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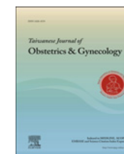

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Original Article

Psychological responses of women infected with cervical human papillomavirus: A qualitative study in Taiwan

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Abstract

Objective: To determine the psychological response of cervical human papillomavirus (HPV) infected women.
Materials and Methods: Twenty oncogenic or high-risk HPV infected cases were collected by purposive sampling, and a 2-hour in-depth interview was carried out with 20 women at a tertiary referring medical center. The interview content was analyzed using the qualitative method. Psychological responses included cognition, emotions, and behavior.
Results: Differences in psychological responses arose more from individual cognition and personality than from whether or not one was single or married. After learning of their infection, most patients searched the Internet for HPV information and for a reputable doctor. They cared about privacy in the outpatient clinic. Most patients had all kinds of negative feelings, principally involving fear, worry, and suspicion. The better a couple's relationship, the less these patients struggled to tell the truth (HPV infection). Patients often urged partners to check-up and advised friends for Pap smear tests.
Conclusions: Most HPV infected women have many kinds of negative feelings. Psychological help for these women is necessary.
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Keywords: Behavior; Cognition; Emotion; Human papillomavirus; Psychological response

Introduction

Research of the psychological aspect of the human papillomavirus (HPV) infected women's sexual trauma suggested that, after diagnosis and during the treatment period, women had lower spontaneous sex interest, frequency of sex, sexual arousal, and fewer orgasms. With discomfort and pain, their negative feelings toward their partner increased [1]. In addition to the adverse changes in sex life, women displayed anxiety and hostility toward sexual intercourse [2]. Regarding the coping aspect, the study by Waller et al [3] emphasized the promotion of a healthy lifestyle and the prevention of HPV infection in terms of biological mechanisms, the immune system, stress coping, and social support.

Many studies focused on the psychosocial impact of HPV-infected patients. The behavioral researchers explored depression, anxiety, and distress resulting from cancer related to the results of the Pap smear tests [4–6]. Some researchers contended that HPV diagnosis would evoke the infected patients' anger, shame, anxiety, or concern about isolation from social intercourse [7]. A recent study pointed out that values for anxiety, worry, and distress of the HPV-infected women were more than those of women with other diseases, with the former group perceiving themselves as having a high risk for cancer [8].

Infection itself has a complicated nature, so it is especially important for the patients to comply with the doctor's treatment. However, distressful emotions and psychological states

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may have something to do with their coping behavior to seek treatment. The study of Linnehan and Groce [9] aimed at the college health environment indicated that clinical psychologists generally regarded the psychosocial issues of the HPV positive cases as the most difficult level of the management aspect because individuals' psychological states were invisible and untouchable. Only when their psychological states were explored in-depth could the patients' physical and psychological health be maintained through counseling and self-help. Accordingly, experts suggested that health education and counseling come before women take Pap smear tests [8].

Therefore, through in-depth interviews, we tried to understand the psychological states of HPV-infected women and their responses in terms of cognition, emotions, and behavior as well as their psychological and treatment needs for the purpose of providing necessary information to assist health bureaus, doctors, and counselors and help the patients to take proper care of themselves.

This study focused on the patient's psychological responses after being informed of HPV infection. Negative emotions were the most common response. Because cognition, emotion, and behavior are the three essential elements of one's personality, it is important to explore the infected patients' emotional responses and how their cognitions affect behavior.

Materials and methods

Research subjects

The purposeful sampling was applied at a gynecologic outpatient clinic of a university-based hospital in Taipei, Taiwan during July–September in 2008.

Twenty consenting adult patients were invited to participate in the study. Of them, 10 were married and 10 unmarried. All were 20–60-year-old patients who had tested for high-risk HPV positive with HPV Hybrid Capture 2.

Research tools

Because this was a qualitative research project [10], the first draft was analyzed and revised based on the reviewed literature and content of the pilot study of three HPV-infected patients before the semistructured questionnaire was written up. A 2-hour in-depth interview on the patients' psychological aspects was then given to the 20 patients. Content included the patients' cognition of HPV infection, physical condition, and their emotional and behavioral responses when and after learning of infection, and the change to daily life schedule.

