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Dementia – Where are we up in Science of Care?

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CHeBA
Healthy Brains Positive Ageing

Today's topics

- Diagnosis & post-diagnostic care
- Commu… Care
- Acute c…
- Reside…
- Care c… …cal symp…
- 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
- ≈ 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 neuro-psychiatric 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 prep[n];
[3]Mukadam 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 Dx[1]**

[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 languages[2]

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

[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 Assoc[n]
- After assessment, paucity of information re:
  - Diagnosis
  - Management
  - Prognosis[1]

[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 & Monughan 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 lacking[1]**

[1] Dawson et al. 2015

Community care: where to from here

- Comprehensive service models
- Societal debate about economic model
- Overcoming barriers[1]
  - 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 ≥ 65yo**
  - **> 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?

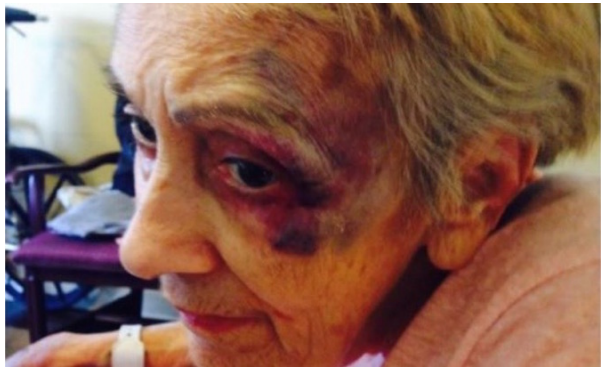
- Top down, bottom up approach
- Economic data
- Staff training, supportive management
- Cognitive Impairment Identifier [1]
- Standards for accreditation: cognitive screening on admission for all pts 65+/70+[2]
- Better diagnosis, management, design of environment → fewer BPSD, less delirium
- Post-discharge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

[1]Yates M et al (submitted); [2]www.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 ≈ 1/2 of *new* facilities embrace design recommendations[1]**

[1]Fleming 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 friendship[1]
- **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**

[1]Casey 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 EA[1]**
- **Knowledge translation: implementation**
- **Future projections will change business models**

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

Residential Care: where to now?

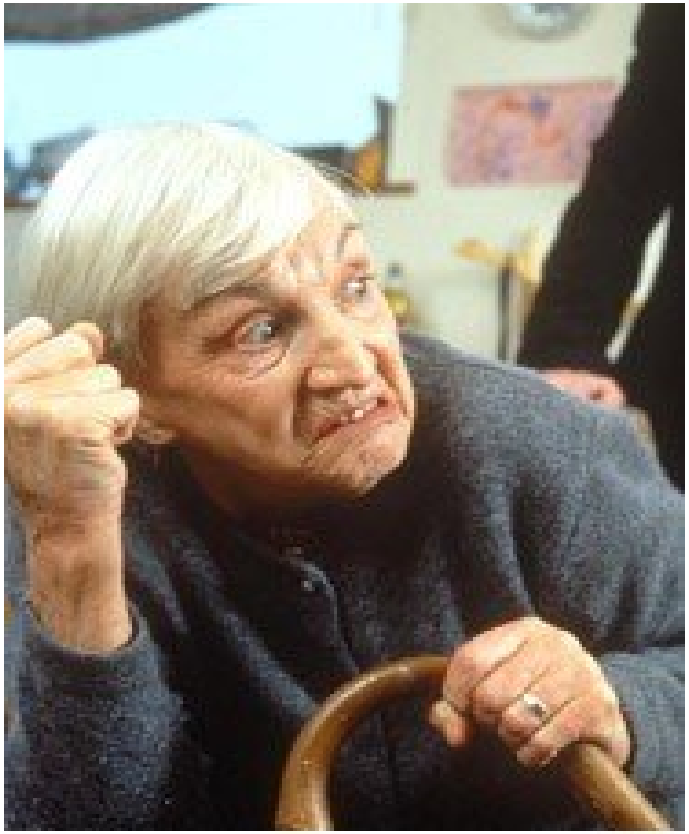
- **Economies of scale of large homes with benefits of small discrete units**
- **Novel models – group homes, more tailored facilities, neighbourhood services**
- **Robots?, assistive technology?**
- **Actual person centred care**
- **Nurse Educators/ Champions – case based, onsite mini-tutorials**
- **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 ←→ community**
  - **Coffee shops, kindergartens, art galleries**
- **Creativity: Singing, dance, Cultural Concierge[1]**

[1]Arts 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 dep^{n} 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]**

