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'You can't feel what we feel': Multifaceted dyspnoea invisibility in advanced chronic obstructive pulmonary disease examined through interpretative phenomenological analysis

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Abstract

Background: More than a symptom, dyspnoea is an existential experience shaping the lives of those afflicted, particularly when its persistence despite maximal pathophysiological treatments makes it pervasive. It is, however, insufficiently appreciated by concerned people themselves, family members, healthcare professionals and the public (dyspnoea invisibility), limiting access to appropriate care and support.

Aim: To provide a better understanding of dyspnoea experiences and its invisibility.

Design: Interpretative phenomenological analysis of data collected prospectively through in-depth semi-structured interviews.

Setting/Participants: Pulmonary rehabilitation facility of a tertiary care university hospital; 11 people (six men, five women) with severe chronic obstructive pulmonary disease (stages 3 and 4 of the 4-stage international GOLD classification) admitted for immediate post-exacerbation rehabilitation.

Results: We identified several types of dyspnoea invisibility depending on temporality and interlocutors: (1) invisibility as a symptom to oneself; (2) invisibility as a symptom to others; (3) invisibility as an experience that cannot be shared; (4) invisibility as an experience detached from objective measurements; (5) invisibility as an experience that does not generate empathic concern. The notion of invisibility was present in all the identified experiential dimensions of dyspnoea. It was seen as worsening the burden of the disease and as self-aggravating through self-isolation and self-censorship.

Conclusions: The study confirmed that dyspnoea invisibility is a reality for people with advanced chronic obstructive pulmonary disease. It shows dyspnoea invisibility to be a multifaceted burden. Future research should aim at identifying individual and collective measures to overcome dyspnoea invisibility.

Keywords

Dyspnoea, breathlessness, chronic obstructive pulmonary disease, rehabilitation, integrative medicine, palliative medicine, qualitative research

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What is already known about the topic?

- Persistent dyspnoea plagues the lives of people with chronic respiratory diseases.
- The nature and impact of persistent dyspnoea are poorly understood and appreciated by others.
- Dyspnoea invisibility increases the burden of the disease and limits the amount of care received.

What this paper adds

- There is not one but several dyspnoea invisibilities, depending on temporality, disease severity and the nature of the interlocutors.
- The fact that dyspnoeic experience cannot be shared is a major driver of dyspnoea invisibility.
- Participants were particularly frustrated with doctors, who were perceived as not addressing dyspnoea thoroughly and not providing enough information.

Implications for practice, theory or policy

- Lifting dyspnoea invisibility is an important clinical challenge.
- By identifying several sources of dyspnoea invisibility, the study provides research avenues for corrective measures.
- These could include specific public health campaigns and targetted training to improve physician-patient communication.

'You must have it to understand how horrible it is'

"They should have doctors experience [. . .] dyspnea,

so they understand what patients are going through"[1]

Introduction

Dyspnoea is 'a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity'.[2–4] More simply, dyspnoea is the complaint that arises from an upsetting or distressing awareness of breathing sensations.

Dyspnoea is a symptom but it is also an experience that changes the brain of those afflicted (through memory/anticipation phenomena, see refs.[5–7]) and therefore shapes their lives.[8,9] This is particularly true when dyspnoea continues despite maximal pathophysiological treatments (persistent dyspnoea).[10,11] Persistent dyspnoea is a pervasive phenomenon[12] associated with anxiety, fear and depression, which are aggravated by helplessness[12] and feelings of unworthiness.[13] It is a major source of physical, psychological and social disability, leading to closing in on oneself and withdrawal from the outside world.[12] Worldwide, millions of people experience persistent dyspnoea associated with chronic respiratory, cardiac and neuromuscular diseases, or with severe obesity.

