Concept of trajectories at the end of life: physical and other dimensions

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World Mortality Rate

- 2005: 100%
- 2006: 100%
- 2007: 100%
- 2008: 100%
Dying now and then

UK1900 / UK 2010

Age at death
46
80

• Top 3 groupings
  1. Infectious diseases
  2. Accident
  3. Childbirth

• Top 3 groupings
  1. Cancer
  2. Organ failure
  3. Frailty/ dementia

• Disability before death
  Not much

  Disability before death
  Months - many years
The three main trajectories of decline at the end of life

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)

Dying in UK: community oriented end of life care

- Organ failure: Months or years
- Cancer: Weeks, months, years
- Acute
- Dementia, frailty and decline

GP has 20 deaths per list of 2000 patients per year
Figure 2. Indicative number of patients needing supportive/palliative care at any point in time, per UK GP

Practice might have 18 patients/full time GP on the supportive and palliative care register.
Thinking trajectories allows better understanding of when to change gear

Caring for people with organ failure: 3 stages

Stage 1  Physically well

Stage 2  Active supportive and palliative care

Stage 3  Terminal care

Sentinel events

Care Plan

Gold standards Framework

Liverpool Care Pathway

Death

Care Plan

Time

High

Low
Murray SA and Boyd K. Recognising and managing key transitions in end of life care. BMJ in press

<table>
<thead>
<tr>
<th>Supportive &amp; Palliative Care Indicators Tool</th>
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<tbody>
<tr>
<td><strong>1. Ask</strong></td>
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<tr>
<td>Does this patient have an advanced long term condition and/or a new diagnosis of a progressive life limiting illness?</td>
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<td>Would you be surprised if this patient died in the next 6-12 months?</td>
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<tr>
<td><strong>2. Look for one or more general clinical indicators</strong></td>
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<tr>
<td>Performance status poor (limited self care; in bed or chair over 50% of the day) or deteriorating.</td>
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<td>Patient has continued to lose weight (&gt;10%) over the past 6 months.</td>
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<td>Patient has had two or more unplanned admissions in the past 6 months.</td>
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<td>Patient is in a nursing care home or NHS continuing care unit; or needs more care at home.</td>
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<td><strong>3. Now look for two or more disease related indicators</strong></td>
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<table>
<thead>
<tr>
<th>Heart disease</th>
<th>Respiratory disease</th>
<th>Cancer</th>
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<tr>
<td>NYHA Class IV heart failure, severe valve disease or extensive coronary artery disease.</td>
<td>Severe airways obstruction (FEV₁,&lt;30%) or restrictive deficit (vital capacity &lt; 60%, TLCO &lt;40%).</td>
<td>Performance status deteriorating due to metastatic cancer and/or co-morbidities.</td>
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<tr>
<td>Breathless or chest pain at rest or on minimal exertion.</td>
<td>Meets criteria for long term oxygen therapy (PaO₂ &lt; 7.3).</td>
<td>Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment.</td>
</tr>
<tr>
<td>Persistent symptoms despite optimal tolerated therapy.</td>
<td>Breathless at rest or on minimal exertion between exacerbations.</td>
<td>Neurological disease</td>
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Frailty: change of setting,
Midlothian Care Homes project

- Routine advance care planning from admission to care homes
- Increase in DNAR status documented from 8 to 71% in patients who died
- Reduction of nearly 50% (from 15% to 8%) of residents dying in hospital
- Interviewed bereaved relatives reported better care

Lothian H board
Dying is a 4D activity

- Physical
- Psychological
- Social
- Spiritual
Spiritual needs

• Everyone has them if faced with a life-threatening illness
• About meaning and purpose of life
• People may or may not use religious vocabulary
• Such needs may cause distress

Grant E, Murray SA, Sheikh A. Spiritual dimensions of dying in different cultures. BMJ In press.
Are there typical 4D trajectories?

Method

• Thematically analysed serial qualitative interviews as case studies longitudinally and then cross-sectionally from a number of studies.

