EXAMINATION OF ONLINE HEALTH INFORMATION SEEKING EFFECTIVENESS: CASE STUDIES OF ONLINE HEALTH COMMUNITIES IN COPD PATIENTS

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Dissertation Prepared for the Degree of

DOCTOR OF PHILOSOPHY

UNIVERSITY OF NORTH TEXAS

December 2020

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Boyce, LeAnn Kendetta. *Examination of Online Health Information Seeking Effectiveness: Case Studies of Online Health Communities in COPD Patients*. Doctor of Philosophy (Information Science), December 2020, 137 pp., 19 tables, 11 figures, 3 appendices, references, 151 titles.

When people access online health information, unfortunately, they have access to both clinically accurate and inaccurate information that they may then utilize to make informed personal health decisions. This research fills a gap in the literature of online health communities as they relate to chronic obstructive pulmonary disease (COPD). The conduct of this research required a multi-phased and multi-method approach, best presented in three distinct essays. In Essays 1 and 2, data gathering within two online health communities specific to COPD allowed this study to address three research questions: (1) what are the information needs of COPD patients that result in their participation in online health communities; (2) what are the information sources offered to the participants in these online communities; and (3) is the information obtained via those communities credible. Essay 1 harvested data from a moderated website hosted by a non-profit organization for patients with COPD and Essay 2 harvested data from a non-moderated Facebook group also serving this unique group. Data Miner, a Chrome extension designed to extract data, was used to collect data, key words and themes which brought an understanding of the health information needs of participants and identified what health information sources were preferred. Using NIH guidelines, the credibility of sources exchanged were evaluated for both groups. The research presented in Essay 1 showed that COPD patients have health information needs and that a clinically monitored social health online community, that is available 24/7 to answer questions that arise at the time of need, provides much needed support. The research in Essay 2 illustrates the need for

healthcare workers to be aware of unmoderated sites and promote these sites for the purpose of socialization only, and not for medical information. Building on the knowledge gained through the data analysis in Essays 1 and 2 and based on the theoretical frameworks established in the health belief model, social exchange theory, and the technology acceptance model, Essay 3 generated a new integrated model that seeks to understand information seeking effectiveness in online health communities was proposed. This model identifies the relationships between the types of disease specific information sought by members of 65 COPD Facebook groups, and member success in acquiring credible and clinically accurate health information to use in making health decisions related to disease management and the development of effective health management behaviors. Structural equation modeling was utilized to analyze survey responses and test the proposed model for statistical significance This study has important implications for health educators and medical professionals that will enhance their understanding of the benefits of online peer health communities and will guide them in providing their patients with an “information prescription” guiding them to clinically accurate and understandable, disease specific health information between office visits and at the patient’s time of need.

ACKNOWLEDGMENT

First and foremost, I would like to express my deepest appreciation to my husband, Timothy, for his continued support and encouragement throughout my academic journey. I also wish to thank my sons, Grant and Luke, for providing support and inspiration.

I would also like to extend my deepest gratitude to my chairs Drs. Gayle and Victor Prybutok for providing me extensive personal and professional guidance. To my other committee members, Drs. Ana Cleveland and Jodi Philbrick, I would like to extend my sincere thanks for your profound belief in my work and my abilities to finish my degree.

Lastly, I would like to thank my Friday research group for their helpful advice, practical suggestions, and constructive feedback.

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CHAPTER 1

INTRODUCTION

1.1 Problem Statement

Health information seeking on the Internet has become a major topic of discussion in many disciplines because of its impact on patients' health decisions. When people access online health information, unfortunately, they have access to both clinically accurate and inaccurate information that they may then utilize to make informed personal health decisions.

It is imperative for health educators and medical professionals to understand the benefits of providing their patients with an "information prescription" directing them to online health information sources where they can find clinically accurate, understandable, disease specific information, at their time of need (Ritterband, 2005).

The lack of research as applied to online health communities specific to chronic obstructive pulmonary disease (COPD) suggests the need for exploratory, deductive research. This research addresses this gap by examining the online health information seeking behaviors of online health communities composed of COPD patients.

1.2 Research Questions

To address this extensive area of research within the context of a testable model, the following research questions were developed.

- What are the information needs of COPD patients that result in their participation in online health communities?
- What are the information sources offered to the participants in these online communities?
- Is the information obtained via those communities credible?

Contextualizing from theoretical frameworks developed in other venues and building upon a portion of the research developed in this dissertation, a testable model is proposed, and this model seeks to answer the last research question: Are participants' information and support needs being met?

1.3 Purpose and Contribution

This research fills a gap in the literature on online health communities as it relates to COPD. The conduct of this research required a multi-phased and multi-method approach, best presented in three distinct essays. The research presented in Essay 1 shows that COPD patients have health information needs and that a clinically monitored social health online community with credible information, that is available 24/7 to answer questions that arise at the time of need, provides much needed support. The research in Essay 2 addresses the gap of knowledge as it relates to the information and emotional needs of the participants in a non-clinically moderated online health community. Essay 2 also addresses the need to educate patients how to effectively evaluate sources exchanged in non-moderated Facebook groups. Essay 3 develops and tests a model that addresses the information seeking effectiveness of participants in disease-specific online health communities.

1.4 Background

1.4.1 Terms

It is important to identify the following key terms, their sources, and definitions in order to lay the foundation of this study.

- *Accurate* - "Free from error, conforming exactly to truth or to a standard" (Merriam

Webster, n.d.)

- *Bullectomy* – This procedure is considered when there is a large vesicle or blister in the lungs that is detected by a chest x-ray. The bulla is surgically removed by a surgeon to improve the ability to breathe (Meyers & Patterson, 2003).
- Chronic obstructive pulmonary disease (COPD) – A a pulmonary disease, ongoing and increasing in severity, characterized by a decline in airflow that does not completely resolve (Giokas et al., 2016).
- *Credibility* – There is not one conclusive definition but credibility has been defined as " a perceived quality based on multiple factors including trustworthiness and expertise (Chung, Nam, & Stefanone, 2012, p.173).
- *DISCERN* – A standardized quality index tool used to judge the quality of health information by both consumers and professionals. Reliability and credibility are the main foci and the evaluation is based on information content such as information currency, lack of bias, and discussion of risk and benefits of treatments (Charnock, Shepperd, Needham, & Gann, 1999).
- *Information seeking effectiveness* – Refers to participants' ability to obtain the information they were looking for, whether it be informational support, emotional support, or socialization (Nambisan, 2011).
- *Internet* – Merriam Webster defines the Internet as "an electronic communications network that connects computer networks and organizational computer facilities around the world" (Merriam Webster Dictionary, 2019).
- *Lung transplant* – This is a complete removal of diseased and non-functional lung(s)

and replacement with healthy donor lung(s)(Meyers & Patterson, 2003).

- *Lung volume reduction surgery* – A surgery where the non-functional, upper portion of one or both lungs is removed (Meek, Lareau, Fahy, & Elysse Austergard, 2006).
- *NIH criteria for resource credibility* – The National Center for Complementary and Integrative Health (NCCIH), part of the National Institutes of Health, established a set of questions to help users to evaluate the credibility of online health information sources. The NCCIH's mission is to define, through research, the effectiveness and safety of health interventions and to provide evidence-based information for healthcare decision making by consumers, policymakers, and healthcare professionals (NIH.gov, 2018).
- *Online community* – An online community is defined as an element of society that involves participants who relate to one another as a group and interact using computer technologies to connect across geographical distances (Demiris, 2006).
- *Online health community* – A subset of the online communities that are becoming more popular in today's society are online health communities, which consist of large groups of individuals from diverse geographic locations, socioeconomic levels, education levels, etc. that share a common interest or diagnosis of a particular disease (Johnston et al., 2013).
- *Peer to peer health information* – Refers to health information that is exchanged between friends, family, and other "online friends" (Fox, 2011).
- *Web 1.0* – Refers to web pages that were connected by hyperlinks in which the user was only able to consume information. They could neither post nor exchange information with others. This was a set of static websites with no interactions between the websites (Techopedia, 2019a).

- *Web 2.0* – Refers to webpages that are connected by hyperlinks, but they are a set of dynamic pages that allow interactions between users and allow individuals to post information to the site. This allows people to collaborate and share information online (Techopedia, 2019b).

1.4.2 Information

Considerable research has focused on the meaning of information. From the field of information science, Claude Shannon proposed that information was a tangible, somatic entity (Shannon & Tukey, 1948). Buckland (1991), a pioneer in information science, suggested that information can be defined as "Information as process," "Information as knowledge," and "information as thing" (Buckland, 1991). Buckland refers to information -as-process as the action of informing. According to Buckland, this would include telling some fact or occurrence. "Information-as knowledge" refers to knowledge (whether it is a fact, subject, or event) being communicated. "Information-as knowledge" is intangible and can be personal and subjective. Buckland also suggested that having information does not always decrease uncertainty. "Information-as-thing" refers to a physical entity, like data or documents. Lastly, Bates (2002) looked at information through a social lens, and believed that information is generated by human beings for social purposes.

The definitions of information are wide ranging. For the purpose of this study, we will specify that information includes documents, data, texts, objects, events, and opinions. Within this definition, we recognize that not all information is factual, and that sometimes, verification of accuracy is required, particularly when the information is used for medical decision making.

1.4.3 Health Information Seeking

While the doctor-patient relationship is critical, health information exchange occurs outside of this relationship to fill knowledge gaps that patients (or caregivers) may have about the illnesses they face between office visits. Health information seeking behavior is a knowledge-gathering activity that results from a health question or need, usually in response to a recognized gap in knowledge (Mukherjee & Bawden, 2012). A study by Lambert and Loiselle (2007) indicated that there are 3 common outcomes of health information seeking: cognitive outcomes, behavioral outcomes, and physical outcomes. They noted that outcomes could be positive or negative. Lambert and Loiselle (2007) also suggested 3 main reasons for seeking health information: coping with an illness, being involved in making personal medical decisions, and learning about preventative health. This shift to information being accessed online instead of through an interaction with a physician or published health education materials was provoked by the birth and expansion of the Internet.

1.4.4 Birth of the Internet

Soon mechanized, searchable storage systems for written information and media came to fruition. In 1962 a network, ARPAnet, was created by scientists from the Advanced Research Projects Agency and MIT. This was the first-time computers connected four universities to form a network. The development of inter-connectivity expanded throughout the 1970s and 1980s. In 1991, the World Wide Web, or Internet, was created by Tim Berners Lee, with the first trials at the European Organization for Nuclear Research (CERN) laboratories in Switzerland (Peter, 2004). This allowed a user to browse documents and navigate text-based documents distributed among different computers. Later that same year, a technology called GOPHER allowed a user, with no computer knowledge, to search for information on the Internet by retrieving information based on a key word search. Growth of the Internet was exponential. In 1993, there were 130 websites, and this number increased to 2,738 websites by the following year (Day, 2003). Today, there are over 1,805,260,010 websites (“How many websites are there in the world?,” 2018).

The birth of the Internet expanded the range of information seeking behaviors and introduced many new topic areas into information seeking behavior, including health information seeking behavior. The Internet greatly expanded the volume of health information available to the public, which introduced new problems related to information accuracy (Cline & Haynes, 2001).

1.4.5 Health Information Seeking on the Internet

The rapid and continuous development of the Internet has created an active stage for health information seeking. There was a monumental change in the capacity of users to create information from the Internet’s initial stage of Web 1.0, where individuals were only able to seek and read information created by an individual or organization. With the transition to Web 2.0, a phrase coined by Tim O’Reilly in 2004 (New World Encyclopedia, 2013), individuals that were not tech-savvy were able to interact with others to exchange information in many ways, including exchanging texts and videos. They could also participate in online platforms, blogs, and social networks (Sarasohn, 2008).

This new and remarkable development of the online health environment increased demand for effective knowledge management. More and more health-related websites are available to provide patients with answers to medical questions and to help them manage their own health. This is a shift from sole reliance on physicians to greater personal access to medical information and improved personal health management. Today, there is greater acceptance of the patient as no longer a passive information recipient (Gerber & Eiser, 2001). Patients are now encouraged to be active participants in their own health care. The Internet offers patients new access to medical information and the greatest impact on medical decision-making may come from the increase in access to medical information prior to the physician-patient encounter. It is important, as researchers, to gain more knowledge in the area of health information exchange, particularly in peer to peer health exchanges (Gerber & Eiser, 2001). Information obtained by the patient must be accurate, timely, and medically appropriate in order to positively effect patient health outcomes, and this is key to quality healthcare (Cleveland & Cleveland, 2009).

A recent Pew Research study (Fox, 2014) found that 72% of adult Internet users have searched for health information online. This number grew to 80% in 2018, according to the MARS Consumer Health Study (Healthcare Client Services, 2018). A report by Health Union, a company that manages 19 condition-specific online health communities, showed that 70% of 2200 people with a serious health condition use condition specific websites, and 59% of the 2200 individuals used Facebook to meet their health information needs (Lawhon, 2016). This same study revealed that 98% of the respondents read health related information or watched a health video online in the past six months, and 48% of them indicated that they shared health related information online with others. Lastly, the Health Union study revealed that 97% of these respondents used the information they gathered online to speak with their healthcare professionals, and 73% stated that this information had at least some impact on their health-related decision making (Lawhon, 2016).

1.5 Organization of the Dissertation

This paper includes an overview of information, information science, health information seeking (through both the patient-physician relationship and through the Internet). The literature review includes the explanation and growth of online health communities, concerns about health information credibility, a discussion of clinically moderated versus non-clinically moderated OHCs, explanation of COPD, information about the two online health communities researched, and the theoretical framework for this research. The next section reports the methodology of each essay. Chapter 4 reports the results and discussion of the three essays. Finally, Chapter 5 concludes the dissertation research.

CHAPTER 2

LITERATURE REVIEW

2.1 Online Health Communities

With the growth of the Internet, online communities (OC) have grown and flourished. According to Faraj, von Krogh, Moneiro, & Lakhani (2016), OCs bring together large groups of individuals that are geographically scattered who collaborate on the basis of an activity, interest or identity. Online health communities (OHCs) are a subset of online communities. Perceived benefits from online health communities are unique to each individual, and lead to a variety of health outcomes (Nahapiet & Ghoshal, 1998). They provide an environment for patients with similar diagnoses to gain knowledge about their diseases, treatment options, and symptom management techniques, and can lead to positive health outcomes (Johnston, Worrell, Gangi, & Wasko, 2013b). OHCs provide individuals a safe place to exchange information related to specific health conditions either for themselves, a loved one, or for a person for whom they are the primary caretaker. Within these communities, the individual can interact with like-minded people with the desire to gain a better understanding of the illness and its treatment or management. Knowledge is gained from interacting with others with the same disease and understanding and management of their diseases improve. This type of community also allows individuals to weigh the shared wisdom of those participating, often resulting in access to first-hand insights about similar disease related experiences (Johnston et al., 2013b). As mentioned, a recent Pew Research Center study on online health communities shows that about 59% of Americans turn to the Internet for health information (Fox, 2014). This is a change from past Pew studies where 70% of U.S. adults got information from their doctors or other health care providers (Fox & Duggan, 2013). From this Pew study, we learn that 16% of the online health information seekers tried to find others who might share the same health concerns, and 26% have read or watched information about someone else's personal health experience (Fox & Duggan, 2013).

Various studies have shown that participation in OHCs have provided patients and caregivers with a variety of positive outcomes such as higher self-esteem, improved self-efficacy, psychological benefits, greater control in their own medical management, improved social well- being, and improved quality of life (Mo & Coulson, 2012; Petric, 2014; Swan, 2009; Uden-kraan, Drossaert, Taal, Seydel, & Laar, 2008). Studies also show that online health communities can have a positive effect on a person's health outcome (Johnston et al., 2013a; Nambisan, 2011; Xing, Goggins, & Introne, 2018). Having a shared health condition creates a strong affinity to OHCs that can help individuals make informed health decisions.

2.2 Concerns about Health Information Credibility

Numerous studies have investigated the credibility of online health sources (Eastin, 2006; Nath, Huh, Adupa, & Jonnalagadda, 2016; Z. Wang, Walther, Pingree, & Hawkins, 2008), and their use for emotional support, and disease self-management (Bender, Jimenez-Marroquin, & Jadad, 2011; Park et al., 2016; Willis & Royne, 2017). Studies have explored communities related to cancer (Blank & Adams-Blodnieks, 2007; Ginossar, 2008; Setoyama, Yamazaki, & Namayama, 2011), diabetes (Gilbert, Dodson, Gill, & McKenzie, 2012; Greene, Choudhry, Kilabuk, & Shrank, 2011), arthritis (Willis & Royne, 2017), and other chronic diseases.

Today approximately 9 in 10 American adults use the Internet. This is almost double the amount of users from 2000 (Pew Research Center, 2018). One of the problems with this growth is the inability of users to distinguish credible from inaccurate sources (Adoni, Cohen, & Mane, 1984). The problem of information accuracy is due to the fact that the Internet has no federal or ethical regulations supervising most available content, which can be posted by any user (Eastin, 2006). Patients are now seeking medical advice in online chat rooms and personal web pages, which can provide inaccurate and potentially fatal advice.

2.3 Moderated vs. Unmoderated Online Health Communities

While one of online health communities' core goals is to offer emotional support, more and more people are turning to these communities for informational support as well (Huh, Mcdonald, Hartzler, & Pratt, 2013). As a result, more online health communities are incorporating 'health experts' to moderate these sites (Huh, Patel, & Pratt, 2012), to ensure that the information exchanged is clinically accurate. In a recent study by Kanthawala, Vermeesch, & Given (2016), accuracy of information provided in response to a question posed to an online health community returned only a 47% accuracy rate for questions that have a definitive medical answer. This is a strong indication that sites should be monitored by a health expert. However, there are some online communities that are utilizing administrative moderators that do not act as 'health experts,' but who recruit new members, moderate the discussion community, and encourage and engage participants in order to maintain a respectful community environment.

2.4 Chronic Obstructive Pulmonary Disease (COPD)

One of the chronic health diseases that has a presence in many disease-specific online health communities is chronic obstructive pulmonary disease (COPD). COPD is a progressive respiratory disease identified by decreased airflow that is not fully reversible (McIvor, Tunks, & Todd, 2010), and usually develops in response to noxious irritants in the environment. COPD includes emphysema and chronic bronchitis. In emphysema, the smallest air passages in the lungs (bronchioles) are destroyed, usually due to cigarette smoke inhalation or other exposures to noxious gases and particulate matter. Chronic bronchitis, on the other hand, is inflammation of the lining of the bronchial tubes, which diminishes air that is available to the air sacs (alveoli) in the lungs (Mayo Clinic, 2019). This increases mucus (sputum) production and further reduces the ability of oxygen to enter the bloodstream. Symptoms of COPD are constant coughing, shortness of breath (SOB), inability to breathe easily or take a deep breath, excessive mucus production, and wheezing (National Institutes of Health, 2017).

While COPD is not curable, it is treatable and manageable. Proper management can control exacerbations and avoid repeated hospitalizations and general ill health. COPD is diagnosed by a physician based on signs and symptoms, lung tests, and individual and family health histories (National Institutes of Health, 2017). Diagnostic tests include pulmonary function tests (PFTs) which measure lung volumes (tidal volume, minute volume, and residual volume), capacity (vital capacity, functional residual capacity, total lung capacity, and forced expiratory volume), rates of flow (forced expiratory flow, and peak expiratory flow) and gas exchange (pulse oximetry). The PFTs are done with pulse oximeters, spirometry, and plethysmography tests (MedlinePlus, 2019).

In the past, the only treatment for COPD was antibiotics for pneumonia that usually accompanied the disease, potassium iodide (mucous thinner), a combination of pharmaceuticals including ephedrine or theophylline to open air passages, and a small amount of a sedative to counter balance the effects of ephedrine (Petty, 2006). In the 1960s, inhaled isoproterenol began to be used. At that time, oxygen, corticosteroids, and exercise were not recommended for patients. Mechanical ventilation was used for COPD patients in acute respiratory failure (Petty., 1971). Also, in the late 1960s and early 1970s, research attention was increasing by both clinicians and scientists. New areas of study included pulmonary rehabilitation, home management, and surgical treatments for emphysema, such as bullectomy or lung volume reduction surgery. The 1980s saw increases in the use of long-term oxygen therapy. The 1990s saw more research being done on inhaled corticosteroids (with conflicting results) (Pett., 2006).

Today, it is recognized that the most essential step in a COPD treatment plan is to stop smoking. There are also several medications used to treat complications and symptoms of the disease. These include bronchodilators (such as Ventolin, Atrovent, Brovana, etc.), inhaled steroids (such as Flonase, Pulmicort, Uceris, etc.), combination inhalers (such as Advair and Symbicort), oral steroids, phosphodiesterase-4 inhibitors (Dalsiresp), theophylline, and antibiotics. Other therapies include oxygen, pulmonary rehabilitation, and surgeries (such as lung volume reduction, lung transplant, and bullectomy) (Mayo Clinic, 2019).

For the purpose of this study, COPD is the umbrella term that includes all chronic lower respiratory diseases such as emphysema, both simple and mucopurulent chronic bronchitis, unspecified chronic bronchitis, and other chronic obstructive pulmonary disease.

2.5 The COPD Foundation

The COPD Foundation is a non-profit (501c3) organization created in 2003 to provide resources that broaden provisions for COPD patients and betters the lives of those touched, either directly or indirectly, by COPD (COPD Foundation, n.d.-a). COPD 360social is the online community, created by the COPD Foundation, that is available to any person affected by COPD. This community includes patients, family members, caregivers, physicians, respiratory therapists, and other healthcare providers. COPD 360social is managed by the foundation. While the content posted does not represent the official policies or views of the foundation, content is monitored for accuracy by a community manager and state captains. The community manager has the ability to delete posts that do not address the goals of the community. State captains are volunteers with the foundation that serve as state and community leaders. State captains can be caregivers, family members, or healthcare providers. The goal of the online community is to provide an inviting and collaborative atmosphere for participants to directly interact with others from all over the world in a safe setting to communicate thoughts and ideas, ask questions, engage in productive discussions, and read/comment on blogs (COPD Foundation, n.d.-b). The COPD Foundation claims to have over 75,000 members.

2.6 COPD Warriors, Hope, Support, Love & Laughter

COPD Warriors, Hope, Support, Love & Laughter is a Facebook, closed online health community, that claims to have 10,660 members. They support, give hope, celebrate holidays, improve self-esteem, and share laughs. It was created on January 20, 2014. Group rules include the requirement to be kind and courteous, to avoid hate speech or bullying, to avoid promotions or spam, no politics or religion, and they ask to refrain from offering medical advice.

2.7 Established Models of Online Health Communication

It is worthwhile to consider relevant models of online health communication that have been established in the literature. This section reviews the theories related to online health communication, shown in Table 2.1.

Table 2.1

Models/Theories of Online Health Communication

Year	Online Health Communities Model	Researcher/s
1950s	Health Belief Model	Hochbaum, Rosenstock, and Kegels
Late 1950s to the early 1960s	Social Exchange Theory	G. Homans, J. Thibaut, H. Kelly, Levi & Strauss, & P. Blau
1989	Technology Acceptance Model (TAM)	F. Davis

2.7.1 Health Belief Model

The health belief model (HBM) was developed to explain why people did not participate in public health programs (Rosenstock, 1974). The earliest tenets of the model proposed that for an individual to take action to avoid a disease, he would need to believe first, that he was susceptible to it, that some component of his life would suffer with at least a moderate severity, that taking a particular action would be beneficial to the disease outcome, and that the action would not have any perceived barriers like cost, inconvenience , pain, or embarrassment (Rosenstock, 1974) . According to Rosenstock, preventive behaviors are influenced by the individual's subjective weighing of the costs and benefits of the recommended action (Abraham & Sheeran, 2015).

