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Psychosocial Research in Dementia: Past, Present, and Future

Henry Brodaty Canada Webinar January 2019




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

[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)

Briefly covered

Diagnosis, post-diagnostic care
Acute care

Not covered

- Prevention in healthy people
- Assistive technology
- Community care
- Palliative and end-of-life care
- Systems based research

Levels of interventions

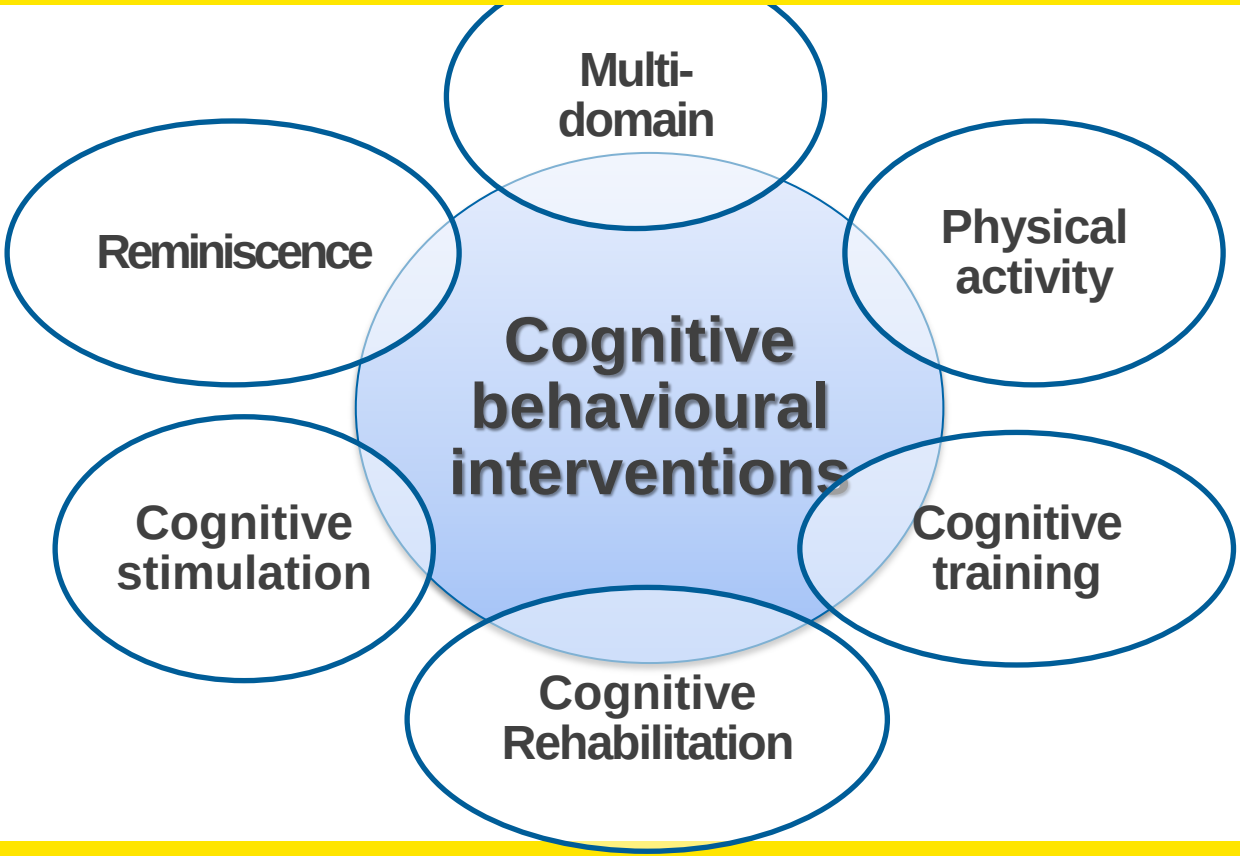
Micro – drug therapies based on molecules

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”

