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Psychosocial Research in Dementia: Past, Present, and Future

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DCRC Dementia Centre for Research Collaboration

Presenter disclosures: nothing relevant to this presentation.

Nutricia Advisory Board, Australia

CHeBA Healthy Brains Positive Ageing

What is psychosocial research?

- Psychosocial or Non-pharmacological[1-3]
  - Maintaining or improving functionality, social relationships & well-being
  - Not disease modification

Psychosocial vs Biological

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

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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

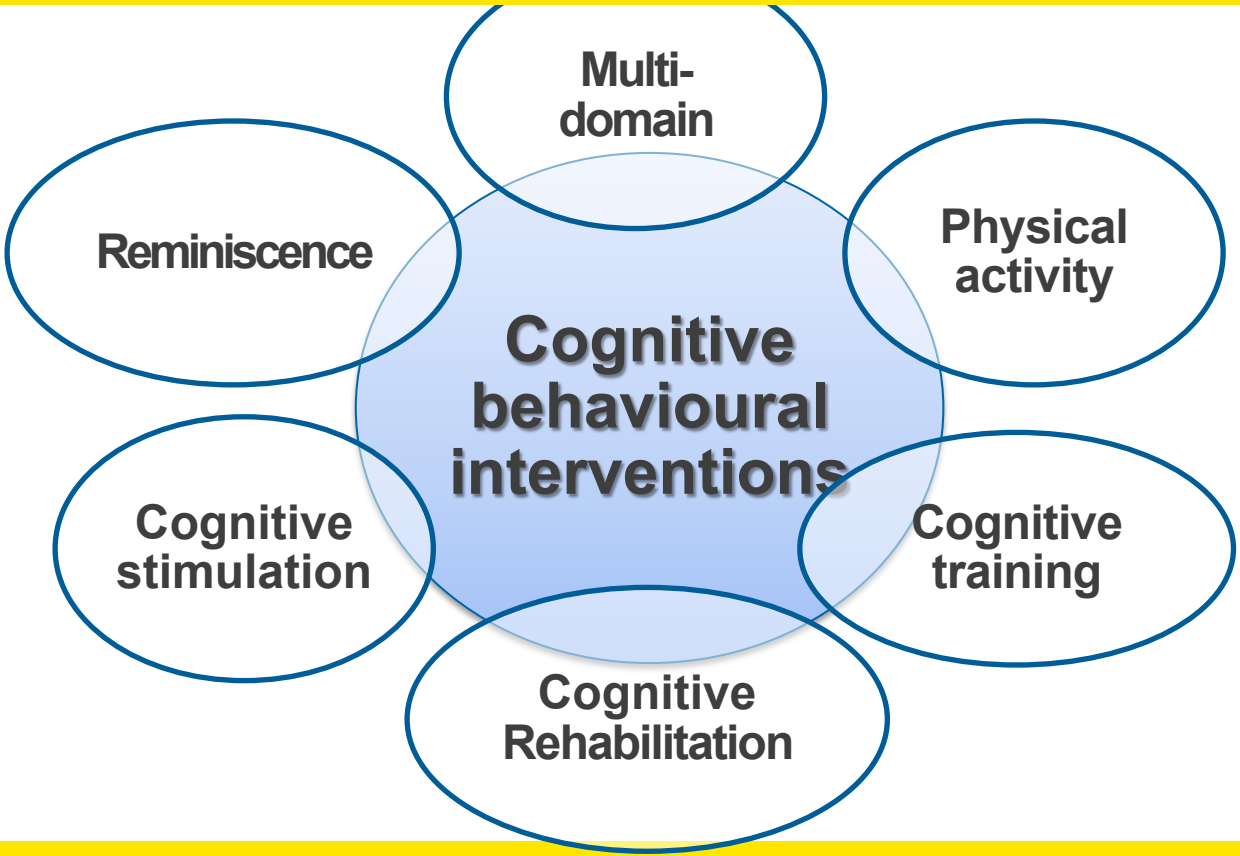
Micro – drug therapies based on molecules

Meso – behavioural, interpersonal

Macro - system changes

Person living with dementia (PLWD)

Interventions: Person living with dementia



Livingston G et al. 2014; McDermott O et al. 2018; Samus QM et al. 2018; Moniz-Cook E et al. 2011

