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### Social Media & Hepatitis C

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#### Abstract

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**Introduction.** Physicians and patients are now able to employ an increasingly broad array of effective medical therapies for hepatitis C virus (HCV) infection. However, misunderstanding of the efficacy and safety of current anti-HCV therapies persists, despite extensive media coverage. Physicians need to explore new means of educating their patients regarding the availability of new therapies and the benefits of treatment.

**Methods.** The YouTube search engine was accessed on November 2, 2016, using the search term “Hepatitis C treatment”. This generated a total of 196 videos. Videos were classified into 8 categories: educational videos for patients, patient testimonials, educational videos for health care providers, public awareness videos, advertisements, physician experience, alternative treatments and unrelated videos. These videos were assessed for the total number of views, total likes, and total dislikes. Mean of all the views, likes and dislikes was generated for each category. Videos in languages other than English, non medical videos and videos beyond the first ten pages of YouTube were excluded from the study.

**Results.** Of the 196 videos reviewed, 131 videos were patient testimonials, 30 were health care education, 20 were public awareness, 7 were patient education, 5 were alternative treatments, 1 was a university advertisement and 1 was a physician experience. The majority of the HCV videos were personal patient experiences. These videos generated 314,071 views. However, the greatest number of likes (n= 3,715) was associated with public awareness videos.

**Discussion.** The large number of views generated by HCV patient testimonials suggests that the general population is inquisitive about HCV therapy. The side effects and intolerability of the past treatments for hepatitis C loom over the minds of the people and prevents many from seeking treatment. Education of the general public in a format they are familiar with and use frequently regarding new medications with fewer side effects and improved cure rate may motivate patients to consult with their physicians. The benefit of YouTube as an outside confirmatory resource, one that most of the community at large has easy access to could be easily utilized. Videos posted on YouTube offer physicians an avenue to connect with their patients, provide education and motivate HCV-infected individuals to seek out treatment. YouTube has internal controls to ensure appropriate information is being posted and physicians can have an active role in providing and reviewing the content.

**Keywords:** YouTube, Hepatitis C, education

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## Introduction

About 3% of the world’s population is suffering from Hepatitis C [1] and the estimated number of people suffering from Hepatitis C in US are 2.7-3.9 million [2]. Most of the people with hepatitis C do not even know they are infected [3]. More people are being diagnosed with hepatitis C as we widened our criteria for screening people for hepatitis C. Physicians and patients are now able to employ an increasingly broad array of effective medical therapies for hepatitis C virus (HCV) infection [4]. These treatments have proved to be curative for hepatitis C [5].

However, misunderstanding of the efficacy and safety of current anti-HCV therapies persists, despite extensive media coverage [6]. Physicians need to explore new means of educating their patients regarding the availability of new therapies and the benefits of treatment. Internet is one such venue which can be employed to educate the masses. In our study, we assessed the usefulness of the readily available videos over popular website “YouTube”, as it can have an impact over the mindset of the general population because, ultimately, it is the patient who has to make the choice of acquiring the new treatments.

Education of the general public in a format they are familiar with and use frequently may motivate patients to consult their physicians. Affecting the mindset of the patient population in a positive way will help bring an end to this epidemic.

## Methods

YouTube search engine was looked upon under the term “Hepatitis C treatment”. Videos of the first ten pages were reviewed as it is less likely that people will search beyond the first ten pages. This generated a total of 196 videos. Of the 196 videos reviewed, 131 videos were patient testimonials, 30 were health care education, 20 were public awareness, 7 were patient education, 5 were alternative treatments, 1 was a university advertisement and 1 was a physician experience (figure 1 and figure 3). Videos in language other than English, videos on animals, non medical videos and videos beyond the first ten pages of YouTube were excluded from the study (figure 2). Videos were further looked up for the total number of views (figure 4), total likes (figure 5) and dislikes (figure 6).

Analysis was done based on the content of these videos.

