SOCIAL MEDIA IN HEALTHCARE: RESPONSIBLE USE OF ILLNESS NARRATIVES

BY

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LIST OF ABBREVIATIONS

American Medical Association............................................................AMA
CaringBridge..................................................................................CB
User Generated Content.................................................................UGC
Patients are using social media to tell stories of their experiences of illness. These stories represent a new sort of illness narrative, which fosters connections between patients, giving rise to online communities that provide support, inform, and empower patients. In this way, the use of social media is able to improve healthcare by fulfilling some of its goals, namely promoting the overall well-being of patients. Moreover, social media offers more opportunities to tell and receive illness narratives. Increased access to patients' stories, especially for physicians, could improve healthcare as they become more aware of the experiences of their patients, which will humanize information presented to them as points of data. However, ethical issues arise when considering physicians' interactions with their patients online. Both parties must use social media responsibly, which involves attentiveness to the potential uses and limitations of social media in the healthcare setting.
CHAPTER ONE

INTRODUCTION

In recent years, increasing numbers of American adults have been turning to the Internet, and more specifically to social media, for information. Queries regarding health related information are no exception to this phenomenon. In light of this development, I ask how social media is being used for healthcare related purposes, whether these purposes are novel, and how physicians, patients, and caregivers should use social media to interact online.

Given the nature of the Internet and, in particular, social media, I recognize that writing this thesis is like trying to hit a moving target. The data available for analysis becomes outdated before it is published; it lags behind reality. I hope that looking at the foundations and ideology behind the rise of social media will help inform and contextualize the data regarding the use of social media in healthcare to overcome some of the limitations imposed by dealing with such a topic. This difficulty, however, should not keep us from asking where we might like to be in the future with regards to the use of social media in the healthcare setting.

In this thesis, I argue that social media in healthcare, specifically what I will call patient-to-patient healthcare, is best at addressing patients’ emotional and day-to-day support needs with which physicians often struggle, or which may fall
outside of a physician’s area of training and expertise. In short, physicians remain the primary source of medical care, but in working with the broader idea of healthcare, other sources of information and support are of great value to patients. Social media is one medium through which patients are offering and receiving health related information and support. In this way, social media has much to offer in the quest to improve healthcare, understood in a broad sense.

Social Media is a medium through which patients are able to easily share their experiences of illness and disease. There are few barriers to its use, which allows for narratives to be told and received easily by patients, physicians, and others who are interested in sharing these stories. In addition to the benefits associated with the telling of illness narratives, such as a greater understanding of self on the part of the patient and the humanization of medical procedures and care for the physician, sharing stories through social media allows for the building of a community that helps to inform and empower patients. The potential for sharing illness narratives with such a wide audience and connecting with people regardless of geographic proximity is part of what makes social media unique from other forms of communication in healthcare. We should embrace and understand social media as a tool that may contribute to better healthcare when it is used appropriately by both physicians and patients.

Ultimately, this thesis aims to respond to the question, “How should social media be used responsibly in the healthcare setting?” In formulating an answer, I will
focus heavily on the experience of the patient who uses social media to share stories of his or her health event with others, namely other patients. It is important to note that, in practice, the role of the physician has not yet been established in this age of heavy use of social media. In the end, I propose a number of recommendations for the responsible use of social media by both patients and physicians. These recommendations aim to promote availability and access to illness narratives, while also addressing concerns of privacy, anonymity, and the availability of false or misleading information.

To address the role of social media with respect to healthcare, it is important to first define and come to an understanding of what social media is, generally speaking. In chapter 2, I will discuss the historical and ideological foundations of social media. This is important because, as I mentioned earlier, we are dealing with a moving target. Identifying the roots of social media may aid in understanding its capabilities to inform and empower patients and serve as a medium through which communities of individuals with similar health concerns may be built.

In chapter 3, I will provide an overview of the available empirical data relating to the use of social media in healthcare and patient-to-patient healthcare, in particular. For example, one in four patients living with a chronic illness use social media to share information related to their disease. Another important finding was that physicians have remained the preferred source of information for
diagnostic and technical information regarding health related issues, while patients more frequently turn to online communities for emotional support, compassion, empathy, convenience, and for practical advice about living with their illness. This could offer a way to improve healthcare by providing physicians with humanized data about the experience of their patients and could allow them to focus on providing medical care while still being assured that their patients are able to find resources and support to cope with the emotional impact of an illness.

In chapter 4, the work of Arthur Frank, most notably his concepts of illness narratives as self-stories and his discussion of narrative types, will allow us to consider the type of illness narratives told through social media, as well as the purpose of this narrative type. I will provide a brief overview of Frank’s work, The Wounded Storyteller, including his discussion of why stories are important and the different types of illness narratives, which will serve as a background to discussion regarding the type of narrative that is told via social media.

I conclude that since Frank first published his work on illness narratives, another body of narratives has grown and the type of illness narrative typically told via social media should be considered as its own collection of stories. Some unique features of storytelling via social media that warrant its consideration as its own narrative type include the reflective distance required to publish online, and that smaller narratives shared both in real time and over time allow patients to
connect and form relationships through storytelling. This narrative type is characterized by periodic updates.

In chapter 5, I will offer a discussion of how social media, specifically patient-to-patient healthcare, should be used to share health related information and illness narratives responsibly. While much of this thesis will focus on the discussion of what I have identified as patient-to-patient healthcare, and how social media is being used most in healthcare at this point in time, I recognize that the use of such technologies in healthcare is constantly evolving. It is beneficial to anticipate the potential and challenges of using social media in the context of healthcare.

Both patients and physicians should have some role in ensuring that such technologies are used responsibly. Patients must learn to be discriminating when searching for information online. They should also be honest with their doctors by disclosing their interactions in online communities. Patients must realize the limitations of these communities and relationships. Additionally, responsible patients will be honest in their own interactions with others online.

As we look toward the future and the potential involvement of physicians in social media, it is important that they are open to their patients’ use of online, peer-to-peer resources, which they have been resistant to in the past (Shapiro). As physicians, they often recognize the limitations of online resources, but they may
not always recognize their own limitations to provide certain types of healthcare. Any physician may benefit from reading accounts of the patient experience and taking the time to reflect on their own involvement and impact. Some, particularly younger, physicians would like to interact with their patients via social media, but no useful professional guidelines exist. Such guidelines would be helpful for any healthcare professional who might want to provide information and support to their patients online.

I conclude that embracing social media in healthcare as a way to tell and receive illness narratives, and consequently health related information, has the potential to lead to better healthcare if used in a responsible manner that recognizes the limitations of the technology. Healthcare, in this case, is to be understood in a broad sense. While medical care includes the treatment for illness or injury, I understand the goals of healthcare to include the maintenance and improvement of health, both physically and mentally, as well as the promotion of overall well-being.

Patient-to-patient healthcare should be used to share narratives, and patients should be encouraged to do so as it is able to fulfill needs, particularly for emotional support and community. However, patient-to-patient healthcare should not replace physicians, nor should it threaten their role as medical experts. Instead, the potential of using social media to improve healthcare lies in its ability to develop a patient’s overall well-being. For now, the proper place for
social media in healthcare remains in its capacity to grow relationships and communities for support, emotional and otherwise.
CHAPTER TWO

DEFINING SOCIAL MEDIA

Before proceeding, social media must be identified and defined. The Internet and American Life Project is among the Pew Research Center’s most notable work. Since 2000, this project has studied the social impact the Internet has had on Americans (Pew Research Center's Internet & American Life Project). In their most recent report on the demographics of social media users, published in February 2013 and using data from late 2012, Pew identified five social networking sites: Facebook, Twitter, Pinterest, Instagram, and Tumblr (Duggan and Brenner). These are examples of what may be considered “major” social media, but the discussion of social media in this thesis will cover more than the use of these specific services.

