



Comparative Effectiveness Review Disposition of Comments Report

Research Review Title: Care Interventions for People Living With Dementia and Their Caregivers

Draft report available for public comment from March 24, 2020, to April 21, 2020.

Research Review Citation: Butler M, Gaugler JE, Talley KMC, Abdi HI, Desai PJ, Duval S, Fort ML, Nelson VA, Ng W, Ouellette JM, Ratner E, Saha J, Shippee T, Wagner BL, Wilt TJ, Yesli L. Care Interventions for People Living With Dementia and Their Caregivers. Comparative Effectiveness Review No. 231. (Prepared by the Minnesota Evidence-based Practice Center under Contract No. 290-2015-00008-I.) AHRQ Publication No. 20-EHC023. Rockville, MD: Agency for Healthcare Research and Quality; July 2020. Posted final reports are located on the Effective Health Care Program [search page](#). DOI: <https://doi.org/10.23970/AHRQEPCCER231>.

Comments to Draft Report

The Effective Health Care (EHC) Program encourages the public to participate in the development of its research projects. Each draft report is posted to the EHC Program Web site or AHRQ Web site for public comment for a 3-4-week period. Comments can be submitted via the Web site, mail or E-mail. At the conclusion of the public comment period, authors use the commentators' comments to revise the draft report.

This document includes the responses by the authors of the report to comments that were submitted for this draft report. The responses to comments in this disposition report are those of the authors, who are responsible for its contents, and do not necessarily represent the views of the Agency for Healthcare Research and Quality.

Comments on draft reports and the authors' responses to the comments are posted for public viewing on the Web site within 3 months after the final report is published. Commentators are not required to provide their names or affiliations in order to submit suggestions or comments. Each comment is listed with the name and affiliation of the commentator, if this information is provided. Comments are not edited for spelling, grammar, or other content errors. To be responsive to commentators' suggested edits regarding labels, we have used PLWD for Persons Living With Dementia and CG/P for Caregivers or Care Partners. These labels may not match the labels used by specific commentators who were responding to and using language from the draft report.



Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #5	Evidence Summary	Evidence Summary, Page 10-12 – Clearly written. Sobering results on evidence limitations and research gaps.	Thank you for the comment.
Peer (TEP) Reviewer #5	Evidence Summary	Page 12, line 10 – spell out CONSORT if first time used.	Thank you, we have made the correction.
Peer (TEP) Reviewer #1	Introduction	As written in the general comments section, the authors have written a great guide for academicians. If the report is meant to be more readable for the general public, greater care is need to simplify key messages. While it is acceptable as is, minor revisions should be considered that make this work more friendly to a lay audience. This is not mean to encourage the authors to hide the details of the work, but more to ask them to consider their audience as the introduction and discussion will be the most read sections of this work.	Thank you for the comment. We have tried to improve the report through the revision process.
Peer Reviewer #2	Introduction	I found table 1.1 to be a bit strange with regard to some outcomes: weight loss should not be an outcome...many medical factors can influence this. Use of restraints, use of antipsychotics, and harm reduction are intervention not health related outcomes.	Thank you. The outcomes Table 1.1 were developed through an extensive topic refinement process. As noted in the table, they were generally organized to correspond to the NASEM Families Caring for an Aging America (2016) framework shown in Figure 1.1.
Peer Reviewer #4	Introduction	Nicely set up for readers.	Thank you for the comment.
Peer Reviewer #4	Introduction	What is 1.2 figure analytic framework based on? It is described as 'traditional' is there a theoretical basis?	The figure is drawn from AHRQ EPC methods guidance, which can be found at https://effectivehealthcare.ahrq.gov/products/methods-guidance-principles/methods/
Peer Reviewer #4	Introduction	Define PICOTS acronym Table 1.1	Thank you, this has been done.
Peer Reviewer #4	Introduction	Overall glossary of terms very useful. Figure from NASEM aging in America very helpful and nice study framework. I appreciate the differentiation between care interventions and care delivery interventions	Thank you for the comment.
Peer (TEP) Reviewer #5	Introduction	Page 13, line 49 (line numbers are a little hard to determine) – Consider using semi-colon after “United States” instead of comma to improve readability (“...across the United States; a decadal review....”	Thank you for the comment. We opted to leave the sentence as is based on our preferred editorial style guidance.

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Published Online: July 31, 2020

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Peer (TEP) Reviewer #5	Introduction	Page 13, line 52 – Consider using semi-colon instead of comma to improve readability (“...(NASEM); as well as other efforts.”	Thank you. We have revised the sentence.
Peer (TEP) Reviewer #5	Introduction	Page 13, line 54 – Consider eliminating split infinitives in the report, e.g., change to “...designed to advance rapidly the science...” instead of “...designed to rapidly advance the science....”	Thank you. We have revised the sentence.
Peer (TEP) Reviewer #5	Introduction	Page 14, lines 8-10 – The first part of this sentence (“However, despite the availability of pharmacological options...”) seems like either a non-sequitur to the second part (“...nondrug interventions are recommended as first-line...”) or seems biased in favor of pharmacological options. Given that there are black box warnings against use of antipsychotics for behavioral management in individuals with dementia, consider re-writing this sentence more clearly/factually along the lines of, “However, there are significant side effects of pharmacological options (e.g., antipsychotics) in the treatment of behavioral and psychological symptoms of dementia (BPSD). Nondrug interventions are recommended as first-line treatments for this purpose.”	Thank you. We have amended the sentence to read: Nondrug interventions have been recommended as first-line treatments for behavioral and psychological symptoms of dementia (BPSD), but pharmacological treatment options such as antipsychotics are also available.”
Peer (TEP) Reviewer #5	Introduction	Page 19, Table 1.1 – Add “CPAP” to list of abbreviations at end of table.	This has been done.
Peer (TEP) Reviewer #5	Introduction	Scope and Key Questions, Pages 16 – 20 – Well written. Analytic Framework, Figure 1.2, Page 21 – Good. Report Organization, Page 21-22 – Well-written. Table 1.2 Glossary of terms – Good to include this table.	Thank you for the comment.
Peer Reviewer #6	Introduction	no specific comments on intro	No response needed.
Peer Reviewer #7	Introduction	The distinction made by the authors between care interventions and care delivery interventions is a novel and useful way to classify interventions in the dementia care field. Key questions are well organized, easy to follow, logical, and thorough in their coverage of the field.	Thank you for the comment.

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Peer Reviewer #7	Introduction	In the PICOTS Table 1.1, should care delivery interventions be mentioned explicitly within the PWD intervention cell, as they are in the PWD caregiver cell?	Thank you for the question. The care delivery interventions are shown in the PLWD Caregiver cell because even while the ultimate goal is to improve care for people living with dementia, the intervention target is the healthcare unit or healthcare system.
Peer Reviewer #7	Introduction	Was caregiver mastery included as an outcome in the review, distinguished from caregiver self-efficacy?	We would have included caregiver mastery as an outcome if it was used in a study. The list of outcomes in Table 1.1 was meant to be a comprehensive list of common outcomes, but not exhaustive. Therefore, we abstracted outcome measures that captured related concepts when available, and reported them using the actual outcome measure used.
Peer (TEP) Reviewer #8	Introduction	The introduction is comprehensive, with the appropriate level of information included.	Thank you for the comment.
Peer Reviewer #9	Introduction	This section is well-written and provides a nice background for the paper. It lays out the key questions and the conceptual framework, as well as the NIH Stage Model for Interventions.	Thank you for the comment.
Peer (TEP) Reviewer #1	Methods	There are no concerns. The authors took great care to accomplish this work.	Thank you for the comment.
Peer Reviewer #2	Methods	I thought the methods were all appropriate	Thank you for the comment.
Peer Reviewer #4	Methods	Inclusion and exclusion criteria well described.	Thank you for the comment.
Peer Reviewer #4	Methods	There was no discussion of whether caregivers included in studies were primary caregivers or whether multiple caregivers per PWD were included.	Thank you. No, we did not exclude studies based on type or number of CG/P. Details related to CG/P in any given study are provided in the relevant Appendix tables for each chapter and intervention section.
Peer Reviewer #4	Methods	Over threshold vs below threshold figure 2.1 is not explained in p.14 (from PDF) where figure first appears--the high risk vs over threshold language between 2 study types is confusing and must be clearly explained for figure to be useful. In tables, analytic studies are described as medium risk of bias etc but in methods and figure the language is over/under threshold which is confusing.	Thank you. We have added text in the Data Extraction section in which the figure resides to more clearly point to the section Assessing Methodological Risk of Bias and NIH Stage of Individual Studies, where more detailed information on risk of bias assessment is provided.

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Published Online: July 31, 2020



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Peer Reviewer #4	Methods	Explanation of the 37 major intervention categories would be helpful in methods- how were these determined, on what basis? Perhaps just some examples for clarity	Thank you for the question. The third paragraph in the Data Synthesis section provides a brief discussion of the approach for determining the intervention categories. The actual categories, since they were based on the literature once identified are first detailed in Chapter 3 Search Results.
Peer (TEP) Reviewer #5	Methods	Study inclusion criteria were explicitly stated (p. 24-25) and justifiable. Study exclusion criteria do not seem to be explicitly stated in Methods chapter, but exclusion results are shown in Chapter 3 Search Results (p. 31, Figure 3.1). Search strategies are explicitly stated (p. 25) and logical. Data Extraction description (p. 25-27) – Good. Assessing Risk of Bias and NIH Stage of Studies (p. 27-28) - Well written. One can learn a lot from reading the methods section of this report. Data Synthesis (p. 28-29) – Approach seems appropriate and is well written. Grading Strength of Evidence (p. 29-30) –Approach seems appropriate and is well written.	Thank you for the comments.
Peer (TEP) Reviewer #5	Methods	Page 24, line 20/21 (line numbers are difficult to determine) – Please correct VA’s name. It is “U.S. Department of Veterans Affairs (VA),” not “Veterans Administration.” (The name changed in 1989.) The sentence should read, “Federal content experts were drawn from the NIA, the Department of Veterans Affairs , the Department of Defense,”	Thank you, we have made the correction.
Peer (TEP) Reviewer #5	Methods	Page 24, line 53, Table 2.1, Study Design – What does the asterisk “*” refer to? I don’t see an asterisk at the bottom of the table.	Thank you, the asterisk has been removed.
Peer (TEP) Reviewer #5	Methods	Page 27, line 11 – Typo, words duplicated – “We extracted relevant data were extracted into Microsoft Excel.”	Thank you, we have made the correction.
Peer (TEP) Reviewer #5	Methods	Page 27, line 15 – Typo, words appear to be duplicated – “...and a second reviewer...by a second reviewer.”	Thank you, we have made the correction.
Peer (TEP) Reviewer #5	Methods	Page 28, Lines 29-34 – This second paragraph seems to be a typo, basically a duplicate of the first paragraph just before it.	Thank you, we have made the correction.

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Published Online: July 31, 2020

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Peer (TEP) Reviewer #5	Methods	Page 29, line 35/36 – Typo, words duplicated, “...any outcome to have to have at least moderate....”	Thank you, we have made the correction.
Peer (TEP) Reviewer #5	Methods	Page 25, line 5, Table 2.1, Publication Type – “Grey literature” is mentioned for the first time but not defined. Consider adding the term to the Glossary of Terms Table 1.2 on page 22.	Thank you, we added a definition for the term in the text below the table. We chose not to include the term in the glossary of terms since it was rarely used in the report (occurring only 5 times) and did not believe the term should receive such emphasis.
Peer Reviewer #6	Methods	All methods and standards are clearly stated and faithfully follow standard methodology for this type of review.	Thank you for the comment.
Peer Reviewer #7	Methods	Study inclusion criteria were thoroughly explained and justifiable. Search strategies were clearly explained and highly appropriate. Definitions and diagnostic criteria for outcome measures were based on individual study definitions, but fell appropriately within boundaries of the concepts that guided the search. Risk of bias approaches were clearly explained and appropriate. Methods used to determine strength of evidence for each outcome were thoughtfully considered and clearly explained, and appear to be well-suited to the heterogeneous nature of the interventions found and assembled for the review.	Thank you for the comment.
Peer Reviewer #7	Methods	It would be useful to know what aspects of bias rendered so many U.S. based studies to be considered ineligible due to high risk of bias. This would be helpful to provide guidance about hoe to move the field forward in a more rigorous fashion in the U.S.	Thank you for the suggestion. We added a sentence to Chapter 3, noting high risk of bias was most commonly due to issues with selection bias, attrition, or intervention fidelity. We provide a Future Research section in Chapter 10 Discussion that delves into possible improvements to future research.
Peer (TEP) Reviewer #8	Methods	The comprehensive inclusion/exclusion criteria are well explained and justifiable. The strategies, definitions, diagnostic criteria and statistical methods were well defined and very appropriate. While some may suggest the report criteria were too stringent, I believe appropriate methods were utilized to identify and examine the interventions this report is intended to review.	Thank you for the comment.



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Peer Reviewer #9	Methods	There's no justification for the requirement that that the methodology is "interrupted time series with at least 3 measures both pre- and post-intervention."	Thank you for the comment. Statistical power for interrupted time series quasi-experimental design increases with the number of observations in each time period. We have added a short statement to the table "therefore excluding simple controlled before/after studies without comparator arm."
Peer Reviewer #9	Methods	It's also not clear why MCI on its own is an excluded study population when it is often a precursor to dementia. In fact, given the broad state of the science on dementia and the movement of pharmacological interventions to the MCI or preclinical phase, MCI as a population should be included for consistency between behavioral and pharmacological interventions.	Thank you for the question. The purpose of the review was to assess the evidence for care interventions for people with dementia. Preventing or delaying dementia has been addressed in a previous AHRQ EPC systematic review. Please see Kane RL, Butler M, Fink HA, Brasure M, Davila H, Desai P, Jutkowitz E, McCreedy E, Nelson VA, McCarten JR, Calvert C, Ratner E, Hemmy LS, Barclay T. Interventions To Prevent Age-Related Cognitive Decline, Mild Cognitive Impairment, and Clinical Alzheimer's-Type Dementia. Comparative Effectiveness Review No. 188. (Prepared by the Minnesota Evidence-based Practice Center under Contract No. 290-2015-00008-I.) AHRQ Publication No. 17-EHC008-EF. Rockville, MD: Agency for Healthcare Research and Quality; March 2017. doi: https://doi.org/10.23970/AHRQEPCER188
Peer (TEP) Reviewer #1	Results	The results are a clear and measured product of the well-applied methods.	Thank you for the comment.
Peer Reviewer #2	Results	My overall comments address what I think could have been overlooked but I think you provide some rational for those exclusions. I felt overall there was a strong focus on community dwelling PWD and individual family caregivers. So much more is needed. Particularly today as we are dealing with Covid in these settings - as a provider in a CCRC it is amazing what we are doing with dementia patients to manage them with and without covid.	Thank you for the comment.

