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Being a woman with HPV: a cultural approach*

SER MULHER PORTADORA DO HPV: UMA ABORDAGEM CULTURAL

SER MUJER PORTADORA DE VPH: ENFOQUE CULTURAL

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ABSTRACT

This study was carried out in order to investigate the level of women's knowledge about HPV, to identify beliefs, myths and taboos about HPV, as well as to analyze the influence of these cultural elements on women's behavior. We performed a study based on the transcultural care theory. The research was developed from the testimonies of 15 women who were undergoing treatment for HPV. Through the investigation, it was possible to perceive that HPV is a disease that is still unknown and surrounded with mystery, despite all the sources of information about Sexually Transmitted Diseases (STD). This lack of knowledge, which interacts with cultural factors, favors the development of wrong concepts, such as beliefs and myths.

KEY WORDS

Condylomata acuminata.
Health knowledge, attitudes, practice.
Sexual behavior.
Women's health.

RESUMO

Este trabalho foi realizado com o objetivo de investigar o nível de conhecimento das mulheres sobre o HPV, para, a partir daí, identificar crenças, mitos e tabus sobre a doença e analisar a influência destes elementos culturais no comportamento da mulher. Realizamos um estudo baseado nos pressupostos da teoria do cuidado transcultural. A pesquisa foi desenvolvida a partir do depoimento de quinze mulheres que realizavam tratamento para HPV. Através da investigação, foi possível perceber que, apesar das inúmeras fontes de informação sobre DST, o HPV ainda é uma doença desconhecida e cercada de mistério. Este desconhecimento, interagindo com fatores culturais, favorece o desenvolvimento de conceitos equivocados, tais como crenças e mitos.

DESCRIPTORES

Condiloma acuminado.
Conhecimentos, atitudes e práticas em saúde.
Comportamento sexual.
Saúde da mulher.

RESUMEN

Este trabajo fue realizado con el objetivo de investigar el nivel de conocimientos de las mujeres sobre el VPH, para así identificar creencias, mitos y tabúes sobre la enfermedad y analizar la influencia de estos elementos culturales en el comportamiento de la mujer. Realizamos un estudio basado en los supuestos de la teoría del cuidado transcultural. La investigación fue realizada en base a los testimonios de quince mujeres en tratamiento para VPH. A través de la investigación fue posible percibir que, a pesar de las innúmeras fuentes de información sobre ETS, el VPH es aún una enfermedad desconocida y rodeada de misterios. Esta falta de conocimiento asociados a los factores culturales, favorecen el desarrollo de conceptos equivocados, tales como creencias y mitos.

DESCRIPTORES

Condiloma acuminado.
Conocimientos, actitudes y práctica en salud.
Conducta sexual.
Salud de la mujer.

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INTRODUCTION

The human papillomavirus (HPV) is an infectious agent that manifests itself through wounds known as condyloma acuminatum, genital warts or cock's crest. It is frequently a sexually transmitted virus, although other forms of transmission have been identified⁽¹⁾.

HPV worries several organizations committed to women's sexual and reproductive health. One reason for this is the high prevalence of the virus, which infects 20% of sexually active women⁽²⁾, and especially in the relation of the virus with the development of cervical cancer.

Over 90% of women with uterine cancer were exposed to HPV⁽³⁾. This is a worrying fact, because cervical cancer has reached high rates of morbidity and mortality. It is estimated that 19 thousand HPV cases will be identified in Brazil in 2008. This type of cancer is the second most common in women, causing nearly 230 thousand deaths per year⁽⁴⁾.

The lack of knowledge about the virus itself, the signs and symptoms of infection, the relation with cervical cancer and the forms of transmission are examples linked with the magnitude of the HPV infection in women.

The lack of adequate information about HPV can favor the development of erroneous conceptions that, in turn, can interfere negatively in the behavior of the human papillomavirus carrier, as well as of the people who are part of her socio-familiar context. These erroneous conceptions are usually based on cultural elements, such as beliefs, myths and taboos, with a great significance for the individual. Cultural values that do not correspond to reality can represent a great barrier for the professionals acting in health promotion and rehabilitation and disease prevention.

