

'Scared to death' dyspnoea from the hospitalised patient's perspective

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ABSTRACT

Because dyspnoea is seldom experienced by healthy people, it can be hard for clinicians and researchers to comprehend the patient's experience. We collected patients' descriptions of dyspnoea in their own words during a parent study in which 156 hospitalised patients completed a quantitative multidimensional dyspnoea questionnaire. These volunteered comments describe the severity and wide range of experiences associated with dyspnoea and its impacts on a patients' life. They provide insights not conveyed by structured rating scales. We organised these comments into the most prominent themes, which included sensory experiences, emotional responses, self-blame and precipitating events. Patients often mentioned air hunger ('Not being able to get air is the worst thing that could ever happen to you.'), anxiety, and fear ('Scared. I thought the world was going to end, like in a box.'). Their value in patient care is suggested by one subject's comment: 'They should have doctors experience these symptoms, especially dyspnoea, so they understand what patients are going through.' Patients' own words can help to bridge this gap of understanding.

Patient-centred care begins with attending to what the patient says. Dyspnoea is common, under-recognised and extremely distressing among hospitalised patients. Unidimensional and multidimensional rating scales are valuable to quantify dyspnoea,^{1,2} but the words volunteered by patients have more power. '**Scared to death**', volunteered by a patient in this report (Subject ID# IVC- 40) conveys emotion better than her rating of 10/10 for 'afraid'.

Dyspnoea is a common symptom encountered by primary care physicians, hospitalists and other members of the healthcare team. About a quarter of the general medical population reports dyspnoea on exertion,³⁻⁵ and about 1 in 10 of patients admitted to our hospital reported dyspnoea at rest.⁶ Dyspnoea causes suffering, and predicts substantially increased mortality.^{5,6}

As part of a larger study,⁷ we collected comments offered by hospitalised patients during and after completion of the multidimensional dyspnoea profile (MDP),² a quantitative instrument comprising patient reports of the unpleasantness, sensory quality and

emotional impact of breathing sensations. Adult patients admitted to the general medicine or surgical floors who reported a rating of dyspnoea 4 or greater on a 0–10 scale on admission were included. Of the 267 patients who were contacted, 156 patients consented to participate. Subject numbers corresponding to the parent study are given to enable future examination of these data sets; subject ID numbers are prefaced by IVC-. study staff approached participants daily throughout their hospitalisation and administered the MDP. After completing the MDP, participants were asked an open-ended question, 'is there anything you would like to add about your breathing discomfort?' Comments the patients made about their breathing sensations at any time during the daily interview were transcribed by the study staff verbatim. Three authors analysed the comments (RWL, KMB and ARS). After independent review, coders agreed on a set of themes found in the comments. Following this consensus, they used the categories to analyse the text. To set them apart from our commentary, actual patient comments are in bold italics.

The verbatim comments volunteered by many participants put a human face on how dramatic and troubling dyspnoea can be, adding to previously published quotes from different patient populations.⁸⁻¹⁰ We summarise the frequency of themes within these comments in [figure 1](#).

SENSORY EXPERIENCE OF DYSPNOEA

Many comments related to the sensation termed 'air hunger'; for example, '***Wish I had more air***' (IVC-22); '***Not being able to get air is the worst thing that could ever happen to you. Air is everything***' (IVC-38); '***Didn't feel like I was getting air, but I was***' (IVC-79). Likewise, in the quantitative parent study patients most often chose the air hunger category to best describe their breathing discomfort, consistent with studies in other patient populations.¹¹



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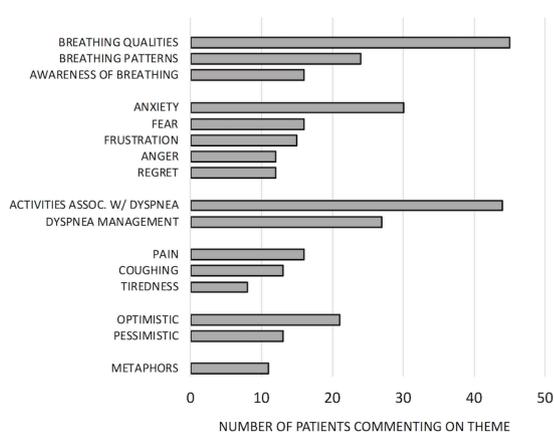


Figure 1 Identified themes that were mentioned by at least 8 of the 156 participants in the parent study (24 of whom made no comments). Patients volunteered comments if they thought they had something to add to their quantitative responses to the multidimensional dyspnoea profile. In general, patients' comments applied to periods during which the patient was experiencing moderate to severe dyspnoea (>60% of rating scale).

AWARENESS OF BREATHING

Many patients were unusually aware of breathing; for example, 'All my life I just took breathing for granted' (IVC-115). Another stated, 'I have to concentrate, I definitely have to focus. My breathing used to be effortless' (IVC-9). Awareness of breathing problems is a common reason to seek medical care, and it drives self-management strategies.

