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Real-time experience of an acute exacerbation of COPD: A qualitative exploration

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Abstract

Introduction: Many qualitative studies have explored patients' experiences of an Acute Exacerbation of Chronic Obstructive Pulmonary Disease (AECOPD) retrospectively. To our knowledge, no study has conducted a real-time investigation of COPD exacerbation experience during hospitalisation.

Objective: To establish an in-depth and comprehensive understanding of the whole COPD exacerbation experience and uncover any unrecognised burdens that might serve as barriers to engagement in discharge services post-AECOPD.

Methods: Semi-structured interviews were conducted, and data were analysed using thematic analysis. The study included participants who were admitted to the hospital with a primary diagnosis of AECOPD.

Results: Twelve participants were included in the study (Male, $n = 9$; Female, $n = 3$), with a mean ± SD age of 66 ± 8 years. Findings generated three overarching themes, and sub-themes: (I) Health deterioration phase (II) Implications of AECOPD and the associated hospitalisation, and (III) Recovery journey.

Conclusion: The impact of breathlessness appears to extend across the COPD exacerbation journey and, for some, well beyond. Breathlessness both within and extending beyond the acute phase was associated with comorbid psychological distress. Interventions should consider appropriate phasing within the management process, focus on breathlessness and involve a behavioural therapy component.

Keywords

COPD, acute excerbation, experience, qualitative research, breathlessness, recovery, impact

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Background

Chronic obstructive pulmonary disease (COPD) is a complex respiratory condition that is characterised by progressive decline in lung function, reduced quality of life, impaired exercise capacity, and increased risks of mortality and healthcare resource utilization.[1] Among individuals with COPD, some may experience sudden deteriorations known as Acute Exacerbation of COPD (AECOPD), triggered by factors such as respiratory infections, temperature variations, and air pollution.[2,3] Research conducted in the United Kingdom (UK) has shown that individuals with more severe COPD are particularly susceptible to frequent exacerbations.[4] Furthermore, a large UK observational study revealed that individuals with higher baseline exacerbation frequency and severity face an elevated risk of mortality from various causes, including COPD and cardiovascular issues.[2] According to statistics from the National Health Services (NHS), over 128,000 people in the UK were hospitalised due to COPD exacerbation between the years 2016 and 2017 and caring for individuals with COPD disease in the UK costs the NHS an estimated £3 billion annually.[5]

Despite the well-documented impact of Acute Exacerbation of COPD (AECOPD) on individuals and healthcare resources as highlighted in quantitative research,[3,6,7] there remains a limited qualitative exploration of its burden on patients. A study by Kessler et al.[8] involving 125 outpatient individuals with COPD, revealed that participants experienced variety of symptoms and emotions during exacerbations, including breathlessness, cough, fatigue, pain, anxiety, isolation, and increased reliance on others for daily activities.[8] In a smaller qualitative study, researchers examined how individuals with COPD in an outpatient clinic typically identify an impending exacerbation. In this study, participants reported worsening physical symptoms such as cough, sputum production, functional limitations, and various chest sensations, including soreness and heaviness.[9]

Further contributing to this body of research, Harrison et al.[10] conducted a qualitative study to explore patient illness perceptions in a post-AECOPD population. This investigation categorised post-AECOPD individuals into three distinct clusters: (1) in control, (2) disengaged, and (3) distressed patient groups. The distressed cluster exhibited higher levels of breathlessness, greater emotional burdens characterised by symptoms of anxiety and depression, poorer health status, and reduced self-efficacy compared to participants in clusters one (in control) and two (disengaged).[11]

While these qualitative studies provided valuable insights into how individuals with COPD experience exacerbations, it is important to note that the data primarily originated from studies that recruited participants in the post-discharge phase. This reliance on patients' retrospective accounts of their AECOPD experiences may lead to underestimations or overestimations of the true impact during the actual episodes.

To enhance the continuity of care for this population, clinicians must gain a comprehensive understanding of the true impact and burden of acute COPD exacerbations. This understanding should encompass the entire exacerbation experience (before, during, and after attack), which is crucial for identifying unreported barriers that might hinder patient engagement in valuable non-pharmacological discharge services, primarily aimed at improving physical activity, such as Pulmonary Rehabilitation (PR) and community based programmes, which are known for their low uptake within this population,[12–14] despite previous efforts to design targeted interventions to enhance participation.[10,15]

Therefore, the primary objective of this study is to gather an in-depth and comprehensive insight into patients' real-time experiences during AECOPD, capturing the most authentic account of COPD exacerbation while it is still fresh in their minds. By doing so, this research aims to uncover any unrecognised burdens of exacerbation that may serve as barriers to engagement with non-pharmacological interventions designed for this population and offered at discharge.

