

The internet's role in HPV vaccine education

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The internet is the second most popular source, after healthcare providers, of information regarding human papillomavirus (HPV). These online searches usually begin with the user entering generic terms in the search engine, and then reading the first few results that the engine returns. Unfortunately, research shows that much of this information obtained about the HPV vaccine is inaccurate and incomplete. In this review, we summarize the literature pertaining to online information concerning the HPV vaccine and review concerns related to obtaining online medical information. Finally, we propose possible solutions medical providers can employ in their everyday practice to help their patients obtain accurate information through their online searches.

Introduction

As many as 86% of adults in North America use the internet to access medical information, making it the third most frequent online activity.^{1,2} The quality of this information varies drastically, raising concerns when the information is used by individuals to make medical decisions.^{3,4} Internet information regarding the human papilloma virus (HPV) vaccine is no exception. In this article, we review the current use of the internet and information available through this forum with regards to the HPV vaccine. We then analyze the potential concerns regarding this mode of information exchange and propose measures that may improve the quality of information available to the public.

Teenagers and the Internet

Up to half of US teenagers use the internet to obtain health information.^{5,6} Having grown up in the digital age, adolescents are able to surf the internet with ease. More importantly, teenagers are able to access medical information anonymously, allowing them to research topics that would otherwise be embarrassing to discuss in person. For example, teenagers often use the internet to obtain information on topics such as depression, eating disorders, sexual health, and sexually transmitted diseases. This was demonstrated by Harvey et al. who found that many of the medical questions teenagers posed to the physician-operated website Teenage Health Freak were related to sexual health.⁷ Even teenagers with lower socioeconomic background seek online health information which may be due to parents with lower education asking their children to search for health information for the entire family.⁸ Unfortunately, this reliance on teenagers to search for health information poses serious issues with regards to the quality of the information obtained and the interpretation of the data retrieved.^{7,9}

Parents and the Internet

Parents of higher education, frequently use the internet to research their children's health problems.¹⁰ In their study of 998 parents who accompanied their child to a primary care doctor's visit, Moseley et al. found that almost all (96%) had used the internet to obtain information on their child's health prior to the clinic

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visit. Parents with graduate-level education were more likely to follow internet-provided health advice, which may be the result of parents with greater education feeling more comfortable with interpreting complex medical information.

With regards to parental use of the internet to search information on the HPV vaccine, 21% of the 773 parents surveyed in the Carolina HPV Immunization Measurement and Evaluation (CHIME) study reported that the internet was a source of information.¹⁰ Internet use was associated with greater knowledge about HPV, the perception that daughters would get HPV if not vaccinated, and less fear of risks associated with vaccination. In contrast, parents who obtained information online regarding HPV vaccination for their sons (17%) were more likely to perceive barriers to vaccinating boys. The authors of this research proposed that the lack of information on vaccinating males may be the cause of the perceived barriers to vaccination.

HPV Coverage on the Internet

After healthcare providers, the internet is the second most popular source for information regarding the HPV vaccination.¹¹ Unfortunately, research on online vaccine information has uncovered a large number of anti-vaccine websites.^{12,13} However, the majority of top results from popular search engines are neutral in tone.² In their study of 89 top search results from these search engines, Madden et al. found that 57% were neutral, 25% were positive, 8% were negative, and 7% were ambiguous (content was both positive and negative). Of these websites, however, nearly 1 in 10 mentioned parental concerns regarding civil liberties, specifically the fear of mandating HPV vaccination in schools. Many had incomplete information with over a quarter failing to mention that infection with HPV can lead to cervical cancer and over a third failing to mention that HPV is a common sexually transmitted infection. The study also showed that only 6% of the websites were from laypeople, while a majority (88%) were from nonprofit academic organizations, governmental agencies, pharmaceutical companies and

news organizations. Only 7% were from medical organizations.

In another study which examined 250 online news headlines from top news search engines, Habel et al. found that 52% were neutral, 33% were positive, and 14% were negative.¹⁴ Most articles had accurate information regarding administration; however, 86% had inaccuracies regarding vaccine efficacy and 69% had inaccuracies regarding vaccine duration. A majority of these articles, however, did connect HPV to cervical cancer.

Although a majority of the research is on English websites, 2 reviews are available that discuss online HPV information published in other languages. One of these studies of 58 Italian websites and 98 English websites, found that Italian websites scored lower than English websites in accessibility, credibility, and content.¹⁵ In addition, Italian websites had lower scores than English websites in all 3 categories. In addition, Italian websites had more content opposing HPV vaccination than did English websites. Content and credibility scores were the highest for government and university-associated websites, but the majority of the websites were private or news websites. In another study analyzing HPV websites and newspaper reports in German and Spanish, the authors scored 102 websites and 434 articles according to completeness, transparency, and correctness.¹⁶ In the German articles, the majority of sources were scientists and doctors, whereas in the Spanish ones, the sources were mainly classified as "others." Only half the German websites mentioned an association with cervical cancer while the epidemiological information was less frequently correct in the Spanish than in the German ones. The authors concluded that websites from both countries "failed to provide correct and transparent information about effectiveness" of the HPV vaccine.

