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Effective Caregiver Interventions

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With thanks to
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Why intervene with Caregivers?

- **Psychosocial effects¹**
- **Effects on CGs are main predictor of nursing home placement²**
- **CGs' and patients' psychological state linked³**



¹Brodaty & Green (in Dementia 3rd Ed, 2005); ²Brodaty et al (1993);
³Brodaty & Luscombe (1998)

Negative Effects of Caregiving¹

There are positive CG effects, however the negative effects can be:

- Psychological (e.g. depression)
 - Physical (eg immune function, BP↑)
 - Social (eg isolation)
 - Financial
- ▽ ↑ use of health services

¹Brodaty H, Green A. Family caregivers for people with dementia: Carer burden and stress, in O'Brien J, Ames D, Burns A (eds), *Dementia*. 3rd Edition. Chapman & Hall, London, (2005).

Psychosocial Interventions

- **Counselling, skills training CBT and behavioural management training shown to:**
 - **reduce CG stress/burden¹**
 - **improve physical activity levels²**
 - **increase immune response³ and**
 - **decrease depression^{4,5}**

Mittelman (2004); ²Castro et al (2002); ³Vedhara et al (2003);
Mittelman et al (2004); ⁵Teri et al (1997)

Psychosocial Interventions

- **Information provision**
 - **Education and**
 - **Support groups alone**
-have limited efficacy in reducing CG stress^{1, 2}**

¹Brodaty et al, 1992; Marriott et al, 2001

Other CG Interventions

Decreased CG burden, depression or psychological wellbeing has also been found for:

- **Multicomponent interventions^{1 2}**
- **Tailored interventions¹**
- **Interventions incorporating cognitive (e.g. problem solving) and/or social components³**

¹Gitlin et al (2003) Psychol Aging;

²Acton, Kang (2001) Research in Nursing & Health;

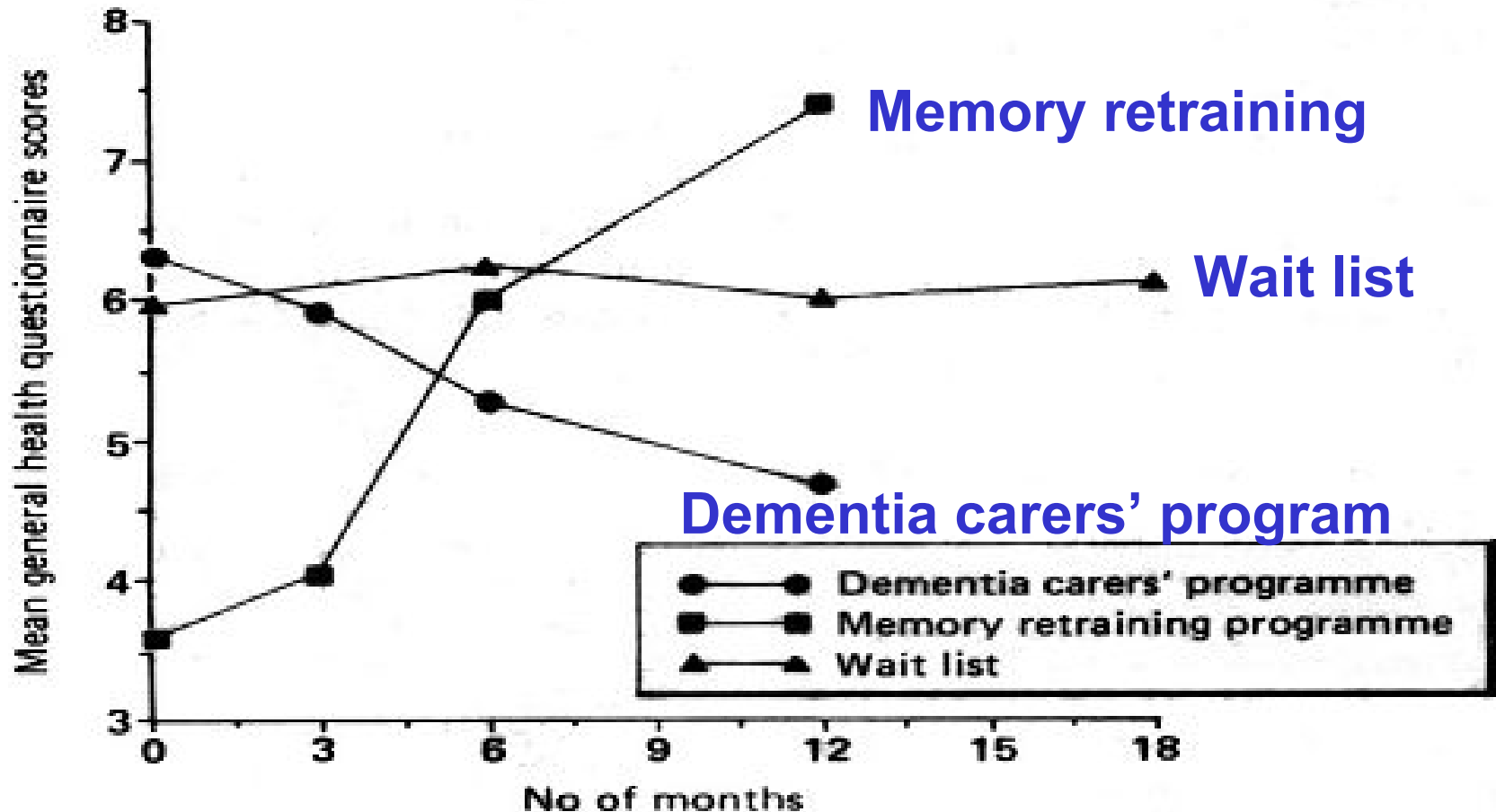
³Cooke et al (2001) Aging & Ment. Health

The Dementia CGs' Program¹

- Ten day program for patients and CGs
- Intensive, comprehensive
- Psychological counselling
- Information, education
- Skills training
- Involvement of patient
- Involvement of extended family
- Follow-up contact and telephone booster sessions over one year

¹Brodaty and Gresham (1989), Brit Med J; 299: 1375-1379

The Dementia CGs' Program Results: GHQ



Brodaty and Gresham (1989)

