

Essential language in palliative care: new understanding of metaphor use

Sheila Payne, International Observatory on of Life Care

Research team: Veronika Koller, Jane Demmen, Andrew Hardie, Paul Rayson, Elena Semino (Lancaster University) and Zsófia Demjén (Open University)

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

Outline

- The Metaphor in End-of-Life Care project:
 - Background
 - Aims and questions
 - Methodology
- Selected findings and some implications:
 - Metaphors for good/bad deaths in interviews with hospice managers
 - Metaphors used to talk about carers' experiences of emotion
 - Violence and journey metaphors
- Implications for policy and practice

Why does language matter?



- 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'
- 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'



2012-13: controversy around the Liverpool Care Pathway

 INDEPENDENT
REVIEW OF THE
LIVERPOOL
CARE PATHWAY

**MORE CARE,
LESS PATHWAY**
A REVIEW OF THE
LIVERPOOL CARE
PATHWAY

Metaphor in end-of-life care project: aims and research questions



- How do members of different groups (health professionals, patients and family 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)?
- 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.

Why metaphor?

Talking and, potentially, thinking about one thing in terms of another, where the two 'things' are different but some form similarity can be perceived between them: e.g. 'chemo veteran'.

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 in the data.

Metaphor

- Metaphors occur frequently in language, and are often conventionalised: e.g. ‘a long battle against cancer’.
- Conventional metaphors in language have been claimed to reflect metaphors in thought – ‘conceptual metaphors’ (Lakoff and Johnson 1980).
- Different metaphors ‘frame’ the topic in different ways.

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

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

Sample corpus: manual methods

- Manual intensive analysis of 90,000-word sample using eMargin



developed by Matt Gee and Andrew Kehoe (Birmingham City University)

<http://emargin.bcu.ac.uk/>

Collaborate: share texts online and amongst groups

Annotate: highlight, view others' annotations, discuss parts of a text

Categorise: use colours and tags/labels

Search: e.g. for metaphors with labelled source domains

Some initial metaphors

Physical ('are there services ... to pick up that need?')

Length ('how long was the ... group session?')

Size ('little talks')

Link ('join in')

Loss ('he lost his sister to cancer')

Possession ('I just keep an open mind')

Burden ('illness well borne')

Body ('you face the truth then')

Visual ('you might as well look forward')

Money ('every day is a bonus day')

Exchange ('you took up the offer')

Value ('if you don't life ain't worth living')

Some initial metaphors

Containment ('they came out with different comments')

Openness ('I just keep an open mind')

Restraint? ('pain control')

Religion ('we all worshipped my dad')

Magic ('[doctors] are not genies')

Sport/Games ('juggling your drugs')

Machine ('“your body's functioning properly”')

Building ('cancer support group')

Destruction ('he was absolutely devastated')

Some initial metaphors: Violence and journey

Violence ('all those family feuds')
Enemy? ('they raged against it')

Military ('he was the one in charge of the aneurisms')

Force ('that knocked us both for six')

Journey ('[the illness] is taking its course now')

Movement ('whether it's going to go from my kidneys to my pancreas')

Speed ('it was grade three which is quite a fast one')

Direction ('he kept seeing me through')

Down ('it gets you down a bit')

Up ('our staff are highly skilled')

Obstacle ('I get over it')

Location ('You want to know where you are')

Closeness ('it's too close to home for her')

From manual to semi-automated analysis

eMargin



The screenshot shows the MELCdb interface with a query result table. The table has columns for ID, Color, Tag, Head, Token, Tail, and File. It displays a list of items with their corresponding tags and text snippets.

