Pathways in Dementia: How has research improved management?

Susan Kurrle

Geriatrician Hornsby Ku-ring-gai and Eurobodalla Health Services

Clinical Director, Aged Care and Rehabilitation Network, Northern Sydney Local Health District

Curran Chair in Health Care of Older People, Faculty of Medicine and Health

THE UNIVERSITY OF SYDNEY

NSW GOVERNMENT Health Northern Sydney Local Health District

Disclosures

- Susan Kurrle has provided consultation or advice to, or has been involved in drug trials with:
  - Anavex Life Sciences, Astra-Zeneca, Axovant, Buck, Forum, Glaxo Smith Kline, Green Valley, Johnson & Johnson, Lilly, Lundbeck, Medivation, Merck, Pfizer, Roche, Sanofi-Aventis, Servier, Tau Therapeutics, Novartis, Wyeth

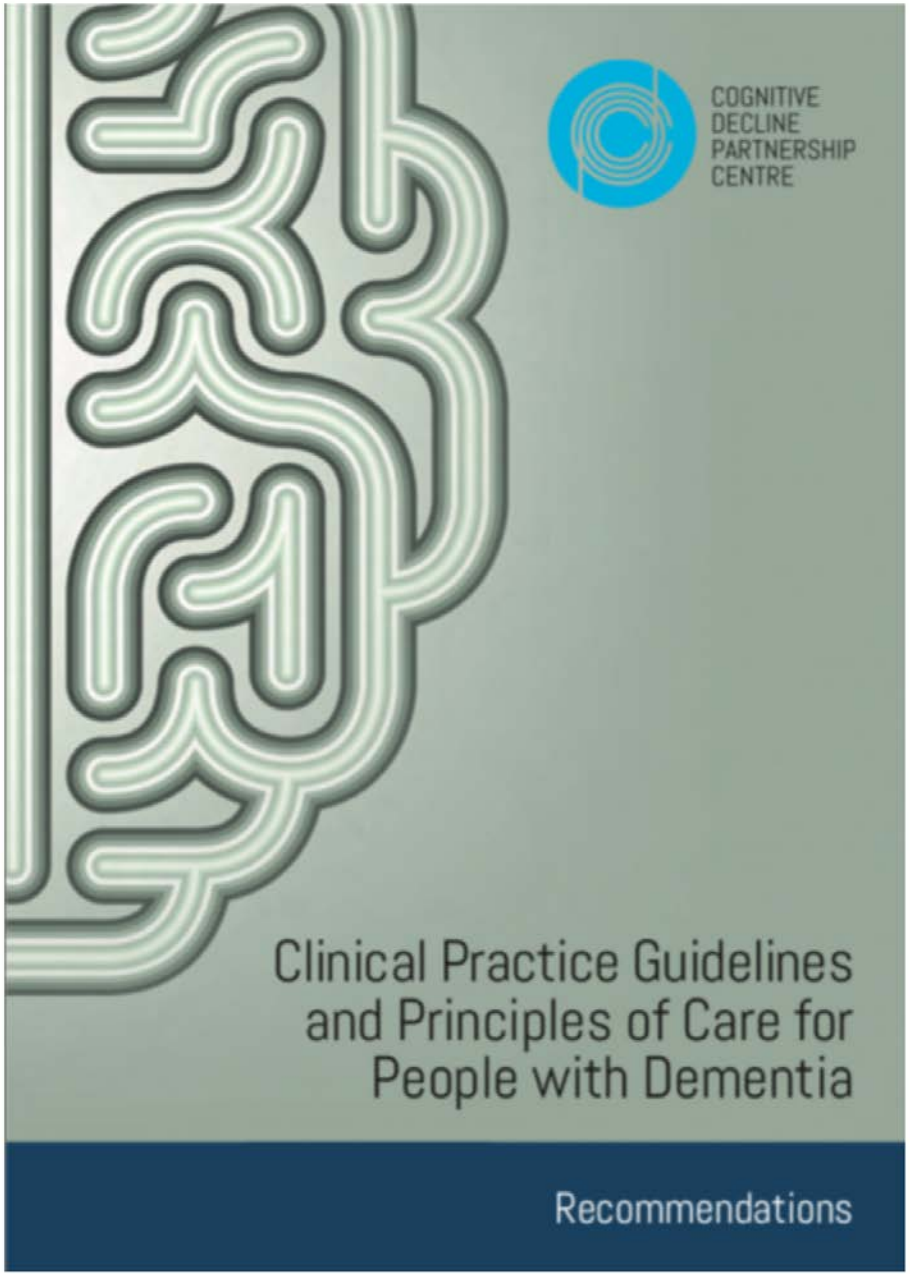
Overview:
How research has improved our management pathways for people with dementia

- Clinical Practice Guidelines for management of dementia
- Appropriate accommodation for people with dementia

Clinical Practice Guidelines

Developed 2015 to 2016 as part of the NHMRC Cognitive Decline Partnership Centre

THE UNIVERSITY OF SYDNEY



https://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/

Why are these guidelines important?

