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The care needs of women infected with the human papilloma virus: a comprehensive approach*

NECESSIDADES DE CUIDADOS DE MULHERES INFECTADAS PELO PAPILOMAVÍRUS HUMANO: UMA ABORDAGEM COMPREENSIVA

NECESIDADES DE CUIDADOS DE MUJERES INFECTADAS CON EL VIRUS DEL PAPILOMA HUMANO: UN ABORDAJE COMPRENSIVO

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ABSTRACT

This study is founded on the phenomenology of Martin Heidegger, with the objective to understand the care needs of women infected with the human papilloma virus. Participants were fourteen women who had been diagnosed with this infection. The guiding questions were: What is it like to have this diagnosis? Tell me your experience, from when you received your diagnosis until today. What has your health care been like? The questions revealed the theme – seeking care as solicitude – which showed the importance of the support of family and friends. The presence of the infection as the cause of marital conflicts and separation was another highlighted aspect. The statements showed that there was a sense of resignation after an unsuccessful attempt to find accurate and clear information in order to make assertive decisions. Health interventions for infected women must overcome the traditional models of care, including interventions for health promotion and prevention, with trained professionals who are sensitive to the subjective dimension.

DESCRIPTORS

Women
Papillomavirus infections
Public health nursing
Qualitative research

RESUMO

Pesquisa fundamentada na fenomenologia de Martin Heidegger que objetivou compreender as necessidades de cuidados das mulheres infectadas pelo Papilomavírus Humanos. Participaram catorze mulheres que haviam recebido o diagnóstico dessa infecção. As questões norteadoras foram: como é, para você, estar com este diagnóstico? Conte-me sua experiência, desde que soube do diagnóstico até hoje. Como está sendo a assistência que você tem recebido? O desvelamento do tema – buscando o cuidado como solicitude – mostrou a importância do suporte dos familiares e de amigos. A presença da infecção como motivo de conflitos e separação conjugal foi outro aspecto ressaltado. Os depoimentos deixam em evidência a resignação após a tentativa frustrada de busca por informações precisas e esclarecedoras para a tomada de decisões assertivas. As ações de saúde à mulher infectada necessitam ultrapassar os modelos tradicionais de cuidado, incluindo ações de promoção e prevenção à saúde, com profissionais capacitados, sensíveis à dimensão subjetiva.

DESCRIPTORIOS

Mulheres
Infecções por papilomavírus
Enfermagem em saúde pública
Pesquisa qualitativa

RESUMEN

Investigación fundamentada en fenomenología de Martin Heidegger que objetivó comprender las necesidades de cuidados de mujeres infectadas por el Virus del Papiloma Humano. Participaron 14 mujeres diagnosticadas con esta infección. Las preguntas orientadoras fueron: ¿Cómo es, para usted, estar con este diagnóstico? Cuénteme su experiencia, desde que supo del diagnóstico hasta hoy. ¿Cómo viene siendo la atención recibida? La revelación del tema: buscando el cuidado como solicitude mostró la importancia del respaldo familiar y de amigos. La presencia de la infección como razón de conflictos y separación conyugal fue otro aspecto resaltado. Los testimonios evidencian la resignación luego de la tentativa frustrada de búsqueda de informaciones precisas y esclarecedoras para la toma de decisiones asertivas. Las acciones de salud con la mujer infectada necesitan sobrepasar los modelos tradicionales de atención, incluyendo acciones de promoción y prevención de salud, con profesionales capacitados, sensibles a la dimensión subjetiva.

DESCRIPTORIOS

Mujeres
Infecciones por papilomavirus
Enfermería en salud pública
Investigación cualitativa

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INTRODUCTION

Human Papillomavirus (HPV), a sexually transmitted disease, has the potential to cause cervical cancer, which makes HPV infection in women a public health problem. Uterine cervical cancer affects nearly 500,000 women and kills 270,000 women worldwide annually⁽¹⁾.

