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ORIGINAL RESEARCH

How People with COPD Perceive and Communicate Exacerbations: A Multicountry Survey Study

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Background and Objective: Exacerbations negatively impact quality of life of people living with chronic obstructive pulmonary disease (COPD) and can accelerate disease progression. Studies suggest that patients find it difficult to recognize exacerbations and, therefore, under-report exacerbations. We aimed to understand how people living with COPD perceive and communicate their experiences of exacerbations.

Methods: A cross-sectional survey including one open-ended question was developed using a targeted literature review, with input from patients and clinicians. People diagnosed with COPD were recruited from online consumer research panels in Brazil, China, France, Spain, UK, and USA and completed the survey. Responses were described overall and in specific subgroups; thematic analysis was used for the open-ended question.

Results: Of 857 respondents (median age 58 years; 50.5% male), 623 (72.7%) reported daily shortness of breath; 417 (48.7%) that daily symptoms changed "a little". In the open-ended question, exacerbations were described through a narrative lens detailing subjective experiences of symptoms, their management, potential causes, and emotions felt during exacerbations, with no single preferred term. In the 671 (78.3%) respondents who reported ever having an exacerbation, these were identified as symptoms being "worse than usual" (52.8%) or because respondents had "more trouble than usual with daily activities" (50.1%).

Conclusion: While people living with COPD report confidence in their ability to identify exacerbations, there is a disconnect between their experience of exacerbations and the language and definitions used in clinical practice. A discussion guide emphasizing the use of plain language could improve communication between healthcare providers and patients.

Keywords: chronic obstructive pulmonary disease, cough, quality of life, observational, symptoms

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Introduction

Chronic obstructive pulmonary disease (COPD) poses a significant global health challenge, profoundly impacting the quality of life of an estimated 392 million people worldwide.[1] COPD is characterized by day-to-day variation in symptoms and, in many patients, periods of exacerbation,[2,3] defined as a deterioration in symptoms, over a period of less than 14 days and where other causes have been considered and excluded.[4,5] Exacerbations are costly for health systems to treat, severely impact quality of life[5–7] and escalate the risk of cardiopulmonary events, including subsequent

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exacerbations, cardiovascular events, and death, as well as other adverse medical outcomes. The prevention of COPD exacerbations is a key therapeutic objective, and prompt treatment of an exacerbation can reduce severity and accelerate recovery.[8] This requires not only the accurate and early identification of exacerbations by patients but also the reporting of exacerbations to their healthcare providers (HCPs). However, COPD exacerbations are often poorly recognized and under-reported. Previous research suggests that one-third of people with COPD are aware when an exacerbation takes place,[9,10] but less than one-third of exacerbations, when perceived, are reported.[11] Several factors may contribute to the poor recognition and under-reporting of COPD exacerbations. Firstly, the major symptoms of COPD exacerbations are diverse and nonspecific.[5] People living with COPD and other comorbidities may misattribute exacerbation symptoms, like breathlessness, to other conditions, such as heart failure or arrhythmia.[5] Furthermore, the variation in symptoms associated with an exacerbation, and for some, the gradual worsening of symptoms,[12] may make it difficult to distinguish between an exacerbation and daily symptom variation.[13] Secondly, miscommunication between patients and their HCPs may lead to under-reporting of COPD exacerbations. For instance, people living with COPD often use nonmedical terms for an exacerbation (eg, “breathless”, “exhaustion”, or “dizziness”).[9,14] Prior research has also indicated that patients and their clinicians rarely agree on what are the most concerning symptoms, exemplifying the potential communication gap between clinicians and people living with COPD.[15] Improved understanding of how people living with COPD recognize and convey their experiences with exacerbations to HCPs is essential for developing strategies to enhance early detection, patient education, and overall management.[16] Recognizing the challenges associated with identifying and reporting COPD exacerbations, few studies have explored how patients experience, recognize, and communicate exacerbations. Moreover, most studies were conducted with small sample sizes and in a limited number of Western countries.[9,10,12–14] The present study aimed to explore how people living with COPD in multiple countries (1) experience day-to-day symptoms; (2) perceive, experience, and describe exacerbations; and (3) distinguish between day-to-day symptom variation and exacerbations.

Methods

This multicountry, observational, cross-sectional study used survey data collected from people living with COPD in Brazil, China, France, Spain, the UK, and the USA and is reported in accordance with the Consensus-Based Checklist for Reporting of Survey Studies (CROSS).[17]

Survey Development

A patients’ survey was developed based on a targeted literature review and guided by members of the “ACT on COPD” taskforce supported by AstraZeneca. This taskforce is an international, multidisciplinary research team with expertise in COPD comprising HCPs, researchers, and patient advocacy group representatives. Briefly, a targeted literature review identified peer-reviewed qualitative studies to better understand the nuances of patients’ experience and build a conceptual framework. Subsequently, a first version of the survey was created, and questions were checked for readability and comprehensiveness by five people living with COPD. The research team conducted several rounds of reviews until consensus was reached on the number and phrasing of questions (detailed methodology; Text S1, Tables S1 and S2).

