

# Revealing the relationship of couples facing prophylaxis of vertical transmission of HIV

Tassiane Ferreira Langendorf<sup>1</sup>  
 Stela Maris de Mello Padoin<sup>2</sup>  
 Cristiane Cardoso de Paula<sup>3</sup>  
 Ivis Emília de Oliveira Souza<sup>4</sup>  
 Renata de Moura Bubaduê<sup>5</sup>

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- 1 RN, Master, Ph.D. Candidate at Escola de Enfermagem Anna Nery, Universidade Federal do Rio de Janeiro – EEAN/UFRJ – Rio de Janeiro – RJ, Brazil.  
email: tassi.lang@gmail.com
- 2 RN, Ph.D. Professor, Universidade Federal de Santa Maria – UFSM – Santa Maria, Rio Grande do Sul, Brazil.  
email: stelamaris\_padoin@hotmail.com
- 3 RN, Ph.D. Professor, UFSM, Santa Maria, Rio Grande do Sul, Brazil.  
email: cris\_depaula1@hotmail.com
- 4 RN, Ph.D. Professor, EEAN/UFRJ, Rio de Janeiro – RJ, Brazil.  
email: ivis@superig.com.br
- 5 RN, Master, Ph.D. Candidate at EEAN/UFRJ, Rio de Janeiro – RJ, Brazil.  
email: renatabubadue@gmail.com

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**Objective.** To reveal the behavior of couples who face prophylaxis of vertical transmission of HIV. **Methodology.** This study, based on Heidegger's theory of phenomenology, included 14 participants (7 couples), who received prophylaxis against HIV vertical transmission. The study was conducted from February 2011 to December 2012 in a prenatal outpatient and child care unit at a hospital in the countryside of Rio Grande do Sul, Brazil. **Results.** Given the possibility of infection and of having a child, the couples revealed the existential movement of staying together to face the situation. The couple learn to take care of themselves in order to be able to care for and become involved with the baby. In this relationship, they teach themselves how to be a family. **Conclusion.** The inclusion of men in women's health care process, with both serving as a unit, makes it possible to develop assistance in the context of considering the family as being a participant in care.

**Key words:** HIV; Acquired Immunodeficiency Syndrome; infectious disease transmission, vertical; philosophy in the nursing; nursing.

## Desvelando la relación de la pareja antes de la profilaxis de la transmisión vertical del VIH

**Objetivo.** Desvelar la manera de ser de la pareja antes de la profilaxis de la transmisión vertical del VIH. **Metodología.** Investigación fenomenológica heideggeriana, desarrollada en el período de diciembre de 2011 a febrero de 2012 en el ambulatorio de prenatal y puericultura de un hospital en el interior del Río Grande do Sul, Brasil, con 14 participantes, siete parejas que vivenciaron la profilaxis de la transmisión vertical del VIH. **Resultado.** Ante el hecho de la infección y de la posibilidad de tener un hijo, la pareja ha desvelado el movimiento existencial de estar juntos para enfrentar la situación. Juntos se cuidan para cuidar del hijo y se envuelven con él. Esta relación se mostró en la manera de ser con para ser una familia. **Conclusión.** En

la inclusión del compañero en la atención de la salud de la mujer como unidad de cuidado se pasa por la posibilidad de desarrollar una asistencia considerando la familia como ser participante del cuidado.

**Palabras clave:** VIH; Síndrome de Inmunodeficiencia Adquirida; transmisión vertical de enfermedad infecciosa; filosofía en enfermería; enfermería.

## Desvelando a relação do casal diante da profilaxia da transmissão vertical do HIV

**Objetivo.** Desvelar o modo de ser do casal diante da profilaxia da transmissão vertical do HIV. **Metodologia.** investigação fenomenológica heideggeriana, desenvolvida no período de dezembro/2011 a fevereiro/2012 no ambulatório de pré-natal e puericultura em um hospital no interior do Rio Grande do Sul, Brasil, com 14 participantes, sete casais, que vivenciaram a profilaxia da transmissão vertical do HIV. **Resultados.** Diante da facticidade da infecção e da possibilidade de ter um filho, o casal desvelou o movimento existencial de estar junto para enfrentar a situação. Cuidam-se para juntos cuidar do filho e se envolvem com ele. Nesta relação se mostram no modo de ser-com para ser uma família. **Conclusão.** Incluir o companheiro na atenção à saúde da mulher como unidade de cuidado perpassa a possibilidade de desenvolver uma assistência considerando a família como ser-participante do cuidado.

