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A Systematic Evidence Review of Interventions for Non-professional Caregivers of Individuals with Dementia

Elizabeth R. Goy, PhD

Core Investigator

Portland Center for the Study of Chronic, Comorbid Mental and Physical Disorders

Portland, Oregon

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Susan Cooley, PhD & Heather Mahoney-Gleason, LCSW, Discussants

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Co-Authors

- Devan Kansagara, MD, MCR
- Michele Freeman, MPH

Advisors/Assistance

- Linda Humphrey, MD, MPH
- Rose Campbell, MLIS, MS

CDA Mentors

- Linda Ganzini, MD, MPH
- Mark Helfand, MD, MS, MPH

Discussants

- Susan Cooley, PhD
- Heather Mahoney-Gleason, LCSW

Expert Panel/Reviewers

- Susan Cooley, PhD
- Mark Kunik, MD, MPH
- Randall Rupper, MD
- Linda Nichols, PhD
- Robert Ruff, MD
- Stuti Dang, MD

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VA Evidence-based Synthesis (ESP) Program Overview

- Sponsored by VA Office of R&D and HSR&D.
- Established to provide timely and accurate syntheses/reviews of healthcare topics identified by VA clinicians, managers and policy-makers, as they work to improve the health and healthcare of Veterans.
- Builds on staff and expertise already in place at the Evidence-based Practice Centers (EPC) designated by AHRQ. Four of these EPCs are also ESP Centers:
  - Durham VA Medical Center; VA Greater Los Angeles Health Care System; Portland VA Medical Center; and Minneapolis VA Medical Center.

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- Provides evidence syntheses on important clinical practice topics relevant to Veterans, and these reports help:
  - develop clinical policies informed by evidence,
  - the implementation of effective services to improve patient outcomes and to support VA clinical practice guidelines and performance measures, and
  - guide the direction for future research to address gaps in clinical knowledge.
- Broad topic nomination process – e.g. VACO, VISNs, field – facilitated by ESP Coordinating Center (Portland) through online process:

http://www.hsrd.research.va.gov/publications/esp/TopicNomination.cfm

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- Steering Committee representing research and operations (PCS, OQP, ONS, and VISN) provides oversight and guides program direction.
- Technical Advisory Panel (TAP)
    - Recruited for each topic to provide content expertise.
    - Guides topic development; refines the key questions.
    - Reviews data/draft report.
- External Peer Reviewers & Policy Partners
    - Reviews and comments on draft report
- Final reports posted on VA HSR&D website and disseminated widely through the VA.

http://www.hsrd.research.va.gov/publications/esp/reports.cfm

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Current Report

A Systematic Evidence Review
of Interventions for
Non-professional Caregivers
of Individuals with Dementia
(October, 2010)

Full-length report available on ESP website:

- http://www.hsrd.research.va.gov/publications/esp/DementiaCaregivers.pdf

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Background

- Dementia
  - Broad term describing cognitive impairments, memory loss, functional and behavioral deterioration
  - Typically lengthy, progressive course of deterioration
  - Community caregivers (CGs) provide increasing care as dementia progresses
  - CG role associated with health and mood complications for CG (Grant et al., 2002)
  - Physical, emotional strain/burden on CG linked to institutionalization of care recipient (CR) (Lieberman & Kramer, 1991)

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Background

- Over half million Veterans with dementia projected for 2010 (*HTTP://WWW4.VA.GOV/HEALTHPOLICYPLANNING/REPORTS1.ASP*)
    - VA patient-centric care includes
        - Geriatrics and Geriatric Psychiatry outpatient clinics
        - Home Based Primary Care
        - Skilled Home Care
        - Adult day health care
        - Homemaker and Home Health Aide Services
        - Home respite, home hospice
        - Community Living Center
        - State Veteran Homes
        - Contract Nursing Home

      http://www.va.gov/GERIATRICS/Programs_and_Services.asp

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Background

- VHA Office of Geriatrics and Extended Care Dementia Steering Committee requested this evidence review
  - What interventions have been created and tested
  - What is effective for the CG
    - Reduce strain
    - Improve mood
    - Improve competence
    - Improve confidence
  - What is effective for the CR
    - Improve cognition
    - Improve adaptive functioning
    - Improve problem behavior
    - Improve mood
    - Delay institutionalization

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Key Questions

- Key Question #1. Do CG interventions affect the CG's knowledge and ability to manage problematic behavior, CG psychosocial burden, CG health and health behaviors, or outcomes in the individual with dementia?

