THE IDEAL PROJECT

A pragmatic cluster randomised controlled trial of facilitated case conferencing versus usual care for improving end of life care and outcomes in aged care residents with advanced dementia and their families

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Funding: Australian Department of Health

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IDEAL PROJECT (ACTRN 12612001164886)

Objectives:

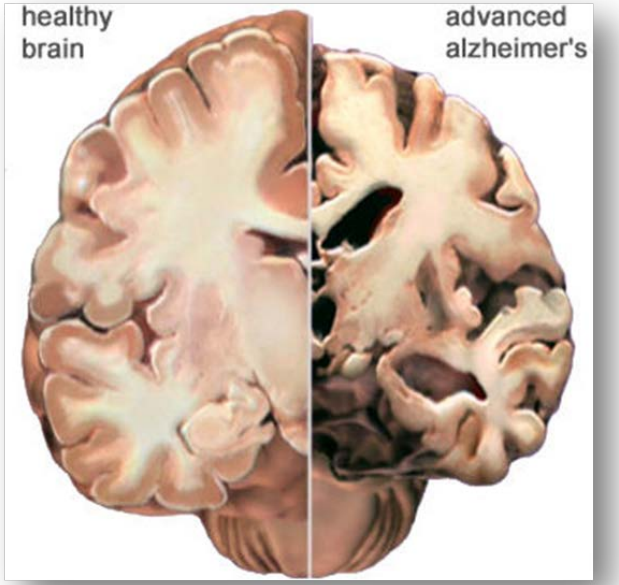
1. To compare the efficacy of facilitated case conferencing (FCC) with Usual Care in improving end of life outcomes for residents with advanced dementia living in residential aged care;
2. To provide insights into facility- and staff-related processes influencing the implementation and sustainability of FCC; and
3. To evaluate the cost-effectiveness of FCC versus Usual care

Study period: May 2013 to November 2014

DEMENTIA

- A collection of symptoms caused by progressive disorders affecting the brain, impacting:
  - Thinking
  - Behaviour
  - Ability to perform everyday tasks

  (Gauthier & Cummings 2001)



- 3rd leading cause of death across Australia in 2010 (Australian Institute of Health and Welfare 2012)
- Most expensive mental health condition in Australia - $6.6 billion in 2005 (McCusker Alzheimer's Research Foundation 2011)
- Most aged care residents have dementia and most people with advanced dementia live in aged care (Australian Institute of Health and Welfare 2012)

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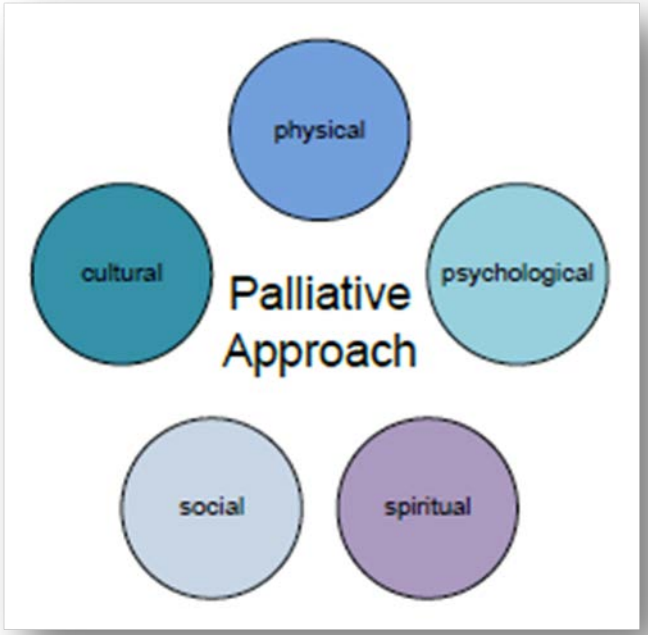
PALLIATIVE APPROACH



- A palliative approach is required for advanced dementia (e.g. Alzheimers Australia 2006)
- BUT often not recognised in aged care:
  - High rates/poor outcomes hospitalisations
  - Symptoms may go unrecognised/managed
  - ‘Aggressive’ treatment for medical problems with little benefit to survival
- Key causes likely to be (DOHA 2003):
  - Transient and poorly educated staff
  - Poor communication/coordination

