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COPD-Related Anxiety: A Systematic Review of Patient Perspectives

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Background: Anxiety in patients with chronic obstructive pulmonary disease (COPD) is prevalent but often unidentified and therefore not adequately managed. Clinicians find it difficult to detect anxiety symptoms and to differentiate subclinical anxiety from anxiety disorders, because of the considerable overlap between symptoms of COPD and anxiety.

Purpose: We synthesized existing qualitative research on patients' experiences of COPD-related anxiety with the purpose of gaining a richer understanding and proposing a model of the construct.

Methods: Searches for qualitative studies of patients' experiences of COPD-related anxiety were conducted independently by two authors in the databases of PubMed (MEDLINE), CINAHL (EBSCO), and PsycInfo (APA). English-language studies including patients diagnosed with COPD were reviewed, and data were analyzed using thematic analysis.

Results: A total of 41 studies were included in the review. Four themes related to COPD-related anxiety were identified: initial events; internal maintaining factors; external maintaining factors; and behavioral maintaining factors. Based on the identified four themes, a conceptual model of COPD-related anxiety from the patient perspective was developed.

Conclusion: A conceptual model of COPD-related anxiety from the patient perspective is now available, with the potential to inform future attempts at improving identification and management of COPD-related anxiety. Future research should focus on the development of a COPD-specific anxiety questionnaire containing domains that are relevant from the patient perspective.

Keywords: qualitative studies, psychological symptoms, chronic disease management, psychological distress, mental health, respiratory illness, chronic obstructive pulmonary disease

Introduction

Patients with chronic obstructive pulmonary disease (COPD) report high levels of anxiety symptoms, and anxiety disorders (eg, panic disorder, generalized anxiety disorder, social anxiety disorder) are among the most prevalent psychiatric comorbidities in patients with COPD.[1–3] Clinically relevant anxiety symptoms in patients with COPD are often unidentified and therefore not managed; and potential anxiety disorders are underdiagnosed and therefore not adequately treated.[4] A review of the literature from 1994 to 2009 shows that the estimated prevalence of anxiety symptoms and anxiety disorders among patients with COPD varies markedly across existing studies (6–74%),[5] potentially due to difficulties in differentiating between symptoms of COPD and symptoms of anxiety.[6]

For patients in general, anxiety is a natural, adaptive psychophysiological response to a real or perceived threat, which is experienced as passing emotional states that the patient feels capable of coping with alone or with social support from significant others.[7] However, for many patients with COPD, symptoms of anxiety are persistent over a longer period of time and can be associated with maladaptive behaviors, such as avoidance of activities that are expected to trigger dyspnea.[8–10] This can lead to isolation, deconditioning, symptom progression, and reduced quality of life and eventually result in the development of an anxiety disorder, per se.[1,11]

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Furthermore, COPD is associated with social and economic disadvantage,[12] and patients with COPD often suffer from multiple comorbid diseases, such as cardiovascular diseases, lung cancer, and osteoporosis,[13] with overlapping physiological (eg, dyspnea, pain, and fatigue) and psychological (anxiety and depression) symptoms and risk factors. In clinical practice, it can be difficult to differentiate psychological symptoms originating from specific life circumstances, physical symptoms or diseases, and there is a need for identification of patient experiences of anxiety that are specifically related to life with COPD.

Terms such as *fear* and *anxiety* are often used interchangeably in the literature, but there are several definitions of the concepts as well as potentially different underlying neurobehavioral mechanisms.[6,14] From the patient perspective, the subjective experience of anxiety is multifaceted, and patients themselves describe states of anxiety using many different terms, including fear, worry, being afraid, anxiety, panic attacks, etc. Altogether, this adds to the confusion around the concept of COPD-related anxiety.

Taken together, the current understanding of COPD-related anxiety is generally limited, and research summarizing the concept from the patient perspective is lacking. Therefore, with the purpose of exploring the complexity of COPD-related anxiety, the present review aims to synthesize the available qualitative research on patients' experiences with COPD-related anxiety and to propose a model of the concept.

Materials and Methods

The present study is a systematic review of qualitative studies identified in a larger systematic review of quantitative and qualitative studies of COPD-related anxiety (PROSPERO ID: CRD42021261124; https://www.crd.york.ac.uk/prospero/) and adheres to the PRISMA 2020 guidelines.[15] The analysis of the quantitative studies is currently ongoing and will be presented elsewhere. The synthesis of qualitative study findings in the present study is based on Thomas and Harden's thematic synthesis approach.[16] The themes and their interrelations were discussed among the group of authors as well as other clinicians and researchers, on the basis of which a conceptual model was proposed.

Search Strategy and Study Selection

The literature search was performed in April 2023 by block search (Supplementary Material, Section 1) in the databases of PubMed (MEDLINE), CINAHL (EBSCO), and PsycInfo (APA). Danish, English, Norwegian, and Swedish-language articles describing qualitative studies of anxiety among people diagnosed with COPD were eligible for inclusion. Interview-based and focus group studies were selected as we were interested in patients' own narratives about their experiences. References were imported to and managed using Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia (available at www.covidence.org).

The screening process was performed independently by two researchers (CFC and IFV). Conflicts were discussed and solved in agreement. If agreement was not reached, a third researcher (AL) reviewed the conflicts and made the final decision. Initially, relevance of the identified references was assessed by reviewing titles and abstracts. Full-text of the remaining references were screened based on the inclusion and exclusion criteria (Supplementary Material, Section 1). Quality appraisal was performed, and studies of low quality were excluded.

