

Data suggest disclosure of a dementia diagnosis reduces safety risks

A recent Johns Hopkins University study of 7,609 Medicare beneficiaries enrolled in the National Health and Aging Trends Study (NHATS) examined whether potentially unsafe activities and living conditions vary as a function of dementia diagnosis status.¹ Study participants were classified into four groups:

1. Individuals with diagnosed probable dementia (participants with self-reported or companion-reported dementia)
2. Individuals with probable dementia but no diagnosis (impaired in at least two cognitive domains)
3. Individuals with possible dementia (impaired in one cognitive domain)
4. Individuals with no dementia (no signs of cognitive impairment)

Highlights of the research study are presented below.

2011 NHATS enrollees with probable or possible dementia¹

More likely to be:

- Older
- Women
- Non-white
- Not married (widowed or never married)
- Less educated with lower income

Dementia is still underdiagnosed.

Only 44 percent of study participants with probable dementia, or their caregivers, reported receiving a diagnosis of dementia.¹ This finding is consistent with other studies,^{2,3,4} including the analysis of Medicare claims data in the 2015 Alzheimer's Disease Facts and Figures, which showed only 45 percent of those who have been diagnosed with Alzheimer's disease, or their caregivers, have been told of their diagnosis.⁵

There is increased risk of potential harm for the undiagnosed.

The study found those with probable dementia but without a diagnosis are significantly more likely to engage in potentially unsafe behaviors (all odds ratios ≥ 2.00 , all $P < 0.01$).¹ (See Figure 1.) Compared with those whose diagnosis has been disclosed, individuals with probable dementia but without a diagnosis are:

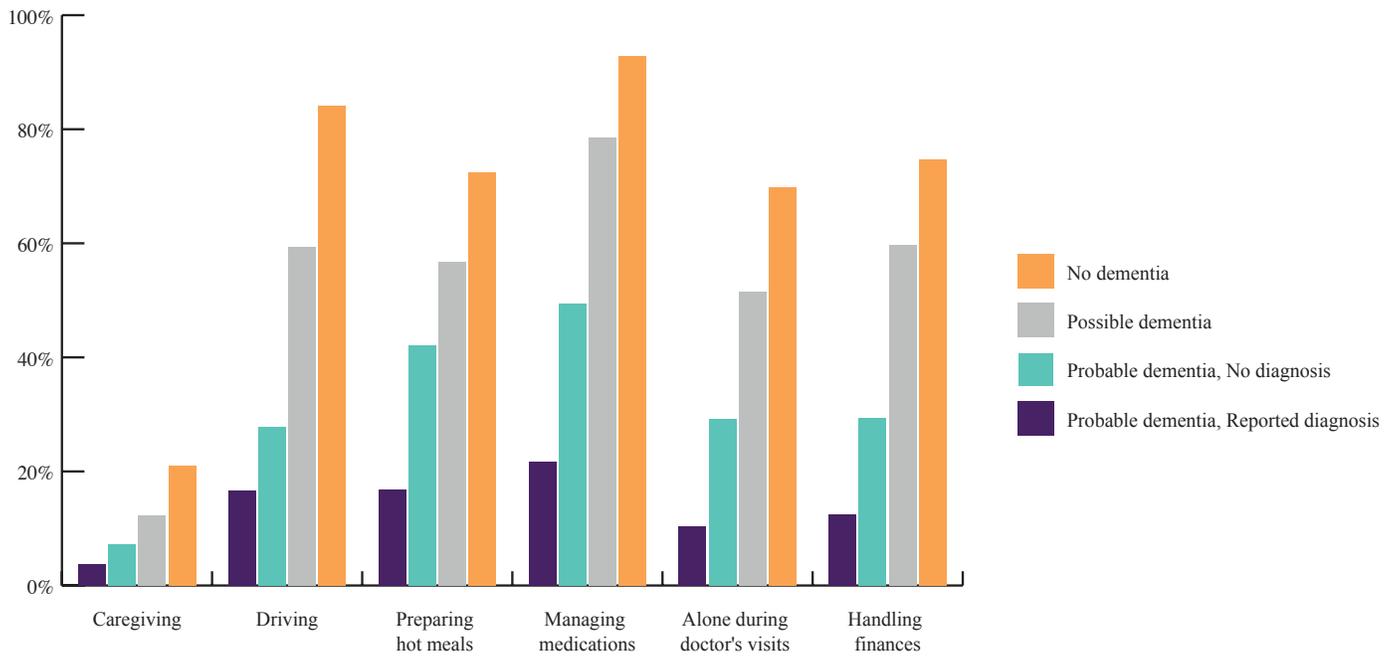
- 2.5 times as likely to prepare hot meals themselves.
- >2 times as likely to manage their own medications.
- >1.5 times as likely to drive.
- Nearly 3 times as likely to attend doctor appointments alone.