Nursing healthcare should be broad in view of the complexity of health problems. The act of caring needs to be reviewed beyond a biologic perspective, and reach the thoughts, feelings and cultural expressions of the client. Therefore, it is necessary that a real commitment exists with the being receiving care in order to contemplate several aspects that may be involved in the health/disease context, such as aspects of subjectivity and intersubjectivity⁽⁵⁾.

Based on what was exposed before, we consider that it is necessary to perform an investigation about HPV that would address cultural aspects present in the reality of several women who carry the virus. Therefore, starting with the knowledge about the beliefs, myths and taboos about HPV, we could guide our educational actions in the sense of clarifying possibly baseless ideas and promote the clients' awareness about the true context involving HPV, so as to not only contribute to the prevention of this virus, but also to improve the coping with the disease and the community life of the infected woman with the individuals in her social network.

OBJECTIVES

General

- Investigate the women's level of knowledge about HPV.

Specific

- Identify beliefs, myths and taboos of women about HPV;
- Analyze the influence of beliefs, myths and taboos about HPV on the behavior of women.

METHOD

We chose a descriptive research because this type of investigation allows for the exploration of a situation where more information is needed, aiming at using its results for the orientation of possibly inadequate practices⁽⁶⁾. The qualitative approach was used because this study was judged as needing subjective data, related to the social context of the subjects who experience the proposed reality, i.e. who are more susceptible to HPV infection and its related complications. Considering that the proposal of this study is to analyze the phenomenon of HPV contamination in women based on a cultural perspective, we use the assumptions of the theory of diversity and universality of cultural care for theoretical support⁽⁷⁾.

The aforementioned theory proposes the broad and systematic comprehension of people's way of life as a strategy to develop efficient nursing care. The theory highlights the importance of investigating their culture for care promotion, and also the need for nurses to use their knowledge about the client's culture to provide care, in agreement with their values and ways of life⁽⁷⁾.

The research was performed at a basic healthcare unit in the city of Fortaleza – CE. Data collection was performed in April, 2005. The study was developed with 15 women, all HPV carriers, who sought gynecological healthcare at the place of study and during the research period. Data were collected until they reached the point of information saturation. The investigation was done only with women since they constitute the population most afflicted by damages caused by HPV.

Participative observation, interviews and the field journal were the strategies used for data collection. *Participative observation* is indicated in cases like this one, where the investigators collect data by taking part in the interview, sometimes even interfering, proposing, and later registering the objective information and observed impressions precisely in the *field journal*⁽⁶⁾. The *interview*, in turn, was chosen since this technique promotes a social encounter, when the clients not only express answers to the questions but, overall, thoughts and feelings about a given topic from

Over 90% of women with uterine cancer were exposed to HPV.

the perspective of their realities. The interview script was made up of open-ended questions, addressing the respondents' knowledge about HPV (*what do you know about HPV?*), the reactions when they found out that they were virus carriers (*what was your reaction when you found out about the HPV diagnosis?*) and the sexual behavior after the diagnosis (*was there any change in your life after you found out that you were a HPV carrier?*). When necessary, the subjects had room to complement their answers.

The analytic process involved four phases. In the first phase, the raw data from the interviews were collected, described and filed, and the information given and observed impressions were written down in the field journal. In the second phase, we identified and classified the descriptions and the components, when pieces of information were added with observations, and when differences and similarities were identified among the findings. The third phase covered contextual analysis and recurrent expressions; at this moment, we discovered saturated ideas and significant data. In the fourth phase, we synthesized the ideas of the collected data and grouped them in broader themes, offering a clear and objective representation of the findings⁽⁷⁾.

The anonymity of the participants was assured, and they are identified herein as letters of the alphabet. Also, they were granted the right to cease their participation at any moment they deemed necessary. It is important to note that authorization for this research was requested from the healthcare unit. The research project was submitted to the Ethics Committee of Federal University of Ceará (UFC) and data collection started after the project was approved (Protocol COMEP n. 60/05).

RESULTS AND DISCUSSION

The results of the research are presented next, in two parts. The first part is the Characterization of the Study Participants; in the second, we describe the results of the interview in three themes that emerged from the participants' statements. These were: *What is HPV?, I have HPV: what now?* and *Now I will take care of myself!*. In the first theme, we addressed the knowledge of the respondents about several aspects of HPV contamination. In the second, we investigated what it was like to discover that one was a HPV carrier. The third theme reflects the behavior of the study participants in view of their disease.

