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Feelings of women with human papilloma virus regarding their infection: an exploratory study

Juliana Alexandra Parente Sa Barreto¹, Mirna Neyara Alexandre de Sá Barreto Marinho^{2,3}, Emery Ciana Figueiredo Vidal^{2,3,4}, Antonio Germane Alves Pinto^{3,4}, Priscila de Souza Aquino⁵, Eglídia Carla Figueirêdo Vidal^{2,3,4}

1 Research Group Technologies in Care in the Brazilian Unified Health System

2 State Health Department of Ceará

3 Research Group Clinic, Care, and Management of Health

4 Cariri Regional University, 5 Ceará Federal University.

ABSTRACT

Aim: to understand the feelings of women infected with the human papilloma virus (HPV) regarding this sexually transmitted disease. **Method:** this is an exploratory study, with a qualitative approach, performed with 14 women who are users of a specialized care service in the municipality of Juazeiro do Norte, in the Brazilian state of Ceará, in the Northeast of Brazil, between March and June 2012, using the Collective Subject Discourse technique. **Results:** it was observed that there were some misconceptions regarding HPV, unfamiliarity with the fact the therapies used do not eliminate the virus, feelings linked to negative characteristics of the diagnosis, and self-protecting and children-protecting attitudes. **Conclusion:** the perceptions described tend to harm the empowerment process of these women to deal with the illness with more confidence. Gaps were found in health education. The discussion about the topic must continue, with directed information regarding living with HPV in a singular approach, respecting the individuality of each woman, providing more humane and effective care.

Descriptors: Women; Papillomavirus Infection; Knowledge; Emotions.

INTRODUCTION

The sexually transmitted diseases (STD) have been increasing in their variety and incidence in recent decades, which represents one of the most common public health issues around the world, according to the World Health Organization⁽¹⁾.

They represent one of the largest contemporary obstacles to healthcare services, requiring this issue to be prioritized due to its transcendence, vulnerability, and magnitude⁽²⁾. Some of the elements considered significant to the increase of STD are: early sexual relationships, multiplicity of sexual partners, little or no use of condoms, lower adherence to pap smear exams, low schooling, and low family income⁽³⁾.

Taking into consideration the social, demographical, and migratory tendencies in the world, the estimate is that the population at risk of STD may increase in the coming years⁽⁴⁾.

The infection by the human papilloma virus (HPV) is the most common STD in the world⁽⁵⁾. The analysis of this data points out that the number of women with HPV in the world may reach 291 million⁽⁶⁾.

In a research study in Spain of 1,007 women, the prevalence of HPV infection was significantly higher among women with cervical intraepithelial neoplasia (CIN) levels 2 and 3 (86%), or carcinoma (87%), than in women with CIN level 1 (64%), and the changes associated to HPV (50%), or in typical cells (40%), and with an elevated proportion of women with infections from different genotypes of HPV 16 and HPV 18⁽⁷⁾.

In Brazil, genital infection by HPV affects 140,000 women per year⁽⁸⁾. Based on these data, HPV infection has an important epidemiological relevance due to its large incidence, transmissibility, and the correlation between the virus and the incidence of cervical-uterine cancer⁽⁹⁾.

Under this setting, in a research study in Brazil among 198 women who presented abnormal cervical smears, the general prevalence of HPV was in 87% of the cases, together with a significant association between the first sexual intercourse before the age of 16 and a positive HPV test result, as well as the diagnosis of cervical cancer⁽¹⁰⁾.

At the same time, North American research, with a sample of 8,182 women between 31 and 65 years old, concluded that women with infections from multiple variations of HPV had a larger tendency to have abnormal cytology than those infected by one single type of HPV⁽¹¹⁾.

HPV infects skin and mucous, presenting more than 100 subtypes, in which 20 of those can influence the genital region, and again these 20 can be separated into two main groups: the ones with high oncogenic risk and the ones with low oncogenic risk⁽¹²⁾. Women infected by the HPV types 16 and 18 have increased risks of developing a CIN when compared to others infected with the other types⁽⁶⁾.

Among the complications related to HPV, there is the known capacity to induce neoplasia in the anogenital region and in the upper gastrointestinal system. This is not the main result from HPV infection, this capacity is considered to be a risk factor for reduced fertility or infertility, and in pregnant women and their partners, HPV detection can be considered a risk for premature birth, abortion, and virus transmission to the newborn. These factors need to be better explored in studies of this topic⁽¹³⁾.

