FINAL MFME 230620 - 1030/1000-1500 words

Editorial COSPC respiratory

Morag Farquhar¹ & Magnus Ekström²

- 1. University of East Anglia, School of Health Sciences, Norwich Research Park, Norwich, NR4 7TJ
- 2. Lund University, Faculty of Medicine, Department of Clinical Sciences Lund, Respiratory Medicine and Allergology, Lund, Sweden

Respiratory diseases are leading causes of death and disability; four million people die prematurely from chronic respiratory disease globally each year. Chronic Obstructive Pulmonary Disease (COPD) is the third leading cause of death worldwide: there are about 65 million people living with COPD and 3 million deaths annually. About 334 million people suffer from asthma, annual deaths from pneumonia are in their millions, over 10 million people develop tuberculosis with over a million people dying from it each year, and lung cancer kills 1.6 million people annually [1]. These conditions place huge burdens on patients, on those relatives and friends who support them (informal carers), and on health and social care providers, services and systems. The symptoms of respiratory diseases are frightening, disabling and isolating for patients and carers and their management, through pharmacological and non-pharmacological approaches, remains a challenge for all concerned. The requirement for supportive and palliative care to identify and address the unmet physical, psychosocial and spiritual needs of patients with a range of respiratory conditions, and those who informally support them, is increasingly recognised.

In this edition we present reviews of the current evidence around the mechanisms and management of respiratory symptoms with a particular focus on more complex factors and vulnerable populations that are more likely to suffer from these conditions but less likely to receive the evidence-based care that they could benefit from.

Physiologic mechanisms of breathlessness are reviewed by Neder et al, exploring the interplay between the heart, lungs and muscles and worsening activity-related breathlessness in advanced cardio-respiratory disease [2]. Multiple factors including ventilatory insufficiency, hypoxemia and neural feedback and metabolic disturbances interact to increase the patient's ventilatory drive and breathlessness. Complementing this, von Leupoldt et al review *psychologic* mechanisms of breathlessness, focusing on recent advances in our understanding of the impact of negative affective traits and mental states [3]. Personality as well as depression, fear and anxiety substantially worsen the patient's breathing discomfort but there is sound evidence that positive affect can alleviate breathlessness and several management strategies are discussed. Given this, understanding and addressing both the physiologic and the psychologic mechanisms of breathlessness is key to managing this challenging symptom.

Moving further into treatment and management, Hui et al [4] and Currow et al [5] provide reviews of the pros and cons around one of the controversies in opioid treatment for breathlessness: what is the role of using short-acting vs. long-acting opioids for chronic breathlessness? The reviews provide a

current state-of-the-art overview, discussing the advantages and disadvantages of each approach, highlighting important future research directions.

Respiratory disease is more prevalent in some sub-populations than others due to increased exposure to risk factors, only some of which are self-determined. Peryer et al [6] report on developments in supportive and palliative care of people with respiratory problems and pre-existing serious mental illness, and in doing so highlight the surprising dearth of relevant research within a population with high smoking rates and potential issues around polypharmacy. They identify key priorities to improve the delivery of respiratory health care pathways supporting prevention, harm reduction, and responsive care that are more inclusive of people living with severe mental illness. Similarly, Gardener et al [7] consider recent work in relation to structurally vulnerable populations, focusing on those experiencing homelessness or aspects of the criminal justice system. Again, the notable lack of research dedicated to supportive and palliative care for this group was remarkable, with the majority of papers focused on disease prevalence. They highlight the need for evidence-based interventions to reduce the risk of communicable respiratory conditions and a greater understanding of disease trajectories and management for these vulnerable populations, including provision of accessible appropriate supportive, palliative and end of life care. Identifying and addressing the needs of those who support them, both formally and informally, is also noted. Brighton et al [8] report the growing literature relating to the care of people with respiratory problems and frailty, which affects at least one in five people with chronic respiratory disease. They present recent evidence suggesting the potential benefits of rehabilitation, early palliative care and advance care planning for people living with respiratory disease and frailty. Their review identifies models of cross-speciality and crossprofessional integration which may have the greatest potential to meet the multidimensional needs of this growing, but underserved, group.