Quality Appraisal and Data Coding

Critical Appraisal Skills Programme Checklist for Qualitative Research (CASP) checklist, recommended by the GRADE working group,[17] was used to assess quality and rigor by identifying strengths and weaknesses of the studies. The studies were assessed by one researcher (CFC) and afterwards discussed with another researcher (IFV).

Data extraction and thematic synthesis were conducted using Thomas and Harden's approach.[16] The thematic synthesis contained three steps: 1) coding text line-by-line, 2) developing descriptive themes, and 3) generating analytical themes. An example of the synthesis is shown in Supplementary Material, Section 2.

Results

For an overview of the results of the study selection process, see Figure 1. A total of 7004 references were identified in the systematic search.

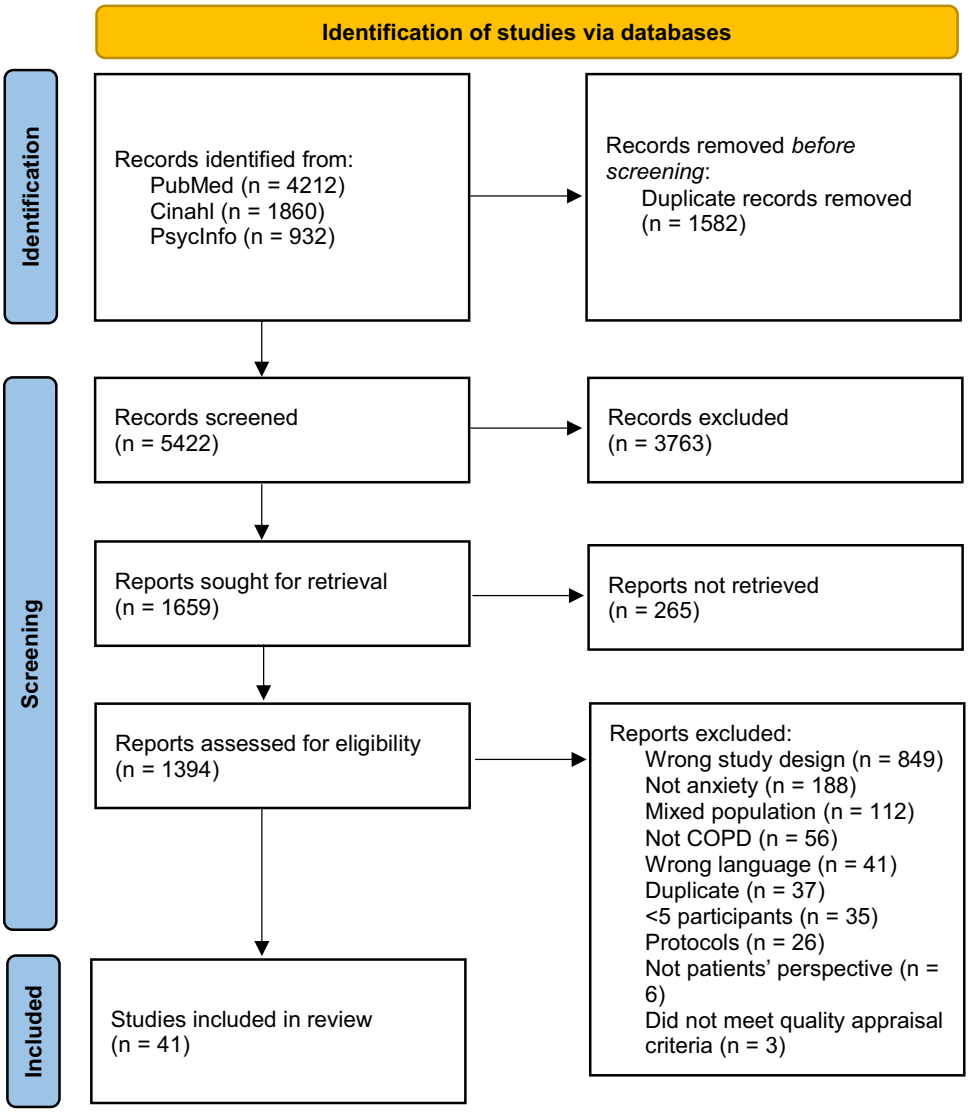

Figure 1 PRISMA flow diagram of the study selection process. From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. Creative Commons. For more information, visit: http://www.prisma-statement.org/.

After removal of duplicates (n=1582), the titles and abstracts of the remaining references were assessed and references irrelevant to the aim of the study were excluded (n=3763). Full-text references (n=1659) were reviewed and assessed for eligibility. A total of 44 studies met the inclusion criteria, but after quality assessment, three studies were excluded due to lack of ethical considerations, lack of ethical approval, and/or not using a qualitative design. The remaining 41 studies were considered rigorous with relevant aim, method, and study population and deemed relevant for inclusion in this review.

Study Characteristics

An overview of study characteristics is presented in Table 1. The majority of studies recruited patients from single countries, while one study[18] recruited participants from five different countries. All studies used qualitative analysis methods including grounded theory, phenomenology, hermeneutics, and social constructivist approaches. In 39 studies, both men and women were included, while one study[19] included women only, and one study included only men.[20] Number of interviewed patients ranged from 5 to 125 across the included studies. All studies included participants with COPD of varying illness severity.