Definitions

- *Reminiscence therapy* - discussion of past activities, events and experiences, aided by .. memory triggers[1]
- *Cognitive stimulation* - engagement in range of activities & discussions aimed at general enhancement of cognitive and social function[2]
- *Cognitive training* - guided practice on set of standard tasks designed to reflect particular cognitive functions[2]
- *Cognitive rehabilitation* - individualised approach where personally relevant goals are identified & addressed[2]

[1] Subramaniam and Woods (2012, p. 545); [2] Woods R et al, 2012

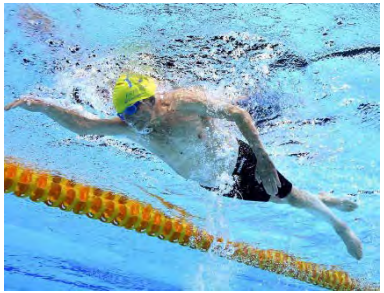
Summary: Cognitive & Behavioral Intvnts.

- **Reminiscence** – Small benefits in QoL, cognition, communication
- **Cog Stimulation** – S/T benefits cognition (> ChEI), QoL, socialisation, communication[1-4]
- **Cog Rehab** - ↓ CG burden, ↓ functional disability & ? delay in institutionalisation [6,7]
  - No cog benefit (xpt ?↑w. computer cog training) [8,9]

[1]Woods B et al. *Cochrane Sys Rev* 2012; [2]Orrell M et al. 2014; [3]Mkenda S et al. 2016; [4]Paddick SM et al. 2017; [5]Clare L et al.; [6]Bahar-Fuchs A 2013; [7]Clare L 2017; [8]Amieva H et al. 2016; [9]Garcıa-Casal et al. 2017

Summary: Cog^{n} & Behav. Interventions

- **Physical training** – physical & cognitive benefits[1]
- **Cog training** – benefits for healthy older & MCI, limited evidence for people with dementia
- **Multi-domain** – ? greater benefit (Train the Brain[2])

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

[1]McDermott et al. 2018; [2]Maffei L et al. *Nature Sci Rep.* 2017

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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”

Photo: © AP

Negative effects

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

Positive effects on carers

- love, reciprocity, altruism

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

Gilleard C, 1984; Brodaty H & Luscombe G, 1998; Luscombe G et al. 1998; Seeher K & Brodaty H, in *Dementia 5th Ed* 2017, Ch 14, pp142-160

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)

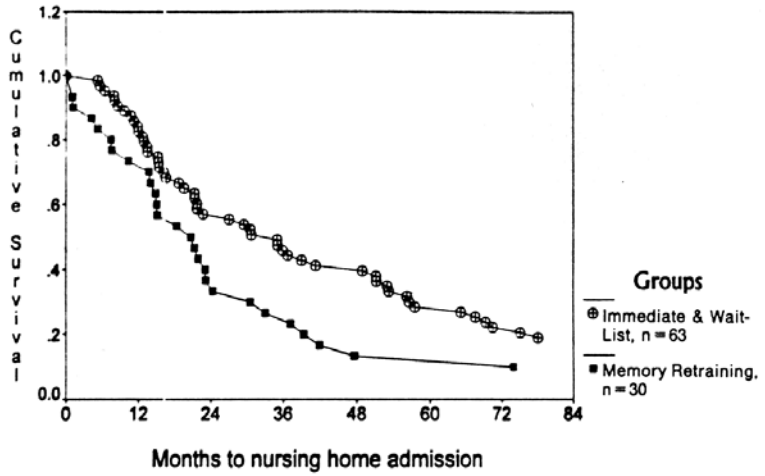


Figure: Kaplan-Meier survival functions for nursing home admission comparing the combined training groups with the memory retraining group

