



Patients' perspectives on COPD: findings from a social media listening study

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ABSTRACT We utilised social media listening (SML) to obtain patients' perspectives on symptoms, diagnosis and comorbidities associated with chronic obstructive pulmonary disease (COPD) and its impact on patients' quality of life (QoL).

A comprehensive search on social media platforms was performed for English language content posted between July 2016 and January 2018 using COPD-related terms. Social Studio, a social media data aggregator tool, was used to capture relevant records. The content was manually curated to analyse and map psychological aspects with descriptive statistics applied on aggregated findings.

A total of 849 posts from patients or caregivers ("patient insights") were considered for the analysis, corresponding to postings of 695 unique individuals. Based on 734 mentions of symptoms from 849 posts by potential patients/caregivers, cough (27%), mucus (25%) and shortness of breath (21%) were the most frequent; analysis by perceived COPD severity indicated these to be common across all severities. Difficulty in mucus clearance (24% of 268 mentions) and sadness (40% of 129 mentions) were top among the aspects impacting physical and emotional QoL, respectively.

SML from patients with COPD indicated that relief from cough, mucus production and shortness of breath would be the most desirable aspects of disease management from a patient's perspective.



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Cough, mucus and dyspnoea are the most frequently discussed symptoms on social media by patients with COPD <http://ow.ly/WdnU30mZ7ZP>

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Introduction

Chronic obstructive pulmonary disease (COPD) is a disease of the airways and lungs characterised by persistent respiratory symptoms and progressive airflow limitation. Patients with COPD experience a range of symptoms, including dyspnoea, cough, sputum production, wheezing and chest tightness [1]. The symptom burden in patients with COPD imposes a significant challenge with a substantial impact on patients' physical and psychological wellbeing [2, 3].

The internet has transformed the communication channels for people in general, and for patients in particular [4, 5], with social media interactions including online forums, blogs, microblogs (*i.e.* Twitter), Wikipedia, video blogs, social networks and content communities. Social media offers an online versatile platform for conversations around health topics relating to patient education, health promotion, public relations and crisis communication. People create and share a wide range of content on health and wellbeing about themselves, their friends, family and surrounding community through social media [6].

Studies have shown the feasibility of using social media to investigate various health-related issues ranging from lifestyle disorders, such as diabetes and metabolic syndrome, to cancer [7, 8]. Studying such online interactions through social media listening (SML) provides an opportunity to track behaviours and interactions of patients, and to understand values and expectations about their disease condition and its management. The utility of SML in COPD to understand patients' perspectives remains untapped. In the present study, we describe insights into symptoms, diagnosis and comorbidities associated with COPD and perceived impact of COPD on quality of life (QoL) from the patients' perspectives, gathered through SML.

Material and methods

Study design and data source

A comprehensive search was performed on the social media platforms (Twitter, blogs, news and forums) for English language content posted online between July 2016 and January 2018, and to evaluate COPD-related posts using the following predefined search terms: "chronic obstructive pulmonary disease" or "COPD" or "emphysema" or "obstructive lung disease" or "chronic bronchitis" or "pulmonary obstructive airflow". These key words were combined with other search terms related to symptoms, disease severity and diagnosis (supplementary table S1). Social media posts from the USA, UK, Canada, Australia and South Africa were retrieved using an online aggregator tool, Social Studio (www.salesforce.com).

Ethical considerations

All data utilised and presented in this study were obtained from publicly accessible sources without accessing password-protected information. Privacy of patients was respected and caution was taken in using the information posted by them: all online content was anonymised, complying with the data privacy obligations and the US Health Insurance Portability and Accountability Act [9]. Additionally, Novartis Social Media Council approval was obtained for the conduct of this study.

Selection of posts

Social Studio provides downloadable links of posts from social media channels based on pre-specified key words with the date of the posts, timestamp and user region. It assigns a unique article ID for each downloadable link from social media. The links available from Social Studio were accessed to retrieve the posted content in Microsoft Excel (Microsoft, Redmond, WA, USA), anonymised and cleaned manually to filter out duplicates (detailed in the supplementary material). Table 1 provides a glossary of the notations used.

