

Person-Centred communication and the care of people living with dementia:
exploring the perspectives of medical students in the UK and Malaysia.

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Dementia – an epidemic

- One of the greatest social, economic and health challenges currently facing societies
- Now about 40 million people living with dementia (PLWD) worldwide
- 115 million by 2050 (?)

Alphonso et al, 2010

Alzheimer's Disease International, 2010, 2012.

The experience of dementia...

- Every experience of dementia is different
- A progressive although rarely linear loss of cognitive functionality
- Confusion, memory issues, language and communication problems
- Anxiety and depression can also accompany the condition, particularly in the early stages.
- Tremendous challenge for PLWD, families...

Research responses

- Thus far, very 'western'
- Largely bio-medical
- Indications communication can make a real difference to QoL

Young et al, 2011a

Communication and dementia

Internationally...

- Poor practice prevalent in social care and (especially) health sectors (e.g. Department of Health, 2009; Alzheimer's Society, 2011; Royal College of Psychiatrists, 2011)
- Stigmatisation, a 'malignant social psychology', socially-constructed 'othering' of PLWD? (Kitwood, 1997)
- Existing advice and protocols:
 - Minimal in scope
 - Non-individualised
 - Context specific
 - Don't link theory and practice
 - Not much used

Young et al, 2011b

A response – The DeMEC Project

A co-constructive project facilitated by the Alzheimer's Society...

- A series of iterative investigations, looking at communicative practice in situ, experiences of PLWD/families
- What's 'good', what 'works'
- Involving a range of stakeholders – PLWD, carers, 'excellent' home managers, SALTs, academics... PLWD had 'final word'

Aim - to build a model of effective communication relevant to the experiences of PLWD and carers, usable by a range of care professionals

Observations of practice, focus groups, individual interviews...

Young *et al*, 2011a

Dementia model for effective communication

- Three 'levels'

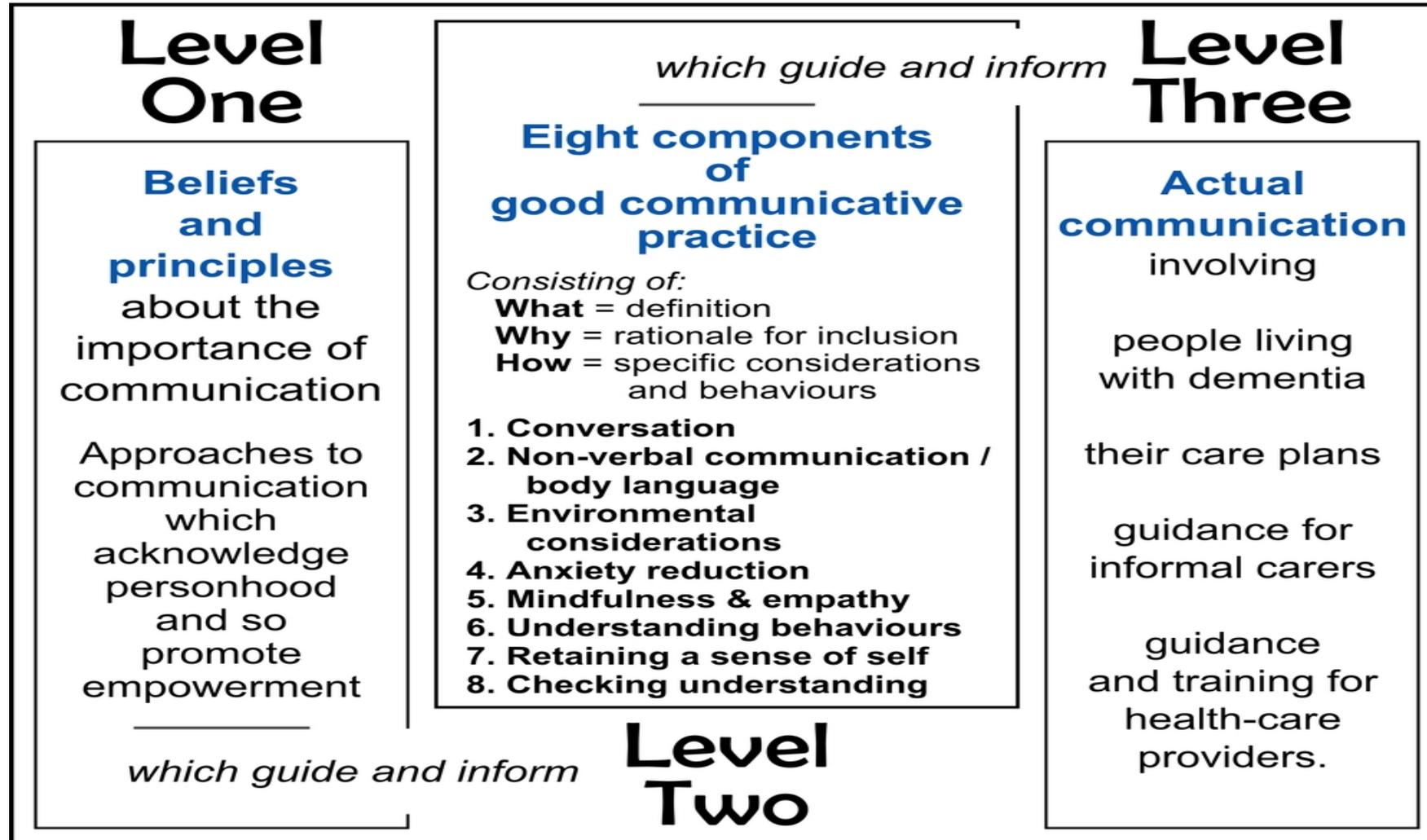
1. **Foundation** - Agreed principles of person-centred communication
2. **Advice** - Components of good communicative practice - what, why, how...
3. **Actual practice** – how to apply the principles and advice in '1' and '2' in real-time communication at home, in hospital, in social care..

