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Communication, person-centeredness and the care of people with dementia: Perspectives of medical students in the UK and Malaysia.

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Communication, person-centeredness and the care of people with dementia: perspectives of medical students in the UK and Malaysia.

Overview

1. The challenge of dementia
2. What we know about care, communication and dementia
   • Importance of communication in care
   • Practice is (probably) poor
3. A response – the Dementia Model for Effective Communication (DeMEC)
4. Some ongoing research – cultural appropriacy of DeMEC in medical education in Malaysia and the UK
5. Interim conclusions and discussion points
The societal challenge of dementia

• 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
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
• Social withdrawal and isolation
• Tremendous challenge for PLWD, families, professionals, carers...
Research responses to date

• Thus far, very ‘western’

• Largely bio-medical – *but* “Forget about a cure, focus on care”
  (Robinson, 2017)

• Indications communication can make a real difference to quality of life

Young et al, 2011a; 2016
Communication and Dementia Care (1)

UK perspectives:

- Person-centred care the aim and goal

- 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)

- **But** – poor communication practice the norm in health care contexts (Tullo & Gordon, 2013)
Communication and Dementia Care (2)

Education and training for health and social care professionals highlighted as an important strategy for improving care of PLWD (Royal College of Psychiatrists, 2011)

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
A response – The DeMEC Project (1)

The Dementia Model for Effective Communication

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

A flexible, adaptable model guiding a set of tools informed by research and good practice
Method - A co-constructive development project facilitated by the Alzheimer’s Society UK

- 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, old age psychiatrists, gerontologists, nursing professionals, … PLWD had ‘final word’

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

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’...
Dementia Model for Effective Communication - overview

Level One

Beliefs and principles about the importance of communication

Approaches to communication which acknowledge personhood and so promote empowerment

which guide and inform

Level Two

which guide and inform

Eight components of good communicative practice

Consisting of:
- What = definition
- Why = rationale for inclusion
- How = specific considerations and behaviours

1. Conversation
2. Non-verbal communication / body language
3. Environmental considerations
4. Anxiety reduction
5. Mindfulness & empathy
6. Understanding behaviours
7. Retaining a sense of self
8. Checking understanding

Level Three

Actual communication involving people living with dementia

their care plans

guidance for informal carers

guidance and training for health-care providers.
Underlying principles of DeMEC (1)

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

• Aiming for agency, support

• Basis for intercultural dialogue – how do ‘others’ see the condition, care, what can we learn from each other...
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 - based conceptually on CAT and derivatives such as the CPAM and the CEM (e.g. Giles and Ogay, 2006; Hummert et al, 1998; Ryan et al, 1998).
Current Work (ongoing) Malaysia/UK Collaboration

Three concurrent projects

1. Lingua-cultural adaptation/translation of the DeMEC model, toolkit for use in Malaysia by different groups – and developing free assistive technologies.

2. Gauge Medical students’ attitudes towards PLWD and their care in the UK and Malaysia – is attitude a/the ‘problem’?

3. Dementia Communication – how interculturally appropriate is a ‘western’ model of effective communication for medics-to-be in a non-western context. Today’s focus...
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 following the same curriculum.

An (ongoing) series of investigations...

Young *et al*, 2016.
Tullo *et al*, 2016.
Methods

Mixed-methods design:
- Questionnaire (N = 673)
- Focus groups (N = 39)
- Individual interviews (N = 10)

Participants:
- Medical students at a medical school with UK and Malaysia sites – common curriculum
- Years 1, 3 and 5
Quantitative data collection (so far…)

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

Please indicate to what extent you agree or disagree with each of the following statements.

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Older people deserve great respect</td>
<td></td>
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<tr>
<td>2.</td>
<td>Conversation can be an important part of their treatment</td>
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<td>3.</td>
<td>Body language (like gesture and posture) are very important</td>
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<td>4.</td>
<td>Conversation can be a way of reducing anxiety</td>
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<tr>
<td>5.</td>
<td>It is acceptable to touch someone gently to get their attention</td>
<td></td>
<td></td>
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<tr>
<td>6.</td>
<td>It is helpful if medical or care staff wear uniforms so their professional roles are clear</td>
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<tr>
<td>7.</td>
<td>Even very confused speech may hold meaning</td>
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<td>8.</td>
<td>It is acceptable to lie to them if you think the truth might be upsetting to hear</td>
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<tr>
<td>9.</td>
<td>You should give them prompts and clues as reminders of who they are or where they are</td>
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<tr>
<td>10.</td>
<td>It is important to check with them that they have understood what has been said</td>
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</tr>
<tr>
<td>11.</td>
<td>It is preferable to try to talk to a member of their family first, before speaking to them.</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
Qualitative data analysis

Round 1: Six focus groups, 3 UK, 3 Malaysia (N = 39)
- 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 sensitive areas
Quantitative Analysis and Results

- No significant differences between pooled responses in Malaysia and the UK on items 1 – 10 of the DCQ – positive orientation across year groups and locations towards PCC

- Only item 11 ‘It is preferable to try to talk to a member of their family first, before speaking to them’ showed significant divergence across the sample.

- Students in Malaysia thought it significantly more preferable to talk to a family member first (p. <0.05).
Results – qualitative data

• General agreement with the majority of DCQ statements – supporting quantitative findings – in both focus groups and individual interviews

• Increasingly sophisticated understanding of nature of, and potential pitfalls of, a PCC approach when applied to actual practice in the different locations – increasingly so from year to year (1 – 3 – 5)

• No major differences between opinions expressed in UK and Malaysia

• Focus today on item 11, as it did show divergence on the quantitative analysis...
Focus group DCQ 11

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

*Majority in both locations 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.’

*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.’

*Students in Malaysia said much more about this question – and identified family involvement in decision-making as a central challenge in practice*
Analysis is ongoing... Looking at:

- Development through the years in each location (year 1s to 3s to 5s)
- Differences between the years in each location (years ones in Malaysia compared to year 1s in the UK...)
- Differences between students exposed to different curricula (UK and Malaysian) – extending the study...
Interim conclusion

- DeMEC principles are helpful but need further development, both conceptually and in terms of making the model applicable to the local clinical environment in different contexts

- Analysis ongoing – papers to follow…
Person-centred communication and the care of people with dementia

• Thank you for your time and attention!
• Any questions?
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• Please visit www.demtalk.org.uk to see/use the model and toolkit (or put ‘demtalk’ into a search engine)
• See also https://tickettotalk.openlab.ncl.ac.uk/ for a free downloadable app (or search for Ticket to Talk wherever you get your apps)
References (1)


References (2)


