Outcome Measures Involving Caregiver Burden

Prepared for:

IMMPACT-XVII (*OMERPACT*)
Assessment of Physical Function in Analgesic Clinical Trials
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Caregiver Burden Overview

Definition and Framing Questions

Epidemiology

Diagnostic Strategies/Assessment

Measurement of the Effects of Interventions on CB

Considerations

Caregiver Burden: **Definition**
The multidimensional toll

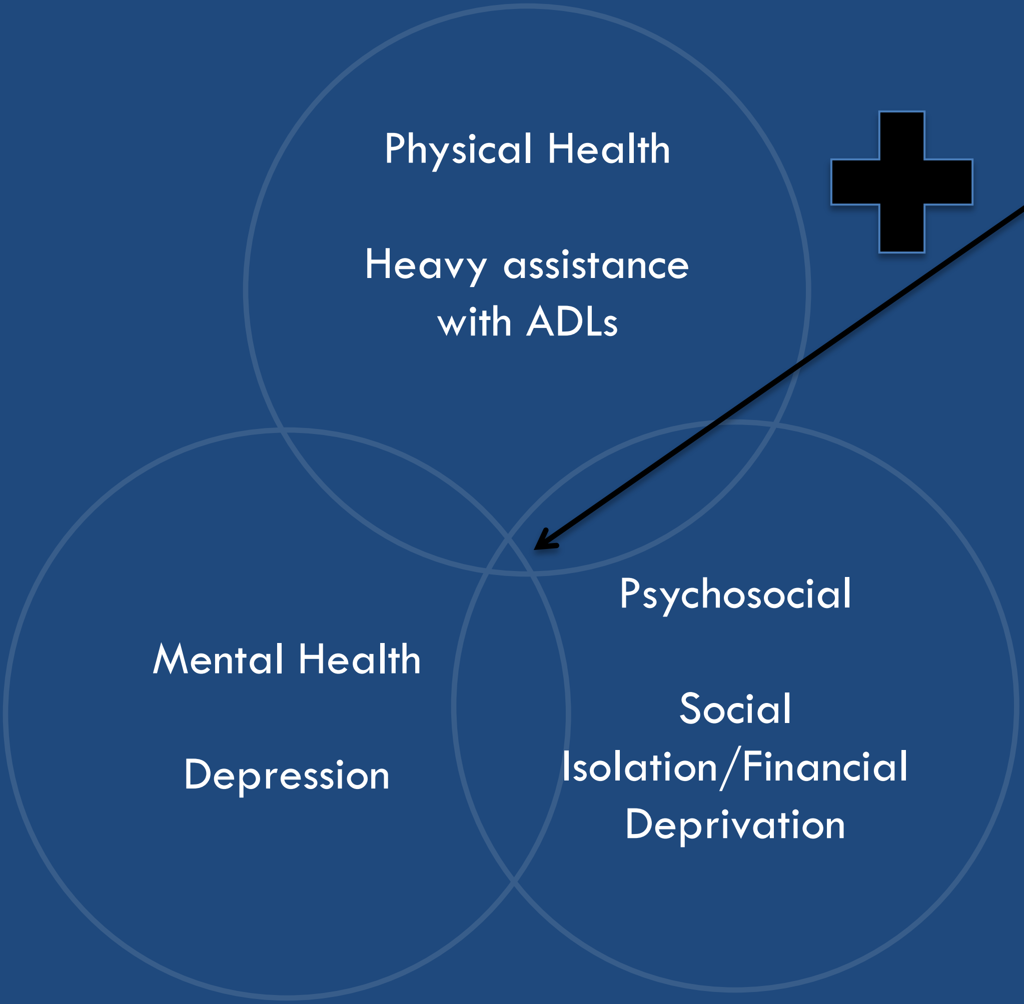
Extent to which caregivers perceive that care giving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning.

Consensus criteria: unpaid

Variable criteria: type of assistance, extent of assistance

Zarit SH et al. Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist*. 1986; 26(3):260-266

Multidimensional Assessment



Physical Health

Heavy assistance with ADLs

Mental Health

Depression

Psychosocial

Social Isolation/Financial Deprivation

Central Questions

To what extent is a patient's pain-related loss of (physical function) reflected in measures of caregiver burden?

To what extent, if any, should patients be exposed to the risks of a therapy intended primarily or secondarily to ease the burden of others-- the friends and family that care for them?

IMMPACT μετάφραση
How is this formulated in terms of clinical trials methods, measurement, pain assessment?

Is it feasible to quantify the amount of time a caregiver saves and the reduced burden borne by caring for a relative or friend with less pain in the intervention/drug/device- treated group v placebo group

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Unpaid or informal caregivers provide ~90% of the in home long term care needed by adults or children

65.7 million unpaid caregivers to adult or child (66% for an adult >50)

32% of caregivers endorse a **high** burden ; 19% endorse a **medium** burden based on time and care recipient's degree of dependency

IOM *Retooling for an aging America: building the healthcare workforce.* 2008
AARP *Caregiving in the United States* 2009
Hurd MD et al Monetary costs of dementia in the United States. NEJM. 2013;368(14)1326-1334

Epidemiology

86% are women caring for a relative; 14% friend

Average time per week : 20.5 hours; 20% spend >40 hours

Cost of informal dementia caregiving $56, 290 per patient per year

IOM *Retooling for an aging America: building the healthcare workforce.* 2008
AARP *Caregiving in the United States* 2009
Hurd MD et al Monetary costs of dementia in the United States. NEJM. 2013;368(14)1326-1334

Risk Factors/Outcomes for Caregiver Burden

Demographic

- Female (>2 fold)
- Low educational level
- Cohabitation with recipient

Clinical Outcomes

- Independent predictor of caregiver mortality (63% increased risk of death)
- Weight Loss, low self care behaviors
- Sleep deprivation

Psychosocial

- Depression –risk factor for and an outcome of
- Social isolation, reduced # of coping strategies, anxiety (advanced Ca) , suicide

Caregiving Context

- Longer duration and more hours
- Financial stress
- Lack of choice
- Inability to continue regular employment

Schulz R et al Caregiving as a risk factor for mortality: the Caregiver Health Effects Study *JAMA.* 1999;282(23)2215-2219

Rodakowski J et al. Role of social support in predicting caregiver burden. *Arch Phys Med Rehabil* 2012;92(12):2229-2236

Caregiver burden study populations emphasize three homogeneous diagnostic groups that may limit extrapolations to people with chronic pain

- Alzheimer Disease and Related Dementias
- Stroke
- *Cancer*

Alzheimer’s disease is the index condition for studying caregiver burden

- Anxiety, depression, chronic fatigue, sleep problems, and high blood pressure are all common among caregivers of patients with AD
- Clinical intuition led investigators to speculate the ChEI (anti-dementia treatment) would have a beneficial effect on caregivers

Broaty H et al Prevalence and predictors of burden in caregivers of people with dementia *Am J Psychiatry* 2013

Harmell AL et al. The relationship between self efficacy and resting blood pressure in spousal Alzheimer’s caregivers. *Br J Health Psychol* 2011;16(Pt 2):317-328

Are the study populations and underlying conditions in which caregiver burden have been studied relevant to chronic pain?

