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

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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:
  o 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:
  
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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:

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Background

• Dementia
  o Broad term describing cognitive impairments, memory loss, functional and behavioral deterioration
  o Typically lengthy, progressive course of deterioration
  o Community caregivers (CGs) provide increasing care as dementia progresses
  o CG role associated with health and mood complications for CG (Grant et al., 2002)
  o 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)

  o VA patient-centric care includes
    o Geriatrics and Geriatric Psychiatry outpatient clinics
    o Home Based Primary Care
    o Skilled Home Care
    o Adult day health care
    o Homemaker and Home Health Aide Services
    o Home respite, home hospice
    o Community Living Center
    o State Veteran Homes
    o 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
  o What interventions have been created and tested
  o What is effective for the CG
    o Reduce strain
    o Improve mood
    o Improve competence
    o Improve confidence
  o What is effective for the CR
    o Improve cognition
    o Improve adaptive functioning
    o Improve problem behavior
    o Improve mood
    o 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
  o Some DSC members also served as technical expert panel members
• Population
  o Nonprofessional community-dwelling family CGs of people with dementia
  o Professional staff excluded, but in-home paid sitters or assistants hired by family included
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Methods

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

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

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

• MEDLINE search for systematic reviews through July 2009
  o “Dementia” OR “dementia” AND “systematic”

• Cochrane Database of Systematic Reviews & Database of Reviews of Effects (OVID) search for systematic reviews through July 2009
  o “Dementia.mp”

• Contacted known researchers to identify recent or ongoing studies

• Per DSC recommendation examined:
  o Individual studies from the Administration on Aging’s Alzheimer’s Disease Supportive Services Program compendium
  o Additional recommended individual studies published since latest review (2006)
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Methods

• Inclusion/Exclusion criteria
  o Systematic review (SR) “Review of reviews” or meta-analysis
  o Nonprofessional CGs of people with dementia
  o Interventions and Outcomes as defined
  o Fairly clean strategy for Respite Care and Technology-based

• Psychosocial interventions
  o Different SRs grouped same studies differently
  o Much overlap – many primary studies included in more than one review
  o Dissimilar studies combined in some cases
Figure 1. Literature Flow

1,711 abstracts imported from PubMed, Cochrane Database of Systematic Reviews, and Cochrane Database of Reviews of Effects (database inception through July 2009)

112 full-text articles retrieved

3 systematic reviews of technology-based interventions

11 systematic reviews (SRs) of psychosocial interventions

9 recent and ongoing studies by VA researchers

224 primary RCTs identified in 11 SRs

224 primary RCTs suggested/published in time by expert panel

3 recent studies found in the 2010 AoA compendium

37 good-quality RCTs of psychosocial interventions

One systematic review of respite services:
- day care
- institutional/overnight
- combination programs
- multi-dimensional CG-support packages

194 RCTs excluded on the basis of study design and sample size
37 Good Quality RCTs of Psychosocial Interventions

- Exercise RCTs
  - N = 2

- Case management RCTs
  - N = 5

- Individual support or counseling RCTs
  - N = 7

- Behavioral management training RCTs
  - N = 4

- Individual and group skills training RCTs
  - N = 14

- Multicomponent intervention RCTs
  - N = 5
Quality Criteria for SRs

- 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

• **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)

- 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

• 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?

- 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?

• Psychosocial (cont)
  • **Exercise Training for CG** (1 study) – home based exercise with supportive phone calls (attention control)
    o 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)
    o 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
    o Insufficient support (1 of 5: Eloniemi-Sulkava et al., 2001) for delayed institutionalization of CR
Q1 Do CG Interventions Improve CG or CR Outcomes?

- 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?

- 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?

• 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).
    o 3 studies demonstrated improved CG mood, also improvements in CR behavior in 2 of these
    o 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.
    o “Savvy Caregiver Program” (Hepburn et al., 2003 & 2007) improved CG confidence and reduced distress but attrition high
    o Individualization of training appeared linked to improvements
Q1 Do CG Interventions Improve CG or CR Outcomes?

• Psychosocial (cont)
  • **Individual, group and combined group/individual supportive counseling** (6 studies) – supportive counseling, empathy, emotional support, identifying sources of support in surroundings
    o No clear superiority of individual or group support over control groups (wait list or usual care)
    o A combined individual/group approach (Mittelman et al., 1995, 1996 & 2004) resulted in delayed institutionalization for CR and **long term** mood & health improvements for CG.
      o Appears resource-intensive
    o No improvements in CG burden reported
KQ1 Do CG Interventions Improve CG or CR Outcomes?

- 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?

• Respite Care: Arksey et al., 2004, SR of 45 articles (15 US-based)
  o Day care, in-home respite, video respite, institutional/overnight respite.
    o 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.
    o 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.
    o 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?

Recent/Ongoing Research

• Resources for Enhancing Alzheimer’s Caregiver Health
  o REACH, REACH II, REACH-VA, REACH OUT
    o Support, skills training
    o Interventions feasible,
    o cost estimates of $2.93 per day

• Partners in Dementia Care (PDC) – HSRD study with collaborating VA and Alzheimer’s Association chapters
  o Dyad assessment followed by phone-based coaching, empowerment, provision of support and information.
  o In data analysis stage

• Telephone Linked Care (TLC) and Rural Telehealth Education Program
  o Phone education and support
  o No significant changes in CG outcomes but decreases in facility costs noted
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Discussion

• Some interventions show promise
  o Strongest support for multicomponent interventions based on individualized assessment
  o BMT and Case Management also had some strong studies supporting but inconsistent overall

• Are we measuring what we should be measuring?
  o Adequate sensitivity for the possible benefits experienced?
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• Additional Limitations of this Review
  o Differences AND overlaps in interventions and outcomes across studies made grouping difficult
  o Difficulty knowing which aspect of intervention was effective
  o Psychosocial studies do not lend themselves to precision
  o There may be good quality primary studies represented in poor quality systematic reviews that we missed
  o Good quality systematic reviews latest publication was 2005 for psychosocial interventions. Added studies per Expert Panel recommendations.
  o 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:

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

http://www.hsrdrresearch.va.gov/publications/esp/