CASE CONFERENCING AS A SOLUTION

Brings together family decision-makers with aged care staff and other health professionals (e.g. GP) to discuss resident needs and agree on a care management plan

- Strongest evidence in community palliative care (e.g. Mitchell, 2008)
- Promoted for aged care by NSW Dementia Services Framework 2010-2015 despite limited evidence in this setting
- Special potential for residents with advanced dementia:
  - provides a formal framework for reaching and documenting shared understanding and decisions re goals of care and ACP
  - may directly improve some outcomes (family communication = better satisfaction)

CASE CONFERENCING AS A 'COMPLEX INTERVENTION' (UK MRC)

- Involves multiple interacting components
- Requires tailoring to local contexts
- During evaluation, requires monitoring of processes as well as outcomes to:
  - assess fidelity
  - clarify causal mechanisms
  - identify influential contextual factors to inform targeting, adaptation and ongoing development, evaluation and implementation

Craig P et al. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ 337: a1655.

FACILITATED CASE CONFERENCING

Palliative Care Planning Coordinator (PCPC) role:

- Existing RN Level 8, 0.4 FTE for 18 months (June 13 – Nov 14)
- Trained + supported by project team to:
  1. use evidence-based ‘triggers’ to identify residents with advanced dementia at a time-point likely to benefit from a case conference
  2. organise, set an agenda, chair and document case conferences with optimal involvement from family, multi-disciplinary facility staff and external health professionals (e.g. GPs)
  3. develop and oversee implementation of palliative care plans
  4. train other staff in person-centred dementia-focused palliative care

IDEAL PROJECT
INTERVENTION GROUP RACFS

- N=10 (Sydney [n=5] and Brisbane [n=5])
- Median 120 beds (IQR 101 – 128)
- 6 private, 4 not for profit
- Mean 13 (SD 4.5) participating residents per RACF (N=130)

EXIT INTERVIEWS WITH PCPCS AND STAFF

- Participant eligibility criteria
  - PCPCs
  - Nursing and allied health facility staff + external health involved in case conferencing

- Semi-structured interviews
- Documentation
  - PCPC interviews audio-recorded and transcribed
  - Staff interviews documented via interviewer notes, including verbatim
- Analysis
  - Both deductive (i.e. informed by the aims of the research) and inductive (i.e. grounded in responses)
  - Coded by two researchers who met to agree themes

INTERVIEW TOPIC GUIDE - PCPCS

1. What (if anything) has changed at your facility?
2. What has worked well?
3. What problems were encountered?
4. What support have you received from managers, staff and GPs?
5. What support have you received from families or residents?
6. What stoppages have there been?
7. Were two days per week enough?
8. What advice would you give to someone else taking on the PCPC role?
9. What plans are there to continue aspects of the PCPC role in your facility?
10. How has your experience of being a PCPC been useful to you personally?

RESULTS - FCC IMPLEMENTATION

- 1/10 RACFs did not implement even to a limited degree
- PCPCs in other 9 RACFs reported ability to work 0.4FTE
  - ‘large extent’ (N=5)
  - ‘moderate extent’ (N=2)
  - ‘lesser extent’ (N=2)
- 3 RACFs had to replace PCPC during 18 months,1 of which moved to a pay-as-you-go contract
- PCPCs facilitated:
  - 341 case conferences (median 28, IQR 12 - 60)
  - An average of 28% of all case conferences in RACFs (IQR 11 – 76%) and may have also influenced others

RESULTS - INTERVIEWS

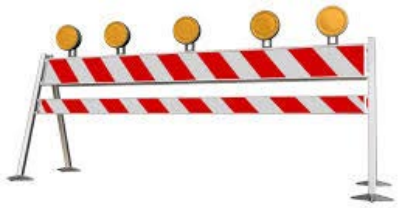
- Sample
  - PCPCs from all 10 RACFs (N=11)
  - Nursing (N=18) and allied health (N=8) staff from 7/10 RACFs
  - Geriatrician, medical officer and GP
- Themes

1. Benefits of implementing facilitated case conferencing
2. Barriers to implementation
3. Facilitators to implementation

