

Understanding what is lived by the being-couple in face of the prophylaxis of vertical HIV transmission

Compreensão do vivido do ser-casal diante da profilaxia da transmissão vertical do HIV

Comprensión del vivido del ser-pareja delante de la profilaxis de la transmisión vertical del VIH



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ABSTRACT

Objective: To understand the couple's perspective, the experience of prevention care against the vertical transmission of HIV.

Method: Heidegger's phenomenological research conducted with 14 participants, through interviews from December / 2011 to February / 2012 in a hospital in the countryside of Rio Grande do Sul, Brazil. Analysis performed with Martin Heidegger's framework.

Results: the being-couple unveiled the sense of fear, initially in the variation of dread when terrified due to the HIV infection discovery, and later in the horror variation when treatment was needed during gestation and finally in the terror variation when considering the chances of viral transmission to their child.

Conclusions: Health care attention that enables the couple to assume a leading role in the prophylaxis of vertical transmission is recommended, which will reflect positively on the health of pregnant women and in reducing neonatal and infant mortality as a result from AIDS.

Keywords: HIV. Vertical transmission of an infectious disease. Caregivers. Nursing. Philosophy in nursing. Millennium Development Goals.

RESUMO

Objetivo: Compreender, na perspectiva do casal, a vivência dos cuidados para a profilaxia da transmissão vertical do HIV.

Método: Investigação fenomenológica heideggeriana realizada com 14 participantes entrevistados entre dezembro/2011 a fevereiro/2012, em hospital no interior do Rio Grande do Sul, Brasil. Análise realizada com o referencial de Martin Heidegger.

Resultados: O ser-casal desvelou-se na disposição do temor, inicialmente na variação do pavor quando ficou apavorado ao descobrir a infecção pelo HIV, posteriormente na variação do horror quando precisou fazer o tratamento durante a gestação e finalmente na variação do terror quando considerou a chance de transmissão do vírus para o filho.

Conclusões: Indica-se atenção à saúde que possibilite o protagonismo do casal na profilaxia da transmissão vertical, o que refletirá positivamente na saúde da gestante e na redução da morbimortalidade neonatal e infantil em decorrência da aids.

Palavras-chave: HIV. Transmissão vertical de doença infecciosa. Cuidadores. Enfermagem. Filosofia em enfermagem. Objetivos de Desenvolvimento do Milênio.

RESUMEN

Objetivo: comprender, en la perspectiva de la pareja, la vivencia de los cuidados para profilaxis de la transmisión vertical del VIH.

Método: investigación fenomenológica heideggeriana realizada con 14 participantes, por entrevista entre diciembre/2011 a febrero/2012 en hospital en el interior del Rio Grande do Sul, Brasil. Análisis realizado con el referencial de Martin Heidegger.

Resultados: el ser-pareja se desveló en la disposición del temor, inicialmente en la variación del pavor cuando quedó apavorado al descubrir la infección por el VIH, después en la variación del horror cuando necesitó hacer el tratamiento durante el embarazo y finalmente en la variación del terror cuando consideró la posibilidad de la transmisión del virus para el hijo.

Conclusiones: se indica atención a la salud que posibilite el protagonismo de la pareja en la profilaxis de la transmisión vertical, lo que reflejará positivamente en la salud de la mujer embarazada y en la reducción de la morbimortalidad neonatal e infantil por el SIDA.

Palabras clave: VIH. Transmisión vertical de enfermedad infecciosa. Cuidadores. Enfermería. Filosofía en enfermería. Objetivos de Desarrollo del Milenio.

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■ INTRODUCTION

With the global definition of the Millennium Development Goals, historic commitments were made and a new global partnership was signed, which aimed to achieve the goals set for this proposal. These objectives include: 1 - reducing hunger and extreme poverty; 2 - basic quality education for all; 3 - gender equality and the empowering of women; 4 - reducing child mortality; 5 - improving maternal health; 6 - combating AIDS, malaria and other diseases; 7 - quality of life and respect for the environment; and 8 - everyone working for development⁽¹⁾.