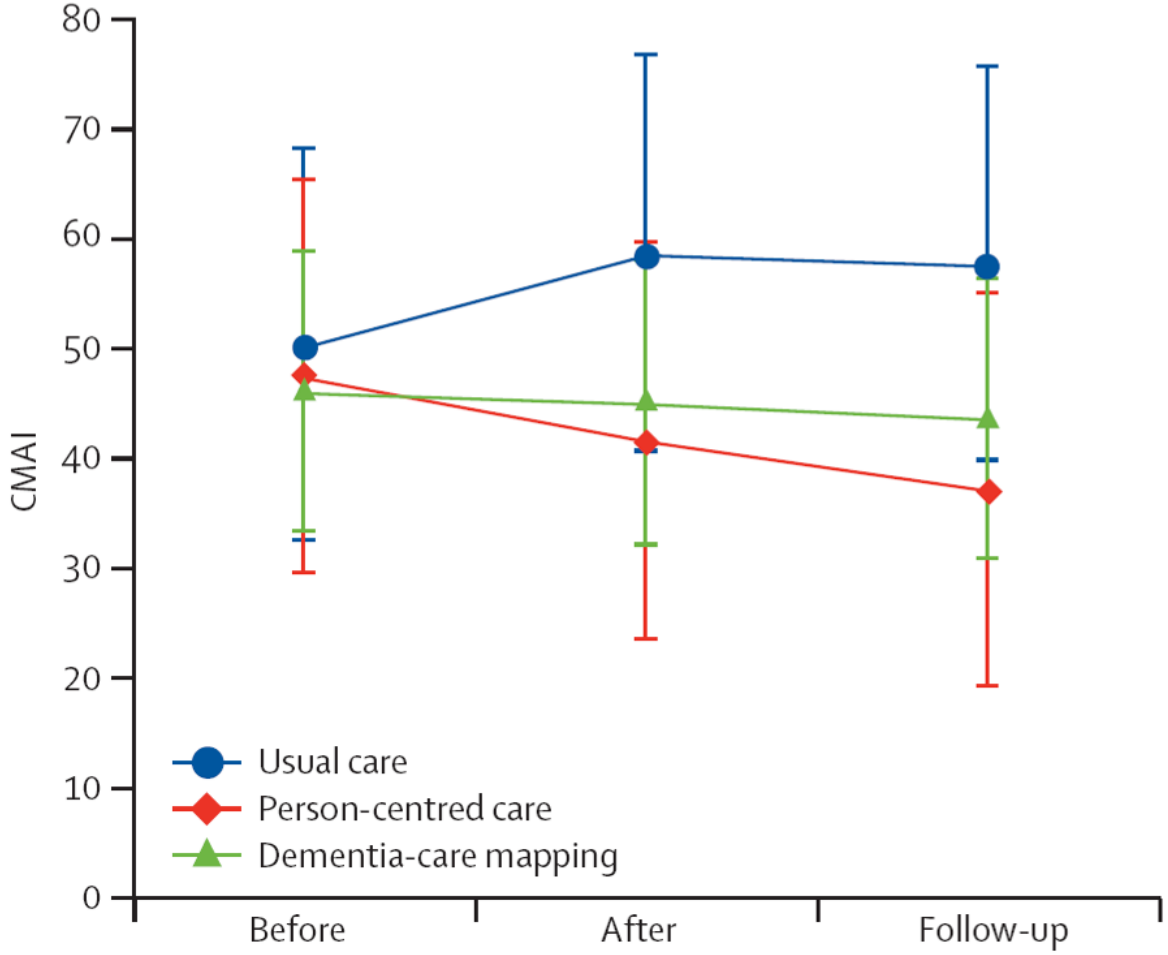
[1] Brodaty & Arasaratnam, Am J Psych, 2012; 169(9):946-53

