ORIGINAL ARTICLE

HIV-POSITIVE PREGNANT AND PUÉRPERAL WOMEN AND THEIR INTERFACES OF CARE

GESTANTES E PUÉRPERAS SOROPOSITIVAS PARA O HIV E SUAS INTERFACES DE CUIDADO

GESTANTES Y PUÉRPERAS SEROPOSITIVAS PARA EL VIH Y SUS INTERFACES DE CUIDADO

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ABSTRACT

Objective: to understand the perception of being a HIV-positive pregnant/puerperal woman. Method: qualitative, descriptive and exploratory study conducted with a HIV-positive pregnant woman and two HIV-positive puerperal women who were hospitalized. The data were collected through interview with semi-structured questions. The analysis of the information occurred through content analysis in the thematic analysis modality. Results: from the analysis, two categories emerged: 'Perception of the disease' and 'The HIV-positive pregnant/puerperal woman'. The outcome of health care is directly related to professional care, in which humanized practices, based on an empathic relationship of support and reception, have shown to be effective for the development of self-care and care for the other. Conclusion: multidisciplinary actions that impact on the care provided to HIV carriers should be implemented, thus raising professionals’ awareness to welcome this public at all levels of care. Descritores: HIV Seropositivity; Prenatal Care; Pregnant Women; Pregnancy, High-Risk; Nursing.

RESUMO

Objetivo: compreender a percepção de ser gestante/puérpera soropositiva para o HIV. Método: estudo qualitativo, descritivo-exploratório, realizado com uma gestante e duas puérperas internadas soropositivas para o HIV. Os dados foram obtidos por meio de entrevista com questões semiestruturadas. A análise das informações ocorreu a partir da técnica de análise de conteúdo na modalidade análise temática. Resultados: da análise, emergiram duas categorias << A percepção da doença >> e << O ser gestante/puérpera soropositiva para HIV >>. O desfecho dos cuidados em saúde tem relação direta com a assistência profissional, em que práticas humanizadas, pautadas numa relação empática de apoio e acolhimento, mostram-se eficazes para o desenvolvimento do autocuidado e cuidado do outro. Conclusão: considera-se necessário criar ações intersectoriais que repercutam na assistência prestada às portadoras do HIV, sensibilizando os profissionais para acolher este público, em todos os níveis atenção. Descritores: Soropositividade para HIV; Cuidado pré-natal; Gestantes; Gravidez de Alto Risco; Enfermagem.

RESUMEN

Objetivo: comprender la percepción de ser gestante/puérpera soropositiva para el VIH. Método: estudio cualitativo, descriptivo-exploratorio, realizado con una gestante y dos puérperas internadas soropositivas para el VIH. Los datos fueron obtenidos por medio de una entrevista con preguntas semi-estructuradas. El análisis de las informaciones fue a partir de la técnica de análisis de contenido en la modalidad de análisis temática. Resultados: del análisis surgieron dos categorías << La percepción de la enfermedad >> y << El ser gestante/puérpera soropositiva para HIV >>. El resultado de los cuidados en salud tiene relación directa con la asistencia profesional, en que prácticas humanizadas, pautadas en una relación empática de apoyo y acogimiento, se muestran eficaces para el desarrollo del autocuidado y cuidado del otro. Conclusión: se considera necesario crear acciones intersectoriales que repercutan en la asistencia prestada a las portadoras del VIH, sensibilizando a los profesionales para acoger este público en todos los niveles de atención. Descritores: Soropositividad para VIH; Atención Prenatal; Mujeres Embarazadas; Embarazo de Alto Riesgo; Enfermería.

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INTRODUCTION

The experience of pregnancy and birth is characterized for many women as a unique event full of feelings and emotions. In this period, the woman experiences ambivalent emotions like love/anger and safety/insecurity. However, for HIV-positive pregnant women, this ambivalence is accompanied by anxiety and fear for themselves and their child.

Many factors determine a high-risk gestation, including HIV-Human Immunodeficiency Virus. In view of this, HIV seropositivity in pregnancy acquires several meanings for the woman, as she lives with the stigma still existing in the face of the diagnosis and the possibility of transmitting the disease to the baby. Thus, HIV/AIDS has a significant impact on maternal and child health.