More than 200 different genotypes of Human Papillomavirus (HPV) are described; however, only a few have oncogenic potential. According to international classification, the ones from Group 1B - HPV types - are considered to be carcinogenic to humans (definitely carcinogenic to human): 16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 59 and 66 and from Group 2B (possibly carcinogenic to humans): HPV 6 and 11⁽¹⁾.

Infected women, on learning of their diagnosis, often feel stigmatized, anxious, stressed and worried about their sexual relationships⁽²⁾. Just as with any sexually transmitted disease (STD), HPV arouses feelings of modesty and shame, which may cause problems in their relationship with their partner, their family, with the health-care team and with society. Thus, HPV infection can have a strong impact on the family structure of women, especially in the marital relationship, and trigger an end of the relationship, a change in the couple's attitude towards one another, separation or denial regarding the disease^(3, 4 - 6).

Being infected with HPV should not be cause for extreme concern, but rather of attention, since most infected women will not develop any new lesions. Many will experience the elimination of the virus naturally via the immune system, or the virus may lay dormant for many years, repeating a common behavior of any virus⁽⁷⁾. However, the initial reaction of most women who receive a diagnosis of HPV is negative, because this arouses a feeling of fear that may remain during the entire process of evolution of the disease⁽³⁾.

Lack of health education, such as lack of quality information about the illness, and the inadequate care of women infected according to their individual needs seems to be the present reality. This deficiency, in general, increases the vulnerability of women, since the suffering experienced by them during the infection process favors the development of misconceptions, myths and erroneous beliefs about HPV⁽⁸⁾.

These findings and observations related to the professional daily work of one of the authors of this study who serves as a nursing faculty member, teaching an undergraduate course in nursing in a Primary Health Unit, caring for women with HPV. From this work arose the following

question: what are the care needs of women who are diagnosed with HPV?

The objective of this study was to understand the care needs of women infected with Human Papillomavirus.

Technological advances in health care are essential; however, radical changes are necessary in our attitudes, in relation to the way we think about and practice health care. The philosophical aspects should be revisited so that the conceptual advances already made correspond to actual changes in health practice⁽⁹⁾.

This study is justified insofar as it seeks to disclose the health care needs of women infected with HPV - a sexually transmitted disease with a carcinogenic potential that is permeated with numerous negative feelings. This will allow health professionals to better understand the experiences of these women, creating awareness of the need for effective actions that will lead to improved quality of care, i.e. care that goes beyond the physical, emotional and social needs and takes into account the individual woman and her way of being in the world, appreciating her experiences, her beliefs and her values.

METHOD

This was a qualitative study, based on the existential phenomenology of Martin Heidegger. The choice of following the methodology of Heidegger was due to the fact that this philosopher addresses the inevitable and inherent movement of the being, a movement which gives meaning to it, is effective and can show, expose or invade itself⁽¹⁰⁾.

Heidegger, when discussing human existence, opens up the possibility of the discussion of care. According to Heidegger, through care man opens up to the universe and has the ability to question and reflect philosophically on the causes and circumstances he is experiencing. In other words, care designates the way of being in the world⁽¹⁰⁾.

The study included 14 women who had been diagnosed with HPV; eleven had been selected from a list of patients users of the Unified Health System, provided by the Health Department of a municipality with about one hundred thousand inhabitants, located in the northern region of Paraná State. These women were enrolled in the Laboratory Information System of the National Program to Fight Cervical Cancer and were diagnosed with HPV in the years 2007 and 2008. The other three women used private health services and were selected by recommendation of health professionals.

The women selected were invited by telephone or by home visit to participate in the study. The individual inter-

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views took place between November 2008 and May 2009, at a time and place of convenience for the women. The interviews were recorded and transcribed immediately after their completion.

The number of participants was determined during data analysis when saturation of the data was reached.

The guiding questions for the women's testimonies were: What is it like for you to be diagnosed with HPV? Tell me about your experience, from the time of your diagnosis to the present. How do you feel about the service/care you have been receiving?

