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Prevalence of dementia subtypes in U.S. Medicare fee-for-service beneficiaries, 2011-2013

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Abstract

Introduction—Rapid growth of the older adult population requires greater epidemiologic characterization of dementia. We developed national prevalence estimates of diagnosed dementia and subtypes in the highest-risk U.S. population.

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Disclaimers: The findings and conclusions in this report are those of the authors and do not necessarily represent the official positions of the Centers for Disease Control and Prevention, Centers for Medicare & Medicaid Services, or Department of Veterans Affairs.

Research in Context

1. Systematic review: Using PubMed, we first identified and reviewed all publications reporting the prevalence of various dementias in the United States. National subtype-specific prevalence estimates are available primarily only for Alzheimer's disease, vascular dementia, and frontotemporal dementia, with sparse data for other subtypes of dementia, such as dementia with Lewy bodies.
2. Interpretation: Of the 3.1 million Medicare fee-for-service beneficiaries who had a claim for a service/treatment for any dementia subtype between 2011 and 2013, “dementia not otherwise specified” was the most common diagnosis (92.9%). The most common subtype was Alzheimer's (43.5%), followed by vascular (14.5%), Lewy body (5.4%), frontotemporal (1.0%), and alcohol induced (0.7%) dementias.
3. Future directions: Our findings help in identifying opportunities and priority needs for improving epidemiologic characterization of the occurrence of dementia and its subtypes through more accurate, reliable, and representative data sources.

Methods—We analyzed CMS administrative enrollment and claims data for 100% of Medicare fee-for-service beneficiaries enrolled during 2011-2013, and age > 68 years as of December 31, 2013 (n = 21.6 million).

Results—Over 3.1 million (14.4%) beneficiaries had a claim for a service/treatment for any dementia subtype. Dementia not otherwise specified was the most common diagnosis (present in 92.9%). The most common subtype was Alzheimer's (43.5%), followed by vascular (14.5%), Lewy body (5.4%), frontotemporal (1.0%), and alcohol induced (0.7%). The prevalence of other types of diagnosed dementia was 0.2%.

Discussion—This study is the first to document concurrent prevalence of primary dementia subtypes among this U.S. population. The findings can assist in prioritizing dementia research, clinical services, and caregiving resources.

1. Background

The rising prevalence of Alzheimer disease (AD) in the United States and its associated economic implications have been previously documented [1-4]. Other subtypes of dementia, such as vascular and Lewy body-associated dementia, further compound the challenges dementia poses for the population and health care system. The rapid growth of the older adult population calls for greater epidemiologic clarity and accuracy regarding the different types of dementia to enable more precise planning for health care and caregiving resources, and to guide prioritization of research needed to support health care policy and health system reform [5,6].

Improved epidemiologic characterization of dementia in the United States is necessary for at least four reasons. First, national subtype-specific prevalence estimates are available primarily only for AD [7,8], vascular dementia (VaD) [8], and frontotemporal dementia (FTD) [9] with sparse data for other subtypes of dementia, such as dementia with Lewy bodies (DLB) [10]. Second, existing estimates for AD are subject to important caveats related to study methodology [11-16] and offer limited insight into how practitioners diagnose dementia. Third, there is no consensus on what standard codes should be used in clinical practice for documenting dementia diagnoses, or on how codes should be used by different clinical specialties. Fourth, prevalence estimates based on single-point-in-time clinical assessments may not be wholly accurate given that the diagnosis of dementia subtypes is often arrived at through an incremental clinical process.

To our knowledge, concurrent national prevalence estimates of the most common dementia subtypes have not been determined for a large, well-defined population at risk of dementia. To address this need, we used Medicare administrative claims data to determine the prevalence of diagnosed dementia, subtypes (alcohol-induced, AD, FTD, DLB, and VaD), and dementia not otherwise specified. Medicare claims data offer a unique opportunity to obtain such estimates because they represent a large proportion of the U.S. older adult population, cover the entire United States, provide a complementary approach to other data sources and methods for measuring dementia prevalence, and allow for estimates by age, gender, and racial-ethnic groups. In this paper, we report our findings and outline relevant implications for clinical practitioners, clinical and basic researchers, and policy makers.

2. Methods

We used the Centers for Medicare & Medicaid (CMS) administrative enrollment and claims data for 100% of Medicare beneficiaries enrolled in the fee-for-service (FFS) program for the years 2011-2013 [17]. The Medicare FFS population includes beneficiaries residing in all fifty states, the District of Columbia, U.S. territories, and eligible beneficiaries who live outside the United States in other countries. In general, Medicare Part A covers services provided by hospitals, skilled nursing facilities, hospice and home health agencies, whereas Part B covers services and supplies needed to diagnose or manage medical conditions, and also preventive health services [18].