In this context, the detection of HPV is essential and the nursing professionals that work in basic care assume a role which is extremely important for an early detection of HPV infections. They are able to control its transmission, supported by the development of strategies in health education, in order to prevent and clarify possible erroneous misconceptions regarding

the infection, improving and assisting care quality.

The therapeutic approach consists of basically eliminating clinical lesions by using chemical, physical, and immunomodulated agents⁽¹⁴⁾. Through its National Unified Health System (SUS, in Portuguese), Brazil has provided the recombinant quadrivalent vaccine against HPV, covering types 2, 11, 16, and 18⁽¹⁵⁾, aiming to reduce and prevent genital warts, CIN, and cervical cancer, especially for women who have not yet been exposed to the virus⁽¹⁴⁾.

This study is based on the following guiding question: What are the perceptions of women bearing HPV regarding the infection? In this sense, the research aimed to learn the perceptions of women with HPV infections regarding this sexually transmitted disease.

The research was performed based on the understanding of women in regard to HPV and cervical cancer after nursing consultation. It showed that there is a large unfamiliarity with the issue, no acceptance of the use of condoms, and that the orientation nurses provide are too close to the exam, with no inclusion of information regarding the illness and its prevention, demonstrating that this moment needs to be guided by listening and dialogue with the patient⁽¹⁶⁾. In this sense, the importance of this investigation is from the perspective to motivate professionals in a more holistic approach to women with HPV, listening to their demands, doubts, and in particular, understanding the context in which they live, so the procedures and guidelines are directed to their everyday needs.

METHOD

This is an exploratory research, with a qualitative approach, performed in the municipality of Juazeiro do Norte, Brazilian state of Ceará, in

the Specialized Medical Care Service unit (SAME, in Portuguese). This is a referential public service supporting sexual and reproductive care in the city, except for women with HIV, who are assisted by the Clinic of Infectious Diseases of Juazeiro do Norte.

The people who became part of the sample of this research were 14 women with HPV, who were above 18 years old, and were being supported against the infection at the SAME. Those excluded were having their first consultation during the period of the study. During the period mentioned, 54 consultations were held at the SAME, in which 36 patients were women, and from those, 14 (100%) with HPV filled the criteria of inclusion. Among those, nine had another STD besides HPV. Ten women were excluded because they were visiting the unit for the first time. It is important to mention that the SAME is the reference location for many other health issues the local population reports, and it also supports the demands of other areas that the Family Health Strategy program (FHS) does not fully cover.

Data collection occurred between March and June 2012, on Tuesdays, in semi-structured interviews, recorded in audio and transcribed by the authors.

The data was organized through the method Collective Subject Discourse (CSD), being the discourse of the participants grouped by central ideas, connected to key expressions, and analyzed based on the literature related to the topic⁽¹⁷⁾.

The result was limited by the ethical and legal prerequisites in research in human beings, with an ethical note approved under protocol number 20/2010 from the Committee of Ethics and Research of Cariri Regional University (URCA, in Portuguese).

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RESULTS

In regard to the age groups, five women were between 20 and 30 years old, eight were between 31 and 40, and the last one was 42 years old. In relation to their marital status, six were married, five single, two declared they were divorced, and one stated she was living under a consensual stable relationship.

The schooling levels of these women were: five did not conclude middle school, six did not have a high school diploma, two finished their high school studies, and one had an undergraduate diploma. The number of children varied from zero to nine: one child (two women), two children (three women), three children (three women), four children (one woman), nine children (one woman), and no children (four women, three of them being pregnant at the moment).

In relation to the object of the study, the perception of women regarding HPV infection, the discourse of the participants generated six central ideas, as found through the CSD methodology, which were: What is HPV? I have HPV: does it have a cure? Can HPV lead to cervical cancer? Fear, sadness, anger, and shame: how did I feel when I found out I had HPV; What changed after the diagnosis; I have HPV: do I divorce or not?

What is HPV?

