle lived Carolina's brother, sister-in-law, and nephew, who was almost the same age as João. To illustrate the difficulties in working with this family, the professional reported that the challenge was to think of a way to bathe the baby, as there was no water or bathroom in the shacks. Therefore, concern about the child's dirtiness relegated the blame to the mother, who supposedly did not have good hygiene habits. However, if we looked more broadly, we realize that this problem reflected her social situation and her family's poor housing conditions.

The absence of UBS2 at the meetings further contributed to the silencing of Carolina and her story. Meanwhile, the search to shelter João José continued and, at the July meeting, it was reported that, just a few days before, he had been in consultation at UBS2, according to a record in the information system. Once again, UBS2 did not contact the CPS, an attitude criticized by some of those present at the meeting: "What is the bond? If he [baby] is not getting treatment and neither is she? Bonding is not just about hugging and kissing if there is a risk of death." (Field diary, 07/06/17).

Thus, Carolina's attempt to link is interpreted as inconsequential. The health network therefore seemed to take a limited view of the complexity of the case, seeking to resolve it via a salvationist attitude. However, what does this attempt to save someone represent, even if only biologically? Such a perspective seems to imply the attribution of an omnipotent position to politics and health workers, both in the biomedical sense and in the broader sense of the search for comprehensive care. In this regard, we remember that health care involves dealing with others, with the otherness and precariousness of life itself, in the search for building relationships based on listening and effective dialogues (Ayres, 2004). Therefore, adopting a caring position in the health field necessarily implies taking risks and seeking practical meaning, including failures, as it is not only important to achieve the ends, but the quality of the means (Ayres, 2004). In this case, several failures of the network could be considered, from João José's HIV infection, Carolina's lack of connection with health

and social assistance services, which even resulted in a greater risk of death for her, the failure to test her partner, the sheltering of her daughters, etc.

Bioethical reflection encourages us to think that effective care for complex cases, such as Carolina's, requires dynamic intersubjective relationships that enable the sharing of different perspectives, both from the point of view of policy guidance and its translation and operation by professionals. A relevant bioethical question from a feminist and Public Health point of view refers to how a situation of epidemiological alarm affects the conditions for providing longitudinal care, from the perspective of comprehensiveness and equity, in promoting the health and autonomy of WLHIV. The tensions that arose in the meetings gave rise to different orientations regarding the ends and means of caring for the case. While part of the network (linked to the hospital, surveillance, and secondary care level) prioritized the baby's biological life, even if this meant ignoring or even losing Carolina, as she had "chosen" not to adhere to the treatment for HIV and tuberculosis, professionals primarily linked to PHC understood that care needed to be based on building a bond of trust with the user. It seems to us that the polarization between models that we call here "surveillance-control" and "PHC-bond" in case management bears witness to the continued fragmentation of actions and the institutional weakening of the leading role of the PHC.

Thus, the concept of programmatic vulnerability helps us think that the creation and maintenance of State devices aimed at producing death among women like Carolina involve processes of weakening health services and the workers themselves. According to Junges, Barbiani and Zoboli (2018), programmatic vulnerability refers to the insufficiency and fragmentation of the structure and organization of health services, as well as the care processes that contribute to the weakening of users' health, by imposing access difficulties and affecting the quality of care. This process demotivates or prevents the user's commitment to treatment, and professionals also feel powerless to modify the conditions of care provision, regarding the infrastructure conditions, human or technical resources required. Aspects that reflect the network's programmatic vulnerability, such as the lack of countertransference between network services and the devaluation of care provided in PHC,

in addition to insufficient continued education for professionals, were cited by workers interviewed in the study by Junges, Barbiani and Zoboli (2018). In the case discussed, we see a sum of these processes, since the social and historically situated vulnerability of WLHIV is compounded by the programmatic vulnerability of the network, especially PHC which, according to the Primary Care Policy (Brazil, 2017), should comply with the role of care organizer. From a decolonial point of view, we draw attention to the systematic erasure of Carolina's history as a necropolitical device that acts on the body and existence of a black woman, making it necessary to consider these contexts to provide comprehensive care.

Final considerations

At the macropolitical level, ethical challenges for the management of HIV VT entail combining knowledge of epidemiological surveillance with the construction of a care network in which PHC plays a leading role in early diagnosis, referral and effective, monitoring of WLHIV and children in its territory, with the support of specialized services and maternity hospitals, in addition to intersectoral actions aimed at tackling the social determinants of the epidemic. Along this path, it is considered important that the policy includes devices that transcend the focus of WLHIV health actions beyond the provision of contraceptives and include strategies for preventing gender-based violence and promoting mental health that are sensitive to racial. class. and sexual orientation inequities. We must point out that it is not a question of holding only the professionals who work with these women accountable, much less blaming them for VT prevention actions restricted to the biomedical approach. However, the services and their professionals operate and translate health policies and, therefore, on the margins of their implementation, in daily work, they can also transform practices aimed at effectively caring for the communities and women under their health responsibility, subverting totalizing and death-producing logics. Accordingly, it is important to support and qualify the teams' performance based on policies that value work in the SUS and the expansion of permanent training spaces that strengthen critical reflection on health work.

