



Three Methods for Identifying Dementia: Implications for the National Plan

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Purpose

1. Strategy 2.G: Ensure a timely and accurate diagnosis
2. Goal 5: Improve data to track progress
 - Identify reliable sources of data for research and surveillance



How do we know if someone has dementia? How do we know if they have been diagnosed?

1. **Ask** “Has a doctor ever told you that you have dementia?”
2. **Assess** executive functioning, memory, orientation
 - Sometimes more in-depth clinical assessments
3. **Administrative data- Medicare claims**
 - Already being collected
 - Less vulnerable to recall issues
 - Person-level
 - Publicly available
 - Inexpensive

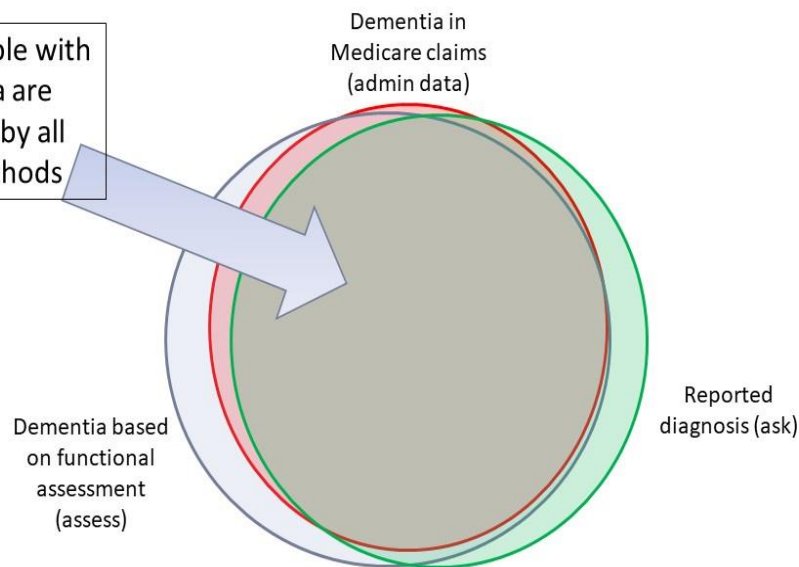
Current Challenges

- Appropriate diagnosis of dementia is necessary to ensure that people receive proper treatment and support.
- Many cases of dementia go undiagnosed or may be misidentified.
- Some people with dementia are not told of their diagnosis, and so may not obtain appropriate treatments and supports.
 - Healthy People 2020/2030 Objective: Improve awareness of dementia diagnosis
- A recent study found that, among people with probable dementia, 39% were undiagnosed and 19% were unaware of their diagnosis (Amjad et al., 2018)
- Understanding the prevalence and characteristics of older adults with dementia, and how those features vary by receipt and awareness of a diagnosis, can help guide the development of appropriate policies and programs to provide the necessary supports.

Research Questions

- What proportion of older adults who are classified as probable dementia based on functional tests have a Medicare claim with a dementia diagnosis code within the last 3 years? (missed diagnosis)
- What proportion of older adults who show indications of dementia on functional test report they have been diagnosed with dementia? (missed diagnosis or not told about diagnosis)
- What proportion of older adults who have a Medicare claim with a dementia diagnosis code in the last 3 years report that they have been diagnosed with dementia? (not told about diagnosis)

Ideally, people with dementia are identified by all three methods



Data and Methods

- 2015 National Health and Aging Trends Study (NHATS): Annual survey of individuals aged 65 and older who are enrolled in Medicare (~8,000).
- Proxy respondents were used when the sample person was unable to serve as a respondent (N=483).
- About 40% of Medicare beneficiaries are in a Medicare Advantage plan. The claims information for MA were not available for these analyses. We only included people who had a full 3 years of claims data so these analyses include only 47.4% of the original sample. People in MA plans were less likely (6%) to be identified with dementia based on reported diagnosis or functional assessment than the entire 65+ population (8.5%)

