COPD and EOLC

Dr Laura McTague
Consultant in Palliative Medicine, St Luke’s Hospice, Sheffield

Sr Jo Lenton
Head of Integrated Community Services, St Luke’s Hospice, Sheffield
“Knowing is not enough: we must apply. Being willing is not enough, we must do”

EOLC overview
Prognostication in COPD
St Luke’s services
Managing breathlessness and symptoms
A story: it’s always complicated

• J, early 50s
• Referred with COPD, history of substance misuse, poor social circumstances
• To AIC St Luke’s
• Attended unwell, no clear ceiling of treatment, variable understanding, no advance care planning
• Collaborative working with GP, Respiratory Consultant, Community Matron, district nurses
• Started O2
• Established ceilings of treatment (Respiratory Consultant) and real choices
• Started to deteriorate, recognised by the team at home
• Seen urgently at home, on waiting list St Luke’s
Preferences and Priorities at the EoL

- Electronic Palliative Care Coordination System (EPaCCS) in North Somerset: 47% of patients preferred home, 33% Hospice, 29% care home and 1% hospital.
- In 2012, 29,776 people died from COPD (5.3 per cent of the total number of UK deaths and 26.1 per cent of deaths from lung disease).
- Majority of chronic lung disease deaths in 65–84 year olds occur in hospital (70%).
- Fear of uncontrolled symptoms, for example breathlessness, which can be accompanied by considerable distress and anxiety for patients and carers, are a significant factor in the high levels of deaths in hospital.
Number of deaths in each trajectory, out of the average 20 deaths each year per UK general practice list of 2000 patients

- Cancer (n=5)
- Organ failure (n=6)
- Physical and cognitive frailty (n=7)
- Other (n=2)
Relationship between Specialist Palliative Care (SPC) and End of Life Care
Experiences of COPD and EOL

- Patients may not realize that COPD is incurable and fatal.
- Some physicians themselves do not consider early COPD to be a fatal disease.
- Patients tend to be poorly informed about the long-term prognosis of COPD and what to expect toward the end of life; this lack of understanding impairs quality of life as the disease progresses.
- Some clinicians have difficulty identifying the beginning of “the end of life,” given the unpredictable course of COPD.
- Divergent meanings and goals of palliative care in COPD lead to confusion about whether such services are the responsibility of home care, primary care, specialty care, or even critical care.
- Palliative end-of-life care may not be anticipated prior to referral for such care.
Clinical barriers to providing integrated palliative care in COPD:

• difficulty with prognostication
• communication barriers surrounding advance care planning
• lack of access to specialty palliative care, so complex symptoms not identified or treated
• unique disease trajectory
• 'curative-restorative' guidelines-based models.
Proactive palliative care

• Early identification of severe COPD requiring palliative care and advance care planning (SPICT, ProPal-COPD, CODEX)
• Assessment of symptoms in patients with COPD using PROMs (patient related outcome measures)
• Anticipatory care plans and ceilings of treatment
• Integrated palliative care
Prognostication?

- **SPICT**: use to identify people with
  - one or more advanced, progressive, incurable conditions
  - or at risk of dying of a sudden, acute deterioration for assessment and care planning.

- **Pro-PAL COPD**: predicts mortality in LYOL
  - the surprise question, Medical Research Council dyspnea questionnaire (MRC dyspnea), Clinical COPD Questionnaire (CCQ), FEV$_1$% of predicted value, body mass index, previous hospitalizations for AECOPD and specific comorbidities

- **CODEX**: short to medium term prognosis after hospital discharge
  - comorbidity, age, obstruction, dyspnea, and previous severe exacerbations index.
SPICT: 1. Look for two or more general clinical indicators of deteriorating health

- Performance status poor (needs help with personal care, in bed or chair for 50% or more of the day).
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
- A new event or diagnosis that is likely to reduce life expectancy to less than a year.
- Lives in a nursing care home or NHS continuing care unit, or needs care at home.
SPICT 2. Now look for clinical indicators of advanced conditions

- **Advanced respiratory disease**
  - Severe chronic obstructive pulmonary disease (FEV1 < 30%) or severe pulmonary fibrosis
  - Breathless at rest or on minimal exertion between exacerbations.
  - Meets criteria for long term oxygen therapy (PaO2 < 7.3 kPa).
  - Has needed ventilation for respiratory failure.
SPICT:3. Ask

• Would it be a surprise if this patient died in the next 6-12 months?
4. Assess and Plan

Assess the patient & family for unmet needs.

