

Psychosocial Research in Dementia: Past, Present, and Future

Henry Brodaty AAIC Chicago 24 July 2018



What is psychosocial research?

- Psychosocial or Non-pharmacological¹⁻³
- Maintaining or improving functionality, social relationships & well-being
- Not disease modification



Psychosocial vs Biological

¹Moniz-Cook E, Vernooij-Dassen M, Woods M, et al. 2011; ²Livingston G, Kelly L, Lewis-Holmes E, et al. 2014; ³Scales K, Zimmerman S, Miller SJ 2018

Past → present → future



Past – describe, prevalence, measure, basic interventions

Present – menu of interventions, uncertainty of place

Future – precision medicine model, complementary, technology

Today's presentation

Covered

- People living with dementia (PWLD) (and MCI)
- Caregivers (CGs)
- Behaviours (BPSD)
- Long-Term Care (LTC)

Not covered

- Diagnosis, post-diagnostic care
- Prevention in healthy people
- Assistive technology
- Community care
- Acute care
- Palliative and end-of-life care

Levels of interventions

Micro – drug therapies based on molecules

Meso – behavioural, interpersonal

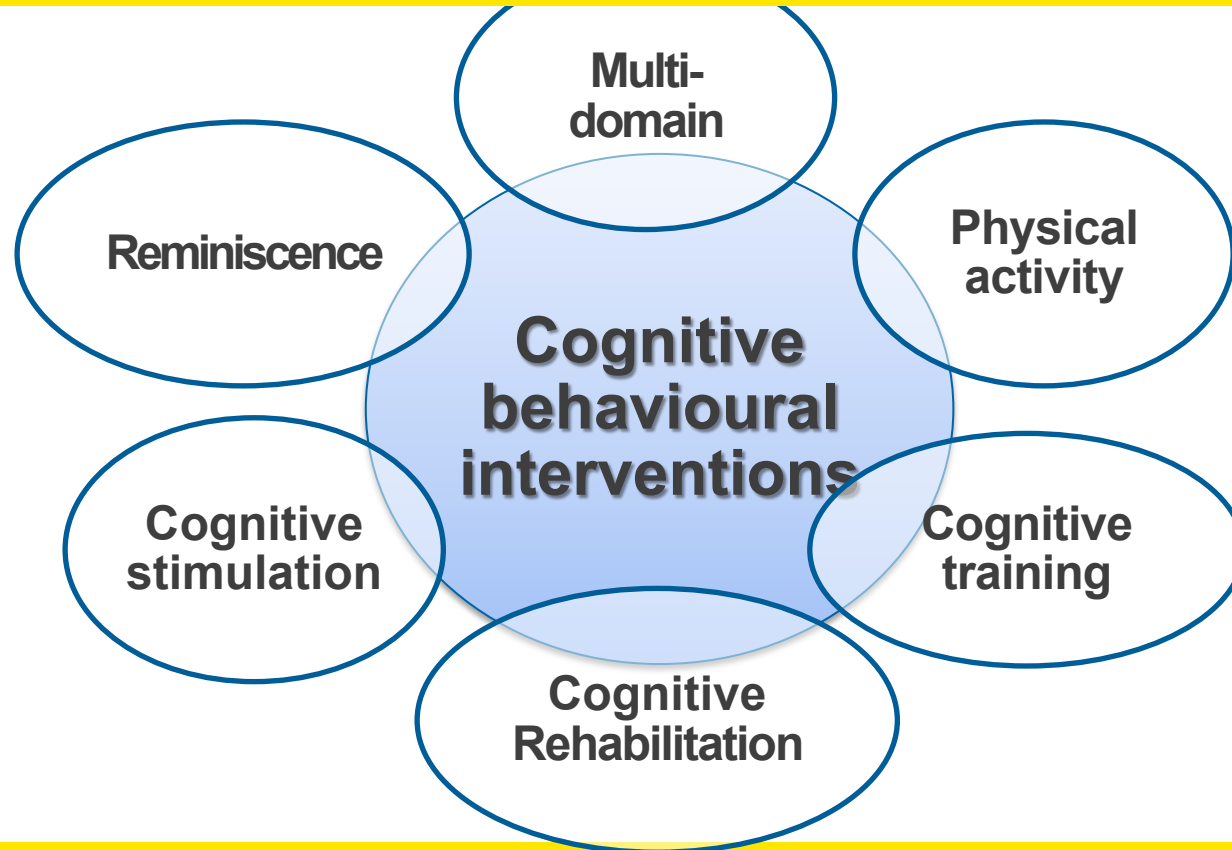
Macro - system changes



Person living with dementia (PLWD)



Interventions: Person living with dementia



Definitions

- ***Reminiscence therapy*** - discussion of past activities, events and experiences, aided by .. memory triggers¹
- ***Cognitive stimulation*** - engagement in range of activities & discussions aimed at general enhancement of cognitive and social function²
- ***Cognitive training*** - guided practice on set of standard tasks designed to reflect particular cognitive functions²
- ***Cognitive rehabilitation*** - individualised approach where personally relevant goals are identified & addressed²

Summary: Cognitive & Behavioral Intervts.

