E-patients and Social Media:

Impact of Online Experience on Perceived Quality of Care

by

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A Thesis Presented in Partial Fulfillment
of the Requirements for the Degree
Master of Science in Design

Approved November 2011 by the
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ARIZONA STATE UNIVERSITY

December 2011

ABSTRACT

Social media sites focusing on health-related topics are rapidly gaining popularity among online health consumers, also known as "e-patients". The increasing adoption of social media by e-patients and their demand for reliable health information has prompted several health care organizations (HCOs) to establish their social media presence. HCOs are using social media to connect with current and potential e-patients, and improve patient education and overall quality of care. A significant benefit for HCOs in using social media could potentially be the improvement of their quality of care, as perceived by patients. Perceived quality of care is a key determinant of patients' experience and satisfaction with health care services, and has been a major focus of research. However, there is very little research on the relationship between patients' online social media experience and their perceived quality of care.

The objective of this research was to evaluate e-patients' online experience with an HCO's social media sites and examine its impact on their perceived quality of care. Research methodology included a combination of qualitative and quantitative approaches. Data for this study was collected from Mayo Clinic's social media sites through an online survey. Descriptive statistics were used to identify basic demographic profiles of e-patients. Linear regression analysis was used to examine the relationship between online experience and perceived quality of care. Qualitative data was analyzed using thematic analysis. Results showed a positive relationship between online experience and perceived quality of care. Qualitative data provided information about e-patients' attitudes

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and expectations from healthcare social media. Overall, results yielded insights on design and management of social media sites for e-patients, and integration of these online applications in the health care delivery process. This study is of value to HCOs, health communicators and social media designers, and will also serve as a foundation for subsequent studies in the area of health care social media.

To Mom and Dad,

It is impossible to thank you adequately for everything you've done. Thank you

for your unconditional love, endless support and encouragement.

ACKNOWLEDGMENTS

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Chapter 1

INTRODUCTION

Background

The rise of Web 2.0 and social media has had a significant impact on the U.S. healthcare system. There has been a tremendous growth in the amount of health information readily available on the Internet. As a result, patients are increasingly using the Internet and social media applications to seek health information relevant to them or their family members. A survey conducted by the Pew Internet and American Life Project in August 2010 revealed that, about 80 percent of adult Internet users had looked online for information pertaining to health concerns, medical treatments, reviews of doctors or hospitals, and personal health experiences (S. Fox, 2011). As the Internet and social media applications continue to evolve and become more accessible via wireless and mobile technologies, an increasing number of people are expected to share their knowledge about health conditions, personal health experiences, reviews of treatments, doctors or hospitals, and raising health awareness (S. Fox, 2011). This has led to the emergence of "e-patients", a term used for patients and/or their family and friends who use the Internet to look for health information (Ferguson, 2007).

The need for online health information paired with popularity of social media among e-patients and health consumers has incited many health care organizations (HCOs) to establish their social media presence, and offer online services through these non-traditional channels. Corporations and businesses all

over the U.S., including a host of HCOs and hospitals, are embracing social media applications such as Facebook and Twitter, to reach a larger pool of existing and potential consumers. As an example, the Mayo Clinic is actively using a wide array of social media applications to engage existing patients and their caregivers, promote their brand and services to potential patients, bolster health education and improve overall quality of healthcare (Yee, 2009). As of October 2011, a total of 1229 hospitals in the United States are using social media applications (Bennett, 2011), and the numbers continue to grow. Thus, social media is a promising technology and could potentially impact the health care experience and quality of care for patients.

Research Problem

Patients' online experience with social media applications and perceptions of health care quality are central to the research problem, and will be the focus of this study. One of the significant potential benefits for HCOs in using social media could be the improvement of their quality of health care, as perceived by patients. Perceived quality of care is a key determinant of patients' experience and satisfaction with healthcare services (Arneill & Devlin, 2002), and has been a major focus of research studies. However, most of these studies relate patients' perceptions and experiences to various health care settings (Lim & Tang, 2000; Rosenthal & Shannon, 1997; Sixma, 1998). With an increasing patient population relying on the Internet and social media, patients' overall healthcare experience is no longer limited to merely healthcare settings. Patients' interactions in the "online settings" add another important dimension to their overall health care

experience (Nambisan, 2011). Moreover, research on online health communities suggests that patients' online experience and interactions in an HCO-led online community can impact their perceptions and attitudes toward the HCO and its services (Nambisan, 2011). Although anecdotal evidence about the benefits of social media in health care does exist, there is need for academic research that can link patients' online experience and their perceived quality of care.

Recent research on health care social media is laying the groundwork for subsequent studies in healthcare communication and branding. These studies, mostly undertaken by marketing research firms and advertising agencies, provide basic information about social media users. However, relatively less is known about: 1. how e-patients use social media sites owned and moderated by an HCO and, 2. how their experiences with these applications impact their perceptions of the HCO's quality of care.

As HCOs increasingly incorporate social media in their web strategies to improve quality of care, it is vital to understand how patients' perceptions of care are impacted in this process. Figure 1 describes the conceptual framework of this study. The overall focus of this research is the relationship between e-patients' online social media experience and perceived quality of care. In addition, the demographic profiles of e-patients, the ways in which they use social media for health-related purposes, and their attitudes, reviews and expectations regarding HCO-maintained social media sites are the secondary research interests of this study. The conceptual framework illustrates these research components.
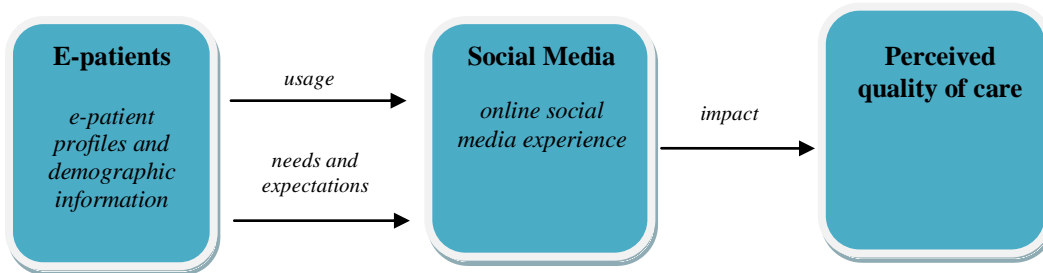
Figure 1. Conceptual Framework.

Purpose of the Study

The purpose of this research is to assess e-patients' online experience with an HCO's social media sites and study its impact on their perceptions of the HCO's quality of care. This study has three primary objectives. The first objective is to describe the demographic and socio-economic characteristics of e-patients and the ways in which they use social media applications. The second objective is to learn more about their attitudes and expectations regarding the utility of social media applications in healthcare. Finally, the third objective is to study the relationship between their online experience with an HCO's social media sites and perceived quality of care of the HCO.

Research Questions

The following research questions were developed to address the three study objectives mentioned above:

1. What are the demographic characteristics of e-patients and in what ways do they use social media applications?

2. What are their attitudes and expectations regarding social media applications in healthcare?

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3. What is the relationship between their online experience with an HCO's social media applications and perceived quality of care of the HCO?

Research Methodology

This study employed a combination of quantitative and qualitative research methods. A literature review was conducted to learn about existing research related to social media, online experience and perceived quality of care. The Mayo Clinic Center for Social Media was identified as the research site for this study. An online survey was used to collect data from the members and/or subscribers of Mayo Clinic's social media sites on Facebook and Twitter, Mayo Clinic blogs and the Mayo Clinic Online Health Community. Details of the survey development and data collection will be provided in Chapter 3. Data was analyzed using regression analysis for quantitative data and thematic analysis for qualitative data. Specifically, multiple regression analysis was used to validate the impact of online experience on perceived quality of care. Thematic analysis and coding techniques were used to analyze data from the open ended questions. Information from qualitative analysis was used to describe the ways in which e-patients currently use social media, and their attitudes, needs and expectations regarding the same.

Definition of terms and research variables

Definitions of the terms and variables relevant to this study are outlined in this section. *Social media* refers to the web-based applications and tools for social interaction which allow users to share and publish content online (Wilcox, 2007).

These applications include blogs, social networking websites, podcasts, music and video sharing etc. Social media applications relevant to this study are Facebook, Twitter, YouTube and blogs. These will be discussed in Chapter 3. *E-patients* is a term used for patients, their family members, caregivers or health consumers who use the Internet to gather health information. The term is used for both those who look up online information for their own self and those who gather information for a friend, family member or someone else (Ferguson, 2007). *Online experience* is defined as the overall experience of e-patients based on their interactions in an online community (Nambisan, Gustafson, Pingree, & Hawkins, 2010). Since this research focuses on social media applications, the term online experience in this study will refer to the overall experience of e-patients with social media applications. *Online health communities* are online groups of people communicating and sharing content related to health and other topics via the Internet. These communities are usually based on shared interests or topics. Perceived quality of care is the quality of health care from the patients' perspective. Patients' perceptions are dependent on the functional aspect of care, which refers to the manner in which patients receive health care services (Babakus, 1992).

Variables. The variables that were utilized in this study included both independent and dependent variables. *Online experience* was operationalized using three independent variables – *information quality, peer support* and *staff support. Information quality* was assessed on a five-point semantic differential scale and included 12 items. *Peer support* and *staff support* were also assessed on

five-point semantic differential scales, and the *peer support* included 9 items and *staff support* included 10 items. The measurement scales for all three independent variables were adapted from a previously validated scale used to measure online community experience (Nambisan, Gustafson, Pingree, & Hawkins, 2010).

Perceived quality of care was the dependent variable and it was measured using an adapted version of the SERVQUAL instrument by Parasuram, Berry and Zeithaml (2001). The items were modified to fit the healthcare context. Finally, the survey instrument also contained questions about *patients' overall online experience*, *quality of content* and patients' *overall perceptions of hospital quality*. These variables were used to provide a basis for further validation. The complete list of items can be found in the online survey in Appendix D.

Significance of the Study

Social media has received much attention recently from both health consumers and HCOs. The significant initiatives and investments made by HCOs in running social media communities for their patient populations, has made it imperative to understand whether HCOs can improve their quality of care perceptions among patients through social media channels. Social media is a relatively new and burgeoning field of research and less is known about how e-patients use social media applications for health-related purposes. There is also very little knowledge about what constitutes their online experience and how that connects to perceived quality of care. The interplay between online experience and perceived quality of care should be considered in order to determine how HCOs can provide better online services in order to improve health care delivery.

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It is the belief of the researcher that by merging these critical areas of research, this study could provide invaluable information that could help HCO's to design, deploy and manage social media applications more effectively.

This study will not only give insights on patients' expectations and needs regarding social media, but will also seek to establish a relationship between their online experience and perceived quality of care. Perceived quality of care has become an important area of research as the United States moves to a patient-centered care model. If the results of this study support the hypothesis, that there is a positive relationship between online experience and perceived quality of care, health care organizations can harness the potential of social media applications in order to improve quality of care perceptions and in the process, strengthen their brand.

Scope and Limitations

This research study examines patients' online experience with social media and its impact on perceived quality of care. There are several opportunities for studying the impact of social media in healthcare. However, this study will solely focus on social media applications mediated by health care organizations. This is because when an HCO extends its online services through social media, it becomes a medium for interaction between patients and health care providers, and adds to patients' positive or negative experiences.

Some potential limitations of the study should be noted. The participants in this study will be subscribers or users of social media applications owned by a health care organization, in this case, the Mayo Clinic. The study aims at

surveying patients and their caregivers who use social media on a regular basis. Those without access to the Internet and who are not members of or do not subscribe to any of the social media applications specific to this study, will not be able to participate. Hence, the results may not be representative of broader patient populations, specifically of the less technology-oriented people. Another potential limitation of this study is the possibility of a voluntary response bias, as participants of the survey will be self-appointed volunteers. As social media evolves rapidly and its adoption becomes more widespread in health care systems, more research will be required to evaluate its impact on health education, patient satisfaction and overall quality of health care.

