

APPENDIX A. INCLUSION/EXCLUSION CRITERIA

<p>1. Is the publication a systematic review/meta-analysis?</p> <p>a. No STOP</p> <p>b. Yes <input type="checkbox"/></p> <p>Most recent year of publication within search strategy: _____</p> <p>2. Does the study population include non-professional caregivers of individuals with dementia of any severity?</p> <p>a. No STOP</p> <p>b. Yes <input type="checkbox"/></p> <p>3. Did the study evaluate the effectiveness, safety, or cost of any of the following types of interventions?</p> <p>Psychoeducational interventions <input type="checkbox"/></p> <p>Cognitive-behavioral interventions <input type="checkbox"/></p> <p>Counseling/case-management <input type="checkbox"/></p> <p>General support services <input type="checkbox"/></p> <p>Respite care <input type="checkbox"/></p> <p>Telephone-based support groups/education <input type="checkbox"/></p> <p>Home TeleHealth/Health Buddy home monitoring device <input type="checkbox"/></p> <p>Internet-based resources and caregiver assistance programs <input type="checkbox"/></p> <p>Physical activity <input type="checkbox"/></p> <p>Multicomponent interventions <input type="checkbox"/></p> <p>Other, specify <input type="checkbox"/></p> <p>None of the above.....STOP</p>	<p>5. Does the study report on any of the following patient outcomes?</p> <p>Use of psychotropic drugs <input type="checkbox"/></p> <p>Cognition <input type="checkbox"/></p> <p>Mood..... <input type="checkbox"/></p> <p>Behavioral disturbances..... <input type="checkbox"/></p> <p>Social function..... <input type="checkbox"/></p> <p>Physical function <input type="checkbox"/></p> <p>Hospitalizations, institutionalization, or other health care visits, including ER visits <input type="checkbox"/></p> <p>Accidents <input type="checkbox"/></p> <p>Health-related quality of life <input type="checkbox"/></p> <p>Satisfaction with health care..... <input type="checkbox"/></p> <p>Other, specify..... <input type="checkbox"/></p> <p>None of the above..... proceed to Q6</p> <p>6. Is the text of the article in English?</p> <p>a. No..... STOP</p> <p>b. Yes..... <input type="checkbox"/></p> <p>7. If this article meets no other criterion, should it be saved for background or discussion?</p> <p>a. No..... STOP</p> <p>b. Yes: narrative review with potentially useful references <input type="checkbox"/></p> <p>c. Yes: primary study, possibly more recent than existing SRs <input type="checkbox"/></p> <p>d. Yes: clinical guidelines <input type="checkbox"/></p> <p>e. Yes: other, specify <input type="checkbox"/></p>
<p>4. Does the study report on any of the following caregiver outcomes?</p> <p>Knowledge and ability to manage problematic behavior..... <input type="checkbox"/></p> <p>Psychosocial outcomes (burden/subjective well-being, depression, anxiety, perceived self-efficacy, quality of life, etc.)..... <input type="checkbox"/></p> <p>Health behaviors (e.g., diet, exercise, sleep)..... <input type="checkbox"/></p> <p>Health (e.g., reported health, symptoms, medication use/ misuse, service use, mortality)..... <input type="checkbox"/></p> <p>Other, specify <input type="checkbox"/></p> <p>None of the above.....proceed to Q5</p>	<p>Key words, notes:</p> <p>Full text code:</p>

APPENDIX B. QUALITY RATING CRITERIA FOR SYSTEMATIC REVIEWS*

Overall quality rating for each systematic review is based on the below questions. Ratings are summarized as: *Good, Fair, or Poor*:

- 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*

Definitions of ratings based on above criteria

Good: Meets 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; and conclusions supported by the evidence reviewed.

Fair: Studies will be graded fair if they fail to meet one or more of the above criteria, but the limitations are not judged as being major.

Poor: Studies will be graded poor if they have a major limitation in one or more of the above criteria.

***Based on the following publications:**

Harris RP, Helfand M, Woolf SH, et al. Current methods of the US Preventive Services Task Force: a review of the process. *Am J Prev Med.* 2001;20(3S): 21-35.

National Institute for Health and Clinical Excellence. The Guidelines Manual. London: Institute for Health and Clinical Excellence; 2006.

Oxman AD, Guyatt GH. Validation of an index of the quality of review articles. *J Clin Epidemiol.* 1991;44:1271-8.

