

Dementia – Where are we up in Science of Care?

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Today's topics

- Diagnosis & post-diagnostic care
 - Community Care
 - Acute care
 - Residential care
 - Care of people with dementia: clinical symptoms
 - Caregivers
 - Conclusion
- *What do we know?*
 - *What don't we know?*
 - *Where to from here?*

Diagnosis and post-diagnosis in primary care



Diagnosis – what do we know?

- 2-3 year gap to diagnosis
- $\approx$ 50% of persons with dementia are not diagnosed in primary care ¹
- Only 42% expected cases diagnosed in UK ²
- Early diagnosis allows people to plan, strategies to reduce cognitive and neuropsychiatric symptoms, access social and voluntary care ³

¹ Connolly A et al *Aging and Mental Health* 2011 15, 978–984.

² Walker IF et al *Primary Health Care Research & Development*, 2017
DOI: <https://doi.org/10.1017/S146342361700007X>

³ Livingston G et al, *PLoS Medicine* 2017

Diagnosis – what do we know?

- Family carers report difficulty in obtaining a diagnosis of dementia for their relative
- Delays cause anxiety and carer burden
- People with memory problems are reluctant to consult their GP about it and deny problems

Livingston G et al, PLoS Medicine 2017

Diagnosis – what do we know?

- **Barriers to seeking help or diagnosis:**
 - **fear, stigma, GP disinclination, negative responses from other family members, normalisation of symptoms, lack awareness about dementia signs**
- **Barriers for GPs – attitude, knowledge, nihilism, time, lack of rebate, fear of alienating patient, etc**

Livingston G et al, PLoS Medicine 2017; Brodaty MJA, 1994

Diagnosis – what do we know?

In Australia:

- Academic detailing did not improve diagnosis in 1994 but did improve identification in 2016^{1,2}
- Systemic review of interventions for GPs
 - GPs' ability to diagnose could be increased but not their rate of diagnosis ³

¹ Pond D et al Fam Pract (1994) 11 (2): 141-147; ² Pond D et al, in prepⁿ;

³Mukadam N, et al Int J Geriatr Psychiatry 2015; 30(1):32–45

Diagnosis – what do we know?

Initiatives to attain timely diagnosis in UK:

- 2014 £55 bounty for GP diagnosis ceased March 2015
- W. Midlands: 2017, introduced £150 for each pt. diagnosed and treated to reduce wait for memory clinic appointments!
- Target patients rather than GPs
 - RCT of letters to GP attendees → more attendances but not more referrals for Dx¹

¹ Livingston J et al, PLoS Medicine 2017

Diagnosis: what do we know?

- Swedish registry (*SveDem*)¹
 - significant improvements 2011 → 2015
 - completed basic investigations increased by 23%
 - diagnosis of “dementia not otherwise specified” decreased by 15%
- GPCOG > efficient than MMSE, >14 languages²

¹ [http://www.ucr.uu.se/svedem/component/edocman/primarvardsres 2011-2015](http://www.ucr.uu.se/svedem/component/edocman/primarvardsres%202011-2015)

² Brodaty et al, 2002; www.gpcog.com.au

Dx in primary care: what we know?

- Interventions can improve knowledge and skills but do not always translate into action
- GP & patient interventions alone don't work
- Low referral rates → specialist, Alz Assocⁿ
- After assessment, paucity of information re:
 - Diagnosis
 - Management
 - Prognosis¹

¹ Brodaty et al, 1990

Primary Care Diagnosis & Management: What don't we know?

- How to improve GP practice
- What is best model for primary care diagnosis?
 - Financial incentive **X**, education?
 - Practice nurses?
 - Memory clinics?
- How to move to *Re-ablement*¹ from *Prescribed disengagement*®²

¹ Low L et al, submitted, ² Swaffer 2016

Primary Care Diagnosis & Management: where to now?