The impact of respiratory disease on informal carers — those family members and friends who, given their role, are probably the common background denominator of all of the contributions to this edition — is considerable and slowly gaining recognition. We need to think of carers as both clients of care and co-workers in care [9]. Patel et al [10] consider both of these roles in their exploration of new evidence on the engagement of informal carers, as well as peer support, in pulmonary rehabilitation. The evidence base for pulmonary rehabilitation is well-established but referral, uptake and completion rates remain poor; the authors outline the potential contributions carers and peer support could make to improving uptake and completion, whilst noting that carers themselves could benefit from participation. Improving our support and involvement of informal carers has potential gains not only for carers themselves, but also for patients, health and social care providers, services and systems.

We write this editorial in the midst of the Covid-19 pandemic which is changing the landscape of formal and informal care to varying degrees internationally. Rapid changes have occurred in the type of formal and informal care required, in the volume of that care, and in the way that care is provided; some of these changes may continue going forward. Inevitably, therefore, when reading this edition, many readers will do so through that new lens. Patients and families living with any of the "big five" respiratory conditions of COPD, asthma, acute lower respiratory tract infection, tuberculosis or lung cancer [1] are more vulnerable than ever, but this new lens provides a remarkable opportunity to review and revise our practice; we have seen during this period how change, and rapid change, is possible. The breadth of this edition reports on recent strides to better understand and treat

breathlessness, and the need to do so inclusively, and can be a stepping-stone for the advances to come.

Acknowledgements

MF was part funded by the National Institute of Health Research (NIHR) Applied Research Collaboration East of England (ARC EoE) programme. The views expressed are those of the authors, and not necessarily those of the NIHR, NHS or Department of Health and Social Care.

References

- 1) Forum of International Respiratory Societies. The Global Impact of Respiratory Disease Second Edition. Sheffield, European Respiratory Society, 2017.
- 2) Neder JA & O'Donnell DE. Heart, Lungs and Muscle Interplay in Worsening Activity-Related Breathlessness in Advanced Cardiopulmonary Disease. Current Opinion in Supportive & Palliative Care [*COSPC to insert citation]
- 3) Von Leupold A & Denutte Y. Affective Traits, States and Breathlessness. Current Opinion in Supportive & Palliative Care [*COSPC to insert citation]
- 4) Hui D & Bruera E. se of Short-Acting Opioids in the Management of Dyspnea: An Evidence-Based Review. Current Opinion in Supportive & Palliative Care [*COSPC to insert citation]
- 5) Currow DC, Kochovska S, Ferreira D, Johnson M. Morphine for the symptomatic reduction of chronic breathlessness: the case for controlled release. Current Opinion in Supportive & Palliative Care [*COSPC to insert citation]
- 6) Peryer G, Barnes S, & Farquhar M. Supportive and palliative care for people with respiratory problems and pre-existing serious mental illness. Current Opinion in Supportive & Palliative Care [*COSPC to insert citation]
- 7) Gardener AC, Kuhn I, Micklewright K, Farquhar M. Supportive and palliative care of adults with respiratory problems experiencing structural vulnerability from homelessness, prison or other criminal justice system involvement. Current Opinion in Supportive & Palliative Care [*COSPC to insert citation]
- 8) Brighton LJ, Bone AE, & Maddocks M- Supportive and palliative care for people with chronic respiratory disease and frailty. Current Opinion in Supportive & Palliative Care [*COSPC to insert citation]
- 9) Stajduhar KI, Nickel DD, Martin WL, & Funk L. Situated/being situated: Client and co-worker roles of family caregivers in hospice palliative care. Social Science and Medicine 2008; 67: 11, 1789-1797.
- 10) Patel S, Man WDC, & Roberts NJ. Informal carers and peer support in pulmonary rehabilitation: an underutilised resource? Current Opinion in Supportive & Palliative Care [*COSPC to insert citation]