Palliative care for Non-Cancer

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Background

• In 2005 cancer was responsible for a relatively small percentage of deaths worldwide (13%)

• Long term conditions caused 47% (WHO 2008, 2005)

• By 2030, ↑ from 58 million to 74 million
  -organ failure,-physical and cognitive frailty (Mathers 2006)

• Palliative care services typically still cater only for people with cancer (WHO 2004)

• Dying of the "wrong" condition (Murray et al, 2005)
• 2/3 of people dying are aged > 75yrs.

• 2012- Leading cause of death

• Male : Heart Disease (15.6%)
• Female : Dementia (11.5%)
Background– Heart Failure

- 900,000 people in UK, 68,000 new cases / year
- To rise by 50% over the next 25 years
- 5% admissions, 50% readmissions in 1 yr
Symptom burden

Dyspnoea: 82%
Fatigue: 79%
Worry: 73%
Insomnia: 67%
Anxiety: 39%
Prognosis

- 40% mortality within first year.
- Worse prognosis than many cancers.
- 10-15% of people aged > 80
- Despite treatment – prognosis poor, condition irreversible, incurable.
- Only 6% referred to palliative care.
Gadoud 2014

- Fewer Heart failure referred/ recognised as Palliative compared to cancer.

- 3122 DIED- 234 on Palliative care register (7%)  

- 69/234 (29%) – entered in the last week.

Non-Cancer patients also Have High symptom burden


Why do we think it’s the case?
Challenges

• The difficulties of recognising dying

• Dealing with uncertainty and prognostic paralysis

• Where and when does palliative care interface?

• Specialist vs. Generalist debate
Kendall et al 2015
Dancing to a different tune: Living and Dying with Cancer, Organ failure and Physical Frailty. 10.1136/bmjspcare-2014-000838.2.

Cancer based end-of-life care poorly suited to the needs of those dying in other ways.

828 interviews

- **Cancer**: Clear beginning, middle and anticipated end.

- **Non cancer**:  
  - Unclear beginning  
  - Further unclear middle...  
  - Many ... Not had a clue about the END.
Trajectory: long term limitations with intermittent serious episodes

End-organ failure  (Murray et al, 2005)

- Heart failure, COPD.
- Usually ill for many months or years
- acute, often severe, exacerbations.
- Deteriorations are generally associated with admission to hospital
- Each exacerbation maybe life-threatening
• If survives such episodes, a gradual deterioration in health and functional status is typical.

• The timing of death, however, remains uncertain.

• In patients with advanced heart failure ->60% died when expected to live for at least a further six months. Levenson et al, 2000.
End of life trajectory

Fig: Disease trajectories for people with cancer and those with COPD

Strategy for Services for COPD in England / DOH Feb. 2010
End of life care for all? Murray PCC 2010

- **Organ failure**: Months or years
- **Cancer**: Weeks, months, years
- **Acute**:
  - 6
  - 5
  - 2
  - 7

GP has 20 deaths per list of 2000 patients per year

- **Dementia, frailty**: Many years
Organ Failure

Organ System Failure Trajectory

High

Function

(mostly heart and lung failure)

Low

Begin to use hospital often, self-care becomes difficult

Time - 2-5 years, but death usually seems "sudden"

Death
Models of care delivery
Lanken et al. 2008; Murray et al. 2005

Needs mirrors the delivery model (integrated model)
Can we use any other tool?
 Surprise question

• Dec’ 2011-Feb’ 2012
• 42 GPs- classified 231 patients (Italy)
• 126 patients –NO- wont be surprised
• 105- yes- will be surprised

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<th>Sensitivity</th>
<th>Specificity</th>
<th>PPV</th>
<th>NPV</th>
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<td>69.3%</td>
<td>83.6%</td>
<td>83.8%</td>
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O’ Callaghan 2014

• New Zealand study- Hospital patients
• 501 Hospitalised patients.
• 56.6% Died in 6 months
• 68% died in 12 months.