- **Reduce stigma, nihilism**
- **Improve diagnosis & post-diagnosis**
- **Different model – positive living with dementia**
 - **Prescribed engagement**
 - **Rehabilitation program cf stroke**
 - **Lifestyle – exercise, cognitive rehab, diet**
- **Blood test could be a game changer but it is far from enough**
- **Assessment is much more than diagnosis**

Community care



Community care: what we know?

- Community nursing, aged care workers, home help, community transport, day centre, respite care
- Variable provision internationally
- Desired by consumers
- Desired by government
 - Cheaper(?) than residential care
 - Different economic models
 - Long-term care insurance in some countries

Community care: what we know?

- Current model largely episodic and reactive
 - i.e. problem → access → service
- Limited availability, flexibility
- Limited evidence of efficacy
- Alternative model: continuous, proactive
 - Key worker or navigator

What do we know?

Case management approaches to home support for people with dementia

- **13 RCTs, 9615 participants, interventions varied**
- **Some evidence case management improves some outcomes at certain time points, both in persons with dementia and their carers**
- **Case management group significantly less likely to be institutionalised at 6 & 18 months but not at 12 or 24 months**

Reilly S et al, Cochrane Database Syst Rev. 2015 Jan 5;1:CD008345

Case management approaches to home support for people with dementia

- **Some evidence from good-quality studies, reduced admissions to care homes and overall healthcare costs in medium-term**
- **Not enough evidence to clearly assess whether case management delays institutionalisation**
- **Some effect on carer burden, BPSD, costs**
- **QOL, hospitalisation, mortality – no effect**
- **All studies show increased use of services**

Reilly S et al, Cochrane Database Syst Rev. 2015 Jan 5;1:CD008345

Community care - What we don't know?

Cost effectiveness

- **Economic analysis of community-based care model (Ireland)**
- **181 people with dementia at home with high risk of residential care admission**
- **Over 3 years formal costs of community care < 1/2 of potential residential care, but ...**
- **Taking informal costs into account, 3x higher!**

O'Shea & Monaghan 2017

Consumer directed care

- **Attractive concept, Is it working?**
- **Real choice for consumers?**
 - **Ability to save unspent funds for future use**
 - **Ability to choose care workers**
 - **Flexibility in activities**
- **Organization and communication?**
- **High admin costs?**

Kaambwa et al. 2015

Gill et al. 2017

Respite care

Day care most commonly investigated

- **Carer: decreased carer stress and burden**
- **Care recipient: reduced behavioural problems and possibly improved sleep**
- **but, day care alone may accelerate nursing home placement**

In-home respite care, limited evidence

Residential respite care, mixed results

Reviews: Neville et al. 2015; Vandepitte et al. 2016; Brodaty & Gresham, 1995

Community care: what don't we know?

Despite intuitive attractiveness....

- How to prove effectiveness?
- What are best outcome measures?
- What is best model?
 - ? 'key worker', continuous, reactive, long-term guide, helper, coordinator
- Evaluation lacking¹

¹ Dawson et al. 2015

Community care: where to from here

- **Comprehensive service models**
- **Societal debate about economic model**
- **Overcoming barriers¹**
 - **Better information & access to services**
 - **Better quality & flexibility of services**
 - **Caregivers' beliefs about their obligations**
 - **Overcoming resistance by care recipients**

¹ Macleod et al. 2017

Acute care



Acute Care – what do we know?

- 50% of all admissions via ED are ≥ 65 yo
 - $> 30\%$ have cognitive impairment
 - 20% dementia, 10% delirium ¹
- Delirium & dementia often undiagnosed
- Pts with dementia twice more likely to experience falls, pressure injuries, infections, delirium ^{2,3} *and* disorientation and fractures (*and* # *NOF* less likely to receive rehab)
- ¹ Australian Commission on Safety and Quality in Health Care 2013
- ² Bail K et al, BMJ Open. 2013; ³ Bail K et al, BMC Health Serv Res 2015

Acute Care – what do we know?