Social media and websites, such as YouTube, are also popular sources for information regarding the HPV vaccine.¹⁷⁻¹⁹ Founded in 2005, YouTube is now frequently used by health professionals and the public as a platform to share medical information due to its free service and easy accessibility.¹⁷ The average user is between 12 and 17 y of age and 70% of YouTube

traffic comes from outside the US.¹⁷ HPV vaccine is the most commonly mentioned vaccine among all YouTube videos.²⁰ A review of 146 YouTube videos obtained using the search terms "Gardasil," "cervical cancer vaccination," and "HPV vaccination" found that 75% of these clips portrayed HPV vaccination positively and 25% negatively.¹⁸ A large percent of videos were produced by YouTube subscribers. This is promising because information on HPV vaccination posted by general YouTube members is usually positive; however, the fact that most video clips are posted by general YouTube members rather than news, government or medical organizations creates concern regarding their accuracy. In a 2012 study, Briones et al. reported on a similar analysis of 172 YouTube videos obtained using the search terms "HPV vaccine," "HPV vaccination," "human papilloma virus vaccine," "human papilloma virus immunization," "Gardasil," and "Cervarix"¹⁷. The authors found that the majority of videos (52%) held negative opinions while only 33% were positive. This study also revealed that negative videos had more likes than positive videos, suggesting a negative public attitude toward the HPV vaccine.

Social media, such as Facebook and MySpace, also may play a critical role in educating the public about HPV vaccination. Although we were unable to find any articles specifically studying the content or impact of HPV Facebook pages, we came across an article analyzing blogs on HPV using the older social media platform MySpace.¹⁹ In this study, the authors identified 303 MySpace blogs using search terms "HPV," "HPV vaccination," "HPV immunization," "HPV vaccine," and "Human Papilloma Virus." Most blogs (95%) were posted from the United States. Although the positive blogs addressed the high prevalence of HPV infections and its link to cervical cancer, only 9% of these blogs addressed safety of immunization and only 6% mentioned side effects. The negative blogs, however, primarily questioned the safety and efficacy of the vaccination and discussed their concerns regarding vaccination requirements by schools. Forty percent of the negative bloggers argued that there were alternatives to HPV vaccination, such as

abstinence and monogamy. Interestingly, only 9% of negative bloggers argued that HPV vaccination would promote sexual activity, whereas a majority argued that recommendations for HPV vaccination were primarily driven by the financial interests of pharmaceutical companies, and not by scientific evidence. These negative blogs cited vaccine-critical websites with misleading authoritative names, such as the National Vaccine Information Center (NVIC).

Concerns and Possible Solutions

Unlike news coverage of the HPV vaccine, which undergoes rigorous research because the network is held liable for the content, internet information not with no association to news networks is subject to little or no background checks. In addition, individuals usually start the search through a search engine and then read the first couple of hits, instead of directly going to a reputable medical source.²¹ This contributes further to the problem as there is no universal accreditation system that monitors accuracy of online medical information.²² In other situations, patients may actually replace physician advice regarding HPV vaccination with advice they find on the internet or may approach the physician after forming steadfast preconceptions based on incorrect information found on the internet. This reaction to the information on the internet may reflect a dissatisfaction that patients have with their patient-physician interactions, compelling them to turn to another source that can meet their needs better. In this section we delve further into these concerns.

Lack of accurate information and the need for a universal accreditation system

Given the broad range of information on HPV vaccination, there is a clear need for standardization that helps determine the accuracy and completeness of each site. This could be accompanied by developing a universally accepted accreditation system that informs the reader about the reliability of the information presented on that website. There are many international medical associations that have attempted

to create such a system, such as the Geneva Ministry of Health in Switzerland which founded the Health On the Net (HON) Foundation in 1995.²³ This non-profit organization offers ethical codes and certification seals for health information providers on the internet. This system, referred to as the HONcode, allocates a certification if the website meets certain criteria including the author's credentials, date of last website update, appropriate source data references, clear conflict of interest reporting and no intention to replace the physician-patient relationship.²⁴ In 2000, the European Union (EU) founded the MedCERTAIN certification system which relies on Platform for Internet Content Selection (PICS)-based content rating to inform users of the quality of specific websites.²⁵ Other accreditation systems developed for medical information on the internet include: the Principles Governing American Medical Association (AMA) Web Sites established in 2000 to regulate AMA websites, the Hi-Ethics Principles established in 2000 and later used to create the Utilization Review Certification Commission (URAC) Accreditation Guide in 2001, the eHealth Code of Ethics developed in 2003 by the Japan Internet Medical Association, and The Guidelines for Medical Facility Sites on the Internet established by the Japan Medical Association for its members.^{26,27} Although no universal system has been adopted, medical providers should still familiarize themselves and their patients with these various certification systems to help direct their patients' medical searches.