These goals highlight implications of the role played by health care and nursing regarding strategies aimed at vulnerable populations. In the study in question, we highlight the commitment to contribute to objectives 4, 5 and 6 when highlighting the couple living with HIV before the prophylaxis of vertical transmission as participants.

In Brazil, the magnitude of the AIDS epidemic in women is evidenced in 18,073 reported cases of HIV infected pregnant women in the last three years. The national transmission detection rate of the virus is 2.5 per 1,000 live births in 2013. Against this background, the Rio Grande do Sul state still shows no drop in incidence, which shows the detection rate of vertical transmission of HIV from 9.3 per 1,000 live births, approximately 4 times higher than the national average⁽²⁾. The municipality of Santa Maria, the scenario of this investigation, occupies the 10th position in AIDS cases in Brazil⁽³⁾.

However, recognizing the potential exposure to infection, injuries and impact not only concern the epidemiological dimension, but also refers to the social, subjective and existential dimension of the human being. Thus, we understand the need to expand studies that give emphasis to subjectivity, understanding that the phenomenon being studied permeates the ability to understand the meanings attributed the experiences of people⁽⁴⁾. Among the experiences, studies show that the chance of being infected by HIV is not regarded by the people and, therefore, the diagnosis becomes an event with a huge impact upon experiences lived⁽⁵⁾.

When the woman is seropositive, revealing the diagnosis to the baby's father is something difficult to do, and that in certain situations, requires the participation and support of health professionals⁽⁶⁾. But, the fact of sharing the diagnosis allows the partner to become more involved with the baby's health and more willing to support the woman and may support the care regarding prophylaxis of HIV vertical transmission⁽⁷⁾.

Therefore, it is understood that the inclusion of the partner in prenatal services and preventative care against

vertical HIV transmission implies in reducing the risk of this means of transmission and subsequently in reducing neonatal and child mortality⁽⁸⁾. The challenges of incorporating this partner in health services remains, as there is need for change and adaptations in the health system to overcome barriers such as the representation of HIV to professionals permeated by fear and prejudice⁽⁹⁾, and facilitating the involvement of the partner or parent^(8,10-11).

When considering this as a strategy of care and nursing and a contribution to the improvement of the epidemiological and social indicators in the field of reducing infant and child mortality; improving the health of pregnant women; and combating AIDS, a guiding question was asked: how does the couple experiences the care for prevention of the vertical transmission of HIV? For this purpose, the objective of this investigation was: to understand, in the couple's perspective, the experience of prevention care against the vertical transmission of HIV.

■ METHOD

Research with a qualitative approach, phenomenological, with theoretical, philosophical and methodological references from Martin Heidegger⁽⁴⁾. Type of research that seeks to uncover the subject matter the way it is in itself, through its significance in this study: the experience of care for prevention of vertical transmission of HIV.

For this reference, the previous position established by science⁽⁵⁻¹¹⁾ does not matter, such as facts that make up a part of the understanding, that is, it is necessary to suspend the factual knowledge (what is already known about the object of study). It focuses on seeking the meanings and senses, through Heidegger's hermeneutics, as a possibility to uncover facets of the phenomenon studied⁽⁴⁾.

The research was developed from the master's thesis⁽¹²⁾, from December 2011 to February 2012 in outpatient prenatal and child care of a hospital in the countryside of Rio Grande do Sul (RS), Brazil, with 14 participants, 7 couples. The couples were selected intentionally through the following inclusion criteria: couples who experienced the daily prophylaxis of the vertical transmission of HIV during pregnancy and the postpartum period; and exclusion criteria: when there was death of a son / daughter from this pregnancy, but use was not required.