Methods

Design

Semi-structured interviews were used to collect the data. The study interview guide was developed by the study author (BA), experts in the field of pulmonary rehabilitation (SS and THD) and a consultant in Respiratory Medicine (NG); (the interview guide is attached in the online supplemental E1). The process started with brainstorming a list of questions related to the AECOPD experience. Open-ended questions were used, and the questions were organised in a logical order using the funnel technique, moving from general questions to more specific ones.[16] Prompts and probes were added to the questions to enable participants to expand on their answers and provide more detail, and a clean-up question was added at the end of the interview to allow participants to raise any uncovered aspects that they considered important. Finally, the questions were tested internally with the study's authors, and the topic guide was revised to its final version for testing externally on a small cohort of target participants (four AECOPD patients), which then did not result in any further changes.

Setting and recruitment

Participants were recruited from a single secondary care NHS site in the East Midlands, UK. Potential participants were identified from the patient admissions list of the hospital respiratory ward.

Table 1. Participant demographics (n = 12).

Participant ID	Age (Years)	Gender	COPD severity classification[a]	eMRCD[b]	Ethnicity	Frequency of exacerbation events in the past year
1	58	Male	Missing	4	White British	3
2	73	Male	Moderate	5a	White British	4
3	58	Female	Very Severe	5a	White British	3
4	66	Male	Very severe	4	White British	2
5	49	Female	Severe	4	White British	5
6	78	Male	Very Severe	5b	White British	2
7	68	Male	Severe	5b	White British	5
8	62	Female	Very Severe	4	White British	10
9	64	Male	Severe	4	White British	3
10	66	Male	Moderate	4	White British	2
11	74	Male	Severe	5a	White British	2
12	74	Male	Moderate	5a	White British	4

Footnote- COPD. Severity Classification.
[a] = COPD severity classified according to the Global Initiative for Chronic Obstructive Lung Disease.
[b]eMRCD = Extended Medical Research Council Dyspnoea Scale.

Participants and sampling

The participants were conveniently sampled based on the inclusion and exclusion criteria. To be eligible for the study, participants were required to meet the following criteria; (I) be admitted to the hospital with an AECOPD, defined as requiring a significant change in treatment (e.g., bronchodilators, steroids, antibiotics); (II) have the ability to provide informed consent; (III) have a prior clinical diagnosis of COPD; (IV) have suffered from one or more AECOPD exacerbation attacks in the past requiring a hospital admission (to facilitate inquiry about the recovery time point); (V) have a smoking history of >10 pack-years); (VI) have a functional limitation when stable (Extended Medical Research Council Dyspnoea Scale[17] (eMRCD) dyspnoea grade 3–5); and VII) be at least 40 years old. Participants were excluded if they were eligible for palliative care (as scope of needs for this population might be different than our target population).

Data collection, analysis, and reporting

This qualitative study was conducted by a female researcher (BA) with a background in respiratory care and clinical rehabilitation. Detailed, face-to-face, semi-structured interviews (online supplement E1) were conducted at a single time point during hospitalisation, either at the patient's bedside or in a nearby ward day room. Participants were approached within 48 h of admission, and Potential eligible participants were identified following a daily review of the respiratory ward admission list. Participants recruitment took place between August 2019 and March 2020. The interviews were audio-recorded, and an authorised external transcription service transcribed the data. After each interview, the researcher made field notes, contributing to a comprehensive understanding of the research findings for each patient.[18] Data collection continued until data saturation was deemed to be reached, which was determined through a preliminary analysis of seven patients' transcripts.[19] Thematic analysis (TA) was primarily conducted by BA, with support from the second reviewer, AB. TA is a method for identifying themes and patterns of meaning in relation to the research question.[16]

The TA process involved seven stages: (I) Transcription, (II) data familiarization, (III) generating initial codes, (IV) searching for themes, (V) reviewing themes, (VI) defining and naming themes, and (VII) producing the analysis report.[16] Deductive, semantic, and latent coding techniques were used during the coding process to explore the pre-identified research concepts (experiences before, during and post AECOPD attack). Base themes were generated during the preliminary analysis of the transcripts. Subsequently, further analysis was conducted on the remaining five patients, during which no new base themes emerged.[16] The textual data analysis was conducted in NVivo, a qualitative data analysis software.[20]

This manuscript has been written in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ).[21] Finally, this qualitative study was part of a larger research project that further explored AECOPD population.

