How I talk about death and dying in palliative focused care.....

("reflections of a palliative care doctor learning from neuropalliative patients and their carers")

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Content

- Contradictions....
- Concepts
- Context
- Conversation
- Consequences
- Conclusions

I am not afraid of death, I just don't want to be there when it happens

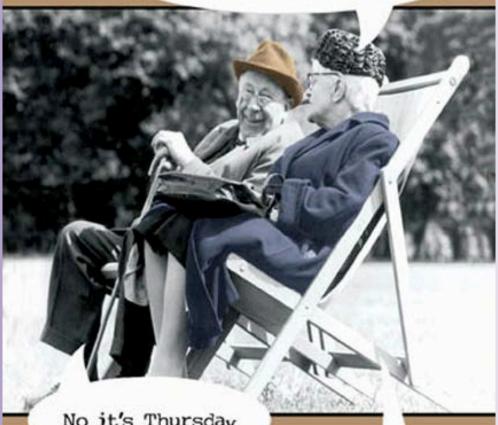
Woody Allen

"You may be the professionals but you are not the experts.."

"The single biggest problem in communication is the illusion that it has taken place."

George Bernard Shaw

Isn't it windy?



No it's Thursday

so am I let's go get a cup of tea

Communication and the MDT

$$C = \frac{n (n-1)}{2}$$

Where

C = number of lines of communication

and

n = number of people

Therefore if 10 people are involved then there are 45 different lines of communication

15 people = 120 lines of communication

Where is our focus?

Person who is DYING

PERSON who is dying

Concepts (principles)

- You matter.....
- Quality of life
- Connectedness
- 'Doing' versus 'being'
- Practical versus emotional

"You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but also to live until you die."

Cicely Saunders

We want to improve 'quality of life', but what is it?

i.e. What are we aiming for....?

Quality of Life

 Quality of life is used widely in medical literature yet the concept is often poorly defined

 Traditionally when looking at the impact, physicians have focused primarily on neurological symptoms and physical impairment

Quality of Life

Quality of life is

- subjective (rather than objectively defined)
- dynamic (rather than static)
- multidimensional (rather than purely limited to physical function).

Nominated domains (n=87)

•	Family		108	(87.8%)
•	Health		65	(52.8%)
•	Leisure		45	(36.6%)
•	Marriage		43	(35.0%)
•	Friends		38	(30.9%)
•	Independence	27	(22.0%)	
•	Walking/mobility		27	(22.0%)
•	Getting out		25	(20.3%)
•	Home/ living conditions		23	(18.7%)
•	Social life		17	(13.8%)
•	Money/ finances		16	(13.0%)
•	Happiness/ contentment		15	(12.2%)
•	Faith/ church/ spiritual life		13	(10.6%)

QoL in PD

QoL in PD

- can be assessed in a subjective manner using SEIQoL-DW
- was highly individual
- was determined more by <u>psychosocial</u> issues than physical ones
- QoL was <u>not</u> predicted by age, stage, symptom load, or disease progression or MMSE <u>but only by depression</u>

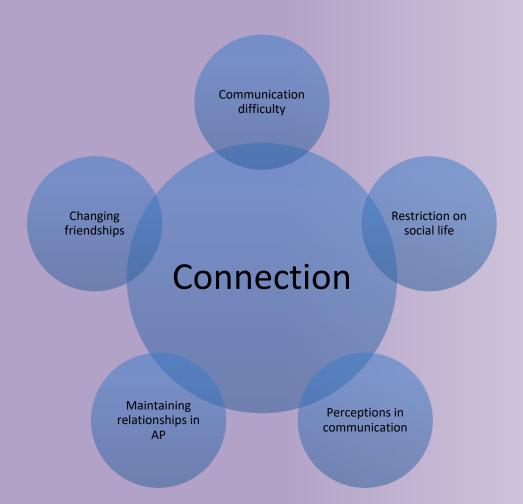
Lee et al Movement Disorders

2006

Psychosocial

- Too much focus on medication with little or no psychological support [Hasson F et al Pall Med 2010]
- Care should move beyond just the disease and consider the person as a whole [Giles S et al Pall Med 2009]
- Lack of support/ uncoordinated support/ lack of communication from care systems [Giles S et al Pall Med 2009/ Hasson F et al Pall Med 2010]
- Huge carer stress ["Life with Parkinson's today room for improvement" 2007]
- Public stigma [Moore S et al 2006]
- 'Staying connected' applied to both patient and carer
 persons speech and capacity to socialise [Hudson et al Pall Med 2006]