The number of participants was not predetermined and the completion of the data collection stage was set as the pre-preliminary analysis of the data, concomitant to the obtention step, the testimony of the participants responded to the purpose of the investigation and there was a sufficiency of meanings⁽¹³⁾. A phenomenological in-

interview was used as a technique to obtain data, which had, as its guiding question: How was / is the care experience to prevent vertical transmission of HIV to her / his / your son / daughter?

The interviews were recorded using a digital recorder and transcribed for further analysis. To guarantee the confidentiality of the participants, the transcripts were coded in M for women, H for man and F for child (when it was mentioned in the interview), followed by the numbers 1-7 (M1, H1, F1, M2, H2, F2 ; and so on).

Data collection occurred through the phenomenological interview that proposes to start by the researcher's activity in suspending his or her comprehension regarding the facts that compose a part of the factual knowledge (prior knowledge given by science). It discusses the possibility of developing a unique encounter between the researcher and each participant, mediated by empathy and intersubjectivity⁽¹³⁾.

It was therefore necessary to consider the ways for the couples to show themselves to the couple, capture what was being said (the spoken) as well as the gestures and silences (what is not voiced, or is unspoken) and respect the space and time of each couple during the interview. Empathic questions were formulated from the couple's own speech, seeking to avoid inducing answers, and deepen the possible meanings. This form of observation and dialogue allowed the phenomenon to emerge and specifically allowed the best possible conduct of interviews⁽¹³⁻¹⁴⁾.

Data analysis was divided into two methodical moments proposed by Martin Heidegger: vague and median understanding and hermeneutics⁽⁴⁾. The strategy used to organize the data to develop vague and median understanding was to carry out chromatic identification of the essential structures (words or phrases that express the same meaning). From this, they gathered up excerpts of the conversations to compose the meaning units (US) and the phenomenological discourse. Understanding the meanings expressed by the participants sought to describe the phenomenon as it shows itself, which is the guiding principle of hermeneutics⁽⁴⁾.

The senses that remain veiled and obscure, should now proceed to interpret the meanings understood, it is understood as a possibility to conquer a common thread with the elaboration of the concept of being. "In light of this concept and the ways of explicitly understanding what is inherent to it is what this understanding of being obscure and not yet being clear means"^(4:41). This movement corresponds to interpretative analysis, Heidegger's hermeneutics.

From the emergence of the US, Heidegger's hermeneutics was developed (analysis and discussion of data), where

the understanding of the meanings was sought in the possibility of unveiling the sense of being, the ontological dimension. Ontology's task is to understand the meaning of being without resorting to preconceptions of science, but to the interpretation of the question of being, which, in the screen study, was based on Heidegger's philosophical reference⁽⁴⁾.

The development of the study met national and international ethics standards in research involving human subjects. The research project was approved by the Research Ethics Committee of the Federal University of Santa Maria (RS) under CAAE 0298.0.243.000-11. The principles of voluntariness anonymity, confidentiality of information, justice, equity, reduction of risks and enhancement of benefits were guaranteed, protecting their physical, mental and social integrity from temporary and permanent damage. The Free and Informed Consent Form was signed by couples who agreed to participate.

■ RESULTS AND DISCUSSION

According to Heidegger's benchmark, understanding vague and median (understanding of the meanings) is hermeneutics' vital thread, which aims to understand the meaning revealed through the discourse of research participants about the phenomenon studied.

As a result, different moments, constituents of fear, were unveiled in Heidegger's reference: the variations of dread, horror and terror. This disposition named by the author reveals how someone is and becomes when faced with a threat, and in the conception of fear, the fear of something can be considered from three perspectives that are anchored in their perception of the familiar / known or not familiar in the world-life of that person, called worldview. It manifests itself in different ways depending on when this threat comes forward, or as in one's personal life, in most cases, suddenly and unexpectedly.

Thus, hermeneutics revealed that the being-couple is prone to the sense of fear, initially in the variation of **dread** when terrified due to the HIV infection discovery, and later in the **horror** variation when treatment was needed during gestation and finally in the **terror** variation when considering the chances of viral transmission to their child.