I don't know it for sure, I almost don't know anything about it. I had never heard about HPV before I found out I was infected by it. I have heard there were sexually transmitted diseases (STD), but almost nothing about HPV itself. We heard a lot about HIV, more than the others. I know that HPV is a virus transmitted by the man to the

woman during sex, and if you don't wear a condom you get it, and there are many types of HPV viruses, which can also be transmitted by the underwear, soap bar, towel, bed sheets, toilet seat, and by the mouth, through the saliva, causing inflammation, itches, and warts in the vagina, more common among women. (DSC)

The transcribed discourse above denotes that HIV has been quite widely discussed and advertised, while there is little emphasis on HPV infection. As a contradiction, some interviewees, despite being treated for HPV, receiving support and instructions, reproduced erroneous conceptions regarding virus transmission, such as the idea that the man is the one who is responsible for hosting and infecting with the virus, and that it can be transmitted through the saliva. However, they also expressed that, as a virus, it is sexually transmitted because of the lack of condoms or by contact with intimate belongings, soap bars, towels, bed sheets, and toilet seats, besides the most common clinical manifestations of HPV infection.

Deeper information regarding the topic were barely reported in this study, which included mentioning the many types of HPV, and that the clinical manifestations are more often seen in women than in men.

I have HPV: does it have a cure?

It has a cure, but you have to follow the treatment word by word. With the treatment, the cure is quite fast. If you look for a doctor right away, he will guide you and solve your problem. The only way is the treatment. Taking care of the warts, but it won't cure you from the disease. My

doctor said they can come back after the treatment, because the virus is still alive inside our bodies. (DSC)

Women present mistaken ideas regarding the cure for HPV, which is a significant lack of information given the fact they live with the infection. It requires understanding and empowerment to properly deal with HPV and a considerable reduction of the risk of relapsing events.

Can HPV generate cervical cancer?

I still don't know. They didn't say anything about it yet. I've never heard about it.

The doctor and the resident doctors that have cared for me said I need to follow the steps of the treatment carefully, because women with HPV have larger chances of developing cervical cancer. (DSC)

The interviewees affirmed they know HPV could generate cervical cancer, however, it was possible to identify women who were unaware of this connection, even though HPV is directly linked to the development of the initial lesions of cervical cancer⁽¹⁰⁾.

Fear, sadness, anger, and shame: how did I feel when I found out I had HPV?

I was afraid to die and leave my children behind, as I started to do research, and I saw it was a disease that if we don't care about it, HPV can end up killing you. I was afraid to know this, and that an HPV infection can spread and I can be discriminated against, or even spread it to my children through a towel, a soap bar, a bed sheet, the toilet seat, or

even during pregnancy and get HIV, as I already have HPV.

To know that I had HPV made me very sad, thinking there was no cure, also with the possibility that my partner cheated on me and did not wear a condom. I felt terrible thinking about the fact I should have been more careful, wearing a condom; also I was supposed to visit a doctor more frequently to have those routine exams. We women are so honest to our husbands, but the opposite is not always true.

I was angry with my partner, I trusted him blindly and I was disappointed, but he denies cheating me, however I don't trust him completely. He couldn't have done that, I never imagined I could get HPV.

In the beginning I was ashamed because I was married for 23 years and I was infected with HPV from an extramarital relationship with a man I met recently. (DSC)

Based on the feelings expressed by the women in this study, during the treatment of HPV lesions, the following emotions were mentioned the most often: fear, sadness, anger, and shame. The fear, mentioned by many participants of this research, involved many reasons, such as: the fear of dying and leaving their children behind, the fear of being discriminated against because the diagnosis could be known by others, the fear of transmitting the virus to their children, and the fear of having another STD, such as HIV. Sadness, a frequently mentioned feeling, was associated with the inexistence of a cure for this infection, to having trusted in their partners and not wearing condoms, and to the possibility of being cheated on, and in this moment, they also demonstrated resentment about this last

described fact. This element demonstrates lack of knowledge regarding the period of incubation of the virus, as the present infection could have been transmitted in a previous relationship from either the woman or her partner.

Only one interviewee reported feeling ashamed for cheating on her partner, a situation considered uncommon in this study, as all the other women imagined they were cheated on, or that they have been infected by indirect contact with inanimate objects.

What changed after the diagnosis?

Nothing changed in my life, everything is the same in my life, and I still don't wear condoms.