- There were none prior to 2015
- Clinical Practice Guidelines have been shown to improve quality and consistency of care for a range of conditions
- Dementia is not managed consistently well in Australia, there is lots of room for improvement, and these guidelines outline how that can be done
- Consumers have had extensive involvement in their development
- These guidelines are the current gold standard and are applicable across all care settings
- Having Guidelines gives dementia "clinical legitimacy" (like stroke, heart disease, arthritis)

How were they developed?

- NHMRC Cognitive Decline Partnership Centre funded the development of the Guidelines
- Existing international guidelines (from NICE in the UK) were taken, and a rigorous review process (the ADAPTE process) was used to modify and adapt them to Australian conditions
- Consumer input ensured that all areas of importance were covered by the Guidelines
- Systematic reviews were conducted to ensure that the Guidelines reflected the most up to date research
- A consultative Guideline Adaptation Committee of 23 people was formed, including consumers, clinicians, aged care providers, representatives from ATSI and CALD communities, and researchers in the dementia field
- Recommendations were classified as Practice Points (PP), Consensus Based Recommendations (CBR) or Evidence Based Recommendations (EBR)

Guideline development and launch

- Guidelines were put out for public consultation and review for 45 days in 2015 with 70 submissions being received. Some modifications were made as a result
- Guidelines document was approved by NHMRC Council in Feb 2016
- Guidelines contain 109 recommendations with 29 evidence based recommendations
- The Guidelines were officially launched by Minister of Health Ley on March 16th 2016

Clinical Practice Guidelines: Dementia Friendly Language

CONTEXT	PREFERRED TERMS	DO NOT USE
TALKING ABOUT DEMENTIA	Dementia Alzheimer's disease and other forms of dementia A form of dementia A type of dementia Symptoms of dementia	Dementing illness Demented Affliction Senile dementia Senility Going on a journey
TALKING ABOUT PEOPLE WITH DEMENTIA	A person/people with dementia A person/people living with dementia A person/people with a diagnosis of dementia	Sufferer, Victim, Demented person, Dementing illness Dements, Afflicted, Offenders, absconders or perpetrators Patient (when used outside the medical context), Subject, Vacant dement, He/she's fading away or disappearing, Empty shell, Not all there, Losing him/her or someone who has lost their mind, He/she's an attention seeker, Inmates (referring to people with dementia in care facilities)

Examples of recommendations: Barriers, screening

8	PP	People with dementia should not be excluded from any health care services because of their diagnosis, whatever their age.
11	PP	Hospitals should implement strategies to maximise independence and minimise the risk of harm for patients with dementia as identified by the Australian Commission on Safety and Quality in Health Care.
22	CBR	General population screening for dementia should not be undertaken.
23	PP	Concerns or symptoms should be explored when first raised, noted or reported by the person, carer(s) or family and should not be dismissed as 'part of ageing'.

THE UNIVERSITY OF SYDNEY

Translation into practice: A better way to care

safetyandquality.gov.au

THE UNIVERSITY OF SYDNEY

Examples of recommendations: Diagnosis

30	PP	A basic dementia screen should be performed at the time of presentation, usually within primary care. It should include the following blood tests: • routine haematology • biochemistry tests (including electrolytes, calcium, glucose, and renal and liver function) • thyroid function tests • serum vitamin B12 and folate levels.
32	PP	Clinical presentation should determine whether investigations such as chest X-ray or electrocardiogram are needed. An electrocardiogram should be considered if intending to prescribe acetylcholinesterase inhibitors.
43	PP	Structural imaging (with computed tomography [CT] or magnetic resonance imaging [MRI]) should usually be used in the assessment of people with suspected dementia to exclude other cerebral pathologies and to help establish the subtype diagnosis, unless clinical judgement indicates this inappropriate. Structural imaging may not always be needed in those presenting with moderate-to-severe dementia, if the diagnosis is already clear.

Examples of recommendations: Treatment

69	EBR *Low*	Any one of the three acetylcholinesterase inhibitors (donepezil, galantamine or rivastigmine) are recommended as options for managing the symptoms of mild to moderately severe Alzheimer's disease. Any one of the three acetylcholinesterase inhibitors could be considered for managing the symptoms of severe Alzheimer's disease.[3]

72	EBR *Low*	Any one of the three acetylcholinesterase inhibitors (donepezil, galantamine or rivastigmine) could be considered for managing the symptoms of Dementia with Lewy Bodies, Parkinson's Disease dementia, vascular dementia or mixed dementia.[3]

75	EBR *Low*	Acetylcholinesterase inhibitors should not be prescribed for people with mild cognitive impairment.

THE UNIVERSITY OF SYDNEY

How are Guidelines translating into improved care?

- **Being placed in HealthPathways for GPs to access easily**

- Cognitive Decline Partnership Centre – Clinical Practice Guidelines & Principles of Care for People with Dementia - Recommendations

THE UNIVERSITY OF SYDNEY

https://sydneynorth.communityhealthpathways.org/33325.htm

Examples of recommendations: Training for staff

59	EBR *Low*	Health and aged care organisations should ensure that all staff working with people with dementia receive dementia-care training (attitude, knowledge and skill development) that is consistent with their roles and responsibilities. Training should reflect programs that have been shown to optimise care for people with dementia. Effective programs tend to be: delivered face-to-face by someone experienced in dementia care; scheduled over several training sessions; involve ongoing mentoring or support from someone experienced in dementia care; and, utilise active learning techniques such as problem solving, case based training and role plays.
60	EBR *Low*	Training programs should be comprehensive and have a strong focus on communicating effectively with the person with dementia and his or her carer(s) and family and recognising, preventing and managing behavioural and psychological symptoms of dementia. Staff should be trained in the principles of person-centred care and how these principles are applied in practice.