In recounting their experience of performing the prophylaxis of the vertical transmission of HIV, the couple revealed what was lived before the pregnancy to be significant, expressing their feelings when being revealed the diagnosis. They did not think they could get infected. When they came to know it was a shock, horrible, difficult. They say that after you have the disease, you have to get used to it.

The HIV infection surprises the couple because they thought that it was a distant disease. It's hard to find out that you have HIV and even harder to tell your partner, but after revealing it to your partner, the couple arrives at the conclusion that they will stay together. Knowing you have this disease further relates to thinking that one can die, and this creates bad feelings that can interfere in the beginning and continuity of care.

After the shock caused by the discovery of the diagnosis, the solution to overcoming this is to get used to the disease, embrace it and go on with life. Although there may be some scary situations in the period between the discovery and acceptance of the diagnosis, such as getting sick from not taking the drugs, afterwards you finally realize and accept the disease.

It was very desperating [...] how am I going to tell him [H1] [I have the disease] [...] then we reached an agreement that we would stay together (M1)

When I learned that she had it, I took a big blow [...] It was hard, I thought it had been me who had passed to it her (H1)

When I got pregnant I had nothing, I never imagined what that this [the disease] could happen [...] the experience was awful, it was terrible (M3)

It's a shock [when I learned of the diagnosis]. [...] If you have an illness you will have to get used to it or you'll have to kill yourself [...] so you have to embrace it and follow on with life [...] You never think it will happen to you (H3)

At first, I was a little upset, as soon as I knew [about the diagnosis]. I thought it was the end, that I was going to die, I did not take the drug [...] After that scare there that I woke up [accepted it] (H4)

The sense unveiled from the meanings, in the understanding of vague and median, reveals a disposal mode of the being in hermeneutics, called fear, which will be determined in the person from their position as a being in the world. The constitution of the being in the world refers to how one understands themselves, relates and manifests in their world of life⁽⁴⁾.

The being in the world is immersed in his or her daily occupation, and in this everyday life, remains in a constant movement of understanding things in the world, making up their worldview. This means that things that people know can be more or less familiar, or even unfamiliar to

them⁽⁴⁾. In this study, the being-couple holds an understanding of the AIDS epidemic and how it impacts people's lives. Thus, people have heard of AIDS, but sometimes do not recognize they can be vulnerable to the infection.

What is terrible is how something that has a threatening character in the overall damage, showing itself within a context, that the possibility of getting infected by HIV was never part of their own understanding as a being in the world.

The **first constitutive moment of fear, dread**, is anchored in what is familiar, threatening and sudden⁽⁴⁾. Thus, interviews showed that while the being-couple knows what HIV and AIDS are and how one can become infected, they never imagined that the infection would happen to them, it was something far away from their reality. Thus, the possibilities of becoming infected shows itself as being closed.

With respect to what is familiar, this is represented by what we have heard about AIDS, and everything that the disease represents to the physical and social integrity of the-couple. In many situations, it was revealed from the woman's diagnosis. The character of threat to the being-couple in this variation of fear is made up by the sudden discovery of the diagnosis, joined by what is familiar to them, AIDS. Thus, what indicates dread is something known, something familiar with a subtle onset⁽⁴⁾.

Therefore, discovering the diagnosis in a sudden / unexpected way is the way AIDS meets the being-couple. Guided by the worldview of the epidemic, expressing shock feeling to find that you have HIV and that the discovery was painful, a very bad experience and awful and never imagined it would catch the virus. The being-couple is terrified with the diagnosis of the HIV infection.

During the experience of care to prevent transmission of the virus to the child, presented as prevention of vertical transmission, the couple is faced with the unknown / unfamiliar regarding the transmission of the virus by a different route than the one already known: sexually. This prevention consists in drug treatment, so the couple realizes they may have done something wrong, like changing the dose of medication. They worry about the late start of treatment for the prevention, either because they didn't arrive on time for the first prenatal consult or because they received a late diagnosis.