Interview outlines

1. Demographic information
2. Marital status, including the length of years of marriage-and relationship with partner.
3. Semistructured questions

   What was your first thought when you had learned of your infection?

   How did the doctor inform you about the cause of your infection?

   How did you feel when the doctor told you that the infection resulted from sexual intercourse?

   Describe your negative emotions or positive feelings.

   Have you ever doubted that the infection came from your partner?

   Did you intend to tell him about the infection? If you did, what was his response?

   Were there any changes to your sexual lifestyle?

   Were there any changes to your routine lifestyle?

   How did your partner give you support in this respect?

   How is your current relationship with your partner?

   Do you worry about getting cervical cancer? How worried, on a scale of 0–10?

Material collection and analysis

A general directive interview method was conducted to obtain information. The researchers collected material from the interview results, which was meaningful to exhibit the patients' psychological states and analyzed with the seven-step material analysis method developed by Taylor and Bogdan [11].

The research protocol was approved by institutional review board and informed consent was obtained from every participant at the beginning of the interviews.

Results

Cognition

Among the 20 patients, only 1 woman had known about HPV infection and its channels; 12 did not know anything about it at all, and 7 vaguely knew what HPV was. The channels with which the patients tried to obtain information on HPV were reported in order: (1) browsing the information on the Internet (13 patients); (2) reading books written by the doctor at the outpatient clinic (10 patients); and (3) reading the medical page of the newspapers (3 patients). Accordingly, women in general lacked common sense in understanding the major and minor gynecological diseases and sexually transmitted diseases. Only nine women had had a Pap smear tests during a regular physical check-up. Most did not have the habit of reading medical and pharmacological information. When accessing new information was required, they would turn to the Internet. Websites became the primary sources for medical information.

When being informed of HPV infection, two patients could not accept the news, and 18 reluctantly accepted it. However, all heeded the doctor's instructions and advice without hesitation. Because sexual intercourse had been the main infection route, 12 of 20 patients suspected that the infection came from their partner. Although they had felt suspicion, not everyone confronted their partner. Three patients denied that the infection came from sexual intercourse, instead explaining that it resulted from the use of a hot spring bath, public toilet, or

unsanitary towel. They generally rationalized with one of the following: “having the same life pace,” “impossible to fool around outside,” “husband’s hygiene habit,” or it was not worth suspecting the partner because “even he did, he would not admit” the condition to not damage the existing relationship. The other five patients were not sure whether the infection came from their sex partner because of prior experiences with other short-term sex mates. Knowing that talking to the former partners was futile, they had confront this information alone. It was obvious that women were still confined to the traditional love, sex, and marriage concepts.

Emotions

During the initial confrontation stage, the patients had very complicated feelings. Their common emotions were ranked in order as confusion, anger, fear, worry, suspicion, struggle, sadness, embarrassment, concern, tension, regret, frustration, and depression. Self-directed soul searching and anger is understandable. However, the three emotions, fear, worry, and suspicion, were different for every patient. Some were scared of negatively impacting their relationship or fertility, having an ovarian tumor or cervical cancer, having cancer because of family medical history with little chance of cure; some were fearful about sharing the infection to their partner. Regarding feelings of worry, the patients were concerned about themselves and their partner. They worried about their infected situation, the efficacy of surgery, reinfection posthealing, and so forth. Six patients worried that their partner would be upset, sad, or stressed because he had been the infection source; or they worried that the boyfriend would inquire about the infection’s source. The suspicion resulted from the individual’s different cognition patterns, such as inaccurate check-up results, doubt of early infection when young, suspicion that the infection had resulted from the partner’s extramarital sexual relationships, and the use of hot spring baths or the partner’s use of a public toilet.

Other emotions the patients had felt were shock, denial, resistance, disgust, helplessness, guilt, injustice, paradox, self-blame, and helplessness. For two patients, the first response was: “It was my fault; what else can I do?,” “The other party was mad at me for giving the infection to him,” “I did not protect myself sexually,” and “Why was I so careless and not protect myself?” One patient felt guilty and shamed, saying, “It was not my fault, but I gave it to my boyfriend;” two other patients expressed similar helplessness without support because their boyfriends had decided to end the relationship. One patient expressed her needs to obtain care and support from friends and medical professionals. The emotions of the unmarried patients seem to be stronger than those for married patients.