Much of the following discussion will be based on an understanding of the technical and ideological foundations that underlie the whole of social media. The purpose of this approach is twofold. First, the available data does not discriminate between social media services, and I do not wish to make assumptions about which types of social media are most frequently used. I will, however, cite examples of ways patients are using social media to share their stories. Second, it is my hope that this discussion remains relevant even as the popularity of certain social media services wanes. For these reasons, it is
important not only to define what I mean by social media, but also to offer a few thoughts regarding the foundations of these technologies and services.

Definition

It is not difficult to find a definition for social media. A quick Web search yields many results, and some websites have compiled lists of various definitions of social media from across the web.

Definitions of social media found via social media include:

"Media is an instrument on communication, like a newspaper or a radio, so social media would be a social instrument of communication" (About.com). “Social media is the democratization of information, transforming people from content readers into publishers. It is the shift from a broadcast mechanism, one-to-many, to a many-to-many model, rooted in conversations between authors, people, and peers” (Solis), and “Social media are media for social interaction, using highly accessible and scalable publishing techniques" (Wikipedia). These definitions are quite helpful for understanding social media in a very general way, but they are not necessarily intended to be sufficient to describe, or be inclusive of, all social media services.

While there are many definitions of social media, the difficulty comes in finding an appropriate one. For this, I will turn to a definition proposed in the world of
academia. Andreas Kaplan and Michael Haenlein offered one of the most frequently cited definitions of social media both inside and outside of the academy. This oft-cited definition describes social media as "a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of User Generated Content" (Kaplan and Haenlein 61). This will serve as a general definition for this thesis, but relevant distinctions between different types of social media will follow, as necessary. Before proceeding, however, it is important to parse out some of the more technical language of the working definition for this thesis.

Web 2.0

Web 2.0 is not a concept with a well-defined boundary, but may be thought of as a "gravitational core" of principles that web sites and Internet applications may adhere to in varying degrees, or at different distances from this core (O'Reilly). Web 2.0 could be described as a movement towards networking for everyone, moving away from the idea that highly trained programmers are required to create sophisticated Web content (Pierce). Web 2.0 has been nicknamed the "social Web" as it allows for co-creation among users and encourages a more democratic use of the Web as users generate content.

In some ways, Web 2.0 appeals to the idea of returning to the roots of the World Wide Web - to share ideas and promote discussion. A relevant distinction
between the two is that Web 1.0 was intended primarily for interaction amongst the scientific community, while Web 2.0 intends to include anyone, regardless of credentials (Boulos et. al).

Technological Foundations of Web 2.0

It is somewhat difficult to pin down the meaning of the term “Web 2.0,” partially because “what it is” depends on whether you are interested in economics, marketing, or another discipline. For most people, identifying a certain group of technologies is the simplest way to comprehend the concept of Web 2.0. Technologies such as blogs, wikis, podcasts, and RSS feeds facilitate the creation and use of the “social Web.” These technologies enable everyone to add to and edit the information space (Anderson 5). The ability of any person to participate in the exchange of information and ideas via an online service characterizes Web 2.0.

If the concept of Web 2.0 is confusing, do realize that it is not entirely different from Web 1.0. Some people, namely Tim Burners-Lee, the inventor of the World Wide Web, would argue that “Web 2.0” is nothing more than a piece of jargon that no one has clearly defined. In a 2006 interview, Burners-Lee pointed out that the Web has always been about connecting people. The Web is an interactive information space and a tool to connect people to people. However, in the past there have been greater technological barriers to the Web functioning
as a truly collaborative workspace. For example, one may have needed technical expertise to be able to edit information existing on the Web. Some people, such as Tim Burners-Lee, see Web 2.0 as nothing more than the natural evolution of the World Wide Web.

I have explained two ways in which one could view the concept of “Web 2.0.” It can be thought about as an entity distinct from Web 1.0, and characterized by co-creation and democratic use. Another way to think of it is as the evolution of the Internet, and a more fully implemented Web. For this discussion, it is most important to understand that social media is distinct from other types of online information sharing because expert knowledge is not required to contribute to the information space.

Ideological Foundations of Web 2.0

Tim O’Reilly, the businessman who coined the term “Web 2.0” in 2004, wrote a paper in which he outlined some of the ideological underpinnings of this concept, the most relevant of which are addressed here. These basic ideas include allowing individuals to produce information and share User Generated Content, which will be discussed further in the next section (Anderson 14).

The focus of O’Reilly’s ideas is what may be referred to as the architecture of participation. This is based on a belief that the way a technology or service is
designed may facilitate user participation en masse. In essence, tools should lower barriers to entering the information space. However, the hope is for something greater than this. Realizing the potential of these technologies would mean that the system is designed in such a way that it improves as a result of individuals’ normal use of it. For example, Jane Doe performs a Google search, and Google is able to use data from that interaction to improve her user experience while performing subsequent Google searches (Anderson 19).

In the interest of not getting bogged down in the technical details, many of which are omitted here, I would like to conclude this section on the ideological underpinnings of Web 2.0 by identifying the significance of these foundations. Web 2.0 is very much about enabling more users to contribute to the information space, and the enrichment of that space by adding to the collective body of knowledge.

Ideologically, it seems, advocates of Web 2.0 technologies are more concerned with the sharing of information – any information – than ensuring credibility. It is easy for someone to post false, outdated, or misleading information online, and given the potential anonymity afforded to users, they cannot always be held accountable for publishing things that are untrue or harmful. Lowering barriers to entry into the information space for every individual equalizes the playing field, in a way. Sharing ideas and information with the world is no longer a privilege of
the few skilled in building websites from scratch, but implies that every individual should share his or her knowledge and ideas with the world.

Finally, let us return to our definition of social media as "a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of User Generated Content." Social media is grounded in these Web 2.0 technologies, and, as such, it is a tool that enables as many users as possible to contribute to the online information space in whatever way they choose to participate. Put simply, social media is important because “normal” people are able to share information online, update websites, write blogs, tweet, and connect with friends on Facebook, for example.

It is in this ideological basis of Web 2.0, that everyone should be able to share information, that there may be complex ethical issues related to healthcare and the sharing of medical information. Examples of these issues include access, privacy, and anonymity. These will be discussed further in chapter 3, while suggestions for dealing with such matters will be given in chapter 5.

User Generated Content

User Generated Content (UGC) is composed of the ways that people make use of social media. UGC is a descriptive term, referring to the information and the content that is contributed by individuals who are using the Web in a public
manner. This does not include those performing professional Web development
tasks (Kaplan and Haenlein 61).

There are three requirements that content must meet in order to be considered
“user generated.” These requirements are as follows: 1) the content must be
available on a website that is accessible to the general public or on a social
networking site that a select group of people have access to; 2) some amount of
creative effort must be shown in the content; and, 3) the content must be created
in a capacity that is not professional in nature (Kaplan and Haenlein 61).

Some websites include a combination of UGC and contributions by professionals
or administrators. Often, an administrator or moderator of a website monitors the
UGC for things like offensive language, copyright infringement, or relevance of
information. Like Web 2.0, UGC is characterized by its participatory nature.
UGC has been called “conversational media” in contrast to “packaged goods
media” which offers a one-way distribution of information (Battelle).

However, there have been concerns raised with the proliferation of UGC
available on the Web. Such concerns are related to identity, anonymity, or
privacy online. Uninformed users may share personal information with a public
audience that makes them vulnerable to harm, perhaps financial or physical.
This could have special implications as we move to look at the use of social
media in the context of healthcare. As with any Web 2.0 tool of technology, there
is concern regarding the availability of false or misleading information. Particularly in the case of healthcare, adhering to advice that is not medically sound may have dire consequences.

Social Media in Health Care

Everything that has been discussed regarding social media as a medium for communication up to this point remains true in the context of healthcare. Many have articulated the thought that new ideas have life cycles, and I think that pinpointing where social media is in this life cycle, particularly in healthcare, is helpful to provide some context for what we are talking about. According to Kevin Kelly, the founding executive editor of Wired magazine, there are four stages in the natural history of a new idea. First, the idea is considered to be outright “wacko,” and “worthless nonsense.” From there it is perceived as an odd but unproven idea. It is an interesting, albeit perverse, idea. The third stage is acceptance that an idea is true, but that it lacks importance. Finally, the idea comes to be considered as obvious, and the sentiment is that this idea is nothing new, but rather what we’ve envisioned all along (Kelly).