ID	Color	Tag	Head	Token	Tail	File
58	yellow	Movement	be given evidence as they	approach	the best hours of their	Orkney Professional 2.xml
59	yellow	Movement	to be alert as they	pass	from one life to the	Orkney Professional 2.xml
60	yellow	Direction	be alert as they pass	them	and life to the next	Orkney Professional 2.xml
62	yellow	Direction	they pass from one life	to	the next	Orkney Professional 2.xml
63	yellow	Location	aware of, not just	at	the end of life	Orkney Professional 2.xml
65	yellow	Journey	I not just at the	and	of life	Orkney Professional 2.xml
116	yellow	Physical	topic and usually will not	spark	too much competing interest with	Orkney Professional 2.xml
119	yellow	Spoken/Written	will not spark too much	competing	interest with some religiously concerned	Orkney Professional 2.xml
130	yellow	Military	think the	interventions	among only the seriously	Orkney Professional 2.xml
173	yellow	Movement	some may wish not to	put	out if they are in	Orkney Professional 2.xml
174	yellow	Location	with which and to end	are	if they are in	Orkney Professional 2.xml



XML export



Wmatrix

Using Wmatrix (USAS): the semantic domain 'Warfare' (G3)

KIIC context results G3

[\[Tagging > Tag Wizard... \]](#) [\[My Tag Wizard... \]](#) [\[Domain Tag Wizard... \]](#) [\[Load file without tagging... \]](#)
[\[Folders > My folders \]](#) [\[Details \]](#) [\[Create... \]](#) [\[Delete... \]](#) [\[Archive... \]](#) [\[Extract... \]](#) [\[Join... \]](#) [\[Share... \]](#) [\[Empty TRASH \]](#)
[\[Options > Switch to Simple Interface \]](#) [\[Edit user options... \]](#)
[\[Help > Contents \]](#) [\[Availability \]](#) [\[Tagsets: POS & Semantic \]](#) [\[USAS: Lexicon & MWEs & Context rules \]](#) [\[Updates \]](#) [\[Feedback \]](#)

[\[You are here > My folders > MELC-CompleteSampleCorpus \]](#) [\[File details \]](#) [\[Summary sheet \]](#)

Export concordance

with tabs between keyword and left/right context (right mouse click on the link and save as a text file)
Note: this only saves the latest concordance - if you open a new window and run another concordance, then that one will be exported.

Change character width: [Go](#)

16 occurrences.			Extend context
usly that 's confidential but about just a	general	what 's going on in the newspaper or just a	1 More Full
itnam" auto="false"> vietnam </normalised>	war	and never got to see his son at all as wife	2 More Full
e if I had to I would be back on it like a	shot	to give it another chance . I feel I have a	3 More Full
still hurt like hell so he gave it another	shot	, still hurting he gave me another and said	4 More Full
d immovable. as I kicked around my blanked	shot	off , my gown shot up giving everyone in th	5 More Full
e to spend on nuclear submarines , Trident	missiles	and parliamentary junkets . This also raise	6 More Full
fittest . Hand me the claret ... hand me a	gun	... If there is one thing I have learned to	7 More Full
est for your family . We spend billions on	munitions	. My father-in-law died this week aged 84 .	8 More Full
an we take enough from other budgets . The	army	needs some boots and bullets and has had sa	9 More Full
er budgets . The army needs some boots and	bullets	and has had savage cuts already , whilst I	10 More Full
s ' educational need rather than a call to	invade	the privacy of our medical workforce . " Dr	11 More Full
s on their final journey . You are now the	general	and you see your troops killed in battle .	12 More Full
. You are now the general and you see your	troops	killed in battle . One day you will face th	13 More Full
nemy and then let 's see how brave you are	under fire	. So do not ask for whom the bell tolls ...	14 More Full
ant . I admire that . I see that in former	soldiers	who should have copped a bullet with their	15 More Full
n former soldiers who should have copped a	bullet	with their mates 40 or 60 years before and	16 More Full

Wmatrix

©2000-13 UCL, Lancaster University.
For technical queries please contact Paul Rayson : p.rayson@lancaster.ac.uk

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

The interview questions

During semi-structured interviews, we asked fifteen hospice managers:

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

How did professionals say what they said?

