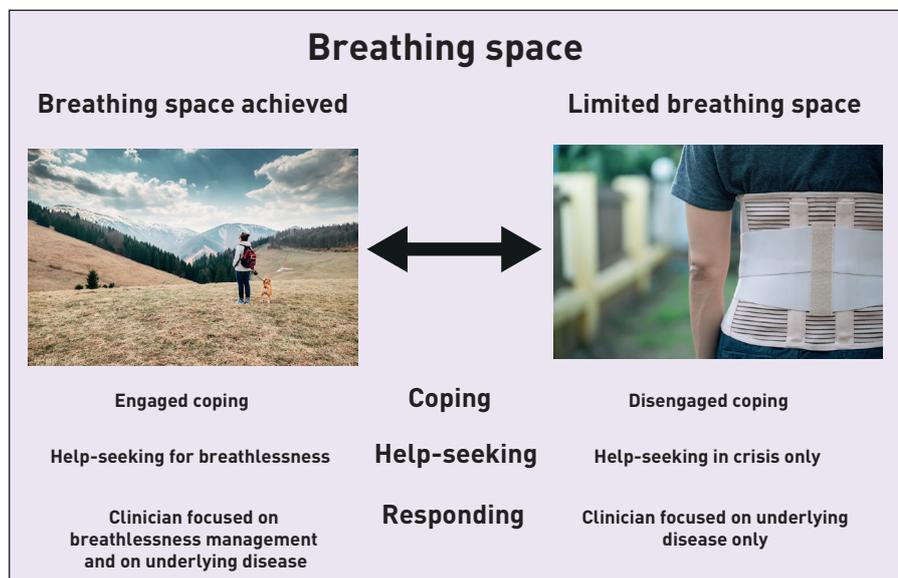


Millions of people around the world live with breathlessness due to underlying cardiorespiratory conditions. Living with breathlessness can be very difficult both for patients and for those who care for them, as it raises physical, psychological, social, and existential issues for all concerned. It causes difficulties moving around and doing everyday things, leads to the sufferer becoming dependent on others, engenders feelings of depression or anxiety, leads to changes in relationships and roles, and creates fears about the future and dying. Clinicians can help people manage their breathlessness better. From our systematic review of qualitative literature on the experience of living with breathlessness, we developed the concept of Breathing Space.<sup>1</sup> This incorporates an old English phrase used since the 1600s meaning 'a period of rest that allows you to get your energy back or try a different solution'<sup>2</sup> and 'sufficient space in which to move and work'.<sup>3</sup> It also includes a specific definition of quality of life: 'The degree to which a person enjoys the important possibilities of his or her life.'<sup>4</sup>

We use Breathing Space as a concept to describe the experience of living with breathlessness: 1) rest from the constraints imposed by breathlessness; 2) space and time to recoup strength and then plan further action; and 3) the circumstances under which one can find one's priorities and then fulfil them.

Figure 1. The Breathing Space concept.



*"... clinicians can support patients to adopt more engaged coping approaches, more self-management techniques, and help 'move' them from 'life stops' to 'life changes'."*

#### ACHIEVING BREATHING SPACE

The Breathing Space concept helps us to understand how clinicians can work with patients and their family members and friends, providing care to improve their lives while living with breathlessness. Figure 1 shows how the way a patient copes with and seeks help for their breathlessness, and whether and how their clinician responds to the symptoms of breathlessness (as distinct from the causal medical condition), is important in how much Breathing Space can be achieved for the patient and those caring for them. Restricted Breathing Space is characterised by avoidance, resignation, and stagnation. It is summarised by the phrase 'Life stops':

*'It just stops your life, stops you from living.'* (Patient)<sup>5</sup>

*'You fall into a huge hole, then the world gets so tiny, it all gets so narrow that it is almost unbearable.'* (Carer)<sup>6</sup>

*'I feel like Sleeping Beauty. The hawthorn hedge has closed around me and I cannot do anything about it.'* (Carer)<sup>6</sup>