APPENDIX C. USPSTF QUALITY RATING CRITERIA FOR RANDOMIZED CONTROLLED TRIALS (RCTS) AND COHORT STUDIES

CRITERIA

- Initial assembly of comparable groups: RCTs—adequate randomization, including concealment and whether potential confounders were distributed equally among groups; cohort studies—consideration of potential confounders with either restriction or measurement for adjustment in the analysis; consideration of inception cohorts
- Maintenance of comparable groups (includes attrition, cross-overs, adherence, contamination)
- Important differential loss to follow-up or overall high loss to follow-up
- Measurements: equal, reliable, and valid (includes masking of outcome assessment)
- Clear definition of interventions
- Important outcomes considered
- Analysis: adjustment for potential confounders for cohort studies, or intention-to-treat analysis for RCTs (i.e. analysis in which all participants in a trial are analyzed according to the intervention to which they were allocated, regardless of whether or not they completed the intervention)

Definition of ratings based on above criteria

- 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.
- Fair: Studies will be graded “fair” if any or all of the following problems occur, without the important limitations noted in the “poor” category below: Generally comparable groups are assembled initially but some question remains whether some (although not major) differences occurred in follow-up; measurement instruments are acceptable (although not the best) and generally applied equally; some but not all important outcomes are considered; and some but not all potential confounders are accounted for.
- Poor: Studies will be graded “poor” if any of the following major limitations exists: Groups assembled initially are not close to being comparable or maintained throughout the study; unreliable or invalid measurement instruments are used or not applied at all equally among groups (including not masking outcome assessment); and key confounders are given little or no attention.

APPENDIX D. ABBREVIATIONS

AA	African American
AD	Alzheimer's Disease
ADL	Activities of daily living
ADRDA	Alzheimer Disease and Related Disorders Association
AHRQ	Agency for Healthcare Research and Quality
AoA	Administration on Aging
BACS	Beliefs about Caregiving Scale
BDI	Beck Depression Inventory
BDRS	Blessed Dementia Rating Scale
BEHAVE	Behavioral Pathology in Alzheimer's Disease Rating Scale
BMT	Behavior management training
CES-D	Center for Epidemiologic Studies Depression Scale
CG	Caregiver
CMIA	Cohen-Mansfield Agitation Inventory
CI	Confidence interval
COPE	Care of Persons with Dementia in their Environments
CQLI	Caregiver Quality of Life Instrument
CR	Care recipient
CSDD	Cornell Scale for Depression in Dementia
CTIS	Computer-Telephone Integration System
DRS	Depression Rating Scale
DSC	Dementia Steering Committee
ECR	Elderly Caregiver Family Relationship
EPC	Evidence Based Practice Center
ESP	Evidence-based Synthesis Program
FIM	Functional Independence Measure
GDRS	Geriatric Depression Rating Scale
GDS	Global Deterioration Scale
GPS	Global Positioning System
GQ-SRs	Good quality systematic reviews
HBPC	Home Based Primary Care
HDLF	Health and Daily Living Form
HDRS	Hamilton Depression Rating Scale
HSR&D	Health Services Research and Development
HTA	Health Technology Assessment
ITT	Intention-to-treat
IADL	Instrumental Activities of Daily Living scale
ICT	Information and Technology Intervention
LSIZ	Life Satisfaction Index
LSNI	Lubben Social Network Index
LTC	Long-term care
MAACL	Multiple Affect Adjective Checklist
MADDE	Medicare Alzheimer's Disease Demonstration and Evaluation program
MAI	Multilevel Assessment Inventory
MBPC	Memory and Behavior Problems Checklist

MMSE	Mini Mental State Exam
MFW	Minnesota Family Workshop
N	Number
NHS	National Health Service
NIA/NINR	National Institute on Aging/National Institute of Nursing Research
NINCDS	National Institute of Neurological and Communicative Diseases and Stroke
NPI	Neuropsychiatric Inventory
NYU	New York University
OARS	Older Americans Resource and Services Multidimensional Functional Assessment Questionnaire
OGEC	Office of Geriatrics and Extended Care
PAC	Positive Aspects of Caregiving scale
PAIS	Psychological Adjustment to Relative's Illness
PAVeD	Preventing Aggressive Behavior in Demented Patients
PCI	Patient Care Index
PDC	Partners in Dementia Care
PHQ9	Patient Health Questionnaire-9 Item
PIC	Partners in Caregiving
POMS	Profile of Moods States
QALY	Quality of adjusted life years
QOL/QoL	Quality of life
RAGE	Rating Scale for Aggressive Behavior in the Elderly
RCT	Randomized controlled trial
REACH	Resources for Enhancing Alzheimer's Caregiver Health
RIL	Record of Independent Living
RMBPC	Revised Memory and Behavior Problem Checklist
RSCSE	Revised Scale for Caregiving Self-Efficacy
SADS	Social Avoidance and Distress Scale
SBP	Stress-Busting Program
SF-36	Short-form health survey
SIP	Sickness Impact Profile
SR	Systematic Review
SSCQ	Short Sense of Competence Questionnaire
STAI	State Trait Anxiety Inventory
STAXI	State Trait Anger Expression Inventory
T1	Timepoint 1
T2	Timepoint 2
TLC	Telephone-Linked Care
Tx	Treatment
UK	United Kingdom
VA	Veterans Affairs
VAMC	Veterans Affairs Medical Center
VHA	Veterans Health Administration
VISN	Veterans Integrated Service Network
ZBI	Zarit Burden Interview

