









NURSING CONSULTATION FOR WOMEN LIVING WITH HIV FROM A PHENOMENOLOGICAL PERSPECTIVE*

CONSULTA DE ENFERMAGEM ÀS MULHERES QUE CONVIVEM COM O HIV NA PERSPECTIVA FENOMENOLÓGICA*

CONSULTA DE ENFERMERÍA A MUJERES CONVIVIENDO CON EL VIH DESDE UNA PERSPECTIVA FENOMENOLÓGICA*

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ABSTRACT

Objective: to unveil the meanings of being an HIV seropositive woman and the experience of nursing consultation in cervical and breast cancer screening. **Method:** a qualitative, phenomenological study based on Heideggerian analysis with 11 women interviewed in a Specialized Assistance Service in Minas Gerais between November/2018 and September/2019. **Results:** in the public world, the women living with HIV assumed an impersonal identity, seeking not to distinguish themselves from other women. They recognized the care provided as systematized, customized, and, even briefly, recovered concern for health care and treatment. **Conclusions:** the meanings unveiled allowed to point that women in their daily lives experience the realism of serology, the fear and anguish of suffering prejudice, they live with the weight of the diagnosis and self-care, they find in the nursing consultation based on the Humanistic Theory the valuing self-with-others in the world of care, in a dialogical practice that places her as active and awakens her interest in continuing with the screening.

Keywords: Cervical Intraepithelial Neoplasia; Nursing; Acquired Immunodeficiency Syndrome; Qualitative Research.

RESUMO

Objetivo: desvelar os significados do ser mulher soropositiva e a vivência da consulta de enfermagem no rastreamento do Câncer de Colo de Útero e de Mama. **Método:** estudo qualitativo, fenomenológico, embasado na analítica heideggeriana com 11 mulheres entrevistadas em um Serviço de Assistência Especializada de Minas Gerais entre novembro/2018 a setembro/2019. **Resultados:** no mundo público, o ser aí mulher-que-convive-com-HIV assumiu a identidade impessoal, buscando não se distinguir das outras mulheres. Reconheceram o atendimento prestado como sistematizado, individualizado e, mesmo de maneira fugaz, recuperaram a responsabilidade sobre os cuidados com a saúde e seu tratamento. **Conclusões:** os sentidos desvelados possibilitaram indicar que as mulheres no seu cotidiano vivenciam a faticidade da sorologia, o medo e a angústia de sofrerem preconceito, convivem com o peso do diagnóstico e do cuidado de si, encontram na consulta de enfermagem embasada na Teoria Humanística a valorização eu-com-o-outro no mundo do cuidado, em uma prática dialógica que a coloca como ativa e desperta seu interesse em dar seguimento ao rastreamento.

Palavras-chave: Neoplasia Intraepitelial Cervical; Enfermagem; Síndrome da Imunodeficiência Adquirida; Pesquisa Qualitativa.

RESUMEN

Objetivo: revelar los significados de ser una mujer seropositiva y la experiencia de la consulta de enfermería en el seguimiento del cáncer de cuello uterino y de mama. **Método:** estudio cualitativo, fenomenológico, basado en el análisis heideggeriano con 11 mujeres entrevistadas en un Servicio de Asistencia Especializada de Minas Gerais entre noviembre de 2018 y septiembre de 2019. **Resultados:** en el mundo público, el ser ahí mujer-que-convive-con-el-VIH asumió una identidad impersonal, buscando no distinguirse de otras mujeres. Reconocieron la atención recibida como sistematizada e individualizada y, aunque de manera fugaz, recuperaron la responsabilidad sobre el cuidado de su salud y su tratamiento. **Conclusiones:** los sentidos revelados permitieron indicar que las mujeres en su cotidianidad experimentan la facticidad de la serología, el miedo y la angustia de sufrir prejuicios, conviven con el peso del diagnóstico y el cuidado de sí mismas, y encuentran en la consulta de enfermería basada en la Teoría Humanística la valorización del yo-con-el-otro en el mundo del cuidado, en una práctica dialógica que las coloca como activas y desperta su interés en continuar con el seguimiento.