According to Susannah Fox in 2011, social media in healthcare probably lies somewhere between “odd but unproven” and “true but trivial.” Two years later, in 2013, I would argue that its use is likely somewhere between “odd but unproven” and “obvious.” Further, I would predict that physicians remain closer to the “odd
but unproven” territory, in part because there has been little to no professional guidance on the use of social media. For patients and families, particularly those in younger generations who have grown up with technology and who are looking to connect with others like them, I would predict that they are more likely to view using social media for healthcare related purposes as obvious.

We see social media being used more frequently for connecting and sharing information related to health and illness. I do not mean to detract from the fluid nature of social media, nor the range of services that may be used by physicians, patients, caregivers, and policymakers. Instead, I would like to focus the discussion on the type of social media being widely used in healthcare, and which remains truest to the historical and ideological foundations of social media. In the following sections, I will focus on the most common uses of social media in healthcare at this point in time. Social media is being used to connect patients with other patients, to connect patients with friends and family, and to connect patients with the public. In chapter 5, I will consider what uses of social media may become more common in the future, such as connecting patients with doctors.

Peer-to-Peer Healthcare

To help avoid confusion and provide some distance from the ambiguity of the term “peer-to-peer,” which carries certain connotations for the technologically
savvy, I would like to use the term “patient-to-patient healthcare” to describe the interactions between patients and/or caregivers through social media services. For simplicity, I will refer only to patients, but caregivers use social media in similar ways to those that they care for. Patient-to-patient healthcare is commonly encountered in online forums or support groups established for patients dealing with a specific disease. Much of the data discussed in chapter 3 deals directly with patient-to-patient healthcare via social media, and a specific example called the Sapient Health Network will be discussed.

Susannah Fox, at the Pew Research Center, offers a relatively simple definition of peer-to-peer, or patient-to-patient, healthcare. She describes social media in the context of healthcare as a technology that helps bring to the surface and organize information or knowledge about a patient’s individual experience, the experience of other patients, and treatment options, for example, making the information useful for as many people as possible (Shapiro). Fox says, “Patients and caregivers know things – about themselves, about each other, about treatments – and they want to share what they know to help other people. Technology helps to surface and organize that knowledge to make it useful for as many people as possible” (Fox “Peer-to-Peer Health Care”).

Patient-to-patient healthcare is an application of the underlying principles of social media grounded in the foundations of Web 2.0 and UGC. Patients are able to share their knowledge and stories via Web services, and engage in
conversations with others. In many cases, this sharing of information is not intended to be unilateral, but the patient publishing his or her story is the recipient of acknowledgment and support from an online community. Sharing personal stories is one way that patients can help others experiencing similar health events. There are other sorts of uses, such as looking for donors, increasing awareness of a disease, or raining money for a cause. Patient-to-patient interactions, however, tend to focus more on sharing personal experiences of illness.

Friends and Family

In addition to using social media to connect with other patients, individuals in the midst of a health related event might use social media to share their experience with friends and family. This is, perhaps, the most inclusive category of social media use in healthcare because it contains status updates on Facebook, tweets, or the use of an online journaling site.

CaringBridge, is a website and social media service that is predominantly used by those experiencing health related episodes to share information with their friends and families. CaringBridge (CB) was established in 1997 and provides easy-to-use, personalized web pages for individuals or their caregivers going through some type of situation where care is needed, including hospitalization and medical care. CB’s features include photo galleries, journal entries where
individuals may write medical or personal updates or stories, and a guest book where others may read and post messages, most often directed toward the author of the website.

In many ways, CB sites are very similar to blogs, or personal journals that the public can access via the web. However, CaringBridge sites are used somewhat differently than traditional blogs. Visitors to the site do not frequently interact with one another, but with the person who set up the website. Comments tend to offer support to the author or patient more often than they engage in a conversation about the information presented in the post. Also, friends, family, and acquaintances of the site's author, rather than by complete strangers, often access CaringBridge sites. Finally, participants' names and email addresses are often posted alongside comments, and are always available to the site's author, minimizing the anonymity afforded by the service.

Daily, CB has over half a million users (CaringBridge). In 2012 alone, about 46 million people visited a CaringBridge site. According to their website, CaringBridge helps families going through a health related event in two ways: by letting everyone know what was happening, and by bringing a loving, supportive community together.

The data regarding patients' use of social media in healthcare discussed in the next chapter offers some insight into why patients are using social media to
share the story of their illness with loved ones in this way. This will be explored further in chapter 4, with an analysis of patient’s use of social media to tell their stories in light of existing literature on the role of narratives in medicine.

It is important to note that while I am attempting to categorize typical uses of social media within the context of healthcare, there is no bright line to distinguish one type from another. Many social media services provide privacy options, so the patient may choose to share their story with only friends and family. Or, they may choose to make their updates and stories public, making the information accessible not only to other patients, but to the general public. This points to the final use of social media that I would like to discuss.

The Public

Some patients choose to publish their stories of illness online with a public audience in mind. Most commonly, this would take place via a social media service such as a blog, where anyone may search for and access the information. In some cases, there may be an agenda in mind, or a cause about which the patient would like to increase awareness. For a variety of reasons, the patient wants to share his or her story with anyone who will take the time to read it. This group could include complete strangers, acquaintances, or physicians that are either connected or unconnected to the particular case.
Chapter Summary

In this chapter, I provided a background of social media, generally. Social media was defined as “a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of User Generated Content,” followed by discussions of the technical and ideological foundations of social media. This approach was important because specific social media services will be constantly evolving, and it is my hope that the ideas brought forth may be applicable after the summer of 2013.

In the latter part of the chapter, I focused on the ways in which social media may be used by patients in the context of healthcare. Susannah Fox and the CaringBridge website offered that the purpose of sharing illness narratives through social media is, at least in part, to participate in a supportive online community. Patients may use social media to share their stories of health events with other patients, family and friends, or the public. While I do not claim that these categories constitute an exhaustive list, I think that they will be useful for guiding the following discussion of available empirical data in regards to the use of social media in healthcare, and the subsequent analysis of its use in light of literature on the use of narrative in medicine.
Americans have always relied on friends and family for support when they are dealing with an illness, but in the digital age, patients’ networks of support are expanding to include people that they may have never met in person. These online communities may be invaluable, particularly in the case of a rare illness or disease. This turn towards patient-to-patient healthcare, as it may be called, serves more than a niche population.

People are using the Internet to connect with others who are living with similar illnesses, and to exchange their illness stories. The data discussed in this chapter indicates that patients are using the Internet to share their stories because they want to help their fellow patients and caregivers. Similarly, patients are able to find support in online communities, as patients are using social media to connect with others like them. They are able to receive support and help one another cope with their health episodes. These sorts of relationships, even online, can facilitate reaching goals of healthcare to promote a patient’s overall well-being by sharing experiences and information that will help the patient maintain as healthy of a life as possible. Social media provides access not only to information, but also to each other.
Patient-to-Patient Healthcare

Nearly one in four (23%) Internet users with a chronic illness such as high blood pressure, diabetes, a lung condition, or cancer, say that they have used the Internet to find other people going through similar things. They want to connect to others through the illness narratives that they tell online. People who have no serious or chronic condition also go online to connect with others, with 15% of Internet users who report no chronic condition seeking out help from others with similar health concerns (Fox “Peer-to-Peer Health Care”).

A similar trend is seen when a patient is diagnosed with a rare condition. A majority of patients and caregivers turn to others who have the same health condition with which they were diagnosed, and often these interactions must happen online. A mother of a young child with a rare illness wrote of her experience of online, or patient-to-patient, support:

When a disease is so rare and there are no folks in your town, and few in your state who are going through what you are going through, you need a support group that encompasses people from all over the world. Getting to know people through the disorder has been an amazing experience and has created incredibly wonderful friendships and ties. (Fox “Peer-to-Peer Health Care”)
There are notable accounts of when these interactions, initially online, create a strong bond between patients and caregivers who later enrich their relationships with face-to-face meetings in addition to their online patient-to-patient interaction (Fox “Peer-to-Peer Health Care”). This may indicate that the Internet is able to fill a need for which face-to-face meetings are not ideal, but it suggests that patient-to-patient healthcare may not be able to replace such face-to-face interaction. For example, it seems that it is easier to search for and find others dealing with a similar illness online, but the connection may not be as deep or personal as it is when the two people are physically present to one another. Nonetheless, illness narratives told via social media serve the purpose of connecting patients and their caregivers, forming online communities of support.

