





Metaphor in end-of-life care

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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.
- 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 of similarity can be perceived between them. For example:
 - 'I am fast becoming a chemo <u>veteran</u>'
 (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 <u>battle</u> 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 girl

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



Characteristics of Violence metaphors

Potential advantages	Potential disadvantages
Rich domain	Illness as enemy, patient as battlefield
Connotations of activity, heroism, elation	Connotations of threat, aggressiveness, etc.
Some evidence of importance of 'fighting spirit'	Lack of success in getting better as 'defeat'



Characteristics of Journey metaphors

Potential advantages	Potential disadvantages
Rich domain	Journey as involuntary, patients as passive passengers
Connotations of activity and possibly companionship	Connotations of difficulty, exhaustion, getting lost etc.
Future orientation	Ultimate end of overall life-as- journey is death

Data: the MELC corpus



1.5 million words; 92,000 manual sample

	Patie	nts	Carers		Healthcare professionals		
Semi-structured interviews	100,8	100,859		1 89,9	943	272,366	
			92,00	00			
Online forum posts	500,1	L34	500,25	6 253,	,168	1,253,558	
Total	600,9	993	581,82	0 343,	,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 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

```
:="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 with the certain the certain that it is a genuinely effective weapon against what we have the agood laugh is stated to buy an AK47 or an automatic weapon at the store of one is choice. It grate
```

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
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
those , feeling a bit more	armed	with responses- still trying
superate ! Maybe that 's the	rebel	popping out in me still!



Metaphors related to end-of-life care in our data

	Patients		Carers			Professionals			TOTALS	
	Interviews	Online	Total	Interviews	Online	Total	Interviews	Online	Total	
Violence	72	899	971	80	807	887	7 3	337	410	2268
Restraint	29	257	286	34	176	210	57	169	226	722
Openness	13	186	199	17	146	163	53	148	201	563
Obstacles	5	71	76	7	56	63	24	62	86	245
Machines	10	29	41	4	36	46	23	12	25	122
Religion and magic	1	139	140	0	92	92	2	24	26	258
Sport and Games	1	124	125	5	72	77	18	50	68	270
Wholeness	4	58	62	3	62	65	16	16	32	159
Journey	56	730	786	28	384	412	98	217	315	1513
Totals	191	2493	2686	178	1831	2015	364	1035	1389	
TOTAL OVERALL	ALL 6090									



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





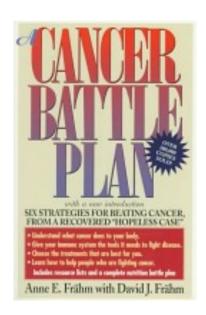
- Military/War/Battle metaphors are conventionally used in relation to difficult enterprises generally, and (terminal) illness in particular:
 - 'Battle against': hunger, autism, cancer, etc.
 - 'Fight against': corruption, homophobia, cancer, etc.
 - 'War on': terrorism, drugs, cancer, etc.
- We prefer the umbrella term Violence metaphors.

Criticism of Violence metaphors in (terminal) illness





- 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.



Voices in favour of Violence metaphors for (terminal) illness



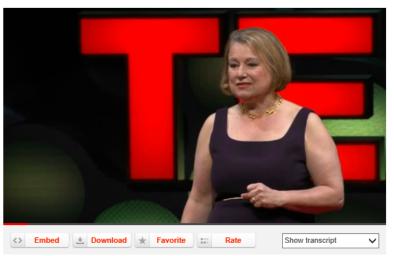


'So we fought, we struggled, we triumphed. It was an exhilarating fight, and I'd repeat the fight today without a moment's hesitation. We fought together, we lived together'

