

12-2013

# Surveys of Women with HPV and Their Healthcare Experiences.

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# SURVEYS OF WOMEN WITH HPV AND THEIR HEALTHCARE EXPERIENCES

Thesis submitted in partial fulfillment of the College of Nursing Honors-in-Discipline Program

By

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November 15, 2013

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## Abstract

Genital human papillomavirus infection is the most common sexually transmitted virus in the United States, with almost 20 million Americans currently infected and an additional 6.2 million becoming newly infected each year. Women rely strongly on their health care providers to educate and comfort them regarding this distressing diagnosis. This study will use an online, self-completion questionnaire to obtain women's opinions regarding their health care providers' performances concerning the initial consultation after learning of their HPV diagnosis. Findings from this study provided insight as to how women prefer receiving information from their health care providers concerning their diagnosis of HPV. In addition, study findings provide suggestions for improving clinical practices regarding HPV consultations in the Tri-cities area of East Tennessee.

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## Background

Each year millions of women worldwide go to their health care providers and learn they are infected with a sexually transmitted disease. The most prevalent viral diagnosis relates to a relatively new virus called human papillomavirus, commonly referred to as HPV. Genital human papillomavirus infection is the most common sexually transmitted virus in the United States, with almost 20 million Americans currently infected and an additional 6.2 million becoming newly infected each year (Friedman & Sheppard, 2007). HPV is diagnosed through cytological examination as enlarged cervical cells with a clear zone around the nucleus, but most women see it in the form of abnormal Papanicolaou (Pap) smear results.

Discovered in 1976, the Human Papillomavirus is a new addition to the long list of universally accepted sexually transmitted infections. Since its initial discovery, over 100 strands of the small, circular, double-stranded, non-enveloped deoxyribonucleic acid tumor virus have been classified (Gelman, Nikolajski, Schwarz, & Borrero, 2011). The HPV DNA incorporates itself into the target cell genome, activates oncogenes then proceeds to suppress the host cell's immune response. HPV protein products prevent cells from causing programmed cell death, which leads to instability and unchecked cell growth (Fey & Beal, 2004).

Each of the different HPV strands have the capability to cause low-grade cell changes in the cervix, but there are several that are more notable because of their tendency to cause high-grade cell abnormalities. "Low-risk" genotypes can cause benign or low-grade cervical tissue changes and genital warts. There is an international consensus that "high-risk" genotypes, including strands 16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 59, and 66, can eventually lead to cervical cancer and have been associated with other cancers of the head and throat. Of the 100+

HPV genotypes, there have been eight that frequently reoccur the most worldwide: 16, 18, 31, 51, 52, 53, 56, and 58 (Cutts, Franceschi, Castellsague, Sanjose, & Garnett, 2007). In 2006, the U.S. Food and Drug Administration approved a quadrivalent vaccine that protects against strands 16, 18, 6, and 11—the culprits responsible for 70% of cervical cancer and 90% of genital warts. The vaccine has since been recommended by the Advisory Committee on Immunization Practices for use in females aged 9 to 26 years (Friedman & Sheppard, 2007).

Prevalence of HPV, is highest in young, sexually active women 18 to 25 years of age (Fey & Beal, 2004). The human papillomavirus is primarily transmitted by genital skin-to-skin contact, usually but not necessarily during sexual intercourse. Risk of HPV infection is directly linked to the number of sexual partners that a woman has had recently and throughout the span of her life (Cutts, Franceschi, Castellsague, Sanjose, & Garnett, 2007). Those who receive the vaccine before the beginning sexual intercourse have a decreased risk of getting HPV, but are not completely immune to all forms of the virus. Women who do become infected with HPV can have high survival rates with routine tests and appropriate follow-up.

In truth, the human papillomavirus is a relatively new sexually transmitted disease and as such there has been little information published regarding the psychosocial effects of being diagnosed with HPV. It is vital that health care providers spend time educating women about HPV prevention and thoroughly discussing the proposed plan of care following diagnosis. before they get it and thoroughly discussing it with those who have already become infected. It is estimated that as many as 80% of sexually active women will be positive for HPV at some point in their lives and health care providers need to be mindful that a large portion of those women are utterly unaware about what HPV is. (Akyuz, Yilmaz, Yenen, Yavan, & Kilic, 2011) Although health care providers may recognize that generally only one-fifth of all untreated human

papillomavirus-associated lesions will lead to cervical cancer, the women just discovering that they have a sexually transmitted disease will not (Fey & Beal, 2004). Ultimately, even with the all of the precautionary care and treatments available, the biggest factors in preventing any adverse outcomes from HPV are the health care providers caring for those at risk.