Dementia Carers Program: survival at home over 7 years

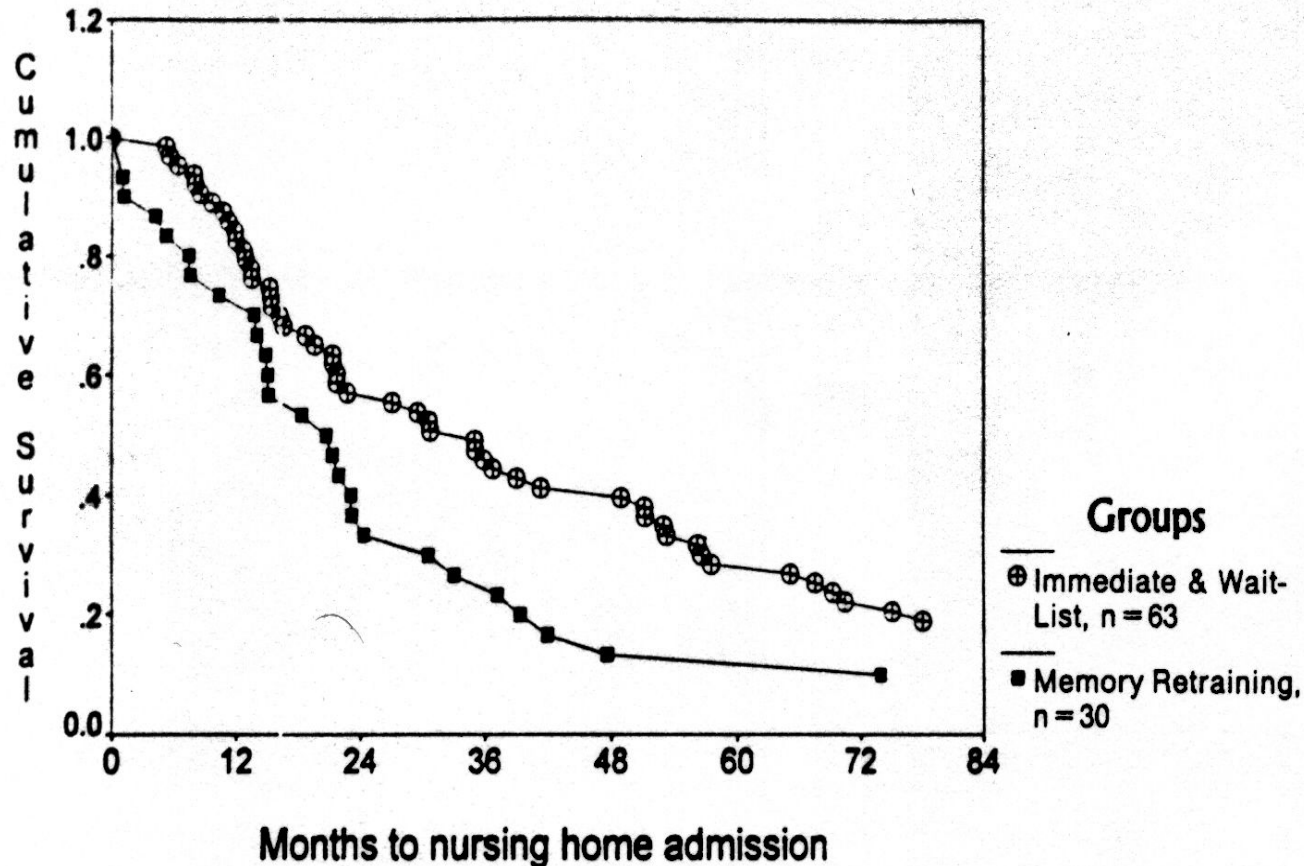


Figure 2. Kaplan-Meier survival functions for nursing home admission comparing the combined training groups with the memory retraining group

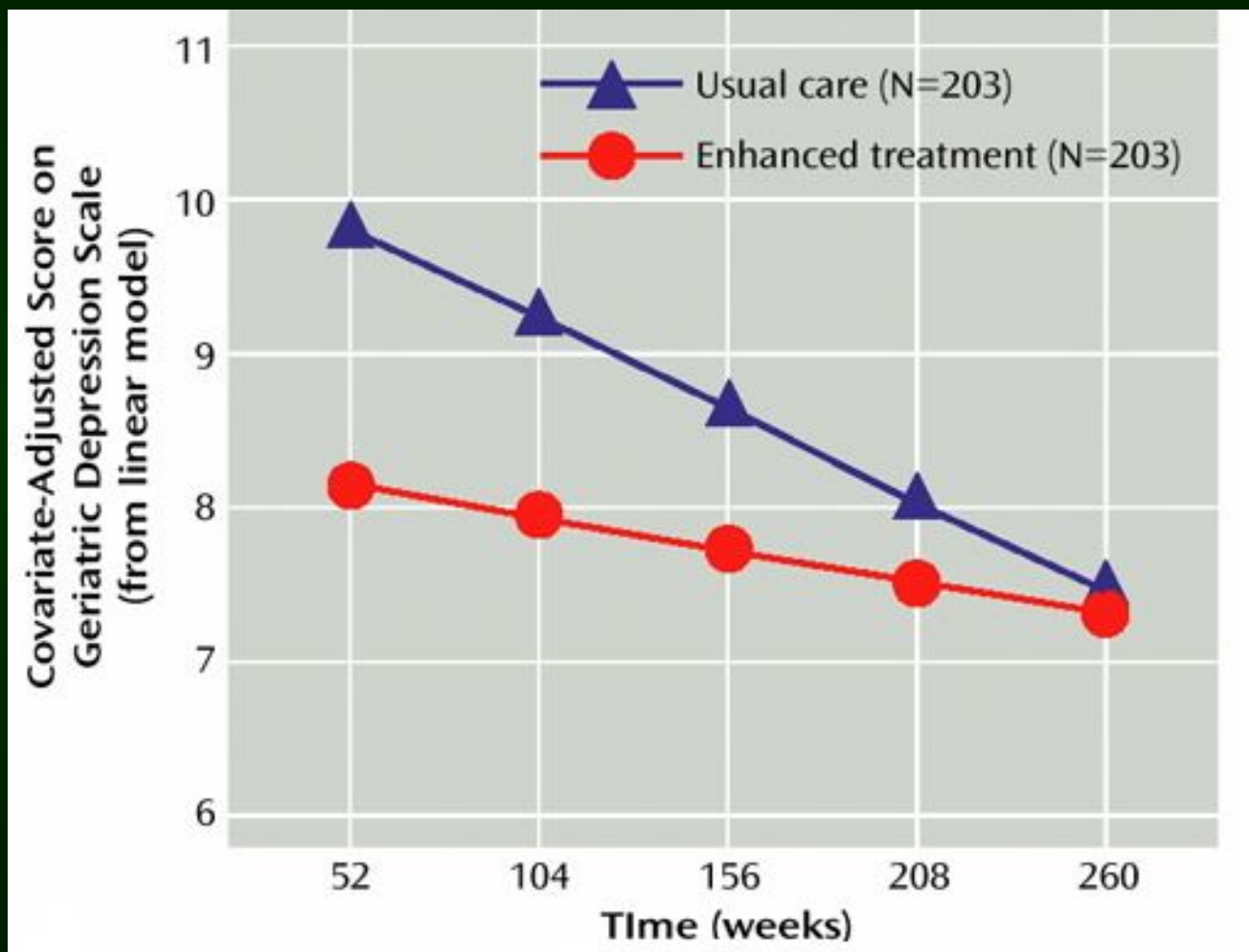
Long Term Effect of the NYU Spouse-Caregiver Intervention on Symptoms of Depression¹

