



# **Are there typical trajectories of social, psychological and spiritual needs in patients with lung cancer and severe heart failure?**

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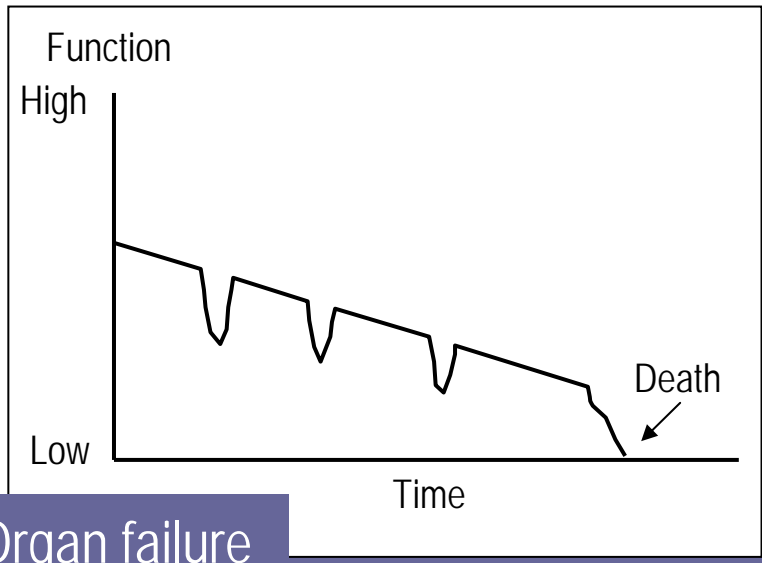
## **Primary Palliative Care Research Group**

Division of Community Health Sciences; General Practice

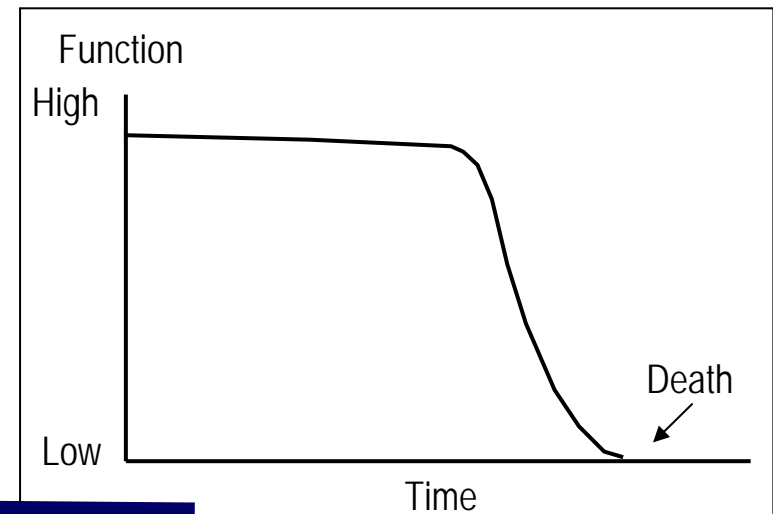
**University of Edinburgh, Scotland, UK**