## Overview of the Study

Genital human papillomavirus is the most common sexually transmitted virus in the United States with the rates becoming higher and higher each year. Women strongly rely on their health care providers to educate and comfort them regarding this distressing diagnosis. This study will be completed through a series of open-ended online questions, conducted anonymously, to obtain infected women's perceptions of their healthcare provider's performance concerning the initial consultation after receiving the news of their HPV diagnosis. Questions asked in the survey will focus on exposing deficiencies in the health care consultation and inquire as to changes women would have liked regarding their HPV diagnosis. The results of this study will offer insight in to what women would appreciate hearing from their health care providers concerning their diagnosis and therefore possibly improve clinical practices regarding HPV in the Tri-Cities area of East Tennessee.

## Objectives

The objective of this study is to determine, through an online survey, whether women infected with the human papillomavirus are satisfied with their health care consultation subsequent to their initial diagnosis. Questions in the survey focus specifically on obtaining personal accounts from women concerning the first meeting with their health care provider regarding their HPV diagnosis. The information obtained in this study should illuminate how

deeply women's lives are affected by this sexually transmitted infection and also how effectively clinicians are addressing the psychosocial aspect of the diagnosis.

## Hypothesis

Health care providers play a detrimental role in providing and promoting health education to their patients. In addition, health care providers are privy to intimate details of patients' lives, especially when dealing with the sensitive topic of sexually transmitted infections. Health care providers who act as both an educator and a confidant are more likely to have an impact on their patients than those who simply educate. Women diagnosed with HPV whose health care providers gave thorough explanations about the virus and addressed the impact the diagnosis will have on future sexual relationships will be more comfortable with HPV than those whose health care providers did not.

## Literature Review

The literature on the human papillomavirus is rather abundant for a disease discovered less than fifty years ago. The largest dilemma concerning the availability of the literature is, because HPV is a relatively new virus, the information is constantly being updated and older studies are being proven completely incorrect or erroneous. A plethora of articles have been published about the biological structure of HPV and how it affects the cervical cells of those who become infected. The American Family Physician journal has had several articles that contain very thorough explanations of what HPV is and does to the female body. FT Cutts, et al, (2007) published an article in the Bulletin of the World Health Organization about human papillomavirus and the current vaccines approved for its prevention. In the article they discuss the numerous

different strands of HPV and the methods by which the vaccines help protect the human body against them.

Newer studies are now beginning to tackle the issue of public knowledge and perceptions of the human papillomavirus. A study done in 2006 by Allison L. Friedman and Hilda Sheppard focused on obtaining the level of knowledge about HPV and the opinions associated with it. They used 315 participants separated into 35 focus groups to develop a set of thematic results which summarized the overall opinions of each group. Categories of questions ranged from knowledge about epidemiology to STD-associated stigmas regarding HPV. Their study found that most of the participants had heard about STD related genital warts and were able to explain that most STDs are treatable. However, there were large misconceptions that men are affected by genital warts more frequently and that all forms of genital warts are related to herpes. Overall, the study found there was low HPV awareness across all of the groups and in general only one or two people from each group had ever heard of the virus.

A more recent study utilized a couple of outpatient gynecology clinics in Turkey to obtain information about women's overall awareness of the human papillomavirus (Akyuz, Yilmaz, Yenen, Yavan, & Kilic, 2011). Using a multiple-choice questionnaire, the study surveyed a total of 229 Turkish women about their knowledge and attitudes towards the vaccines, tests, and the virus itself. After analysis, this study showed that although most women were aware of HPV, most did not know that it is a sexually transmitted. From this study the authors concluded that even women positive for HPV have insufficient knowledge about the virus and the health risks associated with it.

