ASSESSING HEALTH INFORMATION QUALITY IN A CLOSED, NON-MODERATED COPD FACEBOOK GROUP

LeAnn Boyce
University of North Texas
Denton, Texas 76203

ABSTRACT

Online health communities (OHCs) have seen exponential growth in recent years. Numerous studies have researched OHCs related to specific diseases like cancer, diabetes, stroke, and Parkinson's disease. Still, few have focused on the information-seeking behavior of patients with chronic obstructive pulmonary disease (COPD). This research examines a closed Facebook group for COPD patients to understand the information needs of the participants, what sources are being recommended within the site, and is the information exchanged within this group clinically reliable? We found that most online activity is directed at socialization, and participants equally sought disease-specific health information and emotional support. We identified that most posts were based on personal experience, and the most common discussions were about medications, anxiety/depression, and learning about their disease (COPD). Lastly, based on the National Institute of Health Guidelines for evaluating health information sources, we found that 41% of the websites referenced were of questionable credibility and clinical reliability. This study highlights the importance of healthcare professionals' knowledge about the quality of health information exchanged in OHCs, and the importance of selectively promoting these sites to their patients as reliable sources of health information, or sources of socialization only.

Keywords: online health communities, OHCs; Facebook; COPD; health information seeking; online health information sources, peer to peer health

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 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, Dodson, Gill, & McKenzie, 2012; Ginossar, 2008; Sillence, 2013; 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.

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) estimate that about 12 million are diagnosed with COPD in the United State, and about 120,000 people die each year from COPD ("NIH Fact Sheets - Chronic Obstructive Pulmonary Disease (COPD)," 2013). Key indicators for the diagnosis of COPD, according to the Global Initiative for Chronic Obstructive Lung Disease, include severe respiratory symptoms such as chronic shortness of breath and alveolar changes that develop over time. (Global Initiative for Chronic Obstructive Lung Disease Incorporated, 2019). Usually, the symptoms of the disease worsen with physical exertion, recurrent lower respiratory tract infection, chronic cough with a persistent wheeze, or tenacious sputum production. COPD may be related with a family history or specific risk factors (ex. job-related dusts, exposure to cigarette smoke, genetics, smoke from heating fuels and domestic cooking, vapers, and other chemicals), or childhood factors (ex. low lung function at an early age, childhood respiratory infections, etc.) (GOLD, 2018).

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(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.

Online Health Communities

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 Canter 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, Worrell, Gangi, & Wasko, 2013). 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., 2013).

Facebook and Online Health Communities

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, Jimenez-Marroquin, & Jadad, 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.

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.

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. 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 1 gives examples of each category of socialization, emotional support, and informational support.

TABLE 1
POSTS IN FACEBOOK

Socialization Topics	Posts
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." "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	
Topics	Posts
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. 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 Posts 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 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…"

Commonly occurring keywords were identified to understand the knowledge gaps/information needs of the participants. 27 keywords were identified, and posts were coded accordingly. Keywords were:

- 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, 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 analysed for credibility and clinical reliability using the previously validated NIH guidelines (NIH.gov, 2018). Table 2 refers to the recommended categories addressed by the NIH. Each website was evaluated using each question posited in the NIH criteria.

TABLE 2:
NIH Guidelines

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.

RESULTS

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 (PFT's) (110), smoking (110), therapy (98), weather (93), and oxygen (89).

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 were utilized to evaluate whether the websites exchanged between participants were clinically reliable and credible (NIH.gov, 2018). See Table 1. 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 9 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 3).

TABLE 3:
TOP AUTHOR TOPICS

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%)

DISCUSSION

Health Information Needs

While using Writewords, a word frequency program, (www.writewords.org.uk.), 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.

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.

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.

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.

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.

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 analyse 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.

REFERENCES

Apperson, A., Stellefson, M., Paige, S. R., Chaney, B. H., Don Chaney, J., Wang, M. Q., & Mohan, A. (2019). Facebook groups on chronic obstructive pulmonary disease: Social media content analysis. *International Journal of Environmental Research and Public Health*, *16*(20). https://doi.org/10.3390/ijerph16203789

Bender, J. L., Jimenez-Marroquin, M. C., & Jadad, A. R. (2011). Seeking support on facebook: A content analysis of breast cancer groups. *Journal of Medical Internet Research*, *13*(1). https://doi.org/10.2196/jmir.1560

Brady, E., Segar, J., & Sanders, C. (2017). Accessing support and empowerment online: The experiences of individuals with diabetes. *Health Expectations*, *20*(5). https://doi.org/10.1111/hex.12552

Buehler, E. M. (2017). "You shouldn't use facebook for that": Navigating norm violations while seeking emotional support on Facebook. *Social Media and Society*, *3*(3). https://doi.org/10.1177/2056305117733225

