Spiritual Wellbeing and Physical Decline: serial in depth interviews in the last year of life

Scott A Murray
St Columba’s Hospice Chair of Primary Palliative Care
Primary Palliative Care Research Group, University of Edinburgh, UK
www.chs.ed.ac.uk/gp/research/ppcrq.php

Co-Chair, International Primary Palliative Care Research group
• Murray SA, Kendall M, Boyd K, Grant E, Hight G & Sheikh A. Archetypal trajectories of social, psychological and spiritual wellbeing and distress in family caregivers of patients with lung cancer: secondary analyses of serial qualitative interviews. *BMJ* 2010;304:c2581


• Murray SA, Grant E, Grant A & Kendall M. Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers.  *BMJ* 2003;326:368-72

• Grant E, Murray SA & Sheikh A. Spiritual dimensions of dying in pluralist societies.  *BMJ* 2010;341:4859


• Murray SA, Kendall M, Carduff E, Worth A, Harris FM, Lloyd A, Cavers D, Grant L and Sheikh A. Use of serial qualitative interviews to understand patients’ evolving experiences and needs.  *BMJ* 2009;339:b3702
5 key challenges end of life care spiritual care

1. All illnesses

2. Earlier than later

3. All dimensions

4. Community settings

5. All nations
Profile of People who die

Europe 1900

Age at death 46

Top 3 causes
- Infectious diseases
- Accident
- Childbirth

• Disability before death
- Not much

Europe 2000

Age at death 78

Top 3 groupings
- Cancer
- Organ failure
- Frailty/ dementia

Disability before death
- Months - many years
1. Primary care can deliver palliative care for all in need.

GP has 20 deaths per list of 2000 patients per year.

- **Organ failure**
  - Months or years
  - Function: High → Low → Death

- **Cancer**
  - Weeks, months, years
  - Function: High → Low → Death

- **Acute**
  - Function: High → Low → Death

- **Dementia, frailty and decline**
  - Many years
  - Function: High → Low → Death

6% for Organ failure
5% for Cancer
2% for Acute
7% for Dementia, frailty and decline
Challenge for specialist palliative care is how to get involved with generalists in a redesign process to care according to needs.

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)

2 Primary care can integrate curative and palliative care earlier rather than later.
Caring for people with organ failure: 3 stages

Stage 1  Physically well

Stage 2  Active supportive and palliative care

Stage 3  Terminal care

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

Liverpool Care Pathway

Gold standards Framework

Death
When is a patient “palliative”?

• 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% of admissions

• Avoid “prognostic paralysis* ”

**SPICT: supportive and palliative care indicator tool**

## Supportive & palliative care indicators tool

### 1. Ask

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does this patient have an advanced long term condition and/or a new diagnosis of a progressive life limiting illness?</td>
<td>Yes</td>
</tr>
<tr>
<td>Would you be surprised if this patient died in the next 6-12 months?</td>
<td>No</td>
</tr>
</tbody>
</table>

### 2. Look for one or more general clinical indicators

- Performance status poor (limited self care; in bed or chair over 50% of the day) or deteriorating.
- Patient has continued to lose weight (>10%) over the past 6 months.
- Patient has had two or more unplanned admissions in the past 6 months.
- Patient is in a nursing care home or NHS continuing care unit; or needs more care at home.

### 3. Now look for two or more disease related indicators

<table>
<thead>
<tr>
<th>Heart disease</th>
<th>Respiratory disease</th>
<th>Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>NYHA Class IV heart failure, severe valve disease or extensive coronary artery disease.</td>
<td>Severe airways obstruction (FEV$_1$ &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>
</tr>
<tr>
<td>Breathless or chest pain at rest or on minimal exertion.</td>
<td>Meets criteria for long term oxygen therapy (PaO$_2$ &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>Persistent symptoms despite optimal tolerated therapy.</td>
<td>Neurological disease</td>
</tr>
</tbody>
</table>
Competing narratives

• Public: I’m fine

• Private: “Well, now that you mention it” more realistic
Opening up
3. Meeting all dimensions of need

- Physical
- Psychological
- Social
- Spiritual

Grant E, Murray SA, Sheikh A. Spiritual dimensions of dying in different cultures. *BMJ* 2010;341:4859.
Spiritual needs

• Everyone has them if faced with a serious illness
• Accepted definition used internationally relates to meaning and purpose of life
• People may or may not use religious vocabulary
• Such needs may cause distress and increase medical demand

Dying is a 4-D activity

What’s happening with respect to other dimensions of need?

