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## Computer-Mediated Experiences of Patients with Chronic Obstructive Pulmonary Disease

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### Abstract

**Background:** The Internet is an important tool for empowering patients with Chronic Obstructive Pulmonary Disease (COPD) to learn about and self-manage their condition.

**Purpose:** To understand which aspects of the online experience facilitates or hinders the perceived ability of patients with COPD to achieve their information and self-management goals.

**Methods:** Semi-structured interviews were conducted with medically underserved patients with COPD ( $N=25$ ) who access the Internet for health. A conventional content analysis approach was applied and data were analyzed with the constant comparative method.

**Results:** The following themes were derived: (1) desire to associate with “in-group” members; (2) relationship building with other online users; (3) security of information and identity; (4) source and channel credibility appraisal; (5) user assistance and tutorials; and (6) strategies to adapt technological functions.

**Discussion:** Success in using the Internet was dependent on the functional use of technology and the ability and resilience to engage with similar online users to build meaningful and trustworthy connections.

**Translation to Health Education Practice:** Prior to directing patients with COPD to a disease-specific online support platform, certified health education specialists must assess patients’ information goals and their skills to critically appraise and communicate with other online users.

## Keywords

COPD; computer-mediated communication; health communication; social media; eHealth

Chronic Obstructive Pulmonary Disease (COPD) is a progressive lower respiratory condition that disproportionately affects adults over the age of 40 who have a history of smoking tobacco.<sup>1</sup> COPD cannot be cured; however, the debilitating symptoms (e.g., dyspnea, excessive mucus) caused by the progressive physical and physiological damage to the respiratory system can be alleviated with timely and consistent treatment that can be facilitated in socially supportive networks.<sup>2</sup> Patients with COPD experience social isolation due to the physical and social nature of their condition,<sup>3,4</sup> and their engagement in self-management practices remains suboptimal.<sup>5</sup> Contributing factors include limited healthcare access (e.g., rural geographic location, no health insurance), insufficient procedural instruction about how to effectively self-manage symptoms and breathing exacerbations, and uncertain beliefs about the importance and efficacy of treatment.<sup>6-8</sup> Identifying low-cost approaches to engage patients in self-management is a priority in the United States (US).<sup>2,9</sup>

Patients with chronic diseases are increasingly using Internet-capable devices and digital applications (apps) and social media<sup>10,11</sup> to overcome physical, social, and psychological barriers that prevent patient education about diagnosis, self-management, and prognosis.<sup>12,13</sup> In the case of COPD, online support tools and programs are revolutionizing care coordination and delivery.<sup>10,11,14</sup> Online tools are available for healthcare providers to educate patients about inhaler techniques, physical activity, and medication adherence to promote care delivery.<sup>2,14,15</sup> Recent evidence shows that popular and publicly available social online environments, including YouTube and Pinterest, offer patients the opportunity to access and manage their own education and support by communicating with other users.<sup>16,17</sup>

Results from a National Emphysema and COPD Association Survey found that patients with COPD believe that the Internet is an important tool to learn about their condition and its management.<sup>18</sup> Nearly 70% of patients with COPD report using the Internet for health-related purposes, whereas 34% use popular social media (e.g., Facebook, Twitter, YouTube).<sup>11</sup> Many patients also access disease-specific social online support platforms, including COPD360social and PatientsLikeMe®. Patients with COPD, however, are generally older (i.e., over the age of 40) and live with a low socioeconomic status.<sup>1</sup> This combination of demographic characteristics increases the risk that technology-based self-management programs will face challenges in uptake and dissipate due to poor retention.<sup>19,20</sup> COPD self-management is a lifestyle change that requires sustained behaviors;<sup>5</sup> therefore, online support program retention is critical.

## Purpose

To continue the upward trend in technology adoption and to promote its sustained use within the COPD population, research is needed to explore factors related to patients' uptake and retention beyond technology acceptability. The purpose of this study was to understand

which aspects of the online experience facilitates or hinders the perceived ability of patients with COPD to achieve their information and self-management goals.