Organization

This study is composed of five chapters: Introduction, Review of Literature, Research Design, Results, and Discussion. Chapter 2 provides a review of significant research in social media, online experience, e-patients and perceived quality of care. Chapter 2 describes the research design, which includes a discussion of methodology used in this study and development of the online survey. Information on the research site, description of sample respondents and data collection process has also been provided. Chapter 3 also gives a brief description of the measurement strategies used to operationalize the dependent and independent variables. Chapter 4 explains the quantitative as well as qualitative techniques used to analyze data, and results of data analysis. Finally, a discussion of all the research findings, conclusions and implications is offered in Chapter 5.

Chapter 2

REVIEW OF LITERATURE

Introduction

This study examines the relationship between patients' online experience with an HCO's social media sites and their perceived quality of care. In order to do so, the two broad research areas of online experience and quality of health care were studied. Relevant literature was reviewed to gain a better understanding of the two above-mentioned research areas. Since social media in health care is a relatively new and less explored area of research, this study draws on literature from related disciplines such as online health communities, health consumerism, branding in health care, patient-centered care and participatory health. A variety of sources were utilized to collect relevant material, including peer reviewed journal articles, books, white papers, case studies, online magazines and newspaper articles, websites and blogs.

Social Media and Health

Over the past few years, the Internet and social media have created a stir in the healthcare industry. Numerous studies indicate that the Internet has become an important source of health information for many people in the United States. (Cain, Sarasohn-Kahn, & Wayne, 2000; Chou, 2009; Ferguson, 2007; S. Fox, 2008; S. Fox, 2011; Hawn, 2009; Josefsson, 2005; Nambisan, 2011). These studies suggest that the Internet and social media have become valuable tools for patient education and collaboration among patients and physicians. With the advent of Web 2.0, social media applications like Facebook and Twitter are

receiving attention from everyone including patients, health care providers, health care communicators, hospitals and HCOs, administrators and policymakers. Social media on the Internet has led to the "Health 2.0" movement, defined as:

"The use of social software and its ability to promote collaboration between patients, their caregivers, medical professionals, and other stakeholders in health" (Sarasohn-Kahn, 2008).

Some of the trends that are encouraging the popularity of social media in health care are the widespread use of wireless technology, a focus on health and wellness, and motivation among people to connect and share health experiences with others. Wireless devices like mobile phones and tablets are on the rise, and impacting the behavior of health consumers. These devices offer an accelerated pace of information exchange and "just-in-time" multimedia content (S. Fox, 2011), and hence, offer easy access to social media applications. People with mobile devices are more likely to go online to seek health information, or join the online health conversation (S. Fox, 2011). Also, an increase in health awareness among young and older adults is also driving them to use social media related to health.

E-patients and social media. E-patients are increasingly using web-based and social media tools to seek health information, find doctors and treatment options, make appointments, maintain online health records and find emotional support (Catone, 2009, S. Fox, 2011). About 61% of U.S. adults have searched online for health information, according to a report by Pew Internet and American Life Project (Fox, 2011). The report also suggests that e-patients with access to

wireless access are more likely to go online for health-related activities (Fox, 2011). Health information is readily available and easily searchable on the Internet. This proliferation of health information has revolutionized the way people care for themselves and/or their family members. The most common health related activities on the Internet are: reading someone else's stories and experiences, rankings and reviews of health care providers and HCOs, listening to health podcasts, and sharing photos, videos or audio files about health issues (Fox, 2011). As for participation, there are more e-patients who consume health information than those who actively contribute and create online health content (Fox, 2011). In their report, "Health e-People: The Online Consumer Experience", Cain and Sarasohn-Kahn (2000) identify three categories of e-patients based on their health status and related online behavior: "the well", "the newly diagnosed", and "the chronically ill and their caregivers" (Cain et al., 2000). The team at Pew Internet and American Life Project provide an adapted version of the three e-patient categories, by including caregivers in all three groups: "the well", "the acutes", and "the chronics" (Fox, 2011). E-patients who belong to "the well" category are usually healthy, and occasionally browse for general health and wellness information. E-patients who are in "the acutes" category are the ones facing a new health issue or concern, and they search intensively for health care information online. Lastly, e-patients who belong to "the chronics" category suffer from chronic illnesses, and they use online health resources on a regular basis to manage their health conditions (Fox, 2011). Several studies portray the demographic profiles of Internet and social media users who are most likely to be

searching for health information online (Cain et al., 2000; Chou, 2009; Ferguson, 2007; Fox, 2011). Overall, the characteristics of this group include being female, younger than 65 years of age, having a higher education level, and more Internet and social media experience. Studies have also suggested that e-patients with acute and chronic medical issues are more likely to search for health information online (Fox, 2011).

Studies have also identified several kinds of information that online health seekers are pursuing. A recent study by Pew Internet and American Life Project found that the two most frequent health topics of interest to online health information seekers were information related to a specific disease or medical problem, followed by information related to certain treatments or procedures (S. Fox, 2011).

However, there are caveats to be aware of. Patients should make sure that the information they are referring to is medically accurate and from reliable sources (Catone, 2009).

Health care providers and social media. Social media applications have received mixed responses from doctors, physicians and registered nurses. Some health care providers, who claim to be "early adopters" of social media, are putting applications like Twitter and Blogs to use. Physicians are "tweeting" about their areas of medical expertise, gathering medical information, and connecting with other physicians (Terry, 2009). Privacy issues are significant concerns for health care providers too.

HCOs and social media. There is a lack of research studies that could suggest the benefits of using social media in health care. However, anecdotal evidence of its advantages and the increasing adoption of social media by e-patients have sparked an interest in health care organizations to establish their social media presence (Dolan, 2010). Health care organizations across the United States are using social media tools like Facebook and Twitter to connect with their patient communities. Some other ways in which HCOs are using social media are for fundraising events, creating awareness, listening to patients and getting feedback (Galloro, 2011), and emergency response communication (Terry, 2009). The Centers for Disease Control and Prevention (CDC) are actively using social media applications to improve health, safety, emergency preparedness by engaging and interacting with social media users (Nall, 2010).

Mayo Clinic has started their own center for social media to provide training and promote the use of social media among its network of health care organizations (). As a result of using social media, they are expecting better collaboration among patients, physicians and researchers, as well as patients who are better engaged and informed about their own health care (Dolan, 2010).

While some HCOs are actively using social media to connect and communicate, others are treading cautiously. Concerned about challenges and the real worth of social media, some hospitals and medical companies are hesitant in investing into social media efforts, and are raising questions about privacy and confidentiality issues, for example: HIPAA regulations. Risks associated with information security and vulnerability have been major concerns for healthcare IT

departments (Sharp, 2010). To avoid misuse of health information and inappropriate posts and comments, HCOs like Mayo Clinic advocate creating and using social media policies for their organizations (Galloro, 2011).

Found in Cache (Bennett, 2011), a blog run by Edward Bennett, Director of Web Strategy at the University of Maryland Medical System, has updated information on social media adoption by healthcare organizations and hospitals. As of October 2011, 1229 hospitals and healthcare organizations in the United States are using one or more social media applications. According to the blog, Facebook and Twitter are the most popular applications among these (Bennett, 2011).

Social Media and Health Care Branding

Although health care is one of the largest industries among the developed and developing nations, its approach to branding has been traditionally conservative in the past. Although some strong, recognizable brands already exist health care, there is still a lack of significant brands in health care, when compared to other consumer and retail industries (Snihurowych, Cornelius, & Amelung, 2009). However, many successful healthcare organizations are making impressive strides in strengthening their brand, and building brand awareness among their existing and potential patient communities (Berry & Seltman, 2007). HCOs are leveraging social media in order to present their brand to a wider network of patients and physicians. Branding is synonymous with effective communication and alignment of interests between all stakeholders (Berry & Seltman, 2007), In this context, social media are the conduit through which HCOs

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communicate and provide information to their patients and health consumers. Hence, social media applications could be the ideal tools of health care branding.

Branding has been known to positively impact technical and service quality, and allows for innovation in the organization (Snihurowych et al., 2009). "Service quality" is relevant to this study, as it is known to impact patient satisfaction, health outcomes, retention of patients and their word-of-mouth recommendations (Snihurowych et al., 2009). Snihurowych et al. (2009) also state that,

"good branding by a health care organization may not only increase actual quality, but also may affect the perception of quality by patients, positively impacting outcomes in reality" (Snihurowych et al., 2009, page 131)

If social media are one of the mediums for health care branding, could these tools impact perceptions of quality by patients?

Perceived Quality of Care

Quality of care is an important constituent of patients' overall experience with a healthcare facility (Arneill & Devlin, 2002). As the intensity of competition increases among health care providers, HCOs are focusing more on patient satisfaction (Arneill & Devlin, 2002), and looking for innovative and cost-effective ideas to establish and maintain better relationships with their patient communities (Nambisan, Gustafson, Pingree, & Hawkins, 2010b).

The importance of patient perceptions has been emphasized by Rosenthal and Shannon (1997). According to their study, patient perceptions are an important predictor of health care quality and are being increasingly used to

measure care quality (Rosenthal & Shannon, 1997). Patients' perceptions have the ability to capture positive aspects of health care delivery, and thus, are very crucial to improvements in health care quality.

How can perceived quality of care be defined, and what are some of its major attributes? A number of studies have examined perceived quality of care with varied approaches (Arneill & Devlin, 2002; Lim & Tang, 2000; Rosenthal & Shannon, 1997; Sixma, 1998). Arneill and Devlin (2002) studied the impact of waiting room environments on perceptions of care quality of the physician. They suggested quality of patient-provider interaction as a critical predictor of patients' perceived quality of care. Rosenthal and Shannon (1997) examine how patient perceptions can be used to assess health care systems and provide a rationale for using perceived quality of care to evaluate health care systems. Although online experience with social media and perceived quality of care have been studied separately in research, there are no studies that focus on the relationship between the two constructs. This research study attempts to fill the gaps in the literature related to online experience in health-related social media sites and perceived quality of care, specifically related to HCOs.

Chapter 3

RESEARCH DESIGN

Introduction

This chapter provides an overview of the research methodology that was utilized, and design of this study. The following sections describe the research design, methodological approach, research method used to collect data, research setting and participants, design of the survey instrument, and data collection procedure. The following research questions were addressed:

1. What are the demographic characteristics of e-patients and in what ways do they use social media applications?

2. What are their attitudes and expectations regarding social media applications in healthcare?

3. What is the relationship between their online experience with an HCO's social media sites and perceived quality of care of the HCO?

Research Design

The framework of this study was designed keeping in mind the exploratory as well as descriptive nature of the research objectives. The exploratory aspect of this study was rooted in qualitative data gathered through open-ended questions on the survey. This data was used to learn more about e-patients and the ways in which they use health care social media sites, their online experience with these sites, and their needs, expectations and attitudes towards social media. The descriptive aspect was rooted in quantitative data, and was used to describe relationships between data, and to organize it into meaningful patterns

using descriptive statistics and regression analysis. This information was used to describe the relationship between e-patients' perceived quality of care and online social media experience.

Methodology

A combination of quantitative and qualitative methods, also known as the mixed methods model (Creswell, 2003), was used to learn more about patients' online experience, and its impact on their perceived quality of care. This approach was selected because it provides an opportunity to collect quantitative and qualitative data concurrently and gain broader perspectives on the data obtained (Creswell, 2003).

More specifically, the concurrent nested strategy (Creswell, 2003), was used to design the data collection method. According to Creswell (2003),

"The concurrent nested strategy can be identified by its use of one data collection phase, during which both quantitative and qualitative data are collected simultaneously. A nested approach has a predominant method that guides the project. Given less priority, the second method is embedded, or nested, within the predominant method. This nesting may mean that the embedded method addresses a different question than the dominant method, or seeks information from different levels" (p. 218).