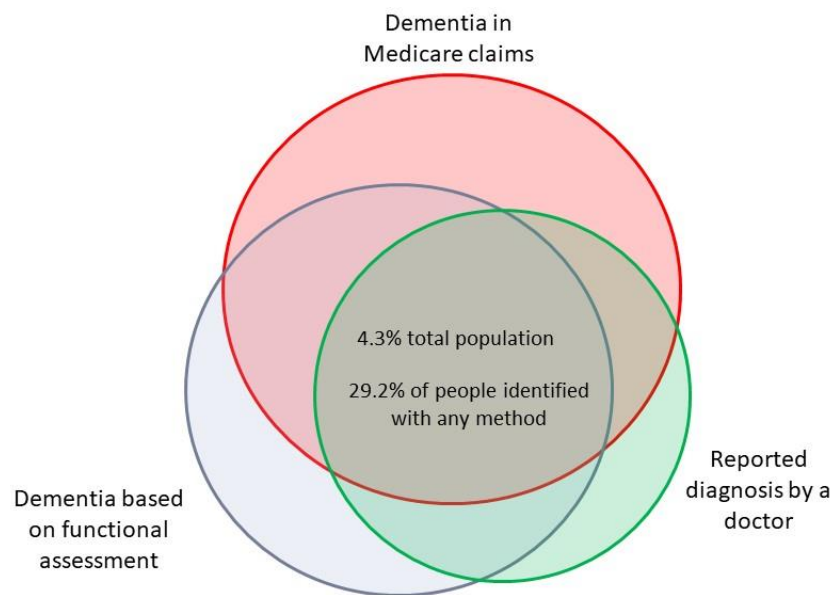
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Measures

- Ask** ▪ Reported diagnosis of dementia: Survey participant or their proxy reported that a physician has ever said they have dementia or Alzheimer's disease.
- Assess** ▪ Functional assessment: Assessed survey participant's cognitive abilities in three domains: cognition, orientation, and executive function and classified as having probable dementia, possible dementia, or no dementia (Kasper et al., 2013). Proxies completed the AD8. Used "probable dementia" for these analyses.
- Admin data** ▪ Claims-based diagnosis: Medicare claims data from 2012-2014 based on one or more diagnosis codes in inpatient, home health, skilled nursing facility, hospice, or Carrier claims. Methods consistent with CCW.

Results

- About 14.8% of community-dwelling older adults were identified as having dementia by one or more methods.
 - 9.1% were identified based on functional assessment
 - 7.1% were identified based on reported diagnosis
 - 10.6% were identified based on Medicare claims
- Only 4.3% were identified as having dementia by all three methods.



Functional assessments and Medicare claims

Approximately 9.1% met criteria for probable dementia based on functional assessment

- Of those 63.4% had a relevant Medicare claim for Alzheimer's disease or dementia in the last 3 years
- So...more than 1/3 of people with probable dementia did not have a dementia claim in the last 3 years

Implications: Large population of older adults **may have dementia but have not been diagnosed**

Functional assessments and reported diagnosis

Approximately 9.1% met criteria for probable dementia based on functional assessment

- Of those 54.3% reported they were told by a physician they had Alzheimer's disease or dementia
- Almost half (45.7%) reported they were not told

Implications: Large population of older adults **may have dementia but have not been diagnosed OR if they were diagnosed, the physician did not tell individual (or proxy) about this diagnosis**

Dementia in claims, report diagnosis, & functional assessment

- Of those with 3 years of Medicare claims, 10.6% had a claim indicating dementia
 - Of these, 53.2% reported they had been told of diagnosis
 - 46.8% were not told of a diagnosis
- BUT...
 - The vast majority (71.2%) of people who had a diagnosis in claims data, but who were not told they have dementia, did not show probable cognitive impairment on functional assessments
- Implications: Erroneous dementia claims, inclusion of dementia claims for subjective complaints, doctors identify cognitive impairment early OR functional assessments are not sensitive enough

Implications and Future Research

- Current methods are imperfect
 - “Has a doctor ever told you that you have dementia” may be affected by memory, proxy awareness, differential diagnosis
 - Medicare claim indicating dementia may be error, result of minor subjective complaints, temporary conditions that resolve
 - Functional assessments through survey like NHATS may not be sensitive enough
- Future research opportunities:
 - Longitudinal follow-up
 - Comparison to other chronic conditions
- We must do a better job getting people a diagnosis and improve data so we can track progress