**[www.chs.ed.ac.uk/gp/research/ppcrg.php](http://www.chs.ed.ac.uk/gp/research/ppcrg.php)**

# Three typical trajectories of physical decline are described at the end of life (Murray et al, BMJ 2005)



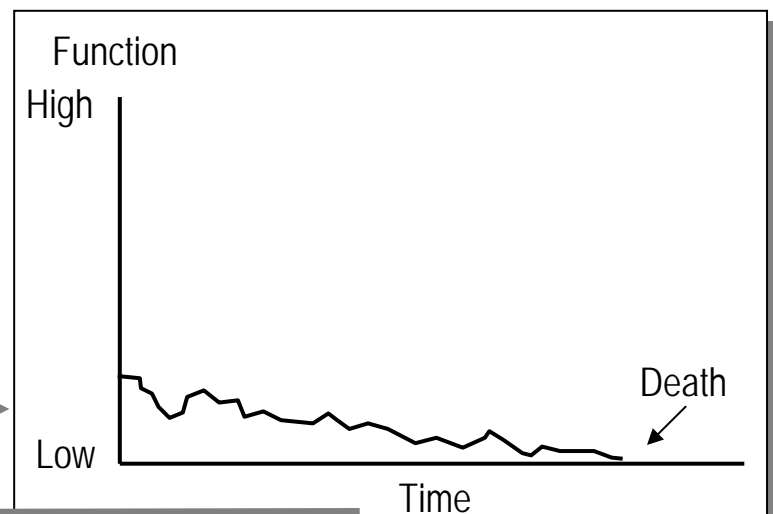
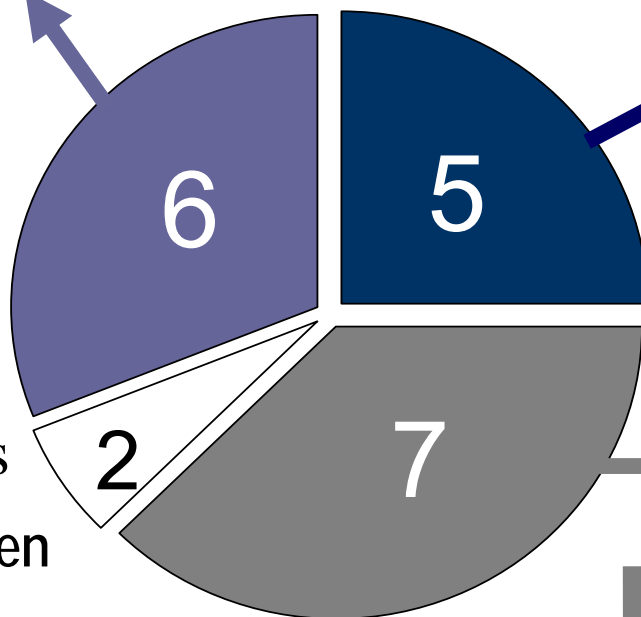
Organ failure



Cancer

GP has 20 deaths per year in list of 2000 patients

Sudden



Dementia, frailty and decline

# **METHODS**

We synthesised qualitative data from two serial interview studies of people with advanced heart failure and lung cancer.