In this study, the predominant approach was quantitative in nature, and a qualitative approach was used to supplement the quantitative component. This approach is illustrated in Figure 2. Qualitative data can be in the form of words, pictures and icons, and is analyzed through thematic analysis; and quantitative

data is in the form of numbers, and statistical procedures are used to analyze it (O'Leary, 2004). In this study, quantitative as well as qualitative data were collected through an online survey of e-patients. The study included a review of literature, identification of the research site and participant sample, development of the survey instrument, data collection from the site, and analysis.
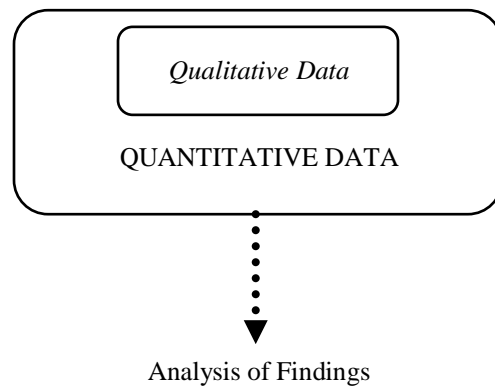
Figure 2. Methodological Approach. (Creswell, 2003)

Literature Review

A review of the literature was performed to examine relevant research pertaining to social media and online communities in health care, online experience, perceived quality of care, e-patients and health information, and health care branding. Materials relevant to the study were collected from various sources: peer reviewed journals, books, white papers, case studies, online magazine and newspaper articles, and blogs. Gaps in the literature were identified and the need for this study was addressed. The findings of the literature review are contained in Chapter 2.

Research Site Description

The Mayo Clinic Center for Social Media was selected as the primary research site for this study. The Center for Social Media was established by Mayo Clinic in July 2010 to "accelerate and enhance effective application of social media tools throughout Mayo Clinic and to spur broader and deeper engagement in social media by hospitals, medical professionals and patients to improve health globally" (*Mayo clinic creates center for social media.*2010). The center manages Mayo Clinic's various social media profiles on Facebook, Twitter and YouTube, and Mayo Clinic Blogs. Details about social media channels relevant to this study are discussed below.

1. *Mayo Clinic Facebook Page*: Provides information on Mayo Clinic and various health-related topics. Patients, their family members and other users are encouraged to interact with other users and the Mayo Clinic staff members. Users can write on the Mayo Clinic "wall", post pictures and videos, ask questions, and participate in discussions via the discussion board. This page has more than 62,000 subscribers, also known as "fans" of the community (*Mayo clinic facebook page.*n.d.).

2. *Mayo Clinic Twitter Community*: Provides real-time information about health, news on Mayo Clinic research and events in the form of "tweets", which are short messages of 140 characters. Patients are also encouraged to join scheduled chats on a variety of health topics. The Mayo Clinic Twitter community has more than 240,000 subscribers, also known as "followers" (*Mayo clinic twitter page.*n.d.).

3. *Mayo Clinic YouTube Channel*: Provides videos on patient education, latest research in health care and treatment options. Some videos are also dedicated to patient stories and testimonials. There are about 1500 uploaded videos and more than 4000 subscribers (*Mayo clinic YoutTube channel.*n.d.).

4. *Sharing Mayo Clinic*: This blog by Mayo Clinic "provides a virtual community for patients and employees to connect and share their experiences. It's the online companion to the new newsletter for patients, also called Sharing Mayo Clinic, and is a hub that links to Mayo Clinic's pages on other social networking sites, such as Facebook and YouTube" (*Sharing mayo clinic blog.*n.d.) .

5. *Mayo Clinic Online Health Community*: This is an online social network launched by Mayo Clinic to connect its community of patients and caregivers with other users. Community members can share their experiences, participate in discussions and also refer to content from Mayo Clinic's other social networking sites, such as Facebook and YouTube and Blogs (*Mayo clinic online health community.*n.d.).

The major criteria used to select this research site were: 1. Mayo Clinic was among the early adopters of social media tools and has become a pioneer of the social media revolution in the U.S. health care industry, 2. The social media sites mentioned above are managed by Mayo Clinic directly, 3. They have a facility dedicated to social media: the Center for Social Media, and their own online

social network, 4. Their social media sites are very active, making them appropriate for data collection.

Research Method

A web-based survey was used for collecting data. The survey was designed using adapted versions of standardized scales from research studies (Babakus, 1992; Nambisan, 2011; Sixma, 1998). Some open-ended questions were also added by the researcher to incorporate qualitative features. The qualitative component was added in order to glean information about e-patients and their online behavior that could not be reduced to numbers; even if this information were coded as numbers, the richness of data would be lost (O'Leary, 2004). After an extensive review of literature, the key areas relevant to the research questions were identified, and based on these the survey instrument was divided into 4 parts. A detailed explanation of the survey design and development is given in the following section.

Survey Instrument. The survey used in this study was comprised of 26 questions which were divided into four sections: social media usage, online experience, perceived quality of care and demographic information. Names of these sections were not indicated on the survey because they were only for the purpose of analysis by researcher and the participants did not need to be aware of this information. The complete survey can be referenced in Appendix D.

Section one of the survey had 12 questions about participants' Internet and social media usage. Three questions were based on general Internet and social

media usage, six questions were specific to the research site, and three questions were open-ended.

Section two of the survey had six questions pertaining to their online experience with the research site's social media communities. They were based on quality of information and multimedia content, interaction with other users and owners of the communities. Five questions were based on a five-point Likert Scale, and one question was open-ended. An optional section for additional comments was provided with each question, except those that were open-ended.

Section three of the survey had three questions pertaining to patients' perceived quality of care. The first question asked participants about their association with the research site, and the other two were based on their perceived quality of care; one was adapted from the SERVQUAL scale (Parasuraman, 1988) and the other one was based on overall perceptions of care quality.

Section four of the survey had five questions about demographics and socio-economic status. Specifically, these questions collected information about participants' age, gender, educational level, employment status and annual household income.

Survey scale development. The variables used in this study were online experience, informational support, peer support, staff support and perceived quality of care.

Online Experience. Online experience was operationalized using a four-dimensional construct called *Online Community Experience* (Nambisan, 2011), that measures online experience of patients and other users in online health

communities owned by health care organizations. As proposed and developed by Nambisan (2011), the four dimensions of online community experience in a health community are *pragmatic experience*, *usability experience*, *sociability experience*, and *empathic experience*.

Pragmatic experience is the "pragmatic or utilitarian value that the patient experiences from their interactions in the online health community. This experience is related to the functional aspect of the online health community" (Nambisan, 2011). Usability experience is the "patients' experience in navigating and using the online community environment. As such, this experience captures the ease of use and clarity of technological features of the online community" (Nambisan, 2011). Sociability experience is the "experience that patients derive from their interactions in the online health community" (Nambisan, 2011). Finally, empathic experience is the "perceived empathy felt by the patient in an online health community" (Nambisan, 2011).

Also, the two most important features of an online health community are informational support and emotional support (Eysenbach et al., 2004; Gustafson et al., 1999). Drawing on these ideas, three key areas were identified: *quality of informational content*, *peer support* and *staff support*. For the purpose of this study, online experience was measured as a function of these three key areas, where informational content, peer support and staff support were considered as independent variables.

Quality of informational content was measured using a 12 item scale, which reflected the main characteristics of informational content obtained from

the health social media community. The set of 12 items were informative, engaging, relevant, easy to understand, readily usable, credible, reliable, valuable, useful, productive, timely and specific. This scale was adapted from measures that were developed to study customer experience in online customer communities (Nambisan, 2009).

Peer support was measured using a nine items scale, which reflected the main characteristics of peer support in the health social media communities. The set of nine items included helpful, responsible, interactive, responsive, polite, empathetic, friendly, knowledgeable and caring. This scale was adapted from measures that were developed to study customer experience in online customer communities (Nambisan, 2009).

Staff support was measured using a 10 items scale, which reflected the main characteristics of staff support in the health social media communities. The set of 10 items included helpful, responsible, interactive, responsive, polite, empathetic, friendly, knowledgeable, caring and trustworthy. This scale was adapted from measures that were developed to study customer experience in online customer communities (Nambisan, 2009).

The three above-mentioned independent variables were assessed on a 5-point semantic differential scale and responses were labeled 5 = "Strongly Agree", 4 = "Agree", 3 = "Neither agree nor disagree", 2 = "Disagree" and 1 = "Strongly Disagree".

Perceived Quality of Care. Perceived quality of care was measured using an adapted version of a standardized scale known as the SERVQUAL instrument

(Parasuraman, 1988). The scale used in this study had 17 items or statements pertaining to patients' perceptions regarding a hospital's health care quality based on five dimensions – Empathy, reliability, responsiveness, communication and caring (Bowers et al., 1994). The complete list of items can be found in Appendix D. The original items on the SERVQUAL scale were modified to fit to the health care context and a few items were removed. Patients' perceptions regarding each of the 17 items were assessed on a 5-point semantic differential scale and responses were labeled 5 = "Strongly Agree", 4 = "Agree", 3 = "Neither agree nor disagree", 2 = "Disagree" and 1 = "Strongly Disagree".

Data Collection procedure

Steps involved in the collection of data for this study included gaining access to the research site, obtaining approval from the IRB, posting the online survey on Mayo Clinic's social media sites, and recording responses from participants. The Director of Mayo Clinic Center for Social Media was contacted via email by the researcher to discuss the research plans and to get permission for conducting research. Upon initial agreement, a draft of the online survey was reviewed by the Center for Social Media team, and minor changes and additions were suggested. The next step was to obtain approval from the IRB.

IRB Approval. The research study was approved by both Mayo Clinic Center for Social Media and Arizona State University's Institutional Review Board (IRB). The study and survey were approved by the medical director of Mayo Clinic Center for Social Media, after a second review of the revised survey. A letter of approval was sent by Mayo Clinic to Arizona State University IRB.

The study was approved by the IRB on June 9th, 2011 and the study was determined to be exempt in accordance with Federal Regulations, 45 CFR Part 46.101(b)(2). Copies of the approval letters from Mayo Clinic Center for Social Media and Arizona State University's IRB can be referenced in Appendix B.

After obtaining approval from both Mayo Clinic Center for Social Media and ASU IRB, the survey was posted on Mayo Clinic's social media communities on Facebook and Twitter, in addition to the Sharing Mayo Clinic blog and Social Media Health Network sites on June 17, 2011. The survey post included a link to the online survey. The following screenshots show the survey posts on Mayo Clinic's social media sites.
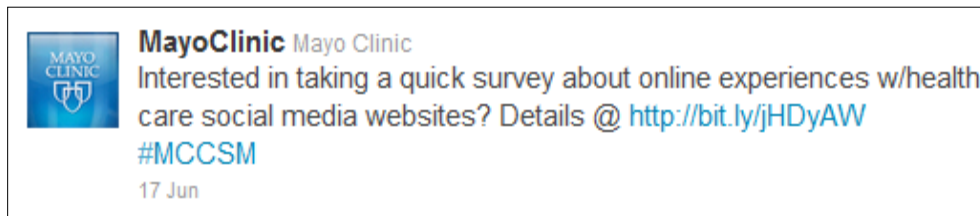

Figure 3. Survey post on Mayo Clinic's Twitter site.

Figure 4. Survey post on Mayo Clinic's Facebook site.

> ## In Need of Survey Respondents
>
> Posted on *June 17, 2011*
>
> The Mayo Clinic Center for Social Media is assisting a graduate student gathering data for a social media related study. The study is focused on learning more about patients' online experiences with health care social media Web sites. Data from this study will help develop a better understanding of patients' expectations and attitudes regarding use of social media by healthcare organizations and factors that can improve their online experience. This research will also provide insights on how to better integrate social media in the healthcare delivery process and improve online patient-provider relationship strategies.
>
> We invite your participation in this study by completing a brief survey online. This process should take no longer than 10 minutes. Your participation in this study is voluntary. You may choose not to participate or to withdraw from the survey at any time. Your responses will be anonymous and all individual responses will be kept strictly confidential. No personally identifiable information will be collected. The results of this study may be used in reports, presentations or publications and will be shared only in the aggregate form. You must be 18 years or older in order to participate.
>
> Your contribution to this study will be invaluable and could help provide information for creating better online experiences for patients and their family members. Your willingness to participate and contribute to this research is greatly appreciated.
>
> Thank you for your time and help!