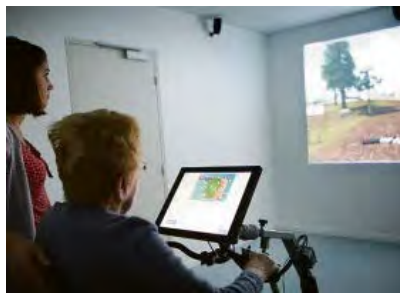
- **Reminiscence** – Small benefits in QoL, cognition, communication
- **Cog Stimulation** – S/T benefits cognition (> ChEI), QoL, socialisation, communication¹⁻⁴
- **Cog Rehab** - ↓ CG burden, ↓ functional disability & ? delay in institutionalisation ^{6,7}
 - No cog benefit (xpt ?↑w. computer cog training) ^{8,9}

¹Woods B et al. *Cochrane Sys Rev* 2012; ²Orrell M et al. 2014; ³Mkenda S et al. 2016;

⁴Paddick SM et al. 2017; ⁵Clare L et al.; ⁶Bahar-Fuchs A 2013; ⁷Clare L 2017; ⁸Amieva H et al. 2016; ⁹Garcia-Casal et al. 2017

Summary: Cogⁿ & Behav. Interventions

- **Physical training** – physical & cognitive benefits¹
- **Cog training** – benefits for healthy older & MCI, limited evidence for people with dementia
- **Multi-domain** – ? greater benefit (Train the Brain²)



Photos: "Boxing Grannies" FP / Gulshan Khan. South Africa; G Coronas aged 99 / Australian Dolphins Swim Team; Virtual reality cognitive therapy / France; Friends, Muslim Aged Care Australia

Cognitive & behavioural interventions – past, present, future

- ***Past*** – basic stimulation eg reality orientation
- ***Present*** – more targeted and personally relevant interventions eg goal directed, CST
- ***Future*** – combination interventions, computer assisted, continual

Interventions: For and by Caregivers (CGs)



Photo: AARP/Jarod Soares

Caregivers: the “second patient”

Negative effects

- High levels of stress
- Physical health suffers
 - eg ↓immunity, ↑mortality
- Social isolation
- Financial hardship

Positive effects on carers

- love, reciprocity, altruism



Photo: © AP

Caregivers: Predictors of negative effect



Photo: © Chicago Policy Review

- ***Caregiver (CG)***
 - Propinquity, cohabitation, spouse
 - Prior psychological morbidity, neuroticism
 - Poor health, coping skills
- ***Person living with dementia (PWLD)***
 - Behavioural symptoms (25% of variance)
 - Younger onset of dementia
- ***Context:*** few informal supports; other caring role

Interventions for caregivers



Sydney Dementia Carers Program

- RCT of 10-day program for PWLD and CGs v 10d respite
- Decreased CG psychological morbidity over 12m
- PLWD stayed home longer
 - Over 7yrs, OR = 5
- Saved US\$6000 per couple over first 3y

(Odds ratio 5.03, 1.73- 14.7)