2.7.2 Social Exchange Theory

Social exchange theory seeks to explain the social interaction of two (or more) parties in order to exchange goods, either material or non-material. There is an effort to create equilibrium to balance the exchange between cost and reward (Homans, 1958). Social exchange theory is broadly utilized to explain individual behavior within many disciplines, including information technology, consumer behavior, and the behavior of participants within an online community (Yan, Wang, Chen, & Zhang, 2016). Yan, Wang, Chen, & Zhang (2016) propose that knowledge sharing is a type of exchange behavior with both benefits and costs. In addition to meeting information needs, other benefits include satisfying the sense of self-worth, providing social support, addressing face or image concerns, and improving personal reputation. The costs include both cognitive and executional cost, or the tangible costs of taking the action. Sense of self-worth captures the extent to which an individual sees themselves as providing value through their knowledge sharing (Bock, Zmud, Kim, & Lee, 2005). Social support is intended to enhance the welfare of the recipient. Social support is gained in online health communities by interacting with peers with similar diseases and receiving different types of social support, including but not limited to, informational support, emotional support, and companionship (X. Wang, Zhao, & Street, 2017). Face concern deals with the length to which a participant will go to in order to protect and/or improve their social image or interaction (Yan et al., 2016). Lastly, reputation refers to a person's perception of earning respect (Yan et al., 2016). In social exchange theory, as it relates to online health communities, costs present themselves in cognitive and executional forms. Cognitive costs are the process of the participant retrieving information by memory. This could conjure up uncomfortable feelings such as irritation, panic, or depression. The executional costs include resources like time, materials, and possibly money (Yan et al., 2016).

2.7.3 Technology Acceptance Model

The technology acceptance model (TAM) (Davis, 1989) was originally created as an information systems theory to model how users come to accept and use a technology. Davis wanted to understand the relationships that exist between user perceptions of usefulness, ease of use, and subsequent system adoption. An online community is basically an information technology-enabled social and communication environment (Wang, Chung, Park, Mclaughlin, & Fulk, 2011). Having a good technological infrastructure and a user-friendly interface is likely to enhance the likelihood of adoption and usage of the online resource. TAM views user behavior related to engagement in online health communities from the technology perspective (Ahadzadeh, De, Sharif, De, & Ong, 2015). Using the TAM framework, (Davis, 1989) studies showed that the three constructs of perceived usefulness, perceived ease of use, and attitude positively influence behavioral intention to use the technology (Lim et al., 2011; Wong, Yeung, Ho, Tse, & Lam, 2014). We focus only on perceived usefulness and perceived ease of use from the TAM model.

2.8 Summary

This chapter includes the explanation and growth of online health communities, concerns about health information credibility, discussion of clinically moderated versus non-clinically moderated OHCs, explanation of COPD, information about the two online health communities researched, and the theoretical framework for this research.

CHAPTER 3

METHODOLOGY

3.1 Essay 1 – An Analysis of a Closed COPD Online Health Community: Identifying Information Needs and Credibility of Sources*

This qualitative study analyzes the historical activity feed posted by COPD360social online participants from December 2017 to September 2018. A total of 4800 online posts were harvested using a Google Chrome extension, DataMiner, and de-identified. Prior to collection, we received approval from the Senior Director of Community Engagement for the COPD Foundation and obtained IRB approval from the university.

Data was manually coded for content analysis using Stuckey's method (Stuckey, 2015). Key words and themes were established based upon the data. To understand the needs of the community, we aggregated data into three defined categories: informational support, emotional support, and socialization. We collected a list of commonly occurring keywords to identify the knowledge gaps/information needs of the participants. We categorized this information into 27 categories as shown in Table 3.1 .

These keywords categorizing participant information needs were coded according to the codebook provided in Appendix A. This codebook proved to have 95% accuracy when randomly selected rows were checked by an independent coder. Due to the overwhelming number of recommended information sources, we developed a systematic method to categorize sources. If a source was recommended 3 times or more, a new category was created. These sources were coded into 8 types: the foundation's resources, consult a doctor,

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* Accepted for publication in the *International Journal of Electronic Healthcare*.

social media, personal experiences, Internet, NIH, academic journal articles, and YouTube videos.

Table 3.1

Twenty-Seven Keywords

- Oxygen
- Concentrators/portable oxygen
- Stem Cell
- Relaxation/sleep
- Breathing/irritants
- Doctors/second opinion
- Clinical studies
- Education/support groups
- Sexual activity
- Medication
- Insurance/Medicaid
- Pulmonary rehab
- PEEP/CPAP/BiPAP
- Lung Transplant
- Diet
- Legislation/advocacy
- Respiratory treatments
- Privacy
- Exercise
- Travel
- Exacerbations
- Weather/humidity
- PFTs/oxygen saturation
- Blood pressure
- Action plan
- Anxiety/depression
- Smoking

The Internet resources were analyzed for credibility using the validated DISCERN instrument (Charnock and Shepperd, 2004) and NIH recommendations (NIH.gov, 2018). Table 3.2 refers to the recommended categories addressed by both DISCERN and NIH.

All de-identified information was analyzed using Excel and SPSS to identify the users' health information needs, knowledge gaps, key words, themes, and preferred information resources, and to ensure that users accessed clinically credible and accurate information about medication, disease management techniques, and therapeutic interventions. We also sought to understand how users assessed whether the information that they are relying on to make health decisions was coming from a reliable and accurate health information source.

Table 3.2

Recommended Categories for Website Evaluation

NIH	DISCERN
Who runs/pays or created the site or app?	Are the aims clear
Can you trust them?	Does it achieve its aims?
Can you communicate with the owner of the Web site?	Is it relevant?
What is the site or app promising or offering?	Is it clear what sources of information were used to compile the publication (other than the author or producer)?
Do its claims seem too good to be true?	Is it clear when the information used or reported in the publication was produced?
When was its information written or reviewed?	Is it balanced and unbalanced?
Is it up-to-date?	Does it provide details of additional sources of support and information
Where does the information come from?	Does it describe how each treatment works?
Is it based on scientific research?	Does it describe the benefits of each treatment?
Why does the site or app exist?	Does it describe the risks of each treatment?
Is it selling something?	Does it describe what would happen if no treatment is used?
Is the information reviewed by experts?	Does it describe how the treatment choices affect overall quality of life?
How does the site collect and manage personal information?	Is it clear that there may be more than one treatment choice?
Is the site secure?	Does it provide support for shared decision-making?
Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices	

3.2 Essay 2: Assessing Health Information Quality in a Closed, Non-Moderated COPD Facebook Group

This qualitative study analyses retrospective posts to the Facebook group, COPD Warriors, Hope, Support, Love, and Laughter. Before collecting the data, we received approval from the site’s administrator and obtained IRB approval from the university. Posts were gathered daily from April 13, 2019, to June 29, 2019 with 4 910 posts harvested using DataMiner, a Google Chrome extension.

Data were coded for content analysis (Stuckey, 2015), and keywords and themes were identified with a codebook. Posts were aggregated into three classifications: informational support, emotional support, and socialization. In order for a post to be assigned to informational support, the post had to ask or give information about a specific topic dealing with COPD. For emotional support, posts would include words of encouragement. And lastly for socialization, posts would include questions of comments about everyday events, pictures of grandchildren/children, etc. Table 3.3 gives examples of each category of socialization, emotional support, and informational support.

Table 3.3

Examples of Posts Exchanged to Understand Socialization, Emotional Support, and Informational Support Categories

Topics	Posts
	Socialization
Weather	• “Ugh.... I think I should become the new weather person. I can feel a storm coming in before they announce it.” • “Good morning warriors. I'm in my shorts. It's going to be weather where you wanna enjoy every ray of sunlight.”
Welcome	• “Welcome from Ohio.” • “Welcome from Tennessee.” • “Welcome” • “Wow. Even just the welcomes are helping us feel less isolated in this!”
Pets	• “”A bit of fun for a Sat if admin allows, let's see each other's pets, here's mine Katie.” • “Aww how sweet. I know most of us in here have pets and I still work and this just made me a little sad but it is still cute.”

(table continues)

Topics	Posts
Grandchildren	• “Had a wonderful time at my youngest grandchild. Granddaughter's Graduation.” • “I have great news I’d like to share. I have a new granddaughter, born this morning. She is my first paternal granddaughter. She looks just like her older (will be 2 next month) brother when he was born (pictured in the phone.) he turned out to be so cute, just like his mother and older half-sister.”
Holidays	• “Easter Happy Hour Humor” • “Happy Easter When the Easter Bunny comes to town..........WOOF!!”
Witticisms	• “A little boy got on the bus, sat next to a man reading a book, and noticed that the man had his collar on backwards. The little boy asked the man why he was wearing his collar backwards. The man, who was a priest, said, 'I am a Father...' The little boy replied, 'My Daddy doesn't wear his collar like that.'... The priest looked up from his book and answered, ''I am the Father of many.' The boy said, ''My Dad has 4 boys, 4 girls and two grandchildren and he doesn't wear his collar that way!' The priest, getting impatient, said. 'I am the Father of hundreds', and went back to reading his book. The little boy sat quietly thinking for a while, then leaned over and said, “Maybe you should wear a condom, and put your pants on backwards instead of your collar." • “The first time my son was on a bike with training wheels, I shouted, ‘Step back on the pedals and the bike will brake!’ He nodded but still rode straight into a bush. ‘Why didn't you push back on the pedals?’ I asked, helping him up. ‘You said if I did, the bike would break.’"
Informational Support	
Medication	• “He gave me samples of Bevespi Aerosphere to try instead. Has anyone tried this daily inhaler? Also, do you rinse your mouth out after using it. There was no mention of rinsing in the directions???” • “Ok I have used Albuterol, but my heart does his thing afterwards like it’s doing back flips and fast! Do any of you have this happen?”
Anxiety/Depression	• “What do you do when insomnia has a hold on you and all that’s runnin thru your mind is that soon you won’t be around to complain any more or how long this disease is gonna let u stick around???” • “For those with anxiety issues!” (linked out to goodhousekeeping.com)
Education	• “FRIENDLY REMINDER 1. Remember to take your medications this morning. 2. Try to stay hydrated best you can. 3. Pace yourself, slow wins the race with our disease. 4. Practice your pursed-lip breathing 5. Exercise best you can. 6. REST WHEN YOU GET TIRED. 7. Have a nice day and breathe easy my friend. “ • “My granddaughter’s grandmom told me to try this for my husband. Has anyone used it and did it work.”

(table continues)

Topics	Posts
Symptoms	• "Does anyone have involuntary deep breaths inward they are happening to me all day long now. Was wondering if anyone knows why?" • "My throat is sore should I call doctor immediately? I just started feeling better...I don't want to get sick again"
Diet/Food	• "Still hanging on to those Easter leftovers? You may want to consider tossing or freezing today. Leftovers are only safe for 4 days in the fridge but can also be frozen for up to 3 months! Plan accordingly." • "I posted on here about a week ago about how pineapple juice helps with mucus. And there was alot of comments that it works so I went out and got a can of it to find out. I will update you on this in a week to let ya all know how it went."
Exacerbation (flair up)	• "So, I had a crazy night and morning in the hospital. My heart rate jumped to 170 last night. I had just had a breathing treatment. They took me to ICU immediately." • "I'm pretty new to this COPD thing. How do I know I'm having a flair up? I'm been feeling some discomfort in my throat and chest for a couple days. My 02 levels are good, I'm not sure if I need to go to the ER or is it my anxieties going haywire because I'm scared.
	Emotional Support Topics
Prayer	• "My daughter is not doing too good, we are probably going back to Duke in the morning, she's tired, scared and giving up, please keep her in your prayers that she can make it until she can get a transplant. Thank you and God bless." • "So I just left the hospital my sister got admitted they said she has fluid on her lungs explains why she can't breath and there checking her heart and running more test on the overnight...I am asking for prayers for her."
Quotes of inspiration	• "Hope your day was filled with smiles. May you have a rejuvenating rest with pleasant dreams." • "Thanks again to a nice bunch of people who have given me great tips, and, encouragement."
Health issues	• "Good morning my special friends Hope you are all well have a great day take care of yourself and breathe easy my friends love and hugs to you from me One of the most beautiful things we can do is to help one another. Kindness doesn't cost a thing." • "Have a blessed day. Breathe easy my friends."
"Vent"	"I need to vent. My honeys aunt came up to visit and at the end of the visit my honeys brother called and the aunt and his brother set up to go out for dinner. Did they ask me if I wanted to go out for dinner or need anything…"

Commonly occurring keywords were identified to understand the knowledge gaps/information needs of the participants. Twenty-seven keywords were identified, and posts were coded accordingly. Keywords are shown in Table 3.4.

Table 3.4

Twenty-Seven Keywords

- Oxygen
- Concentrators/portable oxygen
- Stem Cell
- Relaxation/sleep
- Breathing/irritants
- Doctors/second opinion
- Clinical studies
- Education/support groups
- Sexual activity
- Medication
- Insurance/Medicaid
- Pulmonary rehab
- PEEP/CPAP/BiPAP
- Lung Transplant
- Diet
- Legislation/advocacy
- Respiratory treatments
- Privacy
- Exercise
- Travel
- Exacerbations
- Weather/humidity
- PFTs/oxygen saturation
- Blood pressure
- Action plan
- Anxiety/depression
- Smoking

Due to the overwhelming number of recommended information sources and specific information needs, we developed a systematic method to categorize sources. If a source was recommended three times or more, a new category was created, and a codebook was generated. This codebook proved to have 95% accuracy when an independent coder checked randomly selected rows and was compared with codes that were previously coded. Sources that were exchanged within the posts were hand-coded into five types: personal experiences, websites, doctors, professional organizations, and books.

Furthermore, Internet resources were analyzed for credibility and clinical reliability using the previously validated NIH guidelines (NIH.gov, 2018). Table 3.5 refers to the recommended categories addressed by the NIH. Each website was evaluated using each criterion in the NIH criteria.

Table 3.5

NIH Suggested Guidelines for Evaluating Websites

Who runs/pays or created the site or app? Can you trust them?
Can you communicate with the owner of the Web site?
What is the site or app promising or offering? Do its claims seem too good to be true?
When was its information written or reviewed? Is it up to date?
Where does the information come from? Is it based on scientific research?
Why does the site or app exist? Is it selling something?
Is the information reviewed by experts?
What's the site's policy about linking to other sites?
How does the site collect and handle personal information? Is the site secure?

All de-identified participant information was compiled in Microsoft Excel. Both Excel and SPSS were used to organize and identify the users' health information needs, knowledge gaps, keywords, themes, and preferred information resources, and to ensure that users accessed clinically reliable and credible information about medication, disease management techniques, and therapeutic interventions. We also sought to understand how users assessed whether the information that they are relying on to make important health decisions was coming from a reliable and credible health information source.

3.3 Essay 3: A Proposed Model of Information Seeking Effectiveness in COPD Facebook Groups

3.3.1 Research Design

This research will identify the relationships between the types of disease specific information sought by COPD360social members and the Facebook group, and their success in getting accurate and reliable health information to use in their decision-making process as they work to manage their diseases. A survey was designed to evaluate the proposed online health community model for COPD patients. The health belief model, social exchange theory, affordance theory, and the technology acceptance model (TAM) provided the theoretical foundation for a model specific to COPD patients.

This survey will be the primary tool for data collection for this study. Surveys have historically collected data from large populations. Surveys obtain information about user demographics, personal characteristics, and consumer feedback (Ponto, 2015). A survey is deemed appropriate for this research because surveys are cost effective, have the potential to be generalizable, and tend to be a reliable method of inquiry (Blackstone, 2012), and we were able to survey a targeted group of COPD360social and Facebook users.

3.3.2 Research Methodology

Using the health belief model (Rosenstock, 1974), social exchange theory (Homans, 1958), and TAM (Davis, 1989), Figure 3.1 shows the model proposed as a framework for this study. The constructs of the proposed model are defined in Table 3.6. Also included are the sources from which questions related to each construct have been contextualized.

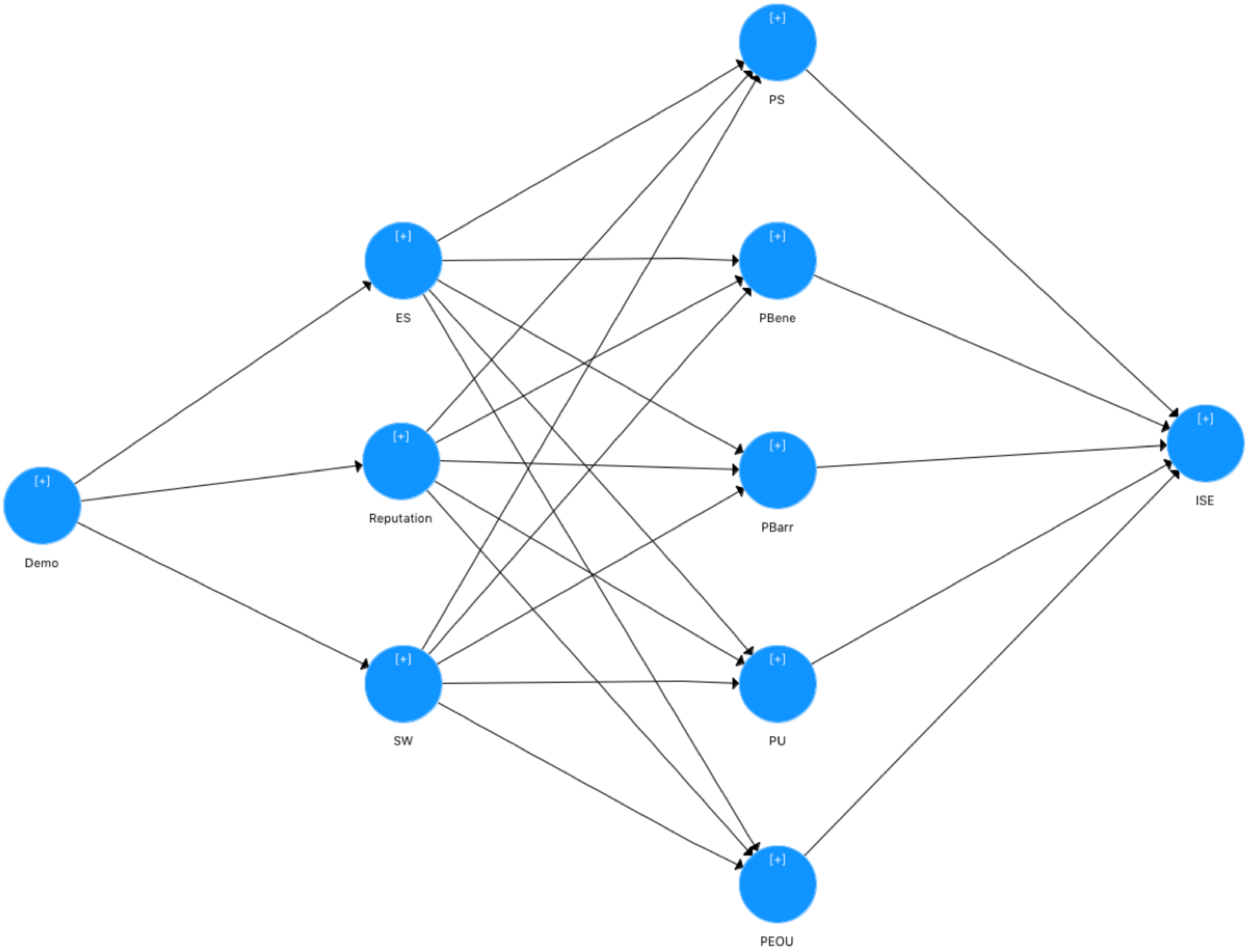

Figure 3.1. Proposed model of information seeking effectiveness in online health communities.

Table 3.6

Constructs of the Model with Definitions, Source, and Contextualized Questions

Construct	Definition	Source	Questions contextualized
Demographics	Age, marital status, education level, and household income	(Abraham & Sheeran, 2015) (Ahadzadeh et al., 2015)	Marital status from U.S. Census Bureau (2 questions) Education level adapted from Bureau of Labor Statistic(2017) (1 question) and Annual income from dissertation (1 question)((Prybutok, 2014)
Perceived Severity	The belief about the magnitude of the threat.	(Abraham & Sheeran, 2015) (Witte, Cameron, Keon, & Berkowitz, 1996)	4 survey items from Abraham & Sheeran, 2015
Perceived Benefits	The perception that a particular course of action will be effective in reducing the treats of a disease.	(Abraham & Sheeran, 2015; Rosenstock, 1974)	2 survey items from Abraham & Sheeran, 2015
Perceived Barriers	Perceptions that a course of action is inconvenient, expensive, unpleasant, costly, or upsetting.	Abraham & Sheeran, 2015; Rosenstock, 1974)	4 survey items from Abraham & Sheeran, 2015
Perceived Usefulness/ Exploration	The degree to which a person believes that a particular system (online health community) will enhance their quality of life.	(Ahadzadeh et al., 2015) (Davis, 1989b)	3 survey items from Ahadzadeh et al., 2015
Perceived Ease of Internet Use	The degree to which a person believes that using a particular system (online health community) would be free of effort.	(Ahadzadeh et al., 2015), (Davis, 1989b)	3 survey items from Ahadzadeh et al., 2015
Emotional Support	The connection and the exchange of resources between at least two persons aimed at enhancing the well-being of another participant.	(Coulson, 2017; Shumaker & Brownell, 1984; X. Wang et al., 2017; Yan et al., 2016)	3 survey items from Yan et al., 2016)
Reputation	A participant's perception of the potential to earn respect or elevate one's social status.	(Yan et al., 2016)	3 survey items from Yan et al., 2016
	The positive/negative image of self that is confirmed through interactions with others	(Goffaman, 1967: Wan, 2011; Yan et al., 2016)	2 survey items from Yan et al. 2016
Information Seeking Effectiveness	Support provided to patients diagnosed with a disease including social and emotional support and information related to accuracy, therapies, rehab, and other services.	(Gustafson & Sheikhm, 1999; Nambisan, 2011)	4 survey items from Nambisan, 2011

3.3.3 Research Question and Hypotheses

- *Demographics* - Age, marital status, education level, and household income

  Research Question 1: Do user demographics correlate with emotional support, reputation, and self-worth?

  Hypotheses:

  H_{a1}: There is a correlation between user demographics and emotional support.

  H_{a2}: There is a correlation between user demographics and reputation.

  H_{a3}: There is a correlation between user demographics and self-worth.

- *Psychological characteristics* – Emotional support, reputation, self-worth

  Reputation - A participant's perception of the potential to earn respect or elevate one's social status.

  Sense of Self-worth - The extent to which participants see themselves providing value to the online community.

  Research Question 2: Do user psychological characteristics (emotional support, reputation, and self-worth) correlate with perceived disease severity, perceived benefits, perceived barriers, perceived usefulness, and perceived ease of use?

  Hypotheses:

  H_{a4}: There is a correlation between user emotional support and perceived disease severity.

  H_{a5}: There is a correlation between user emotional support and perceived benefits.

  H_{a6}: There is a correlation between user emotional support and perceived barriers.

  H_{a7}: There is a correlation between user emotional support and usefulness.

  H_{a8}: There is a correlation between user emotional support and perceived ease of use.

  H_{a9}: There is a correlation between user reputation and perceived disease severity.

H_{a10}: There is a correlation between user reputation and perceived benefits.

H_{a11}: There is a correlation between user reputation and perceived barriers.

H_{a12}: There is a correlation between user reputation and perceived usefulness.

H_{a13}: There is a correlation between user reputation and perceived ease of use.

H_{a14}: There is a correlation between user self-worth and perceived disease severity.

H_{a15}: There is a correlation between user self-worth and perceived benefits.

H_{a16}: There is a correlation between user self-worth and perceived barriers.

H_{a17}: There is a correlation between user self-worth and perceived usefulness.

H_{a18}: There is a correlation between user self-worth and perceived ease of use.

- *Perceived Disease Severity*

  Definition: The belief about the magnitude of the threat.

  Research Question 3: Does perceived disease severity correlate with health information seeking effectiveness?

  H_{a19}: There is a correlation between perceived disease severity and health information seeking effectiveness.

