Published in final edited form as:

Appl Nurs Res. 2016 May ; 30: 137–141. doi:10.1016/j.apnr.2015.08.003.

“I Have Human Papillomavirus”: An Analysis of Illness Narratives from the *Experience Project*

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Abstract

Purpose—Human papillomavirus (HPV) is the most common sexually transmitted virus worldwide. Our purpose was to examine people's experiences with HPV using narratives posted on a website entitled, *Experience Project*.

Method—We conducted a content analysis of 127 HPV narratives to identify stigma, emotion-focused and problem-focused coping, and misinformation.

Results—Negative self-image was the most commonly identified type of stigma. There were more instances of problem-focused than emotion-focused coping. Sources of confusion were mostly about HPV treatment and side effects/symptoms.

Conclusions—These findings have implications for how nurses and other health professionals can care for individuals living with HPV. Based on these findings, it would be beneficial for clinics/providers to implement on-line forums where myths about HPV can be debunked and accurate information provided. Both patients and the public need to be better informed about HPV, in order to decrease the negative stigma that can create a mental burden for individuals with HPV.

Keywords

sexual health; stigma; coping and adaptation; illness and disease; experiences

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The authors have no conflicts of interest.

Human papillomavirus (HPV) is the most common sexually transmitted virus worldwide. Correct and consistent condom use can reduce transmission; however, the virus can be spread through skin-to-skin genital contact with infected areas not covered by a condom. Most HPV infections will resolve on their own, but for some the virus can persist to abnormal cell growth. Low-risk HPV types cause genital warts and high-risk types can cause cervical, oropharynx, and anogenital cancers [Centers for Disease Control and Prevention (CDC), 2013]. Although HPV can cause serious health problems, most infections are symptom-free; therefore, most individuals are unaware that they are infected [CDC, 2013], and can unwittingly transmit HPV to sexual partners.

Despite high HPV prevalence and enormous research progress, misinformation among the public remains, especially about HPV prevalence, transmission, and its association with genital warts and certain cancers [Gerend & Magloire, 2008; Marlow, Wardle, & Waller, 2009; Sandfort & Pleasant, 2009; Tiro, Meissner, Kobrin, & Chollette, 2007; Waller et al., 2003]. Limited HPV knowledge is a public health concern, because limited HPV knowledge might carry over to misinformation about HPV-related cancers, which is often associated with low participation in preventive health behaviors [Ackerson & Preston, 2009; Paskett et al., 2004; United States Government Accountability Office, 2009]. Moreover, people with limited knowledge may be more likely to feel stigmatized by others upon being diagnosed with HPV. For example, in one study researchers found that individuals with low HPV knowledge were more likely to report that they would feel shame if they were diagnosed with HPV than individuals with better HPV knowledge [Gerend & Magloire, 2008].

Sexually transmitted infections (STI) are often accompanied with a host of negative psychological factors including stigma, shame, and anxiety. Stigma is defined as a mark linking a person to negative stereotypes, rendering the person worthy of disrespectful treatment by others [Jones et al., 1984]. People with STIs have been associated with negative stereotypes such as promiscuity, infidelity and amorality [Gilmore & Somerville, 1994; Weiner, 1993]. Perceived and/or experienced stigma can increase the psychological burden on those who test positive for HPV, which can affect the mental and physical outcomes of the disease. Researchers have begun to explore the relationship of HPV to cervical cancer and stigma [e.g., Dyer, 2010; Maissi et al., 2004; McCaffery, Waller, Nazroo, & Wardle, 2006]. The findings suggest that positive HPV test results pose additional psychological burden beyond the impact of abnormal Pap smear test results [Daley et al., 2010; Maissi et al., 2004; McCaffery et al., 2006]. For example, in one study, the majority of HPV positive women reported feelings of stigma, anxiety, worry, shame, self-blame, powerlessness, and anger about their diagnosis [Daley et al., 2010]. But to date, no known researchers have specifically addressed how individuals perceive HPV stigma and/or how they cope with their diagnosis. Thus, a greater understanding of HPV-related stigma, as well as how individuals cope with HPV is needed in order to improve quality of life, and potentially, health outcomes. This is especially important given that women aged 30 and over are beginning to be tested for HPV more routinely [United States Preventive Services Taskforce, 2012], which means more women are becoming aware that they have HPV, and coping with that information may be difficult.