TABLE 1 Glossary

Term	Definition
Article ID	Unique identifier assigned by Social Studio to each downloadable link for social media
Mention	Indicates the total number of times a symptom, treatment, diagnostic test or other parameter is mentioned irrespective of the number of posts
Patients' insights	Description about patients' perceptions of various aspects of chronic obstructive pulmonary disease, mainly including, but not limited to, symptoms, diagnosis, management and its impact on patients' quality of life, posted by either patients or their caregivers
Post	Social media content with a defined article ID
Unique record	Pertains to a unique user identifiable by the same content even if the post has a different timestamp
User	An individual who posted the content on social media

Categorisation and indexing of posts

Each post was reviewed to evaluate the mention of different parameters and tagging was done using a predefined template in Microsoft Excel. Not every post may have mentions of all parameters such as symptoms, treatment, severity, diagnosis, *etc.* Nevertheless, each post has a mention of one or more than one parameter.

Demographic information about users (sex, age and time since diagnosis) was recorded when available. Sex was inferred from the user's name (unless it was ambiguous) or from message content, or categorised as unknown. Additionally, age and time since diagnosis were collected if mentioned in the text.

The records were classified as insights reported by possible patients or possible caregivers, where this could be determined based on analysis of content (*e.g.* direct reference to a "self" within the content, without references to other subjects, was qualified as patient-reported insights; posts with no first-person references but reference to a third person located in the content, such as a mention of a relation like husband, wife, son, daughter, *etc.*, were qualified as insights reported by caregivers).

Where the text allowed, severity of COPD was divided into three groups (mild, moderate and severe) based on the verbatim assessment of each post. COPD was labelled as "mild", "moderate" or "severe" if there was a direct reference to the severity within the content (patient-perceived severity) or after interpretation of the parameters, including sentiment of the comment, lexicon used to describe the condition, and impact on physical and emotional QoL.

Mentions of risk factors, symptoms, comorbidities and diagnosis were aggregated and reported. Moreover, patients' perceptions of the disease, QoL and unmet needs were analysed. We observed some clustering about how potential patients would engage through social media, either with other users or with healthcare professionals during the course of the disease. Cumulatively, we mapped the clustering of online social media posts with a patient's journey and identified specific "touch points" where patients tend to share their experience online.

Statistical analysis

For the anonymised content, only aggregated qualitative findings are reported. Manual curation was used to analyse and map psychological aspects expressed by users. All data were analysed using descriptive statistics. Categorical data were described using number of posts and/or percentages. A word cloud including text from all the posts was generated using an online application (WordArt.com) to visualise the focus on the most frequent words.

Results

Of the total 2461 posts retrieved, 433 were excluded based on the reasons listed in figure 1. Of the remaining 2028 posts, 849 were designated as posts from patients or caregivers, corresponding to 695 unique records.

The most common source of the posts was online forums (41%), followed by blogs (25%) (table 2).

Of the 695 unique records, 82% were from patients and the remaining 18% were from caregivers. Sex could be inferred in 283 of these records, with similar proportions of male (51%) and female (49%) patients. Age was available from 133 of the unique records; 70% of those were patients aged ≥ 60 years. Data for the time since diagnosis were available for 92 unique records; of these, the time since diagnosis was <1 year (26.1%), 1–2 years (17.4%), 3–10 years (39.1%) or >10 years (17.4%).

Among those who reported risk factors ($n=153$ unique records), the majority (81%) perceived that COPD was associated with smoking; the remaining 19% attributed COPD to their working conditions, environment or genetic abnormality. It appeared that individuals were well aware of the ill effects of smoking, identifying it as a cause; however, some patients failed to recognise the benefits of quitting or the drawbacks of continued smoking. Current smoking status was mentioned only in 68 unique records and 71% of those individuals said they had quit.

Disease severity was derived for a total of 213 unique records. Severity of COPD as perceived by patients ($n=40$ unique records) and inferred from verbatim ($n=173$ unique records) posts showed similar proportions of individuals with "mild" (20% *versus* 23%), "moderate" (30% *versus* 29%) and "severe" (50% *versus* 48%) COPD. Hence, the patient-perceived and inferred disease severity status designations were combined for the subsequent analyses.

