DemTalk - the web-based tool to improve dementia communication and its adaptation for culturally and linguistically diverse populations

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DemTalk - the web-based tool to improve dementia communication and its adaptation for culturally and linguistically diverse populations

Overview

1. The *global* 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 *DemTalk* project
4. Some ongoing research – translating *DemTalk* in Malaysia
5. Interim conclusions and discussion points
The global challenge of dementia

• One of the greatest social, economic and health challenges currently facing societies worldwide

• Now about 40 million people living with dementia (PLWD)

• 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**
• Social withdrawal and isolation very common
• Tremendous challenge for PLWD, families, professionals, carers...

Young et al, 2011a, 2011b
Research responses to date

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

• Thus far, very ‘western’ – but 70% of PLWD in ‘developing countries’ by 2050 (ADI, 2018)

• Indications communication can make a real difference to quality of life (e.g. 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 (Worrall & Hickson, 2003)

- But – poor communication practice the norm in health care contexts (Tullo & Gordon, 2013)
Dementia, communication and clinical settings...

- In the UK, 25 – 30% of hospital in-patients are PLWD
- Generally negative experiences for these PLWD – worse outcomes, longer stays, experience of dementia more pronounced
- Interaction/communication central to alleviating the negatives

(See 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, and in advice and guidance available to family members

Young et al. 2011b
A response – The DemTalk Project (1)

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

Provide a flexible, adaptable model guiding a free and accessible 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...

A conceptual model of effective communication in dementia

• 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’...
The DemTalk website

http://www.demtalk.org.uk/

A free web-based resource for different user groups (more on this later...
Conceptual model underpinning DemTalk- overview

**Level One**

Beliefs and principles about the importance of communication

Approaches to communication which acknowledge personhood and so promote empowerment

**Level Two**

which guide and inform

**Nine**

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**

Alert communication involving

- people living with dementia
- their care plans
- guidance for informal carers
- guidance and training for health-care providers.

9. Keeping yourself well
Underlying principles of DemTalk (1)

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

• Aiming for agency, support

• Basis for intercultural dialogue – how do ‘others’ see the condition, care, what can we learn from each other...
Underlying principles of *DemTalk*(2)

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 (2017 – present)

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

2. Dementia Communication – how interculturally appropriate is a ‘western’ model of effective communication for medics-to-be in a non-western context.

3. Lingua-cultural adaptation/translation of *DemTalk* for use in Malaysia and beyond. Today’s focus...
Lingua-cultural adaptation/translation of *DemTalk* in Malaysia – a work in progress...

Collaboration between *Newcastle University, Numed Malaysia, University of Malaya* and the *ADFM*

– work with Malaysia-based partners to adapt the DemTalk materials for Malaysian audiences

**AIM =**

to *adapt* and *translate* the materials into the **three** main non-English languages used in Malaysia – *Bahasa Malaysia, Chinese and Tamil* (also *English*, but in a Malaysia-relevant version).
Lingua-cultural adaptations of DemTalk in Malaysia – background & progress thus far...

Qualitative study
1. to gain insights about CHALLENGES AND COMMUNICATION NEEDS in care provision for PLWDs

- Ethnographic Observations
- Interviews

PHASE 1

ADFM Day Care Centre
- Informal discussions & interactions

ADFM Community Centre

PHASE 2

- Activities involving PLWDs
- Caregiver Training Workshops
- Caregiver Sharing Sessions
- Awareness talks & other activities

PHASE 3, 4 & 5

2. to identify potentials for LINGUA-CULTURAL ADAPTATION of existing PERSON-CENTRED COMMUNICATION RESOURCES
Lingua-cultural adaptation of DemTalk – a work in progress...

What do the DemTalk materials have to offer?

DemTalk is a free, web-based toolkit to help improve communication with people with dementia. It was produced in a project facilitated by the Alzheimer’s Society UK, by teams of stakeholders including communication researchers, technology designers, health and social care experts, carers and people living with dementia.

Welcome to the DemTalk toolkit for Family Carers. Use the links below to read the different sections of the toolkit. If you are new to DemTalk, you might want to start off by reading the introduction.