The final version of the survey comprised 27 questions, including one open-ended question, and was organized into the following four sections: (1) socio-demographics and comorbidities; (2) perceptions and experiences with day-to-day symptoms of COPD, including the modified Medical Research Council (mMRC) dyspnea scale to assess severity of breathlessness;[18] and (3) one open-ended question asking participants to describe “exacerbations” and aiming at understanding how respondents described exacerbations (if any) in their own words

> Some people with COPD have times where their symptoms get worse than usual. During these times, people may do things to make themselves feel better, such as breathing exercises, using an inhaler, contacting their healthcare provider, taking antibiotics or steroids, or going to hospital. How would you describe these times when someone’s COPD symptoms are worse than usual?

All respondents contributed to the survey up until section (3), irrespective of whether they ever had an exacerbation of COPD. This allowed us to collect the respondents’ wording without having to formally define what was meant by an "exacerbation" in the survey and, thereby, influence their responses.[19] For those who reported ever having an exacerbation, section (4) explored perceptions and experiences of, and actions taken during, COPD exacerbations (Figure S1).

The original survey was drafted in English then surveys were translated and back translated into the primary language for each country. Surveys were administered in Portuguese in Brazil, simplified Chinese in China, French in France, Spanish in Spain, and English in the UK and the USA. All questions required a response. The estimated time for completion was 10–12 minutes.

Source Population

To cover various countries, languages, and cultures, participants were recruited from Brazil, China, France, Spain, the UK, and the USA. For the first five countries, people were recruited from existing online consumer research panels run by m360.[20] Panelists were invited via emails, banners, and loyalty programs. Panelists had to confirm their participation via email before being allowed to join the panels, following a double opt in.[21] In the USA, panelists were recruited from Ipsos KnowledgePanel, a probability-based panel which recruits panelists through address-based sampling[22] that can be used in, for example, public health research.[23,24] US panelists who had previously self-reported that they were living with COPD were invited to take part in the survey. Both m360 and KnowledgePanel incentivize participation in surveys through vouchers. The study sponsor was unknown to respondents and was not involved in respondents' identification, selection, or data collection.

Study Participants

All subjects gave their informed consent for inclusion before they participated in the study; this included consent to use de-identified responses for research and academic purposes.

Inclusion criteria were self-completed by respondents using screening questions, including age ≥35 years; COPD diagnosis provided by their HCP; living in Brazil, China, France, Spain, the UK, or the USA at the time of the survey; and willing and able to provide informed consent in the primary language of the country of residence. Regarding COPD, respondents were asked to identify their medical conditions from a group of possible conditions and did not know which one would qualify them for the study, to minimize the risk of self-selection.

A target number of 540 respondents with COPD and a history of exacerbations was determined based on the 20-to-1 sample-to-item rule of thumb.[25] However, it was anticipated that 60–70% of people living with COPD would have ever experienced an exacerbation;[26,27] the target sample size was increased to ≥800 participants with COPD.

Because this was an online survey, several quality checks were conducted namely to identify potential bots and avoid multiple entries from the same respondent; this used the time taken to complete the survey, straight lining of survey responses and nonsensical responses to questions. Surveys completed by suspected bots were discarded, and additional participants were included to reach the target population size.[28]

All surveys were administered online between March 10, 2023 and May 2, 2023.

Ethics

This study was conducted in accordance with the Declaration of Helsinki. This study was deemed exempt by the Pearl Institutional Review Board (IRB number: 00007772; Study: 23-IPSO-179) according to FDA 45 CFR 46.104(d)(2).

Analysis

Data were de-identified by the consumer research panel holders (eg, email address) prior to transfer to the data analysis team, translated into English, and then analyzed using quantitative and qualitative methods. Findings were then integrated to identify common themes.

Quantitative Analysis

Respondents' demographics and survey responses were described overall. To understand how respondents who completed the entire survey may differ from those who completed the first parts (never exacerbated), socio-demographic and clinical characteristics were described by lifetime exacerbation status (ever/never exacerbated). Social and cultural differences were also explored through stratified analyses. The terms used to describe an exacerbation and "ways of identifying an exacerbation" were explored by region and country. Items related to emotions ("feelings associated with day-to-day symptoms of COPD") were described by sex. "Ways of identifying an exacerbation" were described by sex and age (≥60 years / <60 years), and perceived "easiness of identification of an exacerbation" was described by dyspnea severity score. No inferential statistical tests were conducted. R version 4.2.2 and Microsoft Excel were used for analysis and data visualizations.

Qualitative Analysis

The open-ended question was analyzed using thematic analysis.[29] Coding of responses used an iterative and collaborative process involving three members of the research team[30] who provided an initial codebook, which was refined manually. The final codebook was applied to all remaining transcripts, with any additional emergent codes being added based on group discussion. To determine subsequent themes, the team discussed which themes were more prominent in the data[29] (Text S2).

Results

In total, 857 individuals completed the survey, of whom 671 (78.3%) reported ever having an exacerbation in their lifetime (Figure 1). Respondents' socio-demographics and comorbid diseases are summarized in Table 1. Overall, median age was 58 years; 50.5% of participants were male, and 31.5% reported comorbid asthma. Compared with those who never exacerbated, respondents who did were younger (median age 56 and 65 years old, respectively) and more likely to have comorbid asthma (35.6% and 16.7%, respectively) and to report an mMRC grade ≥2 (52.8% and 31.7%, respectively). Results by country are provided in Table S3.

