EXPERIENCE OF PUERPERAL WOMEN WHO LIVE WITH HIV/AIDS TREATED AT A HIGH-RISK MATERNITY HOSPITAL

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ABSTRACT

Objective: To grasp the experience of puerperal women who live with HIV/AIDS treated at a high-risk maternity hospital. Method: Qualitative descriptive approach conducted by means of interviews with 19 puerperal women at a referral public hospital for high-risk pregnant women located in Curitiba, Paraná, Brazil. The puerperal women participating in the research study received prenatal care at a Brazilian primary health center (unidade básica de saúde - UBS) concurrently with the prenatal care received at the maternity hospital at stake. Results: The main results have been the puerperal women's experience regarding user's embracement at the health service, since they felt respected, insofar as they reported to had been heard instead of judged due to their health condition; nevertheless, they also reported concern during pregnancy with vertical transmission and after childbirth they felt distressed by the impossibility to breastfeed. Final remarks: The importance of nurses in the whole clinical care process is emphasized, from pregnancy to the puerperium, as the professional in charge of providing humanized and welcoming care to women who live with HIV/AIDS.

Keywords: Obstetric nursing. Postpartum period. Pregnancy high-risk.

INTRODUCTION

The human immunodeficiency virus (HIV) remains a major public health issue worldwide, accounting for more than 35 million deaths to date. By the end of 2016, 36.7 million people were living with HIV, there were 1.8 million new cases of infection by the virus worldwide, and until this same year 1 million people died from HIV-related causes in the world(1).

HIV targets the immune system and weakens people’s defense systems against infections and some types of cancer. As this virus destroys and impairs the function of immune cells, individuals living with the virus gradually become immunodeficient. Immune function is measured by counting CD4 cells. Immunodeficiency results in increased susceptibility to various infections and diseases that people with a healthy immune system can fight(1).

HIV infection is often diagnosed by means of rapid tests, which detect the presence or absence of anti-HIV antibodies. Mostly, these tests provide the result on the same day. It is worth mentioning that there is still no cure for HIV infection, however, effective antiretroviral drugs can control this virus and others help prevent transmission – the so-called pre-exposure prophylaxis (PrEP)(1).

Research studies suggest that about 70% of people living with HIV are aware of their HIV status. As of mid-2017, 20.9 million people living with HIV were receiving antiretroviral therapy worldwide. It is estimated that the global coverage of antiretroviral therapy reaches 76% among pregnant women and infants living with HIV. In the absence of any interventions during gestational stages, vertical HIV transmission rates can range between 15% and 45%, however, through drug therapy, it is possible to prevent vertical transmission, i.e. from mother to child(1).

Thus, the most important global health organizations recommend a series of measures to prevent this transmission, which includes the administration, for both mother and child, of antiretroviral drugs during pregnancy, childbirth, and the puerperium, as well as treatment throughout life for HIV-positive pregnant women, regardless of their CD4 count. In 2015, 77% among about 1.4 million pregnant women who live with HIV worldwide received effective
antiretroviral drugs to prevent transmission to their children\(^1\). In Brazil, it is estimated that 0.4% of HIV-positive pregnant women, which translates into approximately 12,635 pregnant women/children exposed per year\(^2\).

It is estimated that about 65% of cases of vertical HIV transmission occur during labor and delivery itself, and the remaining 35% occur intrauterine, especially in the last weeks of pregnancy, with the additional risk of postpartum transmission through breastfeeding. Breastfeeding poses additional risks of transmission, which are renewed with each exposure of the child to the breast, and it is between 7% and 22\%^2\).

Vertical HIV transmission can occur in 3 periods: a) intrauterine; b) at birth (intrapartum); or c) during breastfeeding (postpartum). HIV can be transmitted in the uterus by transplacental cell traffic, through progressive infection of the placenta’s trophoblasts until the virus reaches the fetal circulation, or due to breaches in the placental barrier followed by microtransfusions from mother to fetus. Transmission during childbirth occurs through baby’s contact with mother’s infected secretions when passing through the vaginal canal, implicating ascending infection from the vagina to the fetal membranes and the amniotic fluid or absorption in the newborn infant’s digestive system. In the postpartum period, the main form of transmission is breastfeeding\(^3\).