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Published Online: July 31, 2020

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Peer Reviewer #4	Results	Message from Key finding is hard to understand. For example, p.24 “Studies of live animal- and doll-assisted therapy did not advance from the evidence map to further analysis.” An individual browsing this report would have no idea how to interpret this finding on its own without reviewing methods on evidence mapping. Key findings should be more easily interpretable for readers e.g., no substantive evidence to support this therapy (whether there were no analytic studies or whether there were and they were not conclusive)	Thank you for the comment. We have revised the Key Points to read: “Studies of ... were described in the evidence map but not considered for analysis due to limitations in study designs.”
Peer Reviewer #4	Results	In tables, are numbers of PWD- total across all analytic studies only? (e.g., table 5.9)	That is correct. We have revised the tables to explicitly state “Number of PLWD in analytic set”
Peer Reviewer #4	Results	In tables Language re: benefits is inconsistent -- i.e. 1 found benefit-- vs 1 no benefit, no difference throughout tables. What if more consistently stated 0/1 no benefit or 2/3 benefit. Including denominator here would be more meaningful	Thank you for the suggestion. We have revised the tables to present more consistently, to the extent it made sense.
Peer Reviewer #4	Results	In tables I would rather see analytic evidence first before evidence base since more important	Thank you for the suggestion. We have left the order with analytic set coming second since many Basic Characteristic tables do not have analytic sets.
Peer Reviewer #4	Results	Since all strength of evidence columns in tables are insufficient and there is no variation, may not be necessary to include	Thank you for the suggestion. We have left the column in, even with its repetitiveness, because the information is critical to how findings are reported.
Peer Reviewer #4	Results	Figure 6.1. Collaboration network visualization of informal caregiver psychosocial intervention components does not add much except to show overall heterogeneity and it is hard to see.	Thank you for the comment. We have elected to leave the figure in for the support it provides to the decision to not create further subcategories of the intervention.
Peer Reviewer #4	Results	Why are there rows with same comparisons -- e.g., Anxiety Psychosocial vs Usual care in table 6.3	Thank you for the question. The two rows are differentiated by outcome timing. The first row reports results for 6 weeks, while the second reports long-term 2 year results.
Peer Reviewer #4	Results	p. 68 use the term racial/ethnic minorities instead of minorities	Thank you, we have made the suggested change.

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Peer Reviewer #4	Results	Explanations as to why findings are not considered sufficient are not adequate. For example, page 90	Thank you for the comment. The tables are all footnoted with the statement that insufficient ratings were due to study limitations and imprecision in the findings. For intervention categories with more substantial analytic sets, we also provided further detail in the text supporting the tables. We did revise the text for tables 8.16 and 8.17 for collaborative care models.
Peer (TEP) Reviewer #5	Results	Amount of detail presented in the results section is appropriate. Characteristics of the studies are clearly described. Key messages are explicit and generally applicable. Figures, tables, and appendices are generally adequate and descriptive. Inclusion/exclusion of studies appears exhaustive and appropriate.	Thank you for the comment.
Peer (TEP) Reviewer #5	Results	When Key Points say that certain things “did not advance from the evidence map to further analysis,” it would be helpful to remind the reader why some things did not advance, e.g., there were no studies on that topic with sufficiently low risk of bias, or whatever the criterion was for not advancing to the analytic set.	Thank you for the comment. We have revised the Key Points to read: “Studies ... were described in the evidence map but not considered for analysis due to limitations in study designs.
Peer (TEP) Reviewer #5	Results	When specific results sections refer to the NIH Stage Model (e.g., Stage 3, Stage 4, etc.), it would be helpful to remind the reader what type of studies that stage means.	Thank you for the suggestion. We scanned the report for all instances of the use of the NIH Stage Model and revised the text for any mention of a specific stage to also note the type of studies.
Peer (TEP) Reviewer #5	Results	Chapter 3 Search Results (p. 31-33) Overall results of study inclusion/exclusion are clearly described.	Thank you for the comment.
Peer (TEP) Reviewer #5	Results	Chapter 3 Search Results (p. 31-33) Line 41/42 – Need to close the parentheses. Looks like end parenthesis should come after “...readiness for implementation.)” Line 54/55 – Consider re-wording for clarity as “...adapted to multiple race/ethnic...” instead of current “...adapted to other race/ethnic...” given that “other than what” has not been defined. Page 32-33, Table 3.1 – Table is useful. List of abbreviations at end of table (page 33, line 28) – Do you need the ROB (risk of bias) abbreviation here? I didn’t see it in the table.	Thank you for your careful read of the report. We have made the suggested changes.

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Published Online: July 31, 2020



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Peer (TEP) Reviewer #5	Results	<p>Chapter 5 Care Interventions for PWD Well Being (p. 45-70)</p> <p>Page 58, line 29, Table 5.12 – First row, first column on the left – “Cognitive training” is listed in the box twice. Is that a typo? Or is “Cognitive training” intended to be listed, then followed by “Cognitive training vs. usual care”?</p> <p>Page 64, line 48/49 – Word missing. Looks like it should be, “Lastly, two studies examined the use of reality orientation therapy....”</p> <p>Page 66, line 11/12 – Should the word be “aides” rather than “aids”?</p>	Thank you for your careful read of the report. We have made the suggested changes.
Peer (TEP) Reviewer #5	Results	<p>Chapter 6 Care interventions for Informal Caregivers (p. 71-91)</p> <p>Page 71, line 36, Key Points, second bullet – “...found no studies reporting harms....” Does this mean no studies assessed/measured harms? Or did some studies measure harms and found/reported none? If none assessed harms, it would be clearer to say that. If studies assessed harms in some way and found/reported none, would be clearer to say that.</p>	Thank you for your careful read of the report. We have made the suggested change.
Peer (TEP) Reviewer #5	Results	<p>Chapter 6 Care interventions for Informal Caregivers (p. 71-91)</p> <p>Page 72, Figure 6.1 – This figure is very hard to read. The title of the figure uses the term “collaboration network,” which is not used when the figure is mentioned on Page 71, line 46/47. The legend of the figure says the terms move clockwise from the top, but from what I could see at high magnification that’s not the case. I’m not sure it matters. I’m not sure this figure adds anything.</p>	Thank you, we have corrected the order of the legend.

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Published Online: July 31, 2020



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Peer (TEP) Reviewer #5	Results	Chapter 6 Care interventions for Informal Caregivers (p. 71-91) Page 81, line 18/19, Social Support, Key Points, second bullet - Could you add brief statement about why they did not advance from the evidence map to further analysis, e.g., “Studies of ...did not advance from the evidence map to further analysis due to _____.” (This is just another example of the comment made above for Chapter 4. There are other examples throughout the results section.)	Thank you for the comment. We have revised the Key Points to read: “Studies of ... were described in the evidence map but not considered for analysis due to limitations in study designs.”
Peer (TEP) Reviewer #5	Results	Chapter 6 Care interventions for Informal Caregivers (p. 71-91) Page 82, Caregiver Outcomes – Line 37/28, first paragraph – Line 45, second paragraph – Says “Evidence was insufficient to draw conclusions about...” Then the next sentences seem to be drawing conclusions. Can you add something short to the first sentence to say why the evidence was insufficient? Perhaps say what is below Table 6.5 on page 83, i.e., “insufficient...due to study limitations and imprecision in the findings.”	Thank you for the suggestion. We revised the sentence to read: “Table 6.5 summarizes the primary outcomes for informal CG/P.” To avoid excessive redundancy in the report, we have limited to interventions with significant analytic sets more detailed statements about reasons for insufficient findings. As noted, all the Summary of Findings tables include the footnote regarding study limitations and imprecision.
Peer (TEP) Reviewer #5	Results	Chapter 6 Care interventions for Informal Caregivers (p. 71-91) Page 82, Caregiver Outcomes – Line 44/45 – Line 49/50 – “No harms were reported.” If harms were assessed/measured, could you clarify this sentence to say something like “potential harms such as xyz were measured, and none were found/reported”?	Thank you for the comment. The sentence has been revised to: No study assessed harms.
Peer (TEP) Reviewer #5	Results	Page 84, Caregiver Outcomes – Line 29/30 says “evidence was insufficient to draw conclusions...” Then the next paragraph summarizes the outcomes, which sounds like conclusions. To clarify first paragraph statement about insufficient evidence, perhaps say something like what is below Table 6.7 on page 85, i.e., “insufficient...due to study limitations and imprecision in the findings”?	Thank you. All Summary of Findings tables have been revised to improve consistency. Table 6.7 now provides outcomes and the associated number of studies that reported benefit or no difference. To avoid excessive redundancy in the report, we have limited to interventions with significant analytic sets more detailed statements about reasons for insufficient findings.
Peer (TEP) Reviewer #5	Results	Page 89, Table 6.11, Strength of Evidence – Asterisk (*) is missing in farright column heading?	Thank you, we have made the correction.

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #5	Results	Page 91, Conclusions, line 11/12 – “We found, however, that one multicomponent intervention did have low-strength evidence for....” It would be helpful if you named the intervention here, i.e., REACH-II, with its citation.	Thank you, we have made the suggested edit.
Peer (TEP) Reviewer #5	Results	Chapter 7 Care interventions for Formal Caregivers (p. 92) a. Line 17, Key Points – To make the Key Point more meaningful, it would be good to remind the reader why the studies did not advance from the evidence map to further analysis, e.g., there were no studies on that topic with sufficiently low risk of bias, etc.	Thank you for the comment. We have revised the Key Points to read: “Studies of ... were described in the evidence map but not considered for analysis due to limitations in study designs.”
Peer (TEP) Reviewer #5	Results	Line 51 – Consider eliminating split infinitive. Re-word as “We chose not to include....” Line 53/54 – Consider removing comma after “literature.”	Thank you for your careful read of the report. We have elected to leave some text as is for the benefit of narrative flow and/or in accordance with our editorial style guidance, but have adopted other changes as suggested.
Peer (TEP) Reviewer #5	Results	Chapter 8 Care Delivery Interventions (p. 93-114) Page 97, line 47, Key Points Page 100, line 32, Key Points Page 108, line 53, Key Points Page 110, line 4/5 , Key Points Page 110, line 41/42 Key Points - To make the Key Point more meaningful, it would be good to remind the reader why the studies did not advance from the evidence map to further analysis, e.g., there were no studies on that topic with sufficiently low risk of bias, etc.	Thank you for the comment. We have revised the Key Points to read: “Studies of ... were described in the evidence map but not considered for analysis due to limitations in study designs.”
Peer (TEP) Reviewer #5	Results	Page 100, Table 8.10 Page 102, Table 8.14 – Asterisk is missing from column heading “Strength of Evidence.” Abbreviations should include “ACP=advance care planning.”	Thank you, we have made the suggested edits.
Peer (TEP) Reviewer #5	Results	Page 110, Eligible Studies, lines 8-24 – The numbers/types of studies in the narrative paragraph don’t seem to match those in Table 8.20. The narrative paragraph says there was one study in the analytic set. Table 8.20 says 0 studies in analytic set.	Thank you, we have corrected the text to reflect the accurate table information of 0 in the analytic set.
Peer (TEP) Reviewer #5	Results	Page 112, Table 8.23 – List of abbreviations should include “RMB-PC.”	Thank you, we have added the abbreviation.

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Published Online: July 31, 2020



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Peer (TEP) Reviewer #5	Results	Page 113, Conclusion – Should you specify which collaborative care models you’re referring to in lines 43-46, 50-53, and 54-55? Earlier in the report, REACH-II was mentioned by name. Should you mention the collaborative care models by name? (If any models mentioned by name are commercial/for-profit, that fact should be stated).	Thank you, we have made the suggested edit.
Peer (TEP) Reviewer #5	Results	Page 113, Conclusion, line 53 – “These two studies” – It’s unclear which two studies you’re referring to from the rest of this paragraph (“The other pragmatic trials”).	The addition of the named collaborative care models earlier in the paragraph also serves to address this suggested edit.
Peer (TEP) Reviewer #5	Results	Chapter 9 Implementation of Care Interventions (p. 115-116) Page 114, line 6/7 – Should define “gray literature search.” What is “gray literature”?	We have added the definition used in the Methods section as a reminder for readers of this chapter.
Peer (TEP) Reviewer #5	Results	Chapter 9 Implementation of Care Interventions (p. 115-116) The brief description of these online resources and their “inclusion criteria” is good.	Thank you for the comment.
Peer Reviewer #6	Results	The investigators exclude many studies that are well-regarded generally in the field. They do not exhibit any bias in doing so, but raise the question of whether they have set the standard so high that interventions that might be helpful and ready for further study have been rejected.	Thank you for the comment. The purpose of the report was to support the task of identifying interventions that are ready for broad dissemination, which is a different question than what is ready for further study.
Peer Reviewer #7	Results	The entire results section was impressively thorough in its presentation of results. Study characteristics were clearly described, and the use of tables helped distill the copious amount of information into more easily digestible comparisons among types of studies.	Thank you for the comment.