Based on this assumption, motherhood in the context of HIV requires special attention from health teams given the peculiarities of this experience in the life of the pregnant woman and the future baby. Nevertheless, this theme is still a gap in scientific productions on the disease. As it is the case of HIV/AIDS, women of childbearing age who have HIV/AIDS, as it is the case of HIV/AIDS, need to be informed about this option. In this study scenario was the maternity ward of a medium-sized hospital of a municipality in the South of Brazil. This service is a reference in that region for the care of high-risk pregnant women, especially HIV-positive women.

Research participants were a pregnant woman and two postpartum women, all HIV-positive, who agreed to participate in the study. The following inclusion criteria were used: HIV-positive mothers whose children, neonates, were hospitalized in the neonatal and pediatric ICU, Semi-Intensive Care Unit and/or Pediatrics; HIV-positive mothers and their babies hospitalized in rooming-in/maternity ward; mothers who were informed about the diagnosis of HIV. It should be emphasized that the reduced number of participants is due to the refusal of the other subjects, 15 women, who had been invited to participate in the study.

Data were collected from August to December 2013 through an interview with semi-structured questions about maternal health care, treatment information, and family/social support. In order to select the research participants, we decided to approach them individually, in a private place, to explain the research objectives and present the Informed Consent Form, in which confidentiality and anonymity of the information obtained were guaranteed. The research was in agreement with Resolution 466/12 of the National Health Council.

The interpretation of information occurred from the content analysis technique in the thematic analysis modality. The analysis was divided into three stages: pre-analysis, exploration of material, treatment of results and interpretation. From the analysis of the data, two categories emerged: “Perception of the disease” and “The HIV-positive pregnant/puerperal woman.”

The research was approved by the Research Ethics Committee of the Faculty of Medicine of the Federal University of Pelotas under the Ethics Assessment Presentation Certificate.

OBJECTIVE

- To understand the perception of being an HIV-positive pregnant/puerperal woman.

METHOD

This is a descriptive and exploratory study with a qualitative approach. The qualitative approach was chosen because it allows the search of reality from the in-depth analysis of the facts, by describing meanings and the importance of the phenomena. The study was ratified on March 22, 2005, Ordinance No. 426/GM, which establishes the National Policy for Comprehensive Care in Assisted Human Reproduction, and presents assisted human reproduction as a way to reduce vertical and/or horizontal transmission of infectious diseases, as it is the case of HIV/AIDS. Women need to be informed about this option. In this sense, professionals working in the women's health care network need to rethink their way of acting and the guidelines they provide for women of childbearing age who have HIV/AIDS, allowing the empowerment of these women and their partners and minimizing the possibility of horizontal and vertical transmission.
Three women participated in the study, of whom one was pregnant and two were puerperal women. The participants’ ages ranged from 24 to 29 years. As for the sociodemographic profile, one of them had incomplete primary education, another, complete primary education and the other, complete secondary education. The self-declared family income was a minimum wage and a half, and one of the participants reported no income. Regarding marital status, one was single and two had a partner.

Diagnostic time ranged from four months to six years. For two participants, it was the second gestation and for one, it was the first one. The current gestation was planned in the case of two women.

**Perception of the disease**

In this category, we present the results selected in the participant's speeches that refer to the conception about the pathology and the fears and stigmas surrounding it.

An important point is the evolution of the understanding about the disease. The participants emphasized that the reaction regarding the initial impact of the discovery represented an unacceptable situation; however, over time, they began to face their new condition in a more peaceful manner, as can be seen in the testimonies that follow:

[... at first [...] I could not accept. I felt bad, I cried [...]. Today, for me, it is natural. It seems like I am normal. (I1)]

I was more frightened when I discovered I had the virus [...]. I feel good [...] I feel comfortable. Before I used to feel bad, I felt something suffocating me, which was depression [...] because of the disease. (I3)

On the other hand, knowledge about HIV was listed as a tool that assists in the acceptance process, as can be seen in the speech of I2:

*But for me, this was something that I did not know. I found later that I was HIV-positive and talking to some people [...] then, thing become clearer [...] because when you know nothing, it gets more difficult for you to deal with. Nowadays I am very calm about this issue. (I2)*

On the other hand, the lack of information leads to an erroneous perception of the forms of transmission.