Dyspnoea is an afflictive existential experience for a patient, but is not fully appreciated by others. Afflicted people often report poor understanding from those around them, including healthcare professionals[1] and informal carers, who nevertheless express a desire to better understand the experience of breathlessness to help them cope better with the needs of their family members and their own emotions.[14,15] Social stigma and inadequate access to care[16] contribute to dyspnoea invisibility,[8,9,16] which worsens the burden on affected people and, collectively, raises human rights issues.[17]

In theory, multiple reasons can contribute to dyspnoea invisibility. The onset of chronic diseases is slow and surreptitious, leaving time for habituation and rationalisation. In contrast to pain, dyspnoea is not a universal experience, making it difficult for healthy people to identify with afflicted people's sufferings.[18] Seeing dyspnoea in others triggers discomfort,[19] which can lead to empathic distress and avoidance behaviours. Social stigma and the feeling of incomprehension can lead to silence. Few studies have investigated the determinants of dyspnoea invisibility from the point of view of the patient.

Methods

Research question

The study aimed at identifying the determinants of dyspnoea invisibility according to people suffering from severe chronic obstructive pulmonary disease (COPD).

Design

The study followed the principles of interpretative phenomenological analysis, a qualitative research method focussed on exploring someone's 'inner world' to gain a deeper understanding of a particular aspect of human experience. This approach allows to identify new meanings, which can inform how experiences are understood by people.[20] A double hermeneutic (wherein the researchers make sense of how the participants reflect on their own experiences, while simultaneously examining how their own views and biases might impact the analytical process

to ensure that the participants' voices are actually heard) is intrinsic to interpretative phenomenological analysis.

Setting

The study was conducted in the pulmonary rehabilitation division of the *Department of Respiratory Medicine* (22-bed structure entirely devoted to the post-exacerbation rehabilitation of people suffering from COPD) at the Pitié-Salpêtrière Hospital, a 1600-bed tertiary university hospital in Paris, France.

Population

Inclusion criteria were (1) being aged 18 or more, and not under guardianship; (2) an established diagnosis of severe COPD (GOLD classification stage 3 or 4[21]); (3) having been admitted for rehabilitation immediately after severe COPD exacerbation that required hospital admission; (4) be fluent in French and able to provide informed consent. Non-inclusion criteria were known cognitive deficiencies, and insufficient command of French.

Sample

Interpretative phenomenological analysis typically requires small but homogeneous samples.[22] In line with similar studies in the field of palliative care,[23,24] we therefore aimed at including 10–15 purposely selected participants. As the study did not intend to generate theory, data saturation was not considered a priori for sample size determination.[25]

Recruitment

Potential participants were identified according to the inclusion criteria by their physician in charge (AG or JGB) prior to study commencement, on a consecutive basis, without aiming for a gender-balanced sample or a specific age range. AG or JGB then introduced the study in a general manner, during a face-to-face interaction with the identified candidates. If they were interested, appointments with the lead investigator (LS), a palliative care specialist with previous training in qualitative approaches, were organised in such a way as to allow uninterrupted sessions not interfering with usual care. LS then explained the purpose of the study more precisely (*'to explore your experience of dyspnoea, your expectations and your needs, met or unmet'*) and started the interviews in those who had consented.

Data collection

Face-to-face semi-structured interviews were conducted between September 2019 and May 2020 in the participants' rooms by LS. LS was alone with the participants in their rooms, and adopted an attitude of benevolent neutrality. Interviews were recorded and transcribed verbatim. The interview guide included two sensitising questions exploring first the experience of dyspnoea *('How do you live your breathing difficulties?'*) and then its perception by others ('*Do you think that people around you realise what you experience with your breathing is*?'). Follow-up questions could be asked to gain a deeper understanding of the topic[26] (e.g. '*Tell me more about that*', '*What do you mean by this*'). Of importance, the term 'invisibility' was not used as such in the information note or during the interviews. No pilot-testing was conducted, no field notes were taken and no repeat interviews were held.

