2011

Dr. YouTube is Ready to See You Now! Health Benefits of Medical Videos on YouTube

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Recommended Citation
Rosenberg, Jordan A., "Dr. YouTube is Ready to See You Now! Health Benefits of Medical Videos on YouTube" (2011). CMC Senior Theses. Paper 293.
http://scholarship.claremont.edu/cmc_theses/293

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CLAREMONT MCKENNA COLLEGE

DR. YOUTUBE™ IS READY TO SEE YOU NOW!
HEALTH BENEFITS OF MEDICAL VIDEOS ON YOUTUBE™

SUBMITTED TO
PROFESSOR JAMES MORRISON
AND
DEAN GREGORY HESS

BY
JORDAN ANCELL ROSENBERG

FOR
SENIOR THESIS
BACHELOR OF ARTS

FALL SEMESTER 2011
11/28/11

Claremont Colleges
Claremont, California
Acknowledgement:

I must first thank Professor James Morrison for being my advisor and academic mentor throughout my junior and senior years at CMC. You have not only been a guide for my academics in media studies, but as my thesis reader and professor, you allowed me to learn from my mistakes, while always providing unmatched scholarship. I am truly in awe of the way you make yourself available to students. I feel lucky to have been a student of yours. Majoring in media studies and having you as my advisor was the best decision I made as a student here.

I must also show immense gratitude to my sweet mother and father for their unconditional support in my life and in academia. Through the years you both have provided incredible love and guidance in times of both turmoil and peace. I would never be where I am in life without all that you do for me.

Finally, I would like to acknowledge electronic dance music as a genre in loyally providing thesis fuel to my sometimes-silent gas tank.
Introduction

For many Americans, a physician is a luxury. When one becomes ill or injured, a physician may not be an option because of the absence of decent health insurance, sometimes even if they are steadily employed. Due to such concerns, healthcare has become a major topic of social and economic reform. The number of people who are underinsured has grown 60% to a total of 25 million Americans over the past four years. Underinsured are those who have health insurance but still struggle to pay their healthcare bills. The fastest growing segment of the uninsured is middle and upper income families. The rate of underinsured for those with incomes of $40,000 or more nearly tripled in the past four years.¹

This insurance problem for most socioeconomic groups, combined with a serious shortage of physicians creates a problem for all Americans, including the 79 million baby boomers needing more medical intervention as they enter old age. It is estimated that the United States will be short 200,000 physicians by 2020.²

Clearly the United States is in a prolonged economic recession with a serious shortage of reliable health insurance coverage and accessible health care. Physicians’ time is quite limited for those fortunate enough to be evaluated by one. Alternate sources of medical information can be beneficial when a physician is not an option, or the physician does not have sufficient time to answer questions and communicate necessary instructions. Patients and their loved ones

¹ http://money.cnn.com/2009/03/05/news/economy/healthcare_underinsured/
² http://www.healthcareproblems.org/health-care-statistics.htm
can benefit from a cost-free, information-rich, instant delivery service of health and medical information that can be both consumed and interacted with.

To assist in maximizing our consumption of limited healthcare, people have become increasingly attracted to YouTube, a free video-sharing, social networking site founded in 2005 and now owned by Google, as a platform for obtaining and sharing medical information from short videos. The website features free videos on a variety of content that can be watched and also talked about in a text dialogue underneath the video. The discourses around disease and illness on YouTube are created by the videos themselves and the ways in which people talk and share on the site.

As of March 2009, more than 5.4 billion videos and over 13 million hours of video content existed on YouTube. ³ YouTube is the most widely used video-sharing website that has reached unprecedented global success. Not only used by a large number of people, but YouTube has individuals spending large amounts of time watching multiple videos. The average visit to YouTube is 28 minutes/person and the average video length is 4 minutes 12 seconds⁴, thus resulting in over 6 videos consumed per visit. Undoubtedly, people all over the world love using YouTube in their daily lives, and for medical purposes as well. However, YouTube should not be used as a replacement for a physician’s care, but can be exceptionally helpful as a compliment to health care.

According to a Pew Research Center’s Internet and American Life Project (fox, 2008), 75% of patients with a chronic condition reported that recent health

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³ http://www.youtube.com/t/press_statistics
⁴ http://www.sysomos.com/reports/youtube/
searches affected their decision about how to treat their illness or condition.\textsuperscript{5} Patients with chronic illnesses are consuming more user-generated health information: 57\% of patients have read someone else’s blog or commentary, or have listened to a podcast about health issues (Fox and Purcell, 2010).

The benefits of YouTube for health education were not anticipated in the early days of the format. Indeed, the original intention of the creators of YouTube differed from what really occurred. Former PayPal employees Chad Hurley and Steve Chen, who created YouTube, were inspired by the photo sharing site, Flickr.com, and they thought friends and family could exchange home videos through YouTube.\textsuperscript{6} YouTube was originally supposed to be a private medium, yet it developed in the public sphere, and medical content subsequently followed. As its slogan “Broadcast Yourself” shows, YouTube traffics in personal broadcasting, which implies that amateurs deliver their programs to an anonymous audience. However, videos are also created and uploaded by professionals and feature accurate and reliable information.

There is truly an unlimited variety of video content on YouTube that can be consumed as entertainment and general time-wasters. Yet, there are also videos on YouTube, within different medical communities, that have incredible power. Collectively, these videos can change the way people understand and care for themselves.

\textsuperscript{6} YouTube Founders Chad Hurley & Steve Chan. Retrieved 10/10/11 http://www.youtube.com/watch?v=K0nfo_tFtNg
Similar to the vast number of videos in other categories, there are countless medical videos on YouTube with informational and educational content from actual physicians and health universities. These videos feature physicians speaking about all aspects of medical care, performing procedures, reviewing medications and even facilitating dialogue with other YouTube users in the comments sections below their personally uploaded videos. The same medical information can be found with physicians working for health universities. Those medical videos, uploaded by Mayo Clinic for example, have their own “channels” that can be accessed for viewing their medical videos with their own physicians in an unbiased medium.

