

# Quotidian of being-a-couple: meanings of HIV vertical transmission prophylaxis and assessment possibilities

*Cotidiano do ser-casal: significados da profilaxia da transmissão vertical do HIV e possibilidades assistenciais*

*Cotidiano del individuo-pareja: significados de la profilaxis de la transmisión vertical del VIH y posibilidades asistenciales*

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## ABSTRACT

**Objective:** To unveil the meaning of HIV vertical transmission prophylaxis for the couple. **Methods:** Heideggerian phenomenological investigation, developed from December 2011 to February 2012 in the prenatal and childcare outpatient of a hospital in the countryside of Rio Grande do Sul, Brazil, with 7 couples who experienced the quotidian of HIV vertical transmission prophylaxis. **Results:** Being-a-couple shows oneself on yap of being on treatment accordingly and knowing that one can't breastfeed. On curiosity, seeking to understand everything and ambiguous referring not being different of others. **Conclusion:** We elucidate the relevance of the nurse to base caring for the couple in a dialogical meeting, of attention to health on seeking qualified nursing care to the couple, child and family.

**Keywords:** HIV; Acquired Immunodeficiency Syndrome; Infectious Disease Transmission, Vertical; Nursing.

## RESUMO

**Objetivo:** Desvelar o significado da profilaxia da transmissão vertical do HIV para o casal. **Métodos:** Investigação fenomenológica heideggeriana, desenvolvida no período de dezembro de 2011 a fevereiro de 2012 em ambulatório de pré-natal e puericultura de um hospital no interior do Rio Grande do Sul, Brasil, com 7 casais que vivenciaram o cotidiano da profilaxia da transmissão vertical do HIV. **Resultados:** Ser-casal mostra-se no falatório de fazer o tratamento adequadamente e saber que não pode amamentar. Na curiosidade buscando entender tudo e na ambiguidade ao afirmar não ser diferente dos outros. **Conclusão:** Elucida-se a relevância do/a enfermeiro/a pautar o cuidado ao casal num encontro dialógico, (re)conhecendo suas necessidades para aliá-las às possibilidades terapêuticas e de atenção à saúde na busca por um cuidado de enfermagem qualificado ao casal, à criança e à família.

**Palavras-chave:** HIV; Síndrome de Imunodeficiência Adquirida; Transmissão Vertical de Doença Infecciosa; Enfermagem.

## RESUMEN

**Objetivo:** Desvelar el significado de la profilaxis de la transmisión vertical del VIH para la pareja. **Métodos:** Investigación fenomenológica heideggeriana, desarrollada en el periodo de diciembre/2011 a febrero/2012 en un ambulatorio pre-natal y de puericultura de un hospital en el interior de Rio Grande do Sul, Brasil, con siete parejas que vivieron el cotidiano de la profilaxis de la transmisión vertical del VIH. **Resultados:** El individuo-pareja se muestra en el relato de hacer el tratamiento adecuadamente y saber que no puede amamentar. En la curiosidad, buscando comprender todo, y en la ambigüedad al afirmar no ser distinto de los otros. **Conclusión:** Se revela la relevancia del enfermero guiar el cuidado a la pareja en un encuentro dialógico, (re) conociendo sus necesidades para intentar conciliarlas a las posibilidades terapéuticas y de atención a la salud, en la búsqueda por un cuidado de enfermería cualificada para los padres, el niño y la familia.

**Palabras-clave:** VIH; Síndrome de la Imunodeficiencia Adquirida; Transmisión Vertical de Enfermedad Infecciosa; Enfermería.

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Submitted on 07/06/2013.  
Accepted on 06/08/2014.

DOI: 10.5935/1414-8145.20150034

## INTRODUCTION

Increasing the number of women infected with Human Immunodeficiency Virus (HIV) features the feminization of the HIV epidemic. Due to this changing in epidemiology profile, prevention policies, promotion and comprehensive care were established to its cope in order to reduce vulnerabilities that affect women<sup>1</sup>.

With the feminization of the epidemic, it is shown that most of HIV infected women are in childbearing age. In this sense, it is highlighted the situation of pregnancy in the context of HIV, which exposes the risk of vertical transmission (VT) of HIV. It is noteworthy that the VT is the major route of HIV infection in children<sup>2</sup>.