Method: meta-synthesis
• Thematically analysed in-depth serial interviews as case studies longitudinally and then cross-sectionally from a number of studies.

• Identified the presence and characteristics of physical, social, psychological and spiritual needs
His old friends won't even take a cup of tea with me now I've got cancer” Mrs LR.
“great nurses and departments they are so caring”

“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”

“living with uncertainty”
Fig 2 Pattern of spiritual distress at the end of life in patients with lung cancer 4 19.

Trajectories

Wellbeing

Distress

Diagnosis   Return   Recurrence   Terminal   Death
home

A “When I was first told, that was the first thing through my head – how long? It’s been like going through hell and back”

B “I’m not really depressed and yet the doctor gave me antidepressants”

C “Well I got the results back, he said “I’m afraid it’s terminal”. I got such a shock – we were just absolutely gobsmacked”

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

Grant L et al. BMJ 2010;341:bmj.c4859
Dyspnoea crises were multi-dimensional
Fig 1 Unmet spiritual need cycle may result in increased demand and service use.

“I think I have to be punished for the wrongs that I have done”

“Fear and dread come over you, it’s a horrible feeling, absolute total fear because nobody wants to know when they are going to die”

Patient recognising her own angst but feeling unable to address it or access help: “I think I more or less said to the doctor, well if you don’t come I say there’s an easier way”

“I feel down, like an emptiness in my stomach. I get this dead feeling in my stomach”

“I’m not really depressed and yet the doctors gave me antidepressants”

Grant L et al. BMJ 2010;341:bmj.c4859
Fluctuations of physical, social, psychological and spiritual wellbeing in family carers of patients with lung cancer

Awareness of these trajectories

- We can explain the likely course of the illness
- Patient and carers can understand what the future might hold
- We can plan timely 4-D care when needs expected, provide continuity through them
- Avoid futile physical treatment and expenditure and give other dimensions of hope

“The physician who can foretell the course of the illness is the most highly esteemed”. *Hippocrates*

Murray SA, Chinn DJ, Sheikh A. Access to psychological and psychiatric services needs to be improved for the dying. JRSM 2006;99(12):601
Spiritual care

• Well...she just sat down and was there
4. Potential of palliative care in primary care

- Over 50% would prefer to die at home
- But in UK 19% of people die at home
- Gold standards framework in >80% UK practices
- District frameworks Spain
- Kerela, India
Frailty trajectory
Community based: care frameworks

Steps:

1. Identify
2. Assess + communicate
3. Plan
Scottish Care Homes project

- Admission to care homes triggers advance care planning
- Increase in DNAR status documented from 8 to 71% in patients who died
- Reduction of nearly 50% in inappropriate admissions to hospital
- Interviewed bereaved relatives reported better care

Lothian Health Board
5 Primary care can provide care in lower income countries

Murray SA, Grant E, Grant A, Kendall M. Dying from cancer in developed and developing countries. *BMJ* 2003;326:368-72.
## Outline comparison

<table>
<thead>
<tr>
<th>Edinburgh, Scotland</th>
<th>Chogoria, Kenya</th>
</tr>
</thead>
<tbody>
<tr>
<td>main issue existential or spiritual distress</td>
<td>main issue physical suffering, especially pain</td>
</tr>
<tr>
<td>analgesia effective</td>
<td>analgesia unaffordable</td>
</tr>
<tr>
<td>anger in the face of illness</td>
<td>acceptance rather than anger</td>
</tr>
<tr>
<td>“just keep it to myself”</td>
<td>community support</td>
</tr>
<tr>
<td>spiritual needs evident but unmet</td>
<td>patients comforted and inspired by belief in God</td>
</tr>
</tbody>
</table>
spiritual support

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3. All dimensions
4. All settings
5. All nations