

University of Kentucky UKnowledge

Theses and Dissertations--Communication

Communication

2019

A Descriptive Analysis of Health Influencer Videos on YouTube in the Ostomy Community

Sarah Irenke Sophia Bell University of Kentucky, sarah.bell1@uky.edu Author ORCID Identifier: https://orcid.org/0000-0002-3477-4552 Digital Object Identifier: https://doi.org/10.13023/etd.2019.125

Right click to open a feedback form in a new tab to let us know how this document benefits you.

Recommended Citation

Bell, Sarah Irenke Sophia, "A Descriptive Analysis of Health Influencer Videos on YouTube in the Ostomy Community" (2019). *Theses and Dissertations--Communication*. 78. https://uknowledge.uky.edu/comm_etds/78

This Master's Thesis is brought to you for free and open access by the Communication at UKnowledge. It has been accepted for inclusion in Theses and Dissertations--Communication by an authorized administrator of UKnowledge. For more information, please contact_UKnowledge@lsv.uky.edu.



STUDENT AGREEMENT:

I represent that my thesis or dissertation and abstract are my original work. Proper attribution has been given to all outside sources. I understand that I am solely responsible for obtaining any needed copyright permissions. I have obtained needed written permission statement(s) from the owner(s) of each third-party copyrighted matter to be included in my work, allowing electronic distribution (if such use is not permitted by the fair use doctrine) which will be submitted to UKnowledge as Additional File.

I hereby grant to The University of Kentucky and its agents the irrevocable, non-exclusive, and royalty-free license to archive and make accessible my work in whole or in part in all forms of media, now or hereafter known. I agree that the document mentioned above may be made available immediately for worldwide access unless an embargo applies.

I retain all other ownership rights to the copyright of my work. I also retain the right to use in future works (such as articles or books) all or part of my work. I understand that I am free to register the copyright to my work.

REVIEW, APPROVAL AND ACCEPTANCE

The document mentioned above has been reviewed and accepted by the student's advisor, on behalf of the advisory committee, and by the Director of Graduate Studies (DGS), on behalf of the program; we verify that this is the final, approved version of the student's thesis including all changes required by the advisory committee. The undersigned agree to abide by the statements above.

Sarah Irenke Sophia Bell, Student Dr. Nancy Harrington, Major Professor Dr. Bobi Ivanov, Director of Graduate Studies



A DESCRIPTIVE ANALYSIS OF HEALTH INFLUENCER VIDEOS ON YOUTUBE IN THE OSTOMY COMMUNITY

THESIS

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Arts in the College of Information and Communication at the University of Kentucky

By

Sarah Irenke Sophia Bell

Lexington, Kentucky

Director: Dr. Nancy Grant Harrington, Professor of Communication

Lexington, Kentucky

2019

Copyright © Sarah Irenke Sophia Bell 2019 https://orcid.org/0000-0002-3477-4552



ABSTRACT OF THESIS

A DESCRIPTIVE ANALYSIS OF HEALTH INFLUENCER VIDEOS ON YOUTUBE IN THE OSTOMY COMMUNITY

The expansion of YouTube into the mainstream media and its place as the second most-used website in the world makes it a prime place for health information seeking. However, content can be created and uploaded by anyone and thus, the threat of misinformation on YouTube is high. Medical researchers have established that videos created by health professionals on YouTube promote accurate information whereas videos by non-professionals promote generally inaccurate or misleading information. Yet, videos created by non-professionals have more views and higher relevance rankings on YouTube. To begin to understand this phenomenon, a descriptive study is used to lay a foundation for this area of health communication This study focused on the ostomy community of non-professional content creators on YouTube to. The goal of this study was to thoroughly describe the innate features of the videos using media richness theory, and to describe social support and illness narrative using the framework of social presence theory. The results from the study provide deep description into this particular community of non-professional health influencers and make way for a new line of research in the communication of health information.

KEYWORDS: media richness theory, social presence theory, ostomy, YouTube, nonprofessional health influencers

> Sarah Irenke Sophia Bell (Name of Student)

> > 05/01/2019

Date



A DESCRIPTIVE ANALYSIS OF HEALTH INFLUENCER VIDEOS ON YOUTUBE IN THE OSTOMY COMMUNITY

By

Sarah Irenke Sophia Bell

Dr. Nancy Grant Harrington

Director of Thesis

Dr. Bobi Ivanov

Director of Graduate Studies

05/01/2019

Date



ACKNOWLEDGEMENTS

First, I would like to recognize my chair Dr. Nancy Grant Harrington for guiding me through my master's degree and this thesis project. I would also like to thank my committee members, Dr. Allison Scott Gordon and Dr. Anthony Limperos, for their insight and expertise. The three of you have allowed me to merge many areas of communication research, and it has been a rewarding and fulfilling experience. Additionally, I would like to thank my fellow graduate student Katherine Harville for her work on this project as my second coder. This project would not have been possible without the hard work that you put in.

Further, I want to thank my family for their endless support in my academic endeavors. My sweet dog, Belle Bell, also deserves recognition and probably coauthorship on this paper for the countless hours she sat by my side while I typed away. Finally, thank you to my always supportive and loving life partner, Bryce. You keep me calm through moments of stress and always encourage me in every goal I set for myself.



ACKNOWLEDGEMENTSiii
LIST OF TABLES
LIST OF FIGURES
CHAPTER 1: INTRODUCTION
1.1 YOUTUBE MONETIZATION AND REGULATION1
1.2 YOUTUBE, SOCIETY, AND EDUCATION
1.3 PROBLEM AND PURPOSE OF STUDY
CHAPTER 2: LITERATURE REVIEW
2.1 OSTOMY COMMUNITY AND ETIOLOGY9
2.2 OSTOMIES AND STIGMA10
2.3 YOUTUBE AND HEALTH INFORMATION SEEKING12
2.3.1 YouTube Search Function.142.4 MEDIA RICHNESS THEORY AND VIDEOS15
2.4.1 Video Features.182.5 Social Presence Theory.20
2.5.1 Social Support222.5.2 Illness Narrative25
CHAPTER 3: METHOD
3.1 Research Design
3.2 SAMPLING PROCEDURE
3.3 Coder Training
3.4 Analysis
CHAPTER 4: RESULTS

TABLE OF CONTENTS



4.1 VIDEO DESCRIPTIVE INFORMATION
4.2 VIDEO FEATURES RESULTS
4.3 Social Support Results
4.4 NARRATIVE RESULTS
CHAPTER 5: DISCUSSION40
5.1 VIDEO FEATURES DISCUSSION
5.2 Social Support Discussion
5.3 NARRATIVE DISCUSSION
5.4 LIMITATIONS
5.5 FUTURE DIRECTIONS
5.6 CONCLUSION
APPENDIX
REFERENCES
VITAE65



LIST OF TABLES

Table 1 Health Misinformation Studies	6
Table 2 Codebook 3	31
Table 3 Inter-Coder Realiability (Krippendorff's Alpha)	33
Table 4 Descriptive Statistics of the Gender of Channel Owners	35
Table 5 Descriptive Statistics of the Race/Ethnicity of Channel Owners	36
Table 6 Descriptive Statistics of Channel/Viewership Demographics	36
Table 7 Descriptive Statistics of Ratio Video Features	37
Table 8 Descriptive Statistics of Social Support	38
Table 9 Descriptive Statistics of Illness Narrative	38
Table 10 Analysis of Variance (ANOVA) Between Narrative Type and Engagement	39



vi

LIST OF FIGURES

Figure 1. Model of information processing (modified from Daft & Lengel, 1984, p. 14) 16



CHAPTER 1: INTRODUCTION

YouTube launched in 2005 with the goal of allowing people to "Broadcast Yourself" by posting original videos to the Internet. Since then, the site has grown from a cult following to a massive media platform with more than one billion users. Second to Google, which owns it, YouTube is considered the largest search engine in the world, with a massive reach into 91 countries and more than one billion hours of video watched every day ("YouTube for press," n.d.). People often think of YouTube as the place where you go to watch funny animal videos or viral pranks. However, aside from entertainment, YouTube is consistently used as a source of information on topics such as sports, do-ityourself, news, health, and more.

For the purposes of this project, I focused on YouTube as source of health information. On YouTube, a keyword search of the word "health" yields millions of results. In the field of health communication, scholars are often concerned with the quality, source, and dissemination of health information. YouTube is a relatively unexplored source of health information and thus, is the general focus of the study. Throughout this chapter, I provide background information on YouTube's monetization process and video regulation, discuss YouTube's role in our society and education, and finally outline the problem that I explored deeper in this study.

1.1 YouTube Monetization and Regulation

In 2007, YouTube began paying content creators, or "YouTubers," for their work. The belief was that YouTubers' content is just as important and of just as high quality as the three major media networks in the United States (ABC, NBC, and CBS; Kim, 2012). However, not everyone makes money from YouTube; creators must reach certain



requirements in views and subscriber count to qualify for the monetization program. Regardless, money was a big incentive. and people quickly began making massive amounts of content to gain followers and views. Since about 2007, the upload rate has not wavered: There is more uploaded to YouTube in 60 days than all three of the major media companies created in the last 60 years (Drell, 2011). This is attributed the fact that anyone can create an account and upload content to YouTube. Some people are motivated by the monetization aspects, whereas others are just using it as platform to share videos.

Regardless of the intentions of uploading, though, there is a lack of consistent regulation and monitoring of video content. Although there are two primary forms of regulation on YouTube, both are problematic. First, the website created a program called Content ID that scans each video for copyrighted material. However, there are no legal implications for posting copyright materials on YouTube; users are simply removed from the site after they have received three copyright violations (Drell, 2011). Although Content ID is powerful, it can only be used for copyrighted material; it cannot scan for false or misleading information (Drell, 2011). Instead, YouTube video regulation relies on users to report when there is a problem, which is accomplished through a simple digital form available under each video. Individual users can report on the following grounds: sexual content, violent or repulsive content, hateful or abusive content, harmful or dangerous acts, child abuse, promotion of terrorism, spam or misleading content, infringement upon on rights, or caption issues. Once someone reports a video, a staff member at YouTube then manually reviews the video and decides whether the video should be removed from the website. However, this process only works if people decide



www.manaraa.com

to report the video. Further, it is unlikely that the staff members reviewing the videos are content experts and would be able to discern whether the information provided is misleading or not. The system in place for regulation is far from perfect, but is important as YouTube plays an important role in today's society.

1.2 YouTube, Society, and Education

Beyond merely serving as a platform to post videos, YouTube has a major impact on our society. There have been dozens of sensationalized and viral videos on YouTube that have crossed over to mainstream media. For example, Fred Figglehorn was a fictional character that first appeared on YouTube. After proving successful on YouTube by accumulating millions of views and followers, the Fred character was cast in TV shows on Nickelodeon, and three feature films have been made around the character ("Lessons from Fred Figglehorn," 2016). YouTube has also been shown to help artists get discovered and move into the mainstream media (Kim, 2012). For example, Justin Bieber was discovered on YouTube and now has dozens of awards for his music, including a Grammy. In addition, YouTube sometimes creates the news. In December 2017, Logan Paul, who has 18 million subscribers and growing, posted a highly controversial video of himself and his friends laughing and running around the dead body of a man who committed suicide in the Japanese Suicide Forest. This video garnered international attention and brought to light the insensitivities and issues surrounding mental health and suicide. This video set the agenda for a 24-hour news cycle (Shamsian, 2018).

Aside from entertainment-based channels, education-based channels have played a significant role on YouTube. Patrick JMT is a math-based channel offering easy to



www.manaraa.com

follow calculus, geometry, and algebra videos; it currently has more than 274 million views (Chess, 2014; "patrickJMT," n.d.). Another YouTuber named Steve Spangler teaches families and children about science through extreme and creative experiments. Since the success of his YouTube channel, he has made numerous television appearances, created his own television show on Fox, and developed a line of at-home science experiment kits (Gingiss, 2018; TheSpanglerEffect, n.d.). Finally, Dr. Sandra Lee, also known as Dr. Pimple Popper, has made dermatology and "zit popping" a mainstream fascination. She aims to educate her massive audience on different skin, hair, and nail related issues and surgeries. She claims to be "the ultimate source for pimple popping, skincare, and dermatology" and has since garnered her own show on TLC (Dr. Sandra Lee, n.d.). All three of these success stories are professionals: Patrick is a university math professor, Spangler is an elementary school science teacher, and Dr. Lee is a boardcertified dermatologist, and all three are monetized content creators. Whereas content creators like these have formal training and authority on their topics, a lack of regulation on YouTube opens opportunities for non-professionals or non-experts to post so-called educational videos that may contain more problematic material.