**Palavras chave:** HIV; Síndrome da Imunodeficiência Adquirida; transmissão vertical de doença infecciosa; filosofia em enfermagem; enfermagem.

## Introduction

A positive diagnosis of human immunodeficiency virus (HIV) affects the life of the infected individual in a variety of ways.<sup>1</sup> Among these factors is the concern of experiencing prejudice and discrimination when the diagnosis is revealed in the social, professional and family environment. Because of this concern and the experience of other patients, HIV-positive individuals hide their diagnosis; this promotes a silencing pact and social isolation.<sup>2,3</sup> However, this social isolation does not prevent individuals living with HIV from having relationships or a conjugal life, especially because sexual-affective relationships are essential for individuals and may contribute positively to their life.<sup>4</sup> Because reproductive freedom and family formation are civil rights,<sup>5</sup> HIV-infected couples face the possibility of pregnancy.<sup>6</sup> The need to control vertical transmission (VT) of HIV should be emphasized and is a health priority.<sup>7</sup>

In Brazil, strategies to control VT stem from public health policies, such as the integrated

plan for coping with the feminization of the AIDS epidemic and other sexually transmitted diseases (STD). These strategies directs the development and implementation of initiatives to promote health and rights in the area of sexual and reproductive health, with an emphasis on the challenges to achieving advances in high-quality prenatal care.<sup>8</sup> To overcome challenges facing health care practices and nursing policies, actions focusing on women's health have been added; they meet the need to incorporate in praxis societal transformation.<sup>9</sup> For example, the father is included in sexual and reproductive health care, which promotes pregnancy as co-responsibility for both members of the couple.<sup>10</sup>

Although advances have been made in planning policies,<sup>11</sup> care has focused on information about the health-disease process for HIV-positive individuals, health life styles, virus transmission, reinfection, adherence to treatment and prevention.<sup>12-16</sup> For this reason, reproductive issues are not priorities

in care planning. In this sense, reflection on this subject is paramount, especially in terms of how couples address their reproductive possibilities. On the one hand they may be eager to have a child, while on the other hand they must contend with the silencing pact established between them. The decision to have a baby presents an opportunity to break the silence and challenge the stigma against family formation associated with those living with HIV. In addition, the couple must seek strategies, information and ways to achieve their wishes within a life routine in which individuals feel it is necessary to protect themselves against prejudice.<sup>17</sup> Among strategies adopted, the main ones are seeking social support, especially in terms of revealing the diagnosis to the baby's father and his participation in prophylaxis of VT.<sup>2</sup>

Because of the reality of prophylaxis against VT of HIV, care of the couple requires investment in studies that provide scientific and philosophical support that addresses the needs of these individuals. To develop this study, we used Heidegger's theoretical-methodological theory that seeks to understand humans when they know themselves and how relationships in their daily lives occur. Interpretation of these occurrences (ways of being) enables existential understanding of individuals to reveal the essence of the phenomenon, which almost always remains hidden and diluted in their daily routine.<sup>18</sup> This comprehension emphasizes the subjective aspects experienced by individuals and contributes to the care plan that considers this subjectivity. This study seeks to understand the essence of this phenomenon as a possibility for health care and nursing care provided in a helpful and authentic manner to the couple. For this reason, we chose as the phenomenon the experience of couples with prophylaxis against VT of HIV. Our objective was to reveal the behavior of couples facing this type of prophylaxis.

## Methodology

This is a qualitative study of phenomenology based on the theoretical-physiologic method of

Martin Heidegger.<sup>18</sup> The application of nursing phenomenology consists of the search for an investigation method that is both a science and an art. For this reason, aspects such as the sense of life and its meanings require scientific attention by the use of a reference that enables the understanding of aspects of care routine that are not measurable in research<sup>19</sup> and studies of nursing education.<sup>20</sup> Data were collected between December 2011 and February 2012 using phenomenologic interviews.<sup>21</sup> The couple, man, or woman was invited to participate in the study when they were waiting for outpatient consultation at a teaching hospital in the South of Brazil, where prenatal and puericulture infectious consultations were performed.

