Palliative Care and symptom control in non-cancer

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Overview

• The size of the problem
• Palliative needs in COPD, Heart Failure and CKD
• Barriers to care
• When to start a palliative approach
• Management strategies
• Anticipatory Care Planning
The size of the problem

• The physical and mental distress of the dying – experience of patients dying on a medical ward of an acute hospital

• ‘discomfort was not necessarily greatest in those dying from cancer; patients dying of heart failure, or renal failure, or both, had most physical distress’

Hintom JM The physical and mental distress of the Dying Quarterly J Med 1963;32:1-21
Deaths per GP in the UK

- Organ failure: 6
- Cancer: 7-8
- Dementia and frailty: 5
- Other causes: 1-3
Place of death

• 57% of patients in the UK die in hospital
• 33.9% patients die in hospital in the Netherlands

• Home death more likely
  – Cancer
  – Young
  – Live with someone
  – Professionals to support carers
Hospital deaths in Scotland – prevalent cohort study

- Studied 10,743 patients who were in 25 acute hospitals on 31st March 2010
- Excluded long stay MFE wards
- 28.8% died within 1 year
- 9% died during that admission
- Conclusion – what we term as ‘acute’ hospitals have palliative and end of life care as part of their core business

Clark et al. Palliative Medicine. 2014
Palliative needs - COPD

- Death rates from COPD in UK are almost double the EU average (1 in 20 deaths)
- 5th leading cause of death in UK
- Commonest single cause of hospital admission and readmission
- If received NIV for acidotic respiratory failure 50% dead within 2 years
Comparing advanced COPD and lung cancer

• Symptom burden, distress and palliative care needs comparative

• LC more likely to know are dying

• COPD need more help with self-care

• Relatives of COPD less likely to be present at deceased death than LC (majority would have liked to have been)

• COPD patients receive less help from specialised palliative care nurses compared to LC

Edmonds 2001
The experience of breathlessness

• Mrs. W.: “… and you feel as if you're going to die and you take everything off. You open all the windows up because you think if you can open all the windows and the doors, and take your clothes off, you're gonna be able to breathe better but it doesn't mean a thing. But it is the most frightening thing that I have ever experienced

Gysels, Higginson JPSM 2010
Palliative needs in COPD

• 49 patients cancer/69 with COPD

• Median survival
  – Advanced cancer – 107 days
  – COPD (GOLD stage III/IV) – 589 days

• Same symptom burden but coping with it for a much longer time

Bausewein C. Journal of Pall Med 2010;13:1109
SAMsterDAM 1-2 May 2014
Heart Failure – palliative needs (UK)

- Prevalence - 15% of people >75 yrs living with HF

- 30-40% of patients diagnosed with HF die within a year; 21.5% 5 year survival

- UK – 1/3 admitted within 12 months of discharge

- National Heart Failure Audit – only 6% patients on palliative care register
Heart Failure – Palliative Needs

Heart failure have a different illness trajectory from those with lung cancer

• HF patients have a poorer understanding of illness and prognosis and less opportunity to address end of life issues than pts with lung cancer

• Heath, social and palliative care services are less readily available to those with a non-cancer diagnosis

Murray, BMJ 2002
## Symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Cancer %</th>
<th>HF %</th>
<th>COPD %</th>
<th>CKD %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dyspnoea</td>
<td>10-70</td>
<td>60-88</td>
<td>90-95</td>
<td>11-62</td>
</tr>
<tr>
<td>Pain</td>
<td>35-96</td>
<td>41-77</td>
<td>34-77</td>
<td>47-50</td>
</tr>
<tr>
<td>Fatigue</td>
<td>32-90</td>
<td>69-82</td>
<td>68-80</td>
<td>73-87</td>
</tr>
<tr>
<td>Depression</td>
<td>3-77</td>
<td>9-36</td>
<td>37-71</td>
<td>5-60</td>
</tr>
<tr>
<td>Anxiety</td>
<td>13-79</td>
<td>49</td>
<td>51-75</td>
<td>39-70</td>
</tr>
<tr>
<td>Anorexia</td>
<td>30-92</td>
<td>21-41</td>
<td>35-67</td>
<td>25-64</td>
</tr>
</tbody>
</table>

