# YouTube as a Source of Information on Cervical Cancer

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### **Abstract**

Background: Cervical cancer is the third most common cancer worldwide. Accurate information about cervical cancer to general public can lower the burden of the disease including its mortality. Aims: We aimed to look at the quality of information available in YouTube for cervical cancer. Materials and Methods: We searched YouTube (http://www.youtube.com) for videos using the keyword "Cervical cancer" on November 12, 2015. Videos were then analyzed for their source and content of information. Results: We studied 172 videos using the keyword "Cervical cancer" on November 12, 2015. We found that there were videos describing the personal stories, risk factors, and the importance of screening. However, videos discussing all the aspects of cancers were lacking. Likewise, videos from the reputed organization were also lacking. Conclusion: Although there were numerous videos available in cervical cancer, videos from reputed organizations including Center for Disease Control and Prevention, American Cancer Society, and World Health Organization were lacking. We strongly believe that quality videos from such organizations via YouTube can help lower the burden of disease.

Keywords: Cervical cancer, health information, YouTube

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### Introduction

Cervical cancer is the third most common cancer worldwide and the most common cause of death in the developing countries. According to the Centers for Disease Control and Prevention, 12,042 women in the United States were diagnosed with cervical cancer in 2012 and 4,074 died from it. Surveillance, epidemiology, and end results Statistics data in 2012 demonstrated the number of new cases of cervical cancer to be 7.7 per 100,000 women per year and the number of deaths to be 2.3 per 100,000 women per year.

Accurate information about cervical cancer to general public can lower the burden of the disease including

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its mortality. Cervical cancer screening has shown to decrease the incidence of and mortality from this disease. Prevention is possible and involves a risk reduction approach through behavioral intervention for sexual and health care-seeking behavior or through mass immunization against high-risk human papillomavirus (HPV) including HPV-16 and HPV-18.

YouTube is one of the most popular video sharing website. It has over a billion users, which is almost a third of all people on the Internet. Every day, people watch hundreds of millions of hours of YouTube videos

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and generate billions of views. YouTube overall, and even YouTube on mobile alone reaches more 18–34- and 18–49-year-olds than any cable network in the U.S.<sup>[5]</sup>

With a surge in people using YouTube nowadays, we felt a need to analyze the quality of information available in YouTube, since it can play a pivotal role in educating the vulnerable age group for cancer prevention and early screening.

### **Materials and Methods**

We searched YouTube (http://www.youtube.com) for videos using the keyword "Cervical cancer" on November 12, 2015. We included English language videos with primary content related to cervical cancer with all duration of videos and restricted the search results to the first 10 pages and saved them in a playlist because search results on YouTube can change from day-to-day. Duplicate videos, videos without accompanying audio, and non-English videos were excluded. Two independent reviewers analyzed the content of the video.

Videos were then analyzed for their source and the content including useful (containing scientifically correct information about any aspect of the disease: Epidemiology, symptoms, treatment, prevention) or misleading (containing at least one scientifically unproven information, e.g., Yoga and eating bananas decreases cervical cancer) information. They were also studied based on their content of information including personal patient experiences, screening information, lectures, intraoperative videos, and surgical procedure.

### Results

YouTube search revealed a total of 73,800 videos on November 12, 2015. We included only the first 10 pages which included 204 videos. Out of them, 172 videos met our inclusion criteria. 26 videos were not in the English language and excluded from our study. Likewise, 6 (3.48%) videos were classified as misleading and contained information other than cervical cancer (for example, a song, random pictures, advertisement of hospital, etc.).

Out of 172 videos, 46 videos (26.74%) were based on personal experience of cervical cancer. These videos were created by patients and served as mini documentaries of their preoperative and postoperative course. Most of them focused on their diagnosis, the healing process, chemotherapy side effects, chronic pain issues, their frustrations associated with having cancer, clinic visit, and sexual issues after surgery.

41 videos (23.83%) were videos from the Health Care Institutions and doctors. Most of them were able to convey good information to the public. Among them, 3 videos also discussed (1.74%) about new research on cervical cancer (lopinavir and ritonavir for cervical cancer, cannabis role in cervical cancer, and vaccine of cervical cancer with microalgae).

29 videos (16.86%) talked about the screening issue. Most of these videos discussed Pap smear followed by HPV DNA and few talked about the liquid based cytology.

19 videos (11.04%) were based on academic lectures and presentations primarily meant for student and practicing doctors. Among them, 4 videos (2.32%) talked about the signs and symptoms only, 5 videos (2.9%) talked about grading and staging only, 3 videos (1.74%) talked about pathogenesis of HPV and cervical cancer including E6 and E7 oncogenes. Other 7 videos (4.06%) were thorough in covering all aspects of sign, symptoms, and management. Most of these videos were complex for general public to follow.

