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Prevention of vertical mother-to-child transmission of HIV: care and adhesion provided by couples

Profilaxia da transmissão vertical do HIV: cuidado e adesão desvelados por casais

Profilaxis de la transmisión vertical del HIV: cuidado y adhesión develados por parejas

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ABSTRACT

Objective: to unveil the existential movement of a couple when performing vertical HIV transmission prophylaxis. **Method**: qualitative research, using Martin Heidegger's phenomenological approach. A phenomenological interview was conducted with 14 participants between December/2011 and February/2012 in the outpatient facilities of an university hospital, Brazil. A comprehensive and interpretative heideggerian analysis was developed. **Results:** the couple understands that they have followed the guidance of the health professionals as indicated. By not being able to breastfeed, the woman did not fail to be a mother, but it was also not a complete experience. The senses of the occupation of the couple-being unfolded to the prophylactic treatment and facticity due to the fact of not breastfeeding. **Conclusion:** we indicate the need to rethink care, proposing a working relationship that transcends the impersonal that dictates about what the couple must deal with, enabling their active participation in care decisions and actions.

Key words: Vertical Transmission of Infectious Disease; Prenatal Care; Child Health; Nursing; Qualitative Research.

RESUMO

Objetivo: desvelar o movimento existencial do casal ao realizar a profilaxia da transmissão vertical do HIV. **Método**: investigação qualitativa, com abordagem fenomenológica de Martin Heidegger. Foi realizada entrevista fenomenológica com 14 participantes entre dezembro/2011 e fevereiro/2012 no ambulatório de um hospital universitário, Brasil. Foi desenvolvida análise compreensiva e interpretativa heideggeriana. **Resultados:** o casal compreende que seguiu a orientação dos profissionais de saúde conforme o que foi indicado. Ao não poder amamentar, a mulher não deixou de ser mãe, mas não foi uma vivência completa. Desvelaram-se os sentidos da ocupação do ser-casal em realizar o tratamento profilático e o da facticidade diante do fato de não amamentar. **Conclusão:** indica-se repensar o cuidado, propondo uma relação profissional que transcenda o impessoal que dita com o que o casal deve se ocupar, viabilizando sua participação de maneira ativa nas decisões e ações de cuidado.

Descritores: Transmissão Vertical de Doença Infecciosa; Cuidado Pré-Natal; Saúde da Criança; Enfermagem; Pesquisa Qualitativa.

RESUMEN

Objetivo: develar el movimiento existencial de la pareja al realizar la profilaxis de la transmisión vertical del HIV. **Método**: investigación cualitativa, con abordaje fenomenológico de Martin Heidegger. Fue realizada entrevista fenomenológica con 14 participantes entre diciembre/2011 y febrero/2012 en ambulatorio de hospital universitario brasileño. Se desarrolló análisis comprensivo e interpretativo heideggeriano. **Resultados**: la pareja comprende que siguió la indicación de los profesionales

de salud, de acuerdo a lo indicado. Por no poder amamantar, la mujer no dejó de ser madre, aunque no fue una experiencia completa. Se develaron los sentidos de ocupación del ser-pareja en realizar el tratamiento profiláctico y el de la facticidad frente al hecho de no amamantar. **Conclusión**: se sugiere reconsiderar el cuidado, proponiendo una relación profesional que trascienda lo impersonal que expresa cuáles deben ser las ocupaciones de la pareja, viabilizando su participación activa en las decisiones y acciones de cuidado.

Palabras clave: Transmisión Vertical de Enfermedad Infecciosa; Atención Prenatal; Salud del Niño; Enfermería; Investigación Cualitativa.

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INTRODUCTION

With the evolution of the epidemic of AIDS (acquired immunodeficiency syndrome) and due to its epidemiological proportions[1], the implementation of public policies and reorganization of the social services was required[2], implying in health care, in particular related to the treatment itself. The effectiveness of that reorganization has outlined the current feature of aids of being considered a chronic disease, making it necessary, as a result, to monitor health and to use antiretroviral medications permanently[3].