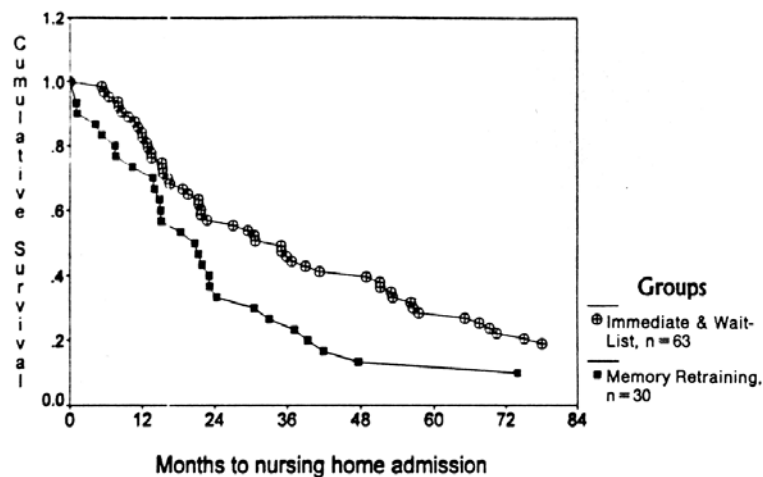


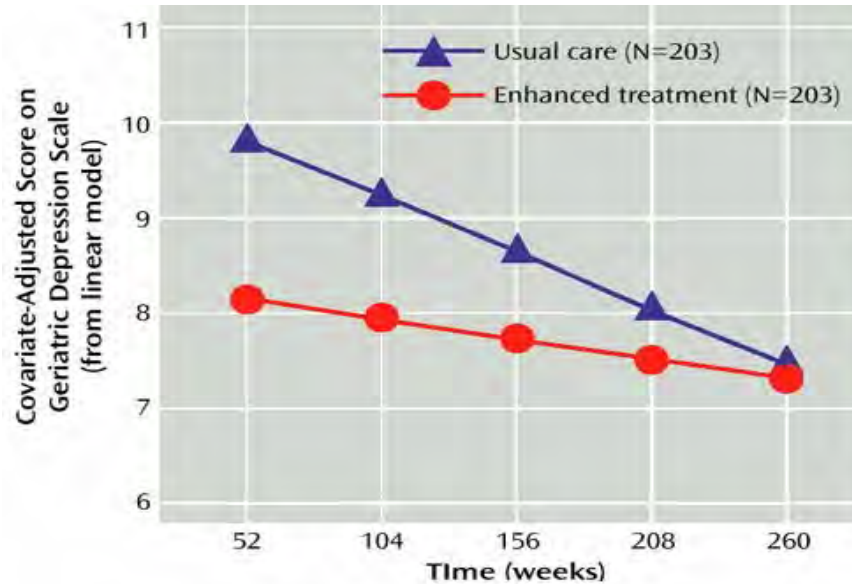
Figure: Kaplan-Meier survival functions for nursing home admission comparing the combined training groups with the memory retraining group

Going to Stay at Home program

- Residential respite care combined with...
- ..Sydney CGs' program condensed to 5-days
- CG depression & burden unchanged despite decreasing function in PLWD
- CGs' unmet needs↓ & BPSD ↓ significantly
- ↓ nursing home admission vs comparison gp

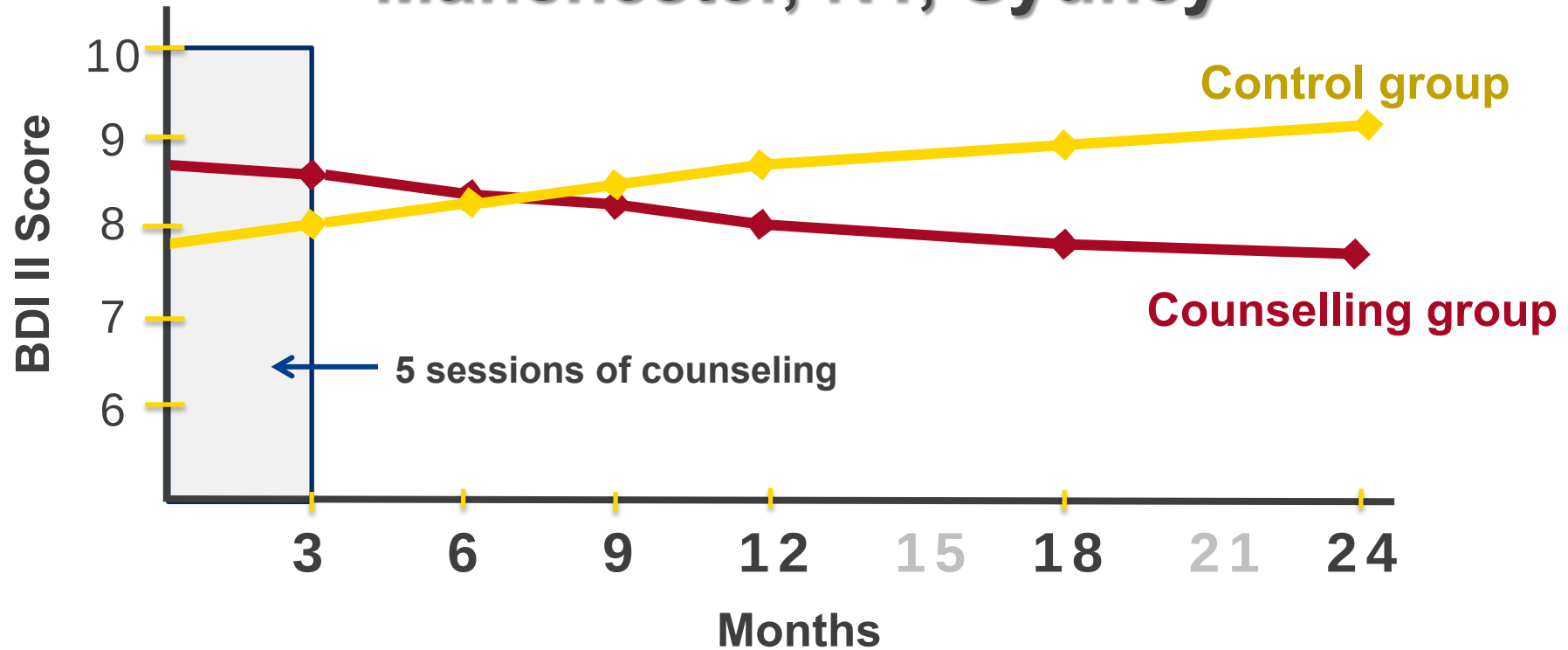
Sustained benefits of the NYU Spouse-Caregiver Intervention on Symptoms of Depression