1.3 Problem and Purpose of Study

As on other social media platforms, communities of people with common interest areas began to naturally form on YouTube. One such area is health education. The communities form around the publication of video content related to a specific disease or condition. People who watch and create the videos can interact through comments, messaging, and liking. Social media influencers (SMIs) is a term used to describe those who use social media to shape audience attitudes (Freberg, Graham, McGaughney, &



Fregberg, 2011). The different genres or topics on YouTube have then coined their own sub-names. Those who make videos about beauty are called beauty influencers, those who focus on gaming are gaming influencers, and those who focus on health are called health influencers. These names are relatively colloquial but are used in pop-culture news articles to describe these communities.

Generally, health influencers focus on one theme or illness, and they often discuss the medical etiology behind the illness and its effects on a person's life. They often drive the conversation on health topics and position themselves as credible sources of health information (Heldman, Schindelar, & Weaver, 2013). For example, some channels focus on fitness or nutrition as an aspect of health, whereas other channels zero in on a disease like breast cancer or asthma. The influencers who make the content are sometimes trained professionals (physicians, nurses, dieticians, personal trainers, etc.), but not always. Instead, health influencers often are simply those who have a direct connection to the disease or condition or have experienced personal success with their own health. In most videos, the health influencers share practical knowledge for self-care and suggest what viewers should be doing with their personal health (Heldman, Schindelar, & Weaver, 2013). But there is some concern with this kind of personal experience sharing because it has potential to lead to the proliferation of misinformation.

The medical research community has shown particular interest in YouTube health videos, and studies have aimed to determine the amount of misinformation on the website. In many of these studies, the authors have shown that much of the medical health information is either misleading or purely anecdotal. Table 1 displays the topic, sample, and conclusions from multiple studies about health YouTube videos. A common



theme throughout these studies is that the "good" videos that provide accurate information are those from health professionals or hospitals. However, these "good" videos often fall toward the bottom of the search list and have fewer views, whereas videos from non-professional health influencers are near the top.

Author(s)	Topic	Sample	Conclusions
Adhikari et al.	Cervical Cancer	172 videos:	More views on non-
(2016)		Mix of	professional videos, but these
		professional and	videos lack the same level of
		non-professional videos	quality information
Bademci et al.	Deep Venous	485 videos:	Most videos were found to
(2016)	Thrombosis	Mix of	only have partly sufficient
	(DVT)	professional and non-professional videos, TV shows, website advertising	and accurate information on DVT
Biggs et al. (2012)	Rhinosinusitis	100 videos: first one hundred videos from keyword search "sinusitis" were selected as the sample	Majority of the videos (55%) were found to contain no useful information; authors do not approve of YouTube as reliable source of information and warned people against watching videos from non- professionals
Murugiah et	Cardiopulmonary	52 videos: mix	An assessment of the videos
al. (2011)	resuscitation (CPR)	of non- professional and professional	as CPR self-instruction concluded that most videos included the vital information and could be useful in teaching CPR or in emergencies
Pant et al.	Acute	104 videos: mix	Concluded that based on
(2012)	Myocardial	of non-	views, comments,
	Infarction	professional and professional	liking/disliking of videos that people are more interested in

Table 1 Health Misinformation Studies



			using YouTube as a source for hearing personal stories of individuals rather than disease etiology
Pathak et al. (2015)	Ebola Virus Disease	118 videos: mix of non- professional and professional	Categorized videos as useful or misleading and found that most videos on Ebola disease, regardless of source, were useful. However, those from non-professionals contained the majority of the total misleading videos
ReFaey et al. (2018)	Glioblastoma	9 videos: official videos only (universities and hospitals)	Designed the DISCERN measurement tool to do an in- depth analysis of all 9 videos; their results suggest that there is limited accurate and reliable information about glioblastoma on YouTube
Sood et al. (2011)	Kidney Stone Disease	199 videos: non- professional and professional videos	These authors categorized videos as useful, misleading, or personal views. Fortunately, those videos that were categorized as misleading only shared about 2.8% of the views. However, the authors argued that the bias within the personal views (non-professional) videos made them more or less useless sources of information
Sunderland et al. (2014)	Respiratory Auscultation	36 videos: only videos meant to represent "breath sounds" related to respiratory auscultation	This study was meant to examine the quality of respiratory auscultation videos meant to act as teaching materials for medical students, only 36 videos were found suitable and received further examination



In the literature, there is a lack of research on why such differential viewing occurs and what makes the non-professional videos more viewed. However, some authors have proposed "solutions" to this problem. The suggestion was for medical professionals and organizations to create more videos to add to YouTube, essentially to "saturate" the market with more medical professional videos to overtake the "bad" videos (Adhikari, et al., 2016; Pant, et al., 2011). I do not think this is a viable solution, nor do I think that saturating the market will have a profound effect on what people want to watch. It is not as simple as pushing more content in front of the viewers. So, in order to begin to fix this problem, we need to have a better understanding of what the nonprofessional videos look like. Through a descriptive content analysis, I can begin to build the foundation in understanding the unique aspects of these videos. A descriptive content analysis provides the clarity necessary when beginning to uncover a new area for health communication research. Therefore, the goal of this study is to gain a deeper understanding of YouTube health information and influencers and to describe various characteristics of these non-professional videos as they currently live in the YouTube landscape.

Copyright © Sarah Irenke Sophia Bell 2019



CHAPTER 2: LITERATURE REVIEW

Health influencers create content on a wide variety of topics; however, most people focus on one topic or disease. For this study, videos from the Ostomy community¹ were sampled and analyzed. The ostomy community was selected because of its size and the availability of non-professionally made videos. The community and etiology of the condition is discussed in further detail in this chapter. One important aspect of the ostomy community is the relationship that patients have with experienced stigma. Thus, I focus attention on stigma in this chapter as well. Additionally, health information seeking is discussed in this chapter as a central feature of online health information and YouTube health videos. The health information seeking process on YouTube is limited by the platform's innate search functions; thus, I provide an explanation of those. Media richness theory acts as one of the theoretical frameworks to understand and shape the questions of this thesis. The theory is discussed and expanded upon as related to the video features. Finally, social presence theory is used to further expand upon two different aspects of these videos: social support and illness narrative.

2.1 Ostomy Community and Etiology

There are dozens of YouTube communities that focus on different health topics. So, when determining the community to choose, I considered several factors. First, I considered the size of the community and availability of videos. The ostomy community has nearly 40 channels that consistently post or have multiple videos on the topic. There are hundreds of non-professional videos to choose from. Further, I wanted to choose a

¹ A group of people who create and watch videos on the topic of ostomies. An ostomy is a procedure that allows bodily waste to pass through a surgical opening and into a disposable prosthetic pouch.



group that had community connections. Community-like behavior can be seen in the nickname "Ostomate," which is given to those who have ostomies and engage with the YouTube videos. Additionally, a sense of community can be seen in the comments sections of videos. Those who have their own channels reach out and comment on each other's videos and even refer to other channels in their videos.

The etiology and prevalence of ostomies is considerable. An estimated 750,000-1,000,000 people in the United States have ostomies. Ostomies, which often are referred to as stomas, are openings in the body that allow for the escape of bodily fluids that are unable to be expelled normally. There are many reasons someone may need to have an ostomy procedure performed, including birth defects, cancer, injury, bowel obstructions, and inflammatory bowel disease (United Ostomy Associations of America Inc., 2005). Ostomies are not a disease but rather a condition that results from a surgical procedure needed to address one or more of a wide variety of diseases and conditions. Colostomies, ileostomies, and j-pouches are the three types of ostomies that require a person to wear a disposable prosthetic pouch on the outside of their body to collect waste (United Ostomy Associations of America Inc., 2005). Due to the pouching system and surgical opening, at-home care is required, and therefore, the content on YouTube often surrounds the required at-home care procedures. Other video topics may include lifestyle advice and discussions of mental health related to being an ostomy patient. Overall, ostomy videos are a good choice for this study due to their availability, size of community, sense of community, and disease prevalence.

2.2 Ostomies and Stigma

Stigma is often a reported fear or actual outcome of an ostomy procedure. Stigma



is a social construct based on stereotypes that people use to characterize a group of people or a condition (Smith, 2011). Research shows that ostomies elicit the emotion of disgust, which leads to its stigmatization (Smith, Loewenstein, Rozin, Sherriff, & Ubel, 2007). Having a stigmatized disease has been shown to delay treatment, affect decision making, lead to poor treatment adherence, and increase the risk of recurrent health problems (Heijnders & Van der Meij, 2006). Poor adherence to the treatment plan is especially dangerous for ostomy patients because there is higher risk for infection due to the direct surgical opening in their body.

For those with a stigmatized disease, they often see their social networks being challenged. In a study of young adults with ostomies, the most commonly reported feelings were embarrassment, feeling different from others, and frustration (Savard & Woodgate, 2009). Sometimes these feelings force those with the disease to limit their social network to just loved ones and close friends in an effort to avoid being stigmatized by others (Smith, 2011). Some patients avoid people altogether due to the fear of leakage and bad odors from the pouch (Persson & Hellstrom, 2002). Those with ostomies have also been shown to feel restricted when it comes to recreation, travel, and leisure and therefore miss out on expanded social connections from those activities (Karadag et al., 2003). Finally, dating and sexual activity are common concerns among ostomy patients (Black, 2004). All of these issues related to stigma can influence the quality of life (QOL) experienced by ostomy patients.

Karadag et al. (2003) discussed how a lack of education, counseling, and therapy opportunities contribute to the negative QOL reported by ostomy patients. The researchers introduced an expanded education and therapy regimen into the lives of 43



ostomy patients. The intervention aimed to teach patients how to better care for their physical bodies and how to cope with the mental toll of having a stigmatized condition. The intervention consisted of regular counseling on issues like body image, stoma appliance choices, and stoma irrigation techniques. Overall, the intervention was successful, and patients began reporting improved QOL (Karadag et al., 2003). However, these kinds of interventions are not readily available to ostomy patients, and thus, patients may be forced to search elsewhere for this kind of support. Due to the challenged social networks because of stigmatization, patients may turn to the Internet for information about ostomies. The Internet allows patients to search for information without having to engage with people. This behavior is called health information seeking.

2.3 YouTube and Health Information Seeking

Health information seeking behavior (HISB) is central to this study. It is defined as "a purposive act intended to satisfy a perceived need for health information" (Galarce, Ramanadhan, & Viswanath, 2011, p. 168). According to Galarce et al. (2011), people generally engage in HISB when they feel they do not have enough information or they dislike or are not satisfied with the information they have been given. Further, HISB is useful in reducing uncertainty and aiding in decision-making processes. The source of information is chosen based on its unique characteristics, which includes accessibility, familiarity, trustworthiness, attractiveness, and reliability (Galarce et al., 2011).

According to Sundar, Rice, Kim, and Sciamanna (2011), the majority of people in the United States engage in HISB by using the Internet. E-health was coined as the term to describe all the health information and platforms available online to help patients. Health websites and online tools like email have begun to not only help patients find



more information but also directly connect them to their physicians. E-health provides several advantages including emotional support, increased access to health information, reduced costs, and tailored health information (Sundar et al., 2011).

Peer-to-peer websites are those where patients can talk with other patients about their questions or worries. Often the sites are disease specific. For example, tudiabetes.org provides peer-to-peer support for those who have diabetes (Shaw & Johnson, 2011). Peer-to-peer websites have produced a phenomenon where patients are now considered "experts" about their disease (Sundar et al., 2011). Ancker et al. (2008) studied peer-to-peer communication on two websites to look at cancer prevention communication. They found that people had four main goals when on the peer-to-peer websites: the sharing and receiving of (a) health information, (b) emotional support, (c) instrumental support, and (d) the creation of social norms and community role models. Due to the stigmatization and life-altering nature of ostomies, there is a need for role models and normalization of the condition. However, the downfall of these peer-to-peer websites is that they only work if people are willing to visit them and engage with others. Unlike traditional social media platforms (Twitter, Facebook, YouTube, Instagram, etc.) that boast millions of users, peer-to-peer sites do not have the same publicity or usership (Shaw & Johnson, 2011). Although traditional social media platforms were not designed to serve as a place for peer-to-peer health information, communities surrounding different diseases and conditions have formed nonetheless. The ostomy community is one such community that has formed on social media. However, in order to understand how one may find the community, it is important to understand the innate search functions of the site.