There are other groups of people that are likely to turn to the Internet to connect with people who share their same health concerns. These groups include Internet users who are caring for a loved one, who have experienced their own medical crisis recently, and those who have experienced a marked change in their own physical health related to weigh gain or loss, pregnancy, or quitting smoking, for example.

**Physician-Patient Relationship**

It is important to note that “in the moment of need” 71 percent of US adults still turn to a health professional for information, care, or support, and only five
percent of adults say that they receive this information from a healthcare professional online (Fox “Peer-to-Peer Health Care”). Even with the availability of online self-diagnostic tools, it does not seem as though these are replacing physicians. However, according to adults participating in a national survey, physicians are not always the most helpful source for all health related information (E-Patients).

US adults find healthcare professionals most helpful when they are seeking diagnostic or technical information related to their health, but non-professionals are preferred for advice regarding how to cope with an illness or to provide a quick remedy to a health related problem. 91 percent of survey respondents identified healthcare professionals as more helpful than other patients, friends, and family when looking for an accurate medical diagnosis. Healthcare professionals were also most useful for information about prescription drugs (85%), alternative treatments (63%), recommendations for a doctor or specialist (62%), and recommendations for a hospital or other medical facility (62%). Other patients, friends, and family were significantly more important for emotional support in dealing with a health issue according to 59 percent of respondents, and for quick remedies for an everyday health issue (51%). Finally, practical advice for coping with day-to-day health situations was sought from both healthcare professionals and non-healthcare professionals equally (Fox “Peer-to-Peer Health Care”).
Another survey that was conducted only among people who used an online social networking site called Sapient Health Network, now acquired by WebMD, showed that of those involved in online communities, physicians (both primary care and specialist, combined) were rated most helpful in only four of 12 identified dimensions of healthcare. Members of the online support community found information from their online interactions to be most useful with regards to cost-effectiveness, best in-depth information on their condition, best help with emotional issues, convenience, helpfulness in finding other medical resources, best practical knowledge of their condition, help with issues regarding death and dying, and with compassion and empathy. This data illustrates that there are dimensions of healthcare that can be improved with the use of social media resources.

When physician groups were combined, online network users felt that their doctors were the most likely to be there for them in the long run, had the best technical knowledge of their condition, gave the best help and advice on management after diagnosis, and were the most helpful in diagnosing their medical problem correctly (E-Patients). In other words, physicians best met medical needs, while other health related needs that contributed to overall well-being were best met by the online community. Social media is able to bring together patients that would otherwise find it difficult to interact because of distance, for example. Particularly in the case of rare illnesses, the Internet and social media make it possible for patients to help one another cope with their
situation on a daily basis. Social media serves as a partial solution to barriers such as geography, money, and time that have made it difficult for patients to find and build relationships with one another in the past.

Comments from this study highlighted the fact that many patients felt overwhelmed, isolated, and discouraged while dealing with a serious medical condition, and their online communities served as a haven where they felt valued and understood. These online communities served to empower, support, and inform their members. Ultimately, it seems that online communities and doctors complement each other. Online communities tend to be best at what doctors are worst at, and worst at that which doctors are best.

Online communities are not threatening to put doctors out of business, and the use of physicians and online communities, together, may lead to better healthcare. However, what interests me the most is that individuals are choosing to tell and receive certain types of illness narratives online. Some parts of patients’ stories, particularly when looking for support, understanding, and acknowledgment, seem to be shared and received through social media in a meaningful way that improves their healthcare experience.

Concerns

Some healthcare professionals and professional medical organizations have
been weary about patients’ use of online resources to find health related
information. Susannah Fox has said that everyone’s role in medicine is changing
as a result of the proliferation of online health information. At first, doctors were
slow to relinquish their role as the primary source of medical information. When
the first Pew Internet and Health study was published in 2000, the American
Medical Association responded with a press release asking patients not to go
online. As a result, patients kept going online but were more reticent in
discussing their findings with their doctor. Fox says that attitudes quickly
changed, and by 2005 most doctors wanted to hear from patients about their
online research (Shapiro). What was it about using the Internet that gave
physicians such pause?

Physicians’ Concerns

In the past, people have tried to answer their health questions at home and they
have made decisions about when to consult a healthcare professional. In this
regard, the Internet has not changed people’s patterns of behavior, but has
served as a tool to help individuals better understand what might be affecting
their health (Fox and Duggan). People have more resources to use in their
search for health related information, and this does not seem to be either
inherently good or bad.

The question remains, what about online information, and specifically social
media, is different? Physicians have complained that patients do not find credible information online. Some patients are able to identify and use websites that offer accurate information, but there is also inaccurate and out-of-date information on the Web. It seems as though this may be even more worrisome when a patient is using social media to gather information on a health condition as anyone may contribute to the available information shared via social media without oversight from a health expert.

Understandably, physicians and the AMA could have been worried about the medical consequences of a patient who follows poor advice found online. As mentioned earlier, patients may have trouble discriminating between reliable and unreliable information online. The health scares and concerns that arise out of unreliable or misunderstood information must be balanced against the benefits of having information available and accessible to such a large audience. Patients are using social media to tell of their personal experiences with illness, and it is possible that others will extrapolate medical opinions and advice from these stories and interpret them as fact.

Physicians have experienced some downsides to their patients’ ability to access any and all available information about drugs or treatments online. Patients may scare themselves by looking up the side effects of a drug or a symptom that they are experiencing. For example, a patient may worry that a tremor is Parkinson’s disease when it is caused by low blood sugar. It seems possible that information
taken from online forums and stories may leave out crucial details that are relevant to making an accurate medical diagnosis.

A closely related phenomenon that physicians have observed is something called “cyberchondria.” Much like hypochondria, patients will research a medical condition, and their own symptoms and feelings may be perceived to match up with the symptoms described online. Particularly in light of the short amount of time that doctors have to spend with their patients, it can be especially frustrating when normal body functions are interpreted as a health crisis after a patient performs online research. To keep the frequency of this phenomenon in perspective, it is more likely that patients who use Internet research to challenge a doctor are those with legitimate illnesses such as a disability or chronic condition (Shapiro).

There are also concerns regarding physicians’ use of social media. As mentioned, the AMA initially spoke out against physicians engaging in the use of social media, and no useful professional guidelines have been developed since then. This leads to a number of unanswered questions regarding the appropriate use of social media by physicians.

There are a number of concerns with regards to the use of the Internet, generally, that must be taken into account when considering the risks and benefits of the use of social media to find and share health related stories and
the information they contain. Briefly, I will discuss the effects of the digital divide, self-selection, privacy, and anonymity concerns. How these concerns should be addressed will be a topic of discussion in chapter 5.

Digital Divide and Self-Selection

The digital divide refers to the inequality between groups of people in terms of access to, use of, or knowledge of, the communication of information via the Internet, including social media services. A 2012 report entitled “Digital Differences,” and part of the Pew Internet and American Life Project describes differences in Internet access within the US. The most significant findings of this study follow.

One in five adults do not use the Internet, and it is likely that even fewer engage in social media use. Those who do not use these technologies are more often older, have less education, earn less than $30,000 per year, and prefer to communicate in Spanish instead of English. Typically, those who do not use the Internet often believe that the Internet is not relevant to them. They have never used the Internet and only one in ten would be interested in using Internet or email in the future (Zickuhr and Smith).