Key Parallels with Dementia

- Highly prevalent/older Population/costly
- Engagement of neural targets may have indirect benefits beyond symptomatic relief
- Analgesics (like ChEIs) may have a favorable effect on complex and inter- related variables of patient and caregiver quality of life, burden, and caregiver resource utilization

Key Contrasts with Dementia

- ADRD trials rely, in part, upon caregiver input to measure patient-specific outcomes (diagnostic role)
- Different behaviors in AD (delusions, hallucinations, aggression) than chronic pain (catastrophizing)
- Drugs for AD more about reducing dysfunction in a **progressive degenerative** condition rather than improving function

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Interventions in Clinical Practice

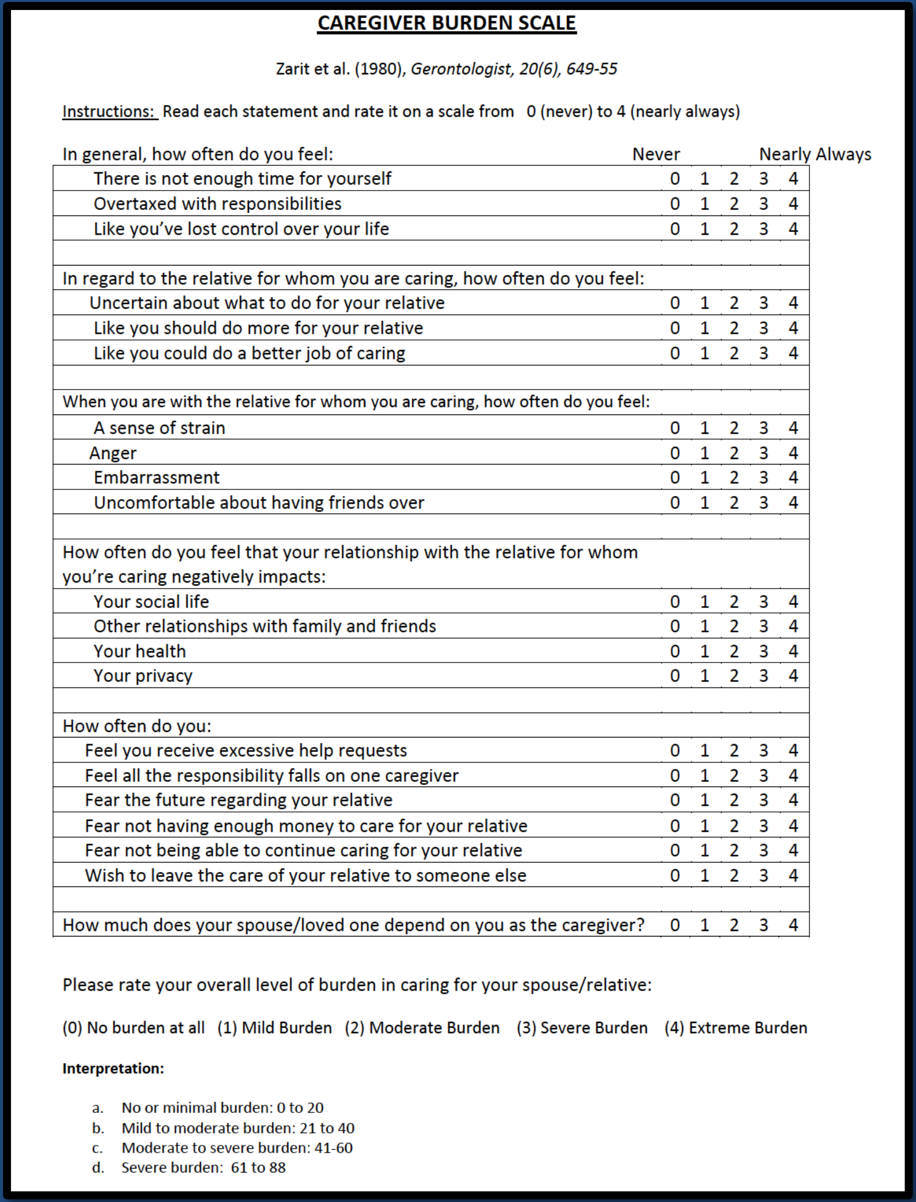
Measures of Caregiver Burden

- Zarit Burden Interview (ZBI)
- Caregiver Assessment Tool (CAT)
- Caregiver Stress Scale (CSS)
- Caregiver Burden Screen (CBS)
- Screen for Caregiver Burden (SCB)
- Research School of Social Sciences (RSS)
- NPI-D Neuropsychiatric Inventory caregiver distress scale (5+)

- Recent meta-analyses and systemic reviews (cancer =1;dementia=7)
- Extensive observational literature

Adelman RD Caregiver Burden A Clinical Review JAMA 2014; 311(10):1052-1059

Zarit: the most commonly used measure of **burden**



CAREGIVER BURDEN SCALE

Zarit et al. (1980), *Gerontologist, 20(6), 649-55*

Instructions: Read each statement and rate it on a scale from 0 (never) to 4 (nearly always)