2.3.1 YouTube Search Function.

There are several innate functions of the search features of YouTube and unique reasons that people click on certain videos over others. Some scholars have observed that more credible health videos from professionals do not tend to be in the top of the search results and lack the views that non-professional videos have (Adhikari et al., 2016). This could be due in large part to the search functions of YouTube. The website allows people to search key words and phrases, similar to the way Google works, but it does not have any advanced search options. As part of YouTube's efforts to regulate videos, programmers developed an algorithm based on watch time. This algorithm considers the amount of time a person watches a video based on their keyword. So, if a person searches the keyword "ostomies" and then watches only a small part of the video they chose, YouTube has interpreted this to mean that the user did not find what they were looking for. The algorithm takes this all into account when organizing the search page, placing the most "relevant" videos at the top and less "relevant" videos at the bottom (Robertson, 2014). Organization of the search page defaults to "Relevance," which is the algorithm at work. Users also have the option of sorting videos by upload date, views, and rating. However, because relevance is the default sorting tool, it is the most important when it comes to a casual user looking for a video or channel.

Another important feature of the search page is titles and thumbnails. The title is an indicator to the audience about the topic of the video. Videos that are mistitled will quickly fall to the bottom of the list because the algorithm will determine them to be less relevant to the keyword search and likely not what users were looking for. The thumbnail, which is an image associated with the video, is located on the search page



next to the title. Normally, it is a frame from the video itself, but sometimes it is an image created specifically to be the thumbnail. Either way, a thumbnail is supposed to be representative of the video content, and it provides viewers with a glance into the video itself. So, a quality thumbnail can often make or break the success of a video (Song, Redi, Vallmitjana, & Jaimes, 2016). Thumbnails are just one of the features of video-based content. There are more technological capabilities to video-based content than print resources. To explain the importance of this and other video-based content features, I used media richness theory as a conceptual framework for the present study.

2.4 Media Richness Theory and Videos

Daft and Lengel (1984) developed media richness theory to explain how information richness can be used by organizations to help reduce uncertainty and clarify ambiguity. Information richness refers to the amount of data a medium carries that allows the receiver to understand the message. A major factor that goes into richness is the ability of the medium to provide feedback. For example, Daft and Lengel (1984) considered face-to-face communication to be the medium highest in richness as it allows the receiver to get immediate feedback. Print information is low in richness because it lacks the immediate feedback associated with face-to-face communication. Further, faceto-face communication is considered richer because the receiver can observe other communication cues, including "body language, facial expression, and tone of voice" (Daft & Lengel, 1984, p. 9). The telephone, for example, provides immediate feedback, but the receiver is unable to observe communication cues like body language or facial expression. Thus, it not as rich as face-to-face communication but is richer than print.

However, information can be too high or too low in richness. There is a "sweet



spot" of information richness, which is called the domain of effective information processing. The domain of effective information processing allows receivers to gain the optimal amount of information. This is based on a positive relationship between the medium's richness and the complexity of the problem. For example, when information is high in richness, it causes over-complication, and the message is overwhelmed by all of the communication cues. The same occurs when the information is over-simplified: The receivers are unable to understand the message (Daft & Lengel, 1984). However, all of this is dependent on the complexity of the issue. If a problem or business matter is already well understood and routine, then a less rich medium may effectively get the message across. See Figure 1 below for a visual representation of information processing.

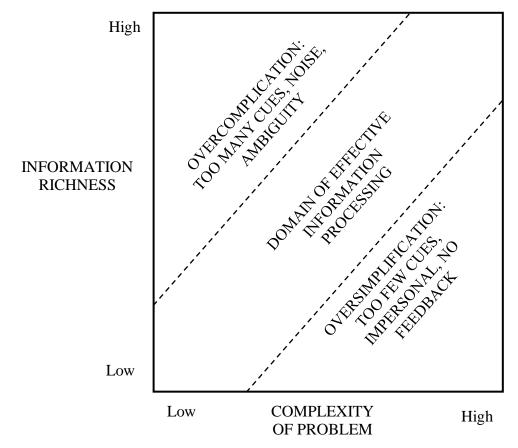


Figure 1. Model of information processing (modified from Daft & Lengel, 1984, p. 14)



Although the theory was initially developed to help understand the communication issues within organizations, scholars have applied media richness theory to individuals and their abilities to reduce uncertainty and ambiguity. As mentioned, reducing uncertainty is often one of the goals of those engaging in HISB; thus, media richness theory is an appropriate framework through which to look at YouTube videos as source for health information. YouTube videos, although not as rich as face-to-face communication due to their lack of immediate feedback, do provide asynchronous feedback in the form of comments and responses. Aside from the feedback processes possible in face-to-face interactions, videos carry much of the same communication cues present in face-to-face communication. Communication cues such as facial expression, tone of voice, and body language can all be seen in a video. Further, YouTube videos as a medium are potentially richer than face-to-face communication. For example, videos can include other audiovisual features such as music, images, and imbedded text.

Some scholars have already use media richness theory as the framework for studying health communication related videos. One study examined how the addition of videos to a breast cancer risk reduction website affected participants' ability to perform environmental reduction techniques, specifically the removal of products containing perfluorooctanoic acid (PFOA) from households (Perrault & Silk, 2014). This is a chemical found in common household products that has been found to increase children's cancer risk later in life. There are a variety of techniques to remove and limit the amount of exposure to PFOA that the videos outlined. The authors found that those who watched the videos found the reduction techniques easier to understand than text-based instructions and were more likely to have performed the technique at a follow-up



interview 15 days later (Perrault & Silk, 2014). Another study examined how biographical videos from primary care physicians aided patients in decision-making about selecting a new provider (Perrault & Silk, 2016). The participants who viewed video biographies had significantly less uncertainty about their provider choice than those who viewed text-only biographies (Perrault & Silk, 2016). According to media richness theory, the results from both of these studies would indicate that the information provided within the videos fell into the domain of effective information processing. The content within the video was neither overcomplicated nor oversimplified; thus, viewers were able to process the information in an effective manner. These two studies clearly illustrate the benefits of videos as a source for health information and demonstrate the usefulness of media richness theory related to this channel of health information. In the present study, media richness theory will be used to examine the production-like features that are unique to the video medium.

2.4.1 Video Features.

Video features encompass all of the innate characteristics of the videos. Videos can incorporate many different features in post-production editing, including the insertion of images or supplementary video clips, imbedded texts, and music. These are important to consider in terms of media richness theory because they contribute additional communication cues. I also considered the quality of audio and video because non-professionals likely do not have the same resources (money, videographers, etc.) as professionals do. Developing a complete understanding of the video quality that non-professionals are able to achieve is essential in describing these videos.

Audio quality has shown to have an effect on the overall quality rating of videos (Joly, Montard, & Buttin, 2001). People tend to rate a video as higher quality if the audio



is clear and easy to understand. Further, background noise or audio distortion takes away from the perceived quality of the video (Joly et al., 2001). According to a chapter from the 2009 book *The YouTube Reader*, video quality matters for users (Müller, 2009). In this instance, Müller (2009) is referring to the visual clarity of the video, essentially how fuzzy or not fuzzy the video is, as well as the steadiness of the image. Other features like poor editing detract from users engaging with the content and considering the video as a whole to be of good quality (Müller, 2009). Therefore, looking at all of the features stated (audio quality, video quality, and post-production editing) will allow me to describe the richness of the videos in this YouTube community.

RQ1: What video features are present in non-professional ostomy videos on YouTube?

In considering media richness theory, I posed two more research questions. The first question is targeting the theory's concept about the domain of effective information processing. The theory argues that if the complexity of the issue and the richness are positively related, then the message is in the domain of the effective information processing. Providing medical related information is generally viewed as a more complex topic, but measuring the complexity of each topic discussed in this study is beyond its scope. However, I posed a question with this concept in mind. Because I looked at video features as contributing to the richness of the medium, the first question is this:

RQ2: Is the number of features present in a video related to user engagement?

Finally, I wanted to see whether the quality of the videos was related to user engagement. If the audio quality or video quality is poor, the amount of communication cues that the viewer is able to pick up on is challenged. So, again using the ideas of media



richness theory, I posed the following question:

RQ3: Is production quality related to user engagement?

2.5 Social Presence Theory

The final section of this chapter addresses the idea of social presence theory and uses it as a guide for the final two areas this study considered. In the simplest terms, social presence theory is the "sense of being with another" (Biocca, Harms, & Burgoon, 2003, p. 1). The need to feel present with other humans stems back to stone sculptures as representations of the human form (Biocca et al., 2003). Authors believe that social presence can be felt between humans or even with artificial intelligence (AI). Modern forms of technology, including telephone, video, email, and more, are often the ways in which people experience social presence or "sensing another being" today. As a whole, the Internet promotes a social atmosphere, and these technologies are being designed to increase social presence (Biocca et al., 2003). YouTube's slogan of "Broadcast Yourself" is a perfect example of why it was created, to connect you with others and to connect others with you, and in this I see the idea of social presence.

The short definition of social presence theory may be somewhat problematic as it insinuates that presence is a binary construct. It either exists or it does not exist. Biocca and colleagues (2003) point out this conceptual flaw in their systematic review of the definitions and measures of social presence. The main argument surrounds whether a person must be physically in the presence of another person for it to be considered "social presence." Biocca et al. (2003) proposed that in order for social presence to occur, the person must be able to sense that another intelligent being is present through any means. Essentially, someone cannot be socially present with a plant because it is not considered



an intelligent being. However, someone could be socially present with an animal or another person regardless of them physically being with the person they sense. Further, social presence represents a spectrum rather than a category, and the degree to which someone feels socially present with another depends on the sensory cues involved. This means that social presence can exist in face-to-face and digital contexts, as well as in synchronous or asynchronous communication. For example, if a person views an image of someone, they may feel minimally present with them. But if they were to watch a video of that same someone and have additional sensory cues and can perceive them as an intelligent being (beyond just a stagnant image), the viewer would likely feel more social presence with that person.

Social presence theory has often been applied in the context of online learning. One study evaluated whether asynchronous video discussion responses would increase the social presence in an online class (Borup, West, & Graham, 2013). In addition, this study introduced the idea of extroversion and introversion in social presence in an online medium. The study found that the extroverts did not feel a need to engage in commenting on their other classmates' discussion posts, but the introverts did. The asynchronous communication gave the introverts more time to think about and respond to the discussion posts and was a more comfortable way for them to learn and participate. Stigmatization of those in the ostomy community has resulted in many people maintaining small social networks (Smith, 2011). Although someone with an ostomy may be an extrovert or an introvert, their limited social network may lead them to engage in more asynchronous digital communication. Social support and narrative are arguably both a form of shared intelligence and could contribute to the feeling of strengthened



social presence with non-professional health influencers. The following two sub-sections of this paper elaborate upon these concepts as they are related to social presence theory and pose additional research questions.

2.5.1 Social Support

Social support has been a topic of interest to communication scholars for decades and is of high importance in the field of health communication. The term social support is used to encompass all of the "theories and concepts that link involvement in social relationships to health and well-being" (Goldsmith & Albrecht, 2011, p. 335). The combination of interpersonal relationships and the associations with mental and physical health is why it is so important to health communication scholars.

The most common types of social support are instrumental, emotional, and informational support. Instrumental support consists of actual tangible goods or services that may help someone, such as money or assisting with household chores. Emotional support messages offer comfort and goodwill toward others to help them manage their feelings. Emotional support may simply be statements like "I am here for you" or "You can do this." Finally, informational support provides knowledge about a topic to help another person. For these ostomy community videos, this information may include how to simply care for a stoma or certain foods that may cause inflammation. The connection between social presence theory and social support is that social support promotes further exposure to others' intelligence, which is a key part of feeling social presence. Social support has already been established as important to health, but social support could not exist without social presence; it is the antecedent to social support. The following paragraphs outline a few ways that social support has been studied on YouTube.