## METHODS

### Sample and Procedures

Twenty-five members of a community-engaged research (CEnR) program in a Southeastern US state enrolled in the study. Table 1 presents the sample socio-demographics of the sample. Participants were  $M = 59.08$  years old ( $SD = 9.46$ ), predominantly female, non-Hispanic and Caucasian, and earned less than \$20,000/year.

The lead researcher collaborated with a research navigator at the CEnR program to identify members who were eligible for the interview study. The CEnR research navigator acted as a gatekeeper; members were contacted and asked for their consent to be contacted by the lead researcher. The lead researcher contacted each member via the telephone to describe the study and ask screening question to determine eligibility. To be eligible, members must report a COPD diagnosis, identify as a current or former tobacco smoker, and having access to or used a smartphone or tablet computer.

When participants arrived to the CEnR program, the lead researcher presented the informed consent approved by the Institutional Review Board (IRB). Before the interview began, participants were asked to complete a brief demographic questionnaire (i.e., income, age, gender, race, ethnicity, smoking behaviors). The interviews, which were audio recorded and conducted in a secured room at the CEnR program, followed a semi-structured interview protocol, including open-ended questions and probing techniques. The first questions served as informative icebreakers, where participants were asked to talk about the various technologies (e.g., tablet, smartphone, desktop) and eHealth programs (e.g., social media, online programs, apps) they have used. The core interview questions covered the following topic areas: (1) beliefs about using eHealth to make a difference (good/bad) in the healthcare experience; (2) recount and describe recent experiences using eHealth to achieve a goal related to managing COPD; (3) aspects of recent eHealth experiences that helped (and those that hindered) to achieve a health-related goal; and (4) features and capabilities of eHealth technologies and programs that (a) are critical for achieving your health-related goal and (b) encourage (or discourage) their future use. Participants were remunerated with a \$40 eGift card.

### Data Analysis

This study applied a conventional content analysis approach, where data were inductively collected and examined without any preconceived theory or codes to guide the initial analyses.<sup>21</sup> Theories and models exist in the literature to explain the factors contributing to technological adoption;<sup>22</sup> however, there are limited theories or models that delve into the interpersonal or technological factors that facilitate or hinder users' experiences to achieve their information and health-related goals. Applying one of these existing theoretical models or frameworks would not have been relevant to the purpose of the study. Moreover, this deductive approach would have constrained the coding procedures to a particular framework

and limited the opportunity to pursue emergent themes that are not central to these frameworks. Given the value in addressing health problems facing unique subgroups of the population, an inductive qualitative approach was selected to identify emergent themes that relate to theories and models across disciplines and attempt to connect them for a broader conceptual understanding of this phenomenon.

The audio-recorded interviews were transcribed verbatim. Audio recordings were listened to once after each interview to report notes about social cues and vocal intonations that could influence interpretation (e.g., sarcasm, crying). Coding ensued after each transcript was read through twice. Data were analyzed using the constant comparative method.<sup>23,24</sup> Transcripts were reviewed according to the unit of analysis, ranging from sentences to a paragraph. All transcripts were reviewed to identify open codes. Axial codes and their properties were developed upon determining overlap and uniqueness of each open code. Axial and selective codes informed the codebook, and were used to guide the extraction of supporting qualitative excerpts. The lead author and a trained research assistant developed the codebook and dual-coded 30% of the transcripts, resulting in adequate inter-coder reliability (*Cohen's Kappa* = .81-.99). Axial codes were collapsed and categorized to identify salient emergent themes. The lead author shared preliminary results with participants via email as a form of member checking to allow them the opportunity to rebuttal or clarify results.