One of the unfoldings of this monitoring when the focus are infected women in association with the possibility of pregnancy, with treatment aimed at prevention of mother-to-child vertical transmission (VT) of HIV. Recommendations and routines for health services and users are implemented[4], aiming at obtaining good therapeutic results, resulting in the maintenance of adherence to the treatment and prophylactic measures[5-6].

Although antiretroviral therapy (ART) enables the increased survival of patients[3] and the prevention of infection in some situations, it does not mean it is easy to be performed[7]. We can consider that the adherence to treatment shows itself as something that is constructed and conquered daily, and its effectiveness occurs when there is clarity of the need of treatment[8-9], among other issues.

On VT prophylaxis of HIV, understanding its need is based on the motivation to adhere to treatment to preserve the health of the child that is being generated. Women feel responsible for their offspring, and thus adhere to treatment during pregnancy for fear of transmitting the virus to their children. As a result, mothers continue the treatment after delivery to be healthy and to be able to take care of the child[10-11].

In this construction, providing a supportive environment and considering the beliefs and culture can contribute to better adherence to ART and the health of people who have HIV/Aids[12-13]. Besides, the care of people by health professionals to offer a warm and understanding structure, considering what is relevant to the user, is also essential to maintaining a positive adherence behavior[14].

Due to those facts and new challenges determined by the occurrence of pregnancy in the context of HIV/Aids, the need to understand how the couple experiences the completion of VT prophylaxis treatment is projected, which includes clinical and laboratory routine, in addition to recommendations on the gravid-puerperal period.

In nursing, the appointment represents one of the spaces and moments to develop caring and understanding attention, with listening and advising[15] as important strategies to be used by nurses in promoting a relationship of empathy and trust, so as to promote membership of the people who have HIV/Aids. The development of this relationship can be beneficial in the process that culminates in therapeutic efficacy[16].

Overcoming the traditional technical and biologicist assistance represents a current trend in search of a wider view of care, which is able to integrate objectivity, subjectivity, and different perceptions in the process of care[16]. Among these different perceptions, nursing care stands out as an ontological possibility, which allows us to recognize that this praxis is configured as a challenge, which awakens the search for a new outlook that enhances the magnitude of care[17].

It is understandable that including both woman and man, as well as giving voice to the couple in the development of this research, reveals the commitment to contribute to the advancement of nursing professional practice and the health field, since this inclusion represents the overcoming of challenges, as extending the assistance to the family. So, the objective of this research is to reveal the existential movement of the couple that performs the prophylaxis of mother-to-child transmission of HIV.

To do so, we chose Martin Heidegger's comprehensive phenomenology as the theoretical and methodological basis for the development of this study, which enables the understanding of the meanings attributed to the experiences of people in their daily lives[18]. Understanding these meanings allows to advance to the ontological dimension of what is veiled by meanings, thus discovering the existential facet of the phenomenon, in which the couple has room to genuinely express themselves in the experience of VT prophylaxis.

METHOD

This is a qualitative, phenomenological research, based on Martin Heidegger's theoretical-philosophical-methodological referential. The heideggerian proposal opens up to an ontological investigation that meets the need to take the darkness involved in human being's meanings, understanding it as a being that exists, relates, and is manifested in the world in an ongoing movement, in constant change[18].

The site of the research was the prenatal and child care outpatient facility of a university hospital in the countryside

of the state of Rio Grande do Sul, Brazil. Data collection occurred through the phenomenological interview from December 2011 to February 2012. This research is configured as the access mode to the participants, which allows for a movement of understanding the human being living as presented in its everyday experience, allowing to establish a unique encounter with the subjects[19].

The inclusion criteria of the participants were: couples that understood and who have experienced VT prophylaxis of HIV during the gravid-puerperal period. Exclusion criteria were when the man or the woman presented cognitive limitation, or when the child was deceased.

The form of selection of the participants and the sample constitution were intentional when, from the conversation with the woman, who demanded or attended the outpatient service was approached with the theme focused on the study. So, the couple was invited to participate and the researcher contacted them later via telephone to confirm the interest of participating. In the case of acceptance, location, date and time were scheduled to conduct the interview, according to the availability.

