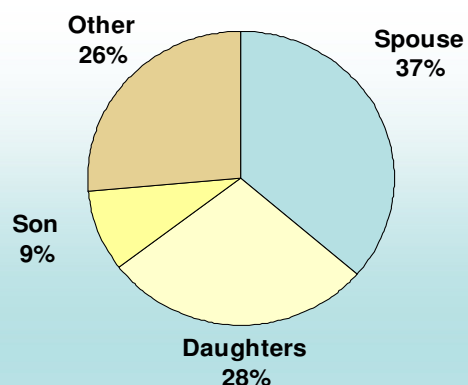


# Assessing Caregiver Outcomes in Cost-Effectiveness Clinical Trials in AD

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## Caregiving in Alzheimer's Disease



- 94% of community patients are cared for by family / friends
- 70% caregivers are women

Canadian Study of Health and Aging, *Can J Aging* 1994

## Caregiver Burden in Alzheimer's Disease

### Health-related

- Stress
- Sleep Disorders
- Fatigue
- Anxiety
- Depression
- Immunosuppression
- Use of anxiolytics, hypnotics, antidepressants

### Social

- Loneliness
- Little or no social life
- Few holidays or breaks

### Financial

- Wage loss
- Out-of-pocket expenses estimated to be \$10-35,000/year

Hux et al., *Can Med Assoc J* 1998; Rice et al., *Am J Manag Care* 2001

## Predictors of Caregiver Burden

- Patient Characteristics
  - Severity of Cognitive Impairment, Disruptive Behaviour (Depression, Aggression), Age (young), Gender (male)
- Caregiver Characteristics
  - Age (younger), Gender (female), Education (lower), Income (lower), Relationship to Patient (child), Years Caregiving (more)

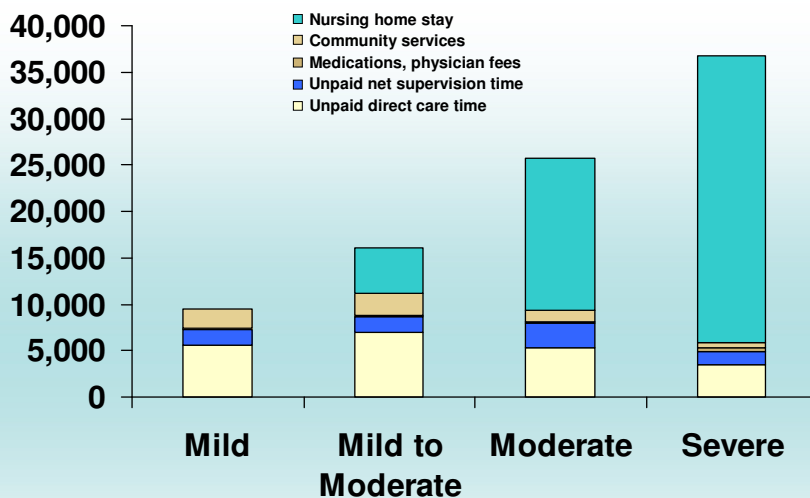
*Reviewed by Torti et al (2004)*

## Economic Relevance of Caregiver Outcomes

- Key component of the cost of AD
  - Overall costs of AD:
    - Direct (health care resources)
      - Diagnostic tests, medications, acute hospital care, physician visits, home health care, nursing home care
    - **Indirect (non-health care resources)**
      - Support services (paid caregivers), family (unpaid caregiver) time
  - Excessive burden could lead to earlier institutionalization
  - Societal and payer perspectives

*Neumann et al (1997)*

## Mean annual cost of AD by disease severity



Hux et al., *Can Med Assoc J* 1998

## BPSD Impact Unpaid Caregiver Time

- Prominent neuropsychiatric symptoms (NPI  $\geq$  13) increase caregiver time by 3.5 hours per day
- \$3,162-\$5,919 (USD) increase in direct costs for NPI  $\geq$  13 vs  $<$ 13 (wage replacement method)
  - Driven predominantly by
    - Increased caregiving time: \$21,524 vs \$11,451 USD
    - Higher long-term care costs: \$7,550 vs \$ 3,123 USD
    - Minimal Impact: medications, physician time
- Monthly incremental cost of a one-point increase in NPI score is \$18 per month (95% CI \$6-\$29)

*Herrmann et al 2006; Murman & Colenda, 2005*

## Measuring Caregiver Outcomes

## What to Measure

- Caregiver Burden
- Time Use
- Sociodemographic Characteristics
- Psychological Morbidity

*Hagerty-Lingler et al (2005)*

## Caregiver Burden

- Neuropsychiatric Inventory—Caregiver Distress Score (NPI-C)
  - Caregiver appraisals of distress in response to 12 behaviours
- Screen for Caregiver Burden (SCB)
  - Subjective and objective burden
  - Validated against theoretical model of caregiver stress
- Zarit Burden Interview
  - Social consequences, psychological burden, feelings of guilt
- Relative Stress Scale
  - Personal distress, life upset, negative feelings associated with caregiving role

*Hagerty-Lingler et al (2005)*

## Caregiver Time

- Allocation of Caregiver Time Survey
- Caregiver Activity Time Survey (CATS)
- IADL Scale—Plus
- Physical Self-Maintenance Scale
- Resource Utilization in Dementia Questionnaire
  
- All assess informal caregiver time spent assisting in ADLs and IADLs

*Hagerty-Lingler et al (2005)*

## Importance of Caregiver Characteristics

- Caregiver characteristics affect level of burden
  - Age (younger)
  - Gender (female)
  - Relationship to Patient (close kinship: spouses, children)
  - Marital Status (single)
  - Duration Caring for Patient (long)
  - Coresidence with Patient (together>separate)
- need for standardized reporting of CG characteristics

