

Introduction

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As the patterns of well-being and illness change across the community, so the way people experience impaired health continues to change. These changes lead to the need for focus on a range of issues, including symptoms that have not enjoyed sufficient attention. CRD, with its cardinal and debilitating symptom of chronic breathlessness, is one such area. Many millions of people around the world suffer from CRD. They experience a prolonged symptom burden, often for decades, which affects every area of their lives and the lives of their family and friends, and which affects their ability to contribute to their communities. This comes at a huge personal and societal cost.

As many respiratory diseases are preventable, public health measures are, quite rightly, a key priority for implementation and research. In addition, much appropriate effort and resources support the quest to find interventions that will cure, or at least ameliorate, the causative pathologies. However, the complex supportive and palliative care needs experienced by people with CRD, often from early on in their disease course, have been poorly recognised and not addressed systematically within clinical practice or research priorities. Despite the progressive and life-limiting nature of many CRDs, access to holistic assessment and management by the usual care team, access to palliative care services, advance care planning with its challenging conversations, optimisation of functional independence as the disease progresses, excellent symptom control during the course of the disease and when dying, and support for families during and after death, are areas of stark inequalities in care compared to people with cancer.

There are several reasons, although not excuses, for this discrepancy. First, palliative care services in many high-income countries have grown up in association with cancer. Thus, the original model of palliative care was one of exhaustion of disease-directed treatments followed by a handing over to palliative care for the very end-stage of life and care of the dying. This model of care is clearly not fit-for-purpose for people with respiratory diseases given the trajectory of many: disease-directed treatments do not have such a clear “use by” date. With the advent of multiple lines of cancer treatment, this traditional model has also become outmoded in oncology palliative care. A more integrated model seems to be more appropriate, with extended team working and involvement of palliative care earlier on in the disease trajectory in response to problems rather than prognosis. However, the non-cancer world has not caught up with this change (and indeed, there are many

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oncology services which have not either); thus, palliative care is thought of as something only for people who are dying very soon, and probably of cancer. Secondly, the situation is compounded by difficulties in definitions, with terms such as “terminal care”, “EOL care”, “palliative” and “hospice” meaning different things to different people in different healthcare settings around the world.

In this *ERS Monograph*, the World Health Organization definition of palliative care is used, with its focus on optimising quality of life for people with progressive life-limiting illness through impeccable assessment of symptoms and other concerns throughout their illness, care of the dying and family support. This approach works in response to people’s needs rather than being limited either by diagnosis or prognosis, and can be initiated at the time it is recognised that the person has a life-limiting illness. In the first section, the issue of palliative care for people with respiratory diseases will be discussed in the context of the epidemiology of the diseases themselves, the palliative care needs resulting from the diseases and how palliative care services can be modelled and delivered.

The second section focuses on the key symptom of breathlessness. Most clinicians only see people who have acute breathlessness, or see chronic breathlessness as an inevitable consequence of the underlying disease process, which, itself, is not worthy of clinical attention. Most people with chronic breathlessness only seek help for the symptom when it worsens acutely. The brief encounters that clinicians have with people who experience chronic breathlessness belies the overwhelming impact that such breathlessness has on millions of people every moment of the day around the world. Although their breathlessness may improve marginally after acute exacerbations, the lived reality for these people is that of severe breathlessness at rest or on minimal exertion, often for years at life’s end.

The predominant cause of such breathlessness remains respiratory disease, with the contribution of tobacco, workplace exposures and domestic smoke from fires in ill-ventilated dwellings being key contributors to this burden of suffering.

As this symptom burden continues to evolve and grow, so has the evidence base for defining and treating this pervasive and debilitating symptom. As is so often the case, the real challenge is not the development of new knowledge that can help to relieve the suffering caused by chronic breathlessness, but ensuring the widespread uptake of that new knowledge into clinical practice and policy. The pervasive nihilism that people with CRDs should silently tolerate chronic breathlessness should be defeated as a matter of urgency. People with chronic breathlessness should be demanding better symptom control and clinicians should be actively offering ways to minimise the impact of this life-changing, long-term disability.

Finally, in the third section, the issue of caring for people with advanced disease and those who are dying is tackled head on. The response to the less clear trajectory of respiratory diseases has been to avoid the issue and, especially, to avoid conversations that discuss progression of disease or plans for future care. This is often for fear of upsetting the patient, exacerbated by lack of training in advanced communication and symptom management skills, and clinical service configurations that mitigate against exploring patients’ concerns, hopes or expectations. Sadly, the experience of patients and families is then one of poor knowledge and understanding of their disease, treatments and goals of care, poor involvement in their plans of care, and poor symptom control. When they come to die, they die by default in an acute care facility, still receiving invasive medical treatments, with poor access to the people they love at the time they need them most.

People with CRD deserve a better deal. This *ERS Monograph* brings together the state-of-the-art in palliative care in this field, with the aim of helping clinicians and researchers provide that better deal and redress the balance after many years of serious neglect.

Disclosures: D.C. Currow is an unpaid advisory board member for Helsinn Pharmaceuticals. He is also a paid consultant and received payment for intellectual property with Mayne Pharma, and is a consultant with Specialised Therapeutics Australia Pty Ltd. M.J. Johnson has worked as a clinical consultant to Mayne Pharma and received institutional payment.