Metaphors for 'good' and 'bad' deaths in interviews with hospice managers

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Structure of talk

- The 'Metaphor in End of Life Care' project
- The data: interviews with hospice managers and 'good/bad' deaths.
- Metaphors for a 'good' death
- Metaphors for a 'bad' death
- Conclusions

The 'Metaphor in End of Life Care' project

- How do members of different stakeholders groups (health professionals, patients and unpaid family carers) use metaphor to talk about their experiences, attitudes and expectations of end-of-life care (e.g. palliative treatment, preparations for dying, etc.)?

- The way in which the experience of end-of-life care is talked about can shed light on people's views, needs, challenges, and emotions, as well as identify areas with a potential for increased anxiety and/or misunderstanding.

Background: hospices and end of life care in the UK

- Hospice care in the UK developed from the work of Dame Cicely Saunders in London's St Christopher's Hospice in the 1960s.

- It involves a holistic approach to the needs of patients with life-limiting or terminal illnesses.

- This approach takes into account the social, emotional and spiritual aspects of the patient's needs, alongside the physical dimension.

- The first End of Life Care Strategy for England and Wales was published by the Department of Health in 2008.

Interviews with hospice managers and 'good/bad' deaths

- As part of the 'Metaphor in End of Life Care' project, we asked thirteen hospice managers:

  'How would you describe a 'good' death? How would you describe a 'bad' death? Can you provide any examples from your experience?'

- While the 'good' vs 'bad' opposition was introduced by the interviewer, the notion of a 'good' death in particular is central to the hospice managers' profession.

Overview of the interviewees' responses

It is essential to give patients options, and to try to fulfill their wishes.

Most people wish to die at home, but hospice care can provide a better overall experience.

A 'good death' is a matter of perspective.

'Bad deaths' in hospices are a minority and tend to involve challenging circumstances, notably a difficult attitude on the patient's part.

'Good' deaths result from successful interventions

Overview of interviewees' answers

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- Interviewees expressed their views about good and bad deaths using:

    a) general statements about the characteristics of a 'good' or 'bad' death

    b) generic narratives about types of people and experiences

    c) narratives about specific individuals.

Method and main finding

- Three analysts used the 'Metaphor Identification Procedure' (MIP) proposed by the Pragglejaz Group (2007) to identify metaphorical expressions in the data.

- We focused on the metaphorical expressions used to describe 'good' and 'bad' deaths.

- Metaphors are used for both 'good' and 'bad' deaths, particularly to express evaluation – positive and negative aspects of different ways of dying.

A quantitative contrast

	Total no. of words	No. of relevant metaphorical expressions
A 'good' death	5,305	167
A 'bad' death	5,341	223

- Metaphors related to dying are more frequent in 'bad' death responses.
- The difference is significant at LL 7.69, p < 0.01

Metaphors of a 'good death'

'being at <u>peace</u>'
'having <u>peace</u>'

Metaphors to do with movement and journeys

'being pain-<u>free</u>', 'being symptom-<u>free</u>';
having one's symptoms '<u>controlled</u>' or 'well <u>managed</u>'

'having <u>open</u> discussions', 'talking <u>openly</u> with the family members about what was happening'

A good death – 'journey' metaphors

"I think a good death is where the patient and the family have <u>reached</u> an understanding that the death is going to <u>come</u> and that they're <u>where</u> they want <u>to be</u> and that they're as comfortable as they can be erm and that that the death happens in a peaceful way.

[…]

she [the patient's daughter] *was able to accept that it was the <u>end</u> so I think that's what you would call a good death. Where both the patient and the family have <u>reached</u> the <u>stage</u> of saying this is now <u>where where</u> it needs to <u>end</u>.*

More 'journey' metaphors

"I guess as a professional I'd like to see them comfortable and not suffering any form of distress or agitation that the patient comfortable, the family erm at peace with the <u>journey</u> as it's <u>going</u> and where things have <u>got to</u> erm and that you know they can <u>go through</u> a natural normal grief. That to me would be a good death."

Metaphors of a 'bad death'

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'where there is some <u>tension</u> or <u>discord</u> and it almost gets <u>amplified</u>'

'you can't quite <u>reach into</u> the scared <u>place</u> to support them'; things <u>hidden</u> or in the <u>background</u>

'they've <u>landed up there</u>'; emotions and situation <u>out of control</u>

'they haven't <u>accepted</u> yet that they're going to die'; help or support <u>pushed away</u>';

'for some people their life is a <u>struggle</u> or a <u>battle</u> or a series of <u>conflicts</u> that never quite resolve, and I suppose it's logical to say if their life's been like that, why would their death be any different?'; 'can't <u>settle</u>';

A bad death – 'battle' and other metaphors

for some people their life is a struggle or a battle or a series of conflicts that never quite resolve, and I suppose it's logical to say if their life's been like that, why would their death be any different? Erm so they are the deaths that I think that are psychologically difficult where somebody where somebody not only doesn't want to address it, cos people can die OK not having addressed it and be OK. But it's where they've not addressed it but actually there's a lot of fear in the background or a lot of battling in the background. And so you'd get this kind of horrible overlay of pretending it's not going on, but actually they're really scared and you can't quite reach into the scared place to support them, because they won't let you, but you know it's there. So I find those deaths really ... difficult, where the conversations that needed to happen haven't happened where the support's been pushed away or where you couldn't work out how to provide the support and you see people very very afraid in ... in the act of dying.

A bad death – 'fighting' and other metaphors

So I think ... dying you know where we <u>can't get</u> the symptoms completely <u>under control</u> erm dying perhaps where they didn't really want to die but circumstances they've <u>landed up there</u> erm and somebody who really still hasn't reconciled themselves and they want <u>to keep fighting fighting fighting</u> and therefore they want <u>all the stops pulled out to keep them going.</u> So those are the sorts of deaths that are that are difficult."

Metaphors for after a 'bad' death

I see her daughter professionally and she <u>carries</u> that distress still two years later and I think will <u>carry</u> it … maybe always and it will I suspect <u>colour</u> her <u>vision</u> of how her death might be or how her father's death might be in the future

the nursing staff have been erm <u>paralysed</u> or <u>overwhelmed</u> by seeing somebody so fearfully dying

Conclusions

- Metaphors help to describe the sensitive notions of 'good' or 'bad' death.

- Metaphors express evaluation:
  - Good deaths are described in terms of 'peace', 'freedom', 'control' and 'openness';
  - Bad deaths are described in terms of 'struggle/battle' and of negative feelings in the background that are invisible and hard to reach.
  - Metaphors help to 'normalize' 'good' deaths as a natural and accepted 'part' of life through 'journey' metaphors that also describe life in general.

- Metaphors are more frequent, varied and elaborate in 'bad death' narratives:
  - Such stories are even more sensitive, emotional and professionally challenging than those of good deaths.
  - Metaphor may be a way of evaluating patients' attitudes negatively without criticizing them too explicitly.

- This is consistent with Cameron's (2013) hypothesis that metaphor 'favours the negative'.

- Metaphors provide particular (but very consistent) evaluative framings of different ways of dying.

- These framings are linked to professional roles, challenges and views, and are likely to influence how professionals interact with patients and carers.

- However, these framings may not be shared with patients/ carers, e.g.
  - a 'good' death may be one where the patient fought until the end;
  - a 'good' death may not necessarily involve being 'open' about dying with one's family and/or the hospice staff.

- The consistency of the hospice managers' metaphors may contribute to preclude alternative framings.

Thank you

For more information:

http://ucrel.lancs.ac.uk/melc/