- *Perceived Benefits*

  Definition: The perception that a particular course of action will be effective in reducing the treats of a disease.

  Research Question 4: Does perceived benefits correlate with information seeking effectiveness?

  H_{a20}: There is a correlation between perceived benefits and health information seeking effectiveness.

- *Perceived Barriers*

  Definition: Perceptions that a course of action is inconvenient, expensive, unpleasant, costly, or upsetting.

Research Question 5: Do perceived barriers correlate with information seeking effectiveness?

H_{a21}: There is a correlation between perceived barriers and health information seeking effectiveness.

- *Perceived Usefulness*

Definition: The degree to which a person believes that a particular system (online health community) will enhance their quality of life.

Research Question 6: Does perceived usefulness correlate with information seeking effectiveness?

H_{a22}: There is a correlation between perceived usefulness and health information seeking effectiveness.

- *Perceived Ease of Use*

Definition: The degree to which a person believes that using a particular system (online health community) would be free of effort.

Research Question 7: Does perceived ease of use correlate with information seeking effectiveness?

H_{a23}: There is a correlation between perceived ease of use and health information seeking effectiveness.

3.3.4 Survey Instrument Development

As indicated in the above proposed constructs, a 30-item questionnaire (see Appendix B) was developed to collect data to measure the relationships in the proposed model to compare results between COPD Facebook groups. A 5-point Likert scale (5 = *strongly agree*, 4 = *somewhat agree*, 3 = *neither agree nor disagree*, 2 = *somewhat disagree*, and 1 = *strongly disagree*) was selected to measure responses for all constructs but the demographic questions. The survey was entered into Qualtrics.

Qualtrics is an Internet-based survey vehicle that is used on five continents. Founded in

2002, Qualtrics allows custom surveys to be created and distributed to participants electronically via a link place in the online community (Qualtrics, 2020). Responses to the survey can then be downloaded for analysis. Benefits of an online survey such as this are the ability to easily distribute an electronic survey to a large population, saving time and money, and the ability to present survey questions in a dynamic and interactive form (Schmidt, 1997).

The Qualtrics questionnaire was pilot tested for face validity by a panel of PhD research students and faculty with knowledge of survey design, and online communities and three faculty members with experience in health communication to ensure clarity before the actual study. Panel recommendations were received and implemented to improve the clarity and detail of the data being collected. Pilot participants also determined the minimum amount of time required to thoughtfully complete the questionnaire, generally between five and ten minutes, allowing us to more effectively clean the data. All data from the study will be secured for a minimum of three years in the university office of the principal investigator (PI), in a locked drawer, for a minimum of three years.

After making the recommended modifications to the survey, a minimal review application was submitted to the University of North Texas Institutional Review Board (IRB) to reflect the changes made. Approval was received from the IRB.

3.3.5 The Study Sample and Survey Administration

3.3.5.1 Determining Study Sample Size

The sample size was calculated using Hatcher's rule of thumb that requires five responses for each survey item to test the statistical power of the proposed model (Hatcher, 1994). With 30 items in the survey, a minimum of 150 usable responses was needed for the survey to be statistically significant. Announcements were posted to willing Facebook groups' participants with a link to connect to the survey. No compensation was offered for participation in the survey. Participants were able to complete the survey at a convenient time and place. The participants could copy and paste the link provided into their computer's browser. Qualtrics was utilized for the survey. No personally identifiable health information was collected or reported in this study or in any publication resulting from this research. The identity of group participants was not captured.

3.3.6 Data Collection

The initial post to 23 separate COPD Facebook groups was posted on October 30, 2019. Due to a low response, a second post was made to an additional 16 Facebook groups on January 18, 2020. Again, there was a low response, so a third post was distributed to 20 of the original groups on April 4, 2020. One last post was made with the original recruitment script on April 7, 2020. There were 264 responses collected on April 12, 2020. Microsoft Excel software was utilized to clean data. After cleaning the data and removing incomplete surveys, surveys completed in less than the established minimum period of time, or surveys where the participants chose the same answer to every question, there were 155 usable surveys. This represents a 58.7% usable response rate. All data were coded using the following method. In the demographics section, age had five levels, gender had three levels, marital status had four levels, and income had three levels. All other variables were answered with a Likert scale and were coded as 5 = *strongly agree*, 4 = *somewhat agree*, 3 = *neither agree nor disagree*, 2 *somewhat disagree*, and 1 = *strongly disagree*.

3.3.7 Analysis with SmartPLS

SmartPLS (v.3.2.9) was used for structural equation modeling. SmartPLS is a tool to perform multivariate data analysis that is primarily an exploratory type of research (Hair, Thomas, Hult, Ringle, & Sarstedt, 2017). The hypothesized model was tested based on partial least squares. SmartPLS has proven to be effective when the model has many constructs, small sample size, nonnormally distributed data, and the goal is theory testing (Hair et al., 2017). PLS-SEM (Structural Equation Modeling) allows both causal relationships among indicators and latent constructs (Hair et al., 2017).

CHAPTER 4

RESULTS AND DISCUSSION

4.1 Essay 1: COPD Online Health Community: Identifying Information Needs and Sources*

4.1.1 Introduction

Online health communities (OHCs) have witnessed incredible growth over the past few years. Numerous studies have investigated the credibility of online health sources, and their use for user support, and self-management. Studies have explored communities related to cancer, diabetes, and other chronic diseases. However, few studies, if any, have examined online communities focused on chronic obstructive pulmonary disease (COPD). This study investigates COPD360social, an online forum for COPD patients, to answer the following research questions: What health information do forum members need; what health information sources do they prefer; and how credible is the information exchanged on the forum?

4.1.2 Literature Review

According to the Pew Research Center, approximately 9 out of 10 adults Americans use the Internet (Pew Research Center, 2018). The rate for adults aged 50- 64 is 87% and for adults over age 65, 65% (Statista, 2018). In a recent study, 98% of surveyed patients with a serious health condition used some form of social media or online resource for health information (Health Union, 2016). The use of the Internet is changing the way individuals find health

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*Essay 1 is presented in its entirety from Boyce, L. & Prybutok, G. (2020). COPD online health community: Identifying information needs and sources. Accepted by International Journal of Electronic Healthcare. **IJEH-248054** information, including information on how to manage their chronic conditions, information about new and existing medication regimes, and treatment alternatives. As the growth of Internet usage increases, it is important for health care professionals to understand the

information needs of the people they serve, the sources of the information they rely on, the credibility of these sources, and the type of information exchanged in online health related peer to peer support groups. The purpose of this paper is to identify these key factors; information needs, information sources, the credibility of the sources, and the types of information exchanged.

Online health communities (OHCs) have witnessed incredible growth over the past few years (Nambisan, 2011). An online community is defined as an element of society that involves participants who relate to one another as a group and interact using computer technologies to connect across geographical distances (Demiris, 2006). A subset of the online communities that are becoming more popular in today's society is the online health community. These health communities consist of large groups of individuals from diverse geographic locations, socioeconomic levels, education levels, etc. that share a common interest or diagnosis of a particular disease (Johnston et al., 2013). OHCs provide individuals a safe place to exchange information related to specific health conditions either for themselves, a loved one, or a person for whom they are the primary caretaker. Within these communities the individual can interact with like-minded people with the desire to gain a better understanding of the illness and its treatment or management. Studies show that online communities can have a positive effect on a person's health outcome (Johnston et al., 2013; Nambisan, 2011; Xing et al., 2018). Some of the benefits include encouragement and motivation, advice and information exchange, success stories, accountability, emotional support, convenience, socialization, anonymity, tangible support, and giving back (Hwang and Fogoros, 2018).

We have implemented the health belief model (HBM) to serve as a framework for this study. HBM, first developed in the 1950s by social psychologists Hochbaum, Rosenstock and Kegels, attempts to explain and predict health behaviors (Abraham and Sheeran, 2015). The model provides an important link between socialization and behavior. HBM is based on an understanding that a person will take health-related actions if that person believes they are at risk and believes that taking a recommend action will mitigate that risk. They will avoid accessing information about a threatening health condition and an individual can take a recommended health action to improve their health status when they believe it will make a difference (University of Twente, 2018). We believe individuals who perceive their health to be at risk are motivated to use online health communities when they believe the online community can provide information on health-related information, emotional support, and socialization that would positively affect their health-related condition.

For this study, we used three categories for reasons participants posted on the site: informational support, emotional support, and socialization. Informational support is the transmission of information, or guidance (Wang et al., 2017) and includes advice, suggestions and information(Heaney and Israel, 2008). Past studies indicate that information seekers may seek advice in both a clearly expressed (explicit) manner or in a not plainly expressed (implicit) manner (Goldsmith, 2000; Sillence, 2013a). Emotional support is represented by expressions of empathy, love, trust ,understanding, encouragement, and caring (Heaney and Israel, 2008; Wang et al., 2017). Online health communities provide participants a renewable source of support due to a shared medical condition. Through participation, members gain emotional support by forming bonds with others that experience similar conditions (Nambisan, 2011). Lastly, socialization consists of chatting, humor, teasing and discussion of offline activities and daily life that may not be directly related to chronic disease (Wang et al., 2017).

Numerous studies have investigated the credibility of online health sources (Eastin, 2006; Nath et al., 2016; Wang et al., 2008), and their use for support, and self-management (Bender et al., 2011; Park et al., 2016; Willis and Royne, 2017). Studies have explored communities related to cancer (Blank and Adams-Blodnieks, 2007; Ginossar, 2008; Setoyama et al., 2011), diabetes (Gilbert et al., 2012; Greene et al., 2011), arthritis (Willis and Royne, 2017), and other chronic diseases. However, few studies, if any, have examined online communities focused on chronic obstructive pulmonary disease (COPD).

COPD is a pulmonary disease, ongoing and increasing in severity, that is characterized by a decline in airflow, and does not completely resolve (Giokas et al., 2016). According to the National Institutes of Health (NIH) (2013), approximately 12 million adults in the United States are diagnosed with COPD, and roughly 120,000 people, die from COPD each year ("NIH Fact Sheets - Chronic Obstructive Pulmonary Disease (COPD)," 2013). According to the Global Initiative for Chronic Obstructive Lung Disease, key indicators for a COPD diagnosis include persistent dyspnea that progresses over time. The disease typically gets worse with exercise, displays a chronic cough with a recurrent wheeze, chronic sputum production, recurrent lower respiratory tract infections, results from family history or risk factors (ex. genetic factors, tobacco smoke exposure, smoke from home cooking and heating fuels, occupational dusts, vapors, fumes, gases, and other chemicals), or childhood factors (ex. low birthweight, childhood respiratory infections, etc.) (GOLD, 2018).

The COPD Foundation is a non-profit (501c3) organization created in 2003 to create resources that result in broadened provisions for COPD patients and to better the lives of those touched, either directly or indirectly, by COPD (COPD Foundation, n.d.-a). COPD360social is the online community, created by the COPD Foundation, that is available to any person affected by COPD. This community includes patients, family members, caregivers, physicians, respiratory therapists, and other healthcare providers. COPD360social is managed by the foundation. While the content posted does not represent the official policies or views of the foundation, content is monitored for accuracy by a community manager and state captains. The community manager has the ability to delete posts that do not address the goals of the community. State Captains are volunteers with the foundation whom serve as state and community leaders. State Captains can be caregivers, family members, or healthcare providers. The goal of the online community is to provide an inviting and collaborative atmosphere for participants to directly interact with others from all across the world in a safe setting to communicate thoughts and ideas, ask questions, start discussions, read and comment on blogs (COPD Foundation, n.d.-b).

The purpose of this paper is to report the results of a recent study that investigated COPD360social to answer the following research questions: What health information do forum members need?; what health information sources do they prefer?; and how credible is the information exchanged on the forum?

4.1.3 Methods

This qualitative study analyzes the historical activity feed posted by COPD360social online participants from December 2017 to September 2018. A total of 4800 online posts were harvested using a Google Chrome extension, DataMiner, and de-identified. Prior to collection, we received approval from the Senior Director of Community Engagement for the COPD Foundation and obtained IRB approval from the university.

Data was coded for content analysis. Key words and themes were established based upon the data. To understand the needs of the community, we aggregated data into three defined categories: informational support, emotional support, and socialization. We collected a list of commonly occurring keywords to identify the knowledge gaps/information needs of the participants. We categorized this information into 25 categories:

- Oxygen
- Concentrators/portable oxygen
- Stem Cell
- Relaxation/sleep
- Breathing/irritants
- Doctors/second opinion
- Clinical studies
- Education/support groups
- Sexual activity
- Medication
- Insurance/Medicaid
- Pulmonary rehab
- PEEP/CPAP/BiPAP
- Lung Transplant
- Diet
- Legislation/advocacy
- Respiratory treatments
- Privacy
- Exercise
- Travel
- Exacerbations
- Weather/humidity
- PFTs/oxygen saturation
- Blood pressure
- Action plan
- Anxiety/depression
- Smoking

These keywords categorizing participant information needs were hand-coded according to the codebook provided in Appendix A. This codebook proved to have 95% accuracy when randomly selected rows were checked by an independent coder. Due to the overwhelming number of recommended information sources, we developed a systematic method to categorize sources. If a source was recommended 3 times or more, a new category was created. These sources were hand coded into 8 types: the foundation’s resources, consult a doctor, social media, personal experiences, Internet, NIH, academic journal articles, and YouTube videos. The Internet resources were analyzed for credibility using the validated DISCERN instrument (Charnock and Shepperd, 2004) and NIH recommendations (NIH.gov, 2018).

All de-identified information was analyzed using Excel and SPSS to identify the users' health information needs, knowledge gaps, key words, themes, and preferred information resources, and to ensure that users accessed clinically credible and accurate information about medication, disease management techniques, and therapeutic interventions. We also sought to understand how users assessed whether the information that they are relying on to make health decisions was coming from a reliable and accurate health information source.

4.1.4 Results

4.1.4.1 Health Information Needs

Univariate analysis indicates that, of the 4800 entries from December 2017 to September 2018, there were 732 authors. Nearly 55% of the authors posted only one comment in the activity feed, 15.7% posted two comments, and together these accounted for 70.6% of the posts. The number of comments per author ranged from one to 330 posts from a single author, with the second highest number of posts from a single author being 233 posts.

Most posts were made in April 2018, (614) followed closely by February 2018 (589), and March 2018 (526). January 2018, and September 2018, were the two months that had the fewest number of posts (415, and 429, respectively).

The activity feed was categorized into informational support, socialization, and emotional support posts (see Figure 4.1). Fifty-four percent were posting for emotional support

34% of the posts were asking for informational support, and 12% were concerning socialization.

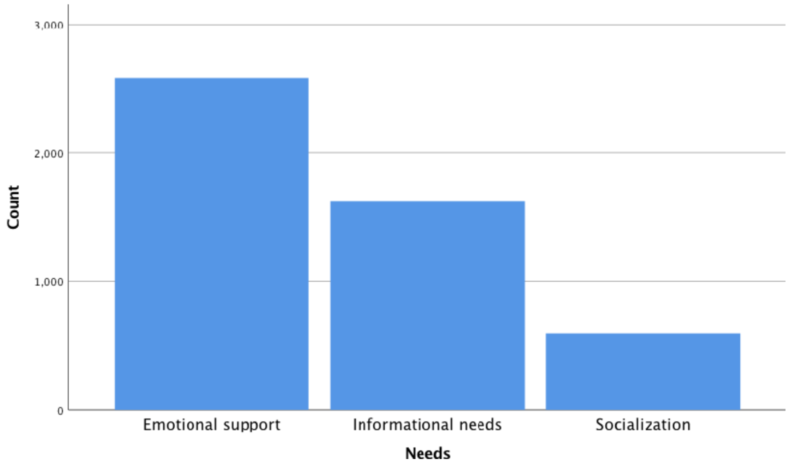

Figure 4.1. COPD360social participant's needs.

The majority (57%) of topics discussed were not related to COPD, and instead ranged from Furry Fridays (about pets), to welcoming new members, trivia, and fun facts. This highlights the value to participants in providing socialization. Topics as they relate to COPD are shown in Figure 4.2. The top nine topics were: medication (674) education (580) doctors (498) oxygen (472) pulmonary function tests (406) exercise (360) anxiety/depression (353) breathing (293) and POC/concentrators (237).

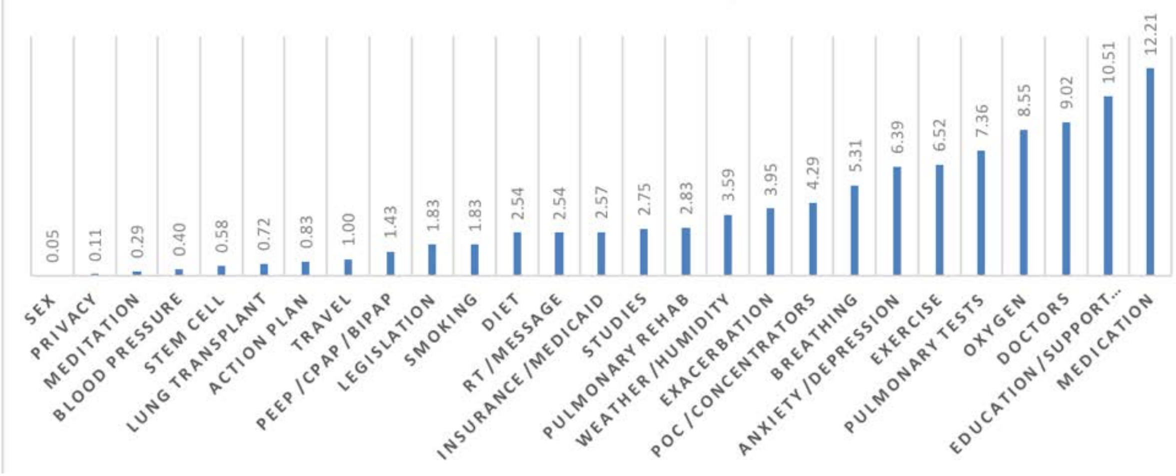

Figure 4.2. Topics discussed in COPD360social.

4.1.4.2 Health Information Sources and Accuracy in the Information Exchanged

Figure 4.3 indicates that information sources included personal experience (78.26%), doctor (12.60%), COPD Foundation (5.0%), Internet (3.4%), and YouTube, academic journals, social media, and NIH, which accounted for just 1.53%.

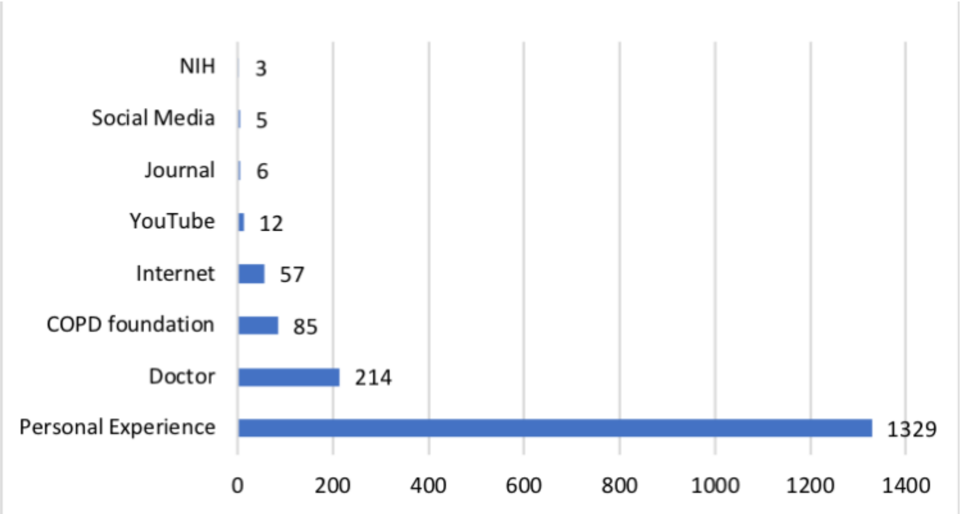

Figure 4.3. Health information resources exchanged in COPD360social.

Websites given (see Figure 4.4) included .com (66.67%), .gov (18.75%), .org (13.54%), and .int (1.04%).

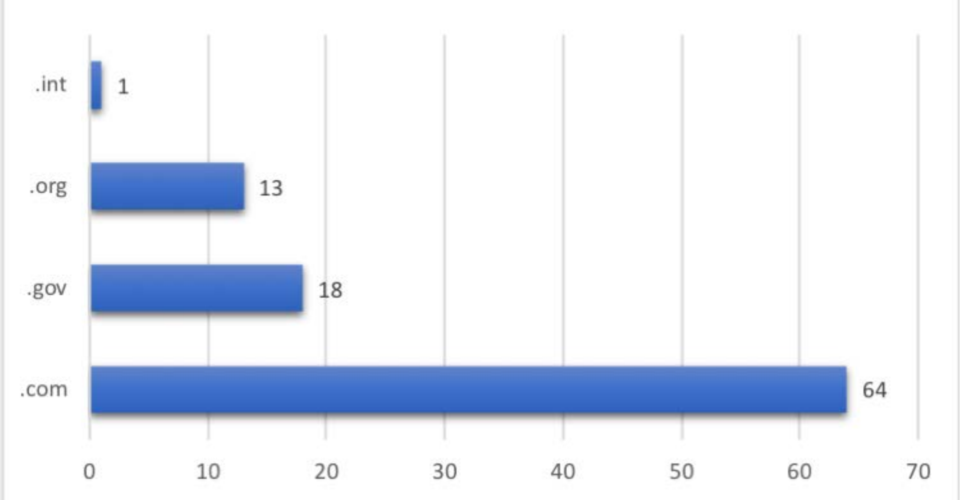

Figure 4.4. Websites shared in COPD360social.

Two prominent tools available to users were published by NIH and DISCERN. DISCERN is funded by the National Institute for Health Research. These websites were analyzed using criteria provided by NIH and the DISCERN (Charnock & Shepperd, 2004). Furthermore, the suggested .com sources (see Figure 4.5) were sites for information (27%), retail (24%), pharmaceutical (19%), news (14%), journals (8%), clinical trials (5%), and social media (3%). Upon evaluation, there was only one questionable site using the aforementioned criteria.

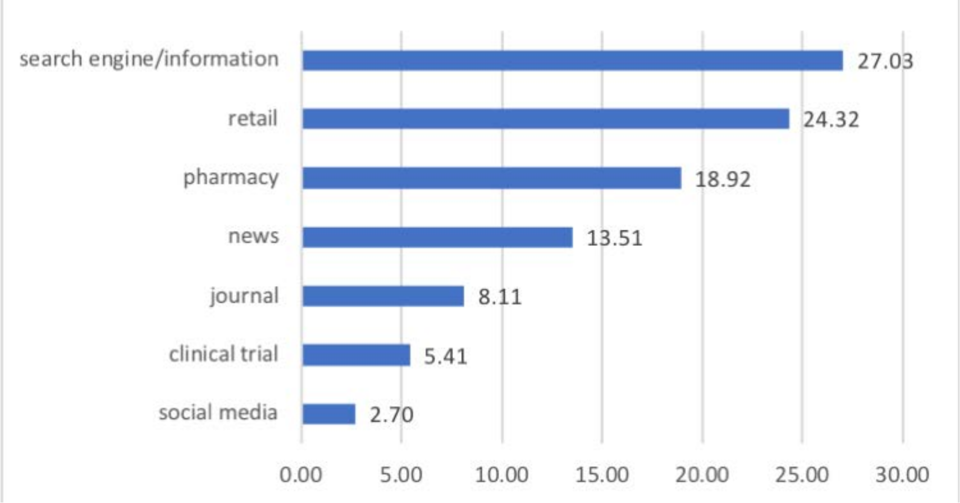

Figure 4.5. Types of .com websites recommended in COPD360social.

Analysis of data indicated there were twelve participants that posted 200 or more posts. The authors are retired teachers, work at pharmacies, in programming, or were retired engineers, judges, executive directors, worked for the foundation, was a respiratory therapist, grassroots manager, data entry technician, or volunteer at a medical center. Three fourths of these top twelve posters have an association with the foundation, whether it be as a State Captain or Manager. The authors represented 10 states within the United States.