For this analysis, the study population was limited to Medicare FFS beneficiaries who were age ≥ 68 years as of December 31, 2013. We chose this age cut-off because we wanted to limit the population to older Medicare beneficiaries (aged at least 65 years) who were age eligible for Medicare during 2011-2013, the three-year period for which we searched claims. We excluded Medicare beneficiaries with any Medicare Advantage enrollment during 2011-2013, as Medicare claims are not available for these beneficiaries, and we excluded beneficiaries who were enrolled at any time in the year in Part A (hospital insurance) only or Part B (medical insurance) only. This resulted in an overall study population of 21,624,228 Medicare FFS beneficiaries.

2.1 Dementia definitions

We identified Medicare beneficiaries with dementia by the presence of *International Classification of Diseases, 9th Revision, Clinical Modification* (ICD-9-CM) dementia-related diagnoses codes included in the Medicare claims data. To construct the set of codes indicating the presence of dementia or a subtype, we first examined ICD-9-CM codes used to characterize dementia in three existing data systems: (i) CMS' Chronic Conditions Warehouse (CCW) [17]; (ii) Veterans Health Administration Dementia ICD-9 Diagnostic Codes for FY2013-FY2015 (Susan Cooley, Geriatrics and Extended Care Services, U.S. Department of Veterans Affairs, personal communication, October 16, 2015); and (iii) the Healthcare Cost and Utilization Project (HCUP)'s Clinical Classification System, which is maintained by the Agency for Health Care Research and Quality [19]. All of these codes are listed in Appendix A. Next, each author independently reviewed these codes in advance of a consensus process that produced a final set of codes for labeling five specific dementia subtypes (alcohol-induced; AD; FTD; DLB; and VaD), as well as the categories of "other" dementias (dementias of Creutzfeld Jacob disease and Huntington's disease), and dementias not otherwise specified (NOS) (see Table 1). We included the category of "dementia not otherwise specified" because routine use of non-specific diagnoses codes is common and leaving them out would result in omission of many affected individuals, and because the timing of a given clinical encounter influences the degree of diagnostic specificity.

To identify beneficiaries with dementia, we searched Medicare claims (claim types: inpatient, skilled nursing facility, home health, outpatient, or physician services) for the period January 1, 2011 – December 31, 2013, as three years has been shown to be an optimal period to identify dementia using these data [20]. We included claims that had any of the selected dementia diagnoses codes in Table 1. The dementia diagnoses codes could be

from any position on the claim, with the result that a single claim can have multiple diagnoses codes for dementia and can indicate more than one type of dementia. We summarized all claims for a given beneficiary into a single beneficiary-level record indicating that the beneficiary has dementia, as well as indicating the subtype (or subtypes) based upon the selected diagnoses codes. Beneficiaries are not categorized into mutually exclusive dementia types because multiple dementia diagnoses codes may be included on claims and multiple claims may indicate different types of dementia.

2.2 Analysis

We present the overall prevalence of diagnosed dementia in the Medicare FFS study population and the prevalence of the dementia subtypes among beneficiaries with dementia. The subtypes of dementia are further characterized by their prevalence across socio-demographic characteristics available from Medicare enrollment data. We examined the most common dementia subtypes that occur alone or in combination with one another.

2.3 IRB approval

The use of these secondary data did not require IRB review as the data are de-identified, pose no disclosure risk to a beneficiary, and conform to CMS privacy requirements.

3. Results

Among the 21.6 million Medicare FFS beneficiaries who had a qualifying claim, we identified 3,110,654 (14.4%) individuals who had a claim indicating that they had received a service or treatment for any dementia subtype. When compared to the overall Medicare FFS population, persons with dementia were more likely to be older, female, and dually-enrolled in Medicaid.

Table 3 presents the prevalence of each dementia diagnosis subtype by socio-demographic characteristics among all beneficiaries with a claim for dementia. The most common dementia diagnosis was dementia NOS which was present in 92.9% of those with a dementia claim. The most commonly defined subtype was AD (43.5%), followed by VaD (14.5%), DLB (5.4%), FTD (1.0%), and alcohol induced dementia (0.7%). The prevalence of other types of diagnosed dementia (e.g., Creutzfeldt-Jakob disease and Huntington's disease) was 0.2%.

The prevalence of AD increased with age (35.7% among beneficiaries aged 70-74 years compared to 45.6% for those aged 85 years and older), was higher among women, and lower among beneficiaries living in rural areas. The race/ethnic-specific prevalence of AD was highest among Hispanics (50.2%) and lowest among American Indians/Alaska Natives (32.8%).

The prevalence of VaD decreased with age, was higher among men (15.3%) and among beneficiaries dually-enrolled in Medicaid (18.3%), and was highest among African-Americans (19.2%). The prevalence of DLB, FTD, and alcohol-induced dementia were all higher among men. The prevalence of alcohol-induced dementia was highest among

American Indians/Alaska Natives (2.2%). The prevalence rates of most subtypes (i.e., AD, VaD, DLB, and FTD) were lower among beneficiaries living in rural areas.

Since the higher burden of dementia among women partly reflects their longer life expectancy compared to men [21], we examined the prevalence of diagnosed dementia subtypes by age group stratified by sex (Table 4). In general, the sex-stratified results mirrored the overall results: for AD, the prevalence among women was higher than among men in each age category. In contrast, for VaD, DLB, FTD, and alcohol induced dementias, prevalence rates were higher among men in each age category.