- Interviewees express 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.
- Metaphors feature most frequently in (a) and (b), as well as (c) but only in the case of 'bad' deaths.
- Metaphors are more frequent and more elaborate in narratives of a 'bad death'.

Summary: Good/bad death metaphors

- Metaphors help to describe the elusive ‘good’ or ‘bad’ death.
- Metaphors express evaluation:
 - Good deaths are described in terms of ‘peace’, ‘freedom’ (facilitated by hospice staff) and ‘openness’.
 - Metaphors ‘normalize’ good deaths (as described by professionals) as a natural and accepted ‘part’ of life through ‘journey’ metaphors that also describe life in general.
 - Bad deaths are described in terms of ‘struggle/battle’ and as resulting from things in the background that are invisible and hard to reach.
- Metaphors are more frequent and more varied in ‘bad death’ narratives
 - This may be because such stories are even more sensitive/painful/emotional, than those of good deaths (cf. Cameron’s 2013 ‘negativity hypothesis’ for metaphor)
 - This could be a way of expressing evaluation, without criticizing the professional or the patient/carers too directly.

So what?

- Metaphorical evaluations of deaths as good or bad are linked to professional roles, challenges and views.
- Both 'good' and 'bad' deaths are particular (but very consistent) framings of what patients experience, and these framings may influence how professionals interact with patients and carers.
- But these framings may not be shared with patients/carers, e.g.
 - A good death may be one where the patient fought until the end; acceptance of death may be perceived as 'giving up'.
 - The professionals' concern for 'openness' in communication may be perceived as unwanted interference for patients and families.
- A greater awareness of implications of shared professional metaphors may be helpful.

Metaphors for carers' emotions

Identifying metaphoric references to emotions in language

- a) both source-domain and target-domain language
'you have to go through this range of **emotions**'; 'she had all this **worry** trapped inside her'

- b) only source-domain language
'driving myself round the bend'
often with relevant evidence in the co-text, such as a reference to the stimulus for the emotional reaction
'it still hurts every time a patient dies'

Research questions and answers

Q: How are metaphors used to represent the emotions of unpaid family carers? How are metaphors used differently by

- a) carers themselves
- b) healthcare professionals representing carer emotions?

A: Carer emotions are represented as:

mostly **outside**, as opponents (mostly by carers: 'that really knocked us both for six') or locations (mostly by professionals: 'for all the parties to be in the right, the same place psychologically at the same time');

mostly **coming out**, with a tendency for carers to refer to them as being released in a safe, controlled environment ('[a carers' meeting] gives you ways of releasing stress and frustration'), and professionals also ascribing agency to carers ('when the anger is directed at people or institutions')

Research questions and answers

- Q:** What are the implications of emotions being constructed as
- a) inside or outside the body
 - b) moving from the inside to the outside or vice versa?

