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Implementing a palliative approach for people with dementia in aged care: key issues in adopting best practice

Sharon Andrews
Research Fellow
Wicking Dementia Research and Education Centre,
Menzies Research Institute, University of Tasmania.

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Supervisors

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Research Question

How can aged care staff facilitate a palliative approach to care for people with dementia and their family caregivers?

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Background

In Australia:

- Overall increase resident dependency and acuity in RACFs over past decade.
- Proportion of people being admitted to highest level of care between 1999 and 2006 almost doubled (12.4% to 20.2%)¹
- Approx 86% of all residents will die in RACFs².
- Almost 50% of residents are estimated to have dementia in residential age care facilities (RACFs)/nursing homes (NHs)²
- Similar trends overseas³.

❖ **Increasing recognition in the literature that dementia is a terminal condition.**

1. Andrews-Hall, S. Howe, A. & Robinson, A. 2007, 'The dynamics of residential aged care in Australia: 8 year trends in admission separations and dependency', Australian Health Review, vol. 31, no. 4, pp. 611-622.
2. AHW 2006, Dementia in Australia: national data analysis and development, AHW, Canberra.
3. Volker, L. 2005, 'End-of-life care for people with dementia in long-term care settings', Alzheimer's Association, viewed 2nd August 2006, <http://www.alz.org/national/documents/longdementia.pdf>

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Best practice in the care of people with dementia

- Palliative approach⁴:
 - Promotes principles of palliative care philosophy.
 - Implemented Independent of the illness, stage or care setting – **broader focus than end-of-life care.**
 - Promotes an open attitude towards death and dying.
 - Focus on early care planning and collaboration with family and client where possible.

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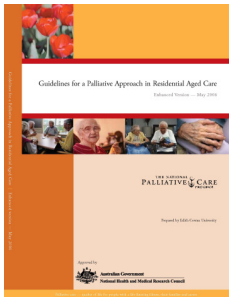
4. ADoHA 2006, Guidelines for a Palliative Approach in Residential Aged Care, enhanced version, Rural Health and Palliative Care Branch, Government Department of Health and Ageing, Canberra

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Best practice guidelines

- "Guidelines For a Palliative Approach in Residential Aged Care"⁴
- Supported by the Australian Government.
- National dissemination strategy to promote implementation

<http://www.palliativecare.org.au/Portals/46/APRAC%20guidelines.pdf>



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4. ADoHA 2006, Guidelines for a Palliative Approach in Residential Aged Care, enhanced version, Rural Health and Palliative Care Branch, Government Department of Health and Ageing, Canberra

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Evidence-practice gap

- While being advocated as best practice, a palliative approach to care has been found lacking within Residential Aged Care Facilities (RACFs).
- Limited evidence of adoption of the Guidelines in RACFs.
- ? strategies to promote evidence based palliative approach to care in RACFs.
- Evidence suggests palliative care for people with dementia in RACFs is "sub-optimal":
 - more likely to undergo futile interventions at the end of life⁵ and less likely to have an advance care directive⁶⁻⁷

5. Mitchell, S.L, Kieley, D.K & Hamel, M.B 2004, 'Dying with advanced dementia in the nursing home', *Archives of Internal Medicine*, vol. 164, no. 3, pp. 321-326.

6. Lamberg, J, Person, C, Kieley, D & Mitchell, S 2005, 'Decisions to hospitalise nursing home residents dying with advanced dementia', *Journal of The American Geriatrics Society*, vol. 53, no. 8, pp. 1386-1401.

7. Chen, J, Lamberg, J, Chen, Y, Kelly, D, Page, J, Person, C & Mitchell, S 2006, 'Occurrence and treatment of suspected pneumonia in long-term care residents dying with advanced dementia', *Journal of The American Geriatrics Society*, vol. 54, no. 2, pp. 290-295.

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Aims of the project

- Investigate the extent to which a palliative approach is currently reflected in practice on a dementia special care unit (SCU).
- Identify barriers to aged care staff in implementing the best practice guidelines on the SCU.
- Develop interventions/ strategies that will assist aged care staff to develop their care practices to support an evidence based palliative approach to care on the SCU.

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Methodology : Action research

- Establishment of Action Research Group (ARG) (2RNs, 1 EN, 2 PCAs)
- Participants develop a shared sense of ownership over the problems in their practice.
- Identify and take strategic action aimed at change/improvement and knowledge development.