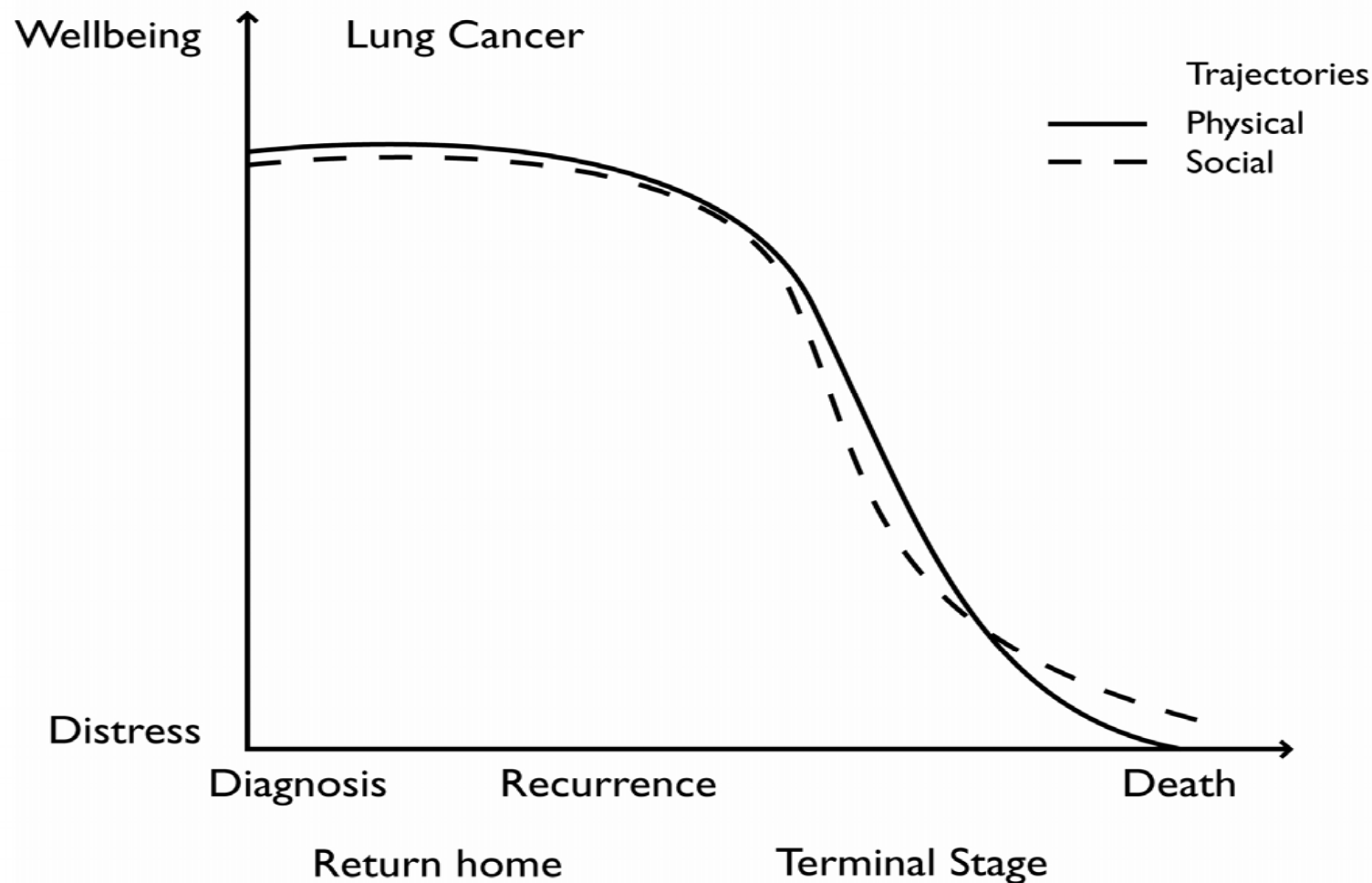
We identified the presence and characteristics of social, psychological and spiritual needs

We thematically analysed the serial interviews as case studies longitudinally and then in cross-section, according to the illness stage.

Data: 108 interviews with patients and 57 with informal carers.

*His old friends won't even take a cup of tea with me now I've got cancer" Mrs LR.*