Since our method of defining dementia allowed beneficiaries to be classified as having more than one dementia subtype, we examined how often beneficiaries had co-occurring subtypes based upon the diagnoses codes on the claims. The top 10 most common diagnoses of dementia accounted for over 97% of dementia diagnoses (Table 5). The most common dementia diagnosis was of the type NOS, with 46.1% having only NOS diagnoses codes, followed by nearly one-third (29.0%) having diagnoses of both AD and NOS. Only 4.5% of beneficiaries with dementia had a diagnosis of only AD, and 1.7% had a diagnosis of only VaD.

4. Discussion

Previous national estimates of dementia prevalence in the United States have been developed through use of a forward calculation approach or representative cross-sectional surveys [7,8,10,22-25] and, because of a multitude of methodologic considerations, have produced widely varying estimates [23]. To our knowledge, the present study is the first to document the concurrent prevalence of the primary dementia subtypes and combinations of subtypes among the large population of older adults who are Medicare FFS beneficiaries diagnosed with dementia.

Over 3.1 million (14.4%) of Medicare FFS beneficiaries had a claim listed for dementia, a rate consistent with an overall dementia prevalence (13.9%) reported by Plassman et al. for a study population in 2002 [8] (Table 6). Consistent with other reports encompassing the United States and other countries, our findings show AD as the most predominant subtype of dementia [8,26-28]. We also found that AD was the subtype most concurrently diagnosed with other subtypes of dementia and we affirmed the high prevalence of the diagnosis of dementia NOS as reported by Butler et al. in a study of veterans receiving care from the Department of Veterans Affairs New England healthcare system [29].

4.1 Key epidemiologic patterns for dementia subtypes

Our estimates of the prevalence of dementia subtypes among Medicare FFS beneficiaries generally are consistent with estimates of the overall occurrence of subtypes reported for studies using a variety of methods and populations. However, most studies have not examined the comprehensive set of dementia subtypes addressed in this study. In addition, direct comparisons of dementia epidemiology across these and other studies must be made with caution because of the wide variability in study design and data sources.

Among the 3.1 million Medicare FFS beneficiaries with a claim for dementia in 2011-2013, 1.35 million (43.5%) had been diagnosed with AD. In their report, Herbert et al. [7] projected 5.0 million prevalent cases in 2013 (Table 6), although the numbers in that study and ours are not directly comparable because of methodologic differences.

Consistent with a recent review of VaD [30], that subtype was the second most common (14.5%) among Medicare FFS beneficiaries and similar to the prevalence reported by Plassman et al. (17.4%) [8]. However, estimates of the occurrence of this subtype likely will change as a function of an evolving understanding of the relation between vascular disease, the role of stroke, and neurodegenerative pathology [30-32].

The third and fourth most prevalent diagnosis subtypes in our study were DLB (5.4%) and FTD (1.0%), respectively. We were unable to find a recent prevalence estimate of DLB for comparison, although Savica et al. analyzed data on a well-defined population in one county to determine a combined incidence rate for DLB and Parkinson disease dementia in that setting (Table 6) [10]. Cross-study comparisons of FTD prevalence is challenging because of the heterogeneous nature of this disorder and related terms (e.g., cognitive syndromes of FTD, behavioral variant FTD, primary progress aphasia) used to define it [9,33,34]. Nonetheless, using prevalence, incidence, and survival data from several countries, Knopman et al. generated a synthetic estimate of the prevalent number of cases of the cognitive syndrome of FTD in the United States in 2010 (Table 6) [9].

Alcohol-induced dementia was diagnosed in 0.7% of Medicare FFS beneficiaries. For this subtype, we also were unable to identify comparator estimates, reflecting several challenges to measuring its incidence and prevalence, such as lack of operationally-defined criteria, failure to view this dementia as a discrete clinical entity, controversy regarding causation, and the use of studies relating patterns of alcohol consumption to dementia in developing epidemiological information [35]. With so little known about the epidemiology of this subtype in the United States, the findings in this study help in establishing a point of reference for population-based prevalence.

The high prevalence of the diagnostic category of “dementia NOS” in our sample (92.9%) far exceeds that of AD (43.5%) and reflects practitioners’ common use of this clinical diagnosis code. An obvious explanation for this finding is the challenge of making a diagnosis of AD or other dementia subtypes in the clinical setting. Previous studies that have examined the accuracy of a clinical diagnosis of AD, as judged by the gold standard of neuropathological examination after death, have reported estimates of approximately 80 percent with varying sensitivity and specificity [12,36-40]. Most of these studies have relied upon a clinical diagnosis of dementia and/or AD made by consensus diagnosis between expert clinicians according to established criteria including DSM-IIIR [41] and NINCDS-ADRDA [42]. Although the NIA-AA clinical criteria for diagnosis [43] were released in 2011, we assumed that these updated diagnostic criteria were not the practice standard in the time period examined in our analysis (2011-2013). Because diagnosis of dementia subtype is a process, we were unable to determine whether the diagnoses included in this analysis were “final” or represent diagnoses from multiple stages of the process. Limiting the analysis to only the final diagnosis may change the prevalence of persons diagnosed with dementia who

are coded as dementia NOS. Examination of the temporal order of diagnoses code(s) used would be required to elucidate how the diagnostic process is documented in the medical record. Thus, our results further underscore the challenges in the subtyping of dementia in practice settings where assessment of cognitive function using standardized testing may not be routinely preformed [44].