Palabras clave: Neoplasia Intraepitelial Cervical; Enfermería; Síndrome de Inmunodeficiencia Adquirida; Investigación Cualitativa.

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INTRODUCTION

By looking at the most prevalent cancers in the female population, breast cancer and cervical cancer stand out. In Brazil, in 2022, there were an estimated 16,710 new cases of cervical cancer, with an estimated risk of 15.47 cases per 100 thousand women, ranking third position⁽¹⁾. Among Sexually Transmitted Infections (STIs), infection with the Human papillomavirus (HPV) is responsible for the development of precursor lesions of cervical cancer⁽²⁾. In women living with the human immunodeficiency virus (HIV), there is a prevalence of HPV infection, with viral persistence and the occurrence of multiple infections with more than one type of HPV. It is worth noting that precursor lesions of cervical cancer tend to progress more quickly in women living with HIV (WLHIV) when there is a reduced level of CD4+ cells⁽³⁾.

A study conducted with WLHIV assisted by a Specialized Assistance Service (SAE) showed that most participants had never participated in an Educational Group on Sexual and Reproductive Health, did not use condoms in all sexual intercourse, were uninformed about it and, did not follow the routine consultation for cervical and breast cancer screening.

WLHIV are subject to inequality concerning their gender identity and are particularly stigmatized, in addition to living in conditions of poverty and social vulnerability⁽⁴⁾. In this sense, when caring for these women, it is essential to address their living conditions, support networks, prejudice experienced, gender inequalities and, their desires regarding the experience of sexuality and preventive practices⁽⁵⁾.

In 2016, allied to the Women's Health Nursing subject at the Nursing School at the Federal University of Juiz de Fora, the extension project began at SAE implemented nursing consultations for WLHIV for cervical, and breast cancer screening, according to Federal Nursing Council Resolution No. 606/2019⁽⁶⁾.

This consultation model follows the precepts of the Humanistic Nursing Theory, considered a theory that emerges from nursing practice. In this sense the Humanistic Nursing Theory, by unveiling the phenomenological experience of this interaction between the nursing self and the person being cared for, begins to take over a phenomenological perspective⁽⁷⁾.

The realistic dimension of being WLHIV raised questions about what it was like for this woman to experience this model of nursing consultation in screening for cervical and breast cancer, and the objective of this study was to unveil the meanings of being an HIV- seropositive

woman and the experience nursing consultation in cervical and breast cancer screening. To unveil this phenomenon, being WLHIV, it became necessary for us to be close to them to give them a voice. From there, what was not said can be revealed.

METHOD

A qualitative study with a phenomenological approach, extracted from the dissertation entitled "Nursing Consultation for HIV-seropositive Women from a Phenomenological Perspective", based on Martin Heidegger. The objective of the study was to analyze the daily lives of WLHIV who experienced this nursing consultation model, aiming to understand, based on the subjectivity of this encounter, which was present in their life-world⁽⁸⁾. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guide was used to design the study^(9,10).

The research was carried out with WLHIV undergoing treatment in an SAE in a municipality in Minas Gerais, from November 2018 to September 2019. The study was approved by the UFJF ethics committee with number 2,879,732, by Resolution No. 466/12 of the National Health Council⁽¹¹⁾.

The inclusion criteria were being WLHIV, age 18 years or over, not having gone through any nursing consultation for cervical and breast cancer screening at the SAE, or having only had a single previous consultation. Considering the precepts of the Humanistic Theory in which links are established, which could consequently bring some bias to the collection, it was considered an exclusion criterion to have participated in more than one nursing consultation in this service.