APPENDIX E. REVIEWER COMMENTS AND RESPONSES

Reviewer	Comment	Response
Question 1. Are the objectives, scope, and methods for this review clearly described?		
2	Yes. This is well written document, and the authors have done a good job of reviewing the current evidence in the field of dementia caregiver support literature - thought provoking and certainly leads to the need for a this important topic to be studied more. It will be important to identify what works to support this very burdened caregiver population.	Noted.
4	<p>Yes. As you state, the categories are sometimes very hard to distinguish why one study is one place and not another. One particular problem I had was with the respite care section. The programs offering variety of services (p. 15, line 1) are hard to distinguish from the institutional/overnight or multi-dimensional support categories. Page 15, line 31 references basic respite care – does this refer to institutional/overnight or some other category?</p> <p>In the text descriptions of the studies, there do not appear to be consistent rules for mentioning authors (these are infrequent and when it happened, I wondered if this was a particularly good study); describing a study as small; or including the number of subjects. The number of subjects was often, but not always, listed in the text for studies pulled from the AoA compendium.</p> <p>One part that was missing, maybe due to the studies, is ethnic and racial diversity in caregiver interventions.</p> <p>p. 28, line 30 –One of the studies in this section did impact burden – line 13. p. 28, line 6 – comparably paced? Not sure what this means. Didn't the intervention group get data collection at the same time, too?</p>	<p>We have removed the sections on multi-dimensional respite care and respite care packages that offer various forms of respite care, in order to condense the sections on respite care, and to focus on clearly defined forms of respite that are offered by or potentially feasible in VA.</p> <p>The information about studies found in the AoA compendium was derived from abstracts that did not consistently report sample size.</p> <p>Because ethnic/racial differences were not specified in the key question, we didn't target the search strategy for literature specifically in this area. However, we did mention findings when the studies reported differential results by racial/ethnic group.</p> <p>We have made the adjustments specified on page 28.</p>
5	Yes. This is the most comprehensive review of caregiver stress related to dementia that I have seen. This is a sorely needed document. This document should become available for widespread use. I hope that HSR plans to produce as a booklet, much as they did for a synthesis of the literature on TBI and PTSD.	Noted.
6	Yes. The objectives and scope were outlined initially, and formed the framework of the review. This strategy was a strength of the review. I appreciated that the review was thoughtful about considering potential adverse effects of interventions, even though the literature surrounding this topic is sparse. The methods were clear as well, but required more from the reader since a full understanding of the methods required the reader to access the text, flowchart, and appendix. As I reader, I did need to interrupt the flow of my reading to understand some methodological issues that I felt were key.	Noted.

Reviewer	Comment	Response
Question 2. Is there any indication of bias in our synthesis of the evidence?		
2	No. (No comment)	Noted.
5	No. This is not an issue that is a focus of commercial interests. Therefore, it is relatively easy to be free of commercial bias. I did not detect any professional bias. The process of selecting studies was fair and appropriate. The synthesis of the information was appropriate and unbiased.	Noted.
4	This isn't a methodological bias but respite care does appear to be the favored intervention, despite being the only one with reported possible negative results. (I do realize that we are already doing it, which helps.) It often has more information on it in a summary or discussion (see p. 57). For example, in the Discussion, p 51, respite is the first intervention mentioned although it is not the first one discussed in the text. I wondered if this was your ranking of the interventions.	In an effort to condense the section on respite care, we have removed sections on respite care on multi-dimensional programs and packages, and selected only clearly defined forms of respite care that are currently offered or potentially feasible in VA.
6	No. This is a very important topic to review, but also a very challenging topic. In some sense, the categorization of studies will always be arbitrary. For instance, I would not characterize a GPS intervention to prevent wandering to be similar to a tele-health (HealthBuddy) study, but these are categorized together under technology. The review notes that prior systematic reviews were not consistent in categorizing the psychosocial studies. While I did not detect bias, I think that the review could provide a stronger rationale for the way that studies were categorized for this review.	Noted. For tech-based interventions, we followed the example of a previous review that included tracking devices as well as network-based communications technology, though we agree that these interventions are dissimilar and would warrant separate categories in a review that focuses specifically on these interventions. We discuss the reasons for and challenges in grouping of interventions.
Question 3. Are there any studies on interventions for caregivers of patients with dementia that we have overlooked?		
2	Not to our knowledge	Noted.
4	Yes. The behavioral studies stop in 2005 before the 2006 publication of the REACH II trial, which is indirectly cited in the two clinical translations, including the one done in VHA (REACH VA). REACH II was the largest behavioral RCT for dementia caregiving funded by NIH looking at racially and ethnically diverse caregiver. REACH is one of the evidence based programs that the Rosalynn Carter Institute for Caregiving funds. AoA has just issued another funding announcement for states to implement evidence based programs and REACH II is one of them. Funding Opportunities page on the AoA website at http://www.aoa.gov/AoARoot/(S(olm2ek45ppxwrg45ioqbknvj))/Grants/Funding/index.aspx	We have added two studies of the REACH intervention to the section on multicomponent interventions. These studies were published more recently than the systematic reviews we had initially identified.
5	No. There are always new studies coming out. I felt that all appropriate studies within the stated collection period were included.	Noted.
6	I think that drawing from multiple past systematic reviews and the AoA catalog provides reasonable coverage. One issue that I think stands out is that there are a few caregiver interventions that enjoy such national prominence that I would have preferred the review make special mention of how they fit into the review. This happened to some extent with REACH, at least so far as the recent VA implementations of REACH are concerned. I would have appreciated some textual section that dealt with how REACH, the New York University Counseling and Support Intervention for Caregivers, and the Savvy Caregiver Program fit into the review. (Note: I am not associated with any of these, but they seem to comprise a special category at the Administration on Aging.)	Thank you for these suggestions. We have added 2 recent studies of the REACH intervention, and 1 study of the Savvy Caregiver program. The New York University Caregiver Intervention (NYUCI) was included in the initial report (Mittelman, et al.) and we have added a more recent 2007 publication of the NYUCI trial.
Question 4. Please write additional suggestions or comments below. If applicable, please indicate the page and line numbers from the draft report.		