Results

Twelve participants (nine males and three females) were recruited during their admission to respiratory ward. The Participants mean and Standard deviation (SD) of age was 66 ± 8 years, with COPD severity classification based on the

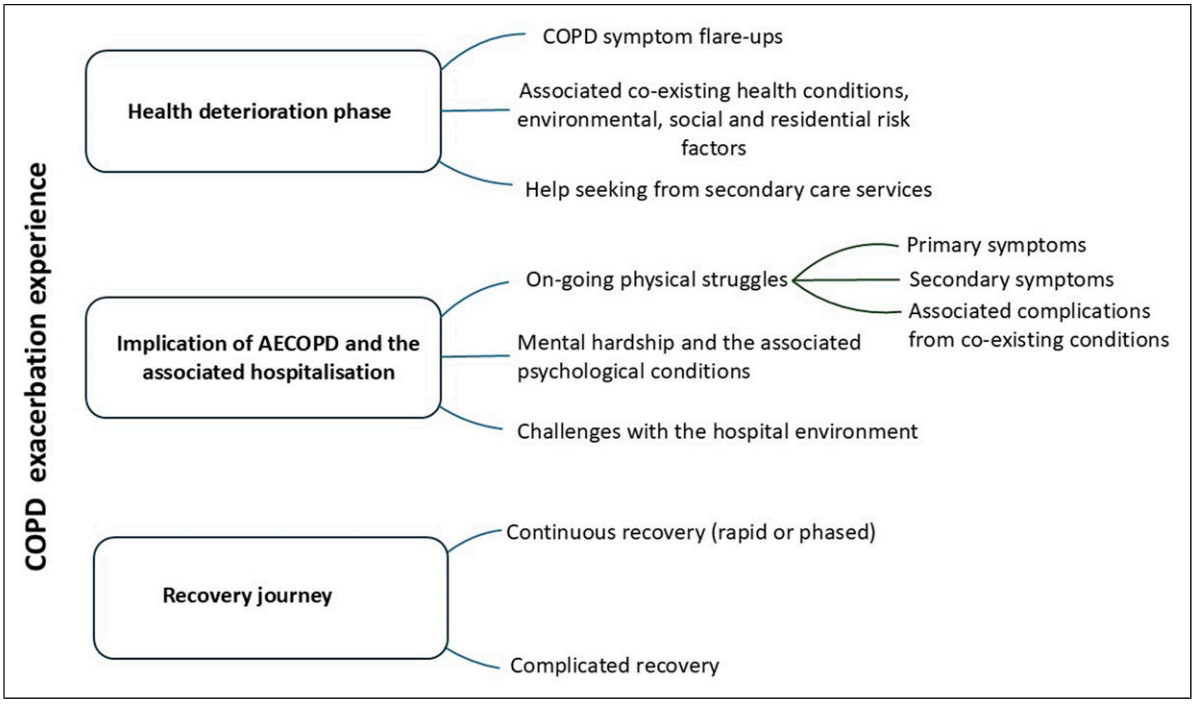

Figure 1. Thematic map.

Global Initiative for Chronic Obstructive Lung Disease (GOLD)[22] ranging from moderate to very severe COPD (25% moderate COPD, 33% severe COPD, 33% very severe COPD). Participant demographics are shown in Table 1.

Semi-structured interviews

The interviews conducted in this study captured three phases (before, during, and post) the AECOPD experience. Through the analysis, three overarching themes, eight themes, and three sub-themes were identified (refer to Figure 1).

Overarching theme 1: Health deterioration phase. This overarching theme encompasses the participants' experiences of health decline prior to their hospital admission. It comprises of three key themes: Theme A) COPD symptom flare ups, Theme B) Associated co-existing health conditions, environmental, social and residential risk factors, and Theme C) Help seeking from secondary care services. Table 2 displays a collection of illustrative participant quotes.

Theme A) COPD symptom flare ups. It was evident that many of the participants perceived their breathlessness to be the first sign of their health deterioration and regarded this as the primary cause behind their hospital admission before any other COPD related symptom that might have co-existed during the AECOPD. Moreover, participants perceived other symptoms as further reasons behind their hospital admission. These symptoms were described as a secondary effect of the breathlessness symptom itself, for example, a decrease in mobility and suffering from panic attacks, or as a standalone exacerbated symptom that happened to cause a heightened level of burden during the exacerbation attack such as suffering from constant cough or mucus build up.

Theme B) Associated co-existing health conditions, and environmental, social and residential risk factors. Flare-up of other co-existing health conditions such as asthma and cardiac diseases were identified as contributing factors to the participants' current AECOPD. Additionally, challenges such as cold weather, and inability to live in a smoke-free environment due to unsupportive partner were among the stated reasons behind the participants' health deterioration and subsequent hospitalisation.

Sub-theme C) Help seeking from secondary care services. Participants articulated various medication-related reasons for their help-seeking behaviour, such as complications from prolonged use of inhaled corticosteroids, lack of availability of rescue medication, and the need for modifications to their prescribed treatments. Additionally, positive treatment outcomes the participants received during their last hospitalisation due to an exacerbation, along with their inability to self-manage their condition in the community during these attacks, were also reported as significant reasons that drove them to seek care from secondary healthcare services

Table 2. Thematic analysis and illustrative participant quotes.