In Brazil, since 1994, the AIDS Clinical Trials Group Protocol (ACTG) 076 reduced VT ratings of HIV<sup>2</sup>. This protocol established prophylaxis for the woman and the baby, which is the administration of antiretroviral medication, routine consultations and the recommendation of not breastfeeding<sup>3</sup>. In addition, women should have access to information about the care of their health to ensure a healthy pregnancy with less risk to children<sup>4</sup>.

From this perspective, there is the need to effect the implementation of public policy in prenatal care in order to ensure the anti-HIV serological screening with suggestion of early pre and post-test. Insufficient coverage in performing this test is shown as a limiting factor for full control of VT<sup>5</sup>.

The TV prophylaxis strategy operationalization of HIV requires attention, support and integration of health professionals to recognize the preventive actions in different scenarios<sup>6,7</sup>, and so develop guidelines through health education. The nurse, as a member of the health team, assumes the corresponding actions to nursing care.

Such actions must be guided by the principles of humanization and empathy between the nurse and who is being cared in order to minimize the doubts and the suffering of the couple and so prophylaxis can be carried out with success<sup>8</sup>. In this view, nursing care is a process of listening to the demands, exchange of information and emotional support to the couple, through a dialogue aimed at establishing a relationship of trust and allows acting on its own merits. Thus, it allows designating specific interventions for each difficulty, looking for a care permeated by ethics and commitment to human life<sup>9</sup>.

The couple experiences the effectiveness of prophylaxis of VT, recognizing the daily effort to do the treatment of prenatal care on behalf of the child. In this sense, it is strongly important to assume the relevance and need for support not only to the woman but to include the man and assist the couple in reproductive care, with also to aid in the everyday prophylaxis<sup>10</sup>.

The relevance of studies about the pregnant women's adherence to the prophylaxis of vertical transmission is undeniable<sup>4,9,11</sup>. However, advances in this topic require to assist this population following what the public policies have shown in the

field of humanization. Thus, to integrate effectively the partner's participation in care and in research is presented as something indispensable.

In this perspective, it is understood the possibility of a proposed contribution to the care of this couple, aiming to reveal the meaning of prophylaxis of HIV vertical transmission to the couple.

## METHOD

This is a qualitative, phenomenological research, based on theoretical-philosophical and methodological framework of Martin Heidegger. The conduct of this study allowed us to understand the feelings, emotions and meanings that the human being experiences situations<sup>12</sup>.

This research was done on an ambulatory in a hospital in the interior of Rio Grande do Sul, Brazil where infectious disease on pre-natal and child care are performed. The subjects of the research were couples that make health monitoring at the clinic. Inclusion criteria were: couples, experiencing or have experienced the prophylaxis of daily vertical transmission of HIV during pregnancy and postpartum period. The couple could be serodiscordant when a woman has HIV/aids and the man did not, or seroconcordant when both have HIV/aids.

The data collection occurred from December 2011 to February 2012. The technique used was a phenomenological interview, which can consist of one or more open questions, with the possibility of deepening the meanings reported from the development of new questions in during the interview<sup>13</sup>. This type of access to participants allowed a motion to understand the couple experience, as presented in their daily life.

The invitation to participate in the study was carried out to the couple, or to the man or woman, when they were waiting for treatment at HUSM. By telephone contact the date, place and time schedule was made for the interview. The couple attended the conference together and it was possible to unveil the meaning of the phenomenon studied when there were seven couples participating.

The interview was mediated by empathy and intersubjectivity, from the reduction of assumptions, allowing a meeting between researcher and participants in an opening movement to capture how the other means the studied phenomenon<sup>14</sup>. The guiding question of the interview was: how was/is for you the experience of care to prevent HIV transmission of to the/your son/daughter?

Their statements were recorded by consent and transcribed as original speech, pointing silences and body expressions. The interviews were coded with the letter W of woman, M for man and C for child, followed by the numbers 1 to 7 (W1, M1, C1, W2, M2, C2; and so on).

Data analysis occurred in two methodical moments: vague understanding and median and hermeneutics. The vague understanding and median is characterized by analyzing the

meanings expressed by the subjects, seeking to describe the phenomenon as it is shown, because the being is only presence, being in the world, when it is understood. Hermeneutics is the interpretative analysis from the concept of being-couple seeking to understand the meanings of the possibility of revealing the being meanings. This movement allows to walk the ontic, factual dimension to the ontological, phenomenal dimension<sup>12</sup>.

The ethical aspects of the study were assured, given the precepts of Resolution 196/96, and the research protocol was approved by the Institutional Review Board (CEP/UFMS) under CAAE number 0298.0.243.000-11.