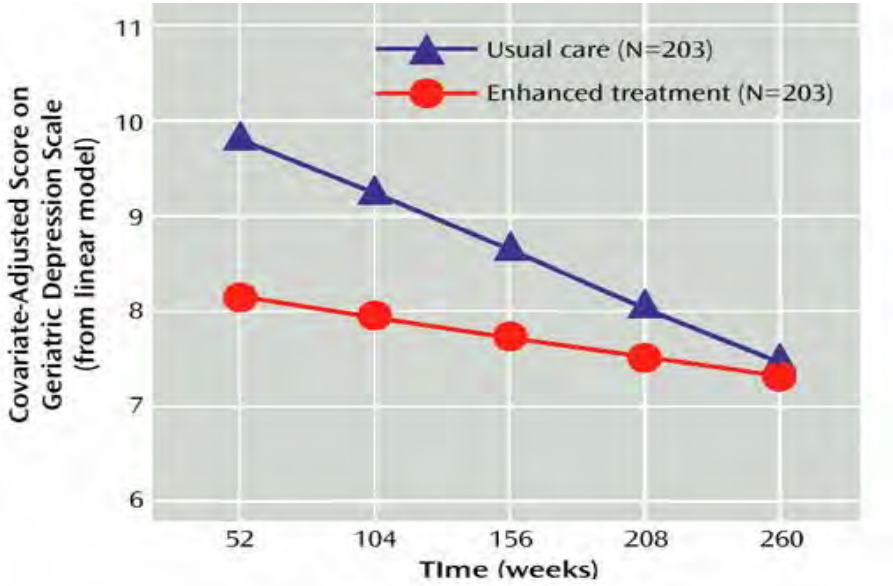
Going to Stay at Home program

- 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

Gresham M, Heffernan M, Brodaty H. *Int Psychogeriatr* 2018

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

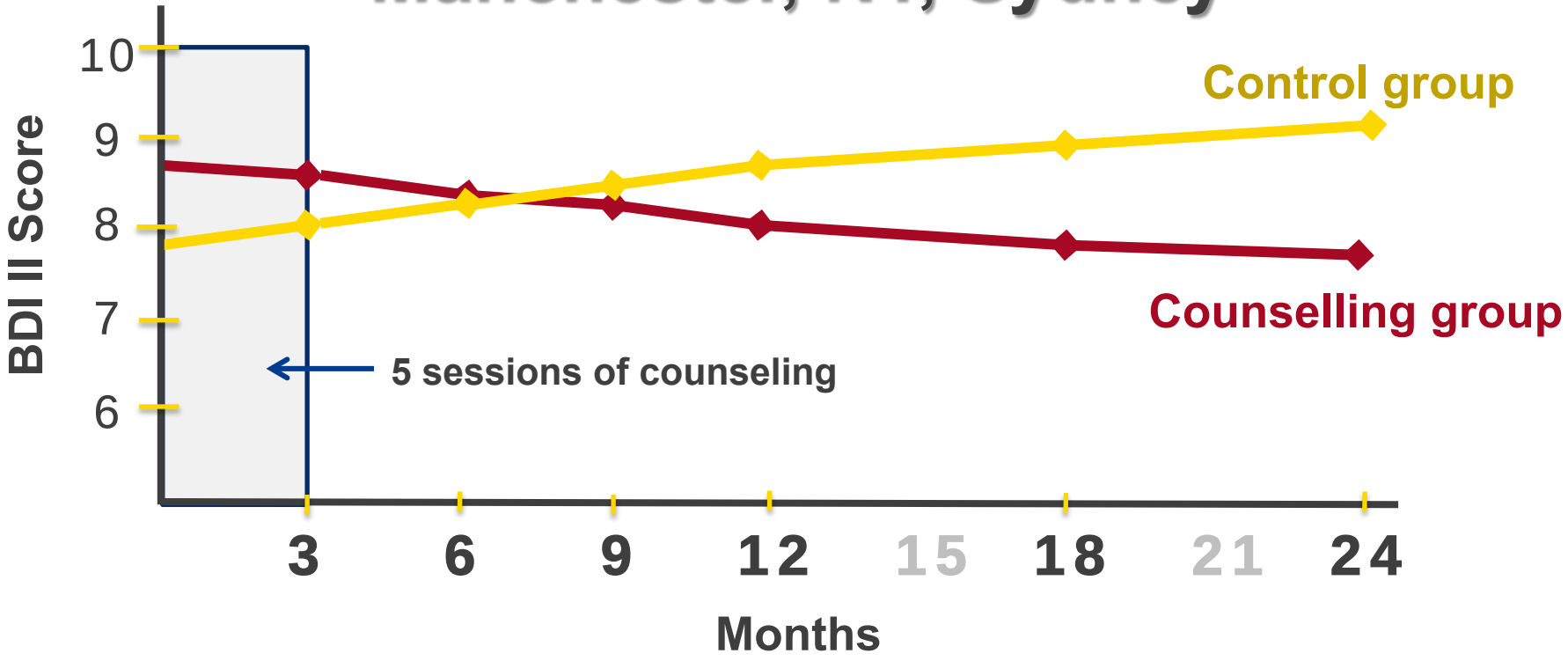
- 2 individual + 4 family tailored counseling sessions
- PRN weekly gp support
- Depression ↓
- 329 days delay in NHA