Characterization of the study participants

The study participants were in the age range of 22-28 years. All of them had either incomplete or complete high school education, with the latter being prevalent. As for their marital status, five mentioned being single with a steady partner (boyfriend), nine mentioned consensual union and mentioned being single and having had sexual intercourse with more than two partners in the past few months. As for the presence of signs and symptoms, only

five clients reported having noticed the HPV infection by themselves, with the other participants being diagnosed during the cervical cancer preventive exam. Only two respondents stated that their partners had the genital wart. Women who had either started or were about to start HPV treatment were interviewed.

Description of the results of the interviews

What is HPV?

By trying to investigate the level of knowledge about HPV, we noticed that the construction of the worldview of an individual starts in her social environment, what she observes, apprehends, analyzes and stores, under the influence of people who are also part of this environment. This worldview, according to some authors, will reveal how the individual sees the world outside her culture⁽⁷⁻⁸⁾.

When performing the interviews, we observed that the participants had several sources of information about STD available, and that these sources offered varied contents. Most (10) stated that the main source of information about STD is the healthcare unit, although they mentioned other means like newspapers, magazines, televisions, and individuals who are part of their socio-familiar context.

However, it is important to remember that HPV infection is still a reality that is not widely discussed, since it is a relatively recent health problem, and also because other types of STD are focused on, such as AIDS. We could notice that in the discourse of two interviewees:

When I was in school I did a seminar about STD for my class, but I didn't go as far as knowing what HPV was (D).

We hear about STD, but knowing about HPV [...] We hear about AIDS more often (F).

Knowledge about HPV, according to the study participants, has only been really acquired recently, during the treatment for their disease, with the help of healthcare professionals. The professional healthcare systems⁽⁷⁾, represented here by the healthcare unit where the interviewees receive care constitute a means of promotion of cultural care, since it is supported theoretically and spread among the professionals or from the professionals to the clients. Although the participation of the professional healthcare system in the assimilation of knowledge about HPV is verifiable, some erroneous conceptions about the ways of HPV transmission were still detected among women.

Especially some women who started treatment expressed incorrect ideas about how HPV can be transmitted, such as the belief that the man is always the one who transmits the virus, that not undergoing the preventive exams for cervical cancer can make the woman more susceptible to HPV infection and that, like HIV, HPV can be transmitted through blood. This can be identified in the following testimonies:

HPV is a virus transmitted from the man to the woman through sexual relations. It can cause warts and itching (J).

I think HPV is a virus that causes pain and inflammation. I think it is transmitted when we do not do the preventive exams for a long time, and also through blood transfusion. (B).

The interviewees stated that their ideas about HPV resulted from daily experiences, the observation of similar situations and knowledge transmission among different generations and members of the social-family collectivity. We noticed the influence of educational factors, cultural values and ways of living on the elaboration of their worldview⁽⁷⁾. Thus, the need emerges to address these factors in the elaboration and implementation of nursing care.

Other interviewees believe that HPV contamination happens only through unprotected sexual intercourse:

HPV is a type of STD acquired when we do not use condoms during sex, and it can cause warts and inflammation (C).

One of the participants, who had not started treatment for HPV, revealed that she always believed that *HPV was a type of HIV* (F).

Like other cultural elements, beliefs seem to have developed through a complex process, through which knowledge could be *created* and modified under the influence of facts, events and experiences of the respondents. We found explanations for this phenomenon in ethnic history, which emphasizes the analysis of the individuals' past experiences in order to understand behaviors in view of a given situation⁽⁷⁾. Culture and education establish a direct and profound relation, since people or groups often determine their choices in the health-disease-care process based on the precepts of their culture. The educational process involves the transmission of knowledge, and these are necessarily influenced by cultural elements⁽⁹⁾.

Another point addressed in this study was the possibility of cure for a HPV carrier. Of the interviewees, seven did not believe in the possibility of cure.

I've heard there's no cure [...] (E).

There's no real cure, but, if you treat it, there's some control over it (H).

Until recently, it was believed that there was no cure for HPV, only treatment. However, some hypotheses have been under study, which say that there may be a cure for some of the prevalent types of this virus. Although the healthcare professionals mentioned this hypothesis when disclosing the diagnosis to the respondents, we still see that the possibility of cure is influenced by the information the study participants obtained in their socio-familiar context.