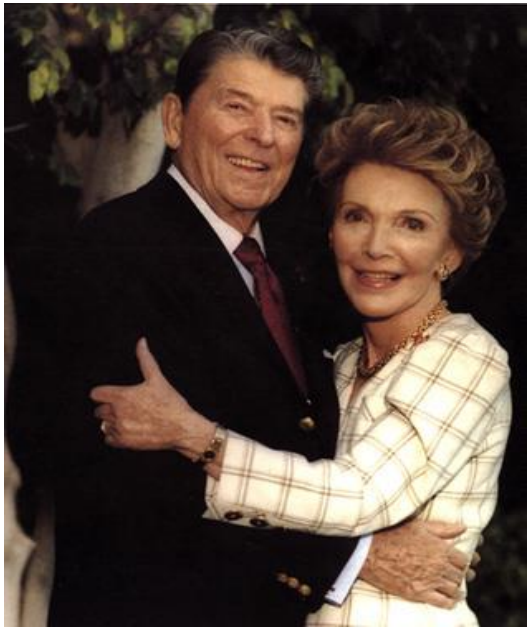

Photo: © AP

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)

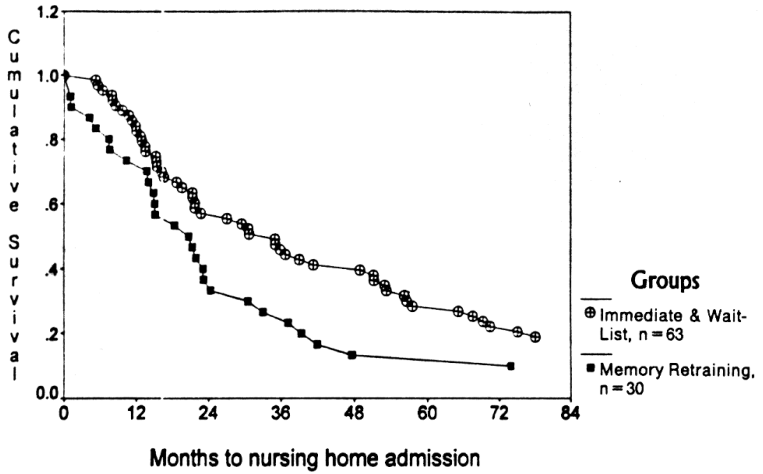

Figure: Kaplan-Meier survival functions for nursing home admission comparing the combined training groups with the memory retraining group

Brodaty H, Gresham M. BMJ 1989; Brodaty et al. Int Psychog 1991; Brodaty et al. IJGP 1997

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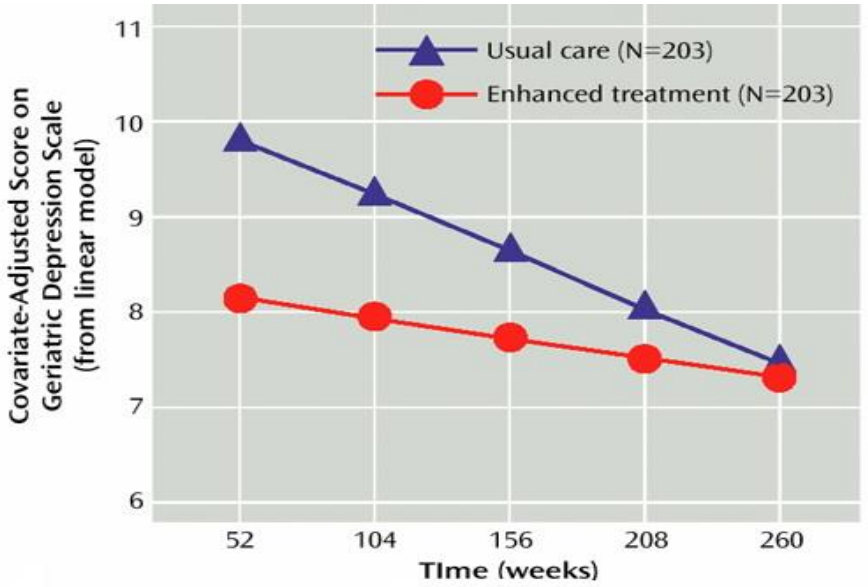
Going to Stay at Home program