EMOTION RELATED TO DYSPNOEA

Dyspnoea evoked several emotions; the most frequently mentioned was anxiety. Anxiety motivates patients to seek help, but it can also become a burden; for instance, one of our subjects said, 'Breathing discomfort gets to a point where it feels like I can't take another breath, feels very stressful and anxious' (IVC-19). Emotion went beyond anxiety to fear; for example, one participant exclaimed, 'Panicking, couldn't get any air in. Scared the shit out of me' (IVC-40), another said it was 'scary, not getting the air in' (IVC-14). Other patients expressed fear of dying, for example, 'You get that feeling that you are dying' (IVC-49); 'Scared. I thought the world was going to end, like in a box... I'm going to die. I might not make it.' (IVC-11).

Dyspnoea signals an existential threat, and therefore appropriately provokes anxiety, motivating behaviours to escape the threat. Conversely, anxiety can increase or even generate dyspnoea.¹²⁻¹⁴ One patient described this as 'a vicious cycle—breathing gets worse—makes me anxious—makes breathing worse' (IVC-98). Understanding these causal relationships can suggest symptom management approaches. If dyspnoea is the primary problem, reduction in anxiety should follow adequate management of dyspnoea. However, in cases where coexisting anxiety disorder or above-average anxiety sensitivity exists, treating the anxiety per se may help alleviate the dyspnoea. Anxiety itself may be related to poor patient

outcomes, and should be a target for palliative therapy in dyspneic patients.¹⁵ A physiological consideration is that dyspnoea, perhaps acting via anxiety, commonly evokes rapid shallow breathing, in turn, leading to increased dead space ventilation, reduced alveolar ventilation, worsening gas exchange, thus worsening dyspnoea. Breaking this vicious cycle with behavioural or pharmacological symptom management can improve physiological status while reducing suffering.¹⁶⁻¹⁸

SELF-BLAME IN ASSOCIATION WITH DYSPNOEA

Some participants expressed regret and inwardly directed anger for their own role. Three participants explicitly blamed their habit of smoking as causing their current dyspnoea; for example, 'I can't be angry, it is my own fault that I smoked' (IVC-27) and 'getting angry because I'm doing this to myself with cigarettes' (IVC-68). Helping patients deal with anger and guilt is an additional therapeutic opportunity.

PRECIPITATING EVENTS AND MANAGING DYSPNOEA

In our hospitalised cohort, the worst dyspnoea of the day usually occurred in patients who were at rest⁷; we expected dyspnoea exacerbations to occur primarily with activity such as visiting the lavatory or undergoing physical therapy—however patients can usually avoid exertional dyspnoea while dyspnoea at rest is largely inescapable. Patients commented on strategies to avoid or manage dyspnoea. A common self-management strategy was avoidance of activity, as one participant noted, 'It's that you have to stay very still to get enough air' (IVC-8). Others managed dyspnoea by concentrating on breathing and relaxation. As one participant explained, 'Quiet deep breathing releases like a sedative. Calms you down, feels like you can get through it' (IVC-80).

SYMPTOMS THAT EXACERBATED DYSPNOEA

Dyspnoea interacted with other symptoms, for example, 'Can't breathe because I am coughing a lot' (IVC-153). Seven patients discussed the trade-off between dyspnoea and pain; describing it as tug-of-war: 'Pain keeps me from breathing deeply' (IVC-33). Another participant said, 'The breathing, when it is being challenged, it causes the pain to increase' (IVC-43).

METAPHORS FOR DYSPNOEA

Patients used colourful imagery to describe dyspnoea, for example, 'It's like an elephant on your chest in the commercial' (IVC-96). Others mentioned intense activities; for example, 'Like I was running in a race and when you stop suddenly and feel like you are going to collapse' (IVC-24). Other notable metaphors included 'Feels like a boa constrictor' (IVC-22) and 'Felt like there was not enough air in the room' (IVC-18).

SUMMARY

Dyspnoea profoundly impacts patients. Our patients' comments about distress are comparable to those previously described in other patient populations. For instance, a ventilated Intensive Care Unit (ICU) patient said, 'It's the worst situation...to lose control of my breathing'.⁹ Fear of death appears in all patient populations studied; for example, a previously described ventilated ICU patient said, 'when the shortness of breath was at its extreme, I thought I was going to die and saw a coffin beside me';⁹ and a lung cancer outpatient said, '...you don't think you'll get it back again—like a suffocation, frightened the life out of me...'.⁸

About 16% of all medical-surgical inpatients experience moderate to severe dyspnoea during their hospital stay and have substantially greater risk for adverse outcomes.⁶ We hope these quotes give providers a sense of the experience of dyspnoea; as one of our subjects stated, 'They should have doctors experience these symptoms, especially dyspnoea, so they understand what patients are going through' (IVC-33).

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