THE UNIVERSITY OF SYDNEY

Translation into practice

- Guidelines used in many resources available for training staff. Dementia Training Australia are funded to provide dementia specific training, University of Tasmania Wicking Institute provides a MOOC

Dementia Training Australia

Dementia training, education and resources

for the Australian workforce

Improving the health and wellbeing of people living with dementia and the staff who support them

UNIVERSITY of TASMANIA
WICKING
Dementia Research and Education Centre

UNDERSTANDING DEMENTIA

FREE ONLINE COURSE

Examples of recommendations: Management of behaviours and psychological symptoms of dementia

79	PP	People with dementia who develop behavioural and psychological symptoms of dementia should usually be treated using non-pharmacological approaches in the first instance. Pharmacological intervention should usually only be offered first if the person, their carer(s) or family is severely distressed, pain is the suspected cause, or there is an immediate risk of harm to the person with dementia or others (i.e., very severe symptoms). If pharmacological management is used, this should complement, not replace, non-pharmacological approaches.
81	EBR *Low*	If a person with dementia is suspected to be in pain due to their distress or behaviour, as indicated by responses on an observational pain assessment tool, analgesic medication should be trialled using a stepped approach. The trial should be for a defined time period, particularly if opioids are used.
86	EBR	People with dementia who experience agitation should be offered a trial of selective serotonin reuptake inhibitor (SSRI) antidepressants (the strongest evidence for effectiveness exists for citalopram) if non-pharmacological treatments are inappropriate or have failed. Review with evaluation of efficacy and consideration of de-prescribing should occur after two months. The need for adherence, time to onset of action and risk of withdrawal effects and possible side effects should be explained at the start of treatment.

Translation into practice

- Used by Dementia Support Australia through the Dementia Behaviour Management Advisory Service and Severe Behavioural Response Team in consultations across community and residential care settings throughout Australia: a consistent approach for people with dementia with changed behaviours

DS Dementia Support Australia

24 Hour Help
1800 699 799

Examples of recommendations: Care

67	EBR *Low*	People with dementia living in the community should be offered occupational therapy interventions which should include: environmental assessment and modification to aid independent functioning; prescription of assistive technology; and tailored intervention to promote independence in activities of daily living which may involve problem solving, task simplification and education and skills training for their carer(s) and family.

THE UNIVERSITY OF SYDNEY

Translation into practice

- COPE: Care of Older People in their Environments – a structured occupational therapy interventions aimed at supporting people with dementia and their carers to independently manage problems with everyday activities

COPE Australia

Example of recommendations: Care

68	EBR *Low*	People with dementia should be strongly encouraged to exercise. Assessment and advice from a physiotherapist or exercise physiologist may be indicated.

THE UNIVERSITY OF SYDNEY

Translation into practice

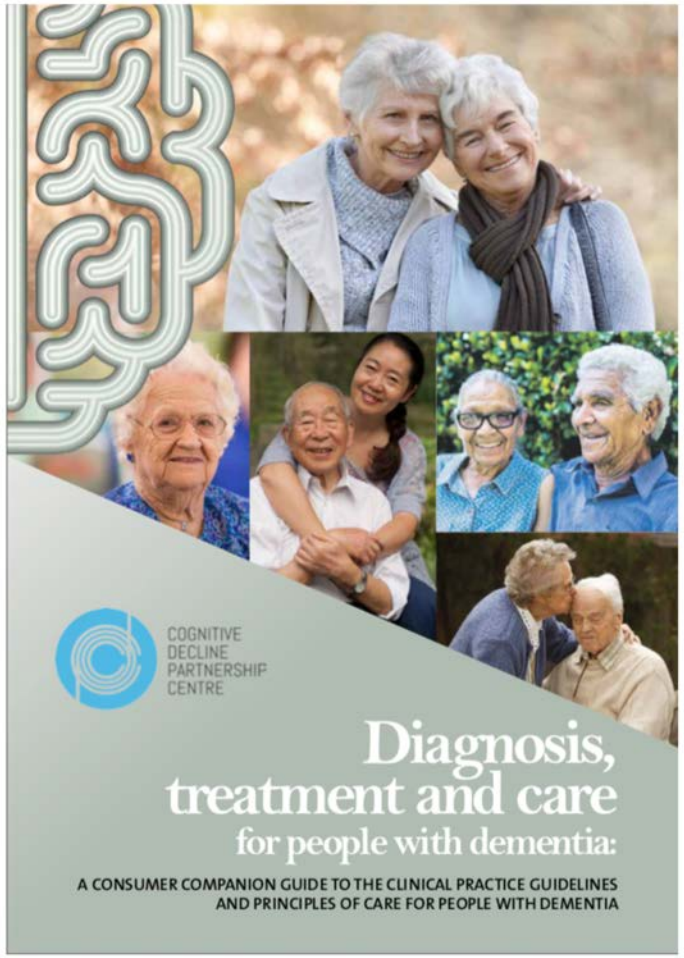
- Encouragement of aerobic exercise (30 minutes 5 times a week) and resistance training (2 to 3 sessions a week)