Figure 5. Survey post on the Sharing Mayo Clinic Blog.

The survey had a cover letter which gave a brief overview of the research study and provided instructions for participation. In order to avoid biased responses from the participants, the survey cover letter did not disclose the intent of studying the relationship between online experience and quality of care. The participants were specifically not told that the study focused on the relationship between online experience and quality of care perceptions in order to prevent their responses from being influenced by that knowledge, either positively or negatively. Participants who were 18 years and older were invited to participate in

the survey. Qualtrics online survey software was used to create the survey and record responses. The complete survey can be found in the Appendix D. Respondents could complete the survey from June 17, 2011 to August 17, 2011.

Participants. Participants were recruited through volunteer sampling. A response rate could not be calculated because it is not known how many community members actually viewed the survey invitation. After two months, the survey link was disabled and all the data were downloaded and prepared for analysis. A sample of 144 responses was obtained. Because participation was voluntary, some participants chose to leave the survey before completion. These incomplete responses were not included in data analysis. The number of completed responses was 86. From the 86 completed responses, 25 were removed as those respondents did not subscribe to any of the social media channels mentioned in the survey. Hence, a final set of 61 completed and usable responses was retained for data analysis. SPSS 19.0 software was used to analyze the data.

Chapter 4

RESULTS

Introduction

This chapter presents analysis of the data collected and research findings. Analysis of the survey has been presented in 3 parts: the first part evaluates data regarding trends in social media usage, the second part describes qualitative data from open ended questions and the third part focuses on the relationship between online experience with social media and perceived quality of care. This information is used to answer the research questions outlined in the previous chapters, and test the research hypothesis. The research questions, reiterated from the Introduction, are:

1. What are the demographic characteristics of e-patients and in what ways do they use social media applications?

2. What are their attitudes and expectations regarding social media applications in healthcare?

3. What is the relationship between their online experience with an HCO's social media applications and perceived quality of care of the HCO?

Participants

A total of 61 participants completed all sections of the survey. Of these, the number of female participants was 43, and the number of male participants was 18. The age range of participants was 23 to 67 years; the average age being 44 years. A majority of the respondents (53%) belonged in the 31-50 years age group. With regard to educational background, most of the participants had an

education level of an undergraduate degree or higher: 29% of the participants had an undergraduate degree, 29% had a Master's degree, and 18% had a post graduate degree. Approximately 69% of the participants were employed full-time, 15% were self-employed and 8% were employed part-time. The distribution of participants among the five income levels was concentrated between $50,000 and $100,000. Sample socio-demographic details are presented in the following figures.
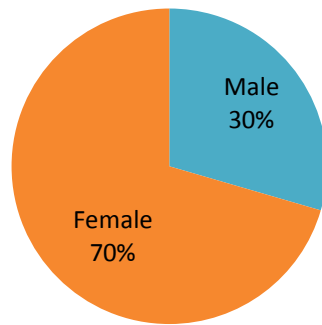
Figure 6. Ratio of female and male participants.
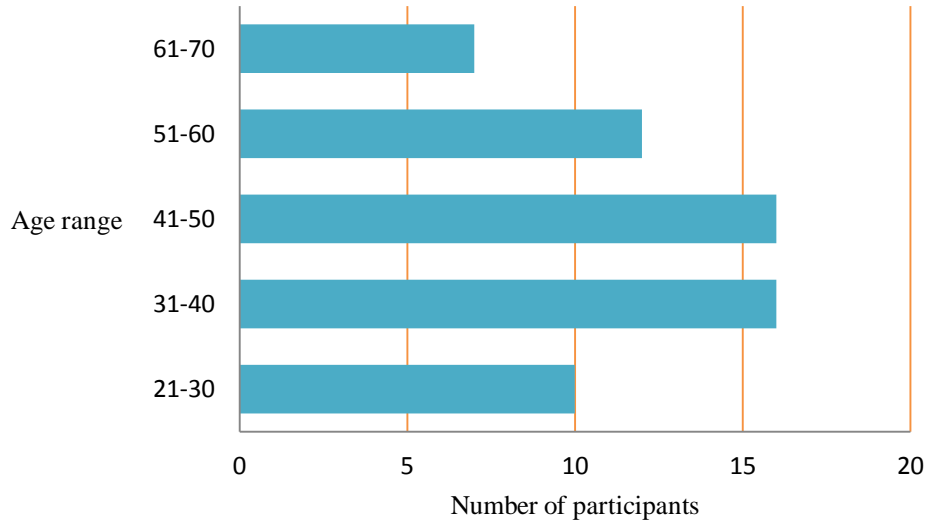
Figure 7. Age range of participants.
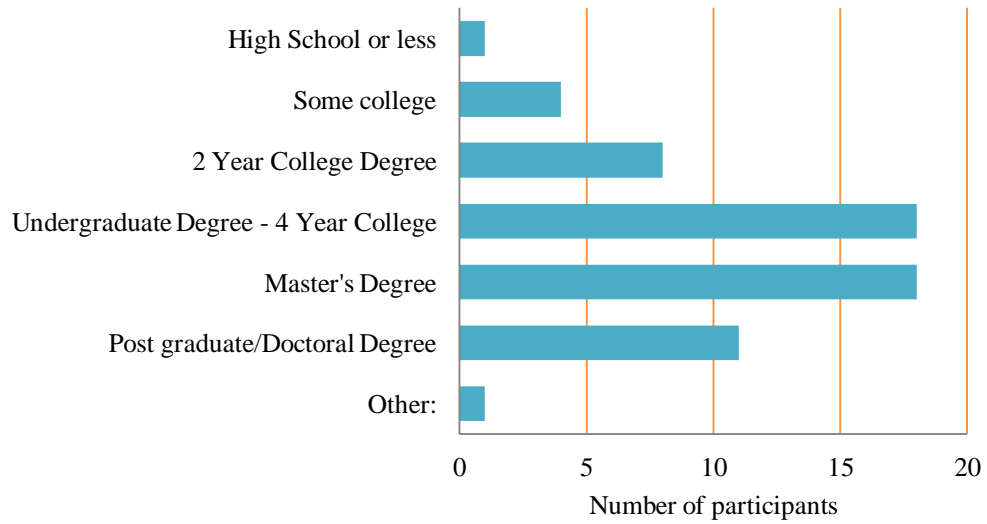
Figure 8. Educational background of participants.
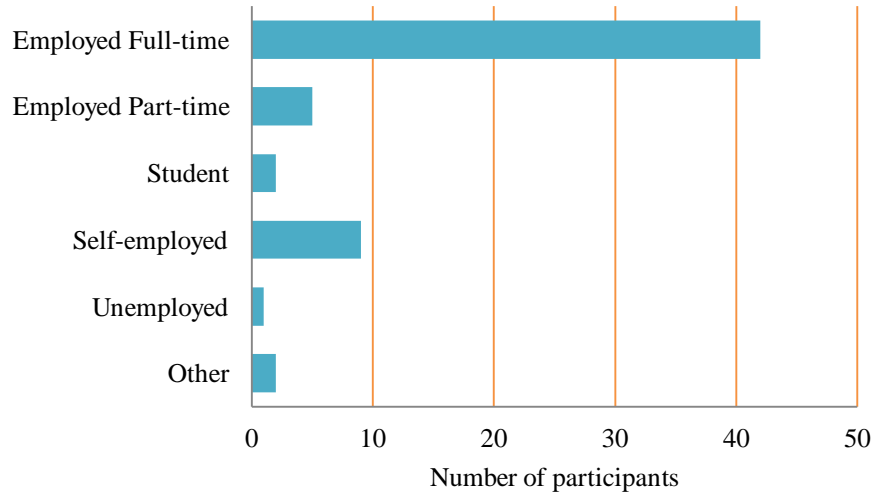
Figure 9. Employment status of participants.
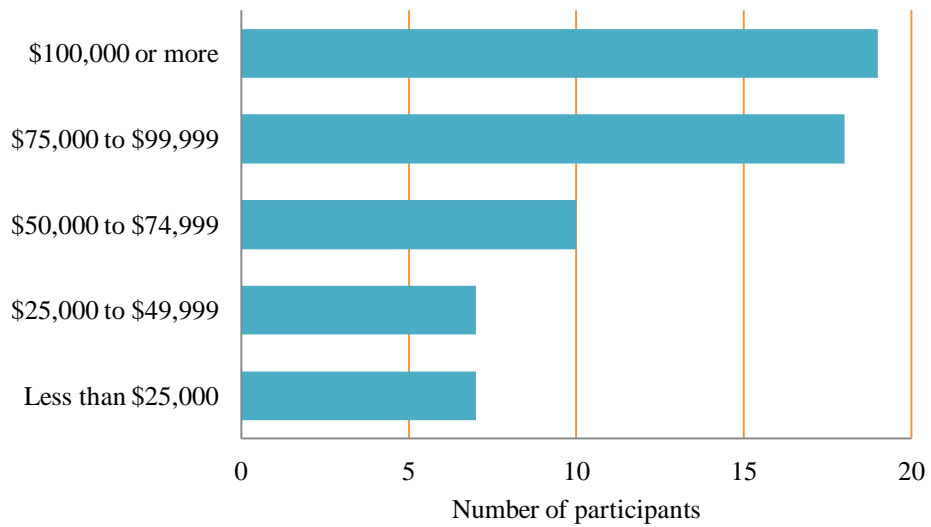
Figure 10. Annual household income of participants.

Internet and Social Media Usage Trends

Internet and social media use was also of interest in this study as these technologies are essential in shaping patients' online experiences and can give insights on factors that shape these experiences, the kind of health activity patients are involved in, and the reasons why they use social media for health.
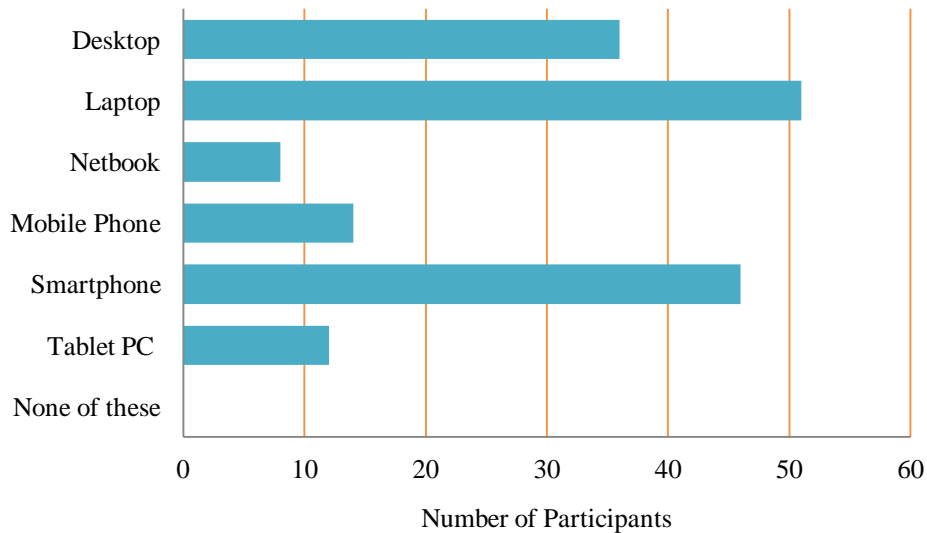
Figure 11. Devices owned by participants. This figure displays the results to the question: "Which of these devices do you currently own?"