First, Frohlich and Zmyslinski-Seelig (2012) did a study on social support messages found in the comments section on YouTube videos about inflammatory bowel disease (IBD) and ostomies. They aimed to compare the social support comments posted on IBD videos against those posted on ostomy videos. Additionally, they examined the differences in comments on lay versus professional videos. They followed a traditional framework of social support and categorized messages into four social support categories: informational, instrumental, emotional, and political/advocacy comments. Their results revealed that social support messages differed by health condition and by video creator. Messages of social support were more prevalent in the comments on videos created by patients than professionals. The authors attributed this to Walther's (1996; as cited in Frohlich & Zymslinski-Seelig, 2012) findings that people would feel more comfortable talking to a lay person than a professional. Further, such comments indicate that there is a presence of social support within the ostomy community amongst laypeople or non-professionals. Frohlich and Zymslinski-Seelig showed that viewers of ostomy videos provide the creator with social support. This thesis study aimed to look at the social support that the content creator is providing to the viewers by examining the videos themselves and not the comments.

A second study examined the kinds of social support messages in health vlogs² from HIV, cancer, and diabetes patients (Huh, Liu, Neogi, Inkpen, & Pratt, 2014). In this case, the researchers examined the messages provided by the content creators within the videos. This is consistent with what the current study aimed to do; however, the authors did not follow a traditional social support framework when coding and reporting their

² Video blogs or video blogging are called "vlogs" or "vlogging"



results. Descriptions of support included an "intense personal connection," "capturing in the moment feelings and facial expressions," and "informational support using props or demonstrations." This study attempted to characterize social support from health content creators; however, a more traditional and theoretical framework of social support should be used to better contribute to the extant literature.

A final study looked at YouTube as a place for grief and bereavement for loved ones (Gibson, 2015). This study suggested that social support was the motivation for the content creators to post the video and not an attempt to provide social support to others. Through personal narrative, people shared their grief, and Gibson (2015) suggested that the grieving were giving viewers an opportunity to support them in the comments section. The emotional exchange between the content creator and the viewers was one-sided. The study highlights motivations for posting vlogs, but it still does not address the idea of the content creator being the *provider* of support.

All three of these studies show the different angles social support can be approached from on YouTube. However, it is evident that there is a gap in the literature when it comes to more fully understanding social support in YouTube videos. The messages within the videos themselves need to be examined in order to get a better understanding of the social support in health videos, specifically in the ostomy YouTube community. Overall, I looked at the social support that content creators are providing to the audience. Therefore, the following research question is proposed:

RQ4: What types of social support are present in non-professional ostomy videos on YouTube?



2.5.2 Illness Narrative

Illness narrative stems from the belief that humans are inherent story tellers and that humans characterize their experiences through varying degrees of narrative (Sharf, Harter, Yamasaki, & Haidet, 2011). Narrative is another way for someone to express their standing as an intelligent being and provides additional sensory cues for the audience, which may lead to greater feelings of social presence. Generally, chronic illness is traumatic and life-changing, and this leads to a patient's desire to share their story. Sharing personal narratives has been shown to help free patients from the pressure their illness puts upon them and allows them to feel heard and validated (Frank, 1998). Further, Frank (1998) believes that in order for people to "recover" their voice that their illness has taken from them, storytelling is essential. YouTube's slogan is "Broadcast Yourself," and YouTube allows anyone to share their story. Some people may not have an audience with whom to share their story, so YouTube may be their only platform on which to share it. Even though the creators of YouTube probably did not envision the platform being used to share stories about ostomies, the need to share has created an entire community of people who do just that. Thus, Frank's ideas surrounding illness narrative and storytelling are particularly relevant to platform and community.

Frank (1998) identified three "narrative types," which he uses to characterize the most general underlying plot of each story. Because stories are complex, most of the time all narrative types can be seen in one individual story, but it is the most prevalent one that commands the most attention. The first narrative type is restitution stories, which idealize "getting better" and make recovery the focus of the story. The story places a lot of faith in the medical care a person is receiving and insinuates that at some point they will no



longer be ill. Sometimes, though, a restitution story is not about "getting better," as some chronic illness cannot be cured, but about the idea that someday the patient will get used to and have learned how to deal with their new lifestyle. The second type of narrative is chaos. Differing from restitution stories in which people assume they will get better or learn to live with their illness, chaos narratives tend to promote a perilous storyline. Chaos narratives generally lack the semblance of a traditional story. They lack a clear timeline and plot, which makes the story difficult to follow. Further, chaos narratives often lack a clear ending; thus, Frank calls them an "anti-narrative," as most stories have a beginning, middle, and an end. The last type of narrative is quest, which take listeners on a journey of the illness. Quest stories do not always come from someone who is now healthy but rather convey lessons they have learned along the way in their illness journey. Quest narratives have an underlying message that there was something to have been gained from the illness. A person telling a quest story is not happy about their illness, but they recognize the influence it has had.

Thomas-MacLean (2004) was interested in examining stories told by breast cancer patients and applying Frank's (1998) narrative types to them. The researcher collected the data from 12 women through one focus group and a series of interviews. She then categorized the stories into the three narrative types based on the most prevalent plot points in the story. Exemplars to represent each of the narratives were shared, although the author did not discuss what the most common type of narrative was. According to Thomas-MacLean chaos narratives are difficult for the common listener to detect. Given their chaotic nature, listeners must pay extremely close attention to discern any bits of the story. Because of this, the overall message of the narrative is never fully



received, which may lead the audience to believe that the illness is not overcomplex or serious. Further, the author argued that restitution narratives and quest narratives have the potential to be helpful but can also be harmful. These types of narratives potentially promote a prescriptive experience that not all breast cancer patients will undergo. These narratives have the potential to paint an unrealistic picture of what breast cancer may be like for all patients (Thomas-MacLean, 2004). This argument highlights the power that different narrative types have, whether that power be beneficial to an individual or not. YouTube is a platform where these messages can be spread far and wide, without the sharer being aware of the effect they can potentially have.

There seems to be little evidence of Frank's (1998) approach to narrative types being applied to health YouTube videos, but some scholars have considered narrative on YouTube more generally. In a study about cancer patients on YouTube, for example, Chou, Hunt, Folkers, and Auguston (2011) used a linguistic approach in their analysis of video content and found that diagnosis was central to the framing of patient narratives. Patients told stories of their symptoms and suspicions leading up to their diagnosis and engaged the audience through description of their illness. It makes sense that patients would frame their diagnosis as central to their story. However, even in narratives where diagnosis is central, the type of narrative being told may differ. Therefore, in this study, Frank's narrative types were used. Understanding what kind of narratives are being told will add to literature and provide a deeper description of the stories about ostomies from patients on YouTube.

RQ5: What types of narratives are being told by non-professionals in the ostomy community on YouTube?



As a follow up question, I wanted to see if the type of narrative made a difference in the level of user engagement. This question was sparked from a desire to understand the type of content users are most interested in watching and not just describe what is available on YouTube in this particular community.

RQ6: Does the level of user engagements differ across narrative types?

Copyright © Sarah Irenke Sophia Bell 2019



CHAPTER 3: METHOD

3.1 Research Design

To best answer the proposed research questions, a descriptive content analysis was the appropriate method (Neuendorf, 2017). A content analysis aims to quantify a variety of variables from a large data set. More specifically, a descriptive content analysis serves the purpose of giving an in-depth review of variables salient to the medium. In this study, the variables that were operationalized were video features, types of social support, and types of narrative. To begin the study, the following sampling process was employed.

3.2 Sampling Procedure

A multi-staged sampling approach was used to gather the complete data set (N = 50). First, to ensure that personal past browser history did not influence the results of the search and selection, an "incognito" window was used. Additionally, a new Gmail account was created in which to search from and store the videos once selected. Next, the following key words were searched to find the videos: "ostomies," "colostomy," "ostomy," "ileostomy," and "j-pouch," and the page was sorted by "relevance." "Relevance" is the default search option on YouTube (see chapter 2.3.1). Next, videos were selected and put into the initial data set based on three specific criteria. First, the video must have been produced in English. Second, the video must have been about ostomies. Third, the channel from which the video came must have been produced by an ostomy patient or family member/caregiver (i.e., a parent of a young child with an ostomy). To ensure the video was about ostomies and created by a non-professional, the title, video description, thumbnail and channel name were reviewed. For each keyword results page, videos were viewed from top to bottom, and the first 25 videos that met all



criteria were saved to a preliminary playlist. Once all five key words had been searched and I had 25 videos in the individual playlists, the next stage of the study was to determine the final data set. From each keyword playlist, the top five videos (by relevance) were selected and added to the final data set. Additionally, a systematic sampling method was used to select 5 more videos from each playlist: Every fourth video in the remaining sample of 20 was selected. This sampling method was used for all five individual keyword playlists, until 50 videos had been saved to a new final playlist. This mixed method of relevance-based sampling (top five) and systematic sampling (every fourth) created both a relevant and representative sample. All videos were saved the same the day (March 1, 2019) to prevent new uploads and changes in the search results from interfering with the sample. The complete sample can be found in the Appendix.

3.3 Coder Training

Once the sample was determined and all videos had been collected, coders were trained using the codebook created in the initial development of this study. The author of this study was one of the coders, and another graduate student served as the second coder. Because human coders were used, a thorough and detailed training process was necessary. Both coders and the thesis committee chair met in person to discuss an initial codebook developed by the author of this study. After discussion and examples of the different codes were presented, both coders were able to ask questions and discuss any variables. The codebook was adapted and modified to reduce ambiguity and clarify questions during the training process. The final codebook can be seen in Table 2 below.\



Table 2 Codebook

Construct	Variables	Codes	Example
Physical Video Features	Audio Quality	1=Poor 2=Fair 3=Excellent	Link demonstrates poor vs. excellent audio quality
	Video Quality	1=Poor 2=Fair 3=Excellent	Link demonstrates fair video quality as it focuses in and out and there are moments of fuzziness in the video
	Music Presence	0=None 1=Present in some parts 2=Present in whole video	Link demonstrates music that is present the entire video
	Music Volume	0=None 1=Hardly Audible 2=Audible but not overpowering the speaker 3=Overpowering the speaker	Link demonstrates music that is audible but does not overpower the speaker's voice; the music in this clip starts out louder and fades while the speaker is talking, because the volume of the music never overpowers the voice of the speaker, this would be ranked as 2
	Text	Count of the number of instances that text is used throughout video	Link demonstrates what text in a video looks like
	Images	Count of the number of instances that images are used throughout video	Link shows the insertion of multiple images while the speaker is talking (begin at 0:44)
	Video Clips	Count of the number of instances that video clips are used throughout video	Link demonstrates the use of multiple inserted video clips into mainframe (see 0:18-0:30)
	Physical Props	Count of the number of instances that physical props are used throughout video	Link demonstrates the use of multiple a physical props in the video, in this case patients "diabetes bag," glucose monitor, and other testing materials



Table 2 (continued.)

Social Support	Informational	0=Absent 1=Present	YouTube shares how to eat after ileostomy surgery (<u>Link</u> , Timestamp: 0:00-15:01)
	Tangible	0=Absent 1=Present	Youtuber does a giveaway for health products (Link, Timestamp: 0:20-8:45)
	Emotional	0=Absent 1=Present	YouTuber promotes messages of emotional social support (<u>Link</u> , Timestamp: 1:02-2:00)
Illness Narrative	Chaos Quest Restitution	0=No Narrative 1=Chaos 2=Quest 3=Restitution	Link demonstrates a quest story about a young girl with cancer (Timestamp: 4:50-2:10), she describes having cancer as being "her Olympics" and that she is able to influence more people because of it Link demonstrates a restitution story about a young girl with celiac and chronic fatigue syndrome, she discusses the medical processes and changes she made in her life as suggested by her medical providers (Timestamp: 5:40- 6:38)

After the training meeting, a random number generator was used to select 10 videos (20% of the sample) for the coders to analyze to assess reliability. Krippendorff's alpha was used to assess inter-rater reliability (Hayes & Krippendorff, 2007). During the first round of coding, adequate levels of Krippendorff's alpha were not achieved across all categories (see Table 3). Therefore, the coders reconvened to discuss discrepancies. Coders discussed until consensus was reached (and the data set was updated for these 10 videos to reflect the consensus), and then they were assigned a new set of 10 videos to code. Again, a random number generator was used to select the 10 videos. Reliability was assessed again using Krippendorff's alpha. Many of the variables showed improvement; however, some of the variables still did not meet a satisfactory level of .80 (Hayes & Krippendorff, 2007). During this time, it was discovered that Krippendorff's alpha was



sensitive to a lack of variance within codes, considering lack of variance to reflect coder error even if the data being coded did actually lack variance (e.g., all 10 videos having no instances of a particular variable). So, even though there were times of 90-100% exact agreement between coders, Krippendorf's alpha could be low or even negative. For example, in round 1, coders had 90% agreement for instrumental support, yet the alpha was 0.0. Regardless, the coders met again to discuss discrepancies in the coding of the second set of 10 videos until a consensus was reached. The data set was updated for these 10 videos. Then, upon the advice of the thesis committee chair (because categories either had an acceptable Krippendorf's alpha or the percentage of exact agreement was acceptable across nearly all variables), the remaining 30 videos were divided amongst the two coders to code individually.