They know that if they continue treatment with the medication they will not transmit the disease and this is therefore a defense for their child. When needed, medication should be changed in order to not harm to the child. Attention should always be paid to the medication so that there are no alterations in the exams.

Although it took a few scares, they were always been very careful with everything in order for everything to work out and not pass the virus to the child. They believe that everything that can be done to avoid transmission to the baby, who is defenceless, is worth it.

Then I realized that it was not 5ml that she [F2] had to take [AZT] and I'm giving her the wrong dose? I panicked (M2)

We arrived at the wrong time [for the first prenatal consultation] and then we panicked, we started crying because I thought it was taking too long [to start] [...] we know we did everything right, but we have taken a few scares as well (H2)

I talked with the doctor and she explained that the odds were very small [to be born with the virus], it wasn't something probable (H4)

I changed medications, I was taking efavirenz, which is bad for pregnant, the child can be born with problems [...] always taking the medication as recommended, being careful so that the exams came back with no alterations (M4)

I was worried about the beginning of treatment coming too late for her [F6] (M6)

It took a while to identify [HIV diagnosis] and it also took some time to start taking the medication [F6] (H6)

I know that I won't transmit while on the medication [...] everything a person can do care wise to not transmit this disease to a helpless little person, its all worth it (M7)

In the **second constitutive moment of fear**, which is **horror**, the threat takes on the character of what is completely unknown and unfamiliar⁽⁴⁾. This variation of fear emerged when the being-couple meant their concern and zeal in performing care to prevent vertical transmission of the virus to the child, who is helpless. They were horrified expressing fear and doubts about the beginning and the characteristics of the treatment and apprehensive when treatment was slow to be implemented. They fear not being sure that prophylaxis, as an early protection, will work out.

The character of the unfamiliar constitutes itself when, during pregnancy, that should be a time marked by less medicaments and risk to the baby and with the least possible interventions, something unusual appears. It is

a process that requires a more rigorous follow-up, which includes a routine in infectious diseases service and high-risk prenatal treatment with numerous blood withdrawals for laboratory tests including CD4 T lymphocytes and viral load surveillance and anti-retrovirals that should be ingested daily, which may cause adverse effects.

Therefore, unveiled the transition from dread to horror was unveiled⁽⁴⁾, in which the being-couple is horrified for facing the unknown routine of prophylaxis of vertical HIV transmission with the uncertainty that despite all the efforts made may not have the expected result – the prevention of transmission to the child. The couple announces they do not know the effectiveness of the vertical HIV transmission prophylaxis.

The couple gets scared when they learn of the women's HIV status and are informed that during pregnancy, childbirth and postpartum, HIV transmission to the child can happen. This way, they come to know the care related to prevention of vertical transmission, but are not 100% sure that the treatment will work. And until they receive the news that the child is released from being subjected to monitoring the infectious disease and have the final result, they won't rest. Questions are made regarding the child's life and how it will be if the parents do everything right and the child still has the disease.

When the wife's diagnosis is discovered during pregnancy, the husband states that he would have tried to perform prophylactic care from the beginning, from the moment the wife got pregnant, to have more security not to transmit to the child. Yet, the husband considers that care to avoid transmission was implemented from the beginning, even if it is a late start.