Furthermore, there are also countless medical videos created not by physicians, but by patients expressing themselves in sickness and in health. These videos are usually in the form of a video-blog. The content consists of patient experiences and, comparable to the physician videos, includes instructional content. The mere existence of these videos on YouTube could be beneficial for healthcare consumers, but combined with the often-flourishing dialogue in the “comments” section of individual videos, communication occurs to further facilitate the sharing of medical information.

The incredible success of the site is due to the implementation of four interdependent features as recounted by Jawed Karim, the third co-founder of YouTube. The first feature is video recommendations via the “related videos” list. This allows the viewer to find videos featured on the side of the screen, which he/she is currently visiting. By utilizing video “Tags”, uploaders
categorize their videos to be searched by a computer algorithm suggesting similar content. The uploader(s) decide what to tag their video as. A Tag can be something like “California” and “Earthquake” to guide viewers through the maze of millions, or even perhaps billions of videos to find what he/she is fascinated in viewing. The Tags allow similar videos to be recommended in the side bar of the screen.

The second successful feature of the site is an email link to enable sharing. This email link that Karim considers a key point in the website’s success, also allows anyone with Internet access to view videos globally and help deliver correct medical information or experience to those in need. The third feature to the website’s success is the capacity to post comments (and other social networking functionality). This is an important aspect of YouTube to facilitate virtual interactions that provides a voice in sharing medical information. The fourth feature that helps YouTube maintain success is an embeddable video player, which ultimately makes anyone with Internet capable of viewing; no downloadable software required. 7

Below are some screenshots of YouTube and their attributes. The first screen shot is of a completed search performed on November 13, 2011 from http://www.youtube.com using the words, “hip replacement”.

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In order to analyze the screenshots accurately, it is beneficial to consider them with a medical example. Perhaps a patient has had persistent hip pain for 10 years and worries that a hip replacement might be their most reliable source of pain relief. The surgery is complex and frightening for most people. Fear of the unknown can be something hid from a physician, and it can be extinguished in privacy. YouTube is the key. It allows private viewing in a public forum. The content can consist of personal or private information that can easily be relayed.

On the above screenshot, one can see that there is a “Promoted Video” on the top of the list. The Promoted Video pays YouTube to have the first slot on each page with the desire of obtaining views and therefore gaining profits from advertisements played before the video starts. “DePuy Hip Replacement” is a video featuring a success story using the artificial hip made by DePuy. DePuy is

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8 http://www.youtube.com/results?search_query=hip+replacement&aq=f
a division operated by Johnson & Johnson™ that makes artificial hips and has YouTube videos explaining success with their product through the experiences expressed by a past patient. This might not be the most beneficial video to a patient needing medical information. The content is biased and heavily edited to have a commercial “feel” to it. DePuy pays to have the video listed first, however it does not have the most views on the first page of results. All of the videos on this first page, besides the Promoted Video, show content uploaded by healthcare organizations or self-uploaded by physicians. Also, the videos feature physicians in front of the camera speaking to an audience of potential hip patients. On the right side of the screen there are “Featured Videos”. These are not advertisements or paid placements like “Promoted Videos”. These are showcased because of popularity and are usually helpful videos for those in need.

A patient searching YouTube for information might think there is simply a dizzying amount of hip videos that could be impossible to sort through and find helpful information. The number of results after this search for “hip replacement” is in the thousands. Over 10,000 videos have keywords associated with “hip” and “replacement”. Some readers may be doubtful of locating helpful content with such large numbers of videos just a click away. In reality, however, there are a plethora of helpful videos, all a click away.

On the next page is a screenshot of YouTube’s 20th page of results after the same search of “hip replacement”. Page 20 features another Promoted Video by DePuy, but also has freely-uploaded content and helpful featured videos. The second video and the 7th video in the center (“Replaced” episodes 3 and 4) are two
video-blog “episodes” from a woman who underwent hip replacement surgery.

The other videos on this page feature abridged surgeries and physicians providing the same medical information they would do face-to-face. There are definitely a large number of YouTube videos in existence for hip replacement content; nonetheless, despite—or even because of—this proliferation, through page 20 of my search, helpful and information-rich videos are still abundant.

Moreover, next is a screenshot of the comments section under a video titled, “HIP PAIN, COMMON CAUSES-Everything You Need To Know – Dr. Nabil Ebraheim”
This clear and concise video (found on the first page of results for “hip replacement”) has various detailed pictures and narrations from the physician about the procedure. There are featured videos on the side of this video to guide patients for additional medical information if he/she chooses.

As you can see, the top of the comments section features dialogue between the physician and patients. With a total of 65 comments, there is a beneficial discourse created under this video about hip replacements that would never be achieved in a hospital or clinical setting. One could never enter a hospital room with questions about a hip procedure from a patient’s perspective. But, by utilizing YouTube’s platform for medical discourses, users have the ability to read

10 http://www.youtube.com/watch?v=0oVTJpVsyBE
comments left by patients, and ensuing responses by ex-patients and the surgeon himself.

Although medical information over YouTube is not a replacement for a physical evaluation with a healthcare professional, people are insisting on using it and in the case on the previous page, they are obtaining accurate medical knowledge from Dr. Ebraheim, a University of Maryland orthopedic surgeon who has been practicing for 36 years.11

At the same time, the proliferation of medical discourses online, and on YouTube in particular, has produced something of a backlash within the medical community. Many practitioners have expressed concern about misinformation, or the possibilities of patients’ misreading accurate information.

In December 2001, the American Medical Association put out a press release suggesting that American’s make a New Year’s resolution to “trust your physician, not a chat room” since the information found online puts “lives at risk.”12 While chat rooms in 2001 may have scared physicians, YouTube in 2011 should excite physicians. As I will discuss in this essay, there is a plethora of accurate medical information that patients are viewing and positively talking about with other patients.