TALKS | TED PARTNER SERIES

Amanda Bennett: We need a heroic narrative for death

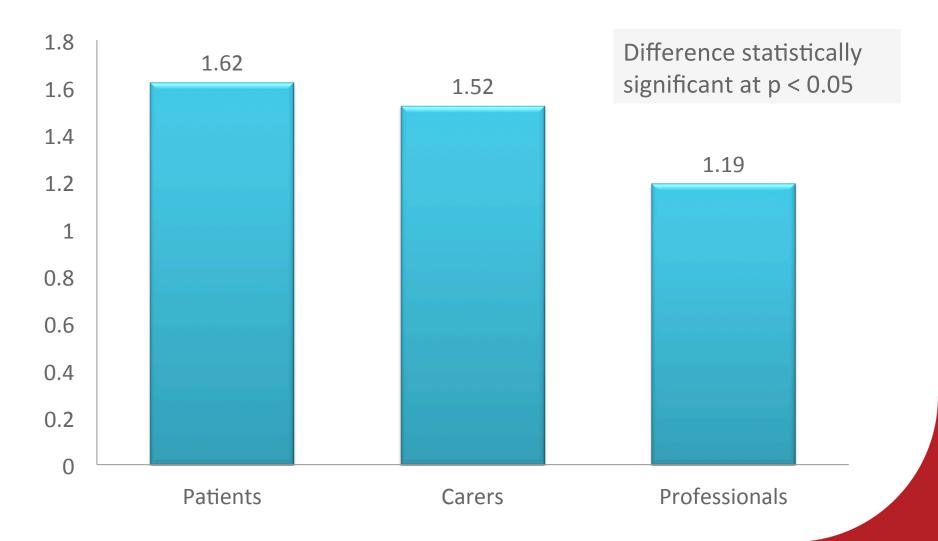
FILMED APR 2013 - POSTED OCT 2013 - TEDMED 2013



'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.'

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





The patient data: many battles...





- Disease against patient: 'But the emotional side of cancer and of BC in particular is the real <u>killer</u> - it <u>strangles</u> and shocks your soul'
- Treatment/doctors against patients: 'what did i think all my normal little cells were doing after being <u>hit</u> by a <u>sledgehammer</u> of both toxic chemicals and radiation'
- Patient against disease: 'I'm ... also <u>sharpening</u> my <u>weapons</u> in case I have to do <u>battle</u>'
- 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 <u>snipe</u> 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 <u>winning</u> this <u>battle</u>.'

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

'I am a walking <u>time</u> 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 <u>fighter</u>'

'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 <u>fight</u> it. I don't want it to <u>beat</u> me, I want to <u>beat</u> 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 <u>fighters</u> amongst us'
- 'let me hear you scream the <u>battle cry</u> to spur us on to <u>win</u> this <u>war</u>.'
- 'Glad to hear you're still smiling, still winning that battle.'







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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 . Sle
                                                                      <post th
                            'I would <u>promote</u> you but a) i
11-08-26 21:23:00" words:
                                                                      mmandant
 but I do n't care cos a
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s ) so you are all invite
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nded me , have n't heard
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                              rank already and b) I can't
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                                                                       the fro
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                    cos
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                                                                  and I am quite open and modern
                   ly want to be my sister ... Touche
                                                      Colon
                   11-09-03 10:15:00" words="79"> see
                                                                 ee ? Look what you have done to
                                      4 occurrences.
                                                  Christine ? ) I have to say that
oon ( can I stay on the site now
                                     commandant
sort of alcohol around (unless
                                                  Christine has been around ) but y
                                     commandant
i am safe for a while longer ...
                                                  Christine is too busy out boozing
                                     Commandant
Brigadier John , even being camp
                                                  wo n't save you from this lot ...
                                     commandant
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(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.

[...]