Perceived comorbidities and usage of diagnostic procedures were analysed based on the number of mentions. Of the 193 mentions of comorbidities, lung diseases, cancer and heart diseases were stated as a comorbidity in 23%, 13% and 12%, respectively. Among 127 mentions of diagnostic procedures,

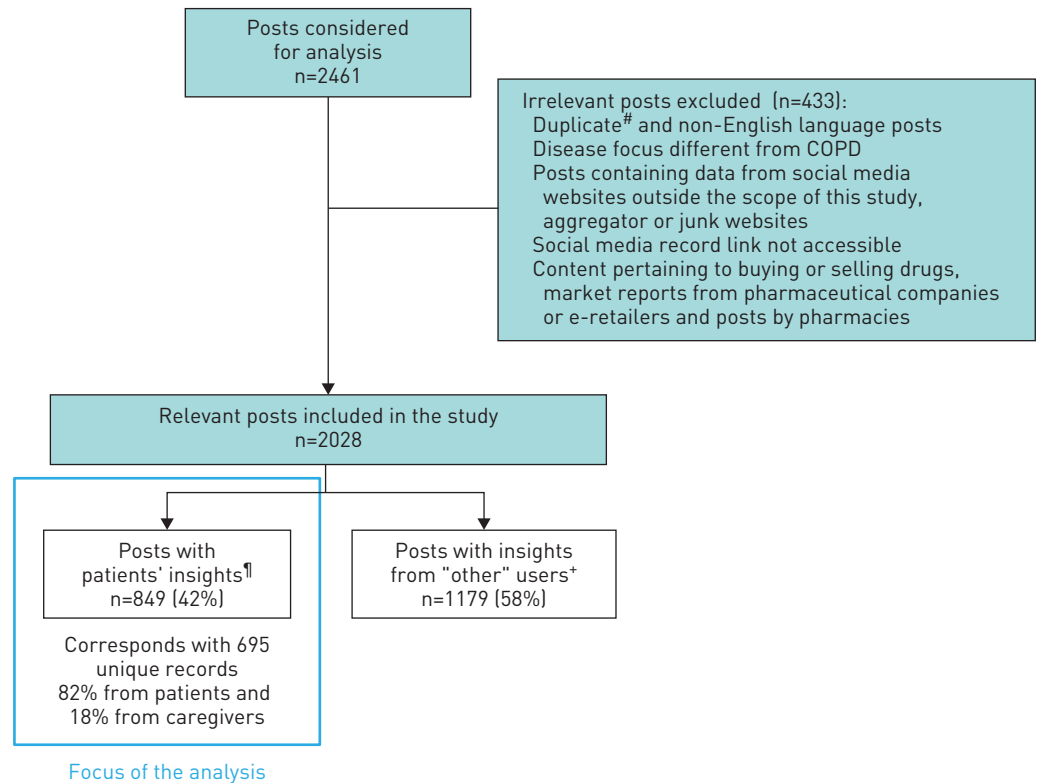


FIGURE 1 Categorisation of social media posts related to chronic obstructive pulmonary disease (COPD). #: based on article ID, social media link and/or content (e.g. posts with similar content on different social media or re-post by the same user identifiable by content); ¶: description about patients' perceptions of various aspects of COPD, mainly including, but not limited to, symptoms, diagnosis, management and its impact on their quality of life by "patients" or caregivers was qualified as "patients' insights"; *: includes users such as healthcare professionals, media reporters, industry personnel, bloggers or nondefined.

"spirometry" (38% of all mentions) and "chest X-ray" (20%) were the most commonly mentioned tests. Patients actively discuss lifestyle changes online (n=98 unique records); quitting smoking topped such discussions (49%). Other lifestyle changes included physical and breathing exercises (27%), dietary modifications (13%), monitoring quality of air (7%), and receipt of flu shots (4%).

Perception of symptoms

Based on 734 mentions of symptoms from 849 posts by patients or caregivers, the most commonly reported symptoms were cough (27%), mucus (25%) and shortness of breath (21%) (figure 2a). An analysis by derived disease severity indicated that cough, mucus and shortness of breath were common

TABLE 2 Source and geographical distribution of posts

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Total included posts	2028
Source	
Forum	831 (41)
Blogs	507 (25)
Twitter	385 (19)
News	304 (15)
Geographical region	
USA	1211 (60)
UK	580 (29)
Canada	178 (9)
Australia	53 (3)
South Africa	6 (<1)
Data are presented as n or n [%].	