To study and analyze such a phenomenon is difficult, but it is important nonetheless. YouTube has forever changed how we consume medical information and interact with it due to its structure as a video sharing site. Patients, their loved ones, and healthy individuals are watching medical videos becoming informed,

12 Pewinternet.org/presentations/2010/feb/media Susannah fox
educated, and having an ability to communicate within a social network of experienced and inexperienced patients.

Together, with medical screenings and evaluations, YouTube can be a useful complement to healthcare and provide ways to learn and share about various health discourses. It provides medical depictions and content through videos not otherwise accessible or as easily accessible to health consumers and their loved ones. That content can improve real world health by increasing awareness and communication about the body and mind.

Some individuals believe that a website like www.WebMD.com is a reliable health website for unbiased and accurate medical information, and also think that YouTube is a useless free-for-all. Fear of YouTube as an undependable site is unwarranted. WebMD is synonymous with Big Pharma. A February 2010 investigation into WebMD’s relationship with drug maker Eli Lilly by Senator Chuck Grassley of Iowa confirmed the suspicions of longtime WebMD users. With the site’s (admitted) connections to pharmaceutical and other companies, WebMD has become permeated with pseudomedicine and subtle misinformation.13

Because of the way WebMD frames health information commercially, YouTube flourishes as a sharing site and not solely a consumption site. The users upload unregulated information; however, videos that are useless or simply misinforming are easily dismissed by the large number of voluntary video commentators and raters. Unbiased public videos are everywhere and provide

13 http://www.nytimes.com/2011/02/06/magazine/06F08-Medium-t.html?_r=1&ref=magazine
medical information and valuable private medical experiences to be viewed and talked about. YouTube is a reliable source of medical information in a real medical community.

In order to highlight the benefits of YouTube’s video community as a medical platform, there needs to be an established chapter to discuss how medical videos work generally on YouTube. Chapter 1 will cover who is uploading the videos and how individuals navigate from professional to amateur videos and visa versa. The discussion will be in context of YouTube as a public sharing space that can contain personal information.

A central advantage of YouTube as a space for health information is health communication. Chapter 2 will focus on social networking and the comments section, where patients voluntarily share their voice in an online medical community.
Chapter 1: YouTube Content and Navigation

YouTube provides platforms for professional dissemination of information with videos uploaded by the best hospitals in the world. The site has several medical institutions that feature regulated information. The combination of physician-led videos and amateur ones both existing in a public record easily and freely accessible, is a natural evolution of the Internet as a source of medical information. With the introduction of the Internet, there has been medical information relayed in text—including amateur information in blogs and other social networking sites. YouTube and its medical discourses are a continuation of medical information on the Internet, just in a very different way: a user-created video sharing site.

The Internet itself has replaced physicians as the main source for health information with hundreds of thousands of health-related web sites and hundreds of millions of people using the Internet to research health information.14 Many physicians might be skeptical towards new forms of media and the delivery of medical information they provide patients. This is understandable if there are no success stories shown to these physicians. However, YouTube is full of people having success in obtaining accurate medical information. Valuable lessons are taught on YouTube in and out of the academic setting. There are formal medical school lectures having thousands of views with dozens of comments as well as

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popular patient video-blogs facilitating optimistic communication in the sharing of emotional experience.\textsuperscript{15} Undoubtedly, physicians should be wary of misleading or incorrect medical information that reaches viewers. Nonetheless, there is quantitative evidence of accurate medical information and valuable sources on YouTube.

A study on YouTube, for example, as a source of information on kidney stone disease found that out of 199 videos with relevant information about kidney stones, personal experiences with suffering/treatment for the stone disease were viewed 49.9\% of the time. Useful videos contained scientifically accurate information and were watched 47.2\% of the time, followed lastly by misleading videos that either had unproven information like treating stones with herbal medicine were viewed 2.8\% of the time.\textsuperscript{16}

The possibilities for finding accurate information on any medical topic are high. Medical videos with an overview of facts proliferate on the site. Videos about symptoms and types of diseases are common. In addition, variation in diagnoses and tests are deliberated on YouTube. The treatment and care of illnesses are available for viewing. Lastly, there is information on living and management skills from professional and amateur users. To explain the vastness of advantageous content regarding a health condition, I chose to explore the videos of urinary stones on YouTube since it is a condition that requires medical care, communication, and various treatment options. Together, these equate to a

\begin{itemize}
  \item \textsuperscript{15} http://www.youtube.com/watch?v=4pyFl0tNMhl
  \item \textsuperscript{16} Sood A, Sarangi S, Pandey A, Murugia K. YouTube as a Source of Information on Kidney Stone Disease. Endourology and Stones. AllIndia Institute of Medical Sciences, New Delhi, India. 2010
\end{itemize}
medical condition that necessitates the many benefits of YouTube as a source of education.

To begin, in 2007, there were a total of 135,000 emergency room visits for urinary stones and a total of 1.8 million physician-office and outpatient visits combined for the care of urinary stones. This cost $2.07 billion for the evaluations and treatment.\(^\text{17}\) A YouTube video showing surgical intervention for kidney stones will not change the number of victims to stones each year. However, the surgical video can be used as a successful and unique platform for those with the condition to view, listen and read, and also to comment and share their own experiences with surgery as treatment. Anxiety from the unknown is lessened through gaining helpful medical knowledge.

Below is a screen shot from a procedure uploaded by a urology surgeon, Dr. Brian Golden, removing a dozen stones from his patient’s kidney in a common surgical procedure. The video has been viewed over 60,000 times and has 100 comments in the comments section of the video from patients, non-patients, and even includes feedback from the surgeon himself.

WARNING: SURGICAL CONTENT

This video exists within a group of other kidney stone videos and medical videos that can improve real world understanding and care of kidney stones. Surgically, the narrative is spectacular, but the camaraderie around the video is particularly special. This video acts as a platform for all kidney stone patients to see, hear, and articulate with.

The Tags to this particular video act as a guide to bring viewers searching for keywords to this video and suggest videos to watch next with similar content (kidney stones and surgical procedures).