## Caregiver Burden and Patient Outcomes

- Most patient-specific outcome measures are based on caregiver input, which can be affected by burden
  - Behavioural or Neuropsychiatric Symptomatology
  - Functional Status for ADL Performance
  - Global Functioning
  - Resource Utilization

**Current Findings**

## Current Findings—Cognitive Enhancers & Caregiver Burden

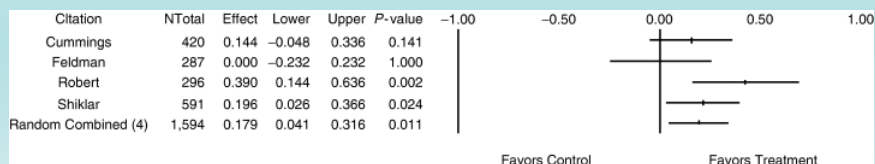
Author	n	Drug	Weeks	Outcome
Cummings, 2004	978	galantamine	21	NPI-D
Feldman, 2003	290	donepezil	24	CSS
Robert, 1999	296	donepezil	12	RSS
Shiklar, 2000	591	metrifonate	26	SCB, PD
Wilcock, 2003	182	galantamine	52	SCB

- In addition, 5 open-label trials of ChEIs with caregiver burden as an outcome

*Hagerty-Lingler et al (2005)*

## Current Findings—Cognitive Enhancers & Caregiver Burden

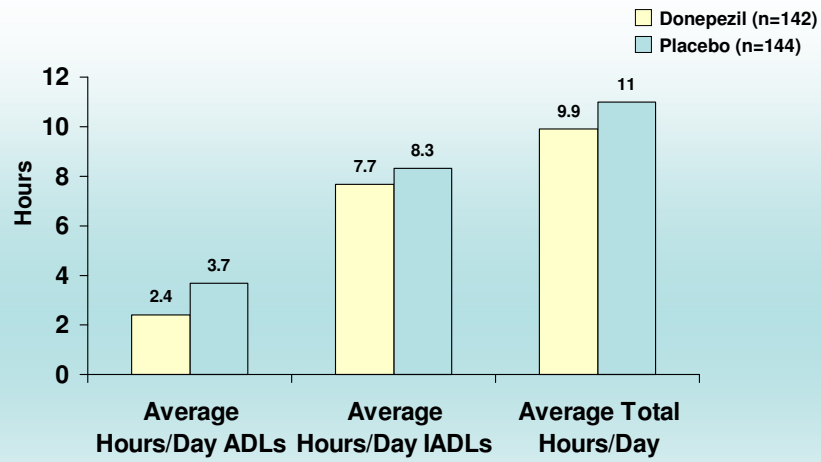
- Significant benefit of ChEIs on caregiver burden
- Small effect size ( $d=0.18$ )
- Different measures used to assess burden across studies



*Hagerty-Lingler et al (2005)*

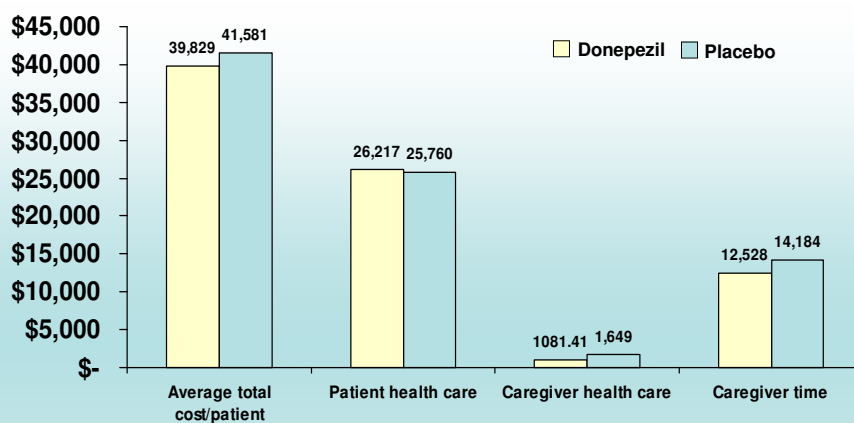


## Caregiver Time



Mastey et al., *Am J Geriatr Psychiatr* 2001

## Caregiver Benefits of ChEIs



### Key Message

Treatment demonstrates caregiver benefits

Wimo et al., *Neurobiol Aging* 2000

## Caregiver Interventions

- Individual Counselling & Support Groups:
  - Reduced depression, increased time to institutionalization by 329 days
- Case Management & Subsidized Community Services
  - Little effect on burden and no effect on time to institutionalization
- Education, Psycho-Education, Respite
  - No significant effect on caregiver burden or time to institutionalization in a meta-analysis of 27 studies including 1,254 caregivers of dementia patients

*Reviewed by Torti et al 2004*

## Summary

- Caregiver outcomes are a key component of the societal costs of AD
- Caregiver outcomes depend on patient and caregiver characteristics
- Various instruments to measure caregiver burden & time
- Cognitive enhancers have a small benefit on caregiver burden & time

## Disclosures

- Research Support:
  - Astra Zeneca, Bayer, Elan, Eli Lilly, Janssen, Lundbeck, Neurochem, Pfizer
- Honoraria:
  - BMS, Pfizer, Janssen, Wyeth
- Peer-Reviewed Funding:
  - Alz Assoc, Alz Soc Canada, Am Health Assistance Fdn, Physicians Services Inc, Ontario Mental Health Fdn, Heart & Stroke Fdn