A: Evaluation



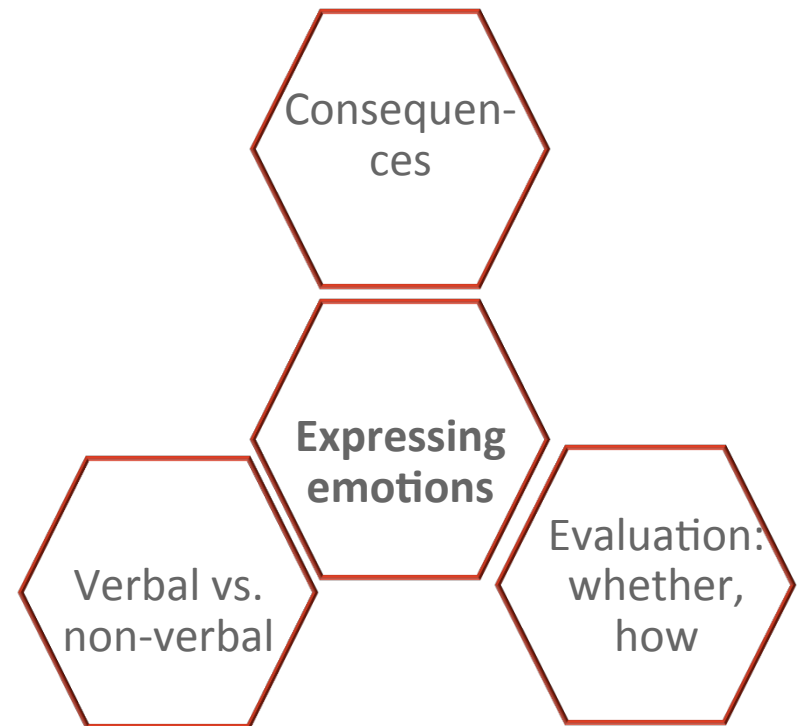
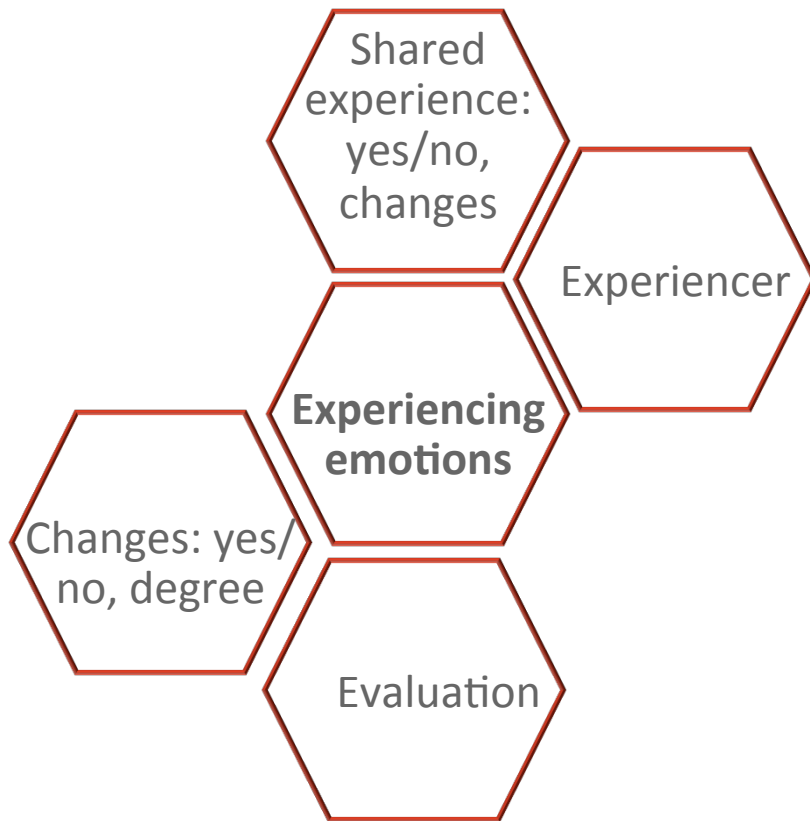
- emotions coming out with no agency on part of experiencer, misdirected expression of emotions
- negatively valenced experience of emotion as obstacles
- controlled release and safe boundaries



- shared emotional space

The evaluation is not attached to the emotion itself but to its interpersonal consequences.

Emotion scenarios



Violence and journey metaphors

Violence metaphors for (terminal) illness



They have been widely criticised, especially in relation to cancer (e.g. Sontag 1979, 1989):

On cancer:

‘The bromides of the American cancer establishment, tirelessly hailing the imminent victory over cancer; the professional pessimism of a large number of cancer specialists, talking like battle-weary officers mired down in an interminable colonial war – these are twin distortions in this military rhetoric about cancer.’ (p.64)

On AIDS:

‘We are not being invaded. The body is not a battlefield. The ill are neither unavoidable casualties nor the enemy ... About that metaphor, the military one, I would say ...: Give it back to the warmakers.’ (p.176)

Violence metaphors for (terminal) illness



Oncology Times, 25 June 2010, p. 20 (R.S. Miller MD):
'Speak up: 8 words and phrases to ban in oncology!'