This context is part of the popular healthcare systems, which consist in knowledge based on certain cultural realities and strongly influence the behavior of people, since they are conveyed and shared by groups with strong emotional bonds, such as family members⁽⁷⁾. We believe that

the belief that there is no cure for HPV, shared for some time by healthcare professionals, is culturally rooted in the context of the respondents.

The relation of the HPV with the development of cervical cancer seems to be most concerning for the respondents. They made it clear that HPV infection is a worrying disease, for which treatment is indispensable.

We get cervical cancer through HPV. There are people who have had the disease for a long time and they don't know it, they keep on spreading it (D).

It's more concerning for the woman, because there aren't many symptoms for the man. In the woman, if you don't treat it, it can cause cancer. And in the woman it's easier for the disease to settle (H).

It's more serious for us, women, because we're always the ones who suffer the consequences of everything, especially the STDs. It's easier for women to get STDs than for men [...] (I).

In the latter two testimonies, we could also see the patients' awareness of women's higher vulnerability to acquire STDs. Questioned about this knowledge, we verified that it had been acquired through facts occurred with individuals in their own social circle. We noticed that we must not judge ourselves as owners of knowledge, since we only have technical and specialized knowledge about a given topic, with this knowledge being somewhat restricted by discarding cultural factors⁽¹⁰⁾.

In the same way as popular knowledge may be riddled with baseless concepts, it can also carry true and relevant information, as seen in the aforementioned testimonies. This characterizes the importance of the approach of the popular healthcare system, through which knowledge and skills can be culturally learned and conveyed⁽⁷⁾.

I have HPV: What now?

Becoming aware that one is a HPV carrier can cause several feelings, especially since it is a relatively unknown STD that can lead to death through cervical cancer. The diagnosis can also cause behavioral changes in the woman, especially in relation to her partner, as seen below:

I was scared when I was told the diagnosis. I regret not having done it with a condom the first time [...] (B).

My reaction was the worst possible, because I had only one person in my life. I had an idea, but I couldn't imagine that he (boyfriend) would do that (cheat) to me, because I always talked a lot with him [...] (D).

I was desperate. I fought a lot with my boyfriend (C).

In submitting to unsafe (without condoms) sexual practices, some women can be led by their trust in their partners, in addition to not being able to impose their wish of preventing STDs⁽¹¹⁾. The onset of the disease, in turn, can arouse the idea that the woman's partner may not be tak-

ing good care of himself and that, therefore, she should take care of herself. In view of this, we noticed that the participants lack knowledge about the virus' period of latency, since the disease is always related to the partner cheating and isolated from the possibility of earlier contamination in other relationships.

Lack of knowledge about HPV can favor the development of fantasies during the client's assimilation of the diagnosis. This happens because taboos and prejudices about topics related to sexuality could even prevent the individual from seeking information⁽¹²⁾. Some study participants confessed that they went through difficult moments until being adequately informed about the disease:

I was so scared! I cried! I thought I had cancer already, that I was going to die [...] Because they said that Ana Maria Braga (a popular TV hostess) had cancer because of HPV (A).

I was desperate. I thought at first that I had HIV. And then I saw it was not like that, it was HPV, which was not the same thing. The doctor told me about it later [...] (F).

This shows the importance of health education actions, especially in the sense of clarifying baseless ideas that can cause discomfort in patients, or even damage their behavior in their quest for health. The re-standardization of cultural care is necessary in such situations, and it happens through actions aiming at reorganizing, replacing or modifying a way of life, in search of another way of life aiming at the client's health and wellbeing, and which respects her values⁽⁷⁾.

Only one of the interviewees mentioned feeling comfortable to talk about the disease with another person than the sexual partner, but taboos and myths could still be identified in relation to HPV:

It's bad, because you can't talk about it to anyone, only to him (partner), because people will think bad things about you. I only told my neighbor, who has already had the disease. Then she told me that many people have it, such as another neighbor of ours, who is very young, beautiful, and lives normally. Then I thought: If it's about dying, everybody dies someday [...] (laughter). My mother can't even hear of it. When she asked me why I'm coming to the health unit so often, I told her that's because of an inflammation. Then she told me that the doctor seeing me was a doctor of venereal diseases, delivered care to hookers [...]. She asked me if I was *burning* it (popular language to talk about HPV treatment). It was really difficult to lie to her (A).