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graph TD
    A[Problem Identification/ Reconnaissance] --> B[Plan]
    B --> C[Take action & collect data]
    C --> D[Analysis/ Evaluation]
    D --> E[Replan]
    E --> F[Reflection]
    F --> B
    
```

Setting

- 30-40 bed dementia special care unit.
- Residents with moderately advanced to severe dementia (80% in two highest care categories).

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Preliminary Investigation:

ARG meetings (n=11)

Action Cycle 1-3:

Staff surveys (n=32): Knowledge of palliative approach and dementia.

Resident file audit (n=21): Palliative approach to care as reflected in staff documentation.

Family caregiver interviews (n=10): Understandings of dementia and experiences of SCU.

Critical dialogues with staff (n=6): Exploring provision of a palliative approach.

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Key findings

Complexity of caring for family members of people with dementia

- Family members were described as often 'anxious', with 'no understanding about dementia' (RN-ARG).
- Staff concerns about their capacity to provide support to family caregivers consistent with a palliative approach to care (ARG, CD).

Workloads and staffing issues – impacting on timely palliative care

- Workloads described as 'horrendous' (RN-ARG). Practice described as 'repetitive' and 'remote control' (PCA-ARG).
- Quality of care for dying residents on the SCU.
 - ...we can't be with the [dying] resident... So they are left lying there...until we can get back...and sometimes we don't (PCA-ARG)

Pain management

- Especially challenging – lack of an evidence based approach (File audit). Described as 'trial and error' (RN,EN -ARG).

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Key findings cont...

Knowledge of best Practice Guidelines

- Limited at best (surveys, CD, ARG)

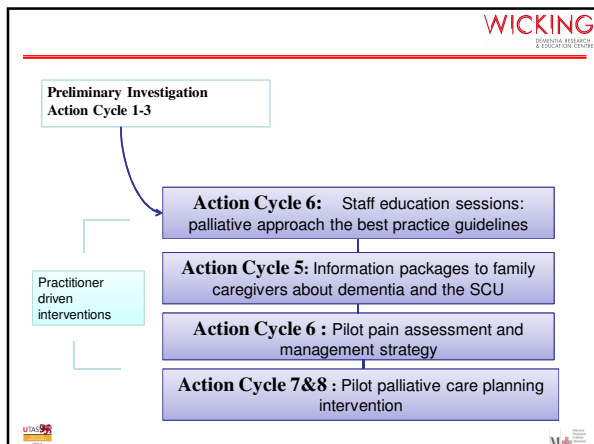
Operationalisation of palliative care

- A palliative approach = terminal care (surveys, ARG, CD)
- Philosophy of maintaining physical functioning – 'trying to rehabilitate' (RN-ARG).
 - 'residents have come here to live...they haven't come here to die!...you just want to make the nursing home their home not a death trap!' (EN-ARG)

Death-averse culture

- Talking about death, dying and palliative care on the SCU not an established or accepted part of practice (ARG, CD, interviews) .
- Considered to be 'anti-social' (EN-ARG)
- Absence of advance care planning (File audit).

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Key Findings – Action cycles 4-8

Impediments to effective implementation

Staffing hierarchies

- Existing staffing hierarchies constrained staff members' ability to effectively support family caregivers of residents.

'[I] used to ...vanish...in case they [family members] asked something I wasn't allowed to answer' (PCA-ARG).

'...we were never allowed to talk to the family [about dementia]...it was just one of their [nursing staff] rules!' (PCA-ARG).

- Reluctance of care staff to talk with GPs – 'overstepping the boundaries' (PCA-ARG).

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Key Findings – Action cycles 4-8

Demarcation of staff roles – difficulty in reconfiguring practice

Piloting collaborative pain assessment and management process

- Contribution of care staff undervalued.
- Care staff lacked staff to formally collaborate.

'PCAs felt isolated...what they had to say ... what they wanted to contribute was not valued... or supported by nursing staff on the SCU' (RN-ARG).

Piloting advance care planning case conferences

- Considered to be the 'doctors' job' (RN-ARG).
- Staff not comfortable to talk about death in the context of dementia.
- Clinical demands were prioritised over discussions about deterioration and dying.

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Changing practice to support a palliative approach to care is complex and there is no simple solution...

- Material/system factors:** short staffing; excessive workloads; casualisation.
 - Enhance capacity to embrace change and receptivity to change
- Cultural factors:** recognise the dominance of restorative focus of care; privileging of routine, death avoidance.
 - Enhance capacity to support innovation, where a culture of best-practice is prioritised; explicit acknowledgement of death and dying.
- Socio-political factors:** recognise the insidious impact of institutional hierarchy, role demarcation, professional isolation
 - Enhance capacity of aged care staff to work in partnership, rather than simply alongside each other.

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Thank you

Email:
Sharon.andrews@utas.edu.au

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