Figure 1: Figure demonstrating the categorization of the different videos into 8 categories

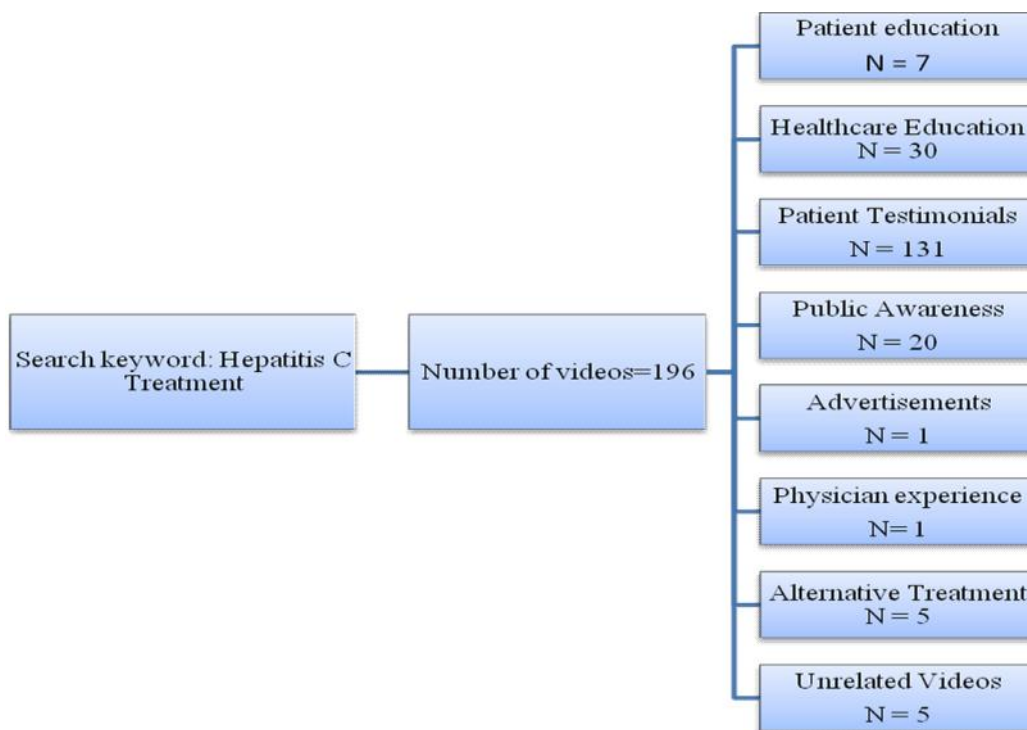


Figure 2: Exclusion criteria

### EXCLUSION CRITERIA

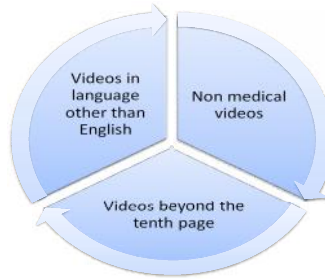


Figure 3: Percentage of videos in each category

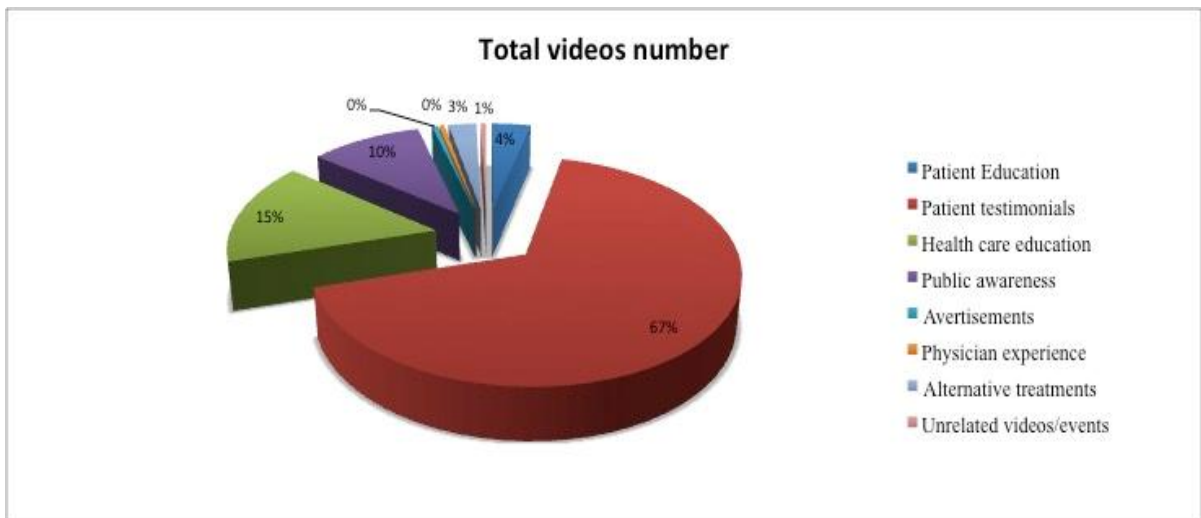


Figure 4: Total views in each category

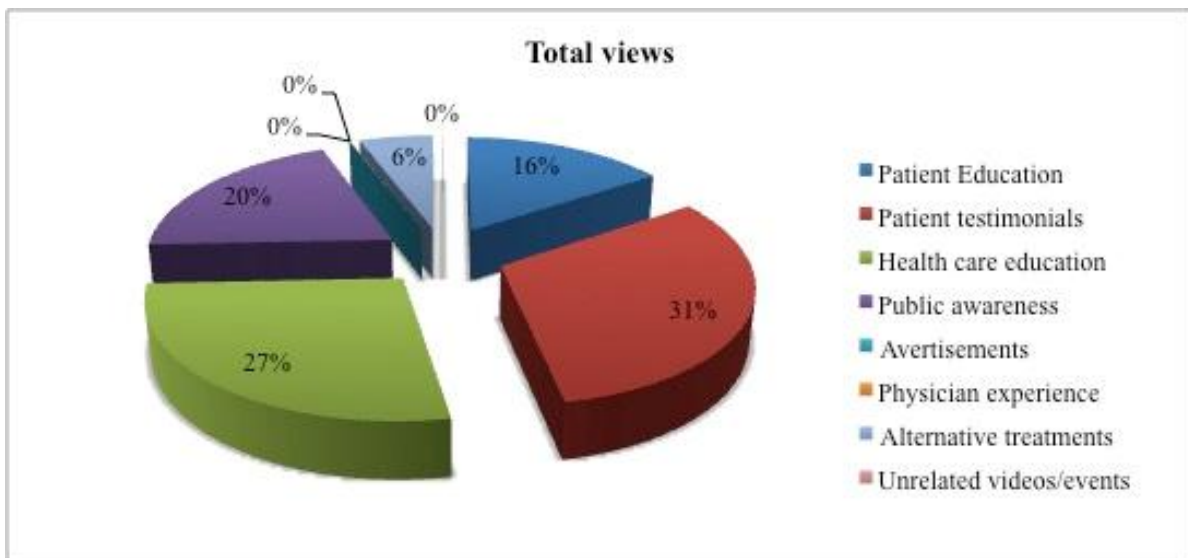


Figure 5: Total likes in each category

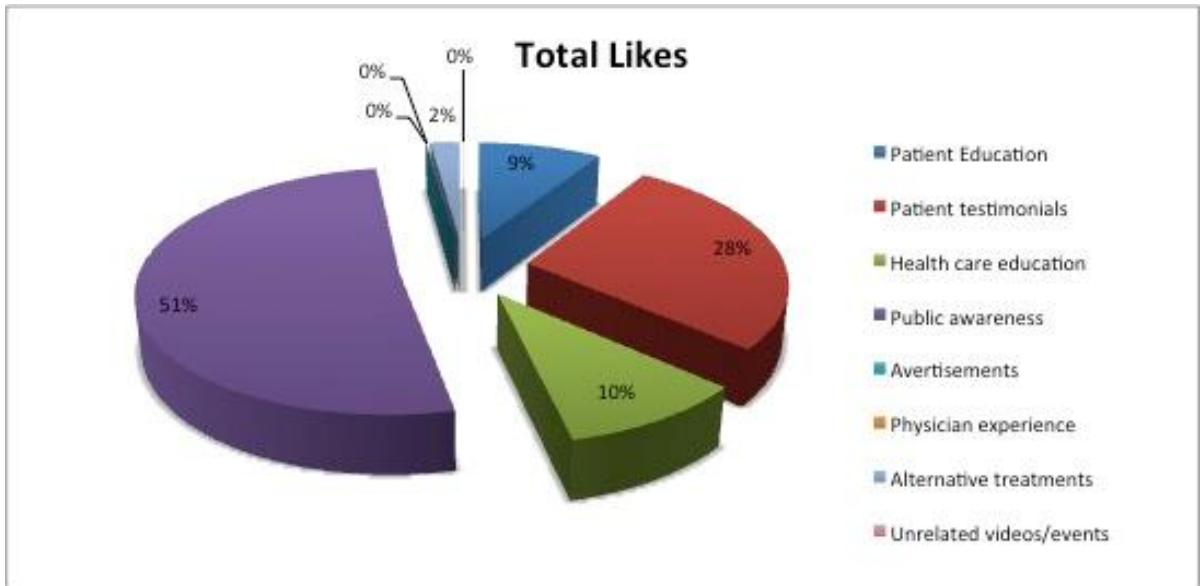
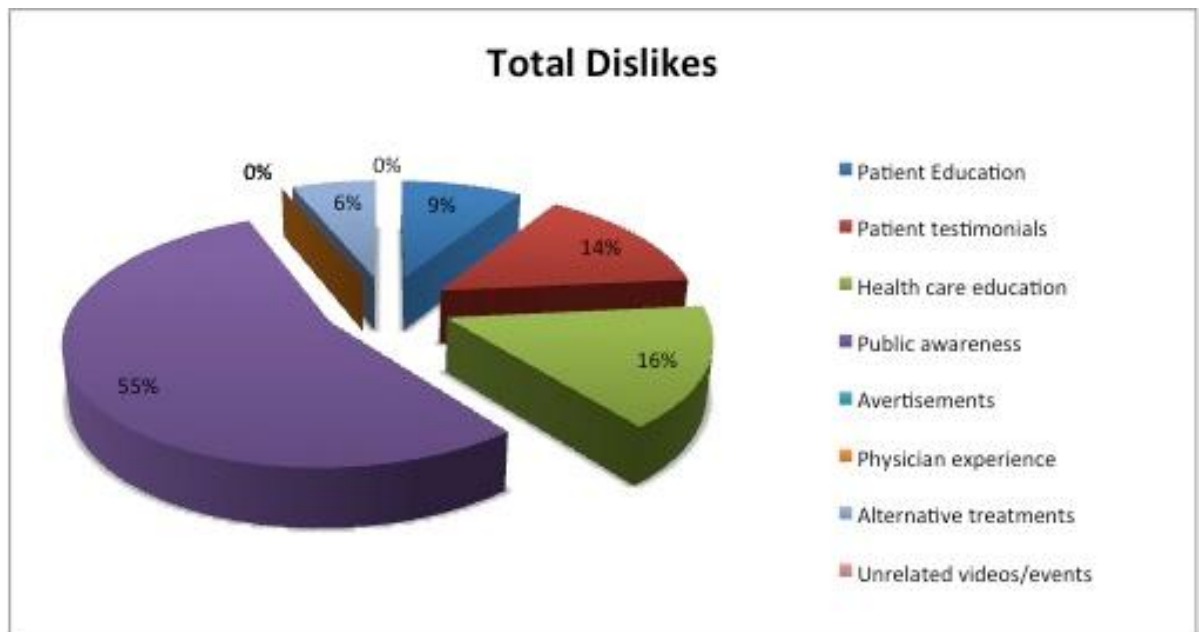


Figure 6: Total dislikes in each category



## Results

Of the 196 videos reviewed, 7 were categorized under “patient education”. These videos discussed the causes, course, prevention, treatments and their side effects for Hepatitis C. One of the videos showcased a registered nurse educating patients on keeping up with their appointments with their doctor. These videos had total views of 1,56,455 with total likes and dislikes of 657 and 26 respectively.

67% (131 of 196) videos were labelled under patient testimonials. These videos were uploaded by patients who were on treatment regimens for hepatitis C. In these videos, patients discussed about the side effects they experienced. They also talked about the time after the treatment when their viral load became undetectable. These videos had total views of 3,14,071 with total likes of 1,987 and dislikes of 42.

30 of the 196 videos were categorized under health care education. 24 of these 30 videos discussed the new breakthrough treatments for hepatitis C. These videos had total views of 272,719; total likes of 722 and dislikes of 46.