Connectedness



Mary: *typing sounds* I sometimes think *typing sounds* ...people don't understand......that I'm not stupid
Mary age 69 who has PSP

...you have people sort of waiting whilst I slowly spoke to them. I didn't want them to think that I'd sort of- I think everybody thinks when you've got that and you slow down it might be a mental thing, which obviously it isn't because inside your head, it's all, it's really going on Rose, age 71 who has MSA

[illness] is a very personal heart-aching thing and lots of the elderly haven't got the backup of families and friends and finances to help through some of the more difficult things

Earl, age 70 carer for Helen who has PSP

'Doing' or 'being'

"We tend to look at caring as an attitude of the powerful toward the weak, of the powerful toward the powerless, of the haves towards the have nots. When we honestly ask ourselves which persons in our lives mean the most to us, we often find it is those who instead of giving much advice, solutions or cures have chosen rather to share our pain and touch our wounds with a gentler and kinder hand...

'Doing' or 'being' (cont)

The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not knowing, not curing, not healing, and face with us the reality of our powerlessness that is the friend that cures."

Henri Nouwen

Practical versus emotional

 Numerous other studies have demonstrated both the <u>practical</u> and <u>emotional</u> stresses of being a carer of someone with PD:

practical stresses

 managing and administering medicines; mobility issues; financial stresses; dependence of relative; lack of care coordination; lack of information; lack of guidance by medical professionals; and poor sleep patterns.

emotional stresses

 anxiety; helplessness; fear of what the future holds; feeling they could do a better job; depression; social isolation; loss of self identity; distress at watching the deterioration; and feeling burdened.

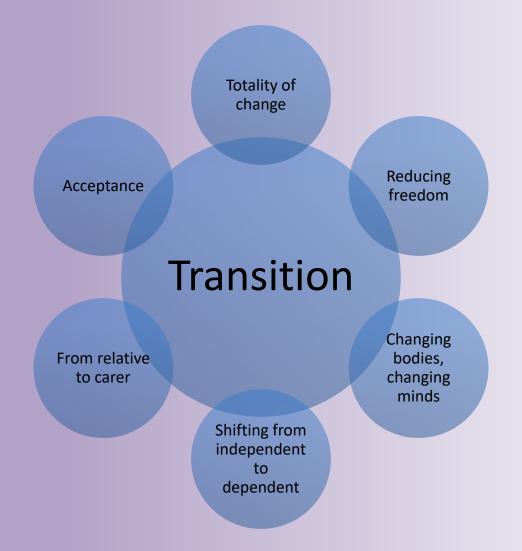
Context

"You never really understand a person until you consider things from his point of view — until you climb into his skin and walk around in it."

Context

- Patient/ Carers
 - The journey and its transitions
 - Accessing support
- Staff
 - Confounding factors/ biases/ internal dissonance
- Social
 - Zeitgeist utilitarianism autonomy

Transitions (patients/ carers)



Seeking a diagnosis

Palliative Care Research as hope

Accessing Support

Importance of expertise

Information on disease

Help from peers

Staff context

- Personal experiences
- Work pressure
 - Extremely busy days "I don't have time"
 - Design of service
 - Models of care
- Dying is
 - associated with questions/ imponderables
 - an emotive subject
 - a 'failure' BUT people still need care

These all shape our response and responsiveness

Biases....

"People generally see what they look for, and hear what they listen for"

Harper Lee

In MND

What are we seeing?

What are we listening for?

Truth telling in discussing prognosis – systematic review (46 studies)

HP

- Majority <u>believed</u> that patients and carers should be told the truth about prognosis
- Many avoided conversations or withheld information

Reasons

- Lack of training / stress
- No time to deal with pts emotional needs
- Fear of negative impact on patient
- Uncertainty about prognosis
- Request from family to withhold information
- A personal feeling of hopelessness/ inadequacy

Yet.....