Reviewer	Comment	Response
2	Executive Summary p.vi, line 7, Individual Skills Training “CRs may benefit with slower declines in self-care when skills training includes a component targeting their activities of daily living.....” It could be a consideration to suggest that individual skills training for the CR may be possible to do in the setting of the ADHC in the VA.	Agree; revised accordingly.
2	Executive Summary p. vii, line 5, Multicomponent Interventions: The outcomes are equivocal across the 2 studies, with 1 documenting differential treatment effects on an outcome of interest – time to institutionalization. Not clear what the “with 1 documenting differential treatment effects on an outcome” means? On page 45 it is clear, stating that it “significantly delayed institutionalization”. Do not know if it needs to be elaborated here.	We have clarified this sentence as suggested.
2	Executive Summary, p. viii, line 12, Future Research Recommendations: The wide range of outcomes used to evaluate the effects of CG interventions reflects the diversity in what CGs and researchers consider effective. May consider using the word important for effective. I think the researchers would design interventions that they think are effective and then would measure outcomes which they think are important.	Agree; revised accordingly.
2	p.13, lines 18-19: ...problems relating to daycare attendance acted as barriers to usage for some CGs. This is a quotation from the NHS report. But it is vague what this statement means.	Agree; we have clarified by adding specific examples.
2	p. 14 lines 18-19: “There was some evidence that CRs returned home in a worse state, but also that medical conditions could be diagnosed during breaks.” This is a very important point—could recommend that we should look at the VA outcomes on this from a CPRS retrospective chart review. This would help pick up the new medical conditions diagnosed, maybe not the worsening.	Agree; we have added this suggestion.
2	p. 14, line 21: “...major benefit to sleep..” Important point—not mentioned in the Executive Summary	The original Exec Summ stated, “Institutional/overnight respite promoted better sleep patterns in CGs during the period of respite...” Therefore, we have not made any changes.
2	p. 14, lines 23-24: “There was mixed evidence on the impact of services in relation to ADL, behavior and dependency, but it is difficult to unravel the potentially negative effects of respite from the natural progression of the disease.” This is a quotation from the NHS report. But would it not be unlikely that a 2 week respite placement (or something like that) would impact the CR ADL, behavior and dependency due to the natural progression of the disease. It is unlikely that the disease would progress enough to impact ADL, and behavior in a short duration.	We have added this discussion point to the overnight respite care section.