*In fact, everyone has this virus; [...] because everyone is born with it, it just does not develop in everyone. [...] No, you already have it, just need a little push to disclose it.*

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[... The same thing if a mosquito bites you. How you will know if a mosquito did not pass my virus to you? (I3)]

It should be noted that one of the factors highlighted by the participants as extremely negative in the experience of HIV is prejudice.

[... I thought, my God, there is a lot of prejudice [...] my mother does not talk to me anymore because I have the disease [...] and this is a very serious prejudice for me. [...] Because my fear is not about the disease [...] A disease is a disease, you have to treat it, you have to take care of it. My fear is about prejudice. I do not admit it at all. (I1)]

About the discrimination my children may suffer; [...] that they do not know how to deal even because they are very small. (I2) Because we judge people by appearance only, we do not know what they feel. We have to be in their shoes to know. I had a friend with the HIV virus but it never crossed my mind how she felt. Now since I have the virus, I know how it feels. (I3)

Besides the participants' fear of prejudice, there is still an understanding of the diagnosis of HIV as fatal, as a disease that condemns the carrier to death, as observed in the speech of I3:

*Because when the person discovers that she has the HIV virus, she has to think not only about her but about who lives with her. My sister asks if I am going to get a husband. I do not want anyone. It is not because I know I am going to die that I am going to kill everybody there [...] If I know that I am condemned, I do not have to condemn anyone else. (I3)*

**The HIV-positive pregnant/puerperal women**

This category presents the statements of the pregnant/puerperal women regarding the care for themselves, for the other and the care received. In this sense, the subjective dimension of prenatal care, human relations, dialogue and reception was identified. Care in planning pregnancy was highlighted by two women.

*So, before getting pregnant I did my follow up with an ID specialist. The CD4 collections, viral load/ I've always done everything very well. [...] When I imagined that I could be pregnant, I went to the doctor to take the tests and find out because I did not take medication before, and I did not have to take it. And I knew I was going to need to take it during pregnancy, so I started to try to find out what it would be like. I mean, when I would start to take the medication; what the side effects would be, whether there would be any risk to the baby. (I2)*

The doctor told me about the fertile days, and then in the fertile days we had a relationship [...], then he injected the
liquid, took a syringe, pulled the liquid from the condom and injected into me […] and we went trying, trying, until it worked out one day. (I1)

Still in the context of self-care, the participants’ statements bring several measures adopted by them, as well as the concern with the gestation and with the well-being of the baby and the partner.

I knew that if I got pregnant I would have to take care from the start, […] all recommendations as well. At the time of intercourse, there, we always used a condom. Even though I was not getting pregnant, we always used protection; we did everything right, because from the beginning I discovered, we always used it. […] We have to have a lot of self-esteem, because without it, we cannot, because the immunity can lower. (I1)

We need to take basic care, it is simple; and there is no reason not to take it. Especially when you have children involved. […] Taking the medication at the right times, making the CD4 collections, and now, the genotyping I did last time to find out how the baby was; anyway, how he was responding to the medication. These were the care we took, well, and then the food, all care taken in a normal pregnancy. And a few more because of HIV, which was actually the medication, taking it at the right times […]. (I2)

Taking the medicine, taking the tests, everything right. (I3)

Participants also reported difficulties in adopting such care measures, such as gastric symptoms to swallow pills. It is also observed in the speech of I2 the possibility of forgetting about the use of medication:

Until I get used to those three pills, those ‘huge’ tablets, which I have difficulty in swallowing. Anyway, heartburn, nausea, even because of the medicine, because of pregnancy. And then forget it, because I was not used to it. Anyway, it's because it's a medicine that you have to take without feeling ill. So it's more difficult because you forget to take it often […]. (I2)

The medicines are horrible, […] so much so that it is difficult to adapt, but I am trying. […] There are some that I put in my mouth and it goes half way and comes back. You have to drink water. Food, there is no way I can eat if I take it now. Because it takes away the appetite, this is bad. (I3)

Another point highlighted in the reports was the importance of the attention received during prenatal care that influences the way in which women understand care for themselves and for the other, exerting a positive effect.