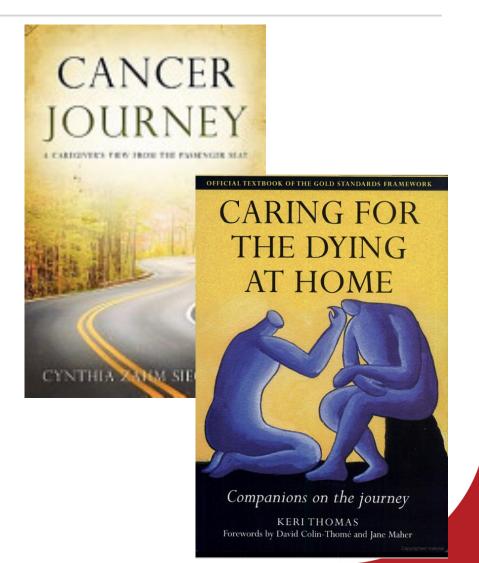
In my world, having cancer is not a fight at all. It is almost a symbiosis where I am <u>forced</u> to live with my disease day in, day out. Some days cancer has the <u>upper hand</u>, other days I do. I live with it and I let its physical and emotional effects wash over me. But I don't fight it. After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

Journey metaphors in (terminal) illness





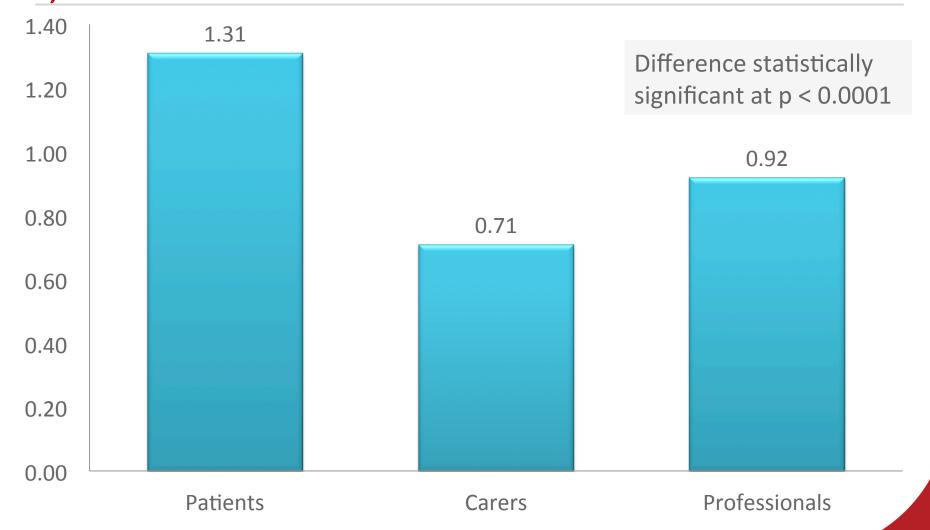
Cancer is a journey, some people have similar experiences to others on that journey, but by and large the journey has many twists and turns that means no two people go the exact same route. I think it is like trying to drive a coach and horses uphill with no back wheels on the coach. You do need to stop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



Journey metaphors in our data: frequency per 1,000 words







Journey metaphors: solidarity and empowerment





se by

Patients in charge of of the jour

- My journey may not be smooth notice of the scenary [sic]!
- just when I think I have gone as far à being able to push myself that little bi
- Its your disease, your life and your <u>pat</u>

Lack up and take

'stay strong on your journeys' 'I wish you both an easy journey' 'best of luck in your

whichever

journey'

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 <u>journey</u> has many <u>twists</u> and <u>turns</u> that means no two people <u>go</u> the exact same <u>route</u>. I think it is like trying to <u>drive</u> a <u>coach</u> and <u>horses uphill</u> with <u>no back wheels</u> on the <u>coach</u>'

patient travelling without control over their journey

- 'if you can think of this chapter in your life as a <u>reluctant journey</u> and each procedure a <u>place</u> <u>along</u> that <u>journey</u> that must be completed before you <u>move</u> onto the next it may help you better deal with it.'
- 'We each have to <u>tread</u> a personal <u>path</u>, and we can not know <u>where</u> that is <u>going</u>'
- 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 <u>navigate</u> this <u>road</u> I do not even want to be on when I've never done it before.'