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

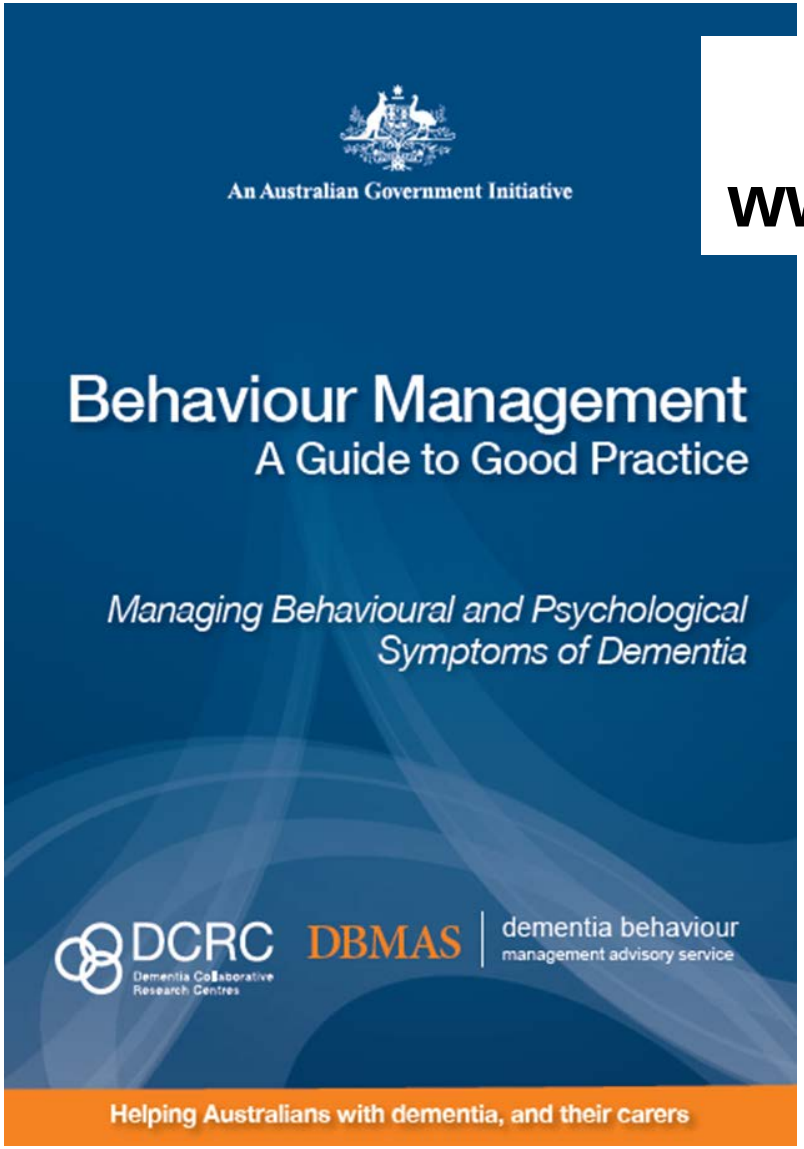
Humor therapy: SMILE study

- 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



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

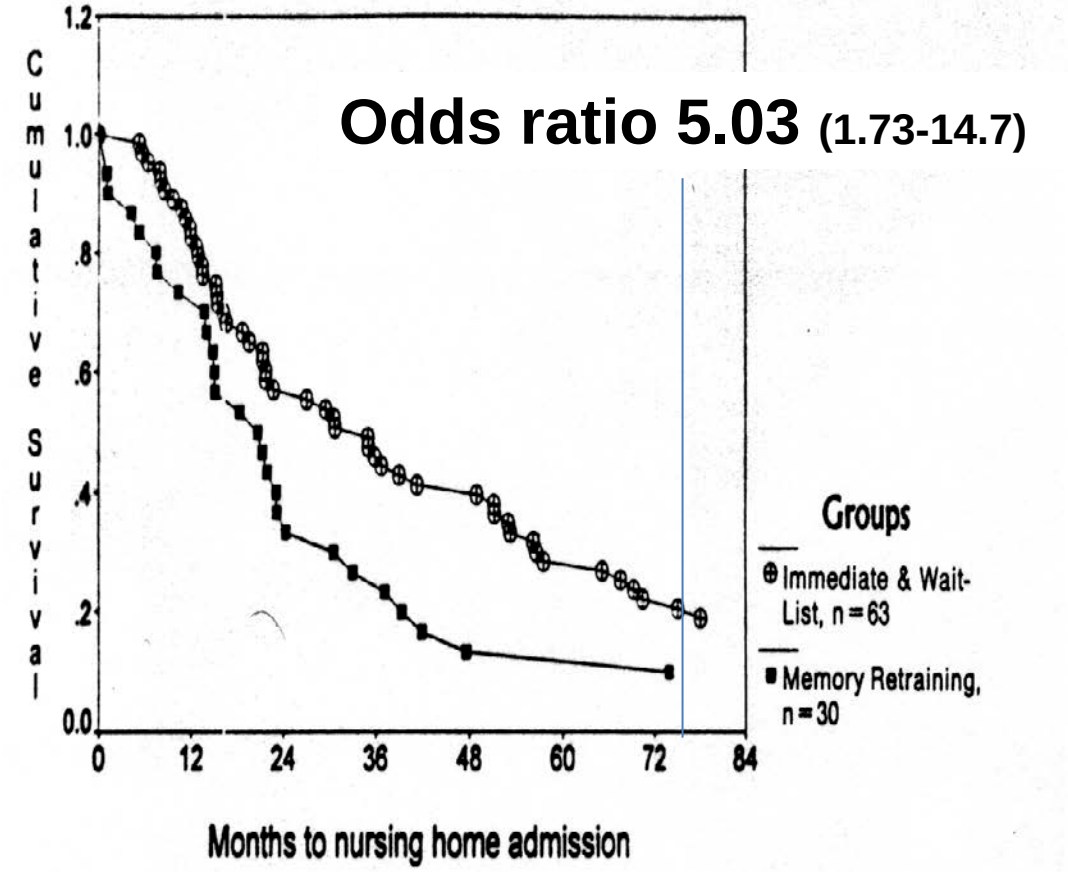
- **Counselling → less depression [1,2]**
- **Comprehensive training programs → less psychological morbidity, care recipients stay at home longer, cost effective [3,4,5]**

Mittelman 1995[1], 2008[2]; Brodaty 1989[3], 1991[4], 1997[5], 2003[6]

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

- Di
- C
- A
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- C

- 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

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Thank you

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CHeBA Healthy Brains Positive Ageing

www.cheba.unsw.edu.au

www.dementiaresearch.org.au