17 videos (9.88%) were based on news agencies. There was one video from a news channel that talked about the safety of HPV vaccine. The news showed the recipient having pain at the injection site and later paralysis, seizures, and headache. It was viewed 77,940 times and liked 397 times. One video also accessed the general knowledge of general public. It showed that most of the people did not know about early symptoms and importance of Pap smear.

10 videos (5.81%) were operative videos only meant for physicians. Table 1 summarizes the nature of videos.

### Discussion

YouTube is a video-sharing website created in February 2005 and is one of the most-visited Web sites on the Internet. As of March 2015, creators filming in YouTube Spaces have produced over 10,000 videos which have generated over 1 billion views and 70<sup>+</sup> million hours of watch time.<sup>[5]</sup> Health information available on the Internet is vast and diverse, ranging from accounts of personal illnesses to medical breakthroughs, lectures about disease, information and updates in health and disease among others. In the present study, we focused on cervical cancer. Prior studies have looked at the quality of information related to acute myocardial infarction,[6] pandemic flu,[7] Ebola virus[8] among others. Quality of information in cervical cancer however has not been described in the literature yet which we believe is of paramount importance. This

# Table 1: Summary of source and content of information

#### Source

- 1. Individual (n=46)
- 2. Healthcare personnel or center (n=56)
- 3. Academic Institution (*n*=29)
- 4. News channels (n=31)
- 5. Miscellaneous: (n=42)

#### Content of information

- 1. Personal experience (n=46)
  - a. Individual story (*n*=10)
  - b. Doctor visit experience (*n*=24)
  - c. Chemotherapy and side effects (n=9)
  - d. Fertility issues (n=3)
- 2. Screening information (*n*=29)
  - a. Pap smear (n=17)
  - b. Information about HPV DNA (*n*=9)
  - c. Liquid based cytology (*n*=3)
- 3. Lectures on anatomy/ cancer signs, symptoms and management (*n*=19)
- 4. Surgical procedure
  - a. Laparatomy (n=10)
  - b. Radical Trachelectomy (*n*=2)
  - c. pelvic Lymphadenectomy (n=2)

is primarily because screening protocols in a timely manner can decrease the mortality and morbidity of cancer.

Our study found out that personal experience one might have during the course of the disease is well covered in YouTube videos. Likewise, the importance of screening in cervical cancer is also given a due importance. One video from a health institution tried to access the general knowledge of cervical cancer of general public. It showed that almost all of them did not know about the Pap smear and HPV DNA test for screening. Likewise, nobody in the video was able to tell the early symptoms of cervical cancer.

We observed that many videos were produced by professional societies, news reports, and lectures. However, these were not the ones with the most views. The videos that were viewed most often were the videos based on personal experience (283,285 views till page two), followed by videos posted by doctors and health institutions (1, 21,918 views till page two). This indicates that people are more interested in their peers' experiences about a disease rather than in professionals.

On June 8, 2006, the Food and Drug Administration licensed the quadrivalent human papillomavirus recombinant vaccine (qHPV) (Gardasil; Merck and Co, Inc., Whitehouse Station, New Jersey) for females aged 9–26 years to prevent infection with genital HPV types 6, 11, 16, and 18.<sup>[9]</sup> Later that month, the Advisory Committee on Immunization Practices recommended routine vaccination of females aged 11–12 years with

three doses of qHPV and catch-up vaccination for females aged 13–26 years. Doses are administered intramuscularly on a schedule of 0, 2, and 6 months. [10] Serious side-effects as much as 6.2% has been reported in the literature including few incidences of death. [11] Our study demonstrated that the side effect of HPV vaccine video was viewed by a large number of people in a single video (77,980 times). Videos that give good information about the side effects of the vaccine can be added. Likewise, video related to screening was viewed by a large number of people.

This was a cross-sectional study based on the content available on YouTube on the day this website was accessed. Videos are constantly added each minute. Hence, variation is possible each day. This is one of the major limitations of our study. Likewise, as users are able to filter the results, it is also possible that a different filter would yield dramatically different results. Moreover, there is no way to ascertain the demographics of the viewers used in our analyses.

### Conclusion

YouTube is a growing source of information to the general public. Although there are numerous videos available in cervical cancer, quality videos that discuss different aspects of cancer viz., risks, symptoms, screening, and treatment are lacking. Videos from reputed organizations including the Center for Disease Control and Prevention, American Cancer Society, WHO, are also lacking. Physicians, professional organizations, and government agencies should also be aware of and embrace this evolving technology to raise awareness about cervical cancer. We strongly believe quality videos from such organizations should be added so that people get detailed and accurate information of this deadly cancer.

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### **Conflicts of interest**

There are no conflicts of interest.

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