



## ‘Good’ deaths and ‘bad’ deaths: professional and lay narratives

Zsófia Demjén (Open University) and Elena Semino (Lancaster University)

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# Outline

- Interviews with hospice managers and general views on 'good' deaths and 'bad' deaths
- Metaphors of 'good' and 'bad' deaths
- Stories of 'good' and 'bad' deaths:
  - What the stories were about: successful and frustrated interventions
  - How these stories were told: pronouns, negation, hypotheticals, metaphor
- Implications of hospice managers' responses, with reference to examples of family carers' views

# The Interviews

- As part of the MELC project, we conducted semi-structured interviews with sixteen hospice managers on their views about end of life and end of life care.
- Towards the end of the approx. 45min interviews, we asked:

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

# Overview of the interviewees' responses

'Good' and 'bad' are a matter of perspective.

Most people wish to die at home, but hospice care can actually provide patients and their families with a better overall experience.

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

'Bad deaths' can occur in hospices but they are a minority and often involve difficult and challenging circumstances.

A 'good death' result from successful interventions

# Metaphors of 'good' and 'bad' deaths

'being at peace';  
'having peace'  
'being pain-free', 'being  
symptom-free'

'having open  
discussions', 'talking  
openly with the  
family members  
about what was  
happening'

'where there is some  
tension or discord and  
it almost gets  
amplified'

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

'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?'

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

# A 'good' death

“Erm I think of another gentleman who came to the hospice. He was a Portuguese speaker, pretty much no English at all and he'd had recurrent hiccoughs for about five months and the medical team put in a referral for him to have some acupuncture and looking at his case history he was getting so depressed not just with the hiccoughs but with his diagnosis of stomach cancer and he'd been suicidal at one stage, he was so depressed that he couldn't enjoy his wife's cooking. He was in one of the wards and was desperate to get better to go home. And we went to see him as a team and did some acupuncture and the recurrent hiccoughs erm reduced considerably in the first instance and then and then stopped and he was able to go home. And so I think that was a good piece of collective collaborative work to actually fulfil the wishes of you know he wanted to get home spend a bit of time and be able enjoy his wife's cooking. Erm He died a few months later but I think that was an illustration of you know an immediate sort of response to a request that worked quite well.”



# Zooming in: negative aspects and negation



*“He was a Portuguese speaker, pretty much **no** English at all and he'd had **recurrent hiccoughs** for about five months and the medical team put in a referral for him to have some acupuncture and looking at his case history he was **getting so depressed** not just with the hiccoughs but with his diagnosis of **stomach cancer** and he'd been **suicidal** at one stage, he was **so depressed** that he **couldn't** enjoy his wife's cooking. He was in one of the wards and was **desperate** to get better to go home.”*

- Detailed background with an emphasis on:
  - Negative aspects of the situation
  - Absence of positive aspects, that would have helped: no English, couldn't enjoy wife's cooking
- In this context, the person is likely to have a bad death.

# Zooming in: pronouns/actors



*“And **we** went to see him **as a team** and did some acupuncture and the recurrent hiccoughs erm reduced considerably in the first instance and then and then stopped and he was able to go home. And so I think that was a good piece of **collective collaborative** work to actually fulfil the wishes of you know he wanted to get home spend a bit of time and be able enjoy his wife's cooking.”*

- Professionals acting together (‘we’, ‘collaborative’, ‘team’) are responsible for solving one of the main problems affecting quality of life. The patient’s main wish is thereby realised.
- As the person’s main problem cannot be solved, success/good death here involves the reestablishment of as much ‘normality’ as possible.