Intervention approach	Number of studies (participants)	SMD(95% CI)	Quality of the evidence (GRADE)
Nonpharmacological approach			
Exercise	6(289)	0.68(0.08 to 1.27)	Low
Dyadic intervention	8(988)	0.37(0.05 to 0.69)	Low
Psychological treatments	2(313)	-0.13(-0.35 to 0.09)	Low
Case management	3(318)	-0.03(-0.25 to 0.19)	Low
Music therapy	6(195)	0.05(-0.23 to 0.34)	Low
Cognitive stimulation therapy	4(260)	0.21(-0.05 to 0.47)	Low
Cognitive training	4(107)	0(-0.38 to 0.38)	Low
Pharmacological approach			
Donepezil	3(733)	0.18(0.03 to 0.32)	Moderate
Galantamine	3(1422)	0.15(0.04 to 0.25)	Moderate
Rivastigmine	1(535)	0.19(0.02 to 0.36)	Moderate
Memantine	5(1773)	0.11(0.02 to 0.21)	Moderate
Latrepirdine	3(1243)	0.06(-0.06 to 0.17)	Low
Melatonin	1(86)	-0.15(-0.58 to 0.27)	Moderate
Selegiline	7(810)	0.27(0.13 to 0.41)	Low
Nimodipine	3(1228)	0.12(0.00 to 0.23)	Moderate
Alternative therapies			
Huperzine A	2(70)	1.48(0.95 to 2.02)	Very low
Gingko Biloba	7(2530)	0.36(0.28 to 0.44)	Very low
Vitamin B sup	3(481)	0.13(-0.05 to 0.31)	Moderate

The effect of different treatment approaches on activities of daily living function in people with dementia.

How are the Guidelines translating into improved care?
The Consumer Companion Guide

- Consumers requested development of a "plain English" guide to accompany the Clinical Guidelines
- Committee was formed of consumers to develop requirements for guide, and how content would be expressed using the Guidelines as the basis
- 3 rounds of consultations and use of a professional medical editor have resulted in the current version



https://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/

LIVING WELL WITH DEMENTIA AND REHABILITATION SERVICES

People with dementia will benefit from maintaining a healthy and active lifestyle to contribute to overall health and wellbeing.

This includes:

- *doing regular exercise*
- *maintaining a healthy diet*
- *regularly monitoring weight and seeking help if there are changes in weight*
- *maintaining good oral health through regular dental appointments*
- *keeping engaged in activities that are meaningful and enjoyable*
- *maintaining a regular routine*
- *Remaining socially engaged and connected*
- *managing other health conditions (comorbidities).*

A multidisciplinary care team which specialises in providing services for people with dementia (involving a medical practitioner, nurse and allied health staff) is best placed to provide a comprehensive assessment and treatment plan.

QUESTIONS TO ASK ABOUT A HEALTHY LIFESTYLE

- What can I do to remain as active and independent as possible?
- How can I create a safe home environment?
- What activities will help me maintain fitness, strength, balance and flexibility?
- What should I do if I have put on weight or lost weight?
- How do I maintain good oral health?

Many treatments have been trialled to reduce the symptoms of dementia. However, while some may be heavily marketed, the scientific evidence does not necessarily support recommending their use:

- Brain training programs aim to reduce decline in memory and thinking skills. Overall, the current research evidence does not show that regular use of these programs leads to better cognitive skills or levels of independence.
- Nutritional drinks are currently being investigated to reduce the symptoms of mild cognitive impairment and dementia, of which one, at the time of publication (Souvenaid®) is marketed in Australia.
  There is currently insufficient evidence to recommend the routine use of Souvenaid® in people with mild Alzheimer's disease. Souvenaid® should not be recommended for people with moderate or severe Alzheimer's disease.

