

What is a 'good death'?

Narratives, metaphors and professional identities in interviews with hospice managers

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*Do not go gentle into that good night,
Old age should burn and rave at close of day;
Rage, rage against the dying of the light.*

~ Dylan Thomas

A red curved shape in the bottom right corner of the slide.

Overview of today's talk



- As part of the ESRC-funded project 'Metaphor in End of Life Care', we asked fifteen hospice managers:
'How would you describe a good death? Can you provide any examples from your experience?'
- Today we discuss the ways in which they use narratives and metaphors in their responses.
- We reflect on the links with interviewees' professional views, challenges and identities.

Overview of the interviewees' responses

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

Professionals have their own views on what is a 'good death', which are linked to their professional roles.

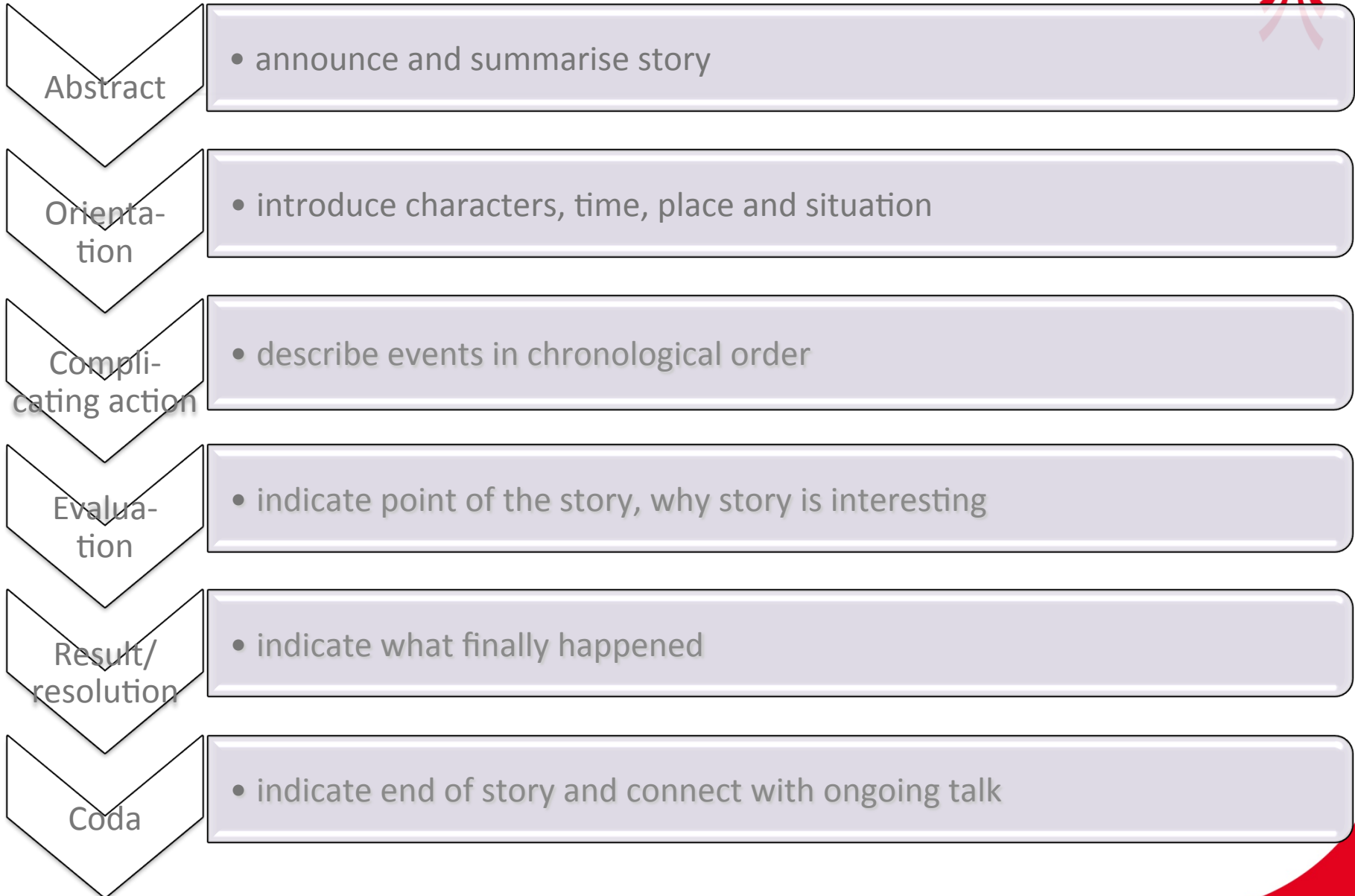
A 'good death' is a matter of perspective.

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

How did professionals say what they said?

- Interviewees express their views about good deaths using:
 - a) general statements about the characteristics of a 'good death'
 - b) generic narratives about types of people and experiences
 - c) narratives about specific individuals.
- Metaphors feature most frequently in (a) and (b).

Labov's Narrative Structure



An example narrative of successful intervention



“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.”