- 2 individual + 4 family tailored counseling sessions
- PRN weekly gp support
- Depression ↓
- 329 days delay in NHA



Five year follow-up

3 country study: NY counseling pgm in Manchester, NY, Sydney



Intervention for Caregivers

Meta analysis: 30 studies, 34 intervent^{ns}

- Home/non-institutional, informal CGs
- ↓CG distress, ↑CG knowledge, ↑ PWLD mood. No benefit on CG burden
- Support for delayed NH admission
- Ingredients for success identified:
 - Involve PWLD, CG & Family
 - Sufficient intensity and duration



Resources for Enhancing Alzheimer's Caregiver Health (REACH)¹

- **REACH I - Differential benefits according to...**
 - **Intervention type ²⁻⁶**
 - **CG relationship – wife², non-spouse³, female⁶**
 - **CG characteristics – low mastery, high anxiety²**
 - **Racial groups- African-American³, Cuban⁵, White⁵**
- **Reach II – confirmed +ve results in racially/ ethnically diverse CGs⁷**

¹Schulz R, Gerontologist 2003; ²Burgio L 2003; ³Burns R 2003; ⁴Eisdorfer C 2003;

⁵Gallagher-Thompson D 2003; ⁶Gitlin L 2003; ⁷ Elliott AF, JAGS 2010

STrAtegies for RelaTives (START)



Photo: © Jesse Tinsley / The Spokesman-Review

- Pragmatic RCT, 8 sessions
- Manual-based coping strategy
- Promote CG mental health
- CGs' anxiety↓, depression↓, QoL↑ @ 8m & 2y ; Cost effective
- No benefit on PWLD QoL

¹Livingston G et al, 2014 Health Technology Assessment, 18 (61):1-242

Caregivers as therapists



Illustration: "Graham and Paula" 2015 original painting by Ann Cape from the exhibition "An Unending Shadow – works exploring dementia by Ann and Sophie Cape"

CGs as therapists

- People with AD and depression
- Trained caregivers in problem solving or pleasurable events schedule
- Patients' depression improved, benefits still apparent 6 months later
- CGs depression better too

Terri L et al. 1999; Seattle Protocols

CGs as therapists for BPSD¹

- **CG interventions can significantly reduce BPSD¹**
ES = 0.34 (95%CI=0.20–0.48; z=4.87; p < 0.01)
- **Bonus: Interventions mildly effective for CGs¹**
ES = 0.15 (95% CI=0.04–0.26; z=2.76, p < 0.01)
- **At least $\equiv$ antipsychotic for delusions, aggression & agitation (ES 0.16)² or for total BPSD (ES 0.13)³**

¹Brodaty H, Arasaratnam C. *Am J Psychiatry* 2012;² Schneider LS et al. *Am J Geriatr Psychiatry* 2006;

³ Yury C, Fisher J. *Psychotherapy Psychosom* 2007

Summary of CGs: past

- Tools to measure CG outcomes¹
- Prevalence of effects on CGs and predictors
- Models of drivers/moderators of CG burden etc^{2,3}
- Interventions → benefits for CGs, less attention to benefits on PWLD
- Not all trials successful
- Predictors of success described

¹Zarit S et al. 1980; ²Poulshock SW, Deimling GT. 1984; ³Pearlin LI.