- Key Question #2. What are adverse effects of CG interventions?

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Methods

- Review requested by the VHA Dementia Steering Committee
  - Some DSC members also served as technical expert panel members
- Population
  - Nonprofessional community-dwelling family CGs of people with dementia
  - Professional staff excluded, but in-home paid sitters or assistants hired by family included

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Methods

- Interventions
  - Psychoeducational
  - Cognitive-behavioral
  - Counseling/case management
  - Supportive interventions
  - Respite care
  - Telephone based support groups/education
  - Home TeleHealth/Health Buddy home monitoring device
  - Internet-based resources
  - Exercise/physical activity
  - Multicomponent

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Methods

- Outcomes for CG
  - Knowledge and ability to manage behavioral problems
  - Psychosocial – burden, well-being, depression, anxiety, self-efficacy, positive experiences of caregiving, satisfaction with health care, quality of life
  - Health behaviors – diet, exercise, sleep
  - Health – self-report, symptoms, medications, services use, mortality

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Methods

- Outcomes for CR
  - Use of psychotropic drugs
  - Cognition, mood, behavioral disturbance, social function, physical function
  - Utilization – hospitalizations, institutionalizations, or health care visits (including ED visits)
  - Accidents
  - Health-related quality of life
  - Satisfaction with care

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Methods – Search Strategy

- MEDLINE search for systematic reviews through July 2009
  - "Dementia" OR "dementia" AND "systematic"
- Cochrane Database of Systematic Reviews & Database of Reviews of Effects (OVID) search for systematic reviews through July 2009
  - "Dementia.mp"
- Contacted known researchers to identify recent or ongoing studies
- Per DSC recommendation examined:
  - Individual studies from the Administration on Aging's Alzheimer's Disease Supportive Services Program compendium
  - Additional recommended individual studies published since latest review (2006)