The doctor is like family. […] Sometimes I am feeling down, then I have an appointment with her, she forwards me to the psychologist. […] So there is no time for me to feel bad. There is no way, no time. A lot of people in the return. A lot of people helping. […] Because everybody there (ambulatory) treats me with great affection to this day […]. It's too good that they have given me this support, to move on. (I1)

On the other hand, when there is a lack of welcoming and bonding, a conflictive relationship can be generated between the professional and the user of the health service, which is evident in the interviewee’s revolt:

I got into them, got into the doctors here. Sometimes they think we are whining. […] but it's not whining. You feel like you're dead, just like dying, and you have to find a way out. And they just wanted me to take a solution (referring to the lack of concern for her) […] my waters 'broke', then they had to make it on time. (I3)

It is also observed that the understanding of the care to be adopted is sought in several sources, as reported by I2:

[…] I search on the internet, we go in, search. I have a HIV-positive friend too, and we exchange information […]. These are the information I have. And from the doctors […] I have my obstetrician […] who helps me a lot; she answers a lot of questions. The ID specialist, too, I always see him. I make my questions and I clarify my doubts with them […]. (I2)

On the other hand, the lack of clarification regarding prophylaxis, prevention and forms of contagion are factors involved in the delivery of the care provided by women that raise fears of vertical transmission, which is one of the great difficulties for women facing discovery and living with the diagnosis, as can be observed in speech:

Then it is difficult[…] being careful to touch him, to what you are going to do with him. You have to be careful with everything. If he has a wound in his hand, you have to be careful to see if you do not have a wound too, not to contaminate him. (I3)

**DISCUSSION**

Upon receiving the HIV diagnosis, many carriers experience many feelings ranging from denial to acceptance of the disease. In many of these stages, fears, anguish and fantasies are present. The discovery of the HIV/AIDS diagnosis is a time of transition in a person’s life. It disorganizes the being, the relationships and the life in society, mainly between the loved ones, as family and friends.6.118

The discovery of HIV in pregnancy is a milestone in the life of women, who must deal with a new reality that generates revolt and despair.7 However, the initial shock of the finding is lessened during pregnancy,8 when the...
woman comes to have knowledge of the disease and its implications.

Heidegger\(^7\) refers to the fact that experiencing a situation so different from the one imagined, which has not been programmed, causes the being to lose emotional control and they have to reorganize their way of being in the world to re-signify their existence. In this process of reorganization of existence, the participants, after the initial shock, have adopted an authentic attitude and began to live harmoniously with the chronicity of HIV.

The human being is a vulnerable being and, as such, exposed to experiencing various situations that make them realize their condition of being in the world. In this existential perspective, humans are able to reflect, to look at their lives and look for ways to modify it. In this sense, research participants have found knowledge/information as a tool capable of assisting them in their process of adaptation to the condition of living with HIV.

Only when the being knows their reality, they can intervene in it.\(^10\) Thus, being empowered about HIV, its forms of contagion, treatments and prognoses brings the possibility for women to make conscious choices about their lives and the life of the other being that they intend to generate or are generating.

On the other hand, misinformation can be pointed out as hindering factor in the process of acceptance of the disease. The lack of knowledge combined to the symbolic representations of HIV makes that the diagnosis is seen in a perspective of threat and fear; in many cases, withdrawing carriers from society and family for fear of contamination. A study found that the discovery of seropositivity is a critical time "marked by anguish and fear not only because of the insecurity of having a disease without cure but also because of the fear of abandonment and rejection",\(^11:42\) so the diagnosis is kept secret to preserve personal identity and family and social relationships. In this sense, HIV-positive women select those to whom they will disclose their diagnosis, in general, people with whom they feel more comfortable.\(^12\)

In a study carried out in Tanzania, pregnant women indicate that they are afraid to know the result of the test because knowing that they have HIV would be the end of their lives. In addition, they fear that others may know of their condition, if positive, for their communities despise those who have HIV.\(^13\) Another study carried out in Sudan shows that, although women are afraid of knowing their HIV status due to the prejudice and stigma surrounding the disease, the physician plays a fundamental role in the positive decision to perform the test.\(^14\)

In contrast, I3's speech shows that she was prejudiced before being a carrier of the virus and changed her understanding from the moment she was diagnosed, establishing a new conception of this health condition from her own experience. It can be seen from the speeches that the greatest challenge faced by the patients is still in the cultural scope, strongly marked by the prejudice that imposes a series of restrictions on the carriers, including the disclosure of the diagnosis.