- 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

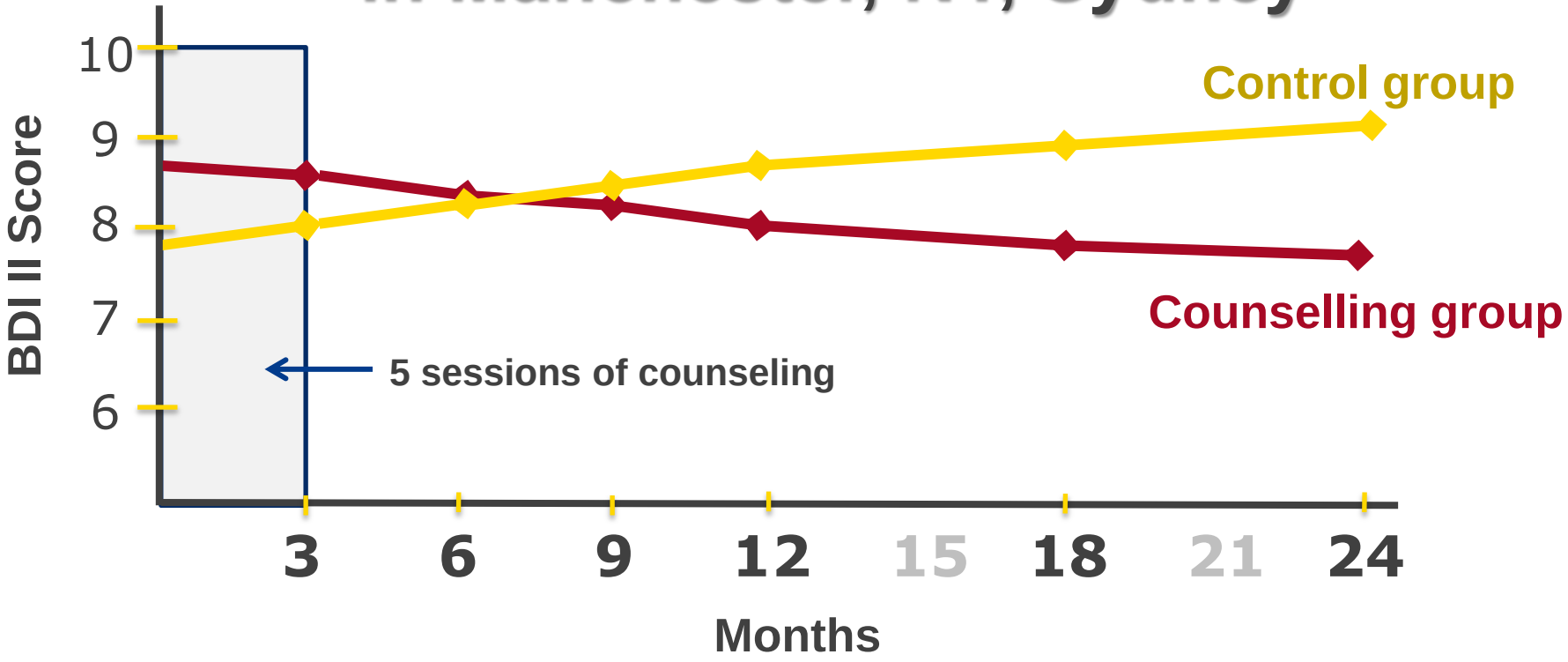
- 2 individual + 4 family tailored counseling sessions
- PRN weekly gp support
- Depression ↓
- 329 days delay in NHA



Five year follow-up

Mittelman et al. 2004

3 country study: NY counselling program 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 interventns

- **Home/non-institutional, informal CGs**
- **↓CG distress, ↑CG knowledge, ↑ PLWD mood. No benefit on CG burden**
- **Support for delayed NH admission**
- **Ingredients for success identified:**
  - **Involve PLWD, 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 – 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 PLWD 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: Future

Photo: M Tobias

- *Personalised intervention*
  - > specific goals, > targeting[1]
- … better match of PLWD, CG & intervention
- Integration of social media, e-health for monitoring & intervention

Challenges in diagnosis

- 2-3 yr gap between onset of Sx and Dx dementia
- Timely diagnosis
- ↑ search for biomarker determined Dx
  - Biomarker positive, no symptoms?
- Main gap is in primary care diagnosis
- 2/3 world's populat^{n} w. dementia in developing countries

Post-diagnosis - current

- Paucity of information
- Lack of referrals eg to AA
- Lack of lifestyle recommendations
- PLWD = Non-person
  - "Prescribed Disengagement" (Swaffer)

Opportunities - Post-diagnosis

- **Remedy all of these**
- **“Prescribed engagement”** **Swaffer K, Low LF 2018**
- **Rehabilitation program cf stroke**
  - **Lifestyle – exercise, cognitive rehab, diet**
  - **Compensation strategies**