Overarching Theme	Theme	Sub-theme	Examples of participants quotes	Participant ID	Participant demographics e.g., gender, COPD severity classification
Overarching theme 1. Health deterioration phase	Theme A) COPD symptoms flare ups	—	"I had to call paramedics out because my airways closed and I couldn't get them open. I couldn't breathe"	(Participant ID 8)	Female, Very severe
		—	"I suffered an exacerbation in my COPD on Wednesday morning: couldn't breathe. I did use the nebuliser at home and that made very little difference. I couldn't string more than two or three words together. And I think most of the time they didn't make a lot of sense even to my wife let alone anybody else. It was obviously time to call an ambulance"	(Participant ID 11)	Male, Severe
		—	"Suffering with breathing, I couldn't breathe really, what do you call it, exacerbation of COPD."	(Participant ID 7)	Male, Severe
		—	"Because I was poorly for a few days. And could not breath and I got to the point where I could not move and I could not seem to get any air in, usually when I have a panic attack I phone the ambulance that when every time I come to the hospital on average, I don't know because I get poorlier and poorlier and I know I am weak and that when I start panic, you feel like you are drowning. It's a horrible sensation"	(Participant ID 3)	Female, Very severe
		—	"I came down with a cold Monday night. Woke up Tuesday, chest was full of mucus, coughing like mad. And went to see the GP, and was told I had a viral exacerbation. They weren't happy with my sats, put me on a nebuliser and oxygen, and then they phoned me an ambulance"	(Participant ID 5)	Female, Severe
		—	"I started getting very breathless…I had a bad cough"	(Participant ID 6)	Male, Very severe
	Theme B) Associated co-existing heath conditions, environmental, social and residential risk factors	—	"Shortness of breath, I've got asthma, COPD attack. And it's just shortness of breath"	(Participant ID 9)	Male, Severe
		—	"Well, because I suffer from angina, heart attack, but I had AF this time which you can't clear. And I couldn't clear it myself so I called 999"	(Participant ID 2)	Male, Moderate
		—	"Well, where I live everyone smokes, I've had to change bedrooms, I don't sleep in with the missus no more, she smokes in bed and it's just no good for me. She won't give up. So that's why I keep getting these flare-ups, because everyone around me is smoking"	(Participant ID 1)	Male, missing
	Sub-theme C) Help seeking from secondary care services	—	"I have several health problems, one of which is I have osteoporosis, which is sometimes triggered by steroids I've been using for my illness. And I have a habit of breaking bones. I've broken ribs on first left- and right-hand side of my front rib cage. Then the next day at about 9.30, when I was just waking up after a fairly sleepless night, I was changing my position and gave a short cough, and I heard something go snap in my back, and I had agonies of pain. So I rang the ambulance"	(Participant ID 4)	Male, Very severe
		—	"I try and give it a couple of days before I do ring the ambulance, you know what I mean, to see if my breathing goes back to normal. But normally I would run out of inhaler or I run out of medication and I can't get any medication because it's normally at the weekend"	(Participant ID 1)	Male, Missing
		—	"My inhalers were working overtime. I thought you've got enough for one more week and that isn't going to last long. So, I rang up 111, and they sent three ambulance drivers out"	(Participant ID 10)	Male, Moderate
		—	"Well, I had a reoccurrence of my breathing problems. Last year I was in the hospital 10 times. It started with pneumonia. And it took me months to get over the pneumonia and it's left me with breathing problems. Someone of my age, your oxygen intake should be 88 to 92, which I mentioned to you. But now and again you get, something happens, and you're breathing heavy and your levels go down. And I've come into hospital to help put it right. And I've found out putting me on steroids and things like that helps"	(Participant ID 12)	Male, Moderate

Table 3. Thematic analysis and illustrative participant quotes.