Catherine Cook, a researcher at the University of Auckland in New Zealand, conducted in-depth research on the psychosocial effects of the human papillomavirus and other sexually transmitted infections. In 2009 she published her doctoral thesis that analyzed a series of interviews she conducted via email in 2007, which were used to gauge the opinions of women diagnosed with HPV and other viral STIs about their clinical experiences. Through her qualitative research she found that although many clinicians are able to de-sexualize gynecological examinations and view the cases as purely “objective,” many patients cannot. She found that women often view clinical consultations regarding sexually transmitted diseases as more taboo than other conditions and thus perceive them as a “moral burden.” The research found that if health care providers followed an objective and routine protocol for their examinations, women would not risk asking anything inappropriate:

“For many women patients, to ask a question that falls outside the parameters of the appropriate knowledge-base already established by the clinician is to risk being constituted as morally questionable, as a ‘risky’ woman rather than a ‘normal’ woman. To ask a question tells the Confessor something about one’s ‘true nature.’” (Cook, *The Pedagogy of the Clinic: Health Professionals and Women with Viral Sexually Transmitted Infections*, 2009, p. 131)

Overall, the thesis concluded that health care providers should initiate questions about the diagnosis and female sexuality with each patient, especially if they have been diagnosed with a sexually transmitted infection.

In her follow up study, Catherine Cook further examined the email interviews she conducted in 2007. Through literary analysis she determined that the majority of medical research

focuses on female anxiety regarding the examination, but rarely does research focus on the influence of the health care providers' practices in adding to the apprehension. During her thematic analysis of the qualitative data she identified that women are more likely to perceive the "normal" gynecological examination differently and become more vulnerable subsequent to learning of their sexually transmitted infection diagnosis. She concluded that when clinicians put an emphasis on "normalizing" somewhat uncomfortable medical procedures they ultimately discourage women from participating in vital follow up testing.

## **Methods**

### **Population and Sample**

To obtain the most authentic results, only female individuals over the age of 18 who have been formally diagnosed with human papillomavirus were included in this study. Women must have had their initial post-diagnosis consultation in the Tri-Cities area of East Tennessee to be included in the qualitative portion of the survey. Recruitment for the study consisted of flyers placed in various locations throughout the Tri-Cities area of East Tennessee such as Health Departments, gynecology offices, public libraries, and campus health centers. An email was also distributed to all students of East Tennessee State University, which contained information and a link to the online survey. Any individual who expressed a desire to participate and meets the inclusion criteria is eligible to participate in the study.

### **Instruments**

The instrument used for this study will be a self-completion questionnaire consisting of two parts. The first part of the survey will include demographic data used for statistical purposes only. These questions will be asked in a closed question format with a predetermined set of responses to choose from. Questions will inquire about gender, age, geographical area, time since

HPV diagnosis, and number of health care providers consulted about the HPV diagnosis. The second portion of the survey will include several questions taken from the study performed in 2009 by Catherine Cook. These questions were deemed as being highly appropriate for use in this study and delivered thorough and in-depth responses from participants in the first study. These questions will be open format questions in which respondents will be able to voice their detailed and factual recollections.

### **Data Collection**

In order to ensure the comfort and confidentiality of the participants, the research study was conducted entirely online. Utilizing SurveyMonkey.com to administer the survey questions ensured that each of the participants were able to remain anonymous, which allowed individuals to speak more freely if they wished to. SurveyMonkey.com creates a secure web link with Secure Sockets Layer encryption. The SSL encryption creates a cryptographic system that secures a connection between a client and a server. By using this website there was absolutely no way to trace information back to a specific server. SurveyMonkey.com reduced the risk of inflicting psychological harm that could have been sustained from feeling pressured or forced into discussing intimate information from face-to-face interviews.

The consent process began as soon as the participant visited the survey URL. The first “question” of the survey served as an electronic consent form. In-depth information about the survey was provided and the participant was asked if they still wished to continue forward with the anonymous online survey. If the participant selected that they did not wish to participate, they were re-directed to a page thanking them for taking the time to read about the study and that they would be asked no further questions. If the participants selected that they were interested in

continuing with the study, they were immediately advanced to the demographic portion of the survey.

Once the participants agreed to participate in the study they were directed through a series of online questions. The first four questions of the survey acted as a demographic, inclusion/exclusion assessment. If the participant was not eligible to answer the qualitative questions, he or she would be re-directed to a conclusion page thanking them for their time. If the participants were eligible, they would proceed to the focused HPV portion of the survey. These questions were both open and close ended; inquiring in to the health care experience they received regarding their HPV diagnosis. If any of the questions made the participant feel uncomfortable they were allowed to omit the question and continue with another question. After they completed the survey they were re-directed to a completion page, which thanked them for their participation and informed them that there were no more questions.

