Review

A Meta-Synthesis of Qualitative Literature to Inform the Selection of Meaningful and Measurable Health Concepts for Clinical Trials in COPD

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Running Header: **Patient-Inspired Health Concepts for COPD Trials**

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Abbreviations**:** CASP = Critical Appraisal Skills Programme; COA = clinical outcome assessment; COPD = chronic obstructive pulmonary disease; DET = data extraction table; FEV_1 = forced expiratory volume in 1 second; GOLD = Global Initiative for Chronic Obstructive Lung Disease; PIVOT = Patient Inspired Validation of Outcome Tools

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ABSTRACT

Objectives: A critical step in designing clinical trials to evaluate treatment efficacy in chronic obstructive pulmonary disease (COPD) is selecting fit-for-purpose outcome measures that reflect health concepts meaningful to people living with COPD. The purpose of this review was to summarize and synthesize qualitative literature addressing how patients with COPD describe aspects of their disease, to inform health concept selection and outcome measure selection.

Methods: A literature review and meta-synthesis of qualitative research published from 2013 to 2023 was performed. Studies meeting criteria underwent critical appraisal and data extraction. Studies were summarized, then synthesized with constant comparative analysis to review author interpretations and direct patient quotes.

Results: Nineteen studies addressing the patient experience of COPD met screening criteria for full review and data synthesis. In total, 507 patients (range: 8–64 individuals per study) across 11 countries participated in these studies via interviews (63.2%), focus groups (15.8%), or online forums (5.3%). Prominent COPD symptoms included breathlessness, cough, mucus, wheezing, chest discomfort, sleeping difficulty, tiredness, and weakness. Patients described significant impacts on physical activity, emphasizing difficulties with activities of daily living. The symptoms experienced and the persistent limitation on physical activity had severe consequences on social and role functioning and psychological and emotional health.

Conclusions: This qualitative meta-synthesis summarizes evidence about symptoms experienced by patients with COPD and the impact of these symptoms on daily life. The synthesis provides an empirical foundation for the development of a standardized set of patient-inspired health concepts to be considered when selecting outcome measures for COPD clinical trials.

INTRODUCTION

The advancement of new medical treatments depends on clinical trial results and regulatory approval, which require that a drug must demonstrate clinical benefit—that is, a favorable effect on a meaningful aspect of how a patient feels or functions in their life, or a favorable effect on survival.[1] In recent years, guidance provided by the Food and Drug Administration on Patient-Focused Drug Development has offered an opportunity to better incorporate the patient perspective into trial design, ensuring, for example, that the needs of the patient population being studied are taken into account when determining what to measure in the trial.[2-4] This is particularly important at the beginning of the measurement strategy process, where meaningful and measurable health concepts are identified. These concepts include aspects of an individual's clinical, biological, physical, or functional state, or health experiences resulting from their disease/condition.[2,5,6] Identifying key health concepts allows for the subsequent selection of "fit-for-purpose" outcome measures for the evaluation of treatment benefit in clinical trials.[6]

In chronic obstructive pulmonary disease (COPD) clinical trials, efficacy evaluation historically relied on forced expiratory volume in 1 second (FEV_1) as a measure of lung function.[7,8] However, a growing body of evidence suggests the need to look beyond FEV_1 for the evaluation of clinical benefit in COPD and to consider more patient-focused measures.[7] The development and validation of patient-focused measures can be strengthened by clearly differentiating between the meaningful and measurable health concept ("what to measure") and the measurement instrument ("how to measure"). Understanding the perceptions of people living with COPD plays a key role in identifying meaningful and measurable health concepts that can be incorporated into clinical trials.

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A substantial amount of qualitative research in COPD describes the patient experience, providing valuable insights to help identify patient-inspired health concepts that can be utilized for clinical outcome assessment (COA) development, validation, and selection.[9,10] Previous qualitative literature reviews in COPD have generally focused on specific targeted aspects of the patient experience, such as advanced COPD, particular COPD symptoms or impacts, or other aspects of disease management, making it difficult to identify shared or different experiences across COPD populations.[11-14] A literature review that synthesizes findings across qualitative studies of patient experience could be a valuable first step in identifying the meaningful aspects of a person's life that are affected by COPD and the terms and phrases patients use to describe them.

As part of the COPD Foundation’s PIVOT (Patient Inspired Validation of Outcome Tools) program,[5,15] this meta-synthesis summarizes qualitative research exploring patient experiences with symptoms and life impacts of COPD to inform the development of a unified set of patient-inspired health concepts to consider when developing, validating, and/or selecting outcome measures for COPD clinical trials.

METHODS

Rationale and Objective

This review summarized and synthesized qualitative research that explores how individuals diagnosed with COPD describe their disease to inform the research question: *“What aspects of COPD influence a patient’s lived experience with the disease?”* A key focus of the review was to compare how researchers and patients name and describe these experiences. Results from this review will support the identification of relevant patient-inspired health concepts that can be considered in the context of COA development and validation for COPD clinical trials.

Pre-Planned Search Strategy

This review was limited to empirical qualitative studies in the MEDLINE/PubMed and Embase databases that were published in the last 10 years. Search terms for Medical Subject Headings and free-text keywords were based on the terms and adjectives for COPD, signs and symptoms, and "quality of life." The search strategy and limits are available in Online Supplement 1. This study is reported according to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research statement checklist.[16]

Inclusion Criteria and Study Selection

The inclusion criteria were based on the population, phenomenon of interest, context, and study design.[17] The phenomenon of interest included patient-reported concepts (COPD symptoms and impacts, quality of life) as it pertained to disease experience. Qualitative research that included concept elicitation interviews, cognitive debriefing, focus groups, or mixed methods incorporating patient interviews was considered. Quantitative observational studies, randomized clinical trials, economic studies, and case studies were excluded. No restrictions were placed on the setting/country of the study. Titles and abstracts were independently screened by two researchers (CJM, AJ) using Nested Knowledge®.[18] Relevant articles were further screened for full-text review, followed by critical appraisal (Online Supplement 2).

Critical Appraisal of Studies

Articles meeting inclusion criteria were assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies,[19] ensuring a standardized and structured approach when assessing the quality of research in the following domains: research design, sampling strategy, data collection, reflexivity (including the relationship between the researcher and the patients), ethical considerations, rigor of the data analysis, clear statement of the findings, and value of the research. The CASP checklist was used because it systematically addresses the basic principles of good scientific design, assessing the trustworthiness, relevance, and reliability of the published results.[20-22]

Two researchers (KK, CJM) conducted the critical appraisal, and a third senior researcher (AD) reviewed the studies to resolve any discrepancies. Articles with a low risk of bias were selected for data extraction (Online Supplement 2). Studies were deemed to have a low risk of bias when high strength evidence was present in at least seven out of the 10 CASP questions; question 5 (data collection addressed research question), question 8 (data analysis was rigorous), and question 9 (clear statement of findings) must have been among those with strong evidence available.

Data Extraction Procedures

Data extracted from eligible studies were entered into a Microsoft Excel® data extraction table (DET), organized by first author, publication year, study design, patient population, methods, and research results, including pre-identified labels based on the Patient-Focused Medicines Development Patient Experience Data patient navigator tool, which outlines key areas that are important for patients in research (i.e., signs/symptoms, functioning).[23] The DET was piloted by extracting a sample of eligible studies and expanded to include labels relevant to COPD, such as disease-specific symptoms and impacts, as well as broader patient experiences related to social determinants, such as financial constraints, environmental factors, and other health factors. Three qualitative researchers (CJM, KK, AJ) extracted data from all eligible studies, and a senior researcher (AD) reviewed the DET for completeness before the meta-synthesis.

Meta-Synthesis

This qualitative meta-synthesis was based on the methodology by Sandelowski and Barroso.[24] This approach is iterative and systematic, focusing on summarizing methods and results from qualitative literature, then synthesizing themes and selected quotes from patients who participated in each study to identify new insights from the patient perspective across all studies.[24] This method allows researchers to preserve themes from original published qualitative research while allowing new themes to emerge across multiple studies. Although other considerations and complexities of qualitative meta-synthesis were considered,[25-27] an applied approach was necessary to develop a nomenclature of health concepts. This was done by preparing and grouping the extracted data in Microsoft Excel, then summarizing the frequencies of high-level themes across studies. To develop a taxonomy of themes that could be applied to the context of clinical trials, patient-level data (quotes available in each study) were further assessed and organized into three levels according to the author's interpretation of quotes, direct patient quotes from the study, and the reviewers' assessment/interpretation of the data.