In general, how often do you feel:	Never				Nearly Always
There is not enough time for yourself	0	1	2	3	4
Overtaxed with responsibilities	0	1	2	3	4
Like you've lost control over your life	0	1	2	3	4
In regard to the relative for whom you are caring, how often do you feel:					
Uncertain about what to do for your relative	0	1	2	3	4
Like you should do more for your relative	0	1	2	3	4
Like you could do a better job of caring	0	1	2	3	4
When you are with the relative for whom you are caring, how often do you feel:					
A sense of strain	0	1	2	3	4
Anger	0	1	2	3	4
Embarrassment	0	1	2	3	4
Uncomfortable about having friends over	0	1	2	3	4
How often do you feel that your relationship with the relative for whom you're caring negatively impacts:					
Your social life	0	1	2	3	4
Other relationships with family and friends	0	1	2	3	4
Your health	0	1	2	3	4
Your privacy	0	1	2	3	4
How often do you:					
Feel you receive excessive help requests	0	1	2	3	4
Feel all the responsibility falls on one caregiver	0	1	2	3	4
Fear the future regarding your relative	0	1	2	3	4
Fear not having enough money to care for your relative	0	1	2	3	4
Fear not being able to continue caring for your relative	0	1	2	3	4
Wish to leave the care of your relative to someone else	0	1	2	3	4
How much does your spouse/loved one depend on you as the caregiver?	0	1	2	3	4

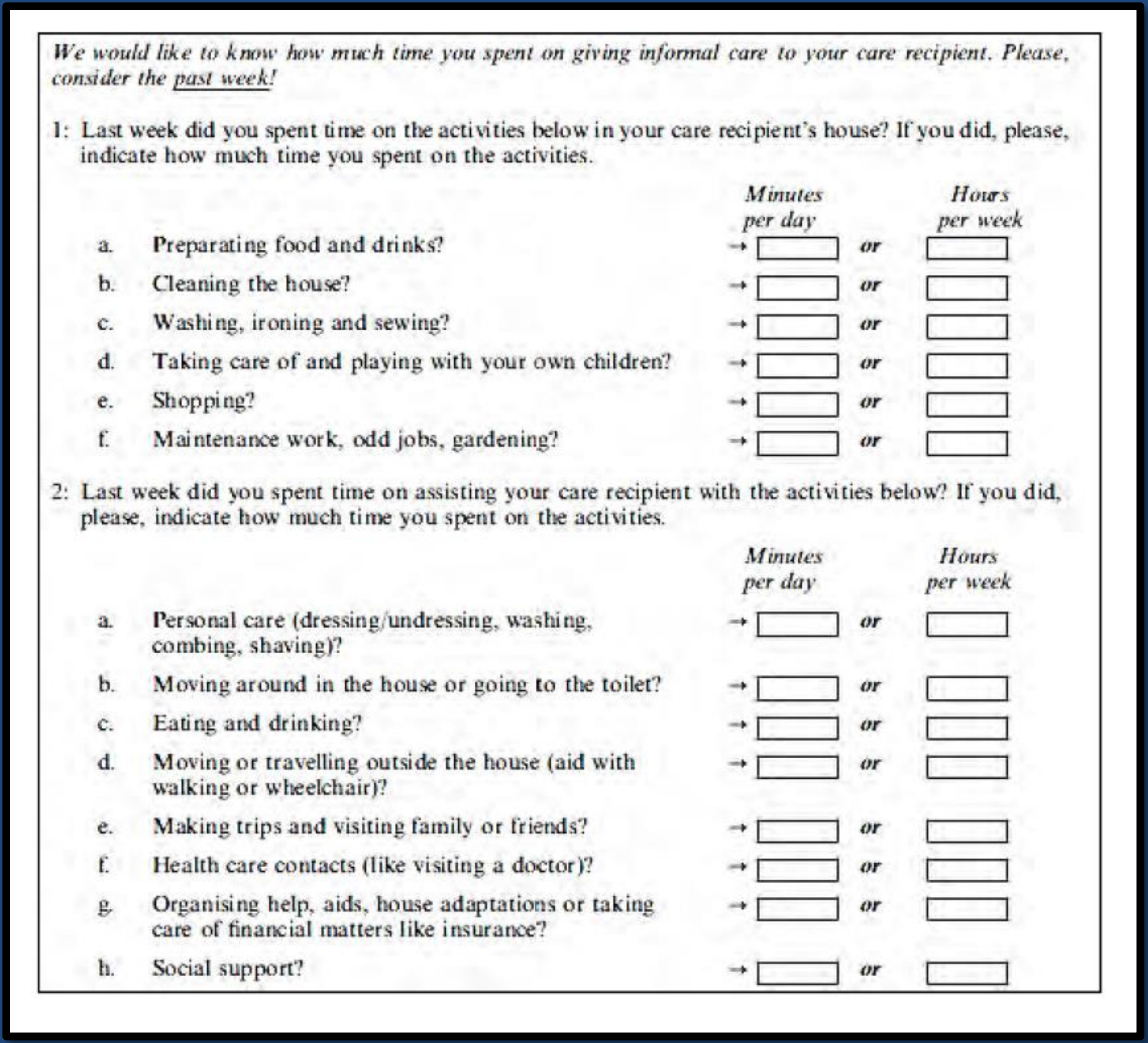
Please rate your overall level of burden in caring for your spouse/relative:

(0) No burden at all (1) Mild Burden (2) Moderate Burden (3) Severe Burden (4) Extreme Burden

Interpretation:

a. No or minimal burden: 0 to 20
b. Mild to moderate burden: 21 to 40
c. Moderate to severe burden: 41-60
d. Severe burden: 61 to 88

Measures of active time use by informal caregivers



We would like to know how much time you spent on giving informal care to your care recipient. Please, consider the past week!

1: Last week did you spent time on the activities below in your care recipient's house? If you did, please, indicate how much time you spent on the activities.