Abstract model expressed as a free usable 'toolkit'... www.demtalk.org.uk

A set of ideas – flexible, adaptable, translatable...

Different tailored versions for different audiences

DEMTEC – Dementia Toolkit for effective communication



Level one of DeMEC

Important to express key ideas/principles to make model tailored to need, flexible and adaptable (over time, in different care contexts, cultural contexts...).

First version (UK consumption):

- Person-centredness the core aim – an under-theorised notion but appealing to PLWD...
 - Resisting (prevalent?) strictly biomedical approach to dementia care and treatment - addresses the disease but not the person
 - Attempts to incorporate knowledge and recognition of an individual's personhood – their life-history, beliefs, values and individual wants, needs and preferences – into interaction.
 - Places appropriate, considerate, communication at the centre of interaction
- Aiming for agency, support
- Basis for intercultural dialogue – how do 'others' see the condition, care...

Some of the latest work – medical education- Background(1)

UK perspectives:

- Proficient communication with people living with dementia (PLWD) key to **person-centred care** (Kitwood, 1997; Brooker, 2004)
- Optimising Person-centred Communication (PCC) linked to improving the quality of life of PLWD *and* their carers (Worral & Hickson, 2003)
- Evidence that poor communication contributes to inadequate care of PLWD in hospital and community settings (Alzheimer's Society, 2009; Care Quality Commission, 2012)
- Education and training for health and social care professionals highlighted as an important strategy for improving care of PLWD (Royal College of Psychiatrists, 2011)

Some of the latest work – medical education- Background (2)

However...

...there is a lack of consensus as to what and how to teach:

- 'Person-centred communication' interpreted and applied variably in different care settings – relevance beyond 'west'?
- Lack of reference to theoretical frameworks and research evidence in education and training for staff (Young et al. 2011b)
- Attitudes towards communication and associated learning needs for staff working with PLWD remain underexplored

Research - some data

Aim:

Determine the extent to which the principles and practices of person-centred communication, as conceptualised by the Dementia Model of Effective Communication (DeMEC, Young et al., 2011a, 2016), relate to the approaches to communication with PLWD of undergraduate medical students in the UK and Malaysia.

An (ongoing) series of investigations...

Young et al, 2016.

Tullo et al, 2016.

Methods

Mixed-methods design:

- Questionnaire (N = 531)
- Focus groups (N = 21)
- Individual interviews (N = 10)

Participants:

- Medical students at a medical school with UK and Malaysia sites – common curriculum
- Years 1, 3 and 5 (UK-based)
- Years 1 and 3 (Malaysia-based) – no year 5 at time of study

The participants...

Medical students are an important target group for education and training about dementia...

- No matter what career trajectory they follow, they are likely to provide care for PLWD upon graduation
- Hitherto, education on dementia neglected learning outcomes related to attitudes and communication skills (Tullo & Gordon, 2013)
- It remains unclear to what extent medical students are aware of, or endorse, a person-centred approach to communicating with PLWD

Quantitative data collection

Dementia Communication Questionnaire (DCQ)

- 12 Likert-style questions, scores from 1-5
- Each item related to aspects of effective communicative behaviour identified by DeMEC (Young et al., 2011a)

Group		UK	Malaysia	Total
Year 1	(responses/year group size)	238/300	45/57	283/357
	% year group	79.3%	78.9%	79.2%
Year 3	(responses/year group size)	103/300	11/20	114/320
	% year group	34.3%	55%	35.6%
Year 5	(responses/year group size)	134/300	n/a	134/300
	% year group	44.6%	n/a	44.6%
Total		475	56	531

Qualitative data collection

Round 1: Six focus groups, 3 UK, 3 Malaysia (N = 21)

- DCQ statements as prompts
- Thematic content analysis (Braun and Clarke, 2006)