Fixing the patient-physician relationship

Some sources suggest that this trend of seeking medical information online is a reflection of a broken patient-physician relationship.²⁸ It appears that medical providers may have a difficult time thoroughly counseling patients regarding their conditions, given the limited time appropriated to clinical visits.²⁹ Given the recent focus on productivity in the US healthcare system, this problem may become worse in the future. In addition, some providers feel threatened by patients that obtain online information

or resources that contradict the provider's recommendations.³⁰

Instead of feeling threatened, medical providers could embrace this reality and guide the patient through decision-making using online resources. Two recent publications both showed that health professionals rarely discuss information patients retrieved from the internet with regards to obstetrics care.^{31,32} Interestingly, the patients did not initiate discussion either, even though most pregnant women preferred that their providers direct them to high quality internet sights to obtain pregnancy-related information.³³ Another survey of 274 patients who had been seen by a physician within the past 30 d found that 68% researched medical information online.³⁴ This behavior was significantly associated with lower trust. With regards to HPV, Verhoeven et al. analyzed 713 e-mail questions posed to a HPV-related website and found that most questions were from individuals who had already seen their physician these questions directly, instead of visiting a website.³⁵ However, possible causes could be a lack of comfort in asking questions in person or the convenience associated with emailing a question rather than calling a physician. Moreover, 10% of these respondents stated that they turned to the internet because their medical provider was unable to answer their question. In such situations, the medical provider could guide the patient through the process of obtaining appropriate information online to further strengthen the patient-physician relationship, rather than leaving the patient to her own means in a jungle of online information.

Increasing the medical presence in social media

Another solution to the concerns regarding medical information on the Internet is to have a bigger medical community presence, especially in the social media scene. Hello Health, a Brooklyn-based primary care practice that uses social media to communicate with its patients, takes medical involvement in social media to another level.³⁶ Physicians in this practice use tweets, video chats, and blogs to triage patients and answer their questions. According to the founders

of this practice, using social media to such an extent “chang[es] the locus of control to the patient,” allowing for better engagement of both parties and thus, a stronger physician-patient relationship.³⁶ Mayo Clinic launched its Twitter, blog, and Facebook page in 2005 on which they post podcasts, texts and videos updating consumers on the latest medical information.³⁷ The Center for Disease Control (CDC) “encourages the strategic use of Twitter to effectively and inexpensively reach individuals and partners with timely health and safety information.”³⁸ However, it may be more useful to post information through less targeted sources, as women usually only go to the CDC or other health-related websites once given an abnormal diagnosis. To adopt a more preventative approach, HPV-related information may serve better on websites that are viewed by a general population that is not actively seeking information on the topic as is usually the case after the diagnosis of an abnormal pap smear.³⁹

Efforts to engage teenagers in their sexual health via online platforms has also taken place, specifically in the field of contraception. In 2011, the Society of Obstetricians and Gynecologists of Canada (SOGC) released the online video game Birth Control Brigade, to teach teenagers about contraceptive options.⁴⁰ Similar to pac-man, players work to prevent sperm from reaching the ovum using an armament of contraceptive options. A similar tool could be used to educate our teenagers about the risks of HPV and benefits of vaccination.

When participating in this forum of medical information, it is important that medical providers remember the audience. Much of the information currently available on the internet is intended for higher than the average reading level of the American public.^{41,42} When trying to educate the public, medical professionals need to actively remember to decrease the complexity of the information to the average non-medically educated individual. The AMA's Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs recommends that medical students and professionals be taught specifically about how to improve consumer-professional communication skills.⁴³ This

recommendation needs to be incorporated with any online medical information produced by medical professionals. In addition, public policy may need to focus on offering courses to underprivileged communities, teaching techniques to improve search quality and interpretation of online health information.

Conclusion

The internet has a critical role in the current exchange of medical information. The medical community needs to accept this and adapt accordingly. With regards to the HPV vaccine, medical professionals can use this forum to educate the public and hopefully increase the uptake rate of the vaccine. Specifically, providers can (1) inform the patients of the various accreditations systems available to rate the various sources of HPV information, (2) engage in a thorough discussion regarding the online information a patient has obtained regarding HPV vaccination, (3) and allow the patients to communicate with the medical staff via email, tweet, or blogs regarding questions or concerns. By embracing this source of information as a supplement to medical care, rather than as part of the competition, we help our patients make educated medical decisions with regards to HPV vaccination.

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

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