



# ASPE ISSUE BRIEF

HHS OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION  
OFFICE OF DISABILITY, AGING AND LONG-TERM CARE POLICY

## INDIVIDUALS' AWARENESS OF A DEMENTIA DIAGNOSIS

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### BACKGROUND

Dementia is an important health concern that affects more than 10% of adults age 65 and older. The number of people with dementia is expected to increase, due to the growing population of older adults, even as the risk of developing dementia may be decreasing (Hudomiet et al., 2018; Langa et al., 2017). Understanding the size of the population and the characteristics of people with dementia is important information for proper planning and policy development. At the individual level, awareness of a dementia diagnosis can affect care planning, health care, and family supports.

Data sources provide three distinct ways of identifying individuals who have dementia: (1) functional tests assess limitations in cognitive skills and abilities that may be indicative of dementia; (2) claims data provide diagnoses reported by the treating health care provider; and (3) survey data provide information about individuals' (including family members') awareness of having such a diagnosis. Prior studies have found that many people with a documental diagnosis of dementia fail to report such a diagnosis when asked, raising concerns that they are unaware of that diagnosis. Healthy People 2020 has established a goal of increasing the percentage of people who are aware that they have such a diagnosis.

This study examined the characteristics of people who do not report having a diagnosis of dementia, despite a documented diagnosis by a health care provider, to help understand the factors that may contribute to their lack of awareness or failure to report. Understanding these factors is a key to taking steps to increasing awareness.

### STUDY METHODS

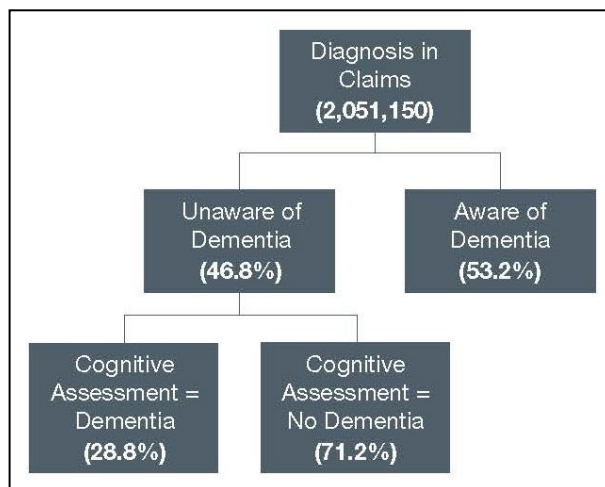
This study identified people with dementia as noted through any of the three methods described above. Data from the 2015 National Health and Aging Trends Study (NHATS), an annual survey of individuals age 65 and older who are enrolled in Medicare, provided information about dementia as identified through cognitive assessment or self-reported diagnosis. The data were linked with Medicare claims data from the preceding 3-year period (2012-2014), which were used to identify people with a documented diagnosis of dementia. The study sample included people who completed the NHATS and for whom there were linked Medicare claims data. People living in nursing homes were excluded, due to the limitations of the NHATS data. People with a

diagnosis in Medicare claims data but who did not report having such a diagnosis were identified as “unaware”.

## FINDINGS

**Slightly less than one-half (46.8%) of people with a claims-based diagnosis of dementia were determined to be unaware of that diagnosis.**

**Most people who were unaware of the diagnosis did not show a cognitive assessment consistent with dementia. However, more than one-quarter (28.8%) of those who were unaware of their diagnosis did appear to have probable dementia based on cognitive assessment.**



**Among those who were unaware of a dementia diagnosis, there were notable differences between those whose cognitive assessment indicated dementia and those whose did not.**

Those whose cognitive assessment responses indicated probable dementia tended to be older, less well educated, have lower incomes, and were more often a racial/ethnic minority. They reported fewer chronic conditions, but were more likely to have depressive symptoms and had a greater number of functional limitations. They were more likely to live in

a residential care setting either in the community or in a nursing home, receive help from others and, when help was received, reported more hours of help each month.