Table 4.1 indicates what topics the top 12 authors discussed in their posts. The top topics discussed by the top 12 authors were education/support groups (10.03%), medication

(9.36%), doctors (7.95%), exercise (7.1%), oxygen (6.91%), pulmonary function tests (PFTs) (6.02%), anxiety/depression (3.53%), portable oxygen concentrators (POC)/concentrators (3.53%), and breathing (3.42%).

Table 4.1

Topics Posted by the Top Twelve Posting Authors

Author	# of posts	Topics
A	233	Oxygen (23), Education/Support groups (23), Medication (18)
B	194	Medication (34), Education/Support group (26), Depression/Anxiety (21), Doctor (21)
C	169	Exercise (31), Doctor (27), Oxygen (23)
D	330	Exercise (76), Doctor (61), PFTs/SO2 (50)
E	105	Medication (18), PFTs/So2 (17), Oxygen (13)
F	164	Oxygen (32), Medication (31), Doctor (25)
G	158	Doctor (27), Oxygen (22), PFT (20), Medication (20)
H	129	Medication (28), Doctor (18), PFTs (14)
I	100	Education/Support Groups (30), Clinical Studies (13), Exacerbation (7)
J	132	Education/Support Groups (18), Exercise (10), Medication (8), Weather (8), Diet (8), Action Plan (8)
K	208	Education/support group (45), Legislation/Advocacy (43), Insurance/Medicaid (5)
L	122	Depression/Anxiety (12), Insurance/Medicaid (9), Education/Support Groups (8)

4.1.5 Discussion

4.1.5.1 Health Information Needs

The data revealed most posts were made in February, March, and April ,2018. What would explain the prevalence of posts in these months? Could this be the result of increased exacerbations at this time, secondary to allergies, or fatigue? Does this correlate to increased depression? According to the Lung Institute, COPD patients notice increased difficulty with breathing with seasonal allergies ("Lung Institute | COPD and Seasonal Allergies," 2018). This is an area worthy of further study.

From the data, we determined that posts were created for informational support, emotional support, and socialization. The largest number of posts dealt with emotional support. Emotional support was represented in many forms including; both emotionally and psychologically that fostered bonds with others that experience similar conditions. Informational support was sought both implicitly and explicitly which agrees with studies by Goldsmith (2000). Table 4.2 represents the needs of the participants for emotional support, informational support, or socialization. Examples of actual posts are included.

Table 4.2

Participants' Statements in COPD360social

Topics	Posts
	Socialization
"Furry Fridays"	"…this made me laugh so hard! He does look pretty sharp. Thanks for all the Gimlet love!"
Welcome	"Welcome. So glad you joined our community and am sure that you will enjoy the information and interactions here. "
T-shirts for COPD	"We had some requests for T-shirts for COPD Awareness Shirts! If the colorful orange t-shirts weren't your thing for COPD Awareness month, how about one of these?"
Everyday life pictures/updates	"Love all your decorations!!! Happy Holidays;"
Sports	"It's been bitterly cold here for the Pirates games. Spring has not yet arrived in Pittsburgh. I root for the Washington Nationals - GO NATS!!"
Weather	"Beautiful! I'm envious, but glad you got to see them--especially since it's been so cold. I was afraid the cold weather was going to spoil them. I was born in D.C. and raised there, and in Northern Virginia. Thanks for posting the pic. I miss going down to the tidal basin to see them, around the Jefferson Memorial."

(table continues)

Topics	Posts
Technical help	“If you navigate to the Question and Answers page you can click the Ask a Question link under the search box and fill out the form. You can also post directly into the Activity Feed, like you did with this post - but for more specific questions you’re better off using the Q&A as it will provide more opportunity for long term visibility of your question in the community ,so you’ll likely get more answers.
Informational Support	
Explicit	• “I want to know how I can avoid being hospitalized during an exacerbation.” • “I need to get my mum an oxygen and blood pressure monitor, can anyone advise of best one from experience?” • “I’m 43yrs old and to be honest with you I’m scared in a way as I still have young child but I’ve heard of stem cell for COPD any advice on this?”
Implicit	• “I don’t use higher levels of oxygen. I don’t wear it outside. I also think it depends where you live.” (problem disclosure) • “I tried the oxymizer, I felt it wasn’t that great. But again, won’t hurt to try. Better than nothing.” (announcement of a plan of action) • “What do you think?” • “What have you all experienced?”
Emotional Support	
Bereavement	“I am so very sorry to read of your painful loss. From my personal experiences, it might also be beneficial to read up on the stages of grief. Grief is considered an actual injury to every pore of our being.”
Smoking Cessation	“Kicking the addiction is very hard, however, it sure beats the alternative! Love You Guys,.”
Aging	“I think I posted this TED talk video in the past, but I would like to share it again. It reminds me that the life that we have is meaningful.;”
Health	“Hello everyone. I hope everyone is having a great breathing day. “
Health status updates	“I am feeling okay today but I need help ... not sure how I feel with this diagnosis - angry, scared, hurt, mad, frustrated, etc., etc. ...I feel like I need a therapist to sort it all out! “

4.1.5.2 Health Information Sources and Accuracy of the Information Exchanged

The majority (78.26%) of posts were related to personal experiences. This meant there were no references to any other sources, doctor’s advice, or online health resources. Some examples of these posts are:

- Was getting excellent results with my breathing on the keto diet in the first three months. I am now feeling short of breath all the time. I am wondering if it is because of the high fat dairy I'm using. Anyone have any ideas?
- I take Symbicort 2x/day and Combivent typically 5x/day. Generally, 3x or 4x is recommended, but I just can't get down to that level. As the day progresses, I get a certain feeling of difficulty breathing. That's when I take a puff.
- My pulmonologist changed me to Anoro recently - had taken 24 doses when I began having severe discomfort in my upper left shoulder. It's not a sharp pain, but more a tingling and an awful soreness. It gets worse by evening.

Other resources referred to in the posts directed participants or those seeking advice to consult with their personal physician/pulmonologist (12.60%).

Furthermore, the COPD Foundation has many resources available through the "Learn More" tab on the foundation's website. In this section, there are educational materials available in both print and video. The printed materials include titles such as "The 1s, 2s, and 3s of COPD," "My COPD Action Plan," "Disaster Preparedness Plan," "What is COPD," "The Impact of Smoking," and "Supplemental Oxygen Guide." Video titles are "Inhaler Training Video" and "COPD 101." External links are also available through the Foundation, giving further tools for the members to learn more about COPD. Some of these links include Alpha-1Association, American Hospice Organization, Administration on Aging, and COPD International. The participants referred to these educational resources 5% of the time.

The Internet provided only 3.4% of resources recommended through the activity feed. Websites recommended included .com, .org, .gov, and .int. The .com sites were the sites most often recommended (66.67%). These .com sites included information (27%), retail (24%), pharmaceutical (19%), news (14%), medical journals (8%), clinical trials (5%), and social media (3%). The sites for information included such sites as Google, Gardening Know How, Space, QuitNet, and Normal Breathing. The retail sites included such sites as Dollar Cannula Club, Nerd Wallet, and OxyTube Control Bags. The majority of these sites dealt with oxygen supplies and concentrators. The pharmaceutical sites were given to assist participants with their pharmacy costs. Included in these sites were Good RX and All Day Chemist. Although these sites are not created by pharmacists, these sites state they are built by people that have diverse backgrounds in technology and healthcare and professionally managed. News websites were the fourth highest category of recommended sites. The sites included in these recommendations were NY Times, MD Magazine, US News, and Medical News Today. Articles were referenced from these three credible journals: *Cell*, *Thorax*, and *European Respiratory Journal*. These journals were found credible due to h indexes of 682, 195, and 209 ("Scimago Journal & Country Rankings," 2017). An h-index is an author-level metric that is based on the productivity and the citations of those authors that publish within the particular journal. For example, an h-index of 682 means 682 articles have 682 or more citations. Two sites were given for clinical trials: Airflowtrial and Nuvaira. Nuvaira is a privately held medical device company whose board of directors include an U.S. patent holder, oncology scientist, and leaders in healthcare industry. Facebook was the only site referenced for social media. YouTube, academic journals, social media, and NIH accounted for just 1.53% of the resources referenced. Using criteria from the NIH, only one site was found to be questionable. This source was found questionable because the individual that medically reviewed the information has conferred an honorable doctorate from Russia, thus does not present as a strong, credible source. This site seemed more directed toward selling books and workshops than providing credible health information. This small number of recommended Internet sites confirms that personal experience is what most participants feel comfortable with in giving information.

In this 9-month period, 732 individuals posted in the activity feed. Of those, only 12 individuals posted over 200 comments. While a majority (75%) of these “top posters” were either employed or State Captains, the other individuals were either patients or caregivers. Individuals came from across the United States and a few individuals were from other countries as well.

4.1.6 Strengths and Limitations

This study has many strengths. First, this study takes advantage of a large sample size as it analyzed nine months’ worth of data, which included 4800 posts from over 700 individuals. Secondly, participant bias is low since we analyzed publicly viewed data where participants were sharing personal experiences to be helpful to others.

As with all research, this study has limitations. First, we were unable to collect demographic information from the participants. Also, the generalizability of this study cannot be applied to a greater population, as this study only focused on participants in a single online site specific to COPD. Lastly, since this is an online community, this study cannot be generalized toward those individuals who are not comfortable using the Internet or that don’t have access to it.

4.1.7 Future Research

Future research is needed to understand other on-line COPD communities. We recommend a comparison with other online sites that are not moderated, or with other sides moderated for different illnesses.

4.1.8 Conclusion

To our knowledge, this is the first study to analyze user information needs, information resources, and the accuracy of the sources provided, and information exchanged in an online health community of COPD patients. Our findings suggest that closed COPD communities, such as COPD360social, contain a variety of participants, including patients, caregivers, healthcare providers and family members with differing interests, health backgrounds, and information needs. These groups simultaneously serve as support groups, and sources of important health information on an as needed basis. Healthcare providers should be aware of OHCs when discussing credible and helpful sources of information for their COPD patients, once the relevance and credibility of the information provided has been validated.

This study investigated COPD360social in order to understand what users seek in an online health information forum, what health information sources they prefer, and how accurate the information exchanged on the forum is. We observed that individuals participated in the online forum to get informational support, emotional support, and socialization. We analyzed 4800 posts and summarized the 25 categories of information that participants discussed. The top 5 health information needs are about medications, education/support, doctors, oxygen, and pulmonary tests. We found that most of the participants' reasons for posting on this site was to look for emotional support. This confirms other studies that suggest that through participation, members gain social support both emotionally and psychologically by forming bonds with others that experience similar conditions. Although many participants would post only once, others participated throughout the nine-month study, exchanging information, pictures of pets, and personal experiences.

We identified the top 5 information sources preferred were those based on personal experience, followed by consulting a doctor, the COPD Foundations' resources, searching the Internet, and information from YouTube, academic journals, social media and the NIH.

It is interesting to note, using criteria from NIH, that only one source recommended was found to be questionable, with regards to credibility. This is not in agreement with previous studies. Future work should assess and compare moderated online communities versus non-moderated online communities.

The findings of this study are beneficial to members of the COPD Foundation, health care profession, and other COPD patients because information needs are identified for those patients or caregivers affected by COPD. That being said, it is important to note the importance of such sites in providing emotional support for the majority of patients. It is also important for health care professionals to recommend sites that are moderated (like COPD360social) so that credible information sources, as well as credible health information, are recommended.

This study also indicates that COPD patients have health information needs and a monitored social health online community that is available to patients 24/7 answers questions that arise at the time of need.

This paper contributes to the body of literature about peer-to-peer online health support groups and makes clear that a site, to be most beneficial to users, must be professionally monitored for clinical accuracy and must have credibly written materials available to users beyond the normal business hours when questions arise at the time of need.

4.1.9 Acknowledgments

We want to thank the COPD Foundation for the approval of the harvesting of data from their website.

4.1.10 Conflicts of Interest – None

4.1.11 Abbreviations

COPD: Chronic obstructive pulmonary disease

OHC: On-line health communities

NIH: National Institutes of Health

PFTs: Pulmonary function tests

POC: Portable oxygen concentrators

4.2 Essay 2: Assessing Health Information Quality in a Closed, Non-Moderated COPD Facebook Group*

4.2.1 Introduction

Chronic obstructive pulmonary disease (COPD) is a leading cause of mortality and morbidity throughout the world and includes chronic bronchitis and emphysema(“WHO | Chronic obstructive pulmonary disease (COPD),” 2017). COPD is the result of a multifaceted interaction of long-term exposure to tobacco smoke and noxious gases and particles. It also can be caused by other factors like genetics, airway hyper-responsiveness, and poor lung growth during childhood (Global Initiative for Chronic Obstructive Lung Disease Incorporated, 2019). COPD was the fourth leading cause of death in the United States in 2015 and

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*Essay 2 is presented in its entirety from Boyce, L. & Prybutok, G. Assessing health information quality in a closed, non-moderated COPD Facebook Group, submitted to the Federation of Business Disciplines Journal.

2016(Kochanek, Murphy, Xu, & Arias, 2017) . Many chronically ill patients and their caretakers are turning to online health communities for support and disease self-management strategies(Willis & Royne, 2017). Much research has focused on online communities focused on cancer, diabetes, and mental illnesses, but few have thoroughly investigated Facebook and the COPD patient(Brady, Segar, & Sanders, 2017; Fatima, Mukhtar, Ahmad, & Rajpoot, 2018; Gilbert et al., 2012; Ginossar, 2008; Sillence, 2013b; Weymann, Harter, & Dirmaier, 2015). Recent work by Apperson, Stellesfson, Paige, Chaney, Wang and Mohan highlight the importance of Facebook interactions between patients with COPD to improve self-management (Apperson et al., 2019) but few studies focus on Facebook and COPD.

This research explores the types of COPD related health information Facebook online participants seek, what kinds of health information is exchanged, what health information sources are recommended by peers, and how clinically reliable the information exchanged in the forum is as a tool in healthcare decision making. This work contributes to our understanding of the value and risks associated with non-moderated peer to peer online support groups and guides health practitioners and educators to selectively recommend online peer to peer support groups based on this understanding.

4.2.2 Literature Review

4.2.2.1 Chronic Obstructive Pulmonary Disease

COPD is a progressive pulmonary disease characterized by a decline in airflow and persistent cough that is preventable and treatable but not curable (Global Initiative for Chronic Obstructive Lung Disease Incorporated, 2019). The National Institutes of Health (NIH) reported that approximately 12 million adults in the United States are diagnosed with COPD, and roughly

120 000 people die from COPD each year (“NIH Fact Sheets - Chronic Obstructive Pulmonary Disease (COPD),” 2013). According to the Global Initiative for Chronic Obstructive Lung Disease (2019), key indicators for the diagnosis of COPD include persistent dyspnea (shortness of breath), respiratory symptoms, and alveolar abnormalities that progress over time. The symptoms of the disease typically worsen with physical exertion, presents with a chronic cough with a recurrent wheeze, chronic sputum production, or a recurrent lower respiratory tract infection. COPD can be associated with a family history or specific risk factors (ex. genetic factors, tobacco smoke exposure, smoke from home cooking and heating fuels, occupational dusts, vapors, fumes, gases, and other chemicals), or childhood factors (ex. low birth weight, childhood respiratory infections, etc.) (GOLD, 2018).

4.2.2.2 Theoretical Framework

We have relied on affordance theory as the framework for this study. Affordance theory states a person’s needs will drive certain actions, and the properties of an object will influence how the object is utilized (Gibson, 1979). Affordance theory focuses attention on the interaction between the participant of the online health community and the functionality afforded by the platform and what are the benefits of these interactions (Coulson, 2017). Research has been accomplished using affordance theory to understand online health communities, including social media and chronic pain (Merolli, Gray, & Martin-Sanchez, 2014) and in women with endometriosis (Shoebotham & Coulson, 2016). To our knowledge, there is no previous work implementing Affordance theory and online health communities specific to COPD.

From the perspective of psychology, affordance theory explains the relationship between individuals and objects in their environment, and how the interaction between them shapes individual behaviors. Affordance theory, in this research, provides a foundation for our understanding of the interaction between the user and our object of study, the online health support group. The affordances of this theory are connection, exploration, narration, and self-presentation. In terms of connection, we want to understand what the health information and social needs of COPD patients within the Facebook group are, and what drives users to engage with this particular online support group. In terms of exploration, we want to understand the ability to access information sought. For narrations, we want to understand the ability of users to share their own experiences as well as to receive information about others' experiences. Lastly, self-presentation expresses how participants present themselves and alludes to the benefit of being able to share with others that are dealing with similar experiences as they relate to COPD. Gibson (1979) believed by learning the affordances of an object (the online Facebook support group in this study), participants are motivated to become a member of that online community.

While COPD patients have traditionally depended on their providers and caregivers for information and support, they now have a venue in which they have access to valuable information and support at their time of need. Affordance theory is one avenue to explore this new phenomenon.

4.2.2.3 Online Health Communities (OHCs)

The landscape of health information retrieval is changing. According to a Pew Research Study in 2013, 70% of U.S. adults got health information about their illnesses from their doctors or other health care providers (Fox & Duggan, 2013). A more recent Pew Research Center study on online health communities (OHCs) indicates that a large proportion (59%) of Americans turn to the Internet for health information (Fox, 2014). We also learn that 16% of online health information seekers look for others who might share the same health concerns, and 26% have read or watched information about someone else's personal health experience (Fox & Duggan, 203).

OHCs are part of this ever-changing online health landscape. The term OHC is a relatively new phenomenon in health care (Hodgkin, Horsley, & Metz, 2018). These are communities of self-organizing patients, caregivers, healthcare providers, and researchers that focus on a particular disease. OHCs are groups of people whose members relate to and interact with one another through the Internet (DeSimoni, Taylor, Griffiths, Panzarasa, & Aziz Sheikh, 2018). OHCs have seen considerable growth (Knight, 2016) and bring together large groups of people outside their geographical areas to collaborate on a variety of interests and to acquire information and input that they would otherwise have no access to (Faraj et al., 2016; Knight, 2016). Disease- specific OHCs play a positive role in improving people's attitudes, health care decision making, and health behaviors related to disease self-management and in turn, in their health outcomes (DeSimoni et al., 2018; Namkoong, Shah, & Gustafson, 2017; Rupert et al., 2016). Research by DeSimoni et al.(2018) found that, on average, 25% of Internet users with chronic illnesses go online to find other people with similar health problems.

These online environments give participants the ability to gain knowledge about their diseases, treatment options, and symptom management techniques, and can lead to positive health outcomes (Johnston et al., 2013b). Studies show that OHCs provide a safe place for users to exchange disease-specific information either for themselves, a loved one, or for a person for whom they are the primary caretaker (Hwang & Fogoros, 2018; Willis & Royne, 2017). These communities foster interaction between like-minded individuals to improve their understanding of the illness and its treatment or management. This interaction with the community often results in access to first-hand insights about similar disease-related experiences (Johnston et al., 2013b).

4.2.2.4 Facebook and OHCs

As mentioned, OHCs have grown and are a convenient avenue for people to exchange information and give support to others that have similar circumstances, such as a chronic disease. Generally, Facebook is one of the most popular and perhaps one of the most successful online communities (Bender et al., 2011).

Studies show that traditional face to face support programs can have a positive influence on behavior change and health outcomes (Christensen, Golden, & Gesell, 2019; Southall, Jennings, Gagné, & Young, 2019). However, traditional support groups have suffered from consistently low attendance or high drop-out rates (Bush, Singh, Hidecker, & Carrico, 2018; Dilgul, MacNamee, Orfanos, Carr, & Priebe, 2018; Resurrección, Motrico, Rubio-Valera, Mora-Pardo, & Moreno-Peral, 2018). Online platforms, such as Facebook, may offer solutions to the barriers that handicap traditional support groups like transportation or lack of anonymity (Bush et al., 2018). Studies show that in 2018, nearly 169.5 million people used Facebook (Kats, 2018) and a majority of those users (75%) accessed Facebook daily (Smith & Monica Anderson, 2018). According to a WEGO Health Solutions study, 87% of the participants share health information via Facebook posts(Nelson, 2018). Facebook has become a popular health information channel and support groups for patients and caregivers with chronic health conditions (Roundtree, 2017).

Many studies have been conducted on Facebook to analyze users, to evaluate improvements to disease and treatment awareness, to evaluate Facebook as a venue for information exchange, and as a venue for emotional support (Buehler, 2017; K. L. Hinson, 2017; K. Hinson & Sword, 2019). However, there are few studies focused on COPD patients' identified health information needs and about the information resources exchanged within a disease-specific Facebook group. This study fills this gap in the literature.

4.2.2.5 Facebook Group: COPD Warriors, Hope, Support, Love & Laughter

Facebook has a feature known as Facebook groups. These groups allow people to interact with one another that have similar interests. COPD Warriors, Hope, Support, Love & Laughter is a closed Facebook online health community (group) that claims to have 10 660 members (now 11 836 members, about a 10% increase over the two months of our study) (COPD Warriors Hope, Support, Love and Laughter, 2019). A closed group in Facebook is a group in which the participants must be approved by the group's administrator or be invited by a current member to view the group's content and participate in the forum. Alternatively, an open group allows content posted to anyone who views the group. This group was a chosen group due to their international presence, large number of members, and the acceptance from the administrator for this type of study. The average amount of posts is 64, and with 43.3 active participants per day. This group offers support, stimulates hope, celebrates holidays, improves self-esteem, and share laughs. It was created on January 20, 2014. Group rules include the requirement to be kind and courteous, to avoid hate speech or bullying, to avoid promotions or spam, politics, or religion, and they ask users to refrain from offering medical advice.

According to one site administrator, the top 12 countries represented in the group are the United States, with 8.1 thousand participants, the United Kingdom, with 916 participants, Pakistan (356 participants), Canada (338 participants), Australia (195 participants), India (172 participants), Philippines (116 participants), South Africa (113 participants), Nigeria (100 participants), and Bangladesh (72 participants). These numbers were reported on May 17, 2019 and show the span of influence of this group. This group was a chosen group due to their international presence, large number of members, and the acceptance from the administrator for this type of study.

The purpose of this study is to understand what kinds of health information is exchanged, what health information sources are recommended by peers, and how clinically reliable the information exchanged in the forum is as a tool in healthcare decision making.

4.2.3 Methods

This qualitative study analyses retrospective posts to the Facebook group, COPD Warriors, Hope, Support, Love, and Laughter. Before collecting the data, we received approval from the site's administrator and obtained IRB approval from the university. Posts were gathered daily from April 13, 2019, to June 29, 2019 with 4 910 posts harvested using DataMiner, a Google Chrome extension.

Data were hand-coded for content analysis, and keywords and themes were identified with a codebook.   Posts were aggregated into three classifications: informational support, emotional support, and socialization. In order for a post to be assigned to informational support, the post had to ask or give information about a specific topic dealing with COPD.

Table 4.3

Posts from Facebook Participants

Topics	Posts
	Socialization
Weather	• “Ugh.... I think I should become the new weather person. I can feel a storm coming in before they announce it.” • “Good morning warriors. I'm in my shorts. It's going to be weather where you wanna enjoy every ray of sunlight.”
Welcome	• “Welcome from Ohio.” • “Welcome from Tennessee.” • “Welcome” • “Wow. Even just the welcomes are helping us feel less isolated in this!”
Pets	• “”A bit of fun for a Sat if admin allows, let's see each other's pets, here's mine Katie.” • “Aww how sweet. I know most of us in here have pets and I still work and this just made me a little sad but it is still cute.”
Grandchildren	• “Had a wonderful time at my youngest grandchild. Granddaughter's Graduation.” • “I have great news I’d like to share. I have a new granddaughter, born this morning. She is my first paternal granddaughter. She looks just like her older (will be 2 next month) brother when he was born (pictured in the phone.) he turned out to be so cute, just like his mother and older half-sister.”
Holidays	• “Easter Happy Hour Humor” • “Happy Easter When the Easter Bunny comes to town..........WOOF!!”
Witticisms	• “A little boy got on the bus, sat next to a man reading a book, and noticed that the man had his collar on backwards. The little boy asked the man why he was wearing his collar backwards. The man, who was a priest, said, 'I am a Father...' The little boy replied, 'My Daddy doesn't wear his collar like that.'... The priest looked up from his book and answered, ''I am the Father of many.' The boy said, ''My Dad has 4 boys, 4 girls and two grandchildren and he doesn't wear his collar that way!' The priest, getting impatient, said. 'I am the Father of hundreds', and went back to reading his book. The little boy sat quietly thinking for a while, then leaned over and said, “Maybe you should wear a condom, and put your pants on backwards instead of your collar."