Opportunities - Post-diagnosis

- **Evaluation – *COGNISANCE* Study JPND/EU**
- **Co-designing dementia diagnosis and post-diagnostic care**
- **Australia, UK, Poland, Netherlands, Canada***

***Isabelle Vedel, Carrie McAinie, Howard Bergman**

Acute Care - challenges

- **PLWD in hospitals have longer length of stay, more complications, higher mortality**
- **Hip# + delirium → higher mortality**
- **Disease/organ specific wards/staff not equipped/ trained to care for older cognitively impaired people**

Acute Care - challenges

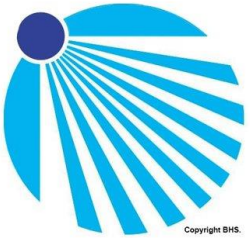
- **1.5 hours longer to analgesia after presentation to ED with long bone # (Fry M et al)**
- **Discrimination against PWD eg rehab after #hip**

(Harvey L, Mitchell R et al)

- **Discharge planning can be unrealistic**

Acute Care Future

- **Staff training**
  - **Cognitive Impairment Identifier + Dementia training package (Yates M et al, IJERPH, 2018)**
  - **Reduce hospital complications in *some* hospitals (Yates M et al in preparation)**
- **Environmental design**
- **Staff training**
- **Post-discharge follow-up**



Regular Early Assessment Post-Discharge (REAP)

- **Prospective RCT, 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**

Cordato N et al, JAMDA, 2018

REAP intervention

- **REAP group had almost 2/3 fewer hospital readmissions (p=0.03; Cohen's d=0.73) and half as many ED visits than controls**
- **Total costs were 50% lower in the REAP intervention group**

Cordato N et al, JAMDA, 2018

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 – lavender, 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

Social robotics

Robotic animals (eg PARO)[1-3]

- mood states and agitation: Robotic seal = plush toy > usual care in improving
- Engagement: robotic seal > plush toy

[1]Moyle W, Jones C et al. 2017; [2]Bemelmans R et al. 2012; [3]Scales K et al. 2018

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

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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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Music therapy

- Short-term increase in positive self-expression, improved depression,[1,2] lower anxiety,[1] & less agitation[3]
- No effect on cognition[4], well-being/QoL[1]
- Receptive therapy more efficacious for agitation [5]
- Individualised music[8], playlists
- *Low quality evidence: outcomes uncertain[1-7]*

[1]van der Steen JT et al. 2017;[2]Zhao K, et al. 2016;[3]Pedersen SKA et al. 2017; [4]Fusar-Poli L et al. 2017; [5]Tsoi KKF et al. 2018; [6]Abraha I et al. 2017; [7]Scales K et al. 2018; [8] Gerdner L, 199