Data analysis

Interpretative phenomenological analysis was conducted by LS, using a typical step-by-step approach,[22,27,28] as follows: (1) initial global reading of the interview transcripts; (2) in-depth reading and re-reading to achieve full familiarity with the content; (3) initial annotations; (4) identification of data-derived emerging themes; (5) selection of themes fully or partially relevant to the sensitising questions; (6) identification of convergences and divergences. Themes appearing in more than 50% of the interviews were considered superordinates (the corresponding information is provided for each theme in 'results'). For each theme, LS produced a personal analysis and purposely selected quotes illustrating the interpretation of participants' thoughts. Once all interviews had been analysed, patterns across interviews were investigated and superordinate themes created that captured the shared experiences of the participants. Throughout the analytical phase, themes were discussed with two other investigators (AG, TS) as a form of triangulation.[29] All the resulting interpretations and the table of superordinate themes supported by verbatim extracts from each participant were then independently reviewed by another investigator (LB) to enhance the credibility of the analysis.

Ethical issues

The study was approved by the Ethical Board of Sorbonne University (*Comité d'Éthique de la Recher*che, decision #19–621). The participants were informed in detail of the purpose of the study (namely gaining knowledge about the burden of dyspnoea and of dyspnoea invisibility). They provided written consent to participate.

Reporting

The report conforms with the consolidated criteria for reporting qualitative research (COREQ).[30]

Table 1. Baseline characteristics of the 11 interviewed participants.

Gender	six men /
number	five women
Age (years)	71
median [interquartile range]	[64.5–73]
Body mass index (kg.m^{-2})	21.8
median [interquartile range]	[16.1–27.5]
Cumulative tobacco consumption (pack-year)	45
median [interquartile range]	[40–65]
FEV1 (% pred)	30
median [interquartile range]	[19.5–36.5]
FVC (% pred)	68
median [interquartile range]	[64–93.5]
FEV1/FVC (%)	30
median [interquartile range]	[27–42]
GOLD 1–2–3–4 stage	0 / 1*/ 4 / 6
GOLD A-B-C-D stage	0 / 3 / 1 / 8
Comorbidities	
At least one	10
Obesity	2
Diabetes	1
Hypertension	6
Ischaemic heart disease	3
Cardiac insufficiency	1
Obstructive sleep apneas	1
Charlson comorbidity index	4 [3.5–5]
Baseline treatment	
LABD alone	2
LABD + ICS	9
Supplemental oxygen (permanent)	5
Supplemental oxygen (intermittent)	3
Non-invasive ventilation (nocturnal)	3
History of exacerbations	
Number during the past 2 years	4 [2.5–5]
ICU admission in the past (y/n))	8
Acute non-invasive ventilation in the past (y/n)	8
Intubation in the past (y/n)	2

FEV1: forced expiratory volume in 1 s; FVC: forced vital capacity; LABD: long-acting bronchodilators (any class; single or combined); ICS: inhaled corticosteroids; ICU: intensive care unit.
*This GOLD stage 2 patient was mistakenly included (FEV1 of 55% pred), but this patient met the GOLD D type definition (intense symptoms, high risk of exacerbation) with a clinical presentation congruent with that of the group. It was therefore decided to keep the corresponding data in the study.

Results

Participants

Fifteen consecutive persons were approached, of whom one declined to participate and one did not attend at the scheduled interview time. Additionally, two interviews were cancelled because of clinical deterioration. A total of 11 interviews was therefore conducted (six men, five women; Table 1, Table 2). The median interview duration was 48 min (interquartile range 34.5–51).

Table 2. Description of the 11 participants at the time of the interview.

History of the exacerbation preceding rehabilitation facility admission	
Duration of hospitalisation prior to rehabilitation facility admission (days) *median [interquartile range]*	14 [8–21]
Non-invasive ventilation during this hospitalisation (y/n)	7
ICU stay during this hospitalisation (y/n)	5
If yes: with non-invasive ventilation (y/n)	5
If yes: with intubation (y/n)	1
Status at the time of interview	
Delay between interview and rehabilitation facility admission (days) *median [interquartile range]*	11 [9–24]
Treatment	
LABD alone	2
LABD + ICS	8
Supplemental oxygen (permanent)	7
Supplemental oxygen (intermittent)	2
Non-invasive ventilation (nocturnal)	6
Non-invasive ventilation (nocturnal + exercise)	0
6 minutes walking distance (m)	165 [116–215]
VQ11 quality of life questionnaire *	43 [36.75–43.5]

*the VQ11 is an 11-item health-related quality of life questionnaire specific to chronic obstructive pulmonary disease,[50] scored from 11 (no impact of COPD on quality of life) to 55 (worst impact). A VQ11 score ⩾22 indicates significantly altered COPD-related alteration in quality of live.