# Another 'good' death



The story of patient who was moved from hospital to the hospice at the last minute:

*“it a was a young patient who in his thirties, his wife was there he got two young children his wife had been told and if he hadn't have come to us and he died the next morning and it was quick we weren't expecting it to be that quick but if he hadn't have been if his wife hadn't have been if he'd have stayed in the hospital acute setting his wife probably wouldn't have been told wouldn't have realised and he might have just died on his own behind some curtains erm you know without you know the level of sort of comfort erm dignity, attention to his needs and his family.”*

# Zooming in: hypothetical scenarios (and negation)



*“and **if** he had**n't** have come to us [...] and it was quick we weren**n't** expecting it to be that quick but **if** he had**n't** have been **if** his wife had**n't** have been **if** he'd have stayed in the hospital acute setting his wife probably would**n't** have been told would**n't** have realised and he **might have** just died on his own behind some curtains erm you know without you know the level of sort of comfort erm dignity, attention to his needs and his family.”*

‘Irrealis clauses serve to evaluate the events that actually did occur in the narrative by comparing them with an alternate stream of reality: potential events or outcomes that were not in fact realized.’ (Labov 2011)

# 'Bad' deaths: narratives of frustrated intervention

*"I mean I have one lady who comes to mind right from my early weeks of working in palliative care. She's a lady who'd suffered a lot of anxiety in her life and had a difficult relationship with her husband, and did battle with everyone. Nothing was ever right, nothing was good enough, nothing, you couldn't physically get her comfortable. You couldn't kind of get in a good place to meet her psychologically erm ... I think she felt that being comfortable was being patronised and that made it really difficult to offer her any support. And she had quite a traumatic death in that she ... not only died vomiting, she had a bowel obstruction, erm but died very fearful and very anxious and wouldn't accept any pain relief. ... So I think her life how she'd lived it play out right into the very last moment. And that was difficult for staff team, cos we couldn't do the things we each felt we could have done."*



# Zooming in: negation, pronouns and metaphor



*“and did **battle** with everyone. **Nothing** was ever right, **nothing** was good enough, **nothing**, **you** couldn't physically get her comfortable. **You** couldn't kind of get in a good **place** to **meet** her psychologically” [...]*

*“And she had quite a traumatic death in that she ... not only died vomiting, she had a bowel obstruction, erm but died very fearful and very anxious and wouldn't accept any pain relief” [...]*

*“And that was difficult for staff team, cos **we** couldn't do the things **we** each felt **we** could have done”*

- Details of difficult circumstances and personality
- Metaphors allow implicit criticism of patient behaviour and attitudes
- Highlights things that did not happen, but should have
- ‘You’ suggests that other people in the same situation would have behaved/felt the same

# Another 'bad' death



*“a bad death to me was a patient that had wanted to stay at home and yet the family clearly weren't coping to look after the patient at home, so eventually the patient agreed to come in and be cared for with us. So we never really got it was they were very very poorly when they came in so we never really got to know them properly erm so we weren't able to have those conversations and we weren't able to really establish what his wishes were properly erm and then I suppose what he wanted was very different to what his family wanted.”*

# Zooming in: negation and external circumstances



*“a bad death to me was a patient that had wanted to stay at home and yet the family clearly weren't coping to look after the patient at home, so eventually the patient agreed to come in and be cared for with us. So we never really got it was they were very very poorly when they came in so we never really got to know them properly erm so we weren't able to have those conversations and we weren't able to really establish what his wishes were properly erm and then I suppose what he wanted was very different to what his family wanted.”*

- Ineffective intervention due to external circumstances:
  - Patient didn't want to go to the hospice, and agreed to go in, but too late, leading to imperfect care
  - Patient's wishes were different from family's
- Focus on what could not happen because of these circumstances

# Story Styles

## *How are 'good' and 'bad' death narratives told?*

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- Interviewees were quite consistent in their descriptions of 'good' and 'bad' deaths
- For 'good' deaths, they told 'narratives of successful intervention', at the centre of which are detail of how hospice staff deal with the problems that would otherwise led to a 'bad death'.
  - Quantitative evidence supports this: Hypotheticals are more frequent in 'good' death narratives, emphasizing the importance of an intervention by contrasting it with alternative scenarios that were averted.

# Story Styles

*How are 'good' and 'bad' death narratives told?*

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- For 'bad' deaths, interviewees tell 'narratives of frustrated intervention', where the staff's efforts to help are frustrated by circumstances beyond their control.
  - Quantitative evidence supports this: negatives are more frequent in 'bad' death narratives; a 'bad' death is described in terms of what it was not (but should have been), so it occurs where expectations are not met.