High viral load and prolonged rupture of amniotic membranes are recognized as the main factors associated with vertical HIV transmission. Viral load in cervical-vaginal secretions and in breast milk has been shown to be a major determinant of risk of intrapartum transmission and by means of breastfeeding\(^2\).

Screening for gestational AIDS has become an exam of the utmost importance. Since vertical transmission of the virus has decreased to 4%, virus detection during pregnancy and appropriate treatment of pregnant women has prevented many babies from becoming HIV positive due to intrauterine and trans-delivery contamination\(^4\).

Every patient infected with HIV should resort to antiretroviral therapy (ART), regardless of their immunological or virological status. Its use must be decided together with the infectologist and having the standards set by the Brazilian Ministry of Health (MoH) as a basis\(^4\).

One study claims that, when faced with confirmed serodiagnosis, women have several reactions. Essentially, the discovery has a negative impact on their lives, which causes sadness, despair, anguish, and fear, associating the infection with feelings of destruction and death, leading them to analyze their personal plans. It has been found that the reactions emerging with serodiagnosis are more intense due to the fact that HIV/AIDS is a disease that still has no cure and because of the fear of abandoning the child after their death\(^5\).

Pregnant women with HIV are classified as high risk, due to the risk of mother-to-child transmission and additional exams should be performed, since HIV makes the patient more susceptible to acquiring such an infection\(^4\).

Given the above, knowing the experience of women who have gone through the process of pregnancy, childbirth, and postpartum with HIV infection is necessary since they are surrounded by a reality that requires specific attention and guidance, thus conducting this study has made it possible to manage care based on the experience of these women. This research aimed to:

- Grasp the experience of puerperal women who live with HIV/AIDS provided with care at a high-risk university maternity hospital in the State of Paraná, Brazil.

**METHODOLOGY**

This research study has a descriptive qualitative approach and it has been conducted at a referral public hospital for high-risk pregnant women in Curitiba, Paraná, Brazil. Puerperal women who live with HIV/AIDS who received prenatal care at this hospital participated in the research. These puerperal women received prenatal care at a Brazilian primary health center (unidade básica de saúde - UBS) concurrently with the prenatal care received at the maternity hospital at stake.

The inclusion criteria were puerperal women: a) hospitalized in the joint accommodation on the second day after delivery; b) over 18 years of age; c) who speak the Portuguese language; and d) who have a stable clinical status. And the exclusion criteria were puerperal women: a) below 18 years of age; and b) who do not speak the Portuguese language. Thus, 23 puerperal women were invited to participate, but 4 refused it and the study sample consisted of 19 women.

Data collection took place through a recorded
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During the selection of participants, after becoming aware of a puerperal woman admitted to the joint accommodation with a positive result for HIV, the researcher called her for a conversation in a reserved room in the sector itself to introduce the research; once the invitation was accepted, her participation was confirmed by signing the Brazilian free and informed consent form (termo de consentimento livre e esclarecido - TCLE).

The analysis took place through thematic Content Analysis, as proposed by Laurence Bardin, which is organized in 3 phases: a) pre-analysis of the material; b) exploration of the material; and c) systematization of ideas. In the first phase, the interviews resulted in a total of 5 hours of recording and 66 pages of transcription. In the second phase, the categories were defined for the interpretations and inferences - 8 registration units were identified and their affinity grouping resulted in 3 categories: a) “Feeling: embracement”; b) “Concern with vertical transmission”; and c) “Impossibility to breastfeed”. And in the third phase there was inference and interpretation.

The precepts of Resolution No. 466/2012 of the National Health Council (CNS) were observed during all stages of this research and the study has been approved by the institution’s Research Ethics Committee, under Opinion No. 2,426,711/2017.

RESULTS

The participants in this study were aged between 18 and 47 years, the number of pregnancies ranged from 1 to 5, 10 reported to be single, 4 were married, 2 had a marriage-like relationship, 1 is separated, 2 are divorced. As for educational level, 6 respondents reported to have completed High School, 3 were attending Higher Education, 5 completed Elementary School, and 5 have not completed Elementary School.

The number of appointments during prenatal care ranged from 6 to 19 and 6 discovered the diagnosis during pregnancy, 12 already knew they had HIV, and 1 was diagnosed in the previous pregnancy.

