

How transculturally appropriate is person-centred communication in the care  
people living with dementia?  
Perspectives of medical students in the UK and Malaysia.

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For

*Showcasing ICLASP15 Research: Selected Projects from the International Association of Language and  
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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.

# 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'

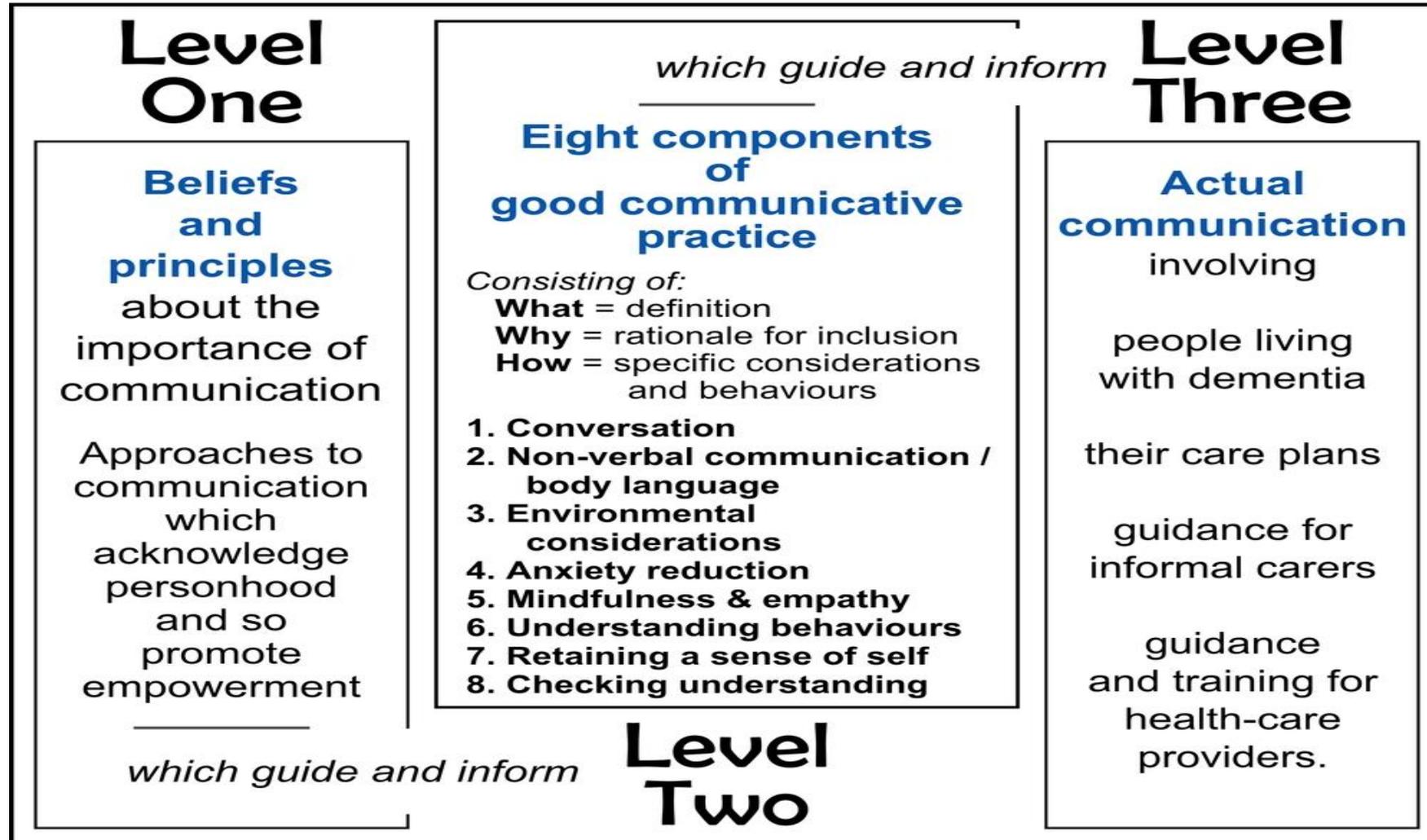
1. **Foundation** - Agreed principles of person-centred communication, based conceptually on Communication Accommodation Theory and derivatives
2. **Advice** - Components of good communicative practice - what, why, how...
3. **Actual practice** – how to apply the principles and advice in '1' and '2'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

Abstract model expressed as a free usable 'toolkit'... [www.dementalk.org.uk](http://www.dementalk.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...

# 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 and Malaysia)

# Findings

- 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, especially related to lying and speaking to members of the family first (especially among year 1s)
- 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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