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Dementia Among U.S. Primary Care Patients Ages 55 Years and Older without Previously Diagnosed Cognitive Impairment

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Abstract

BACKGROUND

Estimates of the prevalence of unrecognized dementia are needed to gauge the potential impact of routine dementia screening.

METHODS

Adults ages ≥ 55 years without dementia or mild cognitive impairment diagnoses were recruited from primary care practices in New York City, NY and Chicago, IL (n = 853). Dementia was defined as significant cognitive impairment, as indicated by score > 1.5 standard deviations below age and education adjusted norms on the Montreal Cognitive Assessment, with impairment in one or more of 7 instrumental activities of daily living (IADL).

RESULTS

Mean age was 67.3 years. Moderate-severe cognitive impairment was observed in 10.3% and impairment in ≥ 1 IADL in 44.8%. Estimated undiagnosed dementia prevalence was 6.2% (95% CI 4.5% to 7.7%) overall and 5.9% (95% CI 3.9% to 9.0%) among participants ages ≥ 65.

CONCLUSIONS

Routine screening in primary care would identify substantial numbers of individuals with previously undiagnosed dementia.

Introduction

In 2020, the United States Preventive Services Task Force issued a grade of “I” for dementia screening in older adults, indicating insufficient evidence for benefit.[1] However, with increasing numbers of persons with dementia across the U.S.,[2] the advent of new and effective treatments for Alzheimer’s dementia,[3] and greater availability of resources and strategies for prevention and support of people living with dementia and their caregivers,[3,4] the tide may turn in favor of screening in coming years.[5]

Many health systems will likely need to expand resources to support dementia care in order to implement routine dementia screening[6,7] and would benefit from estimates of undiagnosed dementia prevalence to gauge the potential impact of routine dementia screening and guide their planning. While prior research provides evidence indicating that dementia is under detected in clinical settings,[7–9] few studies have estimated rates of undiagnosed dementia in primary care, where screening would most

likely occur.[10] To address this gap, we estimated rates of undiagnosed dementia in primary care practices in the U.S. using data from a cognitive screening assessment and an assessment of daily functioning.

Methods

Subjects and Settings

English speaking adults ages 55 years and older without a diagnosis of dementia or mild cognitive impairment were recruited from 4 primary care practices in New York City, NY that serve predominantly minoritized patient populations, including two hospital-based teaching practices and two multi-provider faculty practices and one hospital-based teaching practice in Chicago, IL. Potentially eligible patients were identified by medical record review and a random selection was then mailed a letter describing the study. Letters were followed by a telephone call for eligibility screening. White and Black male patients were oversampled to achieve balanced representation by sex and race. After obtaining informed consent, research coordinators administered a 30-minute interview in clinical exam rooms either before or after their visit with a primary care provider. All study procedures were approved by a single Institutional Review Board of record at the Icahn School of Medicine at Mount Sinai in accordance with the Declaration of Helsinki.

Measuring Cognitive Impairment and Daily Functioning

We defined dementia as cognitive impairment resulting in impairment of daily functioning. Cognitive performance was assessed with the Montreal Cognitive Assessment (MoCA).[11–14] The 12-item MoCA measures visuospatial/executive functioning, naming, memory, attention, language, delayed recall, and orientation. Scores range from 0 to 30. We converted raw scores to age and education adjusted z-scores; values falling below 1.0 and 1.5 standard deviation (SD) of the mean for normative data were defined as mild impairment and moderate to severe impairment, respectively.[12,15–17] Research coordinators were trained to administer the MoCA and were supervised for quality assurance by a licensed neuropsychologist (JB). Daily functioning was assessed by self-report. The instrumental activities of daily living (IADL) questionnaire included ability to use a telephone, shop, prepare food, perform housekeeping chores, do laundry, use public transportation, self-manage medications and handle finances. Responses for each item were categorized as fully independent, needs assistance or fully dependent. We operationalized dementia as moderate to severe cognitive impairment and needing assistance with or fully dependent for one or more IADL.

Other Measures

Other data collected during the interview included age, education, race and ethnicity, English language proficiency (ELP), country of birth, and depression. To determine ELP, participants were asked to rate

their ability to speak and understand English from very poor to excellent on a 6-point Likert scale. Low ELP was defined as very poor, poor or fair. Country of birth was dichotomized as U.S. or U.S. territory-born vs. other. Depression was assessed with the Patient Health Questionnaire-8 (PHQ-8).[18] Depression was defined as score ≥ 10. The full survey is included in the appendix.

