Metaphor in end-of-life care

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Professor Elena Semino (Lancaster University)
Outline of the day

- The ‘Metaphor in End-of-Life Care’ project: questions, data, methods
- Violence and Journey metaphors revisited
- Coffee break
- Metaphors for the relationship between patients and healthcare professionals
- Integrating research insights into healthcare practice: a ‘Metaphor Menu’ for cancer patients
The ‘Metaphor in End-of-Life Care’ (MELC) project: questions, data and methods

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Structure of this presentation

- Background to the project
- Assumptions and research questions
- Why metaphor?
- Data
- Methods: Qualitative and quantitative analysis
Background to the project

- Hospice movement in the UK since the 1960s.
- 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 of 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.
Why metaphor?

- 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’.
- Different metaphors afford different associations, entailments and scenarios.

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.

So sorry to hear what your partner is going through. MM [Malignant melanoma] is a hard road to travel both physically and mentally.
<table>
<thead>
<tr>
<th>Potential advantages</th>
<th>Potential disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rich domain</td>
<td>Illness as enemy, patient as battlefield</td>
</tr>
<tr>
<td>Connotations of activity, heroism, elation</td>
<td>Connotations of threat, aggressiveness, etc.</td>
</tr>
<tr>
<td>Some evidence of importance of ‘fighting spirit’</td>
<td>Lack of success in getting better as ‘defeat’</td>
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</table>
## Characteristics of Journey metaphors

<table>
<thead>
<tr>
<th>Potential advantages</th>
<th>Potential disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rich domain</td>
<td>Journey as involuntary, patients as passive passengers</td>
</tr>
<tr>
<td>Connotations of activity and possibly companionship</td>
<td>Connotations of difficulty, exhaustion, getting lost etc.</td>
</tr>
<tr>
<td>Future orientation</td>
<td>Ultimate end of overall life-as-journey is death</td>
</tr>
</tbody>
</table>
Data: the MELC corpus

1.5 million words; 92,000 manual sample

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Carers</th>
<th>Healthcare professionals</th>
<th>Total</th>
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<tr>
<td>Semi-structured interviews</td>
<td>100,859</td>
<td>81,564</td>
<td>89,943</td>
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<td>Online forum posts</td>
<td>500,134</td>
<td>500,256</td>
<td>253,168</td>
<td>1,253,558</td>
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<tr>
<td>Total</td>
<td>600,993</td>
<td>581,820</td>
<td>343,111</td>
<td>1,525,924</td>
</tr>
</tbody>
</table>
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 92,000-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

Semantic concordances: searching for words belonging to a particular area of meaning
Metaphors related to end-of-life care in our data

<table>
<thead>
<tr>
<th>Metaphors</th>
<th>Patients Interviews</th>
<th>Online</th>
<th>Total</th>
<th>Carers Interviews</th>
<th>Online</th>
<th>Total</th>
<th>Professionals Interviews</th>
<th>Online</th>
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<td>899</td>
<td>971</td>
<td>80</td>
<td>807</td>
<td>887</td>
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<td>Restraint</td>
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<td>Openness</td>
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<td>186</td>
<td>199</td>
<td>17</td>
<td>146</td>
<td>163</td>
<td>53</td>
<td>148</td>
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<tr>
<td>Obstacles</td>
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<td>71</td>
<td>76</td>
<td>7</td>
<td>56</td>
<td>63</td>
<td>24</td>
<td>62</td>
<td>86</td>
<td>245</td>
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<tr>
<td>Machines</td>
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<td>2</td>
<td>24</td>
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<td>258</td>
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<tr>
<td>Sport and Games</td>
<td>1</td>
<td>124</td>
<td>125</td>
<td>5</td>
<td>72</td>
<td>77</td>
<td>18</td>
<td>50</td>
<td>68</td>
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<tr>
<td>Wholeness</td>
<td>4</td>
<td>58</td>
<td>62</td>
<td>3</td>
<td>62</td>
<td>65</td>
<td>16</td>
<td>16</td>
<td>32</td>
<td>159</td>
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<tr>
<td>Journey</td>
<td>56</td>
<td>730</td>
<td>786</td>
<td>28</td>
<td>384</td>
<td>412</td>
<td>98</td>
<td>217</td>
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<tr>
<td>Totals</td>
<td>191</td>
<td>2493</td>
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<td>178</td>
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<td>2015</td>
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<td>1035</td>
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<tr>
<td>TOTAL OVERALL</td>
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Lancaster University
Thank you - any questions?