Two researchers (AD, KK) conducted a constant comparative analysis to independently identify themes across the eligible studies using results (themes and patient quotes) from the DET. The same researchers discussed these results to improve the reflexivity of their interpretation of the data from each study and find any new themes or considerations. One researcher (KK) summarized and aggregated the DET results, which included representative quotes from patients. This summary was then reviewed and revised by another researcher (AD). Subsequent discussions with senior reviewers (AH, NLK) led to the identification of the final themes. Additional information on the meta-synthesis, including a description of steps involved in this process, is provided in Online Supplement 3.

RESULTS

Out of 405 qualitative research abstracts identified and reviewed from database searches, 78 articles were assessed for full-text review, resulting in 42 articles meeting the inclusion/exclusion criteria (see Figure 1). Twenty-three of the 42 articles were excluded after CASP assessment because of limited information on methods/analysis. Consequently, 19 qualitative studies were selected for data extraction and meta-synthesis. Details about the selection of studies and assessment via the CASP checklist are available in Online Supplement 2.

Summary of Eligible Studies

Table 1 summarizes the characteristics of eligible studies and presents qualitative research from 11 countries: the United States, the United Kingdom, Canada, Colombia, Germany, Ireland, Jordan, Portugal, Spain, Sweden, and Thailand. Each study explored an aspect of the patient experience of living with COPD. Study objectives included understanding the symptom burden of COPD, exploring perceptions about the meaning of COPD, identifying unmet needs, and assessing the impacts on specific symptoms (e.g., cough, mucus). Study design methods included semi-structured interviews (12, 63.2%), focus groups (3, 15.8%), or both methods (3, 15.8%), with two studies using qualitative methods as part of a mixed-methods survey design and one study employing a method called social media listening. Thematic analysis was the most common method for qualitative analysis (8, 42.1%).[28-35]

There were a total of 507 participants with COPD across all 19 studies, with samples ranging from eight participants to a maximum of 64 participants. Just over half of the participants across studies were men (259; 51.1%), and all participants were between 38 and 88 years old. Only 36.8% of studies reported on ethnicity/race, employment status, or co-morbidities (see Online Supplement 4).

The severity of lung function impairment was not always described, and only eight studies (42.1%) provided data on FEV_1.[28-30,32,33,36-38] Nine studies included patients with moderate-to-severe impairment (Global Initiative for Chronic Obstructive Lung Disease [GOLD] criteria II to IV; 47.3%),[28,29,31,33,36,37,39-41] with one reference to GOLD I.[42] COPD severity was described as moderate to severe (5.2%)[29] and very severe (5.2%),[34]or was self-reported as "mild," "moderate," or "severe" (5.2%).[34] Seven studies (36.8%)[32,35,36,38,43-45] did not report patients' disease severity level.

Qualitative Meta-Synthesis

COPD themes were first summarized and organized in the DET by signs, symptoms, functioning, global quality of life, perceived health status, and external factors that may impact COPD or disease severity. The exploration of symptoms focused on the themes and descriptive terms presented by study authors, which were compared with the terminology used directly by study participants (from the patient quotes provided in each article). A review of patient quotes found emergent latent themes related to the co-occurrence of symptoms and additional impacts on daily life not specifically reported by the study authors. Overall, while there was variation in the terms used by patients and authors to describe the experience of COPD, it was clear that there was conceptual consistency between the descriptions of patient experiences related to selected symptoms and impacts. These insights from the meta-synthesis yielded four main organizational categories: (1) COPD symptoms, (2) physical activity, (3) social and role functioning, and (4) emotional and psychological impacts.

COPD Symptoms

The symptoms most frequently mentioned by authors across studies are shown in Figure 2. This was compared with the patient terminology and descriptions of symptoms from the available

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quotes within each study publication (see Table 2). Additional patient quotes are presented in Online Supplement 5.

Respiratory symptoms

Breathlessness and/or shortness of breath were hallmark symptoms used in nearly all studies (17, 89.4%).[29-45] Cough was another frequently reported symptom across studies (10, 52.6%), followed by mucus (9, 47.3%). Although there are some similarities between terms used by authors and patients to describe the COPD experience, patients provided more descriptive and narrative explanations when discussing their symptoms and noted the intensity of the symptoms, how often they occur, and overall symptom burden. One example is the term breathlessness, which encompasses various patient phrases describing difficulty breathing or inhaling. Patients also described their cough experience in a variety of ways, using terms such as dry cough, mucus cough, hard cough, and deep and stringent cough.

Other COPD symptoms, such as wheezing (7, 36.8%)[33,34,37-39,42,43] and chest discomfort (6, 31.5%),[33,34,36,37,39,42] are part of the lived experience for some patients. Limited detail was provided within the studies themselves about wheezing or wheeziness, a term patients used without providing further description or context (4, 57.1%).[27,31,32,37] Chest discomfort was reported as chest tightness or pain/burning in the chest area or lung (6, 75%).[22,26,27,30,32,34-37,39] Pain attributed to cough, mucus, or breathing was reported by patients in four of these studies.[34,36,37,39] One study by Lee et al.[36] specifically explored the experience of pain in participants with COPD who have other co-morbid pain-related conditions.

Non-respiratory symptoms

The authors identified fatigue, tiredness, and exhaustion as prominent features of COPD; more than half of the studies (13, 68.4%) highlighted terminology such as “fatigue” and "tired/exhaustion,"[29,33,34,36-38,43] "low energy/lack of energy,"[28,33,37] and "slowing down of life."[30] Patients did not explicitly use the term "fatigue" to describe their experience. Patient narratives on their general day-to-day tiredness, as well as exhaustion, highlight the range of severity (intensity) of this symptom.

Sleep experiences or "sleep disturbances" were also highlighted in eight studies (8, 42.1%).[28,29,33,34,37,39,42,43] Nighttime awakening was one theme identified in a study by Hareendran et al., which specifically evaluated nighttime symptoms of COPD.[42] Sleep disturbances were often attributed to cough, wheezing, and shortness of breath.[33,43]

Concurrent/interactive nature of symptoms

Study participants often described the interaction between breathlessness, cough, and mucus, which led to other downstream symptoms and impacts. For example, cough was a frequent trigger of shortness of breath as reported by Lin and Shune.[38]

- "Well, [breathing gets] definitely worse because I'm coughing which is an anti-breathing process and so I'm not getting- I'm not having control of my breathing."[38]

Svedsater et al. also described that mucus buildup was shown to affect breathing and that coughing was used as a method to dispel mucus.[34] As the frequency of cough intensifies, this triggers further downstream fatigue/tiredness/exhaustion symptoms. The cycle of needing to expel mucus, coughing, and being breathless/short of breath was discussed, along with feeling exhausted from not getting enough rest, "*That's very exhausting, to cough hard with COPD. It really wears you out fast.*"[38] Overall, the narratives from patients show a pattern of distinct COPD symptoms, which may not always occur in isolation.

The intensity of symptoms was also explicitly addressed with acute exacerbations of COPD in four studies.[29,33,39,40] Individuals with a history of exacerbation were more likely to recognize variations in their signs and symptoms, indicating the possible onset of an acute worsening. The articles described these variations as a pattern starting with any of the following: dyspnea, cough, tightness in the chest, throat obstruction, wheezing, hoarse voice, or stuffy nose.[39]

Physical Activity

Limitations in physical activity varied from light (sitting or bending down) to moderate (walking short distances and needing to rest when walking) to more strenuous activity (climbing stairs).[32,33] Patients expressed various difficulties with physical activity, such as weak hand and leg muscles, mobility constraints, performing activities more slowly, needing to rest, and a decreased ability to do any type of physical activity in general. Limitations were often expressed about regular activities of daily living, such as getting dressed, showering, making the bed, getting the kids off to school, gardening, taking a walk, and playing with grandchildren.

Relationship Between Symptoms and Physical Activity

Breathlessness and physical activity were often discussed together when patients described their breathing issues. Various types of ambulatory activity led to breathlessness:

- "…if the grandchildren … went suddenly out the back and I had to make chase after them. You'd get kind of winded, you know …"[44]
- "[. . .] if I take a walk, for example, ta go out [sic] from here where you are now, suddenly I have to rest over there."[41]
- "… I go too fast some place and I get a little bit breathless … [I get breathless] if I went up the stairs too quick."[44]

- "When I try to walk out there, I can go maybe 50 yards and I have to stop and lean up against a post or something to catch my breath."[32]

Breathlessness often limited the participants' ability to perform various regular activities of daily living, including personal care activities, household chores, and hobbies:

- "Taking a shower makes me short…I get short of breath."[32]
- "My chest feels very tight. It seems that I have to make a huge effort to be able to breathe")."[33]
- "And I've got to get the kids off to school, that's when the short of breath gets worse in the morning, and the school run."[34]

Patients described the need to move slowly to control their breath, as well as the avoidance of moving around the house too quickly or walking uphill.[31,44] These types of breathing issues interfered with patients' overall well-being; more severe episodes of breathlessness had a greater impact on patients' lives.