Five year follow-up

Mittelman et al. 2004

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



Mittelman MS, Brodaty H, Wallen AS, Burns A. *Am J Geriatr Psychiatry* 2008

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**

Brodaty H et al. *J Am Geriatr Soc* 2003; 51:657–664

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

- REACH I - Differential benefits according to…
  - Intervention type [2-6]
  - CG relationship – wife[2], non-spouse[3], female[6]
  - CG characteristics – low mastery, high anxiety[2]
  - Racial groups- African-American[3], Cuban[5], White[5]
- Reach II – confirmed +ve results in racially/ ethnically diverse CGs[7]

[1]Schulz R, Gerontologist 2003; [2]Burgio L 2003; [3]Burns R 2003; [4]Eisdorfer C 2003; [5]Gallagher-Thompson D 2003; [6]Gitlin 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

[1]Livingston 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 BPSD[1]

- **CG interventions can significantly reduce BPSD[1]**
  ES = 0.34 (95%CI=0.20–0.48; z=4.87; p < 0.01)
- **Bonus: Interventions mildly effective for CGs[1]**
  ES = 0.15 (95% CI=0.04–0.26; z=2.76, p < 0.01)
- **At least ≡ antipsychotic for delusions, aggression & agitation (ES 0.16)[2] or for total BPSD (ES 0.13)[3]**

[1]Brodaty 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 outcomes[1]
- 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

[1]Zarit S et al. 1980; [2]Poulshock SW, Deimling GT. 1984; [3]Pearlin 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, > targeting[1]
- … 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 agitation[1]
- Animal-assisted therapy[2]: ↓agitation ↓aggression, ↑social behaviour
  - Small samples; short duration,

- Aroma therapy – lavendar, lemon balm
  - Contradictory findings[3,4,5]

[1]Livingston G et al. Lancet 2017;
[2]Filan SL, Llewellyn-Jones RH. *Int Psychogeriatr* 2006
[3]Forrester LT et al. *Cochrane Sys Rev* 2014; [4]Ballard CG et al. 2002; [5]Burns 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