- **2 individual + 4 family counselling sessions tailored to each specific situation**
- **Weekly group support sessions**
- **Ad hoc counselling available when needed**
- **Primary focus:**
 - **Increasing support for the spouse-CG from other family members**

¹Mittelman et al. (1995), *Gerontologist*; 35: 792-802

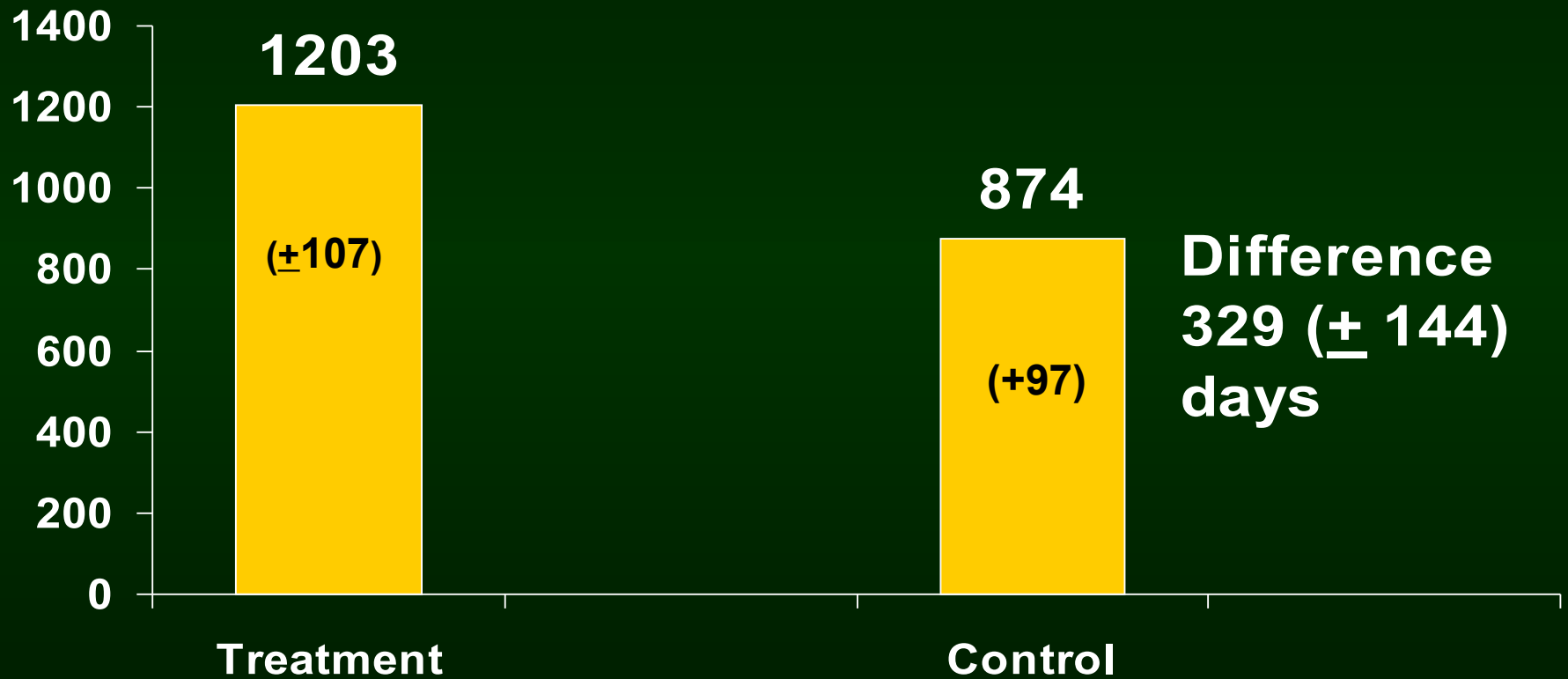
Sustained benefits of the NYU Spouse-Caregiver Intervention on Symptoms of Depression¹

Five year follow-up



¹Mittelman et al. (2004)

Median time before nursing home placement (Mittelman et al. 1993)



Family CBT intervention for AD¹

- **Based on schizophrenia intervention:**
 - **stress vulnerability family coping skills model**
- **2 control groups: No interview; In-depth I/V**
- **Three components to family intervention:**
 - 1. CG education**
 - 2. Stress management**
 - 3. Coping skills training**
- **14 Sessions, 1 every 2 weeks**