The HPV literature is lacking a discussion of the types and usefulness of coping strategies that HPV positive individuals engage in. Coping is defined as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” [Lazarus & Folkman, 1984]. Coping can be conceptualized as either problem-focused or emotion-focused. Problem-focused responses are attempts to change or decrease the stressor (e.g., seeking out information to help solve the problem), while emotion-focused responses are attempts to change one's emotional response to the stressor (e.g., venting, suppressing thoughts) [Carver, Scheier, & Weintraub, 1989]. Problem-focused responses are most useful when the stressor has the potential to be reduced/eliminated, whereas emotion-focused responses are most useful when the stressor cannot be reduced/eliminated [Lazarus & Folkman, 1984]. Due to the complexity of an HPV diagnosis, it is possible that both problem-focused and emotion-focused strategies would be useful. For example, one problem-focused coping strategy that may be helpful for individuals with HPV is to seek reliable information about HPV, which could help them seek the treatment they may need to prevent HPV from developing into cancer. On the other hand, an emotion-focused strategy that may be helpful for individuals with HPV is suppressing the negative thoughts one may have about being diagnosed with HPV, particularly if those thoughts are interfering with one's psychological well-being. Some other emotion-focused coping strategies (e.g., denial), however, may negatively affect health outcomes by making people less likely to disclose and engage in transmission prevention behaviors. Thus, furthering the public health impact. One purpose of this study was to identify the nature of coping strategies used by HPV positive individuals. Understanding coping strategies can help inform healthcare providers and interventions aimed at improving quality of life.

When individuals receive a medical diagnosis, many search for information related to that diagnosis on-line. In fact, in a 2010 Pew Survey 79% of surveyed adults reported using the Internet, and 80% of users search for health information on the Internet [Fox, 2011]. In a qualitative study of women with HPV, more women reported relying on the Internet than on a health professional for HPV-related information [Kosenko, Harvey-Knowles, & Hurley, 2014]. Not only can individuals seek health information online, but they now have the opportunity to share their health-related stories and experiences through various blog forums. A recent study found that anonymous blogs may actually facilitate self-disclosure among individuals with stigmatized illnesses [Raines, 2014]. Although they were not created for such use, these public online spaces provide researchers with unique ways to explore people's honest experiences free from researchers' demand characteristics. As a result, researchers are beginning to use qualitative analysis of blogs as a methodology to understand the impact of health on individuals and attitudes about health behaviors [e.g., Keelan, Pavri, Balakrishnan, & Wilson, 2010; Keim-Malpass, Steeves, & Kennedy, 2014; Marcus, Westra, Eastwood, & Barnes, 2014].

The purpose of this study was to conduct a phenomenological study to understand people's lived experiences with HPV by analyzing unsolicited narratives posted on a public website entitled, *Experience Project*. Specifically, we sought to gain a better understanding of the types of stigma individuals experience, coping strategies, and sources of misinformation about HPV. We expect these narratives to give us a candid perspective of how people

experience and cope with HPV, which can help healthcare providers and researchers address the mental burden associated with the diagnosis.

1. Method

The *Experience Project* (<http://www.experienceproject.com/>) is a free website that connects individuals who have shared similar life experiences. The site provides an interactive network of personal stories, confessions, blogs, and groups. One can browse topics or search for key words that will produce personal narratives that individuals can identify with by clicking “me too”. New stories can be created if a topic has not been addressed. All experiences start with “I” statements. Examples include, “I live in a sexless marriage,” or “I have HPV.” The site is anonymous to promote conversations unhindered by fear of recognition or embarrassment. In the *Experience Project* “Terms and Conditions”, users are notified that anything they post publicly can and may be used by the public including *Experience Project* non-members.