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



# **Lung Cancer -----Psychological Trajectory**

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

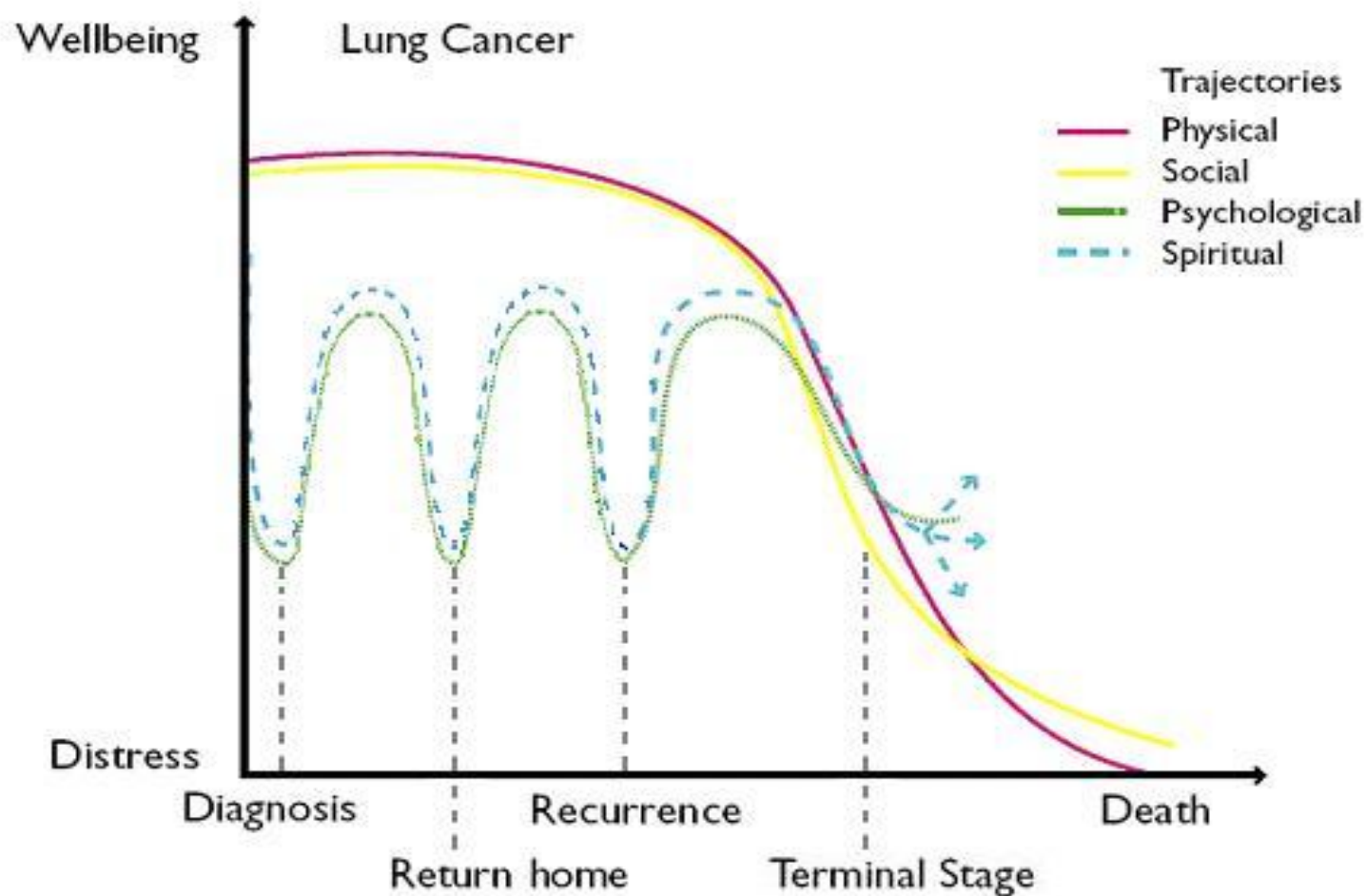
*“The treatment has helped us well, great nurses and departments they are so caring. The oncology people, I mean, they get to know their patients so well” Mr LK.*