SOURCES OF FURTHER INFORMATION

The Dementia Behaviour Management Advisory Service:
www.dbmas.org.au

☎1800 699 799

MEDICATIONS TO MANAGE CHANGED BEHAVIOURS

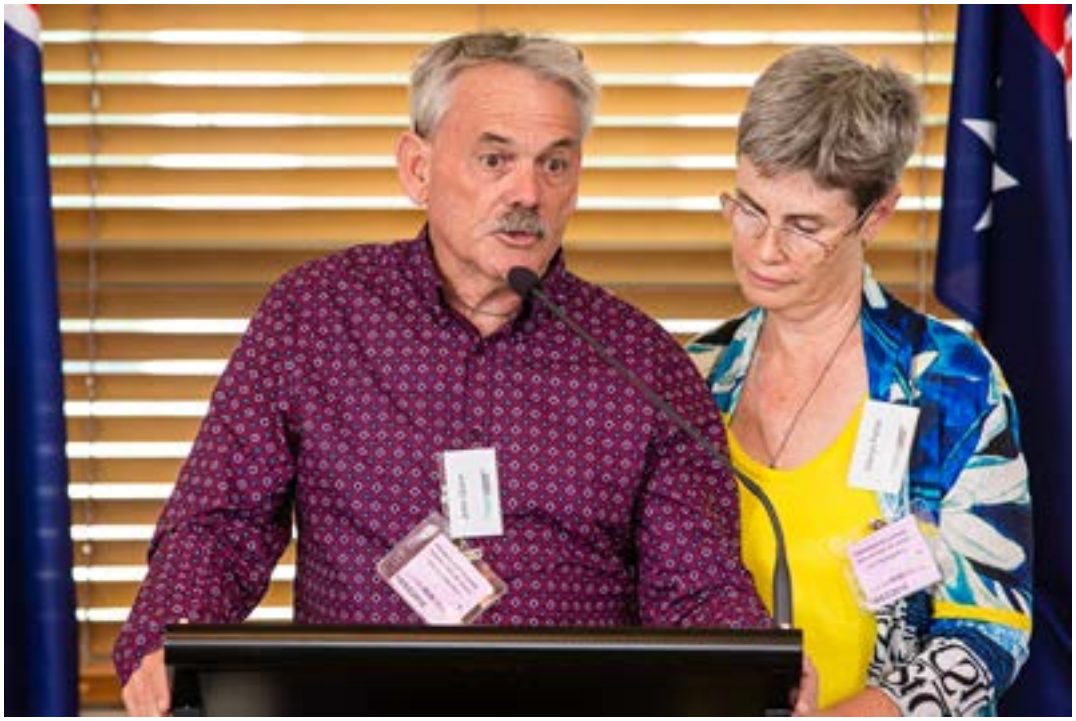
It is recommended that medications are avoided, where possible. However, sometimes medication is required to manage changed behaviour if the person with dementia is severely distressed or at risk of hurting themselves or someone else:

- Analgesia may be recommended if the person is thought to be in pain.
- Antipsychotics should not usually be prescribed for people with mild to moderate symptoms of dementia but may be required for people with severe symptoms which are distressing to themselves or others. They should be avoided in people with Dementia with Lewy Bodies.
- SSRI antidepressants may be trialled in people with dementia who are agitated.

It is uncertain whether antidepressants are helpful in the treatment of depression in people with dementia. However, if the person with dementia has a history of major depression (before their dementia diagnosis), antidepressants should be considered in the usual way.

The final word

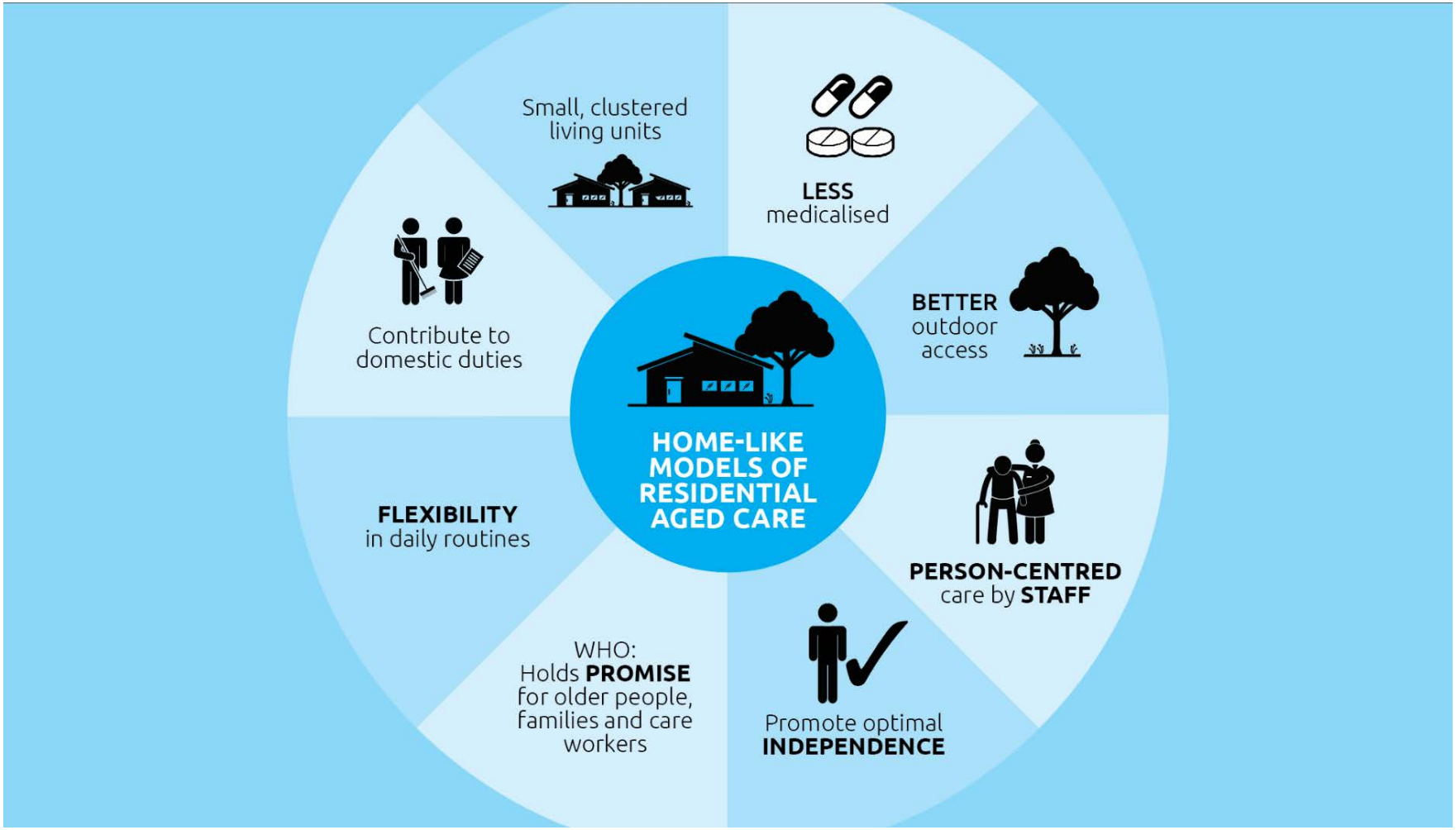
- "If these Guidelines had been available when I was trying to find out what was wrong, I am sure that I wouldn't have had to wait 3 years for a diagnosis….." (John Quinn, person with dementia)