A study\(^9\) points out that seropositivity causes the woman to distance herself from social interaction, avoiding situations that may expose her health status. Prejudice is present in the lives of these women, stigmatizing them in the workplace, among friends and their own family.\(^12\) In this context, fear of prejudice is one of the main drivers of emotional disturbance.\(^7\)

The annulment of important aspects of women's health, such as the experience of their sexuality and affective life, is evident in the speech of I3, and the disease can generate "sequelae in sexuality and affectivity, which may compromise self-esteem and quality of life, […] preventing these women from expressing their sexuality as they wished",\(^15:45\)

Also, one can observe the concept of fatal disease that surrounds the diagnosis of HIV, the stigma of 'being condemned' and also the concern not to pass on the virus that was passed on to them by another person. A study of the images and meanings of AIDS for users of health services corroborates these data, proving that the diagnosis is associated with death, suffering, perpetuation of the disease and other adjectives associated with deterioration of health.\(^16\)

Nurses need to pay attention to the biopsychosocial needs of HIV-positive women, considering their fear of contaminating other family members, thus isolating themselves and/or feeling guilty, as well as the mental conflict and reproductive issues involved, seeking to provide a qualified care.\(^4\) In this context, the role of health education as a way to confront myths and prejudice against HIV is reinforced. Social spaces and health groups can serve as alternatives for sharing experience among the patients and are a privileged space for health promotion since, according to Freire,\(^10:96\) “no one educates anyone, no one educates oneself: men educate themselves in communion, mediated by the world”.

English/Portuguese

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Based on the understanding of the participants’ speeches, it was observed that the understanding of the disease added to professional support is a factor for the development of resilience in these women in the face of a permanent health condition. In order to develop strategies to reduce stigma, it is necessary to guarantee their acceptance in the health services, in which women receive prenatal care. Thus, when the focus to the health care culture is changed and there is understanding of how practices, policies and research can create marginalizing conditions and inequalities, it will be possible to ensure that pregnant women and mothers living with HIV will not feel depreciated and devalued when accessing health services.17

Care is inherent in individuals and represents an attitude of attention and concern for the other. The ontological concept of Heidegger9 proposes care as a way-of-being that permeates human existence, and its absence has an impact on the individual and on what is around him. Care presents itself as a way of being in the world and of being with the other.

From the perspective of health, care should include training and strengthening of the professionals’ bond with women, as well as the welcoming of these, seeking the comprehensiveness of the assistance provided. Thus, expanding women’s access to health services and quality prenatal care can have a major impact on reducing vertical transmission of HIV. The improvement of care for HIV positive pregnant women can be achieved by enabling access to better diagnostic technologies, but also by the qualification of listening processes, which can broaden the approach to women by organizing therapeutic plans specific to the needs of each of them.1

Self-care in the pregnancy-puerperal period is one of the focuses of health care lines targeted at women in Brazilian health policies. In this sense, prenatal care is extremely important, especially for women in chronic health conditions, such as in the context of HIV. A study reinforces the importance of humanized practices as a mechanism for qualifying service delivery, as well as for adherence by the user to prenatal care.18 To that end, primary care and reference services for HIV/AIDS need to have a connection in order to broaden opportunities for care and vertical prevention against HIV among women seeking health care.19

The nursing team has an important role to promote self-care of HIV-positive women, in which “the nurse must be active in the education and prevention of these women in childbearing age to reduce the number of HIV-positive carriers”20,29 as well as to prevent vertical transmission.

The use and counseling of methods to prevent the transmission of the virus can be observed in the speeches. These methods reduce risks, especially in situations where the couple is serodiscordant. It is also noticed that this methods are relatively simple and low cost.