Impacted by negative emotions, the patients experienced some positive emotions as well, including: strength (“I have to face it”), calm (“after reading books and related information, I started to calm down”), and relaxed about the lack of need for surgery (“do not have to wait for gradual recovery after operation”). Another patient who worried about her own physical condition had sympathy for her husband (“He will feel great stress because he knew he was the source of infection”).

On a 0−10 scale of “worry,” three levels were divided: mild (0−3), medium (4−7), and severe (8−10). All 20 patients were evenly spread along the three levels of worry. Because of the different cognitions of HPV infection, some were not very nervous, “because they did get cancer yet;” others felt very nervous because they were “afraid to have cancer,” “concerned about the safety of the surgery,” or “concerned about infertility.” Besides worrying about themselves, some patients worried about their family’s concern (“I do not want to induce family worry or concern”). This phenomenon was generally linked to the individual’s personality. Some were timid by nature (“I am pretty neurotic, even 0 scares to me”). It is common for the patient to worry about her own illness as well as her family. However, five patients worried about the potentially negative impact to their relationship by infection. The reasons for worry were: potential of a negative response on learning of a sexual infection, his guilt, and his psychological self-defense.

Behavior

In the initial stages of learning of infection, each patient was distressed, struggling whether and how to tell their partner. Only 3 of 20 patients confronted their partner on returning home; another even questioned her husband on the phone at the hospital. Eight patients hesitated for several hours to several days before they informed their husbands. One even waited 18 months to tell her husband. Four patients claimed to have a gynecological disease, not daring to mention HPV. Another two patients had no way to inform their partners because the break-up had occurred long ago previously. The husband and mother of another patient discovered the truth accidentally because the mother had received a phone call from a hospital nurse.

One-half of the patients went alone to the hospital for tests and treatment. Only six were accompanied by their partner. Three were escorted by a friend, colleague, or mother. One husband took his wife to the hospital because he did not want some other man to do it (“but she did not discuss the infection or the wife’s physical situation”).

Although some patients were accompanied by their son and daughter, more commonly was a mother as escort, “indicating a good mother-daughter relationship.” So long as it is not a matter of life and death, women with illness, especially gynecological diseases, must take good care of themselves despite feelings of loneliness and helplessness. In general, both unmarried and married women went to the hospital for check-ups. Most husbands were working and took it for granted that certain conditions, such as gynecological problems, were the domain of women. They did not feel an urgency to accompany their wives, even on request.

Regarding informing their families about the infection, only four chose to communicate with the mother or other family members. Eleven patients mentioned having a “gynecological

disease" to her family, although they did not identify HPV in particular out of shame to speak, worry about misunderstanding, or a desire to protect their family from worry. Because patients felt such shame, most did not communicate with friends; however, eight patients vaguely mentioned having an "infection," shared feelings, and listened for advice. Another four patients only reported of "gynecological" problems, never mentioning HPV.

After the initial stage, the patients began to accept the reality of HPV infection: most of them reflected and discussed their marital life with their partner. In turn, there were arguments and fights between couples. Some partners "denied strongly" the circumstances and some teased "each other for fooling around with other women/men." In general, their reactions could be categorized into three phases.

1. *Interpersonal interactions in daily life*
   The patients would advise friends to urge their husbands to get immune shots and persuade female and young friends to get annual Pap smear teats or not have sexual relationships.

2. *Sexual interactions*
   Patients would urge the boyfriend or husband to have a check-up, secretly examine the lower part of their body, ask partners to wear condoms, lessen sex frequency or stop altogether, and so forth.

3. *Information absorption*
   They bought books and sought the Internet as resources for necessary information.

When reacting to the news in the initial stage, most patients did not have physical symptoms. Only complicated feelings stirred in the heart. Four of them had temporary symptoms, such as sweaty palms, difficulty breathing, sleeping problems, and high blood pressure.