Tiredness and exhaustion also impaired patients' ability to do their daily activities.

- "Sometimes it is very tiring. I came back from holiday last Tuesday night and on Friday I was cleaning out a bedroom and I was very tired out. Something that years ago would have 20 min—takes long time."[35]
- "I find changing the bed [the linen] I'm wrecked."[44]
- "This affects me on a daily basis as I am continually tired, the simplest of tasks take ages to complete and leave me exhausted and breathless and depressed as I fear losing my independence."[43]
- "I feel really tired in the morning, I barely get up. As soon as I put my feet on the ground, I start dressing and I'm already tired."[33]

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In one study on the oral intake experience in patients with COPD, patients described how coughing interfered with eating and drinking, causing difficulty in swallowing and a sensation of choking.[38]

Social and Role Functioning

Patients described various limitations in their family roles, relationships, and employment as a result of COPD. These impacts on social activities led to embarrassment, avoidance or withdrawal from social activities, and, in the worst cases, self-isolation. In some instances, the initial limitations with role functioning were specifically linked to breathlessness.

- "I am frustrated because things that I did 2 years ago I cannot do now. My wife won't take me out as it is embarrassing to me because I cannot get my breath."[30]

Patients described feeling like they could not go out or leave the house because they could not "get [their] breath." Spending time with children and romantic relationships were also significantly affected.[29,30,34,36,41,43-45]

Persistent cough, or "coughing all the time," impacted social activities. Avoidance or hiding was described as a method to mitigate the embarrassment of coughing in public or around others.

- "Nobody wants to be near me in the mornings believe me … I get into the bathroom I know it's horrendously bad. I like to go away on my own because I know that I'd embarrass everybody …"[44]

Another example highlights how a heightened sense of awareness about COPD limits hobbies with a social dimension.

- "COPD prevents me from doing a lot of what I once enjoyed, including singing, it can be embarrassing at times when you have to explain why you can't do certain things."[44]

This concern about being singled out as different by coughing or breathing heavily in public indicates the stigmatization of COPD.[35] This issue is also experienced in the workplace where the need to cough to dispel mucus impacted employment, necessitating more frequent breaks during the day and, in some cases, reduced work hours.

Emotional and Psychological Impacts

A myriad of emotional and psychological impacts experienced by patients were described across studies: frustration, irritability, anger, desperation, anxiety, panic, fear; despondence, sadness, helplessness; dependency on others, limitations in sense of freedom and independence; feeling self-conscious, embarrassment; sense of isolation, loneliness; feelings of guilt, not being understood. Although the emotional and psychological experience has many dimensions, an overall theme of the symptom experience is the inability to perform personally meaningful activities daily. Patient narratives often described how this led to embarrassment, frustration, and fear/anxiety.

- "Not being able to breath, and unable to do physical activity. The worst part, your mind tells you that you can do it, because you've been doing it your whole life. Your body shuts the thinking down real quick. Leaving me very frustrated."[43]

This frustration is a common theme of the COPD experience, given the challenges with symptom experience and management. Other themes included anxiety or panic from a fear of losing independence due to episodes of breathlessness. Patients commented on anxiety being a trigger, leading to difficulty breathing, then wheezing and coughing:

- "[When I panic] it's harder and harder [to breathe]. I start into the wheezing phase then coughing."[38]

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Emotionally, patients expressed daily irritability and embarrassment due to COPD symptoms, specifically with visible symptoms such as coughing up mucus in public. The feeling of embarrassment persisted even in the presence of family.

- "I have sticky mucous that makes me cough every day and I feel irritable, thereby I take medications and drink warm water every day to drive out sticky mucous."[45]
- "The sputum makes me feel desperate and then I bother my family, I know it."[33]

Participants reported that their cough led to frustration and other negative emotions due to the impact on basic functions like eating.

- "During your mealtime, you can potentially develop coughing or shortness of breath, and these actions can lead to some negative emotions."[38]

Walker et al.[35] observed that COPD exacerbation was associated with strong negative emotions such as fear and anxiety, *"Like having a plastic bag over your head…so frightening."* This level of anxiety was elevated during exacerbations, with descriptions such as a threat to life, a feeling of terror, and a fear of dying or suffocation.

Additional Insights

Environmental factors such as exposure to smells (detergents, perfumes), pollutants/chemicals, and fumes play a role in triggering COPD symptoms like breathlessness[35] and chest tightness.[37]

- "Fumes from cars give it to me and that cough persisted for a while. I was on a bus and if the doors are open the fumes… make me cough. Usually I get a tickle."[35]

Environmental triggers of exacerbations were also discussed and linked to exposure due to occupation.

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- “Sometimes after finishing repairs on a house, I would feel moody, so I took bronchodilators…and Yes, I was a home improvement technician. It was not good for my illness, because it stimulated [acute exacerbation of] COPD events.”[39]

Weather can also be a significant factor that worsens respiratory distress in patients, affecting how they experience their symptoms. Johannson et al.[31] noted that patients perceived weather (i.e., heat, cold, wind, and moisture) as a barrier to everyday life. Cook et al.[43] also discussed the effect of weather on breathing:

- "Weather affects me so much…Never know what kind of air there will be. Hot is horrible. Cold is horrible. Humid is even worse. I never commit myself to anything. Most of my friends and family get it that I can’t know until the day because I never know what kind of breathing day will be.”[43]

Svedaster et al.[34] also discussed the effects of colder weather:

- "And with me it’s like, shortness of breath on a day-to-day basis, but like the winter, during the winter, I have that sharp tightness in my chest and that wheeziness, so it’s first thing in the morning and at night.”

Although not the primary focus of this study, the ability to cope with and manage COPD symptoms is a crucial aspect of the patient experience. This ability is influenced by factors such as family and social support, the healthcare system in the patient’s country, access to care and services, as well as individual characteristics. Avoidance was common when dealing with the challenges of COPD, as well as isolation from social activities. Avoiding triggers, slowing down, and adhering to treatment were common ways patients adapted to the limitations of daily life with COPD.

DISCUSSION

COPD is a complex, heterogeneous, chronic lung condition caused by abnormalities of the airways (bronchitis, bronchiolitis) and/or alveoli (emphysema) that result in persistent, often progressive respiratory and systemic manifestations, leading to a variety of symptoms and functional impacts. Individual qualitative research studies in COPD offer rich, descriptive data and context-dependent insights into people's experiences and perspectives. While qualitative research can play an important role in driving new hypotheses to inform clinical research addressing unmet needs, it is often underutilized.[46] This meta-synthesis integrates findings across 19 individual qualitative studies, further generating an in-depth understanding of the lived health experience that transcends the context-dependent interpretations in independent research.

In COA research, there can be a misalignment between how researchers and patients understand health concepts. Although patient interviews are commonly used to inform the naming of these concepts, the final decision on terminology rests with the research teams. The challenge is that the label assigned to a health concept may not fully represent the language or terminology used by patients to describe their experience; patients' knowledge of their disease also plays a critical role in the interpretation of health concepts.[14] Measuring the wrong health concept in a trial risks negatively impacting the results, which is why involving patients early in the research process and drawing from high-quality patient-driven research is critical. In our meta-synthesis, the final set of thematic labels was derived from specific words and phrases in patient quotes that were selected by researchers from the respective publications. Prominent symptoms identified in the meta-synthesis include breathlessness/shortness of breath, cough, mucus, wheezing, chest discomfort, sleeping difficulty, tiredness, and weakness. Patients also described major effects on

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physical activity, emphasizing difficulties with regular activities of daily living. Emotional experiences included feelings of anxiety, frustration, and discouragement.