Overarching Theme	Theme	Sub-theme	Examples of participants' quotes	Participant ID	Participant demographics, e.g., gender, COPD severity classification
Overarching theme 2. Implications of AECOPD and the associated hospitalisation	Theme A) On-going physical struggles	Sub-theme: I) Primary symptoms	"My breathing, that's what I'm here for really"	(Participant ID 8)	Female, Very severe
			"I think the breathlessness, which comes and goes really. Thursday and Friday I felt reasonably well. And up to lunchtime on Saturday. For instance I could get from here to the bathroom and back without stopping. You know, I had to use the walker, which I've never used before. But since then just making that short trip, I've lost my breath altogether and need to use the, my reliever inhaler, about six times to try to stabilise it"	(Participant ID 11)	Male, Severe
		Sub-theme: II) Secondary symptoms	"I just can't breathe, I just can't move ..... No, just can't breathe. Everything you do is very painful"	(Participant ID 9)	Male, Severe
			"It's hard work to keep breathing, so you get very, very tired"	(Participant ID 3)	Female, Very severe
			"When you start to get lack of breath, you start to get dizzy. You can be walking out somewhere, you can be keeling over. You can fall down a ditch and nobody's going to see you fall, anything like that"	(Participant ID 10)	Male, Moderate
			"I had a reoccurrence of my breathing problems, not being able to clear my throat. What it is, it's phlegm. Now they gave me tablets for it, which helped a lot"	(Participant ID12)	Male, Moderate
			"I had a bad cough, sometimes it was green, sometimes it would be brown, and that I was really in a bad way"	(Participant ID 6)	Male, Very severe
		Sub-theme: III) Associated complications from co-existing conditions	"Breathlessness, coughing, ... because I've got a hernia, and when I cough that really hurts"	(Participant ID 7)	Male severe
			"I can't breathe, because that's what makes me come in in the first place. I've got an aneurysm in my belly, you see, and that's what kicked it all off because I get a real bad pain in my belly"	(Participant ID 1)	Male, Missing
			"I have tremendous problems with sleep disturbance at home. I can stay for two or 3 days without actually falling asleep. What I do is I just take no notice of it, and listen to the radio, TV, late night stuff, and just go right the way through. I have been known to not sleep for two or 3 days. It sounds impossible but it is possible with me. "	(Participant ID 4)	Male, Very severe
	Theme B) Mental hardship and its associated psychological conditions	—	"I mean I've suffered with COPD now since 2011 I think I was diagnosed. And I've always kept a very positive attitude; in fact friends and people have said they can't understand, even when I'm at my lowest, how positive I am. But that's beginning to wear a bit thin, particularly this time. I'm not lying here worrying myself sick about it, but it's there. Because I know for myself I'm getting worse, it's inevitable really. I had the lung volume reduction surgery in 2013, and that gave me two good years really. Last year the consultant looked at doing the left lung. But that's out the question now, I'd never survive the operation. So we've run out of options really, which again doesn't help the mental state"	(Participant ID 11)	Male, Severe
		—	"The breathlessness, that's the feeling that you can't walk, and you just feel useless really"	(Participant ID 3)	Female, Very severe
		—	"I can't walk very far, I haven't been able to for some time now. And at the moment while I'm here (the hospital), I can't walk at all without the walker. Now I've never needed one before. I've now got two at home that the hospital have supplied. And I can't stand unaided, which I find quite hard because I've been able to do that. I've got to hold onto something if I stand up"	(Participant ID 11)	Male, Severe
		—	"When you start to get lack of breath you start to get dizzy. You can be walking out somewhere; you can be keeling over. You can fall down a ditch and nobody's going to see you fall, anything like that"	(Participant ID 10)	Male, Moderate
		—	"I tend to panic a lot when I can't breathe, because that's what makes me come in in the first place"	(Participant ID 1)	Male, Missing
		—	"I get a bit anxious sometimes. I'm naturally optimistic, always have been, which helped. But, as I say, that is wearing a little bit thin now. I can't walk very far; I haven't been able to for some time now. And at the moment, while I'm here (at the hospital) I can't walk at all without the walker"	(Participant ID 11)	Male, Severe
	Theme C) Challenges with the hospital environment	—	"I think the heat and the dryness of the atmosphere in the hospital's not helping, because my throat feels really dry. My mouth and my lips are really dry, so that's not helping"	(Participant ID 5)	Female, Severe
		—	"That's the third day without sleep ….. but it's always particularly pronounced when I am in the hospital, not being able to sleep…" "I was sleep walking on the ward and they weren't best pleased with me"	(Participant ID 4)	Male, Very severe
		—	"I have been taught to breathe from my nose and out from my mouth and sometimes this is painful"	(Participant ID 3)	Female, Very severe
		—	"I had a doctor come to me, you can put it on tape as well, and he kept saying to me, it's all right dear, I know how you feel. And then I said to him, get out of my room, get away from me, you don't know how I feel. And I was that cross with him the tears were streaming down my face, because I'm not a violent person, so I couldn't hit him, because I don't believe in violence. And I was so mad. He was telling me he understood, I said you don't understand how I feel. I said you do not understand at all how I feel"	(Participant ID 8)	Female, Very severe

Overarching theme 2: Implications of AECOPD and the associated hospitalisation. This overarching theme captured the profound physical and psychological distress experienced by individuals during the hospitalisation phase for an AECOPD. This overarching theme includes three themes labelled as follows: Theme A) On-going physical struggles, Theme B) Mental hardship and its associated psychological conditions, and Theme C) Challenges related to the hospital environment. For a more detailed insight, Table 3 presents a collection of illustrative quotes from the participants.

Theme A) On-going physical struggles. This theme encompasses the symptoms that contribute to the ongoing physical challenges during hospitalisation phase and has categorised the captured information into three distinct subthemes.

I) Primary symptoms

This sub-theme encompasses the symptoms that led to ongoing physical struggles for the participants and were consistently prioritised in their discussions. The primary symptoms identified were breathlessness and chest tightness

II) Secondary symptoms

This sub-theme included symptoms that were expressed or linked by the participants as a consequence of suffering from the primary symptom (breathlessness and chest tightness), and included difficulties with balance, decreases in mobility, pain, fatigue, mucus build-up and cough.

