



“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.

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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

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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, & Mobilizing Minds Research Group, 2012).

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. Methods

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/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).

1.1. 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,

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