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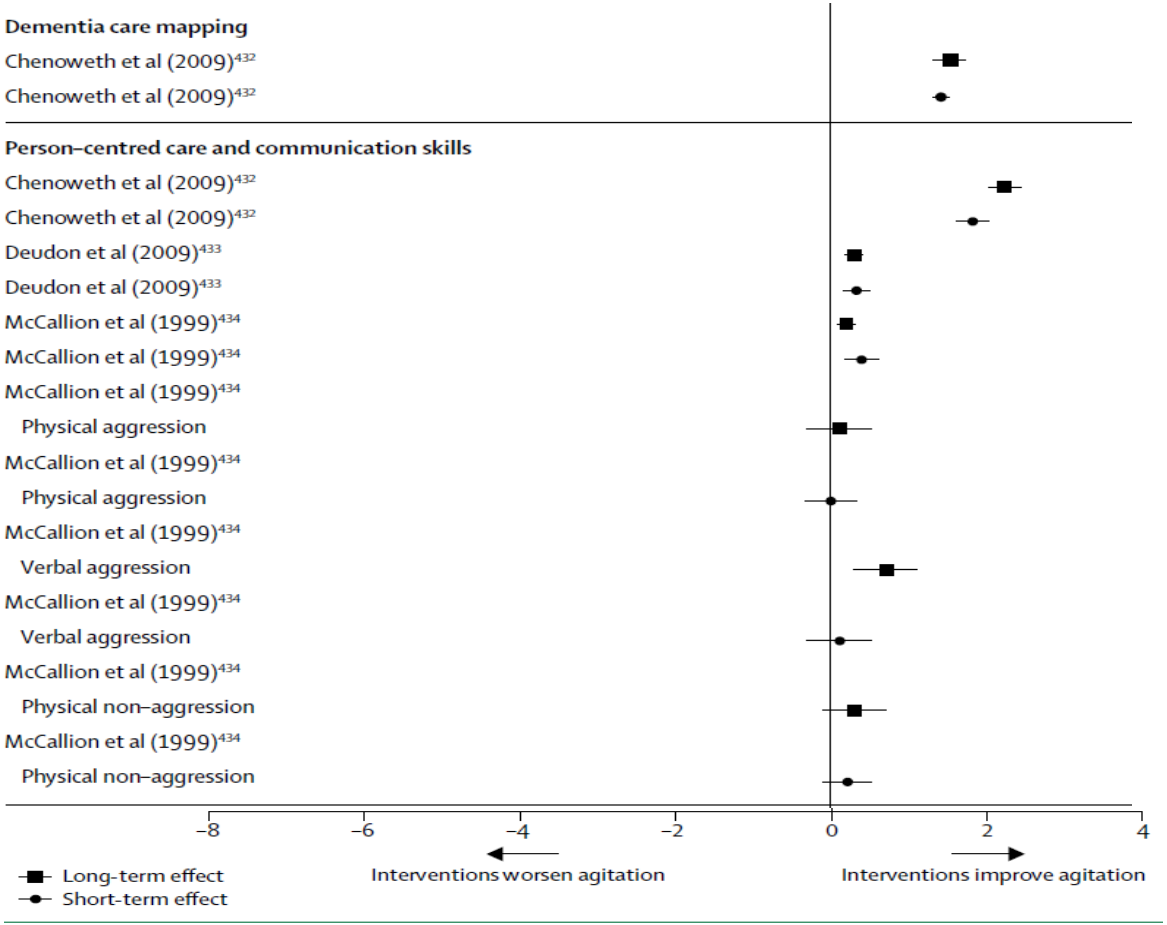
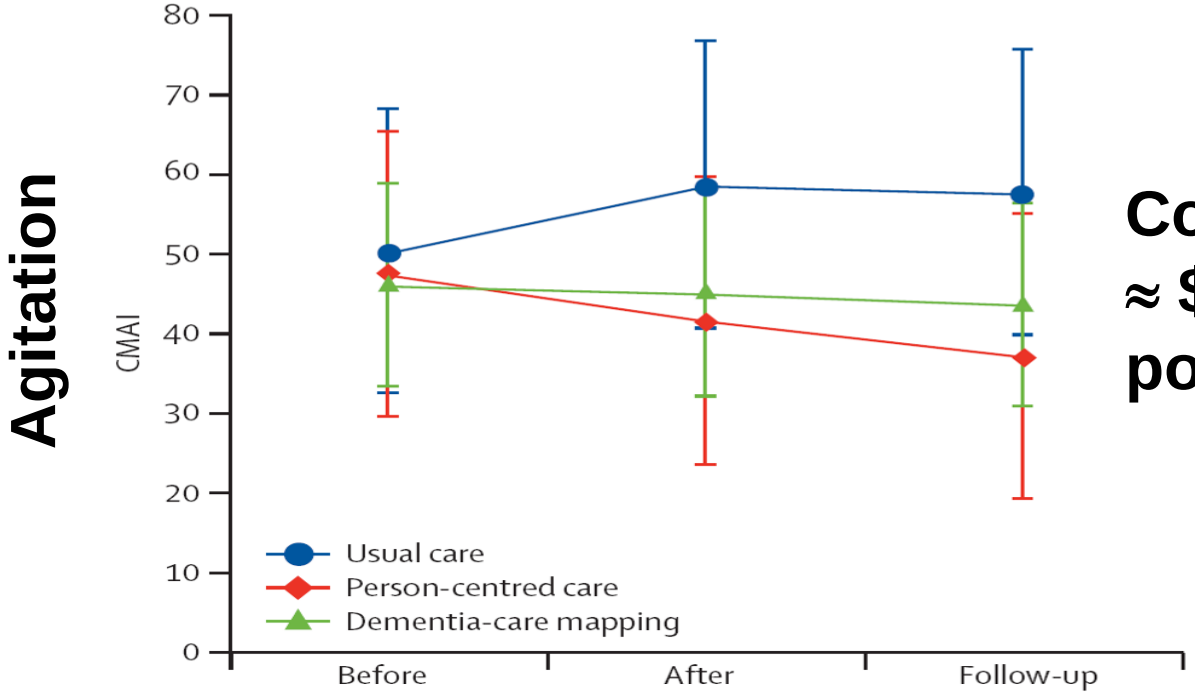