Residential Care for People with Dementia: what are the best models of care?

THE UNIVERSITY OF SYDNEY

Homelike Models of Care
a.k.a. Cottage or Domestic Models



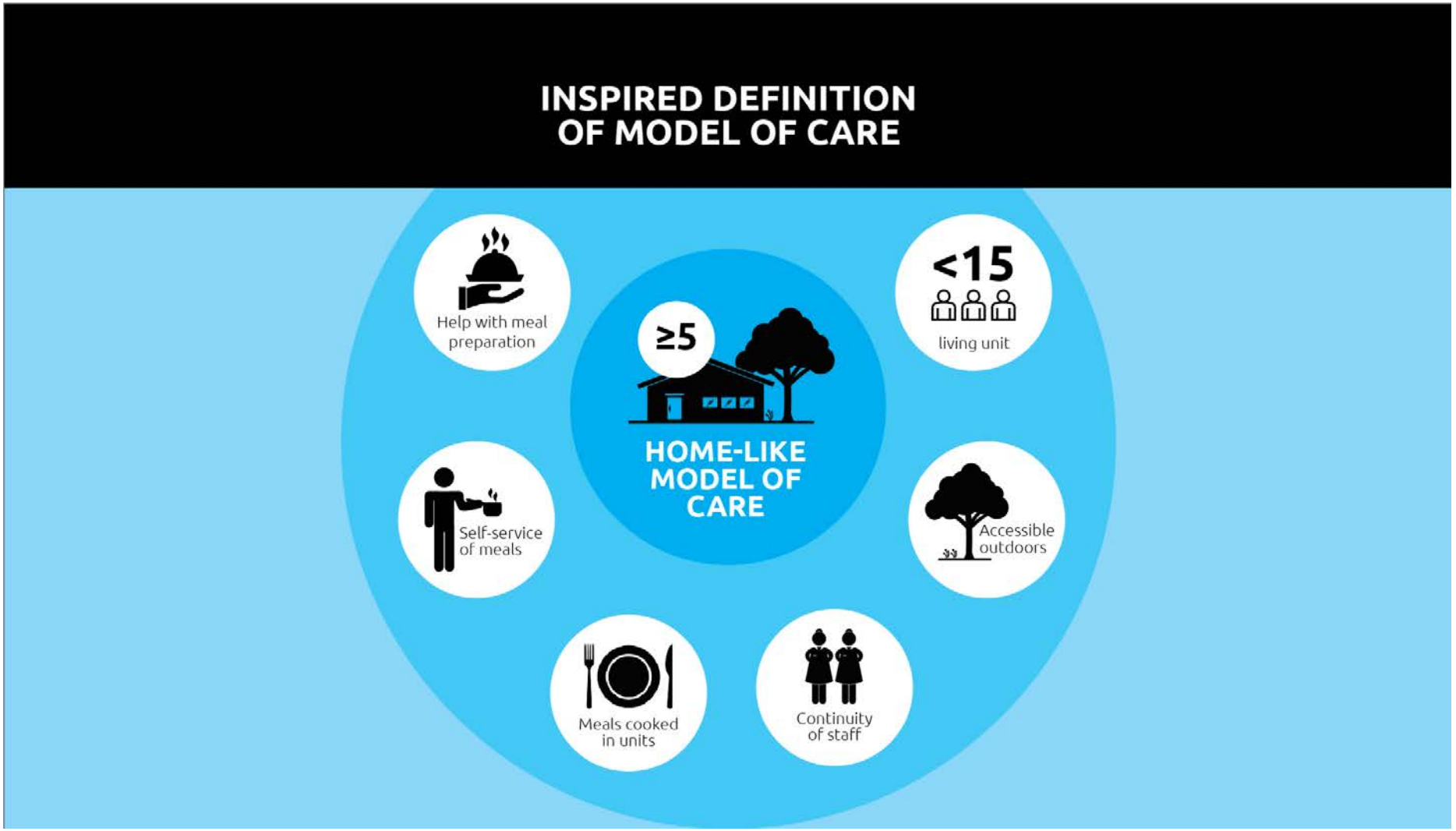
Homelike Models of Care: Existing Evidence

