

Online Supplement

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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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
20	limit 18 to yr="2021 -Current"	638949

Search Number	Search Terms	Results
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 (PICO_S) 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	<ul style="list-style-type: none"> • Patient disease experience in real-world setting • Patient treatment experience in real-world setting • QoL 	—
Study Design	<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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; PICO_S = 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	✓	✓	✓	✓	✓	✓	*	*	✓	✓

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.

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.

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)	<ul style="list-style-type: none"> • Employed n=5/20 • Unemployed n=10/20 • Retired n=5/20
Gabriel et al. 2014 ⁵	Not reported	<ul style="list-style-type: none"> • Employed n=1/20 • Retirement n=19/20
Hareendran et al. 2013 ⁶	<ul style="list-style-type: none"> • 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)	<ul style="list-style-type: none"> • Employed n=11/28 • Unemployed=17/28
Leidy et al. 2015 ¹⁰	<ul style="list-style-type: none"> • Hispanic or Latino: 2 (10.0%) • Not Hispanic or Latino: 18 (90.0%) 	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Employed n=9/28 • Unemployed n=3/28 • Retired n=16/28
Svedsater et al. 2017 ¹⁶	<ul style="list-style-type: none"> • White: n=31/33; 93.9% • Unspecified: n=2/33; 6.1% (COPD data only)	<ul style="list-style-type: none"> • Employed n=9/33 • Retired n=15/33 (COPD data only)
Wangsom et al. 2020 ¹⁹	Not reported	<ul style="list-style-type: none"> • 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)	<p>"With the disease progression, this shortness of breath gets worst and now, I think a lot about tomorrow the pain it might cause."⁵</p> <p>"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</p> <p>"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</p>
Not able to breathe /Can't breathe/ Not breathing well/ Effort to breath/Trouble breathing/ Can't get breath (n=7/17)	<p>"You're trying to get your breath; you can't get your breath."²¹</p> <p>"You're calling for a breath to fill your lungs, but you can't seem to get it"⁶</p> <p>"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</p>
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

^aSome 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

^aSome 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

^aSome 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

^aSome 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

^aPatient quotes were not available for shopping, cooking, talking, riding a bicycle, and driving

^bSome 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

^aSome 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

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

^aSome 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)

^bPatient quotes were not available for overwhelmed, lack of motivation, sense of identity loss, or difficulties in being reciprocal

^cPatient quotes were not available for resilience, stoicism, acceptance, gratitude, altruism, enjoyment, or reassurance

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