If you would prefer to download a full version of the family carer toolkit to read offline, then please click here: Dementia Toolkit for Effective Communication.

Introduction

- DemTalk - Who is it for? Why use DemTalk?
- Dementia and communication
- How to use DemTalk
- How DemTalk is organised
DemTalk in Malaysia – a work in progress...

Phase 1 : Findings
Observations revealed that effective communication = central to PLWDs’ participation. A recurrent theme during the caregiver training workshops and sharing sessions is the question of how to communicate effectively with a PLWD in the various stages of cognitive decline.

Phase 2 : Findings
The participants’ response to interview question on the DEMTALK materials revealed a similar perspective: the beliefs and principles + components of good communication practices = RELEVANT to the culturally diverse MALAYSIAN population

All the participants agreed that DEMTALK IS A USEFUL GUIDE for their interactions with PLWDs.
Phase 2 : Findings (Cont’)

The professional carers confirmed that although these values are norms in the local culture, a timely reminder e.g. “to respect the elders” is often necessary.

while the family carers, revealed a somewhat differing perspectives among the participants who come from culturally and linguistically diverse society and have different life experiences.

• “um, i thi- i think the bit that might be the local part would be perhaps, mm, in an Asian context you may feel more, more, uhm, responsibility towards looking after them when they’re older compared to a western setting whereby uhh, they’re much more independent and they live on their own much longer, uh, and uhm, so, so in that sense you feel the responsibility to looking after them because you kinda respect their role as them being your parent, uhm, and not, and, and, and, so what I’m trying to say is, so you you you accept that, you so i mean y-you look after them because you respect them ...

...but not to say that the western culture you, y’know, you don’t respect them but its different because there there’s more independence, uhm, whereas i think here its like you know its kinda accepted when they get a certain age you you you care for them, to a certain extent y- you know you, er, its accepted. uhm, unless they opt, or they behave in such way where they want to be independent.”

(Interview data : Participant code : AZ , Malay, Female, Academician)

• “ I tend to let him be ... it is not that I don’t care but why impose on him - i mean he is having this, why stress him... As long as it is not causing any harm. “

(Interview data : Participant code : SC , Chinese, Female, Accountant)
DemTalk in Malaysia – a work in progress...

Phase 3 - Focus group discussions at a workshop on Communicating with Older Persons in Clinical Practice and Research at the Faculty of Medicine in University of Malaya
- participants from various backgrounds

Phase 3: Findings
• Confirmed relevance of the core Beliefs and Principles to guide communication with PLWDs – perspectives of family member’s & professional trainees.
• Highlighted slight variation in INTERGENERATIONAL interactions involving PLWDs

Phase 4 – Public Forum at ADFM’s Community Centre (WAM)
Provided opportunities to document “public” opinion about dealing with Dementia

Phase 4: Findings
• Care & Communication/ Participation of PLWDs = requires societal support
  - not just the immediate family members & caregiver burn-out is another concern
• Also highlighted issues in INTERGENERATIONAL interactions involving PLWDs
Based on the **Phase 1 - 4 findings**, lingua-cultural adaptation of DemTalk into Malay language i.e. the most common language of Malaysian bilinguals was initiated first.

Principles of translation e.g. **equivalency** was been adopted in this first attempt. (link to notes on translation)

- some linguistic elements i.e. expressions & lexical items (concepts) do not lend themselves to translation.

 Procedures of **back-translation** helped to identify elements that did not lead us back to the original form.

- these also give us additional insights into the phenomenon of language variety experienced in the context of societal multilingualism

→ **English language version for Malaysian Users** (link to the beta version of DemTalk _my.org )

This was followed by the **Tamil version** & the **Mandarin version** (under construction)
Phase 5: Caregiver talks at AACC/ Seminar presentations – introducing elements of DemTalk - getting feedback for continuous development (ongoing)
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• Thank you for your time and attention!
• Any questions?
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• Please visit www.demtalk.org.uk to see/use the UK-based model and toolkit (or put ‘demtalk’ into a search engine)

• Versions in the languages of Malaysia available soon!
References (1)


References (2)