To our knowledge, this is the first attempt to synthesize patient-relevant health concepts in COPD based on empirical qualitative research that can be used to inform measurement in clinical trials. Our findings were in line with other reviews, such as Disler et al.[11] who identified the need for better understanding the condition, the sustained symptom burden these patients face, and the unrelenting psychological impact of living with COPD as critical themes. Similarly, we found that the significant symptom burden, coupled with the inability to perform regular activities of daily living, has a severe impact on social and role functioning and the psychological and emotional health of individuals with COPD. Our findings are also consistent with results from recent large surveys of people with COPD.[47,48]

The health concepts that we have identified from this meta-synthesis should be considered as provisional. While the concepts provide a valuable starting point for subsequent collaborative discussions between researchers and patients, it is important to recognize their limitations. Currently, the generalizability of these health concepts to the COPD population is constrained by the lack of available data on potentially relevant moderating factors that may influence patient perspectives. We found that authors generally focused on narrow research questions, such as a specific disease stage, experience, or effect, with results not generalizable to the broader patient population. Furthermore, a number of articles did not specify disease severity or present results by severity, education, or socioeconomic status, precluding the ability to analyze results by these factors. The effects of these important variables on patient experience warrant further exploration of the patient symptoms and impacts by disease severity (including early and late COPD) and across diverse patient groups (e.g., gender, ethnicity), health statuses (e.g., comorbid conditions), and study designs. We also appreciate that our study selection criteria for the meta-synthesis may have excluded studies that identified other relevant health concepts; a follow-up systematic exploration of these excluded studies may therefore be warranted. However, unlike a quantitative meta-synthesis, the qualitative synthesis aims to identify purposive rather than exhaustive studies that support an interpretive explanation.[49]

While each symptom described by patients can occur independently, some patients described interactions between symptoms, such as mucus, cough, breathlessness, and tiredness, which affected various aspects of their daily lives. The multidimensional nature of COPD is complex, with symptoms interacting and fueling one another. A better understanding of the independent and concurrent symptoms, physical activity challenges, social and role functioning, and emotional experiences is needed. These findings align with the first chapter of the European Respiratory Society's "COPD in the 21st Century Monograph."[50] As part of a collaboration between patients living with the disease and patient organizations, breathlessness was identified as a priority for patients and plays a key role in the "symptom-activity-emotions" interactive patient experience.[50] Our results support the growing body of qualitative evidence highlighting how physiological aspects of COPD can lead to downstream day-to-day impacts that increase the burden of the disease, particularly emotional changes.[36] These insights underscore the profound and multifaceted impact of COPD on patients' lives, emphasizing the need for comprehensive patient-centered approaches in clinical research.

CONCLUSIONS

As a critical first step in the COPD Foundation's PIVOT initiative,[5] we have integrated findings from relevant qualitative research studies to develop a provisional thematic representation of meaningful aspects of patients' health experiences in COPD. The provisional health concepts constructed from this meta-synthesis will be refined in collaboration with patient research partners and used in a Delphi study to reach patient consensus on terminology and priorities. The goal is to establish a unified set of patient-inspired health concepts that represent treatment benefits, such as improvements in how patients feel and function in their daily lives. It will be imperative that the patient selection process for these collaborative activities ensures a broad representation of the various patient characteristics that may influence perceptions of disease burden and treatment benefit. This prioritized set of patient-inspired health concepts will serve as a patient-centered framework for identifying meaningful and measurable concepts of interest ("what to measure") and selecting fit-for-purpose outcome measures ("how to measure") to demonstrate treatment benefit in COPD clinical trials.

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TABLES

Table 1. Summary of Studies Included in Meta-Synthesis (N=19)

First Author/Year	Study Objective	Methodology	COPD Severity	COPD Sample Size	Country
Ansari et al. 2022[28]	To design a questionnaire suitable for **assessing wellness** in persons with COPD and to determine any association of wellness with other COPD outcome measures	• Type of interview ○ Mixed methods (focus groups, survey) • Analysis ○ Thematic analysis	FEV1 % predicted: 45.40 ± 19 GOLD average 2.75±0.90	N=12	UK
Chatreewatanakul et al. 2022[39]	To explore the lived experiences of **symptom recognition** and to explain the pattern of **symptom management** successfully among **exacerbation COPD patients**	• Type of interview ○ Mixed methods (semistructured interviews, observation techniques) • Analysis ○ Heideggerian hermeneutic phenomenology analysis	GOLD 2 to 4	N=20	Thailand
Cook et al. 2019[43]	To assess the **impact of cough and excessive mucus secretion** on different aspects (including functional and emotional) of the lives of patients with COPD	• Type of interview ○ Online patient community forum/social media listening • Analysis ○ Constant comparative analysis	Not reported	N=20	UK & US
Cooney et al. 2013[44]	To understand the **meaning of COPD** for people and their response to this disease	• Type of interview ○ Semistructured interviews, longitudinal design within clinical trial • Analysis ○ Comparative analysis	Not reported	N=26	Ireland
Gabriel et al. 2014[29]	To understand the **psychosocial impacts** of COPD on family life, during the chronic phase	• Type of interview ○ Interviews (open-ended questions) • Analysis ○ Thematic analysis	FEV1 (% predicted), Mean ± SD 37.3 ± 8.4% GOLD Severe: n=14 (70%) Very Severe: n=6 (30%)	N=20	Portugal

First Author/Year	Study Objective	Methodology	COPD Severity	COPD Sample Size	Country
Hareendran et al. 2013[42]	To describe the **concept elicitation methods for development of a PRO instrument evaluating nighttime symptoms of COPD** and to document evidence of content validity for the study	• Type of interview ○ Focus groups ○ 1:1 cognitive interviews • Analysis ○ Phenomenological analysis	GOLD I to IV	N=37	US
Jarab et al. 2018[30]	To **explore patients' views and perceptions regarding COPD** and its impact on their quality of life. A specific aim is to explore how patients with COPD **cope** with their chronic disease, and their needs and perspectives regarding COPD **management** and its impact on their **quality of life**	• Type of interview ○ Focus groups • Analysis ○ Thematic analysis	FEV1 (L) % mean (SD) Range per focus group: 41.3 (5.1) to 55.4 (5.7) GOLD Moderate to severe	N=28	Jordan
Johansson et al. 2019[31]	To identify and describe the **symptom burden** and its effect on daily life in people with COPD, based on their own lived experiences	• Type of interview ○ 1:1 Structured interviews • Analysis ○ Thematic analysis	GOLD III to IV	N=25	Sweden
Lee et al. 2018[36]	To understand the individuals' **experience of pain** to understand treatment approaches required to achieve effective pain management and minimize impact in those with COPD	• Type of interview ○ 1:1 interviews (open-ended and closed questions) • Analysis ○ Interpretive phenomenological analysis	FEV1/FVC <70) FEV1 % range: 18 to 40 FVC %: 28 to 69 Severity not reported	N=8	Canada
Leidy et al. 2015[37]	**Tool development – COPD case identification**. Signs, symptoms, and indicators of COPD.	• Type of interview ○ Focus groups ○ 1:1 cognitive interviews • Analysis ○ Content analysis	GOLD II to IV Mean post-bronchodilator FEV1 %: 68% (SD=10) Mean FEV1: 2.2 l (SD=0.8)	N=20	US
Leidy et al. 2014[32]	To assess content validity of the E-RS for measuring **respiratory symptom severity** in patients with stable COPD	• Type of interview ○ Focus groups • Analysis ○ Secondary analysis of existing qualitative interviews ○ Thematic analysis	FEV1: 1.3 (0.6) FEV1% predicted, mean (SD): 51.2 (19.6) Stable COPD Exacerbation-free for 12 months	N=84	US

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First Author/Year	**Study Objective**	**Methodology**	**COPD Severity**	**COPD Sample Size**	**Country**
Lin & Shune 2022[38]	To understand the **oral intake experience** for individuals with COPD, including swallowing-related barriers, behaviors, and emotions	• Type of interview ○ Semistructured interviews • Analysis ○ Grounded theory	Not reported FEV1 % range: 33 to 68	N=14	US
Machado et al. 2022[33]	To understand individuals' experiences (i.e., **needs, impact, perceptions**) during mild-to-moderate **AECOPDs**; and to also explore their thoughts on PR during an AECOPD as a secondary aim	• Type of interview ○ Semistructured interviews • Analysis ○ Deductive thematic analysis	AECOPD according to GOLD FEV1% predicted: 41 ± 16%	N=11	Portugal
Martínez-Guiu et al. 2022[51]	To gain an in-depth understanding of COPD patients' **attitudes and needs**, and their influence on the different phases, from the perspective of patients and healthcare professionals	• Type of interview ○ Semistructured interviews • Analysis ○ Inductive analysis	Moderate-to-severe COPD	N=28	Spain
Marx et al. 2016[40]	To explore what it means to live with COPD as an incurable and constantly progressing disease. By developing a theory of **experiencing COPD**, we further tried to describe and understand how single phenomena, which could be reconstructed from the patients' perspectives, are intertwined	• Type of interview ○ Semistructured interviews • Analysis ○ Grounded theory	COPD stage III/IV GOLD	N=17	Germany
Svedsater et al. 2017[34]	To identify COPD- or asthma-related **factors (such as burden, priorities, individual unmet need, and treatment goals**) that may be used to determine patient-defined treatment benefits	• Type of interview ○ Focus groups ○ Individual interviews • Analysis ○ Thematic analysis	Self-reported severity as "mild", "moderate" or "severe"	N=33	UK
Valencia-Rico et al. 2020[41]	To determine the meaning of the **experience** of people with COPD	• Type of interview ○ In-depth qualitative interviews • Analysis ○ Heideggerian hermeneutic phenomenology analysis	GOLD III and IV	N=10	Columbia
Walker et al. 2017[35]	To explore patients' **experience of living with COPD** and their perspective of their **community healthcare** for COPD to extract affective responses in order to develop potential items for a patient-reported experience measure for COPD	• Type of interview ○ Face-to face qualitative interviews • Analysis ○ Thematic and affective analysis	Not reported	N=64	UK