Concluding remarks





- 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

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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



HP as reluctant providers of fighting equipment

'I'm very sorry you haven't been given the opportunity, Anna and it must be dispiriting when you are <u>battling</u> as hard as you can, not to be given the <u>armour</u> to <u>fight in</u>, 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 <u>Hunter</u> today to find his final opinion'

HPs/treatment fighting against patient



- 'they <u>hit</u> me with radiation'
- not sure if I will accept everything they are threatening to throw at me
- 'after a <u>battering</u> from chemo'
- 'what did i think all my normal little cells were doing after being <u>hit</u> by a <u>sledgehammer</u> of both toxic chemicals and radiation'

Patients fighting against HPs



- 'bombard your Mac-nurse will [sic] all the questions and frustrations'
- 'their twin <u>attack</u> has resulted in an appointment on Thursday afternoon'
- 'I now have another thing to <u>beat</u> my surgeon <u>up</u> 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 <u>devil</u> himself?'

HPs as magicians



- '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 <u>Wizard</u> of Onc today to fetch my 4th cycle of Temodal'

HPs as vampires



- 'it's funny but I call them the <u>vampire</u> doctors, there was only one guy on the ward who had fingers like <u>divining rods</u> so I was always pleased when he was on.'
- 'Off for a bloodtest later, so gotta make myself purrrrrrrty for the <u>vampire</u>'
- 'I honestly don't think this <u>vampire</u> was drunk, just useless!'

The 'magic bullet'



- One day some bright scientist will find the <u>magic bullet</u> to end all the type of suffering we and our loved ones endure'
- 'one day hopefully they will discover the <u>magic</u> <u>bullet</u> that just targets the cancer cells'



Machine metaphors

Healthcare processes as machinery



- 'And I changed doctors and their fail-safe <u>mechanism</u> 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 <u>conveyor belt</u>.'
- '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 <u>tool</u> 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 <u>fighting</u> for patient survival against the odds'
- 'You are now the <u>general</u> and you see your <u>troops</u> <u>killed</u> in <u>battle</u>'

HP's 'protecting' patients and families



- 'we (doctors) must focus on the <u>protection</u> 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 <u>ghosts</u> of these patients remain with the physician, not in the sense of a <u>shadowy specter</u>, 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 <u>ghosts</u> help us to make better decisions in the future.'



Patients in hell, HP guarding the potions patients need

'We can only imagine what <u>hell</u> must be suffered by the terminally ill who are denied access to the <u>potions</u> (not invented by doctors, but <u>guarded</u> by them) which could gently end their trauma.'



Machine metaphors



HPs and/or patients on conveyor belt or production line

- 'What happens at the end of the <u>conveyor belt</u> 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 <u>airport</u> walking <u>conveyor belt</u> going faster and faster.'
- 'We are now <u>running</u> a <u>production line</u> with doctors <u>tightening screws</u> and <u>welding</u> on the new <u>bits</u> on compliant <u>production model</u> people while nurse managers with clip boards and bed pressures (the modern version of the pressure sore) and <u>bean counters</u> in their <u>counting houses</u> upstairs overlook the <u>factory</u>.'



Patient as car driver, HP as mechanic

As doctors we are both the <u>mechanics</u> of the <u>car</u> and counsellor to the <u>driver</u>. We have been trained to <u>repair</u> the <u>car</u> and to help the <u>driver travel</u> <u>as far as</u> they may. We do not like to <u>abandon</u> a <u>vehicle</u> <u>by the side of the road</u> without at least trying to <u>gain</u> an <u>extra mile</u> or so for the <u>driver</u>. [...] In this case however there is no hope for the <u>car</u> and the <u>doors</u> have <u>locked themselves</u> and <u>imprisoned</u> the <u>driver</u> <u>within</u>. The <u>driver</u> is just asking us to help him to <u>get out</u> so that he can <u>walk home</u>.'

Conclusions: patients



- 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?

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Integrating research insights into healthcare practice: a 'Metaphor Menu' for cancer patients