Integrated Palliative Care of Respiratory Disease

Stephen J. Bourke • Tim Peel
Editors

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Second Edition

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Preface

One of the major successes of modern medicine has been the integration of the ethos, knowledge and skills of palliative care into the standard care of patients with progressive disease. Substantial improvements have been made in the specialty of Respiratory Medicine in recent years such that many patients are now treated by multidisciplinary teams focused on support, symptom control, restorative care, rehabilitation and psychological interventions throughout the course of the illness, in parallel with disease-modifying therapies. Palliative care of respiratory disease is often complex because of the high level of symptoms experienced by these patients and the variable and sometimes unpredictable trajectories of these diseases. Sudden death is a feature of catastrophic illnesses such as severe pneumonia or acute lung injury. The end-of-life phase may be short and is likely to be in the setting of an intensive care unit (ICU), with very little time for the patient and family to adjust to the circumstances. They need to be supported in coping with a trajectory that moves quickly from good health to death and bereavement. More commonly patients are living their lives with chronic progressive lung diseases such as chronic obstructive pulmonary disease, fibrotic lung disease, neuromuscular disease or cystic fibrosis. They often show considerable resilience and fortitude in coping with the disability and distress of life-limiting conditions. These diseases tend to progress, but often over a period of many years, and are characterized by acute exacerbations. Often treatment will reverse the exacerbation and restore health but an acute exacerbation may be the start of the dying phase of the disease, and it is important to recognize when this is happening. Admission to hospital may be the best way of bringing comfort and control to a patient experiencing severe distress because of an acute exacerbation or a complication such as pneumothorax, infection or hemoptysis. Urgent assessment is required before deciding with the patient and family on the best course of action. A transplant trajectory is a particular feature for some lung diseases such as cystic fibrosis or idiopathic pulmonary fibrosis. The patient is seriously ill, has distressing symptoms and may die but is hoping for a rescue lung transplant which can transform the trajectory of the disease. It is clear that a traditional model of palliative care, based on a cancer trajectory which sometimes artificially divides care into a disease-modifying phase and a palliative phase, is usually not appropriate for patients with chronic progressive lung disease. As more treatments and interventions become possible, a key issue is less about ‘what can we do?’, but more about ‘what should we do?’ This is a concept of ‘Realistic Medicine’

which embodies a personalized approach to healthcare that encourages clinicians to find out what matters most to patients so that their care fits their needs and situation. It is important that the general public does not develop erroneous concepts of death in hospital being an undignified struggle with high-technology interventions being applied inappropriately. Advance Care Planning and Treatment Escalation Plans, developed in partnership between patients and clinicians, can restore control to the patient in the face of progressive disease and define their 'priorities for care'. Death is a natural end to life rather than necessarily a failure of medicine, and improving the quality of end-of-life care is a key priority in healthcare planning. Care must be organized in such a way that disease-modifying treatments, supportive care, emergency care, palliative care and end-of-life care all run in parallel. Flexibility is required to meet the needs of patients, and good quality care must be achieved in a variety of settings including the patient's home, care homes, clinics, emergency departments, medical wards and ICUs.

This book brings together the knowledge and skills of specialists in both Respiratory Medicine and Palliative Medicine in an integrated approach to the care of patients with severe lung disease. We have much to learn from each other, and from our patients, who have much to gain from integrated collaborative models of palliative care.

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Contents

Part I Palliative Care Principles

1 Palliative Care of Respiratory Disease 3
Stephen J. Bourke and Paul Paes

Part II Respiratory Symptoms

2 Breathlessness 21
Tim Peel and Graham P. Burns

3 Hemoptysis 37
Bernard Higgins

4 Cough and Respiratory Secretions 49
Rachel Quibell and Stephen J. Bourke

5 Pain in Respiratory Disease 63
Alice Melville and Eleanor Grogan

Part III Respiratory Diseases

6 Lung Cancer 77
Bernard Higgins, Tim Peel, and Paula Mulvenna

7 Malignant Pleural Effusions and Mesothelioma 103
David Cooper and Tim Peel

8 Chronic Obstructive Pulmonary Disease 121
Graham P. Burns and Katherine E. Frew

9 Interstitial Lung Disease 139
Ian Forrest and Anne-Marie Bourke

10 Cystic Fibrosis 159
Stephen J. Bourke and Rachel Quibell

11 Neuromuscular Disease 173
Ben Messer and Alexa Clark

12 Palliative Care in the Critical Care Unit 199
Katherine E. Frew and David Snell

13 Lung Transplantation 211
Maria McKenna and Stephen C. Clark

Part IV End of Life Care

14 End-of-Life Care 225
Paul Paes

Appendix: Respiratory Palliative Formulary 253

Index 259

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