Out of these 19 women undergoing treatment, 7 started it during pregnancy, 11 were already undergoing treatment before getting pregnant, and 1 did not remember when it started.

Feeling: embracement

The feeling of embracement since prenatal care was reported by 15 out of the 19 women interviewed, and this feeling is based on respect, ethics, suspended judgment, affection, qualified listening, solving problems brought by pregnant women, and good service, according to these utterances:

I was really embraced, so the staff had no prejudice, always with a lot of love, showing us that prejudice is something ridiculous. This is the first thing we feel. You arrive at the health center, you feel ashamed to say that you are sick and they treat this as something normal, you are a normal person. So, first, people’s love for us was really cool [...] there comes a time when you even forget that you have such a problem [...] At first I was afraid the doctors would blame me, “wow, why have you got pregnant?” and this didn’t happen. (A1)

and the staff had no prejudice. They really tried...

...it was really cool, so far everyone treated me with greater affection and respect, they embraced me very affectionately [...] it was the first chance I had to say: “Oh, nobody knows I took it (an antiretroviral drug)”, everyone embraced this idea of not talking when family members were around, you know. It was confidential, just myself and who was with me there, the person who was working with me. (A3)

They really provided me with a good service, you know, they were very considerate, both here and there (at the UBS). They were always trying to make me feel better, they even offered a psychologist for me. (A6)

Ah, the service, the care, the embracement, you know, and also the respect for the patients, for us too, the care, affection, and attention”. Everyone is like, I think, you know, knows what is right, it is not like that, you know, ethics, you know. And I am happy, because it has been very different from what I knew it was going to be. (A7)

The best thing is the people’s way, they did not ignore. They really tried... it is like I told you, they came to help me, they are helping me. Because some people know that you have a disease and they don’t get close to you, you know. So, it is the opposite. (A9)

Three respondents reported that they were provided with good cared, as professionals
emphasized the importance of exams and medication intake to prevent health issues during pregnancy.

 [...] the girls are very considerate, you know, they really explain the importance of the treatment, the medicine, everything [...] it is a good way of saying, I received good treatment, you know, they were always explaining the importance of the medicine, the treatment, you know, the risks for the baby, I received much attention. (A15)

I received good treatment, you know, it was a bit tiring to always have to be there, it is not like a person, let’s say, normal, who is there receiving prenatal care without HIV and has an appointment once a month. And I was right there, infectologist, everything, monitoring viral load, always doing a lot of exams. (A16)

I think that the care provided here, I don’t know about other hospitals, but I think that here [at this hospital], whoever comes here has nothing to complain about, because it wasn’t just me, I saw other patients, too, the attention is the same for everyone, at least so far I haven’t seen anything that discredits the hospital, so I have no complaints. Especially regarding doubts, if we have any doubts, you can ask that, if I ask you and you don’t know, you say: no, I don’t know how to answer you now, but so-and-so knows it, then you talk to so-and-so and the guy explains it, and this is important. (A17)

The safety of being at a referral hospital for high-risk pregnancy has also been reported:

I felt safer, you know, because I was in a rather specialized hospital. Relying on better monitoring, with more ultrasound exams, see him [the baby] more frequently, doing blood tests several times, too, to see if everything is right so that he [the baby] doesn’t contract any disease. (A10)

[...] that here [this hospital] is more specialized, then they have a rather “everything will be all right” attitude. (A10)

In addition to prenatal care embrace at the hospital, they also reported good-quality care at the UBS:

Of course, we were embraced at the UBS, wow, very well, so the medicine, the treatment, everything had started. When something happened, they calmed us down. You know, if I look for those people there [at the UBS] to thank them, I will not find them, you know, I was there today, because now I will change my medication and everything was very fast, between the result of the exam, the appointment with the infectologist, and the medication, everything was very fast, there was not even a week apart. I don’t know if it is because I am pregnant, my husband is already sick, you know, but it was very fast, and the support mainly, the support was really great, we felt really embraced. (A17)

It is because, you know ... I didn’t have any problems with these two, you know, I was always treated very well, you know, all the support I needed, both in the hospital and at the UBS, they really embraced me, you know. I am very grateful for the follow-up here [at the hospital], because then I had all this support, from the beginning, all the explanation of what it would be like, I knew that I would have a chance of having a child without HIV, my child wouldn’t necessarily have HIV or I could have children in spite of the disease. (A18)