## RESULTS

The experiences of patients with COPD in using the Internet to achieve their information and health goals are dependent on their functional use of technology, as well as their ability and resilience to critically engage and exchange information with other online users. Derived themes to support this result include: (1) the desire to associated with members of their “in-group;” (2) relationship building with other online users; (3) security of personal information and identity; (4) information source and channel credibility; (5) user assistance and tutorials; and (6) methods of technological adaptability.

### **Social Identity: Desire to Associate with “In-Groups”**

Participants expressed the importance of receiving online COPD self-management support from small intimate groups of patients who have experienced (or overcome) their shared health challenges. There were also layers of self-identification that contributed to the online experiences and preferences of these participants – healthcare occupation and smoking status.

Participants who disclosed a current or former career in the healthcare sector (e.g., nurse, researcher, administration) were favorable toward incorporating healthcare providers into their online support experience. These participants preferred healthcare providers to serve as “fact checkers” or moderators that guide or redirect online discussions or information sharing. Participants without a healthcare occupational background, however, were less likely to hold this strong belief. These participants described healthcare providers as credible sources of information and important in healthcare planning, but identified them as troublesome in online support forums for COPD where patients share experiences and build relationships with one another. Participants did not believe that healthcare providers could be

helpful in this context for two reasons. The first was because they have only witnessed and studied COPD rather than *experienced* the challenges. The second was because the presence of a healthcare provider could perpetuate feelings of shame, especially in regard to failed smoking cessation attempts.

I've been through a lot of things in my life. I'm not willing to listen to anyone who hasn't done it [smoked tobacco] already. If you didn't do it, you just studied it. I want someone with experience, not book knowledge.

[Female, White, Current Smoker]

Beyond identifying as a patient with COPD, participants also identified as a “current smoker trying to quit... again” or a “former smoker who quit \_\_\_ years ago.” Former smokers reported their tobacco status multiple times and with a proud demeanor, whereas current smokers disclosed their status with less enthusiasm and deep sighs conveying defeat and shame. Interestingly, participants who identified as current smokers expressed the desire to receive smoking cessation support from COPD patients who are former and current smokers. Reciprocal support during cravings was an important aspect of smoking cessation. Knowing that another person like them is going through a similar struggle was considered motivating. Participants also identified former smokers as important sources of mentorship and accountability. This facilitated the mentality of, if they succeeded then so can we. Former smokers expressed enthusiasm and passion for sharing quit stories with other patients. Among current smokers in this study, smoking was considered the most important step in managing COPD and living a healthy life.

### **Establish Connections: Relationship Building with Other Users**

Participants reported value in interactive online activities rather than static educational content, which was considered boring and not helpful. Participants did not want to read fact sheets about COPD self-management; rather, they wanted to connect with others by reading their stories, actively posting their own personal stories, and providing reciprocal support to other users. Interactivity was identified by participants from the perspective of the technology (e.g., features) and the opportunities offered by different platforms to engage with other users. Information presented through multimedia channels enabled fluid communication with other patients, which was most valued by participants in this study.

It would have to be something engaging, something that was stimulating, or somehow connected to someone else that's sharing whatever is happening with you. Needs connectivity or something, just entertaining isn't enough.

[Male, Black, Current Smoker].

Participants noted experiencing challenges in developing these meaningful relationships. Participants expressed challenges in connecting with other online users, especially when an offline relationship does not exist. This perception was driven by the fear of “bothering” another person with too many messages, attempting to interpret the meaning of silence between messages, detecting emotion or sarcasm, and determining the genuine or trustworthy nature of the other person through computer-mediated messages.

I can't feel the person, and I don't know why I have that attachment to actually sensing an individual that I don't get over that device. There are too many layers of separation I guess. But I suppose that relationship could get developed.

[Male, White, Current Smoker].

