"Tango Toscana" (by Quartet San Francisco)

Dancing to a different tune: living and dying with cancer, organ failure and physical frailty

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Paper currently in press with the Journal of Pain and Symptom Management

[Website of the Primary Palliative Care Research Group : http://edin.ac/14vvnGn](http://edin.ac/14vvnGn)

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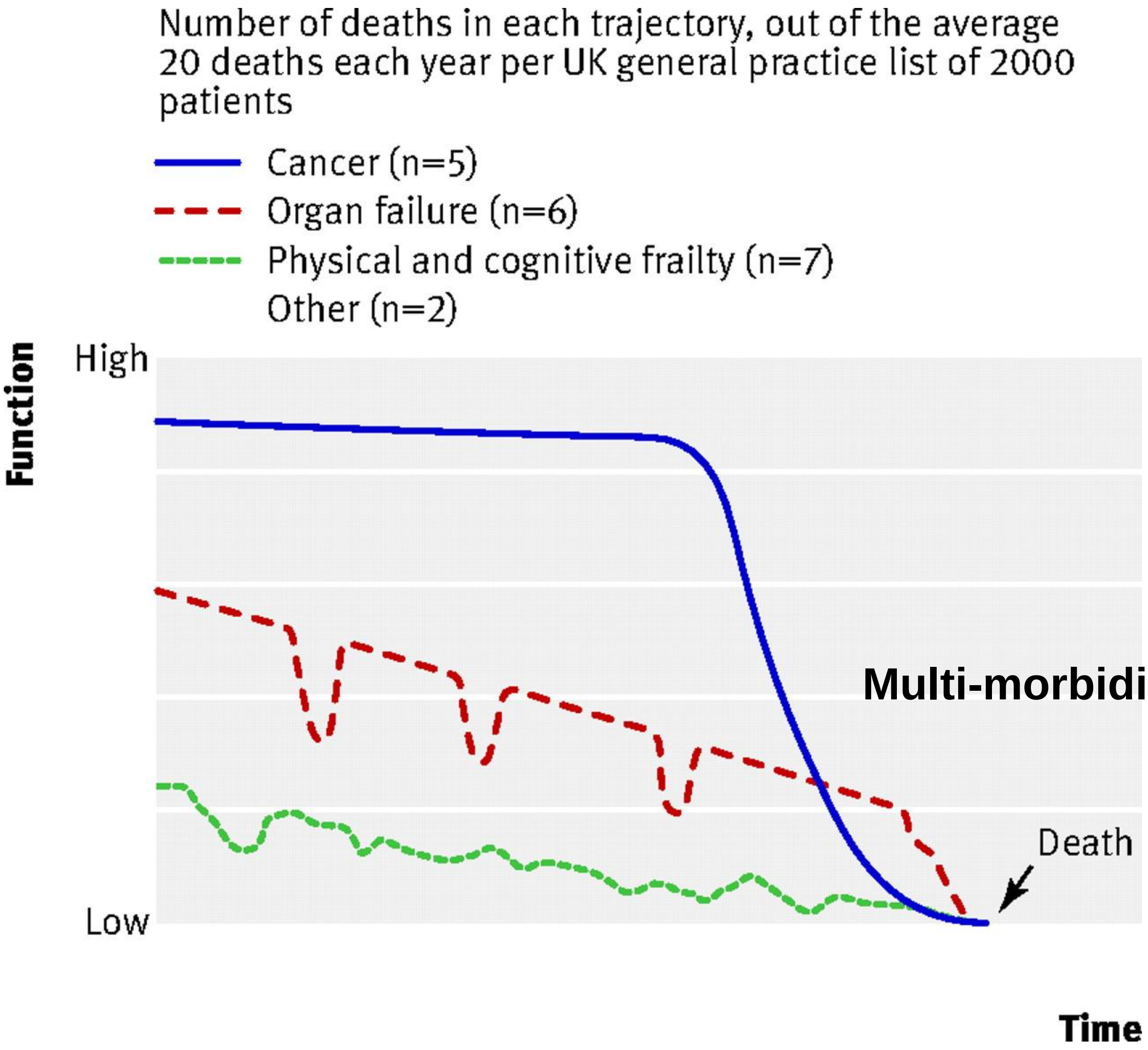

Multi-morbidities normal

Murray, S. A et al. BMJ 2008;336:958-959

Aim

- To establish whether there are archetypal and distinct experiences in different patterns of decline
  - -acute decline
  - -fluctuating deterioration
  - -gradual decline
- Propose any relevant redesign of services

Methods

- Qualitative longitudinal multi-perspective methods (1,2)
- Synthesis of 8 longitudinal studies carried out by the authors in the last 10 years
- 3 in cancer – lung, glioma and colorectal
- 3 in organ failure – heart failure, COPD and liver failure
- One in frailty and one with South Asian participants from all three trajectories
- The interview scripts had all been analysed previously with the support of Nvivo

1. Kendall M, Murray SA, Carduff E, Worth A, Harris F, Lloyd A, et al. Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs. BMJ. 2009 January 1, 2009;339:b4122.

