Lung disease and palliative care

Dr Chi Li
Palliative care physician
SMRPCC 2016
Alan

• 78 year old pensioner from home with wife

• Heavy smoker with severe chronic obstructive pulmonary disease
  – FEV1 20% predicted
  – CO₂ retainer, steroid-dependent
  – Exercise tolerance ~10 metres

• Readmitted a few days ago with yet another “chest infection” (6th time in this year) and started on IV antibiotics

• Wants “everything done” as his great-grandchild is due in August.
Bob

- 55 year old electrician from home alone
- Recently diagnosed with idiopathic pulmonary fibrosis after months of rapid clinical deterioration
- Now oxygen-dependent and largely housebound
- No longer able to work, significant financial stressors, socially isolated
- Breathless, anxious, depressed ++
Chloe

- 32 year old teacher from home with partner

- Diagnosed with cystic fibrosis since childhood, relatively stable until this year
  - Dramatic decline in lung function (FEV1 dropped from 65% to 35%) in the context of a respiratory tract infection
  - Persistent dyspnoea & productive cough, lethargy & anorexia, unable to return back to work

- Sister also had cystic fibrosis and died five years ago while on the waiting list for lung transplantation
Overview

• Lung disease and palliative care

• Evolving models of care

• Discussion
Lung disease in Australia

- 14% of mortality
  - Lung cancer
  - COPD & other chronic respiratory diseases
  - Respiratory infections

- 10% of morbidity
  - Asthma: ~2.3 million
  - COPD: >500,000

Source: Institute for Health Metrics, Global Burden of Disease study 2010 (1).

Lung disease and palliative care needs

- Adult patients with severe COPD or lung cancer (any stage) in Germany

- 50 COPD + 32 lung cancer patients followed up monthly for up to 12 months
  - Modified Borg Scale (NRS 0-10)
  - Karnofsky Performance Status Scale
  - Distress Thermometer
  - Palliative Care Outcome Scale

- 8 COPD + 23 lung cancer patients died during follow up
Lung disease and palliative care needs

Lung disease and palliative care needs

Review Article

Experience of Advanced Chronic Obstructive Pulmonary Disease: Metasyntesis of Qualitative Research

Rebecca T. Disher, MSc, PDAN, BSc, BN, RN, Anna Green, BSS, MDS, Tim Luckett, BA, PhD, Phillip J. Newton, BN (Hons), PhD, Sally Inglis, BN, BHS, PhD, David C. Currow, BMed, MPH, FRACP, and Patricia M. Davidson, BA, ME, PhD

University of Technology Sydney (B.T.D., A.G., T.L., P.J.N., S.I.), and Centre for Cardiovascular and Chronic Care (B.T.D., A.G., T.L., P.J.N., S.I.), Faculty of Health, University of Technology Sydney, Ultimo, New South Wales; ImPaCC (Improving Palliative Care through Clinical Trials) (A.G., T.L., P.M.D.), South Western Sydney Clinical School, Liverpool, New South Wales; and Discipline, Palliation, and Supportive Services (D.C.C.), Flinders Centre for Clinical Change, Flinders University, Adelaide, South Australia, Australia; and Department of Acute and Chronic Care (P.M.D.), School of Nursing, Johns Hopkins University, Baltimore, Maryland, USA
Lung disease and specialist PC utilisation

A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on?

Lorna Rosenwax¹, Katrina Spilsbury², Beverley A. McNamara¹ and James B. Semmens²

- Retrospective cohort study of WA deaths in 2009-10 c/w 2000-2
- Increasing SPC access by non-cancer patients. However
  - Any SPC access within last 12 months: cancer (68%) versus COPD (18%)
  - Median number of days with SPC: cancer (30) versus COPD (8)
So...

- Lung disease is common
- Patients (and carers) living with lung disease have palliative care needs
- Patients (and carers) living with lung disease are less likely to access specialist palliative care
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- Lung disease is common

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- Why is this?
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Prognostic uncertainty / paralysis

**Fig 1. The cancer trajectory.** The traditional cancer trajectory used to be based upon an initial phase of disease-modifying treatments followed by palliative care, with transfer of care from oncology to palliative care teams. Now, early palliative care improves outcomes for patients with lung cancer such that palliative care and disease-modifying treatments often run in parallel.30

**Fig 2. The chronic lung disease trajectory.** The chronic lung disease trajectory is characterised by exacerbations and recovery such that disease-modifying treatments and palliative care must run in parallel.

**Fig 3. The lung transplant trajectory.** In the transplant trajectory, the patient is seriously ill and may die, but is hoping for a rescue transplant. Palliative care is part of the support and symptom control offered when the patient is critically ill, but may not need to continue after transplantation.

Bourke and Peel, *Clinical Medicine* 2014;14(1):79
“But I’m not dying”: the narrative of chronic lung disease

- Synthesised 828 interviews (involving patients, carers & clinicians) from 8 studies

- Chronic lung disease (organ failure) conceptualised quite differently from cancer
  - A story with no beginning
  - Perceived as a ‘way of life’, rather than an illness
    > Chaotic, a ‘daily struggle’, rather than ‘battle’
  - An unpredictable & unanticipated end
    > Not a ‘fatal’ disease, but several ‘brushes with death’
Models of care
Alternative models: SVHM

- Co-located clinic with palliative care fellow / physician attending the public-funded general respiratory clinic

- Variable referral pattern (generally poor)

- Mainly referred for symptom management & advance care planning
Alternative models: RMH

- Co-located clinic with palliative care registrar +/- physician attending a privatised respiratory clinic

- Respiratory & palliative care doctors both discuss symptom management & advance care planning, also facilitate referral to community palliative care services

- Scope for follow up by respiratory nurse after clinic (including home visits)
Alternative models: Barwon

- Multi-disciplinary breathless service staffed by palliative care physician, nurse practitioner and psychologist

- Reviews patients in clinic and at home (depending on need)

- Symptom-focused (refractory breathlessness despite optimal medical management): not restricted to patients with lung disease
Alternative model: Ipswich

- Patients with primary diagnosis of heart or respiratory failure from non-malignant disease identified using the ‘surprise question’

- 23 single face-to-face conferences involving GP, case management nurse, palliative care specialist

- Led to lower rates of ED admissions (13.1 to 2.1 per annum) & reduced LOS (7.0 to 3.7 days)
Summary

• Lung disease is common

• Patients (and carers) living with lung disease have palliative care needs

• These palliative care needs are not being met by current models of care

• Various alternative models of care have been developed in Victoria / across Australia

• Need to engage colleagues / patients / families / community in discussion
Palliative care gives me a quality of life I thought was lost.