Code	Alpha 1	% Agree	e 1 Alpha	% Agree 2
			2	
Picture Quality	0.62	70%	-0.0556	80%
Audio Quality	0.29	50%	-0.0556	80%
Music Presence	0.78	80%	0.8371	90%
Music Volume	0.52	60%	0.8234	70%
Text Count	0.69		1	
Image Count	0.56		0.7646	
Video Clip Count	0.52		0.9961	
Physical Prop Count	0.95		0.933	
Informational Support	1	100%	-0.1176	70%
Instrumental Support	1	100%	0	90%
Emotional Support	0.37	70%	0.24	60%
Narrative Type	0.33	60%	-0.0556	20%

Table 3 Inter-Coder Reliability (Krippendorff's Alpha and Exact Agreement for Nominal or Ordinal Data)

3.4 Analysis

SPSS was used to run descriptive statistics for all variables. Because the main

goal of this project was to describe the content of the videos, descriptive statistics were



the most appropriate form of statistical analysis. First descriptive statistics were run on all of the demographic data that was collected. Then, to answer research questions 1, 4, and 5, the frequencies were run for each variable.

For research questions 2, 3, and 6, an *engagement* variable was created. The variable was created by averaging views, likes, and comments into the new variable, after controlling for the number of days each video had been posted. For research question number 2, the physical video features of images, text, video clips, and physical props were added together to create the *richness* variable. A two-tailed Pearson correlation was run between engagement and richness. Research question number 3 was answered by averaging audio quality and visual quality variables into a variable called *production quality*. A two-tailed Pearson correlation was run between engagement and production as run between engagement and production quality to answer research question number 3. Finally, research question number 6 was answered by running a one-way ANOVA between narrative types and engagement. The next chapter will outline all of the results from the study.

Copyright © Sarah Irenke Sophia Bell 2019



CHAPTER 4: RESULTS

In this chapter, the results from the study are presented. First, descriptive information about the videos, including information about channels, video creators, number of channel subscribers, number of views per video, and average number of likes and dislikes per video, is shared. Next, results for each of the research questions are shared.

4.1 Video Descriptive Information

The videos in the sample (N = 50) were uploaded between August 6, 2011 and March 1, 2019. The videos came from 39 unique YouTube channels; however, the channels named *Grace Lee*³ and *Ostomy Girl* are the same content creator. The former channel is focused on lifestyle and fitness, and the latter pertains to only ostomy related content. However, the creator uploaded a video to her lifestyle and fitness channel about her ostomy that ended up in the sample. The majority of the videos were created by female channel owners (64%), and channel owners were primarily White (88%). To see the complete gender and race/ethnicity statistics, refer to Tables 4 and 5.

Table 4 Descriptive S	Statistics o	of the	Gender	of	Channel	Owners
-----------------------	--------------	--------	--------	----	---------	--------

Gender	Frequency	Percent
Male	18	36.0
Female	32	64.0

³ Italicized text represents the name of a YouTube Channel



Race	Frequency	Percent
Asian	3	6.0
African American	1	2.0
Hispanic/Latino	1	2.0
White	44	88.0
Unsure	1	2.0

Table 5 Descriptive Statistics of the Race/Ethnicity of Channel Owners

The average number of subscribers per channel was 18,567 (SD = 74,931.956), and the average number of views per video was 145,253. The average number of likes per video was 1,399, and the average number of dislikes per video was 58. Comments on videos ranged from 0 to 3,089, with an average of 218 comments per video. For complete details on the channel engagement descriptive statistics, please see Table 6 below.

Table 6 Descriptive Statistics of Channel/Viewership Demographics

Variable	Minimum	Maximum	Sum	Mean	Std. Deviation
Likes	0	26,000	69,941	1,398.82	4,464.275
Dislikes	0	889	2,920	58.40	150.185
View Count	19	2,452,050	7,262,670	145,253.40	385,848.732
# of Comments	0	3,089	10,906	218.12	614.778
# of Subscribers	0	527,028	928,368	18,567.36	74,931.956

Note: Likes, Dislikes, View Count and Comments data were collected during time of coding. Subscriber count data wer collected on March 28, 2019.

4.2 Video Features Results

Research question 1 asked what video features are present in non-professional ostomy videos on YouTube. Table 7 displays the results for use of text, images, video clips or props. The insertion of images was most commonly used with an average of 4.82 images per video (SD = 15.24). The use of physical props in videos, for example,

showing ostomy supplies, was a close second to images, with an average 4.44 props per



video (SD = 4.97). The use of text (M = 2.56, SD = 5.064) and supplemental video clips (M = 1.14, SD = 2.60) was lower than user of images and props. Audio quality was rated as good or excellent 80% (n = 40) of the time, and video quality was rated as good or excellent 82% (n = 41) of the time. Finally, music was present at some point in 48% (n = 24) of the videos. Among the 24 videos that featured music, the volume was rated to not overpower the voiceover 83.33% (n = 20) of the time but was rated as overpowering 16.66% (n = 4) of the time.

 Table 7 Descriptive Statistics of Ratio Video Features

Variable	Minimum	Maximum	Mean	Std. Deviation
Text	0	26	2.56	5.06
Images	0	73	4.82	15.24
Video Clips	0	14	1.14	2.60
Props	0	18	4.44	4.97

Research question 2 asked if there was a relationship between engagement and the number of video features. A two-tailed Pearson correlation showed that the relationship between these variables was not significant: r = -0.022, p = 0.880. Therefore, the number of features present in a video is not significantly related to user engagement. Research question 3 asked if there was a relationship between engagement and video production quality. This time, a two-tailed Pearson correlation showed statistically significant positive relationship between these variables: r = 0.357, p = 0.011. Therefore, the production quality is significantly related to user engagement.

4.3 Social Support Results

Research question 4 asked about the amount of social support present within the ostomy videos. In this study, three types of social support were measured: informational, emotional, and instrumental. Informational support was the most common type of



support, present in 88% of the videos (n = 44). Emotional support came in second, present in 44% of the videos (n = 22). Finally, instrumental support was the least common type of support, present in only 6% of the videos (n = 3). Table 8 displays results for the three types of social support.

Type of Support	Frequency (Present)	Percent (Present)	Frequency (Absent)	Percent (Absent)
Informational	44	(1 resent) 88.0	6	12.0
Instrumental	3	6.0	47	94.0
Emotional	22	44.0	28	56.0

Table 8 Descriptive Statistics of Social Support

4.4 Narrative Results

Research question 5 asked about the types of narrative being told (restitution, quest, chaos, or no narrative). Within this sample of ostomy videos, 40% (n = 20) did not contain any type of narrative. However, when a narrative was present, restitution type narratives were the most common (n = 14, 28%). There were 11 videos (22%) that contained a quest narrative and five videos (10%) that contained a chaos narrative. Table 9 displays results for the presence of narrative in the videos.

Table 9 Descriptive Statistics of Illness Narrative

Narrative Type	Frequency	Percent
None	20	40.0
Chaos	5	10.0
Quest	11	22.0
Restitution	14	28.0

Finally, research question 6 asked if there was any difference between types of narratives and user engagement. A one-way ANOVA showed no statistically significant



effect of narrative on engagement: F(3, 46) = 1.44, p = 0.242. Table 10 presents the results of the ANOVA.

Source	SS	df	MS	F	Sig.
Between	1.012E+11	3	3.369E+10	1.445	.242
Within	10.722E+11	46	2.331E+10		
Total	11.733E+11	49			

Table 10 Analysis of Variance (ANOVA) Between Narrative Type and Engagement

In this chapter, I reported the complete results of this study and provided answers to the research questions. In the next chapter, I go into detail about the implications of these results and discuss the findings in terms of media richness theory, social presence theory, and this context of health communication.

Copyright © Sarah Irenke Sophia Bell 2019



CHAPTER 5: DISCUSSION

Overall, this study aimed to develop a deeper description of the non-professional videos in the ostomy community on YouTube. Throughout this chapter, I go into detail about each research question and provide discussion based on the results from the previous chapter, relating findings to media richness theory and social presence theory. After that, I discuss the limitations of this study. Finally, I provide some ideas for how these findings can be used in future research and help the continued growth of this area in health communication.

5.1 Video Features Discussion

The video features of video quality, audio quality, and music volume allowed me to see whether the non-professionals were able to create high production-quality videos. Professional companies and professional healthcare providers likely have more access to better cameras and equipment than do non-professionals. The results of these features were able to show that non-professional creators were able to create good or excellent quality content the majority of the time. Having videos that are of better quality adds to the richness of the medium.

In terms of the other video features (text insertions, images, video clips, and props), these also were prevalent throughout the videos. These features add an additional element of richness to the medium. They help us describe what the videos by non-professionals look like and the effort the non-professionals are putting into creating the content. Given today's technology, it is easy to just shoot a video on a phone and upload it. However, it requires more effort, time, and skill to create videos that have more features to help the audience better understand the topic. For example, text was often



used to list product names or spell out medical conditions for the audience's benefit. In *Me&MyOstomy's* video on how she changes her ostomy bag, Nicole provides a list of all the supplies she uses at <u>1:57</u>. Another example is the use of images. *Gabby Palacios*, for example, shows an image of the product she is using at <u>0:26</u>. These types of post-production editing techniques add another dimension of richness to the overall video, providing the audience with multiple ways to understand the message being communicated. Examples of physical props can be seen in almost all of the videos in which the non-professional YouTubers were demonstrating how to change an ostomy bag; however, the use of physical props can also be seen in lifestyle-type videos, such as in *LetsTalkIBD's* video about what to wear to disguise an ostomy. The entire video makes use of different clothing items as props, as well as using supplemental videos clips to show the creator modeling the different outfits.

Overall, these non-professional creators in the ostomy community make good use of post-production editing and physical props to make their videos richer. Text insertion, supplementary video clips, images, and physical props were frequently present throughout the sample. Further, the features of video quality, audio quality and music presence contributed to the richness of the videos and demonstrated the capabilities that non-professionals have to create good or excellent quality content.

Although description was the main goal of this study, the data that were collected allowed me to investigate two research questions related to user engagement with the videos. Specifically, I was interested in whether number of video features (RQ2) and video production quality (RQ3) would be related to higher viewer engagement as defined by the combination views, likes, and comments. The correlation between engagement and



number of video features was non-significant. The variable measuring video features analyzed for research question 2 was meant to reflect media richness. It encompassed the individual variables of text, images, physical props and supplemental video clips. However, one thing I did not code in the videos was the complexity of ostomies as a medical topic. Media richness theory argues that there is a linear relationship between the complexity of a problem and the richness needed in order to effectively communicate that message. I assumed that user engagement was a reflection of the video's relevance based on the richness and complexity of the problem. However, I think in order to properly study this relationship between user engagement, richness, and complexity, I need to measure complexity of ostomies or, more specifically, the ostomy-related topic being discussed (e.g., self-care versus dressing to disguise an ostomy). Further, videos themselves have an inherent level of richness that would need to be controlled for.

For research question 3, I explored the relationship between user engagement and production quality. The results indicated a statistically significant positive relationship between these two variables. Therefore, higher quality production is related to higher levels of engagement from the audience. This further illustrates that production quality matters when it comes to videos on YouTube. The next section of this paper discusses social support as revealed within this sample and how it relates to social presence theory.

5.2 Social Support Discussion

Research question 4 focused on identifying the types of social support found in the ostomy videos online. Informational support was the most common, found in 88% (n = 44) of the videos. It was unsurprising to find that informational support was the most common, as this study was formed on the basis of YouTube as a source of health



information. One example of informational support can be found in a video titled "5 Things I wish I knew before my J-Pouch Surgery" created by *Danielle Nicolette*. In this video the creator shares a list of different things that she was not told before her surgery but feels she should have known. In creating this video, Danielle is able to provide support to the audience in the form of information, reflecting on her own personal experiences while providing something of value to the audience.