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Violence and Journey Metaphors Revisited

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Overview

- Violence metaphors in end-of-life care:
  - Violence metaphors and (terminal) illness
  - Findings from our study
- Journey metaphors in end-of-life care:
  - Findings from our study
- Conclusions:
  - Empowerment and disempowerment
  - Wider implications
Metaphorical uses of ‘battle’, ‘fight’ and ‘war’ in English

- Military/War/Battle metaphors are conventionally used in relation to difficult enterprises generally, and (terminal) illness in particular:
  - ‘Battle against’: hunger, autism, cancer, etc.
  - ‘Fight against’: corruption, homophobia, cancer, etc.
  - ‘War on’: terrorism, drugs, cancer, etc.

- We prefer the umbrella term Violence metaphors.
Violence metaphors have been widely criticised, especially in relation to cancer (e.g. Sontag 1979), for their associations with aggression, the implication that the enemy is inside and that not getting better is defeat.

They have been systematically 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.

‘Six Strategies for Beating Cancer’
Voices in favour of Violence metaphors for (terminal) illness

‘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’

‘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.’
Violence metaphors in our data: frequency per 1,000 words

- Patients: 1.62
- Carers: 1.52
- Professionals: 1.19

The difference is statistically significant at p < 0.05.
The patient data: 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: 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?

‘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’

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

‘my consultants recognised that I was a born fighter’

‘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.’
Humour

11 occurrences.

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

4 occurrences.

... I have to say that...
(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 is desired by the person and can be used for their own benefit.
- Agency (or lack thereof) can be expressed semantically and/or grammatically.
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)
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.
Journey metaphors in our data: frequency per 1,000 words

Difference statistically significant at p < 0.0001
Journey metaphors: solidarity and empowerment

Patients in charge of the journey

- My journey may not be smooth, but it certainly makes me look up and take notice of the scenery [sic]!
- just when I think I have gone as far as I can go, I get a happy surprise by being able to push myself that little bit further
- It's your disease, your life and your path to choose.

Patients as travelling companions

- ‘you are not alone, I have walked the same pathway as you for the last three years’
- ‘we are united in our journeys to slay the BC Beast : )’

Patients guide each other

- ‘the best people to help you are the ones who’ve been there before or are heading there with you’
Journey metaphors and disempowerment

patient as traveller on a difficult journey

- ‘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’

patient travelling without control over their journey

- ‘if you can think of this chapter in your life as a reluctant journey and each procedure a place along that journey that must be completed before you move onto the next it may help you better deal with it.’
- ‘We each have to tread a personal path, and we can not know where that is going’
- ‘Well, I have not done so well with my own “cancer journey” through the wilderness of my own local hospitals.’
- ‘How the hell am I supposed to know how to navigate this road I do not even want to be on when I've never done it before.’
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.

Both Violence and Journey metaphors are (still) regularly used by all three stakeholder groups.

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.
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.
- Criticisms often relate to a few words, but the larger concept (e.g. illness as adversary) may be inevitable.
- The problem is not individual words or a particular broad metaphor, but the *passivisation* of the patient that may result from some specific uses of metaphor.
Thank you - any questions?

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BREAK (20 minutes)
Metaphors for the relationship between patients and healthcare professionals

Elena Semino  

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Structure of this presentation

- Metaphors patients use for their relationship with health professionals:
  - Violence/Fight metaphors
  - Supernatural metaphors
  - Machine metaphors

- Metaphors health professionals use for their relationship with patients:
  - Violence/Fight metaphors
  - Supernatural metaphors
  - Machine metaphors

- Conclusions
Patients’ metaphors for their relationship with health professionals
Violence/Fight metaphors
‘I’m very sorry you haven’t been given the opportunity, Anna and it must be dispiriting when you are battling as hard as you can, not to be given the armour to fight in, but maybe as Samantha says, the side-effects would have been so unpleasant.’
HP as fighter/hunter on the patient’s behalf

- ‘Another GOOD - The registrar - all of 12 years old, but jumped in, all guns blazing, when I had a crisis’

- ‘paid a spontaneous visit to the Head Booby Hunter today to find his final opinion’
‘they hit me with radiation’

not sure if I will accept everything they are threatening to throw at me

‘after a battering from chemo’

‘what did I think all my normal little cells were doing after being hit by a sledgehammer of both toxic chemicals and radiation’
‘bombard your Mac-nurse will [sic] all the questions and frustrations’

‘their twin attack has resulted in an appointment on Thursday afternoon’

‘I now have another thing to beat my surgeon up about’

‘We won that battle but imagine what would have happened if she hadn’t had a family to defend her?’