Table 1 Study Characteristics

Reference, Year Country	Study Objectives (Type of Analysis)	N[a]	Mean Age[b]	% Female	Disease Severity[c]
Bakthavatsalu et al, 2023[21] India	To understand the lives experience of hospitalization in advanced COPD (phenomenological, descriptive)	15	66.2 (61–83)	33.3	Stage III and IV
Skär et al, 2023[22] Sweden	To deepen knowledge of how patients with COPD and LOTT think about and expect end-of-life (hermeneutic)	19	74.3 (3.6)	63.2	-
Zanolari et al, 2023[23] Switzerland	To identify sources of illness-related emotional distress (rule-based)	11	67 (51–81)	63.6	50 (17–96)
Lin & Shune, 2022[24] USA	To understand the experience of oral intake for individuals with COPD (grounded theory)	14	68.9 (49–88)	50	-
Ekdahl et al, 2022[19] Sweden	To describe women's experiences of living with COPD (content analysis)	15	75 (50–84)	100	Stage III and IV
Gilliam et al, 2021[25] USA	To gain insights into biopsychosocial experiences of COPD within the context of Tai Chi (social constructivist)	54	68.5 (8.3)	48.2	48.8 (16.4)
Jørgensen et al, 2021[26] Denmark	To explore patients' experiences of admission due to acute exacerbation of COPD (meaning condensation)	13	68.5 (50–86)	61.5	-
Askey-Jones et al, 2020[27] UK	To explore patients' experiences of a psychoeducation session in pulmonary rehabilitation (thematic analysis)	12	70 (34–91)	NR	-
Lundell et al, 2020[28] Sweden	To explore how patients with COPD experience interactions in healthcare professionals (grounded theory)	13	69 (48–80)	61.5	52 (28–91)
Rubio, 2019[29] USA	To examine experiences, feelings and perceptions of living with stage IV COPD (phenomenological, interpretative)	6	70	66.6	20
Sigurgeirsdottir et al, 2019[30] Iceland	To explore patients experiences, needs and coping strategies in COPD (phenomenological, hermeneutic)	10	69.2 (59–74)	30	40.4 (21–83)
Slevin et al, 2019[31] Ireland	To explore potential benefits of digital health technologies in COPD (thematic analysis)	30	68.2 (10.1)	43.3	I: 2 II: 16 III: 9 IV: 3
Wu et al, 2019[32] Canada	To determine patients' needs in wearable devices for management of COPD (thematic analysis)	14	69 (62–81)	50	-
Jarab et al, 2018[33] Jordan	To explore patients' perspectives on the impact of COPD on quality of life (thematic analysis)	28	-	-	-
Østergaard et al, 2018[34] Denmark	To explore barriers and motivation regarding physical activity in COPD (thematic analysis)	5	59.4 (39–75)	80	-
Luckett et al 2017[35] Australia	To seek insights from people with emergency department's "near misses" in COPD (integrative)	20	>65 yrs: 75%	45	-

(*Continued*)

Table 1 (Continued).

Reference, Year Country	Study Objectives (Type of Analysis)	N[a]	Mean Age[b]	% Female	Disease Severity[c]
Bove et al, 2017[36] Denmark	To explore patients' experience of home-based psychoeducation (interpretive descriptive)	20	69 (54–88)	70	32 (14–57)
Korpershoek et al, 2016[37] Netherlands	To explore factors related to self-management of COPD exacerbations (grounded theory)	15	70 (59–88)	46.7	I: 2 II: 5 III: 7 IV: 1
Halpin et al, 2015[38] UK	To understand the experience of fear and anxiety in patients with COPD exacerbation (thematic analysis)	20	67 (47–84)	65	-
Strömberg et al, 2015[39] Sweden	To describe patients' thought and attitudes towards exercise in COPD (grounded theory)	10	75.2 (66–84)	60	53.5 (30–72)
Gabriel et al, 2014[40] Portugal	To explore the impact of COPD on family life (thematic analysis)	20	74.1 (8.5)	20	37.3 (8.4)
Kauffman et al, 2014[41] USA	To describe experiences of insomnia, symptom attribution and treatment preferences in COPD (thematic analysis)	18	57.6 (49–75)	35	-
Schroedl et al, 2014[42] USA	To identify unmet needs of hospitalized patients with COPD (thematic analysis)	20	69 (52–83)	55	39 (22–69)
Strang et al, 2014[43] Sweden	To explore the patients' experience of anxiety in COPD (thematic analysis)	31	69.3 (48–85)	51.6	35.3
Hayle et al, 2013[44] UK	To evaluate patients' experiences of specialized palliative care in COPD (phenomenological, hermeneutic)	8	68.6 (63–77)	37.5	-
Panos et al, 2013[20] USA	To explore patient-reported determinants of health in COPD (inductive)	42	64.6 (1.4)	0	-
Ellison et al, 2012[45] UK	To understand the mental health needs of people with COPD (thematic analysis)	14	64 (10.5)	50	40 (13)
Willgoss et al, 2012[46] UK	To elicit and describe experiences of anxiety in people with COPD (thematic analysis)	14	62.3 (9.9)	64.3	-
Wortz et al, 2012[47] USA	To explore patients' goals and expectations for self-management of COPD (thematic analysis)	47	68.4 (9.3)	46.8	-
Sossai et al, 2011[48] Australia	To explore patients' experiences of living with COPD (thematic analysis)	8	- (55–80)	37.5	-
Willgoss et al, 2011[11] UK	To explore patients' experience of living and coping with anxiety in COPD (framework analysis)	14	- (43–76)	64.3	-
Lewis et al, 2010[49] UK	To describe facilitators and barriers to exercise maintenance in COPD (thematic analysis)	6	69.3 (61–83)	83.3	-
Lohne et al, 2010[50] Norway	To evaluate pain experiences of patients with COPD (meaning condensation)	16	57.9 (4.1)	75	17 (582)

(*Continued*)

Table 1 (Continued).