2. Murray SA, Kendall M, Carduff E, Worth A, Harris FM, Lloyd A, et al. Use of serial qualitative interviews to understand patients' evolving experiences and needs. BMJ. 2009 2009-09-28 00:00:00;339:b3702.

Table 1 – Summary of study participants and interviews included in the synthesis of the eight studies

Study	Inclusion criteria	Number of patients interviewed (who died)	Age of patients in years	Number of family caregivers interviewed	Number of health professionals interviewed	Number of patient interviews	Number of caregiver interviews (bereaved)	No of health profess. interviews	Total number of interviews	Data capture period (months)
Lung Cancer[20]	Advanced disease	20 (8)	48-87	15	28	43	24(4)	40	107	12
Glioma[21]	From diagnosis	26 (14)	21-76	24	67	56	55(9)	67	178	12
Bowel Cancer[22]	Duke's stage D	16 (8)	48-80	8	0	36	19(3)	0	55	12
Heart Failure[23]	Breathless at rest	20 (6)	57-92	12	18	50	29(3)	33	112	12
COPD[24]	MRC4-5	21 (11)	50-83	13	18	52	28(2)	35	115	18
Liver failure[25] **(Kimbell PhD-unpublished)**	Advanced disease	15 (9)	34-84	11	11	32	21(3)	11	64	12
Frailty (Lloyd PhD-unpublished)	Frailty Scale – (Rockwood et al)	13 (5)	75-91	13	8	33	35(3)	8	76	18-24
South Asian participants[26]	Life limiting illness (Sikh or Muslim)	25 (6)	30-90	18	20	53	38 (4)	30	(92) 121	?6-12
Eight studies		156 (67)	21-91	114	170	355	249 (31)	224	828	6-24

20. Murray SA, Boyd K, Kendall M, Worth A, Benton TF, Clausen H. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. BMJ. 2002; **325**(7370): 929.
21. Cavers D, Hacking B, Erridge SE, Kendall M, Morris PG, Murray SA. Social, psychological and existential well-being in patients with glioma and their caregivers: a qualitative study. Canadian Medical Association Journal. 2012; **184**(7): E373-82.
22. Carduff E. Realising the potential: Developing qualitative longitudinal methods for understanding the experience of metastatic colorectal cancer. Edinburgh: University of Edinburgh; 2012.
23. Boyd KJ, Murray SA, Kendall M, Worth A, Benton TF, Clausen H. Living with advanced heart failure: a prospective, community based study of patients and their carers. European Journal of Heart Failure. 2004; **6**(5): 585-91.
24. Pinnock H, Kendall M, Murray SA, Worth A, Levack P, Porter M, et al. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. BMJ. 2011; **342**: d142.
25. Kimbell B, Kendall M, Boyd K, Murray SA. LIVING AND DYING WITH LIVER FAILURE: A SERIAL INTERVIEW STUDY. BMJ Supportive & Palliative Care. 2013; **3**(1): 124.
26. Worth A, Irshad T, Bhopal R, Brown D, Lawton J, Grant E, et al. Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. BMJ. 2009; **338**: b183.

Results

- 828 in-depth interviews
- 156 patients
- 114 family caregivers and
- 170 health professionals
- Many had multi-morbidities

Analysis

- An analysis framework based on three phases of illness narrative – becoming ill, living with advanced illness and dying was constructed
- A researcher from each study used the framework to review data from their own disease specific previous study and generated key themes
- Narratives initially synthesised by illness trajectory and we then compared the three phases of the narrative

Cancer – Am I going to die?

Beginning

- Diagnosis often rapid although sometimes distressingly slow
- People suddenly confronted with the possibility of dying

Middle

- People moving into a cancer world
- Managing treatments and difficulties adjusting to life
- Sometimes dual narratives encompassing hope for recovery alongside fear of dying

End

- Dying inevitable
- Triggering input from primary care

Box 1: Cancer narratives

Beginning

Well what happened was I had retired in the February and after a few months I thought I'm losing an awful lot of weight… and I went to see the GP…. Ms A, Lung Cancer

I was scared when they told me when they said there was a tumour. It knocked me for six. I thought, O my God, I am going to die…Mr C, Glioma

Middle

I honestly sometimes think there's nothing wrong with me…. Mr E, Lung Cancer

Well I think what we're trying to do is try and get back to a normal life as soon as possible… Mr F, Glioma