'aggressive': we sometimes forget that when patients read our dictations, that word is very frightening. Might we not convey that there is a high risk of relapse without an adjective that unnecessarily anthropomorphizes the tumor

The military metaphor. It is well known that many patients, who would prefer that we call their illness anything other than a battle or a war, detest this.² However, it can be challenging to find alternative expressions. ... I welcome suggestions.

Violence metaphors for (terminal) illness

They have been systematically avoided in some recent official documents in the UK:

Living with and beyond cancer

24. Although patients' experience of their care has improved in recent years, we can do more to support and empower patients throughout their cancer journey.

25. We will improve information for patients through a range of product and pathway initiatives. Tumour specific national information pathways will be launched in 2008, making nationally agreed information available to frontline cancer health professionals to offer to patients at key points in their cancer journey. (2007 Cancer Reform Strategy, p.9)

Violence metaphors for (terminal) illness

Chapter 3: The end of life care pathway

3.1 Over the past few years the concept of a care pathway has been found to be useful ... In this chapter the concept is applied to end of life care.

3.2 Individuals differ in many ways as they approach the end of life. No two people will have an identical end of life care pathway. (2008 End of Life Care Strategy, p.45)

‘Did you find your journey a battle
or a steady work(wo)manlike
trudge?’

Violence metaphors for (terminal) illness

Yet there are voices in favour of the FIGHT metaphor as well:

‘So we fought, we struggled, we triumphed. It was an exhilarating fight, and I’d repeat the fight today without a moment’s hesitation. We fought together, we lived together’

TALKS | TED PARTNER SERIES

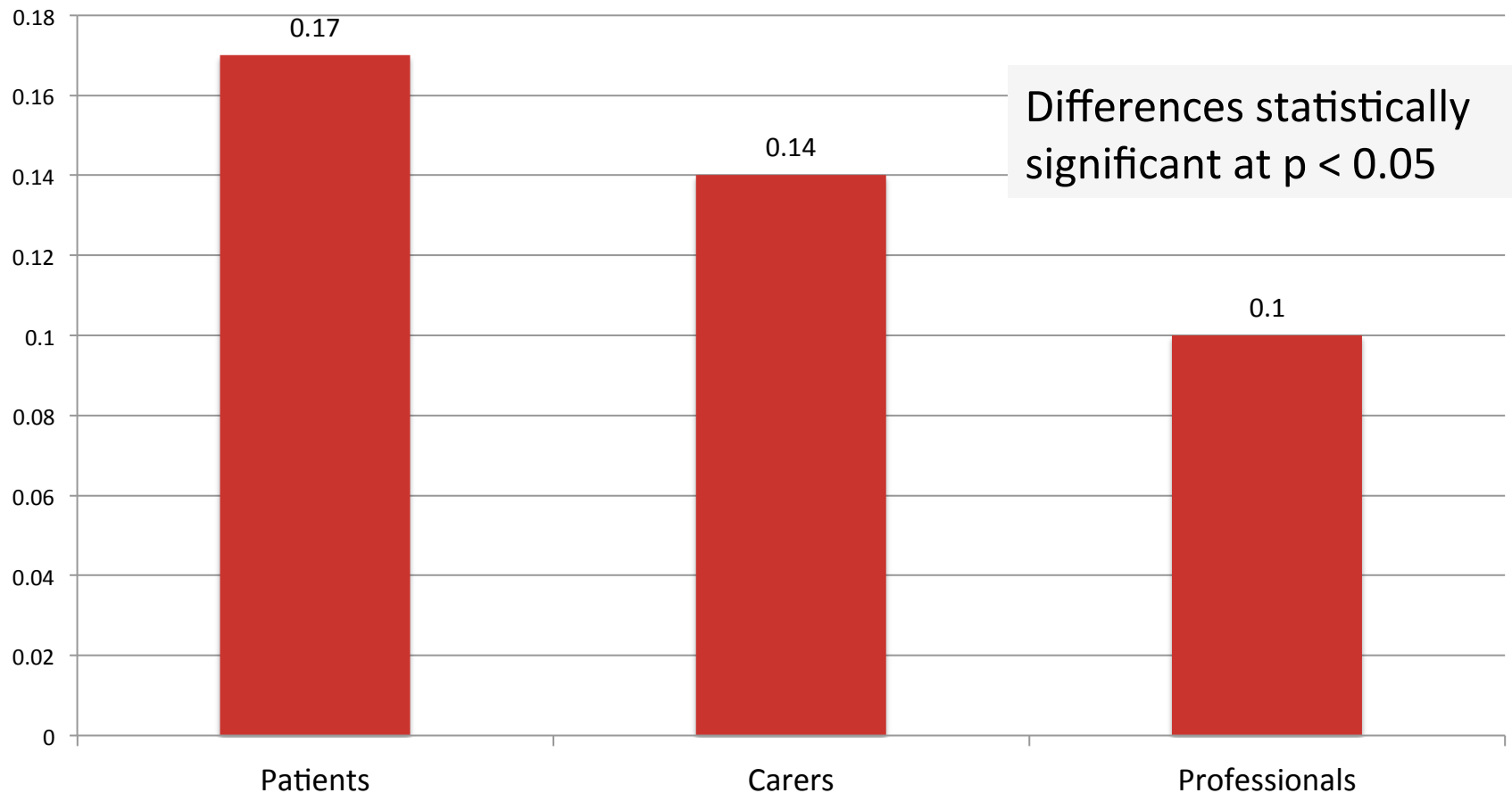
Amanda Bennett: We need a heroic narrative for death