*“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.*

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



## **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.

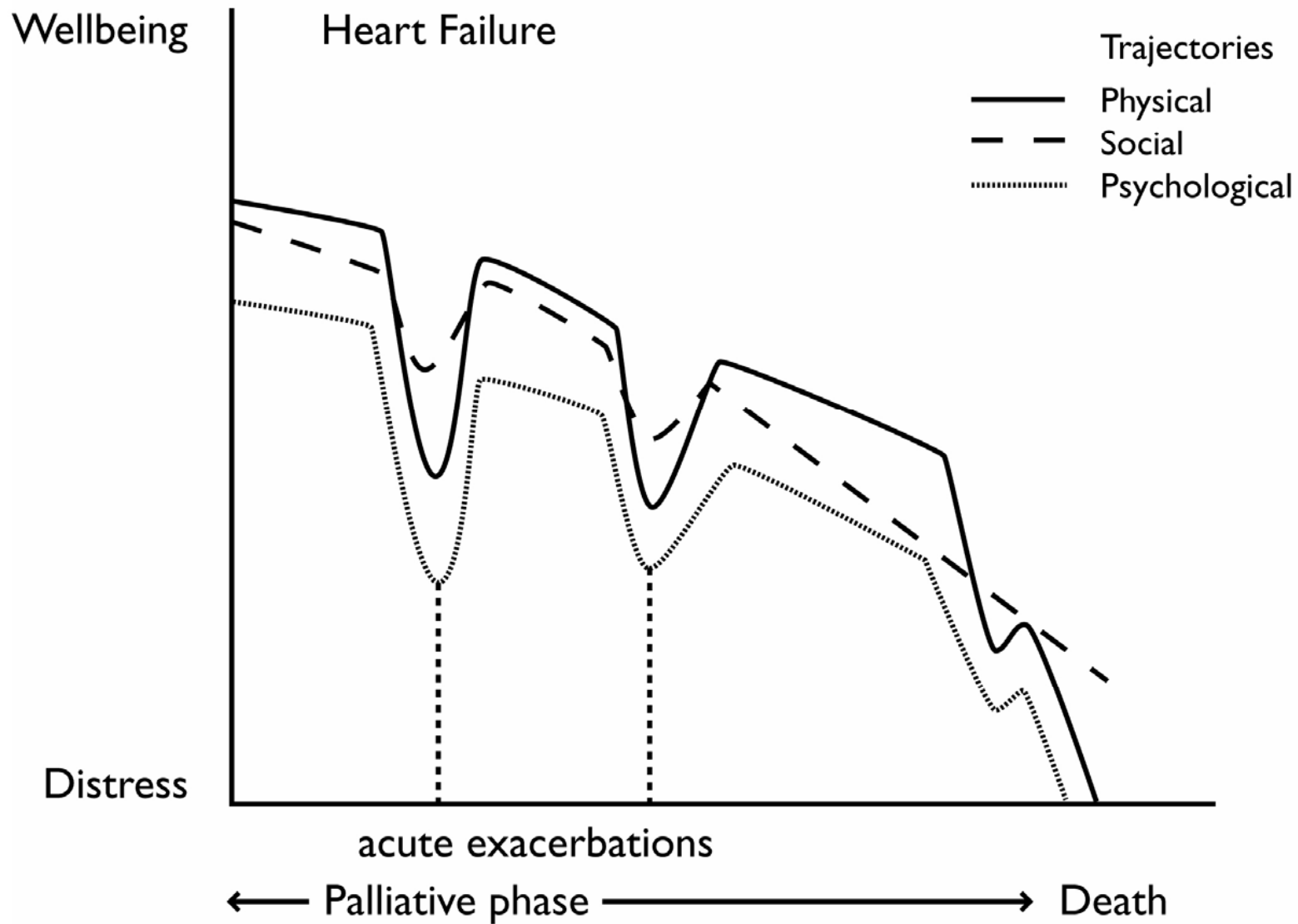
## Heart Failure - Psychological Trajectory

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.