Reviewer	Comment	Response
2	<p>p. 15, lines 13-14: “A respite care model is feasible and already in place in the VA, with admission of eligible patients to skilled nursing or Community Living Center units for respite stays of approximately one week.”</p> <p>If we have VA numbers available, may consider adding numbers here—e.g., last year there were XX respite admissions in the VA nationally. Though not all respite admissions are for patients with dementia alone.</p>	Unfortunately I was not able to track down these figures.
2	<p>p. 21, lines 11-16: “Another study reported no evidence that nursing case management delayed institutionalization of the CR when compared to usual care. . . . Miller et al, data base reported there was no reduction in CG strain, burden, or depression resulting from nursing case management intervention that included respite care, home care, and consultation, but did find that the intervention group was more likely to use community services than the control group.”</p> <p>Miller has reported that the intervention group was more likely to use community services than the control group. What is not known is the impact of the use of community services mentioned above.</p>	Noted; it would be difficult to distinguish whether beneficial effects resulted from the use of community services, which was greater among those who received the nursing case management intervention (but in this case, there was no effect on CG burden). Studies specifically on the effects of the use of community services would be needed.
2	<p>p. 21, lines 22-24: “Summary impact of case management interventions: Overall, there is little evidence to support that intensive nursing case management has a sustained impact on CG mood or strain, or on CR rates of institutionalization.”</p> <p>The Dementia Steering Committee Report (September 2008) has recommended that there be a case manager for every dementia patient. Recommendation #44 Funding for Dementia Care Coordinators which states “VISN Leaders should allocate sufficient funds to VA facilities to ensure that veterans with dementia [have] their care coordinated through Dementia Case Managers or Care Coordinators, or Case Management teams, or CCHT teams”. What do the lack of positive results using case management mean for this recommendation by the Dementia Steering Committee? Maybe the only outcome that will be positive based on the literature is more use of community resources.</p>	Recent evidence from large, good-quality studies show significant benefit, although older studies offered little evidence to support that intensive nursing case management has a sustained impact on CG mood, strain, or rates of CR institutionalization. The 2 recent studies featured individualized assessment and care plans, and reported improvements in CG depression, stress, and confidence in caregiving, and reductions in CR problem behaviors. Although the findings are mixed across studies, there is some evidence of benefit in the most recent studies.
2	<p>p. 48, lines 20-29: “An uncontrolled pilot study of the TLC screen program examined user satisfaction and changes in CG burden, health care utilization, and costs after 12 months.”</p> <p>The CCHT is developing a Dementia Disease Management protocol (DMP) that is scheduled to be piloted in the next couple of months, and to be implemented nationally soon after that. It may be useful to make the recommendation that the outcomes in terms of use of technology, and other outcomes should be evaluated, maybe in a controlled trial. This has been mentioned on Page 57, line 1. But it may be helpful to add here that this should be a priority, before interventions that are not supported by the evidence go nationwide and a lot of money is spent on them.</p>	Noted. Again, our stated purpose is to compile evidence that would help inform the decisions of policymakers. Making policy recommendations about specific interventions is beyond the scope of our report.
2	<p>p. 53, lines 7-10: “This may indicate that the definition of what constitutes meaningful change in this field needs to be reevaluated.”</p> <p>This is a key point. Another one is about the instruments used not being sensitive to change. While it has been mentioned in the Executive summary Page viii, lines 11-12 about the range of outcomes: “The wide range of outcomes used to evaluate the effects of CG interventions reflects the diversity in what CGs and researchers consider effective”, maybe this point needs to be added to it.</p>	Agreed. We have added the point regarding the sensitivity of instruments used.

Reviewer	Comment	Response
4	I would have loved to see you come out with a rousing endorsement of something we need to implement into VHA. As a researcher and an anthropologist, I like the idea of doing more qualitative research. As someone who knows how great the need is for caregivers, I would like to say, “Let’s move forward.” Maybe that is the job of the person who gets the synthesis?	Noted. We concur that the goal of this evidence review is to help inform the decisions of policymakers, although we agree that for most caregiver interventions, the results were disappointing.
4	I wondered if these articles might be of use to you in your Discussion? They are both about why we don’t get findings or why our effect sizes are so small with dementia caregivers. Have you considered a composite outcome – all these studies had an effect on a component of quality of life (such as burden or depression). That would at least give us a sense of what interventions did something. Sörensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. <i>Gerontologist</i> 2002; 42: 356–372. Schulz R, Burgio L, Burns R, et al. Resources for enhancing Alzheimer’s caregiver health: Overview and site specific outcomes. <i>Gerontologist</i> 2003; 43: 514-520.	We have added a discussion of the REACH intervention that includes Schulz 2003. We considered Sorensen 2002 in our initial review of the literature, but excluded it because the included studies were not limited to caregivers of individuals with dementia. The Sorensen 2002 analysis determined, however, that the interventions overall “were less effective at improving caregiver burden, depression, subjective well-being, and ability/knowledge when all care receivers had dementia than when care receivers did not have dementia or when the sample was mixed.” This finding emphasizes that the needs of caregivers of demented individuals differ from other caregivers. Sorensen 2002 writes, “Dementia caregivers cope with unpredictable stressors, such as problem behaviors and personality changes. Because these may be more difficult to cope with and less modifiable than the stressors common to pure physical care (Birkel & Jones, 1989), it may be more difficult to effect change through intervention with this population.”
4	I know it is a horrible thing to say but some people may just read the Discussion or that may be where people take major quotes from. It might make it easier for them if you spell out acronyms there, such as ICT (p. 51, line 21). I had to go back and look that one up myself!	We have added an appendix of abbreviations.
4	On pl 53, line 7, it is not clear that you are talking about all the interventions and not just respite, which leads off that paragraph.	We have clarified this sentence to read, “...among the variety of interventions for dementia caregivers.”
4	For line 12, spelling out what these six important outcomes are would be helpful to the reader (not sure what they are.) Would it be helpful to include them in your methods section so that readers could be watching for the big ones as they go through?	We have clarified the outcomes referred to in that section (depression, burden, coping, quality of life, and CR behavior problems), and we list these psychosocial outcomes in the methods.
4	Discussion, p. 54, line 1 1 and therapist may be a word that has psychological connotations to readers and may not be accurate for all the studies – perhaps interventionist? Line 12 – instrumentation issues (vary? Have different impacts?) across sites. Line 26 – SR= systematic reviews?	We have made the suggested corrections.

