Psychosocial Research in Dementia: Past, Present, and Future

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Nutricia Advisory Board, Australia
What is psychosocial research?

- Psychosocial or Non-pharmacological\(^1\)-\(^3\)
- Maintaining or improving functionality, social relationships & well-being
- Not disease modification

Past → present → future

*Past* – describe, prevalence, measure, basic interventions

*Present* – menu of interventions, uncertainty of place

*Future* – precision medicine model, complementary, technology
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

- Cognitive behavioural interventions
  - Multi-domain
  - Physical activity
  - Cognitive training
  - Cognitive stimulation
  - Reminiscence
  - Cognitive Rehabilitation

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 Interventions.

- **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) \(^8\),\(^9\)

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Summary: Cogn\textsuperscript{n} & Behav. Interventions

- Physical training – physical & cognitive benefits\textsuperscript{1}
- Cog training – benefits for healthy older & MCI, limited evidence for people with dementia
- Multi-domain – ? greater benefit (Train the Brain\textsuperscript{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

\textsuperscript{1}McDermott et al. 2018; \textsuperscript{2}Maffei L et al. \textit{Nature Sci Rep.} 2017
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)
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

Zarit; Schulz; Seeher K & Brodaty H, in *Dementia 5th Ed* 2017, Ch 14, pp142-160
Caregivers: Predictors of negative effect

- **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

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

Mittelman et al. 2004

Five year follow-up
3 country study: NY counselling program in Manchester, NY, Sydney

Intervention for Caregivers

Meta analysis: 30 studies, 34 interventions

- 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 – 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

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$^1$
  $\text{ES} = 0.34 \ (95\% \text{CI}=0.20–0.48; \ z=4.87; \ p < 0.01)$

- Bonus: Interventions mildly effective for CGs$^1$
  $\text{ES} = 0.15 \ (95\% \text{CI}=0.04–0.26; \ z=2.76, \ p < 0.01)$

- At least $\equiv$ antipsychotic for delusions, aggression & agitation (ES 0.16)$^2$ or for total BPSD (ES 0.13)$^3$

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

- **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; 1/2 in China and India combined
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
• COGNISANCE Study: Co-designing dementia diagnosis and post-diagnostic care
Acute Care - challenges

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

1. 1.5 hours longer to analgesia after presentation to ED with long bone # (Fry M et al)
2. Discrimination against PWD eg rehab after #hip (Harvey L, Mitchell R et al)
3. 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
Behavioral and Psychological Symptoms

Alzheimer's Disease

Symptoms:
- Delusions
- Brain
- Age
- Confusion
- Memory Loss
- Irritability
- Dementia
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\(^3,4,5\)

\(^3\)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)\textsuperscript{1-3}

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

\textsuperscript{1}Moyle W, Jones C et al. 2017; \textsuperscript{2}Bemelmans R et al. 2012; \textsuperscript{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
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*\(^1-^7\)

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\(^1\)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
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
Humour 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

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
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

Psychological treatment for depression

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<th>Study or subgroup</th>
<th>Experimental</th>
<th>Control</th>
<th>Weight %</th>
<th>Mean difference IV, fixed (95% CI)</th>
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<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
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<td>4.3 (3.4)</td>
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<td>Total (95% CI)</td>
<td>5.05 (4.61)</td>
<td>5.77 (5.07)</td>
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Heterogeneity: $\chi^2 = 6.33$, df = 5 (p = 0.28); $I^2 = 21\%$
Test for overall effect: $Z = 2.30$ (p = 0.02)
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
Social elements and interventions

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

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

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

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

- Multi-generational living\(^3\); Dementia villages\(^4,5\)
- Systematic review (\(N = 19\) articles, 27 studies)\(^6,7\)
- Small-scale, homelike environments\(^8-10\)
- Outcomes diverse → no 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); \(^8\)OECD 2018; \(^9\)Chaudhury et al. 2017; \(^10\)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

- System changes

Micro

Meso ✓

Macro X

- 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
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