There was a total of 14 participants, seven couples, which were identified with the letters W (woman), M (man), and C (child) (when the child was mentioned by the parents in the interview), followed by numbers (1 to 7). The interviews were suspended and considered sufficient when the couples' testimonials, responding to the guiding question expressed meanings that revealed facets of the phenomenon researched and, as a result, the achievement of the research's purpose. This was possible because the field step is developed concurrently to the analysis, showing the sufficiency of meanings expressed in the speeches of the participants[19].

Five interviews were conducted in the childcare outpatient facility and two at the residences, always in the place the couples chose and with guaranteed privacy. The interviews started with the following question: "how was/is for you to experience care to prevent transmission of HIV to your son/daughter?" From the original question, empathic questions were formulated, highlighting the meanings expressed by couples, to avoid inducing responses that needed to be deepened for better understanding. The interviews were recorded with a digital recorder, upon consent, and the transcribed according to the original speech.

The research protocol was approved by the Human Beings Research Ethics Committee, complying with the protection of the participants through the Informed Consent Form, according to the Brazilian resolution No. 196/96. The research met the ethical principles defined by the Resolution in force at the time, however, it also meets the requested in the current Resolution 466/12 of the National Health Council - Brazilian Ministry of Health.

For the organization of data, the strategy was: a) precise listening and reading of the interviews to understand the meanings expressed by the couples, without imposing predetermined categories for theoretical/practical knowledge; b) chromatic highlighting of essential structures (meanings) expressed in the transcripts of the interviews, composing the analytical framework of the empirical material with the meanings of VT prophylaxis of HIV lived by the couple.

Due to that, the analysis of the data was initiated according to the guidance proposed by Martin Heidegger[18], contemplating two methodical moments. The first one, called vague and median understanding, consists of: I) build units of meaning (UM), being the *caput* (utterance) composed by the couples' testimonials expressions; II) present the results with quotes of the statements, followed by the phenomenological speech (description of the *caput*).

In the second methodical moment, the meanings expressed in the comprehensive analysis were submitted to the interpretative analysis, in search for the unveiling of their senses. That understanding, in the light of the theoretical and methodological frame of Martin Heidegger, is necessarily an interpretation, which discusses what was already understood[20].

For Heidegger, the finding/unveiling occurs on their own experience, which are cared for and revealed as an understanding. So it is important to consider what is the truth from hermeneutics, dealing with the unveiling of what was previously hidden. Being the understanding that which expresses the meaning of the experience of living or of what was lived, what is different from the prior position of the object already elucidated by science is what is searched for[20].

The analytical step based on the philosophical heideggerian referential was developed as an interpretive discussion. In this perspective, the contribution of other referentials whose thought presented in the literature reviewed have enriched the problem of study was dismissed. Thus, the hermeneutics developed enabled to unveil the senses of the occupation and of facticity, which will be the focus of the interpretative discussion.

RESULTS

Vague and median understanding revealed the existential movement of the couple who performs the prophylaxis of the vertical transmission of HIV, signifying relevant care and adherence to required treatment as ways-of-being, presented below, from two units of meaning (UM).

UM 1: Meant to correctly follow the guidance of health professionals

The couple stated that they followed the treatment according to medical advice, and strived to accomplish what was instructed to them. They trusted the health professionals' guidance to prevent transmission. They seized every information obtained and dealt with putting them into practice rigorously, having unprotected sex only in the fertile period.

> *She* [physician] *explained about her fertile period in detail* [W4] *so we would not always have sex without condoms* [...] *we were tempted, relying on the doctor.* [...] *We did everything right as she* [physician] *instructed.* (M4)

> *We tried it once a month* [in the fertile period] [...] *so we would not* [have sexual intercourse] *all the time without a condom.* (W4)

> *She* [psychologist] *said what we could do, what we could not do, how the reaction would be, how they wouldn't be, how people would treat us* [...] *I was prepared* [...] *I already knew more or less what was going to happen. I came to have the baby already knowing that I was going to take a medication.* (W5)

> *We sought to follow what they request us to do* [health professionals]. (W7)

> *Always following* [the treatment] *as requested.* (M7)

The couple says that they were committed to the drug treatment during prenatal care, taking the medication during pregnancy, also coming to all appointments, and taking the required cares during childbirth. Performing the treatment, taking the medications, is not easy. Sometimes the medications cause undesired effects in women, such as stomach pain, diarrhea, vomiting, and being unable to feed appropriately.