Emotional support was the second most common type of social support, found in 44% (n = 22) of the videos. From the channel *Mapleberry Farm—Off Grid & Outdoors*, Jeremy shares his story about ulcerative colitis and his medical discharge from the Canadian military. Throughout the video Jeremy shares a heart wrenching story about the pain of ulcerative colitis and how it led him to receiving an ostomy pouch. However, at the end of the video, he closes on a positive note, explaining that he knows when he was first diagnosed it was "very scary" and that he realizes that this is probably scary to other people. He states that this was his reason for creating the video: because he wants to help support people who are just like him and he recognizes the emotions they are experiencing. Further, Jeremy provides one of the rare instances of instrumental support (30:04) by telling the audience that they can email him at any point because he also recognizes that leaving personal problems in the comments may be hard for people. His offering of his email and being an additional source of personal information is something tangible that he was able to offer to people.

Overall, social support is actively represented in this sample. From the perspective of social presence theory, social support from the content creators likely adds to the feeling of someone else being present. It is possible that medical professionals are



able to provide this kind of social support; however, social support coming from someone who went through the experience may be more powerful. That is why peer-to-peer websites and support groups may be popular. For those with ostomies, the stigma they experience often limits their interaction with others. However, as social beings, the need to feel present with others is still important. Through the videos, the creators are able to provide social support to the audience members and, for some viewers, create a feeling of social presence. The next section of this paper discusses illness narrative and how it relates to social presence theory within this context.

5.3 Narrative Discussion

The sharing of an illness narrative is a powerful and effective way for those who have been through some illness to regain their voice and identity. Further, narrative has a way of normalizing a person and making people feel more connected to them. Narrative was relatively common, with 60% of the total sample containing a narrative. As related to social presence theory, it illustrates the sense that another person or being is with you. Through YouTube people are able to broadcast themselves and their story to the whole world. I think that illness narrative plays a big role in why viewership on nonprofessional videos is so large. It is unlikely that medical professionals are able to share the same personal narratives about the particular illness as non-professionals who live with the illness are. This may be one of the many explanations for the gap in professional viewership as compared to non-professional viewership. It is possible that people are attracted to YouTube as a source of health information not because they want quality information but because they want to feel connected to other people who are



experiencing what they are. Of course, a content analysis cannot answer that question, but future research surveying viewers could.

For these videos, I used Frank's (1988) typology of illness narrative to categorize presence and type of narrative. The most common type of narrative was restitution narratives, represented in 28% (n = 14) of the videos. *K. Willsey* is a young woman who generally just creates videos about her life. She also happens to have a J-pouch and went through the process of having an ostomy after being diagnosed with ulcerative colitis. In her <u>video</u> she placed a lot of emphasis on the medical interventions that were done to help her. She attributes her high quality of life to having gone through the process of having the ostomy and now a j-pouch. Her video represents a strong example of a restitution narrative. She put a lot of trust in the medical process and ultimately is now living a better life.

The second most common type of narratives were quest, present in 22% (n = 11) of the videos. In a <u>video</u> by *Chronically Julia*, she takes us on the journey of her ileostomy surgery and explains the process as it is happening. She takes moments to reflect on the experience and updates the audience as she goes along. Julia is not yet better; in fact, she is truly in the trenches of her illness during this video. However, through YouTube and her ability to share online, she is able to express her story as it relates to her illness.

The final type of narrative was chaos narrative, present in only 10% (n = 5) of the videos. I had anticipated that chaos narrative would appear the least because those who are telling chaos narratives are typically unable to express their story in a coherent way. Therefore, it seemed unlikely to me that I would find a high representation of chaos



narratives. Nonetheless, a video by *Chelcie Mack* was a clear representation of a chaos narrative. Her story addressed what it is like to be sick with a permanent colostomy. However, there was not a clear beginning, middle, or end, and at moments I was confused as she kept jumping forward and backward in time. Chaos narratives have been said to oversimplify the complexities of the medical problem (Thomas-Maclean, 2004). However, there was a level of rawness that was felt within this particular narrative. That rawness made me feel like her problem was complex, and the confusion that she portrayed to the audience made the problem seem real and troubling to the audience. Overall, even though chaos narratives were the least present, it is clear that they are not completely unrepresented.

The results of the one-way ANOVA between narrative types and engagement revealed that there was no statistically significant difference between the groups. I interpret this to mean that the type of narrative being told may not matter to the audience, since engagement does not differ. Perhaps this outcome would be different with a different health condition. I would be curious to see if results were different with a different health condition because past research has shown that some types of narrative can be damaging to people as they are on their own health journey (Thomas-Maclean, 2004). Perhaps the condition of having an ostomy elicits different narrative needs and does not create the damage that Thomas-Maclean (2004) found in her study of narratives with people who have breast cancer.

Overall, I think that the complete results from this study answered the research questions that were posed and have begun to develop a clearer picture of YouTube as a



source of health information. The next section of this paper outlines some of the limitations of the present study.

5.4 Limitations

One limitation of this study was the challenge of establishing inter-rater reliability. I attempted to use of Krippendorff's alpha, which has been advanced as the gold standard among reliability statistics (Hayes & Krippendorff, 2007). Unfortunately, some of the variables measured for this study demonstrated insufficient variation, which is problematic for the KALPHA macro and results in low, and even sometimes negative, reliability scores (Krippendorff, 2004). For those variables that actually did not have sufficient variance (e.g., informational and instrumental support in Round 2 of coding), I then relied on exact agreement percentages to establish reliability. Across all variables except one, then, either Krippendorff's alpha (at least .80; image count approached this level at .76 in Round 2 of coding) or exact agreement percentage (at least 70%; although emotional support dropped to 60% in Round 2, it was at 70% in Round 1) was acceptable. The lone exception was for narrative (60% exact agreement Round 1; 20% exact agreement Round 2.

Upon reflection, I think that using Frank's typology as the way to measure narrative was problematic. Frank (1998) claims that any given narrative may contain all three types (i.e., restitution, quest, chaos) but that one type will stand out amongst the rest. This may be the case; however, if all three types are present in the same narrative, different human coders may perceive different narrative types more or less readily, so one type of narrative type may seem to "stand out" more to one coder than another. Coding categories should be mutually exclusive, equivalent, and exhaustive (Neuendorf, 2017),



and so this narrative categorization that relies on the "most prevalent" type to define the overall narrative is problematic and cumbersome for coders, and it seems to be trying to simplify a complex subject.

Another limitation was focusing on just one YouTube community. If I had chosen another community, like diabetes or breast cancer, results may have been different. This was a limitation of scope of this thesis project.

The other main limitation to this study was the failure to measure the complexity of ostomies as a medical problem. In order to truly put the theory of media richness to work and test the *domain of effective information processing*, the complexity of ostomies or the complexity of each topic in the videos would need to be quantified. Quantifying this complexity, however, was considered to be beyond the scope of this study. That could be an area for future research. The final section of this paper will share my final conclusions and provide some ideas for future research in this expanding area of health communication.

5.5 Future Directions

First, this study attempted to understand narrative as a key piece of this platform; however, I think there is much more to be done. A more in-depth analysis of the narratives within these videos could provide some detailed insight into the kinds of narratives people are telling. To do this, I think that a study using grounded theory would be useful in evaluating the scripts of videos (Glaser & Strauss, 1965). A study like this would allow researchers to see a clearer picture of the narratives and the motivations content creators have in creating the videos. We also need to understand the audience and their motivations for watching and seeking out this kind of information. A study of



viewer uses and gratifications (Katz, Blumer, & Gurevitch, 1973) might allow us to understand the gap between the professional and non-professional viewership. Additionally, I think a study that focuses on following illness narratives over time could be beneficial. YouTube is organized in a chronological manner and is a place where people willingly share their stories. It could be used as a tool to understand how illness narrative changes over time through the complete journey of someone's illness.

YouTube regulations are constantly changing, and the era of monetization appears to be slowly coming to an end. In the past year, YouTube has been automatically flagging videos, demonetizing content, and disabling comments. Many content creators across the platform are frustrated by the unclear regulations, and YouTube has done little to comment on the situation (Alexander, 2019). One thing that is clear is that YouTube has been pushing more professional content on their *Trending* page and suggesting videos that are made by larger companies instead of by individual creators. Although YouTube is not stopping people from uploading content, it is clear that there is now a push for content that is created by professional organizations and companies (Alexander, 2019). If people are not incentivized to make content, then perhaps less personal information will be posted in these health communities on YouTube and the professional content will begin to take over. However, I still believe in the value of the non-professionals' work, and I think that they provide something that medical professionals cannot. They provide a deeper connection of having the lived-experience of the condition or disease. I think collaboration between medical professionals and non-professionals would create a good balance between medically accurate and useful information and the personal connection that the non-professionals provide in this context. I think that research should be done to



explore collaborative type relationships in medical information content creation on YouTube.

5.6 Conclusion

Overall, this study had a goal of deepening our understanding of YouTube as source of health information and adding to the existing body of literature. This studied revealed that non-professionals in the ostomy community have the ability to create videos of high production quality (audio and video) and have the skills to incorporate postproduction editing that makes the videos more media rich (images, texts, video clips). The access to fewer resources does not prevent non-professionals from creating media rich content of high quality. Additionally, a positive relationship was found between production quality and viewer engagement. Further, results from this study found that social support had an active presence within this community. Most frequently, informational support is seen within the videos; however, emotional support also is common throughout. Finally, although there is more to learn about the nature of narratives in these videos, narrative is a key strategy for sharing information on this platform. After all, the platform was born to allow people a space to "Broadcast Yourself."

Copyright © Sarah Irenke Sophia Bell 2019



www.manaraa.com

Date Posted	Channel Name	Title of Video	URL
			https://www.youtube.com/watch?v= 19PYMfqNGm0&index=2&list=PL Pr7eT4r1euhCmU6wbuJXRqn36F3
2/11/2012	Ostomystory	How to change your ostomy bag	DnEk5&t=0s
	Emily Elizabeth	Chit chat & changing my	https://www.youtube.com/watch?v= T2UiklaiBwc&list=PLPr7eT4r1euh CmU6wbuJXRqn36F3DnEk5&inde x=3&t=0s
5/30/2017	Parris	ostomy bag	https://www.youtube.com/watch?v= HRd5104irXg&index=3&list=PLPr 7eT4r1euhCmU6wbuJXRqn36F3Dn
8/25/2015	The Front Butt YouTuber	How to burp and ostomy bag	Ek5 https://www.youtube.com/watch?v=
2/23/2015	Team Rebecca	A day in my life with an ostomy bag (Vlog #1)	X051ZLY3VHU&list=PLPr7eT4r1e uhCmU6wbuJXRqn36F3DnEk5∈ dex=4
10/25/2017	Ostomu Cial	How to change ostomy bag Tips & Tricks	https://www.youtube.com/watch?v= lZyt1Q04- kc&index=5&list=PLPr7eT4r1euhC mU6wbuJXRqn36F3DnEk5
10/23/2017	Ostomy Girl	Colostomy bag	https://www.youtube.com/watch?v= No9o_R8gpaw&index=6&list=PLPr 7eT4r1euhCmU6wbuJXRqn36F3Dn Ek5
11/11/2017	Dave Sutton	change	<u>https://www.youtube.com/watch?v=</u> 1SMcX-I-
1/28/2015	Jack Atkins	Life with my ostomy bag vlog	<u>fvc&index=7&list=PLPr7eT4r1euh</u> <u>CmU6wbuJXRqn36F3DnEk5</u> <u>https://www.youtube.com/watch?v=</u> gPSwWE7jvGE&index=8&list=PL
11/8/2018	Chris Turner	How to change a colostomy stoma bag	Pr7eT4r1euhCmU6wbuJXRqn36F3 DnEk5