As Figure 11 illustrates, 84% of survey participants owned laptops, 75% owned smartphones and 59% owned desktops. Thus, these devices were owned and used by majority of participants. Mobile phones were owned by 23% of participants, and tablet computers and netbooks were owned by 20% and 13% of participants, respectively. It is important to mention that these options were not exclusive - a participant could own one or more of the above-mentioned devices.
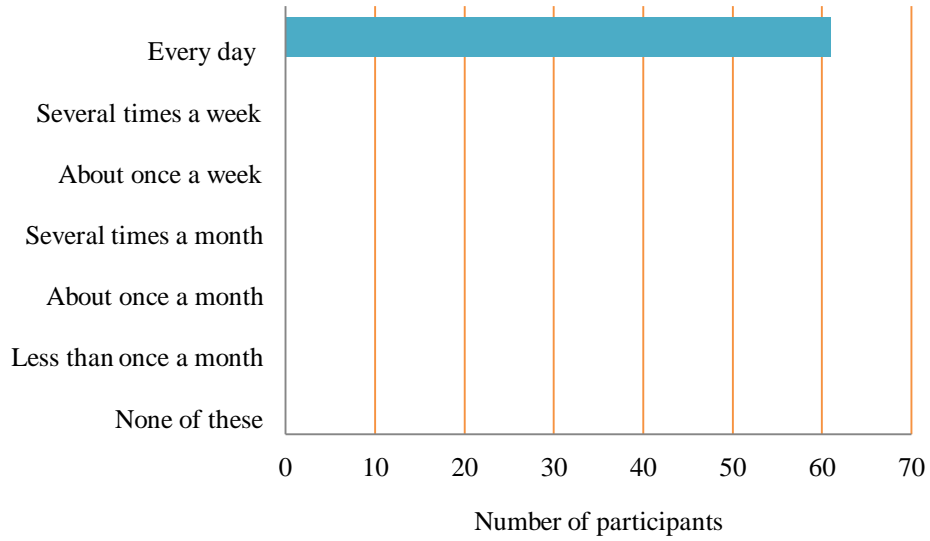
Figure 12. Frequency of Internet usage. This figure displays the results to the question: "How frequently do you use the Internet?" As illustrated by the figure, all of the participants said they use the Internet every day. This suggests an Internet-savvy group of participants.

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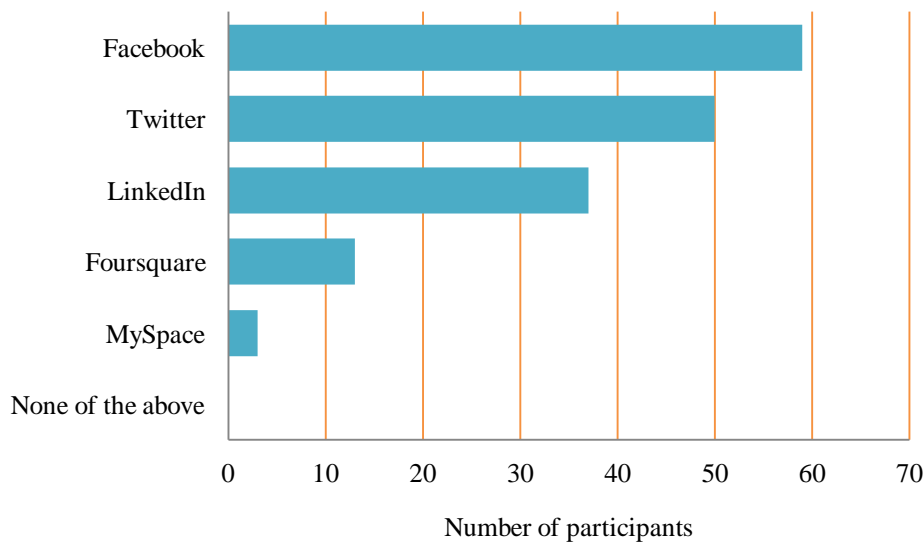
Figure 13. Social media applications used by participants. This figure displays the results to the question: "Which of the following social media applications do you use or visit?"
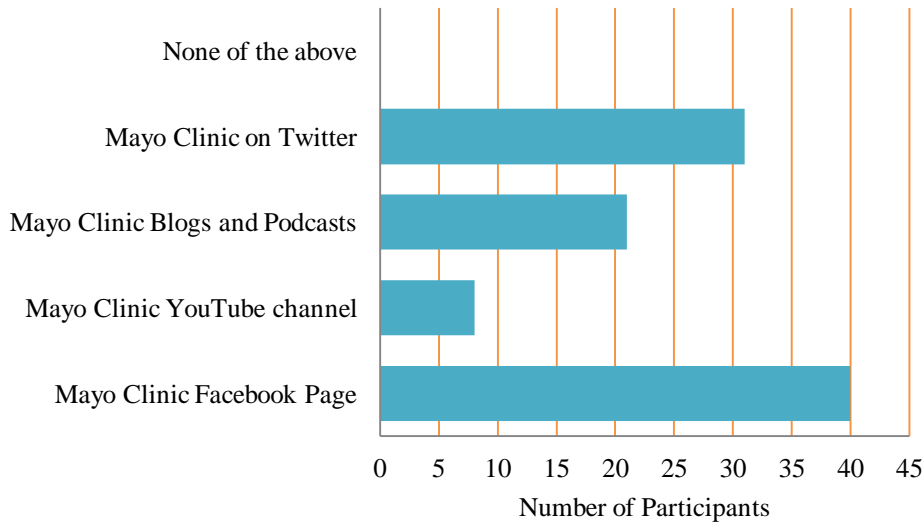
Figure 14. Part 1: Mayo Clinic Social Media. This figure displays the results to the question: "Which of these do you access regularly?"
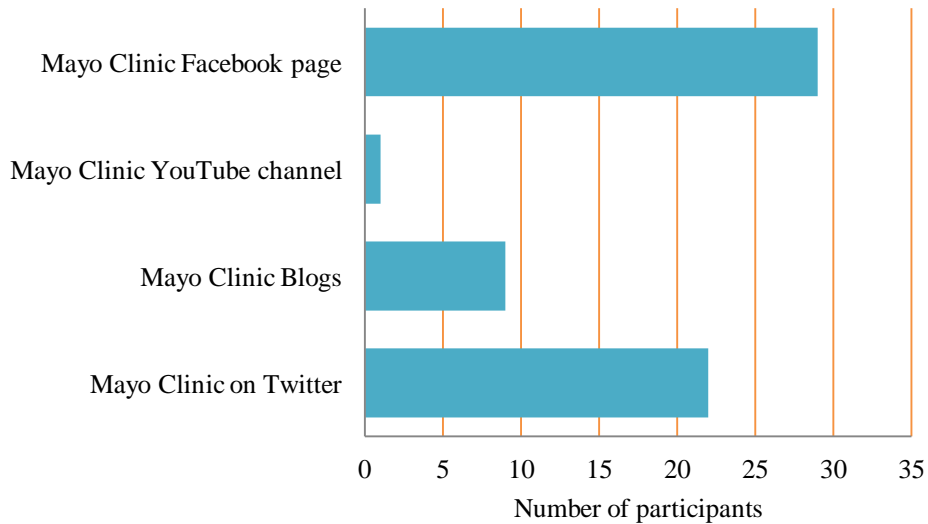
Figure 15. Part 2: Mayo Clinic Social Media. This figure displays the results to the question: "Which of these do you access the most?"
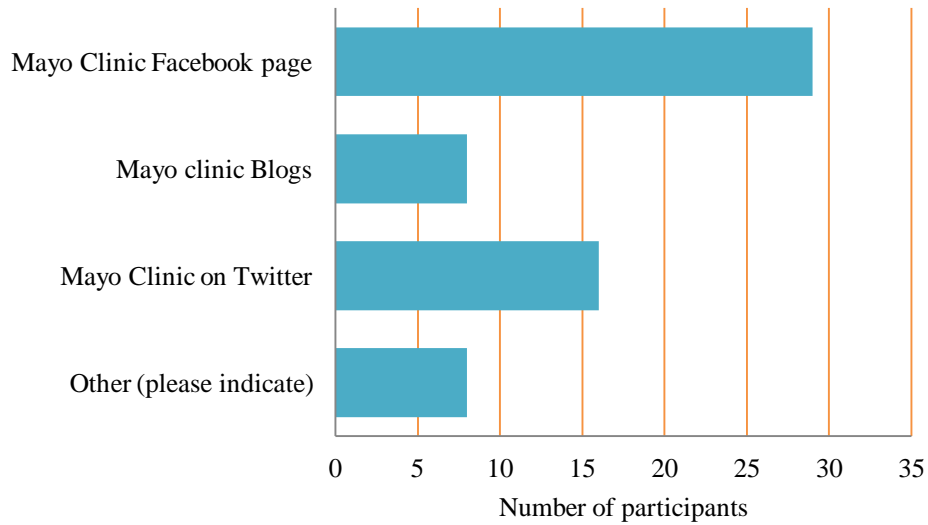
Figure 16. Part 3: Mayo Clinic Social Media. This figure displays the results to the question: "Where did you find the link to this survey?"
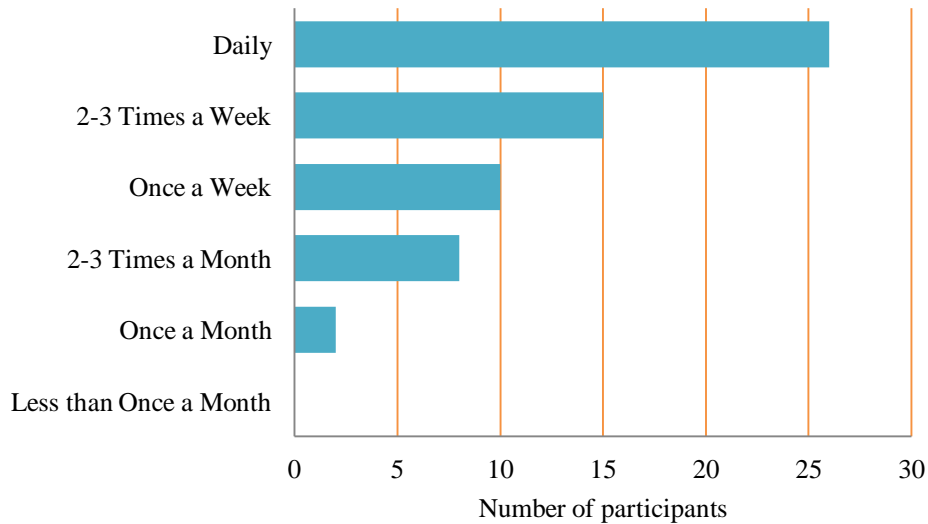
Figure 17. Part 4: Mayo Clinic Social Media. This figure displays the results to the question: "How often do you access these sites?"