¹Marriot et al. (2000), *British J Psychiatry*; 176: 557-562

Family CBT intervention for AD

CG education: 3 sessions

- CG's knowledge of dementia assessed

Stress management: 6 sessions

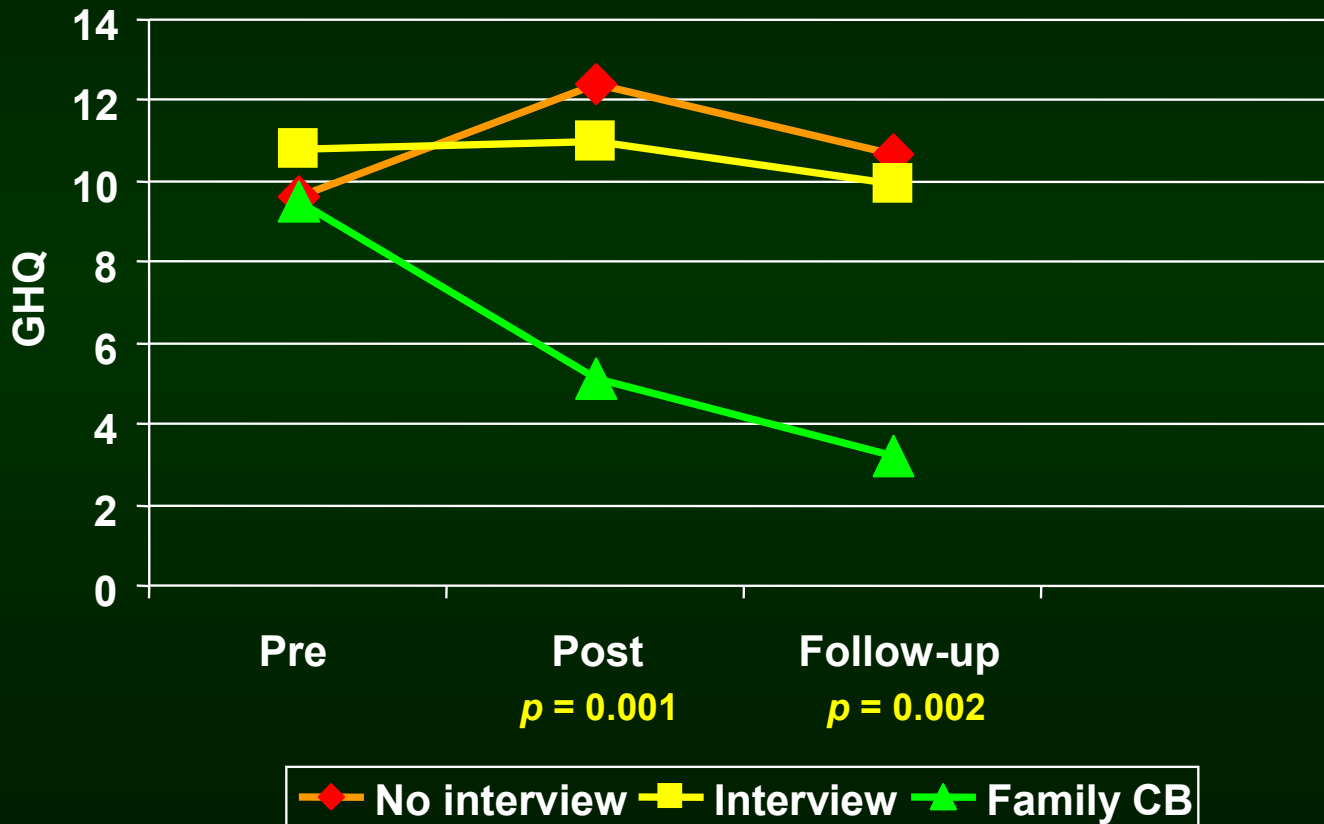
- eg self-monitoring, relaxation training, cognitive and behavioural responses

Coping skills training: 5 sessions

- advice and role-playing of more effective ways of coping with problem behaviours; coping with loss

Family CBT intervention for AD

Results: GHQ levels



Marriot et al. (2000)

Family CBT intervention for AD

Conclusions:

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

Marriot et al. (2000)

Meta-Analysis of Psychosocial Interventions (Brodaty et al. 2003)



- **30 studies (34 interventions)**
- **Setting: home or non-institutional**
- **Participants: Informal CGs**
- **Primary outcomes:**
 - **psychological morbidity**
 - **burden**
 - **knowledge**

Meta-Analysis of Psychosocial Interventions (Brodaty et al. 2003)

- **Significant benefits for**
 - **CG psychological distress**
 - **knowledge**
 - **any main CG outcome**
 - **patient mood**
- **No difference in CG burden**
- **4 studies showed delayed nursing home admission**

Meta-Analysis of Psychosocial Interventions (Brodaty et al. 2003)

Common elements of successful programs:

- Involvement of patient as well as CG**
- Involvement of the whole family**
- Intervention of sufficient duration and intensity**
- Anecdotally, having consistency and flexibility when helping the CG**

Meta-Analysis of CG Interventions (Sorensen et al. 2002)¹

- **78 studies of interventions for CG of *older adults***
- **6 intervention types:**
 - 1. Psychoeducational (38)**
 - 2. Supportive (7)**
 - 3. Respite/Adult day care (13)**
 - 4. Psychotherapy (10)**
 - 5. Interventions to improve CR competence (6)**
 - 6. Multicomponent (12)**

¹Sorensen et al. (2002), *Gerontologist*, 42(3); 356-372

Meta-Analysis of CG Interventions (Sorensen et al. 2002)¹

- **CG interventions taken together produced significant improvement in each of the 6 outcome measures for pre-post tests (uplifts only significant at $p < .10$)**
- **At follow up, CG burden, depression, subjective well being, ability/knowledge were significantly improved**

¹Sorensen et al. (2002), Gerontologist, 42(3); 356-372

Meta-Analysis of CG Interventions (Sorensen et al. 2002)¹

- **Psychoeducational or psychotherapy interventions had significant effects on all outcome measures**
- **Other intervention types had significant effect on at least some (but not all) outcome measures**
- **Most effects persist 7 months on average**
- **Choice of intervention setting should be based on the goals**

¹Sorensen et al. (2002), *Gerontologist*, 42(3); 356-372

Meta-Analysis of CG Interventions (Sorensen et al. 2002)¹

RESULTS 3 (Intervention Characteristics)

- **Group interventions were less effective at improving CG burden and well-being, but more effective at reducing CR Sx**
- **The longer the intervention, the larger the improvement in CG depression, but smaller improvement in ability/knowledge**
- **Interventions < effective if CR had dementia**

¹Sorensen et al. (2002), Gerontologist, 42(3); 356-372

Meta-Analysis of CG Interventions (Sorensen et al. 2002)¹

CONCLUSIONS

- **Providing psychoeducational, psychotherapy or multicomponent interventions = most effective for improving CG well-being in the short term**
- **Clinicians should decide their goals in advance (eg interventions of 7-9 sessions adequate to increase ability/knowledge, but too short to alleviate depression)**

¹Sorensen et al. (2002), *Gerontologist*, 42(3); 356-372

Meta-Analysis of CG Interventions (Sorensen et al. 2002)¹



CONCLUSIONS cont...