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Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #7	Results	<p>Clearly the results are somewhat disappointing; the only question about outcomes is whether every outcome was considered, because I am aware of at least one study that showed efficacious effects on functional independence of PWD, but that study is not featured in the results section. It is possible that I missed this in my review. But otherwise the results section is very well done.</p> <p>Gitlin, L. N., Winter, L., Dennis, M. P., Hodgson, N., & Hauck, W. W. (2010a). A bio-behavioral home-based intervention and the well-being of patients with dementia and their caregivers: The COPE randomized trial. <i>Journal of the American Medical Association</i>, 304(9), 983-991. doi:10.1001/jama.2010.1253</p>	Thank you for the comment. The referenced study was included in the review. It appears in the evidence map for the Chapter 6 “Psychosocial Interventions to Support Informal Caregiver Wellbeing” intervention set
Peer (TEP) Reviewer #8	Results	While i would have liked a little more specificity in the results section - i understand the reason for the level of detail provided. Please see my other comments related to inclusion of deeper insight into those interventions that have seen substantial scaling up across the nation.	Thank you for the comment.
Peer (TEP) Reviewer #8	Results	<p>On Page 155 you note "A fourth source, the Administration for Community Living, provided a list of aging and disability evidence-based programs and practices broadly applicable to aging populations, but not specifically focused on PWD." The list cited it related to ACLs Wellness and Prevention programs. In fact, ACL, through its National Alzheimers and Dementia Resource Center (NADRC) maintains a list of dementia specific evidence based and evidence informed interventions that have been implemented through its grant programs. This compendium resource consists of a list of evidence-based and evidence-informed interventions that meet the Administration for Community Living (ACL) criteria and have been implemented by Alzheimer’s Disease Supportive Services Program (ADSSP), Alzheimer’s Disease Initiative Specialized Supportive Services (ADI-SSS) and Alzheimer’s Disease Program Initiative (ADPI) grantees between 2007-2018 and can be found at https://nadrc.acl.gov/node/140</p>	Thank you for this information. We have revised this section by calling out this resource in a new paragraph in Chapter 9 Implementation of Care Interventions.

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Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #9	Results	It would be very helpful to have the number of studies excluded for each reason at the Title and Abstract review level, not just at full text review.	Thank you for the comment. Systematic review methodology does not require detail for exclusion at the title and abstract level due to the generally large volume of screened articles that are uninformative to the review process.
Peer (TEP) Reviewer #1	Discussion and Conclusions	Factors such as size of sample were well described. The introduction and conclusion match each well from a methodological standpoint.	Thank you for the comment.
Peer (TEP) Reviewer #1	Discussion and Conclusions	Factors such as dementia type, race, sexual orientation, and economic status were discussed. Indeed this report highlights significant disparities in research support for these affected groups.	Thank you for the comment.
Peer (TEP) Reviewer #1	Discussion and Conclusions	The broader research context section seems to miss one important gap if the authors are encouraging collaboration. It is one that is perhaps another significant weakness of the literature to date. The variable use of study endpoints to measure performance is never really discussed as part of the report for similar interventions. One was left to wonder if this was a bridge too far given the state of the science, but if "big science" is to be mentioned, some consideration of this challenge should be considered. The reference to open science just doesn't seem enough without an equal emphasis on tools to promote science that can be measurable and repeatable.	Thank you, we have incorporated your suggestion into the Broader Research Context subsection.
Peer Reviewer #2	Discussion and Conclusions	Yes the implications are very well stated and I appreciated with each conclusion the caveat thatalthough no significance was noted.....	Thank you for the comment.
Peer Reviewer #4	Discussion and Conclusions	Authors appropriately address limitations and highlight decisions that had to be made in review approach.	Thank you for the comment.
Peer Reviewer #4	Discussion and Conclusions	p. 109 change system to "intervention" in the following sentence: Most importantly, the care approaches examined in this review represent complex systems nested within complex systems.	Thank you, we have revised as suggested.
Peer Reviewer #4	Discussion and Conclusions	p. 109 refer to NASEM figure by its content -- framework for care interventions (societal vs individual etc) so that it is better connected to content and discussion	Thank you, we have revised as suggested.

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Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #5	Discussion and Conclusions	Discussion/Conclusion Chapter 10 Discussion (p. 117-124) Implications of the major findings are clearly stated (p. 117). Strengths and weaknesses/limitations of the review are described adequately (p. 117-118). The Future Research section (p. 119-124) is clear and generally translated easily into new research.	Thank you for the comment.
Peer (TEP) Reviewer #5	Discussion and Conclusions	Page 117, lines 15-16 – Can you briefly re-define the NIH Stage Model framework classifications of “pilot,” “explanatory,” and “pragmatic” trials?	We briefly added “real world” to pragmatic trials to clarify the spectrum of trials. We elected not to provide further definitions in order to avoid disrupting the narrative flow of the discussion chapter.
Peer (TEP) Reviewer #5	Discussion and Conclusions	Page 117, line 21/22 – 26, “We found low-strength evidence that collaborative care models....” - REACH-II was mentioned by name. Should you also mention the collaborative care model(s) by name? (If any models mentioned by name are commercial/for-profit, that fact should be stated).	Thank you for the suggestion. We have added the names of the studies upon which the low-strength evidence was most strongly weighted. These were the ACCESS and Care Ecosystem studies.
Peer (TEP) Reviewer #5	Discussion and Conclusions	Page 117, line 48/49 - Consider eliminating split infinitive. Re-word as “...in order to answer best the question....” Or “...in order to answer the question....” Page 118, line 17/18 – Spell out abbreviation “EPC.” Page 118, line 25/26 - Consider eliminating split infinitive. Re-word as “Likewise, our decision not to include” Page 118, line 40 – Can you say briefly what is the “PRECIS-2 tool”? Page 119, line 27 – What is “the CONSORT statement”? Page 119, line 55/56 at bottom of page – Is “Latinx” the correct word? Page 120, line 3 – Spell out abbreviation “LGBTQ.”	Thank you for your careful read of the report. We have elected to leave some text as is for the benefit of narrative flow and/or in accordance with our editorial style guidance, but have adopted other changes as suggested. Latinx is the appropriate term when gender is not specified.
Peer (TEP) Reviewer #5	Discussion and Conclusions	Page 120, line 20/21, “Harms were also rarely reported” – Can you clarify whether harms were rarely assessed, rarely reported, or both? Does this mean studies rarely assessed/measured harms? Or some studies measured harms and rarely found/reported them? Page 120, line 22/23, “Other harms ... were completely absent.” – Does this mean such other harms were not assessed/measured? Or they were assessed/measured and were not found/reported?	Thank you, we have revised to use the word “assessed.”

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #5	Discussion and Conclusions	<p>Page 120, line 35/36 – Should you mention the intensive multicomponent intervention by name, (REACH-II?) by name, as you do in the next paragraph?</p> <p>Page 120, line 41 – You mention REACH-II by name. Should you also mention the collaborative care model(s) by name (or say “collaborative care models such as x, y, z” as you do with REACH-II)?</p> <p>Page 120, line 47/48 – Is “Care Ecosystems intervention” an intensive multicomponent intervention or a collaborative care model?</p>	Thank you for your careful read of the report. We have amended the section incorporating lines 35 through 48 to clarify Care Ecosystems is a collaborative care model, while not creating too much redundancy in the report narrative.
Peer (TEP) Reviewer #5	Discussion and Conclusions	<p>Page 121, line 23 – Consider eliminating split infinitive. Re-word as “...reviews such as this one to classify interventions....”</p> <p>Page 122, line 5/6 – Consider changing word to capitalize “Veteran-centered” if you are referring to a culture change effort in U.S. Dept. of Veterans Affairs (VA) health care system. Spelling Veteran with capital “V” is VA style preference.</p> <p>Page 122, line 19/20 - Consider eliminating split infinitive. Re-word as “...training requirements to deliver them successfully.....”</p>	Thank you for your careful read of the report. We have elected to leave some text as is for the benefit of narrative flow and/or in accordance with our editorial style guidance. We capitalized the “V” to meet the VA style preference.
Peer (TEP) Reviewer #5	Discussion and Conclusions	Page 122, lines 44/45 – 50, Intervention Fidelity, second paragraph – Somewhat unclear what the point is in this paragraph. First sentence, “...this research treats...differently....” Last sentence “Although ...may use mixed methods research to probe...fidelity is tracked differently....” Is it good or bad that this research tracks fidelity differently for informal and formal caregivers? Or are you just making neutral statements about this fact?	Thank you for the comment. We have revised the paragraph to note that whether an intervention is delivered as designed and trained is rarely tracked for informal caregivers.
Peer (TEP) Reviewer #5	Discussion and Conclusions	Page 123, lines 9-14, Threats to scalability – Good paragraph.	Thank you for the comment.
Peer (TEP) Reviewer #5	Discussion and Conclusions	Page 123, line 17/18 – Spell out abbreviation “GRADE” if first time used in this chapter.	Thank you, we have made the suggested edit.
Peer (TEP) Reviewer #5	Discussion and Conclusions	Page 123, line 18/19, “...benefits weighted against potential harms” – Should you say something here about lack of assessment of potential harms in this body of research?	Thank you for the question. We believe the issue of lack of assessment is better handled in the preceding report subsection on Outcomes.

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Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #5	Discussion and Conclusions	Page 123, lines 32-45, Broader Research Context, first paragraph – First sentence mentions research. Rest of paragraph sounds like opinion, especially last sentence. Can you tie these ideas back to research at end of paragraph?	Thank you for the comment. This paragraph has been shortened to reduce the appearance of opinion. The paragraph now reads: “ Another concern is how informal caregivers are perceived, and the way in which this perception informs research designs. While caregiving for PLWD presents challenges, burdens, and risks to the health of caregivers, it is not a pathological condition. Interventions aimed at mitigating burdens for informal caregivers can also recognize and build on the rewards of caregiving and the bonds it nurtures between caregivers/partners and care recipients.”
Peer (TEP) Reviewer #5	Discussion and Conclusions	Page 123, line 51/52 – Spell out abbreviation “BRI” on first use in this chapter. Briefly re-define it or give its citation so the reader can know what it is.	Thank you, we have made the suggested edits.
Peer Reviewer #6	Discussion and Conclusions	Implications are clear but devastating -- that there is almost no research ready for wide implementation. In the conclusion I wanted some more detail on how we can generate adequate research for this extremely pressing problem. Do we need training programs, more funding, programs to explicitly attract researchers to this domain?	Thank you for the comment. The Discussion chapter discusses potential future actions to improve future research activities. However, research funding policy is beyond the scope of this review.
Peer Reviewer #7	Discussion and Conclusions	The implications of major findings are clearly stated, and limitations are described adequately, with the only exception being to possibly highlight the reasons for high bias that excluded a number of intervention studies from the review, as mentioned above.	Thank you for the comment.
Peer (TEP) Reviewer #1	General	This is a well structured and methodologically consistent report. Given the breadth of the space of the topic, this is an extremely well put together report, and the methods are well described at an academic level. The fact that 37 intervention categories were captured is a tribute to the precision of the authors. It also suggest an ontology that could be used for others to classify future research initiatives.	Thank you for the comment.

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #1	General	Perhaps, the most significant weakness is that the report is technically dense. An average person will have challenges reading this manuscript. Unfortunately, it does appear that the report is as simple as possible, with the exception of chapter 10. Chapter 10 and the introduction will no doubt be the most focused on chapters by the general public. While some of the sections are well written, they still require significant time to read through, especially when interpreting different possible explanations for a result. This is particularly true for the REACH II intervention section, which seems a key piece of relatively positive evidence from this report and may deserve follow-up.	Thank you for the comment. We attempted to write the report in the most readable, accessible, and digestible format using plain language as much as possible. We share the sense that, unfortunately, because the report covers such a wide range of complex interventions for complex groups of people, there are limits to what can be reduced, condensed, or simplified without losing important nuance.
Peer (TEP) Reviewer #1	General	One other issue is the repeated reference to the NIH Stage Model. Many will go to the NIA website for clarification as they read the report. The website does not use the term "explanatory". The authors are urged to go through the manuscript, and when using such descriptors, provide the actual stage. The report should also provide the link to the NIA guidelines. If these somehow differ from the publication cited in the report, this inconsistency needs to be noted in the report. The NIA should also be alerted to the differences between the manuscript (reference 15) and the website.	Thank you. Chapter 3 on Methods provides definitions of the terms and information on assessing NIH stage of individual studies. Specifically, explanatory studies and pragmatic studies are defined in Table 1.2 and page 16 of the Methods chapter. We have scanned through the report to assure all uses of the descriptors also note actual stage. The publication cited is by the developer of the NIH Stage Model and was provided as the definitive reference.
Peer (TEP) Reviewer #1	General	Another issue is the layout of some of the tables. Many times I found myself reviewing the tables and then going back to the narrative to understand what was trying to be conveyed. A good example is the use of "Number of PWD" used on page 69, line 55. This is apparently all of the individuals pooled from 2 studies. I found myself going back to the narrative, and having to scan and add to confirm this result.	Thank you for the comment. We have revised the tables to include the more complete descriptor "Number of PLWD for analytic set."
Peer Reviewer #2	General	The review is generally very comprehensive. It was certainly depressing to see the lack of evidence of so many interventions and millions upon millions spent on those interventions.	Thank you for the comment.

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #2	General	I do alot of work in the area of treatment fidelity and was disappointed to see that was not addressed at all....till the discussion where it was acknowledged but not strongly enough. The bottom line...we don't know if the treatment - particularly treatment given to a challenging group who are either impaired or too busy sometimes to receive the intervention- might have benefited if the treatment was given as intended.	Thank you for the comment. In Chapter 3 Methods, we note that fidelity was explicitly considered when assessing risk of bias. We have added to Chapter 3 that intervention fidelity was a common reason for high risk of bias assessments. We also added a sentence to the discussion subsection titled Intervention Fidelity: "Even so, problems with fidelity was a common contributor to high risk of bias.
Peer Reviewer #2	General	I also don't know that it is fair to say that today's DSMBs and more rigorous oversight really will make better studies. I would venture to say no...or show me the evidence.	Thank you for the comment.
Peer Reviewer #2	General	Lastly a focus on settings of care was sorely missing- nothing about assisted living where are large number of older adults with dementia are living.	Thank you. We noted where appropriate whether settings were community-based or other. The vast majority of non-community-based included studies were conducted in nursing homes. Unfortunately, the terms used for non-U.S. locations do not necessarily easily translate U.S. nursing homes or assisted living. We have added a paragraph to the Future Research section to note the lack of research for this setting.
Peer Reviewer #2	General	A call for studies even looking at outcomes across settings; also a call for future studies looking at more personalization of interventions - who might benefit for what was addressed but again this may be where we need to go in the world of personalized medicine.	Thank you for the suggestions. We have added to the future research section a sentence on outcomes across settings. While understanding for how to personalize interventions can be helpful, we suggest that developing some consensus on intervention taxonomies is a fundamental challenge that needs addressing first.
Peer Reviewer #4	General	Authors did an excellent job compiling diverse studies for PWD and caregivers including examining bias. I agree with conclusions that the amount of high-quality evidence is insufficient to draw firm conclusions about interventions. Their focus on heterogeneous specific interventions is very helpful.	Thank you for the comment.
Peer Reviewer #4	General	Most of my concerns are with the terminology and representation of data and findings in tables and throughout report for clarity. For example, the term 'low-strength evidence' should be defined before it is first used-- even in abstract. Key findings are hard to understand unless one reviews introduction and methods. This can be improved so findings are more accessible to readers.	We have attempted to write the report using plain language as much as possible. For example, while low-strength evidence does have a specific definition in the methods section, the general concept of low versus high strength has relative evident meaning. The AHRQ EPC program and the GRADE working group have both been developing plain language approaches as well, thus our use of "may" for low-strength evidence findings.