Reference, Year Country	Study Objectives (Type of Analysis)	N[a]	Mean Age[b]	% Female	Disease Severity[c]
Torheim et al, 2010[51] Norway	To explore experiences of mask treatment in patients with acute COPD exacerbation (phenomenological)	5	- (45–78)	60	-
Clancy et al, 2009[52] UK	To describe the meaning of living with COPD (phenomenological, hermeneutic)	10	68.9	40	-
Gardiner et al, 2009[53] UK	To determine the needs of patients in advanced COPD (thematic analysis)	21	70.3 (7.5)	38.1	-
Harris et al, 2008[54] UK	To identify a strategy for improving pulmonary rehabilitation uptake in COPD (grounded theory)	16	66.8 (6.9)	25	-
Kessler et al, 2006[18] Multiple, Europe	To gain insight into patients' experiences of COPD exacerbation (thematic analysis)	125	66.4 (8.5)	34.5	40.9 (18.1)
Barnett et al, 2005[55] UK	To explore the experience of living with COPD (hermeneutic)	10	-	-	-
Jones et al, 2004[56] UK	To explore compliance with medication and lifestyle modification in COPD (thematic analysis)	29	67 (51–79)	31	-
Jeng et al, 2002[57] Taiwan	To explore patients' experiences of daily life after hospital discharge in COPD (content analysis)	9	- (65–80)	22.2	-

Notes: [a]N denotes the number of participants interviewed in the study; [b]Mean age reported with standard deviation or range; [c]Disease severity reported as mean predicted forced expiratory volume in the first second (FEV1) with standard deviation or range. When not available, disease severity is reported as GOLD stage frequencies.

Main Results

In total, four analytical themes described COPD-related anxiety from the patients' perspectives: initial events; internal maintaining factors; external maintaining factors; behavioral maintaining factors. The distribution of the themes by study is shown in Table 2. Based on the identified four themes, a conceptual model of COPD-related anxiety from the patient perspective was proposed (Figure 2).

Table 2 Data Supporting Themes

Reference, Year	Theme 1: Initial Events	Theme 2: Internal Maintaining	Theme 3: External Maintaining	Theme4: Behavioral Maintaining
Askey-Jones et al 2020[27]			X	
Bakthavatsalu et al, 2023[21]	X	X	X	
Barnett 2005[55]	X	X	X	
Bove et al 2017[36]	X	X	X	X
Clancy et al, 2009[52]	X	X		X
Ekdahl et al, 2021[19]	X	X	X	
Ellison et al, 2012[45]			X	
Gabriel et al, 2014[40]	X			
Gardiner et al, 2009[53]	X	X	X	

(*Continued*)

Table 2 (Continued).

Reference, Year	Theme 1: Initial Events	Theme 2: Internal Maintaining	Theme 3: External Maintaining	Theme4: Behavioral Maintaining
Gilliam et al, 2021[25]		X	X	
Halpin et al, 2015[38]		X		
Harris et al, 2008[54]			X	X
Hayle et al, 2013[44]	X	X		
Jarab et al, 2018[33]		X	X	
Jeng et al, 2002[57]		X	X	X
Jones et al, 2004[56]	X			
Jørgensen et al, 2021[26]	X	X	X	X
Kauffman et al, 2014[41]		X	X	
Kessler et al, 2006[18]	X	X		
Korpershoek et al, 2016[37]	X			X
Lewis et al, 2010[49]		X		X
Lohne et al, 2010[50]	X			
Luckett et al, 2017[35]	X	X	X	X
Lundell et al, 2020[28]	X	X	X	
Panos et al, 2013[20]		X		
Rubio 2019[29]	X	X		
Schroedl et al, 2014[42]	X	X		
Sigurgeirsdottir et al, 2019[30]		X		
Skär et al, 2023[22]	X	X	X	
Slevin et al, 2019[31]	X			
Sossai et al, 2011[48]	X			X
Strang et al, 2014[43]	X	X	X	X
Strömberg et al, 2015[39]	X	X		
Lin & Shune, 2022[24]	X	X		X
Torheim et al, 2010[51]		X		
Willgoss et al, 2011[11]	X	X	X	
Willgoss et al, 2012[46]	X	X		
Wortz et al, 2012[47]		X		
Wu et al, 2019[32]	X			
Zanolari et al, 2023[23]	X	X	X	X
Østergaard et al, 2018[34]	X	X		X