III) Associated complications from co-existing conditions

This sub-theme includes both diagnosed and undiagnosed comorbidities that existed during the AECOPD and hospitalisation, impacting the patient's overall health and exacerbating their physical struggles. These included abdominal aneurysm, hernia, and sleep disturbance.

Theme B) Mental hardship and the associated psychological conditions. Participants described various emotions and psychological conditions during the AECOPD and hospitalisation. Some participants expressed a growing sense of pessimism about their recovery and prognosis stemming from to the continuous deterioration of their health and the perception that their treatment options were becoming increasingly limited.

Additionally, participants reported feelings of uselessness, loss of independence, and vulnerability associated with their current health state. They also experienced sensations of panic and fear, which were often triggered by their inability to breathe as normally as they were accustomed to.

Anxiety emerged as another commonly reported psychological condition, driven by participants' awareness of their health status and their understanding of the inevitable deterioration associated with AECOPD.

Theme C) Challenges with the hospital environment. Some participants reported feeling agitated by the dryness of the hospital environment, which contributed to pronounced sleep disturbances during their hospitalisation. Additionally, they faced challenges in implementing the new advice provided by their healthcare providers to manage their current condition. One participant noted experiencing pain while attempting the breathing techniques suggested by their healthcare provider, while others reported conflicts with hospital staff and fellow patients.

Overarching theme 3. Recovery journey. Within this overarching theme, participants provided insights into their experiences with the recovery process following an AECOPD. Two distinct themes were identified: (A) continuous recovery (rapid or phased) and (B) complicated recovery. (See Table 4 for illustrative participant quotes).

Theme A) Continuous recovery (rapid or phased). In this theme, some participants reported achieving full recovery in a rapid manner during hospitalisation due to the pharmacological treatment they received, while others experienced a phased recovery, beginning in hospital and continuing to progress after discharge.

Theme B) Complicated recovery. Several participants articulated that they could achieve full recovery from other related respiratory symptoms such as cough, but they consistently noted that breathlessness would always be present, viewing it as a never-ending struggle. Additionally, another participant emphasised that any improvement in breathlessness would be in terms of its severity, but it would never completely disappear.

An element of uncertainty regarding prognosis and anticipation of another relapse of symptoms was also evident in the participants' statements. One participant articulated that their recovery largely depended on their ability to effectively manage their exposure to passive smoking. They believed that their current living situation with an actively smoking partner would likely lead to further COPD events in the future.

Discussion

This study aimed to explore the experiences of individuals with AECOPD at different exacerbation phases (before, real-time, and post-AECOPD). By obtaining firsthand accounts of the exacerbation event, we aimed to minimise

Table 4. Thematic analysis and illustrative participant quotes.

Overarching Theme	Theme	Sub-theme	Examples of participants' quotes	Participant ID	Participant demographics, e.g., gender, COPD severity classification
Overarching theme 3. Recovery journey	Theme A) Continuous recovery (rapid or phased)	—	"I mean I can still talk, I'm holding this interview. If I was very bad, I wouldn't be able to continue without taking short bursts to speak, and just a little bit wheezy. It is getting a lot better than it was. Another day on steroids and I'll be completely clear"	(Participant ID 4)	Male, Very severe
		—	"I would say the day when I finish my course of antibiotics, I will feel more myself on average"	(Participant ID 3)	Female, Very severe
		—	"I think most times I've been in hospital I've obviously felt better and gone home and I've felt a lot better"	(Participant ID 5)	Female, Severe
	Theme B) Complicated recovery	—	"Well the longest I've stopped out of hospital is about 6 weeks, and then I'm usually back in ... Cough usually goes away, but the breathing doesn't. The breathing's always going to be poor"	(Participant ID 7)	Male, Severe
		—	"Some days I breathe easier than other days. And some days I'm really gasping for breath, I really struggle, really, really bad to breathe. Because my saturation levels, my oxygen levels drop right down. That's all part and parcel of the COPD."	(Participant ID 8)	Female, Very severe
		—	"It'll be on-going. This COPD, it'll never go away"	(Participant ID 10)	Male, Moderate
		—	"Well, I would hope the severe breathlessness will have largely altered before I leave, which is what happened last time. It won't disappear altogether. And I hope the walking will improve but I don't know"	(Participant ID 11)	Male, Severe
		—	"It'll come back again but you can't, you can't prognose when it's coming back"	(Participant ID 2)	Male, Moderate
		—	"I'm all right for about a month, you know what I mean? Well, it depends on the situation, where I am. If I'm around smokers .... unless I've got the right tools to cope with it, then I'll be all right. But if I haven't then that's when I start going downhill again"	(Participant ID 1)	Male, Missing

potential recall bias often found in retrospective studies.[8,9] Our study revealed that breathlessness was consistently identified as the primary and most burdensome symptom contributing to health deterioration during AECOPD. Participants sought help from secondary healthcare services, as they believed that their current medical regimen and self-management strategies were inadequate to resolve their exacerbated condition. Exacerbated comorbidities and seasonal changes were identified as perceived risk factors for hospitalisation. Notably, mental hardship emerged as a critical theme during the hospitalisation phase, highlighting the emotional toll experienced by individuals with AECOPD.