Summary of CGs: Present

- CG studies in developing countries (10/66 group)
- More nuanced, home-based interventions



Photo: © Cathy Greenblat. Global Alzheimer's and Dementia Action Alliance. Ghana.

www.alz.co.uk/1066

Summary of CGs: Future



Photo: M Tobias

- *Personalised intervention*
 - > specific goals, > targeting¹
- ... better match of PWLD, CG & intervention
- Integration of social media, e-health for monitoring & intervention

Behavioral and Psychological Symptoms



Therapeutic practices for BPSD

Sensory interventions



Aroma therapy



Massage



Light therapy



**Snoezelen:
multi-sensory
stimulation**

Sensory interventions

- Light therapy worse than placebo for agitation¹
- Animal-assisted therapy²: ↓agitation
↓aggression, ↑social behaviour
 - Small samples; short duration,
- Aroma therapy – lavender, lemon balm
 - Contradictory findings^{3,4,5}



¹Livingston G et al. *Lancet* 2017;

²Filan SL, Llewellyn-Jones RH. *Int Psychogeriatr* 2006

³Forrester LT et al. *Cochrane Sys Rev* 2014; ⁴Ballard CG et al. 2002; ⁵Burns A et al. 2011

Psychological Mx approaches to BPSD

- 1632 studies identified → 162 met inclusion criteria → 9 studies with Level 1 evidence
- Psycho-education for caregivers is effective
- Behaviour Mx techniques centering on individual pts' or CG behaviours → similar benefits
- Residential care staff education beneficial

Psychological approaches to PTSD

- Music therapy
 - Snoezelen
 - Sensory stimulation
- } Useful during treatment
but not long term