- Green House model and Eden Alternative showed better care outcomes in:
  - Standard quality of care indicators such as re-hospitalisations, catheter use, pressure injuries
  - Better quality of life
  - Improved function in activities of daily living
  - Less behaviours and psychological symptoms of dementia

INSPIRED: Investigating Services Provided in the Residential Care Environment for Dementia

- Aimed to examine associations between living in an Australian 'homelike' model of care versus a traditional aged care facility on:
- Consumer-reported outcomes:
  - quality of life (EQ5D-5L)
  - consumer-rated quality of care (CCI-6D)
- Healthcare resource use:
  - hospitalisations, ED presentations
  - medical services (MBS data)
  - pharmaceutical use (PBS data)
- Involved 541 residents in 17 care facilities across 4 states
- Average age 86 years, 83% cognitive impaired

Definition of Home-like Model of Care



What was important to residents?

- Small size (< 15 residents)
- Access to outside areas independent of staff
- Staff member allocated to resident to provide continuity of care
- Meals prepared in the unit kitchen
- Residents assist in meal preparation
- Residents assist in other daily activities eg laundry, gardening

Summary of INSPIRED results

- Quality of care (assessed by residents and family) was higher in home-like models
- Medication use - Participants living in a homelike model of residential care were:
  - 52% less likely to be exposed to a Potentially Inappropriate Medication (PIM) (PPIs, antipsychotics, benzodiazepines)
    - OR= 0.48, 95% CI 0.28 to 0.83, p=0.008
  - 76% less likely to be exposed to a psychotropic medication
    - OR= 0.24, 95% CI 0.12 to 0.46, p<0.001
- *Adjusted for potential confounding factors, compared to people living in a more standard model of care
- Service use – fewer hospitalisations and ED presentations in home-like models, GP visits – similar numbers
- Costs of accommodation and hotel services – very similar or less for home-like models vs traditional models

ISQua
International Society for Quality in Health Care

International Journal for Quality in Health Care, 2019, 31(6), 419–425
doi: 10.1093/intqhc/mzy181
Advance Access Publication Date: 28 August 2018
Article

OXFORD

Article

Clustered domestic model of residential care is associated with better consumer rated quality of care

EMMANUEL S. GNANAMANICKAM[1,2,3], SUZANNE M. DYER[1,2], RACHEL MILTE[1,2,4], ENWU LIU[1,2,5], JULIE RATCLIFFE[1,2,6], and MARIA CROTTY[1,2]

Main outcome measure: Consumer rated quality of care was measured using the Consumer Choice Index–6 Dimension instrument (CCI-6D) providing a preference weighted summary score ranging from 0 to 1. The six dimensions of care time, shared-spaces, own-room, outside and gardens, meaningful activities and care flexibility were individually evaluated.

Results: Overall consumer rated quality of care (Mean Δ: 0.138, 95% CI 0.073–0.203 $P < 0.001$) was higher in clustered domestic models after adjusting for potential confounders. Individually, the dimensions of access to outside and gardens ($P < 0.001$) and flexibility of care ($P < 0.001$) were rated significantly better compared to those living in standard model of care.

Conclusions: Homelike, clustered domestic models of care are associated with better consumer rated quality of care, specifically the domains of access to outdoors and care flexibility, in a sample of individuals with cognitive impairment. Including consumer views on quality of care is feasible and should be standard in future evaluations of residential care.

Preference-Based Assessments

What Characteristics of Nursing Homes Are Most Valued by Consumers? A Discrete Choice Experiment with Residents and Family Members

Rachel Milte, PhD[1,2,3,], Julie Ratcliffe, PhD[3,4], Gang Chen, PhD[4,5], Maria Crotty, PhD[1,2]*

models to determine preferences for potential attributes. **Results:** The findings indicate that all six attributes investigated were statistically significant factors for participants. Feeling at home in the resident's own room was the most important characteristic to both residents and family members. Care staff being able to spend enough time with residents, feeling at home in shared spaces, and staff being very flexible in care routines were also characteristics identified as important for both groups. The results of the Swait-Louviere test rejected

Harrison *et al. BMC Geriatrics* (2018) 18:9
DOI 10.1186/s12877-018-0704-8

BMC Geriatrics

RESEARCH ARTICLE Open Access

Costs of potentially inappropriate medication use in residential aged care facilities

S. L. Harrison[1,2*], L. Kouladjian O'Donnell[2,3], R. Milte[1,2,4], S. M. Dyer[1,2], E. S. Gnanamanickam[1,2], C. Bradley[1,2,5], E. Liu[1,2,6], S. N. Hilmer[2,3] and M. Crotty[1,2]

Results: Of all of the medications dispensed in 1 year, 15.9% were PIMs and 81.4% of the participants had been exposed to a PIM. Log-linear models showed exposure to a PIM was associated with higher total medication costs (Adjusted $\beta = 0.307$, 95% CI 0.235 to 0.379, $p < 0.001$). The mean proportion (±SD) of medication costs that were spent on PIMs in 1 year was 17.5% (±17.8) (AUD$410.89 ± 479.45 per participant exposed to a PIM). The largest PIM costs arose from proton-pump inhibitors (34.4%), antipsychotics (21.0%) and benzodiazepines (18.7%). The odds of incurring costs from PIMs were 52% lower for those residing in a home-like model of care compared to a standard model of care.