Analysis

We report estimated rates of undiagnosed dementia with 95% confidence intervals, as well as impairments in IADLs stratified by cognitive performance (normal or mild impairment vs. moderate to severe impairment). We conducted a multivariable logistic regression analysis of the association of participant characteristics with dementia, adjusting for age, sex, race and ethnicity, ELP and depression. All analyses were conducted in SAS, version 9.4 (SAS Institute, Cary, N.C.).

Results

Recruitment and Participant Characteristics

Phone outreach was attempted for 3,815 persons, 2,894 (75.9%) were contacted, 1,737 (60.0%) declined participation, 208 (7.2%) did not speak English, 949 (32.8%) agreed to participation, 872 (30.1%) completed the interview and 853 (29.5%) had complete MoCA and IADL data. The mean age of participants in the analytic sample was 67.3 (8.0) years, 47.3% were male, 32.9% were Black and 26.3% were Hispanic and 61.3% had a college level or higher education (Table 1).

Table 1
Participant Demographics (N = 853)

Age, *mean (sd)*	**67.3 (8.0) years**
Male	47.3%
Race	
Black, non-Hispanic	32.9%
White, non-Hispanic	32.8%
Hispanic	26.3%
Other	8.0%
Education	
<12 years	15.7%
High school graduate	23.0%
Any college	40.1%
Graduate school	21.2%
Foreign born	24.1%
Low English language proficiency	5.8%
Depression	16.3%
≥ 1 IADL impairment	44.8%

Estimated Rates of Previously Undiagnosed Dementia

Moderate to severe cognitive impairment was present in 10.3%. For IADLs, 44.8% (95% confidence interval [CI] 41.5% to 48.1%) of participants reported needing assistance with one or more activity and 24.4% (95% CI 21.5% to 27.2%) were fully dependent in one or more activity. Undiagnosed dementia was observed in 6.2% (95% CI 4.5% to 7.7%) of subjects. A similar rate was observed for the subgroup of persons ages 65 years and older (5.9%, 95% CI 3.9% to 9.0%).

Common Functional Impairments

The IADLs for which patients most commonly needed assistance or were dependent were shopping (27.4%), housekeeping (30.8%) and food preparation (20.1%) (Table 2). The rates of co-occurring moderate or severe cognitive impairment and impairment for these IADLs were 4.1%, 4.1% and 3.0%, respectively.

Table 2
Rates of IADL Impairments Stratified by Cognitive Function (N = 853)

		Cognition	
Instrumental Activities of Daily Living	**All Patients N (%)**	**Normal or Mild Impairment N (%)**	**Moderate-Severe Impairment N (%)**
Telephone			
Any impairment	45 (5.2)	36 (4.1)	9 (1.0)
Fully dependent	2 (0.2)	2 (0.3)	0
Shopping			
Any impairment	238 (27.4)	202 (23.2)	36 (4.1)
Fully dependent	26 (3.0)	20 (2.3)	6 (0.7)
Food preparation			
Any impairment	175 (20.1)	149 (17.2)	26 (3.0)
Fully dependent	62 (7.1)	51 (5.9)	11 (1.3)
Housekeeping			
Any impairment	267 (30.8)	232 (26.7)	35 (4.1)
Fully dependent	102 (11.7)	84 (9.7)	18 (2.1)
Laundry			
Any impairment	203 (23.4)	173 (19.9)	30 (3.5)
Fully dependent	133 (15.3)	114 (13.1)	19 (2.2)
Transportation			
Any impairment	218 (24.1)	187 (21.6)	31 (3.6)
Fully dependent	122 (14.1)	104 (12.0)	18 (2.1)
Medication organization			
Any impairment	49 (5.6)	39 (4.5)	10 (1.2)
Fully dependent	6 (0.7)	4 (0.5)	2 (0.2)
Managing finances			
Any impairment	83 (9.6)	70 (8.1)	13 (1.5)

		Cognition	
Instrumental Activities of Daily Living	**All Patients N (%)**	**Normal or Mild Impairment N (%)**	**Moderate-Severe Impairment N (%)**
Fully dependent	10 (1.2)	9 (1.0)	1 (0.1)
Any impairment for ≥ 1 IADL	386 (44.8)	333 (38.7)	53 (6.2)
Fully dependent for ≥ 1 IADL	210 (24.4)	182 (21.1)	28 (3.3)
IADL, instrumental activities of daily living. Note rounding errors for some percent values in the All Patients column.			