First Author/Year	Study Objective	Methodology	COPD Severity	COPD Sample Size	Country
Wangsom et al. 2020[45]	To examine factors **predicting HRQOL** and exploring a comprehensive in-depth understanding of the factors associated with HRQOL. An aim is to inform the development of care interventions that will improve HRQOL in this population	• Type of interview ○ Mixed methods (questionnaires, semi-structured interviews) • Analysis ○ Content analysis	Not reported	N=30	Thailand

Abbreviations: AECOPD = acute exacerbation of chronic obstructive pulmonary disease; COPD = chronic obstructive pulmonary disease; E-RS = Evaluating Respiratory Symptoms; FEV1 = forced expiratory volume in 1 second; FG = focus group; FVC = forced vital capacity; GOLD = Global Initiative for Chronic Obstructive Lung Disease; HRQOL = health-related quality of life; PR = pulmonary rehabilitation; PRO = patient-reported outcome; SD = standard deviation

Note: Two of the 19 studies did not offer any thematic description related to the patient experience of breathlessness: Ansari et al.[28] focused on the meaning of wellness in COPD, and Martínez-Guiu et al.[51] investigated different types of patient behavioral profiles and unmet needs related to “Education and Information” and “Patient Management.”

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Table 2. Patient-Reported Symptom Descriptors From the Qualitative Literature

Symptom Concept	**Common Patient Descriptors**	**Patient Quotes***
Breathlessness/shortness of breath	• Shortness of breath • Not being able to breathe/can't breathe/not breathing well/having to put effort to breathe/having trouble breathing/can't get breath • Dyspnea • Not able to inhale or exhale fully • Breathing attack	*"It started with* ***shortness of breath*** *and resulted in not being able to fully inhale."*[39] *"It feels like* ***I can't get enough breath****, and then when I get the breath, I-I know I have a hard time trying to get rid of it."*[42] *"Dyspnea in AECOPD state is different from normal days. I felt that when I had* ***dyspnea*** *from working, my heart would beat hard, like I was just tried, but I could breathe clearly."*[39]
Cough	• Deep/stringent cough • Wet cough • Dry Cough • Hacking • Coughing all the time	"I cannot lay down flat without **coughing my head off**."[42] "Well, if I get a hard cough it seems like I keep coughing, and it's a **dry cough**. It seems like you want to get something up, but there's nothing there to get up, and you cough and cough and cough. Finally, for some reason, you just quit"[32]
Sensation of mucus	• Mucus • Phlegm • Sputum • Clear, thick, sticky cough	*"It's all* ***clear, thick mucus*** *that I cough up and it's not all that pleasant to describe."*[32] *"I have* ***sticky mucous*** *that makes me cough every day and I feel irritable, thereby I take medications and drink warm water every day to drive out sticky mucous"*[45]
Wheezing	• Wheezing or wheeziness	*"When I felt like dyspnea…* ***wheezing*** *would occur before dyspnea increased."*[39] *"During the winter, I have that sharp tightness in my chest and that* ***wheeziness****, so it's first thing in the morning and at night."*[34]
Chest discomfort	• Breathing pain • Tight chest/chest pain • Burning in chest • Sharp/dull/aching/ burning sensation • Lung pain	"I feel a **tightness** and when breathing not full the lungs. This made me feel not so good."[39] "**You're trying to breathe** and it hurts, **and it hurts and you have pain** and then it hurts and …then go to the hospital for it—**it's the lungs**."[37] "Well, I have mucous coughs, too, you know where you got to cough up something, but most of the time it's not the mucous. It's just a **burning sensation right in my chest**."[42]
Tiredness/ exhaustion symptoms	• Feeling tired • Exhausted • Drained	*" 'Will you play table tennis with me mammy?' 'I'm not able to, honey'. I'm drained all the time." "*[44] "I walk up the driveway to my car, and--I'm really tired after that. I feel me [panting] breathing…you kind of feel **tired** all the time."[37]
Sleep disturbances	• General sleep disturbances • Nighttime awakening • Insomnia • Difficulty falling asleep • Bad sleep	"My breathing isn't good… **sleep is really bad** coughing all the time."[43]

Abbreviation: AECOPD = acute exacerbation of chronic obstructive pulmonary disease

*The patient quotes in this table are a selection of quotes based on the information available from the published articles as presented by the study authors.

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Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses Diagram

Abbreviation: RoB = risk of bias

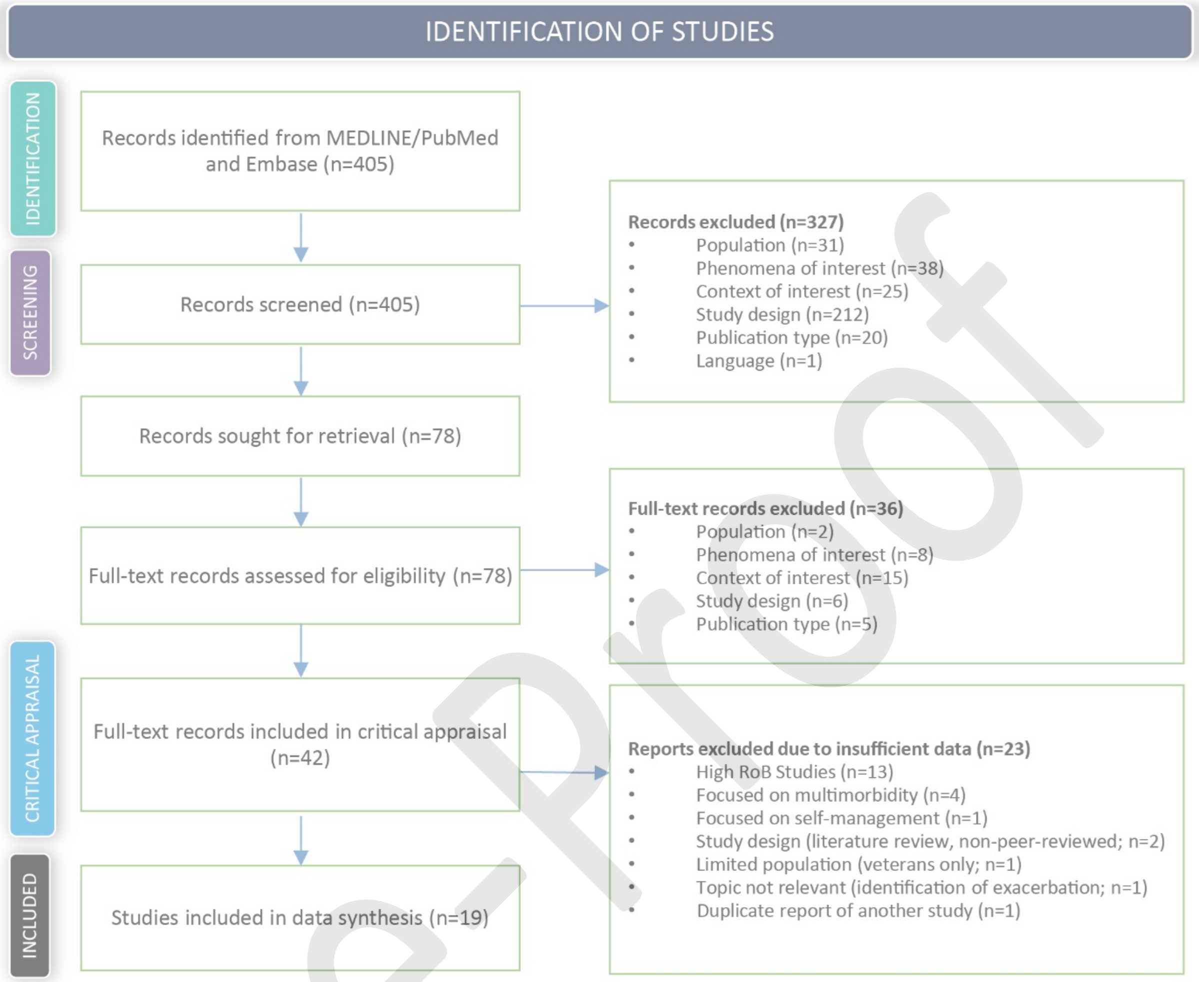
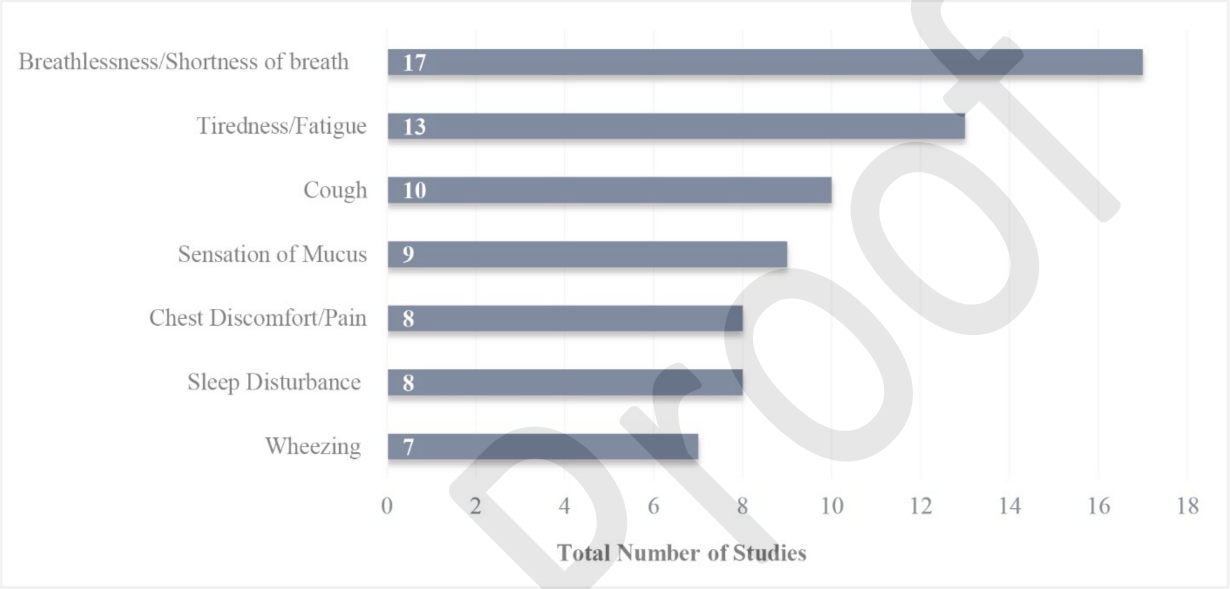