FILMED APR 2013 - POSTED OCT 2013 - TEDMED 2013



‘And during Terence’s illness, I, we, we wanted to believe the story of our fight together too. Giving up the fight ... meant giving up not only his life but also our story, our story of us as fighters, the story of us as invincible.’

'Warfare' metaphors: occurrences per 1,000 words



Violence metaphors: disempowering?

(Dis)empowerment:

- An increase or decrease in the degree of agency that somebody has.
- Agency can be as a reaction to something that happens (outside of the person's control) or control over what happens in the first place.
- Such agency can be used for the person's own benefit.
- Agency (or lack thereof) can be expressed semantically and/or grammatically.

The patient data: too many battles...

- **Disease against patient:** 'But the emotional side of cancer and of BC in particular is the real killer - it strangles and shocks your soul'
- **Treatment/doctors against patients:** 'what did i think all my normal little cells were doing after being hit by a sledgehammer of both toxic chemicals and radiation'
- **Patient against disease:** 'I'm ... also sharpening my weapons in case I have to do battle'
- **Patient against (hospital) situation:** 'my secret weapon is keeping the ultra sound at the hospital on side'

The patient data: too many battles...

- **Patients against health professionals:** ‘We won that battle but imagine what would have happened if she hadn’t had a family to defend her?’
- **Patients against family/friends:** ‘Although he has been really caring we still snipe and argue out of the blue nearly every day.’
- **Patients against themselves:** ‘I am destroying myself with my mind right now, torturing myself’; ‘So I woke up this morning and gave a very large kick to myself!’

...but are all the battles bad?

Violence metaphors and disempowerment

'I feel such a failure
that I am not winning
this battle.'

'it must be dispiriting when
you are battling as hard as
you can, not to be given the
armour to fight in.'

'I am a walking time
bomb.'

Violence metaphors and empowerment

'I am such a fighter'

'my consultants recognised that I was a born fighter'

'we are young women with families but that is our trump card, that alone is my desire to fight and win'

'Your words though have given me a bit more of my fighting spirit back. I am ready to kick some cancer butt!'