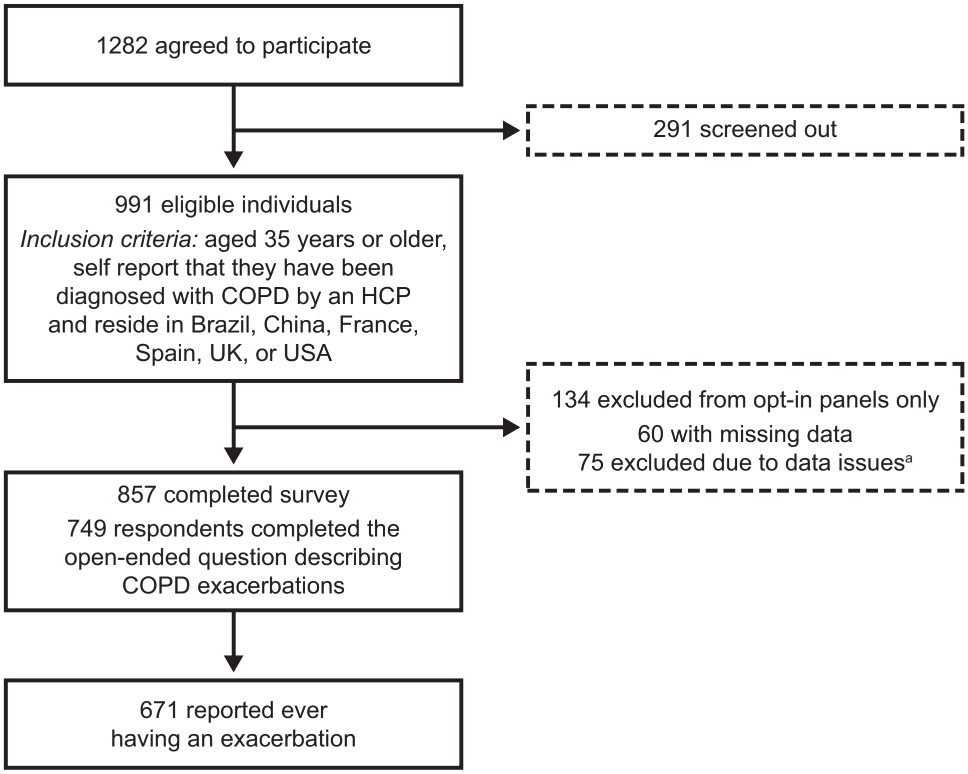

Figure 1 Flowchart of respondents. Brazil, China, France, Spain and the UK used opt-in panels, whereas the USA used a recruitment-based panel. An additional 70 respondents completed the survey while it was closing and were excluded. [a]Data issues were identified based on the time taken to complete a survey, straight lining of survey responses and nonsensical responses to survey questions.[28]

Abbreviation: COPD, chronic obstructive pulmonary disease.

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Table 1 Socio-Demographic Characteristics and Comorbid Diseases of Respondents, Overall and by Lifetime Exacerbation Status, [N = 857]

n (%)	**Total N = 857**	**Ever Had an Exacerbation n = 671**	**Never Had an Exacerbation n = 186**
Sex			
Male	433 (50.5)	323 (48.1)	110 (59.1)
Female	424 (49.5)	348 (51.9)	76 (40.9)
Median age in years (interquartile range)	58 (46, 67)	56 (46, 66)	65 (54, 72)
Age group			
35–44 years	150 (17.5)	136 (20.3)	14 (7.5)
45–54 years	200 (23.3)	165 (24.6)	35 (18.8)
55–64 years	216 (25.2)	173 (25.8)	43 (23.1)
65–74 years	221 (25.8)	155 (23.1)	66 (35.5)
75+ years	70 (8.2)	42 (6.3)	28 (15.1)
Average household income			
A lot below average	228 (26.6)	183 (27.3)	45 (24.2)
About average	522 (60.9)	401 (59.8)	121 (65.1)
A lot above average	101 (11.8)	81 (12.1)	20 (10.8)
Decline to answer	6 (0.7)	6 (0.9)	0
Distance from main HCP			
Within 1 km	235 (27.4)	175 (26.1)	60 (32.3)
Within 5 km	310 (36.2)	246 (36.7)	64 (34.4)
Within 10 km	179 (20.9)	143 (21.3)	36 (19.4)
Within 20 km	72 (8.4)	59 (8.8)	13 (7.0)
Within 50 km	35 (4.1)	25 (3.7)	10 (5.4)
50 km or more	21 (2.5)	19 (2.8)	2 (1.1)
Decline to answer	5 (0.6)	4 (0.6)	1 (0.5)
Country			
Brazil	152 (17.7)	134 (20.0)	18 (9.7)
China	136 (15.9)	115 (17.1)	21 (11.3)
France	141 (16.5)	110 (16.4)	31 (16.7)
Spain	141 (16.5)	103 (15.4)	38 (20.4)
UK	141 (16.5)	102 (15.2)	39 (21.0)
USA	146 (17.0)	107 (15.9)	39 (21.0)
Comorbidities			
Asthma			
Yes	270 (31.5)	239 (35.6)	31 (16.7)
Decline to answer / missing	6 (0.7)	5 (0.7)	1 (0.5)
Diabetes			
Yes	183 (21.4)	150 (22.4)	33 (17.7)
Decline to answer / missing	10 (1.2)	8 (1.2)	2 (1.1)
Heart disease			
Yes	143 (16.7)	111 (16.5)	32 (17.2)
Decline to answer / missing	9 (1.1)	7 (1.0)	2 (1.1)
Time since COPD diagnosis			
Less than 5 years	344 (40.1)	259 (38.6)	85 (45.7)
5 or more years	509 (59.4)	410 (61.1)	99 (53.2)
Missing	4 (0.5)	2 (0.3)	2 (1.1)
mMRC dyspnea scale			
<2 threshold	*437 (51.0)*	*315 (46.9)*	*122 (65.6)*
Grade 0	145 (16.9)	91 (13.6)	54 (29.0)
Grade 1	292 (34.1)	224 (33.4)	68 (36.6)