Among persons with previously undiagnosed dementia, rates of any impairment for individual activities ranged from 17.0% (telephone use) to 66.0% (shopping) (Table 3). Full dependence in IADLs were mostly commonly reported for doing laundry (35.9%), housekeeping (34.0%), transportation (32.1%) and food preparation (20.8%).

Table 3
Rates of IADL Impairments Among Patients with Previously Undiagnosed Dementia (N = 53)

	Any Impairment	**Fully Dependent**
Activity of Daily Living	**N (%)**	**N (%)**
Telephone	9 (17.0)	0
Shopping	35 (66.0)	6 (11.3)
Food preparation	25 (47.2)	11 (20.8)
Housekeeping	34 (64.2)	18 (34.0)
Laundry	30 (56.6)	19 (35.9)
Transportation	30 (56.6)	17 (32.1)
Medication organization	10 (18.9)	2 (3.8)
Managing finances	13 (24.5)	1 (1.9)

Multivariate Analysis of Undiagnosed Dementia

In logistic regression analysis, men had significantly lower odds than women for undiagnosed dementia (odds ratio [OR] 0.3, 95% CI 0.2 to 0.7) and Black and Hispanic participants had higher odds than white participants (OR 11.5, 95% CI 2.4 to 56.6 and OR 9.1, 95% CI 1.8 to 45.8, respectively). Age, education, birth outside the U.S., ELP and depression were not significantly associated with undiagnosed dementia.

Discussion

Interpretation and Implications

Moderate to severe cognitive impairment with co-occurring impairment of daily activities, suggesting dementia, was found in approximately 6% of patients 55 years and older without clinically documented dementia in primary care practices in the U.S. Although findings from prior studies indicate that dementia is often undiagnosed,[7–9] estimates of undiagnosed dementia in clinical settings have been very limited. One study of federally qualified health centers in Indiana reported a 12.3% rate of dementia among patients ages 65 and older without previously diagnosed dementia or MCI.[19] A non-peer reviewed evaluation of Veteran Administration patients estimated rates of undiagnosed dementia of 9.5% to 15.3%, but used machine learning methods applied to electronic medical record data to arrive at its estimation.[20] The current study provides a lower estimate of undiagnosed dementia rates in urban primary care practices serving a diverse patient population. Taken together, the current body of literature suggests that health systems may expect 3% to 15% of their primary care patients over age 55 to have undiagnosed dementia.

Consistent with prior research, our findings suggest that Black and Hispanic patients are at greater risk of having undetected dementia.[19,21] Routine and systematic screening in primary care settings could help reduce health inequities in dementia. The findings of this study also highlight some of the most common home support needs these patients may be facing, including needs for assistance with shopping, food preparation and housekeeping. For health systems, awareness of the prevalence of undiagnosed dementia and its attendant burdens can aid infrastructure building to support the care of this debilitating condition.

Limitations

An important limitation of this study is its reliance on screening tools rather than comprehensive neuropsychiatric assessment for dementia, including a determination of whether functional impairments resulted from cognitive impairment. Physical impairments could have preceded or have been independent of cognitive impairment, leading to overestimation of undiagnosed dementia rates.

Conclusion

In conclusion, findings from this study suggest that routine screening in primary care would identify substantial numbers of individuals with previously undiagnosed dementia.

Abbreviations

MoCA, Montreal Cognitive Assessment; IADL, instrumental activities of Daily living; ELP, English language proficiency; PHQ, Patient Health Questionnaire; SD, standard deviation; OR, odds ratio; CI, confidence interval

Declarations

Ethics approval and consent to participate: This study was approved by the Icahn School of Medicine at Mount Sinai Institutional Review Board in accordance with the Declaration of Helsinki. Informed consent was obtained prior to enrollment of all study participants.

Consent for publication: Not applicable.

Availability of data and materials: The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests: The authors declare that they have no competing interests.