### Data Analysis

Data analysis for this study consisted of both statistical and thematic review of the collected data. Quantitative survey responses were entered into an Excel spreadsheet for grouping purposes. Data was checked for input errors and corrected. IBM Statistical Product and Service Solutions (SPSS) version 20.0 was used to analyze the data after being transferred from the Excel spreadsheet. The qualitative data was analyzed thematically under the standards developed by Braun and Clarke. Under these standards, the information from the study was reviewed in six distinct steps: familiarization with the data collected; generating initial codes; searching for themes; reviewing themes; defining and naming themes; and then the production of the report. Both a qualitative data analysis expert and a women's health specialist reviewed the material to ensure the relevancy and validity of the results. The thematic analysis examined and pinpointed

trends in the data collected; this form of analysis was useful in producing a compilation of topics that needed to be addressed by health care providers.

## Results

### Qualitative Responses

On the survey conclusion date of October 11<sup>th</sup>, 2013, a total of 233 individuals had taken the online survey regarding HPV. To ensure validity of the qualitative responses received, each of the demographic questions doubled as inclusion/exclusion criteria for individuals such as those who were male, had not been diagnosed with the human papillomavirus, or had been diagnosed outside of the Tri-Cities area of East Tennessee. SurveyMonkey was instructed to automatically exclude individuals who did not meet these criterion for the suvery, as well as participants who opted out of answering the demographic questions.

**Table 1. Consent**

#### Women with HPV and your Healthcare Experiences

Do you consent to participate in this study?		
Answer Options	Response Percent	Response Count
Yes	88.0%	205
No	12.0%	28
<b><i>Answered question</i></b>		<b>233</b>
<b><i>Skipped question</i></b>		<b>0</b>
<b><i>Missing</i></b>		<b>0</b>
<b><i>Total</i></b>		<b>233</b>

The initial question in the survey was an electronic consent. Individuals who responded that they did not consent, 28 participants (12%), did not progress through the rest of the survey and were included in the overall “missing” total for Table 2 and the remainder of the results.

**Table 2. Gender**

What is your gender?		
Answer Options	Response Percent	Response Count
Female	91.6%	186
Male	8.4%	17
<b>Answered question</b>		<b>203</b>
<b>Skipped question</b>		<b>2</b>
<b>Missing</b>		<b>28</b>
<b>Total</b>		<b>233</b>

The first actual question of the survey inquired as to the gender of the participant taking the survey. The 17 individuals (8.4%) who answered “Male,” as well as the 2 individuals who skipped the question, were not allowed to progress through the survey and were therefore included in the “missing” total for Table 3 and the remainder of the results.

**Table 3. HPV Diagnosis**

Have you ever been diagnosed with Human Papillomavirus (HPV)?		
Answer Options	Response Percent	Response Count
Yes	35.1%	65
No	64.9%	120
<b>Answered question</b>		<b>185</b>
<b>Skipped question</b>		<b>1</b>
<b>Missing</b>		<b>47</b>
<b>Total</b>		<b>233</b>

Of the females who consented to take the survey, 35.1% (65 participants) had been diagnosed with the human papillomavirus. One individual opted to leave the question blank and was therefore included in the “missing” total, as were the 120 participants without HPV.

**Table 4. Age**

<b>Which category below includes your age?</b>		
<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Count</b>
17 or younger	0.0%	0
18-20	7.7%	5
21-23	20.0%	13
24-26	26.2%	17
27-29	9.2%	6
30-40	29.2%	19
40 or older	7.7%	5
<b>Answered question</b>		<b>65</b>
<b>Skipped question</b>		<b>0</b>
<b>Missing</b>		<b>168</b>
<b>Total</b>		<b>233</b>

Of the 65 individuals diagnosed with HPV, all 65 reported an age. Although women under the age of 18 who are diagnosed with HPV were relevant to this study, they were to be excluded. The 5 females over the age of 40 diagnosed with HPV (7.7% of those who responded) were also excluded from taking the qualitative portion of the survey and were included in the overall “missing” total.

**Table 5. Location of Diagnosis**

<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Count</b>
Bristol, TN	8.5%	5
Bristol, VA	1.7%	1
Elizabethton, TN	1.7%	1
Johnson City, TN	28.8%	17
Kingsport, TN	6.8%	4
Outside of East Tennessee	52.5%	31
<b>Answered question</b>		<b>59</b>
<b>Skipped question</b>		<b>1</b>
<b>Missing</b>		<b>173</b>
<b>Total</b>		<b>233</b>

In the last exclusion eligible question, participants were asked the location of their initial HPV diagnosis. Individuals were given five cities classified as being within the “Tri-Cities” area of East Tennessee and Southeast Virginia. The 31 participants (52.5%) of females diagnosed with HPV outside of East Tennessee were ineligible to take the qualitative portion of the survey.