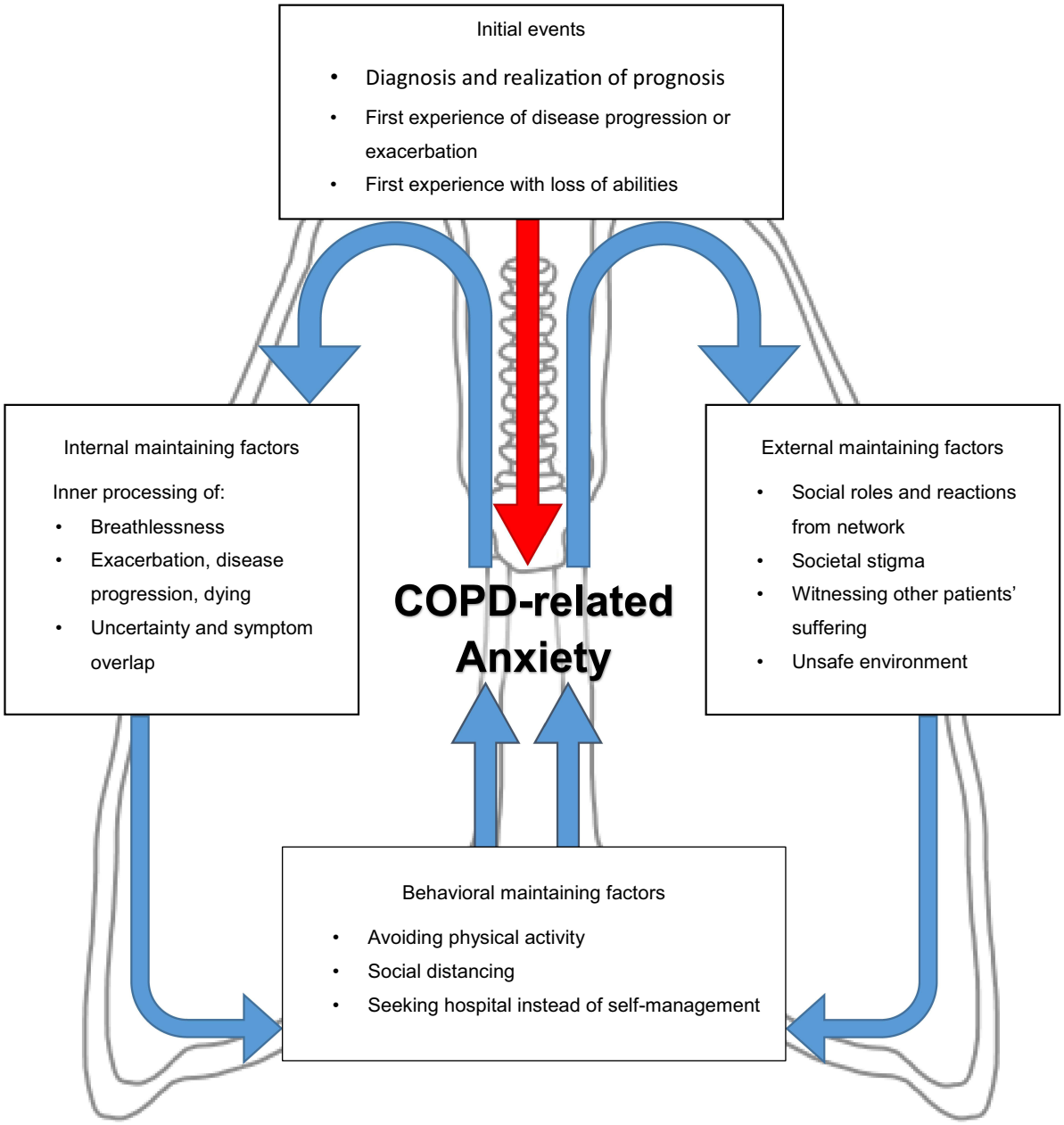

Figure 2 Conceptual model of COPD-related anxiety from the patient perspective.

The four themes in the conceptual model of COPD-related anxiety are interrelated, which is indicated by the arrows in the model. According to the model, COPD-related anxiety is a process that begins with the initial triggers and develops over time through maintaining factors that can be either internal (eg, inner states, thoughts, and feelings), external (eg, physical and social environment), or behavioral (eg, fear-induced avoidance).

Theme 1: Initial Events

Initial events refer to specific experiences that trigger first episodes of COPD-related anxiety: 1a) when the patient is diagnosed with COPD or realizes what the prognosis can be; 1b) the first experience of symptom progression or exacerbation; 1c) the first experience with loss of specific abilities or functions.

The Diagnosis and Realization of Prognosis

Patients described being diagnosed with COPD as a major life transition, followed by a period of psychological crisis with worry, fear, and anxiety.[31,34,39] The impact of the diagnosis left patients feeling anxious about both living with and dying from COPD, and the uncertainty of the prognosis further contributed to anxiety.[11,22,23,43] Being offered palliative care as a part of patients' COPD care pathway increased anxiety, due to the realization that death was part of the prognosis.[43,44,50]

The First Experience of Disease Progression or Exacerbation

Patients expressed worries and fear related to the symptoms and progression of COPD.[18,23,26,28,31,40,47,52] The experience of a severe exacerbation induced panic and constant fear and worry of rehospitalization.[18,32] Patients described medication as "life-saving" in the event of an exacerbation. Being without it or misplacing it caused anxiety.[11,46] Thoughts about potential ineffectiveness of medical treatment and having difficulty judging when inhalers (medicine) were empty led to increased anxiety during an exacerbation.[18,28,37,52,56] Emergency admissions often involved quick medical decisions and immediate treatment, which at times could be overwhelming and anxiety provoking.[21] When experiencing progression, patients expressed fear of dying – not of being dead but of the dying process involving suffocation.[21,28,36,42,43]