In these moments, the companion insists that the woman take the medication and help seeking strategies to facilitate its intake. When required, medication exchange so that it does not harm the child, because he understands that medication is the only way not to pass HIV on to her child. She attends the appointments because she has to, but does not enjoy it.

> *And I cried at times to take these meds and he* [M1] *fixed me juice, made tea so I could take them* [...] *the medication had to be on time, it was tough.* [...] *There has to be compromise, I don't come to the appointments because I want to, but because I know I have to.* (W1)

> *Sometimes, I fought with her because of the medications, made her swallow them.* (M1)

> *Taking medication during pregnancy, care during childbirth.* (W2)

> *From the moment we found out about it* [the pregnancy], *the first concern was: she has to start taking medication.* (M2)

> *I switched medications, I was taking Efavirenz* [...], *used AZT, then after the baby was born I kept it.* [...] *And I didn't think it was going to be* [natural childbirth], *but a cesarean section, for further prevention.* (W4)

> *Every month you have to control your blood, immunity, and it requires other kinds of care* [...] *arriving an hour earlier* [than delivery time] *in order to take the medication.* (W5)

> *Each dose, each tablet I swallowed I cried of stomachache, I vomited, had diarrhea* [...] *I only took the treatment because of her* [C6]. (W6)

> *I knew that the medication should have been started earlier.* (M6)

To complete the VT prophylaxis of HIV, she states that, after childbirth, she does not breastfeed and gives the medication to her son. The child's health is monitored, going to childcare consultations and performing exams. Thus, as she followed a rigorous treatment during pregnancy, the couple describes that they do not neglect the treatment of their son. They take care not to forget any dose of medication, giving it at the right times. They also seek strategies to remember the medication time, doing whatever it takes to get it right.

In addition to the medication on time, the mother knows that she cannot breastfeed and accepts this condition. To monitor the child's health, the couple goes to all scheduled appointments, take all the exams, and wait for the test which will give the final result of the serological status of the child.

> *He was not breastfed* [C3] *and he had taken a medicine* [...], *and in the 1st exam we underwent* [in C3] *nothing came out as a result.* (W3)

> *45 days* [adding to W3 speech] - *the medicine that he had to take.* (M3)

> *He underwent all the exams* [in C4] *that he had to.* (M4)

> *Not breastfeeding, providing the medication appropriately when he left the hospital* [...] *giving that medicine every 6 hours. I woke up at dawn to give him the medicine. And he has to come to the appointments, do the follow-up correctly, exams.* [...] *A year and a half from now he is going to be tested* (W4)

> *When she was born, I did not breastfeed her, because I couldn't breastfeed* [...] *took that medicine.* (W5)

UM 2: Meant that not breastfeeding was complicated and sad

The couple said that with other children it was different because they were breastfed. The women understand that they are not less mothers for not breastfeeding, but something is missing for achieving complete happiness. Women know that it is important that the child is breastfed, because this can protect against diseases and provides the child with a healthy and strong growth. However, they also consider that, when they have the virus, the best option is not to breastfeed, thereby giving continuity to the care they initiated in pregnancy.

During pregnancy, women learn that they cannot breastfeed, because they sough after information or heard about it. When experiencing the impossibility of breastfeeding, they find it difficult to deal with that reality. The spouse thinks the pregnant woman should be prepared not to breastfeed, because she had already been informed about the fact, and is surprised with the woman's reaction.

