

International Observatory  
on End of Life Care




# The 'Metaphor in End-of-Life Care' project: data, questions and methods

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Metaphor in End-of -Life Care Project (ESRC grant ES/J007927/1)

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# Background to the project



- Hospice movement in the UK since the 1960s.
- 2008: first End of Life Care Strategy for England and Wales published by the Department of Health.
- 2009: the UK's National Council for Palliative Care creates the 'Dying Matters' coalition: it aims 'to promote public awareness of dying, death and bereavement'.
- 2012-13: controversy around the 'Liverpool Care Pathway'.
- 2013: the European Association for Palliative Care (EAPC) launches 'The Prague Charter', which 'urg[es] governments to relieve suffering and recognize palliative care as a human right.'

# Assumptions and research questions

- 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.
- How do members of different stakeholders groups (health professionals, patients and informal carers) use metaphor to talk about their experiences, attitudes and expectations of end-of-life care (e.g. terminal illness, palliative treatment. preparations for dying)?
- What does the use of metaphor by these stakeholder groups suggest about the experiences and needs of the members of these groups and their mutual relationships?

# Why metaphor?

- Metaphor involves talking, and potentially thinking, about one thing in terms of another. The two ‘things’ are different but some form similarity can be perceived between them. For example:
  - ‘I am fast becoming a chemo veteran’  
(from a patient writing an online forum post in our data)
- Metaphors are often used to communicate about experiences that are subjective, complex and sensitive, including emotions, illness, life and death.

- Metaphors occur frequently in language, and are often conventionalised: e.g. ‘a long battle against cancer’.
- Different metaphors ‘frame’ the topic in different ways: e.g. having cancer as a ‘battle’ or a ‘journey’.

You have a lot to dig in and fight for and I know you can and will. Dust yourself down and prepare for the battle girl

So sorry to hear what your partner is going through. MM [Malignant melanoma] is a hard road to travel both physically and mentally.

# Data: the MELC corpus

1.5 million words; 90,000 manual sample

	Patients	Carers	Healthcare professionals	Total
Semi-structured interviews	100,859	81,564	89,943	272,366
		90,000		
Online forum posts	500,134	500,256	253,168	1,253,558
Total	600,993	581,820	343,111	1,525,924

# Interview data

- 16 interviews with senior healthcare professionals working in hospices or hospital-based palliative care (for this project, 2012).
- 29 interviews with terminally ill patients, in their homes or hospice day care settings (for the Ethnicity and Cancer Care project carried out by Sheila Payne & colleagues, 2006-2008).
- 17 interviews with unpaid family carers, in the carers' homes and by telephone (for the evaluation of the Help the Hospices Major Grants Programme for Carers of those who are terminally ill, carried out by Sheila Payne & colleagues, 2005-2009).



# Online forum data

- Patient and carer data mass-downloaded from a publicly accessible online cancer support forum, then relevant data around end-of-life care extracted manually for inclusion.
- Criteria for inclusion:
  - participants self-identify as being terminally ill
  - participants self-identify as caring for someone who is now terminally ill, or has recently died following terminal illness.
- Professional data mass-downloaded from a publicly accessible online forum for medical professionals, then relevant data around end-of-life care extracted manually.
- Supplemented with posts on end-of-life care from UK doctors' blogs, and online comments from medical professionals on *British Medical Journal* articles addressing end-of-life/palliative care .

# Manual analysis of 90,000-word data sample: identifying and grouping metaphors



there's that phrase that people die as they've lived. And 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

# Computer-aided analysis of the whole dataset

Lexical concordances: searching for a specific word

```
;"239"> Anthony Chemo can be a powerful weapon which can halt or slow down the progress  
the key to the armoury so I may choose a weapon and load the magic bullet to dispatch wi  
erday . These things happen . My secret weapon is keeping the ultra sound at the hospit  
or . I think it 's a genuinely effective weapon against what we have : a good laugh is s  
ean free to buy an AK47 or an automatic weapon at the store of one 's choice . It grate
```

# Computer-aided analysis of the whole dataset

Semantic concordances: searching for words belonging to a particular area of meaning

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. I 've been in palaces and battlefields and I 've got so many medals  
omy but still get occasional shooting pains on the site of my surge  
t know when . I am a walking time bomb , so I have added this blog  
n this whole thing is such a mine field and for someone like me , who  
r those , feeling a bit more armed with responses- still trying  
superate ! Maybe that 's the rebel popping out in me still ... !
```

# Computer-aided analysis of the whole dataset

Parts-of-Speech concordances: searching for grammatical categories

and yet the family clearly were	n't	coping to look after the patient
now them properly erm so we were	n't	able to have those conversations
those conversations and we were	n't	able to really establish what his
g is the family felt that we had	n't	done the best and so that was rea
e felt you know I suppose it was	n't	necessarily a bad death cos we fe
ll we could for him but we could	n't	make do make it right for the fam
cases where people erm people do	n't	have a good death and I think oft
hrashing around erm it just does	n't	feel under control . I suppose th

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Any questions?

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# References



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eMargin (2011-2013) Developed by Matt Gee & Andrew Kehoe. Research and Development Unit for English Studies, Birmingham City University. <http://emargin.bcu.ac.uk/>

Rayson, P. (2008) From key words to key semantic domains. *International Journal of Corpus Linguistics*. 13(4), 519-549. <http://ucrel.lancs.ac.uk/wmatrix/>