Phenomenological results

We divided our findings into two broad domains: The experience of: A. *Living with COPD-related dyspnoea*; and of B. Dyspnoea Invisibility. Each domain included themes that logically fit together.

Living with COPD-related dyspnea. The experience of living with COPD-related dyspnoea was organised around four themes, three of them being superordinates (Figure 1): (A1) Envisioning one's death by suffocation; (A2) Losing autonomy and hope; (A3) Coping strategies; (A4) Being exhausted by a long-lasting burden.

Envisioning one's death by suffocation was an experience shared by most participants (10/11). As breathing is a vital function and as breathlessness is frequent at the end of life, participants faced the threat of a fully conscious and suffocating death, and thus experienced pervasive death anxiety. *'It is as if you died many little deaths. Every time you suffocate, you wonder if you are going to die' (participant #11).* Participants expressed their sense of isolation and contrasted their experience with the unawareness of most people, who are not constantly reminded of their own mortality. *'COPD patients do not*

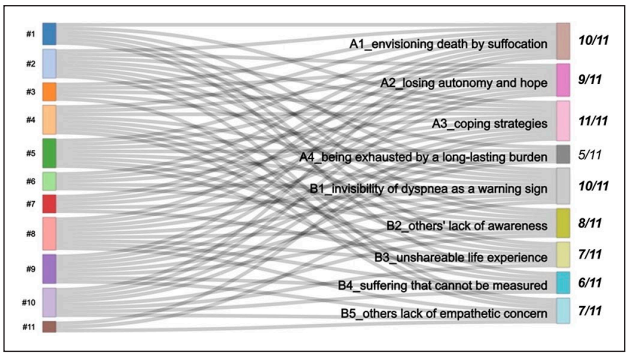

Figure 1. Sankey diagram linking the study participants (left) to the identified themes (right), with indication of the number of respondents for each theme (superordinate themes appear in bold typeface). Themes A1 to A4 pertain to the lived experience of dyspnoea. Themes B1 to B5 pertain to the invisibilities of dyspnoea. A dynamic version of the figure (html format) is provided in the electronic supplement to the manuscript (Supplement 1).

forget that they are going to die, they are reminded of it 50 times a day'.

Losing autonomy and hope was a concern for most participants (9 out of 11) who listed the activities, hobbies and projects that they were unable to continue, for example, walking in the street, hurrying to catch a bus, going shopping, driving alone, taking the train, playing with the grandchildren, swimming, climbing rocks, buying a house, continuing to work or starting a new job. *'You cannot do anything [. . .] I would like to buy a house, this is impossible. With this disease, you can't live your life anymore'* (participant #8). Limitations were mostly attributed to dyspnoea, but also at times to logistical aspects such as oxygen therapy (see Breaden et al.[31]). The participants stressed the progressive component of their disability, describing an ongoing – and distressing – deterioration to their lives over time. *'As time goes by, you get more disabled, there is no secret about that. The more things go on, the less you can do, and there is nothing you can do about it. It never gets better, it worsens, it worsens until you stop breathing. That's COPD'* (participant #6). As a participant stated, *'the only thing is to surrender to it'* (participant #6).