When the video is finished, a patient video-blog is one of 9 suggested videos. The video does not feature a physician like the previous one, but a woman discussing in a time of 7:46, her own kidney stone experience from a non-medical point of view. This video has been viewed 52,060 times and has 204 comments talking about urinary stones. In a combined time of 13 minutes and 45 seconds, thousands of people have watched perhaps both of these videos and

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18 http://www.youtube.com/watch?v=je6SPs8KSao&feature=related&oref=http%3A%2F%2F
learned from both medical and non-medical standpoints, priceless information about a painful and sometimes confusing condition. YouTube is worth trusting for medical information due precisely to its balance of professional and amateur videos (kidney stone surgery and kidney stone diary).

Within any medical topic - and not just urinary stones - there are a substantial number of videos containing information from physicians and a substantial number uploaded by patients. Together on a single YouTube search, a curious individual can encounter both types of videos. Seeing and hearing the differences between a medically trained doctor and a non-physician can encourage the viewing of both patient and professional videos, thus lessening the chances of encountering misleading information from one or the other, and encouraging the assimilation of beneficial content from a range of perspectives.

The navigation through the site enhances learning by making video-blogs and physician videos immediately accessible, however some search terms result

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19 http://www.youtube.com/watch?v=Be0A6nCrMLg
in less than accurate content. An example of this is with infantile spasm videos. Accurate videos can be extremely beneficial for parents, but finding such videos requires some specific searching.

The information relayed to parents of children that suffer from seizures can provide support and education. Educated parents are usually proactive parents when handling mysterious illnesses. West Syndrome, is an uncommon to rare epileptic disorder in infants. Prevalence is around 1:3200 to 1:3500 live births. Infantile spasms are often seen in children between 3 and 10 months who present suddenly with brief extensor or flexor head and arm jerks. These spasms can be very distressing both to infants and to parents as the initially subtle spasms become more forceful, often coinciding with a regression in development, such as loss of babbling. Often these beginning spasms are unnoticeable. Videos of children suffering from West Syndrome can positively enhance future children’s chances of early diagnosis.

Because infantile spasms are often associated with several underlying conditions and poor developmental outcome, neurologists and other health practitioners aim for early recognition through the education of parents, the community, and primary care physicians. This is significant because early treatment can enhance outcomes for children.

YouTube has thousands of videos pertaining to spasm disorders, and a group of physicians attempted to see if YouTube could be a reliable teaching tool.

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22 http://emedicine.medscape.com/article/1176431-overview
and patient resource for this disease. In this study, videos were searched using the terms, “infantile spasm, spasm, epileptic spasm, and west syndrome”. The top 25 videos under each term were selected according to set criteria. Technical quality, diagnosis of infantile spasms, and suitability as a teaching resource were each assessed by two neurologists using a Medical Video Rating Scale. Raters found 62% of videos to accurately portray infantile spasms. Ten videos were considered excellent examples by at least one neurologist rater. They concluded that YouTube might be used as an excellent patient resource for infantile spasms if guided search practices are followed.\footnote{Fat, Doja, Barrowman, Sell. \textit{YouTube Videos as a Teaching Tool and Patient Resource for Infantile Spasms}. Journal of Child Neurology 2011 26: 804. 2011} Search term in this study affected both relevance of the video and the degree of diagnostic accuracy in the top 25 results. Words like “infantile spasm” revealed better results than a general search term such as, “spasm”. More concentrated searches allow for more concentrated content to be delivered to the user.

The appeal for patients to post videos on YouTube lies in large part in the fact that it is free and usually anonymous. Patients do not need to reveal their identities to express private matter like their infant seizing, thus sharing beneficial information that would difficult to release in a real life situation. Familial suspicions of West Syndrome can successfully be analyzed with videos demonstrating what actual West Syndrome spasms look like. By showing the seriousness of infantile spasms, viewers can effectively alter an outcome of a West Syndrome infant case by early detection, thanks to the voluntary uploader.
Through the use of the public aspect of YouTube, some health problems can be brought into the spotlight and create more knowledgeable patients through physician and patient videos. An example of this occurs with medical anxiety videos. Anxiety disorders are the most common mental illness in the U.S., affecting 40 million adults age 18 or older (18% of the population). The condition is highly treatable, yet only about 1/3 of those suffering receive treatment.

YouTube has thousands of videos pertaining to anxiety disorders. Health care professionals have YouTube channels, such as UCtelevision’s channel, which is operated by the University of California schools and features a section of videos about anxiety. A search for “Social Anxiety Disorder” had 82,600 results. The top video, titled “Health Matters: What is Social Anxiety Disorder?” has two University of California San Diego medical doctors talking all about the prevalence and medication treatment of social anxiety disorder in 28 minutes. The video has been viewed over 187,000 times and had a remarkable 2,453 comments. It has valuable information for those interested in social anxiety disorder and the medical aspects of the disorder.

A video on the side slot of the screen, titled, “Steve, Xanax, and the floor.” is one of 18 video suggestions. It does not feature beneficial medical information, but rather shows a patient with anxiety poorly treating it with high quantities of Xanax.

26 http://www.youtube.com/watch?v=4truuD_xMP0
“Steve, Xanax, and the floor.” has over 8,000 views. The tags, which allow search words to connect to the video are: Drugs, Addicted, Xanax, Behavior, Prescribed Drugs, Abuse, Overdose, Disorder, Funny. The video features a wife video-taping and talking to her unconscious husband simply lying on the floor from an apparent drug overdose. Xanax overdose is a serious medical condition that is possibly deadly, and an actual video depiction can perhaps provide an unparalleled understanding, like infantile spasm videos for parents. A video like this can influence a real-world decision of treatment.