We had that fear as well: I did everything right and who will guarantee it will actually work? [...] And we wondered, what if it does not work out, how will this child's life be? (M1)

But while you do not receive that news that the child is ok, all you do is wonder [...] you're not 100% sure that your child will not have the disease (H1)

I think it was the care at the beginning to avoid transmission to him. [...] If it had appeared [test results] I would have felt more security that I would have felt more secure that I would not transmit it to him [F3] (M3)

Because the right thing to do is to stay on the treatment once you're pregnant in order to not transmit, and this step wasn't taken (H3)

Kind of worried about everything, there could be a problem [...] he could be born with the virus (H4)

I think it will be all right, I will not transmit anything to him (M4)

My concern is only the two of them [M5 and F5], especially her [F5] to not transmit, not catch the disease (H5)

It was a careful pregnancy. Everything, to make sure my blood pressure won't rise and my immunity will not drop (M5)

The **third constitutive moment of fear**, which is **terror**, conjugates dread with horror. So, fear emerges when the threat has the character of something known and familiar that suddenly strikes the couple, being signified by the woman's seropositive diagnosis. When the fear is associated with the horror of facing the care of chemoprophylaxis for vertical transmission with the uncertainty of the success of prevention, which is the unknown, the fear shows itself in the variation of horror⁽⁴⁾.

That moment of fear was unveiled with the sudden and unknown threat, which is the possibility of the child having the disease. The being-couples express they are terrified with the possibility of transmitting HIV to the child. Thus, they consider the possibility of a yes and a no in the face of the threat of vertical transmission.

As a being of possibilities, the being-in-world experiences the facts in their daily lives driven by the expectation that they can happen (possibility of yes) or not (possibility of not). This disposition to open the being to the yes and the no and to not regulate its ways-of-being before experienced phenomena⁽⁴⁾.

For Heidegger, fear may extend to others when one is afraid in another's place. What is feared might be the very existence, living with each other or fear in the other's place (the son), prejudice, discrimination, illness or death. To be afraid in another's place, the being showing itself ready to be afraid together with the other⁽⁴⁾. In this study, sharing fear, unveils in the threat to the child's health from pregnancy under a seropositive result.

This availability of being indicates that the couple is afraid and feels threatened by something that they can not escape, facts they they will be faced with⁽⁴⁾. This is an existential movement in which the person feels threatened by something and by the way this thing happens in their life, with the availability to be understood as a way of the human being showing its existence, without expressing any negative evaluation.

■ FINAL CONSIDERATIONS

The main findings of this research show that the being-couple, when faced with the sudden diagnosis, is terrified by the discovery of HIV, horrified by the treatment during pregnancy and with the uncertainty of this treatment being effective, and terrified by the possibility of transmitting the virus to the son.

As implications to the body of knowledge in Nursing and Health in healthcare practice, based on the framework that values subjectivity, it is recommended that careful attention to the couple be extended, reaching beyond only women in their pregnancy and childbirth periods. When contemplating the couple, that they can be protagonists of health care resulting from the HIV infection, implied in their means of transmission, prevention and treatment.

It is important to understand that the space / time contemplating the subjective needs of this couple become frequent during the health monitoring of the baby. In order for the couple to understand the health professional as someone with whom they can share their fears and seek strategies to minimize them and overcome them when experiencing the care for prophylaxis against the vertical transmission of HIV.

Health care attention involving the couple as protagonists reflect positively in the health of the pregnant woman, reducing neonatal and child morbimortality as a result of AIDS, and with it, the combat against AIDS. Thus, care is shown as a contribution from Nursing in the fulfillment of the Millennium Development Goals.

The phenomenological look of Martin Heidegger allowed facets of the experience of the being-couple in the care for prevention of vertical transmission of HIV to be unveiled, indicating the expansion of health care for the couple, adding a comprehensive perspective to the body of knowledge in Nursing and Health.

The challenges faced during the field stage, and the difficulties to access research participants, since the subjects were couples can be highlighted as limitations to this study. More specifically, the difficulties were: divergence between the couple on the willingness to participate in the survey, resulting in the withdrawal of the couple; time and space to find a common time during which the two were available and a suitable place where the child could be taken care of while the couple attended the interview. Thus, considering the complexity of the interview with the couple in the context of HIV / AIDS, it is concluded that an extended period for the field stage, in order to manage the difficulties experienced and minimize losses is needed.

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