Bush, E. J., Singh, R. L., Hidecker, M. J. C., & Carrico, C. P. (2018). Parkinson's disease support groups in rural America: Barriers, resources, and opportunities. *The Qualitative Report*, *23*(6), 1381–1400. Retrieved from https://search.proquest.com/docview/2062628918?accountid=14472%0Ahttp://r esolver.ebscohost.com/openurl?ctx_ver=Z39.88-2004&ctx_enc=info:ofi/enc:UTF-8&rfr_id=info:sid/ProQ%3Asocabs&rft_val_fmt=info:ofi/fmt:kev:mtx:journal &rft.genre=article&rft.jtitle=The+Q

Christensen, E. R., Golden, S. L., & Gesell, S. B. (2019). Perceived benefits of peer support groups for stroke survivors and caregivers in rural North Carolina. *North Carolina Medical Journal*, *80*(3), 143–148. https://doi.org/10.18043/ncm.80.3.143

COPD Warriors Hope, Support, Love and Laughter. (2019). Retrieved from https://www.facebook.com/pages/category/Personal-Blog/Copd-Warriors-support-Hope-love-and-laughter-2187240991545005/

Coulson, N. S. (2017). Affordance theory can help understanding of individuals' use of online support communities. *British Journal of Health Psychology*, *22*(3), 379–382. https://doi.org/10.1111/bjhp.12247

DeSimoni, A., Taylor, S., Griffiths, C., Panzarasa, P., & Aziz Sheikh. (2018). Online "Superusers" as allies of the health care workforce. *NEJM Catalys*. Retrieved from https://catalyst.nejm.org/superusers-allies-online-health-communities/

Dilgul, M., MacNamee, P., Orfanos, S., Carr, C. E., & Priebe, S. (2018). Why do people attend and not attend mental health groups in the community: a qualitative study. *PLoS ONE*, 1–23. https://doi.org/10.1371/journal.pone.0208448

Faraj, S., Krogh, G. Von, Monteiro, E., Lakhani, K. R., Faraj, S., & Monteiro, E. (2016). Online community as space for knowledge flows. *Information Systems Research*, *27*(4).

Fatima, I., Mukhtar, H., Ahmad, H. F., & Rajpoot, K. (2018). Analysis of user-generated content from online social communities to characterise and predict depression degree. *Journal of Information Science*, *44*(5), 683–695. https://doi.org/10.1177/0165551517740835

Fox, S. (2014). The social life of health information. Retrieved from http://www.pewresearch.org/fact-tank/2014/01/15/the-social-life-of-health-information/

Fox, S., & Duggan, M. (2013). Health online 2013. Retrieved from http://www.pewinternet.org/2013/01/15/health-online-2013/

Gibson, J. (1979). The theory of affordances. In *Ecological approach to visual perception*. Boston: Houghton Mifflin Harcourt.

Gilbert, K., Dodson, S., Gill, M., & McKenzie, R. (2012). Online communities are valued by people with Type 1 Diabetes for peer support: How well do health professionals understand this? *Diabetes Spectrum*, *25*(3), 180–191.

Ginossar, T. (2008). Online participation: A content analysis of differences in utilization of two online cancer communities by men and women, patients and family members. *Health Communication*, *23*(1), 1–12. https://doi.org/10.1080/10410230701697100

Global Initiative for Chronic Obstructive Lung Disease Incorporated. (2019). *Global Initiative for Chronic Obstructive Lung Disease*. Retrieved from www.goldcopd.ort

GOLD. (2018). Pocket guide to COPD diagnosis, management and prevention: a guide for health care professionals. *Global Initiative for Chronic Obstructive Lung Disease, Inc*, *1*(1), 3–14. https://doi.org/http://dx.doi.org/10.1164/rccm.201701-0218PP

Hinson, K. L. (2017). Framing illness through Facebook enabled online support groups. *Communication Design Quarterly Review*, *4*(2b), 22–31. https://doi.org/10.1145/3068755.3068758

Hinson, K., & Sword, B. (2019). Illness narratives and Facebook : Living illness well, *Humanities 8*(2).

Hodgkin, P., Horsley, L., & Metz, B. (2018). The emerging world of online health communities. *Stanford Social Innovation Review*. Retrieved from https://ssir.org/articles/entry/the_emerging_world_of_online_health_communities

HON, T. (2019). About health on the net. Retrieved from https://www.hon.ch/en/

Hwang, K., & Fogoros, R. (2018). 10 benefits of online health communities for patients and caregivers. Retrieved from https://www.verywellhealth.com/benefits-online-health-communities-1739168?print

Johnston, A. C., Worrell, J. L., Gangi, P. M. D., & Wasko, M. (2013). Online health communities: An assessment of the influence of participation on patient empowerment outcomes. *Information Technology and People*, *26*(2), 213–235. https://doi.org/10.1108/ITP-02-2013-0040

Kats, R. (2018). How many people use Facebook. Retrieved from https://www.emarketer.com/content/the-social-series-who-s-using-facebook

Knight, S. (2016). Social services innovations: Online patient communities. *Social Work Today*, *16*(3).