**Table 6. Healthcare Providers & Impact**

<b>How big an impact have you found doctors and nurses to have on your overall experiences to date living with HPV?</b>		
<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Count</b>
Big impact	4.5%	1
Some impact	36.4%	8
No opinion	27.3%	6
Little impact	18.2%	4
No impact	13.6%	3
<b>Answered question</b>		<b>22</b>
<b>Skipped question</b>		<b>6</b>
<b>Missing</b>		<b>205</b>
<b>Total</b>		<b>233</b>

The very last question of the survey was also a quantitative question, which asked participants how big of an impact they felt their health care providers had on their overall experiences of living with HPV. This question was answered by 22 of the 28 eligible participants, 8 of which (36.4%) stated that their healthcare providers had some impact on their experience.

### **Qualitative Findings**

The qualitative portion of the survey allowed for the participants to voice their thoughts anonymously and truthfully. Participants were asked a series of seven open-ended questions that sought in-depth descriptions of their experiences with healthcare professionals and their feelings

regarding their diagnosis. Several trends appeared throughout the responses that can be categorized by one major theme.

### Unmet Client Needs

Based on the responses provided through the online SurveyMonkey survey, it was apparent that the main theme was ‘unmet client needs.’ Two distinct subthemes also emerged in the process of analyzing data, which are explained in detail later in this section.

**Figure 1. Theme Analysis**

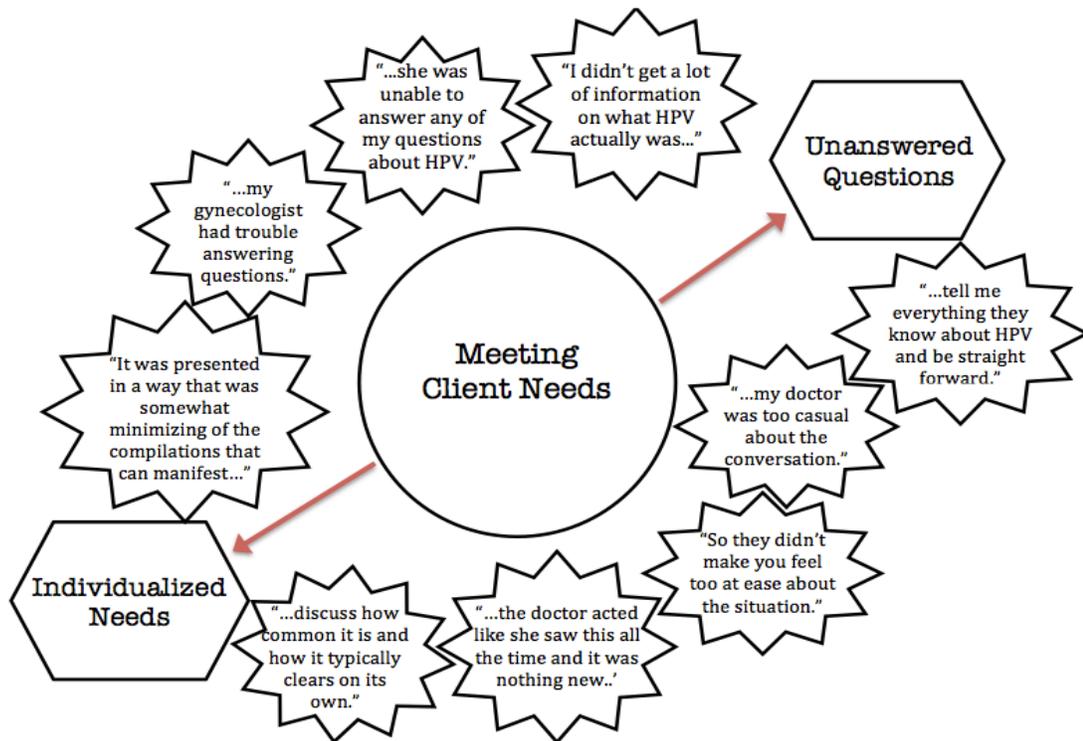


Figure 1 is a visual interpretation of the theme and the two subthemes developed through the responses given for the qualitative portion of the survey. With the major theme being, ‘Meeting Client Needs,’ the quotes show trends in the responses that were provided which link to both of the subthemes, ‘Unanswered Questions’ and ‘Individualized Needs.’