Our findings also expand epidemiologic characterization of dementia subtypes on key factors, such as age, sex, race-ethnicity, and residence. However, because most previous studies report findings only for individual or a smaller subset of subtypes, and for fewer descriptive factors, only limited comparisons can be made on these factors. For example, when comparing findings in relation to age, among the Medicare FFS population the prevalence of diagnosed vascular dementia declined slightly by age, whereas in the Aging, Demographics, and Memory Study (ADAMS) the prevalence of that subtype increased by age [8] (Table 6).

4.2 Implications for clinical practice, research, and policy

The high prevalence of diagnosed dementia NOS based on the study of the Medicare fee-for-service population reported here has important implications for clinical education, training, and practice. Dementia syndromes pose a unique diagnostic challenge in medicine: in the absence of confirmatory laboratory tests or characteristic neuroimaging findings that can be routinely assessed during evaluations, a differential diagnosis usually is made on clinical grounds that sometimes include neuropsychological testing and, when indicated, imaging and laboratory testing. Use of non-specific dementia coding (i.e., dementia NOS) may be appropriate when applied toward patients who have demonstrable cognitive impairment but whose clinical course is uncertain, or for whom potentially reversible causes are being sought and excluded. However, the frequent use of such coding also may reflect the need for training to increase clinical proficiency and confidence in diagnosing dementia and its subtypes. Attaining an accurate, specific subtype diagnosis enables better prognostication, tailored counseling, cessation of diagnostic testing, and access to clinical trials.

Future studies should explore Medicare FFS claims data by specialty (i.e., primary care or sub-specialty) and other variables to identify the scope and nature of this problem among providers. Findings of such analyses may help focus training of clinical practitioners to increase their confidence in the routine assessment of dementia patients and, consequently, to enable more accurate and consistent subtyping of dementias. One approach to alleviating this problem may be by encouraging the use of existing clinical decision support tools that incorporate evidence-based recommendations for the diagnosis and management of dementia [45]. Further refinement of such clinical decision frameworks by incorporating the diagnosis of non-AD dementias and mild-cognitive impairment (MCI) may improve accuracy of dementia subtyping. A refined framework also might allow for clinical evaluation that helps to focus the diagnosis because, even in the absence of disease-modifying treatments, individual risk assessments provide for the utility of appropriate planning by the patient and family members, as they deem appropriate.

Our findings also suggest important directions for healthcare and health services policy makers and policies. A working group of the Alzheimer's Association recently

recommended that evaluation of cognitive impairment by structured assessment tools should form part of the routine clinical examination during annual wellness visits, a new Medicare benefit [46]. Increased awareness and understanding of dementia subtype prevalence and patterns could better inform policies for eligibility for health care and community-based services, and for redesigning health benefits directed to needs of patient subgroups. The notable prevalence of VaD as the second most common subtype bolsters the case for supporting implementation of aggressive cardiovascular risk management. Finally, these findings are responsive to the scope of, and assist in informing the focus of, the National Alzheimer's Plan – although the Plan in name is specific to AD, its mission in reality is to meaningfully improve the management of all types of dementia with the ultimate goal of achieving a cure [5].

4.3 Limitations

The findings in this study should be viewed in the appropriate context: the results reported here are based on diagnostic codes applied during the course of care delivery. This point underscores the importance of early and accurate diagnosis in the population of persons at high risk of dementia who may not be captured in the Medicare claims data because they are not receiving care from Medicare-enrolled healthcare providers, or because they have cognitive impairment that has not yet been detected or dementia that has not yet been diagnosed.

In addition to the aforementioned contextual considerations, this study's findings are subject to at least three limitations. First, affected individuals and/or their families may not seek treatment for dementia and some providers may hesitate to use dementia codes because of the potential for stigmatization. This would tend to cause our estimate to be lower than the true value. However, we attempted to minimize this potential effect by using a 3-year time window and including Part B physician claims. These strategies have been shown to improve the accuracy of findings based on Medicare claims when compared with earlier estimates [16,20]. We also note that a comparison of dementia diagnosis in ADAMS [8] and Medicare claims found that Medicare claims and ADAMS agreed on 85% of subjects and had a kappa statistic of 0.70 [16], a finding that provides some assessment of the constancy of diagnostic codes and clinical diagnosis. Second, the findings reported here are based on Medicare fee-for-service administrative claims data and exclude beneficiaries enrolled in Medicare Advantage since claims are not available. In 2012, 28% of Medicare beneficiaries aged 65 years or older were enrolled in Medicare Advantage [47]; thus, our findings might not fully generalize to all Medicare beneficiaries. Third, we choose to allow multiple diagnosis codes on a single individual, and consequently we did not identify beneficiaries by mutually exclusive dementia subtypes. We opted to include all diagnosis codes because it is common clinical practice to code for the presence of one or more dementias in cases where it is believed the etiology is mixed.