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #4	General	<ol style="list-style-type: none"> 1. Note: Using page numbers at TOP OF PAGE for this review. 2. This report topic is highly clinically meaningful. 3. The report is well written. The decision to use plain language (p. 16) is great. 4. The target population is explicitly defined (p. 16, lines 28-35; p. 19, Table 1.1). 5. The audience is explicitly defined (p. 2, p. 16): 6. The key questions are appropriate and explicitly stated (p. 16-18). Well-written. 	Thank you for the comment.
Peer Reviewer #4	General	Key Informants and Technical Expert Panel, Page 4, line 18 – Spell out PICOTS if first time used (and all other abbreviations on first use).	Thank you, the edit has been made.
Peer Reviewer #4	General	Structured Abstract, Page 5 – Clearly stated. No comments.	Thank you for the comment.
Peer Reviewer #4	General	Keep in mind that some readers will have limited time to peruse/scan this lengthy report and will be looking quickly for results/conclusions on specific topics. They may not see or remember details from the methods section when they look quickly through the results. Some methodological things may need to be repeated briefly in the specific results sections (e.g., why some topics did not advance from the evidence map; why evidence was considered insufficient to draw conclusions, etc.).	Thank you for the comment. We hope the revisions to the report improved the report readability and usability.
Peer Reviewer #6	General	The report is quite clinically meaningful. Target populations and key questions are clear and appropriate.	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #6	General	<p>Overall, this review provides an incredibly damning summary of the state of nonpharmacological research to support PWD and caregivers. The report's assessment essentially throws out decades of research as insufficiently well-designed and tested to serve as the basis for large scale intervention. If the report's conclusions are broadly accepted, it can only be seen as a call to arms. The state of non-pharmacological research related to ADRD described here represents a totally unacceptable state of affairs. Their concluding comments that overall quality has increased in recent years and that possibly better research is in preparation offers rather minimal comfort for the millions of Americans living with dementia and their family members.</p> <p>The report's conclusion that almost no relevant research is of sufficient quality to merit widescale implementation will doubtless be controversial. Patients and families who have enjoyed and claimed a benefit from programs related to music, exercise, and other therapies will be greatly disappointed by the report's conclusions. Certainly the many researchers whose studies, whose whole careers, were found wanting are very likely to push-back and demand a reassessment. Crushing, the report concludes not merely that good research produced conclusive negative assessments of a range of interventions. Rather, and far more embarrassingly, the report concludes that the research is of such inadequate quality that no judgement at all can be made about the interventions. That leaves the existing research essentially worse than nothing, for it has cost money and imposed a tax of time, effort and possibly risk on participants without any benefit. One would need to start from the beginning to evaluate any promising intervention. The report's authors clearly anticipate criticism and have defended their conclusions in a variety of ways. They repeat as a kind of mantra of the report that, "our being unable to draw a conclusion does not mean that the intervention has no effect." I doubt that the researchers will find comfort in this statement.</p>	<p>Thank you for your thoughtful response to the report draft. We would like to confirm that we did not state that any given intervention has no benefit. There were many studies that reported no benefit for measured outcomes, however, we found the uncertainty of the evidence base too high to draw conclusions – either positive or negative – in those cases. We do not suggest that the literature base should be discarded; it can continue to provide foundations for future work. We also note it is a basic tenet of systematic reviews that judgement of risk of bias is not dependent on the publication source, and the correlation between high impact journals and low risk of bias ratings is surprisingly less strong than many may expect. We agree that other forms of inquiry and scientific research are also valid and can contribute to our understanding in this field. However, we disagree that RCTs do not have a place in difficult-to-study populations or for important outcomes such as health-related quality of life, or even well-being. We do agree that the wide-ranging nature of the interventions that may be used to improve QoL and well-being requires deeper conversations about the artificiality of health-related vs other domain contributions to well-being and their interactions. This is the context within which this report resides, but is beyond the scope that a single report like this can address. Likewise, we acknowledge the statements about researcher training, but this too is beyond our scope.</p>

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #6 (cont'd)	General (cont'd)	<p>The report authors are quite explicit about the type of studies and quality of evidence that met the established standards. One might ask whether those standards were set too high or inappropriately. Interestingly, quite a number of the studies evaluated were published in distinguished peer reviewed journals -- Lancet, NEJM, and JAMA among them. The report's authors note that pilot and small studies were not included in the analytic set, and perhaps some of these were high quality but preliminary studies.</p> <p>Or perhaps the standards used to assess research evidence in this report were not the only or the best standards for the particular types of research related to dementia. For instance, are there challenges in this particular domain that make it difficult/inappropriate to use the RCT as the sole standard for judging quality in research? Increasing interest in quality improvement research and qualitative research has generated a lively debate about whether the RCT is the right benchmark for every type of research. Relevant to dementia, are questions of well-being and quality of life best measured in traditional RCTs or through other research designs? Similarly, the report authors state that they were "generous" in assessing risk of bias, for instance by permitting high levels of attrition before assigning high risk of bias. (p 106) However, one may question whether standard acceptable levels of attrition, or other measures of risk of bias, are appropriate for research on dementia, a progressive, ultimately fatal disease that gradually undermines the subject's capacity to participate.</p>	

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #6 (cont'd)	General (cont'd)	<p>The caveats above might possibly (but not certainly) salvage some studies that were rejected in this report's assessment. On balance, however, the report's conclusions stand. They are unassailably correct in stating that pilot studies, those with tiny cohorts, and those that don't define the stage of dementia are not ready for wide-spread implementation. In this vast review of non-pharmacological interventions, the authors find that only 30% of the surveyed studies are from the US. In a number of the surveyed domains, almost no US studies were found. Chapter 5 addresses, among other topics, the important area of studies related to exercise; of 45 studies, 40 are not from the US. This paucity of research on an important question suggests a lack of attention, respect and/or lack of funding for non-pharm research on ADRD in America. Even if some additional programs might be deemed acceptable, that still leaves us without anything like an acceptable number and variety of effective interventions for a large and growing group of Americans who face a disease with a massive impact on survival, quality of life, and health care costs. This has to change, right now.</p> <p>The report authors offer some comfort in the report's conclusions, noting that stricter research standards have been applied to dementia research in the last five years. Those contemporary studies would not generally have made it into this review, and so there may be hope on the horizon. Nonetheless, the current lack of effective non-pharmacological interventions raises the question of whether we have failed to attract, train and fund competent researchers in this important field, especially in the US. If so, how is this serious problem to be corrected? That question is raised by this report, but its answer lies beyond the report's scope. Is it too much to suggest that all clinical research training programs should be encouraged, even required, to include courses on the design and implementation of non-pharmacological interventions for ADRD? I hope the report generates serious concern and new efforts to generate the tools we need to support people living with dementia.</p>	

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Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #7	General	This review was extremely thorough in its review of targeted interventions. The target populations are clearly and explicitly defined. Key questions are highly appropriate and explicitly stated. As for clinical meaning, it might be challenging for stakeholders to determine whether "low strength" evidence is sufficient to adopt a given intervention, but perhaps in the end such decisions must be made based on clinical judgment as is the case with many decisions in medicine and health care.	Thank you for the comment.
Peer (TEP) Reviewer #8	General	A tremendous amount of ground was covered in this report. The targets and audience we well defined, but after reading, i believe that one key consideration is missing. While i think that it is clinically meaningful, I would have liked to see it take it one step beyond the research and provide some insight into the translation activities. There have been translations of interventions that have resulted in peer reviewed journals - documenting outcomes that align with research findings. It is unfortunate that this work was not able to examine the real work application of all of the interventions reviewed.	Thank you for the comment. We found many articles that were companions to the index publication of a study's primary outcomes, and cited the publications along with the index article for the benefit of readers. These companion papers included protocols, process evaluations, qualitative pieces, and secondary analyses of data. However, given the size of the review and the number of included unique studies, further attention to translation had to remain out of scope. We agree that this would be an important contribution to make.
Peer (TEP) Reviewer #8	General	<p>The following statement: "The lack of sufficient evidence to support widespread dissemination of all other interventions analyzed in this review leaves PWD, caregivers, programs that support PWD and caregivers, funders, and policymakers without clear answers." is challenging.</p> <p>There are several interventions that have had widespread dissemination - BRI Care Consultations, SAVVY Caregiver, REACH, etc. - this report seems to ignore these translations beyond the initial research. Many of these community implementations have resulted in peer reviewed publications and evaluations.</p>	Thank you for your comment. The goal of the report was to understand the evidence base for effective care interventions and to assess the potential for broad dissemination of that evidence. We agree that other forms of inquiry and scientific research such as program evaluations are also valid and can contribute to understanding. However, understanding whether care interventions effect change is a causal question. Therefore, we focused on experimental or quasi-experimental study designs to address that goal. We note that an insufficient finding does not mean that the intervention was determined to be of no value but that the uncertainty was too high to draw a conclusion.

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #8	General	<p>In the conclusion you state: "In order for federal funders and stakeholders to fulfill their goal of expediting the translational pipeline of idea development to implementation, critical improvements must be made in dementia care and caregiver research".</p> <p>In terms of the translational pipeline, it is imperative that research projects include implementation manuals in their required deliverables. On too many occasions the research is complete and on the shelf, but there is no manual to support program delivery. On more than one occasion ACL/AOA funded grantees have had to use precious grant funds to develop implementation manuals rather than training and scaling up community level implementation of solid interventions.</p>	Thank you for the comment. We have added the importance of implementation manuals to threats to scalability in the Implementation subsection.
Peer (TEP) Reviewer #8	General	I was a little surprised that the SAVVY caregiver, as probably the intervention that has reached the most people across the nation was not identified as a program having positive effects and being embraced by caregivers as effective – perhaps that is because this is most focused on the original research, rather than including taking interventions to scale?	The report methods were planned following a progressive logic – a study had to contribute to a low strength of evidence finding (or better) to move forward into understanding the translational literature. As the number of low-strength finding was so few, we did not focus on these studies, as this may have created a biased presentation. Instead, we provided more information about the articles related to these studies in the appendixes. For each index articles, we listed companion articles, including protocols, process evaluations, qualitative pieces, and secondary analyses of data, and cited them in the appendixes with the index article.
Peer Reviewer #9	General	The target population(s) are very clearly defined, as are the key questions. They key questions are appropriate and explicitly stated.	Thank you for the comment.

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Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)	Evidence Summary	The evidence summary provides a brief, clear summary of the extensive review of non-drug interventions for people with dementia and their caregivers that was conducted by AHRQ's Minnesota Evidence-based Practice Center and is intended to support the work of the NASEM committee charged with providing recommendations about which care interventions are supported by sufficient evidence to be widely disseminated and implemented and to identify research gaps. GSA acknowledges and applauds the huge effort and careful analyses that went into conducting the review and preparing the draft report.	Thank you for the comment.

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Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
<p>Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)</p>	<p>Evidence Summary</p>	<p>GSA has one suggestion for the Evidence Summary: the Summary indicates that only seven or eight of the almost 600 reviewed interventions met the evidence criteria that were used for the review. The Summary names only one of those programs, REACH II, and provides 3 references, including one for the original REACH II study (Belle et al., 2006), one for a German adaptation of REACH II (Berwig et al., 2017), and one for a comparative effectiveness analysis (Luchsinger et al., 2018) that compared two U.S. interventions, REACH-OUT (REACH Offering Useful Treatments) and NYUCI (the New York University Caregiver Intervention), both of which were provided for Hispanic family caregivers in New York. (It is not clear to GSA whether the report intends to identify both these interventions as meeting the evidence criteria for the review.) The comparison found no statistically significant differences between the two programs, and both programs resulted in positive outcomes for the caregivers. The other four interventions that met the evidence criteria for the review are not named in the Evidence Summary but are presented as “collaborative care models” and are identified by references for 1) ACCESS (Alzheimer’s Disease Coordinated Care for San Diego Seniors (Vickery et al., 2006), 2) a telephone-based adaptation of ACCESS for family caregivers in a Latino community in Los Angeles (Chodosh et al., 2015), 3) Care Ecosystem (Possin et al., 2019), and 4) Dementia Care Management, a German intervention (Thyrian et al., 2017). GSA suggests that all of these interventions should be named in the Evidence Summary.</p>	<p>Thank you for the comment. We have clarified that the ACCESS or Care Ecosystem collaborative care models may improve select outcomes. We chose not to name the Thyrian et al intervention because it was an intervention for German locations. So while we considered it when assessing the strength of evidence for collaborative care models, we felt the applicability of the model was of question. We elected to retain the simpler language of REACH II, and the cited references as support, for the benefit of report readability.</p>

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Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Public Commenter #1 Gerontological Society of America (See Appendix X for full letter) (cont'd)	Evidence Summary (cont'd)	<p>Adding the intervention names, rather than referring to them more generally as “REACH II” and “collaborative care models” would add clarity and accuracy to the Evidence Summary. It would allow readers to understand that the review found that only these specific interventions, not all adaptations of REACH II and not all interventions often said to be “collaborative care,” met the evidence criteria. Adding the intervention names to the Evidence Summary would add complexity and make the Summary longer, but GSA thinks it would increase the value of the Summary for all readers. GSA also suggests that consistently naming the interventions or, preferably, using a clearer and more accurate phrase than “REACH II and collaborative care models” would increase the value of other sections of the report.</p>	
Public Commenter #10 Scott Trudeau, American Occupational Therapy Association	Evidence Summary	<p>This is a daunting undertaking for sure and the authors are to be commended, It is however quite disheartening to read the summary that there was so little evidence to support interventions in dementia care. The summary was overall well organized and clear to read.</p>	Thank you for the comment.