With 40 million Americans having anxiety disorders, it is important that discourses around this prevalent condition are being talked about. Perhaps with more people informed, more can be done for those alienated by the condition. Discussion and sharing of such videos can turn a private condition into a publically understood disorder through video content showing physical manifestations of anxiety treatment. After “Steve, Xanax, and the floor”, a suggested video titled, “Ex-addict talks about side effects of Xanax”, viewed over 11,000 times and had 33 comments, is a valuable patient-video blog with a woman telling her story working with physicians to handle her Xanax prescription, abuse, and withdrawal. Such information would never be available from a patient’s perspective without the use of a public video source.

Navigation through YouTube facilitates the successful duality of both physician and patient videos by suggesting both types of content with most videos. After watching a UC San Diego medical video and two amateur videos,

27 Steve, Xanax, and the floor Retrieved 10/6/11. http://www.youtube.com/watch?v=7q3php9CgNc
28 http://www.youtube.com/watch?v=L1t3ZRCrvh8&feature=related
another suggested video takes me back full circle to a physician’s point of view. The title of the suggested video is, “What is a social anxiety disorder?”

The flow from video to video can increase the quantity of information. But it also increases the chances of “relate-ability” for a searcher. Individuals in need of medical information may truly connect with a video-blog featuring a same-sex, same-age individual with similar health problems, or perhaps an individual can relate to a series of symptoms described by a well-spoken physician, all while remaining in the privacy of one’s own home.

It is vital to have a strong relationship in the real world with a physician for treatment of a chronic condition. The long-term treatment and communication is needed for a successful outcome. For some, however, a treatment may sometimes require independent care away from a physician. Type 1 diabetes, also known as juvenile diabetes, does not have a cure and is therefore a chronic condition with great responsibility on the patient for disease management.

29 http://www.youtube.com/watch?v=i-jHGYWAFTQ
30 http://www.mayoclinic.com/health/type-1-diabetes/DS00329/DSECTION=coping-and-support
Living with type 1 diabetes is not easy. Proper diabetic management requires a lot of time and effort, especially in the beginning.

Management of this disease also requires a lot of courage. People with type 1 diabetes often find that talking to other people with type 1 diabetes is helpful.\(^{31}\) Besides the sharing of information, those with type 1 need instructions for insulin injections, which can be quite scary for anyone, especially a juvenile. YouTube has a series of videos with patient-video blogs featuring teens with type 1 diabetes giving injections and talking to other people about their experiences.

Type 1 diabetes is often diagnosed in children, adolescents, and young adults. Social and familial stressors are common for that age group. Finding a relatable person with the same disease, whether face to face or through a YouTube video, can make the care of this disease more manageable for that young person.

Treatment for type 1 diabetes is a lifelong commitment to taking insulin as well as exercising regularly and maintaining a healthy weight. (Mayoclinic.com)

Management of diabetes may be overwhelming and it is important for the patient to take each day at a time. Anyone with type 1 diabetes needs insulin to survive. Injections are taught by physicians but can also be taught by YouTube videos. Below is a video of an injection with helpful instructions to viewers.

\(^{31}\) http://www.mayoclinic.com/health/type-1-diabetes/DS00329/DSECTION=coping-and-support
These how-to videos are not only beneficial for simple and clear instructions available in video format, but the discourses in the video show what it truly is to live with type 1 diabetes. A young person can easily find a video featuring someone his or her age with more experience for treatment of type 1 diabetes. A study found that college student’s greatest reasons for using YouTube for information is because it is easy and free. While a diabetic clinic may have social support groups for those living with the chronic condition, the information

32 http://www.youtube.com/watch?v=9GBR6XhjGs&feature=related
is not available at all times nor is the ability to talk about it. But through the 24/7 access to YouTube the medical videos, it has never been easier or more plentiful to share personal stories in a public cost-free media space.
Chapter 2: Social Networking in a Privately-Public Space

Section 1: Examination of Ulcerative Colitis Videos

Social networking can help one learn a great deal about all aspects of healthcare, from prevention, the symptoms and diagnosis, treatment options and overall disease management. Social networking is exactly what it sounds like: conversations with others on a casual and social basis. Offline, and not on the web, it would be like having lunch with a group of friends chatting in the coffee shop. Online, through many websites including YouTube, it is a way of carrying on conversations with people you know and people you don’t know, but with whom you have mutual interests. YouTube facilitates the possibility to learn from others, as well as for others to learn from you. If individuals approach social networking as a way to get health information they need, it is easily accessible. The ways people use YouTube to share experiences and free expression is in a unique, privately public network. On YouTube, some participants broadcast extensive information about their identity and lives on a completely public website.

Analysis of social networking on YouTube is not limited to the comments section that can create an interactive dialogue. The video-blog itself stands as an expressive pillar to allow a dialogue to exist within the context of the public video content. A video-blog is an expressive monologue that features a one-way conversation to the viewer. The topic of the video-blog can be a very personal
narrative regarding a disease and the successful or struggling treatment of it.

Once the video has been uploaded, it exists within a sphere of social networking capabilities that allow interactive development surrounding the public video from multiple perspectives.

The number of “thumbs-up” can rank the video in terms of popularity among similar tagged videos. Directly below the video is a bar with a thump pointing up and one pointing down. Viewers, in private, may collectively find the video misleading, pointless, or generally not worth one’s time, then the video is usually negatively rated with many thumbs down.

Because the number of people accessing high speed Internet is greatly expanding, many patients turn to video blogs to learn about symptoms and treatments never discussed on TV with similar details. Within the sphere of a certain health care topic, there is the sharing and expression of experiences that greatly benefit the video-blog creator and those viewing, and then subsequently interacting with the video, and patient, socially. Public expression in the form of a video-blog is rarely shared in the real world, and not nearly as expressive or common like the videos present on YouTube.