### **Anonymity: Security of Personal Health Information and Identity**

The opportunity to remain anonymous on these online support forums was important for two reasons: securing personal health information and preserving identity. Participants expressed positive and negative aspects of uncertainty regarding the degree that sharing personal health information on the Internet was safe. Personal information was reported as demographic (e.g., name, age, sharing image) and health-related (e.g., physiologic health data, disease status). The negative aspect of uncertainty appeared to manifest as fear; specifically, the fear of identity theft, being located by people they do not want contact with, or unintentionally sharing information with their healthcare provider that could compromise their relationship and care (e.g., stigma, shame). Uncertainty also manifested as a form of empowerment, where participants expressed comfort in sharing or asking information that they would not otherwise discuss with a caregiver or healthcare provider.

### **Critical Appraisal Skills: Information Source and Channel Credibility**

Identifying the source of the information, the domain (e.g., healthcare organization vs. personal blog), and the location of websites according to their "hit number" in the search results were identified as common indicators of determining online health information credibility. Despite these indicators, the professional design of websites and persuasive communication strategies (e.g., testimonials, narratives) challenged participants' ability to determine the credibility of unfamiliar websites that presented new COPD information, specifically if the content presented hopeful or groundbreaking research about COPD (e.g., the cure).

I don't want to miss something new. There is a [website] that's advertising stem cells for COPD, and I think it's bogus, nothing but testimonials and no research. But I cannot be sure.

[Female, White, Former Smoker]

Information sources and channel credibility was also assessed by the amount of scientific or technical jargon. Participants reported a lack of comfort with jargon about health or technological programs (e.g., instructions to download, software privacy policies). This information was described as difficult to understand, thus presented challenges to assessing its veracity and quality. Ultimately, this led to avoidance or discontinuation of the programs.

Especially now, you're so afraid to download anything for fear you're going to download malware. So, I'm really hesitant about downloading things. The computer language sometimes is... I don't know what they're talking about. And then you're afraid to try because you may ruin it.

[Female, White, Former Smoker].

## Health Information and Technology Management: User Assistance and Tutorials

Participants described themselves as needing help to search for information, download online support tools, and navigate new features of a mobile device. The preferred type of assistance was most often younger children or adolescents, rather than adults or peers. Participants felt that children or adolescents knew more about the usability procedures and were able to describe the process in a clearer and more simplistic manner.

But when [my neighbor's kid] helps me that's great. When I have adult friends help me, in moments, they're just so far over my head or further depth in the material that I go, 'where did I miss, what did I miss, and how did we get here?'

[Male, White, Current Smoker]

Hospital staff were identified as an important conduit for support related to downloading and navigating formal online support tools, like hospital-based electronic health records (EHRs). Receiving a tutorial on how to download an app, register a username, and navigate its features was considered important for becoming familiar with online support. Learning how to independently navigate and use online support tools in order to communicate with healthcare providers and accessing online health information was seen as an opportunity to feel empowered.

## Technological Strategies: Methods of Adaptability

Participants described enjoying the option to send text-based messages, rather than verbal communication through video or audio communication. Moreover, texting was more desirable than verbal communication due to excessive coughing and shortness of breath that hinders the ability to verbally communicate with others face-to-face.

Despite the interest and value in creating text-based messages, participants still experienced challenges reading and using virtual keyboards displayed on small illuminated screens of smartphones and tablets. The small nature and close proximity of the virtual buttons often resulted in an autocorrect malfunction, causing poor communication and frustration. To overcome this challenge, participants adapted features of the technology and became more familiar with online support tool platform capabilities. Several mobile features were described. One assistive feature was the continuous scrolling feature on webpages, which allow users to browse through content by swiping their finger along the screen rather than selecting buttons to move from page-to-page (e.g., "next" button). Another feature held in high regard included dictation or voice commands (e.g., Apple's Siri©) where verbal language is transduced to text-based messages. These are functions that allow users with dexterity/motor impairments to more easily search for information and exchange text-based messages on the Internet.<sup>25,26</sup>

I prefer this button [the voice command option] because I don't do this thing like kids where they do 100 words a minute. I just push on the little button and tell it what I want.