(table continues)

Topics	Posts
	• “The first time my son was on a bike with training wheels, I shouted, ‘Step back on the pedals and the bike will brake!’ He nodded but still rode straight into a bush. ‘Why didn't you push back on the pedals?’ I asked, helping him up. ‘You said if I did, the bike would break.’"
	Informational Support
Medication	• “He gave me samples of Bevespi Aerosphere to try instead. Has anyone tried this daily inhaler? Also, do you rinse your mouth out after using it. There was no mention of rinsing in the directions???” • “Ok I have used Albuterol, but my heart does his thing afterwards like it’s doing back flips and fast! Do any of you have this happen?”
Anxiety/Depression	• “What do you do when insomnia has a hold on you and all that’s runnin thru your mind is that soon you won’t be around to complain any more or how long this disease is gonna let u stick around???” • “For those with anxiety issues!” (linked out to goodhousekeeping.com)
Education	• “FRIENDLY REMINDER 1. Remember to take your medications this morning. 2. Try to stay hydrated best you can. 3. Pace yourself, slow wins the race with our disease. 4. Practice your pursed-lip breathing 5. Exercise best you can. 6. REST WHEN YOU GET TIRED. 7. Have a nice day and breathe easy my friend. “ • “My granddaughter’s grandmom told me to try this for my husband. Has anyone used it and did it work.”
Symptoms	• “Does anyone have involuntary deep breaths inward they are happening to me all day long now. Was wondering if anyone knows why?” • “My throat is sore should I call doctor immediately? I just started feeling better...I don’t want to get sick again”
Diet/Food	• “Still hanging on to those Easter leftovers? You may want to consider tossing or freezing today. Leftovers are only safe for 4 days in the fridge but can also be frozen for up to 3 months! Plan accordingly.” • “I posted on here about a week ago about how pineapple juice helps with mucus. And there was alot of comments that it works so I went out and got a can of it to find out. I will update you on this in a week to let ya all know how it went.”
Exacerbation (flair up)	• “So, I had a crazy night and morning in the hospital. My heart rate jumped to 170 last night. I had just had a breathing treatment. They took me to ICU immediately.” • “I'm pretty new to this COPD thing. How do I know I'm having a flair up? I'm been feeling some discomfort in my throat and chest for a couple days. My 02 levels are good, I'm not sure if I need to go to the ER or is it my anxieties going haywire because I'm scared.”

(table continues)

Topics	Posts
	Emotional Support Posts
Prayer	• “My daughter is not doing too good, we are probably going back to Duke in the morning, she's tired, scared and giving up, please keep her in your prayers that she can make it until she can get a transplant. Thank you and God bless.” • “So I just left the hospital my sister got admitted they said she has fluid on her lungs explains why she can't breath and there checking her heart and running more test on he overnight...I am asking for prayers for her.”
Quotes of inspiration	• “Hope your day was filled with smiles. May you have a rejuvenating rest with pleasant dreams.” • “Thanks again to a nice bunch of people who have given me great tips, and, encouragement.”
Health issues	• “Good morning my special friends Hope you are all well have a great day take care of your self and breathe easy my friends love and hugs to you from me One of the most beautiful things we can do is to help one another. Kindness doesn’t cost a thing.” • “Have a blessed day. Breathe easy my friends.”
“Vent”	• “…I'm talking about now I'm questioning everything I know about death. I'm making my self worse. I'm sorry this long. I needed to vent. I have no famliy just my daughter.” • “I need to vent. My honeys aunt came up to visit and at the end of the visit my honeys brother called and the aunt and his brother set up to go out for dinner. Did they ask me if I wanted to go out for dinner or need anything…”

For emotional support, posts would include words of encouragement. And lastly for socialization, posts would include questions of comments about everyday events, pictures of grandchildren/children, etc. Table 4.3 gives examples of each category of socialization, emotional support, and informational support.

Commonly occurring keywords were identified to understand the knowledge gaps/information needs of the participants. Twenty-seven keywords were identified, and posts were coded accordingly. Keywords are shown in Table 4.4.

Table 4.4

Twenty-Seven Keywords

- Oxygen
- Concentrators/portable oxygen
- Stem Cell
- Relaxation/sleep
- Breathing/irritants
- Doctors/second opinion
- Clinical studies
- Education/support groups
- Sexual activity
- Medication
- Insurance/Medicaid
- Pulmonary rehab
- PEEP/CPAP/BiPAP
- Lung Transplant
- Diet
- Legislation/advocacy
- Respiratory treatments
- Privacy
- Exercise
- Travel
- Exacerbations
- Weather/humidity
- PFTs/oxygen saturation
- Blood pressure
- Action plan
- Anxiety/depression
- Smoking

Due to the overwhelming number of recommended information sources and specific information needs, we developed a systematic method to categorize sources. If a source was recommended three times or more, a new category was created, and a codebook was generated. This codebook proved to have 95% accuracy when an independent coder checked randomly selected rows and was compared with codes that were previously coded. Sources that were exchanged within the posts were hand-coded into five types: personal experiences, websites, doctors, professional organizations, and books.

Furthermore, Internet resources were analyzed for credibility and clinical reliability using the previously validated NIH guidelines (NIH.gov, 2018). Table 4.5 refers to the recommended categories addressed by the NIH. Each website was evaluated using each question posited in the NIH criteria.

Table 4.5

NIH Recommended Guidelines for Evaluating Websites

Who runs/pays or created the site or app? Can you trust them?
Can you communicate with the owner of the Web site?
What is the site or app promising or offering? Do its claims seem too good to be true?
When was its information written or reviewed? Is it up to date?
Where does the information come from? Is it based on scientific research?
Why does the site or app exist? Is it selling something?
Is the information reviewed by experts?
What's the site's policy about linking to other sites?
How does the site collect and handle personal information? Is the site secure?

All de-identified participant information was compiled in Microsoft Excel. Both Excel and SPSS were used to organize and identify the users' health information needs, knowledge gaps, keywords, themes, and preferred information resources, and to ensure that users accessed clinically reliable and credible information about medication, disease management techniques, and therapeutic interventions. We also sought to understand how users assessed whether the information that they are relying on to make important health decisions was coming from a reliable and credible health information source.

4.2.4 Results

4.2.4.1 Health Information Needs

Univariate analysis showed that within the 4910 posts from April 2019 to June 2019, there were 775 authors. The number of posts per participant ranged from one to 526 posts, with the average number of posts being 6.33 posts per author. The second-highest number of posts per author was 284, followed by 273, 266, and 253 posts (top 5 participants). Nearly fifty-five percent (54.2%) of the authors posted only one comment in the activity feed, 17.4% posted two comments, and together these accounted for 71.6% of the posts.

Data was collected for 77 days, between April 13, 2019, to June 29, 2019. The average number of posts each day was 64.

The posts were categorized into information support, social support, and socialization. 56% of participants posted information classified as socialization. Information support had the second-highest number of posts (22%), and social support came in close to information support at 22% of the posts.

The majority of topics posted were not related to COPD and its management but were instead classified as socialization. Instead, posts classified as socialization referenced pets, children, grandchildren, “what’s for dinner,” fun facts, songs, pictures of nature, and welcomed new members. The top eleven COPD related postings pertained to medication (266), anxiety/depression (256), education (194), symptoms (175), diet (174), exacerbations (173), pulmonary function tests (PFTs) (110), smoking (110), therapy (98), weather (93), and oxygen (89).

4.2.4.2 Health Information Sources and the Clinical Reliability and Credibility of the Information Exchanged

Sources exchanged within the Facebook group included personal experiences (73%), websites (21%), doctor (5%), professional organizations (2%), and a book only once. Websites given included .com (79.89%), .net (6,35%), .gov (6.35%), .org (5.82%), .CA (website from Canada) (1.06%), and .co (0.053%). The .co is a fairly new domain that is often used for many online businesses.

Of the 151 .com websites, 63 (41.45%) websites were given as an informational resource such as rumble.com (video licensing platform), healthyfoodhouse.com (an information portal), and clark.com (practical advice to help people save money). Fifty-four (35.53%) websites were exchanged, giving news headlines via major news stations such as CBS, CNN, and Fox. Nineteen of the 151 .com websites (12.50%) incorporated YouTube videos, 6 (3.95%) websites referred to Facebook, and also to retail sites (such as Amazon and Etsy), and four websites referenced Instagram pictures.

NIH guidelines (NIH.gov, 2018)were utilized to evaluate whether the websites exchanged between participants were clinically reliable and credible (see Table 4.5). Each website exchanged was evaluated using these NIH guidelines and based on the criteria that were found to be either credible and clinically reliable or of questionable credibility and clinical reliable. Of the 63 websites given as informational resources. 26 (41%) websites were found to be of questionable clinical reliability. This assessment was based on the websites having no information about contributing authors, no references or citation information, no review board, the site was dedicated to selling services or products but fronted as an information site, or, the site presented itself as an information source yet on closer inspection of the “About Us” page, the site assumes no responsibility for errors or “consequential damages” resulting from using the information posted there.

Multivariate analysis indicated that nine authors posted over 100 posts. Socialization was the most substantial by the top nine authors, followed by diet/food, education, shortness of breath (SOB), and medication (Table 4.6).

Table 4.6

Top Authors' Topics of Discussion

Author	# of posts	Topics
A	526	Socialization (83%), Education (5%), Diet/Food (4%)
B	284	Socialization (93%), Diet/Food (3%), Weather (2%)
C	273	Socialization (74%), Education (8%), Diet/Food (5%)
D	266	Socialization (87%), Diet/Food (3%), Weather (2%)
E	253	Socialization (78%), Diet/Food (19%), Weather (2%)
F	229	Socialization (94%), Diet/Food (2%), Medication (1%)
G	160	Socialization (100%)
H	142	Socialization (8%), Education (42%), SOB (9%)
I	108	Socialization (91%), Diet/Food (2%)

4.2.5 Discussion

4.2.5.1 Health Information Needs

While using Writewords, a word frequency program, (Bruce, Reynolds, & Brown, 2020)in addition to the topics that were previously mentioned frequently, the word “husband” was also mentioned often. We determined that more women search for information for their husbands than husbands search for information for their wives. This is an area that is worthy of further investigation.

Data analysis revealed that posts were generated for informational support, emotional support, and socialization. Of these three categories, most posts were made purely for socialization. Socialization appeared in the form of posting information about the weather, welcome posts, pictures of user's pets and grandchildren, holidays, and witticisms. Emotional support and informational support were found to be equally represented. Emotional support was represented with participants asking for prayer from others, by inspirational quotes, requests for information about troublesome health issues, or just being able to "vent" about their current situations related to their health condition or concerns about family members. Finally, information support deals with direct or indirect answers to specific questions or health information needs.

4.2.5.2 Health Information Sources and Clinical Reliability of the Health Information Exchanged

The majority of posts (77%) concerning information support were based on users' personal experiences. This meant there were no other references for the information given, such as doctor or website. Some of the examples were "I am only stage two, but it has changed my life. Having to slow down is the worst. Wellbutrin has helped a lot" and "-I was like you no relief from inhalers & I take 5mg prednisone daily & new inhaler maintenance treatment Trimbow brilliant better relief (ask for it) & Solomol best wishes to you, 5 mg twice a day." At times posts were of questionable clinical accuracy. Example: "You can blow holes in your lungs by trying to do that." There was also mention of a shot to help with COPD. As a registered respiratory therapist researching about an injection to help with COPD, none were identified. The only shot given to help with COPD is an injectable steroid. There was a clinical trial for

Mepolizumab, but there was no difference in the placebo group and the patients placed on the medicine (Pavord et al., 2017). This was also verified with a Registered Pharmacist. Other participants in the group also questioned this comment. Unlike a clinically moderated group, this non-moderated group's participants will challenge each other's posts if there is a perception that the information given is not accurate.

Websites were also referenced as information resources (18%). Of the 189 websites mentioned, 151 were .com websites. Of these .com references, 41% were evaluated using the NIH guidelines and found to have questionable credibility and clinical reliability. The determinations of questionable credibility and clinical reliability were due to the sites' lack of citations for the information posted, lack of an established review panel, and fronting as an informational site when in truth, they were only selling products or services. NIH guidelines warn against sites that do not base their information on scientific research and are not reviewed by experts. This should be of concern to all users, and the NIH guidelines should be posted in the group to educate users on selectively relying on information posted on the site. The Facebook group does warn against posting any medical advice. There were also references to .gov (6.35%), .org (5.82%), .net (6.35%), .co (0.53%), and .CA (only mentioned once). A .gov is the United States government's official web portal in which the domain must meet strict eligibility criteria and can be considered a credible source of information of all types. Examples of the .gov sources are the Centers for Disease Control and Prevention (CDC.gov), United States Department of Agriculture, Food Safety, and Inspection Service (FSIS.USDA.gov) and National Center for Biotechnology Information, a division of the National Library of Medicine at the National Institutes of Health (ncbi.nlm.nih.gov). The .org is a domain name for miscellaneous organizations that include non-profits, open-source projects, and personal sites that are generally non-commercial entities. Any individual can purchase these sites, and these sites may contain inaccurate or clinically inappropriate information. The American Lung Association (27%) was the most exchanged .org and was found to be clinically reliable as they have scientists, healthcare, and policy professionals on their boards that recommend topics relating to lung health. Another of the .orgs listed was eurekalert.org (18%), which releases information that is produced by universities, journal publishers, medical centers, government agencies, corporations, and other organizations that are engaged in scientific research (https://www.eurekalert.org/aboutus.php). Another .org that was referenced was from ConsumerReports.org (18%), which is also found credible due to the fact the company was launched in 1936, has earned more than 100 awards, and has a mission to create a safe, fair, and transparent marketplace (https://www.consumerreports.org/cro/about-us/what-we-do/index.htm). There were just a few other .org mentions, and, of those, one was found to be more about selling a product than providing information. Another appeared to represent a social security disability website but was an advertisement for an attorney. These are issues that participants need to understand. Another category of domain exchanged within the group was .net domains. These domains also must be critically evaluated for credibility and clinical reliability. COPD.net and asthma.net were the only exchanged entities under the .net domain that were found to be credible and clinically reliable as they rely on only trustworthy sources, peer-reviewed journals, and follow the principles of the “Health on the Net Foundation” (HON) to provide credible health information (https://www.hon.ch/en/). The HON promotes transparent and reliable health information online. It is a not for profit organization that has ties to the World Health Organization and is the oldest and most regarded sign for quality information since 1996 (HON, 2019). Lastly, .CA and .co were referenced. .co is a fairly new domain and has no restriction on who can register, so it is imperative to check for credibility and clinical reliability. The .co domain that was referenced provides “social news” and any information obtained should be evaluated for credibility. The .CA was evaluated and determined credible and clinically reliable as it was a Canadian agency established under the Conservation Authorities Act of Ontario in 1947 (https://www.nation.on.ca/about/about-snc).

Doctors are referenced 5% of the time in online exchanges, and professional organizations were referenced only 1% of the time. Only once was a book was mentioned. One author posted a large amount of information on the disease in general and was clinically accurate but provided no citations for the information posted.

4.2.6 Contributions

This study offers several contributions. First, this study has a large and highly engaged user population of COPD patients that are globally dispersed. There are 4800 posts from 775 authors, with an average daily number of posts at 64 posts per day (with 43.3 active daily authors). Study data came from a closed COPD group where participants were screened for acceptance by a group administrator. Participants were asked if they had COPD or were a caregiver of a person with COPD. This verification adds credibility to the study. We verified that participants sought emotional support, engaged in the available socialization, and exchanged information that helped them to manage their illnesses more effectively. Just over 4800 posts were analysed. The top five health information needs identified concerned medication, anxiety/depression, education topics on COPD, and COPD symptoms. Affordance theory allows researchers to understand the connection, exploration, narration, and self-presentation of participants' interactions in online health communities specific to COPD. This understanding will assist healthcare professionals in providing the information and support needed by COPD patients at their time of need. Having an online community of people in the same situation, like this closed non-monitored Facebook support group, can improve the quality of life for chronically ill patients. These communities provide an understanding and knowledgeable community of those facing the same illness. They can also reduce the embarrassment felt by some users, such as being seen in public with portable oxygen.

4.2.7 Limitations

Since posts are self-reported experiences and recommendations, their accuracy cannot be verified. In addition, we were unable to collect demographic information on the participants. Both of these limitations make it impossible to generalize this study to other online health support group populations. Finally, this study focuses on only one Facebook group and reflects only the experiences of those participants that have a computer and are comfortable, and with exchanging personal health information online.

4.2.8 Future Research

Future research should focus not only on other COPD support groups but on a variety of different disease-specific closed and publicly available online health communities. It would also be beneficial to explore the role of gender in online health communities. For comparison, future research can focus on face to face disease-specific support groups and compare the information exchanged and user satisfaction between those and online groups.

4.2.9 Conclusion

This study investigated a closed, non-monitored Facebook group to understand what participants pursue in an online health information forum, what their information needs are, what health information sources they favor, and how clinically reliable the health information exchanged within the forum is. This study is the first to analyze a closed and non-monitored COPD Facebook group's user information needs, information resources exchanged, and the credibility of the resources that were exchanged within the group. This study found that the majority of health information exchanged came from the patients' own experiences. Also referenced were websites, recommendations to see their doctor or pulmonologist, to check out other professional organizations, and one book. Many of the websites given were news outlets and YouTube videos. Retail sites were also promoted. Instagram was a source used to exchange photos. Unfortunately, many websites were evaluated as having questionable clinical reliability due to a lack of citations for website authors or other references. As they took no responsibility for the information given within the website. Healthcare professionals must be aware of these kinds of sites and promote these sites to their patients as sources of socialization only, and not for the medical information provided there.

4.3 Essay 3: A Proposed Model of Information Seeking Effectiveness in COPD Facebook Groups

4.3.1 Introduction

A recent Pew Research study (Fox, 2014) found that 72% of adult Internet users have searched for health information online. This number grew to 80% in 2018, according to the MARS Consumer Health Study (Healthcare Client Services, 2018). A report by Health Union, a company that manages 19 condition-specific online health communities, showed that 70% of 2200 people with a serious health condition use condition specific websites, and 59% of the 2200 individuals used Facebook to meet their health information needs (Lawhon, 2016). This same study revealed that 98% of the respondents read health related information or watched a health video online in the past six months, and 48% of them indicated that they shared health related information online with others. Lastly, the Health Union study revealed that 97% of these respondents used the information they gathered online to speak with their healthcare professionals, and 73% stated that this information had at least some impact on their health-related decision making (Lawhon, 2016).

Since its launch in 2004, Facebook has seen enormous growth as seen in a recent report (Aboulhosn, 2020), Facebook experiences nearly 2.45 billion active users each month and an estimated 1.62 billion daily users. The growth of Facebook as well as Web 2.0 has generated a new type of information seeking behavior, including disease-specific inquiries. Facebook groups facilitate the exchange of information as well as offer support to those with chronic illness. This includes such chronic diseases as diabetes, cancer, and many lung diseases, including chronic obstructive pulmonary disease (COPD). Through Facebook, participants can share phots, discuss symptoms, pose questions that are disease-specific, and connect with others that have the same disease and are experiencing the same emotions. The main purpose of this study is to examine information seeking effectiveness by using partial least squares-structural equation modeling (PLS-SEM). This study proposes a theoretical framework based on theories of the health belief model, social exchange theory, affordance theory, and technology acceptance model.

4.3.2 Literature Review

4.3.2.1 Chronic Obstructive Pulmonary Disease (COPD)

COPD refers to a progressive pulmonary disease that affects airway passages by increased mucous productions or inflammation with in the airway itself, (Global Initiative for Chronic Obstructive Lung Disease Incorporated, 2019). This disease includes chronic bronchitis and emphysema. Although this disease is uncurable, individuals can stay active and slow the progression of the disease with proper care and treatment. Patients with COPD experience shortness of breath, wheezing, tightness in the chest, constant coughing, and are more susceptible to frequent colds and the flu(Morrison, Mair, Yardley, Kirby, & Thomas, 2017). Worldwide, COPD affects 65 million people and 3 million die from this disease each year (COPD Gold, 2019). COPD is an umbrella term meaning there are many diseases that are considered to be COPD. Two of the main diseases are emphysema and chronic bronchitis.

4.3.2.2 Online Health Communities

The birth of the internet had a significant impact on health information-seeking behaviors(Cline & Haynes, 2001). Patients are now able to interact with others in online platforms, social networks, and blogs with the ability to exchange information in texts and videos (Sarasohn, 2008). Traditional means of physician-patient communication are changing, and with OHCs, patients are now able to take an active part in their healthcare (Lu & Zhang, 2019).

The research found that adults from the ages of 50 -64, 88% use the Internet, while for those over 65, drops to 73% (Pew Research Center, 2019). A study by Health Union, a company that manages 19 disease-specific online health communities, indicated that 70% of individuals with a severe health condition use a disease-specific OHC, and 59% of those individuals use Facebook as their primary source for health information (Lawhon, 2016).

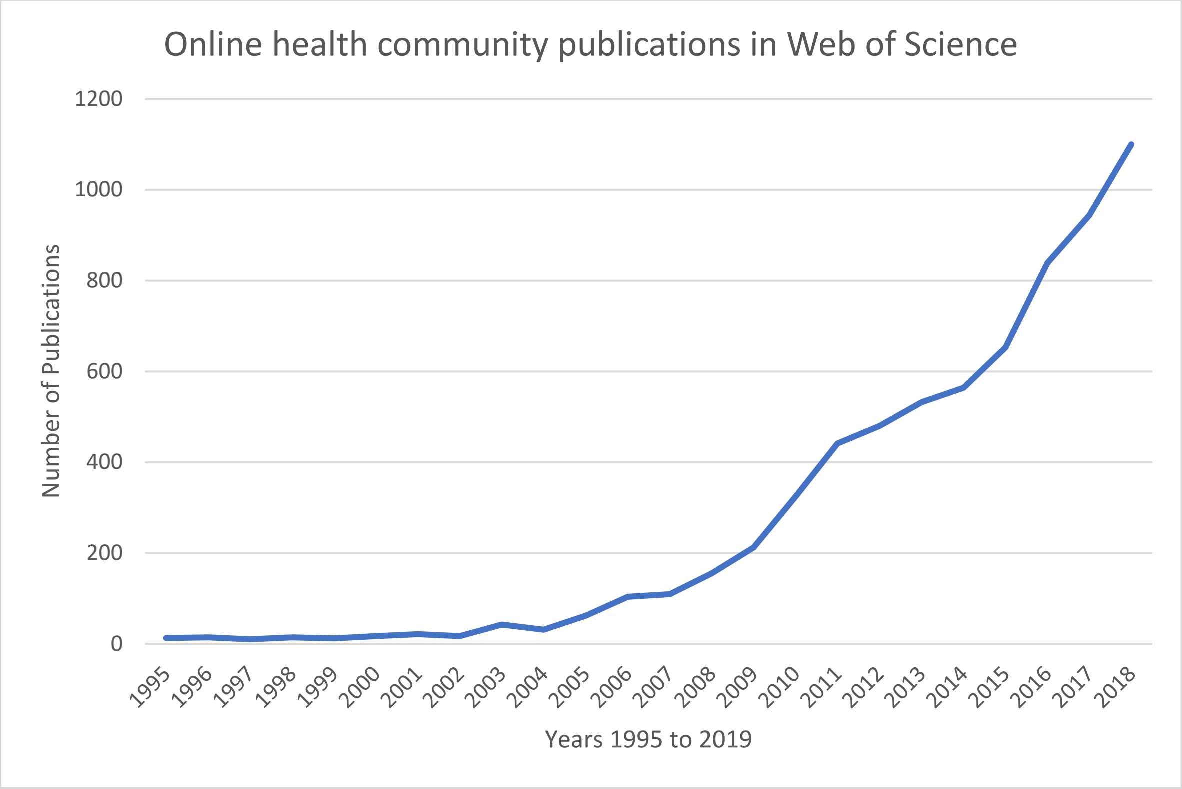

Figure 4.6. Publications in Web of Science from 1995 to 2015 with keyword search "online health communities."