End

The main thing is, how long am I going to live? Ms I, Lung Cancer

Well obviously if it becomes terminal, we'll obviously be in a position to help, you know, we really would become involved. We would normally get the local palliative team. (GP of Mr W, 58 year old male, GBM)

Organ Failure – *"I know I won't get better but I hope I won't get worse"*

Beginning

- Patients, family caregivers and professionals often held different views about how their illness would progress
- Many patients struggle to say when their illnesses started or to make meaningful connections between acute episodes and their condition as a whole

Middle

- Chaotic seemingly unrelated events
- Frustration, isolation, hopelessness

End

- Few concerned about dying
- Described previous exacerbations

Box 2: Organ failure narratives

Beginning

It's hard to say when it started. Maybe a couple of years ago. I mean this is the third time I have been jaundiced…Mr M, Liver Failure

How it started is anybody's guess…Mr N, COPD

Middle

It's one day on top and the next day back under again…Mr O, Heart Failure

We are paddling downstream to Niagara. GP of Ms R, Heart failure

End

I know it won't get better, but I hope it won't get any worse… Ms S, Heart Failure

As long as the damn thing just keeps working the way it is working I'll be quite happy…Mr T, Liver Failure

Frailty – *"This isn't the real me"*

Beginning

- Patients, carers and service providers all struggled to recall when their health began to deteriorate

Middle

- People focussing on staying well and maintaining autonomy
- Frustrated as decline capacitated

End

- Viewed death as normal aspect of ageing

Box 3: Frailty narratives

Beginning

It was all due to an accident [story of a fall] but I've never really been the same you see… Mr V

Well, they haven't got an answer for it, neither have I… Mr W

Middle

*It's just a gradual deterioration, you can't expect anything else…*Mr X

You get annoyed at yourself for not being able to do it Ms Y

End

I said "I'm going home" I said "you're no putting me into any [nursing] home" Mrs X

I find, em preparing people for something that could happen tomorrow but actually might not happen for a year or two, you know, so it's quite difficult. GP Mr W

Box 4: Typical features of the three phases by illness trajectory

	Cancer	**Organ failure**	**Frailty**
Beginning	Usually a sudden, memorable event	Often no clear event, sometimes an illness episode	Often no clear event, just functional decline
Middle	Busy with treatment, then dual narrative of hope for ‘normality’ or even cure while fearing relapse	Uncertainty between exacerbations; trying to live ‘normally’ with frustrating limitations	Normalising and adapting; fear of dementia or nursing home admission
End	Hospice & palliative care involved; focus on a ‘good death’	Keeping going; hospice & palliative care limited and late	Slow or rapid final decline; hospice & palliative care rarely involved

Box 4: Typical features of the three phases by illness trajectory and patient perception of death

	Cancer	Organ failure	Frailty
Beginning **Death**	Usually a sudden, memorable event Death as a real threat	Often no clear event, sometimes an illness episode Death rarely considered	Often no clear event, just functional decline Death not a concern
Middle **Death**	Busy with treatment, then dual narrative of hope for ‘normality’ or even cure while fearing relapse Death backstage with occasional appearances	Uncertainty between exacerbations; trying to live ‘normally’ with frustrating limitations Brushes with death during exacerbations	Normalising and adapting; fear of dementia or nursing home admission Worries about “fates worse than death”
End **Death**	Hospice & palliative care involved; focus on a ‘good death’ Death centre stage	Keeping going; hospice & palliative care limited and late Might die, but might not, so why discuss it?	Slow or rapid final decline; hospice & palliative care rarely involved Death will happen in due course

Discussion

- We identified marked differences in people's experiences of progressive cancer, organ failure and frailty
- Patients with progressive cancer followed predictable trajectory and shared understanding of this with family and professionals
- Open acceptance about dying which facilitated hospice and palliative care involvement
- Patients with organ failure and frailty and their family carers were less aware of causes and likely progression and shared different views to health professionals
- Less coherent stories and focus on maintaining normality

Conclusions

- Dying was final chapter in illness narratives
- All patients and carers want support to avoid crises and enable them to manage ongoing restrictions while retaining normality
- Palliative care and hospice are currently too inextricably linked to imminent death to be acceptable and appropriate for some patients, carers and professionals
- We must learn from our experiences delivering palliative care for people with cancer, and develop new integrated approaches to provide patient-centred supportive care for people living with unpredictability and general frailty

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Dancing with Death

http://edin.ac/14vvnGn

Primary Palliative Care Research Group

A multi-disciplinary team with strong international links researching to improve end of life care in the community.

Professor Scott Murray explains
the vision of the group in a 1 minute video

Primary care is well placed to undertake palliative care for patients

- with all life-threatening illnesses
- from early in the course of the illness
- with all dimensions of need
- in all settings
- in all countries

and to support carers through the journey of illness and bereavement.