



ERS | *monograph*

Palliative Care in Respiratory Disease

Edited by Claudia Bausewein,
David C. Currow and
Miriam J. Johnson

Contents

Palliative Care in Respiratory Disease

Number 73
September 2016

Preface	v
Guest Editors	vii
Introduction	x
List of abbreviations	xiii
Palliative care and respiratory disease	
1. Definitions and policy <i>Joshua B. Kayser, Kim Mooney-Doyle and Paul N. Lanken</i>	1
2. The need for palliative care <i>Sabrina Bajwah, Eve Namisango, Daisy J.A. Janssen, Deborah Dudgeon, Anna-Marie Stevens and Jayne Wood</i>	21
3. Access to palliative care <i>Tim Peel, Lynn F. Reinke and Claudia Bausewein</i>	35
4. Supporting informal carers <i>Morag Farquhar</i>	51
Symptoms	
5. Symptom patterns in populations <i>Magnus Ekström, David C. Currow and Katrien Moens</i>	70
6. The construct of breathlessness <i>Sara Booth and Robert Lansing</i>	85
7. Patient and carer experience of breathlessness <i>Ann Hutchinson</i>	102
8. Mechanisms of breathlessness <i>Dennis Jensen, Kyle Pattinson and Caroline Jolley</i>	111
9. Measurement of breathlessness <i>Mark B. Parshall and Janelle Yorke</i>	134

10. Management of chronic breathlessness	153
<i>Miriam J. Johnson, Carlo Barbetta, David C. Currow, Matthew Maddocks, Vanessa McDonald, Ravi Mahadeva and Martina Mason</i>	
11. Service planning and delivery for chronic adult breathlessness	172
<i>Siân Williams and Chiara De Poli</i>	
12. Palliative care in respiratory disease in low-resource settings	197
<i>Talant M. Sooronbaev</i>	
Care of the dying	
13. Recognising advanced disease, advance care planning and recognition of dying for people with COPD	204
<i>Karen Margaret Detering, Elizabeth Anne Sutton and Christine Faye McDonald</i>	
14. Symptom management at the end of life	221
<i>Jane L. Phillips and Meera R. Agar</i>	
15. End-stage respiratory diseases and respiratory support	233
<i>Paola Pierucci and Annalisa Carlucci</i>	



Preface

Robert Bals

Palliative care has developed in the last decades. While many of its concepts have been part of respiratory medicine for a long time, the concept of structured palliation for patients with lung diseases is still evolving. The term “palliative care” describes a multidisciplinary approach to offer relief to patients with severe diseases for which causal therapy is limited. Historically, palliative care in its basic form has always been a part of medicine, but many of its aspects have taken a back seat due to the development of technical medicine at the beginning of the 20th century. Modern palliative care has been linked to the hospice movement, an important root of which can be seen in the St Christopher’s Hospice, founded by Cicely Saunders in London in 1967. In the last decades, the field has undergone many developments in its methods and structures.



While the primary focus of palliative care has been on patients with cancer, this view has widened and palliation is seen today to be an integral part of the care of patients with many other diseases. In fact, numerous lung diseases currently cannot be cured and progress to a stage where symptom load drastically reduces the quality of life of the patient. While most respiratory physicians deal with aspects of palliation every day, palliative medicine is rarely integrated in a systematic curriculum for medical students or residents. In addition, palliative care as part of a structured programme is in many cases only available at more specialised centres.

This *ERS Monograph* focuses on palliative care for patients with lung diseases. The first section covers general items, such as definitions, epidemiology and access structures. The second section provides detailed information on individual symptoms and care in special settings, such as in low-resource settings, and the third section focuses on care of the dying.

The Guest Editors, Claudia Bausewein, David C. Currow and Miriam J. Johnson, have worked very successfully to select these

topics and to integrate these aspects into a comprehensive book on the current knowledge. I thank the Guest Editors and all authors for their work on this excellent book. I am sure that this comprehensive review will be useful for the clinical practice of a broad range of respiratory physicians and improve the care of our patients.

Disclosures: R. Bals has received grants from the German Research Ministerium and the Deutsche Forschungsgemeinschaft. He has also received personal fees from GSK, AstraZeneca, Boehringer Ingelheim and CSL Behring.



Guest Editors

Claudia Bausewein

Claudia Bausewein is Professor for Palliative Medicine at Ludwig-Maximilians-University Munich (Munich, Germany) and is Director of the Dept of Palliative Medicine at Munich University Hospital. Her medical background is internal medicine and she has been involved in palliative care in Germany for more than 25 years.

She worked as Consultant in Palliative Medicine at the University of Munich and as a senior clinical research fellow in the Cicely Saunders Institute at King's College London (London, UK), where she obtained her PhD in 2009.

Claudia Bausewein is national co-lead for the German Guideline for Palliative Care and was a member of the European Association for Palliative Care Board of Directors from 2011 to 2015 and vice president of the German Association for Palliative Medicine from 2004 to 2010.