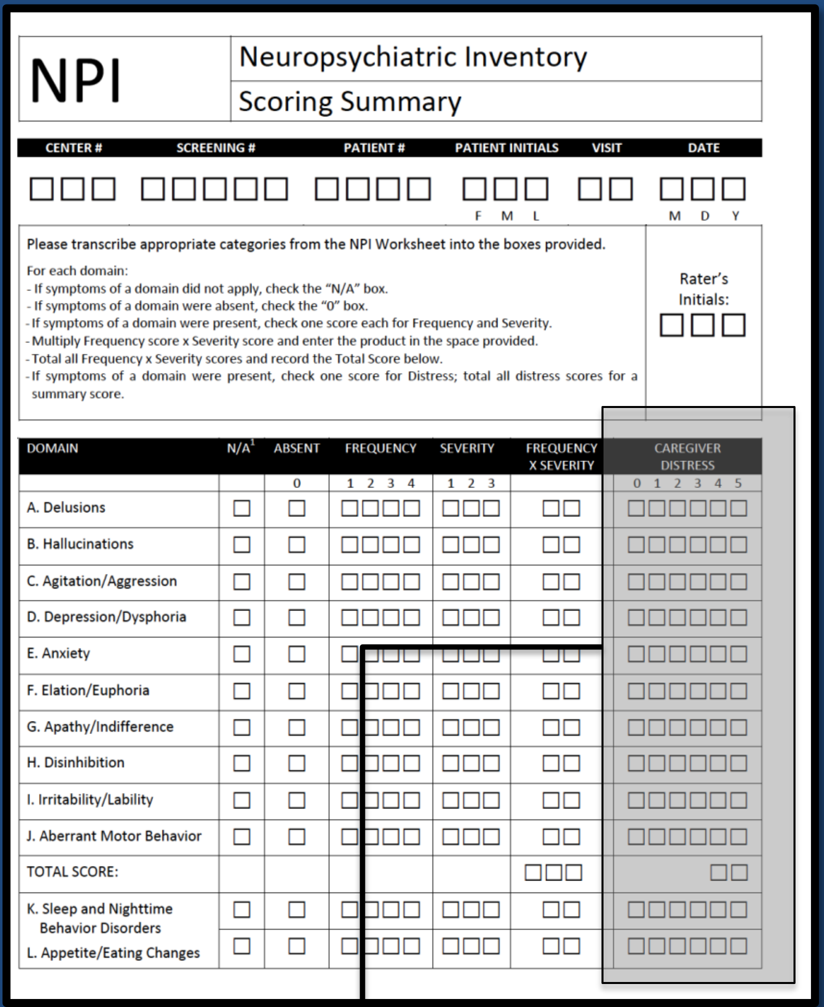
			Minutes per day		Hours per week
a.	Preparating food and drinks?	→	☐	*or*	☐
b.	Cleaning the house?	→	☐	*or*	☐
c.	Washing, ironing and sewing?	→	☐	*or*	☐
d.	Taking care of and playing with your own children?	→	☐	*or*	☐
e.	Shopping?	→	☐	*or*	☐
f.	Maintenance work, odd jobs, gardening?	→	☐	*or*	☐

2: Last week did you spent time on assisting your care recipient with the activities below? If you did, please, indicate how much time you spent on the activities.

			Minutes per day		Hours per week
a.	Personal care (dressing/undressing, washing, combing, shaving)?	→	☐	*or*	☐
b.	Moving around in the house or going to the toilet?	→	☐	*or*	☐
c.	Eating and drinking?	→	☐	*or*	☐
d.	Moving or travelling outside the house (aid with walking or wheelchair)?	→	☐	*or*	☐
e.	Making trips and visiting family or friends?	→	☐	*or*	☐
f.	Health care contacts (like visiting a doctor)?	→	☐	*or*	☐
g.	Organising help, aids, house adaptations or taking care of financial matters like insurance?	→	☐	*or*	☐
h.	Social support?	→	☐	*or*	☐

Van den Berg, B et al. *Health Economics* 2006;15:5(447-460)

NPI-D: A Measure of Caregiver **Distress**



NPI	Neuropsychiatric Inventory Scoring Summary

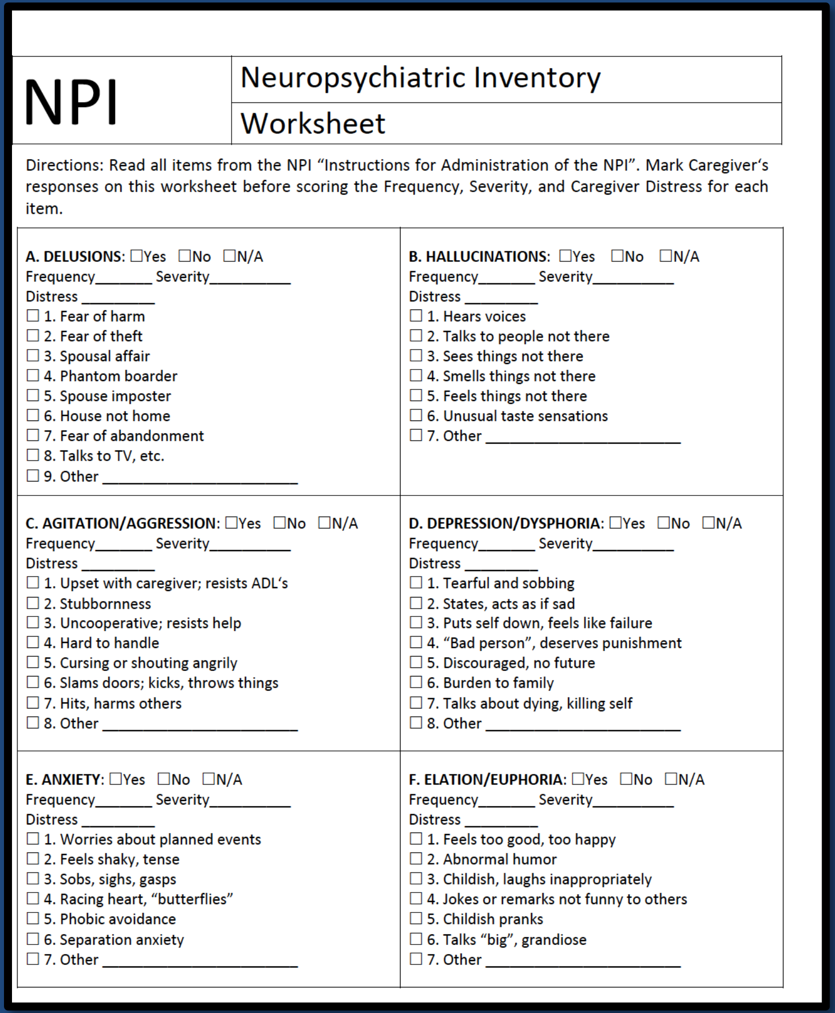
CENTER #	SCREENING #	PATIENT #	PATIENT INITIALS	VISIT	DATE
☐☐☐	☐☐☐☐☐	☐☐☐☐	☐☐☐ F M L	☐☐	☐☐☐ M D Y

Please transcribe appropriate categories from the NPI Worksheet into the boxes provided.