First Experiences with Loss of Abilities

COPD-related anxiety was described as a vicious circle, a downward spiral, and an uncontrollable force of nature,[11,24,26,35,46] which had a debilitating effect on daily life and led to feelings of worry and grief due to lost abilities.[19,26,48,53] Patients struggled to manage daily activities due to uncertainty related to physical activities, which increased breathlessness and panic attacks. For example, feeling breathless walking around town with their families and having to stop due to fear of collapsing, or when eating or drinking, which could trigger fear or breathlessness, coughing, or choking.[24] For some patients, anxiety also resulted in profuse sweating and incontinence, which made them embarrassed and subsequently avoid social situations.[11,19,21,23,29,32,52,55]

Theme 2: Internal Maintaining Factors

Internal maintaining factors refer to patients' inner processing of 2a) breathlessness; 2b) exacerbation, disease progression, and dying; 2c) uncertainty and the overlapping symptoms of COPD and anxiety.

Inner Processing of Breathlessness

Breathlessness was a central part of all patients' experiences and was identified as the most troublesome symptom of COPD.[22,23,25,26,29,30,55] Metaphors used to describe breathlessness, eg, fear of breathlessness, were compared to fighting a war without weapons[30] and as an iron ring across the chest.[26] Breathlessness was experienced as an attack, feeling of suffocation, shortness of breath, lack of air, and smothering.[21,24,26,34,39,47,49,51,52,55] Breathlessness led to feelings of potentially life-threatening situations, fear of dying, and uncertainty of when it was the last breath.[19,20,23,24,28,35,42,43,47,51,55] Breathlessness and thoughts of suffocation were described as the worst, horrible, dramatic experience ever experienced.[51]

Inner Processing of Exacerbation, Disease Progression, and Dying

Patients' descriptions of inner processing related to exacerbation, disease progression, and dying were divided into two thought directions: the memories of previous experiences (thinking back), and the fear of having another similar experience in the future (thinking ahead). Experiences of breathlessness, panic, and anxiety had a long-term impact, and former experiences were frequently revisited as flashbacks. Flashbacks to previous attacks acted as a trigger for further attacks in a vicious cycle of events.[11] As an example of fear of future events, patients described being afraid of infections due to potential life-threatening consequences. Being breathless and running out of oxygen without access to help led to feelings of fear and panic.[19,22,25,38,41,44] Patients, who had never experienced episodes of severe breathlessness, still felt anxiety and fearful, imagining future episodes of breathlessness.[11,30,34,38,49,57] Patients were affected by the COPD diagnosis and prognosis and the realization that they had to live with COPD for the rest of their lives. These thoughts initiated worry and fear of the future.[22] Patients used metaphors such as fear of ending their days as a vegetable, fading away slowly, or

being pronounced dead prematurely and buried alive.[43] The inner processing was described as fear of the process of dying; the long struggle of breathlessness, struggling for air, and painful suffocation.[18,19,25,36,41,43,53]

Inner Processing of Uncertainty and Symptom Overlap

Patients described episodes of anxiety as idiopathic and easily triggered without warning.[11,33,46] The uncertainty increased feelings of losing control and resulting in panic.[11,55] Their daily life was affected by meta-worry (worry about worry) about previous panic attacks, which caused escalating fear, worry, and new panic attacks.[44,46] Moreover, patients were continually considering an array of possible causes for future attacks.[18–20,23,33,35,46,57] Patients described how they had been living with anxiety for years without being aware of it, due to the confusing overlap of COPD and anxiety symptoms.[11,46]

Theme 3: External Maintaining Factors

External maintaining factors refer to patients' surroundings that can intensify feelings of anxiety in the patient: 3a) social roles and reactions from network; 3b) the societal stigma towards having COPD; 3c) being faced with the condition of other patients; 3d) being in an unsafe environment.

Social Roles and Reactions from Network

Patients described feeling lonely when experiencing COPD-related anxiety, as they believed their symptoms were distressing for their families, and they expressed fear of becoming a burden to their network. At the same time, patients expressed anxiety of separation and leaving relations behind.[11,21–23,43,53] Patients felt that relatives had difficulties understanding their situation and feelings.[36,45,57] Loss of role within the family, including loss of intimacy in personal relationships due to embarrassment of breathlessness, was perceived by patients as an increase in social distancing from others.[25,45,55]

Societal Stigma

Patients were affected by what they perceived as societal stigma and feelings of not being taken seriously in the healthcare system,[19,23,25,27,28,53] based on the assumption that causes of COPD are self-inflicted and that COPD could be compared with human immunodeficiency virus (HIV) or addiction.[19,23,25,26,28,45,54]

Witnessing Other Patients' Suffering

Patients' perception of COPD and progression worsened by speaking to and/or witnessing the condition of other patients with COPD. This self-other-awareness gave a feeling of being vulnerable, as it increased feelings of anxiety due to the imagination that their self-efficacy slowly would decrease as COPD progressed.[22,36,52]

Unsafe Environment

Patients feared or dreaded not being able to speak to others or call for help during an exacerbation, especially during the night.[22] When feeling a small change in the quality of breathing or during the first signs of an exacerbation, patients would seek hospital intervention instead of relying on self-management or coping.[33,35,41]

Theme 4: Behavioral Maintaining Factors

Behavioral maintaining factors refer to behaviors that are initiated by patients with the purpose of protecting themselves, but which ends up maintaining COPD-related anxiety: 4a) avoiding physical activity, 4b) social distancing, and 4c) seeking hospital admission instead of self-management as common behavioral strategies.