With the utilization of YouTube for the terminally ill population of the world, for example, individuals can positively express themselves and also simultaneously support a similarly experiencing human being. Death can be regarded as a very private and personal matter, but the option for public expression can ease the loneliness in a video viewer as well as the creator.
Jackson, Rem, Schneider, Andrew, Baum, and Neil (2011) completed a study with evidence that socially supportive communication can lead to positive health benefits. They define social support as “an advocative interpersonal process…that is centered on the reciprocal exchange of information and is context specific.” The ways in which people communicate on YouTube can seem infinite, however. The professors in the study concluded that socially supportive communication on YouTube can be studied by analyzing the communication around medical videos into three categories: there are informational (technical details about illness, condition, or treatment), emotional (provision or request for emotional support like prayer) and instrumental seeking comments (questions to other users about practical details of living with the disease or condition).

The study they performed shows the quantitative aspects of social communication on YouTube. A related study, a case study focusing on the social support messages of ulcerative colitis videos, used similar social networking categories (informational, emotional, and instrumental) to analyze in a medical context. It was performed by a member of the College of Journalism and Communications and University of Florida and was completed looking at discrepancies and variations in social support messages regarding ulcerative colitis. Their data concluded that out of the 16 professional and 18 lay person videos that informational messages were most frequently at 65.1% (questions to other users about technical details of the illness, condition or treatment and answers to those questions), followed by emotional support messages at 18.3%.

(provisions or request for emotional support, e.g., encouragement and prayers and replies). This category can be understood as a release of a private topic into the YouTube public domain. Other private information that would not be discussed in a public space in the world are questions to other YouTube users about practical details of living with the disease and answers to those questions. Those were categorized as instrumental support messages that occurred in 8.2% of ulcerative colitis videos. Conflict messages were infrequent with only 1.9% of comments fell into the category of antagonism toward views and ideas expressed by other users).\textsuperscript{35}

Through the utilization of the data above, I will examine the medical discourses talked about in ulcerative colitis videos within the privately public medium that is YouTube. This particular disease usually creates more health issues than digestive ones. A substantial amount of information on life management and the psychological impacts of this disease are available on YouTube.

Collectively, there are both thousands of videos and comments from other diagnosed sufferers, that one can easily relate and learn valuable tips from those more experienced. These videos have an incredible ability to be positively impact the lives of anyone living with ulcerative colitis.

Ulcerative colitis is an autoimmune disease of the intestine, specifically the large intestine, or colon, and the main symptom is usually diarrhea mixed with

\textsuperscript{35} Frohlich, Dennis, and Anne Zmyslinski-Seelig. \textit{The Presence of Social Support Messages on YouTube Videos About Inflammatory Bowel Disease and Ostomies}. College of Journalism and Communications, University of Florida. 2011. Digital Download.
blood, of gradual onset. The symptoms are often socially taboo and therefore can further alienate those suffering from this disease. Ulcerative colitis affects less than 0.1% of the US population. Treatment of this disease can be mediated with anti-inflammatory drugs and biological therapy targeting specific components of the immune response, however, this is often not successful. Finally, those with untreatable ulcerative colitis may have to undergo a colectomy, which is a partial or total removal of the large bowel through surgery. This is intended to be the only cure for the disease. Without a colon, there can be no inflammation and therefore symptoms. In order to still digest, an ileo-anal pouch, a bag situated near the abdomen, forms a reservoir to handle excrements and requires self-disposal.

Due to the disease’s rarity in the population, it can be very difficult to gain understanding as a direct patient or as a friend of a patient. One suffering from ulcerative colitis may lack social support altogether, or rather there is an absence of social support from others suffering from ulcerative colitis as well.

Ulcerative colitis disease affects people of all ages, especially children and teens. Symptoms start between the ages of 15-30. The symptoms of this disease can be debilitating physically if not always mentally and emotionally and usually results in a lowering of the quality of life. Embarrassment and even

37 http://www.mayoclinic.com/health/ulcerative-colitis/DS00598
shame often accompany those who are symptomatic in public (before or after surgery).

Privately, patients discussed their conditions with a limited number of supporters (some healthy and some perhaps similarly diagnosed) and also obtained information from a personal physician. With the use of the Internet as a medium of disease information, as well as videos on YouTube, what was once a private-only matter like managing symptoms of ulcerative colitis, can be made public and have a number of outlets for expressive dialogue as well as information.

The most popular video that is a result for an “ulcerative colitis” search on YouTube led me to the following video from the Cleveland Clinic’s channel of YouTube videos (there was a total of 2,200 results for ulcerative colitis on the initial search). The Cleveland Clinic is one of the most elite hospitals in the world. Their YouTube channel consisting of 42 videos on a variety of medical conditions has a total of over 830,000 views. Topics such as nuclear medicine, transplant, epilepsy, kidney cancer, and gynecological surgery are available videos. The only thing that the Cleveland Clinic can guarantee is delivery of accurate information, but the additional benefits of social networking is out of their control. Faithfully, each video has beneficial dialogue for users to read and also add to.

One of their more popular videos on their YouTube channel is about ulcerative colitis and tells the story of a woman (Kelly) who underwent surgery at their hospital to remove her entire large intestine and add an ileo-anal pouch.
This particular video is educational and includes physicians speaking about the disease and patient treatment options to improve quality of life. Also, the video features Kelly discussing her experiences with ulcerative colitis and life after surgery within physical and mental discourses surrounding this personal disease. She explains in great detail what her personal experiences were before and after surgery at the Cleveland Clinic, and Dr. Geisler, her surgeon, explained his diagnosis and treatment options for Kelly’s management of a disease without a cure. Patients can obtain as much information as possible from doctors trained in that specialty, but rarely does another patient hear and see a person giving their own story in real life. YouTube makes this phenomenon of sharing and consuming of experiences easy and accessible. Below are screen shots.

The woman (Kelly) takes the viewer on an emotional journey through her own experiences. She begins her narrative by discussing her stomach pain while

39 Ulcerative Colitis: Diagnosis and Treatment. Retrieved 10/13/11
http://www.youtube.com/watch?v=-WX4Inkgt4&feature=related
she was a teenager happily unaware of her condition. And then at the age of 21, away from home at college, she found blood in her stool. Soon after that fateful day, she was diagnosed with ulcerative colitis.