Kochanek, K., Murphy, S., Xu, J., & Arias, E. (2017). *Mortality in the United States, 2016*. Retrieved from https://www.cdc.gov/nchs/products/databriefs/db328.htm

Merolli, M., Gray, K., & Martin-Sanchez, F. (2014). Therapeutic affordances of social media: Emergent themes from a global online survey of people with chronic pain. *Journal of Medical Internet Research*, *16*(12). Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4285739/

Namkoong, K., Shah, D. V., & Gustafson, D. H. (2017). Offline social relationships and online cancer communication: Effects of social and family support on online social network building. *Health Communication*, *32*(11), 1422–1429. https://doi.org/10.1080/10410236.2016.1230808

Nelson, K. (2018). 50 social media healthcare statistics to watch. Retrieved from https://www.wegohealth.com/2018/04/02/social-media-healthcare-statistics-to-watch/

NIH.gov. (2018). Finding and evaluating online resources | NCCIH. Retrieved October 31, 2018, from https://nccih.nih.gov/health/webresources

NIH Fact Sheets - Chronic Obstructive Pulmonary Disease (COPD). (2013). Retrieved February 3, 2018, from https://report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=77

Pavord, I., Chanez, P., Criner, G., Kerstjens, H., Korn, S., Lugogo, N., … Mayer, B. (2017). Mepolizumab for Esinophilic Chronic Obstructive Pulmonary Disease. *The New England Journal of Medicine*, *377*, 1613–1629.

Resurrección, D. M., Motrico, E., Rubio-Valera, M., Mora-Pardo, J. A., & Moreno-Peral, P. (2018). Reasons for dropout from cardiac rehabilitation programs in women: A qualitative study. *PLoS ONE*, *13*(7), 1–14. https://doi.org/10.1371/journal.pone.0200636

Roundtree, A. K. (2017). Social health content and activity on facebook: A survey study. *Journal of Technical Writing and Communication*, *47*(3), 300–329. https://doi.org/10.1177/0047281616641925

Rupert, D. J., Gard Read, J., Amoozegar, J. B., Moultrie, R. R., Taylor, O. M., O'Donoghue, A. C., & Sullivan, H. W. (2016). Peer-generated health information: The role of online communities in patient and caregiver health decisions. *Journal of Health Communication*, *21*(11), 1187–1197. https://doi.org/10.1080/10810730.2016.1237592

Shoebotham, A., & Coulson, N. S. (2016). Therapeutic affordances of online support group use in women with endometriosis. *Journal of Medical Internet Research*, *18*(5).

Sillence, E. (2013). Giving and receiving peer advice in an online breast cancer support group. *Cyberpsychology, Behavior, and Social Networking*, *16*(6), 480–485. https://doi.org/10.1089/cyber.2013.1512

Smith, A., & Monica Anderson. (2018). Social media use in 2018. Retrieved from https://www.pewinternet.org/2018/03/01/social-media-use-in-2018/

Southall, K., Jennings, M. B., Gagné, J. P., & Young, J. (2019). Reported benefits of peer

support group involvement by adults with hearing loss. *International Journal of Audiology*, *58*(1), 29–36. https://doi.org/10.1080/14992027.2018.1519604

Weymann, N., Harter, M., & Dirmaier, J. (2015). Quality of online information on type 2 diabetes: A cross-sectional study. *Health Promotion International*, *30*(4), 821–831. https://doi.org/10.1093/heapro/dau019

WHO | Chronic obstructive pulmonary disease (COPD). (2017). *WHO*.

Willis, E., & Royne, M. B. (2017). Online health communities and chronic disease self-management. *Health Communication*, *32*(3), 269–278. https://doi.org/10.1080/10410236.2016.1138278

ABOUT THE AUTHOR

LeAnn Boyce is a Ph.D. candidate in the College of Information in the Department of Information Science, at the University of North Texas. She holds a Bachelor's in General Studies from Texas Woman's University, an MA in Government from Texas Woman's University, and an MIS from the University of North Texas. She is simultaneously completing a Masters' in Data Analytics at the University of North Texas. LeAnn worked for many years as a Registered Respiratory Therapist in the critical care units, general floor therapy, emergency room, in home health and in medical transit flights.