For each domain:
- If symptoms of a domain did not apply, check the "N/A" box.
- If symptoms of a domain were absent, check the "0" box.
- If symptoms of a domain were present, check one score each for Frequency and Severity.
- Multiply Frequency score x Severity score and enter the product in the space provided.
- Total all Frequency x Severity scores and record the Total Score below.
- If symptoms of a domain were present, check one score for Distress; total all distress scores for a summary score.

Rater's Initials: ☐☐☐

DOMAIN	N/A[1]	ABSENT	FREQUENCY	SEVERITY	FREQUENCY X SEVERITY	CAREGIVER DISTRESS
		0	1 2 3 4	1 2 3		0 1 2 3 4 5
A. Delusions	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
B. Hallucinations	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
C. Agitation/Aggression	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
D. Depression/Dysphoria	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
E. Anxiety	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
F. Elation/Euphoria	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
G. Apathy/Indifference	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
H. Disinhibition	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
I. Irritability/Lability	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
J. Aberrant Motor Behavior	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
TOTAL SCORE:					☐☐☐	☐☐
K. Sleep and Nighttime Behavior Disorders	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
L. Appetite/Eating Changes	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐



NPI	Neuropsychiatric Inventory Worksheet

Directions: Read all items from the NPI "Instructions for Administration of the NPI". Mark Caregiver's responses on this worksheet before scoring the Frequency, Severity, and Caregiver Distress for each item.

A. DELUSIONS: ☐Yes ☐No ☐N/A
Frequency_______ Severity__________
Distress _________
☐ 1. Fear of harm
☐ 2. Fear of theft
☐ 3. Spousal affair
☐ 4. Phantom boarder
☐ 5. Spouse imposter
☐ 6. House not home
☐ 7. Fear of abandonment
☐ 8. Talks to TV, etc.
☐ 9. Other ____________________

B. HALLUCINATIONS: ☐Yes ☐No ☐N/A
Frequency_______ Severity__________
Distress _________
☐ 1. Hears voices
☐ 2. Talks to people not there
☐ 3. Sees things not there
☐ 4. Smells things not there
☐ 5. Feels things not there
☐ 6. Unusual taste sensations
☐ 7. Other ____________________

C. AGITATION/AGGRESSION: ☐Yes ☐No ☐N/A
Frequency_______ Severity__________
Distress _________
☐ 1. Upset with caregiver; resists ADL's
☐ 2. Stubbornness
☐ 3. Uncooperative; resists help
☐ 4. Hard to handle
☐ 5. Cursing or shouting angrily
☐ 6. Slams doors; kicks, throws things
☐ 7. Hits, harms others
☐ 8. Other ____________________

D. DEPRESSION/DYSPHORIA: ☐Yes ☐No ☐N/A
Frequency_______ Severity__________
Distress _________
☐ 1. Tearful and sobbing
☐ 2. States, acts as if sad
☐ 3. Puts self down, feels like failure
☐ 4. "Bad person", deserves punishment
☐ 5. Discouraged, no future
☐ 6. Burden to family
☐ 7. Talks about dying, killing self
☐ 8. Other ____________________

E. ANXIETY: ☐Yes ☐No ☐N/A
Frequency_______ Severity__________
Distress _________
☐ 1. Worries about planned events
☐ 2. Feels shaky, tense
☐ 3. Sobs, sighs, gasps
☐ 4. Racing heart, "butterflies"
☐ 5. Phobic avoidance
☐ 6. Separation anxiety
☐ 7. Other ____________________

F. ELATION/EUPHORIA: ☐Yes ☐No ☐N/A
Frequency_______ Severity__________
Distress _________
☐ 1. Feels too good, too happy
☐ 2. Abnormal humor
☐ 3. Childish, laughs inappropriately
☐ 4. Jokes or remarks not funny to others
☐ 5. Childish pranks
☐ 6. Talks "big", grandiose
☐ 7. Other ____________________

SUB SCALE DESIGNED TO ASSESS CAREGIVER **DISTRESS** IN ASSOCIATION WITH BEHAVIORAL DISTURBANCE

Norhouse Meta-Analysis
Interventions with family caregivers of cancer patients

- **Illness Appraisal Domain**
  - Appraisal of caregiving burden (negative reaction to caregiving)
  - Appraisal of caregiving benefit (opportunity for personal growth)
  - Information needs (cancer prognosis, available resources)
- **Coping resources Domain**
  - Coping strategies (promote problem solving, reduce ineffective coping-denial)
  - Self efficacy (caregivers perceived confidence, preparation, mastery)
- **Quality of Life Domain**
  - Physical functioning (performance of self care behaviors)
  - Distress and Anxiety
  - Depression-interventions not successful in reducing caregiver depression
  - Marital-family Relationships
  - Social Functioning

Northouse LL et al *CA* Interventions with Family Caregivers of Cancer Patients Meta-Analysis of Randomized Trials 2010 60:5 (317-339)

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Interventions: Recent Meta-Analyses

- Support groups or psycho-educational interventions were modestly effective and had effect sizes ranging from 0.09-.23

- Pharmacologic interventions : 0.18-0.27
  - Anticholinergic medication in ADRD
  - Antipsychotic medication in ADRD

- Psycho educational interventions + skills training + therapeutic counseling for cancer patients
- 0.22 at 3 months, and 0.08 after 6 months

- Symptoms of caregiver burden (mood, coping, self efficacy) improved even though burden itself not improved

Schoenmakers B et al. *Fam Pract.* 2009;26(4):279-286; Lingler JH. et al Caregiver-specific outcomes in anti dementia clinical drug trials a systematic review and meta-analysis. *J Am Geriatr Soc*. 2005;53(6):983-990; Gitlin LN et al Effect of multicomponent interventions on caregiver burden and depression the REACH multisite initiative at 6 month follow-up. *Psychol Aging* 2003;18(3):361-374