Online health communities (OHCs) have gained momentum in many disciplines of research (see Figure 4.6)(Web of Science, 2019a). A search in Web of Sciences indicates 7,488 records are using a search of the keywords “online health communities.” Disciplines with research on this topic include behavioral sciences, psychology, sociology, public environmental, occupational health, computer science, and educational research(Web of Science, 2019b). Online health communities bring together globally diverse groups that have a strong focus on similar interests, activities, or identities withing the group(Preece, 1999). This type of online platform allows participants to interact and communicate with others within the community.

Perceived benefits have been researched and have found to provide patients a safe environment to gain disease information, information on alternative treatments and medications, disease management techniques, and in the long run, lead to beneficial health outcomes (Johnston et al., 2013a). Some of the positive health outcomes include higher self-esteem, improved self-efficacy, psychological benefits, greater control in their medical management, improved social well- being, and improved quality of life (Mo & Coulson, 2012; Petric, 2014; Swan, 2009; Uden-kraan et al., 2008). These communities have also proven to help individuals to make informed health decisions (Sarasohn-Kahn, 2008).

4.3.2.3 Theoretical Foundation, Research Hypotheses, and Proposed Model

- *Demographics*

It is believed that demography dates back to the seventeenth century (Bijak, Courgeau, Franck, & Silverman, 2018). The demographics of the population in this study are age, marital status, education level, and household income.

H_{a1}: There is a correlation between user demographics and emotional support.

H_{a2}: There is a correlation between user demographics and reputation.

H_{a3}: There is a correlation between user demographics and self-worth.

- *Social exchange theory*

Social exchange theory's (SET) roots originate in the 1920s. This theory seeks to explain the social relations between two (or more) parties. Within these interactions individuals, exchange goods, either material or non-material. Continuous effort is generated to create a balance between cost and reward (Homans, 1958). Many disciplines, including information technology, consumer behavior, and the behavior of participants within an online community, have utilized SET to explain human behavior (Yan et al., 2016). Research by Yan, Wang, Chen, & Zhang (2016) Identify knowledge sharing as a type of exchange behavior where both benefits and costs can be balanced equally.

Benefits are the positive portion of the interaction. Benefits include informational needs, increased personal reputation, provision of social support, gratifying the sense of self-worth, and increased personal reputation. Information need is a question that needs an answer. Participating in an online health community is a tool that patients use to get questions answered in a timely and efficient manner (Hwang & Fogoros, 2018). Social support is also intended to be a positive exchange that enhances the welfare of the participant and allows participants to interact with others that have similar diseases. Social support includes, but not limited to, socialization, emotional support, and companionship (X. Wang et al., 2017). Sense of self-worth captures the extent to which an individual sees themselves as providing value through their knowledge sharing (Bock et al., 2005). Lastly, reputation refers to a person's perception of earning the respect of other participants in the group (Yan et al., 2016).

The costs are the negatives in the interaction and can include cognitive or executional costs of taking action. These negatives diminish the social exchange within the OHC. In SET, as it relates to online health communities, costs present themselves in both executional and cognitive forms. Executional costs include resources like time, materials, and possibly money. Cognitive costs are the process of the participant retrieving information by memory. By retrieving information in the past, feelings such as irritation, panic, or depression could be reimagined by the participant (Yan et al., 2016). The constructs being implemented from this theory are emotional support, reputation, and sense of self-worth.

(i) *Emotional support*

Emotional support is obtained in online health communities by helping participants reduce feelings of anxiousness, receiving social support, and receiving comfort and care. This is the bases of the following hypotheses:

H_{a4}: There is a correlation between user emotional support and perceived disease severity.

H_{a5}: There is a correlation between user emotional support and perceived benefits.

H_{a6}: There is a correlation between user emotional support and perceived barriers.

H_{a7}: There is a correlation between user emotional support and usefulness.

H_{a8}: There is a correlation between user emotional support and perceived ease of use.

(ii) *Reputation*

Reputation refers to a participant’s perception of the potential to earn respect or elevate one’s social status by participating in the Facebook group. Participants build their reputation by sharing their expertise on disease-specific information sharing. We, therefore, propose that if a participant believes they have a good reputation within the group, there will be enhanced knowledge sharing within the Facebook group (Yan et al., 2016). Thus, we propose:

H_{a9}: There is a correlation between user reputation and perceived disease severity.

H_{a10}: There is a correlation between user reputation and perceived benefits.

H_{a11}: There is a correlation between user reputation and perceived barriers.

H_{a12}: There is a correlation between user reputation and perceived usefulness.

H_{a13}: There is a correlation between user reputation and perceived ease of use.

(iii) Sense of self-worth

Sense of self-worth describes the extent to which participants see themselves providing value to the online community by sharing their knowledge with the community. Participants come to realize through sharing information they feel more confident in their standing within the Facebook group, therefore, their involvement in the online community improves(Yan et al., 2016). Here we propose the following hypotheses:

H_{a14}: There is a correlation between user self-worth and perceived disease severity.

H_{a15}: There is a correlation between user self-worth and perceived benefits.

H_{a16}: There is a correlation between user self-worth and perceived barriers.

H_{a17}: There is a correlation between user self-worth and perceived usefulness.

H_{a18}: There is a correlation between user self-worth and perceived ease of use.

- *Health belief model*

G.M. Hochbaum developed the health belief model (HBM) in 1958 to study the uptake of Tuberculosis screening (Hochbaum, 1958). Rosenstock later expanded the model to understand why people did not participate in public health programs provided by the Public Health Service between the 1950s and 1960 (Rosenstock, 1974). At the time, it was evident that the public was unwilling to accept disease preventatives and screening tests for early detection of diseases such as Tuberculosis (TB), cervical cancer, polio, and dental disease (Rosenstock, 1974). Rosenstock based his HBM on Lewin's (1951) idea of 'valence' which refers to forces that pull an individual toward a desirable object and not toward an undesirable object. Rosenstock posits for an individual to take action to avoid an undesirable object (disease), he would first need to believe that he was susceptible to the disease and that some section of his life would suffer from some severity. Furthermore, the individual would trust that taking a disease prevention or screening would create a positive outcome and that this action would not have any perceived barriers such as embarrassment, inconvenience, pain, or cost (Rosenstock, 1974). According to Rosenstock, individual's subjectively weigh of balance between perceived costs and benefits of the recommended action (Abraham & Sheeran, 2015). The constructs being implemented from this theory are perceived severity, perceived benefits, and perceived barriers.

(i) *Perceived severity*

Perceived severity is a participants' beliefs about the seriousness and magnitude of threat brought on by their disease. The participants may also be concerned with the effects of the disease such as physical deterioration (Rosenstock, 1974). We propose:

> H_{a19}: There is a correlation between perceived disease severity and health information seeking effectiveness.

(ii) *Perceived benefits*

Perceived benefits are the users' perception that a particular course of action will be effective in reducing the threats of a disease. Rosenstock (1974) states perceived benefits can also be influenced by the "norms and pressures of his social group (p.331). We therefore propose:

> H_{a20}: There is a correlation between perceived benefits and health information seeking effectiveness.

(iii) *Perceived barriers*

Perceived barriers are ideas that a course of action in itself is inconvenient, hard or not useful in managing their disease. Rosenstock (1974) asserts that in order for an action to be followed through the barriers (negative) must be far less than the benefit (positive). If the negative has a higher value than the positive outcome, the participant will believe the action to be highly unpleasant and will not find participation to be beneficial.

$H_{a21:}$ There is a correlation between perceived barriers and health information-seeking effectiveness.

- *Technology acceptance model*

In the field of information systems, Davis created the technology acceptance model (TAM) (to understand how individuals use and accept new technologies Davis, 1989). To understand these relationships, TAM calculates participants' behavior through perceptions of usefulness, ease of use, and subsequent system adoption (Lazard et al., 2016). An online community is a peer-to-peer technology that brings together patients, caregivers, and healthcare providers through the internet (Hodgkin et al., 2018). Using the TAM framework, research showed that perceived usefulness, perceived ease of use, and attitude positively influence behavioral intention to use the technology (Lim et al., 2011; Wong, Yeung, Ho, Tse, & Lam, 2014). Having a positive attitude toward technology, good technological infrastructure, and a user-friendly interface is likely to enhance the likelihood of adoption and usage of the online resource. TAM is be used to view user behavior related to exchanges within online health communities from the technology perspective, which in this study is driven by OHC. (Ahadzadeh, De, Sharif, De, & Ong, 2015). The constructs that are implemented from this model are perceived usefulness and perceived ease of Internet use.

(i) *Perceived usefulness*

Perceived usefulness is the degree to which a person believes that a particular system (online health community) will enhance their quality of life(Davis, 1989b). A system

(OHC) must enhance or benefit the users. In turn, this would affect the degree in which users participate in the Facebook group.

H_{a22}: There is a correlation between perceived usefulness and health information-seeking effectiveness.

(ii) *Perceived ease of internet use (PEIU)*

Lastly, perceived ease of (Internet) use is the degree to which a person believes that using a particular system (online health community) would be free of effort (Ahadzadeh et al., 2015). We therefore hypothesize:

H_{a23}: There is a correlation between perceived ease of use and health information-seeking effectiveness.

4.3.2.4 Proposed Research Model

Using the health belief model (Rosenstock, 1974), social exchange theory (Homans, 1958), and TAM (Davis, 1989), Figure 4.7 shows the model proposed as a framework for this study.

The dependent variable in this model is information seeking effectiveness. Information seeking effectiveness is the support provided to patients diagnosed with a disease, including social and emotional support and information related to accuracy, therapies, rehab, and other services (Gustafson & Sheikhm, 1999; Nambisan, 2011). Recent studies show that informational support and health information seeking in online communities affect the online participants' decision making and their active participation in their healthcare (Nambisan, 2011).

More and more health-related websites are available to provide patients with answers to medical questions and to help them manage their own health. This is a shift from sole reliance on physicians to greater personal access to medical information and improved personal health management.

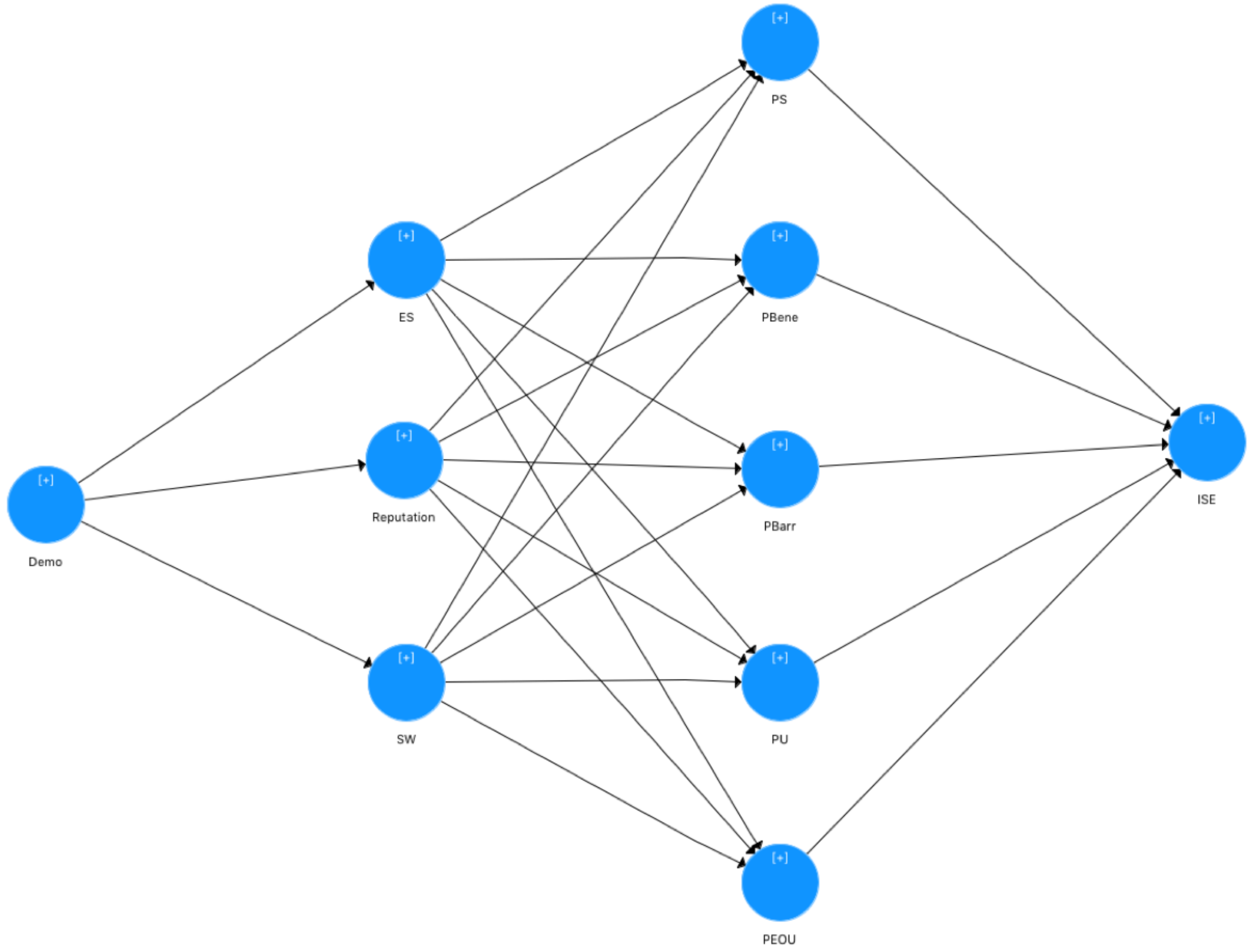

Figure 4.7. Proposed research model.

Today, there is greater acceptance of the patient as no longer a passive information recipient (Gerber & Eiser, 2001). Patients are now encouraged to be active participants in their own health care. The Internet offers patients new access to medical information and the greatest impact on medical decision-making may come from the increase in access to medical information prior to the physician-patient encounter. It is important, as researchers, to gain more knowledge in the area of health information exchange, particularly in peer to peer health exchanges (Gerber & Eiser, 2001). Information obtained by the patient must be accurate, timely, and medically appropriate in order to positively effect patient health outcomes, and this is key to quality healthcare (Cleveland & Cleveland, 2009).

4.3.3 Research Method

4.3.3.1 Research Design

This research will identify the relationships between the types of disease-specific information sought by COPD Facebook members and their success in getting accurate and reliable health information to use in their decision-making process as they work to manage their diseases. A survey was designed to evaluate the proposed online health community model for COPD patients. Social exchange theory, health belief model, and the technology acceptance model (TAM) will provide the theoretical foundation for a model specific to COPD patients.

This survey will be the primary tool for data collection for this study. Surveys have historically collected data from large populations. Surveys obtain information about user demographics, personal characteristics, and consumer feedback (Ponto, 2015). A survey is deemed appropriate for this research because surveys are cost-effective, have the potential to be generalizable, and tend to be a reliable method of inquiry (Blackstone, 2012). We can also survey a targeted group of COPD Facebook users.

The purpose of this paper is to develop and test the proposed model on information seeking effectiveness of participant in COPD Facebook groups.

4.3.3.2 Survey Instrument Development

As indicated in the above-proposed constructs, a 30-item questionnaire (see Appendix

B) was developed to collect data to measure the relationships in the proposed model to compare results between COPD Facebook groups. A 5-point Likert scale (5 = *strongly agree*, 4 = *somewhat agree*, 3 = *neither agree nor disagree*, 2 = *somewhat disagree*, and 1 = *strongly disagree*) was selected to measure the for all constructs but the demographic questions. The Likert scale is a widely accepted scale to measure participants' degree of agreement or disagreement and has been in use since 1932 (Likert.R, 1932). The survey will be entered into Qualtrics.

Qualtrics is an Internet-based survey vehicle that has over 20 offices on five continents. Founded in 2002, Qualtrics was acquired by SAP in 2019 for $8 billion (Qualtrics, 2020). Qualtrics uses a simple platform that even a novice can navigate. Qualtrics allows custom surveys to be created and distributed to participants electronically via a link place in the online community.

Benefits of an online survey such as this are the ability to access a large population, saving time and money, and the ability to present survey information in a dynamic and interactive form (Schmidt, 1997).

The Qualtrics questionnaire was pilot tested for face validity by a panel of PhD research students with knowledge of online communities and three faculty members with experience in health communication to ensure clarity before the actual study. Panel recommendations were received and implemented to improve the clarity and detail of the data being collected. Panel participants also determined the minimum amount of time required to thoughtfully complete the questionnaire, generally between five and ten minutes. All data from the study will be secured for a minimum of three years in the university office of the primary investigator (PI), in a locked drawer, for a minimum of three years. Tables 4.7 and 4.8 give information on each construct, code, and questions used in the survey. Table 4.7 contains information about the demographic section of the survey. Four questions relate to demographics. Table 4.8 is an exhaustive list of each construct and the source information, as well as the original and modified questions used in the survey. Each independent variable (construct) has three questions, and the dependent variable, information seeking effectiveness (ISE), has five questions.

Table 4.7

Demographic Questions in the Survey

Question	Response
What is your age?	< 30 31 - 54 55 – 64 65 – 74 > 75
What is your gender?	Female Male Other
What is your marital status?	Single Married Divorced Widowed
What is your income?	< $49,999 $50,000 - $99,999 > $100,000

After this implementation of the suggested modifications to the survey, a minimal review application was submitted to the University of North Texas Institutional Review Board. In addition to the survey questions, a recruitment script, and informed consent were also sent for IRB approval. Approval was received by the University of North Texas IRB.

Table 4.8

Constructs with Source and Questions in the Facebook Survey

Source	Original	Modified
	Emotional Support (Code = ES)	
(Yan et al., 2016)	Through knowledge sharing in online health communities, I pour out my troubles and feel relaxed.	By sharing knowledge in this forum, I pour out my troubles and feel relaxed.
(Yan et al., 2016)	Through knowledge sharing in online health communities, I get some understanding, help or supports from other participants in the community	By sharing knowledge in this forum, I get some understanding, help, or support from other participants in the community.
(Yan et al., 2016)	Through knowledge sharing in online health communities, I get comfort and care from other participants in the community.	By sharing knowledge in this forum, I get comfort and care from other participants in the community.
	Reputation (Code = Rep)	
(Yan et al., 2016)	Sharing knowledge can enhance my reputation in the online health community.	Sharing knowledge enhances my reputation in this forum.
(Yan et al., 2016)	I get praises from others by sharing knowledge in the online health community	I get praises from others by sharing knowledge in this forum.
(Yan et al., 2016)	I feel that knowledge sharing improves my status in the online health community.	Sharing knowledge sharing improves my status in this forum.
	Sense of Self-worth (Code = SW)	
(Yan et al., 2016)	My knowledge sharing would help other members in the online health community solve problems.	Sharing knowledge will help other participants in this forum solve problems.
(Yan et al., 2016)	My knowledge sharing would bring positive influence on other members in the online health community.	Sharing knowledge brings a positive influence on other members in this forum.
(Yan et al., 2016)	My knowledge sharing would bring all my facilities into full play and make me more confident	It is important that members in this forum think positively about me.
	Perceived Severity (Code = PS): Cronbach’s alpha = 0.70	
(Abraham & Sheeran, 2015)	The thought of breast cancer scares me.	The thought of COPD scares me.

(table continues)

Source	Original	Modified
(Abraham & Sheeran, 2015)	Breast cancer is a hopeless disease.	COPD is a hopeless disease.
(Ahadzadeh et al., 2015)	I am afraid of facing attack or deterioration of chronic diseases (.756)	I worry about my physical health deteriorating as my COPD progresses.
	Perceived Benefits (Code = Pbene): Cronbach's alpha = 0.61	
(Abraham & Sheeran, 2015)	I have a lot to gain by doing self-breast exams.	I have a lot to gain by participating in this forum.
Abraham & Sheeran, 2015)	If I do monthly breast exams, I may find a lump before it is discovered by regular health exams. 5	Participating in this forum helps me in controlling my COPD
Abraham & Sheeran, 2015)	I would not be so anxious about breast cancer if I did monthly exams.	I am less anxious about my disease by participated in this forum.
	Perceived Barriers (Code = Pbarr): Cronbach's alpha = 0.76	
(Abraham & Sheeran, 2015)	In order for me to do monthly breast exams, I have to give up quite a bit.	It is convenient for me to participate in this forum.
(Abraham & Sheeran, 2015)	The practice of self-breast exams interferes with my activities.	Participating in this forum does not interfere with my daily routines.
(Yan et al., 2016)	It is laborious to share knowledge in the online health community.	It is easy for me to share knowledge in this forum.
	Perceived Usefulness/Exploration (Code = PU)	
(Ahadzadeh et al., 2015)	Using the Internet is useful in managing my daily health (.873)	Using this forum is useful in managing my COPD.
(Ahadzadeh et al., 2015)	Using the Internet for health information is advantageous in better managing my health (.937)	Using this forum for health information is advantageous in better managing my health.
(Ahadzadeh et al., 2015)	Using the Internet for health information is beneficial to me (.890)	Using this forum for health information about my COPD is beneficial to me.

(table continues)

Source	Original	Modified
	Perceived Ease of Internet Use (Code = PEIU)	
(Ahadzadeh et al., 2015)	My interaction with the Internet for health information is clear and understandable (.857)	My interaction in this forum for health information is understandable.
(Ahadzadeh et al., 2015)	I find the Internet for health information to be flexible to interact with (.880)	It is easy to navigate to find health information in this forum.
(Ahadzadeh et al., 2015)	It is easy for me to become skillful at using the Internet for health information (.878)	It is easy for me to become skillful at using this forum for health information.
	Information Seeking Effectiveness (Code = ISE)	
(Nambisan, 2011)	I obtain information that is readily usable. (.920)	I obtain information that is accurate in this forum.
(Nambisan, 2011)	I obtain information that is credible (.906)	I obtain information that is credible in this forum.
(Nambisan, 2011)	I obtain information that is relevant (.905)	I obtain information that is relevant in this forum.
(Nambisan, 2011)	I obtain information that is reliable (.897)	I obtain information that is reliable in this forum.
(Nambisan, 2011)	I obtain information in a timely manner (.886)	I obtain information in a timely manner in this forum.

4.3.3.3 Determining Sample Size

The sample size was calculated using Hatcher's rule of thumb that requires five responses for each survey item to test the statistical power of the proposed model (Hatcher, 1994). With 30 items in the survey, a minimum of 150 usable responses was needed for the survey to be statistically significant. Announcements were made to willing Facebook groups participants with a link to connect to the survey. There was no compensation for participation in the survey. Participants were able to complete the survey at a convenient time and place. The participants could copy and paste the link provided into their computer's browser. Qualtrics was utilized for the survey. No personally identifiable health information was collected or reported in this study or in any publication that results from this research. The identity of group participants was not captured.