Dementia Care Mapping and Person Centred Care for agitation

Livingston G et al. Lancet, 2017

Dementia Care Mapping & Person Centred Care for agitation



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

Chenoweth L et al. *Lancet Neurol* 2009

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**

Depression

Antidepressants for depression

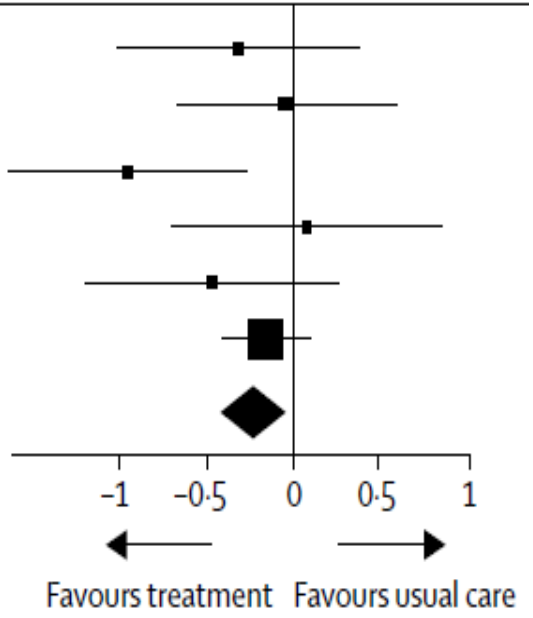
- DIADS 2: sertraline = placebo but > AEs; N 131
- HTA-SADD Trial; Sertraline, mirtazapine, PBO
  - No signif difference at 13 or 39 wks; N 507

Weintraub D et al. *Am J Geriatr Psychiatry* 2010;18:332-340; Banerjee S et al. *Lancet* 2011

Psychological treatment for depression

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 = 2·30 (p = 0·02)



Livingston et al. *Lancet* 2017

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Psychosocial interventions for BPSD: present

- Psychosocial Rx ≥ effective than drug Rx eg Depression [1]
- Drug Rx modest efficacy; significant AEs
  - eg antipsychotics - ↑CVA, mortality

[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] (Canada 1.1%)

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…
- 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

Personally tailored activities in LTC

- Specific models eg Montessori, PCC, person-based
- Offer >1 activity [8 studies, N 957] mod to severe dementia[1]
  - ↓agitation (CMAI, SMD −0.21, 95% CI −0.49 to 0.08)
  - ↑ positive affect (SMD 0.88, 95% CI 0.43 to 1.32)
  - Effects for engagement and QoL less clear
  - Little or no effects for negative affect, mood
- No specific model/ intervention superior

[1]Möhler R et al. *Cochrane Sys Rev* 2018

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

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]

[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)

Culture change models

- Eden Alternative, Green House, EverCare, Pioneer Network, the VIPS Practice Model, Planetree)
  - Diverse outcomes precluded strong conclusions re specific outcomes across models
  - Most positive findings for QoL rather than clinical measures, although trends
  - Concerns re resident inactivity and staff availability

[1]Petrewsky et al 2016a; [2]Petrewsky et al 2016b

Small-scale, homelike environments[1-7]

- OECD summary: promising results
  - ↑ resident QoL
  - ↓physical & chemical restraint use
  - ↑ family satisfaction & ↓ burden[1]
- Narrative review: Support autonomy, engagement in daily activities, informal social interaction & ↓ BPSD[5]

[1]OECD 2018; [2]Tolson et al. 2011; [3]Livingston et al. 2017; [4]Ausserhofer et al. 2016; [5]Chaudhury et al. 2017; [6]Kok et al. 2016; [7]Calkin M 2018

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**
- **Assistive technology**
- **Community care**
- **Staff training**
- **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 PLWD, 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