4.4 Options for Improving Epidemiologic Characterization of Dementia

Improving understanding of the epidemiology of dementia in the United States is a national priority [5,48-50]. Our study responds to this priority through its approach to estimating the prevalence of diagnosed dementia and its subtypes in one well-defined population. The

findings of this and other studies on dementia occurrence point to opportunities for improving the accuracy, reliability, and representativeness of data that are needed ultimately for priorities in research, policy making, and patient care. Accordingly, we propose the following recommendations for improving surveillance and epidemiologic characterization of dementia subtypes. Importantly, these recommendations should be considered for implementation collectively rather than as mutually exclusive options.

- Standardize the use of administrative claims and other data sources, and of core methodologic elements – such as diagnostic criteria and terminology for different subtypes, representativeness of study populations, and surveillance, survey, and study design.
- Develop training on diagnostic coding based on the stage of clinical work up, including results of laboratory testing and imaging, and delivering training tailored to specialties (i.e., primary care providers [internal medicine, geriatrics, and family medicine], non-neurologist specialists [e.g., radiologists], and neurologists, particularly those specializing in cognitive impairment in the older adult population).
- Develop focused training and education of clinical practitioners in making diagnoses of dementia and of AD as the most common dementia subtype.
- Promote use of standard guidelines for dementia (DSM-IIIR) and AD (NIA-AA [43]) in routine clinical practice.
- Emphasize the importance of efficient and standardized screening to detect cognitive impairment, determine when further investigations and/or referral to expert opinion is necessary, and develop pathways to enable efficient referral and effective management across providers and settings within health systems.

4.5 Conclusion

This study is the first to provide reliable diagnosis-based estimates of the frequencies of common dementia subtypes and combinations of subtypes in the Medicare beneficiary population, a major U.S. population at risk of dementia. The findings also underscore the need for targeted training to improve clinical proficiency and confidence in diagnosing dementia and its subtypes. These results can assist in prioritizing dementia research, clinical services, and caregiving resources.

This study demonstrated challenges in measuring the prevalence and epidemiology of subtypes. Medicare FFS claims data offer a unique and useful data source because they represent a large and well-defined population at high risk of dementia, encompass the entire United States, and allow for estimates by multiple variables. Accordingly, Medicare administrative data may help in shaping further epidemiological research on dementia subtypes, particularly when coding classifications can represent a combination of factors that previously have been reported in the literature as clinical and epidemiologic expert opinion.

As the size of the population at-risk for dementia in the United States continues to grow, identifying and implementing approaches to improving estimates of the occurrence of dementia subtypes will help in providing important data to health policy makers, health care delivery systems, clinical practitioners, and basic researchers for confronting the challenges of dementia.

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Appendix A

ICD-9 Diagnoses Codes for Dementia used in three data systems: (i) CMS' Chronic Conditions Warehouse (CCW) [17]; (ii) Veterans Health Administration (VA) Dementia ICD-9 Diagnostic Codes for FY2013-FY2015 (Susan Cooley, Geriatrics and Extended Care Services, U.S. Department of Veterans Affairs, personal communication, October 16, 2015); and (iii) the Healthcare Cost and Utilization Project (HCUP) maintained by the Agency for Health Care Research and Quality [19].

ICD-9-CM Code	ICD-9-CM Code Description	Study defined type of dementia	CMS CCW	VA	HCUP-CCS
331.0	Alzheimer's diseases	Alzheimer's disease	X	X	X
290.40	Vascular dementia, uncomplicated	Vascular	X	X	X
290.41	Vascular dementia, with delirium	Vascular	X	X	X
290.42	Vascular dementia, with delusions	Vascular	X	X	X
290.43	Vascular dementia, with depressed mood	Vascular	X	X	X
331.82	Dementia with Lewy bodies	Lewy body		X	X
332.0 + 331.0	Parkinson's disease + AD code => syndromic LBD (same claim)	Lewy body			
331.1	Frontotemporal dementia	Frontotemporal			X
331.11	Pick's disease	Frontotemporal	X	X	X
331.19	Other frontotemporal dementia	Frontotemporal	X	X	X
291.2	Alcohol induced persisting dementia	Alcohol induced		X	
046.11	Creutzfeldt-Jakob disease, variant	Other		X	
046.19	Creutzfeldt-Jakob disease, other and unspecified	Other		X	
292.82	Drug induced persisting dementia	Other		X	
333.4	Huntington's Chorea	Other		X	
290.0	Senile dementia, uncomplicated	Not otherwise specified	X	X	X
290.10	Presenile dementia, uncomplicated	Not otherwise specified	X	X	X
290.11	Presenile dementia, with delirium	Not otherwise specified	X	X	X