Reviewer	Comment	Response
4	P. 56, recommendations. Are the studies mentioned research or clinical translations? Different connotation if they are translations – already trying to implement.	Noted. We have changed “research” to “studies” to include both types. We have also specified “feasibility of implementation” to convey the need to assess interventions that are already being implemented in VA.
5	I did not go through the document as a copy editor, so I do not have specific formatting issues to raise. My only suggestion is that this needs to be available to people outside of VHA as well as within VHA. This may already be the plan to publish this study as an HSR&D Evidence Based Booklet. If not, I urge you to do so. This is a truly useful document.	Noted.
6	This is a valuable review that should assist policy-makers and researchers to address logical next steps. The sections describing relevance to the VA were concise and accurate.	Noted.
6	I found a fragment at the end of the sentence on line 12 pg. 54	We have made this correction.
3	In general, I found the executive summary difficult to follow and that it did not reflect the careful methods and clearer writing found in the full report.	Noted: we have revised the exec summary to provide more detail.
3	Exec Summ p. iv: “We did not assess the quality of these studies, but noted whether these more recent studies were consistent with the synthesis of findings from previous studies.” Not sure what this means	We proceeded to quality-rate the studies we selected from the AoA compendium.
3	Exec Summ p. iv: “...systematic reviews that had performed comprehensive, qualitative syntheses of the primary literature on these topics.” - Did you do an assessment of the quality of the reviews?	We rated the quality of systematic reviews using the criteria shown in Appendix B.
3	Exec Summ p. iv: “The systematic reviews of psychosocial interventions contained 224 primary studies, of which we identified 30 RCTs that met our criteria for study” - I would like to see a more detailed description of the number of articles that came from reviews and from other sources and how many were excluded from each, etc.	See response below (46C)
3	I am confused why you go back and forth between systematic review and the primary articles. I am used to seeing evidence based synthesis that primarily use the systematic review to help find the studies to include.	Because of the sheer breadth of this topic, we conducted this primarily as a review of existing systematic reviews – we took it a step further by actually going to the primary studies (the ones we felt were best quality within the reviews we examined). The benefit of such an approach is that we can cover quite a bit of ground in a systematic way and give a “bird’s eye view” of a vast/complex topic. This approach allows us to identify the types of interventions that have been studied, major gaps in the literature, and common methodologic issues in this area of study. The downside is primarily that, for any given subtopic, we are not able to do an up-to-date, complete systematic review of primary studies.
3	“significant or sustained reductions” - Are these mutually exclusive?	We have added “and/or” to indicate that these are not mutually exclusive.
3	“Three systematic reviews” - How many studies were included?	We have added the number of studies, as suggested.

Reviewer	Comment	Response
3	Exec Summ, p. v: that aimed to increase patient safety and reduce CG stress including ???	We have made this correction.
3	Exec Summ p. vi: "Implementation of exercise interventions within the VA setting might be feasible as an outpatient group or possibly through the Home-Based Primary Care program." - These summary statements are not consistently used in each section.	We have removed the sections on feasibility from the Results sections, and added a brief section on feasibility and implementation in the Discussion.
3	Exec Summ p. vi: "Studies in which BMT for the CG was augmented by CG self-care instruction" - How many studies?	We have clarified the number of studies, as suggested.
3	Exec Summ p. vi: "The VA has provided an important training avenue for geropsychology" - Be clearer about what this means.	We have removed the statements on feasibility from most sections, and this wording was removed in the process.
3	Exec Summ p. vii: "Individualized training programs are feasible within the VA, although they would require more resources of staff to evaluate the dyad and generate a tailored program. Physical and occupational therapists and psychologists could appropriately deliver this kind of intervention." - What criteria is used to come to these conclusions? Feasibility determined by? What resources would be needed? You say that PT, OT and psychologist could deliver the interventions, but is this how they were delivered in the studies?	We have removed the sections on feasibility from the Results sections. We have added a discussion on the considerations of feasibility and implementation of interventions in VA to the Discussion section, with substantial rewording.
3	Exec Summ p. viii: "A recently completed 6-month implementation study of the REACH VA intervention found positive effects on CG burden and CR problem behaviors, and appears to be feasible and low-cost in VA settings." - I would argue that it is not truly low cost. It is delivered by psychologists over multiple in home sessions.	We have removed "low-cost" from this statement, as suggested. Because individualized, resource-intensive interventions appear to be more effective, in the report we discuss the need to determine the cost-benefit of interventions that would be widely implemented in VA.
3	Exec Summ p. viii: "systematic review of respite care" - # of studies?	We have specified the number of studies, as suggested.
3	Methods, data abstraction: "and how frequently the study was included in systematic reviews." - What is the relevance of this?	The DSC had originally wondered whether these studies were widely cited but not very good evidence. We therefore sought to determine whether there were any studies that were widely known but were poor quality, and we mention this in the Discussion. We removed the data on how frequently studies were cited by other SRs from the tables, however, as we agree that this information is not obviously relevant within the tables.
3	Methods, data synthesis: We compiled a qualitative synthesis of the evidence on specific forms of therapy" - I understand what you mean by this, but I would like to know more about what went into the qualitative synthesis. Was this done by expert panel?	By this we mean that we compiled a descriptive synthesis of the evidence, as opposed to a quantitative synthesis that would combine numeric data from studies (e.g. meta-analysis). The synthesis of findings was conducted by the authors of the report, rather than the expert panel.

