The need to research refractory breathlessness

To the Editor:

The joint American Thoracic Society (ATS)/European Respiratory Society (ERS) statement "An official American Thoracic Society/European Respiratory Society statement: research questions in COPD" by Celli *et al.* [1] is a timely summary of the current evidence and the questions that arise directly from where that evidence reaches its limits. Such documents are crucial in framing research strategies for researchers and research funders.

Daily breathlessness at rest or on minimal exertion is experienced by many of the 330 million people living with chronic obstructive pulmonary disease (COPD) globally. It is a debilitating and burdensome symptom, experienced for long periods of time, not just in the last weeks or months of life. It occurs despite inhaled treatments prescribed to reduce breathlessness: their failure to fully relieve breathlessness may add to patients' despair and, at the very time when more support is needed, doctors often turn away. The majority of people with COPD will have a prolonged period of life with such severe breathlessness. The ATS/ERS statement signals the need for research into: 1) methods of alleviating breathlessness by modifying the underlying disease course; 2) pulmonary rehabilitation; and 3) symptom control and advance planning during the terminal stages of the disease. While these are important goals and the document flags symptom control as important (and laudably notes that pulmonary function tests and imaging are surrogates for assessing breathlessness), the statement ignores the pressing need for research that ensures relief of breathlessness for the prolonged duration when COPD is already maximally treated; this seems a significant omission.

This burden of breathlessness in COPD starts well before the "end of life" for most people [2–4]. Palliating chronic refractory breathlessness must be an ongoing focus for research if we are to make a difference to the lives of these tens of millions of people now and into the future [5, 6]. Even if a treatment were to be found today that could cure or prevent COPD, there is a generation of people who experience breathlessness as a daily challenge that deserve the combined intellectual expertise of the global research community.

The inclusion of ways to treat chronic refractory breathlessness more effectively in optimally treated COPD is a worthy research goal, building on the emerging evidence of the mechanisms and management of breathlessness. Managing breathlessness has the potential to improve markedly people's function for day-to-day activities, such as self-care, and ensure that they are more comfortable, even when the underlying cause(s) of their breathlessness cannot be reversed or stabilised. Level 1 efficacy evidence (meta-analyses), which needs to be confirmed by adequately powered trials, already identifies an important role for nonpharmacological interventions, oxygen, and regular, low-dose morphine in reducing breathlessness in this population [7–12]. A research programme also needs to include subsequent effectiveness studies. The recognition that breathlessness is truly multidimensional, and that modification of its affective component can bring significant clinical benefits even in the absence of measurable pathophysiological changes, also opens new avenues for research [13].

There is an urgently needed research agenda that aims to improve the quality of life for people with chronic refractory breathlessness caused by progressive COPD. Routine assessment of breathlessness and its impact on the person's quality of life [13], followed by evidence-based management of refractory breathlessness, can be seen as a fundamental human right, and is an urgent priority for researchers and funders alike [14, 15].

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High-quality research is needed to improve quality of life for people with chronic refractory breathlessness in COPD http://ow.ly/Q2GDY

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