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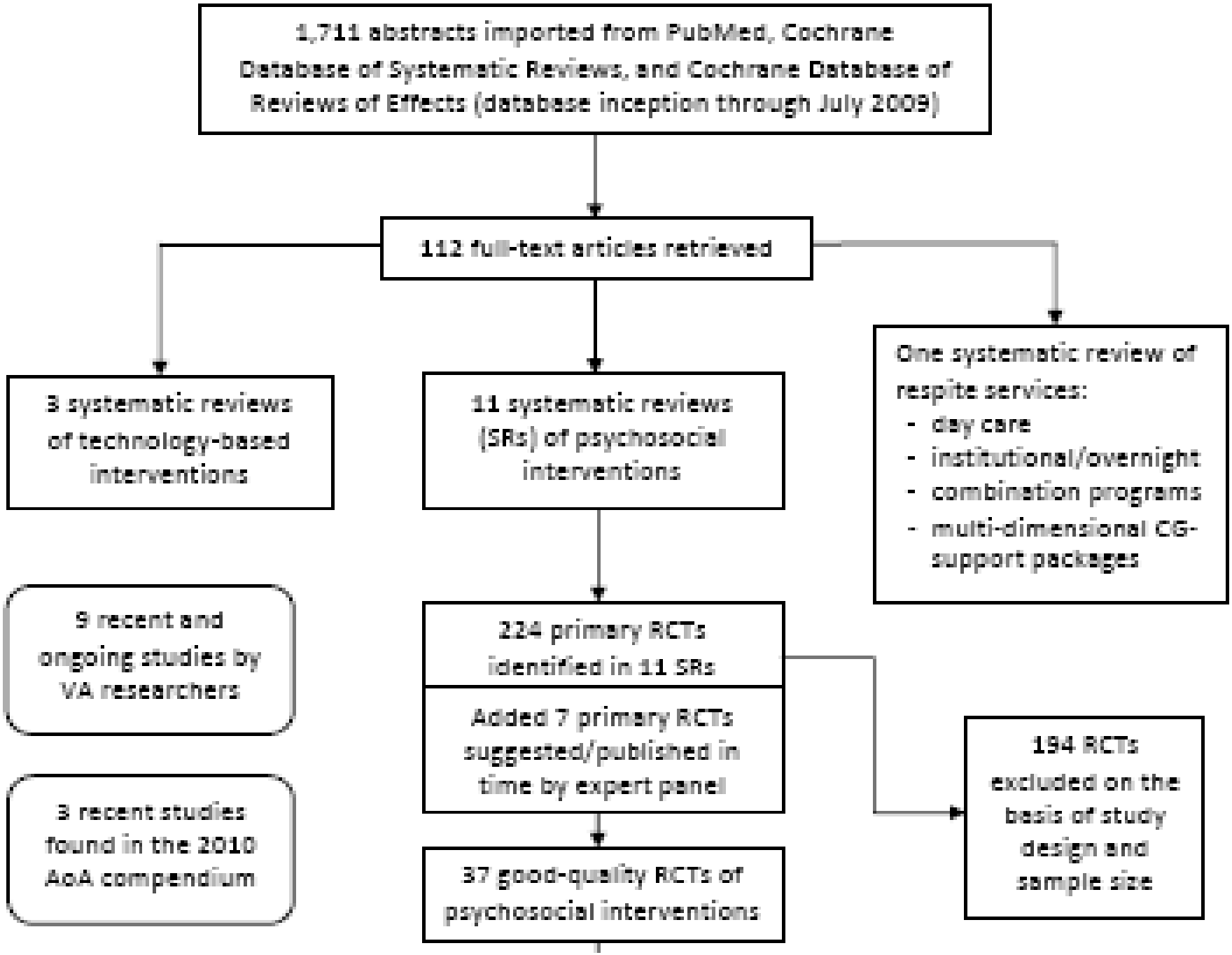
Methods

- Inclusion/Exclusion criteria
  - Systematic review (SR)"Review of reviews" or meta-analysis
  - Nonprofessional CGs of people with dementia
  - Interventions and Outcomes as defined
  - Fairly clean strategy for Respite Care and Technology-based
- Psychosocial interventions
  - Different SRs grouped same studies differently
  - Much overlap – many primary studies included in more than one review
  - Dissimilar studies combined in some cases