Convenience sampling was used to select participants in two ways: those who scheduled a nursing appointment were invited to participate in the research on the day and time of the appointment; and those who had at least one consultation were contacted by telephone, scheduling a return consultation, that way inviting them to participate. All invited women agreed to participate in the study. A total of 11 women participated in the research, being interviewed by the nurse, who is a master's student and the main author of this article. The interviews were conducted after a prior introduction and interaction with the service's multidisciplinary team. After signing the Informed Consent, the participants gave their statements in the Women's Nursing Office, a private, comfortable, and fresh environment, located in the SAE. The process of collecting statements occurred in three moments: pre-consultation,

consultation, and post-consultation. The collection of statements ended when the meanings expressed proved to be consistent in understanding the phenomenon.

The conversation lasted an average of 40 minutes and was recorded on an MP4 device. In the end, they were organized and transcribed in full, without any loss of content. During the recordings, the accuracy of the participants' language was kept, without worrying about the truth or untruth of the experiences described. The objective was to understand the phenomenon and how it manifested itself in each of them⁽⁸⁾. To guarantee anonymity, the statements were identified with the letter I (interviewee), followed by Arabic numbers assigned to the participants (from I1 to I11).

In the pre-consultation phase, the researcher aimed to obtain prior information and the experiences of WLHIV concerning the prevention of cervical and breast cancer and STI contamination. Afterward, the participant underwent the nursing consultation itself, following the precepts of Humanistic Theory⁽¹²⁾. Humanistic Theory is a scientific method structured both to direct care and conduct research. Its use allowed the establishment of a bond between the nurse and the patient and emphasized the value of existential conversation, which manifested itself through empathy and the search for comprehensive, quality care. The Humanistic Theory enables to reflect on the choice of the most appropriate care based on scientific evidence, rescuing the importance of the combination between "doing" and "being" with others, since it is centered on people, recognizing them as independent beings capable of making decisions^(7,12-14). Next, the post-consultation took place in the office itself or on a day previously scheduled with the participant. During this stage, a phenomenological interview was conducted using the self-report method. Open questions were asked aiming to have them describe their experiences and understand how they lived their existential daily lives, recognizing the uniqueness of others.

Phenomenology, according to Martin Heidegger's perspective, emerged as a theoretical-methodological-philosophical option of investigation. In the first part, the ontological dimension was sought through questions that aimed to portray the participants, focusing on data such as age, education, religion, job market, marital status, income, number of children and, skin color. In the second part, we focused our thinking on a non-causal approach, the phenomenological one, whose objective was to understand experiences and meanings. To do this, we used the following guiding questions: How did you experience the nursing consultation to prevent cervical

cancer? How did you experience the health care provided by the nurse throughout the nursing consultation for women?^(8,15)

The hermeneutic analytical movement began with a vague and average understanding, where initially, repeated listening and readings of the transcribed material were carried out, allowing an immersion in the experience, seeking to get straight to the questions themselves. At this point, starting the analytical phase with scientific rigor, it was necessary to carry out a phenomenological reduction of data. This made it possible to focus on the ontological dimension of the phenomenon, which is being a woman living with HIV. The objective was to reach the space where facts are configured and where common and different meanings of experience emerge. This was done to understand and describe the phenomenon, without explaining it, since this subject has already been addressed by tradition^(8,15).

The vague and average understanding allowed the meanings expressed by the participants to be approached, resulting in three Units of Meaning (UM): The shame of HIV status, of the examination of their sexual organs, and the fear of prejudice, preceded the nursing consultation; a qualified, embracing nursing team, that values communication favors satisfaction and follow-up; benefits by early detection as well as the guidance provided. The UM denotes what the individual thinks and says about being, expressing themselves enough to make way for the next stage of the analytical movement, interpretative understanding or Hermeneutics, elucidating the phenomenon based on Heidegger's propositions⁽⁸⁾.

RESULTS

The 11 participants were aged between 23 and 42 years old. Nine women declared themselves mixed race and eight had attended high school or elementary school. Regarding religion, ten declared themselves Catholic and only one stated not having a religion. Ten women were working at the time of the interview. Family income ranged from one to three minimum wages. Seven women declared themselves single and all had at least one child.