This implies that the information-rich get richer, while the poor get poorer, particularly in light of the finding that those adults who already use the Internet
are doing more with it. There is already discussion about inequalities in medical care, but it seems reasonable to conclude that some of the same groups of people that are already marginalized may be the same ones that find it harder to connect with online communities of people like them. In this case, patients will engage in self-selection, where certain groups of patients will be more likely to actively select social media as a medium through which they share stories, while other groups will be more likely to make the choice not to engage in the use of these technologies. We cannot, therefore, make an assumption that all patients are able to find certain types of support outside of the clinical setting.

The digital divide with respect to age is observed in the use of social media. The age-based classification of the digital divide is an important consideration, but I think this is not as worrisome as it may appear. While this trend is still observed, certain devices, such as tablets, are more popular with thirty- and forty-year-olds than with their younger counterparts. Individuals aged 18 to 24 years old are most likely to use social media to connect with others who share health related concerns, but older Americans are using the Internet for this purpose, as well (Zickuhr and Smith).

Another finding relevant to this discussion is that almost half of the 27% of adults living with a disability do not use the Internet, while only 2% of adults have a disability that hinders their ability to do so. Again, this implies that certain groups of patients may not benefit from, or be able to participate in, the use of social
media related to healthcare. In some cases, these may be particularly vulnerable groups, such as those suffering with mental illness, for example. Internet access and adoption is dividing communities that we typically think of as groups. There is no longer only a consideration of whether an individual is disabled or not, but their status regarding Internet use may be relevant.

Again, it is important to emphasize that these statistics lag behind the times. While we see the digital divide growing among some groups, new technologies such as wireless connections via mobile devices are promoting changes in Internet and social media use. Groups such as African Americans and English-speaking Latinos are just as likely as whites to own a mobile phone, and they are more likely than whites to use these devices to engage of a wider range of online activities (Zickuhr and Smith).

Privacy and Anonymity

I would like to conclude this section with a discussion of, perhaps, the most abstract concern as related to the sharing of health information online, but also one of the most worrisome: privacy. Theoretically, individuals publishing their health information and stories online should recognize that they are choosing to share information about themselves in a traditionally public forum. However, with the advent of privacy controls and the ability to select a network of individuals with whom a patient would like to share information, the line between public and
private space online has been blurred. In some ways, this can create a false sense of security online, particularly when third parties take it upon themselves to share information about a patient in a public forum without the patient’s knowledge or permission.

Technology has made it much easier and more efficient to send and receive information. However, the increased ability to share information has led to new ways in which privacy can be breached. One of the first published works advocating privacy rights in the United States was written by Louis Brandeis and Samuel Warren in response to the increase in newspapers and photographs due to the development of new printing technologies (Brandeis and Warren). In general terms, as it becomes easier to gather and transmit information, it also becomes easier for third parties to intercept that communication, and it becomes more difficult to maintain privacy. The desire to provide personal information in order to connect with other patients and maintain privacy seems to be in conflict with one another (Barrows and Clayton). This tension between the benefit of connecting, and the risk of losing control of information should be recognized.

To further complicate this scenario, in the case of private medical information, such as that shared through a social media service, people are not directly in control of the distribution of their own medical information. Instead, they must rely on privacy agreements and website security measures to protect the use of their data (Partners Human Research Committee). Past experience tells us that
unauthorized parties can access secure information online, but it seems that this is of little consideration when individuals choose to share their stories of illness via the Internet, and social media, specifically.

The privacy settings that these services offer may lure patients into a false sense that the information they share is secure. Because patients do not seem to be aware of the potential effects of having their information online, this is worrisome. Patients are concerned that insurance companies may have access to their medical records and find evidence of a preexisting condition, for example, but these issues are not often discussed with respect to an individual’s concern about posting such information on his or her blog. People are often under the illusion that they have the savvy to use social media to share their health related stories and experiences, without this information falling into the “wrong” hands.

Related to the concern for privacy is the misconception of anonymity assumed by social media users. Patients may take some steps to hide their identity, such as using an alias or choosing to hide any contact information on a social media website. However, some patients may believe that these steps ensure anonymity in their storytelling. While it may be difficult to track or recognize an author, locations, pictures, or other identifying characteristics of the patient may be present in their posts and stories. If friends, family, acquaintances, or caregivers were to read the patient’s blog and approach him or her about the
online content, the patient may feel violated, particularly if under the illusion that their website was anonymous.

Anonymity is also of concern because it can be very difficult, sometimes impossible, to identify social media users who have hidden all personal information. This could cause problems if, for example, an anonymous user were to post false or misleading information online. In these cases where the offending user cannot be identified, he or she cannot be accountable for the content posted, even if it leads to harm of another user.

Chapter Summary

In this chapter, I provided an overview of the available data related to the use of social media in the healthcare setting. One study found that patients and caregivers turn to the Internet and social media when they are experiencing a health event, particularly if the patient has a rare illness or chronic disease. Another study found that social media resources are not taking the place of physicians, but complement their medical expertise by providing a community in which patients can find emotional support and the most helpful information about living with their illness on a day-to-day basis.

Then, I cited concerns held by physicians in the past, such as the availability of false information, the inability of patients to accurately interpret medical
information embedded in others’ stories, and phenomena such as “cyberchondria.” Concerns relating to the digital divide, self-selection, privacy, and anonymity are also raised in this chapter.
In this section, I would like to use Arthur Frank's *The Wounded Storyteller* to guide a discussion regarding illness narratives in social media. Frank’s work has been influential in narrative ethics and in understanding the experience of illness. Frank has not only shown why narratives are important in healthcare, but his framework for illness narrative types has become part of the vocabulary of medical humanities (Frank “Publications”).

Frank identifies the restitution, chaos, and quest narrative types, and acknowledges that other narrative types not only exist, but “should be proposed” (Frank 76). I would like to show how the sorts of narratives typically told through social media constitute a narrative type that has not yet been described by Frank, or others. These narratives are often a collection of shorter stories, told in real time and over time. Many narratives told via social media share this general structure beneath the various plots and tensions of individual stories. In addition to the benefits of storytelling that Frank discusses, this narrative type lends to the formation of relationships and communities.

To clarify, I am not proposing a new framework for considering illness narratives. Rather, I would like to use the framework proposed by Frank, and identify a fourth narrative type that has its own characteristic structure and general
storyline. This narrative type is used for the purpose of sharing support and forming connections with other patients and caregivers, in addition to helping the patient to gain an understanding of self. This approach of storytelling via social media allows for more opportunities to share stories among an audience that is wider than a patient’s direct caregivers and medical providers. Illness narratives told through social media, in particular, have the potential to improve healthcare by lowering the barriers for patients to share their experiences of illness with one another and providing a supportive community in which they may interact.

The medium of social media, itself, which is used within the online information space and is often public, makes is easy for anyone to publish their own illness narrative or read someone else’s. The traditional benefits associated with the use of narrative in medicine, such as humanizing data points, are true in this case, but there is also the possibility of these stories spreading to a wider audience. There are more opportunities to share and read illness narratives, which could play a role in improving healthcare.

When healthcare is understood to encompass more than a person’s medical care, but also their emotional state and well-being, social media makes it easier for patients to connect with others experiencing similar health events, and build online communities of support, as discussed in chapter 3. Illness stories have the potential to do more than share an experience. Online, these narratives can serve as an opening for conversation and they can be the starting point for
patients to build meaningful relationships with one another in a way that reading a book or journal does not allow.

**Illness’ Call for Narrative**

According to Frank, illness calls for narratives in at least two different ways (Frank 53). One sense is relatively literal; others want to know how the patient is doing, they want insurance information, or they want to know what symptoms the patient is experiencing. In a more abstract sense, stories are the vehicle through which patients may understand their illness and themselves. Illness narratives allow a patient to begin drawing a new map with new destinations because the old plan they had created for their lives no longer makes sense. These are not two separate and distinct purposes for which stories are told, but according to Frank, are complementary to one another.