Figure 1. Literature Flow



37 Good Quality RCTs of Psychosocial Interventions

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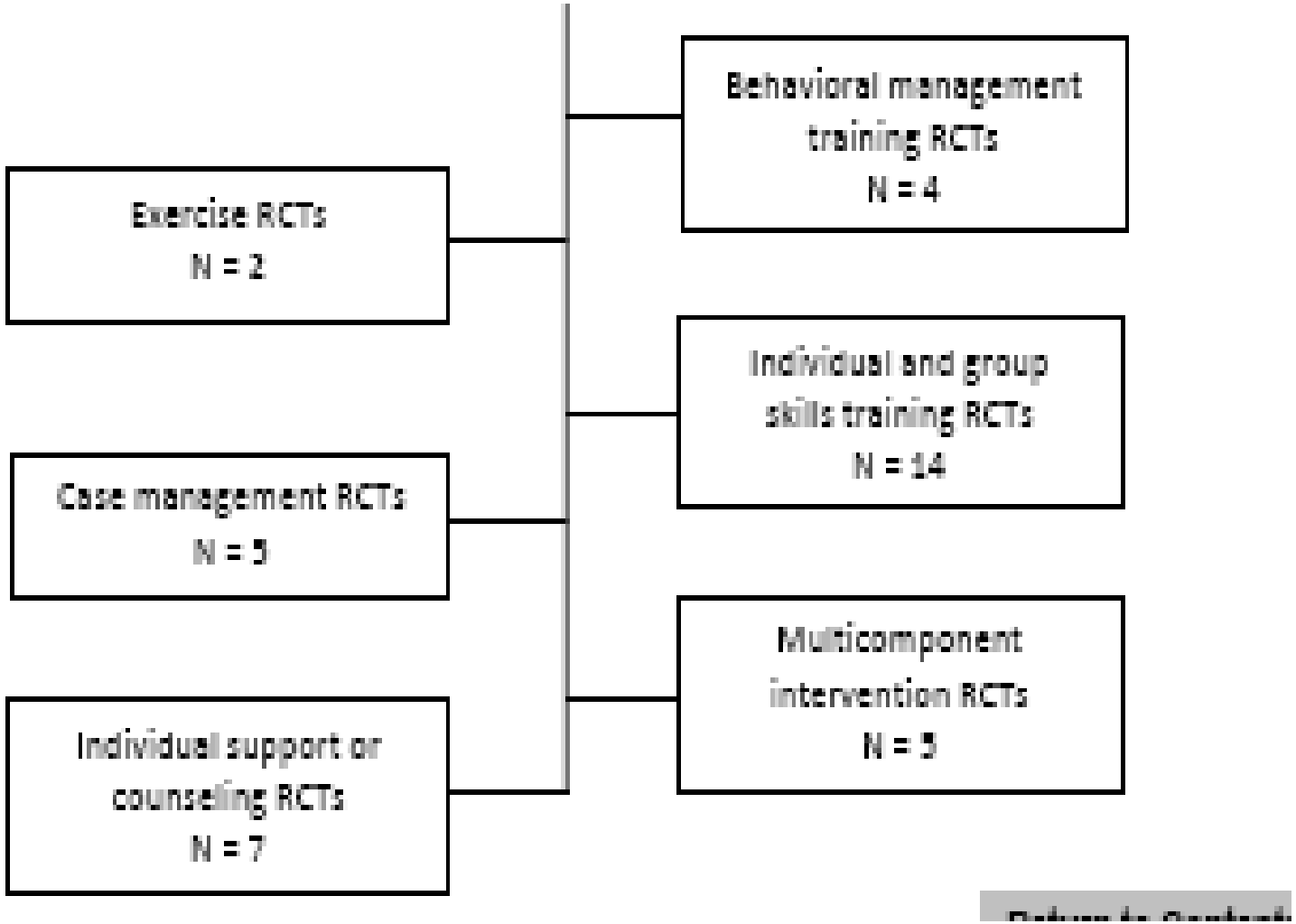

Quality Criteria for SRs

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- Search dates reported? *Yes or No*
- Search methods reported? *Yes or No*
- Comprehensive search? *Yes or No*
- Inclusion criteria reported? *Yes or No*
- Selection bias avoided? *Yes or No*
- Validity criteria reported? *Yes or No*
- Validity assessed appropriately? *Yes or No*
- Methods used to combine studies reported? *Yes or No*
- Findings combined appropriately? *Yes or No*
- Conclusions supported by data? *Yes or No*

Quality Criteria for SRs

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- Good: Meet all criteria: Reports comprehensive and reproducible search methods and results; reports pre-defined criteria to select studies and reports reasons for excluding potentially relevant studies; adequately evaluates quality of included studies and incorporates assessments of quality when synthesizing data; reports methods for synthesizing data and uses appropriate methods to combine data qualitatively or quantitatively; conclusions supported by the evidence reviewed.

Quality Criteria for Primary Studies (USPSTF)

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- Adequate randomization, concealment/blinding, balancing of confounds
- Maintenance of comparable groups
- Important differential loss to follow-up or overall high loss to follow-up
- Measurements: equal, reliable, and valid
- Clear definition of interventions
- Important outcomes considered
- Analysis: intention-to-treat analysis for RCTs

Quality Criteria – Primary Studies

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- Good: Meets all criteria: Comparable groups are assembled initially and maintained throughout the study (follow-up at least 80 percent); reliable and valid measurement instruments are used and applied equally to the groups; interventions are spelled out clearly; important outcomes are considered; and appropriate attention to confounders in analysis.