- To read what other patients say about a medication or treatment
- To research other patients' knowledge and experiences
- To get health information that helps me manage a health condition
- To get emotional support
- To build awareness around a medical condition or cause
- To share my knowledge of and experience with a health issue
- To find recommendations and opinions about treatment options
- To find recommendations and opinions about doctors and hospitals
- To feel I belong to a group or community
- To share stories
- To get referrals
- To seek medical advice
- None of the above
- Others

Figure 18. Part 5: Mayo Clinic Social Media. This figure displays the results to the question: "What are your primary reasons for visiting these websites?"
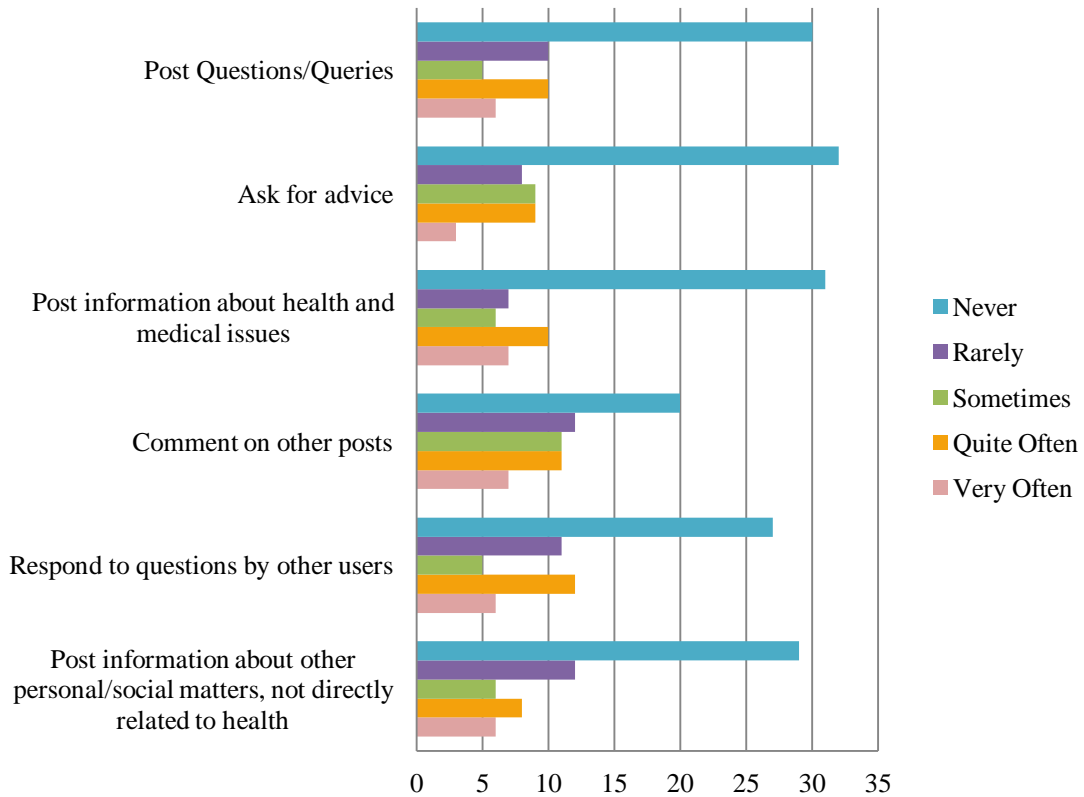
Figure 19. Part 6: Mayo Clinic Social Media. This figure displays the results to the question: "How often do you:"

Quantitative analysis

The primary focus of quantitative data analysis was the application of multiple regression analysis, formulation of the regression model, and interpretation of the results.

Regression Analysis. The relationship between online experience and perceived quality of care was examined using regression analysis. Specifically,

multiple linear regression analysis was used to examine how much the three independent variables: information support, peer support and staff support, predicted a change in the dependent or outcome variable: perceived quality of care. Statistical Package for the Social Sciences (SPSS) version 19.0 was used to analyze the quantitative data. Prior to conducting regression analysis, the basic descriptive statistics (mean, standard deviation and reliability) were evaluated for all the variables. Table 1 provides this information. The reliability coefficients (α) for all variables were in a range of 0.84 to 0.86, exceeding the acceptable value of .70 (Gliem & Gliem, 2003). The overall reliability score for all variables was 0.91, which is very high and indicates good internal consistency among all the variables. Correlations were also examined among all the variables to examine the degree of relationship between all variables. Table 2 provides the correlation values.

Table 1

Descriptive Statistics: Mean, Standard Deviation, and Reliability measures

Variables	Minimum	Maximum	Mean	Std. Deviation	Chronbach's α
Informational Support	1.00	5.00	4.13	0.76	0.86
Peer Support	2.00	5.00	3.98	0.76	0.86
Staff Content	3.00	5.00	4.08	0.78	0.84
Perceived Quality of Care	3.00	5.00	4.03	0.75	0.84

Table 2

Correlation Coefficients for independent and dependent variables

Variables	Informational Support	Peer Support	Staff Support	Perceived quality of Care
Informational Support	1.00			
Peer Support	0.56**	1.00		
Staff Support	0.69**	0.77**	1.00	
Perceived Quality of Care	0.73**	0.73**	0.85**	1.00
** Correlation is significant at the 0.05 level (2-tailed).				

Tables 3 and 4 show the results of multiple regression analysis. Results from the Table 3 indicate an overall support for the study hypothesis. It was predicted that patients' online experience would have a positive association with their perceived quality of care. The value of R Square is 0.76, implying that approximately 76 percent of the variance in perceived quality of care is explained by the three independent variables in the model. Thus, the overall strength of association between online experience and perceived quality of care is good. Moreover, the P value (Sig.) of 0.000 from the F-test is much lesser than the alpha value of 0.05, suggesting that the overall model is significant and the independent variables reliably impact the dependent variable (*Regression with SPSS - annotated SPSS output for multiple regression analysis.*). It should be noted that the information in Table 4 gives an overall assessment of the combined impact of all three

independent variables. It does not reflect the relationship of any single independent variable with the dependent variable.

Table 3

Linear Regression Analysis: overall model fitting information

R Square	Adjusted R Square	F	Sig.
0.76	0.75	59.55	0.000

The ability of each independent variable to predict a change in the dependent variable is addressed in Table 4 below. The standardized Coefficients (β) for each of the independent variables are listed along with their t values and p values. Informational Support and Staff Support had a significant and positive impact on perceived quality of care. However, Peer Support was not a significant predictor of perceived quality of care, even though the two variables were highly correlated. Thus, except for one variable – peer support, the overall results supported the hypothesis that patients' online experience with an HCO's social media can play a crucial role in shaping their perceptions of the HCO's quality of care.

Table 4

Linear Regression Analysis: values of standardized coefficients

Model	β	t	Sig.
(Constant)		0.84	0.40
Information Support	0.21	2.38	0.02
Peer Support	0.15	1.43	0.16
Staff Support	0.60	5.57	0.000
Dependent Variable: Perceived Quality of Care			

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Additional Validation. The overall online experience was expected to correlate with overall quality perceptions. This prediction was used to provide a basis for additional validation of the regression results. Both variables were Likert scales with a five-point response where a higher score indicated a more favorable response. The correlation between overall online experience and overall quality perceptions was statistically significant, with a score of 0.83. These results provided additional validation for the research findings.

Qualitative analysis

Analysis of the open-ended responses was done using thematic analysis. The process involved an initial review of data, organizing and preparing data for coding, assigning codes to various segments of data, identifying themes and relationships from the codes, and summarizing the findings. In the preliminary step, responses for each open ended question were read carefully by the researcher with an eye for recurring keywords, ideas and topics. Reading also helped to get an overall sense of the data. After the initial observations were recorded, responses were re-read and a list of keywords and topics was created. The responses were then grouped together into clusters based on the list of keywords and topics, and organized into a two column table; the first column contained all the responses and the second column was for adding codes. The next step was developing codes for various segments of the text. Codes were informed by the list of keywords and topics predefined in the initial step, and also by new themes that became apparent during clustering. Data was reviewed again and corresponding codes were assigned to segments of text. Within the clusters, codes

were further divided into sub-codes and assigned to appropriate segments of data. This process helped uncover themes and categories for analysis. The next step was to identify underlying themes, categories, patterns and relationships that would result in meaningful findings and interpretations. The final step included writing a summary or narrative of these findings and interpretations.

Two word analysis tools were utilized in analyzing and interpreting qualitative data. One of the tools was Wordle™. This is an online tool that generates word clouds from text that is provided. The words with a higher frequency in the source text appear prominent compared to the less frequent ones. The other tool was the Word Tree, which belongs to the IBM-sponsored website, "Many Eyes". This tool allows users to upload a data set and then search within that data set to develop visual relationships and frequencies of words. The following images give an example of the use of the two above-mentioned tools. The first image shows a word cloud formed by Wordle™, and the second image shows all the uses of the word "social media" in the transcripts.

Figure 20. Example of a word cloud created for qualitative responses.

Figure 21. Example of word tree analysis. The figure shows all the uses of the word "social media" in the transcripts.

The recurrent themes in their responses were communication, health information and education. Almost all participants were of the opinion that hospitals should keep up with the changing trends in web technologies and use these emerging technologies to improve health education and awareness, provide a reliable and credible source of health information. Participants repeatedly described their experiences as "fantastic", "awesome", "good", "great" and "wonderful". Other commonly used superlatives were "necessity", "empowering", "accessible", and "effective". While participants had positive views on using social media for managing their health online, most of them believed that doctors and health professionals continue to be their first choice for health concerns. Social media applications were a significant supplement for obtaining health information but they did not replace the importance of traditional health care and caregivers.

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A communication tool for HCOs. Participants were asked their views about HCOs communicating through social media. Many participants felt that social media was one of the important emerging trends in communication technologies, and health care organizations should keep up with the changing trends. Overall, positive responses associated with social media outweighed the negative and neutral ones. Participants repeatedly used words and phrases with positive connotations, like "awesome", "fantastic", "great", "powerful", "effective", "good", "wonderful", "love it", and "ideal". This suggests their positive experiences with social media. Communication was an important aspect for most of the participants. They viewed social media as a medium for HCOs to communicate and engage with patients, reach out to a large number of populations, and "be in the conversation". Creating a culture of open communication and transparency were described as "extremely necessary in today's world" by participants. They also reported social media to be a useful tool for connecting with other patients, families and health providers, policy makers and HCOs. Almost all participants indicated the importance of reliable and trustworthy health information. Social media sites owned by HCOs were viewed differently from other online sources, as respondents were confident that content in these sites was mediated by an HCO and health information would be accurate and reliable. Other aspects outlined by participants were easy access to latest research, new treatments and medical updates, and quicker dissemination of health information. One participant also mentioned their preference for "short

messages with relevant health information" as opposed to overload of information.

A health care management tool. Each of the participants shared their unique perspectives on using social media to manage their health, but a common theme was apparent: participants were keen on using social media for their health as long as their concerns about privacy, credibility and trust were addressed. Participants repeatedly voiced their concerns about sharing personal health information and experiences on a public forum. Tackling inaccurate information, privacy and confidentiality and identity fraud were also listed as other important concerns. However, most participants found social media tools to be a great health information resource when used in conjunction with care from "real doctors". According to them, health care providers and practitioners remain vital to the health decision making process, and social media could supplement the care process. Participants described social media tools as "valuable", "realistic", "wonderful", "helpful", "useful", "convenient" and "effective". The top health-related social media activities included researching information, community building, reading other patients' stories and experiences, and taking part in online events. On the other hand, a few participants did not believe that social media tools were appropriate for health care as they did not have the ability to provide "individualized information" to patients and could possibly lead to wrong self-diagnosis.

Other health-related websites. Participants were asked to cite the online health websites and tools they frequently used for health information. Table 5

lists some of the most commonly used online health resources, as mentioned by survey participants.

Table 5

Examples of online health resources used by e-patients

Hospital/Clinic websites	Mayo Clinic, Cleveland Clinic, Johns Hopkins
Government websites	Better Health Channel, Centers for Disease Control and Prevention (CDC), U.S. Food and Drug Administration (FDA), National Institutes of Health (NIH), National Cancer Institute (NCI), National Library of Medicine (NLM),
Health portals and organizations	WebMD, JDRF, American Diabetes Association (ADA), Healthline, American Heart Association (AHA), Healthy children, KidsHealth, Crohn's and Colitis Foundation (CCFA)
Health-specific search engines	Google health
Social networks	PatientsLikeMe, Sermo, Sharecare,
Online medical journals and publications	PubMed, Medscape, Harvard Health, Diabetic living,

Potential areas of improvement. Participants had a variety of suggestions when asked how their online experience could be improved in an HCO's social media site. As before, priority was given to health information and credibility. Participants listed disease-specific health information, interactivity and credibility as their major requirements from HCOs and their social media sites. Participants also mentioned that they would like to hear and read more personal stories from patients and physicians. Suggestions for improving

interactivity and engaging more e-patients included live chats, more virtual events, mobile "apps" for health and fitness, and more multimedia and videos. Building a health network, an overall health portal and integration of text message information services were also suggested in order to build a stronger community of connected e-patients and benefit those patients who could not visit the health care facility in person.