(*Continued*)

Table 1 (Continued).

n (%)	Total N = 857	Ever Had an Exacerbation n = 671	Never Had an Exacerbation n = 186
2+ threshold	*413 (48.2)*	*354 (52.8)*	*59 (31.7)*
Grade 2	255 (29.8)	214 (31.9)	41 (22.0)
Grade 3	110 (12.8)	98 (14.6)	12 (6.5)
Grade 4	48 (5.6)	42 (6.3)	6 (3.2)
Decline to answer	*7 (0.8)*	*2 (0.3)*	*5 (2.7)*
Inhaler used	780 (91.0)	623 (92.8)	157 (84.4)

Abbreviations: HCP, healthcare provider; COPD, chronic obstructive pulmonary disease; mMRC, modified Medical Research Council.

Perception and Experience of Daily Symptoms

Daily symptoms most commonly reported were "shortness of breath" (72.7%), "tiredness" (57.8%), and "cough" (48.5%). In 755 (88.1%) respondents, the number of daily symptoms was ≥2 (Table S4). The most common pairwise combinations of symptoms were shortness of breath + tiredness (47.1%; 404/857) and shortness of breath + cough (38.3%; 328/857) (Table S5 and Figure S2).

Regarding variability of daily symptoms, the most common responses were that daily symptoms changed "a little" (48.7%; 417/857) and "always the same" (45.3%; 388/857); only 5.5% (47/857) of respondents reported that their symptoms changed "a lot". COPD symptoms impacted daily lives "a lot" or "a great deal" for 35.0% (300/857) of respondents. Table S6 summarizes emotions associated with daily symptoms: 49.0% felt "worried", 44.9% "frustrated", and 34.5% "depressed". Males felt more frequently "frustrated", while females felt more frequently "depressed" or "panicked".

Describing COPD Exacerbations in Their Own Words

Among the 857 respondents, 749 (87.4%) provided a reply to the open-ended question ("How would you describe these times when someone's COPD symptoms are worse than usual?"). The large number of open-ended responses coupled with the brevity of responses meant that while saturation was reached for the themes, these were direct and brief rather than detailed. Respondents described an "exacerbation" in terms of their symptoms experienced, actions taken to treat or alleviate symptoms, and triggers of and the emotions that come with experiencing new, worse, or prolonged symptoms (Table 2). Exacerbations were described through a narrative lens detailing overall experiences. Only a minority of open-ended responses (1.3%; 10/749) used a single term or a couple of words like "exacerbation".

Table 2 Categories of Describers for an Exacerbation, Using Free Text (N = 749)

Concepts Mentioned	Illustrative Quote
Symptoms experienced	"Usually for me these times [COPD exacerbations] cause me much pain. Everything seems to get worse. Cough is persistent. Breathing gets harder. Tightening of chest doesn't go away" – Male, 74 years old, UK "What I feel is a lot of shortness of breath, difficulty sleeping, tiredness with increased dyspnea" – Female, 63 years old, Brazil "Feeling chest tightness and short of breath, feeling like I can't breathe" – Female, 38 years old, China

(*Continued*)

Table 2 (Continued).

Concepts Mentioned	**Illustrative Quote**
Actions taken to manage or alleviate symptoms	"I try to stay as calm as I can and use my inhalers to help regulate my breathing but if this doesn't work and the symptoms get worse I phone 999" – Male, 58 years old, UK "I resort to the nebulizer and the asthma pump, and if the symptoms persist or even worsen I immediately go to the doctor I trust" – Male, 39 years old, Brazil "I reduce my current activities, I practice breathing exercises to reduce stress and panic symptoms" – Female, 47 years old, France
Triggers of exacerbations	"Symptoms tend to worsen in winter or colder climates, when exerting too much effort suddenly, or when running too fast …" – Female, 37 years old, Brazil "At this time of year with colds I have more difficulty breathing, I get tired and the choking feeling does not allow me to do some activities normally" – Male, 60 years old, Spain "When I carry out many activities at the same time and when I am exposed to dust" – Male, 61 years old, UK
Emotions and feelings related to experiencing exacerbation symptoms	"These are particularly disturbing periods, with increased irritability, frustration and restlessness" – Male, 63 years old, Spain "Feeling powerless to do even the simplest everyday things" – Female, 51 years old, Brazil "When COPD worsens, along comes depression and despair, thinking that the day will come for me to die" – Female, 48 years old, Brazil

Abbreviation: COPD, chronic obstructive pulmonary disease.

