



## Effective Health Care Support for Caregivers of Individuals With Dementia

### Results of Topic Selection Process & Next Steps

The nominator is interested in a new evidence review on support for caregivers of individuals with dementia to share with other caregivers.

We identified an ongoing systematic review covering the scope of the nomination. No further activity on this nomination will be undertaken by the Effective Health Care (EHC) Program.

### Topic Brief

**Topic Name:** Caregiver Perspective on End of Life Care Decisions, #783

**Nomination Date:** 5/26/2018

**Topic Brief Date:** 6/11/2018

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**Conflict of Interest:** None of the investigators have any affiliations or financial involvement that conflicts with the material presented in this report.

### Background

- Dementia is the loss of cognitive functioning and behavioral abilities that interferes with a person's daily life and activities.<sup>1</sup>
- Types of dementia include Alzheimer's disease, Lewy body dementia, frontotemporal disorders, and vascular dementia.
- Studies of the prevalence of Alzheimer's disease and other dementia in the U.S. estimate that 14% of those over age 70 are affected<sup>2</sup>
- Family members are the main source of informal care: one in five caregivers were spouses, 29.3% were daughters, 18.3% were sons, and 22.3% were other relatives, about half of whom were sons-in-law or daughters-in-law or grandchildren<sup>3</sup>.
- In 2011 18 million informal caregivers provided 1.3 billion hours of care per month to over 9 million older adults.<sup>3</sup>
- Two-thirds of caregivers report positive aspects of caregiving, most commonly confidence that the recipient is well cared for (86%) and feeling closer to the recipient (69%).
- Caregivers also reported having more to do than they can handle (17%), being exhausted by the end of the day (16%), and lacking time for themselves (15%)<sup>3</sup>.
- Common difficult decisions by family caregivers on behalf of people with dementia include accessing dementia-related health and social services; legal-financial matters; non-dementia related healthcare including end-of-life care and resuscitation; and making plans for the person with dementia if the caregiver became too ill to care for them.<sup>4</sup>

The key question for this nomination is: What interventions can support healthcare decisionmaking of caregivers of people with dementia?

To define the inclusion criteria for the key questions we specify the population, interventions, comparators, and outcomes (PICO) of interest (Table 1).

**Table 1.** Key Questions and PICOTS

<b>Key Questions</b>	
<b>Population</b>	Informal caregivers of people with dementia making healthcare decisions on their behalf
<b>Interventions</b>	Support interventions
<b>Comparators</b>	Usual care
<b>Outcomes</b>	Caregiver burden, anxiety, distress, depression and physical health

## Methods

We assessed nomination for priority for a systematic review or other AHRQ EHC report with a hierarchical process using established selection criteria (Appendix A). Assessment of each criteria determined the need for evaluation of the next one.

1. Determine the *appropriateness* of the nominated topic for inclusion in the EHC program.
2. Establish the overall *importance* of a potential topic as representing a health or healthcare issue in the United States.
3. Determine the *desirability of new evidence review* by examining whether a new systematic review or other AHRQ product would be duplicative.
4. Assess the *potential impact* a new systematic review or other AHRQ product.
5. Assess whether the *current state of the evidence* allows for a systematic review or other AHRQ product (feasibility).
6. Determine the *potential value* of a new systematic review or other AHRQ product.

### Appropriateness and Importance

We assessed the nomination for appropriateness and importance.

### Desirability of New Review/Duplication

We searched for high-quality, completed or in-process evidence reviews published in the last three years on the key questions of the nomination. See Appendix B for sources searched.

## Results

### Appropriateness and Importance

This is an appropriate and important topic. See Appendix A for details.

### Desirability of New Review/Duplication

A new evidence review would be duplicative of an existing product. We identified an in-process systematic review that addresses the concern of the nominator, “Managing uncertainty in dementia care: systematic review of decision aids.”<sup>5</sup> In addition we identified three in-process systematic reviews that may be of interest more generally on support and education interventions for caregivers of people with dementia<sup>6-8</sup>. See Appendix A for details.

## **Summary**

- We identified an ongoing systematic review that will address the concerns of the nominator.

## References

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## Appendix A. Selection Criteria Summary

Selection Criteria	Assessment
1. Appropriateness	
1a. Does the nomination represent a health care drug, intervention, device, technology, or health care system/setting available (or soon to be available) in the U.S.?	Yes
1b. Is the nomination a request for a systematic review?	Unclear
1c. Is the focus on effectiveness or comparative effectiveness?	Unclear
1d. Is the nomination focus supported by a logic model or biologic plausibility? Is it consistent or coherent with what is known about the topic?	Yes
2. Importance	
2a. Represents a significant disease burden; large proportion of the population	Yes. Studies of the prevalence of Alzheimer's disease and other dementia in the U.S. estimate that 14% of those over age 70 are affected <sup>2</sup> In 2011 18 million informal caregivers provided 1.3 billion hours of care monthly to more than 9 million older adults. <sup>3</sup>
2b. Is of high public interest; affects health care decision making, outcomes, or costs for a large proportion of the US population or for a vulnerable population	Yes. The yearly cost per person with dementia, including both the cost of care purchased in the marketplace and the cost of informal care, was \$41,689 (95% CI, \$31,017 to \$52,362). Calculating the value of informal home care yielded an estimate of the cost of unpaid caregiving that was 31% of the total cost. <sup>9</sup>
2c. Represents important uncertainty for decision makers	Yes
2d. Incorporates issues around both clinical benefits and potential clinical harms	Yes
2e. Represents high costs due to common use, high unit costs, or high associated costs to consumers, to patients, to health care systems, or to payers	Yes

Selection Criteria	Assessment
3. Desirability of a New Evidence Review/Duplication	
3. Would not be redundant (i.e., the proposed topic is not already covered by available or soon-to-be available high-quality systematic review by AHRQ or others)	<p>We found one in-process systematic review on the concern of the nominator: “Managing uncertainty in dementia care: systematic review of decision aids.” One of the review questions specifically addresses topics in end of life care. It is anticipated that this review will be completed in October 2018<sup>5</sup>.</p> <p>We also identified relevant literature review “End of life decisionmaking by family caregivers of persons with advanced dementia: A literature review of decision aids.” While this is not a systematic review, the information may be useful to the nominator.<sup>10</sup></p> <p>We also identified additional systematic reviews in progress that may be of interest to the nominator:</p> <ul style="list-style-type: none"> <li>• “Substitute decisionmakers’ experiences of making decisions for older persons diagnosed with major neurocognitive disorder at the end of life: a qualitative systematic review protocol.”<sup>6</sup></li> <li>• “Information, support and training for informal caregivers of people with dementia: a protocol.”<sup>7</sup></li> <li>• “Care interventions for individuals with dementia and their caregivers.”<sup>8</sup></li> </ul>

## Appendix B. Search for Evidence Reviews (Duplication)

Listed are the sources searched.

<b>Search date: May 31, 2015 to May 31, 2018</b>
AHRQ: Evidence reports and technology assessments, USPSTF recommendations
VA Products: PBM, and HSR&D (ESP) publications, and VA/DoD EBCPG Program
Cochrane Systematic Reviews and Protocols <a href="http://www.cochranelibrary.com/">http://www.cochranelibrary.com/</a>
PubMed
PROSPERO Database (international prospective register of systematic reviews and protocols) <a href="http://www.crd.york.ac.uk/prospero/">http://www.crd.york.ac.uk/prospero/</a>