Review treatment / care plan, and medication.

Discuss and agree care goals with the patient & family.

Consider specialist palliative care referral if symptoms are complex or poorly controlled.

Consider using GP register to coordinate care in the community.

Handover: care plan, agreed levels of intervention, CPR status
St Luke’s service development

• Community team development: 7 days 9-5, intensive treatment team, Zone, integrated nursing and medical team
• Use of PROMs: IPOS, Phase of Illness and Karnofsky
• Complexity Framework (CF): case find and agree case management
• Integrated MDT using CF based on PROMs, Phase of illness and Karnofsky
• Innovative delegating clinician technology (Encompass)
• ECHO project
Day to day visits: 9-5/7 days a week

- **ITT Team**: Urgent referrals and Red (unstable patients) same/next day, hands over to Zone when stable
- **Delegation and Consultation during visits**: use of holistic assessment, PROMs and CF during visit
- **Zone team**: Routine referrals and ongoing care
- **MDT weekly**:
  - Confirm plan and CF RAG
- **Morning Huddle**: ITT discuss team available, assign visits
- **Board round**: whole team
  - Discuss Red: IPOS ¾, unstable, red flags, new patients, plans for next day
- **AIC**: weekly attendance up to 8 weeks, multiprofessional, clinic attendance, outpatients as needed
- **St Luke’s IPC 24/7**
St Luke’s Complexity Framework

- Describes how we case find and case manage complex palliative situations at home
- Used by all Community team members
- From each **face-to-face** assessment, to MDT discussions
- Use innovative technology to record holistic assessments: on visits, allows delegation
- Delegation all visits: senior clinician 9-5 available for advice

**Case find:**
  - Use PROMs/phase during our specialist holistic assessment
  - Agreed “red flag” complex situations not usually managed by GP/DN alone at home

**Case manage:**
  - Immediate face-to-face management plan
  - Agreed when we reassess, discuss and how we facilitate care at home

- **High** to **medium** to **low** complexity (RAG)
Operational detail: September

- Number on caseload: 445
- Referrals/month: 167 (99 routine/68 urgent)
- Total visits/month: 542
- ITT (highly complex) visits/month: 181
- Visits/day: up to 30

RAG September

- Red 23%
- Amber 60%
- Green 17%
Symptoms at the end of life

- https://www.blf.org.uk/support-for-you/end-of-life/physical-signs
- feeling more **severely out of breath**
- **reducing lung function** making breathing harder
- having **frequent flare-ups**
- finding it **difficult to maintain a healthy body weight**
- feeling **more anxious and depressed**
- troublesome cough, poor appetite, chest pain and **disturbed sleep patterns**.
Non-pharmacological interventions - Cochrane

- Non-pharmacological interventions for breathlessness in advanced stages of malignant and non-malignant diseases
- Demonstrated efficacy for:
  - Neuro-electrical muscle stimulation
  - Chest wall vibration
  - Walking aids
  - Breathing training
  - Hand-held fans

Non-pharmacological interventions for breathlessness in advanced stages of malignant and non-malignant diseases. Cochrane 2008
Opioids in COPD

- Review and meta-analysis of double-blind RCTs of opioids in refractory breathlessness in people with COPD
- Main findings:
  - Low dose opioids reduced breathlessness in COPD
  - Strongest evidence for systemic therapy
  - No effects on exercise capacity
  - No serious adverse effects reported in any study (no reports of hospitalisations, respiratory depression, or CO2 retention)
How do opioids work?