The existentialist phenomenological analysis movement allowed us to understand the meaning expressed by WLHIV concerning the phenomenon they experienced, resulting in the elaboration of the following UM.

The shame of HIV status, of the examination of their sexual organs and the fear of prejudice preceded the nursing consultation

WLHIV reported that throughout the nursing consultation for cervical and breast cancer screening, they felt embarrassed when having their sexual organs examined, as well concerning their serological status. They repeatedly compared health care at SAE, where they are not afraid of suffering prejudice, with that of other health services in the Unified Health System (SUS) that they avoid attending, because they fear prejudice.

I'm a little embarrassed, but they (nurses and students) explain everything, I didn't have any doubts about anything. So, after a while, I didn't even care. (E4)

The atmosphere here is better [...] even better than when I consulted at the clinic. It's easier to talk here, there's no prejudice. It's not even possible to compare. (E5)

I'm a little embarrassed about these things (consultation). Because I am very ashamed of my (seropositive) condition [...]. (E7)

I never suffered prejudice there (in Health Service A), but I know that people don't understand it well (HIV) [...]. I'm embarrassed to go to the clinic (Health Service A), there everyone talks about everyone's life, and there's prejudice. (E9)

I'm a little embarrassed, mainly because, when we say we are HIV seropositive, some people change their ways, but not here, because everyone already knows what we are like, so I feel more comfortable. (E11)

A qualified, embracing nursing team, that values communication favors satisfaction and follow-up

The participants recognized that the nursing consultation was conducted by a qualified team, offering systematic, detailed, and customized care. Referrals for additional exams were provided and care was provided in a thoughtful manner. This gained the participants' attention to the guidance provided, which, added to the learning acquired, reinforced the relevance of the guidance and follow-up in consultations.

[...] there (X Health Service) they did it like that, we would lay down, did the exam collection, and left and there was no explanation, we didn't even know what they were doing [...]. Here I liked it because she (nurse) explains everything [...]. It creates closeness. And then I felt calmer when, after she (nurse) explained it to me, I saw that I had nothing severe. And now

I leave here calmer, paying attention to some things I wasn't paying attention to before. (I1)

I had other information, they taught me how to do a breast exam and touch, things that I didn't do, I was very careless. They taught me more: to be attending more often (SAE), scheduling more gynecological appointments, participating. Today I understand better, I ask more questions. Here I feel more comfortable. In other places (Y Health Services), no one paid much attention to explaining and teaching me. So, for me here it was suitable. (I2)

They (Nurse and students) explain it so well that I can understand everything. It was totally different. They don't just do preventative care, they want to know how we feel, they teach us how to get to know about our breasts and our body, to look for problems and changes, which is totally different. I had it (Pap smear) at the (K Health Service) in my neighborhood, but here I thought it was great, they inspect the whole body, and they even explain it all. Even if it were a private service, it wouldn't be that good. (I3)

The consultation is very good. I was very comfortable with the entire consultation, despite there being three people (Nurse and two students) who were in the room on my day, I learned a lot: I learned things about my body, things that sometimes we take for granted. They taught me to observe more myself, get to know myself better, and I participated, asked a lot of questions and they answered me in a way that I understood, there was also the way they welcome us for consultation, all of this is very good! (I6)

Benefits by early detection as well as the guidance provided.

Some participants reported that they were referred for colposcopy after consultation at the SAE. They noted benefits in early detection, as well as in the guidance provided on the prevention and treatment of gynecological conditions and STIs, especially those related to HPV. This characterizes a distinct factor compared to other services.