4.3.3.4 Data Collection

The initial post to 23 separate COPD Facebook groups was on October 30, 2019 (Appendix C) . Due to a low response, a second post was made to an additional 16 Facebook groups on January 18th, 2020. Again, there was a low response, so a third post was distributed to 20 of the original groups on April 4th, 2020. One last post was made with the original recruitment script on April 7th, 2020. There were 264 responses collected on April 12, 2020. Microsoft Excel software was utilized to clean data. After cleaning the data and removing incomplete surveys, there were 155 usable surveys. This represents a 58.7% usable response rate. All data were coded using the following method. In the demographics section, age had five levels, gender had three levels, marital status had four levels, and income had three levels.

All other variables were answered with a Likert scale and were coded as 5 = *strongly agree,* 4 = *somewhat agree*, 3 = *neither agree nor disagree*, 2 = *somewhat disagree*, and 1 = *strongly disagree*.

4.3.3.5 Analysis with SmartPLS

SmartPLS (v.3.2.9) was used for structural equation modeling. SmartPLS is a tool to perform multivariate data analysis that is primarily an exploratory type of research (Hair et al., 2017). The hypothesized model was tested based on partial least squares. SmartPLS has proven to be effective when the model is has many constructs, small sample size, nonnormally distributed data, and the goal is theory testing (Hair et al., 2017). PLS-SEM allows both causal relationships among indicators and latent constructs (Hair et al., 2017).

4.3.4 Results

4.3.4.1 Overview of Demographics

The summary of the demographics on the participants is noted in Table 4.9. SPSS was utilized to obtain descriptive statistics. The analysis revealed that 76.8% of the respondents were female, 22.6 % were males, and 0.6% noted “other” for their gender. Of the 155 participants, 0.6% were below the age of 30, 11.0% were between 31 and 54, 44.5% were between 55 and 64, another 34.8% were between 65 and 74. lastly, 9% were over the age of 75. The majority of respondents were married (45.8%), followed by 26.5% were divorced, then 14.2% were single, and lastly, 13.5% were widowed. The last demographic to be recorded was income. The majority of people (71.6%) had less than $49,999 reported income, then $50,000 to $99,999, and then 5.2% reported over $100,000 income.

Table 4.9

*Breakdown of Demographic Data (*N *= 155)*

		n	%
Age	<30	1	0.6
	31 - 54	17	11.0
	55 - 64	69	44.5
	65 - 74	54	34.8
	> 75	14	9.0
Gender	Male	35	22.6
	Female	119	76.8
	Other	1	0.6
Marital Status	Single	22	14.2
	Married	71	45.8
	Divorced	41	26.5
	Widowed	21	13.5
Income	<$49,999	111	71.6
	$50,000 - $99,999	36	23.2
	> $100,000	8	5.2

4.3.4.2 Structural Model

The following analysis was run using SmartPLS v. 3.2.9. Figure 4.8 illustrates the initial model with all constructs. We can see by the p-values, reputation was not significant, except in one construct (PS), and therefore was eliminated from the final model. The model is read from left to right, with each construct on the left being the independent construct(s) to the dependent construct(s) to the right. Thus, the independent construct(s), on the left, predicts the dependent construct(s) to the right. Table 4.10 gives further details of the model illustrated in Figure 4.8. The p-values for the construct reputation are not statistically significant, so we cannot reject the null hypothesis. We are, therefore, going to eliminate this construct from the new proposed model.

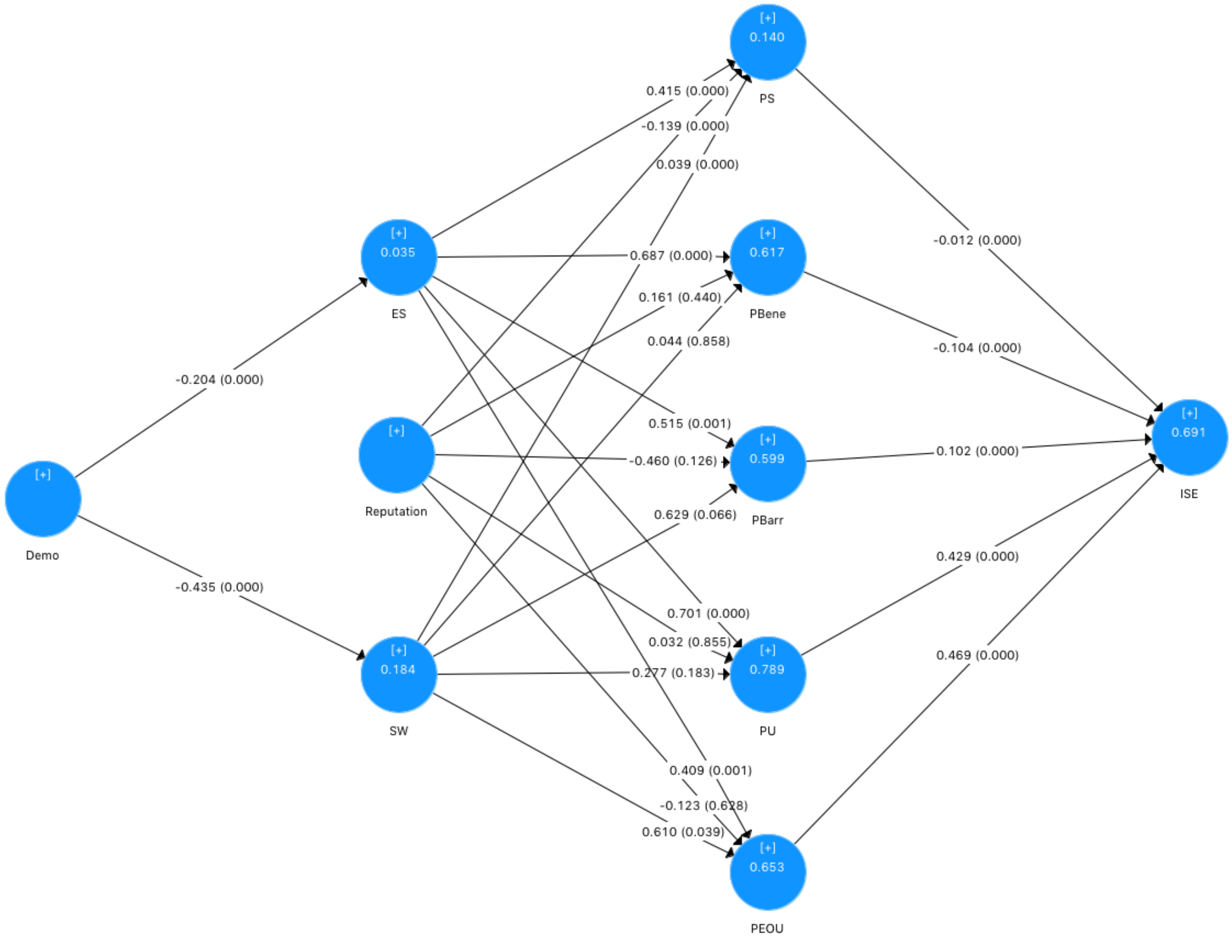

Figure 4.8. A proposed model with path coefficients and *p*-values.

Table 4.10

Details from the Proposed Model with Path Coefficients and p-*Values*

Construct	Adjusted R^2	Path Coefficients	p-values
Demo - ES		-0.204	0.000
Demo - SW		-0.435	0.000
ES – PS	0.035	0.415	0.000
ES – PBene		0.687	0.000

(table continues)

Construct	Adjusted R^2	Path Coefficients	p-values
ES - PBarr		0.515	0.001
ES - PU		0.701	0.000
ES - PEOU		0.409	0.001
REPU – PS		-0.139	0.000
REPU – PBene		0.161	0.440
REPU - PBarr		-0.460	0.126
REPU - PU		0.032	0.855
REPU - PEOU		-0.123	0.628
SW - PS	0.184	0.039	0.000
SW - PBene		0.044	0.858
SW - PBarr		0.629	0.066
SW - PU		0.277	0.183
SW - PEOU		0.610	0.039
PS - HISE	0.140	-0.012	0.000
PBene - HISE	0.617	-0.104	0.000
PBarr - HISE	0.599	0.102	0.000
PU - HISE	0.789	0.429	0.000
PEOU - HISE	0.653	0.469	0.000
HISE	0.691		

Note. ES= Emotional Support, SW= Self-worth, PS= Perceived Severity, PBene= Perceived Benefit, PBarr= Perceived Barrier, PU= Perceived Usefulness, PEIU= Perceived Ease of Internet Use, ISE= Information Seeking Effectiveness, AVE= Average Variance Explained

Figure 4.9 is the new proposed model. To test the structural model, bootstrapping was applied to this ISE model, once the construct, reputation, was removed. Bootstrapping was applied using 5000 sample models. Bootstrapping is a nonparametric method that tests the significance of the model by creating randomly selected observations and compares these random sets against the initial set of data. This process continues until the set number of random samples is reached. We set this to 5000 subsets. This model illustrates the path coefficients, p- values, and adjusted R^2 values.

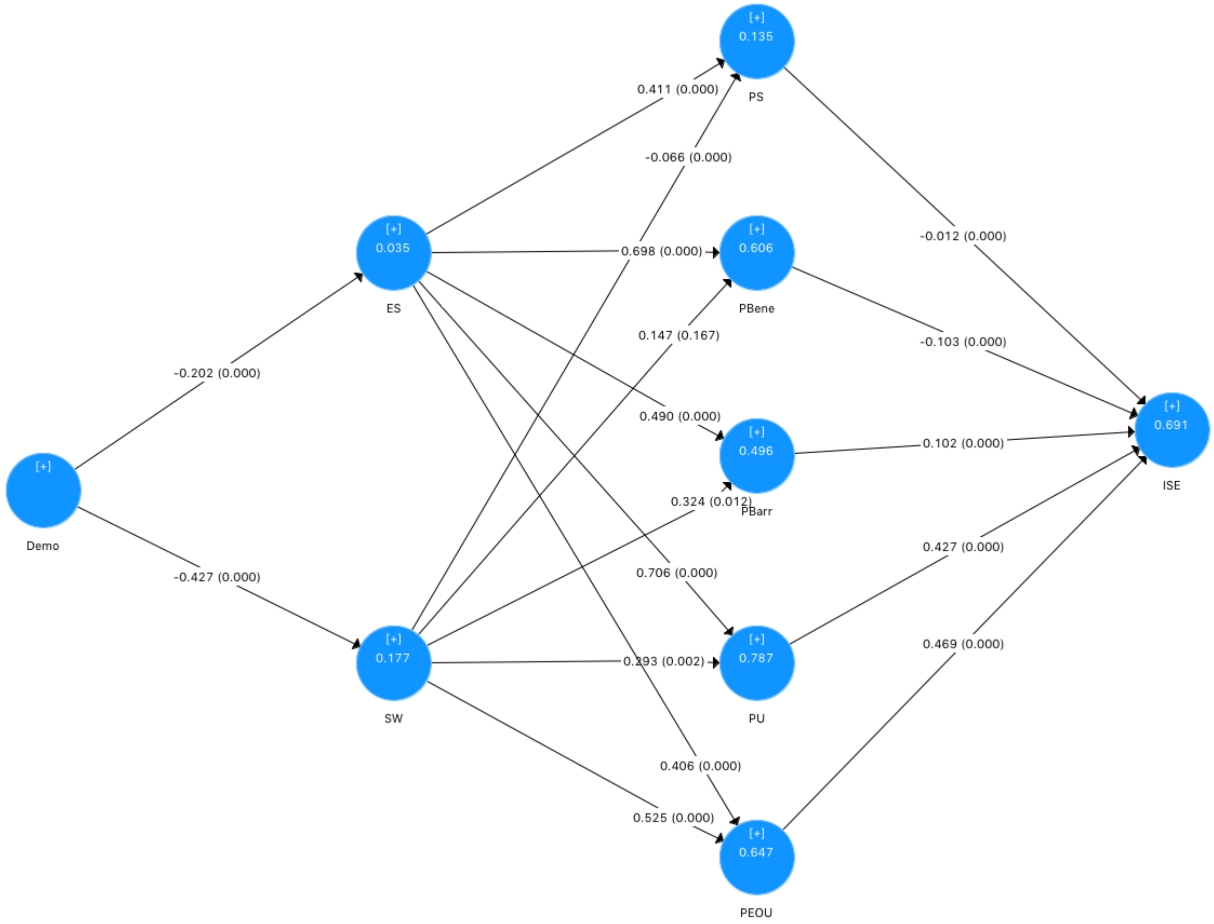

Figure 4.9. Information seeking effectiveness model within COPD Facebook groups.

4.3.4.3 Quality Criteria

Table 4.11 shows all constructs from the model with the corresponding adjusted R^2, average variance extracted (AVE), rho_A, Cronbach's Alpha and Composite Reliability. The efficiency of a model is determined by evaluating the reliability and validity of each construct (Kerlinger & Lee, 2000). The first value we see in this table is the Adjusted R^2 (0.69.1) This value explains the variance between the latent variables, and we see that 69.1% of the variance is explained by this model. The average variance extracted (AVE) value measures the convergent validity of the variance between constructs. An acceptable AVE should be higher than 0.50.

This indicates that those values with less than 0.50, there is more variance in the error of the items than in the variance explained by the variable (Hair et al., 2017). Variables that are above 0.050 indicate there is strong convergent validity. We see two measures in our mode that fall beneath this accepted value, but they fall within the less restrictive criteria from Cronbach's Alpha and rho_A values.

Table 4.11

Proposed New Model with Convergent Validity Including the Construct, Adjusted R-squared, AVE, Cronbach's Alpha, rho_A, and Composite Reliability

Construct	Adjusted R^2	(AVE)	Cronbach's Alpha	rho_A	Composite Reliability
ES	0.035	0.602	0.819	0.820	0.820
SW	0.177	0.391	0.622	0.698	0.636
PS	0.135	0.474	0.791	0.830	0.655
PBene	0.606	0.538	0.775	0.778	0.77
PBarr	0.496	0.530	0.770	0.773	0.772
PU	0.787	0.692	0.871	0.871	0.871
PEOU	0.647	0.572	0.806	0.812	0.798
ISE	0.691	0.689	0.915	0.921	0.917

Note. ES= Emotional Support, SW= Self-worth, PS= Perceived Severity, PBene= Perceived Benefit, PBarr= Perceived Barrier, PU= Perceived Usefulness, PEIU= Perceived Ease of Internet Use, ISE= Information Seeking Effectiveness, AVE= Average Variance Explained

Cronbach's alpha is another tool that measures the reliability of the scale. A generally accepted Cronbach's alpha is 0.70, and 0.60 is the lowest acceptable threshold (Salkind, 2010). As we see in Table 4.11, all constructs fall within the range. Therefore, we can assume the constructs observed score variance is close to that of the true score.

Lastly, we analyzed the fit of the model with the root mean square (SRMR). This value was 0.068, which is below the accepted value of 0.08 (Valaei & Baroto, 2017). This calculation is fairly new to PLS-SEM, but it is well known in covariance-based structural equation modeling (Hair et al., 2017). SRMR is a tool to analyze model fit that measures the difference between the observed correlations, and the model suggested correlations.

4.3.4.4 Hypothesis Testing

To validate the hypotheses, *p*-values < 0.05 were employed (Table 4.12). From this analysis, we can see that all constructs are statistically significant (p-values), except for the relationship between self-worth and perceived benefits. We can also see that of the constructs, perceived ease of use, perceived usefulness, and perceived benefits have the highest statistical significance. Path analysis confirm our hypotheses in all constructs with the except reputation. (There is one correlation in reputation that showed a weak negative correlation in relationship with perceived severity). There were a few constructs that have weak negative significance effect. These are demographics on emotional support (β = -0.202, p = 0.000) and self-worth (β = -0.427, p = 0.000); self-worth on perceived severity (β= -0.066, p = 0.000); perceived severity on information seeking effectiveness (β= -0.012, p = 0.000); and perceived benefits on information seeking effectiveness (β= -0.103, p = 0.000). The top five constructs with strongest positive relationships are emotional support on perceived usefulness (β= 0.706, p = 0.000). emotional support on perceived benefits (β= 0.698, p = 0.000), self-worth on perceived ease of internet use (β= 0.525, p = 0.000), emotional support on perceived barriers (β= 0.490, p = 0.000), and perceived ease of internet use on information seeking effectiveness (β= 0.469, p = 0.000).

Table 4.12

New Proposed Model with Constructs, Path Coefficients and p*-Values*

Construct	Path Coefficients	p-values
Demo → ES	-0.202	0.000*
Demo → SW	-0.427	0.000*
ES → PS	0.411	0.000*
ES → PBene	0.698	0.000*
ES → PBarr	0.490	0.000*
ES → PU	0.706	0.000*
ES --L PEOU	0.406	0.000*
SW → PS	-0.066	0.000*
SW → PBene	0.147	0.172
SW → PBarr	0.324	0.011
SW → PU	0.293	0.002
SW → PEOU	0.525	0.000*
PS → ISE	-0.012	0.000*
PBene → ISE	-0.103	0.000*
PBarr → ISE	0.102	0.000*
PU → ISE	0.427	0.000*
PEOU → ISE	0.469	0.000*
ISE	0.691	

Note. *$p < 0.001$; Demo = Demographics, ES = Emotional Support, SW = Self-Worth, PS = Perceived Severity, PBene = Perceived Benefits, PBarr = Perceived Barriers, PU = Perceived Usefulness, PEOU = Perceived Ease of Internet Use

4.3.5 Discussion

Overall, except for the construct reputation, all hypotheses are supported with statistical evidence. While the health belief model addresses the importance of perceived severity, perceived benefits, and perceived barriers ((Abraham & Sheeran, 2015; Ahadzadeh et al., 2015; Davis, 1989a), and the social exchange theory discussed the importance of emotional support, self-worth, and reputation ((Gustafson & Sheikhm, 1999; Nambisan, 2011), and Davis and Ahadzadeh et al. (2015) report the importance of the technology acceptance model, new significant relationships were identified in this research as they relate to information seeking effectiveness.

Below are the answers to the posited research questions:

1. Do user demographics correlate with emotional support, reputation, and self-worth?

Reputation was taken out of the model due to low p-values. Otherwise, the answer is yes, demographics do correlate with emotional support and self-worth. There are, however, negative correlations between these constructs.

2. Do user psychological characteristics (emotional support, reputation, and self-worth) correlate with perceived disease severity, perceived benefits, perceived barriers, perceived usefulness, and perceived ease of Internet use?

Again, reputation was taken out of the model. The answer for the other two constructs is yes, emotional support and self-worth correlate with perceived disease severity, perceived benefits, perceived barriers, perceived usefulness, and perceived ease of Internet use. Each of these constructs had a positive relationship on each other.

3. Does perceived disease severity correlate with health information seeking effectiveness?

The answer is yes, it was statistically significant, although it was a weak, positive relationship.

4. Does perceived benefits correlate with information seeking effectiveness?

The answer is yes, it was statistically significant, and it had a moderate, positive relationship.

5. Do perceived barriers correlate with information seeking effectiveness?

The answer is yes, it was statistically significant, and it had a moderate, positive relationship.

6. Does perceived usefulness correlate with information seeking effectiveness?

The answer is yes, it was statistically significant, and it had a strong, positive relationship.

7. Does perceived ease of Internet use correlate with information seeking effectiveness?

The answer is yes, it was statistically significant, and it had a strong, positive relationship.

4.3.6 Conclusion

This study questioned if demographics. psychological characteristics (i.e., emotional support and self-worth), perceived disease severity, perceived benefits, perceived barriers, perceived usefulness, and perceived ease of internet use had any relationship to their information seeking effectiveness in online health communities specific to their disease (COPD). This study shows there are correlations between all of these constructs on the outcome of information seeking effectiveness. This information can be beneficial to those that design and maintain such sites participation is positively affected by the ease of use. Participation in such platforms can be of great use to those with chronic illnesses. It is also important for healthcare professionals to understand the benefits of online health communities in the maintenance and overall health outcomes of patients living with COPD. It is important for the healthcare professionals to explain the severity of the disease and at the same time lead their patients to online health communities that provide easy access to informational support, emotional support, and environments that are safe for socialization.

As in all studies there were limitations in this research. One of the largest limitations was that all data was self-reported. The small sample size and response rate were also limitations. Even though invitations were sent out over several postings, response rate was low.

Future work could focus on a comparison between patients that do not access information digitally with those who access information online. Also, it would be interesting to research gender differences in greater depth.

CHAPTER 5

DISCUSSION, CONCLUSION, STUDY LIMITATIONS, AND FUTURE WORK

5.1 Discussion

This research was initiated with three research questions, that were answered with Essays 1 and 2.

5.1.1 Research Question 1

RQ1 asked what are the needs of COPD patients that result in their participation in online health communities. After collecting and analyzing data from both a moderated online health community and an unmoderated Facebook group, this first essay uncovered that emotional support and socialization were just as important as the informational support needs of the participant. This was unexpected. As far as informational support needs, this study found that in the first group (moderated) the top 5 health information needs were about medication, education, doctors, use of oxygen, pulmonary test but in this online community emotional support was addressed more than informational needs. Some of the emotional needs had posts asking for prayer, inspirational quotes, or just “venting” about their current situation. In the second group, the majority of posts were made purely for socialization. By this, many posts addressed such topics as the weather, pictures of pets and family, and witticisms. As far as informational support, the second group had inquiries on medication, depression, education, disease symptoms, diet, and exacerbations.

5.1.2 Research Question 2

RQ2 asked what are the information sources offered to the participants in these online communities? First group, most participants based their answers to questions posed on their personal experiences, this was followed by suggestions to consult the inquired physician, use the sources within the online community, and lastly, information given on YouTube sites, academic journals, other forms of social media, and the NIH. Like the first group, the second group researched also based the majority of their posts on personal experiences. Unlike the first group, the non-moderated group exchanged websites more often than directing posted questions to a physician or healthcare profession. There was a problem with this because there were some issues with the websites as you will read below.

5.1.3 Research Question 3

RQ3 asked whether the information obtained via those communities credible. In this first group, we found that there was only one source that was found questionable using the criteria set forth by the NIH. This was interesting, in that, we read in several places, how much information in these online communities disseminated false information. This was the driving force behind the second essay, examining a non-moderated Facebook group. While most websites in the first moderated group were overwhelmingly credible, many of the websites (41%) in the non-moderated group were found to be of questionable credibility. This was based on using the NIH guidelines.

5.1.4 Essay 3

Essay 3 was based upon the findings in the two prior essays. These studies lead to using prior research and theories to build an integrated model to understand information seeking effectiveness within Facebook groups using partial least squares – structural equation modeling (PLS -SEM). There were 7 research questions with 23 hypotheses.

1. Do user demographics correlate with emotional support, reputation, and self-worth?

Reputation was taken out of the model due to low p-values. Otherwise, the answer is yes, demographics do correlate with emotional support and self-worth. There is however, a negative correlations between these constructs.

2. Do user psychological characteristics (emotional support, reputation, and self-worth) correlate with perceived disease severity, perceived benefits, perceived barriers, perceived usefulness, and perceived ease of Internet use?

Again, reputation was taken out of the model. The answer for the other two constructs is yes, emotional support and self-worth correlate with perceived disease severity, perceived benefits, perceived barriers, perceived usefulness, and perceived ease of Internet use. Each of these constructs had a positive relationship on each other.

3. Does perceived disease severity correlate with health information seeking effectiveness?

The answer is yes, it was statistically significant, although it was a weak, positive relationship.

4. Does perceived benefits correlate with information seeking effectiveness?

The answer is yes, it was statistically significant, and it had a moderate, positive relationship.

5. Do perceived barriers correlate with information seeking effectiveness?

The answer is yes, it was statistically significant, and it had a moderate, positive relationship.

6. Does perceived usefulness correlate with information seeking effectiveness?

The answer is yes, it was statistically significant, and it had a strong, positive relationship.

7. Does perceived ease of Internet use correlate with information seeking effectiveness?

The answer is yes, it was statistically significant, and it had a strong, positive relationship.

Based on validity and hypotheses testing, the new proposed model indicates that it is a statistically significant model for information seeking effectiveness in online health communities.