• Via their μ-opioid receptor activity
• Central effect – modulation of breathlessness
• Peripheral effect – bind to opioid receptors within bronchioles and alveolar walls
• Decrease higher cortical awareness of dyspnoea and response to hypoxia and hypercapnia

Opioids for the palliation of refractory breathlessness in adults with advanced disease and terminal illness. Cochrane 2016
Opioids in terminal illness

• Relief of breathlessness in adults with advanced disease and terminal illness
  – Quality of evidence low or very low
  – Some evidence of benefit for use of PO opioids
  – No evidence to support nebulised opioids
  – Possible short-term increase in exercise capacity
• Only 4 studies assessed QoL, none demonstrated significant change
• Adverse effects (included drowsiness, N+V, constipation)
• BUT opioids used to treat other symptoms....
What dose do we use?

- Study aimed to determine the minimum effective dose of **SR morphine**
- 10–30mg SR morphine titrated for one week then long term on the dose of clinical benefit
- 62% patients had at least a 10% improvement in baseline breathlessness
- Of those who improved:
  - Just over 50% improved with 10mg/day
  - Over 90% by 20mg/day
- Safe in ≤30mg/day, can use more, seek specialist advice

Slide taken from Oxford Advanced Course Currow et al 2011
Benzodiazepines Cochrane 2016

- Despite frequent use the evidence for efficacy is unclear
- No evidence for or against benzodiazepines for the relief of breathlessness in people with advanced cancer and COPD
- More drowsiness compared to placebo, but less compared to morphine
- May be considered as a 2\textsuperscript{nd} or 3\textsuperscript{rd} line treatment, when other measures have failed
- BUT may be used for other symptoms....
Safety of benzodiazepines and opioids

- Population based longitudinal consecutive cohort study
- Patients with COPD, dependent on oxygen
- Benzodiazepines and opioids not associated with increased admission
- Benzodiazepines were associated with increased mortality, with a dose response trend
- Opioids also had a dose response relation with mortality – not if ≤30 mg oral morphine equivalent/day
- Concurrent benzodiazepines and opioids in lower doses were not associated with increased mortality
- Associations not modified by being naive to the drugs or by hypercapnia

Ekström et al 2014
Oxygen

• Most evidence doesn’t support use of O2
• One short-term study in cancer related breathlessness suggests O2 generally better than medical air in severe hypoxaemia (SpO2<90%)
• Sensation of airflow an important determinant of benefit

• National guidelines recommend O2 should not be prescribed unless hypoxaemic and other treatment options ineffective
• Guided by degree of symptom relief rather than SpO2
• Caution in hypercapnic respiratory failure, smokers, sources of heat
Secretions when unable to swallow

• Non-pharmaceutical

• Pharmaceutical:
  – Hyoscine Butylbromide
  – Hyoscine Hydrobromide
  – Glycopyrolate
  – Furosemide
  – Octreotide
  – im antibiotic for bronchorrhhea
COPD and EOLC

- **Proactive palliative care:**
  - Early identification of severe COPD requiring palliative care and advance care planning (SPICT, ProPal-COPD, CODEX)

- **Advance care planning:**
  - Developing and implementing anticipatory care plans both inpatient, outpatient settings and the community

- **Integrated palliative care:**
  - MDT working devoted to complex advanced lung disease and optimizing palliative care

- **Support for development, education and sharing of knowledge:**
  - ECHO for severe COPD
Any questions?

• “Knowing is not enough: we must apply. Being willing is not enough, we must do”
Resources


• Feedback on end-of-life care in dementia: the study protocol of the FOLlow-up project. Boogaard et al. BMC Palliative Care 2013,12:29http://www.biomedcentral.com/1472-684X/12/29


• Symptom burden, palliative care need and predictors of physical and psychological discomfort in two UK hospitals. Ryan et al. BMC Palliative Care 2013, 12:11 http://www.biomedcentral.com/1472-684X/12/11


Website resources

- Supportive and Palliative Care Indicators Tool [http://www.spict.org.uk/](http://www.spict.org.uk/)