The analysis of the testimonies followed the steps adopted in the study⁽¹¹⁾: reading and rereading each interview to detect the meaning units and grouping of similar units (convergent) that culminated in the themes: being there with HPV, being-with in relationships, seeking care and solicitude and the path of transcendence with HPV. The theme of *seeking care and solicitude* was chosen for this text, considering the emphasis on the care needs of women infected with Human Papillomavirus. This theme was discussed according to the theoretical reference of Martin Heidegger⁽¹⁰⁾ and other references on the subject.

To ensure anonymity, the women interviewed were identified by fictitious names. This study was approved by the Ethics Committee of Universidade Estadual de Londrina (*Protocol CEP no. 184/08).

RESULTS

All of the women interviewed had received the diagnosis of HPV during an outpatient visit and maintained their daily routine, such as caring for the house and their children, work, and leisure activities, among others. The experience of living with HPV was felt along with the experience of the world in terms of these women's common sense. Thus, being infected with HPV caused distress for the women interviewed, and consequently, allowed them to open up to new possibilities and different care needs:

Nobody wants to get sick or have a disease, let alone knowing it can be incurable, which may limit her sexual life, which can disrupt her relationships. I would not want this to happen. [...I began to cry a lot...]. It's as if I had AIDS and did not want anyone to know. (...) a diagnosis that is often not even a final diagnosis, but it interferes with people's lives. (...). This situation opens a window to several others. It would mess with my inner life, which sometimes you're not ready to talk about with people, and not all are friends with whom you can talk about these things(Nice).

Among the needs for care, we emphasize the importance of support from family and friends:

What helped me was also the strength and the support from my family. They said that it was not cause for me to panic, that everything would be all right, that I would get over

it(Fabia). I just talked about this with a friend of mine (Elsa). Those who spoke to me about it were my friends (Joyce).

Some women reported that they only had the support of the professionals who saw them, not having revealed their situation to other people:

I just went to the station... I did not talk to anyone about it(Gilda). The nurse comforted me... (...) I just talked to the nurse about it(Ilda). I just talked about it with the doctor (...) (Mara).

We revealed that women infected with HPV often did not have the support of their marital partner:

I did not talk about it with my husband, because he says it is a disease that one catches from a sexual relationship. I just have him, and he is a sexist, and will say: 'what have you done? Where did you catch that?' And I know that man is a shameless creature, right? That is where the fight starts at home. Therefore, I was quiet, said nothing(Dora).

Another issue unveiled, associated with gender issues, was the difficulty of acceptance on the part of the partner, and on the married women themselves, of condom use:

If I wanted to use a condom, he had to use one. I go to the station, I get some; there are a whole lot in my drawer [laughs]. I think the singles take better care of themselves. The risk of infection is within marriage. We talk with our girlfriends, the married ones, and no one uses condoms. But the unmarried, no! They are more aware of the risk. The wife trusts her husband, the husband trusts his wife. They say, right? But in fact, they are unfaithful(Elsa).

The presence of HPV infection as a cause of conflict and separation was another aspect highlighted:

I felt alone when I needed him most; he left me. (...) It was a difficult time for me because my husband left me soon afterwards; he thought I had betrayed him. It was very painful (...) My daughter got sick because of it, wow! [crying]. (...) I lived in other people's house out of charity. This was a difficult phase. (...) My husband thought I had betrayed him, because his friends said that this disease was sexually transmitted(Celia).

And yet, when they looked for a health service, their needs were often not met.

(...) I think he should have explained more, explained when I should return to see if the warts had returned. He should have asked. (...) throughout my pregnancy, he did not say anything about it. (...) I still have doubts. I want an explanation from the doctor. Because he only told me what I had to do and did not explain anything (Helena).

The statements also make evident the resignation felt after the failed attempt to seek care. The women felt the need for a different kind of care than that which they were receiving, as well as more accurate and insightful information about what was happening to them, so they could make accurate and informed decisions.