Figure 2. Most Frequently Reported COPD Symptoms[a] Across Qualitative Studies (N=19)[b]

Abbreviation: COPD = chronic obstructive pulmonary disease

[a] Other reported symptoms included incontinence (n=1), hoarse voice (n=1), stuffy nose (n=1), snoring (n=1), choking (n=1), sweating and high body temperature (n=1), headache (n=1), and weight loss (n=1).

[b] These symptom categories were defined by the study authors based on the emerging themes from patients.



Online Supplement

Supplement 1. Search Strategy, Screening, and Studies

Search Strategy

Search Number	Search Terms	Results
1	*chronic obstructive lung disease/ or exp *Pulmonary Disease, Chronic Obstructive/	138786
2	((chronic adj3 (obstructi$ or airflow) adj3 (lung$ or pulmonary or airway$ or respiratory or limitation$ or diseas$ or disorder$)) or (copd or coad)).ti. or ((chronic adj3 (obstructi$ or airflow) adj3 (lung$ or pulmonary or airway$ or respiratory or limitation$ or diseas$ or disorder$)) or (copd or coad)).ab. /freq=3	150954
3	1 or 2	183317
4	*"Signs and Symptoms"/ or *physical disease by body function/	1348
5	(signs or symptom$ or manifestation$ or impact$).ti. or (signs or symptom$ or manifestation$ or impact$).ab. /freq=3	2274517
6	exp *"Quality of Life"/ or exp *quality of life/	253808
7	(quality of life or QoL or hrql or hrqol or hr-qol).ti. or (quality of life or QoL or hrql or hrqol or hr-qol).ab. /freq=3	341128
8	or/4-7	2589071
9	exp *qualitative research/ or exp *Interviews as Topic/ or exp *interview/ or exp *questionnaire/ or (interview$ or focus group$ or lived experience or narrative analysis or conceptual framework or debriefing or content analysis or discussion group or ethnograph$ or qualitative or grounded theory or phenomenology).ti. or (interview$ or focus group$ or lived experience or narrative analysis or conceptual framework or debriefing or content analysis or discussion group or ethnograph$ or qualitative or grounded theory or phenomenology).ab. /freq=3	744331
10	3 and 8 and 9	1007
11	(case report or case series or woman or man or child or adolescent or female or male or boy or girl or infant).ti. or case reports/ or case study/ or case report$.jw.	4125627
12	10 not 11	1003
13	("Introductory Journal Article" or News or "Newspaper Article" or Editorial or Comment or Overall).pt. or in vitro Techniques/ or in vitro study/ or (commentary or editorial or comment or letter or mice or rat or mouse or animal or murine).ti.	7066227
14	12 not 13	989
15	14 not (animals/ not humans/)	989
16	15 not ((exp animal/ or nonhuman/) not exp human/)	987
17	limit 16 to english language	925
18	conference abstract.pt.	4776545
19	17 not 18	785

Search Number	Search Terms	Results
20	limit 18 to yr="2021 -Current"	638949
21	17 and 20	19
22	19 or 21	804
23	limit 22 to (article or article in press)	769
24	limit 23 to yr="2012 -Current"	494
25	**Remove duplicates from 24**	**390**

Population, Phenomenon of Interest, Context, Study Design (PICoS) Inclusion and Exclusion Criteria

Category	Inclusion Criteria	Exclusion Criteria
Population	Adults with COPD	Pediatric populations ≤17 years old
Phenomena of Interest	Any patient-reported concept related to the disease and treatment experience, including but not limited to COPD symptoms and impacts	NA
Context of Interest	• Patient disease experience in real-world setting • Patient treatment experience in real-world setting • QoL	–
Study Design	• Qualitative research studies (e.g., concept elicitation, cognitive debriefing, focus groups) • Mixed-methods studies with an element of qualitative design • Literature reviews of qualitative data including descriptive research or explanatory qualitative research • Ethnographies	• Observational quantitative studies with no qualitative element • Interventional studies or RCTs • Economic studies (i.e., economic evaluation, cost effectiveness) • Surveys (categorical data) • Studies not addressing topics not related to patient experience or quality of life of COPD • Case studies
Language/Publication Type	• English language only • Conference proceedings 2021 to the present Journal articles 2012 to the present	Publications that are not studies (e.g., editorials)
Geographical Regions	Global scope	NA

Abbreviations: COPD = chronic obstructive pulmonary disease; NA = not applicable; PICoS = population, phenomenon of interest, context, study design; QoL = quality of life; RCT = randomized controlled trial

Supplement 2. Appraisal via CASP Checklist

		Questions and Rating									
	Title	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and patients been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Ansari et al.[1]	To design a questionnaire suitable for assessing wellness in persons with COPD and to determine any association of wellness with other COPD outcome measures.	✓	✓	*	*	✓	*	*	✓	*	✓
Chatreewatanakul et al.[2]	Early symptom recognition and symptom management among exacerbation COPD patients: A qualitative study	✓	✓	✓	✓	✓	✓	✓	✓	✓	*
Cook et al.[3]	Impact of cough and mucus on COPD patients: primary insights from an exploratory study with an Online Patient Community	✓	*	✓	*	✓	*	✓	*	✓	✓
Cooney et al.[4]	Life with chronic obstructive pulmonary disease: striving for 'controlled co-existence'	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Gabriel et al.[5]	Day-to-day living with severe chronic obstructive pulmonary disease: towards a family-based approach to the illness impacts	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Hareendran et al.[6]	The development of a patient-reported outcome measure for assessing nighttime symptoms of chronic obstructive pulmonary disease	✓	✓	*	✓	✓	*	*	✓	*	✓
Jarab et al.[7]	Patients' perspective of the impact of COPD on quality of life: a focus group study for patients with COPD	✓	✓	*	✓	✓	✓	✓	✓	✓	*
Johansson et al.[8]	To live a life with COPD - the consequences of symptom burden	✓	✓	✓	✓	✓	*	✓	*	*	*
Lee et al.[9]	An exploration of pain experiences and their meaning in people with chronic obstructive pulmonary disease	✓	✓	✓	✓	✓	✓	*	*	✓	✓

