Caregiver Mediated Intervention
Trumps Pharmacotheraphy for BPSD

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Assessment and Better Care

Translating dementia research into practice
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Dementia – not only a memory problem!

Behavioural & Psychological Symptoms of Dementia (BPSD)

- Depression
- Delusions
- Hallucinations
- Aggression
- Wandering
- Apathy
- Agitation

⇒ BPSD ubiquitous >90%
Acronyms & abbreviations

- BPSD = Behavioural and psychological symptoms of dementia
- CG = caregiver (aka carer)
- CR = care recipient
- PWD = person with dementia
- BMT = behaviour management therapy
- Sig = significant
Prevalence of BPSD

• PWD up to 40x > rates of BPSD than rest of age matched population\(^1\)
• 61% any NPI disturbance\(^1\); Mean NPI = 7
• 32% severe disturbance \(^1\) (NPI \(\geq 6\))
  – Delusions: AD > VaD;
  – Depression: VaD > AD
• Rates just as high in developing countries\(^2\)
• Rates >90% in nursing homes\(^3\)

\(^1\)Lyketsos et al 2000; \(^2\)Prince M et al 2004; \(^3\)Brodaty et al, 2001
Effects of BPSD

• BPSD increase the cost of caring for a person with dementia in an institution\(^1\)
• BPSD increase nurse stress, especially aggression\(^2\) & calling out\(^3\)
• Residents with BPSD are more likely to\(^4\):
  – be physically restrained, receive antipsychotic medication, negatively influence care staff & other residents

\(^1\)O’Brien JA, Shomphe LA, Caro JJ 2000; \(^2\)Rodney, 2000; \(^3\)Draper et al, 2000
\(^4\)Maslow K 1994
Effects of BPSD

- Greatest burden on family
  CG is BPSD$^{1,2}$
- Predicts CG decision to institutionalise PWD$^{3,4}$

Limited drug efficacy

• Can have adverse effects
• Antipsychotic drugs associated with increased risk of stroke and death\textsuperscript{1-3}
• Little effect of antidepressants\textsuperscript{4}

\textsuperscript{1}Schneider et al. (2005). \textit{JAMA}, 294(15), 1934-1943.
\textsuperscript{3}Brodaty et al. (2003). \textit{J Clin Psychiatry}. 64(2), 134-143.
Non-pharmacotherapy intervention

- Demonstrated effectiveness in residential care
- CG intervention reduce stress$^{1,2}$
- Modest efficacy comparable to psychotropics but w/o adverse effects$^3$
- Most studies in residential care, not community

Non-pharmacological interventions in residential care

- Person-centred care
- Dementia Care Mapping
- Massage, lavender, music
- Pets, Snoezelen
- Individual attention
- Environment
What is efficacy of CG interventions in community on BPSD?
Systematic review criteria

- Peer reviewed, English language
- Non-pharmacological interventions
- Outcomes relevant to BPSD
- >5 participants with dementia diagnosis
- Primary CG = family member living w/ PWD
- For principal analysis – control group
- Exclude review papers & respite care
Systematic Review: Results

1568 relevant articles based on title & abstract

74 retrieved for full review

30 relevant articles

32 relevant articles

22 met all review criteria

1494 excluded based on title & abstract

44 articles excluded, did not meet criteria

2 articles included: reference list & recommended

6 articles excluded due to insufficient outcome information to calculate effect sizes

4 articles that did not meet NHMRC criteria for Level II or Level III-1 evidence were excluded
Results

• 22 studies met all criteria
• Categorised into 6 groups
  1. Skills training for CG
  2. Education for CG
  3. Occupational therapist led intervention for CG
  4. Enhancing support for CG
  5. Self-care techniques for CG
  6. Miscellaneous
1. Skills training for CG

- Better management of BPSD
- Better communication with CR
- Using role play, videos modelling management, vignettes, live interviews
- Enhancing CR quality of life
  - (eg increasing pleasant events)
1. Skills training for CG

• Gormley et al. (2001): Education & aggressive behaviour management training
  – 4 in-home sessions over 8 weeks
• Outcomes: CR aggressive behaviour & overall behavioural problems
• Results: Sig reduction in aggressive behaviour score for treatment group (controlling for baseline aggression)

Gormley et al. (2001). *Age and Ageing*, 30(2), 141-145
2. Education for CG

- Psychoeducation
- Improved homecare
- Tailored advice/recommendations
- Problem solving methods
- Improving support network
- Computer mediated automated voice response
- Planning, legal, financial
2. Education for CG

- Teri et al. (2005): CG taught communication strategies & BMT, enhanced CG support
  - 8 weeks plus 4 months phone support
- Outcomes: frequency & severity of problem behaviours, CG reactions to behaviours
- Results: Significantly reduced frequency & severity of problem behaviours
  - Significantly improved CG reactions to CR problem behaviours