BENEFITS OF FACILITATED CASE CONFERENCES

Sub-theme	Illustrative data
Better communication between staff and families	*Families have been involved in decisions earlier than previously. This has enabled a softer approach to advance care planning.* (AIN)
More multi-disciplinary involvement in case conferences and care planning	*A lot of the personal carers … have a lot to say about resident's care, and the families or the resident themselves may be very interested in what they had to say about their care.* (PCPC)
Improved staff knowledge and attitudes	*There is more openness, ownership, whole-care-team … People are not afraid to talk about death and dying.* (RN)
Improved palliative care and resources	*They didn't have that demarcation where they know this resident is now palliative … [but now] we'd have a butterfly on the bedside to identify that that resident was palliative so the noise levels would be down and we'd have nice scented sprays in the room, keeping it clean all the time.* (PCPC)

BARRIERS TO IMPLEMENTATION



Sub-theme	Illustrative data
Management, staff and GP resistance	*The facility manager, so she wasn't really interested… so she didn't really make time or tell me I need to take time – I had to go to her and say, "I need some time now, you know, for this project".* (PCPC)
Time pressures and staffing levels	*[Name of PCPC]'s resignation and a new director of nursing – the new staff were not involved with the new project, and they did not have the same information and passion.* (Clinical Manager)
PCPC/staff lack of confidence	*I was a little bit hesitant in getting involved straight away so I had to do those more introductory case conferences first to get myself, you know, prepared, as I wasn't really confident in talking to families as much, but it got a lot easier.* (PCPC)

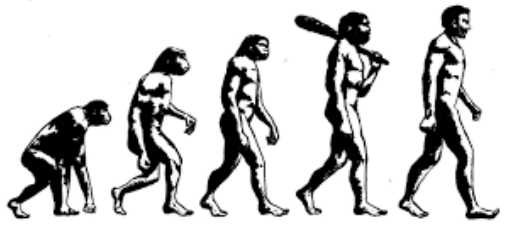
FACILITATORS TO IMPLEMENTATION

Sub-theme	Illustrative data
Management, staff and GP support	*Absolutely freedom, flexibility, freedom. And they trusted me. They knew that I was doing my job alright.* (PCPC)
Positive family feedback	*There are less complaints especially from those who went through the case conference sessions. Families felt they had a voice. There was communication about pain management and everyone was treated the same.* (RN)
Dedicated PCPC role/time	*Having a directive, someone to lead, someone to help others understand dementia care and to have the best resources available when you need them. Now there is someone to go to and get an answer.* (Physio aide)

LIMITATIONS

- Sample
  - Small size
  - Relied on volunteers
  - Family voice not directly included
- Analysis predominantly deductive
- Staff interviews were documented via interviewer notes rather than audio-recordings

CONCLUSIONS



- A **facilitated approach** to case conferencing …
  - Overcame some documented barriers, including:
    - confusion about case conferencing purpose/roles (Halcomb, 2009)
    - lack of knowledge about dementia / individual residents and limited multidisciplinary involvement (Holle, 2015)
  - BUT:
    - Struggled to initiate a collaborative culture where this was lacking
    - Faced structural challenges from RAC business model and 'bottom line' *even when* PCPCs were funded 0.4FTE
- Further studies are needed to document families' perceptions of benefits, as consumer advocacy is likely to increase the priority given to case conferencing within the sector

WEB RESOURCES FOR FCC IN ADVANCED DEMENTIA

- CareSearch supported
- Will include guidance on:
  - Triggers for case conferences
  - Optimal attendance
  - Engaging GPs
- Illustrative cases
- ‘Talking heads’ videos
- Templates for organising and documenting case conferences
- Applicable to settings beyond aged care

ACKNOWLEDGEMENTS

Mid North Coast (NSW) Division of General Practice (MNCDGP) 2007, Toolkit: Creating a Multi-Disciplinary Team Approach to Care Planning In Residential Aged Care Facilities 2nd Edition. MNCDGP: Rural Palliative Care Project, Aged Care GP Panels Initiative and Integrated Network Palliative Care Project, Coffs Harbour
http://www.mncdgp.org.au/system/files/RACFMDTToolkit2ndEdition2007PrintFormatrevisedNov2008_1.pdf

Managers, staff, families and residents at participating aged care facilities in Sydney and Brisbane

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