20 out of the 196 videos were placed under the category of public awareness. These videos had total views of 199,020; total likes of 3,715 and total dislikes of 158. These videos included the talk shows with the health care personnel discussing the new upcoming treatments for Hepatitis C. 20 percent of these videos (5 out of the 20) discussed the cost of the new medication for hepatitis C.

1 video was an advertisement. It was uploaded by one of the medical center and discussed the research and treatments for hepatitis C being undertaken at that center. This generated total views of 384, total likes of 2 and had no dislikes.

1 video was a physician experience. It showcased physician discussing his experience within his practice, with the patients acquiring new treatment for hepatitis C. This had total views of 254; 3 likes and no dislikes.

5 of the 196 videos were categorized under alternative treatments. It had total views of 56,967; total likes of 154 and 18 dislikes. These videos were uploaded by physicians practising alternative forms of medicine like ayurvedic treatments for hepatitis C.

1 of the 196 video was categorized under “unrelated videos/events”.

## Discussion

Based on the study above, it was seen that maximum number of videos were uploaded by the patients on their personal experiences. Patients discussed about their treatment regimens and the side effects they experienced on those regimens. Patient testimonials can help the patients to share their journey and can provide a support system for them. It can also help other patients who are on treatment with the same drugs to better understand the side effects of the medications.

On the contrary, the side effect profile of the medications and the treatment failures might be detrimental for other patient population yet to start the treatment. The large number of views generated by personal testimonials suggests that the general population is inquisitive about the HCV therapy.

Only 7 of the 196 (3 percent) videos were educating patients on hepatitis C and its treatment. Only 1 video discussed the prevention and the causes of hepatitis C. There was no video explaining the importance of screening tests. 3 of the 7 videos discussed the new treatments for hepatitis C.

The videos on alternative forms of treatment might suggest that in the past, the treatment regimen which included interferon, was not very well tolerated by the patients. The side effects and intolerability of the those treatments [7][8][9][10], loom over the minds of the people, because of which patients are discouraged away from the allopathic treatment for hepatitis C; without knowing the fact that new medications have come up in the market with fewer side effect profile and better tolerability besides been proved to be curative [5]. As said before, lesser number of educational videos for the patients and the fact that past medications have not been better tolerated brings up the question of how well the general population is educated on the new hepatitis C treatment options. Lesser number of YouTube educational videos directed towards the patient education, highlight the inadequacy in this regard. Our data suggests that only 5 of the 20 videos on public awareness discuss about the new treatments for hepatitis C, which is inadequate. This brings into light the importance of educating the general population of the new medications, their better tolerability and lesser side effect profile [11].

Most number of likes was generated on the videos on public awareness. This highlights that the general population is interested in knowing the new advances on hepatitis C and thus YouTube gives an opportunity to spread awareness on hepatitis C screening and treatments. Hence, quality control on these videos is important so that high quality videos with flags or logos from the approved societies or accredited organizations could be differentiated from the low quality videos.

### Limitations

Everyday new videos are uploaded on YouTube. Statistics reveal that 100 hours of video are uploaded to YouTube every minute [12]. Being a highly dynamic site, it is not possible to regenerate the same data collected at one point in time. Number of views does not differentiate the demographics of the population watching the videos. Hence it is difficult to know if the person watching the video is an actual patient or not.

### Conclusion

Hepatitis C is a silent epidemic [13]. Adequately treating hepatitis C will reduce the subsequent burden of the end stage liver disease. As we diagnose people with hepatitis C, their anxiety and curiosity to instigate more about their new diagnosis turns them towards the internet to learn more about the disease and the various treatment options. The benefit of YouTube as an outside confirmatory resource, one that most of the community at large has easy access to, could be easily utilized. Videos posted on YouTube offer physicians an avenue to connect with their patients, provide education and motivate HCV-infected individuals to seek out treatment. YouTube has internal controls to ensure appropriate information is being posted and physicians can have an active role in providing and reviewing the content. Thus, providing optimum medical treatment requires integration of the sources that are available on the internet and on the popular websites like YouTube, so that enough information, which is precise and accurate, is available to the patient population.

This will help the patients in not only making informed decisions but also prevent any delay to get the treatment.

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