‘will fight for Avastin. magic bullet/ media hype whatever!!’
Supernatural metaphors
HPs as saints or devils

- ‘I can honestly say that I would put my mac nurse in the “saint” category! She has done so much for me’

- ‘was your surgeon adorable or the devil himself?’
‘The Doc will wave his magic wand and make the pain go away!!’

‘Just waiting to see the oncologist to see if he thinks he can work the necessary magic to shrink the things.’

‘No magic potion tonight fraid - think they waiting for thursday night now’

‘Off to see The Wizard of Onc today - to fetch my 4th cycle of Temodal’
‘it’s funny but I call them the vampire doctors, there was only one guy on the ward who had fingers like divining rods so I was always pleased when he was on.’

‘Off for a bloodtest later, so gotta make myself purrrrrrrty for the vampire’

‘I honestly don’t think this vampire was drunk, just useless!’
The ‘magic bullet’

- ‘One day some bright scientist will find the magic bullet to end all the type of suffering we and our loved ones endure’
- ‘one day hopefully they will discover the magic bullet that just targets the cancer cells’
Machine metaphors
Healthcare processes as machinery

- ‘And I changed doctors and their fail-safe mechanism kicked in and they sent me with this surgery for a mammogram’
- ‘I think the worst thing was waiting for treatment to happen - once you get into it you get on the conveyor belt.’
- ‘I’m afraid there are a lot of medical staff out there who have lost any compassion they once felt, and lack imagination. They look on us all as just another appointment, and into the sausage machine we go.’
HP as patient’s tool

- ‘my mac nurse - she has been the most valuable tool in my tool box not just for me but friends and family as well’
Health professionals’ metaphors for their relationship with patients
Violence/Fight metaphors
HPs fighting for the benefit of patients

- ‘sometimes one is fighting for patient survival against the odds’
- ‘You are now the general and you see your troops killed in battle’
HP’s ‘protecting’ patients and families

- ‘we (doctors) must focus on the protection of our patients and on advancing palliative care’
- ‘I think we want to protect families from the reality’
Supernatural metaphors
Patients who died as ghosts

- ‘I have a couple of ghosts who haunt me - not because I could have done better - although one I kept on trying to treat even when he should have been left’

- ‘The ghosts of these patients remain with the physician, not in the sense of a shadowy specter, but, as a reiteration of thought. What was the ultimate cause of demise, could an intervention have been done differently, should the procedure be performed or deferred? These ghosts help us to make better decisions in the future.’
Patients in hell, HP guarding the potions patients need

- ‘We can only imagine what hell must be suffered by the terminally ill who are denied access to the potions (not invented by doctors, but guarded by them) which could gently end their trauma.’
Machine metaphors
‘What happens at the end of the conveyor belt in the big blue bins outside is just too much. We’d rather not know.’

‘Diagnosis and death are sped up. We are all on an airport walking conveyor belt going faster and faster.’

‘We are now running a production line with doctors tightening screws and welding on the new bits on compliant production model people while nurse managers with clip boards and bed pressures (the modern version of the pressure sore) and bean counters in their counting houses upstairs overlook the factory.’
Patient as car driver, HP as mechanic

- ‘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. [...] In this case however there is no hope for the car and the doors have locked themselves and imprisoned the driver within. The driver is just asking us to help him to get out so that he can walk home.’
Patients use a variety of metaphors to express their perception of their relationship with health professionals.

Different metaphors frame the relationship differently, especially in terms of:

- Who has agency, power and control;
- Whether and how HPs act for the patient’s benefit;
- Emotional associations;
- Evaluations;
- Humour.
Conclusions: patients

- In most cases, the metaphors used by patients emphasize their perception of an imbalance of power in their relationship with health professionals.
- Some metaphors cast health professionals as opponents and as not acting for the patient’s benefit.
- Some metaphors are used humorously, and potentially contribute to in-group intimacy and cohesion.
- The more negative metaphors express views, attitudes and emotions that need to be addressed in the provision of healthcare.
Conclusions: health professionals

- Health professionals use a variety of metaphors to express their perception of different aspects of their relationship with patients.
- Metaphors are used to express:
  - Professional goal of intervening for patients’ benefit (fighting, protecting);
  - Professional frustration of inadequacies of system they operate in, and of negative consequences for patients of their own role (conveyor belt, production line, guarding potions);
  - Vulnerability and negative emotions when they cannot save patients (haunted by ghosts);
  - Views in favour of sensitive topic of assisted dying for benefit of patients.
Thank you - any questions?

http://ucrel.lancs.ac.uk/melc/
Integrating research insights into healthcare practice: a ‘Metaphor Menu’ for cancer patients