- Choice of intervention setting should be based on the goals of the intervention (eg individual intervention better for CG subjective well-being vs group better for CR symptoms)



¹Sorensen et al. (2002), *Gerontologist*, 42(3); 356-372

Pinquart and Sorenson 2006¹

- **Meta-analysis of 127 intervention studies with dementia CGs (1982 - 2005)**
- **Significant but small effects on burden, depression, subjective well-being, ability/knowledge, symptoms of CR**
- **Not on institutionalisation risk**

¹Pinquart & Sorensen (2006) International Psychogeriatrics

Pinquart and Sorenson 2006¹

- **Active CG participation → broadest effects**
- **CBT, support, counselling, day care, and CR training effects → domain-specific**
- **Multi-component interventions had no significant effect on outcome measure**
- **Effect sizes varied by study characteristics, such as CG gender and year of publication**
- **As most interventions domain-specific outcomes, clinicians must tailor interventions according to the specific needs of the individual caregivers**

Pinquart and Sorenson 2006¹

- **As most interventions domain-specific outcomes, clinicians must tailor interventions according to the specific needs of the individual caregivers**
- **More recent interventions showed stronger effects**
- **Room for improvement of interventions esp. of multi-component interventions**

¹Pinquart & Sorensen (2006) International Psychogeriatrics

Selwood et al (submitted)

- **Systematic review of 62 psychological CG interventions**
- **Excellent evidence for efficacy of 6+ sessions of individual behavioral management therapy centered on CRs' behaviour in ↓ CG symptoms for up to 32 months**

Selwood et al (submitted)

- **Teaching CGs coping strategies (individual or group) effective in ↑ CG psychological health**
- **Effectiveness of group interventions < individual interventions**
- **Education about dementia, group behavioural therapy, or supportive therapy not effective**

Meta-meta-analysis

Why differences?

- **How interventions categorised eg Sydney study = group BT or multimodal intervention**
- **Grouping of studies**
- **Grouping of outcome measures**
- **Numbers of studies, exclusions**
- **Years of studies included**

How CG interventions help

- More knowledge
- New skills
- ✓ ↑ Coping strategies
- Recruit > supporters
- Support from intervention
- Changing appraisals of stressors
- Reduce BPSD
- Reduce CG depression



Next stage CG intervention research

- **Dichotomy: psychosocial vs drug**
- **Until recently pharma ignored CGs in their research**
- **Most protocols still do not measure CG outcomes despite.....**

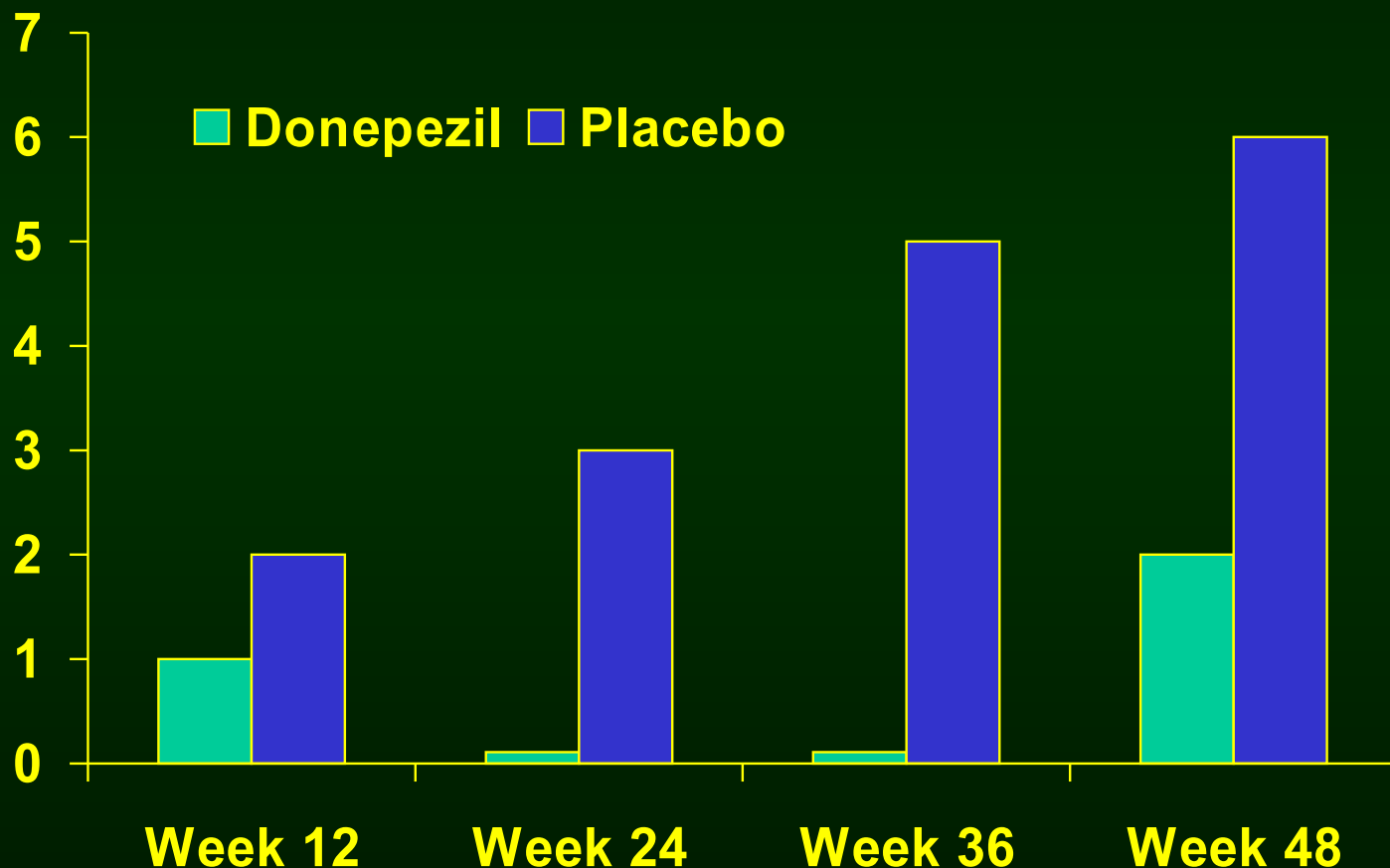
CGs and Pharmacotherapy

- **Cholinesterase inhibitors for people with dementia ↓ time spent caring and ↓ CG burden/distress¹**
- **This may be achieved through less functional dependence and reduced behavioural disturbances^{2 3 4 5}**
- **Pharmacotherapy also → hope**