'I don't intend to give up; I don't intend to give in. No I want to fight it. I don't want it to beat me, I want to beat it. ... It's a hard job but in the long run I hope to achieve ... we'll achieve something.'

Mutual solidarity and encouragement

- ‘Soldier on everybody’
- ‘you are such a fighter’
- ‘I ... wanted to know if there are any other younger bowel cancer fighters amongst us’
- ‘let me hear you scream the battle cry to spur us on to win this war.’
- ‘Glad to hear you’re still smiling , still winning that battle.’

Mutual solidarity and encouragement

11 occurrences.

e what the top one is ... I think Brigadier is my favourite ... what 's yours
And which numbers would those be Brigadier eh ? eh ? you saying we are mental
:00" words="172"> hey , well done Brigadier , you found it ! Did the sat nav h
stine is too busy out boozing and Brigadier John wo n't find me if I take a qu
8-24 22:45:00" words="128"> ha ha Brigadier , you found out my smuggling secre
. ha ha even better . Sleep tight Brigadier and a big hug xxx </post> <post th
11-08-26 21:23:00" words=
but I do n't care cos a
s) so you are all invit
nded me , have n't heard
20:59:00" words="79"> D

'I would promote you but a) i
think you have reached top
rank already and b) I can't
think of other ranks'

cos
er for a few days ... you ex
ly want to be my sister ... Touche
11-09-03 10:15:00" words="79"> see Colon
just do n't listen ... we are
... lower gone to your head and you n
... and I am quite open and modern
See ? Look what you have done to

4 occurrences.

oon (can I stay on the site now commandant Christine ?) I have to say that
sort of alcohol around (unless commandant Christine has been around) but y
i am safe for a while longer ... Commandant Christine is too busy out boozing
Brigadier John , even being camp commandant wo n't save you from this lot ...

Journey metaphors: empowering?

Cancer is a journey, some people have similar experiences to others on that journey, but by and large the journey has many twists and turns that means no two people go the exact same route. I think it is like trying to drive a coach and horses uphill with no back wheels on the coach. You do need to stop occasionally and rest the horses, review the situation with your husband.

Mutual solidarity and encouragement

Patients/Carers are travelling companions

- 'I feel exactly as you described, this is an awful journey we are going through but we are all here for each other'
- 'Safe journey'
- 'you are not alone, I have walked the same pathway as you for the last three years'
- 'Continued strength to everyone on this journey, whatever your situation, we are united in our journeys to slay the BC Beast :)'

Mutual solidarity and encouragement

Patients/Carers guide each other

- 'The rocks in our paths are easier to handle when we're all in it together ... the best people to help you are the ones who've been there before or are heading there with you'
- 'you extend you [sic] hand and kind thoughts helping people find their own path but aided by the light you shine for them'
- 'we will try to help you on this journey you have *been forced* to take'

Journey metaphors and empowerment

Illness is a travelling companion: ‘On my journey so far with cancer I have learnt to expect the worst.’

Grieving is a journey: ‘After all you have been through while he was ill you have stepped onto a different kind of journey now.’

Professionals guide patients:

- ‘Marie Curie nurses ... did everything for me and made Terry’s journey a lot less stressful.’
- ‘As doctors we are both the mechanics of the car and counsellor to the driver. We have been trained to repair the car and to help the driver travel as far as they may. We do not like to abandon a vehicle by the side of the road without at least trying to gain an extra mile or so for the driver.’

Journey metaphors and disempowerment

‘I only pop by every now and again because it saddens my heart to read of the passengers nearing the end of their journey and those recently having finished their journey.’

‘Well, I have not done so well with my own “cancer journey” through the wilderness of my own local hospitals.’