A time of great turmoil and fear can be eased with knowledge of others’ similarly scary experiences. She shares a lot of information about her fears. She had reservations for leaving her home for subsequent semesters once she was diagnosed. The disease overwhelmed her mentally and physically. She was constantly worrying of finding the nearest bathroom wherever she was.

The platform for communication is filled with dialogue between patients diagnosed with ulcerative colitis. One nervous user wrote in, “I got diagnosed with this today please don’t tell me you need surgery [to remove colon]”. When clicking on the username one sees that user is in the United States and is 15 years old. A response to this comment was made around the same time period. The comment reads:

@RichKJR14 Surgery to remove parts of the stomach which is affected is the LAST thing your doctors will want. First they will want to put you on medication, for a while, maybe the rest of your life to contain it, ask about Asacol, i find it the most helpful, but as i said, surgery is a permanent solution to Ulcerative Colitis but it's a last option, i hope you find this information useful! I was diagnosed with Ulcerative Colitis when i was 13! I'm currently 16, good luck to you mate!“

As such threads indicate, patients are using YouTube’s videos as not simply a medically informative medium, but as a portal to a virtual community with hopes of sharing and learning about experiences. Some comments are not

40 http://www.youtube.com/watch?v=--WX41nkgt4&feature=related
simply in response, but include people sharing their own personal stories about past and present battles. A 28 year old writes,

I was just diagnosed with Ulcerative Colitis this week after not knowing for 5 months what was wrong with me. Lost 25 pounds, it caused me to be anemic. I haven't worked in 3 months. Just hoping the medication works and I start feeling better 41

Another comment reads, “I'm going to have my colon removed this Friday. I'm looking forward to returning to a normal life.” says a 46 year old YouTube viewer and interactive member. Without a real-life support group accomplishing the needs of these individuals, they turn to the public sphere in search of answers. YouTube allows for the constrictive privatization of illness discourses to be dilated in a safe public platform and perhaps improve future experiences.

Section 2: Cancer Narratives

Personal narratives hold enormous potential as cancer communication tools, especially as social media continues to transform the way people interact with cancer-related information.

41 http://www.youtube.com/watch?v=--WX4lNkgt4&feature=related
It has been proven that cancer has an ability to be affected by the expression of emotion and experiences of the cancer patient. Cancer stories are especially significant in the context of digital communication because of both the disease’s lethality and sensitivity to positive thinking and expression. YouTube ultimately provides a stage for this dissemination of information and experience.

To determine whether incorporating a narrative approach in patients with cancer decreases pain intensity and improves their global sense of well-being, scientists performed in a single-blind study where cancer patients with an average pain rating of 5/10 were placed into three groups for study. One group was the narrative group \((n = 79)\), in which patients wrote a story about how cancer affected their lives for at least 20 minutes once a week for three weeks; (the second group was given a questionnaire \((n = 77)\), in which patients filled out the McGill Pain Questionnaire; and the third group was the control \((n = 78)\), in which patients came weekly to medical visits during which they received usual customary care. Patients rated their pain on a 0–10 scale and their well-being on a seven-point scale, weekly for eight weeks. There was no significant difference between the three groups after the eight weeks. However, subgroup analyses showed that patients whose narratives had high emotional disclosure had significantly less pain and reported higher well-being scores than patients whose narratives were less emotional.\(^{43}\)

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\(^{42}\) Chou, Hunt, Folkers, Auguston. *Cancer Survivorship in the Age of YouTube and Social Media: A Narrative Analysis*. National Cancer Institute,

The storytelling in this study was completed with pen and paper, however, it can be somewhat extrapolated to the storytelling on YouTube. The power of emotional expression occurs every day on YouTube, and hopefully the ability to showcase emotion flourishes. And according to the research, pain can perhaps be alleviated.

There is a beneficial symbiosis between medical information and medical experiences on YouTube cancer videos. Not only is there emotional expression, but also there is simultaneous access to medical information making the connection between information and expression fluid.

To examine the dichotomy of expression and information, it must be clear that the diagnosis of cancer and its subsequent treatments are often psychologically intense, in addition to the evident physical problems of cancer cell growth. Patients usually meet regularly, or weekly, with their cancer physician to discuss treatment and other discourses around the disease.

Oncology is a specialty in the medical field that requires knowledge of the type of cancer, the therapy (often consisting of a combination of chemotherapy, radiation, and surgery), knowledge of follow-up treatment and additional ethical questions surrounding cancer care.

All of these responsibilities can be a quite a lot for one patient and one oncologist to understand. Many Americans have no access to other cancer patients or other oncologists to help shape their overall discourse around a deadly disease. YouTube changes these rarities into consistencies through its use of
video-blogs and comments as ways of expressing private matters in a public website.

Combining narrative with a platform for YouTube-mediated communication, American Cancer Society (ACS) has a YouTube channel with a total of 3,194,682 views spread over 184 total videos. The ACS is a nationwide community-based voluntary health organization dedicated to, in their own words, “to eliminate cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service.” Their YouTube channel has content spreading over all pillars of their fight on cancer. The videos are another option of delivering information rather than real-life platforms for the ACS. When typing into YouTube’s search bar, “cancer survivor” the fourth video includes content with three individual stories of survivorship. The video has been uploaded and edited by the ACS in a series called “Stories of Hope”.

There are 34 comments on this particular video and over 13,000 views. As a promotional video for the ACS, this video pledges to aid in emotional and physical support for cancer patients. The patients in the video tell stories of survivors using the assistance of the ASC. These stories can help cancer patients relate to experiences and also leaving expressive comments and questions after the video. These contain both the pros and cons of the ACS. For example, one survivor says in the comments, “I was diagnosed with leukemia. Telling your mother, and dad, and sisters, and brother it is very difficult to let them know if

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44 www.cancer.org/aboutus/index
45 http://www.youtube.com/watch?v=TNFZNSXijM
you will live or die. That’s the beginning. We did not know where to go. ACS was helpful, but they love S” This video shows some viewers that there are similar people also with families that understand the complexity of the disease’s impact on your life, and in the comments section one viewer writes in, “My brother had cancer and did not tell us for quite some time…the video makes a lot of sense”, this sharing of opinions shows the effectiveness of the private material in the public platform of YouTube.