APPENDIX



6/16/2015	Rachel Clements	Stomawise basic & quick bag change for ileostomy and colostomy	https://www.youtube.com/watch?v= aaNhnztTpOQ&list=PLPr7eT4r1eu hCmU6wbuJXRqn36F3DnEk5&ind ex=9
2/22/2019	20 years of ME	More cancer and the colostomy bag!!!	https://www.youtube.com/watch?v= R6zg4mVziB4&list=PLPr7eT4r1eu hCmU6wbuJXRqn36F3DnEk5&ind ex=10
11/5/2014	Vegan Ostomy	Ostomy clothing guide for men	https://www.youtube.com/watch?v= dZkP5koouQs&list=PLPr7eT4r1euh CmU6wbuJXRqn36F3DnEk5&inde x=11
		Ostomy care: Healing the skin	https://www.youtube.com/watch?v= kVbB7pMFoYg&list=PLPr7eT4r1e uhCmU6wbuJXRqn36F3DnEk5∈ dex=12
2/26/2015	Vegan Ostomy The Crohnie	around the stoma	https://www.youtube.com/watch?v= UQsoBnIAQpQ&index=13&list=PL Pr7eT4r1euhCmU6wbuJXRqn36F3
2/19/2018	Mom	How I change my ostomy bag	DnEk5 https://www.youtube.com/watch?v= c2Ow2zY_cPY&list=PLPr7eT4r1eu hCmU6wbuJXRqn36F3DnEk5&ind
4/17/2017	Grace Lee	What happened to me? Ostomy story	ex=14 https://www.youtube.com/watch?v= LRIRWqQsdm0&index=15&list=P
10/18/2018	Gabby Palacios	how to change an ostomy bag	<u>LPr7eT4r1euhCmU6wbuJXRqn36F</u> <u>3DnEk5</u> <u>https://www.youtube.com/watch?v=</u> hgofh8AT4jQ&index=16&list=PLP
9/29/2017	STOMATHEL ETE	Do I regret getting a permanent ileostomy bag???	<u>r7eT4r1euhCmU6wbuJXRqn36F3D</u> <u>nEk5</u> <u>https://www.youtube.com/w</u>
10/1/2016	Joseph Greenly	Living with Crohn's & Colitis Bulking with an ileostomy Building muscle	atch?v=B2FwprDM3Eo&list=PLPr7 eT4r1euhCmU6wbuJXRqn36F3Dn Ek5&index=17



8/6/2011	cmarcikic	Ileostomy bag change	https://www.youtube.com/watch?v= GqTGkvZZCP4&list=PLPr7eT4r1e uhCmU6wbuJXRqn36F3DnEk5∈ dex=18 https://www.youtube.com/watch?v= zntP8Vzf8Ko&index=19&list=PLPr
9/11/2010	Outpatient	Ostomy care: How I empty my ostomy bag	7eT4r1euhCmU6wbuJXRqn36F3Dn Ek5 https://www.youtube.com/watch?v=
9/29/2017	Chronically Julia	Ileostomy surgery the time has come $(9/15/17)$	86hcp5uCeKk&list=PLPr7eT4r1euh CmU6wbuJXRqn36F3DnEk5&inde x=20
8/22/2018	Emily Elizabeth Parris	1 year with my Jpouch Pros and Cons	https://www.youtube.com/watch?v= wfNyQUqwjqc&list=PLPr7eT4r1eu hCmU6wbuJXRqn36F3DnEk5&ind ex=21
0,22,2010	Got Guts? IBD	Step 1 J-pouch	https://www.youtube.com/watch?v= 3l3apFK4U8g&index=22&list=PLP r7eT4r1euhCmU6wbuJXRqn36F3D nEk5
12/28/2016	Information	surgey	https://www.youtube.com/watch?v= ihfqXY90_Qo&list=PLPr7eT4r1euh CmU6wbuJXRqn36F3DnEk5&inde
8/19/2017	Emily Elizabeth Parris	Getting my J-pouch Surgery Journey	<u>x=23</u> <u>https://www.youtube.com/watch?v=</u> <u>g5VaXn4ZCdA&list=PLPr7eT4r1e</u>
9/23/2018	Danielle Nicolette	5 things I wish I knew before J- pouch surgey	<u>uhCmU6wbuJXRqn36F3DnEk5∈</u> <u>dex=24</u> https://www.youtube.com/watch?v=
6/6/2017	K. Willsey	I don't have a large intestine? J pouch update	q6HRKgZaVu0&list=PLPr7eT4r1e uhCmU6wbuJXRqn36F3DnEk5∈ dex=25
1/5/2018	LetsTalkIBD	Ostomies & Hydration	https://www.youtube.com/watch?v= 7yTg- SvPD5c&list=PLPr7eT4r1euhCmU 6wbuJXRqn36F3DnEk5&index=26



2/18/2017	LetsTalkIBD	Things they don't tell you about ostomy surgery!	https://www.youtube.com/watch?v= ZgJvT3jEeX0&list=PLPr7eT4r1euh CmU6wbuJXRqn36F3DnEk5&inde x=27 https://www.youtube.com/watch?v= RYu6W8dcqKQ&list=PLPr7eT4r1e
2/3/2012	LetsTalkIBD	Casual Spring Fashion for Ostomies	uhCmU6wbuJXRqn36F3DnEk5∈ dex=28
1/18/2015	TeamRebecca	Top 5 ostomy bag products	https://www.youtube.com/watch?v= 1Y75dpoudF0&list=PLPr7eT4r1euh CmU6wbuJXRqn36F3DnEk5&inde x=29
1, 10, 2010	Anna Spicer-	Fromme	https://www.youtube.com/watch?v= US9YLdbNG28&index=30&list=P LPr7eT4r1euhCmU6wbuJXRqn36F
8/30/2017	Girl WithOut Guts	Ostomies and Dating	<u>3DnEk5</u> https://www.youtube.com/watch?v=
3/1/2019	Chelcie Mack	Being sick with a permanent colostomy	<u>cBc_SuDFK_s&list=PLPr7eT4r1eu</u> <u>hCmU6wbuJXRqn36F3DnEk5&ind</u> <u>ex=31</u>
10/4/2018	chutchai world	My colostomy story via photo collage	https://www.youtube.com/watch?v= Kr98f8x01No&list=PLPr7eT4r1euh CmU6wbuJXRqn36F3DnEk5&inde x=32
10/4/2018			https://www.youtube.com/watch?v= 3YaLmw5UyOs&list=PLPr7eT4r1e uhCmU6wbuJXRqn36F3DnEk5∈
10/20/2013	Ann Francis	Colostomy care for Mike	dex=33 https://www.youtube.com/watch?v=
3/26/2018	Donavon Bebo	Blocked stoma or colostomy not working?	<u>6TTkcavJVdE&index=34&list=PLP</u> <u>r7eT4r1euhCmU6wbuJXRqn36F3D</u> <u>nEk5</u>
4/17/2018	Hannah Witton	What the heck is a stoma? (showing you my ileostomy) Hannah Witton	https://www.youtube.com/watch?v= cUM05Xvq8vQ&list=PLPr7eT4r1e uhCmU6wbuJXRqn36F3DnEk5∈ dex=35



2/5/2017	California Cracker	How to change your ostomy bag	https://www.youtube.com/watch?v= gvI1wbfdDpA&index=36&list=PLP r7eT4r1euhCmU6wbuJXRqn36F3D nEk5
		The worst ostomy bag change Let's	https://www.youtube.com/watch?v= ggRrzc59QDs&list=PLPr7eT4r1euh CmU6wbuJXRqn36F3DnEk5&inde x=37
12/22/2018	LetsTalkIBD	talk IBD	<u>https://www.youtube.com/watch?v=</u> 6TsY0xlsXxc&list=PLPr7eT4r1euh
10/17/2017	CrohnsFighting	How to change an ostomy bag	CmU6wbuJXRqn36F3DnEk5&inde x=38
			https://www.youtube.com/watch?v= QE_EqqlduOQ&list=PLPr7eT4r1eu hCmU6wbuJXRqn36F3DnEk5&ind
11/29/2013	Me&MyOstom y	How I change my ostomy bag	<u>ex=39</u> <u>https://www.youtube.com/watch?v=</u> <u>UzWS2kuY4HY&list=PLPr7eT4r1e</u>
9/18/2017	LetsTalkIBD	What it feels like to have an ostomy	<u>uhCmU6wbuJXRqn36F3DnEk5∈</u> <u>dex=40</u>
	The Front Butt	What is ileostomy	https://www.youtube.com/watch?v= Fx36UqGbFSU&list=PLPr7eT4r1eu hCmU6wbuJXRqn36F3DnEk5&ind ex=41
9/8/2014	YouTuber	surgey like?	https://www.youtube.com/watch?v= GDzCNUw4jX8&list=PLPr7eT4r1e uhCmU6wbuJXRqn36F3DnEk5∈
5/7/2014	Ostomism Not Pessimism	Preparing for planned ileostomy surgey	<u>dex=42</u> https://www.youtube.com/watch?v=
1/27/2019	Sienna Grace	Living with an ileostomy: Blockage / complications	qs774ZhAs0w&index=43&list=PLP r7eT4r1euhCmU6wbuJXRqn36F3D nEk5
		Ileostomy reversal wound care (Post	https://www.youtube.com/watch?v= JAMsTonV9mA&list=PLPr7eT4r1e uhCmU6wbuJXRqn36F3DnEk5∈ dex=44
2/10/2019	MiggyRox	op)	



4/19/2016	Tom Brooks	Living with an colostomy/ileostom y lakeages (My experience)	https://www.youtube.com/watch?v= XIHXCykhZr4&list=PLPr7eT4r1eu hCmU6wbuJXRqn36F3DnEk5&ind ex=45
			https://www.youtube.com/watch?v= MDT3TiVgeB8&list=PLPr7eT4r1e uhCmU6wbuJXRqn36F3DnEk5∈
3/11/2016	Team Rebecca	My JPouch surgery update	<u>dex=46</u>
		-	https://www.youtube.com/watch?v= zOwbSQKNg5U&list=PLPr7eT4r1e uhCmU6wbuJXRqn36F3DnEk5∈
4/3/2018	Wess World	Jpouch 1 year update **Failure**	<u>dex=47</u>
			https://www.youtube.com/watch?v= m3I8FBApq7o&index=48&list=PL Pr7eT4r1euhCmU6wbuJXRqn36F3
3/20/2018	Danielle Nicolette	Was J-pouch surgery a mistake?	DnEk5
			https://www.youtube.com/watch?v= 20Wif5xXYk8&index=49&list=PL Pr7eT4r1euhCmU6wbuJXRqn36F3
	Moni and flexx		DnEk5
9/10/2018	Tv	J pouch surgery!!!!	https://www.voutube.com/westels9
		My story of being medically released	https://www.youtube.com/watch?v= QKcrfnUKA3o&list=PLPr7eT4r1eu
	Mapleberry	from the military	hCmU6wbuJXRqn36F3DnEk5&ind
1/21/2019	Farm Off Grid & Outdoors	JPouch, UC Surgery	<u>ex=50</u>
1/21/2017	a Outdoors	Burgery	

Copyright © Sarah Irenke Sophia Bell 2019



References

- Adhikari, J., Sharma, P., Arjyal, L., & Uprety, D. (2016). YouTube as a Source of information on cervical cancer. *North American Journal of Medical Sciences*, 8(4), 183-186. doi:10.4103/1947-2714.179940
- Alexander, J. (2019, April 5). The golden age of YouTube is over. *The Verge*. Retrieved from <u>https://www.theverge.com/2019/4/5/18287318/youtube-logan-paul-pewdiepie-demonetization-adpocalypse-premium-influencers-creators</u>
- Ancker, J. S., Carpenter, K. M., Greene, P., Hoffmann, R., Kukafka, R., Marlow, L. A. V.,... Quillin, J. M. (2009). Peer-to-peer communication, cancer prevention, and the internet: Workgroup discussion of peer-to-peer about primary and secondary prevention. *Journal of Health Communication*, 14(1), 38-46.
- Bademci, M. S., Yazman, S., Gunes, T., Ockalogu, G., Tayfur, K., & Gokalp, O. (2016).YouTube as a potential source of information on deep venous thrombosis.*Phlebology*, 32(8), 543-547.
- Biggs, T. C., Bird, J. H., Harries, P. G., & Salib, R. J. (2013). YouTube as a source of information on rhinosinusitis: The good, the bad and the ugly. *The Journal of Laryngology & Otology*, 127(8), 749-754.
- Biocca, F., Harms, C., & Burgoon, J. (2003). Towards a more robust theory and measure of social presence: Review and suggested criteria. *Presence: Teleoperators and Virtual Environments*, 12(5), 456-480.
- Black, P. K. (2004). Psychological, sexual and cultural issues for patients with a stoma. *British Journal of Nursing*, 13(12), 692-697.

Borup, J., West, R. E., & Graham, C. R. (2013). The influence of asynchronous video



communication on learner social presence. Distance Education, 34(1), 48-63.