The various opportunities for solicitude on the part of health professionals in terms of the interactions that occurred during health interventions have not been exploited to achieve quality care. When receiving health care, women sometimes felt too intimidated to ask questions and sometimes were subjected to tests and procedures without understanding the reason for them:

(...) I wanted to know exactly what that was like. How we catch that. Because we go to the doctors and it is all in a rush and we never get to ask anything. We are embarrassed to ask. I asked the doctor, and he said: I'll send you to a specialist. With the specialist, I did not go into details, I did not insist, I asked only one question, that that was it! On the day I went, she was running late, she was seeing everyone in a hurry, right? So I did not ask any more questions. (...) lately, I have been accepting everything very easily. (...) Until this day, I do not understand... When they gave me the diagnosis I thought that it was HIV; do these two have something to do with each other?(Dora).

The women further unveiled other difficulties they had experienced while seeking health care. In some cases, they were referred to other services without any explanation regarding their diagnosis, and they also reported a lack of professionalism:

The doctor said (...) that things here at SUS take a long time (...) They sent me there as a referral. I arrived there on the biopsy day and the woman who would perform the procedure was not there. I had to go back home. Then I had to go and have the treatment privately (Celia).

The concern was manifested as a real need for informed care. HPV-infected women felt the need to learn more about the disease, and knowing that health professionals cared about them, they sought care.

DISCUSSION

The woman as a relationship being goes through different emotions and experiences and has opportunities to share these experiences. The 'being-with' is another way of 'being-there', that is, it by means of relationships that the being completes itself in its own way of being. It is from the world that the being relates to all things⁽¹⁰⁾.

Being the woman in a 'being-relationship', among the need for care and acceptance, the importance of the role of family as a means of support to cope with the difficulties experienced by the women with HPV is revealed. The interaction of the participants in this study with family and friends indicated the importance of support in facing negative feelings and doubts and to meet several needs. The everyday relationship is distinguished by a constant being with others. The being-there is not only in the world, but mainly relates to being with other human beings⁽¹⁰⁾.

In this study, the issues of gender relations are evidenced, also permeating care needs. We recognize the

feminization of guilt relating to the infection. It was unveiled that marital fidelity was put to the test, since HPV is a sexually transmitted disease. Some women reported strife in their marital relations, including accusations of betrayal and mistrust on both sides.

HPV can have a strong impact on family structure and, in most cases, women cannot count on the support of their partner^(4, 6). Oftentimes, the woman feels doubly victimized. She feels guilty for suspecting her partner and also because he distrusts her⁽⁴⁾.

It was also revealed that these women face difficulties in taking action to prevent STDs. Knowing the risks and how to protect themselves from sexually transmitted diseases does not seem to guarantee changes in practice or preventive attitudes of women. This does not only apply to the prevention of HPV. Even when contemplating a life-threatening sexually transmitted illness such as AIDS, although women have the knowledge to preventing these diseases, the sense of security within the marital relationship and confidence in their partner generated by stable marital union drives them away from preventive practices - the use of condoms⁽¹²⁾.

This fact contradicts itself when one observes that most of the guiding groups on methods of contraception are made up of women who seem not to exercise autonomy in their own choices in their marital relationships⁽¹³⁾. The concept of autonomy includes the freedom of the person to be herself⁽¹⁰⁾. The magnitude of this concept still needs to be understood by most people.

This study reinforces the need for investments to expand HPV prevention education. There is a need to stimulate and encourage the use of preventive measures to avoid viral transmission, and for new diagnostic methods that are more sensitive, less expensive and more easily accessible to all women⁽⁷⁾.

There is no denying that there are still inequalities between men and women when it comes to fidelity. Women may have the desire to stray, but this is often hidden. They hold traditional values about the stereotypes regarding the security and stability of marriage and, in parallel, prove to be more modern, with more autonomy, independence and privacy in their marital relationships⁽¹⁴⁾.

For Heidegger, these experiences have an idiosyncratic meaning, i.e., they constitute a unique experience for every human being and determine the path to be taken by each individual. When a being is in a submissive role to another, it is considered to be living in a non-authentic way, restricting individual life in favor of another, which in reality is not possible⁽¹⁰⁾. When the woman puts herself in this role, she may be discounting herself as a human being, traveling away from what should be her main objective: becoming herself, quite often by experiencing feelings such as fear, and insecurity, and lacking autonomy.

