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Invisible suffering: breathlessness in and beyond the clinic - a reply

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We were delighted to read the Spotlight on invisible suffering. Chronic refractory breathlessness [1] affects millions of people worldwide, but is yet to receive the same attention, both clinical and research, as the causative conditions. The Spotlight resonates strongly with a growing body of work in this field arising from interdisciplinary research collaborations between respiratory physicians, physiologists, palliative care specialists, nurses, psychologists, neuro-radiologists, geneticists, clinical pharmacologists, physiotherapists and sociologists.

The impact of refractory breathlessness on everyday living is far-reaching, as the Spotlight authors suggest. Indeed research found that this distress and limitations are often hidden from family, friends and health care professionals. [2] Meticulous observation of clinical and laboratory findings has led to a useful model of breathlessness of perception (intensity and unpleasantness), emotional response and functional consequences, leading to an emerging delineation of pathophysiological pathways, both peripherally and centrally.[3] Such understanding is assisting the development of drug (opioids) [1] and non-drug interventions,[4] and markedly improved models of delivering care and support to people with refractory breathlessness.[5] We are conducting primary and secondary research to gain further insight into patient experience, to investigate the prevalence and role of breathlessness in the emergency room and other healthcare settings, to identify mechanisms of breathlessness perception evaluate interventions.

We welcome ‘The life of breath’ programme of Jane McNaughton and colleagues, which was presented at our recent multi-professional breathlessness research meeting. We agree that there is much still to do. It is timely that a Spotlight is turned on chronic refractory breathlessness itself as a target for intervention as well as the biomedical cause.

Reference List

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