Table 3 Terms Used to Describe an Exacerbation, Overall and by Region, [N = 857]

%	**Total N = 857**	**Brazil n = 152**	**China n = 136**	**Europe n = 423**	**USA n = 146**
Worsening	20.3	26.3	19.9	21.3	11.6
Lung attack	11.2	15.1	28.7	5.9	6.2
COPD attack	29.4	25.7	58.1	23.4	24.0
Attack	11.4	15.1	19.1	7.8	11.0
Feeling worse than usual	40.1	39.5	39.0	42.1	36.3
Flare-up	19.8	9.9	27.9	15.1	36.3
Exacerbation	17.7	7.2	36.8	16.1	15.8
Crisis	22.5	61.8	12.5	18.0	4.1
Chest infection	21.1	5.3	22.8	27.9	16.4
Lung infection	21.0	15.1	30.9	22.7	13.0
Cold	26.3	36.8	30.1	22.7	21.9
Another name, please describe:	2.5	0.7	0	2.8	5.5
None of the above	11.9	3.3	0	14.4	24.7
Decline to answer	1.4	1.3	0	0.7	4.8

Note: Question: "Do you use any of the following to describe times when someone's COPD symptoms are worse than usual? (Please select ALL that apply)".
Abbreviation: COPD, chronic obstructive pulmonary disease.

Among the list of possible terms to describe "times when someone's COPD symptoms are worse than usual", a great diversity of terms were selected (Table 3), "feeling worse than usual" (40.1%), "COPD attack" (29.4%), and "cold" (26.3%) being the most commonly selected. "Flare-up" (19.8%) and "exacerbation" (17.7%) were used less frequently. There were variations by region: 61.8% of respondents in Brazil preferred "crisis" and 58.1% in China preferred "COPD attack". One in four respondents from the USA did not use any of the terms listed and did not suggest an alternative phrase. A variety of terms were used in Spain, France, and the UK, without one clear dominant term across or within countries (Figure 2).