- One in 4 persons with dementia → hospital/ yr ¹
- Longer length of stay, more behavioural complications, more hospital-acquired complications; higher rates of discharge to residential care ; higher morbidity ²
- Older people in ED with cognitive impairment and long bone # wait 2¼ hours for analgesia (compared to 41' for younger person without cognitive impairment)³

¹ Draper B et al Int Psychoger. 2011; 23(10):1649-58

² Yates M et al, submitted.

³ Fry, M et al Int Psychoger 2015

Acute Care – what do we know?

- People with dementia can have difficulty ...
 - Providing a history
 - Remembering & following instructions
 - Completing forms, dietary requests
- Nurses, doctors etc
 - Often lack skill; ageist; organ orientated
- Environment not dementia friendly
- Training can improve diagnosis, attitudes
- Post-discharge: communication **X**, continuity **X**

Regular Early Assessment Post-Discharge (REAP) (Cordato N et al, in preparation)

- **Prospective RCT of assertive follow-up, NH residents recently discharged from hospital,**
- **REAP intervention: monthly coordinated specialist geriatrician and nurse practitioner assessments within residents' NHs for 6m**
- **43 NH residents → REAP intervention (n=22) or control (n=21) groups**
- **≈ 2/3 fewer hospital readmissions (p=0.03; Cohen's d=0.73) and ½ # ED visits, ½ costs**

Acute Care – what don't we know?

- **How to change policy?**
- **How to prove cost effectiveness?**
- **How to change attitudes, improve skill, create dementia-friendly environment?**
- **How to make changes sustainable?**
- **How to ensure smooth transition and future care after discharge?**

Acute Care – where to now?

- Top down, bottom up approach
- Economic data
- Staff training, supportive management
- Cognitive Impairment Identifier ¹
- Standards for accreditation: cognitive screening on admission for all pts 65+/70+²
- Better diagnosis, management, design of environment → fewer BPSD, less delirium
- Post-discharge support planning



¹Yates M et al (submitted); ²www.bhs.org.au/node/130
www.safetyandquality.gov.au/media_releases/caring-for-cognitive-impairment-a-national-campaign/



Residential Care



Residential Care – What we know?



- High rates of Long-Term Care
- Expensive; projections economically unsustainable
- Excellent services, innovative, creative, hard working vs ...
- *Scandals, physical, verbal & financial abuse*
- High rates of Behavioural and Psychological Symptoms of Dementia (BPSD)



Residential Care – What we know?

- Variable staff ratios, quality & training
- Lack of trained nurses
- Suboptimal medical care in many countries
- High levels of psychotropic medication, including antipsychotics
- Person Centred Care in name, not practice
- Variable design quality - only $\approx 1/2$ of *new* facilities embrace design recommendations¹

¹Fleming R, www.dementiaresearch.org.au or
www.dementiaresearch.org.au/images/dcrc/output-files/1426-t&d7_final_report.pdf

Residential Care – What we know?

- Residents isolated, many negative relationships
33% isolated; 33% initiated/received friendship¹
- Homes isolated from community
- Lack of services for YOD, CALD, LGBTIQ, Indigenous, homeless, other minorities
- Lack of choice for rural communities
- Funding rewards disability, not re-ablement
- Developing countries models differ

¹Casey A-N, 2016

Residential care: what we don't know



- Best use of sticks (standards/ accreditation) vs carrots (attract residents/ families)
- How well do novel models work, eg Eden Alternative, De Hogeweyk Village
 - Negative outcomes of EA¹
- Knowledge translation: implementation
- Future projections will change business models



¹Coleman MT_J Gerontol A Biol Sci Med Sci (2002) 57(7):M422-27

Residential Care: where to now?

- **Economies of scale of large homes with benefits of small discrete units**
- **Novel models – group homes, more tailored facilities, neighbourhood services**
- **Robots?, assistive technology?**
- **Actual person centred care**
- **Nurse Educators/ Champions – case based, onsite mini-tutorials**
- **Better environmental design**
- **Competition to drive improvement**

Residential Care: where to now?