Characteristic of an illness narrative is the “shipwreck,” caused by an interruption and in which a patient’s sense of temporality is suddenly gone. The convention where a past leads to a present and then into a future that is foreseeable does not hold in these stories. The subject of the illness narrative finds him- or herself in a place where he or she is not supposed to be. This is the “narrative wreckage.” The way out, Frank says, is by telling “self-stories,” a term coined by Roy Schafer (Frank 55). The point of this type of story is not to describe what is happening, but to form the self. The self-story is told to one’s self and others.
simultaneously, and both the self and the relationship are affirmed in the process of storytelling.

Frank notes that there is now a proliferation of these kinds of self-stories. He claims that there is a market for them to be published, but recognizes that published stories are only a token of the broader oral discourse (Frank 69). Moreover, Frank cites what he calls a “significant truth” underpinning the idea of “finding one’s voice.” He says that people who are written about from the outside have lost their voice, and so speaking in a voice recognizable as one’s own becomes more difficult. In such times, a search for one’s own voice ensues and self-stories proliferate (Frank 71).

Narrative Types

Narrative types, as Frank uses them, are very general storylines. In fact, they are the most general storylines that he was able to identify underneath the plot and the tensions of each individual story. Each individual tells a unique story, which includes multiple narrative types, such as the three identified by Frank and discussed briefly below. These narrative types are important because later in the thesis, I would like to consider whether or not stories told via social media fit well into these categories. I conclude that while the restitution, chaos, and quest narratives Frank describes may be present, the type of narrative often told through social media has a distinctly different structure than any of these types,
and serves a purpose in addition to those identified by Frank. By telling each part of the illness narrative as it occurs, the author allows others to offer advice and support on each step of the journey. This structure allows for conversation to take place, and for patients and caregivers to connect to one another, sharing experiences and support.

Social media encourages an individual’s story to be told in small “chunks” as events and information are unfolding. This way of episodic storytelling is distinct from the narrative types that Frank has included thus far in his work. I will briefly discuss the three narrative types identified by Frank, as well as the narrative type that appears to be seen frequently through social media.

Restitution

The first type of illness narrative that Arthur Frank identifies is the restitution narrative (Frank 75), and this type often dominates a patient’s illness narrative, although all three narrative types are woven together in some way to tell the story. Patients want to believe in restitution, and they believe that this is the type of story that others want to hear (Frank 77). The plot of a restitution narrative follows the storyline of “Yesterday I was healthy, today I am sick, but tomorrow I will be healthy again” (Frank 77). These narratives are often characterized by mentions of tests, treatments, and cures, which fit nicely with medicine’s obsession with cure and its inability, at times, to place a patient’s story into
anything but a narrative of restitution (Frank 83).

The power of the restitution narratives lies in the fact that it is not only often true, but it is also heroic (Frank 92). Physicians are actively heroic, while the patient is passively so. This type of narrative is limited because when restitution is no longer an option, the patient is often left with no other story to fall back on. Without an alternate story, the “narrative wreckage” is a reality. In today’s world, it seems that people can practically purchase restitution, while others are not so fortunate financially, and so the availability of the narrative, too, may be restricted (Frank 95). Still, this faith in medical progress is what gives the restitution narrative its power.

Chaos

Frank describes the chaos narrative in opposition to the restitution narrative, because in the chaos narrative, life never gets better (Frank 97). There is no coherent sequence, as one event does not cause another in these narratives. Chaos stories provoke anxiety and reveal vulnerability and futility in modern medicine. For these reasons, these stories are not only difficult to tell but they are difficult to hear.

In The Wounded Storyteller, Frank states, “The teller of chaos stories is, preeminently, the wounded storyteller, but those who are truly living the chaos
cannot tell in words. To turn the chaos into a verbal story is to have some reflective grasp of it” (Frank 98). Frank goes on to say that distance is a prerequisite for such a reflective grasp, and he identifies a unique challenge presented by the telling of the chaos narrative: no one wants to hear it. The listener will undercut the narrative, or try to steer the teller toward a more positive ending and away from his or her feelings. The challenge to the listener is to hear the story.

Quest

The final narrative type that Frank identifies is the quest narrative. Quest stories do not brush off suffering, and the teller does not get lost underneath it, but rather the teller tries to use the suffering and illness to gain something from the experience (Frank 115). Quest narratives are narratives of a journey. First, there is the teller is called into action via a symptom, maybe a lump or dizziness, for example (Frank 117). Following the call is initiation, where the teller must confront the call via her first hospitalization, perhaps. Finally, there is a return. The teller is not sick any longer, however, she continues on in life with the mark of her illness (Frank 118). The quest narrative is very similar to, and perhaps an example of, a story of a hero’s journey.

All three of these types of narrative help people make sense of their suffering, according to Frank. The narratives that he is working with are, primarily, written
and printed illness narratives. These stories include the telling of numerous moral choices, upon which we may later reflect on the course of action pursued, and from which we may be pointed toward a social ethic. Another type of narrative that is seen more frequently with the increased use of the medium of social media for storytelling exists, which also allows patients to connect to one another and form online communities.

Narratives told through Social Media

I do not mean to take away from Frank’s three narrative types that have been identified, and I would like to reiterate that all narrative types are often present in an illness narrative in some way, woven together to create an individual’s story. First, the structure of an illness narrative told via social media is unique. These stories are told in “chunks” of information. One day, a patient may post about a diagnosis. Another day, the same patient may post about treatment options or the side effects of treatment. The patient may post about shopping for a new wig, or a recipe that they cooked for the first time. Posts about birthday parties, relationships, and book reviews may be found in between updates about a patient’s prognosis. Sometimes, a patient may post longer entries, written after a period of time and with a more reflective tone. The narrative types already identified by Arthur Frank may be seen in these posts, in particular.

While the story of the illness and the disease is very much present in these
narratives, it is in varying degrees depending on the patient. These stories are not necessarily about life getting back to normal or about the process of getting well. These stories are about living in the present. Posts are about the struggles that a patient is encountering today, and inviting the online community to offer suggestions and support to make it through this challenge or celebrate this small victory of the day.

Illness narratives told through social media are, by nature, in the moment. What happened yesterday is old news, and becomes part of the storyteller’s history; it becomes a part of the patient’s whole experience of illness. The story is begun, and continues to be written without an outline or a final destination. Stories of illness told through social media tell of the experience of the patient, which is a focus that is different than those already identified by Frank.

Comparison to Frank’s Narrative Types

As discussed in a previous section, it is reasonable to say that there is difficulty in the telling and the receiving some illness narratives, particularly chaos narratives. Perhaps, the telling of such a narrative to another in a face-to-face setting is difficult because the other is not prepared to hear it. For the storyteller who wants to publish his story, it there has typically been a time-delay. He may write in a journal, more-or-less in the midst of the chaos, but he may edit the story before sharing it.
In the digital age, there is an outlet to share one’s story almost immediately with a public audience that cannot interrupt or try to redirect the story as easily as if it were shared in person. There is some degree of anonymity available if it is desired, in which the patient may find comfort. While most posts on social media are written, there are other forms of storytelling online that may convey what speech cannot. Also, a narrative told through social media could be more compelling than a written and printed account because the person receiving the narrative must, alongside the patient, face the suspense of not knowing what is next. Perhaps, these stories aid in understanding the complexity of the experience of illness.

Frank seemed to support the widespread sharing of illness narratives, both those told by well-known authors and the private testimonials of individuals, for both the patients’ understanding of themselves and the ability of these stories to point toward a social ethic. If a patient is creating his or her self-story through telling an illness narrative, surely it will be impacted by the medium through which the patient chooses to express him or herself. Stories found in academic journals or that are otherwise printed serve the purposes that Frank identifies. However, the telling of narratives in this way is mostly a unilateral act.

When illness narratives are told using social media, each period of time between posts, updates, or “chunks” of information allows for others, such as friends,
family, and other patients, to offer support and advice. In this way, others become participants in the patient’s illness narrative, and something akin to a conversation can take place online. This sort of interaction allows for the formation of relationships and communities that continue to offer support and encouragement to the patient throughout his or her illness. This sort of interaction is good for patients because it provides emotional support and promotes their overall sense of well-being. In this way, storytelling through social media can contribute to the improvement of healthcare.