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<p>Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors</p>	<p>Evidence Summary</p>	<p>The EVIDENCE SUMMARY needs to emphasize the self-imposed limitations of this systematic review. While we acknowledge the enormity of the task at hand and the necessity of establishing certain parameters the decision to utilize a narrow clinical lens and the rationale for doing so needs to be made more explicit. This decision severely restricted the findings and imposed the use of a biomedical evidence standard which further restricts the utility of the findings. Care interventions and services and supports aimed at a persons well-being, happiness, identity, privacy, capacity, autonomy, or authority. (p. 2, Introduction) are, by necessity, complex, diverse, multifaceted and experienced individually. Aggregating N of 1• may have been better suited to capturing the full range of bio-psycho-social-spiritual interventions. In other words, the evidence base evaluation tool must be able to evaluate the broad spectrum of potentially effective, multi-factorial interventions that are not always amenable to sufficient power, randomized controlled trial design, and other scientific benchmarks that meet biomedical evidence standards but end up eliminating many potentially effective interventions. Ideally, the study could have yielded more practical and useful results had that prism been explored and reported. Instead, the study potentially is producing one more report concluding that the amount of high-quality evidence is insufficient to draw firm conclusions about interventions. The study should not be an academic exercise. The well-being and quality of lives for millions of individuals and families living with dementia across the country are impacted by the lack of congruence on what substantiates an evidence level of effective and helpful care interventions.</p>	<p>Thank you for the comment. The goal of the report, stated in the evidence summary, is to understand the evidence base for a very wide range of care interventions in order to assess the potential for broad dissemination and implementation of that evidence.</p>

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Published Online: July 31, 2020

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Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Evidence Summary	<p>While the current state of the draft report is unsettlingly, it importantly provides opportunities. With all due respect and acknowledgement to the vast accomplishments of the committee members, there is an inherent insularity from a pool of people drawn primarily from academic and research environments. The above-referenced disconnect could have been more readily identified at the study outset had the committee membership been more broadly represented by a diversity of stakeholders including people living dementia, more than one care partner, and non-clinical dementia specialists who work daily with individuals and families living with dementia. To move beyond this somewhat glaring oversight and exclusion the status quo will require change. The DAA recommends that before the draft report is finalized by committee members, the committee members meet for half a day with 10 - 15 people who represent the diversity of excluded stakeholders noted above.</p>	<p>Thank you for your comment. The systematic review underwent a comprehensive topic refinement phase. This refinement included a NASEM committee public 1-day workshop during which several people living with dementia and advocates (for people living with dementia) presented their perspectives and opinions. This NASEM committee is now re-convening to assess the AHRQ report findings and to “take stock of the current state of knowledge and inform decision making about which care interventions ... are ready for dissemination and implementation on a broad scale.” (please see https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers---phase-two for more information and to follow the NASEM process)</p>
Public Commenter #13 Amy Lewitz, Member of GAPNA	Evidence Summary	Clear and supported by the literature reviewed.	Thank you for the comment.
Public Commenter #16 Andrea Rink, Yale Connecticut Older Adult Collaboration for Health 4M	Evidence Summary	Interesting but would like more detail on methods.	Thank you for the comment. The report includes the full protocol for more interested readers.
Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)	Introduction	<p>The introduction provides useful information about the origin and goals of the review; the complexity of interventions for persons with dementia, their families, and formal/paid care providers; and the key questions selected for the review. This information helps the reader understand the rationale for the review and the organization of the report.</p>	Thank you for the comment.

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Published Online: July 31, 2020



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Public Commenter #10 Scott Trudeau, American Occupational Therapy Association	Introduction	The framework for interventions was clear but then the key questions and analytic model for the project got quite cumbersome quickly.	Thank you for the comment.
Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Introduction	The DAA feels the study's framework and perspective about living with dementia as currently written is pathologized and missing important and fundamental elements about living with dementia. These omissions undermine the quality of information in the INTRODUCTION section. Specifically, these are:	Thank you for the comment. We have revised the sentence in the Introduction's second paragraph to state: As a clinical syndrome and a disability, dementia is characterized by an acquired cognitive deficit that interferes with independence in daily activities. We also believe the wide range of interventions reviewed in this report reflect that dementia is both a clinical syndrome and a disability.
Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Introduction	The INTRODUCTION frames dementia as a clinical syndrome as opposed to a chronic disability condition that people and families need to learn how to live with. These are two vastly different paradigms and is a major reason why some vital progress to enhance the well-being and quality of lives for individuals and families has been, perhaps unintentionally but with serious repercussions, stifled. Dementia, for example, is not addressed as a disability needing support, accommodations and strategies for symptoms and changing abilities. Treating dementia as a disability is widely accepted and recognized in the United Nations Conventions of the Rights of Persons with Disabilities. The NIA can contribute to progress by also recognizing dementia as a disability in its commissioned report.	Thank you for the comment. We have revised the sentence in the Introduction's second paragraph to state: As a clinical syndrome and a disability, dementia is characterized by an acquired cognitive deficit that interferes with independence in daily activities.
Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Introduction	The INTRODUCTION treats symptoms of dementia as homogenous. There appears to be an orientation to advanced symptoms rather than as progressive with differing needs and supports throughout the course of the illness. Unfortunately, there is no mention of the needs of individuals and families living with early symptoms as opposed to those with moderate and advanced symptoms.	Thank you for sharing your perspective.

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Published Online: July 31, 2020



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Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Introduction	The INTRODUCTION has a bias towards caregivers sometimes to the exclusion of persons living with dementia. There seems to be a premise that people living with dementia cannot manage aspects of their lives without caregivers. Nothing is included about proactive living approaches during the early symptoms of dementia that is customary for cancer, heart disease, and cystic fibrosis among many other health conditions where affected persons are taught proactive living approaches to manage their symptoms.	Thank you for the comment. The Introduction necessarily must cover a wide range of people living with dementia, from early through advanced stages, types of dementia, wide range of ages, and specific populations such as Down syndrome or racial/ethnic minorities. We have revised the introduction where possible to acknowledge the full range of people living with dementia who may benefit from the report.
Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Introduction	The INTRODUCTION is silent about the fact that the most common forms of dementia (e.g., frontotemporal, Lewy Body, vascular, Alzheimer's, and mixed) have differing symptoms and effects. Constructive care interventions need to be targeted to specific symptoms, build on strengths, and support changing abilities for each of these forms of dementia. Treating dementia as a disability also opens consideration to rehabilitative therapies that have shown efficacy in implementing compensatory and adaptive strategies for people living with dementia.	Thank you for the comment. We wrote the Introduction Chapter to be a very high level introduction to minimize what was a long report. The length was unavoidable due to the complexity and size of the evidence base. The wide range of included outcome categories were intended to demonstrate the importance of function and person-important outcomes. We believe the wide range of included interventions, for example in Chapter 5 cognitive rehabilitation and psychotherapies, support the concept of treating dementia as a disability.
Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Introduction	The INTRODUCTION is also silent about person-centeredness. Person-centered practices are recognized as the gold standard by the World Health Organization and by the National Academy of Medicine (formerly the Institute of Medicine) in its 2001 report, Crossing the Quality Chasm. Person-centeredness is widely recognized by national organizations such as Eden Alternative and The Pioneer Network, that promote well-being for persons with dementia and others who are impacted by chronic conditions or illnesses.	Thank you for the comment. While we did not use the term "person-centered" in the introduction, person-centered care was foundational to determining the included outcomes during the topic refinement phase of the project. As part of AHRQ's Effective Health Care Program, EPCs such as ours follow patient-centered care as a guiding principle. (please see https://www.ahrq.gov/research/findings/evidence-based-reports/overview/index.html)
Public Commenter #13 Amy Lewitz, Member of GAPNA	Introduction	Clear and goal directed.	Thank you for the comment.

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Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Public Commenter #17 Lynn Feinberg, AARP Public Policy Institute	Introduction	Highly recommend that in the final report the term “informal” be changed to “unpaid” caregiver (typically spouse, family, friends and others). The use of the term “informal caregiver” devalues the work that family caregivers do. See the National Academies report, Caring for an Aging America, for a review of why the term “informal caregiver” perpetuates a view of caregiving by family and friends that doesn’t match the complexity of what family caregivers do today.	Thank you for the comment. Definitions and terms for this report are challenging given the wide range of stakeholders. To address this, we have added a paragraph to the Scope of the Review section acknowledging the challenge and stating our approach. We also revised the definition for informal caregivers, or CG/P, in the Glossary of Terms, Table 1.2, to note that informal caregivers are typically unpaid.
Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)	Methods	The review is based on AHRQ’s Systematic Review Methodology and generally follows processes used in other systematic reviews. As required by the review funders, the review applies narrow inclusion criteria and excludes interventions that are in stages 0-2 of NIH Stage Model for Behavioral Interventions, thus limiting the number and types of interventions in the final analytic set (96 interventions). These inclusion criteria and processes are clearly explained in the Methods section, and that clear explanation helps the report reader understand the discussion in the following chapters. As noted in our response to question 14 below, GSA believes that it would have been better to use broader inclusion criteria. This is not a criticism of the report since the criteria were dictated by the report funders. In addition, the review will benefit from engaging individuals with dementia and caregivers in the review development. Stakeholders involvement in review studies is gaining popularity. Patient and public involvement (PPI) is mandatory in countries such as the United Kingdom for funded research activities, including systematic reviews. They play a vital role in informing what is known about a topic, and what is not known, to support better programs, services, health care and policy. It has the goal to gain further knowledge about the patient/user barriers and challenges as well as to enhance the actual and perceived usefulness of synthesized research evidence.	Thank you for the comment. The inclusion criteria based on the key questions and PICOTS (population, intervention, comparator, outcomes, timing, setting) were derived from a comprehensive topic refinement phase. This refinement included a NASEM committee public 1-day workshop during which several people living with dementia and advocates presented their perspectives and opinions. We believe the methods applied focused attention on those studies best able to inform the question of what is ready for broad dissemination and implementation.

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Published Online: July 31, 2020

Commentator & Affiliation	Section	Comment	Response
Public Commenter #10 Scott Trudeau, American Occupational Therapy Association	Methods	Methods were described well. The risk of bias discussion remained somewhat unclear and it seemed that this classification by two reviewers may have had inherent bias built in to this procedure.	Thank you. We are uncertain what aspect of the dual independent review of risk of bias was concerning. We followed AHRQ EPC methods guidance, which is quite standard in the use of two qualified and trained reviewers.
Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Methods	We recommend that the Methods chapter include a list of the search terms used to identify studies. Based on the fact that many crucial and fundamental elements widely recognized by the dementia advocate community are missing from the draft report, we suspect that some key search terms were not included. Other Methods section comments are included in the comments provided in the Evidence Summary section above.	Thank you for the comment. The full search algorithm was available in Appendix A of the report.
Public Commenter #13 Amy Lewitz, Member of GAPNA	Methods	Clear about using historical research review methods.	Thank you for the comment.
Public Commenter #16 Andrea Rink, Yale Connecticut Older Adult Collaboration for Health 4M	Methods	Further explanation for low strength evidence - and how it was determined	Thank you for the comment. In addition to the methods section, appendix tables with detailed information for each intervention category were provided, including tables with the assessments for specific strength of evidence domains.
Public Commenter #17 Lynn Feinberg, AARP Public Policy Institute	Methods	Caregiver baseline characteristics (Analytic Framework Figure 1.2) should include employment, because most family caregivers now work at a job on top of their caregiving responsibilities.	Thank you for the comment. Employment was abstracted in the evidence tables if a study captured it.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)	Results	The Search Results section provides a useful graph that helps the report reader understand how the 595 unique interventions that met the inclusion criteria were further reduced to 96 interventions that are in the analytic set. The table in this section of the draft report is a valuable resource for the whole report because it provides a concise picture of the number and types of studies that were reviewed and addressed in more detail in chapters 4-8.	Thank you for the comment.
Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)	Results	It is not clear why the grey literature was not included since there is potential to gain further knowledge by including evidence that might be not available in the standard literature databases.	Thank you for the comment. Chapter 3 on Methods in the Study Selection section describes how grey literature was used for this review. The review incorporates a very large literature set focused on well-designed and conducted experimental or quasi-experimental studies that can address causality for a wide range of interventions. Systematic reviews of specific interventions can investigate and report very fine details. This review was not intended for that purpose. Our use of the NIH Stage Model as a framework to focus on studies that would best support broad dissemination precluded reporting deeply on pilot, small sample, and high risk of bias studies.
Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)	Results	The Care Intervention sections (chapters 4-8) provide details about the results of the review for particular types of interventions, using the same, highly structured format in each section. Use of the same format in all these sections helps the reader make sense of and draw conclusions from the many detailed results.	Thank you for the comment.