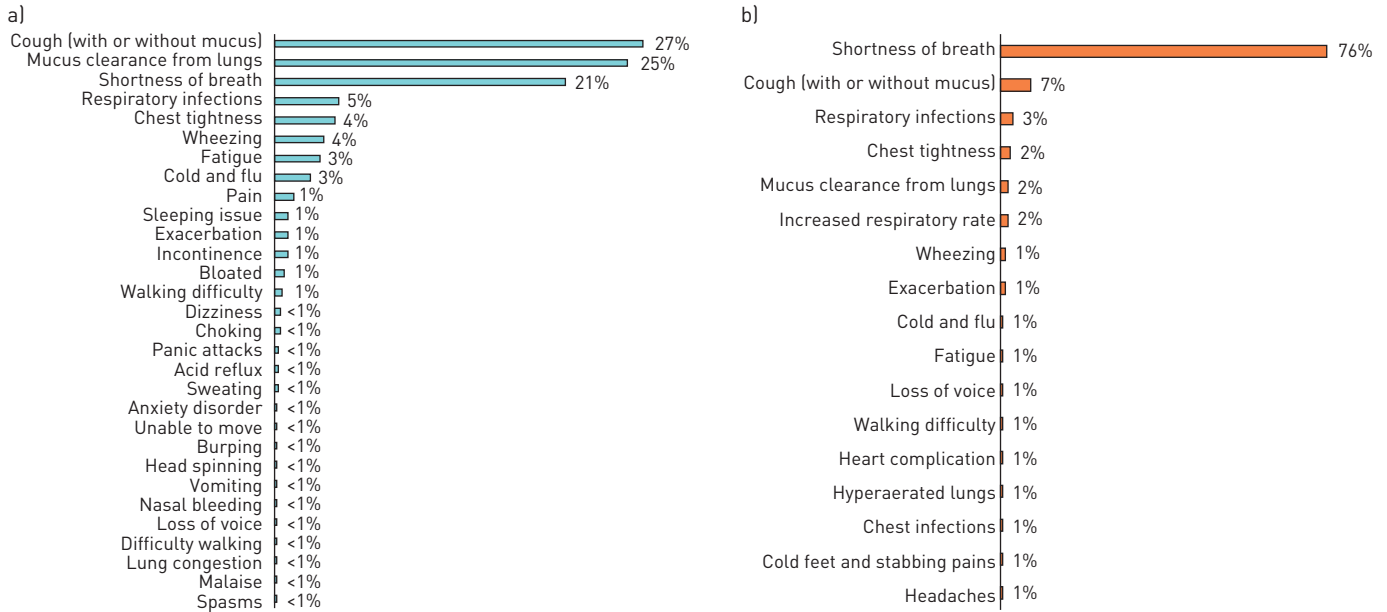


FIGURE 2 Mention of common symptoms for a) potential patients or caregivers (n=734 mentions, based on 849 posts) and b) "other" users (n=170 mentions, based on 1179 posts).

across all COPD severities, albeit these symptoms became more progressively "bothersome" with advancing severity of COPD (figure 3).

Urinary incontinence was mentioned in seven unique posts (1% of the total). Four out of the seven mentions associated incontinence with cough. This might not be a true reflection of frequency due to the fact that patients feel uncomfortable talking about this (see supplementary material).

Of note, assessment of the content of posts by "other" users indicated that shortness of breath was by far the most commonly mentioned symptom (76% of the total 170 symptom mentions from 1179 posts); cough and mucus had 7% and 2% of mentions, respectively. Incontinence was not mentioned in the posts by the "other" users (figure 2b).