[Female, White, Current Smoker]

## DISCUSSION

Allen and colleagues<sup>27</sup> report that patients with long-term chronic diseases use online patient communities for social and emotional support rather than static information seeking. Membership to these online communities affords patients access to relationships with minimal negotiation and expectations for reciprocation, primarily because group membership is nearly immediate and the support provided by its members is a “public good.” This essentially means that enlisting as a member on a patient online community assumes homogeneity and belonging within the group. In this study, patients with COPD desired meaningful connections (i.e., strong ties) with other online users for emotional and informational support, but loose and superficial connections prevailed. Patients felt they could obtain new information shared from online users but they could not develop strong emotional connections or supportive relationships.

Computer-mediated communication (CMC) literature posits that strong ties are difficult to develop and sustain on the Internet without engagement or reciprocal exchange.<sup>28</sup> Moreover, the anonymity and de-individualization of an online user may be compromised if these situational group norms are violated during engagement; as such, these violations would be a threat to group homogeneity and identification that a user is an “out-group” member.<sup>29–32</sup> CMC and interpersonal communication theory also posits that group identity and following a rate of self-disclosure consistent with group norms is the crux of developing strong ties with others.<sup>33–35</sup> As such, language expression and communication serves an important role in CMC and group identity.<sup>36</sup> Without timely, appropriate, and reciprocal self-disclosure that leaves a favorable impression on other users, there is limited opportunity to develop strong ties that are grounded in sincere and sustained support. Group identity alone is not likely to ensure strong ties within online patient communities; rather, group identity coupled with the use of communication strategies in a particular context can influence how users obtain online information and social support.

Anonymity is a protective affordance of online support forums, allowing patients the ability to disclose information without fear of judgment or confrontation that is more likely in face-to-face conversations.<sup>37</sup> In this context, patients may censor or adjust the content of disclosures to maintain a certain online appearance (e.g., save face). This study found that concerns about privacy preservation and underdeveloped eHealth skills (i.e., critical, communicative) appeared to threaten technological resilience and precluded patients with COPD from engaging in online behaviors resulting in supportive relationships with other online users. There is no evidence that proficient eHealth skills can strengthen “strong ties” on the Internet; however, the ability to access, evaluate, and act on online health information can increase the availability of “weak ties,” especially for users who regularly use and rely on social media.<sup>38</sup> This is consistent with a recent study reporting that stronger eHealth skills, which are dependent on digital security management abilities, tend to increase the frequency of online activities.<sup>39</sup>

Instruments that measure the social aspects of eHealth skills assess functional confidence and knowledge using technology to create and disseminate information (e.g., “I know how to post...,” “I can type...”),<sup>39,40</sup> rather than from the perspective of interpersonal CMC or



online social competence.<sup>33–35</sup> Patients with COPD may not build strong ties within online communities because they are not engaging with other users frequently or meaningfully enough (i.e., avoidance due to privacy concerns) or perhaps the method of communication used (e.g., jargon used, rate of self-disclosure) is not consistent with the implicit group norms of the online community. Research is needed to explore the relationship between privacy concerns and online social competence among patients with COPD, and how these two function in terms of being resilient to use and overcome adversity of technology. This research could benefit from applying CMC theory to conceptualize how eHealth skills and perceptions of privacy contribute to employing relationship-building strategies conducive to positive self-management behaviors.

This study presents a number of novel findings with practical implications; however, it is not without limitations. Although the sample size is relatively low, this study represents a unique subgroup of the population with low socioeconomic status, a COPD diagnosis, and CEnR program membership. Second, participant data was elicited through in-person interviews; therefore, the results of this study may be prone to social desirability bias. Finally, this study was exploratory and did not quantitatively assess the eHealth skills or online behaviors of patients with COPD. Thus, the qualitative data provided by these patients should be considered formative research used to extend theoretical approaches for explaining social support and information seeking among this patient population. Data from this formative qualitative study can be used to inform subsequent pilot studies to advance COPD patients' experiences using online support platforms for self-management advancement.