## RESULTS

From the comprehensive analysis of the statements, there are the meaning units: (1) do everything right from pre-natal and not breastfeed; (2) is the couple's interest to participate in lectures, seeking information with professionals and communication media and (3) follow a normal life, as if they do not have the disease.

In the meaning of daily prophylaxis of vertical transmission of HIV, the couple announced that does the treatment properly. They do all that have to do, from pre-natal to not breastfeeding, so that the child is healthy.

The couple emphasizes that given the concern for not transmitting HIV to the child, they do everything and what is right, to the end. They repeat that they sought to do and did everything I ever spoke to them. When the diagnosis was discovered during pregnancy or childbirth, the couple regrets the late discovery and it would be nice to have early treatment.

They repeat information from health professionals that to gestate and have HIV requires more care than those that which there is no infection in pregnancy and the son has disease risk.

*Because doing all right we know we were doing (W1) All we had to do we did (M1).*

*We're going right [AZT] (W2) We did everything right [...] (M2).*

*It was made an examination only when I got pregnant and I think the right thing, is that the doctor should have more done another test (W3) and good was if we had discovered during pregnancy [to do treatment since when pregnant], when the test was done. In fact it was discovered only after the time of birth (M3).*

*We did everything right [...] so he was born with health (M4). Do everything right [...] did all the pre-natal, from beginning to end, I did everything (W4).*

*What we could do, we did it (M5). I did everything right so far [...] it was a careful pregnancy [...] starting with prenatal care (W5).*

*That's what we did [follow all directions] (W6).*

They reflect that when they have the virus, the best option is not to offer her milk, so the care continues similar from pregnancy. However, with experiences about breastfeeding, women know that it is important for the child to receive breast milk because it may protect him against diseases and provide the child grow healthy and strong.

However, in the context of HIV when receiving and seeking information during pregnancy, they learn that they can not breastfeed. They were informed or heard about it. When they experience this (im) possibility, they feel that it is difficult. The partner thinks she should already be prepared for not breastfeeding, because she knew it would be so, and he surprised at the reaction of the woman.

Not breast-feed causes discomfort, since there is wide dissemination of breastfeeding support in the media, health services and professionals, in opposition to the lack of disclosure in situations where a woman can not do it. Even in the health service where they do this treatment, this problem is not disclosed and treated naturally, it remains silent.

*From pregnancy I knew I could not breastfeed him [C1] (W1).*

*I should have been prepared, but it hurt at the time [...] so sad not breastfeed (W2) I did not expect that her reaction, for me it was something that she was processing that she was not going to breastfeed (M2).*

*I thought when he was born [C4] my breasts were going to be this big [makes gesture of full breasts], I did not know what I would do with the milk (W4).*

*I know I can not [breastfeeding] [...] you get there [prenatal] and you read those huge poster that is very good [breastfeeding], that does it, that makes it, but there is not a something to let mothers [who has HIV] more calm, a sign there saying, to comfort us. (W7) only that they [health professionals] do not clarify that those who are HIV positive mother can not breastfeed. This lack of [...] In the media does not, this focus also lack (M7).*

In daily prophylaxis of vertical transmission of HIV, the couple meant that it is their interests to attend lectures, seeking information with professionals and the media. They demand listening and watching to see what will happen.

They search information by reading newspaper, magazines and informative booklets, watch news reports on television, do research on the internet. They seek to be updated on new therapies and news involving the prevention and treatment of HIV.

*And I thought I was not going to [be a normal delivery], I thought it would be cesarean section to prevent more [...] I think I can ask the doctor today about the examination that he did when he left the hospital (W4).*

*We participated in the lectures and they said there is the window period (M5) coming an hour before [delivery] to put serum [...] I've had enough lectures [...] I went to get enough assistance for the nine months watching lectures, I knew more or less what would happen (W5).*

*We see on TV, we watch, we try to learn, try to listen to information (W7). news, research, results, this and that, things that we observe enough (M7).*

In the meaning of daily prophylaxis of vertical transmission of HIV, the couple says that continues with the normal life. It is as if they do not have the disease. HIV in the couple's life is minimal, sometimes not even remember they have it, only when they see a television report or when taking medicine. Having HIV is not something to be thought 24 hours a day, it is just one more item to be careful.

It is the difference of taking medication and using condoms. However, this is part of the couple's habit like brushing their teeth, which is already naturalized and diluted in routine, it is normal.