Coping strategies were used by all participants (11/11) to adapt to their situation. Four of them managed their condition through self-teaching: *'I have enough knowledge now to understand and manage my disease as well as possible, to be aware as soon as something goes wrong. I read, I informed myself, I read everything on the internet to get exactly what COPD is'* (participant #7). Three participants engaged in acceptance and resilience. *'Acceptance is fundamental, an acceptance that is not resignation. We must not be delusional, we must be realistic and we must try to do our best, to be resilient, to change the poison into an elixir'* (participant #5). Four participants engaged in acceptance and resignation, *'you have to take it as it is. It's destiny, you have to accept it'.* Relativising their situation was the coping strategy used by three participants. *'I saw a 38-year-old man with one leg cut off and they were taking him away to cut off the second one. So when I see that I say thank you, my God. We talk, we see, we walk what we can, it's already not that bad'* (participant #3). Five participants asked for support from others. *'I have the support of my wife and children and the caregivers here. Otherwise, one would put a bullet in one's head. They are there to boost us to recover, to stand'* (participant #3). Two participants coped by isolating themselves from others. *'When there are a lot of people around I get stressed, but when I'm alone I can take my time, I'm in my bubble'* (participant #4).

Five participants reported being exhausted by their long-lasting burden and the ongoing suffering *'It's unbearable in the long run, like that all the time all the time all the time. There's no respite'* (participant #11). These participants felt deprived of any prospect of improvement while not being able to count on the relief of that a quick death would bring. *'I wish I had terrible cancer. It is too long. I don't know why. I drink too much, I smoke too much, I die too slowly'* (participant #10).

Dyspnoea invisibility. The invisibility of dyspnoea was experienced from the early (pre-diagnostic) phase of the disease and in the advanced stages evolved into an existential experience. We organised the analysis around five themes (Figures 1 and 2): (B1) having been fooled by the invisibility of dyspnoea as a warning sign; (B2) others' lack of awareness; (B3) an unshareable life experience; (B4) a suffering that cannot be measured; (B5) others' lack of empathetic concern.

Almost all participants had been fooled by the invisibility of their dyspnoea as a warning sign (10/11). The insidious nature of COPD led them to minimise breathlessness – *'for a long time I didn't take it seriously'* (participant #7) – considering it a normal experience for tobacco smokers (rationalisation). *'I was a living with cigarettes, so I put the shortness of breath down to smoking'* (participant #10). Most participants admitted having been reluctant to face reality (denial). *'When the doctor said 'do the breath test' I didn't go right away, I didn't do the X-ray, nothing. Maybe the unconscious desire not to know'* (participant #4). However, some participants believed that they had not been sufficiently informed about the risks by their doctors or that imprecise diagnoses had led them to overlook the problem. *'My GP told me I had chronic bronchitis but I didn't understand what chronic meant, I thought it would pass, that it was repeated bronchitis'* (participant #9).

The lack of awareness of others was a concern for most participants (8 out of 11). They considered that the general public lacked information about COPD. *'People don't know much about COPD. They make a big deal about other diseases, but COPD is not talked about, I don't know why'* (participant #6). Family members and friends were