### **Translation to Health Education Practice**

Certified health education specialists should favor disease-specific online support forums over generic social media platforms in delivering health education to patients with COPD. Disease-specific platforms can provide concentrated support and patient education to facilitate self-management behaviors and positive health outcomes,<sup>41</sup> while also reducing the potential for stigma or shame associated with the condition.<sup>42</sup> This study provides evidence that patients with COPD have positive perceptions about the potential of using disease-specific online platforms. The COPD Foundation developed COPD360social, which promotes patient to patient and patient to provider communication, knowledge translation, and community building through social support and recognition for patient influencers.<sup>43</sup> COPD-specific forums are also available on Pinterest and YouTube, where self-management education is disseminated and consumed by patients.<sup>16,17</sup> Research is needed to understand factors that facilitate patients' decisions to participate in these COPD-specific support platforms.

Certified health education specialists should not presume that all patients with COPD are homogenous in their health information needs and preferred source of interaction (e.g., patients vs. providers). This study found that the health information and relational needs of patients in this unique population vary by occupation experience in the healthcare sector and their smoking status (e.g., current vs. former). Certified health education specialists who work with patients living with COPD who want to use online support tools to better self-manage their condition could recommend a program that is unique to values and needs

associated with their source and information preferences. If patients know that they are being directed to a resource that is tailored to their preferred needs then they are cognitively prepared to attend and process that information,<sup>44</sup> theoretically increasing the likelihood of program acceptance, sustained use, and ultimately behavior change.

Certified health education specialists should continue to enhance both technology and health literacy of patients with COPD, with a specific emphasis on online critical appraisal and communicative skills. As reported in this study, scientific and technical jargon evoked feelings of technological avoidance and uncertainty surrounding the online experience. One type of technological jargon included the privacy disclosures and agreements presented prior to creating an online account or downloading a mobile application. Threats to privacy and information security may influence patients' disclosure tactics when seeking preferred online health information, ultimately hindering their online experience to obtain desired information and receive the support they need. This phenomenon may have implications for online support forums where patients disclose and recommend treatment regimens and medication side effects to other patients on social media. This may also influence self-reports of personal physiologic and behavioral data within electronic health records. Translating this information in a manner that is easy to understand and does not question the safety of the online experience will be important for optimizing patients' online experiences, as well as maintaining the credibility of these online platforms as key tools to facilitate healthcare delivery and management in COPD.

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**Table 1.**

## Demographic Characteristics of Patients with COPD (N = 25)

Demographic Characters	n(%)
Age (in years), <i>M(SD)</i>	59 (9.4)
Gender	
Male	6(24)
Female	19 (76)
Race	
White	18 (72)
Black/African American	5 (20)
Asian American	0 (0)
American Indian	0 (0)
Multi-Racial	2 (8)
Ethnicity	
Hispanic	1 (4)
Non-Hispanic	24 (96)
Education	
Less than high school	5 (20)
High school/GED	4 (16)
Some college	7 (28)
College graduate	4 (16)
Missing	5 (20)
Income (Annual \$)	
Less than \$20,000	16 (64)
\$20,000-\$34,999	3 (12)
\$35,000-\$49,999	0 (0)
\$50,000-\$74,999	1 (4)
\$75,000 or more	0 (0)
Missing	5 (20)
Smoking Status	
Current	15 (60)
Former	10 (40)
Smoking Frequency in Past 12 Months <sup>a</sup>	
Every day	12 (80)
Some days	3 (20)
Attempt to Quit Smoking for > 1 Day in Past Year <sup>a</sup>	
Yes	8 (53.3)
No	7 (46.7)

<sup>a</sup>Includes only participants who identify as a “current smoker”