Even current concepts related to sexuality still carry the essence of previous generations⁽¹³⁾. In these, several myths are prevalent, such as stating that only promiscuous people can acquire STDs, and some taboos about the theme. The aforementioned behavior can be justified through ethnic history⁽⁷⁾, since the identified myth seems to have developed through the first reports of contamination by the AIDS virus, which occurred in homosexuals and prostitutes.

Strong influences of the environmental context and language about the healthcare patterns and the expressions can be identified, hindering the participant's wellbeing.

During the interviews, we identified that the clients have strong fears of being discriminated and rejected. In a previous study with HPV carriers, it was seen that:

Those who acquire HPV suffer, among other pressures, the shame of being promiscuous, the fear of being rejected by their man or woman, the sadness of being considered as lacking dignity by family and friends; they suffer the fear of disgust caused in those they deal with, and overall, they suffer the fear of social and affective death⁽¹¹⁾.

Now, I'll take care of myself!

When they were faced with the reality of HPV contamination, the clients adopted actions of self-care or care with the partner. Only one of the interviewees confessed not using any preventive care during her sexual relations. Most (09) stated avoiding having sexual relations until their disease was treated. The others (05) mentioned still having sexual relations, but stated that they had been using condoms.

I changed my sexual life with him (partner). Now we only do it with a condom, but, since it's difficult to get used to it, all we do is practice (laughter) I know that from now on we'll have to get used to doing it with a condom (A).

All patients considered their treatment as an extremely important measure and encouraged their partners to undergo exams. About preventive measures, such as using condoms, we observed that the respondents presented behavioral changes after being diagnosed with HPV. According to results of another study, also performed among women carrying HPV, the onset of contamination in the interviewees caused a reflection and search for behaviors that were favorable to health⁽¹¹⁾.

After being clarified about HPV, the interviewees reported that, in addition to adopting behaviors of better healthcare, they felt calmer:

After I got informed and saw that it wasn't all that I was thinking about, I felt more at ease. I thought: now I'm gonna take care of myself! (laughter) (A).

Besides technical skills, we verified the importance of elucidating concepts about HPV. This attitude, in addition to contributing to treatment compliance, provides emotional comfort, since the client understands the context of her disease and sees that behavior in favor of health will benefit the treatment. We, healthcare professionals, have the duty to help and deliver care to individuals in order to preserve or recover their health and wellbeing through a beneficial educational approach that enables, among other things, coping with diseases and the search for health through care in harmony with culture⁽⁷⁾.

FINAL CONSIDERATIONS

Although they have several means of information about sexually transmitted diseases (STD) available, some women still present gaps regarding their knowledge of HPV. This happens because the disease is not as well-known as others, such as AIDS.

As a consequence of the lack of coherent information about HPV, several erroneous conceptions are developed, such as the belief that HPV can only be transmitted from the man to the woman, the myth that HPV is a disease of promiscuous women and the taboos about STDs.

On the other hand, there is evidence of some women's awareness about the higher vulnerability of the woman's body when exposed to STD and about the importance of STD treatment for women's health. This awareness, however, seems to have been developed through empirical means, which shows us that popular knowledge is not fully based on erroneous ideas.

As for the contamination phenomenon, the study participants justify it, especially, by the trust placed in their sexual partner. However, the onset of the disease awakes, in addition to fear, regret and despair, and the feeling of

disappointment in the partner. Still, some respondents talked to their partners about HPV, fearing that they would be rejected and discriminated by their family and friends. This behavior represents the taboo and the feelings of self-prejudice, linked to HPV.

After facing the impact of the HPV infection diagnosis and of being informed about the treatment, the respondents adopted a favorable attitude to self-care and care for the other. They felt calmer, although they did not believe in the possibility of cure.

In view of the results of this study, we noticed that lack of knowledge about HPV can awaken feelings and fantasies, creating a *wall* that makes it difficult to seek for health or its maintenance. Beliefs, myths and taboos appear as results of the interaction between the lack of information and the cultural values of the individuals or the community they belong to.

Therefore, we highlight the need to direct our attention at a type of care that considers the cultural values of the client. Care that is directed at the investigation and clarification of baseless concepts, through actions of sexual education that does not only aim at STD prevention but, overall, at promoting women's awareness about what is *true* or *false* about reproductive health/disease.

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