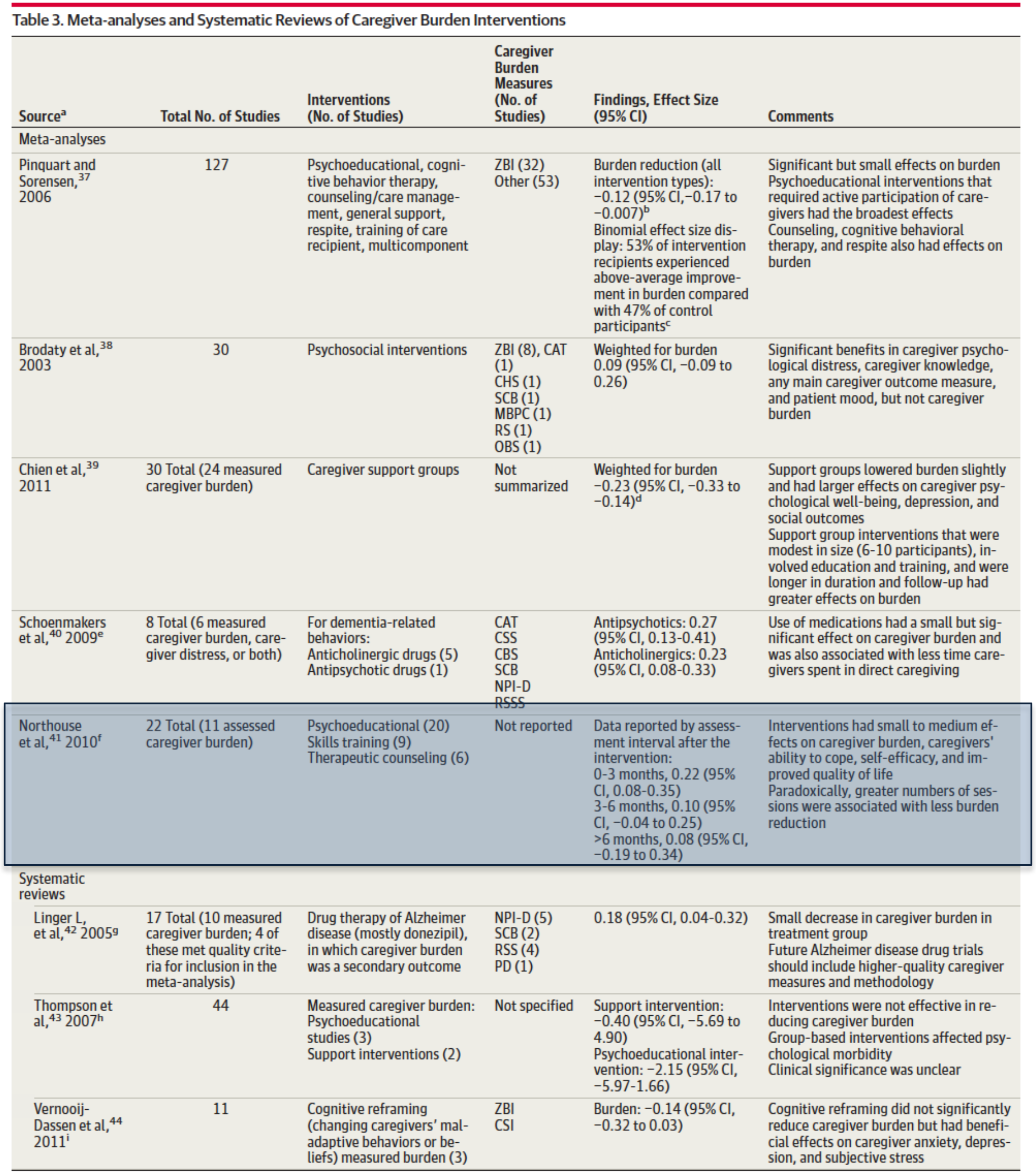


Table 3. Meta-analyses and Systematic Reviews of Caregiver Burden Interventions

Source[a]	Total No. of Studies	Interventions (No. of Studies)	Caregiver Burden Measures (No. of Studies)	Findings, Effect Size (95% CI)	Comments
Meta-analyses					
Pinquart and Sorensen,[37] 2006	127	Psychoeducational, cognitive behavior therapy, counseling/care management, general support, respite, training of care recipient, multicomponent	ZBI (32) Other (53)	Burden reduction (all intervention types): −0.12 (95% CI,−0.17 to −0.007)[b] Binomial effect size display: 53% of intervention recipients experienced above-average improvement in burden compared with 47% of control participants[c]	Significant but small effects on burden Psychoeducational interventions that required active participation of caregivers had the broadest effects Counseling, cognitive behavioral therapy, and respite also had effects on burden
Brodaty et al,[38] 2003	30	Psychosocial interventions	ZBI (8), CAT (1) CHS (1) SCB (1) MBPC (1) RS (1) OBS (1)	Weighted for burden 0.09 (95% CI, −0.09 to 0.26)	Significant benefits in caregiver psychological distress, caregiver knowledge, any main caregiver outcome measure, and patient mood, but not caregiver burden
Chien et al,[39] 2011	30 Total (24 measured caregiver burden)	Caregiver support groups	Not summarized	Weighted for burden −0.23 (95% CI, −0.33 to −0.14)[d]	Support groups lowered burden slightly and had larger effects on caregiver psychological well-being, depression, and social outcomes Support group interventions that were modest in size (6-10 participants), involved education and training, and were longer in duration and follow-up had greater effects on burden
Schoenmakers et al,[40] 2009[e]	8 Total (6 measured caregiver burden, caregiver distress, or both)	For dementia-related behaviors: Anticholinergic drugs (5) Antipsychotic drugs (1)	CAT CSS CBS SCB NPI-D RSSS	Antipsychotics: 0.27 (95% CI, 0.13-0.41) Anticholinergics: 0.23 (95% CI, 0.08-0.33)	Use of medications had a small but significant effect on caregiver burden and was also associated with less time caregivers spent in direct caregiving
Northouse et al,[41] 2010[f]	22 Total (11 assessed caregiver burden)	Psychoeducational (20) Skills training (9) Therapeutic counseling (6)	Not reported	Data reported by assessment interval after the intervention: 0-3 months, 0.22 (95% CI, 0.08-0.35) 3-6 months, 0.10 (95% CI, −0.04 to 0.25) >6 months, 0.08 (95% CI, −0.19 to 0.34)	Interventions had small to medium effects on caregiver burden, caregivers' ability to cope, self-efficacy, and improved quality of life Paradoxically, greater numbers of sessions were associated with less burden reduction
Systematic reviews					
Linger L, et al,[42] 2005[g]	17 Total (10 measured caregiver burden; 4 of these met quality criteria for inclusion in the meta-analysis)	Drug therapy of Alzheimer disease (mostly donezipil), in which caregiver burden was a secondary outcome	NPI-D (5) SCB (2) RSS (4) PD (1)	0.18 (95% CI, 0.04-0.32)	Small decrease in caregiver burden in treatment group Future Alzheimer disease drug trials should include higher-quality caregiver measures and methodology
Thompson et al,[43] 2007[h]	44	Measured caregiver burden: Psychoeducational studies (3) Support interventions (2)	Not specified	Support intervention: −0.40 (95% CI, −5.69 to 4.90) Psychoeducational intervention: −2.15 (95% CI, −5.97-1.66)	Interventions were not effective in reducing caregiver burden Group-based interventions affected psychological morbidity Clinical significance was unclear
Vernooij-Dassen et al,[44] 2011[i]	11	Cognitive reframing (changing caregivers' maladaptive behaviors or beliefs) measured burden (3)	ZBI CSI	Burden: −0.14 (95% CI, −0.32 to 0.03)	Cognitive reframing did not significantly reduce caregiver burden but had beneficial effects on caregiver anxiety, depression, and subjective stress