- Families (where available) part of care team
- Flexible care arrangements e.g. weekdays, night care or day care
- Regular multi-disciplinary team reviews
- Dedicated GPs (&/or Nurse Practitioners)
- Integrate: homes $\leftrightarrow$ community
 - Coffee shops, kindergartens, art galleries
- Creativity: Singing, dance, Cultural Concierge¹

¹Arts Health Institute

Behavioural and psychological symptoms of dementia (BPSD)



Rex

BPSD – What do we know?

- **Nomenclature debate (reflecting theoretical understanding) too simplistic**
- **High rates in people with dementia**
 - **90% of residents in long-term care**
 - **60% of people with dementia in community**
- **High reliance on drug therapy**
 - **1 in 2 on psychotropic**
 - **1 in 4 on antipsychotic**
- **Lack of psychosocial strategy implementation**

BPSD – pharmacotherapy

What do we know?

- **Antidepressants – major trials, no benefit over placebo for depⁿ but more Adverse Effects**
- **Antipsychotics – some evidence for benefit for aggression and agitation, but**
...concern about AEs, especially stroke, death
- **Other medications – sparse or no evidence**
- **Family caregivers can successfully reduce BPSD ¹**

¹ Brodaty & Arasaratnam, Am J Psych, 2012; 169(9):946-53

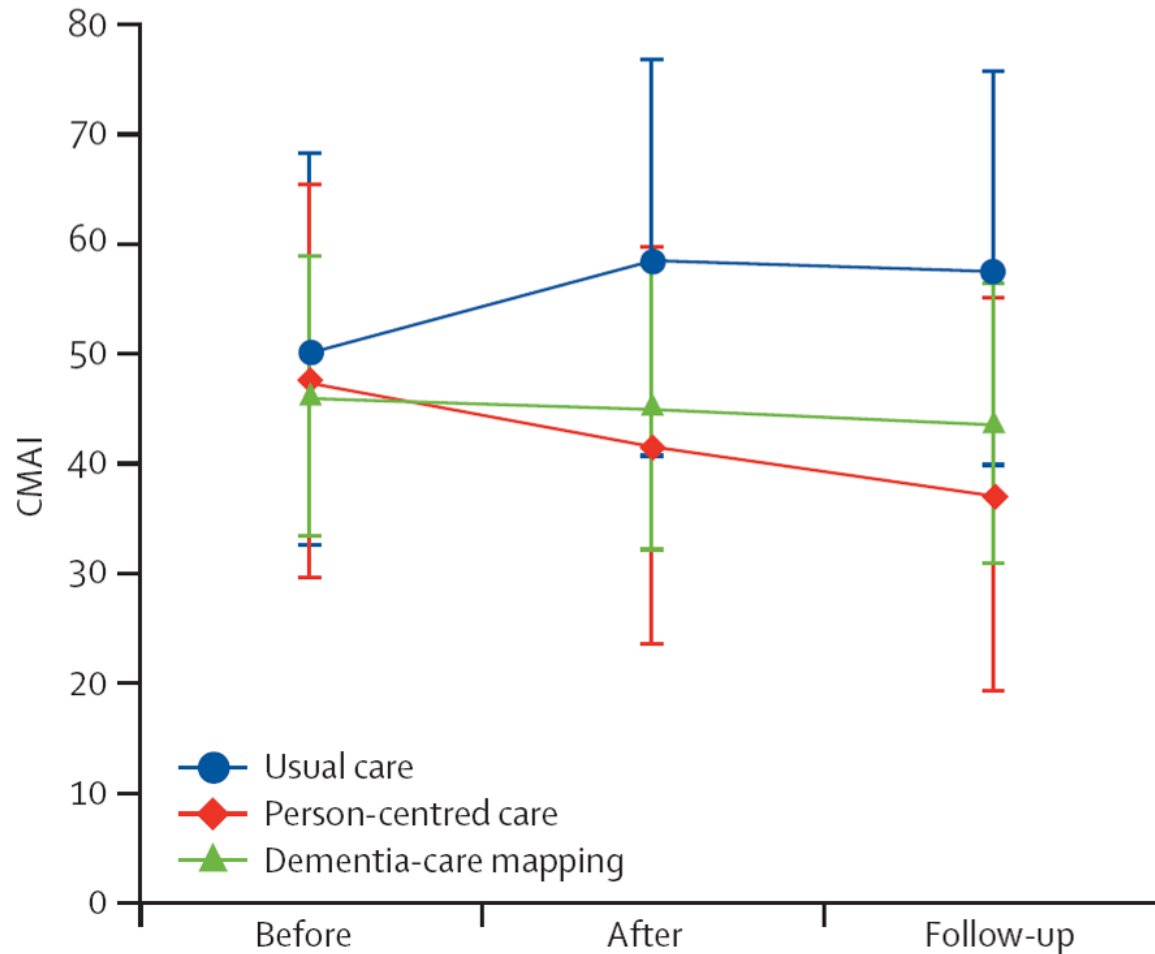
BPSD – What do we know?