ICD-9-CM Code	ICD-9-CM Code Description	Study defined type of dementia	CMS CCW	VA	HCUP-CCS
290.12	Presenile dementia, with delusions	Not otherwise specified	X	X	X
290.13	Presenile dementia, with depressed mood	Not otherwise specified	X	X	X
290.20	Senile dementia, with delusional features	Not otherwise specified	X	X	X
290.21	Senile dementia, with depressive features	Not otherwise specified	X	X	X
290.3	Senile dementia, with delirium	Not otherwise specified	X	X	X
290.9	Unspecified dementia without behavioral disturbance	Not otherwise specified			X
294.1	Dementia in conditions classified elsewhere	Not otherwise specified			X
294.10	Dementia in conditions classified elsewhere without behavioral disturbance	Not otherwise specified	X	X	X
294.11	Dementia in conditions classified elsewhere with behavioral disturbance	Not otherwise specified	X	X	X
294.20	Dementia, unspecified, without behavioral disturbance	Not otherwise specified	X	X	X
294.21	Dementia, unspecified, with behavioral disturbance	Not otherwise specified	X	X	X
294.8	DEMENTIA NOS/Other persistent mental disorders due to conditions classified elsewhere	Not otherwise specified	X	X	X
331.2	Senile degeneration of the brain	Not otherwise specified	X	X	X
797	Senility without psychosis	Not otherwise specified	X		X
046.3	Progressive Multifocal Leukoencephalopathy	Not included in study definition of dementia		X	
290.8	Senile psychosis NEC	Not included in study definition of dementia			X
293.0	Delirium due to conditions classified elsewhere	Not included in study definition of dementia			X
293.1	Sub acute delirium	Not included in study definition of dementia			X
294.0	Amnestic disorder in conditions classified elsewhere	Not included in study definition of dementia	X		X
294.9	Unspecified persistent mental disorders due to conditions classified elsewhere	Not included in study definition of dementia			X
310.0	Frontal lobe syndrome	Not included in study definition of dementia			X
310.2	Post concussion syndrome	Not included in study definition of dementia			X
310.8	Other specified nonpsychotic mental disorders following organic brain damage	Not included in study definition of dementia			X
310.81	Pseudobulbar affect	Not included in study definition of dementia			X
310.89	Other specified nonpsychotic mental disorders following organic brain damage	Not included in study definition of dementia			X
310.9	Unspecified nonpsychotic mental disorder following organic brain damage	Not included in study definition of dementia			X
331.7	Cerebral degeneration in diseases classified elsewhere	Not included in study definition of dementia	X	X	

ICD-9-CM Code	ICD-9-CM Code Description	Study defined type of dementia	CMS CCW	VA	HCUP-CCS
331.89	Other Cerebral Degeneration	Not included in study definition of dementia		X	
331.9	Cerebral Degeneration Unspecified	Not included in study definition of dementia		X	
333.0	Other degenerative disease of the Basal Ganglia	Not included in study definition of dementia		X	

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Highlights

- Rapid growth of the older adult population requires greater epidemiologic characterization of dementia.
- We developed national prevalence estimates of diagnosed dementia and subtypes in the highest-risk U.S. population by analyzing CMS administrative enrollment and claims data for 100% of Medicare fee-for-service beneficiaries enrolled during 2011-2013, and age ≥ 68 years as of December 31, 2013 (n = 21.6 million).
- Over 3.1 million (14.4%) beneficiaries had a claim for a service/treatment for any dementia subtype.
- Dementia not otherwise specified was the most common diagnosis (present in 92.9%); the most common subtype was Alzheimer's (43.5%), followed by vascular (14.5%), Lewy body (5.4%), frontotemporal (1.0%), and alcohol induced (0.7%).
- This study, the first to document concurrent prevalence of primary dementia subtypes among this U.S. population, provides findings that can assist in prioritizing dementia research, clinical services, and caregiving resources.

Table 1

ICD-9 Diagnoses Codes used to identify dementia in the Medicare study population

Dementia Subtype	ICD-9 Diagnosis Code
Alzheimer's disease	331.0
Vascular	290.40, 290.41, 290.42, 290.43
Lewy Body[1]	331.82, 332.0 + 331.0[1]
Frontotemporal	331.1, 331.11, 331.19
Alcohol induced	291.2
Other[2]	046.11, 046.19, 292.82, 333.4
Not otherwise specified	290.0, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.9, 294.1,294.10, 294.11, 294.20, 294.21, 294.8, 331.2, 797

Notes:

[1]Diagnosis code 332.0 had to have a diagnosis code of 331.0 on the same claim to be considered Lewy Body.

[2]Other dementia includes Creutzfeldt-Jakob disease, Huntington's Chorea, and drug induced dementia.