• Identified the presence and characteristics of social, psychological and spiritual needs as identified by patients and their families

Lung cancer and heart failure


Murray SA, Kendall M, Grant E, Boyd K, Barclay S, Sheikh A. Patterns of social psychological and spiritual decline towards the end of life in lung cancer *J Pain Sympt Man* 2007; 34: 393-402

*His old friends won’t even take a cup of tea with me now I’ve got cancer*” Mrs LR.
Lung Cancer - psychological trajectory

Four times when distress was common

1. At diagnosis
2. After initial treatment
3. At recurrence or disease progression
4. At terminal stage
“living with uncertainty”

“great nurses and departments they are so caring”

“Wellbeing

Lung Cancer

Trajectories
- Physical
- Social
- Psychological
- Spiritual

“It was like a black hole”

“It’s much worse the second time round”

“You don’t know what is going to happen to you, fear is the worst thing”

Murray SA, Kendall M, Grant E, Boyd K, Barclay S, Sheikh A. Patterns of social psychological and spiritual decline towards the end of life in lung cancer J Pain Sympt Man 2007; 34: 393-402
Pattern of spiritual distress at the end of life in lung cancer patients

Quote 1 – “When I first was told that was the first thing through my head – how long? It’s been like going to hell and back”. Mr LF

Quote 2 – “I’m not really depressed and yet the doctor gave me anti-depressants”. Mrs LU

Quote 3 – “Well I got the results back he said “I’m afraid it’s terminal” I got such a shock – we were just absolutely gob smacked” Mrs LQ

Quote 4 – “I’ll say god just let me die tonight. There must be something that’s better than this”.

Trajectories
- Physical
- Spiritual

Wellbeing

Distress

Diagnosis

Return home

Recurrence

Terminal Stage

Death
The diagram illustrates the trajectories of well-being and distress over the stages of lung cancer: diagnosis, recurrence, return home, terminal stage, and death. The graph shows different lines representing physical, social, psychological, and spiritual trajectories throughout these stages.
Heart Failure

Social Trajectory
“I feel like I’m in prison here with him and each day is just like that” Mr HM’s carer.

Psychological trajectory
Psychological wellbeing appeared to mirror the physical and social trajectories “I slipped down the bed and oh panic attacks I got, Mr HQ.

Spiritual trajectory
This reflected gradual loss of identity and growing dependence.
“Where is god in all this, has god forsaken me” Mr HU.
Awareness of these trajectories

• Help realise we should plan 4D care
• We can plan timely care, both anticipatory and in emergency
• Patient and carers can understand what the future might hold and be empowered “The physician who can foretell the course of the illness is the most highly esteemed”. Hippocrates
• Avoid overzealous treatment: help us do what we should do not everything we can do
Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family caregivers of patients with lung cancer: secondary analysis of serial qualitative interviews

Scott A Murray, St Columba’s Hospice professor of primary palliative care, Marilyn Kendall, senior research fellow, Kirsty Boyd, honorary clinical senior lecturer, Liz Grant, senior lecturer, Gill Highe, research fellow, Aziz Sheikh, professor of primary care research and development

Are there archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family caregivers?
Fig 1 Fluctuations in psychological wellbeing in family carers of patients with lung cancer

Fig 2 Fluctuations of spiritual wellbeing mapped with other trajectories of physical, social, and psychological wellbeing in family carers of patients with lung cancer

Trajectories
- Physical
- Social
- Psychological
- Spiritual

Wellbeing

Distress
- Diagnosis
- Return home
- Recurrence
- Terminal stage
- Death

Limitations

• All dimensions may vary greatly in rate of progression
• Inter-dependent
• Previous experiences, education, services available and culture may moderate
• Patients and carers are unique individuals
Strengths

• Conceptual basis and understanding of dynamic experiences
• Consider redesigning services to meet needs of 3 physical trajectories of decline
• Give clinicians clues as to when to change gear
• Consider patients’ (and carers’) 4D needs and services at key times