In the present study we analyzed blog posts belonging to the experience “I have HPV.” The posts were obtained in April, 2013. At that time there were 155 posts. We eliminated posts that were advertisements or SPAM. In addition, for screen names that had multiple blog posts, we analyzed the first post of that individual. This was to avoid having the data over-represent one individual's experiences. The final sample consisted of 127 blog posts which were analyzed according to principles of content analysis [Coffey & Atkinson, 1996; Hsieh & Shannon, 2005]. A directed approach was used in our analysis of coping and stigma. Content themes regarding stigma and coping (explained below) were driven by well-known psychological theories including problem and emotion-focused coping and stigma [Berger, Ferrans, & Lashley, 2001; Carver et al., 1989]. In addition, we coded for instances of confusion/HPV misinformation using a conventional approach whereby coded categories were derived directly from the text data. Finally, the summative approach was also used in that we counted the frequencies of each code and report those in our results section. Data analyses were conducted by two trained research assistants in order to strengthen the validity and reliability of the results. The research assistants read each narrative line-by-line and kept a log of frequencies for each theme. Throughout the coding process discrepancies in coding were discussed and resolved between the two coders to enhance validity and reliability. The principal investigator, who has extensive qualitative and HPV research experience, reviewed and supervised this process. This study was approved by the Institutional Review Board at the first author's institution (institution name removed to maintain blinded review process).

Stigma

We used Berger and colleagues' factors from their HIV Stigma Scale (personalized stigma, disclosure concerns, negative self-image, concerns with public attitudes) as a framework, and applied them to HPV [Berger et al., 2001]. Personalized stigma is defined as “personal experiences or fears of rejection”; an example is, “I have been hurt by how people reacted to learning I have HPV” [Berger et al., 2001]. Disclosure concerns are “controlling information, keeping one's status secret, or worrying that others who knew one's status would tell”; an example is, “I am very careful who I tell” [Berger et al., 2001]. The third

type of stigma, negative self-image, is feelings such as shame, guilt, feeling unclean; an example is, “Having [HPV] makes me feel unclean” [Berger et al., 2001]. Finally, examples of concerns about public attitudes are, “Most people believe a person with [HPV] is disgusting”, and “Most people believe a person who has [HPV] is dirty” [Berger et al., 2001].

Coping

In order to assess problem-focused and emotion-focused coping, we used Carver and colleagues' definitions that were discussed previously [Carver et al., 1989]. Examples of problem-focused coping include problem solving, planning, and seeking information about the stressor. Examples of emotion-focused coping include seeking emotional support, denial, and cognitive restructuring [Carver et al., 1989]. Research assistants were educated about the different dimensions of stigma and coping using these frameworks.

Misinformation

Finally, misinformation, or confusion about HPV, including incorrect statements about transmission, treatment, and side effects were also coded and categorized. Research assistants were thoroughly educated about HPV in order to identify instances of misinformation.

2. Results

Stigma

We identified 148 instances of stigma among the 127 blogs. The most common type of stigma was negative self-image ($n = 65$). For example, one individual wrote, “I really feel disgusted of myself. I really hate myself and I can't stop crying. I feel so dirty and lost.” Another wrote, “The stigma of having this ‘thing’ is mind blowing...somehow it makes me think I was ‘dirty’.” The next most common was personalized stigma ($n = 39$). One example was, “I just don't think a lot of people would understand my situation and might think I'm a horrible person [because] I have made some bad choices.” Another wrote, “Its all pretty upsetting, and isolating...trying to look on the brighter side of things but its hard when you feel so alone.” There were 33 instances of disclosure concerns. For example, an individual wrote about wanting to limit the people who knew about their diagnosis, “Only two of my family members know and my boyfriend and I plan on keeping it that way.” Another individual wrote about the fear of disclosure, “What about when I tell a guy I want to be with that I have HPV? Will he run away as if I'm some dirty girl that sleeps around, which I'm anything but?” Finally, there were 11 instances that represented the stigma of concerns about public. Examples included, “And people will make you feel dirty. Every STD joke now has your name in the punch line.”; and “If they really knew that I had HPV they probably wouldn't see me as beautiful anymore.”