Commentator & Affiliation	Section	Comment	Response
Public Commenter #8 Anonymous	Results	<p>The results of this section of the report differ greatly from a recently completed related initiative called “Best Practice Caregiving”; Best Practice Caregiving includes 44 non-pharmacological programs for family and friend caregivers or people living with dementia that not only have ample research evidence of efficacy (the majority including studies that were RCTs), and in many cases effectiveness, but all these programs also have been implemented as regular parts of organizations’ service portfolios. In essence, all these programs have moved into stage 5 of the NIH framework that guided this report. The analysis of programs in Best Practice Caregiving included collecting data from program developers and organizations that delivered programs as a regular services; content analysis of program manuals and delivery tools; and comprehensive reviews of all published articles for each program. This comprehensive review enabled a detailed description of the evolution of programs as they were tested, refined, re-tested, and moved into community implementations. This comprehensive program assessment could not have been completed by only looking at published manuscripts. Best Practice Caregiving also used the “program” as the unit of analysis, rather than grouping studies into non-discrete categories and “averaging”; statistical results cross studies that had different methodologies and interventions. The authors of the NASEM report should have focused on programs as the unit of analysis and collected a broader array of data. At a minimum, they should have critically assessed the limitations of their methodology and how it may have impacted the report’s conclusions. As it currently stands, the report discredits decades of research that has resulted in hundreds of healthcare systems and community organizations implementing one or more of these programs as regular service offerings that are being used by thousands of persons with dementia and family caregivers.</p>	<p>Thank you for the comment. The Best Practice Caregiving resource is discussed in Chapter 9 and highlighted again in Chapter 10. We agree it is an important resource. However, this report used a different evidentiary standard, as noted in Chapter 9. This report’s evidentiary standard is based on experimental research standards, while the Best Practice Caregiving resource is informed by a program evaluation approach. As noted in Chapter 9, the Best Practice Caregiving resource criteria required at least one statistically significant outcome from any empirical research design, plus have been implemented in at least one organization’s regular service portfolio</p>

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



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Public Commenter #10 Scott Trudeau, American Occupational Therapy Association	Results	The analytic set is too small and too representative of non-US research than is helpful to draw programmatic determinations in the US.	Thank you for the comment.
Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Results	As already noted, because of the limitations of the biomedical inclusion criteria many valuable studies were excluded from consideration. The following is a small sample of researchers whose studies are considered seminal to support well-being and person-centered interventions for living with dementia that appear to have been excluded “ <ul style="list-style-type: none"> ï,§ Dawn Brooker UK ï,§ Linda Clare UK ï,§ Kate DeMedeiros US ï,§ Sherrie DuPuis Canada ï,§ David Edvardsson Sweden & Australia ï,§ Tom Kitwood UK ï,§ Pia Kontos Canada ï,§ Brendon McCormack UK ï,§ Wendy Moyle Australia ï,§ Steven Sabat US 	Thank you for the comment. Many of the listed names are represented in the included literature, both the analytic set and those in the evidence map.
Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Results	The current 37 major intervention categories as currently organized in the draft report are missing some important categories. Specifically - MANAGING PWD BPSD. None of the current categories include understanding the root cause of BPSDs. The root cause must be understood before identifying interventions. We recommend including a category for “root causes”.	Thank you for the comment. We agree that understanding root causes is fundamental to designing effective interventions. Most included articles outlined the theoretical approach they used when designing the intervention. Categorizing the care interventions in Chapter 4 Care Interventions for Managing BPSD in PLWD by their root causes was not feasible for this report.

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



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Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Results	PWD WELL-BEING Well-being is subjective and experienced individually. Therefore, interventions targeted to elements of well-being should include categories for “personhood,” “purpose and meaning,” “social supports including peer supports,” “proactive approaches to living with a chronic, progressive illness,” “lifestyle,” and “spirituality”. The above-referenced researchers’ work contributes to the peer-reviewed literature for these categories. Another category missing from this section is “rehabilitative therapies” including occupational, physical and speech and language therapies. Care interventions are important for functionality as well as communication. One of the categories in this section is titled, “Psychosocial Therapies for PWD Well-Being”. The companion category for Informal Caregiver Well-Being is titled, “Psychosocial Interventions for Informal Caregiver Well-Being”. We recommend using the word “Interventions” for the PWD Well-Being category instead of “Therapies”.	Thank you for the comment. We did not exclude any intervention for the well-being of people living with dementia. If lifestyle, spirituality, or rehabilitative therapy studies were found with the search algorithm, and met other inclusion criteria, they were included in the review. Functionality as an outcome was included. Interventions were not excluded based on what field developed the interventions. We have revised the section title in Chapter 5 as suggested to “Psychosocial Interventions.” We have also listed the noted interventions in the Broad Research Context subsection as possible future research directions.
Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Results	The DAA feels that the placement of this chapter before the “Care Interventions for PWD Well-Being” section leans to a biomedical orientation. The DAA recommends placing the well-being chapter ahead of the chapter on symptoms of dementia. Our rationale for this order is that to understand and manage the symptoms of dementia expressed by individuals one must first have knowledge about them including what constitutes well-being for them. For example, if someone living with dementia had a life-long love of the outdoors and was being kept inside, the “behavioral symptoms” expressed might not have anything to do with the pathology of his/her dementia but rather an emotional response to missing being outdoors.	Thank you for the suggestion. We understand and acknowledge the reason for this request. The key questions were finalized after a comprehensive topic refinement period with public comment. The chapters are organized in the order of the key questions, and at this time we believe leaving this order in place is the least disruptive.

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



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Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Results	The opening paragraph of this chapter notes that, “interventions to improve the quality of life and well-being” use a wide range of approaches from physical to cognitive to environmental (p.33).” There are no environmental interventions included in the draft report. The INTRODUCTION section of the draft report states that, “care interventions comprise an array of options that contribute to a person’s well-being, happiness, identity, privacy, capacity, autonomy, or authority.” (p. 2). These options are not reflected in this chapter.	Thank you for the comment. The report includes all identified studies that met the inclusion criteria. No study was excluded for being an environmental intervention. If an intervention category was not present in the report, it was because we did not locate an intervention to represent that category. The search algorithm provided in Appendix A was designed to be sensitive to a wide range of interventions. However, the possibility always remains that we may missed studies with our search process.
Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Results	The first section in this chapter, “Psychosocial Interventions to Support Informal Caregiver Well-Being” describes the “wide range of psychoeducational and psychotherapeutic interventions that seek to improve the well-being of caregivers” This, indeed, is important. It also is important to include psychoeducational and psychotherapeutic interventions in the companion chapter for “Care Interventions for PWD Well-Being”. Currently that chapter is silent about these interventions.	Thank you for the comment. We did not require the same intervention categories for the well-being of people living with dementia (Chapter 5) or their caregivers (Chapter 6). We instead organized the included interventions by chapter into like categories to present results. The Psychosocial Therapy section, now revised to be the Psychosocial Interventions for PLWD Well-being section, does note one UK study of psychoeducational self-management group intervention for early stages of dementia.
Public Commenter #13 Amy Lewitz, Member of GAPNA	Results	Easy to read. For this, and items 6-10, the tables helped to illustrate the less than significant findings/differences based on treatment results.	Thank you for the comment.
Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)	Discussion and Conclusions	GSA appreciates the many important ideas presented in this section, most of which match strong interests and concerns of GSA’s diverse membership. Many of the limitations and gaps in the research literature mentioned by the authors may also present opportunities for future research. Some related to populations, outcomes, interventions, implementation, broader research context, and additional questions may be addressed as follows:	Thank you for the comment.

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020

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Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)	Discussion and Conclusions	Additional areas of exploration related to functional and health status limitations, access to care and intervention services as well as accessibility, transportation, culture, race and related factors should be explored and discussed. (This speaks to the authors' note that due to the selection criteria and framework employed in the review process, some community-based interventions may not have been included in the review.)	Thank you for the comment. These suggested future research areas have been added to the Broad Research Context subsection of the Discussion chapter.
Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)	Discussion and Conclusions	The report states, "Unfortunately, quality of life was often not measured, and rarely as the outcome of primary interest." We recommend that this be linked with a recommendation for future development of better measures for psycho-social outcomes in persons living with dementia and better methods of measurement.	Thank you for the suggestion. We have revised the Outcomes subsection to include the recommendation.
Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)	Discussion and Conclusions	As a next step / action item, GSA recommends that the authors consider presenting the gaps noted in the research literature as opportunities to researchers, including GSA members, who work in dementia care research and practice, especially regarding underrepresented populations mentioned in the report draft (e.g. PWD with Down syndrome, frontotemporal dementia, racial or ethnic differences, LGBTQ populations, and those in low-resource areas including rural and/or tribal communities). In addition, presenting the gaps as opportunities to members of specific GSA interest groups (such as the Alzheimer's Disease and Related Dementias, Family Caregiving, Rainbow Research Group, Lifelong Disabilities, and Rural Aging interest groups) could provide opportunities to reach large numbers of members with similar interests and encourage them to consider collaborating on research, practice and interventions that may help reduce these gaps.	Thank you for the comment. The Discussion chapter discusses potential future actions to improve future research activities. However, research policy is beyond the scope of this review.

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020

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Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)	Discussion and Conclusions	A current topic relevant to this discussion is the ability to deploy rapid response research on various aging topics, notably employed during the COVID-19 pandemic. New technologies allow researchers to rapidly develop and quickly implement surveys via methods such as websites, email, and social media. The ability to collect data in real time, while participants are experiencing challenges, difficulties, and positive outcomes, may provide robust data that can inform future research and interventions.	Thank you for the comment.
Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)	Discussion and Conclusions	GSA agrees that those involved in dementia care research should work to make it more efficient and effective, as PWD living with this debilitating disease and their caregivers need help and support sooner rather than later. We appreciate the citing of the Benjamin Rose Institute’s Best Practice Caregiving website as an example of a “way to close feedback loops and gain knowledge from real-world applications”.	Thank you for the comment.
Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)	Discussion and Conclusions	GSA is in strong agreement with the authors that, “Without clear answers, PWD, caregivers, programs that support PWD and caregivers, funders, and policymakers will continue to depend on subjective observations, low-quality evidence, economics, and local and institutional policies.” Time is of the essence to provide evidence-based interventions and support to persons with dementia, their caregivers, and the organizations who serve them.	Thank you for the comment.

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Discussion and Conclusions	<p>The DAA has already made comments noted above concerning our disappointment with the decision to apply a high bar of scientific, clinical standard to identify the evidence base of care interventions as to exclude most of the psycho-social-spiritual intervention studies. We highly recommend that the opening sentence of the “Outcomes” section of the DISCUSSION chapter be rewritten. The sentence currently reads, “Ultimately, care interventions aim to support quality of life and prevent harm for PWD and caregivers, while enabling caregivers to continue in their roles, both within their families and society.” Care interventions, both for people living with dementia and care partners, extend well beyond quality of life and preventing harm. Care interventions should additionally aim to: support well-being (which includes emotional and social supports); understand and manage symptoms; identify accommodations and strategies to support changing abilities; enhance or delay functional decline; and provide comfort. The statement, “while enabling caregivers to continue in their roles, both within their families and society.” is offensive as it focuses only on care partners and excludes the concept of enabling people living with dementia to continue in their roles, both within their families and society.</p>	<p>Thank you for the suggested edit. We have revised the sentence to read: Ultimately, care interventions aim to support quality of life and well-being and prevent harm for PLWD and caregivers, while enabling both to continue in their roles within their families and society.</p>
Public Commenter #13 Amy Lewitz, Member of GAPNA	Discussion and Conclusions	A good summary.	Thank you for the comment.
Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors	Acronyms and Abbreviations	<p>The DAA recommends using the term people living with dementia (PLWD) as it importantly reinforces the understanding that people are living with a chronic condition. Since there is an acronym used for people with dementia, parity suggests an acronym for care partners as well.</p>	<p>Thank you for the suggestion. We have changed the term throughout the report to people living with dementia (PLWD). We understand the request for parity in acronyms. While the term and definition for care partners or informal caregivers is somewhat more complicated, we have used the acronym CG/P for informal caregiver or care partner in many places throughout the report as well.</p>

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Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Public Commenter #13 Amy Lewitz, Member of GAPNA	Acronyms and Abbreviations	Helps the reader to understand the content.	Thank you for the comment.
Public Commenter #10 Scott Trudeau, American Occupational Therapy Association	References	<p>There seem to be major gaps. See references below for methodologically sound systematic reviews that found evidence to support a variety of occupational therapy interventions in dementia care. Somehow most of this literature is not represented in this report.</p> <p>Smallfield, S., & Heckenlaible, C. (2017). Effectiveness of occupational therapy interventions to enhance occupational performance for adults with Alzheimer’s disease and related major neurocognitive disorders: A systematic review. American Journal of Occupational Therapy, 71, 7105180010. https://doi.org/10.5014/ajot.2017.024752</p> <p>Piersol, C. V., Canton, K., Connor, S. E., Giller, I., Lipman, S., & Sager, S. (2017). Effectiveness of interventions for caregivers of people with Alzheimer’s disease and related major neurocognitive disorders: A systematic review. American Journal of Occupational Therapy, 71, 7105180020. https://doi.org/10.5014/ajot.2017.027581</p> <p>Jensen, L., & Padilla, R. (2017). Effectiveness of environment-based interventions that address behavior, perception, and falls in people with Alzheimer’s disease and related major neurocognitive disorders: A systematic review. American Journal of Occupational Therapy, 71, 7105180030. https://doi.org/10.5014/ajot.2017.027409</p>	Thank you for the references. The inclusion criteria for the reviewers of the noted systematic reviews of occupational therapy interventions, while limited in reported detail, included a wider range of populations and study designs than this EPC report. There is some overlap of studies from these reviews and our report, reflecting that occupational therapy interventions, if they met the report inclusion criteria, were included. There are also considerable differences in review methodology applied between the set of reviews and this report. There is not sufficient information provided regarding risk of bias assessment, and the approach to strength of evidence differs considerably from EPC program methods.
Public Commenter #13 Amy Lewitz, Member of GAPNA	References	Very thorough	Thank you for the comment.