Solano, Gomes and Higginson JPSM, 2006
Renal Failure - Prognosis of patients with advanced CKD

- **Long Term Dialysis**
  5yr survival 65-74yrs ~ 30%, 5yr survival >75yrs ~ 20%

  If >75yrs, co-morbidity and poor performance status – no survival advantage

  47% days in hospital v 4%

- **Conservative Management**
  20% of patients reaching CKD Stage 5
  Median survival 8-10 months
  
  (Chandna, NDT 2010)
Davison: End of Life preferences

- 554 patients on dialysis
- 91% - extremely important to be informed of prognosis
- 83% - wished to be prepared and plan ahead in case of death
- 61% - regret starting dialysis
- 83% - thought about future deterioration
- 91% - had NO conversation with a doctor about prognosis

(Davison, CJASN 2010)
What do people want at the end of life

• To be with loved ones

• To avoid life prolonging treatments and interventions

• To put their affairs in order

• To have good symptom control
Barriers to palliative care in non-malignant disease

• Difficulty in recognising patient may be in last months / year of life
• Prognosis paralysis “Are we there yet”
• Unco-ordinated care / communication between primary and secondary care
Barriers to palliative care in non-malignant conditions

• Concern that conversation removes hope
• Patient / carer lack of understanding ‘I don’t have cancer’
• Medical perception that death is a failure
• Lack of skills in symptom control
• Lack of specialist palliative care resources
WHO definition of palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
When should a palliative approach begin?
Early Palliative Care in metastatic NSC lung cancer

- Patients randomised at diagnosis
- Standard oncology Rx + Pall care n=74
- Standard oncology Rx                   n=77

- Combined arm
- Less aggressive Rx at end of life
- Survival longer 11.6 v 8.9 mths p=0.02
- QOL better 98 v 91 FACT –L p=0.03

Temel, NEJM 2010
SAMsterDAM 1-2 May 2014
Prognostication
Disease Trajectories

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Supportive and Palliative Care Indicators Tool (SPICT™)

The SPICT™ is a guide to identifying people at risk of dying within the next 12 months.

SPICT™ is designed to:
- Include evidence-based clinical indicators of advanced conditions and multimorbidity
- Be used by a range of professionals in all care settings; community, care homes and hospitals
- Provide clear guidance, in accessible language, that can be discussed with patients and families and communicated between professionals and teams
- Use a one-page format
- Prompt assessment and review of the current and future needs of patients and their families
- Promote early supportive and palliative care in parallel with optimal management of the patient’s underlying condition(s)

The SPICT™ is sometimes used in combination with the “Surprise Question”: Would you be surprised if this patient died within 12 months?

To access SPICT™ and join with a growing community of SPICT users, please register.
SPICT – Supportive and Palliative Care Indicators Tool

- Combines clinical judgement and evidence based clinical indicators to improve patient-centred care and goals towards the end of life

- Less emphasis on prognostic accuracy but aims to ensure patients who may be in the last year of life have opportunity to plan and have good symptom management
Triggers for palliative care approach and assessment – 2 or more

- 2 or more hospital admissions in past 6 months
- Poor or deteriorating performance status (spends 50% or more of waking hours sitting / lying)
- Weight loss 5-10% in 3-6 mths or BMI<20
- Uncontrolled persistent symptoms despite optimal disease management
- Lives in care or requires more care to stay at home
• Heart Failure
  – NYHA Class III/IV, SOB on minimal exertion
• COPD
  – Has required NIV
  – LTOT
  – SOB at rest or minimal exertion
• CKD
  – Stage 4/5 with deteriorating health
  – Kidney failure due to another life-limiting condition
  – Dialysis withdrawal
Symptom management - case 2

- 73 yr old man admitted to AMU with COPD admitted with breathlessness, PaO₂ – 7.1kPa
- 3 admissions in 12 months – last admission NIV, did not want again
- Housebound but independent at home

- Started on course of steroids, bronchodilators, antibiotics
- FiO₂ – 24% breathless and distressed
- FiO₂ – 28% less breathless but hypercapnic, drowsy
- Optimal medical management
Case 2 – on optimal medical Rx
What will you do?

