Editorial | Symptom Management in Palliative Medicine and Palliative Care

The evolution of breathlessness management

Kris Mooren[1]^, David Currow[2]^

[1]Department of Pulmonary Medicine, Spaarne Gasthuis, Haarlem, The Netherlands; [2]Faculty of Science, Medicine and Health, University of Wollongong, Wollongong, NSW, Australia

Correspondence to: Kris Mooren, MD, PhD. Department of Pulmonary Medicine, Spaarne Gasthuis, Boerhaavelaan 22, 2035RC Haarlem, The Netherlands. Email: k.mooren@spaarnegasthuis.nl.

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A long time ago, we called breathlessness 'dyspnea'. In those days, researchers unraveled the physiology of breathing in people with severe chronic obstructive pulmonary disease (COPD), heart failure, and other conditions that compromise normal respiration. As became apparent, chronic breathlessness had multiple physiological components, correlated poorly with measurable markers of disease (such as pulmonary function), and was difficult to palliate. In other words, there was not much that could be done beyond optimizing disease management. And if there is not much to be done, then there is little point in even asking about the symptom (1). This, combined with the shame and self-blame that is prevalent in many people with breathlessness, lead to invisibility (2,3).

Fortunately, we have started to move beyond these Dark Ages: important research into the effectiveness of morphine led us into a new era, in which the experiences of people with breathlessness became more visible. Positive results in relatively small studies on the effect of morphine suggested that this might well be a solution—we were just too reluctant to use it. All we had to do was prove, in adequately powered randomized clinical trials, that morphine was indeed helpful, and then we would have something to offer to our patients.

When those adequately powered trials finally came, during the upheaval of '20–22', it turned out that for most patients with chronic breathlessness, morphine was not helpful (4-6). Perhaps we had been looking too hard for a plaster to put on the wound, without acknowledging the complexity of the symptom. In the words of Havi Carel (patient and professor of philosophy): "*Breathlessness descends on you, paralyzing you. Until you get that breath in, nothing else can happen. Nothing else matters. Your world closes in on you and nothing is present except the terrible need to breathe, get more air in and out, and slowly regain control over the panting and panic that have taken over.*" (7).

What Professor Carel describes here in chilling detail is a so-called breathlessness crisis. These crises should be regarded as a different entity from chronic breathlessness—and call for a different mode of action. Our trusted measuring instruments, such as the purely functional Medical Research Council (MRC) breathlessness scale, are of no use in measuring crises. Qualitative research complements any quantification of the symptom in order to gain more insight in how these crises should be recognized, assessed, and managed. From such studies, we learned that it is useful to do some breathlessness hairsplitting. Some patients have triggered, predictable breathlessness episodes—which they can often find ways to manage. However, some have untriggered, unpredictable episodes ("it hits you")—which are closely linked to panic attacks (8). This close link between breathlessness and panic demands further exploration—because it offers insights that may lead to potential management strategies.

^ ORCID: Kris Mooren, 0000-0001-7815-0488; David Currow, 0000-0003-1988-1250.

This is one of the reasons why Schloesser *et al.* should be congratulated on their paper on the interaction between panic and breathlessness in the manuscript of *Annals of Palliative Medicine* (9). They interviewed 46 people experiencing episodic breathlessness, due to life-limiting illnesses (mostly COPD). Only a small minority of those never felt panic during an episode. Furthermore, one-quarter had a panic disorder or panic syndrome. The authors highlight the importance of 'breathlessness catastrophizing thoughts', which should be explored by clinicians. Indeed, those catastrophizing thoughts offer clues for simple cognitive behavioral strategies that are helpful for patients. The most well-known is that although you have COPD, you should know that you are unlikely to suffocate—even if you are very breathless, air will still move through the airways. Another important strategy is explaining the breathlessness-anxiety-breathlessness vicious cycle. Just lengthening the outbreath may stop the vicious cycle.

In this brave new world of breathlessness management, breathlessness services offer the kind of support that is needed (10). They are multidisciplinary services with elements of palliative medicine, psychology, occupational therapy, and music therapy. These services—and publications such as the one by Schloesser and colleagues—inspire us to be resourceful. To sit down with our patients, listen to their experiences, learn from their coping strategies. Avoiding the incomprehensible word 'dyspnea' and calling it 'breathlessness' is a vital step in recognizing that this is not just a physiological puzzle, but a huge problem for hundreds of millions of people and their carers worldwide.

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References

1. Gysels M, Higginson IJ. Access to services for patients with chronic obstructive pulmonary disease: the invisibility of breathlessness. J Pain Symptom Manage 2008;36:451-60.
2. Kochovska S, Chang S, Ferreira D, et al. Invisibility of breathlessness in clinical consultations: a cross-sectional, national online survey. Eur Respir J 2022;60:2201603.
3. Ahmadi Z, Sandberg J, Shannon-Honson A, et al. Is chronic breathlessness less recognised and treated compared with chronic pain? A case-based randomised controlled trial. Eur Respir J 2018;52:1800887.
4. Currow D, Louw S, McCloud P, et al. Regular, sustained-release morphine for chronic breathlessness: a multicentre, double-blind, randomised, placebo-controlled trial. Thorax 2020;75:50-6.
5. Verberkt CA, van den Beuken-van Everdingen MHJ, Schols JMGA, et al. Effect of Sustained-Release Morphine for Refractory Breathlessness in Chronic Obstructive Pulmonary Disease on Health Status: A Randomized Clinical Trial. JAMA Intern Med 2020;180:1306-14.
6. Ekström M, Ferreira D, Chang S, et al. Effect of Regular, Low-Dose, Extended-release Morphine on Chronic Breathlessness in Chronic Obstructive Pulmonary Disease: The BEAMS Randomized Clinical Trial. JAMA 2022;328:2022-32.
7. Carel H. Breathlessness: the rift between objective measurement and subjective experience. Lancet Respir

Med 2018;6:332-3.
8. Simon ST, Higginson IJ, Benalia H, et al. Episodic and continuous breathlessness: a new categorization of breathlessness. J Pain Symptom Manage 2013;45:1019-29.
9. Schloesser K, Bergmann A, Eisenmann Y, et al. Interaction of panic and episodic breathlessness among patients with life-limiting diseases: a cross-sectional study. Ann Palliat Med 2023;12:900-11.
10. Maddocks M, Brighton LJ, Farquhar M, et al. Holistic services for people with advanced disease and chronic or refractory breathlessness: a mixed-methods evidence synthesis. Southampton: NIHR Journals Library; 2019.

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