For me it was very important because it was through here that I had diagnosed my problem and had to have my cervix cauterized and, if I hadn't been here, and hadn't been so detailed, it would have deteriorated, it could have become a problem or even an illness. Before here I participated in the joint effort, and as I was already booked here [...] I decided to come out for release of conscience, and it was here that my problem was diagnosed. If you hadn't worried about me,

calling me, I might not have come, because I had already done another exam and I wasn't going to diagnose the lesion at the beginning as it was, it would have been much worse. [...] It was very important to come here. (I3)

For me, it's great because last time I came, it showed that I was full of those HPV blisters, and then I was referred to the hospital where I was treated with some medications, and it got better. The doctor said that since it was discovered early, only medications would work out, and if I waited longer, I would have to undergo surgery. After that, I always come here (nursing consultation) at the right time. (I9)

The special care provided, by calling me to inform that the findings were abnormal and that I needed to come here, explaining about the lesion, and referring me right away to a consultation tomorrow (colposcopy), all of this was great! Because, even if it's something more serious, you all dedicated yourselves to helping me quickly. (I10)

DISCUSSION

Studies conducted with women who underwent screening consultations for cervical and breast cancer found that they felt embarrassed when their bodies were exposed. When they were undressed, they felt fragile, submissive to the actions of others, powerless, unprotected and, due to their gynecological position, they felt that they had lost control of their own bodies. However, this discomfort can be minimized when combined groups are formed(16-18).

In the public world of interpersonal relationships, the WLHIV being appeared in a state of decadence. It revealed the prevalence of impersonality in everyday life, seeking not to stand out from other women, assuming their uniqueness and mixing features and expressions that were accepted by the majority. When interacting with others, she did not allow them to observe or suspect that she was undergoing treatment, keeping this fact secret due to the fear of being rejected. In an impersonal way, the being moves away from oneself, getting lost in the collective and starting to build a public identity that is acceptable to everyone(8).

Thus, the woman abandoned herself to the world, avoided herself and did not accept the singularity of living with HIV, but only as a woman. In everyday life, WLHIV was expressed in common speech and in an occupation(8). In her statement, she reported the following: "At first, I was embarrassed, she (nurse) was going to touch

me, but it was necessary." Then, she worried about screening and faced the difficulties that involved her being-in-the-world. The being-in-the-world of decadence, tempting and calming, is also alienating(8). The participants cared about what was said, referring to prejudice as something inherent to being an HIV sero-positive woman. In their daily lives, when interacting with others, the fear of being rejected due to their HIV status was present. Dasein considers fear as a mood state in which it can be found(8).

Humanistic nursing has its dimensions resulting from the human situations that the individual goes through and experiences, being, in this case, the fear and prejudice reported by the participants of this study(11). Fear and anguish are states of mind that are continually repeated in the lives of WLHIV, as they involve having their serological status revealed and, as a result, go through prejudice, discrimination, family discrimination, domestic violence, suffering and death. The stigmatized condition and the anguish caused by being a WLHIV, being identified as different and having one's physical appearance evaluated by others are the result of negative behaviors that persist to this day(19-20). Both fear and anguish led Dasein to a position of scape and decay, characterized by its most typical way of being, inauthenticity. Worrying and seeking treatment to be in good clinical condition is also a way to avoid prejudice(8).

In the act of existing, the WLHIV being revealed itself through the understanding of care, a necessary and unchangeable condition that constitutes her being-in-the-world. The impact that seropositivity had on their lives was reported. Studies indicate that these women are immersed in a care routine, with medication intake, returning visits to specialized services, laboratory tests and monitoring by health professionals. For this reason, her world was described as tiring, heavy and full of difficulties, including responsibilities as a mother, housewife, wife, worker, and caregiver. Furthermore, they face the weight of diagnosis, treatment and their own care, which cannot be neglected in relation to caring for others(19-20). The being was thrown into an unexpected and unplanned situation(8).

According to the precepts of phenomenology, care is a way of being that can be found in all behaviors. Its actions are carried out both with oneself and with others(21). The participants reported feeling embraced during the consultation by professionals who were interested in interacting with them, offering social support, clarifying doubts, and providing information and guidance about what they were doing and the required care for their health. Social support has become essential to motivate women

to adhere to HIV treatment⁽²²⁾. In this study, it was concluded that the actions carried out during the nursing consultation, based on its intentionality, made women feel satisfied with their professional performance, supported to use their autonomy, which was related to the information accessed at the time of the interview.