Finally, when compared with the types of published illness narratives to which Frank most commonly refers, narratives told through social media are more accessible to others to read. There are more opportunities to share and read illness narratives online, which could improve healthcare by increasing healthcare providers’ understanding of the complexity of the patient experience. Because there is no kind of gatekeeper, such as a journal editor, who chooses which stories will be shared, anyone who wants to tell his or her story is able to do so.

Chapter Summary

In chapter 4, I presented Arthur Frank’s framework for considering illness narratives. After identifying Frank’s three narrative types, I demonstrated that the sort of narrative often told through social media is not a chaos, restitution, or
quest narrative. Instead, these stories constitute a fourth type of illness narrative. The structure of these narratives is periodic in nature, and they consist of chunks of information told in real time and over time. These narratives also serve a purpose beyond self-understanding and pointing toward a social ethic. This type of illness narrative allows patients to connect with one another and form supportive relationships and online communities, which promote well-being. In addition, the widespread availability of narratives told through social media, has the potential to improve healthcare.
I have already given an overview some of the concerns associated with the use of social media to tell illness narratives in chapter 3. Here, I will discuss how these problems may be addressed. Then, I will move on to consider the responsibilities that both patients and physicians may have in using social media in the healthcare setting. The absence of practical professional guidelines for physician use of social media might be keeping some willing physicians from learning about patients’ stories, while others may be overstepping a boundary.

Addressing Physicians’ Concerns

Physicians have expressed concerns that patients do not find credible information online, and that they struggle to identify appropriate sources for medical advice. This concern is bound to be more prevalent with the use of social media, where patients are sharing their experiences in a way that is not moderated by a medical expert. Authors may write about a diagnosis or treatment in a matter-of-fact way, though they misunderstand or have trouble expressing the reality of the situation.

Some may be inclined to read these posts, written by patients, and draw conclusions about their own illness or medical care. If patients were to interpret
illness narratives told through social media as providing medically sound advice, this could be problematic. At first, the same concern seems as though it would hold true for any illness narrative, however, regardless of the medium through which it is told.

Social media is unique, however, in that it can be more difficult to identify which sources are credible. Robert Hawkins conducted a study of how breast cancer patients conducted research on their illness. He compared patients who were given books and pamphlets, patients who had open, undirected access to the Internet, and patients who had directed access to online information and groups that had been vetted by doctors. Hawkins believes that the Internet is making healthcare better, particularly because of how well the latter group did in this experiment. The patients who received directed access to online information were able to find information from cancer experts and participate in online support groups. These patients were better informed, more willing to ask their doctors questions, and took more responsibility for making choices about their treatment (Shapiro).

Physicians do have a legitimate concern that patients who use the Internet, and specifically social media, may be exposed to false or misleading medical information. There is a tension between these risks and the benefits of patients' ability to easily share their stories and find supportive communities. Doctors and patients can work together to determine the best way to use the social media
resources that are available.

Addressing Digital Divide and Self-Selection Concerns

The digital divide is a concern for the purposes of understanding social media’s role in healthcare. Because older individuals and some ethnic minorities are less likely to use the Internet and social media services, it is possible that their stories would not be represented. The existence of the digital divide, in itself, is an ethical issue according to some (Floridi), however this particular discussion is beyond the scope of this thesis. Instead, I am more concerned with the implications that the existence of a digital divide may have in communicating illness narratives.

Given that increasing numbers of individuals are turning to the internet for emotional support and to connect with others experiencing similar medical problems instead of their physicians, some groups of people may find it hard to find information that is relevant to them. Certain illness narratives are not being told online, and this could be problematic if it lends to the silencing of some patients’ voices, at least in the online community. Patients and physicians who use social media should not assume that they have access to stories that describe every sort of experience of illness, or that the stories told online mirror their own experience. Rather, these illness narratives may be representative of a certain segment of the whole population.
The ethical issues associated with patient access to social media to share their illness narrative seem to be more or less concerning depending on how prevalent the use of social media is. The more that social media is perceived as a necessary medium for emotional support and validation, the more harmful it would be to have groups of voices absent. The higher the value of using social media, the higher the ethical stakes for the problem.

Given that there is unequal access to Internet, and therefore, social media resources, should every effort be made to decrease this discrepancy? I do not think this is the case. I believe that responsible use of social media resources may be promoted for those who do have access to these technologies without significantly detrimental effects on those who do not have access. Those patients who do not participate in telling their stories through social media cannot reap the benefits that these services offer, such as the formation of online communities of support.

That being said, healthcare facilities and providers could familiarize themselves with the availability of public resources, such as library computers and classes, to which they could refer patients. Additionally, computers and information about social networking sites, such as CaringBridge, could be available at the hospital along with information about other types of support groups for patients and their caregivers. Many hospitals already have resources such as these for patients’
family members. Taking steps such as these may help ensure that all patients have access to the types of support that they may need in the midst of a health event.

Addressing Privacy and Anonymity Concerns

As discussed earlier, patients may have a false sense of security with regards to their privacy online. Patients may not be aware that someone other than their friends and family would be accessing their information. Other patients who want to share their stories to help others may be sharing information online that they would not otherwise feel comfortable sharing with their acquaintances, co-workers, physicians, or even friends and family. This sort of discrimination of information that is passed along to the physician may have effects on the patient’s care.

Many concerns related to privacy and anonymity stem from some patients’ lack of understanding or ignorance of how to protect their privacy. While advocates of Web 2.0 and social media have encouraged lowering barriers to its use and creating a service where any individual to contribute to and edit the online information space, there has not been as much attention given to ensuring that the privacy of these users is protected. Using social media services has become more intuitive, while privacy settings have grown increasingly complex. Here, there is a tension between allowing users to have as much control over their
privacy as possible, and promoting user-friendly privacy settings.

If people do not feel secure online, they will be less likely to share their personal stories of illness through social media. Patients should be aware of their privacy online, or lack thereof. If patients are well informed, and have control over who can access their information, they will likely be more comfortable sharing their stories and interacting in online communities. Privacy concerns must be taken seriously to allow for social media to reach its potential as a way in which patients’ well-being and healthcare can be improved.

Patient Responsibility

A consideration relevant to the topics addressed so far in this thesis is the idea of patient responsibility. There is already a literature available with regards to this concept of patient responsibility (e.g. Arekapudi; Draper and Sorrell; National Health Council Board of Directors; Tauber 2005). For the purpose of the discussion here, I would like to address what would constitute responsible use by patients who use social media to share personal health information. Patients should pay attention to what websites they are visiting and where they are getting their health information. Are there moderators? Are there doctors endorsing medical tips? If looking for tips on how to cope with day-to-day issues, should the patient consult his or her doctor before beginning a new practice or activity suggested by a fellow patient? Is the patient using this for medical information or
to improve their well-being, a more general notion of health?

A responsible patient, as a user of social media, would also understand the limitations of social media. Patients must understand that “digital memory” will store their posts forever. Any information that is published online may be hidden or deleted, but has already been captured in the information space. With privacy settings on many sites, there is a false sense of control over one’s information. It is important to understand that just because only close friends can see a patient’s online information, that does not mean that those few will not share information with a wider circle of people.

In light of physicians’ concerns regarding the availability of false information online and Hawkins’ findings that patients who were guided in their online activities related to healthcare, patients should be forthcoming about the online resources they use. When patients mention their online interactions, their doctor may be able to affirm their activities, or point them in the direction of more credible information, as well as the most useful online communities for support.

Many of these practices are generally best practices for social networking, not specifically related to the use of social media for healthcare. But, they are, nonetheless, good to acknowledge here. There are certain traits, such as the anonymity associated with the Internet, that are double-edged swords. For example, individuals with “taboo” diseases may interact without fear of becoming
a social outcast. The anonymity afforded by the Internet, had it been around when HIV was still looked upon as a taboo illness, could have provided an outlet for accurate information to be disseminated among those with and those without HIV. We know that the Internet, and social media, in particular, is capable of affecting social change, not from the “top-down” or from a typical public health approach. Rather, these changes have started with individuals connecting with one another.