In addition, participants with probable dementia but without a diagnosis had higher rates of reported difficulty (a little, some or a lot) in completing all activities when compared to participants with possible or no dementia.

References

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5. Alzheimer's Association. 2015. Alzheimer's disease facts and figures. *Alzheimer's & Dementia*. 2015;11(3):332-384.

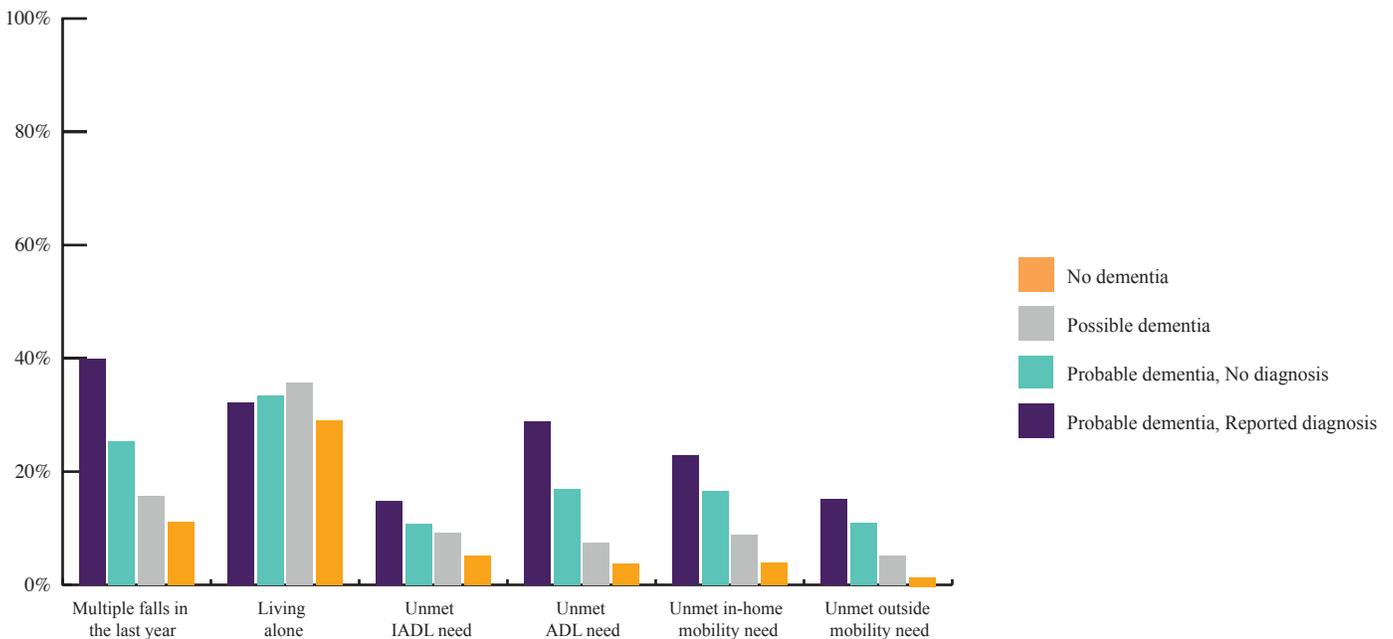
Figure 1. Prevalence (%) of Potentially Unsafe Activities by Dementia Status¹



Probable dementia leads to higher levels of unsafe living conditions.

Individuals with probable dementia, whether with reported diagnosis or not, had the highest rates of multiple falls and difficulty with instrumental activities daily living (IADLs), activities of daily living (ADLs) and outside mobility needs suggesting the unmet needs of these two groups are similar. Notably, the likelihood of living alone appears independent of dementia diagnosis status and unmet needs. (See Figure 2.)

Figure 2. Prevalence (%) of Potentially Unsafe Living Conditions by Dementia Status¹



Summary

Data suggest assessing IADLs and ADLs may help detect dementia and allow for addressing unmet needs. Early diagnosis – and disclosure of that diagnosis – allows people affected by Alzheimer’s to better plan for their future and could lead to fewer unsafe behaviors.