Avoiding Physical Activity

Avoidance was a common coping mechanism resulting in limited ability to perform adequate self-management actions during anxiety attacks, due to the lack of exposure to anxiety-related situations or events.[24,35–37,43] COPD-related anxiety was a barrier for meaningful activities due to fear of situations that were out of their control. Patients further elaborated barriers such as fear of being too far away from home, worry about collapsing due to breathlessness, and anxiety related to unfamiliar places.[23,24,34,48,49,52,54,57] Physical activity revealed the illness in front of others, which further contributed

to making physical activity a source of distress.[23] Fear of experiencing a panic attack was described as disabling, and patients were anxious of being too breathless, which ultimately limited their activities.[23,24,34,46]

Social Distancing

As examples of memories of earlier experiences leading to fear of future events, patients described an exacerbation as a traumatic life-changing crisis or attack that affected their relationships with others and led to isolation during an exacerbation.[18,46] Fear of dependency and becoming an additional burden to their network led to further social distancing.[23,45,57] Patients expressed that relatives had difficulties comprehending their situation, which led to social distancing.[36,45,57] Patients were affected by societal stigma and feelings of not being taken seriously in the healthcare system, which led to not seeking help for mental health issues.[19,25,27,28,53] The stigma and blame were external barriers for patients seeking help from others.[19,25,45]

Seeking Hospital Intervention Instead of Self-Management

Patients misinterpreted their panic attacks as an acute exacerbation of COPD, which resulted in needless hospital admissions.[11] Patients would often seek hospital intervention instead of relying on self-management or coping.[33,35,41] Patients were afraid that they would be discharged from the hospital too soon, and they felt safe in the hands of health-care professionals at the hospital.[26]

Discussion

Our study summarized the findings from 41 existing qualitative studies of patients' experiences of COPD-related anxiety. Four themes were identified in the analysis: initial events; internal maintaining factors; external maintaining factors; and behavioral maintaining factors. Altogether constituting a conceptual model of COPD-related anxiety from the patient perspective. According to the model, specific initial events can trigger COPD-related anxiety, ie, realizing the diagnosis and/or prognosis, experiencing exacerbation/symptom progression for the first time, and loss of function and/or abilities due to COPD. Multiple studies have explored the psychological effect of specific events in other illness trajectories,[58,59] and the psychological burden of receiving a cancer diagnosis has been extensively studied.[60,61] Meanwhile, it is not common to consider these events in the COPD illness trajectory as potential anxiety provoking experiences, and the psychological burden of receiving a COPD diagnosis has not been given the same degree of attention in the literature. One possible explanation for this lack of focus might be related to the consideration that smokers should expect to be ill from smoking, which is a widespread understanding of COPD, despite also being the case for certain cancers and cardiovascular disease.[62] Another explanation may be the relatively slow progression of the disease, often resulting in several visits to the doctor with symptoms and declining lung function before the diagnosis is confirmed by the physician and disclosed to the patient.[63] Nonetheless, cancer and COPD may have similar disease burden and survival rates,[61] and patients' reactions to this should be explored more extensively in the future – clinically and empirically.

Results of our study indicated that as soon as COPD-related anxiety had been triggered, it was maintained and potentially worsened over time by internal, external, and behavioral maintaining factors. The anxiety-maintaining effect of the inner processing of breathlessness, for example in the form of breathlessness catastrophizing, has been more extensively studied,[10,64,65] and a number of questionnaires have been developed to assess this specific aspect of COPD-related anxiety, eg, the Breathlessness Catastrophizing Scale,[66] and the Interpretation of Breathing Problems Questionnaire.[67] Other internal factors maintaining anxiety in COPD have been largely overlooked in COPD-specific anxiety questionnaires. For example, the results of the present review showed that patients were troubled by thoughts of death and the process of dying. Patients alluded that even shortly after being diagnosed with COPD and understanding the prognosis, death became a near reality, which affected their internal processes. Results elucidated that patients were not afraid of being dead, but feared the process of dying. While it is intuitive to think that death-anxiety refers to the absence of life or missing out, patients described that they were afraid of how they were going to die, ie, through suffocation. Other studies have found that patients with COPD want information on what dying might be like for them in order to prepare themselves.[68,69] Patients described thoughts and fear of death as having a great impact early in the course of illness and not only towards end-of-life.[70] In spite of being aware of patient needs, many health-care providers

feel inadequately prepared for discussing end-of-life issues and might therefore tend to avoid bringing up the subject.[71] Moreover, appropriate timing of these conversations can be challenging, due to the unpredictability of the general illness trajectory in COPD compared to cancer.[70]

The results of the present study indicated that patients were suppressing information about mental health, believing that their network and health-care providers could not understand or comprehend their situation, and therefore refrained from asking for help. Avoidance and social distancing were initiated by patients for protective purposes, but most likely ended up maintaining and/or worsening the symptoms, because they remain largely unidentified in a clinical setting.[6,72] Studies have shown that non-pharmacological interventions, such as pulmonary rehabilitation programmes psychological interventions, improve exercise capacity, dyspnea, emotional functioning, health-related quality of life, general anxiety symptoms, and COPD-related anxiety.[73–75] However, lack of attendance for such activities is common,[76,77] which is in line with the findings of our study, where patients try to protect themselves by avoiding physical activity.