3. Occupational therapist led intervention

• Planning activities with CG for CR
• Modifying CR physical and social environment
3. Occupational therapist led intervention

- Graf et al. (2007): CR taught to use compensatory/environmental strategies to improve performance of daily activities
  - OT in 10 sessions over 5 wks
- Outcomes: CR mood (depression)
- Results: CR mood (depression) was significantly improved

4. Enhancing support for CG

- Social support
- Web/phone support
- Strategies on how to access support
- Family counselling
4. Enhancing support for CG

- Belle et al. (2006): Education & support for CG
  - In-home & phone sessions: 12 sessions, 6 months
- Outcomes: change in problem behaviours
- Results: Significant improvement in problem behaviours for Hispanic/Latino group (ns for white & African-American groups)

5. Self-care techniques for CG

- Health management
- Stress management
- Coping with change as a result of caregiving
- Music therapy
- Counselling
5. Self-care techniques for CG

- OT prescribed plan for managing problem behaviours & CG self-care, skill building
  - Up to 11 home/phone contacts over 16 wks
- Outcomes: change in frequency of most distressing behaviour; CG upset & confidence in managing behaviour; overall CG upset
- Results: Significant improved target behaviour,
  - reduced upset & enhanced confidence
  - less overall upset with all behaviours

6. Miscellaneous

- Collaborative care with a health professional/care manager
- Exercise for care recipient
6. Miscellaneous

- Teri et al. (2003): Exercise for CR; CG taught Behaviour Management Therapy & education on dementia
- Outcomes: CR depressive symptoms, delay in institutionalisation, CG distress
- Results:
  - sig reduced rates of CR depression
  - 2 yr trend for sig less institutionalisation due to behavioural disturbance

Resources for Enhancing Alzheimer's Caregiver Health (REACH) II intervention for CGs

- Multicomponent using a variety of interventions
- 6 year study conducted over 6 locations in US
- RCT with Hispanic/Latino, Caucasian/White and Black/African American carers (N=642)

REACH II intervention for CGs

• Intervention in English or Spanish by certified interventionists (> bachelor’s degree)
• Over 6 months:
  • 12 sessions = 9 x 1.5 hours in-home
  • 3 x 0.5 hours telephone
  • PLUS 5x structured telephone support group sessions

REACH II intervention for CGs

• Participants given resource notebooks with educational materials and ...
• Telephones with display screens linked to a computer-integrated telephone system to information and facilitate group support conference calling
REACH II intervention for CGs

- **Intervention included:**
  - Provision of information
  - Didactic instruction
  - Role playing
  - Skills training including focus on BPSD
  - Stress management
  - Telephone support

- **Control:**
  - Minimal support
  - No skills training
  - No component focused on BPSD

REACH II BPSD intervention for CGs

1. Provide educational materials on symptoms of dementia and managing behaviours
2. Structured problem solving and brainstorming specific strategies
3. Provide written behavioural prescriptions that specify step-by-step strategies to manage BPSD
4. Demonstrate and practise strategies, role-play
5. Refer to computerised telephone system

REACH II intervention for CGs: Findings

• Compared to controls, significant improvements in
  – CG depression, burden, self-care, social support
  – CR (care recipient) problem behaviours
• …for Caucasian and Hispanic carers, but not African Americans (except for spouses)

REACH OUT for CGs

- Modified feasible REACH II
- Hepburn et al – CG reaction↓ and burden ↓\(^1\)
- Burgio et al - pre-post test in social service agency, 236 dyads \(^2\)
- Significant ↓ BPSD
- Positive effects on CG burden, social support, frustration, depression and health

\(^2\) Burgio LD et al, 2009. Gerontologist; 49(1): 103-16
Family CBT for AD – 14 sessions

Carer education: 3 sessions
• Carer’s knowledge of dementia

Stress management: 6 sessions
• Eg self-monitoring, relaxation training, cognitive and behavioural responses

Coping skills training: 5 sessions
• advice and role-playing of > effective ways of coping with problem behaviours & loss

Marriott A et al, 2000
Family CBT for AD

• Single session of discussion & expression of feelings is comparatively ineffective
• Information/education alone little impact
• Focused combined cognitive-behavioural and educational intervention ↓ CG stress
• Modest reduction in behavioural disturbances

Marriott A et al, 2000
Family CBT intervention for AD

Results: GHQ levels

Marriott et al. (2000)
CGs administer behavioural therapy for depression to pts with AD ¹

- Behaviour therapies (pleasurable events schedule or problem solving techniques) improved pt depression - symptoms and diagnoses - better than control conditions
- Improvements maintained at 6 months
- **Bonus**: CGs’ depression better (BTs > Controls)