Chapter 5

DISCUSSION AND CONCLUSION

Introduction

This chapter will focus on the interpretation of the results that were reported in chapter 4 and conclusions about the study's findings. Analysis of results has been presented with respect to the three research questions outlined in chapter 1. The various sections of this chapter include discussion of significant findings and their interpretation, limitations of the study, recommendations for future research, implications and conclusions.

Discussion of Results

The main purpose of this study was to examine through research the relationship between patients' online experience with an HCO's social media sites and their perceived quality of care. Findings of this research suggest that the two above-mentioned elements are positively correlated. As discussed in Chapter 3, a mixed-methods approach was used to glean valuable insights from the three research questions:

1. What are the demographic characteristics of e-patients and in what ways do they use social media applications?

2. What are their attitudes and expectations regarding social media applications in healthcare?

3. What is the relationship between their online experience with an HCO's social media applications and perceived quality of care of the HCO?

Demographic trends. Findings related to demographics suggest that social media communities contain a plurality of participants, including patients, family members, researchers, marketers, and health care professionals including registered nurses and doctors. These people have divergent interests and modes of communication. Among the survey participants, patients and their family members were interested in information specific to their health conditions, whereas nurses and physicians were keener on learning about the latest research and news on medical advancements. Participants belonging to marketing and branding teams reported having a completely different motive – to learn about social media marketing strategies and policies in health care.

The fact that 70% of survey respondents were female was consistent with other research studies that suggest that women are more likely than men to use the Internet for health information and participate in social media sites (S. Fox, 2011). Furthermore, findings related to age of e-patients also correlated with research that suggests that e-patients aged 25-50 are more likely to use social media for health. Majority of survey participants were in the age group 31-50 (Chou, 2009). However, the number of participants between ages 51-70 was also significant (31%). These findings suggest that efforts to improve health awareness, promote effective communication and maximize reach through social media would benefit most from targeting female e-patients belonging to the age group 31-50. Also, the promising number of survey participants between ages 51-70 implies an increase in social media adoption in the coming years within this age group. Thus, a

continually updated record of socio-demographic trends in social media would help HCOs leverage these communication channels more effectively.

Social media usage. The top reasons given by participants for using social media were, building awareness around a medical condition or cause (16%), getting health information (15%), reading reviews about treatment options (11%), and reading what other e-patients say about a medication or treatment (10%). The less popular choices were sharing personal stories (6%), community building (4%), sharing knowledge and personal health experiences (5%), and getting emotional support (4%). In fact, all participants reported being involved in one or more of the "reading", "observing" and "listening" online activities. Additionally, majority of participants rarely or never posted information about their health, commented on other e-patients' posts, asked for health advice, or responded to queries by other e-patients. These findings reveal a lopsided nature of online health activities. While the number of participants reading online health information and listening to online health conversations was significantly high, only a fraction of participants reported writing or contributing to the online content as part of their online health activities. These observations are in sync with other studies which have established that there are more passive consumes of information in the form of readers and listeners than there are active contributors in the form of writers and creators of online content (Cain et al., 2000; Chou, 2009; S. Fox, 2011). This trend is somewhat understandable, as e-patients would possibly write and contribute on a daily basis if they or someone in their family had an ongoing health issue, or if they possessed enough knowledge about a

health topic. Previous research on online health consumer behavior also suggests that all e-patients are not same (Cain et al., 2000). According to Cain (2000), interests and motivations of e-patients are diverse, and depend on overall health status and levels of information seeking urgency.

The "information seeking" aspect was more prominent than the "community and networking" aspect associated with social media. This finding is a little surprising, given the nature of interactions in social media applications. Networking and community building are the core ideas and concepts around which social media applications are designed (Johnson, 2006; Wilcox, 2007). Therefore, it is interesting to note that informational support was sought more frequently by participants than emotional support. Concerns of privacy and security of personal health information were reported by almost all participants, and could possibly prevent potential e-patients from using social media for health-related activities.

Peer support. Results of regression analysis provided an overall support for the study hypothesis that e-patients' online experience would impact their care quality perceptions. The only unsupported relationship was that of peer support with the perceived quality of care. This is another important research finding, and suggests that e-patients may not attribute peer support to be a quality of the health care organization. Thus, peer support, as an isolated independent variable, may not necessarily be a strong indicator of an HCO's care quality. However, in conjunction with other independent variables, peer support had a significant contribution to the overall impact on care quality.

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Limitations

Data for this study was collected from users and subscribers of Mayo Clinic's social media profiles on Facebook, Twitter, blogs and Mayo Clinic's online health community. The Mayo Clinic is highly reputed and one of the leading health care organizations in the United States (Berry & Seltman, 2007). They have a powerful social media presence and their profiles on various social media applications are very popular among e-patients. Thus, it is difficult to generalize the findings of this study to health care organizations which are not as prominent and social media-savvy. Moreover, a sample size of 61 participants was not large enough to generalize the findings to broader patient populations. Also, 70 percent of the participants were female. Such a demographic composition limits the generalizability of research findings to a sample that may be comprised of equal number of female and male respondents, or more number of male respondents. A surveyed population with an equal ratio of male and female participants or more number of male participants than the 30% in this study could possibly lead to results more easily correlated to the general population.

As discussed in Chapter 1, a potential voluntary response bias was another limitation. Participation in this study was voluntary and there were no incentives provided to complete the survey. This implies that participants who completed the entire survey might have felt strongly about the research topic. Moreover, all participants in the sample were avid Internet and social media users. Thus,

participants' responses could be different from those who did not respond, or those who did not use the Internet and social media applications as frequently.

Another limitation stems from the differences in design and purpose of the social media applications used in this study. The user interfaces and nature of interactions are significantly different in Facebook, Twitter and blogs. Whereas Facebook focuses on relationships and group interactions, Twitter is a microblogging tool, which aims at broadcasting quicker and shorter content. Blogs differ from these two applications, and focus on self-expression and sharing stories. These differences in the design of user interface and nature of interactions between users could have impacted participants' responses. As an example, participants who used Mayo Clinic's Twitter site more than their Facebook site, would potentially give more importance to quality of information and multimedia content than peer support. A comparison study could be conducted for different social media applications to check for inconsistencies.

Recommendations for future research

This research has addressed some of the elements that health care organizations should take note of, and implement or integrate in their social media strategies. As the Internet and social media technologies continue to evolve rapidly, health care organizations will need to keep up with the pace in order to use these online tools effectively. More research will be required to understand the behavior of e-patients in an online environment provided by health care organizations. In the future, a more extensive study that can reach wider e-patient populations may be undertaken to provide broader insights. Better generalization

in future studies will also increase the significance of findings and will provide support to the study results. This can be done by using a larger sample size and a diverse range of data.

The current research relied on surveying as the primary research method. Future studies could benefit by including a mix of qualitative and quantitative research methods. For example, focus groups or interviews with patients and their family members could further help in understanding the dynamics of health communication and interaction, and how it affects health behaviors or outcomes.

Some of the primary concerns that e-patients have regarding social media, emerged as a result of this study. Two of these concerns are issues of privacy and confidentiality of personal health information. These concerns might be preventing e-patients from having a positive online experience with social media applications, and using the diverse array of interactive features that these applications offer. Research efforts need to be directed at these issues and concerns, and the factors that can help overcome them.

Implications

Research Implications. By setting up their social media sites, HCOs not only create an online community of patients, providers and other health consumers, but also offer an online space for interactions between online health consumers (Nambisan, 2010). Positive or negative experiences derived from these social media communities could play an important role in shaping an HCOs brand, and are an important part of the overall healthcare communication context. There needs to be more research in the area of health care social media to further

understand how e-patients' online experience may supplement their offline healthcare experience. Research efforts also need to be directed at understanding the e-patient population, who are accessing and being reached through social media channels. E-patients' online experience must be regarded as a dynamic and constantly evolving concept. A number of prior studies have examined the significance of online support for patients and its impact on their health outcomes (Eysenbach et al., 2004). However, very few studies have attempted to measure online experience and examine its association with perceived quality of care. This study provides a theoretical and research foundation for empirical studies in health care social media.

Practice Implications. A key research finding of this study offers important implications for health care organizations communicating through social media. Among online health consumers, social media is becoming the most popular and sought after technology regardless of age, gender, education level and race/ethnicity {{48 Chou,Wen-Ying W.Y.S. 2009}}. This implies the tremendous potential these online applications offer for impacting health and health-related behaviors of e-patients. HCOs could use social media to reach larger groups of patients, maximize the impact of health communication, and build robust health networks. Social media also offers potential opportunities for reducing the digital divide by reaching wider audiences than traditional forms of media have done in the past.

The promising relationship between online experience and perceived quality of care also holds important implications for HCOs. Social media

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communities could be cultivated to improve patients' overall health care experience, with minimum investment. Also, social media sites could be designed or customized to improve the online experience for e-patients, for example, by providing health information on a broader range of topics, improving interactivity and promoting health awareness. HCOs could spur innovation and creativity by identifying ways to facilitate online interactions between health consumers. One possible solution would be to recognize and address the integration of e-patients and information systems in an optimal manner. For example, HCOs could integrate text messaging and mobile apps to maximize their reach to wider patient populations. A robust design of digital communication and information exchange framework at the organizational level would promote effective health communication by channeling short messages, queries and knowledge sharing to more appropriate platforms like instant messaging, texting, online chat rooms and discussion forums.

As e-patients and health consumers increasingly migrate to social media applications to manage their health, it is imperative for HCOs to deliver rich and contextually relevant health information to motivate their patients make better decisions about their health and well-being. Also, concerns about access, privacy, safety and security of information could be addressed by HCOs. For example, e-patients who cannot access a medical facility directly due to physical location constraints could rely on the online services provided by the facility. The online services would be the first point of contact between the e-patient and the health care organization. Currently, there is an enormous amount of health information

online, and more information gets added each day. Each health community has a wealth of information, but is isolated. Moreover, e-patients expressed concerns about proliferation of misinformation through social media communities. This is an important aspect of online communication, and given the sheer breadth and volume of online health information, HCOs could reduce the problems of fragmented and inaccurate information significantly by providing reliable and accurate health information e-patients can trust. The inhibitions associated with digital interactions can be taken care of if e-patients are reassured that the source of health information is trustworthy.

Health care organizations also need to be aware of the "one size doesn't fit all" concept in health care. There are marked differences in the online behaviors of e-patients based on gender, age, and heath status. HCOs should take this into account and know their target population really well before developing their social media strategies. This study provided insights into e-patients' needs and expectations from HCO-owned social media sites.

A broader theme that emerges from this study is that social media sites can be treated as a medium to connect with e-patients and enhance brand loyalty. The study findings imply the potential for HCO's to improve their image and brand value among patients. This could be done by shaping patients' positive perceptions towards the HCO and its services.

Conclusion

In conclusion, evaluating e-patients' experience in HCO-run social media communities is of paramount importance and should not be ignored, as it could

potentially shape patient attitudes toward the HCO and its care quality. Many HCOs carefully measure and evaluate patient experience within the hospital setting and also collect feedback regarding the utility of their websites (Nambisan, 2000). However, feedback about their social media sites is also important and could give important insights on the needs and expectations of patients from the HCO. This study suggests that it is beneficial for e-patients as well as health care organizations to include patients' experiences with their social media as part of their overall patient experience within the HCO.

One of the ways in which HCOs can create a patient-centered model of care, is by using social media tools to further their goals. These tools could be used to promote transparency and advocacy in health care, and would make health care systems easier to navigate. It would also make HCOs a trusted source with a focus on patient-centered care. To design a model of patient-centered care, HCOs and hospitals are making efforts to effectively engage their existing patient communities, promoting their health care brand to potential patients and their care givers, as well as making health information more accessible and transparent to its community. The insights obtained from the findings of this study could help HCO's and hospitals design their social media strategies to further these goals of creating a patient-centered model of care.