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General Observations

- No unequivocal findings
- In general, studies improved over time
- The inclusion of primary studies published after the systematic reviews was persuasive to our conclusions

KQ1 Do CG Interventions Improve CG or CR Outcomes?

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- Psychosocial Interventions
  - Multicomponent (5 studies) – combinations of skills training, group support, respite care, problem solving, stress management, environmental modifications
    - Best when individually tailored to dyad needs
    - Improve CG depression
    - Improve CG report of burden, well-being, confidence
    - Improve CG self-care and ratings of social support
    - Interventions predicted less grief after death of CR (REACH, Holland et al., 2009)
    - No consistent support for delay of CR institutionalization
    - When diverse populations studied (Belle et al., 2006), all Hispanic/Latino and White CGs reported improved depression, burden, self-care, and social support; spousal CGs reported similar improvements among Black/African American participants

Q1 Do CG Interventions Improve CG or CR Outcomes?

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- Psychosocial (cont)
  - Exercise Training for CG (1 study) – home based exercise with supportive phone calls (attention control)
    - No evidence of impact on key outcomes, though demonstrated success in cultivating adherence to program for less depressed CGs
  - Case Management (5 studies) – intensive nurse care case management including problem solving, behavior management, skills training (usual care control)
    - 2 of 5 (Callahan et al., 2006; Vickrey et al., 2006) showed promise for improving CG stress, depression, confidence, and CR problem behaviors for at least 1 year
    - Insufficient support (1 of 5: Eloniemi-Sulkava et al., 2001) for delayed institutionalization of CR

Q1 Do CG Interventions Improve CG or CR Outcomes?

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- Psychosocial (cont)
  - Behavior Management Training (4 studies, additional 3 from AoA compendium) – train CG to identify antecedents of problem behaviors and their consequences, then devise strategies to reduce frequency of problem behaviors. Two were augmented (CR exercise or CG self-care pamphlets)
    - Inconsistent evidence of improved CG mood or well-being
    - Improvements in CR aggression and/or CG reactivity to problem behaviors in 5 of 7 reports
    - Need for greater methodological rigor in these studies

Q1 Do CG Interventions Improve CG or CR Outcomes?

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- Psychosocial (cont)
  - Individual Skills Training (6 studies) – problem-solving, environmental modifications, increase CG sense of self-efficacy
    - 2 studies demonstrated improved CG mood (effects may not be sustained beyond 6 mos) (Buckwalter et al., 1999; Bass et al., 2003)
    - 3 studies (Buckwalter; Gerdner et al., 2002; Gitlin et al., 2001) demonstrated reduced CG reactivity to problem behaviors
    - Positive but varied outcomes for CR include: CR mood improved, less decline in self-care, reductions in behavioral disturbance in 2 studies.
      - Significantly larger proportion of CRs remained at home post intervention in one study (Wright et al., 2001)
    - No compelling evidence of impact on CG burden, anxiety, QOL. No consistent delay of institutionalization

Q1 Do CG Interventions Improve CG or CR Outcomes?

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- Psychosocial (cont)
  - Group Skills Training and combined group/individual (8 studies) – Individualized in-home assessments (for many) followed by teaching of problem solving, behavior management, stress management, environmental modifications, education about dementia (wait list or usual care control).
    - 3 studies demonstrated improved CG mood, also improvements in CR behavior in 2 of these
    - 1 study (Burgio et al., 2003) reported findings for diverse populations: skills training effectively reduced "bother" for AA CGs, minimal support control more effective in White CGs. Desire to institutionalize increased over time among White CGs, remained stable in AA CGs.
    - "Savvy Caregiver Program" (Hepburn et al., 2003 & 2007) improved CG confidence and reduced distress but attrition high
    - Individualization of training appeared linked to improvements

Q1 Do CG Interventions Improve CG or CR Outcomes?

