



1700 K Street, NW | Suite 740 | Washington, DC 20006
T 202.293.2856
www.agingresearch.org
@Aging_Research

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Kim Wittenberg, M.A.
Task Order Officer
Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
5600 Fishers Lane
Rockville, MD 20857

Dear Ms. Wittenberg,

We are writing in response to the Agency for Healthcare Research and Quality (AHRQ) call for comments concerning the Draft Comparative Effectiveness Review, “Care Interventions for People With Dementia (PWD) and Their Caregivers.” The [Alliance for Aging Research](http://www.agingresearch.org) is the leading nonprofit organization dedicated to accelerating the pace of scientific discoveries and their application to vastly improve the universal human experience of aging and health. The Alliance believes advances in research help people live longer, happier, more productive lives and reduce healthcare costs over the long term. For more than 30 years, the Alliance has guided efforts to substantially increase funding and focus for aging at the National Institutes of Health (NIH) and Food and Drug Administration (FDA); built influential coalitions to guide groundbreaking regulatory improvements for age-related diseases; and created award-winning, high-impact educational materials to improve the health and well-being of older adults and their family caregivers. Additionally, the Alliance chairs the [Accelerate Cures/Treatments for All Dementias \(ACT-AD\) Coalition](#), a group of more than 50 national nonprofit organizations, founded in 2005, urgently working to speed up the development of potential cures and more effective treatments for all dementias.

Overall comments on review structure

According to the Evidence-based Practice Center Systematic Review Protocol for this review, the National Institute on Aging (NIA) of the NIH, in collaboration with the National Academies of Science, Engineering, and Medicine (NASEM), commissioned “a summary of the available evidence for care interventions for people with dementia (PWD) and their formal and informal caregivers.” The goal of the review “is to understand the evidence base for effective care interventions, and to assess the potential for broad dissemination and implementation of that evidence.” The protocol acknowledges that “Unfortunately, no consensus has been reached on classification systems for types of interventions, leaving categorization up to empirical rather than theoretical approaches.”

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.

- ✓ 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?

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.

Medicare and Alzheimer’s disease

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.

In 2019, the Alliance for Aging Research commissioned a study with the actuarial firm Milliman to examine the real-world costs of Alzheimer’s disease on the Medicare program.¹ We undertook this work because actual Medicare spending on the disease is rarely discussed. Instead, “associated costs of care”—that combines Medicare and Medicaid spending, often with out-of-pocket spending by families, is generally used to effectively advocate for increased federal investment in research. The preference for using associated costs is understandable, however, direct costs better demonstrate what the Medicare program is doing, and not doing, for people with Alzheimer’s disease.

Published in the July 2019 issue of the *Journal of Managed Care and Specialty Pharmacy* the study found that Medicare spending on Alzheimer’s disease is low. The study examined almost 340,000 Medicare beneficiaries for up to 10 years and found that risk-adjusted annual costs were \$2,101 (2015 U.S. dollars) higher for Alzheimer’s disease and \$1,870 higher for general dementia than beneficiaries without a diagnosis. In the last year of life, Medicare spent \$1,300 less on patients with Alzheimer’s disease than other beneficiaries. The lower costs were often due to avoiding complex care, such as chemotherapy for cancer, for loved ones with advanced dementia.

The relatively low Medicare spending on Alzheimer’s disease makes sense. Medicare pays for medical care and only some short-term supportive care.

Additionally, turning to nonpharmacologic interventions is not standard practice in the nursing home setting. While evidence-based psychosocial (i.e. non-pharmacologic) interventions have shown some promise in managing these symptoms, they are rarely used in everyday clinical practice. CMS developed a training program and care plans to promote “person-centered high-quality care” and the use of non-pharmacologic treatment alternatives to antipsychotics.² Section 6121 of the Affordable Care Act of 2010 requires Centers for Medicare & Medicaid Services (CMS) to ensure that nurse aides receive regular training on caring for residents with dementia and on abuse prevention. CMS, supported by a team of

¹ The Real-World Medicare Costs of Alzheimer Disease: Considerations for Policy and Care, Bruce Pyenson, Tia Goss Sawhney, *Journal of Managed Care & Specialty Pharmacy* 2019 25:7, 800-809. Open-access available at: <https://www.jmcp.org/doi/pdf/10.18553/jmcp.2019.25.7.800>.

² <https://qsep.cms.gov/pubs/HandinHand.aspx>

training developers and subject matters experts, created this training to address the need for nurse aides' annual in-service training on these important topics. Unfortunately, less than 2% of facilities consistently implement the person-centered care approaches for NPS³ and most staff lack the knowledge, skills, or experience to effectively implement nonpharmacologic approaches.^{4 5} Such person-centered care requires resources, including reimbursement for implementation, and commitment to these goals.

On the other hand, there has been a lot of resources devoted to addressing the use of antipsychotics in residents with dementia. In 2012, CMS launched the National Partnership to Improve Dementia Care in Nursing Homes to "improve the quality of care" for nursing home residents with dementia, primarily by achieving reductions in the use of antipsychotics.⁶ Also in 2012, the American Board of Internal Medicine initiated "Choosing Wisely,"⁷ targeting "low-value care," including the first-line use of antipsychotics for NPS. Since the establishment of these efforts, antipsychotic use has reportedly been significantly reduced by 40% among long-term care residents from 2011 to 2019.⁸

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.

Conclusion

The Alliance appreciates the opportunity to provide feedback on this important evidence review. If you have questions for our organization, please do not hesitate to contact the Alliance's Public Policy Manager, Ryne Carney at (202) 688-1242 or rcarney@agingresearch.org.

Thank you for your consideration and please consider our organization a resource.

Sincerely,



Susan Peschin, MHS
President and CEO



Ryne Carney
Public Policy Manager

³ Grabowski DC, O'malley AJ, Afendulis CC, et al. Culture Change and Nursing Home Quality of Care. *Gerontologist* 2014;54:S35-S45.

⁴ Kolanowski A, Van Haitsma K, Penrod J, et al. "Wish we would have known that!" Communication breakdown impedes person-centered care. *Gerontologist* 2015;55:S50-S60.

⁵ Marx KA, Stanley IH, Van Haitsma K, et al. Knowing Versus Doing: Education and training needs of staff in a chronic care hospital unit for individuals with dementia. *J Gerontol Nurs* 2014;40:26-34.

⁶ CMS announces partnership to improve dementia care. 2012. Available at: <https://www.cms.gov/newsroom/press-releases/cms-announces-partnership-improve-dementia-care-nursing-homes>.

⁷ Choosing Wisely: A Special Report on the First Five Years. Available at: www.choosingwisely.org/choosing-wisely-a-special-report-on-the-first-five-years/?ve-things-physicians-and-patients-should-question-press-release-april-4-2012/

⁸ Available at: <https://www.cms.gov/files/document/antipsychotic-medication-use-data-report-updated-01242020.pdf>