Thus, the care provided to these women contemplates the guiding axes of the Program for Humanization of Childbirth and Birth of the Ministry of Health,1 which has as a foundation the humanization of care through the creation of a welcoming environment by professionals and an ethical and solidarity assistance towards the woman and her family, aiming at a comprehensive care.

Self-care and baby care are clear in reports that point to antiretroviral therapy as the primary care for these women and is evidenced by the focus and repetition of the word ‘medicine’ in the participants’ speeches. This data is in agreement with a study that indicates that the lack of adherence or voluntary discontinuation of antiretroviral therapy is still one of the great challenges faced by professionals.21 Failure to accept the diagnosis, absence of signs or symptoms, lack of understanding about the severity of clinical symptoms and the existence of side effects are factors that may be associated with non-adherence to treatment.21

Regarding the care taken during pregnancy, the importance of the information provided by health professionals was highlighted, since by informing and clarifying about the diagnosis and associated issues, the professional empowers the woman for autonomy in her care.

The formation of bond and welcome are indispensable for adherence to the treatment, as highlighted in the testimonies, and affective care brings the users closer to the professionals. The statements evidence the importance of professionals’ attention, as they are considered as members of the family, since there is a relationship of affection, trust, acceptance and support, affecting the way in which women experience their health condition.

The proposal of knowing the interfaces of care provided to HIV-positive pregnant and post-partum women allowed understanding that the health professional stands out and is extremely important in the health context as a whole. On the other hand, it can be seen in the speech of the participant I3 that the lack of
understanding and support by the health team impairs trust and bonding, which generates a negative perception of the assistance received. The fragility of humanized actions distances women from professionals. On the other hand, services that provide support and clarification favor the acceptance of diagnosis and treatment.11

Therefore, there is the need for a broad intervention of the health professional, given the evident role they play in the quality of life of these people, as demonstrated by the participants’ statements. Investing in health promotion activities, including family and non-virus carriers, are ways of conducting health in a context in which the sociocultural aspect overlaps with the biological one.

The understanding of the necessary care, both in the gestational and in the puerperal period, is essential for the self-care and for the care of the baby. Therefore, if the HIV-positive pregnant/puerperal woman has access to information from safe and clear sources, she may adopt appropriate care measures. On the other hand, lack of access to reliable information can impair the self-care and the care of the baby.

In this context, a multidisciplinary approach is required so that pregnant women and puerperal women are guided on the therapeutic possibilities and implications of the use of antiretroviral therapy, as well as to create a space for listening and dialogue about living with this disease and the necessary care. These measures, besides facilitating the therapeutic process, help in the process of coping with the disease, providing an integrated care based on the health needs and effective communication of each woman.8

It is also important to emphasize the need to broaden the focus of health care to beyond maternal and child prevention, focusing on the mother’s mental health, in order to protect children in their development.9 In order to do so, it is necessary to understand the social components that surround HIV in the gestation, welcoming the women and helping them to know their rights and to find effective family and social support.9

CONCLUSION

The health care provided to pregnant and puerperal women comprises a range of actions that go beyond welfare practices, centered on the therapeutic process. Knowing the perception of these women about their health and the associated care allows discovering important aspects for these groups, as well as reflecting on those who are deficient.

This study shows that the outcome of health care is directly related to professional care. Humanized practices, based on an empathic relationship of support and reception, are effective for the development of self-care and care for others.

As a limitation of the present study, there is the reduced number of participants and the representation of a specific reality, not intended to generalizations. However, the results can point out strategies of care, especially for nursing field, which occupies an extremely important role in the assistance of women in the pregnancy/puerperal period. Showing availability to welcome and dialogue with the woman and her family, guiding and clarifying the diagnosis and the health conditions of the patients become essential in this type of care.

There is also the need to create multidisciplinary actions that impact on the care provided to HIV carriers, especially in the context of maternity. Raising professionals’ awareness to welcome this public at all levels of care is shown as an alternative for qualification of human resources and health care.

Further research should be carried out on this subject, seeking to know the perception of the family and the support network towards the HIV-positive pregnant/puerperal woman.


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