Person centred care in NHs...

- **Less agitation, less depression**
- **Better quality of life for person with dementia**
- **Less use of antipsychotic medications**
- **Greater staff satisfaction, less turnover**
- **Cost effective**

Examples: CADRES, SMILE and HALT studies

Dementia Care Mapping & Person Centred Care for agitation



Cost for PCC
≈ \$6 to reduce a point
on CMAI

Chenoweth et al.
Lancet Neurology
2009

Humor therapy: SMILE study

- 20% reduction in agitation
- Effect size = antipsychotic medications for agitation
- Adjusting for dose of humour therapy
 - Decreased depression
 - Improved quality of life



Low LF et al BMJ Open 2013

Brodaty et al Am J Ger Psych 2014

Low LF et al JAMDA 2014

HALT study

- **Resident on long-term antipsychotics**
- **Family consent, GP detailing, nurses trained in person centred care, pharmacists recommended deprescribing schedule to GPs**
- **94.7% of participants ceased antipsychotic(s)**
- **75-80% remained off antipsychotics over 12 m**
- **Regular & prn antipsychotic low during follow-up**
- **Behaviours did not increase despite stopping Rx**



An Australian Government Initiative

Behaviour Management

A Guide to Good Practice

*Managing Behavioural and Psychological
Symptoms of Dementia*



DBMAS

dementia behaviour
management advisory service

Helping Australians with dementia, and their carers

Internet Guide

www.dementiaresearch.org.au

- **APP for clinicians**
BPSD
- **APP for caregivers**
Care4dementia

BPSD: What we don't know/ Where to

- **How to translate knowledge into practice**
 - **Standards, regulations eg hospitals, NHs?**
 - **Education of consumers → drive demand?**
 - **Education of providers → quality of care?**
 - **Economic models – reward good care, innovation?**
- **Multidisciplinary care, planning, education**
- **More nuanced use of psychotropic Rx, regular review, informed consent**



Family caregivers

‘Families have been, currently are, and will continue to be the primary therapeutic agents in dementia care’ Gitlin & Hodgson 2015

‘The mainstay of treatments for AD is supportive care from family ..’ Scheltens P et al, Lancet, 2016:388:505-17

Caregivers – what do we know?

Effects on caregivers

- High rates of depression, distress
- ↓ physical health, ↑ social isolation, ↑ mortality

Interventions

- Counselling → less depression ^{1,2}
- Comprehensive training programs → less psychological morbidity, care recipients stay at home longer, cost effective ^{3,4,5}