¹Tariot and Truyen (2001); ²Cummings et al. (2004);

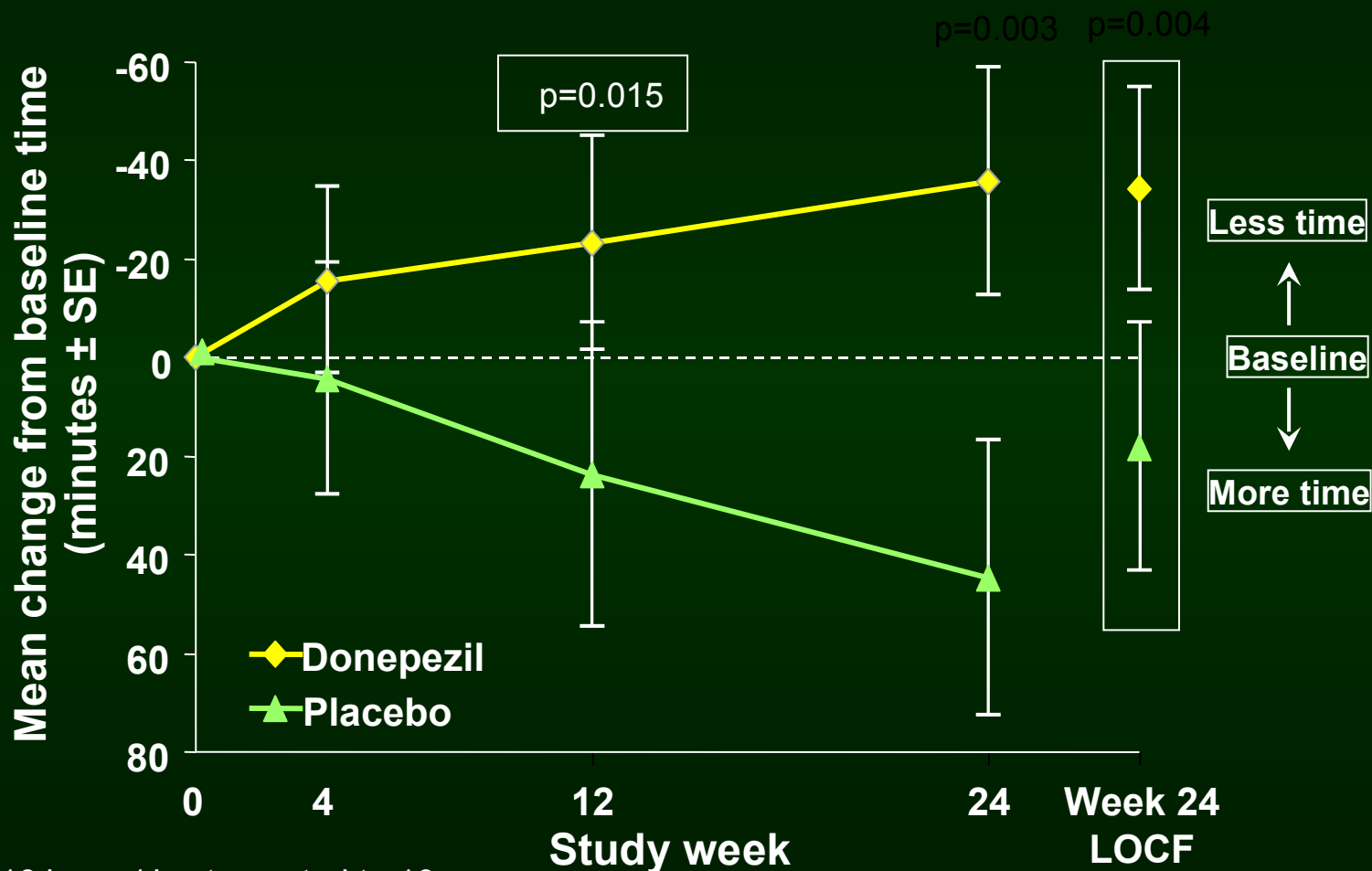
³Fillit et al. (2000); ⁴Matthews et al. (2000); ⁵Feldman et al. (2003)

% Caregivers spending \geq 16 hrs/day giving care



Mastey V, Wimo A, Winblad B et al. (2001), Poster presented at the 14th Meeting of the American Association of Geriatric Psychiatry, San Francisco