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		Questions and Rating									
Leidy et al.[10]	Identifying cases of undiagnosed, clinically significant COPD in primary care: qualitative insight from patients in the target population	✓	✓	*	✓	*	X	*	*	*	*
Leidy et al.[11]	Measuring respiratory symptoms in clinical trials of COPD: reliability and validity of a daily diary	✓	✓	*	✓	*	X	*	*	*	*
Lin & Shune[12]	The mind-body-breath link during oral intake in chronic obstructive pulmonary disease: A grounded theory analysis	✓	✓	✓	✓	*	*	*	*	*	✓
Machado et al.[13]	Giving voice to people - experiences during mild to moderate acute exacerbations of COPD	✓	✓	*	*	✓	*	✓	✓	✓	✓
Martínez-Guiu et al.[14]	Impact of patients' attitudes and dynamics in needs and life experiences during their journey in COPD: an ethnographic study	✓	✓	✓	✓	✓	✓	*	*	*	✓
Marx et al.[15]	Meaning of living with severe chronic obstructive lung disease: a qualitative study	✓	✓	✓	✓	✓	✓	*	*	*	*
Svedsater et al.[16]	Life impact and treatment preferences of individuals with asthma and chronic obstructive pulmonary disease: Results from qualitative interviews and focus groups	✓	*	*	*	*	X	*	*	*	*
Valencia-Rico et al.[17]	Living with chronic obstructive pulmonary disease: A story conditioned by the symptoms	✓	*	✓	✓	✓	✓	✓	✓	*?	*
Walker et al.[18]	Stage 1 development of a patient-reported experience measure (PREM) for chronic obstructive pulmonary disease (COPD)	✓	*	✓	*	*	✓	*	*	✓	✓
Wangsom et al.[19]	The factors predicting the health-related quality of life among persons with chronic obstructive pulmonary disease in public health region 4, Thailand: A mixed-methods study	✓	✓	✓	✓	✓	*	*	*	*	*

✓ = high strength evidence is present; * = evidence is present but the strength is moderate or low; X = no evidence is available; ? = unclear.

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Supplement 3. Steps of the Meta-Synthesis

Evidera used a meta-synthesis approach as outlined by Sandelowski and Barosso.[20] Qualitative meta-synthesis is an interpretive integration of qualitative findings, it follows a coherent approach to analyzing the data so that the findings from the data are accessible and understandable.[20] The aim of this initial meta-synthesis activity was to develop a coherent description of the taxonomy of concepts associated with COPD experience. The individual steps of meta-synthesis are systematic and iterative, and include:

Meta-Synthesis Step	Description
Data preparation, data cleaning, and grouping	Data extracted were cleaned and the text was reduced by including only the relevant information and summarizing findings from the individual studies to improve readability. After that, an initial grouping process began. The data were initially grouped into high-level themes of signs, symptoms, and impacts. At the data abstraction stage, the emerging themes were grouped into higher categories to describe their contents and highlighting contradictions and similarities across and within groups. This iterative process continued until a set of categories that comprehensively captured the contents of the dataset was available.
Data summary/meta-summary	To summarize the data, the frequencies of reporting of each high-level theme were tallied and expressed as a number and percentage of studies based on themes across the studies. This was then further explored by patient level data (patient quotes) from each study.
Taxonomic analysis approach	The taxonomic grouping of the emerged themes allowed for a better understanding of the conceptual range of findings that will provide the foundation for future conceptual models of patients' experience of COPD. The taxonomy process began with an initial grouping of concepts by area of impact into specific categories and subcategories, inductive from the data. For example, the symptoms (objective and subjective) were grouped to reflect the different areas impacted, such as respiratory symptoms, energy-related symptoms, or cognitive symptoms. Similarly, impacts were grouped into categories reflecting the functional areas impacted by the disease. Treatment experience, resource use, and patient journey impacts were used to group life-impacts of the disease. Where necessary, subcategories were created to retain data nuances and highlight contrasting findings. Study patient quotes were included to provide evidence for the taxonomy groups. The research team members reviewed the initial grouping and discussed these to iteratively create the final taxonomy of concepts and ensure there is alignment in definitions. The links and inter-relations between the different concepts were highlighted based on the data obtained from studies.

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Supplement 4. Ethnicity and Employment Information of the Study Populations

First Author/Year	Ethnicity/Race	Employment
Ansari et al. 2022[1]	Caucasian	Not reported
Chatreewatanakul et al. 2022[2]	Asian *(assumed as recruited in Bangkok and metropolitan area)*	• Employed n=5/20 • Unemployed n=10/20 • Retired n=5/20
Gabriel et al. 2014[5]	Not reported	• Employed n=1/20 • Retirement n=19/20
Hareendran et al. 2013[6]	• Mixed; predominantly White (78.3%) • White: FG 24 (88.9%); CI 5 (50%) • Black or African American: FG 2 (7.4%); CI 5 (50%) • Native American or Alaska Native: FG 1 (3.7%); CI 0 (0%) • Hispanic or Latino (not exclusive of race): FG 2 (7.4%); CI 0 (0%)	Not reported
Jarab et al. 2018[7]	Mid-eastern *(Arabic-speaking; assumed based on location)*	• Employed n=11/28 • Unemployed=17/28
Leidy et al. 2015[10]	• Hispanic or Latino: 2 (10.0%) • Not Hispanic or Latino: 18 (90.0%)	• Employed n=6/20 • Retired n=8/20 • Disabled n=6/20 • Other (student, unemployed, other) n=3/20 *(COPD data only)*
Lin et al. 2023[12]	Non-Hispanic: 100.0% (14/14)	Not reported
Martínez-Guiu et al. 2022[14]	Not reported	• Employed n=9/28 • Unemployed n=3/28 • Retired n=16/28
Svedsater et al. 2017[16]	• White: n=31/33; 93.9% • Unspecified: n=2/33; 6.1% *(COPD data only)*	• Employed n=9/33 • Retired n=15/33 *(COPD data only)*
Wangsom et al. 2020[19]	Not reported	• Quantitative arm: Unemployed = 86.7% • Qualitative arm: Unemployed = 68.3%

Abbreviations: CI = cognitive interview, FG = focus group

Note: Cook et al.,[3] Cooney et al.,[4] Johansson et al.,[8] Lee et al.,[21] Leidy et al.,[11] Machado et al.,[13] Marx et al.,[15] Valencia-Rico et al.,[17] and Walker et al.[18] did not report any ethnicity/race or employment information.

Supplement 5. Thematic Descriptors – Patient Quotations

This section presents patient quotes for the most frequently reported symptoms and impacts across the included studies. Patient quotes for other symptoms and impacts are available on request.

Symptoms

Breathlessness/Shortness of Breath

Descriptors[a]	Illustrative Quotes
Shortness of breath (n=7/17)	"With the disease progression, **this shortness of breath** gets worst and now, I think a lot about tomorrow the pain it might cause."[5] “Mine fluctuates so much I can have it-like talking I’m fine but walking from here to my car **I’ll be short of breath** and I have to be on oxygen. I don’t have a consistent-I’m up and down”[11] “Oh, for sure, immediately [when things go down wrong during mealtime and you start coughing, the coughing can turn into more **shortness of breath**.]”[12]
Not able to breathe /Can’t breathe/ Not breathing well/ Effort to breath/Trouble breathing/ Can’t get breath (n=7/17)	“You’re trying to get your breath; **you can’t get your breath.”[21]** “You’re **calling for a breath to fill your lungs**, but you can’t seem to get it"[6] “It feels like **I can’t get enough breath**, and then when I get the breath, I-I know I have a hard time trying to get rid of it.”[6]
Dyspnea (n=1/17)	"When I had a hoarse voice, I would have more dyspnea immediately"[2]
Not able to inhale or exhale fully (n=1/17)	"My dyspnea increased until **I couldn't exhale**."[2]
[Breathing] Attack (n=1/17)	“I only get these **attacks** if I rush about quick but then it can come on just going out of the bedroom to the toilet…"[4]
Breathing like a horse (n=1/17)	“**Breathing like a horse**”[11]
Choking (n=1/17)	“feeling like I’m **choking to death**…like somebody’s got a pillow over your face and you’re smothering”[11]
Take my breath away (n=1/17)	“**take my breath away** from me’[11]
Not getting enough oxygen (n=1/17)	“not breathing adequately, **not getting enough oxygen**”[11]
Gulp for air (n=1/17)	“**gulp air** trying to get air into my lungs”[11]
Bricks on chest (n=1/17)	“Just feels like you've got like something like a ton of **bricks just sitting on your chest**.”[10]
Get out of breath (n=1/17)	“I can’t exercise as I **get out of breath”[7]**
Breathlessness (n=1/17)	". . .I’m always breathless all day! So they hook me up to the oxygen [. . .] this **breathlessness** doesn’t make me calm down [. . .]."[17]