## Unanswered Questions

A number of respondents found that their diagnosis of human papillomavirus left them “nervous,” “frightened,” and “shaken up.” These women most often stated that they were notified of their diagnosis via a letter sent in the mail informing them of their “abnormal” Papanicolaou test results. The women that did receive phone calls from their gynecology office spoke to an uninformed office staff member rather than their actual healthcare provider. One of the individuals stated:

When the office staff member called me she was unable to answer any of my questions about HPV. I was frustrated. I called back to ask more questions, but the staff member was unable to answer anything. I was told to come back in three months. I then called my friend who’s a women’s health nurse practitioner to get information.

Following suit, another participant who had the same experience suggested that only health care professionals make phone calls to patients because the office secretaries add to the stress of the new diagnosis.

I would also encourage health professionals to not have staff members that can’t answer questions call patients with results. I was scared and freaked out by the diagnosis and the person on the phone couldn’t give me any information about what that meant or how it would be treated.

Some of the women who received the letter in the mail attempted to contact their clinician in an attempt to learn more about their diagnosis but felt were poorly treated for doing so.

After getting the letter in the mail I had to get into contact with my gynecologist to learn more about what the lab results meant. She did not call me back for a couple of days and then she was very short with me when I asked questions about it.

The theme of unanswered questions does not end with the initial diagnosis. Women in the survey reported that they still felt uneducated about their diagnosis months after they had received their abnormal results. Some women were even unsure of how exactly they were diagnosed with HPV:

For me, no one had told me about HPV when I was having the pap test done. I still to this day do not know if you can find out if you have HPV through a pap test or if it has to be a specific test for HPV.

In addition to medical questions, most respondents had unanswered questions regarding their sexual relationships. Women in the study were often seeking answers about their relationships that could not be directly answered by laboratory results or a medical consultation. Information pertaining to relationship fidelity and sexuality were identified by many of the participants as topics health care providers should address in the initial consultation. One woman stated:

I think it is difficult to ask questions regarding the length of time I'll have the STD and also about what it means for my current/future sexual partners.

The concern for contamination of others was reiterated throughout the open-ended responses as a topic that needed to be discussed by health care providers in the initial consultation for the new HPV diagnosis. Another participant was worried about what it would mean for her current relationship as well:

It's hard to ask about spreading the disease because once you know you have a responsibility to be careful and tell your partner, which was really hard for me since I had just started dating the man of my dreams.

These responses from the study reiterate that a new diagnosis of human papillomavirus is stressful and can leave the patient extremely worried. In addition, most participants felt that they were not receiving adequate information regarding their diagnosis nor were they receiving any empathy from their health care providers regarding their situation.

### Individualized Needs

The second theme that was apparent from the collected data was the difference of the needs of each woman in the study. The new diagnosis of HPV combined with numerous other life stressors leaves these individuals vulnerable and confused. Women in the study all sought different things from their health care provider and the only commonality between these needs was that none of them were met. In the responses some women stated that they wanted their health care provider to tell them “everything they know about HPV and be straight forward,” whereas others felt that a good majority of the information was irrelevant. One participant stated:

There are way too many scare tactics out there with HPV. I would want a health professional to discuss how common it is and how it typically clears on its own.

Other women also supported the assumption that health care professionals try to use “scare tactics” to coerce women into agreeing to do unnecessary procedures regarding their diagnosis.

The health department makes you think you have cancer when they inform you that you have HPV. I don't think they should scare us into thinking we need unnecessary procedures for mild dysplasia.

Yet other participants were disappointed that they weren't given more education or support regarding their diagnosis. They felt their health care professionals were unfeeling of their situation. One participant was extremely affected by the perceived insensitivity of her health care provider, writing:

I sat there feeling gross and helpless while the doctor seemed not to care. I was crying and she made me feel like complete shit by her attitude. I had so many questions that she did not answer. Granted, I did not ask many questions at the time because I was still shocked to learn I had an STD. I had recently been sexually assaulted by two different guys at a party and was feeling the anger and hurt all over again. While I don't remember if she knew this information, I really needed some emotional support and she seemed overall unfazed by my diagnosis. She had me go ahead and get the Gardasil shots and prescribed me a cream to get rid of the warts.

Although this situation was not the norm for most of the participants, other women were also affected by the perceived lack of empathy given by their health care providers. One participant was so deeply affected by the attitude of her healthcare provider she chose to go to someone else:

My first experience was very different than anything else in that I felt so lost and confused while the doctor acted like she saw this all the time and it was nothing new to her. She was so cold about the whole thing; I immediately switched to a different doctor.

