CARE INTERVENTIONS FOR INDIVIDUALS WITH DEMENTIA AND THEIR CAREGIVERS

OPEN SESSION DISCUSSION

Friday, May 29, 2020
VIRTUAL MEETING VIA *ZOOM*
Open Session: 2:30-3:15pm EDT

Open session objective: A group of people living with dementia and caregivers will provide perspectives on the draft AHRQ/EPC systematic review and input into the National Academies committee's report.

Discussion questions:

- What would you like the National Academies committee to consider in drafting its report?
- The draft AHRQ/EPC systematic review identified two interventions as supported by low strength evidence (see background information below):
    - How important to you are the outcomes targeted by these two interventions?
    - Based on the brief descriptions below, would you be inclined to seek out these two interventions, and would you welcome them if they were offered to you?

2:30pm **Welcome**

Eric Larson, Committee Chair; Kaiser Permanente Washington Health Research Institute

2:35pm **Opening remarks on the questions above (~3 minutes each)**

Cynthia Huling Hummel, living with dementia, Elmira, New York

Karen Love, Dementia Action Alliance

Maria Martinez Israelite, care partner, Washington, DC

John Richard (JR) Pagan, living with dementia, Woodbridge, Virginia

Ed Patterson, living with dementia, Orlando, Florida

Brian Van Buren, living with dementia, Charlotte, North Carolina

Geraldine Woolfolk, care partner, Oakland, California

3:00pm **Discussion with committee members**

3:15pm **Adjourn open session**

Background Information

About the project: Research on care interventions for individuals with Alzheimer's disease and related dementias, as well as on interventions aimed at their caregivers, has expanded tremendously in recent years. And, some care-related programs are starting to be disseminated and more broadly implemented. Despite important progress in this domain, however, there remain gaps in understanding. The National Institute on Aging has asked the National Academies of Sciences, Engineering, and Medicine to convene an expert committee to take stock of the current state of knowledge, and make recommendations to inform decision making about which care interventions for individuals with dementia and their caregivers are ready for dissemination and implementation on a broad scale.

The National Academies committee's work will be based on a systematic review commissioned by the Agency for Healthcare Research and Quality (AHRQ) and conducted by the Minnesota Evidence-based Practice Center (EPC). The draft systematic review was recently released for public comment.

Context for this open session: The committee is interested in hearing perspectives from people with dementia and care partners on the draft AHRQ systematic review and on the committee's task.

In addition, the committee is interested in any specific reflections on the two interventions that were identified as being supported by "low strength evidence" for particular outcomes. These interventions are summarized in below, and the following two questions may guide the discussion:

- How important to you are the outcomes targeted by these two interventions?
- Based on the brief descriptions, would you be inclined to seek out these two interventions, and would you welcome them if they were offered to you?

It is important to note, as described in the draft AHRQ systematic review, "For all other interventions and outcomes, we found the evidence insufficient to draw conclusions. Insufficient evidence does not mean that the intervention is determined to be of no value to PWD [people with dementia] or their caregivers. Rather, it means that due to the uncertainty of the evidence, we could not draw meaningful conclusions at this time."

Interventions Identified as Supported by Low Strength Evidence in the Draft AHRQ Systematic Review on Care Interventions for People With Dementia (PWD) and Their Caregivers

Multicomponent Interventions for Caregivers

- *Brief description of intervention:* An intensive multicomponent intervention with education, group discussion, in-home and phone support sessions, and caregiver feedback for informal caregiver support.
- *Outcome supported by low-strength evidence:* This intervention improved caregiver depression at 6 months.

Collaborative Care Models

- *Brief description of intervention:* Collaborative care models use multidisciplinary teams to integrate medical and psychosocial approaches to healthcare for PWD. Collaborative care is organized at the healthcare system level and may be provided through services either in the community or in residential facilities. As such, these approaches try to leverage local care and support resources. Most are aimed at providing informal caregiver support, along with coordinating care for PWD.
- *Outcomes supported by low-strength evidence:*
  - Collaborative care models may improve PWD quality of life.
  - Collaborative care models may reduce emergency department visits.

SOURCE: Taken from the *Draft* Comparative Effectiveness Review on Care Interventions for People With Dementia (PWD) and Their Caregivers, prepared by the Minnesota Evidence-based Practice Center for the Agency for Healthcare Research and Quality. Draft released for public comment on March 24, 2020.