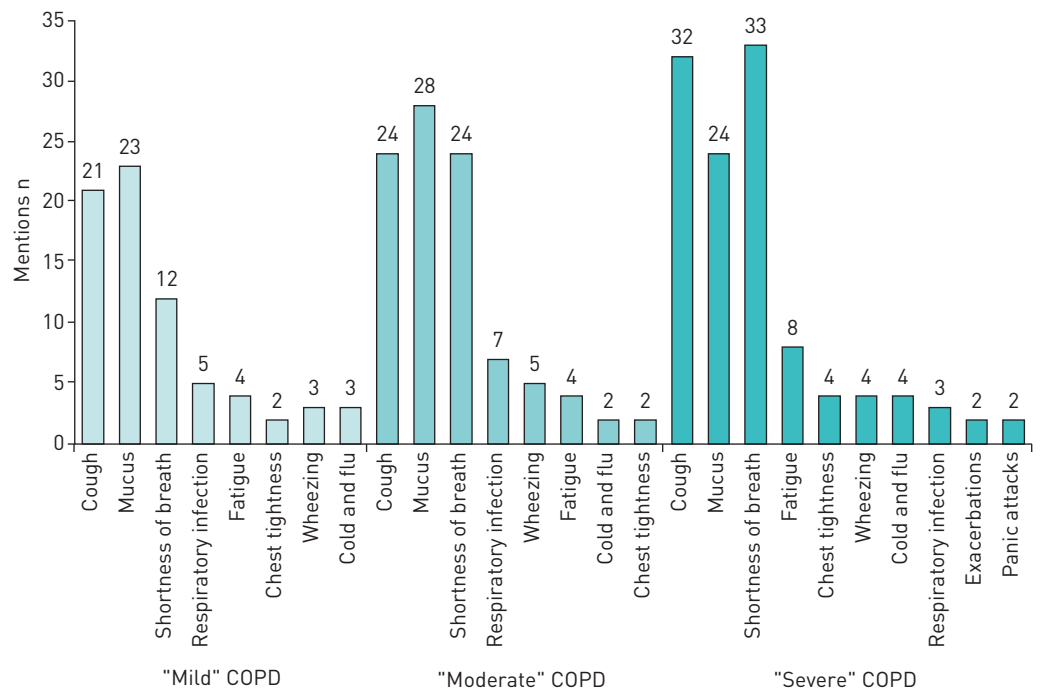


FIGURE 3 Mention of chronic obstructive pulmonary disease (COPD) symptoms by perceived "severity".

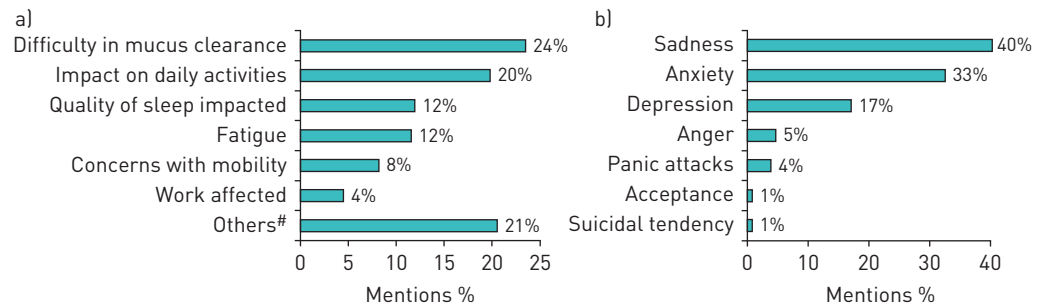


FIGURE 4 Mention of aspects pertaining to: a) physical quality of life (n=268 mentions) and b) emotional quality of life (n=129 mentions). [#]: includes chest tightness, hospitalisation and wheezing.

Quality of life

Overall, there were 397 mentions related to various aspects of QoL that broadly covered two domains, *i.e.* physical and emotional QoL (figure 4). Difficulty in mucus clearance (24% of the total 268 mentions) and impact on daily activities (20%) were the most common aspects impacting physical QoL. Sadness and anxiety (40% and 33%, respectively, of the total 129 mentions) were the most commonly perceived themes affecting emotional QoL. Supplementary table S3 provides an additional illustrative list of verbatim mentions pertaining to perceived impact of COPD on QoL.

Illustrative patient journey

An empirical illustration of a patient's journey in terms of touch points with the medical community, symptoms, diagnosis, treatment and disease management, as derived from the social media posts, is shown in figure 5 (additional details in supplementary table S4).

Typically, patients first present with symptoms at a general practitioner's office and a specialist referral is then given on a needs basis. Patients post symptoms and severity of COPD online after diagnosis; they actively share experiences on forums and appear to seek information using various social media channels. Most patients reported quitting smoking and adaptation of dietary modifications and exercise after the diagnosis; some patients advocated continued pulmonary rehabilitation in addition to standard treatment for better disease management, mentioning prevention of exacerbations and improvement in lung function. Patients with COPD spread awareness on social media and recommend newly diagnosed patients to reach out to support groups for information.