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APPENDIX A

LETTER OF PERMISSION FOR RESEARCH

Online Research Survey

E-patients and Social Media: Impact of Online Experience on Perceived

Quality of Care

Dear Director,

Mayo Clinic Center for Social Media

I am a graduate student under the direction of Dr. Michael Kroelinger in the The Design School at Arizona State University. I am conducting a research study to learn more about patients' online experience in hospitals' social media websites and its impact on their perceptions of the hospitals' quality of care. I am inviting your permission to allow the members of Mayo Clinic social media websites (Facebook, Twitter, YouTube and Blogs) to participate in this study. Participation entails completion of an online survey of 27 questions. This process should take no longer than 20 minutes.

Members' participation in this study is voluntary. They may choose not to participate or to withdraw from the study at any time. Responses will be anonymous and all individual responses will be kept confidential. The results of this study may be used in reports, presentations or publications but participants' names will not be known. All responses will be shared only in the aggregate form. There are no foreseeable risks or discomforts to their participation. Eligible participants must be 18 years or older.

If you have any questions concerning the research study, please contact the research team at: leena.admane@asu.edu or michael.kroelinger@asu.edu. If you have any questions about subject/participant rights in this research, or if you feel they have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788.

As members of your organization's social media communities, their contribution to this study will be invaluable and could help provide inputs for creating better online experiences for patients and their family members.

Completion of the online survey will be considered their consent to participate.

Thank you for your time and help.

Sincerely,

Leena Admane

Arizona State University

APPENDIX B

IRB EXEMPT STATUS APPROVAL

Office of Research Integrity and Assurance

To:	Michael Kroelinger
	Dixie Gamm
From:	Mark Roosa, Chair
	Soc Beh IRB
Date:	06/09/2011
Committee Action:	**Exemption Granted**
IRB Action Date:	06/09/2011
IRB Protocol #:	1105006473
Study Title:	E-Patients and Social Media

The above-referenced protocol is considered exempt after review by the Institutional Review Board pursuant to Federal regulations, 45 CFR Part 46.101(b)(2) .

This part of the federal regulations requires that the information be recorded by investigators in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.   It is necessary that the information obtained not be such that if disclosed outside the research, it could reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability, or reputation.

You should retain a copy of this letter for your records.

APPENDIX C

SURVEY COVER LETTER

Mayo Clinic Center for Social Media Survey
Cover Letter

Dear Participant:

The Mayo Clinic Center for Social Media is conducting a survey to learn more about patients' online experiences in healthcare social media websites. We invite your participation to complete an online survey. This process should take no longer than 10 minutes.

Your participation in this survey is voluntary. You may choose not to participate or to withdraw from the study at any time. Your responses will be anonymous and all individual responses will be kept strictly confidential. The results of this study may be used in reports, presentations or publications and will be shared only in the aggregate form. There are no foreseeable risks or discomforts to your participation. *You must be 18 years or older in order to participate.*

Your contribution to this study will be invaluable and could help provide information for creating better online experiences for patients and their family members. Your willingness to participate and contribute to this research is greatly appreciated.

Please click the '*Next*' button to proceed. Thank you for your time and help!

APPENDIX D

ONLINE SURVEY

Dear Participant:

The Mayo Clinic Center for Social Media is conducting a survey to learn more about patients' online experiences in healthcare social media websites. We invite your participation to complete an online survey. This process should take no longer than 10 minutes.

Your participation in this survey is voluntary. You may choose not to participate or to withdraw from the study at any time. Your responses will be anonymous and all individual responses will be kept strictly confidential. The results of this study may be used in reports, presentations or publications and will be shared only in the aggregate form. There are no foreseeable risks or discomforts to your participation. You must be 18 years or older in order to participate.

Your contribution to this study will be invaluable and could help provide information for creating better online experiences for patients and their family members. Your willingness to participate and contribute to this research is greatly appreciated.

Please click the 'Next' button to proceed. Thank you for your time and help!

1. **Which of the following devices do you currently own or use? (Please check all that apply)**

❑ Desktop

❑ Laptop

❑ Netbook

❑ Mobile Phone

❑ Smartphone (For example: iPhone, Blackberry, Android etc.)

❑ Tablet PC (For example: iPad, HP Slate, Dell Streak, Google HTC etc.)

❑ None of these

2. **How frequently do you surf the Internet?**

○ Every day

○ Several times a week

○ About once a week

○ Several times a month

○ About once a month

○ Less than once a month

○ None of the above

3. Which of the following social media applications do you use or visit? (Please check all that apply)

❑ Facebook

❑ Twitter

❑ LinkedIn

❑ Foursquare

❑ MySpace

❑ Flickr

❑ YouTube

❑ Others (please indicate) _____

❑ None of the above

4. Where did you find the link for this survey?

○ Mayo Clinic Facebook page

○ Mayo Clinic YouTube channel

○ Mayo clinic Blogs

○ Mayo Clinic on Twitter

○ Other (please indicate) _____

5. Which of these websites do you follow or visit regularly? (Please check all that apply)

❑ Mayo Clinic Facebook Page

❑ Mayo Clinic YouTube channel

❑ Mayo Clinic Blogs and Podcasts

❑ Mayo Clinic on Twitter

❑ None of the above

6. What are your primary reasons for visiting these websites? (Please check all that apply)

❑ To read what other patients say about a medication or treatment

❑ To research other patients' knowledge and experiences

❑ To get health information that helps me manage a health condition

❑ To get emotional support

❑ To build awareness around a medical condition or cause

❑ To share my knowledge of and experience with a health issue

❑ To find recommendations and opinions about treatment options

❑ To find recommendations and opinions about doctors and hospitals

❑ To feel I belong to a group or community

❑ To share stories

❑ To get referrals

❑ To seek medical advice

❑ None of the above

❑ Other (Please Indicate): _____

7. Which of the following websites do you access THE MOST?

○ Mayo Clinic Facebook page

○ Mayo Clinic YouTube channel

○ Mayo Clinic Blogs

○ Mayo Clinic on Twitter

8. How often do you access this website?

○ Daily

○ 2-3 Times a Week

○ Once a Week

○ 2-3 Times a Month

○ Once a Month

○ Less than Once a Month

9. How often do you:

	Very Often	Quite Often	Sometimes	Rarely	Never
Post Questions/Queries	❍	❍	❍	❍	❍
Ask for advice	❍	❍	❍	❍	❍
Post information about health and medical issues	❍	❍	❍	❍	❍
Comment on other posts	❍	❍	❍	❍	❍
Respond to questions by other users	❍	❍	❍	❍	❍
Post information about other personal/social matters, not directly related to health	❍	❍	❍	❍	❍

Comments:

10. What are your views on healthcare organizations communicating through social media? (Example: Facebook, YouTube, Twitter)

11. How do you feel about using social media for managing your health or the health of your family? (Example: Facebook, YouTube, Twitter)

12. Are there any other websites that you visit for health information? If yes, please list the names of those websites.

The following set of items relate to the information you obtain from Mayo Clinic's social media channels on Facebook, Twitter, YouTube and the Sharing Mayo Clinic Blog. Please indicate your agreement/disagreement with each of the following.

13. The information I obtain from Mayo Clinic's social media websites is:

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Informative	○	○	○	○	○
Engaging	○	○	○	○	○
Relevant	○	○	○	○	○
Easy to understand	○	○	○	○	○
Readily usable	○	○	○	○	○
Credible	○	○	○	○	○
Reliable	○	○	○	○	○
Valuable	○	○	○	○	○
Useful	○	○	○	○	○
Productive	○	○	○	○	○
Timely	○	○	○	○	○
Specific	○	○	○	○	○

Comments:

The following set of items relate to the users or visitors of Mayo Clinic's social media channels on Facebook, Twitter, YouTube and the Sharing Mayo Clinic Blog. Based on your interactions with them, please indicate your agreement/disagreement with each of the following.

14. The users of Mayo clinic's social media websites are:

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Helpful	○	○	○	○	○
Responsible	○	○	○	○	○
Interactive	○	○	○	○	○
Responsive	○	○	○	○	○
Polite	○	○	○	○	○
Empathetic	○	○	○	○	○
Friendly	○	○	○	○	○
Knowledgeable	○	○	○	○	○
Caring	○	○	○	○	○

Comments:

The following set of items relates to the owners/moderators of Mayo Clinic's social media channels on Facebook, Twitter, YouTube and the Sharing Mayo Clinic Blog. Based on your interactions with them, please indicate your agreement/disagreement with each of the following.

15. The owners/moderators of Mayo clinic's social media websites are:

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Helpful	○	○	○	○	○
Responsible	○	○	○	○	○
Interactive	○	○	○	○	○
Responsive	○	○	○	○	○
Polite	○	○	○	○	○
Empathetic	○	○	○	○	○
Friendly	○	○	○	○	○
Knowledgeable	○	○	○	○	○
Caring	○	○	○	○	○
Trustworthy	○	○	○	○	○

Comments:

16. How would you rate the quality of content posted in these social media websites? (Blog posts, videos etc.)

○ Excellent

○ Very Good

○ Good

○ Average

○ Poor

Comments:

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17. How would you describe your overall experience in the Mayo Clinic social media websites?

○ Positive

○ Somewhat positive

○ Neither positive nor negative

○ Somewhat negative

○ Negative

Comments:

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18. How can your online experience be improved? Please suggest potential areas of improvement. (For example: up-to-date information, range of topics, multimedia, interactivity, website content)

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19. Have you or your family member(s) received care or treatment at Mayo Clinic? (Please check all that apply)

❑ I have received care at Mayo Clinic in the past

❑ I am currently receiving care at Mayo Clinic

❑ My family member(s) have received care at Mayo Clinic in the past

❑ My family member(s) are currently receiving care at Mayo Clinic

❑ None of the above

❑ Other (please indicate): _____

The following set of statements pertains to Mayo Clinic, services offered by them and their staff.

20. Based upon your perceptions, please indicate your level of agreement/disagreement with each of the following statements:

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Patients receive prompt services	❍	❍	❍	❍	❍
Staff are always willing to help patients	❍	❍	❍	❍	❍
Staff respond to patient requests and queries in a timely manner	❍	❍	❍	❍	❍
Staff are sympathetic and reassuring towards patients' health	❍	❍	❍	❍	❍
Staff show sincere interest in solving patients' problems	❍	❍	❍	❍	❍

The attitude of staff instills confidence in me	❍	❍	❍	❍	❍
I would feel secure and safe in receiving care at Mayo Clinic	❍	❍	❍	❍	❍
Staff is courteous with patients and family members	❍	❍	❍	❍	❍
Staff are knowledgeable to answer questions from patients and family members	❍	❍	❍	❍	❍
Patients receive individual attention from staff	❍	❍	❍	❍	❍
Staff have patients' best interests at	❍	❍	❍	❍	❍

heart					
Staff understand specific needs of patients	○	○	○	○	○
Staff are available for help at all times	○	○	○	○	○
Staff listen to patients and keep them informed	○	○	○	○	○
Staff provide emotional support	○	○	○	○	○
Staff are caring in their interactions	○	○	○	○	○
Staff are approachable and easy to communicate with	○	○	○	○	○

Comments:

21. What is your overall impression of the quality of care at Mayo Clinic?

○ Excellent

○ Very good

○ Good

○ Average

○ Poor

Comments:

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22. Please provide the following demographic information:

Please enter your age:

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Gender:

○ Male

○ Female

Highest level of education completed:

○ High School or less

○ Some college

○ 2 Year College Degree

○ Undergraduate Degree - 4 Year College

○ Master's Degree

○ Post graduate/Doctoral Degree

○ Other: _____

Employment status:

○ Employed Full-time

○ Employed Part-time

○ Student

○ Self-employed

○ Unemployed

○ Other _____

Annual household income:

○ Less than $25,000

○ $25,000 to $49,999

○ $50,000 to $74,999

○ $75,000 to $99,999

○ $100,000 or more