At the micropolitical level, it is necessary to equalize HIV VT prevention actions and policies considering the vulnerability and human rights of WLHIV, toward promoting their autonomy and empowerment and paying attention to the structural dynamics of power intersected by class, race, gender, sexual orientation, generation, and other markers. Carolina's case makes us question how care can be operationalized in order to effectively produce material, physical and mental health conditions so that women can exercise their citizenship rights in a more autonomous and positive way for themselves and their children. In this direction, a starting point would be to think about the production of care based on the social and affective paths of women which, together with historically constructed dynamics, increase the abandonment of treatment and the stigmatization of WLHIV. We believe that the inclusion of other civil society actors (for example, representatives of the black, LGBTI+, feminist, and HIV activism movements) in the debate and decision-making regarding TV prevention strategies would allow us to challenge the hegemony of biomedical vision in policy-making, making room for intersectional and decolonial practices.

References

AYRES, J.R.; PAIVA, V.; BUCHALLA, C. Direitos humanos e vulnerabilidade na prevenção e promoção da saúde: uma introdução. In: PAIVA, V.; AYRES, J. R.; BUCHALLA, C. *Vulnerabilidade e Direitos Humanos*: prevenção e promoção da Saúde - Livro I: da doença à cidadania. Curitiba: Juruá, 2012. p. 9-22.

AYRES, J. R. C.M. Cuidado e reconstrução das práticas de Saúde. *Interface - Comunicação, Saúde, Educação*, Botucatu, v. 8, n. 14, p. 73-92, 2004. DOI: 10.1590/S1414-32832004000100005

AZEVEDO, A F; GUILHEM, D. A vulnerabilidade da gestante na situação conjugal de sorodiferença para o HIV/Aids. *Journal Brasileiro de Doenças Sexualmente Transmissíveis*, Niterói, v. 17, n. 3, p. 189-196, 2005.

BELLENZANI, R. Promoção às DST/HIV e promoção da saúde sexual: como os direitos sexuais e reprodutivos podem orientar a estratégia da Saúde da Família? In: PAIVA, V.; CALAZANS, G.; SEGURADO, A. (Org.). *Vulnerabilidade e Direitos Humanos*: Prevenção e Promoção da Saúde - Livro II - Entre indivíduos e comunidade. Curitiba: Juruá, 2013. p. 241-275.

BELLOTTO, P. C. B. et al. Entre a mulher e a salvação do bebê: experiências de parto de mulheres com HIV. *Interface - Comunicação, Saúde, Educação*, Botucatu, v. 23, e180556, 2019. DOI: 10.1590/Interface.180556

BRASIL. *Lei n.º 6.259, de 30 de outubro de 1975.* Dispõe sobre a organização das ações de vigilância epidemiológica, sobre o Programa Nacional de Imunização e estabelece normas relativas à notificação compulsória de doenças e dá outras providências. Brasília, DF: Ministério da Saúde, 1975.

BRASIL. *Portaria Nº 33, de 14 de Julho de 2005.* Inclui doenças à relação de notificação compulsória, define agravos de notificação imediata e a relação dos resultados laboratoriais que devem ser notificados pelos Laboratórios de Referência Nacional ou Regional.. Brasília, DF: Ministério da Saúde, 2005.

BRASIL. *Protocolo de investigação da Transmissão Vertical.* Brasília, DF: Ministério da Saúde, 2014.

BRASIL. *Boletim Epidemiológico de HIV e Aids*. Brasília, DF: Ministério da Saúde, 2019.

COLLINS, P. H.; BILGE, S. O que é interseccionalidade? In: COLLINS, P. H.; BILGE, S. (Org.). *Interseccionalidade*. São Paulo: Boitempo, 2021. p. 15-49.

CONNELL, R. *Gênero em termos reais*. São Paulo: nVersos, 2016.

DANTAS, S. M. V.; COUTO, M. T. Sexualidade e reprodução na Política Nacional de Saúde do Homem: reflexões a partir da perspectiva de gênero. *Sexualidad, Salud y Sociedad*, Rio de Janeiro, n. 30, p. 99-118, 2018. DOI: 10.1590/1984-6487.sess.2018.30.05.a

DAS, V. *Stigma, Contagion, Defect*: Issues in the Anthropology of Public Health. Bethesda, MD: [s.n.], 2001. Available from: http://docshareo4.docshare.tips/files/13843/138431942.pdf>. Access on: Jan. 22, 2022

DINIZ, D.; GUILHEM, D. Bioética feminista: o resgate político do conceito de vulnerabilidade. *Bioética*, Brasília, DF, v. 7, n. 2, p. 181-188, 1999.

FONSECA, P. L.; IRIART, J. A. B. Aconselhamento em DST/Aids às gestantes que realizaram o teste

anti-HIV na admissão para o parto: os sentidos de uma prática. *Interface - Comunicação, Saúde, Educação*, Botucatu, v. 16, n. 41, p. 395-407, 2012. DOI: 10.1590/S1414-32832012000200009

GOFFMAN, E. *Estigma*: notas sobre a manipulação da identidade deteriorada. 4. ed. Rio de Janeiro: LTC, 1988.

