Patterns of social, psychological and spiritual decline towards the end of life in lung cancer and heart failure

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Dying in economically developed countries: A Century of Change

<table>
<thead>
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<th>1900</th>
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<tbody>
<tr>
<td>Age at death</td>
<td>46 years</td>
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<td>Top Causes</td>
<td>Infection</td>
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<td></td>
<td>Accident</td>
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<td>Childbirth</td>
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Dying a 4-D experience

- What’s happening with respect to other dimensions of need in people with advanced illness?
- Are there typical pathways of decline or even growth?

Why are these questions important?
- Might help us anticipate needs and plan care
METHODS

Synthesised qualitative data from two serial interview studies of people with advanced heart failure and lung cancer and their carers.

Identified the presence and characteristics of social, psychological and spiritual needs

Thematically analysed the serial interviews as case studies longitudinally and then in cross-sections.

108 qualitative interviews with patients and 57 with family carers.
His old friends won’t even take a cup of tea with me now
I’ve got cancer” Mrs LR.  Social death

Lung Cancer -----Psychological Trajectory

Four key stages –Diagnosis, end of treatment, disease progression and terminal stage.

“The treatment has helped us well, great nurses and departments they are so caring. The oncology people, I mean, they get to know their patients so well” Mr LK.

“It was like a black hole” Ms LP.

“It’s much worse the second time round”

“You don’t know what is going to happen to you, fear is the worst thing” Mrs LI.
Lung cancer - physical and social trajectories interrelated, while psychological and spiritual distress tends to increase at four specific transitions.

**Figure 1**: Physical, social, psychological and spiritual wellbeing in the last year of life

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<table>
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<tr>
<th>Trajectories</th>
<th>Physical</th>
<th>Social</th>
<th>Psychological</th>
<th>Spiritual</th>
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**Lung Cancer – Spiritual Trajectory. Same four key stages.**

“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 at diagnosis.

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

“Well I got the results back that afternoon and he said “I’m afraid it’s terminal” I got such a shock – we were just absolutely gob smacked” Mrs LQ at disease progression.

“I’ll say god just let me die tonight. There must be something that’s better than this” terminal stage
Heart Failure – Social Trajectory

It was a parallel shrinking social world with the physical decline “places you can’t go, people you can’t see, things you can’t do”.

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

Heart Failure - Psychological Trajectory

Psychological wellbeing appeared to mirror the physical and social trajectories “I slipped down the bed and oh panic attacks I got, and had to sit up. I couldn’t get my breathe. You can’t actually tell people” Mr HQ.

“It’s going to be what it’s going to be – the rest of the time I’ve got left – I’m just taking each day as it comes” Mrs MW.
Heart – Spiritual Trajectory

This reflected gradual loss of identity and growing dependence.

“Where is god in all this, has god forsaken me” Mr HU.

“Is it real, is there life after death, where am I going, what happens if I’m wrong and there is something after all” Mrs HB.

“The most important thing that my GP does – well he assures me that I’m not away yet – he always listens” Mr HU.
Trajectories

- Road maps which simplify the terrain, sometimes too much
- Yet can be critical guides to our patients on their final journeys
- Allow us to predict the future, the “how”
- Engage in transformative conversations with people
- Each dimension has high and low points
Summary Points

Three typical trajectories of physical decline for patients with progressive chronic illness are already described: cancer; organ failure; and the frail elderly.

We can now add

- Patients with cancer and organ failure may also have typical trajectories of social, psychological and spiritual needs towards the end of life.
- Being aware of these trajectories may help clinicians plan timely care to meet their patients multi-dimensional needs better, and may help patients and carers cope.
- Death is 4-D.

Lung cancer - physical and social trajectories interrelated, while psychological and spiritual distress tends to increase at four specific transitions.

Figure 1: Physical, social, psychological and spiritual wellbeing in the last year of life