Some reports have shown the difficulty in obtaining, on the part of women, the necessary information about HPV. Knowledge has been provided in an incomplete way, leaving women unclear as to their diagnosis but focused on the need to use the medications prescribed by the doctor.

The ethical dilemmas include: therapeutic failures, provision of inaccurate information, failure to protect privacy, poor service organization and others, often permeating common situations of daily practice in health services, including primary care. These problems are difficult to identify and may jeopardize the quality of care provided. It is necessary that these issues be identified and overcome in the health work process⁽¹⁵⁾.

For some women, the nurse and the doctor appear to be the only professionals who are knowledgeable about the diagnosis and have the ability to offer care. This fact leads to greater concern about the responsibility of these providers towards these women, since they are often the only source of care and information available.

The delay in the scheduling of tests, errors in the scheduling of the same and conflicting information among professionals have also been reported. These results demonstrate that there is need to rethink the organizational structure of the work process in health services. Often, some facilities provide barriers to women's prevention behaviors, making access to care more difficult, which generates anxiety⁽¹⁶⁾.

Adequate information regarding the illness and respect for the needs of the women are a form of authentic care. However, it is necessary that women have the opportunity to actually participate in decisions regarding their own health.

We seek to relate the care needs of these women with the phenomenology of Heidegger, by understanding that solicitude is how to be with another⁽¹⁰⁾; It is the essence of man's way of being, translated as an anticipated occupation in relation to something. In the sense of caring, it is having the intention of accomplishing something or seeking care⁽¹⁰⁾.

For Heidegger, solicitude can mean two things: to care for the other, replacing your needs with his, or not substituting the other in care. In the first instance, the other can become dependent, manipulated and dominated, even if this domain is silent and remains veiled. It is removing the problems of the other, making it impossible for him to tread his own path. In this case, this being is not very concerned with the other, but rather with the things that he should provide. This would be an example of inauthentic care⁽¹⁰⁾.

Inauthentic care was demonstrated in the remarks of the women, when they stated that they were subjected to tests and procedures without understanding the reason

for them, or when they were denied the opportunity to participate in decisions regarding their health condition.

The health professionals, according to the informants in this study, did not seize the opportunity when they were with these women to carry out the necessary guidance. Considering that these professionals work in primary care, they should have, as one of their primary care activities, acted as educators and mentors of positive attitudes. In the interaction between the actors involved in health care, sensitive listening capable of effecting care is of paramount importance and demonstrates a real concern for the other⁽¹⁷⁾.

It is essential, furthermore, to include ethical and technical values in the care activities. The professional must provide care from the determination of the demands and needs of his clientele, taking into account the technological resources available in reality⁽¹⁸⁾.

Existentially, taking proper care of the being cannot be seen as a temporary role, but as a mark of the human condition. Heidegger expresses concern as providential, planning, caring for the other, and calculating and predicting actions⁽¹⁹⁾ and, based on these actions, determining the necessary decisions/actions to preserve the being. Concern allows man to anticipate himself, that is, to care and preserve himself, in the spatial and temporal sense. This feeling is understood as a movement for the future, stemming from the past⁽¹⁹⁾.

CONCLUSION

This study shows that women infected with Human Papillomavirus (HPV) have care needs in their family relationships and relationships with healthcare professionals. Family support is particularly important, as is the partner and the support of health professionals.

The health professionals involved in the care should take into consideration the women's experiences. Accordingly, information about HPV should be shared with the women, respecting their needs and their level of understanding. There must be more effective and affective care, in which infected women play an active role in the process of health, so that interactions can be true and authentic. It is therefore necessary to incorporate a more comprehensive care, adding to the actions of nursing care attention, involvement with the other, respect and empathy.

From this study, the value of health professionals emerges and emphasizes their important role in assisting women with HPV comprehensively and in an individualized way, strengthening the support network available to these women.

Albeit restricted to the understanding of the meanings of woman being with HPV within a specific group, this study points out important reflections and boosts

the performance of research seeking understanding of professionals working with women suffering from the disease. The results of this investigation subsidize the growth

of education, directing the activities of professionals in search of comprehensive care, thus contributing to improving the quality of care.

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