• A – trial of benzodiazepines
• B – Increase his oxygen to FiO2 28%
• C – trial of opioids
• D - Nebulised saline
Management of dyspnoea - opioids

• 1 Cochrane review – all aetiologies
• 3 systemic reviews – cancer
• 1 adequately powered placebo RCT: all aetiologies
• 1 pilot placebo RCT (CHF)
• 1 longitudinal cohort study 4 yrs (COPD)

• All support the regular use of low-dose morphine / diamorphine / dihydrocodeine by oral or parental route

• Improvement in refractory dyspnoea and sleep
Are opioids safe in dyspnoea?

- Dose titration / pharmacovigilance study
- 83 participants (54% COPD)
- Titrated to 10-30mg daily morphine and maintained long term on effective dose
- NNT 1.6 NNH 4.6
- Most common side-effect – constipation
- No episodes of resp depression or hospital admission due to morphine side-effects
Use of opioids in practice

- Start low and go slow – 4 weeks
- 2mg morphine bd to start
- Convert from immediate release to sustained release when titration complete
- If eGFR<30ml avoid morphine
- use opioids with less renal excretion or toxic metabolites
  - oxycodone / buprenorphine / fentanyl / alfentanil
Benzodiazepines

• There is no evidence that benzodiazepines improve dyspnoea in non-malignant disease or cancer

• In practice – Reserve for panic

• Lorazepam 0.5mg PRN

• If regular use required – consider Mirtazepine, avoid regular diazepam

Simon ST et al. 2010 Cochrane Review
SAMsterDAM 1-2 May 2014
oxygen therapy

• LTOT – improves survival if PO2 < 7.3kPa
  – Improves QOL, anxiety and depression for some
  – Others find it intolerable

• Frequently prescribed
  – 70% clinicians in one study, irrespective of SpO2
  – For refractory dyspnoea (65%); at request of patient (35%)
  – More likely if patient had a carer

Johnson, JPSM 2012
Oxygen for refractory breathlessness

- 239 adults with refractory dyspnoea and PaO$_2$ > 7.3 kPa
- Randomised to 7 days O2 or air delivered through a concentrator
- Outcome – air / oxygen both as effective
- Passage of air past the nasal mucosa may be as effective and tried first (hand held fan)
- If not helpful – trial of oxygen

Abernethy, Lancet 2010
SAMsterDAM 1-2 May 2014
Nebulised saline

• RCT in 40 patients with COPD
• I: 4mls saline with efficient nebuliser
• C: 4mls saline with inefficient nebuliser
• O: FEV$_1$ – no difference
  – breathlessness 23% improvement v 4% improvement (p=0.0001)
  – Mucous clearance – 65% reported easier in intervention group v 5% control group
• Conclusion – nebulised saline should not be considered a placebo intervention

Khan, BMC Pulm Med 2004
Discuss his wishes - Anticipatory Care Planning

• A conversation to help us provide patient centred care, based upon an informed patient making their wishes known about their future priorities for care / ceiling of care.

  – “What do you know about your COPD?”
  – “As doctors and nurses, we want to do the right thing for you. Would you like to talk about how you would want us to look after you if your COPD gets bad again?”……
Summary

• Palliative Care needs in non-malignant disease are high
• Optimal medical management can occur alongside palliative approach
• Find out what the patient understands and wants to know about future care
• Opioids and nebulised saline beneficial in breathlessness management
• Should focus on the problems not prognosis for non-malignant disease
Oscar jumps onto her bed and again sniffs the air. He pauses to consider the situation, and then turns around twice before curling up beside Mrs. K. One hour passes. Oscar waits. A nurse walks into the room to check on her patient. She pauses and notes Oscar’s presence. Concerned, she leaves the room and returns to her desk. She takes Mrs. K.’s chart off the medical-records rack and begins to make phone calls.
Oscar the ‘death cat’ predicts 50 deaths
2nd February, 2010
Other important points

• Opioids in people with eGFR<30ml/min
  – Monitor for toxicity (hallucinations, drowsiness before respiratory depression)
  – Avoid codeine, morphine, diamorphine
  – oxycodone, buprenorphine, fentanyl, alfentanil

• Dementia
  – Don’t forget pain as a cause of agitation (paracetamol not antipsychotics)
  – Routine use of gastrostomy tubes in severe dementia is not warranted