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The Best Value in Dementia Care

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Alzheimer's Disease, the most common cause of dementia, affects about 5.4 million persons in the US and is the 6th leading cause of death (1). While research is underway to discover effective treatments, we don't currently have the means to prevent the disease or halt its advance. Annual costs associated with the health care of persons with Alzheimer's disease and other dementias exceeded \$235 billion in 2016 (1). Given the prevalence of dementia and its high associated costs, it is critical to understand the drivers of those costs and to seek to spend our dollars on interventions that offer the greatest value.

Agitation, aggression, psychosis, and other so-called behavioral and psychological symptoms often complicate dementia syndromes, burden caregivers, and contribute significantly to the overall cost of dementia care, including costs associated with emergency department (ED) visits, hospital admissions, and nursing home placement. It is reasonable to suppose that these symptoms may in themselves be key drivers of service utilization, and there is some evidence supporting this (2). But it is also reasonable to consider that caregiver variables – independent of the symptoms themselves – might impact the decision to seek health services.

The paper by Maust et al in this issue of the Journal (3) suggests that caregiver distress may be such a variable – at least when you focus on distress associated with agitation, delusions, and hallucinations. Using a nationally representative sample of 322 persons with incident dementia, they identified a subset with agitation, delusions, and/or hallucinations (as measured by responses on the Neuropsychiatric Inventory obtained from knowledgeable informants). They measured informant distress associated with these symptoms on a 5-point self-report scale. Not surprisingly, they found higher levels of distress among the informants for persons with at least one of these three symptoms than among the informants for those with none of these symptoms. They also found trends toward higher Medicare costs and greater ED and inpatient hospital utilization among persons with at least one of these three symptoms, but – contrary to their expectation - the differences did not achieve statistical significance. Strikingly, however, in the fully adjusted analysis, they found that persons whose informants reported

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