The prominent and on-going burden of breathlessness was also reported in a previous retrospective qualitative study that looked into patients' experiences of identifying

approaching AECOPD. Participants identified increased breathlessness, labelled the "invisible symptom" as a burden that has to be faced during the acute exacerbation phase.[9] Additionally, this qualitative study highlighted other findings similar to our study with regard to the presence of other exacerbated symptoms, which they called the "visible symptoms" that individuals usually experience during an exacerbation attack, such as cough and limited mobility.[9] The recent findings, along with our own, could help clinicians understand the most commonly perceived symptomatic burden experienced by individuals with acute exacerbations of chronic obstructive pulmonary disease (AECOPD). This understanding could guide interested clinicians in implementing symptom management strategies for AECOPD patients that focus on the most burdensome impacts. Ultimately, this approach could further enhance the patient-centered care and potentially improve engagement in health-related discharge interventions.[23]

Similarly, a previous quantitative study by Calverley et al.[24] identified the level of breathlessness score (measured by the modified Medical Research Council scale breathlessness score) was among the most critical risk factors of hospitalisation due to COPD.[24] Furthermore, it has been reported in the literature the dyspnoeic experience causes AECOPD sufferers to exhibit a cycle of emotional and physical disabilities that have a complex relationship, which can result in intractable breathlessness that leads individuals to display help-seeking behaviours in the form of emergency room visits and subsequent hospitalisation.[25]

Participants in our study identified cardiac disease and adverse weather conditions as significant risk factors for their hospitalisation. This aligns with recent research that has established a link between cardiac comorbidities and AECOPD readmissions.[26] Common cardiovascular diseases associated with AECOPD include pulmonary arterial hypertension, systolic dysfunction, and coronary artery disease.[27] Moreover, another study found that AECOPD hospital admissions peaked during the midwinter months,[28] and highlighted seasonal factors as an independent contributor to increased hospitalisations.[29]

Interestingly in our study, some participants noted that a lack of available rescue medication during their COPD exacerbation led them to seek help from secondary healthcare services. This finding may explain the frequent and short hospital admissions experienced by certain groups of patients with AECOPD. It highlights the vital role of a comprehensive COPD action plan, which empowers patients to effectively manage their symptoms.

A previous study investigated primary and secondary care perspectives in multiple European countries regarding self-management approaches for AECOPD. In this study, many respiratory clinicians expressed support for using rescue packs, which may include steroids alone or in combination with antibiotics, as a means for patients to self-manage exacerbation attacks. However, they emphasised that access to these options should be limited to selected patients who have received appropriate education and risk management.[30]

The idea of a pharmacy-based model of the COPD action plan has been implemented recently in a pilot study,[31] which has shown promising results; however, its proven efficacy requires further investigation in larger trials. By prioritising medication management and patient education, these innovative strategies hold considerable potential to enhance self-management and reduce frequent hospital admissions.

During hospitalisation, individuals with AECOPD in our study often encountered mental challenges, such as panic attacks triggered by the sensation of breathlessness. Barrera et al.[32] described how panic attacks in COPD patients can be induced by the combination of breathlessness and a heightened state of anxiety, leading to physiological sensations and anxious apprehension that culminate in a panic attack.[32] Research has shown that individuals with panic attacks tend to engage in avoidance behaviours, such as evading breathlessness, which can lead to reduced physical activity, increased risk of disability, diminished quality of life, and higher hospitalisation rates among COPD patients.[33,34] In the case of AECOPD, individuals experiencing complex recovery due to breathlessness may develop even more escalated avoidance behaviour, potentially influencing their decision to participate in non-pharmacological interventions with an exercise component, such as pulmonary rehabilitation (PR), which they might perceive as a reason that could lead to a heightened level of breathlessness.

Furthermore, our study findings align with previous research, indicating that ongoing anxiety about future breathlessness episodes and feeling vulnerable due to AECOPD have a significant psychological impact, leading individuals to express pessimistic attitudes about never achieving full recovery and feeling of being useless.[35,36] These pessimistic attitudes can be understood as a consequence of the challenging recovery journey experienced by patients. In the literature, complicated recovery post-AECOPD has been associated with viral and cold symptoms, wherein the affected individuals usually require oxygen therapy and assistance with physical limitations to extend beyond hospitalisation.[37,38]

Moreover, our data suggest that the accumulated experiential knowledge of individuals with AECOPD during complex recovery, along with the perception that breathlessness is an inherent part of COPD, may contribute to patients declining new treatment options in the future, as they might perceive that nothing seems to work for their deteriorating condition. These findings uncover hidden

barriers that might influence uptake of discharge services such as PR within this population, indicating a growing need to incorporate targeted behavioural interventions as intermediate interventions before patients are prompted to make decisions about discharge services. Among the interventions that have shown promising results with COPD and other chronic illnesses in tackling negative illness perceptions and fostering positive transformative changes in behaviour and illness perceptions are Cognitive Behavioural Therapy (CBT),[39] Acceptance and Commitment Therapy (ACT)[40] and the Meaning Perspective Transformation Model (MPT).[41–43]

Overall, this study highlights the multifaceted experiences of individuals with AECOPD and underscores the importance of integrating both pharmacological and behavioural interventions for effective AECOPD management. However, it is essential to acknowledge that our study demonstrates one key strength and several limitations that merit consideration.