Adelman RD et al Caregiver Burden A Clinical Review. JAMA 2014:311(10):1052-59

Review of pharmacological treatment of behavioral disturbances in elderly patients

Effect on Burden

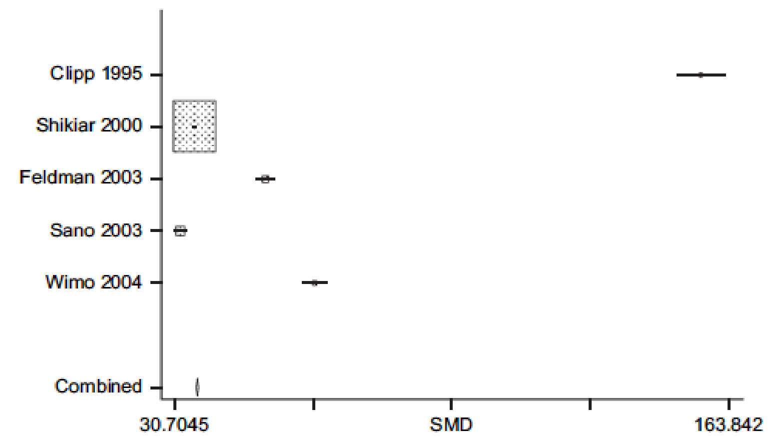


FIGURE 2 *Effect size of drug therapy on burden (score on burden inventory) in caregiver (fixed effects model)*

Effect on Caregiver Time (min/day)

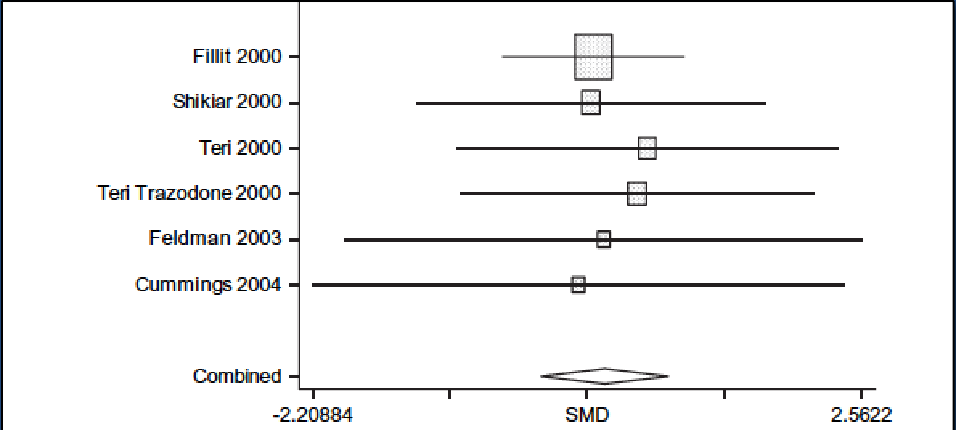


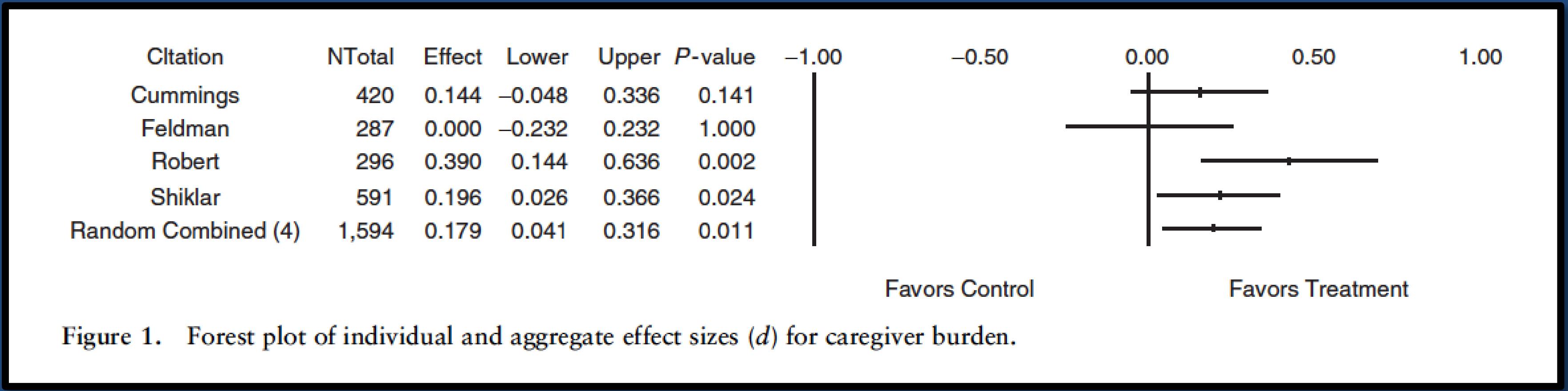
FIGURE 3 *Effect size of drug therapy on time spent in minutes/day by the caregiver (fixed effects model)*

PLACEBO RESPONSE RATE FOR REDUCED CB

TERRI reported 31% Haloperidol 0.5mg vs Trazadone 50mg vs PBO

Teri L, Logsdon RG, Peskind E et al. Treatment of agitation in AD: a randomized, placebo-controlled clinical trial. Neurology 2000; 55: 1271–8.

