

International Observatory  
on End of Life Care



# Metaphors at the end of life: results from a large study

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

# Structure of this presentation



- Background to the project
- Assumptions and research questions
- Data
- Methods: Qualitative and quantitative analysis
- Findings: 'Violence' metaphors used by patients
- Conclusions

# 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'.
- Debates about metaphors and illness/cancer.

# 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. In view of that, we ask:
  1. *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)?*
  2. *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

# 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



# Identifying and grouping metaphors using eMargin



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

- In the analysis of the sample, we identified:
  - Metaphorically used words to be searched for in the rest of the data (e.g. ‘weapon’);
  - Areas of meaning (semantic fields) that generate metaphors to be searched for in the rest of the data (e.g. ‘warfare’).
- We then used an online software tool, Wmatrix, to identify ‘metaphor candidates’ in the complete data set by searching for words and/or semantic fields.

# 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  
r . 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

```
. 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 ... !
```

- We then manually identified metaphorical expressions and analysed them quantitatively and qualitatively.

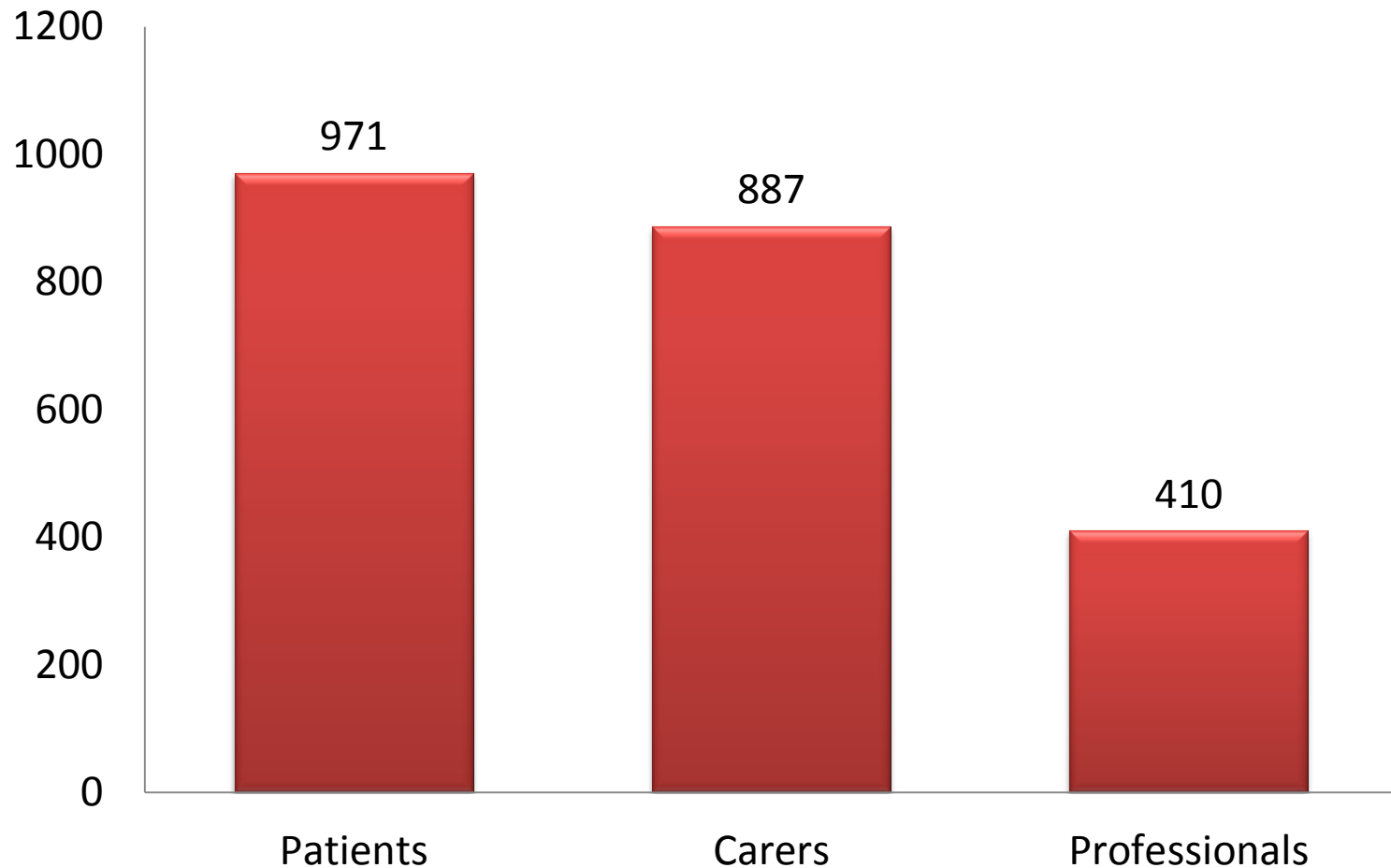
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# 'Violence' metaphors in patient data