# Story Styles

*How are 'good' and 'bad' death narratives told?*

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- Overall, interviewees use narratives to help to convey the value and contribution of their own profession, and to counter the view that the best death is necessarily in the person's home.
- 'I' is rarely used to refer to the interviewee as a story participant. Instead, the 'we' or a generic 'you' are used to refer to interviewee and colleagues as a team doing their best for the patient.
- 'We' is more often used in 'good' death narratives and 'you' is more frequent in 'bad' death narratives.
- Metaphor is also more frequent in 'bad' death narratives. It is used to implicitly/indirectly evaluate patients.

# Implications of story styles



- Professionals' role, responsibility and actions are emphasized in 'good' death narratives, while they are backgrounded in 'bad' death narratives
- In 'bad' death narratives, external circumstances and patient attitudes and behaviour are emphasized.
- A relatively unified view:
  - Both 'good' and 'bad' deaths are particular framings of what patients experience and these framings presumably influence how professionals interact with patients and carers.
  - Such a consistent professional view may leave little room for alternative conceptualizations.

# Family carers' views from online forums: an example



“I just want to be able to talk to him and hold him in my arms. He was in **too much pain** prior to his death for me to be able to do that so I feel that **we were robbed of that** long before he died. [...]

I know this next statement will sound irrational but I feel that **the last two days at the hospice were stolen from us** because of **a couple of the people who decided they knew what would help you**. Well **they didn't did** they because **they couldn't save you** and just **ruined the last visit** my poor sister had with you. At least they had the grace to **let me do the last possible service I could for you** after you died. Not that they had any choice **because I told them I was doing it**. I only hope that you know it was me and not some stranger. [...]

# Another example

- “My mum chose the same route as yours choosing to **lock herself away** and **wasting the little time she had left** and i found it very frustrating as i was her carer 24/7 and i feel guilty admitting this but **i thought she was selfish** as **i felt like i was dying too** by the end **i was like a cork on a bottle waiting to explode** by the end.”

# Concluding reflections

- We have no systematic data on family carers' views on 'good' and 'bad' deaths.
- However, these few examples show that:
  - Like the hospice managers we interviewed, family carers tend to lay at least part of the blame for a 'bad' death on someone else;
  - There can be tension over what is seen as a 'good' death, both between family carers and patients, and between family carers and health professionals:
    - What is help and support for health professionals could be 'ruining' or 'stealing' the last few days for family carers;
    - What is 'peacefulness' and 'acceptance' for the patient may be 'locking oneself away' selfishly for their families.

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Thank you

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# References



Carpentier, N. & Van Brussel, I. (2012) On the contingency of death: a discourse-theoretical perspective on the construction of death, *Critical Discourse Studies*, 9(2), p99

Clarke, A. and Seymour, J. (2010) “At the foot of a very long ladder”: discussing the end of life with older people and informal caregivers, *Journal of Pain and Symptom Management*, 40(6), p857

Dempster, P.G. (2012) Memorialisation and the metaphor of final journeys: workers’ experiences of dealing with death within care homes for the elderly, *Mortality: Promoting the interdisciplinary study of death and dying*, 17(3), p221

Holmes, J. (2005) Story-telling at work: a complex discursive resource for integrating personal, professional and social identities. *Discourse Studies* 7 p671

Kövecses, Z. (2000) *Metaphor and Emotion: Language, Culture, and Body in Human Feeling*. Cambridge: Cambridge University Press.

Labov, W. (1972) *Language in the Inner City*. Philadelphia: University of Pennsylvania Press.

Labov, W. (2011) Narratives of Personal Experience. In Patrick Hogan (ed.), *Cambridge Encyclopedia of the Language Sciences*. Cambridge: Cambridge University Press.

Norricks, N. (2005) The dark side of tellability, *Narrative Inquiry*, 15(2), p323

Pragglejaz Group (2007) MIP: A method for identifying metaphorically used words in discourse, *Metaphor and Symbol*, 22(1), p1

Ryan, M-L. (2005) Tellability. In D. Herman et al. (eds). *Routledge Encyclopedia of Narrative Theory*. London: Routledge, p589