‘[the family] now appeared to be in a strange and uniquely vulnerable state, waiting to *be told* what would happen next, waiting to *be led forwards*’

‘After much discussion the patient *was discharged* home on a palliative pathway with a life expectancy of a few weeks’

Concluding remarks on violence and journey metaphors

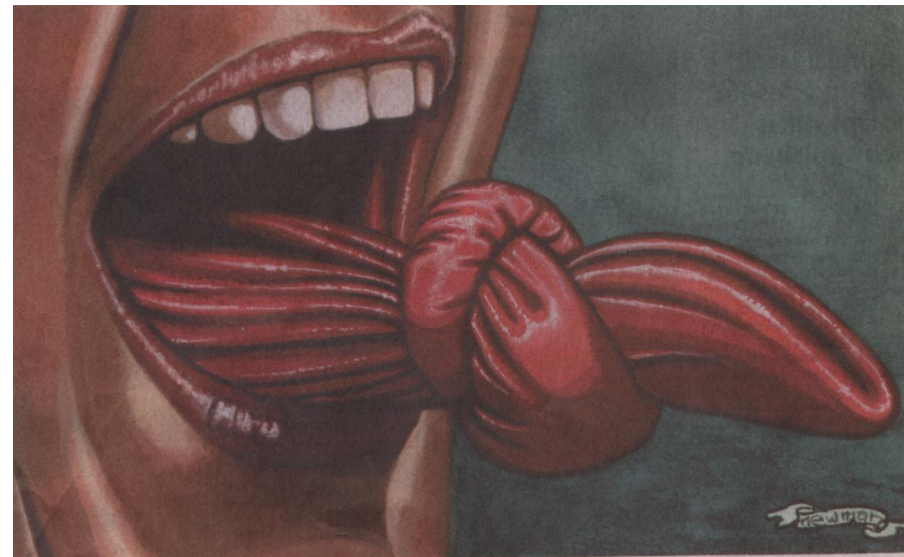
- Both violence and journey metaphors are (still) regularly used by all three stakeholder groups.
- There is no single 'WAR metaphor' or 'JOURNEY metaphor': patients use a variety of violence and journey metaphors to talk about a wide range of experiences.
- Violence metaphors can sometimes have a positive, empowering function, such as expressing personal determination and mutual solidarity.
- Journey metaphors can sometimes be used in disempowering ways, with little semantic and/or grammatical agency for patients and carers.
- The specific meanings, associations and functions of particular uses of metaphors can only be properly explained in terms of the individual linguistic expressions and the scenarios they evoke (as opposed to broad source domains).

So what?

- Both the *negative* and the *positive* attitudes, emotions and experiences that are expressed by means of violence and journey metaphors need to be addressed in the provision of healthcare.
- A blanket rejection of violence metaphors would deprive some patients of the positive functions that these metaphors can have.
- An uncritical acceptance of journey metaphors overlooks the disempowering ways in which it can be used.
- The problem is not a particular broad metaphor as such, but the **passivisation** of the patient that may result from some specific uses of metaphor.

Implications for policy and practice

- Awareness that metaphors are present in all policy documents
- There are no 'good' or 'bad' metaphors
- Become aware of your own assumptions and use of metaphors which may or may not be helpful for patients
- Listen for the use of metaphors in patients and family talk and be prepared to reflect them



EAPC 2015

14th World Congress of the European Association for Palliative Care

Building Bridges

8 – 10 May 2015

Copenhagen, Denmark



EUROPEAN ASSOCIATION
FOR PALLIATIVE CARE
www.eapcnet.eu



DSPaM

Dansk Selskab for Palliativ Medicin
Danish Association for Palliative Medicine

www.palliativmedicin.dk

Congress Organisation
INTERPLAN AG

Email: eapc2015@interplan.de

**9th World Research Congress
of the European Association
for Palliative Care**
9-11 June 2016 • Dublin Ireland



www.eapcnet.eu/research2016


Irish Association For Palliative Care

A collective voice for Palliative Care in Ireland

Thank you.

Any questions?

s.a.payne@lancaster.ac.uk
<http://ucrel.lancs.ac.uk/melc/>

A large, solid red curved shape in the bottom right corner of the slide, resembling a quarter-circle or a large arc.