Narratives of 'successful intervention'

- In Labov's terms:
 - Orientation: details of problems likely to lead to a 'bad death'
 - (De-)complicating action: solution of problems on the part of professionals acting as a team, often in a hospice setting, ensuring a 'good death'.
 - Resolution: the person's death
 - Evaluation in different places but often at the end: 'irrealis clauses' and a variety of expressions of positive or negative evaluation.

Abstract

“Erm I think of another gentleman who came to the hospice.”

- Reference to patient and the main event that transforms the patient's experience of end-of-life: 'came to the hospice'.

Orientation

“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: recurrent hiccoughs, depressed, stomach cancer, suicidal, desperate
 - Absence of positive aspects: no English, couldn't enjoy wife's cooking
- In this context, the person is likely to have a bad death.

(De-)complicating action/ Successful intervention

“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.”

- Professionals acting together solve one of the main problems affecting quality of life, so that the patient's main wish is realised.
- As the person's main problem cannot be solved, success here involves the reestablishment of as much 'normality' as possible: no hiccoughs, going home.
- Use of 'we' to refer to the group of colleagues of which interviewee is part.

Resolution?

“Erm he died a few months later.”

- This is almost an afterthought as the death of the patient is an obligatory and predictable part of the story.

Evaluation

“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. [...] I think that was an illustration of you know an immediate sort of response to a request that worked quite well.”

- The appropriateness, success and ‘tellability’ of these stories hinges on what makes the death ‘good’.

Narratives, death and tellability: previous studies

- Labov on (danger of) death stories:
 - ‘At one end of the scale [of reportability/tellability], death and the danger of death are highly reportable in almost every situation.’ (Labov 2011)
- Ryan (2005) describes death as an eminently ‘tellable’ topic.
- Norrick (2005), in contrast, includes stories about death as examples of potentially ‘untellable’ events – above what he calls a ‘tellability threshold’.
- NB ‘Evaluation’ can mean:
 - describing a death as ‘good’(everyday sense)
 - outlining why a story is worth telling (Labovian sense)
 - in the case of our data, the two are inextricably linked

A narrative consisting almost entirely of evaluation?

“Well it it's perceptions as well because you know people do feel it's a really good death to have perhaps got somebody home to die and they've died at home or whatever erm but equally there can be times when someone's really struggled at home we've got somebody in to the hospice and they've died half an hour later and actually that would have been a far nicer death than than struggling in a crisis at home or in the back of the back of the ambulance coming to the hospice. [...]

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.”

Orientation

*“it a was a young patient who in his thirties, his wife was there
he got two young children his wife had been told”*

- The details provided suggest a difficult situation: ‘young patient’, ‘young children’, ‘his wife’.

Minimal complicating action?

“and he died the next morning”

- The main action of this story is not made explicit because it can be inferred from what has been said before:
 - The patient was moved from elsewhere (a hospital) to the hospice just in time to die in the hospice.

Evaluation

“and if he hadn't have come to us [...] 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.”

‘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)

What is metaphor?

Talking and, potentially,
thinking about one thing
in terms of another.

Metaphor

Often used to
communicate about
experiences that are
subjective, complex and
sensitive, including death
and the emotions around
death (e.g. Kövecses
2000).

We apply a well-
established analytical
method (Pragglejaz
Group 2007) in order to
identify the metaphors
that were used by
interviewees to describe
the characteristics of a
good death.

Metaphors of a 'good death'

'being peaceful', 'being
at peace'; 'having peace'
'being pain-free', 'being
symptom-free'
(cf. Carpentier and van
Brussel 2012)

Metaphors to do
with movement
and journeys
(cf. Lakoff and Turner
1989, Dempster
2012)

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

Metaphors to do with journeys and movement



“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 journey as it's going and where things have got to erm and that you know they can go through a natural normal grief. That to me would be a good death.”

Metaphors to do with journeys and movement cont.

"I think a good death is where the patient and the family have reached an understanding that the death is going to come and that they're where they want to be 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 end so I think that's what you would call a good death. Where both the patient and the family have reached the stage of saying this is now where where it needs to end.

Summary: the role of narratives

- 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.
- They tell 'narratives of successful intervention', at the centre of which is arguably not a 'complicating action' (in Labov's terms) but a 'de-complicating action': the professionals deal with the problems that would otherwise led to a 'bad death'.
- The ending (the person's death) is fixed and predictable.
- They are narratives of personal experience in that the speaker suggests that they were directly involved in each case.

Summary: the role of narratives cont.

- However, 'I' is never used to refer to the interviewee as a story participant.
- The exclusive 'we' is used to refer to interviewee and colleagues as a team successfully and sensitively tackling problems that would prevent a good death → group professional identity.
- The tellability of each narrative hinges on evaluation (a *good* death). This is realised in a variety of ways, including conditional clauses expressing alternative events that would have led to a 'bad death'.

Summary: the role of metaphor

- Metaphors are used to express:
 - The ways in which patients having a good death feel (e.g. ‘at peace’, ‘pain-free’);
 - Explicit conversations and shared awareness that the patient is close to death (‘open discussions’);
 - States and changes in the patient’s and family’s experience, grief, overall success in dealing with end of life, often with a euphemistic component (‘journey’ metaphors).

Thank you!!

Any questions or comments?

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