Conclusions: The use of PIMs for older adults in residential care facilities is high and these medications represent a substantial cost which has the potential to be lowered. Further research should investigate whether medication reviews in this population could lead to potential cost savings and improvement in clinical outcomes. Adopting a home-like model of residential care may be associated with reduced prevalence and costs of PIMs.

Harrison *et al. BMC Geriatrics* (2018) 18:60
https://doi.org/10.1186/s12877-018-0752-0

BMC Geriatrics

RESEARCH ARTICLE Open Access

Psychotropic medications in older people in residential care facilities and associations with quality of life: a cross-sectional study

Stephanie L. Harrison[1,2*], Clare Bradley[1,2,3], Rachel Milte[1,2,4], Enwu Liu[1,2,5], Lisa Kouladjian O'Donnell[2,6], Sarah N. Hilmer[2,6] and Maria Crotty[1,2]

Results: Overall, 70.8% ($n = 380$) of the population had been prescribed/dispensed at least one psychotropic medication in the 100 days prior to recruitment. An increased number of psychotropic medications was associated with lower quality of life according to DEMQOL-Proxy-Utility scores (β (SE): − 0.012 (0.006), $p = 0.04$) and EQ-5D-5L scores (− 0.024 (0.011), $p = 0.03$) after adjustment for resident-level and facility-level characteristics. Analysis of the individual classes of psychotropic medications showed antipsychotics were associated with lower DEMQOL-Proxy-Utility scores (− 0.030 (0.014), $p = 0.03$) and benzodiazepines were associated with lower EQ-5D-5L scores (− 0.059 (0.024), $p = 0.01$). Participants residing in facilities which had a home-like model of residential care were less likely to be prescribed psychotropic medications (OR (95% CI): 0.24 (0.12, 0.46), $p < 0.001$).

Conclusions: An increased number of psychotropic medications were associated with lower quality of life scores. These medications have many associated adverse effects and the use of these medications should be re-examined when investigating approaches to improve quality of life for older people in residential care. Home-like models of residential care may help to reduce the need for psychotropic medications, but further research is needed to validate these findings

Clustered domestic residential aged care in Australia: fewer hospitalisations and better quality of life

Suzanne M Dyer[1,2], Enwu Liu[1,3], Emmanuel S Gnanamanickam[1,2], Rachel Milte[1,4], Tiffany Easton[1,2], Stephanie L Harrison[1,2], Clare E Bradley[1,5], Julie Ratcliffe[2,4], Maria Crotty[1,2]

The known Models for providing residential care are changing around the world, with increasing emphasis on care in home-like environments. Large residential aged care facilities are still typical in Australia.

The new A clustered, domestic model of residential aged care was associated with fewer hospitalisations and emergency department presentations and higher quality of life for residents, without increasing whole of system costs.

The implications Smaller scale, clustered domestic models of care may better meet the preferences of residents and their families, and also improve health and quality of life outcomes for older people, at similar or lower costs.

Abstract

Objective: To compare the outcomes and costs of clustered domestic and standard Australian models of residential aged care.

Design: Cross-sectional retrospective analysis of linked health service data, January 2015 – February 2016.

Setting: 17 aged care facilities in four Australian states providing clustered (four) or standard Australian (13) models of residential aged care.

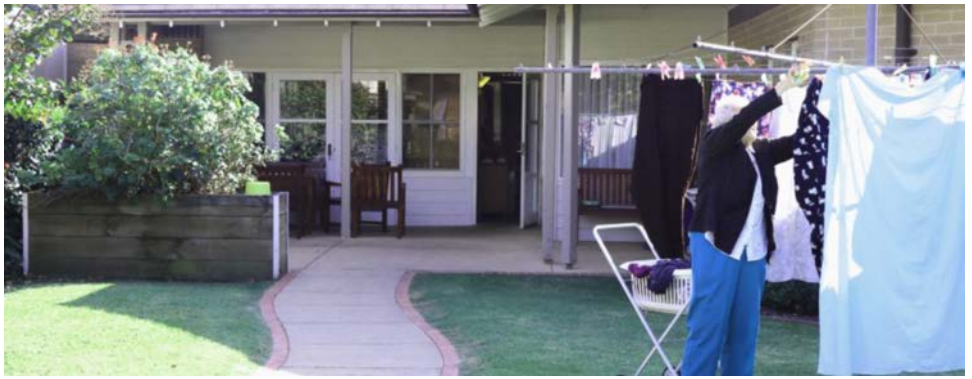
Participants: People with or without cognitive impairment residing in a residential aged care facility (RACF) for at least 12 months, not in palliative care, with a family member willing to participate on their behalf if required. 901 residents were eligible; 541 consented to participation (24% self-consent, 76% proxy consent).

Dyer et al (2018) Med J Aust 208 (10): 433-438. doi: 10.5694/mja17.00861

Conclusions

- To improve resident quality of life without associated increase in costs, we should all encourage aged care providers to consider adopting a ‘homelike’ clustered domestic model of care







Thank you

THE UNIVERSITY OF SYDNEY