

David Christopher Currow, Małgorzata Krajnik

¹University of Technology Sydney, Australia

²Department of Palliative Care, Nicolaus Copernicus University in Toruń, Collegium Medicum in Bydgoszcz, Poland

Relieving chronic breathlessness is a human right

Abstract

Chronic breathlessness, defined as breathlessness that persists despite optimising the treatment of underlying causes, is recognised by recent international consensus as a distinct clinical syndrome. Across our communities, population-based studies of chronic breathlessness expose an enormous burden from this. Among the palliative care population, one in four people die with severe breathlessness despite treatment from a palliative care service. Recently, the relief of breathlessness was claimed to be a human right, particularly when there are treatments available to alleviate the unnecessary suffering caused by chronic breathlessness. The timely recognition of, and response to chronic breathlessness is a crucial clinical skill.

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Introduction

For many people, breathlessness is an ever present, lived, daily experience. One patient described it as: "... an effort just to be".

Chronic breathlessness — breathlessness that persists despite optimising the treatment of underlying causes — is a distinct clinical syndrome defined by recent international consensus process [1]. As we recognise chronic breathlessness across our community, we need to consider how this syndrome affects people's lives on a day-to-day basis. These are people for whom breathlessness impacts on the ability to bathe, toilet, dress and prepare food, for months or years of life [1]. Such chronicity has a toll on the physical and mental health components of quality of life, when adjusted for age and sex across the community [2]. As clinicians, we often assume that when we see people acutely short of breath, their breathlessness settles between episodes of care. In fact, for many of these

people, we see acute-on-chronic breathlessness with significant ongoing breathlessness experienced [3].

Extensive data have demonstrated over a long period of time that with increasing severity of chronic obstructive pulmonary disease (COPD), functional status declines markedly. This sees people with GOLD grade IV exerting themselves at approximately one third the distance that healthy, age-matched volunteers do [4]. Even people with GOLD grade I COPD, their daily exertion is still approximately 80% of age-matched people with no respiratory disease [4]. This decrement represents the mobility forgone in order to avoid breathlessness.

There are very few population-based studies of breathlessness. A study by Frostad *et al.* published in 2006 followed almost 20,000 people in Oslo for thirty years [5]. The higher the symptom score for breathlessness, the more likely that death was going to ensue from COPD. This reached a hazard ratio of 9.6 (95% CI 5.1, 18.3) for death from COPD, when

Adres do korespondencji: David Christopher Currow
University of Technology Sydney, Australia
e-mail: david.currow@uts.edu.au



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associated with higher breathlessness scores. Another Norwegian study that followed people for 12 years across the age range indicated, that persistent respiratory symptoms were evident in 6.9% of women and 4.3% of men [6]. Australian population-based data indicates that from the modified Medical Research Council (mMRC) scale, 8.9% of people have a score of ≥ 2 , 1% had a score of ≥ 3 and one in three hundred had a score of 4 [7]. This reflects an enormous burden of chronic breathlessness across the community. Of note, that latter group is almost invisible to health services, because they are house bound and present only with the most severe exacerbations.

When we consider the palliative care population, we see that one in four people die with severe breathlessness despite treatment from a palliative care service [8]. Those most likely to have breathlessness at the end of life are those with respiratory diseases such as COPD [9]. Again, a scale analogous to the mMRC breathlessness scores in people with COPD is a far better prognostic factor than looking at forced expiratory volume in one second (FEV₁) [10]. Data from 50 years ago at a population level indicated that breathlessness was a predictor of short-term mortality with a mortality ratio of 2.08 at 24 months in a population survey of more than 1 million people across the United States of America [11].

Claiming a “right”

It is an extremely serious issue to claim something as a right. For example, it is estimated that last year 1.5 million people in the world died because they did not have access to clean water. As such, a fundamental to human existence, clean water should arguably be seen as a “right”. Health has been proposed as a “right”, again fundamental to our being [12]. If we are to live with dignity, then we must be able to attain the best level of health [12]. As outlined in the 1946 constitution of the World Health Organisation, health is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” [13]. It goes on to say, that there should be “the enjoyment of the highest attainable standard of “physical and mental” health as a fundamental right of every human being”. Of note, this is not a right to be healthy, but to attain the highest standard of health possible [12]. In the 1966 International Covenant on Economic, Social and Cultural Rights it asserts the right for everyone to enjoy the highest attainable level of health together with access to essential medication and health-related education [14]. Later, the Declaration of Alma-Ata talks of promotion of health, prevention of health, cure and rehabilitation, but, in-

terestingly, does not mention palliation [15]. Arguably, this is a significant oversight given the importance of the 1978 declaration. Moving to contemporary times, the 67th World Health Assembly noted that “... access to palliative care ... contributes to the realisation of the right to the enjoyment of the highest attainable standard of health and well-being ... as an ethical responsibility of health systems” [16]. It further notes, that health care professionals have a duty to alleviate pain *and* [other] *suffering*.

To that end, it can be argued that the relief of breathlessness (whose prevalence is akin to levels of pain and fatigue for many people with chronic complex illnesses and certainly with chronic progressive illnesses) is a right particularly when there are evidence-based treatments available to alleviate the unnecessary suffering caused by this syndrome. One can argue that 30 years ago many clinicians shrugged their shoulders when patients with cancer had pain, claiming that it was expected that they would have pain because they have cancer. We would no longer accept that argument anywhere in the world. Why should we accept the same argument when someone with COPD is so limited in what they can do?

There is now an excellent evidence base in the literature relating to breathlessness. The Canadian Thoracic Society breathlessness ladder gives clear guidance to:

- addressing all reversible causes of breathlessness;
- utilising non-pharmacological interventions; and
- ensuring that the pharmacological options use the best available evidence base which currently is regular, low-dose, extended-release morphine [17].

There is an evidence base available for the safe use of regular low-dose extended-release morphine to reduce chronic breathlessness that is as strong as any other evidence base that we have in the therapeutic interventions in palliative care [18, 19].

There are academic, policy and clinical responsibilities that need to be put in place if we are to accept that the relief of chronic breathlessness is a human right.

- Academically, we need to develop more predictable and acceptable therapies with clear delineation of patient groups who would benefit, and those who may more predictably experience harms.
- The policy responsibilities are to ensure access to medications particularly given that morphine is otherwise significantly restricted across our communities.
- Clinically, there is a responsibility to actively seek out and identify people experiencing this clinical syndrome and use the best available evidence to reduce its impact on patients and their caregivers. Of note, we often ask: „Are you breathless?“, when

we should be asking: “What have you given up in order to avoid being breathless?”.

Ultimately, as with other symptoms, there is a need to develop our evidence base and apply it to maximise benefits and minimise harms. Our responsibilities as clinicians and policy makers are to relieve suffering with the tools that are available. The evidence base available here demands that we respond in order to reduce the burden from chronic breathlessness across our community.

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