This does have a downside, because not everyone on the Internet is in it for the good of helping others. There are individuals who purposefully spread false or hurtful information, or perpetuate stereotypes of certain groups of people. Those who adhere to the foundations of social media most strongly would oppose silencing of these voices, or trying to stop them from posting online. These comments have the potential to hurt patients going online in both physical ways, by providing poor medical advice, and emotional ways, by perpetuating myths, unless patients are attentive to what information is legitimate and that which is not. Patients can be on guard against such malicious use of the Internet by being open and honest with their physicians regarding the online resources that they consult.

Professional Recommendations

There are not universally accepted professional standards to guide physicians' in
their use of social media. In some situations, it may be difficult to identify who should address the information made available by patients and their caregivers online, particularly when the case is complex and there is false or misleading information being published. Particularly in health related cases, there may not be time to deliberate about the best way to respond to each instance of a patient using social media for his or her own agenda. If the medical community cannot respond to these episodes in a timely manner, it is easy to see how the story might become difficult to handle.

This is one reason why guidelines regarding the use of social media by physicians and other healthcare professionals may be beneficial. As mentioned previously, patients should be aware of the sources of information they are using. A Facebook page created by a family who is advocating for a policy change that would affect their daughter may not be the most reliable source of general information about an illness. Physicians can help by pointing their patients to reputable websites, online support groups, or other social media pages. Giving patients some direction in seeking out these resources seems to be helpful. This approach may be most feasible for specialists, who can familiarize themselves with a relatively small number of resources that would benefit most of their patients.

When it comes to physicians visiting social media sites where their patients share their stories, questions may arise regarding appropriate use. It does not seem
problematic for a physician to visit social media sites, generally, and read patient narratives when the physician has no personal connection or contact with the patient.

Whether or not it is appropriate for a physician to read his or her own patient’s social media site, however, may be more complicated. In this case, interacting via social media, even if it is just to receive the patient’s narrative of the experience, may have detrimental effects on the physician-patient relationship, particularly if the physician is made aware of an issue that he or she wants to address with the patient. For example, if the patient finds out that the physician has been reading his or her online posts without talking about it beforehand, the patient may wonder why the physician looked him or her up, specifically, or may feel as though there has been some breach of trust or crossing of boundaries in the relationship.

Knowing who should act and the appropriate way to respond to stories brought forth via social media may improve communication between physicians, patients, and the public. Reading a patient’s online account of his or her experience may help a physician identify when a patient lacks understanding of an illness or treatment, for example, but there are many ways in which a physician could respond. Addressing such a misunderstanding in a public comment section on the patient’s website may leave him or her feeling embarrassed, or even betrayed. Because the physician is aware of the misunderstanding, the matter
could be addressed privately, either through a personal message or during the next office visit.

In light of the privacy concerns discussed, I would suggest that physicians do not make a practice of searching for their patients online without first talking to their patients about the subject of social media. Even though physicians may have been able to access the patient’s public posts, it is possible that the patient did not intend for his or her information to be available to the physician, in particular, and may feel betrayed if a physician were to discuss personal information found online.

It would be appropriate in many cases for a physician to have a conversation with a patient about the use of social media. If patients seem interested in the idea of sharing their story via social media, I feel that it would be appropriate for physicians to ask their patients about whether or not they would prefer that their physician be free to read or refrain from visiting this site. Moreover, I think that the physician should discuss other sorts of interaction, such as commenting on a post, with their patients before acting in this way. Under normal circumstances, I do not think that physicians should be compelled to interact with their patients online, but I do think that it would be good practice for physicians to have a conversation with their patients before visiting their social media sites.

There will, of course, be some situations that do not fit neatly into this suggestion.
For example, a physician may be reading a blog written by an “anonymous” user about his or her experience of illness. While reading this patient’s narrative online, a physician may notice some similarities between this “anonymous” user and a patient that is currently in his care. Details in the post may make it obvious that this is, in fact, one of the physician’s own patients. Additionally, there are some posts and pictures that indicate that the patient is not following the treatment plan prescribed by the physician, or that a misunderstanding may become evident, as described above. In this case, how should the physician respond?

There are many options open to this physician, such as not indicating to the patient that he or she read the blog posts, commenting on the blog posts as an anonymous user and suggesting that the patient talk to his doctor about the things he has posted online, or talking directly to the patient about the blog. It would seem that the general public could access the blog, so the physician cannot be at fault for reading this particular illness narrative. However, I do not think that it would be appropriate or responsible for the physician to hide his or her reading of the blog from the patient, particularly given that there is evidence that this treatment plan may not be working for the patient. In order to deliver the best medical care to the patient, ensure that the patient understands and can adhere to the treatment plan, and avoid potential physical harm to the patient, the physician should bring up these kinds of concerns and address misunderstandings in a sensitive way to avoid feelings of betrayal and broken trust.
In this situation, the best course of action is for the physician to approach the patient, honestly and without judgment, about the blog that he or she read online. Ideally, this situation would result in the physician having a better understanding of the patient, and the patient feeling able to talk freely with the physician. In other words, if possible, the physician should use the stories he or she reads online to improve his or her relationship with patients.

However, online interactions should have boundaries, just as relationships between people have boundaries. Generally speaking, it would be best for physicians to refrain from becoming “friends” with patients on certain social networking sites, like Facebook or Twitter. These sites are often used to share intimate details of the user’s private life, which may be inappropriate for a relationship that should be more professional in nature. This is commonly accepted across other professions, particularly those that have an obvious power imbalance. For example, teachers must often follow a set of rules that dictates that they cannot be “friends” with their students in this way (Strauss).

I can imagine that there may be some social networking services where it would be acceptable for physicians to make connections with patients. These services may include distinct personal and professional pages or sections. Perhaps, a social media website targeted at facilitating communication between physicians and patients will be developed, which will have certain features, such as privacy
settings, catered to this special type of relationship.

Chapter Summary

In this chapter, I began by addressing the concerns identified in chapter 3. Physicians’ concerns regarding false information can be addressed by providing guidance to patients in their online research and interactions. Providing certain technologies and information about online resources in hospitals could help to lessen the digital divide that we see with respect to social media in the healthcare setting. Finally, privacy is a concern that will require attentiveness to privacy settings and controls available within social media services.

The final sections of this chapter addressed patient responsibility and professional recommendations. Patients who use social media responsibly will learn about the potential of social media, and also of its limitations. Responsible patients should be open with their physician about their use of online resources, and they should provide truthful representations of their experiences when they participate in the use of social media. For their part, physicians should be open to directing their patients to appropriate online resources. Though they are under no obligation to do so, physicians who read their patients’ online accounts of illness, in particular, should be sensitive in their responses to these narratives. If possible, a physician should discuss a patient’s use of social media and his or her preferences with regards to the physician’s participation before consulting.
this information. Given the lack of commonly accepted, and useful guidelines for physicians’ use of social media, the establishment of online boundaries for the physician-patient relationship is important.

Conclusion

In this thesis, I have shown that social media in healthcare, specifically patient-to-patient healthcare, can improve healthcare because it provides more opportunities for illness narratives to be shared and received. Patients use social media to tell their stories of experiencing illness.

This group of stories constitutes its own narrative type, in addition to those types proposed by Arthur Frank. The type of narrative often told through social media is characterized by periodic updates, and “chunks” of information that are told both in real time and over time. This narrative structure invites conversation and support from readers throughout the patient’s experience. These narratives serve the purpose of fostering online relationships and communities, upon which patients can rely for support and advice. Participation in these groups can increase a patient’s sense of overall well-being, and improve healthcare, understood in a broad sense.

However, the use of social media in healthcare does raise some concerns. Physicians are concerned about the credibility of the information available online,
and their patients’ ability to interpret it correctly. Also, concerns related to the
digital divide, self-selection, privacy, and anonymity are raised. To use social
media responsibly in the context of healthcare means that patients must educate
themselves about the technology and function of the services that they are using
to tell their stories. Physicians must remain open to guiding their patients’ use of
online resources and ensure that appropriate boundaries are maintained in their
online interactions.
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