[a]Some studies reported more than one descriptor; therefore, the n counts in this column exceed the total n count of the studies (n=17/19)

Fatigue

Descriptors	Illustrative Quotes
Tired/exhausted/drained (n=8/13)	"You're always feeling a bit tired, yeah... I mean, I have to go to bed sometimes about half past nine... I'm **tired**, I've done now."[16]

Cough

Descriptors[a]	Illustrative Quotes
Cough (n=7/10)	"It started from **coughing** and resulted in dyspnea to the point the body was shaking."[2]
Deep, stringent cough (n=1/10)	"It's a very **deep and stringent cough**"[11]
Dry cough (n=2/10)	"I had a **dry cough**…coughing without sputum for about a half an hour. When I recognized this sign, I would ask my wife to slap my back."[2]
Wet cough (n=2/10)	"Well, I **have mucous coughs**, too, you know where you got to cough up something, but most of the time it's not the mucous. It's just a burning sensation right in my chest."[6]

[a]Some studies reported more than one descriptor; therefore, the n counts in this column exceed the total n count of the studies (n=11/19)

Mucus

Descriptors[a]	Illustrative Quotes
Mucus – clear/thick/sticky (n=5/9)	"Early morning, back of throat totally **clogged up with mucus**, I start the process of ridding the mucus by retching hacking and it is so exhausting this takes around 45 mins to 2 hrs."[3] "And then that starts scaring me because when I don't have enough breath then I start getting more and more **mucus** on my chest."[21]
Phlegm (n=2/9)	"I cough when I have **phlegm** building up in the chest and that's the way you expel it."[11]
Sputum (n=2/9)	"Dyspnea, increased **sputum**, and increased coughing did not improve after resting. I had still dyspnea"[2]
Mucus with wet [cough] (n=1/9)	"I have **two different kinds of cough, and wet and dry** doesn't really… There's the kind that comes with congestion"[11] "Because **when I cough sometimes I'll kind of bring up some** mucus and I don't want it to come up. … You know it needs to come up because your body tells you need to cough it up"[11]

[a]Some studies reported more than one descriptor; therefore, the n counts in this column exceed the total n count of the studies (n=10/19)

Impacts

Physical Functioning

Physical Activity[a]	Illustrative Quotes
Walking limitations/need for rest when walking (n=6/16) [4,8-11,17]	"[If I] take it at my own slow pace. I'm alright … **I don't walk** at all now anyway … The daughter brings me every place …"[4] "**I walk at my own speed** and stop and rest and then move on."[8]
Climbing or going down the stairs (n=5/16)	"I have no problem really. Unless I go too fast some place and I get a little bit breathless … [I get breathless] if I went **up the stairs** too quick…"[4]
Weak physical strength (n=2/16)	"But it's a terrible thing! It's like difficulty breathing or something: like **my legs didn't have enough strength** to hold my body up!"[17]
Performing activities slowly (n=2/16)	"If I have to perform activities requiring a lot of force, I get tired, thereby I had to remind myself to **do activities slowly**."[19]
Constraint mobility (n=2/16)	"…**but I can't go up a flight** of stairs if I get in a hurry"[10]
Decreased ability on doing any physical activities in general (n=1/16)	"**Anything physical** [is] gone now because I haven't got the breath"[4]

[a]Some studies reported more than one physical activity impact, therefore the n counts in this column exceed the total n count of the studies (n=18/19)

Instrumental Activities of Daily Living

Instrumental Activities[b]	Illustrative Quotes[a]
Doing housework (n=3/13)	"I came back from holiday last Tuesday night and on Friday I was **cleaning out a bedroom** and I was very tired out. Something that years ago would have 20 min—takes long time"[18]
Hobbies (i.e., dancing, singing) (n=4/13)	"I used to enjoy going out dancing. Nowadays I go, but I am not the same person, I feel tired, **I can only watch the others dancing**."[5]
Gardening (n=3/13)	"**Gardening, as I say**, I just go out and do my little bit and come in and go out again… one time you'd have stayed out there for a couple of hours. I can't."[4]
Catching public transportation (n=2/13)	"… I can't even leave the house to **catch the bus**."[13]
Lifting heavy objects (n=1/13)	"I drove a vehicle to transport monks, …. I couldn't lift heavy objects. If I lifted heavy objects, I would experience signs that AECOPD was imminent."[2]
Taking kids to school (1/13)	"And with me it's like, shortness of breath on a day-to-day basis, but like the winter, during the winter, I have that sharp tightness in my chest and that wheeziness, so it's first thing in the morning and at night. **And I've got to get the kids off to school**, that's when the short of breath gets worse in the morning, and the school run."[16]

[a]Patient quotes were not available for shopping, cooking, talking, riding a bicycle, and driving

[b]Some studies reported more than one instrumental activities of daily living impact; therefore, the n counts in this column exceed the total n count of the studies (n=14/19)

Social

Social Impacts[a]	Illustrative Quotes
Social isolation (n=7/13)	"...The restrictions to the quality of life in some cases **I can't even take part in family celebrations**…"[15]
Self-isolation (n=4/13)	"I don't go to my relatives' house, I don't go on vacations, I'm restricted to my home."[5]
Feeling self-conscious around other people (n=2/13)	"**I don't want to expectorate in front of others**, it is not pleasant. Not for me, even less for the others."[13]
Hard to keep up with others (n=2/13)	"I'd go out to lunch with…people from my office… I'd really have to kind of push myself to keep up with them ….**had to work to keep up**."[10]
Loneliness (n=1/13)	"I don't even go out, **I stay home**. For me to go out, I have to walk down the stairs and that's so hard I can't even do that. So I say no"[21]

[a]Some studies reported more than one social impact; therefore, the n counts in this column exceed the total n count of the studies (n=16/19)

Emotional and Psychological

Negative Emotions[a]	Illustrative Quotes[b]
Stress and anxiety (n=9/16)	"You **get that type of stress**, do I have a job tomorrow or not and that plays on the mind which plays on the body, which plays on the heart, which plays on the lungs."[21] "Pain makes you depressed, then you start getting anxious"[21]
Fear in relation to shortness of breath (n=6/16)	"Sometimes [the shortness of breath] **scares me**. Sometimes I'm- sometimes, not all the time, I'm scared."[12]
Depression (n=4/16)	"I guess it did get you a little bit **depressed** knowing that you can't sort of get out of that hole right?"[21]
Embarrassment (n=4/16)	"She [wife] helps me with everything, but most of the times I do not ask for help because I feel **embarrassed**."[5]
Frustration (n=4/16)	"I am **frustrated** because things that I did 2 years ago I cannot do now."[7]
Sadness (n=4/16)	"There are somedays that I prefer to be alone, in those days, I have **no joy** to go out."[5]
Feelings of powerlessness (n=3/16)	"At first I didn't take any of it all that seriously (sniffle) until last year, when **nothing more was possible**…"[15]
Feeling helpless (n=3/16)	"There is no way out, and I don't have the will to do something else anymore."[14]
Anger (n=2/16)	"Sometimes I **get angry** because I want to do something, and I can't… I feel frustrated."[13]
Feeling of not being understood (n=2/16)	"I feel that sometimes I am a little bit aggressive in my answers, but she [wife] needs to understand my problems. **She doesn't understand me**!"[5]
Fear of death (n=2/16)	"I have **anxiety about dying** from COPD, I once thought that I would die in that year when I experienced increased AECOPD."[2]
Become withdrawn/loss of motivation (n=2/16)	"There is no way out, and **I don't have the will** to do something else anymore."[14]

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Positive Emotions	Illustrative Quotes[c]
Hope (n=2/16)	"What I didn't expect was that this disease is not curable […] I thought well, try hard and you'll manage it, but not a bit of it, it's not the case […] but as it's there, yes now it's there now I must try to accept it, I'm about to do so, yes, and **hope** that I'll get it soon."[15]

[a]Some studies reported more than one emotional impact; therefore, the n counts in this column exceed the total n count of the studies (n=43/19)

[b]Patient quotes were not available for overwhelmed, lack of motivation, sense of identity loss, or difficulties in being reciprocal

[c]Patient quotes were not available for resilience, stoicism, acceptance, gratitude, altruism, enjoyment, or reassurance

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