Another participant was upset because, although she knew that her healthcare provider frequently saw HPV patients, she felt the conversation was not what she needed it to be. She stated,

I felt that my doctor was too casual about the conversation, perhaps because of his experience in seeing these infections clear on their own.

When asked about what ‘prescription’ participants would give health professionals about an ideal consultation process in relation to a new human papilloma diagnosis one participant wrote,

I think you have to be compassionate. Just because this is an STD that most people have (men just don’t know it) doesn’t change how it makes you feel. Plus they may not know each woman’s circumstances.

The majority of participants in this study believed that their health care providers were uninformed of their needs and thus were unable to connect with them emotionally. A few participants thought highly of their health care providers because they were “comforting” and treated them “with great professionalism and respect.”

## Discussion

Although there were several positive comments about the experience of the initial human papillomavirus consultation, for the most part these responses illuminate that there is a large psychosocial component of the consultation that is being neglected by women’s health providers. Due to the sensitive nature of the topic, women often felt as if they were completely alone in coping with their new diagnosis and their healthcare providers completely avoided the opportunity to act as a confidant. Most often these women were dealing with numerous issues separate from the diagnosis, which added to the stress of learning they had a sexually transmitted disease. Some women were frustrated, even angry, with their healthcare providers for not being more thorough with explanations and acting nonchalant about the effect this would have on their wellbeing.

In general, this study is rather unlike the majority of most literature available at this point in time. Whereas other studies sought to learn more about the overall knowledge and perception

of the human papillomavirus, very few have tackled the psychosocial component of the virus. The 2009 study done by Catherine Cook titled, "The Pedagogy of the Clinic: Health Professionals and Women with Viral Sexually Transmitted Infections," focused mainly on genital herpes but sought the same type of information. She found that although clinicians most commonly adopt a "nonjudgemental, sex positive approach" to the consultation, women felt unable to seek additional help. Her conclusion is similar to the interpretations made in this study regarding the unmet client needs. Women feel that by having a clinician use the minimalistic method when addressing the human papillomavirus they are not getting all the answers they need concerning the diagnosis nor are they receiving adequate emotional support.

### **Implications for Nursing Practice**

Nurses working with women newly diagnosed with the human papillomavirus should be thoroughly educated on the topic and its progression. Based on the findings in this study, most of the women who were frustrated with their clinical experiences were disappointed by their inability to learn more about their diagnosis. Health care providers should experiment with addressing both the medical 'normalcy' of the human papillomavirus while also discussing the potential for these infections to disrupt women's personal, sexual and social relationships. The current practice of discrediting the stigma of HPV on scientific grounds does not translate smoothly for women or transform their view.

Also based on the responses in this study, it seems appropriate for health care providers to initiate questions about the effects of the diagnosis upon women's lives, especially addressing the impact upon both current and future sexual relationships. These questions indicate to the patient that the healthcare provider is okay with talking about HPV and open to all sexual habits. This

recommendation does not mean that health care providers need to become ‘sex therapists.’ It would be acceptable to ask simple questions, such as, “have there been any changes within your sexual relationships since you’ve been diagnosed with HPV?” which may then guide clinicians in the incorporate of medical ‘facts’ where they specifically relate to each individual’s circumstances.

It would also be helpful for healthcare providers to offer materials regarding the human papillomavirus prior to the initial consultation. The women in the study most frequently learned of their diagnosis via a letter in the mail, which was then followed by a call from a receptionist or office nurse who was unable to answer any case specific questions. While it would be preferable for the diagnosing provider to individually call each of his or her clients newly diagnosed with HPV, this is highly unrealistic due to the volume of work healthcare providers are assigned. Instead, it may be helpful to mail several informational brochures or a list of websites in which the individual can independently learn about her or his diagnosis. It is useful for healthcare providers to demonstrate knowledge of internet resources and to recommend specific websites. Women will use the internet regardless of what they are told via the phone or a consultation, so showing an awareness will more likely enable women to disclose internet use to clinicians.

## **Limitations**

There are a number of limitations present in this study, which may provide direction for future research studies. It may have been useful for the purposes of this study to interview healthcare providers in addition to the individuals diagnosed with HPV in order to receive a more balanced perspective on the initial consultation. It would have also been relevant to have used a different form of communication to receive the responses, because although the internet can allow

for more open communication it would have been theoretically better to perform interviews via email.