*And everything is so happy that [disease] ends up being the minimum [...] or sometimes not even taking medicine I remember [that has the virus] [...] We invest, we spend, but we buy one [condom] comfortable which is what we can use (W2) It's not something that I get 24 hours honking in my head [AIDS] [...] that [taking medicine] is part of us like brushing our teeth and like everything else in our habit (M2).*

*We just know we have [virus] because we take medicine [...] The only thing different that we have to use a condom (W4) as if we had nothing. [...] At home the only difference is to use medicine (M4).*

*Only care on the day of the couple [who is not HIV] would not need it [not using condoms] (W6) Only one more item to be careful, that is the treatment [...] more preventions necessary, condom use, things like that (M6).*

*It looks like I do not have [...] [a life] normal as yours [...] the only time I see that I have it is when I go there to take medication [...] (W7).*

The couple expressed following a normal life. They do not have restrictions with regard to making decisions about the activities of their daily lives. Having HIV does not change anything in their life, had no difficulty, it improved, it is a way to fight more and more.

They do not stay thinking they have HIV, and they will not let the virus be greater than their lives, then they do not live, but they live with it. They report that they have a life like any other person who has nothing, working, having fun and living.

*This we will continue normal [...] (M1).*

*There was all normal [...] life continues (W2).*

*We are leading normal [...] Everything normal, normal life (M3) we can not be thinking that we have this [disease] if not you do not live [...] my life remains the same (W3).*

*We have a normal life (W4) Same thing that people see in other people who have nothing, work (M4).*

*For me nothing changed, it improved. Because she [C5] is a way to fight more and more (W5).*

*We had no difficulty, it was normal (W6) at home in everyday life, it did not change anything (M6).*

*I do not think that I have [HIV] [...] A normal life (W7) The principle has not any limitation, a normal life [...] will not let the virus be greater than your life. [...] it does not have great weight in relation to make decisions, to do any kind of activity [...] You have it there, you will live with it [HIV] leave it there quietly and follow your normal life (M7).*

## DISCUSSION

When showing how they experienced care for the prevention of vertical transmission of HIV, the being-couple without understanding, repeat what was said about doing everything right for the prevention of HIV transmission to their child, passing along the information. Therefore, they reveal how to be the idle talk (Gerede), the language seems to have understood all without having been previously appropriate of the thing. Things are as they are because that is how we speak of them, (impersonally, and that is the way of being of impersonality, in everyday life)<sup>12</sup>.

The being-couple repeats the information they know they can not breastfeed and should already be prepared for it. The knowledge that they could not breastfeed shows again on the way to be the idle talk (Gerede) when expressed they did not expect the reaction of not breastfeeding, that this information was something that was already being processed (understood), when in fact was just being passed on without being understood.

In this way of being, the misunderstanding of it refers to the person's situation not acquiring in his living the knowledge of what was expressed in his speech, it just takes speech possession of the other and so perpetuates it. Thus, the being does not reach the essence of speaking, only passes on not reaching the appropriation originally from talking<sup>12</sup>.

The idle talk (Gerede) also guides the ways to search for information, then being-couple guides what will observe and read from the perspective of health professionals. The being-couple seeks information with professionals and media to understand what is happening and what can happen and more willing to participate in lectures. Thus, it remains the way of being of curiosity<sup>12</sup>.

Curiosity is concerned just to see, not to understand what is seen or to get to its essence. It searches what is new in order to, as soon as it is known, redirect its search for another new<sup>12</sup>.

This mode of being in the world, does not search the rest of a basis that contemplates and admire the knowledge discovered. Instead of it, it is interested in the excitement and anxiety at what is always new and changing what is coming together. Curiosity provides knowledge to simply becoming conscious<sup>12</sup>.

In this way, the being-couple as being in the world first told that followed treatment with rigor since the discovery of HIV status and prenatal care. Thus, they repeated information that they have said, since it is primarily being-with-others. After that, they tried to listen to lectures and watch for news to know what was happening and what could happen, declaring be in the mode of being of curiosity<sup>12</sup>.

The the sum of the idle talk (Gerede) and curiosity reveals another mode called ambiguity. "The curiosity that loses nothing, and the idle talk (Gerede) that understands everything, give presence to ensure "a life full of life", totally authentic"<sup>12:237</sup>. Guided by this claim, it is proven a third mode of being characteristic of the opening of everyday presence, the ambiguity<sup>12</sup>.

In this study, the interpretation was when the couple said to have a normal life where there are no restrictions in developing activities and making decisions. This points to not be thinking that they have HIV because if they keep thinking they will be holding the disease and can not live.