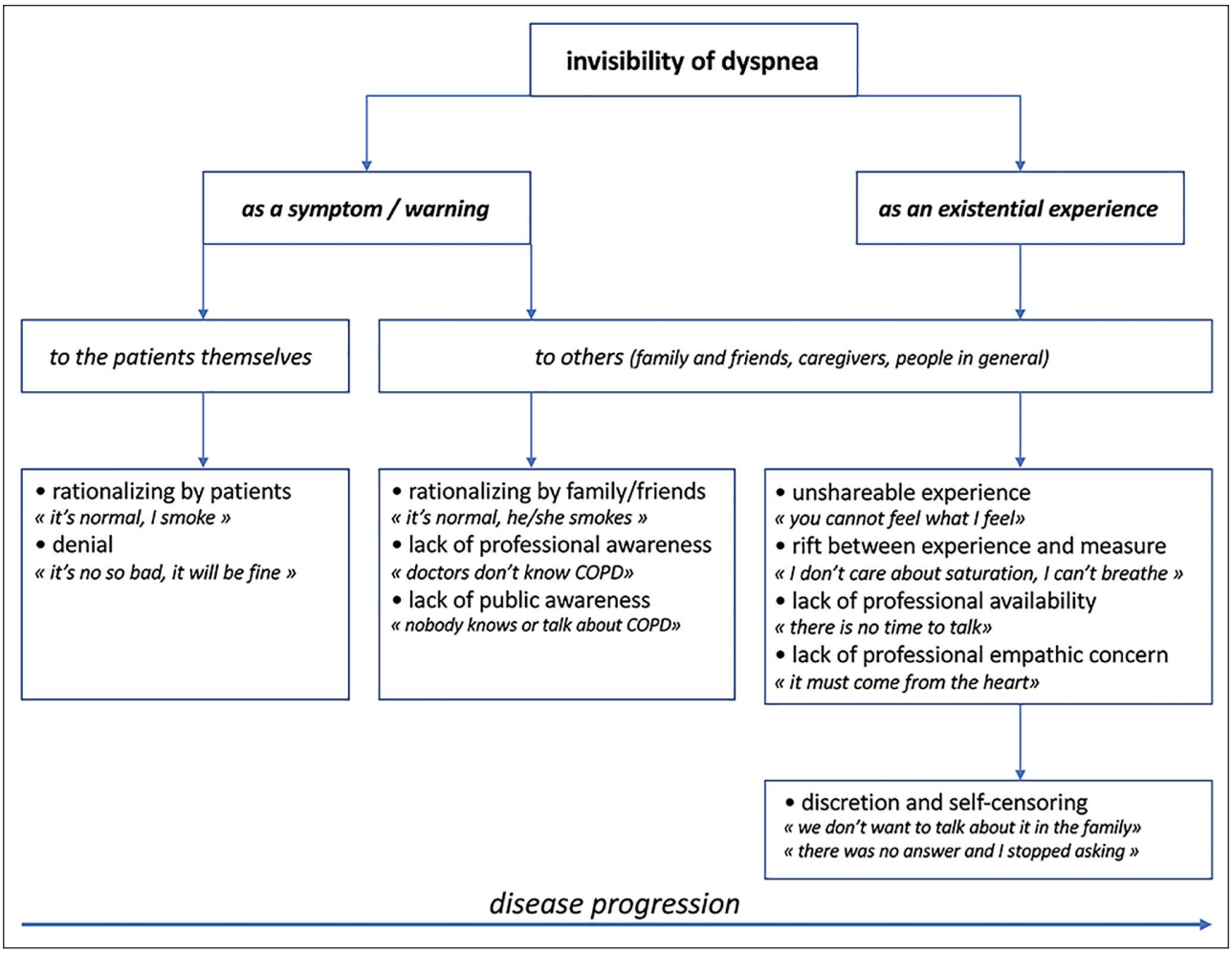

Figure 2. The invisibilities of dyspnoea according to the Interpretative Phenomenological Analysis of 11 interviews. The horizontal 'time' arrow at the bottom of the figure denotes the notion that the invisibility of dyspnoea as a symptom appeared characteristic of the early (pre-diagnostic) phase of the disease, while the invisibility of dyspnoea as an experience appeared characteristic of more advanced stages.

described as having been dismissive of dyspnoea. *'My relatives saw that I was out of breath and said well, it's the cigarettes'* (participant #2). Also, physicians were described as lacking knowledge *'My GP didn't take me seriously either, my GP didn't know about COPD'* (participant #7).

For seven participants, dyspnoea was described as an *unshareable life experience*. They stressed that it would be impossible for a healthy person to feel that they were lacking air and that their illness experience was distinct from sport-related breathlessness. '*The person close to you knows that it is shortness of breath [like during sport] but he doesn't feel it from the inside'* (participant #2). Participants mentioned that observable cues, such as oxygen supplementation or speech difficulties resulted in more attention, and compared them to the visibility of cancer. *'People who have cancer lose weight, their hair, they are in pain. We see how to support them. People who have COPD we don't see at all'* (participant #11). Sharing the same experience led participants to build a strong connection, based on common knowledge and a feeling of isolation from others. *'We, patients, understand each other, we feel the illness. . . You cannot feel what we feel'* (participant #8).