However, two respondents reported not feeling comfortable at the UBS:

They [at the UBS] treat us with a certain indifference, and here I didn’t see any of that, you know. I felt good here. (A5)

At the UBS I went there until the fourth month of pregnancy. Because it is actually the same thing they did there, I did it here, but here it is ten times better than there. Here there is excellent, good-quality service. There, I felt that, you know, people were doing everything unwillingly, you know. So I gave up a little bit, then I said: “Oh, there I weigh myself, too, I have appointments, I talk to the doctors, but there is more attention there. I will remain only at the hospital and not at the UBS”. (A8)

Issues involving lack of privacy in both prenatal and postpartum periods were reported by three respondents:

The only thing I say about breastfeeding is when, outside, all pregnant women are together, and unfortunately, no, fortunately, one cares about the other, she wants to know, she is curious. And then you are very embarrassed because, oh, she will ask: “oh, and how was your delivery?” Or they sometimes ask questions right away and you have nothing to say. And if it were a part there, for mothers like that, or, a certain day just for this type of pregnant woman, it would be easier, because they would know that it would be a day just for that, and we, it would be much easier, that we would exchange doubts and talk more openly about them, without any prejudice. Of course we feel included, everyone is together there, but I think that, on that day, it had to be only those who really need care. (A2)

It just happened a little while ago, it was like, everyone knows, when we have this diagnostic
result, we are aware that nobody wants it, nobody needs to know it, we could have been called out, you know. (A10)

And the doctor looking at my face and talking, you know [laughter], but this is normal for them and the huge audience watching childbirth, there were many people [laughter]. My husband said: “I thought I wasn't going to watch it”. (A11)

Concern about vertical transmission

Eleven respondents reported that, during prenatal care, their greatest concern was about the child and the fear of contamination, according to these utterances:

[...] just anxious, because she is undergoing exams, whenever someone says ‘okay’ there is a party. But I am still anxious. [...] And our concern is this, you know, not contaminating the baby. (A1)

But I was, oh, think about it, to bring a child into the world with this. And I don’t accept myself with that anymore, you know. Brining a child into the world with this problem is something terrible [...] If he is fine, everything else is bullshit, you know. (A6)

My biggest concern was afterwards, when I got pregnant with him, because my viral load was not undetectable. [...] I stopped several times, stayed for nine months without taking any medication, came back again. And then I found out that I was pregnant, and then I really settled on my treatment. I was thinking beyond me, I was thinking about him. [...] oh, let’s say that a child is more than a motivation, so that you want to fight, to live, to live a normal life. (A8)

I only thought of him: "My God, what if he also has this disease?”, then he will have to undergo treatment, too, and I cannot, I have to keep treating him and I also need to treat myself. (A9)

My concern was about him [the baby], you know, I found out I was pregnant on a late basis, I was pregnant with him for six months, it was a short time taking medication during pregnancy. My fear was to pass it on to him, not knowing where it came from, because I had no sexual intercourse with someone who had it, the baby’s father doesn’t have it, he didn’t use anything to get it. [...] when you go to the bathroom, when you go to bathe, you feel dirty, I don’t know, then I thought of the baby and if that was the right medicine. (A15)

Regarding the impossibility to breastfeed, six women reported discomfort, according to these utterances:

Prenatal care itself is a little embarrassing, because you are there with the other women who don’t have it, then they keep saying “oh, but you have to breastfeed” and it is very complicated, this contact you have with other people. Of course I wanted to breastfeed my daughter, but unfortunately I cannot [...] to see other mothers breastfeeding is very complicated. I think they should focus more on that [breastfeeding], because she has to learn how to suck and unfortunately I have to keep use that damn little cup, and they know that when I get home I will have to bottle. It is very sad that a hospital that manages to treat this, which provides such a follow-up treatment during pregnancy just forgets about us at that time, because nobody gives breast milk in a cup. (A2)