The largest limitation of this study is that it is not necessarily generalizable to other areas outside of East Tennessee and Southeast Virginia. Due to the exclusion of those diagnosed outside of this area the results are only applicable to healthcare providers in this area. A larger study that examines a wider variety of ethnic, religious, and cultural backgrounds would be beneficial in confirming or disproving the results found through this study.

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## Survey Questions

1. Gender
  - a. Female
  - b. Male
2. Have you ever been diagnosed with Human Papillomavirus (HPV)?
  - a. Yes
  - b. No
3. Which category below includes your age?
  - a. 18 – 20
  - b. 21 – 23
  - c. 24 – 26
  - d. 27 – 29
  - e. 30 – 40
  - f. 40 or older
4. In what area were you living when you learned of your HPV diagnosis?
  - a. Bristol, TN
  - b. Bristol, VA
  - c. Elizabethton, TN
  - d. Johnson City, TN
  - e. Kingsport, TN
  - f. Outside of East Tennessee
5. Can you tell me about when and how you came to find out about your HPV diagnosis?
6. What do you recall about the initial process of consulting a health professional about your diagnosis of HPV?
7. How similar or different was the HPV consultation process compared to experiences consulting health professionals about other conditions?
8. What questions, if any, are difficult to ask health professionals about HPV? Why?

9. Are there any topics you would find helpful for a health professional to initiate in a conversation related to HPV that would make you more comfortable?
10. Based on your experiences, what is the 'prescription' you would like to give health professionals about an ideal consultation process in relation to women with HPV? What would you want for them to change about the whole process?
11. Have health professionals ever initiated a conversation with you about the possible effects of living with HPV (both the physical and emotional impact) on sexual relationships?
12. How big an impact have you found doctors and nurses to have on your overall experiences to date living with HPV?
  - a. Big Impact
  - b. Some Impact
  - c. No opinion
  - d. Little Impact
  - e. No Impact



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**IRB APPROVAL – Initial Exempt**

April 18, 2013

Danielle Defayette

RE: Surveys of Women with HPV and their Healthcare Experiences  
IRB#: 0313.22s  
ORSPA#: ,

On **April 18, 2013**, an exempt approval was granted in accordance with 45 CFR 46.101(b)(2). It is understood this project will be conducted in full accordance with all applicable sections of the IRB Policies. No continuing review is required. The exempt approval will be reported to the convened board on the next agenda.

- New Protocol Submission form, Bibliography, CV, Women's Participant Information Sheet, Flyer, Questionnaire

**Projects involving Mountain States Health Alliance must also be approved by MSHA following IRB approval prior to initiating the study.**

Unanticipated Problems Involving Risks to Subjects or Others must be reported to the IRB (and VA R&D if applicable) within 10 working days.

Proposed changes in approved research cannot be initiated without IRB review and approval. The only exception to this rule is that a change can be made prior to IRB approval when necessary to eliminate apparent immediate hazards to the research subjects [21 CFR 56.108 (a)(4)]. In such a case, the IRB must be promptly informed of the change following its implementation (within 10 working days) on Form 109 ([www.etsu.edu/irb](http://www.etsu.edu/irb)). The IRB will review the change to determine that it is consistent with ensuring the subject's continued welfare.

Sincerely,  
George Youngberg, M.D., Chair  
ETSU/VA Medical IRB



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**IRB APPROVAL – Minor Modification**

August 22, 2013

Danielle Defayette

RE: Surveys of Women with HPV and their Healthcare Experiences  
IRB #: 0313.22s

On 08/22/2013, a final approval was granted for the minor modification listed below. The minor modification will be reported to the convened board on the next agenda.

- Modification request to use East Tennessee State University's Office of the Provost to send out an "all-student" email to all students

Unanticipated Problems Involving Risks to Subjects or Others must be reported to the IRB (and VA R&D if applicable) within 10 working days.

Proposed changes in approved research cannot be initiated without IRB review and approval. The only exception to this rule is that a change can be made prior to IRB approval when necessary to eliminate apparent immediate hazards to the research subjects [21 CFR 56.108 (a)(4)]. In such a case, the IRB must be promptly informed of the change following its implementation (within 10 working days) on Form 109 ([www.etsu.edu/irb](http://www.etsu.edu/irb)). The IRB will review the change to determine that it is consistent with ensuring the subject's continued welfare.

Sincerely,  
George Youngberg, M.D., Chair  
ETSU/VA Medical IRB



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