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- Psychosocial (cont)
  - Individual, group and combined group/individual supportive counseling (6 studies) – supportive counseling, empathy, emotional support, identifying sources of support in surroundings
    - No clear superiority of individual or group support over control groups (wait list or usual care)
    - A combined individual/group approach (Mittelman et al., 1995, 1996 & 2004) resulted in delayed institutionalization for CR and long term mood & heath improvements for CG.
      - Appears resource-intensive
    - No improvements in CG burden reported

KQ1 Do CG Interventions Improve CG or CR Outcomes?

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- Technology-Based Interventions (3 systematic reviews)
  - Networked information and communications technology to support CGs. Examples: e-mail, e-encyclopedia, bulletin board Q&A; Telephone-Linked Care (part of REACH study) with automated stress-monitoring and counseling information; support group calls and information access; GPS monitoring
    - Overall, insufficient evidence to support effectiveness of technology-based interventions.
    - TLC, COMPUTERLINK, and CTIS combined in meta-analysis: increased subjective report of CG social support, knowledge, confidence in decisions, and mental health, but no overall effect on CG depression.
    - Uncontrolled studies suggest GPS tracking of CR may improve CR function and safety and reduce CG depression, burden and stress; need robust trials.

KQ1 Do CG Interventions Improve CG or CR Outcomes?

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- Respite Care: Arksey et al., 2004, SR of 45 articles (15 US-based)
    - Day care, in-home respite, video respite, institutional/overnight respite.
        - Overall, small, statistically-significant improvements on some outcomes (e.g. better sleep patterns for CG), but overall evidence regarding impact on CG health or well-being inconsistent.
        - Institutional/overnight respite – 2 studies conducted at VA hospitals. Transient improvement in CG burden and depression at time of discharge but no health/well-being improvements sustained beyond 2 weeks.
        - Despite lack of support of health/well-being improvements on study measures, CGs expressed high satisfaction with the services

KQ1 Do CG Interventions Improve CG or CR Outcomes?

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Recent/Ongoing Research

- Resources for Enhancing Alzheimer's Caregiver Health
  - REACH, REACH II, REACH-VA, REACH OUT
    - Support, skills training
    - Interventions feasible,
    - cost estimates of $2.93 per day
- Partners in Dementia Care (PDC) –HSRD study with collaborating VA and Alzheimer's Association chapters
  - Dyad assessment followed by phone-based coaching, empowerment, provision of support and information.
  - In data analysis stage
- Telephone Linked Care (TLC) and Rural Telehealth Education Program
  - Phone education and support
  - No significant changes in CG outcomes but decreases in facility costs noted

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Discussion

- Some interventions show promise
  - Strongest support for multicomponent interventions based on individualized assessment
  - BMT and Case Management also had some strong studies supporting but inconsistent overall
- Are we measuring what we should be measuring?
  - Adequate sensitivity for the possible benefits experienced?

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- Additional Limitations of this Review
  - Differences AND overlaps in interventions and outcomes across studies made grouping difficult
  - Difficulty knowing which aspect of intervention was effective
  - Psychosocial studies do not lend themselves to precision
  - There may be good quality primary studies represented in poor quality systematic reviews that we missed
  - Good quality systematic reviews latest publication was 2005 for psychosocial interventions. Added studies per Expert Panel recommendations.
  - Statistical versus clinical significance rarely discussed.

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Future Research Indications

- Need feasibility and cost analysis studies
- Replication of exact interventions and outcomes successful with originating author
- Mixed methods designs – to better define outcome measures

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Questions?

If you have further questions,
feel free to contact:

Elizabeth (Betsy) Goy PhD
503-220-8262, ext. 57470
elizabeth.goy@va.gov

The full report and cyberseminar presentation is available on the ESP website:

http://www.hsrd.research.va.gov/publications/esp/