Her research interests focus on breathlessness in advanced malignant and non-malignant disease, outcome measurement in palliative care and complexity in palliative care. Her methodological expertise covers systematic reviews, cross-sectional and longitudinal studies, surveys, clinical trials and evaluation of complex interventions. She heads a multiprofessional and multidisciplinary research team, including medicine, pharmacy, psychology, sociology, health services research and statistics. Her research is funded by the German Ministry of Research, the German Cancer Aid and various charities. She has published widely and is collaborating with various national and international groups.



David C. Currow



David C. Currow is an internationally recognised expert in supportive and palliative care, with a particular emphasis on chronic breathlessness and in improving health service delivery. He has a strong track record in competitive research funding (National Institutes of Health (Bethesda, MD, USA), National Health and Medical Research Council (Canberra, Australia) and Cancer Council (Sydney, Australia)) and publishing research that influences practice and policy. He leads the Palliative Care Clinical Studies Collaborative (Adelaide, Australia), the world's largest palliative care phase III clinical studies collaborative. This has generated several randomised, placebo-controlled trials of off-label use of off-patent medications frequently used in symptom control internationally. He is also a leader in the Palliative Care Outcomes Collaborative (Wollongong, Australia), a national programme for point-of-care data collection and service improvement in palliative care. He was a leader in the creation of the first patient-defined section of the Australian Pharmaceutical Benefits Scheme (the palliative care section).

He is frequently an invited plenary speaker at international conferences. He continues to supervise doctoral candidates from a variety of clinical backgrounds. He is senior associate editor of the *Journal of Palliative Medicine* and is on the editorial boards of *Journal of Oncology Practice*, *Journal of Pain and Symptom Management* and *BMJ Supportive and Palliative Care*. He was the 2015 recipient of the Tom Reeve National Award for Outstanding Contribution to Cancer Care from the Clinical Oncological Society of Australia, a team member winning the 2012 National Team Award for Postgraduate Education from the Australian Learning and Teaching Centre, the 2012 Alumni Medal from the University of Newcastle (Newcastle, Australia) for professional excellence and was a joint winner of the 2015 *Medical Journal of Australia*/Medical Defence Association National Research Award.

Miriam J. Johnson



Miriam J. Johnson is Professor of Palliative Medicine at Hull York Medical School, Director of the Wolfson Palliative Care Research Centre and Co-Director of the Supportive care, Early Diagnosis and Advanced disease research group at the University of Hull (Hull, UK). Her clinical and research interests include mechanisms and management of breathlessness and inequalities in palliative care service provision, e.g. for people with non-malignant disease such as heart failure and respiratory disease. The projects employ a wide range of research methodologies (clinical trials of drug or complex

interventions, qualitative studies, observational, secondary data analysis and data linkage studies) and collaborative partners are involved across different disciplines and countries. She has published widely and holds grants from a variety of bodies (National Institute for Health Research (London, UK), National Health and Medical Research Council (Canberra, Australia), The Dunhill Medical Trust (London, UK), Marie Curie Cancer Care/ Cancer Research UK (London, UK), Yorkshire Cancer Research (Harrogate, UK) and the British Heart Foundation (London, UK)).

She is palliative care specialty joint lead for the Yorkshire and Humber Clinical Research Network (Sheffield, UK). She has also set up one of the UK's first integrated palliative care services for people with heart failure.



Introduction

Claudia Bausewein¹, David C. Currow² and Miriam J. Johnson³

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

¹Dept of Palliative Medicine, LMU Munich, Munich University Hospital, Munich, Germany. ²Palliative and Supportive Services, Flinders University, Adelaide, Australia. ³Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, UK.

Correspondence: Miriam J. Johnson, Wolfson Palliative Care Research Centre, Hull York Medical School, Hertford Building, University of Hull, Hull, HU6 7RX, UK. E-mail: Miriam.johnson@hyms.ac.uk

Copyright ©ERS 2016. Print ISBN: 978-1-84984-071-2. Online ISBN: 978-1-84984-072-9. Print ISSN: 2312-508X. Online ISSN: 2312-5098.

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.

List of abbreviations

BMI	body mass index
CHF	chronic heart failure
CNS	clinical nurse specialist
COPD	chronic obstructive pulmonary disease
CRD	chronic respiratory disease
DALYs	disability-adjusted life-years
ED	emergency department
EOL	end of life
ESRD	end-stage renal disease
FEV₁	forced expiratory volume in 1 s
FVC	forced vital capacity
GP	general practitioner
ICU	intensive care unit
ILD	interstitial lung disease
IPF	idiopathic pulmonary fibrosis
LST	life-sustaining treatment
MDP	Multidimensional Dyspnea Profile
NIV	noninvasive ventilation
NPPV	noninvasive positive pressure ventilation
NRS	numerical rating scale
NSCLC	nonsmall cell lung cancer
PEOLC	palliative and end-of-life care
RCT	randomised controlled trial
SCLC	small cell lung cancer
VAS	visual analogue scale