Photo: Musical memories. Erskine, Glasgow



Photo: Sensory room. Lutheran Social Ministries of New Jersey

Dementia care mapping

Chenoweth et al (2009)⁴³²

Chenoweth et al (2009)⁴³²

Person-centred care and communication skills

Chenoweth et al (2009)⁴³²

Chenoweth et al (2009)⁴³²

Deudon et al (2009)⁴³³

Deudon et al (2009)⁴³³

McCallion et al (1999)⁴³⁴

McCallion et al (1999)⁴³⁴

McCallion et al (1999)⁴³⁴

Physical aggression

McCallion et al (1999)⁴³⁴

Physical aggression

McCallion et al (1999)⁴³⁴

Verbal aggression

McCallion et al (1999)⁴³⁴

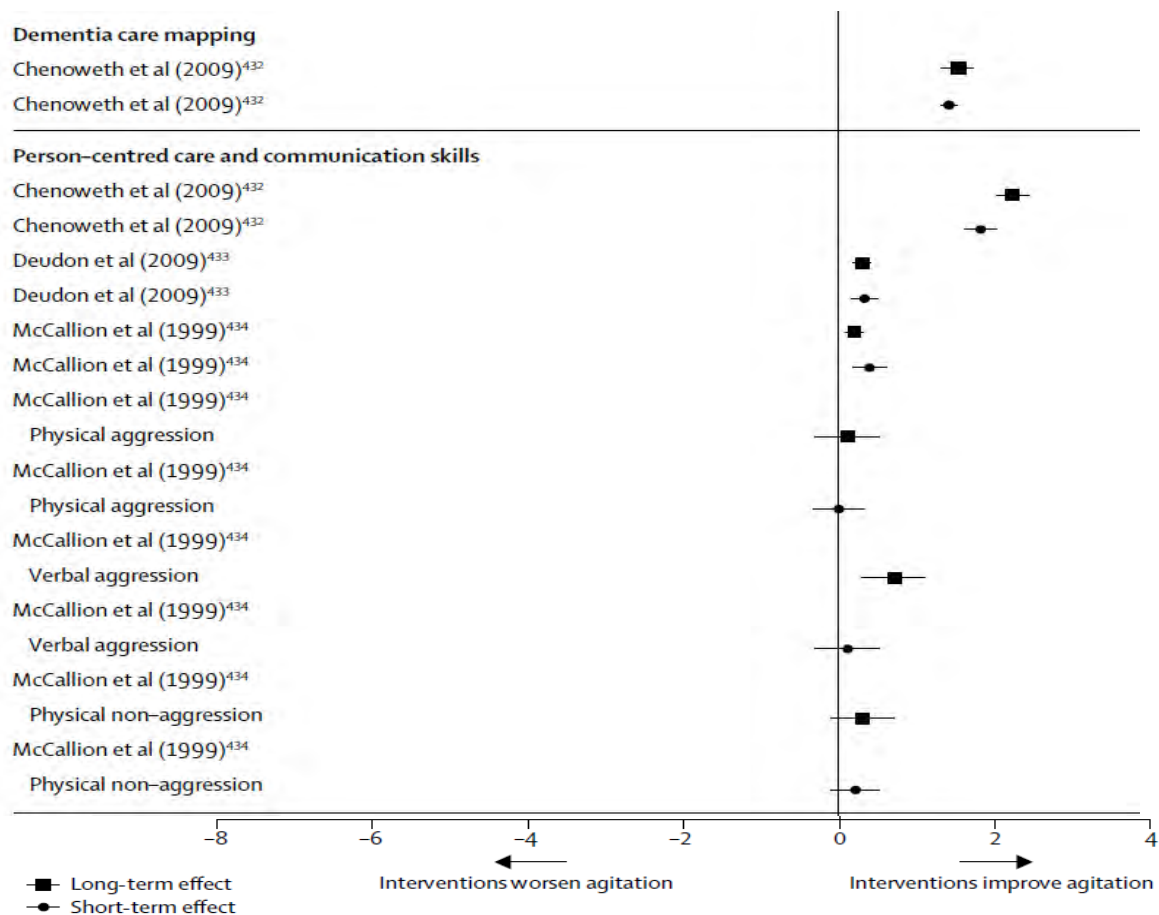
Verbal aggression

McCallion et al (1999)⁴³⁴

Physical non-aggression

McCallion et al (1999)⁴³⁴

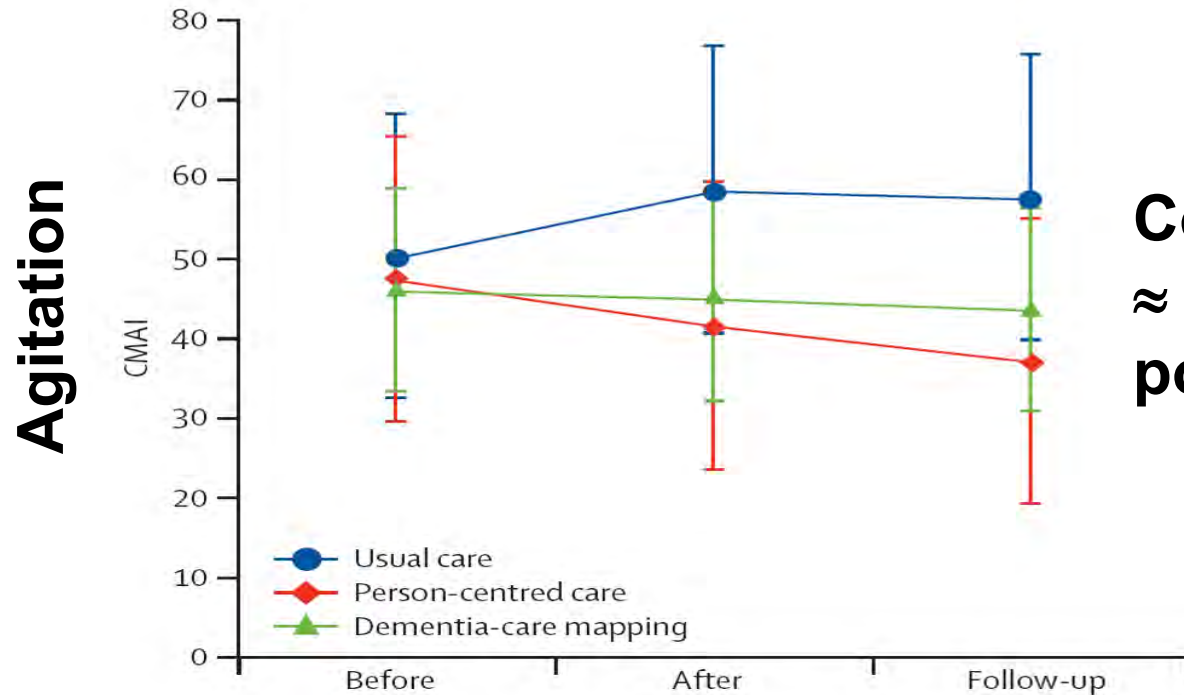
Physical non-aggression



Dementia Care Mapping and Person Centred Care for agitation

Livingston G et al.
Lancet, 2017

Dementia Care Mapping & Person Centred Care for agitation



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

Novel strategies

- Humour therapy
- Volunteers, singing, dance therapy
- Integrating kindergarten/ babies



Photo: Lancet / The SMILE Study



Photo: Llanyravon Court Care. South Wales Argus

Humor therapy: SMILE study

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



Photo: Arts Health Institute / The SMILE Study

Low LF et al. *BMJ Open* 2013; Brodaty H et al. *Am J Ger Psych* 2014;
Low LF et al. *JAMDA* 2014

Psychosocial interventions for BPSD: past

- Prevalence and measurement*
- Drug treatment



*Innovators: Jiska Cohen-Mansfield, Barry Reisberg, Jeffrey Cummings

Psychosocial interventions for BPSD: present

- Principles:

