ASPE ISSUE BRIEF

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

IMPLICATIONS OF ALTERNATIVE METHODS OF IDENTIFYING POPULATIONS WITH DEMENTIA

BACKGROUND

Dementia is an important health concern that affects more than 10% of adults age 65 and older. Due to population growth, the number of older adults with dementia is expected to increase, even as the risk of having dementia may be decreasing (Hudomiet et al., 2018; Langa et al., 2017). As a society, 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 may 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. Although the populations defined by these three methods should align, it is possible that they do not. One recent study found that among people with probable dementia based on cognitive assessment, 39% were undiagnosed and 19% were unaware of their diagnosis (Amjad et al., 2018).

This study sought to identify the amount of overlap among these three methods of identifying people with dementia, and to obtain national estimates of the number of people with dementia. It also explored key characteristics of people identified as having dementia by the various methods, to understand potential causes and implications of differences for policy and practice.

STUDY METHODS

Data from the 2015 National Health and Aging Trends Study (NHATS), an annual survey of individuals aged 65 and older who are enrolled in Medicare, identified people with probable dementia based on cognitive assessment of limitations in memory, orientation, and executive function (Kasper et al., 2013). It also identified people who reported, or whose proxies reported, that they had been given a diagnosis of dementia. The data were linked with Medicare claims data from the preceding 3-year period

(2012-2014), which were used to identify people who have a diagnosis of dementia (CMS, 2018). 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.

FINDINGS

About 10% of the United States older adult population (exclusive of those living in nursing homes) were identified as having dementia by one or more methods. Only 2% of the total population was identified as having dementia by all three methods.

Cognitive Assessment of Probable Dementia	Claims-Based Diagnosis	Self-Reported Diagnosis	
		No	Yes
No	No	36,598,764 (89.8%)	388,855 (1.0%)
	Yes	683,545 (1.7%)	257,482 (0.6%)
Yes	No	1,169,478 (2.9%)	528,445 (1.3%)
	Yes	277,066 (0.7%)	833,057 (2.0%)

Of those with symptoms of dementia determined through cognitive assessment, only 39.5% had a diagnosis indicated in claims data. This is consistent with previous studies, and raises concerns about delays in diagnosis. However, the data also indicate that 46% of those who had a diagnosis reported in claims did not exhibit probable dementia based on cognitive assessment.

Just over one-half (53%) of people with a claims-based diagnosis of dementia reported having such a diagnosis. Again, this is consistent with prior studies and underscores concerns about a lack of awareness.

People with dementia identified by various methods differ in their demographic characteristics and socioeconomic resources.

- People with dementia identified only by cognitive assessment are less likely to be White non-Hispanic than are people with dementia identified in other ways, and are more likely to have never married. They have low levels of education and of income. Their health and functional needs are similar to those of people with dementia identified in other ways. These findings may suggest a need to review the cultural sensitivity of cognitive assessments.

    People who are unaware of a diagnosis (i.e., who do not report a diagnosis when one is observed in claims) are more likely to be female, older, and living alone than are people with dementia identified in other ways. When they do not have a cognitive assessment supporting the diagnosis, people who are unaware are more likely than other groups to have no functional impairments, and they receive the fewest hours of help per month.

- People with dementia identified only by self-report, without a claims-based diagnosis and without a cognitive assessment indicating probable dementia, are more likely than any other group to have three or more chronic conditions.

- People with dementia identified only by claims are the most highly educated group and are the most likely to be living alone.

IMPLICATIONS

Few people with dementia identified by any of the three methods are identified by all of the methods. Studies of people with dementia must consider the method and sources used to identify them when interpreting findings. Studies of the size of the population of people with dementia must acknowledge how those estimates are created, and the limitations associated with the approach. Similarly, studies of the characteristics and needs of people with dementia must specify how the population is identified, and the implications of those methods for their conclusions and recommendations.

Disagreements in the identification of dementia by the various methods used may suggest delays in diagnosis or a lack of awareness, but are as likely to suggest other reasons for disagreement as well. A diagnosis in claims data without a corresponding cognitive assessment may indicate an inappropriate diagnosis, but also might indicate an early diagnosis. Self-report of dementia without a supporting diagnosis or cognitive assessment may suggest misunderstanding on the part of the individual or their proxy. Additionally, some respondents may perceive memory loss or other issues as a sign of dementia, and may self-report as a result. Ongoing education efforts are needed to provide health professionals and the public with up-to-date tools and information related to dementia diagnosis (Alzheimer's Association & CDC, 2018).

Comparisons of characteristics of people with dementia identified by various methods suggest opportunities to improve identification of dementia. Data suggest a need for improved screening for people whose dementia is undiagnosed, and may suggest improved communication with people from racial and ethnic minorities who may not obtain--or perhaps do not understand--the diagnosis. Approaches and tools to best identify and communicate information about dementia need to be consistently implemented and expanded. Such work would support progress toward the Healthy People 2020 goal of increasing awareness of dementia diagnoses.

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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