We included a total of 14 individuals (seven couples) who met the inclusion criteria: a couple who experienced the routine of prophylaxis against vertical transmission of HIV during pregnancy and puerperal period. Exclusion criteria were man or woman with cognitive limitations and death of the baby during gestation. However, no couples were excluded because none presented these problems. The interviewing question was: How was/is your experience of taking care to prevent VT of HIV for your son/daughter? The parameters to define the number of participants were the point at which the content of the couples' testimonials revealed the studied phenomenon, responses to the main interviewing question, and the objective of the study. The analysis was developed along with the field stage, which enabled sufficient meanings.<sup>22</sup>

The analysis was subdivided into two methodological times proposed by the author: vague, medium and hermeneutic understanding. The strategy used for data organization to develop vague and medium understanding was performed by chromatic identification of essential structures. From this point, we grouped passages of testimonials to compose the units of meaning (UM). The understanding of meaning expressed by participants sought to describe the phenomenon as they are shown.<sup>18</sup> From the immersion of two UM, we developed a heideggerian hermeneutic (analysis and discussion of data), in which we

sought to understand meaning as the possibility of revealing the meaning of being, ontology dimension. The ontology task is to acquire the meaning of being without seeking previous a conception of science but by using the interpretation of issue of being, which in this study was based on heideggerian philosophy.<sup>18</sup>

This study development was in agreement with National Health Council 196/96 resolution of the Brazilian Ministry of Health, which establishes guidelines and norms that guides research with human subjects.<sup>23</sup> This resolution was current during the period of this study, but our study is also adequate with regard to 466/12 resolution, established by the same council. To guarantee confidentiality of participants' data, transcriptions were coded using W for woman and M for man and C for child (son/daughter) along with a number 1 to 7 (W1, M1, C1, W2, M2, C2, successively). The protocol of this study was approved (approval process number 23081.014981/2011-86) by the Ethical and Research Committee of the Universidade Federal de Santa Maria.

## Results

### **Unit of meaning 1. The couple is together and one takes care of the other**

Suffering while experiencing care to prevent HIV transmission to the child contributes to close the couple in such a way that the child become the reason for them remaining together. Participants reported that despite difficulties faced during prophylactic treatment, they learned to take care of one another. The woman expresses the importance of having a partner at her side and the couple passes from "survive" to "live": *We suffered together [...] We're fine, we understand [the disease] better, we're happy [...] before we survived, but today we live very well (W1). In the beginning it was complicated [...] after all these we went through [...] we learnt to care for one another [...] (M1). We were terrified (W2). She [C2] was born to justify why we're together*

*(M2). Life goes on. And, preferably, with a dad by my side, surely, he will help me to raise my child [...] of course it's hard, but it is not the end of the world (W3). We do our treatment [...] we took advantage when our immunity was good [...] (W4) We talked with our doctor (M4).*

The couples express that prejudice contributes to silence and isolates them; it defines the virus as the problem. The prejudice is present in the testimonials from the beginning to the end, in one manner or another, with high or low intensity. It comes from different manners because they already suffered prejudice from their families or from their partner's family, from health professionals, and from other individuals. After experiencing such situations, they prefer to not tell anyone the diagnosis and they keep their life going as if nothing has happened, and no one perceives this movement: *What kills us is not the disease, but people's prejudice [...] But I closed myself off! So I prefer to spend my time with her [W1], at home (M1). The prejudice comes from inside my house, from my mother [...] we don't want to tell no one about [...] So we decide to isolate ourselves from others (W1). People have plenty of prejudice, including those from our family (M3). I think somebody commented she [W3] had the disease in the labor room, the nurse who helped in the delivery [...] so people leave the room commenting (W3).*

### **Unit of meaning 2. The couple take care of the child so that the child is healthy and they become involved with the baby. Now, they are a family**