Discussion

Because HPV infection mainly comes from sexual intercourse, individuals, no matter single or married, are vulnerable to infection. Between unmarried and married patients, there are no differences in psychological responses. The differences largely depend on the patient's personality, partner, and identity, and not marital status.

Cognition

Less than one-half of patients discovered the infection through an annual check-up using Pap smear tests; most went to the doctor because of gynecological condition and did not have any preventive concepts in mind. They had only come to the doctor for a diagnosis. With regard to Warren's suggestion, it is true that health education and counseling should come before women take Pap smear tests [8] to inform of prevention or recognition of diseases, such as HPV infection.

Most did not know about HPV infection and its seriousness before obtaining the necessary information from doctors, books, newspapers, and the Internet. Their first response was naturally to suspect partner infidelity, but they were torn between confrontation and silence, with much deliberation. Those who denied their condition believed that the infection came from other possible channels, likely because of female adherence to traditional Chinese concepts of love, sex, and marriage [12]; sex is still a taboo concept within a couple, and a wife's confrontation about infidelity with her husband might threaten the relationship.

Gynecological problems have long been regarded as unspoken diseases, including HPV infections or more serious diseases. However, women, facing the condition, understanding the importance of their health, and assimilating the gathered information, were not confined to local hospitals or nearby clinics, but started to learn about their hospital and doctor choices. They understood the professionalism and privacy of the medical environment and cared much about doctor-patient relationship. Therefore, they were able to make confident decisions about where to go and whom to see [13].

Emotions

When learning about the HPV infection, the patients' negative emotions were commonly more complicated than those found in past studies by Kahn et al [4]: confusion, anger, scare, worry, suspicion, struggle, sadness, embarrassment, concern, tension, regret, anger, and depression, among which, the degree of fear, worry, and suspicion was different. To every human, death represents a threat, especially to patients who perceive themselves as having higher high risk of cancer [8]. The remainder of negative feelings included shock, startle, denial, resistance, disgust, helplessness, guilt, wrongness, paradox, self-blame, and helplessness. The four subsequent positive emotions were strength, calm, relaxation, and sympathy.

On the 0–10 scale of "worry," broken down into three levels, 20 patients were evenly distributed (0–3, 4–7, and 8–10). This has something to do with patient cognition of infection and his or her personality. Accordingly, a few patients had positive emotions—specifically, strength, calm, relaxation, and sympathy. Interestingly, one patient had sympathy for her husband because he had possibly transmitted the virus to her.

In short, single patients had stronger emotional reactions than the married ones.

Behavior

According to Scrivener [14], 67% of the patients reported having informed their partner of the diagnosis; the main reasons included honesty, transparency, desire to prevent transmission, and stress related to preventing disclosure. Some patients were exactly like the nondisclosers. Scrivener mentioned that they felt embarrassed and fearful of negative reaction, and their relationship to their partner was not close enough.

In general, patients tended to disclose HPV infection to partners on diagnosis [15]. However, among the 16 patients who chose to tell their partner, only four said gynecological disease, not HPV infection. Another four who did not inform their partner had a poor relationship or had already broken up with their partner. Thus, it is apparent that the better the couple relationship, the more willing the patient will be to inform their partner of HPV infection. Both disclosers and non-disclosers felt positive about their decision [15] and developed stress coping mechanisms that may not be good for them, as pointed out by Waller et al [3].

During frequent revisits to the clinic, six patients were accompanied or picked up by the partner, one was accompanied by her mother, and the rest attended alone. It was apparent that they lacked familial support because of perceptions that this infection was related to sex, a common taboo in family and society.

Some patients, depending on their personality and cognition of HPV, had three kinds of reactive behavior: interpersonal interactions in daily life, sexual interactions within the couple, and information absorption for the purpose of protection and care for others. Only four patients displayed physical symptoms, such as sweaty palms, insomnia, or high blood pressure, which would disappear after a period of time depending on degree of individual stress.

Suggestions to the doctors, patients, medical institutes, governmental health department, sex educators, and sex counselors were proposed in the hope of assisting HPV patients to enhance their physical and sexual health. For future studies, a well-designed assistance program is thus suggested.

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