The study's main strength lies in its recruitment of hospitalised individuals suffering from AECOPD, allowing for a more accurate capture of their experiences during the real COPD exacerbation event while it is still fresh in their minds. By conducting interviews during hospitalisation, the study overcomes the limitations of relying on post-event recollection, which can be affected by memory issues, particularly in older adults.[44] Episodic memory, defined as the long-term explicit memory of a person's unique recollection of experiences and events, has been shown to improve with environmental support, such as cues or instructions.[45] Thus, the study utilised the patients' current experiences as cues or stimuli to evoke their episodic memory, enhancing the authenticity of their recollections (reflecting on how challenging things were before, during (real time), and after the exacerbation while it is still fresh in their minds).

Conversely, It is important to mention that the results of this study are limited in their generalisability to the entire AECOPD population due to the qualitative design and specific limitations: a single-centre approach, a predominance of participants from a single ethnic group (White British), and a higher proportion of males. We believe that replicating this study with a more diverse participant group and employing different sampling techniques to capture maximum variation in the condition would facilitate future data triangulation. This would enable the building of evidence and provide a clearer and more inclusive picture of the lived experiences of these individuals. Additionally, in this study the fact that the second reviewer did not independently code the study's transcripts during the initial steps of the analysis may be viewed by some qualitative researchers as a limitation to the reliability of the findings. Methods of quality checks in qualitative research, such as calculating inter-rater reliability, which involves two or more researchers coding the data independently and then assessing the level of agreement in a quantitative manner, have sparked considerable debate in the field.[16] Thus, we believe that since reliability checks pertain to the trustworthiness of interpreting textual data, the iterative process we employed in the subsequent steps of our analysis could still ensure a reasonable level of reliability in the produced findings. Furthermore, in this study, the sample from the targeted population was only involved in testing of the study guide, but not in its development. This could also be viewed as limitation to the validity of the constructed research tool, as involving participants in the development of the interview guides not only the testing is increasingly recognized as an important aspect of enhancing the face validity research tools.

Finally, in this study, we focused on individuals experiencing Acute Exacerbation of Chronic Obstructive Pulmonary Disease (AECOPD) during hospitalisation, aiming to help them use their current experiences as cues to recall how they felt before, during, and after the AECOPD event. However, it is important to note that while this approach may enhance their recall ability, it may not completely eliminate recall bias, as accounts of recovery were still collected retrospectively. Thus, we recommend conducting interviews at two distinct time points: during the AECOPD attack and after recovery. This dual approach could provide valuable insights and significantly enhance the quality of the research.

Conclusion

COPD symptoms, co-existing conditions flare ups, and lack of ability to self-manage these symptoms lead patients to a hospitalisation for AECOPD. In our study, it was evident that breathlessness was considered by the patients to be the most burdensome symptom throughout different COPD exacerbation time points. The on-going struggle with this symptom led to various other associated physical and psychological distress. Some individuals with AECOPD navigate a complicated recovery journey, which can lead to significant psychological consequences that require targeted behavioural interventions. It is crucial that interventions aimed at individuals with AECOPD are appropriately phased within the management process to facilitate patient engagement and optimise treatment outcomes.

Moreover, empowering patients with effective self-management strategies and resources is essential in reducing hospitalisations and improving quality of life. Future research should focus on the implementation of tailored interventions and evaluate their effectiveness in enhancing self-management and overall health outcomes for this population. By addressing these challenges, we can potentially move toward a more patient-centred approach in managing AECOPD and further enhance the healthcare delivery.

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Ethical statement

Ethical approval

The study protocol was approved by the East Midlands Research Ethics Committee-Leicester Research Ethics Committee (Ethics Ref: IRAS 239167).

Informed consent

Informed patient consent was obtained prior to the interview according to the Good Clinical Practice Guidelines.[46]

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Declaration of conflicting interests

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Data Availability Statement

The information regarding the interview guide are available within Figshare link 10.6084/m9.figshare.25254574.

Supplemental Material

Supplemental material for this article is available online.

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Appendix

Abbreviations

AECOPD	Acute exacerbation of chronic obstructive pulmonary disease
PR	Pulmonary Rehabilitation
ACT	Acceptance and Commitment Therapy
CBT	Cognitive Behavioural Therapy.