Table 2

Characteristics of the Medicare Fee-for-Service (FFS) study population, ages ≥68 years: 2013

	Study Population (N = 21,624,228)	Study Population with D i a gn osed Dementia[1] (N = 3,110,654)
	Percentage (%)	
Overall		14.4
Age, years		
68-69	11.7	2.7
70-74	28.1	10.1
75-79	22.1	15.5
80-84	17.2	21.7
85+	20.9	50.0
Sex		
Men	42.3	34.3
Women	57.7	65.7
Race/ethnicity		
Not Hispanic, White	84.3	82.2
Not Hispanic, Black or African American	7.2	9.2
Hispanic	4.9	5.6
Asian or Pacific Islander	2.4	2.1
American Indian or Alaska Native	0.4	0.4
Other/unknown	0.9	0.6
Medicare-Medicaid enrollee		
Yes (dual eligible)	14.0	33.6
No	86.0	66.4
Urban/rural residence		
Metropolitan statistical area	76.2	78.3
Micropolitan statistical area	13.7	12.9
Rural	9.8	8.7
Missing	0.3	0.1

Notes:

[1] Dementia is identified by any dementia diagnoses codes on the claim.

Table 3

Prevalence of dementia subtypes among Medicare Fee-for-Service beneficiaries ages ≥68 years, with diagnosed dementia (N = 3,110,654): 2013

	Dementia Subtypes[1]						
	Alzheimer's Disease (N = 1,354,282)	**Vascular (N = 450,162)**	**Lewy Body (N = 168,629)**	**Frontotemporal (N = 30,985)**	**Alcohol Induced (N = 22,264)**	**Other[2] (N = 7,019)**	**NOS[3] (N = 2,888,150)**
	Percentage (%)						
Overall	43.5	14.5	5.4	1.0	0.7	0.2	92.9
Age, years							
68-69	30.6	15.9	5.3	2.3	3.3	0.9	87.0
70-74	35.7	15.5	6.2	1.9	2.1	0.6	88.7
75-79	41.7	15.3	6.9	1.4	1.1	0.3	90.7
80-84	45.5	14.7	6.5	1.0	0.6	0.2	92.6
85+	45.6	13.9	4.4	0.6	0.2	0.1	94.8
Sex							
Men	40.4	15.3	7.8	1.3	1.4	0.3	91.8
Women	45.2	14.0	4.2	0.9	0.4	0.2	93.4
Race/ethnicity							
Not Hispanic, White	43.1	14.1	5.5	1.1	0.7	0.2	93.2
Not Hispanic, Black or African American	44.5	19.2	4.0	0.6	1.0	0.2	93.6
Hispanic	50.2	13.3	6.1	0.7	0.6	0.2	88.2
Asian or Pacific Islander	41.2	12.7	5.4	0.8	0.2	0.1	88.8
American Indian or Alaska Native	32.8	12.1	4.4	0.6	2.2	0.2	94.2
Other/unknown	40.1	15.5	5.7	1.1	0.6	0.2	90.1
Medicare-Medicaid enrollee							
Yes (dual eligible)	47.6	18.3	5.7	0.8	0.9	0.2	94.4
No	41.5	12.5	5.3	1.1	0.6	0.2	92.0
Urban/rural residence							
Metropolitan statistical area	44.2	15.1	5.5	1.1	0.7	0.2	92.6
Micropolitan statistical area	41.7	12.7	5.2	0.8	0.7	0.2	93.6

	Dementia Subtypes[1]						
	Alzheimer's Disease (N = 1,354,282)	**Vascular (N = 450,162)**	**Lewy Body (N = 168,629)**	**Frontotemporal (N = 30,985)**	**Alcohol Induced (N = 22,264)**	**Other[2] (N = 7,019)**	**NOS[3] (N = 2,888,150)**
Rural	40.2	11.4	4.7	0.7	0.7	0.3	93.6

Notes:

[1] Dementia is identified by any dementia diagnoses codes on the claim. Frequency of dementia subtypes are not mutually exclusive.

[2] Other dementia includes Creutzfeldt-Jakob disease, Huntington's Chorea, and drug induced dementia.

[3] Dementia Not Otherwise Specified.

Table 4

Prevalence of Dementia Subtypes among Medicare Fee-for-Service Beneficiaries, 68+ years, with Diagnosed Dementia by Sex and Age (N = 3,110,654): 2013

	Men (N = 1,065,803): Dementia Subtypes[1]						
	Alzheimer's disease (N = 430,159)	**Vascular (N = 163,321)**	**Lewy Body (N = 83,395)**	**Frontotemporal (N = 13,615)**	**Alcohol induced (N = 15,083)**	**Other[2] (N = 2,665)**	**NOS[3] (N = 978,848)**
	Percentage (%)						
Overall	40.4	15.3	7.8	1.3	1.4	0.3	91.8
Age, years							
68-74 (N = 177,667)	32.3	16.9	7.8	2.3	4.0	0.6	87.8
75-84 (N = 449,289)	41.2	15.8	9.1	1.4	1.4	0.3	91.1
85+ (N = 438,847)	42.8	14.2	6.5	0.7	0.4	0.1	94.2
	Women (N = 2,044,851): Dementia Subytpes[1]						
	Alzheimer's disease (N = 924,123)	Vascular (N = 286,841)	Lewy Body (N = 85,234)	Frontotemporal (N = 17,370)	Alcohol induced (N = 7,181)	Other[1] (N = 4,354)	NOS[3] (N = 1,909,302)
	Percentage (%)						
Overall	45.2	14.0	4.2	0.9	0.4	0.2	93.4
Age, years							
68-74 (N = 222,899)	36.4	14.5	4.5	1.8	1.0	0.7	88.8
75-84 (N = 706,885)	45.6	14.4	5.1	1.1	0.4	0.3	92.2
85+ (N = 1,115,067)	46.7	13.7	3.5	0.5	0.2	0.1	95.1

Notes:

[1] Dementia is identified by any dementia diagnoses codes on the claim.