Since I found out I have HPV I started to have sexual intercourse with condoms, because I am afraid of getting another STD as I am the only one who knows really what I've been through. I won't trust any other man anymore. I avoided having sex during the treatment, not even wearing condoms, because I didn't want to spread the disease.

After I found out I have HPV, I separated all my intimate belongings, such as towel and bar soap, because there is a risk my children will use them and then they will get infected too. They didn't use my towels before, but now there is not even a chance it can happen.

From now on I'll start having my preventive exams twice a year with a doctor, instead of only once. (DSC)

The discourses above emphasize that women have placed themselves in a more self-protective position after they received the diagnosis of HPV infection, including the care of their partners. On the other hand, some decided not

to adhere to the required changes, having a risky behavior in their sexual relationships without the use of condoms, due to the option given by their partner or because they wished to get pregnant. The feeling of protecting their children, believed to be inherent to motherhood, was evidenced by the interviewees in the reports that they have separated intimate belongings, such as towels and bar soaps, to protect their children.

In their discourses, they also demonstrated the lack of autonomy regarding their own bodies, exposing themselves to risky situations by not wearing condoms, only respecting the desire of their partners, as well as the lack of knowledge regarding continuing the preventive exams, thus leading to unnecessary procedures.

I have HPV: do I divorce or not?

After I found out I have HPV, I don't trust in my partner as I used to, and now I am suspicious of him all the time – I didn't care when he went out before, but now it's different.

My partner was upset because I avoided having sexual intercourse with him during the treatment.

I already thought to divorce, but then I thought about my children, and of the possibility I had got HPV from a toilet seat somewhere.

So far I haven't said anything about having HPV. (DSC)

From the discourses of the participants of this investigation, it noticeable they had different outcomes regarding their partners, from omitting to mention the diagnosis of HPV infection to divorcing. Some women reported that they were suspicious of their partners after they found they were infected with HPV, as the relationship of the couple was based on a mutual

trust, and thinking there is a possibility of an extramarital episode changes the perspectives of this relationship. Others mentioned they avoided sexual intercourse with their partners during treatment, thus making the husbands angry with the situation, representing that after they discovered bearing an STD they prioritized their health status. Many women expressed the desire to divorce their husbands, but only one changed her *status quo*.

Some women reported they did not communicate the HPV infection to their partner, due to the fact they were afraid to lose them, or be accused of acquiring HPV with another, extramarital partner. This fact made the men more vulnerable to becoming infected by HPV because they are unaware their partners are infected by the virus.

DISCUSSION

It is known that the highest incidence of HPV occurs between the ages of 20 and 29 years old⁽¹⁸⁾, and in the scenario investigated, a third of the women interviewed were in this age group. Under marital status, women in stable relationships can become victims of an STD by adopting a line of thought in which the confirmation of affection is demonstrated by not wearing condoms⁽¹⁹⁾. In regard to schooling, the lack of knowledge connected to unsafe sexual practices consubstantially places women under stable marital statuses and with low schooling and income to be more vulnerable to STD⁽²⁰⁾, and the few years of schooling of the interviewed women point to this possibility.

It was recognized that the elevated number of pregnancies, as seen in this investigation, is another risk factor to HPV infection⁽²¹⁾. Hence, the participants of this study have some risk factors that may have contributed to the onset of the

infection and its possible repeated occurrences. Notwithstanding, education in health and/or guidance are indispensable, as they enable the perception of the associated conditions, mainly to risky sexual behavior, which directly influences the adherence to the treatment⁽²²⁾.

The unawareness of the elements that involve HPV, and notably its relationship to cervical cancer, reproduced in the discourse of women in this study, leads to a necessary and indispensable use of resources and the media by health professionals, such as magazines, newspapers, TV broadcasting, internet channels, and other educational technologies, to share the information about this type of STD. Thus, aiming to clarify the doubts regarding HPV infection, contributing to reduce the high levels of this infection, and consequently, reducing the development of cervical cancer among the population.

Another aspect that requires special attention is the mistaken concepts found. Women with HPV need to understand that even with adequate treatment recurrent events may happen, and are frequent, as they are directly related to the immunological response of each individual. Furthermore, some procedures contribute to a better result from the treatment, such as adequate hygiene, association of vitamins to boost immune resistance (vitamins A, C, and complex B), besides sexual abstinence during treatment⁽²³⁾.