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References

1. Owens DK, Davidson KW, Krist AH, et al. Screening for Cognitive Impairment in Older Adults: US Preventive Services Task Force Recommendation Statement. *JAMA*. 2020;323(8):757-763.
2. Alzheimer's disease facts and figures. *Alzheimers Dement*. 2022;18(4):700-789.
3. Livingston G, Huntley J, Liu KY, et al. Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission. *Lancet*. 2024;404(10452):572-628.
4. Medicare introduces GUIDE model of dementia care delivery. *Alzheimers Dement*. 2023;19(9):4287-4289.
5. Hilsabeck RC, Perry W, Lacritz L, et al. Improving Early Detection of Cognitive Impairment in Older Adults in Primary Care Clinics: Recommendations From an Interdisciplinary Geriatrics Summit. *Ann Fam Med*. 2024;22(6):543-549.
6. King M, Peckham A, Marani H, et al. Gaps in the System: Supporting People Living with Dementia. *J Aging Soc Policy*. 2024;36(5):963-983.

7. Wilkins CH, Wilkins KL, Meisel M, Depke M, Williams J, Edwards DF. Dementia undiagnosed in poor older adults with functional impairment. *J Am Geriatr Soc*. 2007;55(11):1771-6.
8. Savva GM, Arthur A. Who has undiagnosed dementia? A cross-sectional analysis of participants of the Aging, Demographics and Memory Study. *Age Ageing*. 2015;44(4):642-7.
9. Connolly A, Gaehl E, Martin H, Morris J, Purandare N. Underdiagnosis of dementia in primary care: variations in the observed prevalence and comparisons to the expected prevalence. *Aging Ment Health*. 2011;15(8):978-84.
10. Amjad H, Roth DL, Sheehan OC, Lyketsos CG, Wolff JL, Samus QM. Underdiagnosis of Dementia: an Observational Study of Patterns in Diagnosis and Awareness in US Older Adults. *J Gen Intern Med*. 2018;33(7):1131-1138.
11. Nasreddine ZS, Phillips NA, Bedirian V, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc*. 2005;53(4):695-9.
12. Rossetti HC, Lacritz LH, Cullum CM, Weiner MF. Normative data for the Montreal Cognitive Assessment (MoCA) in a population-based sample. *Neurology*. 2011;77(13):1272-5.
13. Davis DH, Creavin ST, Yip JL, Noel-Storr AH, Brayne C, Cullum S. Montreal Cognitive Assessment for the diagnosis of Alzheimer's disease and other dementias. *Cochrane Database Syst Rev*. 2015;(10):CD010775.
14. Freitas S, Simoes MR, Alves L, Santana I. Montreal cognitive assessment: validation study for mild cognitive impairment and Alzheimer disease. *Alzheimer Dis Assoc Disord*. 2013;27(1):37-43.
15. Trittschuh EH, Crane PK, Larson EB, et al. Effects of varying diagnostic criteria on prevalence of mild cognitive impairment in a community based sample. *J Alzheimers Dis*. 2011;25(1):163-73.
16. Jak AJ, Preis SR, Beiser AS, et al. Neuropsychological Criteria for Mild Cognitive Impairment and Dementia Risk in the Framingham Heart Study. *J Int Neuropsychol Soc*. 2016;22(9):937-943.
17. Busse A, Hensel A, Gühne U, Angermeyer MC, Riedel-Heller SG. Mild cognitive impairment: long-term course of four clinical subtypes. *Neurology*. 2006;67(12):2176-85.
18. Kroenke K, Strine TW, Spitzer RL, Williams JB, Berry JT, Mokdad AH. The PHQ-8 as a measure of current depression in the general population. *J Affect Disord*. 2009;114(1-3):163-73.
19. Kulshreshtha A, Parker ES, Fowler NR, et al. Prevalence of Unrecognized Cognitive Impairment in Federally Qualified Health Centers. *JAMA Netw Open*. 2024;7(10):e2440411.
20. Shao Y, Todd K, Shutes-David A, et al. Identifying probable dementia in undiagnosed Black and White Americans using machine learning in Veterans Health Administration electronic health records. *medRxiv*. 2023;doi:10.1101/2023.02.08.23285540
21. Lin PJ, Daly AT, Olchanski N, et al. Dementia Diagnosis Disparities by Race and Ethnicity. *Med Care*. 2021;59(8):679-686.