[2] Other dementia includes Creutzfeldt-Jakob disease, Huntington's Chorea, and drug induced dementia.

[3] Dementia Not Otherwise Specified.

Table 5

Most Common Diagnosed Dementia Subtypes among Medicare Fee-for-Service Beneficiaries, 68+ years, with Dementia: 2013 (N = 3,110,654)

Top 10 Dementia Subtype Diagnoses[1]	Frequency	Percent
Dementia, not otherwise specified (NOS)	1,432,753	46.1
Alzheimer's disease (AD)/Dementia NOS	902,727	29.0
AD/Vascular dementia/Dementia NOS	195,499	6.3
Vascular dementia/Dementia NOS	156,422	5.0
Alzheimer's disease	139,833	4.5
Lewy body dementia/Dementia NOS	64,338	2.1
AD/Lewy body dementia/Dementia NOS	62,345	2.0
Vascular dementia	52,575	1.7
AD/Vascular dementia/Lewy body dementia/Dementia NOS	17,041	0.6
AD/Frontotemporal dementia/Dementia NOS	10,523	0.3

Notes:

[1] Dementia is identified by any dementia diagnoses codes on the claim.

Table 6

Selected Reports on occurrence (prevalence or incidence) of dementia and dementia subtypes[1] in the United States, by population setting, and study type

Author	Dementia subtype(s)	Population / setting	Study type	Occurrence (prevalence or incidence)	Comment
Plassman [8], Langa [25]	Dementia, AD, VaD	Stratified random sample drawn from a nationally-representative cohort study (beginning in 1992) of persons born before 1954.	In-residence clinical assessment during 2001-2003 of participants aged ≥71 years for dementia with final diagnoses assigned by a consensus expert panel.	Prevalence in 2002 in those age ≥71 years: - Dementia: 13.9% (3.4 million) - AD: 9.7% (2.4 million) - VaD: 2.4% (0.6 million) Distribution of dementia subtypes: - AD: 69.9% - VaD: 17.4% - Other: 12.7%	Reported as the first population-based study of dementia to include persons from all regions of the United States and using a single standardized diagnostic protocol in a community-based sample [23]. By sex, prevalence increased by age for dementia, AD, and VaD.
Herbert [7],Bienias [22], Evans [24]	AD	Household residents over age 65 years in a geographically-defined biracial neighborhood of the south side of Chicago.	In-home clinical evaluation for AD of a stratified random sample of participants in longitudinal, population-based study of chronic health problems during 1993-2011, with U.S. prevalence estimates then developed using incidence rates from the Chicago sample, U.S. mortality, education, and U.S. Census Bureau population estimates.	Number of persons age >65 years in U.S. with AD in 2013: 5.0 million	National-level prevalence projections based on incidence estimates using persons residing in a single urban area, and assumed no incident dementia under age 65 years. Also assumed risk of dementia same for persons of Hispanic origin and the racial group with which they identify.
Savica [10]	DLB, PDD	Geographically-defined total population of Olmsted County, Minnesota, for the period 1991-2005.	Medical records linkage system was used to identify all persons who developed DLB or PDD; diagnosis confirmed through review of complete medical records by a movement disorders specialist.	Among persons in Olmsted County: - DLB incidence: 3.5 per 100,000 person-years overall, increasing with age and higher in men - PDD incidence: 2.5 per 100,000 person-years overall, increasing with age - Combined incidence: 5.9 per 100,000 person-years overall, increasing with age and higher in men	Noted by authors that both dementia subtypes share the same neuropathology and are difficult to differentiate at autopsy.
Knopman [9]	FTLD	5 prevalence studies (4 from Western Europe and 1 from Japan) and 3 incidence studies	To estimate the prevalence of cases of the cognitive syndromes of FTLD (CS-FTLD, including behavioral variant frontotemporal dementia	Estimated number of cases CS-FTLD: 20,000 – 30,000, with 10% under age 45 years and 30% over age 64 years.	

Author	Dementia subtype(s)	Population / setting	Study type	Occurrence (prevalence or incidence)	Comment
		(1 from United States and 2 from Western Europe).	[bvFTD] or primary progressive aphasia [PPA]) in the United States in 2010,the authors used data from prevalence and incidence studies of FTLD and 7 studies of survival in FTLD		

[1] Alzheimer's disease: AD; dementia with Lewy bodies: DLB; Parkinson disease dementia: PDD; Frontotemporal lobar degenerations: FTLD; vascular dementia: VaD