In their reports, women highlighted the importance of following a screening routine after diagnosis. They showed knowledge about HIV and the benefits of adhering to treatment. Many reported that returning to consultations at the specialized service after referral for colposcopy was established as a way of preventing complications related to HPV, which is often associated with HIV. In this way, the women got involved with the guidance they received: "I learned things about my body, things that sometimes we don't pay attention, right? They taught me to take a better look at myself, get to know myself better, and I participated, asking a lot of questions and they answered me in a way that I understood." In everyday life, Dasein always shows itself to be shared, being-with-others. When we find ourselves in public life, we are everyone and we are nobody. We live in an impersonal and inauthentic way, which puts us downward. Talking is one of the inauthentic forms of opening Dasein that occurs in everyday life. Curiosity and ambiguity are two developments of speaking that emerge as inauthentic possibilities of vision and as fallen modes of interpretation⁽⁸⁾.

The WLHIV was talkative, expressing that what was said to them was always understood, as it was something they had always heard about. However, the information they held did not reach the primary ontological reference and did not communicate properly at first. This occurred because they were just repetitions of previous statements, which were repeated and passed on without there being toughness in the content learned⁽⁸⁾. The way of seeking clarification about her body and treatment, in the phenomenon of chatter, is called curiosity⁽⁸⁾. In curiosity, there is the pretension that what they were informed, through talk, and investigated by them was completely understood. At this moment, another phenomenon of presence openness emerges, called ambiguity, where it is assumed that everything appears to have been understood, assimilated and discussed authentically when, in fact, it was not⁽⁸⁾.

Humanized care, free from prejudice, combined to the fact that they do not need to keep their serological status secret in the SAE and the trust found in professionals, is similar to the objective of the Humanistic Theory that understands and bases the nursing profession as one that, through its many ways of care, it offers responses

to human illness throughout the different phases of one's life cycle⁽¹²⁻²³⁾.

Thus, care involves fundamental concepts related to the environment in which the individual lives and moves, in addition to nursing, seeking to understand their way of being in everyday life, both individually and interacting with the environment and the collective, respecting their capabilities and limitations⁽²⁰⁻²³⁾.

When deciding to schedule the nursing consultation, the WLHIV acted authentically. This decision-making demonstrates responsibility for taking care of herself and considers the continuity of her treatment. Presence is temporal, being and existing at every moment⁽⁸⁾.

It is important that health professionals, including nurses, understand the reality of the people who will receive care. It is crucial that they seek to improve their skills and competencies through enhancement opportunities, critical discussions, and scientific updating. This can be achieved through in-service training, which is necessary for planning, decision-making and implementing preventive healthcare practices. Knowledge from common sense, combined with scientific knowledge, is inseparable when seeking to promote and prevent various health problems, such as HIV⁽¹⁶⁻²³⁻²⁵⁾.

The single scenario is highlighted as a possible limitation for the present study. However, due to the purpose of this investigation, the theoretical framework and the methods used, the intended understanding was achieved, constituting an important scientific discovery based on the appreciation of women living with HIV, their life-world, permeated by dialogues with nurses who are theoretically grounded and focused on the comprehensive care of these women.

FINAL CONSIDERATIONS

At each meeting with the participants, we could get closer to the way of existing of the WLHIV person in their daily lives through the search for SAE, helping to understand their way of being-with and being-in-the-world. The uniqueness of each of them allowed us to understand how they live, using Martin Heidegger's theoretical-philosophical framework. It was observed that these women only feel safe when they receive care in specialized services. This calls attention to the need to investigate, in future studies, why WLHIV feel vulnerable in other services and how we, professionals, can contribute to changing this feeling and ensuring that people with HIV have their rights consolidated, in accordance with the doctrinal principles of the SUS: universality, equity

and comprehensiveness in health services and actions. This study reinforces the need to carry out new research that addresses health professionals who care for WLHIV, especially nurses, seeking to identify possible difficulties found in daily care. It is important to avoid omissions, resignations, or alienations, favoring comprehensive care.

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