Figure 6 shows a world cloud drawn using all of the words from the posts by patients or caregivers (~12800 words). The font size correlates with the relative frequency of each word (words in bigger size being the most frequently used). The word cloud reveals that the most common words used by patients in online posts are "breath", "lung", "mucus", "cough" and "smoke" (supplementary table S5). Of note, patients using social media did not use the word "sputum" while describing their symptoms, rather they used "mucus" and "phlegm" interchangeably to indicate this symptom.

Discussion

Patient experience data are intended to provide information about the impact of a disease or condition (or therapy or clinical investigations) on patients, and remain a cornerstone for medical product development and regulatory decision making [10]. Collecting such data provides important insights on the impact of disease on the patient's daily life. Traditionally, approaches such as conducting face-to-face interviews, telephone surveys or focus group discussions have been used to understand the patient's experiences and perspectives on a disease condition [11, 12].

Patients are increasingly active online [13], and use social media to participate and express themselves freely, in an open and uninhibited way. Studying patients' perspectives on a disease by analysing open-source social media exchanges provides an innovative approach to collect patient experience data. Evaluating such information can inform patient-centred drug development and provide patient-based evidence to inform discussions with health authorities [14] as the contribution of patients' perceptions in healthcare decision making becomes increasingly important [15–18]. Integrating such patients' insights in drug development represents an opportunity to listen to the patients' voices early in drug development models. Such integration would be a step towards including patient engagement in clinical trial design and guidelines development.

The findings from our study suggest that patients with COPD actively share experiences with their peers and seek information on social media platforms. The results also indicate that patients are familiar with