¹Teri et al, J. Gerontol. 1997; 52B:159-166
STAR-C: CGs trained by community consultants to minimise BPSD

- Randomised-controlled trial of 95 pt-CG dyads with 6 masters-level health care professionals
- Intervention: CG training w consultant (STAR-C)
  - ABC approach, improving CG communication, ↑ pleasant events, enhance caregiver support
  - Structured but tailored to needs
- Control: Routine medical care
- 8 wkly in-home sessions+ 4x monthly phone calls

STAR-C: Findings

• Consultants successfully implemented behavioural intervention with family CGs
• STAR-C training showed sig improvements in CG depression, burden, sleep, QoL
• 62% improvements in CG reactivity
• 57% ↓ frequency of BPSD
• 52% ↓ in BPSD severity
• Results were maintained at 6-month follow-up.
Structured behaviour problem-solving techniques for CGs¹

• Psychosocial group program for 4.5 months
• Intervention: education, communication techniques and structured problem-solving to handle neuropsychiatric symptoms
• For whole group no significant improvement
• For female CRs significant improvement

¹Ulstein et al, Dement Geriatr Cogn Disord 2007;24:469–475
In-home behaviour management program (IHBMP) - Chinese CGs

- Training modules on behaviour management, unhelpful thoughts, communication, directives for end-of-life & shared pleasant activities
- 16 wks, < 9 OT and 2 RN visits
- 8wks maintenance, 3x OT tel calls
Pilot in-home behaviour management program (IHBMP)

- Control group: telephone support
- Treatment modified to recognise Chinese cultural values and include other family members
IHBMP on Chinese CGs: findings

• No improvement in stress BUT compared to telephone-support, CGs in IHBMP:
  - had ↓ depressed
  - were less bothered by caregiving-specific stress (i.e. memory and BPSD)
In-home training for CGs to manage BPSD

- Occupational therapist led over 11 home and telephone contacts vs no intervention
- Intervention:
  - education, communication techniques,
  - physical & social environment modifications
  - stress reduction and self-care techniques

Gitlin et al JAGS 58:1465–1474, 2010
In-home training for CGs to manage BPSD

- For BPSD: significant improvement in target behaviour
- For CGs: ↓ upset with BPSD; ↑ confidence in managing problem behaviour and ↓ overall upset with all occurring problem behaviours.
- CGs reported significantly ↓ burden, ↓ negative communication, ↓ depression and ↑ well-being

Gitlin et al JAGS 58:1465–1474, 2010
Findings?
What is a meta-analysis?

• Statistical technique for combining multiple studies

• Effect size = way of standardising measurement
  – 0.2 = small
  – 0.5 = moderate
  – 0.8 = large
Caregiver Outcomes

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<th>Study or Subgroup</th>
<th>Std. Mean Difference</th>
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Total (95% CI)

Heterogeneity: $\tau^2 = 0.05$; $\text{Chi}^2 = 46.79$, df = 17 ($P = 0.0001$); $I^2 = 64$

Test for overall effect: $Z = 0.70$ ($P = 0.49$)

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Interpretation

- CG interventions can significantly reduce BPSD
  - ES = 0.46 (95% CI = 0.24-0.68), significant
- Interventions less effective for CG outcomes
  - ES = 0.05 (95% CI = -0.09-0.18), not significant
- At least comparable to ES of antipsychotics on
  - delusions, aggression and agitation ES = 0.16\(^1\)
  - BPSD generally 0.13\(^2\)

\(^1\) Schneider et al. (2006). *Am J Ger Psychiat*, 14(3), 191-210
Limitations

• Categorisation of interventions
• Different BPSD may differ in response
• Based on grouping of group data
  – Finer grained questions
  – Which intervention for which problem with which CG for which CR
Which elements are effective?

- Structured and ….
- Tailored to needs of CG and CR
- In home
- OT? RN?
- Minimum “dose”
- Booster sessions – telephone
Which CGs benefit most?

• Those with:
  – least previous input
  – coping with difficult behaviours
  – most depression, distress

• Which CRs benefit most?
  – ???
Conclusions

• Psychosocial interventions can reduce BPSD in residential care
• AND in community
• Working with carers = intervention at least as powerful as drugs without side effects
Implications

• More programs in partnership with CGs
• Tailored to needs
• In home supplemented by telephone boosters; group calls may help
• New technologies – internet based interventions being developed
• Evidence for te
Implications

- Role for Alzheimer’s Australia & DoHA
- More programs in partnership with CGs
- Tailored to needs
- In home; supplemented by telephone boosters; group calls may help
- Timing – before or after BPSD develop?
Simply sensational - Sydney in September – a must

Sydney, Australia
22 & 23 September 2011

National Dementia Research Forum
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Translating dementia research into practice
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