Meta-Analysis and Systematic Review of Caregiver-Specific Outcomes in Anti-dementia Clinical Trials



Citation	NTotal	Effect	Lower	Upper	*P*-value
Cummings	420	0.144	–0.048	0.336	0.141
Feldman	287	0.000	–0.232	0.232	1.000
Robert	296	0.390	0.144	0.636	0.002
Shiklar	591	0.196	0.026	0.366	0.024
Random Combined (4)	1,594	0.179	0.041	0.316	0.011

Figure 1. Forest plot of individual and aggregate effect sizes (*d*) for caregiver burden.

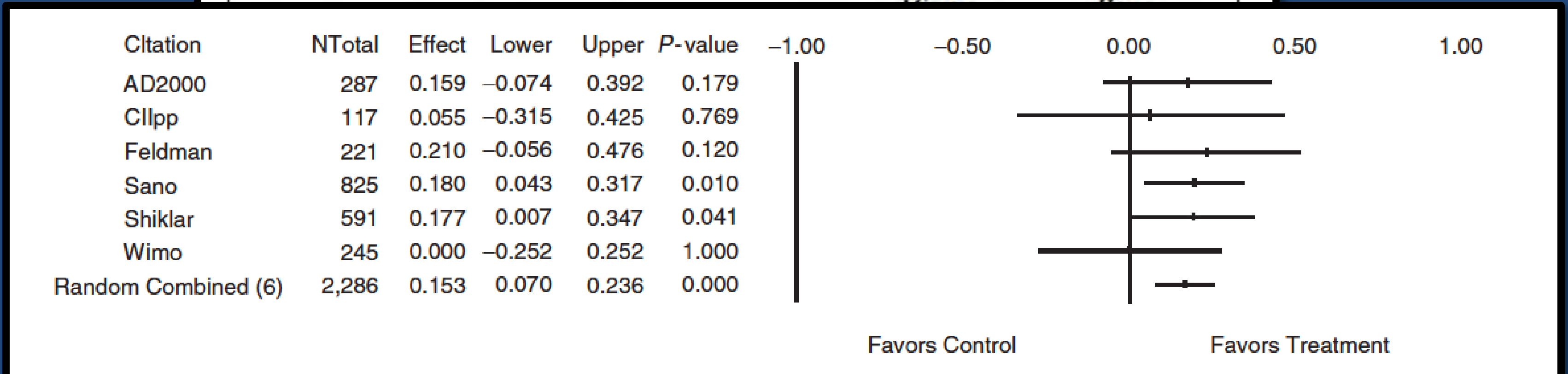
- 17 eligible trials; 4,744 subjects
- Head to head design (4); open label (3)
- Majority involved drugs now FDA-approved; donezepil (7)
- Mean sample size 279; mean duration 35 weeks
- 10 trials evaluated caregiver burden
- Range of one (*k*=6) to three burden measures (*k*=1)
- NPI D (5 trials), four relied on this tool solely
- NPI-D measures distress appraisals in response to up to 10 behaviors

Lingler JH et al Caregiver-specific Outcomes in Antidementia Clinical Trials: A Systematic Review and Meta-Analysis *J Am Geriatr Soc* 53:983-990,2005

Measures of active time use by informal caregivers

We would like to know how much time you spent on giving informal care to your care recipient. Please, consider the past week!

1: Last week did you spent time on the activities below in your care recipient's house? If you did, please, indicate how much time you spent on the activities.



Cltation	NTotal	Effect	Lower	Upper	*P*-value
AD2000	287	0.159	−0.074	0.392	0.179
Cllpp	117	0.055	−0.315	0.425	0.769
Feldman	221	0.210	−0.056	0.476	0.120
Sano	825	0.180	0.043	0.317	0.010
Shiklar	591	0.177	0.007	0.347	0.041
Wimo	245	0.000	−0.252	0.252	1.000
Random Combined (6)	2,286	0.153	0.070	0.236	0.000

Figure 2. Forest plot of individual and aggregate effect sizes (*d*) for caregiver time use.

b. Moving around in the house or going to the toilet? → ☐ *or* ☐

c. Eating and drinking? → ☐ *or* ☐

d. Moving or travelling outside the house (aid with walking or wheelchair)? → ☐ *or* ☐

e. Making trips and visiting family or friends? → ☐ *or* ☐

f. Health care contacts (like visiting a doctor)? → ☐ *or* ☐

g. Organising help, aids, house adaptations or taking care of financial matters like insurance? → ☐ *or* ☐

h. Social support? → ☐ *or* ☐

Van den Berg, B et al. *Health Economics* 2006;15:5(447-460)

Caregiver pain appears to be a predictor of caregiver burden and emotional/physical domains of burden

- 20-50% of informal caregivers are estimated to be over age 65

- *n*=116; mean age 73.3, convenience sample
  - Self report questionnaires (Townsend Disability/Geriatric Pain Measure/Caregiver Burden Inventory/Geriatric Depresssion Scale

- Caregiver pain predicts response to caregiving in this sample (depression)

- Time dependence was uniquely correlated with AD, cohabitation, degree of disability of recipient

Jones SL et al The Relation of pain and caregiver burden in informal older adult caregivers *Pain Medicine* 2011

Caregiver Burden Overview

Definition and Framing Questions

Epidemiology

Diagnostic Strategies/Assessment

Interventions in Clinical Practice

Considerations

Problems with caregiver burden assessment in clinical trials disclosed by Lingler's meta-analysis that have implications for clinical trials in chronic pain populations

1. None of the reports specific caregiver eligibility criteria
    - For these AD trials the patient inclusion criteria specified need for a reliable informant to accompany to study visits (some delineate amount of contact)

2. Lack of information about caregiver baseline characteristics

3. Operational definitions of caregiver outcomes were unspecified (most problematic for burden/psychological morbidity)
4. Lack explicit theoretical basis for including caregiver burden

Lingler JH et al Caregiver-specific Outcomes in Antidementia Clinical Trials: A Systematic Review and Meta-Analysis *J Am Geriatr Soc* 53:983-990,2005

Conclusions: Applicability of this measure to pain

1. The amount of time the caregiver saves and the reduced burden by caring for a patient (family/friend with reduced pain and pain-related activity limitation)
   - Which domains from Cancer/ADRD trials are appropriate?

2. Need to Identify pain conditions in which feasibility of assessing caregiver burden has greater feasibility
   - spinal cord injury related to neuropathic pain
   - study populations in which pain-related distress is more manifest

1. Pain in older adults is highly prevalent and there is emerging evidence on high rates of informal caregiving

2. Cost shifting of healthcare is going to accelerate informal caregiving

Outcome Measures involving Caregiver Burden

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