"Studies suggest that patients can discuss the topic without it having a negative impact on them"

Therapeutics of truth telling....?

Social context

- Worth
- What it means to be human
- Utilitarianism
- Autonomy/ control
- Notions of dignity
- Not being a burden to others
- Medicalisation/ expectations
- Life/ death as a right
- Meaninglessness of suffering
- Death as a concept (Death denying)

Conversation

Die, my dear? Why, that's the last thing I'll do

Groucho Marx

Conversation

- Setting the tone/ rhythm / currency
 - Building or burning bridges?
- Defining our role
 - Overt provide therapy
 - Covert orientating/ navigation/ milestones
- Helpful techniques
- Helpful phrases

Helpful techniques...

- Silence
- Reflection
- Summarising
- You don't know what to say.....don't say anything..
- Hypothetical scenarios
- Acknowledgement
- Permission
- Establish 'rules of engagement'
 - Eg completing sentences/ emotional lability

Helpful phrases

- "How did that make you feel?"
- "That sounds hard"
- "We find a lot of patients tell us that"
- "What things in life are most important to you?"
- "How are you finding life as a carer?"
- "How do you see the future?"

Advance Care Planning

(sits with the Mental Capacity Act 2005)



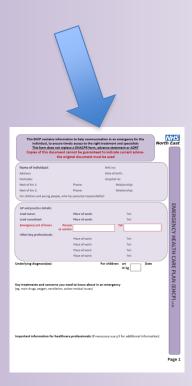


Advance Statement (AS)



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	Telephone Number
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Advance
Decision to
Refuse
Treatment
(ADRT)



Emergency Healthcare Plan (EHCP)



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Abbress	Date of birth:					
Particular Society Society or						
Of and practice:						
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	and has refused consent for CPR					
	e capacity for this decision but has a valid					
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DNACPR

Consequences

What questions do you fear?

What reactions do you fear?

How are we at living with uncertainty?

Conclusions

Patient experience overall.....



- 1998-2013
- 110 systematic reviews

Review of 110 systematic reviews

The table signposts to evidence about what works best to enhance patient experience. Initiatives in bold have the most evidence to support them.

Focus	Improves knowledge	Improves experience	Improves service use and costs	Improves health outcomes
Targets patients	 Information to help choose providers¹ Patient decision-aids^{2,3,4} Clinician rating websites⁵ Educational materials for carers⁶ Family conferences⁷ 	 Clear communication^{8,9} Clinicians focusing on psychosocial issues^{10,11,12,13,14} Electronic medical records^{15,16} Patient portals¹⁷ Support workers and breaks in mental health^{18,19,20} 	 Clear communication²¹ Family conferences²² Telehealth²³ 	 Clear communication²⁴ Person-centred consultations^{25,26,27} Group education²⁸ Self-monitoring²⁹ Carer support services³⁰
Targets professionals	 Communication skills training for clinicians³¹ 	 Communication skills training for clinicians^{32,33,34,35,36,} 37,38,39,40,41,42,43 Email between patients and professionals⁴⁴ Female doctors^{45,46,47} 		 Communication skills training for clinicians^{48,49,50,51, 52,53,54,55} Empathy from doctors⁵⁶
Targets systems / organisations	• Longer consultations in primary care ⁵⁷	 Longer consultations^{58,59} Continuity of care^{60,61,62} Using patient surveys⁶³ 	 Using patient reported outcome measures^{64,65} Public reporting of performance data^{66,67,68,69} Continuity of care^{70,71} Hospital at home⁷² 	• Reducing waiting time ⁷³

Reflections

- Importance of the approach?
 - Communication esp. listening
 - Setting the tone
 - Creating the currency
 - Rhythm/ time
 - Continuity
 - Signposting
- The concept of 'quality of life'? Who defines it?
 - Subjective, multidimensional and dynamic
- What is really important to patients?
 - Physical or psychosocial symptom
- The importance of time....

"It's the first time in a long time met someone and had a long discussion. Prepared to talk, that was something different this morning. Got more out of me than others- felt he understood more, put me at ease"

Any questions?