[...] even that is strange. Because my first baby was born and they brought him directly to me, I breastfed him immediately, so it is really strange, right. It is like something is missing, because I breastfed my first baby for 1 year and 4 months. [...] then you see the other mothers breastfeeding, you know I already knew that if one day I could get pregnant, since when I detected the virus, people said to me “oh, if one day you get pregnant, don’t even think about breastfeeding” then it was something I already knew. [...] I don’t know how to explain it, but it is strange, it is mine, I just made it, but the others have to bring the milk or take it to feed the baby, so this is strange, you know. But it is something I can’t explain. (A3)

[...] at first, for me, it was very difficult. Because I saw the other mothers breastfeeding and I couldn’t. But now I am used to it. (A4)

It is sad, you know, because you wanted to be there breastfeeding, then they ask: “why does your baby go there [nursing station], to take medicine? Why aren’t you breastfeeding?” Then I said: “because I don’t have milk, in other pregnancies I didn’t have it either”, just to avoid explaining too much. (A12)

But what matters most is that the mother, in my case, was not being able to breastfeed. This is the main problem, you know, because it affects our psychological state, you know, being unable to breastfeed is more difficult [...] but at first when you see everyone breastfeeding and you cannot, this affects our psychological state because you want to breastfeed, he is your baby and you want to feed him, this is very complicated. (A12)

Impossibility to breastfeed

DISCUSSION
User’s embracement is a practice used in the health area, in order to grasp patients’ needs, this helps to strengthen the bond between the patient, the health professional, and the institution, improving patient care and follow-up. Regarding the pregnancy of female HIV/AIDS patients, embracement can be a major factor for adherence to prenatal care and treatment.

Interaction based on humanization and embracement contributes so that the pregnant woman keeps a bond with health services throughout the gestational period, minimizing anxiety and the risk for obstetric complications, favoring a rather peaceful and healthy delivery for the mother and the baby (7).

The nurse is extremely important for these pregnant women with guidance and embracement, mainly during prenatal care, in order to facilitate understanding of the guidelines, clarify doubts, and help these women throughout treatment so that the risks of vertical transmission are reduced.

Vertical transmission during the gravidic cycle is frequent among pregnant women and during prenatal care, the nurse can advise them about risks and preventive measures to avoid transmissibility and, if possible, refer them to psychological care. Early HIV diagnosis is important for proper treatment, reducing a mother’s fear of transmitting HIV to her child (8).

Although late diagnosis makes prophylaxis difficult, every woman should be tested for HIV before delivery. It is necessary to reinforce with health professionals the procedures recommended by the MoH to reduce the HIV vertical transmission rate, as well as providing means for all pregnant women to take the test within the first trimester of pregnancy (8).

Counseling to women, pregnant women, and puerperal women regarding preventive measures must be clear and objective so that they can be monitored, since this procedure is key for the follow-up of prophylactic measures and, consequently, the child’s health and wellbeing (8).

To contribute to healthy changes in women’s attitudes, a health professional, during their prenatal appointments, must embrace them and take individual or group educational action, which is of paramount importance for adherence to treatment and care during the gravidic cycle to avoid vertical transmission (9).

The nurse is a social player in the transformation of these women into self-care practitioners. The exchange of experiences between female nurses and pregnant/puerperal women observed in the interviews and in the focus group have paved the way to incorporate self-care measures (10).

Breastfeeding means much more than nourishing the child. It is a process that involves deep interaction between mother and child, with repercussions on the child’s nutritional status, on his ability to avoid infections, on his physiology, and on his cognitive and emotional development. HIV can also be transmitted during breastfeeding, so it is recommended not to breastfeed, avoiding HIV transmission to the child through breast milk (11,12).

Breastfeeding is crucial to the survival of newborn infants in many countries. However, it can account for 1/3 to 1/2 of vertical transmission. The first days are susceptible due to the absence of gastric juice, capable of inactivating the virus, and by the ingestion of HIV-infected macrophages existing in the maternalcolostrum (5).

It is recommended that a HIV-infected mother replaces breastfeeding with artificial milk, as a strategy for HIV prevention. The exclusion of breastfeeding in infected women reduces the chances of child contamination by up to 20% (13). For a woman who has already experienced breastfeeding, it becomes more difficult to accept that she cannot express such an act of love for that child, something that combines with the feeling of helplessness, guilt, and inability (14).