It is important to highlight that the treatment does not eliminate HPV, and wearing condoms continues to be significantly important, as there are possibilities to transmit the virus even without lesions appearing⁽¹⁾. Therefore, the main objective of the treatment is the removal of visible warts, and even eliminating clinical lesions, however, it is impossible to totally extinguish the virus in the genital area⁽²²⁾. It is known that there is a long period of latency from the infection

to the development of a lesion, as well as the association with other factors, such as having multiple partners, genetic predisposition, diet habits, smoking, compromised immunological system, socioeconomic level, viral virulence, and the relationship with other sexually transmitted diseases⁽¹⁵⁾. Thereby, it is fundamental that the woman who is the bearer of HPV understands the pathological process of this STD, in order to reduce the transmission of the virus due to lack of information, besides understanding that the recurrent events are a natural characteristic of this type of infection.

In a study performed with 54 pregnant women with HPV, from January 2007 to December 2008 in a hospital located in the state of São Paulo, the aim was to evaluate the understanding of some aspects related to infection by the HPV, and at the same time provide a socio-demographical profile of the sample. It was possible to observe that 66.7% of the interviewees declared they knew the relationship between HPV and cervical cancer⁽²⁴⁾. Thus, HPV represents the main risk factor to developing cervical cancer⁽²⁵⁾.

It is fundamental that women infected by HPV know the risks of developing cervical cancer, increasing the adherence to the treatment and the performance of pap smear exams, which not only has low costs, but also is a determinant to prevent this type of cancer and its early diagnosis, improving the results of the prognostic.

In regard to the perspective of observing the feelings mentioned by the women with HPV, this is related with another research that demonstrated that suffering and despair are feelings strongly mentioned by the population observed, especially due to the lack of support when they are diagnosed with HPV. In this context, it is important to know the feelings of women infected with HPV, with the purpose of penetrating into the field of experiences and emotions that are difficult for them to express,

as they are related to women's sexuality⁽²⁶⁾. In this sense, it is primordial that nursing professionals understand the feelings demonstrated by each woman infected with HPV, in order to provide adequate care based on the reality of each patient, thus providing individualized and efficient care, paying attention to the economic, cultural, and social issues involved.

In addition, the suffering of women with HPV is manifested by the possibility of betrayal from their partners, as the unhappiness seen is not only related to the impact HPV can generate on their health statuses, but also in the repercussions of the virus into the affectionate relationship with the partner, reflected in the feelings of low self-esteem in living with the disease⁽²²⁾.

CONCLUSION

Based on the analysis of the information described here, it was apparent that the participants of this study still presented erroneous and incipient perceptions regarding HPV, which negatively influenced their empowerment to better deal with the situation.

The information related regarding the treatment and a possible cure to the illness shows some gaps in the guidance provided by the professionals that support these women. These professionals also need to observe the feelings of the client towards the diagnosis in a singular intervention, respecting the individuality of each woman, and providing a more humanized and effective care practice.

In regard to the feelings, reactions and procedures reported by the women in dealing with the issue, it was observed that a couple approach is required, in order to support both during the difficulties imposed by the treatment, and possible crises that this situation may generate.

Because it is a medium complexity service, there are some challenges in creating bonds, once the demand for health care comes from the whole city. Efforts in breaking the HPV transmission chain must be strengthened, as it was seen that there is much to be done to achieve the changes required for a safer sexuality.

The research highlights that the specialized service needs a structural and patient care reorganization, thinking about the possibility of a reception service, creation of educative groups, and also the participation of other professionals that can contribute in the follow-up of these women, aiming for a more qualified care service.

The limitations of the research regarding the scenario of this study must be mentioned. The performance of a study in a medium complexity service provider, in which its demand is spontaneous or eventually referred by the FHS, implies a lack of a bond between professionals, the service provided, and the users, which compromises the number of assistances of the institution for HPV cases. However, even from the challenges just presented, this study signals there is a requirement for the development of competencies and abilities of the professionals who work in the specialized health care units, especially the nursing staff that are responsible for the cytological harvest and potential health educators.

It is also necessary to reinforce other research in this field, in order to amplify the debate and the understanding of the scientific community, as well as searching for a care that is not only humanized, but resolute.

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