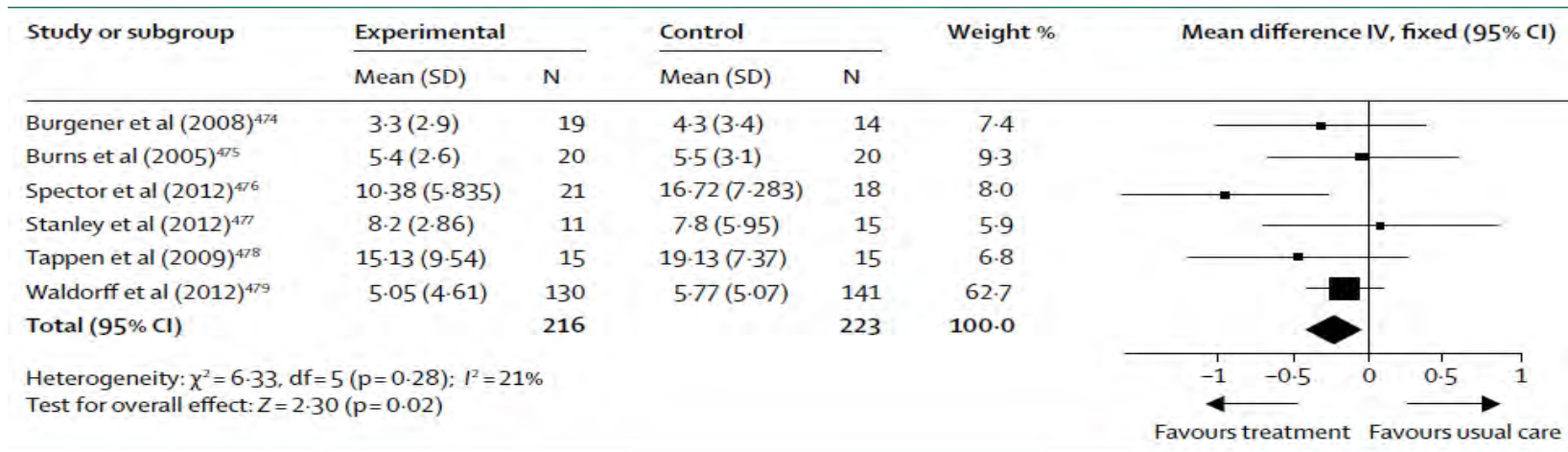
- Psychosocial interventions = first-line therapy
...after pain & acute care needs addressed
- Help the person, do not treat the symptom
- Behaviours = form of communication
- Innovation, creativity, partnership with family/ staff

¹Livingston et al. *Lancet* 2017

Jiska Cohen-Mansfield, Bob Woods, Linda Clare, Clive Ballard

Psychosocial interventions for PTSD: present

- Psychosocial Rx $\geq$ effective than drug Rx eg Dep^{n 1}
- Drug Rx modest efficacy; significant AEs
 - eg antipsychotics - $\uparrow$ CVA, mortality



¹Livingston et al. *Lancet* 2017

Psychosocial interventions for BPSD: future

- **Prevention of behaviour problems**
- **Helping workforce in community, residential care, hospitals through better systems, technologies, training, materials, mentoring**
- **Education, tools for family CGs eg Apps, web**
- **Institutional practices designed for residents**

Long-term Care

OECD %GDP on LTC: 0 - 4.3%²

Diagnosed dementia prevalence^{1,2}

- Nursing homes 50-80%
- Assisted living 45-67%
- ...but most likely more
- 90%+ have BPSD³



¹Harris-Kojetin L, National Center for Health Statistics. Vital Health Stat 3(38). 2016;

²OECD. OECD Health Policy Studies. Paris: OECD Publishing, 2018

³Brodaty et al, 2003 Int Psychoger

Social elements and interventions¹⁻⁵

- NHs are lonely⁶; median # friends =1
- Role for friendship & supportive social relationships...⁶
- Interventions & environment may help



Photo: © Green House Project. USA

¹Livingston G et al. 2017; ²Abraha I et al. 2017; ³McDermott O et al. 2018; ⁴Scales K et al. 2018; ⁵Möhler et al. 2018; ⁶Casey A-N et al 2015; ⁷Jao Y-L et al. 2018; ⁸Mitchell JI et al 2015

Summary of comparative reviews¹⁻⁵

- Interventions to improve communication, activities, & sensory interventions, approach are first-line therapy
- Evidence of benefits eg agitation, affect⁵
 - No specific intervention superior ⁵
- Positive effects in the moment (eg increased positive self-expression)



Photos: Institute of Health & Nursing Australia, School of Community Services; © Chicago Dance Therapy, North Shore Dance Therapy; *Dog therapy* © Straits Times. Singapore

Environment¹



- Supportive, therapeutic, prosthetic vs debilitating¹
- Institution → home-like
- Person centred, smaller scale → agitation↓, <cognitive decline
- Community, Courtesy, Comfort, Choice