With the purpose of strengthening the identification of COPD-related anxiety in the future, there are a number of potential barriers among health-care providers that need to be overcome, such as not recognizing the scale of the problem, not considering anxiety as part of the remit, and lack of knowledge about or access to appropriate interventions.[78] Both health-care providers and patients can benefit from implementing systematic, psychological screening processes, because it can potentially increase confidence in assessing and managing psychological symptoms.[79]

The questionnaires most often used to assess anxiety symptoms in COPD, eg, the Hospital Anxiety and Depression Scale (HADS)[80] and the Hamilton Rating Scale for Anxiety (HAM-A),[81] do not include questions about the internal (eg, fear of dying), external (eg, unsafe environments), and behavioral (eg, fear-based avoidance) factors that appeared to be characteristic of anxiety in patients with COPD. Even disease-specific anxiety questionnaires like the COPD-Anxiety-Questionnaire (CAF)[82] and the Anxiety Inventory for Respiratory Disease (AIR)[83] do not contain questions assessing the central aspects of COPD-related anxiety that were described in our study. If patients are not questioned on fear-inducing and difficult to cope with topics, the severity of anxiety may be underestimated or unidentified in clinical settings. This could potentially explain why the estimated prevalence of anxiety levels in COPD varies markedly across studies and should prompt a reconsideration of the sensitivity of existing questionnaires to identify aspects of anxiety in patients with COPD. Not addressing COPD-related aspects of anxiety leads to poorer identification, and leaves patients to deal with anxiety themselves.

When interpreting the results of our study, it is important to bear in mind that experiencing COPD-related anxiety does not necessarily mean fulfilling the criteria of an anxiety disorder. Theoretically, not all patients with COPD and a comorbid anxiety disorder will experience COPD-related anxiety and vice versa. Furthermore, it is also important to differentiate COPD-related anxiety from episodic, passing experiences of anxiety that can be normal reactions to events such as diagnosis or symptom exacerbation.[84] According to the conceptual model of our study, COPD-related anxiety involves persistent anxiety symptoms that are related to an individual's processing of COPD-related internal and external factors, as well as accompanying fear-induced behavior, such as avoidance of physical activity, social distancing, and seeking hospital intervention instead of self-management. Consequently, COPD-related anxiety should be described neither as a momentary feeling nor as a mental disorder, but as a biopsychosocial pattern that develops over time and reduces an individual's functional capacity, quality of life, and ability to cope with the illness. Additionally, comorbid physical diseases and specific life circumstances that are not directly related to COPD symptoms could also impact patients' experience of anxiety, and it may be difficult for the individual patient and the clinician to differentiate between anxiety symptoms emerging from one or the other condition. Participants in the included studies of the present review were recruited on the basis of their COPD diagnosis, but a certain proportion may also be diagnosed with other diseases, which may have influenced their narrative. It is therefore important to differentiate between COPD-*related* anxiety and COPD-*specific* anxiety, the latter being exclusively caused by or associated with COPD diagnosis. Future studies directly comparing anxiety narratives in COPD and other physical diseases are needed with the purpose of expanding our knowledge of COPD-specific anxiety.

Strengths and Limitations

The present review was protocol-based and systematically adhered to existing guidelines for review and analysis of qualitative studies. It represents one of the first attempts to systematically review the existing literature on COPD-related anxiety from the patients' perspective and to propose a conceptual model of COPD-related anxiety.

A number of limitations should be considered when interpreting the results of the study. First, the results were based on study samples that were heterogeneous in terms of participants' sociodemographic characteristics and symptom level as well as the geographical location where studies were conducted. Based on the present study, it is not possible to draw conclusions in terms of potential variation in the experience of COPD-related anxiety related to age, gender, symptom severity, or cultural norms. Second, caregivers' and health-care providers' experience of COPD-related anxiety was not included in the present review. Their observations are highly relevant in fully understanding the concept of COPD-related anxiety and should be explored in future studies. Third, exploring COPD-related anxiety was not the primary focus of all of the included studies; hence, patients were not asked specifically to describe their experience of COPD-related anxiety. With the purpose of studying the subjective specificity of the concept in the future, there is a need for studies directly prompting patients to describe their experiences with COPD-related anxiety and asking them to differentiate between COPD-related fears, fears associated with comorbid diseases, and other types of fears.

Conclusion

The present review synthesized the results of existing qualitative studies of COPD-related anxiety from the patients' perspective. According to our proposed conceptual model, patients' experiences of COPD-related anxiety are initially triggered by specific events in the illness trajectory and thereafter maintained by COPD-related internal, external, and behavioral factors. The present study represents one of the first steps towards understanding the complexity of COPD-related anxiety. In the future, there is a need for work that aims to 1) improve the identification of anxiety symptoms in patients with COPD, 2) differentiate between subclinical anxiety patterns and comorbid anxiety disorders, and 3) develop and deliver targeted treatment. Future research should focus on the development of a COPD-specific anxiety questionnaire for research and clinical purposes and could preferably draw on the conceptual model proposed in the present study with the purpose of assessing domains of COPD-related anxiety that are in line with patients' experiences.

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Author Contributions

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

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