**Figure 2:** Physical, social, psychological and spiritual wellbeing in the last year of life



## Heart – Spiritual Trajectory

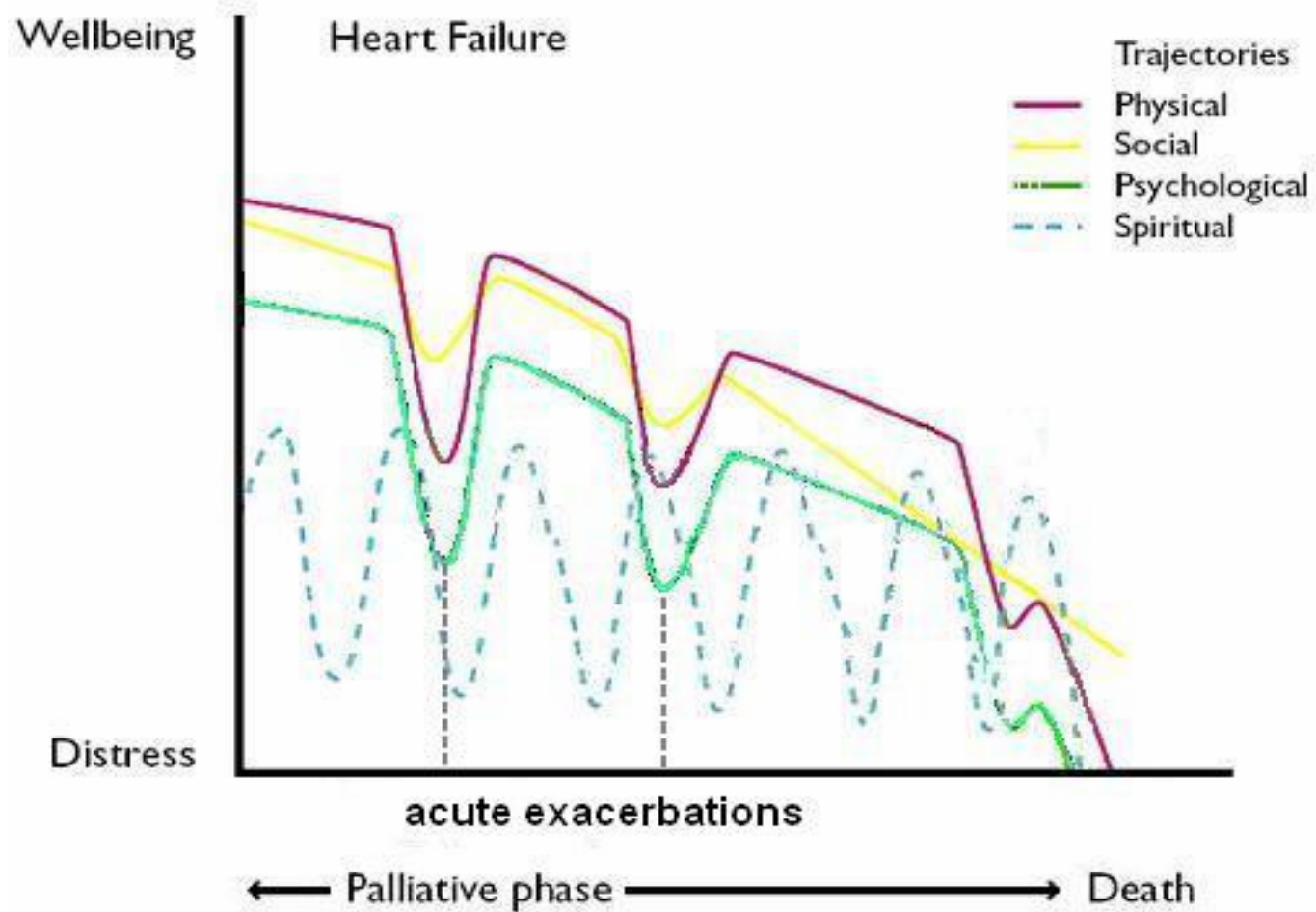
This reflected gradual loss of identity and growing dependence.

*“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.