IÑIGUEZ, L. Manual de análise do discurso em ciências sociais. Petrópolis: Vozes, 2004.

JUNGES, J. R. Bioética na perspectiva coletiva e social. In: JUNGES, J. R. (Org.). *Bioética sanitarista: desafios éticos na saúde coletiva*. São Paulo: Loyola, 2014. p. 19-38.

JUNGES, J. R.; BARBIANI, R.; ZOBOLI, E. L. C. P. Vulneração programática como categoria explicativa dos problemas éticos na atenção primária à saúde. *Trabalho, Educação e Saúde*, Rio de Janeiro, v. 16, n. 3, p. 935-953, 2018. DOI: 10.1590/S1414-32832012000200009

LEAL, A. F.; KNAUTH, D. R.; COUTO, M. T. The invisibility of heterosexuality in HIV/AIDS prevention for men. *Revista Brasileira de Epidemiologia*, São Paulo, v. 18, n. suppl 1, p. 143-155, 2015. DOI: 10.1590/1809-4503201500050011

LÓPEZ, L. C. O conceito de racismo institucional: aplicações no campo da saúde. *Interface - Comunicação, Saúde, Educação*, Botucatu, v. 16, n. 40, p. 121-134, 2012. DOI: 10.1590/S1414-32832012005000004

LUGONES, M. Colonialidad y Género. *Tabula Rasa*, Bogotá, n. 9, p. 73-102, 2008.

MATTAR, L. D.; DINIZ, C. S. G. Hierarquias reprodutivas: maternidade e desigualdades no exercício de direitos humanos pelas mulheres. *Interface - Comunicação, Saúde, Educação*, Botucatu, v. 16, n. 40, p. 107-120, 2012. DOI: 10.1590/S1414-32832012005000001

MBEMBE, A. Necropolítica: Biopoder, soberania, estado de exceção, política de morte. *Arte & Ensaios*, v. 2, n. 32, p. 123-151, 2017. DOI: 10.18316/redes.v7i1.5048

MEYER, D. E. E. Uma politização contemporânea da maternidade: Construindo um argumento. *Gênero*, Niterói, v. 6, n. 1, p. 81-104, 2005. DOI: 10.22409/rg.v6i1.198

PALÁCIO, M. B.; FIGUEIREDO, M. A. C.; SOUZA, L. B. O Cuidado em HIV/AIDS e a Atenção Primária em Saúde: Possibilidades de Integração da Assistência. *PSICO*, Porto Alegre, v. 43, n. 3, p. 360-367, 2012.

PARKER, R. Intersecções entre estigma, preconceito e discriminação na saúde pública mundial. In: MONTEIRO, SIMONE; VILLELA, WILZA V (Org.). *Estigma e Saúde.* Rio de Janeiro: Fiocruz/FAPERJ, 2013. p. 25-46.

PEREIRA, G. F. M. et al. Epidemiologia do HIV e aids no estado do Rio Grande do Sul, 1980-2015. *Epidemiologia e Serviços de Saúde*, Brasília, DF, v. 27, n. 4, 2018. DOI: 10.5123/S1679-49742018000400004

PORTO ALEGRE. *Saúde lança Comitê para reduzir a transmissão vertical do HIV e sífilis.* Boletim Epidemiológico, *Porto Alegre*, v. 15, n. 52, 2013 Available from: http://lproweb.procempa.com.br/pmpa/ prefpoa/cgvs/usu_doc/boletim_epidemiologico_52_ agosto_2013.pdf>. Access on: Sep. 02, 2021. ROBLES, A. F. Da gravidez de "risco" às "maternidades de risco". Biopolítica e regulações sanitárias nas experiências de mulheres de camadas populares de Recife. *Physis: Revista de Saúde Coletiva*, Rio de Janeiro, v. 25, p. 139-169, 2015. DOI: 10.1590/S0103-73312015000100009

SOUTO, K. M. B. A Política de Atenção Integral à Saúde da Mulher: uma análise de integralidade e gênero. *SER Social*, Brasília, DF, v. 10, n. 22, p. 161-182, 2008. DOI: 10.26512/ser_social.v10i22.12950

VILLELA, W. V.; MONTEIRO, S. Gênero, estigma e saúde: reflexões a partir da prostituição, do aborto e do HIV/aids entre mulheres. *Epidemiologia e Serviços de Saúde*, Brasília, DF, v. 24, n. 3, p. 531-540, 2015. DOI: 10.5123/S1679-49742015000300019

YIN, R. K. *Estudo de caso*: planejamento e métodos. 4. ed. Porto Alegre: Bookman, 2010.

Contribution of the Authors

Gonçalves conceptualized the study. Gonçalves, Tavares, and Guimarães conducted data collection and analysis, in addition to writing the first version of the manuscript. López and Junges carried out a critical review of the literature and participated in the interpretation of the findings. All of the authors reviewed the final version of the manuscript and are responsible for all aspects of the work, including ensuring its integrity.

Received: 24/11/2023 Represented: 24/11/2023 Approved: 4/12/2023