Calkin MP, Gerontologist 2018

Environment: evidence for ...¹

- Unobtrusive safety measures
- Homelike, small unit size
- Vary ambience, size, shape of spaces
- Single rooms; maximize visual access
- Outdoor access
- Control levels of stimulation: ↓unhelpful stimuli eg noise, busy entry door; Optimise helpful stimuli eg light
- QOL $\propto$ quality of environment²



Innovative environments



De Hogewyk village



Eden Alternative



Green Care Farms^{1,2}

- **Multi-generational living³ ; Dementia villages^{4,5}**
- **Systematic review ($N = 19$ articles, 27 studies)^{6,7}**
- **Diverse outcomes precluded strong conclusions**

¹de Boer B, Hamers JPH, Zwakhalen SMG, et al. 2017; ²de Boer B...Tan FES, Verbeek H 2017; ³Harris J 2016; ⁴Chrysikou E, Tziraki C, Buhalis D 2018; ⁵Haeusermann T 2018; ^{6,7}Petrewsky 2016a, 2016b)

Long-term care: past



- Chemical & physical restraints
- De-personalised group activities
- Poor/absent training in dementia care
- Medical model
- Hospital-like institutional settings



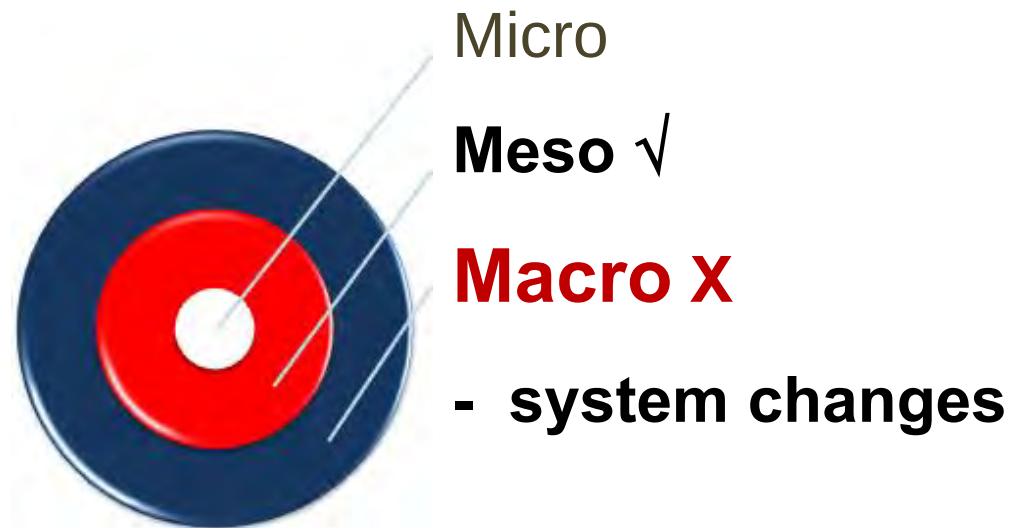
Long-term care: present

- Personally tailored programs, only in minority of facilities
- Care staff training ↑interactions & ↓agitation longer-term
- Culture change models ↑QoL & ↑satisfaction
- Small-scale homes ↑functioning & ↑social engagement
- Innovative environments provide tailored alternatives for varied needs & preferences, limited evidence

Long-term care: future

- **Care & interventions tailored to person
→ Business As Usual**
- **Enabling workforce through adaptable systems, technologies, training, materials, mentoring**
- **Evidence-based culture-change & environmental design based on consumers' needs, input & preferences eg smaller, homelike**

Other psychosocial research **X**



- **Prevention in healthy people**
- **Dx & post-diagnosis**
- **Assistive technology**
- **Community care**
- **Acute care**
- **Palliative/ end-of-life care**

The promise of psychosocial research

- **Important across whole journey of dementia**
- **Increasing quantity and quality of research**
- **More nuanced interventions**
- **Psychosocial *and* pharmacological therapies complementary**
- **Creativity, person-centred, inclusive (diversity, heterogeneity, families)**
- **Collaboration with technology advances**

Personalised psychosocial interventions

- ***Precision Medicine aka Personalised Medicine***
- **Psychosocial $\equiv$ *Personalised Care***
- **Sustainability, needs continual administration just like medications**
- **Barriers & Drivers**

Barriers for *Personalised interventions*

- Lack of knowledge
- Time, money
- Attitudes
- Public expectations
- Research
- Cost benefit analysis

Drivers for *Personalised interventions*



- Demand – from PWLD, families, public
- Competition in LTC
- Training for staff, families
- Standards for assessments of facilities
- Regulations
- Compelling research



Thank you

- Centre for Healthy Brain Ageing (CHeBA) at UNSW
- Dementia Centre for Research Collaboration (DCRC) at UNSW

www.dementiaresearch.org.au

www.cheba.unsw.edu.au



Dr Anne-Nicole Casey