Round 2: one-to-one interviews (N = 10), 5 UK, 5 Malaysia

- Semi-structured
- Further explored areas of divergent opinion and controversy

Results – quantitative data (1)

- Preferred nomenclature was ‘person with dementia’ (57.7%), followed by ‘person living with dementia’ (30.2%)
- Majority of DCQ items scored 4/5 or 5/5
- Significant differences between UK and Malaysia responses among year 1s, not year 3s. In Malaysia year 1s:
 - Significantly less likely to select ‘PWD’ as designation
 - Significantly more likely to speak to a member of the family first

Results – quantitative data (2)

- Items 8 and 11 showed divergence across the sample:
 - *'It is acceptable to lie to them if you think the truth might be upsetting to hear.'*
 - *'It is preferable to try to talk to a member of their family first, before speaking to them.'*

The interviews concentrated on these two items...

Results – qualitative data

Generally supportive of questionnaire findings...

- General agreement with the majority of DCQ statements
- But, no differences between opinions expressed in UK and Malaysia
- Today's focus: DCQ 8 and DCQ 11

Focus group DCQ 8 (1)

'It is acceptable to lie to them if you think the truth might be upsetting to hear.'

Students believed that honesty should be the default position when communicating with PLWD, but disagreed as to how honesty should inform action...

They agreed that PLWD had an autonomous right to information concerning them, coupled with a professional expectation that doctors should not lie to patients...

'Trust is like, important. I think it's different, like, as a doctor, you can't really lie. I mean as a health professional, you've got to tell the truth.' (Focus Group 5)

Some felt that an intention to avoid stress, as a form of harm, could justify lying to a PLWD...

'I suppose you're weighing up what the benefits and the costs are, aren't you? You're, like, it's not really kind of, lying in that situation is not necessarily a bad thing because the overall benefit is good.' (Focus group 6)

Focus group DCQ 8 (2)

'It is acceptable to lie to them if you think the truth might be upsetting to hear.'

Others thought that strategies that did not depend on giving false information constituted an acceptable alternative to lying...

'They have a right to hear the upsetting news. And maybe choosing the moment is an important point rather than lying because then that's going to make them even more confused.' (Focus Group 5)

→ Other acts to avoid lying included 'delaying', 'distracting' and 'changing the subject'

Many felt that there were no definite rules...

'I think, like you were saying, it's very circumstantial, different with every situation and every person. But I think there has to be an element of using your best judgement for, the person, because I think sometimes it maybe just isn't worth it.' (Focus group 4)

Focus group DCQ 11

'It is preferable to try to talk to a member of their family first, before speaking to them.'

Majority agreed that it would be preferable to talk to each individual PLWD before speaking to their family...

The most common reason was a need to remain objective and unbiased...

'I mean, it's to start a relationship, it's to get general information, like as much of it as possible, and I think you get that best from the person first hand.' (Focus group 4)

A compromise was often endorsed, with information sought from different sources...

'it's good to talk to them, like briefly, and then talk to the family members, just to get a clue how severe the condition is, and then come back to the patient.' (Focus group 2)

Some differences among year 1s – Malaysia – more ambivalence

Interview findings

Dementia was generally thought to make communication more challenging...

'I think a lot of students when they first come, you know, into a clinical setting ((I: m-m)), whether it be mental health or otherwise, it's just talking with patients ((I: yeah)), just generally, so when somebody has dementia, it is erm, you know ((I: yeah)), doubly difficult.' (Interview 4)

Regular supervised context with PLWD seen as helpful...

'I think as you go along you kind of pick up little things ((I: m-m)) that you just don't think are quite right and I think it's good to have an experience of all the good and the bad things you know ((I: m-m)), to see things done well is equally as productive, you know.' (Interview 1)

Discussion points

- Preference for positions which adhered to a person-centred communication approach among Year 3s (and 5s?) in both locations
- Complexities of applying principles of person-centred communication in the clinical environment in the two countries
- Honesty thought to be a key professional principle to be upheld **BUT** students did not support an absolutist view that lying was never consistent with a person-centred approach
 - Consistent with the literature which shows that 'white lies' and deception to occur in dementia care (Elvish et al., 2010)

Conclusions

- DeMEC principles need further development, both conceptually and in terms of making the model applicable to the clinical environment
- Year 1s in Malaysia less 'PC' , less 'person-centred' (quantitative data) – reflecting societal attitudes? – family orientation?(cf. Nikmat et al, 2011).
- Future research directions to include:
 - Conceptual work around the self and person-centredness – intercultural perspectives, is essentialism of 'selfhood' essential?...
 - How do student's attitudes and beliefs relating to person-centred communication with PLWD translate into professional behaviour in the clinical environment?
 - Free assistive technologies based on the model (ESRC)
 - Lingua-cultural adaptation/translation of the model, toolkit
 - Explore social categorisation aspects – effects of self-labelling by groups 'people living with...'

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