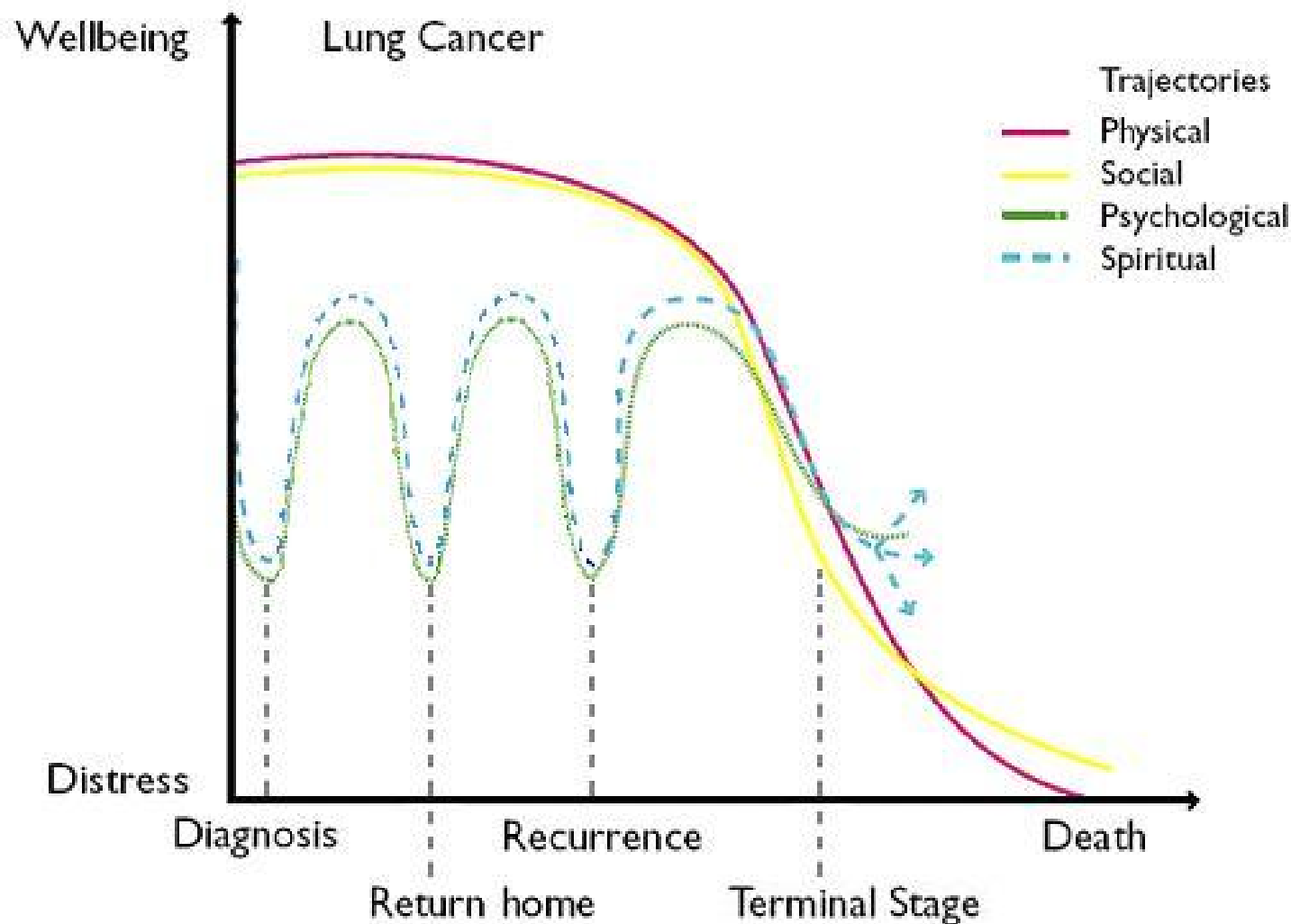
*“The most important thing that my GP does – well he assures me that I’m not away yet – he always listens”* Mr HU.