- Chess, Y. (2014). YouTube math star PatrickJMT explains math and science concept behind Yamie Chess STEM education aid to parents and teacher. *Cision PR Newswire*. Retrieved from https://www.prnewswire.com/news-releases/youtubemath-star-patrickjmt-explains-math-and-science-concept-behind-yamie-chessstem-education-aid-to-parents-and-teachers-244733751.html
- Chou, W. Y. S., Hunt, Y., Folkers, A., & Auguston, E. (2010). Cancer survivorship in the age of YouTube and social media: A narrative analysis. *Journal of Medical Internet Research*, 13(1), e7.
- Daft, R. L., & Lengel, R. H. (1984). Information richness: A new approach to managerial behavior and organization design. In B. Staw & L. L. Cummings (Eds.), *Research in Organizational Behavior* (Vol. 6, pp. 191-233). Greenwich, CT: JAI Press.
- Dr. Sandra Lee (aka Dr. Pimple Popper). (n.d.). About [YouTube Channel]. Retrieved from https://www.youtube.com/user/DrSandraLee/about
- Drell, L. (2011). The history of advertising on YouTube. *Mashable*. Retrieved from https://mashable.com/2011/07/26/youtube-advertising-infographic/
- Frank, A. W. (1998). Just listening: Narrative and deep illness. *Families, Systems & Health*, 16(3), 197-212.
- Freberg, K., Graham, K., McGaughey, K., & Freberg, L. A. (2011). Who are social media influencers? A study of public perceptions of personality. *Public Relations Review*, 37, 90-92.
- Frohlich, D. O., & Zmyslinski-Seeling, A. (2012). The presence of social support message on YouTube videos about inflammatory bowel disease and ostomies.



Health Communication, 27(5), 421-428.

- Garlace, E. M., Ramanadhan, S., & Viswanath, K. (2011). Health information seeking. In
 T. L. Thompson, R. Parrott., & J. F. Nussbaum (Eds.), *The Routledge handbook* of health communication (2nd ed., pp. 167-180). New York, NY: Routledge.
- Gibson, M. (2015). YouTube and bereavement vlogging: Emotional exchange between strangers. *Journal of Sociology*, *52*(4), 1-15.
- Gingiss, D. (2018). How the student experience can provide learnings for the customer experience. *Forbes*. Retrieved from https://www.forbes.com/sites/dangingiss/2018/04/30/how-the-student-experiencecan-provide-learnings-for-the-customer-experience/
- Glaser, B. G., & Strauss, A. L. (1965). Awareness of dying: By Barney G. Glaser and Anselm L. Strauss. Chicago: Aldine.
- Goldsmith, D. J., & Albrecht, T L. (2011). Social support, social networks, and health. InT. L. Thompson, R. Parrott., & J. F. Nussbaum (Eds.), *The Routledge handbook* of health communication (2nd ed., pp. 335-348). New York, NY: Routledge.
- Hayes, A. F., & Krippendorff, K. (2007). Answering the call for a standard reliability measure for coding data. *Communication Methods and Measures*, *1*(1), 77-89.
- Heijnders, M., & Van der Meij, S. (2006). The fight against stigma: An overview of stigma-reduction strategies and interventions. *Psychology, Health, & Medicine,* 11(3), 353-363.
- Heldman, A. B., Schindelar, J., & Weaver, J. B. (2013). Social media engagement and public health communication: Implications for public health organizations being truly "social." *Public Health Reviews*, 35(1), 1-18.



- Huh, J., Liu, L. S., Neogi, T., Inkpen, K., & Pratt. W. (2014). Health vlogs as social support for chronic illness management. ACE Transactions on Computer-Human Interaction, 21(4), 1-31.
- Joly, A., Montard, N., & Buttin, M. (2001). Audio-visual quality and interactions between television audio and video. *International Symposium on Signal Processing and its Applications*, 2, 438-441.
- Karadag, A., Mentes, B. B., Uner, A., Irkorucu, O., Ayaz, S., & Ozkan, S. (2003). Impact of stomatherapy on quality of life in patients with permanent colostomies or ileostomies. *International Journal Colorectal Disease*, 18(3), 234-238.
- Katz, E., Blumler, J. G., & Gurevitch, M. (1973). Uses and Gratifications Research. *The Public Opinion Quarterly*, 37(4), 509–523.
- Kim, J. (2012). The institutionalization of YouTube: From user-generated content to professional generated content. *Media, Culture, and Society*, 34(1), 53-67.
- Krippendorff, K. (2004). Content analysis: An introduction to its methodology (2nd ed.).Thousand Oaks, CA: SAGE Publications.
- Lessons from Fred Figglehorn. (2016). *Casting Frontier*. Retrieved from https://castingfrontier.com/2016/07/25/lessons-from-fred-figglehorn/
- Müller, E. (2009). Where quality matters: Discourses on the art of making a YouTube video. In P. Snickars & P. Vonderau (Eds.), *The YouTube Reader* (1st ed., pp. 126-129). Stokholm, Sweden: Mediehistoriskt.
- Murugiah, K., Vallakti, A., Rajput, K., Sood, A., & Challa, N. R. (2011). YouTube as a source of information on cardiopulmonary resuscitation. *Resuscitation*, 82, 332-334.



- Neuendorf, K. A. (2017). *The content analysis guidebook* (2nd ed). London, England: SAGE Publications.
- Pant, S., Deshmukh, A., Murugiah, K., Kumar, G., Sachdeva, R., & Mehta, J. L. (2012). Assessing the credibility of the "YouTube Approach" to health information on acute myocardial infarction. *Clinical Cardiology*, 35(5), 281-285.
- Pathak, R., Poudel, D. R., Karmacharya, P., Pathak, A., Aryal, M. R., Mahmood, M., & Donato, A. A. (2015). YouTube as a source of information on ebola virus disease. *North American Journal of Medical Sciences*, 7(7), 306-309.
- patrickJMT. (n.d.). Social Blade. Retrieved from

https://socialblade.com/youtube/user/patrickjmt

- Perrault, E. K., & Silk, K. J. (2014). Testing the effects of the additions of videos to a website promoting environmental breast cancer risk reduction practices: Are videos worth it? *Journal of Applied Communication Research*, 42(1), 20-40.
- Perrault E. K., & Silk. K. J. (2016). The uncertainty reducing capabilities of primary care physicians' video biographies for choosing a new doctor: Is a video worth more than two hundred words? *Health Communication*, 31(12), 1472-1481.
- Persson, E., & Hellstrom, A. (2002). Experiences of Swedish men and women 6 to 12 weeks after ostomy surgery. *Journal of Wound, Ostomy and Continence Nurses Society*, 29(2), 103-108.

ReFaey, K., Tripathi, S., Yoon, J. W., Justice, J., Kerezoudis, P., Parney, I.
F.,...Quinones-Hinojosa, A. (2018). The reliability of YouTube videos in patients
[*sic*] education for glioblastoma treatment. *Journal of Clinical Neuroscience*, 55, 1-4.



- Richardson, C. G., Vettese, L., Sussman, S., Small, S. P., & Selby, P. (2011). An investigation of smoking cessation video content on YouTube. *Substance Use & Misuse*, 46, 898-897.
- Robertson, M. R. (2014). Watch time: A guide to YouTube's top search ranking factor. *Tubular Insights*. Retrieved from https://tubularinsights.com/youtube-watch-time/
- Savard, J., & Woodgate, R. (2009). Young peoples' [*sic*] experience of living with ulcerative colitis and an ostomy. *Gastroenterology Nursing*, *32*(1), 33-41.
- Shamsian, J. (2018). Logan Paul returns to YouTube with a documentary about suicide survivors: "I know I've let people down." *Insider*. Retrieved from https://www.thisisinsider.com/logan-paul-documentary-video-suicide-youtube-2018-1
- Sharf, B. F., Harter, L. M., Yamasaki, J., & Haidet, P. (2011). Narrative turns epic:
 Continuing developments in health narrative scholarship. In T. L. Thompson, R.
 Parrott., & J. F. Nussbaum (Eds.), *The Routledge handbook of health communication* (2nd ed., pp. 36-51). New York, NY: Routledge.
- Shaw, R. J., & Johnson, C. M. (2011). Health information seeking and social media use on the Internet among people with diabetes. *Online Journal of Public Health Informatics*, 3(1), 1-9.
- Sholl, J. C. (2007). The use of humor to promote patient-centered care. *Journal of Applied Communication Research*, *35*(2), 156-176.
- Smith, D. M., Loewenstein, G., Rozin, P., Sherriff, R. L., & Ubel, P. A. (2007). Sensitivity to disgust, stigma, and adjustment to life with a colostomy. *Journal of Research in Personality*, 41(4), 787-803.



- Smith, R. A. (2011). Stigma, communication, and health. In T. L. Thompson, R. Parrott.,
 & J. F. Nussbaum (Eds.), *The Routledge handbook of health communication* (2nd ed., pp. 167-180). New York, NY: Routledge.
- Song, Y., Redi, M., Vallmitjana, J., & Jaimes, A. (2016). To click of not to click: automatic selection of beautiful thumb. *Yahoo Research*. Retrieved from https://arxiv.org/abs/1609.01388
- Sood, A., Sarangi, S., Pandey, A., & Murugiah, K. (2011). YouTube as a source of information on kidney stone disease. *Urology*, 77(3), 558-562.
- Stellefson, M., Chaney, B., Ochipa, K., Chaney, D., Haider, Z., Hanik, B.,... Bernhardt,
 J. M. (2014). YouTube as a source of chronic obstructive pulmonary disease
 patient education: A social media content analysis. *Chronic Respiratory Disease*, *11*(2), 61-71.
- Sundar, S. S., Rice, R. E., Kim, H., & Sciamanna, C. N. (2011). Online health information conceptual challenges and theoretical opportunities. In T. L. Thompson, R. Parrott., & J. F. Nussbaum (Eds.), *The Routledge handbook of health communication* (2nd ed., pp. 181-202). New York, NY: Routledge.
- Sunderland, N., Camm, C. F., Glover, K., Watts, A., & Warwick, G. (2014). A quality assessment of respiratory auscultation material on YouTube. *Clinical Medicine*, 14(4), 391-395.
- Syed-Abdul, S., Fernandez-Luque, L., Jian, W., Li, Y., Crain, S., Hsu, M.,...Liou, D. (2012). Misleading health-related information promoted through video-based social media: Anorexia on YouTube. *Journal of Medical Internet Research*, *15*(2), e30.



- Thomas-MacLean, R. (2004). Understanding breast cancer stories via Frank's narrative types. *Social Science & Medicine*, *58*(9), 1647-1657.
- TheSpanglerEffect. (n.d.). About [YouTube Channel]. Retrieved from https://www.youtube.com/user/TheSpanglerEffect/about
- United Ostomy Associations of America. (2010). What is an ostomy? Retrieved from http://www.ostomy.org/ostomy_info/whatis.shtml
- Yiannakoulias, N., Tooby, R., & Sturrock, S. L. (2017). Celebrity over science? An analysis of Lyme disease video content on YouTube. *Social Science & Medicine*, 191, 57-60.

YouTube for press. (n.d.). Retrieved from https://www.youtube.com/yt/about/press/

Copyright © Sarah Irenke Sophia Bell 2019



VITAE

Sarah Bell, B.S.

EDUCATION University of Kentucky, Lexington, Kentucky Masters in Communication, focus in Health Cumulative GPA: 4.0	Expected Completion May 2019
Ohio University , Athens, Ohio B.S. in Communication Studies, focus in Health Cumulative GPA: 3.50, Major GPA: 3.75	Completed December 2016
PROFESSIONAL WORK EXPERIENCE Account Executive GSW Worldwide Marketing & Advertising Columbus, Ohio	February 2017-August 2017
Account Coordinator GSW Worldwide Marketing & Advertising Columbus, Ohio	January 2017-February 2017
Account Service Intern GSW Worldwide Marketing & Advertising Columbus, Ohio	May 2016 – August 2016
Customer Service Representative MobileXUSA Columbus, Ohio	June 2013 – August 2015
SCHOLASTIC AWARDS Martha and Howard Sypher Memorial Graduate Scho	alarship Awarded March 2019

PUBLICATIONS

Journal Articles

Thompson, C. M., Frisbie, A., Hudak, N., Okamoto, K., & Bell, S. (2017). "Understanding" as support for emerging adults whose parents have chronic health conditions: A lifespan communication perspective. *Journal of Family Communication.17*(4), 301-318.