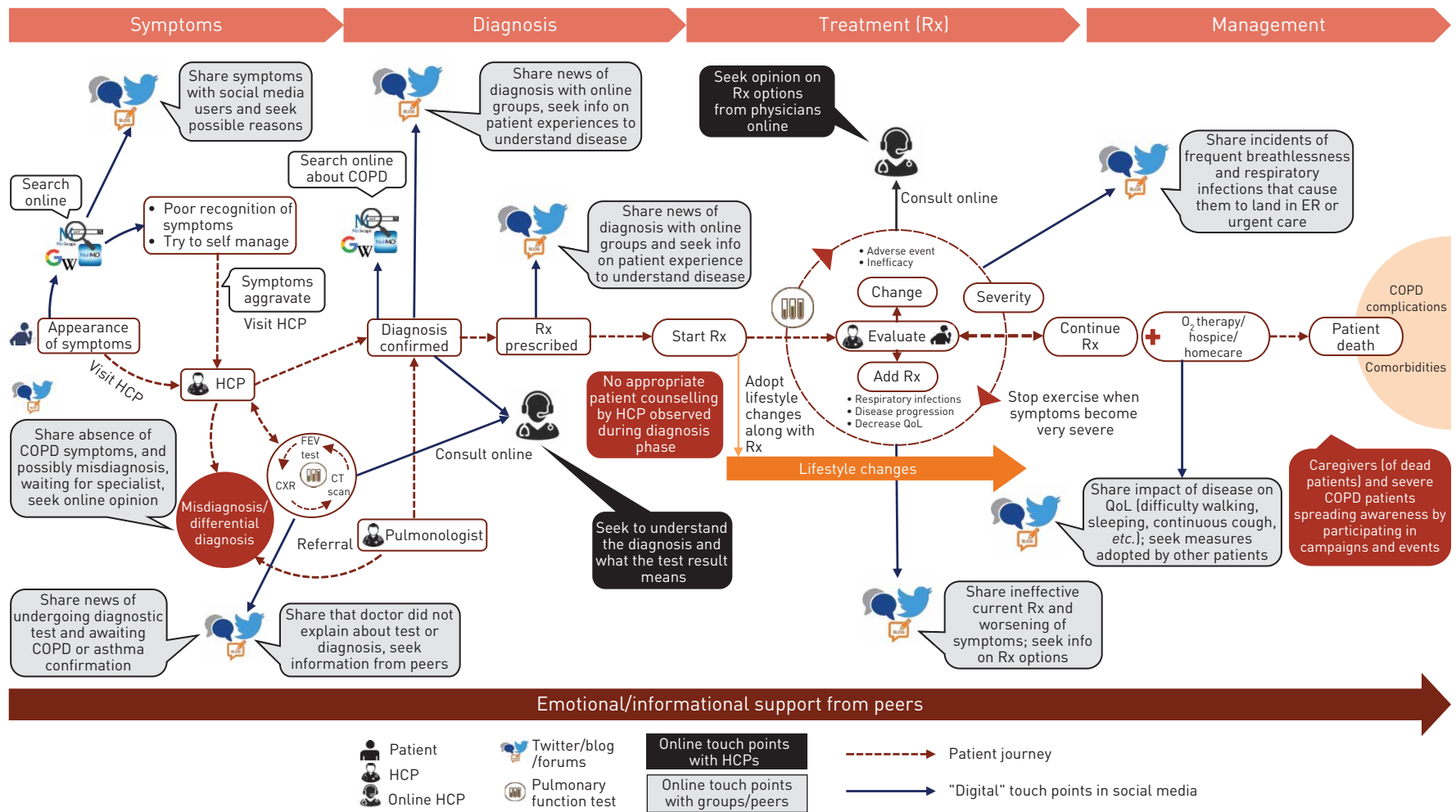


FIGURE 5 Digital touch points along the patient journey. HCP: healthcare professional; COPD: chronic obstructive pulmonary disease; FEV: forced expiratory volume; CXR: chest radiography; CT: computed tomography; QoL: quality of life; ER: emergency room.

Our findings need to be interpreted on the backdrop of inherent limitations of SML studies. The legitimacy of the views gathered from online posts cannot be confirmed and patients may deliberately or inadvertently adopt multiple identities in virtual forums [14, 33]. Moreover, not everyone is actively contributing to social media content online. Thus, the results reflect views of people who have access to the internet and actively engage in online forums. Consequently, generalisability of findings needs consideration of the “demographic” and “digital” divide. The posts on social media are typically short, unstructured and may contain minimal information on the patient’s experience, with limited background or lack of detail, which can make insight generation from such material challenging. Discourse was observed based on the findings focused around more tangible issues in COPD, such as physiological symptoms. However, it is likely that the online users found it is easier to articulate more abstract variables such as emotions, relationships, adaptation to illness or fulfilment of human needs, which are important elements in COPD, and might not have deliberated on other issues warranting further studies to validate the findings in patients. Owing to the passive observational nature, a SML study does not allow further probing to seek clarification on the views expressed by individuals. The diagnosis of COPD and categorisation of severity in the present study was based on the verbatim assessment for each post. Although it is recognised that the categories for severity may be imprecise, the grouping was nevertheless valuable for interpreting the posted information according to the stage of the disease. Also, previous publications evaluating the reliability of self-reported diagnoses of chronic diseases and treatments have reported high validity [34–39]. Lastly, there are emerging ethical issues surrounding this new form of ethnography, with unparaphrased quotes from individuals potentially being able to be found when such quotes are searched online. Although we purposely did not include original quotes from posts in this article, there is a need for guidance about issues of informed consent where discourse is being utilised for research.

In summary, patients with COPD actively share experiences on forums and seek information on social media. SML presents a new approach to derive unfiltered and uninfluenced patient insights on patients’ experiences with chronic diseases such as COPD. The insights derived from SML have the potential to complement more traditional approaches to drive more patient-focused drug development. SML in patients with COPD indicates that relief from cough, mucus production and shortness of breath would possibly be the most valuable aspects of disease management from the patients’ perspectives. The findings from qualitative SML studies should be interpreted considering the fact that the online research question was pertaining to symptoms and also taking into account the inherent limitations of SML study methodology. Nevertheless, the outcome of such studies may be used to design further studies aimed to derive patient insights.

Conflict of interest: N.S. Cook is an employee and shareholder of Novartis. K. Kostikas is an employee and shareholder of Novartis. J-B. Gruenberger is an employee and shareholder of Novartis. B. Shah is an employee of Novartis. P. Pathak is an employee of Novartis. V.P. Kaur is an employee of Novartis. A. Mudumby is an employee of Novartis. R. Sharma is an employee of Novartis. F.S. Gutzwiller is an employee and shareholder of Novartis.

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