What is psychosocial research?

- Psychosocial or Non-pharmacological\textsuperscript{1-3}
- Maintaining or improving functionality, social relationships & well-being
- Not disease modification

\textsuperscript{1}Moniz-Cook E, Vernooij-Dassen M, Woods M, et al. 2011; \textsuperscript{2}Livingston G, Kelly L, Lewis-Holmes E, et al. 2014; \textsuperscript{3}Scales 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

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) \(^8\), \(^9\)

\(^1\)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; \(^9\)Garcia-Casal et al. 2017
Summary: Cogn & 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

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

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 vs 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

BDI II Score

Control group
Counselling group

5 sessions of counseling

Months

BDI II Score

6
7
8
9
10

3 6 9 12 15 18 21 24

Intervention for Caregivers

Meta analysis: 30 studies, 34 interventions

- 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 – 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\(^7\)

\(^{1}\text{Schulz R, Gerontologist 2003; } ^{2}\text{Burgio L 2003; } ^{3}\text{Burns R 2003; } ^{4}\text{Eisdorfer C 2003; } ^{5}\text{Gallagher-Thompson D 2003; } ^{6}\text{Gitlin L 2003; } ^{7}\text{Elliott AF, JAGS 2010}\)
STrAtegies for RelaTives (START)

- 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 BPSD**

- 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)\(^3\)

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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 Ll.
Summary of CGs: Present

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

www.alz.co.uk/1066
Summary of CGs: Future

- Personalised intervention
  - > specific goals, > targeting
  - ... better match of PWLD, CG & intervention
- Integration of social media, e-health for monitoring & intervention
Behavioral and Psychological Symptoms

- Alzheimer's
- Dementia
- Memory Loss
- Irritability
- Depression
- Age
- Delusion
- Brain
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

Psychological approaches to BPSD

- Music therapy
- Snoezelen
- Sensory stimulation

Useful during treatment but not long term

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 $\approx 6$ to reduce a point on CMAI

Novel strategies

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

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 BPSD: present

- Psychosocial Rx > effective than drug Rx eg Depn
- Drug Rx modest efficacy; significant AEs
  - eg antipsychotics - ↑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%\textsuperscript{2}

**Diagnosed dementia prevalence\textsuperscript{1,2}**

- Nursing homes 50-80%
- Assisted living 45-67%
  
  …but most likely more
- 90%+ have BPSD\textsuperscript{3}

\textsuperscript{1}Harris-Kojetin L, National Center for Health Statistics. Vital Health Stat 3(38). 2016;
\textsuperscript{2}OECD. OECD Health Policy Studies. Paris: OECD Publishing, 2018
\textsuperscript{3}Brodaty et al, 2003 Int Psychoger
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
Interventions to improve communication, activities, & sensory interventions, approach are first-line therapy

Evidence of benefits eg agitation, affect

No specific intervention superior

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
**Environment**

- Supportive, therapeutic, prosthetic vs debilitating
- Institution $\rightarrow$ home-like
- Person centred, smaller scale $\rightarrow$ 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 environment²

Innovative environments

- Multi-generational living\(^3\); Dementia villages\(^4,5\)
- Systematic review \((N = 19 \text{ articles, 27 studies})\)\(^6,7\)
- 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

- 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

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