Coping

With regard to coping, we identified more instances of problem-focused coping ($n = 123$) than emotion-focused coping ($n = 106$). Some individuals were actually using the *Experience Project* site as a coping mechanism in both problem-focused and emotion-

focused ways. For example, one person wrote, “So I’m just looking for advice/support about having HPV and about what a colposcopy is like and all that.” (informational support - problem-focused). While another wrote, “It helps having a community like this to come to, to vent and share thoughts and feelings.” (emotional support – emotion-focused). Additional examples of problem-focused coping included, “Now I have an appointment to discuss my situation with my doctor.”; and “My [gynecologist] has referred me to a specialist in HPV whom I see next week. I’ll feel better in an expert’s hands.” Other examples of emotion-focused coping included, “I am praying for it to go away on its own.”; and “I blamed myself for this and fell into a deep depression.”

HPV Misinformation

There were 47 examples of HPV misinformation. Most were in regards to treatment (n = 18). Many individuals were confused about whether HPV resolves on its own without treatment or whether it was curable (e.g., “First of all, does HPV stay with you the rest of your life? Some sites say it does, others say it clears up naturally?”). Another source of misinformation concerned side effects/symptoms (n = 15). Individuals did not always know whether HPV causes genital warts or which types of HPV cause which types of cancers. There were 10 instances of misinformation about transmission. One individual wrote, “How did I get it? Is it sexually transmitted? If its just a virus, & I don’t have cancer, then what’s the big deal? Can I give this to a guy & can he give it to another girl without having ANY affects himself at all??? Is there something my boyfriend should take? Does he have it now?” A couple other sources of misinformation were concerning the HPV vaccine (n = 2) and just not having any knowledge of HPV (n = 2).

3. Discussion

Our analysis of unsolicited, HPV narratives revealed that individuals with HPV experience stigma, turn to the Internet for support, use both emotion- and problem-focused coping strategies, and are confused/misinformed about many aspects of HPV. The most commonly identified type of stigma was negative self-image, followed by personalized stigma, and concerns about disclosure. This is important because previous researchers have found perceived stigma to be associated with maladaptive coping and poorer psychological adjustment among individuals living with another sexually transmitted virus (herpes) [Barnack-Tavlaris, Reddy, & Ports, 2011].

Individuals in the present study were using the *Experience Project* as a source of support for problem-focused (e.g., seeking information/advice) and emotion-focused (e.g., venting) purposes. In addition, individuals expressed other problem-focused and emotion-focused ways in which they were coping - more of those coping strategies were of the problem-focused nature. What is concerning is the extent to which individuals with HPV are confused or misinformed. As blog members share their information with each other, it is possible that they could become even more confused or misinformed. Misinformation can be a source of uncertainty for individuals with HPV, which can impact coping, disclosure, and thus psychological adjustment [Kosenko, Hurley, & Harvey, 2012]. These findings demonstrate a need for people diagnosed with HPV to be given more accurate and thorough

information in a way that is understandable. Moreover, having individuals with HPV not know the potential effects or how HPV is transmitted is a public health issue.

The findings of the present study support the previous literature. In a qualitative study conducted from 2001-2003, women with HPV expressed negative feelings such as guilt, blame, and disclosure concerns [McCaffery et al., 2006]. Furthermore, Kahn and colleagues found the majority of HPV positive women in their study had disclosure concerns and were reluctant to disclose to people other than sexual partners [Kahn et al., 2005]. It is discouraging that the blogs written on *Experience Project* revealed the same feelings and concerns as previous literature, despite the advances in HPV awareness and prevention that have happened over the past decade.

Our findings contribute to the extant literature and have many practical implications. To begin, nurses and other health professionals are in a position to help individuals find healthy ways to cope with HPV and the negative feelings individuals may experience. This is important because those who experience stress or are unable to manage stress are most vulnerable to the persistence of types of HPV, which can result in cancer [Coker, Bond, Madeleine, Luchok, & Pirisi, 2003]. The present findings contribute to the literature by examining the types of coping individuals with HPV are utilizing. Few studies have assessed specific coping skills among those with HPV. In a study with HIV+ women with HPV, emotion-focused (avoidant) coping predicted non-adherence to clinic visits, which is problematic given the importance of follow-up care after an abnormal cervical cancer screening result [Pereira et al., 2004]. In the present study, we found several instances of problem-focused coping, which can help alleviate an individual's stress if the stressor can in fact be decreased or resolved. However, problem-focused coping strategies that include information seeking via the Internet could actually exacerbate distress and uncertainty [Kosenko et al., 2014]. Future researchers should investigate whether or not the use of certain problem-focused coping strategies actually reduce psychosocial burden among individuals with HPV.