Altogether, the benefits of telling cancer stories are encouraging viewers also while positively changing beliefs and attitudes about cancer patients and victims. The content in a cancer video can often be an “elephant in the room” and through a patient’s expression on camera or in text, the “elephant” be recognized and perhaps provide support to others feeling the same way. Among the common threads of the details to cancer patient stories is the moment of cancer diagnosis. This was present in almost every cancer story studied in a peer-reviewed journal. Ultimately, sensitive subjects can be publically expressed and through that expression, patients themselves can better understand their own anxieties and problems.

Patients consistently framed the cancer diagnosis as something very unexpected, tense, and emotional, and always beyond their control. YouTube’s


social networking platform allows the sharing of similarly personal experiences of feeling out of control. The comments sections can be a painless and rapid way to express thoughts after viewing the video. For some, the comments are the ways in which they share and cope with their cancer.

Perhaps more unexpectedly than the fact that cancer videos usually contain the experiences at the moment of diagnosis, is that patients rarely highlighted the role of their physicians in their videos, suggesting it was not a central part of their experience. Since the personal cancer discourses for these patients did not manifest itself discussion of physicians in their videos, it is clear that expression on YouTube is generally personal and only focused on themselves and their loved ones. YouTube offers patients to talk with one another and show empathy in absence of a physician to freely express fears.

The other element of cancer videos on YouTube is the simultaneous ability to learn and express. In addition to cancer stories delivered from patients that ultimately facilitate communication, there is information from Johns Hopkins. They uploaded a video containing cancer surgeons and their patients. The video features well-versed physicians with great experience in saving people’s lives. The viewers received practical medical information independent from their own physician and perhaps also volunteering to interact with the content by posting or reading comments. While it is important to have trust in one’s physician, it is always an advantage to gain as much information about a disease as possible, and Johns Hopkins accomplishes this. The introduction to the video is a still shot of a patient and his diagnosis: Grade II astrocytoma (brain
tumor), followed by a narrative of his experiences and his surgeon’s experiences. Carlos explains,

In June, I had brain surgery for a tumor that was found in the same month. Now, I am living the brain cancer life of seeing to what is on a day-by-day basis and MRI-to-MRI basis. It like being in a comic book and living my life with a question mark over my head. I just laugh to myself and take my life day by day.\(^\text{48}\)

The video then cuts to his Johns Hopkins surgeon who says, “Carlos is just an incredibly upbeat person no matter what he was facing. He wanted to have insight and talk all it through. He faced it fearlessly.”\(^\text{49}\)

The video’s symbiosis between information and expression is beneficial for viewers to gain two different types knowledge, while also interacting in a social discourse in the comments section. A screen shot of such the video is present below. Discourses around cancer are discussed by an unbiased physician in this video and offer incredible insight into a successful cancer story. Below are screenshots of the video and also the comments section.

\(^{48}\) http://www.youtube.com/watch?v=soKTLcW3vSI
\(^{49}\) http://www.youtube.com/watch?v=soKTLcW3vSI
\(^{50}\) http://www.youtube.com/watch?v=soKTLcW3vSI
These comments range from positive reinforcers to the sharing of personal experiences. The comments originate from loved ones of cancer survivors and even survivors themselves. Collectively, there is a magical community of strangers creating a discourse around a cancer video unlike anything that could be done in the real world. The comments can be saved and re-read at future times. Sharing of additional videos can be posted on the comments and facilitate further cancer story videos to watch. Also there is the anonymity and privately public nature of the comments that makes some more comfortable to express rather than in a real-life scenario. The quantity of expressed experiences is unlimited. With

51 http://www.youtube.com/watch?v=soKTICw3vSI
millions of YouTube users watching videos every minute, a cancer patient has the opportunity to read and hear from a large number of individuals. The information is available any time of the day. Understandably, YouTube’s medical content contributors may not communicate as vividly in a real world situation.

Social support groups or other real-life scenarios for may be helpful for some cancer patients, but YouTube is another accessible outlet for learning and sharing. The examples conclude that there is little for physicians to be fearful of, and a lot for patients to be excited about. Ultimately YouTube’s medical community allows confidence and knowledge to potentially overpower some health concerns
Conclusion

Physicians today are increasingly aware of the Internet and computer-mediated-communication as vehicles for transmitting medical information. This is important since YouTube will undoubtedly remain a successful video-sharing site, and further use of it as a source of medical content is warranted through both empirical and anecdotal evidence.

Shedding unforeseen light onto serious medical conditions, YouTube has a unique ability to inform those with limited knowledge about the scientific details of diseases. Comments and questions from patients and physicians allow for communication within an easy social networking platform. The sharing of stories flow effortlessly in the form of both comments and video-blogs within practically any condition described in medical textbooks.

YouTube can be extremely beneficial for physicians as well as patients for obtaining helpful information regarding various medical discourses. Empathy is crucial for a successful patient-physician relationship. By understanding the troubles and overall experiences of patients, physicians can better tailor their treatment of the patient as a whole. Emotional and social well being is a pillar that every patient hopes their physician will comprehend. YouTube can function as an interlocking community of numerous individuals with similar experiences and therefore promote communication not normally discussed in the presence of their physician. Finally, a physician may stumble upon a video-blog and learn
about some emotional point of view, and thus positively benefit future relationships he/she has with patients.

Overall, the unification of patients on YouTube, through video watching creating, and interacting with, allow for a democratic representation of diseases to prosper in a time when healthcare is restricted. Both physician and patient-created videos create a “Dr. YouTube” that is capable of incredible aid.

As a country in serious economic issues and an uncompromising shortage of physicians, the use of YouTube as an interactive medical media outlet may be the best cost-effective option for alternative medical content, and hopefully can improve the quality of lives, one view at a time.
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