Livingston G et al. *Am J Psychiatry* 2005; 162:1996-2021

Psychological approaches to BPSD

- Music therapy
- Snoezelen
- Sensory stimulation

} Useful during treatment but not long term

Photo: Musical memories. Erskine, Glasgow

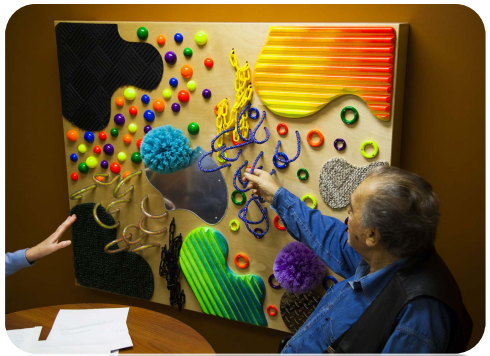


Photo: Sensory room. Lutheran Social Ministries of New Jersey

Livingston G et al. *Am J Psychiatry* 2005; 162:1996-2021

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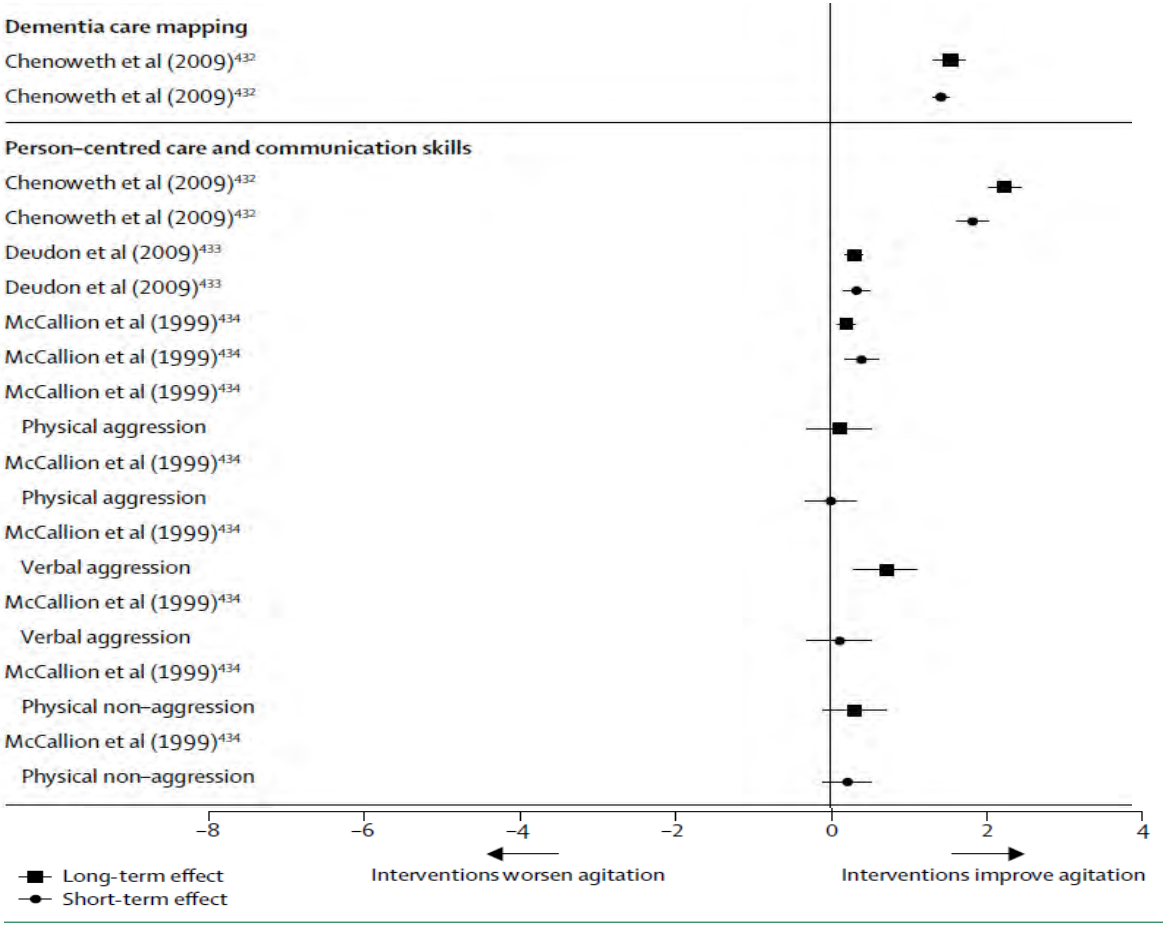
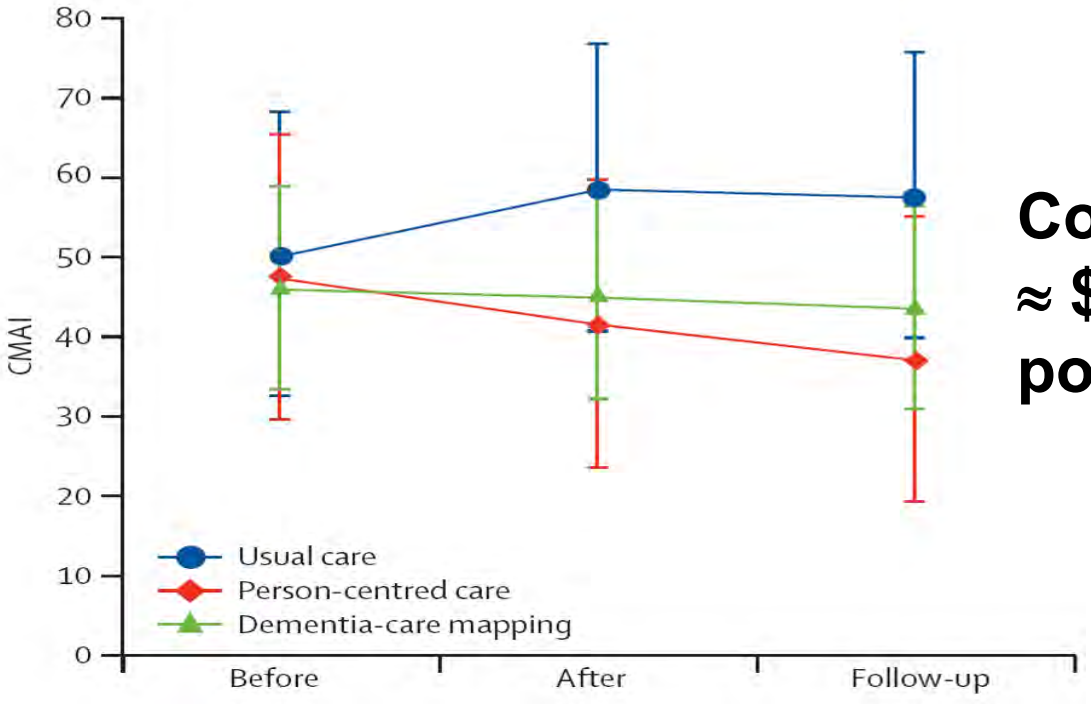