It is considered that failing to breastfeed can be frustrating, given that being unable to offer her breast milk often goes against the wishes of a nursing mother, since a woman who does not breastfeed does not correspond to the socially idealized model, because she doesn’t provide her child with the best nutrition (15). This situation can trigger feelings like guilt, frustration, and anguish in the face of reality, reinforcing the importance of the nurse’s role, as well as other health professionals’, in embracing this woman (16). Thus, it is necessary to seek health promotion, which should not be focused only on preventing vertical transmission, but also on providing these women and children with physical, social, and emotional balance (14).

Some studies corroborate the results obtained in this research, whose outcome is the importance of embracement and counseling in prenatal care for

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good adherence to treatment and prevention of vertical transmission, as well as to avoid non-acceptance of the disease and pregnancy due to the clinical situation, thus promoting self-care among HIV-positive pregnant women(17).

In contrast, other studies report the importance of expanding the focus of healthcare beyond maternal and child HIV prevention, paying special attention to maternal mental health in order to protect the developing child, too. Such attention also consists of grasping the social and still stigmatizing components that surround HIV, to which these mothers are subject. Embracing them, promoting the search for their rights, and helping them to find effective social and family support are key aspects of the care provided to these mothers(18).

**FINAL CONSIDERATIONS**

The experiences reported by these puerperal women regarding care during the gravidic cycle were diverse, however, the term embracement was the most frequently observed in the interviews, both positively and negatively. Embracement during prenatal care, according to the reports, was what helped them to follow the treatment and appointments correctly. Other situations that were regarded as an incentive for the follow-up of prenatal appointments and correct use of ART during pregnancy consisted in concern with the baby, fear of vertical transmission, and wish that their children live a healthy life. For most pregnant and puerperal women, breastfeeding is one of the most expected moments in the postpartum period, in which a bond is established between the woman and her child, and breastfeeding was referred to as something that affects their emotional state and mental health.

Having this as a basis, the importance of care and embracement throughout the gravidic cycle has been found out, since positive results were observed regarding adherence to treatment by HIV-positive pregnant women. The promotion of self-care aiming at the baby’s protection has also been noticed in the reports of these women, who claim to undergo the correct treatment just because of their babies. We may use this position to make them aware that they should practice self-care, undergo proper treatment, and do prenatal care for the baby, but also for themselves, as they deserve to be cared for and enjoy good health. It is also necessary to pay attention to the feelings of these pregnant women in relation to pregnancy, promoting the wellbeing of this pregnant woman throughout such a period, seeking to understand her fears, anxieties, and frustrations, in order to help her without judgment and without criticism.

It is worth emphasizing the importance of a nurse throughout the gravidic cycle, since she/he is present during prenatal care, childbirth, and postpartum and she/he is the health professional qualified to provide embracement and humanized care at health services.

It is recommended that further research is carried out in order to identify potential actions to cope the situations at stake, in addition to considering the participation of the other players involved in this process, with a view to improving health healthcare and the quality of life of pregnant and puerperal women who live with HIV/AIDS.
EXPERIENCIA DE PUÉRPERAS QUE CONVIVEN CON VIH/SIDA ATENDIDAS EN MATERNIDAD DE ALTO RIESGO

RESUMEN

Objetivo: comprender la experiencia de puérperas que conviven con VIH/sida atendidas en una maternidad de alto riesgo. MÉTODO: abordaje cualitativo descriptivo mediante entrevistas con 19 puérperas en un hospital público de referencia para gestantes de alto riesgo en Curitiba (PR-Brasil). Las puérperas que participaron de la investigación realizaron el prenatal en la unidad básica de salud (UBS) concomitante con el prenatal en la maternidad nombrada. Resultados: los principales resultados fueron la experiencia de las puérperas en cuanto a la acogida en el servicio de salud, puesto que se sintieron respetadas, mientras se sentían oídas y no juzgadas debido a su condición de salud; no obstante, ellas también relacionaron preocupación durante la gestación con la transmisión vertical y tras el parto ellas se sintieron incomodas con la imposibilidad de la lactancia. Consideraciones finales: se señala la importancia del enfermero en todo el proceso asistencial, desde la gestación hasta el puerperio, como profesional responsable por la prestación del cuidado humanizado y acogedor a las mujeres que conviven con VIH/sida.

Palabras clave: Enfermería obstétrica. Periodo postparto. Embarazo de alto riesgo.

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