**Figure 2:** Physical, social, psychology and spiritual wellbeing in the last year of life



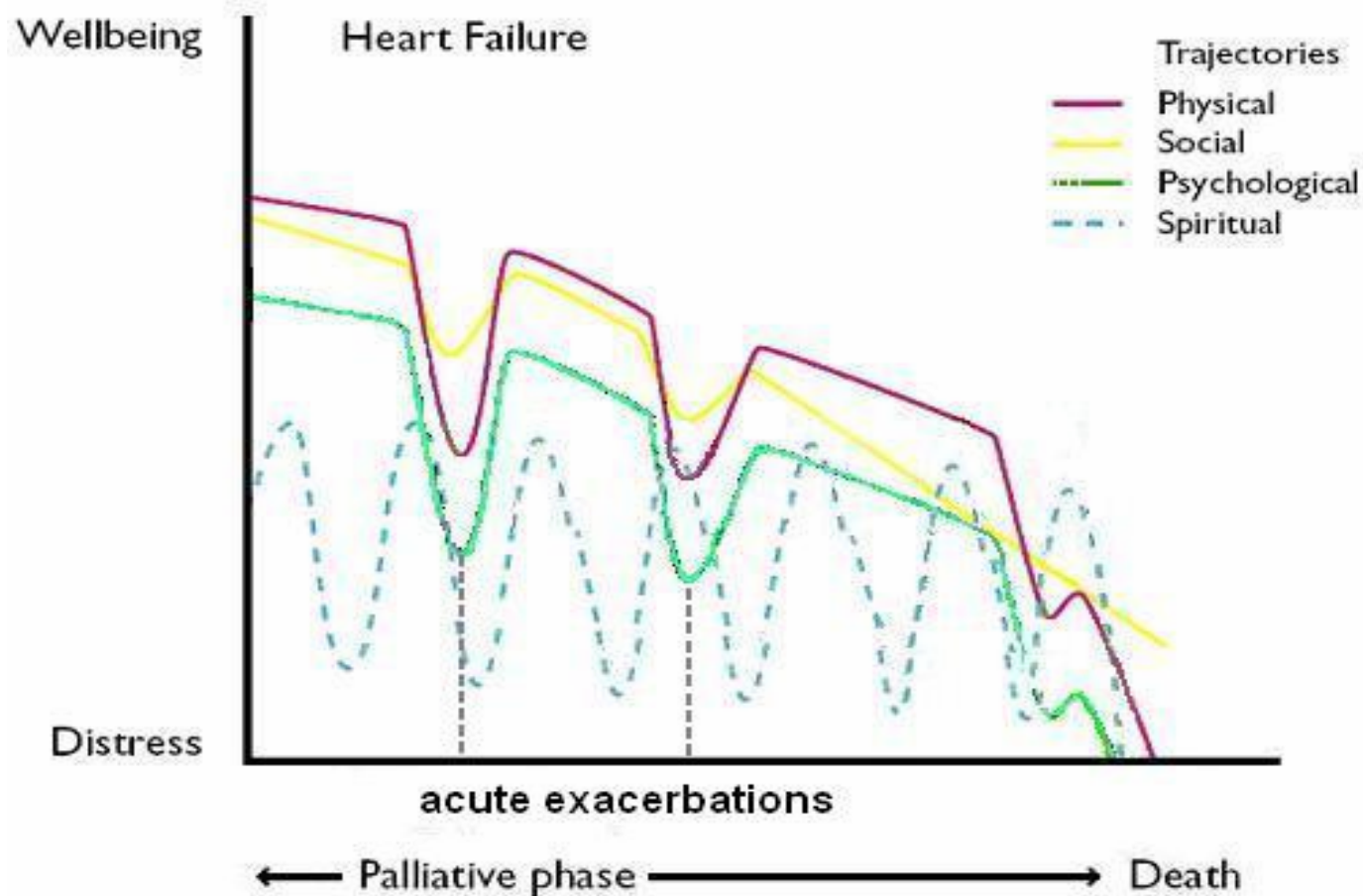
Lung cancer - physical and social trajectories interrelated, while psychological and spiritual distress tends to increase at four specific transitions.

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



Heart failure - social and psychological decline tend to track physical decline while spiritual distress tends to increase over time.

**Figure 2:** Physical, social, psychology and spiritual wellbeing in the last year of life



## Summary Points

What already known:

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

What this study adds:

- 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 care to meet their patients multi-dimensional needs better and may help patients and carers cope with their situations.

# **2nd Meeting of the International Primary Palliative Care research group**

*Primary Palliative Care Research: Current State  
and Future Agenda''*

**A pre-conference workshop at the UK Society  
of Academic Primary Care, University of  
Keele, near Manchester, England,  
11th and 12July, 2006**