Dementia Care Mapping and Person Centred Care for agitation

Livingston G et al. Lancet, 2017

Dementia Care Mapping & Person Centred Care for agitation

Agitation



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

Chenoweth L et al. *Lancet Neurol* 2009

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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

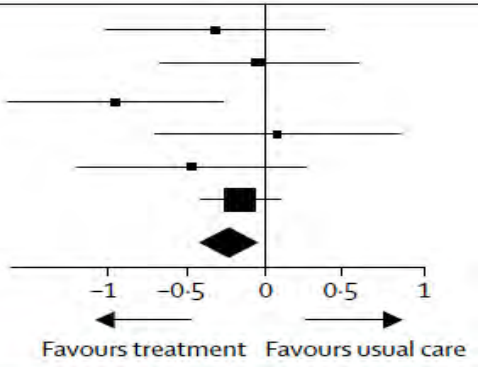
[1]Livingston et al. *Lancet* 2017

Psychosocial interventions for BPSD: present

- Psychosocial Rx ≥ effective than drug Rx eg Dep^{n} [1]
- Drug Rx modest efficacy; significant AEs
  - eg antipsychotics - ↑CVA, mortality

Study or subgroup	Experimental		Control		Weight %
	Mean (SD)	N	Mean (SD)	N	
Burgener et al (2008)[474]	3·3 (2·9)	19	4·3 (3·4)	14	7·4
Burns et al (2005)[475]	5·4 (2·6)	20	5·5 (3·1)	20	9·3
Spector et al (2012)[476]	10·38 (5·835)	21	16·72 (7·283)	18	8·0
Stanley et al (2012)[477]	8·2 (2·86)	11	7·8 (5·95)	15	5·9
Tappen et al (2009)[478]	15·13 (9·54)	15	19·13 (7·37)	15	6·8
Waldorff et al (2012)[479]	5·05 (4·61)	130	5·77 (5·07)	141	62·7
Total (95% CI)		**216**		**223**	**100·0**

Heterogeneity: $\chi^2 = 6{\cdot}33$, df = 5 (p = 0·28); $I^2 = 21\%$
Test for overall effect: $Z = 2{\cdot}30$ (p = 0·02)



[1]Livingston 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 BPSD[3]

[1]Harris-Kojetin L, National Center for Health Statistics. Vital Health Stat 3(38). 2016;
[2]OECD. OECD Health Policy Studies. Paris: OECD Publishing, 2018
[3] Brodaty et al, 2003 Int Psychoger

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Social elements and interventions[1-5]

- NHs are lonely[6]; median # friends =1
- Role for friendship & supportive social relationships…[6]
- Interventions & environment may help

Photo: © Green House Project. USA

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

Summary of comparative reviews[1-5]

- Interventions to improve communication, activities, & sensory interventions, approach are first-line therapy
- Evidence of benefits eg agitation, affect[5]
  - 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

[1]Livingston G et al. 2017; [2]Abraha I et al. 2017; [3]McDermott O et al. 2018; [4]Scales K et al. 2018; [5]Möhler R et al. 2018

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Environment[1]

- Supportive, therapeutic, prosthetic vs debilitating[1]
- 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 ∝ quality of environment[2]

[1]Fleming R, Purandare N. *Int Psychogeriatr* 2010; [2] Fleming R et al *Dementia* 2016

Innovative environments

De Hogewyk village

Eden Alternative

Green Care Farms[1,2]

- Multi-generational living[3] ; Dementia villages[4,5]
- Systematic review (*N* = 19 articles, 27 studies)[6,7]
- Diverse outcomes precluded strong conclusions

[1]de Boer B, Hamers JPH, Zwakhalen SMG, et al. 2017; [2]de Boer B…Tan FES, Verbeek H 2017; [3]Harris J 2016; [4]Chrysikou E, Tziraki C, Buhalis D 2018; [5]Haeusermann 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

Micro

Meso √

Macro X

- system changes

- **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 ≡ *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