Among the strengths of this study are analyzing unsolicited HPV-related experiences and expanding our knowledge about some of the ways in which individuals cope with HPV. In addition, analyzing previously written illness narratives reduces participant burden and recall bias [Keim-Malpass et al., 2014]. Although this study is unique, it is not without limitations. The narratives are anonymous, which could improve the honesty of the illness experience that is divulged; however, we must also consider the authenticity of the blogs. While Hookway has made a case that it does not matter if the blogger always tells the truth, we felt it important to search for elements of truth and authenticity [Hookway, 2008]. Based on the authors' expert knowledge in the field, we have confidence that the blogs were credible reflections of lived experiences. In addition, because of the anonymity of the blogs, we were not able to analyze any sociodemographic factors that could be associated with these experiences [Keim-Malpass et al., 2014]. It would have been useful to examine gender differences because past researchers have found men to have lower levels of knowledge/awareness and perceive greater HPV-related stigma than women [Gerend & Magloire, 2008; Sandfort & Pleasant, 2009]. Age and socioeconomic differences in how people cope with HPV and the extent to which they turn to Internet sources to share their experiences should

also be examined in future studies. Furthermore, it is possible that individuals with HPV who share their experiences on the Internet are significantly different than those who do not. Perhaps this sample is having a more difficult time coping with or adjusting to the diagnosis than individuals with HPV who do not share their experiences online. There is limited policing of available information regarding HPV on the internet, and it is possible that the narratives in this study reflect post-dated information, which may contribute to the finding supporting limited knowledge. Exploring effective ways to learn about the experiences of those not seeking Internet support would be valuable. It would also be useful to examine the experiences of those who read the blogs for support and information but do not take to posting themselves.

4. Implications and Conclusions

Our findings have several practical implications. Given that the Internet provides a source of support for many individuals with HPV, it would be beneficial for nurses and/or other health providers to implement on-line forums where myths can be debunked and accurate information provided. What is needed is more than just an informational website, but rather an interactive online community where health professionals respond to individuals' questions and concerns. Individuals can gain emotional support from each other, but the informational support should come from a trained professional who has current and correct information about HPV.

Individuals can be informed of their HPV diagnosis in a variety of ways (e.g., phone, face-to-face, e-mail). Harvey-Knowles and Kosenko (2012) found that when HPV positive women received their diagnosis over the phone, sometimes they were in situations where they could not ask the provider questions because of privacy concerns. In these circumstances, women were more likely to seek more information about their diagnosis on the Internet [Harvey-Knowles & Kosenko, 2012]. If timely and accurate forums were available nurses and/or other health care providers could direct patients to these forums for reliable information and ways to have their questions answered privately.

Our findings support that despite the common occurrence of HPV infection, stigma remains a significant component of living with an HPV diagnosis. It would be useful for health care providers to be made more aware of the mental burden that results from an HPV diagnosis. Waller and colleagues found that when women were informed that HPV was sexually transmitted and then asked to imagine having been diagnosed, they experienced more stigma and shame than women who were informed that HPV has a high prevalence [Waller et al., 2003]. Perhaps when people are informed of their HPV diagnosis, they are not made aware of its high prevalence rates, which would help normalize the experience. Some of the stigma may also come from the vast amount of misinformation that the public has about HPV and the problems that may result from it. This suggests that not only do those diagnosed with HPV need to be better informed, but so does the general public.

By studying unsolicited, HPV narratives, we have gained a unique understanding of HPV-related stigma, coping strategies, and the substantial misinformation people have about HPV. No studies to date have examined experiences with HPV via blog analysis. These narratives

have provided us with a fresh and candid perspective and have implications for how health professionals can care for individuals with HPV.

Acknowledgments

This research was supported by Award Number R25CA093423 from the National Cancer Institute. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National cancer Institute or the National Institutes of Health.

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