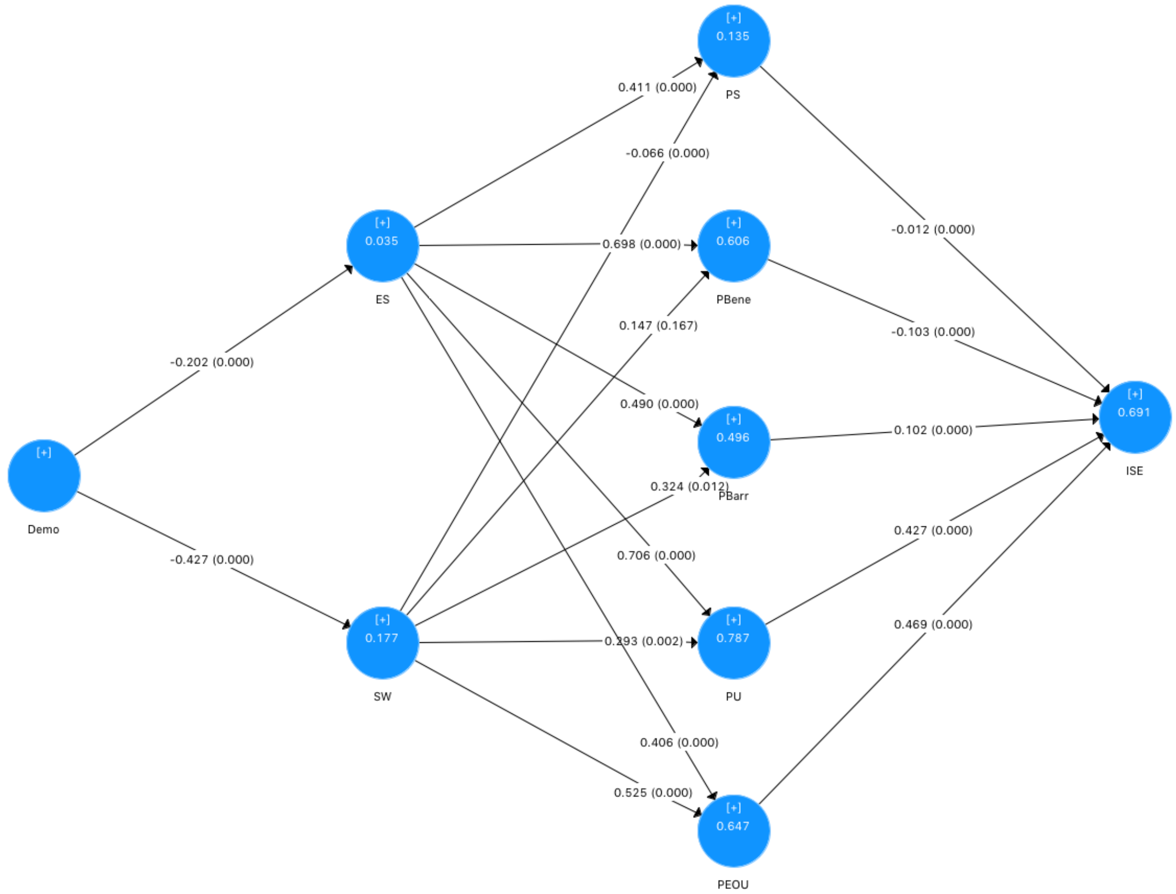

Figure 5.1. The proposed model for information seeking effectiveness.

5.2 Conclusion

This dissertation examined information in the context of disease-specific, namely COPD, online health communities. The online communities in this research met the emotional and socialization needs more than the informational needs of the participants. It is important that healthcare professional understand the existence of the information sources and avenues of support for their patients. Many people with COPD are homebound for many reasons. As we reported, people with chronic disease are apt to feel depressed and depression can affect the disease maintenance and well-being of chronically ill patients. That being said, it is essential to note the importance in the availability of such sites in providing emotional support for chronically ill patients. However, it is also important for health care professionals to recommend sites that are moderated (like COPD360) so that credible information sources, as well as credible health information, are recommended.

The results of this research show that COPD patients have health information needs and a monitored social health online community that is available to patients 24/7 answers questions that arise at the time of need. COPD online communities, that are not moderated, can also play an important role in socialization of the patients. Healthcare professionals must only recommend these sites as socialization only, and not for the medical information provided in those sites.

This study contributes to the body of literature about peer-to-peer online health support groups and makes clear that a site, to be most beneficial to users, must be professionally monitored for clinical accuracy and must have credibly written materials available to users beyond the normal business hours when questions arise at the time of need.

Lastly, he proposed Information Seeking Effectiveness Model within COPD Facebook Groups illustrates the importance to explain the severity of patients' disease and highlight the benefits of OHCs in order for patients to partake in the perceived benefits of online health communities specific to COPD. It is also important that designers understand the importance of building interfaces that are free of effort in order to COPD patients to partake in the OHC that will enhance participants' overall quality of life.

5.3 Study Limitations

As in all research work, there were limitations to this study. Posts in online communities are self-reported and their accuracy cannot be verified. Additionally, essays one and two focused on only one Facebook group and one other online health community, making this study ungeneralizable to other online health communities. Furthermore, this study also met challenges in sample size. Participants were generally resistant to surveys as was evidenced by the multiple dismissals of requests for replies. The survey work was also biased toward a female population as evidence by the breakdown of the demographics. Despite these limitations, this research provides an important first step in the development of other integrative models in online health communities.

5.4 Future Work

The foundation provided by this research allow for extension and future studies. In particular, it is interesting that more females utilize the online health communities and needs seem to differ than the males that frequent the same community. This suggests further research that examines the role of gender in online information seeking. In addition, it is suggested that this model extended and tested in other disease-specific online communities and also communities within other regions of the world.

APPENDIX A

CODE BOOK FOR COPD STUDY

1. Oxygen: including oxygen, cannulas, LPM (liters per minute), #L (number & liters of oxygen), O2, pulsed oxygen, oxygen supplies, home oxygen, supplemental oxygen, oxymizer, tubing, oxygen tube, nasal pillows, oxyview, portable O2, machine hose, oxygen tank, tank, 50ft/25ft. tube, airline, E tanks, oxygen supplier, prongs, batteries, silicone (for prongs), cylinders, oxygen therapy, pulse flow,

2. Medication: including Trelegy, Anoro, prednisone, meds, Daliresp, Advair, Disc., nebulizer, inhaler, inhaled steroids, antibiotic, CVS, Airphysio, flu shot, Foradil, corticosteroid, drugs, Spiriva, Combivent, Endo, probiotic, Breo, Albuterol, Symbacort, Zpak, Claritin, supplements, sprays, Flonase, prescription, nasal spray, Ventolin, anticholinergics, Duoneb, oregano oil, Stiolto, vitamins, antioxidants, gargle, mouth wash, Valsartan, LABA, LAMA, SAMA, SABA, side effects, melatonin, shots, blood thinner, foracort, Brovana, shelf life, neb., budesonide, mobilised delivery, Mucinex, air puffers, 250- 500, methypredisoline, Quinine, puffers, ProAir, epidural, pharmacy, AlldayChemist, Airvo, Azithromycin, Unmeclidinium, Incruse, Performist, Chantix, Ellipta, brand-name Synthroid, Hydrogen Peroxide, bronchodilator, muscle relaxers, Medrol pack, nasal saline, cigarette patch, Nystatin, earache drops, Avelox, Zebata, caffeine, vaccine

3. Exercise : including Yoga, weights, cycle, walking, not active, work out, treadmill, hike, gym, increase the speed, active, run out of steam, physical activity, working with a trainer, swimming, pushups, pool, running, fitness, dumbbells, activity, fitness center,

4. Concentrators/POCs : including InogenOne G3, OxyGo, LOX, oxygen equipment, oxygen machine, liquid oxygen, machine, SimplyGo, Responics, Portable Oxygen Concentrator, Concentrator, oxygen source, water traps, humidity canister, homefill, humidifier, face mask, oxygen provider, home unit, humidity (in context), O2 machine,

5. Insurance/Medicaid: including Part B, Health insurance, Medicare, insurance policy, prescription cards, insurer, insurance provider, Medicaid, Part D, Social Security benefits,

6. Travel: including flying, plane trips, traveled, travel, cruise, United, United, fly, airlines, TSA, ships, vacation, flights,

7. Stem cell therapy: including stem cell therapy., stem cell, cellular therapy, stem cell research,

8. Pulmonary rehab: including pulmonary rehabilitation, pulmonary rehab, cardio/pulmonary rehab, rehab, program, rehab. program, sessions, rehab, Wellness, PR,

9. Omitted, combined with 2

10. Exacerbation: including tend to go south, mucous production, worsening of your COPD, sinus infection, no chances of anything else, hospitalized, emergency room, urgent care, triggers, coughing again, infection, sick again, hospital, chronic cough, flare ups, sick more often, surgery, COPD attack, flu every year, feel worse, avoiding the ER, went to the doctor, went to ER, readmission, reoccurring, very sick, prone to pneumonia, coming down with a cold, recover, pneumonia, sick,

11. Relax/meditation: including relaxation, relax, sleep

12. PEEP/CPAP/BiPAP: including Trilogy, PEEP device, CPAP, sleep apnea, BiPAP, ventilator, NIV,

13. Warmer weather/humidity: including warmer weather, weather, humidity, hot, smoke fires, hurricane, air quality alerts, atmospheric pressure, ozone, rain, mold, pollen, dust, cold winter air, dewpoint, elevation, sun, clean air, 100, summer, temperatures, scorcher, degrees, heat, allergy, winter, windy, artic blasts, wildfires, outside

14. Harmonica/breathing: including short of breath, harmonicas, talking, breath management, SOB, shortness of breath, irritants, cleaners, sanitizers, chemicals, hospital bed, recliners, perfumes, breathing difficulty, mouth, exhale, lip pursing, dust, cleaning supplies, dust, smoking cessation, PLB, hurts to breathe, cologne, Active Cycle of Breathing, problem in the back of my throat, Adam's apple, clear my throat, breathlessness, cough, could not breathe, pursed lip breathing, exhale, inhale, breathing through mouth/nose, singing, slack jawed breathing, quit smoking, breathless, out of breathe, fine particulate matter, bras, singing, air hungry,

15. Lung transplant: including lung transplant, transplant, new lung, lung reduction surgery, lung volume reduction surgery, receiving a pair of lungs,

16. Pulmonary function test breathing test/SO2 : including PFT, pulse oximeter, MRI, PET scans, CT, x-ray, test for amount of air your lungs, hold, respiratory rate, FEV1, CT scan, pulmonary function test, oxygen saturation, 43di brand, oximeter reading, oximetry, bronchoscopy, lung function, tests, CO2, pulse ox number, spirometry test, biopsy, full diagnostic workup, Alfa1 test, results, blood test, saturations, pulse ox, Nonin Go2, AccuMed, oxygen levels, SpO2, low numbers, full pulmonary exam, sleep test, numbers, breathing test, Alpha 1, lung age, heart age

17. Improper diagnosis/ 2nd opinion/pulmonologist/doctor : Including doctor, PCP, pulmonologist, pulmo, second opinion, consultation, VA, primary doctor, practices, specialist, doc, misdiagnosed, advice, provider, pain guy, DR, dr, physician's office, docs office, family doctor, GO, better hospital, pulmy, visit, appointment, referral, medical team, lung doctor, physician assistant, primary, medical professionals, MD, misdiagnosed, Dr. appt., Disease Physician, checkup

18. Diet: including yogurt, overweight, diary, weight, dehydration, diet, eat, eating, Eat healthy, milk, food, low carb, coffee, Keto diet, clean eating, broccoli, vinegar, losing weight, dietician, meal, eaten well, extra weight, nutrition, eat right, cider vinegar, eat, soup, calories, eat too much, eating, metabolic rate, supplements, high sugar, water, pressure cookers, recipes, oats, bacon, weight loss

19. Blood Pressure: including high blood pressure, HB, blood pressure,

20. Omitted, combined with 14

21. Clinical studies: Including FDA, potential cures, research, Zephyr valve treatment, valves, research lab, O2VERLAP, study, research studies, program, clinics, NIH, M3global research, RENEW trials, survey, open enrollment, INSIGHT COPD, project, PER, work being done, big step, questions, interviews, cohort study, Endobronchial valve treatment, trial,

22. Legislation/advocacy: including proactive, write, representatives, reaching out, get the word out, set up some meetings, make your voice heard, Congressman/woman, advocating, awareness, Congress, petition, register, session, House of Representative, senators, House and Senate, DC, Rights and Responsibilities, petition, proactive

23. Action plan: including action plan, GOLD, expect from our healthcare providers, communication, plan

24. Omitted, combined with 25

25. Support groups/education: including support groups , online PR, web article, myths, article, posts with statistics, homework, not true, link, information, case, answers, education, reason, asking, educating, figure out why, COPD definition, telling, explaining, newsletter, awareness, research(think context), signs and symptoms, don't know much about, club, more info., how to post questions, do we communicate, patient led organizations, try, COPD hotline, know, misinformation, early warning signs, facts, live stream, what to expect, curious, seminars, lectures, advice, evidence, resources, learn, fact, program, idea, event, Pulmonary Paper, webinar, training, conference, initiative, reference, discuss, understand, check on your own, confused, materials, guide, app, AskMe, shared, questions, data, learn, sharing, check this out, support, sharing, relationship, telling your story, story, reading, spread the word, discussion, explain, news

26. Sex: including sexual, intimacy, critical moment

27. RT therapy/massage/muscles/acupuncture: including clearance device, Afflovest, vests, valves, massage, neck and shoulder, air cleaner, Power Lung, airway clearance device, acupuncture, endobronchial valves, air-dyne, flutter device, stair lift, salt room therapy, pain, medical O2 analyze, service dog, chest therapy vests, muscle weakness, wedge

pillow, leg cramps, swelling, cramps, RC cornet, painful, muscular skeletal issues, bra, support bra, ear aches, shower chair, therapy, mobility scooter, tools, NettiPot, spacer

28. Anxiety/Depression/confusion/life expectancy: including depression, boost energy, depressed, panic, confused (in context), anxiety, therapist (in context), stress, going through this alone, fatigue, emotional, emotional management, afraid of dying, really scared, worried, tired of being…, bipolar disorder, terrifying, dark times, suicide, feeling overwhelmed, killing me, mental health, scared of dying, dying, feeling lousy emotionally, attitude, I get down, things getting worse and worse, swings of high and low, mentally under the weather, trouble coming to grips with, upset, feeling hopeless, life expectancy, dark cloud, stressful, comorbidities, tough time, worrying, sensitive subject, trying to cope, feeling badly about everything, very scary, scary, fear of the unknown, nervous, awful, piece of mind, very sad, losing hope, in despair, doesn't appear happy, discouraging, doom and gloom, suffering, cried, desperate, frustrated, isolation, afraid, feeling lonely and sad, not doing good, feeling very sad, feeling down, not feeling up to par, mental exhaustion, apprehensive, down in the dumps, no life limit, 18, unique in your disease, refuse to let it defeat me, hated the idea, taking the bull by the horns, life doesn't stop, quality of life, stay in the game, lung age, not fighting this alone, how hard that was, all deceased, die tomorrow, sorry, hospice, difficult day, fighting, problems, loss, teared up, life has meaning, life, lived to 70, behavioral health issues, anger, keep on living, coping, overwhelmed, bad days, quality of life, death sentence, happy life, timeline, palliative care

29. Privacy: including privacy, open to the public, indexed in Google,

30. Smoking

APPENDIX B

SURVEY

1. What is your age?
    a. Under 30
    b. 31 - 54
    c. 55 - 64
    d. 65 - 74
    e. Over 75
2. What is your gender?
    a. Male
    b. Female
    c. Other
3. What is your marital status?
    a. Married
    b. Single
    c. Widowed
    d. Divorced

4. What is your annual income?
    a. Less than $49,000
    b. $50,000 - $99,000
    c. More than $100,000
5. What country are you living at this time?
6. What is your cultural background and how does it affect your healthcare decision making?

For each of the questions below, circle the response that best characterizes how you feel about the statement, 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, and 5 = Strongly Agree.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
1. The thought of COPD scares me.	1	2	3	4	5
2. COPD is a hopeless disease.	1	2	3	4	5
3. I worry about my physical health deteriorating as my COPD progresses.	1	2	3	4	5
4. I have a lot to gain by participating in this forum.	1	2	3	4	5
5. Participating in this forum helps me in controlling my COPD.	1	2	3	4	5
6. I am less anxious about my disease by participating in this forum.	1	2	3	4	5
7. It is convenient for me to participate in this forum.	1	2	3	4	5
8. It is easy for me to share knowledge in this forum.	1	2	3	4	5
9. Participating in this forum does not interfere with my daily routines.	1	2	3	4	5
10. By sharing knowledge in this forum, I pour out my troubles and feel relaxed.	1	2	3	4	5
11. By sharing knowledge in this forum, I get some understanding, help, or support from other participants in the community.	1	2	3	4	5
12. By sharing knowledge in this forum, I get comfort and care from other participants in the community.	1	2	3	4	5
13. Using this forum is useful in managing my COPD.	1	2	3	4	5
14. Using this forum for health information is advantageous in better managing my health.	1	2	3	4	5
15. Using this forum for health information about my COPD is beneficial to me.	1	2	3	4	5

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
16. My interaction in this forum for health information is understandable.	1	2	3	4	5
17. It is easy to navigate to find health information in this forum.	1	2	3	4	5
18. It is easy for me to become skillful at using this forum for health information.	1	2	3	4	5
19. Sharing knowledge enhances my reputation in this forum.	1	2	3	4	5
20. I get praises from others by sharing knowledge in this forum.	1	2	3	4	5
21. Sharing knowledge improves my status in this forum.	1	2	3	4	5
22. Sharing knowledge will help other participants in this forum solve problems.	1	2	3	4	5
23. It is important that members in this forum think positively about me.	1	2	3	4	5
24. Sharing knowledge brings a positive influence on other members in this forum.	1	2	3	4	5
25. I obtain information that is credible in this forum.	1	2	3	4	5
26. I obtain information that is accurate in this forum.	1	2	3	4	5
27. I obtain information that is relevant in this forum.	1	2	3	4	5
28. I obtain information that is reliable in this forum.	1	2	3	4	5
29. I obtain information in a timely manner in this forum.	1	2	3	4	5

30. What about this forum encourages you to join and continue to participate?

31. What is the most valuable asset this forum offers you?

32. How do you evaluate the medical accuracy of the information you are receiving in this forum when you plan to make health decisions for yourself or someone else you care about?

APPENDIX C

FACEBOOK GROUPS TO WHICH SURVEY LINKS WERE SENT

Open Link posted:

I am a registered respiratory therapist with a great concern for COPD patients. I am currently a PhD student at the University of North Texas and am conducting a study on the effectiveness of health information seeking in Facebook groups. I would greatly appreciate your help. If you would like to participate in this short study, please click on the following https://unt.az1.qualtrics.com/jfe/form/SV_cU3zXjfjUcnSI1D

CLOSED (moderated) Link:

I am a registered respiratory therapist with a great concern for COPD patients. I am currently a PhD student at the University of North Texas and am conducting a study on the effectiveness of health information seeking in Facebook groups. I would greatly appreciate your help. If you would like to participate in this short study, please click on the following link. https://unt.az1.qualtrics.com/jfe/form/SV_06akuJc8YBRrVtj

Group	Asked to join	Posted	Repost
Lets Talk COPD Support Group – joined	Accepted a while ago	Private, 11-30-19 Pending approval Denied. DO NOT CONTACT	
COPD Warriors Hope, Support, Love and Laughter – joined		Posted in October, 2019	
COPD Support	NA	Open 11-30-19	4- 4-20
COPD and Cannabis – A new beginning	Joined 11-30-19	Private 11-30-19	4-4-20
COPD – Learn More Breathe Better NHLBI	NA	Moderated, 11-30-19	
COPD.net	NA/ sent another request 1-18-20	Open 11-30-19	4-4-20 DON' Post again
COPD Awareness	pending	closed 1-18-20	open
Healthline: Living with COPD	11-30-19	Private 11-30-19	Open
COPD – NewLive Outlook	NA	Open 11-30-19	4-4-20
COPD	Yes, accepted a while ago	Private, 11-30-19	4-7-20
COPDLiving.today	NA	Open 11-30-19	4-4-20
COPD Friends for Friends		No longer available	NA
COPD Aware	NA	Open 11-30-19	4-4-20
COPD Support	Yes, accepted a while ago	Closed 11-30-19	4-4-20
U.S. COPD Coalition	NA	Open 11-30-19	4-4-20
COPD Options		Clinical research group to connect people with research studies	NA
COPD Information and Support		Open 11-30-19	4-4-20
COPD Store		Open 1-18-20	4-4-20
COPD Athlete	NA	Pending approval 11-30-19, posted 11-20-19	Open 4-7-20

Group	Asked to join	Posted	Repost
myCOPDteam	Have to have approval to post	Pending Approval 11-30-19 Closed 1-18-20	Denied
COPD – I have COPD- COPD does not have me		You have to be a patient to enter	NA
COPD News Today	NA	Open 11-30-19	4-7-20
Alpha1 COPD Information			
MY COPD Life	NA	Open 11-30-19	4-7-20
COPD Travels		Not able to make a post	NA
COPD Navigator	Joined a while ago	Closed 11-30-19	4-4-20
COPD Awareness		Closed 1-18-20	4-7-20
Asthma/COPD Safe		Not able to post	NA
COPD “Can’t Kill Me”		Not able to post	NA
COPD Center		Open 1-18-20	4-7-20
COPD -Support, Inc		open 1-18-20	NA
COPD Warriors – Now COPD a Journey Shared	Pending approval 11-30-19	Approved asked to post 12-11-19 Closed 1-18-20	4-4-20 Removed from site D0 Not Post
COPDTips		Last post 2016	NA
COPD International	NA	Open 11-30-19	NA
COPDTopics		Last post 2015	NA
Stop COPD		open	NA
COPD Stompin’ Out COPD	NA	Open 11-30-19	NA
COPD Exercise to Health Living			
COPD -new treatments and advice	Joined a while ago	Private 11-30-19	4-7-20
COPD Craziness and Support		Closed 1-18-20	No spam
COPD Breathe Easy, Talk Easy	pending	11-30-19	Kicked out of group
COPD Breathing Buddies		closed	4-7-20
COPD – Get Educated	Pending approval 12-11-19	Closed 1-18-20	4-4-20
Lift Up – COPD Support Group	Joined a while ago	Closed 12-11-19 – waiting on approval for the post	4-4-20- pending approval
(COPD) Emphysema/chronic bronchitis Support Group	Joined a while ago	Waiting on approval for the post closed 12-11-19 Approval obtained (Karen Bauereiss) and posted on the 11th.	
Ultimate Pulmonary Wellness: COPD, PF, Pulmonary Hypertension and Others		Online pulm boot camp Noah Greenspan	
COPD/ A Warm Loving Place to Hang Out		NA	NA

Group	Asked to join	Posted	Repost
COPD Get Physical			No college studies
COPD – Breathe Easy	Pending approval		4-4-20
COPD Friends and Support	approval 12-11	Asked for permission to post 12-11 Open	
COPD friends – stage 4	Need to be a patient		NA
COPD friends for Friends		Open 1-18-20	4-4-20
COPD Options		Unable to post	NA
COPD friends with COPD Asthma, and resp illness		Open 12-11-19	closed
American Lung Association		Open, 1-31-19, could not post	NA
COPD Life UK		Open 1-18-20	closed
Combating COPD		Open 1-18-20	4-7-20
Team COPD		Open 1-18-20	4-7-20
COPD Breathe Strong		Open 1-18-20	NA
Chronic Lung Alliance		Open 1-18-20	
COPD New Outlook		Open 1-18-20	4-7-20
COPD Support Ireland		Open 4-4-20	4-4-20
COPD alert		Last post 2016	NA
CPOD Treatments		closed	4-4-20 must be approved
COPD Healthy		open	4-7-20

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