





Palliative care educational needs analysis: Issues identified for aged care staff






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Dementia in Context – Residential Aged Care

- People with dementia (PWD) comprise >½ of the residential aged care (RAC) population
- Up to 80% of those requiring high care in RAC have dementia
- PWD living in RAC progressively have moderate to advanced forms of dementia with associated higher order needs





Dementia in Context – RAC Workforce

- 2003-2008 saw a 23% reduction in registered nurses (RNs) and an 11% reduction in enrolled nurses (ENs)
- Personal care attendants (PCAs) currently provide approximately 70% of hands on care
- 80% of carers are casual or part-time workers
- Annual turnover rate of 20%+

Context continued...


- RNs are estimated to spend >25% of their time completing documentation
- PCAs are *not* nurses – 20% receive no preparatory education – of the remainder the quality of preparation is variable
- Older residents' co-morbidities mandate they receive skilled assessment and care








Disconnect...

...between resident acuity, dependency & need...

...and staff capacity to respond to these needs





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This presentation

- Reports on part of a larger project designed to:
 - Enhance knowledge of dementia as a terminal illness among care staff and family
 - Improve communication between care staff and family members of residents with moderate to advanced dementia living in RAC
- Project aims acknowledge the role of knowledge & skill as mediators in communication & care

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Needs analysis

Tool modified from Whittaker *et al.* (2007)¹ addressing nursing & care staff confidence in responding to a variety of clinical & communication issues encountered when caring for seriously ill and dying residents

¹ Whittaker, E., Kernohan, W. G., Hasson, F., Howard, V., & McLaughlin, D. (2007). Palliative care in nursing homes: exploring care assistants' knowledge. *International Journal of Older People Nursing*, 2(1), 36-44.

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Sample reported here

- 129 personal care attendants (PCAs)
- 77 nursing staff (registered and enrolled)
 - employed at 4 RACFs in Tasmania and Victoria
- Plus supplementary qualitative data derived from family of PWD interviews and staff focus groups connected with DSUs at the above RACFs

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Areas of Confidence Addressed

- Pain control
- Breathlessness
- Constipation / incontinence
- Mouth care
- Nutrition & hydration
- Identifying & reporting symptoms to the nurse in charge
- Care issues in the last days of life
- Awareness of the spiritual & cultural needs of residents & families
- Communicating with residents about death & dying
- Communicating with relatives about death & dying
- Communicating with relatives prior to death of a loved one
- Care of the deceased at time of death
- Support of relatives at time of death

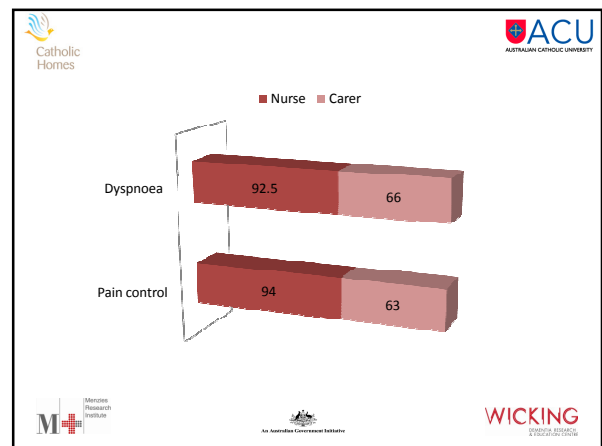
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Results

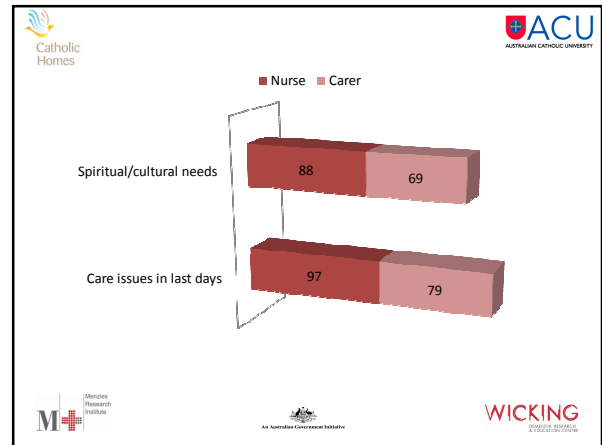
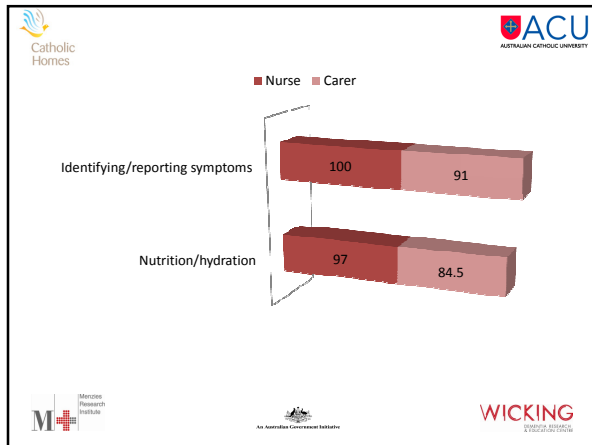
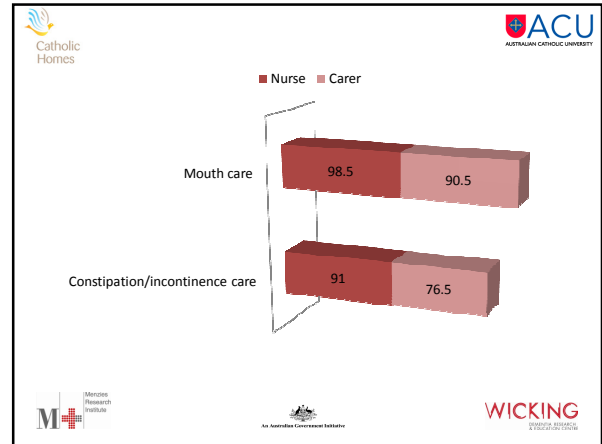
- Overall, the majority of staff were 'often' or 'always' confident with most practices
- Nursing staff were significantly more confident than care staff across all response categories