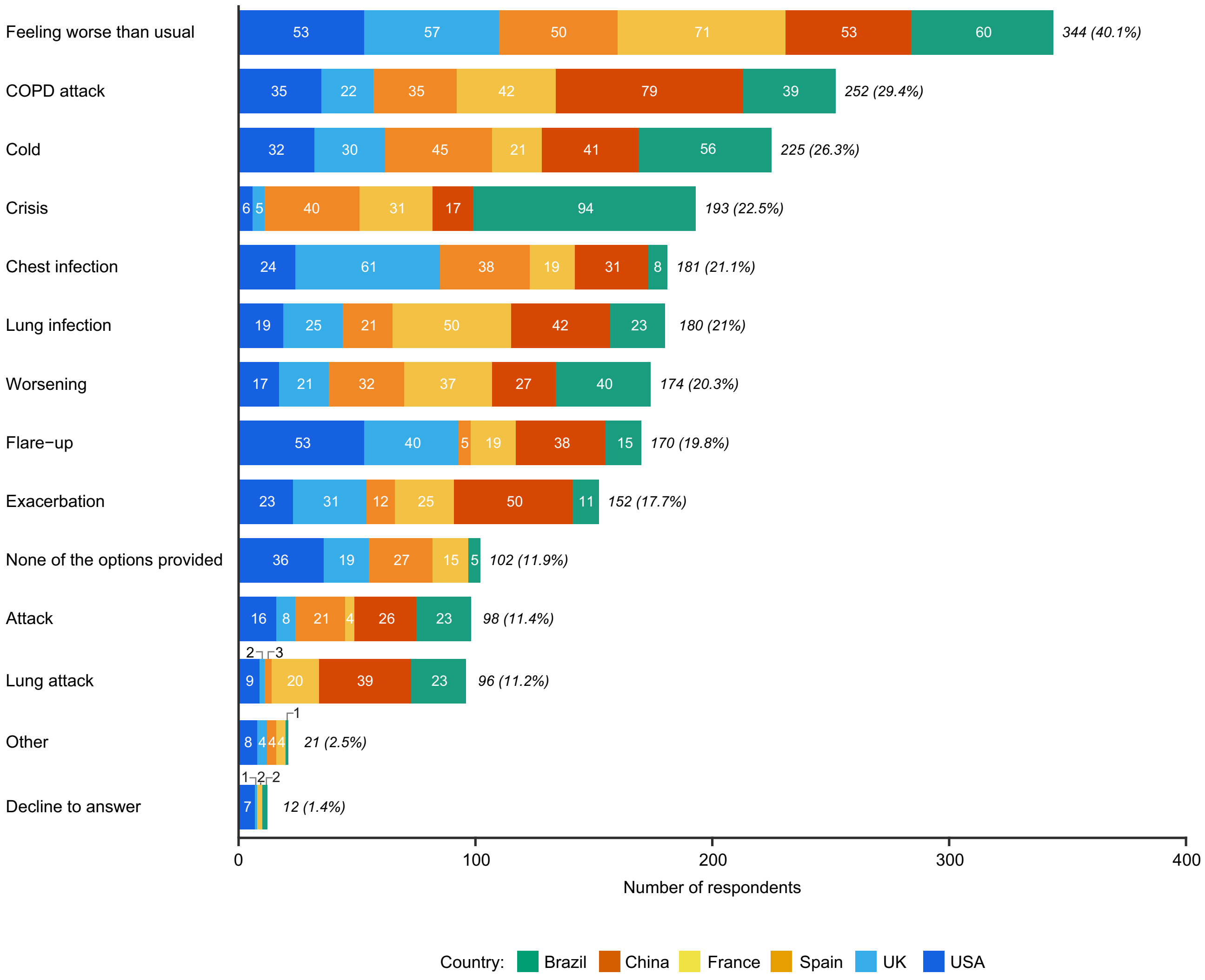

Figure 2 Terms used to describe an exacerbation, by country (N = 857). The question of the survey was, "Do you use any of the following to describe times when someone's COPD symptoms are worse than usual? (Please select ALL that apply)". Numbers reported in each square are the number of respondents in each country, and the number (%) reported after each colored bar is the result for the entire group and the item.
Abbreviation: COPD, chronic obstructive pulmonary disease.

Perception and Experience of Exacerbations

Of the 671 respondents who ever exacerbated, 78.5% (527/671) had their latest exacerbation in the past year. Exacerbation symptoms were considered to impact them a "great deal" or "a lot" in 54.1% (363/671) of respondents. In terms of how exacerbations impacted respondents, 73.5% (493/671) described greater difficulty than usual "doing everyday activities" and 48.1% (323/671) reported that they stayed "at home more than usual".

Symptoms considered most alarming during an exacerbation were "shortness of breath" in 47.4% (318/671). Other symptoms were selected by less than 10% of respondents (eg, "chest tightness", "cough", or "difficulty doing everyday activities"). Regarding emotions, respondents reported feeling "worried" (57.2%; 384/671) or "frustrated" (40.8%; 274/671) during an exacerbation.

According to respondents, common causes of exacerbations were colds or lung infections (60.8%; 408/671) or changes in the weather (51.1%; 343/671), with 5.2% (35/671) not knowing what caused COPD exacerbations.

Distinguishing Between an Exacerbation and Daily Symptom Variation

The majority of respondents reported that recognizing an exacerbation was either “very easy” or “fairly easy” (“very easy”: 16.4% [110/671]; “fairly easy”: 35.3% [237/671]; “somewhat easy”: 37.4% [251/671]; “not easy” for 10.7% [72/671]). Recognizing an exacerbation was less frequently considered as “very” to “fairly” easy in individuals with a mMRC grade <2 versus grade ≥2 (46.3% and 56.2%, respectively) (Table S7).

Figure 3 describes the way respondents identify exacerbations either based on changes in daily symptoms, difficulties in daily activities, or by relying on other people or personal past experiences: 70.3% (472/671) of respondents identified exacerbations by noticing changes in daily symptoms (thus, 29.7% did not use symptoms to identify an exacerbation), including 52.8% (354/671) who recognized exacerbations as symptoms being “worse than usual”. In 50% (336/671) of respondents, exacerbations were identified because they had “more trouble than usual with daily activities”. Over half of the respondents (60.4%; 405/671) used two or more methods to identify an exacerbation. The most common combinations were using change in symptoms coupled with their ability to do daily activities (“activities”), described by 22.5% (106/472). There was no observable difference in ways to identify an exacerbation based on age, sex, or country. Changes in symptoms and trouble with daily activities were the most common ways to detect exacerbations across subgroups (Tables S8.1 and S8.2).