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
<p>Public Commenter #1 Gerontological Society of America (See Appendix X for full letter)</p>	<p>General</p>	<p>The report provides an extensive review of those studies reviewed. It offers an opportunity to guide recommendations for grant proposal development to address the gaps noted. Though the report is informative, the GSA suggests caution in how the findings are interpreted and applied due to the narrow scope of the research reviewed. The report provides an excellent starting point to establish an agenda for future work and areas of focus for funding and research. However, due to its narrow scope to care intervention and care delivery, there is a potential for the recommendations to limit creativity, innovation, and relational delivery from a family-centered context. It is suggested to consider more exploratory and inclusive designs for developing the recommendations to fill the research gaps. There are three major areas for consideration the GSA is identifying regarding this report:</p> <p>The narrow scope of the research reviewed fails to include the context within which the experience of the health condition and the caregivers occurs, therefore the complexity of the dynamic of health management is underrepresented. This becomes significant when identifying broad, “real-world” interventions. Gaps in intervention/program effectiveness will occur because the complexities have not been adequately identified and addressed to guide the research in a systematic manner.</p> <p>The recruitment of this population not only encounters the traditional challenges of conducting research, e.g. lack of diversity, low-economic status, and special interest groups, e.g. LGBTQ, dementia-related diagnoses are riddled with additional challenges. These include the societal stigma for those experiencing the symptoms and not wanting to report them to a health care professional, an inability for people to differentiate between normal cognition decline and early symptoms of dementia, and cultural implications within the family. This may be the reason for smaller sample sizes and limited generalization of findings.</p>	<p>Thank you for the comments. The Discussion chapter discusses potential future actions to improve future research activities and has been revised based on peer and public comments. However, policy is beyond the scope of this review. A NASEM committee is re-convening to review the AHRQ report and to “take stock of the current state of knowledge and inform decision making about which care interventions ... are ready for dissemination and implementation on a broad scale.” (please see https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers---phase-two for more information and to follow the NASEM process)</p>

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020

Commentator & Affiliation	Section	Comment	Response
Public Commenter #1 Gerontological Society of America (See Appendix X for full letter) (cont'd)	General (cont'd)	Progressive nature of trajectory of the dementia-related diseases is a challenge to demonstrate outcome improvement. Due to this dynamic of the disease trajectory, improvement outcomes need to be thought of differently and further defined, for clarity of research findings and its applications, not only for the person with dementia but for the caregiving related aspects. More longitudinal studies are needed to capture this changing dynamic over time.	
Public Commenter #2 Alliance for Aging Research (See Appendix X for full letter)	General	<p>Our first request is that the systematic review clearly define the evidentiary standard needed for “broad dissemination and implementation.” While reading the review we were often left wondering what standard is needed for broad dissemination of these interventions. To help the research community, patients, providers, payers, advocacy community, and other stakeholders better understand an evidentiary standard to meet the goal of “broad dissemination and implementation,” we ask the review to answer the below three questions.</p> <ul style="list-style-type: none"> • What should the basic components of any evidence-based care intervention for PWD include? • What are the evidence gaps that need to be filled for a care intervention for PWD to meet the evidence criteria for broad dissemination and implementation? • What are the evidence gaps that need to be filled for a care intervention for PWD to qualify for coverage and reimbursement by private and public, including Medicare? 	<p>Thank you for the comments. The Discussion chapter discusses potential future actions to improve future research activities and has been revised based on peer and public comments. However, policy is beyond the scope of this review. A NASEM committee is re-convening to review the AHRQ report and to “take stock of the current state of knowledge and inform decision making about which care interventions ... are ready for dissemination and implementation on a broad scale.” (please see https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers---phase-two for more information and to follow the NASEM process)</p>

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Alliance for Aging Research (See Appendix X for full letter)	General	Our second recommendation would be for AHRQ to develop a standard for the type of intervention that should be involved in a systematic review. The objective of the review was to understand the evidence base of care interventions that have the “potential for broad dissemination and implementation.” However, there were interventions included in the systematic review that would very likely not scale nationwide and would almost certainly not be reimbursed by a payer.	Thank you for the comment. A NASEM committee is re-convening to review the AHRQ report and to “take stock of the current state of knowledge and inform decision making about which care interventions ... are ready for dissemination and implementation on a broad scale.” The NASEM committee will be addressing the question of what standard could be used to recommend interventions that may be ready for dissemination (please see https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers---phase-two for more information and to follow the NASEM process)
Public Commenter #2 Alliance for Aging Research (See Appendix X for full letter)	General	It would be helpful for the review to include a specific section on whether/how certain interventions—if evidence gaps were filled—could be considered for eventual coverage and reimbursement in the Medicare program.	Thank you for the comments. The Discussion chapter discusses potential future actions to improve future research activities and has been revised based on peer and public comments. However, policy is beyond the scope of this review.
Public Commenter #2 Alliance for Aging Research (See Appendix X for full letter)	General	While CMS currently promotes the use of non-pharmacologic interventions over medication for NPS, there is not sufficient evidence for any such care interventions to be widely disseminated or implemented. We are concerned about the impact this could have on dementia patients experiencing NPS, and the professional caregivers tasked with managing them. We recommend that this systematic review 1) identify those interventions that demonstrate the most promise to help with NPS; and 2) highlight evidence gaps so that NIA/NIH can conduct or fund the research necessary for such interventions to be broadly disseminated and implemented as soon as possible, as well as eventually covered by payers.	Thank you for the comments. The Discussion chapter discusses potential future actions to improve future research activities and has been revised based on peer and public comments. However, policy is beyond the scope of this review. A NASEM committee is re-convening to review the AHRQ report and to “take stock of the current state of knowledge and inform decision making about which care interventions ... are ready for dissemination and implementation on a broad scale.” (please see https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers---phase-two for more information and to follow the NASEM process)

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020

Commentator & Affiliation	Section	Comment	Response
Public Commenter #3 Alzheimer's Los Angeles (See Appendix X for full letter)	General	<p>Alzheimer's Los Angeles appreciates the opportunity to comment on the Agency for Healthcare Research and Quality (AHRQ) report entitled, "Care Interventions for People With Dementia (PWD) and Their Caregivers." We fully support the AHRQ's goal of understanding the evidence base for care interventions for people with dementia (PWD) and their caregivers as well as assessing the potential for broad dissemination and implementation of that evidence. We also understand the report's conclusion that the level of current evidence at this time is insufficient and agree that this conclusion demonstrates the need for larger, longer-term and more rigorous studies of these interventions. However, we are concerned that these results will be used to decrease or eliminate funding and/or reduce support for adoption of evidence-supported programs to assist people living with dementia and their family caregivers. By contrast, we believe additional supports are needed now to sustain this growing population, which experiences high levels of distress.</p>	<p>Thank you for the comments. The Discussion chapter discusses potential future actions to improve future research activities and has been revised based on peer and public comments. However, policy is beyond the scope of this review. A NASEM committee is re-convening to review the AHRQ report and to "take stock of the current state of knowledge and inform decision making about which care interventions ... are ready for dissemination and implementation on a broad scale." (please see https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers---phase-two for more information and to follow the NASEM process)</p>

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Public Commenter #4 American Psychiatric Association (See Appendix X for full letter)	General	<p>Our primary concern relates to the way in which evidence was selected for inclusion in the analytic portion of the review. The description of the methods section notes that pilot studies and small sample size studies were excluded, each of which seems reasonable and appropriate. However, the text also notes that studies at stages 0 to 2 of the NIH development model were excluded. Within the NIH description of the behavioral intervention stages, stage 2 is described as consisting of traditional efficacy testing (Stage II) in which there is experimental testing of promising behavioral interventions in research settings with research-based providers. As shown in the evidence maps, some of these studies do seem to be reasonable in size and many of these studies are conducted in outpatient or nursing home settings that would be generalizable to many PWD or caregivers. In addition, studies of this type are often included in systematic reviews, particularly if they have low to moderate risk of bias. We recognize that the review was requested by the National Academies of Sciences, Engineering, and Medicine (NASEM) to identify interventions that are ready for widespread dissemination and implementation. Nevertheless, given the paucity of studies at higher levels of the NIH development model, we are concerned that excluding typical efficacy-based research studies will deprive other readers of important information that could aid in decision making.</p>	<p>Thank you for the comment. Studies deemed to be at Stages 0 to 2 of the NIH Stages Model were included in the report but not in the analytic set. They are briefly presented in the report text in the Intervention Research Context subsections of the Results chapters. They are also provided in the appropriate appendixes in evidence map tables. It is true that these studies may be included in systematic reviews that ask narrow questions about whether a specific intervention works. This review addresses a different decisional issue – what is ready for broad dissemination and implementation. Interested readers are encouraged to use the evidence maps, the full analytic set tables, and related cited companion articles, to explore more deeply specific interventions of interest.</p>
Public Commenter #4 American Psychiatric Association (See Appendix X for full letter)	General	<p>Our other comments are related to the current layout of the document and tables, which make it difficult to synthesize the substantial amount of information in the report. Part of the difficulty with the document organization is related to the way in which the key questions were defined. However, even if the document text must remain separated by key questions to fit AHRQ requirements, the layout could still be adjusted to enhance the clarity of the information that is provided.</p>	<p>Thank you for the comment. The report text and tables, and appendix tables, were constructed to support the task of identifying which approaches are ready for broad dissemination. The report document and tables were optimized for this purpose. The NASEM committee is reconvening to review the AHRQ report and to “take stock of the current state of knowledge and inform decision making about which care interventions ... are ready for dissemination and implementation on a broad scale.” (please see https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers---phase-two for more information and to follow the NASEM process)</p>

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020

Commentator & Affiliation	Section	Comment	Response
Public Commenter #5 Staff of American Psychological Association (See Appendix X for full letter)	General	We appreciate your inclusion of diverse populations in your search and review of the literature and agree that there needs to be more research in this domain within diverse populations. We also appreciate the call for developing a taxonomy of care interventions so that inconsistent reporting of interventions used in studies, such as “cognitive training” versus “cognitive rehabilitation,” can be eliminated. We were wondering if you would be able to provide further explanation of how “informal caregiver” was operationalized in the studies reviewed, noting whether spouses, children of PWD, siblings of PWD, or grandchildren of PWD were considered “informal caregivers” as well.	Thank you for the question. Table 1.1 notes CG/P may include spouses, family, friends, and volunteers. The appendix tables present how each study captured more detailed information. No study was excluded based on an CG/P definition.
Public Commenter #5 Staff of American Psychological Association (See Appendix X for full letter)	General	We were surprised to see “reminiscence therapy” categorized separately from psychosocial or psychological interventions as this therapeutic intervention is considered a psychological intervention (see for example the group life-review/reminiscence therapy as a recommended intervention for the treatment of depression in older adults in American Psychological Association, 2019a, 2019b).	Thank you for the comment. We categorized reminiscence therapy interventions as its own category when reminiscence therapy was specifically identified and was not tested with other intervention components. We agree another possible grouping would be to include it in the psychosocial intervention category. However, we still would have grouped reminiscence therapy interventions as their own separate “lineage” of research, so the results would remain the same. We believe the current placement makes the intervention more easily found by people outside of the psychology field.

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Public Commenter #5 Staff of American Psychological Association (See Appendix X for full letter)	General	<p>We are concerned that the following underlined sentence in the background section unintentionally gives a negative connotation to nondrug interventions: “However, despite the availability of pharmacological options (e.g., antipsychotics), nondrug interventions are recommended as first-line treatments for behavioral and psychological symptoms of dementia (BPSD).” There are a variety of reasons that nondrug interventions might be recommended by some as first line, such as concern about the risk of negative side effects of pharmacological interventions like antipsychotics or concern about drug to drug interaction for older adults who might already be taking other medications. We agree it is important to obtain information on any potential harms or unintended consequences of nondrug interventions. However, we suggest modifying the underlined sentence above to a more neutrally toned statement such as the following: “Nondrug interventions have been recommended as first-line treatments for behavioral and psychological symptoms of dementia (BPSD) although pharmacological treatment options such as antipsychotics are also available.”</p>	<p>Thank you. We have made the suggested edit.</p>
Public Commenter #7 Dementia Action Alliance Advisory Board Members (See Appendix X for full letter)	General	<p>To individuals living with dementia it is obvious that our voices and experiences were not involved in the study. In fact, the draft report feels tone deaf in many regards to our needs as well as containing some stigmatizing elements.</p>	<p>Thank you for the comment. We apologize for causing unnecessary discomfort or distress. The key questions and PICOTS (population, intervention, comparator, outcomes, timing, setting) were derived from a comprehensive topic refinement phase. This refinement included a NASEM committee public 1-day workshop during which several people living with dementia and advocates presented their perspectives and opinions. We have added a paragraph in the Scope and Key Questions section to address the challenges of choosing terms and definitions that balance the needs and perspectives of the many varied report audiences. We believe the methods applied focused attention on those studies best able to inform the question of what is ready for broad dissemination and implementation. We hope the revisions to the report have improved the final product, and we thank you for helping us to understand how to make the report better.</p>

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Public Commenter #7 Dementia Action Alliance Advisory Board Members (See Appendix X for full letter)	General	<p>The report had a bias toward “caregivers.” We noted that the report is filtered primarily through the lens of caregivers and the effect that dementia has on them. This is disconcerting and sends a not so subtle message that persons living with dementia are not valuable themselves and are unable to manage our lives without a caregiver (see Chapter 1, Background). The word caregiver has patriarchal overtones and not all people living with dementia have care partners.</p>	<p>Thank you for the comment. We apologize for causing unnecessary discomfort or distress. We have added a paragraph in the Scope and Key Questions section to address the challenges of choosing terms and definitions that balance the needs and perspectives of the many varied report audiences. As established by the key questions, we captured outcomes for the person living with dementia if available regardless of who was the intended intervention target.</p>
Public Commenter #7 Dementia Action Alliance Advisory Board Members (See Appendix X for full letter)	General	<p>There is a bias in the draft report towards a biomedical orientation rather than from a living with a chronic condition orientation. Where are the considerations of needing to learn how to live with dementia? Of learning how to manage our symptoms? Where are the considerations of building self-reliance or of the importance of a proactive orientation? A “living orientation” would provide approaches and strategies that would be helpful to many stakeholders including persons with dementia and care partners. A living orientation is standard practice for other chronic conditions such as heart disease, diabetes, and Parkinson’s. The biomedical orientation is stigmatizing and suppresses progress.</p>	<p>Thank you for the comment. The review methods were designed to capture as wide a range of interventions as were present in the literature using a sensitive search algorithm. While we acknowledge in the Limitations section that some studies may have been missed, we believe the approach captured studies that represent both the biomedical and living orientations. The report organization included chapters for both PLWD and care partner well-being, and many intervention sections noted studies that might be considered living orientation. However, it is true that many studies were designed and written from a biomedical orientation. And very few from either the biomedical or living orientations met the level of rigor required for inclusion in an analytic set.</p>
Public Commenter #7 Dementia Action Alliance Advisory Board Members (See Appendix X for full letter)	General	<p>Another bias that was evident to us in the draft report was the focus on older adults with an Alzheimer’s diagnosis in the mid to later stages. The report seems to examine dementia primarily through a homogeneous lens rather than a heterogeneous lens. The reality is that we will experience different symptoms depending on our diagnosis, that in turn will necessitate different care interventions. There is little attention in the draft report to non-Alzheimer’s dementias; they are however mentioned in passing. Additionally, we were hoping that this report might cite studies that examine diversity beyond our medical diagnosis to take into account the heterogeneity of the lived experience with considerations of race, language, education, culture, socio-economic considerations and more.</p>	<p>Thank you for the comment. We share your frustration with the lack of studies for different populations segments and noted the lack as an important research gap. It is an unfortunate fact that the majority of studies were concentrated on specific segments of people.</p>