Prophylaxis means protecting the child so that the child can live well. The couple announces that they care and live for the child and that, because of the child, they now constitute a family unit. The couple express the completeness of their family after the child's birth. Therefore, the child becomes the center of the family and the couple double their care because they are generating life. It is all worth it in order to care for the child and continue to live. In this sense, the preparation for care of the

child begins before pregnancy, when the process of getting pregnant begins. They plan the future by imagining what education will be necessary to raise an individual with a good personality, they encourage the child's development from gestation by reading and playing music to the child: *I'm always close to him [C1], I see his growth every day (M1). To spend hours talking just like us will probably educate our C2, because we encourage reading [...] we encourage reading, playing music since her gestation [...] she [C2] is what was missing to our family [...] (W2) it's a matter of constituting a family [...] Now it is not just me and W2, the couple; now we are a family (M2). Until now, we were just thinking about him [...] we just think to live to raise him [C3] [...] to do everything for him live well, to have good health, to be educated, to grow and become a good person [...] A child involves us as a couple even more (W3) [we have done everything was possible] for C4 to be born with health [...] we followed all steps in pregnancy process (M4) to take care of ourselves for him sake [C4] (W4).*

## Discussion

The results of this study have qualitative limitations; however, we did not aim to generalize the results but to deepen the understanding of the experience of couples who faced prophylaxis against VT of HIV. In this way, we developed a heideggerian hermeneutic approach in order to reveal the feelings hidden within these meanings and reach the ontology dimension (existence) of the studied phenomenon. In this interpretation, we revealed the relationship of the couple facing prophylaxis against VT of HIV from the transition from being a couple who stayed together to the being-with revealing the being-family.

### **“Being-couple,” staying together and being-with**

Understanding how the women and her partner experience care in prophylaxis against VT of HIV revealed that both individuals recognize and

constitute the couple unit. In this unit, the being-couple was revealed; they experienced together the care needs during prophylaxis and found that this constitution was paramount for achieving treatment success, which, in turn, resulted in a healthy child. In the meaning of how they experienced care in prophylaxis against VT of HIV, the women and her partner showed themselves as a couple. As a “being-couple,” they understood and recognized themselves as such. They showed themselves as a “being-couple” when they used the pronoun “we” and used such phrases as “we lose”, “we were” and “our treatment” and expressed complicity of care between them.

The concreteness of the structure of being is revealed during the study and is revealed as the ability to have presence. This presence concerns the closest possibility of being when manifested as they themselves are in their own world and in their relationship with others.<sup>18</sup> We understand as the beginning point for the analysis, these determinations from presence of the being to interpretation of being constitution, which designate how being-in-the world. The being-in-the world is part of the fundamental make-up of the individual; and this person as the builder this can be seen and can be used to configure a personality that refuses cover-ups and distortions.<sup>18</sup> Therefore, it enables individuals to reveal the understanding of their way of being and how they relate to what is covered up. In this study each individual was revealed as a being-couple in their own existential comprehension.

Couples reported about care experienced in prophylaxis against VT of HIV as something they understand as a unit, of being together, as one. They suffered this experience together, and this experience made them closer, and it has joined them. They experienced care that enabled them to understand that their status would not end up being the end of the world, they embraced the situation together and learned how to take care of one another, even facing the prejudice. This way of being involves skill in being oneself; this also means that the being understands his or her own existence.<sup>18</sup> Therefore, the couple understand



themselves in terms of the possibility of experiencing together the care involved in prophylaxis against VT of HIV. In this experience, the being-couple revealed the relational character that permeates the essential constitution of being-there-in-the-world. The relationship is related to a way of being-with, which can be understood as a fundament structure of being-there and to mean that something or someone shares the presence of the other.<sup>18</sup> The being-couple was together, became more unified and showed themselves as being-with.

The being-couple described a difficult and complicated survival experience regarding the prophylaxis and after that life went well. They opened up to the possibility of being-with as they faced their experience with prophylaxis; they then became closer and learned how to care for one another and, therefore, in the being-with manner, came to understand that living well was possible and that the diagnosis was not the end of the world. Based on being-in-the world determined by the “with” the world is always a shared world with others.<sup>18</sup> In the being-with and concerning others, what exists is an existing relationship from one to another, shared with the presence of one to another. When this is expressed as the importance of having a partner by one’s side and acknowledging that the child justifies their being together, the being-couple reveals the relational movement from being-there-women to the being-there-partner and from being-there-couple to the being-there-child.