**Compared to people who were unaware of their diagnosis, regardless of their cognitive assessment, people who were aware were more likely to be married/living with a partner, less likely to be living alone, and had a greater number of functional limitations.**

## IMPLICATIONS

**Less than one-half of people with a claims-based diagnosis of dementia reported having such a diagnosis.** It may be that people with dementia do not always report reliably when asked by a surveyor. Inaccurate response might indicate a design not to report a diagnosis that may be thought of as undesirable or stigmatizing. It also is possible that individuals responding to the survey are truly unaware of the diagnosis, either because physicians do not communicate it clearly to them, or because the physician may have shared the diagnosis with someone other than the individual

responding to the survey, who may not have then shared the information with the person who is responding to the survey.

**People who were aware of their diagnosis, whether or not they had cognitive assessment that supported that diagnosis, were more likely than those who were unaware to be married and living with others. They also had higher levels of functional impairment.** This suggests that awareness of a diagnosis may be lower at earlier stages of the condition. It also suggests the important role that spouses and other caregivers play in awareness of a diagnosis. These care partners may encourage the person with dementia to see a physician for evaluation. They may also attend appointments, where they may help ask questions and help the person with dementia understand the information that is shared.

**Most people who were unaware of a dementia diagnosis did not have a cognitive assessment that indicated probable dementia.** It may be that physicians are inaccurately noting a dementia diagnosis due to clerical error in creating the claims or due to clinical error in diagnosing dementia. A more in-depth review of medical records or a more thorough clinical assessment of this group could help to shed light on the reasons for this discrepancy.

**People who were unaware of a diagnosis and did show probable dementia on cognitive assessment questions appear to be socioeconomically disadvantaged.** It may be that they were not told of their diagnosis, or perhaps the diagnosis was communicated in a way that they did not understand. It is possible that diagnoses are not being well-communicated to many patients, but particularly to those who are the most vulnerable--that is, those who have lower incomes, lower education, and are of a racial or ethnic minority group. Research suggests that some physicians are more skilled at communicating information about dementia than are others. It may be that physicians who treat patients of lower socioeconomic status lack skills and training in how to communicate a dementia diagnosis (Zaleta & Carpenter, 2011). Communication of this important information from the provider to patient must be improved if we are to make progress toward the Healthy People 2020 goal of increasing awareness.

**People who are unaware of their diagnosis and who have a cognitive assessment of probable dementia are receiving extensive help.** However, in some cases this help may be entirely comprised of support from family members. It does not necessarily represent use of the range and type of services for which they may be eligible or from which they may benefit. Awareness of a diagnosis is an important first step toward accessing services and supports that can help both the individuals with dementia and their family caregivers.

## REFERENCES

Hudomiet, P., Hurd, M.D., & Rohwedder, S. (2018). Dementia prevalence in the United States in 2000 and 2012: Estimates based on a nationally representative study. *Journals of Gerontology*, 73, S10-S19.

Langa, K.M., Larson, E.B., Crimmins, E.M., Faul, J.D., Levine, D.A., Kabeto, M.U., & Weir, D.R. (2017). A comparison of the prevalence of dementia in the United States in 2000 and 2012. *JAMA Internal Medicine*, 177, 51-58.

Zaleta, A.K. & Carpenter, B.D. (2011). Patient-centered communication during the disclosure of a dementia diagnosis. *American Journal of Alzheimer's Disease and Other Dementias*, 25(6), 513-520.

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# INDIVIDUALS WITH DEMENTIA

## Reports Available

### **Implications of Alternative Methods of Identifying Populations with Dementia**

HTML <https://aspe.hhs.gov/basic-report/implications-alternative-methods-identifying-populations-dementia-issue-brief>

PDF <https://aspe.hhs.gov/pdf-report/implications-alternative-methods-identifying-populations-dementia-issue-brief>

### **Individuals' Awareness of a Dementia Diagnosis**

HTML <https://aspe.hhs.gov/basic-report/individuals-awareness-dementia-diagnosis-issue-brief>

PDF <https://aspe.hhs.gov/pdf-report/individuals-awareness-dementia-diagnosis-issue-brief>