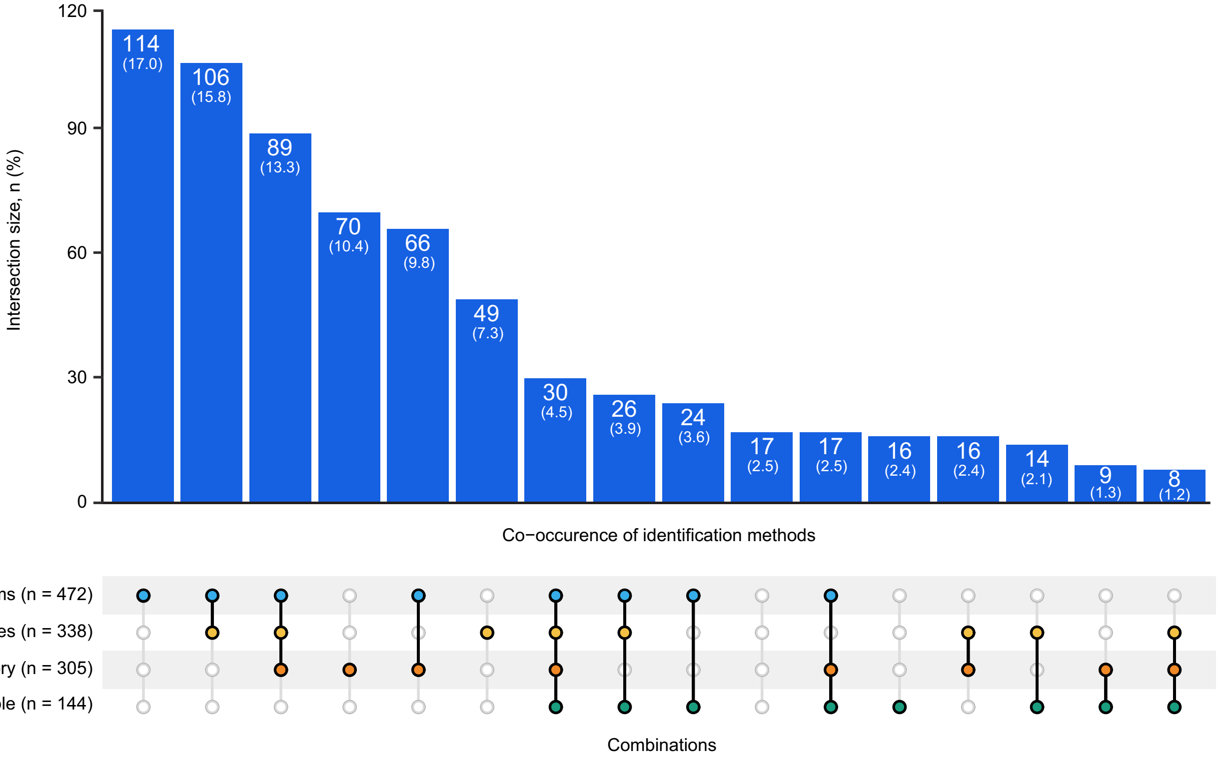

Figure 3 Ways of identifying an exacerbation (N = 671). The question of the survey was, “Compared to your usual day-to-day symptoms, how do you know that you are starting a COPD flare-up? Please select ALL that apply”. The items “My symptoms are worse than usual”, “My symptoms last longer than usual”, and “I have additional or different symptoms than usual (such as a cough, phlegm or difficulty breathing)” formed the category “Symptoms”; the items “I have more trouble than usual with my daily activities” formed the category “Activities”; the items “I know what changes to look out for based on previous COPD flare-ups” and “No specific symptoms, I just know based on previous COPD flare-ups” formed the category “History”; and the items “My family, friends, or caregiver tell me that my symptoms have changed”, “My HCP tells me I am having a COPD flare-up” formed the category “People”.

Abbreviations: HCP, healthcare provider; COPD, chronic obstructive pulmonary disease.

Discussion

In this multicountry study encompassing six nations, a comprehensive survey was conducted with a large sample of people living with COPD to gain insights into their perspectives on exacerbations.

Key Findings

Daily symptoms of COPD were common and varied between respondents. Most respondents did not experience significant day-to-day variation in symptoms. Strong emotions were associated with daily symptoms: more than one-third felt frustrated, depressed, or worried by daily symptoms, which significantly impacted daily lives for 35% of respondents. The majority of respondents felt somewhat confident they were able to tell when an exacerbation was about to occur. Most respondents identified an exacerbation through new, worsening, or prolonged symptoms, often in combination with other indicators like changes in daily activities. In contrast, one-third of respondents relied on changes in their daily activities, prior exacerbations, or other people telling them. A small proportion did not know how to distinguish between exacerbations and daily symptoms.

A second finding of this study is the apparent disconnect between respondents' experience of exacerbations and the symptom-centric language used by HCPs in clinical practice. A range of terms was used by respondents, who conceptualized exacerbations beyond symptoms describing their feelings or changes in their daily activities. Functional definitions, such as difficulties doing daily activities, were often used to identify exacerbations. In contrast, clinical literature focuses on the duration and type of symptoms experienced and objective signs of clinical deterioration.[5] In addition, strong emotions were reported in relation to exacerbations and are rarely used by clinicians to refer to these events (eg, being worried, frightened). To describe an exacerbation, plain language like "feeling worse than usual" was preferred to "exacerbation" or "flare-up". These results indicate that while most respondents were confident that they could recognize an exacerbation, they often describe them in ways that differ from clinical guidelines,[5] which may make it challenging to communicate their experiences to care providers.

A third result is the predominance and impact of both breathlessness and fatigue as daily symptoms. "Shortness of breath" was the most reported daily symptom, and breathlessness was considered as the "most alarming" symptom associated with COPD exacerbations. Almost half of respondents describing breathlessness as a daily symptom also reported tiredness and over one-third reported a cough. The prevalence of the reports of tiredness aligns with prior evidence indicating that fatigue is a common occurrence among patients with severe respiratory disease;[31] however, the results of this population study indicate that fatigue is not restricted to patients with severe disease but may also be experienced by patients with mild or moderate COPD.