Mittelman 1995¹, 2008²; Brodaty 1989³, 1991⁴, 1997⁵, 2003⁶

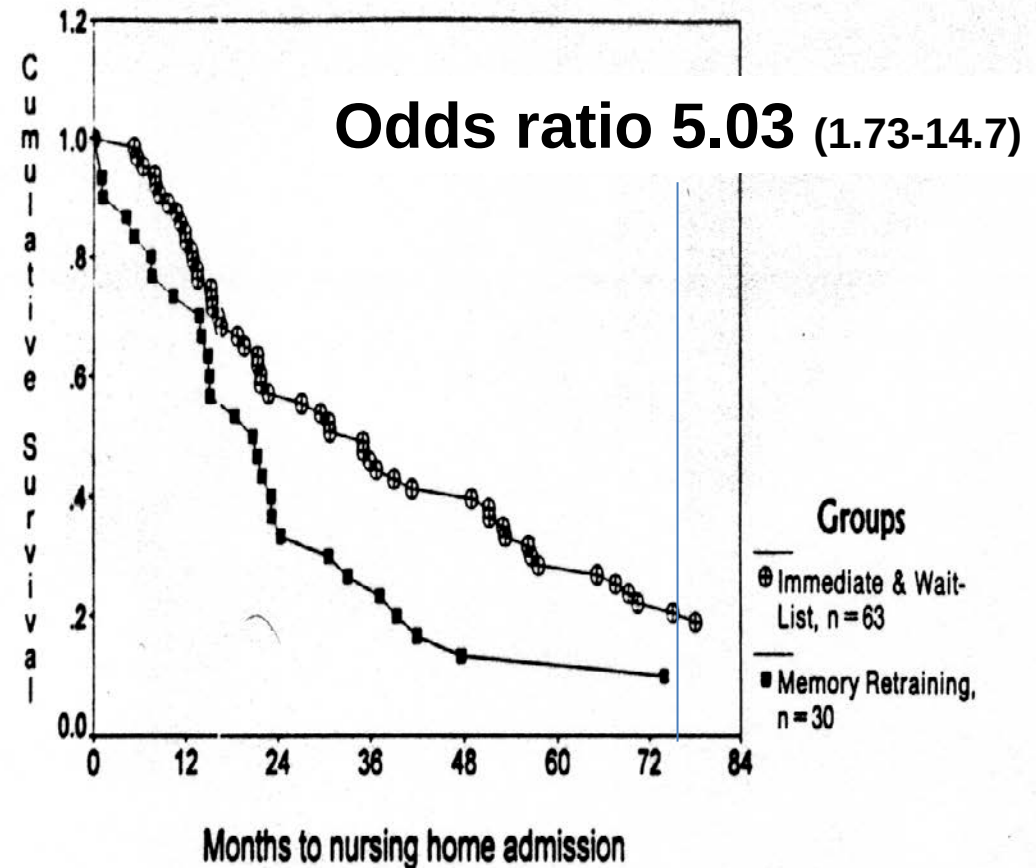
Dementia Carers Program: survival at home over 7 years

- Multidisciplinary
- ↓ CG psychological morbidity @ 12m
- Person w. dementia stayed home longer
- Saved money

Brodaty & Gresham BMJ 1989

Brodaty et al Int Psychoger 1991

Brodaty et al IJGP 1997



plan-Meier survival functions for nursing home admission comparing the combined training groups with the m
oup

Tailored Activity Program

- In-home training for CGs to manage BPSD
- 4-month (8 sessions) occupational therapy intervention tailored based on neuropsychological and functional testing
- Fewer problem behaviours (specifically for shadowing and repetitive questioning)
- Greater participant activity engagement
- Caregiver benefits (fewer hours on duty)
- Cost-effective

Gitlin LN et al. Am J Geriatr Psychiatry 2008 & 2010

Many other issues in science of care

- Palliative care
- Western vs Asian vs Developing countries
- Importance of policy, consumer involvement
- Methodological challenges in research
- Competitive disadvantage for funding
- Communities of researchers
 - Interdem in Europe
 - PROMOTE in Asia-Pacific
- Internet based care and prevention

<http://www.maintainyourbrain.org/>

Conclusions

- Despite care science being difficult in practice and to fund..
- We know a lot but
- Major issue = knowledge translation
- Future – partnership between consumers, researchers, economists and policy makers

Thank you



www.cheba.unsw.edu.au

www.dementiaresearch.org.au