Therefore, the being-couple unveils the mode of being of ambiguity in which "everything seems to have been understood, and authentically captured and discussed when, in the background, was not"<sup>12:238</sup>. In this study the facts are positive serological condition for HIV, which determines differentiated care and routines. However, the couple keeps in his speech having some differences, but tries to hang out and have a normal life.

The person does not see in their projects. Thus, it is always ambiguously in everyday life-world, that is, is out there on the public opening of coexistence. In this mode, the idle talk (Gerede) and curiosity control what is spoken and seen in daily life. And the ambiguity offers the curiosity which it seeks (what the couple wants to know and demand to know) and idle talk (Gerede) is the appearance that everything is set (that is why they repeat what they hear of professionals and others)<sup>12</sup>.

As being with possibilities, the being-couple is consolidated in order to be *ambiguity* in understanding a normal life. However, this understanding conceals what is veiled, for this being-power the being-couple wants to look like everyone else.

The being-couple highlights dealing in differentiating from who has and who does not have the disease. They said that they do not seem to have the disease, as this is the minimum in their life and is not something that should be thought of, remembered all the time. Having the virus is just something else to be careful in their daily lives.

When they said it seems like they do not have the disease, the being-couple unveils the movement of the next world, surrounding the public world of us. In the surrounding world is concerned and knows the routine of having HIV, walking for what seems to be what the public world awaits the person as being in the world.

Be lost in the public character may indicate that the being-power in their most authentic presence has fallen and strives to maintain an appearance. Moved by the idle talk (Gerede), curiosity and ambiguity<sup>12</sup>, the being-couple strives to seem not to have HIV/AIDS and claiming to have a normal life.

The impropriety of the presence appear to be, revealing a special way of being in the world where there is absorption by the co-presence of others in impersonal. It should be considered that inappropriateness as a mode to be closer to the presence, in the manner that most of the time, it stays daily<sup>12</sup>.

The being in the world that remains in appearance and impersonal is tranquilizer, for sure of having seen it all and understood all the idle talk (Gerede) and the ambiguity provide the security presence and fullness of all possibilities of their being. Thus, the peace of mind that understands everything directs the presence for an alienation, which covers its being-power more authentic an personal<sup>12</sup>.

Therefore, in their everyday life, the being-couple remains in the idle talk (Gerede) of making the treatment properly and know that they can not breastfeed. It is shown in the curiosity to try to understand everything that happens. Ambiguously even if they have to take medication, use condoms and not to breastfeed, they refer not be different from others and thus make them feel better not revealing they have HIV/AIDS.

To reassure the being-couple manifested its commitment to coexistence with others, as a positive possibility of ones (others) that are primarily engaged in the world of occupations. Thus, it keeps the appearance of being as everybody and as everyone expects being in the public world of impersonal.

## FINAL CONSIDERATIONS

In everyday couple who experienced the care to avoid VT of HIV, hermeneutics makes possible to understand the way of being-couple attached to the idle talk (Gerede), in repeating the speech of others to do everything right for the prevention of transmission of HIV to their child and knowing that they could not breastfeed. It also showed that the mode of curiosity, they sought information with professionals and media to understand what is happening and what can happen. And in ambiguity, they said to have a normal life like everyone else, but with the need to take medicine and use condoms.

In these modes of being in the world, being-couple showed striving to keep the impersonal, the reassuring appearance of not having HIV/AIDS to keep living with the people in their world of everyday life. They stopped in the impersonal daily care for the prevention of vertical transmission of HIV, thinking they have understood all actions, information and how their lives are when in fact they remain in appearance of how the public world expect them to be.

Therefore, they elucidate the importance of the health professional to show open to the possibility to share their knowledge with the couple, requiring unconfigure merely prescriptive character

of health care. Thus, the professional has the chance to become co-responsible in health care in the daily of being-couple who experienced the prophylaxis of VT.

Seeking strategies to overcome the impact of seropositivity of the partner or couple, it facilitate access to information on the effectiveness of prophylaxis and reducing the risk of infection by VT, so that the couple understands not just repeat what they should do.

It is emphasized the importance of professional nursing care guiding the planning to the couple who experiences the care on the VT prophylaxis enabling the opening and maintenance of a meeting empathic and authentic between those who watch and who is assisted. From this perspective, it can be (re) meet the needs of the couple and put them together with the therapeutic possibilities and health care in the search for a qualified nursing care to the couple, the child and family.

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