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Public Commenter #7 Dementia Action Alliance Advisory Board Members (See Appendix X for full letter)	General	The draft report contains some words we find problematic. We prefer the term care partners to caregivers because partner implies a relationship where both are working toward a common goal. We certainly understand that more care will be needed as our dementia progresses. We want people to understand that we are not just recipients of care and services; we are able to offer something of ourselves to the relationship and want to weigh in on our care and services. As in every relationship, the balance may shift with one person being the one who is doing more of the support.	Thank you for sharing your perspective. The terms and definitions for care partners or informal caregivers are complicated, shaped by many stakeholders. We have used the acronym CG/P for informal caregiver or care partner throughout the report in an attempt to address this concern, and to provide parity in the use of acronyms.
Public Commenter #7 Dementia Action Alliance Advisory Board Members (See Appendix X for full letter)	General	We prefer the term people living with dementia instead of people with dementia because it underscores the fact that we are living with a chronic condition which is generally overlooked. We recommend the report incorporate these terms throughout and change the title to, "Care Interventions for People Living with Dementia and their Care Partners".	Thank you for the suggestion. We have changed the term throughout the report to people living with dementia (PLWD).
Public Commenter #7 Dementia Action Alliance Advisory Board Members (See Appendix X for full letter)	General	In general, we prefer the word support to care. The word care carries patriarchal overtones while support denotes assisting and partnering together.	Thank you for the suggestion. We have looked for opportunities to increase the use of the term "support." There do remain interventions in the report where the term "care" may best describe the action.
Public Commenter #7 Dementia Action Alliance Advisory Board Members (See Appendix X for full letter)	General	The use of the term behavioral and psychological symptoms of dementia or its acronym BPSD are deeply offensive and not acceptable to the community of people living with dementia because it underscores a biomedical orientation and the absence of understanding actual symptoms and triggers. We experience people using the term as a pejorative label and as if it were a sufficient explanation for a reaction or behavior. The draft report goes even further and uses the term non-BPSD. We take exception to the use of either label to describe us or our actions.	Thank you for sharing your perspective. We are sorry to hear of your experiences and apologize for causing unnecessary discomfort or distress. We have added a paragraph in the Scope and Key Questions section to address the challenges of choosing terms and definitions that balance the needs and perspectives of the many varied report audiences. Lacking a better term to use, we have continued to use BPSD. We do so with the motivation of honoring the original intention of the term to draw care and support resources to attend to unmet needs of people living with dementia.

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020



Commentator & Affiliation	Section	Comment	Response
Public Commenter #7 Dementia Action Alliance Advisory Board Members (See Appendix X for full letter)	General	We find the use of the word burden is offensive. Burden implies fault and has a negative connotation. Synonyms include hardship, hindrance and albatross. Other health conditions have elements that cause strain, such as autism and ALS, yet don't have a burden mentality. This is another example of the stigmatization we experience living with dementia.	Thank you for sharing your experiences. To avoid confusion, we are obligated to use the term “caregiver burden” when it is the proper name of a measurement tool, such as the Zarit Caregiver Burden Scale. The term “burden” has also been applied generally in a patient-centered model of patient complexity to help people understand the impact of treatment, management, and illness burden on patients. The term has helped expand understanding past the biomedical clinical model to a more comprehensive understanding of the impact of a chronic medical condition on a person. Please see Shippee et al., Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. Journal of Clinical Epidemiology. 2012;65(10): 1041-1051. DOI 10.1016/j.jclinepi.2012.05.005
Public Commenter #7 Dementia Action Alliance Advisory Board Members (See Appendix X for full letter)	General	AHRQ’s systematic review include the evidence base on sex and gender differences in dementia and caregiving burden.	Thank you for the comment. We did capture where available sex and gender differences and note in the lack of such research available.
Public Commenter #7 Dementia Action Alliance Advisory Board Members (See Appendix X for full letter)	General	AHRQ’s final report prioritize sex and gender differences in caregiving research to address knowledge gaps.	Thank you for the comment. We did capture where available sex and gender differences and note in the lack of such research available.

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020

Commentator & Affiliation	Section	Comment	Response
Public Commenter #9 Anonymous	General	<p>The draft report has several important strengths and weaknesses. Significant strengths of the report include: 1) identification of the problem/issue facing individuals with dementia, informal and formal caregivers, and health care delivery systems; 2) inclusion and comprehensive review of programs that target/address specific issues related to individuals with dementia, informal family caregivers, formal caregivers, and health care delivery systems; and 3) the inclusion of different types of research designs. Significant weaknesses of the report primarily stem from the methodological approach and the subsequent findings and conclusions. Several methodological sections were not clear or lacked sufficient details to fully understand how findings were interpreted and conclusions drawn. Specifically, there were two key methodological weaknesses: 1) it was unclear the rationale and development of the categories used to group and compare studies, especially given the multi-component nature of most studies, the range of differing research designs used, and the variability in focus of research question; and 2) it was not clear how studies that were grouped together (based on the developed categories) were compared/analyzed to determine the level of evidence for that specific category.</p>	<p>Thank you for the comment. The Methods chapter provided information regarding grouping. In the absence of consensus on taxonomies for interventions, we grouped the interventions empirically, qualitatively assessing the interventions for likeness and differences and “best fit” to a group. We acknowledge there is an element of arbitrariness and that others may offer differing approaches to grouping. The Methods chapter also lays out the approaches for synthesis and strength of evidence assessment. Each results section notes the inability to combine studies, and indeed only two meta-analyses were conducted, due to heterogeneity of the literature. In the large majority of cases, a single study constituted the evidence base. All detailed information on the outcomes extracted and the strength of evidence assessment are provided in the appendixes.</p>

Source: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

Published Online: July 31, 2020

Commentator & Affiliation	Section	Comment	Response
Public Commenter #9 Anonymous (cont'd)	General (cont'd)	<p>For example, in the summary findings tables, the number of studies that found significant results along with the number of studies that did not find significant results were included for each developed category. A general pattern that emerged throughout the report was that if all of the studies did not find significant results within the developed category then the level of evidence was determined to be insufficient/low. However, it was not clear how this determination was made and it was not clear whether key study factors within each study were considered when making comparisons across studies, such as sample size, effect size, program/intervention dosage, sample characteristics, study design, and measurement issues which is typically achieved by conducting a meta-analysis when comparing results across studies. It also was not clear whether programs that have received extensive investigation were grouped together and examined for the collective larger body of existing research evidence or not (i.e., programs that have been systematically tested for efficacy, effectiveness, and translation/real-world implementation).</p>	

Commentator & Affiliation	Section	Comment	Response
Public Commenter #9 Anonymous (cont'd)	General (cont'd)	<p>Due to the aforementioned methodological concerns, it was unclear how best to evaluate the findings from the report and the resulting conclusions. This was especially relevant for the findings pertaining to the programs for informal caregivers. Specifically, within the field there has been nearly 30 years of well-conducted and well-studied programs for informal caregivers of individuals with dementia. More recently, at the first National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers (2017) one of the main findings and summary conclusions was that there was sufficient research evidence pertaining to programs for informal family caregivers of individuals with dementia. Additionally, based on this evidence it was recommended that research programs designed for informal family caregivers should take the next step forward and should be tested within “real-world”; implementations that focus on the translation and scalability of the program to fit within existing health care and social service organizations. As such, it was difficult to interpret and reconcile the findings/conclusions from this draft report given the prior work that has been done in this area along with the aforementioned methodological concerns.</p>	



Commentator & Affiliation	Section	Comment	Response
<p>Public Commenter #10 Scott Trudeau, American Occupational Therapy Association</p>	<p>General</p>	<p>The organization of the sections is somewhat challenging. There is a lack of emphasis on meaningful outcomes like maintenance or improvement of functional status and inattention to the key role that the physical environment plays in supporting both caregivers and optimizing the performance of PWD. While I concede that evidence may not be as prevalent as we would like to support interventions - this report is unrealistic in the assertion that more, larger studies will be the simple fix. The complex nature of testing interventions with vulnerable populations may be calling us to do different kinds of research. The research machine has long been driven to a reductionistic approach to evidence. The variables that matter in this population may not be amenable to this rigid approach. It is also important to note that there has been disparity in the way that funding has traditionally been allocated to fund research in the favor of more reductionistic biomarker studies to the detriment of intervention trials to improve quality of life. Nonpharmacologic care intervention studies could potential be improved significantly with more support from funding sources for these studies.</p>	<p>Thank you for the comment. We collected functional outcomes when available. We believe the methods used for this review is one of many methodological approaches that can lead to useful insights. While no one methodological approach may be sufficient to address a complex phenomenon, multiple methodological approaches allow us to triangulate on the phenomenon.</p>

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Commentator & Affiliation	Section	Comment	Response
<p>Public Commenter #11 Karen Love, Dementia Action Alliance Board of Directors</p>	<p>General</p>	<p>Stigma is perpetuated through words spoken and written. Rosa’s Law, for example, was signed into law in the United States in 2010 to mandate the use of the term ‘intellectual disability’ to replace ‘mental retardation’ and ‘mentally retarded’. That law can be found at https://www.govinfo.gov/content/pkg/PLAW-111publ256/html/PLAW-111publ256.htm. Unfortunately, persons living with dementia continue to experience stigma in the form of some words used. The draft report currently contains some of those words. We recommend those words be replaced with the words/terms provided below. CAREGIVER: “Caregiver” is considered a dated word and connotes a patriarchal relationship to the receiver. The recommended term is care partner as it is reflective of the relationship and reciprocal nature between the person living with dementia and their care partner. BURDEN: The word “burden” carries a negative meaning, and when used in research can contribute to bias perceptions and lead to further and unnecessary misunderstanding. A better word choice is strain. BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA (BPSD) While understanding this is the term used in DSM 5, used in other contexts labels individuals’ actions inappropriately. Many other health conditions such as cancer, ALS, Parkinson’s and even what every woman who lives to a certain age experiences, menopause, can cause “behavioral and psychological symptoms” yet the health and research communities do not seem to label their actions as BPS of cancer, etc. Using this term for dementia is stigmatizing for individuals and families living with dementia as well as many dementia researchers and specialists who advocate for the well-being of persons living with dementia. The recommended term is “expressions” as it is explanatory without being prejudicial. NON-BPSD The use of this term in the draft report provides a pathologized orientation and should not be used.</p>	<p>Thank you for sharing your perspective. We apologize for causing unnecessary discomfort or distress. We have added a paragraph in the Scope and Key Questions section to address the challenges of choosing terms and definitions that balance the needs and perspectives of the many varied report audiences. While the term and definition for care partners or informal caregivers is somewhat more complicated, we have used the acronym CG/P for informal caregiver or care partner in many places throughout the report as well. We have continued to use BPSD and do so with the motivation of honoring the original intention of the term to draw care and support resources to attend to unmet needs of people living with dementia. The term “burden” has also been applied in a patient-centered model of patient complexity to help people understand the impact of treatment, management, and illness burden on patients. The term has helped expand understanding past the biomedical clinical model to a more comprehensive understanding of the impact of a chronic medical condition on a person. Please see Shippee et al., Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. <i>Journal of Clinical Epidemiology</i>. 2012;65(10): 1041-1051. DOI 10.1016/j.jclinepi.2012.05.005</p>

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Commentator & Affiliation	Section	Comment	Response
Public Commenter #12 Laura Thornhill, Alzheimer's Association	General	<p>The Alzheimer's Association appreciates the Agency for Healthcare Research and Quality (AHRQ) undertaking this important review and we agree that more research is needed on care interventions for persons living with dementia and their caregivers. We also appreciate AHRQ's clarification that insufficient evidence does not mean that an intervention is ineffective. It is critically important that interventions remain available for those individuals for whom they are helpful, as well as to continue to gather evidence that can speak to widespread dissemination. We urge AHRQ to regularly revisit this topic as the evidence develops.</p>	Thank you for the comment.
Public Commenter #13 Amy Lewitz, Member of GAPNA	General	<p>Well done. It does illustrate the point that despite years of effort, validated intervention has not been substantiated by the research process. For example, intervention for BPSD could be delineated by identifying common target behaviors across the spectrum of neurocognitive disorders and then testing the most common interventions with clear concise instruction on how to employ consistent intervention. There can never be a true controlled experiment, but simplicity and consistency may yield more useful results for patients and their caregivers and/or families.</p>	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #14 Marla Berg-Weger	General	<p>I appreciate the authors' work on this document and hope that it can be used to further advance the funding for and study of dementia care and caregiver interventions. My comments include:</p> <p>1) The analysis lacks recognition of the fact that large scale dementia care and caregiver interventions is challenging to conduct, specifically due to the fact that: a) large grant opportunities are not typically available to researchers in these areas and b) interventions with these populations do not usually involve large numbers of participants and are seldom multi-site (see a above).</p> <p>2) While the conclusion that data is insufficient may be accurate, I did not find it helpful. Instead, researchers and funders could be better enlightened by recommendations for designing and implementing intervention studies that would help to determine their efficacy.</p> <p>3) Assuming the authors agree that additional funding is needed to improve the quality of studies and data being reported in the literature, might they provide recommendations for increased funding, particularly that would enable smaller studies to be completed.</p>	<p>Thank you for the comment. The Discussion chapter discusses potential future actions to improve future research activities. However, research funding policy is beyond the scope of this review.</p>
Public Commenter #15 Linda Buscemi, Taproot Interventions	General	<p>I found this report interesting but did not find the conclusion surprising. I found some factors missing that could be crucial to the success of an intervention. Each intervention used should be based on a set of criteria to determine true effectiveness. I appreciate this report to validate that there is not one intervention that will work for all, but rather understanding multiple factors answered to then determine the appropriate intervention to use for the prevention or reduction in behaviors and an increase in the quality of life for the PWD and the carer.</p>	<p>Thank you for the comment.</p>



Commentator	Section	Comment	Response
Public Commenter #16 Andrea Rink, Yale Connecticut Older Adult Collaboration for Health 4M	General	“Low-strength evidence shows that an intensive multicomponent intervention for informal caregiver support, with education, group discussion, in-home and phone support, and caregiver feedback (REACH II), may improve informal caregiver depression at 6 months.” What was some of the low-strength evidence? What were the categories used. Did you look beyond 6mos? A brief summary about the REACH II program would be helpful. What part of the program was most helpful to caregivers? To PLWD?	Thank you for the questions. Appendix E provides detailed information on the studies that support this low-strength evidence finding, including references for companion articles. We encourage interested readers to fully explore the materials.

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