By giving meaning to care in prophylaxis, the being-couple described that they take care in order to the child being healthy, and they get involved and follow-up the child growth. They make reference of what the child must have to growth as a good person. They though, mainly, on the child and take care of themselves, and live to take care of the child. The child was what missing to complete their life, now they are family.

### **Being-couple, being-with and being-family**

The being-couple sought to make an effort during their journey toward understanding the relevance

of caring for the child. The effort expended during prophylaxis resulted in the benefit of a child born healthy and into a family. Therefore, we understand that moving from being-couple to being-family completes the sense of the couples’ own existence in the reproductive experience of those who live with HIV. In being-with, the being-couple revealed the relational character with the child, in which there is an ontology relationship among their presences.<sup>13</sup> Therefore, the being-couple makes an effort in their existing life to relate to the child. This effort clarifies the characteristics of this way of being, in which how being-in-the world the being is being-with-others. In factual dimension, the being-couple manifested to involve themselves with the care, follow-up and growth of the child, which reveals in the existential dimension a way of being-with. The being-with-the-child was affirmed by the being-couple to occupy the routine with its care to live well and with that the possibility of care of the child to his/her be healthy.

In thinking about the child’s education, the being-couple reveals the way of freely anticipating the solicitude. This way of being shows when the being expresses the self in relation to the other, which is anticipated to the other, to become free in his or her own possibility of understanding the world.<sup>24</sup> To anticipate the need of the other is to be concerned with the possibility that he/she participates in an active manner in order to offer freedom of choice in the type of care involved. The being in relation to other has the possibility of being-with in relation to freedom. The solicitude shown a status of being-there that, according with its different possibilities, which is linked with the being relation with the his/her care world, and their authentic relationship.<sup>18</sup> Based on that, the being-couple understand it is important to think about the education of the child in order to he/she recognizes and understands someone can achieve and have the possibility of become better. Being is understood as being-in-the world with the possibility of free choice. In understanding the importance for caring in a free manner, the being-couple encourages the education of the child by reading and playing music to him or her during

gestation; they think that the child will continue to be educated during his/her development.

In this solicitude-freedom relationship with the child, the being-couple understands that the presence of the child in their lives is extremely significant ever since gestation. They mentioned that the three of them were a unit in this experience: being-woman, being-partner and being-child. They affirmed that because of the presence of the child and of the union they are a family. They revealed that all care is worth it when you are responsible for generating another life, and they found that all care experiences in prophylaxis against VT were rewarding. The satisfaction with this experience constitutes the re-discovery of the being that kept their existence hidden, the being-family. The interpretation of the experience of the couple in prophylaxis against VT of HIV based on the philosophical referral of Martin Heidegger revealed the existential movement that transformed the way of being to being-together. This was shown from the conjugal relationship facing the reality of life with a virus and the prospect of conceiving and raising a child. In this routine, the couple was joined in the way of being-with that transformed to a way of being-family because of the presence of the child.

In conclusion, to consider the anti-family paradigm associated with AIDS epidemic, this study reinforces the discussion concerning sexual and reproductive rights. In this sense, it is possible to reflect about the way in which health professionals and nurses deliver care for these families. This suggests that health care and nursing practice incorporate, in a forthcoming manner, an authentic encounter between those who deliver care and those who receive care, which will enable those experiencing the situation to listen and understand the main meanings. In other words, it should help overcome reduced care during the prenatal period (centered on the woman) and during the puericulture (centered on the child). In the practice, the partner would be included in the health care of the woman and be involved in the unit of care; such a change would also involve political and legal support. It will be

necessary to overcome the barriers placed by the culture, professionals, academia, the structure of health services, and social construction of the role of being a man and a woman. Faced with this situation, we have the possibility of seeking integrated care to the couple, enhancing the effectiveness of public policies and actions to promote the reduction of morbidity and mortality indexes of VT against HIV and pediatric AIDS.

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