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Hiding in plain sight – the evolving definition of* chronic breathlessness *and new ICD-11 wording.

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Reflecting the evolving understanding of breathlessness and its impacts, the International Classification of Disease (ICD) version 11 has recently listed b*reathlessness* (the patients' descriptor of their subjective symptom) as a synonym for *dyspnoea* for the first time [1]. ICD-11 also now incorporates wording for three durations of breathlessness: *acute* (hours to three weeks); *subacute* (three to eight weeks); and *chronic* (more than eight weeks).

Separate wording for *chronic breathlessness* is a critical step to ensure adequate recognition and identification of this condition's multi-dimensional impacts on the wellbeing of patients and their health service utilisation. Indeed, being able to identify people with long term breathlessness may help to lessen some of the, as yet unexplained variance in measures such as inpatient length of stay, and improve clinicians' recognition and management of people who experience this debilitating symptom [2,3].

Breathlessness for most healthy people only occurs on exertion. This is not usually a matter of serious concern. Sadly, for many people around the world, breathlessness occurs on minimal exertion or even at rest causing disability (defined by the American Disability Association (ADA) as a person who has a physical or mental impairment that substantially limits one or more major life activity) [4]. Such breathlessness is prevalent [5], increases with age and may be present for years or decades [6] affecting patients, and their family and friends [7].

In high income countries, the most frequent causes of *chronic breathlessness* are chronic obstructive pulmonary disease (COPD), chronic heart failure or obesity [6,8,9]. Chronic breathlessness affects every part of someone's personhood when untreated, reflected in associations with:

- poorer self-rated health, greater disability and increasing need for help with self-care;
- worse physical and mental quality of life; [10]
- more limited physical function and reduced sexual activity; [11,12]
- diminishing social interactions, increasing numbers of activities foregone, and increased rates of anxiety and depression; [11,13]
- lower workforce participation (in working aged people); [14]
- greater unplanned use of primary and emergency healthcare; [15,16] and
- poorer prognosis [17,18] (noting greater prognostic utility from the severity of long-term breathlessness than pulmonary function tests) [19].

Why has there not been specific recognition of this pervasive condition until now? Long-term breathlessness is largely invisible to health professionals for reasons related to both patients and practitioners [20-22]. Many health practitioners assume or hope that people have marked decreases in their breathlessness in response to disease-directed treatment. However, many people have breathlessness for the rest of their lives and stop telling their health professionals about their breathlessness. Both patients and many clinicians dismiss the symptom as 'expected' for which "nothing further can be done". The widespread and serious impact of long-term breathlessness on the person's life is therefore left unexplored, evidence-based interventions are not offered and there have been relatively few studies of long term breathlessness when compared with acute breathlessness. This situation is aggravated by the lack of unambiguous naming available to designate patients' experiences.

The ICD-11 wording using time-bound qualifiers to delineate “acute”, “subacute” and “chronic” breathlessness is a good step forward. It is helpful to recognise that breathlessness of different durations is likely to differ in cause and nature. Use of this new wording will make this invisible symptom more visible. However, neat categorisation is difficult given the many contexts in which chronic breathlessness is encountered. For example, a person experiencing an exacerbation of chronic obstructive pulmonary disease, will have “acute-on-chronic” episodes of breathlessness, and as the underlying disease advances, acute overwhelming crises may occur with little or no precipitant, described as a ‘dyspnoea crisis’ by the American Thoracic Society [23]. All too often, the acute symptom may be eased, but the daily grind of living with ongoing breathlessness is left unaddressed [24]. The risk is that a person presenting with acute breathlessness may have this acknowledged but underlying long term breathlessness ignored.

The term *chronic breathlessness* was proposed in 2017 for situations where patients experience disabling breathlessness despite the underlying cause(s) having been optimally treated [25]. The term replaces wording such as *refractory breathlessness* with its intrinsic nihilistic implication given that evidence-based symptomatic therapies reduce symptomatic burdens [24]. We need a paradigmatic change in therapeutic approaches, with the symptom itself becoming a specific and substantial target of care [2]. In other words, this means adding "the brain" to "the lung" or “the heart” in the scope of clinical therapeutic targets.

"Chronic" implicitly suggests "long-term", but in most clinical situations, such as during exacerbations of chronic diseases or while awaiting a definitive diagnosis, patients should not be deprived of symptomatic treatments just because they have not suffered ‘long enough’. The term "persistent breathlessness" and removing the clause regarding optimal disease-treatment might render this name more universal, allowing clinicians and researchers to address both short- and long-term disabling aspects of the condition [26]. The 2017 consensus did not include a required duration. The new ICD wording for chronic breathlessness, with a requirement of at least eight weeks, does not recognise this nuance. However, it <u>does</u> provide a flag, acting as a prompt for clinicians to assess the impact on the person and intentionally manage the breathlessness as a therapeutic target. This is of the utmost importance given the impact of long-term breathlessness.

Advocacy for the new ICD-11 wording has come from many clinicians, researchers and organisations throughout the world. It is noteworthy that their efforts have been backed and endorsed by the European Respiratory Society, which should be gratefully credited for this.

A logical next step will be to introduce “persistent” as a modifier to acute, subacute, or chronic breathlessness/dyspnoea, to clearly distinguish the recognition of cases where the duty of health professionals is to initiate disease-directed therapies from patients where this duty also includes introducing symptomatic treatments in parallel with seeking to optimise management of the underlying causes. This is work for the coming years. Meanwhile, appropriate concepts are now available to improve the recognition, management and description of breathlessness: how disease-directed and symptomatic treatments are combined and articulated will be the required clinical change in responding to these advances.

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