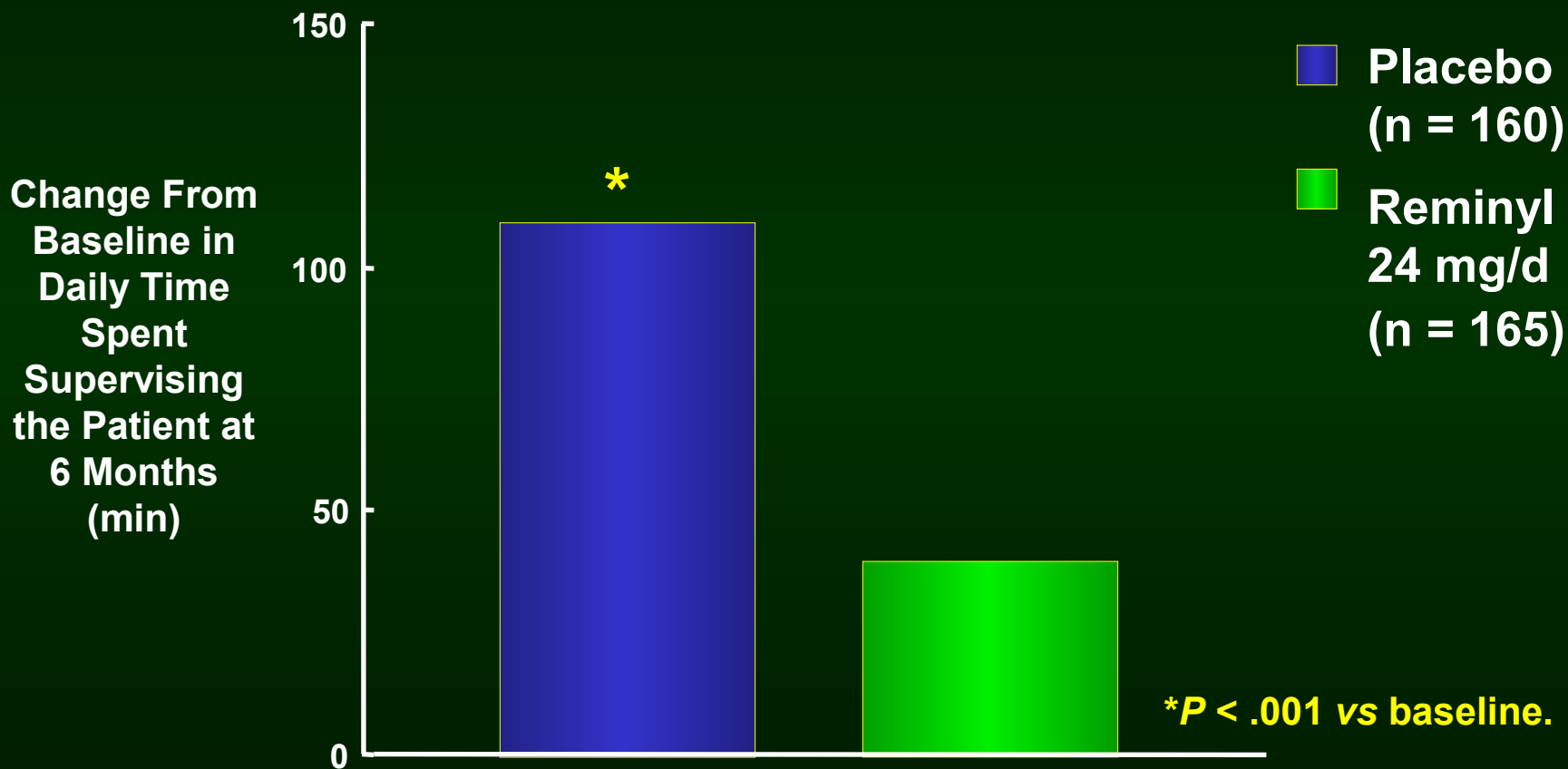
Aggregate Caregiver Time for Basic & Instrumental ADL



All times >16 hours/day truncated to 16 hours/day
P-value based on Wilcoxon rank sum

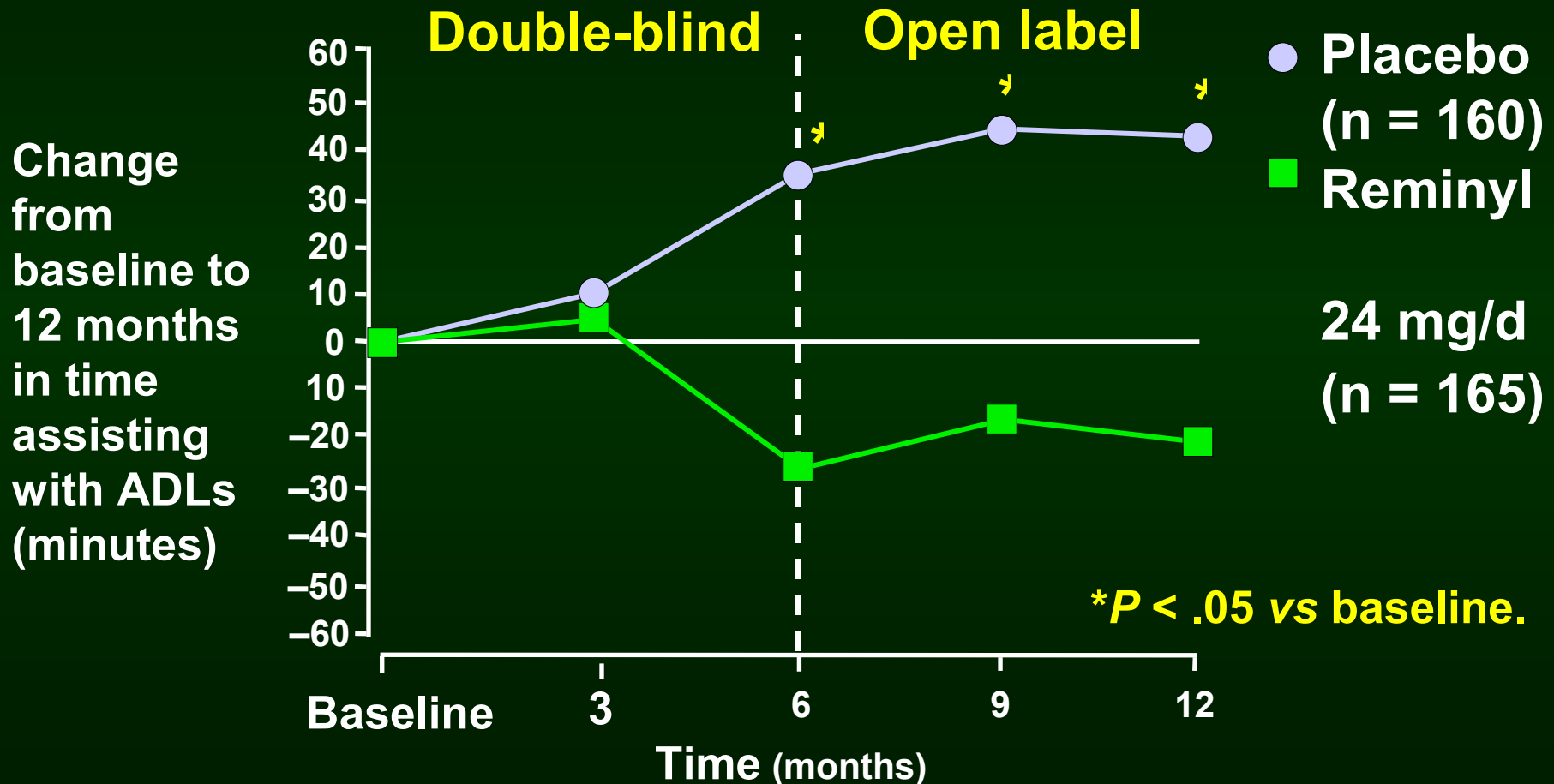
Feldman H et al *JAGS* 51; 737-741; 2003

Caregivers and galantamine - time supervising PWD



Wilcock & Lilienfeld (2000), Poster presented at the 7th International World Alzheimer Congress, Washington, DC, 9-18 July

Caregivers and galantamine - time on ADLs



Lilienfeld & Gaens (2000), Poster presented at the 5th Congress of the European Federation of Neurological Societies, Copenhagen, Denmark, 14-18 October