The fact that their suffering could not be measured contributed to dyspnoea invisibility, according to six participants. The gap between their subjective experience and any 'measurable physiological abnormality', led others to invalidate their distress. *'When I say I am not okay, people don't necessarily believe me! But if I can show that I'm at 83 of saturation, they think 'OK, let's increase the oxygen'* (participant #11). The fact that a 'reassuring oxygen saturation' was not necessarily correlated with respiratory comfort was stressed as a major issue. *'Doctors are always talking about saturation, but my saturation is always good, but my problem is that I can't breathe. It's*

the breathing, not the saturation. I don't give a damn about saturation' (participant #6).

Others' lack of empathic concern was mentioned by seven participants. The lack of time, attention and involvement of doctors was at the forefront of participants' complaints. They felt that caregivers avoided the relational component of their work and missed the past when doctors had more time to spend with their patients. *'I would like to see more communication, to get to know the person behind the professional. It's a matter of openness, of empathy. I don't know what kind of training doctors have nowadays when it comes to human relationships. It should come from the heart. When I see my doctor, the relational aspect is reduced to the minimum'* (participant #5). *'It often makes me think of a factory here. We are in an extremely technical world. The nurses, they're nice, but they don't care. There is some humanity missing'* (participant #10).

The invisibility of dyspnoea caused participants to self-censor to their families with motivations as 'shielding others from negative things' or 'not bothering anymore'. '*When we meet as a family it's to talk about things that are important to us, to relax and try to smile*' (participant #1). When asked to discuss the prospect of death, caregivers provided evasive and inappropriate answers, leading participants to stop asking questions. *'Every time I asked about the prognosis, I was told it wasn't like cancer because we don't know. So, there was no answer and I stopped asking because I know my question won't be properly addressed'* (participant #1).

Discussion

Main findings

This study confirmed that dyspnoea invisibility is an integral part of the lived experience of people with persistent dyspnoea and that it worsens their burden. The study showed that dyspnoea invisibility is multifaceted, depending on disease severity, evolution and the participants' interactions with others. Participants were particularly frustrated with doctors who were described as insufficiently knowledgeable about COPD, dismissive of dyspnoea and lacking relational skills (empathy, communication). Breathlessness being an unshareable experience was a major driver of dyspnoea invisibility. Our results were consistent with the literature describing advanced COPD as chronic deteriorative, life-shrinking experience, physically, psychologically, and socially.[12,31–34] The *death anxiety* reported by the participants *('fear to die, try to live, and wait for the end'*, participant #1) echoed previous studies.[12,31,35] The obsession with breathing identified by Van de Meide et al.[12] was vividly expressed by our participants, who felt deprived of freedom by their persistent dyspnoea. The despair of an *'agonizingly long and slow deterioration process'* (participant #10) was combined with a frustrating lack of information regarding the course of the disease and the corresponding threats.[36] All participants described a variety of *coping strategies*, some of these involving the support of others. This finding contradicts previous data suggesting that people with advanced COPD rarely ask for help, either because they accept their limitations or because they have no hope for possible improvement.[37] The fact that our participants were receiving active care for a particularly severe COPD (9 out of 11 dependent on oxygen) might explain this discrepancy. Doctors' avoidance of prognosis is consistent with data on medical communication regarding chronic or fatal illnesses.[38,39]

What this study adds

The notion of dyspnoea invisibility was first put forward by Gysels and Higginson,[16] already in COPD. Gysels and Higginson[16] focussed on the interactions between patients and health services and concluded that health care services tended to discredit the experience of people with COPD, leading to inadequate management trajectories.[32] Habraken et al.[37] found that patients with end-stage COPD minimised the severity of their status and considered that no help could be provided. Since these early studies, dyspnoea invisibility has been discussed from a theoretical point of view through a critical medical humanities analysis,[40] and from personal and philosophical points of view.[8,9,41] Literature searches find a limited amount of clinical data on this topic (e.g. Breaden et al.,[31] with a focus on long-term oxygen therapy), with dyspnoea invisibility not being specifically addressed in COPD and/or dyspnoea qualitative studies.[12,13,34,35,42,43] Our study therefore contributes to fill a knowlege gap about dyspnoea invisibility. It emphasises that there is not one but several dyspnoea invisibilities, which depend on temporality, disease severity and the nature of the interlocutors. Also, the study shows a major driver of dyspnoea invisibility to be the difficulty of sharing the dyspnoeic experience with others. Lastly, participants were particularly frustrated with doctors, who were perceived as not addressing dyspnoea thoroughly and not providing enough information and attention.