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<th>Sensitivity</th>
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<td>12 months</td>
<td>62.6%</td>
<td>91.9%</td>
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<th>Died</th>
<th>Alive</th>
<th>Total</th>
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<tr>
<td>No</td>
<td>87 (83.6%)</td>
<td>39</td>
<td>126</td>
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<tr>
<td>Yes</td>
<td>17 (16.4%)</td>
<td>88</td>
<td>105</td>
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Comparison

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<th>sensitivity</th>
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<tr>
<td>PSA (at 3)</td>
<td>59%</td>
<td>87%</td>
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<tr>
<td>Surprise Q</td>
<td>62.6%</td>
<td>91.9%</td>
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<tr>
<td>Surprise Q</td>
<td>69.3%</td>
<td>82.6%</td>
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<tr>
<td>Urine dipstick (Nitrates)</td>
<td>45-60%</td>
<td>85-98%</td>
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<tr>
<td>D-Dimer for DVT</td>
<td>74%</td>
<td>66%</td>
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Defining End of Life:

Patient likely to die within next 12 months, including those whose death is imminent (few hrs or days) and those with:

- **Advanced, progressive, incurable conditions**
- **General frailty and co-existing conditions** that mean they are *expected to die within 12 months*
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events”

*General Medical Council, 2010*
Systematic review 2014

- The challenges of uncertainty and inter-professional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals.

Oishi 2014

- 30 studies - **719 patients, 605 carers and over 400 professionals.**
- Patients and carers expect primary care physicians to provide compassionate care, have appropriate knowledge and play central roles in providing care.

- **The roles of professionals are unclear to patients, carers and professionals themselves.**

- **Uncertainty of illness trajectory and lack of collaboration between health-care professionals were identified as barriers to effective care.**

- The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals.
COPD – Poor Prognosis

- At least two of the indicators below:
  - Disease assessed to be severe (e.g. FEV1 <30% predicted)
  - Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
  - Fulfils long term oxygen therapy criteria
  - MRC grade 4/5 – shortness of breath after 100 metres on the level of confined to house
  - Signs and symptoms of right heart failure
  - Combination of other factors – i.e. anorexia, previous ITU/NIV resistant organisms
  - More than 6 weeks of systemic steroids for COPD in preceding 6 months.
SPICT (Supportive and Palliative care Indicators Tool)

- a clinical guide designed to help health and social care professionals identify people who are at risk of deteriorating and potentially dying with one or more advanced long term conditions
COPD

• Severe chronic lung disease with:
  • bloodlessness at rest or on minimal exertion between exacerbations.
• Needs long term oxygen therapy.
• Has needed ventilation for respiratory failure or ventilation is contraindicated.

• SPICT website (www.spict.org.uk)
Heart Failure: Indicators of Poor Prognosis

- NYHA III / IV, refractory symptoms despite OMT
- 3 or more hospital admissions last 6 months
- Dependent for more than 3 ADLs
- Advanced age
- Co-morbidities
- Cardiac Cachexia
- Albumin < 25
- Resistant hyponatraemia
- Multiple shocks from ICD

- *End of life care in heart failure: A framework for implementation; NHS Improvement 2010*
SPICT

- NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:
- breathlessness or chest pain at rest or on minimal exertion.

- SPICT website (www.spict.org.uk) for information and updates.
Neurological conditions

Conditions
- MND
- Multiple Sclerosis
- Parkinsons

Indicators
- Rapid deterioration
- Intractable complex symptoms
- Complex Psychosocial needs
- First episode of aspiration pneumonia
Triggers

- Marked decline in physical function
- Dysphagia
- Aspiration pneumonia
- Infection
- Cognitive impairment
- Weight loss
- Complex symptoms
- Pain
What can Palliative care do?

- Review of symptoms
- Psychosocial support
- Help with Advance Care Planning (ACP)
- Respite

Symptom control

Advance Care Planning
COPD– Morphine, Lorazepam, Physio
CCF: Furosemide in syringe driver
Neurology– spasms, communication
Specialist palliative care: potential models

- Hands-off advice.
- One-off consultative visits/Out Patients
- Short-term involvement (Day therapy).
- Long-term involvement.
- (inpatient admissions, Respite care, Home care support, combined care with GP)
In summary

• Trajectories need to be better defined and better understood
• Collaborate across boundaries and disciplines
• Palliative care itself needs to develop increasing flexibility and adaptability
• Recognise dying OR
  – Enable the Living
• Exploring preferences and priorities
When is a patient palliative OR in need of a palliative care approach?

• Would you be surprised if Mrs A were to die within the next 12 months?

• Study in cardiology ward revealed that this question identifies 60 -70%.

• **Avoid “prognostic paralysis”**

Discussion...
Consultant mobile numbers

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for families facing terminal illness