> *Not being able to breastfeed was a grief for me, it was the hardest part.* [...] *I should have been prepared, but it hurt at the time.* (W2)

> *I did not expect that reaction from her* [grief for not breastfeeding], *for me it was something that she was already processing, that she wouldn't breastfeed.* (M2)

> *It was new to me, because I did breastfeed the other* [children]. (W5)

> *I know I can't* [breastfeed]. [...] *You don't stop being a mom because you're not breastfeeding* [...] *you get there* [prenatal care] *and you keep reading those really big posters that it is good to do it* [breastfeeding] [...] *but there is nothing there to let mothers* [with HIV], *a sign there saying something that comforts us*. (W7)

> *Only they* [health professionals] *do not clarify that anyone who is a mother with HIV cannot breastfeed. That is missing.* [...] *The media does not have that focus, it is missing out on it as well* (M7)

The couple reports that, facing society, it is complicated not to breastfeed. People demand and judge, judging parents negatively because they are depriving the child of something as healthy as breast milk. Facing the demands, parents allege other fictitious reasons to justify that they are not going to breastfeed, because people do not know the real reason, which is HIV. The couple ends up accepting that fact that is put into their daily lives, because other mothers do not breastfeed for other reasons besides HIV.

> *I wish I could breastfeed when she was searching for my breast* [...] *there are babies that are not breastfed, and we ended up accepting it*. (W2)

> *There are so many babies who do not breastfeed, not only for that reason* [HIV]. (M2)

> *You see the other mothers who can breastfeed and it is a bad thing*. (W3)

> *I also thought he* [C4] *was going to miss breastfeeding*. (W4)

> *You hearing people asking you about breastfeeding is very complicated* [...] *they* [people] *are judging you, demanding of you* [...] *I give them a lot of excuses*. (W7)

> *We do not tell people* [why we do not breastfeed] *due to prejudice issues* (M7)

DISCUSSION

From the interpretative analysis, based on Martin Heidegger's philosophical reference, two meanings were unveiled: the occupation of the couple-being in the prophylaxis treatment, and facing the fact of not being able to breastfeed. These two senses are in the focus of the hermeneutic analysis.

In the experience of VT prophylaxis of HIV, the couple-being explained that they follow the orientation of health professionals step by step to perform the treatment. They do as the professionals request them and as it is commanded to them. Among the types of care, they comply with the treatment for prophylaxis, give the medicine to the child and do not breastfeed. From this meaning, it was possible to unveil the sense of the occupation[18], in which the couple expresses to be busy with the VT prophylaxis of HIV.

The being deals with tasks that are assigned to it. When carrying out these tasks, there is no understanding because the person makes use of the instrument required to fulfill certain action, and does so without thinking about what is being done. In a first approach, the being is committed in the world of occupations, performing what needs to be done in daily life[18].

The occupation is guided by a broad point of view, an overview of the being-in-the-world, in which the being realizes information captured by their senses to interpret them in their daily lives, even without understanding them. That interpretation unveils the instruments (the material, the user, and the usage) that are at hand for the being to use in his/her occupations[18].

Thus, the couple develops its everyday broad point of view to accomplish this VT prophylaxis of HIV, realizing and recognizing the instruments required to carry it out. With the interpretation of these instruments, in the clinical follow-up routine, medications, procedures during labor, among other factors that involve this process the couple-being is busily committed to adhering to the treatment. It is revealed that, in their daily lives, the couple expresses being lost in the way of being of inauthenticity.

Inauthenticity means the diversion of each individual from his/her essential project in favor of daily occupations, confusing it with the collective mass, in which being everyone is not him/herself, i.e., being all is being nobody. The being in his everyday life is a public being, not a proprietary one, reducing his life with others and for others, alienating himself from the main task, which would be becoming himself[21].

Due to that occupation, the substitutionary-dominating solicitude of health professionals[18] is unveiled. This behavior occurs when there is a leap over the other so that he/she is dominated, when one takes care of the other. The professional faces the couple-being, deciding how the care for prophylaxis are going to be taken, without providing parents the possibility of choosing and understanding that care.

Facticity regulates the possibilities of yes and no[18], thus establishing the inability to breastfeed. Facing the negative possibility, they show that this situation is complicated for society in general, since people charge and judge when parents say they aren't going to breastfeed. The couple does not report to others that they will not breastfeed to deflect from the possibility of revealing why (having HIV), because it involves prejudice issues. Thus, parents prefer to think that there are other babies who are not breastfed for reasons other than HIV.