Caregivers and Donepezil¹



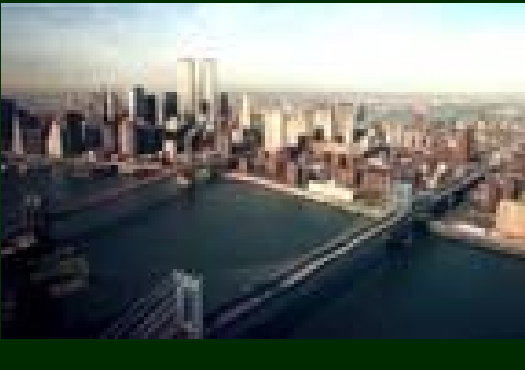
- Point prevalence survey of CGs of patients on donepezil (≥ 9 months) compared to matched CGs of patients not on donepezil
- CGs of patients on donepezil significantly $<$ subjective distress
- No difference between groups on demand scale (time spent caring)

¹Howard et al. *International Psychogeriatrics* (2000)

The three country study: Aricept ± counselling



Manchester, UK - Alistair Burns



New York, USA - Mary Mittelman

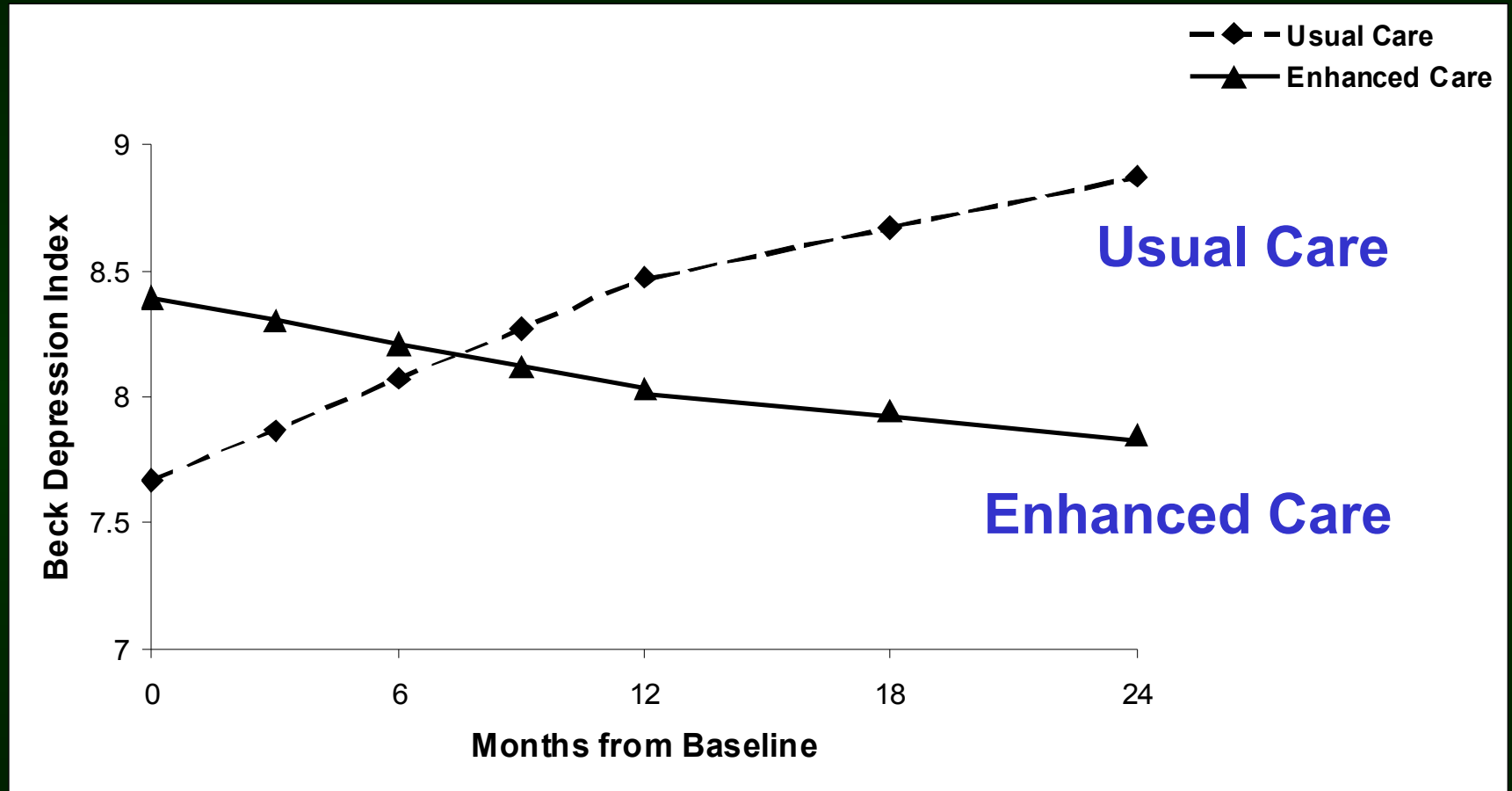


Sydney, Australia - Henry Brodaty

3 Country Study

- **156 CR-CG dyads, \approx 50+ per site**
- **RCT, all patients on donepezil**
- **50% of CGs receive 1# of individual and 4# of family counselling**
- **Follow-up 3 monthly for 12 m and then 6 monthly for further 12 months**

The 3 Country Study: Caregiver Depression



The treatment group started off more depressed than control group and ended up less depressed

Other CG interventions

- **Alzheimer's Associations**
- **Respite Care**
- **Drug treatments for CGs**

Future research

- **Difficulty applying drug trial paradigm to psychosocial interventions**
- **Avoid floor effects**
- **Options**
 - **Omnibus - something for everyone**
 - **Match CG (&PWD) to intervention (& vv)**
 - **Individualise outcome measure eg GAS**

Conclusions 1

- **CG interventions have modest efficacy**
 - Reducing CG distress/ psychological morbidity
 - Decreasing CG burden
 - Improving CG knowledge
 - Delaying NH admission
- **Combinations of pharmacotherapy + CG intervention may be more effective**

Conclusions 2



Tailoring interventions

- **What - type; single or in combination?**
- **Who - spouse, child?; only distressed CGs?**
- **When - early, late?**
- **Context - individual, group**
- **Mechanism of success**