MISUNDERSTANDING_DEMENTIA – KEY CHALLENGES IN PROVIDING EVIDENCE BASED DEMENTIA CARE

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Acknowledgements

Research Team + collaborators
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- A/Professor Christine Toye, Curtin University of Technology
- Dr Sharon Andrews, University of Tasmania
- Dr Chris Stirling, University of Tasmania
- Professor Michael Ashby, Tasmanian DHHS
- Susan Leggett, University of Tasmania
- Dr Claire Eccleston, University of Tasmania
- Cath Donohue, Australian Catholic University

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- Curtin University
The growing significance of aged care

- Residential aged care a growth industry. Between 2007 – 2020 demand for residential aged care places predicted to increase by 40%¹

  - 2006-07 govt expenditure in Aus on aged care 0.7% of GDP – will grow to 1.9% by 2046-47 (higher than both education and defence)²

  - Changing resident profile - Upward shift in age at admission associated with increasing dependency and dementia - 36% turnover of residents every 12 months³

RACF Profile

Escalating trend to older age admissions, higher dependencies, growing separations via death and increasing incidence of residents with dementia.

What is the impact of dementia and what are the implications for the aged care workforce?
Challenges in providing services to people with dementia

• Dementia generally not regarded as a **terminal condition** – ‘dementia is not often fatal in itself’ (AIHW 2011).

  - Difficulties relating to prognostication, illness trajectory & identification of proximal cause of death.
  - Consequences include inadequate pain and symptom management, invasive and futile diagnostic tests & inappropriate hospitalisations

• Dementia now linked unequivocally to high mortality rates (Mitchell et al, 2009)
The link between dementia and palliation

- Need increased attention on palliative approaches to care for people with dementia (PWD) in RACFs
- A palliative approach involves partnership between staff and family.
- Care planning impacted by knowledge of dementia
- Knowledge a mediator in care planning communication between staff & families – will impact on capacity to work together
Our First question

What are the differences in dementia knowledge between RACF staff and family members?
Survey RACF staff and family members to ascertain their knowledge of dementia – implications for their capacity to collaborate in implementing a palliative approach to care

- We found no single instrument that facilitated a comparative evaluation of families’ and formal carers’ knowledge.

- To assess knowledge we adapted the Dementia Knowledge Assessment Tool (DKAT) used in Dementia Essentials program.
DKAT2 survey administered in 8 x RACFs (Tas x 2 + Vic x 2 + WA x 4).

Care (RNs, ENs, PCAs) & other staff (n = 315).

- Interviewer administered

- In Tas & Vic RACFs, 70% of all care staff working in the facilities responded. In WA RACFs, 39% of care staff responded.

Family carers of PWD resident in the same 8 RACFs (n = 163).

- Tas and Vic: 3rd party recruitment and surveys mailed to their home address, 52% response rate

- WA: surveys mailed to their home address, 28% response rate
Staff profile

- 82% female
- 20% NESB
- 24% aged < 36, 18% aged > 55
- 13% RNs, 14% ENs
- 39% have TAFE certificate

Family carer profile

- 57% female
- 2% NESB
- 64% are aged > 55 (26% are > 65)
- 15% spouse
- 56% daughter/son
- 46% have education beyond year 12
Findings: Staff and family carer training

### Education in dementia care

<table>
<thead>
<tr>
<th></th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>RN</td>
<td>84%</td>
</tr>
<tr>
<td>EN</td>
<td>80%</td>
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<tr>
<td>PCA</td>
<td>71%</td>
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<tr>
<td>Other staff</td>
<td>50%</td>
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<tr>
<td>Family carers</td>
<td>17%</td>
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</tbody>
</table>
Findings: Staff and family carer training

**Education in palliative care**

- RN: 70%
- EN: 76%
- PCA: 63%
- Other staff: 37%
- Family carers: 11%
<table>
<thead>
<tr>
<th>Dementia Knowledge Assessment Tool version 2</th>
<th>Staff</th>
<th>Family</th>
</tr>
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<tbody>
<tr>
<td>Dementia occurs because of changes in the brain</td>
<td>98% (314)</td>
<td>98% (155)</td>
</tr>
<tr>
<td>Only older adults develop dementia</td>
<td>90% (311)</td>
<td>85% (153)</td>
</tr>
<tr>
<td>Brain changes causing dementia are often progressive</td>
<td>90% (315)</td>
<td>93% (156)</td>
</tr>
<tr>
<td>When a person has late stage dementia, families can often help others to understand that person's needs</td>
<td>85% (313)</td>
<td>80% (156)</td>
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<tr>
<td>Uncharacteristic distressing behaviours may occur in people who have dementia (e.g. aggressive behaviour in a gentle person)</td>
<td>96% (315)</td>
<td>92% (155)</td>
</tr>
<tr>
<td>A person who has dementia can often be supported to make choices (e.g. what clothes to wear)</td>
<td>85% (314)</td>
<td>88% (154)</td>
</tr>
</tbody>
</table>
Findings: Comparative knowledge

Dementia is likely to limit life expectancy

- RN: 58%
- EN: 51%
- PCA: 47%
- Other staff: 50%
- Family carer: 41%

Percentage correct
Findings: Comparative knowledge

Alzheimer's disease is the main cause of dementia

Percentage correct

- RN: 58%
- EN: 40%
- PCA: 49%
- Other staff: 43%
- Family carer: 32%
Findings: Comparative knowledge

It is impossible to tell if a person who is in the later stages of dementia is in pain

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<td>Family carer</td>
<td>34%</td>
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Findings: Comparative knowledge

Confusion in an older person is almost always due to dementia

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<td>76%</td>
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<tr>
<td>Family carers</td>
<td>59%</td>
</tr>
</tbody>
</table>
Findings: Comparative knowledge

Incontinence always occurs in the early stages of dementia

Percentage correct

- RN: 85%
- EN: 84%
- PCA: 69%
- Other staff: 62%
- Family carer: 54%
Findings: Comparative knowledge

Difficulty swallowing occurs in late stage dementia

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<td>Family carer</td>
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Findings: Comparative knowledge

Movement is limited in late stage dementia

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<td>Family carer</td>
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Findings: Comparative knowledge

Changing the environment will make no difference to a person who has dementia

Percentage correct

- RN: 78%
- EN: 60%
- PCA: 50%
- Other staff: 68%
- Family carers: 49%
Comparison of RACF staff & family carer knowledge

![Box plot showing comparison of DKAT Total Score for RN, EN, PCA, Other staff, and Family carers.](image_url)
The impact of education on staff knowledge

![Box plots showing the impact of education on staff knowledge in dementia and palliative care.](image)
Knowledge of dementia among RACF staff and families is in general poor.

To institute a palliative approach to the care of people with dementia resident in aged care facilities it will be important to address these knowledge deficits.

Staff education is important but given the findings is it effective?

What might be the impact of education for family carers?

Need to ascertain GPs knowledge of dementia and if necessary institute remedial action.
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