Strengths and limitations

The small number of participants could be viewed as a limitation, although similar sample sizes have been used in comparable studies.[43–45] We studied a very homogeneous group of people (advanced COPD, GOLD stages 3–4) in a very specific context (early post-exacerbation rehabilitation). This limits the generalisability of the results but compensates for the population size. Many of the identified themes qualified as superordinates suggesting that inductive thematic saturation might have been reached.[46]

Of note, interpretative phenomenological analysis involves leaving participants to describe their experience but also interpret personal histories with personal words, feelings and codes.[22] Thus, researchers can grasp the complexity of the phenomenon explored despite small population sizes.[47]

Further implications

Our study sheds new light on dyspnoea invisibility. Our analysis suggests that there is not one but several types of dyspnoea invisibility, depending on the aspect of dyspnoea considered (symptom vs experience), on time, and on the people close to the participant (Figure 2). Interestingly, dyspnoea invisibility was perceived by the participants as a significant contribution to their distress. One can only imagine the additional limitations and suffering caused by the omnipresence of dyspnoea in people with severe chronic respiratory diseases, and the unshareability of the dyspnoea experience was an important driver of its invisibility. Our participants emphasised that their experience separated them from other individuals, who were unable to understand their experience. Before the irruption of dyspnoea in their lives, participants had not experienced death anxiety that would become a constant presence when living with dyspnoea. This situation led them to value the gift of health and of not having to care about breathing *('breathing is a miracle, when is troubled it can be hell'; 'breathing is life, breathlessness announces death')*. These findings echo a recent survey of healthy people regarding their breathing discomfort when using COVID-19 protective face masks.[18] In this study, people experiencing what can objectively be defined as a very light constraint provided surprisingly high dyspnoea ratings (median of 7 on a 1–10 numerical rating scale interrogating 'the worst dyspnoea that you can imagine') and reported changes in their opinions about breathing and respiratory diseases.[18] This suggests an inability to envisage what 'the worst' might be, in line with the non-universal nature of dyspnoea as a human experience.

Conclusions

Deconstructing dyspnoea invisibility into related but distinct phenomena has implications for clinical practice, education and research. Our study suggests that corrective measures of dyspnoea invisibility are possible and could lead to improvements in patient care and quality of life. For example, it is vital that the wider respiratory health community stress that, whether a smoker or not, it is never normal to be bothered by one's breathing. Regarding the training of healthcare professionals, dyspnoea should be described as an existential experience, leading to the development and evaluation of a curriculum increasing knowledge about the experience of people with dyspnoea. Such training should provide guidelines for the assessment of dyspnoea and incorporate the experiential discovery of breathing discomfort, for example through the use of tools such as the straw breathing challenge. Expert-patient teaching – an approach that has proven effective in other contexts[48] – could improve physicians' empathy and relational skills. Specific research should then assess the effectiveness of these educational approaches in making dyspnoea more visible and improving the care provided to people with persistent dyspnoea.[49]

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Author contribution

LS, SL and TS made substantial contributions to the concept or design of the work. **LS, AG, JD, JGB** made substantial contributions to the acquisition and analysis of data. **All authors** made substantial contributions to the interpretation of data. **LS and LB** drafted the article. **NN, SL, CMP, JGB, TS** revised the article or revised it critically for important intellectual content. **All authors** approved the submitted version of the article. **All authors** have participated sufficiently in the work to take public responsibility for appropriate portions of the content and approved the final version of the manuscript.

Data management and sharing

All data will be made available by the authors upon reasonable request.

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Research ethics and participants' consent

The study was conducted according to the principles of the Declaration of Helsinki. It was approved by the '*Comité d'Éthique de la Recherche –CER– Sorbonne Université*' Paris, France (decision #19-621 dated October 16, 2019). Participants consented in writing to take part in the study.

Supplemental material

Supplemental material for this article is available online.

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