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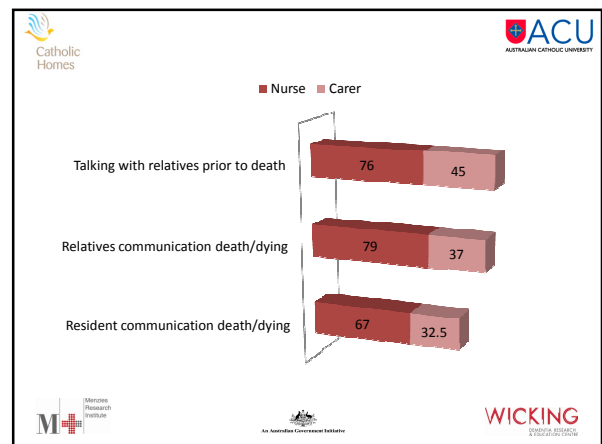
Pain control?

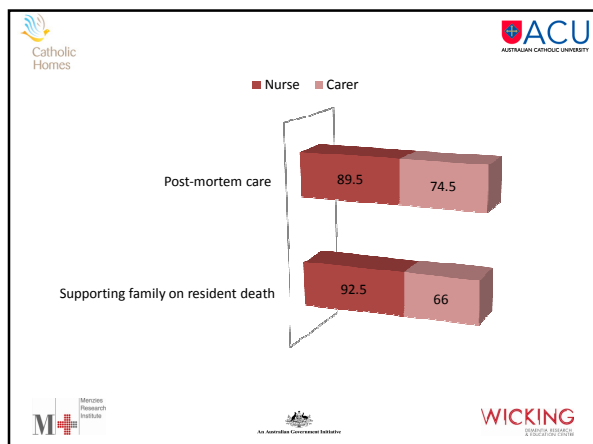
- All levels of staff were largely confident re their capacity here, however elsewhere:
 - approx 40% incorrectly identified 'it is impossible to tell if a person in the later stages of dementia is in pain'
 - 62.5% of senior nursing staff thought 'complete pain relief' to be a reasonable goal of care
 - 87.5% of senior nursing staff thought patients should be maintained in a 'pain free' state
 - 37.5% of senior nursing staff unclear about relationship between therapeutic analgesic administration & addiction



More revealing results...

However, confidence in communicating around dying & death was a notable deviation from this pattern, most particularly among non-nursing care staff





Family bereavement support measures

- 235 respondents provided qualitative data to the question 'what support do you give to the family when their loved one dies?'
- 'Emotional support' was a key theme, along with 'physical support'. 'Talking', 'time', 'hugs', 'listening', and 'hot drinks' were common strategies – little detail provided

Family bereavement support measures

- Some more problematic responses included:
 - Try and refer on to a more specialised person
 - Usually none/offer drinks and snacks
 - Leave it to the nursing sister
 - Emotional support is ongoing 24/7
 - I am not usually involved at work
 - Try to let other people do the work - EN/RN - we do not have time for this
 - Not much - don't know what to say or do and leave for more confident person
 - Only if the family approach me will I give support

Talking with families about dying & death

- A senior EN in a focus group, when asked how she communicates with families of residents with dementia who are approaching death responded:


'Yeah, I can't cope with it. I've just got very, very short answers to their questions and find somebody else to deal with it... I just don't know what to say to them, basically... I just find someone else... if someone's there and if they're good... [here indicating a PCA in the group]'

Talking with families about dying & death

- Of nine interviews of family of people with moderate/severe dementia in two Victorian RACFs, none could recall having a conversation with a staff member about their loved one's possible death or its relationship to dementia
- For eight of these respondents, they would not be surprised if their loved one died within the next 12 months




Resident bereavement support measures


- 220 respondents provided qualitative data to the question 'what support do you give to other residents when a resident dies?'
- Here 'comfort' was a key theme. 'Reassuring', 'sharing', and 'informing' were prominent descriptors used – again, little further detail provided by respondents

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Resident bereavement support measures




- Again, more problematic responses included:
 - We try to keep death of a resident confidential
 - Not to tell other residents unless he/she is their close friend/relation
 - Usually not talk to them about the death; shield them from the body (on the trolley – not let them see that – talk if they ask). It's distressing to them
 - Try and divert the attention
 - No, we don't tell other residents. We don't want to scare [sic]
 - Whole matter appears to be somewhat hush-hush


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Dementia & dying/death dialogues?




- Conversations limited – variously characterized by silence/avoidance/aphorisms
- Repeated statements made that 'confidentiality' precluded conversations with family
- Underpinned by questionable confidence & knowledge/skills in later and end-of-life care in general and dementia as a life-limiting condition in particular

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Project Strategies

- Focused on increasing knowledge of carers and family members – targeted education
- Identification of link nurse to champion change in facilities – supported by both substantive education and establishing action groups
- Development of family communication tool and related resources designed to support staff currently arguably ill-equipped to respond to a growing area of need

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