Implications for Clinical Practice

In contrast to prior studies, respondents did not report significant variation in daily COPD symptoms and were relatively confident that they could identify an exacerbation.[5,9,11,32] Identifying an exacerbation does not mean that exacerbations are reported to HCPs.[11] Our results suggest reasons why under-reporting of exacerbations may persist despite some confidence in recognizing them. In line with prior studies, the survey results showed that respondents identified exacerbations through their functional impact, associated emotions, and using nontechnical terms to describe an exacerbation.[9,33] The discrepancy between the perspectives of HCPs and patients' perspectives may lead to patients under-reporting exacerbations even when asked about their occurrence. This lack of shared language and a common understanding of what a COPD exacerbation is makes it more difficult for patients and clinicians to communicate, potentially leading to poorer patient satisfaction, understanding, and outcomes.[34] Based on the study findings, several ways to reduce the communication gap between clinicians and people living with COPD are suggested. First, less technical terms and multiple lines of questioning may need to be used by clinicians to ascertain if someone has had an exacerbation. Asking how individuals felt may also help to identify periods of exacerbation. Additionally, open-ended questions and probes focused on actions taken, symptoms, times that they could not do their normal activities, or times that they felt fatigued may allow patients to describe changes in their COPD symptoms, which in turn could facilitate identification of an exacerbation by a clinician. Such techniques are part of narrative medicine practices, which can enhance clinical analysis and facilitate more accurate diagnoses, prognoses, and treatment plans by immersing HCPs in the patient's world and allowing them to view COPD from the patient's perspective.[35,36] To help implement narrative medicine techniques, a discussion guide could be developed for (and by) HCPs and patients, providing example questions and prompts for HCPs and illustrating the variety of ways people living with COPD conceptualize their exacerbations, to support earlier diagnosis of COPD exacerbations. A discussion guide could also be coupled with educational programs on the importance of early recognition, prevention, and treatment of COPD exacerbations by providing a shared understanding and common language to describe exacerbations and thereby facilitate discussions between clinicians and patients.

Regarding breathlessness, one way to improve patient wellbeing would be for HCPs to acknowledge breathlessness as a concern and to incorporate patient concerns around breathlessness within pulmonary rehabilitation (PR) programs. PR has been shown to improve the clinical outcomes and wellbeing for those living with COPD.[5,37,38] However, PR programs are highly variable, ranging in length, services offered, and comprehensiveness of the program.[37] There is some evidence that PR programs that have a longer period of follow up and are more comprehensive, such as offering breathlessness support services, may be more effective at improving patient outcomes.[38–41] Therefore, incorporating education focused on self-management of breathlessness may be effective. However, most PR programs do not consider dyspnea as the most important outcome.[42] It is unclear which components of PR are the most effective in improving dyspnea, and future research could focus on understanding which interventions provide the most benefit to breathlessness.

Study Limitations

This study relied on respondents to self-report of COPD diagnosis, which may lead to selection bias.[43] For instance, nearly one-third of respondents also reported asthma, indicating a possible misdiagnosis of asthma as COPD. More than 60% of respondents reported an exacerbation in the past year compared with an expected proportion of 30–50% given prior studies.[44,45] Respondents could have misidentified exacerbations, especially since uncontrolled asthma and cardiovascular disease may present with similar symptoms to COPD exacerbations.[46] It is also unclear whether this study population consists of people with severe COPD (73% reported shortness of breath and 53% had an mMRC grade ≥2) or if their ability to detect exacerbations is superior to the average. However, to minimize self-selection of individuals with more severe COPD, invited panelists were not told that the survey would focus on COPD. Another source of selection is the use of the online survey, which requires a high-level of digital literacy.[47] Prior research has suggested that greater digital literacy is associated with higher interest in health and access to information.[48] As a result, the study population may have over-selected respondents who are more engaged and involved in their health and thus more confident and/or able to detect COPD exacerbations. Finally, responses provided to the open-ended question were brief, so themes derived from qualitative analysis were not as rich or as descriptive.[49] As a result, the findings were presented using a mixed-methods approach.

Conclusions

This study suggests that people living with COPD feel confident that they can detect exacerbations, but they experience and describe exacerbations in a variety of ways. This may contribute to a communication gap with clinicians. Clinicians should use plain language when educating patients on ways to identify and manage exacerbations. A discussion guide could facilitate patient-clinician discussions around recognizing and managing exacerbations.

Abbreviations

COPD, Chronic obstructive pulmonary disease; CROSS, Consensus-Based Checklist for Reporting of Survey Studies; HCP, Healthcare provider; mMRC, Modified Medical Research Council; PR, Pulmonary rehabilitation.

Data Sharing Statement

The data that support the findings of this study are available on request from the corresponding author.

Human Ethics Approval Declaration

This study was deemed exempt by the Pearl Institutional Review Board (IRB number: 00007772; Study: 23-IPSO-179).

Artificial Intelligence Disclosure

The authors declare that they have not used any type of generative artificial intelligence for the writing of this manuscript, nor for the creation of images, graphics, tables, or their corresponding captions.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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