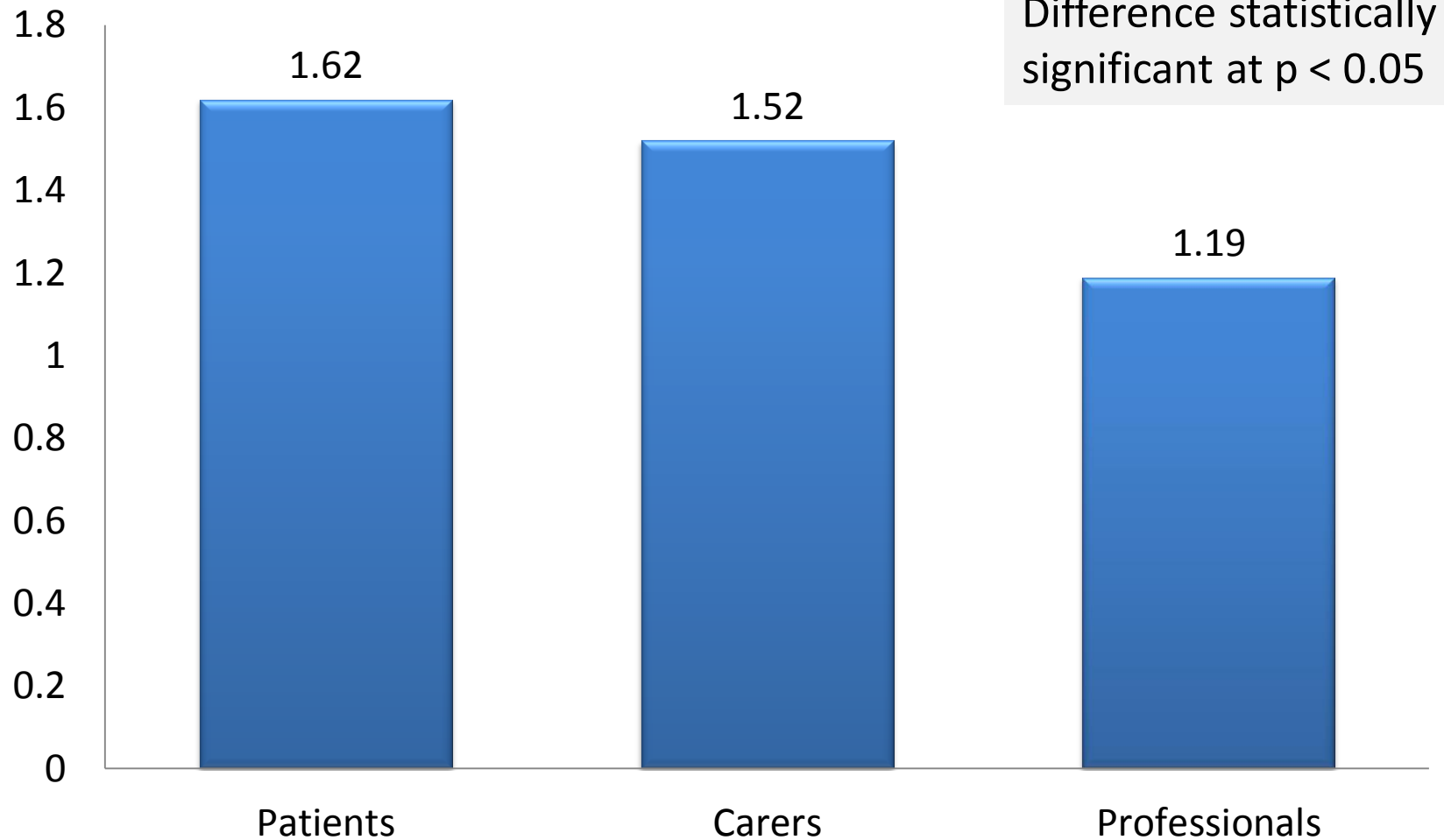
# Background

- 'Military' / 'War' / 'Battle' metaphors are conventional in relation to illness, and difficult enterprises generally.
- They have been widely criticised, especially in relation to cancer (e.g. Sontag 1979).
- They have been avoided in some recent official documents in the UK: e.g. the 2007 Cancer Reform Strategy contains no references to 'war', 'battle' or 'fight', but rather talks about a cancer 'journey', with clinical 'pathways' delineated as models of care.

# Violence metaphors in our data: raw frequency by stakeholder group



# Violence metaphors: frequency per 1,000 words





# 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!'

# Violence metaphors: disempowering or empowering?



## (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.

# ...but are all the battles bad?

## Violence metaphors and disempowerment

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'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.'

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- Patients jokingly addressing one another online as 'Brigadier', 'Colonel' and 'Commandant'.
  - 'I would promote you but a) i think you have reached top rank already and b) I can't think of other ranks'

# The persistence of 'Adversarial' metaphors for illness

“She lost her brave fight.” If anyone mutters those words after my death, wherever I am, I will curse them.

[...]


In my world, having cancer is not a fight at all. It is almost a symbiosis where I am **forced** to live with my disease day in, day out. Some days cancer has the **upper hand**, other days I do. I live with it and I let its physical and emotional effects wash over me. But I don't fight it. After all, cancer has arisen from within my own body, from my own cells. To fight it would be "waging a war" on myself. I have used chemotherapy on two occasions to **bring** the cancer **back under control** and alter the natural history of the disease. I submitted myself to this treatment gently, and somewhat reluctantly, taking whatever each day had to **throw at** me. I certainly didn't enter the process "with all guns blazing". (Kate Granger, *The Guardian*, 25/4/2014)



# Conclusions

- Violence metaphors are still regularly used by patients.
- There is no single ‘war metaphor’ or ‘military metaphor’: patients use a variety of Violence 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.

- The *negative* attitudes, emotions and experiences that are expressed by means of violence metaphors need to be addressed in the provision of healthcare.
- The *positive* attitudes, emotions and experiences that can also be expressed by means of violence metaphors need to be recognised in the provision of healthcare: a blanket rejection would deprive some patients of the positive functions that these metaphors can have.
- 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.

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- Our methods enables us to analyse metaphors in large data sets, and to combine qualitative and quantitative analyses.
  - This approach tends to produce nuanced understandings of language use that may have relevance for practice and training.
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Thank you

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