A greater degree of Breathing Space is characterised by acceptance, adaptation, and participation, and can be summarised by the phrase 'Life changes':

*'I've sort of changed my life. You can't do the things you used to do, so you've got to say "well, okay, what can I do?" and do it.'* (Patient)<sup>7</sup>

Despite the widespread effects of breathlessness on people's lives, it is possible to achieve a reasonable degree of Breathing Space by using engaged coping strategies (such as, pacing, prioritising, accepting the situation, being active, and keeping in touch with others) and by seeking help from clinicians who can guide people on how to manage their breathlessness:

*'Walking was so difficult and we were supposed to bring our swimming gear and bottles [referring to oxygen tanks], so I got a wheelchair and the children pushed me and then parked me somewhere ... I sat there and drank coffee and read ... and occasionally they came over to touch base ... it was great ... but they could hardly reach the handles to steer and people didn't get out of the way ... so I had to call out beep beep [laughter] ... it probably looked pretty funny ... but we had an outing anyhow, and that was the main thing.'* (Patient)<sup>8</sup>

#### PROVIDING SUPPORT AS A CLINICIAN

Clinicians could support people living with breathlessness to achieve Breathing Space by assessing how breathlessness is affecting their lives, how they are coping with it, and how they are seeking help for it by using Breathing Space as a framework for a review. Breathlessness management strategies should then be

tailored to match their patients' needs using the Breathing, Thinking, Functioning model<sup>9</sup> and the holistic approach to breathlessness developed by the London Respiratory Network.<sup>10</sup> By focusing on the symptom as a therapeutic target in its own right, clinicians can support patients to adopt more engaged coping approaches, more self-management techniques, and help 'move' them from 'life stops' to 'life changes':

*'She has got me organised and now I understand how the disease works. As a result I have had a good summer. It makes me feel more resilient.'* (Patient)<sup>11</sup>

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#### REFERENCES

1. Hutchinson A, Barclay-Klinge N, Galvin K, Johnson MJ. Living with breathlessness: a systematic literature review and qualitative synthesis. *Eur Respir J* 2018; **51(2)**: pii: 1701477.
2. Rundell M. *Macmillan English dictionary*. London: Macmillan Education, 2007. <https://www.macmillandictionary.com/> [accessed 26 Nov 2019].
3. House R. *The Random House dictionary of the English language*. New York, NY: Random House, 1987.
4. Raphael D, Brown I, Renwick R, et al. Measuring the quality of life of older persons: a model with implications for community and public health nursing. *Int J Nurs Stud* 1997; **34(3)**: 231–239.
5. Caress A, Luker K, Chalmers KI. Promoting the health of people with chronic obstructive pulmonary disease: patients' and carers' views. *J Clin Nurs* 2010; **19(3–4)**: 564–573.
6. Bove DG, Zakrisson AB, Midtgaard J, et al. Undefined and unpredictable responsibility: a focus group study of the experiences of informal caregiver spouses of patients with severe COPD. *J Clin Nurs* 2016; **25(3–4)**: 483–493.
7. Nicholls DA. The experience of chronic breathlessness. *Physiother Theory Pract* 2003; **19(3)**: 123–136.
8. Ek K, Ternstedt BM. Living with chronic obstructive pulmonary disease at the end of life: a phenomenological study. *J Adv Nurs* 2008; **62(4)**: 470–478.
9. Spathis A, Booth S, Moffat C, et al. The Breathing, Thinking, Functioning clinical model: a proposal to facilitate evidence-based breathlessness management in chronic respiratory disease. *NPJ Prim Care Respir Med* 2017; **27(1)**: 27.
10. Hopkinson NS, Baxter N, London Respiratory Network. Breathing SPACE — a practical approach to the breathless patient. *NPJ Prim Care Respir Med* 2017; **27(1)**: 5.
11. Robinson T. Living with severe hypoxic COPD: the patients' experience. *Nurs Times* 2005; **101(7)**: 38–42.

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