Reviewer	Comment	Response
3	Recent/ongoing research: “A 6-month feasibility study of implementing the REACH VA intervention among 24 HBPC programs in the VHA system found decreases in CG burden, depression, and time spent in caregiving; as well as decreases in CR behavior problems. REACH VA is based on the NIA/NINR funded REACH II study, and provides CG support and skills training in safety, behavior management, and self-care via 12 in-home and telephone sessions, and 5 telephone support group sessions. The analysis found that the VHA costs of delivering the full intervention would be \$2.93 per day over 6 months, and that satisfaction and perception of benefit from the intervention were high among both staff and CGs.” Yes, but provided to a small number of HBPC patients by psychologists. Each HBPC psychologist saw a limited number of patients. It is not clear that VA current number of HBPC psychologists or other VA psychologist would have capacity to deliver this intervention to many patients.	We agree and have emphasized that although individualized, resource-intensive interventions appear to be more effective, the need to determine the cost-benefit of interventions that would be widely implemented in VA.
3	I like how the discussion is written much more than how the Executive Summary is currently written.	Noted.
1	Methods - “We also examined recently published studies, found in a compendium compiled by the Administration on Aging’s Alzheimer’s Disease Supportive Services Program, that were not captured in previous systematic reviews. We did not assess the quality of these studies.” - Why not?	We did not formally “include” the AoA compendium because it was not a systematic review in the traditional sense, so we could not quality rate it. However, it was a very valuable resource as it has an up-to-date bibliography. Our approach was to use it as an adjunct – we looked through the compendium for more recent studies that may have had a substantial impact on the body of evidence (e.g. larger RCTs). We proceeded to quality-rate the studies we selected from the AoA for the final report.
1	Exec summary, Future research recommendations: “Respite care is already implemented in skilled care settings in the VA...” Why limit your comments to skilled care settings? VA offers respite in non-institutional settings, including home, as well as institutional (VHA Handbook 1140.02 Respite Care, Nov. 10, 2008). Respite care: “we excluded in-home respite and host-family respite care” Why exclude these? We’re interested in non-institutional interventions as well as institutional. VA offers non-institutional respite care, including in-home respite services. See VHA Handbook 1140.02 Respite Care Nov. 10, 2008.	We have made this correction and have added a section on in-home respite care.
1	Wherever possible, suggest you use “individual with dementia” rather than “dementia patient”; Suggest you use “Individual with Dementia” or “Care Recipient (CR)” instead of patient	Done.
1	Page 9 -ICT interventions: Add reference for REACH study	Done.
1	p. 10 “allocation concealment” - Explain this item	We have reworded “inadequate allocation concealment” to read “potential for selection bias.”
1	Respite care: “3) Respite programs – offer CGs, and CRs, a chance of combining together different forms of respite care and short breaks 4) Multi-dimensional CG-support packages – provide a range of services to CGs and CRs, including a respite or short-break option” Difference between these 2 categories is not entirely clear.	We have deleted these sections in order to condense the respite care section to represent interventions that are most applicable to VA.