The interpretation has unveiled that breastfeeding is more immediately at hand, and can be found as something not to be employed or as a damaged device, for women who have HIV/AIDS there is the recommendation for not breastfeeding. The tool is designed as an *instrument*, which meets the way-of-being of the occupation, that which is available for handling[18].

To signify the prophylaxis, especially the woman-being reveals that she has experiences in breastfeeding. As other children always received breastmilk, the fact that they cannot breastfeed now that they have HIV it something new, it is different. Fearing prejudice and discrimination, she silences her diagnosis and, consequently, the reason why she will not breastfeed. This goes beyond silencing, because the couple-being chooses to isolate itself rather than living constantly suffering prejudice and discrimination, even though sometimes it occurs in a concealed way.

In this perspective, the instrument (breastfeeding) is at hand to be used (women-mother's physiological possibility), since there is the production of milk and the child needs to be fed. However, for the woman-being in this study, the instrument is represented by being unable to handle it, considering the transmission of the aids virus, resulting in the situation where the woman does not breastfeed.

The women state they recognize the importance of breast milk, because they have heard about it or experienced breastfeeding of other children. They also report that they know they cannot breastfeed due to HIV infection, which comprises their overall point of view about breastfeeding and VT prevention of HIV.

When this instrument is at hand and the impossibility of using it is unveiled, there is a surprise. Feelings of sadness, difficulty given the inability to breastfeed arise. In awe, not only what cannot be employed arises, but also stumbles upon what is missing, what not only cannot be handled, but also which not at all handy for handling[18].

After birth, experiencing the inability to breastfeed surprises the woman-being, although during pregnancy she thought of not developing the practice, therefore to complete the care of VT prevention of HIV, breastfeeding is not within her reach in any way. When not breastfeeding, she understands that she is not less of a mother, but is faced with the lack of something to complete the happiness in experiencing pregnancy and being a mother.

Facing the facts, the mother expresses acceptance for not being able to breastfeed, and another sense is revealed, that of *facticity***.** In that way of being, the presence is related to a fact that is given, which cannot be changed, from which one cannot escape[18]. The being surrenders to what it is and to what it supposed to be, facing the facts imposed upon their world-of-life, thus being absorbed by the inauthenticity of the impersonal aspect that permeates this way of being.

In the facticity of not breastfeeding, the woman considers the positive possibility, to be authentic in that moment that she says she wanted to have breastfed when the child was looking for the breast, because she considers that the child could miss breastfeeding. However, she remains attached to the fact that she can't breastfeed, and surrenders to this condition, being absorbed in the way-to-being of inauthenticity, having to accept the fact of not breastfeeding.

FINAL CONSIDERATIONS

The hermeneutics of the couple-being in prophylaxis of mother-to-child transmission of HIV has unveiled the movement of occupation and facticity. This movement reveals the character of impropriety in that the couple remains to adhere to treatment, without the possibility to understand and reflect over that care, just performing it.

The implication for the nursing professional practice goes through the need to rethink care, proposing a relationship that enhances the intersubjectivity and transcends the impersonal aspect, which dictates with what the couple-being should be busy.

In this perspective, in the assistance field, the possibility of other approaches to take care of the couple, including multi-professional consultations and group activities. These practices provide a dialogical space where the couple's needs could emerge, which in the traditional service are not always included.

It is understandable that such relationship can be permeated by the liberating solicitude of the professional for the couple-being, for whom the health team enables parents to participate actively in the care decisions and actions related to the prevention of mother-to-child transmission of HIV, in reproductive and perinatal health, and childcare. Thus, the couple-being has the possibility to understand the instructions that are provided, as well as having the freedom to decide autonomously and authentically about the care that they perform for themselves and the child, resulting in adhesion to the prophylaxis.

This study presents the limitations of a qualitative research, since this methodology does not try to measure the facts nor the generalization established by the extent of the universal character truth. However, it enables us to deepen the quest for understanding what the subjects have experienced, allowing facets that express truths about the phenomenon investigated to be unveiled, which indicate favorable implications for quality of nursing care and the effectiveness of the public policy that addresses the issues of HIV/Aids, especially concerning adhesion and prophylaxis of vertical transmission.

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