Reviewer	Comment	Response
1	Respite care, Page 14: Overall, a day treatment model is feasible within the VA, and is currently deployed in individual VA settings with other populations (e.g. substance abuse treatment, chronically mentally ill). We did not find a VA-specific utilization/cost report for dementia day care, but community hospital programs have demonstrated cost savings through dementia day care programs. ¹⁴ Are you including VA's Adult Day Health Care in this discussion of "day treatment model"? Seems like it should be mentioned. See VHA Handbook 1141.03 Adult Day Health Care, Sept. 29, 2009. There was a VA HSR&D evaluation of the ADHC program in the distant past, I believe – not dementia-specific, but of the program as a whole.	We have removed the feasibility statements from the Results section and in the process, the text cited was deleted.
1	Respite Care – Institutional/overnight Services "This model appears suitable for a VA setting , " This is already an option in VA.	We have made this correction.
1	"Respite Care – Programs Offering a Variety of Respite Services and Short Breaks" Not entirely clear how this group differs from those in the next section.	We have added a description of the multi-dimensional CG support packages that distinguishes those interventions from respite services alone.
1	"Respite programs provide a variety of forms of respite to accommodate the needs and preferences of the CG and CR." Can you describe the range of services/studies a little more? Not sure what this group actually includes.	We have added a description of the different respite programs offered in the included studies.
1	"A respite care model is feasible and already in place in the VA, with admission of eligible patients to skilled nursing or Community Living Center units for respite stays of approximately one week." VA CLCs are skilled nursing, so "or" seems wrong here; can you clarify meaning or wording?	We have removed the sections on feasibility from the Results sections and in the process, this sentence was eliminated.
1	"Respite Care – Multi-dimensional CG Support Packages The NHS report identified 4 studies in which a range of services was provided, including a respite or short-break option." Can you describe the range of services/studies a little more? Not sure what this group actually includes.	We have added the description of the range of services provided by the NHS report.
1	Respite Care – Multi-dimensional CG Support Packages: "This program would require more specialized resources within the VA system, and does not appear to have a clear advantage in long-term outcome over basic respite care." What do you mean by "this program"? You have not described a specific program.	We have deleted this section and condensed the respite care section to represent interventions that are most applicable to VA.
1	"Psychosocial Interventions – Exercise Training: Two studies evaluated exercise training (Table 1). In one study, CGs participated in an exercise training program that successfully cultivated adherence to regular exercise participation" Is this exercise by CR or CG?	We have clarified this, as suggested, in the tables and text.
1	Psychosocial Interventions – Case Management: Can you take a look at the following two studies and see if they fit this or one of the other categories of studies you are reviewing? These are multi-component care management models that may have effects on CG and CR. Callahan, Boustani, et al., 2006, JAMA 295(18);2148-57. Vickrey et al., 2006, Ann Intern Med 145:713-26.	We have added the suggested studies to the case management section.

Reviewer	Comment	Response
1	Table 3: There are CG outcome measures, so aren't there CG results to report?	We have clarified the tables to indicate whether CG (or CR) outcomes were measured as covariates only or analyzed as outcomes of the intervention.
1	Discussion: p.56 "Future studies should use ... adequate duration of follow-up" - Did you mention this earlier as a limitation?	We have changed "adequate" to "appropriate" duration of follow-up, given that benefit from some interventions may be short-term.
1	last paragraph of discussion (before references): "supportive" - Clarify what you mean by this term. Is it all other intervention types examined in this review, or just some types?	We have removed the term "supportive" to convey that we are referring to all CG interventions.
1	"Our informal survey of recently completed and ongoing research using VA e-mail listservs identified preliminary studies of psychosocial interventions (REACH OUT57; REACH VA56; Stress-Buster's Program62) and technology-based interventions (Telehealth Education Program60; TLC58) that found improvements in CG burden with some of the interventions, and short-term savings in health care costs in one study ." Add reference citation number (for last study)	Done.
1	Future research recommendations: In this section or somewhere else in the Discussion – Do you think any of the specific interventions that we don't already provide are ready for wide-spread roll-out/implementation in VA?	It appears that the salient feature in effective interventions is the individualized assessment and construction of interventions that are tailored to the needs of the dyad. Multicomponent interventions appear to be more effective than single-intervention approaches. We have added this to the Discussion.
1	Future research recommendationsAt the end of this section, are there any more specific research recommendations to make? This final section seems almost all about respite.	We have removed some of the text in this section to de-emphasize respite care.
1	Discussion: "We attempted to examine the performance of measures for CG depression, burden, and CR behavior problems across the 30 studies reviewed here, but the samples were too small to derive strong conclusions about the hit rates of the measures." - Clarify term (hit rates)	We have replaced "hit rates of the measures" with "whether specific measures were more likely to detect improvements".
1	Discussion: "global ratings of distress and burden may not reflect the changes or possible benefits that CGs may be experiencing. Yet these measures continue to be used widely." - What is an alternative that should be used instead?	We discuss in Future Research Recommendations the need to develop/identify alternative measures to gauge the effectiveness of CG interventions, given the complexity in the needs of CGs.
1	"we did not proceed to search for recently published RCTs ." I don't understand this reasoning. I think you should search for more recent ones!	We agree and have quality-rated the studies we selected from the AoA compendium.